LONG-TERM HEALTH AND SOCIAL CARE

Iva Kuzníková

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Readers' note

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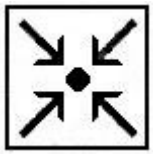
CONTENTS

Notes to the symbols used

Study guide – author's entry within the text, specific way in which the author communicates with the student, gives encouragement, provides additional information to the text.



Example – explanation or example from concrete life situation, practice, social reality etc.

Important note

Literature – cited or referred to in the study text, complementing or broadening knowledge.

Comprehension questions and tasks – check student's understanding of the text and the subject matter, retaining essential information as well as student's readiness to apply the information at solving problems.

Correspondence tasks – the student proceeds as instructed using considerable amount of own initiative. The tasks are continually monitored and assessed throughout the entire course.

Tasks to the text – any task, including partial, which students are obliged to fulfill.

INTRODUCTION

The present text was created as study support material to accompany the study programme Health and Social Care at the Faculty of Social Studies, University of Ostrava.

Demographic changes – especially ageing of the population as well as changes in structure and patterns of disease occurrence, increase in the number of patients not only suffering from chronic diseases, but those affected by diseases or injuries that had previously been incurable, brought an increased number of people with impaired self-sufficiency. At the same time, life expectancy is on increase and so is the number of people living up to a very old age (*oldest old / old old – persons older than 80 years of age*), people with a long-term disease as well as persons with disabilities (Holmerová, 2016).

The above characteristics of the target long-term care persons can generally be dealt with as part of the concept of *physically disadvantaged persons*, for whom we observe changes in the quality of life, self-sufficiency and health, both somatic (e. g.: frailty syndrome with the old old elderly) and mental (e. g.: dementia, mental disease).

For these people, modern societies have developed systems to limit their exclusion. On the one hand, systems of long-term care are set up which are based in accordance with the objectives of the humanity societies, with respect for the right to dignity. On the other hand, however, we are faced with discrimination against persons from within the target group of the long-term patients (refer to previous paragraph, but they may also be users of services or patients receiving long-term care) who may not have equal access to long-term care. The unavailability of care results from numerous social factors (local unavailability, absence of networking services, limits on affordability for long-term patients and their families, education, information etc.), but it can be handled at all social levels (formal and informal at the level of individual persons, community, municipalities, regions, state, churches etc.). (More on the social constructs of reality in the form of discriminatory labelling of target groups and stereotyping can be found in L. Vidovičová (2011) in her publication “Křehký pacient a primární péče“ (Frail Patient and Primary Care), which I highly recommend to students as a key study resource on the issue).

At present, the ***system of long-term care*** in the Czech Republic is neither incorporated into the country’s legal system nor linked to the concept of coordinated rehabilitation. Long-term care is currently provided at different sectors and by different types of providers (ministries of health, labour and social affairs, regions, cities, municipalities…) and since it finds itself on the border between the health and social sectors, a delimitation of long-term care is complicated. From general practice, from professional texts, analyses and proposals of legislative documents it is clear that the area of providing long-term care and related forms of assistance is an integral part of the coordination process, an overall ***coordination of rehabilitation***.

Leading Czech experts in the field focus on the analysis of the current situation, on design and development of concepts in the field of long-term care, which could be systematically integrated into coordinated rehabilitation. The current initiative of the Ministry of Labour and Social Affairs to adopt a Coordinated Rehabilitation Act is perceived as very promising, representing a qualitative shift in health and social care. The working group for the

preparation of the Coordinated Rehabilitation Act has dealt with the definition of the target group and the process, as well as with the providers of rehabilitation. Pursuant to the measures of the National Plan for the Promotion of Equal Opportunities for Persons with Disabilities 2015-2020, the substantive intent of the Coordinated Rehabilitation Act is to be submitted by the end of this year. The Ministry of Labour and Social Affairs has continually dealt with the topic of coordinated rehabilitation since 1999. Since then, several materials have been prepared and submitted to the legislative process. In addition to the working group that is preparing the subject matter of the future Act, the working group for the employment of persons with disabilities also dealt with the issue.

For example, the resolution of the Government Board for People with Disabilities of 2016 implies that the so called ***rehabilitation coordinator*** should work in the Czech Social Security Administration as it is this institution that manages the area of disability pensions. Extending the competences of social workers in healthcare to work with people with disabilities is under consideration, too.

The key concept for long-term care in the Czech Republic has currently been the *National Plan for the Promotion of Equal Opportunities for Persons with Disabilities*. A system of long-term care is proposed integrating the necessary health and social services in accordance with special legislation and making effective use of existing capacities in the health and social services system. ***The aim and the defining feature of long-term care is the provision of health and social services to those who, for various reasons, need health (especially nursing) care and social services.*** The primary task is to address the availability, quality and funding of healthcare provided in housing facilities of social services.

This implies that the long-term care system addresses a variety of target groups of physically disadvantaged persons, including children, people with disabilities, the mentally ill, senior citizens with impaired self-sufficiency, the dying and other groups. The organization of providing aid belongs to the competence of several ministries, where mutual interdisciplinary debate and cooperation in fulfilling the goals of the humanitarian society are expected. The issue of long-term care has also been a challenge for the development and cultivation of effective forms of social assistance for physically disadvantaged persons as well as creation of space for finding constructive ways of dealing with current and future social changes.

The study support guides students through the respective *issues* of long-term care and approaches questions that are not clearly addressed by Czech legislation which sets the legislative outset for the practice social services in healthcare. The scheme of long-term care is shaped by both experience of professionals from abroad and by partial experience of experts from various areas of long-term care in the Czech Republic. The text, therefore, refers not only to resources and experience worldwide, but addresses primarily the area of long-term care within the cultural and social environment of the Czech Republic.

The present text will only provide students with a *basic outline* of related concepts and facts. It does not address the topic of long-term care funding, which varies depending on current legislation. Therefore, students should check information on funding from the sources currently available and from materials published by the ministries of the Czech Republic.

In Ostrava, 1st September 2017 Iva Kuzníková

On studying the text you will learn about:

- Delimitation of the term *long-term care* (in further text LTC) and related terminology.
- Available information on long-term care and its indispensable role in helping the target groups of clients such as persons with long-term disease and persons with long-term adverse state of health.
- Types of long-term care, its subjects and objects.
- The concept of shared care.
- Needs and quality of life aspects of people with long-term disease.

You will get:

Individual chapters of the text gradually present both a delimitation of terminology, the preliminaries of long-term care, and an outline of the current situation of the issue in the Czech Republic. The chapters make students acquainted with desectorialization of long-term care and the tendencies of overcoming it.

Students will encounter the needs of persons requiring long-term care and aspects related to their quality of life.

The issue of persons with adverse state of health requiring long-term care is outlined in the study support by Hana Lukšová (2017): *Target groups of long-term care*.

1 LONG-TERM CARE

Keywords of the chapter:

Long-term care, health and social, self-sufficiency, daily life activities, multi-disciplinarity

Study guide:

Long term care (LTC) – a combination of health and social services needed by persons dependent on the assistance of another person because of their long-term unfavourable health condition.

Definition:

- According to the Organization for Economic Cooperation and Development (OECD), these are offers of health services, social services and their combinations for persons with reduced self-sufficiency dependent on external assistance. *"This is care provided to people who need help and care in their daily self-service activities to ensure a dignified life."* (OECD definition).
- The European Union defines long-term care as *"care provided to people whose health is stabilized, but at a level so unsatisfactory that they are not self-sufficient and need both health and social services"*.
- Long-term care is also defined by the National Ageing Preparation Programme (Ministry of Labour and Social Affairs CR, 2009): *"Long-term care is both health and social care. Health and social needs are inseparable within a particular part of people… The long-term care system must be based on the integration of health and social services provided by institutional, outpatient and home services. The development of the long-term care system requires the transformation of long-term care facilities and homes for the elderly. The decreasing extent of care services provided in particular homes in most regions can be assessed negatively."*
- However, long-term care can also be defined as medical care provided to people with long-term disease (chronic disease), which has not yet led to a limitation in self-sufficiency or dependence on external assistance. This care is also long-term and aims at extending the period of self-sufficiency and minimizing the complications of the disease.

The long-term care system should enable people to remain in their natural environment and create conditions for their family members.

1.1 HEALTH AND/OR SOCIAL CARE?

Whether we are talking **about long-term health care and / or social care** has already been partially answered in the above-cited definitions, and in the text below, the answers appear in a more detailed specification of the LTC topic. Here, let me call for students to be responsive and sensitive to interdisciplinary topics and, in addition to theoretical passages, to perceive the issue from the perspective of a person who requires long-term care.

If a person finds themselves in a life situation with an unfavourable state of health, in accordance with a holistic concept, their life is affected in all key areas. In the mental, somatic, social (both interpersonal and environmental) and last but not least, spiritual area. Each area varies according to the individual condition of the person. This is crucial for understanding the goals of long-term care, as it cannot be unified and standardized under any social conditions. An expert in long-term care coordination should keep on top of things while planning and assessing each client's life situation.

The system of long-term care is based on the integration of health and social services (institutional, outpatient, field). It is the transformation of hospitals for long-term patients and homes for the elderly that is crucial for the development of LTC. The decrease in availability in terms of scope and capacity provided by field care services (in homes of clients) is a negative trend. The provision of these services is legally anchored in particular:

1) in the Social Services Act No. 108/2006 Coll. (Zákon o sociálních službách), as amended
2) in the Act on Health Services No. 372/2011 Coll. (Zákon o zdravotních službách), as amended

Basic objectives and principles of the LTC concept:

- Fair access to health and social services
- Protection of human dignity and provision for individual care
- Support of autonomy and functional status of clients
- Ensuring an optimal way of providing long-term care (LTC type)
- Support for development and quality of LTC services
- Support for informal carers (family, community)
- Support for the professionalisation of informal carers (education and training, financial provision)
- Improving individual assessment of clients´ needs and providing compensation (benefits, aids, services)
- Providing information about services
- Coordination of services, support of LTC service networks, ensuring coherence, availability
- Intelligibility and orientation in the service system
- Defining the position of health and social professions participating in LTC

At present, funding and a clear distinction between health and social care are not delimited in legislation, clients are often unsystemically relocated from health and social services to homes, from homes to various service facilities, between the service facilities etc. Therefore, LTC should offer interconnection of health and social services in the Czech Republic, which are interconnected functionally at the level of municipalities and meet the needs of senior citizens and people with disabilities. As part of coordinated rehabilitation, it should introduce a multidisciplinary assessment of clients´ health and social needs. Existing or potential clients and their family members need to be more involved in the providing of LTC system.

Emphasis is on the maximum possible provision of long-term care services in the client's natural environment.

Questions for consideration:

Do you know about any long-term services in the place where you live? Are you involved in helping or caring for a disabled person? What services could make this care easier? Have you thought about ways of financing services for the disadvantaged?

Task: Study the bill amending Act No. 108/2006 Coll., On Social Servicess, as amended, and Act No. 582/1991 Coll., On Organisation and Implementation of Social Security Services, as amended, https://apps.odok.cz/veklep-detail?pid=ALBSAGVLATVS

Follow the current state and development of legislation as amended.

Consider the comments of Public Defender of Rights (Mgr. A. Šabatová, Ph.D., on 13.01.2017) on prepared amendments of what is known as the amendment act.

1.2 TYPES OF LONG-TERM CARE[1]

Long–term care (LTC)[2] means both home care and institutional care. It is a complex of services **needed by people with long-term limited self-sufficiency**, especially in the ***basal areas*** (hygiene, dressing, food preparation and consumption, medication, mobility) and ***instrumental areas*** (enabling people to live independently of their community, such as shopping, obtaining finance, ordinary housework etc.). The condition causing long-term limited self-sufficiency is mainly (not exclusively) a result of chronic disease or disability.

Like the term “rehabilitation”, the content of the term “long-term care” has historically been subject to linguistic distortion in the Czech context, especially for a priori association with long-term institutional care. However, LTC can be understood both in a broader sense and in a narrower sense as a legislative, organisational and fiscal unification of elementary ***health and social support and care*** at the level of the intersection of health and social services.

[1] The topic is also discussed in the chapters on providers and subjects of long-term care.
[2] Material for discussion on the onsets of long-term care in the Czech Republic http://www.mpsv.cz/files/clanky/9597/dlouhodoba_pece_CR.pdf (cit. 2013-08-16)

In practice, these services are offered in the form of **residential** (provided by, for example, hospitals for long-term patients, hospices, specialized medical institutions, nursing workplaces in hospitals and follow-up care, residential social services etc.), **outpatient** (rehabilitation centres, day or night centres etc.) and **field** (health and social services at home and in the field). An integral and essential part are the ***informal long-term care providers in households***, whose support should be focused on in future reforms of the long-term care system (see the draft of what is referred to as the amendment law, 2016).

Some authors divide the forms of long-term care provided into **professional and family care**. I also add the term of **informal care**, which includes not only family care, but also care by lay caregivers from the client's close neighbourhood (neighbours, friends…). However, there are already attempts to promote the professionalisation of family care for people with long-term disease (persons with long-term adverse health state) as one of the ways of developing and innovating the concept of long-term care.

However, long-term care is not made use of by all the long-term patients. On the contrary, most of these persons strive to maintain the quality of life to date or try to prevent its further deterioration!

1.3 INDICATORS OF LONG-TERM CARE

The population ageing rate is expected to grow rapidly in the Czech Republic, in Europe and as well as worldwide.[3]

Ageing can be viewed from a dual perspective. It is a phenomenon characterizing the progress in developed countries, so ageing can be understood as a demographic change (described as early as 1934 by A. Landry, French demographer) where mortality is gradually decreasing as a result of improved living conditions, while natality is decreasing. This leads to the so called ***"the ageing of population"***, with an increasing number of older people and a decrease in the proportion of children in the population.[4]

Furthermore, ageing can be understood as a term that also refers to the sum of the terminating (regressive, involutionary) changes in morphology and function which occur

[3] Demographic situation is dealt with in following chapters.
[4] For more details on the age structure of developed countries and the poorest countries in relation to demographic development see OECD Health Policy Studies: A Good Life in Old Age? OECD, EU 2013; European Commission: Long-Term Care for the Elderly, 2013; Concept of Family Policy of the Czech Republic (2017)

gradually and individually. Involutionary changes overlap with disease and lifestyle changes (e.g. atrophy – which is often confused with ageing). I refer in more detail to the terminology of ageing and old age mainly from the field of geriatrics and gerontology.

Population ageing is a challenge for development of the LTC concept. The growth in the need for LTC is mainly due to the growth in the number of seniors. The figures speak for themselves; the number of people aged 65 and over is estimated to be nearly 3.2 million, which will be almost one third of all people living in the Czech Republic. At the same time, by 2050, the number of people aged 85 and over will more than triple to more than 0.6 million, representing around 6 % of the population[5].

Given the likely reduction in the availability of informal and formal care providers and the expected up to double increase in LTC expenditure by 2050, the only possible (and difficult) solution is:

Coherent vision of long-term care, a comprehensive approach involving a policy that focuses on both **informal LTC providers** (family, community) and **formal LTC services**. Also a policy promoting the relationship between the informal and the private sector of the LTC.

Historically, shaping long-term care is a serious and long-term issue of international importance, influenced by, for example: the Vienna negotiations in the 1980s, the OECD study on long-term care and disability development, the WHO concept on successful ageing and healthy ageing or a chain of EU professional conferences.

Government Council for the Elderly and Population Ageing

is a permanent government advisory body on issues related to the elderly and the ageing population. In its activities, it strives to create conditions for healthy, active and dignified ageing and old age in the Czech Republic and active involvement of older people in the economic and social development of society in the context of demographic development. Currently, the Council plays a key role in the issue of providing long-term care on the health-social border.

Self-study link: http://www.mpsv.cz/cs/2860

[5] PROJECTIONS OF THE POPULATION OF THE CZECH REPUBLIC UNTIL 2100, CZSO [online]. [cit. 2017-05-08]. Available from: https://czso.cz/csu/czso/projekce-obyvatelstva-ceske-republiky-do-roku-2100-nfu4s64b8h4

The main **transformation objectives of LTC** were formulated as follows:

- Deinstitucionalization
- Desectorialization
- Deprofessionalization
- Demedicinalization
- Preventing the need for LTC

Deinstitutionalization should lead to a reduction in the number of institutions, while respecting the subordination of autonomy to dignity and arraging the availability of dignified institutions to people suffering from dementia. Furthermore, it should help anchor the centre of gravity of LTC at community level and strengthen community services.

Desectorialization should aim at increasing the flexibility of the system, breaking down barriers between professions, ministries and systems and **strengthening the health and social concept of LTC**.

Deprofessionalization is understood in terms of shifting care to informal carers, family, volunteers, community (neighborhood, social groups, social networks).

Demedicinalization is the removal of clients from purely medical long-term care, removal of purposeful medical interventions.

Preventing the need for LTC - preventing, averting, healing, early rehabilitation of a decline in health potential and loss of self-sufficiency.

Who is LTC important for?

Human ageing is undoubtedly one - not the sole - reason for explaining the necessity and importance of long-term care. Obviously, an elderly person with physiological loss of function, reduced fitness, resilience and adaptability, who is experiencing functional deterioration, increase of stressors and pathological changes, is becoming a potential object of long-term care.

Another reason for the development of the concept of long-term care is the area of **chronic diseases** (both congenital and acquired). These affect not only the elderly, yet in old age there is an increase in their incidence and development of disability associated to them. Their increase in population is related not only to the ageing of the population, but also to the level of health and medical care provided, to the development of scientific knowledge in the field of medicine, but also to the lifestyle of the population reflecting living (bio-psycho-social and environmental) conditions.

The third category of persons in need of long-term care are **people with disabilities** (congenital, acquired).

Long-term care also plays an important role in the process of dismissing **clients from acute health care.**

Need for LTC is determined by clients´ needs:

However, long-term care focused on the elderly, chronically ill, people with disabilities, including children or discharged from acute care, differs in its implementation, can take many forms and, above all, **must respond to the individual needs of clients** (not only) of the above mentioned categories.

Long-term care is an integral part of coordinated rehabilitation. **Coordinated rehabilitation**[6] means *"combined and coordinated use of therapeutic, social, occupational, educational, technical and technological means to gain / regain functional capacity that is limited due to temporary or long-term adverse health conditions. At the same time, rehabilitation focuses on the stabilization of health state, eventually. Mitigating the risk of progression and multiplying the consequences of disease or injury, respectively. secondary disability. Rehabilitation is an effort to flexibly interconnect professional support tools and activities in order to improve personal and social functioning of a person with reduced health condition and to positively support interdisciplinary quality of their life. The current foreign trend is the focus on community based rehabilitation, which aims to provide rehabilitation support in the natural human community."*

[6] Coordinated rehabilitation, VÚPSV 2012. Available from http://praha.vupsv.cz/Fulltext/vz_344.pdf (cit. 14. 4. 2013)

Therefore, the rehabilitation process does not only concern healthcare professionals and healthcare, but also ***multidisciplinary teams*** participate in it so that rehabilitation covers all aspects of the client's life. Long-term care provided within the rehabilitation process must be linked to the formulation of clients' needs, the assessment of the needs and the formulation of standard or above-standard ways of satisfying them.

Clients formulate their needs themselves (with the help or advice of a rehabilitation or health and social worker), they should specify which needs are the key ones and which ones are not so important. In his article, Libor Novosad draws attention to the Czech practice, when the NRZP CR (National Council of Persons with Disabilities) and patient organizations point out that this is not the case and the forms of satisfying clients' needs are not decided in a systematic manner.

In accordance with Novosad (2011), it is necessary to emphasize that the needs of people with disabilities differ from those of the elderly or those with long-term disease. The needs of clients determining the need for LTC are diverse, which reflects the level of functional ability, personality traits, client background, availability and coherence of services.

Questions for comprehension check and self-study:

Find in literature and define: oldest old, syndrom frailty, long-term care, person with long-term disease.

Why can we not strictly separate long-term care in the health and social care sector?

Try and formulate the distinction between “a person with a long-term disease“ and “a person with a disability“.

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2. PEOPLE WITH LONG-TERM DISEASE

Keywords of the chapter:

Person with health handicap, long-term disease, social support, demography

Study guide:

People with long-term disease

"The equivalent of the term long-term disease is a chronic, or permanent, protracted disease. People with long-term disease may be of any age group, suffering from a disease that will last for a long time, with a poor prognosis and hope for a complete cure. Long-term disease may, depending on severity of the diagnosis, lead to disability (note: decrease or loss of work capacity) or many consequences in personal, social life, and, therefore, the application of coordinated rehabilitation of persons with long-term disease is becoming an essential effective method in delaying possible institutionalization."

Long-term diseases bring innumerable problems of health, mental and social character, with which they try to cope with their wider social environment, which provides the so called ***social support*** (note: this is a form of help that comes to a person in difficulty from another person).

Depending on the severity of the diagnosis, long-term disease can lead to disability (note: decline or loss of work ability) or many consequences in personal, social life and thus require ongoing collaboration between the patient, medical professionals and care providers, i. e. a ***team approach***.

The term "long-term disease" may be confused with the term "disability".

The context of treatment of long-term patients is different from acute (short-term) patients. When patients encounter this difficult life situation, they use different strategies to manage a long-term disease, learn to live with the disease and adapt to the symptoms of the disease. Ending the hospitalization of people diagnosed with chronic disease does not mean returning to normal social life from which they were taken out as a result of hospitalization, but means *"discovering the limitations of the disease likely to increase with disease progression"*. It is important to help long-term patients accept the **changed health situation as their future**

normality. Most of the long-term patients are dispensarized (*followed up)* (note: long-term regular check-up by a physician who leads and evaluates the treatment). According to law, dispensarization is compulsory for many diseases (AIDS, tuberculosis, cancer etc.).

People with long-term disease are repeatedly hospitalized, both as scheduled and suddenly. They are clients of all types of health facilities (hospices, hospitals for long-term disease, outpatient and follow-up health-care facilities etc.). Or they are clients of social care services.

The most frequently diagnosed long-term diseases include: cardiovascular diseases, cerebrovascular diseases, cancer, neurodegenerative disorders (Vascular dementia, Alzheimer-type dementia, Parkinson's disease, Huntington's disease, Epilepsy, demyelinating diseases), autistic spectrum disorders, mental diseases and behavioral disorders, musculoskeletal disorders, metabolic diseases (Diabetes mellitus, metabolic syndrome, obesity), chronic respiratory diseases (Chronic obstructive pulmonary disease, Bronchial asthma), kidney diseases, work-related diseases, ageing-related diseases, post-traumatic conditions including post-traumatic CNS damage. We also know an association between infectious agents of long-term infections, which cause chronic diseases (tumors of the digestive tract, cervix, liver).

Mental diseases are primarily dementias (e.g. caused by Alzheimer's disease). People over 60 years of age have a significant risk of developing dementia, as many as ¼ of people over 85 years of age suffer from dementia, of which 62 % suffer from Alzheimer-type dementia. It is a global disease, regardless of the development level of the regions in the world. In the Czech Republic, this issue is intensively studied by the Czech Alzheimer Society. (ČALS: www.alzheimer.cz), which annually updates the "*Dementia Status Report*". It is estimated that in 2050 there will be up to 383,000 people living with this disease in the Czech Republic. The worldwide development of this disease is charted by an international company called Alzheimer's Disease International.

An integral part of long-term care is the provision of palliative care to persons in terminal stages of incurable diseases and to the dying people. Bed and mobile hospices have been established in the Czech Republic since the 1990s, but their number still does not cover the need for palliative care.

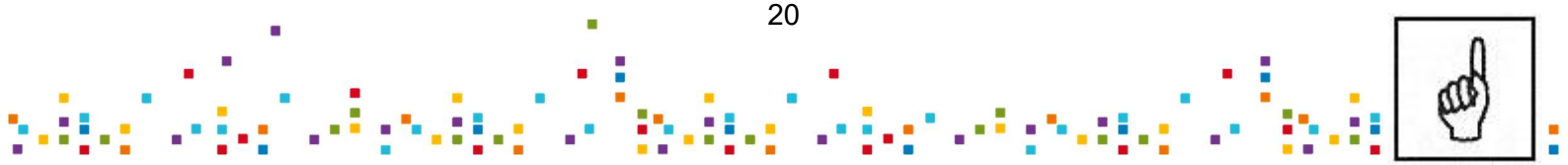
However, not only persons with long-term diseases are exclusive clients of long-term care, but also people at risk with changed health conditions (persons with disabilities, including children and senior citizens).

Sometimes there is a change in the social role/social roles due to a chronic disease or reduced physical ability of a client. Here, recovery plays an important role – it starts with the diagnosis and initiation of ***coordinated*** (*complex/comprehensive*) ***rehabilitation***, which is an integral part of the therapeutic process, with the transfer of information by the doctor, education by medical staff, effective forms of assistance and psycho-social support after the disease. Comprehensive rehabilitation also involves initiating steps to *reintegrate* the patient in order to prevent possible consequences in working life and the resulting financial uncertainties, in the educational process of children, in the structure, dynamics and atmosphere of the patient's family, in housing conditions and leisure time activities. Also to avoid ***stigmatization*** and permanent ***social isolation*** and, on the contrary, to promote ***autonomy*** of people with long-term disease. Where a full return to original social roles is not possible, it is social work providing psycho-social support, financial security, legal advice and the availability of services saturating the needs of people with long-term diseases that play a fundamental role.

Demographic situation in the Czech population:

Demography deals with the reproduction of human populations, the conditions that affect it and the regularities that govern the process of demographic reproduction. It is crucial for orientation in the issues of population ageing, sociology of senior population related to lenght of life, percentage of seniors and people with health disadvantages in society. It influences the concept of their social role, approach to politics, employment, housing policy, etc.

At present, there are several strategic documents in the Czech Republic dealing with demographic changes and population ageing. This is mainly the National Action Plan to promote positive ageing for the period 2013 to 2017. However, there is no coherent legislation which require to take demographic changes into account or to adapt the existing one to demographic trends when drafting new legislation. Demographic changes needs to be approached in a systematic way, because only well-timed and coherent preparation of society and its public policies for demographic changes is a guarantee that they will not be threatening to society but, on the contrary, they will be an opportunity, for example in the form of new sectors of the economy linked to the care and needs of older people. Preparing for demographic changes must cover a wide range of areas, from the education system and the labour market to social services or the social system. Systematic planning of public service capacities in response to demographic trends is an integral part of the timely reaction



to demographic change. Given the ageing of the population, preparation for demographic development should also include support for informal carers, further education or support for the retention of the elderly population in the labour market and, in general, support for the policy of active ageing and meaningful leisure time for older people and seniors (active participation in community life, culture, travel etc.)

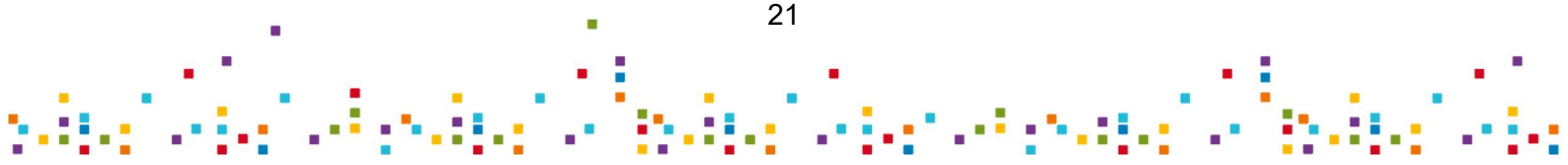
Basic processes of demographic reproduction:

Natality (birth rate) and **mortality** (death rate). The mortality process is described in the life tables, which result in **life expectancy**. In average, this indicates the expected number of years that a person of a given age and sex has ahead of him/her. It is necessary to distinguish the **average age of the living** (the arithmetic mean reflecting the age structure) from life expectancy. **Age median** refers to the age that divides a given population into two equally large halves (the lower the more children and young adults are compared to middle-aged and older people).

Currently, ageing population is a demographic trend in developed countries. In the EU, the population continues to grow (expected to grow by 2060), but grow older significantly. While in 2008 the number of children was three and a half times higher than the number of very old people (80 years old and older) **in 2060, this number will have been almost equalized**. With the increasing process of demographic ageing and the growth in the number of older people, the quality of life is increasingly important, i.e. in what state of health and under what social conditions people live their increasing longevity. According to the so called healthy life expectancy at birth, men in the Czech Republic live, in average, only 62 years in good health, i.e. without health limitations, and in case of women it is 64 years. Thus, both men and women spend a relatively large part of their senior age with some health hindrances. In 2014, life expectancy at birth in the Czech Republic was approximately 75.8 years for men and 81.7 years for women; the EU average in 2013 was about 77.8 years for men and 83.3 years for women.

Healthy life expectancy is a related term, formerly referred to as life expectancy without disability / lack of self-sufficiency. Healthy years of life, healthy life expectancy represented 63 years for women and 61 years for men according to calculations performed on the basis of mortality tables and subjectively perceived disability (ÚZIS research, 2007).

The term **disability rates** then refers to the rates that specify the part of the population (seniors) who are likely to need long-term care services. This parametre is defined as a **dependency in at least one of daily activities** (Activity Daily Living, ADL).



An extensive type of reproduction characterized by high rates of both natality and mortality, especially with new-born babies and children, continued approximately until the peak of the Renaissance in Europe. Life expectancy was low, families had many children, only a fraction of the population lived to old age. At the peak of the Renaissance there was a change from extensive to intensive reproduction – decrease in mortality was followed by decrease in natality. The age structure then changed to a stationary type (gradual life expectancy) and to a regressive type (low marriage rate, childless families or with only one child) in countries with a low birth rate.

From the middle of 20th century to the middle of 21st century, demographic development is dramatic and is taking place asynchronously in economically developed countries and in developing countries (the so called third-world countries), where it is delayed. Demographic ageing is defined as an increase in the proportion of seniors, where the **age of 65 is now considered the limit of old age**.

By 2050, it is estimated that every twentieth citizen will have been over 85 years old in the Czech Republic.

This prognosis is most likely to be fulfilled. Therefore, it is also important to estimate the health and functional condition of future seniors, who will differ from current seniors in terms of health, function and life ambitions. As it will depend on their state of health, their ability to work, it is necessary to think about creating conditions for their social participation, including employment, it will depend on the level of social support and nursing needed in case of serious functional deficits and health problems of unsuccessful ageing.

Deaths

Around 100,000 people die each year in the Czech Republic (of which 62 % of the deaths can be defined as deaths due to chronic causes). 25 % of all deaths are cancer patients. By the age of 40, men die more often (in a ratio of 3: 1), most often as a result of accidents. After 40th year of age, malignant neoplasms appear as the causes of death. With increasing age, cardiovascular system failures begin to dominate. In the long-term perpective, an increase in deaths due to respiratory diseases or diabetes can be observed (2.6 % of death due to respiratory diseases in 2004 and 5.0 % in 2015; 1.3 % of deaths due to diabetes in 2004 and 3.4 % in 2015).

People die in hospitals. **More than two thirds of deaths in the Czech Republic take place in a health facility**. An autopsy was performed in 26 % of the deaths.

Long-term circulatory diseases remains the most frequent group of causes of death, which in 2015 contributed to the total standardized mortality (standardized by applying the WHO European Standard) of 43 % (men 41.8 %, women 44.9 %), followed by malignant neoplasms with a share of 25.7 % for men and 25.4 % for women.

The structure of deaths by cause is comparable to other developed countries of Central and Western Europe. It is possible to say that most people die of the progression or complication of a chronic disease. In case of many individuals, **death is preceded by a period in which patients are functionally limited by a disease** that causes them a number of health, mental, and social problems. This period may last for months or years, depending on the type of underlying disease. This group of patients need a specific form of long-term care, including palliative care. In the Czech Republic, however, there are currently no conditions for high-quality palliative and long-term care to be available for a given group.

The statement can be based on statistical data concerning the place of death of people in the Czech Republic. In the European countries as well as in the Czech Republic, acute and long-term care hospitals are the most frequent places of death.

According to estimates, only 5-10 % of deaths at home are expected, others are sudden, unexpected, when the patient dies before the arrival of the emergency medical service.

The data show a low share of patients in home care and an persisting trend of institutional long-term care, especially in health services.

In accordance with the data on the demographic situation in the Czech Republic and, consequently, in Europe, the social policy of the state should set systemic support for various forms and types of long-term care (support for formal and informal care), especially support for their funding. In view of these demographic trends, the provision of LTC in the home / natural environment of ageing people will play a key role. In order to provide field and home forms of LTC, not only financial support for informal carers is necessary, but also the **development of a range of services** that would complement informal care centreed on one carer (most often women – daughters or wives of long-term ill and non-self-sufficient people).

For more details see the chapter on shared care.

2.1 PEOPLE WITH LONG-TERM DISEASE IN SOCIETY

Social segregation? Stigmatization?

Separation from the so called majority population, or segregation, contributes to discrimination against long-term ill or disabled people. **Segregation** prevents the spreading of knowledge about individual characteristics of individuals, thereby strengthening the strictness of the usually negative (not only thought) stereotypes we have about the whole group. Social status changes with the commencement of life phases or disease phases. The perception of differences is greatly influenced by the media. **Stigmatization** may be a consequence of differences of individuals from the majority, the individual does not meet the expectations or demands of society (the majority). *(cf. labelling theory)*.

On the contrary, we can also meet the so called islands of positive deviation, i.e. positive attitude from which long-term patients can profit. These are (not only) volunteer activities for target groups of the long-term ill and seniors, promotion of hospice care, non-profit organizations, activities of endowment funds etc.

Task: Find articles about the elderly (or about dying) in the selected press over the course of the last half a year. Compare their reperesentation with topics such as healthy diet, weight loss etc.

How to approach persons with long-term disease?

Experts associate social environment and life of people with long-term disease as well as seniors and people with disabilities with terms such as personal autonomy, freedom, dependence, meaningfulness of life with limitations, and also the issue of barriers. Below we present their explanations, without a deeper analysis of the complex issue of the position of patients in society. We will leave this area to experts, i.e. authors from the field of sociology. For example: Sýkorová, D., 2007; Štěpánková, H. et al., 2014 or social medicine

Autonomy is considered to be "*relative independence of individuals with respect to social environment, their ability, will and ability to lead, decide and control life in a given environment*" (Sýkorová, 2007: 75), it is closely related to respect for individual privacy, it is the control of information about one's own person, i.e. not interfering with others (not to be under their supervision e.g.: employees of an institution), so called *self direction*.

Freedom as "*the absence of interference and, at the same time, the presence of alternatives of actions is a necessary prerequisite for the autonomy of an individual, for the development of their goals and interests. Freedom is freedom if it leaves enough room for human choice and activity*" (Sýkorová, 2007: 75).

If one becomes **dependent** on the care of others, there is a greater sensitivity to the behaviour of others. People are often "touched" by not being a constant centre of interest of others, at the same time they realize the loss of vigour, prestige and importance. There is a growing sense of threat and distrust. If a long-term patient is cared for by a specialist (health care professional, carer…), he / she must respect him / her as a personality at the highest level. It is supposed to be: **partnership approach**. The main manifestation of the partnership approach is **personal interest in the patient** and his / her biography. An example of an approach in professional work with clients that deals with a personal life story is the so called ***narrative approach*** (e. g: people with dementia, long-term mental and physical diseases) or so called ***autobiography***. An approach by C. Rogers is another suitable person-centreed approach. Via non-directive interviews and using the manifestations of empathy, truthfulness and unconditional acceptance of the patient, a highly personalized relationship and approach to a **person** with long-term disease can be achieved.

The opposite is the paternalistic relationship, where patterns of superior behaviour are applied by a caregiver, expert etc.

Meaningfulness of life with limitations, long-term disease, disability etc. Every person is heading somewhere. Via their activity they are approaching their goals. However, this may change due to disability or disease, that is why it is really important to focus on the meaning of life, on its values in suffering. The so called ***Logotherapy*** **was developed by V. E. Frankl** who defined three kinds of human values which people can turn their attention and life to. **Experience values** – they concern issues that awaken positive emotions in us. We are receivers of experience values (in art, music etc.). They bring us emotions such as joy and pleasure. **Values created by one´s own activitiy** – i. e. volitional. Our creative activity and potential, by which we enrich other people as well as the whole world are the key factors

here. **Attitude values** – for example: a respectable attitude by people who are very brave in their suffering and hardship. This approach is very important when working with long-term ill and dying people. Likewise, an approach called ***Empowerment*** (author K. W. Thomas) or strengthening one´s resources for coping with situations. It also requires the art of asking proper questions leading to encouragement when coping with a given situation as well as to lesson learned for the future (of one´s own and of others').

Maintaining former social roles, which provide psychosocial support for patients with long-term disease, is crucial to maintain the essence of one´s existence.

Health 2020 Programme (National Strategy for Health Protection and Promotion and Disease Prevention):

In Czech society, the position of long-term patients requiring forms of long-term care is largely dependent on the organization, structure and legislative anchoring of the provision of LTC in the Czech Republic. Therefore, I consider it essential to acquaint students with the steps of the responsible department – the Ministry of Health. For more detail see the document.

In 2014, intensive negotiations were launched between the Ministry of Labour and Social Affairs and the Ministry of Health, taking the government's policy statement into account, as well as meetings of both ministers on the topic of health and social border. The action plans cover areas falling mainly within the competence of the Ministry of Health of the Czech Republic with overlaps into other areas. In these cases it is necessary to collaborate with other ministries, in this case, it is the Ministry of Labour and Social Affairs in particular. The submitted action plan of follow-up, long-term and home care focuses mainly on the health part of this care, but when performing particular activities it will take into account and act in accordance with the outcomes of ongoing interdepartmental negotiations between the Ministry of Labour and Social Affairs and the Ministry of Health. The action plan aims to deal with these three areas:

- continuous improvement of quality of follow-up, long-term and home care,
- improving the availability of indicated care in line with the demographic development of the population,

- increasing the effectiveness of follow-up, long-term and home care services provided.

The action plan aims to achieve the performing of activities in all three areas during the action plan, i. e. by 2020, thus improving the conditions for the provision of follow-up, long-term and home care. The Ministry of Health will be the coordinator of all planned activities, some of which will be provided by an external supplier in accordance with valid legal regulations.

In the Czech Republic, follow-up, long-term and home care belong to the complex of the system of health and social services among health services and social care services. This boundary also determines its extent, content and interfaces with the two segments.

For the area of healthcare services the action plan refers to Act. No. 372/2011 Coll., On Healthcare Services and Conditions of Their Provision (further referred to as the "Healthcare Services Act"). In the area of social care services, Act. No. 108/2006 Coll., On Social Care Services (further referred to as the "Social Care Services Act" is applied.

Follow-up and long-term in-patient care is defined in Act No. 372/2011 Coll. (Section 9 (c) and (d)) on healthcare services:

- Under the current reading of the law, **follow up in-patient care** (Section 9 In-patient care (c)) is provided to a patient who has been diagnosed and whose health state has been stabilized, who has coped with sudden illness or sudden worsening of chronic disease and whose health contidion demands follow-up treatment, in particular, medical rehabilitation care; within tthe follow-up in-patient care intensive care may also be provided to patients who are partially or fully dependent on the support of basic vital functions.

- **Long-term in-patient care** (Section 9 In-patient care (d)) is a type of care provided to a patient whose health condition cannot be significantly improved by medical care and without the continuous provision of nursing care it gradually deteriorates; intensive nursing care for patients with impaired basic vital functions may also be provided as part of the in-patient care.

- **Home care** (Section 10 Healthcare provided in the patient's own social environment) is, together with the visiting service, provided as part of the "healthcare provided in the patient's own social environment". Home care includes nursing care, medical rehabilitation care or palliative care.

- **Spa care** (Section 5 Types of health care (f)) is provided to a patient whose health condition corresponds to the conditions for the provision of spa therapeutic rehabilitation care using a natural curative source or climatic conditions suitable for treatment under the spa act.

The term "**post-acute care**" is also used for the above-mentioned types of provided care, as it is care provided after acute care and it is also used in this sense. In the past, health and social care in the Czech Republic was provided in a simple regime of health care, which included in-patient and outpatient health facilities with a developed system of hierarchy of services and prevention, connected to health care facilities (specialized treatment institutions and hospitals for long-term patients) since 1972, and to the segment of social services (e.g. nursing services and homes for the elderly). Health and social care also included specialized nurses - e.g. geriatric and pediatric field nurses. After 1989, a new system of health services was created. It was modified by a completely new concept of care based on providing services to patients also with regard to their informed decisions or wishes and also by fundamental changes in the reimbursement schemes of health services. The system of health services in the Czech Republic thus started a long-term comprehensive transformation within which the importance and necessity of the post-acute care segment (especially transformation of specialized medical institutions and hospitals for long-term patients) was strengthened on the basis of the relevant legislation and regulations. At the same time, the relevant "nursing days" or "treatment days" or use of beds during days were introduced into the list of medical procedures.

The basic **characteristics of post-acute care** today are:

- professional heterogeneity of the segment;
- demand for follow-up, long-term and home care provided by social and health care in the Czech Republic exceeding the coverage of services, possibilities of the segment;
- inadequate staffing and technical equipment that does not correspond with the scope of provided care and services;
- inadequate investment in the segment of post-acute care with regard to the needs of the system;

- non-motivating settings of the post-acute system in terms of improving quality and efficiency on the level of providers as well as efficiency of services on the level of patients;
- inadequate use of post-acute care services considering health needs and functional capabilities of patients;
- insufficient system of collecting data and appropriate indicators to measure the quality and effectiveness of the care provided;
- insufficient system of control of the functioning, quality and effectiveness of particular types of services in the post-acute care segment.

The post-acute care segment serves as another intermediate step in the progress of patients through the system of health and social services in the Czech Republic. On admission, it accepts patients mainly from acute hospitalizations to stabilize their health and return to functional abilities, and at the exit it collaborates with the system of social services very closely. Given the gradual shortening of hospitalization period for acute care and the increasing number of patients in higher levels of dependence, the need for as well as use of post-acute care services will continue to increase.

Questions for comprehension check and self-study:

Find in literature and define the terms: stigmatization, social isolation, autonomy.

Which diseases lead to the need to help people via a long-term care system?

Find out mortality rate in 2010 - 2017 in the Czech Republic.

Try and explain the difference between life expectancy and healthy life expectancy. Refer to the data provided by the Czech Statistical Office (Český statistický úřad).

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3. LONG-TERM CARE PROVIDERS

Keywords of the chapter:

long-term care providers, entities, social services, healthcare services, professional care x informal (family / lay) care, capacities of professional caregivers and institutional care, family care – supportive care, impersonal care, personal care

Study guide:

A long-term care provider offers and implemets services to clients – **subjects** receiving care.

LTC providers

The principal providers should be

1) attending physician, i.e. a registering general practitioner or attending physician of a patient in an in-patient health facility.

2) Ministry of Labour and Social Affairs, in collaboration with the Ministry of Health, manages and supervises the performance of civil service in the area of long-term care. It sets rules for LTC funding, provides conditions for further education of long-term care workers, creates conditions for collaboration of public authorities in the area of long-term care, keeps records of long-term care providers.

3) The Labour Office of the Czech Republic participates in deciding on the granting of social benefits and allowances.

4) Regions and municipalities in mutual collaboration and in collaboration with service providers create conditions for providing quality long-term care, participate in strategic planning, networking and community development of long-term care services and guarantee availability of information and services.

3.1 FORMS OF LONG-TERM CARE

Long-term care is provided in the **field, outpatient or institutional form**. At the same time, the following alternatives occur:

1) **a system of community care** at the level of municipalities, optimally in collaboration with the community nurse, general practitioner and health and social worker.

2) **a system of coordination of rehabilitation** at the local level (municipalities, towns, regions) in collaboration with municipalities and representatives of providers of assistance and support (formal and informal).

Field care is provided in the form of health or social care (see chapter 3.2). **Field healthcare can take up the following forms of:** hospice care (professional medical palliative care or mobile hospice is provided in the home environment only if the patient's family also participates in the care), long-term healthcare, home hospitalization (such as with post-traumatic and post-operative care following hospitaliyation or hospital treatment), preventive home care, but also one-time provision of healthcare.

For illustration, I give examples of **long-term home care**:

In some cases, chronic lung and respiratory diseases lead to a partial dependence of a client on breathing apparatus, oxygen supply from oxygen bombs and oxygenators. Usually, it is a well trained client who has the main responsibility and knowledge of this type of care (home care). During his / her treatment, the client is educated, informed and supported by the home care team and a general practitioner. For the client, the treatment at home is clearly cheaper and more pleasant.

Gastroenterological diseases. Specialized intervention is focused on stoma care and, in cases of large intestinal resections even on intravenous nutrition, or, alternatively, other form of nutrition, applied by a nurse from the home care agency. In addition to general practitioners, surgeons and gastroenterologists also take care of clients from the medical point of view.

Metabolic diseases. Training of insulin application in children with diabetes mellitus type 1 - it is an integral part of the procedures in the expertise of 925for two weeks in home care. Care for clients with diabetes mellitus type 2, who are dependent on professional care (clients after complications accompanying diabetes mellitus type 2 – after amputations, blind, disoriented, etc.) is also part of home care. Other metabolic diseases require management of pain, hydration of the client's organism, including removal of metabolites from the client's blood (peritoneal dialysis).

Neurological diseases, degenerative diseases of the central nervous system include care for clients after ictus, with Parkinson's disease, Alzheimer's disease, multiple sclerosis, syringomyelia, paraplegics, quadruplegics and others are, due to the frequency of occurrence, in the basic register of diagnostic and indication groups of each general practitioner and home care agency. This is usually a time-consuming care provided by the entire home care team together with the general practitioner and family members of the client.

Oncological diseases require the application of painkillers and an environment that would minimize stress and impact of infections on immune system of a client weakened by chemotherapy. Longer hospital stays usually have a negative impact on mental condition of clients. In close collaboration with oncologists and general practitioners, it is possible to treat nad nurse cancer patients in the home environment. In some cases, outpatient chemotherapy including check-up is performed by an oncologist, and the administration of pain medications or procedures is indicated by the general practitioner. Based on the GPs indication, the pain management is performed by the home care agency team. The benefits of the combination of outpatient and home treatment, its beneficial effect on the overall condition of clients and on the course of the disease is undoubt. In addition, considerable savings for hospitalization and shorter period of incapacity for work are achieved.

Mental diseases require monitoring clients with mental disease, medication administration, activation, resocialization, information transfer and education for people close persons. If home care is provided to the right extent and quality, there is no unnecessary decompensation. Health condition of clients must be monitored regularly. Immediate provision of information about the change of mental and social condition of the client to the psychiatrist and his/her subsequent targeted intervention help significantly improve the quality of life of this diagnostic group of clients and their relatives.

Examples of preventive home care:

Home care is particularly suitable for tertiary prevention, which is aimed at preventing complications in an ongoing disease. This includes, for example, regular monitoring of the overall condition and measuring of physiological values in clients (fully or partially dependent on the assistance of the other person) with cardiovascular disease, collection of biological material in clients with metabolic disease, monitoring the level of resocialization and compensation of the condition in clients with mental disease. Within the community it is possible to use the home care system also for secondary prevention. i.e. uncovering early stages of diseases via screening tests.

In the field of the **provision of social services, field care** is offered in the form of:

Personal assistance – Field service provided to persons with reduced self-sufficiency due to age, chronic disease or disability, whose situation requires the assistance of another individual. The service is provided without time limitations, in the natural social environment of the persons and during activities that the persons need.

Nursing service – Field or outpatient service, which is provided to persons with reduced self-sufficiency due to age, chronic disease or disability, and to families with children whose situation requires the assistance of another individual.

Support for independent living – Field service provided to persons with reduced self-sufficiency due to disability or chronic disease, including mental disease, whose situation requires the assistance of another individual.

Respite services – Field, outpatient or residential services provided to persons with reduced self-sufficiency due to age, chronic disease or disability, who are usually cared for in their natural social environment; the aim of the service is to provide the caring individual with the necessary rest.

Emergency care – Field service providing continuous distance voice and electronic communication with persons exposed to a constant high risk of health or life threats in the event of a sudden deterioration of their health or abilities.

Outpatient care is also provided by services offered by various resorts. Typical outpatient services are offered by following health services: ambulances of doctors, day care centres – mostly part of the services of health facilities, hospitals (e.g. rehabilitation day care centres for children, day care centres for clients of psychiatric wards). Social services offer both outpatient social and respite services or social-activation services in the form of day centres, day care centres etc.:

Respite services – Field, outpatient or residential services provided to persons with reduced self-sufficiency due to age, chronic disease or disability, who are usually cared for in their natural social environment; the aim of the service is to provide the caring individual with the necessary rest.

Daily Service Centres – Outpatient services provided to persons with reduced self-sufficiency due to age, chronic disease or disability, whose situation requires the assistance of another individual.

Day care centres – Outpatient services provided to persons with reduced self-sufficiency due to age or disability and persons with chronic mental disease whose situation requires regular assistance of another individual.

Institutional care is provided in residential facilities of various departments. Hospitalization in a health care facility or long-term stay in a residential facility of social services have their rules and specifics, which are governed by valid legislation. Providing residential social services in healthcare facilities is a specific situation:

Social services provided in inpatient health care facilities - Residential social services are provided to persons who no longer require institutional health care but, because of their state of health, are unable to do without the assistance of another individual and cannot therefore be discharged from a health care facility until they are provided with assistance by a close person or other individual or provided by field or outpatient social services or residential social services in facilities of social services.

3.2 NETWORK OF LONG-TERM CARE PROVIDERS

Long-term healthcare providers

Based on the National Health Information System, we distinguish the following **types of health care facilities and workplaces designed to provide follow-up nursing care**. Follow-up nursing care is defined as "*care provided to long-term chronically ill persons, which usually follows immediately acute care*."

Long-term care in health facilities is considered to be health care and is defined by Act No. 372/2011 Coll., On health services and conditions for their provision (Act on Health Services) and Act No. 373/2011 Coll., On Specific Health Services.

In-patient health facilities:

Follow-up care hospitals – provide follow-up nursing care following the care in acute care hospitals.

Hospitals for long-term patients – specialized medical institutions, where seniors with long-term chronic disease are provided with nursing follow-up and rehabilitation care.

Hospices – specialized medical institutions where palliative care is provided to persons in pre-terminal and terminal stages of diseases.

Other specialized medical institutions – specialized medical institutions providing nursing follow-up and rehabilitation care which are not included in the above mentioned categories.

Departments and workplaces of follow-up nursing care, long-term intensive nursing care and long-term intensive care in acute care hospitals and teaching hospitals – reserved beds for patients with long-term chronic diseases within hospitals providing mostly acute or highly specialized care.

Gerontopsychiatric wards – usually in psychiatric hospitals – care provided to persons with mental disorders for whom specialized institutional care is necessary.

In terms of the length of care provided, facilities that provide long-term care also include:

Psychiatric hospitals – specialized medical institutions belonging to health facilities, which are intended to provide institutional care to persons with mental disorders, for whom specialized institutional care is necessary.

Rehabilitation institututions – specialized medical institutions belonging to health care institutions, which are designed to provide comprehensive long-term rehabilitation in-patient care.

Children's medical institutions – include children's psychiatric hospitals and so called the other children's hospitals that provide institutional care either to children with mental disorders in need of specialized care, or other specialized institutional care in one of the medical fields.

Other therapeutic institutions (department of tuberculosis and respiratory diseases and other medical institutions for adults).

Home health care:

Home health care agencies – health facilities that provide citizens with professional nursing care in their home environment. These facilities provide comprehensive care – health, social etc.

Social services for the area of long-term care

A wide **range of social services** is relevant for long-term care area. At present, no regulation specifies precisely which types of social services pursuant to Act No. 108/2006 Coll., On Social Services, can be analyzed. Therefore, it is important to distinguish the types of social services into:

- social counselling,
- social care services (SCS) and
- social prevention services

pursuant to §32 of the Social Services Act.

Among the three groups of social services, **social care services** are the most relevant to ensure long-term care.

For long-term care, services which provide *assistance in coping with routine personal care*[7] a *and assistance in personal hygiene or in providing conditions for personal hygiene*[8]. are relevant. Social care services providing other forms of support and assistance also have the potential to provide long-term care. It is possible to use all 14 types of social care services defined by the above mentioned legislation (Act No. 108/2006 Coll., On social services).

3.3 SPECTRUM OF THE CARING PROFESSIONS

Specific professions for long-term care are difficult to identify due to the problematic definition of LTC by existing legislation.

Therefore, the chapter lists the specialists of health and social departments separately, according to valid legislation.

Study guide: At present in the Czech Republic, care for persons with health disadvantages, the long-term patients and senior citizens is mainly in the hands of **healthcare workers, workers of registered social services providers and family (informal, community) carers.** Informal carers can also include persons providing care in institutions that do not fall under the above mentioned detention centres, prisons, religious institutions – orders, monasteries and convents). These are also referred to as *institutional households* where persons living there do not take personal responsibility for the management of the household.

[7] Pursuant to the Social Services Act, these activities are basic for the following social care services: personal assistance, nursing service, respite services, day care centres, weekly care centres, homes for people with disabilities, homes for the elderly, homes with special arrangements and social services provided in health care institutions.
[8] This is a basic activity for the same types of SCS as in the previous case. In addition, it is also a core activity in daily service centres. In case of personal assistance, its scope is limited to assistance with personal hygiene.

Spectrum of the professional caring professions

Sometimes the term health-social care is considered synonymous with long-term care, which can evoke the performance of the **profession of a health and social worker (health and social work)**. However, they participate in satisfying the needs and achieving the goals of long-term clients only partially. Especially in the area of satisfying psycho-social needs, in supporting and maintaining self-sufficiency, in providing conditions for maintaining self-sufficiency, social counseling, psychological support and further performance of social work. Profession and education in the field of health and social work continued the tradition of social work in health care in the Czech Republic, where it was performed by so called social nurses (for more details refer to Kuzníková, 2013). It is an expert in the profession of social work, a non-medical health care worker without professional supervision (in accordance with the valid legislation it is a university field of study with a favourable opinion of the Ministry of Health), who does not participate in direct care and satisfying biological needs.

Here, it is necessary to distinguish professional social and health and social workers (educated at tertiary level) from the so called **workers in social services** (direct care workers, service workers). They are prepared specifically for social services and educated in courses and they primarily focus on helping with self-service and service for clients with reduced self-sufficiency. Some of these workers are completely unqualified, others have education in various fields.

Employees in the field of nursing, pedagogy etc. are also involved in meeting the needs. The term of long-term care is associated with nursing (Pflege) in foreign literature. However, **nursing** is a field that is part of health care – including care for patients with acute diseases, preventive, community care, and assistance in medical care. The nursing approach in long-term care has both positive and negative aspects. The positives include high professionalism and complexity of care in terms of all (bio-psycho-social) needs. On the contrary, medicinalization of problems and high qualifications are understood as negative, which reduces motivation in performing simple activities where qualified workers do not use their skills. Consequently, it results in dissatisfaction, which can lead to burnout syndrome and, paradoxically, worsening the level of client care.

Specialized competence is a prerequisite for the independent pursuit of the profession of doctor and some non-medical professions (clinical psychologist, speech therapist, physiotherapist), and special professional competence is related to narrowly defined

activities and is obtained by successful completiion of certified courses in accordance with the legislation below.

Medical competence and integrity and lifelong learning are required in the pursuit of long-term care professions. The duty of lifelong learning is common to all health care workers, other health care professionals and is also imposed on workers in social services. Fulfillment checks differ.

Long-term care workers in the healthcare area

The following legislation regulates the eligibility to pursue medical professions and other professional workers. Both competency laws define particular medical professions in terms of education requirements and other components of competence (medical fitness, personal integrity) and their content.

From the point of view of Act No. 95/2004 Coll., On the Conditions of Acquisition and Recognition of Professional Qualification and Specialized Qualification for the Medical Occupation of Doctor, Dentist and Pharmacist, as amended, the **profession of doctor** is relevant for LTC e.g. in geriatrics, gerontopsychiatry, psychiatry, palliative medicine, rehabilitation and physical medicine (physiotherapy), internal medicine, general medicine for children and adolescents, general practical medicine and other specializations e.g.: algesiology, child and adolescent psychiatry, long-term care medicine, addictive diseases etc.

From the perspective of Act No. 96/2004 Coll., On the conditions for acquiring and recognizing the competence to perform non-medical health professions and to carry out activities related to the provision of health care and amending certain related acts (the Act on non-medical health professions), as amended, the following professions with professional competence or professional and specialized competence are relevant: **general nurse** (nurses for community nursing care, nursing care in paediatrics or psychiatry), **occupational therapist**, **health and social worker**, **nutritional therapist**, **physiotherapist**, **clinical speech therapist**, **clinical psychologist**.

There are also professions without professional competence i.e. under professional supervision: **health care assistant**, **attendant**, **medical orderly**.

And other professional workers, non-professional doctors with professional competence: **social worker** and **psychologist**.

Furthermore, in the chapter we will focus on the specifics and competences of particular professions in relation to long-term care in health service.

Physician

The scope of the physician‘s activity is determined only as a framework in the Act on medical professions – a physician without specialized competence (with professional competence) is authorized to pursue the profession only under the professional supervision of a physician with specialized competence. The specialist may also commence the profession in another medical field, but again only under the professional supervision of another specialist.

The **senior physician in long-term care must be a physician with specialized competence** (specialized skills are listed above).

A geriatrist’s competences (in relation to long-term care):

- They evaluate what the norm and pathology are in older age, influence of age on values of common laboratory and instrumental examinations, specific symptoms of diseases in older age
- They perform and evaluate functional geriatric examination and the use of standardized tests
- They comprehensively assesses a senior patient in acute, follow-up and long-term care and sets a comprehensive care plan
- They apply preventive strategies at older age, healthy/successful ageing, gerontohygiene
- They apply principles of palliative and terminal care, hospice care, thanatology
- They evaluate and assess lay care, support the role and function of the family, provide psychological support and expert advice to carers, prevention of social pathology phenomena (abuse, neglect of seniors in home care)
- They organize geriatric services, lead[9] a multidisciplinary team in senior care, assess the quality and effectiveness of health care

[9] The team leader need not necessarily be a physician, the role of a team leader can be taken over by a coordinator, health and social worker etc.

- They diagnose and treat: specific geriatric syndromes (senior fragility syndrome, incontinence, mobility, instability with falls , sarcopenia, delirium and cognitive disorders, temperature load syndrome, social syndromes etc.), acute and life-threatening conditions in geriatrics, the most common diseases in senescence, including chronic skin defects, they evaluate and treat sensory defects, seek the possibilities to compensate for disabilities, diagnose nutrition disorders and establish the basics of medical nutrition in geriatric patients
- They evaluate pain, provide a comprehensive approach to pain management
- They supervise effective pharmacotherapy in geriatrics (pharmacokinetics, pharmacodynamics, compliance, adverse drug reactions and interactions, prevention of iatrogenic damage)
- They evaluate self-sufficiency, mobility, participate in prevention of injuries and falls at older age
- They assess rehabilitation potential, indicate compensation and rehabilitation aids
- They perform examination of mental functions in geriatric patients, diagnostic and differential diagnosis of frequent mental diseases in old age
- They perform orientation neurological examination and neurological differential diagnosis in geriatric patients

A psychiatrist's competences (in relation to long-term care):

- They perform comprehensive internal examinations, diagnose and treat basic internal diseases and master basic therapeutic methods
- They diagnose and treat psychiatric diseases and disorders, are well informed in psychotherapeutic methods
- They perform consulting examinations of somatically diseased patients and set the contribution of somatic condition and somatic treatment to mental disorders
- They prepare psycho-educational programmes for patients and their relatives

A rehabilitation specialist's competences (in relation to long-term care):

- They perform comprehensive internal and neurological examinations, diagnose and treat, master basic therapeutic and diagnostic methods (drug application, lumbar puncture…)
- They perform functional assessment of both particular systems and an individual as a whole - especially kinesiology diagnostics, ergodiagnostics with knowledge of the basics of ergonomics and professiography, orientation psychological and social diagnostics and basic stress tests, preparation for work or social rehabilitation
- They prepare short and long term rehabilitation plans
- They determine and apply diagnostic and therapeutic procedures in the field, including basic methods of reflex therapy of functional disorders, physical therapy, therapeutic physical education, ergodiagnostics with ergotherapy, kinesiotherapy, therapy using natural therapeutic sources and practical implementation of basic therapeutic procedures, rational prescription of appropriate pharmacotherapy
- They indicate technical aids, provide basic training in using them
- They provide assessment activities in the field, including assessment of working potential of persons with long-term disease and persons with disabilities

An internist's competences (in relation to long-term care):

- Are very wide, he/she is involved in all internal disciplines, including geriatrics, which is especially important for long-term care. His/her competences therefore overlap with geriatrics, but they are not as specific due to the broader range of an internist. An internist is useful primarily as a consultant, but also in the place of a geriatrist in in-patient follow-up care.

A general practitioner's competences (in relation to long-term care):

- They provide continuous care to residents from 15 years of age, in the surgery and during the visiting service, perform preventive and dispensary examinations

- They provide advice on social matters
- They classify patients with chronic diseases in dispensary care (DM II, high blood pressure, IHD…)
- They provide long-term care for people with sensory and physical impairment as well as patients with infaust prognosis and the dying, provide the necessary psychological support and pain treatment
- They provide long-term care to high-risk groups of inhabitants (lonely, drug addicts, ethnic minorities, religious communities etc.)
- They collaborate with health facilities in secondary care, in the area of primary care they collaborate with nurses, including home care agencies, other health and social facilities, local government institutions, sanitation, voluntary health and charity organizations (community services)
- General practitioners should be an essential element in treatment of long-term care clients located outside in-patient healthcare facilities. At present they are coordinators of all types of care, their irreplaceable role is in seeking endangered persons in need of long-term care.

A gerontopsychiatrist's competences (in relation to long-term care):

- They evaluate somatic, psychological, social and economic factors in etiology and pathogenesis of mental changes, reactions and mental disorders of individuals in senescence
- They perform diagnoses, differential diagnoses, treatment, rehabilitation, prevention and assessment of these disorders taking age specifics into account
- They indicate and evaluate psychological and other laboratory methods
- They elaborate a therapeutic and rehabilitation plan, an assessment report and a proposal for preventive measures
- Organizationally and administratively,they manage and plan an operation of all types of gerontopsychiatric facilities

Competences of a physician with special expertise in long-term care medicine:

- They are physicians specialized in almost any field, the aim of this new field is to prepare physicians in different clinical disciplines who would be able to provide adequate care to patients with complex health and social problems, mainly caused by chronic or protracted diseases and limited self-sufficiency, to judge self-sufficiency, health condition and social situation of the patient, to design and provide adequate procedures
- They provide specialized care in follow-up healthcare departments and long-term care facilities
- They assess the socio-economic aspects of care
- They lead a multidisciplinary team in long-term care or participate in team coordination
- They carry out assessment activities especially with regard to providing long-term care
- They prescribe rehabilitation and compensatory aids, including aids for fully immobile patients in case of discharge to home care
- They indicate health and social services, in collaboration with a client, his/her family and members of a multidisciplinary team

A general nurse

General nurses can specialize in the three branches related to long-term care (as mentioned above).

1) They are autonomous experts and can carry out a range of professional activities concerning the provision of nursing care - care of a patient´s needs - without the indication of doctor.
2) They assist a physician and participate in preventive care for which the physician is responsible. Nurses participate in these activities under professional supervision of a physician.

Nursing care is divided into basic, specialized and highly specialized. A nurse is capable of independent planning, implementing and evaluating the clients' biopsychosocial needs, assessing self-sufficiency, risks associated with immobilization syndrome, performing orientation tests, practicing self-care, administering medicinal products and performing therapeutic and diagnostic methods based on physician´s indication. He/she is able to elaborate a care plan.

Competences of a nurse in pediatrics

When caring for children, special qualification in this field is necessary as this type of care is more demanding (performances of specialized nursing care where failure of basic life functions is probable, care for children with mental disorders, performance of some interventions). In long-term care, specialists in home care and in-patient care for children with disabilities and long-term diseases are needed.

Competences of a nurse for community nursing care

- When providing nursing care to individuals, groups in their own social environment. He/she analyzes a health and social situation of an individual in their own social environment or a group of citizens in terms of coordination of provided health and social care, all appropriate health and social care facilities and coordinates integrated care, analyzes the health and social situation of patients and close relatives in terms of nursing care, offers counseling, elaborates health risks assessment of individuals or groups of citizens in social environment.
- It is an expert whose potential is not fully used within the scope of all his/her competences in the current system in the Czech Republic, apart from competences in home care. It is obvious that this is a profession that can form the basis of coordination and evaluation activities in long-term care, including the search for endangered individuals.

A health and social worker

They are the bordering profession of the regulation of health and social care, between both legal regulations, i. e. Act on Non-medical Health Professions and the Act on Social Services.

In the Czech Republic, two professions in the field of social work are regulated by the legislation: a health and social worker (gaining professional qualification to perform a non-

medical health worker, for which the Ministry of Health gives a positive opinion, and needs lifelong education). A social worker is the other profession, which is primarily regulated by the legislation of the Ministry of Labour and Social Affairs and the Social Services Act. In health service he/she acts as other professional worker.

Competences of a health and social worker

- Activities within preventive, diagnostic and rehabilitation care in the field of health and social care.
- They participate in nursing care in the area of meeting social needs of a patient. They conduct screening activities aimed at targeted and timely search for individuals who, due to disease or disease of close people of theirs, may find themselves in an unfavourable social situation. They carry out social investigations in patients, assess the life situation in relation to a disease or its consequences, and, if necessary, analyze the social situation by visiting service in families. They assess the life situation of a patient and prepare a report for public authorities or other entities.
- They elaborate a plan of psychosocial intervention in a life situation of a patient, including the scope, type and need of social measures, in collaboration with other health care professionals they implement these measures, provide social and legal counseling in relation to the disease or its consequences, make arrangements for the discharge of patients, including the provision of further care.

This is a social worker focusing on health care whose role is to provide and satisfy social needs in relation to disease.

A healthcare assistant

It is a nursing profession, assistants to nurses. The qualification is obtained by graduating from secondary vocational school. They provide nursing care under the professional supervision of a general nurse in all areas of health care, including long-term care. They also provide nursing care associated with self-care and satisfaction of basic needs. Their role is suitable especially in in-patient care, particularly for the necessity of professional supervision, which limits their role in home care.

An attendant

The competence of an attendant seems to be the most suitable for providing care for daily needs of immobile long-term care clients. They should be used only exceptionally and under the direct guidance of a nurse to perform medical actions. These persons also have the qualification to perform the profession of a worker in social services, namely direct service care in all types of facilities providing social services, and care activities in clients' homes. If they are not classified as attendants in social services but as social services workers, they can practise their profession without professional supervision.

A medical orderly

They perform auxiliary activities within the framework of provided health care, exclusively under professional supervision or direct guidance. In long-term care, they can perform auxiliary instrumental actions and service activities necessary for the provision of nursing care (environmental hygiene, auxiliary activities in dielivery of food, linen handling, accompanying clients etc.) and basic nursing care activities (assistance with hygiene of a patient, positioning patients and manipulation with them, basic prevention of bedsores, bed adjustment, help with food, care during emptying). A nurse assesses the risk of the patient's performance., in positioning of patients and manipulation with them, basic prevention of bedsores, bed adjustment, help with food, care during defecation). A nurse also assesses the risk of their performance for patients.

A nutrition therapist

They provide preventive care in the field of clinical nutrition and the provision of specific nursing care aimed at satisfying nutritional needs.

A physiotherapist

The content of the occupation is activities within preventive, diagnostic, therapeutic and rehabilitation care in the field of physiotherapy. They carry out their profession exclusively without supervision, but it is necessary to collaborate with a physician who determines the diagnosis and goal of physiotherapy. Physiotherapists then perform their own examinations, determine variants of procedures in order to achieve the goal set by a doctor. Their activities, including field care, are absolutely necessary in long-term care. They can also be successful within multidisciplinary teams, especially for people with disabilities.

An occupational therapist

The profession is also one of non-medical health care professions providing rehabilitation care. Occupational therapists perform activities within preventive, diagnostic or therapeutic and rehabilitation care in the field of occupational therapy. Their independence is significant, they can carry out a number of activities based on the indication and diagnosis of a physician, however, they set the combination of procedures themselves, based on their own examinations.

They have an independent role in counseling and mentoring in the area of prevention of occupational diseases and musculoskeletal disorders. It is a profession suitable for long-term care, especially due to activities to develop and maintain self-sufficiency of clients.

Questions for consideration:

Who should and ideal multidisciplinary team involved in achieving client goals and long-term care planning consist of?

What role should a coordinated rehabilitation worker play in the team?

Can anyone else be a member of the team? Who and why?

To illustrate, consider the situation - a statistical estimate of the number of professional staff in long-term healthcare in the Czech Republic (data correspond to the end of 2010):

- **Workers in long-term in-patient health care** include workers in in-patient health care facilities providing long-term care in the Czech Republic. The data presented in the text come from the report of Institute of Health Information and Statistics of the Czech Republic. At the end of 2010, 216 physicians, 1,425 healthcare staff with non-medical qualifications (independent healthcare staff) provided in-patient nursing care (in departments and workplaces of follow-up nursing and long-term intensive care and long-term intensive nursing care) in hospitals in the Czech Republic. Most of the capacity of follow-up care hospitals and long-term hospitals was made up of departments of institutional nursing care, where over 250 doctors and 2,650 healthcare staff with non-medical qualifications worked. In hospice care, there were 35 doctors and 183 healthcare staff with non-medical qualifications. Further follow-up care (including nursing care) is provided in

specialized treatment institutes, where more than 762 physicians and 4,200 health care professionals with non-medical qualifications worked.

- **Workers in home healthcare**. Home healthcare services were provided by more than 3,000 healthcare professionals throughout the Czech Republic in the same period of time. On average, there were 57 physiotherapists, 1,070 general nurses, 22 health and social workers, over 220 other professional workers and 114 volunteers.

Long-term care workers in facilities of social services

Eligibility to pursue a profession in social services is regulated by Act No. 108/2006 Coll., On Social Services. It regulates several autonomous professions, requirements for their professional competence, defines requirements for health fitness and integrity for all professions. The obligation of lifelong learning is also regulated.

A social worker

They acquire qualification only at tertiary level of education. The university must have a consent from the Ministry of Labour and Social Affairs. Under the Act on Non-medical Health Professions, social workers - other professional workers - and health and social workers also have the competences of a social worker, but limited only to the provision of social services within health care facilities. Given that the qualification of a social worker - other professional health care worker - is also achieved by secondary school graduates, it is up to the employer whether he/she requires additional education in the field of Health and Social Worker. There is a great deal of inconstistency in this area and we see a great benefit in the potential of the Health and Social Worker field.

For the area of long-term care, health and social workers should be favoured, provided they have obtained tertiary education in the field and, in addition to their ability to perform social work (MPSV), are qualified to pursue a non-medical health profession.

A worker in social services

According to their activities, they are divided into four groups: workers for direct service care, workers for basic non-teaching activities, workers for care activities and workers participating in social work. Unlike auxiliary workers in health care, they do not have to have any

qualification at the beginning of their employment, it is sufficient to complete it within 18 months. They are the cheapest employees in social services.

Health care workers operating within the framework of social services - only health care workers and health care workers under supervision are authorized to perform health care.

A coordinator

(support coordinator for caregivers and persons dependent on the help of the others)

Coordinator is a new profession whose establishing in the Czech environment will depend on spreading awareness of the concept of rehabilitation coordination in both the professional and lay public as well as the anchoring of the legislative standards discussed above. Given the absence of field experts to provide comprehensive community services (e.g. related to the development of the concept of "community nurse", which would focus primarily on community care for seniors with long-term diseases), the coordinator appears to be a key expert **in ensuring continuity of assistance and integration of services to selected target groups** of long-term health and social care and rehabilitation.

A document called *The Study on the Possibilities and Importance of Establishing a Support Coordinator for Caregivers and Persons Dependent on Assistance (2015: 19)*, published by the Further Education Fund, states that *"… it is supposed, among other things, that positions of coordinator and acontact person will be established, where the workload of both of them, as defined in the latest proposal, will partially overlap with the expected workload of a position of support coordinator proposed by us. They would be employees of the so called Rehabilitation Coordination Centre (RCC). The RCC should be a specialized body ensuring coordination of rehabilitation at the regional level."* The afore-mentioned can be described as plans which will enforced at the regional level.

Note: At present, so called regional coordinators operate at regional levels only within the framework of the project of the Ministry of Labour and Social Affairs (Project name: *Support of family and ageing policies at regional and local levels*). The project will also involve so called regional advisors, who will provide an advisory points for the target group and coordinate activities of regional platforms composed of relevant participants in the given region. The aim is to create a family policy methodology at regional and local levels (MLSA, 2017).

What findings lead to proposing the position of a coordinator?

The concept of coordinated rehabilitation is close to the support coordinator via the idea of interconnection, coordination and timely acquisition of comprehensive social, health/medical, educational and occupational care, as well as support in the field of law, finances, technology etc. Related systems of support coordination in Europe can be found, for example, in Poland, Germany or the United Kingdom.

The results of the analyses of the above-mentioned study show that tools for supporting people from different target groups overlap to some extent, so there is no need to have one single coordinator for each target group at local level.

Kompetence koordinátora

- They are knowledgeable professionals well-educated in the field of providing coordination of rehabilitation, health and social work and with interdisciplinary overlap.
- They establish and maintain contacts with institutions, persons and other participants in the system of coordinated assistance.
- They use methods of networking resources of help and support, case management.
- They actively seek endangered target groups of coordinated rehabilitation and operate at local/community level.
- They actively communicate with all components in the process of coordination of rehabilitation, provide information, education, intervention and, consequently, evaluation of assistance by all participants.
- They create **plans of coordinated rehabilitation** including: analysis of client needs, ICF, overview of available services, plan of related services, proposal and recommendation of forms of financial support or mediation of social counseling in given life situation of clients, all in **collaboration** with clients and their families.
- They monitor information on the needs of target groups and their families, and pass this information to service providers, municipalities, regions.

- They support informal ways of assistence and their development at community level (community self-help), and they support other activities with regard to the development and anchoring of the rehabilitation coordinator.

Questions for consideration and self-study:

Look up the meaning of *network therapy.*

Who are providers and subjects of long-term care?

What are the specifications for employing a coordinator on the level of municipalities, towns, or regions?

3.4 INFORMAL CAREGIVERS

Informal care is one that is granted to persons outside the environment of social and healthcare facilities. The necessity of this type of care arises as a result of reduced self-sufficiency of the client caused by disease, injury, disability (mental, sensory, physical) or by advanced age. Informal care is currently unpaid, i. e. care that is not performed as part of an employment contract or a similar relationship, i. e. care for which no wage or salary is received. In the Czech Republic, an informal caregiver can currently receive a part of the client's care allowance, which the client (as the subject of care) may draw upon meeting the statutory requirements.

Irrespective of a particular country's long-term care system, most care is provided by family carers in a social relationship. In OECD countries, more than one in ten persons over the age of 50 provides informal unpaid care to people with functional limitations.

Information on provision of informal care in the Czech Republic can be obtained from the SILC survey module (the survey entitled – European Union – Statistic on Income and Living Conditions EU – SILC, 2010). In the Czech Republic, a total of 230.6 thousand informal care providers have been surveyed, i. e. 2.7 % of the population over 15 years of age. Among them, 70 % are women aged 55-64. In about 69 % of cases, the informal carer‘s household has difficulties getting on with their income. Moreover, the total amount of hours of informal care provided equals to an alarming approximate 190,000 full-time employments.

The above stated implies that **provision of long-term care is based predominantly on informal care.** This area should be of key interest with planning LTC concepts, for that matter. Paying attention to informal carers is the potentially ideal solution for all parties involved. **Supporting caregivers is beneficial for:**

- recipients of care who prefer informal care from family and friends
- carers who take up the economic, medical and social consequences voluntarily, i. e. as a result of affection or a feeling of commitment

- public finances, since support of informal care may help to increase the accessibility of formal long-term care.

Among the main consequences of providing informal care without making use of support systems there are mainly **the psychosocial, irrespective of the length (duration) of care provision.** Current research has shown, for instance, that the excess of the care burden, depressive and anxiety symptoms at early stages of dementia can arguably be comparable to that of the care burden borne at the more advanced stages of dementia. **The care burden** is referred to as the organism's multidimensional response to stressors relating to the process of care and as a term for the complex expression of problems in the mental, physical, emotional or social levels.

The objective care burden: is direct care for the diseased person, the necessity to cope with the patient's emotional needs, the effects the care has on family interactions, leisure activities, the impact on work, mental and physical health, social network, the financial implications etc.

The subjective care burden: idepends on one's own reflection of one's role, on the experience of a close person's disease, it is a reaction to stressors influenced by family relationships, social environment, cultural and family habits. It is the carer's individual performance in trying to cope with the objective burden.

Provision of demanding and intensive informal care is associated with limited presence and participation on the labour market, higher risk of poverty and a prevalence of caregivers' mental health problems resulting from the care burden, which effectively provokes the question:

What should potential support for providers of informal care be like?

The issue of financial support for caregivers who bear the medical risks and face difficulties on the labour market remains unsolved. Contributions to caregivers are an acknowledgment of the social value of their care. Yet, they raise complex questions of adjusting, determining an adequate amount of reasonable reward.

The issue of support for caregivers balancing their private and professional lives. Compared to parental leave, which is commonly available and paid out in almost all OECD countries, the conditions of granting leave for carers are stricter. Given the expected growth in the need for long-term care, the Czech Republic, following the example of Austria, set up **the institute of long-term nursing** which enables carers who take care of close relatives to adopt to the new life situation and helps to maintain the quality of life of the caregiver. The aid is granted in the form of a benefit of 60 % of the daily assessment base. This includes labour-law protection during the care period (cf. amended Health Insurance Act).

An effective solution is to offer caregivers part-time work. Good practice examples of flexible forms of employment. The publications by Hana Geissler and Kristina Koldinská (Diakonie ČCE and MPSV, 2016) deal with this issue in more detail.

Services for caregivers, offers of flexible support (not mere respite care). Carer services – respite care, education and training courses, counselling, support groups – can all contribute towards improving the quality of care. Respite care allows caregivers to rest, it is the most widespread type of support for caregivers, but it is not enough. It is usually financed by families, and it is seldom financially supported. Carers frequently complain about lack of psychological support or assistance; there is an open area for the development of support groups, counselling and development of their availability.

Although family carers form the backbone of the system, all OECD countries need a well-functioning formal long-term care system. Institutional professional care, professional domestic and community services are, therefore, greatly desirable. It also links cooperation and continuity between the formal and informal LTC systems. In the Czech environment, there is a debate about the possibilities of what is called **shared care** (refer to a separate subchapter for more details), which would require greater coordination and planning of care.

Specific social policy instruments are used to support carers. The key difference in support depends on whether the social policy instruments are tied to the caregiver's care activities or are primarily addressed to the subjects of care – the persons to whom care is granted. Their review compiled by Triantafilla et al. (2010).

Family caregivers

Caring for a family member is based on a sense of solidarity and requires a degree of social cohesion in the family which provides the care. Social cohesion is both the condition and result of family care.

Jeřábek (2005) distinguishes among two types of a family's social cohesion.

The first type is **mechanical social cohesion** – the family is agrees on the decision to care for its member, it is united in willingly accepting the situation of family care.

The second type is **organic social cohesion** – it affects managing the situation of newly started family care, and how the roles in the family are delimited. Organic cohesion involves renunciation of family members' own priorities to the detriment of the common needs of the family as a whole. A family that decides to take care of a family member and is able to set up new modes of functioning as well as to adapt shows both types of social cohesion.

Family care is typical primarily in the form of care for the elderly and in the form of care for a child with disabilities.

Caregivers most often include a spouse, partner, children and their partners. The most frequent carers are wives and daughters, and they mostly care for a close relative without any external help. They are exposed to **critical moments of personal care**:

- carers' own health problems, including mental suffering
- abandonment / social isolation, also related with the following fact:
- long-term personal care receives minimum support from the state ort he municipalities, neither is community care yet ready to assist persons providing long-term care at home, this is a fundamental shortcoming
- trauma resulting from transferring a close person to institutional care, this is a critical moment in the decision about a close person

Family care for the elderly occurs in the form of a "*guardianship or supportive assistance or services rendered for the happiness and well-being of elderly persons who, as a result of chronic or mental disease or disability, cannot carry out these activities themselves*". It has several specific features:

- care is looked upon as carried out with love, and it goes on being done even though love may sometimes have its ups and downs, it includes emotions and a firm tie between the carer and carer
- includes not only care for a “healthy family” but also for the needs of other family members, people with disabilities, a diseased partner, child …
- the experience of never-ending duty which is only visible when not fulfilled
- keeps the person in isolation, both the caregiver and the subject of the care
- involves the medical, social, emotional aspects

Long-term elderly care is only partially covered by health systems, which are rather made use of in the phases of acute care, outbreaks of disease, health deterioration, as soon as there is no immediate threat for the diseased / elderly person‘s life and health, they return home and their social environment is bound to ensure the conditions for return.

Increased demands on care are managed either by the family or by facilities alternative to family care in the post-acute period of disease, which are institutions of the health system or social system (mentioned above). The problem lies in the continuing “side-by-side” system of two parallel branches of institutionally rendered care for persons with reduced self-sufficiency **which lack systematic cooperation, mutual interconnectedness as well as absence of services and links to the private sector.**

In terms of the intensity and urgency of the needs an elderly person requires, we distinguish three levels of care:

1) **subsidiary care** – supportive, is important, but less demanding as regards time, physical and mental effort. It includes financial support, repairments at home, driving to the doctor‘s, organizational assistance, allows the elderly to remain in their natural environment
2) **impersonal care** – includes activities related to household care, cooking or transportation of food, cleaning, doing the laundry. The care is regular, frequent, more time-consuming and requires a continuity (it cannot be postponed). It encorporates a material and emotional component. This form of care can also be provided by home care agency service.

3) **personal care** – is the most demanding level of care for a person with reduced self-sufficiency. The care is time-consuming, intense, continuous. It includes intimate care, hygiene, dressing, eating, movement / positioning… Personal care requires regularity, responsibility, stamina and dedication. If it is not possible to provide it in the form of informal care (family care), then it can only be rendered in the institutional form.

As stated in the OECD Long Term Care Report for Older People (2005), family carers should not merely be looked upon as the granted, natural source of care, but they also require support in a variety of ways.

These include, in particular, the following **Measures for support of family caregivers:**

a) financial support for caregivers

support of the person directly cared for is tied with the person‘s approved partial or complete lack of self-sufficiency, or tax relief for caring families with average or higher earnings. In Germany or the United Kingdom, the care period is included in the pension system. In many countries, there is financial compensation for lost income (UK, Australia, Canada, Ireland, Sweden).

b) supporting service for caregivers

home care service – it is a developed system of paid care in family environs, its availability or accessibility may be a problem

respite service – provided mainly by non-profit and charitable organizations or social care services, it involves a temporary relief from care duties (may take the form of daily or short-term institutional care), entitlement to leave

right to having caregivers‘ needs assessed (existing in Great Britain, for instance)

c) courses, counselling and support groups for caregivers

mediate the acquisition of practical skills in order to for caregivers to gain independence from professional assistance, mediate practical information on the demands, aids and possibilities of professional assistance, and finally, group meetings mainly provide with emotional support and relaxation

d) social changes

measures developing support for care in domestic environment, support for carers' rights (for example, expressing expectations or the requirement that care for a beloved person should be comparable with, for example, infant care); Informal care exposes carers to a risk of losing their job and reaching the poverty line

e) psychosocial assistance and support for caregivers

includes counselling and support in the form of information, advice, recommendations, support groups, but also professional psychosocial assistance such as: emergency (and telephone) assistance, psychotherapy, relaxation techniques, reconditioning and spa stays, education and training. It also includes the use of care services (retirement homes with special care services, day centres, respite services, field services, but also hospitalization or residential services for the elderly), medical care (for more detailed information on the importance of both the formal and informal role of general practitioners in interconnecting the medical and social care resources for patients refer to Dobiášová, K. et al., 2015).

f) personal support for caregiver

should the caregiver be perceived as exhausted, the basic prerequisite is a professionally conducted interview with the caregiver to identify his or her needs, coping up with the burden, practical difficulties with the provision of care in daily life. Many carergivers are unaware or lack information about the possibilities of assistance. Some are uninformed about care allowances, respite services, training courses, possibilities of aid borrowing etc.

What and how to ask? How to conduct an interview with a caregiver?

- Set definite time and space for the interview, you will have the interest of the caregiver if you reserve the time only for him / her (without the presence of the client – the care recipient)
- Have the caregiver tell you how they are going on with the care
- Reflect their experiences / feelings (“you probably feel exhausted“…)
- Map their needs – ask open questions (“what does it look like when…”, “what helps you manage it?”, “when you plan time for yourself, how do you want to use it?”…)
- Always remember that the caregiver to some extent isolated and rarely receives feedback on what he / she is doing, remember to show appreciation and encouragement!

- Seek some motivation for change with the caregiver, but include realistic ideas of the long-term care provided and its future development! ("You may no longer be able to provide care on your own if the health condition worsens, have you considered further support?…"). You can also make use of experience from your own practice, from other caregivers.
- Offer concrete possibilities of support – using the services locally available.
- Be aware that the caregiver may not be ready for making a change yet, making a single decision may be very difficult for him / her. Give him / her time and keep in touch!

According to Roubal (2012), the proportion of population dependent on long-term assistance amounts to approximately 400,000 people in the Czech Republic. Almost all people with ADL / IADL problems are chronically ill (suffering from hypertension, musculoskeletal disorders - arthritis, osteoporosis, backache, consequences of ictus and heart attack, dementia and Alzheimer's disease. One third of these people stay in institutional care. Approximately 70,000 patients in healthcare facilities, 60,000 clients are staying in social services facilities. Two thirds of these persons live in households, 25 % of them live alone at home. Not everyone receives care allowances. In this context, it is appropriate to draw our attention once again to the connection with expenses and workload of informal carers who amount to approximately 200,000 persons (in the rate of working hours).

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4. SUBJECTS OF LONG-TERM CARE

Keywords of the chapter:

recipient of care, subject, long-term patient, patient, client, ICF evaluation

Study guide:

The subject of long-term care is the care recipient. That is, a person with a long-term disease, disability, impaired fitness or self-sufficiency deficit. The subject of long-term care have the right to assistance and, at the same time, have the right to decide on the form of assistance to be provided, on condition that this does not jeopardize their safety and health or the safety and health of people in their vicinity. They also have the right to make decisions concerning termination of the type of care provided.

4.1 TARGET GROUPS OF LONG-TERM CARE

- Dying people and their families
- Long-term patients, including children
- Informal long-term carers
- The elderly with decreased self-sufficiency (poor health condition, oldest old, frailty) and others

Demographic predictions have revealed that the most significant increase is expected in the oldest age groups, that is ages 85 and more. It should, according to the medial variety of the projection, have increased 7.5 times before the year 2066. Higher demands on social and healthcare can be expected with the age group of elderly citizens. Taking in mind the

demographic predictions, it can be estimated that the number of diseases typical for higher age, such as the **neurodegenerative diseases**, mainly Alzheimer's disease, will increase in the future. According to qualified estimates by Alzheimer Europe and Alzheimer Disease International, the number of people with dementia will have increased from 88,000 in the year 2000 up to 227,000 by 2050. Considering the difficult situation in provision of appropriate services for this group in some regions, it has been proposed that the National Action Plan for Alzheimer's disease and similar diseases declares as its goal the improvement of access to appropriate care, help in securing appropriate care and its coordination – the use of flexible forms of care with the goal of providing the longest possible time to stay at home with the care of family members with professional help. A net of specialized departments should be created. The Ministry of Health should be the main guarantor.

The mentally ill people present a very specific and wide target group. Regardless of causes or prognosis, these diseases are altogether of long-term character. The goal of this text is not to give an idea of the complex problem of mental diseases, but to demonstrate certain target groups. I believe it to be of crucial importance to make students familiar with current trends in the development of mental healthcare in the Czech Republic. Let me refer to the Mental Health Reform for this purpose. Its goal is to improve lives of people with mental disease by improving the quality, accessibility and interconnectedness of necessary health and social services. It aims towards decreasing of the rate of stigmatization and rejection in the society and improvement of social integration of mentally ill.

People with acquired disability who undergo long-term rehabilitation with the goal of returning to the original quality of life or to get as close to it as possible, are also classified as long-term patients. Among these patients there are especially **patients with acquired brain injury**. Not only people with head and brain injuries, but also a great number of patients who suffered an infectious brain disease (meningitis, encephalitis, and other inflammations, such as the inflammation of middle ear, inflammation of inner ear, vasculitis etc.), apoplexy, brain hypoxia, and anoxia. This target group is mentioned especially because of its importance and the necessity for a specific follow-up health and social rehabilitation. It should be functional and accessible since patient's admittance in the acute phase until patient's discharge after achieving the highest possible level of self-sufficiency.

The CEREBRUM organisation has made a proposal of the model of rehabilitation that includes 4 stages:

1. Acute rehabilitation stage (in-patient rehabilitation in a particular hospital or acute care facility)
2. Interim rehabilitation stage (rehabilitation in rehabilitation centres organised on regional principle or higher type acute care hospitals, in some cases complemented by specialized medical facilities complying with the standards)
3. Regional rehabilitation stage (rehabilitation in stationary rehabilitation centres and specialized outpatient rehabilitation facilities in respective regions)
4. Community rehabilitation stage (long-term and maintenance rehabilitation in community)

The above mentioned example (rehabilitation following brain disease) can demonstrate that especially the third- and fourth-stage care show serious deficiencies in the Czech Republic. An example of good community rehabilitation can be providing of field physiotherapy at households in Canada.

It is the author's opinion that the quoted model is transferable to other areas of long-term medical care. Or more precisely to areas of long-term care for other target groups of long-term patients who, after being released from the 'acute bed', demand other forms of help and professional care, even though it is often not available to them.

MUDr. Zdeněk Kalvach dedicates his effort to the development of the system of integrated support services in his expert publication which students are kindly referred to.

Most clients (from within the target group) of long-term care are hospitalised in initial phases of the disease. And precisely this time of **discharge from hospital** is crucial for the choice and organisation of a professional 'after-care'. The indispensable professions from the multidisciplinary team are in this phase especially: the general practitioner (who currently, in the Czech Republic, does not have to be notified at all about the patient's hospitalization), the attending physician, and the social worker who has several roles, among other things: He/she is an informant, and intermediary of further help, there is also the possible role of advocate of client's rights (for example if our family / institution has different interests than the client), the role of advisory and supporter, and in current situation also the role of coordinator. Still, in current practice, coordination is not a crucial and main content of their

work. And mainly, they have opportunity to ensure the continuity of patient's care, with consideration of continual evaluation of patient's current state and his/her changing needs.

In this part of the text, let me refer students to the evaluating tools, including ICF - International Classification of Functioning, Disability and Health. It is an appropriate, though in practice not very often used, tool to evaluate the state of long-term patients.

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Useful references:

Registry of social services providers http://iregistr.mpsv.cz

Regional catalogues of social services

Communal plans of municipalities and cities

Czech National Disability Council http://nrzp.cz

Home Care for senior citizens http://www.pecujdoma.cz

Czech Alzheimer Society http://www.alzheimer.cz

Organisation for support of people with mental disease http://www.fokus-cr.cz

Mental healthcare reform http://www.reformapsychiatrie.cz

5. COORDINATION OF LONG-TERM HEALTH AND SOCIAL CARE

Keywords of the chapter:

Coordination, case management, integration, LTC coordination elements

Study guide:

Coordination is important in home environment – if there are more service providers attending the household, it is important to ensure their continuity and mutual awareness of each other. It is also important to coordinate the providing of services among individual institutions and service providers. In some countries, this need to ensure continuity and coordination of services has led to adoption of certain specific measures to make these long-term care services more effective and efficient.

Continuity and inter-connectedness of services are considered to be a necessary condition for the services of long-term care to correspond to the needs of clients/patients. But they also contribute, in other words, are a necessary condition for effective use of the resources invested into long-term care. A part of this problem is also the coordination of services, so that they comply with the needs of individual persons (case management). One of the possible forms of cooperation and coordination of care in practice is provision of help exactly in the form of *case management*[10]. In Anglo-American literature also assertive community approach or assertive community treatment (Stuchlík, 2001), which has the potential[11] of solving problematic questions of fragmented follow-up services to healthcare at inpatient wards. And not only in the area of psychiatric care, where it usually comes to be applied in practice.

[10] In Czech terminology the translated term "případové vedení" is sometimes used.
[11] Research orientation and open discussion of case management approach in social work (not only in healthcare) has been a current topic of the professional public. For more information refer to http://casemanagementcr.wordpress.com.

Particular health conditions bring specific issues which must be solved in the long-term according to patients' needs. People after apoplexy, for instance, need long-term care with substantial part of rehabilitation. In order for their condition to continue improving or at least stabilize (without rehabilitation care it would only deteriorate). But if all of this is done in a specific setting and the care is ensured, it is possible to stay at home even in the case of high rate of self-insufficiency. On the other hand, for example Alzheimer's disease and other forms of dementia are progressive diseases. Although there are certain possibilities of slowing down this progress and pharmacological and non-pharmacological management of other symptomatology, these diseases progress in a way that requires a very demanding and psychologically exhaustive care. If this care is provided in domestic environment, it is necessary to ensure the support of family members, so that they could continue their caring role. If there is no such family setting that would provide this care, it is necessary to provide an institutional solution. Because providing for a patient with dementia at his own home via field services is very problematic, and can be overall considered little effective (the prevalence of apoplexies is tenths of thousands annually, one third leaves serious consequences, especially in the area of the ability to move, but also psychologically, these could be primary or secondary). Certain inter-stage between these situations are conditions after brain injuries (or brain damage caused by other than a traumatic mechanism – hypoxia, poisoning). These disabilities count also in tenths of thousands annually, one third of them continue living with serious consequences, functional disorders, but also a wide spectre of psychological problems and behavioural disorders.

These people also need rehabilitation and other specialized therapies (ergotherapy, physiotherapy, logotherapy, psychological support), and their family members also need support. For dealing with the issue of injuries and apoplexies national and international strategies have been prepared (the Helsingborg74 and Mannheim75 declarations). These strategies have been implemented uniquely within acute hospital care (for example creation of stroke wards, traumatic centres etc.) in the Czech Republic

In the foreground of the efforts of creation of concepts and systems of long-term care there should be better **integration of medical and social services.** In practice, there are several problems that are obvious, for example discharge of patients from the hospital, there is a lack of coordination of services (re-organisation of living, living conditions, providing of services, taking over a close person with a change in self-sufficiency without proper training, tools, conditions etc.).

Coordination of long-term care is highly demanding in practice. Discussion about LTC coordination have shown that it is difficult to manage, the competences are not clear, there are no functional multidisciplinary teams and no flexibility in ensuring the conditions for services of long-term care at home.

The policy and measures taken in the areas of long-term care are connected with other areas of social policy, such as health, housing, pensions, and social facilities. There are great challenges in the area of administrative and institutional effectiveness.

Let us emphasize in the text some **potentially useful approaches** that have emerged from the practice evaluation in particular countries of the European Union:

- creation of information basis for providers and users of long-term care (awareness of the long-term services net, its accessibility)
- setting up standards for managing and decision making on local level and on providers' level
- planning of care based on individual needs evaluation with health and social care providers' participation. The connection of needs evaluation with assigning of financial means
- sharing data across resorts and levels of public administration with the goal of facilitation of managing of possible links in long-term care funding
- elimination of incentives to relocate funds between health and social care

Coordinated long-term care should be understood in a wider sense in the context of integration of social services, as a complex, health and social care system of integrated support services for people with limited self-sufficiency, oriented on the use of residual potential with support of higher levels of social functioning and life quality. It is not mere blending of basic nursing care and home care on the outpatient or institution level.

The coordinator of particular cases needs to consider all elements integrated in LTC in a wider sense. His or her primary task lies in informing of clients, families, providers, in a way that would ensure maximal efficiency and complexity of support to those that want it. It is expected that in the future not all the elements will be payed from public funds. On the other hand, a competition of private services should be supported.

A team of Czech experts who are involved with proposing legislation in the area of long-term care in the Czech Republic have dealt with the model of **coordinated long-term care.** Among other things, they delimited elements of coordinated LTC which will next be introduced in further text.

Among the LTC coordination elements there are:

Client – his or her needs, wishes, priorities, options (including control over financing)

Informal care – family, communal

General practitioner – basic element of primary care

Services provided for care in the home environment – they lower the need for institutional care (risk of institutionalisation), they support informal carers (currently especially home care, nursing care, services of long-term care – including the combination of nursing and home care, personal assistance, emergency care)

Services that participate in the improvement of functional state and the adaptation to the health disability (physiotherapy, occupational therapy, prosthetics, lending of aids, psychotherapy, speech therapy, cognitive rehabilitation)

Services that deal with social consequences of health disabilities and diseases (health and social care, social work)

Methods of identification of threatened people and people in need, so called screening observation of persons, coordination, awareness etc. (screening and dispensarization, case management, social counselling, LTC counselling, community centres, multidisciplinary teams, community nurses)

Specialized medical services at communal level, that provide prevention of institutional care (community psychiatric care, community children's nurse, palliative care, mobile hospice care, geriatric ambulance, nutritional counselling)

Relief services, support care for families (day centres, relieve residence services, education, supervision, support groups)

Services that improve life in natural environment (barrier-free environment of public spaces and transport, concept of EU accessibility, protected housing, AAL – ambient

assissted living, life supporting environment, such as information and communication technologies, tele-monitoring home care…, centres for people with health disability)

Services enriching lives of people with health disability (voluntary activities, companionship, free time activities, LTV, reconditioning programmes)

Services improving safety and expediency at hospitalisation of people with health disability (hospital wards of early rehabilitation, geriatric wards)

Institutional care for long-term stays or short-term specific interventions (long term hospitals, after-care hospitals, sanatoriums, institutions of social care, homes for the elderly, hospices, nursing care centres)

Public Administration (support of municipalities, local administration and government, community planning, networking)

5.1 ISSUES OF DIFFERENTIATED LONG-TERM CARE

The above stated list of course states already existing and working services. Nevertheless, it provides a new outlook and it does not suppose existing differentiation structuring. Differentiation of LTC services into health and social clients and providers of health and social care does not improve anything and it often makes the practice more complicated.

In the first place, current organisations and their funding is non-systematically divided between the departments of MZ and MPSV, municipalities and regions. This only leads to significant inequalities between comparable needs of client's health and social services, improper ensuring of quality and accessibility of care, ineffective providing of care and high transaction expenses.

Complexity of community service

Family has always been and still is at the first place in the line of institutions that help in difficult life situations. People have been helping and supporting each other within families and communities. They were forced to take care for the disabled together. Within the community they were forced by the inevitable into collective defence and collective earning of

living. "*these formations were natural for the majority of human history and they were the basic building blocks of all traditional societies." (Keller, 1995).* Today, the role of family and community is equally important, although a huge part of responsibility for the care is being overtaken by institutions of health and social departments.

To secure the complex health and social services in countries of EU, different strategies are being used. In Germany, Austria, USA, and Great Britain, there are '**discharge managers'** who plan patient's discharge from the hospital. They also ensure the follow-up services for patients after their release from hospitalization to home care. In our country this role is held by social and health and social workers. Unfortunately, in the Czech healthcare system, this procedure is unpaid and not funded (such as medical and nursing interventions), therefore, this role is not demanded. Social workers are often dismissed, or they are made redundant because of the low rate of social workers to number of beds in particular medical institution. Although especially the health and social workers are competent for these activities, there is, to the detriment of the long-term ill, a low number of them. And the role of coordinator is, in this particular area, seen as crucial.

In Great Britain, the '**rapid response teams'** provide continual care and '**intermediate care facilities'.** They focus on rehabilitation and creation of conditions and positive environment for the discharge from a medical institution, taking on mind client's needs. They support the fluency of client's transition from the institution into domestic care.

Centres of **multidisciplinary evaluation** and counselling exist in France. They have participated in improvement of communication between institutions of medical care and social services.

A system of community care that stems from community teams, including a nurse, physiotherapist, occupational therapist, and a social worker, has been created in Sweden.

Question for consideration:

How would you consider devising community long-term service based on mapping of the needs of people in your area in the form of a public inquiry?

The crucial elements of starting LTC services are, according to OECD

a) good cooperation with general practitioners on the evaluation of functional abilities of the client

b) unity of the contact place and its accessibility. Clients and their families can get counselling and information here.

The above stated can serve as inspiration for innovations in the Czech environment.

Crucial goal of complex community services (integrated community care) is to keep long-term patients and the elderly in their natural home environment as long as possible while keeping the highest possible level of health, self-sufficiency, and autonomy. It is possible to secure this goal if there is a flexible net of services in the community and if there is a continuity to them.

5.2 CONCEPT OF SHARED CARE

Shared care

While understanding the role of informal care in the system of long-term care, it is important not to deal only with informal care, individually, but to focus also on the relation between formal and informal care.

The optimal model seems to be the so called shared care. The elderly stay in their home environment. The care is shared by the family members and formal institutions. In this way, the professional and in-expert care mix, support and complement each other.

Family can participate in the services of social care. If there is a need, family can participate in healthcare as well. The efficiency of the shared care model is connected to the coordination of services so that they suit the needs of particular persons. Coordination is necessary in the home environment attended by more service providers. They need to informed about each other and it is necessary to provide their fluent continuity. The effort for the most possibly intense care in home environment should be in the foreground, even for people with significant disability. This should be done by organisational measures, providing of modern technologies and aids, and support of family members. This care is understood as a replacement of institutionalization. It aims at the community model of long-term care. This model is used in practice for example in Australia (Community Aged Care Packages) as a community alternative of providing care for frail elderly citizens whose self-insufficiency would require them to stay at an institution. Shared care should be a model that precedes the placement of clients into long-term institutional care.

Family care is one of the most frequented models of care for people with lowered self-sufficiency and no self-sufficiency. At the same time self-sufficiency and self-reliance of an individual are highly valued values and this area should be supported and should be a crucial topic of social changes and regulations.

The role of coordination and rehabilitation worker lies in supporting not only inter-departmental services for clients of long-term and family carers, but also in looking for strategies of cooperation and team work for representatives of stated professions. What seems to be crucial and deciding for the planning of LTC is primarily the client, his or her functional state and needs.

Questions for consideration:

How is it possible to help the families so that family care works well also in the future when the number of lonesome and ageing people will increase?

Care for older members of family is one of the areas of family care. Which other persons can be the subject of family (informal) care?

Try and create a model of shared care for the elderly in home environment.

Instead of a summary:

While ensuring the development of health and social care, continuity and coordination of LTC, especially these principles should be followed!

1. respecting LTC clients, their dignity and autonomy
2. developing education of professionals in the area of LTC, workers in state administration and self-government.
3. developing and following the community principle of providing services (with the goal of ensuring care in home environment or in the place of client's residence, ensuring of accessibility of LTC – 'client does not attend the service, but the service attends client'.)
4. ensuring LTC capacities, including real-estate services, day-care centres and community services for daily and stay-in care.

5.3 INTERDISCIPLINARY TEAM COOPERATION

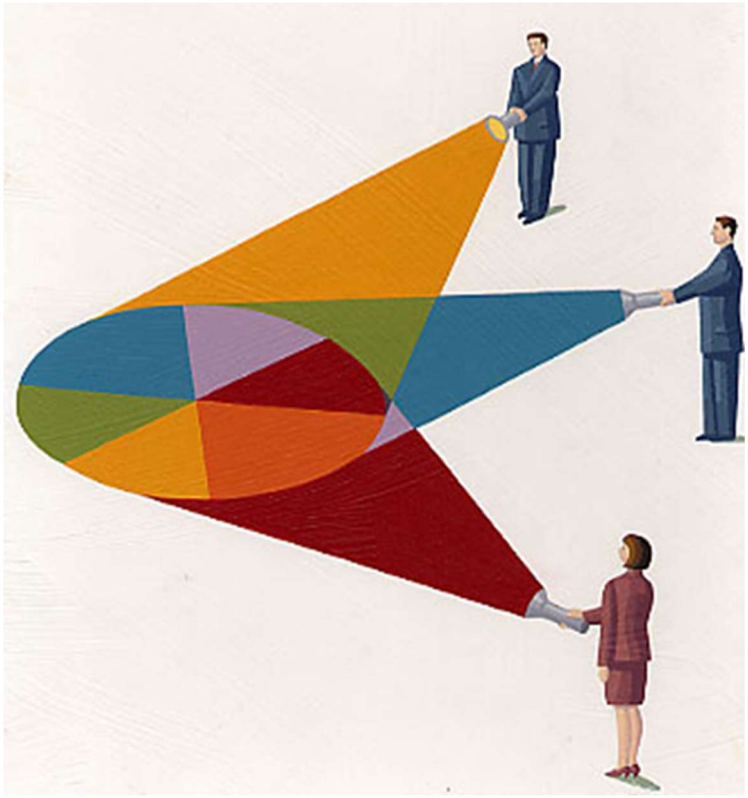
Study guide:

TEAM – composition of the words: TOGETHER EVERYBODY ACHIEVES MORE. If we want to work on building of coordinated team cooperation, it is crucial to come to know the meaning of **the term team**: it is a clearly defined unit of cooperating people with a goal limited in time, limited in size, clear rules, clear roles, and with characteristic process of work.

Cooperation supposes primarily **the decision to take responsibility for your own steps and to be a part of a bigger whole.** The development of capabilities and abilities to cooperate in team may follow after that. The main prerequisites are:

- To work on yourself and revise routine procedures
- To accept feedback
- To give feedback
- Kindly and willingly listen to other opinions
- To be aware of the goals of cooperation
- To respect the diversity of colleagues. Everybody has their own version of truth

Coordinated interdisciplinary cooperation can be shown as **cooperation on common planning and implementation of approaches of diverse medical professions.**



Key presupposition: no decisions of participants of collaborative team work are done without the person concerned! *(cf. Patient managed therapy – self management).*

In concordance with I. Holmer, it can be said that the basis of cooperation is common interest and good communication. It is an advantage if the teams meet regularly and their activity is structured and controlled. The result of this cooperation is creation of an effective plan of (long-term) care.

Questions for self-study and revision:

What lines of profession project into the area of inter-disciplinary cooperation team in long-term care?

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6. PREVENTION OF LONG-TERM CARE

Keywords of the chapter:

primary, secondary, tertiary prevention.

Study guide:

The term is understood as prevention of commencement. Traditionally, prevention is divided into **primary,** in brief, this means prevention of a negative phenomenon or delay of its occurrence. **Secondary** prevention is understood as the prevention of relapse or further progress of an already present phenomenon. **Tertiary** prevention is understood as prevention of complications of a phenomenon that already occurred.

The Czech Republic necessitates the development of the EU *Policy of active ageing (PAA).* It emphasizes that an active life at older age is overall conditioned by the absence of more serious medical problems – they need to be prevented.

Healthy ageing and the prevention of physical and mental health deterioration of persons with the long-term care need can be and effective way to improve health and lower the expenses. According to OECD, healthy ageing and the increase of productivity could partially compensate for the future increase of expenses for long-term care and lower the predicted increase in expenses approximately by 5 – 10 % until 2050. Prevention and focus on support of health can influence life style, identify high-risk groups and react to the development of the disease. The support of programmes that strengthen the interest in care for your own health supports user orientation. It is in compliance with the attitudes of the elderly. They prefer active and independent life in their own environment and community. Healthy ageing and prevention may be very useful. But it must be complimented by information on expenses and contributions of particular interventions.

PAA – puts emphasis on educational and preventive medical interventions and development of geriatric medicine but also on the need to prepare for the fact that an increasing number of people will live longer. Which will be marked by an increased number of chronic diseases, conditions and disabilities.

That will cause an increase in the demand for health and social services of long-term care. **Creating a system for provision of long-term care** must necessarily be a part of the policy of active ageing.

Particular clinical fields deal with the prevention of diseases (Novotný In Kuzníková, 2011), geriatrics (In Čevela, Kalvach, Čeledová, 2012), psychiatry and other connected fields associated with health and social care.

The goal of the prevention of the need for long-term care is in general the prevention of the need itself. Taking in mind the discussed context (population ageing, occurrence of chronical diseases etc.), this state is not a realistic one. The prevention of the progress of the need for long-term care in home environment with the goal of returning to the original self-reliance level of the individual should be seen as the primary prevention of the need for long-term care. Secondary prevention should focus on support and preservation of the level of self-sufficiency. With an additional goal of prevention of the need for institutional care. Repeated deterioration of the health condition leading to the repeated need for using institutional healthcare services is prevented by tertiary prevention.

Coordinated rehabilitation, by its processes, it greatly participates in and significantly influences all the levels of preventive measures.

Self-sufficiency and self-reliance are of crucial importance

Self-reliance – is the ability to lead an autonomous and dignified life in a natural, generally demanding environment and the ability to take care of yourself, without anyone else's help.

Self-sufficiency in instrumental activities of daily living (IADL) – is the ability to do everyday tasks (transport, shopping, management of finances, keeping the house, doing the laundry)

Self-sufficiency in basic activities of daily living – is the ability to take care of the basic self-care activities (to feed yourself, to get dressed, to perform hygienic care, bowel-movements, movement from one place to another). It is the ability to get on well without any help in care for yourself.

In judging the need for long-term care in the population, it is necessary to evaluate the amount of self-sufficiency and dependency.

Disability rates – it determines the part of the population that probably needs the services of long-term care. The criterion is defined as dependency in at least one of the areas of activities of daily living. It was determined on the basis of the SHARE research in EU.

Dependency rate – is an indicator that determines the degree of care. It is obvious that this need can be satisfied by providing of informal care (this has been so far the majority of the cases in most of the countries of the EU). Or by various services payed from public funds.

Cited and recommended literature:

Čevela, R., Kalvach, Z., Čeledová, L. *Sociální gerontologie. Úvod do problematiky.* Prague: Grada, 2012.

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7. NEEDS OF LONG-TERM PATIENTS

Keywords of the chapter:

Self-sufficiency, functional abilities, psychological needs, biological/physical, social, spiritual, sublimation/frustration, strain situations, theory of needs, classification of needs, evaluation of needs in chosen target group

Study guide:

The need for care is not primarily connected with age. It is connected with the decrease of functional abilities and self-sufficiency that limits people in their ability to satisfy their daily needs.

Need

It is the basic form of motive. Referring to any lack (deficiency) in biological or social dimension of being. It can be the motive to act, a manifestation of deficiency, its elimination is desirable.

Needs may be satisfied – saturated. Or not satisfied – frustrated. While saturating one need, paradoxically, a frustration of other needs might occur. For example, the feeling of safety in placing somebody in a home for the elderly, the need for social ties may be frustrated.

As well as in the case of the elderly, the priorities of needs change during the course of the disease. Spiritual needs (not only psychological) also come to the fore in the terminal stage of the disease, not only the need to cope with the pain.

For further studying of the theory of needs I refer the readers to its authors **A. Maslow** or **Max-Neef.**

The satisfying of needs is also influenced by many factors. For example, individuality of an individual (personal characteristics), developmental stages of the individual (starting with the new born, finishing in the involutionary stage of life), culture (models of satisfying of needs),

family (functional, dysfunctional), disease (its character, type of treatment, hospitalization…). Dissatisfaction of the below mentioned needs is strongly reflected in ill persons (acutely and chronically), in the elderly, children and everybody whose life situation, place of residence, have changed.

If a person cannot implement, for various reasons, his or her needs, it becomes the task of the environs to help with satisfying the need.

The goal of the helping professions in LTC, is to provide the satisfying of the needs in all of the areas of human needs. With the goal of keeping the highest possible quality of life. This should be based on a detailed analysis, evaluation, and establishing of the plan for their fulfilment through the coordination of the LTC services.

Overview of basic needs:

Area of needs	**Needs**	**Physical manifestations of dissatisfied needs**	**Psychological manifestations, and manifestations in behaviour of dis-satisfied needs**
Physical needs (biological, physiological)	intake of water, food, getting a sleep, relaxing, defecation, sex, shelter, physical well-being	Thirst Hunger Cold Heat Pain Fatigue	Stress Boredom, apathy Fatigue Lowered attention Irritation Aggression
Psychologi-cal needs	**The need for security, safety** (self-sufficiency, independence, awareness, the need of order)	Fatigue Palpitation Upset stomach Inner tremor	Danger, insecurity Fear, insecurity Dependence on others Chaos Remorse, anger Withdrawal

	Need for love (sense of belonging, positive acceptance, confidence, friendship, communication)	Dissatisfaction of this need may reflect in psychosomatic displays	Feelings of uselessness Uncertainty Loneliness, sadness Anger, aggression Distrust Withdrawal Sorrow and hopelessness Feelings of grievances, injustice, inferiority Apathy
	Open future		
	Self-respect and self-determination (respect, intimity, autonomy, liberty, appreciation, need for aesthetics)		
Social needs	(Křivohlavý, 2001): - **need for affiliation** – social contact – meeting others - **need for friendly relationships** – credibility of a person - **need for social attachment** – mother and child relationship - **need for mutuality** – to be in somebody's care and to take care for somebody - **need for social communication** – talk to somebody, lead a conversation, share, not only give out - **need for social comparing** – to cross limited individual possibilities - **need to ensure social safety** – against unsolicited aggressions of others - **need for cooperation** – to cross limited individual possibilities - **need for positive social evaluation** - need to have your value acknowledged by others, need for respect (respect, social acknowledgement, praise etc.) - **need for social integration** – to be accepted by other people and to belong to particular social group - **need for social identity** – to be 'somebody' within the frame of certain group - **need for love** – to be loved, valued, appreciated as a person 'sui generis' and the need to love somebody		

Spiritual needs	**Spiritual needs** Specifically human needs of beauty and harmony, justice and forgiveness, truth and reconciliation, joy of life		Sadness Futility Depression Hopelessness Implacability

Table 1: overview of human needs

For assessment of needs, there are research tools that measure the rate and quality of human needs with specific needs. For a group of people with mental disease, as an example, an overview of tools is provided by Kalvoda, Nelepa, Probst (2005). For geriatric patients by Gallo et. al. (2006). For children and families in danger Matoušek and Pajzlar (2010). These tools are useful for evaluation of the needs and risks connected to their un-fulfilment. Some of them measure only their existence, others measure also the rate of current satisfaction. They focus on psychological and social needs.

Evaluation of physiological needs is then the domain of tools that are at disposal of nursing care. Sikorová (2011) deals with the needs of children. Šamánková (2011) deals with human needs in good health and in illness. Let me refer the reader to her work on the need of long-term patients.

Notes on needs at old age

As Janečková (2005) confirms, many people lose in old age the ability to satisfy their everyday needs, to fulfil plans, keep control over their live to a level they were used to. That **reduces the quality of their living.**

The needs of a person are individual. They change in time and relation to the environment they live in.

Among the most important needs for the elderly are, according to many studies, the need for safety and security, trust, stability, love, social contacts, reliability, and physical and psychological well-being. The need for **autonomy**, free deciding for themselves, is often overlooked and forgotten when trying to help the elderly. **Dignity** of the elderly should especially be foregrounded (e.g. in the case of the elderly with dementia, autonomy should not be placed before dignity). Nevertheless, while satisfying the need for safety, there should be no exaggerated protection. That could lead to the elderly being dependent on the others.

Notes on the needs of children with long-term disease

The knowledge of the disease should not be in the foreground of the care for long-term ill children. The knowledge of the child and his or her needs should be primary. The needs depend on the age (developmental stages), and satisfying of the emotional needs (emotional relations in family x missing family), demonstrations of disease and personal experience with hospitalization, care etc.

Primary needs are always in the foreground of the carer's interest – the needs for feeding, nutrition, sleeping, resting, bowel movements… Psychological and social needs are important as well, especially the need for support of the others towards self-sufficiency, self-realization, open future. It is difficult to find the correct rate of satisfying of the needs in the care for the child, so as not to put prematurely high demands on the self-sufficiency that the child is not yet capable. Or on the other hand, excessive protection of the child could lead to stagnation and stop the ability to 'stand on your own two feet'.

The protection and worries for the child with disability or long-term disease can lead to development of dependency of the child, in-self-sufficiency, and displays of dissatisfaction, apathy or, on the contrary, aggression.

It is important to find balance between these two extremes when the child, because of the illness 'can do everything' and 'can't do anything.'

It is important to realise as well that the serious medical condition of the child affects especially the family members (parents, siblings, and grandparents) who are often overlooked while satisfying the needs. They also have the right for support and help in finding the structure of live with a child with a disability, illness.

Notes on the needs of people with long-term disease

As well as in the case of the elderly, also in this group the spiritual needs are in the foreground. They are often overlooked in institutionary care. The point of the spiritual care for the clients is not to provide it only to religious people. On the contrary, all humans have spiritual needs and everybody should be given the same amount of attention in this area.

The help in satisfying of the spiritual needs includes:

- attention of carers for the past of the person (it leads to reconciliation with themselves, life, people, God)
- attention of carers for the present / current time of the person (in the fight with the disease, managing of difficult situations, problems with treatment, searching for meaning, acceptance of suffering and its values)
- attention of carers for the future of the person (guiding of the ill on their life journey, displays of love)

Disease and treatment (including hospitalization, healthcare) are stressful situations for people. The current needs derive from it. They are not stable but changeable. The work with the needs of such a person should lead to successful managing of stressful situations with the support of his or her functioning and keeping of the autonomy and dignity of human being.

The needs are affected by the clinical type of disease, specific area of needs satisfying are especially visible in people with mental disease, oncological diagnosis, disease of the movement apparatus, and people with permanently damaged bodily functions and appearance.

As the area of needs is quite wide, let me refer (not only) to the recommended literature section.

Practical task:

Prepare an ADL/IADL evaluation, Barlett test, and make an overview of the needs and a plan of activities, their satisfaction with a diseased person (acutely /chronically).

Try and think about the possible social health services that could contribute towards satisfying of the preset needs.

Prepare it in the form of a commented description, add the evaluated tests as attachments.

Cited and recommended literature:

Dvořáčková, D. *Kvalita života seniorů v domovech pro seniory.* Prague: Grada, 2012.

Gallo, J.J. *Handbook of Geriatric Assessment.* Sundbury, MA: Jones and Barlett, 2006.

Janečková, H. Sociální práce se starými lidmi. In Matoušek, O. et al. *Sociální práce v praxi.* Prague: Portál, 2005.

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Křivohlavý, J. *Psychologie zdraví*. Prague: Portál, 2009.

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8. QUALITY OF LIFE OF LONG-TERM PATIENTS

Keywords of the chapter:

Quality of life, quality of long-term care

Study guide:

„It is a multidimensional, subjective and measurable construct that expresses how one evaluates one's life situation. It is used to monitor the effectiveness of comprehensive psychosocial and medical interventions. The concept is delimited and defined in different ways by different disciplines.“ (Dragomerická, 2013)

According to Křížová (2005), the quality of life involves three main areas: physical experience, mental well-being and social status of an individual and his / her relations with other people.

Categories of quality of life

were, with respect to a variety of disciplines, proposed by Ruut Veenhoven (2000) in **his four model types of quality of life**. The model allows it for concepts to be categorized according to what type of quality of life they involve:

A – ecological, social, economic and cultural environment

B – physical and mental health, knowledge, abilities

C – ethical issues

D – interdisciplinary assessment of quality of life

	Outer qualities of life	Inner qualities of life
Chances	**A. livability of the environment** (environment, social capital, prosperity, standard of living)	**B. life-ability of the individual** (psychological capital, resilience, health, self-efficacy)
Results	**C. utility of life** (higher values than mere surviving, transcendental conception)	**D. inner appreciation of life** (subjective well-being, content, happiness, sense of accomplishment)

Table 2: Four qualities of life according to Veenhoven (adapted from Dragomerická, 2013)

From the perspective of healthcare, monitoring quality of life means moving attention towards the psychological and social aspects of health. Interest in personal experience with the disease and the treatment process has come to put emphasis on humanistic values establishing desirable counterbalance to technological advances in the medical sciences. In the field of social care, measuring quality of life is an important part of evaluating comprehensive preventive and rehabilitation programs and psychosocial interventions.

Quality of life is observed at different levels: micro (personal) / mezzo (groups, population) / macro (nations).

The mezzo level of quality of life measurement includes evaluation of interventions and services provided; it compares and examines the needs of different groups and identifies risks and projective factors which affect the life situation of the persons monitored.

The personal (micro) level of quality of life measurement is used to setting up a personal plan and its evaluation as well as for customization of personal care.

General / generic questionnaires are used to carrying out measurement – they are applicable to any set of patients / clients as well as members of the healthy population, and they allow mutual comparison. The questionnaire EQ-5D (EuroQol Group, 1990), SF-36 (Medical Outcome Study 36-Item Short Form, Ware, 1992), questionnaires WHOQOL (WHOQOL-100, WHOQOL-BREF, WHOQOL-OLD, WHOQOL-DIS, WHO) are an example.

Special questionnaires are designed for patients with certain difficulties and determine the impact of these difficulties on their life. They capture clinically significant changes but the results cannot be compared or generally applied. The international database PROQOLID provides an overview of special questionnaires (www.proqolid.org).

Experts on quality of life in medicine (Musschenga, A., Křivohlavý, J.) distinguish three interrelated meanings of the term quality of life: quality of life as a degree of normal functioning, quality of life as a degree of satisfaction with life and quality of life as a level of human development.

For the elderly, the second point is important as they can feel they are at the end of their journey and tend to understand the quality of life in the sense of satisfaction with their life. If they consider life to be meaningful and are satisfied with the way they lived, then they tend to feel high about quality of life.

Overview of quality-of-life affecting factors with long-term patients and elderly people (with respect to considerable amount of subjectivity they cannot be exactly delimited):

- a set of health, social, economic and environmental factors
- specific factors such as age, sex, family situation, polymorbidity, education, values, economic situation, culture
- health as the outcome of a variety of factors
- factors contributing to the decline in self-sufficiency (chronic disease, ageing-related involutionary changes, poor housing conditions, lack of financial security, inaccessibility of care and services, absence of social support and relationships)

The term **conditional quality of life** – in relation to long-term patients and the elderly it refers to a health-related quality of life which is determined by the main health indicators. These particularly include the presence of health problems, whether or not these problems require treatment, the extent to which they are accompanied by pain and other unpleasant side effects, and the extent to which present a limitation to the patient's normal activities.

Evaluating the quality of life of long-term patients and the elderly is essential for understanding the current needs of the target groups, planning services to these groups and assessing the existing services and assistance they receive.

Quality of long-term care

Is being discussed worldwide, the attention of research and the general public primarily directed towards the quality of institutional care; results shows that it varies significantly from country to country. Few studies deal with the quality of field services.

Within the context of LTC quality it is necessary to pay attention to the following (OECD, 2005):

1) personnel / those who provide care and quality of their education
2) optimal / standard quality of LTC services provided in the area of structure, processes as well as results

LTC service structure indicators:

- quality and safety of buildings, fire safety, sanitary equipment
- environment
- size of rooms
- numbers of qualified personnel

LTC service process indicators:

- ways of protecting clients' rights
- functioning mechanisms of client admission, transfer, dismissal
- needs assessment and care planning procedures
- availability of services needed to achieve optimal functional status
- non-stop availability of qualified staff
- quality diet
- services availabilty (rehabilitation, hygiene inspection, pharmaceutical care, physiotherapy, ergotherapy, logotherapy and others)
- adequate care documentation
- quality of care supervisor

Results indicators

- prevalence of bedsores, incidence of new ones
- prevalence of malnutrition, dehydration, adequacy of enteral nutrition
- maintaining clients' self-sufficiency in ADLs / IADLs
- pain management
- means of restraint (pharmacological, non-pharmacological)
- prevalence of infections
- prevalence of medication (such as antipsychotics)
- prevalence of probes, permanent catethers
- number of falls and injuries, prevention of falls
- prevalence of fecal incontinence
- urinary continence management
- social interaction and privacy protection

The indicators should lead to **standardization of LTC**. The Czech Republic still lacks predefined sets of long-term care standards. Adherence to standards certainly does not mean ensuring the quality of care, but it can be of much help. (Evidence is based on experience from quality inspections in social services, healthcare facilities accreditation.)

Cited and recommended literature:

Dragomerická, E. Kvalita života. In Matoušek, O. et al. *Encyklopedie sociální práce.* Prague: Portál, 2013.

Dvořáčková, D. *Kvalita života seniorů v domovech pro seniory.* Prague: Grada, 2012.

Křížová, E. *Sociologické podmínky kvality života.* Prague: Triton, 2005.

CONCLUSION

Dear students,

The present text has provided you with an opportunity to research numerous reference and information sources which were only valid and completely up-to-date at either the time of compiling this study support or at the date of arranging for its more recent editions. Please never lose track of fresh updates as well as new publications on the respective topic of your interest.

Let me firmly believe you will be able to make use of the information obtained for the benefit of developing coordination of the long-term care system in the Czech Republic and, in the course of time, to make your own contribution in the form of more recent publications or studies to enhance both strategic development in this area and practical use of the long-term care concept and tools.

In conclusion to this study support let me avoid the traditional content summaries or reflections on what information you may or may not have been able to look up in the text. Hand in hand with the constantly growing field of rehabilitation coordination, I merely wish for both you and all of your patients that the above discussed concepts, visions and strategies should become real and truly fulfilling.

Yours, Iva Kuzníková, in Ostrava on 1st September 2017

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