Environment and Social Psychology (2024) Volume 9 Issue 5
doi: 10.54517/esp.v9i5.2304

Research Article

Quality of life of seniors living with dementia

Lukáš Stárek

Department of Pedagogy, Institute of Education and Communication, Czech University of Life Sciences Prague, Praha 5—Malá Chuchle, 159 00 V Lázních 3, Czech Republic

starekl@ivp.czu.cz

ABSTRACT

Demographic changes are changing the age structure of the population, and we perceive how the population is aging and the number of people in senior age is increasing. The phenomenon of aging, especially in the context of dementia, is a topic that resonates even in professional society, and thus points to the aspect of the perception of aging of people with dementia in the context of quality of life. Providing care to aging people living with dementia should be aimed at improving the quality of their existence. It is a disease that has a huge impact not only on the person who suffers from the disease, but also on their loved ones, on their surroundings and also on society as a whole. In particular, older seniors living with dementia significantly require a more specific approach and support. The aim of this professional study is to point out the reality of real aspects of the quality of life in the context of dementia and to present here not only general knowledge about dementia, but also research data.

Keywords: aging; dementia; quality of life; support; threat

1. Introduction

The factors that cause dementia are still under research. These factors do not involve risk factors. According to Rektorová[1] into group of risk factors involve “older age, being female, previous dementia illness in family, higher blood pressure, repeated bran traumas, genetical factors and lower attained education. Further risk factors can be anaemia of infarct, stroke, and general vessels issues, depressions, other psychological issues, and unpleasant socio-economic environment.” Another risk factors are involved by Holmerová, Jarolímová, Suchá[2], these are smoking, alcohol usage, head injuries, anti-inflammation medicaments, and hormonal substitute treatment. Further, they involve depressions, infections, and lack of vitamins.

Dementia is viewed as progressive illness which causes decline and further loss of cognitive process mainly memory, focus, learning, thinking, sensorimotor skills, speech, and ability to communicate, social skills and emotional displays. Some decline of cognitive skills is during ageing normal, and it is natural part of growing old. However, it is crucial to be able to differentiate and for everyone these processes are different. In context of dementia, the decline of cognitive skills influences speech, but also logical thinking processes, and ability to process information. Thus, cognitive skills are huge part of daily life from dressing up, personal hygiene, reading a book, having a conversation. Unfortunately, dementia is still an illness, and we must approach it like that even though there are researchers and experimental treatment is undergoing there still is

ARTICLE INFO
Received: 11 December 2023 | Accepted: 23 January 2024 | Available online: 1 February 2024

CITATION
Stárek L. Quality of life of seniors living with dementia. *Environment and Social Psychology* 2024; 9(5): 2304. doi: 10.54517/esp.v9i4.2304

not a cure for dementia. Even though studies and research are working on medicaments which might slow down the illness.

Almost 90% dementia are vascular type dementia which is so called arteriosclerotic dementia and Alzheimer's disease[3]. On the other hand, Buijssen[4] states that almost 55% people with dementia have Alzheimer's disease and in their clear form. Hauke et al.[5] claim that 60% dementia is Alzheimer's disease. The next closest illness is vascular dementia which is presented within 15% cases. Another 15% is combination of two or more illnesses. The last 15% are rare illnesses which are Parkinson's disease, Bingswanoger's disease, Lewy Body's disease, and Huntington's disease which are more presented within younger patients.

2. Dementia in number and demographic changes

WHO[6] published in 2017 in Global action plan on the public health response to dementia 2017–2025 following alarming information. Specifically in 2015 there was 47 million people with dementia illness which 5% of worldwide population. The perspective is that in 2030 we will be talking about 75 million, and in 2050 it will be 132 million. From speculation is obvious that every year there is 9.9 million new cases of patients with dementia. Almost 60% people live with dementia in low- and middle-income countries and it is believed that majority of new cases (71%) will be patients from these countries[7]. This thought is supported by Alzheimer's Disease International organisation from whom date were used by Matl, Matlova, Holmerova[8]. "… majority of people with dementia (58%) lives in less developed countries or in middle income countries. Published comparisons of Alzheimer's Disease International organisation signalize that in central Europe, where is Czech Republic, the population of people living with dementia is lower than average in rest of the world. While paying closer attention to the statistics and data from Europe and European Union we can almost say that countries which entered European Union in 2004 shows lower numbers of patients with dementia that is average of European Union." Further, it is crucial to highlight that dementia does not appear only within elderly people and this illness is currently present with 9% younger people (means people before age of 65 years).

Dementia is of the biggest risks factors for everyone. Nevertheless, the economical context is important as dementia significantly influences not only one's social life but also their financial situation moreover the whole society and its economic situation. In 2015 the costs related to dementia were predicted to be 818 million USD, which is 1.1% worldwide GDP on scale of 0.2% for low- and middle- income countries and 1.4% for higher income countries. It is predicted that in 2030 worldwide costs for care of people with dementia will be 2 billion USD (WHO, 2017).

Further WHO (2017) together with world bank predicts that till 2030 will be worldwide need for 40 million workplaces in health care and social care and approximately 18 million of medical staff mainly in low-income countries. Thus, the needed health care and be effectively provided for people living with dementia.

In Czech Republic elderly people are one of the biggest groups which has own specifics that need to be reflected while taking care of them. "Even though we can assume that active age of future seniors will be higher that within current elderly people their growth of numbers within this groups will significantly influence the whole society"[9]. From statistical predictions and data, we can assume that "…2040 will be for Czech Republic periods when generation of baby boomers from 70's of 20th century will cross the line for elderly people… The change in numbers of population will not be significant as the predicted growth of elderly people over 65 years will be more than 2,75 million of people which will be 25% of Czech's population"[8]. Every year the numbers of people with dementia in Czech Republic grows and generally also in Europe by 5.4%. Every 20 or 25 years this number doubles up[10].

Average age of men is Czech's population is 40.8 years and 43.6 years for woman. There is almost one fourth of people over 60 years. Demographic predictions show that in next 30 years there will be significant growth in numbers of people over 60 years and inhabitants over 65 years. Within this development there will be connected higher morbidity within population. Population models presents expected growth in number of ill elderly people with neurodegenerative illnesses mainly with diverse forms of dementia[11].

Wirth regards to the world trend it is logical that growth in numbers of people living with dementia is related to Czech Republic as well. In historical context according to Matl, Matlova, Holmerova[8] "The percentage of people living with dementia was expected to be twice as high as it currently is. In 60's of 20th century there was between 49–55 thousands of people with dementia, during red velvet revolution in 1989 there was 73–81 thousands of people with dementia. In 2000 there was 89–98 thousands of people with dementia and in 2015 there was almost 156 thousands of people with dementia. Thus, if we take the numbers and combine them in median variation and if we apply the last revelation study conducted by Alzheimer Europe, we can assume that in 2020 there will be almost 183 thousands of people living with dementia, and in 2050 there will be 383 thousands of people living with dementia in Czech Republic."

Czech Alzheimer Society published in 2006 strategy labelled as P-PA-IA[12] which describes needs of people living with dementia in diverse stages of the illness. The aim of the strategy is to maintain the needs of people with living with dementia. The strategy is divided into three phases which mirror three stages of dementia.

Let us now consider neighbours of Czech Republic and their statistics about people living with dementia.

In Slovak Republic live around 5,500,000 inhabitants and there is around 50–60 thousand of people living with dementia. It is estimated that around 15% of people above age 65 lives with dementia. Further it is considered that only 5–10% of patients are treated adequately that means in way the symptoms are eliminated and quality of life is improved for the patient and for the care givers as well. The Slovak Republic does not have enough information about this illness in manner of base information. Based on estimation it is believed that there is 1.07% population affected by this illness. Unfortunately, there are not statistics for this claim as for whatever the reasons dementia and other illness of dementia characters are underdiagnosed in Slovak Republic[13].

In Poland (Poland Republic) where lives 38 million inhabitant similarly as in other countries dementia is significant challenge for Poland's medical resort. Diagnostics and treatments of this illness are responsibility of neurologists, psychiatrists, and geographers. From available information it is obvious that geriatric care is insufficient in Poland. For 100 000 inhabitants there is not even one specialist (0.8). To compare in Czech Republic there is 2.1 specialists for similar number of inhabitants, in Slovak Republic is 3.1 in Sweden the number is 8. In recent years Poland's government have invested significant will to improve the care and diagnostics of this illnesses related to ageing. Available data reveals that in Poland there is 14.7% of population older than 65 years, and the number will grow to 24.5% in 2035. Further, in 2050 the number will reach over 30%. With dementia there live over 300,000 people and significant percentage is without diagnosis. This number is huge, and it is important to highlight that this illness affects around similar number of people as the number of caregivers. Till 2050 the number of people living with dementia will grow three times and it will reach almost one million. In 20105 there was research conducted from which derives that almost 90% of caregivers are family members including 32% husbands and 62% children of a person living with dementia[14].

In Federal Republic Germany (further just Germany) where live around 83 million of inhabitants the number of elderly people is growing up and overall population is lowering. The reasons are lengthening live expectancy. Plus, the long-term stagnation in fertility question and starting a family. There is also decrease in numbers of young people underage of 20 years when estimation is that in 2030 there will for one fourth less children and young people in comparison with the first decade of new millennial. In connect of elderly people (over 65 years) the growth is estimated by 40%[15]. Therefore, even Germany must face the reality of lengthening live expectancy and illnesses related to ageing.

Germany is in the fifth place regarding the number so f people living with dementia similar position have Brazil. In front of Germany is only China, the USA, India, and Japan. According to estimations there is around 1.6 millions of people living with dementia in Germany, Majority of them have Alzheimer disease. In average there is around 900 new cases every day. Thus, during a year it is 300,000 new cases. Due to demographic changes, there are more new cases of any dementia illness than demises. Almost two thirds of elderly people living with dementia are women and one third are men. If there will not be any change in treatment and prevention programs the number of people living with dementia will grow to 2.4–2.8 million. This is equal to the growth of 25,000–40,000 in a year or 70–110 new cases in a day. Further, the number of people who are not over 65 years old and live with dementia is 25 thousand. The growth of new cases will slow down when the last generation of baby boomers will reach elderly age. According to prognosis of middle length of live this will happen in 2050 or even after 2060[16].

Austria where live 9,000,000 inhabitants is facing dementia illnesses as well. The topic of dementia is not a new topic for society, and it is one of the main topics which needs to address in care system which is focused on developed on care for patients, their families, and their caregivers. The services orientated on care are coordinated through all areas of care are permanently available for people living with dementia and their families. They require coordination of all responsible parts not only in health and social care. Austria's federal ministry for social things, health, care, and protection of a client (Bundesministerium für Soziales, gesundheit, Pflege und Konsumentenschutz) cooperates with federal countries, cities, institutions of social security, leisure centres, science, people living with dementia and their families during fulfilling the National Strategy for Dementia (Demenzstrategie Angebote für Angehörige von Menschen mit demenziellen Beeinträchtigungen, 2021). With aim to provide successful care for everyone affected by dementia.

In 2000 in Austria lived 90,500 people affected by the illness from which majority suffered Alzheimer disease. In 2016 the number was 130,000 people. Based on current projection the number of people living with dementia will be in 2050 only 270,000[17].

In Netherlands[18] lives approximately 17,740,000 inhabitants. In 2021 there was around 290,000 people living with dementia and 125,000 from this number were people underage of 65 years. In context of age structure there is only 10% under 65 years diagnosed with dementia and over 40% is diagnosed with dementia in age over 90 years. However, these numbers will dramatically grow in upcoming years. It is estimated that the number of people living with dementia will grow up to half million in 2050 (Alzheimer Nederland). On the other hand, scientist's opinions differ in question of growth's size. There is still open discussion regarding the number of needed care where over- or underestimation can lead to over fulfilment of care of lack of care providers.

Not only with regards to already mentioned arguments, data, and numbers the overall situation in Europe when the whole European Union was created by population growth it is obvious that Europe is ageing. Together with North America and eastern Asia Europe is becoming society with linger life expectancy, lower fertility, and gained higher education. Together with new reality Europe is facing new question "Who will live and work in Europe of upcoming decades?" By investigating current models of migration, birth-rate, and deathrate, attained education, ad work flown we can assume more complex picture of future Europe. Thus, demographic changes question not only for social work.

Every year there is growth in percentage of elderly people in population. There is decrease in numbers of children and young people. The result is growth in average age. The prognosis of inhabitant's developments is expected within Czech population. Currently into age group over 65 years are falling people born after the second world war[19].

3. The quality of life of an elderly person with dementia

Aging is a natural physiological process that involves a number of changes affecting the organism. Changes in the physical field are reflected in education primarily by worsening resistance to adverse and disruptive influences, loss of energy, by reducing sensory capacity[20].

Demographic changes influence the age structure of inhabitants, and we reflect the ageing population and the growth in number of elderly people. Mainly elderly people with higher age require more specific care and support. In context of this paper, it is crucial to highlight the topic of multisensorial cooperation. With regards to the focused group of this paper the medical social care needs to cooperate more intensively while working with elderly people. The doctor must know the family environment and should be able to provide information that will support the patient and their family.

In sense of responsible approach of state organs—mainly self-authorised parts (cities, districts) there is significant change in attitude towards people living with dementia. This, if dementia is recognised as international trend, it must be reflected within our approach towards everyone. Therefore, questions related to housing, provided care, financial support and financial resources, quality of life, support of field care and ambulant care are begging to be discussed more openly. There are changes in society's understanding of importance of this topic. We can say that main catalysator of these changes is simply the fact that society is in more frequent contact with people living with dementia. In recent years there were famous people who died due to the illness for example in worldwide context former president of the USA Roald Reagan (1911–2004), actor of detective Colombus Peter Falk (1927–2011), or English writer Terry Pratchett (1948–2015). Thus, revelation of these information helped with more awareness. Further, it is obvious that to build more awareness help also diverse special days such as the International Alzheimer's disease day which is on 21st September. The main society aims it to overcome and avoid assumptions, segregation, exclusion, and stigmatisation of people living with dementia. The assumptions such as people with dementia cannot do anything or only limited things prevent their full inclusion. The main issue is stigmatisation and lack of information about disease and available help and support. The question of stigmatisation is further studies by Plichtová, Brandoburová[21] who highlight the fact that the assumptions actively prevent people with dementia to be included into society, and it harms people with dementia and their families. Further, dementia causes fear and worries no matter the culture context. Thus, the negative social environment leads to stigmatisation and explains why dementia is often diagnosed in later stages of the illness. From psychological perspective it is logical hence the person with diagnosis of dementia might feel like they are labelled. Thus, they refuse the diagnosis, and they postpone the treatment and refuse the help. However, the picture of getting a diagnosis being viewed as getting death sentence is prevailing. On the other hand, if a person with dementia lives in positive social environment where they are supported in their activities and their rights are respected, they can lead fulfilled life. Plus, they can maintain their abilities and skills which allows them to end their life as dignified person.

According to Kisvetrová[22] quality of life is very subjective topic and everyone imagine something different under term quality of life. Sleezer et al.[23] characterises quality of life as subjective, holistic, dynamic, multidimensional, values orientated, which involves subjective and objective factors related to fulfilling one's needs. The quality of life is also involving environment in which one lives regarding their needs and requirements. Holmerová[24] defines quality of life as follows "It is complex term which involves subjective understanding of life, health and functional state so that social interactions and overall satisfaction with life can be met.”

WHO defines quality of life as process of understanding of an individual and their position in society, their value system and relation to other members of society. Further, it involves one’s aims, expectations, norms, and fears. Nowadays, people are encouraged to think about their quality of life (QOL). “WHO established deviation of individual areas of QOL for their definition of QOL. WHO recognizes four main areas which are related to QOL which are adequate for each no matter their age, gender, ethnicity, or handicap:

- Physical health and level of self-efficacy (energy, tiredness, pain, rest, mobility, everyday life, requirement for medical help, ability to work etc.).
- Psychological health and spiritual area (self-awareness, negative and positive feelings towards yourself, self-evaluation, thinking, memory, learning, concentration, spirituality, belief etc.).
- Social relations (personal relations, social support, sexual activity).
- Environment (financial resources, security, freedom, availability of social and health care, home environment, opportunities to develop knowledge and skills, physical environment—cleanest, noise, clime)[25].

This definition assumes that a person can intellectually and complexly decide about themselves[22].

There should be attention paid to QOL of elderly people with lower ability to look after themselves as their numbers will grow. Mainly we should focus on people who need care and residency. Currently, there is strong emphasis on fulfilling quality of care. The workers in social institutions should be aware of subjective understanding of QOL and they should be able to react to their individual needs[26].

Extensive categorization of according to WHO proves that term QOL is mirroring development of society, and it mirrors the client and their understanding. The provided care should reflect the individual and their needs. The role plays several factors:

- For years the care and its provision were defined by providers and this shift in requirements needs shifts in thinking as well.
- Care providers should limit their power and they should be asking for permission of offer wider explanation.
- With wider provision of care there might appear addiction of clients on it, and it should be limited.
- There is significant difference between situation when I cannot vote and when I learn to who.

According to Lužný[27] the evaluation of QOL of people living with dementia strictly subjective. The QOL is reflected in many areas of one’s life. The significant influence on perception and evaluation has self-efficiency or appearance of other illnesses, or health complication. An elderly person living with dementia is already facing many changes either physical, mental, psychological, or social which are related to the illness[28]. With regards to the reality that this topic is studied there are new information. For example, it has been proved that dementia itself does not lower the quality of life, but it is one of the factors which influence it[29].

Quality life and quality of life are terming whose meaning might be obvious. However, they are often mistaken one for other. Therefore, let us provide some definitions here. Quality life is term which is nowadays commonly used not only by academic but by public as well[30]. It is an important saying which is used in many areas. We can say that it is relatively new term which is interdisciplinary and multidimensional. Although it might eb controversial and hard to handle. Payne[31] states, this term was coined firstly in political and economic areas approximately around 20’s in 20th century in context of socially and economic lower groups within topic of providing social support. Further the term disappeared, and it was used again after the end of the second world war when developing countries tried to make their economies grow up. In the USA it was proved that economic growth and consumption does not mean growth of quality life. The current president J. F. Kennedy stared to care about quality of life of his inhabitants with meaning to provide satisfied and good life. Therefore, the QOL started to be recognized individually without economic growth.

According to Heřmánková[30] research and studies about OQL started to be conducted around 1960's. However, this topic was a subject of research even before influence of J. F. Kennedy, as it was researched due to materialistic and richness issues of Western Europe and the USA. In the 60's of 20th century the QOL began to be studies from sociological perspective where researchers concluded that the QOL must be studies from diverse perspectives not only from economic status of a person. Gullone and Cummins[32] state that due to this conclusion researchers started to focus on other indicators laid in social context which allowed for more subjective and objective perspective. In 80's 20th century the research about the QOL stagnated but the QOL indicators improved. Further, it was identified that deeper philosophical and theoretical base is missing, and that only empirical research is not enough. From 90's of 20th century the development in research is obvious and tendencies to capture and define theoretical base and thus create sufficient style to capture the QOL are visible. The term stated to be more frequently used in health and medical care.

The QOL in social work is more focused on daily activities and abilities that are for a person living with dementia crucial. Plus, they are used as indicator of self-efficiency. Dementia influence not only the person living with it, but it influences life of their family and care givers involved in care for the person living with dementia. It is logical that daily activities change and adapt based on the needs of the person living with dementia. Sometimes, one cannot do everything similarly as before but the right for daily activities remains. The reflection of previous lifestyle is important. Similarly, as personal options, values, culture habits, education, or profession. Permanent and specialized team guides everyone involved in the care through their activities.

The QOL is subjective question, and their evaluation is subjective and should reflect the opinion of the individual living with dementia. The list below allows us to see and understand to the term QOL in more depth. However, whether the person sees their life as quality is based on their subjective evaluation. Several diverse methods to assess QOL were developed. The evaluation of QOL has meaning not only for the individual whose life is being assessed but for the care providers as well. However, we must reflect the mental and physical state of an individual as it might influence how they feel about their life. Generally, we can that these areas influence QOL:

- Definition of oneself—this area can be influenced by one's influence and it can be control of what is happening in one's life. However, no one can control their whole life hence people are too much addicted on their environment. On the other hand, if we could experience freedom only in questions such as "what will I eat today?" we would not enrich our life much.
- Personal development and sense of life—creation and development of identity, and self-awareness. Gaining abilities and skills which are an individual important. Plus, competencies and responsibility which might be problematic or some individuals.
- Physical satisfaction—in this area we focus on health, nutrition, movement, but we cannot forget on option of reflection and relaxation.
- Emotional satisfaction—this area focusses on feeling of emotional safety. Too many challenges in one's life might lead to their emotional drains. On the other hand, lack of challenges can cause feeling of boredom. It is important to highlight that emotional satisfaction can influence QOL life, but it does not mean that the life is quality.

- Relationships—this area mainly focus on relationships within family, friends, and other clients, and even care providers. The frequency of contacts is important and its diversity as well. Plus, the meaning of these meeting is important such as love, friendship, warmness, and solidarity.
- Life clime—what does housing offer and environment we live in. Whether the housing is safe, provide enough privacy, where it is located etc.
- Material satisfaction—this area includes financial and material resources which should create the base of satisfied living.
- Social position—this is crucial position which one has in society, and it provides opportunities for an individual to be involved in society.

The main aim of care givers is to register daily abilities and activities in process of provided social care, or health care. with regards to the process of evaluation exist several tools to track the evaluation progress. Kisvetrová[22] divides the evaluation tools into three main groups based on from who's perspective the evaluation is conducted.

- Objective observation—from this perspective the person who evaluates only objectively assess emotional behaviour of a person living with dementia. This process involves for example six step questionnaire Affect Rating Scale (ARS).
- Caregiver's assessment—in this perspective the family members or caregiver is asked to assess five areas of life (social interactions, self-awareness, feelings and mood, enjoyment of activities, reactions of surrounding) and it involves preferred areas which might be helpful for client. This method involves Alzheimer's Disease-Related Quality of Life (ADRQL). Further it can involve Barthel Index (MBI) which is external evaluation scale in which care givers assess the skills and abilities of a person living with dementia. Assessment of individual parts has point scale where points are added up, and with higher amount of point the higher the independency is.
- Combination of self-evaluation and caregiver's assessment—this involves subjective view of a person living with dementia but assessment from a caregiver as well. The most frequently used tool for this assessment is Quality of Life—Alzheimer's Disease Questionnaire (QOL-AD).

The opinions of some specialist on QOL within elderly people living with dementia—according to Breitkreuz[33] derives from research and opinions that QOL of elderly people living with dementia is very low. The main issue is inadequate or lack of communication between elderly person living with dementia and their environment. Further, low level of empathy from their close family. The caregiver, family, or a specialist are often mystified by fact that elderly person living with dementia is not able to communicate. Thanks to non-verbal communication they can read emotions and reaction from their faces.

Further research in context of QOL of elderly people living with dementia is Moyle et al.[34] who conducted qualitative research within elderly people living with dementia in residency care provision. Overall, they conducted 32 interviews during which they aimed to gain opinions and thoughts of elderly people living with dementia. The results showed that elderly people living whit dementia often feel useless and left out from society. The positive sides of the research where relationships with families, control over own life, being involved in community of the residency program, or being able to be involved in group or institution.

The context of QOL and social work can be significant subject to discuss as there are many changes undergoing which bring into life of elderly people living with dementia more empathy and focus on QOL. Further, the thought of self-definition and self-awareness which allows an individual living with dementia to define their own value is becoming crucial in social work.

There is significant number of tools for assessment and monitoring of QOL available and that include all stages of this illness even in context of care. conceptualization of this phenomena without any doubt is becoming more relevant and discussed due to growing number of people living with dementia. Nevertheless, all methods for assessment have similar core and that is based on self-evaluation and changes conducted due to the moment when the changes required due to the illness were not made. However, it is still proved how little we know about needs of people living with dementia.

With regards to the topic of QOL within elderly people living with dementia arise many questions or areas to which we still need to understand and should be studied.one of these topics is autonomy of elderly people living with dementia.

The principle of autonomy is f the most ethical topics that is reflected within social work and that should be linked to everyone. This ethical principle points to the fact that every person should be able to influence their behaviour according to their ethical codex. Everyone should reflect autonomy of an elderly person living with dementia and reflect their choices personal values, and beliefs. Mainly in social work autonomy is strongly discussed[35].

The area of autonomy is with regards to diverse limitation viewed as individual for each elderly person. Uncomfortable feelings can be evoked by own experience with ageing. Even though, ageing might have negative sides the attitude towards it should be only negative. The attitude towards ageing is often influenced by personal or society's opinions about elderly people. Sometimes the feeling of exclusion or inability to be involved in society can appear.

Pichaud and Thareau[36] state that "for a person to feel autonomy it is crucial to fulfil three main conditions:

1) To be able to self-define—"ability to choose, to freely decide and behaving in agreement with my needs",
2) To want to apply this ability, to be motivated to decide about myself (some elderly clients resign, and heteronomy is relieved for them) and finally:
3) To be able to apply autonomy—that means to have changes and environment to be able to apply this even from others around me.

The term autonomy should be viewed as way to freedom which is important during deciding about life and behaviour. In everyone's life there are stages which are related to personality development. Thus, if the opportunities to decide are interrupted the person is becoming addicted on help of others. This state is directly linked to dementia when cognitive processes, thinking, memory, place, and time orientation are interrupted. Form this we can assume that the less autonomy a person is the more help they require. In autonomy it is not about an individual being able to do something. Rather it is about allowing them to decide about themselves. According to Lukasova, Hradilova et al.[37]"…it is important to add and compensate principles of human dignity protection or adequate step with management to avoid the interruption of human dignity and rights." The authors further formulate requirements:

1) "Client is human who is ill diagnosed in standardized way and by doctor.
2) Personnel know diagnosis—so they know what applies to the client, at what stage is their illness. They even know what dementia illness brings to the care and they can orient in the problem.
3) Personnel pay attention to register of client's needs, their feelings, and risks in diverse situations. This requirement expects a certain level of expertise from personnel. Another requirement is documentation of these activities.
4) Another service provided to a person living with dementia is organisation of daily schedule and activities which are provided.

5) This is accompanied by documentation in any material about client and their illness.

They also stress that these conditions are created to meet basic needs and dignity of a client and for this a care provider is responsible not the client with interrupted cognitive skills[34].

Sýkorová[38] discusses voluntarily and involuntary loss of autonomy. By voluntary loss of autonomy, we mean moment when a client is realistic, they assess their abilities and skills, and they can voluntarily lose a bit of their autonomy. From practical experience derives that it is easiest to lose some autonomy in areas of self-efficiency, or movement ability is acceptable manner. In my life I often meet elderly people who give up their autonomy even when they still can take care of themselves. The other side is involuntary loss of autonomy. This happens when an elderly person has significantly interrupted psychological, or physiological area—this is the case of dementia illness.

An interesting study in this area is "How people living with dementia participate in decision process about health and daily care?" conducted by Norwegian researchers Smebye, Kirkevold and Engedal[39]. They tried to understand how people living with dementia participated in decision process about health care, how their family member and specialist influenced their decision. This Norwegian study involved 30 participants—specifically it involved 10 people living with dementia, 10 family caregivers, and 10 caregivers. The criteria from people living with dementia were given as follows: the person must be older than 67 years, they must be diagnosed with dementia illness in any stage, they must be able to verbally communicate. The family caregivers and caregivers were chosen based on the context of people living with dementia. During interviews with family caregivers and caregivers the semi-structed interviews were used. The field notes from observation of interactions between client and caregiver during morning care or morning activities in residency centre were used as well. The observation length was 30-90 minutes, and it was focused on how the caregivers' helped clients during their decision processes. Pseudo-autonomy decision (when caregiver did not provide choice) and delegation of decision (purposeful decision of elderly person to let the caregiver decide, which was the most common approach) were new categories which appeared. There were some autonomy decisions, but the shared decision was most common form. Lower cognitive ability, lack of available opportunities or lack of possibilities to participate/be involved lead to less participation of clients. Not all decision were based on logic, so the personal values and interpersonal relations were reflected. People with middle hard dementia showed some variability in their involvement in decision processes. Optimal combination was their involvement in decision process when they should explain their values and understanding to relationships[39].

Autonomy during life of elderly people living with dementia can be reflected in diverse areas of their life. For example, in psychological area where significant role plays social relationships. Social contacts in context of social isolation should be viewed ad risk factor. Mainly during elderly age when there is higher possibility to lose life partner, family members, or friends. Social connections, and contacts can lower the possibility that an elderly person will close themselves.

Another important area of autonomy is in health and medical decisions. In these areas, however, is important to reflect recommendations and advice from diverse specialist and medical experts. Plus, it is the medical experts and specialist who should be able to say whether the person living with dementia is able to decide about themselves. It is also curial to consider the movement and motorial abilities of a person. These skills relate to autonomy of health status. On the other hand, this is related to decision to go for a medical check-up. However, this is linked to several self-efficiency activities such as dress up, and independently face to social contacts. This overlaps with autonomy in self-efficiency. An advantage has people who even in older age individually perform hygiene and eat alone. Thus, it is important to recognize the link and cooperation diverse activities which depend on autonomy. However, everyone is unique and have unique needs and feelings which should be reflected.

4. Conclusion and discussion

Currently, at the beginning of the third millennium, we are confronted with several phenomena that significantly determine society around the world. Among these phenomena, we primarily include the growing geriatric population worldwide, which is also linked to the issue of aging, old age and the life of seniors in contemporary society. Depending on the increasing number of elderly people in the population, interest in their quality of life is also gaining importance. We can characterize the quality of life as a concept that is individual and deeply personal, because each individual creates a unique hierarchy of what he himself subjectively perceives as the values that make up the quality of his life. Different factors from the physical, psychological, social, environmental and spiritual fields are included in the quality of life understood in this way. So, we include physical functions and self-sufficiency, experience, social relationships and support, and the environment. Quality of life is therefore referred to as a multidimensional concept that is conditioned by several factors.

Not only in European countries, seniors are one of the most numerous groups in society, which has its own specificities and which must necessarily be reflected in the approach and care for them themselves. Dementia therefore becomes the main risk factor in the life of each of us.

The number of people living with dementia will continue to increase, not only due to their older age, but also people with chronic diseases. Currently, the issue of availability and intensity of care is being addressed, not only within the framework of home care or residential social or health services. We do not want to claim here that there are enough services, but we are rather referring to the question of cooperation or cohesion not only of social service providers, but also of the experts themselves, who are expected to cooperate professionally regardless of their employment affiliation, as the client should always come first, with which should be worked on in the context of the idea of uniqueness and individuality regardless of diagnosis, illness or social status. The availability of information about dementia should be available not only for experts and caregivers, but also for people living with dementia. This information must be easily accessible not only to the above-mentioned target groups, but special attention should also be paid to the comprehensibility of the mentioned information. Quality of consulting services—the quality of the consulting process can only be ensured by educated workers/experts[7].

People living with dementia and their loved ones and other members of society often do not know what dementia means and what consequences it has for a person’s functioning. Coordination and cooperation of information and people will certainly contribute to improving the quality of the system, as improving the quality of care is a continuous process that also requires attention focused on the demographic development mentioned several times. This is also related to the cultural diversity of the recipients of support/help/care and the challenges that the future labor market will bring us.

Another point that needs to be paid attention to is the structural and systematic financing of not only services, but also of people who provide care for people living with dementia, not only at the level of employees or at the level of family/relatives. As one of the topics of risk in the context of not only the care of seniors living with dementia, there is an insufficient personnel policy in the context of the absence or shortage of workers - especially workers in social services, when the illness or absence of an employee to work threatens the quality of care. Insufficient regeneration, loss of productivity, increasing risk of depression, diabetes, high blood pressure, burnout, etc. are related to this topic. A balance between work and private life is also important. For family caregivers, there is the issue of sharing ideas within self-help groups or other support that has a positive effect on the caregiver’s psyche.

Conflict of interest

The author declares no conflict of interest.

References

1. Rektorová I. Neurodegenerative dementia (Czech). Cesk Slov Neurol N. 2009, 72/105(2): 97–109.
2. Holmerová I, Jarolímová E, Suchá J. Caring for patients with cognitive impairment (Czech). Česká alzheimerovská společnost a Gerontologické centrum. 2009.
3. Viqué J. Health for the Third Age (Czech). Rebo Productions CZ. 2016.
4. Buijssen H. Dementia. A guide for family members and caregivers (Czech). Portál.
5. HAUKE M. When dementia enters your life or A practical guide to caring for people with dementia not only at home (Czech). Asociace poskytovatelů sociálních služeb ČR. 2017.
6. World health organization. Global action plan on the public health response to dementia 2017–2025. Available from: https://www.who.int/publications/i/item/global-action-plan-on-the-public-health-response-to-dementia-2017---2025 (accessed on 19. November 2023).
7. Stárek L. Social work with seniors living with dementia. Issue I. Educa Service, 2022.
8. Mátl O, Mátlová M, Holmerová I. Dementia Status Report. How much will you pay for care? Česká alzheimerovská společnost, o. p. s. 2016.
9. Ondrušová J, Krahulcová B. Gerontology for social work (Czech). Univerzita Karlova, Karolinum. 2019.
10. Holmerová I, Horecký J, Hanuš P. Specifics of the care system for people with dementia and other specific needs in the Czech Republic and Switzerland (Czech). Asociace poskytovatelů sociálních služeb České republiky; 2016.
11. NAPAN—National Action Plan for Alzheimer's Disease and Related Disorders 2020-2030 (Czech). Available from: https://www.mzcr.cz/wp-content/uploads/2021/04/NAPAN-2020-2030.pdf (accessed on 01. November 2023).
12. Kolektiv Autorů. Strategy of the Czech Alzheimer's Society P-PA-IA. Care and support for people affected by dementia syndrome (Czech). Česká alzheimerovská společnost, o.p.s. 2018.
13. Antalová A, Kaššaiová Z, Plichtová J. Risk of dehumanization in people living with dementia (Slovakian). Československá psychologie. 2020, LXIV(6), 690-702.
14. Szczudlik A. The situation of people with Alzheimer's disease in Poland (Poland). Biuro Rzecznika Praw Obywatelskich. 2016.
15. Pohlmann S. Sozialgerontologie. Reinhardt. 2011.
16. DEUTSCHE ALZHEIMER GESELLSCHAFT E.V. Dementia. The most important facts A compact guide (German). Available from: https://www.deutsche-alzheimer.de/fileadmin/Alz/pdf/Broschueren/Demenz-das_wichtigste_.pdf (accessed on 01. November 2023).
17. Kojer M, Schmidl M, Heimerl K. Demenz und Palliative Geriatrie in der Praxis. Springer Heidelberg. 2022.
18. Alzheimer Nederland. Is the number of people with dementia increasing or decreasing (Dutch)? Available from: https://www.alzheimer-nederland.nl/contact (accessed on 15. November 2023).
19. Sak P, Kolesárová K. Sociology of old age and the elderly (Czech). Grada Publishing. 2012.
20. Špatenková N, Smékalová L. Education of the elderly. Geragogics and gerontodidactics (Czech). Grada. 2022.
21. Plichtová J, Brandoburová P. Lay representations of dementia and the risks of its stigmatisation (Slovakian). PSYCHIATRIA—PSYCHOTERAPIA—PSYCHOSOMATIKA. 2021, 28(1), 23-29.
22. Kisvetrová H. Dementia and quality of life. Palacký University in Olomouc (Czech). 2020.
23. Sleezer CM, Conti GJ, Nolan RE. Comparing CPE and HRD Programs: Definitions, Theoretical Foundations, Outcomes, and Measures of Quality. Advances in Developing Human Resources. 2004, 6(1), 20-34.
24. Holmerová I. Long-term care: geriatric aspects and quality of care. Grada Publishing, a.s. 2014.
25. Pipeková J. Chapters from Special Education (Czech). Paido. 2006.
26. Dvořáčková D. Quality of life of the elderly: in homes for the elderly. Grada Publishing, a.s. 2012.
27. Lužný J. Quality of life in patients with dementia (Czech). Česká a slovenská neurologie a neurochirurgie. 2013, 76/109(1): 90–95.
28. Huber M, Knottnerus JA, Green L, et al. How should we define health? British medical journal/British Medical Association. 2011, 343(d4163), 1-3.
29. Banerjee S, Samsi K, Petrie CD, et al. What do we know about quality of life in dementia? A review of the emerging evidence on predictive and explanatory value of disease specific measures of health related quality of life in people with dementia. International Journal of Geriatric Psychiatry. 2009. 24(1), 15–24.
30. Heřmanová E. Quality of life and its models in contemporary social research (Czech). Available from: https://www.sav.sk/journals/uploads/09101219Hermanova%20- %20OK%20upravena%20studia.pdf
31. Payne M. The Politics of Case Management and Social Work. International Journal of Social Welfare. 2000. 9(2), 82-91.

32. Gullone E, Cummins RA. The Universality of Subjective Wellbeing Indicators. Springer Science+Business Media Dordrecht. 2002.
33. Breitkreuz G. Alzheimer's and dementia Prevention and cure through early detection (German)? Düren: Shaker Media; 2020.
34. Moyle W, Venturto L, Griffiths S, et al. Factors influencing quality of life for people with dementia: A qualitative perspective. Aging & Mental Health. 2011, 15(8), 970–977.
35. Kutnohorská J. Etika v ošetřovatelství. Praha: Grada Publishing, a.s. 2005.
36. Pichaud C, Thareau I. Living with older people: practical information for those caring for older people at home and for social and health professionals (Czech). Portál. 1998.
37. Lukasová M., Hradilová A. Protecting the rights of the elderly in an institution with an emphasis on persons with dementia (Czech). Kancelář veřejného ochránce práv. 2014.
38. Sýkorová D. Autonomy in old age. Chapters in gerontosociology (Czech). Sociologické nakladatelství (SLON). 2007.
39. Smebye KL, Kirkevold M, Engedal K. How do persons with dementia participate in decision making related to health and daily care? A multi-case study. BMC Health Services Research. 2012, 12(1). doi: 10.1186/1472-6963-12-241