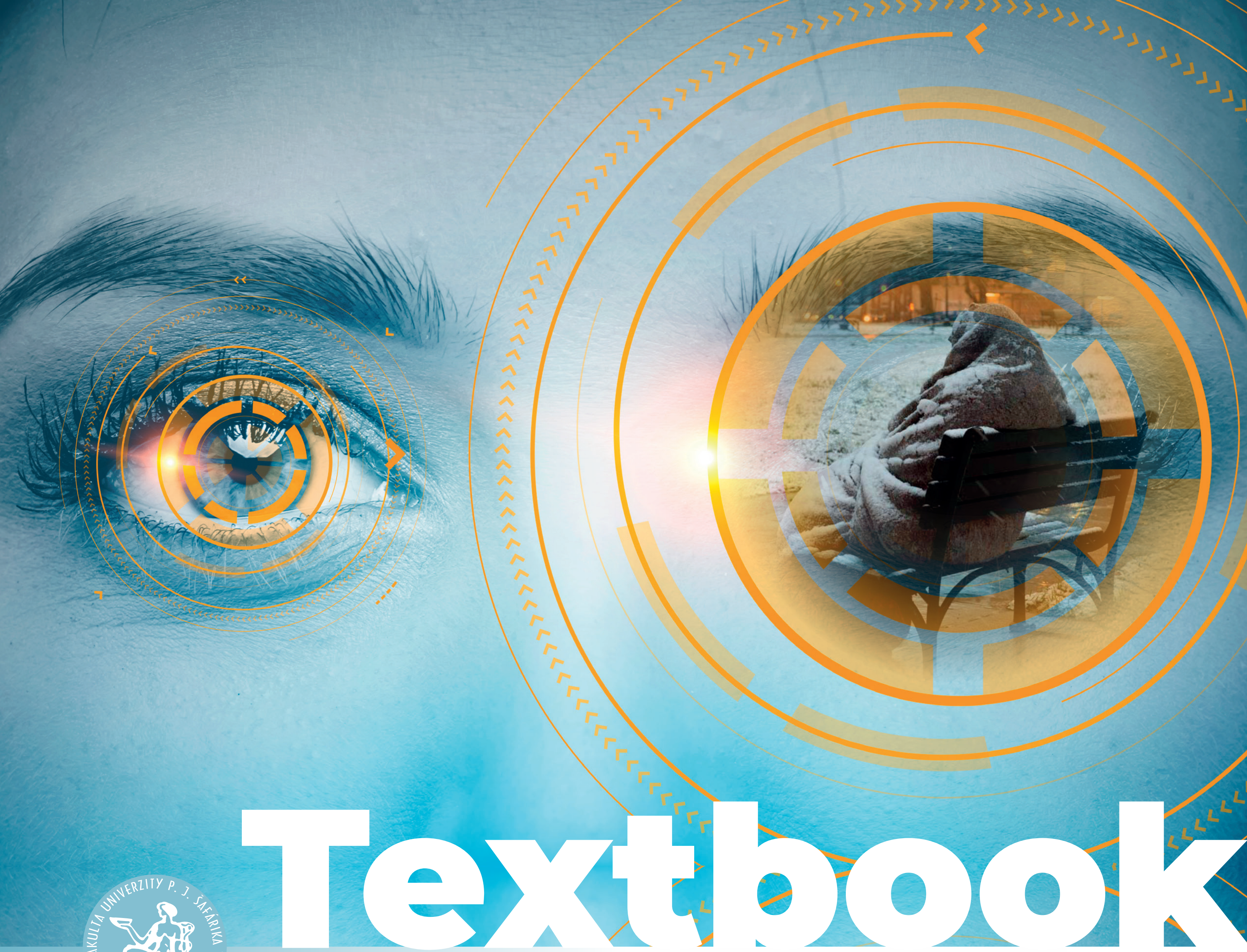

# Textbook of Social Medicine

Iveta NAGYOVA, Zuzana KATRENIAKOVA (eds.)

LEKÁRSKA FAKULTA UNIVERZITY P. J. ŠAFÁRIKA V KOŠICIACH • 1959 •

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# Contents

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# PREFACE

## *The Necessity of Social Medicine in Medical Education*

Research and clinical experience reliably and repeatedly demonstrated the increasing evidence documenting the role of social, economic, and political forces in determining health, diseases, treatment, and recovery. Health is most accurately conceptualized as biopsychosocial phenomena, in which health and disease emerge through the interaction between biology and the social environment. Social processes drive the epidemiology, severity, and experience of disease. Quantitative and qualitative research methods provide strong evidence that health outcomes inequitably disperse across the social class, culture, gender, and race both within and between countries. Socioeconomic status, education, housing, employment, environment, all of which are forcibly shaped by societal, behavioural, and structural factors, determine 90% of health outcomes, while only 10% are determined by biomedical healthcare. Medical education, however, places primary emphasis on biomedicine and often fails to emphasize and educate students about the social forces that shape disease patterns. Without explicit education about social context factors, clinicians may never learn to recognise and respond to social and behavioural factors that are in the roots of patient's risk for, response to, and experience with disease. For example, physicians tell obese patients from poor neighbourhoods to change their lifestyle by exercising and eating healthy without recognizing the lack of affordable eating options, green spaces, and physical activity opportunities. Similarly, conditions like menopause, Asperger's syndrome, AIDS, and suicide can have profoundly different cultural meanings. Intensified engagement with the environments and social spaces in which people live, work, study, and play are essential elements of improving population health. This understanding forms the basis of the discipline of social medicine, and can dramatically change a diagnostic picture or therapeutic plan.

Our teaching methods built upon Freirean critical pedagogy, which merges field visits, classroom-based presentations and discussions, group reflections, films, theatre, and patient clerking to create an innovative and interactive learning environment. The course curriculum also places considerable importance on encouraging students to reflect upon their personal experiences with power, privileged, race, class, and gender. The aim is to equip students with skills to integrate principles of social medicine into future clinical practice, curricular or political work. Such training prepares practitioners to improve health through building community partnerships, utilizing narrative medicine in patient care, participating in social movements, practicing community-based participatory action research, and deeper understanding of social and behavioural determinants of health. To help patients achieve optimal health, physicians must synthetize the micro-perspective of biomedical research with the macro-perspective of social medicine. Social medicine recognizes that physicians must engage with social realities outside the clinic or hospital to optimize human health. As the late psychiatrist Leon Eisenberg noted, "all medicine is social medicine", and all physicians should find something relevant to their own practices in these cases.

*Editors*

# 1

# Introduction into Social Medicine

## 1.1 THE SCOPE OF SOCIAL MEDICINE

*Zuzana Katreniakova*

The presence and future of social medicine is based on its 170 years of history and also on the changing context within which medicine operates in the 21st century.

There are two historical views on social medicine. The first one is related to the vision of Guérin and, particularly, Virchow who declared, that "*doctors are natural advocates of the poor, and social problems are largely within their jurisdiction*". The second view was defined by McKeown and Lowe who stated, that "*Social medicine is concerned with a body of knowledge and methods of obtaining knowledge appropriate to a discipline. This discipline may be said to comprise epidemiology and the study of the medical needs of society, or in the contemporary short hand medical care.*".

In the years after World War II medicine itself became more and more specialized and less and less able to recognize that to deal with more than biological determinants of health and apply this knowledge effectively, requires work with a broad range of professions and organizations. To deal with social, economic, and behavioural determinants of health as well as with globalization, digitalization and demographic changes, medical doctors cannot practise social medicine alone.

### 1.1.1 History and principles of Social Medicine

As the forerunner of social medicine, the science of medical police can be regarded. Its scientific basis was laid by the German physician and professor of medicine in Pau, and later in Vienna, **Johann Peter Frank** (1754-1821). His work "A system of complete medical police" was based on the idea that social factors are crucial to the development of a health impairment (Seidler, 1991). **The term "social medicine" appeared for the first time in 1848.**

French physician **Jules René G. Guérin** (1801-186) opened a current column in his Gazette Médicale de Paris, entitled "Médecine Sociale". The title should more accurately characterize and replace previously used titles such as "police médicale", "hygiéne publique", or "médecine légale" (Hegyi, Takacova, 2004). He appealed to the French medical profession and argued that achieving the goal could be more effective if knowledge and information on the relationship between medical issues, social factors and public affairs were systematically integrated into the framework of social medicine (Hobson, 1949). In the same year, German physician **Rudolf Virchow** (1821-1902) in his report on the outbreak of typhus in Silesia concluded that the root causes of this epidemic were not biological, but social factors such as poverty, lack of education and democracy (Stonington, Holmes, 2006; Anderson, Smith, Sidel, 2005).

His experience eventually led him to the concept of **artificial epidemics** as "*the attributes of society, products of a false culture or culture that is not available to all classes. These are indicators of defects created by political and social arrangements, and therefore affect predominantly those social classes that do not participate in the benefits of a particular culture*" (Rosen, 1974). As one of the pioneers in understanding these widespread social forces in relation to health, Virchow is till today considered as the founder and "father of social medicine" (Anderson, Smith, Sidel, 2005).

Unfortunately, the fact that "**social and economic conditions profoundly impact health, disease, and the practice of medicine**" remains true and is considered first common principle underlying the term "social medicine" today. Second and third principles are following: "**the health of the population is a matter of social concern**;" and "**society**

**should promote health through both individual and social means.**” (Anderson, Smith, Sidel, 2005). In 1912, German physician **Alfred Grotjahn** (1869-1931) published the book “Social Pathology”, which laid the theoretical basis of social medicine.

After World War I, the institutes of social medicine began to be established at the faculties of medicine - in Utrecht (1918), Berlin (1920), Nancy (1920), Brno (1922) and Prague (1935). After World War II, the number of institutions dealing with bio-social issues increased sharply. As early as 1950, there were more than 50 definitions of social medicine.

### 1.1.2 Social Medicine in contemporary medical practice

Social medicine has gone through its historical development stages and today it is a developed scientific and educational, and in practice very much needed complementary medical discipline. **Social medicine examines how social and economic conditions impact on health, disease and medical practice and supports the conditions that can lead to a healthier society**. Together with epidemiology and hygiene, it is one of the pillars and an important source of knowledge for public health, in terms of strengthening essential public health operations, and especially in relation to public health services i.e. health promotion, health protection and disease prevention (WHO Europe, 2015).

One of the most serious inequalities in recent years has been **health inequalities** that relate to the **unequal distribution of good or bad population health status**. These inequalities have significant social and economic costs both to individuals and societies.

Most of them are due to the uneven impact of **social determinants**, i.e. social conditions in which people were born, grow up, live and work and are therefore considered unacceptable, unfair, not necessary and removable (Wilkinson, Marmot, 2003). In all countries, no matter whether belong among low-, middle- or high-income - there are wide disparities in the health status of different social groups. The lower an individual’s socio-economic position, the higher their risk of poor health.

Although physicians generally recognize that these social determinants influence the health of their patients, many are unsure how they can intervene. An increasing existence of evidence (e.g. clinical decision aids, practice guidelines and other tools) provides guidance on a number of concrete actions that **physicians and allied health workers can use to address social determinants in their day-to-day practice** to improve patient health and reduce inequalities (Andermann, 2016):

- A new generation of physicians need to understand why some patients are easier to adopt a health care plan than others, which conditions are the cause of these differences and how they can prevent them;
- At the patient level, they can be alert to clinical flags, ask patients about social problems in a sensitive and caring way, and help them access benefits and support services;
- At the practice level, they can offer culturally safe services, use patient navigators where possible, and ensure that care is accessible to those most need it;
- And at the community level, they can work with local organizations and public health, get engaged in health planning and advocate for supportive environments for health.

Although physicians and allied health workers can take action at these various levels, there are multiple barriers identified to adopting a social determinants of health approach in clinical practice (Table 1). Nonetheless, many of these barriers can be overcome (Andermann, 2016).

**Table 1.** Overcoming barriers to adopting a social determinants of health approach in clinical practice.

| Barrier | Facilitator |
|---|---|
| Medical model bias and the treatment imperative in health care | Health care provider reminder and recall systems to adopt a more holistic and biopsychosocial approach |
| Patients who experienced prior stereotyping and discrimination in clinical care | Treating patients with dignity and respect and creating "safe spaces" for disclosure |
| Physicians feeling overwhelmed, overworked and lacking time | Taking a few extra minutes per consultation to address complex health and social needs |
| Physicians not knowing what resources exist in the local community | Providing a mapping of benefits and local referral resources for specific social challenges |
| Physicians unsure of what concrete actions to take to address social determinants | Resources, training and ongoing support of physicians and allied health care workers |

Source: Andermann, 2016.

Another important determinant of population health contributing to health inequalities is **health care**. Its long-term sustainability, in the context of current health systems, requires changes at several levels especially at the level of policies, funding, legislation, organizational structure, and further education of health workers. Therefore, one of the important tasks of social medicine is linked to support of the implementation of **evidence-based** and **patient-oriented integrated (health and social) care** into the process of transforming healthcare systems.

## 1.2 APPROACHES TO HEALTH AND DISEASE

### 1.2.1 Determinants of health and disease

Everybody knows that being not-healthy means not only having physical problems but also experiencing psychological and social negative changes. That is why the World Health Organization (1948) defined **health** as "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*". And today the spiritual dimension of health is also increasingly recognized.

Health is regarded by the WHO as a **fundamental human right**, and correspondingly, all people should have access to basic resources for health (WHO, 1998). The WHO definition of health goes beyond disease categories. It is reinforced today by a perception of **health as an outcome of a wide range of political, social and economic developments and as an asset linked to individuals, communities and societies' capabilities and resources**. Accepting this complexity is a key characteristic of a 21st century perspective of health and health risks (WHO, 2014).

### Illness-Wellness Continuum

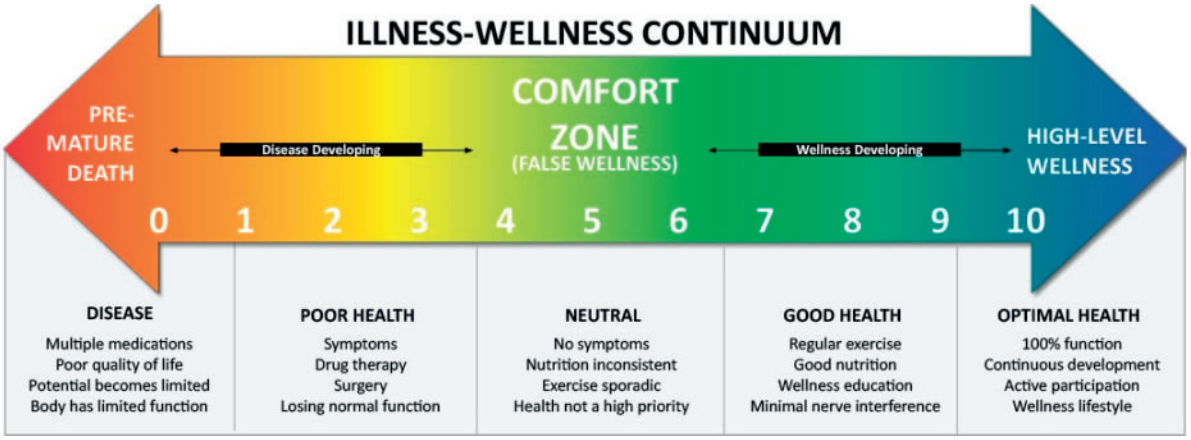
Most of us have tendency to think of wellness (well-being, health) in terms of illness; we simply assume that the absence of illness indicates wellness. However, both, wellness and illness are not presenting a static state. There are actually several degrees of wellness, as well as several degrees of illness recognised.

In 1972, for the first time John Travis envisioned the "**Illness-Wellness Continuum**" as a result of merging the health risk continuum created by Lewis Robbins and Abraham Maslow's concept of self-actualization (Strohecker, 2015). As seen at Figure 1, it is two arrows in opposite direction which can be viewed at as the “positive” vs. “negative “, or “pre-mature death” vs. “high-level wellness”. The direction towards the pre-mature death represents sub-optimal function, disease, disability and poor quality of life, and deals with surgeries, and medications to manage pain, blood pressure, diabetes, and other chronic diseases. In the centre of the continuum there is the “comfort zone”, where most are satisfied to be, but it can be a slippery slope to maintain. The direction towards to high-level wellness involves providing good care to our physical self, using our mind constructively, expressing our emotions effectively, being creatively involved with those around us, and being concerned about our physical, psychological, and spiritual environments.

Pre-mature death and high level wellness are independent states and eliminating negative conditions does not create automatically positive conditions. To achieve high level wellness, specific efforts must be taken, supportive, nurturing, and encouraging environment must be consciously and thoughtfully developed and improved continuously (Becker, 2013).

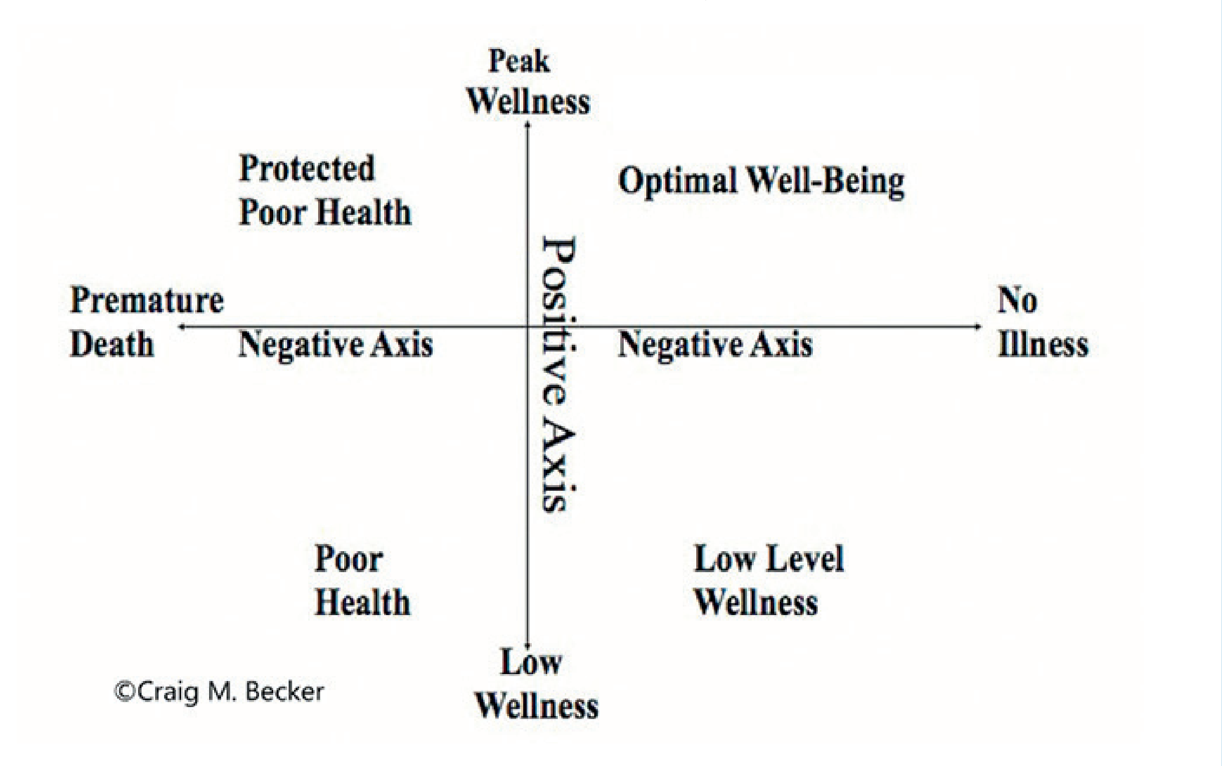
From this perspective a more appropriate is the “**Two-dimensional Model of Illness and Wellness**” developed by Craig Becker and the National Wellness Institute and showing positive and negative states on different axes (Fig. 2). Even so, today’s approach to health and wellness is within health systems (medical practice) still more frequently based on what is wrong, instead of what is right.

**Figure 1.** The Illness-Wellness Continuum by J. Travis.



Source: http://www.physioac.com/illnesswellnesscontinuum.html

**Figure 2.** The Two-dimensional Model of Illness and Wellness by C. Becker



Source: http://kchealthandwellness.com/what-is-the-role-of-physical-therapy-for-your-upper-right-quadrant/

## Determinants of health – main models

All factors affecting our health are today known collectively as **determinants of health**. This term was for the first time used in 1972 by **Thomas McKeown** - a British physician, epidemiologist and historian of medicine, who argued that these influences should be considered in framing health policy and in any efforts to improve the health of the population (Glouberman, Millar, 2003).

Health determinants can influence our health in either a positive or negative way. Determinants affecting our health in a positive way are known as **protective factors**. Examples of positive determinants are: good nutrition, regular physical activity or safe sexual behaviours. All these help with maintaining good and optimal health, and can assist in effective management of health conditions.

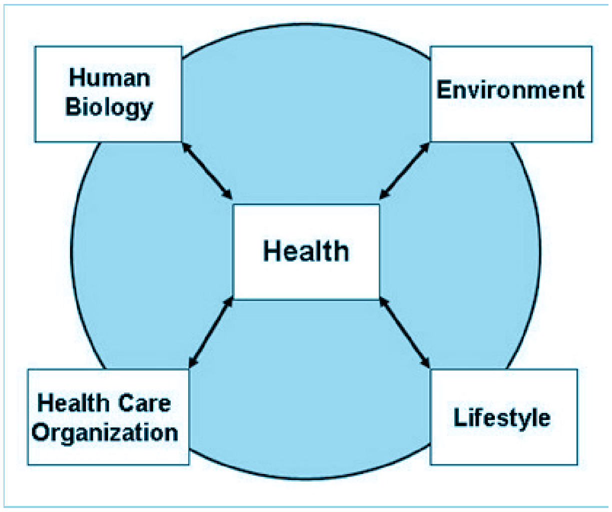
Determinants affecting our health in a negative way are commonly referred to as **risk factors**. They can increase the likelihood of developing chronic disease, or hinder (in) the management of existing conditions. For example, high blood pressure can increase the likelihood of developing cardiovascular disease. Risk factors influence health with varied levels of severity, and measuring this can be quite complex. During the last decades several models have been developed to describe all potential health determinants and their interrelationships on different levels.

Using McKeown's ideas the first framework was developed in Canada. **Lalonde's Health Field Concept** (1974) identified four broad elements related to health (Fig. 3):

» Human biology includes the genetic inheritance of the individual, the processes of maturation and aging, and the many complex internal systems in the body, and contributes to many chronic diseases (such as arthritis, diabetes, atherosclerosis, cancer) and others (genetic disorders, congenital malformation, mental retardation).

- Environment includes all those matters which are external to the human body and over which the individual has little or no control e.g. quality and safety of foods, drugs, water supply, and air, but also the social environment.
- Lifestyle consists of the set of decisions by individuals over which they more or less have control, and if these personal decisions e.g. on diet, physical activity, or using drugs, are bad, from a health point of view, create self-imposed risks.
- Health care organization, generally defined as the health care system, consists of the quantity, quality, arrangement, nature and relationships of people and resources needed for the provision of health care.

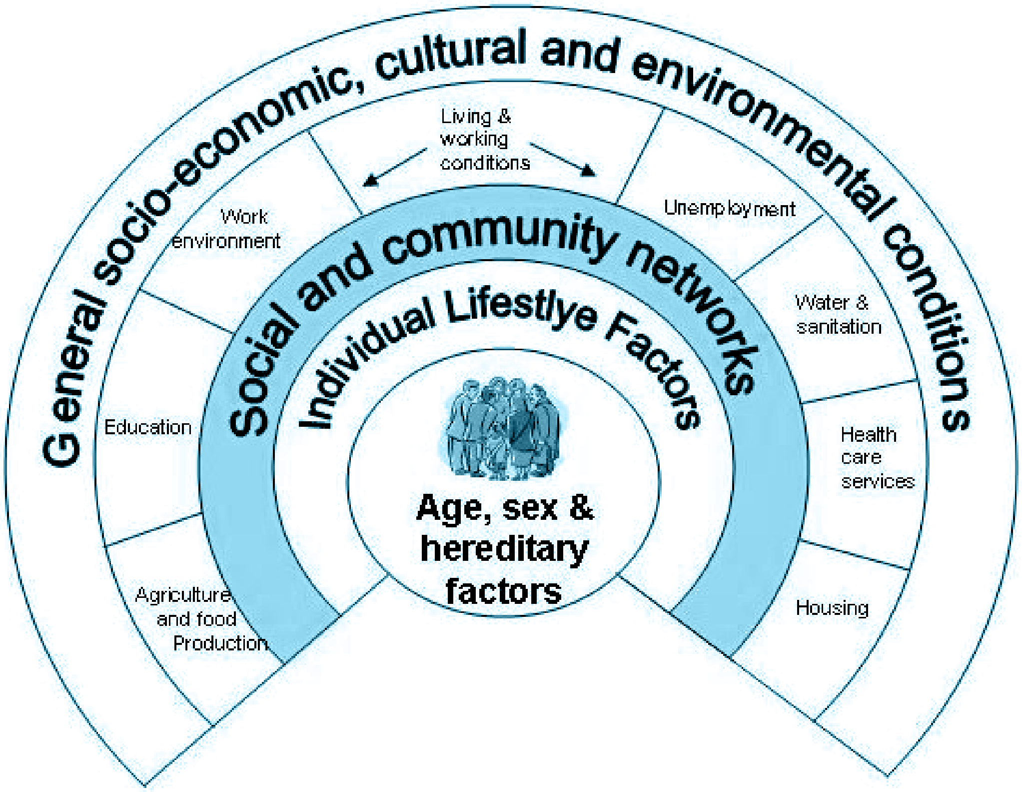
**Figure 3.** Lalonde's Health Field Concept



Source: https://www.med.uottawa.ca/sim/data/Models/Lalonde.htm

**Figure 4.** Lalonde's Health Field Concept

Source: https://www.healthknowledge.org.uk/public-health-textbook/disease-causation-diagnostic/2h-principles-health-promotion/responsibilities-health-physical-mental

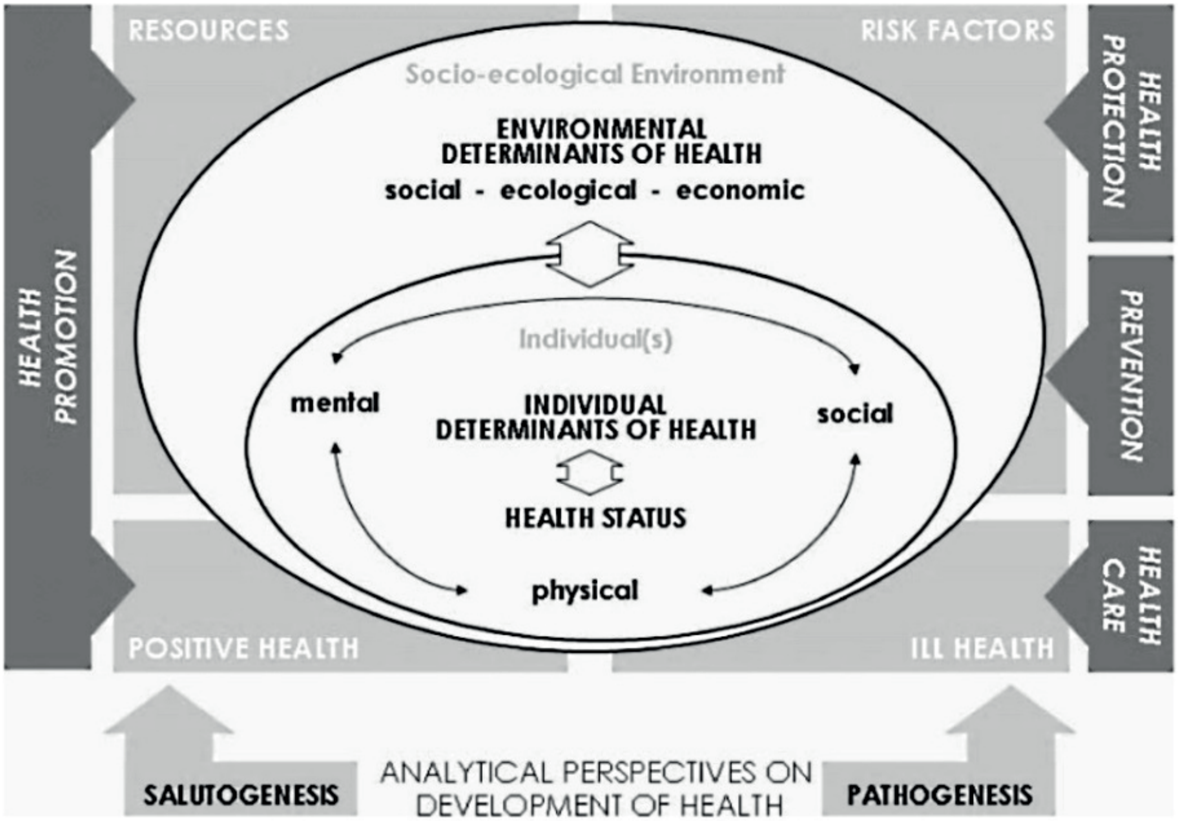


**Dahlgren and Whitehead's model** (1991) highlights a causal relationship between individual lifestyle choices, social networks, working and living conditions and economic, political and environmental factors, globally, nationally and locally (Fig. 4). These forces are highly significant for health, yet they are largely seen as beyond the reach and influence of public health improvement strategies, policies and practices. However, other factors, that can in turn be influenced, extend out in layers from the model's core (Dahlgren, Whitehead, 1991).

One of the latest is the **EUPHID health promotion model** (2006). Following the WHO definition, the model distinguishes three qualitatively different dimensions of health, i.e. the physical, mental and social, which are highly interdependent (Fig. 5). For example, good physical functioning positively influences mental health and supports good social health by facilitating interaction and communication with others. Consistent with the three-dimensionality of health, three closely interrelated dimensions of individual determinants of health are distinguished: the physical (e.g. bodily fitness), mental (e.g. sense of coherence) and social (e.g. accessing social support) dimensions. This distinction allows us and forces us to measure and analyse individual determinants of health in a more differentiated way. Looking beyond the individual, the health of individual(s) is not created and lived in isolation but results from an ongoing, close interaction with their relevant environmental determinants of health, which include social (e.g. density of social networks and cultural diversity), ecological (e.g.

**Figure 5.** EUPHID health promotion model.

Source: Bauer et al., 2006.

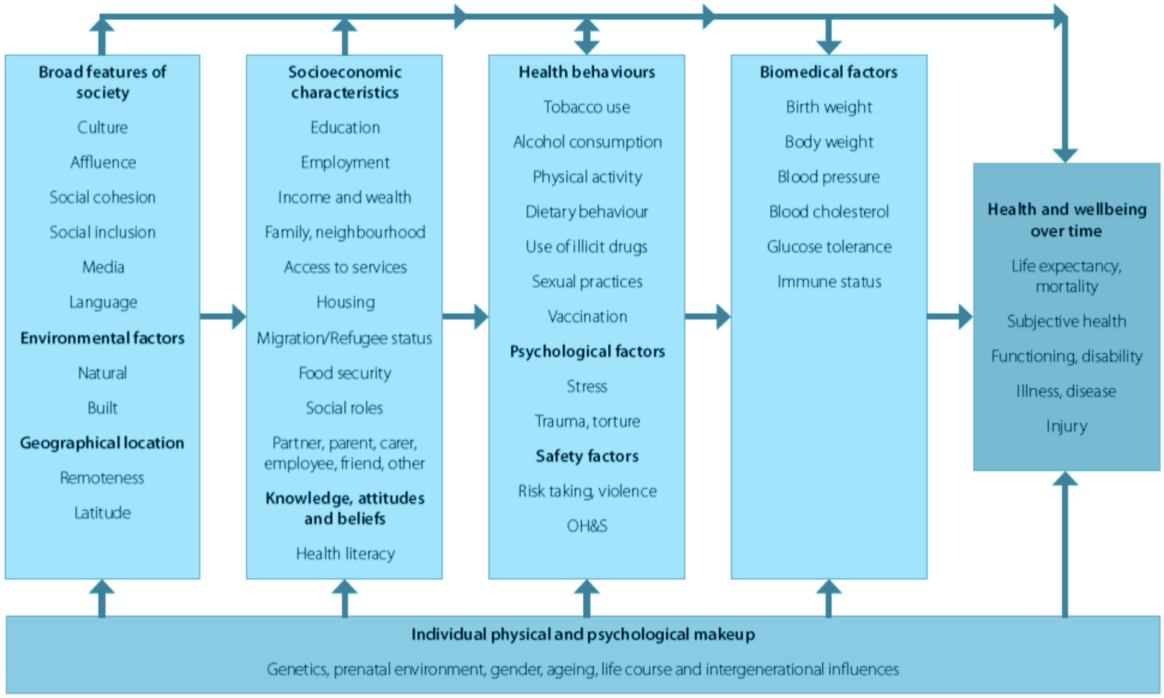


ergonomic workplaces), and economic (e.g. equal income distribution) dimensions. An individual can, depending on his/her capacities, partly influence his/her environment by choice and can try to change it. However, it should be considered that persisting inequities in health status in our societies are in large part due to persisting, unequal distribution of these environmental determinants (Bauer, Davies, Pelikan, 2006).

Health determinants can be thought of as part of broad causal pathways that affect health. Figure 6 presents a conceptual framework of the pathways involved in the health and functioning of individuals and the population. Looking left to right, the framework is divided into four main components that flow from "upstream" (background) factors, which include culture, policies and environment, through to the more immediate (downstream) factors, such as body weight and blood pressure. Non-modifiable factors of individual physical and psychological make-up, such as age and intergenerational influences, underpin these pathways. Although the pathways in the framework are presented as flowing from left to right, it should be noted that sometimes these can happen in reverse. For example, illness or injury can influence a person's health behaviour, such as their ability to do physical activity (AIHW, 2012).

**Figure 6.** A conceptual framework for health determinants.

Source: AIHW, 2012.



## 1.2.2 Health promotion, health protection, and disease prevention

### Public health

From health systems perspective, health promotion, health protection, and disease prevention are currently recognised as "the three Ps of public health". The term "public health" is widely used today, but understandings of it vary among countries in Europe and the term is difficult to translate into some European languages.

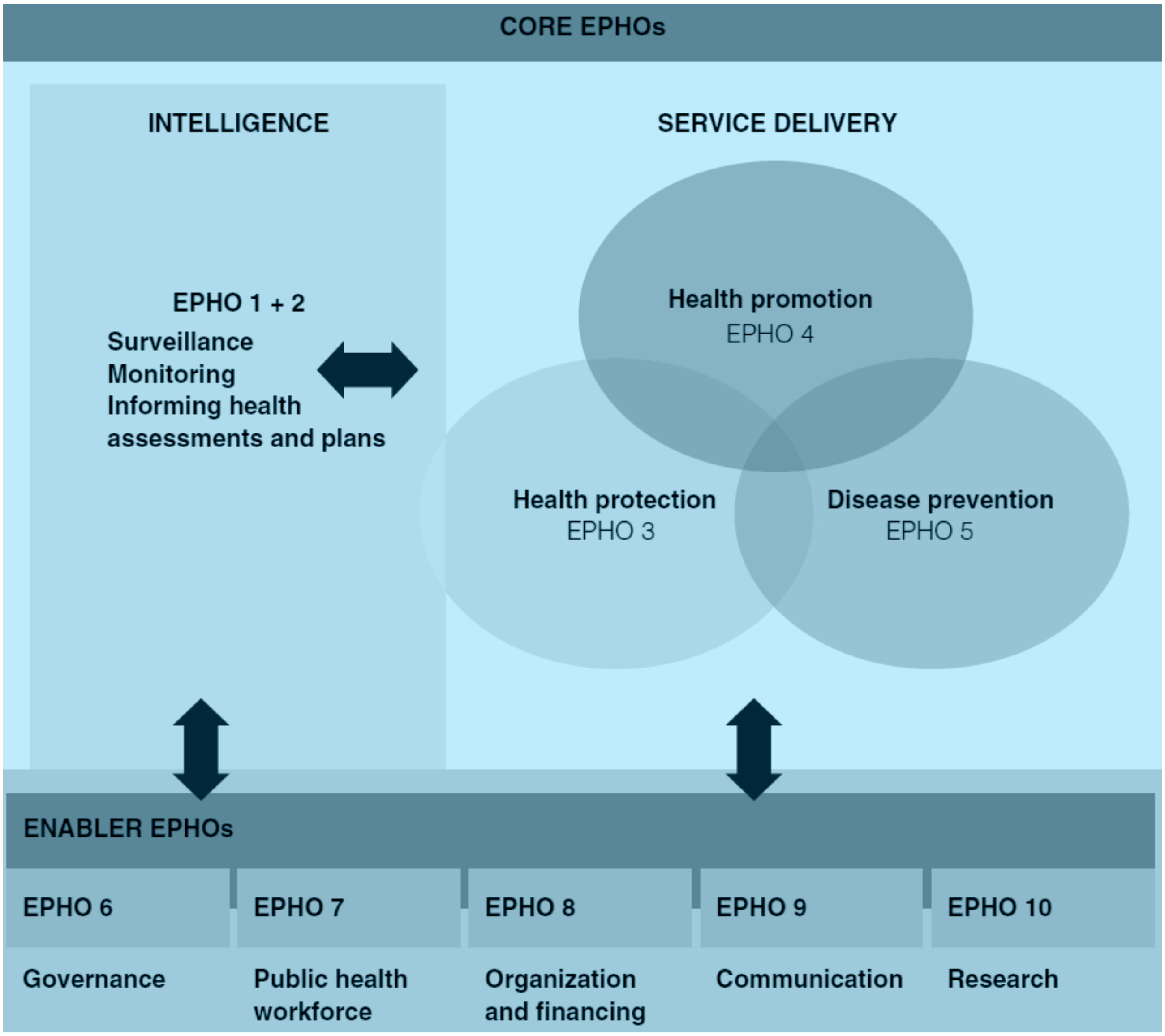
Although there is no generally accepted definition, the WHO European Region uses one of the most modern-day definitions of public health by Sir Donald Acheson (1988): "**Public health is the science and art of preventing disease, prolonging life and promoting health through the organized efforts of society.**". This definition can be traced back to an earlier definition by Charles-Edward Amory Winslow, who in 1920 wrote: "Public health is the science and the art of preventing disease, prolonging life, and promoting physical health and efficiency through organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in personal hygiene, the organization of medical and nursing service for the early diagnosis and preventive treatment of disease, and the development of the social machinery which will ensure to every individual in the community a standard of living adequate for the maintenance of health." (Moreno et al., 2016).

### Essential public health operations

What kinds of actions (activities) are needed to achieve these goals? Since 1994, a number of essential public health services, functions, and operations have been suggested in different parts of the world, including e.g. the United States (1994), Australia (2000), the United Kingdom (2001), and New Zeeland (2011).

In the WHO European region, development of an assessment tool for **essential public health operations (EPHOs)** did not begin in earnest until 2007, when the South-Eastern Europe Health Network began a regional initiative to reform and modernize its health systems. At the same time, the "Tallinn Charter on Health Systems for Health and Wealth" stressed that health systems are more than health care and also encompass disease prevention, health promotion, and efforts to influence other sectors to address health concerns in their policies (Moreno et al., 2016). Significantly, development of the EPHOs became an important pillar of the **European Action Plan for Strengthening Public Health Capacities and Services** (WHO, 2012) and the latest European health policy - **Health 2020** (WHO, 2013). The latest list of EPHOs was published as part of the revised version of the assessment tool released in 2015 (WHO, 2015). The 10 EPHOs are divided into five core and five enabling operations (Fig. 7).

**Figure 7.** The 10 essential public health operations. Source: WHO, 2015.



1. Surveillance of population health and well-being (EPHO 1);
2. Monitoring and response to health hazards and emergencies (EPHO 2);
3. Health protection including environmental, occupational, food safety and others (EPHO 3);
4. Health promotion, including action to address social determinants and health inequity (EPHO 4);
5. Disease prevention, including early detection of illness (EPHO 5);
6. Assuring governance for health (EPHO 6);
7. Assuring a competent public health workforce (EPHO 7);
8. Assuring organizational structures and financing (EPHO 8);
9. Information, communication and social mobilization for health (EPHO 9);
10. Advancing public health research to inform policy and practice (EPHO 10).

## Health promotion

The definition of health promotion as "**the process of enabling people to increase control over their health and its determinants and thereby to improve it**" has been adopted at the First Global Conference on Health Promotion in Ottawa (1986). Health promotion addresses determinants of both communicable and non-communicable diseases and includes the promotion of changes in lifestyle, practices and environmental and social conditions to facilitate societal development among individuals and the community that promotes public health and reduces societal inequalities in health across the social gradient, promoting a "culture of health" among individuals and the community (WHO, 2015).

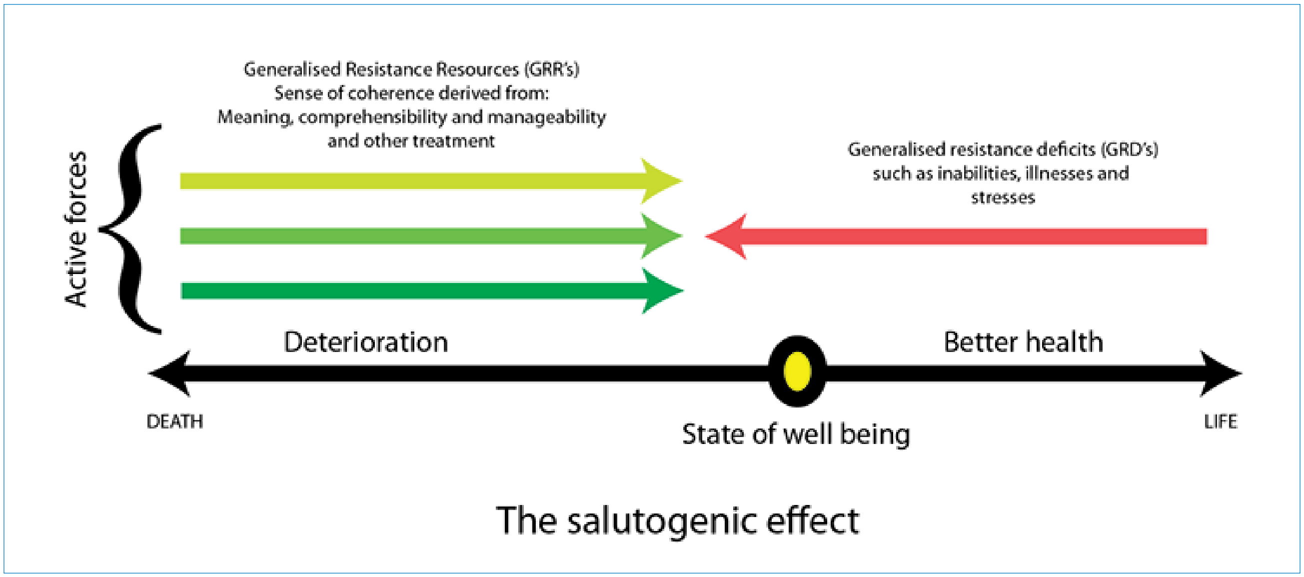
### *Salutogenetic approach to health is crucial*

Development of health promotion concept is very significantly connected with an Israeli American medical sociologist **Aaron Antonovsky** (1979-1994) and his salutogenetic theory of three resources that combine to provide a Sense of Coherence – a forward thrust that resists the entropic forces of illness and infirmity (Fig. 8). The sense of coherence is made up of resources that:

- improve manageability – the capacity to maintain homoeostasis and physical function;
- improve comprehensibility – an ability to negotiate circumstances in order to maximise their benefit; and
- enrich a sense of meaningfulness – the desires, causes and concerns that give us the need to resist illness in the first place.

**Figure 8.** Salutogenetic effect on health.

Source: http://psychological.design/salutogenics.html



**The salutogenic orientation** is a radically different approach than the pathogenic orientation. Through six different aspects, Antonovsky illustrated the distinction between salutogenesis and pathogenesis as he saw it (Table 2). He claimed that these six different aspects have implications for research, for understanding health and illness, and for clinical practice. His fundamental philosophical assumption was that all human beings are in the "river of life". Nobody stays on the shore. Much of the river is polluted, and there are forks in the river that leads to gentle streams or to dangerous rapids and whirlpools. This metaphor illustrates that the prototypical characteristic of the living organism is the heterostasis (Vinje et al. 2017).

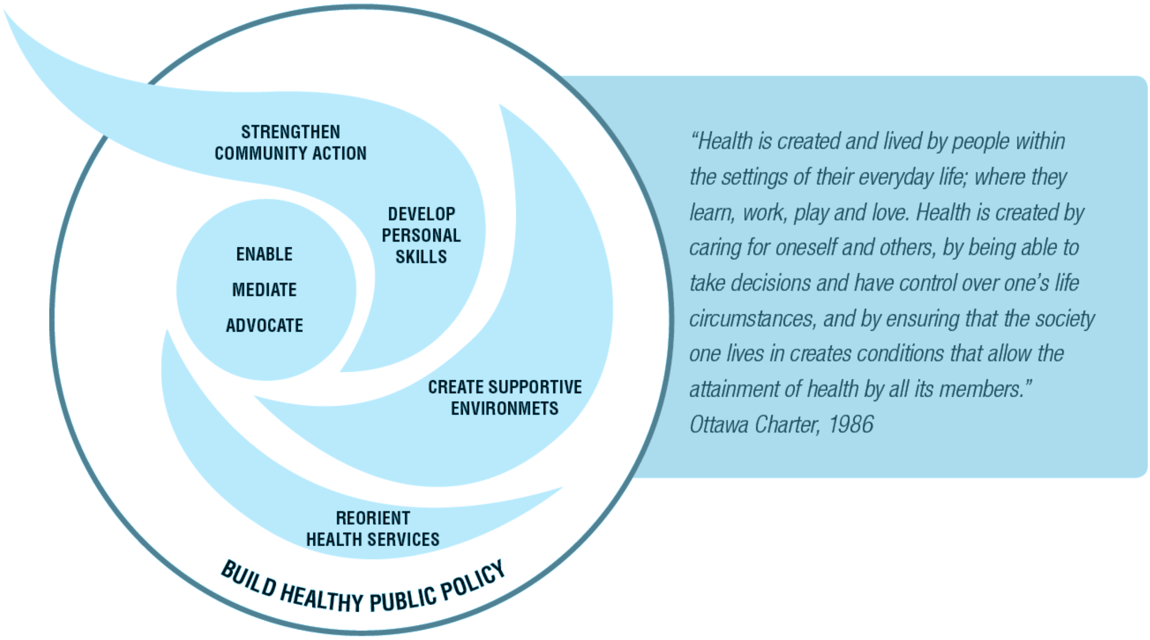
**Table 2.** A summary of six main aspects of the salutogenic and the pathogenic orientation as presented by Antonovsky in Unravelling the Mystery of Health (Antonovsky, 1987).

| SALUTOGENIC ORIENTATION | PATHOGENIC ORIENTATION |
|---|---|
| **Heterostasis** | **Homeostasis** |
| 1. Health ease - dis/ease continuum | 1. Healthy/sick dichotomy |
| 2. The history of the person | 2. The person's disease / diagnosis |
| 3. Salutary factors | 3. Risk factors |
| 4. Stressors and tension might be pathogenic, neutral or salutary | 4. Stress is pathogeni |
| 5. Active adaptation | 5. The magic bullet |
| 6. The "deviant" case | 6. Hypothesis confirmation |

Source: Vinje et al., 2017.

**Figure 9.** Health priority areas. Source: WHO, 2017.

Source: WHO, 2017.



*"Health is created and lived by people within the settings of their everyday life; where they learn, work, play and love. Health is created by caring for oneself and others, by being able to take decisions and have control over one's life circumstances, and by ensuring that the society one lives in creates conditions that allow the attainment of health by all its members."*
*Ottawa Charter, 1986*

*Priority areas of health promotion*

Health promotion action means (Fig. 9):

**Build Healthy Public Policy**

Health promotion puts health on the agenda of policy makers in all sectors and at all levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health. The leading country strengthening the health in all policies approach among the EU countries was Finland (during its EU presidency in 2006 and 2013).

**Create Supportive Environments**

The inseparable relations between people and their environment constitutes the basis for a socioecological approach to health. Health promotion supports creating living and working conditions that are safe, stimulating, satisfying and enjoyable.

The protection of the natural and built environments and the conservation of natural resources must be addressed in any health promotion strategy. Systematic health impact assessment of a rapidly changing environment - particularly in areas of technology, work, energy production and urbanization - is essential and must be followed by action to ensure positive benefit to the population health.

**Strengthen Community Actions**

Community development draws on existing human and material resources in the community. Health promotion works through specific and effective community involvement in setting priorities, making decisions, planning strategies and implementing them to achieve better health. At the centre of this process is the empowerment of communities - their ownership and control of their own endeavours and destinies.

**Develop Personal Skills**

To increase the options available to people to exercise more control over their own health and over their environments, and to make choices conducive to health, enabling people to learn and to prepare themselves for all stages of life is essential. Health promotion participate in this process by supporting personal and social development through providing information, education for health, and enhancing life skills.

**Reorient Health Services**

The role of the health sector must move increasingly in a health promotion direction. Health services need to embrace an expanded mandate which should support the total needs of the individual as a whole person, the needs of communities for a healthier life, and open channels between the health sector and other - social, political, economic and physical environmental sectors. It also requires stronger attention to health research as well as changes in professional education and training, attitudes, and organization of health services.

*Health promotion in the SDG era*

In 2016, at the latest Global Conference on Health Promotion, The Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development was adopted. The declaration contains clear statements advocating (WHO, 2017):

- improved governance for health at all levels;
- the development of healthy cities that are inclusive, safe and resilient; and
- the importance of health literacy to empower individual citizens and enable their engagement in collective health promotion action.

Furthermore 12 tips to be healthy were presented with aim to increase public awareness on health related behaviour (Fig. 10).

**Figure 10.** WHO – 12 tips to be healthy.

Source: https://www.who.int/healthpromotion/conferences/9gchp/infographic_health_promotion_12_tips.jpg?ua=1

## Health protection

Health protection includes **risk assessments and actions needed for environmental, occupational safety, food safety and others**. Public health authorities supervise enforcement and control of activities with health implications. It also includes the institutional capacity to develop regulatory and enforcement mechanisms to protect public health and monitor compliance with accepted norms, as well as the capacity to generate new laws and regulations aimed at improving public health and promoting healthy environments (WHO, 2015). At the EU level there are several agencies operating meaningfully in the field of health protection:

**European Agency for the Evaluation of Medicinal Products (EMEA)**

The EMA is responsible for the scientific evaluation, supervision and safety monitoring of **medicines** in the EU. It protects public and animal health in the EU Member States, as well as the countries of the European Economic Area, by ensuring that all medicines available on the EU market are safe, effective and of high quality (https://www.ema.europa.eu/).

**European Agency for Safety and Health at Work (EU-OSHA)**
The EU-OSHA contributes to the European Commission's Strategic Framework for Safety and Health at work 2014-2020 and other relevant EU strategies and programmes, such as Europe 2020. The EU-OSHA works to make European **workplaces safer, healthier and more productive** - for the benefit of businesses, employees and governments. It promotes a culture of risk prevention to improve working conditions (https://osha.europa.eu).

**European Centre for Disease Prevention and Control (ECDC)**
The ECDC is aimed at strengthening Europe's defences against **infectious diseases**. Its core functions include: surveillance, epidemic intelligence, response, scientific advice, microbiology, preparedness, public health training, international relations, health communication, and the scientific journal Eurosurveillance. The ECDC monitors 52 communicable diseases and its disease programmes cover antimicrobial resistance and healthcare-associated infections; emerging and vector-borne diseases; food- and waterborne diseases and zoonoses; HIV, sexually transmitted infections and viral hepatitis; influenza and other respiratory viruses; tuberculosis; and vaccine-preventable diseases (https://ecdc.europa.eu/en/home).

**European Environment Agency (EEA)**
The EEA aims to support sustainable development by helping to achieve significant and measurable improvement in Europe's **environment**, through the provision of timely, targeted, relevant and reliable information to policymaking agents and the public. Through The European environment information and observation network (Eionet), it brings together environmental information from individual countries and supports environmental management processes, environmental policymaking and assessment, as well as citizen participation (https://www.eea.europa.eu/).

**European Food Safety Authority (EFSA)**
The EFSA is a source of scientific advice and communication on risks associated with the food chain. As the risk assessor, EFSA produces scientific opinions and advice that form the basis for European policies and legislation in the following areas: food and feed safety, nutrition, animal health and welfare, plant protection, plant health, and possible impact of the food chain on the biodiversity of plant and animal habitats. It has delivered scientific advice on a wide range of issues such as Bovine Spongiform Encephalopathy, Salmonella, food additives such as aspartame, allergenic food ingredients, genetically modified organisms, pesticides, and animal health issues such as avian influenza (http://www.efsa.europa.eu).

**European Monitoring Centre for Drugs and Drugs Addiction (EMCDDA)**
The EMCDDA provides the EU and its Member States with a factual overview of European **drug problems** and a solid evidence base to support the drugs debate. It offers policymakers the data they need for drawing up informed drug laws and strategies. It also helps professionals and practitioners working in the field pinpoint best practice and new areas of research (http://www.emcdda.europa.eu).

## Disease prevention

Disease prevention is aimed at both communicable and non-communicable diseases, and has specific actions largely delivered to the individual. It is complement to health promotion and health protection, but its content and strategies are defined separately, and related to **identifiable risk factors and risk behaviours**. There are four levels of services provided within the disease prevention (WHO, 2015):

*Primary prevention services*

- vaccination of children, adults and the elderly;
- vaccination or post-exposure prophylaxis for people exposed to a communicable disease;
- provision of information on behavioural and medical health risks and consultation and measures to decrease them at the personal and community levels;
- maintenance of systems and procedures for involving primary health care and specialized care in disease prevention programs;
- production and purchasing of childhood and adult vaccines;
- storage of stocks of vaccines; and
- production and purchasing of nutrition and food supplements.

*Secondary prevention services*

- evidence-based screening programs for early detection of diseases;
- maternal and child health programs, including screening and prevention of congenital malformations;
- production and purchasing of chemo-prophylactic agents;
- production and purchasing of screening tests for the early detection of diseases; and
- ensuring capacity to meet current or potential needs.

*Tertiary prevention services*

- rehabilitation of patients with an established disease to minimize residual disabilities and complications and maximize potential years of enjoyable life, thereby improving quality of life even if the disease itself cannot be cured.

*Quaternary prevention services*

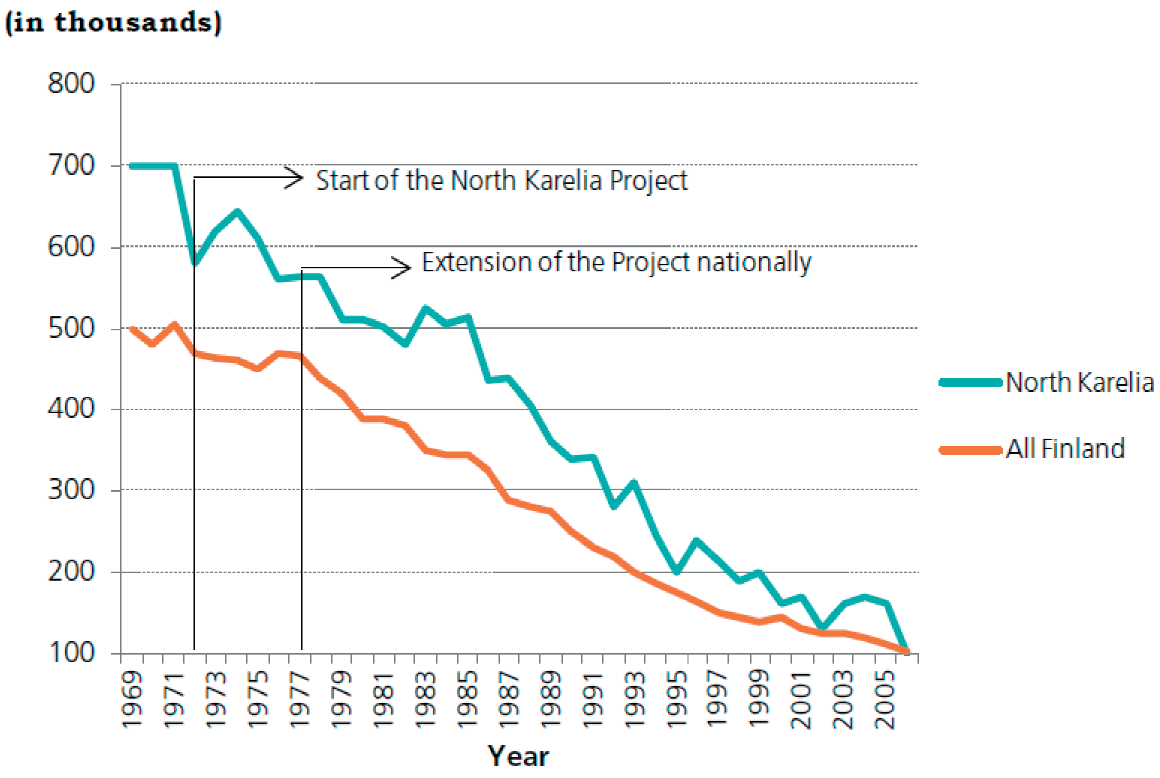
- avoiding over medicalization of patients, protecting them from unnecessary interventions and suggesting ethical alternatives.

*Does prevention make a difference?*

In the early 1970s, the coronary heart disease mortality rate in Finland was the highest in the world. The most affected was the North Karelia region, where in every family, physically active men in their prime were dying prematurely (Baril, 2013). The goal of the **North Karelia Project** - to reverse the situation by changing the population's lifestyles - was successfully attained. Over a 35-year period, **cardiovascular disease mortality rates dropped 85% among North Karelian men 35 to 64 years of age** (Fig. 11).

**Figure 11.** Decline in the mortality rate* by coronary heart disease among men 35 to 64 years of age, from 1969 to 2006, in North Karelia and all of Finland.

*Mortality per 100 000 individuals; adjusted for age based on the European population.



Source: TOPO, 2013.

The project's strategy involved the following actions (Baril, 2013):

- Improving preventive services to help the public identify its risk factors and devote the desired attention to them;
- Disseminating information on the relationship between health and lifestyles;
- Persuading people to get involved in efforts targeting their health;
- Training people, providing them with new skills to make them more capable of managing their habits and environment;
- Ensuring that social support be provided to encourage individuals committed to change to pursue their efforts;
- Implementing environmental changes that tackle obstacles to healthy lifestyles and that create new possibilities to make better choices for one's health; and
- Joining forces with local organizations and mobilizing the community to create a social climate conducive to the adoption of healthy lifestyles.

The winning aspects of the North Karelia project (Baril, 2013):

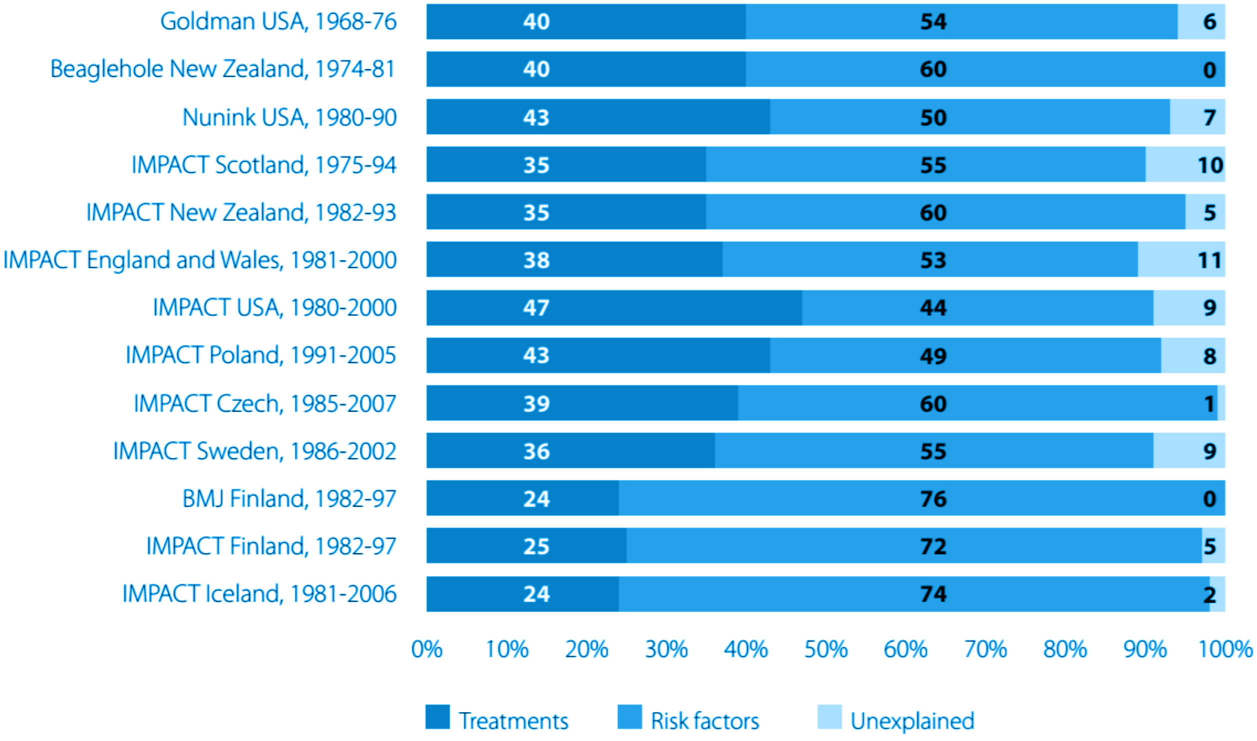
- Adopting a long-term vision.
- Maintaining close ties with the political bodies and decision makers concerned.
- Making the theoretical bases of the intervention explicit.
- Influencing individual and environmental factors.
- Using the media and a variety of channels for disseminating information.

- Involving champions and influential community members in the project.
- Developing collaborative cross-sector ways of changing environments.
- Mobilizing structures and networks existing in the community

In 1972, the approach of mobilizing an entire population to change its lifestyles was very innovative. The leading role in the project was given to a young graduate **Dr. Pekka Puska** (only 27 years old). In 1978 he was named project director and would provide the project with continuity for 25 years. With his medical training, completed a master's degree in social and political science, experiences and interests he was prepared to adopt such approach successfully. Today, he claimes that "*changing the world may have been utopic, but changing public health was possible.*" (Baril, 2013).

The North Karelia project is not the only study which has resulted to decline in coronary heart disease mortality through preventing rather than treating the consequences of disease. A reduction in risk factors - such as reducing cholesterol, blood pressure and smoking, and increasing physical activity - has been observed in many countries and accounted for an estimated 50–70% of the decline in global coronary heart disease mortality, with treatment contributing approximately 25–50% (Fig. 12).

**Figure 12.** The Contribution of treatment and risk factor reduction to the decline of global coronary heart disease mortality.



Source: Ford et al., 2007.

## Cancer screening in the European Union

In the EU, cancer is the second most common cause of deaths, next to the diseases of the circulatory system (cerebrovascular disease, ischemic heart disease and other heart diseases) is cancer. The evidence shows that population-based screening programmes play important role in early diagnosis and treatment leading to more promising prognosis and overall quality of life.

All the EU countries except Bulgaria, Greece and Slovakia have population-based **breast cancer screening** programmes which include mammography (digital or film screen). For the majority of the programmes (16/25; 64.0%), the target population is women in the age group of 50-69 years and the interval between two rounds of screening is 2 years for most of the countries except Malta and United Kingdom with 3-year interval (IARC, 2017). Slovakia announced the beginning of the implementation for the year 2019.

The implementation of cervical cancer screening across the EU countries varies more than the breast cancer screening. Population-based **cervical cancer screening** programmes exist in 22 Member States either nationally or regionally, including Germany and Slovakia that have taken steps to implement nationwide population-based programmes in the year 2016. Most countries have raised the screening intervals to 3-5 years (IARC, 2017).

Population-based **colorectal cancer screening** programmes have been implemented nationally or regionally in 20 EU countries and the majority of them have completed the rollout. Estonia initiated a population-based pilot screening programme in 2016, and non-population-based programmes are ongoing in Germany, Greece and Latvia. Additionally, Germany and Luxemburg have planned to start population based programme in 2016. The most common screening test used in the EU is the immuno-chemical faecal occult blood test (iFOBT or FIT), followed by the guaiac-based faecal occult blood test (gFOBT), endoscopy, or flexible sigmoidoscopy (IARC, 2017).

## What works

Current trends predict unsustainable increases in the costs of ill health unless **cost-effective preventive approaches** are put in place. These approaches can contribute to health outcomes improvements at lower and more sustainable costs, while supporting universal health coverage. If nothing is done the cost of health care will double by 2050 and it will bring strain on health and social systems which may decrease the quality of care and increase the risk of health inequalities widening.

The evidence shows that prevention is cost-effective in both the short term ("quick wins") and longer term (WHO, 2014). There is a wide range of cost-effective preventive approaches including interventions that address the environmental and social determinants of health, build resilience and promote healthy behaviours, as well as vaccination and screening (Fig. 13):

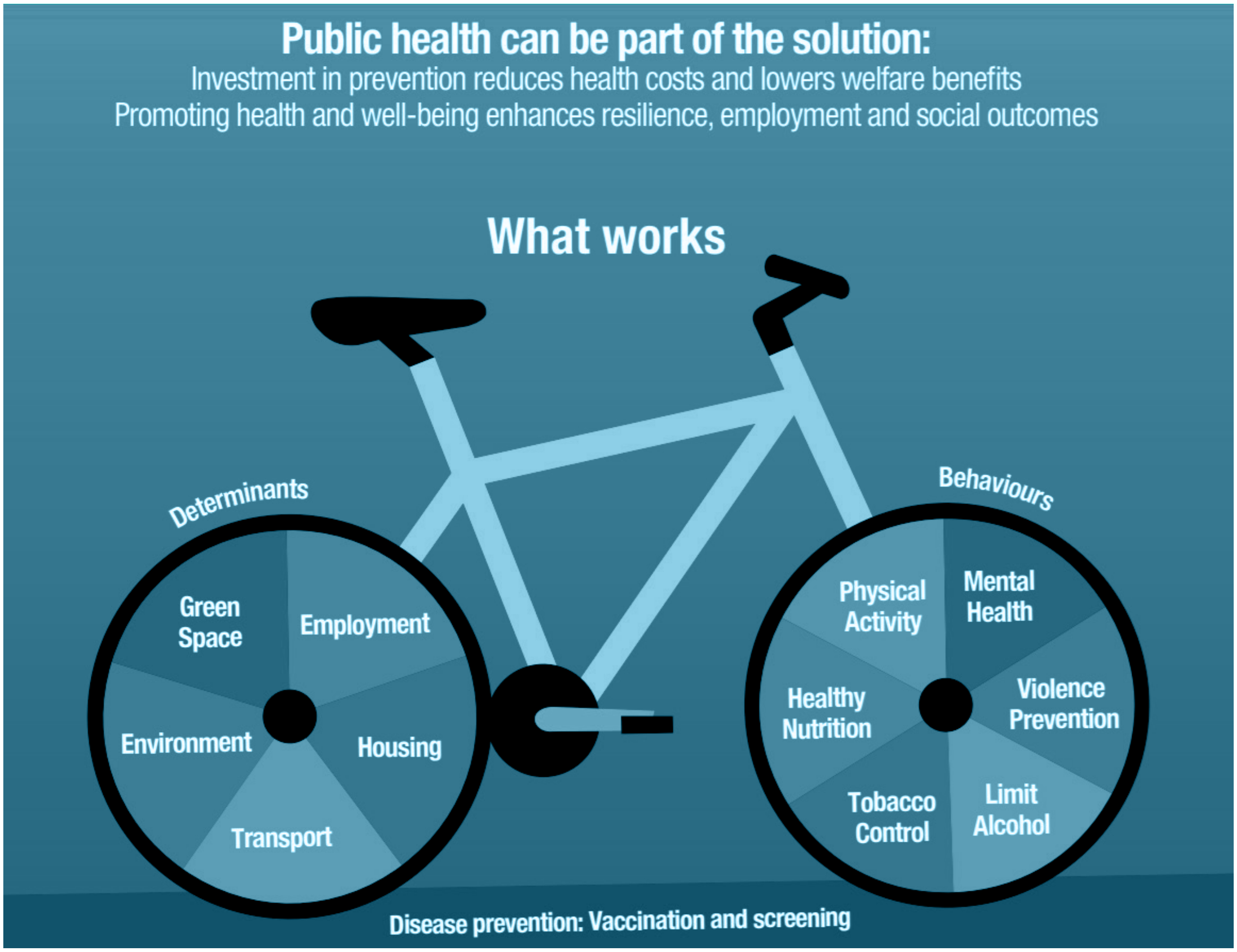
» Highly cost-effective interventions for non-communicable diseases include tobacco and alcohol legislation, reducing salt and increasing physical activity.

» Interventions that affect health behaviours and enhance resilience (including improving mental health and reducing violence) can result in short-term and longer-term returns on investment, with improved and social benefits.

- Interventions addressing social and environmental determinants such as promoting walking and cycling, green spaces, or safer transport show early returns (1-2 years) on investment, with additional social and environmental benefits.
- Disease prevention interventions such as vaccinations generally achieve a good return on investment, while some screening programmes are shown to be cost-effective.

**Figure 13.** Cost-effective public health interventions.

Source: WHO, 2013.



### 1.2.3 Biomedical and biopsychosocial models of disease

*The **good** physician treats the **disease**; the **great** physician treats the **patient** who has the disease.*

William Osler (1849 – 1919), Canadian physician,
one of the Big Four founding professors
at Johns Hopkins Hospital.

#### Biomedical models

Since the mid-20th century the biomedical models had dominated industrialized societies. These models are clearly relevant for many diseases based illnesses, have intuitive appeal, and are supported by a wealth of supporting biological findings. Such models combine several closely related sets of beliefs (Wade & Halligan, 2004):

- All illness and all symptoms and signs arise from an underlying abnormality within the body (usually in the functioning or structure of specific organs), referred to as a disease;
- All diseases give rise to symptoms, eventually if not initially, and although other factors may influence the consequences of the disease, they are not related to its development or manifestations;
- Health is the absence of disease;
- Mental phenomena, such as emotional disturbance or delusions, are separate from and unrelated to other disturbances of bodily function;
- The patient is a victim of circumstance with little or no responsibility for the presence or cause of the illness; and
- The patient is a passive recipient of treatment, although cooperation with treatment is Expected.

The advantages of biomedical models are:

- Large role in prolonging life expectancy;
- Decreases mortality rate;
- Creates advances in research and technology (e.g. antibiotics);
- Common problems treated effectively;
- Improves quality of life;
- Everyone can benefit, even low SES (e.g. in USA it is subsidised through Medicare).

The disadvantages of biomedical models are:

- COSTLY as it relies on professional health workers and technology, specialist knowledge and specialist machines;
- DOESNT ALWAYS PROMOTE GOOD HEALTH as it encourages reliance on quick fix solution as the focus
- is on condition itself and not determinants that caused it, does not encourage people to be responsible for their own health;
- Although some treatments are subsidised, ongoing treatment may be needed meaning it may be more expensive, even with safety net, some may be unable to afford it;
- Doesn't take into account the impact of other factors like social determinants;
- Ignores mental and social aspects of health;
- NOT EVERYTHING CAN BE TREATED as those relying on biomedical model to restore health may experience untreatable conditions e.g. cancer, treatment no cure;
- AFFORDABILITY as not everyone can afford the medical technologies and resources required.

### Biopsychosocial models

**George Libman Engel** (1913 - 1999), an American psychiatrist, believed that to understand and respond adequately to patients' suffering, and to give them a sense of being understood - **medical doctors must approach simultaneously to the biological, psychological, and social dimensions of illness**. He offered a new holistic model known as the biopsychosocial model (Borrell-Carrio et al., 2004).

In 1977 he wrote: "*The dominant model of disease today is biomedical, with molecular biology its basic scientific discipline. It assumes diseases to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioural dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent of social behaviour, it also demands that behavioural aberrations be explained on the basis of disordered somatic (biochemical or neurophysiological) processes.*" (Engel, 1977). Engel's ideas were crucial for reversing the dehumanization of medicine and disempowerment of patients and for bringing more empathy and compassion into medical practice (Table 3).

**Table 3.** Engel's Critique of Biomedicine.

Source: Borrell-Carrio et al., 2004.

1. A biochemical alteration does not translate directly into an illness. The appearance of illness results from the interaction of diverse causal factors, including those at the molecular, individual, and social levels. And the converse, psychological alterations may, under certain circumstances, manifest as illnesses or forms of suffering that constitute health problems, including, at times, biochemical correlates
2. The presence of a biological derangement does not shed light on the meaning of the symptoms to the patient, nor does it necessarily infer the attitudes and skills that the clinician must have to gather information and process it well
3. Psychosocial variables are more important determinants of susceptibility, severity, and course of illness than had been previously appreciated by those who maintain a biomedical view of illness
4. Adopting a sick role is not necessarily associated with the presence of a biological derangement
5. The success of the most biological of treatments is influenced by psychosocial factors, for example, the so-called placebo effect
6. The patient-clinician relationship influences medical outcomes, even if only because of its influence on adherence to a chosen treatment
7. Unlike inanimate subjects of scientific scrutiny, patients are profoundly influenced by the way in which they are studied, and the scientists engaged in the study are influenced by their subjects

Engel's biopsychosocial model was a call to change the way of understanding the patient and to expand the domain of medical knowledge to address the needs of each patient. These theoretical principles play important role in developing a **biopsychosocial-oriented clinical practice** that consists of following pillars (Borrell-Carrio et al., 2004):

(1) self-awareness;

(2) active cultivation of trust;

(3) an emotional style characterized by empathic curiosity;

(4) self-calibration as a way to reduce bias;

(5) educating the emotions to assist with diagnosis and forming therapeutic relationships;

(6) using informed intuition; and

(7) communicating clinical evidence to foster dialogue, not just the mechanical application of protocol.

## Example case

Source: Adopted from (Wade & Halligan, 2004)

*A 54-year old man who had a stroke eight months ago. He still has some weakness in his left leg and clumsiness in his left arm. He has not returned to his work in a hospital finance department and is depressed and irritable. His condition can be considered in the following domains:*

*Personal context*

*His expectation was for a full recovery; he is still afraid that any stress will cause a second stroke; he believes that work and anything outside the house is stressful; he wants more treatment to cure him*

*Social context*

*His wife and friends tell him to take it easy and offer to do anything to help, including paying for private therapy once a week. They want him to get a disabled badge and are angry that it is not given. His employers want him signed off as fully fit and to return to work full time*

*Physical context*

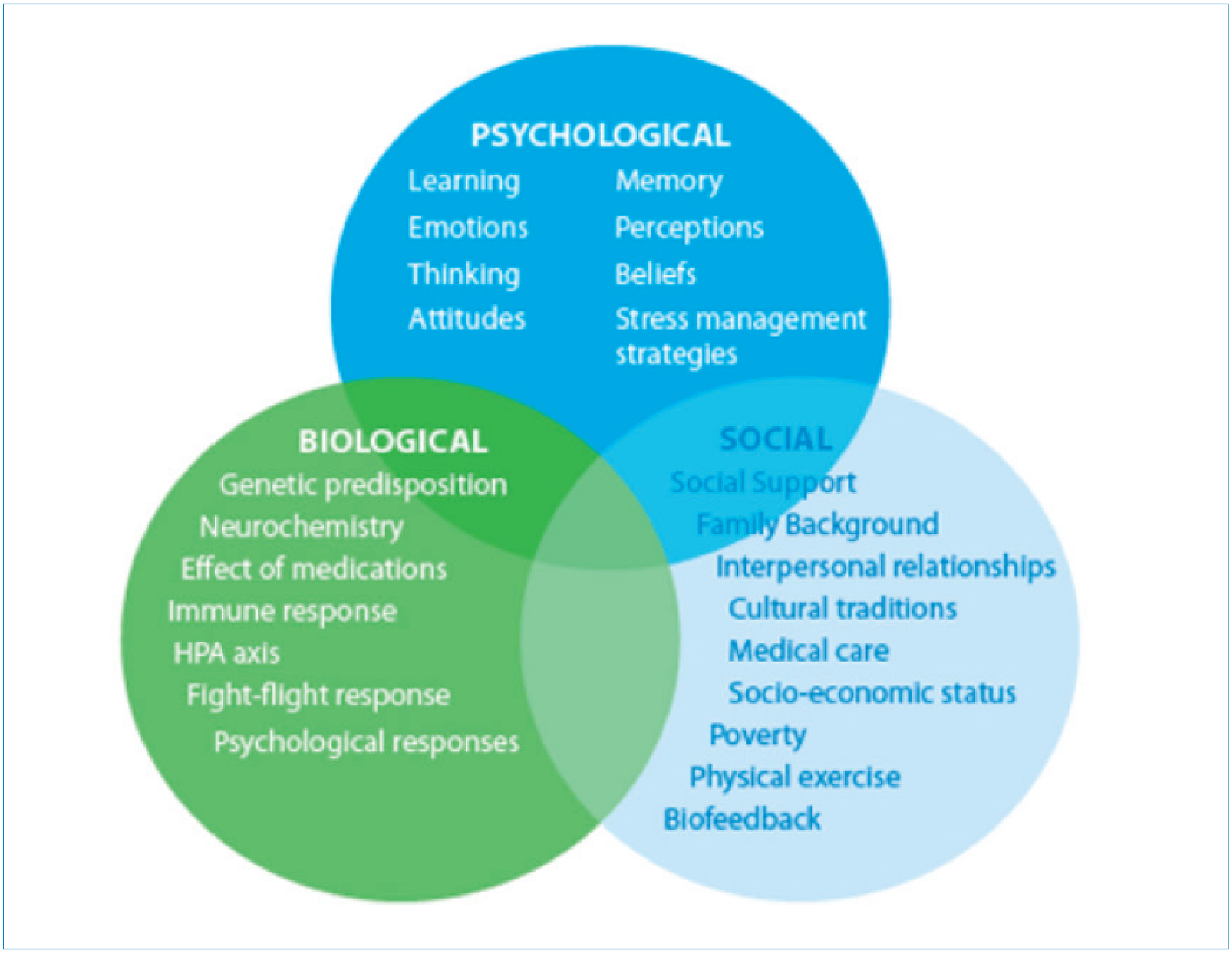
*He can access all parts of his house and wear and use normal things. Work is also accessible.*

*The primary problem here is a disjunction between the view of the healthcare system and the view of the patient and his immediate friends and family. The best solution is to take time to educate him and his family, to help his self confidence in community activities, to help him back to driving his car, and to persuade his employers to take him back on a planned and agreed graduated basis over several months. Therapy as such should not be given because it reinforces the patient role. His mood disturbance is secondary to his loss of roles.*

| | Objective (medical) description | Subjective (patient's) description |
|---|---|---|
| **Pathology** | Mild stroke (right lacunar infarct) due to hypertensive vascular disease, with incidental osteoarthritis of the right hip | Severe stroke |
| **Impairment** | Mild clumsiness of the non-dominant left hand with slight weakness of the left leg and mild hip pain; Cognition is normal | Left arm is useless and the left leg is weak and unreliable |
| **Activities** | Good recovery of personal activities and has the ability to do most activities if he wishes | Still feels severely disabled, unable to garden, fish, or work or to shop alone |
| **Participation** | He has returned to being a father and husband and a few roles within family and close friends. | Still feels a patient, unable to fulfil any roles well |

The biopsychosocial model is today widely accepted and recommended holistic approach to chronic pain (Fig. 14), chronic communicable and non-communicable diseases, and also to mental disorders. Furthermore, application of this model to co-morbidities is very effective.

**Figure 14.** Biopsychosocial model of pain



Source: Moselley & Butler, 2015.

## Key messages

- Social medicine examines how social and economic conditions impact on health, disease and medical practice and supports the conditions that can lead to a healthier society.
- In recent years, the most health inequalities are caused by social determinants and health care.

- Social medicine examines how social and economic conditions impact on health, disease and medical practice and supports the conditions that can lead to a healthier society.
- In recent years, the most health inequalities are caused by social determinants and health care.
- Traditional biomedical models of disease have been associated with huge improvement in medical care, but its focus on discovering the pathology rather than understanding the illness is not enough for explaining functional somatic syndromes and illness without discernible disease.

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# 2

# Major Health Challenges

Societal processes of globalisation, migration, urbanisation, the so-called westernisation of diets and lifestyles, and changes in employment activities, have all been viewed as primary drivers of changes in human health. Such shifts have been thought to lead to deteriorating diets, rising obesity, decreased physical activity, and, ultimately, to worsening levels of metabolic risks, with associated higher rates of cardiovascular diseases, cancers, diabetes, mental health problems, and other chronic diseases.

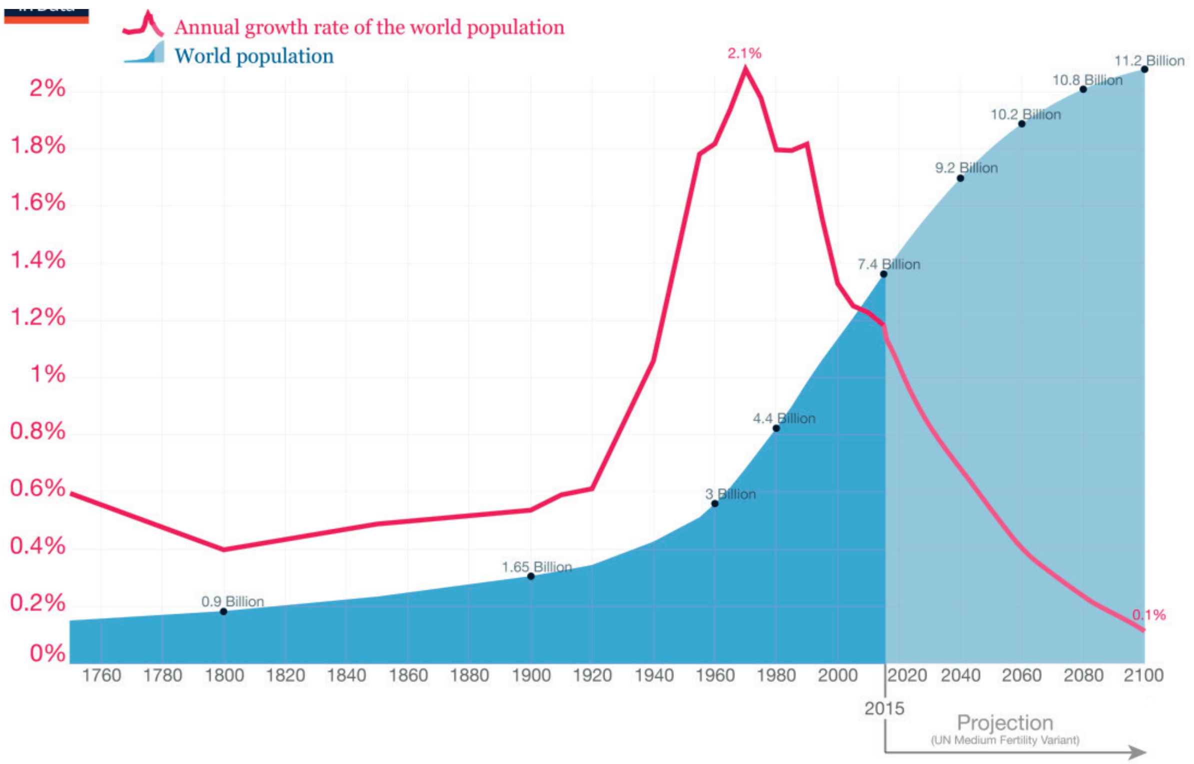
## 2.1 CHRONIC DISEASES AND POPULATION AGEING

*Iveta Nagyova*

### Population ageing from global perspective

Two centuries ago, the global population stood at under a billion inhabitants. Presently, as per estimations by the United Nations, the world's populace exceeds 7 billion. Recent assessments propose that the current population size represents approximately 6.9% of all individuals ever to have lived. This demographic trend stands as the most apparent phenomenon regarding global population expansion: while growth was sluggish for millennia, it has surged notably in recent centuries. Between 1900 and 2000, the population surge surpassed that of the entire preceding human history, skyrocketing from 1.5 to 6.1 billion within a mere century. To analyze the dynamics of global population shifts across time, it proves beneficial to assess the rate of change rather than solely fixating on absolute population figures. The period spanning from 1750 to 2010 marks a notable era of flux in population dynamics (Fig. 1). Before 1800, global population growth consistently remained below the 1% threshold. However, in the initial five decades of the 20th century, annual growth rates surged to a peak of 2.1%—the highest in recorded history, occurring in 1962. Subsequently, growth rates have steadily declined, with projections indicating an annual rate of 0.1% by 2100 (Roser & Ortiz-Ospina, 2017). Population expansion is particularly pronounced in less developed regions (Fig. 2).

**Figure 1.** World population growth 1750-2100.



Data sources: Up to 2015 OurWorldInData series based on UN and HYDE. Projections for 2015 to 2100: UN Population Division (2015) – Medium Variant.
The data visualization is taken from OurWorldinData.org. There you find the raw data and more visualizations on this topic.

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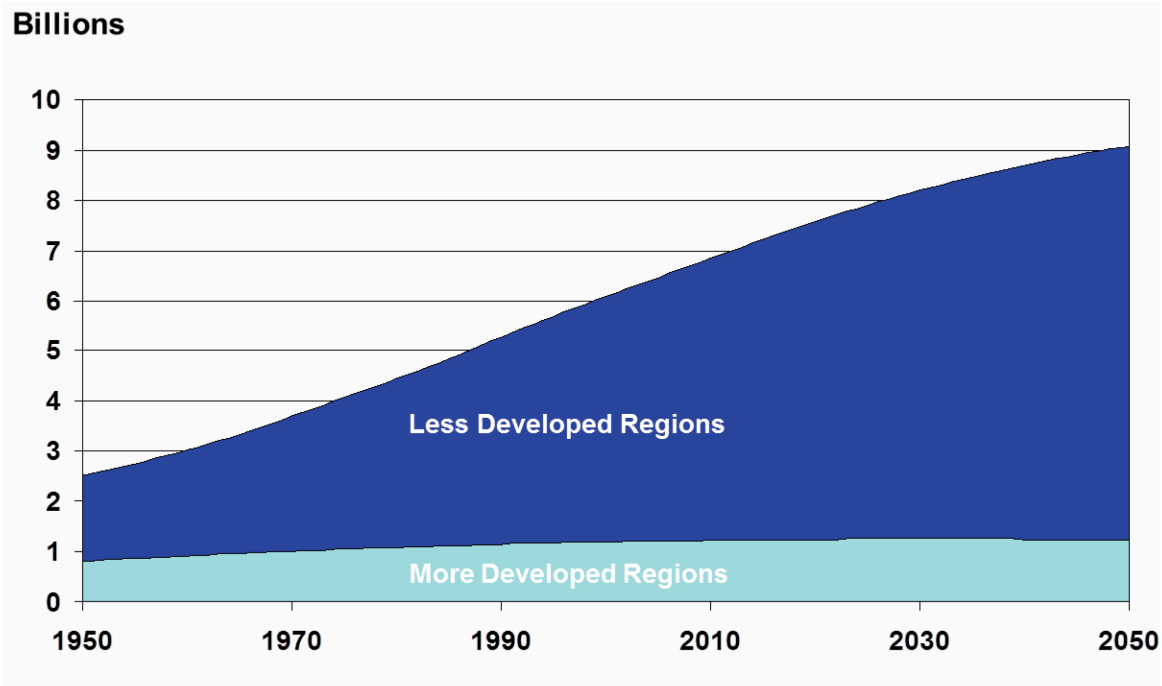
Source: Roser & Ortiz-Ospina, 2017.

**Figure 2.** World population growth 1950-2050, less vs more developed regions.

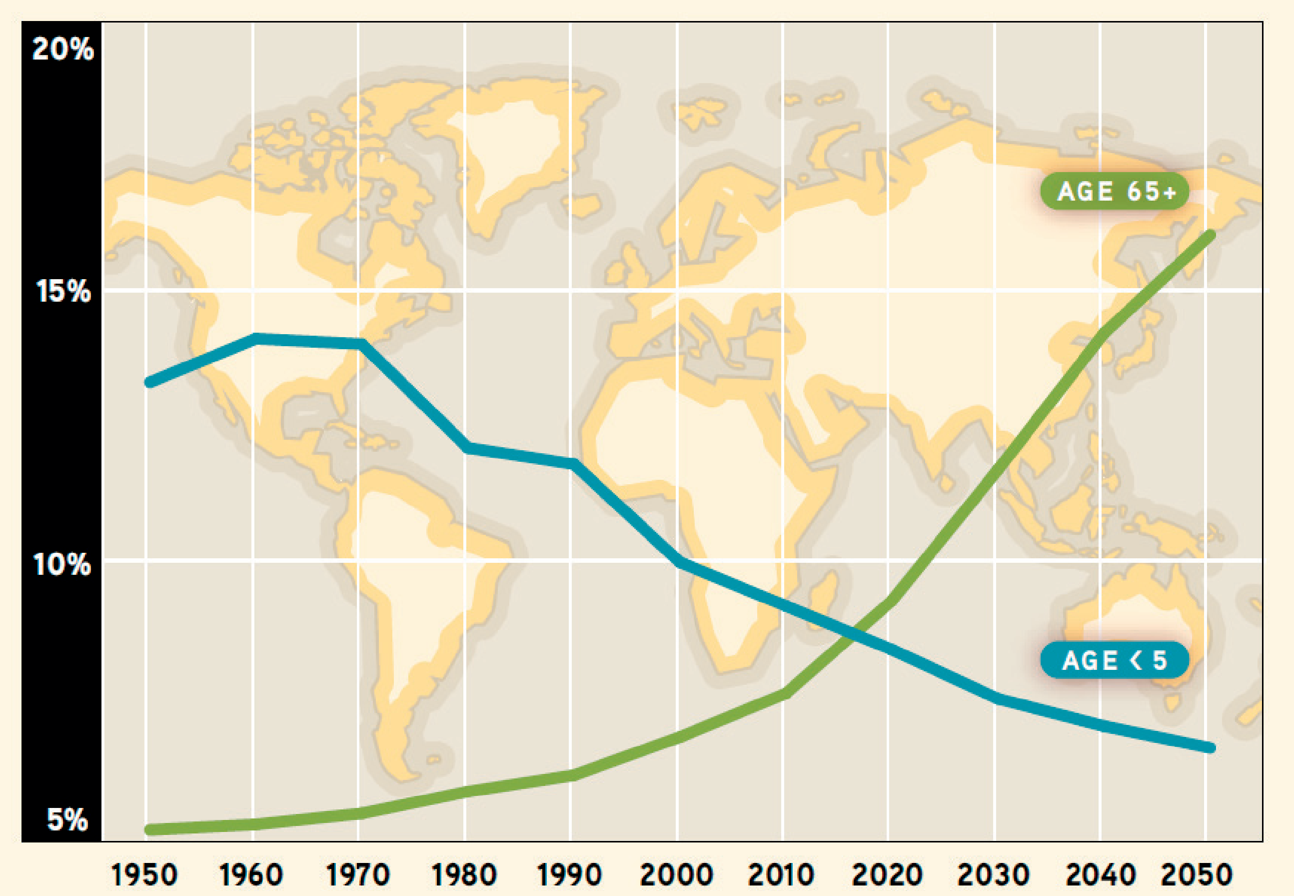


Source: United Nations, *World Population Prospects: The 2004 Revision* (medium scenario), 2005.

## Key trends in population ageing and the living arrangements of older persons

- The global population aged 60 years or over numbered 962 million in 2017, more than twice as large as in 1980 when there were 382 million older persons worldwide. The number of older persons is expected to double again by 2050, when it is projected to reach nearly 2.1 billion.
- In 2030, older persons are expected to outnumber children under age 10 (1.41 billion versus 1.35 billion); in 2050, projections indicate that there will be more older persons aged 60 or over than adolescents and youth at ages 10-24 (2.1 billion versus 2.0 billion) (Fig. 3).

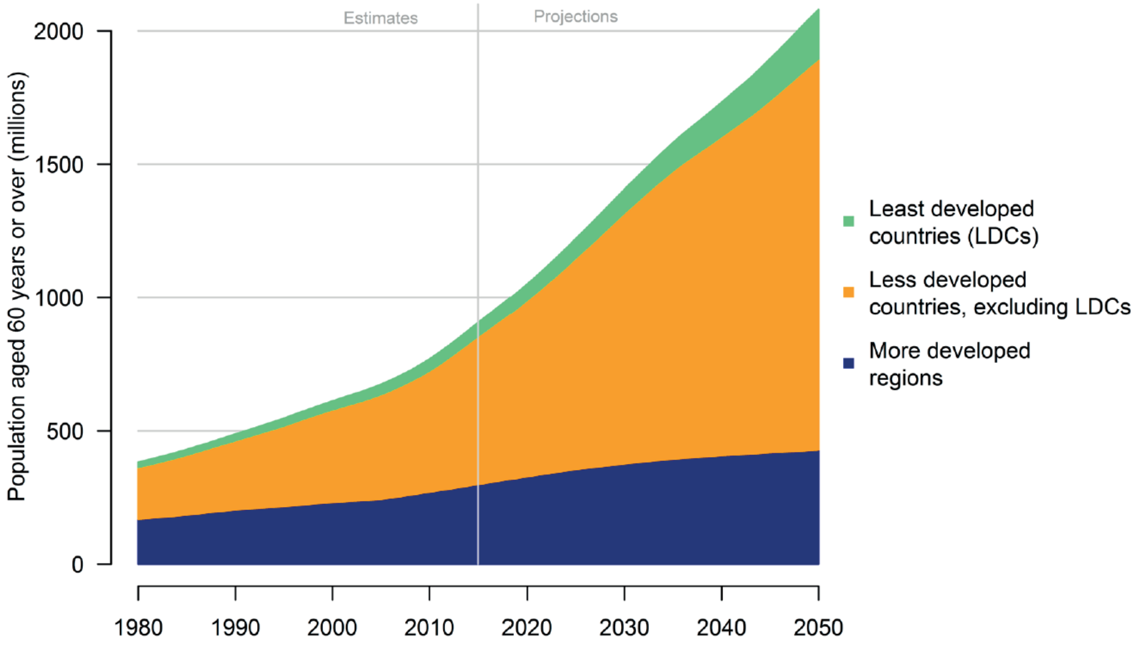
**Figure 3.** Young children and older people as a percentage of global population



Source: United Nations Department of Economic and Social Affairs, Population Division. *World Population Prospects. The 2004 Revision.* New York: United Nations, 2005.

- Globally, the number of persons aged 80 years or over is projected to increase more than threefold between 2017 and 2050, rising from 137 million to 425 million.
- Two thirds of the world's older persons live in the developing regions, where their numbers are growing faster than in the developed regions. In 2050, it is expected that nearly 8 in 10 of the world's older persons will be living in the developing regions (Fig. 4).

**Figure 4.** Number of persons aged 60 years or over by development group,1 from 1980 to 2050



*Data source*: United Nations (2017). World Population Prospects: the 2017 Revision.

Note: Following common practice, the "developed regions" include Europe and Northern America plus Australia, New Zealand and Japan, while the "developing regions" include all other parts of the world. The use of these terms in the present report does not imply any judgement as to the current developmental stage of a particular country or region.

- Population ageing - the inevitable increase in the share of older persons that results from the decline in fertility and improvement in survival that characterize the demographic transition - is occurring throughout the world. Each of the 201 countries or areas with at least 90,000 inhabitants in 2017 is projected to see an increase in the proportion of persons aged 60 or over between 2017 and 2050.
- While Europe and Northern America lead in the progression of population aging, with over 20% of individuals aged 60 or above in 2017, this demographic shift is also evident in other global regions. Projections indicate that by 2050, the elderly demographic will constitute 35% of Europe's population, 28% of Northern America's, 25% of Latin America and the Caribbean's, 24% of Asia's, 23% of Oceania's, and 9% of Africa's.
- Among 143 countries for which data is accessible, the percentage of individuals aged 60 or above residing "independently" - exhibited considerable diversity, ranging from a minimum of 2.3% in Afghanistan to a maximum of 93.4% in the Netherlands.
- Around 2010, in Asia, Africa, and Latin America, a significant majority of individuals aged 60 or above lived with a child, surpassing the halfway mark. Conversely, in Europe and Northern America, only about 20% of older individuals lived with their children.
- In general, older women are more likely than older men to live alone. Both in Africa and in Europe, older women were more than twice as likely as their male counterparts to be living alone.
- Data for 67 countries indicate that older persons have become more likely in recent decades to live independently (around 37 per cent circa 2010 compared to 24 per cent circa 1990), whereas co-residence with children has become less common (53 per cent circa 2010 compared to 65 per cent circa 1990).
- With the ongoing increase in population age averages, it is imperative for governments to enact policies catering to the requirements and concerns of older individuals. These policies should encompass aspects such as housing, employment, healthcare, social welfare, and fostering intergenerational bonds. By foreseeing this demographic transition, nations can implement proactive measures to accommodate the aging populace, thereby aligning with the commitment of the 2030 Agenda for Sustainable Development to ensure inclusivity for all.

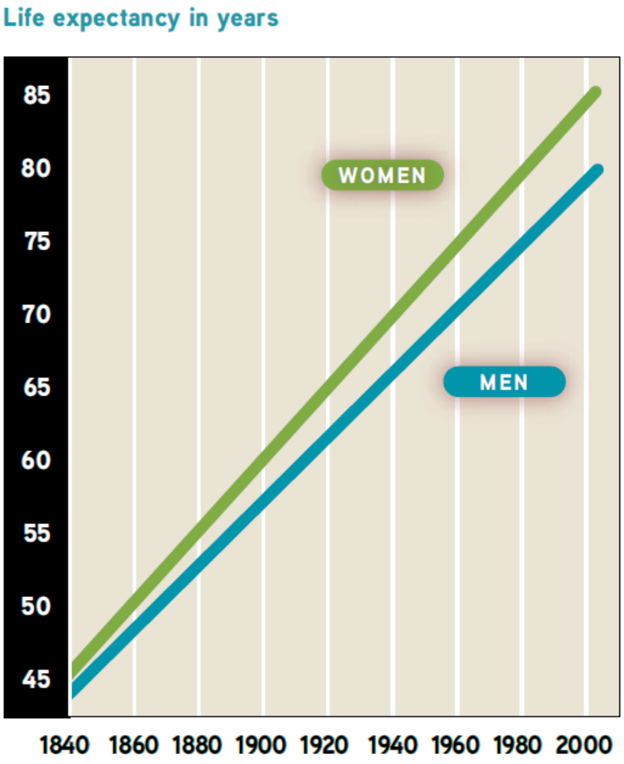
## Population ageing from health and social perspective

Certain countries witnessed a notable doubling of average life expectancy throughout the 20th century. Presently, Japan boasts a life expectancy at birth nearing 82 years, the highest among developed nations, while several other developed countries maintain life expectancies of at least 79 years. Despite speculations suggesting a plateau in life expectancy, data tracking female life expectancies from 1840 to 2000 reveal a consistent increase of 3 months annually (Fig. 5).

Over the forthcoming decade to decade and a half, the global burden of health loss and mortality across all regions, including Africa, will predominantly stem from non-communicable or chronic ailments such as heart disease, cancer, and diabetes, surpassing that caused by infectious and parasitic diseases.This represents a shift in disease epidemiology that has become the focus of increasing attention in light of global aging (Fig. 6).

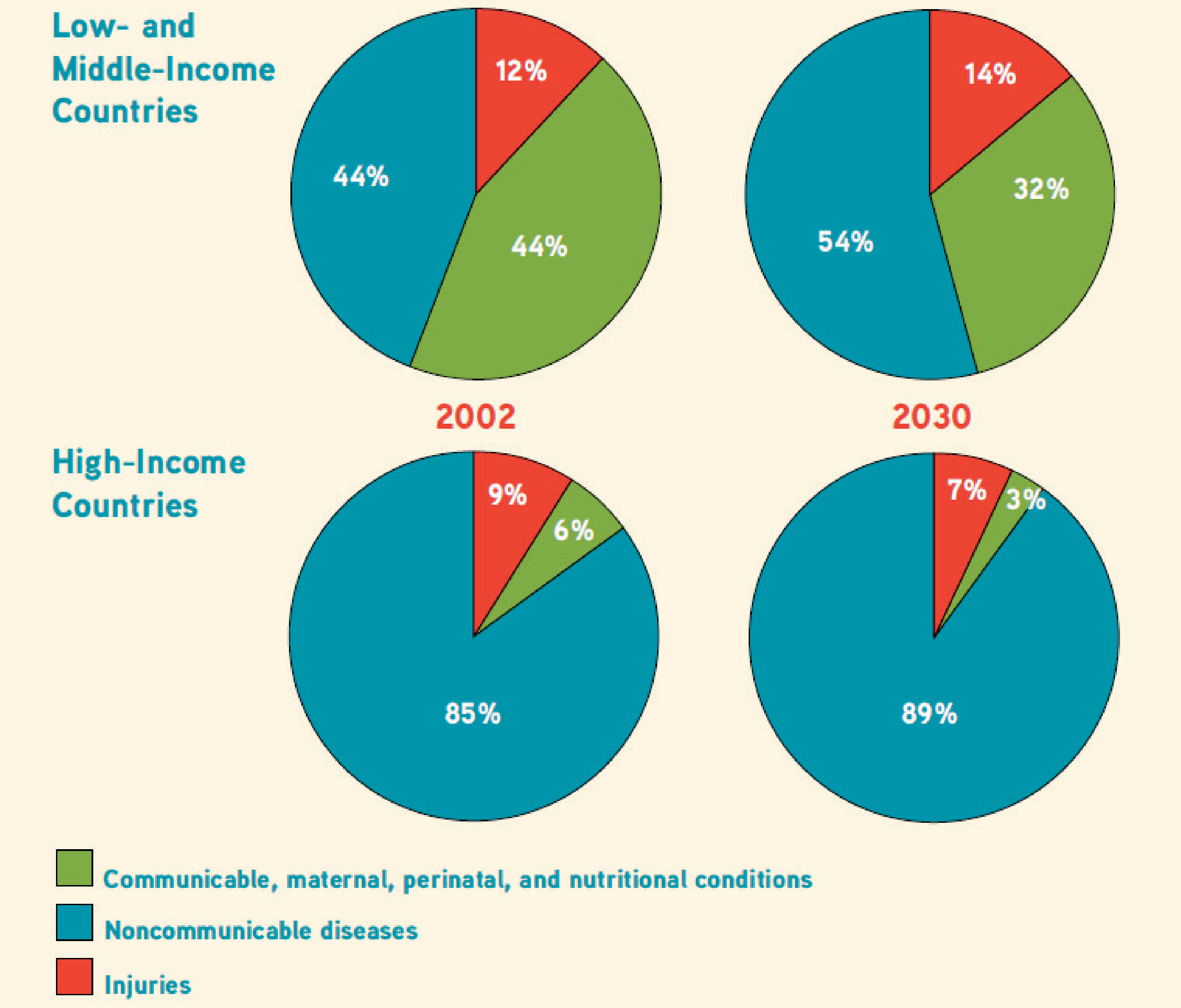
With increased longevity and reduced fertility rates, family dynamics undergo significant changes, impacting the provision of elderly care. The discourse surrounding population aging is predominantly fueled by concerns regarding employment, retirement, and financial stability in old age. Across Western democracies, transitioning economies in Eastern Europe, and many developing nations, policymakers grapple with finding the right equilibrium between public and private income support systems. In light of escalating pension costs, an expanding array of countries at various stages of development are scrutinizing the viability of social insurance schemes for the elderly (National Institute on Aging, 2007).

**Figure 5.** Highest national life expectancy at birth: 1840-2000



Source: Adapted from Oeppen J, Vaupel JW. Broken Limits to Life Expectancy. *Science*. 2002;296;1029-1031.

**Figure 6** The increasing burden of chronic non-communicable diseases: 2002-2030



Source: Lopez AD, Mathers CD, Ezzati M, Jamison DT, Murray CJL, eds. *Global Burden of Disease and Risk Factors*. Washington, DC: The World Bank Group, 2006.

The world's population is ageing: older persons are increasing in number and make up a growing share of the population in virtually every country, with implications for nearly all sectors of society, including labour and financial markets, the demand for goods and services such as housing, transportation and social protection, as well as family structures and inter-generational ties. Preparing for the economic and social shifts associated with an ageing population is thus essential to fulfil the pledge of the 2030 Agenda for Sustainable Development that "no one will be left behind". Trends in population ageing are particularly relevant for the Sustainable Development Goals (SDGs) related to poverty eradication, the promotion of health, gender equality, employment and sustainable human settlements, as well as those on reducing inequality within and across countries and promoting peaceful and inclusive societies (United nations, 2017).

The **10 Priorities** provide the actions needed to achieve the SDGs and objectives of the **Global strategy and action plan on ageing and health** (WHO, 2017):

**1. Build a Platform for Innovation and Change -** Igniting change for Healthy Ageing by connecting people and ideas from around the world.

**2. Support country planning and action -** Countries get the skills and tools they need to create policies that enable people to live long and healthy lives.

**3. Collect better global data on Healthy Ageing -** What gets measured gets done - together we collect accurate up-to-date and meaningful data on Healthy Ageing.

**4. Promote research that addresses the needs of older people -** Research includes and benefits older people by answering relevant questions in innovative ways.

**5. Align health systems to the needs of older people -** Older adults get the health care they need - where and when they need it.

**6. Lay the foundations for a long-term-care system in every country -** Older people and care givers get the care and support they need to live with dignity and enjoy their basic human rights.

**7. Ensure the human resources necessary for integrated care -** People have the skills to deliver quality health and long-term-care services for older people.

**8. Undertake a global campaign to combat ageism -** Changing the way, we think, feel and act towards age and ageing is possible - we can make it happen.

**9. Make the economic case for investment in Healthy Ageing -** Better understanding the costs and opportunities of Healthy Ageing - the starting point for sustainable, equitable and effective responses.

**10. Develop the Global Network for Age-friendly Cities and Communities -** Cities and communities, around the world, enable older people to do the things they have reasons to value.

## 2.2 GLOBALIZATION, MIGRATION, URBAN HEALTH

### The city - An urban area

What defines a city? A city is a large human settlement, it is comprised of a large system for housing, transportation, sanitation, utilities, land use and communication (Freudenberg et al., 2007). A city is distinguished from other human settlements by its great size, function and central authority. The size of the population, its typical infrastructure, dense residential areas and the constant expansion of the city are characteristics that are typical for a so called "urban" area (Schwela, 2011).

The site of a city in most countries share the same general characteristics, they are usually situated close to water, this due its major role in natural, economical, technological and military context. Historically, when railways, airplanes and motorways did not exist, shipping of goods where usually carried by water. Also, as urban areas cannot produce food for the vast population, the importance of a connection with a rural city is very important and therefore being situated close to a port is essential (Dye, 2008). In modern times the extensive network of railways is very typical for an urban area as well as access to airports. A city also comprises of a city centre, which is central are containing building with special economic, political and religious significance (Clifford et al., 2008).

Public space is common in cities, they are areas that are open to the public, they can be privately owned or be a part of a public domain. Parks and recreational areas are examples of public spaces (Gilbert, 1982). The internal structure of a city depends on the geographical characteristics of the landscape, but most cities share the same type of structures, which are the typical "radial" or "concentric" structures. They are structured in a way that the roads are all connected to a main point in the city, which is usually the city centre (Adler et al, 1994). An urban area is an area that is extended beyond the city, it is comprised of the surroundings of a city. It has a typical pattern of dense residential areas and most inhabitants are non-agricultural workers (Fortmann et al., 2011).

### Population in cities - growth

At the beginning of the 19th century, only 5 % percent of the world's population was living in urban areas (Ford et al., 1991). Up to 60 % of the world's population will live in urban areas by year 2030 and the overall population in the world is estimated to reach 4,98 billion by year 2030 (Chaloupka et al., 2004). This suggest that there will be a rapid growth of cities and acceleration of urbanization. The major increase of population in cities will occur in developing countries compared to developed countries. Overall global population growth will be primarily in cities; approximately one million city residents will be added to the world's population weekly (van Loon et al., 2002). The pace of increase in urban areas is different by regions of the world and by initial city size. Most global population growth will occur in less wealthy regions of the world, with most rapid pace of growth expected to occur in Asian and Africa (Brancati et al., 2003).

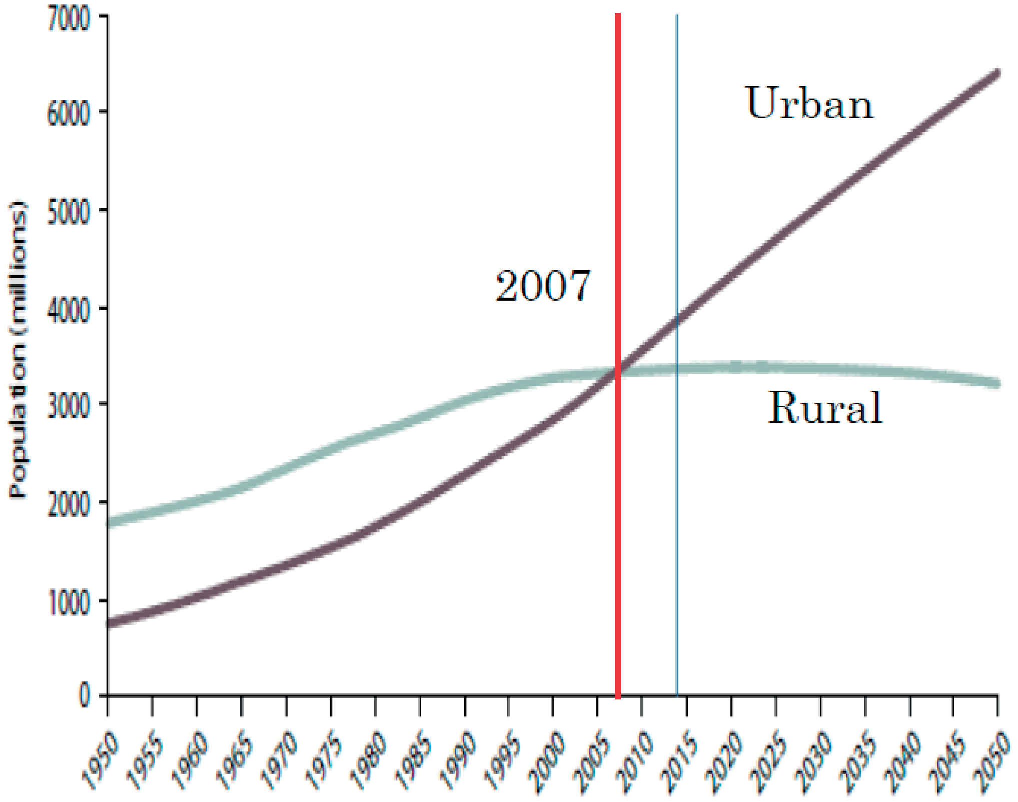
There are approximately 50,000 urban areas in the world today with close to 400 cities with at least one million people inhabitants. Urban areas with a population of at least 10 million is referred to as a "mega-city", today there are more than 15 mega-cities in the world. Although, in the coming decades, mega-cities will grow, most of the world's population growth will occur in smaller cities. The growth rate of mega-cities in the developing world will be much higher. This is important in assessing health of an urban populations as increased population will lead more challenges concerning health and well-being (Loose et al., 1997).

**Urbanization** is the movement of people from rural to urban areas, leading to expansion of urban areas.

World populations are increasingly moving from rural to urban centres, making up for larger cities with greater population density than ever before. This is a global phenomenon across the spectrum of developed and developing countries (Bredin et al.).

Urban population was less than 1/3 (30%) Urban population was less than 1/3 (30%) in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 1950 and exceeded rural population in 2007. It is 54 % in 2014 and will be more than 66 % by 2050 (Fig. 7).

**Figure 7.** Urban and rural population



Source: World Urbanization Prospects The 2011 revision.

### Causes of urbanization

Causes of urbanization are many, but some are regarded as definitive causes as they play a big role in people's choice in moving in to large cities. The main causes of urbanisation include:

- Industrialization
- Commercialization
- Modernization

*Industrialization* is a transition from traditional agrarian economies to non-agricultural sectors, fostering the development of modernized societies. The industrial revolution has spurred rural-to-urban migration due to enhanced job prospects in urban centers. By opening up employment avenues in contemporary industries, industrialization fuels economic progress and facilitates broader participation in modern workforce roles (Kant, 1996).

*Commercialization* play a major role in urbanization. The evolution of modern marketing institutions and exchange mechanisms in the distribution of goods and services has greatly contributed to the proliferation of urban centers. The perception that towns and cities provide superior commercial prospects and returns compared to rural areas underscores the association between commercialization, trade, and urban growth (Burr et al., 1989).

There are numerous *social benefits and services* attributed to life in the cities and towns. Examples include better educational facilities, better living standards, better sanitation and housing, better health care, better recreation facilities, and better social life in general. Consequently, an increasing number of individuals are drawn to migrate to urban areas to access the diverse array of social benefits and services unavailable in rural regions (Bucca & Romano, 1996).

In cities and towns, there are plenty of *employment opportunities* that continually draw people from the rural areas to seek better livelihood. Therefore, the majority of people frequently migrate into urban areas to access well-paying jobs as urban areas have countless employment opportunities in all developmental sectors such as public health, education, transport, sports and recreation, industries, and business enterprises. Services and industries generate and increase higher value-added jobs, and this leads to more employment opportunities (Custovic et al., 2005).

The process of urbanization is deeply intertwined with *modernization*. With urban areas evolving into hubs of technology and sophisticated infrastructure, alongside improved communication, healthcare, dress codes, education, and other social amenities, people perceive cities as conducive to a fulfilling life. Urban dwellers embrace changes in lifestyle, including residential patterns, attitudes, attire, dietary preferences, and beliefs. Consequently, urban migration intensifies, fueling the continual expansion of cities as they absorb a growing populace on a daily basis (Braman, 2006).

As regions experience increased productivity driven by mineral discoveries, resource utilization, or agricultural activities, rural areas transition into urban landscapes. This heightened productivity stimulates economic growth and fosters the creation of higher-value employment opportunities (NIHM, 1979). In response, there emerges a pressing need for enhanced infrastructure, educational institutions, healthcare facilities, transportation networks, banking services, governance structures, and housing options. This transition prompts rural communities to adopt urban lifestyles, eventually transforming into urban centers that persistently attract more inhabitants seeking improved living standards (Epstein et al., 2001).

Urbanization can more easily be explained by "pull" factors which are conditions that attract people to urban areas and "push" factors that are conditions in rural areas that lead people to move away (Galea and Vlahov, 2005; Table 1).

**Table 1:** Pull and push factors regarding moving from rural to urban areas

| "Pull" factors | "Push" factors |
|---|---|
| • Potential for employment<br>• Better service provision<br>• A safer atmosphere<br>• Low crime rates<br>• Fertile land<br>• Good food suppliers<br>• Less risk of natural hazards<br>• Greater wealth or affluence<br>• Political security<br>• A more attractive climate<br>• A more attractive quality of life | • Unemployment<br>• A lack of services or amenities<br>• Poor safety and security<br>• Concerns about high crime rates<br>• Crop failure<br>• Drought<br>• Flooding<br>• Poverty<br>• War |

### Effects of urbanization

Urbanization brings about numerous positive outcomes within appropriate limits. These include the generation of employment opportunities, advancements in technology and infrastructure, enhancements in transportation and communication networks, the provision of quality educational and medical services, and overall improvements in living standards. However, extensive urbanization mostly results in adverse effects. Below listed points are few of them: Urbanization attracts people to cities and towns which lead to high population increase. With the increase in the number of people living in urban centres, there is continued scarcity of houses. This is due to insufficient expansion space for housing and public utilities, poverty, unemployment, and costly building materials which can only be afforded by few individuals (Behanova, 2014).

*Overcrowding* is a situation whereby a huge number of people live in a small space. This form of persistent urban congestion arises from overpopulation, a trend perpetuated by the continuous influx of people and immigrants seeking improved living conditions in cities and towns. Individuals from rural or underdeveloped regions are often compelled to migrate to urban areas, exacerbating population density within limited spaces (Geronimus, 2000).

*Unemployment* rates are most pronounced in urban settings, particularly among those with limited education. It is reported that over half of the world's unemployed youth reside in metropolitan areas. Despite higher income potential in urban locales, the elevated cost of living often renders incomes insufficient. The escalating migration of individuals from rural or developing regions to urban centers remains a primary driver of urban unemployment (Pacione, 2005).

The urban environment presents significant challenges due to its high cost of living. When coupled with haphazard growth patterns and unemployment, this leads to the proliferation of informal settlements, such as *slums and squatter communities*. The expansion of these marginalized areas within urban centers is exacerbated by rapid industrialization, limited availability of suitable land for housing, substantial influx of rural migrants seeking improved livelihoods, and soaring land prices beyond the means of the urban underprivileged (Newman & Thornley, 2011).

Due to overpopulation and the swift rise in urban population densities, insufficient sewage infrastructure is a prevalent issue in many urban areas. Municipalities and local administrations grapple with significant resource *shortages in effectively managing sewage systems*. Consequently, sanitation conditions deteriorate, leading to uncontrolled sewage flow into nearby water bodies such as streams, rivers, lakes, or seas. This situation fosters the rapid spread of communicable diseases like typhoid, dysentery, plague, and diarrhea, resulting in widespread suffering and even fatalities.

*Water scarcity* is exacerbated by overcrowding, as demand outstrips supply (van Kempen & Marcuse, 2002). The social, economic, and residential circumstances in densely populated urban regions influence the accessibility and utilization of public healthcare services. Particularly in slum areas, inadequate sanitation and limited water resources heighten the vulnerability of residents to communicable diseases. Furthermore, environmental issues such as urban pollution contribute to various health ailments including allergies, asthma, infertility, foodborne illnesses, cancer, and premature mortality (Collins et al., 2011).

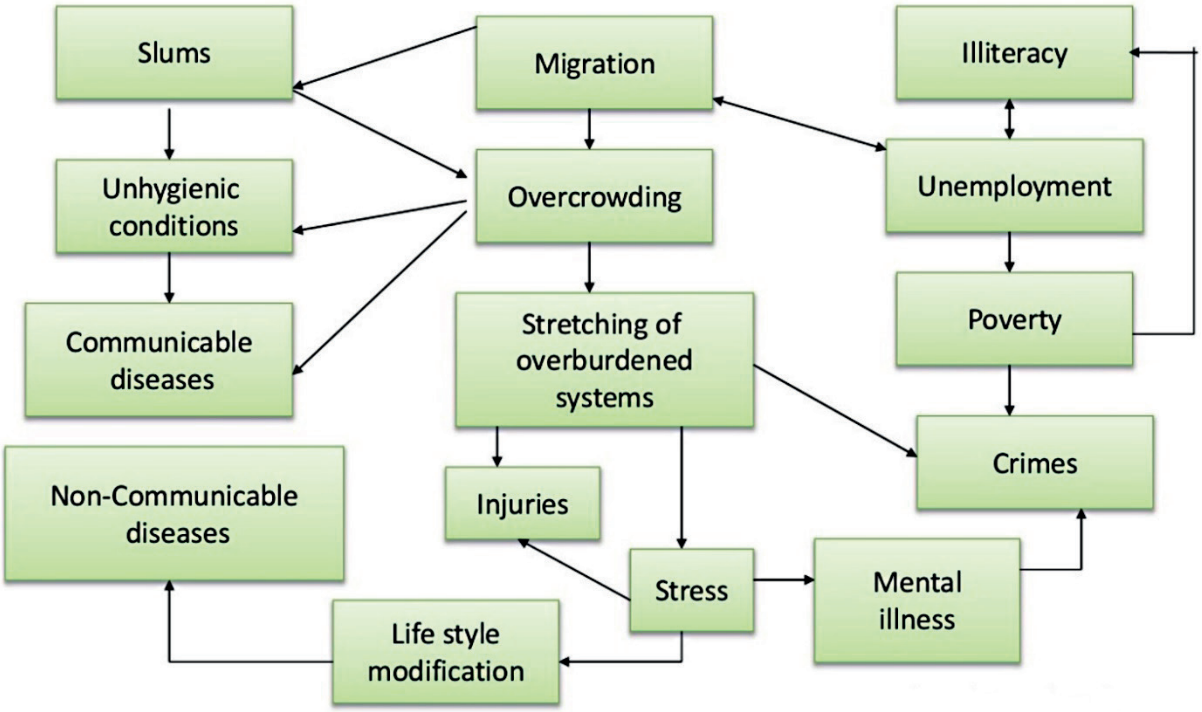
The influx of people into urban areas poses significant challenges for transportation systems. The growing population results in a higher volume of vehicles on the roads, leading to traffic congestion and increased vehicular pollution. In urban settings, many individuals commute to work by car, exacerbating traffic issues, particularly during peak hours. Additionally, as cities expand, residents travel to fulfill various social and shopping needs, further contributing to traffic congestion and blockages (Bond et al., 2009).

Challenges stemming from resource scarcity, overcrowding, unemployment, poverty, and inadequate social services and education often precipitate various social issues, including violence, drug misuse, and criminal activities. Urban areas typically witness higher rates of crimes such as murder, rape, kidnapping, riots, assault, theft, robbery, and hijacking. Additionally, regions experiencing rapid urban growth tend to exhibit elevated levels of poverty-related crimes. These instances of urban crime frequently disrupt the peace and harmony of cities and towns (Garrett, 2007).

### Urban health

With rapid urbanization and increased population in urban areas, urban health has become more important, as it has a profound meaning in understanding the quality of life of habitants of a city. As a growing proportion of the world's population lives in cities, the health of urban populations contributes increasingly to overall population health worldwide. Therefore, factors that influence health in cities gain in importance in influencing global population health. As more people live in urban areas, it becomes increasingly likely that aspects of the urban environment in which people live will affect them. There are three broad categories of theories and mechanisms that may explain how city living can affect health-the physical environment, the social environment, and availability of and access to health and social services (Shiffman, 2009; Fig. 8).

**Figure 8.** Health-related problems of urbanization

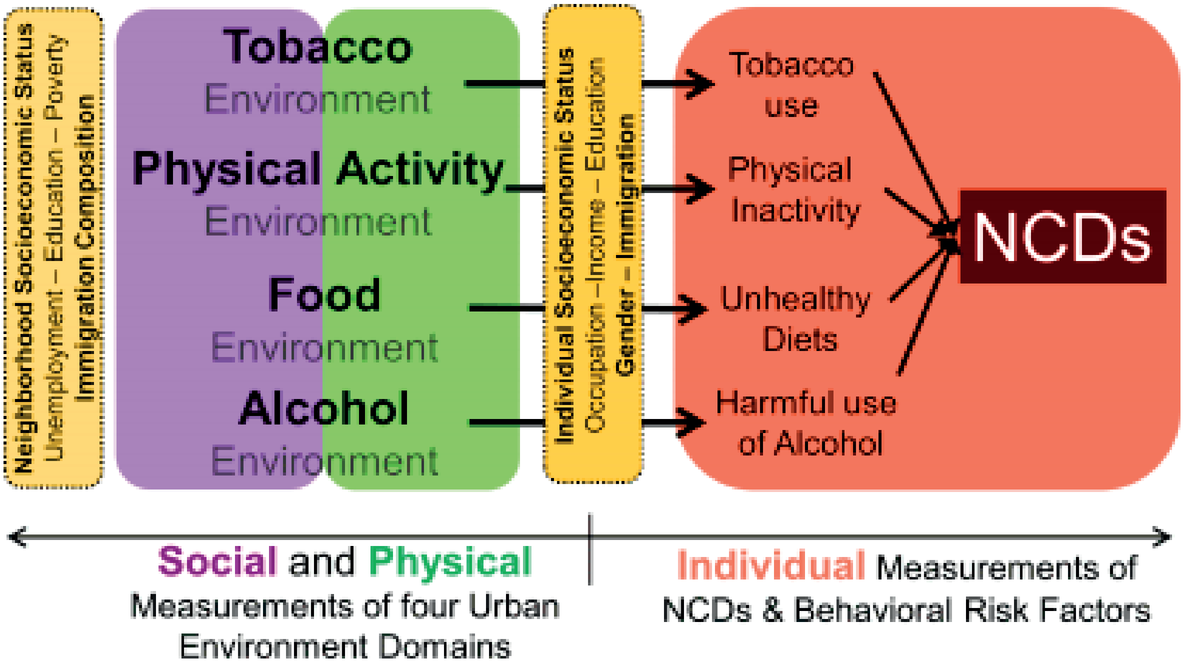


Source: Galea and Vlahov, 2005, adjusted.

### Non-communicable diseases in urban population

Urbanization have led to lifestyles characterized by unhealthy nutrition, reduced physical activity, increase in alcohol consumption and tobacco smoking. These unhealthy lifestyles are associated with common modifiable risk factors for chronic diseases such as hypertension and diabetes mellitus and also an increase of people with asthma, suggesting environmental factors as triggers (Macintyre et al., 2005; Fig. 9).

**Figure 9.** Behavioural risk factors for chronic diseases typical for urban populations.



### The urban physical environment

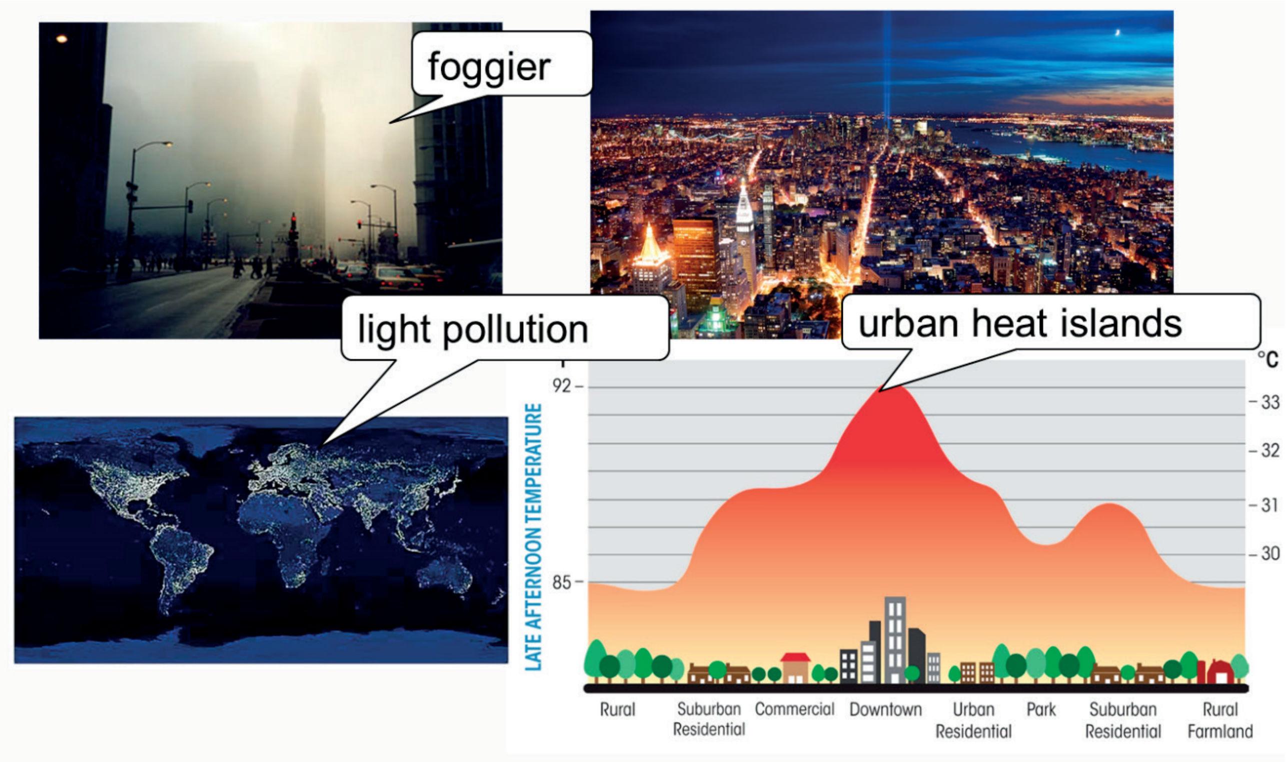
The *urban physical environment* encompasses various elements such as the built infrastructure, air and water quality, noise levels, parks, and climatic conditions, all of which urban residents encounter daily and which have the potential to impact health outcomes (Jones et al., 2008). The *human-built environment* can influence both physical and mental well-being; research indicates correlations between aspects of the built environment and health conditions such as asthma, injuries, psychological distress, and child development (Buist & Mannino, 2007). Specific features of the built environment, such as development density, land use diversity, street scale, aesthetic attributes, and street network connectivity, have been linked to particular health outcomes. For instance, urban areas with low levels of physical activity are associated with increased risks of cardiovascular disease and overall mortality (Lopez & Murray, 1997).

There is also a relation between housing and health. Urban design may also affect health behaviours, crime, and violence rates suggesting close interactions among the urban physical and social environments (Bobak et al., 2004).

*Urban infrastructure plays* a pivotal role in the provision of essential services such as water supply, waste disposal, and energy distribution within a city. In less affluent nations, water scarcity and pollution present significant urban challenges (Kant, 1996). In established urban centers, the deterioration of aging infrastructure, coupled with dwindling municipal resources, can jeopardize the city's ability to ensure access to safe water and sanitation for its residents (Fiscella & Williams, 2004). Meanwhile, in rapidly urbanizing regions, particularly in less affluent countries, cities often struggle to meet the escalating demand for fresh water and manage the increasing accumulation of sewage and waste (Drewnowski & Popkin, 2009). Inadequate provision for solid waste collection frequently results in contamination of water bodies, which together with the population density in the cities, is a substantial risk for rapidly spreading epidemics (Armar-Klemesu, 2000).

While *pollution* levels in cities in affluent nations have shown improvement over the past fifty years, urban areas still account for approximately 80% of global carbon dioxide emissions and three-quarters of industrial wood consumption worldwide (Tanner, 2013). Both indoor and outdoor air pollution are believed to contribute to an estimated 3 million deaths annually worldwide, with 90% of these fatalities occurring in less developed countries (Eggleston et al., 2007). Globally, atmospheric pollution affects over a billion individuals, predominantly residing in urban areas. Research indicates that residing in regions with accessible green spaces is associated with increased physical activity, better functional health, reduced cardiovascular disease risk, and enhanced longevity among the elderly (Reijneveld, 1998). Ultimately, *climate* in cities can affect population health. Due to global climate change, heat has become a concern in urban areas, as they are usually warmer than surrounding areas, and usually leads to hospitalizations and deaths yearly (Kant, 1996). Particular groups may be at most risk of the effects of heat in urban areas. Epidemic heat-related deaths have been prevalent among socio-economically disadvantaged and socially isolated elderly persons (Eberhardt & Pamuk, 2011).

Other features of the urban physical environment that may have specific relations to human health include the vulnerability of urban structures to natural or human- made disasters, for instance earthquakes or terrorist attacks, hazardous waste landfills, often located in or near urban areas, which may be associated with risks of low birth weight, birth defects, malignancies, and noise exposure, a common urban problem, that may contribute to hearing impairment, hypertension, and ischemic heart disease (Ewing et al., 2008).



### The urban social environment

There are many ways in which the *urban social environment* may affect health. There are results from studies that suggest that there are sources of tension in modern living, including unpleasant stimuli that may be associated both with deviant behaviour and with poor health (Hynes & Lopez, 2006). Extensive research has established a relation between stress and social tension and mental and physical health, and newer reports has theorized that features of the urban neighbourhood context are associated with social tension, and adverse health behaviours (Larsen-Gordon et al., 2006). Apart from social tension or stress, *individual social resources* also may be important determinant of health in cities. For example, limited social support may predispose persons to poorer coping and adverse health (Craig et al., 2012).

Social networks have been shown to be importantly associated with a range of social behaviours. In recent years, groups practices and social norms have been considered particularly important in transmission of sexually transmitted diseases and the transmission of human immunodeficiency virus (HIV) (Butz et al., 2004). Newer theories include the possibility of *contagiousness of ideas and social examples*. Epidemiological studies have shown that urban population, characterized by high population density are at higher risk of transmission of biological organisms (Behanova, 2014). Also, because concentrated urban populations share common resources (e.g. water) the practices of one group can affect the health of others (Prasad et al., 1966).

The *spatial separation* of various racial/ethnic and socioeconomic communities could significantly influence urban health outcomes. Numerous cities globally exhibit high levels of segregation, characterized by multiple historical, logistical, and practical obstacles to social integration among diverse groups. Spatial segregation can have many effects, including the enforcing of homogeneity in resources and social network ties, suppressing diversity that may benefit persons of lower socioeconomic status (Epstein et al., 1998). Persons who live in segregated communities may have unequal contact, vulnerability, and response to economic and social deprivation, toxic substances, and hazardous conditions. One study of infectious disease transmission suggested that residential segregation contribute to the transmission of tuberculosis through concentrated poverty resulting in conditions such as run-down housing and inadequate access to health care (Jiang et al., 2004).

While interconnected with various facets of the urban social landscape, *inequality* emerges as a significant influencer of health outcomes in urban settings. Despite robust evidence linking poor individual and group socioeconomic status to health disparities, urban environments often witness the coexistence of affluent and impoverished populations in close physical proximity (Cohen et al., 2017). Both empirical research and theoretical frameworks suggest that this disparity in income distribution and access to resources may independently influence health outcomes through multiple channels (Marques et al., 2017). Perceived and actual inequalities stemming from disparities in income distribution ruin social trust and weaken societal well-being and health (Strosnider, 2017). Thus, inequalities within urban settings may serve as significant modifiers in shaping the impact of various other social environmental factors.

The relation between providing **health and social services** and urban living is complicated and varies between cities and countries. In wealthy countries, cities are characterized by a wide selection of health and social services (UN, 2014). Although many cities are characterized by great differences in wealth between relatively close neighbourhoods. These differences are often associated with differences in the availability and quality of care (Vardoulakis et al., 2014). The presence of well-equipped, lucrative, practice opportunities in the same city decreases the likelihood that service providers will work in lower paid, public service clinics, particularly when these last-mentioned services face limited resources and uncertain political assurance. Also, low-income urban residents continue to face significant obstacles in finding health care both in wealthy and less-wealthy countries (Heal et al., 2013). In some countries, person with lower socioeconomic status are more likely to lack health insurance coverage. In turn, uninsured persons face barriers to care, receive poorer quality care, and are more likely to use emergency system. This burdens the health system not adequately funded or prepared to care for them (Heaviside et al., 2015).

There are multiple mechanisms that may explain how cities affect health, with different mechanism being potentially important for different morbidities. Several characteristics of cities may be associated with poor health, but several others may bestow an urban health "advantage" (Wilkinson et al., 2009).

## Key messages

- An important feature of population aging is the progressive aging of the older population itself.
- Because of chronic disease, the oldest old have the highest population levels of disability that require long-term care. They consume public resources disproportionately as well.
- Population aging will have dramatic effects on local, regional, and global economies. Most significantly, financial expenditures, labour supply, and total savings will be affected.

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# 3

# Social Determinants of Health

## 3.1 SOCIAL INEQUALITIES IN HEALTH

*Zuzana Katreniakova, Marketa Lachytova*

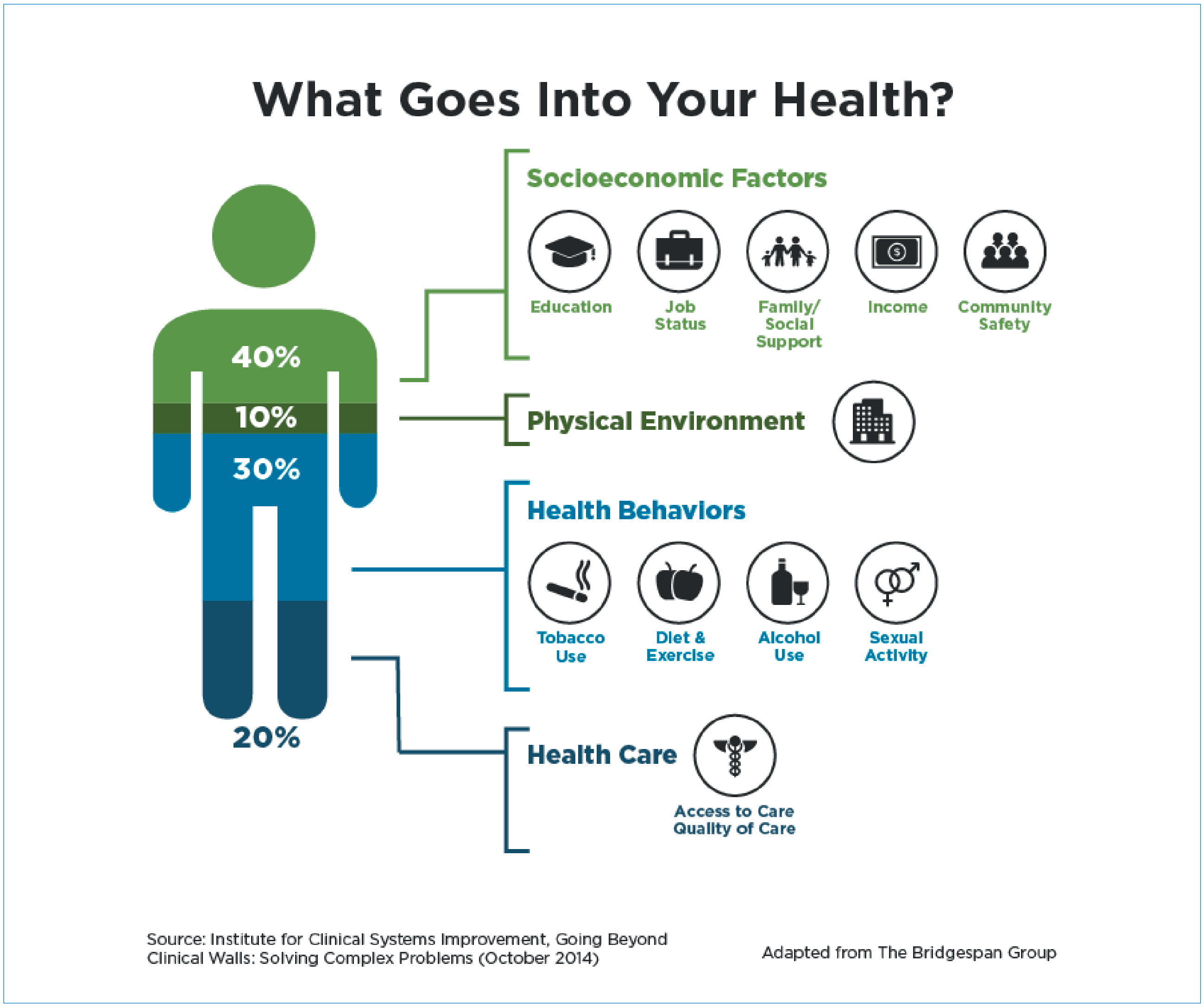
### Social determinants of health

It is now widely recognized that health outcomes of individuals and communities are deeply influenced by a variety of factors outside of health care. To a large extent, factors such as where we live, the state of our environment, genetics, our income and education level, and our relationships with friends and family all have considerable impacts on health, whereas the more commonly considered factors such as access and use of health care services often have less of an impact (Fig. 1).

Providing a comprehensive review of the evidence base of health determinants' influence on health is not simple. It needs to draw on the best available evidence - that from reviews and research papers, and including qualitative and quantitative evidence. This information must be supplemented with local and expert knowledge, policy information, and proposal specific information. The field of social determinants of health is one of the most complex and challenging of all.

**Figure 1.** The impact of determinants on health.

Source: Feeding America, 2018



Source: Institute for Clinical Systems Improvement, Going Beyond Clinical Walls: Solving Complex Problems (October 2014)

Adapted from The Bridgespan Group

**The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels.** In 1998, a new and stronger evidence has been developed and presented as the 2nd edition titled "Social determinants of health: the solid facts". The ten topics included e.g. lifelong importance of health determinants in early childhood, and the effects of poverty, drugs, working conditions, unemployment, social support, good food and transport policy. It brought deeper view on social gradient in health and expalnations how psychological and social influences affect physical health and longevity (Wilkinson & Marmot, 2003).

Since 2003, when the **WHO Commission on Social Determinants of Health** (CSDH) has been set up, a lot of evidence was summarized on how the structure of societies, through myriad social interactions, norms and institutions, are affecting population health, and what governments and public health can do about it. As the result of this expertise **the CSDH conceptual framework** (Fig. 2) was developed (WHO, 2010).

The CSDH framework shows how social, economic and political mechanisms give rise to a set of socioeconomic positions, whereby populations are stratified according to income, education, occupation, gender, race/ethnicity and other factors; these socioeconomic positions in turn shape specific determinants of health status (intermediary) reflective of people's place within social hierarchies; based on their respective social status, individuals experience differences in exposure and vulnerability to health-compromising conditions. Illness can "feed back" on a given individual's social position, e.g. by compromising employment opportunities and reducing income; certain epidemic diseases can similarly "feed back" to affect the functioning of social, economic and political institutions.

"Context" is broadly defined to include all social and political mechanisms that generate, configure and maintain social hierarchies, including: the labour market; the educational system, political institutions and other cultural and societal values. Among the contextual factors that most powerfully affect health are the welfare state and its redistributive policies. The structural mechanisms are those that generate stratification and social class divisions in the society and that define individual socioeconomic position within hierarchies of power, prestige and access to resources. These mechanisms are rooted in the key institutions and processes of the socioeconomic and political context. The most important structural stratifiers and their proxy indicators include: Income, Education, Occupation, Social Class, Gender, Race/ethnicity.

Together, context, structural mechanisms and the resultant socioeconomic position of individuals are "structural determinants" and in effect it is these determinants we refer to as the "social determinants of health inequities." The underlying social determinants of health inequities operate through a set of intermediary determinants of health to shape health outcomes. The main categories of intermediary determinants of health are:

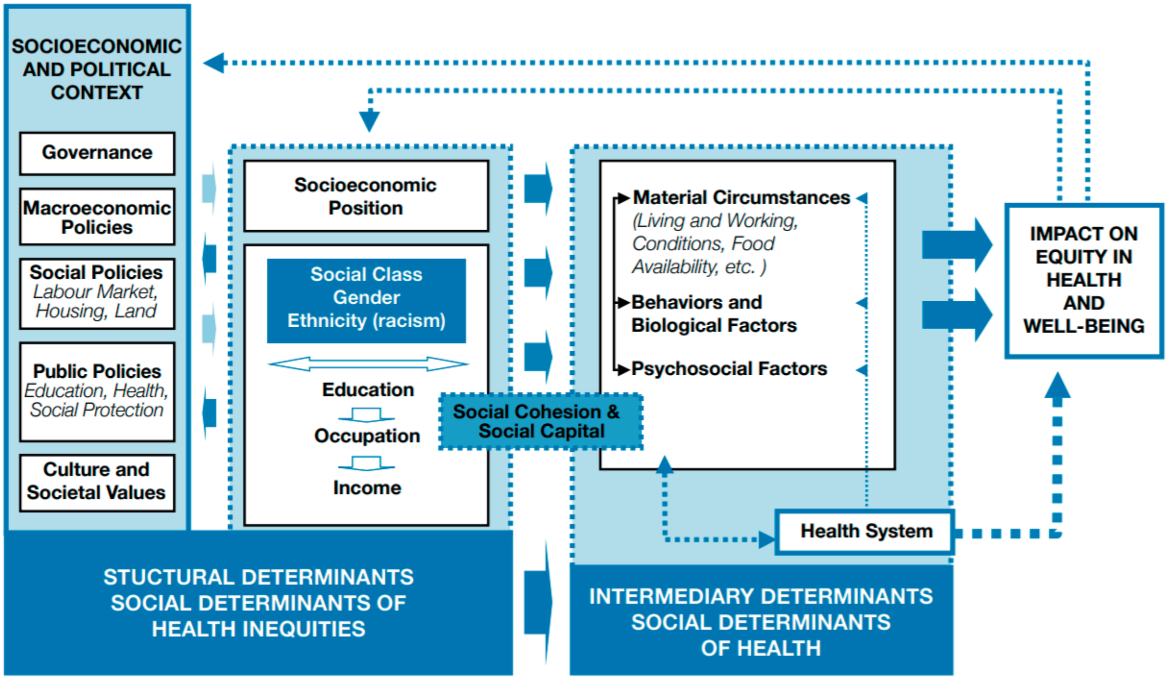
- Material circumstances
  include factors such as housing and neighborhood quality, consumption potential (e.g. the financial means to buy healthy food, warm clothing, etc.), and the physical work environment.
- Psychosocial circumstances
  include psychosocial stressors, stressful living circumstances and relationships, and social support and coping styles (or the lack thereof).

- Behavioral and biological factors include nutrition, physical activity, tobacco consumption and alcohol consumption, which are distributed differently among different social groups. Biological factors also include genetic factors.
- and the health system itself as a social determinant.
  The role of the health system becomes particularly relevant through the issue of access, which incorporates differences in exposure and vulnerability, and through intersectoral action led from within the health sector.

## Social inequalities in health

Health inequalities are avoidable differences in health between groups of people ***within countries*** and ***between countries.*** These differences arise from inequalities within and between societies. The dramatic differencies in morbidity, mortality, and risk factors that have been documented within and between countries are patterned after classic social deteminants of health, such as education and income (Link and Phelan, 1995) as well as place-based characteristics of the physical and social environment in which people live and the macrostructural policies that shape them. Social and economic conditions and their effects on people's lives determine their risk of illness and the actions taken to prevent them becoming ill or treat illness when it occurs.

**Figure 2.** Final form of the CSDH conceptual framework.



Source: WHO, 2010.

*Examples of health inequities between countries:*

- The infant mortality rate is 2 per 1000 live births in Iceland and over 120 per 1000 live births in Mozambique;
- The lifetime risk of maternal death during or shortly after pregnancy is only 1 in 17 400 in Sweden but it is 1 in 8 in Afghanistan.

*Examples of health inequities within countries:*

- In Bolivia, babies born to women with no education have infant mortality greater than 100 per 1000 live births, while the infant mortality rate of babies born to mothers with at least secondary education is under 40 per 1000;
- Life expectancy at birth among indigenous Australians is substantially lower (59.4 for males and 64.8 for females) than that of non-indigenous Australians (76.6 and 82.0, respectively);
- Life expectancy at birth for men in the Calton neighbourhood of Glasgow is 54 years, 28 years less than that of men in Lenzie, a few kilometres away;
- The prevalence of long-term disabilities among European men aged 80+ years is 58.8% among the lower educated versus 40.2% among the higher educated

Source: www.who.int/social_determinants/final_report/key_concepts_en.pdf.

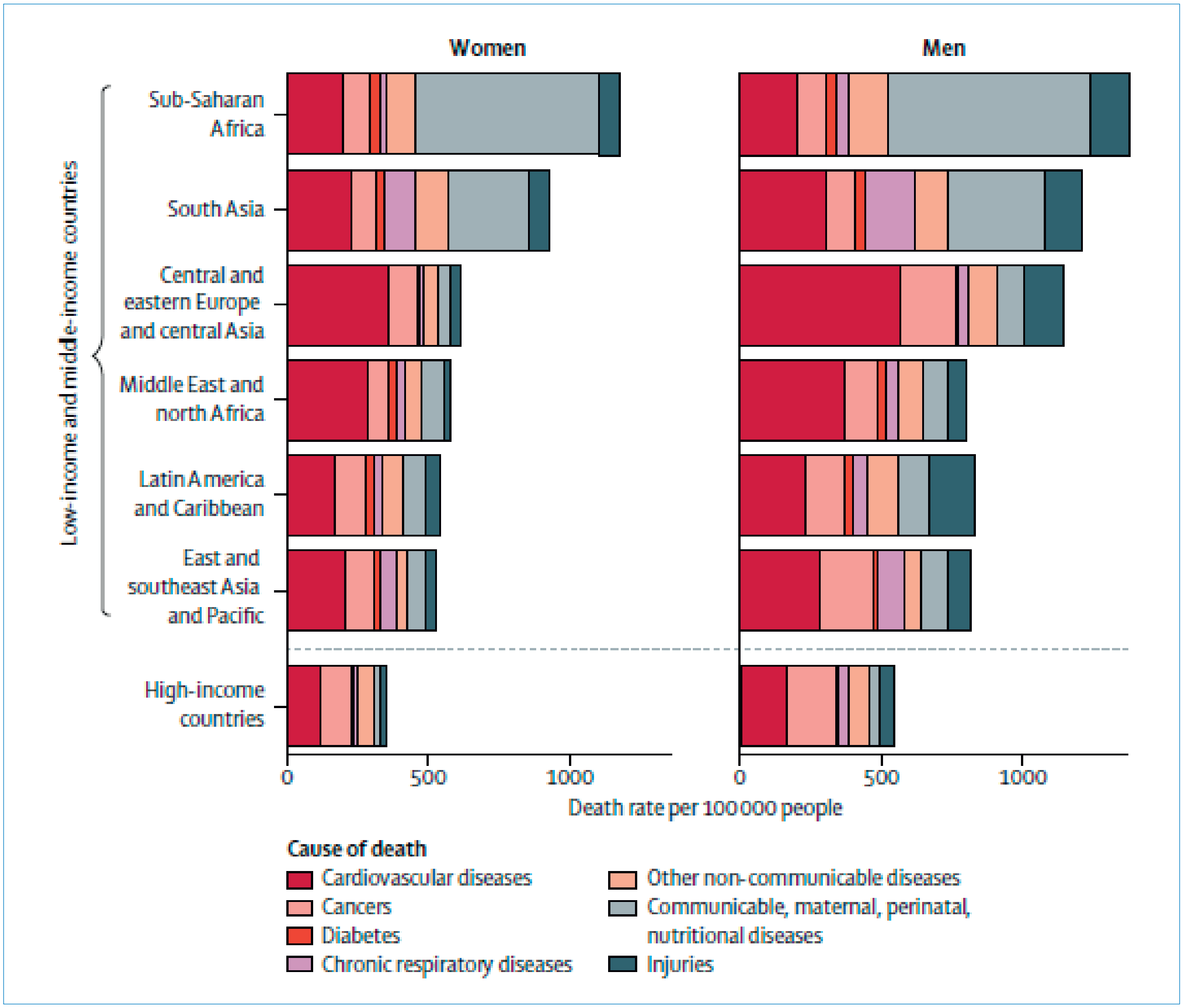
## Social inequalities in non-communicable diseases

Non-communicable diseases (NCDs) contribute to more than two-thirds of deaths worldwide. Four-fifths of NCDs occur in low-income and middle-income countries (LMICs), and a third of deaths from NCDs affect people younger than 60 years. NCDs are often thought to increase with affluence and westernization, however in reality, this notion applies only to some NCDs, such as colorectal and breast cancers, which are more prevalent in high-income than in low-income countries (Stringhini et al., 2010).

Worldwide, the age-standardised NCD death rate in men is highest in eastern and central Europe and central Asia, mainly because of very high cardiovascular disease death rates; in women, this rate is highest in south Asia, mainly because of high cardiovascular and chronic respiratory disease death rates. The contribution of NCDs to the all-cause mortality gap between these countries is more than 50% in all regions, except for sub-Saharan Africa and south Asia (for both sexes) and Latin America (men only; Fig. 3).

**Figure 3.** Age-standardised death rates by region in 2010

Source: Lozano et al., 2010.



Risk factors for many common mental disorders are heavily associated with social inequalities, whereby the greater the inequality the higher the inequality in risk. The prevalence and social distribution of mental disorders has been well documented in high-income countries. While there is growing recognition of the problem in low- and middle-income countries, a significant gap still exists in research to measure the problem, and in strategies, policies and programmes to prevent mental disorders.

Populations with low economic status in high-income countries are much more likely to have a higher chronic disease burden than groups with high economic status, due to people living in poverty are restricted in their ability to practise healthy behaviours that promote health and are predisposed to chronic diseases and late (and hence more advanced) diagnosis (Wagstaff, 2002). NCDs behavioural risk factors such as tobacco smoking, heavy alcohol consumption, physical inactivity, and unhealthy eating are socially patterned in high-income countries, with individuals of low socioeconomic status generally experiencing a higher burden of risk factors (Stringhini and Dugravot et al., 2014; Stringhini et al., 2010).

### Social inequalities in communicable diseases

Acute respiratory infection and diarrhea is the leading cause of child mortality (Liu et al., 2012; Bhutta et al., 2013). There are countries with the lowest infant and child mortality rates in the world, but mortality in countries with the highest rate for children under 5 years is up to 20 times higher than that in countries with the lowest rate. Every year, too many children die before the age of 5 – 52% of them in the first month of life.

Much of the morbidity and mortality among children and young people is preventable. Children still die due to preventable causes such as pneumonia and diarrhoea, and there are warning signs of the return of diseases previously under control, such as diphtheria and tuberculosis (http://www.euro.who.int/en/health-topics/Life-stages/child-and-adolescent-health/child-and-adolescent-health).

Most children and adolescents in the WHO European Region enjoy a high standard of health and well-being. However, disparities in their health between and within countries persist. Although adequate approaches and guidelines have been in existence for many years and have often proven effective in some countries - in low- and middle-income countries (LMICs) is often restricted due to limited resources and underdeveloped infrastructure.

Besides, hospital-acquired infections, especially those caused by multidrug-resistant Gram-negative rods, have become a top global priority on account of they are associated with significant morbidity and mortality, particularly in developing countries (Rosenthal and Maki et al., 2006).

### Strategies to tackle social inequalities in health

A difference or disparity in health outcomes is systematic, avoidable, and unjust (Braveman, 2003).

Every aspect of government and the economy has the potential to affect health and health equity – finance, education, housing, employment, transport, and health etc. Social policies and programmes that improve opportunities and capabilities for economic productivity and social participation, and facilitate healthy lifestyles and environments, are essential to improve health and reduce inequalities. The most important are those that (Marmot et al., 2012):

- **enhance early childhood development,**
- **improve access to highquality education,**
- **create home and school environments that facilitate good educational outcomes, and**
- **remove barriers to secure employment for disadvantaged groups.**

It is of major importance that action is taken to improve the conditions of everyday life, beginning before birth and progressing into early childhood, older childhood and adolescence, during family building and working ages, and through to older age. **Action throughout all life stages** would provide opportunities for both improving population health, and for reducing risk of those disorders that are associated with social inequalities. There is a considerable need to raise the priority given to the disease prevention and health promotion through action on the social determinants of health (Allen & Marmot, 2014).

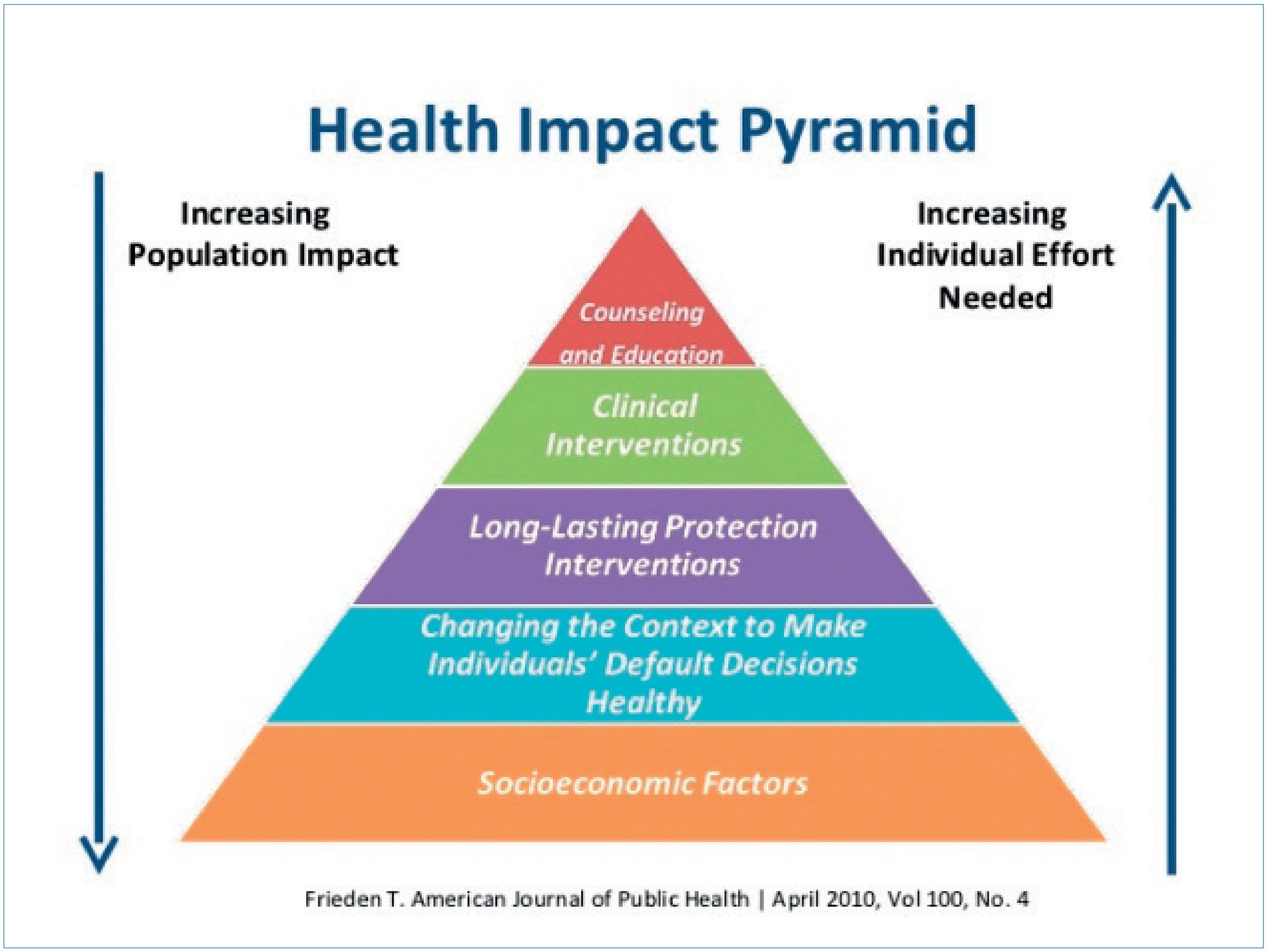
A **5-tier pyramid** best describes the impact of different types of public health interventions and provides a **framework to improve health** (Fig. 4). At the base of this pyramid, indicating interventions with the greatest potential impact, are efforts to address socioeconomic determinants of health.

In ascending order are interventions that change the context to make individuals default decisions healthy, clinical interventions that require limited contact but confer long-term protection, ongoing direct clinical care, and health education and counseling. Interventions focusing on lower levels of the pyramid tend to be more effective because they reach broader segments of society and require less individual effort. Implementing interventions at each of the levels can achieve the maximum possible sustained public health benefit (Frieden, 2010).

**The World Medical Association has prioritised addressing the social determinants of health as central to health improvement and tackling health inequity, through the declaration of Oslo 2015** (WMA, 2015). This is in response to a growing body of evidence demonstrating that doctors working at all levels can make significant impact on health inequity through action on the social determinants. Whether its social prescribing, designing services to meet the needs of marginalised communities, partnering with community leaders and organisations, working to ensure that the health service provides good quality work, advocating for a basic income or working with governments to ensure health equity is at the heart of all policy decision.

Figure 4. Health impact pyramid.

Source: Frieden, 2010.



It is clear that doctors, national medical associations and the WMA have a key role to play in tackling health inequity internationally, at a national level, at the local level, and for communities, individuals and their families. This requires action in the following areas (WMA, 2016):

1. **The education and training of doctors**, to inspire and equip doctors with the necessary skills to improve social determinants for individuals and at national level.

2. **Effective monitoring and evaluation of programmes**, to better understand the impact of the social

determinants of health at the local and national level, to evaluate impact of actions and policies and and, importantly, to provide an imperative for action.

3. **Working with individuals and communities**, reevaluating the patient–physician relationship, and the relationship of doctors in the community, so that health services can be better designed to meet the needs of those most in need.

4. **Tackling inequity within the health system**, a large source of employment the world over, by setting an example as a provider of good quality work to everyone it employs and considering the broader social impact of procurement by the health service.

5. **Working in partnership** to ensure that community organisations, other sectors and the health and

public health services are effectively taking action on social determinants.

6. **Extending doctors' responsibility** to advocate on social determinants on behalf of patients and communities and at national level and international level.

**Key messages**

- Low and middle-income countries have higher NCDs mortality and most of NCDs risk factors than the higher-income countries. Also, within the same country, NCDs and some of their most important risk factors tend to be higher in people and communities with a lower SES.
- A social determinants of health approach requires action across multiple sectors and levels.

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## 3.2 SOCIAL GRADIENT, EARLY LIFE, FOOD, AND TRANSPORT

*Marketa Lachytova*

### 3.2.1 Social gradient – the position at the ladder matters

The health impact of social factors is supported by the strong and widely observed associations between a wide range of health indicators and measures of individuals' socioeconomic resources or social position, typically income, educational attainment, or rank in an occupational hierarchy. There is a **social gradient** in health that runs from top to bottom of the socioeconomic spectrum. The gradient of health is observed almost throughtout the range of **socio-economic status** (SES), so that the middle class have better health than the poor, and the wealthy have better health than the middle class or in another words the higher the level of household income, wealth, education, or occupational ranking, the lower the risks of morbidity and mortality. This is a global phenomenon, seen in low, middle and high income countries (Berkman and Kawachi et al., 2014).

There are four major models used to explain social class related differences in health (Bartley and Blane, 2008; Bartley, 2004):

**1. Behavioural model**

There are social class differences in health damaging or health promoting behaviours such as dietary choices, consumption of drugs, alcohol and tobacco, active leisure time pursuits, and use of immunisation, contraception and antenatal services. However, differences in health behaviour explain only one-third of social class differences in mortality.

**2. Materialist model**

Poverty exposes people to health hazards. Disadvantaged people are more likely to live in areas where they are exposed to harm such as air-pollution and damp housing. There is some specific evidence for materialist explanations. For example, many studies have associated higher rates of childhood respiratory disease with damp housing. The full impact of living standards, however, can only be understood over the course of the life term. While most experts in public health agree that materialist explanations play a role in explaining health inequalities, many find a simple materialist model to be insufficient.

**3. Psycho-social model:** Social inequality may affect how people feel which in turn can affect body chemistry. For example, stressful social circumstances produce emotional responses which bring about biological changes that increase risk of heart disease. Psycho-social risk factors include social support, control and autonomy at work, the balance between home and work, and the balance between efforts and rewards. Evidence shows that people who have good relationships with family and friends, and who participate in the community, have longer life expectancies than those who are relatively isolated. Evidence of an association between stress at work and health is less clear, but most well designed studies show a higher risk of heart disease among individuals who work in jobs where demands are high and control is low.

**4. Life-course model:** Health reflects the patterns of social, psycho-social and biological advantages and disadvantages experienced by an individual over time. The chances of good or poor health are influenced by what happened to a child in-utero and in early childhood and disadvantages are likely to accumulate through childhood and adulthood. For example, individuals who experienced poor home conditions in childhood are more likely to experience occupational disadvantage.

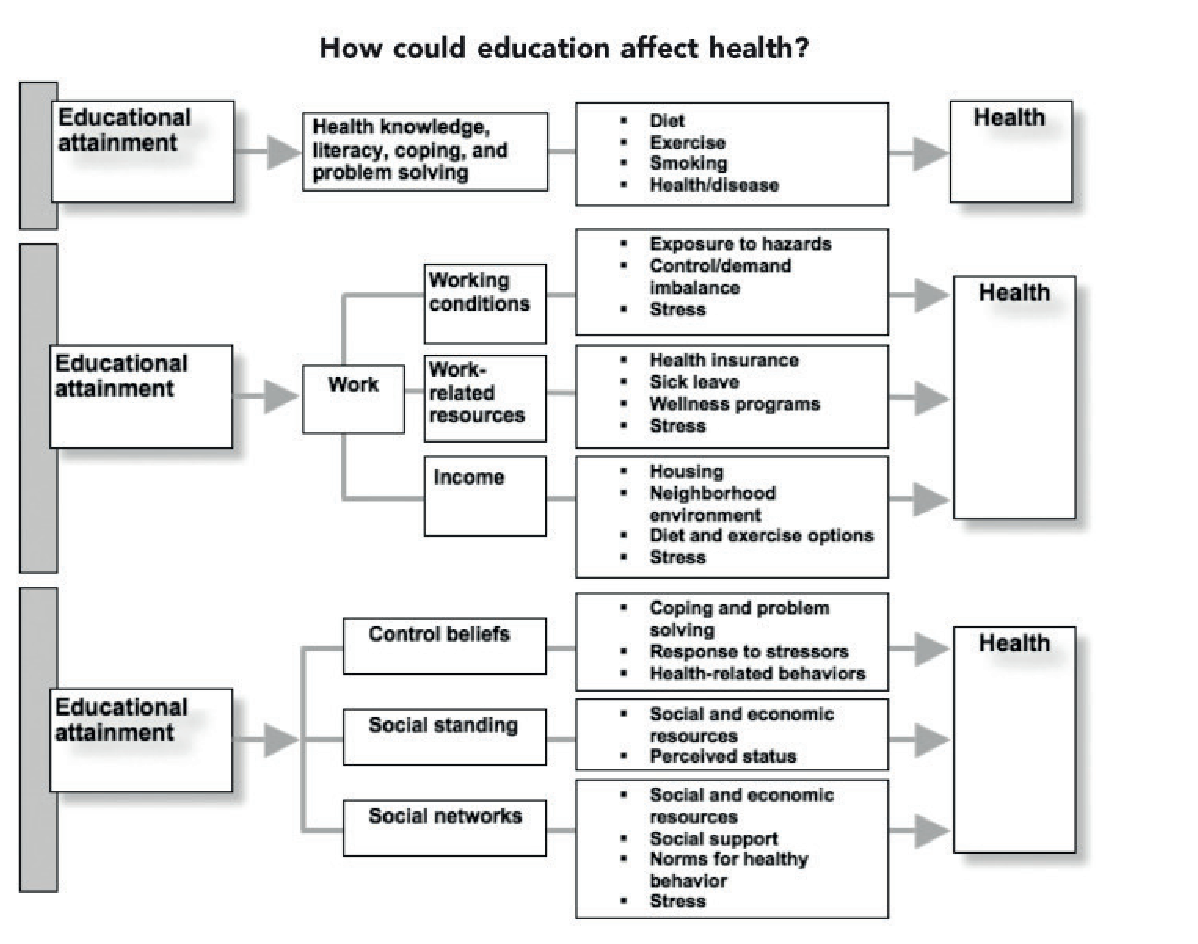
Among all potential factors that participate on the socioeconomic status of individuals' the level of education represents kind of "corner stone" for others. There are three general pathways through which **education** can influence many health outcomes (Fig. 5). While there is not necessarily a consensus about each step depicted here, all are plausible in light of current knowledge, including biological knowledge (Egerter et al., 2011). The first pathway is widely accepted: education increases knowledge and skills and, thus, can facilitate healthier behaviors. The second pathway also is biologically plausible. However, while its left-sided branches (i.e., education leading to better, higher-paid work) are not disputed, subsequent links from income to health through various pathways, such as work-related benefits, neighborhood opportunities, and stress, are not typically considered as education effects. The third pathway depicts health effects of education through psychobiological processes such as control beliefs, subjective social status, and social networks, again based on existing literature (Gallo and Penedo et al., 2009).

### Social gradient and non-communicable diseases

Unhealthy behaviours recognized as the key risk factors of non-communicable diseases such as **cardiovascular diseases and cancer**, were more frequent in high socioeconomic groups at the beginning of the 20th century, but the burden later shifted towards the disadvantaged socioeconomic groups. A similar transition of the NCDs burden has also

**Figure 5.** Pathways through which education can affect health.

Source: Egerter et al., 2011.



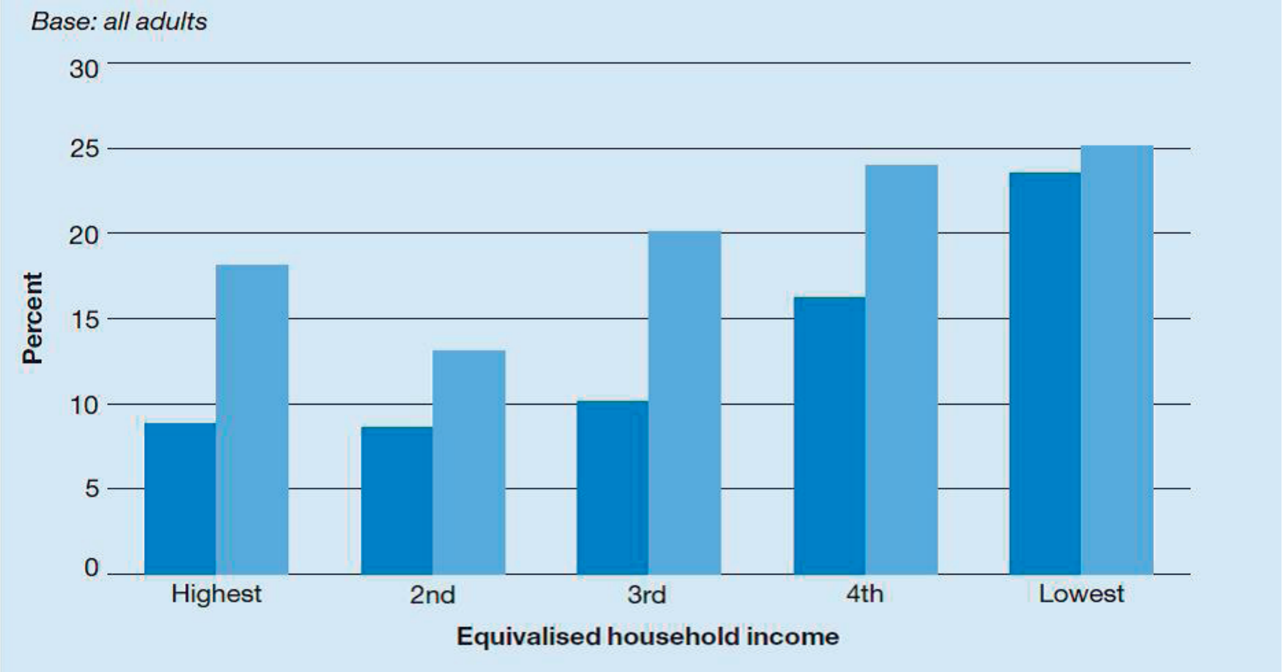
been documented in several middle-income countries (Mayen et al., 2014).

A person's mental health and many common **mental disorders** are shaped by various social, economic, and physical environments operating at different stages of life. A review of population surveys in European countries found that higher frequencies of common mental disorders - depression and anxiety - are associated with low educational attainment, material disadvantage and unemployment (Fryers et al., 2005) and for older people with a social isolation. Poorer mental health was found in women, poorer groups, and among those who reported weak social support (Lehtinen et al., 2002). The pattern of social distribution of common mental disorders is observed as a social class gradient, more marked in women than in men (Fig. 6).

**Figure 6.** Prevalence of any common mental disorder by household income, England 2007

*Notes: pale bars – women, dark bars - men*

Source: McNamus S et al., 2007.



A two-way relationship exists between mental disorders and socioeconomic status: mental disorders lead to reduced income and employment, which entrenches poverty and in turn increases the risk of mental disorder. Those lower on the social hierarchy are more likely to experience less favourable economic, social, and environmental conditions throughout life and have access to fewer buffers and supports. These disadvantages start before birth and tend to accumulate throughout life, although not all individuals with similar exposures have the same vulnerabilities; some are more resilient or have access to buffers and supports to mitigate the potential mental health effects of disadvantage and poverty. There is a clear relationship between poverty, mental illness and disability, with the presence of any one factor increasing the likelihood of the others (Patel et al., 1998; Patel et al., 2002). Reducing mental illness and disability, and the poverty that is so commonly a consequence, requires strengthening of human rights protections and development of mental health systems that ensure equitable access to skilled treatment, rehabilitation, social support, housing and employment.

### Key messages

- » Socioeconomic status is a strong predictor of various cardiovascular diseases and cancer, lower status is associated with increased cardiometabolic disease prevalence and mortality.
- » A level of education represents a "corner stone" of other potential factors that participate on the socioeconomic status of individuals.

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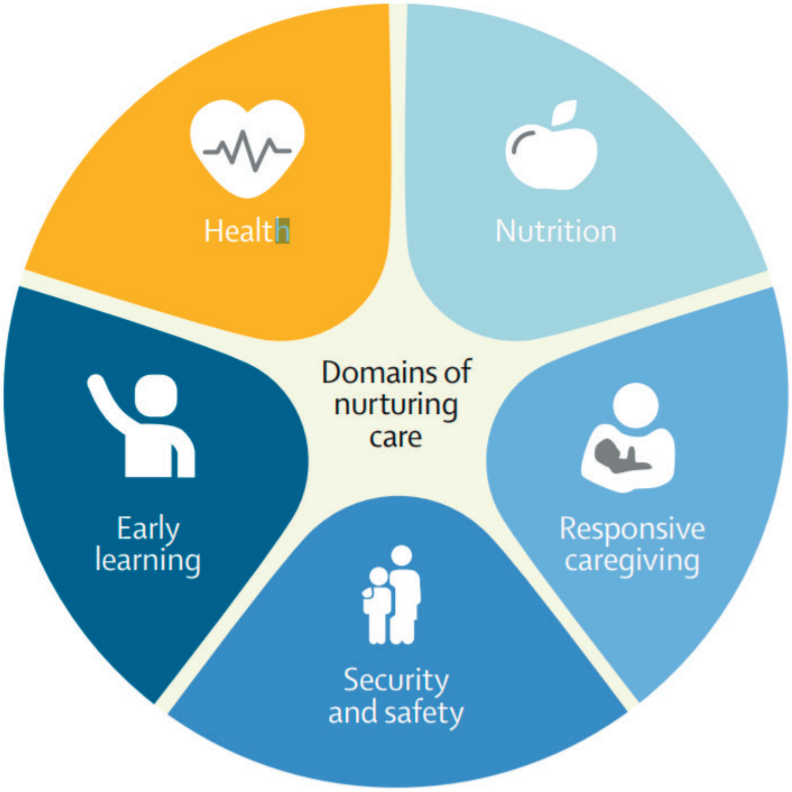
### 3.2.2 Health related risk factors in early life

Early childhood, defined as the period from birth to eight years old, is a time of remarkable growth with brain development at its peak. During this stage, children are highly influenced by the environment and the people that surround them (https://en.unesco.org/themes/early-childhood-care-and-education).

Childhood development is a maturational process resulting in an ordered progression of perceptual, motor, cognitive, language, socio-emotional, and selfregulation skills. Thus, the acquisition of skills through the life-cycle builds on the foundational capacities established in early childhood. Multiple factors influence the acquisition of competencies and skills, including health, nutrition, security and safety, responsive caregiving, and early learning (Fig. 7). Each are necessary for nurturing care. Nurturing care reduces the detrimental effects of disadvantage on brain structure and function which, in turn, improves children's health, growth, and development (Singla et al., 2015).

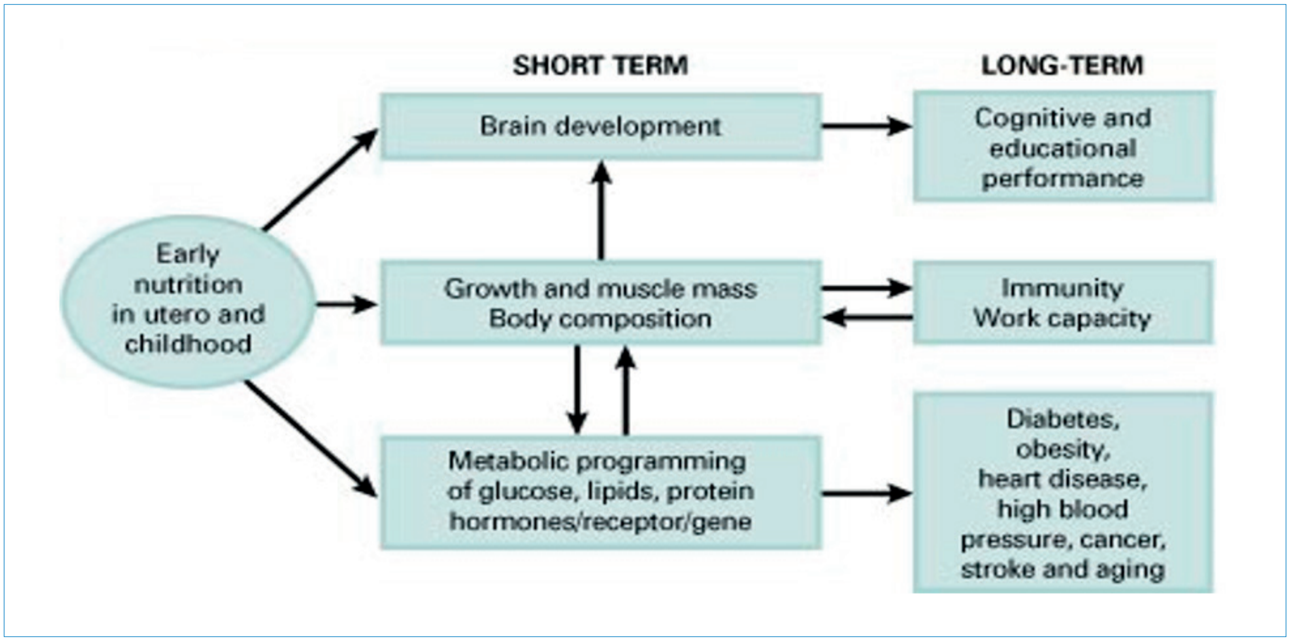
Early childhood development is linked and inseparable from mother's health, where **nutrition plays a major role in maternal and child health** (Fig. 8). Although the association between maternal nutrition and birth outcome is complex and is influenced by many biologic, socioeconomic, and demographic factors, poor maternal nutritional status has been related to adverse birth outcomes (Villar et al., 2003).

**Figure 7.** Domains of Nurturing Care Necessary for Children to Reach Their Developmental Potential



Source: Black et. al., year.

**Figure 8.** The short-term and long-term effects of early nutrition



Source: Ending Malnutrition by 2020: An Agenda for change in the millenium. 2000.

A healthy maternal dietary pattern, during the periconceptional period and throughout pregnancy, reduces the risk of maternal and infant complications, as well as longlife consequences. A healthy diet must be balanced not only in terms of macronutrients content (intake of proteins, carbohydrates and fats), but also in terms of micronutrients intake (vitamins and mineral). Imbalances of micronutrients before and during pregnancy can negatively influence both mother and fetus with significantly high reproductive risks, ranging from infertility to fetal structural defects, abnormal fetal development and growth and longterm diseases. On the other side, healthy dietary patterns and micronutrients supplementation, particularly during the periconceptional period, are related to improved birth outcomes, probably through alterations in maternal and fetal metabolism (Cetin, Berti et al., 2010). Dietary patterns with better micronutrient intakes (green leafy vegetables, fruits, whole-grain breads/cereals, oily fish etc.) positively influence the formation of a normal placenta at the beginning of pregnancy, fundamental later on in the developing fetus, thus decreasing the risk preeclampsia, premature delivery and abnormal fetal growth (Cetin and Laoreti, 2015).

The impact of maternal nutrition on birth outcomes may be attenuated by socioeconomic and environmental factors in various ways. For example, social gradient status that influence the quality of habitual and pregnancy dietary intake can result in chronic undernutrition, as well as in multiple rather than single nutrient deficiencies, that cannot be overcome by a few months of supplementation during a single pregnancy (Fall et al., 2003). Cultural factors may influence parameters such as maternal age at initiation of childbearing (King and Sachet, 2000) and length of the interpregnancy interval and of the entire reproductive cycle, including lactation (Allen, 2005).

**Parental maltreatment and socioeconomic disadvantage**

There are many severe chronic stressors to which children could be exposed. However, nearly all of the extant research linking early stress to adult health has focused on two experiences: **parental maltreatment** and **socioeconomic disadvantage.**

While both of these experiences are chronic psychological stressors they obviously differ in some critical respects – the kind of threats they pose, the duration, frequency, severity of those threats, and the opportunities for coping. It is clear that disadvantage and maltreatment co-occur more often than expected by chance alone (Crouch et al., 2000). The long-term health consequences of childhood maltreatment include cardiovascular, respiratory, metabolic, musculoskeletal, and autoimmune conditions (Wegman & Stetler, 2009). All of these conditions develop through etiologically complex transactions between genetics, lifestyle, and the environment, as mediated via dysregulation of multiple physiological systems. Yet, over the past decade, it has become apparent that chronic, low-grade inflammation is a common soil that helps fertilize the development and progression of many of them (Scrivo et al., 2011). These conditions range from traditional psychiatric disorders, like depression and substance misuse, to allergic, metabolic, cardiovascular, neoplastic, and rheumatic diseases (Haroon et al., 2012; Nathan & Ding, 2010). Catalogue of these health problems disproportionately prevalent among persons who experienced childhood adversity. These problems span the continuum of what are traditionally understood to be mental and physical illnesses. For example, children maltreated by their parents not only go on to develop psychiatric disorders like unipolar depression and substance abuse at higher than expected rates (Teicher & Samson 2013), but also show increased prevalence of metabolic syndrome, coronary heart disease, some cancers, and autoimmune conditions as they age (Danese & McEwen 2012; Shonkoff & Boyce, 2009). Over the past 10 years it has revealed that childhood adversity is associated with subtle differences in multiple aspects of neural, cardiovascular, neuroendocrine, and immune functioning (Miller et al., 2011; Danese & McEwen, 2012).

Children raised in families of low socioeconomic status (SES) experience disproportionately high rates of many of these same conditions (Galobardes et al., 2008; Reiss, 2013). , children from low-SES families tend to carefully monitor their environment for danger and maintain a low threshold for judging situations as threatening (Chen et al., 2006). When confronted with ambiguous stimuli, whose threat value is uncertain, low-SES youth exhibit larger cardiovascular responses than higher SES youth (Chen et al., 2004).

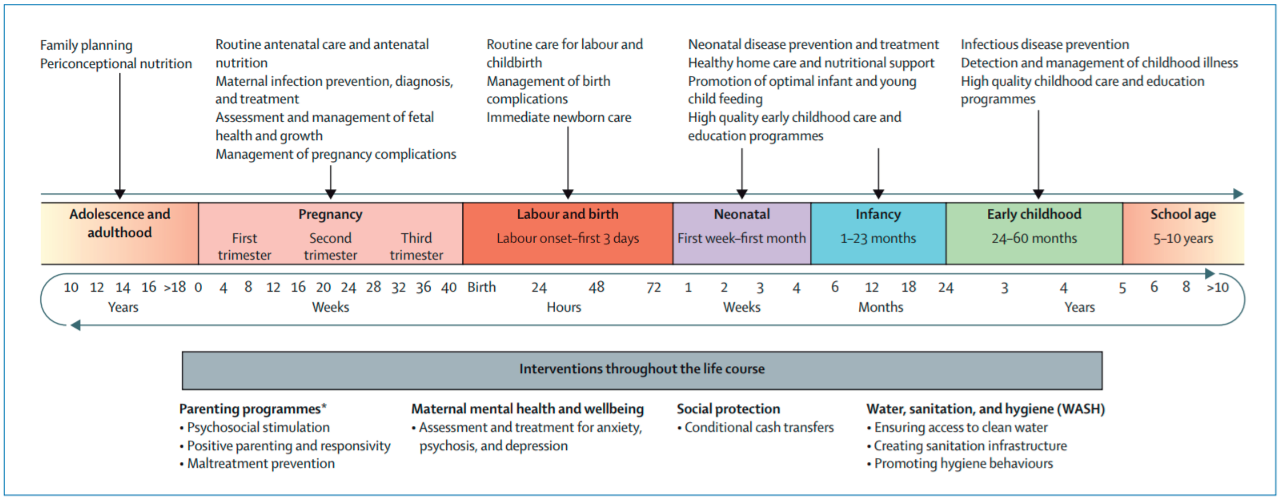
Maltreated and disadvantaged children are also disproportionately exposed to pollutants, secondhand smoke, and high-fat and high-sugar diets, along with psychosocial stressors like family instability, insensitive caregiving, and neighborhood violence (Cicchetti & Toth, 2005). Maltreated children display higher levels of inflammatory biomarkers relative to control subjects, including C-reactive protein and interleukin-6 (Slopen, Kubzansky et al., 2013; Danese and Caspi et al., 2010) and so do low-SES youth (Khandaker, Pearson et al., 2014). This low-grade inflammation persists into adulthood; multiple studies report that inflammatory biomarkers are elevated in adults exposed to maltreatment and/or disadvantage during childhood (Matthews, Chang et al., 2014). Across the life course, childhood maltreatment is associated with higher rates of cigarette smoking, excessive alcohol consumption, drug misuse, physical inactivity, and high-fat eating (Felitti, Anda et al., 1998). The same trends are seen with low childhood socio-economic status (Miller, Chen et al., 2011).

### Evidence-based interventions on nurturing care

The majority of approximately 140 million births that occur globally every year are among women without risk factors for complications for themselves or their babies at the beginning and throughout labour. Nevertheless, the time of birth is critical to the survival of women and their babies, as the risk of morbidity and mortality could increase considerably if complications arise. In line with the targets of ***Sustainable Development Goal 3 – ensure healthy lives and promote well-being for all at all ages*** – and the new ***Global Strategy for Women's, Children's and Adolescents' Health (2016–2030),*** global agendas are expanding their focus to ensure that women and their babies not only survive labour complications if they occur but also that they thrive and reach their full potential for health and life (WHO recommendations Intrapartum care for a positive childbirth experience, 2018).

The effectiveness of interventions could be improved by taking into consideration the major insights gained over the past decade about how human development is affected across generations by complex and multifaceted experiences. Sectoral interventions combined with elements of nurturing care and protection, can boost the effect on child outcomes. This approach encourages interventions directed at the family as a unit rather than the child alone. Interventions shown to have significant benefits for childhood development, are summarised and organised into packages in Figure below. Many of the health and nutrition interventions have additional benefits for improved child survival and growth, as well as reduced morbidities and disabilities (Advancing Early Childhood Development, 2016). Understanding the relation between maternal nutrition and birth outcomes may provide a basis for developing nutritional interventions that will improve birth outcomes and long-term quality of life and reduce mortality, morbidity, and health-care costs (Fig. 9).

**Figure 9.** Evidence-based interventions that affect aspects of nurturing care.

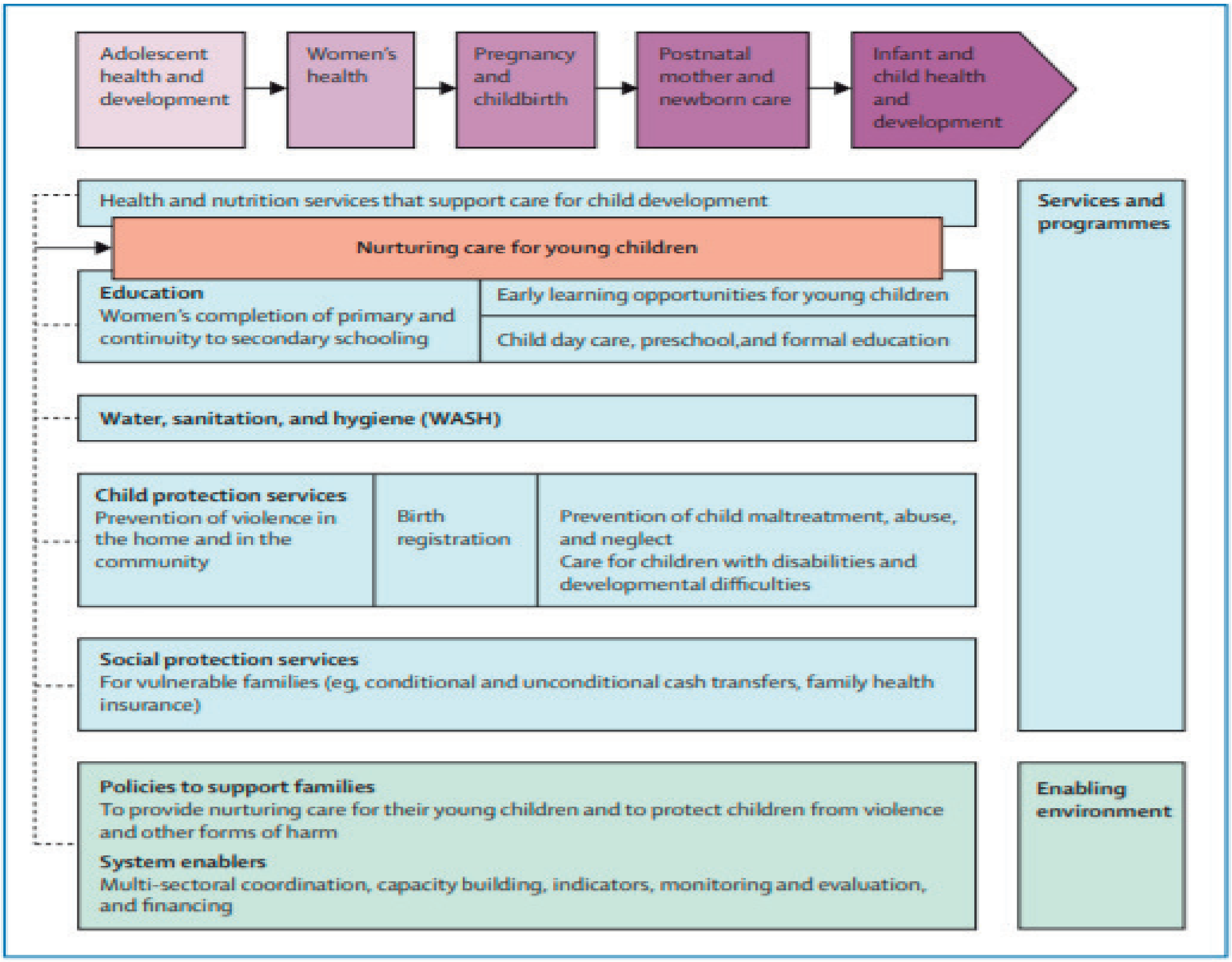


Source: Series Paper ECD 2 (www.thelancet.com/series/ECD2016)

- **Family support and strengthening package:** Three elements of family strengthening increase the likelihood that families are able to provide nurturing care for their children: *access to quality services* (eg, antenatal care, immunisation, nutrition); *skills building* (eg, nurturing care and reduction of harsh discipline); and *support* (eg, social protection, safety networks, and family support policies).
- **Caring for the caregiver package:** This two-generation package emphasises care and protection of parents' physical and mental health and wellbeing, while enhancing caregivers' capacity to provide nurturing care to their child.
- **Early learning and protection package:** This set of interventions integrates the support of young children with parental support and the facilitation of teachers' and caregivers' ability to create a nurturing environment in day care and early childhood centres. The emphasis is on quality and family support through parental empowerment, guidance on nutrition and care, and child protection.
- ***Parent support programmes*** that promote nurturing care, particularly those employing several behaviour change techniques, can substantially augment the positive effects on early childhood development outcomes of basic health and nutrition, education, and protection interventions. In contrast, maltreatment during childhood is associated with reduced volume in brain regions involved in learning and memory (Teicher and Samson, 2013). Children who receive inadequate care, especially in the first 24 months of life and often from mothers who themselves were neglected or abused, are more sensitive to the effects of stress and display more behavioural problems than do children who receive nurturing care (Bick and Zhu et al., 2015).

To promote health and wellbeing across the life course at scale requires interventions provided through several sectors—and a supportive environment of policies, cross-sectoral coordination, and financing (Fig. 10). At the heart of this intervention framework is the '**nurturing care of young children'**, provided by parents, families, and other caregivers. Particularly successful are parent support programmes to promote nurturing care, among which the most widely implemented in low- and middle-income country settings are the ***WHO/UNICEF Care for Child Development*** (WHO/UNICEF, 2012) and ***Reach Up and Learn***, a parenting programme tested in trials in Jamaica over the past 20 years and now expanding to other regions (Reach Up early childhood parenting programme, 2016).

**Figure 10.** Framework to promote young children's development through a multi-sectoral approach.



Source: Richter, Daelmans et al., 2016

Strong biological, psychosocial, and economic arguments exist for intervening as early as possible, starting from and even before conception, to promote, protect, and support children's development. An emphasis on the first years of life is articulated within a life course perspective. High-quality care in families, child day care services, and preschools during the earliest years needs to be followed by high quality schooling and services into adolescence in order to capitalise on inter-dependence between investments made in the successive stages of the life cycle. Multi-sectoral interventions, with health services as an entry point, are particularly well-placed to reach children early with services that support families to deliver nurturing care and promote, protect, and support early childhood development. Interventions to promote nurturing care can feasibly build on existing health and nutrition services at only a limited additional cost. Coordination with education is needed to promote learning, and with social and child protection, to reach the most vulnerable populations. All sectors must play their part in supporting families to provide nurturing care for children.

## Key messages

» All children have the right to be raised in a family and to have access to quality health care, good nutrition, education, play and protection from harm, abuse and discrimination.

» Children have the right to grow up in an environment in which they are enabled to reach their full potential in life

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### 3.2.3 Food and Nutrition

Nutrition is the intake of food, considered in relation to the body's dietary needs. Good nutrition – an adequate, well balanced diet combined with regular physical activity – is a cornerstone of good health. Poor nutrition can lead to reduced immunity, increased susceptibility to disease, impaired physical and mental development, and reduced productivity (WHO, 2010).

#### Main trends

Rapid changes in diets and lifestyles that have occurred with industrialization, urbanization, economic development and market globalization, have accelerated over the past decade. This is having a significant impact on the health and nutritional status of populations, particularly in developing countries and in countries in transition. While standards of living have improved, food availability has expanded and become more diversified, and access to services has increased, there have also been significant negative consequences in terms of inappropriate dietary patterns. Nutrition is coming to the fore as a major modifiable determinant of chronic disease, on account of diet have strong effects, both positive and negative, on health throughout life. Most importantly, dietary adjustments may not only influence present health, but may determine whether or not an individual will develop such diseases as cancer, cardiovascular disease and diabetes much later in life.

Changes in the world food economy are reflected in shifting dietary patterns, for example, increased consumption of energy-dense diets high in fat, particularly saturated fat, and low in unrefined carbohydrates. Because of these changes in dietary and lifestyle patterns, chronic NCDs - including obesity, diabetes mellitus, cardiovascular disease, hypertension and stroke, and some types of cancer - are becoming increasingly significant causes of disability and premature death in both developing and newly developed countries, placing additional burdens on already overtaxed national health budgets (WHO, 1990). In many developing countries, food policies remain focused only on under nutrition and are not addressing the prevention of chronic disease. Many low- and middle-income countries are now facing a "double burden" of disease. While these countries continue to deal with the problems of infectious diseases and undernutrition, they are also experiencing a rapid upsurge in noncommunicable disease risk factors such as obesity and overweight, particularly in urban settings. It is not uncommon to find undernutrition and obesity coexisting within the same country, the same community and the same household. Children in low- and middle-income countries are more vulnerable to inadequate pre-natal, infant, and young child nutrition. At the same time, these children are exposed to high-fat, high-sugar, high-salt, energy-dense, and micronutrient-poor foods, which tend to be lower in cost but also lower in nutrient quality. These dietary patterns, in conjunction with lower levels of physical activity, result in sharp increases in obesity while undernutrition issues remain unsolved (WHO, 2018).

#### The most important current challenges

**1. Food insecurity**

Food insecurity can include the inability to access to nutritional food, disrupted eating patterns, or reduced food intake. Restricted availability of healthy meals often drives individuals to seek other measures to avoid starvation, including eating low-cost foods that lack nutritional value, skipping meals, and overeating during concentrated periods of time. Food-insecure individuals not only struggle with hunger but also can experience weight gain and obesity, caused by overconsumption of inexpensive food that has high levels of sugar and fat. Lack of access to healthy food and the subsequent adoption of coping habits can lead to chronic conditions, including ***hypertension, diabetes, cardiovascular disease, anemia, decreased nutrient intake, asthma, tooth decay, infection, and birth defects*** (Schrag, 2014). Hunger and food insecurity are closely related, but distinct, concepts. **Hunger** refers to ***a personal, physical sensation*** of ***discomfort***, while **food insecurity** refers to ***a lack of available financial resources*** for food at the level of the household. Food insecurity is a complex problem. It does not exist in isolation, as low-income families are affected by multiple, overlapping issues like affordable housing, social isolation, health problems, medical costs, and low wages.

While households are often described as either *food secure* or *food insecure*, there are four levels of food security, that describe the range of households' experiences in accessing enough food (https://hungerandhealth.feedingamerica.org/understand-food-insecurity/, Fig. 11):

- **High food security:** no reported indications of food-access problems or limitations.

- **Marginal food security:** one or two reported indications—typically of anxiety over food sufficiency or shortage of food in the house. Little or no indication of changes in diets or food intake.

- **Low food security**: reports of reduced quality, variety, or desirability of diet. Little or no indication of reduced food intake.

- **Very low food security**: Reports of multiple indications of disrupted eating patterns and reduced food intake

**Figure 11.** Definitions of Food Security.

Households had no problems, or anxiety about, consistently accessing adequate food

Households had problems or anxiety at times about accessing adequate food, but the quality, variety, and quantity of their food were not substantially reduced

Households reduced the quality, variety, and desirability of their diets, but the quantity of food intake and normal eating patterns were not substantially disrupted

At times during the year, eating patterns of one or more household members were disrupted and food intake reduced because the household lacked money or other resources for food.

Source: Adapted from the USDA Economic Research Service.

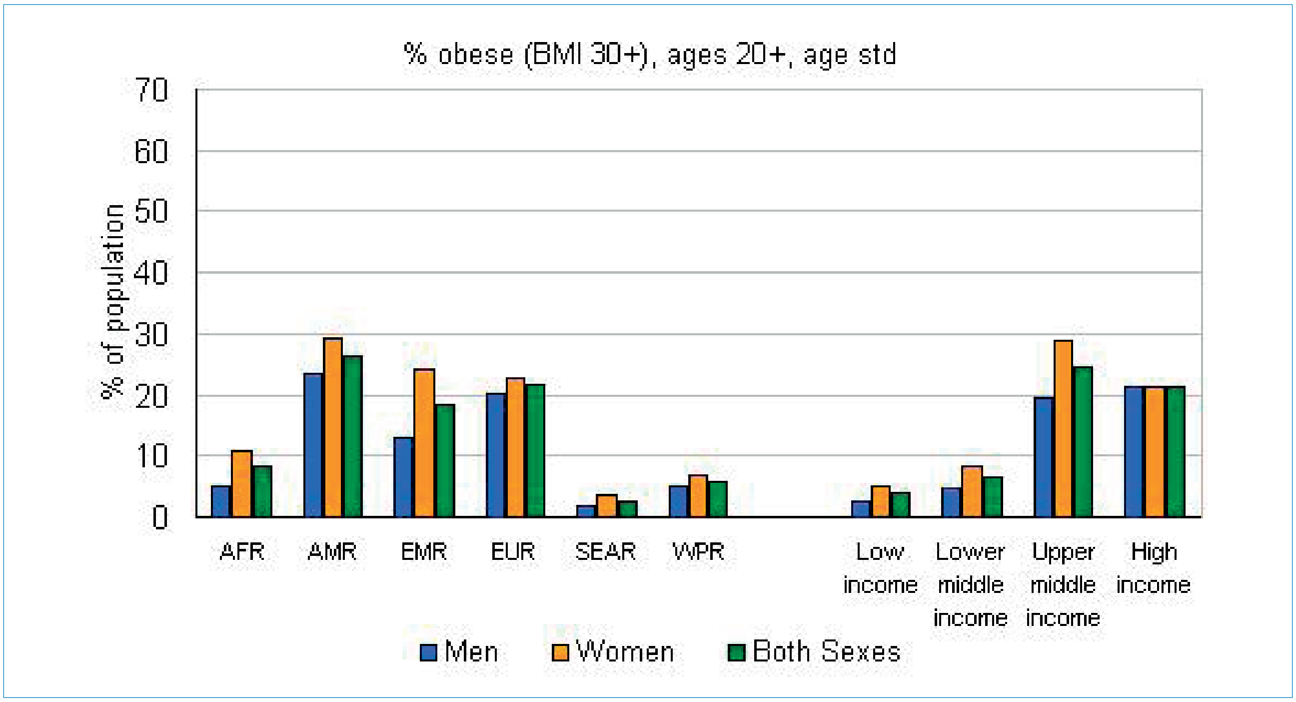
Source: United States Department of Agriculture Economic Research Service.

## 2. Obesity

The worldwide prevalence of overweight and obesity is at alarming levels (Ahluwalia et al., 2015). Obesity has been associated with several non-communicable diseases, such as diabetes, cardiovascular diseases, and cancers, and is a major cause of premature death (NCD Risk Factor Collaboration (NCD-RisC, 2017). Furthermore, ***obesity is a major cause of osteoarthritis and chronic disabilities.*** Owing to the increase of obesity and population ageing, especially in low-income and middle-income countries, the obesity-related burden of disease will rise (Hugues, 2013). There is association between obesity and loss of diseasefree years, which was observed across all categories of physical activity, smoking, and socioeconomic status (Nyberg, Batty et al., 2018).

The worldwide prevalence of obesity has nearly doubled between 1980 and 2008. In 2008, 10% of men and 14% of women in the world were obese (BMI ≥30 kg/m$^2$), compared with 5% for men and 8% for women in 1980. The prevalence of overweight and obesity ***is highest in the WHO Regions of the Americas*** (62% for overweight in both sexes, and 26% for obesity) and ***lowest in the WHO Region for South East Asia*** (14% overweight in both sexes and 3% for obesity). In the WHO Region for Europe and the WHO Region for the Eastern Mediterranean and the WHO Region for the Americas over 50% of women are overweight. For all three of these regions, roughly half of overweight women are obese (23% in Europe, 24% in the Eastern Mediterranean, 29% in the Americas). ***In all WHO regions women are more likely to be obese than men.*** In the WHO regions for Africa, Eastern

**Figure 12.** The prevalence of overweight and obesity were highest in the WHO Regions



Source: WHO, https://www.who.int/gho/ncd/risk_factors/obesity_text/en/

Mediterranean and South East Asia, women have roughly double the obesity prevalence of men.

The prevalence of raised body mass index increases with income level of countries up to upper middle income levels. The prevalence of overweight in high income and upper middle income countries is more than double that of low and lower middle income countries. For obesity, the difference more than triples from 7% obesity in both sexes in lower middle income countries to 24% in upper middle income countries. Women's obesity is significantly higher than men's, with the exception of high income countries where it is similar. In low and lower middle income countries, obesity among women is approximately double that among men (WHO, 2010).

### 3. Ways of eating

Unhealthy eating and body image concerns are equally widespread and increase risk for more chronic and severe weight-related problems. Eating disorders (ED), symptoms of disordered eating and body dissatisfaction disproportionately affect young girls and women, yet health problems related to unhealthy eating and exercise habits impair all sexes and ages. Unhealthy dieting is a risk factor for binge eating and is associated with the development of overweight and obesity (Cuypers et al., 2012). Binge eating, a common symptom of unhealthy eating, is also common in overweight and obese individuals (Zeiler et al., 2016) and is closely associated with depression, impaired work productivity, absenteeism, impaired non-work activity, poorer quality of life and social functioning, even more than obesity itself (Perez & Warren, 2012). Frequent dieting, unhealthy eating, and over-evaluation of weight and shape are the most potent and best replicated risk factors for full- and sub-threshold EDs (Jacobi et al., 2007). Healthy weight regulation and eating behaviors are essential for preventing and treating EDs, ED symptoms and preventing disorders and sequelae related to overweight and obesity. Given the multiple interrelations between symptoms and syndromes of disordered eating and obesity, a comprehensive approach targeting all eating related problem behaviors is critical (Bell et al., 2018).

The traditional approach to weight loss has been to restrict food intake (i.e. 'go on a diet') and exercise more. Such an approach, however, is generally unsuccessful in decreasing body mass in the long term. Moreover, there is evidence that dieting, and particularly repeated dieting attempts (i.e. 'yo-yo dieting'), may be harmful to both physical and mental health (Bacon & Aphramor, 2011). There is also research indicating that rates of eating disorders, which may have their genesis in low-energy diets (Hill, 2007) appear to be increasing in recent times (Currin et al., 2005). In response to the failure of restricted-energy diets to reduce individuals' body mass in the long term and/or in reaction to the possible link between dieting and disordered eating, some clinicians have begun to explore an approach to weight management known as 'intuitive eating', sometimes also referred to as 'normal eating' or 'adaptive eating'. Its basic tenets are to respond to innate hunger and satiety signals (i.e. eat when hungry and stop when satiated, without restrictions on types of food consumed. The fundamental premise behind intuitive eating is that, if listened to, the body intrinsically 'knows' the quantity and type of food to eat to maintain both nutritional health and an appropriate weight. There is no restriction on the types of food one can eat, unless dictated by specific health issues (e.g. diabetes, food allergies), because the body will instinctively choose a variety of foods that provide nutritional balance (Tylka, 2006).

**Intuitive Eating comprises four central features:**

1, unconditional permission to eat when hungry and what food is desired;

2, eating for physical rather than emotional reasons;

3, reliance on internal hunger and satiety cues to determine when and how much to eat and

4, honouring one's health, or practising 'gentle nutrition' (Hawks, Merrill et al., 2004).

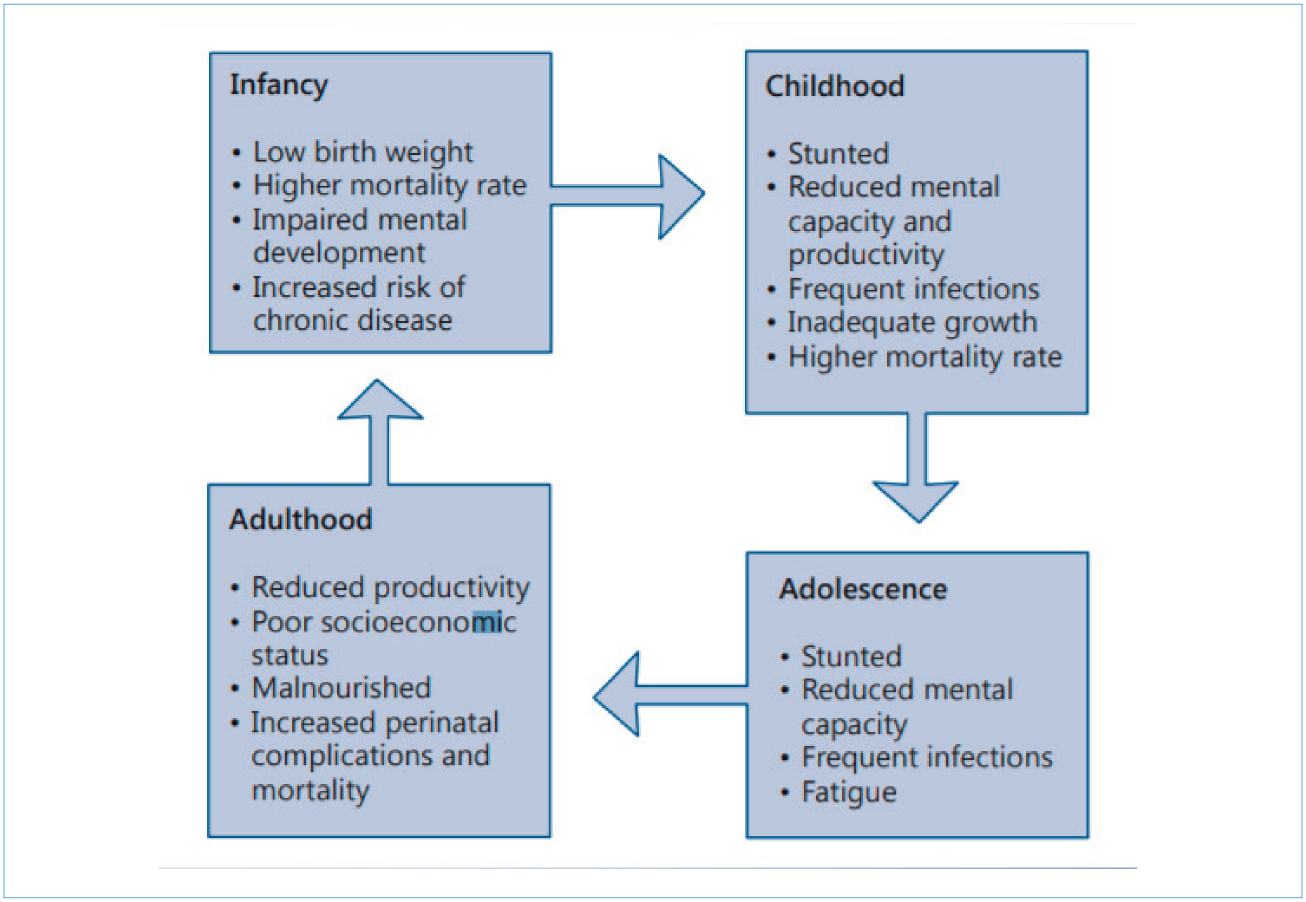
**Mindful eating** involves full awareness of one's eating, including the taste and texture of one's food, and generally slowing down the pace of one's eating. Proponents of mindful eating encourage people to remove all distractions, such as television, while eating, and refrain from multi-tasking, such as working while eating (Gast & Hawks, 1998).

### 4. Undernutrition - Micronutrient deficiencies (MNDs)

At the most basic level, MNDs, like all forms of undernutrition, occur due to insufficient intake or sufficient intakes combined with impaired absorption due to infection, disease, or inflammation (UNICEF, 2013). The basic root cause of most undernutrition is poverty. As a result, low- and middle-income countries have the highest burden of MNDs; however, MNDs exist even in certain population groups in higher-income countries. MNDs have a direct impact on individuals and on societies, resulting in poorer health, lower educational attainment and decreased work capacity and earning potential. ***MNDs are preventable*** and the return on investment for the provision of micronutrients is high. Around the world, ***pregnant women and children under 5 years of age*** are at the highest risk of MNDs. Iron, iodine, folate, vitamin A, and zinc deficiencies are the most widespread MNDs and are common contributors towards poor growth, intellectual impairment, perinatal complications, and increased risk of morbidity and mortality. Of greatest concern is the fact that the cycle of MNDs perpetuates across the generations, with farreaching consequences on the future population (Bailey et al., 2015).

Single MNDs rarely occur alone; often, multiple MNDs coexist (Muthayya et al., 2013). Of note, ***intervention in the first 1,000 days of life is most effective for breaking the cycle of malnutrition***; however, a coordinated, sustainable commitment to scaling up nutritional interventions at the global level is needed. Supplementation is a cost-effective solution but does not address the root cause of the MND. Over the long term, food fortification may offer a more effective means to address MNDs, as it enables a larger segment of a population to be targeted (Regan et al., 2015).

**Figure 13.** Micronutrient deficiencies have consequences throughout an individual's life span and are perpetuated across the generations.



Source: Regan, Bailey et al., 2015

**Global interventions on food and nutrition**

Overweight and obesity, as well as their related noncommunicable diseases, are largely preventable. The Political Declaration of the High Level Meeting of the United Nations General Assembly on the Prevention and Control of Noncommunicable Diseases of September 2011, recognizes the critical importance of reducing unhealthy diet and physical inactivity. The political declaration commits to advancing the implementation of the "***WHO Global Strategy on Diet, Physical Activity and Health***", including, where appropriate, through the introduction of policies and actions aimed at promoting healthy diets and increasing physical activity in the entire population. WHO has also developed the "***Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020***" which aims to achieve the commitments of the UN Political Declaration on Noncommunicable diseases (NCDs) which was endorsed by Heads of State and Government in September 2011. The "Global Action Plan" will contribute to progress on 9 global NCD targets to be attained by 2025, including a 25% relative reduction in premature mortality from NCDs by 2025 and a halt in the rise of global obesity to match the rates of 2010.

***At the individual level, people can:***

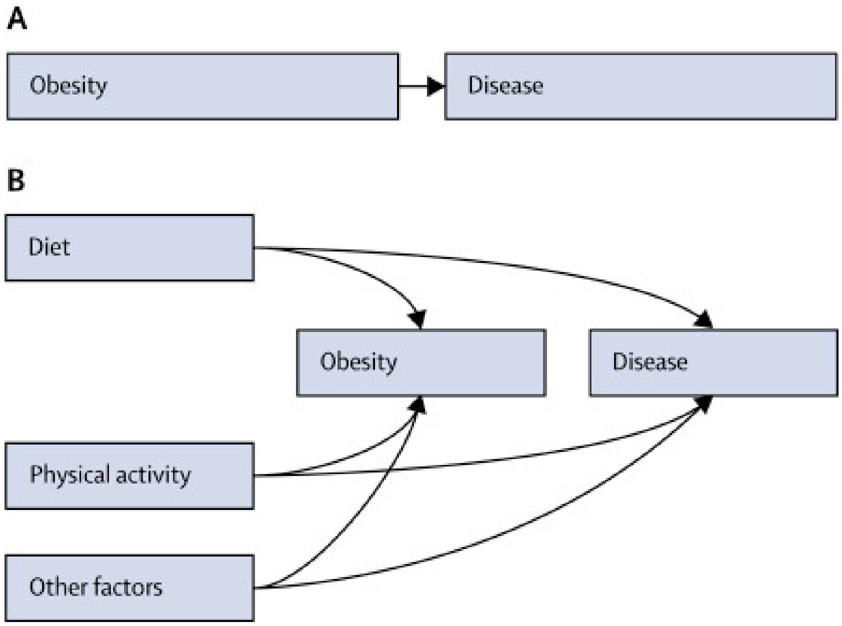
- limit energy intake from total fats and sugars;
- increase consumption of fruit and vegetables, as well as legumes, whole grains and nuts; and
- engage in regular physical activity (60 min. a day for children, 150 minutes for adults spread through the week).

Individual responsibility can only have its full effect where people have access to a healthy lifestyle. Supportive environments and communities are fundamental in shaping people's choices, by making the choice of healthier foods and regular physical activity the easiest choice (the choice that is the most accessible, available and affordable), and therefore preventing overweight and obesity (WHO, 2018). Therefore, at the societal level it is important to support individuals in following the recommendations above, through sustained implementation of evidence based and population based policies that make regular physical activity and healthier dietary choices available, particularly to the poorest individuals.

***The food industry can play a significant role in promoting healthy diets by:***

- reducing the fat, sugar and salt content of processed foods;
- ensuring that healthy and nutritious choices are available and affordable to all consumers;
- restricting marketing of foods high in sugars, salt and fats, especially those foods aimed at children and teenagers; and
- ensuring the availability of healthy food choices and supporting regular physical activity practice in the workplace.

**Figure 14.** Simplified causal relationship between obesity and disease.



(A) A direct causal effect of obesity on the occurrence of diseases.

(B) Diet, physical activity, and other factors have a direct effect on obesity and diseases, but there is no direct effect of obesity on the risk of disease. In both cases, obesity is associated with a loss of disease-free years

Source: Chiolero A. Why causality, and not prediction, should guide obesity prevention policy, 2018.

### ***What are the true policy implications of these findings?***

A straightforward implication is that preventing obesity will decrease the number of years lived with diseases. This statement implies a causal link between obesity and these diseases (Fig. 14).

Although this implication seems evident, stating that we can prevent diseases or delay their occurrence if we reduce obesity raises several complex issues (Chiolero & Paccaud, 2009). Causal links between obesity and the risk of disease are not so simple. Obesity results from a mix of factors such as diet or physical activity, embedded in a causal web of environmental and socioeconomic determinants, which have direct and specific effects on the risk of obesity-related diseases (figure). If you target physical activity to prevent high BMI, you may not have the same effect on the burden of disease than if you target diet, even if you have the same effect on BMI. One can assume that BMI has per se no direct causal effect on the risk of disease, only related causal mechanisms (Hernán and Taubman, 2008). In this perspective, high BMI is merely a marker of risk, and as such should not be the primary target of prevention strategies. One major issue is the scarcity of strong evidence on how to prevent obesity. Prevention surely requires a complex, multilevel, environmental, socioeconomic, and life-course approach (Dietz, 2015).  A second major—and difficult to solve—issue is that the impact of an obesity prevention programme on the burden of disease depends on the method used to prevent weight gain (Chiolero & Paccaud, 2009). Such a perspective on obesity is also key because it helps deal with the fact that optimal BMI might increase with age; evidence suggests that BMI in the overweight or obesity I range, particularly in older adults, is associated with a lower mortality risk compared with normal weight (Hugues, 2013).

### Key messages

- » The strategies and actions undertaken to prevent obesity and their resulting outcomes varyaccording to the different environments in which they are undertaken. The most promising approaches for obesity prevention are population-based and multilevel, focus on environmental and policy change, and require participation from actors in multiple sectors
- » Adequate nutrition may reduce the burden of diseases and death across the life span around the world. MNDs have direct effects on individuals and indirect effects on societies. Although, there have been substantial gains made globally to improve the nutritional status, there is still a tremendous work to be done to reach all individuals with or at risk for MNDs.

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### 3.2.4 Transport and urban environment

Transport is so fundamental to connecting people, businesses and services; whether it is connecting our residents to jobs, education, leisure or community facilities, or connecting visitors and residents to our vast open green spaces and sports stadiums. There are transport connections associated with almost everything we do, and this section will explore these links to provide a better understanding of the opportunities, themes and joint values that need to be exploited to provide wider benefits as a result of transport enhancements and improvements (https://www.wigan.gov.uk/Docs/PDF/Council/Strategies-Plans-and-Policies/Transport-Strategy/05-Chapter6.pdf).

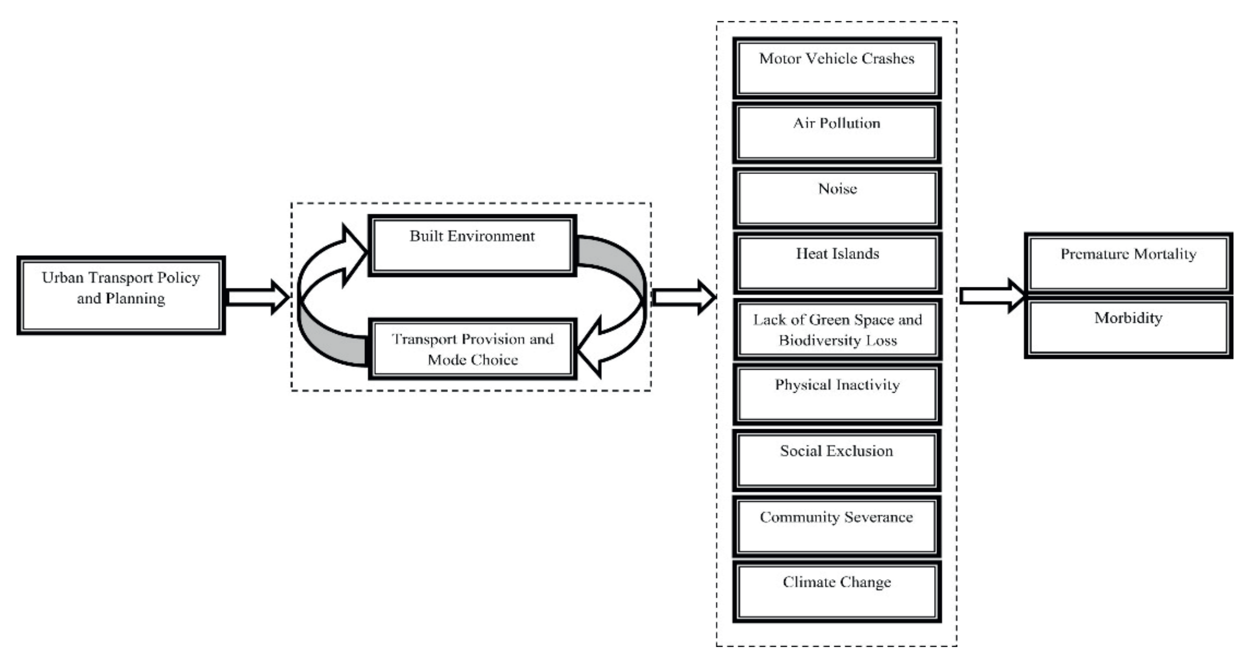
#### Main trends

Significant global health challenges are being confronted in the 21st century, including injuries from road trauma, combined with population growth, rapid urbanisation, and climate change, increases in unhealthy diets, physical inactivity, non-communicable diseases (NCDs), prompting repeated calls to rethink approaches to prevention (UNFPA, 2010). The current world population of 7.6 billion is expected to reach 8.6 billion in 2050 and 11.2 billion in 2100, according to a new United Nations report (https://www.un.org/development/desa/en/news/population/world-population-prospects-2017.html). Rapid changes in motorised transport have increased the geographical size of urban areas, combined with unprecedented urban population growth, this change has put transport mobility at the forefront of city planning.

According to WHO and UN Habitat's report Hidden Cities, all urban environments have the ability to produce health inequalities (WHO, 2010). As such, transport practices have the potential to increase existing health inequalities (Marmot, 2005), contributing further to the ill health of the most deprived groups, who exhibit a variety of other factors that makes them more vulnerable to environmental exposures (e.g. poor diet, suboptimal health care, stress, and violence). The nature and extent of these health inequities vary within and between countries, partly as a result of differing progress in nutritional, demographic, and epidemiological transitions.

Besides the widely-acknowledged health impacts associated with **road traffic injuries and premature mortality** due to motor vehicle crashes, there is a whole range of other health consequences, including premature mortality and numerous morbidity outcomes, related to urban transport exposures and practices. Figure 15 illustrates the linkages between urban transport exposures or practices and adverse health impacts, which current evidence suggests. Adverse health impacts occur through motor vehicles air pollution and noise, local urban heat exposures, lack of green space and biodiversity loss, climate change effects, social exclusion, community severance and physical inactivity from sedentary behaviour and an over reliance on motorised travel. These exposures, and hence their associated health impacts, are not equally distributed in the population, with lower socioeconomic groups being exposed more and bearing the highest burden (Carrier et al., 2016).

**Figure 15.** Linkages between urban transport and adverse health impacts



Source: Khreis, May et al., 2017.

There are several environmental, social, and behavioural risk exposures related to urban and transport planning and design decisions, which in turn affect NCDs, injuries, and other adverse health outcomes:

### 1. Traffic exposure

A higher reliance on private motor vehicles increases traffic volumes and road trauma (Peden et al., 2004) resulting in injury and early death (Burch et al., 2014). Indeed, deaths from road transport injuries exceed those from HIV/AIDS, tuberculosis, and malaria (Bhalla et al., 2014).

### 2. Air pollution

There is a relationship between air pollution exposure and health impacts, including the incidence and prevalence of childhood asthma and wheeze (Gasana et al., 2012), asthma exacerbation (Yang & Omaye, 2009), impaired lung function, cardiovascular mortality and morbidity all-cause mortality, hospital admissions, and restricted physical activity (Samet & Krewski, 2007). Physical activity outdoors, including walking and cycling, can increase exposure to air pollution (Giles & Koehle, 2014). However, air pollution exposure is substantial for car occupants and is higher for those in cars than for cyclists travelling through the same environment (Kent & Thompson, 2014).

### 3. Noise

Chronic noise exposure has implications for physical and mental health through annoyance, sleep disturbance, and chronic stress pathways (Ising & Kruppa, 2004). Road traffic noise exposure influences physical health outcomes such as cardiovascular disease and hypertension (Moudon, 2009; Clark & Stansfeld, 2007) and airport noise is associated with reduced quality of life, impaired cognitive development in children (Clark & Stansfeld, 2007) and reduced psychological wellbeing (Evans, 2003).

**4. Social isolation**

Loneliness and social isolation are associated with worse mental health (Halpern, 1995), adverse health behaviours (e.g. physical inactivity and smoking), and detrimental biological processes (e.g. higher blood pressure and C-reactive protein, and poorer immune functioning) compared with regular social contact (Kent & Thompson, 2014).

**5. Safety from crime**

Crime can affect NCDs because people might constrain their own, and their children's, social and physical activities to avoid places or situations they perceive to be unsafe. Although evidence is mixed, the associations of crime-related safety and physical inactivity with increased obesity levels are more consistent for groups who perceive themselves to be physically vulnerable to crime (e.g. women and older adults) or who are economically vulnerable to crime (eg, low-income and minority populations (Foster & Giles-Corti, 2008).

**6. Physical inactivity**

Physical inactivity and unhealthy diets are the largest contributors to NCDs, and much of the evidence on city planning and health has focused on physical activity.

**7. Prolonged sitting**

Sedentary behaviours, too much sitting, as distinct from too little physical activity - have emerged as a new concern for chronic disease prevention (Owen, 2012) and are associated with increased risk of type 2 diabetes, cardiovascular disease, some cancers, and all-cause mortality (Thorp et al., 2011). Urban-dwelling working adults can sit for 10 h or more per day, which increases health risks, even among those who meet physical activity guidelines (Owen et al., 2010). Prolonged periods of sitting include time spent in cars and can be associated with increased cardiovascular disease risk (Sugiyama et al., 2013) and poorer mental health (Vallance et al., 2011).

**8. Unhealthy diets**

Worldwide 2·6 million deaths a year are attributable to insufficient fruit and vegetable intake (Lock, Pomerleau et al., 2005) and an estimated 2·1 billion people are overweight or obese (Ng et al., 2013). A growing evidence base has examined the relationship between food purchasing, diets, and urban food environment landuse characteristics: food availability (ie, food supply) and food accessibility (ie, food supply location and physical proximity).

### Urban transport policy and planning strategies

Associations between city planning and health are not new. In the 19th century, planning curbed infectious disease outbreaks in industrialising cities through improvements in sanitation and housing and separation of residential areas from industrial pollution (Corburn, 2007). In the 21st century, well planned cities have the potential to reduce NCDs and road trauma and to promote health and wellbeing more broadly. This could be achieved by reducing automobile dependency, traffic exposure, pollution, noise, and urban heat-island effects, while enhancing mental health, contributing to climate change mitigation, and promoting walking and cycling in ways that are safe, comfortable, and desirable.

Policies that prioritise the needs and safety of pedestrians, cyclists, and public transport users should be encouraged. Stevenson and colleagues' findings (Stevenson al., 2016) highlight that a modal shift away from private motor vehicles would deliver substantial population health benefit. This recommendation is globally relevant, given that NCDs are the leading causes of death on all continents and that the NCDs burden is increasing in the most populous regions (UN General Assembly, 2011). Young, low-density, and highly motorised cities, such as those in North America, Australia, and New Zealand, have unhealthy patterns of land use. These cities will need to change density and zoning policies to retrofit established areas and revise regional, transport, and employment-planning and urban-design policies to create more accessible, pedestrian-friendly and cycling-friendly greenfield developments. In contrast, older cities in Europe are well designed for walking and have good public transport, but many cities in Europe are yet to develop high-quality cycle facilities, and new growth is often motor vehicle-oriented. High-density cities in Asia and Latin America typically have a good mix of land use to support walking.

New urban mobility in which transport policies encourage walking, cycling, and public transport and reduce subsidies for private motor vehicle use are being supported by cities across many high-income countries (EC, 2011). Cities such as Helsinki (Finland) and Zurich (Switzerland) have seen substantial modal shifts from private motor vehicle use to walking, cycling, and public transport. For example, 52% of Zurich's daily vehicle km travelled (VKTs) are now undertaken by either walking or cycling, 19% are undertaken on public transport, and only 29% are undertaken using a private motor vehicle. Cities embracing new urban mobility are setting ambitious targets to achieve safe and sustainable transport over the coming years and are building infrastructure to the quality previously built for motor vehicles. Cities adopting new urban mobility are doing so in the knowledge that it delivers benefits in terms of reduced overall congestion, additional opportunities for multimodal travel, and increased efficiency. Many countries concerned by the costs associated with the mounting burden of lifestyle-related chronic disease (Murray et al., 201) have put in place plans and public policy initiatives that encourage increased levels of physical activity (National Physical Activity Plan Alliance, 2013). Although the extent to which these plans are successfully disseminated, enacted, and monitored varies (Evenson, et al., 2013) the findings reported here suggest that government policies need to actively pursue integrated urban and transport planning and design interventions - particularly those focused towards achieving more compact cities - that support and encourage modal shifts away from private motor vehicles towards new urban mobility. Such interventions are required if city planners are to positively influence the overall health and sustainability of growing cities (Stevenson et al., 2016).

## Key messages

- Deaths from road transport injuries exceed those from HIV/AIDS, tuberculosis, and malaria. By 2030, road traffic injury-related DALYs are estimated to be more than ten-times those of tuberculosis and malaria combined and twice those of HIV/AIDS.
- Significant global health challenges are being confronted in the 21st century, and well planned cities that encourage walking, cycling, and public transport use have an important role to play in addressing these challenges.

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## 3.3 STRESS, WORK, ADDICTION AND SOCIAL SUPPORT

*Pavol Mikula*

Social determinants of health affect human life from the very beginning, and while some of the factors from early life and socioeconomic status do have impact on later life as well, they do not stop there. New life situations and social circumstances might occur in any stage of ontogenesis, with young adulthood standing as particularly turbulent transition period with young adults entering labour market and changing their behavioural patterns in a significant way. Stress, while present in various forms during formative years of children and adolescents, may cause serious health issues and is traditionally closely linked to work environment. Substance and non-substance addictions may have even more damaging health consequences. Underlining all other determinants of health and either mitigating their negative effects, or making its adverse effects even more potent is social support (or lack of social support respectively).

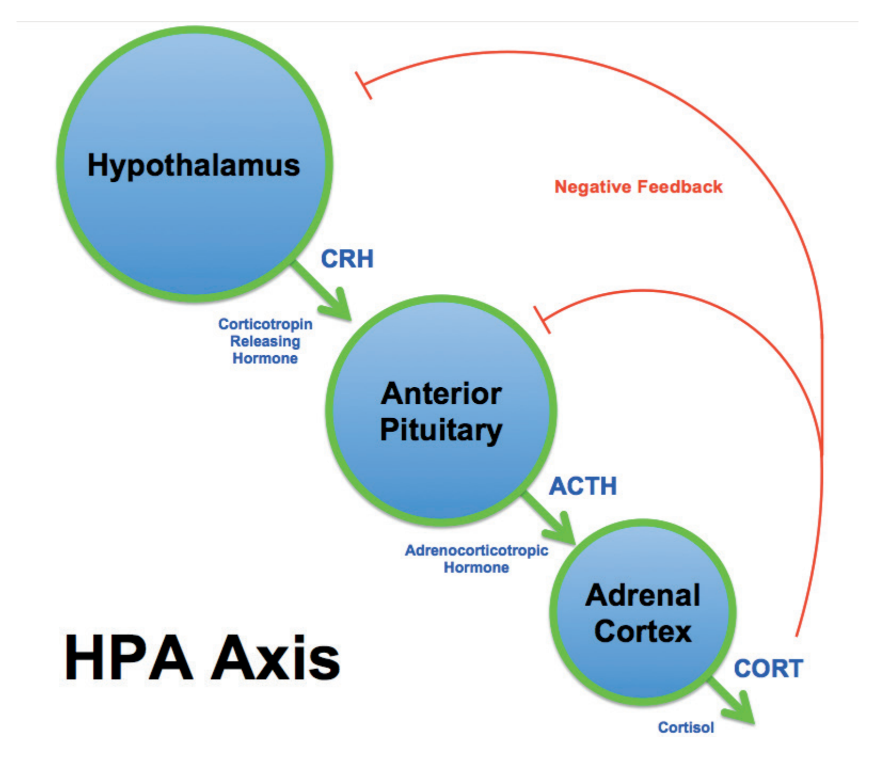
### 3.3.1 Stress and coping

Human life is full of numerous psychosocial risks which tend to accumulate if not handled correctly. Phrases such as 'long-term stress' or 'burn out syndrome' are now well established expressions in general speech as a result of scientific interest in the field of stress and coping, and of attention it garners from media and social networks. The word stress is hardly new, it was used as early as the 14th century to mean hardship, straits or adversity (Lumsden, 1981). Although word itself is not new, its systematic usage in psychology can be tracked to relatively recent times and specifically Hans Selye who described it as coordinated set of bodily defences against any form of noxious stimulus (including both physical and psychological threats) and named it General Adaptation Syndrome (GAS) (Selye, 1950).

*So what is stress and how does it affect physical health?*

All vital physiologic systems of the body are inherently programmed, through rigorous fine-tuning achieved during evolution, to preserve a predefined steady state, *i.e. homeostasis* or *eustasis*. This equilibrium is constantly threatened though various adverse forces both intrinsic and extrinsic, both real and perceived, usually described by the term stress (Chrousos, 2009). This state of disharmony is counteracted by intricate repertoire of physiologic and behavioural responses aimed at re-establishing homeostasis. So whether the stress originates in exam one has to take, death of relative or job interview, our bodies react by activating Hypothalamic Pituitary Adrenal (HPA) system (Fig. 1), which regulates long term stress. Short term responses are produced by "The Fight or Flight response" produced of the via the Sympathomedullary Pathway (SAM) (Currie and Symington, 1955).

**Figure 1.** Schematics of the hypothalamic pituitary adrenal (HPA) axis



*Source:* The hypothalamic pituitary adrenal axis and its regulation by glucocorticoid negative feedback. Illustration by Brian M. Sweis (2012)

Short-term fight-or-flight stress response is one of nature's fundamental defensive mechanisms that stimulates the neuroendocrine, cardiovascular, and musculoskeletal systems into action to enable survival (Dhabhar, 2009). The physiological changes that occur during the fight or flight response are activated in order to give the body increased strength and speed in anticipation of fighting or running. Some of the specific physiological changes and their functions include:

» Increased blood flow to the muscles

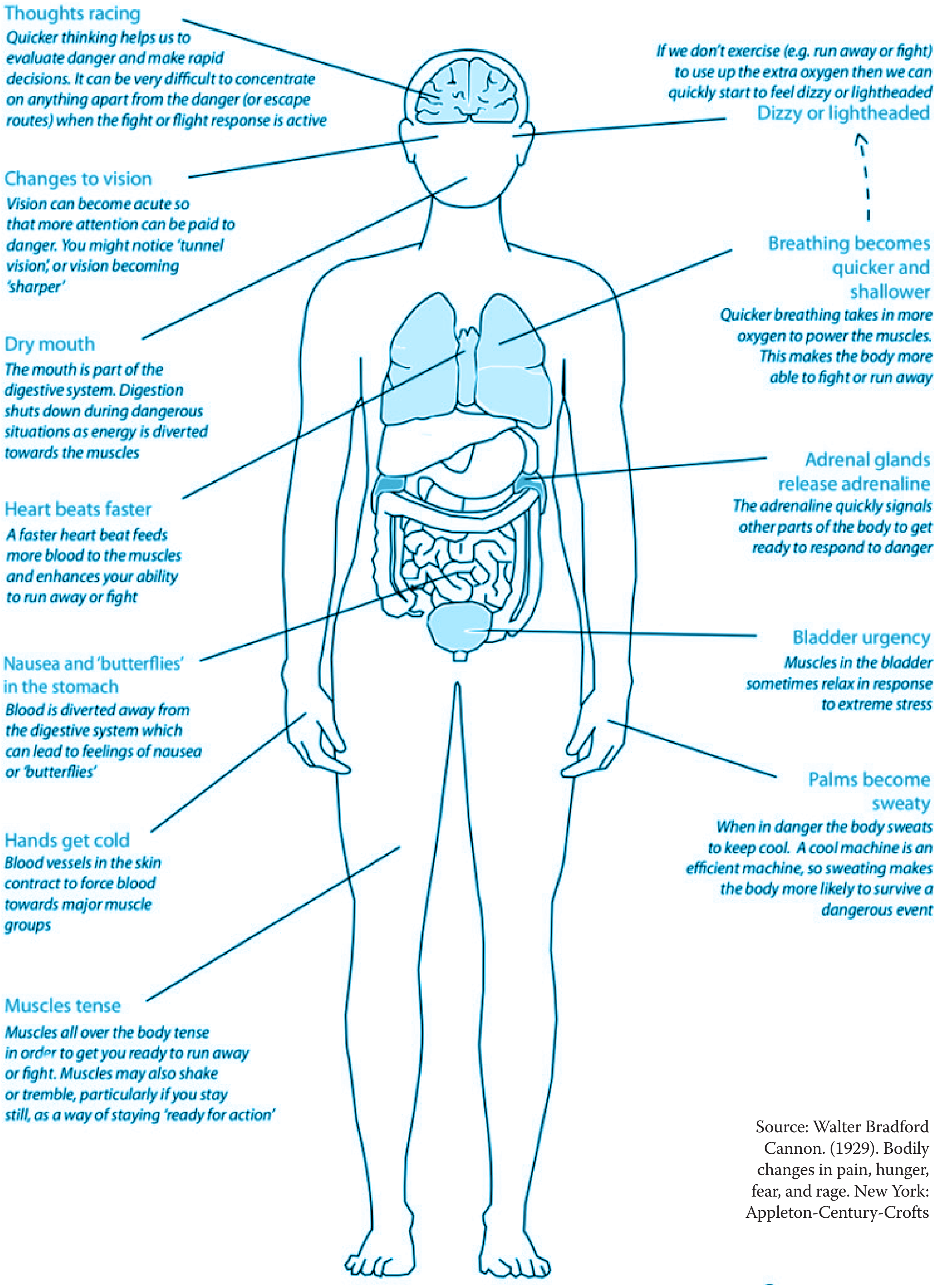
» Increased blood pressure and heart rate

» The blood clotting function of the body, which speeds up in order to prevent excessive blood loss in the event of an injury sustained during the response.

» Increased muscle tension (Rice, 1992).

When someone experiences event that is perceived as stressful, the amygdala, an area of the brain that contributes to emotional processing, sends a signal of distress to the hypothalamus. This command centre is communicating with the rest of the body through the nervous system and is responsible for the changes in the body that result in producing the energy for fight or flight (Kandel et al. 2013). All these changes were especially important for our ancestors, whose life was depending on quick responses and physical prowess in the face of present physical and specific danger such as wild animals. This response is fast, does not require cognitive appraisal of the situation and is still useful nowadays in situations that are sudden or threatening. Various changes occurring in human body during fight-or-flight response can be seen in Figure 2.

**Figure 2.** Bodily changes during fight-or-flight response



**Thoughts racing**

*Quicker thinking helps us to evaluate danger and make rapid decisions. It can be very difficult to concentrate on anything apart from the danger (or escape routes) when the fight or flight response is active*

**Changes to vision**

*Vision can become acute so that more attention can be paid to danger. You might notice 'tunnel vision,' or vision becoming 'sharper'*

**Dry mouth**

*The mouth is part of the digestive system. Digestion shuts down during dangerous situations as energy is diverted towards the muscles*

**Heart beats faster**

*A faster heart beat feeds more blood to the muscles and enhances your ability to run away or fight*

**Nausea and 'butterflies' in the stomach**

*Blood is diverted away from the digestive system which can lead to feelings of nausea or 'butterflies'*

**Hands get cold**

*Blood vessels in the skin contract to force blood towards major muscle groups*

**Muscles tense**

*Muscles all over the body tense in order to get you ready to run away or fight. Muscles may also shake or tremble, particularly if you stay still, as a way of staying 'ready for action'*

*If we don't exercise (e.g. run away or fight) to use up the extra oxygen then we can quickly start to feel dizzy or lightheaded*

**Dizzy or lightheaded**

**Breathing becomes quicker and shallower**

*Quicker breathing takes in more oxygen to power the muscles. This makes the body more able to fight or run away*

**Adrenal glands release adrenaline**

*The adrenaline quickly signals other parts of the body to get ready to respond to danger*

**Bladder urgency**

*Muscles in the bladder sometimes relax in response to extreme stress*

**Palms become sweaty**

*When in danger the body sweats to keep cool. A cool machine is an efficient machine, so sweating makes the body more likely to survive a dangerous event*

Source: Walter Bradford Cannon. (1929). Bodily changes in pain, hunger, fear, and rage. New York: Appleton-Century-Crofts

Fight-or flight response is short-time answer to a stressful event. But what happens if the person cannot fight the stressor and flight is also impossible? Example of that is angry boss who gives the employee undesirable feedback. Fight response would be to punch the boss and while it could bring temporary relief to the person, from the long-term perspective could lead to even more stress. Flight response would not be adaptive either as it would only postpone stressful event to later date. Evolutionary importance of stress and its adverse effect is very aptly described by Sapolsky (2004) in his book *why zebras don´t get ulcers*: if you are that zebra running for your life, or that lion sprinting for your meal, your body's physiological response mechanisms are superbly adapted for dealing with such short-term physical emergencies. For the vast majority of beasts on this planet, stress is about a short-term crisis, after which it's either over with or you're over with. When we sit around and worry about stressful things, we turn on the same physiological responses—but they are potentially a disaster when provoked chronically. A large body of evidence suggests that stress-related disease emerges, predominantly, out of the fact that we so often activate a physiological system that has evolved for responding to acute physical emergencies, but we turn it on for months on end, worrying about mortgages, relationships, and promotions (Sapolsky, 2004).

### *Stress…prolonged…*

Many social stressors require long-term stress management and coping with the source of these noxious stimuli for prolonged periods of time and fight-or-flight response just will not do. Such situations require adaptation processes, which can be encapsulated by the term General Adaptation Syndrome (GAS) (Selye, 1950).

GAS can be described as a reaction to stressor that consists of three stages. "**Alarm Reaction**" is the first stage and is dominated by physiological responses to stressful situation like tissue catabolism, hypoglycaemia, gastro-intestinal erosions, and discharge of secretory granules from the adrenal cortex. In the next stage called "**Stage of Resistance**" many or all of these reactions are reversed and disappear. They can reappear in the final stage called "**Stage of Exhaustion**" (Selye, 1950). If these processes take place over longer period of time without phases of relaxation, it can lead to exhaustion. Lack of reserve of energy can easily lead to diseases, fatigue, irritability and other health problems (Dickerson and Kemeny, 2005).

Stress, especially long-term stress is one of the leading factors of why would be our current patterns of disease unrecognizable to our great-grandparents. At the beginning of 20th century pneumonia, tuberculosis and influenza were leading causes of death in western world. These fast-developing diseases are different from accumulative diseases that plague our society now like heart disease, cancer and cerebrovascular disorders (Sapolsky, 2004). These diseases differ from the infectious diseases dominating in the past by incorporating elements of our emotions into pathological process of disease development. Slowly accumulative diseases as those mentioned above can either be caused or made far worse by stress. Lowered immunity, prolonged high levels of sugar and fats in bloodstream can be deciding factor in many physiological situations such as whether cholesterol gums up blood vessels or is safely cleared from circulation, whether our fat cells stop listening to insulin and plunge organism into diabetes, whether neurons in our brain will survive five minutes without oxygen during a cardiac arrest (Sapolsky, 2004).

*Human body and stress*

Organ systems of human body respond to adverse effects of stress in many different forms. Examples of adverse impact on physiology include effects on:

1. **Cardiovascular system**

   During prolonged sessions of stress, cardiovascular system works harder and faster. If this happens often, it can lead to **hypertension** – chronically elevated blood pressure. Blood vessels which regulate blood flow, have to work harder to regulate blood flow. They become more rigid, more resistant to blood flow and this in turn elevates blood pressure. Higher blood pressure of course impairs negatively heart muscles by causing irregular heartbeat because of left ventricular hypertrophy, which is one of the chief predictors of cardiac arrest (Sapolsky, 2004).

2. **Gastrointestinal system**

   Adverse effects of stress in gastrointestinal system include wide range of gastrointestinal disorders: irritable bowel syndrome, diarrhoea, bloating and ulcers. Another issue caused by stress is stress eating and stress fasting. Why are some people eating a lot in times of stress and others cannot eat a thing? Answer lies in secretion of various hormones during prolonged episodes of stress. Corticotropin-releasing hormone (CRH) inhibits appetite and glucocorticoids stimulate it. Both of these hormones are involved in the physiological response to stress, the difference is mainly in timing. While CRH secretion is high in the beginning phase of the stressful event, glucocorticoids are present in the system for longer periods of time and are found in highest quantities after the stressor is gone (Sapolsky, 2004).

3. **Reproductive system**

   Stress drives down testosterone levels in men and can cause problems with erection. Stress was also linked with impotency and premature ejaculation in men, which in turn can lead to even more stress and cause the cycle of stress and sexual problems to continue. Women can suffer from amenorrhea and irregular or prolonged menstrual cycles. Akin to male problems with erections, libido in females may be greatly diminished by effect of stress. Extreme cases of stress can even cause psychogenic abortions, preterm childbirth, miscarriage and problems with lactation (Ponholzer et al. 2005; Kalantaridou at al. 2004).

4. **Immune system**

   Stress will suppress the formation of new lymphocytes and their release into the circulation, and shorten the time pre-existing lymphocytes stay in the circulation. It will inhibit the manufacturing of new antibodies in response to an infectious agent, and disrupt communication among lymphocytes through the release of relevant messengers. And it will inhibit the innate immune response, suppressing inflammation. Thus, with immune system suppressed, people are much more likely to get sick in times of stress (Sapolsky, 2004).

These are but a few examples of how stress affects health and human physiology. But the list is far from complete. Sleep length and sleep quality, foetus development, cognitive functions like memory and attention are all affected by stress and stressful encounters.

### *Difficult life situations and coping. Or "my stress is worse than yours!"*

Stress comes in many forms and from various sources. While some of the events may be threatening (undergoing an operational procedure in the hospital), some may be more of a challenge (interview for a desirable job position). This differentiation in quality of stressful situations is reflected in use of words eustress and distress. These terms do not describe objectively different kinds of stress, but rather appraisal of person who is in the situation and how this person perceives the situation (La Fevre et al. 2016). Eustress, in this context, is a result of positive cognitive response to stress that is healthy, or gives one a feeling of fulfilment or other positive feelings. Distress on the other hand, have negative impact and is most commonly referred simply as stress (Lazarus, 1966).

Holmes and Rahe constructed scale where different life events were weighted according to the amount of adjustment they require, their desirability and controllability. Each of life events listed in their scale has been assigned the number of "**life change units**" (**LCU**) that apply to events in the past year of an individual's life. These numbers are counted together and the final score gives a rough estimate of how much stress has affected the health in the span of previous year. Their scale has become one of the most popular way to measure the effects of stress on somatic and mental health and as so, became very important is research of stress in people with different chronic conditions (Table 1) (Lazarus and Folkman, 1984; Holmes and Rahe, 1967).

**Table 1.** Stress scale of Holmes and Rahe

*Holmes and Rahe, 1967; LCU – Life Change Units*

| Life event | LCU | Life event | LCU | Life event | LCU |
|---|---|---|---|---|---|
| Death of a spouse | 100 | Business readjustment | 39 | Revision of personal habits | 24 |
| Divorce | 73 | Change in financial state | 38 | Trouble with boss | 23 |
| Marital separation | 65 | Death of a close friend | 37 | Change in working hours or conditions | 20 |
| Imprisonment | 63 | Change to different line of work | 36 | Change in residence | 20 |
| Death of a close family member | 63 | Change in frequency of arguments | 35 | Change in schools | 20 |
| Personal injury or illness | 53 | Major mortgage | 32 | Change in recreation | 19 |
| Marriage | 50 | Foreclosure of mortgage or loan | 30 | Change in church activities | 19 |
| Dismissal from work | 47 | Change in responsibilities at work | 29 | Change in social activities | 18 |
| Marital reconciliation | 45 | Child leaving home | 29 | Minor mortgage or loan | 17 |
| Retirement | 45 | Trouble with in-laws | 29 | Change in sleeping habits | 16 |
| Change in health of family member | 44 | Outstanding personal achievement | 28 | Change in number of family reunions | 15 |
| Pregnancy | 40 | Spouse starts or stops work | 26 | Change in eating habits | 15 |
| Sexual difficulties | 39 | Beginning or end school | 26 | Vacation | 13 |
| Gaining new family member | 39 | Change in living conditions | 25 | Christmas | 12 |

Concept of coping with difficult life situations is not new, although terminology concerning ways and strategies of handling difficult life situations may reach only few decades into the past. Coping is action directed at the resolution or mitigation of a problematic situation (Ray et al. 1982). Literature concerning coping works often with the term **problem-focused coping**, which encompasses all strategies that try to actively eliminate threatening factors or actively try to diminish the impact of such factors (Carver and Scheier, 1994). **Emotion-focused coping** implements strategies such as searching for social support, understanding from other people and seeking positive emotions in time of strife (Carver et al. 1989). **Coping focused on stopping unpleasant emotions and thoughts** is, as the name suggests, focused on avoiding unpleasant feelings associated with the stressful situation. It differs from the avoidant coping in ignoring not the stressor itself, but only negative behavioural and emotional correlates. Although avoidant tendencies were generally perceived as maladaptive, in some specific cases (situation of chronic disease when the patient cannot actively change the source of stress) avoidant coping can yield positive results especially in mental quality of life (Carver and Connor-Smith, 2010; Mikula et al. 2014).

Reason why avoidant coping was considered not very helpful and sometimes even maladaptive (Weiner and Carton, 2012) roots in number of escape defences which do not cope with problem in traditional understanding, but rather avoid problem or stressful situation altogether. Examples of such behaviour include:

1. **Denial**

   Denial is an ego defence mechanism that operates unconsciously to reduce anxiety by refusing to acknowledge the "ugly truth". Denial is being used in situations when person is faced with a fact that is uncomfortable or painful to accept. He or she rejects it and simply insists that it is not true, despite what may be overwhelming evidence. The subject may deny the reality of the unpleasant fact altogether (simple denial), admit the fact but deny its seriousness (minimization), or admit both the fact and seriousness but deny responsibility (transference). The concept of denial is particularly important to the study of addiction (Freud, 1993).

2. **Displacement**

   Displacement is an unconscious defence mechanism, whereby the mind redirects emotion from a "dangerous" object to a "safe" object. In psychoanalytic theory, displacement is a defence mechanism that shifts sexual or aggressive impulses to a more acceptable, or less threatening target that can serve as an emotional substitute (Freud, 1993). Most often these frustrations are taken out on loved ones.

3. **Fantasy**

   Fantasy (daydreams, literature, television, Internet) is a way to escape real problems. Imagining that one is successful may lead to feelings of success, especially when one's reality is the opposite of success (Freud, 1993).

4. **Rationalization**

Rationalization is making excuses for one's mistakes, and by doing so avoiding self-condemnation or condemnation by others. Rationalization is a post-hoc (after the fact) defence mechanism, connected to the self-serving bias: failure is ascribed to outside factors, whereas success comes from oneself (Freud, 1993). For example, diseases that are partially caused by unhealthy lifestyle like smoking, bad eating habits or excessive consummation of alcohol, may be seen only as result of hereditary characteristics and not by own actions.

5. **Regression**

Regression involves the reversion to an earlier stage of development in the face of unacceptable impulses. When we are faced with anxiety, for example from diagnosis of chronic disease, we tend to retreat, as if in a "psychological time machine," to the point in time when we last felt secure and safe—our childhood. Under stress, or in an anxiety-provoking situation, people can very often become more childish and primitive. Even an adult may want to curl up in bed in a foetal position (Freud, 1993).

6. **Identification**

Identification (sometimes also called introjection) involves identifying with someone else, taking on their personality characteristics, in order to solve some emotional difficulty and avoid anxiety. This was originally Freud's solution to Oedipus and Electra complexes: identify with the same sex parent and try to become like him or her (Freud, 1993).

7. **Substitution**

Substitution is a defence mechanism, operating unconsciously, in which an unattainable or unacceptable goal, emotion, or object is replaced by one that is attainable or acceptable. One of the more adaptive defence mechanisms, patients with chronic diseases can focus their efforts onto achieving other goals in life like finishing long term projects, spending more time with family or getting more involved in leisure time activities, instead of trying to cure usually untreatable diseases.

## Key messages

- Long-term stress has negative consequences on both mental and physical health especially because of constant stimulation of hypothalamic-pituitary adrenal axis.
- Reducing effects of stress can lead to longer and healthier life.

### 3.3.2 Work-related health

Work plays very significant role in human life. Generally, workplace is where significant part of adulthood is spent, and working conditions can have tremendous effect on health and well-being. It is often place of earning livelihood, stress, friendships, feelings of accomplishment or frustration. Most important work factors concerning health are work conditions and unemployment. This chapter will focus on work conditions and how they can affect health, while unemployment with its consequences for health, will be discussed in next chapter.

*Stress again?*

Working in stressful environment is very common for various professions. Some professions are by their nature very stressful (firefighters, ambulance drivers) but every job can become stressful under certain circumstances. Social organization of work, management styles and social relationships in the workplace all matter for health. Evidence shows that stress at work plays an important role in contributing to the large social status differences in health, sickness absence and premature death. Several European workplace studies show that health suffers when people have little opportunity to use their skills and low decision-making authority. Having little control over one´s work is particularly strongly related to an increased risk of back pain and cardiovascular disease for example. These risks have been found to be independent of the psychological characteristics of the people studied and thus they seem to be associated with work environment (Wilkinson and Marmot, 2003). This brings interesting concept of control into relationship between workplace and stress. Personality psychology works with term locus of control which describes the degree to which people believe that they have control over the outcome of events in their lives, as opposed to external forces beyond their control. The place of control can be conceptualized as internal (a belief that one´s life can be controlled) or external (a belief that life is controlled by outside factors which they cannot influence, or that chance or fate controls their life) (Rotter, 1966). Locus of control is understood as a scale with two sides representing two sources of control (Figure 3).

**Figure 3: Locus of Control**

While psychological locus of control may influence general activity of the person and behaviour in many situations, control over one´s job is not insignificant in determining health and quality of life. Internal locus of control, and generally control over work environment, be it control over specific steps in project completion or control over room temperature, knowing that that control lies within individual, has positive effects on task management, social experiences and job motivation and results in lower levels of stress (NG et al. 2006).

### *Work as social determinant of health*

Work is the means through which most people provide for their daily sustenance, and it also is a central social concept to understand the way society distributes wealth and power, integrates and excludes some population groups, causing a more or less egalitarian distribution of goods and allocation of resources. It determines not only people's standard of living but also their risk of exposures and hazards, all of which are significant determinants of health. Work and employment conditions are the result of different historical pathways and are greatly influenced by a number of institutions and social relations, so while some of the important concepts may be similar in different countries, gaping differences are present as well (Benach et al. 2006).

A major determinant of employment quality and workers' health is the excessive orientation of economic production towards profit and capital accumulation. One of the way of attaining wealth can be reduced labour payment and the increased intensity/rhythm of manpower utilization. These can be recognized as dominant features in modern society, particularly in developing countries. In addition, prevailing models of economic development neglect the impact of the productive process on the environment or workers' health (Benach et al. 2006).

WHO recognizes main problems in work environment besides stress in inequalities in work pay between genders and between people of different ethnic and cultural backgrounds, in unequal opportunities to get a job and in work insecurity. WHO thus recommends few key policy implications, that can possibly make working conditions and health of workers better:

- There is no trade-off between health and productivity at work. A vicious cycle can be established: improved conditions of work will lead to healthier work force, which will lead to improved productivity, and hence to the opportunity to create a still healthier, more productive workplace.
- Appropriate involvement in decision-making is likely to benefit employees at all levels of an organization. Mechanisms should therefore be developed to allow people to influence the design and improvement of their work environment, thus enabling employees to have more control, greater variety and more opportunities for development at work.
- Good management involves ensuring appropriate rewards – in terms of money, status and self-esteem – for all employees.
- To reduce the burden of musculoskeletal disorders, workplaces must be ergonomically appropriate.
- As well as requiring an effective infrastructure with legal controls and powers of inspection, workplace health protection should also include workplace health services with people trained in the early detection of mental health problems and appropriate interventions (Wilkinson and Marmot, 2003).

*A word on burnout and medical professions*

One of the most common mental health problems in medical professions is burnout. Burnout syndrome is a psychological state resulting from prolonged exposure to job stressors and is often found especially in employees who work with people on daily basis. Doctors, nurses and hospital staff is very likely to develop a burnout syndrome because besides high psychological difficulty of the job, it is physically very demanding as well. Severe burnout syndrome was found in about 50% of critical care physicians and in one third of critical care nurses. What can cause such high numbers? Research shows that especially employees who have high number of working hours, high number of night shifts and rarely go for vacations (Taylor et al. 2013). Recommendation for this affliction focuses mainly on prevention of burnout. Psychological hygiene, regular vacations and relaxation from work seem to be very important for preventing physicians from burning out and thus being in return more effective in doing their job.

### Key messages

» Level of control over work environment is one of the key variables that determines job satisfaction and health consequences stemming from working conditions

» High number of working hours, night shifts and working in critical care units are all risk factors in developing burnout syndrome in medical professions

### 3.3.3 Substance and non-substance addictions

Alcohol dependence, illicit drug use and cigarette smoking offers a mirage of escape from adversity and stress, but usually what they do is making the problems worse. These activities are often closely associated with markers of social and economic disadvantage (Wilkinson and Marmot, 2003).

Addiction is defined as a brain disorder characterized by compulsive engagement in rewarding stimuli, even though it is associated with negative consequences. The cope pathology is linked with biological process that is induced by repeated exposure to an addictive stimulus. Properties that characterize all addictive stimuli, whether it concerns, alcohol, cocaine or non-substance addiction such as gambling, are that they are reinforcing (increasing of likelihood of exposure) and intrinsically rewarding (they are perceived as positive, desirable, and pleasurable) (Taylor et al. 2013). American Society of Addiction Medicine (ASAM) defines addiction as follows:

> Addiction is a primary, chronic disease of brain reward, motivation, memory and related circuitry. Dysfunction in these circuits leads to characteristic biological, psychological, social and spiritual manifestations. This is reflected in an individual pathologically pursuing reward and/or relief by substance use and other behaviours. Addiction is characterized by inability to consistently abstain, impairment in behavioural control, craving, diminished recognition of significant problems with one's behaviours and interpersonal relationships, and a dysfunctional emotional response. Like other chronic diseases, addiction often involves cycles of relapse and remission. Without treatment or engagement in recovery activities, addiction is progressive and can result in disability or premature death (American Society for Addiction Medicine, 2012).

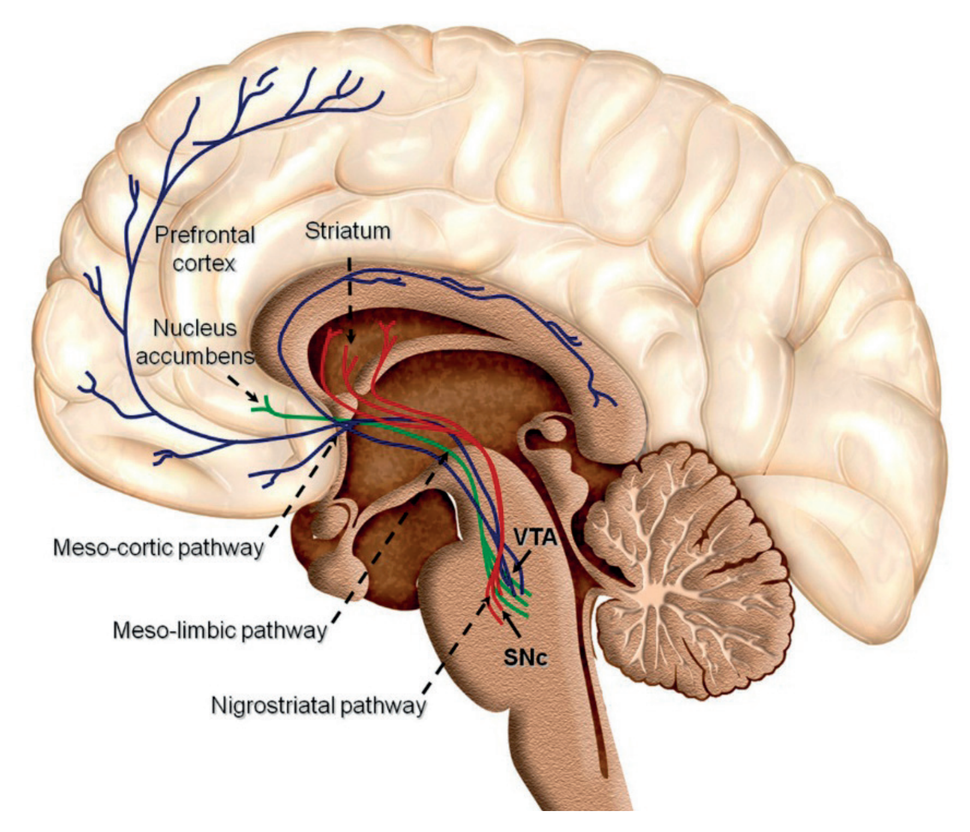
*Physiology of addiction*

Physiology of addiction is complex process involving mesolimbic pathway (sometimes referred to as reward pathway) – which is a dopaminergic pathway in the brain. Release of dopamine from this pathway into the nucleus accumbens regulates motivation and desire for rewarding stimuli and is one of the chief factors in developing addictions because it facilitates reinforcement and reward-related motor function learning and leads to subjective perception of pleasure (Malenka et al. 2009; Berridge and Kringelbach, 2015) (Figure 4).

Dopamine is the primary neurotransmitter of the reward system in the brain. Almost all addictive drugs, directly or indirectly, act upon the reward system of the brain by increasing dopaminergic activity. Excessive intake of many types of addictive drugs results in repeated release of high amounts of dopamine, which in turn affects the reward pathway directly through heightened dopamine receptor activation. Prolonged and abnormally high levels of dopamine in the synaptic cleft can induce receptor downregulation in the neural pathway. High levels of dopamine production can lead to brain adaptation and reducing of the ability of cells in the reward circuit to respond to it, which in turn can lead to diminishing of positive effects a person felt in the beginning of the drug use. Person can become less

**Figure 4.**

The mesolimbic pathway – the green projections from ventral tegmental area to the nucleus accumbens



Source: Arias-Carrión et al. 2010. Dopaminergic reward system: a short integrate review. International Archives of Medicine. Vol. 3, p. 24.

and less able to derive pleasure from other things he or she previously enjoyed like food or social activities (Volkow et al. 2007; National Institute on Drug Abuse, 2012).

### *Diagnostic criteria*

According to International Classification of Diseases – 10th Revision, a definite diagnosis of dependence should be made if at least three or more of the following symptoms are present in a person together at some time during previous year:

1. A strong desire or sense of compulsion to take the substance (craving)
2. Difficulties in controlling substance-taking behaviour in terms of its onset, termination, or levels of use
3. A physiological withdrawal state when substance use has ceased or been reduced, as evidenced by: the characteristic withdrawal syndrome for the substance; or use of the same (or a closely related) substance with the intention of relieving or avoiding withdrawal symptoms
4. Evidence of tolerance, such that increased doses of the psychoactive substances are required in order to achieve effects originally produced by lower doses (clear examples of this are found in alcohol and opiate dependent individuals who may take daily doses sufficient to incapacitate or kill nontolerant users)
5. Progressive neglect of alternative pleasures or interests because of psychoactive substance use, increased amount of time necessary to obtain or take the substance or to recover from its effects
6. Persisting with substance use despite clear evidence of overtly harmful consequences, such as harm to the liver through excessive drinking, depressive mood states consequent to periods of heavy substance use, or drug related impairment of cognitive functioning; efforts should be made to determine that the user was actually, or could be expected to be, aware of the nature and extent of the harm (World Health Organization, 2016).

International Classification of Diseases – 11th Revision, builds on this definition and adds specific definitions for wide range of psychoactive substances such as alcohol, cannabis, opioids, sedatives, hypnotics or anxiolytics, cocaine, stimulants such as amphetamines or methamphetamine, hallucinogens, nicotine and others (World health Organization, 2018).

Generally, we can surmise that for one to be diagnosed with dependence syndrome, one has to feel **craving** for the substance or activity, **loss of control** (especially over behaviour and motivation), **withdrawal symptoms** (also called abstinence syndrome) and a high **tolerance** for the substance, which is not found in non-addict population.

### *Alcohol*

Alcohol consumption can lead to serious health consequences, but the threat of it is often underestimated by general population. Globally, alcohol use was the seventh leading risk factor for premature death, and it accounted for 2.2% of deaths in women and 6.8% deaths in men. It also carries with it significant disease burden as consumption of alcohol is affecting negatively number of diseases, especially various forms of cancer, but many deaths attributable to alcohol were also due to injuries, self-harm, injuries and mental health problems (Griswold et al. 2018; World Health Organization, 2018). World Health Organization estimates in the global status report on alcohol from 2018 that there are about 2.3 billion current drinkers in the world and that in three WHO regions – the Americas, Europe and Western Pacific – more than half of the population consumes alcohol (World Health Organization, 2018). When it comes to alcoholism Globally an estimated 237 million men and 46 million women suffer from alcohol-use disorders with the highest prevalence among men and women in the European region (14.8% and 3.5%) and the Region of Americas (11.5% and 5.1%). Alcohol-use disorders are more common in high-income countries (World Health Organization, 2018).

Health and social harms stemming from alcohol consumption and alcoholism can be categorized according to Babor into three main groups:

1. The toxic effects of alcohol on diverse organs and tissues in the consumer's body (resulting, for instance, in liver disease, heart disease or cancer)
2. Development of alcohol dependence whereby the drinker's self-control over his or her drinking is impaired, often involving alcohol-induced mental disorders such as depression or psychoses
3. Through intoxication – the psychoactive effects of alcohol in the hours after drinking (Talhout et al. 2011).

Health issues that are preventable by lowering alcohol consumption or abstaining altogether include Fetal Alcohol Spectrum Disorders (diagnoses associated with drinking of mothers during pregnancy), infectious diseases such as AIDS by alcohol induced risky sexual behaviour, viral hepatitis or tuberculosis. Some non-communicable diseases may be negatively affected as well such as cardiovascular diseases or liver diseases (World Health Organization, 2018).

Alcohol consumption is associated with social and psychological consequences as well. The most common and most economically and psychologically damaging are:

1. **Work absences** - There is ample evidence that people with alcohol dependence and drinking problems are on sick leave more frequently than other employees, with a significant cost to employees, employers, and social security systems.
2. **Work accidents** - In Great Britain, up to 25% of workplace accidents and around 60% of fatal accidents at work may be linked to alcohol. In India about 40% of work accidents have been attributed to alcohol use.
3. **Lower productivity** - Heavy drinking at work may reduce productivity. Performance at work may be affected both by the volume and pattern of drinking. Co-workers perceive that heavy drinkers have lower performance, problems in personal relationships and lack of self-direction, though drinkers themselves do not necessarily perceive effects on their work performance.
4. **Unemployment**- Heavy drinking or alcohol abuse may lead to unemployment and unemployment may lead to increased drinking.
5. **Family problems** - The impact of drinking on family life can include substantial mental health problems for other family members, such as anxiety, fear and depression. Drinking outside the home can mean less time spent at home. The

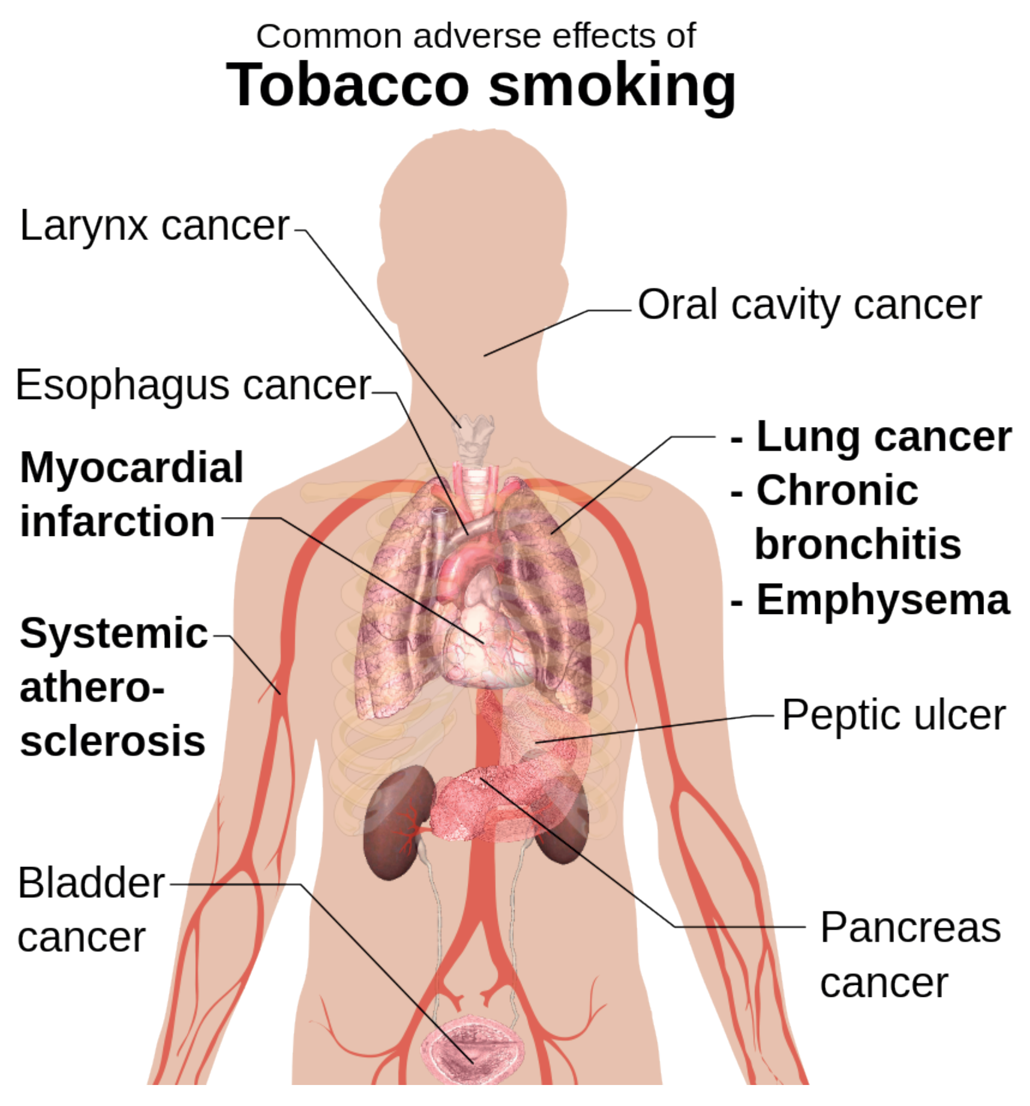
financial costs of alcohol purchase and medical treatment, as well as lost wages can leave other family members destitute. When men drink it often primarily affects their mothers or partners who may need to contribute more to the income of the household.

6. **Poverty** - The economic consequences of alcohol consumption can be severe, particularly for the poor. Apart from money spent on drinks, heavy drinkers may suffer other economic problems such as lower wages and lost employment opportunities, increased medical and legal expenses, and decreased eligibility for loans. A survey in Sri Lanka indicated that for 7% of men, the amount spent on alcohol exceeded their income.
7. **Domestic violence** - Alcohol plays a role in a substantial number of domestic violence incidents, especially in the case of abusing husbands. Often both the offender and the victim have been drinking. The relationship between alcohol and domestic violence is complex and the precise role of alcohol remains unclear. Heavy drinking has been strongly linked to violence between partners and to a lesser extent to violence towards others, possibly because proximity increases the opportunities for violence.
8. **Social and economic costs** cover the negative economic impacts of alcohol consumption on the material welfare of the society as a whole. They comprise both direct costs - the value of goods and services delivered to address the harmful effects of alcohol, and indirect costs - the value of personal productive services that are not delivered as a consequence of drinking. In industrialized countries, estimates of social and economic costs of alcohol use can reach several percent of the Gross Domestic Product (GDP), ranging for instance from 1.1% in Canada to 5-6% in the case of Italy (World Health Organization, 2018).

*Other substances*

**Tobacco** – Tobacco is usually consumed in form of **cigarettes**, which do contain around 5000 toxic substances with negative effects on majority of organ systems (Figure 5). Nicotine which is present in cigarettes is linked with increased risk of cardiovascular, respiratory, and gastrointestinal disorders. It also decreases immune response and has adverse effect on reproductive health. Another danger stemming from nicotine itself is affecting of tumor proliferation and metastasis in cancer patients undergoing chemotherapy and makes them partly resistant to chemo and radio therapeutic agents (Talhout et al. 2011; Mishra et al. 2015). That is why smokers currently on chemotherapy ae not advised to use even nicotine patches instead of smoking, but to cease smoking altogether.

**Figure 5.** Health consequences of tobacco use



Source: Häggström, M. (2014). Medical gallery of Mikael Häggström 2014. WikiJournal of Medicine Vol. 1, no. 2, DOI:10.15347/wjm/2014.008. ISSN 2002-4436

Cigarettes are but one of the ways of tobacco and nicotine use today. One of the forms of tobacco use that is gaining popularity especially in Europe is **snus**. Scandinavian snus is moist form of smokeless tobacco and can be sold either as loose snus in one container, or as pre-packaged into pouches and is thus called portion snus. Stance of European Union on snus is generally negative, focusing mainly on the health risk associated with it. In 2016 EU removed word "can" from the warning printed on the packs of snus, which read: "*This tobacco product (can damage) damages your health and is addictive*" (Nilsen et al. 2018). Use of this form of tobacco is growing rapidly, especially in Scandinavia. Norway for example reports increase in snus use from 9% in males and 2% in females in 2003 to 33% in males and 23% in females in 2013 (Norwegian Institute of Public Health, 2014). Health risks associated with snus use are in many cases similar to cigarette use, but there are some differences as well. Oral health is at even higher risk compared to cigarettes as it can cause snus-induced lesions in the oral mucosa, and it can lead to permanent recession of the gums at the sites where the snus is placed. It is also associated with different forms of cancer, with pancreatic cancer being the most common. Snus is also associated with increased risk of early death after stroke or myocardial infarction (Norwegian Institute of Public Health, 2014). The biggest advantage of snus from the population health perspective is the absence of passive smoking and less strain on people occupying the same household as snus users, compared to cigarettes users.

While not being tobacco products themselves, electronic cigarettes are in the centre of attention of public health workers today, as **vaping** is getting more and more popular recently. Electronic cigarettes may or may not contain nicotine, and were considered as healthier alternative to cigarettes (Burstyn, 2014). Absence of tar as the man carcinogen in cigarettes is great boon, but formaldehyde is present in electronic cigarettes as well, which has also carcinogenic effect. Lung irritation caused by propylene glycol is fairly common and lungs are affected by ultrafine particles of water and nicotine in a similar pattern as the different ultrafine particles in tobacco smoke (Hua et al. 2013).

**Cannabis** – Cannabis or marijuana is one of the most controversial substances, that can cause addiction, and legalisation of cannabis use varies from country to country and even countries with more benevolent approach vary in their laws regarding levels of legalisation. From the health perspective, there are two points of view – one is positive focusing on medical use of marijuana in treating muscle spasms in multiple sclerosis patients, chemotherapy induced nausea, low appetite and weight loss caused by HIV, in seizure disorders, in Crohn´s disease or other conditions where endocannabinoid receptors are involved in the pathway (Bridgeman and Abazia, 2017). The negative point of view perceives cannabis as a gateway drug, as almost all adolescents who had tried cocaine and heroin, started with cannabis. Other health issues traditionally associated with marijuana use are psychotic symptoms and disorders and it is believed that cannabis use precipitates schizophrenia in persons who are vulnerable to the disorder, and dependence, which can lead even to cognitive dysfunction (especially short-term working memory, and long-term decision making) (Hall, 2006; Morral et al. 2002; Crean et al. 2011).

**Cocaine** - Cocaine causes a short-lived, intense high that is immediately followed by the opposite—intense depression, edginess and a craving for more of the drug. People who use it often don't eat or sleep properly. They can experience greatly increased heart rate, muscle spasms and convulsions. The drug can make people feel paranoid, angry, hostile and anxious. Regardless of how much of the drug is used or how frequently, cocaine increases the risk that the user will experience a heart attack, stroke, seizure or respiratory (breathing) failure, any of which can result in sudden death. Interestingly, cocaine was used as a component of many medicines throughout 19th century and that it was present in Coca-Cola up until 1903.

**Methamphetamine** – Crystal meth as is methamphetamine also called, creates a false sense of well-being and energy, and so a person will tend to push his body faster and further than it is meant to go. Thus, drug users can experience a severe “crash” or physical and mental breakdown after the effects of the drugs wear off. Because continued use of the drug decreases natural feelings of hunger, users can experience extreme weight loss. Negative effects can also include disturbed sleep patterns, hyperactivity, nausea, delusions of power, increased aggressiveness and irritability. Other serious effects can include insomnia, confusion, hallucinations, anxiety and paranoia. Users may suffer brain damage, including memory loss and an increasing inability to grasp abstract thoughts. Those who recover are usually subject to memory gaps and extreme mood swings (European Monitoring Centre for Drugs and Drug Addiction, 2008).

Other substances such as heroin, ketamine, or opioids, cause in many cases similar health problems for user, but the mechanism of addiction is similar. Neuro-hormonal reward system strengthens behaviour that leads to obtaining and consuming drug and **complex behavioural patterns** emerge. While these are harmful by themselves, addictions are usually affecting all parts of human life. Financial problems are usually present as well, since many of the substances are quite expensive, social relationships get under tremendous pressure as addictions push the addict away from his or her loved ones. Education, work functionality and even health of the population get worse as negative phenomena like increase of sexually transmitted diseases, and high financial strain on health systems emerge. So what should be the policy implication in terms of addictions? WHO suggests few main points that should be implemented in strategies aimed at substance addictions:

- Work to deal with problems of both legal and illicit drug use needs not only to support and treat people who have developed addictive patterns of use, but also to address the patterns of social deprivation in which the problems are rooted.
- Policies need to regulate availability through pricing and licensing, and to inform people about less harmful forms of use, to use health education to reduce recruitment of young people and to provide effective treatment services for addicts.
- None of these will succeed if the social factors that breed drug use are left unchanged. Trying to shift the whole responsibility on to the user is clearly an inadequate response. This blames the victim, rather than addressing the complexities of the social circumstances that generate drug use. Effective drug policy must therefore be supported by the broad framework of social and economic policy (Wilkinson and Marmot, 2003).

### *Non-substance addictions*

Non-substance addictions or behavioural addictions are bit tricky to categorize as they lack some of the diagnostic criteria that substance addictions do have. Nevertheless, behavioural science experts believe that all entities capable of stimulating a person can be addictive and whenever a habit changes into an obligation, it can be considered an addiction (Alavi et al. 2012). Behavioural scientists argued that the concept of addiction should not be restricted only to the ingestion of substances and Brown (1993) came with summarization of criteria for behavioural addictions which are:

1. **Salience**: Domination of a person’s life by the activity
2. **Euphoria**: A ‘buzz’ or a ‘high’ is derived from the activity
3. **Tolerance**: The activity has to be undertaken to a progressively greater extent to achieve the same ‘buzz.’

4. **Withdrawal Symptoms**: Cessation of the activity leads to the occurrence of unpleasant emotions or physical effects
5. **Conflict**: The activity leads to conflict with others or self-conflict
6. **Relapse and Reinstatement**: Resumption of the activity with the same vigour subsequent to attempts to abstain, negative life consequences, and negligence of job, educational or career opportunities (Brown, 1993; Griffiths, 1996; Charlton, 2002).

Terminology is not agreed upon to this day and there is number of way to describe problematic behaviour. Despite this, diagnostic manual ICD-11 recognizes behavioural patterns that are harmful for health of the person who performs them or t his or her social surroundings. Closest to the terminology of substance addictions is title *disorders due to addictive behaviours* which encompasses gambling disorder (6C50) and gaming disorder (6C51). Other categories associated closely with behaviour found in ICD-11 are:

**Impulse control disorders**

» *Pyromania (6C70) – Failure to control strong impulses to set fire*

» *Kleptomania (6C71) – Failure to control strong impulses to steal objects in the absence of an intelligible motive*

» *Compulsive sexual behaviour disorder (6C72) – Persistent pattern of failure to control intense, repetitive sexual impulses or urges resulting in repetitive sexual behaviour*

» *Intermittent explosive disorder (6C73) – Failure to control aggressive impulses*

**Factitious disorders**

» *Factitious disorder imposed on self (6D50) – Feigning, falsifying, or inducing medical, psychological, or behavioural signs and symptoms or injury associated with identified deception. The individual seeks treatment or otherwise presents himself or herself as ill, injured, or impaired, even though it is not true.*

» *Factitious disorder imposed on another (6D51) - The individual seeks treatment for the other person or otherwise presents him or her as ill, injured, or impaired, even though it is not true (usually child).*

Other problematic behaviours include:

**Hypochondriasis (6B23)** - Hypochondriasis is characterized by persistent preoccupation with or fear about the possibility of having one or more serious, progressive or life-threatening diseases. The preoccupation is associated with catastrophic misinterpretation of bodily signs or symptoms, including normal or commonplace sensations, and is manifest either in repetitive and excessive health-related behaviours or in maladaptive avoidance behaviours related to health.

**Hoarding disorder (6B24)** - Hoarding disorder is characterised by accumulation of possessions due to excessive acquisition of or difficulty discarding possessions, regardless of their actual value. Excessive acquisition is characterized by repetitive urges or behaviours related to amassing or buying items. This diagnosis can be closely associated with shopping (World Health Organization, 2018).

Some other afflictions are not formally recognized, but are studied anyway, such as **pornography addiction**, or as it is often described – self-perceived pornography addiction (SPPA). This behavioural pattern includes excessive consummation of pornography material, which leads to problems in social and psychological domains of the person (Duffy et al. 2016).

*Gambling disorder*

Gambling disorder or pathological gambling is form of excessive playing of hazardous game where the main incentive for playing is the possibility to win incentive (usually in form of money). There are many forms of gambling, some them entirely chance-based forms (lotto, slot machines, bingo, roulette, scratch tickets) and skill-based forms (poker, blackjack, horse race betting, sports betting), and while skill plays some role in there, chance is still important factor in those. While successful sports betting requires knowledge of teams and odds of win or lose, the expected outcome is never 100% guaranteed. (Ronzitti et al. 2016). The danger of gambling lies in the consequences for players and their families. The scope of the consequences can be demonstrated by stories, that are usually illustrating gambling disorder on one of the websites focused on helping people with gambling problem. Below is one example from such website:

January 3, 1983, will forever be ingrained in Dianne's mind as the night her husband, Don, started their family down a long and winding path of deceit, disappointment, and disaster. That Monday night, the Minnesota Vikings were playing the Dallas Cowboys. Don had placed $1,500 bet on the game...and lost.

After that game, it wasn't long before Don's debts began to pile up and reach unmanageable levels. As Don explained to his children that their video cassette player was broken—and that's why the men were here to take it back—he was only telling the first of what was to be many lies in order to conceal his gambling addiction from his children. They eventually found out anyway.

Don's betting expanded to more than just football. Soon, he had his own bookie. "I bet every day of the year except the Monday and Wednesday before and after the baseball all-star game, the only two days of the year when there was no sports betting," says Don. Don controlled the family's finances, and so, could get away with numerous tricks and sneaky behaviours that would have not only been met with disapproval by his wife but were illegal.

He forged his wife's signature to take out loans to pay off gambling debts. Don learned how to kite checks between three different checking accounts, essentially loaning himself large amounts of money interest-free by writing bad checks between the accounts, and then clearing the checks with more bad checks, and so on and so forth. Don found himself visiting one banker or another on a daily basis. "I could at least relax on the weekends when the banks were closed," he says.  Don rushed home from work daily to beat the mailman to the house in fear that his wife would see any bank statements.

When Dianne didn't get one-day Don's afternoon call (which came every day like clockwork), she knew something was wrong. When Don finally called, he asked if she would mind if he cashed in another $100 check. She told him, "Do whatever you want, stay as long as you want, I don't care." She felt too defeated to argue it anymore.

When Don came home late that night, the bedroom door was locked. He knew he had screwed up bad. Because of all the pain he had caused the family, every broken promise big or small, his daughter refused to let Don attend her graduation or her wedding (Addiction Resource, 2018).

This story ends with Don entering group of Gamblers Anonymous (GA), and in the end turned his life around. Consequences of gambling disorder can be quite damaging, especially for mental health as internet gambling frequency is significantly associated with poor mental health, especially in presence of comorbidities such as mood disorder or anxiety disorder. Depressive symptomatology is not uncommon with suicidal attempts or even suicides being the most extreme consequences of gambling (Petry and Weinstock, 2010; Lorains et al. 2011). Gambling addiction develops in 4 steps and phases:

**Winning phase** - The winning phase often starts with a big win, leading to excitement and a positive view of gambling. It is viewed as fun, source of easy income. Problem gamblers believe they have a special talent for gambling and that the winning will continue and while they may be aware of other people who lost significant sums of money because of gambling, they believe this cannot happen to them and that they are masters of their destiny. They begin spending greater amounts of time and money on gambling.

**Losing phase** - Problem gamblers become more and more preoccupied with gambling. They start to gamble alone, borrow money, skip work, lie to family and friends, and accumulate first debts. They also begin to "chase" their losses. Activity that was at first done openly is now more of a personal secret.

**Desperation phase** - Problem gamblers lose all control over their gambling. They feel ashamed and guilty after gambling, but they can't stop. They isolate themselves even more. They may cheat or steal to finance their addiction. The consequences of compulsive gambling catch up with them: they may lose their jobs, get divorced, or get arrested. Social and financial problems lead to self-esteem problems and symptoms of depression and anxiety.

**Hopeless phase** - In the hopeless phase, problem gamblers hit "rock bottom." They don't believe that anyone cares or that help is possible. They don't even care if they live or die. They may abuse drugs and alcohol to numb the pain. Many problem gamblers also consider or attempt suicide (Grohol, 2016).

### *Gaming disorder*

Gaming disorder can be described as a pattern of gaming behaviour which is characterized by impaired control over gaming, increasing priority given to gaming over other activities, and continuation and escalation of gaming despite the negative consequences. WHO adds that for gaming disorder to be diagnosed, the behaviour pattern must be of sufficient severity to result in significant impairment in personal, family, social, educational, occupational or other important areas of functioning and would normally have been evident for at least 12 months (World Health Organization, 2018). Increase in gaming behaviour is evident in recent years. Besides adding gaming disorder among officially recognized conditions in ICD-11, it can be seen in such occurrences as esports TV channels – which broadcast competition events of playing various videogames.

Games that are usually played excessively belong to the group of games titled Massive Multiplayer Online Role-Playing Games (MMORPG). World of Warcraft is arguably the most well-known with over 7 million players worldwide, The Elder Scrolls Online, The Black Desert Online, Guild Wars 2, Final Fantasy XIV, Star Wars: The Old Republic, EVE Online, Lord of the Rings Online and others. Another category of popular games are competitive games such as Counter Strike, League of Legends or DOTA 2, where player or team of players try to prevail over their competition. Addictive nature of some videogames can be attributed to few incentives they can provide for the player:

1. Very attractive scenarios
2. Continuous feedback on actions taken by the player, making the games truly interactive activities
3. Worlds organized in stages and adjustable levels of difficulty, which allows any user to become a potential player
4. The completion of phases, levels or goals produces feelings of competence, generating an increasingly desire to play, becoming activity that reinforces and motivates intrinsically
5. On many occasions, the contents of the game are fascinating. United with the sense of mastery and the fact that it is an activity that takes place freely, games can foster a sense of self-determination in player
6. The relationship between ability and difficulty, along with the interest in the task on hand induces the absorption of reality and long-time dedication in the gaming activity (Chóliz and Marco, 2011).

*One...more...level...*

Reason why video games can be quite addictive is that from early development, they are designed to be that way. Video game designers, like anyone else trying to make a profit, are always looking for ways to get more people playing their games. They accomplish this by making a game just challenging enough to keep you coming back for more but not so hard that the player eventually gives up. In other words, success for a gamer often feels just out of reach. Even if the goal is reached, there are many others that can motivate player to play more. Different achievements or deeds that are part of many games are strong motivator, especially if one needs long time for their completion.

Symptoms of gaming disorder may include both physical and emotional symptomatology:

» Fatigue

» Migraines due to intense concentration or eye strain

» Carpal tunnel syndrome caused by the overuse of a controller or computer mouse

» Poor personal hygiene

» Feelings of restlessness and/or irritability when unable to play

» Preoccupation with thoughts of previous online activity or anticipation of the next online session

» Lying to friends or family members regarding the amount of time spent playing

» Isolation from others in order to spend more time gaming

» Depressive symptomatology (American Addiction Centers, 2018).

Though most of the symptoms listed above have short-term effects, they can lead to more severe long-term repercussions if not addressed properly. Sleeping or eating proper meals may be interrupted or of low quality, in order to continue gaming. While the short-term effects of this may include hunger and fatigue, it could eventually lead to a sleep disorder or diet-related health issues. People who isolate themselves from others in order to play video games may experience family problems because of their absence or defensive stance when confronted by family members about their gaming (American Addiction Centers, 2018).

Other long-term effects of video game addiction to consider are the **financial**, **academic** and **occupational** consequences involved. Video games and video game equipment can be very expensive, especially when factoring in recurring costs such as the high-speed Internet connection required for online multiplayer games. These games can also be very time-consuming, leaving addicted gamers with less time to focus on their education or career with serious personal and social consequences (American Addiction Centers, 2018).

### Key messages

- Development of addictions is a complex process involving learning, desirability of the reward associated with specific addiction and social surroundings of an addict.
- Main symptoms associated with addictions are craving, loss of control, physiological reaction to absence of substance and high tolerance of the substance.

### 3.3.4 Social support

While stress and addiction are social determinants that have mainly negative health consequences and work is determinant where negative effects receive much more attention from researchers, social support is determinant which is usually associated with protective and positive effects. Social support along with social capital describe how health of people is shaped by their social circumstances [62]. Social capital approach concerns social integration of social networks with key characteristics of norms of reciprocity, trust among members or a neighbourhood and co-operation. It is suggested that social capital can influence health by facilitating the sharing of health-related knowledge (e.g., sharing the facts about health, access to health-related services, and interventions), by promoting healthy norms (e.g., to exercise, to eat well), and by providing access to social support (Haslam et al. 2018; Kawachi et al., 2008).

Social support has been defined as information from others that one is loved and cared for, esteemed and valued, and part of a network of communication and mutual obligations from parents, a spouse or lover, other relatives, friends, social and community contacts or even a devoted pet (Rietschlin, 1998; Allen, 2003). Social support is crucial for well-being as sometimes even the idea of social support can be helpful. Many of the benefits of social support may actually come from the perception that social support is available. Feeling confident that social support will come when it will be needed can be enough for people with less severe limitations to manage number of challenging tasks on their own. Social support reduces psychological distress, such as depression or anxiety, and as such is very important for quality of life. On the other hand, lack of social support, especially for people with high needs for social support but insufficient opportunities to obtain it, can lead to high levels of distress. People who are often threatened by this include (but are not limited to) the elderly, the recently widowed or victims of sudden, severe, uncontrollable life events (Sorkin et al. 2002).

### *Social support and health*

Social support and good social relations make an important contribution to health especially by giving people the emotional and practical resources they need (Wilkinson and Marmot, 2003). It can be provided by friends, family or physicians in a number of forms like emotional support or informational support. Research focused on effect of social support on health and quality of life of patients suffering from chronic conditions showed that social support is protective factor for health in cancer-related distress (Badger et al. 2013; Smith et al. 2011). Research shows that if newly diagnosed cancer patient receives supportive responses from family and friends, facilitation of other types of processing of the cancer may occur. People around the patient may point out positive or meaningful aspects of the cancer experience (Manne et al. 2018; Ochoa et al. 2018). Quality of life usually decreases dramatically at the time of diagnosis of chronic disease, but with social support (particularly positive emotional and informational support), health related quality of life rises again, if the level of social support is adequate (Leung et al. 2014). Social support seems also to be a protective factor in HIV, where it was negatively associated with social stigma (Farber et al. 2014; Wohl et al. 2013).

### *Stigma and social support*

Social stigma is especially damaging for health and stems from false preconception about words not having enough power to affect health, probably most appropriately expressed in infamous child´s rhyme: "*Sticks and stones may break my bones but words can never hurt me* ", which is unfortunately not true. Term stigma originates in ancient Greek and Roman cultures, where those who were considered different, morally delinquent, or blemished were often subjected to skin burning or cutting that left them with a permanent mark, referred to as stigma. This made their inferior status clear to everyone (Goffman, 1963). Stigma of chronic condition, especially AIDS, which is associated with risky sexually behaviour, is further damaging for physical and especially mental health, so while social support is a boon for health, lack of support or even stigmatization of condition, can make the health actually worse.

Similar positive effects of social support where it either improved health related quality of life or diminished negative effects of symptoms of chronic diseases were found in number of long-term diagnoses like dementia (Eshkoor et al. 2014), patients with need of cardiac device (Cheng et al. 2014), survivors of stroke (Kruithof et al. 2013), patients suffering from fibromyalgia, rheumatoid arthritis, ankylosing spondylitis and osteoarthritis (Kool et al. 2013) and some forms of social support proved helpful even in case of eating disorders (Akey and Rintamaki, 2014). These examples are only the tip of the iceberg; as social support can be beneficial in almost all conditions.

**Social support** is one of the tools mostly used by group psychotherapy techniques. Social support groups can be a source of informational support, by providing valuable educational information, and emotional support, including encouragement from people experiencing similar circumstances. Studies have generally found beneficial effects for social support group interventions for various conditions, like alcoholism or gambling (Hogan and Najarian, 2002). Support groups can be very beneficial for people with stigma, as these support groups are usually suffering from same condition, or at least with similar problems, and people who facilitate these meetings restrain from judgement. It's the feeling of acceptance, of renewed social belonging and social identity, that can be especially helpful. Group life is central to what we are as humans and it is a key source of meaning, purpose and direction. If social identity is what makes group behaviour and group life possible, then it too, must be essential for us to thrive. But if we lack valuable group memberships, then the social identity processes will tend to be implicated in poor health outcomes (Haslam et al. 2018).

### *Types of social support*

Social support is by the definition intended to be helpful and is not provided in forms of angry criticism, hassling or undermining, no matter how much the sender claim that "*they mean well*". There are 4 types of social support one can provide: **Emotional**, **Instrumental**, **Informational** and **Appraisal** support.

1. **Emotional support** - is the offering of empathy, concern, affection, love, trust, acceptance, intimacy, encouragement and caring. All of these are very important for patients with chronic diseases specifically, as feelings of acceptance and love in face of long term (and in some cases debilitating) disease encourage patients to fight the fight even in most serious cases. It also builds feelings of self-worth of patients. To have a value for someone so he or she takes care of me can be very healing feeling for people who may doubt their self-worth when they cannot do most of the stuff they used to do when they were still healthy (Langford et al. 1997). Positive effects of social support are not excusive to patients going through treatment, but also for caregivers and family members. Evidence shows that siblings of children with cancer who report more social support had significantly reduced levels of anxiety, depression and had fewer behavioural problems compared to siblings who reported lower levels of social support. Same was true for parents of these children, and while kinds going through chemotherapy benefit from emotional social support greatly, so do those close to them (Barrera et al. 2004).
2. **Instrumental (Tangible) support** - is the provision of financial assistance, material goods or services. This support can be provided in form of money, help around the house, by running errands for someone or helping with difficult tasks. Patients after surgery or difficult treatment procedure require a lot of assistance. Depending on the condition it can vary from walking the dog, to help with personal hygiene or even cooking meals for patient. Help with challenging tasks, especially physical and running one´s errands may speed up the recovery, as patient focuses more on resting and healing, rather than daily chores and tasks.
3. **Informational support** - is the provision of advice, guidance, suggestions or useful information. In situations when health is concerned, this type of support is expected mainly from doctors, nurses and other medical staff. Information about their disease is much more easily received from someone who has expertise in the field, rather than from a someone who does not (Tilden and Weinert, 1987). In some cases, though, needs of patients are not fulfilled in this area of social support. Doctors may not have enough time to spend with each individual patient to fully cover everything there

is to know about managing their disease. **Google and social networks** are getting used more and more as source of information on many medical conditions (Escarrabill et al. 2011). Searching for symptoms and diseases associated with these symptoms is double edged sword though. While it may unburden the health system in cases of minor problems, they can cause much distress and anxiety in patients. Let´s take headache for example. Common symptom that can be related to changes in atmospheric pressure, or can be present in people with brain tumours. If the patient can´t put headache into context with other symptoms and see his or her condition holistically, the resulting effect may be high anxiety, fear and stress. The question of **treatment adherence** is also very much associated with informational support. **Treatment adherence** refers to the extent to which a patient´s behaviour is consistent with health care recommendations and good it was found to be associated with better health recovery and disease management results (Haynes et al. 1979; Dunbar-Jacob and Mortimer-Stephens, 2001). Improving adherence can be done by simplifying regimen characteristics – either by reducing times needed for medication, or associating them with meals, but one of the most helpful is imparting appropriate knowledge. Their research demonstrated that patients´ understanding of their conditions and treatments is positively related to adherence, and that adherence, satisfaction and treatment understanding are all related to the amount of information given. Patients who understand the purpose of the prescription are twice more likely to fill it than those who do not understand the purpose (Atreja et al. 2005).

4. **Appraisal (Companionship) support** - is the type of support that gives someone a sense of social belonging. This can be seen as the presence of companions to engage in shared social activities with. Community and social network is as important for chronically ill population as it is for healthy population. Being part of a church community, hobby group, group therapy or neighbourhood community, can have very positive impact on health related quality of life (Cruwys et al. 2014; Hays et al. 2011).

If we take a look at various sources of social support a newly diagnosed cancer patient (let´s name her Andrea) can receive from various sources, they can look like this: (Table 2)

**Table 2:** types of social support

| Social support | Application |
|---|---|
| **Emotional** | Andrea´s best friend provides hope and will hear her out about her fears concerning treatment procedure and effect the treatment process may have on her relationship with her husband and children. |
| **Instrumental** | Andrea´s husband will help with chores, and will do activities that he did not do before like shopping for groceries or emptying the dishwasher. |
| **Informational** | Doctors provide information about cancer. They explain what behaviour is beneficial and what behaviour is harmful. They explain what side effects of the treatment she can expect and how to lessen their impact on her life. |
| **Appraisal** | Amanda´s mother and father, will be there for her and remind her of all the qualities she has, even though she cannot do all the things she used to. People in online forums will share their stories, be there with her during rough times. |

Social support as one of the key determinants of health has great potential to make recovery and quality of life better. Good social network of friends and family might mitigate a lot of adverse effects of chronic conditions.

## Key messages

- Social support is a strong protective factor against negative health consequences of chronic diseases
- Social support can be provided in form of emotional, instrumental, informational or appraisal support

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## 3.4 UNEMPLOYMENT AND SOCIAL EXCLUSION

*Alexandra Husivargova & Zuzana Katreniakova*

### 3.4.1 Unemployment

**The importance of work for a person**

Work has an irreplaceable place in life of a person. It is an important condition of a decent existence and it brings not only material benefit but also gives a feeling of self-realisation and social usefulness. Work does not only serve as a mean to produce goods or provide services but it also creates a social field of structured contacts with an opportunity to have conversations, meet people and make friendships. While performing tasks an individual can objectify one's skills and gain a sense of professional competence. Group work provides social environment in which a person evaluates oneself and compares oneself to others. From the point of mental hygiene labour enables the ventilation of excessive mental and physical energy.

In the context of a person's life work determines the beginning and end of economic activity. Working people demonstrate values to children in their upbringing. It gives them the opportunity to identify, imitate and find a personal example. Nowadays children do not see their parents work as much as before, but they share their professional successes and also failures.

A long-term loss of gainful employment takes away wages as the main source of satisfying life necessities, creates personal and domestic economic uncertainty, disrupts the usual time routine of a workday and eliminates the possibility of gaining and maintaining professional habits and skills. With long-term unemployment the purpose of life is lost, social contacts with friends and co-workers are limited, integrity of a personality is gradually eroded. Activities that used to be a firm part of a daily routine are disappearing.

With long-term unemployment people lose the strongest bond to reality and are taken over by uncertainty and fear of the future and subsequently doubts about their own capabilities. Losing a job is a stressful life experience in a society that still considers gainful employment to be of great social and personal value and where employment is the key to life's aspirations and the source of identity and self-respect of a person. This subjectively stressful experience is also still perceived by society as a sign of a personal failure of an individual (Buchtová, 2002).

**Definition and causes of unemployment**

International Labour Organization (ILO) defines unemployed people as all persons of working age who were: a) without work during the reference period (were not in paid employment or self-employment); b) currently available for work (were available for paid employment or self-employment during the reference period); and c) seeking work (had taken specific steps in a specified recent period to seek paid employment or self-employment). The working-age population is often defined as all persons aged 15 and older, but this may vary from country to country based on national laws and practices (some countries also apply an upper age limit).

Among the **main causes of unemployment** different authors include (Paukovič, 2007; Selická 2016; Vondráková 2016):

- Regional differences in unemployment together with low mobility of workforce
- Jobs with low wages that become uninteresting and demotivating

- » Excessively high taxation and levies that create a significant difference between the costs of employment for the employer and the net income of the employee
- » Technological development decreasing the demand for human labour (automatization, computerization and robotics)
- » High fertility and high increase of population
- » Lengthening of workhours and more overtime that lower the amount of created jobs
- » High company indebtedness and liquidation of small producers and companies
- » Low level of capital accumulation and low investment in expanding production
- » Level of economic prosperity and material wealth of a country
- » Insufficient job opportunities
- » Inflexibility of the workforce
- » Insufficient conditions in territorial mobility
- » Underdeveloped information network on the job market
- » Fatalism of long-term unemployed people
- » Prejudice of employers towards long-term unemployed people

### Groups at risk

- **Young people** – high school and university graduates applying for their first job. Their lack of experience is a grave disadvantage and they also lack work habits and contacts.
- **Older people** – people in pre-retirement age have a hard time finding employment. Their age limits their adaptation and learning new things and technologies. The older they are, the more rigid are their work habits and stereotypes and the more difficult it is for them to adapt to new life situations.
- **Women** - with little children are another group at risk. The disadvantageous status of women in the job market is caused by the preference of employers to hire men for their higher mobility and for not managing their households as much as women. Giddens (2013) notes these differences in economic activity are reducing every year.
- **People with impairment** – people with impairment have different work skills and their economic, social and psychological issues are more evident, with the issues of adequate meaning of life and of feeling of decency are also present. The period of them being listed at employment bureau is several times longer than with healthy people. This often puts them in a helpless life situation and it is a burden for their families as they have to support an unemployment person with impairment.
- **People with low qualification** – unqualified workers represent the largest part of long-term unemployed people. They are most people who are difficult to educate, have little interest in working and take part in socially unacceptable deviant behaviour (alcoholics, repeated offenders etc.). People with low qualification are frequently replaced by new technologies that are cheaper and more precise.
- **Social division of society** – noticeable on the job market when it comes to people from lower social class, members of ethnic groups and people with impairment. These people often have lower chance to find gainful employment.

### Types of unemployment

Typology of unemployment according to Mareš (1994):

- **Frictional unemployment** occurs in the job market in every moment as a result of worker mobility. This type of unemployment represents a regular change of employment when unemployment is only a short period of time in which people search for a new job or are transitioning from one job to another. These people are labelled as "people between two jobs" and from a macroeconomic point of view this type of unemployment is unavoidable.
- **Structural unemployment** represents a situation then workers lose their jobs because of the dissolution of ineffective companies and institutions as it reflects the changes in national economics. It occurs when a labour market is unable to provide jobs for everyone who wants one because there is a mismatch between the supply and demand of workers and the skills of the unemployed workers and the skills needed for the available jobs. The imbalance often occurs in certain sectors or regions and can remain prolonged and relatively high.
- **Technological unemployment** is a special part of structural unemployment when people lose jobs as a result of jobs being cancelled and replacement of workers by new technologies.
- **Cyclical unemployment** is a classical model of unemployment when the capacity of workers is not used because of the lack of demand for final goods and services and therefore for workforce caused by an economic recession. It occurs during cyclical changes of the dynamics of economy on a macroeconomic level (various crises – financial, economic etc.).
- **Seasonal unemployment** has a short-term character because it is tied to natural cycles and it affects certain professions (construction, agriculture, tourism etc.).
- **Hidden unemployment** represents the situation when unemployed people are not officially registered as unemployed. This type of unemployment often includes married young women, who have given up looking for work as a result of motherhood, people with low qualification, senior age or other handicaps, and therefore they are not on the job market (Mareš, 1994).
- **Incomplete unemployment (underemployment)** includes people that accept part-time jobs working fewer hours than they would prefer or in a job that doesn't make good use of their capabilities thusly lowering the unemployment statistics.
- **False (voluntary) unemployment** concerns people who are registered as unemployed but are working illegally.
- **Potential unemployment** is the category of people who are working but are threatened by imminent danger of losing their jobs. The danger is usually the expectation of being fired by their employers (liquidation, privatisation, restructuring).

**Voluntary unemployment** occurs when free time is more important for a person than work. The job market provides opportunities for people to work but they look for the best possible job for them. **Involuntary unemployment** is the result of rigid jobs. People are willing to work for any wages but there are no job opportunities for them (Buchtová, 2002).

**Work reduction** represents unemployment caused by lack of demand for products of companies or as a result of problems of the economy as a whole. **Job reduction** represents unemployment caused by the introduction of new technologies to production. Professions and occupations go “extinct” and different new skills are required on the job market (Selická, 2015).

Based on the duration of unemployment we recognise **short-term** (0-6 months), **intermediate** (6-12 months) and **long-term** unemployment (more than 12 months) (Matulay, Matulayová, 2004).

**Long-term unemployment** is usually obstructed from finding a job by some “barrier” are disadvantaged and remain in this situation for a longer period of time. In general, long-term unemployment affects mostly inflexible workforce (the more stable was the previous job, the harder it is to get a new one), people with low income, unqualified workforce, women, people with cumulated personal and social handicaps, ethnic groups and migrants, rural population, people with health impairment, young people, fresh graduates and elderly unemployed.

### The impacts of unemployment

Unemployment affects mainly following areas of life of the unemployed (Buchtová, 2002):

- **Standard of living** - unemployment means the loss of income from a gainful employment and living on welfare or social benefits means a decline of the standard of living and financial issues for the unemployed people and their families. Long-term unemployment leads to poverty, social isolation and loss of some social contacts. Social benefits usually do not amount to even a half of previous income.
- **Family** as a social unit is affected not just by the decrease of income but also in other areas like the disruption of family habits, changing the position and authority of the unemployed person in the family, disruption of relationships, lower fertility, limiting social contacts of the family and often the educational role of the family.
- **Structure and perception of time** - unemployment disrupts the usual daily regime, time structure of the day and changes the perception of time. Time loses its importance and value to an unemployed person and it is often filled with boredom or socially unacceptable activities. The disruption of daily routine is especially dangerous to adolescents who do not yet have a firmly established work habits.
- **Physical and mental health** - for many people unemployment is a traumatic life experience. It means the loss of social status and prestige. It evokes the feeling of inutility, uselessness, incompetence and leads to loss of self-confidence. Stress caused by unemployment often has effects on a person’s health. The results of numerous researches prove that the rate of unemployment has correlation with immunity disorders, cardiovascular diseases, disorders of neural system and also the rate of psychological issues and diseases. The higher risk of alcohol, drug or medicinal abuse, excessive smoking, suicidal behaviour and criminality are also listed (Hamráčková, 2014). Economic crisis and unemployment affects not only health conditions of people who lost their jobs but also the behaviour and health of employed people. In crisis employees seem to be healthier but it is caused by the fear of repercussions from the

employers as the employees' fear losing their jobs so they postpone medical examinations, hospitalisation, lengthy rehabilitation etc.

The changes occurring in particular areas of psyche include: change of cognitive and affective processes, changes of satisfying needs, and of behaviour. The most important social consequences of unemployment are: loss of social status, lowered standard of living, social role of an unemployed person, social isolation, and social failure (Vaska, 2004).

These facts should not be absolutized, of course. It depends on each individual, their individual values, morals and economic background how they deal with unemployment. Unemployment is perceived as a serious failure of the system and represents an economic, social and political problem for the society.

Chmura (2016) also analyses so called "social parasitism" as a tolerated way of life of unemployed people that live solely on welfare and impart this pattern of behaviour on the next generations. This situation leads to a gap of unemployment which contains people for whom it is not profitable to work simply because it would mean only a slight financial improvement of income. It seems that high social benefits lead to decreased motivation to find employment. People that for a long period live solely on social benefits (or occasional illegal income) and become dependent on social state are labelled as "underclass" (déclassé, people degraded from their social class). Because their unemployment is not temporary but social benefits become their regular income these people are often secluded from the majority of the population to the margins of society as its unwelcome element and this result in life in poverty.

The Harrison model of the effects of unemployment on mental stability of an unemployed person based on time recognizes (Selická, 2006):

- **Shock** is the initial reaction, refusing the fact of unemployment
- **Optimism** is the period of intensive search of a new job and faith in the future, usually lasts for approximately 3 months
- **Pessimism** is the period of decreased activity in searching for a new job, increasing feeling of inferiority, lasts up until 6 months
- **Fatalism** is the period of growing apathy towards society and employment, refusing basic values of society

A typology of culture of long-term unemployed people has been created (Mikšík, 1999):

- **Tenacious type** – people who are optimistic and plan for the future. This group includes unemployed people with various attitudes: conformist (they perceive unemployment as a temporary state), autonomous (they do not seek employment and engage in their own activities, often studying or volunteering, but this attitude includes also bohemians and homeless people) and speculative attitude (they increase their income with illegal work).
- **Resigned type** – people do not perceive their unemployment as burden and despite uncertain future have a feeling of general satisfaction with their situation as they do not consider it as an urgent problem. After many failed interviews and declined applications motivation and active job search start to fade.
- **Desperate type** – people suffer from unemployment and after many failures in looking for a job they feel useless. They often give up on searching and do not even report to

the employment bureau but in contrast to the previous group they are not satisfied with their situation and they suffer from it.

- **Apathetic type** – the desperate type can be lead to apathy. They have given up on looking for a job, they do not care for themselves, do not plan anything and live a withdrawn life. They can escape reality by abusing drugs and alcohol, often even displaying criminal behaviour.

### Family and unemployment

Unemployment of a family member is as an interference of family's functioning and as a stressor that each family copes with differently. It is important to take into account economic, social, relationship and other important factors that influence the functionality of a family of an unemployed person. Unemployment of a family member can lead to a great crisis of the family and its eventual disintegration. The signs of loss of professional role are: changes of relationships between family members; loss of roles and changes of status; disorganisation and crisis of family's system caused by disruption of the stereotype of family's life and habits; and disruption of family's habits in consumption and the necessity of reduction of needs of all members of the family causes by the lack of funds.

Unemployment is often concentrated and affects families in "weaker" social groups that are often socially handicapped and the risk of disintegration and deprivation is more significant in these families.

Social work with unemployed people has to focus not only on working with an individual or a group as a part of institutionalised social work, but has to focus also on working with the family of the unemployed person whether it is within the frame of an institution or field work in areas mostly at risk. In an environment where unemployment becomes pathological the need for social work is even greater as in this environment unemployment becomes a multigenerational issue and projects into reproductive behaviour.

For successful management of unemployment, it is necessary to recognise its causes, identify its form, understand its potential negative consequences and based on this information choose correct methods and measures to find a solution, prevent it or mitigate it.

### 3.4.2 Ethnicity

The term ethnic is derived from the Greek word ethnos. An ethnic group is defined as a collective that identifies itself and is identified by others with regard to certain common elements, such as language, religion, tribe, nationality, race or a combination thereof, and whose members share a common feeling of identity (Ford, 2010). An indigenous group is a particular type of ethnic group: its members have an established history in a particular territory and have a common language and culture (Stavenhagen, 2008). At least four elements should be taken into account in defining **indigenous people**:

- recognition of identity (sense of belonging to a group)
- common origin (idea of coming from common ancestors)
- territoriality (Traditional occupation of a specific territory)
- the linguistic-cultural dimension (an attachment to a culture, language, worldview and way of life)

#### Ethnicity and language

Ethnic group expresses its culture and social identity through language, because language is intimately associated with mental and ideological processes and the perception of internal and external worlds. Language is a fundamental point of reference by which an ethnic group defines its own identity. Many indigenous cultures have traditional knowledge that is transmitted only orally (Sheet, 2018). Despite the issue of how to deal with data on multilingual individuals, people who report speaking an indigenous language are highly likely to be members of the indigenous group that speaks a certain language as it is more than a simple mean of communication. It is also a central element of culture and the process of socialization (Sheet, 2018). Language is therefore important for studying health care in indigenous groups: it can be used as a proxy for membership of an indigenous group and it is a strong determinant of access to health care (Montenegro, 2006). The presence of a language barrier has been closely linked to limited access to health care that stems from being unable to communicate with health-care personnel. Several studies have documented poor health outcomes are more likely when there are language and cultural barriers between patients and health-care providers (Nerenz, 2009). Language barriers may also influence patients' perception of the quality of care. Conversely, it is also possible to use the criterion of language to indirectly investigate differences in health care associated with these barriers (Paulino, 2019). In Slovakia this barrier in health care is evident with the Roma population that we will focus on in this chapter.

#### Roma population

One of the oldest historical proofs of Roma people - a note from the monastery on Mount Athos in Greece – mentions people called „Athinganoi" (Acinganoi), which have lived in 9th century Greece and they are described as wandering potters, musicians, jugglers and acrobats. This name has most likely been the root word for their name in Slavic languages – Cigán, Cikán, Cygane, and also other languages - Zingari in Italy, Zigeuner in Germany and Austria, Tsiganes in France, Cigányok in Hungary, Tsiggánoi in Greece, etc., used today. The other name given to them by majority population comes from countries where the ancestors of Roma people have settled. They were called

Egyptians based on the legends of their Egyptian origin, which is apparent in the UK – Gypsies, in Spain – Gitanos, in Greece – Gyftoi (Dávidová, 2010). Contemporary term Roma means a man/husband/companion (or woman/wife). However, they are not a homogenous ethnicity, they differentiate substantially based on individual groups or bloodlines. Nevertheless, a significant part of European Roma people declare their unity based on their common representatives and organisations.

Qualified estimates say that there are about 8 million Roma people living currently in Europe (Table 1). They do not have their own country and they differ from the majority above all with their culture and language. Demographically Slovakia is one of the countries with the highest percentage of Roma people (Popper, 2010).

**Table 1.** Average prevalence of Roma population in selected countries

| Country | Average estimate | Minimum | Maximum | Average estimate as % of total population |
|---|---|---|---|---|
| European Union | 6 162 100 | 4 338 700 | 7 985 500 | **1,18%** |
| Bulgaria | 750 000 | 700 000 | 800 000 | **9,94%** |
| Slovakia | 490 000 | 380 000 | 600 000 | **9,02%** |
| Romania | 1 850 000 | 1 200 000 | 2 500 000 | **8,63%** |
| Hungary | 750 000 | 500 000 | 1 000 000 | **7,49%** |
| Turkey | 2 750 000 | 500 000 | 5 000 000 | **3,78%** |
| Czech Republic | 200 000 | 150 000 | 250 000 | **1,90%** |
| Spain | 750 000 | 500 000 | 1 000 000 | **1,63%** |
| Greece | 175 000 | 50 000 | 300 000 | **1,55%** |
| Ireland | 37 500 | 32 000 | 43 000 | **0,84%** |
| France | 400 000 | 380 000 | 600 000 | **0,62%** |
| Russian Federation | 825 000 | 450 000 | 1 200 000 | **0,58%** |
| Ukraine | 260 000 | 120 000 | 400 000 | **0,57%** |
| Sweden | 50 000 | 35 000 | 65 000 | **0,53%** |
| Portugal | 52 000 | 34 000 | 70 000 | **0,49%** |
| United Kingdom | 225 000 | 150 000 | 300 000 | **0,36%** |
| Italy | 150 000 | 120 000 | 180 000 | **0,25%** |
| Finland | 11 000 | 10 000 | 12 000 | **0,21%** |
| Norway | 10 100 | 4 500 | 15 700 | **0,21%** |
| Germany | 105 000 | 70 000 | 140 000 | **0,13%** |
| Poland | 32 500 | 15 000 | 50 000 | **0,09%** |

Source: Council of Europe for Roma Issues

### Cultural differences in upbringing

We cannot forget the different life style and traditional culture of Roma communities. Multiple researches indicate that the upbringing and approach to education in traditional Roma families is considerably different than in the majority population. Functions of family changed in the past decades, but it is still fundamental in primary socialization and upbringing of children.

Following basic characteristics of upbringing in Roma families can be find (Vavrinčík, 2018):

- The upbringing is collectivistic – it is the matter of mother and older siblings, but wider kinship and the whole community also interferes (an essential difference to the majority population, where upbringing is more individualistic, protective and is considered a primarily personal matter of the family).
- The basic principle is the freedom of the child – there are less inhibitors, orders and restrictions than in the majority population, children explore the world on their own, they experiment, and learn by observing the actions in the community (because of this the Roma children are more vivid, playful and relaxed and rarely demonstrate neurotic behaviour, but this behaviour of Roma children is often considered rude).
- Children are not lead to independence and development of an individuality, but are perceived as members of a community, there is much less emphasis on the development of personality and own interests, qualities and skills – because they are part of a large family they will rarely make their own decisions (this educational influence is in stark contrast with the influence of school – this phenomenon is known as double socialization which cannot guarantee a full social integration into society).
- Children are not lead to introspection and self-knowledge which leads to lower rate of empathy – this also impacts the success in school because this approach can lead to apathy, insufficient competitiveness and less effort to improve their own results. Moreover, the family usually does not expect the child to put a lot of effort to school preparation which is also demonstrated by a lower self-discipline. Spontaneity and aimlessness with emphasis on emotionality prevail in their upbringing.
- The gender stereotypes are still considerably present in Roma families in the upbringing of boys and girls and children learn mostly by imitating their parents, they take part in domestic chores very early.
- The family passes on the Roma culture, values, norms and behaviour patterns which differ from the majority culture. For many Roma people from segregated and separated settlements the society is a synonym to the Roma community because they have no possibility to integrate into a higher social class. Roma children are therefore raised for a life in their own community and that limits them and does not prepare them for a life in general society.
- Majority is also convinced that Roma people (Roma parents) do not care about education. The truth is however that every culture in the world values education and upbringing of their progeny but every culture might consider different things to be more important in upbringing and preparation for a life.

### Life expectancy, mortality and lifestyle

» the Roma population is demographically different from the majority European populations insofar as it is noticeably younger — and consistently so across Europe

» life expectancy data is very limited on a national and regional level. Most data are based upon estimates. The most widely cited data stems from the Council of Europe

» Roma experience substantially lower life expectancy compared to non-Roma (up to 20 fewer years).

» some evidence exists suggesting that shorter life expectancy in Roma populations occurs as a result of the broader environmental conditions they experience

» higher rates of infant mortality are reported in some Roma populations (those living in poor housing, with low educational levels and migrant Roma) compared to non-Roma in countries including Bulgaria, the Czech Republic, Hungary, Italy and Slovakia

**Figure 1.** Data collected for this study in the Czech Republic

| | Life expectancy at birth in 2011 | | Average age of death in 2011 | |
|---|---|---|---|---|
| | Roma | Roma | Roma | non-Roma |
| Men | 64 years | 64 years | 59.2 years | 63 years |
| Women | 70 years | 70 years | 65.6 years | 80.2 years |

Source: Insight, 2014.

Overall life expectancy for the Roma community are estimated to be between 5 and 20 years lower. (Italy -20 years; The Netherlands and Romania -12 years; Bulgaria and Croatia -10 years; Hungary -9 years; Spain -7 years; Ireland and Slovakia -5 to -10 years; The United Kingdom -2 to -10 years). 14.6% of the Roma population suffers from a disability or chronic diseases. In Slovakia this number is even higher – 18.8%. 15.5% of Roma population in Europe has been hospitalised over the last year (Dávidová, 2010).

A large percentage of Roma people **smoke** every day (44%). The highest percentage of Roma smokers is in the Czech Republic (58% - 64% men/ 54% women) and the lowest is in Portugal (27% - 50% men/ 4% women)). 56% of overall Roma population has **consumed alcoholic** beverages over the last year. The highest rate of alcohol consumption has been discovered in Slovakia (70%) and the lowest in Portugal (36%). Average age when Roma people start to actively drink alcohol is 17 years of age. Only 54% of Roma people surveyed have regular weight, 27% have been **overweight** and 17% has been **obese.** Men have more problems than women, even though the percentage of obese people is similar.

60% of Roma population conducts **no physical exercise** in their spare time, 29% does it occasionally and 11% exercise regularly (Dávidová, 2010).

### Health care

Roma populations in Europe are also frequently socially excluded, suffer discrimination and consequently face barriers accessing good-quality housing, health care and education. UNDP survey data from 2004 and 20112 on Roma show that:

» 33% of Roma respondents aged 35 to 54 reported health problems limiting their daily activities

» 20% of Roma respondents were not covered by medical insurance or did not know if they were covered

» 66% of Roma said they could not afford prescription drugs compared to 29% of the majority population

» 15% of Roma children under the age of 14 are not vaccinated compared to 4% of children from non-Roma households

Vaccination is a key factor in reducing and eliminating the spreading of infectious diseases. Lack of medical services poses obstacles for segregated communities of Roma population that significantly impact their ability to follow vaccination programs. The percentage of children properly vaccinated by the type of vaccination. The percentage of vaccinated children in Roma population (according to the results of this research) compared to the percentage of vaccinated children in Slovak majority population, 2006 (WHO, 2009).

### The availability of medical services in settlements

In the specific context of the health status of Roma, it is important to understand that the health status of Roma populations, and variations of health status amongst Roma populations in different countries, may be due to factors that are unrelated to a person's status as a member of the Roma population, but may be a result of other socio-economic, cultural or environmental conditions.

For example, in the specific context of Roma accessing regular health check-ups with primary care physicians, uptake of services or lack thereof could be due either to (INSIGHT, 2014):

- barriers created by **social exclusion**, i.e. living far from service providers
- **discrimination**; such as by primary care services preventing Roma without proof of domicile from registering
- the result of a **lack of health literacy** due to barriers in accessing health education programmes and hence limited understanding of the benefits of preventative education
- **cultural definitions of 'ill'** health which decrease Roma engagement with health services unless symptoms arising from serious health problems impact on functioning.

Also Roma may not have adequate access to care because they lack ID cards or other documents required to obtain health insurance (Silva, 2011).

### Roma population in Slovakia

According to researches and strategic documents Roma people in Slovakia are regularly among social groups most at risk of poverty, social exclusion and discrimination. In this part of population there is a combination of multiple disadvantages: poverty caused by unemployment, poverty caused by the lack of education, and poverty caused by demographic conditions and discrimination all occur. The worst situation lies with the part of Roma population living in segregated settlements (Atlas rómskych komunít, 2013). Popper (2010) based on the different characteristics of the way of life of Roma people in Slovakia differentiated tri major group:

**The first group (30%)** is the most socially developed, most educated and most professionally qualified group, whose way of life does not differ significantly from the majority of the. It includes Roma people dispersed and/or integrated in all parts of Slovakia, from rural areas, small towns to metropolitan areas. The most common issue they have to face concerns their ethnicity. They are often exposed to prejudice and stereotypes that the majority population has based on sporadically negative experiences or public cases presented by the media, and projects them automatically on the minority as a whole.

**The second group (40%)** consists of partially integrated Roma people. In some cases, the settlements they live in do not differ substantially from the first group, but they often approximate to the life conditions of the third group. However, from the point of view of integration they are not a really problematic group and their problems can be seen as similar to the part of majority living on the borderline of poverty. In addition to this they are disadvantaged by racial discrimination.

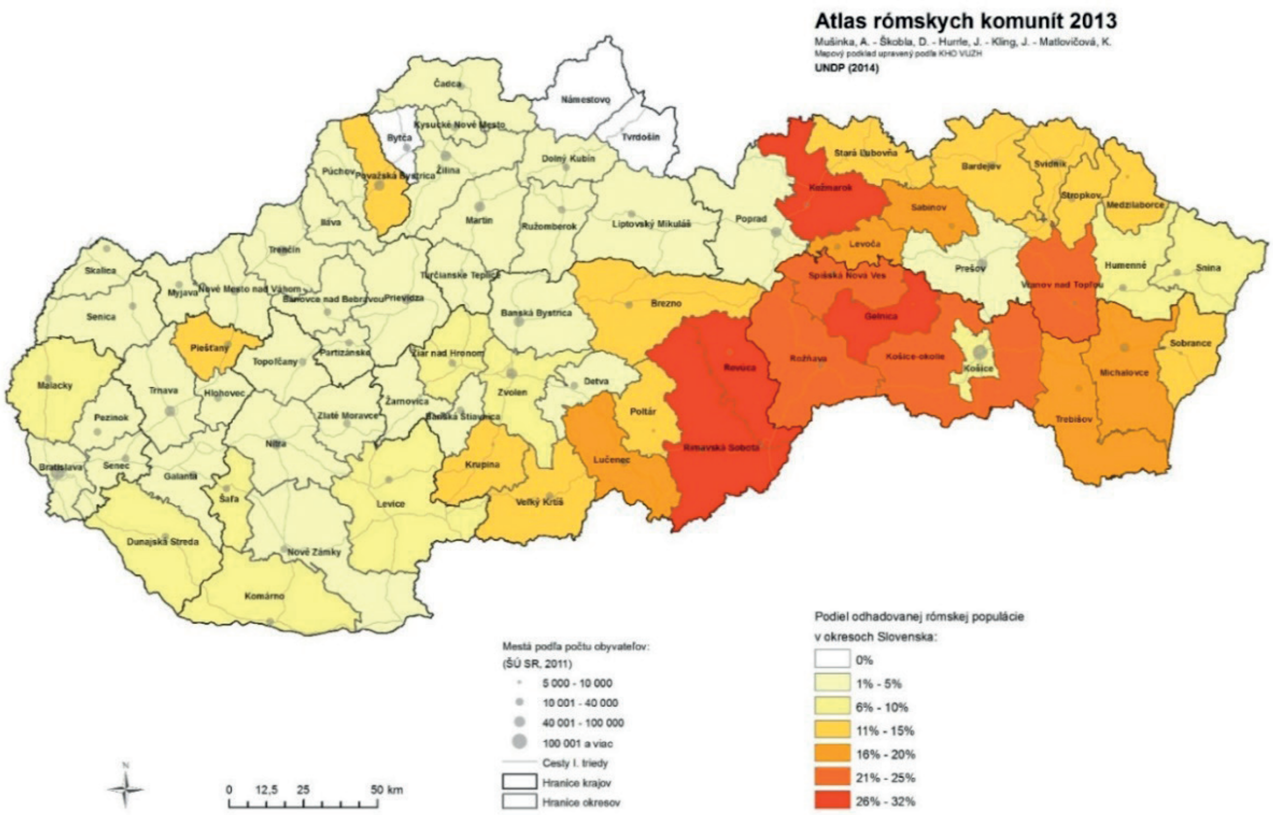
**The third group (30%)** of Roma people lives mostly in Roma localities, settlements and ghettos completely isolated from the majority of the population. Part of its members live in shacks and lower standard housing provisionally built without foundations, water, electricity, and building permission. The other part lives in ghettos in the cities, where most Roma people from the whole city have been gradually concentrated. A significant part of this group lives on or under the poverty level, mostly on social security benefits and welfare. The situation is complicated by the fact that the government itself deepens the segregation with programs of building lower standard flats, with most of these flats being built in remote parts of municipalities, outside the settlements of the majority population. One of the basic determinants of health alongside housing is undoubtedly drinking water. In many Roma settlements there is only one well for all its inhabitants. Water in these wells is not regularly checked and its consumers often discover its contamination only after a breakout of an infection.

## Living conditions

According to the Atlas of Roma communities (2013) there are 803 settlements in Slovakia (there may be more settlements in one town), 246 are inside town residential areas, 324 are on the outskirts of town residential areas and 233 are located outside town residential areas (Fig. 2). Over 60% of these settlements are in Eastern Slovakia (in Košice and Prešov regions) - 484 settlements in total, while Trenčín region (13), Žilina and Bratislava regions (both 19) have the least Roma settlements.

There are more than 400.000 Roma people in Slovakia almost half of which (46.5%) are dispersed amongst the majority population. Over 11% live inside town residential areas, 23% lives on the outskirts of town and 18% lives outside town residential areas (Atlas rómskych komunít, 2013).

**Figure 2.** Roma population in Slovakia



Source: Atlas rómskych komunít, 2013.

There are 14 settlements (1579 Roma people) in Slovakia without any infrastructure – no access to electricity, public water supply network, sewage and gas distribution system. Six of these settlements are located in the Košice region with four of them directly in Košice. Regarding the sources of drinking water 58.8% of Roma population has access to public water supply network, almost a quarter (23.7%) uses wells, 15% has other sources of drinking water, while 7.2% have no access to drinking water. When it comes to the types of sewage system 30% of Roma population has access to general sewage system, 24.7% use cesspits, 0.6% has domestic sewage tanks, while 44.7% live in the absence of any sewage system.

Social exclusion of Roma localities is caused foremost by natural migration of poor Roma families to areas with more affordable housing, and by pushing Roma families out of lucrative areas and assignation of substitute housing in "cheaper" localities with often high percentage of Roma population, directed migration (mostly on part of the municipalities) of rent nonpayers and people considered "inadaptable" or "problematic" to lodging houses and empty flats (Dávidová, 2010).

## Age structure

One of the most notable specifics of the Roma population is its different age structure – the youth of Roma population. Demographically their age structure is the progressive type which is illustrated by their age pyramid. In respect of a large number of children their age pyramid has a wide base and narrow top because of a low amount of seniors. Children under 15 years of age represent over 40% of Roma population (Kalibová, 1999) while in the majority population the ratio is approximately between 19-25%. People in productive age (15-49) is roughly the same in both populations. However, the ratio of people over 50 years of age is three times higher in the majority population. These demographic prognoses demonstrate the growing amount of Roma population. The average age of Roma population in Europe is 25.1 years while the total population average is 40.2 years. For every 100 Roma inhabitants over 65 years there are 1343 Roma children under 15 years of age, in comparison with the rest of the population average of 92.1 children (Dávidová, 2010).

### Reproductive behaviour and child mortality

The reproductive base of Roma women is significantly higher than with most Slovak women. The main reason for this is the fact that Roma women use their whole reproductive age to give birth. Even though some Roma women use contraception not all can afford it and its use is also influenced by the traditional perception of the concept of family.

At a young age there is an intraethnic ceremony (so called mangavipen, valued as much as a civil or religious marriage) after which Roma women try to prove their fertility. This is to avoid shame because this day they often uphold a traditional belief that a Roma man cannot love a woman who cannot provide him with children because a childless family is a sad one and is to be laughed at. An infertile woman can be abandoned by her partner. They usually become mothers between the age of 14 to 19.

Neonatal mortality (first 28 days) is still high in Roma population, in Slovakia it is around 8.4-17.8%. The reasons listed are wrong living habits of pregnant Roma women and insufficient care for infants. The mortality in the first 5 years of life is still around 2.5x higher in comparison to other children. The reasons are again bad social situation and living conditions of many families, bad eating habits and late seeking of medical attention.

### Health status

The most common diseases are hypertension (10.2%), migraines and headaches (10.3%), asthma and bronchitis (8.3%) and cardiovascular diseases (8%). The prevalence of diabetes is surprisingly low (3.7%) that is around 8% in general population, which still seems to be underestimated. The overall morbidity still appears relatively low, for example according to surveys MONIKA (Baráková, 2002) and CINDI (Avdičová, 2005)) up to 30% people suffer from hypertension, 10% to 72% (depending on age) suffer from high cholesterol, 28.3% suffer from cardiovascular diseases. At the same time cardiovascular diseases are the cause of 2/3 of deaths in Slovakia. The factors mentioned together with smoking, lack of exercise and incorrect diet are the most significant risk factors of developing cardiovascular diseases (WHO 2002, in: Jurkovičová, 2005), that are the most common cause of death. Low prevalence of chronic diseases found in this research most likely does not certifity a better state of health of the Roma population, but a low awareness of their own health and a large amount of undiagnosed diseases. In experience of social workers most Roma people living in segregated settlements visit a doctor only in critical or life threatening situations. The reason alongside poverty is Roma population's lack of trust towards official institutions including health facilities and doctors. Roma people in segregated communities often do not even know they are entitled to medical services. They are also discouraged by the price of travelling and the additional payments for medicine. Many Roma people only consider diseases as such when they are obvious and can be directly observed. It is the usual scale of diseases and their symptoms (inflammations, fever, wounds, fractures, poisoning, burns and their consequences, regular infectious diseases, flu etc.). Symptoms of other serious diseases (hereditary, degenerative diseases, autoimmune diseases, tumours or mental illness) are underestimated, overlooked and neglected, often treated only in acute situations. This brings many complications which could be avoided with early diagnostics and adequate treatment (Popper, 2010).

### Work

Approximately 15 % of Roma population in Slovakia has legal employment in comparison to 65% of the rest of the population. There are several important reasons (Vavrinčík, 2018):

- Most Roma people live in less developed regions in central and eastern Slovakia, where the general unemployment rate is higher.
- They cannot meet the qualification requirements. The children enrolled in elementary school are less prepared, they have higher absence rate than majority population, have worse results and often have to repeat classes. Some do not even finish elementary school and many do not follow their studies at high school or drop out early. This means that the amount of Roma students at universities is extremely low. Lower education level obviously leads to further problems and lack of success in their future. It makes finding a well-paid job that could provide a decent accommodation and higher life standard very difficult. The outcome is that this vicious cycle of poverty repeats itself and is passed from one generation to another (a phenomenon known as **cyclical poverty**).
- Inability to commute to work
- Employment they gain is usually Unstable, temporary and eventually leads back to unemployment
- Extremely high discrimination in the job market. In many cases even if a Roma person possesses necessary qualification a non-Roma applicant is hired. In some cases the job offers specifically say “gypsies” should not apply. Their chance of getting invited to a job interview is 50% lower.

## Conclusion

The life style of many Roma people is diametrically different from the style of the majority population. A large part of Romas living in marginalised settlements has never been on a vacation, does not have a habit of active leisure and has exercised only in childhood. To this incorrect life style adds also the consumption of unhealthy fast-saturating food. This condition is caused by traditions and more importantly the unreachable prices of healthy groceries. Hygiene is also a factor that impacts the health situation of Roma people. For example, dental hygiene is often neglected, as a large part of Roma population is not used to budgeting for toothbrush and toothpaste. The same applies to cosmetics which are on the bottom of their needs. Isolation of their settlements causes a severe ignorance of the availability and entitlement to health care as well as their distrust to official health institutions. Because of hindered access to health care due to numerous factors (a long distance of health care facilities, insufficient hygiene, sings of discrimination in health care facilities, financial inaccessibility of prescribed medicine, communication difficulties between health care workers and Roma patients etc.) a part of Roma population only seeks medical attention in most severe health conditions (Popper, 2010). Researches in the field of medicine show that the importance of participating approach to health is on the rise in the majority population. Healthy life style and due prevention is becoming a cultural norm that reflects the current zeitgeist. As most of Roma population do not uphold the rules of prevention and healthy life style their approach differs greatly and causes lesser quality of health and also hinders their social position and their integration with the majority population (Dávidová, 2010).

### 3.4.3 Migration

People have been migrating for thousands of years. There is a steady increase in the global number of refugees and migrants, including in the WHO European Region. Globally, in 2017, 258 million people (approximately one in every 30) lived outside their country of origin. In the WHO European Region, almost 10% of the population of almost 920 million are international migrants, accounting for 35% of the global international migrant population (WHO, 2018). Many indicators suggest that the number is going to increase in the future. Over the past few years the topic of international migration has become the focal point of interest of the media, politicians and general public mostly with regard to the migrants coming to Europe (Jeleňová, 2017).

On one hand intercultural interaction can enrich us but on the other hand it can present a significant challenge because of the differences between cultures. Psychologists studying cultures confirm that cultural similarities and differences influence the way we perceive ourselves and other people and how we communicate with people of other cultures (Liu, Gallois, 2014). To effectively handle intercultural interaction it is vital to know the basic norms of their speech, how these norms depend on the situation and that people with a different cultural background (speaking a different language) may have different expectations regarding language and behaviour (Bowe, Martin, 2007).

Maude (2011) explains people do not communicate in a vacuum and the intercultural communication is affected by their engrained values, persuations and practices of their culture. The focus is therefore also aimed at cultural values and their selected models.

### Types of migration

Jeleňová (2017) defines different types of migrations:

**Based on time:**

- Short-term migration - 3-12 months, if it is not because of aforementioned reasons or even during a longer stay with a singular purpose (e.g. international students).
- Long-term migration – moves for more than a year and the new country becomes the country of residence

**Based on choice:**

- Voluntary migration – free movement of people, e.g. family unification, education, work
- Involuntary migration – refugees, asylum seekers, people from disaster areas

The possibility of choice significantly affects coping with stress related to migration.

**Other types of migration:**

Based on the direction, motives, legality of stay.

### Migration in numbers

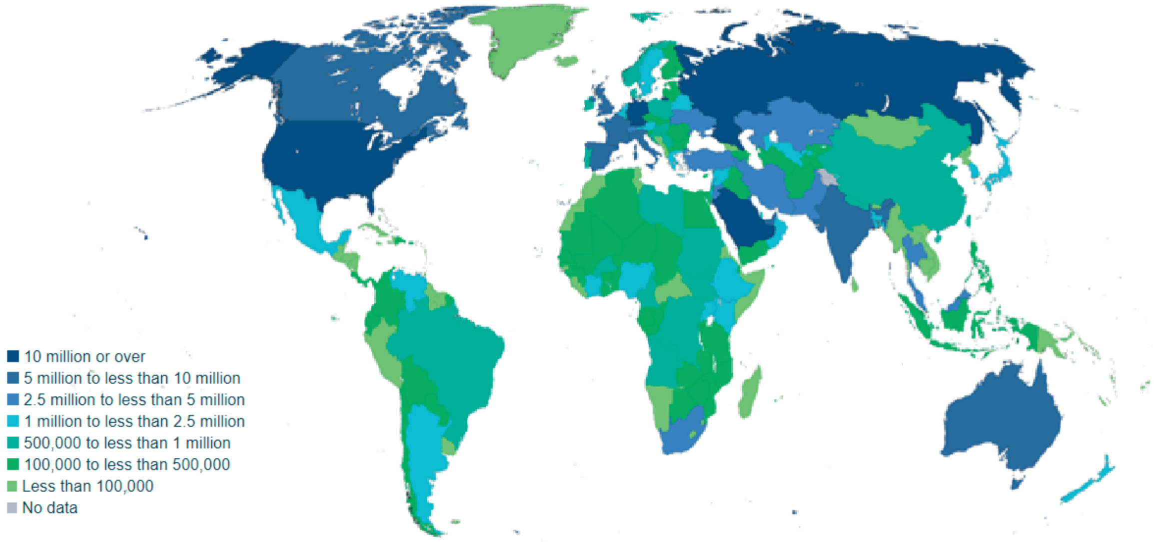
International migrant is "any person who changes his or her country of usual residence" (United Nations, 1998). International Organization for Migration (IOM) defines a migrant as any person who is moving or has moved across an international border or within a State away from his/her habitual place of residence, regardless of

- the person's legal status
- whether the movement is voluntary or involuntary
- what the causes for the movement are
- what the length of the stay is

According to UN guidelines (1998) for the international migration statistics migrant is defined as "any person that changes the country of his/her residence". Based on this definition temporary stay during a vacation, visit to friends or relatives, business trip, health care or religious pilgrimage is not considered migration as it does not require the change of residence.

In a poll taken in autumn of 2016 in 34 countries and territories (Standard Eurobarometer 84, 2016) migration was selected as the most serious issue the European Union was facing at the time. Several science fields are devoted to understanding migrants and the process of migration, among other sociology, political sciences or economy.

**Figure 3.** Migration in numbers by UN.



Map data source : Geospatial Information Section, United Nations
Disclaimer: The designations employed and the presentation of material on this map do not imply the expression of any opinion whatsoever on the part of the Secretariat of the United Nations concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries.Dotted line represents approximately the Line of Control in Jammu and Kashmir agreed upon by India and Pakistan. The final status of Jammu and Kashmir has not yet been agreed upon by the parties. Final boundary between the Republic of Sudan the Republic of South Sudan has not yet been determined. A dispute exists between the Governments of Argentina and the United Kingdom of Great Britain and Northern Ireland concerning sovereignty over the Falkland Islands (Malvinas).

Source: UN, 2017.

In 2017 United Nations estimated the amount of migrants globally to be over 258 million of international migrants (Fig. 3), with the highest share in Asia (79,6 million) and Europe (77,9 million). If we look at the numerical values, most migrants live in the USA (49,7 million), followed by Saudi Arabia (12,2 million), Germany (12,1 million), Russia (11,6 million), United Kingdom (8,8 million), UAE (8,3 million), and France (7,9 million) (United Nations - International migrant stock 2017). The number of international migrants has increased by 60% since 1990 until 2015, while in 2017 they represented 3,4% of the global population (United Nations). With the exception of small island countries, countries with the highest percentage of migrants are UAE (88,4%), Kuwait (75,5%), Qatar (65,2%), Liechtenstein (65,1%), China (Macao SAR) (56,8%) and Andorra (53,3%).

According to this statistic in Europe the percentage of migrants is 10,5% of the total population (Table 2). The highest percentage of international migrants in Europe was in Liechtenstein (65,1%), Andorra (53,3%), Monaco (54,9%), Luxembourg (45,3%) and Switzerland (29,6%). The percentage of migrants in Slovakia is very low - 3,3%, the lower is only in five other countries: Albania (1,8%), Poland (1,7%), Bulgaria (2,2%), Romania (1,9%) and Bosnia and Herzegovina (1,1%).

**Table 2.** Situation on migration in the EU.

| Countries in EU | Migrants | % |
|---|---|---|
| Luxembourg | 264 073 | 45,3% |
| Austria | 1 660 283 | 19,0% |
| Sweden | 1 747 710 | 17,6% |
| Ireland | 806 549 | 16,9% |
| Germany | 12 165 083 | 14,8% |
| United Kingdom | 8 841 717 | 13,4% |
| Spain | 5 947 106 | 12,8% |
| France | 7 902 783 | 12,2% |
| Belgium | 1 268 411 | 11,1% |
| Greece | 1 220 395 | 10,9% |
| Italy | 5 907 461 | 10,0% |
| Finland | 343 582 | 6,2% |
| Hungary | 503 787 | 5,2% |
| Czech Republic | 433 290 | 4,1% |
| Slovakia | 184 642 | 3,4% |
| Bulgaria | 153 803 | 2,2% |
| Romania | 370 753 | 1,9% |
| Poland | 640 937 | 1,7% |

Source: EU, 2017.

## Process of migration

Process of migration begins before the actual exit from a country, and it has three broader phases (Bhugra, 2005):

1. Pre-migration phase – includes the decision to move and preparation

2. Physical relocation from one place to another

3. Refers to the absorption of migrants into new society and learning new social and cultural rules and roles.

After moving to a new country, migrants can experience psychological or physical discomfort. This discomfort is the reaction to their view of life and behaviour patterns not being appropriate or as effective in their new country as they were at home (Jeleňová, 2017).

The term acculturative stress was introduced by Berry (1997) as an alternative to the term culture shock (Oberg, 1960). K. Oberg (1960) defined culture shock as "anxiety arising from the loss of all our familiar signs and symbols of social contact". These signs and symbols represent everything we use to orientate in ordinary everyday situations even if we do not notice it – words, gestures, facial expressions, habits or norms we acquired during our lives as a part of our culture. Even though the term culture shock is older and more frequently used, especially in popular literature, Berry (1997, 2005) suggests the use of the concept of acculturative stress. This term relates to type of stress caused by stressors associated with the process of acculturation (Berry, 1987). Reactions of migrants to stress are not the uniform as they can differ in intensity and in quality. Schmitz (1997) lists some typical reactions to acculturative stress identified in literature: anxiety, homesickness, depression associated with feelings of estrangement and hopelessness, psychosomatic diseases or a general proneness to diseases and psychosocial inadaptability. Typical symptoms experienced by people in new and unknown culture are also psychological disorders (depression, insomnia etc.), relationship issues (with work colleagues etc.), insecurity regarding role and status, shock and disgust caused by some cultural practices usual in their new culture and homesickness (Maude, 2011). Smart and Smart (1995) identified certain important characteristics associated with acculturative stress in the population of Hispanic migrants in USA. Acculturative stress affects (disrupts) physical health, decision making (possibilities perceived as feasible are limited), work process, is associated with being stuck in a role (stereotypes and expectations of the dominant culture) and can increase when migrants get only minimal reward for learning English. The intensity of reactions to a new culture depends on a number of factors: the degree of control, interpersonal factors (the scale of social networks), biological factors (physical condition), intrapersonal factors (age, language ability, independence, previous experience abroad etc.) and current geopolitical factors (Steward, 1988). According to Berry et al. (1987) the relation between acculturation and stress is moderated by factors such as the character of general society (tolerant to cultural diversity v. pressure to assimilate), type of acculturational group (refugees, voluntary migrants e.g.), various demographic, social and psychological characteristics of an individual, but also the chosen strategy of acculturation.

Acculturation is not only a reaction to changes that individuals face in cultural context but it can also be perceived as active coping with challenges that migrants face when confronting cultural changes (Schmitz, 1997).

Berry created a model with which he describes acculturational changes of attitude and behaviour with two independent dimensions. First represent maintain or loss of original culture and identity, the second represents participation or acceptance of aspects of a new culture.

Berry (2001, 2005) describes four strategies of acculturation from the point of view of migrants. Assimilation occurs when individuals lose their original culture and identity and gain a new one. If migrants try to maintain their original cultural identity and at the same time participate in the life of the new cultural group, we speak of integration. Separation means that migrants value maintaining their original culture and identity and avoid contact with members of their new society. The fourth strategy – marginalisation – is defined as giving up their original cultural identity and having little interest in establishing relationships with members of the host society (often because of exclusion or discrimination). The preferences of strategies can vary even among members of a single family.

**Figure 4.** Four acculturation strategies of ethocultural groups (from the point of view of migrants).

| | | Maintaining original culture and identity | |
|---|---|---|---|
| | | + | - |
| Seeking relationships with the other group | + | integration | assimilation |
| | - | separation | marginalisation |

Source: Jeleňová, 2017

The described strategies from the point of view of the minority group are based on a presumption that migrants can choose how to acculturate (Berry, 2001, 2005). Dominant group may support or even enforce a certain strategy. In that case we use different terminology. A strong contact between groups and low maintenance of cultural heritage leading to one group absorbing the other thus creating a mixture is called a "melting pot" by Berry. Multiculturalism is a strategy when a society is open to cultural diversity and enables migrants to choose their degree of integration. Segregation occurs when the dominant group enforces separation on migrants. The enforcement of marginalisation is called exclusion.

**Figure 5.** Four acculturation strategies from the point of view of the dominant group

| | | Maintaining original culture and identity | |
|---|---|---|---|
| | | + | - |
| Seeking relationships with the other group | + | multiculturalism | „melting pot“ |
| | - | segregation | exclusion |

Source: Jeleňová, 2017

## Culture, communication and intercultural communication

The term "intercultural" literally means "between cultures" so the is naturally the question of defining the concept of culture. In everyday language the term culture can have various meanings; it relates to trends in art, fashion, rituals, heritage or people originating from a certain country. Sometimes it is inappropriately identified with terms nationality or ethnicity. It is necessary to mention that culture is not only based on nationality or ethnicity but it can be linked to a region or religion, simply with something that a certain group of people have in common (Jeleňová, 2017).

The term culture has been defined in many ways by experts from various fields. Jeleňová (2017) mentions Kroeber and Kluckhohn (1952) have defined six categories of definitions of culture that have been discussed until then:

a) Descriptive definitions emphasise the enumeration of content, activities and behaviour associated with culture

b) Historic definitions put an emphasis on the heritage or tradition of a group of people

c) Normative definitions are concerned with the rules and lifestyle of individuals in a society. They include definitions emphasizing ideals or values and behaviour associated with them.

d) Psychological definitions emphasise adaptation, problem solving, learning, habits or highlight the psychological aspect

e) Structural definitions put an emphasis on pattern and organised elements of culture

f) Genetic definitions view culture as a product or artefact created by humans.

Culture can be defined as a relatively stable (however with potential to change over time) "depository of knowledge, experience, persuasions, values, attitudes, meanings, social hierarchy, religion, perception of time, roles, spatial relations, concepts of the universe and material objects and property gained by a group of people over the course of generations through individual and group effort" (Samovar, 2003).

A briefer definition by Matsumoto and Juang (2013) defines culture as "unique system of meanings and information shared by a group and carried across generations that enables the group to satisfy basic needs of survival, pursuit of happiness and well-being and enables finding the meaning of life."

Hofstede (2001) defines culture with an analogy with computers as collective programming of the mind that distinguishes the members of one group or category of people from others.

The common theme of the definitions listed above is the idea of shared persuasions, norms or values by a group of people. Important point of the definitions of cultures is also the notion of learnt system of meanings passed on by generations and the ability of culture to empower the potential of individuals to adapt to their environment (Ting-Toomey, 1999).

## Cultural values and typology of cultures

Cultural values are an important factor that represents the basis of culture. Cultural group differ in their perception of good and evil, what is moral and immoral, permitted and prohibited etc. Values represent a set of deeply rooted persuasions shared by a cultural group that reflects their world view (Martin, Nakayama, 2013). Hofstede defines them as "broad tendencies to prefer certain states of affairs over others" (Hostede, 2001).

"Culture is a network shared by a group of people that identify with the given culture." However, it is necessary to keep in mind that culture is dynamic and constantly evolving, changing with trends and modern habits, what is demonstrated also by the intergenerational differences (Launikari - Puukari, 2009).

There are many variables we could focus on. Not all of them are equally distinct in different cultures, in some they are remarkably similar and in others they are different. Cultural variables and models represent general definitions of some of the most noticeable characteristics of human behaviour and persuasions in the scope of infinite variability of human cultures therefore they can be trusted only to a certain point. Despite this fact they provide useful tools and methods that help us understand and explain the main attributes of various cultures different from ours (Launikari-Puukari, 2009).

### 5-D Model

5-D Model was created by Dutch expert Geert Hofstede. Based on many years of professional experience he realised how different and specific are various factors of cultures. According to Hofstede national culture corresponds with individuals' country of origin. Every person that meets members of another nation perceives their differences – recognises a different language, behaviour, clothing etc. Even laymen are aware that people of various nationalities have their typical national mentality (Prucha, 2010). Based on his empirical research for which he collected over 116.000 questionnaires in more than 50 countries he designed four dimensions of national culture to which two more were added later. The first four dimensions were: **power distance, uncertainty avoidance, individualism – collectivism** and **masculinity – femininity** that comprised the four-dimensional model. As he continued his research he later added **long-term – short-term orientation** as the fifth dimension and in 2010 he -added a sixth dimension: **indulgence - self-restraint**. All of these dimensions can be expressed with a numeric index so they can be easily compared to other nationalities. Here is a closer look on these dimensions according to Prucha (2010).

- **Power distance**

  This dimension of national culture represents the intensity with which citizens, institutions and organisations expect and accept that power is divided unequally as it reflects the distance between people in different social situations (e.g. between superiors and subordinates). In societies with small power distance everyone has equal rights and inequality is considered unacceptable. Countries with small power distance are e.g. Austria, Denmark, Ireland and New Zealand; on the other hand, countries with large power distance are e.g. Malaysia, Philippines, Mexico, France and Turkey.

- **Uncertainty avoidance**

  According to Hofstede uncertainty avoidance relates to the stress members of the society feel when facing uncertain or unknown situations. It indicates their attitude towards changes that bring risky or uncertain situations and how do they try to avoid these changes (e.g. change of employment). Countries with significant uncertainty avoidance are e.g. Greece, Portugal, Japan or Belgium, on the contrary countries like Singapore, Denmark, United Kingdom or Hong Kong view these changes in a positive way.

- **Individualism - collectivism**

  This index explores the degree to which people in a society are integrated into groups. On the individualist side we find cultures in which the ties between individuals are loose: everyone is expected to look after themselves and their immediate family. On the collectivist side we find cultures in which people from birth onwards are integrated into strong, cohesive in-groups, often extended families (with uncles, aunts and grandparents) that continue protecting them in exchange for unquestioning loyalty, and oppose other in-groups. Individualistic countries are e.g. USA, United Kingdom, Canada, Australia, Belgium or Netherlands, collectivistic countries are e.g. Guatemala, Ecuador, Pakistan, Indonesia or Portugal.

- **Masculinity - femininity**

Masculinity versus its opposite, femininity refers to the distribution of values between the genders. The assertive and competitive pole of values has been called 'masculine' and the modest, caring pole 'feminine'. The women in feminine countries have the same modest, caring values as the men; in the masculine countries they are somewhat assertive and competitive, but not as much as the men, so that these countries show a gap between men's values and women's values. In masculine cultures there is often a taboo around this dimension. This dimension also reflects on the equality of women in a workplace. Masculine countries are e.g. Japan, Austria, Italy, Switzerland or Mexico, while Hofstede lists Sweden, Norway, Denmark, Netherlands or Finland as feminine countries.

*Dominant values are also projected in the opinion on migrants – masculine societies expect the migrant to assimilate (migrants should give up their original culture) while feminine societies prefer integration (migrants should only assimilate aspects of their culture that are incompatible with the laws of their host country) (Jeleňová, 2017).*

- **Long-term – short-term orientation**

According to Hofstede long-term dimension of the culture means nurturing people's characteristics relating to future rewards, perseverance, systematic work and the willingness to sacrifice for the benefit of long-term goals. Short-term perspective focuses on immediate results and goals. This dimension is tied to values and attitudes reflecting the differences between the "Western" and "Eastern" culture (mostly in comparison to Confucian long-term oriented philosophy). Long-term oriented countries are e.g. China, Japan, Hong Kong or South Korea, while countries like Pakistan, Nigeria, Canada, USA or United Kingdom are considered short-term oriented.

- **Indulgence - self-restraint**

The sixth dimension has been added in 2010 and is more or less complementary to long-term – short-term orientation; in fact, it is weakly negatively correlated with it. This dimension is essentially a measure of happiness; whether or not simple joys are fulfilled. Indulgence stands for a society that allows relatively free gratification of basic and natural human desires related to enjoying life and having fun. Restraint stands for a society that controls gratification of needs and regulates it by means of strict social norms. Indulgent societies believe themselves to be in control of their own life and emotions; restrained societies believe other factors dictate their life and emotions. Indulgence tends to prevail in countries like USA, France, United Kingdom, Mexico or Brazil, restraint is prevalent in countries like Poland, Japan, China, Pakistan etc.

### Six mental frames

Expanding on the Hofstede model of cultural dimensions we can divide society into six basic different mental frames that influence people's behaviour and actions. They are comprised of combined Hofstede's dimensions to serve practical and current use for better characterisation of people from different countries. Here is the definition of these particular models according to the explanation of Launikari-Puukari (2009):

| | | |
|---|---|---|
| **Competition model** | Directed by the motto "winner takes it all". It is specific to highly competitive cultures with low power distance and uncertainty avoidance and strong individualism and masculinity | Anglo-Saxon countries (UK, USA, Australia and New Zealand) |
| **Network model** | Based on consensus. It is prevalent in countries with similarly low power distance and strong individualism as the first model, but instead of strong masculinity in this there is strong feminity. In this model everyone regardless of their gender and social role is expect to participate in the decision-making process. | Netherlands and Scandinavian countries |
| **Family-like organisation** | Depends on loyalty and is based on hierarchic order of its members. It is characteristic for culture with high power distance, strong collectivism and masculinity based on dominant paternalistic leaders. | China, Hong Kong, India, Indonesia, Malaysia, Philippines, Singapore |
| **Pyramid organisation** | Similar to the previous model in loyalty and maintained hierarchy but it also follows unwritten order. This model represents higher power distance and uncertainty avoidance and stronger collectivism. | Latin America (mainly Brazil), Greece, Portugal, Russia, Thailand |
| **Solar system** | Defines cultures with strong hierarchy and impersonal bureaucracy. They also rely on higher power distance but they have stronger individualism. | Belgium, France, northern Italy, Spain and French-speaking part of Switzerland |
| **Well-oiled machine** | Includes cultures with strong emphasis on order. They are distinct by their low power distance and high uncertainty avoidance. People of these cultures strictly follow careful procedures and rules. Hierarchies are not very important to them. | Austria, Germany, Czech Republic, Hungary, German-speaking part of Switzerland |

### 7-D Model

In 1994 Trompenaars revised Hostede's 5-D model and created the theory of three main cultural variables: the attitude towards time, attitude towards environment and interpersonal relations that consist of five subcategories (Launikari- Puukari, 2009).

**Attitude towards time** – relates to the importance people attribute to the past, present and future and the organisation of time. In Japan, USA and some other countries past is not as important as the present or the future. On the contrary e.g. in France or Spain the results in the past greatly affect the present and the future. The organisation of time represents another divergent factor. Some individual (so called "sequential") usually focus on one activity and after it is finished move on to the next one. This type is frequent in USA, United Kingdom or Netherlands. On the other hand, there are individuals that tend to pursue multiple causes at once and have a synchronic attitude towards the organisation of time. They are common in Mexico, France or Italy among other countries.

**Attitude towards environment** – over the course of time the fear of nature that could end the human existence has shifted towards the opposite: the fear of humans destroying nature. There are two opinions on how to protect the environment. Some societies, e.g. Brazil, Portugal, Hungary, Nigeria or China, try to protect the nature by developing specific technologies, while others like Japan, Egypt, Austria, Singapore or Sweden prefer to pass protective legislation in an effort not to change the nature anymore.

**Interpersonal relations:**

| **Universalism** | | **Particularism** | |
|---|---|---|---|
| Switzerland, Canada, USA, Sweden, Australia, Netherlands | represents the duty to respect universal standards and treat everyone equally | based on evaluating the specific circumstances of every particular case. There are strict rules in these cultures but people often find reasons to break them as a result of special circumstances. | Venezuela, Korea, Russia, China, India |
| **Individualism** | | **Communitarianism** | |
| Israel, Canada, USA, Denmark, Netherlands, Finland, Australia | refers to people regarding themselves as individuals | refers to people regarding themselves as part of a group | Egypt, India, Japan, France, Mexico, China |
| **Neutral** | | **Emotional** | |
| Ethiopia, Japan, Hong Kong, China | people from neutral cultures tend to be more objective and impartial | people from affective cultures express their emotions openly even in the workplace | Kuwait, Egypt, Spain France, Italy, Russia, Argentina |
| **Specific** | | **Diffuse** | |
| Sweden, Netherlands, Denmark, UK, Canada, USA | individuals have a large public space they share with others and small private space they guard closely and share with only close friends and associates | public space and private space are similar in size and individuals guard their public space carefully, because entry into public space means entry into private space as well | China, Nigeria, Kuwait, Venezuela, Singapore, South Korea |
| **Achievement** | | **Ascription** | |
| Canada, Australia, UK, Sweden, Denmark Germany | people are accorded status based on how well they perform their functions | status is based on who or what a person is | Egypt, Argentina, Czech Republic, South Korea, Poland, Japan, China |

### Predictors of migrant adaptation

Intercultural adaptation of migrants is very important for host countries in the current world. Migrants often prefer the strategy of integration (Kunst, 2013). This strategy seems to be most effective. Metaanalysis of 83 studies (Nguyen, 2013) shows strong positive relation between biculturalism (dual cultural orientation) or integration and psychological and sociocultural adaptation of migrants. Integrated people for example demonstrate better physical and mental health (Jang, 2007), stronger feeling of competence (van Selm, 1997) or higher self-esteem (Pham, 2001). Migrants who chose integration and assimilation report higher rate of well-being in comparison to those who chose the strategy of separation or marginalization (Berry, 2016). Adolescents who use the strategy of separation show higher rate of antisocial behaviour like aggression, revolting against norms, drug abuse and occasional consumption of alcohol that can be understood as a nostalgic reaction to the loss of original cultural identity (Jeleňová, 2017).

The adaptation of migrants to a new culture can be affected by their age with younger migrants being more likely to choose integration (Jang, 2007). The age in which they move has a negative correlation to mental health, life satisfaction and contact with host culture which means a lower age is beneficial to psychological adaptation (Polek, 2008).

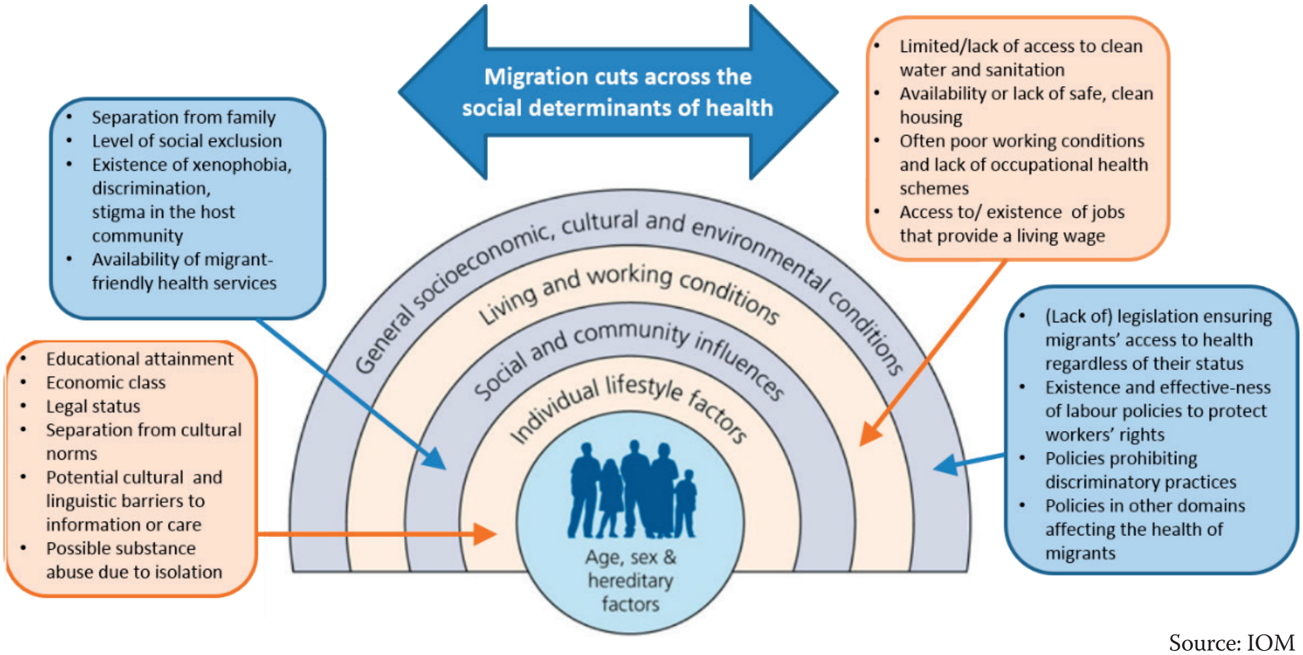
Intercultural adaptation of migrants is affected by a number of factors as not only demographic factors or their personality are important. To understand acculturation it is necessary to understand the context in which it occurs taking into consideration the characteristics of migrants, their country of origin and their host country, their knowledge of a new language or the socioeconomic status and resources at their disposal (Schwartz, 2010).

### Social Determinants of Migrant Health

Individual lifestyle factors, social and community influences, living and working conditions, general socio-economic, cultural and environmental conditions determine the state of heath of individuals. These social determinants of health are mostly responsible for health inequalities and inequities within and between countries. Conditions surrounding migration often fuel health inequities and may expose migrants to increased health risks and negative health outcomes: restrictive migration policies cause an increasing number of migrants to travel in a risky manner using irregular means of transportation; economic downturns and anti-migrant sentiments allow them limited access to health care, education, and safe and dignified working and living conditions.

Migrants have diverse backgrounds and include both international and internal migrants, regular and irregular migrants, individuals migrating for work or educational opportunities, internally displaced persons, refugees, asylum-seekers, and victims of trafficking. These sub-populations have varying levels of risk and vulnerability based on the circumstances surrounding their migration process. Most migrants face a combination of legal, social, cultural, economic, behavioural and communication barriers which put their physical, mental, and social well-being at risk. These determinants are more severe for women, minors, and lower skilled migrants, especially if in an irregular situation. However, even migrants with legal documents and a higher socio-economic position may experience challenges and limitations to accessing services due to language and cultural differences, as well as institutional and structural obstacles or psycho-social stressors.

**Figure 6.** Social determinants of migrant health.

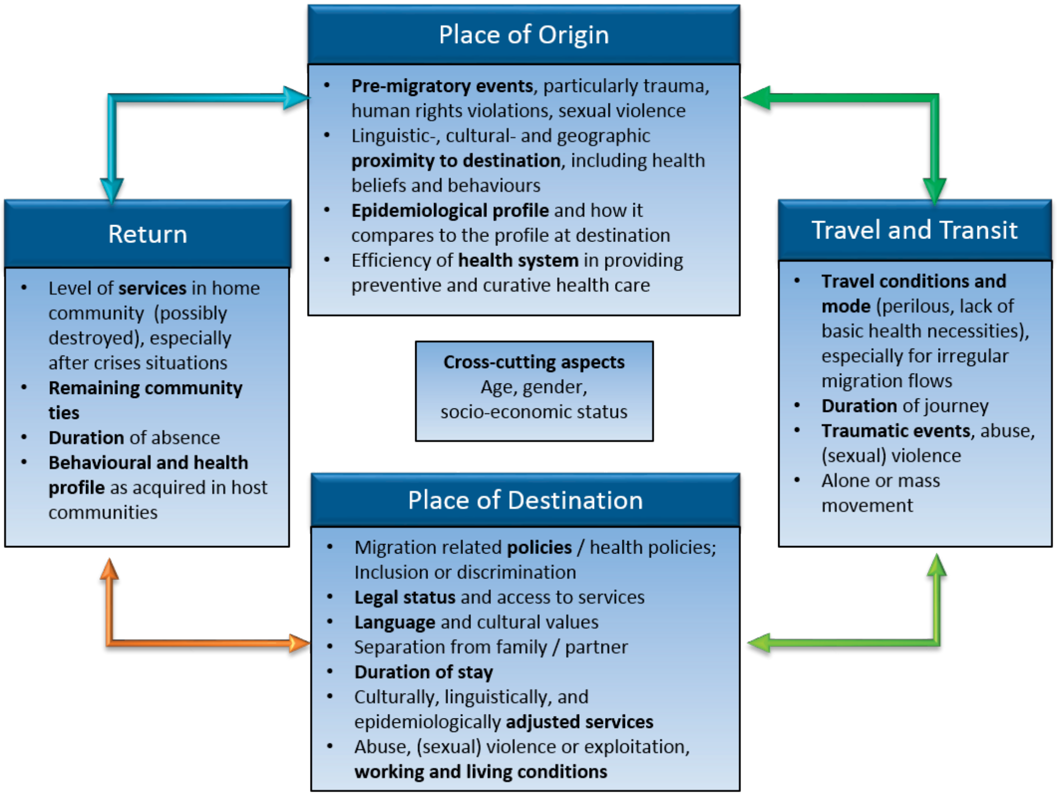


Source: IOM

## The migration process and health outcomes

The health of a migrant is shaped by the experiences and situations in the place of origin, during transit, in the place of destination, and in some cases during the return to the place of origin (Fig. 7):

**Figure 7.** The migration process and health outcomes.



Source: IOM

It is important to recognize the need of coherent migrant-inclusive health policies to address health inequalities and risks affecting migrants and to ensure that they are able to lead healthy lives and contribute as productive members of society (IOM).

### 3.4.4 Homeless

Barták (2011) notes that Levison does not present homelessness as a new phenomenon. Homelessness is not uncommon in human society and the first mentions of homelessness are more than 10.000 years old and publicly available in various writings, songs, religious texts, chronicles etc. Rheinheimer (2003) reports the amount of wandering people in Europe comprised 2-10% of the population (e.g. in 18th century Germany where because of a crisis many people lost their homes). He also quotes Martin Luther who mentions that even in medieval times there was limited solidarity with these people (only the domestic, resident, „truly" poor people deserve help, not strangers, foreigners and beggars – they should not be tolerated). Help and care for the homeless was for a long time mostly random and sporadic. Levison sees a certain change in the passing of social laws in the UK in 1601 which were very stern by today's standards. The punishment for wandering was imprisonment and hard work was considered the "medicine" for homelessness. Only in the 20th century there was a significant alleviation of these laws in the UK (Barták, 2011).

#### Definition

Homelessness is perceived and tackled differently according to the country. European Typology of Homelessness and housing exclusion (ETHOS) was developed through a review of existing definitions of homelessness and the realities of homelessness which service providers are faced with on a daily basis. ETHOS categories therefore attempt to cover all living situations which amount to forms of homelessness across Europe:

- rooflessness (without a shelter of any kind, sleeping rough)
- houselessness (with a place to sleep but temporary in institutions or shelter)
- living in insecure housing (threatened with severe exclusion due to insecure tenancies, eviction, domestic violence)
- living in inadequate housing (in caravans on illegal campsites, in unfit housing, in extreme overcrowding).

Barták (2011) lists one of the definitions of homelessness according to the United Nations that describes "absolute homelessness as conditions in which people live without physical housing, sleep outside, in cars or houses that are about to be demolished. Relative homelessness is defined as conditions in which individuals have physical housing but it does not meet basic hygiene and safety standards. … According to this definition the homeless are people who sleep in homeless shelters and people whose situation meets the definition of absolute homelessness." Other definitions also include people who do not have a household and means to pay rent and live in bad conditions, or live at their friends' house or family etc.

As there is no unified definition of homelessness it is almost impossible to measure it precisely. There are various statistics around the world but the numbers are never accurate (as they change on a daily basis, it is difficult to decide who should be included in them, not all homeless people visit shelters or seek help, they migrate etc.).

### The causes and risk factors of homelessness

It is necessary to know the causes of homelessness to create public and social policies dealing with the issue of homelessness.

Barták (2011) lists a few types of their classification:

- Hradecká and Hradecký recognise **objective and subjective determinants**
- Classification to **structural and individual determinants** is often used abroad
- There is also classification to **social, economic, psychological determinants** etc.

Barták analyses structural and individual causes based on Levison and Fitzpatrick:

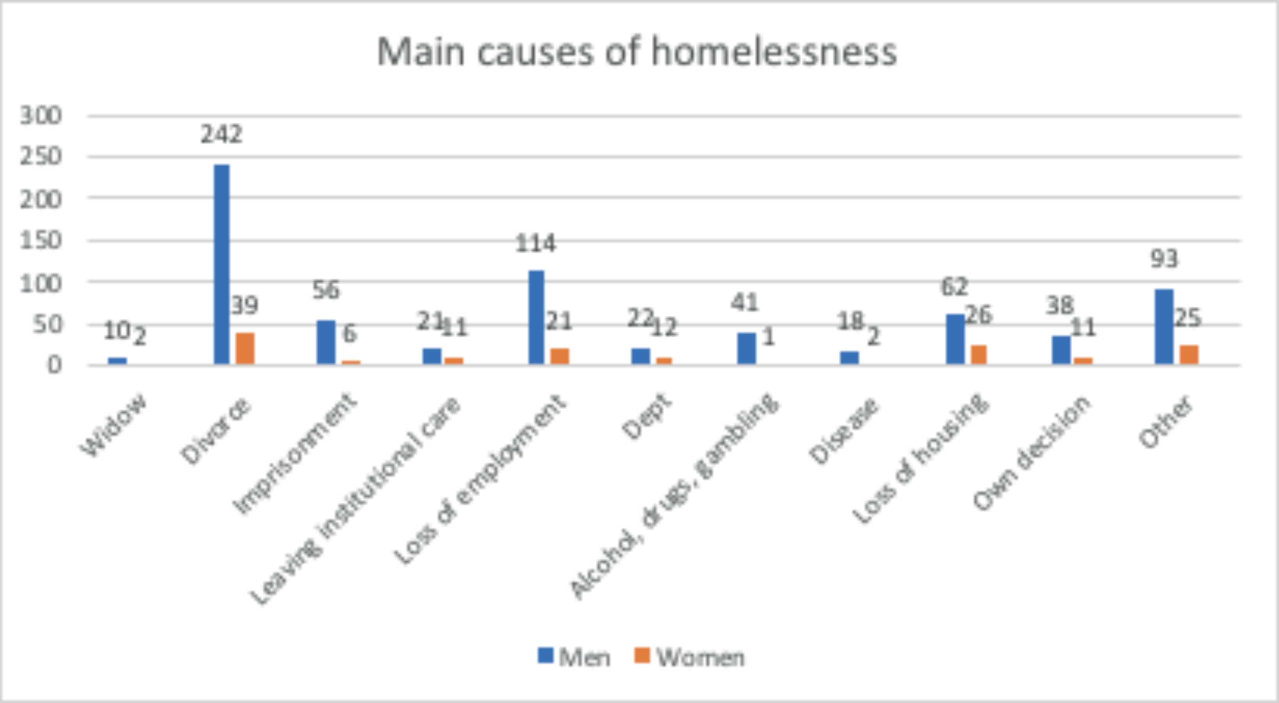
Most common **structural causes** of homelessness include poverty, job market situation, housing availability, changes in family life and inaccessibility of social security.

**Individual causes** of homelessness are in a simplified way usually described as personal failures of individual who did not react well to problems caused by the aforementioned causes. According to this perception homelessness is the result of personal failure in the job market, family life and inability to secure sufficient resources and housing.

However, it is very difficult to distinguish the degree of one's own fault. In literature homelessness is analysed mostly in relation to the structural causes that does not rate individual fault as fundamental in causing homelessness.

Barták (2004) describes the causes of homelessness in Czech Republic within the "State of health of the homeless population in Czech Republic and its determinants" (Fig. 8).

**Figure 8.** Main causes of homelessness – study from Czech Republic.



Source: Barták, 2004.

Based on research Fitzpatrick (2000) reports following **risk factors of homelessness**:

- sexual and psychological abuse in childhood and puberty
- family conflicts and breakdown of marriage
- background of care in local institutions
- delinquent behaviour and incarceration
- previous military service
- lack of support from the social system
- debt, unpaid rent or mortgage
- neighbour conflicts
- drug and alcohol abuse
- school expulsion and insufficient qualification
- deteriorating health

Fitzpatrick sees the following specific incidents as trigger mechanisms, so called "**breaking points**" that can initiate homelessness – losing a home:

- leaving parental home after an argument
- breakdown of marriage or partnership
- widowhood
- leaving the army
- leaving institutionalised care
- leaving prison
- sudden deterioration of mental health
- increase drug and alcohol abuse
- financial crisis with growing debts
- eviction from one's own home or rented housing

### Homeless children and women

Barták (2011) mentions many researches focusing on the health of homeless children. The common conclusion of these researches is that children are at risk of drug addiction, often have psychological issues, injuries caused by life on the street and deficient family background. The state of health in childhood characterised by comorbidity is later apparent in adulthood and leads to premature death. There were 2064 homeless people in total in Bratislava (Slovakia), of which 1780 were adults and 284 were children.

A Canadian research led by Stephen Hwang (2001) focuses on the issue of premature morbidity. He has reached a conclusion that the probability of premature death is 31x higher for homeless women in comparison to the majority population. He also notices a high prevalence of skin diseases, tuberculosis, HIV/AIDS and frequent injuries.

Little's study (2005) points out the serious health complications of pregnant homeless women with and addiction with frequent miscarriages, premature births, low weight and health issues of infants.

### "Career" of homelessness

Based on works of other experts Barták (2011) lists following traits:

- majority of homeless people are men
- regarding marital status (in Europe) single people are more prevalent over families
- mostly younger people as they usually do not reach senior age
- mostly in Canada and USA homelessness is linked to the native population and minority ethnic groups
- mostly people from poorer class
- they mostly concentrate in bigger cities

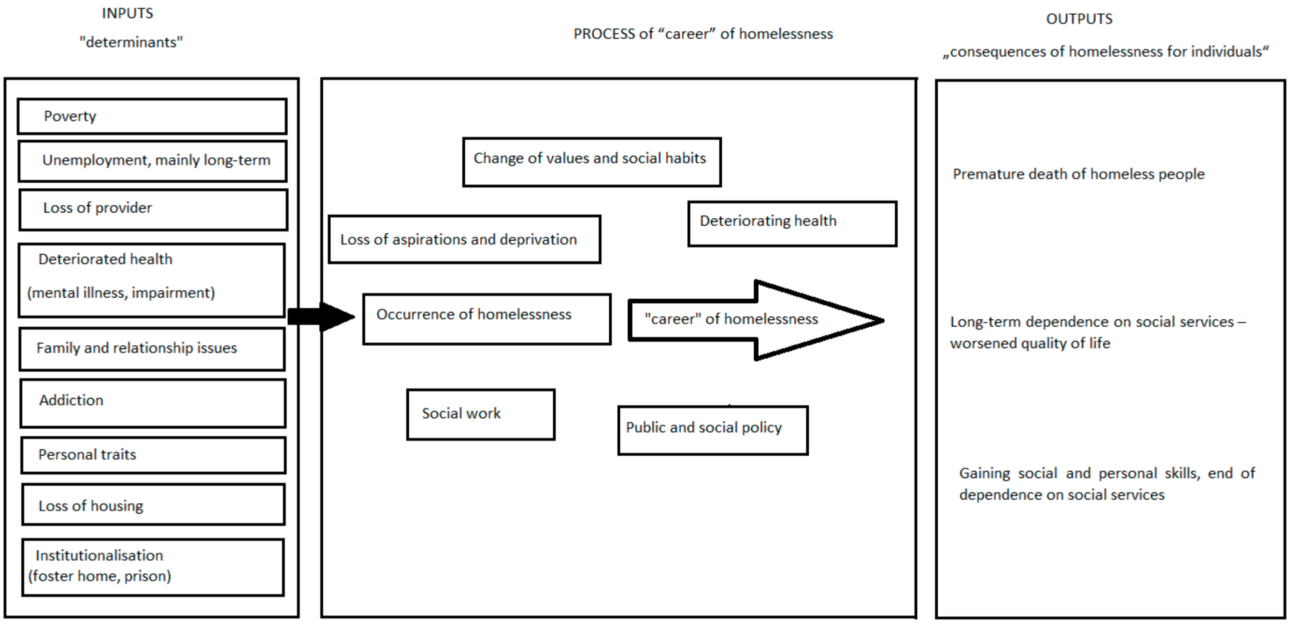
However, homelessness has consequences not only on homeless people themselves but on the society as a whole as the society generates some of the causes of homelessness and affects or on the contrary does not affect homeless people. Homelessness presents a certain menace to social values and highlights the failures of public policies (Barták, 2011).

Barták (2011) also mentions determinants of the state of health of homeless people in a focus group that have agreed that the "career" of homelessness begins a few years before a person becomes homeless. There are many people from disrupted, incomplete or dysfunctional families, people who spent some time in foster home, prison, psychiatric institutions or addict rehabilitation centres (unsuccessfully) among homeless people. Homeless people often experienced breakdowns of marriage of partnership in which usually men left the household without having a substitute.

With regard to education they are mostly people with elementary education or from vocational schools, they are rarely illiterate or on the opposite people with university education.

In last few years the number of young homeless people is growing in Czech Republic, on the other hand the number of senior homeless people remains relatively low. Homelessness concerns more men than women (men comprise 80% of total number of homeless people in Czech Republic). The most significant risk factor is excessive alcohol consumption and the consequential addiction (Fig. 9).

**Figure 9.** "Career" of homelessness according to Barták.



Source: Barták, 2011.

**Health of homeless people**

Wendy Bines (1994) in The Health of Single Homeless People study lists the most common physical illnesses:

- pulmonary diseases (including TB) and headaches, the prevalence among homeless people in shelters was double and triple among homeless people living on the street
- skin diseases (particularly ulcers) was 2 to 3 times more prevalent
- muscular and skeletal diseases were twice more prevalent

The issue of mental health of homeless people is just as serious. The prevalence of mental illness in comparison to majority population was 8x higher among homeless people in shelters and 11x higher among homeless people living on the street. One quarter of homeless people has been hospitalised in a psychiatric institution. It has also been noted that in comparison to majority population they have more health issues associated with excessive alcohol and drug consumption (even in countries not associated with homeless people e.g. Japan (McCurry, 2005)).
Other longitudinal research states that mental health of homeless people deteriorates with time spent living on the street (Weinreb et al., 2006).

Marek (2012) also mentions the distrust between homeless people and medical workers. Life on the streets causes many serious health issues that should be treated however homeless people often refuse treatment. One part of homeless people sees hospitalisation as a way to get a warm bed and food and try to prolong their stay in a hospital. Another part perceives hospitalisation as a restraint of their rights, does not care about their health, sign waivers and return to the streets (mainly because of the absence of drugs in a hospital). Both groups repeatedly return to the hospital with same chronic diseases. Complete recovery is almost impossible as the treatment at home is absent therefore their health deteriorates even further.

Rescue services often refuse to transport homeless people as it means complete disinfection of the ambulance. Doctors refuse to admit homeless people to the hospital as they suspect them of only being interested in food and shelter. There are often problems with unpaid insurance, missing health insurance card, missing address etc. The continuity of the treatment is interrupted as most homeless people do not have a general practitioner or district general hospital. Despite all these complications doctors in Slovakia and many other European countries are obliged to check homeless people for symptoms of diseases.

**Table 3.** Types of help available to homeless people

| | |
|---|---|
| **Street work** | Making contact with homeless people in their own environment – on the street |
| **Shelters with the condition of alcohol abstinence** | Most common low-threshold shelters |
| **Shelters without the condition of alcohol abstinence** | Low-threshold shelters targeted mostly towards addicted people |
| **Hygiene centres** | Provide showers, washing machines etc. - for the time being they are very rare in Slovakia |
| **Clothing** | There is usually enough clothing for homeless people as people often think of giving away clothes as the primary way of helping homeless people |
| **Food** | For free or for a symbolic fee |
| **Social counselling** | Social counselling is crucial as many homeless people need assistance when communicating with official institutions |
| **Health care** | Many homeless people suffer from chronic diseases caused by the roughness of living on the streets |
| **Lodging-houses** | Low-cost option of accommodation |
| **Work programs** | In contrast to general opinion many homeless people have temporary work and try to find a decent and stable job. However they are often scammed and do not get paid for their work so they are usually very careful when being offer a job. |
| **Clubhouses** | Homeless people have the same need for social life as the rest of the population |
| **Spiritual programs** | Spiritual support and help is more than welcome in the harsh reality of life |
| **Addiction recovery programs** | It is difficult not to drink when living on the streets. Alcohol is also often the cause of homelessness even though it is widely known alcoholism is a disease. Gambling is a widespread phenomenon alongside alcohol. |
| **Adult day care centres** | Many people do not like to see homeless people in front of shopping malls, on the streets, in parks, but they have to be somewhere. |
| **Sheltered workshops** | Sheltered workshops make provisions for homeless people and gradually prepare them for obtaining a regular job with a kind of work therapy. |

## Key messages

- Unemployment, especially if it is long-term, is stressful and can have serious consequences on person's life.
- The groups at higher risk of social exclusion are ethnic minorities, migrants, unemployed and homeless people.

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# 4

# Vulnerable Population Groups

## 4.1 CHILDREN, ADOLESCENTS AND FAMILY

*Vladimíra Timková*

*„The health of a mother and child is a more telling measure of a nation´s state than economic indicators.“ - H. Gill*

The life of individual through childhood and adolescence is marked by enormous personal and interpersonal growth. The many "firsts" which occur, such as saying "mama" for the first time of taking the first steps, mark the achievement of numerous developmental milestones. However, the fascinating interplay between child´s genes and his or her environment can create significant variablity in the individual development (Wedding and Stuber, 2010). From the first spark of life and throughout our lives, our mental and physical health is affected by the place we live and the people with whom we spend time and interact (Haslam et al., 2018). In line with this, accross the world governments and policy makers are increasingly recognising the importance of social determinants for health (Haslam et al., 2018), including family interactions (WHO, 2018a). Furthermore, the physical and psychological health in childhood represents another key determinant of health capacities in older age of an individual (WHO, 2018a). Therefore, this chapter aims to:

» explore *the main risks for children and adolescents health as well as for health of the family*,

» introduce some *basic solutions and implications for clinical practice* related to the most common health-related impairments in the population of children and adolescents,

» describe *the basic principles of dealing with domestic violence in medical care* settings.

### 4.1.1 Health of children and adolescents in the global context

The various modern world's crises, moral decay, abuse, and poverty always hit children the hardest, as they are the most vulnerable segment of any society. Children and adolescents make up almost a ¼ of the world's population with 85% living in low- and middle-income countries (United Nations, 2011). The substantial progress that has been made in maternal and child health has shown the strength in collaborations among governments, civil societies, international organizations, and private–public sectors (Bhutta and Black, 2013) *However, these improvements have not been uniform and unnecessary deaths still occur (*Kissoon et al., 2015). Children have reached significant health gains, e.g. **the under-five mortality rate has declined by nearly half** since late 20th century. It has dropped from 90 deaths per 1,000 live births in 1990, to 46 deaths per 1,000 live births in 2016 (WHO, 2018a).

Despite the significant progress, 6.6 milion of children under five years of age die each year (Detels et al., 2015). *Diarrhea, malaria, pneumonia, measels, and HIV* represent **the main causes of death and illness** in children under-five in developing countries. *Poverty, low levels of maternal education, and poor quality of healthcare* were also identified as another underlying determinants of under-five deaths (Detels et al., 2015). Moreover, there has been found a strong relationship between under-five mortality and *several economic and governance indicators*, such as the *gross domestic product of a country and the Corruption Perceptions Index* across the European Region (WHO, 2018a).

The *armed conflicts* may also be one of the under-recognised risk factors for under five mortality. Furthermore, the evidence of increased child mortality risk from an armed conflict was found up to 100 kilometers away and persisted for 8 years after conflicts (Wagner et al., 2018).

Approximately two-thirds of under-five deaths could be **prevented** by small set of interventions such as: promotion of breastfeeding, or prevention of poor neonatal conditions (Detels et al., 2015). For example one third of people don't have access to basic sanitation facilities such as safely managed toilets. This lack of safe sanitation leads to diarrhea, a main cause of death among children under five. Even in cities, extending pipes to consumers in developing countries is too expensive — and perhaps impossible in water-scarce areas (WHO, 2018a).

Some efforts focused on building toilets that are less reliant on government-run collection. For example, the Gates Foundation's, have spended $200 million to develop waterless toilets over the past seven years. These toilets now cost less than five cents a day, without the need for running water and external sources of electricity (Nagpal et al. 2018).

Today´s generation of **adolescents** is, relative to other age groups, the largests in history. A cluster of health risk states and behaviours that start in childhood and adolescence such as physical inactivity, unhealthy eating habbits, or alcohol abuse, may serve as a triggers for future development of non-comunicable chronic diseases. In comparison to younger children, adolescents have reached fewer health gains; e.g. mortality among adolescents had improved only marginally. The major global causes of disease represent neuropsychiatric conditions for both genders, injuries in males, and poor maternal health in females. Indeed, around 10% of adolescents suffer from some type of chronic condition, while leading position have mental health problems (Detels et al., 2015).

#### 4.1.1.1 Trends in child and adolescent mental health

*“It is easier to build strong children than to repair broken men.” - F. Douglas*

This section focuses on trends in the most commonly occurring types of child and adolescent mental health problems. Research indicates that up to one in five children worldwide experience mental health problems (Bor et al., 2014). Mental disorders are estimated to be the leading cause of disease burden for adolescents across the globe (Detels et al., 2015). Over ½ of all cases of mental disorders begin by the age of 14 and ¾ of all psychiatric disorders begin before 18 years of age, with high persistance into adulthood. As the majority of these mental illnesses remain untreated into adulthood (WHO, 2014; WHO, 2018a), there is a clear need to invest in screening and prevention in young people.

*A global prevalence of the most common mental disorders in children and adolescents*

| | |
|---|---|
| Overall prevalence of mental disorders | 6.7% |
| Conduct disorder | 5.0% |
| Attention-deficit hyperactivity disorder (ADHD) | 5.5% |
| Autism spectrum disorders (ASDs) | 16.1% |
| Eating disorders | 4.4% |
| Depression | 6.2% |
| Anxiety | 3.2% |
| Experience of traumatic event | 31% |
| Self-harm | 10% |
| Child suicides in WHO European region | 0.6 -20.4% |
| Binge drinking in WHO European region | 60% |
| Victimization | 1.0 - 61.1% |

(Copeland et al. 2018; WHO, 2018a; Erskine et al., 2017; Collishaw, 2015)

### *Suicide and self-harm*

Suicide globally represents the second leading cause of death in adolescents. **Care for suicidal** children and adolescents may be improved with the pediatrician's knowledge, skill, availability of appropriate community resources and mental health professionals. Standardized, valid, brief and easy-to-administer screening tools based on brief training in suicide risk, can be utilized to detect risk of suicide in children and adolescents. Targeted suicide screening in schools, and universal suicide screening in primary care clinics and emergency departments may be the most effective way to recognise and prevent self-harm (Gould et al., 2005; Horowitz and Ballard, 2009; Wintersteen, 2010).

*Risk factors for suicide in children and adolescents*

- Depression, substance abuse, personality disorders (Detels et al., 2015)
- Bullying, impaired parent–child relationship, academic pressure, social isolation, stressful life events, romantic difficulties, being LGBT (Říčan and Krejčířová, 2006; Hatzenbuehler, 2011)
- Suicidal depression of caregiver (Kawabe et al., 2016).
- Exposure to the suicide of a schoolmate, or family, media exposure (Mars et al., 2018)
- Cultures encouraging individualism and high expectations (Říčan and Krejčířová, 2006)
- Problematic Internet use (Twenge et al., 2018).

### *Interpersonal violence. Bullying and Cyberbullying*

A total of 565 of young people aged 10-29 die every day across the world due to interpersonal violence, with higher prevalence of male victims (Krug et al., 2013). **Bullying** is a well-established risk factor for mental health problems in children and adolescents (Collishaw, 2015). It represents repeated physical, verbal, or emotional violent acts, which have hostile intent and involve an imbalance of power between aggressor and victim (Hellström et al., 2015). Most studies point to a reduction in prevalence of bullying, but there are exceptions. For example, there is a higher prevalence of bullying in poorer countries, which have important inequalities in health, income, and education (Elgar et al., 2015). Victims of bullying and cyberbullying are more likely to use alcohol and drugs, to not attend school, have poor academic performance, lower self-esteem and more health problems than others. Survivors of such abuse express the severity of the impact, which sometimes leads to suicide or suicidal ideation (WHO, 2017).

## Substance use

The **early initiation of substance use is harmful** for two main reasons. First, alcohol and drugs seems to have considerably more adverse consequences at this age than later in life in terms of neural and endocrine development; and secondly, the earlier adolescents start taking drugs, the more likely they are to experience drug-related injury and drug dependence later in life (WHO, 2018a). **Alcohol abuse** continues to be incerasing among adolescents, especially in western European countries, and the gender gap in adolescent alcohol use has become narrower (WHO, 2018a). **Abuse of anxiolytics and hypnotics** is considerd to be a silent epidemy, partly because people believe these drugs to be safer than so-called street drugs. In the USA in 2009, the use of prescription drugs without a prescription occured among 20% of adolescents and continues to increase. In 2010, non-medical opiates were found to be used by 4.8% of children under 12 years of age. Prescription drugs such as opioid pain relievers, transquilizers, stimulants, and sedatives have become a greater cause of death from overdosage than heroine and cocaine in 2013 (Tulchinsky and Varavikova, 2014).

Increased understanding of the negative effects of drugs on adolescent development and enforcement/enhancement of compliance with the legal age limit for alcohol sales is key to success (WHO, 2018a). Promoting alternative recreational activities, strengthening family ties, improving self-efficacy, building social competence, and broadening cultural experiences were found to be the most **effective strategies** for delinquency and drug abuse prevention (Milkman, 2017).

### *Explaining trends in child and adolescent mental health*

Identifying reasons for changes in mental health may be difficult. Society has changed in many ways, and it would be an oversimplification to draw valid conclusions at the population level. Explaining the trends in child and adolescent mental health may be according to Collishaw (2015) partially based on changes in: *individual vulnerability, family life, extrafamilial psychosocial influence, and the broader socioeconomic and cultural determinants.*

#### *Individual vulnerability*

It may be assumed that **changes in perinatal conditions** have influenced patterns of individual vulnerabilities across successive generations of children. For example, epidemiological evidence suggests risk for neurodevelopmental disorders such as ASD and ADHD may be associated with increased survival of very premature or extreme low birth weight babies, in utero exposure to anxiolytics or antidepressant medications, and advanced parental age Furthermore, early pubertal timing is associated with increased risks for poor mental health and psychosocial problems that often persist into adulthood Collishaw (2015). **Substantial personality changes across successive generations** also indicate a possible contribution of personality traits to changes in mental health (Twenge, 2011). **Child internal factors** such as medical problems, difficult temperament, low IQ, poor academic achievement, and social skills deficits were identified as determinants of poor mental health. On the contrary, factors that contribute to better mental health and resilience in children were found to be related to external supports (I have), inner strengths (I am), and interpersonal problem solving skills (I can) (Pomerantz, 2017).

#### *Family life*

Recent studies suggests that changes in family composition do not represent primary triggers for mental health problems. Nonmarital cohabitations and divorces are now much more common, and show only a little differences in terms of child health-related outcomes when compared to marriages (Twenge, 2011). The psychologists emphasize that *living with both parents is more beneficial than single parenthood* as it may contribute to poor mental health (Pomerantz, 2017). However, *staying with one mentally stable parent is better* than both parents living in a destructive relationship. One of the established risk factors for child and adolescent mental health problems is considered having a parent with mental health problems (Pomerantz, 2017), especially depression (Collishaw, 2015). Rates of adult depression have also increased considerably over time (Collishaw, 2015), and this may consequently contribute to increase in child and adolescent emotional problems. Further, serious *emotional conflict among parents, low parent IQ, an excessive number or children at home, hypercritical tendencies in parents, and poverty* may contribute to poor mental health in children (Pomerantz, 2017). All in all, it may be assumed that configuration of the family is not considered to be the most important determinant for child mental health. Rather, **the stability of the family and the socio-economic situation** has more significant impact on mental health of children (Fedewa et al., 2015; Miller and Mazza; Pomerantz, 2017).

### *The stability of the family and the socio-economic situation*

A meta-analysis of 34 studies of the effect of sibling relationships on children´s mental health found that those with loving, warmer brothers and sisters had fewer mental health problems (Pomerantz, 2017). According to recent meta-analyses, sexual orientation of parents and gay couples themselves, do not represent risk factor for mental health of children (Fedewa et al., 2015; Miller and Mazza, 2017). Moreover, children of gay fathers had significantly better mental health outcomes than did children of heterosexual parents. However, these results may be attributable to potential higher socio-economic status for gay fathers traditionally associated with dual earner households, better preparedness for fatherhood in the face of strong antigay stigma directed at same-sex families, and more egalitarian parenting roles (Miller and Mazza, 2017).

### *Extrafamilial psychosocial influences*

Environmental factors such as *neighbourhood, or poor schooling represent risk factors for poor mental health* in children and young people (Pomerantz, 2017). Some previous studies have examined the possibility that educational experiences have become more stressful for young people e.g. proximity of data collection to school exams was associated with higher prevalence of depressive symptoms (Collishaw, 2015).

Changing adherence to harmful gender and social norms, community mobilization programmes, bystander interventions, counselling and therapeutic approaches, screening combined with interventions, treatment programmes for juvenile offenders, education and life skills; establishment of a safe and enabling school environment; improve children's knowledge about domestic abuse and how to protect themselves against it; life and social skills training, and adolescent intimate partner violence prevention programmes may **help to improve students' mental health** and reduce interpersonal violence (WHO, 2017).

### *Broader socioeconomic and cultural influences*

Finally, broader socioeconomic and cultural factors are relevant for understanding mental health trends. Many studies have established strong links between **poverty** and child and poor adolescent mental health. These inequalities in health, income, and education seem to be one of the importnant determinants of youth violence, including bullying and cyberbullying (Elgar et al., 2015).

In addition to social inequality, it has been suggested that increasingly **consumerist and individualistic values** and attitudes have contributed to increasing levels of psychological distress among young people (Twenge, 2011). It has been noted the rise of the individualistic, narcissistic, self-centered "California self," associated with expecting perfection in relationships and at work. The primary reason for living became ability to make the right choices and to consume right things in order to maximize pleasure and minimize pain (Schumaker, 2001).

Another significant factor that may influence mental health in young generation is the **disconnection between expectations and reality** — young people are told "they can be anything they want to be" and that "they are special" and later find out that reality is more difficult. Twenge and colleagues conducted in 2008 found that self-esteem, self-evaluations, and narcissism **levels** in American college students have significantly risen over the past two decades. These traits are usually negatively correlated with anxiety and depression. Thus, it is possible that young people in the 21st century have buffered themselves against psychological distress with positive self-feelings. However, this strategy may eventually backfire as people with narcissistic traits often become depressed later in life after they alienate others with their self-centeredness (Twenge, 2011).

Another possible reason for the suspected increase in mental health problems is the **growing popularity of electronic communication, especially social media**. Indeed, the opportunities for self-promotion afforded by social media vastly exceed that allowed by traditional media, but it is likely the rise in narcissism has influenced the ways individuals use technology, as this rise in narcissism had occurred before such technology was extensively adopted (Twenge et al., 2008). Adolescents who spent more time on social media or smartphones were found to be significantly more likely to report mental health issues such as depression or suicide when compared to adolescents who spent more time on nonscreen activities (Twenge et al. , 2018). Daily use of video games and Internet use exceeding five hours were also found to be associated with higher levels of depression and suicidal behaviour in adolescents (Messias et al., 2011). Depressed young people were more envious, especially after seeing the atractive profiles on social media. Envy was further associated with low self- esteem and consequent feeling of inferiority (Appel et al., 2015). *But we may wonder what makes social media such as Instagram such a source of physical and mental strain for young people?* Much has been discused about the way social media functions as a person's "highlight reel," rather than a true reflection of their everyday life. In comparison to other social networks, Instagram is uniquely poised to set unrealistic expectations, feelings of inadequacy, and low self-esteem.

*#StatusOfMind*

**Instagram** was by young people ranked as **the most negative platform** in terms of sleep, body image, and the"fear of missing out,"or the fear that people are missing out by not being present in their various social circles (Cramer and Inkster, 2017). Nevertheless, it has been found that loneliness still remains pervasive in societies with the highest usage of social media. Young people are supposed to be lonelier when compared to other age groups and current generation of young people is considered to be the loneliest ever (Olds and Schwartz, 2009).

### 4.1.1.2 Sexual health

Adolescent sexuality is considered to be a sensitive issue in some countries of the European Region, despite a quarter of 15-year-old adolescents reporting having had sexual intercourse and reports from some countries showed that more than 30% do not use any form of contraception (WHO, 2018a). Another source of concern is that some behavioural patterns such as unintended pregancy and fatherhood among adolescents tent to persist from one generation to another and may form some so called intergenerational cycle (Detels et al., 2015).

#### 4.1.1.3 Dietary risk behaviour

*“If someone wishes for good health, one must first ask oneself if he is ready to do away with the reasons of his illness. Only then it is possible to help him” Hippocrates*

Today, we live in a world of sharp contrasts which, on the one hand, is inhabited by people suffering from hunger and poverty, while others spend millions to lose excess weight. **Obesity** has become a worldwide epidemic (Detels et al., 2015). Many children who have overweight or obesity before puberty may develop obesity in early adulthood, which is associated with increased morbidity and mortality, increased risk of chronic conditions such as diabetes, cardiovascular problems, or cancer with occurence in younger age than in the past (Tulchinsky and Varavikova, 2014). The pandemic of obesity was observed in US, Western Europe, Eastern Europe, South America, and East Asia Detels et al., 2015) over the last decade. A 1/3 of children aged 6–9 years in European Union countries were classified as overweight or obese in 2010, with estimates ranging from 18.4% (Belgian 6-year-old girls) to 49.0% (Italian 8-year-old boys) (Wijnhoven et al., 2013).

According to National survey Nutrition of Children implemented by the Slovak Pediatric Society improving **nutrition during pregnancy and in the first two years of childs´ life** can reduce the susceptibility to future chronic conditions such as obesity, type 2 diabetes, allergy, asthma, or cardiovascular diseases. Nevertheless, there are still many mothers who can not even prepeare simple meals and rely on processed foods (Kuchta, 2018). Study has further identified the most serious concerns related to intake of increased amount of sugar and salt, intake of procesed food, inappropriate drinking regimes, lack of fruit, and especially vegetables, poor sleep, lack of physical activity (Kuchta, 2018), and intake of saturated and trans fats.

***How to promote healthy eating?***

There is a need to r*educe dietary intake of high-sugar drinks and foods, as well as fried foods and support physical activity* in young people. Institutional changes such as banning of sugary drinks and sweets at school (WHO, 2018a), *restriction of advertising for sweets, improved labelling, education, toghether with promotion of healthy food, introducing standards for kindergarten and school meals, and fiscal measures*, depending on local circumstances (Fidler et al., 2017) may represent vital elements in the prevention of obesity and setting healthier lifelong habits. Nevertheless, twenty European states still have no policy that affects the availability of unhealthy foods at schools and marketing to children is not effectively regulated (WHO, 2018a).

***Mirror, mirror can´t you see? What you show is killing me***

The age limit for patients suffering from **eating disorders** is still decreasing and also children of 9 years old may be affected. US survey showed that 5% of girls and 3% of boys used laxatives or vomited to lose weight (Detels et al., 2015). The mass media’s portrayal of an ultrathin physique for women and a too muscular, body-builder physique for men is though to be reason of body discontent and eating pathology. As this thin ideal is transmitted also in communication between individuals, interventions at the level of the friendship group to change norms and communication styles may break the link between societal risk factors and individual risk of eating disorders (Cruwys et al., 2016).

***You can‘t weigh inner beauty***

It is also worth of noting that **cultural standards of beauty may be permeated** not just by the friends and media, but also **by health care setings**, and thereby contribute to stigmatization of those body shapes do not conform societal standards (Haslam et al., 2018). Many healthcare providers hold strong *negative attitudes and stereotypes about people with obesity*. Moreover, these negative attitudes may impact the provided care. Experiences or expectations of poor treatment may cause stress and avoidance of health care, mistrust of doctors and poor adherence among patients with obesity. Stigma can reduce the quality of care for patients with obesity despite the best intentions of healthcare professionals to provide high-quality care (Phelan et al., 2015).

#### *4.1.1.4 Physical activity*

Globally, lack of physical activity is the cause of 3.2 milion deaths and 32.1 milion Disability-Adjusted Life Year (DALYs). Those who have insufficient physical activity have an estimated 20 to 30% increased risk of death from any cause, compared to physically active people. Nevertheless, only two in ten high school students take at least one hour of physical activity daily (Tulchinsky and Varavikova, 2014). The HBSC Study further showed, that physical activity in young people decreases with age.

*Is the human body the best picture of the human soul?*

Higher levels of physical activity among young people together with lower levels of leisure-time screen use were found to be associated with better mental health (Kremer et al., 2014). Therefore, it is necessary **to promote physical activity** in school and medical settings. To guide physical activity counseling, accurate and reproducible screening measures are needed. For the clinical setting, the practical measures, assessing targeted behaviours, were found to be useful (Prochaska et al., 2001).

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**Key messages**

- The under-five mortality rate has dropped from 90 deaths per 1,000 live births in 1990, to 46 deaths per 1,000 live births in 2016.
- Diarrhea, malaria, pneumonia, measels, and HIV represent the main causes of death and illness in children under-five.
- Optimal nutrition during the first 1,000 days forms the basis for optimal metabolism development, can positively affect and form eating habits, and decrease risk of civilization diseases.
- Pediatric research has revealed the most serious concerns related to intake of increased amount of sugar and salt, intake of procesed food, inappropriate drinking regimes, lack of fruit, and especially vegetables, poor sleep, and lack of physical activity.
- Over ½ of all cases of mental disorders begin by the age of 14 and ¾ of all psychiatric disorders begin before 18 years of age. As the majority of these mental ilnesses remain untreated into adulthood, there is a clear need to invest in screening and prevention in young people.

### 4.1.2 Domestic violence

*„Happy families are all alike; every unhappy family is unhappy in its own way.“- L. N. Tolstoj*

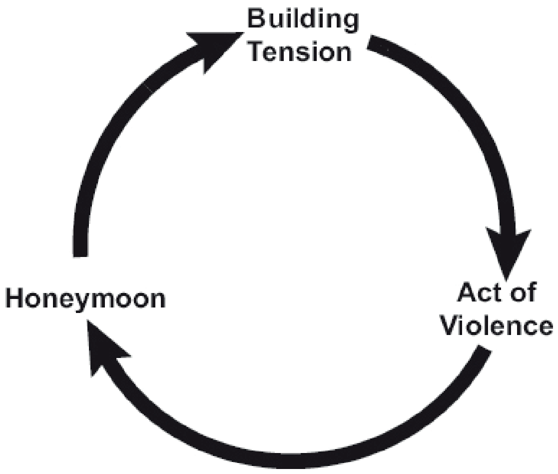
Much of the focus of medical student education is on the doctor-patient interaction. However, sucessful treatment of medical illness often requires the **physicians look beyond the individual to the social context** in which patient exists. The family structure provides the most important foundation for the physical and emotional health of the individual and the community. The family represents one of the few securities in the modern world. Its failure, for instance in the form of domestic violence, may provoke a feeling of threat or fear from „social chaos“. Nevertheless, family is vulnerable to allow rise of violent behaviour. Intimate and private character of interactions, together with asymmetrical distribution of power may help to create and keep violence (Buriánek and Pikálková, 2013). The purpose of this chapter is to:

- *answer some fundamental questions about family violence*,
- *describe myths and risk factors* related to domestic violence,
- *introduce the basic principles of dealing with child abuse and neglect as well as intimate partner violence in medical care* settings.

#### Definition and main types of domestic violence

Domestic violence refers to abuse between members of a nuclear family or intimate system. (Bloomberg, 2004). It is a complex and multidimensional phenomenon that *permeates gender, racial, religious, cultural, social, economic, and educational boundaries*. The abuser uses **physical, psychological, economical, social, and sexual power** tactics that escalate in frequency and severity over time. Moreover, no one in the family is protected from the violent attacks of the abuser. Within the context of domestic violence, partner, child, elder and sibling violence tend to coexist. Domestic violence involves the repeated use of coercive and controlling behaviours to influence, limit, and direct the victim's behaviour, thoughts, and emotionality (Buriánek and Pikálková, 2013).

**Figure 1:** Cycle of domestic abuse



*Myths associated with domestic violence*

It was sociological research by Gelles in 1998 that identified, **the myths** concerning the problem of domestic violence. One of these myths is that domestic violence appears only in *poor, uneducated families, socially excluded families, or that the real causes of violence are drugs and alcohol*. Another dangerous myth is an idea that the aggressor must be a *psychotic*. Next myth is the conviction that the aggressor is violent because *victim deserves it* (Buriánek et al., 2015). Finally, some people may believe that *victims must like the abusive behaviour*, otherwise, they would leave. However, people may stay in such a relationship because of their fear of the offender. A treath may be related to unpleasant consequnce such as loss of children, suicide, loss of prestige, economical loss, or loss of residence (Buriánek and Pikálková, 2013; Burianek et al., 2015).

**Myths and misconceptions about domestic violence may also persist in medical care settings** and consequently undermine the medical response to domestic violence. The most harmful of these misconceptions include the following: (1) domestic violence *is rare*, (2) violence *does not occur in relationships that appear 'normal'*, (3) domestic violence is a *private matter that should be resolved without outside intervention* (4) *abused people are responsible for their situation* (5), or fear of *offending the patient*. Finally, physicians' lack of awareness of the prevalence of domestic violence contributes to their reluctance to consider abuse in the differential diagnosis and to disbelieve that abuse has occurred even when the signs are evident (Ben et al., 2012). Thus, systematically including domestic violence in the education curricula of health-care professionals, teachers, and social workers may **help** them **to better address the issue and help to prevent violence**. Targeted age- and gender- education should address the root causes of domestic violence, such as gender inequality and sociocultural norms. However, only about 2/3 of countries in the Europen Region report having appropriate education to address domestic violence (WHO, 2018b).

### 4.1.2.1 Risk factors for domestic violence

Hormonal, neurological, and personality factors, mental health problems, and early years exposure represent the main risk factors for domestic violence. Another discussed aspect are socio-cultural and institutional factors such as influence of media, or role cultural or religious traditions in the expression of domestic violence. All in all, domestic violence is not explained by one isolated factor but is usually ***caused by combination* of individual and structural factors**. Identifiying risk factors of domestic violence may help in building intervention strategies for survivors as well as in counselling for abusers. The structure of introduced models of risk factors for domestic violence is adapted form Buriánek and Pikálková (2013) and Capaldi et al. (2012).

#### The psychiatric model

The psychiatric model focuses on the personality characteristics related to domestic abuse such as intraindividual processes including role of genotype, personality characteristics, personality disorders, and mental ilness such as depression and substance abuse.

*Personality features and disorders*

Some previous studies showed that **personality traits** *such as jelousy and hostility* may be associated with domestic abuse. Previous research further identified higher prevalence of some *Cluster B* (histrioninc, narcissistic, and borderline) and *Cluster C* **personality disorders** (avoidant, dependent, and obsessive compulsive personality disorder), in aggressors when compared to general population. *Schizoid personality features* (associated with social detachment, restricted emotionality, and avoidant features), were also found to be related to domestic abuse (Capaldi et al., 2012).

*Depression*

There is evidence that men who are violent against their partner are more likely to be depressed (Fulu et al., 2013). However, it is not clear whether depression causes violence, or it represent a consequence of used violence. Depressive symptoms were associated with aggression and victimization, but this association was may be stronger for female population than for male (Capaldi et al., 2012).

*Alcohol and drug use*

Alcohol and drug abuse have an economic impact on families, leading to greater financial strain, and may represent trigger for conflicts over finances (Detels et al., 2015). Findings indicate associations between alcohol use and interpersonal violence, particularly for men, and for polysubstance users of both sexes (Low et al., 2017). Systematic review by Capaldi et al. (2012) indicated that although there is robust evidence of an association between alcohol use and domestic violence perpetration and victimization, *it is not so strong or consistent as generally supposed*. Despite the link between mind altering substances and domestic violence, there are myriad cases where domestic violence is independent of these substances (Al-Adavi and Al-Bahani, 2007).

### Genotype and the role of endogenous opioid mechanisms

There is an evidence that genes may be important in the development of aggression. The monoamine oxidase A gene (MAOA) has been described as impacting on a heritable tendency for antisocial behaviour. For example, child maltreatment has much stronger association with subsequent antisocial behaviour in males with low MAOA enzyme activity, when compared to those with higher enzymatic activity (Detels et al., 2015). Abusive and aggressive behaviour was partially explained by worse function of the opioid system, which can not fully suppress pain or impulsivity. However, this deficiency can be partially managed by psychological interventions such as autogenous training (Bruehl et al., 2009).

### Domestic abuse: the birth of a damaged person?

**Early years´ exposures and/or experience of child abuse** is the other frequently studied risk factor, as related to family violence. Emotional abuse emerged as the main independent predictor of psychiatric symptomatology – over and above other maltreatment types (Cecil et al., 2017). Previous studies described a phenomenon known as '**identification with an aggressor"**, where the victim takes the role of perpetrator, and showed that those who commit domestic violence have often been victim of violence in their nuclear family (Detels et al., 2015; Al-Adawi and Al-Bahlani, 2007). There has been also identified a strong **link between currently experienced** domestic violence **and violence experienced as either a child or an adult** (Al-Adawi and Al-Bahlani, 2007). Child sexual abuse is considered a predisposing factor for the transition from victim to offender in male population. However, no evidence was found to support for existence of a cycle of abuse for female child sexual abuse victims (Plummer and Cossins, 2018). **The consequences can last a lifetime and a**dults who were abused or neglected as children have also a higher risk of *depression, obesity, high-risk sexual behaviours and unintended pregnancies, harmful use of tobacco, drugs, and alcohol* (WHO, 2017).

### The sociocultural model

Can we assume that the anxiom "*ontogeny recapitulates phylogeny*" addresses an issue of domestic violence? Is it Eros versus Thanatos enacted on a large-scale societal level? Based on sociocultural model we will examine domestic violence considering socially structured variables such as *inequality, patriarchy, or cutural norms* and attitudes about violence and family relations.

*Is a kiss with a fist is better then none?*

It seems likely that in the post-industrial society there remain some traditional values that make a woman particullarly responsible for maintaining a marriage, especially if there are children involved. Moreover, divorce is still considered by some people to be stigmatizing (Buriánek et al., 2015). Another aspect is that a *woman's social identity is often* *constructed on the basis of her being in a relationship*. Girls are taught from a young age that being in a romantic relationship should be one of their primary goals and that the romantic relationships are the one of the most important aspect in a woman's life. Thus, in an attempt to maintain the status of girlfriend or wife, women may accept partner behaviour that has the potential to be controlling and damaging. Many people may also choose to accept abusive relationships and suffering due to the *lack of alternatives*. These people may feel that the roller-coaster emotions that are part of emotionally abusive relationships are a better choice than being alone and abandoned (Papp et al., 2017). According Fromm (2001):*"both the sadistic and the masochistic trends are caused by the inability of the isolated individual to stand alone and his need for a symbiotic relationship that overcomes this aloneness."* However, we cannot say that people with morbidly dependent tendencies are responsible for the behaviour of those who abuse them. It is important to keep in mind the words of psychoanalyst Horney (2013): *morbid dependency "is an outcome of many other factors and not their root."* It can be argued that these factors are not only psychological but also socio-cultural.

### *No one can pour from an empty cup*

Psychology has named some conditions assumed to disproportionately affect women, such as borderline personality disorder or masochistic traits, but there is little questioning of the type of society that paves the way for these mental disturbances by **blocking off opportunities** for real self-development (Vigier, 2012). For example, despite the narrowing gender gap in housework, women continue to perform the bulk of this labour (Bianchi et al., 2012). While overall participation in paid work may be converging among men and women, most men still engage in full-time employment (or self-employment) for the majority of the life course, while over 40% of women report part-time work. The need to undertake unpaid work, including housework, childcare (parenting and grandparenting) and ill/elderly care, remains a particular constraint to women's participation in paid work (Wheatley et al., 2018). Thus, the **role of family-caregiver** may be percieved by women as stressful. For example, a total of 95% of elderly, and 90% of elderly people with disabilities live at home and caretaking is provided by their family, mostly by women. Of these women, 52% have full-time job, 17% have part-time job and 39% have to take care also of their children. Women spend average 17 years of life by taking care of their children and 18 years by helping elderly parents or parents in law (Renzetti and Curran, 2005). Working for long hours and for relatively low pay and still having responsibility for household management, many women have little free time or money. This psychological and financial caregiver stress in this difficult situation may lead to increased pressure and consequently may cause the abuse (Wedding and Stuber, 2010). In line with this hypothesis, the abusers of an elderly person are usually adult daughters that take care of their partners, children, and are employed. Furthermore, since 80s there has been identified 300% increase in **elder abuse**. The prevalence of elder abuse in Western countries represents 2.2 to 18%. Most fragile are disabled or diseased elderly women over 75 years (Renzetti and Curran, 2005).

### *Fairytale narrative and cultural constructions of romance*

*„Jim raised me up,*
*He hurt me but it felt like true love,*
*Jim taught me that,*
*Loving him was never enough"*
*- L. Del Rey, Ultraviolence*

Although the causes of domestic violence are complex, certain beliefs about romantic relationships may increase the likelihood of its occurrence, e.g. Western culture has been critiqued as representing romance in problematic ways to young people. The prevalence of violent romance in the media may encourage some young people, to conflate controlling behaviours with signs of love. For example, many young women report that a man telling his girlfriend what to wear or how to behave is the evidence of his love and commitment. Additionally, some young people believe maintaining cross-sex (and in some cases, same-sex) friendships while partnered is inappropriate. This can result in controlling and isolating behaviours being seen as understandable and even as a sign of love (Papp et al., 2017). Scenario based study showed that *romantic beliefs* can contribute to viewing *jealousy as a sign of passion* and investment in a relationship (Puente and Cohen 2003; Hartwell et al. 2015). Moreover, violence in the context of a non-jealousy-related argument was perceived quite negatively, but it lost a great amount of its negativity in the jealousy case scenario (Puente and Cohen 2003).

*Suffering* can also be perceived as a proof of investment in a relationship, or a form of self-sacrifice. Some artists show themselves in their lyrics and/or music videos about to be strangled by partner, beaten or bleeding or possibly raped. The narrative video Love the Way You Lie by Eminem portrays a relationship with increasing violence that ends with the bed in the apartment on fire. This media portrayal of intimate partner violence was found to contribute to the minimization of warning signs of intimate partner violence in young people (Rhodes et al., 2018). Therefore, it may be extremely unhealthy when artists express the desire being physically or psychologicaly attacked or to imagine that this is a normal part of a relationship (e.g. Placebo, 2006; Del Rey, 2014). Being totally absorbed in a relationship to the exclusion of all else, being obsessed with someone who is clearly abusive may be harmful. But as Del Rey sings "*You're no good for me but I want you,*" she may well be expressing the paradoxical feelings of many women, and men too. Although seemingly romantic, but controlling, behaviour may initially appear to be a sign of desire or passion, people may later realize it is a form of abuse (Vigier, 2012).

### *'Honour' based domestic violence*

*„Violence against women isn't cultural, it's criminal". - S. Power*

In some cultures, there is also a great concern for a man's reputation based on his toughness and ability to protect his family and possessions. Thus, honor cultures often establish norms where female chastity, purity, and modesty are valued. This chan can serve as a precursor or catalyst to domestic violence. Honor may be used as a justification for violence. Furthermore, female loyalty is expected in the face of domestic violence. Loyalty is not understood as weakness but as a sign of goodness, and woman who stays inviolent situation may be perceived by community more positively than the woman who leaves (Vandello and Cohen, 2003). The need to preserve honour and social collectivity may override personal distress, even if it means submission to unremitting and lifelong abuse (Al-Adawi and Al-Bahlani, 2007).

**Socio-demographic factors**

One of the most consistent factors is the age of the offender and the victim; between 18 and 30 years of age. Similarly, as with the prevalence of non-intimate violence, men are more likely to be violent in relationships when compared to women (Buriánek and Pikálková, 2013). Although most poor parents and partners do not use violence toward children and intimates, self-reported surveys and official report data finds that the rates of all forms of family violence, except sexual abuse are higher for those whose family incomes are bellow the poverty line (Detels et al., 2015).

**Situational and envirnonmental factors**

Other situational and envirnonmental factors of domestic violence represent stress or social isolation, (Capaldi et al., 2012; Buriánek et al., 2013). Victimization in women was found to be higher in unemployed, childless women with depressive symptomatology Capaldi et al., 2012).

**Key messages**

» Domestic violence is a complex and multidimensional phenomenon that permeates gender, racial, religious, cultural, social, economic, and educational boundaries.

» The abuser uses physical, psychological, economical, social, and sexual power tactics that escalate in frequency and severity over time.

» Physicians may share a number of **pervasive societal misconceptions** about screening for domestic violence that undermine the medical response to domestic violence, e.g.: (1) domestic violence is rare, (2) violence does not occur in relationships that appear 'normal,' (3) domestic violence is a private matter that should be resolved without outside intervention (4) abused people are responsible for their situation (5), or fear of offending the patient.

### *4.1.2.1 Child abuse and neglect*

*„In what disorder we lived, how many fragments of ourselves were scattered, as if to live were to explode into splinters." - E. Ferrante*

**What is child abuse?**

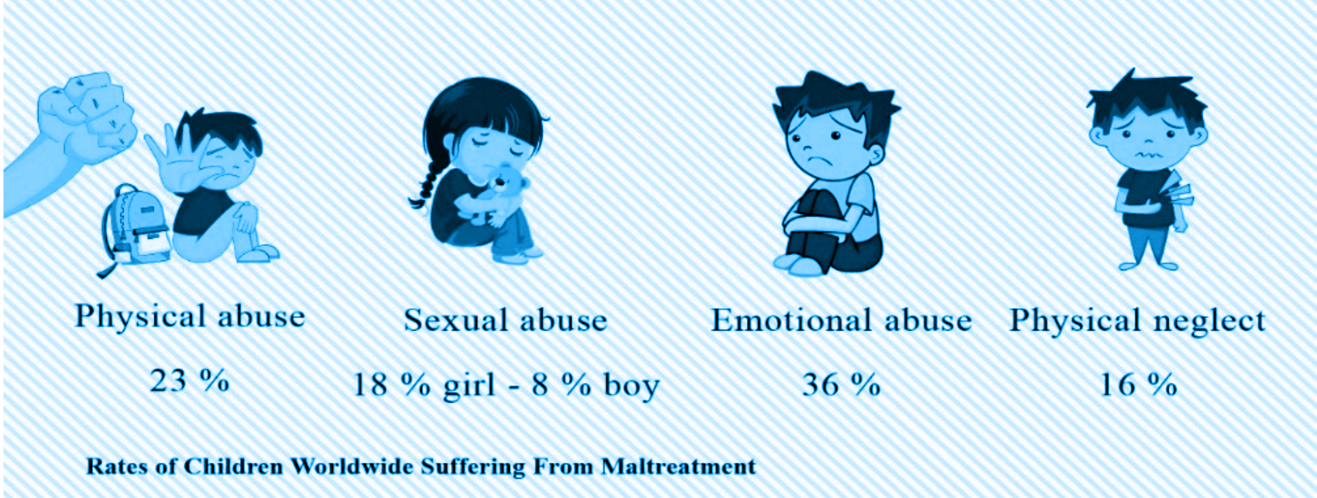
Any behavior with a negative impact on the physical and psychological health of children during their growth and development is considered child abuse and/or neglect. Childhood trauma, including domestic violence and neglect, is considered to be one of the most important public health challenge that has the potential to be largely resolved by appropriate prevention and intervention. Chronic maltreatment has pervasive effects on the development of mind and brain. Developmental trauma sets the stage for unfocused responses to subsequent stress, leading to dramatic increases in the use of medical, correctional, social, and mental health services (Van der Kolk, 2017).

**How common is child maltreatment?**

Girls are abused less commonly than boys. Boys are most often abused physically and are more commonly neglected when compared to girls. (Renzetti and Curran, 2005). One of the by-products of enormous poverty in Asia and Latin America is increased prevalence of child prostitution and it is quite common that children are kidnaped by their own parents and sold into prostitution (Renzetti and Curran, 2005). Globally, an estimated 200 million women and girls have undergone female genital mutilation in 30 countries and 700 million were married as children (250 million before the age of 15) (European Comission, 2018). However, neglect continues to receive less scientific, medical, and public attention than other types of child maltreatment (Bland and Lambie, 2018).

*Figure 2: Global prevalence of child maltreatment according WHO (2017)*

*WHO, 2017, (Bland and Lambie, 2018).*



Disproportionate number of abused children are considered to be unattractive and their faces reminded those of adults. Abused children were found to have head and face proportions that make them look less infantile and cute. Such children may be abused more likely because their faces do not elicit the automatic reaction of protection and care that more infantile faces do. Moreover, parents who abuse their children often have more unrealistic expecations, especially when child looks older and less infantile (Etcoff, 2002).

## Child abuse and neglect in medical care

Healthcare professionals are **mandatory** reporters in cases of child abuse. The medical provider has a key role in gathering the medical history, evaluating the medical and mental health needs of the child, as well as educating families, multidisciplinary partners, judges, and jurors in the appropriate assessment, interpretation of findings, and management of abused patients (Adams et al., 2016). There is a need for health care workers to recognise the signs of abuse and neglect and make serious efforts to **intervene as early as possible**. The later the intervention, the more difficult the change process becomes (Widom and Maxfield, 2001). Clinicians should become familiar with **regional resources and recommendations** regarding child abuse (Tsokos, 2015; Adams et al., 2016). Health care professionals should avoid showing anger, sadness, shock or distress regarding the alleged abuse. Finally, a thorough examination of the whole body of the affected child should be done in a calm and neutral atmosphere.

## Physical abuse

Physical abuse of children has many manifestations. The following part introduces classification of physical injuries in abused children according to the recent guidelines (Committee on Child Abuse and Neglect, 2001;Tsokos, 2015; Faedda et al., 2018).

### Classification of cutaneous injuries

*Clustered injuries*

The term clustered injuries refers to three or more individual injuries in the same body region (Tsokos, 2015).

*Localization*

The criterion localization of injuries may significantly contribute to differentiation between accidental origin of injury and abuse-related injuries (Figure 3). *The forehead, chin, and tip of the nose* represent locations typical of accidental injuries. Typical locations for abuse-related injuries to the *face are the eyes (monocular hematoma or "raccoon eyes"), lips and oral mucosa, cavity, or the outer ears.* Injuries on the back and buttocks and on the lateral and posterior sides of the thighs and soles of the feet are also typical abuse-related injuries. The same applies to so-called **"defensive injuries"** - injuries localized on the outer sides of the forearms and back of the hands. **Bilateral or symmetrical injuries** (including grabmarks) speak against an accident (Tsokos, 2015).

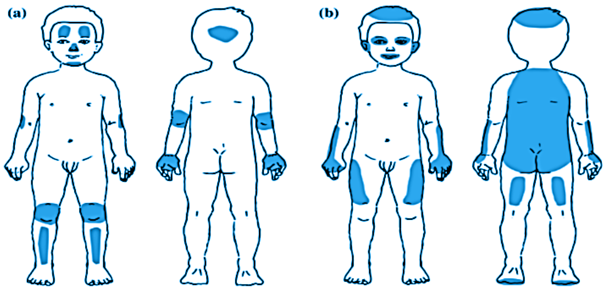


*Figure 3: Injury localization on a child:*

*a) Localizations typical of accidental falling*

*b) Localizations typical of abuse*

*Source: Tsokos (2015) Forecsic Sci Med Pathol 11:235-242*

*Bite injuries*

Bite marks are rarely accidental and thus, are highly decisive in diagnosing cases of child abuse. They usually have a *rounded to oval form* because of the two opposing horseshoe-shaped imprints of the upper and lower jaws. In adult *dentition, the distance between the canines* **exceeds 2.5 cm**; in children this distance does not exceed 2.5 cm. The center of a bite hematoma may also show a suction component near the actual bite injury. Older children reflect bitemarks which represent either assault in which bites are inflicted in a rapid, random, enraged manner; or sexual abuse in which a well-defined bitemark is evident (the causal mechanism is the same as for a *"love bite" or "hickey"*). Elliptical or oval pattern containing tooth and arch marks can be *matched against* the dentition and dental impressions of the suspects (Tsokos, 2015).

*Repeated injuries*

*Injuries of different ages* represent important indicators of child abuse. The coloration of a hematoma can help indicate the time when the injury occurred. Radiological evidence of fractures of different ages, i.e., coexistence of fresh fractures alongside healing or healed fractures, is also a diagnostic criterion of abuse — considering differential diagnoses (Tsokos, 2015).

*Hidden injuries*

Even in a completely unclothed child, injuries to the oral cavity and the region behind the ears are not seen at first glance and are only revealed by a more detailed examination (Tsokos, 2015).

*Thermal injuries*

Hypothermia induced by cold water, e.g., from long-lasting showering of the child with ice-cold water, is not detectable by any outwardly visible signs such as necrosis. Children may be showered with hot/boiling water. Heated objects might be pressed onto their skin (cigarette, iron, or a metal spoon). Abusive scalds are usually characterized by *a symmetrical impression and localization with sharp delineation of the scald wound edges*, in contrast to accidental scalding injuries with radiating splash patterns ending in tapered points (Tsokos, 2015).

*Patterned injuries*

Patterned bruising or injuries can be caused by various objects such as electric cables, cooking spoons, forks, or dog leashes (Tsokos, 2015).

**Injuries of internal organs**

Localized results of abuse beneath the protective layer of skin include fractures and distortions affecting bones, ligaments, and joints. Life-threatening or even fatal bleeding inside the abdomen often results from injuries of internal organs; such as the liver, spleen, and pancreas, the stomach and/or intestines (Tsokos, 2015). **Shaken baby syndrome** is a serious and clearly definable form of child abuse. It results from extreme rotational cranial acceleration induced by violent shaking or shaking/impact, which would be easily recognizable by others as dangerous. Some healthcare professionals consider the term *shaken-impact syndrome* or *shaken/slam syndrome* to be more accurate in reflecting the age range of the victims (who are not always babies) and the mechanisms of injury seen. Shaken baby syndrome injuries are the result of violent trauma. Shaking by itself may cause serious or fatal injuries. Such shaking often results from tension and frustration generated by a baby's crying or irritability, yet crying is not a legal justification for such violence. Survivors of shaking injury often have long-term disabilities ranging from mild learning disorders to profound cognitive and developmental delays, paralysis, cortical blindness, and in some cases, a permanent vegetative state (Committee on Child Abuse and Neglect, 2001).

**Don´t judge book by its cover: Factitious Disorder Imposed on Another**

*Factitious Disorder Imposed on Another* (FDIA), also known as *Munchausen Syndrome by Proxy* is a very serious form of child abuse. The perpetrator, usually the mother, invents symptoms or causes real ones in order to make her child appear sick. Usually this is due to a maladaptive disorder or to an excessive of attention-seeking on her part. A mortality rate between varies between 6 and 10% of all FDIA victims, making it one of the most lethal forms of abuse. An early diagnosis represents a challenge for the clinician and is essential in order to limit complications and to improve the outcome (Faedda et al., 2018).

| FDIA red flags: the perpetrator | FDIA red flags: the victim |
|---|---|
| Extremely involved in the management of the childs´ treatment | Atypical presentation of disorder |
| Vague and inconsistent details about child's medical history | Tests and observations are normal |
| Invasive diagnostic and surgery procedures are accepted without concern | Medical problems don't respond to treatment |
| The perpetrator shows medical knowledge | Symptoms and signs occur only in the caregiver's presence |
| Requests are made for further procedures | Multiple hospitalizations and surgeries |
| Attention and approval of medical staff are sought | Presence of medical illness (e.g., mental disorder, microcephaly) |
| Previous history of psychiatric disorder | Occurrence of complications or of new pathology when the findings prove negative |
| No relationships, family and marital problems | Father is usually absent |

Source: Faedda N, Baglioni V, Natalucci, G, et al. (2018). Don't judge a book by its cover: Factitious Disorder Imposed on Children-Report on 2 Cases. Frontiers in Pediatrics 6: 110.

### Lack of a coherent and comprehensible explanation. Delayed presentation

Lack of a coherent and comprehensible explanation for accidental injury constitutes grounds for suspecting abuse. The medical professional must be very attentive to undercover the discrepancies in explanation of how the injury occurred. It must be determined initially **whether the explanation as provided by the caregivers is congruent with the medical findings**. For example, *bilateral or symmetrical injuries*, not only to the face or on the head, would speak against an accidental fall. It must be further determined whether *the motor and cognitive development of the child is congruent with what is described by caregivers*. For example, an unassisted 2-year-old child would not be capable of climbing onto a cooker and switching it on (and subsequently suffering thermal injuries from the hotplates), either in terms of the motor capabilities or the cognitive development and execution required for such a complex action. Another source of concern **represent delayed visit to a health care** professional, and/or **waiting unusually long before calling for medical help** (Tsokos, 2015).

### Sexual abuse

All children who are suspected victims of sexual abuse should be offered an examination performed by a medical provider **with specialized training** in sexual abuse examination. **Culture of potentially infected sites** has traditionally been the diagnostic gold standard for cases of possible sexual abuse. In case of sexual abuse, **antibiotics, antivirotics should be used to prevent sexually transmitted diseases, including medication to prevent pregnancy**. Clinicians should become familiar with **regional resources and recommendations** regarding **collection of evidence** (Adams et al., 2016).

### Other signs and symptoms in abused children

Common **physical and psychosomatic** signs and symptoms in abused and/or neglected children are dirty clothes, malnutricion, headache, vomitting, stomach ache, abdominal pain, muscular pain, enuresins, encopresis, ulcers, obstipation, diarrhoea, symptoms of asthma, urogenital problems, urinary tract infection, or sexually transmitted diseases (Bendixen et al., 1994; Hyland et al., 2013). Some of the presenting symptoms may just mas the abuse, e.g. presence of pain without identifiable cause.

**Psychological symptoms** in abused and/or neglected children are represented by anxiety, memory and concentration problems, suicidal behaviour, self-harm, aggression, apathy, letargy, substance abuse, delayed or altered cognitive and emotional development, sexual risk-taking, or violent behaviour. Child abuse and/or physical and emotional neglect may also contribute to the development of som abnormal psychological traits associated with personality disorders (Bendixen et al., 1994; Dias et al., 2015; Bland and Lambie, 2018).

Common is an **abnormal behaviour of the child** during the examination (e.g. fear, utter passivity, extreme submissiveness, excessive conformity, aggression, and destructive behaviour) (Tsokos, 2015). Abused children may be *affraid of physical contact* with adults. Warning sign may also be *an inappropriate reaction to injury* such as failure to cry from pain, or lack of reaction to frightening events. In sexually abused children, especially girls, seductive, *flirting behaviour* may occure (Mausert-Mooney, 1992). Abnormal behaviour of the child during the examination should be interpreted as an urgent indication for *consultation with a child psychiatrist and/or a psychologist* with appropriate training and experience

### Not ‚just the facts‘: How to effectively communicate with child victims of domestic violence?

- Where a professional is concerned about / has recognised the signs of domestic abuse, s/he can approach the subject with a child (or a caregiver) with **a framing question**. That is, the question should be ‚*framed*‘ so that the subject is not suddenly and awkwardly introduced, e.g.: *„We know that many mums and dads have arguments, does that ever happen in your family?”*
- Health care professional should continue with direct, clarification questions related to: (1) **Types and frequency** of exposure to domestic abuse *(„What kinds of things do mum and dad fight about?”„Do they hit one another?”)* (2) **Risks** posed by the domestic abuse *(„Have you ever been hit or hurt when mum and are fighting?”)* (3) **Impact of exposure** to domestic abuse *(„Are you afraid to be at home? „What or who makes you afraid?”)* (4) **Protective factors** *(„Does anybody else know about the fighting?”).*
- **Do not minimise** the violence
- Do not assume that the child will consider themselves as being abused
- You should **not press** the child for answers, instead: (1) Listen and believe what the child says; (2) Reassure the child/ren that the abuse is not their fault, and it is not their responsibility to stop it from happening
- **Never promise complete confidentiality** - explain your responsibilities
- Promise to **keep the child informed** of what is happening
- Use age appropriate language
- Emphasise that the violence is **not the child‘s fault**
- Let the child know that she/he is not the only children experiencing the abuse
- Do not assume that the child **will hate the abuser**, it is likely that the child may simply hate the behaviour

- Check with the child patients whether they know what to do to keep themselves safe and have a **safe network** of adults
- Recognise that children will have developed their own **coping strategies** to deal with the abuse
- Give the child information about sources of advice and support
- Give the message that the child **can come back** to you again

**Key messages**

- Healthcare professionals are mandatory reporters in cases of child abuse.
- Clinicians should become familiar with regional resources and recommendations.
- Consultation by medical specialists is usually essential.
- Where a professional is concerned about / has recognised the signs of domestic abuse, s/he can approach the subject with a child (or a mother) with a framing question.
- The diagnostic criteria for child abuse represent localization, patterned bruising, repeated injuries (juxtaposition of injuries of different ages), and clustered injuries (three or more individual injuries in the same body region).
- Detailed documentation of findings (i.e., photographic documentation with a visual scale), is absolutely essential for any subsequent criminal proceedings.

### 4.1.2.2 *Intimate partner violence*

**Only female problem?**

The reported prevalence of domestic violence against women ranges between 23 and 35% (Usta et al., 2012). A total of 30% of domestic abuse begins or escalates during pregnancy. Intimate partner violence is primarily an asymmetrical problem of men‘s violence to women, and women‘s violence does not equate to men‘s in terms of *frequency, severity, consequences and the victim‘s sense of safety and well-being* (Dobash and Dobash 2004). Surveys from different parts of the world have shown that a woman is more likely to be injured, raped or killed by an intimate partner than by any other person (Al-Adavi and Al-Bahani, 2007).

However, *men often do not perceive themselves as victims of domestic violence*, although they are often victimized by their partner. Weak perception of abuse, or ignoring their own victimization, consequently leads to the fact that men do not report domestic violence. Women as aggressors use less of physical violence, use more hidden techniques such as humiliation of partner, jelousy, social isolation, common is also threatening victim by loss of children, or commiting suicide.

All in all, domestic abuse affects millions of children, women, and men around the world each year and causes more deaths and entail much higher economic costs than homicides or civil wars. However, men are considered to be abused less frequently and the use of physical violence against male victims is not so common (Buriánek et al., 2015).

### Intimate partner violence in medical care

*I woke to find myself within a dark wood because I had strayed from the correct path. Oh how hard it is to describe how harsh and tough that savage wood was The very thought of it renews the fear! ...“and thence we came forth to see again the stars”*
*- D. Alighieri*

Although numerous medical associations, governmental agencies, and advocacy groups recommend routinely screening for or inquiring about domestic violence, many physicians, even in developed countries, do not follow these recommendations (Usta et al., 2012). In two surveys of health professionals only a minority of doctors and half of nurses were in favour of screening (Ramsay et al., 2002). A systematic review of barriers to screening for domestic violence found that healthcare professionals reported wide range of problems: lack of education, lack of knowledge, fear of offending or endangering patients, lack of effective interventions, and limited time (Waalen et al., 2000). Finally, certain barriers may also represent myths associated with domestic violence described above. Nevertheless t ½ to ¾ of women in primary care think that screening for domestic violence in healthcare settings is acceptable (also in conservative societies such as Lebanon) (Usta et al., 2000).

### Signs and symptoms suggestive of intimate partner violence

*“There‘s only one kind of happiness, but misfortune comes in all shapes and sizes.”*
*- H. Murakami*

Intimate partner violence has many manifestations. Signs and symptoms suggestive of intimate partner violence represent physical signs and injuries, physical symptomatology such as gynecological symptoms, or cardiovascular problems, psychological symptoms, and behavioural signs (Phelps, 2000; Usta and Taleb, 2014). Therefore, an effective response to victims of intimate partner violence requires thought and action outside of traditional biomedical models.

#### Physical signs and symptoms

» Cutaneous injuries: *clustered, repeated* (Injuries and bruises of various colours, indicating injuries occurring regularly over a period of time, often with an excuse of “accidents”), *hidden, thermal, patterned* injuries, *localization* (bilateral or symmetrical injuries speak against an accident, injuries associatet with the defensive position – forearms) (Tsokos, 2015).

» Head, neck, and facial cuts or bruises

» Tooth loose or broken tooth, tympanic membrane rupture

» Injuries to the chest and stomach, reproductive organs, and anus, breasts, buttocks

» The illness or injuries do not match the cause given

» Injuries during pregnancy

» Fractures and distortions affecting bones, ligaments, and joints.

» Bleeding inside the abdomen often results from injuries of internal organs (Tsokos, 2015).

**Repeated chronic medical complaints**

*Common gynecological symptoms:*

- Urogenital problems
- Urinary tract infection
- Pelvic problems and pains
- Painful sexual intercourse
- Irritable bowel syndrome
- Sexually transmitted diseases
- Repeated reproductive health problems

*Domestic violence during pregnancy increases the risk factor for:*

- Repeated miscarriage
- Early delivery
- Antepartum hospitalisation
- Obstetrical complications
- Low birth weight delivery

*Cardiovascular symptomatology:*

- High blood pressure
- Heart attack in young age
- Coronary disease

*Psychological problems*

- Depression
- Insomnia, sleep problems
- Alcohol and drug abuse - sleeping pills, anxiolytics
- Self-harm
- Signs of depression
- Anxiety – e.g., Generalized Anxiety Disorder, Panic attacks
- Suicide attempts, suicide, homicide

*Common physical and/or psychosomatic symptoms:*

- Headache
- Backpain
- Chest pain
- Choking problems
- Chronic pain

**Behavioural signs**

- Multiple visits of health-care professionals
- Repeated and/or chronic medical complaints
- Lack of commitment to appointments
- Frequently miss work or social occasions
- Delay in requesting medical care
- Dress in to hide injuries
- Not displaying emotion or crying easily
- Inability to undertake daily interactions
- Negligence
- Defensive positions
- Stilted speech
- Avoiding eye contact and animosity in body language
- Women with a history of intimate partner violence have significantly higher healthcare utilization and costs, continuing long after domestic violence ended. Healthcare utilization is still 20% higher 5 years after women‘s abuse ended compared to women with no experience of violence (Usta et al., 2012).

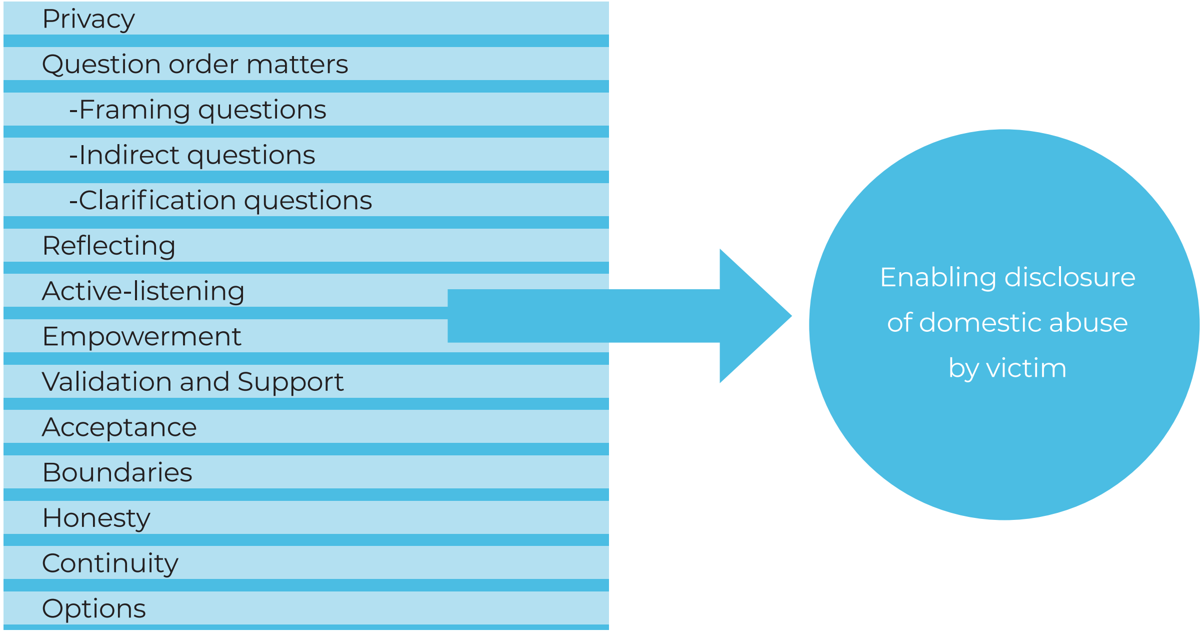
### Partner’s behaviour

- Jealousy or possessiveness
- Attempts to control time spent with the healthcare providers
- Speaking on behalf of the patient
- Insisting on staying close to the patient, who hesitates to speak before the partner

### “You‘re Not a Victim of Domestic Violence, Are You? How can physicians effectively communicate with domestic violence victims?

As a health-care provider, it is important to screen all patients for domestic violence; to provide the required medical treatment; as well as to refer the patient to relevant multidisciplinary colleagues. In this part we summarized the main principles of effective communication with victim of intimate partner violence. We shed light on screening behaviours that might increase patient disclosure and open the door to a meaningful discussion.

**Figure 5:** Overview of the main principles of effective communication with victim of domestic violence



Source: http://www.nyc.gov/html/ocdv/downloads/pdf/Materials_Medical_Providers_DV_Guide.pdf.

### *Privacy*

Domestic violence screening must be conducted in privacy, in the absence of all friends and family members. Make eye contact; assure confidentiality while stating its limitation (possible self harm or harm to others, child harm).

### *Question order matters*

- Patients are more likely to disclose experiences with abuse when providers use open-ended questions to initiate the topic and probe for abuse by asking at least one follow-up question (Rhodes et al., 2007).
- It is important to explain the purpose of asking questions about domestic violence. This can be achieved by universalizing the problem in order to provide a context that is less threatening.
- State that questions are *asked routinely to all patients because of the prevalence of domestic* violence and its potential to harm the victims. It may be uncomfortable at first, but with practice it will become easier. To minimize the patient's discomfort as well as manage the time constraints, include domestic violence screening questions in a general health status questionnaire, which is routinely administered to all patients. You can then follow-up verbally during the medical examination. It is suggested to first normalize the situation by stating that these questions are asked of all patients.
- You can start medical interview with framing questions: *"Because unfortunately violence is so common in our society, I have started asking all of my patients about it."*
- You can continue with indirect questons*: "What about your stress levels? How are the things at work?*
- Then you can continue asking a direct, clarification question: *("I see the bruising around your eye. Are there any other injuries that you would like to show me?", "Are you in a relationship where you have been hit or threatened?")*, slowing down for the screening question, and pausing for a response.
- If the patient says "no" or hesitates, a follow-up question is appropriate. Although this is a matter of style, some examples might be: *"Is there anyone you are afraid of?" "Is there a lot of stress in your relationship?"*

### *Reflecting*

*"You seem uncomfortable when I ask you about the cause of your injury. Would it be okay to ask you a few questions? "*

### *Active-listening*

*"Could you please explain to me what you mean by your partner freaking out?"*

### *Safety*

*"Do you feel safe at home? "* Discuss a safety plan.

### *Validation and Support*

Responsiveness to clues, including use of empathy and creating "windows of opportunity" for sharing highly charged or emotion-laden information, results in patients feeling known and understood (Rhodes et al., 2007). Use encouraging statements: *"Violence is not your fault"; "You deserve to be safe and respected";* show **empathy** *"I'm sorry this has happened"* Convey that abuse is wrong, unacceptable and against the law.

- Universalize the patient's experience by explaining that many people are subject to abusive relationships and that domestic violence is a worldwide problem.

- Reassure the victim that her/him feelings and reactions are understandable.
- Tell the victim that you believe her/him and that you care enough to want to assist her/him in resolving her/him situation.

### *Empowerment and strength*

*"You have a choice about your safety and whether you remain in your relationship. There are various resources available to assist you in attaining safety."*

- Encourage the victim to take an active role in decision-making.
- Praise the victim's courage to seek help. *"It is usually difficult for people to talk about violence. You did it."*
- Empathize with the patient, without showing pity. Pity can increase the victim's sense of powerlessness.
- Try to be solution-oriented. Assure the patient that she/he can survive her abusive relationship by working within a larger support system of caring professionals.
- Affirm positive decisions made by the patient regarding her physical and mental health.

### *Acceptance*

*"It is understandable that you feel sad about your relationship with your partner."*

- It is important to maintain a non-judgmental attitude toward the patient's beliefs, behaviour, and values.
- Respect the patients´ right to make their own choices about her abusive situation, and accept that your perception of how this situation should be managed, may be different.

### *Boundaries*

- Avoid showing anger, sadness, shock or distress regarding the alleged abuse, as this may cause the patient to feel that she/he has to comfort the practitioner.
- Avoid playing the role of therapist.
- In some cases, a medical practitioner may also be a victim of abuse or an abuser. Such unresolved issues can compromise the practitioner's objectivity and limit his/her ability to effectively treat a patient who is seeking help. In such case, a practitioner is encouraged to seek assistance.
- Maintain reasonable limitations with respect to providing support, so the patient does not develop false expectations of the practitioner's availability.

### *Honesty*

*"Would you mind if I discuss your situation with the social worker? I feel that we can assist you more effectively by combining our different areas of expertise."*

- Explain to the patient the relevance of your communicating with other professionals regarding the alleged abuse.

### *Options*

Discuss options *"If you decided to leave, where you could go?", "What would be your children's reactions if you requested divorce?".* Provide information about legal tools and community resources (e.g. women's shelters, support groups, legal advocacy).

### *Continuity*

Show willingness to continue taking care of the survivor *"You are not alone in this situation"*; offer a follow-up appointment. Check for barriers to access and discuss solutions.

### *Cultural competence*

Knowledge of diverse cultures is one of the core elements of cultural competence. The cultural groups discussed span *ethnicity, religion,* and *sexual orientation.*

***Cultural and religious factors:***

- When dealing with potential victim, health care professional should consider that the patient may not know that her/his mistreatment is abuse; e.g.  a total of 80% of Arab men and women asserted that abuse of a wife is not a criminal act, and some considered it legitimate and acceptable. In **Middle Eastern culture**, the welfare of the family has much greater significance than individual autonomy and independance (Pomerantz, 2017).
- **Asian patients** are usually more collectivistic and constancy, equilibrium, duty, and obligation as well as appearance of harmonious family relations are important (Pomerantz, 2017).
- Abused Orthodox woman may have to contend with a number of issues such as face a legacy of disbelief, skepticism, and recrimination from the community, built on the myth that domestic violence does not exist in **Jewish** households (Sweifach et al., 2007).
- Reporting abuse may in some cultures imply that the woman has failed as a wife and mother.
- The woman may be affraid of loosing emotional and financial support.
- Patient may believe or be told not to discuss private issues with outsiders.
- Family members may be present at medical appointments, inhibiting the process of disclosure.
- Some family members may condone and even participate in the abuse.
- A family's misinterpretation of religious text may sanction abuse.
- Community members may deny the presence of domestic violence.
- Family reputation may be perceived as being more important than an individual's needs.
- An immigrant woman's negative experience with police in her country of origin may affect her expectations of the police in this country (Usta and Taleb , 2014).
- Some religious traditions hold that even in the face of violence, women must not separate from or divorce their partners. Furthermore, some aggressors may use religion as a reference to legitimize abuse (Bell and Mattis, 2000).
- **Examples of questions that assist in understanding a person's culture** or "world view":

  *- "What is it like for you to talk about the abuse with people from your community?"*

  *- "You said that abuse is part of your culture. Can you please explain what you mean by that?"*

  *- "Do you have someone in your life that you can talk to about your situation at home?"*
- Finally, when working with **sexual minority patients**, health care professionals should be aware that these patients have learned to carefully assess the extent to which health care providers are affirmative. Health care professionals should be aware that it is even more difficult to leave aggressor for victims living in homosexual relationships due to lack of institutional support, lack of law enforcement, homophobia (Pomerantz, 2017) or high devotion to the partner (Renzetti and Curran, 2005).

**Figure 4:** How to manage a patient if she/he discloses or denies intimate partner violence

**How do I manage a patient if she/he discloses domestic violence?**

- Listen supportively and validate patient’s experience. You may be the first or only person that she/he tells about the abuse
- Provide necessary medical treatment
- Discuss existing support services, give victim a general safety plan
- Make appropriate referrals based on the patient’s needs:
- Advocacy services
- Community organizations
- Medical services
- Social services

**What if the patient is being abused but either denies the abuse or refuses help?**

- You need to respect patient’s choice of whether to disclose abuse and/or to seek help.
- Don´t push her/him: It may take several visits to the provider before the victim discloses the abuse.
- Don´t mask suggestive questions
- Attempting to leave an abusive relationship is frequently problematic and dangerous.
- Explain again why were you asking about the domestic violence
- Inform your patients that domestic violence increases in frequency and intensity.
- Let your patient know that you are available in the future if she/he chooses to seek assistance.
- Document your feelings, concerns, and treatment in the medical record.
- Screen for abuse during subsequent visits.
- Give your patient an oportunity to talk to your colleague.
- Give your patient a telephone number of help line.
- Provide information pamphlets in the waiting rooms, examination rooms, and bathrooms

Source: http://www.nyc.gov/html/ocdv/downloads/pdf/Materials_Medical_Providers_DV_Guide.pdf.

*Failing to plan is planning to fail. Safety plan.*

- Call the police if you are in danger.
- Have a signal or secret pasword to alert your neighbours. Have a person who will call the police on your behalf
- Teach your children how to call the police.
- Teach your children to go to a safe place during a violent incident (bedroom or a neighbour's house).
- Gather important documents (for you and your children), including: money, car keys, a bag with extra clothes passports, IDs, social security cards, work permit, marriage license and birth certificates, children's immunization and school records, driver's license, bank account details, order of protection, custody papers, medical insurance card, welfare identification card, and medications. Keep these documents in a safe and immediately accessible place - outside the home.
- Gather sentimental photographs (including photographs of the abuser).
- Identify a place to stay in case of an emergency.
- Know the location of your local police.
- Memorize the number of a domestic violence agency.
- Document your abuse: photographs of injuries; copies of medical and police reports; or write down each incident in a journal.
- When the perpetrator is around, stay away from rooms with weapons, such as the kitchen, or with hard surfaces, such as a bathroom, to decrease the risk of injury in times of escalating conflicts.
- You can explain patient to beware of any signs of possible domestic violence in the future relationship such as exaggerated emotional reactions, manipulation, jealousy, control, mood swings, dependence.

Source: http://www.nyc.gov/html/ocdv/downloads/pdf/Materials_Medical_Providers_DV_Guide.pdf.

## Documentation

The results of the medical evaluation should be summarized carefully with unambiguous language. Using patient's quotes is recommended.

*Medical records and telephone/written reports to (child) protective services should include:*

1. Demographic information including patient (and parent) name and address
2. Time and date of presentation
3. Comments on comorbidities; pregnancy, if present; and degree of disability
4. History, including detailed sequence of events, discovery of the injury, and the persons present at the time of injury
5. Detailed physical findings, including exact location, nature, size, colour, and of each individual location, use of photodocumentation - if the patient permits. The photographs must include the patient's face or identifying features with the injury to be useful as evidence. If a camera is not available, you can make a sketch, or use body maps
6. Psychological state, symptoms
7. Results of RTG, MR, or laboratory tests
8. The medications prescribed and the referral
9. Conclusion stating that this incident represented nonaccidental trauma and a potential for reinjury

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### Key messages

» Domestic violence screening must be conducted in privacy.

» Medical interview with patient who may be a victim of intimate partner violence should be based on Privacy, Reflecting, Active-listening, Empowerment and strength, Validation and Support, Acceptance, Boundaries, Honesty, Continuity, and Cultural competence.

» Health care professional should focus on physical signs and symptoms suggestive of intimate violence (e.g. cardiovascular or urogenital problems), psychological symptoms such as anxiety, or psychosomatic symptoms.

» Record the patient's words, describe the observed behaviour, and injuries (drawings, body map, or photographs - after obtaining patient's approval).

» The assessment of the mental status, danger severity, and follow up plans, including Safety plan.

» It is impotrant to know that child abuse usually occurs together with intimate partner violence.

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## 4.2 PEOPLE WITH DISABILITIES

*Alexandra Husivargová*

The relationship of majority population to people with various disabilities has evolved significantly over time and currently tries to achieve total degree of their socialisation, integration and inclusion (Ralbovská, 2012). Impairment can be defined as loss or damage of a certain organ system and subsequent disruption, limitation or complete lack of some of standard functions or abilities. From psychological point of view disability is demonstrated not only by the disruption of functions of a single organ system but it affects the whole personality of an individual and contributed to the creation of a specific social situation determining one's social status. A handicap represent a disadvantage caused not only by a certain limitation or impairment but also by the degree of its subjective coping and social position of an individual (Vágnerová, 2008).

Communication is one of the essential conditions of successful socialization of every person. Interpersonal communication of people with impairment with their environment is complicated by the fact that their impairment becomes the source of ridicule, contempt or humiliation. Direct communication with a person with the stigma of a certain diagnose leads in many cases even subconsciously to inadequate and particularly non-partner approach. This causes more barriers in interpersonal contact instead of eliminating them (Slowík, 2010). It is necessary to use all possible means to prevent misunderstandings. If a person with impairment articulates badly, is hard of hearing or does not comprehend the content of a conversation it is necessary to ask, repeat and do not presume what they say or expect them to understand us (Novosad, 2011).

Two categories of causes of impairment are distinguished:

- » Congenital impairment (or acquired at an early age)
- » Impairment acquired in a later age

People with impairment and their families and close people go through typical phases which duration may vary in individuals:

1. **Shock and denial** – represent the primary reaction to a subjectively unacceptable reality („it is not possible, it is not true“). Shock is evident in paralysis, incapability of any reaction. Denial of the unacceptable information is a defence of one's own psychological balance. The impaired people (or their parents) do not want to hear about the available care as they do not accept the existence of the impairment. The person bearing the news is often subjected to criticism and becomes a surrogate culprit.
2. **Helplessness** – impaired people/parents do not know what to do as they have never faced such an issue and do not know how to deal with it (they feel pain they have never experienced before; the feeling of disappointment has been replaced by helplessness, they think about where is the mistake). Feelings of guilt and shame often occur associated with the expected reactions of others. Their experience is often ambivalent as they are afraid of condemnation and refusal but at the same time expect help even though they do not know what it should be like. They have heightened sensibility to the behaviour of others.
3. **Gradual adaptation and coping** – typically includes increased interest in searching for more information and in the future. Rational processing of information is often complicated by their emotional situation. Negative emotional reactions are still present (sadness, depression, mourning, anxiety, fear, anger etc.). They use various coping and defence strategies for processing that may seem incomprehensible

to others but help them maintain psychological balance and acceptable self-evaluation. The choice of the method of coping is usually not random and stems from their life experience. Strategy of coping may have an active (tendency to fight the unacceptable situation) or passive character (an escape from the situation they cannot handle). This phase does not include only processing the situation but also looking for solutions.

4. **Bargaining** – a transitional phase when they already accept the reality but try to improve it. The meaning of this phase is to express a certain hope which is not unrealistic. It is a sign of compromise that can be understood as a signal of acceptance of previously unacceptable reality.
5. **Realistic approach** – impairment is accepted as a fact. Their behaviour is more adequate and plans are more realistic and achievable.

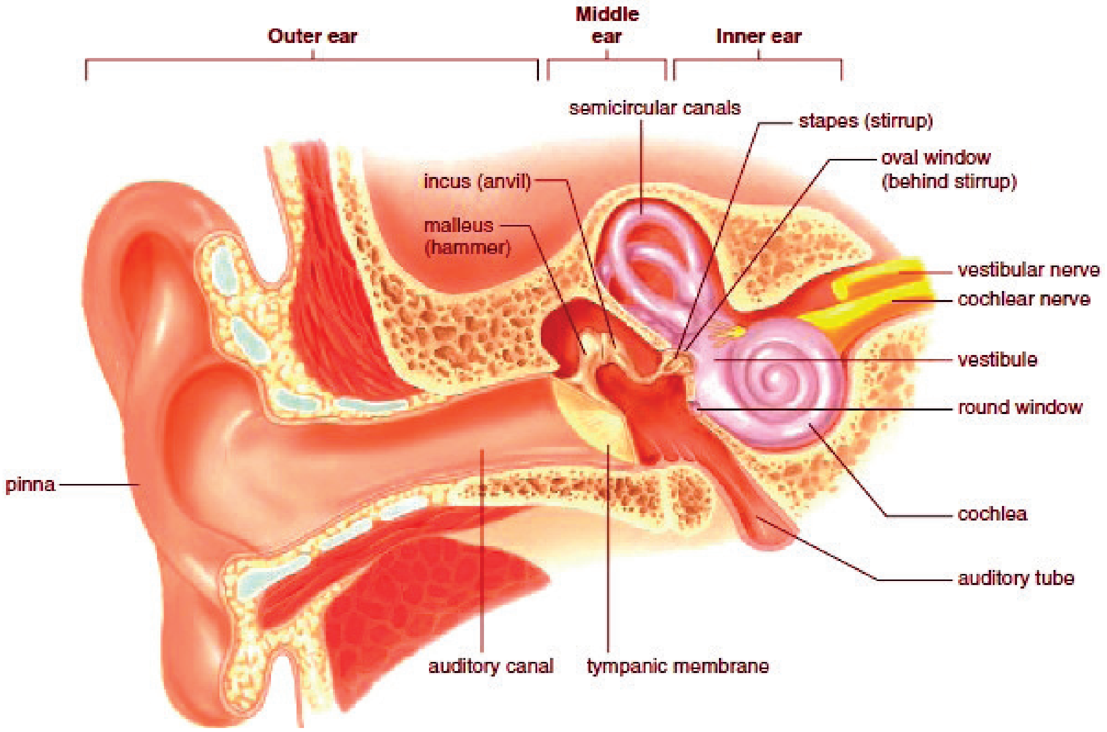
### 4.2.1 Sensory disabilities

**People with hearing impairments**

„Speaking as a deaf person I believe that the most effective “cure” for deafness is not medicine, not mechanical or electronic devices nor the surgical blade, but understanding! And, ironically, understanding is free. Before we can develop understanding, however, we must create awareness.“ (Gannon, 1979).

Auditory organ (the ear) is a sensory-acoustic organ (greek statikos = regarding balance, akostikos = regarding hearing). They are a paired organ consisting of peripheral and central part and combining two sensory organs (auditory organ and organ of balance) which have different functions – not only hearing but also perceiving the positioning of the body. Therefore, people with hearing impairments often suffer balance disorders, a fact that is important to realise when caring for and providing therapy for these people (Beňo, 2014).

**Figure 1.**



Source: Anatomy.

## Deafness prevalence

The hearing impairment prevalence depends on many factors. Socio-economic and health care conditions have an important role. This is confirmed by data from the World Federation of Deaf (WFD) that state there are about 70 million deaf people in the world 20% of which are in the Northern and 80% in the Southern hemisphere. WHO states **around 466 million people worldwide have disabling hearing loss, and 34 million of these are children** (WHO, 2018).

Generally, it is estimated that there are about 7-8% of hearing impaired in global population, regardless of age, degree and type of hearing loss. In regards of gender men suffer hearing impairment more often in a ratio of 5:4. In the population of school children there is approximately 0.05% of deaf and around 4-6% hard of hearing. Percentage of people with hearing impairment increases with age. Under the age of 20 it is around 4%, between the age of 20-40 11%, between 40-60 40% and over 60 years of age 45% of people (Leonhardt, 2001). Considering the prevalence of deaf children WHO states that for every 1000 newborns there is 1 deaf and around 3-6 that are hard of hearing. WHO also states the amount of people with hearing impairment is rapidly growing – 42 million in 1985, 120 million in 1995 and 250 million in 2001. WHO it is estimated that by 2050 over 900 million people will have disabling hearing loss. 60% of childhood hearing loss is due to preventable causes. 1.1 billion young people (aged between 12–35 years) are at risk of hearing loss due to exposure to noise in recreational settings (WHO, 2018).

## Hearing loss and deafness

A person who is not able to hear as well as someone with normal hearing – hearing thresholds of 25 dB or better in both ears – is said to have hearing loss. Hearing loss may be mild, moderate, severe, or profound. It can affect one ear or both ears, and leads to difficulty in hearing conversational speech or loud sounds.

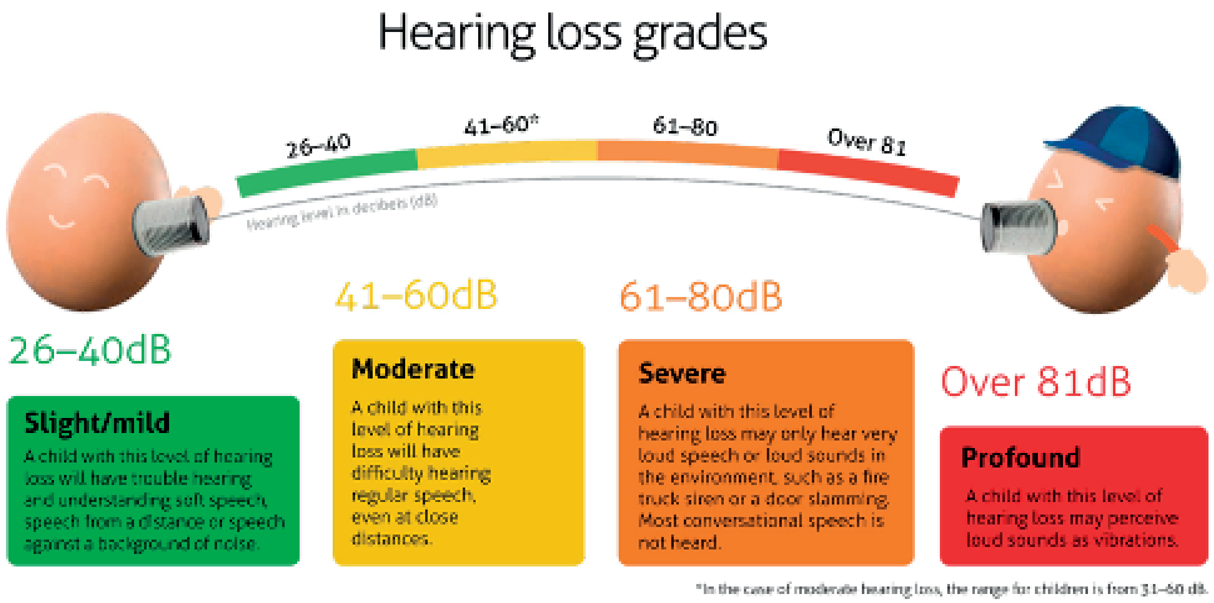
'Hard of hearing' refers to people with hearing loss ranging from mild to severe. People who are hard of hearing usually communicate through spoken language and can benefit from hearing aids, cochlear implants, and other assistive devices as well as captioning. People with more significant hearing losses may benefit from cochlear implants.

'Deaf' people mostly have profound hearing loss, which implies very little or no hearing. They often use sign language for communication (WHO, 2018).

The "90% rule" is valid for deaf people (Ward, 2009)

- 90% of deaf people has unimpaired parents
- 90% of deaf people has unimpaired children
- 90% of deaf people marries with another deaf person

**Figure 2.** WHO classification.



**Slight/mild**
A child with this level of hearing loss will have trouble hearing and understanding soft speech, speech from a distance or speech against a background of noise.

**Moderate**
A child with this level of hearing loss will have difficulty hearing regular speech, even at close distances.

**Severe**
A child with this level of hearing loss may only hear very loud speech or loud sounds in the environment, such as a fire truck siren or a door slamming. Most conversational speech is not heard.

**Profound**
A child with this level of hearing loss may perceive loud sounds as vibrations.

*In the case of moderate hearing loss, the range for children is from 31–60 dB.

Source: WHO, 2018.

### Causes of hearing loss and deafness

Congenital causes

Congenital causes may lead to hearing loss being present at or acquired soon after birth. Hearing loss can be caused by hereditary and non-hereditary genetic factors or by certain complications during pregnancy and childbirth, including:

- maternal rubella, syphilis or certain other infections during pregnancy;
- low birth weight;
- birth asphyxia (a lack of oxygen at the time of birth);
- inappropriate use of particular drugs during pregnancy, such as aminoglycosides, cytotoxic drugs, antimalarial drugs, and diuretics;
- severe jaundice in the neonatal period, which can damage the hearing nerve in a new born infant.

Acquired causes

Acquired causes may lead to hearing loss at any age, such as:

- infectious diseases including meningitis, measles and mumps;
- chronic ear infections;
- collection of fluid in the ear (otitis media);
- use of certain medicines, such as those used in the treatment of neonatal infections, malaria, drug-resistant tuberculosis, and cancers;
- injury to the head or ear;
- excessive noise, including occupational noise such as that from machinery and explosions;
- recreational exposure to loud sounds such as that from use of personal audio devices at high volumes and for prolonged periods of time and regular attendance at concerts, nightclubs, bars and sporting events;

- ageing, in particular due to degeneration of sensory cells; and
- wax or foreign bodies blocking the ear canal.

Among children, chronic otitis media is a common cause of hearing loss (WHO, 2018).

### Hearing impairment in relation to age

Classification of hearing impairment based on the age in which it occurs is important for certain specific areas of treatment. It impacts the whole process of special pedagogic intervention and often also the means of communication a person prefers, understands and uses (Beňo, 2014):

- **Prelingual hearing impairment** (hearing loss occurs before speech is developed)
- **Postlingual hearing impairment** (hearing loss occurs after speech is developed)

For people with **pre-lingual hearing impairment** it is primarily development of appropriate means of communication, mastering a language (spoken and/or sign language) and based on this education and achieving functional literacy. These people have not only problems with perception but also reception of spoken language. As they do not know what they miss in the world without sound they are less prone to psychological issues.

People with **post-lingual hearing impairment** have already developed means of communication, usually including written communication and reading with understanding. They do not have problems with reception of spoken language, but its perception. They have acoustic imagination so they can assign appropriate sounds to individual objects, animals, events etc. They are more likely to develop psychological issues because they have experienced environment filled with sound and realise what they are missing. Their primary mean of communication is spoken language to which their values and behaviour patterns are bonded (Beňo, 2014).

### People with congenital hearing impairment or hearing impairment acquired in an early age

This group includes people whose hearing impairment has developed during prenatal period, during childbirth or soon after birth (up until 3 years of age). It is comprised most of deaf people, but also of people that are hard of hearing, who usually attended school for people hard of hearing or for deaf people – this includes both elementary school and also professional preparation (Tarcisiová, 2008). Currently especially in the older age group there are very few of them who have been educated along with the non-impaired or have achieved higher education (universities). Most people in this group have been educated in traditional trades of people with hearing impairment (tailors, shoemakers, painters, bookbinders etc.) or work as qualified or unqualified labourers. After professional preparation and gainful employment, the graduates are usually professionally and socially integrated. Over time they also assume the identity of deaf or hard of hearing. In most cases their partners in life also have a hearing impairment (regardless of the degree), they were often schoolmates. They predominantly use sign language as the primary form of communication in their households which they use also in communication with their non-impaired children. In closer and broader social interactions, they communicate with spoken language that has certain peculiarities and twists. Their unquestionable communication issues are usually solved with assistance of their non-impaired relatives (commonly their children who have mastered sign language), sign language translators or by creating basic form of communication from a combination of multiple other communication forms (written communication, gestures, symbolic signs, spoken language). Because of their lower level of reading with understanding written form communication is usually not suitable as the primary form of communication. They spend their leisure time in organisations for deaf people and people hard of hearing with whom they also most frequently meet in private, even though they do not avoid private social contact with non-impaired people. With this group of people with hearing impairment we can simplistically say because they do not "know" what it means to hear or live in environment with sounds that they do not fully realise what they "miss". They have learnt to compensate for their "shortcomings" therefore they do not experience psychosocial issues and problems tied to coping with hearing loss (Beňo, 2014).

The consequence of hearing impairment and late intervention is a deformation of speech development and subsequent cogitation, development of both verbal and abstract thinking is affected. Children have a limited view; they lack perspective or their perspective is distorted. Personality formation and the formation of social relationships (family, school, friends etc.) are also affected. (Houdková, 2005)

Dissuasive attitude of some experts and non-impaired parents towards using sign language because of its negative impact on development of speech is unfounded. It has been proven deaf children whose parents communicated with them using sign language have had a communication advantage after the embedding of an cochlear implant and have had very encouraging results in their speech development (Horáková, 2012).

**People with hearing impairment acquired in school age**

The group of people who acquired hearing impairment in school age can but does not necessarily have to substantially differentiate from the previous group. The most important factors are the degree of hearing loss, at what age it has occurred, what was the level of speech development and what type of further education has the person had.

Compared to the first group there are more people who attended regular schools for a while, partly attended schools for the hearing impaired and in some cases managed to achieve higher education thanks to their developed communication skills as they usually have an advantage of having mastered reading with understanding even in case of people with severe hearing loss.

They can have speech developed to a decent degree regarding the syntactic-semantic level and morphological level even though there are obvious particularities when it comes to the phonetical-phonological level e.g. vocal intensity, vocal fluctuation, incorrect articulation, monotonousness etc. With proper logopedic care their speech can preserve a high level of comprehensibility (Beňo, 2014).

Their choice of partners in life depends on the schools they attended, the degree of hearing loss and the age in which it occurred. Most of them have partners with hearing loss but there are many whose partners have no hearing impairment. The primary mean of communication in their households varies – there are families using predominantly sign language but also families that use spoken language depending on different factors.

The first two groups mention have a common characteristic in that even though the individuals may have different degrees of hearing loss they maintain contact with other people with hearing impairment, have experience with education for people with hearing impairment, know at least the basics of sign language and do not have problems with their identity because they identify with people with hearing impairments, their values and means of communication (Beňo, 2014).

### People with hearing impairment acquired in adulthood - productive age

Acquiring hearing impairment in productive age means disrupting "normal living conditions in adulthood by impairing auditory and communicative skills that can induce a crisis for these people". Their knowledge and mainly abilities in spoken and written language are not a guarantee of an unlimited participation in life and cultural events in the society of non-impaired people (Leonhardt, 2001). Most of them have no knowledge of hearing loss and its consequences, the means of compensating their shortcomings and of organisations for deaf and hard of hearing.

A deep life crisis occurs frequently depending on the degree of hearing loss and mainly depending on the severity of negative experiences that follow. The loss of hearing is the reason for suspension, change or deceleration of professional career together with impeding the social status. The particularities of hearing loss in productive age are the cause of the specific psychosocial issues that people who lose hearing in productive age face. People who acquire hearing impairment in productive age face numerous problems both in private and professional life that bring up a lot of unnecessary misunderstandings and conflicts. As a result of hearing loss the life conditions worsen and a person is forced to change fixed routines and habits (Beňo, 2014).

This group is not as compact and well-knit as the prelingually hearing impaired. The degree of hearing loss and the fact whether hearing loss occurred swiftly or gradually play an important role aside the age in which hearing loss occurred. The requirements for support and help for these people differentiate greatly. Alongside aforementioned factors (the degree of hearing loss, the course of hearing loss and the age in which hearing loss occurred) the requirements are influenced by the previous development of personality, social situation, achieved education, individual interests and other circumstances e.g. professional and marital status (Leonhardt, 2001).

For some people the consequences of acquiring a hearing loss can be subjectively so severe they can trigger psychosomatic disorders that require care of a psychiatrist.

### People with hearing impairment acquired in post-productive age

A significant part of people with hearing impairment has acquired it in an advanced age. Most of them are hard of hearing as a result of presbyacusis. Hearing loss occurring in an advanced age is part of the aging process. Approximately after the age of 30 the auditory functions of a person deteriorate. Between the ages of 55 to 65 hearing impairments are beginning to show on speech frequencies. Physiological presbyacusis is basically a disease of longevity that impacts a growing percentage of the population. The consequences of hearing loss manifest in two areas: in spoken communication and in the orientation capabilities of an individual in an (acoustic) environment (Leonhardt, 2001).

Speech is becoming distorted and incomprehensible and therefore also loses its purposefulness.

Hardships appear in everyday life – it is harder to hear the telephone, the refridgerator, doorbell, talking children etc. Hearing loss can occur over a long period (several years) and the afflicted person does not even have to realise the issue. They often react negatively to the suggestions of their relatives or close friends and they refuse to visit a specialist or to use a hearing aid (Beňo, 2014).

Presbyacusis does not only limit perception of acoustic stimuli but also damages social relationships and private life of the afflicted and can lead them to trying to avoid social situations and even isolation.

This group is very numerous and steadily growing with increasing life expectancy of the population. This demographic trend will require creating a support system to help people overcome the consequences of hearing loss.

People who acquired hearing impairment in adulthood or in advanced age are not a homogenic group as the previous two. These individuals identify with non-impaired people and their values and norms, and they see their limitations as serious medical conditions that prevent them from participating in regular professional and social life (Beňo, 2014).

### The consequences of hearing loss

Hearing loss of various degree, aetiology or type usually causes problems in following areas:

- linguistic
- cognitive
- educational
- social
- emotional
- professional

The consequences of hearing impairment are very individual and depend on many factors (both external and internal) therefore it is not possible to precisely describe the consequences based on a single trait (e.g. the degree of hearing loss or age in which it occurs). There will always be a certain level of simplification and generalisation because hearing loss has different effects on each individual and their lives.

Experts agree that the primary area impacted by hearing impairment is the linguistic area by which we mean mastering language and speech that are the means of thinking, education, social integration and an important requirement for employment. Communication skills have a vital role in the social integration of a person, their educational and professional aspirations (Beňo, 2014).

All the aforementioned areas are important for people who acquired hearing impairment in early age or in school age, the situation of people who acquired hearing impairment in adulthood or in post-productive age is a little bit different. However, the most important consequence of hearing loss in this group also concerns the linguistic area in form of a communication and information barrier. Communication barrier is a barrier in interpersonal relations which manifests itself in various range considering objective and subjective factors that influence everyday communication. Communication barrier is not a stable factor, it does not have to be constantly present, but it undoubtedly impacts the life of people with hearing impairment (Beňo, 2014).

Inability to perceive acoustic language signals in early and preschool age prevents children from spontaneously mastering speech which causes them to learn via special educational techniques and methods. Despite the efforts of many experts their level of spoken language is very often insufficient. In many cases this also limits their development of written form of language and of reading with understanding and does not allow them to master lip reading even in cases when they learn the technique of lip reading perfectly (Strnadová, 1998).

The language barrier is less noticeable for people who have acquired hearing impairment after they have mastered spoken language as they do not have problems with its reception but its perception. In certain situations, communication is impossible or limited (e.g. without eye contact, in darkness, when there are obstacles between the people, inability to communicate during routine activities like cooking, writing). Not so long ago long-distance communication over the phone was an important barrier for people with hearing impairment but the technological advancements (e-mail, chat, text messages) have improved the situation dramatically.

Besides the level of development of speech that influences the comprehensibility for the majority population people with hearing impairment encounter a lot of situations that impede their communication and their ability to gather information (e.g. insufficient lighting, situations or technological equipment that require solely acoustic perception – name being called out in a waiting room, municipal radio, information in a workplace). The willingness to actively participate in a communication and overcome difficulties is required on both sides involved in the communication. An important factor on the side of non-impaired people is the lack of opportunities to meet people with hearing impairment and one-sided information about people with hearing impairments that they only communicate with sign language (Beňo, 2014).

Hearing loss also makes random learning that is one of primary sources of general knowledge that accompany non-impaired people in their everyday lives inaccessible. Inaccessibility of random information and random learning leads to insufficient orientation in common situations and the lack of feedback can incite frequent misunderstandings. People with hearing impairment are not able to react appropriately to the course of events, cannot understand the behaviour of people around them or react inappropriately themselves. For example, someone in a group mentions that there is a road block on the next street so the group should take a detour, but the person with a hearing impairment does not understand why plans have changed. These situations are more frequent in group situations when even a person who is experienced in lip reading has problems with communication (Beňo, 2014).

Overcoming the communication and information barrier is also supported by legislature on national, international and global scale.

### Communication with people with hearing impairment

In the heterogenic population of people with hearing impairment there are many forms of communication that have emerged or have been developed for regular communication without problems or particularly for educational purposes. They can be used separately or in combination in everyday life, in education process, over the course of whole life or in certain periods.

*Primary forms of communication*

### 1. Spoken language

Spoken language is the basis of communication process of the majority population. It has two components – perceptional and executive. Perceptional component enables a person to perceive speech (passive spoken language) and the executive component produces words and sentences (active spoken language). Hearing impairment (impairment of perception) usually causes difficulties in both perceptional and executive part. The deficiency of hearing is compensated by sight (Beňo, 2014).

The level of development of spoken language of people with hearing impairment can vary, however in general we can find particularities or distinctions in following areas:

- Voice intensity (the person does not hear himself/herself, lacks feedback and therefore speaks very loudly or very quietly)
- The voice usually has an unnatural range (unnaturally high or low, in contrast with gender and age)
- Defects of speech resonance (so-called mumbling)
- The rhytm of speech (speech is monotonous or the vocal pitch fluctuates unnaturally)
- Incorrect breathing
- Strenous and incorrect articulation
- Limited vocabulary (some people do not understand even basic words with declension, usage of abbreviations, jargon, slang or regular foreign words)
- Grammar of spoken language

Aforementioned reasons make spoken communication with people with hearing impairment difficult for non-impaired people who are not in regular contact with them less comprehensible or even unintelligible (Tarcsiová, 2008). When hearing impairment occurs later in life, a person has a bigger chance to preserve his/hers level of speech. Speech therapy is required because after a certain time the tempo, melody and voice intensity can change even for people who acquired hearing impairment late in life.

### 2. Written form of language

The lay opinion is that people with hearing impairment can overcome the communication barrier by reading and writing. The inability to master spoken language by imitation of speech in appropriate social conditions has in fact a negative impact also on reading and writing. However, it is obvious that the importance of written form of communication is rising which is correlated not only with technological advancements (e-mail, chat, text messages) but also with the emphasis on functional literacy and implementation of new educational methods.

People with hearing impairments have problems both in impressive (reading with understanding) and in expressive (creating written content) areas. The level of written communication of an individual depends on many factors, most importantly the degree of hearing loss and the age when it occurred. People with hearing impairment often dislike written form of communication because they are aware of their shortcomings in this area. Reading written information is often problematic for them therefore this way of gathering or providing information is not always effective for them.

There is no direct correlation between the level of spoken language and written form of communication. There are people with great written communication whose speech can be very flawed in the phonetic-phonological aspects and vice versa (Beňo, 2014).

### 3. **Sign language**

Laymen often consider sign language to be the form of communication used by all people with hearing impairments. This is not true as sign language is most used by people with severe hearing loss acquired in an early age.

There are many myths about sign language, most commonly the opinion that is a kind of „sign esperanto“, an opinion that is incorrect. Individual sign languages vary similarly to spoken languages. Different sign languages have certain common traits but also their own particularities. The sign languages of the USA, UK and Australia differ even though English is the primary language in these countries. Every country has their own name for its sign language: – USA – American sign language (ASL), England – British sign language (BSL), Australia – Australian sign language (Auslan), Slovakia – Slovenský posunkový jazyk (SPJ), Poland – Polski jezyk migowy (PJM), Germany – Deutsche Gebärdensprache (DGS) etc.

Sign language has following characteristics:

» a non-vocal but verbal language system

» a visual and spatial language

» visual-motoric modality (perceived by sight and produced by hand movements)

» its own grammar

» has its own sign vocabulary

» independent from spoken language

» has its own planes

» the form of communication and expression of people both with and without hearing impairment (Tarcsiová, 2005)

*Secondary forms of communication*

### 1. Finger signs

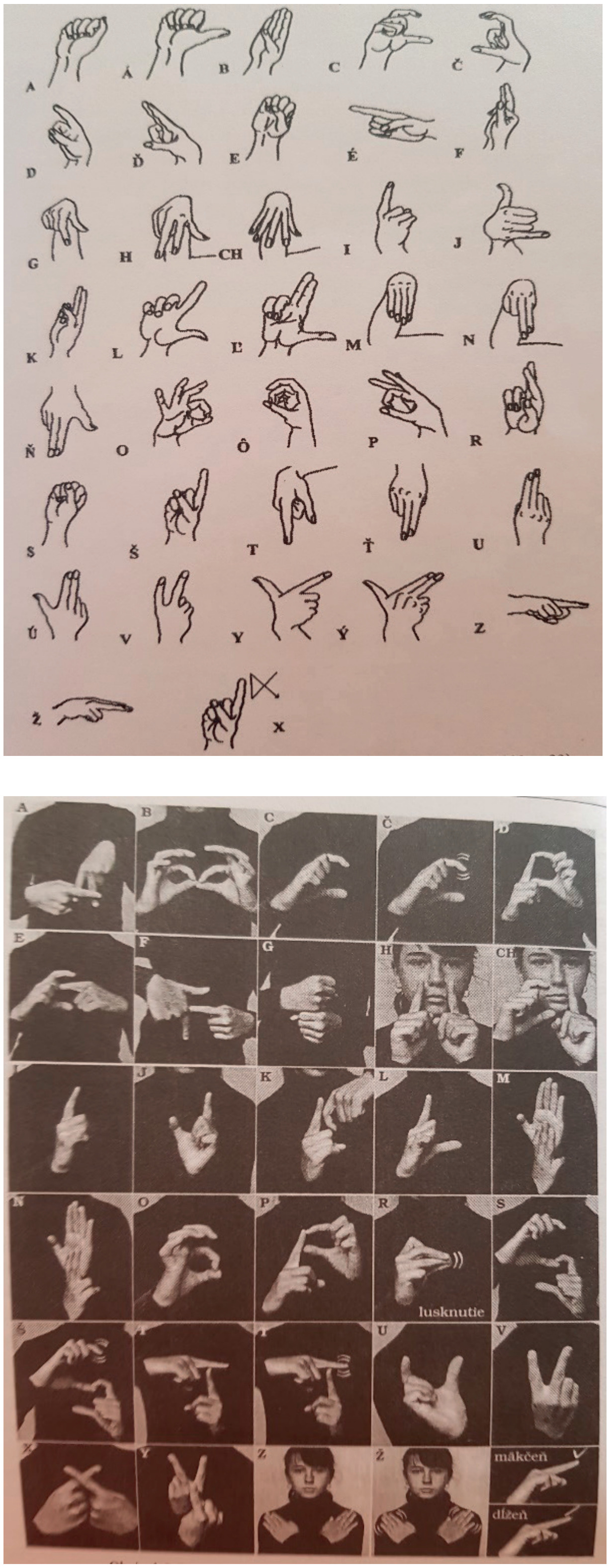
Artificially created systems of communication with a primary goal of visualising spoken language are used in education of children with hearing impairment and also in regular communication.

The finger-alphabet is the best-known system of finger signs. It is a system of finger configurations and movements that represent the alphabet. These symbols usually depict the block capital letters. There are two systems of finger-alphabet: one-handed and two-handed. The basic principle of one-handed finger-alphabet is the use of the dominant hand. The number of signs in individual alphabet varies and depends of the number of letters of the given language (Mistrík, 1984).

It is used for unknown words, geographical names, names and surnames, abbreviations or for words that do not have their own sign in the sign language yet.

The use of finger-alphabet is not suitable for fluent communication because the production of finger-alphabet is around 60 words per minute compared to 100-150 words per minute in spoken language. This can lead to a delay of spoken language or to an acceleration of production of finger-alphabet that would make its perception impossible (Woll, 1987). The other reason is that the finger-alphabet is very tiring and it requires the knowledge of the respective spoken language to understand it (Fig. 3).

**Figure 3.** Finger signs - one-handed and two-handed.



Source: Woll, 1987.

## 2. Lip reading (visual perception of speech)

Lip reading is a form of communication of people with hearing impairment about which non-impaired people have a lot of misinformed ideas. It is automatically presumed that people with hearing impairment have more developed sight so they are all skilled at lip reading. Even though the situation around lip reading is much more complicated its importance is unquestionable.

When it comes to lip reading it is important to remember that it is the ability to understand spoken language by visual perception of the movements of visible articulatory organs, lips, facial expressions, gestures and logical combination of received information. It is a form of communication of people with hearing impairment that is less reliable and very demanding on attention.

While lip reading is generally associated with people with hearing impairment it is also used, even though to a much lesser extent, by non-impaired people that have no issues with hearing, for example communication between a person on a bus and a person outside, or communication when we do not want to or cannot use voice (e.g. during a lecture, concert or loss of voice). For non-impaired people it is an alternative used in certain specific conditions usually for a short period of time and it is not the basic mean of communication so the issues and misunderstandings that arise can be explained using a different form of communication. Therefore, non-impaired people do not fully realise the difficulties that occur with the use of lip reading (Beňo, 2014).

A person can only lip read words that the person knows and has in vocabulary so a student is better at lip reading when discussing a current singular subject than during general recapitulation when the subjects change rapidly. Lip reading is less effective outside the school environment when the topics change swiftly and often. In these situations, there are so-called gaps, holes in the flow of words. A deliberate attention when lip reading and focus on both the content and logical filling and combination of spoken language is very tiring and difficult

Certain external and internal conditions are necessary to read lips. The external conditions are:

- Perfect and uninterrupted eye-contact
- Lighting of the room
- Distance between the speaker and the reader (0,5m to 2-3m)
- The height of the speaker and the reader
- The speech technique
- The topic
- The choice of linguistic resources used by the speaker
- The number of people participating in the conversation

A chewing gum, food or other objects in or around the mouth, damaged teeth structure or even moustache or beard can be obstacles when lip reading.

The most important internal conditions are:

- Ability to anticipate
- Developed speech
- Range and flexibility of vocabulary
- Development of grammatical aspects of speech
- Emotional development
- Non-impaired sight
- Use of residual hearing
- Topic of the conversation
- Positive emotional relationship to the speaker

Psychological state also influences the internal conditions – e.g. current state of health, fatigue, attention, emotional and motivation aspect, satisfaction (Horákova, 2012).

### 3. Non-verbal communication

It includes facial expressions, gestures, proxemics, posture, haptics, kinesics, eye contact, colour, olfaction etc. All these components are a natural part of communication of all people, including people with hearing impairment. In communication of people with hearing impairment, especially with severe hearing impairment, these components have their specifics or more pronounced importance.

*Auxiliary technological means of communication*

Scientific and technological development influences also the communication of people with hearing impairments as there are lot of companies dedicated to development, manufacture and distribution of compensational aids (Beňo, 2014).

These aids can be divided into three groups:

- **communicational aids** (their purpose is helping with communication – hearing aids, cochlear implants, phones for the hard of hearing, specialised cell phones, e-mail etc.)

- **informational aids** (used to gain information - lavalier microphones, headphones, computers and internet, television programming with subtitles, aplifiers etc.)

- **signalling aids** (alarms, watches, alarm clocks, doorbells, fire alarms and other signalling devices with modified visual signals (optical compensational aids), auditory signals (amplifying the primary source of sound) and vibrations)

*Interpreters*

The diversity of the population of people with hearing impairment is also proven by the fact that there are three types of interpreters – sign language interpreters, articulation interpreters and interpreters for deafblind people or tactile interpreters.

Sign language interpreters for deaf people is primarily focused of prelingually deaf and hard of hearing who communicate with sign language since an early or school age and secondarily on people with post-lingual hearing impairment who communicate with sign language but have developed speech.

### Family of a person with hearing loss

Family is the fundamental social unit of the society. The issue of families of people with hearing impairment is very broad and depends on whether the impaired person is a child, a parent or both.

*Child with a hearing loss in a non-impaired family*

Birth of a child with impairment is a great challenge for many parents for which they are not prepared. They feel frustrated and hopelessly ask “Why does it have to be my child?” Approximately 95% of children with hearing impairment are born to non-impaired parents (Tarcsiová, Hovorková, 2002). In the beginning they look for a culprit or for a way to “miraculous healing” but in the end they realise that the only way is to cooperate with experts and their own commitment. The parents must not wait until preschool or elementary school to start working with an impaired child. They should communicate (with spoken language or gestures) with the child throughout the whole day and the use of compensational aids should be implicit. Some mothers stop speaking to a child when they discover the child has hearing impairment. That causes the child to be restless, less adaptable and it can demonstrate stereotypical reactions.

The process of creating and developing speech and language of these children is in the competence of special pedagogues and speech therapists. As parents learn sign language mothers are usually more adept but only few learn to communicate in it fluently.

*Child with a hearing loss and hearing impaired parents*

The problems in communication are less frequent in families where both child and parents have hearing impairment. In these families sign language is usually the primary form of communication which the child adopts similarly as non-impaired children learn spoken language (Tarcsiová, 2010). Spoken language is also used as a part of sign language or independently while its level development can vary significantly.

*Non-impaired child of deaf parents – CODA*

Non-impaired children of deaf parents gave been recently referred to as CODA - Children Of Deaf Adults, which is also the name of an international organisation associating these children. Their focus is on the main issues of such families - two languages, two cultures, two worlds and somewhere in between the life of non-impaired children with deaf parents. A non-impaired child grows up in an environment of deaf culture as the parents involve the child in activities and events associated with deaf culture. But with education in regular schools, engaging in activities associated with non-impaired environment and relationships with their non-impaired peers the children enter the world of the non-impaired.

Communication in these families is influenced by following factors:

- One or both parents with hearing impairment
- Degree of hearing loss of the parents

- Skills and preference of communication forms of the parents
- How many children there are in the family
- Gender of the child
- Living alone or living with grandparents who may or may not have hearing impairment

In general CODA children can adapt sign language first and then they learn spoken language. Many children do not learn sign language very well and for example may choose spoken language as their primary mean of communication with their non-impaired sibling. Usually the firstborn child masters sign language fluently and becomes a kind of "family interpreter" for younger siblings and the rest of the family.

Beginning education in a regular school does not only bring more intense contact with the world of the non-impaired and the discovery of the specifics of a family with hearing impairment but can in some cases mean only the beginning of difficulties of such family. School attendance presents a series of everyday situations, duties and difficulties (e.g. homework, preparation, dictation, enriching the vocabulary, learing foreign languages, parent-teacher conferences etc.), it is therefore vital to inform the school about the specific needs of a child with a family with hearing impairment.

### *Family with a person with hearing impairment acquired in post-productive age*

Hearing loss is the third most common chronical disease of elderly people. The estimated prevalence of significant hearing impairment among people over 65 years of age is between 40-45% and among people over 70 years of age it exceeds 80% (Gordon- Salant, 2005). Despite the wide prevalence of hearing impairment only around 20% of people with significant hearing impairment uses hearing aids. Aside hearing loss their communication deficit is emphasised by a general decline of cognitive functions and slowed-down processing of speech. Lip reading is essential for their communication which becomes problematic in a presence of more people or in context of their worsening sight in seniority. Often misunderstandings lead to frustrations in the satisfaction of their communicational needs in family life, work environment and in their social life. Adaptation to hearing impairment is often dysfunctional and leads to isolation, decline of aspirations, manifestations of anger, exhaustion, which influences the family relationships and the emotional state of the person with hearing impairment.

### Communication with people with hearing impairment in medical care and social work

Services of sign language interpreters were for a very long time available solely as work of charities. They were usually provided by children of deaf or hard of hearing parents or non-impaired parents of deaf children. Situation has changed mainly in the last 20 years of the 20th century in most countries of Europe and North America. Professional interpreter service has been established, there is special education for interpreters mainly in form of bachelor programs at universities. The sign language of deaf people has been officially recognised by legislation, interpreters for deaf people are mentioned in educational laws, statutes of universities and other legislation (Metzger, 1999). Despite significant progress there are still many issues that need to be resolved including the financing of these services and the unavailability for all those who need them. UNESCO has officially recognised sign language in 1984 and the European Parliament has done the same in 1988. Law guarantees deaf people the right to use sign language, education in sign language, information in sign language in TV broadcast, libraries and the right to an interpreter.

It is not realistic to expect all doctors and nurses to learn sign language however it is vital they learn basic principles of communication with patients with hearing impairment. When an interpreter is present at the appointment the doctor should always ask questions directly to the patient, not to the interpreter. In such situation a deaf patient might feel inferior as an unequal part of the interaction. The doctor should absolutely avoid speaking about the patient in third person (e.g. "Tell him…").

Doctors and nurses have to be aware that people with hearing impairment often have trouble reading with understanding. This means they understand the meaning of individual words but they misinterpret the meaning of the full text. They also tend to have problems with foreign words – in this case professional medical terminology. It is necessary to phrase things as simply as possible. Aside from using medical terminology the most common mistakes of medical personnel are raising their voice, yelling at the patient, very slow speaking and exaggerated articulation that make lip reading much more difficult.

Patients with hearing impairment just as patients with visual impairment are very sensitive to the general atmosphere in the doctor's office. Medical personnel might have some misconceptions when it comes to people with hearing impairment regarding their behaviour, intelligence, traits etc. Sometimes they even avoid eye contact (without it communication with people with hearing impairment is impossible) or they feel embarrassed when the patient looks at their lips then they speak. Patients with hearing impairment can feel this quickly and so the communication gets stuck. They are offended when their individuality is not respected, when the doctor or nurse are impatient or unwilling to speak more slowly, precisely or to repeat a sentence. In these cases, the patient might leave the office with a bad feeling. The way in which doctors or nurses speak to a patient with hearing impairment can have significant impact on the patient. With a correct way of communication, they can influence the well-being to a patient and improve their psychological and medical state. Patients with hearing impairment usually welcome every opportunity to communicate with medical personnel that creates trust between the patient and the medic.

It is not shame, on the contrary, it is part of the professional behaviour of doctors and nurses to let the patients with hearing impairment advise them on their preferred form of communication.

Communication between a person with hearing impairment and medical personnel can sometimes fail on little things. Doctors often speak while they write prescriptions or diagnosis without maintaining eye contact. In such situations patients with hearing impairment might be confused whether the doctor speaks to them or to a nurse (Eliášová et al., 2010).

Another specific of communicating with people with hearing impairment is disruption of personal space. Non-impaired people are not used to signalling in advance they want to annouce something while people with hearing impairment are used to giving various signals before they speak (Linhartová, 2007). People with hearing impairment are generally more tolerant to touch compared to non-impaired people. If they want to make contact, they draw the other person's attention by touching hand, tapping one's shoulder, hand or leg if they sit next to each other. Tapping on the back is unsuitable because they do not see and hear the person behond them so an unexpected touch on the back can shock or scare them.

It is always advisable to ask patients with hearing impairment to tell us what they understood (not whether they understood).

**Summary**

Hearing impairment (particularly its most severe form - deafness) is the second most severe impairment when it comes to personal development right after mental illnesses. In comparison to other impairments such as visual impairment or physical disabilities (that the general populations usually respects) it is not evident on the first glance. However it is the least understood type of impairment. General (all-encompassing) term of people with hearing impairment includes all kinds of issues with hearing loss. They consist of multiple groups with their own specific problems and their needs may vary drammatically – in some cases they might be even contradictory (e.g. deaf – hard of hearing) (Hrubý, 1999).

The diversity of people with hearing impairment and their forms of communication are based to the degree of hearing loss and the age in which it occurs. Based on the degree of hearing loss the people with hearing impairment can be essentialy divided to deaf and to hard of hearing. When it comes to the age in which hearing loss occurs we differenciate betwenn prelingual and postlingual hearing impairment.

The most important issue of people with hearing impairment is a communication and information barrier. People with hearing impairment use various forms of communication, most often spoken language, sign language, written language, lip reading, finger signs etc.

### 4.2.2 People with visual impairments

**Definition and prevalence**

The International Classification of Diseases 11 (2018) classifies vision impairment as:

1. Distance vision impairment:

- Mild – presenting visual acuity worse than 6/12
- Moderate – presenting visual acuity worse than 6/18
- Severe – presenting visual acuity worse than 6/60
- Blindness – presenting visual acuity worse than 3/60

2. Near vision impairment:

- Presenting near visual acuity worse than N6 or N8 at 40cm with existing correction.

A person's experience of vision impairment varies depending upon many different factors. This includes for example, the availability of prevention and treatment interventions, access to vision rehabilitation (including assistive products such as glasses or white canes), and whether the person experiences problems with inaccessible buildings, transport and information (WHO, 2018).

According to the WHO estimates approximately 1.3 billion people globally live with some form of vision impairment. With regards to distance vision, 188.5 million people have mild vision impairment, 217 million have moderate to severe vision impairment, and 36 million people are blind. With regards to near vision, 826 million people live with a near vision impairment. Population growth and ageing will increase the risk that more people acquire vision impairment. The majority of people with vision impairment are over the age of 50 years (WHO, 2018). 80% of people over 75 years of age have severe vision impairment (Kimplová, 2014).

Approximately 80% of vision impairment globally is considered avoidable. There are effective interventions available to prevent and treat eye diseases. For example, uncorrected refractive error can be corrected with glasses while cataract surgery can restore vision. Vision rehabilitation is also effective in improving functioning for people with irreversible vision impairment (WHO, 2018). There is some variation in the causes across countries. For example, the proportion of vision impairment attributable to cataract is higher in low- and middle-income countries. In high income countries, diseases such as diabetic retinopathy, glaucoma and age-related macular degeneration are more common (WHO, 2018). Globally 9 out of 10 people with visual impairment live in developing countries (Kimplová, 2014).

### Causes and types of visual impairments

Globally, the leading causes of vision impairment are (WHO, 2018):

- uncorrected refractive errors
- cataract
- age-related macular degeneration
- glaucoma
- diabetic retinopathy
- corneal opacity
- trachoma

The causes of vision impairment among children vary considerably across countries. For example, in low-income countries congenital cataract is a leading cause, whereas in high income countries it is more likely to be retinopathy of prematurity (WHO, 2018).

There are four groups of visual impairment:

- *loss of visual acuity* – a person does not see clearly, can have issues with recognising details but have no problems with large objects or can see details but have problems with objects further away
- *impairment of the field of view* – represents the limitation of space a person can see. There can also be loss of visual acuity, difficulties with differentiating colours, worsened sight in shade etc. This type of impairment is probably the hardest to understand for non-impaired people as people with this type of visual impairment for example may be classified as blind and use a white cane while walking but they can be able to read newspapers. It is so-called tunnel vision (retinis pigmentosa) when they are unable to safely and independently move around the environment without compensational aids.
- *oculomotor issues* – these issues occur with incorrect coordination of eye movement. People with this type of impairment can have problems with grasping objects and precise movements.
- *difficulties with the processing of visual stimuli* – eye as an organ is intact but an individual is unable to process incoming visual stimuli correctly.

**Figure 4.** Normal vision vs. early cataract and advanced cataract

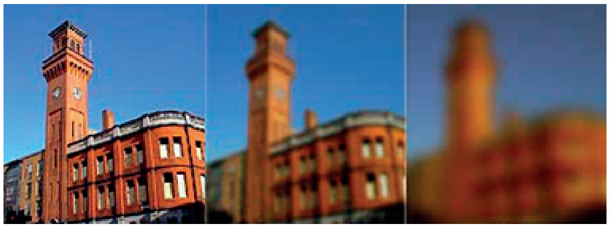


**Figure 5.** Normal vision and retinitis pigmentosa

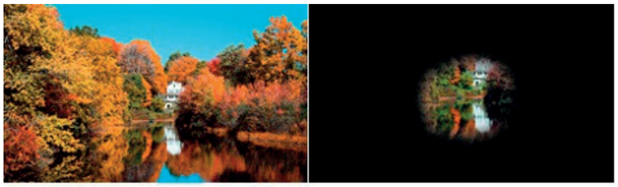
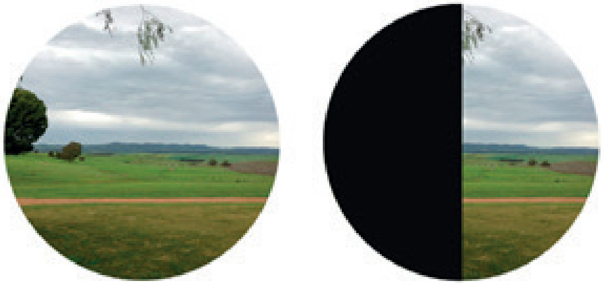


**Figure 6.** Normal vision and macular degeneration

**Figure 7.** normal vision – homonymous hemianopsia (hemianopia)



## Children with visual impairment

Birth of a child with visual impairment is a very difficult situation for most families as parents try to look for answers regarding its consequences and limitations, they are left helpless over medical reports, do not understand the impairment and have no clue how to proceed with the upbringing in an effort not to neglect their duties (Kimplová, 2014).

Prenatal factors have the highest percentage share of contribution (55%) to the prevalence of visual impairment. They can be divided into physiological (injury of the mother, RTG etc.), chemical (medicine, alcohol, drugs) and biological factors which include also viruses and microbiological agents (rubeola, syphilis, AIDS, tuberculosis etc.). However out of these 55% the largest contributor is heredity (37%) (Kimplová, 2014).

The impact of visual impairment on the development of child's personality and individual psychological processes is affected by multiple factors. Some of the most important are the age in which it occurs, the degree of impairment and also the personal characteristics of a child and the functioning of its family. Aside the impact on range and quality of sight external symptoms might have negative influence of the development of a child and its social relationships. Many children with visual impairment blink excessively, rub their eyes, press their eyelids, squint or have problems with establishing and maintaining eye contact. They may collide with objects, their movement in unknown environment is very insecure and they may have problems with visuomotor coordination with manipulating with objects (Květoňová-Švecová, 1998). Říčan and Krejčířová (2006) point out that in terms of activation of a child there are some noticeable actions like rocking, swaying, swinging hands or pressing eyelids that are ways in with children activate themselves. These symptoms are often linked to neuroticism, automatisms or social deprivation but they are also prominent with children living in stimulating and functional families. It is advisable to turn these symptoms into socially acceptable form of activities with involves contact with surroundings (e.g. nursery rhymes, swinging on a seesaw etc.) (Kimplová, 2014).

In general, congenital impairment is not that subjectively traumatising for a child but it present a bigger challenge for its psychological development. Impairment acquired later represents an irrevocable loss of existing ability and is therefore much more traumatising. The age in which it occurs significantly determines the subjective reaction of people and their families to visual impairment. Visual impairment rids a person of the advantages of simple and quick orientation in current social situation that can bring useful information (Vágnerová, 2008).

Children with visual impairment already begin to realise that they are at approximately 5 years of age. They begin to express this observation and talk about it with adults. It is necessary to answer very carefully because at this time the children begin to accept their impairment and shape their self-esteem. The children should fully participate in family life so they can identify with the family and its healthy members and can emulate their actions and the sentiments of their parents and siblings (Čálek, 1986). Vágnerová (1999) mentions the beginning of school attendance as the time of crisis for these children as they have disproportionately developed skills and knowledge required to handle the school demands. The phase of adolescence after school is a sensitive period of their life as people with visual impairment are at a bigger risk arising from a more difficult way of satisfying their needs when it comes to their self-fulfilment regarding their choice of profession, life partner or more problematic beginning of work process. People with visual impairment often consider their impairment to be the reason of all their trouble.

Children and adolescents who acquire visual impairment as a result of a progressive disease, after an operation or injury are subject to individually traumatising experience.

For children and adolescents, the process of accepting visual impairment according to Čálek (1986) is just as important as for adults because it concerns the development and functioning of their whole personality.

### *Children and their development*

Sight provides a lot of important information about the environment, encourages curiosity, learning, movement and social interaction. Visual impairment of any degree presents a deficit of stimuli which can cause sensory deprivation. Sensory deprivation can develop both on a quantitative (less incoming information) and qualitative (content, properties and value of incoming information) level. It is very important that other senses and psychological processes are stimulated and developed right after the diagnosis of visual impairment. That lowers the risk of developing sensory deprivation or limits its extent and protects the healthy development of the children especially in cognitive, motoric and social areas. In this context we talk about so-called **compensational mechanisms** that are divided between **lower (hearing, taction, taste, olfaction, residual sight)** and **higher (cogitation, memory, attention, imagination, speech).**

- Auditory perception - in comparison to other senses brings the fastest information about the environment, warns about imminent danger and helps with spatial orientation. Vágnerová (2008) notices that the auditory perception of blind people becomes more sensitive and differentiated based on its more active use in learning and spatial orientation. Smýkal (1986) advises the families of children with severe visual impairment that these children might be more sensitive to sounds and that is why it is necessary to communicate with them as much as possible but silently and to avoid strong or sudden sounds. The children learn with time to estimate the distance of the source of a sound, to not pay attention to white noise, identify characteristic sounds or familiar people by their voice or way of walking. The children also learn to perceive the psychological state, traits, mood etc. of the person they communicate with based on the paralinguistic characteristics of speech (rhythm, intensity, range, speed, fluidity, melody).

- Tactile perception - non-impaired people tactile perception is relatively underdeveloped when it comes to gaining information, its development is not spontaneous (Vágnerová, 2008). Methodical drill has to follow a whole scale of rules. It is important to teach the child from the beginning to perceive slowly and carefully. A precise verbal description is needed to create a correct image of perceived objects. The younger the child the easier it is to learn new objects. Not only hands stimulation but also the development of tactile perception with feet (e.g. learning to distinguish quality and type of surface, changes of surface etc.) is very important for spatial orientation and independent movement (Keblová, 1999).
- Olfactory perception - non-impaired person olfactory perception is by far not as important as to people with severe visual impairment. Olfaction helps blind people with spatial orientation (e.g. to find an entrance to a specific shop, recognising familiar people etc.), provides information about objects and events in their vicinity and helps shape children's visualization of the environment (Keblová, 1999). It is important to methodically develop olfactory perception of children so they can in the future identify also hazardous materials (e.g. natural gas, smoke, gasoline etc.).
- Gustatory perception - helps with the projection of the environment. Keblová states it is necessary to methodically develop also gustation and to name and learn to orientate in the terms of sweet, salty, sour, bitter, to distinguish the intensity of the taste and to recognise the typical sources of certain tastes. Gustation can have mainly preventive use when learning to distinguish healthy taste from rotten products. It can also be connected to emotional life as pleasant tastes can be a motivational factor.
- Visual re-education - is important in case there is residual visual perception or light perception is preserved.

The following higher compensational mechanisms can be developed in case cognitive processes are available to use.

- Attention - significantly influences quality of all psychological processes as attentiveness of the organism is the basis for exploring the environment. The primary (and fastest) source of sensory stimulation is vision. If vision is impaired it is crucial to activate the organism in other ways to avoid arrested development.
- Thinking of children with severe impairment has its specifics as blind children often have trouble comparing objects or identifying objects with the same or similar traits and characteristics and with generalisation. Požár

(2007) states thinking is very particular and it is important for children to distinguish relevant and irrelevant attributes.

- Memory - children with severe visual impairment use memory a lot more that healthy children e.g. whereas a healthy child can use sight to orientate itself in a room a child with visual impairment has to evoke memories of known space or has to explore the environment with other senses.
- Imagination - similarly to non-impaired people imagination is a psychological process used to shape images with the use of other psychological processes and conditions, knowledge, experience, character of activities, educational conditions etc. Blind people create tactile, auditory, olfactory, gustatory, vibrational, motoric images and self-awareness.
- Speech - is a very important compensational mechanism for children with severe visual impairment as it connects them to their surroundings. The socialisation of a child depends on speech. Blind children often use speech to establish and maintain contact or to draw attention. The impairment of communication skills is less evident if there is more residual vision. Mild visual impairment usually has very little to none impact of the development of speech but the influence on speech of children with severe impairment is very significant. Niemann and Jacob (2000) mention other specifics of the development of speech of blind children. Small children more often repeat after others rather than express their own thoughts. They ask a lot of questions to gain information about their surroundings as they cannot see the events around them.
- Non-verbal communication is especially impaired primarily by the lack of eye contact and feedback. Children with severe visual impairment have limited possibility to establish spontaneous non-verbal communication. Limited facial expressions and different method of communication make communication and establishing natural relationship between children and parents more complicated. The lack of distinct emotional expressions of a blind child's face can also be a significant complication when it comes to establishing a relationship. Compared to non-impaired people facial expressions are less pronounced and have less value. Children have to learn how to smile, has to learn its value and how to recognise it based on voice. Small blind children do not turn to the person to which they speak. Children with visual impairment do not realise at first that their non-verbal communication has informational value which often means they do not regulate their motoric automatisms.

### Different psychomotor learning

Psychomotor learning of children with visual impairment has its specifics. Psychomotor learning of these children in early age is very dependent on ear-hand coordination (children mostly observe objects they have touched) and only later they start to move towards objects connected to sounds. Crawling according to the "sound key" appears at the end of the first year with the children not crawling on all fours but sliding on their behinds or on their back or standing up and moving along the walls. Most children start walking at 18 months with some starting at 2 years of age.

Fine motor skills are usually well developed. Capabilities in graphomotor skills and drawing depend on the severity and the age in which visual impairment occurs, on the ability to perceive projected objects, distinguish their characteristics and create visual images (Davido, 2001).

### Families of children with visual impairment

How a family reacts to a child's impairment depends on many factors including family and community resources, current stressors, financial resources, number of children in a family, severity of the impairment, communication between family members etc. Birth of a child with visual impairment affects the general mood of the family. Necessity to withstand such an issue can sometimes bring a family closer together, enhance the relationships, bonds and support while in some cases it leads to families falling apart (Vágnerová, 2009).

Birth of any child means a great change to family dynamics and its internal relationships. When a child is born with impairment the parents are shaken and their plans of their child's future are ruined. Parents with an impaired first child are often afraid to have another child because they expect it to also have impairment. If they decide to have another child and it does not have impairment the family life usually settles and starts functioning in a "healthier" way (Dytrych, Matějček, 1997).

If the child with impairment is born as a second child it is also perceived as a loss but it is not as threatening to the identity of the parents as with a firstborn child with impairment. The family is already accustomed to a life with child and it is less demanding to organise it. Other people also view the birth of a second child with impairment to be more "advantageous" and it is usually perceived as a misfortune that has occurred to an already functioning family.

Another group consists of children with sudden vision loss or deteriorating vision. Children are less prone to tumultuous reactions in comparison to adults who acquire vision loss. There can also be apathy, tearfulness or other emotional reactions that depend on the reaction and behaviour of adults in their proximity, the age in which impairment occurs (children in puberty usually have worse reactions), their social connections etc. It is vital the previous relationship between parents and the child are not disrupted for further functioning of the family and successful acceptance of the impairment.

*Divergence in adaptation and its impact on upbringing of a child with impairment*

#### 1. Hyperprotectivity

Hyperprotectivity is an exaggerated or extreme care for a child when the parents pay an unhealthy attention to the well-being and satisfying the child's needs at the expense of other members of the family. The consequence of this approach is a hindered development of the child in some areas as the parents do not pose demands and requests on the child's development. If only one of the parents is hyperprotective it can lead to the marriage falling apart. Matějček (2001) lists four types of hyperprotective nurture: pampering, anxious, perfectionist and protective.

#### 2. Rejection of the child

The rejection of the child usually occurs when the impairment is visible since birth while a strong bond has not yet been created. Rejection usually occurs with only one of the parents who avoids the child and distorts the relationships and the functioning of the family. This can lead to jeopardy of abuse or negligence. Matějček (2001) differentiates two types of rejection – condemning and negligent.

*Extreme nurturing approaches in families with more children*

In ideal cases the family adapts and fulfils the needs of the child with impairment while at the same time fulfilling the needs of other members of the family. However, there are two extremes that often occur – parents focus all their attention on the impaired child and neglect its siblings or they try to focus on the siblings while neglecting the development of the child with impairment.

### Adults with visual impairment

People born with visual impairment who have grown up in a stimulating environment, know how to use compensational aids, have built their own identity in adolescence, know their own abilities and direction in life and have a system of values do not experience major changes and transformations in adulthood.

Loss of vision in adulthood means a difficult life situation for them and their families. It is a traumatic experience that affects almost every aspect of their lives. The psychological impact on their personality is individual depending on the shaping of a personality before the loss of vision and on the social environment. Loss of vision can have various degrees, types and can occur in a number of ways. People usually experience primary shock followed by reactive depression (a phase of looking for a culprit, aggression towards the world and oneself) and then they reach the phase of reorganisation (see phases of acceptance of impairment).

On the question whether vision loss changes the personality of the impaired person Souček (1992) notes that: "In its essence the personality remains intact. It is rather consolidated and if it was weak before, its weaknesses are enhanced. There are many examples of people who have done their best work after losing vision."

### Prejudice and visual impairment

Prejudice is a major part of our attitude towards people with visual impairment and there are many myths and half-truths about them in the public. People with visual impairment are often considered to be inferior and there are some emotions tied to approaching them: pity, compassion, charity. It seems the impairment attracts all of the attention of non-impaired people and covers all of the other characteristics that people with visual impairment have just like everyone else. This distorted view of people with visual impairment shapes the behaviour of non-impaired people toward them. Many of these behaviours have persevered over the course of time and are even now present in different variations. There are three types of prejudice: underestimating, dismissing and idealising.

The most common myths about people with visual impairment are:

- Blind people only see **darkness**. Clients with complete vision loss describe their inability to see as more of a "nothingness". And what is nothing? Definitely not darkness. Some blind people have visual hallucinations, perceive flashes of light or have a "darkness" of colour etc.
- People with visual impairment since birth **have much better hearing (often musical) and touch**. Blind children do not have these advantages it is all a matter of training, experience and partially talent.
- In the company of a blind person we **should not talk about colours and other visual stimuli** and we **should not say things like "look", "we'll see"** etc. Blind people use these phrases

in their everyday lives and are surprised if non-impaired people try to avoid these phrases.

- A person using a **white cane or wearing black glasses is blind. The more dioptres the worse is the vision.** This is not a valid statement as most people do not realise the vast number of different visual impairments.
- Loss of vision brings **total dependence on others**. This misconception usually stems for people's own fear and notions of "how it is to be blind".
- We have to **talk loudly and clearly** to a blind person. In many cases people address **the guide** of a person with visual impairment. In most case blind people are not deaf or mentally impaired and it is necessary to talk directly to them.
- A person with visual impairment **is always grateful for our help**. It is necessary to ask in advance whether they need help and if they refuse we should not understand it as a sign of ungratefulness.
- There is no reason for blind people **to have paintings and mirrors in their homes**. Aesthetics is not only a question of sight.
- We should not let people with visual impairment **know about things like their dirty shoes or shirt** because we would offend them. They **do not care about it as they cannot see their clothes**. It is important to tactfully let them know about such matters as we would anybody else.

### How to help properly

We have chosen a few examples of how to help a blind person from the guidebook of the Association of blind people in Slovakia [Únie pre nevidiacich na Slovensku] (1996). If a blind person accepts our help we offer them our arm (forearm). We do not drag the person by their hand nor do we push them in front of us. While walking we can describe what we see – but not to absolute details, it is enough to describe things as we would in a normal conversation as blind people gain a lot of information through other senses. It is usually enough to alert them to what comes next, for example first or last stair (it is not necessary to count all stairs), curbs (up or down) etc. We can also notify them about inoperative escalators, new shop on the corner etc. When approaching doors or tight spaces the guide enters first.

People with visual impairment who are able to move and travel independently know how to travel. If they accept our help it is enough to lead them to the door and show them the door handle by putting their empty hand on it and telling them how big of a step, they have to make. If we want to leave a seat or navigate blind people to an empty seat in public transportation, we put their hand on the empty seat or the handle on the seat and tell them the empty space is on the right of left. We should definitely not push them down or turn by their arms. With regular cars we may lead blind people to the space between the car and the door and place their hand on the top of the car.

We should never say "there is the chair", "the table is back there" etc. as this has not informational value for blind people. We should rather say "the chair is in front of you" or "the table is around three meters behind you" in the same way as when we hand them water, ideally into their hands or putting it on the table commenting on where we are putting it.

If we take a coat or a bag from a blind person e.g. in a train or a hospital, we should always tell them where we are putting it "Your coat is on the first coat hanger on the right".

When we leave we have to inform them. In loud environment it might happen they do not hear us and it is uncomfortable to speak to an empty chair. We also have to announce or return.

When we are receiving payment or changing money for a blind person we should always inform them beforehand about how much money they are giving us so we avoid mistakes and misunderstandings.

When a person with visual impairment needs to use the bathroom we can enter the bathroom together if we are of the same sex. Before use we can check whether the toilet is clean, show them where is the toilet paper, toilet flush, sink, soap and hand dryer. We should not hesitate to tell them if e.g. the towels or toilet are dirty. We should always behave tactfully as we would want other people to treat us and if we are waiting for them we should not stay close to them. If a person of opposite sex guides a person with impairment they should ask staff or someone of the same sex for help. If there is not anyone around we should follow the previously listed rules.

If a blind person asks us to read a text or letter for them, we should always start with telling them who is the sender. They might be expecting a different letter and it would be uncomfortable for them if "a stranger" reads this letter. It is often uncomfortable when it comes to personal correspondence, administrative letters or financial documents. When reading these documents, we should proceed tactfully and discreetly. We should read slowly and clearly and we should never open a letter without a clearly expressed permission.

Order and punctuality are very important for blind people and these rules should be respected. If we touch any belonging of a blind person we should return it to its place, if we are not certain we should let them put it back. Make sure you do not leave doors ajar or misplaced object like brooms or buckets. The punctuality of a meeting also has its importance.

A blind person with a guide often hears questions like "Madam, would this gentleman like a drink?", "Sir, would this lady like to sit?" People often talk to the guide instead of the blind person. One lady answered: "You can ask my husband; he really isn't dangerous!" People are accustomed to eye contact and when it is lacking they feel insecure. Asking these indirect questions is extremely impolite - if we have a question we should always direct it at the person and not their guide.

As people learn about the independence of blind people it can lead to some people hesitating to offer their help even in case they see a blind person struggling on the street, at a railway station or anywhere else. Other extreme includes people who follow a blind person to stop them at a critical moment from sudden touch with an object that is in their way. Their intentions are good as they presume a blind person will not notice anything. In most situations – especially outside – blind people focus on their other senses as they have to compensate for their lack of vision. Hearing play a vital role in this and the blind people realise they have a "guardian angel" and it disturbs them, makes them anxious and the good intentions lose their effect.

### Deafblindness

Deafblindness is combined sight and hearing impairment, which causes educational learning, communication and development problems. According to Best´s classification, we divide deafblind people into four basic categories:

1. Totally deaf and blind
2. Totally blind and hearing impaired
3. Totally deaf and sight impaired
4. Sight and hearing impaired (with residues of sight and hearing)

**Communication**

*What do we understand under the term communication? It is a means through which people connect with their environment and with other people.* Children with limited or compete loss of sight and hearing need longer time to develop their language than healthy children. In the development of their communication skills, non-verbal communication evolves through communication by means of objects or pictures to the sing language. Not every individual, however, is able to manage those methods of communication, therefore some of them, even in their adult age, communicate though pictures and objects, or are able to passively recognize sign language signs, but they don´t use most of them actively.

Gradual development of communication in the case persons with dual sight and hearing impairment:

**Non-verbal communication** (facial expressions, laugh, crying, head and body movements, muscle toning and relaxing, fast breathing, gestures and other

**Communication through** objects (individual objects refer to specific activities, e.g. a spoon inform a child that ”now you are going to eat", a ball means that you are going to exercise

**Object-based calendar** (a calendar made of objects, through which a child orientates himself/herself about what he/she is going to do during a day

**Symbols** (after managing object-based communication, a real spoon is replaced by a small plastic one, a large ball by its small replacement)

**Pictures** (symbol-based communication is gradually replaced by pictures, showing specific activities (a picture of a spoon, a ball, etc.))

**Pictorial calendar** (a programme for a whole day, compiled from pictures)

**Sign language** (sings of deaf people, as well as hand in hand sign language and tactile sings are used)

**Finger alphabet, writing of words on the palm of a hand, writing and reading** (these methods of communication are less frequent than previous ones)

**Drawing of experiences, pictures** (using a drawing to express experiences or a certain need that a deafblind person is unable to express with a sign)

**Braille alphabet** (the principle of raised dots, embossed into paper, which the reader perceives by his/her touch)

**Lorm alphabet** (touching of arts of palm and fingers of other person with an index finger (each letter has its place on the palm)

**Tadoma** (perception of spoken language through a deafblind person´s palm´s touch of the area of the throat and the lower jaw of the speaking person (perception of the vibration of the vocal cords)

Beňo (2014) described communicating with people with both hearing and sight impairment there are certain rules that need to be automatic. Cooley lists the following rules:

» announcing presence

» identification – the person has to recognise us, we identify with a gesture, tactile keys, certain objects, etc.

» anticipation of the future – one must be able to predict next steps

» independence – to develop independent movement it is necessary to follow a thorough schedule and use of sensory keys by everyone involved

- a freedom of choice – the independence of a child is supported by choices - we always try to offer a child more activities which enable the child to choose what it wants to do in the future
- ending of an activity – when ending an activity we use a signal so the child can anticipate the end
- announcing departure – the deafblind are entitled to privacy and intimacy, when we leave, we have to announce it

Example of activities of Maják (Lighthouse) – specialised facility for deafblind adults near Košice:

morning cycle, exercise and walks in the vicinity, art therapy, massages, visit to equestrian school, trips to the nature and to the city, visit to exhibits, exposition and museums, occasional visit to pool, social rehabilitation, relaxation in a salt cave, visits to the library, chess club, participation in bowling competitions for visually impaired, making of postcards, making pastry, making of interior decoration for Christmas and Easter and birthday celebrations of clients and staff.

### 4.2.2 Physical disabilities

Current society significantly values performance, image and success of an individual. Those with disadvantages or distinctions are perceived as unattractive, potentially and practically removed from the main social course of events causing the decreased quality of life of people with physical disabilities (PD). PD is still commonly perceived as a primary characteristic, the main personality trait of an individual even though the existence of impairment does not have a bearing on the personality and real capabilities of the person with impairment (Michalík, 2011). Visible physical deformity always has an impact, mostly negative, and social importance that can be larger than the impact of a functional handicap (Vágnerová, 2008).

Currently PD is defined as a **long-term or permanent state characteristic by an organ or functional disorder that cannot be completely eliminated or significantly alleviated with health care**. This state represents an impairment of a single or multiple areas of usual functioning of a person that brings significant reduction of their abilities and life opportunities, limits their professional possibilities and negatively affects many areas of their quality of life. In accordance to this definition Michálek (2011) classifies people with impairment into two groups:

- Chronic diseases (or lasting adverse health conditions) – damage or debilitation of physiological functions that requires maintaining a certain lifestyle and therapeutic procedures. Significantly decreases their quality of life, performance, endurance and may lead to limited mobility. It is also referred to as internal impairment as it does not have to be externally noticeable and therefore does not stigmatise a person as much.

- Physical (locomotive, motoric) impairment – limited or disabled movement and dysfunction of motoric coordination in causality to damage, evolutionary flaw or functional disorder of supporting and locomotor system; central or peripheral disorder of innervation, amputation or deformation of a part of motoric system. These flaws or dysfunctions are usually visible and cause a permanent decrease of functional performance and loss of ability in a single or multiple areas of locomotion.

Vágnerová (2008) divides PD into locomotive defect (functional handicap) and bodily deformity (aesthetic handicap).

**Congenital v. acquired impairment**

Social status and psyche of people with congenital impairment (and their parents) develops differently compared to people whose health condition changed during the course of their life. It is impossible to say in general whether one of these groups is in a more “advantageous” position. The life’s journey of people with congenital impairment has always included the reality and individual aspects of the impairment. They have gradually established necessary experience and skills and created a relevant self-perception. It does not mean they always received proper support and that they do not experience crises, failures and disappointments. It can be argued that people with congenital impairment has the time, empirical experience and a variety of support mechanisms to adapt to their situation, accept it, find a way to their self-realisation and learn to live in a best possible way.

A sudden change of health and social situation thwarts this opportunity for people with impairment acquired later in life. We can agree that the pressure on human psyche during an injury, operation or acute onset of a disease and functional insufficiency or even impairment is very severe. If the problems are successfully dealt with (pains, successful rehabilitation) a person overcomes psychological trauma and returns back to life. Crisis arises when permanent disability in form of chronic disease or physical impairment occurs to people who did not have prior health issues. For them impairment represents an interference of the quality of life, limitation of activities and opportunities, negative impact on social, personal, family and professional life and forces a change of attitudes. It can also result in a breakdown of a family, loss of existential security and change of social environment’s approach towards them (Michalík, 2011). In these cases, a timely intervention is crucial.

People with PD should cooperate with a whole team of medical personnel: experts (orthopaedist, neurologist etc.), rehabilitation physicians, physiotherapists, psychologist, special pedagogues and social workers.

Lechta (2010) notes the basis of a correct treatment of people with PD is respect towards them. Respect means expressing the knowledge of a person’s value and must be internalised to impact the thinking and experiencing to the extent of emanate from every word, action, approach and method of help.

### 4.2.3 Mental disabilities

**Mental retardation**

Mental retardation (MR) is an impairment of cognitive abilities demonstrated by an inability to understand one's surrounding and adapt accordingly. MR is congenital and permanent. There are approximately 3% of people with MR in the general population out of which 70% have mild MR. The cause of MR is an impairment of the CNS (Vágnerová, 2008).

**Classification**

| MKN - 10 | Verbal denomination | Old name | IQ range |
|---|---|---|---|
| F 70 | Mild MR | Moron | 70 – 50 |
| F 71 | Moderate MR | Imbecile | 49 – 35 |
| F 72 | Severe MR | Idiot | 34 – 20 |
| F 73 | Profound MR | Idiot | 19 - 0 |

**Psychological characteristic of MR**

Typical sign of cognitive abilities of people with MR is limited curiosity and preference of stimulation stereotype meaning people with MR are usually more passive and depend on mediation of information from others. Orientation in regular surroundings is more challenging as they have trouble distinguishing important and non-important part of individual objects and situations and understanding their mutual relationships. The world is less comprehensible to them and may seem more threatening resulting in stronger dependence on others (Vágnerová, 2008).

*Cognitive disorders*

The cogitation of people with MR can in best case achieve the level of specific logical operations. Their thinking is restrained to reality and it is important to them how the situation seems to be, as they are not able to think about its essence. They are unable to dissociate from themselves, their emotions and desires that impact their cogitation. Their lack of insight results in impaired judgement, heightened suggestibility and stereotypical and rigid thinking (Vágnerová, 2008).

*Speech disorder*

Speech of people with MR is usually impaired both in form and content:

- Less precise pronunciation
- Limited vocabulary and misunderstanding of context associated with it (inability to understand complicated collocation of words, jokes, irony, metaphors etc.)
- Verbal insensitivity
- Simplistic expressions (short sentences, specific terms – necessary to communicate briefly and simply with them)

People with severe MR are unable to communicate verbally therefore non-verbal communication is important (Vágnerová, 2008).

*Learning disorder*

Learning ability is limited because of the lack of understanding and lack of concentration and memory. Their learning is mechanical so everything they learn they fixate in rigid form and use these information/skills in the same way. They have significant trouble reacting to changes or new situations. Learning new things is unattractive so it is important to motivate them with compliments or material rewards (e.g. favourite food). They are more willing to learn with a person with whom they have a positive relationship as they are motivated emotionally, not cognitively (Vágnerová, 2008).

*Emotional experiencing*

Overall emotional experiencing changes in regard to the aetiology of the MR, usually they have heightened irritability, are more inclined towards affective or moody behaviour. Their emotional experiencing is the basic mechanism of their self-regulation. Insufficient rational evaluation and inadequate control of their own emotions limit the development of more efficient means of self-regulation. This fact combined with the focus on the present leads to the preference of behaviour that brings immediate satisfaction. Their inability to regulate their own emotional experiencing increases the possibility of inadequate reactions to stimuli (Vágnerová, 2008).

*Behaviour*

People with mild MR are able to understand values and norms and comprehend their essence. People with MR may have problems evaluating new situations and applying usual rules to changing circumstances. In case of even minor changes they may be disoriented and may react inadequately as they are controlled primarily by their emotional impulses. The ability of self-regulation is underdeveloped and often causes affective reactions. This behaviour may be a signal of being overloaded and unable to react in a more mature way. These uncomfortable, affective or even aggressive expressions are a defence mechanism to situations they do not understand or are not able to handle and an inability to express their current feeling in more regular way, in a way more comprehensible for others (Vágnerová, 2008).

*Self-acceptance*

Self-acceptance is an important part of one's personality that is affected in people with MR by their way of thinking causing their self-evaluation to be subjective, non-critical and emotionally based. Because of their limited judgement they are dependent on the opinion of others. People with MR accept their opinions automatically and together with heightened suggestibility this makes them prone to being easily manipulated (Vágnerová, 2008).

**Characteristics based on the degree of MR**

*Mild MR (IQ 50-70)*

People with mild MR in adulthood have mental capabilities of a middle school child. They respect basic rules of logic, they are incapable of abstract thinking and their verbal communication is limited (e.g. in abstract terms). Their verbal expression consists of shorter sentences with occasional inaccuracies and mispronunciation. Their cognitive skills and speech are concrete. They are able to learn if motivated and if their abilities are respected. They can achieve a certain level of independence in adulthood, may be integrated into work environment if they have proper supervision and support (Vágnerová, 2008).

*Moderate MR (IQ 35-49)*

Their mental capabilities can be compared to those of a preschool child that does not always respect the rules of logic. Their vocabulary lacks less common concrete words. Their verbal communication is usually poor, ungrammatical and with wrong articulation. Their learning is limited to mechanical conditioning and requires repetition. They can acquire common habits and simple skills mainly in self-service and can perform simple work tasks that do not require speed and precision. They require permanent supervision (Vágnerová, 2008).

*Severe MR (IQ 20-34)*

In adulthood people with severe MR can understand basic context and relationships compared to babies. Their verbal communication is scares and usually consists of only a few badly articulated words that they use inaccurately (in a generalised way) or they do not use verbal communication at all. Their learning is very limited and requires long-term effort to acquire the most basic self-service tasks. They often have combined impairment with many having motoric impairment, epilepsy etc. They are completely dependent on the care of others (Vágnerová, 2008).

*Profound MR (IQ 0-19)*

People with profound MR in most cases have combined impairment. Their cognitive skills do not develop or develop only marginally as they are at best able to differentiate between known and unknown stimuli and react to them positively or negatively. There is no speech developed and they are completely dependent on the care of others as they are usually placed at institutions of social care (Vágnerová, 2008).

### Social aspects of MR

MR is often perceived as a stigmatising impairment by the majority population. Similarly, to mental disorders, the main issues are the difficulty of communication with people with MR, limited understanding of their reactions (often unusual) and dependence on others which cause them to be underestimated and negatively evaluated and their social status to be very low (they are often perceived as "stupid" and that they do not understand anything and should not be considered). This attitude affects the behaviour of their family members, causes discomfort, affects emotional status and increases the need of defence mechanisms (Vágnerová, 2008). ocial stigmatisation usually correlates to the visibility of appearance and behaviour of people with MR or the degree of difference compared to the expected standard.

Problematic behaviour of people with MR is a serious issue as it remains misunderstood. Problematic behaviour is defined as behaviour which intensity; frequency or duration differs from the usual social norms enough to be gravely dangerous to physical safety of themselves or others. It also includes behaviour that can limit the use of common community centres or can lead to their expulsion from such institutions (Emerson, 2008).

### Communication and education

Limited development of communication skills is a major obstacle of socialisation that is demonstrated in problems in understanding and inadequate verbal expression. Communication of healthy people with people with MR has certain characteristic traits:

» Less empathetic

» More schematic

» More projective

» Shorter

» Person with MR is usually passively receiving information

Healthy people are less flexible in these situations. The rigidness of their behaviour is caused by the lack of information, communication being time-consuming and lack of respect towards the abilities of people with MR. People with MR, especially in childhood, usually prefer stereotypes even in social relationships and prefer contact with known people that behave in an usual and comprehensible way. Later in life isolation often becomes an issue as they are not attractive enough for their peers (Vágnerová, 2008).

In terms of social handicap of people with MR are not only limited by the primary defect of their cognitive abilities but also by the resulting lack of experience. Complete development of social skills may take more time but they are usually able to learn basic social norms and habits and simple communication skills that help them to adapt to other surroundings than family. School enrolment is very important even though integration to regular school is very difficult. In such cases special schools are beneficial as they are more accommodated to the abilities and needs of children with MR. Children with MR may be aware of being different and may perceive it as a burden (Vágnerová, 2008).

### Sexual need

The topic of sexuality of people with MR is still very complicated. Its realisation is difficult because of social myths and prejudice associated with the notion that people with MR are asexual and do not desire sex, that they are "eternal children" or that they are sexually impulsive and unable to control their sexual behaviour (Mandzáková, 2013). Growing up affects people with MR more biologically as psychosocially and newly acquired sexual need may become an issue. People with MR often cannot cope with their sexuality, do not have opportunity to satisfy it and often do not know how. This need is usually saturated with self-stimulation (Vágnerová, 2008). This topic has been a taboo in the past showing the lack of knowledge, especially regarding problematic aspects of sexual realisation of people with MR such as denudation and sexual satisfaction in public, unsolicited sexual expressions, intimate expressions towards parents and other close people (including medical personnel) or pathological sexual expressions (Venglářová, 2013).

Lasting dependence, inability to distinguish the degree of social acceptance of behaviour (both their own and of others), indiscrimination and suggestibility are the reason why people with MR can be easily manipulated, mistreated, harassed or abused. They are often unable to defend themselves and even do not realise they could or should defend themselves (Vágnerová, 2008). Michalík (2011) reports that only approximately 3% of cases of sexual abuse of people with MR is revealed to the public.

### Work, partnership and parental role

Employment and its regular daily routine positively stimulate and maintain abilities of people with MR. It gives their lives content and meaning but it is necessary their activity matches their abilities, cognitive skills, concentration and focus, does not require quick reactions and frequent changes of work tasks. Protected workshops fit this goal as they accommodate the tasks to the abilities of people with MR and serve as a place of necessary social contact that gives them background (Vágnerová, 2008).

The need for partnership does not always develop as in some cases people with MR are completely saturated by their relationships with parents and other family members. Sometimes they do not even have the opportunity to establish contact with a potential partner of similar mental level and need. Partnerships often do not have a standard character but are more of an expression of a desire of a close person and includes common activities at work and in free time. Some institutions enable life in a partnership for people with MR (families often prevent it). In partnerships of people with MR others often try to regulate parenthood as people with MR are unable to meet the requirements of a parental role (Vágnerová, 2008).

### Treatment and care

All therapeutic methods support possible development of a person as the MR is permanent: pharmacotherapy, psychotherapy, cooperation with the family, sociotherapy and social education. Types of social rehabilitation: community, psychotherapy, art therapy, social counselling, workshops, spare time activities, protected housing, protected employment and personal assistance.

Institutional care is advisable for severe or combined impairments (Švarcová, 2006). For people with mild impairment day care institutions are more suitable and complementary to family care. Institutional care is usually sought in cases when the parents of a person with MR are older and cannot take care of a person with MR (and there are no siblings or other family members) (Vágnerová, 20080.

Ageing of people with MR depends on the aetiology of their impairment, e.g. many adults with Down syndrome show signs of accelerated, premature ageing at the age of 40-50 (Silverman, 1998).

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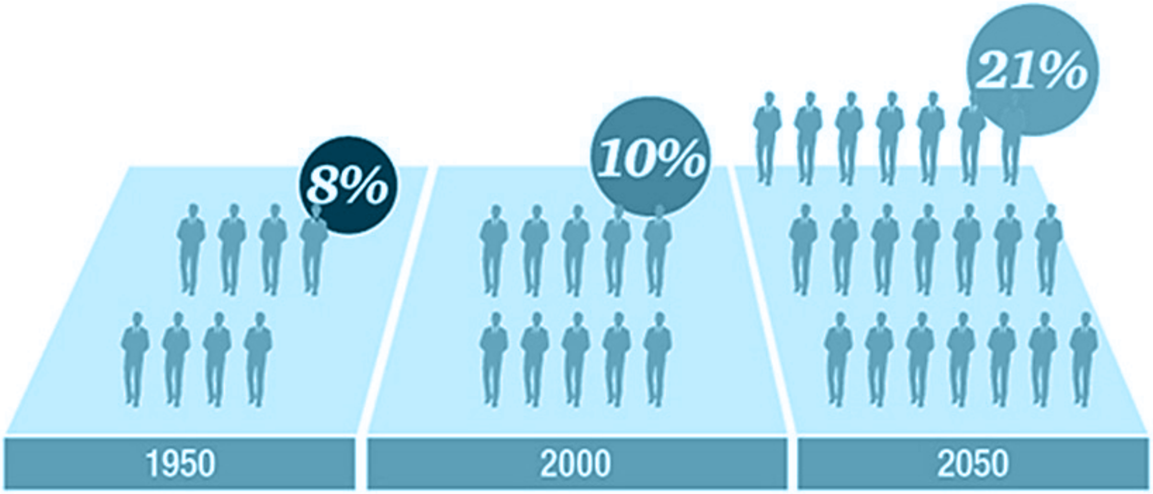
## 4.3 PEOPLE IN OLDER AGE

*Marta Nemcikova*

Ageing is a natural process which touches all living organisms, included human beings. In this part, factors influencing health in the last decades of life, process of ageing and health characteristics of people in older age (over 65 years old) are described. Selected geriatrics syndromes and the methods of its assessments are presented in more details. Biological, psychological and social aspects of ageing, possible ways of its understanding (positive or negative) and illustrations of ageing prevention within health and social care are presented. Although historically ageing is more connected with illnesses, two current public health concepts of "Active Ageing" and even "Healthy Ageing" are introduced.

Ageing is a world-wide phenomenon and it belongs to the major health challenges. In the contemporary society people are living longer. Longevity is an outcome of good medical care, vaccination and better social conditions. The pace of population ageing is much faster than ever in a history and its tempo is in time rapidly increasing (see at Figure 1). In 2017, the global population aged 60 years was over numbered 962 million. By 2050, the number of older persons is expected to double, when it is projected to reach nearly 2.1 billion people (United Nations, 2017). Among the first places with an experience of this global phenomenon are Europe and Japan.

**Figure 1.** Proportion of the world population aged 60 years or more.



Source: UN report World Population Ageing 1950-2050, 2015

### 4.3.1 Ageing process and health in older age

#### Process of Ageing

Ageing is a process that occurs over all the body, but the pace may be different at both, a human being and human organs levels (A review of the universe 2018). Ageing leads to a gradual decrease in physical and mental capacity, a growing risk of disease, and ultimately, death. But these changes are neither linear nor consistent, and they are only loosely associated with a person´s age in years. While some 70 years-old enjoy extremely good health and functioning, other 70 years-old are frail and require significant help from other. It turns out that people´s lifestyle also has additional influences on ageing (WHO, 2018b).

At the biological level, ageing consequences impact a wide variety of molecular and cellular damage over time. Certain cells in the tissues simply stop working after a while. These cells deaths do not happen all the same time. Some tissues remain viable form many decades (e.g. brain), some wear out rather quickly (e.g. skin). Muscles trade off pics up at age 40, bone mass tends to decrease at a rate of up to 1 % per year after age 35 (and faster after menopauses), heart disease typically began in around age 65.

From psychological point of view ageing is accompanied by the following **cognitive changes**: deterioration of senses (90% of people in age over 60 have worse vision perception and 30% have severely impaired hearing bring problems situation in the form of suspecting, anxiety and anger in the communication), memory impairment and decreased intelligence. **Emotional changes** are related to the outcome of the entire previous period and with the necessary adaptation to the underlying changes related to the higher age.

Social, economic and demographic changes bring a series of challenges to the people in older age and jeopardize their role in society.  In social perspective, there are many challenges  faced by the people in older age. Zastrow (1996) featured low status, (early) retirement, social emphasis on youth, health problems and costs of health care, inadequate income, loss of family and friends, substandard housing, transportation, crime victimization, parent abuse and death. In addition, older people and even more older people with mental disorders carry a burden of **stigmatization**. Their stigma "results from process whereby certain individuals and groups are unjustified rendered shameful, excluded and discriminated against " (WHO, APA, 2002 ).

Health of people in older age refers to underlying changes in organism, to specific health conditions and other complex problems (geriatric syndromes) which impact on intrinsic capacity and functional ability. Selected characteristics for a better understanding health trends in older age are shown in detail below  (WHO, 2015b):

*Underlying changes*

- **Movement function**

  After achieved a top in early adulthood, muscle mass tends to decline in strength and musculoskeletal function. A progressive form and generalized loss of skeletal muscle mass and strength with a risk of adverse results such as physical disability, poor quality of life and death is defined as **sarcopenia** (Cruz-Jentoft et al. 2010). Ageing is also related with significant changes in **bones** and **joints.** Bone mass tends to go downhill at a rate up to 1 % per year after age 35 and faster after menopause (A review of the universe 2018). With aging bone mass, there is a growing risk of fractures, especially of the hip joint, referred to as fractures due to osteoporosis. Numeracy increases especially among women. As time passes, cartilage breaks down, the fluid around the joints, becomes rigid and fragile. Motion limitations are reflected in step speed, which is influenced by muscle strength, joints limitations, and other factors such as coordination (WHO 2015b).

- **Sensory functions**

Age-related hearing loss known as **presbyacusis** is bilateral and most market at higher frequencies. It is caused by cochlear ageing, environmental exposures, genetic predisposition and increased vulnerability from physiological stressor and modifiable lifestyle behaviours (Yamasoba 2013). By the age upper 40 years began range of sign declines. Often are appearances of **presbyopia** with decreasing ability to accumulate and causing blurring in near vision. Opacity of the crystalline lens is increasing and can finally results in **cataract.** People older than 70 years are threatened by age-related **macular degeneration**, which causes retinal damage and leads rapidly to severe visual impairment or to blindness (A review of the universe 2018). In social interaction, hearing problems cause limitations in communication, lead to social isolation, to depression and cognitive decline. Visual impairments can restrict mobility, barrier to accessing information, cause depression and increase risk of falls. Using of assistive technologies may increase a quality of older people with sensory disability, as well as creation of age-friendly environment (WHO 2015b).

- **Cognitive functions**

Cognitive functions are those mental processes that lead to the acquisition of knowledge and allow people to carry out the daily tasks. They allow the subject to have an active role in the processes of receiving, choosing, transforming, storing, processing and retrieval of information, allowing him or her to navigate the world around him. The most important cognitive functions are attention, orientation, memory, gnosis, executive functions, praxis, language, social cognition and visuospatial skills (Eysenck, Keane 2008). They vary greatly among people and are closely related to years of formal education (Anstey et al. 2015). Many cognitive functions initiate to decrease at a relatively young age, with different functions decreasing at different rates. As a consequence, functioning becomes increasingly heterogeneous with increasing age. Some deterioration in memory and the speed of information processing is common, and complaints about it are frequently reported by older people. Crucially, the subtle and heterogeneous changes in cognitive functioning that are observed in healthy older people are quite distinct from the changes associated with dementia (WHO 2015b).

**Dementia** as a syndrome in which is deterioration in memory, thinking, behaviour and the ability to perform every day activities is not a natural part of ageing (SAS 2018). **Cognitive stimulation activities** belong to protective factors of dementia of various aetiologies. Reading, playing puzzles, visiting museums and concerts are related to reducing their risk. The extent and type of cognitive activity is not reliably proven. For healthy brain aging, it is recommended to maintain protective support and risk reduction. For typical and normal aging, it is necessary to focus on reducing the risks and increasing protective behaviour, whereas for pre-clinical dementia or mild cognitive impairment it is important to focus on urgent risk control and reduction of modifiable health and behavioural risks (Anstey et al. 2015).

- **Sexuality**
  Numerous physiological changes, as well as multiple psychosocial and socio-environmental factors influenced sexuality in older age which occur as part of the ageing process in both men and women. One often overlooked issue is sexual functioning in older people living in care facilities. This touches the rights of these older people to express their sexuality and the need to protect vulnerable individuals. Particular ethical dilemmas may arise in relation to sexuality and dementia (WHO 2015).

- **Immune function**
  In older age is decreasing function to react on new infections falls and vaccination because of the declining T-cells activity. There is also some evidence that chronic stress for example, the need to care providing, can reduce the immune response (WHO 2015b).

- **Functions of the skin**
  In the life-course, skin suffered progressive decrements that result from damage caused by physiological mechanism, genetic predisposition and external insults, particularly sun exposure.

These normal aging changes are partially responsible for the increased risk of developing health-related problems within the elderly population (Fulmer 2012). According to Reichard (Langmeier, Krejčírová 2006), five counter-aging strategies are recognised:

1. Constructive strategy - balanced with reality of higher age, aware of its own possibilities;
2. Dependence strategy - passive approach, dependent on other people, children;
3. Defence strategy - exaggerated activity tries to cover the worries, respectively fear of death;
4. Strategy of hostility - hostility and anger against others (family, caregivers); and
5. Hate strategy - aggression towards the person, over-self-blame.

*Health conditions*

According to actual definition provided by Barnett et al. (2012), **multimorbidity** is defined as "the presence of two or more disorders". In the past, from 1970 the term comorbidity was used as presence of one chronic disease and the presence of a "distinct additional clinical entity" (Almirall, Fortin 2013).

Multimorbidity is more common with age and is associated with high mortality, reduced functional status and increased use of health care. Management of the rising prevalence of long-term disorders can cause duplicative and ineffective use of many services. For patients in older age it is burdensome and unsafe (Barnett et al. 2012).

***Case study*** as the example of multimorbidity of person in older age as well as it is shown how falls of person in older age influence his or her activities of daily living (ADL):

"75-years old woman was hospitalized with ongoing atrial fibrillation and over-warfarinization. She was mobile, fully self-contained. The sum of ADL test was 110 points, which meant independence. On the fourteenth day of hospitalization the patient slided down in a shower bath and she fallen on her back. Diagnosed was a fracture of the twelfth spondyl. Considering of patient´s "multimorbidity and age" was proposed conservative cure. On the 36th hospitalization day occurred acute Clostridium difficile which was treated. After the accident was patient immobile, she received food in lying position, she needed help with hygiene, it was particular urine incontinency and over the acute diarrhea functional fecal incontinency presented. She was incommunicable, apathetic; she refused rehabilitation and verticalization with corset. ADL test showed 35 points with high dependency" (Vozická 2017).

The primary goal of older people´s treatment is to restore or maintain certain functions, reducing mortality and improving quality of life. Pharmacotherapy should be individualized, rational, safe and effective, implemented with a relatively small number of drugs and at the lowest cost (Komjáthy 2016). In pharmacotherapy of people in older age polypragmazia and prescription errors are more often present. **Polypragmazia** means that the patient is being treated by more of the drugs or with their overdose. Specific borders are not clearly defined, literally the number exceeding 4 drugs; sometimes a higher number of drugs is reported. Certain of the diseases are polypragmazia more risk. This concerns in particular: cardiovascular disease, bronchial asthma and psychiatric diseases. The consequences of polypragmazia consist in the *increase the risk of undesirable effects*, *drug interactions* (caused by the current ordination of multiple medicines by different physicians, known as **polypharmacy**; *hospitalization and rehospitalisation* and *morbidity*.

**Prescription errors** are found in up to 30% of seniors, and means (Suchý, Hromádka 2011):

- use of inappropriate drug dosing or incorrect dosing interval;
- use of inappropriate medicine;
- drug duplication; and
- use through relative contraindication or drug interaction.

For the elimination the drugs ´undesirable effects following general valid principles of treatment are recommended (Fulmeková, Masaryková, Lehocká, 2012):

- minimal medication,
- drug administration the shortest possible time,
- varying with low but effective doses,
- considering drug interactions, and if possible treating not pharmacologically.

### *Other complex problems (geriatric syndromes)*

**Geriatric syndromes (GS)** are "several complex health states that tend to occur only later in life and that do not fall into discrete disease categories" . At the turn of the 1960s and 1970s, clinical experience has led to the fact that some serious health problems and symptoms are very often repeated and unrelated to a particular disease to formulate so called geriatric syndromes. At that time, British geriatrician Bernard Isaac described geriatrics as medicine 5 "Is". These include instability, immobility, intellectual disorder (dementia, delirium), incontinence and iatrogenic damage. At the beginning of the 20th century, the concept of geriatric syndromes was modified. The term "syndrome" has been used in this concept differently than in clinical practice, where its meaning means a set of symptoms caused by one reason. On the contrary, geriatric syndromes have typical geriatric significant symptoms or a set of multiple and various combined causes. **Brief characteristics of GS according to Isaac** (1992 in Kalvach et al., 2008) are: multi-causal aetiology, chronic course, limiting patient independence (functional severity), and the absence of causal treatment.

Modified-Delphi process was used by Saliba et al. (2004) for the expert estimation of severe problems and symptoms of clients of nursing home. By this method following 68 geriatrics syndromes were defined arrayed in alphabet order (Table 1).

**Table 1.** Review of geriatrics syndromes

anhedonia
agitation
amnesia
androgen deficiency
anorexia
apathy
aphasia
apraxia
aspiration
bradykinesia
chronic pain
decondition
decubitus
dehydration
delirium
dementia
dependence on others aid
depression
deprivation
diarrhoea
dysphagia
dyspepsia
dysuria
dying
elder abuse
exhaustion
falls
hypomobility
hypotension
hypothermia
immobility
impotence
inactivity
insomnia
instability
cognitive deficits
fatigue accidents
frailty
loneliness
malnutrition
memory disorders
obstipation
onychogryposis
orthostatic hypotension
paranoia
presbycusis and
other hearing disorders
presbyopia and
other visual disturbances
rigidity
sarcopenia
self-neglect
self-contained disorders
shake
syncope
tinnitus
trauma
dizziness
confusion
retardation of psychomotor rate
stool incontinence
loss of sense of thirst
loss of sense of life
urinary incontinence
urinary retention

Source: Saliba et al. 2004

## Frailty

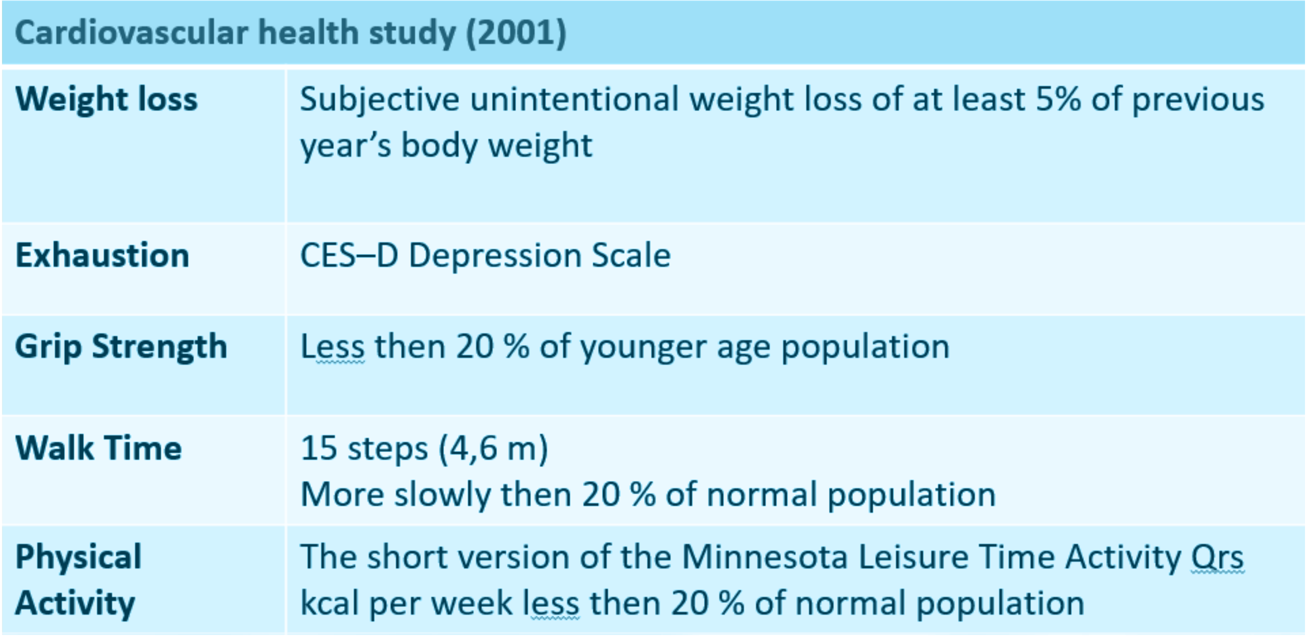
Frailty was defined by Fried et al. (2001) as “a clinical syndrome in which three or more of the following criteria were present: unintentional weight loss (10 lbs in past year), self-reported exhaustion, weakness (grip strength), slow walking speed, and low physical activity”. Frailty is either physical or psychological or combination of the two components (Morley et al. 2013). The prevalence of frailty is markedly increased in persons older than 80. Women are twice more likely to be frail as men.

To recognize frail persons, identify the level of frailty or person at risk of frailty some simply screening tests are available to be used by physicians:

- **Cardiovascular Health Study Frailty Screening Measure** (Fried et al. 2001, Table 2).
- **Clinical frailty scale** (Table 3) is a measure of frailty based on clinical judgement. The scale ranges from 1 (robust health), to 7 (complete functional dependence on others) and up to 9 (terminally ill). The Clinical Frailty Scale is easy to use and may readily be administered in a clinical practice. It helps to plan preventive interventions (Table 4), need for institutional care or predict patients ´risk of death (Rockwoood et al., 2005).
- The simple **“FRAIL” questionnaire Screening Tool** (Morley et al. 2006).
- **Gérontopole Frailty Screening Tool** (Subra et al. 2012).

**Table 2.** Cardiovascular Health Study Frailty Screening Measure

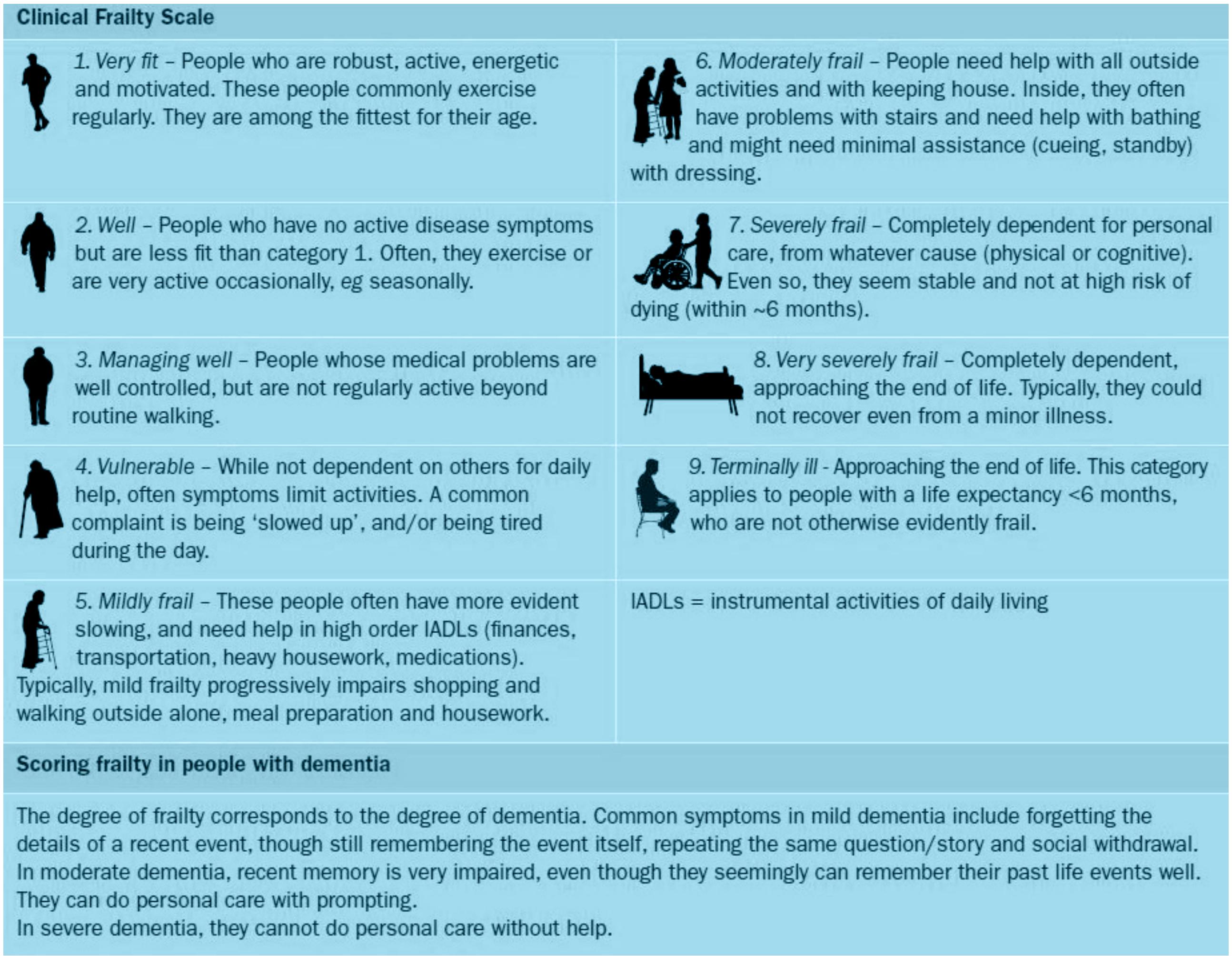
Source: Fried et al., 2001



| Cardiovascular health study (2001) | |
|---|---|
| **Weight loss** | Subjective unintentional weight loss of at least 5% of previous year’s body weight |
| **Exhaustion** | CES–D Depression Scale |
| **Grip Strength** | Less then 20 % of younger age population |
| **Walk Time** | 15 steps (4,6 m)<br>More slowly then 20 % of normal population |
| **Physical Activity** | The short version of the Minnesota Leisure Time Activity Qrs<br>kcal per week less then 20 % of normal population |

**Table 3.** Clinical Frailty Scale

Source: Rockwood et al. 2005



| Clinical Frailty Scale | |
|---|---|
| 1. *Very fit* – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age. | 6. *Moderately frail* – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cueing, standby) with dressing. |
| 2. *Well* – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, eg seasonally. | 7. *Severely frail* – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~6 months). |
| 3. *Managing well* – People whose medical problems are well controlled, but are not regularly active beyond routine walking. | 8. *Very severely frail* – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness. |
| 4. *Vulnerable* – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being 'slowed up', and/or being tired during the day. | 9. *Terminally ill* - Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail. |
| 5. *Mildly frail* – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework. | IADLs = instrumental activities of daily living |

**Scoring frailty in people with dementia**

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.
In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.
In severe dementia, they cannot do personal care without help.

**Table 4.** Principles of prevention and early intervention of frailty

Source: Morley et al. 2006

| | |
|---|---|
| **F Food intake maintenance** | Anorexia and malnutrition prevention, adequate income of qualitative proteins, vitamins, other nutrients and energy in nutrition |
| **R Resistance exercise** | Physical activity, resistive and aerobic* |
| **A Atherosclerosis prevention** | Prevention of atherosclerosis´ origin, influencing its risk factors |
| **I Isolation avoidance** | Prevention of isolating meeting with people |
| **L Limit pain** | Diagnostic and active treatment of the pain |
| **T Tai-Chi or other balance exercise** | Exercises aimed at strengthening stability and balance, such as Tai-Chi |
| **Y Yearly functional checking** | Observance of regular health and functional status checks |

* Goal: maintaining muscle strength (especially lower limbs); isometric exercises (8 -15 repetitions min. 2x per week); walk (20 min. daily), 50-75% max. pulse rate for a given age; preservation of the momentum range - stretching daily (15 s for muscle group).

- **Syndrome of Incontinency**

  Incontinency of urine, stool or double incontinency is a neglected problem in regard mostly to frailty persons. Urinary incontinence is the unintentional leakage of urine. According to the assessments of WHO, urine incontinence suffers approximately 5-8 % of world population, mainly women. Incontinence is a symptom of many urological, neurological, gynaecological and other diseases (Kalvach et al. 2008). Medical impact of incontinency is associated with decubitus ulcers, sepsis, renal failure, urinary tract infections, and increased mortality. Psychosocial implications of incontinence include loss of self-esteem, restriction of social and sexual activities, and depression (WHO 2015).

- **Syndrome of Falls**

  Impaired balance in older persons often manifests as falls and fall-related injuries. Approximately one third of community-living older persons fall at least once per year, with many falling multiple times. Falls are the leading cause of hospitalization and injury-related death in persons 75 years and older (WHO 2015). The falls in the hospital are significantly associated with new placement in a nursing home (Basic, Hartwell 2015). *Guideline for the Prevention of Falls in Older Persons* (American Geriatrics Society (2001) specifically recommends:

  » long-term exercise and balance training (e.g. tai-chi), environmental modifications and reviewing of medication;

  » use of assistive devices: bed alarms, canes, walkers and hip protectors;

  » behavioural and educational programs and other potential interventions: bone strengthening medications, cardiovascular, visual and footwear intervention.

## Determinants of health in older age

There is clearer information on epidemiology of ageing currently. In populations aged 60 years and older, the most important health conditions associated with years of healthy life lost due to disability and causes related years of life lost to mortality (Table 5).

**Table 5**. Review of 10 health conditions associated with disability and 10 causes of lost years in 60 +.

| ***A.*** ***10 health conditions associated with disability*** | ***B.*** ***10 causes of lost years in 60 + (2012)*** |
|---|---|
| Hearing loss | Ischemic heart disease |
| Back and neck pain | Stroke |
| Chronic obstructive pulmonary disease | Chronic obstructive pulmonary disease |
| Unipolar depressive disorders | Cancers of the trachea, bronchus and lungs |
| Falls | Lower respiratory infections |
| Diabetes mellitus | Diabetes mellitus |
| Alzheimer disease and other dementias | Hypertensive heart disease |
| Refractive errors | Cirrhosis of the liver |
| Osteoarthritis | Stomach cancer |
| Cataract | Colon and rectum cancers |

Source: WHO, 2012

The trends on health in older age are significantly influenced by individual characteristics, especially genetics, age-related changes, behaviour, and diseases, as well as environmental conditions such as housing, assistive technologies, transport, and social facilities, where people in older age spend most of their time (WHO, 2015a). There is growing evidence that key health-related behaviours, such as **engaging in physical activities and sustaining sufficient nutrition**, may exert powerful influences on intrinsic capacity in older age and may reduce the risk of non-communicable diseases.

Key environmental risk presents emergency situations such as natural or technological disasters and human-induced conflicts. By these humanitarian catastrophes people in older age are more often neglected. Data from five major natural disasters show that more than half of the deaths related to these events occurred among people aged 60 years and older. Reasons of these vulnerable situations are limitation in mobility, social isolation, and cognitive impairment. At the physiological level, older people may be more predisposed to dehydration, hypothermia, hyperthermia and injuries (WHO, 2015b).

A major public health problem associated with social environment of people in older age is **elder abuse**. It leads to serious health consequences on victims, including increased risk of morbidity, mortality and institutionalization, and hospital admission (Yon et al., 2017). Elder abuse takes many forms including physical, sexual, psychological, emotional, financial and material abuse, abandonment, neglect and serious losses of dignity and respect. It may arise in care giving relations or such as violent crime occurring in the community. Victims are mostly women with physical disability, or having poor mental health or both; those who have a low income; and lack of social support. Family members who abuse older people are more like to have personal disorders or substance abuse related disorders (or any other mental diseases/. Abusers themselves are often dependent on the abused person (WHO, 2015b).

## 4.3.2 The concepts of healthy and active aging

In the context of population aging, it is important how older people experience the old age. Whether it is a passive experience of illness, depression or loneliness, or it is a period filled with activities that bring personal satisfaction and are beneficial to the community and society.

**Healthy ageing**

is an onward theoretical concept based on "intrinsic capacity" and "functional ability" of people. World Health Organisation in *Report on healthy ageing and health* (2015b) defines „**healthy ageing as the process of developing and maintaing the functional ability that enables well-being in older age**".

**Figure 2.** Healthy Ageing

Source: WHO Report on Ageing and Health, 2015b

Figure 2 well illustrates the four major characteristics of healthy ageing:

- **Well-being** is considered in the broadest sense and includes domains such as happiness, satisfaction and fulfilment.
- **Functional ability** comprises the health-related attributes that enable people to be and to do what they have reason to value. It is made up of the intrinsic capacity of the individual, relevant environmental characteristics and the interactions between the individual and these characteristics.
- **Intrinsic capacity** is the composite of all the physical and mental capacities of an individual.
- **Environments** comprise all the factors in the extrinsic world that form the context of an individual's life. These include – from the micro-level to the macro-level – home, communities and the broader society" (WHO 2015b).

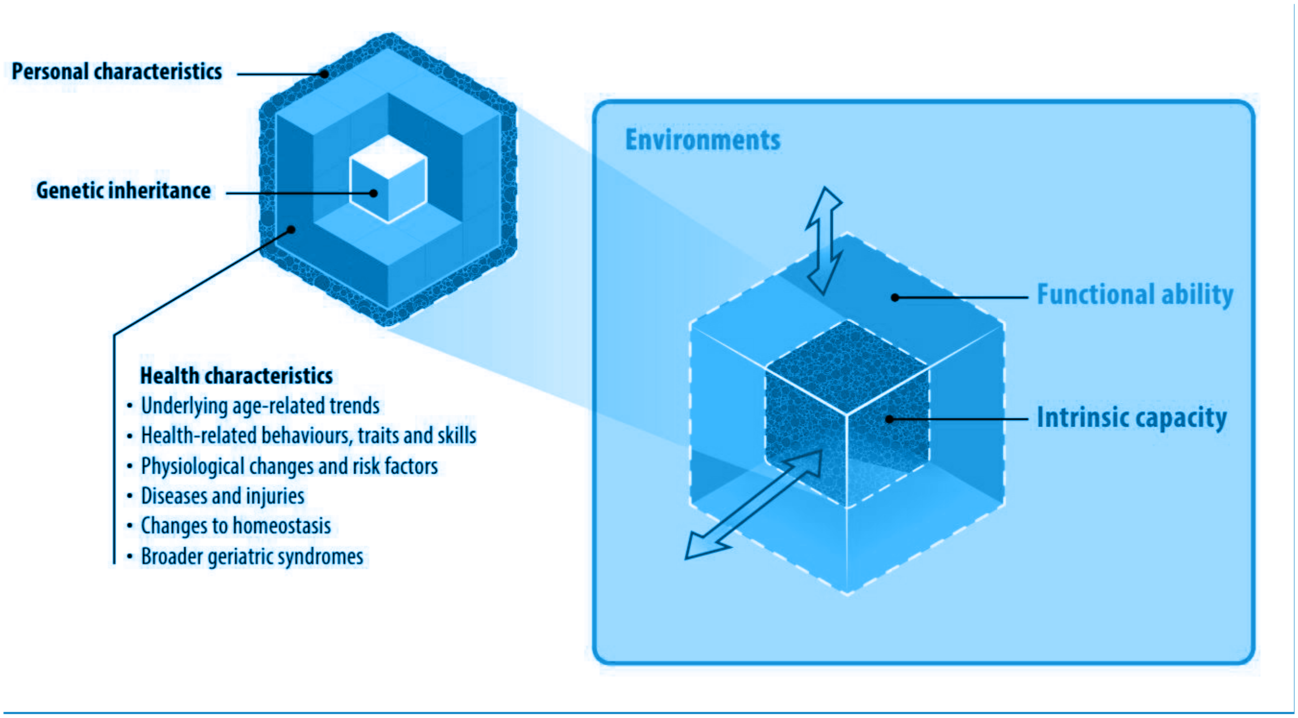
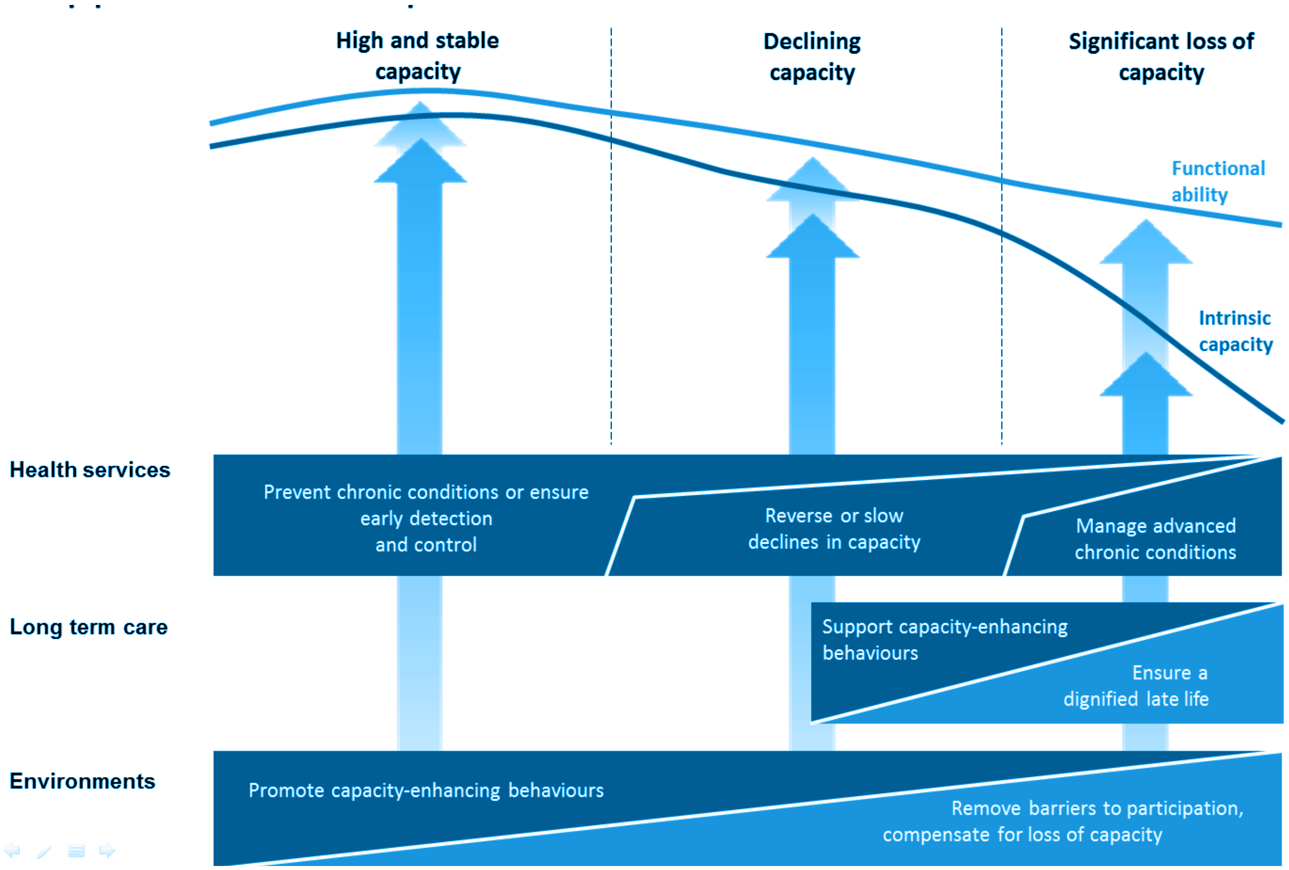


**Figure 3**. Public-health framework for healthy ageing. Opportunities for public-health action across the life course



Source: WHO Report on Ageing and Health, 2015b

**Healthy living** means to be able to do things that are valued for people in older age for a long as possible. But, this concept acquires changes in people´s minds. There is an acute need to change the way of thinking about ageing and older people. For example, the creation of age friendly environments (e.g. concepts of age-friendly cities, age-friendly communities, age-friendly universities. Arrangements of health system to the needs of older people. At least, but not last, development of systems for long-term care (WHO 2015a).

**Active ageing**

is beneficial to the individual, as active people live longer. Its content is reflected in active participation:

» in the labour market,

» in domestic work or work in garden,

» in care for a family member (for grandchildren or reliant spouse or friends),

» in volunteer activities in the community (eg church, sports, etc.),

» in leisure time activities (eg training courses at third-age universities, travelling, activities in day-care centers).

WHO (2002) defined **active ageing** as "the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age". The active ageing approach is based on the recognition of the human rights of older people and the United Nations Principles of independence, participation, dignity, care and self-fulfilment. The word "active" refers to continuing participation in social, economic, cultural, spiritual and civic affairs, not just the ability to be physically active or to participate in the labour force.

Active ageing depends on a variety of influences or "determinants" that surround individuals, families and nations. Understanding the evidence, we have about these determinants helps to design policies and programs that work.

"Culture, which surrounds all individuals and populations, shapes the way in which they age because it influences all of the other determinants of active ageing. Gender is a "lens" through which to consider the appropriateness of various policy options and how they will affect the well-being of both men and women. Girls and women have in many societies lower social status and less access to nutritious foods, education, meaningful work and health services. Women's traditional role as family caregivers may also contribute to their increased poverty and ill health in older age" (WHO 2002).

### 4.3.3 Innovative approaches in health and social care for older people

#### Comprehensive geriatric assessment

**Comprehensive geriatric assessment (CGA)** is defined as "a multidisciplinary diagnostic and treatment process that identifies medical, psychosocial, and functional limitations of a frail person in older age in order to develop a coordinated plan to maximize overall health with ageing "(Ward, Reuben 2018). From the view of Elsawy, Higgins (2011), the geriatric assessment is multidimensional assessment designed to evaluate older person´s functional ability (A), physical health (B), cognition and mental health (C), and socio-environmental circumstances (D). It is initiated when the clinician identifies a potential problem. An important parts of geriatrics assessment are well-validated tools and survey instruments for evaluating.

Increasingly, CGA programs are moving towards a "***virtual team***", concept in which members are included as needed, assessments are conducted at different locations on different days, and the team communication is completed via telephone or electronically, often through the electronic health record.

**(A) Functional Ability**

refers to a person ´s ability to perform tasks that are required for living. Assessment begins with a review of two key divisions of functional ability:

- *Activities of daily living (ADL)* are self-care activities that a person performs daily (e.g. eating, dressing, bathing, transferring between the bed and chair, using the toilet, controlling bladder and bowel functions). Instrument used for assessing ADL is Katz ADL scale (Katz et al., 1963) and Barthel index of ADL (Collin C. et al., 1988).

*Instrumental activities of daily living (IADL)* are activities that are needed to live independently (e.g., doing housework, preparing meals, taking medications properly, managing finances, using a telephone). Its survey instrument is called Lawton IADL scale (Lawton, Brody 1969).

Deficits in ADL and IADL can signal the need for more in-depth evaluation of the person´s socio-environmental circumstances and the need for additional assistance.

## (B) Physical Health

Geriatrics assessment incorporates main problem, current illness, past and current medical problems, family and social history, demographic data, and review of systems. In the evaluation should be included: screening of disease, nutrition, vision, hearing, faecal and urinary continence, balance and fall prevention, osteoporosis, and polypharmacy.

### *Screening for disease*

In the normal aging process, there is often decline in physiologic function that is usually no disease-related. But, screening for malignancies may allow for early detection, and some are curable if treated early. **Sample Focused Geriatric Physical Examination** (Elsawy, Higgins 2011) is an example of such geriatric screening.

### *Nutrition*

Apepsia, loss of weight and malnutrition are often in population in older age. The most common reasons of malnutrition are: malabsorption, anorexia, polypragmasia, loss of ability to shop, poor oral health (Asseessment on current oral care by Chalmers et al, 2014), thyreopathy (ang.), residential care, dependence in instrumental activities, low content of cholesterol in diet, depression, and inadequate finances (Topinková, 2003). One simple screening tool for nutrition in older persons is the **Mini-Nutritional Assessment** ™ (Vellas et al. 1994).

### *Vision and hearing*

An advised tool is Snellen chart to screen for visual acuity. For screening older patients for hearing impairment periodic questioning about hearing, audio scope examination, othoscopic examination, and the whispered voice test is recommended. Screening questionnaires such as The Hearing Handicap Inventory for the Elderly also help to identify persons with hearing problems (Ventry, Weinstein, 1983). Hearing aids minimize hearing loss and improve daily functioning.

### *Faecal and urinary continence*

An assessment for urinary incontinence should include the evaluation of fluid intake, medications, cognitive function, mobility and previous urologic surgeries.

### *Balance and fall prevention*

People in older age can decrease their fall risk with exercise, physical therapy, a home hazard assessment, and with-drawl of psychotropic medications. **The Tinetti Balance and Gait Evaluation** is a useful tool to assess a patient´s fall risk (Tinetti, 1986).

### *Osteoporosis*

Osteoporosis can be diagnosed clinically or radiographically. It may result in low-impact or spontaneous fragility fractures, which can lead to a fall.

### *Polypharmacy*

**The Beers criteria** list medications and classes that should be avoided in older persons to reduce adverse effect (Beers et al. 1991).

### (C) Cognition and Mental Health

#### ■ *Depression*

As worldwide about 10% of elderly have depressive symptoms (Bouwens, 2004). Of the several validated screening instruments for depression, the **Geriatric Depression Scale** – short form (Sheikh & Yesavage, 1986) and the **Hamilton Depression Scale** are the easiest to use and most widely accepted. Accept of these scales there is a possibility to use a simple two-questions screening tool: "During the past month, have you been bothered by feelings of sadness, depression, or hopelessness?" and "Have you often been bothering by a lack of interest or pleasure in doing things?".

#### ■ *Dementia*

Early diagnosis of dementia permits patients timely access to medications and helps families to make preparations for the future. It can also help in management of other symptoms (depression, irritability). **Mini-Cognitive Assessment Instrument** (Borson et al., 2000) is the preferred test for the clinician because of its speed, convenience, and accuracy.

### (D) Socio-environmental Circumstances

are prejudiced by social interaction network, available support resources, special needs, and environmental safety. Determining the most suitable living arrangements for older patients is an important function of geriatric assessment.

An aim of the geriatrics assessment is aid in the diagnosis of medical conditions; development of treatment and follow-up plans; coordination of management of care; and evaluation of long-term care and optimal placement.

## Long–term care

Human rights for people in older age ensure to live in dignity and meaningfully. Because of the significant loses of intrinsic capacity, ensuring of these rights is often possible only with regular care, selfless support and assistance of others (WHO 2015b).

WHO in the *World report on ageing and health* (WHO 2015b) **defined long term care** (LTC) as "the activities undertaken by others to ensure that people with or at risk of significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity." The form of care introduces many variations among and even within countries.

Long-term care services are increasingly being provided in care recipients´ homes. In 2010, over 8% of people aged 65 years and over received care at home while less than 4% of them received care by institutions such as home care, day-care centres, elderly homes, specialized homes for people with dementia (OECD 2013). People aged over 80 compose on average more than half of all LTC recipients (OECD 2017).

In institutions, a **wide spectrum of professionals** helps to people in older age with basic living activities, with medical services, nursing care, prevention, rehabilitation and palliative care (OECD 2013 Better). These facilities included recipients´ homes, community centres, assisted living facilities, nursing homes, hospitals and other health facilities (WHO 2015b).

Significant role in providing of LTC play key **aspects of quality** with an aim to maintain or when feasible, to improve the functional and health status of frail, chronically ill and people with physical disability: effectiveness and safety, patient-centeredness and responsiveness, and care co-ordination (OECD 2013).

## A) Health care – primary care, hospital-at-home, hospital services, disease-specific services

According to view of WHO, current health systems are better designed to respond the acute health needs than to the complex and chronic health needs of people in older age. There is an urgent need to develop comprehensive and coordinated **integrated care** approach (WHO 2017).

Great heterogeneity in trajectories of intrinsic capacity is characterized for the population of older people. Persons in the second half of life may experience three periods of decreasing capacity, whereby every of these phases need different response of health care (Figure 4):

1. People with high and stable capacity

   The goal is to continue to build and maintain these levels for as long as possible by **preventing diseases** and by the **reduction of risks**.

2. People with declining capacity

   In this stage the key role plays effective **intervention** which slowed or partly reversed the process becoming frailty or care-dependent. An accent in primary health-care settings is put on comprehensive assessment of the intrinsic capacity, treatment and on the multicomponent programs (focused to improving nutrition and encouraging physical exercise).

3. People with a significant loss of capacity

   Because of high level of care dependency, in this period health system plays the important role which consists in providing continuing **management of disease**, **rehabilitation** (in hospitals, in communities or at home), and **palliative and end-of-life care** (with an aim to inform about treatment and prognosis, initiating advanced care planning and to manage pain and symptoms) (WHO 2015b).

**Figure 4.** Conventional care versus older-person-centred care

Source: WHO Report on Ageing and Health, 2015b

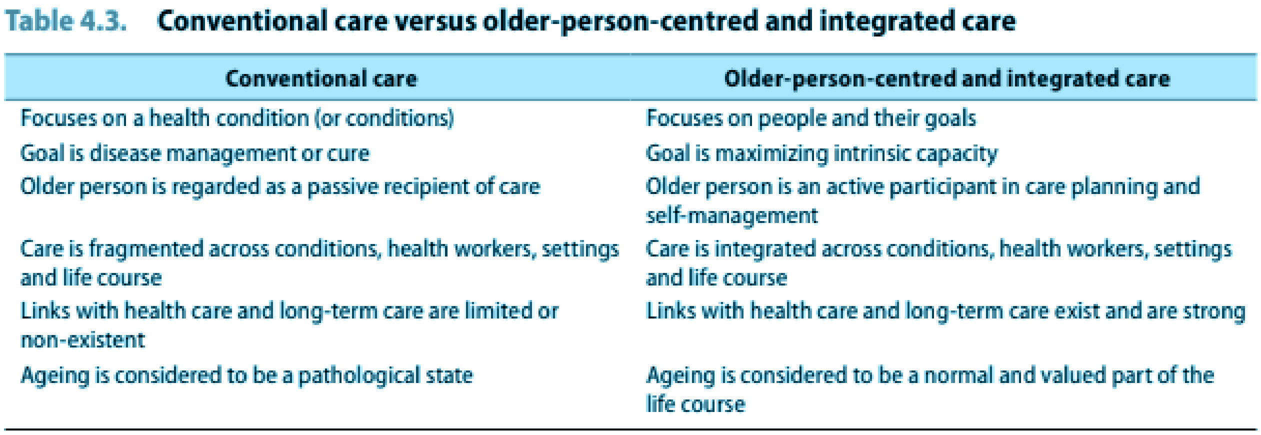


**Table 4.3. Conventional care versus older-person-centred and integrated care**

| Conventional care | Older-person-centred and integrated care |
|---|---|
| Focuses on a health condition (or conditions) | Focuses on people and their goals |
| Goal is disease management or cure | Goal is maximizing intrinsic capacity |
| Older person is regarded as a passive recipient of care | Older person is an active participant in care planning and self-management |
| Care is fragmented across conditions, health workers, settings and life course | Care is integrated across conditions, health workers, settings and life course |
| Links with health care and long-term care are limited or non-existent | Links with health care and long-term care exist and are strong |
| Ageing is considered to be a pathological state | Ageing is considered to be a normal and valued part of the life course |

**Figure 5.** Three common periods of intrinsic capacity in older age; risk and challenges, goals and key responses of health system (Note: NCDs are non-communicable diseases)

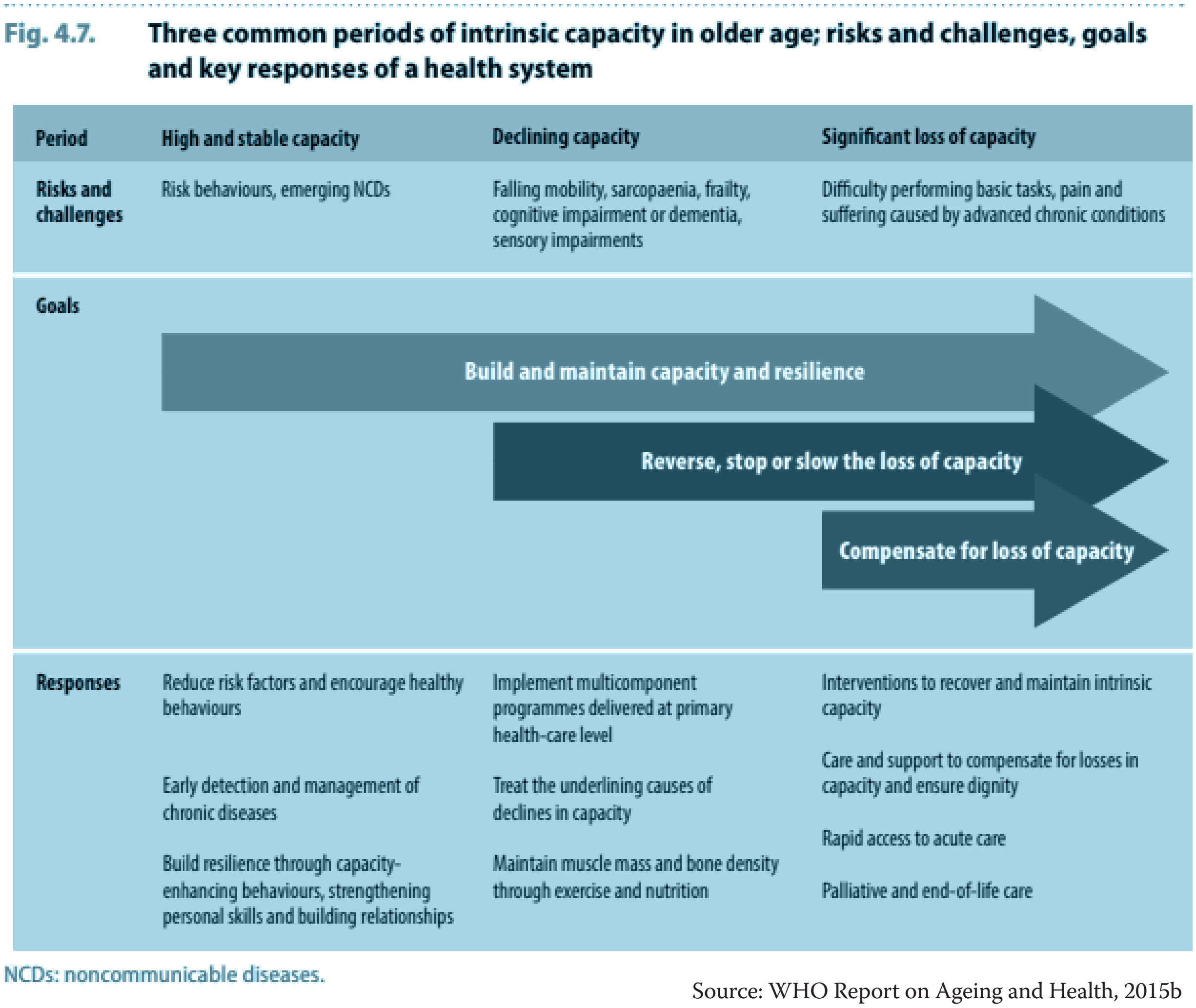


**Fig. 4.7. Three common periods of intrinsic capacity in older age; risks and challenges, goals and key responses of a health system**

| Period | High and stable capacity | Declining capacity | Significant loss of capacity |
|---|---|---|---|
| **Risks and challenges** | Risk behaviours, emerging NCDs | Falling mobility, sarcopaenia, frailty, cognitive impairment or dementia, sensory impairments | Difficulty performing basic tasks, pain and suffering caused by advanced chronic conditions |
| **Goals** | Build and maintain capacity and resilience |  |  |
|  |  | Reverse, stop or slow the loss of capacity |  |
|  |  |  | Compensate for loss of capacity |
| **Responses** | Reduce risk factors and encourage healthy behaviours<br>Early detection and management of chronic diseases<br>Build resilience through capacity-enhancing behaviours, strengthening personal skills and building relationships | Implement multicomponent programmes delivered at primary health-care level<br>Treat the underlining causes of declines in capacity<br>Maintain muscle mass and bone density through exercise and nutrition | Interventions to recover and maintain intrinsic capacity<br>Care and support to compensate for losses in capacity and ensure dignity<br>Rapid access to acute care<br>Palliative and end-of-life care |

NCDs: noncommunicable diseases.

Source: WHO Report on Ageing and Health, 2015b

**B) Social care – formal and informal care**

**Forms of social care:**

- **Community-based care** allows advance ageing at own home combined with services offered in a community and aim to hold off entry to nursing homes, to reduce days spent in hospitals and to improve quality of life.
- **Residential care** was often based on medical model of service delivery (social care was realized like in the hospitals, perception of people in older age was like patients) in the second half of the last century. More recently, in countries like Germany, Japan, the Netherlands, Sweden and the United States the institutional care was redesigned to smaller group homes with more home-like approach with an accent lying on residents as people first, not patients (WHO 2015b).

Generally, **caregiving** refers to attending to another person's health needs. Caregiving often includes assistance with one or more activities of daily living (ADLs), as well as multiple instrumental activities of daily living (IADLs). A caregiving of people with dementia also contains emotional support and sense of security (Alzheimer ´Association 2017).

### Types of caregivers:

**Formal caregivers** are educated employees of the chosen health equipment and social care services (with home, ambulatory or resident basis).

Although, of the desire to keep a family member or friend at home, proximity to a lovely person, and duty to take care of a partner which are the motivation for care by **informal caregivers** (Alzheimer's Association 2017), can this care be causing significant psychological, social and economic impacts (WHO 2015b). The time perspective of burden on family caregivers is illustrated on Figure 6.

There are two groups among informal caregivers:

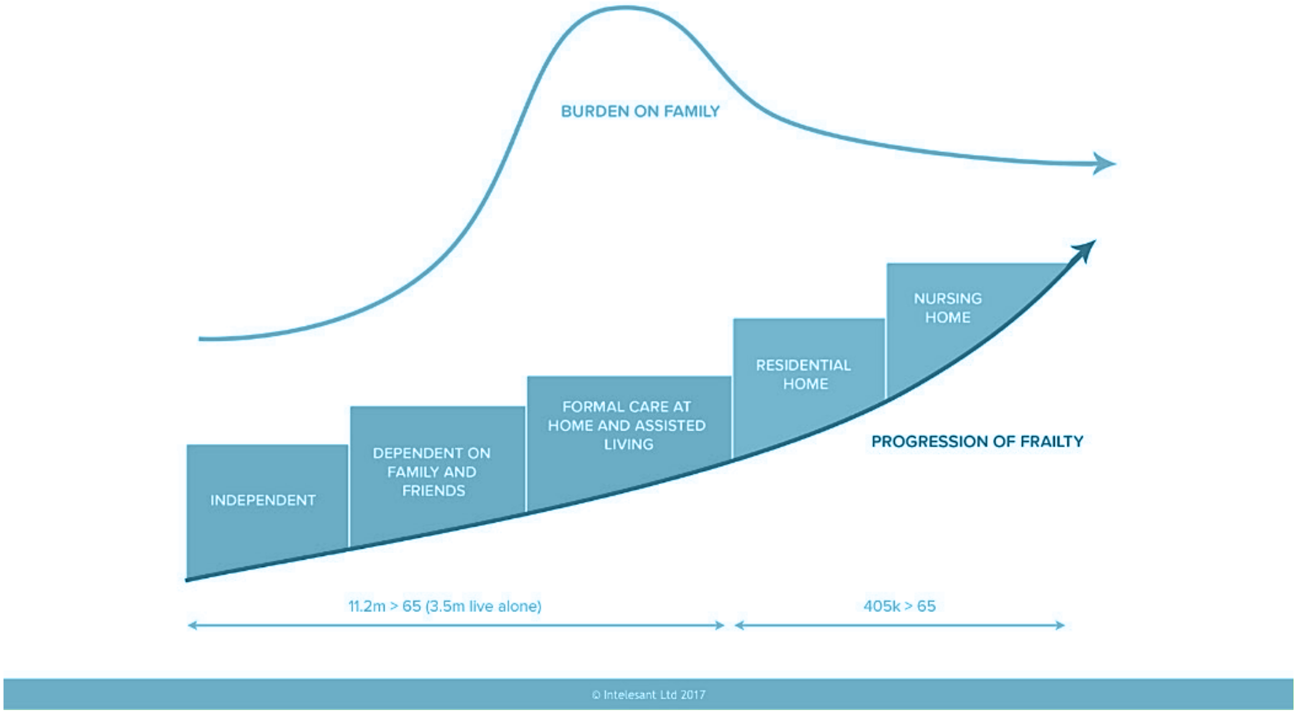
1. **Primary informal caregivers** - unpaid care secure by old-age pensioners mostly 24 hours per day, 7 days per week.
2. **Secondary informal caregivers** - unpaid care secure by relatives in productive age, who are employed. They use services of a day-care (health or social) centres for their relatives and take care evenings, nights and during weekends.

### Home care in Europe

Because of the changing lifestyle trends, smaller families and growing labour market participation of women reduced the providing care informally. Current demographic developments in Europe have as a consequence increasing interest in home care realized by professional staff (Genet et al. 2011).

**Figure 6.** Burden on family when participating on long-term care

Source: https://www.howz.com/frailty-means-independence-loss/



## Palliative care

Disease, suffering and death are the natural part of human existence. The criteria of immatureness of society show how it tries to identify and to answer the needs of dying person, reflects the loss of ill person and his or her relatives and close persons.

**One division of medical care distinguishes:**

- *Curative care* with an aim to cure ill person.
- *Palliative care* improves the quality of life of patients with life-threatening illness and their families in physical, psychological or spiritual level. This care is applicable for adults as well as for children.

Case study: *Dolores' Story*

"Choosing hospice does not have to be a permanent decision. For example, Dolores was 82 when she learned that her kidneys were failing. She thought that she had lived a long, good life and didn't want to go through dialysis, so Dolores began hospice care. A week later, she learned that her granddaughter was pregnant. After talking with her husband, Dolores changed her mind about using hospice care and left to begin dialysis, hoping to one day hold her first great-grandchild. Shortly after the baby was born, the doctors said Dolores' blood pressure was too low. At that point, she decided to re-enroll in hospice (UW Medicine 2018)."

WHO (2018) characterizes **palliative care** as follows:

1. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other difficulties.
2. It uses a <u>team approach</u> to support patients and his families in practical cases and by providing of bereavement counselling. Specially-trained team consists of doctors, nurses and other specialists, such as social worker, physiotherapist, nutrition´s experts, psychology, special educator (for children), pastor/priest, volunteers, etc.
3. It is a human right to health.
4. It is provided through person-centred and integrated health services reflected on the specific needs and preferences of individuals.
5. It is essential for wide range of diseases of adults: cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%), and by kidney failure, chronic liver disease, multiple sclerosis, Parkinson´s disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.
6. It is an ethical duty to relieve suffering and to respect the dignity of people by using of opioid analgesics for treating the pain associated with many advanced progressive conditions.

Dobríková-Porubčanová (2005) holds the view that palliative care may be realized at the following places: home of patient, hospice day-care centres, ambulance of hospice care, stationary hospice care, ambulance of palliative care and ambulance for pain treatment, in a hospital – specialized palliative beds, department and clinic of palliative care.

**What are the gaps of palliative care?**

86 % of people who need palliative care do not receive it.

82 % of the world ´s population lack access to pain relief.

98 % of children needing palliative care live in low and middle income countries (WHOa 2018).

Palliative care can be helpful at any stage of illness and is best provided from the point of diagnosis. For those entering the last phase of life, end-of-life care (care about dying person in his/her last days, hours or minutes before death) is arranged. A model for delivering end-of-life care presents hospice (Figure 7). In some definitions of hospice is mentioned a time frame: life expectancy is less than 6 months, according to doctor´s assumption.

An idea of hospice is relative to respect of life and to man, which is a unique and non-repeatable being. Hospice is not only a building; it is a complex approach to dying person (Svato□ová 2001). Improving life quality for patients with serious illness is possible to affect by comprehensive hospice care including ergo-therapy, art-therapy, and musical therapy.

**Figure 7.** Palliative care - terminology explanation

Source: UW Medicine, 2018

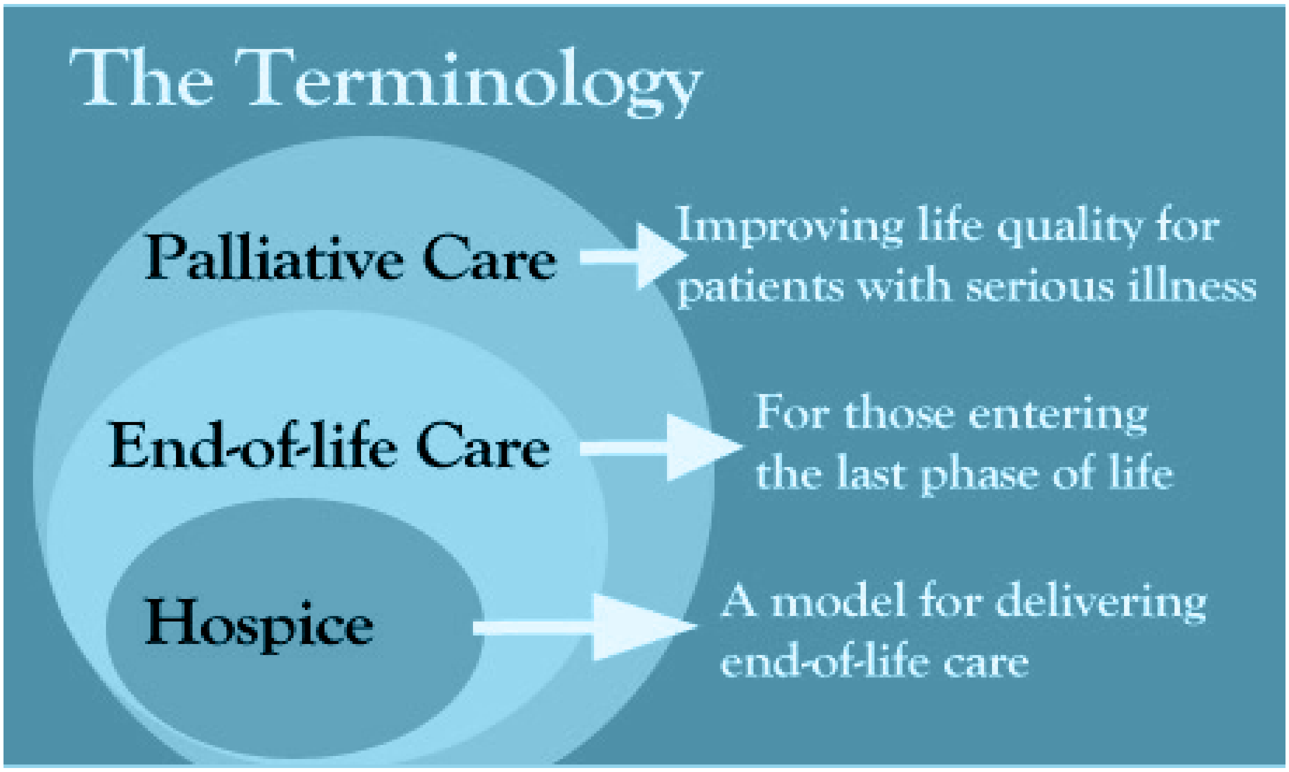
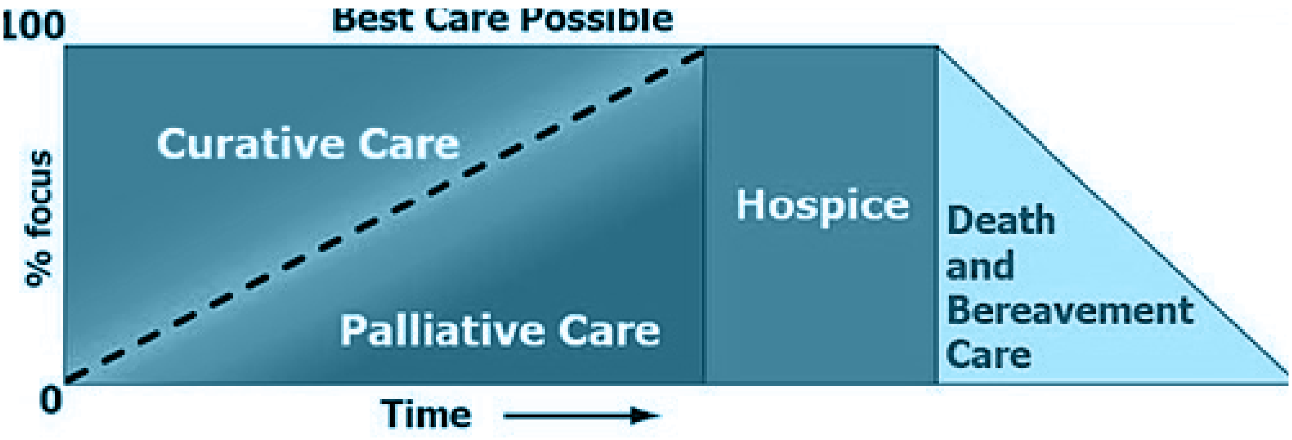


**Figure 8.** Model of care for people with life-threatening disease

Source: https://www.kindredhealthcare.com/resources/blog-kindred-continuum/2012/10/11/palliative-care-summit



**Key messages**

- Ageing is a process that occurs over all the body and leads to a gradual decrease in physical and mental capacity, a growing risk of disease, and ultimately, death.
- Health of people in older age refers to underlying changes in organism, to specific health conditions and other complex problems (geriatric syndromes) which impact on intrinsic capacity and functional ability.
- To the geriatrics syndromes belong: syndrome of frailty, syndrome of incontinency and syndrome of falls.
- In the context of population aging, it is important how older people experience the old age. Whether it is a passive experience of illness, depression or loneliness, or it is a period filled with activities that bring personal satisfaction and are beneficial to the community and society.
- *Healthy ageing* is the process of developing and maintaining the functional ability that enables well-being in older age.
- *Active ageing* is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age.
- Comprehensive geriatric assessment is a multidisciplinary diagnostic and treatment process that identifies limitations of a frail person in older age in order to develop a coordinated plan to maximize overall health with ageing. It is designed to evaluate older person´s functional ability, physical health, cognition and mental health, and socio-environmental circumstances by well-validated survey instruments.
- Long-term care belongs to innovative approaches in health and social care for older people.

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# 5

# Health Systems and Policies

## 5.1 HEALTH SYSTEMS AND POLICIES AS DETERMINANTS OF HEALTH

*Zuzana Katreniakova*

Although lifestyle factors like diet, and physical activity have an influence on our health today, it's also clear that the huge differences in the way different health systems are set up plays an important role too. The **health systems** represent the ensemble of all public and private organizations, institutions, and resources mandated to improve, maintain or restore health. Health systems encompass individual and population services as well as activities to influence the policies and actions of other sectors to address social, environmental and economic determinants of health (WHO, 2008).

Organized health systems are barely 100 years old, even in industrialized countries. Many of them have gone through several, sometimes parallel and sometimes competing, generations of development and reform, shaped by national and international values and goals. The financial optimism of the 1970s was soon dispelled in many parts of the world by a combination of high oil prices, low tax revenues and economic adjustment. As the crisis in many countries deepened in the 1990s, so many governments looked to the wider environment for new solutions. In the first decade of the 21st century, many of the pressures remain. But there are also signs of change. There is a wider recognition of inter-dependence and the importance of wider policy choices on health systems, particularly the impact of migration and trade (WHO, 2007).

A well functioning health system responds in a balanced way to a population's needs and expectations by: improving the health status of individuals, families and communities; defending the population against what threatens its health; protecting people against the financial consequences of ill-health; providing equitable access to people-centred care; and making it possible for people to participate in decisions affecting their health and health system (WHO, 2010).

To achieve these goals, it is essential to ensure effective set-up of the key elements of the health system (Fig. 1) for which leadership and governance, health information systems, health financing, human resources for health, essential medical products and technologies, and service delivery, are considered (WHO, 2007; WHO, 2010):

» Good **health services** are those which deliver effective, safe, quality personal and non-personal health interventions to those who need them, when and where needed, with minimum waste of resources.

» A well-performing **health workforce** is one which works in ways that are responsive, fair and efficient to achieve the best health outcomes possible, given available resources and circumstances; i.e. there are sufficient numbers and mix of staff, fairly distributed; they are competent, responsive and productive.

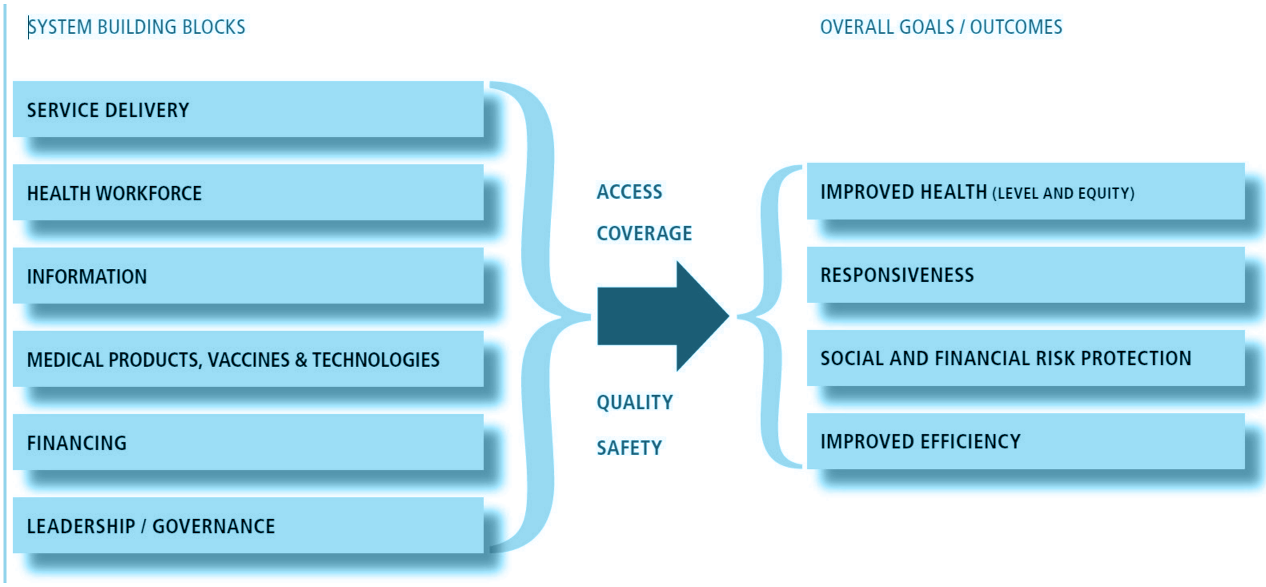
» A well-functioning **health information system** is one that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status.

» A well-functioning health system ensures equitable access to essential **medical products, vaccines and technologies** of assured quality, safety, efficacy and cost-effectiveness, and their scientifically sound and cost-effective use.

» A good **health financing** system raises adequate funds for health, in ways that ensure people can use needed services, and are protected from financial catastrophe or impoverishment associated with having to pay for them.

- **Leadership and governance** involves ensuring strategic policy frameworks exist and are combined with effective oversight, coalitionbuilding, the provision of appropriate regulations and incentives, attention to system-design, and accountability.

**Figure 1.** The WHO health systems framework.



Source: WHO, 2007.

### 5.1.1 Health systems typology and financing

#### Health systems typology

There are four major models for health systems (Chung, 2017):

- the Beveridge model (*United Kingdom, Spain, New Zealand, Cuba),*
- the Bismarck model (*Germany, Belgium, Japan, Switzerland*),
- the National Health Insurance model (*Canada, Taiwan, South Korea*),
- the out-of-pocket model (*rural areas in India, China, Africa, South America*).

**The Beveridge model** (single-payer national health service) was first developed by Sir William Beveridge in 1948. Established in the United Kingdom and spreading throughout many areas of Northern Europe and the world, this system is often centralized through the establishment of a national health service. A central tenant of this model is health as a human right. Thus, universal coverage is guaranteed by the government and anyone who is a citizen has the same access to care. The government acts as the single-payer, eliminating competition in the market and generally keeping prices low. Funding health care through income taxes allows for health care to be free at the point of service - after an appointment or operation, the patient does not have to pay any out-of-pocket fees because of their contribution through taxes. Under this system, a large majority of health staff is composed of government employees.

With the government as the sole payer, costs can be kept low and benefits are standardized across the country. However, a common criticism of this system is the tendency toward long waiting lists. Because everyone is guaranteed access to health services, over-utilization of the system may lead to increasing costs. Another practical concern is the government response to crisis. In the case of a precarious national emergency, such as war or a health crisis, funding for health services may decline as public revenue decreases, exacerbating the financial burden inherent in a large influx of patients. Such a situation would require careful allocation of emergency funding before the crisis.

**The Bismarck model** (social health insurance model) was created near the end of the 19th century by Otto von Bismarck. Employers and employees fund health insurance in this model - those who are employed have access to "sickness funds" created by compulsory payroll dedications. In addition, private insurance plans cover every employed person, regardless of pre-existing conditions.

Health providers are generally private institutions, though the Social Health Insurance funds are considered public. In some countries, there is a single insurer (France, Korea); other countries may have multiple, competing insurers (Germany, Czech Republic) or multiple, non-competing insurers (Japan). Regardless of the number of insurers, the government tightly controls prices while insurers do not make a profit. These measures allow for the government to exercise a similar amount of control over prices for health services seen in the Beveridge model.

The requirement of employment for health insurance provides benefits and causes problems. These measures ensure that employed people will have the healthcare needed to continue working and ensure a productive workforce. Because it was not initially established to provide universal health coverage, the Bismarck model focuses resources on those who can contribute financially. With a shift in mindset from health as a privilege for employed citizens to a right for all citizens, the model faces a number of concerns, such as how to care for those unable to work or those who may not be able to afford contributions. More immediate practical concerns include how to contend with aging populations, with an uneven number of retired citizens compared to employed citizens, and how to stay competitive in attracting international companies that may prefer locations without these required payroll dedications.

**The National Health Insurance model** (single-payer national health insurance) incorporates aspects of both the Bismarck and Beveridge models. Like the Beveridge model, the government acts as the single payer for medical procedures, and like the Bismarck model, providers are private. The universal insurance does not make a profit or deny claims. There has been a tendency in recent years for countries with Beveridge-type health care systems to incorporate Bismarck characteristics or vice versa, leading to the health care policies in a number of countries like Hungary and Germany to trend towards the mixed model. In some countries like Canada, private insurance contracting is permitted for those who would prefer them.

The balance between public insurance and private practice allows hospitals to maintain independence while also reducing internal complications with insurance policies. Financial barriers to treatment are generally low, and patients usually are able to choose their healthcare providers.

Like the Beveridge model, this system covers most procedures regardless of income level. The model also may reduce the costs involved with administration of health insurance, as the government processes all claims and reduces the amount of duplication of services. Perhaps the largest complaint is that these systems can suffer from long waiting lists for treatment. Waitlists are not limited to elective surgeries or other non-emergency procedures, as patients waiting to be seen in some fields like neurosurgery often may face long delays until they can see a physician. Aging population demographics and overutilization of health resources in non-urgent situation are also problems for the long-term stability of this model.

**The Out-of-Pocket model** (market-driven health care) is used in less developed areas with too few resources to create mass medical care. Without enough money, the poor are unable to afford appropriate health care. Unfortunately, this situation is common in most countries since only the wealthiest countries have robust health care systems. Disparities in wealth lead to disparities in health outcomes in these areas.

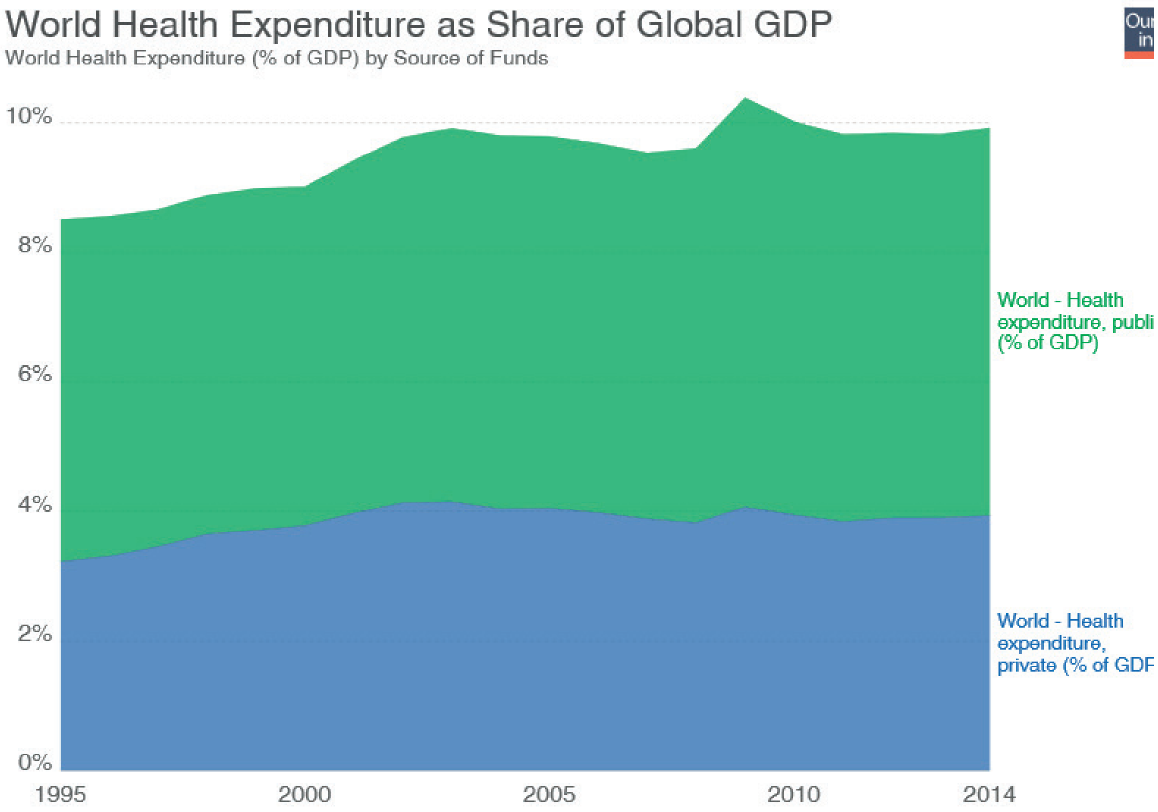
While in theory these models have distinct policy separations, in reality most countries have a blend of these approaches, though they generally have a single health system.

## Health systems financing

Health is a fundamental driver of our overall quality of life and healthcare is one of the most important inputs to produce health. Publicly funded healthcare is a legacy of the Age of Enlightenment. The first examples of legislation on health insurance date back to the late 19th century. Data from these early systems shows that healthcare expenditure only began rising several years after the expansion of insurance coverage, with the discovery of powerful new treatments.

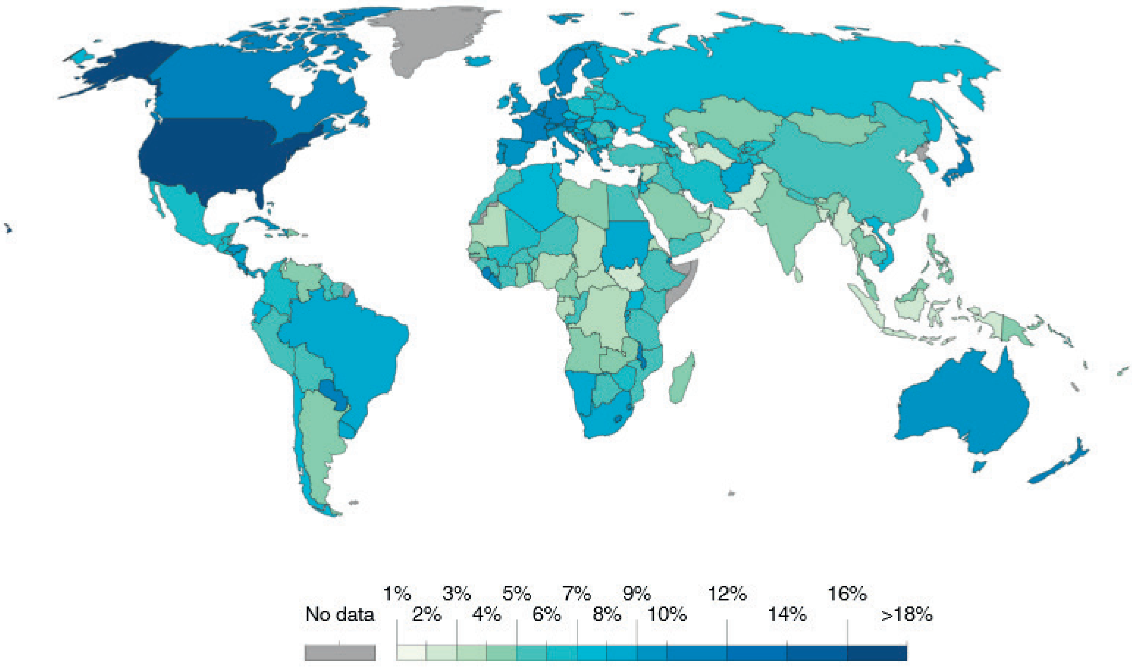
In the last two decades, total aggregate global expenditure on healthcare has been relatively stable, albeit with a slow steady increase (Fig. 2). Total healthcare spending as a percent of GDP has seen an overall increase of roughly 1.5 perceptual points over the last two decades, with a relatively constant share of resources coming from the public sector. However, global trends in healthcare expenditure mask a great deal of heterogeneity (Fig. 3) and the huge differences in average health care spending per capita between different countries (Fig. 4). In 2013 it ranges from 23.65 international-$ in the Central African Republic to 9,145 international-$ in the USA, which means that on average Americans spend more per day on health than people in the Central African Republic spend per year.

**Figure 2.** World health expenditure as share of global GDP



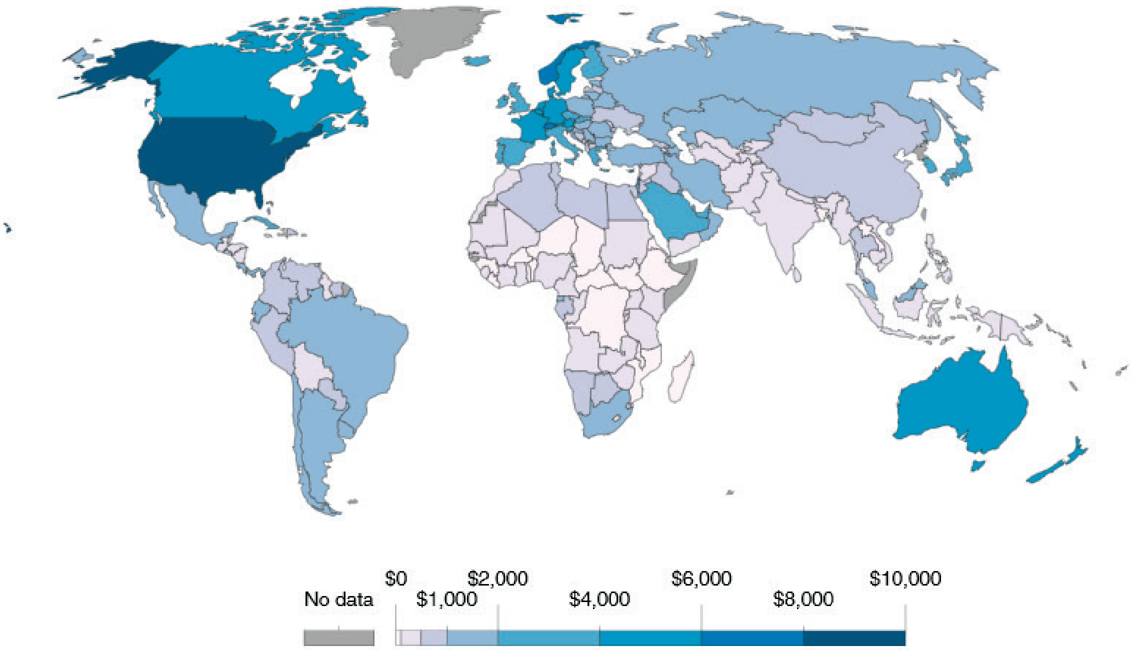
Source: https://ourworldindata.org/financing-healthcare.

**Figure 3.** Total healthcare expenditure as share of national GDP by country, 2013.



Source: https://ourworldindata.org/financing-healthcare.

**Figure 4.** Annual healthcare expenditure per capita, 2014.

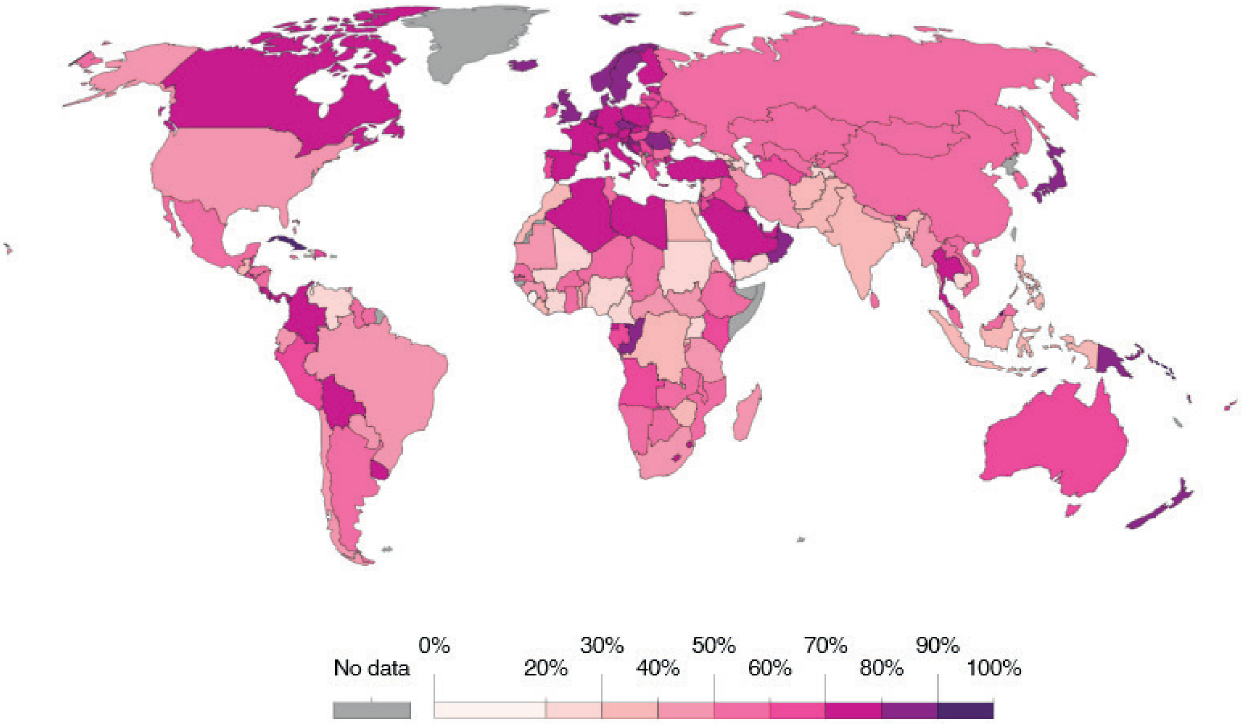


Source: https://ourworldindata.org/financing-healthcare.

World-wide cross-country data shows that, while the public share of resources used to finance healthcare has been stable in the aggregate, there is substantial underlying heterogeneity. There are large differences even among relatively homogeneous industrialized market economies in public spending on healthcare as a share of total healthcare spending by country (Fig. 5). Aggregating countries by income levels (World Bank classification) there have been substantial underlying shifts across regions – especially in countries in the low-income and upper-middle-income brackets, there has been a marked increase in the share of public resources used to finance healthcare (Fig. 6).

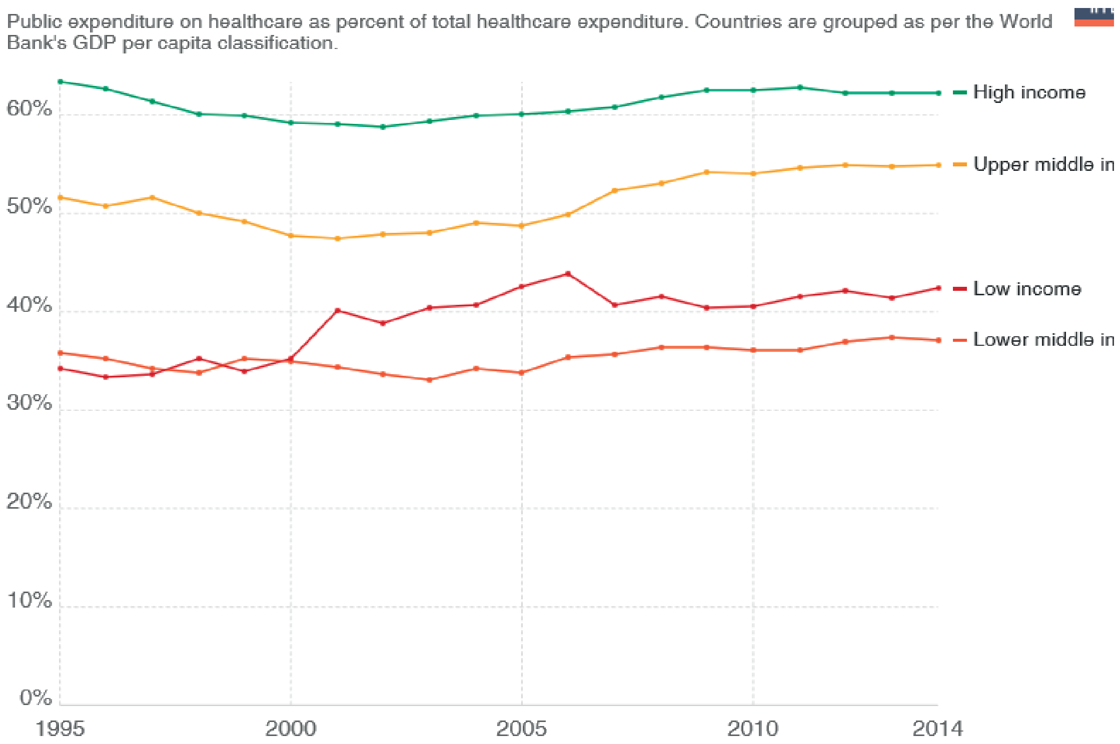
In many countries an important part of the private funding for healthcare takes the form of 'out-of-pocket' spending. This refers to direct outlays made by households, including gratuities and in-kind payments, to healthcare providers. As it can be seen at Figure 7, in high-income countries these outlays tend to account for only a small fraction of expenditure on healthcare (e.g. France), while in low-income countries, they account for the majority of funding (e.g. Afghanistan). Many countries have followed a clear path in the direction of reducing this type of expenditures (particularly in the developing world), yet some countries have moved in the opposite direction (Russia is a notable case in point, with a threefold increase in the share of out-of-pocket expenditure in the last decade).

**Figure 5.** Public expenditure on healthcare as percent of total healthcare expenditure, 2014.



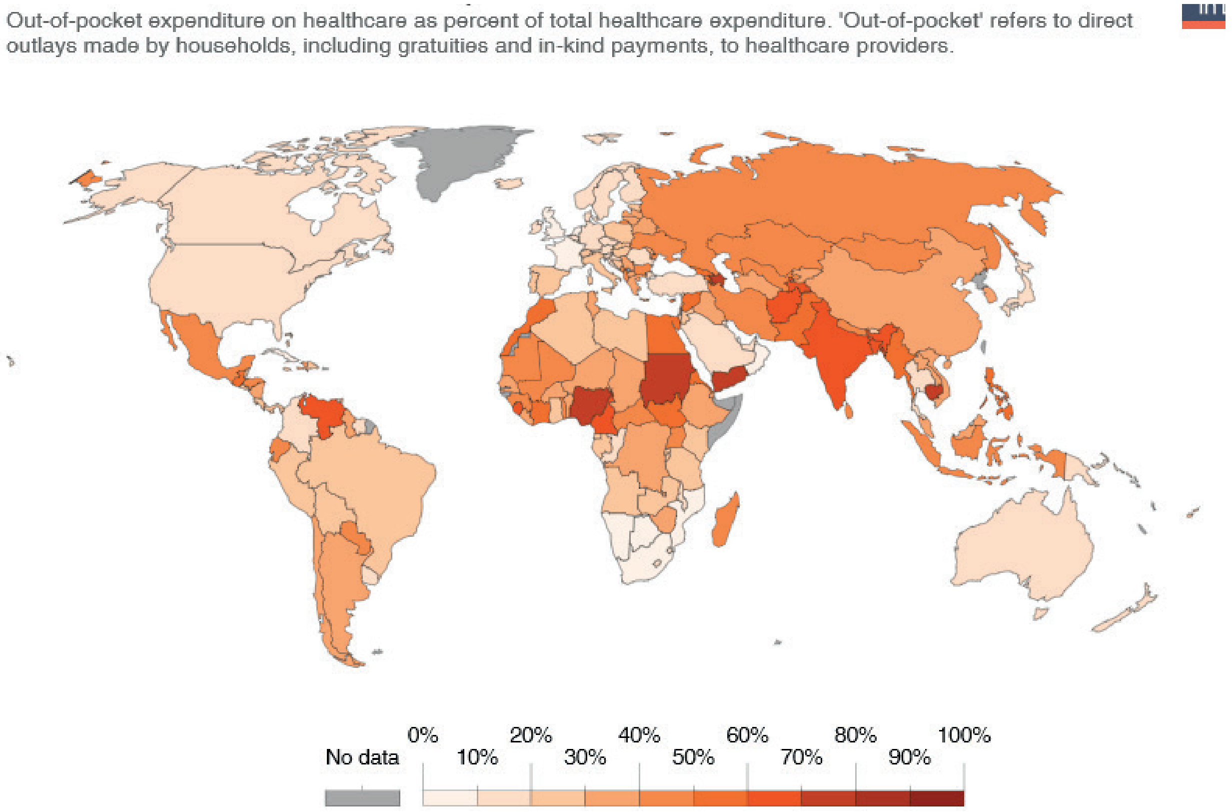
Source: https://ourworldindata.org/financing-healthcare.

**Figure 6.** Public expenditure on healthcare by country income groups.



Source: https://ourworldindata.org/financing-healthcare.

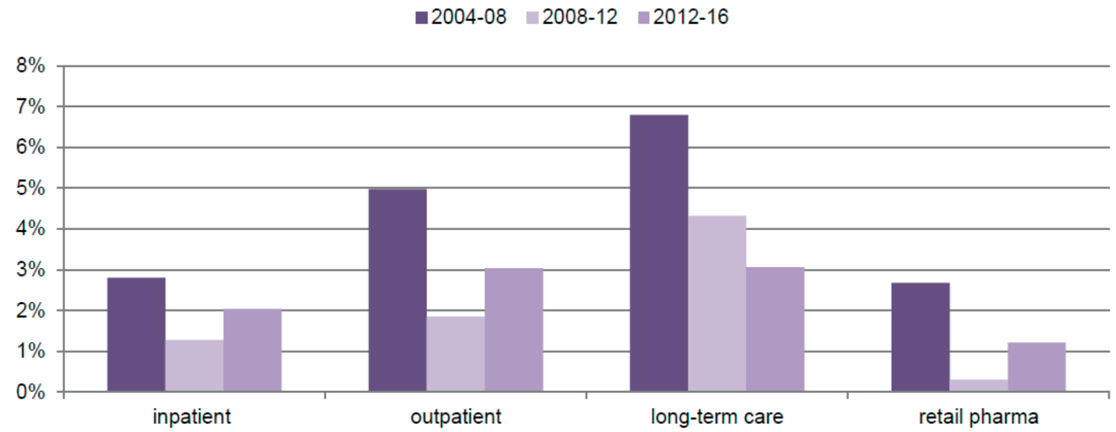
**Figure 7.** Share of out-of pocket expenditure on healthcare, 2014.



Source: https://ourworldindata.org/financing-healthcare.

From perspective of spending on key health care services, the pattern on spending growth has been less than uniform over the last decade among the OECD countries (Fig. 8). In the years preceding the crisis (2004-2008), spending on outpatient care was typically growing at around twice the rate of inpatient care. During the crisis (2008-2012), there was a dramatic slowdown in both inpatient and outpatient care due to salary freezes and reductions in service payments. Since the crisis (2012-2016), outpatient spending has once again outpaced inpatient spending. The fastest growing area of health spending prior to the crisis was long-term care (OECD, 2018).

**Figure 8.** Average annual growth of selected health care services, OECD average 2004-2016.



*Note*: Retail pharmaceuticals exclude the costs of pharmaceuticals used as part of an inpatient treatment episode.
*Source: OECD Health Statistics 2018.*

Source: OECD, 2018.

**How strong is the link between healthcare expenditure and population's health?**

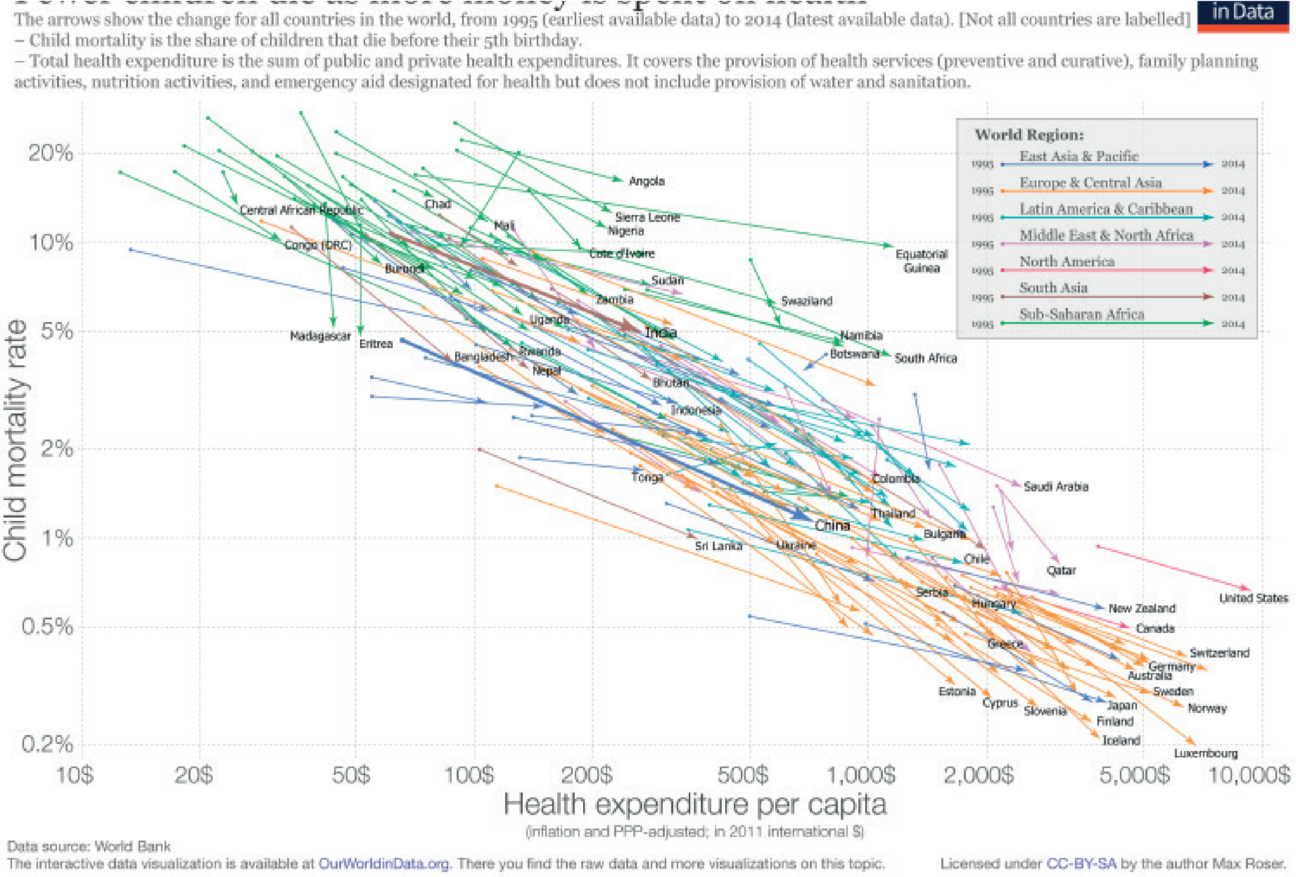
Figure 9 presents the relationship between child mortality (measured as the share of children dying before their fifth birthday) and healthcare expenditure per capita. As it can be seen, child mortality is declining as more money is spent on health. Focusing on change over time we can see a particularly striking fact: while there is huge inequality in levels – child mortality in the best-performing countries is almost 100-times lower than in the worst – inequality in trends is surprisingly stable. Specifically, if you look at the paths over time it is surprising how little heterogeneity there is between very different countries in the world. No matter whether it is a rich country in Europe or a much poorer country in Africa, the proportional decline in child mortality associated with a proportional increase in health expenditure is remarkably similar.

Figure 10 shows the relationship between life expectancy at birth and healthcare expenditure per capita. As it can be seen, countries with higher expenditure on healthcare per person tend to have a higher life expectancy. And looking at the change over time, we see that as countries spend more money on health, life expectancy of the population increases. But, the relationship in this chart seems to follow a pattern of 'diminishing returns': the proportional highest gains are achieved in countries with low baseline levels of spending. This pattern is similar to that observed between life expectancy and per capita income.

Many of the Sub-Saharan Africa countries achieved remarkable progress over the last 2 decades: health spending often increased substantially and life expectancy in many African countries increased by more than 10 years. The most extreme case is Rwanda, where life expectancy has increased from 32 to 64 years since 1995 (which was one year after the Rwandan genocide). The African countries that suffered the most under the HIV/AIDS epidemic – Lesotho, Swaziland, and South Africa – experienced a decline of life expectancy from which they have not yet recovered.

The association between health spending and increasing life expectancy also holds for rich countries in Europe, Asia, and North America. The US is an outlier that achieves only a comparatively short life expectancy considering the fact that the country has by far the highest health expenditure of any country in the world.

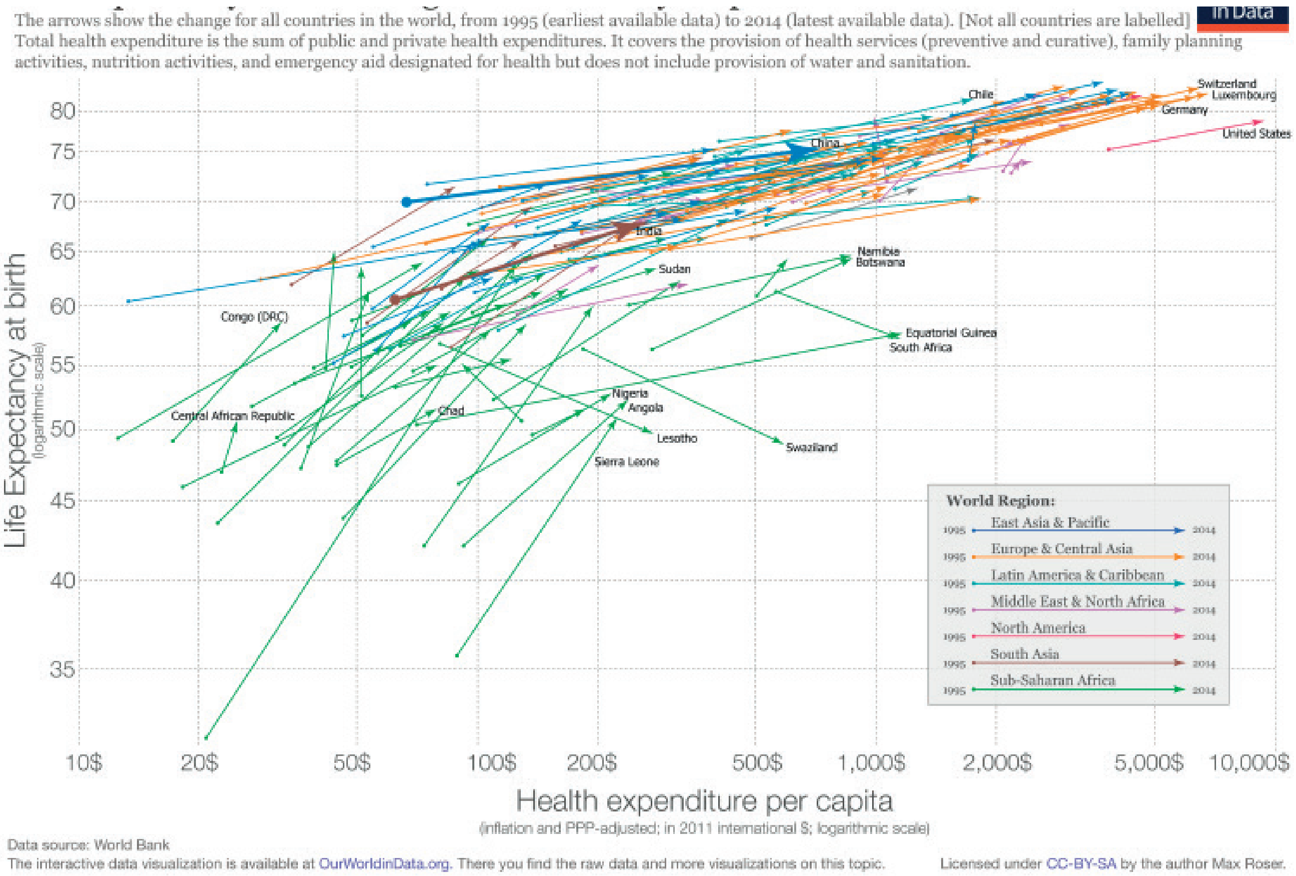
**Figure 9.** Fewer children die as more money is spent on health.



Data source: World Bank
The interactive data visualization is available at OurWorldinData.org. There you find the raw data and more visualizations on this topic.

Source: https://ourworldindata.org/financing-healthcare.

**Figure 10.** Life expectancy is increasing as more money is spent on health.



Source: https://ourworldindata.org/financing-healthcare.

Current health systems face tough and complex challenges, such as ageing populations, growing prevalence of chronic illnesses, and intensive use of expensive yet vital health technologies. On the other side, these systems must deal with higher expectations of citizens and resolve persistent inequities in access and in health conditions among different groups. Globalisation in general, and trade liberalisation in particular, also affect healthcare, via constrained pricing and trade policies of pharmaceuticals, and the need for enhanced health surveillance across borders and populations. Furthermore, the evidence shows that health performance and economic performance are interlinked. Wealthier countries have healthier populations for a start, and poverty, mainly through infant malnourishment and mortality, adversely affects life expectancy. National income has a direct effect on the development of health systems, through insurance coverage and public spending, for instance.

Countries with weak health and education conditions find it harder to achieve sustained growth. Indeed, economic evidence confirms that a 10% improvement in life expectancy at birth is associated with a rise in economic growth of some 0.3-0.4 percentage points a year (Frenk, 2004).

### 5.1.2 Global and European health policies for 21st century

The effects of health on development are clear. Good health is vital for economic and social development and supports economic recovery. Thus, investment in health is not only a desirable, but also an essential priority for most societies. However, the crucial challenge is to harmonise health and economic policies to improve health outcomes, but also to minimise any negative impacts while promoting synergies wherever possible (Frenk, 2004).

Health policy refers to decisions, plans, and actions that are undertaken to achieve specific health care goals within a society. An explicit health policy can achieve several things: it defines a vision for the future which in turn helps to establish targets and points of reference for the short and medium term. It outlines priorities and the expected roles of different groups; and it builds consensus and informs people.

#### The 2030 Agenda

In 2015, 193 members committed to the **United Nations Sustainable Development Goals (SDGs)**, a new vision for the future entitled *Transforming our world: the 2030 agenda for sustainable development (*Resolution A/RES/70/1, 2015), which addresses existing global health inequalities through comprehensive, cross-sector strategies (Nugent, Bertram et al., 2018). The 17 main targets (Fig. 11) cover the economic, educational, environmental, and social pillars of sustainable development with a strong focus on equity across all goals at national and international levels (Chan, 2016).

The 2030 Agenda presents a unique opportunity to renew national commitments to advancing health and well-being. It has a strong emphasis on leaving no one behind. Five SDGs set explicit targets that relate to the reduction of health inequalities both nationally and worldwide. These goals are: ***poverty reduction, health and wellbeing for all, equitable education, gender equality, and reduction of inequalities within and between countries.*** These SDGs cover 78 of the 169 targets set 4 indicating a new central role of health in development (LeBlanc, 2015). The reduction of both poverty and health inequalities have become leading topics in the promotion of the SDGs (Chan, 2016). For the first time, the UN has explicitly recognised the broad socioeconomic determinants of health and wellbeing and the strong interdependencies between socioeconomic development and health (Jamison et al., 2013).

#### HEALTH 2020

Health 2020 is the new European health policy framework aiming to support action across government and society to: "significantly improve the health and well-being of populations, reduce health inequalities, strengthen public health and ensure people-centred health systems that are universal, equitable, sustainable and of high quality".

The policy framework is evidence-based and peer-reviewed. It is the product of an extensive two-year consultation process across the WHO European Region and beyond, and was adopted by the 53 Member States of the Region during the 62nd session of the WHO Regional Committee for Europe in September 2012. It gives policy-makers a vision, a strategic path, a set of priorities and a range of suggestions about what works to improve health, address health inequalities, and ensure the health of future generations. It identifies strategies for action that are adaptable to the many contextual realities of the WHO European Region (Fig. 12).

Health 2020 fully aligns with the 2030 Agenda (Fig. 13). Both aim to improve health and well-being for all at all ages through **whole-of-government, whole-of-society and health-in-all-policies approaches**. Both tackle the social, economic, cultural and environmental determinants of health.

**Figure 11.** UN Global Goals, charting sustainable development for people and planet by 2030.

Source: https://www.un.org/sustainabledevelopment/sustainable-development-goals/

**Figure 12.** Health 2020: overarching policy framework.

Two strategic objectives

Working to improve health for all and reducing the health divide

Improving leadership, and participatory governance for health

Four common policy priorities for health

Investing in health through a life-course approach and empowering people

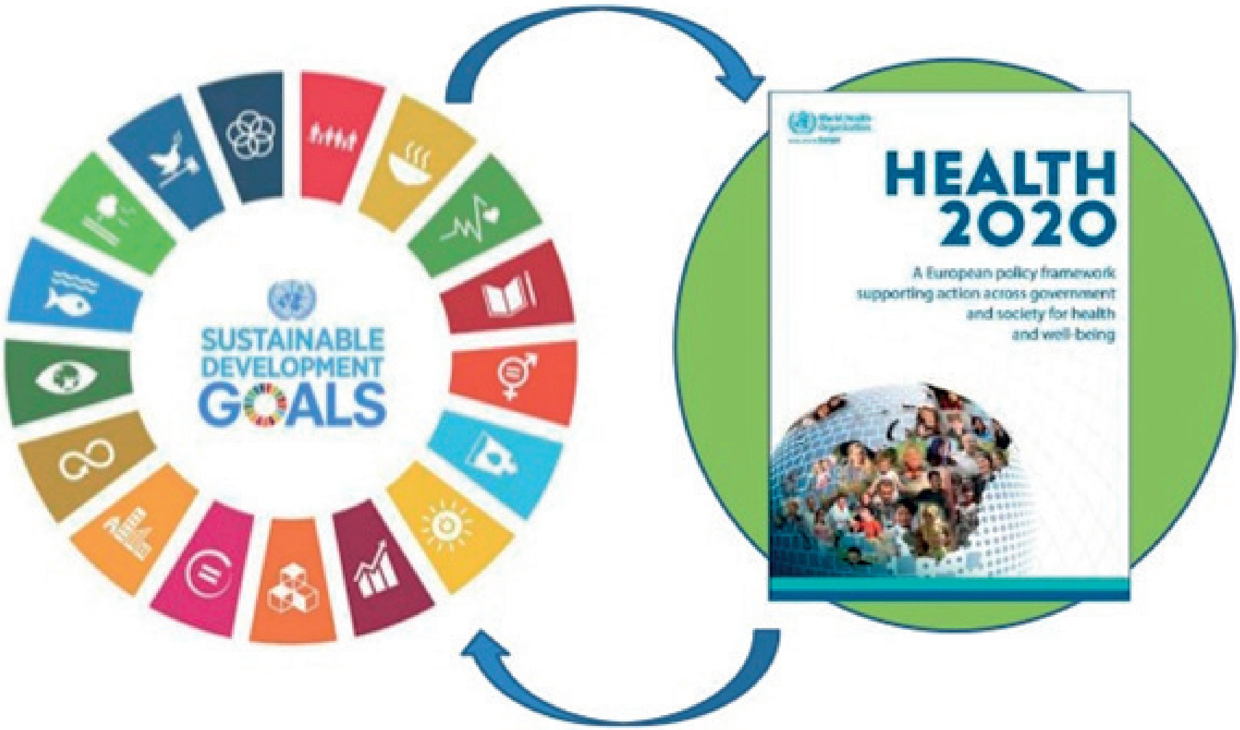
Tackling the Region's major health challenges of noncommunicable and communicable diseases

Strengthening people-centred health systems, public health capacities and emergency preparedness, surveillance and response

Creating resilient communities and supportive environments

Source: WHO. 2014.https://www.slideshare.net/who_europe/regional-directors-report-on-the-work-of-the-who-regional

**Figure 13.** Health 2020 and SDGs are aligned.



Source: WHO, 2017.
https://www.slideshare.net/who_europe/roadmap-to-implement-the-2030-agenda-for-sustainable-development-building-on-health-2020-the-european-policy-for-health-and-wellbeing-79673894

### 5.1.3 Quality of health care and public health services

Ensuring health care that is of high quality is an important component of high-performing health systems. That is why systematic approaches to ensure and enhance the quality of health care have been implemented widely in many settings. However, the application of similar principles and processes to public health services, as inevitable part of well-functiniong health systems, has lagged behind.

**Defining quality in health systems**

In spite the fact, that there has been considerable work done on the development of taxonomies and capturing the domains of health care quality, a commonly agrred systematic framework is still lacking (Nolte et al., 2011). Our current understanding of quality in health care has been shaped funadamentally by the work of **Avedis Donabedian** (Donabedian, 1980). His definition has at its core the performance of the individual practitioner in their interaction with the patient, distinguishing technical and interpersonal performance. He further proposed that the qulity of health care can be assessed by evaluating its structure, processes and outcomes (Donabedian, 1988).

**The most common domains of quality in health care** that have been described include (Williams & Nolte, 2018):

- **Effectiveness**

  The extent to which a service achieves the desired result(s) or outcome(s) at the patiet, population or organizational level;
- **Efficiency**

  The relationship between a specific product (output) of the health system and the resources (inputs) used to create the product;
- **Access**

  The extent to which services are available and accessible in a timely manner;
- **Patient focus on responsiveness**

  The extent to which the planning and delivery of services involves clients, provides them information to support their decision-making, and is positive, acceptable and responsive to their needs and expectations, and respectful of privacy, confidentiality and differences;
- **Safety**

  The extent to which health care processes avoid, prevent and ameliorate adverse outcomes or injuries that stem from the processes of helath care itself;
- **Equity**

  The extent to which the distribution of health care and its benefits among a population are fair; it implies that, in some circumstances, some individuals will receive more care than others to reflect differences in their ability to benefit or in their particular needs.

To enable strengthening the quality in public health the following **domains of quality in public health practices** have been formulated (Public Health Quality Forum, 2008):

- **Population-centred**

  Protecting and promoting healthy conditions and health for the entire population;
- **Equitable**

  Working to achieve health equity (encompassing health and the social determinants of health);
- **Proactive**

Formulating policies and sustainable practices in a timely manner, while mobilizing rapidly to address new and emerging threats and vulnerabilities;

- **Health promoting**

  Ensuring policies and strategies that advance safe practices by providers and the population and that increase the probability of positive health behavior and outcomes;

- **Risk-reducing**

  Diminishing adverse environmental and social events by implementing plicies and strategies to reduce probability of preventable injuries and illnesses or negative outcomes;

- **Vigilant**

  Intensifying practices and enacting policies to support enhancements to surveillance activities (technology, standardization, system thinking/ modelling);

- **Transparent**

  Ensuring openness in the delivery of services and practices, with particular emphasis on valid, reliable, accessible, timely, and meaningful data that are readily available to stakeholders, including the public;

- **Effective**

  Justifying investments by using evidence, science, and best practices to achieve optimal results in areas of greater need;

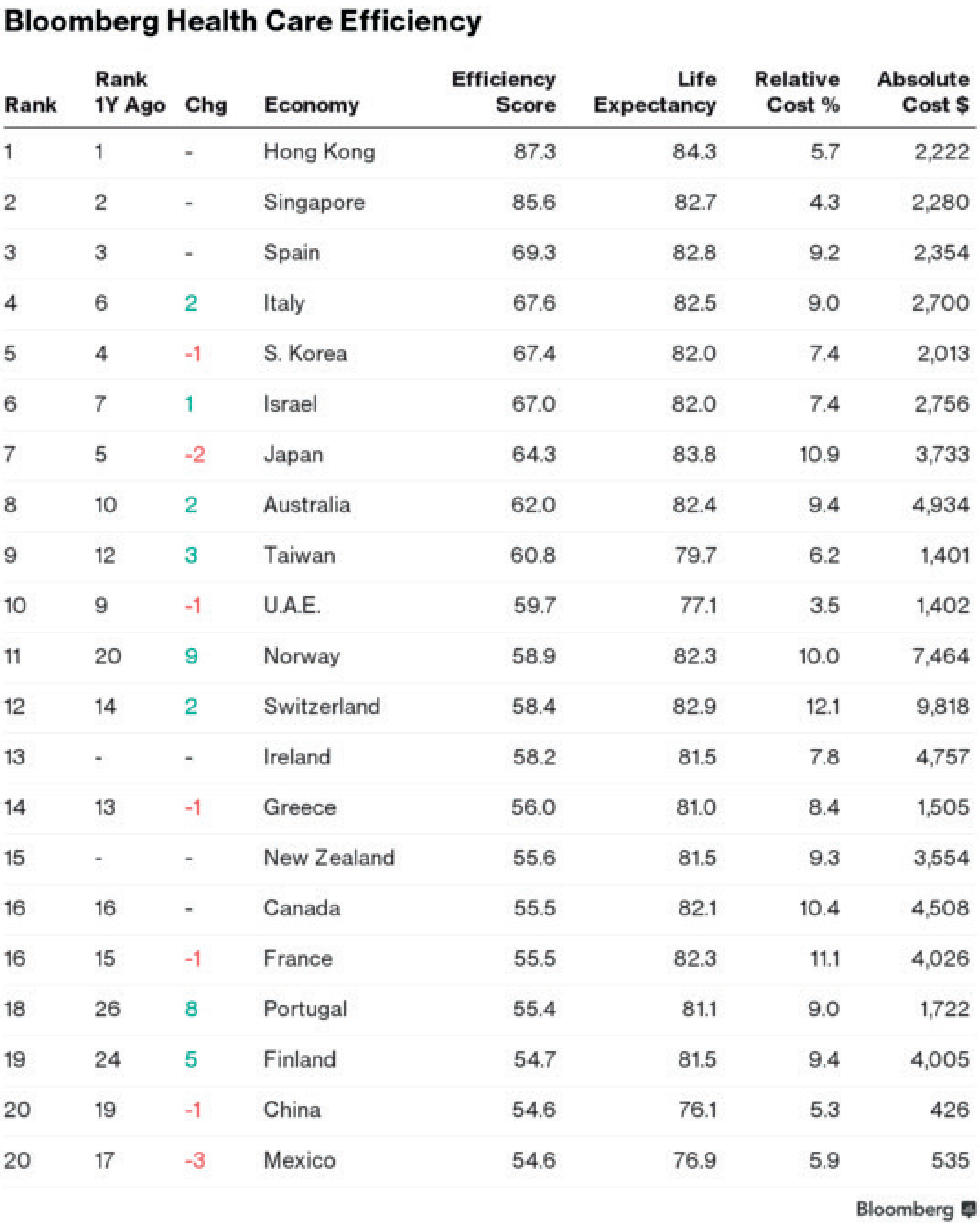
- **Efficient**

  Understanding costs and benefits of public health interventions, to facilitate the optimal use of resources to achive desired outcomes.

### Health care efficiency

According to Bloomberg analysis, the most efficient health care is provided in Hong Kong, Singapore, and Spain. A health efficiency index was created to rank those countries with average life spans of at least 70 years, GDP per capita exceeding 5,000 USD and a minimu population of 5 million. Rankings can change substantially year-over-year because of such things as recession, currency fluctuations and volatile spending patterns relative to the slow pace of improvement in life expectancy (Fig. 14).

**Figure 14.** Health care efficiency index by Blomberg, 2014-2015.



**Bloomberg Health Care Efficiency**

| Rank | Rank 1Y Ago | Chg | Economy | Efficiency Score | Life Expectancy | Relative Cost % | Absolute Cost $ |
|---|---|---|---|---|---|---|---|
| 1 | 1 | - | Hong Kong | 87.3 | 84.3 | 5.7 | 2,222 |
| 2 | 2 | - | Singapore | 85.6 | 82.7 | 4.3 | 2,280 |
| 3 | 3 | - | Spain | 69.3 | 82.8 | 9.2 | 2,354 |
| 4 | 6 | 2 | Italy | 67.6 | 82.5 | 9.0 | 2,700 |
| 5 | 4 | -1 | S. Korea | 67.4 | 82.0 | 7.4 | 2,013 |
| 6 | 7 | 1 | Israel | 67.0 | 82.0 | 7.4 | 2,756 |
| 7 | 5 | -2 | Japan | 64.3 | 83.8 | 10.9 | 3,733 |
| 8 | 10 | 2 | Australia | 62.0 | 82.4 | 9.4 | 4,934 |
| 9 | 12 | 3 | Taiwan | 60.8 | 79.7 | 6.2 | 1,401 |
| 10 | 9 | -1 | U.A.E. | 59.7 | 77.1 | 3.5 | 1,402 |
| 11 | 20 | 9 | Norway | 58.9 | 82.3 | 10.0 | 7,464 |
| 12 | 14 | 2 | Switzerland | 58.4 | 82.9 | 12.1 | 9,818 |
| 13 | - | - | Ireland | 58.2 | 81.5 | 7.8 | 4,757 |
| 14 | 13 | -1 | Greece | 56.0 | 81.0 | 8.4 | 1,505 |
| 15 | - | - | New Zealand | 55.6 | 81.5 | 9.3 | 3,554 |
| 16 | 16 | - | Canada | 55.5 | 82.1 | 10.4 | 4,508 |
| 16 | 15 | -1 | France | 55.5 | 82.3 | 11.1 | 4,026 |
| 18 | 26 | 8 | Portugal | 55.4 | 81.1 | 9.0 | 1,722 |
| 19 | 24 | 5 | Finland | 54.7 | 81.5 | 9.4 | 4,005 |
| 20 | 19 | -1 | China | 54.6 | 76.1 | 5.3 | 426 |
| 20 | 17 | -3 | Mexico | 54.6 | 76.9 | 5.9 | 535 |

Bloomberg

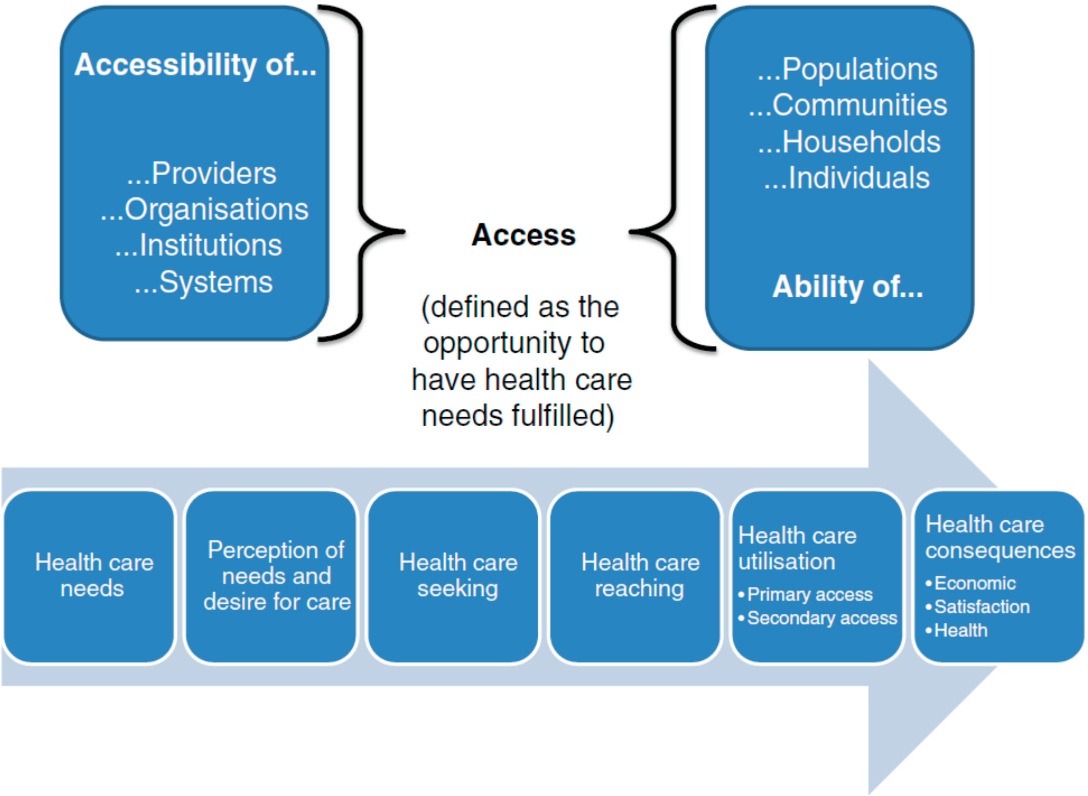
Source: https://www.bloombergquint.com/global-economics/u-s-near-bottom-of-health-index-hong-kong-and-singapore-at-top#gs.IlVWuOI3.

### Access to health care

Access to health services is central to the performance of health care systems around the world. It can be described as the **opportunity to reach and obtain appropriate health services in situations of perceived need for care**. As a result from the interface between the characteristics of persons, households, social and physical environments and the characteristics of health systems, organisations and providers, access can be seen as the possibility to identify healthcare needs, to seek healthcare services, to reach the healthcare resources, to obtain or use health care services, and to actually be offered services appropriate to the needs for care (Fig. 15).

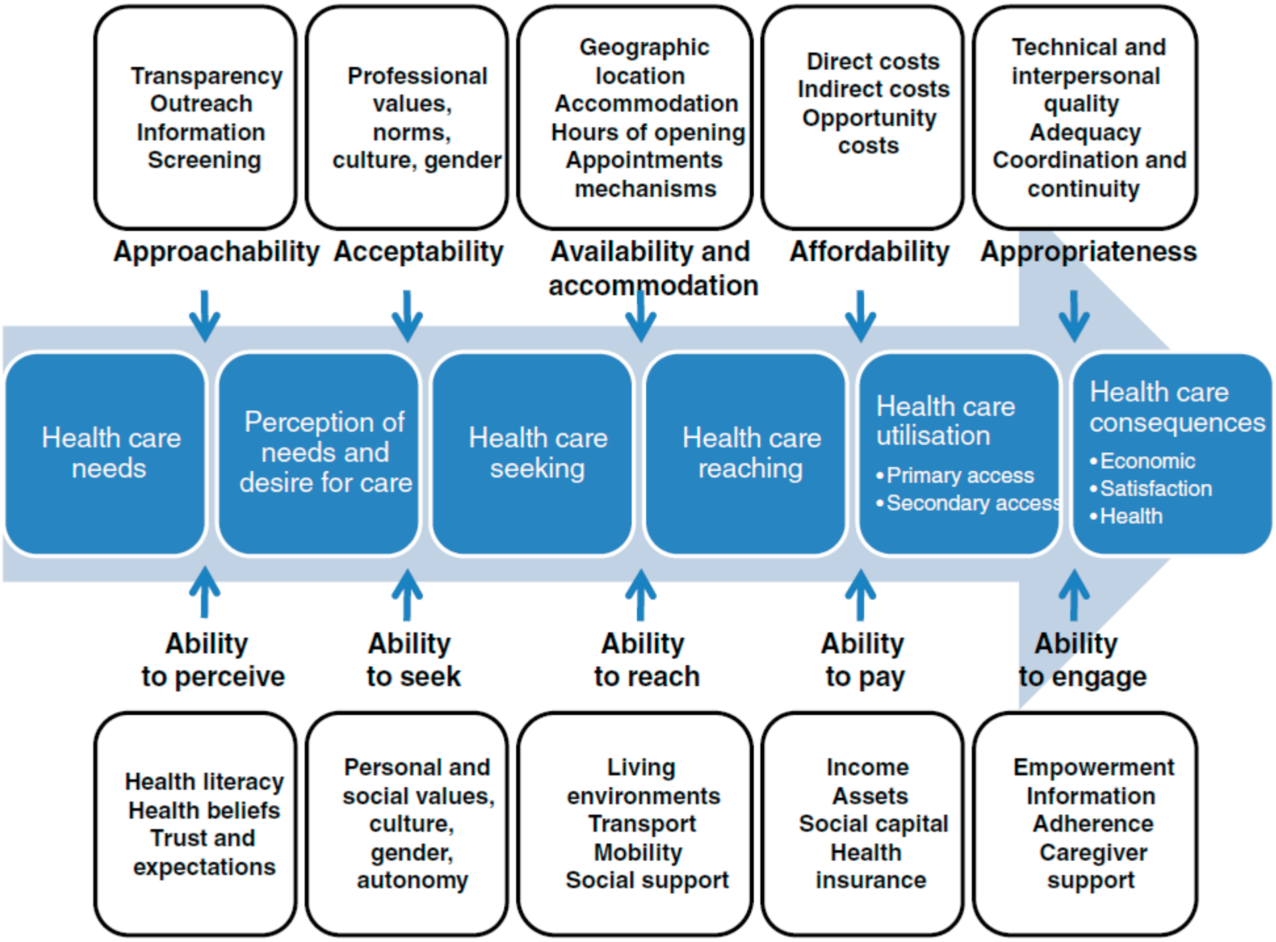
One of the latest proposed comprehensive conceptualisation of access is consistent with recent literature and emphases the need to take an ecological approach to indigenous health and a people-centred approach to healthcare (Fig. 16). The framework looks at the access to health services as resulting from the interaction between five corresponding dimensions identified on the supply-side (healthcare resources, service providers) and on the demand-side (healthcare users, service seeking and obtaining).

**Figure 15.** A definition of access to health care.



Source: Levesque et al., 2013.

**Figure 16.** A conceptual framework on access to health care.

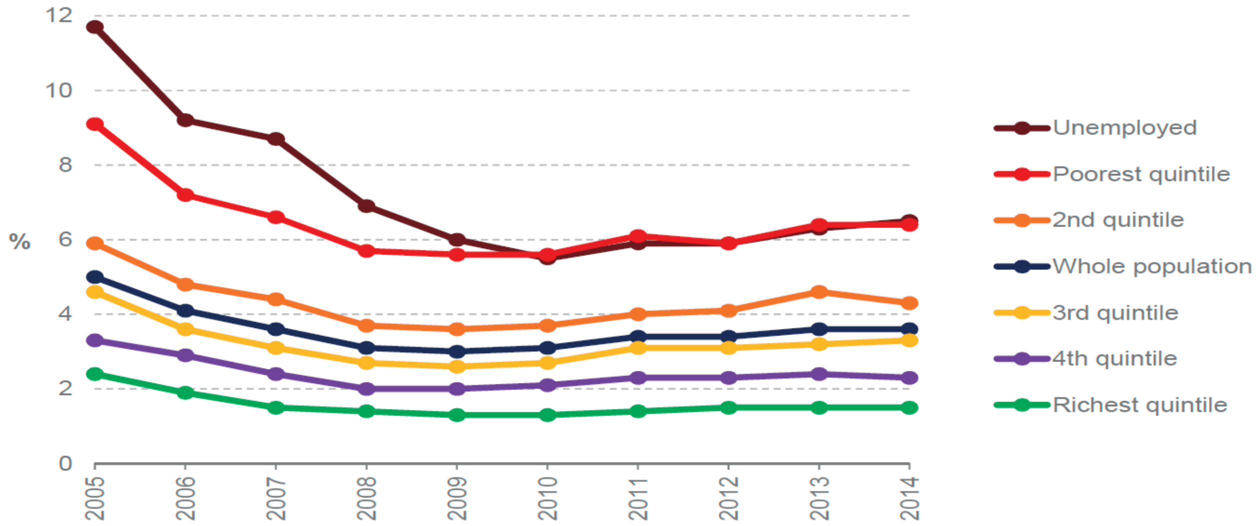


Source: Levesque et al., 2013.

***Campaign on Access to Healthcare in Europe***

*Across the EU28, unmet need due to cost, distance or waiting time had fallen substantially before the crisis began, but has risen steadily since 2009. In 2014, unmet need for these three reasons was back at the level it had been in 2007 (Fig. 17).*

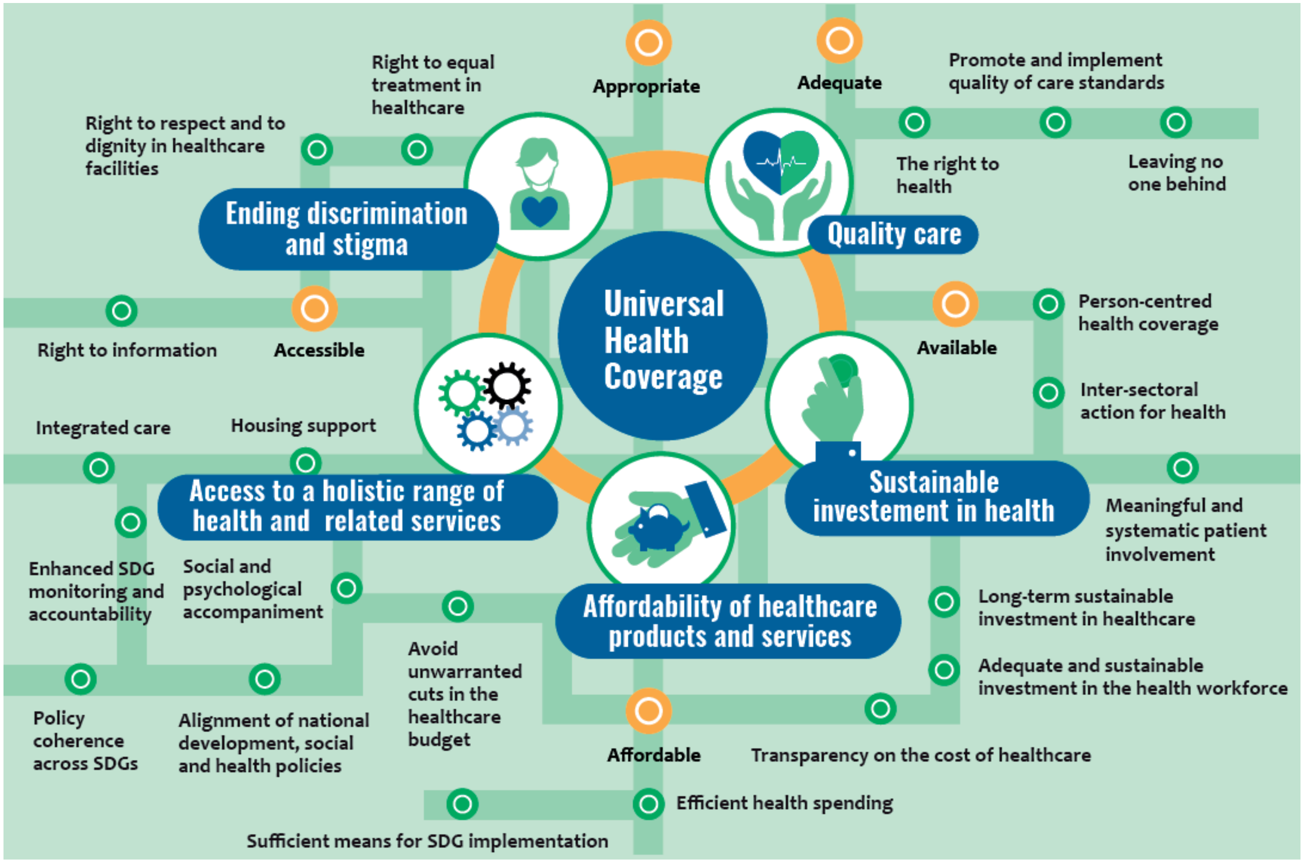
**Figure 17.** Unmet need for health care due to cost, distance or waiting time, 2005 – 2014, EU28.



Source: Thomson et al., 2016.

*From January 2017, The European Patients Forum (EPF) carries a flagship campaign on Access to Healthcare. "The EPF Access campaign will contribute to make universal access a reality for EU patients by 2030, through defining and promoting concrete actions, in concert with the health community, to which decision makers need to commit, to ensure we achieve the Health SDGs by 2030." (Fig. 18).*

**Figure 18.** Campaign on Access to Healthcare: „Universal Health Coverage For All".



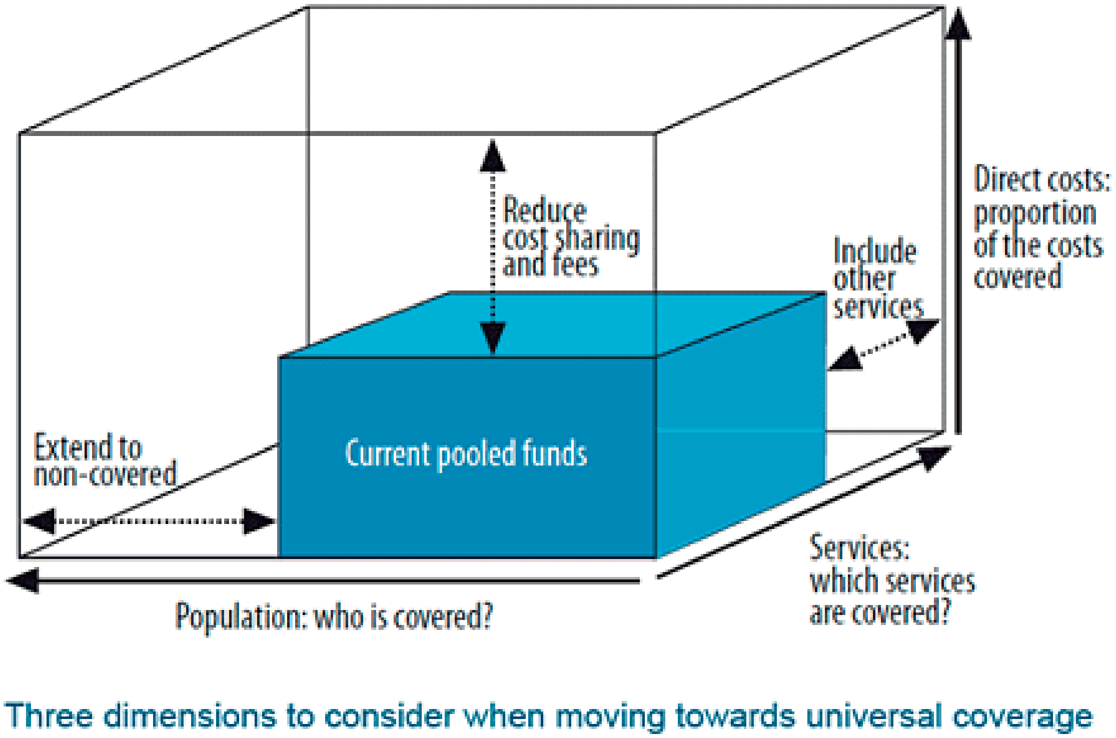
Source: http://www.eu-patient.eu/globalassets/campaign-on-access/access_to_healthcare_ii.pdf

### Universal health coverage

Universal health coverge (UHC) means **everyone can use effective health services when they need them without experiencing financial hardship**. Moving towards UHC involves meeting three distinct health system goals: access to needed health services; the provision of services of sufficient quality to be effective; and financial protection, with equity being central to each goal (Thomson et al., 2016).

**The path to universal coverage** involves important policy choices and inevitable trade-offs. The way that pooled funds – which can come from a variety of sources, such as general government budgets, compulsory insurance contributions (payroll taxes), and household and/or employer prepayments for voluntary health insurance - are organized, used and allocated, influences greatly the direction and progress of reforms towards universal coverage. Pooled funds can be used to extend coverage to those individuals who previously were not covered, to services that previously were not covered or to reduce the direct payments needed for each service (Fig. 19). These dimensions of coverage reflect a set of policy choices about benefits and their rationing that are among the critical decisions facing countries in their reform of health financing systems towards universal coverage. Choices need to be made about proceeding along each of the three dimensions, in many combinations, in a way that best fits their objectives as well as the financial, organizational and political contexts. Extending the coverage from pooled funds along the three dimensions calls for health financing reforms and actions leading to an increase of available funds for health, and to upholding and increasing the quality of health services.

**Figure 19.** Three dimensions to consider when moving towards universal health coverage.



Source: WHO. https://www.who.int/health_financing/strategy/dimensions/en/.

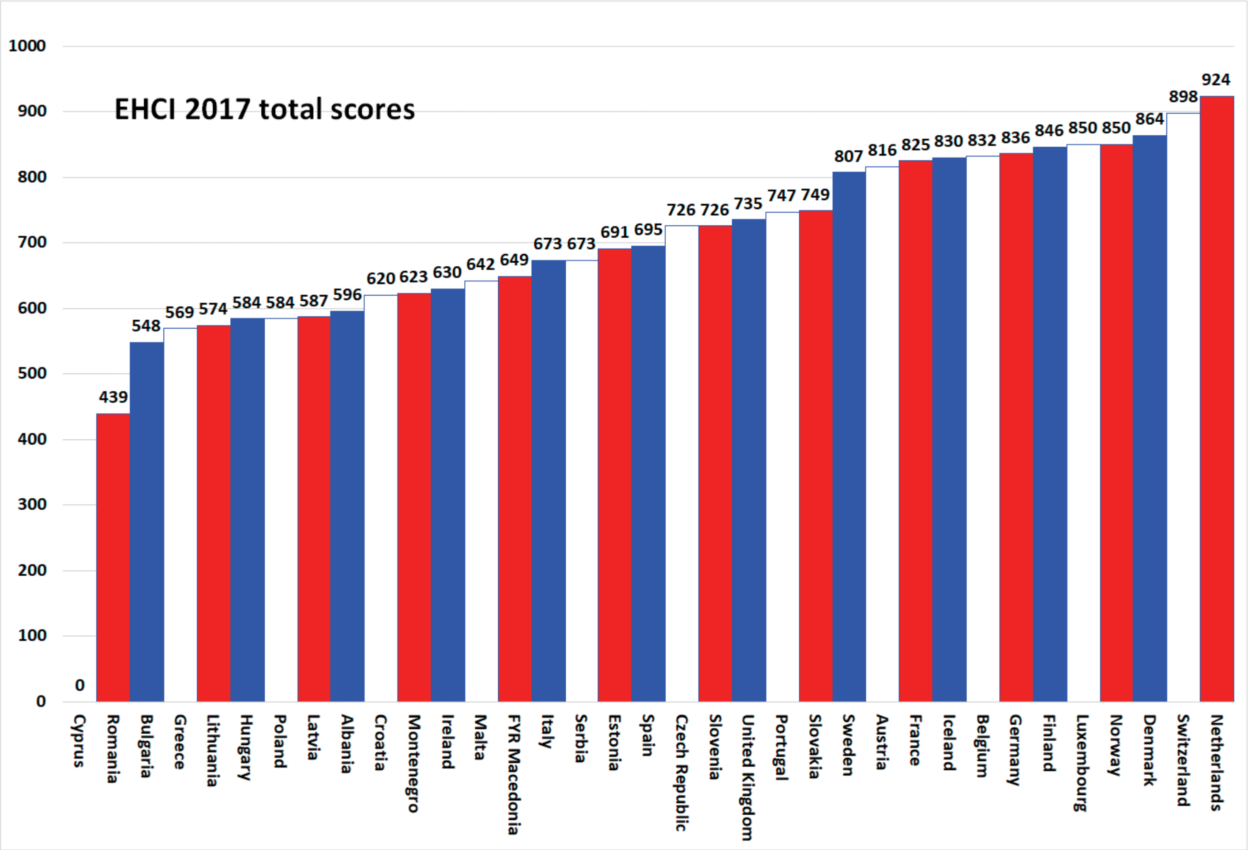
### Quality and performance assessment of health systems

Quality dimensions of health care and publich health services such us those described above provide the basis for the development of indicators to measurig and comparing quality and overall performance across providers, sectors and systems.

### European Health Consumer Index (EHCI)

The EHCI is the leading comparison for assessing the performance of national healthcare systems in 35 countries. Since 2005, the EHCI analyses national healthcare on 46 indicators, looking into areas such as Patient Rights and Information, Access to Care, Treatment Outcomes, Range and Reach of Services, Prevention and use of Pharmaceuticals (EHCI, 2017; Fig. 20).

**Figure 20.** European Health Consumers Index, 2017.



| Sub-discipline | Top country/countries | Score | Maximum score |
|---|---|---|---|
| 1. Patient rights and information | Netherlands, Norway | 125! | 125 |
| 2. Accessibility | Switzerland, Slovakia | 225! | 225 |
| 3. Outcomes | Finland, Norway | 289 | 300 |
| 4. Range and reach of services | Netherlands, Sweden | 125! | 125 |
| 5. Prevention | Norway | 119 | 125 |
| 6. Pharmaceuticals | Germany, Netherlands | 89 | 100 |

Source: EHCI, 2017. https://healthpowerhouse.com/media/EHCI-2017/EHCI-2017-report.pdf

### Value based health care

Health systems that suffer from disagreement over reimbursement models may become a global issue sooner than expected. Since cost pressure requires a shift to new incentive models, value-based metrics might be a key concept to achieve lasting change.

**Value-based healthcare (VBHC) is a healthcare management strategy focusing on costs, quality, and, most importantly, outcomes**. Its goal is to create a culture of health within an organization by removing barriers and encouraging participants to pursue healthy lifestyles that ultimately lead to a healthy workforce. VBHC involves collaboration among plan sponsors, participants, and providers to pursue high-quality and high-value care while reducing the need for high-cost medical services.

### Key messages

- No health system is completely alike, and none is completely free of problems; a method that works for one country is not likely to be completely transferrable to another due to different health concerns, priorities, and mindsets.
- The 2030 Agenda and Health 2020 aim to improve health and well-being for all at all ages through whole-of-government, whole-of-society and health-in-all-policies approaches. Both tackle the social, economic, cultural and environmental determinants of health.

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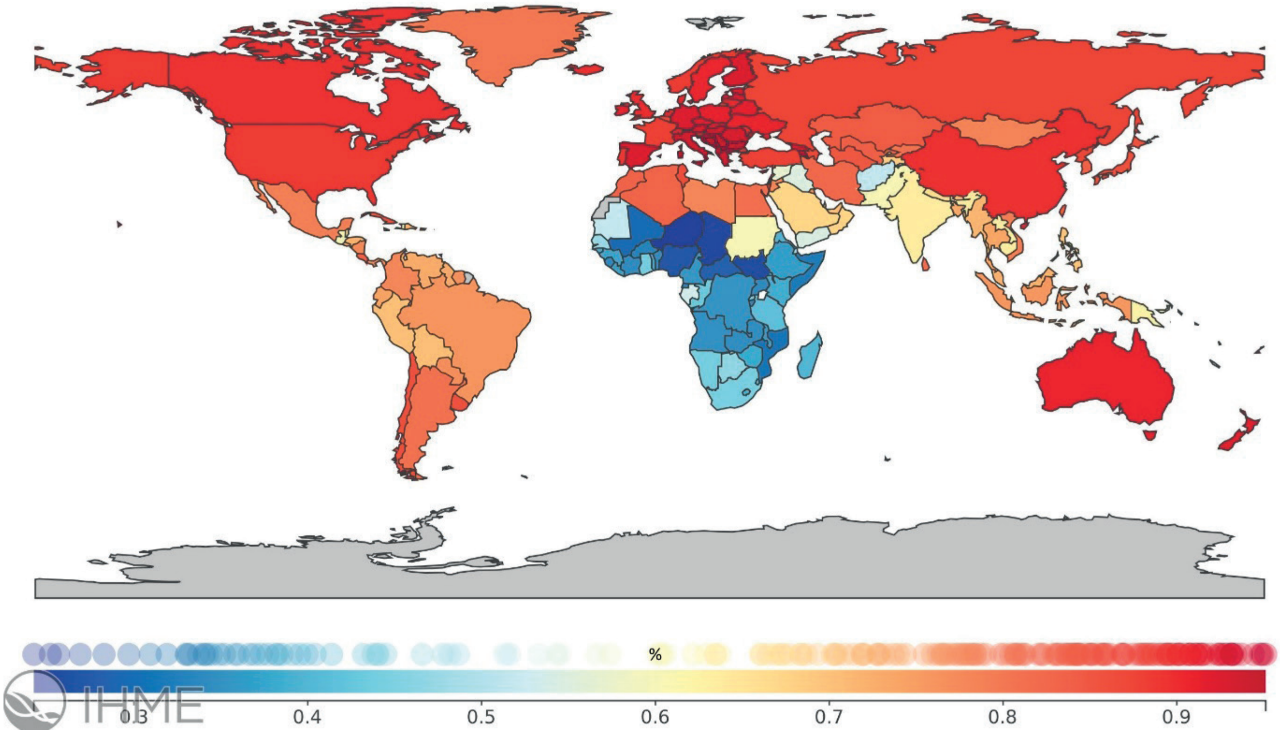
## 5.2 RETHINKING HEALTH SYSTEMS: INTEGRATED AND PATIENT-CENTRED CARE

*Iveta Nagyova*

### The burden of chronic disease

In past decades, the combination of population growth, largely decreasing death rates and an increased average age globally has led to a broad shift from communicable to non-communicable diseases. Premature death from chronic diseases continues to be one of the major development challenges in the 21st century. According to the most recent Global Burden Disease study (GBD study Lancet 2018a), non-communicable chronic diseases (NCDs) contributed to 73·4% of total deaths in 2017, while communicable, maternal, neonatal, and nutritional causes accounted for 18·6%, and injuries 8·0% (Figure 1). **Non-communicable chronic diseases**, such as cardiovascular diseases, cancer, diabetes, and chronic respiratory diseases are long-term conditions brought on by our living environments and the behavioural choices we make. The chronic disease epidemic is driven by poverty, globalization of marketing and trade of health-harming products, rapid urbanization, and population growth (WHO 2017).

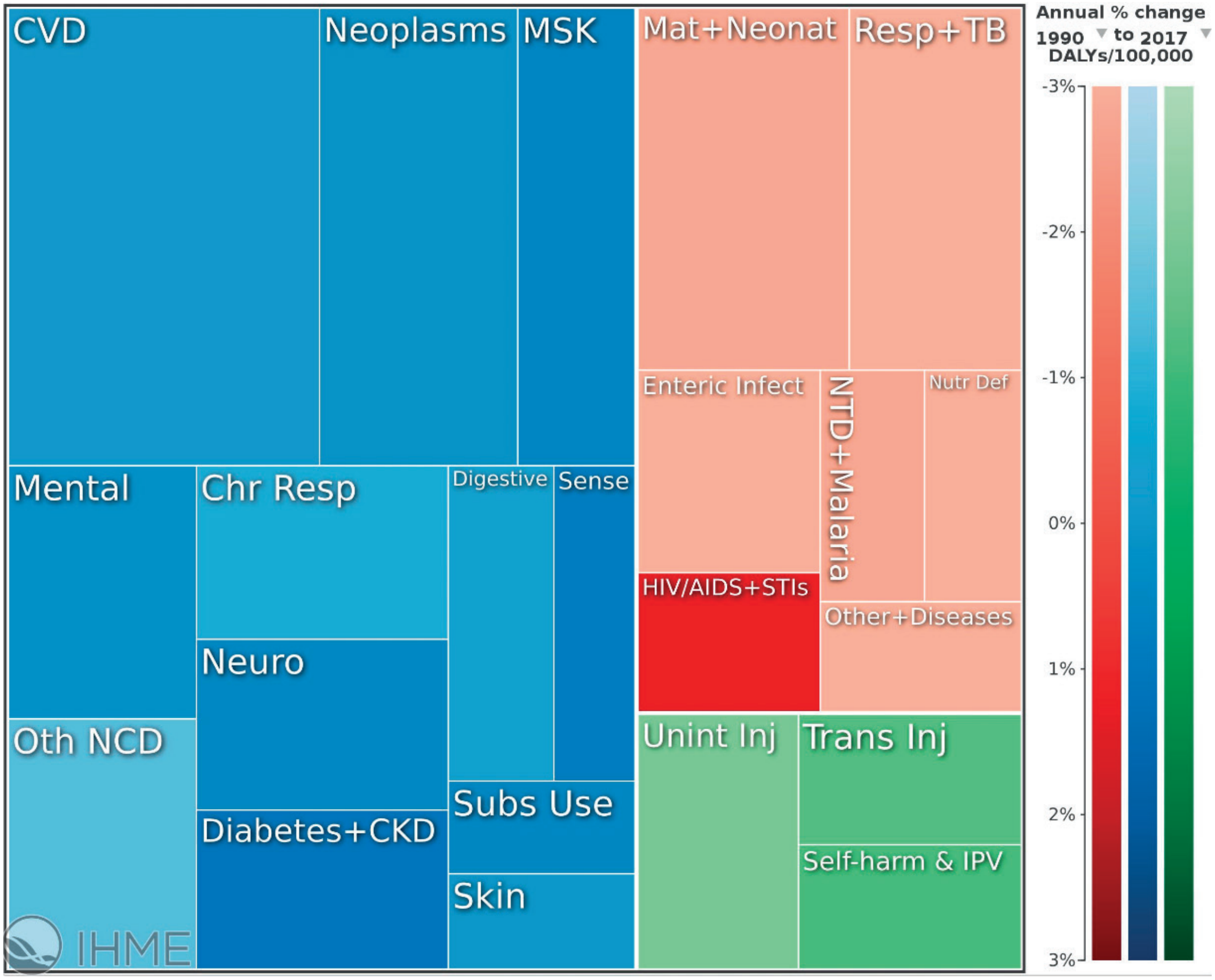
**Figure 1.** Non-communicable chronic diseases. Percent of total deaths. Both sexes, all ages, 2017



Source: Global Burden of Disease Study (Lancet 2018) and www.healthdata.org

As chronic diseases are long-term conditions, which tend to worsen over time, they are a major contributor also to morbidity, or more specifically, to disability-adjusted life years (DALYs). According to the GBD study, chronic conditions are accounting for over 60% of all causes of DALYs globally (Figure 2) (GBD study Lancet 2018b). This has led to a continued shift away from premature death to years lived with disability and means that more people are living for longer in a worse state of health.

**Figure 2.** Leading causes of disability-adjusted life years (DALYs) in 2017, Both sexes, all ages.

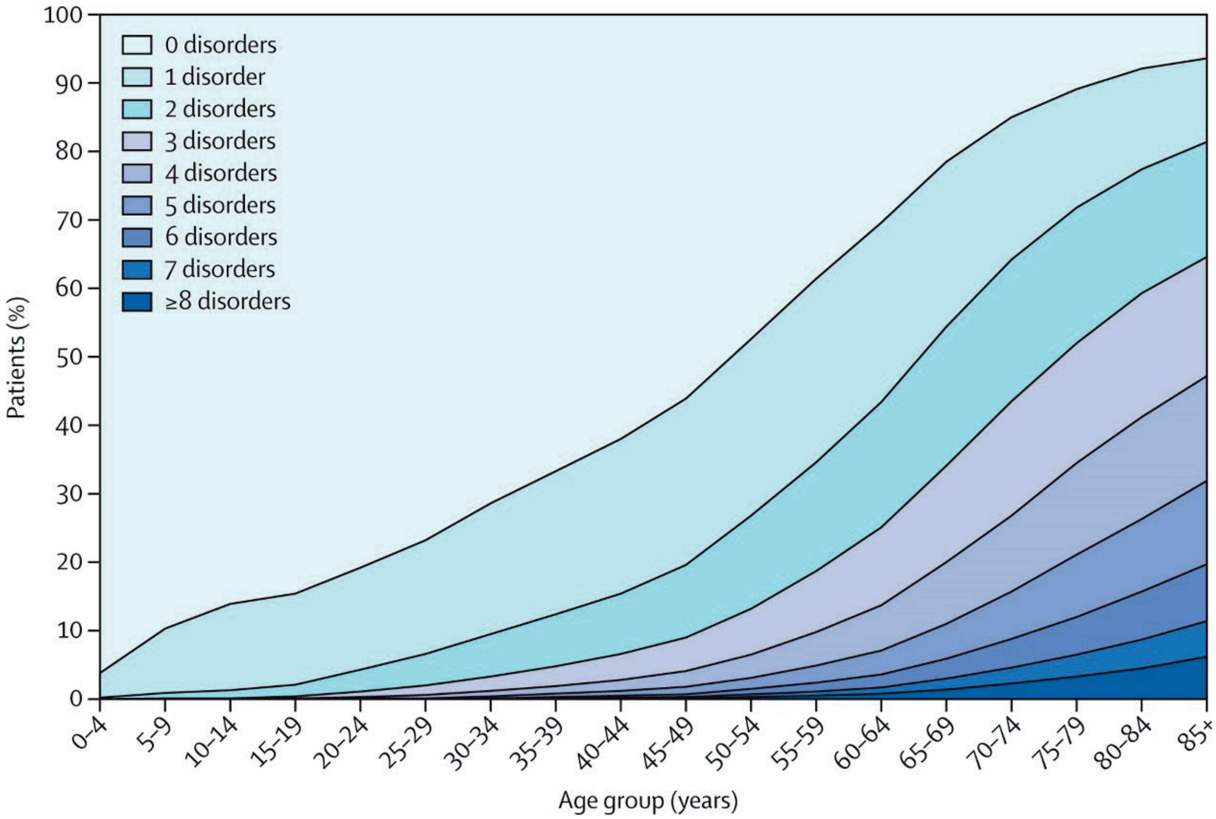


*Source: Global Burden of Disease Study (Lancet 2018) and www.healthdata.org*

However, increasingly people are not only suffering from one chronic condition, but from multiple conditions. By contrast with the assumptions implicit in healthcare organisation, the analysis of a large, nationally representative primary care dataset shows that multimorbidity is common, and that most of those with a long-term disorder are multimorbid (Barnett et al. 2012, Figure 3).

**Multimorbidity** is defined as the co-existence of two or more chronic conditions, where one is not necessarily more central than the others (Boyd et al. 2010).

**Figure 3.** Leading causes of disability-adjusted life years (DALYs) in 2017, Both sexes, all ages.



*Source: Barnett et al. 2012*

Although the strong association of multimorbidity with age is already well recognised (up to two thirds of those at pensionable age suffer from multimorbidity) other aspects are less well described. In particular:

» More than half of people with multimorbidity and nearly two-thirds with physical–mental health comorbidity are younger than 65 years.

» A substantial excess of multimorbidity has been found in young and middle aged adults living in the most deprived areas. These young and middle aged adults having the same prevalence of multimorbidity as people aged about 10–15 years older living in the most affluent areas.

» Mental health disorders, particularly depression, are more prevalent in people with increasing numbers of physical disorders, and this association also has a consistent social gradient.

» Women have higher rates of multimorbidity than men, and consistently higher rates of mental health disorders.

This data strongly suggests that clinicians working in highly deprived areas treating patients with common physical disorders have a greater number of both physical and mental health disorders to manage simultaneously than do their colleagues working in the most affluent areas (Barnett et al. 2012).

### Social and economic consequences of chronic diseases

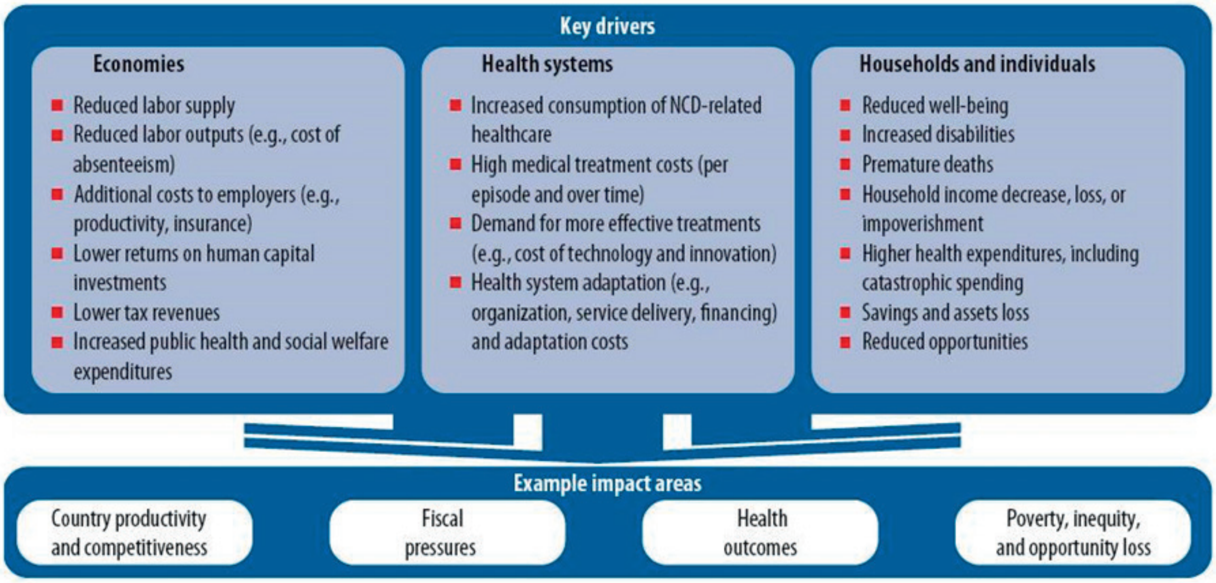
Health is about more than just physiology; people want to lead fulfilled, meaningful lives. In view of this broader importance of health, considerable effort has gone into understanding not just the health consequences of chronic diseases, but also the social effects of these diseases on individuals, families, and societies.

*What are the costs of chronic disease?*

One common approach is to divide costs into 3 categories:

1. healthcare costs; involving treatment, medical procedures, doctor visits, and hospitalisations;
2. labour-market (work-related) costs; involving loses of earnings, early retirement, and missed work days;
3. ‘direct’, ‘indirect’, and ‘intangible’ costs; such reduced well-being, reduced quality of life, savings and assess loss (Stuckler & Siegel 2011).

**Figure 4.** The socioeconomic impact of chronic diseases



Source: World Bank analysis Nikolic et al. 2011

Rising costs of chronic diseases threaten to overwhelm resource-poor health systems. Left unchecked, rising chronic diseases are likely to slow economic growth. Traditionally, economists have treated health like any other consumer good and assumed that the direction of causality was from income to health. Currently we have good reasons, and strong evidence, for believing that health improvements also stimulate economic development. This is known as ‘phenomenon of mutual reinforcement’, acknowledging the bi-directional relationship between health and wealth - *people are healthy, because they are rich; people are rich, because they are healthy* (Bloom & Canning 2000). Evidence about the social consequences of disease enables policy makers to envision a richer and happier society. The ‘virtuous spiral’ can transform an impoverished; disease-prone country into one that offers its people a much higher quality of life. Persuasive examples of such a transformation can be found in the economic history of Ireland or East Asia.

Regrettably, the mutual reinforcement between health and income can also operate in reverse. Declines in health status in some counties are having staggering impacts on economic well-being. In Russia, for example, the economic transition to a market economy, which began in the early 1990s, coincides closely with a precipitous fall in life expectancy, including disproportionately large numbers of working-age men. There are many reasons to believe that Russia’s economic and political instability and reducing incomes are to blame for this health crisis, which left the life expectancy of Russian males in the mid-1990s below the average for developing countries. Among the factors that link falling incomes to the worsening of Russians’ health are deterioration of the diet, increased alcohol consumption, mental stress, and the related surge in accidents and injuries. Negative income growth took a major toll on public spending on health care, and many parts of the Russian medical system have descended into chaos as a result (Stuckler & Siegel 2011, Bloom & Canning 2000).

## New challenges for health systems

Management of the increasing prevalence of long-term chronic conditions is the main challenge facing governments and health-care systems worldwide. With the rising prevalence of chronic disease and multimorbidity, this worse state of health has led to a marked increase in need for and utilisation of health care around the world. In the UK, Wilson et al. (2005) found that chronic disease patients account for 80% of general practitioner (GP) consultations and that just 15% of patients with at least 3 conditions account for as many as 30% of inpatient days. It is estimated that this high utilisation of health care now accounts for 70-80% of European health care costs (€700 billion) (WHO 2017).

Traditionally health care is designed to react to specific acute conditions and this is not conducive to caring for those with long-term conditions. The needs of those with long-term conditions differ vastly from those with more acute conditions, and this is magnified by the increasing prevalence of multimorbidity. We think of a health problem as being "acute" or "chronic". Between acute and chronic conditions are however distinct differences in several aspects, such as: cause of diseases, duration, certainty of a diagnosis or roles of patients and physicians (Figure 5).

**Table 1.** Differences between acute and chronic diseases

| | ACUTE | CHRONIC |
|---|---|---|
| **Beginning** | Rapid | Gradual |
| **Cause** | Usually one | Many |
| **Duration** | Short | Indefinite |
| **Diagnosis** | Commonly accurate | Often uncertain |
| **Diagnostic tests** | Often decisive | Often limited value |
| **Treatment** | Cure common | Cure rare |
| **Role of professional** | Select and conduct therapy | Teacher/ coach and partner |
| **Role of patient** | Follow orders | Partner/ Daily manager |

Source: Lorig at al. 2006

The traditional reactive systems are acute-focused and fragmented. Use of many services to manage individual diseases can become duplicative and inefficient, and is burdensome and unsafe for patients because of poor coordination and integration (Barnett et al. 2012). The result is long, complex care pathways which are often not well co-ordinated (Shoen et al. 2011); patients normally see a different clinician for each individual aspect of their condition(s), which reduces the quality of care that they receive and takes up a lot of time and resources for both the patient and the health system. What is required for people with long-term conditions is not a reactive system that treats their acute exacerbations individually, but an integrated system that delivers *disease management*.

**Disease management** is generally considered a programmatic approach to care provided by multidisciplinary teams of care providers, supporting patients' self-management, and collecting data on patient outcomes to monitor individual progress, and program results (Nolte et al. 2014).

Disease management takes a very different approach to health care in that it aims to prevent acute episodes from occurring in the first place and to ultimately control long-term conditions. Control is an extremely important part of caring for long-term conditions and this is recognised by the World Health Organisation (WHO 2005), along with a wealth of research. The challenge that this presents to current health systems is that this cannot be delivered by health systems that are structured in the traditional way. They must be reconfigured to integrate care and so improve the patient pathway. In addition, a change in the well-established culture is required.

People with multimorbidity need an even broader approach. Hansen and colleagues (2015) found better (self-rated) health outcomes in people with multimorbidity living in countries with a strong primary care structure, high continuity of care and a comprehensive primary care system. Nevertheless, many people with multimorbidity also need specialized care, and inter-sectoral coordination as well as collaboration between primary care and specialized care. In addition, specialist and hospital care in European countries are almost entirely organized around medical specialties focusing on specific organ systems. The so-called vertical silos are an important reason why care for people with multimorbidity is suboptimal in many countries (Rijken et al. 2018). There is need to reorient healthcare delivery from acute, episodic care to long-term, pacient-centered management.

## 5.2.1 Integrated care

**A new model of care**

The common theme in chronic condition is that they confronts patients with a spectrum of needs that requires them to alter their behaviour and engage in activities that promote physical and psychological well-being, to interact with healthcare providers and adhere to treatment regimens, to monitor their health status and make associated care decisions, and to manage the impact of the illness on physical, psychological and social functioning (Nolte et al. 2014). It is clear that these goals are unlikely to be accomplished by means of the traditional approach to healthcare that is largely built around an acute, episodic model of care and is ill-equipped to meet the requirements of those with chronic health problems.

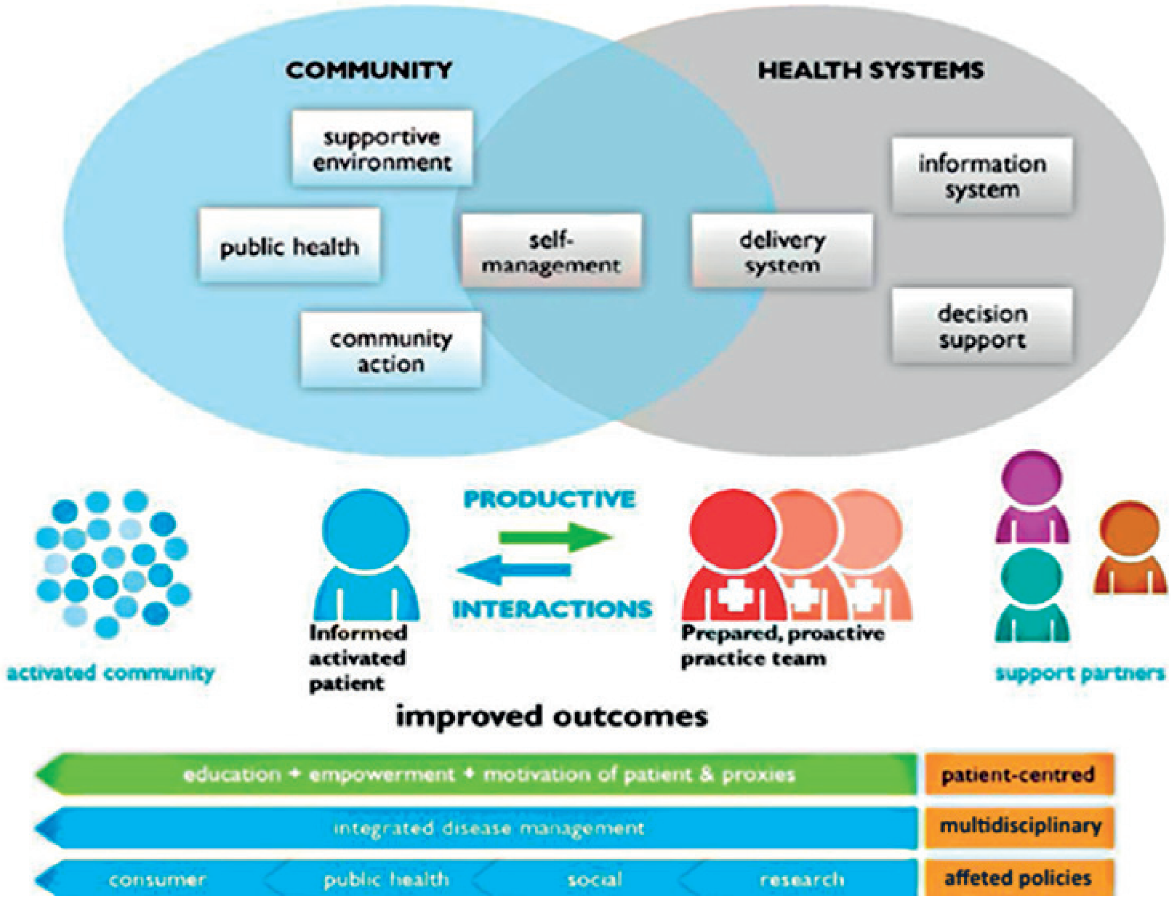
What is needed is a complex response over an extended time period that involves coordinated inputs from a wide range of health professionals and access to essential medicines and monitoring systems, all of which need to be optimally embedded within a system that promotes patient empowerment. A model of care that takes a patient-centred approach by working in partnership with the patient and other healthcare personnel to optimize health outcomes (Nolte and McKee 2008).

In the early 1990s a review of chronic care interventions was undertaken by The MacColl Institute for Healthcare Innovation in the United States. The conclusion of this review was that there were specific elements of practice that could be changed to maximise improvements in health outcomes for those with chronic conditions. This led to the development of the Chronic Care Model which was published in its current form in 1998 and has been widely accepted in the research and health care communities and become perhaps the most influential framework for chronic disease care (Wagner 1998). The model is based on the interactions between an informed, activated patient and a prepared, proactive practice team, drawing on resources from both the health system and the community. This model comprises four interacting system components considered key to providing good care for chronic illness:

- » Decision Support,
- » Delivery System Design,
- » Clinical Information Systems,
- » Self-Management Support

These are set in a health system context that links an appropriately organized delivery system with complementary community resources and policies (Wagner et al. 2005). The main system elements are discussed below.

**Figure 5.** The Chronic Care Model



Source: Epposi White Paper 2012, Wagner 1998

### *Informed, activated patient*

Although the Chronic Care Model assumes that the ultimate responsibility of chronic care planning remains with the lead clinician, it also recognises that patients must take an active role in their care in order for it to be effective. This is due to the fact that clinicians only see their patients for a very small proportion of their lifetime while patients live with their condition every day. In fact, this can make motivated patients experts in their own condition. Patient empowerment is therefore extremely important in chronic care but patients need to be supported to gain knowledge and confidence.

### *Decision support*

There are two effective ways to directly improve quality of care for any patient. The first is to embed evidence-based guidelines into daily clinical practice; these are required for optimal patient safety and it is important that clinicians undertake ongoing training to stay up-to-date with these. The second is to include patients in any decision-making processes regarding their care. This will create a more engaged and motivated patient who is directly contributing to their own health and health care.

In relation to patient involvement this is very timely as, with increasingly wider use of the internet, health information is more readily available now than ever before. Already this is creating a change in the patient-provider relationship as this allows patients to be more informed and proactive in their care. However, this can be a bit of sea change for some clinicians as the previous imbalance in knowledge is going some way to being redressed.

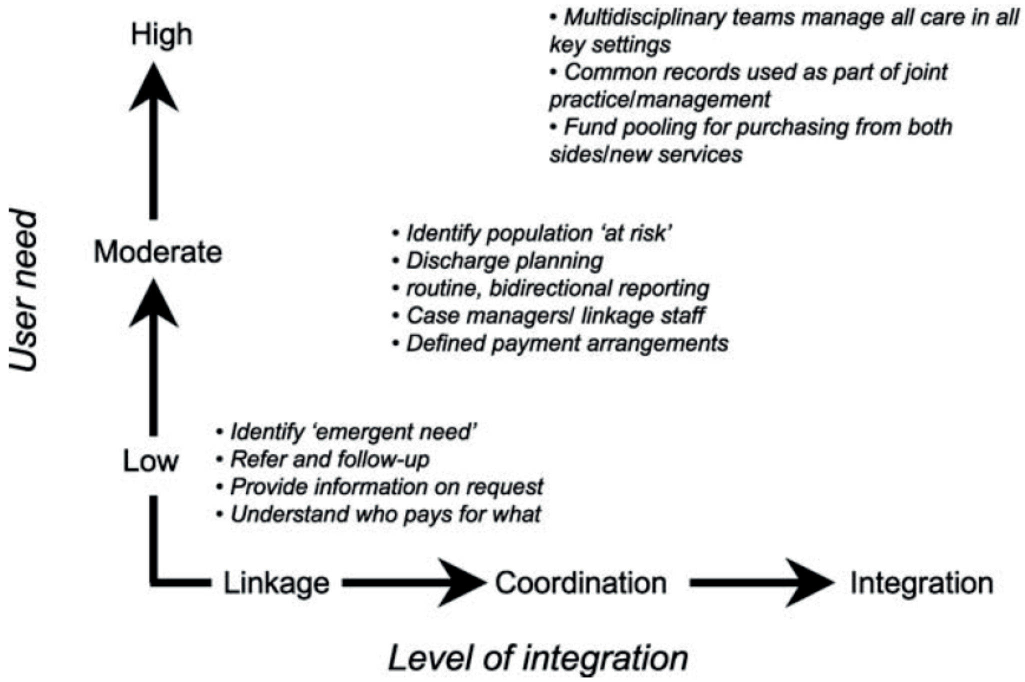
### *Delivery system design*

As mentioned previously, the reconfiguration of a health system is one of the biggest challenges in chronic care. The first step in this is to determine what care is needed; this personalisation will already increase quality of care for a patient. The next step is to define roles and distribute tasks around the prepared, proactive practice team according to this care plan. This is where integrated services come in as the practice team could be made up of several different disciplines.

Within the context of the Chronic Care Model, integration aims to link the "cure" and "care" sectors by bringing together primary and secondary care. This is important in the decision-making process and is included in the concept of shared decision-making. In terms of organisation, the best examples of integrated care tend to come from insurance-based health systems. One example is the Netherlands where contracting allows the purchase of bundles, or care packages which are negotiated between the health care provider and the insurance fund. This is based on the personalised care plan that is drawn up between the patient and the health care team. Another example is Germany which brings together primary and secondary care through a well-established system of group practice, or polyclinics.

As we know from the Kaiser triangle, there are three levels of need but according to *Nolte & McKee (2008)*, there are also three levels of integration that increase with need. These are illustrated in Figure 6. At the linkage level, where self-management is most prevalent, primary care will be key. At the coordination level, there will be a mix between primary and secondary care and this is when polyclinics should work well. At the highest level of integration, multidisciplinary teams will be needed at all times and so data sharing would be essential here. It is at this point of integration that the Netherlands model of bundles should function best.

**Figure 6.** The Integrated Care Matrix



*Source: Nolte & McKee 2008*

*Clinical information systems*

Clinical information systems are the crux of effective chronic care. This element of the Chronic Care Model incorporates electronic patient records and the sharing of data and is vital for integration. The advantage of these systems is the immediate availability of key information for any provider, including a single care plan that can be seen by all, regardless of whether the patient requires planned or unplanned care. In addition these systems can be built to include follow-up reminders for both providers and patients which, yet again, improves care coordination. Finally at the population-level, this information would be invaluable in monitoring performance and assessing whether specific groups are in need of additional care.

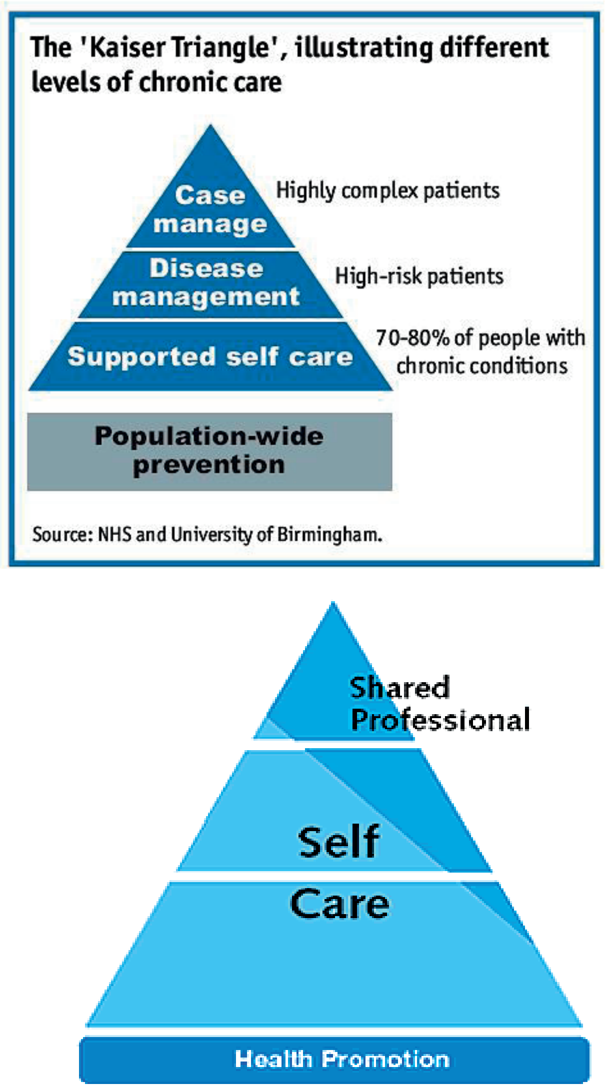
*Self-management support*

Further to the Chronic Care Model, an insurance group in the US, *Kaiser Permanente*, created a triangle that stratified the chronic disease population according to clinical need; this has been widely adapted by various health organisations around the world (see Figure 7). *Kaiser Permanente* estimated that the vast majority of chronic disease patients hardly require any professional care; these low-risk patients have their chronic condition well controlled and should be able to manage it themselves.

Higher-risk patients may have unstable conditions that could decline without structured support through specialist disease management. However, these patients can still largely care for themselves. Finally, highly complex patients are likely to have several multi-morbidities or they may have reached the end-stage of their conditions. This group are more likely to need emergency or unplanned care and will require case management and regular contact with specialists.

In addition, over time many adaptations of the Kaiser triangle, as it has become known, have included the general population at the bottom of the triangle. This is to emphasise the need for general health promotion and primary disease prevention.

**Figure 7.** The 'Kaiser Triangle', illustrating different levels of chronic care



*Sources: Economist Intelligence Unit, 2012*

With self-management being such a well-recognised part of chronic disease care, it is important to encourage and support patients to do this. If patients are supported with educational resources, skills training and psychosocial support, they can increase their knowledge and understanding of their condition and become empowered to manage their own health and health care.

In the Chronic Care Model, this element spans *Organisation of Health Care* and *Community*, emphasising the need for regular support and enablement. This reflects the three tiers of the Kaiser triangle with highly complex patients requiring more specialist support from secondary and tertiary care, and low-risk patients needing not much more than low-level primary care support.

To provide this support to patients, self-management programmes have been developed and one such programme is the Chronic Disease Self-Management Program (CDSMP) developed by a group of researchers at the Stanford School of Medicine (WHO 2005). This is a community-based workshop that brings together patients suffering from a range of chronic diseases and has been shown to be quite effective. The CDSMP is built on the basis that chronic disease patients suffer from similar consequences of disease, related both directly and indirectly to quality of life. This assumption was put to the test in Slovakia (see Box 1).

*Box 1 Comparing quality of life across five chronic diseases in Slovakia*

Context: Chronic disease puts a huge burden on both the individual and society through increased health care utilisation and loss of productivity. It is well-known that chronic disease negatively impacts quality of life (QoL) but the comparative impact across diseases is under-studied. This has implications for chronic disease care. The objective of this study, therefore, was to compare QoL to identify similarities among five chronic diseases in Slovakia.

Methods: Data were collated from five datasets within the LORIDIS project: rheumatoid arthritis (n=296), end-stage renal disease (n=220), Parkinson's disease (n=175), multiple sclerosis (n=165), and coronary heart disease (n=710). QoL was measured using the SF-36 which has proven to be a valid and reliable tool across diseases. QoL profiles were developed to visualise similarities across diseases while Kruskal-Wallis tests and General Linear Modelling (GLM) were used to statistically compare the diseases and control for socio-demographic factors and co-morbidity.

Results: Mental quality of life (MCS) was more found to be similar across the five diseases than physical quality of life (PCS). After controlled GLM analyses MCS (F=1.175, p=0.320), role-emotional (F=0.607, p=0.658) and role-physical (F=1.271, p=0.279) were found to be similar across all five diseases. In addition pairwise comparisons showed that similarities occurred in every SF-36 score: eight of the ten pairs of diseases had similar social functioning, five pairs had similar mental health, vitality and bodily pain, and four pairs had similar PCS, general health and physical functioning.

Conclusions: The results of this study show that QoL, particularly mental QoL, is similar across chronic diseases. This supports the idea that patients with different chronic conditions may benefit from similar care. It is therefore hoped that this study might begin the discussion of introducing mixed self-management programmes to chronic disease care in Slovakia.

*Source: Baird & Nagyova 2013*

*Community*

When it comes to health care, gaps in needed services are often provided through community-based programmes. For chronic care, the community is integral in that it provides a supportive environment for people to self-manage; it is in this environment that people feel most comfortable. Patient education is often delivered in the community, as is peer support. In addition, being outside of a clinical environment also allows local health workers and possibly even non-medical staff to assist in chronic care.

Because of the nature of this aspect of care, this is often the least expensive way of providing care to chronic disease patients, especially with programmes that "train the trainer". In fact, health care providers sometimes develop partnerships with community organisations and it would be great if these could be used to identify effective programmes and encourage chronic disease patients to attend where appropriate; increasingly social prescribing allows clinicians to refer patients to community programmes.

### Scaling integrated care in context

The evidence suggests that developing more integrated person-centred care, has the potential to generate significant improvements in the health and care of all citizens, including better access to care, health and clinical outcomes, health literacy and self-care, increased satisfaction with care, and improved job satisfaction for health and care professionals, efficiency of services, and reduced overall costs (Goodwin et al. 2014). Countries in Europe and elsewhere are attempting to drive transformation of their health and social care systems, with many implementing some form of integrated care even though the nature and scope of the related approaches differ. However, the transition to integrated care is a highly complex process and the challenge still remains about how best to design, implement and evaluate integrated care in Europe (EC 2017).

Designing integrated care requires operating simultaneously at three levels:

» *system level*: strategy, governance and allocation of resources

» *service level*: commissioning, operations and service re-design;

» *interface between service users, carers and their care providers*: delivery of care in new and better ways.

Scaling-up good practices or innovations requires changes in existing systems that are not easy to achieve. Nevertheless, there are cases where the implementation of integrated care has been successful. One key lesson learned from the successful cases of implementation and scaling-up of integrated care is that it matters a lot how integrated care is designed and implemented to fit the local context and needs. Other lessons that can be drawn from successful integrated care implementations concern the defining elements that have been deemed to make them work well – i.e. the "system levers" and elements that can be considered as "transferable" (EC 2017).

A collaboration of over 30 European regions has resulted in the development of a self-assessment tool enabled by the EU-funded project - SCIROCCO. The SCIROCCO tool, the so-called Maturity Model (MM), is derived from an observational study, based on interviews with stakeholders in these regions. The tool is designed to assess the progress and maturity in provision of integrated care and encourage knowledge transfer and scaling-up of good practices. The model consists of 12 dimensions for integrated care, each of which addresses a part of the overall transformation process. An organisation can consider each dimension by allocating a measure of maturity within that domain. As a result, a radar diagram is developed which reveals strengths and gaps in the provision of integrated care. The tool enables regions to:

a) assess maturity requirements of good practices;

b) assess readiness of healthcare systems for integrated care;

c) facilitate the twining and coaching in integrated care.

The tool also stimulates multi-stakeholder discussions, encourages regions to share their experience and reach out to regions who are interested to learn what work when implementing integrated care.

**Figure 8:** SCIROCCO Self-assessment tool for integrated care

Source: SCIROCCO 2016

## 5.2.2 Patient-Centred Care

Patient-centered care has emerged as a focal point in discussions surrounding healthcare quality. The phrase is now commonplace in the vocabulary of healthcare institutions, planners, lawmakers, and hospital PR departments. Moreover, insurance reimbursements increasingly hinge on the delivery of patient-centered care. Yet, amidst these discussions, the profound and transformative essence of patient-centeredness often gets overlooked. The pioneers of client-centered and patient-centered healthcare were acutely aware of the ethical implications of their work. Rooted in a profound respect for patients as unique individuals, their approach prioritized caring for patients on their own terms. Consequently, patients are recognized as individuals within the context of their social worlds, where they are listened to, informed, respected, and actively engaged in their care—while their preferences are acknowledged and respected (albeit not blindly obeyed) throughout their healthcare journey. Patient-centered care represents a hallmark of interpersonal, professional, and organizational relationships. Thus, endeavors aimed at fostering patient-centered care should encompass the patient-centeredness of patients (and their families), clinicians, and healthcare systems alike. Empowering patients to take a more active role in consultations signifies a departure from centuries-old physician-dominated dialogues, towards engagements where patients are active participants. Meanwhile, training physicians to cultivate mindfulness, transparency, and empathy signifies a shift in their role—from one characterized by authority to one defined by partnership, solidarity, empathy, and collaboration (Epstein & Street, 2011).

*What is patient-centered care?*

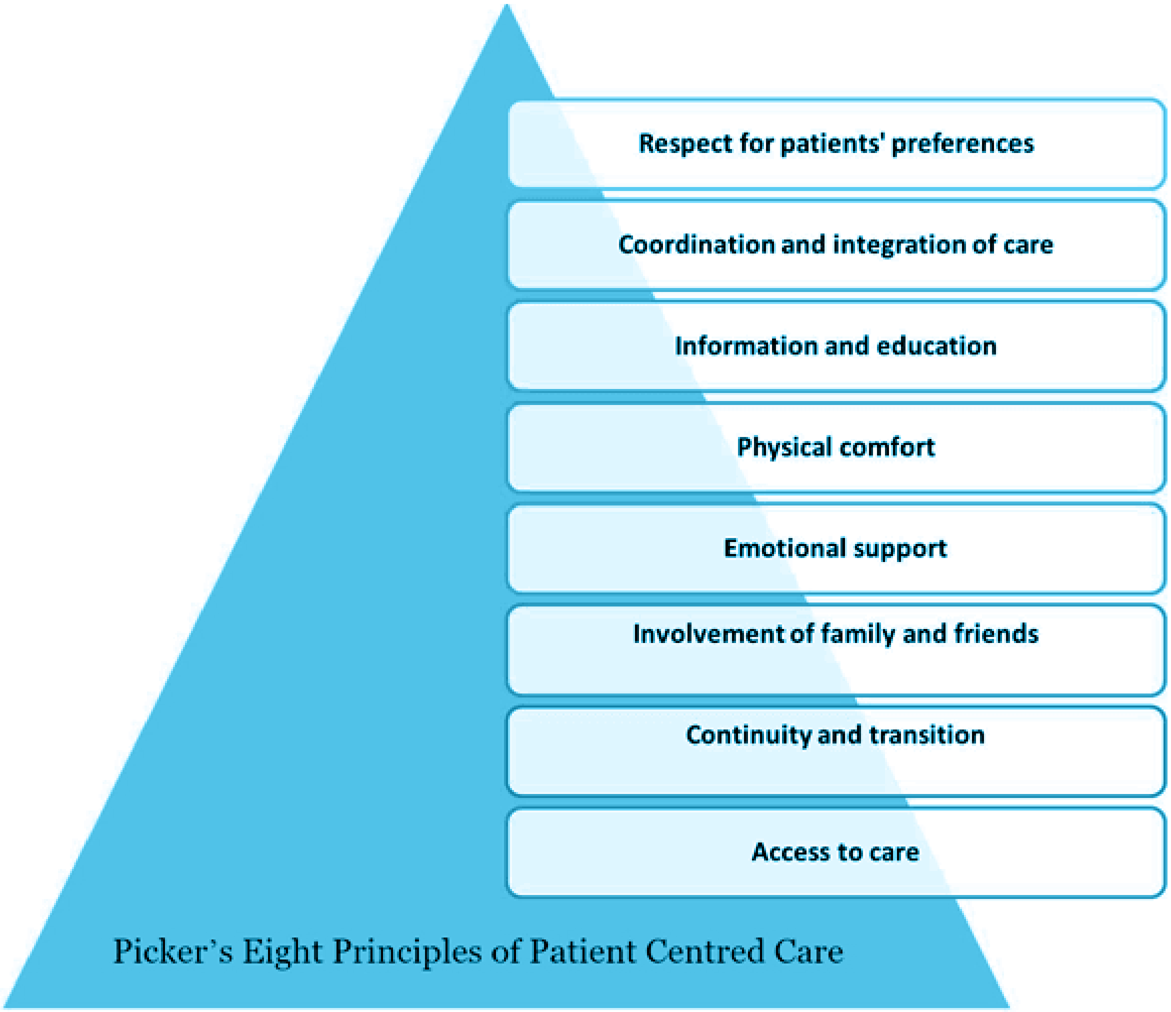
In the past, individuals were expected to conform to the established routines and practices dictated by health and social services. However, to adopt a person-centered approach, services must adapt to become more adaptable in meeting individuals' needs in a manner that suits them best. This entails collaborating with individuals and their families to determine the most effective way to deliver their care. Such collaborative efforts can occur on an individual basis, where individuals participate in decisions regarding their health and care, or on a collective level, involving the public or patient groups in decisions regarding the design and implementation of services. The underlying principle remains consistent: it involves working alongside individuals, rather than imposing actions upon them. Patient-centered care prioritizes the unique health requirements and desired health goals of each individual, guiding all healthcare decisions and quality assessments. Patients are regarded as partners by their healthcare providers, who approach patient care not only from a clinical standpoint but also from emotional, mental, spiritual, social, and financial perspectives.

With social changes in medicine, the operational definition of patient-centered care is changing, and measures should reflect those changes. Early measures of patient involvement in care, for example, asked patients whether they had opportunities to ask questions. A patient who is accustomed to a pas-sive role in care might be satisfied by the physician's rushed, *"Any questions?"* at the end of a visit and ha-bitually answer no; this patient may never have ex-perienced a more active invitation for involvement. A patient-centered approach should do more. The physician should *invite* the patient to participate: *"I want to make sure that I've helped you understand everything you need to understand about your ill-ness. Patients usually have questions because it can be complicated. Could you tell me what you under-stand, and then I can help clarify…?"*

*The eight principles of patient- centered care*

Using a wide range of focus groups — recently discharged patients, family members, physicians and non-physician hospital staff—combined with a review of pertinent literature, researchers from Harvard Medical School, on behalf of Picker Institute and The Commonwealth Fund, defined seven primary dimensions of patient-centered care. These principles were later expanded to include an eighth – access to care. The researchers found that there are certain practices conducive to a positive patient experience and their findings form Picker's Eight Principles of Patient-Centered Care (Figure 9; IOM 2001, OneView healthcare 2015).

**Figure 9.** Picker's Eight Principles of Patient-Centered Care



Source: IOM 2001, Oneview Healthcare 2015

*1. Respect for patients' values, preferences and expressed needs*

Involve patients in decision-making, recognizing they are individuals with their own unique values and preferences. Treat patients with dignity, respect and sensitivity to his/her cultural values and autonomy.

*2. Coordination and integration of care*

During focus groups, patients expressed feeling vulnerable and powerless in the face of illness. Proper coordination of care can alleviate those feelings. Patients identified three areas in which care coordination can reduce feelings of vulnerability:

- Coordination of clinical care
- Coordination of ancillary and support services
- Coordination of front-line patient care

*3. Information and education*

In interviews, patients expressed their worries that they were not being completely informed about their condition or prognosis. To counter this fear, hospitals can focus on three kinds of communication:

- Information on clinical status, progress and prognosis
- Information on processes of care
- Information to facilitate autonomy, self-care and health promotion

*4. Physical comfort*

The level of physical comfort patients report has a significant impact on their experience. Three areas were reported as particularly important to patients:

- Pain management
- Assistance with activities and daily living needs
- Hospital surroundings and environment

*5. Emotional support and alleviation of fear and anxiety*

Fear and anxiety associated with illness can be as debilitating as the physical effects. Caregivers should pay particular attention to:

- Anxiety over physical status, treatment and prognosis
- Anxiety over the impact of the illness on themselves and family
- Anxiety over the financial impact of illness

*6. Involvement of family and friends*

This principle addresses the role of family and friends in the patient experience. Family dimensions of patient-centered care were identified as follows:

- Providing accommodations for family and friends
- Involving family and close friends in decision making
- Supporting family members as caregivers
- Recognizing the needs of family and friends

*7. Continuity and transition*

Patients expressed concern about their ability to care for themselves after discharge. Meeting patient needs in this area requires the following:

- Understandable, detailed information regarding medications, physical limitations, dietary needs, etc.
- Coordinate and plan ongoing treatment and services after discharge
- Provide information regarding access to clinical, social, physical and financial support on a continuing basis.

*8. Access to care*

Patients need to know they can access care when it is needed. Focusing mainly on ambulatory care, the following areas were of importance to the patient:

- Access to the location of hospitals, clinics and physician offices
- Availability of transportation
- Ease of scheduling appointments
- Availability of appointments when needed
- Accessibility to specialists or specialty services when a referral is made
- Clear instructions provided on when and how to get referrals

(IOM 2001, Oneview Healthcare 2015)

*Why is person-centred care important?*

Person-centred care is a high priority. Making sure that people are involved in and central to their care is now recognised as a key component of developing **high quality healthcare**.

There is much work to be done to help health and social services be more person-centred and this has become more of a priority over the past decade. This is because it is hoped that putting people at the centre of their care will:

- improve the quality of the services available
- help people get the care they need when they need it
- help people be more active in looking after themselves
- and reduce some of the pressure on health and social services

(HIN 2018, Epstein & Street 2011)

## Key messages

- There is need to reorient healthcare delivery from acute, episodic care to long-term, patient-centered management.
- Long-term disorders are the main challenge facing health-care systems worldwide, but health systems are largely configured for individual diseases rather than multimorbidity.
- Health systems need to be reconfigured to cope with the burden of chronic disease. Integration of health and social care is important.
- Primary and community care are key.

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## 5.3 INNOVATIVE APPROACHES TO IMPROVE HEALTH OUTCOMES

*Iveta Nagyova*

The healthcare sector is ripe for innovation as health plans, providers, life sciences firms, and government entities grapple with escalating costs and inconsistent outcomes. Their collective aim is to achieve the triple aim: enhancing care quality, fostering better health outcomes, and curbing expenditure. Despite the positive changes brought about by healthcare reform, persistent inefficiencies and communication breakdowns impede progress toward the overarching objective—delivering superior healthcare and enhancing population health outcomes while reducing costs. These challenges are most pronounced in the care of patients with multiple chronic conditions. During care transitions, the lack of integration across various sectors and inadequate communication among providers result in delays in delivering appropriate healthcare services to these vulnerable patients and their caregivers, leading to suboptimal health outcomes and escalating costs. Established acute care-focused treatment and reimbursement paradigms further impede the effective allocation of existing resources to improve ongoing patient care. Novel care coordination models for transitions, longitudinal management of high-risk patients, and unplanned acute episodic care have been conceived and piloted with promising outcomes. Leveraging existing resources, Mobile Integrated Healthcare emerges as a novel model aimed at addressing these care gaps through a round-the-clock, technologically advanced, physician-led interprofessional team that manages care transitions and chronic care services on-site in patients' homes or workplaces.

It can be a challenge for regulatory agencies, policymakers, and governing bodies to keep up with the rapid evolution of technology and new and evolving threats to public health. What innovations are most likely to help stakeholders achieve these goals and transform health care? What is the potential and possible use of artificial intelligence (AI), next-generation sequencing (NGS), virtual reality (VR), point-of-care (POC) diagnostics or leveraging social media to improve patient experience? A growing body of evidence shows that social needs, including housing and other environmental factors in patients' lives, are at least as important as medical care in contributing to population health. Many health conditions, including high-cost chronic illnesses such as cardiovascular disease, type 2 diabetes, and asthma, start or worsen when basic human needs—such as shelter, food, clothing, and safety—aren't adequately met. Furthermore, in a typical, service-oriented health care system, people with complex and interrelated conditions, including substance addictions and behavioral health problems, are not always well served.

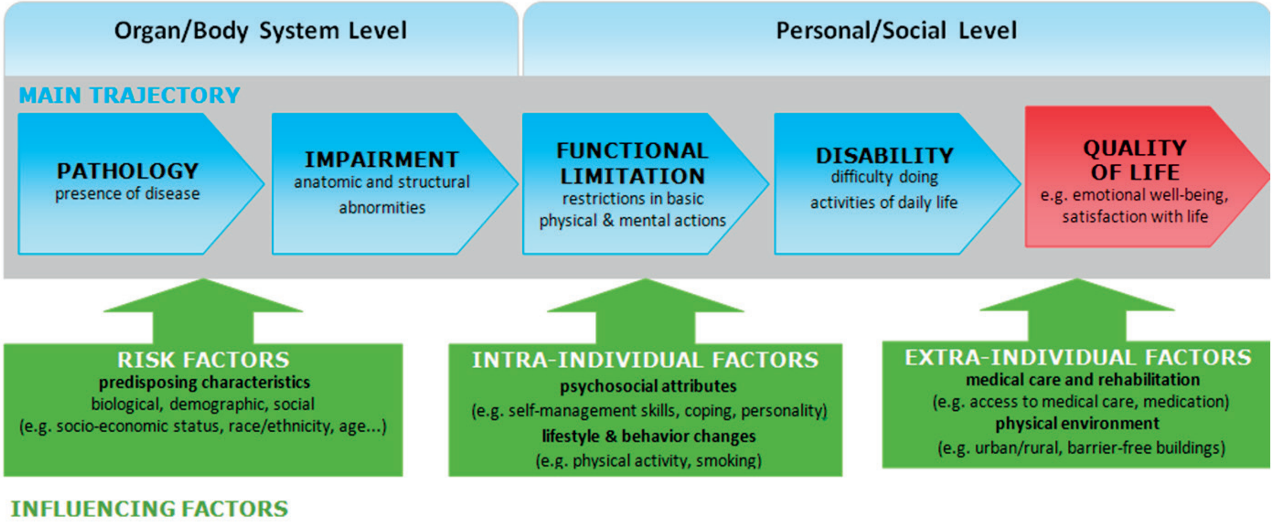
Innovation: Any combination of activities or technologies that breaks existing performance tradeoffs in the attainment of an outcome, in a manner that expands the realm of the possible. Defined in health care as providing "more for less"—more value, better outcomes, greater convenience, access and simplicity; all for less cost, complexity, and time required by the patient and the provider, in a way that expands what is currently possible. Copeland et al. 2016

### 5.3.1 Patient-reported outcome measures and quality of life

The increasing life expectancy and higher burden of chronic diseases has led to international interest in how to improve the quality of human life while extending its quantity. In line with this, researchers in healthcare are increasingly focussed on the measurement of the outcomes of service provision and interventions. Various objective and subjective measures are together taken to reflect health status and quality of life, which are ideally in conjunction with quantity of life when considering the benefits of an intervention. Consequently, an intervention which extends life by several years, but which brings about markedly reduced quality of life over that time period, may be considered less desirable than one which offers less quantity but greater quality of life. Although the conceptualization and methods of measurement of outcomes is still controversial, there is a general consensus that meaningful measures of people's health status and quality of life should be used.

This book accepts a broad definition of **quality of life**, which encompasses not only 'overall quality of life', but also symptoms and side effects that may or may not reflect/or affect quality of life. Some researchers prefer to use term 'health-related quality of life', emphasizing that we are interested only in health aspects, while others are adopting a new term **'patient-reported outcomes' (PROs),** because that term indicates interest in a whole host of outcomes such as pain, fatigue, depression, or physical symptoms (Fayers & Hand 2002).

**Figure 1**. The Disablement process



Source: Verbrugge & Jette 1994, adjusted.

PROs is an umbrella term that covers a whole range of potential measurements, but it specifically refers to "self-reporting" by the patient. As per US-FDA, ''a PRO is any report of the status of a patient's health condition that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else" (US-FDA 2009).

By using PROs, various types of outcomes can be measured such as physical functions, symptoms, global judgments of health, psychological well-being, social well-being, cognitive functioning, role activities, personal constructs, satisfaction with care, and adherence to medical regimens in clinical trial outcomes.

The most commonly used PROs assess one of the following constructs (US-FDA 2009, Krabbe 2017):

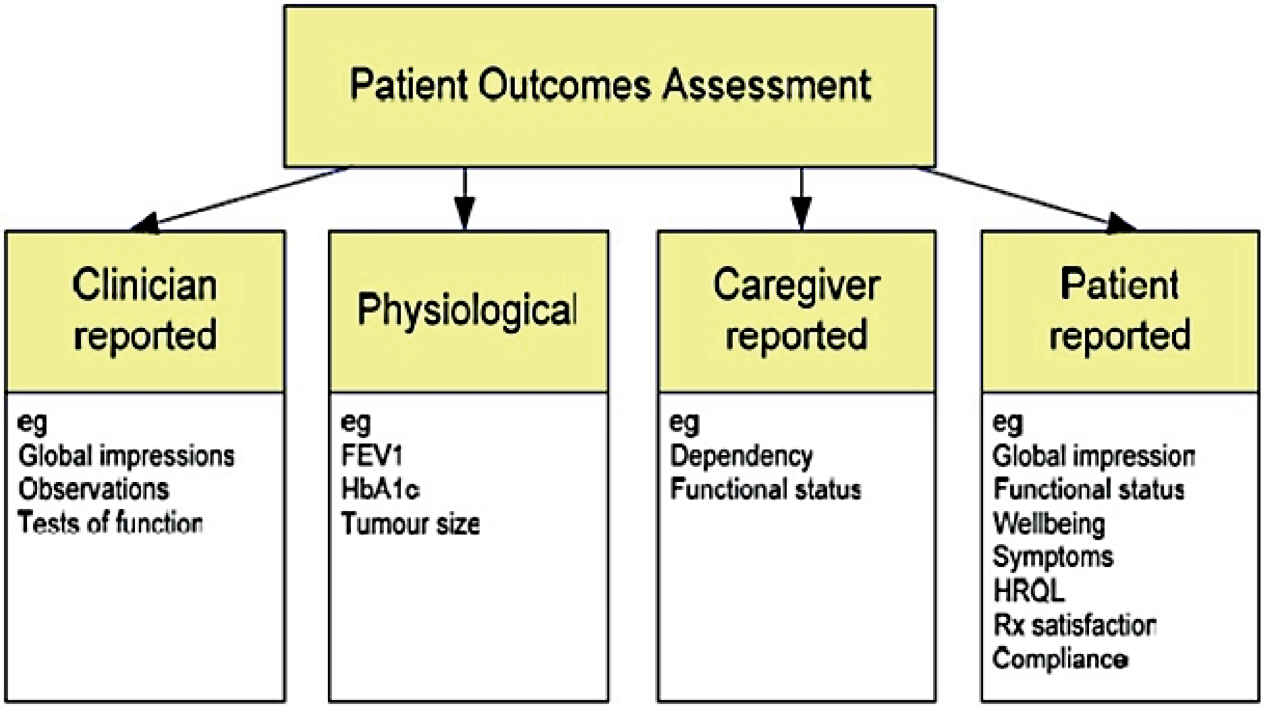
Various tools (e.g., instruments, scales, single-item measures) that enable researchers, administrators, or others to assess patient-reported health status for physical, mental, and social well-being are referred to as PROs. Many of the common generic PRO tools assess health-related quality of life or patients' evaluations of health care. For example, the SF-36 Health Survey, SF-12 Health Survey, the Nottingham Health Profile, the Health Utilities Index, the Quality of Well-Being Scale, the EuroQol (EQ-5D), or the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey instruments are consider to be PRO instruments (Fayers & Hand 2002).

The PRO instruments should satisfy several quality properties. As per the literature, the following properties are considered to be 'ideal' for a PRO instrument:

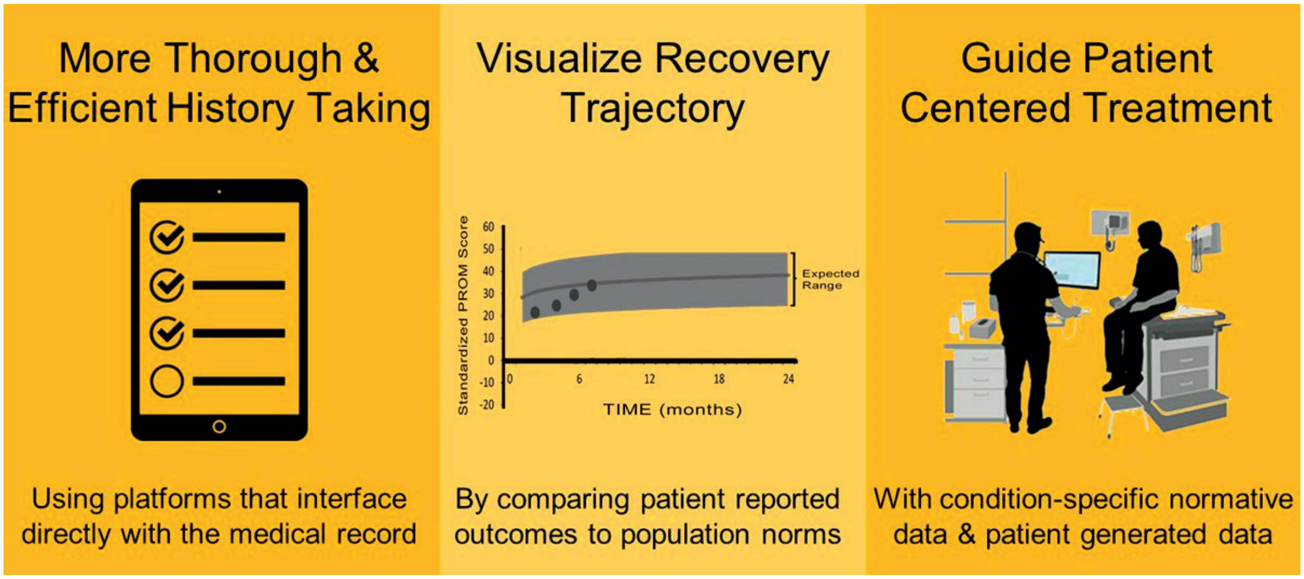
- It should be specific to the concept being measured
- It should be based on end-point model
- It should have conceptual equivalence
- It should be based on the conceptual framework
- It should contain optimum number of items
- It should have easy and specific measurement properties i.e. use of the scales which is easiest for the intended population to understand
- It should have proper evidences for the conceptual framework
- It should maintain the confidentiality of the patient
- It should be reproducible (US-FDA 2009)

### Patient-reported outcomes and patient-centered care

Patient-reported outcomes (PROs) provide a unique method of including the patient perspective at the point of clinical care. Patient-centered care has taken pivotal stage in discussions of quality provision of healthcare. The originators of patient-centeredness were well aware of the moral implications of their work, which was based on deep respect for patients as unique living beings, and the obligation to care for them on their terms (Epstein & Street 2011). Information from the patient's perspective is indispensable to support a patient-centred approach to care. As such, PROs are increasingly recognized as valuable and essential information for achieving health system goals and seem to be of more importance in future than other outcomes like clinical, physiological or caregiver-reported. For example, enhanced treatment adherence and outcomes can be obtained by giving attention to patient feedback on healthcare outcomes and patient behaviour change. Similarly, within the context of shared decision making, clinicians and other healthcare staff can use the instrument, scale, or single-item measure (PROs) to engage patients in their own preferred self-management and goal attainment by identifying outcomes important to them and tracking change over time.



PROs are unique indicators of impact of disease on the patient, essential to understanding whether health care services and procedures make a difference to patients' health status and quality of life. PROs are necessary for determination of efficacy of the treatment, helpful in empowerment of the patients, useful in the interpretation of clinical outcomes and treatment decision making. PROs can be used to inform clinical practices; health services programming, planning and policies; performance measurement; comparative effectiveness analysis; and quality improvement initiatives.


More Thorough & Efficient History Taking

Using platforms that interface directly with the medical record

Visualize Recovery Trajectory

By comparing patient reported outcomes to population norms

Guide Patient Centered Treatment

With condition-specific normative data & patient generated data

**What is Quality of Life?**

In the developed world, for which the increasing longevity of populations and the emphasis on affluence is typical, there is a general interest in how to achieve the 'goodness of life', sometimes also called 'life satisfaction' or 'quality of life.' In general terms 'quality' can be defined as a grade of goodness or a degree of excellence of a characteristic. But what is quality of life? This term is typically used to evaluate the general well-being of individuals and societies. Furthermore, it is used in a wide range of contexts, including the fields of international development, political science and healthcare. Current interest in quality of life as ranging from the concerns for the environment to the marketing of the product we buy, and to evaluation of the benefit-burden ratio involved in medical treatment. Rapley in his book outlines the development of the quality of life construct, from being a social scientific index of the relative well-being of whole populations (an index of the state of states) to being a measurable aspect of individual subjective experience (an index of the state of persons) (Rapley 2003). Quality of life means different things to different people, and takes on different meaning according to the area of application. The term quality of life appears in the discussion of everything from the relative 'liveability' of towns to the aims and effects of social policy, from the relative benefits of differing models of human service provision to the individualized outcomes of vast number of medical and psychotherapeutic practices (Rapley 2003).

Undoubtedly, quality of life is a hazy term. To define, describe and understand quality of life is one of the most sustained efforts of contemporary social sciences. Hughes et al.'s survey identified 44 separate definitions between 1973 and 1993. Antaki and Rapley in their literature review reported over

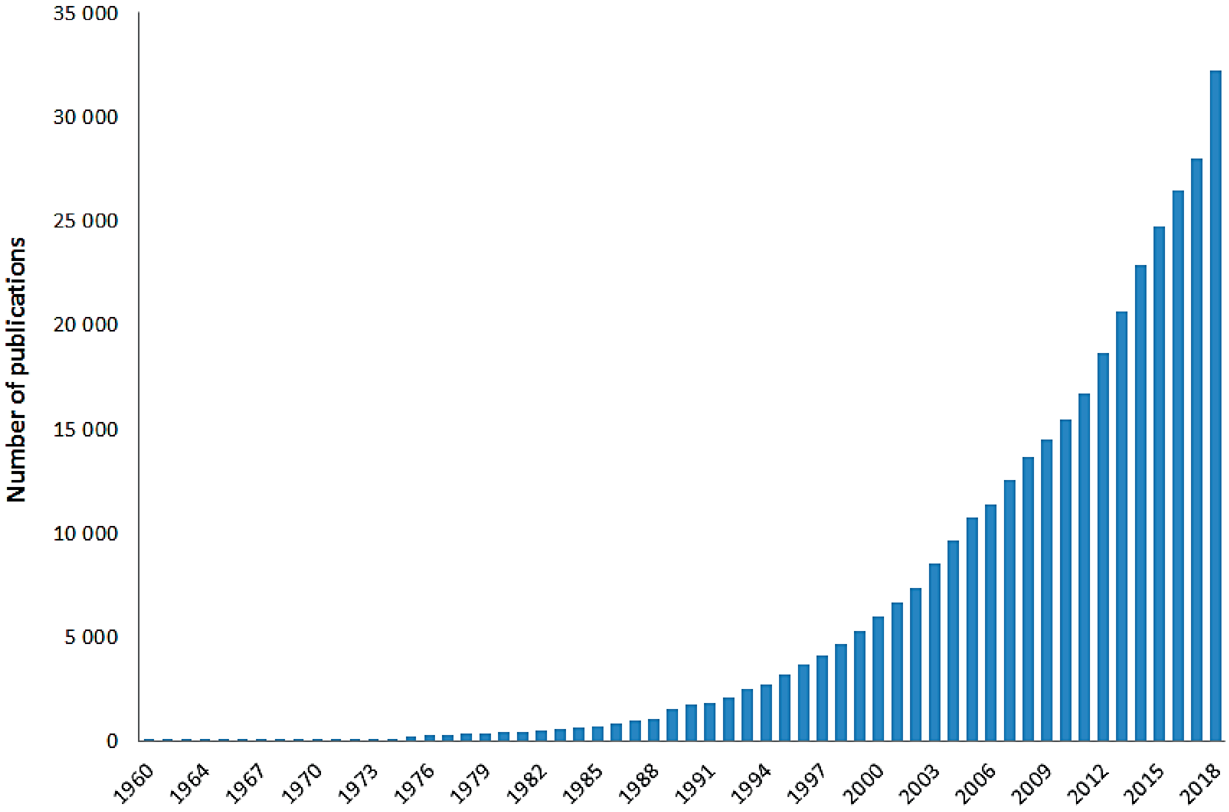
2,500 articles specifying 'quality of life' as a key word. Quality of life research spans a wide range of topics across many disciplines – geography, literature, philosophy, advertising, economics, and the medical and social sciences. However, the literature is considerably fragmented and often contradictory. In addition, various social scientific literatures conduct their own quality of life debates in isolation from each other. Given these facts we can only agree with Rapley and Cummins  who say that there is no hope of a comprehensive overview as 'the literature is now too vast for any individual researcher to fully assimilate'. Undoubtedly, the quality of life concept is increasingly popular as end points in the evaluation of public health policy including the outcomes of health and social care, but the wider research community has accepted no common definition or theoretical framework of quality of life. Quality of life remains to be a vague amorphous concept; it is a multidimensional and multilevel construct that theoretically incorporates all aspects of an individual's life (Bowling 2001).

**Where Has Quality of Life Come From?**

In order to better understand the quality of life concept it is important to placing it into historical context. In the first half of the 20th century the quality of life concept was viewed within the context of the whole society and as such it was largely measured by the material level of living. The higher that level in a country (measured by GNP related measures) the better the life of its citizens was assumed to be. According to Veenhoven this materialistic conception of quality of life was never unquestioned, but criticism long remained marginal. Nevertheless, in the 1960's, the opinion climate changed and this was mainly due to reaching the saturation levels as well as seeing the ecological limits of the economic growth. Consequently, this change gave rise to a call for broader indicators of quality of life, which manifested in the so called 'social indicator movement'. In line with Veenhoven, also Cummins, Noll and Zapf locate the beginnings of the quality of life research in the 'social indicator movement'. It was stated that the impetus of this research was the joint project of the NASA (National Aeronautics and Space Administration) and the American Academy of Arts and Sciences which aimed to predict the side effects of the space program on the American society. This project came to the conclusion that there was almost a complete lack not only of adequate data, but also of concepts and the methodology for this purpose and most likely it was Raymond Bauer, the director of the project, who invented the term 'social indicators'. According to his definition social indicators are "statistics, statistical series, and all other forms of evidence that enable us to assess where we stand and are going with respect to our values and goals"' . When thinking of the 'quality of life' term in its modern form there is a general consensus in attributing the coining of this term to a 1964 speech by former U.S. President Lyndon Johnson who stated that "the great society is concerned not with how much, but with how good - not with the quantity of goods but with the quality of their lives". During the 1980s there was an intensive discussion and plenty of investigations into the quality of life, but compared to previous years the concept itself became 'individualized'. New interest in individual, personal values began to emerge and the quality of life was conceptualized more and more as individual well-being, which is determined not only by good objective living conditions but also by subjective well-being (Zapf 2000).

Issues of definitions and measurement were the subject of critical investigation previously and the debate continues till today. Since the 1960s the exponential rate of increase of papers on quality of life began. Spitzer reports that only four papers mentioned quality of life in their titles between 1966-1970, while it applied to 33 papers over the next five years (Spitzer 1987). Moons et al.(2004) in their review state that a Pubmed search of articles published from 1966 to 2005 identified 76,698 articles containing 'quality of life' as a Medical Subject Heading or as a title or abstract term and hey have also illustrated the exponential growth of the number of publications on this subject. Moreover, they analyzed the proportion of quality of life studies versus all publications cited in Pubmed. Their outcomes reveal the same 'exponential growth' pattern; in 1966, 0.002% of all publications were on quality of life, whereas this proportion has risen to 1.36% in 2005. In 2019 we performed the same analysis and we discovered that currently over 30,000 articles dealing with quality of life are published each year (Figure 2).

**Figure 2**. Number of publications in the Pubmed database (1960–2018) referring to quality of life



*Source: PubMed data, search performed on Jan 08, 2019*

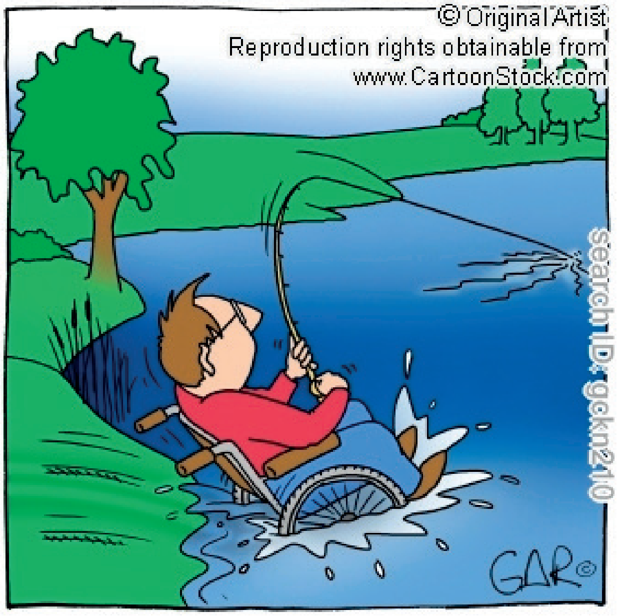
**Health-Related Quality of Life**

HRQoL is a health-focused quality of life (QOL) concept that encompasses aspects of QOL that affect health such as function, physical, and emotional health. Quality of life research in medical settings if one of the fields that focussed most intensively on issues of the objective operationalisation and quantification of this construct. Health is consistently included as an important aspect of quality of life. Consequently, health-related quality of life measures have been developed to assess aspects of an individual's subjective experience that relate both directly and indirectly to health, disease, disability and impairment. Quality of life in this context is about the 'goodness of life' that relates to health. Accordingly, health-related quality of life is one dimension of wider quality of life (Bowling 2005).

Nevertheless, the 'health-related quality of life' concept requires a more precise definition. In healthcare, outcome assessment has long tradition, but most existing clinical indicators reflect a 'disease model'. This model is a medical conception of pathological abnormality which is indicated by signs and symptoms, but a person's 'ill health' is indicated by feelings of pain and discomfort or perception of change in usual functioning and feeling. Encouragingly, during the last decades a relative shift from 'cure' to 'care' can be recognised. What matters nowadays is how the patient feels; rather than how professionals think they feel. So in addition to the so-called 'objective' measures of health such as morbidity, mortality, symptoms response or survival rates, the quality of life issues have emerged as important parameters when evaluating the outcome of healthcare. This is especially important for patients with a chronic condition for whom quality of life is a critical outcome measure, since complete cure of disease is often unlikely. With incurable condition the realistic goal of care is to provide a life that is comfortable, functional and satisfying as possible. Consequently, for these people the therapy is/should be evaluated in terms of whether it is more or less likely to lead to an outcome of a life worth of living (Bowling 2005).

Health-related quality of life is often operationalised by assessing physical, mental (cognitive, emotiona), and social functioning domains of patients following treatment, mirroring the WHO definition of health (Bowling 2005) "It is a double-sided concept, incorporating positive as well as negative aspects of well-being and life, and it is multidimensional, incorporating social, psychological and physical health."…"Taking these definitions into account, health-related quality of life is defined here as optimum levels of mental, physical role (e.g. work, parent, carer) and social functioning, including relationships, and perception of health, fitness life satisfaction and well-being". Yet, the 'health-related quality of life' concept is of great confusion for many researches and it is often used interchangeably with such concepts as health status, perceived health status and functional status assuming that a fully healthy life is identical to a high quality of life (Bradley 2001) This assumption can be questioned however due to the fact that persons with significant health and functional problems do not necessarily have commensurable low quality of life scores (Carr & Higginson 2001). This can be illustrated by an example of Moons's 'ardent fisherman'. A fisherman "is a paraplegic —obviously, a bad health state in terms of mobility— but he can still have a good quality of life if he is able to go fishing, even though he is confined to his wheelchair when doing so" (Moons et al. 2006). This phenomenon of a 'high quality of life against all odds' is referred to as the 'disability paradox'.

**Figure 3.** Disability paradox: The example of ardent fisherman



"Arrh! I must remember to put my brakes on."

*Source: Moons et al. 2006*

The interchangeable use of 'quality of life' and 'health status' is reflected also in the measurement of these concepts. For instance, generic instruments, such as the MOS Short Form Health Survey (SF-36), the Sickness Impact Profile (SIP) or the Nottingham Health Profile (NHP) were primarily developed to measure health; therefore it is reasonable to ask why some researchers often refer to these instruments as 'health-related quality of life' instruments when they were in fact measuring 'perceived health status' (Moons 2004).

Some researchers are sceptical about the health-related quality of life concept (Rapley 2003). They argue that health-related quality of life assessment is in contrast to assessment of quality of life in healthy people and it becomes especially apparent if ill people are asked to make a distinction between their overall quality of life and health-related quality of life. This seems to be definitely artificial, since patients must distinguish between the part of their life influenced by health and other parts of their life not appreciably influenced by health. Also, by focusing on health-related quality we may substantially overestimate the impact of health-related factors and conversely, may seriously underestimate the effect of nonmedical phenomena. Moreover, people whose health has changed may report the same level of quality of life over time. These authors further state that health should be considered as a determinant of quality of life, contributing to a good or bad quality of life, instead of being regarded as an indicator of quality of life itself. And given these considerations, the necessity or usefulness of the term health-related quality of life is questionable in their opinion. Hence, the concept of health-related quality of life is still subject for debate.

## Methodological Considerations in Measuring Health and Quality of Life

*Why is a standardized approach to PROMs important?*

A common approach to collecting and reporting PROMs data is more cost-effective and provides much more comparable data with which to drive health system enhancements (e.g., in the areas of quality, funding and patient-centred care). Having defined the objectives of outcomes assessment and the conceptual basis for measuring health and quality of life, attention must be given to the scientific or psychometric properties of instruments. The main properties to consider are reliability, validity, discriminatory power and responsiveness to change. The full definitions of these concepts can be found in most research methods textbooks. Nevertheless, their consideration is crucial because, different scales are suitable for providing different types of data and for answering different types of questions; and an introduction to some of the basic psychometric properties is required for the interpretation of description of scale reliability and validity in the text.

### *Psychometric Properties of the Instruments*

Measuring health and quality of life of patients is unavoidably difficult. Questions about the sensitivity, reliability, validity and generabilizity of data continue to be raised because of the complex nature of diseases, treatments, and expected recovery times and of course the concepts of health and quality of life itself. Whichever questionnaire, scale or inventory is selected all instruments should satisfy the criteria for reliability and validity. Another important psychometric properties of health status and quality of life scales when used as outcome measures are their discriminatory power and responsiveness to change, and in particular clinically important change.

### *Reliability*

Reliability refers to the ability to produce consistent results on different occasions where there is no evidence of change. In other words, it refers to the property of reproducibility, i.e. producing unchanged results on an unchanged population. The reliability of the instrument can be tested in a number ways. *Test-retest reliability (stability over time)* is evaluated by making repeated assessments under the same conditions at different points (i.e. administration of the scale on different occasion to the same population) and examining correlations between the two time points. The interval between administrations must be long enough that respondents simply do not remember and replicate their original answers, but not so long that real change is likely to have occurred. An interval of 2 to 14 days is generally recommended. A high level of consistency between the measurements is desired. A test-retest correlation of 0.85 or more indicates that instrument has an acceptably low level of random measurement error (Streiner & Norman 1989). However, the observed outcomes can be sometimes difficult to interpret, since a low correlation may reflect a genuine change in health status, rather than poor reliability. *Internal consistency* is an estimate of the homogeneity of the items purporting to measure a particular health concept. Commonly used indicators of internal consistency are Cronbach's alpha, item-total correlation, and mean inter-items correlation (Clark & Watson 1995). These are basically measures of the strength of the associations between constituent items of the scale. It is generally accepted that Cronbach's alpha should be in excess of 0.7 and that item-total correlations and mean inter-item correlations should exceed 0.20 (Kline 1986). The interpretation of alpha is that, for instance if Cronbach's alpha is high (e.g. above 0.85), then the implication is that the responses are consistent and, and the sum of the item responses yields a score for the underlying dimension that the item represents. Other tests of reliability include *inter-rater agreement* (i.e. the concordance, or reliability of scores by different raters on a single occasion). This is important for observer and interviewer administered measures. If the measure is categorical the most appropriate method statistical method to use is Cohen's Kappa Test of Concordance (Cohen 1968). Kappa has a value of 0 if agreement between the observers is no better than a chance, a negative value us equal to worse than chance, and a value equal to 1.0 is perfect agreement.

### *Validity*

Although reliability of an instrument is an essential property, it is not itself a sufficient criterion for instrument selection. In addition to reliability the scale also has to be valid. Validity refers to the extent to which the scale measures the underlying concept of interest; or put differently, validity means that instruments must indeed measure what they purport to do. A measure may be reliable without being valid, but validity cannot be obtained without reliability. There are different types of validity. *Face validity* answers the question whether, at face value, the instrument appear to be measuring what is intended to measure. *Content validity* relates to the choice, appropriateness, importance and representativeness of the instrument's content. It answers the question whether the scale taps all relevant concepts of the attribute to be measured. *Criterion validity* is the degree to which a given measure produces results which correspond well to those obtained through the simultaneous use of 'gold standard' (=concurrent validity – a correlation with an existing measure of the same construct) or which predict a future outcome or event (=predictive validity – a correlation against other measures to assess predictive powers) .The main problem in assessing criterion validity is the paucity of true 'gold standard' measures of health [9]. Finally, *construct validity* is supported when expected patterns of relationships are empirically observed. Construct validity is usually divided into 'convergent validity' (tests for correlations with other indicators intending to measure the same concept) and 'discriminant validity' (lack of correlation with unrelated indicators). A thorough approach to the establishment of construct validity is the application of multitrait-multimethod techniques (Campbell & Fiske1959). Another way of assessing construct validity is the so-called 'known group technique' or 'known-group validity'. This approach involves applying the instrument to groups of individuals known to differ due to the construct of interests (e.g. to compare a sample of chronically ill patients with a general population). In general, any difference between the groups which is in line with the expectations supports the validity of a measure. Finally, statistical techniques such as factor analysis can also be used to determine whether theoretical constructs or factors as defined by the instrument's developers are observable empirically. This type of validity is often referred to as 'factorial validity' or 'empirical validity'. This approach uses factor analysis for the assessment of a number of dimensions that underlie a variable. By employing factor analysis it is possible to determine whether the measurement model fits the hypothesised theoretical structure. This technique determines how far the various items of the instrument accord in measuring one or more common themes. Exploratory factor analysis is generally used in scale development in order to identify and discard items that are not correlated with the items of interest. Confirmatory factor analysis is typically used in scale validation in order to identify whether the underlying conceptual structure of the instrument can be retrieved. While relatively small samples may be used in analysis, ultimately a confirmatory factor analysis should include a larger sample for assessment of stability (Trochim et al. 2016).

### *Discriminatory power*

Another psychometric property of an instrument is its discriminatory power. Discriminative instruments are those which are able to detect differences between individuals and groups at a given point in time. This property is sometimes termed 'sensitivity'. Sensitivity refers to the proportion of cases (e.g. people with verified diagnosis of depression) score as positive cases on an instrument (e.g. a scale of depression). Closely related to 'sensitivity' is 'specificity', which is a measure of the probability of the scale correctly identifying non-cases (e.g. people without depression) with the measure (e.g. a scale of depression) (Trochim et al. 2016).

*Responsiveness to change*

In healthcare the ability to detect relatively modest responses to treatment is often required. The property of an instrument being able to detect change over time is termed 'responsiveness to change'. Several researchers have highlighted the inability of many otherwise valid and reliable instruments to pick up small but clinically important changes over time (Guyatt et al. 1987). In line with these authors we state that responsiveness to change is perhaps the most difficult of all properties to establish. Laboratory tests or physical findings often do not correspond with change in health status. Also, usually there is no 'gold standard' for what constitutes a real change in health status. There are several reasons for unresponsive to change. Nevertheless, 'ceiling' and 'floor' effects are among the most frequently reported. The former means that in patients with a maximal pre-treatment score, improvements in health status cannot be registered, while the later means that deterioration in health status cannot be detected in patients with minimal pre-treatment scores (Hutchinson et al. 1987).

## Technical aspects of health status and quality of life measures

*Generic, disease-specific and domain-specific measures*

It is important to define different types of instrument: generic, disease-specific and domain-specific. Measures which implicitly or explicitly aim to address quality of life and encompass physical, mental and social health are termed as 'generic'. The validity and reliability of these measures is generally rigorously assessed and population norms are established for several. These scales are most appropriate to use in studies of general populations, as opposed to those defined on the basis of health problem or diagnosis. But they are also useful when the investigator wish to make comparisons of results between different diseases and conditions. On the other hand, generic instruments have important constraint as they are unable to identify the condition-specific aspects of a disease that are essential for the measurement of outcome. Their universality means that generic measures are likely to contain some items that are not particularly relevant to a specific disease group (Hutchinson et al. 1987). For instance, many include questions on pain, but it is not a salient feature for the majority of patients with asthma or cardiovascular disease. Generic instruments may also be unresponsive to small but important changes following an intervention within a particular population with a specific health problem. Therefore, generic instruments will always require supplementation with disease-specific measures in order to detect change. 'Disease-specific' measures have the aim of being more clinically and socially significant in relation to specific conditions. These measures are used when disease or condition-related attribute need to be assessed and greater sensitivity to clinical condition under consideration is required. More in detail, disease specific measures are being able to discriminate more finely between patients' levels of severity of condition, and are being more sensitive to small, but clinically significant changes, in health status and levels of disease severity. A 'domain-specific' measure is used when the area covered is of particular relevance, and where generic and disease-specific instruments neglect that area. For example, disease-specific measures of quality of life are often criticized for being too narrow in focus, while neglecting the measurement of important outcomes or modifying variables such as social support, self-esteem, coping, adjustment, depression and other domains. The ideal may be a combination of one or two generic instruments (allowing findings to be compared across disease groups as well as allowing to address broader policy questions)  and a number of disease- and condition-specific measures (allowing to detect unexpected clinically significant positive or negative effects of intervention) (Guyat et al. 1986, Krabbe 2017).

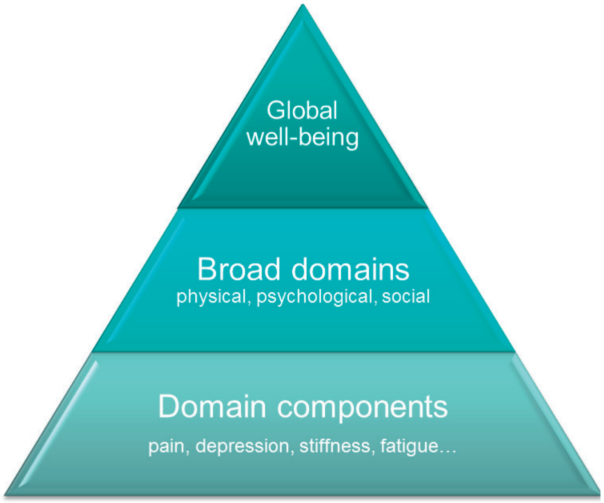
### *Single item vs multiple items instruments*

Health and quality of life instruments range from single global questions such as the classic self rated health status item asking respondents to rate their health as "excellent, good, fair, or poor" (Mossey & Shapiro 1982) through multidimensional measures with a single item tapping each domain or dimension, for example the WONCA/COOP charts (Nelson et al. 1987), to multi-item multidimensional measures like the SF-36 (Ware & Sherbourne 1992). The main attraction of single global questions is their practicality; they are quick, easy to complete and analyze. Furthermore, research has shown a reasonable concordance between responses to global questions and to more complex instruments. Also, it has been proposed that concepts such as health status or quality of life, when used as outcome variables, are more appropriately measured with a global single item. Given these facts, a frequently asked question by researchers is why they should use a lengthy, multi-item measurement scale to assess patients' perceptions of their health, or quality of life, when there is evidence that a measure containing a single, global question is likely to suffice. The answer is that the main limitations of single item measures lie in lack of their discriminatory and power and responsiveness to change (De Boer et al. 2004). Nevertheless, the investigators have to make their selection of longer or shorter multidimensional scales and/or single item measures depending on the purpose needs of the study. Single item measures have obvious benefits for both research and policy in terms of reduced burden and costs, and ease of interpretation; however they have also their limitations. Single item measures can be used alongside multidimensional measures, and are useful as broad summary ratings of diverse aspects of respondents' health and quality of life, especially where respondents might have improved on one domain (e.g. physical functioning) but not on another (e.g. mental functioning) (Bowling 2005).

### *Unidimensional vs multidimensional* / Domain vs dimension

The scales are reported to be unidimensional or multidimesional and measuring one or more domains or dimensions. In literature there is a great degree of confusion on health status and quality of life measures regarding the distinction between concepts 'domain' and 'dimension'. Several authors tried to bring some clarity in differentiation between these two terms. For example Albrecht (1994) uses the term 'domain' to refer to the various facets that go together to make up a construct. Ac-cordingly, health related quality of life can be seen to include such domains as physical, mental and social functioning. He uses the term 'dimension' for sub-components of these domains, e.g. ambulation and self-care are dimensions of domain of physical function. In line with the multi-faceted definition of health and quality of life, the majority of generic and disease-specific measures cover multiple do-mains and dimensions (Hutchinson et al. 1997).

**Figure 3.** Hierarchical model of quality of life



*Source: Spilker 1990, adjusted*

"Health-related Quality of life (HRQoL) is an **individual's perception** of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns.

It is a broad-ranging concept, incorporating in a complex way the person's **physical** health, **psychological** state, level of independence, **social** relationships, and their relationship to salient features of their environment."

*(WHO definition of HRQoL, 1995)*

## 5.3.2 Behaviour change and non-pharmacological interventions

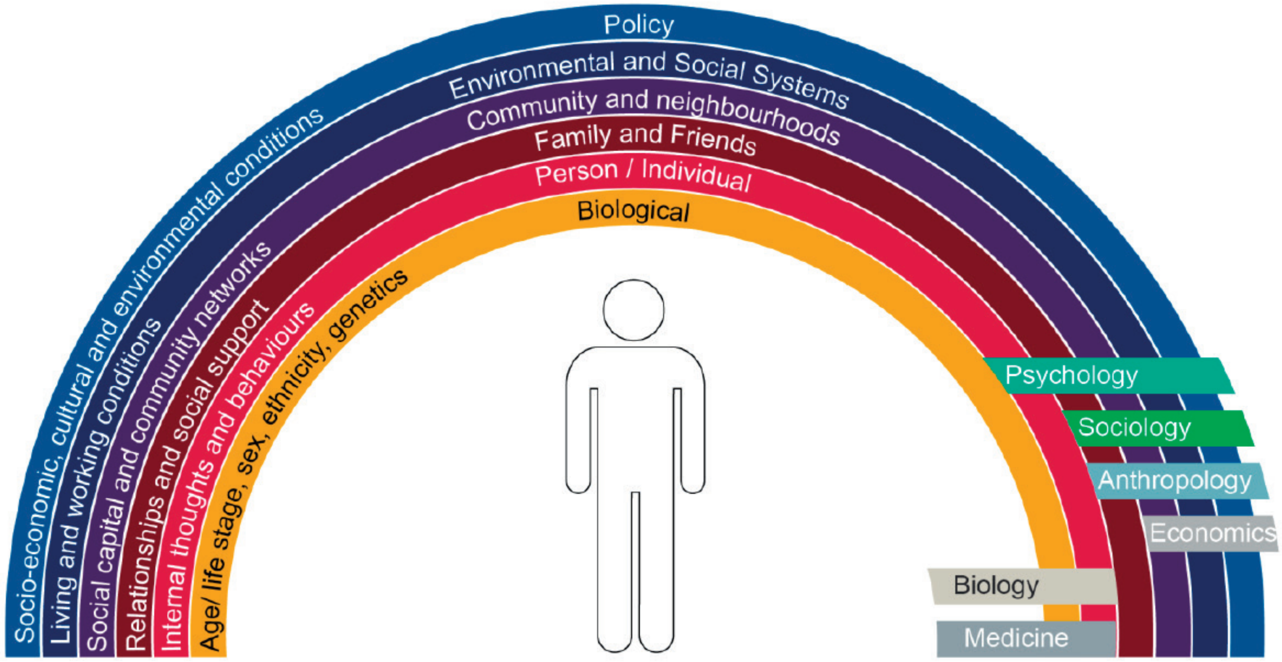
### The role of behavioural and psychosocial factors in prevention and management of chronic conditions

We live in a time when our population faces complex health and well-being challenges that stem from biological, psychological, economic, environmental, and social causes. Chronic non-communicable conditions share behavioural risk factors such as tobacco smoking, low-quality diets, alcohol abuse, and physical inactivity (Murray & Lopez 2013). Other risk factors include depression, loneliness, negative outlook or social isolation. Risk factors influence one another and are exacerbated once someone is sick leading to one or more chronic conditions. Multimorbidity is revalent and health behaviors change can benefit patients by positively impacting on more than one condition (Rijken et al. 2018). In chronic conditions self-management support is one of the crucial element of sustainable health systems. Self-management is defined as complex endeavour, involving adherence to treatment, change to multiple health behaviors and regular contact with healthcare providers. Interventions addressing risk factors and supporting behaviour change for the effective self-management of chronic conditions can make a considerable difference to health and well-being and reduce the costs of delivering health care to an aging population living longer with chronic conditions (GBD Lancet 2018). The response to and understanding of these epidemics must involve human behaviour. However it is not just individual behaviour which drives these epidemics. Behaviour takes place in social environments and efforts to change it must therefore take account of the social context and the political and economic forces which act directly on people's health regardless of any individual choices that they may make about their own conduct (Kelly 2016). Behaviour is central to the development, prevention, treatment, and management of the preventable manifestations of diseases and health conditions (heart disease, cancer, stroke, chronic obstructive pulmonary diseases, unintentional injuries, pneumonia and influenza, diabetes, suicide, kidney diseases, chronic liver disease and cirrhosis, HIV/AIDS) on which we spends 75% of our annual healthcare costs. The breadth of connections between behaviour and health is formidable. These include risk factors like smoking, the influence of stress on the course of many diseases, stress management, chronic disease management, psychological and behavioural interventions addressing quality of life, and gene X behaviour interactions, including major roles of behaviours in moderation of gene expresion (PHE 2018).

In recent years, there has been increasing recognition of the valuable contributions made by behavioral and social sciences—encompassing fields like psychology, behavioral economics, sociology, and anthropology—to enhancing public health. However, these contributions remain underutilized in practice and inadequately integrated into public health initiatives. Furthermore, the workforce equipped to offer expertise in behavioral and social sciences remains limited. Given the intricate social dynamics and contemporary challenges faced by individuals, along with the advent of digital innovation and systemic restructuring, there is a pressing need to harness and learn from these sciences more comprehensively. Embracing a transdisciplinary approach, grounded in problem-solving and person-centered principles, is essential for effecting meaningful and efficient change. Many of the current challenges impacting population health, such as smoking, unhealthy diet, and physical inactivity, could be mitigated through modifications in individual behaviour. While individual behavior change remains crucial, a comprehensive strategy to address these challenges must encompass a broader spectrum, drawing extensively from behavioral and social sciences to address structural and social issues. Substantial evidence indicates that many factors influencing our health outcomes—both positively and negatively—are rooted in structural, social, and behavioral determinants (Marmot & Bell, 2012). These determinants encompass various aspects, including the environments where we reside, work, and engage in recreation; the distribution of education, employment, income, and access to healthcare services; as well as our interactions with and perceptions of physical and digital environments, social norms, stigma, and discrimination. Moreover, many of these aspects are also influenced by digital advancements.

This chapter presents the contributions of selected foundational behavioral and social sciences to public health, outlining opportunities for advancing current practices and enhancing the cost-effectiveness of interventions (see Figure 4). Our focus primarily revolves around comprehending and modifying behaviors and practices, with evaluation playing a pivotal role in this endeavor. The behavioral and social sciences offer valuable tools for evaluation, and practitioners in these fields possess expertise in their application. Embracing transdisciplinary approaches, wherein professionals from diverse disciplines collaborate on public health issues, holds considerable potential for broader implementation. Our aspiration is that this approach will stimulate continued systemic evolution in transdisciplinary approaches to public health. It is not intended to be exhaustive or definitive, but rather the initial step in an ongoing process (Sniehotta et al., 2017; Schneiderman, 2001).

**Figure 4.** Conceptualising the contributions of behavioural and social sciences



*Source: PHE 2018*

**Five key principles for good practice**

Since this strategy brings together a variety of stakeholders, including people coming from different disciplinary traditions that may have different terminologies, we agreed in a stakeholder workshop on 5 key principles to govern our common approach:

1. We should all use inclusive language that does not alienate.
2. We should all think outside of our disciplinary boundaries and cooperate across disciplines in order to ensure a multi-disciplinary approach.
3. We should promote our common focus on improving public health and reducing health inequalities.
4. We should involve end users in the development and implementation of behavioural and social sciences to benefit the public's health.
5. Our approach should be reflective and critical, informed by the evidence, and involve the highest possible standard of evaluation.

While this strategy emphasizes various disciplines and their potential contributions to public health, our aim is to develop policies and interventions through a transdisciplinary approach. We envision a future where the analysis of issues and their causes is not confined to specific disciplines but draws upon insights from across the spectrum of behavioral and social sciences.

The utilization of behavioral and social sciences is crucial for optimizing health outcomes in this fifth wave, especially in the era of digital transformation, which presents both opportunities and challenges.

This cultural wave necessitates action on the wider social and structural environment that impacts the population, rather than solely focusing on individual interventions. Such broader approaches are typically more effective, cost-efficient, and help reduce inequalities.

## What can behavioural and social sciences contribute to public health?

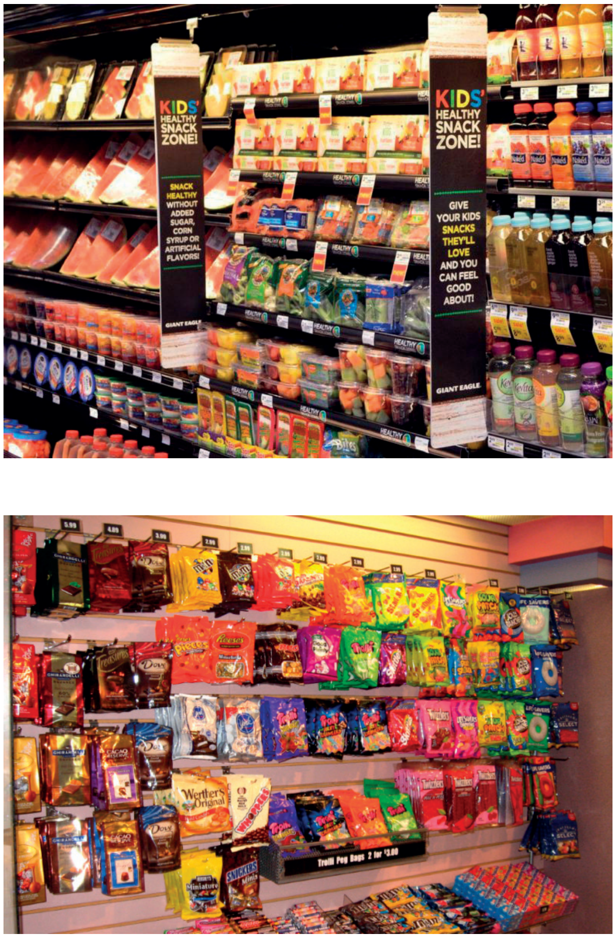
Behavioral sciences offer a structured approach to designing, developing, and evaluating interventions. They employ explicit theories and models to underpin interventions and contribute to an accumulating evidence base of effective strategies. Behavioral and social scientists possess valuable research and methodological skills, which can lead to innovative avenues for public health, such as leveraging large datasets to inform practice. They bring quantitative and qualitative skills to evaluation, enabling a comprehensive understanding of the effectiveness, mechanisms, and target populations of interventions. As previously mentioned, we advocate for public health to leverage a diverse range of skills and expertise from the behavioral and social sciences through a transdisciplinary approach.

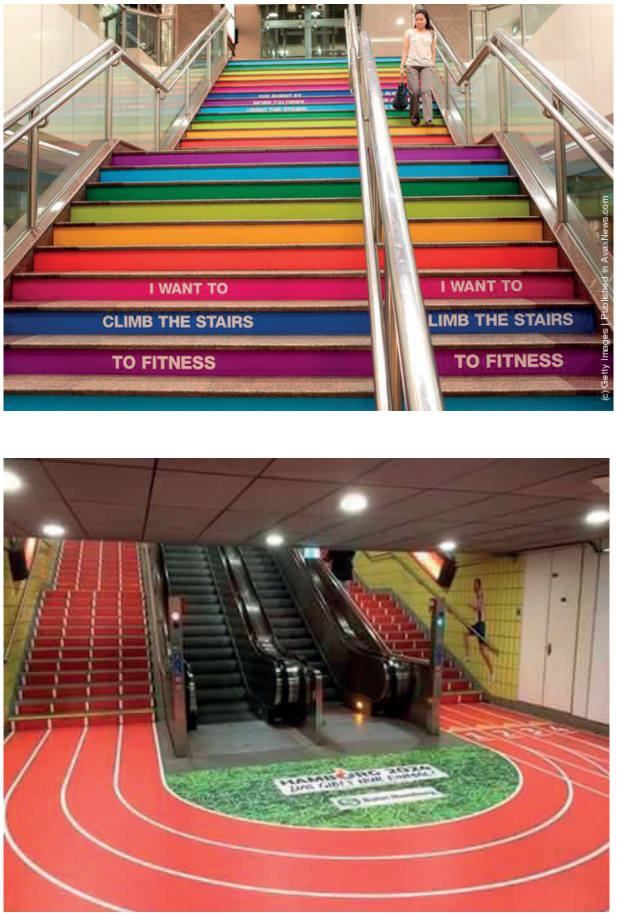
Tackling obesity across the life course

Obesity is a complex contemporary public health problem that involves a range of social, environmental, individual, physiological, biological and cultural components. Halting (and ultimately reversing) the current obesity epidemic requires systemic change by taking a holistic view that addresses the individual, social, environmental, and fiscal influences over the long term. (PHE. 2018) Strategies to tackle obesity, at a national and local level, include a mix of preventative population level approaches (eg, the soft drinks industry levy, improving the nutrient content of food and drink at the point of purchase); curative secondary prevention services (eg, family and adult weight management services); and targeted community asset based approaches. Alongside this, it is imperative to create local places that promote healthier defaults through our built, active, and food environment. Applying behavioural and social sciences and building behavioural insights into the design of these approaches is key, and is already contributing to the delivery of both population approaches at a systems level and targeted individual interventions. (Sniehotta et al. 2017).

Historically, public health practitioners have sought to modify behavior through both informative approaches, such as health education and promotion, and structural interventions. However, in recent years, it has become evident that many behaviors targeted by educational campaigns can be more effectively influenced by addressing psycho-social and structural factors, such as food environments and broader determinants of health. These interventions can drive systemic changes toward healthier states, foster the adoption of healthier behaviors, and promote the concept of "making the healthier choice the easier choice," often referred to as "choice architecture" (see Figure 5). Therefore, it is imperative to integrate individual-focused and socio-structural approaches within public health initiatives (van Kleef et al., 2012).

**Figure 5**. Choice architecture

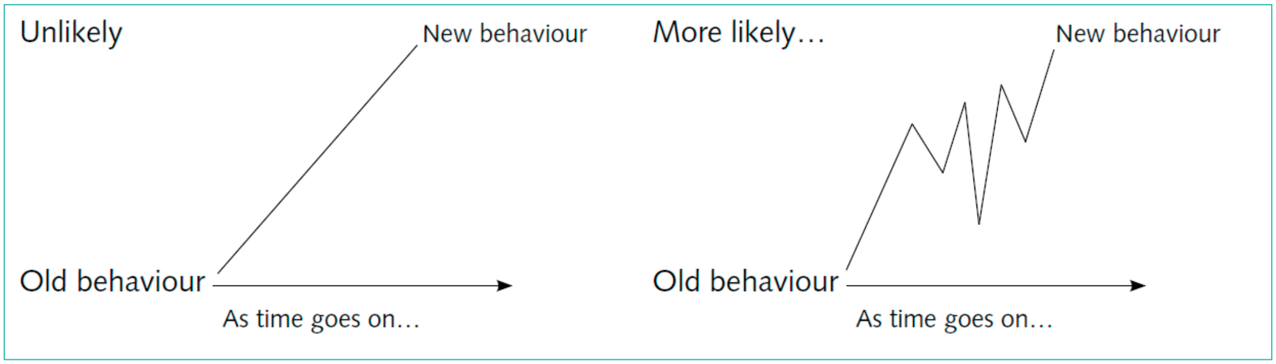




### The process of behaviour change

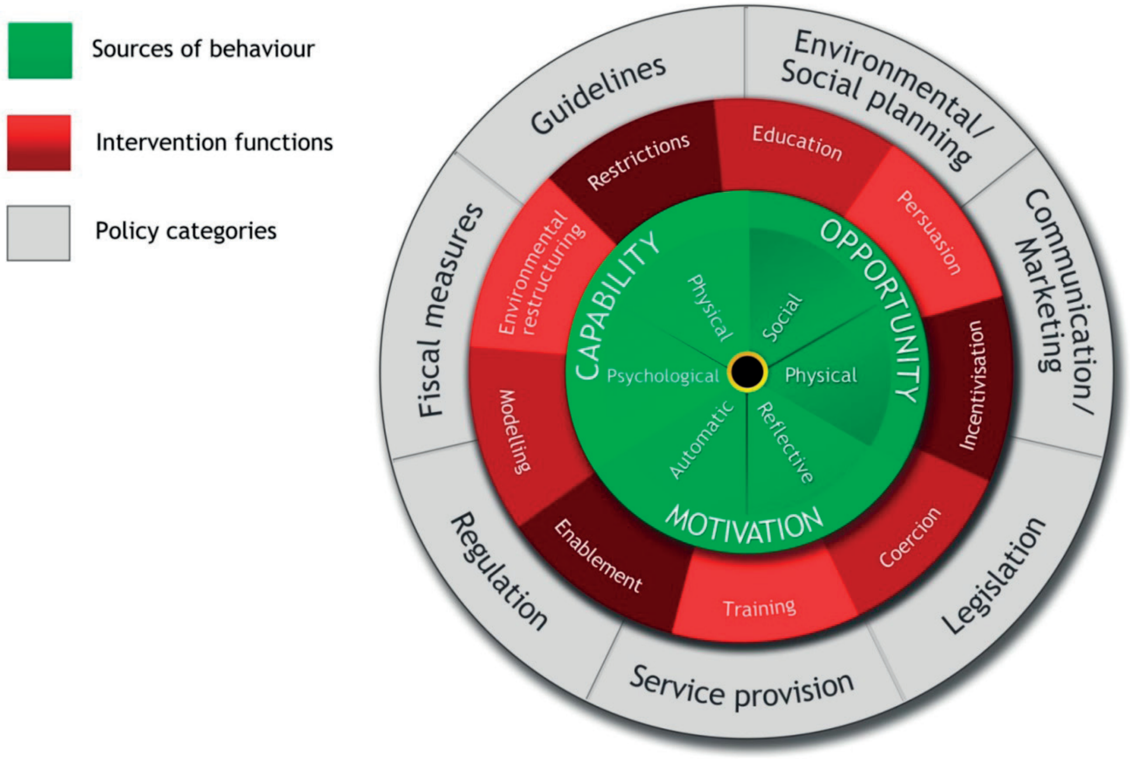
Change is not a smooth process. It is important that the patient/client understands that successful behaviour change is not a smooth process and it takes time and effort. Encourage them to think of behaviour change as a long process, where they build on each small success, learning from any setbacks (Figure 6, MIchie et al. 2008),

**Figure 6**. Behaviour change scenarios



Improving the design and implementation of evidence-based practice depends on successful behaviour change interventions. This requires an appropriate method for characterising interventions and linking them to an analysis of the targeted behaviour. There exists a plethora of frameworks of behaviour change interventions, but it is not clear how well they serve this purpose. This chapter evaluates these frameworks, and develops and evaluates a new framework aimed at overcoming their limitations. At the centre of a proposed new framework is a 'behaviour system' involving three essential conditions: capability, opportunity, and motivation (what we term the 'COM-B system'). This forms the hub of a 'behaviour change wheel' (BCW, Figure 7) around which are positioned the nine intervention functions aimed at addressing deficits in one or more of these conditions; around this are placed seven categories of policy that could enable those interventions to occur. The BCW was used reliably to characterise interventions within the English Department of Health's 2010 tobacco control strategy and the National Institute of Health and Clinical Excellence's guidance on reducing obesity (Michie et al. 2011).

**Figure** 7. Behaviour change wheel

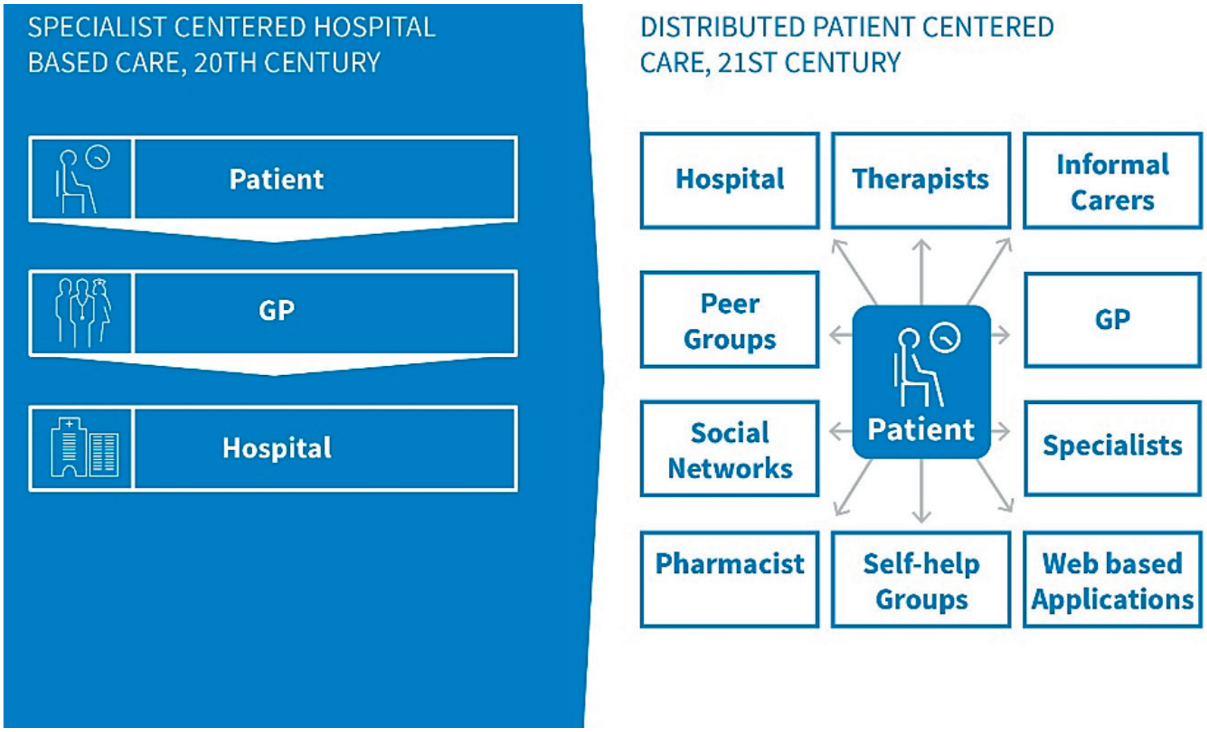


*Source: Michie et al. 2011*

## 5.3.3 Digital health, e-health/m-health

E-Health is referred to the application of Information and Communication Technologies (ICT) to the wide range of issues affecting the health care field. For example this may include the process starting with the registration and the diagnosis, to patients' follow-up as well as the organizational management related to each of these activities. From a citizen' viewpoint, e- Health provides considerable advantages related to information personalization which in some cases can include alternative diagnoses. From a health professional's viewpoint, e-Health refers to the actual improved access to relevant information, which, for example, can be directly associated with major medical journals and associations, electronic prescribing and overall accessibility to patients' personalized health information by ease of access to Medical Records (MR) (Figure 8), Copeland et al. 2016).

**Figure 8**. Past and future technologies

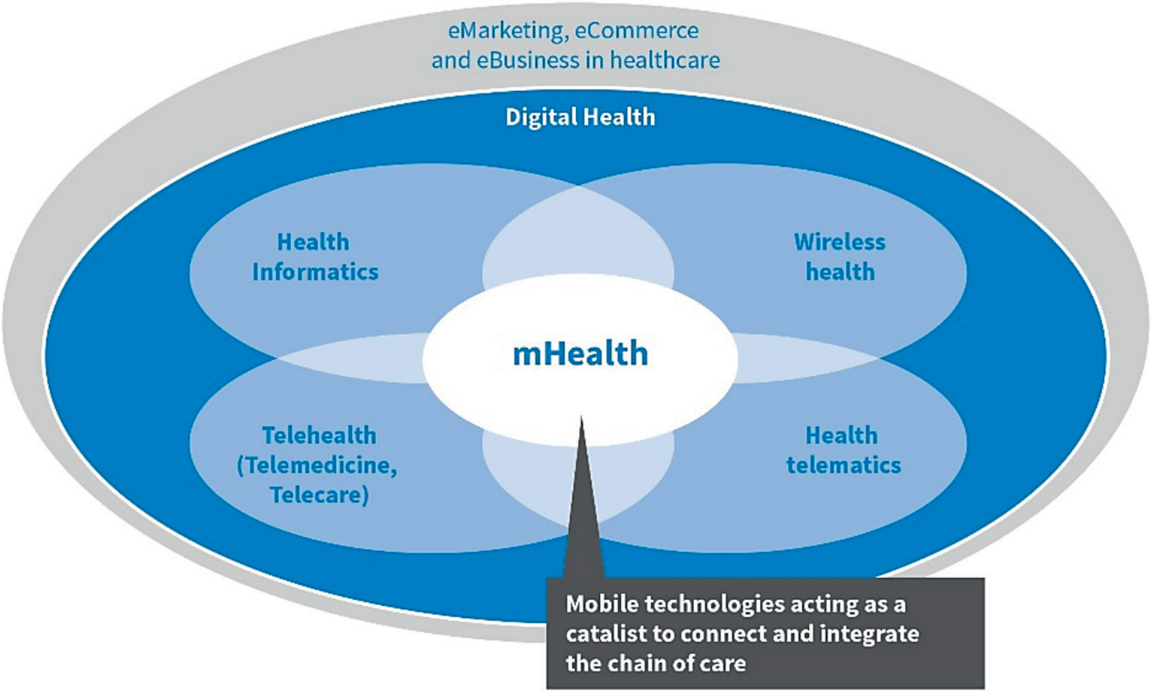


Source: Copeland et al. 2016

Information and Communication Technologies (ICT) are constantly creating progressive impact in our daily lives including the health sector (e-Health). E-Health involves wide range of applications to aid and support the Health Care Sector; for example, patients' registration, diagnosis and follow up as well as organizational management required to facilitate the administration that supports the necessary process for each of these activities. Paramedics, doctors and nurses can have easy access to their patients' medical records, retrieving laboratory tests results quickly so to send instant prescriptions directly to the pharmacists. Furthermore, by accessing such a support e-Health system, the patient is more informed and connected to the relevant information pool and medical support related to any part of the process. Consequently, there are numerous benefits for the participants in the whole sanitary system (Lluch 2011).

According to WHO (2004), e-Health refers to *"the use in the health sector of digital information, transmitted stored, or obtained electronically to support the health care users, locally and remotely".* It is based on the ICT implementation in areas ranging from organizational management, access to relevant information, constant monitoring, and provision of even alternative diagnoses by doctors located in different countries via Tele-consultation to name a few. On one hand, the health care professionals appreciate the ICT benefits for remote collaboration for sharing information with their colleagues across systems. On the other hand, there are great advantages for electronic diagnosing and prescribing for patients living in remote areas who cannot attend an appointment

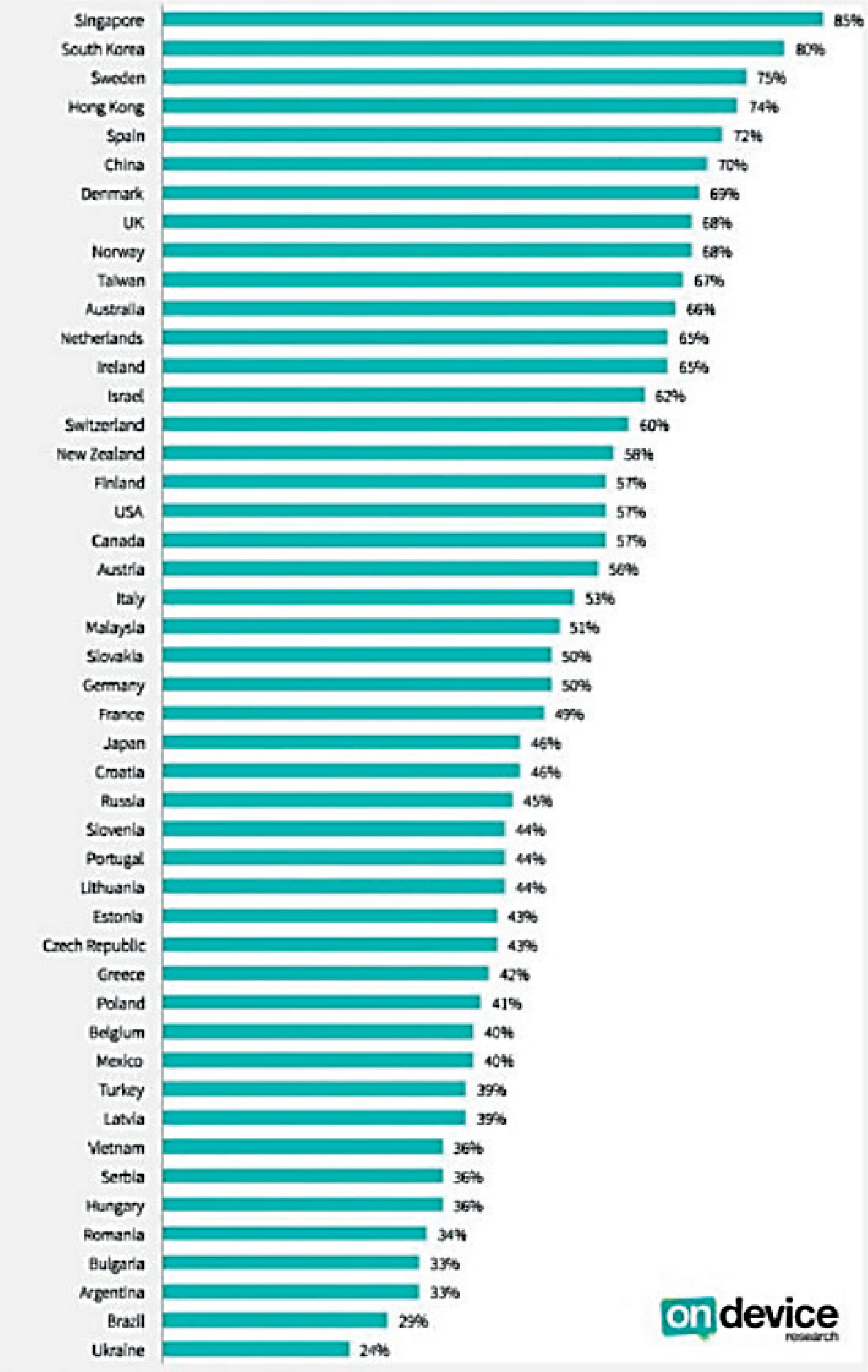
**Figure 9**. Digital healthcare: variety of concepts



*Source: Holanec. 2015*

The Internet and mobile technology have prompted a new generation of digital health interventions that leverage websites and mobile apps to promote positive health behaviour change (Figure 10). It is estimated that more than 40,000 mobile health apps are available for download on mobile electronic devices, with functions ranging from health education and self-diagnosis to medication reminders.

**Figure 10**. Global smartphone penetration



Source: Consumer Barometer, 2014

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## 5.4 PATIENT-DOCTOR INTERACTION

*Dagmar Breznoscakova*

*“Medicine is an art whose magic and creative ability have long been recognized as residing in the interpersonal aspects of patient-physician relationship.”*

### 5.4.1 Moving from paternalistic to participatory approach

#### The doctor-patient relationship

The doctor-patient relationship is always dependent on:

- **the medical situation**, in which the doctor’s and patient’s ability for self-reflection and communication as well as any technical skills are embodied; and
- **the social scene**, which refers to the socio-political and intellectual-scientific climate at the time (Kaba & Sooriakumaran, 2007).

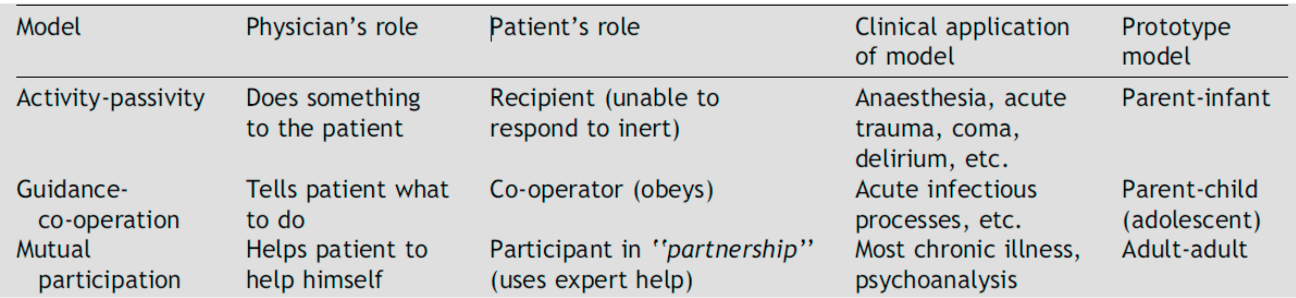
From historical perspective, in the past, patients were most often considered to be too ignorant to make decisions on their own behalf, and informing patients about the uncertainties and limitations of medical interventions served only to undermine the faith that was so essential to the therapeutic success. Later on, doctors became separated from their patients politically, economically, and socially and the distance between the doctor and patient widened. Today, there is a new alliance required between the doctor and patient, based on co-operation rather than confrontation.

Traditional **paternalistic (doctor-centred) approach** focuses on the disease and its management rather than the individual and his/her family and what they value as important. Paternalism is characterised by a concentration of decision-making power that gives little consideration to an individual’s preferences. In health care it means that medical practitioners instruct and prescribe treatments with limited input from patients and families, and the decisions reached are primarily based the opinions and preferences of medical professionals. This approach lacks parity between the doctor and patient and can compromise a patient’s rights to self-determination and autonomy, which are inevitable for the development of a therapeutic alliance based on respect for each individual’s competences, decision-making abilities and personal values and preferences (Delaney, 2018).

Source: Wilkins, 2015

In 1956, Szasz and Hollender presented three basic models of the doctor-patient relationship: activity-passivity, guidance-co-operation and mutual participation (Table 1). The first and second models are entirely paternalistic and thus predominantly doctor-centred. The third one has a greater emphasis on patient-centred medicine and is based on participatory approach (Kaba & Sooriakumaran, 2007).

Table 1. Three basic models of the doctor-patient relationship



| Model | Physician's role | Patient's role | Clinical application of model | Prototype model |
|---|---|---|---|---|
| Activity-passivity | Does something to the patient | Recipient (unable to respond to inert) | Anaesthesia, acute trauma, coma, delirium, etc. | Parent-infant |
| Guidance-co-operation | Tells patient what to do | Co-operator (obeys) | Acute infectious processes, etc. | Parent-child (adolescent) |
| Mutual participation | Helps patient to help himself | Participant in ''*partnership*'' (uses expert help) | Most chronic illness, psychoanalysis | Adult-adult |

*Source: Kaba & Sooriakumaran, 2007*

## Participatory (patient-centred) medicine

Today, patient-centred medicine can easily be confused with a narrowly defined personalised medicine, which means using the patient's unique genetic map or individual biomedical parameters to optimize treatment, i.e. a biomedical centred approach based on technology. However, **patient-centred (relationship-centred, client-centred) approaches** mean more than uncovering a correct biomedical diagnosis. They represent movement toward a relationship in which the clinician is: aware of and careful with his or her use of power; gives the patient space to articulate his or her concerns; and finds out about the patient's expectations.

Underlying the using of power, the way how the clinician handles the strong emotions is crucial. There is a **reactive clinical style**, in which the doctor reacts swiftly to expressions of hostility or distrust with denial or suppression. On the other hand, a **proactive clinical style** is characterized by a mindful openness to experience, that might lead the doctor to accept the patient's expressions with aplomb, using the negative feelings to strengthen the patient-doctor relationship. It is important to avoid the tendency to label patients as "those with whom I get along well" or "difficult patients." However, without a sufficient degree of self-understanding, it is easy for the physician to confuse empathy with the projection of his or her needs onto the patient (Borrell-Carrio et al., 2004).

As proposed by Mead and Bower (2000), the concept of **patient-centred medicine** can be described through the following five key dimensions:

» **Biopsychosocial perspective**

It is linked to the willingness to become involved in the full range of difficulties patients bring, not just their biomedical problems, to be open to the patient's "hidden agenda", to feel responsible for non-medical aspects of patients' problems.

» **Patient as person**

In order to understand illness and the patient's suffering doctors must first understand the personal meaning of illness for the patient, that can have many dimensions such as for example financial insecurity may make a patient reluctant to interpret symptoms as illness for fear of being labelled unfit to work. To develop a full understanding of the patient's presentation and provide effective disease management the doctor should strive to understand the patient as a distinctive personality within his or her unique context.

- **Sharing power and responsibility**

  It is related to much greater patient involvement in care, through recognition of patients' needs and preferences by using behaviours such as encouraging the patient to voice ideas, listening, reflecting, and offering collaboration.

- **Therapeutic alliance**

  It can be considered as the overall level of the personal relationship between doctor and patient. The core therapist attitudes needed for effecting therapeutic change in clients include empathy, congruence and unconditional positive regard. Furthermore, also the following aspects are important: (a) the patient's perception of the relevance and potency of interventions offered, (b) agreement over the goals of treatment, and (c) cognitive and affective components, such as the personal bond between doctor and patient. Thus, the likelihood of patient adherence to treatment can be increased by a friendly and sympathetic manner. Conversely negative emotional responses by either party (e.g. anger, resentment) may serve to complicate medical judgment (causing diagnostic error) or cause patients to default their treatment.

- **Coordinated care**

  It means "two-person medicine", whereby "the doctor and patient are influencing each other all the time and cannot be considered separately".

## Communication – a vital skill for participatory approach

A doctor-patient **communication and interpersonal skills** are the core clinical skill in building a therapeutic doctor-patient relationship, which is the **heart and art of medicine**. Much patient dissatisfaction and many complaints are due to breakdown in the doctor-patient relationship. However, many doctors tend to overestimate their ability in communication. Effective doctor-patient communication is determined by the doctors' "bedside manner," which patients judge as a major indicator of their doctors' general competence. Good doctor-patient communication has the potential to help regulate patients' emotions, facilitate comprehension of medical information, and allow for better identification of patients' needs, perceptions, and expectations. Patients reporting good communication with their doctor are more likely to be satisfied with their care, and especially to share pertinent information for accurate diagnosis of their problems, follow advice, and adhere to the prescribed treatment. Patients' agreement with the doctor about the nature of the treatment and need for follow-up is strongly associated with their recovery. Studies have reported correlations between a sense of control and the ability to tolerate pain, recovery from illness, decreased tumour growth, enhanced psychological adjustments and better mental health. Furthermore, satisfied patients are less likely to lodge formal complaints or initiate malpractice complaints, they are advantageous for doctors in terms of greater job satisfaction, less work-related stress, and reduced burnout (Ha et al., 2010).

### 5.4.2 Motivational Interviewing (MI)

Scientists have recently advocated for the study of processes that cut across diseases, a paradigm that fits nicely with the shared elements and factors approach to treatment (Norton 2012). By identifying shared elements and relational factors and applying them across different behaviours and symptoms (with specific adaptation for symptom clusters as necessary), promotes more widespread dissemination of evidence-based treatments and improve the ease of implementation and training. This approach can more easily address common comorbidities and address multiple behaviour change. "Transdiagnostic" or "unified" treatments are defined as those that apply the same underlying treatment principles across conditions or behaviours instead of delivering different specific treatments for different conditions (McEvoy et al. 2009). Instead, the protocols are individualized in the treatment planning process. The term "unified" has also been used to refer to unified treatment plans that address mental and physical health such as depression and medication adherence or obesity and substance use. General factors, sometimes called "common factors," refer to the personal, interpersonal, and other processes that are shared among all psychosocial treatments—for example, therapeutic alliance, empathy, and optimism. These account for much of treatment outcome beyond the specific treatment techniques. "Shared elements" refer to the components of evidence-based clinical practice that are common across distinct treatment protocols—for example, self-monitoring, cognitive restructuring, and refusal skills (Barth et al. 2012).

#### What is motivational interviewing?

**MI** is a collaborative, guiding conversational style used for strengthening a person's own (intrinsic) motivation and commitment for change. After over 30 years of empirical study, MI has proved to be a frontline, evidence-based, successful intervention approach for facilitating positive behavior change, and is increasingly utilized in the areas of substance abuse, mental health, and primary and specialty health care. MI specifies communication behaviors that underlie the relational factors of psychotherapy and thus provides a foundation for client–therapist/practitioner communication in multiple settings.

#### The spirit of MI

MI is not just a compendium of techniques; it is a style of interacting with people. As such, the foundation of MI is its spirit. According to Miller and Rollnick (2012), the MI spirit consists of **four interrelated elements**: *(1) Partnership, (2) Acceptance, (3) Compassion, and (4) Evocation (PACE).*

1. *Partnership* is a collaborative, guiding relationship with you and the client side by side instead of one in front of the other.
2. *Acceptance* involves autonomy support by which you emphasize respect for the person's self-determination and freedom of choice. Acceptance also includes expressing accurate empathy and supporting self-efficacy with an inherent appreciation for the person's worth and an affirming stance.
3. *Compassion* is a dedication to promoting the welfare of others, but is distinct from personal feelings of sympathy or personalization of the experience.
4. *Evocation* is the idea that the client has inherent wisdom and strength for change that you draw out instead of a missing ingredient that you must provide as in CBT approaches.

**MI as four processes**

In addition to the above-mentioned four elements, MI is organized in terms of **four processes**: *(1)*

*engaging, (2) focusing, (3) evoking, and (4) planning.* These elements are meant to be overlapping and not necessarily sequential. All four processes may be present in each session.

1. *Engaging* is the process of developing rapport with the client and understanding of the client's dilemma. Why is or isn't the person considering change and what is getting in the way? Engaging is the process of establishing the working relationship, the therapeutic alliance. While a strong working alliance is the foundation of any intervention approach and is consistently discussed in the CBT literature, the therapist communication behaviours necessary to promote alliance and address ruptures in alliance are rarely specified. MI specifies these behaviours.

2. *Focusing* is the process by which a practitioner and a client become clear on the direction and goal of the conversation. Often the direction and associated goals are about changing behaviors, but not necessarily so. The focus may be about a choice (e.g., forgiveness, a job change) or about an internal process (e.g., tolerance, acceptance). The process of focusing is more than agenda setting or treatment planning, with a list of goals or tasks. It is the collaborative process of determining the scope of the conversation, which can include goals and tasks as well as thoughts, feelings, and concerns.

3. *Evoking* is the process of drawing out the client's own words about change so that the client him- or herself argues for change instead of the practitioner doing it for the client. In the evoking process, you build intrinsic motivation to change the target behaviour/concern of focus. In MI, this is done by eliciting and verbally reinforcing change talk with the kind of reflections and affirmations described below. Change is driven by a person's own desire, ability, reasons, or need to change as opposed to those of somebody else. This is central to MI and particularly relevant for CBT. Typically, the provider often presents the rationale for treatment components, presents reasons for why particular skills or relevant homework is important, and/or tries to underscore the negative consequences of current thoughts and behaviours. Yet, most people are more likely to believe what they say themselves compared to what someone else tells them. Evocation may run counter to the natural instinct to "help" clients by correcting what you construe as flawed reasoning or poor decision making or by imparting unsolicited advice. Miller and Rollnick (2012) describe this phenomenon as the righting reflex, the human tendency to correct things that are perceived as wrong. This tendency often translates into premature problem solving and advice giving, which prevents clients from being actively involved in their own treatment process and leads to other forms of disengagement (e.g., emergence of language against change, avoidance of homework assignments). This is a dilemma for CBT practitioners because education about a mental health problem followed by skills training are typically the key elements of treatment. Motivation for change is a function of how important change is to the client and his or her confidence about making the change. MI skills address both of these components of motivation, and MI skills support the client's own motivation for change even when the provider is sharing relevant information or skills training.

4. If ambivalence is the balancing between change and the status quo, the *(4) planning* process occurs when the balance begins to tip toward

change. The conversation naturally turns to statements about a possible commitment to change and options for a plan of action. Miller and Rollnick (2012) subsume the process of implementing change plans and enacting and maintaining change (the targets of CBT elements) within the planning process.

### A brief overview of core MI skills

MI uses a set of core communication skills, in the spirit of MI, to promote the four processes described above. These skills are asking open questions, affirming, making reflective statements, summarizing, and informing and advising. Reflective statements and open questions are the core skills necessary for MI–CBT integration. Reflective statements are used to communicate accurate empathy and to test your hypotheses about how the client experiences the world. Offering reflections involves stating to the person what you heard, possibly adding an emphasis or meaning. Reflections are also used to reinforce or emphasize components of the conversation for strategic purposes (e.g. to explore ambivalence, to strengthen motivation). Reflective statements can also be affirming because they are reflections of what the person said that emphasize his or her strengths or efforts. You can also use a string of reflections to summarize what the client has said. The string can tie together earlier points, can emphasize the transition from ambivalence to change, and can be used to transition to different components of the session.

While a significant amount of communication can occur from reflective statements alone, open questions can continue to evoke the person's views, concerns, and motivations. In MI, you facilitate conversation with open-ended questions and deemphasize closed-ended questions that elicit a single-word response. Questions and reflections can also be used to provide information and advice in an MI style.

## 5.4.3 Integrating cognitive-behavioural therapy with motivational interviewing

MI was originally developed to build motivation for initial change; MI strategies for enacting and maintaining change have only recently begun to be specified. Miller and Rollnick (2012) note that once initial motivation for change has been established, it may be time to move to more action-oriented treatments such as cognitive-behaviour therapy (CBT). Thus, incorporating more action-oriented treatments may strengthen the behaviour changes that MI has helped to initiate. Yet motivation still fluctuates in strength and direction during enactment and maintenance of change, suggesting that integrating MI with CBT may create a more potent behavioural treatment than either set of strategies alone. Westra and Arkowitz (2011) discuss several ways in which MI can be combined with CBT.

1. MI may be delivered as a brief pre-treatment to build motivation for multisession intervention.
2. MI can be used at specific moments during CBT when client discord or ambivalence arises.
3. MI can serve as an integrative framework in which other interventions, such as CBT strategies, could be delivered.

### What is Cognitive Behavioural Therapy (CBT)?

Cognitive Behavioural Therapy (CBT) is one of the most used tools in the psychologist's or psychotherapeutic toolbox. It's based on a fairly simple idea which, when put into practice, can have wildly positive outcomes. Cognitive therapy (CT) and behavioural therapy (BT) are the most validated psychosocial treatments in psychiatry, with numerous RCTs and meta-analyses showing evidence for efficacy (Bee, 2008). CBT aims to change our thought patterns, the beliefs we may or may not know we hold, our attitudes, and ultimately our behavior in order to help us face our difficulties and more effectively strive towards our goals.

*The simple idea is that our unique patterns of thinking, feeling, and behaving are significant factors in our experiences, both good and bad. Since these patterns have such a significant impact on our experiences, it follows that altering these patterns can change our experiences (Martin, 2016).*

The founder of CBT is a psychiatrist Aaron Beck, a man who practiced psychoanalysis until he noticed the prevalence of internal dialogues in his clients, and realized how strong the link between thoughts and feelings can be. He altered the therapy he practiced in order to help his clients identify, understand, and deal with the automatic emotion-filled thoughts that arise throughout the day. Beck found that a combination of cognitive therapy and behavioural techniques produced the best results for his clients. In describing and honing this new therapy, Beck laid the foundations of the most popular and influential form of therapy of the last 50 years. This form of therapy is not designed for lifelong participation but focuses more on helping clients meet their goals in the near future. Most CBT treatment regimens last from five to ten months, with one 50 to 60-minute session per week. CBT is a hands-on approach that requires both the therapist and the client to be invested in the process and willing to actively participate. The therapist and client work together as a team to identify the problems the client is facing, come up with new strategies for addressing them, and thinking up positive solutions (Martin, 2016).

## Cognitive Distortions

Many of the most popular and effective CBT techniques are applied to what psychologists call "cognitive distortions" (Grohol, 2016). Cognitive distortions are faulty ways of thinking that convince us of a reality that is simply not true.

*Cognitive distortions: inaccurate thoughts that reinforce negative thought patterns or emotions.*

There are *15 main cognitive distortions* that can plague even the most balanced thinkers at times.

Many tools and techniques found in CBT are intended to address or reverse these cognitive distortions:

1. *Filtering*

   Filtering refers to the way many of us can somehow ignore all of the positive and good things in our day to focus solely on the negative. It can be far too easy to dwell on a single negative aspect, even when surrounded by an abundance of good things.

2. *Polarized Thinking / "Black and White" Thinking*

   This cognitive distortion is all about seeing black and white only, with no shades of grey. This is all-or-nothing thinking, with no room for complexity or nuance. If you don't perform perfectly in some area, then you may see yourself as a total failure instead of simply unskilled in one area.

3. *Overgeneralization*

Overgeneralization is taking a single incident or point in time and using it as the sole piece of evidence for a broad general conclusion. For example, a person may be on the lookout for a job but have a bad interview experience, but instead of brushing it off as one bad interview and trying again, they conclude that they are terrible at interviewing and will never get a job offer.

4. *Jumping to Conclusions*

   Similar to overgeneralization, this distortion involves faulty reasoning in how we make conclusions. Instead of overgeneralizing one incident, however, jumping to conclusions refers to the tendency to be sure of something without any evidence at all. We may be convinced that someone dislikes us with only the flimsiest of proof, or we may be convinced that our fears will come true before we have a chance to find out.

5. *Catastrophizing / Magnifying or Minimizing*

   This distortion involves expectations that the worst will happen or has happened, based on a slight incident that is nowhere near the tragedy that it is made out to be. For example, you may make a small mistake at work and be convinced that it will ruin the project you are working on, your boss will be furious, and you will lose your job. Alternatively, we may minimize the importance of positive things,  such as an accomplishment at work or a desirable personal characteristic.

6. *Personalization*

   This is a distortion where an individual believes that everything they do has an impact on external events or other people, no matter how irrational the link between. The person suffering from this distortion will feel that they have an unreasonably important role in the bad things that happen around them. For instance, a person may believe that the meeting they were a few minutes late in getting to was derailed because of them and that everything would have been fine if they were on time.

7. *Control Fallacies*

   Another distortion involves feeling that everything that happens to you is a result of external forces or due to your own actions. Sometimes what happens to us is due to forces we can't control, and sometimes what happens is due to our actions, but the false thinking is in assuming that it is always one or the other. We may assume that the quality of our work is due to working with difficult people, or alternatively that every mistake someone else makes is due to something we did.

8. *Fallacy of Fairness*

   We are often concerned about fairness, but this concern can be taken to extremes. As we know, life is not always fair. The person who goes through life looking for fairness in all their experiences will end up resentful and unhappy. Sometimes things will go our way, and sometimes they will not, regardless of how fair it may seem.

9. *Blaming*

   When things don't go our way, there are many ways we can explain or assign responsibility for the outcome. One method of assigning responsibility is blaming others for what goes wrong. Sometimes we may blame others for making us feel or act a certain way, but this is a cognitive distortion because we are the only ones responsible for the way we feel or act.

10. *Shoulds*

    "Shoulds" refer to the implicit or explicit rules we have about how we and others should behave. When others break our rules, we are upset. When we break our own rules, we feel guilty. For example, we may have an unofficial rule that customer service representatives should always be accommodating to the customer. When we interact with a customer service representative that is not immediately accommodating, we might get angry. If we have an implicit rule that we are irresponsible if we spend money on unnecessary things, we may feel exceedingly guilty when we spend even a small amount of money on something we don't need.

11. *Emotional Reasoning*

    This distortion involves thinking that if we feel a certain way, it must be true. For example, if we feel unattractive or uninteresting in the current moment, we must be unattractive or uninteresting. This cognitive distortion boils down to: *"I feel it, therefore it must be true."* Clearly, our emotions are not always indicative of the objective truth, but it can be difficult to look past how we feel.

12. *Fallacy of Change*

    The fallacy of change lies in expecting other people to change as it suits us. This ties into the feeling that our **happiness** depends on other people, and their unwillingness or inability to change, even if we push and press and demand it, keeps us from being happy. This is clearly a damaging way to think since no one is responsible for our happiness except for us.

13. *Global Labeling / Mislabeling*

    This cognitive distortion is an extreme form of generalizing, in which we generalize one or two instances or qualities into a global judgment. For example, if we fail at a specific task, we may conclude that we are a total failure in not only this area but all areas. Alternatively, when a stranger says something a bit rude, we may conclude that he or she is an unfriendly person in general. Mislabeling is specific to using exaggerated and emotionally loaded language, such as saying a woman has abandoned her children when she leaves her children with a babysitter to enjoy a night out.

14. *Always Being Right*

    While we all enjoy being right, this distortion makes us think we must be right, that being wrong is unacceptable. We may believe that being right is more important than the feelings of others, being able to admit when we've made a mistake or being fair and objective.

15. *Heaven's Reward Fallacy*

    This distortion involves expecting that any sacrifice or self-denial on our part will pay off. We may consider this karma, and expect that karma will always immediately reward us for our good deeds. Of course, this results in feelings of bitterness when we do not receive our reward (Grohol, 2016).

**Figure 1.** Faulty thinking: 15 cognitive distortions

**Filtering**
Focusing solely on the negative and ignoring all the positive.

**Polarized thinking**
Black and white thinking, not seeing the grey.

**Overgeneralization**
Assuming all experiences and people are the same, based on one negative experience.

**Jumping to conclusions**
Being convinced of something with little to no evidence to support it.

**Catastrophizing**
Asuming the worst case scenario, magnifying the negative and minimizing the positive.

**Personalization**
Believing that you are at least partially responsible for everything bad that happens around you.

**Control fallacies**
Thinking everything that happens to you is either all your fault or not at all your fault.

**Fallacy of fairness**
Being too concerned over wether everything is fair.

**Blaming**
Pointing to others when looking for a cause of any negative event, instead of looking at yourself.

**Shoulds**
Holding tight to your personal rules on how people ought to behave.

**Emotional reasoning**
Believing "If I feel it, it must be true!"

**Fallacy of change**
Expecting others to change to suit your needs or desires.

**Global labeling / mislabeling**
Generalizing one or two instances into an overall judgment, using exaggerated and emotionally loaded language.

**Always being right**
Believing that it is absolutely unacceptable to be wrong.

**Heavens' reward fallacy**
Believing that any good act on your part will be repaid or rewarded.

Source: freely taken from Ackerman 2017

## Eessential CBT techniques and tools

There are many tools and techniques used in CBT, many of which have spread from the therapy context to everyday life. The nine techniques and tools listed below are some of the most common and effective CBT practices:

1. *Journaling*

   This technique is a way of "gathering data" about our moods and our thoughts. This journal can include the time of the mood or thought, the source of it, the extent or intensity, and how we responded to it, among other factors. This technique can help us to identify our thought patterns and emotional tendencies, describe them and find out how to change, adapt, or cope with them.

2. *Unraveling Cognitive Distortions*

   This is a main goal of CBT and can be practiced with or without the help of a therapist. In order to unravel the cognitive distortions you hold, you must first become aware of which distortions you are most vulnerable to. Part of this involves identifying and challenging our harmful automatic thoughts, which frequently fall into one of the categories listed earlier.

3. *Cognitive Restructuring*

   Once you identify the distortions or inaccurate views on the world you hold, you can begin to learn about how this distortion took root and why you came to believe it. When you discover a belief that is destructive or harmful, you can begin to challenge it. For example, if you believe that you must have a high paying job to be a respectable person, but you lose your high paying job, you will begin to feel bad about yourself. Instead of accepting this faulty belief that leads you to think unreasonably negative thoughts about yourself, you could take this opportunity to think about what makes a person "respectable," a belief you may not have explicitly considered before.

4. *Exposure and Response Prevention*

   This technique is specifically effective for those who suffer from obsessive compulsive disorder (OCD). You can practice this technique by exposing yourself to whatever it is that normally elicits a compulsive behavior, but doing your best to refrain from the behavior and writing about it. You can combine journaling with this technique, or use journaling to understand how this technique makes you feel.

5. *Interoceptive Exposure*

   This technique is intended to treat panic and anxiety. It involves exposure to feared bodily sensations in order to elicit the response, activates any unhelpful beliefs associated with the sensations, maintains the sensations without distraction or avoidance, and allow new learning about the sensations to take place. It is intended to help the sufferer see that symptoms of panic are not dangerous, although they may be uncomfortable.

6. *Nightmare Exposure and Rescripting*

   Nightmare exposure and rescripting are intended specifically for those suffering from nightmares. This technique is similar to interoceptive exposure, in that the nightmare is elicited, which brings up the relevant emotion. Once the emotion has arisen, the client and therapist work together to identify the desired emotion and develop a new image to accompany the desired emotion.

7. *Play the Script Until the End*

   This technique is especially useful for those suffering from fear and anxiety. In this technique, the individual who is vulnerable to crippling fear or anxiety conducts a sort of thought experiment, where they imagine the outcome of the worst case scenario. Letting this scenario play out can help the individual to recognize that even if everything they fear comes to pass, it will likely turn out okay.

8. *Progressive Muscle Relaxation (PMR)*

   This is a familiar technique to those who practice mindfulness. Similar to the body scan, this technique instructs you to relax one muscle group at a time until your whole body is in a state of relaxation. You can use audio guidance, a YouTube video, or simply your own mind to practice this technique, and it can be especially helpful for calming nerves and soothing a busy and unfocused mind.

9. *Relaxed Breathing*

   This is another technique that is not specific to CBT but will be familiar to practitioners of mindfulness. There are many ways to relax and bring regularity to your breath, including guided and unguided imagery, audio recordings, YouTube videos, and scripts. Bringing regularity and calm to your breath will allow you to approach your problems from a place of balance, facilitating more effective and rational decision making (Megan, 2016).

These techniques can help those suffering from a range of mental illnesses and afflictions, including anxiety, depression, OCD, and panic disorder, and they can be practiced with or without the guidance of a therapist.

**Figure 2.** Nine essential CBT techniques and tools

**Journaling**
Gathering data about your moods, their source / intensity, and your responses to them.

**Unraveling cognitive distortions**
Become aware of the distortions you are likely to be vulnerable of.

**Cognitive restructuring**
Challenge your harmful or destructive beliefs and restructure them.

**Exposure and response prevention**
Expose yourself to whatever it is that normally provokes a compulsive behavior.

**Interoceptive exposure**
Exposure yourself to sensations you are afraid of and recognize they are not dangerous.

**Nightmare exposure and rescripting**
Identify the emotion caused by a nightmare and cultivate a new emotion to replace it.

**Play the script until the end**
Finish a worst case scenario in your head to see that everything will likely turn out okay.

**Progressive muscle relaxation**
Relax one muscle group at a time until your whole body is in a state of relaxation.

**Relaxed breathing**
Bring regularity and calm to your breath and create a sense of balance.

Source: freely taken from Ackerman 2017

## MI–CBT integration

Cognitive-behavioural therapy (CBT) focuses on changing maladaptive thoughts and behaviours that maintain symptoms and interfere with functioning. CBT approaches are some of the most widely disseminated evidence-based treatment elements and they share elements across many diagnoses such as depression, anxiety, substance abuse, attention-deficit/hyperactivity disorder (ADHD), and obesity (Tolin 2010). CBT is hard work for clients! It requires in-session practice and between-session "home- work," work that involves making changes in areas that have been difficult for clients to master in the past. This is why experts (Driessen & Hollon 2011) say that MI can make CBT work better by specifying strategies to build clients' own motivation to do the hard work, and thereby to help, as the therapist, avoid being the "bad guy" in this process. Although CBT has some of the strongest evidence for change in its favor (Hofmann et al. 2012), it is also true that many individuals do not respond to treatment, do not adhere to treatment tasks, discontinue treatment prematurely, or, after initial success, are unable to maintain change (Naar-King et al. 2013). Experts in both CBT and MI have suggested this may be at least in part because some CBT approaches do not specify the skills necessary to support the practitioner's/ therapist's relationship with the client and do not help practitioners strengthen motivation for change at both the onset and during the course of CBT (Miller & Moyer 2015). Thus, integrating MI with CBT may improve both initial response rates and maintenance of change after treatment is completed. MI can make CBT work better!

## MI–CBT integration card sort

Integration can take a number of different forms. Treatment integration involves looking beyond the boundaries of single-school approaches to see what can be learned from the theories and techniques of other perspectives (Strickler, 2011). Technical integration is when you integrate techniques from different approaches, while theoretical integration refers to the process of bringing together concepts from different approaches that may differ in fundamental ways. Assimilative integration is a more recent concept that allows you to maintain a solid grounding in one theoretical worldview while incorporating strategies from other approaches.

» ACTIVITY GOAL: This activity asks you to consider the theoretical and technical components of MI and CBT and decide the approach to integration that will work best for you as you utilize this guide.

» ACTIVITY INSTRUCTIONS: In the table below, place an X over the words you consider to be descriptors of MI, an O over those you consider to be descriptors of CBT, and an X and an O over those for MI–CBT. When you've finished, answer the questions that follow. This activity may also be done as a card sort: copy and cut out each box in the table. Sort MI-only descriptors into one pile, CBT-only descriptors into another pile, and MI–CBT descriptors into a third pile.

| | | | | |
|---|---|---|---|---|
| Collaborative | Providing feedback | Agenda setting | Problem solving | Therapeutic alliance |
| Evoking motivation | Asking permission | Exposure | Case formulation | Providing rationales |
| Triggers | Empathy | Goal oriented | Assessment | Autonomy |
| Psycho- education | Identifying triggers | Functional analysis | Identifying distorted cognitions | Eliciting feedback |

| | | | | |
|---|---|---|---|---|
| Reflective listening | Making plans for change | Skills training | Identifying antecedents and consequences | Personal growth and responsibility |
| Homework | Addressing discord | Treatment planning | Reinforcing change language | Eliciting the client's perspective |
| Menu of options | Guiding | Self-monitoring | Assessment | Outcome oriented |
| Increasing activities and mastery | Nonjudgmental | Hypothesis testing | Noticing positive emotions | Socratic questioning |

**Consider the following questions:**

1. Where are the natural overlaps between MI and CBT (boxes with X's and O's)

2. Where MI and CBT don't overlap, are these theoretical concepts or techniques and strategies?

3. Where can you creatively integrate the theoretical concepts?

4. If the concepts do not seem like they can be integrated, how might this affect your use of the strategies? This issue will be important later when you might need to make choices between MI and CBT strategies because integration does not seem feasible.

## From CBT to MI in clinical practice: Building alliance and motivation

What are the discussion facing the therapist integrating MI and CBT in the initial sessions? That is, where are MI and CBT potentially at odds here? In MI is continuing with building motivation and potentially postpone planning and action if the client is not yet "ready." However, ambivalence may not fully resolve before engaging in CBT. It's recommended to spend more than a session or two on building motivation before a client is ready to move to the next steps, at some point you need to suggest moving on to the next steps in CBT. If the ambivalence is severe, the client may need to return to treatment at a later date. During subsequent CBT sessions, when ambivalence interferes with progress, is important continue to engage, focus, and evoke motivation for changing target behaviours and attending sessions.

### *Sequences: Eliciting and Reinforcing Change Talk for Session Attendance*

As was described above, "change talk" refers to language about desire, ability, reasons, need, and commitment for changing the target behaviour and attending sessions. It's necessary elicit change talk with targeted open questions, reinforce change talk with reflections and asking for elaboration if reflections aren't enough to continue the conversation. Thus, when listening to MI-based conversations, is important hear sequences like this: (1) therapist question; (2) client change talk; and (3) therapist reinforcement with reflection and possibly a follow-up question.

ACTIVITY GOAL: This activity promotes the recognition of these sequences and practice of practitioner strategies to elicit and reinforce change talk.

## CBT-MI: Evaluation and treatment planning

An ongoing dilemma is how to proceed if ambivalence is still present. This problem might be most obvious when the client does not commit to the treatment plan, but it can also be noticed throughout the other processes with sustain talk and discord. It's possible to choose continuation with MI-only following the previous guidelines, or to might decide to forge ahead with CBT and see what happens. That can be there some ambivalence about change, but that CBT should proceed if you can get some agreement on a treatment plan. An option is to see if the client will commit to trying just one or two treatment strategies (e.g., self-monitoring, physical activity) before deciding to commit to the whole plan. Sometimes a time limit will help the client to commit, trying one intervention strategy for a few weeks before deciding to continue. If the client absolutely refuses to engage in CBT, exist some experiences that a few MI sessions can tip the scale of ambivalence in favor of change, but most studies of MI by itself have not included more than a few sessions (Lundahl & Burke, 2009). Thus, recommendation is an approach from motivational enhancement therapy (Miller, Zweben, & DiClemente, 1994), where is option to see the client for a few initial motivational sessions and then follow-up in a month and see if the client is ready to engage in CBT or would prefer to continue on his or her own. An ongoing dilemma is how to proceed if ambivalence is still present. This problem might be most obvious when the client does not commit to the treatment plan, but it can also be noticed throughout the other processes with sustain talk and discord. You might choose to continue with MI-only following the guidelines in the previous chapter, or you might decide to forge ahead with CBT and see what happens. We believe that there is always some ambivalence about change, but that CBT should proceed if you can get some agreement on a treatment plan. An option is to see if the client will commit to trying just one or two treatment strategies (e.g., self-monitoring, physical activity) before deciding to commit to the whole plan. Sometimes a time limit will help the client to commit, trying one intervention strategy for a few weeks before deciding to continue. If the client absolutely refuses to engage in CBT, we believe that a few MI sessions can tip the scale of ambivalence in favor of change, but most studies of MI by itself have not included more than a few sessions (Lundahl & Burke, 2009). Thus, we recommend an approach from motivational enhancement therapy (Miller, Zweben, & DiClemente, 1994), where you see the client for a few initial motivational sessions and then follow-up in a month and see if the client is ready to engage in CBT or would prefer to continue on his or her own.

Another dilemma occurs when the client's preferences for the treatment plan run counter to what is known of the evidence. Sometimes the client's ideas can simply be added to the plan, for example, if the client believes that nutritional supplements will help with depression. Other times the client's goal clearly contradicts the evidence. For example, the client prefers a goal of alcohol moderation, but the evidence suggests that an abstinence approach would be more likely to succeed. Between therapist and the client can consider the client's choice of goal as a hypothesis, and both will gather evidence to see if the plan is effective over a set time frame (long enough to test the hypothesis but not so long as to result in treatment failure). Is possible to consider other options if desired outcomes are not achieved. If the client's preference is contraindicated (e.g., "I only want to take my HIV medications every other day"), then ethically is necessary provide this information and cannot follow this approach.

Finally, is possible come across a client who refuses to consider homework. Good idea is try to elicit the rationale for homework and the client's ideas for homework that seem relevant, palatable, and feasible. CBT approaches stress the idea that much of the progress occurs between sessions, and that homework is the vehicle for that progress. If the client absolutely refuses to do homework, and therapist believes that CBT cannot proceed without homework, is needed explain that you cannot do CBT until the client is ready for homework and move on to the motivational enhancement therapy approach described above. Alternatively, is possible decide to provide some components of CBT, explaining that they may not work as efficiently without homework but therapist is certainly willing to work with the client and try. There is no right answer here. Is general faith that any treatment is better than no treatment at all as long as therapist doesn't undermine the client's belief in the treatment's efficacy because outcomes may not be strong without all treatment components.

### *Functional Assessment Three Ways*

Traditional functional assessment follows a question-and-answer interview format. Two alternatives maintain MI spirit and skills and build motivation for the treatment plan. One way is to follow each open question with a reflection, and summarize after every three questions. Even better is reflecting the information have already obtained in previous conversations and integrating them into a functional assessment using pauses and open questions to guide the client to elaborate.

ACTIVITY GOAL: In this activity is practised how to complete a functional assessment in an CBT-MI integrated approach.

### CBT-MI: Self-Monitoring

The question is how to manage when the client is not ready to engage in self- monitoring and general faith it is a critical ingredient for successful treatment. There are some choices. It's possible inform the client that self-monitoring is necessary for the CBT and that if the client is not ready to complete the task, then he or she may not be ready for CBT. Alternative option is decide to provide MI–CBT without self-monitoring, perhaps asking the client to revisit the idea if progress is not sufficient. Finally, is possible may try to negotiate alternatives to full monitoring such as brief yes-or-no checklists, a call or text check-in during the week to elicit target information, or a recall interview at the beginning of the next session.

*The Experience of Self-Monitoring*

Self-monitoring in some form appears to be an important ingredient for successful CBT, but it isn't easy! Common complaints include lack of time, forgetting, lack of privacy, and simply not wanting to deal with target concerns on a regular basis as required for monitoring. MI skills can help to build the client's intrinsic motivation for self-monitoring assignments.

ACTIVITY GOAL: In this activity are observed own self-monitoring so that you can experience and understand how your clients might feel. Is possible experience the links between motivation (importance and confidence) and completion of monitoring assignments.

*Sequences: Eliciting and Reinforcing Change Talk for Self-Monitoring*

ACTIVITY GOAL: In this activity is developing evoking questions to elicit change talk specifically for self-monitoring with developing a reflection to reinforce the change talk.

### CBT-MI: Cognitive skills

To help a client to manage thoughts adaptively, treatment focuses on "cognitive restructuring," a term referring to the range of strategies that help the client recognize, challenge, and modify unhelpful thoughts and beliefs. The components of cognitive restructuring include (1) education regarding the links between situations, thoughts, behaviors, and emotions (engaging the client in the intervention); (2) identification and categorization of negative thoughts (focus- ing on the thoughts most relevant for the client); (3) exploration and challenging of those negative thoughts through Socratic dialogue and hypothesis testing (a process of questioning and probing to stimulate critical thinking); and (4) develop- ing between-session plans to continue the restructuring process in the real world (planning for restructuring). Thus, it necessary refer to Step 1 in the engagement process, Step 2 in the focusing process, Step 3 in the evoking process, and Step 4 in the planning process (as below).

*Cognitive Restructuring: Four Steps*

1. *Engaging:* Education regarding the links between situations, thoughts, behaviours, and emotions (engaging in the intervention). *Sample applications:* a/ set the agenda, b/ discuss rationales, c/ return to the engaging process as needed when working on challenging thoughts and beliefs, or sustain talk and discord.
2. *Focusing:* Identification and categorization of negative thoughts (focusing on the thoughts most relevant for the client). *Sample applications:* a/ ask permission to assist the client with identifying automatic thoughts

and core beliefs (guide the client in use of visualization, role-play the situation, elicit the meaning of the situation from the client, offer a menu of options - helpful/unhelpful thoughts), b/ avoid the expert trap by emphasizing autonomy (elicit client ideas and observations on potential thinking patterns, collaboratively name the patterns)

3. *Evoking:* Exploration and challenging of those thoughts through Socratic dialogue and hypothesis testing (a process of questioning and probing to stimulate critical thinking). *Sample applications:* a/ use Socratic questioning collaboratively for the purpose of guided discovery (listen, summarize, and ask synthesizing or analytical questions), b/ use open questions, reflective listening, summarizing, and asking a key question, c/ evoke importance and confidence during cognitive restructuring work (use open questions, rulers, reflections, and affirmations of strengths)
4. *Planning:* Development of between-session plans to continue the restructuring process in the real world (planning for restructuring). *Sample applications:* 1/ move from whether and why to change thinking to *how* to change thinking (recall that this is not necessarily separated from the other processes, 2/ guide the client in: a/ Making a plan for change (evaluate between-session thoughts, develop alternative thoughts, develop self-statements) b/ Focusing on between-session activities (conduct behavioral experiments to test thoughts, practice graduated exposure—mutually agree on steps to take to face the avoided or feared situations, assist the client with planning for different outcomes of the plan for change. c/ Consolidating commitment to the plan (develop action steps including implementation intentions, identify potential barriers to implementation, generate solutions to potential barriers, elicit commitment language, assist in generating a rationale response/coping statement to be used during difficult situations).

*Cognitive restructuring*

As in self-monitoring, the key discussion when guiding a client in cognitive restructuring is how to manage when the client is not ready to engage in cognitive restructuring and is faith for a critical ingredient for successful treatment. Again, exist some choices - to inform the client that cognitive restructuring is necessary for the CBT you provide and that if the client is not ready to complete the task, then he or she may not be ready for CBT. Alternatively, is possible decide to provide CBT-MI without cognitive restructuring, perhaps asking the client to revisit the idea if progress is not sufficient. Finally, providing a menu of options including cognitive restructuring but also other options such as mindfulness, acceptance, and commitment therapy strategies, and problem-solving approaches.

Another question concerns traditional CBT's view of automatic thoughts as one level of cognitions with beliefs, particularly core beliefs, at a deeper level that requires restructuring. Schema therapy is an example of an approach that addresses deeply held beliefs and patterns of thought (Farrell, Reiss, & Shaw, 2014). In CBT-MI, if symptoms begin to resolve by evaluating and replacing automatic thoughts and patterns of thoughts, it may not be necessary to dig down to uncover core beliefs. Furthermore, if core beliefs are tied to core values, is possible encounter significant difficulty (sustain talk and discord) by addressing core beliefs. Is possible continue to address core beliefs or you can move onto other strategies to guide the client to resolve concerns. This is a dilemma if is considering a core element of CBT to be practice within as well as between sessions. Is recommended exploring ambivalence around practicing including eliciting the rationale, but supporting the client's autonomy to not practice and consider practicing the next session if the client struggles during the week.

*Open-Ended Socratic Questions*

Socratic questions guide the client to evaluate his or her own thoughts. In CBT- MI, the spirit should be collaborative and exploratory versus expert renovation. Is important open-ended versus closed-ended questions promotes this spirit.

ACTIVITY GOAL: In this activity is integrated MI and CBT by converting Socratic questions that are closed-ended into open-ended questions to guide cognitive change. *Example:* Closed ended- Could you put that another way? Open ended- How would you put that another way?

## CBT-MI: Behavioural and emotion regulation skills

The dilemmas here are quite similar to those when integrating MI with cognitive skills; however, they may be even more challenging because skills involve actively doing something different versus just thinking differently. If this way isn't successful, the client needs to decide whether he or she is ready to change or would rather take some time to think about changing. Can exist a menu of options for other skills that may address the target concern, being clear that while prefers a second choice, the client's preference is your priority. For example, the client may choose to address distress with mindfulness though seems exposure is more beneficial. Of course, is possible ask the client to revisit the skill in the future if progress is not sufficient.

Another dilemma might occur when a client is unwilling to do between-session practice (i. e., homework) or consistently does not do it. Choices include reviewing the ratio- nale and utilizing MI strategies to address motivation for between-session practice; engaging the client to practice in the session and prepare for slower progress without between-session practice; or ultimately deciding that CBT cannot work without this practice and refer the client elsewhere. An exploration of the lack of progress and helping clients understand the links between limited practice and limited outcomes may increase motivation for between-session practice over time. Again, is possible consider a different, or less difficult, skill that the client is ready to practice between sessions. Specifically, using self-monitoring, clients can be encouraged to take smaller steps, to monitor how they feel after taking these smaller steps, and to determine what the outcomes are after the steps. This process will help the client make an informed decision about whether or not to use the skills.

*Chunk Check Chunk*

Skills-building sessions typically include the provision of a lot of information. Rosengren (2009) suggests the chunk–check–chunk strategy to ensure that the client do not overwhelm information with continue to maintain the spirit of MI throughout the interaction, particularly evocation. It's important to provide the information in small chunks, if possible, two to three sentences at a time, and then check with the client for his or her reactions ubefore providing another chunk.

ACTIVITY GOAL: In this activity, it works with skills-related information and break it into chunks as deliver it to a client, using the chunk–check–chunk strategy. In this way, begins to translate CBT into CBT-MI integration. Chunk–Check–Chunk.

## CBT-MI:  Session practice and session attendance

In his seminal report on mental health, the Surgeon General (1999) declared that preventing a problem from occurring is inherently better than having to treat the problem. By using MI skills to demonstrate the MI spirit of partnership, acceptance, compassion, and evocation, is more probable likely to prevent noncompliance with treatment tasks and poor session attendance. Although not every session will include every MI process, take time to discuss the rationale for treatment tasks and evoke change talk in every session. If the client is not ready to engage in activities between sessions, is always a choice to make - to inform the client that practice is necessary for the CBT, and perhaps the client is not ready for CBT at this time. It's possible to decide provide treatment without assignments but with risk that progress may be slower. After is needed revisit the idea of between-session activities at a later point in treatment. In terms of session attendance, ultimately it is the client's decision whether or not to participate in treatment. The important is hope that the client will manage without treatment and emphasize personal choice and responsibility and increase the likelihood that clients will return to the treatment when they are ready for it.

*Sequences: Eliciting and Reinforcing Change Talk for Between-Session Practice*

ACTIVITY GOAL: In this activity is practice developing evoking questions to elicit change talk specifically for between-session practice. After is following develop a reflection to reinforce the change talk.

## CBT-MI:  Maintenance

A key question is when to move on to the maintenance phase. In CBT-MI, isn't choosing—rather, it is a collaborative decision. Is it time for termination when objectives been met? When symptoms have completely remitted? When abstinence has been achieved for a period of time? When the client is no longer engaged in the target behavior? What happens if the client wants to prepare for termination, but therapist has different opion? What happens when therapist thinks that the client is ready for maintenance and termination but the client does not? Don't exist right answers as the decision is between therapist and client. Using ATA /Advanced Training Analyst/, is important influent elicit clients' perceptions, provide own perspective, and then elicit their response. Ultimately, that it is the client's decision. The therapist and client may disagree about whether treatment is close to termination, but completion of treat- ment objectives to the client's satisfaction may be a good indicator that it is time to move into the maintenance phase. Similar to previous discussion of dilemmas, if seems the client is not ready, is important building the alliance so that advice of therapist can be considered in the future if the client is still struggling.

*Eliciting and Reinforcing Change Talk about Maintenance*

Change talk in the earlier phases of treatment may address desire, ability, reasons, need, and commitment toward making initial changes or behaviour change in general. Change talk about maintenance is specifically about maintaining changes—for example: "It is important for me to stay healthy because I like having energy"; "I like the way I am feeling since I started exercising and I want it to stay that way." Change talk about maintenance may also include desire, ability, reasons, needs, and commitment to the maintenance phase of treatment—*for example:* "I know I need a few more sessions because I want to make sure I don't slip back." To elicit change talk about maintenance, the language what is used must be specific to maintenance, both in terms of the strategies to elicit change talk and the skills to reinforce change talk.

ACTIVITY GOAL: In this activity is practiced how to elicit and reinforce change talk about maintenance. Each statement below is designed to elicit change talk or to reinforce change talk with reflections or open questions. Some words to consider are "maintain," "continue," "stay," "keep up," "keep it going," "remain," "preserve," and "persist." *Examples:* 1. What are some of the reasons why you want to stop drinking? Open questions to elicit change talk: What are some of the reasons why you want to continue to cut back on your drinking? 2. So you would like to exercise to have more energy. Reflection to reinforce change talk: So you would like to continue to exercise to have more energy.

## CBT-MI in clinical practice: Application in some mental disorders

### *Generalized Anxiety Disorder (GAD)*

MI with CBT may lead to greater improvement in long-term treatment outcomes for patients with generalized anxiety disorder (GAD) compared with CBT alone, according to research published in the Journal of Consulting and Clinical Psychology. Although CBT has shown efficacy in treating anxiety disorders, a review of 25 studies found that only 46% of patients with GAD demonstrated significant improvement after CBT.

Recent studies have explored various adaptations to CBT with the aim of improving response rates. A complementary and alternative way of adapting traditional CBT for GAD stems from considerations that client ambivalence about change may limit response rates to established CBT approaches (Westra et al, 2016). Findings from previous research "underscore the need for flexible intervention in response to readiness for change." While preliminary findings on the combination of CBT and MI for anxiety have been promising, well-controlled trials are lacking. A group of 43 patients underwent 15 weekly sessions of CBT, while another group of 42 patients underwent 4 sessions of MI followed by 11 sessions of CBT combined with MI to address resistance or ambivalence. Most of the participants were white women who had high rates of comorbidity. In the 4 initial MI sessions, therapists did not push for change but explored participants' feelings and any ambivalence they might have about reducing their worry. During the MI-CBT phase, therapists supported patients in exploring ambivalence and resistance as these topics arose in session.

While the results show no differences between groups in terms of pre- and post-treatment outcomes, between-group differences were observed at the 6-month and 12-month follow-up points. The MI-CBT group reported greater reductions in worry and general distress compared with the CBT-only group. The MI-CBT group was also 5 times as likely to no longer meet diagnostic criteria for GAD compared with the CBT-only group, and twice as many CBT-only participants dropped out of treatment compared with MI-CBT participants (23% vs 10%). Although "CBT-alone clients generally retained their gains, MI-CBT clients continued to improve after treatment ended," the researchers reported. These results align with previous findings regarding long-term effects of MI.

While further trials could help identify the treatment components of MI that are linked with ongoing improvement, "it may be that having the opportunity to openly explore and resolve one's ambivalence about change as it arises during treatment may confer greater resilience to relapse after treatment ends," the researchers wrote. Additionally, the

"MI spirit" that advocates an empathetic, collaborative, "client-as-expert" approach may be particularly beneficial post-treatment by helping patients develop autonomy and self-trust to encourage maintenance of their treatment gains.

### *Comorbid depression and alcohol use disorders*

Alcohol use disorder is frequently comorbid with major depressive disorder, and the disease burden associated with this dual diagnosis is considerably greater than that attributed to each disorder in isolation. This creates a problem for clinicians who are trying to treat depressed problem drinkers, because many services are set up to deal with only one of these disorders. Furthermore, comorbidity may not be immediately apparent. For example, a client may present to treatment services with depression, but further investigation will reveal an undiagnosed alcohol use disorder.

CBT and MI are effective for both disorders. Until recently, the effectiveness of these treatments for comorbid alcohol use disorders and major depressive disorder had not been studied. However, some controlled trials have emerged in recent years. For example, one study evaluated a treatment intervention made up of components of the CBT course 'Coping with Depression', together with cognitive-behavioural alcohol coping skills training.

Methods: The meta-analysis considered data from 1,721 participants in total from 15 trials, which meant that the overall meta-analysis was powered to detect a small effect size, allowing for moderate heterogeneity between studies. Ten of the 15 studies applied CBT / MI that was designed to treat alcohol use disorders and depression together, four were CBT trials targeted only at depression, and one study applied CBT for alcohol problems only. Most of the studies compared CBT/ MI to treatment as usual which was usually psychological counselling and / or medication. This is a real strength of this study: we know from previous trials of CBT that comparison with no treatment tends to yield very large effect sizes, whereas comparison with alternative forms of psychological therapy often yields small effect sizes that are frequently not statistically significant. For example, in the substance misuse field, CBT often comes out as no better but no worse than alternative psychological therapies. Authors computed effect sizes for both alcohol use and depression, as well as the Number Needed to Treat (NNT).

Results: Compared to alternative forms of psychological therapy, CBT / MI led to small but significant reductions in symptoms of depression ($g = 0.27$, 95% CI = 0.13 to 0.41, $p < .001$; NNT = 6.58). CBT / MI also produced small but statistically significant effects on alcohol consumption in comparison to alternative forms of psychological therapy ($g = 0.17$, 95% CI = 0.07 to 0.28, $p < .001$, NNT = 10.42). Both analyses were highly powered and between-study variance was small. For both outcomes, it made no difference when the analysis was repeated using only one comparison per study, which reduced the total number of comparisons to 12. Subgroup analyses revealed that digital CBT / MI was more effective than face-to-face treatment for symptoms of depression. The number of sessions was negatively associated with the effect size for alcohol consumption, i.e. more sessions were less effective than fewer ($\beta = -0.016$, $p < .01$), but this relationship not seen for depression. Meta-regression revealed that a higher effect size for alcohol consumption was associated with a higher effect size for depression ($\beta = 0.511$, 95% CI = −0.04 to 0.99, $P = 0.003$). Importantly, the reverse relationship was not significant. This means that the effect of treatment on alcohol consumption predicted reductions in depression, but reductions in depression did not predict reductions in alcohol consumption. Seven studies (8 comparisons) included a follow-up at 6-12 months after end of treatment. The effect size for depression was similar to that seen at the end of treatment (g = 0.26, 95%, CI = –0.01 to 0.54, and the difference only approached significance (p = 0.063). For alcohol consumption at follow-up (8 studies and 9 comparisons), the effect of CBT / MI was actually much bigger compared to the effect immediately after the end of treatment (g = 0.31, 95% CI = 0.16 to 0.47, p < .001). There was no publication bias for depression outcomes, but a small publication bias for alcohol outcomes (adjustment for) which reduced the effect size from g = 0.17 to g = 0.14.

Discussion: Compared to other psychological therapies, CBT and / or MI for comorbid alcohol use disorder and major depressive disorder produced small but robust beneficial effects on both depression and alcohol consumption. The effect size for alcohol consumption tended to increase between the end of treatment and follow-up, which may reflect a 'sleeper effect' as participants continued to practice the coping skills needed to resist alcohol consumption even after the end of treatment. A previous meta-analysis (Nunes & Levin, 2004) revealed that antidepressants could also be effective for the treatment of comorbid substance use disorders and depression. That analysis suggested that effect sizes for depression and alcohol outcomes were larger after antidepressants compared to those reported here (NNTs for depression were 4.72 vs. 6.58 in the present study, and for alcohol use they were 7.14 vs. 10.42 in the present study). Findings from the two meta-analyses are informative regarding the psychological processes that underlie comorbidity and the mechanism of action of different types of treatment. In this paper, meta-regression revealed that the effect of treatment on alcohol consumption predicted reductions in depression. In other words, if clients can reduce their drinking, their mood may start to improve. By contrast, the Nunes & Levin (2004) meta-analysis of antidepressant effectiveness revealed that improvements in negative mood as a result of medication were associated with improved substance use outcomes. In other words, clients who receive antidepressants should experience an improvement in mood and if they do, they may start to drink less alcohol soon afterwards.

While it is tempting to speculate that antidepressants and psychological interventions may work through different mechanisms, there really isn't enough data to say this with any confidence. In addition to conducting more trials, Riper et al suggest that future meta-analyses could use patient-level data to investigate the temporal sequence of changes in mood and alcohol consumption during and after therapy.

Limitations: The studies included in the meta-analysis tested outpatients only, so it remains to be seen if CBT / MI would be equally effective for inpatients, who would probably have more severe depression and drinking problems.

Clinical implications: Treatment of comorbid alcohol use disorder and major depressive disorder with CBT / MI seems to produce beneficial effects on both outcomes. Clinicians don't need to identify a 'primary' diagnosis and treat that in the hope that the other will resolve; both can be treated at once.

### 5.4.4 Ethical issues

For physicians in clinical practice, the individual patient has the highest priority. This fiduciary responsibility is the basis of medical ethics, creating a bond of trust between medical professional and patient.

**Medical ethics** involves examining a specific problem, usually a clinical case, and using values, facts, and logic to decide what the best course of action should be. Some ethical problems are fairly straightforward, such as determining right from wrong. But others can also be more perplexing, such as deciding between two "rights" - two values that are in conflict with each other - or deciding between two different value systems, such as the patient's versus the doctor's. Doctors may deal with a great variety of perplexing ethical problems even in a small medical practice.

Here are some common problems identified in a 2016 Medscape survey:

- *Withholding treatment to meet an organization's budget, or because of insurance policies;*
- *Accepting money from pharmaceutical or device manufacturers;*
- *Up-coding to get treatment covered;*
- *Getting romantically involved with a patient or family member;*
- *Covering up a mistake;*
- *Reporting an impaired colleague;*
- *Cherry-picking patients;*
- *Prescribing a placebo;*
- *Practicing defensive medicine to avoid malpractice lawsuits;*
- *Dropping insurers; and*
- *Breaching patient confidentiality owing to a health risk.*

Many professional ethicists recommend using four basic values, or principles, to decide ethical issues:

- **Autonomy**
  Patients basically have the right to determine their own healthcare.
- **Justice**
  Distributing the benefits and burdens of care across society.
- **Beneficence**
  Doing good for the patient.
- **Non-malfeasance**
  Making sure you are not harming the patient.

However, ethical values are not limited to just these four principles. There are other important values to consider, such as truth-telling, transparency, showing respect for patients and families, and showing respect for patients' own values. In addition, medical ethics is not just a thought process. It also involves people skills, such as gathering the facts needed to make a decision and presenting your decision in a way that wins over the confidence of all parties.

**Professional standards** are a way to provide some guidance on ethical problems, but they cannot address every issue, and they may not address troubling nuances, such as reconciling two conflicting values. Also the documents such as **code of medical ethics** and **patients' rights** offer some regulation on ethical related decisions. These are mostly elaborated at country level and implemented based on the national legislation.

## Code of medical ethics and patients' rights

The World Medical Association has been adopted the International Code of Medical Ethics in 1949. The code recognizes duties of physicians: in general, to patients, and to colleagues (Table 1). Since 2005, Medical Ethics Manual has been distributed to medical journals and medical schools throughout the world and is translated into several languages (WMA, 2015). Formalized in 1948, the Universal Declaration of Human Rights recognizes "the inherent dignity" and the "equal and unalienable rights of all members of the human family". And it is on the basis of this concept of the person, and the fundamental dignity and equality of all human beings, that the notion of patient rights was developed. In other words, what is owed to the patient as a human being, by physicians and by the state, took shape in large part thanks to this understanding of the basic rights of the person.

Patients' rights vary in different countries and in different jurisdictions, often depending upon prevailing cultural and social norms. Different models of the patient-physician relationship - which can also represent the citizen-state relationship - have been developed, and these have informed the particular rights to which patients are entitled. Assuring that the rights of patients are protected requires more than educating policy makers and health providers; it requires educating citizens about what they should expect from their governments and their health care providers - about the kind of treatment and respect they are owed. Citizens, then, can have an important part to play in elevating the standard of care when their own expectations of that care are raised (https://www.who.int/genomics/public/patientrights/en/).

**Table 1**. The International Code of Medical Ethics

Source: WMA. 2018. https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/

**DUTIES OF PHYSICIANS IN GENERAL**

A PHYSICIAN SHALL:

- always exercise his/her independent professional judgment and maintain the highest standards of professional conduct.
- respect a competent patient's right to accept or refuse treatment.
- not allow his/her judgment to be influenced by personal profit or unfair discrimination.
- be dedicated to providing competent medical service in full professional and moral independence, with compassion and respect for human dignity.
- deal honestly with patients and colleagues, and report to the appropriate authorities those physicians who practice unethically or incompetently or who engage in fraud or deception.
- not receive any financial benefits or other incentives solely for referring patients or prescribing specific products.
- respect the rights and preferences of patients, colleagues, and other health professionals.
- recognize his/her important role in educating the public but should use due caution in divulging discoveries or new techniques or treatment through non-professional channels.
- certify only that which he/she has personally verified.
- strive to use health care resources in the best way to benefit patients and their community.
- seek appropriate care and attention if he/she suffers from mental or physical illness.
- respect the local and national codes of ethics.

**DUTIES OF PHYSICIANS TO PATIENTS**

A PHYSICIAN SHALL:

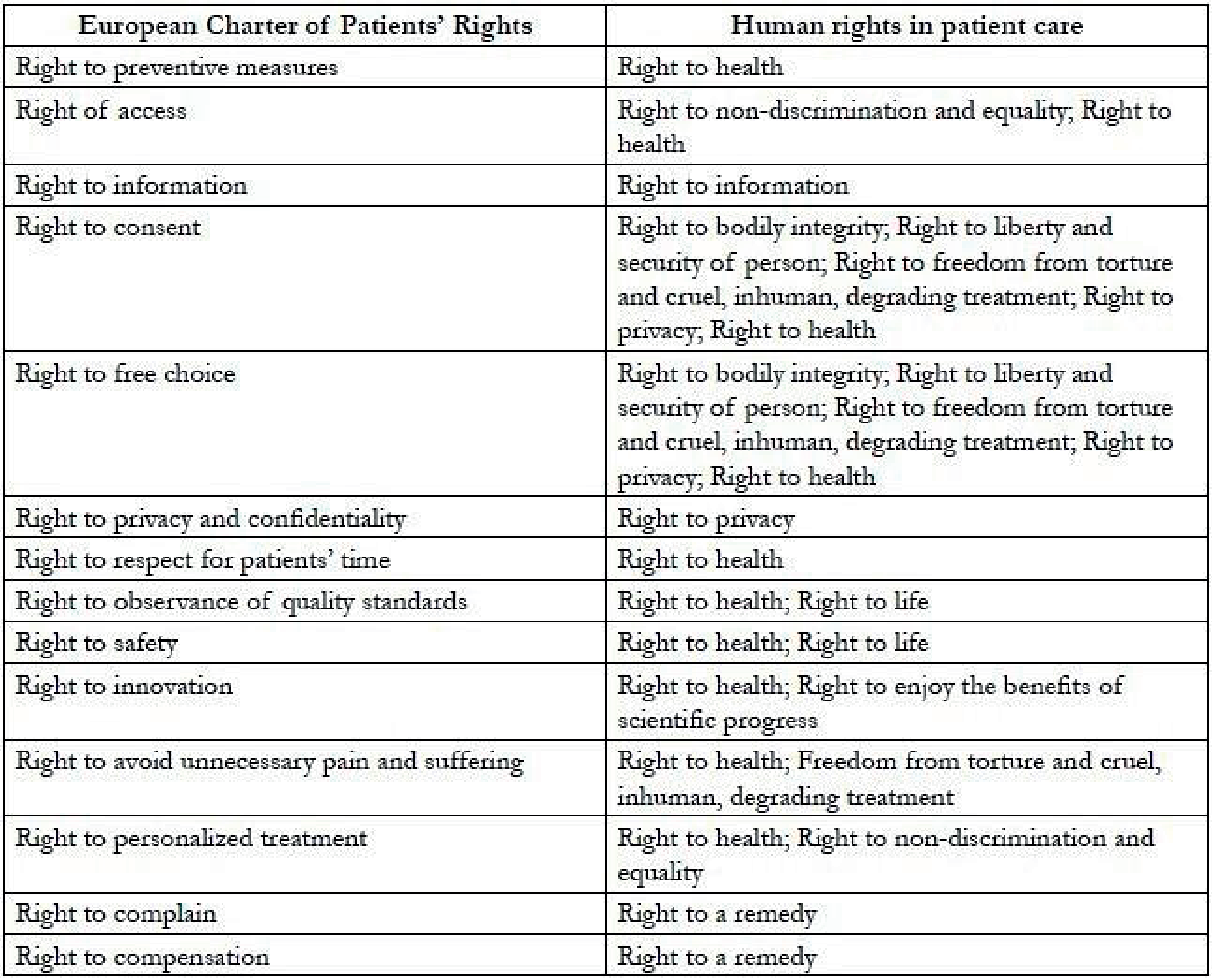
- always bear in mind the obligation to respect human life.
- act in the patient's best interest when providing medical care.
- owe his/her patients complete loyalty and all the scientific resources available to him/her. Whenever an examination or treatment is beyond the physician's capacity, he/she should consult with or refer to another physician who has the necessary ability.
- respect a patient's right to confidentiality. It is ethical to disclose confidential information when the patient consents to it or when there is a real and imminent threat of harm to the patient or to others and this threat can be only removed by a breach of confidentiality.
- give emergency care as a humanitarian duty unless he/she is assured that others are willing and able to give such care.
- in situations when he/she is acting for a third party, ensure that the patient has full knowledge of that situation.
- not enter into a sexual relationship with his/her current patient or into any other abusive or exploitative relationship.

**DUTIES OF PHYSICIANS TO COLLEAGUES**

A PHYSICIAN SHALL:

- behave towards colleagues as he/she would have them behave towards him/her.
- NOT undermine the patient-physician relationship of colleagues in order to attract patients.
- when medically necessary, communicate with colleagues who are involved in the care of the same patient. This communication should respect patient confidentiality and be confined to necessary information.

**Table 2.** Cross-references the rights in the European Charter of Patients' Rights with human rights of general



| European Charter of Patients' Rights | Human rights in patient care |
|---|---|
| Right to preventive measures | Right to health |
| Right of access | Right to non-discrimination and equality; Right to health |
| Right to information | Right to information |
| Right to consent | Right to bodily integrity; Right to liberty and security of person; Right to freedom from torture and cruel, inhuman, degrading treatment; Right to privacy; Right to health |
| Right to free choice | Right to bodily integrity; Right to liberty and security of person; Right to freedom from torture and cruel, inhuman, degrading treatment; Right to privacy; Right to health |
| Right to privacy and confidentiality | Right to privacy |
| Right to respect for patients' time | Right to health |
| Right to observance of quality standards | Right to health; Right to life |
| Right to safety | Right to health; Right to life |
| Right to innovation | Right to health; Right to enjoy the benefits of scientific progress |
| Right to avoid unnecessary pain and suffering | Right to health; Freedom from torture and cruel, inhuman, degrading treatment |
| Right to personalized treatment | Right to health; Right to non-discrimination and equality |
| Right to complain | Right to a remedy |
| Right to compensation | Right to a remedy |

Source:
https://www.hhrjournal.org/2013/12/human-rights-in-patient-care-a-theoretical-and-practical-framework/

*Case 1:* ***Risky refusal***

*Debbie has diabetes and her physician advises her to start insulin treatment. Debbie understands the risks of refusing insulin, but is also unwilling to live by a schedule and monitor her medication. Against medical advice, Debbie decides to try to manage her diabetes with diet and exercise. Debbie's physician is morally and legally prohibited from injecting Debbie with insulin against her wishes.*

In ***risky refusal***, Debbie has the right to refuse insulin treatment against medical advice. Indeed, it would be immoral for Debbie's physician to force her to use insulin, to mislead her about the risks and benefits of treatment, to lie to Debbie about her condition or to coerce her into taking the treatment. All physicians are obligated to respect the doctrine of **informed consent**, which states that patients are entitled to refuse any medical treatment, even against advice (Flanigan 2012).

### *Case 2:* ***Risky access***

*Danny has diabetes and his physician advises him treat his condition with diet and exercise. Danny doesn't want to invest the time or energy in diet and exercise, and would prefer to just begin using insulin right away. Against medical advice, Danny wishes to try to manage his diabetes with insulin. However, Danny cannot legally access diabetes medication without a prescription from his physician.*

In ***risky access*** Danny's authority to make treatment decisions is not similarly protected. Danny is legally prohibited from carrying out his treatment plans (Flanigan 2012).

## Key messages

- The doctor-patient relationship built on mutual participation is important part of participatory medicine and enhance the safety and quality of care provided.
- The integration of motivational interviewing (MI) and cognitive-behavioural therapy (CBT) can serve as a unified treatment approach to improve mental and physical health.

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# 6

# Evidence-Based Social Medicine

## 6.1 MEASURING, MONITORING, AND EVALUATING THE HEALTH OF POPULATION

*Zuzana Katreniakova*

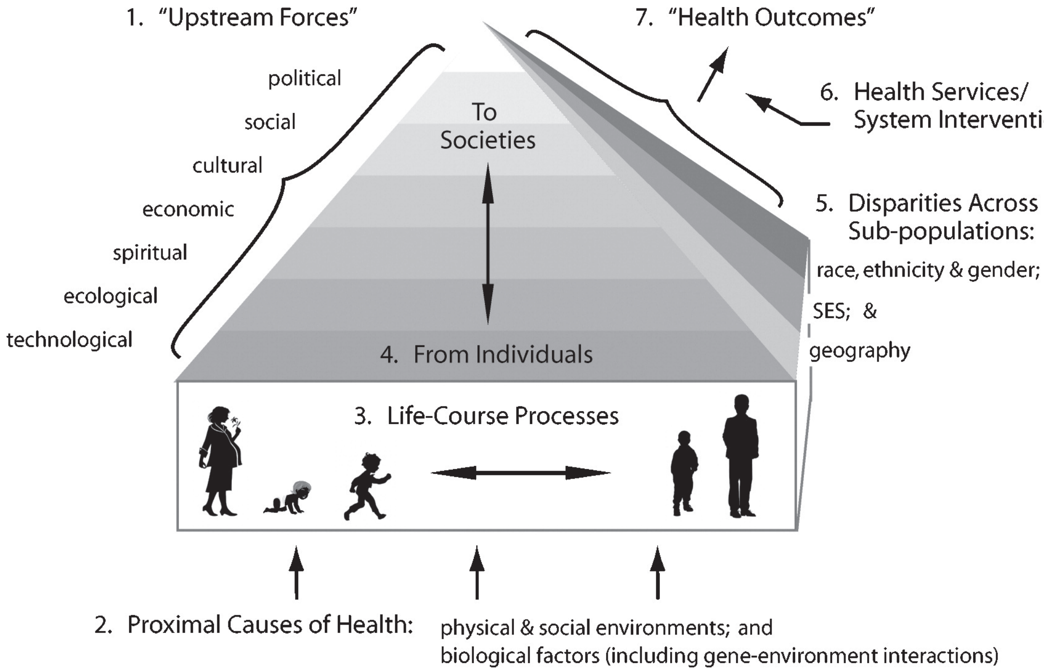
Whether to ensure fit soldiers and labourers, to improve the plight of the poor, for normative or other purposes, interest in measuring the health of populations has a long history. Population health indicators in common use today are built on mortality measures initiated in the 1500s, regular censuses started in the 1800s, civil registration of vital statistics commencing in the 1850s, regular national surveys first initiated in the 1950s, and health system and other administrative databases facilitated by computer applications used on a wide scale since the 1960s. The uses of health indicators should contribute to overall population health goals, namely improving the health of populations and reducing health inequalities (Etches et al., 2006).

### Measuring the health of Population

Figure 1 reflects a current synthesis of the broad determinants of population and individual health. The return to a focus on poverty, inequalities in the distribution of resources, and other societal and environmental determinants of health may be seen as another turn of the full circle wheel. This suggests that concepts of what makes a population healthy will develop, recede, and re-emerge in the future. Nonetheless, the ideas that health should be measured in multiple ways, at the population level, and that multiple nonmedical factors influence health are likely to remain. In contrast to the fairly stable uses of broad concepts of population health, data sources for constructing indicators have steadily improved over time (Etches et al., 2006).

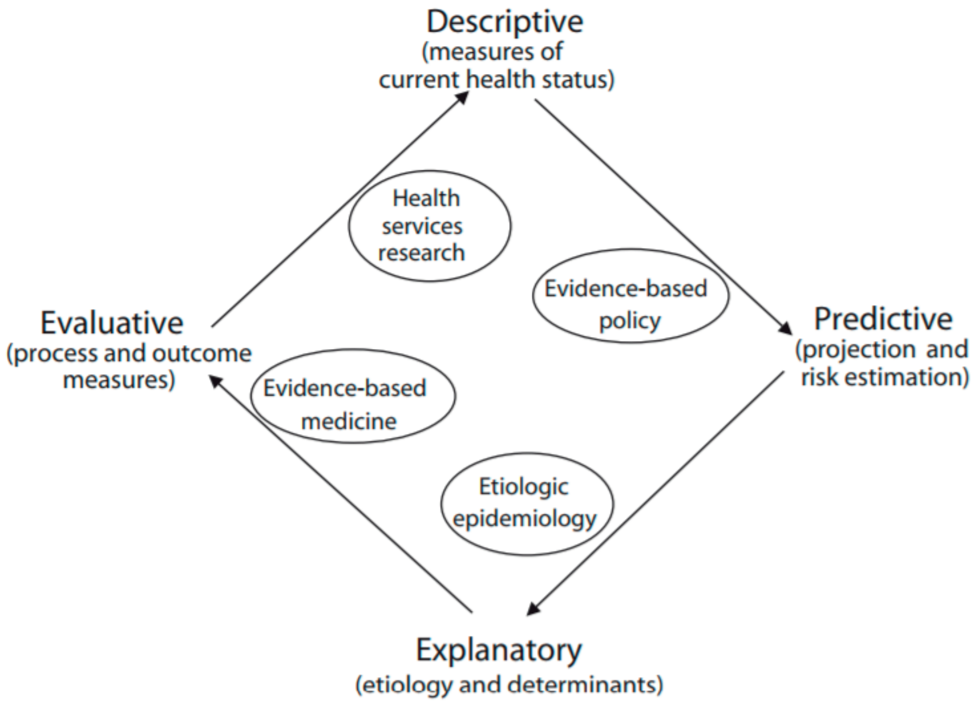
The first step in selecting a measure is to arrange the vast array of potential indicators into a framework that clarifies their appropriateness for various purposes. A measurement protocol for population health must include a broad set of measures that includes aggregate measures of health outcomes used for **descriptive** purposes, plus environmental and global measures of dynamic population characteristics used for **predictive, analytic, and explanatory** purposes. The four applications are presented in Figure 2 in a sequence that follows the logic of health research. It begins with studies ofcurrent and projected future health status to identify important population health issues, then proceed to analytic stages that inform the design of interventions, and finally proceed to studies that evaluate those interventions. Rarely would measures of all 4 types be included in a single study; the placement of the ovals within the figure illustrates the blend of measurement approaches typically found in selected academic fields: evidence based policy, for example, relies on predictive and, to a lesser extent, descriptive measures (McDowell et al., 2004).

**Figure 1.** Canadian Institutes of Health Research - Institute of Population and Public Health (CIHR-IPPH) conceptual framework of population health.



Etches V, et al. 2006.
Annu. Rev. Public Health 27:29–55

**Figure 2.** Population health measurements and the fields of research for which it is suited.



Source: McDowell et al., 2004.

Another approach to classifying measures is according to their level of aggregation. In discussing population health measures, aggregate measures, environmental indicators, and global indexes are distinguished.

**Aggregate measures** combine data from individuals, summarized regionally or nationally, as with rates of smoking or lung cancer. Measures based on aggregated individual data are typically used in descriptive studies of health status as in a prevalence survey; they may also serve as outcome indicators in evaluative studies. They represent the descriptive model of population health. The focus is on the individuals within the population; the intention might, for example, be to evaluate a community health promotion program or to identify gaps in health services. Here the population forms a convenient context within which to analyse personal health, and the relevant indicators record "health in the population."

Environmental measures cover factors external to the individual, such as air or water quality, but these can have analogues at the individual level (exposure levels), even though these may not often be assessed. Environmental measures are most commonly used in analytic or explanatory studies. These may also be idiographic if the goal is to understand how environmental factors influence the health ofparticular groups of people, as in occupational health research. Here, environmental indicators form the independent variables, whereas aggregate measures may be used to record health outcomes. Research of this type lies midway between the descriptive and analytic models of population health and corresponds to the "variables approach to analysis". But analytic studies may also be more abstract, seeking to delineate general principles, such as the association between social capital or income inequalities and health. Generalizing, or nomothetic, studies of this type aim to generate theory.

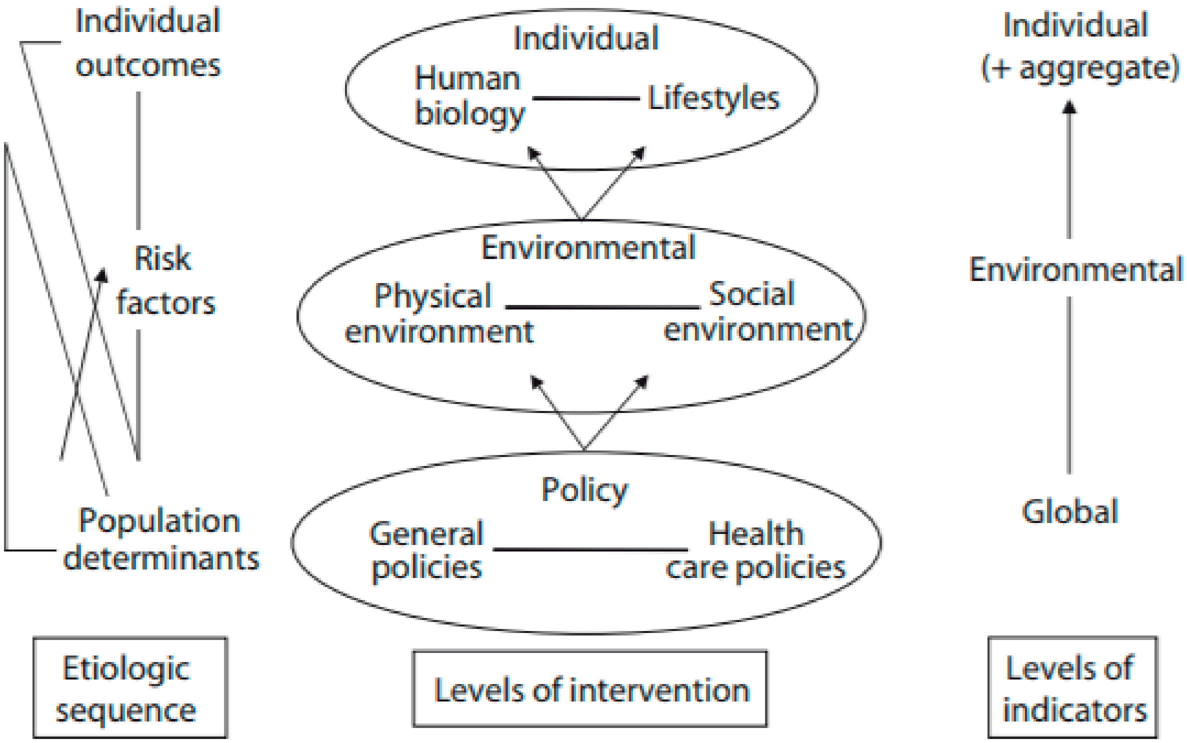
**Global indicators** have no obvious analogue at the individual level. Examples include contextual variables such as policies promoting equity in access to care, or laws restricting smoking in public places. Here, global indicators represent the explanatory factors, and they can also form the outcome variables: for example, a study might examine how the political system influences social cohesiveness.

As the research goal tends toward the explanatory and nomothetic, the population health measurements must include more than aggregated individual health indicators; the global indicators provide measures of the "health of a population."

A measurement protocol for population health must include a broad set of measures that includes aggregate measures of health outcomes used for descriptive purposes, plus environmental and global measures of dynamic population characteristics used for predictive, analytic, and explanatory purposes. One way to establish a logical structure for such a set of measures is to base it on the etiologic sequence from underlying determinants to final individual health outcomes, and on the range of interventions that correspond to each etiologic stage (Fig. 3).

The underlying causal sequence is illustrated at the left of the figure, and the centre column illustrates a range of public or population health interventions. These can directly target individuals (as with immunization campaigns) or modify the environment, or they may work through policy. At each level there is a spectrum of interventions, shown in the ellipses. The overlapping triangles suggest that although population determinants are chiefly addressed via policy interventions, environmental interventions may target risk factors at the population or individual levels. The arrows indicate the general temporal sequence (McDowell et al., 2004).

**Figure 3.** The correspondence between population health measures and types of intervention to enhance health.



Source: McDowell et al., 2004.

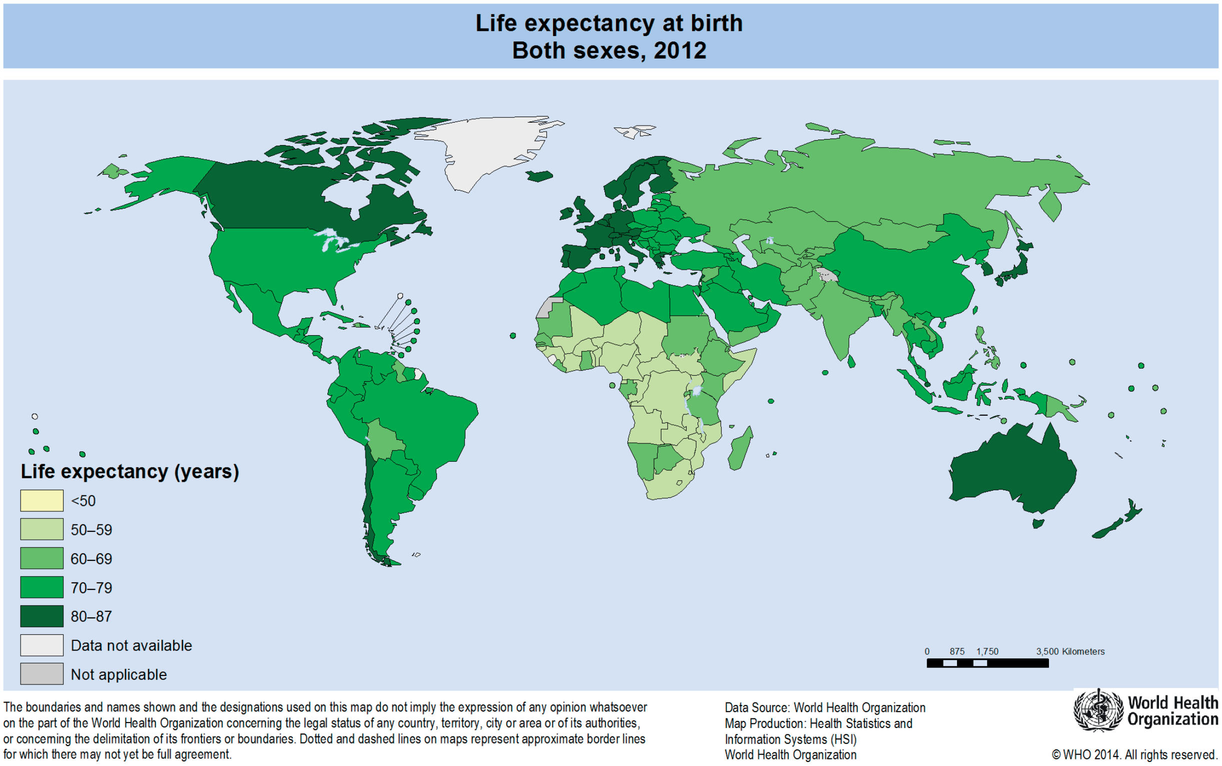
### Summary composite measures of population health

Indicators that summarise the health status of a population and that provide comparable measures of a population disease burden are increasingly vital tools for health policy decision making. Decisions concerning health systems across the world are greatly affected by changes in disease profiles and population dynamics, and must develop the capacity to respond to such changes effectively within the resources of each nation. Decisions must be based on evidence of the patterns of diseases, their risk factors and the effectiveness of alternative interventions. Recent developments in the measurement of population health status and disease burden include the increasing use of summary composite measures of health that combine the mortality and morbidity effects of diseases into a single indicator. Such measures facilitate comparisons within and across populations (Hyder et al., 2012).

**Life expectancy (LE)** at birth reflects the overall mortality level of a population. It summarizes the mortality pattern that prevails across all age groups and represents the average number of years that a new born is expected to live if current mortality rates remain unchanged (WHO, 2008).

In 2012, life expectancy at birth for both sexes globally was 70 years, ranging from 62 years in low-income countries to 79 years in high-income countries (Fig. 4). Women live longer than men all around the world. The gap in life expectancy between the sexes was 5 years in 1990 and had remained the same by 2012 (68.1 years for men and 72.7 years for women). This gap is much larger in high-income countries (more than six years) than in low-income countries (around three years). The main driver of this improvement in life expectancy at birth has been the rapid decrease in child mortality seen in many countries over the last decade (Global Health Observatory, 2014; WHOa, 2014).

**Figure 4.** Life expectancy at birth – both sexes, 2012.



The boundaries and names shown and the designations used on this map do not imply the expression of any opinion whatsoever on the part of the World Health Organization concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

Data Source: World Health Organization
Map Production: Health Statistics and Information Systems (HSI)
World Health Organization

Source: WHOa, 2014.

**Years of life lost due to premature mortality (YLL)** is a measure of premature mortality that takes into account both the frequency of deaths and the age at which death occurs. YLL are calculated from the number of deaths at each age multiplied by a global standard life expectancy for the age at which death occurs. However, taking age at death into account causes major shifts in the relative importance of the major causes of death (WHO, 2008).

During the period 2000–2012, a major shift occurred in the main causes of YLL, away from MDG conditions and towards NCDs and injuries, with the proportion of YLL due to MDG conditions declining in almost every country in the world. The top three causes of YLL in 2012 were ischaemic heart disease, lower respiratory infections (such as pneumonia) and stroke (WHO, 2014).

Globally, the proportion of YLL resulting from NCDs has increased from 38% in 2000 to 47% in 2012. This reflects the successes achieved in reducing mortality from a number of leading communicable diseases (measles, diarrhoeal diseases, malaria and tuberculosis). Combined with reduced levels of neonatal, infant, child and maternal mortality, and the resulting substantial increases in life expectancy now seen in many developing countries, people are increasingly surviving to ages at which NCDs are the primary causes of death (WHO, 2014).

**Years lost due to disability (YLD)** measures the equivalent years of healthy life lost through time spent in states of less than full health. When all the years of life with reduced capability for all the sufferers of each condition are added up and weighted by the disability weight, a total YLD for each condition is obtained: thus YLD for a particular cause in a particular time period are estimated as follows: the number of incident cases in that period × average disease duration × weight factor. The weight factor reflects the severity of the disease on a scale from 0 (perfect health) to 1 (death). YLD estimates are restricted to loss of health experienced by individuals and do not take into account other aspects of quality of life or well-being, or the impacts of a person's health condition on other people (except as far as they experience directly assessed losses of health themselves). In both males and females, as well as for high-income and low- and middle-income countries, unipolar depressive disorders are in first place among the 10 leading causes of YLD. The measures of ill-health used thus far (incidence, prevalence and YLL) do not give a good indication of the burden of disease borne by individuals in different communities (WHO, 2008).

Two types of **composite summary measures** have been developed:

- *health gap measures* such as healthy life years (HeaLYs), disability adjusted life years (DALYs), and quality-adjusted life years (QALYs), and
- *health expectancies* such as disability-free life expectancy (DFLE) or health-adjusted life expectancy (HALE).

**Healthy life year (HeaLY)** also called **healthy life expectancy (HALE)** or **disability-free life expectancy (DFLE)** is a better indicator then LE. It is a health expectancy indicator which combines information on mortality and morbidity. HLY at birth by gender represents the number of years that a person at birth is expected to live in a healthy condition. A healthy condition is defined by the absence of limitations in functioning/disability (WHO, 2008).

The HeaLY was the first of the composite measures to be used as a tool in national health planning. In the early 1980s the Ghana Health Assessment Team undertook a study to assess the burden of disease in low- and middle-income countries (LMICs). The HeaLY combines the amount of healthy life lost due to death with that lost due to morbidity. Life lost from a disease due to death is based on the years of life expectancy had the disease not occurred. The information needed to estimate this, in addition to the incidence rate and case fatality ratio, is the age of disease onset, the age of death, and the expectation of life at these ages. Life lost from disability must have comparable dimensions to that lost due to death.

The healthy life approach focuses on the pathogenesis and natural history of disease as the conceptual framework for assessing morbidity and mortality, and for interpreting the effects of various interventions. Interventions may also be directed at reducing identifiable risk factors, such as tobacco smoking or risky sexual behaviour. To the extent that risk reduction can be translated into disease reduction, the approach to measuring the benefits and costs of a risk reduction intervention programme remains the same as that for disease reduction.

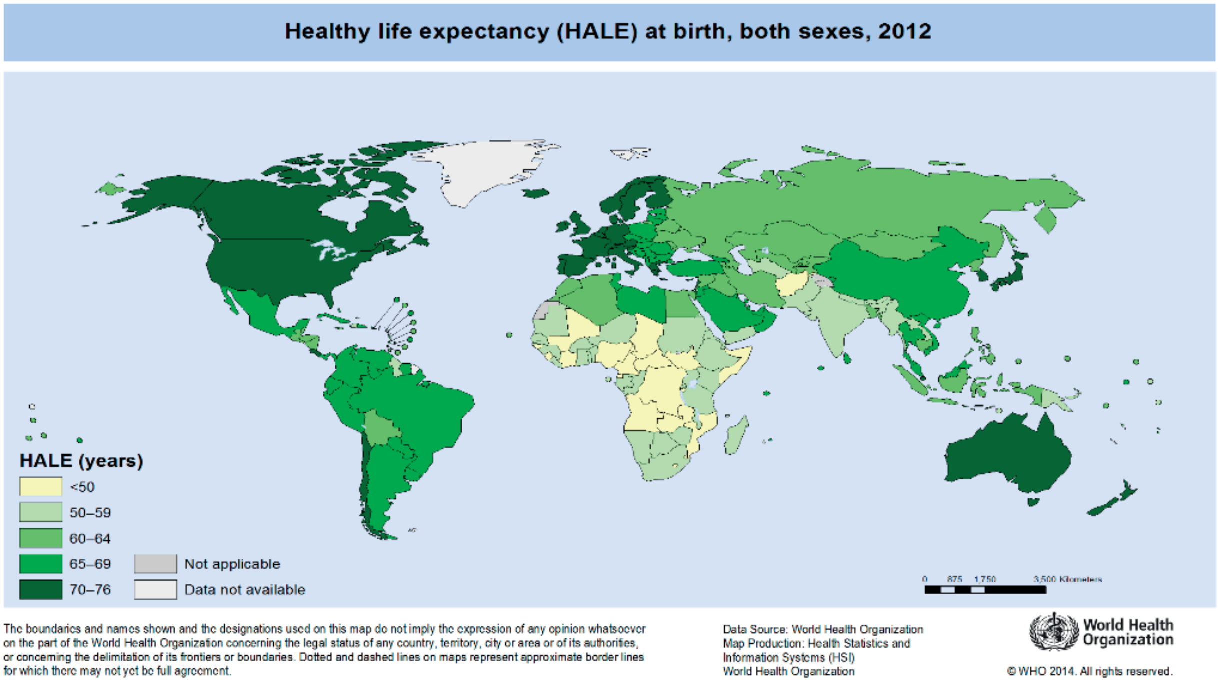
The healthy life lost from death and from disability are added and expressed as the total years of life lost per 1000 population per year; the loss is attributed to the year in which disease onset occurs and includes the stream of life lost from disability and death at any time after onset, even if these events happen many years later. This is a prospective view of the event (disease onset) and its natural history (or as modified by interventions) over time.

An important benefit of the HeaLY formulation is that the effects of different kinds of interventions can be readily explored to determine their expected gains in healthy life. Interventions may usefully be divided into two broad categories: those that are used to prevent the initiation of the disease process, and those that are used to treat a disease process already under way, which includes rehabilitative care.

Some interventions fall into both categories. The primary effect of preventive strategies is to reduce the incidence of new cases of disease. The main effects of treatment strategies are to interfere with the natural history of the disease process, thereby reducing the case fatality and/or case disability ratios or extending life by providing a later age at death for conditions such as diabetes and AIDS (Hyder et al., 2012).

Overall, global HeaLY at birth in 2012 for males and females combined was 62 years, 8 years lower than total life expectancy at birth (Fig. 5). In other words, poor health resulted in a loss of nearly 8 years of healthy life, on average globally. Global HALE at birth for females was only 3 years greater than that for males. In comparison, female life expectancy at birth was almost 5 years higher than that for males (WHOb, 2014).

**Figure 5.** Healthy life expectancy at birth – both sexes, 2012.



Source: WHOb, 2014.

**Disability-adjusted life year (DALY)** was introduced in the first Global Burden of Disease (GBD) WHO Study as a single measure to quantify the burden of diseases, injuries and risk factors (Murray et al., 1996). The DALY extends the concept of potential years of life lost due to premature death to include equivalent years of "healthy" life lost by virtue of being in states of poor health or disability. One DALY can be thought of as one lost year of "healthy" life, and the burden of disease can be thought of as a measurement of the gap between current health status and an ideal situation where everyone lives into old age, free of disease and disability. Using DALYs, the burden of diseases that cause early death but little disability (e.g. drowning or measles) can be compared to that of diseases that do not cause death but do cause disability (e.g. cataract causing blindness). DALYs for a disease or injury cause are calculated as the sum of the YLL in the population and the YLD for incident cases of the disease or injury. Differences in burden of disease are associated with countries income levels, and they vary between the WHO regions (WHO, 2008).

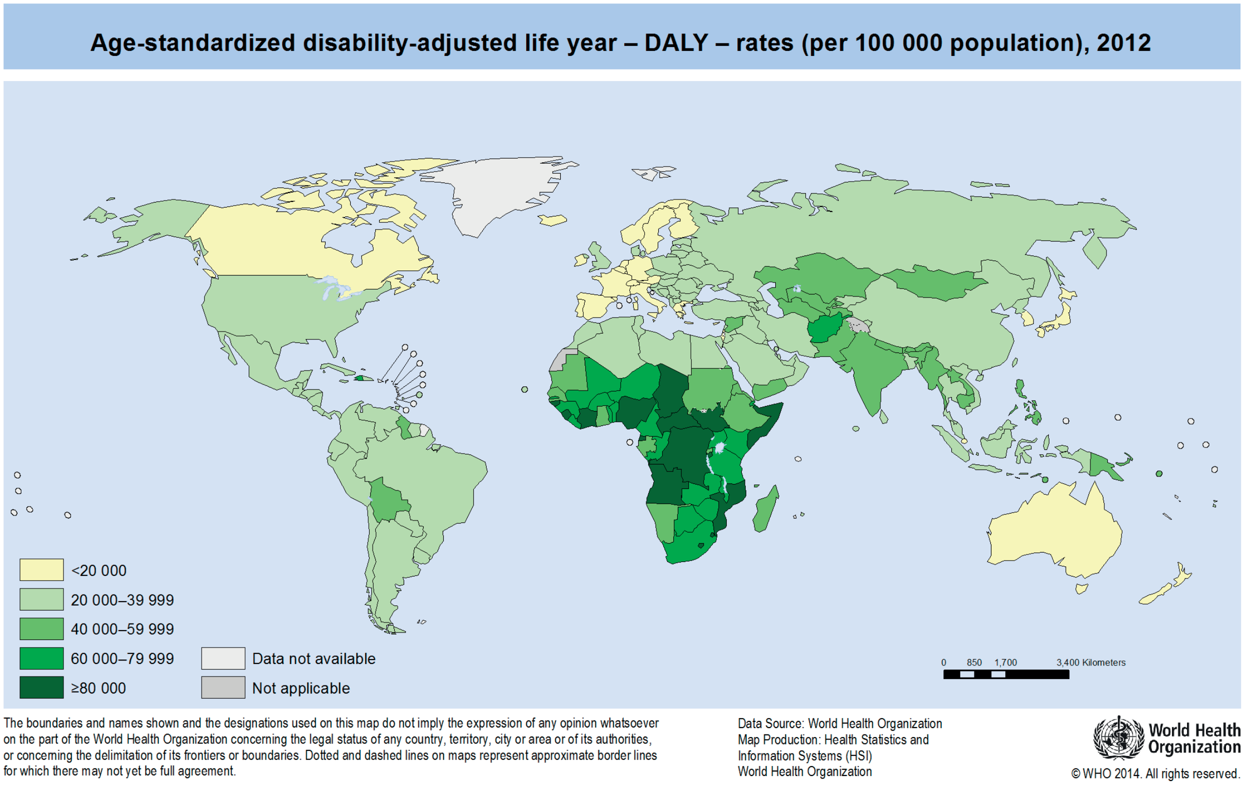
The disability-adjusted life year (DALY) is a health gap population summary measure that combines time lost due to disability with that which is due to death (life that would have been expected had the disease not occurred) in a manner similar to the healthy life year measure. It first appeared in the World Development Report of 19939 and has become the most widely used composite measure of population health. DALYs are calculated as two separate components for the measurement of life lost due to disease, and they also directly include three social value choices. The two components are: i) years of life lost (YLL), the loss of healthy life from death; and ii) years of life lived with disability (YLD), the loss of healthy life from disability. The social value choices that can be included are: i) life expectation values; ii) discount rates for future life; and iii) weighting for life lived at different ages, as discussed below. The calculation for YLL in a population uses the age distribution of all deaths by cause in one year multiplied by life expectation at each age to estimate loss of life for each disease that would have been expected if that disease had not occurred. The expectation of life is obtained from a model life table based on best achievable low levels of mortality, such as in Japan, and thus the DALY (and the HeaLY) directly incorporates this social value choice.

For disability, the DALY uses estimates of incidence, duration, and severity to calculate the time lived with disability (YLD) for each disease. The YLD component equals the number of incident cases in the period multiplied by the average duration of disease multiplied by a weight factor for the degree of severity (extent) of disability from the disease. The second social value choice directly incorporated in the DALY is the discount rate of 3% per annum. This social time preference has been used for most estimates; however, DALY results discounted at % are also available. The third social value choice concerns weighting life lived at different ages. DALYs are age-weighted according to an arbitrary exponential curve designed to give the most value to life lived as a young adult. Weighting by age was the most controversial component of the DALY when they appeared and caused great dissent among other health professionals.

An important difference between the HeaLY and DALY is that the starting point for the HeaLY is the onset of disease; the loss of healthy life is based on the natural history of the disease (as modified by interventions). This is true for the YLD component of the DALY, but the YLL is based on mortality in the current year. In a steady state there is no difference, but when there is a changing incidence, such as with HIV in many parts of the globe, the DALY approach can greatly understate the true situation (Hyder et al., 2012).

The burden of disease, expressed in DALYs per 1000 population, has decreased in all regions during the period of 2000-2012, with the WHO African region having attained the largest decline (32%). This region, however, still bore the highest burden in 2012, 740 DALYs per 1000 population (Fig. 6). This is almost three-fold the burden of disease in the region with the lowest DALY rates (273 per 1000 population) in 2012: the low- and middle-income countries in the WHO Western Pacific region. High-income countries experienced the lowest decline (7%) in DALY rate per 1000 population: from 323 in 2000 to 301 per 2012 (WHOc, 2014).

**Figure. 6** Age-standardized disability-adjusted life year rates, 2012. Source: WHO, 2014.

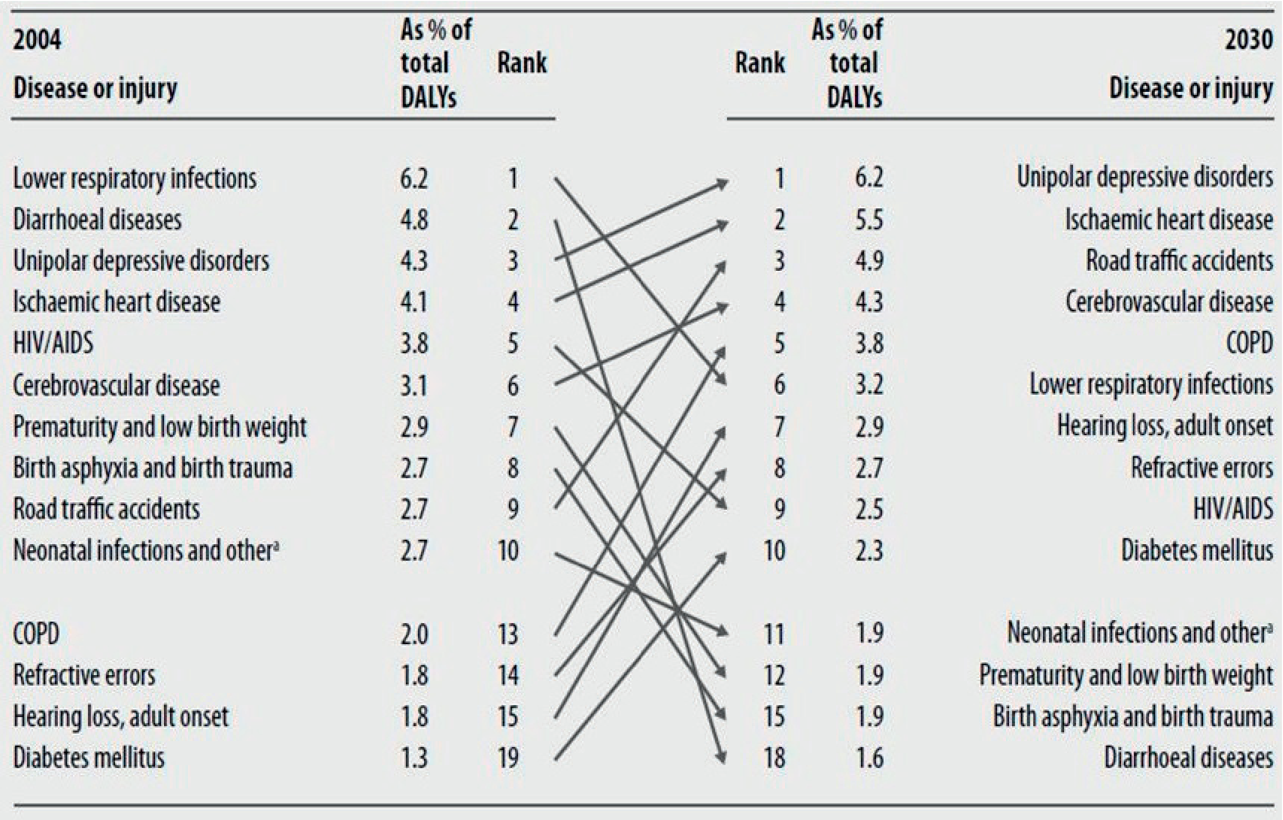


Source: WHOc, 2014.

Globally, one third of total DALYs were caused by communicable, maternal, neonatal and nutritional causes (referred to as “MDG conditions”) in 2012, a decline from 43% in 2000. The WHO African region has strikingly high proportion (65%) of DALYs due to the MDG conditions compared to other regions, with 10% due to HIV/AIDS alone. In high-income countries, 83% DALYs were due to NCDs, including cardiovascular diseases (21%), cancers (17%) and mental disorders (12%). Road injuries caused a loss of nearly 80 million years of full health among the world’s population in 2012; making it among the 10 leading causes of DALYs (WHOc, 2014).

Global DALYs are projected to decrease from 1.53 billion in 2004 to 1.36 billion in 2030, an overall decline of about 10%. Since the population increase is projected to be 25% over the same period, this represents a significant reduction in the global per capita burden (Fig. 7).

**Figure 7.** Ten leading causes of burden of diseases, world, 2004 and 2030



| 2004 Disease or injury | As % of total DALYs | Rank | Rank | As % of total DALYs | 2030 Disease or injury |
|---|---|---|---|---|---|
| Lower respiratory infections | 6.2 | 1 | 1 | 6.2 | Unipolar depressive disorders |
| Diarrhoeal diseases | 4.8 | 2 | 2 | 5.5 | Ischaemic heart disease |
| Unipolar depressive disorders | 4.3 | 3 | 3 | 4.9 | Road traffic accidents |
| Ischaemic heart disease | 4.1 | 4 | 4 | 4.3 | Cerebrovascular disease |
| HIV/AIDS | 3.8 | 5 | 5 | 3.8 | COPD |
| Cerebrovascular disease | 3.1 | 6 | 6 | 3.2 | Lower respiratory infections |
| Prematurity and low birth weight | 2.9 | 7 | 7 | 2.9 | Hearing loss, adult onset |
| Birth asphyxia and birth trauma | 2.7 | 8 | 8 | 2.7 | Refractive errors |
| Road traffic accidents | 2.7 | 9 | 9 | 2.5 | HIV/AIDS |
| Neonatal infections and other[a] | 2.7 | 10 | 10 | 2.3 | Diabetes mellitus |
| COPD | 2.0 | 13 | 11 | 1.9 | Neonatal infections and other[a] |
| Refractive errors | 1.8 | 14 | 12 | 1.9 | Prematurity and low birth weight |
| Hearing loss, adult onset | 1.8 | 15 | 15 | 1.9 | Birth asphyxia and birth trauma |
| Diabetes mellitus | 1.3 | 19 | 18 | 1.6 | Diarrhoeal diseases |

Source: The Global Burden of Disease: 2004 update. Switzerland: WHO Press; 2008; 51.

**The quality-adjusted life year (QALY)** was introduced in 1976 to provide a guiding principle for selecting among alternative tertiary health care interventions.20 The idea was to develop a single measure of quality of life in order to compare expected outcomes for a disease from different interventions; a measure that valued possible health states for their quality of life as well as their duration.

The central notion behind the QALY is that a year of life spent in one health state may be preferred to a year spent in another. It is a generic measure that sums time spent in different health states using weights for each health state on a scale of 0.00 (dead) to 1.00 (perfectly healthy) i.e. the arithmetic product of duration of life and a measure of quality of life (health state weight) (Table 2). So, five years of perfect health = 5 QALYs while two years in a state measured as 0.5 of perfect health followed by three years of perfect health = 4 QALYs. The QALY was originally developed as a differentiating indicator for individual choices among tertiary health care procedures, not as a measure of disease burden in a population. It was used to assess individual preferences for different health outcomes from alternative interventions. Since its introduction, a wide variety of QALY measures have been developed, along with an extensive literature on alternative methods incorporating a range of disability domains and a diversity of methods to assign weights to generate QALYs. The most widely used measure is the EQ-5D (European Quality of Life with Five Domains and Perhaps the most important use of QALYs has been as a common denominator to measure utility in cost-utility analysis (CUA) and effectiveness in cost-effectiveness analysis (CEA) to assist in resource allocation among alternative health interventions by ranking interventions in terms of cost per QALY. An early and widely publicised attempt to make the best use of health care resources by maximising QALYs per dollar spent was the well-intentioned but rather unfortunate effort in Oregon in the early 1990s.25,26 In the UK, as part of its 1997 NHS reforms, the National Institute for Clinical Excellenc (NICE) was created to advise about the effectiveness and cost effectiveness of various health interventions. In order to introduce economic considerations in addition to medical judgments for the allocation of resources, NICE has produced a large collection of studies on the cost per QALY produced by the interventions it appraises (www.nice.org.uk). The QALY as originally used is essentially equivalent to the YLD of the DALY. In fact, it would be similar to the YLD when: i) there is no discounting ($r = 0$); ii) no age weighting is used ($K=0$); and iii) the same disability weights are used. More recently (as used in some cost-effectiveness studies) QALYs have also incorporated life expectation (Hyder et al., 2012).

During the 1990s, **disability free life expectancy (DFLE)** and related measures were calculated for many countries. However, these measures incorporate a dichotomous weighting scheme in which time spent in any health state categorised as disabled is assigned, arbitrarily, a weight of zero (equivalent to death). Thus, DFLE is not sensitive to differences in the severity distribution of disability in populations. In contrast, the **disability-adjusted life expectancy (DALE)** adds up expectation of life for different health states with adjustment for severity weights.

The term DALEs was replaced by the term HALEs (health-adjusted life expectancy) by the WHO in 2001 and this is the term that we will use here. The HALE is a composite summary measure of population health status that belongs to the family of health expectancies. It summarises the expected number of years to be lived in what might be termed the equivalent of full health. Some consider the HALE to provide the best available summary measure for measuring the overall level of health for populations.

Health expectancy indices combine the mortality experience of a population with the disability experience. Some versions of the HALE are calculated using the prevalence of disability at each age in order to divide the years of life expected at each age according to a life table cohort into years with and without disability. Mortality is captured by using a life table method, while the disability component is expressed by additions of prevalence of various disabilities within the life table. This indicator allows an assessment of the proportion of life spent in disabled states. When compared with the total expectation of life, this translates to a measure of the total disability burden in a population.

The various methods and specific indicators have been compared in the literature. Alternative methods are given in the WHO National Burden of Disease Studies manual. As originally designed, the HALE does not relate to specific diseases but rather to the average extent of disability among that proportion in each age group that is disabled. The lack of correlation between a condition or disease entity and the measure makes it intuitively less valuable for resource allocation and cost-effectiveness calculations (Hyder et al., 2012).

### Monitoring and Evaluation

Monitoring and evaluation of any health programme or intervention is vital to determine whether it works, to help refine programme delivery, and to provide evidence for continuing support of the programme. Evaluation will not only provide feedback on the effectiveness of a programme but will also help to determine whether the programme is appropriate for the target population, whether there are any problems with its implementation and support, and whether there are any ongoing concerns that need to be resolved as the programme is implemented. Generally, the process consists of three steps (Global Road Safety Partnership, 2007):

**1) Planning the evaluation:**

This important initial stage involves collecting data, in a baseline study, to assess the situation before going on to develop the programme. Based on the information collected, it is then necessary to define the aims of an evaluation, and to consider the different types of evaluation methods that could be used for your evaluation. Evaluation may take several forms, and one or more may be appropriate, depending on the aims of the specific programme to be evaluated.

***Process evaluation***

Rather than measuring change in outcomes, this aspect of evaluation examines whether the programme was carried out as planned. This involves creating a list of indicators that need to be measured, depending on the aims of the programme. The results will help to identify the strengths and weaknesses of the programme, and where improvements may be made.

For example, in a media campaign designed to reduce drinking and driving, a process evaluation may ask these sorts of questions: Have the campaign products (posters, billboard, radio and television spots) been pre-tested? How often were the campaign advertisements run? How many people saw them? Was the target group being reached?

Process evaluations are what are known as "formative". That is, the enquiries carried out are designed to provide information to guide programme improvement. For example, it may be considered important to determine whether the TV adverts shown as part of a drinking and driving programme are appropriate – do they adequately address the issue, does the behaviour portrayed reflect drinking customs in the region where the adverts will be seen?

***Impact assessment***

This will determine whether the programme has brought about a change. The impact, or programme effect, refers to a change in the target population that has been brought about by the programme – that is, a change that would not have occurred if the programme had not happened.

For example, if the programme involved airing television advertisements on drinking and driving, the impact assessment might examine whether people who had seen the advertisements believe that there is a good chance that they will be stopped and breathalysed by the police if they drink and drive. Unlike a process evaluation, this would tend to take place at the end of a programme, as the focus would be on the outcome.

***Outcome evaluation***

This is where the outcomes are measured to see if the programme was successful. Are less people now drinking and driving than before? Have road crashes involving alcohol been reduced? Are fewer injured drivers/riders admitted to hospital with high BAC levels? Measuring a change in outcomes is probably the most common form of evaluation as it provides information as to whether the programme or intervention has actually made a difference.

**2) Choosing the evaluation methods:**

Once the type of evaluation has been determined, there are different methods that can be applied to carry out an evaluation. Both qualitative and quantitative methods can be used within the design of an evaluation. Qualitative methods may be employed for formative and process evaluations, e.g. focus groups, shortanswer or open-ended questionnaires.

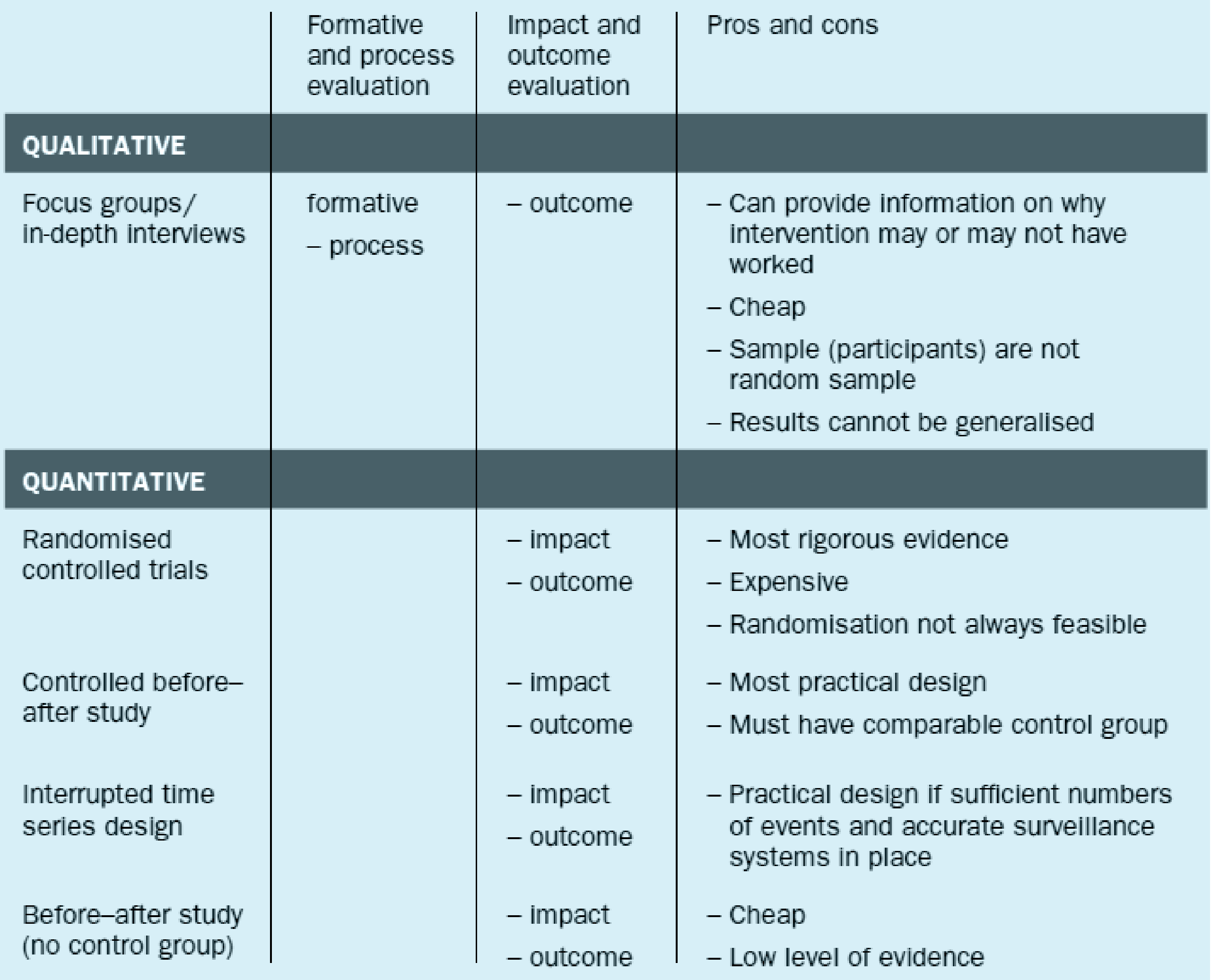
Impact and outcome evaluations may be carried out using a variety of quantitative methods. Using an experimental or quasi-experimental design to demonstrate a change (or not) is the most powerful programme evaluation for detecting changes in outcome. The methods used will depend on the aim and the budget for the evaluation (Table 1).

**3) Dissemination and feedback:**

Once an evaluation is complete it is important to provide feedback to the stakeholders involved in the programme. Dissemination of the results will help garner further support for the programme if it is successful, and help others gain support for the introduction of similar programmes. Publicity from dissemination activities may also increase the impact of the programme. If the programme has not been successful it is important to share this with others so that weaknesses or relevant issues are considered in other similar interventions, including whether or not to introduce such interventions.

Dissemination may involve presenting the results at public meetings, using the media to publicise the outcomes of the programme, or publishing reports and papers in the scientific literature.

**Table 1.** Study types and their advantages and disadvantages.



| | Formative and process evaluation | Impact and outcome evaluation | Pros and cons |
|---|---|---|---|
| **QUALITATIVE** | | | |
| Focus groups/ in-depth interviews | formative<br>– process | – outcome | – Can provide information on why intervention may or may not have worked<br>– Cheap<br>– Sample (participants) are not random sample<br>– Results cannot be generalised |
| **QUANTITATIVE** | | | |
| Randomised controlled trials | | – impact<br>– outcome | – Most rigorous evidence<br>– Expensive<br>– Randomisation not always feasible |
| Controlled before–after study | | – impact<br>– outcome | – Most practical design<br>– Must have comparable control group |
| Interrupted time series design | | – impact<br>– outcome | – Practical design if sufficient numbers of events and accurate surveillance systems in place |
| Before–after study (no control group) | | – impact<br>– outcome | – Cheap<br>– Low level of evidence |

Source: Global Road Safety Partnership, 2007.

### Evaluation of integrated health promotion programs

Effective health promotion programs contribute to improved health outcomes, such as healthier lifestyles, more effective health services, healthier environments and, ultimately, decreased morbidity and disability and increased life expectancy, functional independence and quality of life. These changes in health status are referred to as the outcomes and they reflect fulfilling the goal of the program.

These ultimate outcomes are influenced by a wide range of determinants, including a person's physical, social and economic environment. Only a very small proportion of such determinants may be directly affected by a particular health promotion program. Moreover, changes to outcomes are likely to take place over a time period beyond the time-scale of most evaluations. For these reasons, when assessing the effects of health promotion programs, the more immediate changes in populations, individuals or their environments are considered (Table 2).

**Table 2.** Program management for integrated health promotion programs

| 1. PLANNING | 1(a) Vision setting | 3. EVALUATION |
|---|---|---|
| | 1(b) Priority setting and Problem definition<br>▼ | |
| | 1(c) Solution generation<br>▼ | 3(a) PROCESS EVALUATION |
| | 1(d) Capacity building – Support and resourcing for quality program delivery<br>▼ | |
| 2. IMPLEMENTATION | Implementation of a mix of health promotion interventions and capacity building strategies to achieve the program goal and objectives | |
| | ▼ | |
| 3(b) IMPACT EVALUATION including: | | |
| Health literacy | Social influence and action | Healthy public policy and organisational practice |
| Healthy lifestyles | Effective health services | Healthy environments |
| | ▼ | |
| 3(c) OUTCOME EVALUATION including: | | |
| Quality of life, functional independence, equity, mortality, morbidity, disability | | |

Source: VG DHS 2003

### Key messages

- The uses of health indicators should contribute to overall population health goals, namely improving the health of populations and reducing health inequalities.
- Monitoring and evaluation of any health programme or intervention is vital to determine whether it works, to help refine programme delivery, and to provide evidence for continuing support of the programme.

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## 6.2 KNOWLEDGE TRANSLATION AND IMPLEMENTATION RESEARCH

*Iveta Nagyova*

### Knowledge translation within the wider context of current health challenges

The rise in chronic diseases is currently one of the biggest challenges for health systems, social systems, but also for the economies of states (GBD Lancet 2018). Of particular importance in this context is the increase in the incidence of mental illnesses and disorders. Mental disorders are increasingly seen as a significant cause of disability. Currently in Europe, 30-50% of all new applications for invalidity retirement benefits are due to mental illness, and this share rises to more than 70% for young adults (OECD 2012). Population aging and lifestyle factors such as smoking, overuse of alcohol, unhealthy eating, and lack of physical activity are mentioned among the main causes of rise in chronic diseases. Factors associated with work and employment, and especially with the 24/7 economy, are less frequently acknowledged (Oostrom et al. 2016). We are witnessing an important shift from post-industrial economies to service economies, "24/7 economies". We have entered a new era of economies, characterized by intensive use of information and communication technologies that enable globalized production and distribution of goods and services. Economies 24 hours a day and 7 days a week require continuous work services in the evenings and during the weekends. These labour market trends lead to negative impacts on the physical and mental health of employees. Physical health problems include sleep, fatigue, obesity, digestive problems and a higher risk of developing cardiovascular disease. Alcohol and smoking problems are common. Psychological problems include memory problems, reaction times, mood disorders and anxiety disorders, chronic anxiety, and depression (Li et al. 2014).

### Socio-economic consequences of chronic diseases

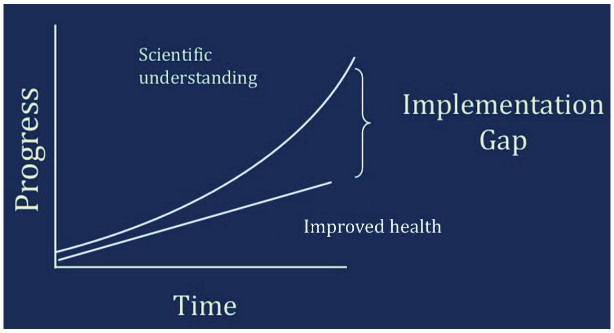
From the point of view of an individual, chronic diseases bring about a loss of income, reduced work participation and labour productivity, as well as a reduced quality of life for the patient and his/her loved ones (Bloom et al. 2011). From the employer's point of view, chronic health problems are associated with reduced labour productivity, high job fluctuation, disability, invalidity, and early retirement (OECD 2012). For this reason, health care providers, policymakers and employers are increasingly trying to find solutions that would help develop better chronically ill care models that are more appropriate for people with complex health needs. In the recent years, increased attention has also been paid to chronic diseases at the political level, e.g. 'High Level Meeting on the Prevention and Control of Non-Communicable Diseases (NCDs)' in New York 2018 (UNGA 2018), WHO 'Ministerial Conference on Non-Communicable Diseases in Ashgabat', Turkmenistan 2013 (WHO 2013) or the European Union Chronic Disease Summit, Brussels 2014 (EC 2014). Similarly, in December 2013, the Government of the Slovak Republic approved the document 'A Strategic Health Care Framework for 2014-2030', which addresses chronic diseases and defines measures to improve the quality, efficiency of healthcare provided, and improve the health status of the population (MoH SR 2013).

Despite these efforts, the effective implementation of new health care models and new innovative interventions, whether on the part of healthcare providers or employers, **is hampered by a lack of knowledge transfer** of scientific research and ineffective interconnection of research, practice and policies. Worldwide, billions of dollars a year are spent from the public and private sectors to carry out biomedical and clinical research, as well as research on health services to improve population health. Investments go into higher education for health workers, postgraduate, and lifelong learning. It also invested in research on improving the quality of healthcare provided, increasing patient safety and managing workplace risks. Nevertheless, healthcare systems are unable to ensure that effective and cost-effective programs reach all those who need it, and health professionals can not provide the quality of care they seek (Grimshaw et al. 2012). The results of the research point to a consistent failure to transfer the findings of scientific research into practice. Only 55% of patients receive the recommended health care and the quality of healthcare varies between 79% of the recommended care for patients with cataracts (cataracts) at 11% of the recommended care for alcohol-dependent patients. Similar data is reported in primary, secondary, and tertiary care in all medical fields (McGlynn et al. 2003, Grol 2001). As a result of these knowledge transfer shortcomings, patients and their families are unable to make optimal use of the benefits of research progress, resulting in poor quality of life and productivity losses at both the personal and the community level.

## Research-practice gap: What is it and why does it exist?

The problem with current systems is that the knowledge transfer process is generally slow and inconsistent. Insufficient use of evidence-based research is often described as the difference between "what we know" and "what is being done" in health care policy and practice. In science and research, we record unprecedented progress in public health and health care in the context of discovering new approaches and interventions that have the potential to improve the health and well-being of employees at the workplace while strengthening health systems and state economies. However, if these findings are not actually implemented in practice, the expected benefits will not be carried out.

**Figure 1.** Research-practice gap



Although the very notion of knowledge transfer is relatively new, discussions about the need for effective implementation of research results into practice date back to the early 20th century, when French sociologist Gabriel Tarde tried to explain why some innovations would apply in practice and others did not. Similarly, Dr. Lee Jong-wook, Director-General of the World Health Organization in 2003-2006, said: *"There is a gap between current scientific knowledge and its application in practice: between what we know and what is actually going on. Actions without knowledge and knowledge without deeds mean wasting resources and not taking advantage of opportunities"* (WHO 2004).

"There is a gap between today's scientific advances and their application: between what we know and what is actually being done. Action without knowledge and knowledge without action means wasted resources and missed opportunities".

Dr. Jong-Wook Lee, WHO Director-General 2003-2006

Several factors contribute to the explanation for the continued gap between our knowledge base and evidence based practice. First, the lag between discovery and application is exceptionally long. This is due in part to the length of the conventional research pipeline, which has been described as a continuum from basic science discoveries to clinical application in research settings under controlled conditions (efficacy research) to testing in applied settings under more natural conditions (effectiveness research) and finally to the broader application in the population at large (Figure 2). However, not only the length of time for research findings to be applied in medicine (17 years for 14% of original research to get translated to patient care), but also the various sources of leakage or loss of knowledge in the pipeline (e.g., time from inception to grant funding to publications to development of practice guidelines). Second, an inherent problem exists in relying on journals and guidelines for dissemination: They place the responsibility on the practitioner to read, accurately interpret, and effectively apply the findings in their settings. This pushing of information into practice is compromised by several factors, including but not limited to the following issues:

(a) relevance of the research findings to practice,

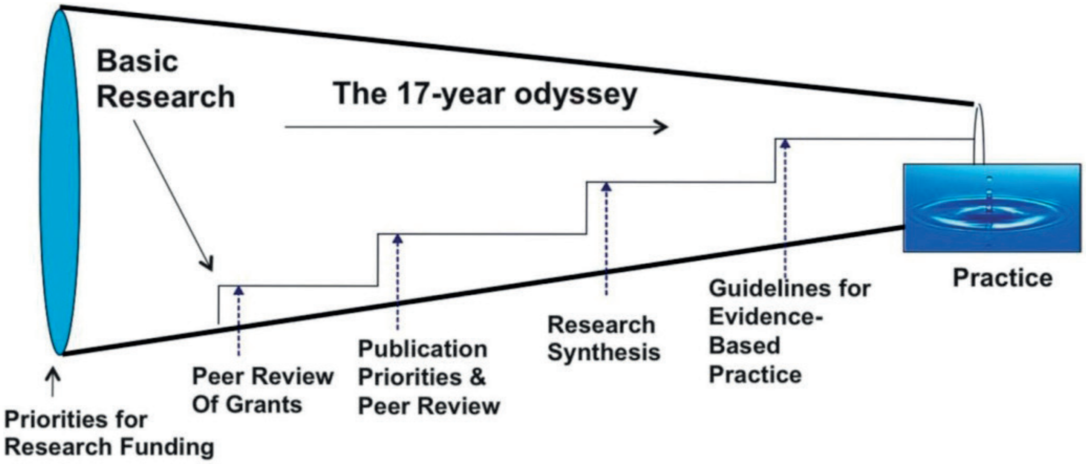
(b) sufficient treatment descriptions that can be implemented with fidelity,

(c) access to an organizational structure that embraces and supports the adoption of treatment innovations,

(d) practitioners' motivation to change what they are currently doing,

(e) realized benefits for a targeted population sufficient to sustain application (Olswang & Prelock 2015)

**Figure 2.** Depiction of pipeline of evidence from basic research to practice and policy



*Source: Olswang & Prelock 2015*

## KNOWLEDGE TRANSLATION

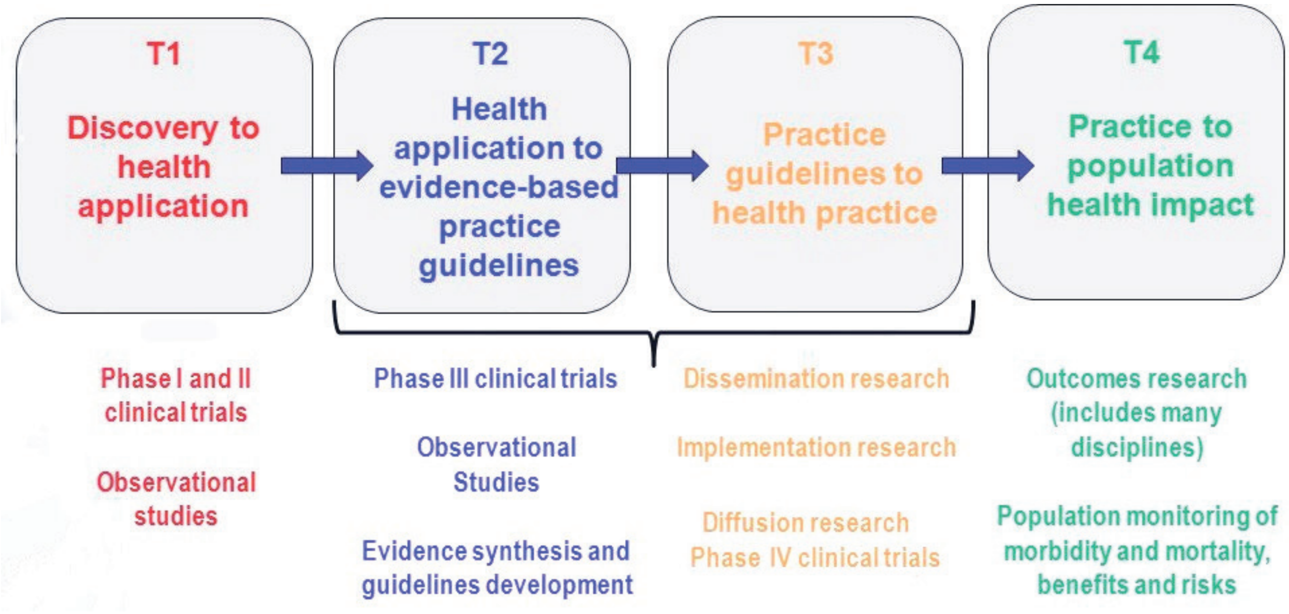
### Definition of knowledge translation

Over the course of the remaining 10-15 years, there has been an increasing international interest in transferring knowledge in various fields. In the literature, we find several interrelated and overlapping constructs used to describe this process, such as: quality improvement, use of knowledge, knowledge transfer, technology transfer, innovation diffusion, research implementation, research use, evidence-based policy, or evidence-based health systems (McKibbon et al. 2010).

Knowledge translation is the process of extracting and disseminating the best available research evidence and using this evidence to improve health practices and policies, including mental health of employees. Knowledge transfer means “Ensure that stakeholders are aware of the results of scientific research and take advantage of these results in health and healthcare decision-making.” (Grimshaw et al. 2012).

This definition indicates that there is a wide range of stakeholders or target groups for translation of scientific knowledge.

**Figure 3.** The translational blocs in the clinical research continuum



*Source: Sung, JAMA 2003, Khoury et al. 2018*

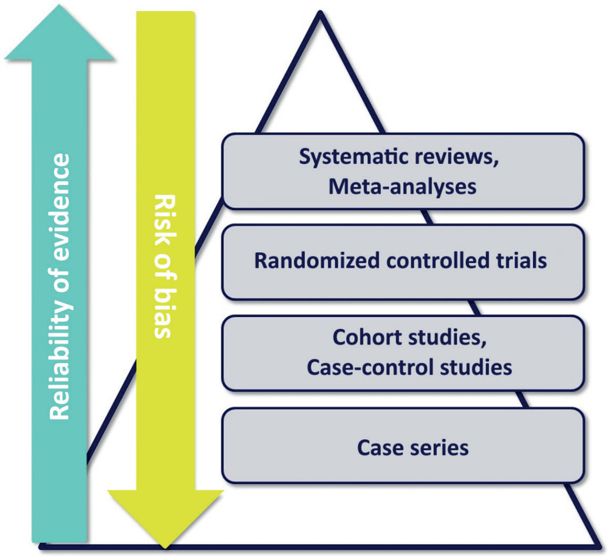
### Stakeholders and relevant target groups for transfer of knowledge

Relevant target groups for knowledge transfer are policy makers, healthcare professionals, patients and their relatives, scientists as well as industry and employers. The relative importance of transfer of knowledge depends on the type of research. For example, the primary target group for the results of the transfer of knowledge gained from basic research is the academic community or industry, while the primary target group for applied population health research is policy makers, healthcare providers or employers. The relative importance of different target groups also varies according to research results. For example, the main target group for clinical research, which points to the lack of efficacy of the test drug, may be national policy makers (including regulators) and industry, while the primary target group for clinical research aimed at testing the benefits of drug use can be patients, healthcare professionals or industry (Grimshaw et al. 2012). Similarly, the target group for testing the effectiveness of an intervention program for work-related stress reduction, a healthy lifestyle education program, or work environment interventions can be employees, employers, or national policy-makers.

### Basic content units for knowledge translation

Increased interest in the transfer of knowledge means that the relevant information for transfer of knowledge is considered to be the results of the research of individual studies. However, given that the results of individual studies may often be contradictory, as evidenced by the Ioannidis 2005 study, the relevant units for implementation into practice should be the lessons learned from several independent scientific studies (Ioannidis 2005). In other words, the basic unit of knowledge transfer should be systematic review articles or meta-analysis  (Grimshaw et al. 2012, Merlin et al. 2009).

**Figure 4.** Hierarchy of scientific evidence



*Source: Merlin et al. 2009, adjusted*

### Barriers to effective transfer of knowledge

The best evidence available is an important element of the interactive process of transferring knowledge into policy and practice, but the barriers to which experts are exposed may prevent rigorous implementation of the decision-making principles. The results of research on the use of interventions to improve mental health at work have shown that employers are not confident in selecting appropriate interventions and do not know how to interpret available evidence to find answers to these questions (Tetroe  et al. 2008).

Several barriers have been identified that slow or completely obstruct the transfer of knowledge.

We include **barriers at the level of individuals**:

» a huge amount of newly published research findings,

» insufficient time to study the amount of literature,

» restricted access to research resources (limited access to search databases and in-extenso-type articles); and

- lack of skills to assess and understand the results of research (insufficient training in research methodology and statistics).

However, there are also **barriers at the level of organizations** that prevent efficient transfer of knowledge and we advise:

- structural barriers (eg financial barriers),
- organizational barriers (eg lack of equipment),
- professional barriers (eg knowledge, attitudes, skills);
- cultural barriers (eg local standards are not in line with the required practice);
- communication barriers (barriers at the level of the employer - employee, doctor - patient).

Another type of barriers are **barriers at the level of specific interventions**: information management process, clinical uncertainty, responsibility and competence perception, entity expectations, standards and standards, financial barriers, administrative constraints and others  (Grimshaw et al. 2012)

## EVALUATION OF THE EFFECTIVENESS OF INTERVENTIONS FROM THE PERSPECTIVE OF TRANSLATIONAL RESEARCH

### Types of interventions

The effectiveness of behavioural change also depends on the type of intervention implemented. The Cochrane Effective Practice and Organization of Care (EPOC) research team evaluated interventions to improve individuals' health and identified over 7,000 randomized experimental and quasi-experiments to create over 80 systematic reviews of intervention programs targeting professionals, organizations, and legal interventions (Ballini et al. 2011). The most common types of interventions included: educational materials, educational meetings, educational outreach, local opinion leaders, audit and feedback, system of comments and complex interventions (Grimshaw et al. 2012).

*1. Printed educational materials*

EPOC defines educational materials as "distribution of published or printed recommendations, including audio-visual materials and electronic publications". Materials may be delivered to the entity either in person or through bulk mail. In general, educational materials are aimed at widening knowledge. They can also be focused on changing motivation if they are written as 'persuasive communication'. Educational materials are often used, as relatively low costs are needed to create them and are, in most cases, easily distributable.

*2. Educational meetings*

EPOC defines educational meetings such as "attending conferences, lectures, workshops or internships". Educational meetings are divided into didactic meetings (usually aimed at disseminating knowledge) and interactive workshops (aimed at changing attitudes or acquiring new skills). Educational meetings are relatively often used and are relatively easy to implement.

*3. Educational outreach*

Active learning is understood to mean "sending a trained person (an educator) who encounters the target objects of knowledge transfer in their environment to provide information in order to change the functioning of those individuals. The information the educator sells may contain feedback about the operation of the target objects ". This type of intervention is inspired by the principles of social marketing. The learner tries to interpret a maximum of three relevant links within 10-15 minutes. It is most commonly used to influence the behaviour of doctors when prescribing medication.

Implementation requires considerable costs, including financial costs of preparing materials.

*4. Local opinion leaders*

EPOC characterizes opinion leaders as "individuals who are identified by their colleagues as educationally influential, i.e., they are opinion makers. This leadership, this ability of the individual to informally influence others, is not the result of a formal position or state of the system, but it is the personal competence of the individual. "Manifesto leaders are able to influence the knowledge, attitudes and social norms of their group. Costs related to the use of opinion leaders within the intervention programs include the costs of identifying leaders, their training and the additional costs of services.

*5. Audit and feedback*

Audit and feedback are characterized as "any performance evaluation over a defined changeover period." Information can be obtained from health records, from computer databases or from observation of subjects (patients, employees). The aim of this intervention program is to create cognitive dissonance as a stimulus for behavioural change. The resources needed to implement this intervention include the cost of data collection and analysis and the cost of disseminating information. The feasibility of the intervention depends on the availability and quality of the feedback data and the so- "Corporate culture", i. whether the organization is open to auditing and feedback.

*6. Reminders*

The comments are defined as "specific information designed for the body designed to evoke a memory of the activity to be performed." This information can be verbal, printed or electronic, and most of the early commentary studies were conducted in highly-powered US academic health centers and the generalization of the knowledge gained from these environments for other systems has been questioned. Today interest in using the feedback system exponentially increases with regard to the use of mobile technologies and the support of integrated care systems The resources needed to implement this intervention vary and depend on the feedback mechanism.

*7. Tailored interventions*

Tailored interventions are 'strategies to improve professional practice that are planned taking account of prospectively identified barriers to change'. Barriers to change refer to factors that have the potential to impair the effectiveness of interventions designed to improve professional behaviour/practice

*8. Multifaceted interventions*

Complex interventions are "any interventions that consist of two or more components." Complex interventions that are based on behavioural change theories are more effective than simple interventions. At the same time, however, they are usually more costly than simple interventions. When designing complex interventions, it is necessary to consider how each component of the program affects each other in order to maximize the effect of the intervention.

### Effectiveness of knowledge transfer strategies

At present, there is still little good scientific evidence on the effectiveness of knowledge transfer strategies, especially those aimed at decision-makers, whether politicians or senior managers. Perrier et al. (2011) conducted a systematic screening study, which included two research studies (Perrier et al. 2011).

The first research study focused on testing the intervention when decision-makers received five relevant systematic review papers. The use of these surveys was evaluated 3 months and 2 years after the intervention. Research results showed that within 3 months, 23% of policy makers have used at least one intervention to implement policy decisions. Within two years, this percentage has risen to 63%. The second research study evaluated three different ways of transferring information:

1) access to the online database of systematic surveys,

2) access to the online database of systematic surveys + targeted reports,

3) access to the online database of systematic surveys + targeted reports + cooperation with the knowledge maker for one year. The results of this study showed that access to the online database of systematic review work in combination with targeted reports had a statistically significant effect on health policies and programs.

The review by Lavis et al. (2005) focused on the analysis of factors that influence the process of using scientific evidence for decision making (Lavis et al. 2005). Sixteen studies were included in the survey. The results of the analyses showed only two factors that appear to be important in the use of scientific evidence by decision-makers. The <u>first factor</u> was the existence of interactions between researchers and decision makers, regardless of whether this interaction was formal (researchers as members of advisory bodies) or informal. The <u>second factor</u> was research that corresponds to the beliefs, values, interests, or political goals of decision-makers and their interest groups.

## Key messages

- We are currently experiencing unprecedented advances in public health and health care in the context of discovering new approaches and interventions that have the potential to improve the health and well-being of employees at the workplace, while strengthening health systems and states economies. Yet, the implementation of these findings into practice has been facing many barriers, and has been slow and inconsistent, resulting into the existence of a significant gap between the latest research evidence and what is occurring in practice.
- Knowledge translation is the process of extracting and disseminating the best available research evidence and using this evidence to improve health practices and policies, including mental health of employees. Knowledge transfer means "Ensure that stakeholders are aware of the results of scientific research and take advantage of these results in health and healthcare decision-making." (Grimshaw et al. 2012).

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