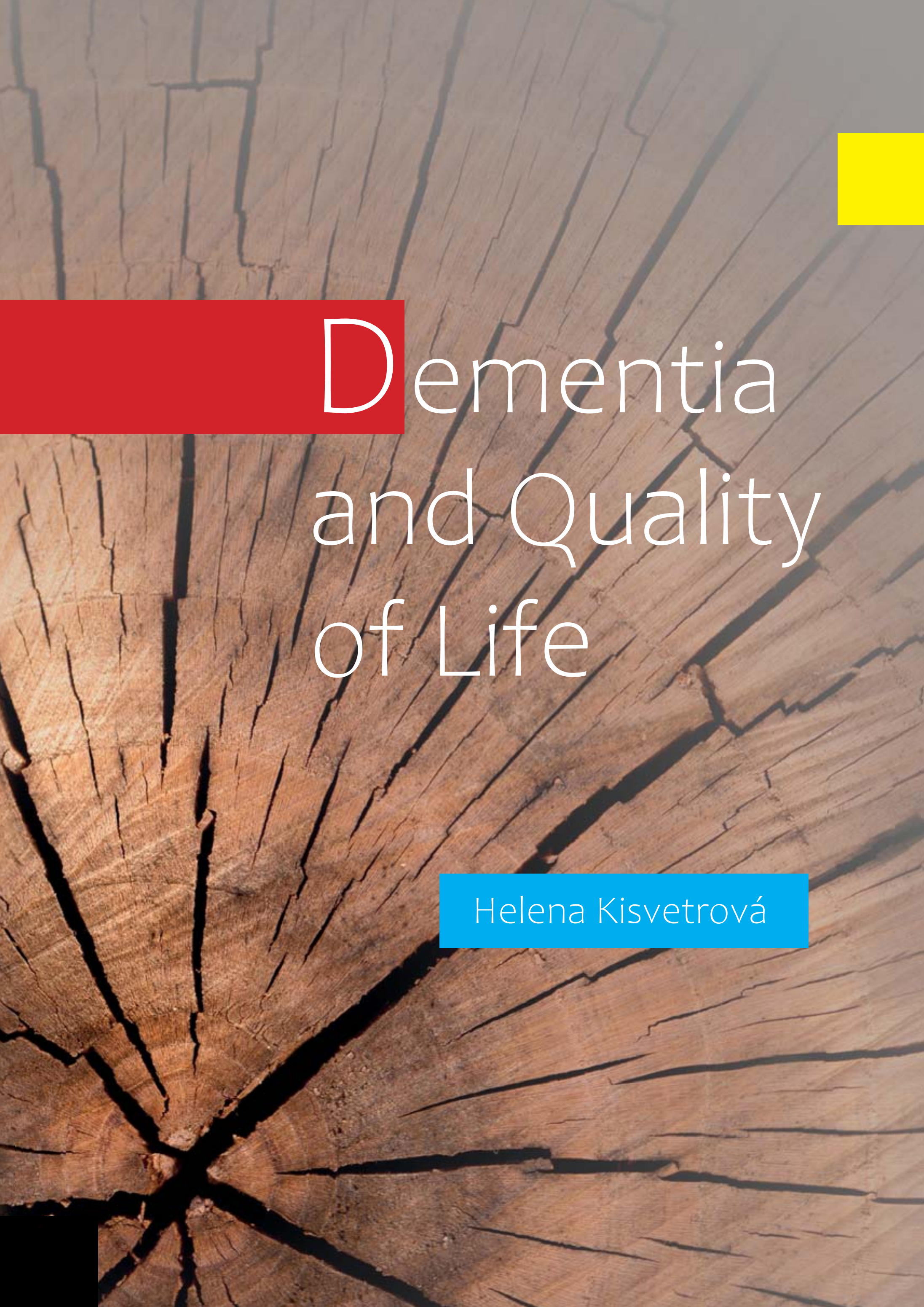

Dementia and Quality of Life

Helena Kisvetrová

PALACKÝ UNIVERSITY OLOMOUC

FACULTY OF HEALTH SCIENCES

DEMENTIA
AND QUALITY OF LIFE

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Reviewers: prof. MUDr. David Školoudík, Ph.D., FESO, FEAN
MUDr. Milena Bretšnajdrová, Ph.D.

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List of abbreviations

α	alpha
7MST	7 Minute Screen Test
AAQ	Attitudes to Ageing Questionnaire
AC1	Gwet’s Coefficient
ACE	Addenbrooke’s Cognitive Examination
ADI	Alzheimer’s Disease International
ADL	Activities of Daily Living
ADRQL	Alzheimer’s Disease-Related Quality of Life
ALBA	Amnesia Light and Brief Assessment
ARS	Affect Rating Scale
ATOA	Attitude toward Own Aging
AZV CR	Czech Health Research Council
BADLS	Bristol Activities of Daily Living Scale
BDI-II	Beck Depression Inventory
BV	Brief Version
CDT	Clock Drawing Test
CR	Czech Republic
CZSO	Czech Statistical Office
EFA	Exploratory Factor Analysis
e. g.	For example
EV	Expanded Version
FES-I	Falls Efficacy Scale-International

G8	Group of Eight (association of the most economically advanced countries in the world)
GDS	Geriatric Depression Scale
HAMD	Hamilton Scale of Depression
HRQOL	Health-related Quality of Life
HVAS	Horizontal Visual Analogue Scale
ICC	Intraclass Correlation Coefficient
ICD	International Statistical Classification of Diseases and Related Health Problems
i. e.	That is
IGA UP	Internal Grant Agency of Palacký University Olomouc
IHIS CR	The Institute of Health Information and Statistics of the Czech Republic
KMO	Kaiser-Meyer-Olkin Measure
MCI	Mild Cognitive Impairment
MMS	Mini-Mental State
MMSE	Mini-Mental State Examination
MoCA	Montreal Cognitive Assessment
NIA	The National Institute on Aging
NIH	The National Institutes of Health
NINDS	The National Institute of Neurological Disorders and Stroke
p	Statistical significance
PCA	Principal Component Analysis
PDI	Patient Dignity Inventory
ProFaNe	Prevention of Falls Network Europe
QOL-AD	Quality of life-Alzheimer’s Disease Questionnaire
SCD	Subjective Cognitive Decline
SPPB	Short Physical Performance Battery
SV	Standard Version
UN	United Nations
UNPF	United Nations Population Fund
VAS	Visual Analogue Scale
VIF	Variance Inflation Factor
WHO	World Health Organisation

Preface

Dementia presents a worldwide challenge in the 21st century. It is a global phenomenon in the field of health and society and it affects the whole population. The Alzheimer Europe Organisation (2019) states that in 2018 the estimated prevalence of dementia in Europe was around 9.8 million people and by 2050 they expect this to grow up to 12.3 million people. Thus, according to the WHO, dementia presents one of the most significant global problems that the health system is dealing with at the beginning of the 21st century. Therefore, the treatment to support or increase the life quality of patients with dementia is among the key aims of the health services. In order to be able to provide such care, it is necessary to know how the patients with dementia themselves evaluate their own quality of life, which factors influence dementia and how the patients' evaluation of the quality of life changes in the long run. That was the reason to conduct a study whose theoretical sources and results are presented in this work.

The aim of this monograph is to bring a basic overview of information on dementia, the quality of life and the results of the longitudinal multicentre prospective study focusing on the trajectory of quality of life in older adults in the early stage of dementia, which was conducted in 2016–2019 in three regions of the Czech Republic (Olomouc, Hradec Králové, and Ostrava). The book is divided into three chapters. The first one deals with dementia, its definition, classification and potential screening assessment needed to create theoretical sources for the study. For this reason, the text does not include information about pharmacotherapy or non-pharmacological treatment used for the patients with dementia. The second chapter deals with the quality of life, both in general terms and in people with dementia. It also informs about the assessment tools for the life quality field. The focus of the third chapter is on the individual determinants of the quality of life and the tools that can be used to assess it. Greater attention is paid to the assessment tools that have been used in the study. The last chapter describes the evaluation of the quality of life by people in the early stage of dementia and compares it to the quality of life in older adults with no cognitive deficit. In the conclusion, we can read about the predictors of change of life quality in people with dementia that were detected within the two years.

I believe that this monograph and the study results it presents may contribute to a better understanding of the life quality in older adults in the early stage of dementia in the long-term perspective, including the identified predictors indicating its change.

Helena Kisvetrová

Introduction

The ageing of the population is one of the most significant and important demographic challenges of the 21st century. It has a wide impact on the whole society. In almost all the regions of the world, the number of inhabitants over the age of 60 is growing faster than does the whole population. In 1950 this category consisted of 205 million people. In 2017 the number grew to 962 million and according to the population prognoses, in 2050 there will be more than two billion people aged over 60 which will correspond to approximately 22% of the global population (UNPF, 2012; UN, 2017).

Due to the increasing geriatrisation in population, older people represent a much larger part of all the inhabitants than they have ever done in the past. Globally, the number of people over the age of 80 is growing much faster than any other category of the elderly population. In the Czech Republic, the demographic evolution is similar and our population has been ageing since the end of the 1980s. Recently, there has been an exceptional acceleration in the growth of the category of people aged 80 and over (CZSO, 2018).

At present, there are about 47 million people with dementia in the whole world. Local estimates of the dementia prevalence in people aged 60 and over range from 4.6 % in central Europe to 8.7% in North Africa and in the Middle East. There is an estimate that by 2050 there will be up to 131 million people with dementia in the world (ADI, 2016; ADI, 2018). By this, dementia is becoming one of the most frequent diseases in the current society. In the Czech Republic about 156 thousand people suffer from it and this number is expected to grow up to 383 thousand by 2050 (Mátl et al., 2016). Dementia not only affects the patients, it also has a significant impact on their caregivers, families and the whole society. Therefore, it presents a global problem with crucial health and social consequences and is becoming a great challenge for the health and social policies of individual countries (Moniz-Cook et al., 2008).

In 2013 the Summit of Group of Eight (G8, an association of the most economically advanced countries in the world) dealt with the topic of dementia research. It gave a recommendation that a research priority to focus on should be the maximisation of the quality of life and social well-being of people with dementia (Shah et al., 2016). The quality of life as a subjective multidimensional construct includes both the individual experience and evaluation regarding the mental well-being and physical fitness, one's social and cognitive competence, as well as one's interaction with the surroundings (Whitehouse, Rabins, 1992). From a long-term perspective, observing the quality of life in people with dementia, the knowledge of factors influencing it and the identification of the predictors that might change it can be a significant source for the definition of optimal intervention to support the protection and maximisation of the quality of life in older adults with dementia.

1 ⁄ Dementia

Dementia is a global medical and social challenge that affects the whole society. On average, people with dementia have a chance to live seven to ten years after they are diagnosed (Mátl et al., 2016) and the number of people dying of dementia is gradually growing. In the period of 2000–2016 the number of deaths caused by dementia more than doubled and in 2016 dementia became the fifth main cause of death. This was a big shift from the year 2000 when it occupied only the fourteenth position worldwide (Fymat, 2018).

1.1 Definition of dementia

In its report "Dementia: A public health priority" the WHO defines dementia as "a syndrome caused by a brain disease which is mostly of chronical and progressive character. It causes the failure of advanced brain functions including memory, thinking, orientation, understanding, counting, learning, language and judgement. The consciousness is usually not affected. The decrease in the cognitive functions is usually accompanied by a worsened emotional control, social behaviour or motivation, which in some cases can precede the worsening of the cognitive function" (IHIS CR, 2012, p. 1–2). The dementia syndrome appears with various diseases affecting the brain in a primary or secondary way. This progressive irreversible organic mental illness originates after an individual's development of cognitive functions is completed and it can be affected by a number of factors (Pereira et al., 2015).

The basic areas that are affected by advanced dementia include both the cognitive and the non-cognitive functions (behavioural and psychological symptoms, associated psychotic symptoms and deliria) and activities of daily living (failures in executive functions) (Jirák, 2004; Dijkstra et al., 2004). Therefore, dementia presents the main cause of the loss of self-sufficiency, of dependence on the provision of care and of disability in elderly people (IHIS CR, 2012). This means that individuals will live about 12% of their lifetime with a disability caused by this chronic incurable disease.

According to the World Health Organisation (WHO), the term of dementia is therefore an overall term for more diseases affecting the memory, other cognitive skills and behaviour by which they significantly disturb the individual's ability to keep their self-sufficiency in activities of daily living (ADL). Although age is the best known risk factor for dementia, dementia is not a common part of normal ageing (WHO, 2017).

The National Institute of Neurological Disorders and Stroke (NINDS) and the National Institute on Aging (NIA), which are part of the National Institutes of Health (NIH), state that dementia is a group of symptoms caused by failures that affect the brain. It brings the loss of cognitive functions, which disturbs the individual's everyday life and activities. The functions that are affected by dementia include memory, language skills, visual perception, problem solving, and the ability to concentrate and pay attention to something. Although memory loss is a typical dementia syndrome, the memory loss itself does not indicate dementia. Dementia cannot be mistaken for the age-related deterioration of cognitive functions when performance is slower in the areas of thinking, memory and information processing but the level of intelligence does not change. Even though it is normal for older adults to be forgetful from time to time, many elderly people live without any symptoms of dementia even at a very high age (NIH, 2017).

1.1.1 Risk factors for the development of dementia

Factors that can increase the risk in individuals for the development of a type of dementia include both those that cannot be influenced (e. g. age, sex, genetic predisposition) and those that can be influenced, such as the cardiovascular risk factors (e. g. the arterial hypertension, Diabetes Mellitus, dyslipidaemia, obesity), psycho-social factors (depression), health manners (low amount of physical or mental activity, smoking, alcohol consumption), head trauma (brain injuries) and the level of education (Hanyu, 2018; Livingston et al., 2017; National Academies of Sciences, Engineering, and Medicine, et al., 2017). In older patients, dementia risk factors also include the loss of weight connected with the frailty and sarcopenia, hearing impairment and social isolation (Kuiper et al., 2015; NICE, 2015).

Basic information on the selected factors is listed below:

- ***Age*** – This is the best known primary risk factor for the development of dementia (NIH, 2017). For this reason, the demographic shift in the society is connected with a higher occurrence and prevalence of dementia which increases exponentially with age (in Western and middle Europe the occurrence of dementia doubles when age increases by 6.5 years).
- ***Sex*** – Women occur more frequently among older patients with dementia. This is connected to their higher life expectancy as compared to men. ADI (2015) states that in some regions there has been noted an independent influence of sex on the prevalence of dementia. In regions such as East Asia, the Caribbean, Western Europe and Latin America the presumed prevalence of dementia was 14–32% lower in men than that in women. However, this effect has not been proven as statistically significant in other regions.
- ***Genetic predisposition*** – The risk of developing a genetically-caused form of dementia increases if it has occurred in more than one family member.
- ***Down syndrome*** – In middle-aged individuals with Down syndrome we are more likely to encounter the symptoms of Alzheimer’s disease.

- ***Atherosclerosis*** – This means building up fat and cholesterol together with changes in the artery structure, infectious processes, bleeding in the atheroma, gradual narrowing of arteries, necrosis in the atheroma, thrombosis and subsequent decrease in blood circulation in the brain and the risk of brain infarct in these veins. These factors increase not only the risk of vascular dementia but also other dementia types including Alzheimer's disease.
- ***Arterial hypertension*** – It is connected with the dementia types that damage the white brain matter; it is a risk factor both for the onset of vascular dementia and for Alzheimer's disease.
- ***Stroke*** – This increases the risk of developing vascular dementia, in some cases it is its sole cause.
- ***Diabetes Mellitus*** – In patients with the compensated but mainly in patients with decompensated Diabetes Mellitus, the risk of dementia is higher, especially that of the vascular dementia.
- ***Parkinson's disease*** – Degeneration and dying of brain cells in patients with this disease often leads to a significant loss of memory and other cognitive functions and to the development of dementia; similarly, in patients with Alzheimer's disease, this leads to the increased risk of parkinsonian symptoms.
- ***Education*** – It is assumed that a low level of education makes people prone to cognitive decreases. This results in a smaller cognitive reserve (Valenzuela, Sachde, 2006) which enables the individual to keep the cognitive functions in spite of the brain pathology (Valenzuela, 2008).
- ***Head injury*** – This can cause trauma to the brain and lead to the onset of dementia and other serious cognitive problems.
- ***Alcohol abuse*** – Regular consumption of excessive amounts of alcohol increases the risk of a specific dementia (Wernicke-Korsakoff syndrome).
- ***Smoking*** – This increases the risk of a cardiovascular disease which slows or blocks the blood flow into the brain and can thus contribute to the development of dementia.

- ➲ ***Social isolation*** – This can cause lack of cognitive activities which is connected to the faster decrease in cognitive functions and therefore it is a risk factor for dementia.
- ➲ ***Movement*** – The lack of regular physical activity is also considered a risk factor for the onset of dementia (Livingston et al., 2017). In this respect, some authors state that physical activity can help slow down the worsening of the cognitive deficit in individuals with dementia (Dishman et al., 2006; Rockwood, Middleton, 2007; Vaughan et al., 2014; Leckie et al., 2014). On the contrary, Sabia et al. (2017) have not found any proof of a neuroprotective effect that physical activity would have. They assume that the results of the previous studies showing lower risks of dementia in physically active people can be assigned to the reverse causality, specifically to the result of the decrease in physical activity in the pre-clinical phase of dementia.

1.2 Basic classification of dementias

There are more criteria to classify dementias upon. The basic classification includes ***classification based on the cause*** into two basic groups, i. e. *primarily degenerative dementias*, originating due to atrophic-degenerative processes and *secondary* (symptomatic) *dementias*.

1.2.1 Atrophic-degenerative dementias

In atrophic-degenerative impairment, dementia originates due to processes leading to the decrease in the number of neurons, to a disruption in the function of neurons and neuroglia (supporting nerve cells) and to the reduction of the number of neuron synapses. This kind of dementia creates over 60% of all dementias. It is characterised by the creation and storage of pathological protein with many other degenerative processes. Neurodegeneration then results in a brain malfunction and a subsequent onset of the dementia syndrome (Jirák et al., 2009).

The most frequent atrophic-degenerative dementia is Alzheimer's disease.

- ***Alzheimer's disease*** accounts for almost 70% of all dementias. It usually affects individuals over the age of 65 and its incidence and prevalence rises with age. A higher occurrence has been proven in women; in women aged 85 and over its incidence is almost 50%. Similarly to other neurogenerative dementias, Alzheimer's disease has a typical slow onset with memory impairment and gradual deterioration of cognitive functions. This leads to the complete loss of self-sufficiency and ability to have meaningful communication with others (Krombholz, 2011).
- ***Lewy body dementia*** is the second most frequent neurogenerative dementia, following Alzheimer's disease. Besides the basic dementia symptoms it is characteristic for its fluctuating impairments in cognitive functions, recurring visual hallucinations, extrapyramidal syndrome and occasional delusions (Maj, Sartorius, 2003; Sanford, 2018). The prevalence of Lewy body dementia in people aged 85 and over is more than 20% (Krombholz, 2011).
- ***Parkinson's disease dementia*** is characterised by the damage in all kinds of memory (especially the explicit and procedural one), as well as by an executive dysfunction (disability to plan and manage more complex motoric chains) and by the visuo-spatial impairment causing problems with orientation and visual analysis. Speech impairment is less marked in this kind of dementia than it is in Alzheimer's disease (Aarsland et al., 2017). In contrary to Lewy body dementia, delusions in Parkinson's disease dementia occur only as a result of pharmacotherapy. There can also occur, as well as in Lewy body dementia, delusional contents in thinking. These are usually paranoidly persecutional and often systematised. We also often encounter emulational (jealousy) bizarre delusions (Krombholz, 2011).
- ***Frontotemporal dementia*** represents a heterogeneous group of neurodegenerative diseases which are characterised by clinically dominating behavioural impairments, changes in executive functions and personality changes. This is a so-called *behavioural variant fronto-*

temporal dementia. There are also linguistic variants characterised by speech impairments, which include the *semantic variant of the primary progressive aphasia* and the *nonfluent variant primary progressive aphasia* (Vyhnálek, 2017). Frontotemporal dementias are typical with their selective degeneration of frontal and temporal cortices. They are seen in the progressive deterioration in the areas of behaviour, executive functions and speech. By their behavioural symptoms they can imitate some psychiatric diseases. These dementia types occur mainly in people under the age of 65 (Bang et al., 2015; Olney et al., 2017). The deficit of cognitive functions in frontotemporal dementias is often connected with motoric comorbidities (Vyhnálek, 2017).

- ✓ The best known frontotemporal dementia is ***Pick's disease***, which progresses slowly and often affects personality characteristics. At its onset, the memory is usually not impaired and the deficit lies in the area of recalling in combination with a relatively preserved ability to imprint. Executive functions are usually impaired significantly; there is a deterioration of attention, planning and visuo-spatial function. Social behaviour is often impaired and we encounter emotional numbness. Other symptoms include fixed thinking, utilitarian behaviour, and stereotypy (Krombholz, 2011).

- ✓ Frontotemporal dementias also include ***Huntington's disease dementia***, typical for its progressive motoric, behavioural, and cognitive deficit. Psychiatric symptoms occurring in this dementia include depression and anxiety. Huntington's disease dementia starts before the older age rather than in the older age itself (Wyant, Ridder, Dayalu, 2017).

- ✓ Another frontotemporal dementia is ***Steele-Richardson-Olszewski syndrome*** (progressive supranuclear palsy), which is connected with the cognitive deficit and dementia of the subcortical type. Progressive supranuclear palsy is characterised by the parkinsonian syndrome, axial rigidity, postural instability with frequent falls, and disruption of eye movement (Williams et al., 2005).

1.2.2 Secondary dementias

Secondary or symptomatic dementias originate when the brain function is damaged e. g. by a system disease chronic intoxication, trauma or infection. They can be further classified as vascular dementias and other symptomatic dementias (Jirák, 2004).

- ***Vascular dementia*** (vessel-related dementia) is the second most common dementia after Alzheimer's disease and it accounts for up to 20% of all dementias (Krombholz, 2011). It is characterised by the loss of cognitive functions resulting from ischaemic, haemorrhagic or hypoperfusion brain lesions caused by cerebrovascular or cardiovascular diseases. Dementia symptoms usually occur within three months of the incidence of a haemorrhagic stroke (Pidrman, 2007). Vascular dementia consists of three basic groups: *strategic infarct dementia, multi-infarct dementia,* and *Biswanger's dementia* (subcortical ischaemic leukoencephalopathy) (O'Brien, Thomas, 2015).
- ***Other symptomatic dementias*** include *infectious dementia*, whose incidence is rather rare (e. g. progressive paralysis and other forms of brain luetic infection), *dementia caused by prion diseases* (Creutzfeldt-Jakob disease), *metabolic dementias* with a hereditary basis (Wilson's disease) or without a hereditary basis (resulting from liver encephalopathy, uremic encephalopathy or with a metabolic damage), *dementia caused by intoxication* (alcohol dementia [Wernicke-Korsakoff syndrome]; dementia after exposure to carbon monoxide), *dementia caused by tumours* (primary brain tumour, metastasis in the brain, paraneoplastic dementias), and *dementias after excessive brain traumas* (Jirák, 2004).

1.3 Disorders in the cognitive functions and dementia stages

Cognitive functions can be defined as all mental processes that enable the individual to distinguish, recall, learn and adapt to permanently changing conditions of the environment. These functions include memory, thinking, learning, receptive functions (perception of stimuli, their remembering and sorting), and expressive functions (speech, writing, drawing, expressive skills) (Raboch et al., 2008). These functions can be weakened or disturbed by various causes.

Subjective cognitive decline (SCD) is characterised by a very light cognitive decrease which appears before the incidence of an objective cognitive impairment. SCD is considered to be a pre-clinical manifestation of Alzheimer's disease (Lin et al., 2019). The state in which all dementia criteria are not fulfilled but the individual has an objectifiable cognitive deficit is called mild cognitive impairment (MCI). Memory impairment with a parallel presence of at least one cognitive function impairment is called dementia syndrome and it can be divided into a couple of stages (Fymat, 2018).

To assess the cognitive functions, the Mini-Mental State Examination (MMSE) is most commonly used. Some studies state that the cognition impairment is diagnosed at the MMSE score of 24 and lower (Folstein et al., 1983; Folstein et al., 2001). However, the classification of impairments based on the total MMSE score is not completely unified in specialised literature. The division based on the individual authors is seen in the Tables 1–3.

Tombaugh and McIntyre (1992) consider the number of 24 points in the MMSE score to be the limit for individuals without cognitive impairment. However, they recommend the assessment with the MMSE to be performed in individuals who have been through at least eight years of schooling.

Table 1 Cognition assessment (Tombaugh, McIntyre, 1992)

	MMSE score
no cognitive impairment	24–30 points
mild cognitive impairment	18–23 points
serious cognitive impairment	0–17 points

The MMSE scores for the individual dementia stages, as defined by Fymat (2018), are presented in Table 2.

Table 2 MMSE scores for individual dementia stages (Fymat, 2018)

	MMSE score
mild cognitive impairment	27–30 points (normal value)
early dementia stage	20–25 points
middle dementia	6–17 points
late dementia	lower than 6 points

In the Czech Republic, the MMSE has been used for a number of years. The division of the amount of cognitive impairment according to the MMSE score, as presented by Jirák and Koukolík (2004), is shown in Table 3. However, Štěpánková et al. (2015) have proven in a Czech normative MMSE study that the assessment of the cognition with the MMSE in healthy older adults depends on their age and education. Therefore, in an older adult with a university degree, the MMSE score of 30 points does not have to clearly indicate the absence of a cognitive deficit.

Table 3 Cognitive impairment assessment (Jirák, Koukolík, 2004)

	MMSE score
no cognitive impairment	27–30 points
limit value (suggesting a mild cognitive impairment)	25–26 points
early stage of dementia	24–18 points
middle dementia	6–17 points
late dementia	lower than 6 points

➲ Subjective cognitive decline (SCD)

The concept of the subjective cognitive decline (SCD) was introduced by Reisberg et al. (1982). Jessen et al. (2014) describe the SCD as the patient's subjective feeling of a permanent deterioration of cognitive skills compared to the normal state. At the same time, there are no abnormalities in objective neuropsychological assessments. The subjective cognitive decline is considered to be a pre-clinical manifestation of Alzheimer's disease (Lin et al., 2019). While being a prodromal stage of the mild cognitive impairment (MCI), the subjective cognitive decline can affect the individual's emotional and social functioning as well as the overall quality of life (Jenkins et al., 2015). Therefore, recently there has been an increase in studies dealing with the subjective cognitive decline (Rabin et al., 2017; Molinuevo et al., 2017; Lin et al., 2019). Yet, there is no consensus on how to assess or classify the subjective cognitive impairment and the approaches that have been used show a great amount of heterogeneity (Rabin et al., 2017).

➲ Mild cognitive impairment (MCI)

This is a state in which the individual does not fulfil the dementia criteria but has an objectifiable cognitive deficit. It is a transition phase between the cognitive changes connected with normal ageing and the early dementia stage (Bartoš, Hasalíková, 2010). Mild cognitive impairment is characterised by memory problems which are not serious enough to affect the individual's ability to perform the activities of daily living. Other cognitive functions are within the normal range (speech, executive functions, cognition). People with a mild cognitive impairment are clinically and neuropathologically heterogeneous (DeCarli, 2003). A simple way to test the memory takes only three minutes and is called Amnesia Light and Brief Assessment (ALBA; Bartoš, 2019).

As soon as mild cognitive impairment is diagnosed, it is important to evaluate the reversible causes. At present, there is no pharmacological treatment that would be proven to slow down or cure the progression of mild cognitive impairment to prevent it from developing into dementia. However, there has been evidence that modification of one's lifestyle including diet, exercise, and cognitive stimulation can be effective in this respect (Tangalos, Petersen, 2018). The estimated prevalence of mild cognitive impairment varies from 4 to

19% in people aged 65 or over. This depends on the definition and its interpretation used (Livingston et al., 2017). Most commonly, in the progress of about five to eight years, mild cognitive impairment gradually develops into dementia in 50–70% of people suffering from MCI (Fymat, 2018).

➲ Early stage of dementia (mild dementia)

In the early stage of dementia, patients experience a decrease in memory, problems with communication (fluent expression is becoming more difficult), impairment in executive functions, personality changes, changes of moods (depression, anxiety), and apathy (Fymat, 2018). In the early stage of dementia, individuals are still able to acknowledge their disease. In this respect, they experience fear, sadness, but also anger and refusal. Security can be established by providing order, regular daily routine and keeping rituals which help the patient with time orientation. Any changes are very confusing for them (Ritter-Rauch, 2016). In order to support the quality of life and protect the patients' dignity in this phase, it is necessary to provide them with as much information as they are able to understand. If this is not done, patients feel insecure and become suspicious and distrustful.

➲ Middle stage of dementia (developed dementia)

Dementia at this stage is typical for increasing trouble with problem solving, worsening of social judgement, disorientation in time and space, gradual reduction of vocabulary, and lack of self-sufficiency in self-care and hygiene. Besides, patients show changes in behaviour and accentuation of negative personality characteristics (e. g. egocentrism) (Fymat, 2018). Patients forget a lot, including important events from their own past. They need a permanents caregiver's assistance in activities of daily living and hygienic care. There is also deterioration in the ability to express oneself clearly and communicate meaningfully. The spatial disorientation worsens even in familiar surroundings and as regards orientation in time patients cease to be able to distinguish the seasons of the year. Patients experience hallucinations, unease, and aimless wandering. This stage can take rather long and it is very demanding for family caregivers as the patient's dependence on the provided care grows. Most commonly, patients are able to move outdoors. In relation to the patient's personal dignity, it is necessary to save them in public from any mockery by the surrounding people due to their behaviour or imperfections in clothing. It is also necessary to provide the patient with the opportunity to make their own decisions in simple matters (Ritter-Rauch, 2016).

➲ Late (severe) stage of dementia

This stage is characterised by serious impairments to long-term memory; patients do not recognise even their closest family and friends. Speech is reduced to a couple of simple words, patients depend on the care of others, there are big changes in behaviour and both time and space orientation deepen (Fymat, 2018). Patients are more prone to infections and these are the most frequent causes of death. There are serious problems with eating and drinking (troubled chewing, swallowing, fits of cough), the risk of aspiration increases and causes the risk of aspiration pneumonia. The patient's mobility decreases, unsteady walking often leads to falling and immobility due to accidents. This stage is typical for its gradual withering away (frailty syndrome in older people). If dementia keeps progressing, permanent institutional care is usually inevitable. That presents patients with further burdens and stress. They need to cope with a transfer to an unfamiliar environment, which makes them very insecure. In order to maximise the quality of life and to protect the patients' dignity in this phase of dementia, it is necessary to provide them with social contacts in their surroundings and with manifestation of respect.

1.4 Screening tools to assess cognitive functions

Assessing cognitive functions with various screening tools focuses on memory, speech, visuo-spatial, executive (performance) and cognitive functions, emotional and psychological adaptation. Falk et al. (2018) state that in case of suspected dementia there can be used short screening tests such as the Mini-Cog. If the results are worse, it is necessary to use more detailed tools for further assessment. These include the Mini-Mental State Examination (MMSE) or Montreal Cognitive Assessment (MoCA). The most commonly used screening test worldwide is the Mini-Mental State Examination (Velayudhan et al., 2014) and it is therefore described below in detail.

1.4.1 Mini-Mental State Examination

The Mini-Mental State (MMS), later called the Mini-Mental State Examination (MMSE), has been used since its creation and publication in 1975 in clinical practice as a screening method to detect the dementia syndrome, especially in relation to the identification of individuals with middle to serious cognitive deficit (Folstein et al., 1975; Tombaugh, McIntyre, 1992). The test is valid for psychiatric, neurological and older patients. The MMSE is also used in research studies to confirm the normal level of cognition of people taking part in the research. The MMSE provides the assessment of global cognitive functions and the level of impairment. It covers five assessment domains that focus on:

① Orientation (by the person, in time and space);

② Memory (immediate remembering and repetition of three words);

③ Attention and counting (subtracting the number 7 from the number 100, five times in a row);

④ Short-term memory (recalling – repeating three objects named earlier);

⑤ Speech, communication and construction abilities.

The test is administered in about ten minutes, so it is not too demanding on the patient. The maximum score is 30 points; the better the score, the better the cognitive performance.

The tasks contained in the test are relatively simple and for this reason this test cannot be reliable as a tool to assess a mild cognitive impairment in a patient. However, the MMSE makes is possible to differentiate a middle dementia stage from normal ageing. The MMSE is a screening tool, therefore its most important psychometric characteristics is its sensitivity that makes it possible to correctly identify individuals with dementia (Lezak et al., 2012). To detect dementia, the required sensitivity is 89% and the specificity of 81% (Lin et al., 2013). Low sensitivity in the MMSE in patients with mild cognitive impairment is affected by the relative simplicity of the test in terms of memory and by a low representation of items testing the memory and also by the absence of tasks testing functions such as planning (Wind et al., 1997). The criteria for screening tests to detect the mild cognitive impairment in patients aged over 60 are better met by the Montreal Cognitive Assessment (MoCa; Nasreddine et al., 2005; Ciesielska et al., 2016). Based on a vast analysis of studies that have used the MMSE, Creavin et al. (2016) support the usage of the MMSE as a part of the decision making process about the individual's having or not having dementia. However, the test results should be interpreted in a wider context of the specific patient (personality, behaviour, and the way they perform activities of daily living). There has also been confirmed the dependence of the MMSE results on age, education and literacy (Mitchell, 2009; Štěpánková et al., 2015).

In the second half of 1990s, a Czech version of the MMSE (Brázdil et al., 1995) was created. A validation study was conducted and pilot normative data was obtained without the stratification according to education and age (Tošnerová, Bahbouh, 1998). Later, Czech norms were set for the MMSE. These were based on the percentile and standard deviations of 650 older adults with unimpaired cognitive functions (aged 69 ± 8 years; with the MMSE score of 28 ± 2 points). The norms are divided based on education and age. In patients with dementia, there was noted a significantly lower score than in those with mild cognitive impairment. Both groups of patients had a significantly lower MMSE score than the older people with unimpaired cognitive functions. An optimal limit value was assigned (≤ 27 points) with the sensitivity of 86% and specificity of 79% for the timely detection of patients with dementia (Bartoš, Raisová, 2016). The dependence of the MMSE assessment on age and education was confirmed in a study of healthy Czech older adults by Štěpánková et al. (2015). At present, the MMSE is still the most commonly used tool in the Czech Republic for the assessment of cognitive functions. This is because its performance is required by health insurance companies to start and monitor the cognitive therapy. Since 2001, copyright laws have been applied to the MMSE and there is a fee to pay for its usage. For this reason, a sample of the questionnaire is not included in this work. Authorised translations of individual language versions of the MMSE, including the Czech one, are available at https://www.parinc.com/products/pkey/237.

At present, there is also a MMSE-2 test with its standard, brief, and expanded version. Thanks to the three different MMSE-2 versions, the examiner can choose a variant that corresponds best to the specific patient's needs.

- ✓ *Standard version* (MMSE-2: SV) keeps the structure and scoring of the original MMSE. Its completion takes about 10–15 minutes. The scores of the MMSE and MMSE-2: SV are comparable.
- ✓ *Brief version* (MMSE-2: BV) consists of 16 points. It can be used in clinical or research situations where fast cognitive screening is needed.
- ✓ *Expanded version* (MMSE-2: EV) consists of 90 points. It is more sensitive to subcortical dementia and changes connected with ageing. This version includes two new tasks assessing story recalling and speed of processing.

The Czech translation of the MMSE-2 has not been done yet. Information on the MMSE-2 is available at https://www.parinc.com/products/pkey/238.

1.4.2 Other screening tools

In a brief overview below, you can find a selection of screening tools used for the assessment of cognitive functions in elderly patients.

➲ **Addenbrooke's Cognitive Examination**

The Addenbrooke's Cognitive Examination (ACE; Mathuranath et al., 2000) and its revised version ACE-R (Mioshi et al., 2006) enable the assessment of all cognitive domains including the memory, speech, executive and visuo-spatial functions. As the ACE-R version included also some MMSE items and these have been charged for copyright since 2001 (Seshadri, Mazi-Kotwal, 2012), the usage of ACE and ACE-R has become more complicated (Newman, 2015). Therefore, the authors of the original ACE test created a new version, **Addenbrooke's Cognitive Examination – III (**ACE III; Hsieh et al., 2013) without the MMSE items. The ACE-III has been translated to several languages and validated for various cultural environments (Mirza et al., 2017; Bruno et al., 2019). At present the ACE-III is available for example in Portuguese (Machado et al., 2015), Spanish (Matias-Guiu et al., 2015), Chinese (Wang et al., 2017) or Japanese (Takenoshita et al., 2019). The test takes about 25–30 minutes to administer, so it is more time-demanding than the MMSE.

➲ **Montreal Cognitive Assessment**

The Montreal Cognitive Assessment (MoCA; Nasreddine et al., 2005) consists of 11 tasks for the assessment in five cognitive domains. It enables an earlier recognition of a mild cognitive impairment (Damian et al., 2011). The test takes about 10–15 minutes to administer. The total score is 30 points, the higher the score, the better the cognition.

➲ 7 Minute Screen Test

The 7 Minute Screen Test (7MST; Solomon et al., 1998) consists of test sets dealing with:

- ✓ Assessment of *detailed orientation in time* (Benton Temporal Orientation);
- ✓ Assessment of *memory* (Grober and Buschke's enhanced cued recall);
- ✓ Assessment of *executive and visuo-spatial functions* (Clock Drawing);
- ✓ Assessment of *speech* (Verbal Fluency).

The 7MST is designed to identify mild cognitive impairment and early stages of Alzheimer's disease (Meulen et al., 2004). The test takes longer to administer than the seven minutes suggested in its name (Rektorová, 2011).

➲ Mini-Cog

The Mini-Cog (Borson et al., 2000) is a brief test to examine the memory and visuo-spatial functions – remembering three words, Clock Drawing Test and recalling three words (Galvin et al., 2012). The test is very brief: it takes only about three minutes. To detect a cognitive impairment, the patient must have the specificity between 54–85% and sensitivity of 76–100% (Lin et al., 2013).

➲ Clock Drawing Test

The Clock Drawing Test (CDT; Sunderland et al., 1989) is an orientation simple test focusing on a couple of cognitive functions at the same time: space memory, visuo-spatial coordination, executive functions, semantic memory, ability to plan and concentrate (Shulman et al., 2000; Shulman et al., 2006). Due to its simplicity and briefness, it is very frequently used (Amodeo et al., 2015; Kim, Chey, 2010; Souillard-Mandar et al., 2016; Sugawara et al., 2010). The tested person is asked to draw a circular clock face with numbers where the hands are supposed to show the time of 2:45. The result is assessed on the scale from 1 to 10 points. There are a couple of assessment systems to interpret the score (Mainland et al., 2014; Ricci et al., 2016; Souillard-Mandar et al., 2016). Each of the systems uses different methods and instructions for the clock drawing. Based on the meta-analysis they have conducted, Park et al. (2018) recommend the Shulman's system.

2 ⁄ Quality of life

The quality of life is an important indicator of the level of care for older people. The Second International Plan of Action on Ageing by the United Nations (UN) stresses the importance of the support of active ageing, well-being, and the quality of life of older adults (Fernandez-Ballesteros et al., 2007). Due to the increasing geriatrisation of population worldwide, it is therefore crucial that research focuses on the quality of life of the ageing population.

2.1 Definition of quality of life

The quality of life is an individual and very personal concept as every individual has a unique standard of what they perceive as values creating the quality of their life (Fayers, Machin, 2016). This concept includes not only objective indicators of well-being assessed according to socionormative criteria but also subjective perception by the people during the individual periods of life. The quality of life includes both objective determinants such as health or function abilities and subjective factors such as satisfaction (Selai, Trimble, 1999). Therefore, the quality of life presents a multidimensional and complex approach connected with the individual's aims, expectations, and concerns which include both the physical and psychological area, independence, social interaction, environment, and spiritual aspects (Birren, Dieckermann 1991).

According to the World Health Organisation's definition, the quality of life is the way individuals perceive their place in life with respect to the culture and value system they live in and in relation to their own aims, standards, expectations, and concerns (The WHOQOL Group, 1993; 1995). Such understanding of the quality of life presumes that individuals have the intellectual ability to make complex subjective judgements about their lives.

The quality of life is defined and assessed in various ways depending on the context in which the term is used and on the conceptual focus of the researcher. The term of the quality of life can also denote "how good or bad something is" or "how high the level of the value or excellence is" in relation to the individual's life. In this sense the quality of life in older age is not a simply neutral description of an older adult, but rather a complex assessment of their level of life and conditions that affect it. In literature dealing with the quality of life in older age such assessment is commonly used (Sirgy et al., 2006; Rokne, Wahl, 2011). If an older person suffers from a chronic impairment, they must gradually adapt to changes and cope with physical, emotional, and social challenges which arise from their impairment. For this reason, patients often revise their aims and expectations related to the quality of life (Huber et al., 2011). However, older adults do not consider the quality of life to reflect only good health. As has already been seen in past researches, older adults consider social contacts to be equally important for their quality of life as is their health (Farquhar, 1995a).

Therefore, the definition of the quality of life in older age often varies author by author. For example, Halvorsrud and Kalfoss (2007) state that in the specialised literature we can find more than 100 various definitions of the quality of life in older age. Walker (2005) notes that there has been no consensus in the way of defining and measuring the quality of life. Rosenberg (1995) includes a couple of constructs into the term of the quality of life: the physical, functional, emotional, social, and cognitive domains. On the other hand, some authors believe that these domains represent various dimensions of a single phenomenon (Bowling et al., 2003; Walker, 2010; Rokne, Wahl, 2011).

Due to the large number of existing definitions of the quality of life in older people, there have been created a couple of taxonomies that divide the definitions based on various aspects. These include the Farquhar's taxonomy (Farquhar, 1995b) and the typology of the quality of life in old age based on the contents of the definitions (Brown et al., 2004). In the latter, however, authors do not mention the method used for the development of their classification system. In relation to the classification of definitions of quality of life in old age, Boggatz (2016) has described basic concepts that are most appropriate for the assessment of results of the care provided to older people.

Farquhar's taxonomy

Farquhar (1995b) created a taxonomy that sorts out definitions of the quality of life in old age based on formal aspects. However, it is less informative as regards the contents of the definitions. This taxonomy distinguishes four basic types:

- ✓ **Global definitions** which refer to the general satisfaction with one's life or luck;
- ✓ **Component definitions** which specify subjective or objective aspects of the quality of life;
- ✓ **Focused definitions** which are limited to a single aspect, such as functional capacity;
- ✓ **Combination definitions** which consist of both general satisfaction and individual aspects.

Brown's taxonomy of models of quality of life in the old age based on their contents

Brown recommends that models should be classified based on their contents in relation to the categories that the models focus on (Brown et al., 2004). These categories are divided into:

- ✓ Objective indicators;
- ✓ Subjective indicators;
- ✓ Human needs satisfaction;
- ✓ Psychological models;
- ✓ Health and functioning models;
- ✓ Social health models;
- ✓ Social cohesion and social capital;
- ✓ Environmental models;
- ✓ Idiographic or individualised hermeneutic models.

Some of the categories above may partly overlap each other. For example the objective indicators include aspects that are also part of health models and environmental models. On the other hand, other categories do not refer to different contents but rather to different ways of approaching them, e. g. subjective indicators and idiographic approaches (Brown et al., 2004).

Boggatz's classification of definitions based on the basic concepts of quality of life in old age

Boggatz (2016) identified three basic concepts of the quality of life in old age as related to the nursing care:

- ✓ Fulfilment of life conditions;
- ✓ Subjective general well-being;
- ✓ Subjective satisfaction of human needs.

Out of the concepts above, the satisfaction of human needs is the most relevant one to evaluate the nursing care, as it includes several dimensions that can alter when the older person’s life conditions change. In this respect, these dimensions can enable the assessment whether the nursing interventions increase or decrease the overall quality of life (or its individual dimensions) of older adults who receive nursing care (Boggatz, 2016).

2.2 Quality of life in people with dementia

More and more, the quality of life is considered to be a significant factor in assessing the clinical progression of an illness and the effectiveness of assigned interventions. Also in patients with dementia the quality of life is an important indicator to assess the effectiveness of interventions. Therefore, the research dealing with the quality of life in patients with dementia has an increasing clinical significance. This is caused by the fact that due to growing life expectancy dementia incidence has also grown in the population and dementia has therefore become one of the main challenges in the sphere of public health care (WHO, 2012). However, conducting a research of quality of life in patients with dementia is quite limited by the existence and level of cognitive deficit of the research subjects. It has been stated that people with mild to moderate dementia (Brod et al., 1999; Logsdon et al., 1999; Schölzel-Dorenbos et al., 2007; Trigg et al., 2007; Arlt et al., 2008; Banerjee et al., 2009) and sometimes even patients with the more severe dementia level (Thorgrimsen et al., 2003; Hurt et al., 2008) are able to provide a meaningful assessment of their quality of life and to speak about their needs in a relevant way (Orrell et al., 2008).

The quality of life also significantly correlates with the individual’s health and thus it presents a multi-dimensional concept which includes the perception of mental, physical, emotional and social functioning in relation to various dementia stages in a patient with dementia (Ettema et al., 2005). Health-related quality of life is also affected by the level of self-sufficiency and functional fitness, comorbidity, sex, and the depression level (Setiati et al., 2011; Garrido-Abejar et al., 2012). Patients with dementia therefore have to adapt to the changes caused by their disease and cope with physical, emotional, and social challenges presented by their disease (Huber et al., 2011).

Lawton (1983; 1991; 1997) suggested that understanding and conceptualisation of the quality of life by a patient with dementia should consist of both subjective and objective factors categorised into four dimensions:

- ✓ Behavioural capability;
- ✓ Mental well-being;
- ✓ Objective environment;
- ✓ Perceiving the quality of life.

The most commonly used definition of the quality of life was suggested by Whitehouse and Rabins (1992). They considered the quality of life to be a combination of cognitive functioning, activities of daily life (ADL), social interaction, mental well-being, and subjective perception of one's own position in life.

2.3 Assessment of quality of life

Assessing the quality of life is a very complicated process of introspection and evaluation consisting of a couple of cognitive components including implicit and explicit memory. Therefore, in case the cognitive functions drop below a certain level, the self-rating of the quality of life is considered too difficult for the patient and also rather invalid (Selai et al., 2001).

In recent decades the usage of the quality of life assessment has increased both in clinical practice and research (Rabins, Black, 2007). More methods can be used for the assessment of quality of life in patients with dementia (Logsdon et al., 2002; Naglie, 2007; Vogel et al., 2012). Each of these methods has its positive and negative aspects when used for older adults with cognitive impairments. These aspects usually depend on how serious the disease is (Whitehouse et al., 1997).

In order to assess the quality of life, we can use three basic approaches or their combination. These include the direct observation, self-rating of the quality of life by the patient with dementia, and assessment of the quality of life in a patient with dementia from the caregiver's perspective.

- ✓ **Direct observation**

  Direct observation of behaviour and activities, which supposedly relate to the quality of life, has the advantage that it can be considered "more objective". The presumption is based on the fact that such an assessment can be based on pre-defined behaviour manifestations and can be continuously assessed in a longer time span. The assessment of the observed influences (Lawton et al., 1996; 1999) and events (Logsdon, Teri, 1997; Teri, Logsdon, 1991) has been suggested for the measurement of observable attributes of the quality of life (Albert et al., 1999).

  The limitations of the approach described above include the uncertainty whether we really observe what the individual with dementia considers significant for the quality of their life. Direct observation can also be subject to many stereotypes connected with the assessment of the quality of life in people with dementia from the family or professional caregiver's perspective. It is therefore vital that before the observation starts, the observer is trained in using observation strategies to assess the quality of life in patients with dementia (Lawton et al., 1999).

- ✓ **Self-rating the quality of life by patients with dementia**

  A couple of studies have proven that in the early stages of dementia patients can provide a reliable assessment of their quality of life (Buckley et al., 2012; Gómez-Gallego et al., 2012b). As the subjective dimension of the quality of life is very important, the patient's assessment of the quality of life should be preferred with the exception of patients with severe dementia (Brod et al., 1999). On the other hand, some authors emphasise that the subjective element in the perception of the quality of life makes it doubtful whether patients with dementia can give a reliable assessment of the quality of their life. This can be due to their decreased ability to make decisions, to understand complex problems; they can have impaired memory and a communication deficit, which are common dementia symptoms (Rabins, 2000). Besides, the patients' assessment of quality of life can also be affected by behavioural or non-cognitive dementia symptoms including depression, agitation or psychosis (Logsdon et al., 2002).

- ✓ **Assessment of quality of life by a relative or caregiver**

  Assessment of the quality of life by a caregiver or relative is often used in patients in advanced stages of dementia (Clare, Quinn et al., 2014). Caregivers usually assess the dementia patient's quality of life less positively in comparison with the patient's own assessment (Thorgrimsen et al., 2003; Cahill et al., 2004; Vogel et al., 2006; Arlt et al., 2008; Hurt et al., 2008). The factors that can have a negative influence on the caregiver's interpretation of the quality of life in a patient with dementia include for example the caregiver's burden and depression (Naglie, 2007; Orgeta et al., 2014). There is sometimes also a discrepancy between the assessment of people with greater limitation in activities of daily living, which has a greater influence on the assessment by family and caregivers but not on the subjective assessment of the quality of life by the patient (Moyle et al., 2011a). Also the patients' adaptation to the cognitive impairment (similarly to other chronic states) and the loss of insight may increase the quality of life perceived by the patient as opposed to the caregiver's view (Naglie, 2007).

- ✓ **Combination of assessment methods**

  According to Banerjee et al. (2009), when comparing assessments of the quality of life done by patients with dementia and by their caregivers, research has repeatedly shown differences. The discrepancy in the assessment can be for example in the patients with dementia who have greater limitations in ADL. According to Moyle et al. (2012), the degree of self-sufficiency affected only the caregiver's assessment but it was not reflected in the self-rating by patients with dementia. Therefore, the usage of a combined assessment by the patient as well as by the caregiver has its positives. It enables wider and complementary views on the quality of life among patients with dementia and the realisation of more effective interventions to support or improve the quality of their lives (Logsdon et al., 2007; Bosboom et al., 2012; Gómez-Gallego et al., 2012b). However, in case of patients with more advanced dementia, their self-rating of the quality of life can be unreliable due to their worsened speech skills, understanding, and the level of consciousness (Albert et al., 1996; Ready et al., 2006). In such cases, the caregivers' assessment can provide important and meaningful complementary information to assess the quality of life in patients with dementia (Buckley et al., 2012).

2.4 Assessment tools

A couple of assessment tools have been developed and validated to assess the quality of life in patients with dementia. The choice of the tool for a specific research is guided by the degree of dementia as well as by the type and organisation of the care for the patient with dementia (Schölzel-Dorenbos et al., 2007). Assessment tools can be divided into three groups according to whose perspective guides the assessment of quality of life in the patient with dementia.

- ✓ **Objective observation**

  This group consists of tools based only on the objective observation of a patient with dementia by the assessor. Objective observation of emotional behaviour of the patients with dementia makes it easier to understand their preferences and aversions, which can help to assess their quality of life better. One of the tools in this group is for example the 6-point **Affect Rating Scale** (ARS) questionnaire. It evaluates the positive (pleasure, interest, contentment) or negative feelings (sadness, fear/anxiety, anger) of the person with dementia based on the direct observation of their face expressions, body language, and other non-verbal signals. This assessment is independent of the patient's own self-rating of the quality of life (Lawton et al., 1996).

- ✓ **Caregiver’s assessment**

  This group consists of tools which are only based on the assessment by a family or professional caregiver. A representative of this category is the **Alzheimer’s Disease-Related Quality of Life** (ADRQL) questionnaire. The tool assesses five domains of the quality of life (social interaction; awareness of self; feelings and mood; enjoyment of activities; response to surroundings) and it includes preferences that reflect the caregiver’s idea about the benefits of the individual items to the health-related quality of life (Rabins et al., 1999). In 2009 the ADRQL was revised (Kasper et al., 2009). The questionnaire is available upon registration in the Mapi Research Trust (https://eprovide.mapi-trust.org/instruments/alzheimer-s-disease-related-quality-of-life).

- ✓ **Combination of self-rating by the patient with dementia and caregiver’s assessment**

  The assessment tools in this group include both the subjective view on the quality of life by the patient with dementia and the caregiver’s assessment. Accessing the quality of life from both of these perspectives is very important because not paying attention to the patients’ subjective individual experience can lead us to measuring such aspects of the quality of life that are not meaningful for the people with dementia (Russell, 1996). As has earlier been pointed out by Walker et al. (1998), aspects of the quality of life of people with dementia are affected by various sociocultural influences and factors which are different from factors affecting the quality of life of people without cognitive impairment. The most commonly used tool in this group is the **Quality of Life – Alzheimer’s Disease Questionnaire** (QOL-AD; Logsdon et al., 2002). Since the QOL-AD was used in the study dealing with the trajectory of quality of life in older adults in the early dementia stage, whose results are presented in this work, the questionnaire is described below in detail.

2.4.1 Quality of Life – Alzheimer's Disease Questionnaire

The QOL-AD is an assessment tool developed specifically for patients with dementia (Logsdon et al., 1999; 2002). It is based on Lawton's model that defines the concept of quality of life in patients with dementia as a multidimensional one consisting of both subjective (e. g. perceiving the quality of life and psychological well-being) and objective components (e. g. behavioural competence and the environment) (Lawton, 1991). Even though the QOL-AD questionnaire was originally designed as a self-rating tool for individuals with dementia living in a community, it has also often been used as an assessment tool by caregivers in long-term care institutions and nursing homes (Dichter et al., 2015; Beerens et al., 2016; Nielsen et al., 2016).

Another variant of the questionnaire is the ***QOL-AD version for patient and caregiver*** (Logsdon, et al., 2002), which is the most frequently used tool to assess the quality of life related to health in people with dementia (Edelman et al., 2005; Hylla et al., 2016; Barrios et al., 2013). It includes the assessment of quality of life both from the position of the patient and of the caregiver. It has been proven that the QOL-AD is reliable and valid for people with the MMSE score above 10 points, so it cannot be used to assess the quality of life in patients with mild or moderate dementia (Logsdon et al., 1999; 2002; Thorgrimsen et al., 2003; Wolak et al., 2009; Novelli et al., 2010). In comparison with other questionnaires which assess the quality of life in patients with dementia, the QOL-AD has a couple of advantages.

- ✓ First – it is relatively brief (the questionnaire completion takes about 10–15 minutes on average) and the items are easy to understand (Bowling et al., 2015).
- ✓ Second – the reliability of patients' and caregivers' responses was evaluated as excellent ($\alpha = 0.88$ [patient] and 0.87 [caregiver]), which shows that the items really measure the cohesive construct. Also the correlation between the items is good (ICC = 0.76 [patient] and 0.92 [caregiver]) (Logsdon et al., 1999).

The QOL-AD version for the patient with dementia has 13 items identical to the version for the caregiver. They are assessed with respect to the current quality of life of the patient. Simple and easy-to-understand formulations are used for the individual items. Every item has a four-grade Likert scale (1 = poor; 2 = fair; 3 = good; 4 = excellent) to assess the degree of agreement with the specific statement. The list of items is shown in Table 4.

Table 4 QOL-AD questionnaire items

QOL-AD questionnaire items	
1.	Physical health
2.	Energy
3.	Mood
4.	Living situation
5.	Memory
6.	Family
7.	Marriage / closest personal relationship
8.	Friends
9.	Self as a whole
10.	Ability to do chores around the house
11.	Ability to do things for fun
12.	Money
13.	Life as a whole

The parallel forms validity of the QOL-AD has strong correlations with questionnaires measuring activities of daily living and the degree of depression (Logsdon et al., 1999; Longsdon et al., 2002; Bruvik et al., 2012; Klapwijk et al., 2016). Intercultural validity of the QOL-AD has been confirmed in countries with various cultures, including the Czech Republic (Matsui et al., 2006; Wolak et al., 2009; Novelli et al., 2010; Gómez-Gallego et al., 2012a; Akpinar et al., 2012; Bárrios et al., 2013; Buasi, Permsuwan, 2014; Kisvetrová et al., 2018a).

The QOL-AD has been used in studies conducted in various environments, both in communities (Novelli et al., 2010) and in acute (Sheehan et al., 2012) and long-term care (Hoe et al., 2006). The assessors included both family caregivers (Léon-Salas et al., 2011) and professional caregivers (Gómez-Gallego et al., 2012b). The QOL-AD is used with patients with mild cognitive impairment (Teng et al., 2012) and with various types of dementia who scored above 10 points in the MMSE (Wolak et al., 2009; Novelli et al., 2010).

In case one or two items of the QOL-AD are not filled-in, the recommended procedure is to replace them by an average score of other items. In case more than two items are missing (are not filled-in), the questionnaire is no longer valid and the patient is considered "unable or unwilling to complete the assessment" (Logsdon et al., 2002). The total QOL-AD score is obtained by adding points of the individual items, so it could be interpreted as a global rate of the perceived quality of life (Lawton, 1991). The score can be calculated as two separate results for the patient with dementia and for the caregiver or as a weighted composite score. As the patient's assessment is considered to be more significant, the weighted composite score is calculated in the following way: the patient's score is doubled, the caregiver's score is added and the result is divided by three. The total QOL-AD score is within the range of 13–52 points. Higher values of the total score indicate a better quality of life. Lower values of the QOL-AD score are often connected with the incidence of depression, a certain level of cognitive impairment, degree of self-sufficiency in activities of daily living, and a higher comorbidity (Logsdon et al., 1999; 2002; Bárrios et al., 2013; Conde-Sala et al., 2009; Bosboom et al., 2012).

✓ Czech version of the QOL-AD (version for the patient and family)

The Czech translation of the QOL-AD is available upon registration with the official distributor Mapi Research Trust (PROQOLID. Quality of Life in Alzheimer's Disease [QOL-AD], accessible at https://eprovide.mapi-trust.org/).

Due to the non-existence of a psychometric validation of this Czech translation, after the official Czech versions of the QOL-AD were obtained for the patient and family, including the translated instructions for examiners by Mapi Research Trust, a psychometric validation was realised in Czech patients in the early dementia stage. This study was part of the first phase of the Czech Health Research Council grant (No. 16-28628A).

The study of the psychometric validation of the Czech version of the QOL-AD involved 212 patients in the early stage of dementia (with the MMSE score of 22.6 ± 1.7 points; ranging from 20 to 25 points) and their family caregivers. The study was part of a multicentre longitudinal study dealing with the trajectory of quality of life in older adults in the early stage of dementia which was supported by the Czech Health Research Council (grant No. 16-28628A).

The reliability of the Czech version of the QOL-AD for patients and caregivers was good (Cronbach's $\alpha = 0.85$; ICC = 0.25–0.54). When evaluating the convergent validity, a positive correlation was proven between the QOL-AD and physical fitness (SPPB; $r = .45$, $p < 0.0001$ for the patients' assessment; $r = 0.37$, $p < 0.0001$ for the caregivers' assessment and $r = 0.48$, $p < 0.0001$ for the composite score). Negative correlation existed between the QOL-AD and the level of self-sufficiency (BADLS; $r = –0.47$, $p < 0.0001$ for the patients' assessment; $r = –0.61$, $p < 0.0001$ for the caregivers' assessment and $r = –0.59$, $p < 0.0001$ for the composite score). Negative correlation was also proven between QOL-AD and depression (GDS): $r = –0.67$, $p < 0.0001$ for the patients' assessment; $r = –0.40$, $p < 0.0001$ for the caregivers' assessment and $r = –0.66$, $p < 0.0001$ for the composite score). In construct validity the results of the factor analysis have confirmed the three-factor solution (factors: Physical and mental health; Family life; Social security). Cronbach's alpha was calculated for each factor. The alpha values were in the range of 0.86 to 0.44. Lower alpha values in the factors of Family life and Social security were caused by a low number of items contained in these factors. The results of the study have confirmed that the Czech version of the QOL-AD has good psychometric characteristics which are in compliance with the international recommendation (Kisvetrová et al., 2018a).

3 ⁄ Determinants of quality of life

At present the quality of life in older adults with dementia is one of the priorities of health policies in individual countries (Department of Health, 2011). Therefore, there has been an increased interest in research dealing with the quality of life in people with dementia and in interventions that can improve it (Kane, 2001; Rabins, Black, 2007; Kisvetrová et al., 2019a). There is a presumption that in older people with dementia the quality of life will change due to the progression of the cognitive deficit. However, Beerens et al. (2015) suggest that the natural progression of dementia does not necessarily have to be connected with the decrease in the quality of life. In order to preserve or improve the quality of life in people with dementia, it is necessary to have more knowledge about the determinants of quality of life and about the factors that they include. Their identification in the individual stages of dementia can contribute to a better understanding of the quality of life and the dementia progression.

Determinants of the quality of life present independent variables consisting of sets of factors which affect the specific individual's quality of life. These factors can be divided into a couple of groups corresponding to the determinants of the quality of life.

- ✓ Demographic characteristics;
- ✓ Health;
- ✓ Psychological and emotional factors;
- ✓ Social and relationship factors.

3.1 Demographic characteristics

Basic demographic factors, including age, sex, education, and marital status, are often among the examined variables in research dealing with the quality of life. Study results confirm that the degree of education, sex, marital status, and age affect the individual's quality of life. Studies that have dealt with the individual factors are outlined in Table 5.

Table 5 Demographic characteristics

Factor	Source
age	Banerjee et al., 2006; Mjørud et al., 2014; Song et al., 2019; Bilgili, Arpacı, 2014
sex	Barca et al., 2011; Woods et al., 2014; Bilgili, Arpacı, 2013
education	Li et al., 2012; Marventano et al., 2015; Mjørud et al., 2014; Bilgili, Arpacı, 2013
marital status	Samus et al., 2005

3.2 Health

Health as the determinant of quality of life in people with dementia includes factors focusing mainly on physical health, independence in ADL, cognitive functions, and physical symptoms (pain), as outlined in Table 6.

Table 6 Health factors

Factor	Source
physical fitness / self-sufficiency in ADL	Beerens et al., 2015; León-Salas et al., 2015; Orpwood et al., 2007; Potter et al., 2011; Silberfeld et al., 2002; Giebel et al., 2015
cognitive state	Sloane et al., 2005; Wetzels et al., 2010; Winzelberg et al., 2005; Black et al., 2012; Marventano et al., 2015; Mjørud et al., 2014; Samus et al., 2005; Barca et al., 2011; Beerens et al., 2013; Beer et al., 2010; Beerens et al., 2015; Garre-Olmo et al., 2012; Hodgson et al., 2014; León-Salas et al., 2015; Missotten et al., 2007; González-Salvador et al., 2000; Oudman, Veurink, 2014
physical symptoms (pain)	Beer et al., 2010; Hendriks et al., 2014; Hodgson et al., 2014; Tan et al., 2014

3.2.1 Physical fitness

Decreasing physical fitness is typical for the older age. To assess the old adult's physical fitness, we can use the tool *Short Physical Performance Battery* (SPPB; Guralnik et al., 1994; Berková et al., 2013). The SPPB is easy to use also for patients with dementia (Pitkälä et al., 2013).

3.2.1.1 Short Physical Performance Battery

The Short Physical Performance Battery (SPPB) consists of three tested areas that are described in Table 7.

Table 7 Areas tested in SPPB

Test	Activity
Test of balance	1. Standing with feet together. 2. Standing with feet in a semi-tandem position. 3. Standing with feet in a full tandem position. **The maximum score for this part is 4 points.**
Test of walking speed	Walking four metres in an ordinary way – two tries. We measure the time the individual needs to make a specified distance. There are two tries, the better one is recorded. **The maximum score for this part is 4 points.**
Test of repeated chair stands	Tested individuals are sitting on a chair with their arms folded across the chest. Then they are asked to stand up five times without using their arms (i. e. getting from the sitting position to the upright position as fast as possible without using their arms). The total time is measured in seconds. We record how much time the individual needs to perform five chair stands in a row as fast as possible without using their arms. **The maximum score for this part is 4 points.**

The total SPPB score is calculated by adding points in the individual tests and it comes in the range of 0–12 points (Berková et al., 2013; Guralnik et al., 1995).

- ✓ The score of 10–12 points represents good physical fitness.
- ✓ The score of 7–9 points indicates deteriorated physical fitness.
- ✓ In case the score is 6 points or lower, the older adult is assessed as frail and there is a high risk of lack of self-sufficiency in the future.

Li et al. (2020) confirm the correlation in older people of the parallel incidence of frailty, cognitive impairment, and health-related quality of life. Therefore, we identify frailty as one of the significant factors of the quality of life in the early stages of a cognitive impairment (Mhaoláin et al., 2012).

3.2.2 Self-sufficiency in activities of daily living

The lack of self-sufficiency in performing activities of daily living (ADL), which include activities such as mobility, personal hygiene, dressing, eating and using the toilet, significantly influences the quality of life in people with dementia. To assess the self-sufficiency in ADL a number of tools have been developed but only a few of them have been designed specifically for individuals with mild dementia living in a community. In such a case, the assessment is performed by a caregiver (Bucks, Haworth, 2002). At present the Bristol Activities of Daily Living Scale (BADLS) standardised questionnaire is often used to assess the self-sufficiency in older adults with dementia.

3.2.2.1 Bristol Activities of Daily Living Scale

The Bristol Activities of Daily Living Scale (BADLS) contains both basic and instrumental ADL and covers a wide spectre of activities ranging from completely independent ones to completely dependent ones. This aspect is especially significant in dementia. The questionnaire is completed by a close person who assesses the performance of the examined person in twenty basic activities of daily living within the recent two weeks.

The BADLS has a good sensitivity in relation to the changes in the disease progression (Byrne et al., 2000), good psychometric features (Bucks et al., 1996; Sikkes et al., 2009) and its results do not depend on the basic demographic characteristics of the assessed person (age, sex, education), as stated by Bartoš and Hasalíková (2010).

Bucks et al. (1996) confirmed that the BADLS has a good convergent validity ($r = 0.65$, $p < 0.001$). The tool correlates well with the MMSE ($r = -0.67$, $p < 0.001$) and shows excellent test-retest reliability ($r = 0.95$, $p < 0.001$). When using the Cohen's kappa coefficients, seven items reached a lower kappa score (0.30–0.59) and 13 items reached a good or very good kappa score (0.62–0.94). The analysis of the main components has confirmed four factors with their own values higher than 1, which explained 65% of the total variability (Instrumental activities of daily life; Self-care; Orientation; Mobility).

➲ Czech version of BADLS

In 2010 a Czech version of the questionnaire was created – BADLS-CZ (Bartoš et al., 2010; Bartoš, Hasalíková, 2010). It is available at https://www.nudz.cz/adcentrum/dotazniky.html#BADLS. The list of activities assessed by the test is shown in Table 8.

Table 8 BADLS-CZ questionnaire items

Assessed activities			
1	Preparing meals	**11**	Walking
2	Eating	**12**	Orientation in time
3	Preparing drinks	**13**	Orientation in space
4	Drinking	**14**	Communication
5	Dressing	**15**	Telephone usage
6	Hygiene	**16**	Household chores, DIY
7	Caring for own or false teeth	**17**	Shopping
8	Taking a bath/shower	**18**	Money
9	Toilet hygiene	**19**	Hobbies and games
10	Basic movement	**20**	Transport

There are five assessment statements assigned to each questionnaire item, each assessed by 0–3 points or “X” = irrelevant. The score of “0 points” means that the patient performs the specific activity without any limitations. If they have any trouble with performing the specific activity, the assessment is in the range from 1 to 3 points. A larger deficit in self-sufficiency in the performed activity is manifested by a higher number of points. The total score of the questionnaire is in the range of 0 (completely self-sufficient) up to 60 points (completely dependent). In the Czech version (BADLS-CZ) the score is also expressed as a percentage (0–100%). This value shows the self-sufficiency in percent. The result of 0% means a complete lack of self-sufficiency of the assessed person.

3.2.3 Cognition

The correlation between the level of the cognitive state (or cognitive impairment) and the quality of life in people with dementia is suggested by results of a couple of studies. Marventano et al. (2015) and Mjørud et al. (2014) state that the quality of life in patients with dementia has a tendency to decrease with the increasing seriousness of dementia. This is confirmed by the correlation between the levels of cognitive functions and the quality of life in patients with dementia mentioned for example in the work by Lužný (2013). On the contrary, Beerens et al. (2015) believe that the natural progression of dementia does not necessarily have to cause the decrease in an individual's quality of life. Also Oudman and Veurink (2014) state that the quality of life in patients with severe dementia can be stable in spite of the global cognitive deterioration; especially in the later dementia stages. In the Czech clinical practice, the most frequently used tool to assess the cognitive functions is the Mini-Mental State Examination (MMSE) that is described in detail in Chapter 1.4.1.

3.2.4 Pain

Pain is a physical symptom that negatively affects the quality of life in older adults with dementia (Hendriks et al., 2014; Hodgson et al., 2014). Corbett et al. (2012) point out that the incidence of chronic painful states in older patients with dementia can be comparable to that in individuals without dementia. However, as regards the assessment of pain, a great majority of patients with moderate to severe dementia may not be able to assess their pain with an assessment tool and therefore the pain is rather reported by informal caregivers than by the patients themselves (Bullock et al., 2019). The incidence of pain in older adults with cognitive impairment is often underestimated and that has a negative effect on their independence in ADL and on their quality of life. The correlation between pain and the quality of life in patients with dementia has been confirmed in past as well as contemporary studies (Katz, 2002; Wróblewska et al., 2019).

Self-rating tools for pain assessment are relevant for people with mild to middle cognitive impairment. Patients in the middle dementia stage (with the MMSE score of 10–19 points) manifest a good correlation between all the used scales to assess pain (Álvaro González, 2015). In case of patients with severe dementia, it is better when caregivers observe the non-verbal expressions in order to assess the pain (Cravello et al., 2019).

When patients communicate, we can use a simple visual scale – descriptive verbal scale, visual analogue scale (VAS), and a numeric scale. Using these assessment tools, the intensity of the subjectively perceived pain can be quantified in the following ways:

- ✓ matching the score to the individual verbal assessments (ranging from "no pain" to "the worst possible pain");
- ✓ marking the numeral value from 0 to 10 by numbers;
- ✓ making a graphic mark on a horizontal line (e. g. in VAS).

The *Horizontal Visual Analogue Scale (HVAS)* consists of a 10-centimetre line where the patient marks the level of the subjectively perceived pain (ranging from no pain to extreme pain). The HVAS can be successfully used in most elderly patients with mild to moderate dementia (Pautex et al., 2005).

3.3 Psychological and emotional area

In the subjective assessment of quality of life by older patients with dementia, psychological and emotional factors play a significant role. This group includes mainly depression, fear and mood (Beerens et al., 2016), autonomy, dignity, and self-confidence. The list of studies dealing with the specific factors is shown in Table 9.

Table 9 Psychological and emotional factors

Factor	Source
depression	Beerens et al., 2013; Winzelberg et al., 2005; Black et al., 2012; Li et al., 2012; Marventano et al., 2015; Barca et al., 2011; Beerens et al., 2015; Byrne-Davis et al., 2006; Heggie et al., 2011; González-Salvador et al., 2000; Sivertsen et al., 2015; Song et al., 2019
fear of falling	Uemura et al., 2014; Akosile et al., 2014
satisfaction with life	Byrne-Davis et al., 2006
attitude to old age and ageing	Yamada et al., 2015; Trigg et al., 2012; Kisvetrová et al., 2019a
feeling of usefulness to the society	Byrne-Davis et al., 2006; Moyle et al., 2011a; O'Rourke et al., 2015; Silberfeld et al., 2002;
control over one's own life	Moyle et al., 2011a
autonomy	Crespo et al., 2011; O'Rourke et al., 2015
dignity and respect	Manthorpe et al., 2010; Russell et al., 2008; Venturato, 2010; Tranvag et al., 2015, 2016

Research results suggest that the positive mood, being useful to others, and life satisfaction correlate with a better quality of life (Byrne-Davis et al., 2006; Clare, Woods et al., 2014). Also one's autonomy (Crespo et al., 2011; O'Rourke et al., 2015), positive perception of one's dignity (Tranvag et al., 2015; Tranvag et al., 2016), and control over one's life (Moyle et al., 2011a; Moyle et al., 2015) have been confirmed as positive predictors of the quality of life. Other factors affecting the quality of life in older patients with dementia include the fear of falling (Uemura et al., 2014; Akosile et al., 2014) and the attitude to one's own age and ageing (Yamada et al., 2015; Trigg et al., 2012).

3.3.1 Depression

Epidemiological studies confirm that the incidence of depression is more and more common in the general population and it increases with age and has an invalidating effect (Naismith et al., 2012). There is an estimate that up to 50% of people with dementia suffer from depression and the persistence of depressive symptoms is high. The incidence and persistence of clinically significant depression symptoms is connected with the type of provided care. There is high incidence for example in older people in institutional care (Barca et al., 2010). Depression is considered to be a risk factor for all dementia types (Diniz et al., 2013, Deckers et al., 2015) and the trajectory of depression symptoms is related to the speed of the dementia progression (Barca et al., 2017). Depression significantly influences the quality of life both in terms of psychological well-being and of the self-perception of the individuals (health, personal performance, abilities) and their other personal and environmental needs (Houtjes et al., 2011).

In institutions, correlation has been proven to exist between serious depression and the deterioration of the quality of life in older patients with dementia (Barca et al., 2011). Depression is therefore considered to be the main predictor for the quality of life at all dementia stages as has been suggested by cross-sectional as well as longitudinal studies (Gómez-Gallego et al., 2012b; Hoe et al., 2009; Missotten et al., 2007; Naglie et al., 2011; Tatsumi et al., 2009).

Several tools are used to assess the number of depressive symptoms. The most frequently used ones include the Hamilton Scale of Depression (HAMD; Hamilton, 1960), the Beck Depression Inventory-II (BDI-II; Beck, 1996; Preiss, Vacíř, 1999; Filip, 1997) or the Geriatric Depression Scale (GDS; Yesavage et al., 1983). As the brief version of the Geriatric Depression Scale (GDS-15; Yesavage, Sheikh, 1986) was used in the research on the trajectory of quality of life in older adults in the early stage of dementia, which is described in this work, the GDS-15 is described in detail below.

3.3.1.1 Geriatric Depression Scale

In order to detect the incidence of depression symptoms in older adults, we often use the Geriatric Depression Scale (GDS; Yesavage et al., 1983) consisting of 30 items. In the clinical environment it presents a useful screening tool that makes the depression assessment in older people easier. The GDS can be administered either verbally, which means that the assessor asks the individual questions and records the answers into a form, or the older adults can complete the questionnaire by themselves. The GDS can be used both in healthy and ill older people including patients with mild to middle impairment of cognitive functions. However, some authors point out that the GDS completed by patients with cognitive impairment has a lower validity (Kørner et al., 2006). The GDS has a sensitivity of 92% and the specificity of 89% when assessment is based on diagnostic criteria. In a validation study comparing the usage of the long version (GDS) and the brief version (GDS-15) for self-rating of depression symptoms, both the versions proved the ability to successfully distinguish depression patients from non-depression individuals with a high correlation ($r = 0.84$, $p < 0.001$) (Sheikh, Yesavage, 1986).

The GDS-15 (Yesavage et al., 1986; Tošnerová, Bahbouh, 1999) consists of 15 self-rating items (yes/no answers) in which older people themselves rate their mood in the recent week (the items are listed in Table 10). Each answer is evaluated with 0 or 1 point. The total GDS-15 score ranges from 0 to 15 points. Scores up to 5 points are evaluated as "no depression". The growing number of points means a growing seriousness of depression (Yesavage, Sheikh, 1986). Conradsson et al. (2013) state that the GDS-15 is a brief, valid instrument for depression screening and is relevant to use in individuals with mild to moderate dementia.

Table 10 GDS-15 questionnaire items

GDS-15 questionnaire items	
01	Are you basically satisfied with your life?
02	Have you dropped many of your activities and interests recently?
03	Do you feel that your life is empty?
04	Do you often feel sad and bored?
05	Are you in good spirits most of the time?
06	Are you afraid that something bad is going to happen to you?
07	Do you feel happy most of the time?
08	Do you often feel helpless?
09	Do you prefer to stay at home rather than go out and do new things?
10	Do you think you have more problems with memory than your peers?

GDS-15 questionnaire items	
11	Do you think it is wonderful to be alive now?
12	Do you feel pretty worthless the way you are now?
13	Do you feel full of energy?
14	Do you feel your situation is hopeless?
15	Do you think that most people are better off than you are?

3.3.2 Attitudes to old age and ageing

Attitudes represent stable and integrative judgements which summarise the individual's ideas, feelings, and memories about objects or situations (Low et al., 2013). They derive from observation or from direct experience and consist of three main elements – cognition, influence, and behaviour (Ibrahim, Bayen, 2019). Attitudes to ageing differ across cultures and are formed by tradition, religion, as well as socio-cultural belief (Kickbusch, 2005; Moberg, 2005). Therefore, they present social constructs set in cultural and historical contexts which are interpreted individually. In older people, positive approaches to ageing contribute to the support of mental and physical health (Bryant et al., 2012). They can influence the older adults' view of their own health (Beyer et al., 2015), level of well-being and life satisfaction (Faudzi et al., 2019), physical performance (Gale, Cooper, 2018), and self-sufficiency in ADL (Moser et al., 2011). The perception of one's own ageing affects the older adults' psychological and physical health (Robertson et al., 2016) and the attitude to one's own ageing therefore significantly reflects the subjective assessment of one's own quality of life (Trigg et al., 2012; Yamada et al., 2015; Low et al., 2013; Chachamovich et al., 2008a; Top et al., 2012). Results of studies dealing with attitudes toward the old age in older people confirm that their attitudes toward psychosocial changes are more positive than attitudes toward physical changes (Top, Dikmetas, 2015; Korkmaz Aslan et al., 2017). Older people also connect positive attitudes toward their own ageing with the social support and participation in the community (Lu et al., 2010).

In comparison with individuals without any cognitive deficit, patients with dementia often show tendency to a more negative attitude to ageing as to the time of psychosocial loss. A negative attitude to ageing in the early stage of dementia is usually connected to the acknowledgement of a gradual decrease in cognitive abilities (Siebert et al., 2018).

A frequently used tool to assess one's own ageing is the subscale called the **Attitude Toward Own Aging** (ATOA) derived from the Philadelphia Geriatric Morale Scale consisting of five statements to assess the general attitude to ageing (Lawton, 1975; Liang, Bollen, 1983). Due to some opinions that the ATOA as a general instrument is insufficient to an overall assessment of attitudes toward one's own ageing, there has been an effort to create a tool that would make it possible to assess the process of ageing as an individual experience viewed by older adults. The resulting product is the Attitude to Ageing Questionnaire (AAQ). The methods used by the WHOQOL have provided a unique approach to develop an instrument that ensures intercultural validity in the assessment of attitudes to ageing and lowers the risk of cultural distortion (Laidlaw et al., 2007).

3.3.2.1 Attitude to Ageing Questionnaire

The Attitude to Ageing Questionnaire (AAQ) constitutes a multidimensional conception usable in various cultures. The final version of the questionnaire was made with focus on three different aspects of ageing which create three subcategories (domains) of the AAQ. The first domain focuses on psychosocial losses related to the older adults who perceive age as a negative experience connected with the losses in the psychological and social area. The second domain deals with the physical area of ageing including aspects such as health, exercise, and one's own experience of ageing. The third domain is connected to the wisdom and growth in old age. It shows the perceived positive aspects in relation to the individual and others (Laidlaw et al., 2007). In total, the AAQ consists of 24 items divided into three domains which are seen in Tables 11–13.

The AAQ questionnaire has shown very good psychometric features across cultures. The psychometric analysis of the AAQ was conducted for example in Spain, Brazil, Scotland, Norway, Canada and Iran (Lucas-Carrasco et al., 2013; Kalfoss et al., 2010; Chachamovich et al., 2008b; Shenkin et al., 2014; Rejeh et al., 2017). It has been proven that the AAQ has a corresponding validity and reliability.

It has also been confirmed that older people with dementia are able to give valid answers to questions about their attitudes to ageing (Trigg et al., 2007).

Table 11 Domain I

	Contents	
Psychosocial loss	***Feelings of loneliness, social exclusion, seclusion, and gradual loss of self-sufficiency.***	
	Items	
	03	Old age is a time of loneliness.
	06	Old age is a depressing time of life.
	09	I find it more difficult to talk about my feelings as I get older.
	12	I see old age mainly as a time of loss.
	15	I am losing my physical independence as I get older.
	17	As I get older I find it more difficult to make new friends.
	20	I don't feel involved in society now that I am older.
	22	I feel excluded from things because of my age.

Table 12 Domain II

	Contents	
Physical change	***Assessment of physical health, condition, exercise and the overall reflection on ageing.***	
	Items	
	07	It is important to do exercise at any age.
	08	Growing older has been easier than I thought.
	11	I don't feel old.
	13	My identity is not defined by age.
	14	I have more energy now than I expected for my age.
	16	Problems with physical health do not hold me back from doing what I want to do.
	23	My health is better than I expected for my age.
	24	I keep myself as fit and active as possible by exercising.

Table 13 Domain III

	Contents	
Psychological growth	***Positive experience, positive attitude to oneself and to the world around in relation to one's own ageing.***	
	Items	
	01	As people get older they are better able to cope with life.
	02	It is a privilege to grow old.
	04	Wisdom comes with age.
	05	There are many pleasant things about growing older.
	10	I am more accepting of myself as I have grown older.
	18	It is important to pass on the benefits of my experience to younger people.
	19	I believe my life has made a difference.
	21	I want to give a good example to younger people.

(Processed according to Dragomirecká, Prajsová, 2009)

The individual items in the AAQ domains, as shown in Tables 11–13, are completed with a 5-point Likert scale (ranging from 1 = strongly disagree to 5 = strongly agree). Every domain has eight items, the minimum score per domain is 8 points, and the maximum is 40 points. The total questionnaire score is calculated by adding all the domain scores and it comes between 24 and 120 points. A higher score indicates a more positive attitude to one's own ageing and old age (Laidlaw et al., 2007). The creation and psychometric validation of the Czech version is described by Dragomirecká and Prajsová (2009). Their book contains the psychometric characteristics of the questionnaire, orientation Czech norms, and a detailed scoring manual.

3.3.3 Dignity

We can describe dignity as a multidimensional concept that includes perception, cognition, and emotions related both to the feeling of one's value and respect and to the respect and esteem shown by other people to the individual (Manthorpe et al., 2010). Jacelon (2004) describes it as inherent characteristics of a human being which can be perceived as an attribute of one’s own “self” and is manifested by behaviour demonstrating respect to oneself and others. Dignity can also be understood as a dual concept including absolute and relative dignity (Edlund et al., 2013), objective and subjective dignity (Gallagher, 2004), human, also called basic, and social, also called personal, dignity (Jacobson, 2007; Jacobson, 2009).

Human dignity is an abstract universal value belonging to all human beings due to the fact they are human.

- ✓ *Spiritual concept* of human dignity is based on the belief that human beings have a privileged position among God’s creations (Quante, 2005).
- ✓ *Secular concept* of human dignity is based on the belief that the meaning of dignity is rooted in the rationality of human beings and their ability to behave as moral individuals (Nordenfelt, 2004).

Therefore, it is impossible to measure, create or destroy human dignity.

Social dignity of individuals originates based on their interactions with other people, groups, and society. It can be classified as dignity which:

- ✓ *Individuals attribute to themselves* (manifesting self-respect and pride).
- ✓ *Is attributed to individuals by others* (including the ways of showing value and respect to individuals by individual and collective behaviour).

As social dignity arises due to social interaction, it can be measured, violated or improved. In old age, this form of dignity is easy to be influenced either in the positive or negative way when care is provided.

The terms of absolute and relative dignity give rise to four **dignity categories** that have been described by Lennart Nordenfelt (2004).

- ✓ The first category is *dignity as a human right* (*Menschenwürde* in German), which represents an absolute value. All people have the same amount of this dignity due to the fact that they are human. It is therefore inborn (internal) and belongs to all people regardless their sex, age, race, education, status or religion.

Menschenwürde creates the basis for the moral commitment to respect other people and for the experience of dignity or humiliation in three more categories. These include the dignity of credit, dignity of moral strength, and dignity of personal identity.

These three categories represent dignity as a relative value. It depends on the behaviour, autonomy, and integrity of the individual and the people one is in contact with. It provides a base for the individual's self-esteem.

- ✓ *Dignity of merit* is identified by the individual's formal and informal status in the society. It is attributed to people due to the roles they play, due to their functions or credits for their action.
- ✓ *Dignity of moral stature* is based on the moral integrity and stresses the individual's ability to live in compliance with the moral principles.
- ✓ *Dignity of identity* is related to the identity of a specific person, to the self-esteem, and to the terms of integrity, independence, and inclusion. This dignity can be endangered and violated if older adults are offended and treated as things. Regarding the older adults, this is the most significant type of dignity.

While Nordenfelt (2004) describes four positive categories of dignity, Jonathan Mann (1998) has created the **taxonomy of four categories of dignity violation**.

Mann's taxonomy

- ✓ The first category can be called *not being seen*. This is the situation when an individual has a feeling of being ignored and not respected. For example an older patient in the nursing care is trying to attract the attention of the nurse who is taking care of them. But the nurse is avoiding eye contact with the patient and ignores them.

- ✓ The second category can be described as *being subsumed into a group identity*. This is a situation when older adults are only stereotypically perceived as members of specific groups (e. g. pensioners or the demented). In this respect, Mann (1998) emphasises that the group classification can cause pride but in this case the perception of the older adult only as a member of a group is rather pejorative.
- ✓ The third category can be defined as *dignity violation via invasion of personal space*. This can happen while performing personal hygiene if the older people do not have enough privacy.
- ✓ The fourth category is *humiliation*. It is seen in situations when the older people are excluded, differentiated or separated from a group or society and are subjects of criticism or mockery.

The model of dignity in illness has been presented by Oosterveld-Vlug et al. (2014). In this model they describe how an illness can affect the patient's personal (social) dignity.

- ✓ According to this two-level model, the illness does not have a direct effect on the patient's dignity. It influences it indirectly in the way the patient is perceived via three elements forming the self-concept: individual self, relational self, and societal self.

Dignity from the older adults' view

When assessing their dignity, older adults connect the idea of dignity especially with *esteem* (to themselves [self-esteem] as well as toward others and by others) and *participation*, i. e. the possibility to join in activities. Older adults most often connect the dignity endangerment in care provision with:

- ✓ Dependence on the care provided by others;
- ✓ Wrong communication;
- ✓ Depersonalisation of care.

From the older adults' view, preserving dignity means that they have their lives under control and are treated with respect to their autonomy and personal identity. In order to achieve this, older people must be perceived by others as unique human beings as well as integrated and respected society members. Older adults who are aware of the deterioration of their cognitive abilities often perceive this as a stigma lowering their self-esteem (Burgener et al., 2015) and the consequent personal dignity which is negatively reflected in their assessment of the quality of life.

Understanding problems that could endanger the older adults' dignity enables the medical staff to protect older people from losing their personal dignity. Relevant tools to assess the dignity in the old age, including that of patients with dementia, include for example the Jacelon Attributed Dignity Scale (JADS) or the Patient Dignity Inventory (PDI).

➲ Jacelon Attributed Dignity Scale

The Jacelon Attributed Dignity Scale (JADS) has been created specifically for the population of older adults. It consists of 18 positively formulated statements focusing on the degree of the older person's attributed dignity. A high value of the attributed dignity indicates a protective factor in relation to health, self-sufficiency, independence, quality of life, and successful ageing (Jacelon et al., 2009). Psychometric validation has shown that the JADS has four factors with high internal consistence for each of the factors as well as for the questionnaire as a whole. Construct validity has been determined based on the JADS correlation with the self-esteem assessment tools – the Rosenberg Self-Esteem Scale (SES; Rosenberg, 1965), and social desirability assessment tools – the Crowne and Marlow Social Desirability Scale (SDS; Crowne, Marlow, 1960). The results have confirmed the validity of the JADS and have shown that the attributed dignity is a unique concept that is stable over time (Jacelon, Choi, 2014).

Another relevant questionnaire to assess dignity is the Patient Dignity Inventory (PDI). As the PDI was used in the research on the trajectory of quality of life in older adults in the early dementia stage, whose results are presented in this work, the questionnaire is described below in detail.

3.3.3.1 Patient Dignity Inventory

The Patient Dignity Inventory (PDI) is a screening tool providing the medical staff with a rather easy way to identify a wide spectre of problems that can cause anxiety and concerns in an individual related to the endangerment of their dignity (Chochinov et al., 2008). Although it was primarily designed as an assessment tool for terminally ill oncological patients, it is now used also with patients in the early dementia stage (Johnston et al., 2016) and with older adults who are not in a terminal stage of an illness but are experiencing the final phase of their life (Kisvetrová et al., 2019a).

The PDI has 25 items with a 5-point Likert scale which describes how problematic or concerning the specific situation has been for the individual in recent days (1 = no problem; 2 = slight problem; 3 = problem; 4 = serious problem; 5 = overwhelming problem). The total questionnaire score is in the range of 25 to 125 points. A higher score indicates a higher endangerment of dignity (Chochinov et al., 2008).

- **Patient Dignity Inventory in Czech (PDI-CZ)**

  Creating a Czech version of the PDI questionnaire (Patient Dignity Inventory in Czech; PDI-CZ) and its linguistic and psychometric validation were part of the first phase of the longitudinal multicentre study (Czech Health Research Council; grant No. 16-28628A) where the PDI-CZ was used to assess the perception of dignity by older adults with and without dementia.

  Having received the approval by Professor H. Chochinov (Manitoba Palliative Care Research Unit, CancerCare Manitoba, Canada), the author of the original PDI English version, the questionnaire was translated to Czech. The transformation of the PDI English version was done according to the process suggested by Beaton et al. (2000; 2007) and Guillemin et al. (1993). The suggested methodology is based on the needs of the medical, psychological, and sociological research and the creation of assessment tools for the HRQOL concept (health-related quality of life). A five-phase process has been recommended (A–E phases).

A) *Translation to the mother tongue*

The translation of the PDI original English version into Czech was done by two translators (a clinical and a professional one), both Czech natives. The criteria for the selection of a clinical translator were: medical specialist with an excellent knowledge of the English language (living in an English speaking environment or permanently using English in their profession in the Czech Republic). The resulting translation versions were marked T1 and T2.

B) *Translation synthesis*

The synthesis was done by an independent professional translator with the participation of the T1 and T2 translators. Comparing the two versions and the original PDI, a common version called T12 was created.

C) *Reverse translation to the original (English) language*

In this phase, the T12 version was translated back to the English language by two translators who did not take part in the first phase of the translation. The criteria for the selection of translators were: native English speakers with an excellent knowledge of the Czech language, one of the translators was a medical specialist. The new translation versions were called BT1 and BT2. The aim of this phase was to find out whether the presented T12 version reflected exactly the contents of the items of the original PDI version.

D) *Translation review by a board of specialists in the specific field*

A board of specialists was selected based on the following criteria: knowledge of English, medical profession (doctor, nurse) in the field of nursing the incurable and patients in the final phase of their life, and a professional translator. The task was for the committee to judge any differences between the translated versions (T1, T2, T12, BT1, and BT2) and verify that the translations correspond by using semantic, idiomatic, expressive, and conceptual equivalence. The translation compliance was judged based on the work by de Vijver, Tanzer (2004), and Beaton et al. (2000; 2007). The discussion resulted in a *pre-final Czech version of the questionnaire* to be used in the pre-test. The abbreviation for the Czech version was preserved as PDI with a CZ index so that the original resource and translation into Czech would be clear also in the international context (PDI-CZ).

E) *Questionnaire pre-test*

The pre-test method was used in order to evaluate the clarity of the pre-final questionnaire version. The sample of respondents consisted of 40 patients. The inclusion criteria were: 1) age: over 18 years old; 2) suffering from an incurable disease in an advanced or terminal stage; 3) consent with the research participation; 4) ability to complete the questionnaire by oneself or with a researcher. The exclusion criterion was: a serious cognitive deficit. Having been informed about the pre-test aim, the respondents were asked to fill in the questionnaire. With every item, the researcher asked the respondent how they understood it. This made it possible to find out whether the translated version of the questionnaire preserved the meaning of the original English items (Beaton et al., 2007).

Based on the pre-test results a board of specialists adapted the final Czech version of the PDI-CZ questionnaire. Two items were modified in order to be better understandable for the Czech environment. In item 22 the expression “health care provider” was replaced with the expression “health care professional”. Most respondents matched the term of health care provider with an image of an institution where care is provided and not with a caregiver as a person. In item 23 the term "challenge" was changed for "obstacles" as respondents often said that they do not consider the illness to be a challenge but that they perceive it as an obstacle in their life.

The psychometric validation of the PDI-CZ was conducted with a sample of 239 incurable patients (136 [56.9%] with oncological and 103 [43.1%] with non-oncological diagnoses). The average age of respondents was 72.2 ± 11.5, ranging from 25 to 96 years old; 144 (60.3%) of the respondents were female. Regarding the questionnaire validity, the internal structure of the PDI-CZ was assessed together with its internal consistence and test-retest reliability. The internal structure of the questionnaire was assessed by the factor analysis using the principal component method with the Varimax rotation. The overall KMO (Kaiser-Meyer-Olkin Measure) score (for all items) was good (0.88) and confirmed, together with the Bartlett's test of sphericity, the relevance of the factor analysis by the Principal Component Analysis method (PCA). The factor analysis resulted in a four-factor solution that presented 56.3% of the total variability. The PDI-CZ reliability was very good. The internal consistency expressed by Cronbach's alpha for the whole PDI-CZ questionnaire was 0.92. The individual factors had the following alpha values: Loss of purpose of life = 0.90; Loss of autonomy = 0.84; Loss of confidence = 0.67; Loss of social support = 0.58. The lowest value of Cronbach's alpha in the last factor was due to the low number of items. Test-retest reliability was assessed by the Gwet's coefficient (AC1 in the range of 0.58–1.00). There was also proven a significant correlation among all the factors (subscales). The individual correlations are shown in Table 14. The study has shown that the PDI-CZ Czech version has good psychometric features and is therefore appropriate to use also in international studies (Kisvetrová et al., 2018b).

Table 14 Correlation of factors (subscales) in PDI-CZ

	Loss of purpose of life *r*	Loss of autonomy *r*	Loss of confidence *r*	Loss of social support *r*
Loss of purpose of life	1			
Loss of autonomy	0.517*	1		
Loss of confidence	0.582*	0.350*	1	
Loss of social support	0.302*	0.210*	0.187*	1

r = Pearson's correlation coefficient; **p* < 0.01

In the Czech version of the PDI-CZ, items are divided into four subscales corresponding to the four factors determined based on the result of the factor analysis (Kisvetrová et al., 2018b). The classification of items in the individual subscales is seen in Table 15.

PDI-CZ subscales

- ✓ *Loss of purpose of life* – this includes the items dealing with the loss of the purpose of life in relation to the illness, self-rating, and the future.
- ✓ *Loss of autonomy* – consists of items focused on dependence, self-care, and community reactions.
- ✓ *Loss of confidence* – includes items related to mental and existential insecurity.
- ✓ *Loss of social support* – consists of items reflecting social support by friends, nursing staff, and care provided with respect.

Table 15 Structure of subscales in PDI-CZ

Loss of purpose of life	
12	Not feeling worthwhile or valued
24	Not being able to accept the way things are
15	Feeling that I have not made a meaningful and lasting contribution during my lifetime
13	Not being able to carry out important roles (e. g., spouse, parent)
11	Feeling like I am no longer who I was
19	Feeling that I don’t have control over my life
23	Feeling like I am no longer able to mentally ‘fight’ the challenges of my illness
16	Feeling I have ‘unfinished business’ (e. g., things left unsaid, or incomplete)
08	Worrying about my future
18	Feeling that I am a burden to others
03	Experiencing physically distressing symptoms (such as pain, shortness of breath, nausea)
14	Feeling that life no longer has meaning or purpose
07	Feeling uncertain about my illness and treatment
Loss of autonomy	
01	Not being able to carry out tasks associated with daily living (e. g. washing myself, getting dressed)
02	Not being able to attend to my bodily functions independently (e. g. needing assistance with toileting-related activities)
10	Not being able to continue with my usual routines
20	Feeling that my illness and care needs have reduced my privacy
04	Feeling that how I look to others has changed significantly
Loss of confidence	
05	Feeling depressed
06	Feeling anxious
17	Concern that my spiritual life is not meaningful
09	Not being able to think clearly
Loss of social support	
21	Not feeling supported by my community of friends and family
22	Not feeling supported by my health care providers
25	Not being treated with respect or understanding by others

3.3.4 Fear of falling

The fear of falling can be defined as permanent concerns about falling which result in the individual's avoiding activities they would otherwise be able to perform. People therefore lose the self-sufficiency in such activities even though no real fall has happened (Tinetti, Powell, 1993). The fear of falling is considered to be a multifactorial (Katsumata et al., 2011; Kumar et al., 2014; Liu, 2015) and multidimensional construct (Boyd, Steven, 2009). Research shows that it occurs more frequently in women (Scheffer et al., 2008; Donoghue et al., 2013; Zijlstra et al., 2007a; Le Bouthillier et al., 2013; Friedman et al., 2002; Kurková et al., 2020) and older adults (Zijlstra et al., 2007b). The fear of falling is connected with a deteriorated functional fitness (Yardley, Smith, 2002; Dias et al., 2011), geriatric frailty (Kurková et al., 2020), cognitive capacity (Yardley, Smith, 2002), and with depression (Austin et al., 2007). The prevalence of the fear of falling in older adults is also related to the occurrence of falling in the anamnesis, polypragmasia, hearing impairment, functional dependence in the ADL, lower walking speed, and depression symptoms (Malini et al., 2016). The fear of falling therefore represents a significant psychological factor connected with the limited living space of older people (Auais et al., 2017) which increases the risk of falling and worsens the quality of life (Esbrí-Víctor et al., 2017; Trombetti et al., 2016).

At present, the fear of falling is a factor often occurring in the assessment of older adults. The nursing staff providing care to older patients should not only make a routine evaluation of the previous fall anamnesis in them but also assess their fear of falling and the related factors (Lavedán et al., 2018). The most common tool to measure various levels of the fear of falling is the Falls Efficacy Scale-International (FES-I; Yardley et al., 2005).

3.3.4.1 Falls Efficacy Scale-International

The Falls Efficacy Scale-International (FES-I) was created and verified within the Prevention of Falls Network Europe (ProFaNE; Yardley et al., 2005). The previous studies have confirmed that the FES-I is a valid tool to assess the fear of falling in older people across cultures (Ruggiero et al., 2009; Baharlouei et al., 2013; Billis et al., 2011; Ulus et al., 2012; Camargos et al., 2010; Figueiredo et al., 2018; Halaweh et al., 2016; Kempen et al., 2007; Kovács et al., 2017; Kwan, 2013; Kisvetrová et al., 2019b). FES-I has been used in various groups of older adults, for example in older adults living in a community (Kovács et al., 2017; Ulus et al., 2012), in day care centres for older people (Figueiredo et al., 2017), and in older adults staying in hospitals (Denkinger et al., 2009). However, only a couple of studies focused also on people with cognitive impairment (Hauer et al., 2010; Hauer et al., 2011).

FES-I consists of 16 items providing information about the degree of concerns of falling for a number of activities of daily living (Yardley et al., 2005). Out of the 16 items, ten items assess basic activities and the other six items assess the more demanding physical and social activities. On a 4-item Likert scale, each item assesses the degree of the fear of falling when performing a specific activity (1 = not concerned at all, 2 = slightly concerned; 3 = quite concerned; 4 = seriously concerned). The overall score ranges between 16 points (no fear at all) and 64 points (greatest fear). The score between 16 and 19 points indicates low fear of falling, the score between 20 and 27 points reflects mild fear, and the score over 27 points shows serious fear of falling (Delbaere et al., 2010).

➲ Fear of Falling (Czech translation of the FES-I)

The Czech translation of the FES-I (Reguli, Svobodová, 2011) has not been validated yet. Therefore, in the first phase of the Czech Health Research Council grant (No. 16-28628A) its psychometric validation was conducted with a sample of patients in the early stage of dementia.

The sample consisted of 282 respondents who were diagnosed with any type of dementia in its early stage (their average age was 80.0 ± 7.7, ranging from 60 to 97; the number of women was 177 [62.8 %]; the MMSE score = 22.7 ± 1.7 points). The internal reliability of the questionnaire was measured by Cronbach's alpha ($\alpha = 0.98$). The item-total correlation was between 0.81 and 0.93 which shows strong to very strong correlation. The ICC coefficients were used to evaluate the test-retest reliability. The ICC for the total scale was 0.90 (95% CI 0.83–0.94). The ICC for the individual items ranged from 0.71 to 0.90 which indicates good to very good reliability.

The internal structure of the scale was examined by the exploratory factor analysis (EFA). The number of factors was determined by the Principal component method with the Varimax rotation. Sixteen items of the Czech version of the FES-I were divided into two factors which explained the 83.7% of the overall variability. The first factor was called Basic activities and consisted of the first nine items. The second factor was called Risky activities and included items 10–16 as shown in Table 16. The convergent validity was checked by the correlation of the overall score of the Czech version of the FES-I with the SPPB scales (physical fitness), GDS-15 (depression), QOL-AD (quality of life), and BADLS-CZ (self-sufficiency). This showed a medium negative correlation with the SPPB ($r = -0.639$, $p < 0.0001$) and the BADLS-CZ ($r = -0.637$, $p < 0.0001$), weak negative correlation with the QOL-AD ($r = -0.358$, $p < 0.0001$), and a medium positive correlation with the GDS-15 ($r = 0.419$, $p < 0.0001$).

The results of the validation study have proven excellent internal reliability of the Czech version of the FES-I and have confirmed its relevance to be used with patients in the early dementia stage (Kisvetrová et al., 2019b).

Table 16 Classification of FES-I items (Kisvetrová et al., 2019b)

Factor I: Basic activities	
1	Cleaning the house (e. g. sweeping, vacuuming, dusting)
2	Getting dressed or undressed
3	Preparing simple meals
4	Taking a bath or shower
5	Going to the shop
6	Getting in or out of a chair
7	Going up or down stairs
8	Walking around in the neighbourhood
9	Reaching for something above your head or on the ground

Factor II: Risky activities	
10	Going fast to answer the phone before it stops ringing
11	Walking on a slippery surface (e.g. wet or icy)
12	Visiting a friend or relative
13	Walking in a place with crowds
14	Walking on an uneven surface (e.g. rocky ground, poorly maintained pavement)
15	Walking up or down a slope
16	Going out to a social event (e.g. religious service, family gathering or club meeting)

3.4 Social and relationship area

Relationships, communication, social inclusion, and volunteering represent important factors of the quality of life in older adults with dementia. Results of several studies (Clare, Woods et al., 2014; Moyle et al., 2011a; Moyle et al., 2015; Nikmat et al., 2015; O'Rourke et al., 2015; Orpwood et al., 2007) confirm that quality relationships with family, friends, neighbours, and caregivers are connected with a better quality of life in older patients with dementia. Also the participation in social events contributes to the higher quality of life in older adults with dementia (Moyle et al., 2015; Orpwood et al., 2007; Silberfeld et al., 2002). Inclusion in the life of a religious community can also keep patients with dementia in touch with their social network and this social support helps to lower their sadness, anxiety, and depression (McNamara, 2002).

As regards the location of the permanent residence, older people living in their own social environment usually assess the quality of their life as better than older adults living in residential institutions (Kuo et al., 2010; Nikmat et al., 2015; González-Salvador et al., 2000; Winzelberg et al., 2005).

The gradual progression of the worsening of cognitive functions, which is common in dementia, also has a significant effect on the social relationships and interactions. Older adults in the early dementia stage are sensitive to the feelings of loneliness which lead to social isolation. It is therefore necessary to consider and support social relationships of patients with dementia in order to keep up their personal well-being as well as the well-being of their family members (Moyle et al., 2011b).

Social relationships include the interactions with family, friends, and professional care providers (O’Rourke et al., 2015; Orpwood et al., 2007; Beerens et al., 2016; Gräske et al., 2015). Relationships characterised by closeness, kindness, esteem, and respect improve the quality of life in older people (Sorrell et al., 2006; Cahill, Diaz-Ponce, 2011). If older patients with dementia feel connected to others, they assess their quality of life better. On the other hand, missing or negative social interactions, experience of distrust, conflicts or manifestations of ignorance and disdain by the others cause loneliness and worsen the quality of life. The overview of selected studies dealing with the individual factors of the social and relationship field is shown in Table 17.

Table 17 Social and relationship factors

Factor	Source
quality of relationship with care providers	Woods et al., 2014; Clare, Woods et al., 2014; Moyle et al., 2011a
social interaction, partner, family, friends	Byrne-Davis et al., 2006; O’Rourke et al., 2015; Orpwood et al., 2007; Beerens et al., 2016
family visits	Gräske et al., 2015; Moyle et al., 2011a
relationships with children	Nikmat et al., 2015
loneliness, social isolation	Moyle et al., 2011b
involvement in community / social activities	Castillo et al., 2010; Orpwood et al., 2007; Silberfeld et al., 2002; Burgener et al., 2015
contact with volunteers	George, 2010; León-Salas et al., 2015
ability to communicate	Young et al., 2011; Moyle et al., 2011a
permanent residence location / environment	Kuo et al., 2010; Nikmat et al., 2015; Wolf-Ostermann et al., 2014; Moyle et al., 2014

4 ⁄ Trajectory of quality of life

The results of a vast research conducted by the Alzheimer's Disease International organisation (ADI, 2019) have shown that almost 80% of the population are afraid of dementia at some point in life. In this respect, one out of four people believe that there is nothing that could be done at present to prevent dementia. In order to be able to realise programmes aimed at patients with dementia (dementia-friendly programmes), to protect and support their quality of life, it is necessary to know how the individuals with dementia themselves perceive and assess the quality of their life and what factors affect it (ADI, 2019). The significance assigned to the self-rating of the quality of life is based on the fact that the quality of life is a multidimensional construct based on both the personal experience of the individuals with their own lives and on objective criteria in the context of culture and values in the society where the individuals live (The WHOQOL Group, 1995).

4.1 Theoretical background and aims of the study

At present, the awareness about dementia and the quality of life of patients with dementia is increasing in many countries. However, it is still true that the dementia diagnosis brings the patients stigma, social isolation, and worsening of the quality of life (ADI, 2015). This is because older adults suffering from dementia in the early stage acknowledge their illness and this often causes insecurity, changes of mood, depression, and anxiety (Kalvach et al., 2011). On the other hand, security is provided by a regular daily routine and keeping the personal rituals. Lowering the performance of complex cognition-directed daily activities of the individuals therefore has negative effects on the quality of their lives. Therefore, the support of the quality of life of older adults in the early dementia stage has become one of the key aims of medical care (Moniz-Cook et al., 2008; Rodakowski et al., 2014) and the importance of research focusing on self-rating of the quality of life of these people has been stressed (Woods et al., 2014).

Cross-sectional studies and observation studies aimed mainly at long-term observation of the trajectory of quality of life in patients with early dementia are very important as foreign literature points out at the fact that the quality of life in older adults has not been researched enough; especially from a long-term perspective (Clare, Woods et al., 2014; Vogel et al., 2012). Even though in the past Selwood et al. (2005) recommended watching the changes in the quality of life in people with early dementia in the long run and in bigger groups of respondents, the quality of life in these people was usually observed in connection to the relatively limited number of factors, in a short-term perspective, and in smaller groups of patients (St John, Montgomery, 2010; Bowling et al., 2015). Therefore, research has recently started to focus on the trajectory of self-rating of the quality of life and on the factors that affect it in older patients with dementia and to compare it with the quality of life in older adults without any impairment of the cognitive functions (Goyal et al., 2018; van de Beek et al., 2019; Joanovič et al., 2019; Kožený et al., 2019).

Factors directly affecting the assessment of quality of life of older adults in the early stage of dementia include the level of *functional ability and self-sufficiency in the activities of daily living* (ADL). Worsening in the cognitive functions in older adults leads to a progressive loss of their self-sufficiency in ADL and in the ability to get involved in social activities. All this then negatively influences the older adult's quality of life (Giebel et al., 2015; Barbe et al., 2017). A significant factor connected with age is *physical fitness*, as the geriatric frailty lowers the ability of the individual's organism to react to stressors and therefore affects their quality of life.

For this reason, the correlation between the frailty and the cognitive impairment is studied at present (Robertson et al., 2013). Another factor is the *chronic pain* (Tan et al., 2014; 2016). In patients with dementia, pain often causes discomfort and distress (Herr, 2011; Scherder et al., 2009), which consequently influences their self-rating of the quality of life (Corbett et al., 2012; Cordner et al., 2010).

One of the significant psychological factors is the *attitude to ageing* (Trigg et al., 2012). Ageist attitudes lead to the worsening of the quality of life, to the limited access to medical or rehabilitation services, and also to frequent indecent treatment of older adults with dementia (ADI, 2019). In older people with mild cognitive impairment and in early dementia stages the quality of life is also significantly affected by the *fear of falling* (Akosile et al., 2014; Uemura et al., 2014). Other factors include the *depression*, which often occurs in older people and is considered to be a variable with a significant effect on the quality of life in patients with dementia (Selwood et al., 2005, Banerjee et al., 2009; Gómez-Gallego et al., 2012b).

Social and interpersonal characteristics of an individual represent another factor with an important role in the subjective perception of the quality of life (Burgener, Twigg, 2002; Fukushima et al., 2005). This area includes a deteriorated ability to communicate which secondarily deepens the *limitation of social participation* in patients in the early dementia stage which is then negatively reflected in the subjectively perceived quality of their lives (Moyle et al., 2011a; Burgener et al., 2015). These factors affecting the quality of life often occur not only in patients with dementia but also in people without a cognitive deficit (Gobbens, Van Assen, 2014). However, the older adult's dignity has not been included among the variables in examining the quality of life of older people with dementia and its changes in a long-term perspective. Yet, the results of several studies show that even the *dignity* can affect the quality of life (Tranvag et al., 2015; Tranvag et al., 2016).

Therefore, the aim of the longitudinal prospective study called "Trajectory of Quality of Life in Older Adults in Early Stage of Dementia" was to determine how older people in the early dementia stage asses their quality of life and what factors affect it. Later on, the results in the patients with dementia were compared with a comparative sample of older adults without any cognitive deficit and predictors were defined of the changes of the quality of life within two years (Kisvetrová et al., 2020).

4.2 Sample and methodology

The research sample of the multicentre study consisted of two groups of older adults. One contained people who were diagnosed with dementia and the other were individuals without dementia.

The first group (patient group) included patients in the early stage of dementia who complied with the inclusion criteria below:

① Is 60 years old or over;

② Lives in one's own social environment;

③ Has been diagnosed in recent 12 months with any dementia type at its early stage (diagnosed by MKN-10 (2020): F00, F01–F03; MMSE score of 20–25 points);

④ Is in touch with a family caregiver at least once a week;

⑤ Has signed an informed consent for the participation in the study.

The researchers engaged in the study addressed patients and their family caregivers via neurological and geriatric clinics where the patients with dementia were treated.

The other (control) group consisted of older adults without dementia who complied with the inclusion criteria below:

① Is 60 years old or over;

② Lives in one's own social environment;

③ Has not been diagnosed with any dementia type (MMSE score of 26–30 points).

These older adults were addressed by the research team via adult general practitioners' offices.

Exclusion criteria for both the groups of respondents were:

① Permanent institutional care (old people's home);

② Complete immobility;

③ Serious mental disease (bipolar disorder, schizophrenia);

④ Terminal stage of an oncological or non-oncological disease.

The sample size calculation was based on the expected difference of 0.5 point in the QOL-AD tests (quality of life) within 24 months between the patients with dementia and the respondents without dementia (control group), $\alpha = 0.05$ (two-tailed) and $\beta = 0.8$. Supposing that 30% respondents do not complete the study, it was necessary to screen at least 290 respondents for every group.

Realisation of the research

The study was approved by the Ethical boards of the institutions involved in the realisation of the research (Faculty of Health Sciences at Palacký University Olomouc, University Hospital Hradec Králové, University Hospital Ostrava) and before the first patient was involved in the study, it was registered at: www.clinicaltrials.gov (Identified: NCT02845830).

The research was conducted in three regions of the Czech Republic (Olomouc, Ostrava, and Hradec Králové) in 2016–2019. To conduct the research, we used a prospective longitudinal design. The research consisted of three phases of measurements in which the older people completed a set of questionnaires either by themselves or in structured interviews with the researchers – first when they were involved in the study, then 12 months later and 24 months later. All respondents signed an informed consent for the participation in the study and were examined by a medical doctor (general practitioner, neurologist or geriatrist) upon the entry into the study. The doctors performed a basic examination of the vision and hearing and recorded the socio-demographic characteristics of the respondents (age, sex, education, social situation [who the respondent lives with], frequency of involvement in social activities, visits and telephone contacts with friends/relatives, and time spent alone during the day).

The questionnaire battery consisted of a set of Czech versions of the standardised tools to assess the quality of life (Quality of Life-Alzheimer's Disease; QOL-AD), depression (Geriatric Depression Scale; GDS-15), dignity (Patient Dignity Inventory; PDI-CZ), attitudes to ageing (Attitude to Ageing Questionnaire; AAQ), fear of falling (Falls Efficacy Scale International; FES-I), physical fitness (Short Physical Performance Battery; SPPB), self-sufficiency in ADL (Bristol Activities of Daily Living Scale; BADLS-CZ), and pain (Horizontal Visual Analogue Scale; HVAS).

Statistical data processing

The sample of respondents was described with absolute and relative frequencies (mean, standard deviation [SD], and median). Comparing the two respondent groups (patients diagnosed with dementia and individuals without dementia) in quantitative traits was done by a *t*-test for independent samples. The comparison of quantitative values of the first (entry) and third (24 months later) measurement was done by a pair *t*-test. In qualitative values the groups were compared by a *chi*-square test. All the tests were performed on the level of statistical significance of 0.05. Stepwise multivariable linear regression was used to find significant predictors of the quality of life. The following variables were included into the model as independent predictors: age, sex, education, social conditions (lives alone – lives with another person), social activities (social events, visits, telephone contact, time spent alone), hearing and vision impairment, cognition, pain, physical fitness, self-sufficiency in ADL, depression, fear of falling, attitudes to ageing, and dignity. Normality was checked by Shapiro-Wilk test. The independence of residuals was verified by Durbin-Watson test where values close to 2 show the absence of autocorrelation. Multicollinearity was checked with the VIF (variance inflation factor) where VIF > 10 indicates the potential multicollinearity among dependent variables. Data from this study complied with the presumptions of multivariable linear regression. The model quality was evaluated with the coefficient of determination R^2 and adjusted R^2. The statistical processing was performed on statistical software IBM SPSS Statistics for Windows, Version 23.0 (IBM Corp., Armonk, NY, USA).

4.3 Results

In the first phase of the multicentre longitudinal study, 623 respondents were screened and included into the study. Out of those, 294 were patients who had a diagnosis of any dementia type in its early stage (average age of 79.6 ± 7.5 years; 109 [37.1%] of them were male; MMSE score = 22.7 ± 1.7 points) and 329 respondents without dementia (average age 72.7 ± 7.0 years; 99 [30.1%] of them were male; MMSE score = 29.2 ± 1.3 points).

Patients diagnosed with dementia in the early stage were significantly older ($p < 0.001$), they had lower education ($p = 0.004$), participated less in social activities ($p = 0.036$), had a lower frequency of telephone contacts with friends and family members ($p = 0.002$), spent more time alone ($p < 0.001$), and had more occurrence of hearing impairment ($p = 0.026$) and vision impairment ($p < 0,001$). A complete overview of the sociodemographic characteristics of all the respondents participating in the study is shown in Table 18.

Factors affecting the quality of life

Patients diagnosed with dementia differed a lot from the control group (consisting of older adults without dementia). The factors that affected the quality of life were identified in the first phase of the study.

The results showed that *depression* was the only common factor affecting the quality of life both in the patients with dementia ($p < 0.0001$)

Table 18 Demographic and clinical characteristics of the sample

		Patients with dementia (n = 294)	Patients without dementia (n = 329)	Statistical significance *p*
		Average (SD) / number (%)	Average (SD) / number (%)	
demographic characteristics				
age		79.6 (7.5)	72.7 (7.0)	< 0.0001
sex	male	109 (37.1)	99 (30.1)	0.074
	female	185 (62.9)	230 (69.9)	
education	elementary	71 (24.1)	44 (13.4)	0.004
	vocational	97 (33.0)	114 (34.7)	
	secondary	100 (34.0)	143 (43.5)	
	tertiary	26 (8.8)	28 (8.5)	
social involvement				
living	alone	104 (35.4)	103 (31.3)	0.307
	with a partner/ relative	190 (64.6)	226 (68.7)	
taking part in social events	≥ 30 days ago	101 (34.4)	87 (26.4)	0.036
	< 30 days ago	193 (65.6)	242 (73.6)	
visiting family/friends	> 7 days ago	60 (20.4)	50 (15.2)	0.093
	≤ 7 days ago	234 (79.6)	279 (84.8)	
contact with family/friends (phone, e-mail)	> 3 days ago	127 (43.2)	101 (30.7)	0.002
	≤ 3 days ago	167 (56.8)	228 (69.3)	
time spent alone daily	≥ 8 hours	88 (29.9)	59 (17.9)	0.0005
	< 8 hours	206 (70.1)	270 (82.1)	
clinical characteristics				
hearing impairment	none/minimal	254 (86.4)	303 (92.1)	0.026
	middle/serious	40 (13.6)	26 (7.9)	
vision impairment	none/minimal	244 (83.0)	311 (94.5)	< 0.0001
	middle/serious	50 (17.0)	18 (5.5)	

SD = standard deviation

and in the respondents without dementia ($p < 0.001$). This result is in compliance with the past findings which confirm that the seriousness of depression negatively affects the quality of life (Gómez-Gallego et al., 2012b). In order to improve the quality of life in older patients, the early diagnosis and depression treatment are key clinical priorities both in the area of primary medical care and in the community nursing care provided to older people in their own social environment.

It was proven in the entry assessment (first research phase) that *dignity* is one of the factors that affect the quality of life in patients in the early stage of dementia. A higher quality of life was in older adults with dementia who self-rated their dignity in a more positive way ($p < 0.0001$). Dignity is a multidimensional construct that includes perception, cognition, and emotions related both to the feeling of self-esteem and self-respect and to the respect and esteem that others show to the individual. Patients in the early stage of dementia do acknowledge their own deterioration of cognitive abilities and they often consider this to be a stigma lowering their self-esteem (Burgener et al., 2015) and consequently the personal dignity that is negatively reflected in the assessment of their quality of life. Up to now, other studies have not presented a proof that the dignity is a significant factor affecting the quality of life in older patients with dementia living at home.

Another factor was the *attitude to ageing*. A more positive attitude to ageing was connected with the patients' better quality of life ($p = 0.011$). Older people in the early stage of dementia often connect the negative attitude to ageing with the realisation of their gradual decrease in cognitive abilities (Siebert et al., 2018) which then significantly decreases their quality of life. The study findings also indicate that the quality of life among patients with dementia was affected by the *degree of self-sufficiency in ADL.* Patients with dementia who demonstrated a higher degree of self-sufficiency assessed their own quality of life better ($p < 0.0001$). This finding is in compliance with other authors' results (Ydstebø et al., 2018; Conde-Sala et al., 2016).

The other (control) group of the research sample consisted of patients without dementia in whom the better quality of life was connected with a lower degree of depression ($p < 0.001$), lower fear of falling ($p < 0.001$), lower intensity of pain ($p = 0.009$), female sex ($p = 0.004$), higher frequency of participation in social events ($p = 0.004$), and a more frequent telephone contact with family and friends ($p = 0.019$). An overview of the individual factors affecting the quality of life in patients with and without dementia is presented in Table 19.

As the study results have shown, the *fear of falling* has proven to be a factor affecting the quality of life only in older adults without dementia. This can be due to the fact that individuals with cognitive impairment do not always have to be able to acknowledge the deterioration of their physical fitness and the risk of falling related to it. Therefore, their fear of falling is manifested less. Cognitive impairment especially in the area of executive functions can therefore be connected with the absence of fear of falling (Shirooka et al., 2017; Uemura et al., 2012; Uemura et al., 2014). De Borges et al. (2015) confirm similar results in older patients with Alzheimer's disease. Other authors relate the absence of fear of falling in people with cognitive impairment to anosognosia which can be described as the patient's lack of awareness about one's own deterioration of the physical or mental state (Starkstein et al., 2006; Lin et al., 2010).

The fact that the correlation between the *intensity of pain* and the quality of life has proven only in patients without dementia can be a consequence of a worse ability of the patients with dementia to assess their own pain. The deficit in the ability to assess the present state and the intensity of pain is often connected with impaired communication or with deteriorated short-term memory (Jensen-Dahm et al., 2015).

Social inclusion (frequency of participating in social events and telephone contacts with family and friends) affected the quality of life only in the patients without dementia. These findings are in compliance with the results of an earlier study which also states that the decrease in the quality of life in older people relates to the low frequency of social relationships (de Belvis et al., 2008).

Changes in the assessment in the course of 24 months

The measurement results in the individual phases of the project in patients with and without dementia are shown in Table 20. A two-sample *t*-test showed that patients with and without dementia significantly differed in all the examined areas. In all the three measurements, respondents with dementia had lower average values (i. e. worse assessment) in the scales assessing cognition (MMSE), pain (HVAS), physical fitness (SPPB), attitude to ageing (AAQ), quality of life (QOL-AD), and the degree of self-sufficiency (BADL-CZ). On the other hand, they had significantly higher values (i. e. worse assessment) in scales measuring depression (GDS-15), fear of falling (FES-I), and dignity (PDI-CZ).

Comparison of results of the first (entry) and third (24 months later) measurement showed that both the patients diagnosed with dementia and patients without dementia experienced a significant deterioration in the level of cognition, physical fitness, and degree of self-sufficiency (in all cases $p < 0.0001$). Respondents also experienced an increase in the fear of falling ($p = 0.002$ in patients with dementia and $p < 0.0001$ in patients without dementia). In patients with dementia there was also a decrease in the quality of life ($p < 0.0001$) and in the assessment of the intensity of pains ($p = 0.022$). Patients without dementia showed a significant deterioration of the attitude to ageing ($p = 0.0001$) and the assessment of dignity ($p = 0.006$). An overview comparing all the results is shown in Table 21.

Predictors of the change in the assessment of the quality of life

Twenty-four months after the beginning of the study, the quality of life worsened only in patients with dementia (see Table 21). For that reason, we were looking for predictors that affected the dimensions of the change in the assessment of quality of life in these patients. In the model of multidimensional linear regression, dependent valuables were represented by the difference between the values of the QOL-AD score in the first (entry) and third (24 months later) measurement. The dimensions of the change in the quality of life (i. e. the difference between the first and the third measurement) in patients with dementia were affected by *age*. Men manifested a greater deterioration of the quality of life (average QOL-AD score = 2.8) than did women (average QOL-AD score = 1.8). Another predictor was the *time spent alone daily*. Patients who spent alone fewer than 8 hours reported a greater worsening of the quality of life (average values = 2.6 hours vs. 1.1 hours). Another predictor affecting the change in the quality of life in patients with dementia was the *social situation* (i. e. who the respondent permanently resides with). Patients who lived alone reported a greater worsening of the quality of life (average score values = 3.2 vs. 1.7). Also the *frequency of visiting family or friends* was a significant predictor affecting the change in the quality of life. Patients who had a lower frequency of visits had a greater worsening of the quality of life (average values = 3.5 vs. 1.9; $p = 0.039$). Social relationships and social activities constitute the main source of the subjective personal well-being which is composed of both the positive evaluation of the current situation and the balance of positive and negative emotions in patients with dementia (de Belvis et al., 2008). Also Verloo et al. (2018) state that more frequent visits of friends and family have a positive effect on the quality of life in patients with dementia. As opposed to our study, Ydstebø et al. (2018) confirmed just a minor decrease of quality of life in patients with dementia 18 months later. The difference can be explained by a higher heterogeneousness of their research sample in terms of age, cognitive and functional limitation in comparison to the respondents in our study. As the quality of life has a highly subjective nature, it is also possible that the generally positive or generally negative perception of life by some individuals might have had a stronger influence on the assessment of quality of life than that of dementia.

Other predictors were the *total scores of the first measurement by QOL-AD and BADLS-CZ*. Patients with dementia who had a higher quality of life in the first measurement (a higher QOL-AD score) showed a greater change 24 months later, i. e. their quality of life deteriorated more ($p < 0.0001$). A higher degree of self-sufficiency (BADLS-CZ) in the entry measurement correlated with a smaller change in the quality of life ($p = 0.011$).

The list of all predictors of the change of life quality in respondents with dementia is shown in Table 22.

Table 19 Factors affecting the quality of life in patients with and without dementia

Factor	Respondents with dementia		Respondents without dementia	
	beta (95% CI)	p	beta (95% CI)	p
sex (male vs female)			1.254 (0.405; 2.104)	0.004
social activity (≥ 30 days ago vs more often)			1.335 (0.426; 2.244)	0.004
contact with family/friends (phone, e-mail: > 3 days ago vs more often)			1.019 (0.165; 1.872)	0.019
pain (HVAS)			−0.251 (−0.441; −0.062)	0.009
fear of falling (FES-I)			−0.106 (−0.161; −0.050)	0.0002
depression (GDS-15)	−0.299 (−0.419; −0.179)	< 0.0001	−0.664 (−0.821; −0.506)	< 0.0001
dignity (PDI-CZ)	−0.05 (−0.139; −0.071)	< 0.0001		
self-sufficiency (BADLS-CZ [%])	0.085 (0.063; 0.107)	< 0.0001		
attitude to ageing (AAQ score)	0.066 (0.015; 0.117)	0.011		
fit model (R2/R2 adj)	0.557/0.551		0.434/0.423	
Durbin-Watson test/VIF	2.147/1.539		1.948/1.223	

GDS-15 = Geriatric Depression Scale; PDI-CZ = Patient Dignity Inventory; BADLS-CZ = Bristol Activities of Daily Living Scale; AAQ = Attitude to Ageing Questionnaire; FES-I = Falls Efficacy Scale – International; HVAS = Horizontal Visual Analogue Scale; VIF = variance inflation factor; CI = confidence interval.

Table 20 Results of individual measurements in patients with and without dementia

	Respondents with dementia			Respondents without dementia			$p^{1,2,3}$
	Initial (n = 294)	12 months later (n = 209)	24 months later (n = 157)	Initial (n = 329)	12 months later (n = 297)	24 months later (n = 277)	
	M ± SD (median)	M ± SD (median)	M ± SD (median)	M ± SD (median)	M ± SD (median)	M ± SD (median)	
quality of life (QOL-AD)	35.85 ± 4.81 (36)	34.99 ± 5.69 (36)	33.87 ± 5.84 (35)	40.24 ± 4.65 (40)	40.20 ± 3.85 (40)	40.03 ± 4.46 (40)	$< 0.0001^{1-3}$
cognition (MMSE)	22.69 ± 1.70 (23)	21.32 ± 3.40 (22)	19.95 ± 4.74 (21)	29.19 ± 1.30 (30)	29.02 ± 1.42 (30)	28.57 ± 1.64 (29)	$< 0.0001^{1-3}$
physical fitness (SPPB)	5.98 ± 3.88 (7)	5.67 ± 4.09 (6)	5.11 ± 3.93 (6)	10.53 ± 2.44 (12)	10.21 ± 2.20 (11)	9.85 ± 2.22 (10)	$< 0.0001^{1-3}$
pain (HVAS)	2.14 ± 2.67 (1)	1.69 ± 2.40 (0)	1.75 ± 2.41 (1)	2.85 ± 2.36 (2)	2.66 ± 2.21 (2)	2.74 ± 2.22 (2)	0.0005^{1} $< 0.0001^{2-3}$
depression (GDS-15)	5.21 ± 4.09 (4)	5.52 ± 4.21 (4)	5.61 ± 4.31 (4)	2.80 ± 2.81 (2)	2.72 ± 2.72 (2)	2.66 ± 2.75 (2)	$< 0.0001^{1-3}$
self-sufficiency (BADLS-CZ; %)	76.42 ± 19.21 (82)	69.99 ± 23.20 (74)	66.22 ± 27.39 (72)	96.81 ± 6.02 (98)	96.79 ± 5.36 (98)	95.76 ± 8.16 (98)	$< 0.0001^{1-3}$
fear of falling (FES-I)	31.98 ± 14.89 (27)	33.15 ± 15.56 (30)	32.76 ± 14.81 (31)	23.15 ± 8.41 (21)	23.77 ± 8.36 (21)	24.29 ± 8.95 (21)	$< 0.0001^{1-3}$
dignity (PDI-CZ)	42.65 ± 15.74 (39)	44.99 ± 18.43 (39)	43.85 ± 18.00 (36)	34.93 ± 12.17 (31)	36.48 ± 14.51 (32)	36.10 ± 13.75 (31)	$< 0.0001^{1-3}$
attitude to ageing (AAQ)	66.81 ± 7.42 (67)	66.93 ± 7.74 (67)	66.50 ± 8.49 (68)	69.50 ± 8.13 (70)	69.44 ± 8.22 (70)	71.47 ± 6.66 (72)	$< 0.0001^{1,3}$ 0.0006^{2}

QOL-AD = Quality of Life–Alzheimer's Disease; MMSE = Mini-Mental State Exam; GDS-15 = Geriatric Depression Scale; PDI-CZ = Patient Dignity Inventory; BADLS-CZ = Bristol Activities of Daily Living Scale; SPPB = Short Physical Performance Battery; AAQ = Attitude to Ageing Questionnaire; FES-I = Falls Efficacy Scale – International; HVAS = Horizontal Visual Analogue Scale; M = mean; SD = standard deviation.

Difference (*p*) between the patients with and without dementia: p^1 – first measurement (initial); p^2 – second measurement (12 months later); p^3 – third measurement (24 months later).

Table 21 Comparison of the first and third measurement in patients with and without dementia

	Respondents with dementia (n = 157) M ± SD			Respondents without dementia (n = 277) M ± SD		
	initial	**24 months later**	***p***	**initial**	**24 months later**	***p***
cognition (MMSE)	22.97 ±1.70	19.95 ± 4.74	<0.0001	29.23 ± 1.26	28.57 ± 1.64	< 0.0001
pain (HVAS)	2.26 ± 2.73	1.75 ± 2.41	0.022	2.71 ± 2.24	2.74 ± 2.22	0.812
depression (GDS-15)	5.17 ± 4.12	5.61 ± 4.31	0.058	2.75 ± 2.86	2.66 ± 2.75	0.535
physical fitness (SPPB)	6.52 ± 3.74	5.11 ± 3.93	<0.0001	10.76 ± 2.12	9.85 ± 2.22	< 0.0001
fear of falling (FES-I)	29.78 ± 14.19	32.76 ± 14.81	0.0002	9.85 ± 2.22	24.29 ± 8.95	< 0.0001
attitude to ageing (AAQ)	66.28 ± 7.38	66.50 ± 8.49	0.716	69.33 ± 7.94	71.47 ± 6.66	0.0001
quality of life (QOL-AD)	36.05 ± 4.66	33.87 ± 5.84	<0.0001	40.43 ± 4.68	40.03 ± 4.46	0.135
self-sufficiency (BADLS-CZ [%])	79.09 ± 18.34	66.22 ± 27.39	<0.0001	97.12 ± 5.47	95.76 ± 8.16	< 0.0001
dignity (PDI-CZ)	42.51 ± 15.79	43.85 ± 18.00	0.193	34.42 ± 11.73	36.10 ± 13.75	0.006

QOL-AD = Quality of Life–Alzheimer's Disease; MMSE = Mini-Mental State Exam; GDS = Geriatric Depression Scale; PDI-CZ = Patient Dignity Inventory; BADLS-CZ = Bristol Activities of Daily Living Scale; SPPB = Short Physical Performance Battery; AAQ = Attitude to Ageing Questionnaire; FES-I = Falls Efficacy Scale – International; HVAS = Horizontal Visual Analogue Scale; M = mean; SD = standard deviation

Table 22 Predictors of a change (deterioration) in quality of life in patients with dementia

Predictor	Beta (95% CI)	*p*
sex (male vs female)	−1.606 (−0.246; −2.966)	0.021
living alone vs with a partner/other people	−2.907 (−1.296; −4.519)	0.0005
time spent alone daily (≥ 8 hours vs less)	2.808 (4.392; 1.225)	0.001
visiting family/friends (≥ 7 days ago vs less)	−1.750 (−0.093; −3.408)	0.039
quality of life (QOL-AD score)	0.349 (0.515; 0.184)	< 0.0001
self-sufficiency (BADLS-CZ [%])	−0.056 (−0.013; −0.100)	0.011
model quality (R^2/R^2 adj)	0.224/0.193	
model presumptions (Durbin-Watson test/VIF)	1.844/1.331	

QOL-AD = Quality of Life-Alzheimer’s Disease; BADLS-CZ = Bristol Activities of Daily Living Scale; VIF = variance inflation factor; CI = confidence interval

Conclusion

Current demographic trends leading to the ageing of population affect also the continuing increase in older adults suffering from dementia. The quality of life in these patients and their changes in the individual dementia stages therefore present a challenge that must be researched. However, observing the quality of life in people with dementia in the long run has been a rather rare topic in Czech studies as compared to several foreign studies dealing with this topic.

The results of the first Czech longitudinal multicentre study focusing on the trajectory of quality of life in older adults in the early stage of dementia and its comparison to the control group of older people without any cognitive deficit have shown that patients with dementia evaluated their quality of life as significantly worse than did the individuals without dementia. The set of factors which have influenced the quality of life only in older adults with dementia included dignity, attitude to ageing, and the degree of self-sufficiency in ADL. Depression was then identified as a factor affecting the quality of life in older adults both with and without dementia. It has also been confirmed that the quality of life deteriorated within the two years only in the patients with dementia. The predictors of this change included being male, living without a partner, high number of hours spent alone daily, lower frequency of visiting family or friends, and a higher quality of life (QOL-AD score) and higher self-sufficiency (BADLS-CZ score) in the initial measurement.

The results therefore demonstrate that relationships and social involvement are crucial for the preservation of the quality of life in older people in the early stage of dementia who are living at home. These findings can be useful when planning medical and social strategies which should concentrate more on the intervention of social support to older adults with dementia in home care. The study results can also serve as a basic source of information for a subsequent longitudinal research specifically dealing with the quality of life in older adults with dementia receiving permanent institutional care in the Czech Republic.

Summary

The first chapter of this publication deals with the terminological definitions of dementia, the basic classification according to its causes and the individual stages of dementia. In addition, it introduces risk factors for the development of dementia and the most popular screening tools for assessing cognitive functions. The second chapter focuses on the quality of life, its definition and evaluation for people with dementia. The third chapter describes the basic determinants of the quality of life, which include demographic characteristics and health factors, as well as psychological, emotional, social, and relationship factors. Individual factors related to the basic determinants of the quality of life were used as variables in a longitudinal multicentre prospective study examining the trajectory of quality of life in older adults in the early stage of dementia (Czech Health Research Council; grant no. 16-28628A). Its implementation and results are described in the fourth and final chapter of the publication. The study involved 623 respondents, of whom 294 were diagnosed with early-stage dementia. The results showed that depression was the only common factor that influenced the quality of life in both the patients with and without dementia at baseline (first phase of the project). Among patients with dementia, better quality of life was associated with a lower incidence of depressive symptoms, as well as a more positive assessment of their dignity. It has been confirmed that dignity is one of the factors affecting the quality of life among people with dementia. Positive attitudes to ageing and a higher degree of self-sufficiency in ADL were other factors associated with a higher assessment of the quality of life among older adults with dementia. Older adults without dementia had a better quality of life associated with lower fear of falling, less pain, being a female, more frequent partaking in social events, and a higher frequency of phone contacts with relatives and friends. The quality of life within two years only significantly deteriorated among older adults with dementia. The degree of this deterioration was influenced by interactions with being a male, social contacts (daily time spent alone, life without a partner, and frequency of visits), and the level of quality of life plus the degree of self-sufficiency at baseline determined in the first phase of the study. The results of the study thus confirm the fundamental impact of social contacts on maintaining the quality of life among older adults with dementia.

Keywords: quality of life; dementia; older adult; trajectory; depression; dignity; attitude to ageing; social involvement; self-sufficiency

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