



**SELINUS UNIVERSITY**  
OF SCIENCES AND LITERATURE

**PSYCHOLOGICAL DISTRESS OF DEMENTIA  
CAREGIVERS RESIDING IN RUSSIA AND  
KAZAKHSTAN**

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**A DISSERTATION**

Presented to the Department of Clinical Psychology Program  
at Selinus University

Psychology in fulfillment of the requirements for the degree of  
**Doctor of Philosophy in Clinical Psychology**

2020

## **DECLARATION**

I do hereby attest that I am the sole author of this thesis and that its contents are only the result of the readings and research I have done.

*Telzhan.* Venera Telzhan.



## ACKNOWLEDGEMENT

The first word I would like to sincerely thank Selinus University and the Doctor Salvatore Fava who directed me to implement the topic. He has been dedicated to helping me navigate research, gain knowledge, give me valuable advice and suggestions so that I can complete my research.

I would like to thank the faculty of the Clinical Psychology, for guiding and supporting with rich library for my research.

Besides, I would like to thank my close friends for wholeheartedly helping and encouraging me during the past time.

I also thank my colleagues and volunteers from Russia and Kazakhstan for directly and indirectly assisting me in participating in group discussion research, helping to answer and collecting survey questionnaires for this thesis. Your contribution is important to the success of your research.

I am really thankful to all Doctors, Professionals and Clinical specialists for always being supportive and for guiding every time and being with me in my research.

I am also grateful to the clinic “Talmas Medicus” of Professor Doshyanova A.M, Nursultan city, where I had a chance to work with my qualified doctors.

And I want to thank from my soul and heart my dear husband for being supportive in my research and being kind for all my life from the day we met.

Finally, my deep gratitude to my Parents and family members who have always encouraged and supported me to complete my thesis.

I would like to dedicate this thesis to my mother, who was always with me, wherever I was, always inspired and encouraged me. I love You, Mother!!!

### Abstract

The present work addresses the question of psychological distress of the caregivers of patients with dementia. The research covers the caregivers residing in Russia and Kazakhstan. The thesis starts with concluding the pre-existing knowledge on the research question, from which, the author develops the methods for collection of the primary data. Methodology of the research is designed to analyze the data in a qualitative approach. The results of the analysis are presented with links to the transcript of the survey answers given in the appendices. The results allow the author to conclude that from moderate to severe levels of psychological distress are experienced by Russian and Kazakhstani caregivers due to number of reasons including insufficient funding and informational support.

*Keywords:* psychological distress, dementia, caregiver, caregiver burden,

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### Psychological distress of dementia patient caregivers residing in Russia and Kazakhstan

The present thesis focuses on studying the psychological distress among the people who take care of patients with dementia. Dementia is one of the problems that have not been solved by the healthcare organizations, scientists and states. According to a fact sheet provided by the World Health Organization (further WHO), dementia is a chronic syndrome often with rapid deterioration pace that affects the cognitive abilities of a person due to a disease, ageing, stroke or other factors ("Dementia", 2021). Patients suffering from dementia may have a various level of impairment of cognitive function. Areas of cognition such as “memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement” can be damaged ("Dementia", 2021, para 2). In addition, patients may experience degradation of emotional state, worsened behaviour, and lack of motivation.

As the number of patients with Alzheimer’s disease and other diseases that lead to dementia is steadily rising. In fact, according to the information provided by WHO, there are around fifty million people with dementia worldwide, and this figure rises by 20% each year ("Priority setting for research on mental Health", 2021). Almost every 20th person aged 60 and more add to the list of the dementia patients. What is even more dispiriting, this number is about to increase by 36% by 2030 and by 153% by 2050. This means that in 10 years, there will be at least 80 million caregivers.

It is clear that caregivers and people living with a patient with dementia in one household suffers from a combination of stressful emotions. In addition to that, taking care of such patient requires high finance and time contribution. Moreover, as dementia patients need continuous support, the social lives of caregivers and family members are restricted as well.

With the rising number of dementia patients the number of people suffering from stress associated with the following causes will rise as well. Thus, the society will face a problem of maintaining the mental health of the named contingent. In order to prevent worsening of the situation and in order to develop efficient measures for treating stress of dementia caregivers, sufficient research needs to be conducted. Moreover, according to WHO, a greater proportions of such patients live in countries with middle or low household incomes ("Priority setting for research on mental Health", 2021). This means that caregivers are not provided with needed material and psychological support. All of this signifies of the high importance of studying dementia caregiver's psychological stress.

The present dissertation aims to study psychological stress related to giving care to dementia patients and the ways these people cope with this stress. In other words, feelings of caregivers, triggers for stressful situations, general awareness of caregiver mental health, availability of organizations for stress-relief, and many other details affecting the extent of psychological stress will be studied. To fulfil the aim of the thesis, the author will conduct an survey of acting dementia caregivers in order to analyse their perception on the research topic. In order to do that, the basis for the research needs to be built. For this purpose, the study will be conducted based on systematically reviewing the existing literature. Studying the literature on the relevant topic will help to build the research on existing up-to-date knowledge. Thus, a thorough analysis of theoretical and practical aspects of the research subject will be conducted. Correspondingly, the following part will present an overview of the literature review.



### **Literature review**

Numerous scientists have studied dementia disease: emergence, symptoms, preventive measures and treatment. As the number of patients rose, the caregivers became focus of studies as well. It is evident that taking care of a patient with Alzheimer's is challenging and costly. Moreover, these patients need constant care, devotion and considerable physical effort to provide basic hygienic treatment.

#### Definition of dementia and symptomatology of disease

For the purpose of the research, it is important to examine the theoretical perspective of the disease and define how the knowledge of dementia has evolved. To begin with, according to Bukhanovsky, Kutuyavin and Litvak (2000), the disease can be acquired as a result of a combination of factors or one factor at a time. These factors are personal disorder or intellectual negative disorder. The authors define three classification groups of mental disorders based on severity of the personal or intellectual disorder. Three groups of acquired mental defect are the following three:

- Personal disorders such as mental activity depletion, changes in a person's attitude towards his own "Self" and other objectively determined changes in personality are included in the first group. These can be generally described as defects in personality and self-determination.
- The patients in the second group are those who suffer from deep personality defects, which came along with signs of intellectual insufficiency such as a personality disharmony, deteriorated energy potential, worsened personality level, and regression of the personality).

- The patients are classified into the third group, if they have severe mental defects with significant decline in intellectual and cognitive abilities such as amnesic disorders and dementia (Bukhanovsky, Kutuyavin and Litvak, 2000).

Thus, authors summarize that dementia is on top of the mental disorders' classification, and, it signifies of low intellectual ability of the patient. The term dementia is initially constructed from Latin words such as "de" and "mentis", where the first means termination and the latter translates as a mind or cognition. Thus, it has a meaning of partial or total destruction of the person's cognition, intellect and sense of self, which can be caused by a number of external and internal brain damage factors. Majority of dementia cases are accompanied by other symptoms such as loss of memory, misuse of lexical units, lower quality of speech, poor judgment, worsened cognitive abilities deterioration of spatial orientation and motor skills. Mendelevich (2001) states that dementia cannot be reversed. However, there is a possibility of preventing the disease by eliminating the factors causing it. According to the author, the organic mental disorder is based on more or less common lesions of cortical functions. The latter can be diagnosed using various diagnostic equipment such as neurological and electroencephalographic studies, computer tomography and magnetic resonance imaging (Mendelevich, 2001).

The main sign of dementia is the progressive deterioration of intellectual functions, observed most often after the completion of brain maturation (in people over 15 years old). At the very beginning of the disease, a person responds vividly and adequately to environmental events. In the early stages of the disease, the functioning of episodic (memory for events), but not necessarily semantic (language and concepts) memory, is usually disrupted; the memory of recent events is particularly suffering. Patients suffering from dementia show a progressive deterioration in abstract thinking, acquisition of new knowledge and skills, visual-spatial

perception, motor control, problem solving and the formation of judgments. This deterioration takes place along with personal impairment and loss of motivation. Usually, dementia takes place along with violations of emotional control, moral and ethical susceptibility. For instance, the person may have unacceptable and demeaning sexual claims (Mendelevich, 2001)

#### Aetiology of dementia

It is clear that the triggers of dementia are very diverse and in some cases unexpected. These include degenerative processes that often, but not always, develop in older people. The cause may be repeated cerebrovascular disorders or strokes; some infectious diseases such as HIV, AIDS, syphilis, and meningitis; intracranial tumors and abscesses; a certain nutritional deficit; severe or multiple head injuries; anoxia (lack of oxygen); ingress of toxic substances into the body.

The most common cause of dementia is degenerative brain diseases, primarily Alzheimer's disease - 47.7% of cases, followed by vascular diseases, hydrocephalus and intracranial tumors - 10%, 6% and 4.8% of cases, respectively. HIV infection and AIDS can also lead to dementia (1% of all dementia cases). Schizophrenia, epilepsy, as well as organic brain diseases in which its substance is destroyed (senile psychoses, syphilitic lesions, vascular and inflammatory diseases of the brain, severe traumatic brain injuries) can also lead to dementia (Carson, Batcher, Mineka, 2004).

Dementia has certain features depending on the disease it is caused by. In some cases, the resulting mental defect still allows the patient to show a certain degree of critical position in relation to his condition, in others, such criticality and consciousness of the disease are absent.

#### Types of dementia

By the structure and depth of the intelligence lesion, dementia can be divided into lacunar, global and partial dementia:

1. Lacunar dementia - with this dementia, despite the formed intellectual and mnemonic defect, the moral and ethical properties of the personality are preserved. First of all, with lacunar dementia, memory and attention are affected. Memory disorders are manifested mainly by hypomneses, the degree of severity of which can increase. Reduced performance, increased fatigue, exhaustion and distraction of attention are observed. This type of disorder is characterized by unevenness of the involvement of mental processes, "flickering" of symptoms, sometimes manifesting for a rather short time. A number of properties of intelligence itself are preserved, primarily the criticality of thinking. This type of dementia is inherent in cerebral atherosclerosis, other vascular lesions of the brain, as well as nearby brain tumors.

2. Global (diffuse) dementia - we can talk about such dementia in cases where the personality sharply degrades, the consciousness of the disease is absent, criticism and reason are sharply reduced, and the moral properties of the personality are also reduced or completely lost. In this type of dementia, the most complex and differentiated properties of the intelligence itself are primarily affected. Typical is the violation of such qualities and properties of the mind as logic, proof, independence, curiosity, originality, resourcefulness, productivity, breadth and depth of thinking. The most reliable differential-diagnostic criterion for global dementia, allowing it to be distinguished from lacunar dementia, is the non-critical attitude of the patient to his defect. Global dementia is observed in the clinic of diffuse brain lesions (for example, senile dementia, progressive paralysis). In some progressive brain diseases, it develops after the stage of lacunar dementia.

Partial dementia is the result of damage to individual brain systems that indirectly relate to intellectual activity and play a role in its organization. This dementia can be observed, for example, in brain contusions, its tumors, as well as in encephalitis (Dmitrieva, 1999).

By the nature of the course, three types of dementia are distinguished - progredient, stationary and relatively regredient dementia:

1. Irreversibility and further growth of intellectual insufficiency, having a certain sequence, are obligatory for the progressive flow. First of all, creative thinking suffers, then - the ability to abstract reasoning, last of all, the impossibility of performing simple tasks within the framework of "practical" intelligence is noted.

2. With a stationary course, the lack of intelligence is stable. There are no signs of heaviness and progression of dementia.

3. In a number of diseases, there may be a relative regularity of dementia. This is due to the fact that violations of the prerequisites of intelligence and extra-intellectual processes are functional, reversible, and when they disappear, the impression of reducing the degree of dementia is created. However, this regression does not concern the intellectual disorders themselves, which are the result of organic destructive damage to the brain (Dmitrieva, 1999).

The following types of dementia are distinguished by severity:

1. Mild dementia - with this type of dementia, working and social activity are reduced, but the ability to live independently, self-care and relatively undisturbed judgments remains.

2. Moderate dementia is the main criteria: independent life is difficult, certain care and support are required.

3. Severe - since everyday activity and self-care are disrupted, constant supervision is required. Most patients are grossly upset with speech and judgment (Dmitrieva, 1999).

Isaev (2002) differentiates the dementia into total and partial dementia:

1. Total dementia deeply covers the whole psyche, including intelligence and memory, with it there is a sharp decrease or lack of criticism, slowing down mental processes, a general decrease in the patient's personality to a complete loss of individual features. In this type of dementia, there are diffuse lesions of the cerebral cortex.

2. Partial dementia is characterized by uneven loss of intellectual functions, slowing down intellectual processes, reduced intelligence, and the predominance of various memory disorders. The personality remains to a certain extent preserved, the criticism disorder is weaker, professional skills are preserved, emotional instability, tearful helplessness, and easily arising confusion are observed. In this type of dementia, there are focal lesions of the cerebral cortex.

Also in the literature there is a division of dementia into senile and presenile:

1. Senile dementia (senile dementia) is a mental disorder that accompanies brain degeneration and is most often found in old age (senile dementia, Alzheimer's disease). It begins with the manifestation of character traits previously unusual to the patient (for example, stinginess, cruelty), or uttering previously moderately expressed. Former interests are lost, passivity, emotional impoverishment appear, memory disorders (Korsakov syndrome, violation of information preservation) are growing.

2. Presenile dementia is a mental disorder associated with early brain degeneration (Alzheimer's disease, Peak disease, Huntington's disease). Presenile dementia differs from senile dementia not only in that it manifests itself at an earlier age, but also in behavioral features and changes in brain tissues.

3. An important exception in this classification is Alzheimer's disease, which is a typical and common senile disorder that in some people may begin at an earlier age. Alzheimer's disease

is associated with a characteristic dementia syndrome and is characterized by an inconspicuous onset, usually slow, but with progressive disorders (Carson, Batcher, Mineka S, 2004).

Karvasarsky (2004) also mentioned the distinguishing features of the intellectual impairment in presenile and senile dementia. Presenile dementias include diseases that manifest mainly in the prosthetic age and are characterized by a gradually occurring and occurring without stops and remissions (but also without exacerbations) weakening process. MKB-10 refers to presenile dementia dementia in Peak disease, dementia in Huntington's disease, and dementia in early onset Alzheimer's disease. The morphological substrate of presenile dementia is a primary atrophic process. However, etiopathogenetically and morphologically, the diseases of this group differ significantly - for example, atrophy at the early onset of Alzheimer's disease is different from that of Peak's disease.

Intellectual impairment in total dementia is another part of knowledge that is important to be discussed.

With total dementia, gross violations of higher and differentiated intellectual functions come to the fore: comprehension, adequate operation of concepts, ability to correct judgments and conclusions, generalization and classification. There is a slowdown in the pace of thinking. The focus of thinking persists, but it loses its previous depth and latitude, deplete and sparse the associative process.

Thus, thinking becomes unproductive. Defects in intelligence and its prerequisites are relatively uniform, although there are gross violations of criticality (decrease or absence of criticism), slowing down mental processes and pronounced changes in personal properties (sometimes until the complete loss of individual features) (Marilov, 2002).

The following types of total dementia are distinguished:

1. Simple dementia - its structure is entirely represented by negative disorders in the field of intellectual-mnestic functions in combination with signs of personality regression of various degrees of expression. The patient does not have a critical attitude to these disorders.

2. Psychopathic dementia - in its structure, pronounced personality changes occupy a significant place either in the form of an uttered sharpening of the premorbid personality of the patient, or in the form of the appearance of new abnormal (psychopathic) character traits developing in connection with the pathological process.

3. Hallucinator-paranoid dementia - with the above-described signs of intellectual disorder, hallucinations and delusions are combined, closely related to the features of destructive brain damage, its localization, structure and severity of negative symptoms.

4. Paralytic dementia - manifests itself in the rapid disappearance of criticism of his words and actions, in the pronounced weakness of judgments, ridiculous and alien to the personality of the patient, non-tactical statements. A gross intellectual defect is combined with euphoria, pronounced memory disorders and paralytic confabulations (false memories of ridiculous content - for example, the patient believes that he has a large number of orders and awards or untold wealth). The structure of paralytic dementia includes delusions and delusional statements with a reevaluation of one's own personality, which often achieve a degree of ridiculous delusions of greatness. . A typical feature of this dementia is the pronounced depletion of mental activity.

5. Asemic dementia - combines signs of dementia and symptoms of focal loss of cortical activity (aphasia, agnosia, apraxia, alexia, agraphy, acalculia). In asemic dementia, fixation amnesia is observed, manifesting itself in a sharp weakening or lack of ability to remember current events. It should be noted that the degree of expression of fixation amnesia is gradually



increasing. In this regard, an increasing number of current events and facts begin to fall out of memory. Then the process begins to spread to the memory of the past, capturing first a close period, and then more and more distant periods of time (Marilov, 2002).

#### Intellectual impairment in partial dementia

Partial dementia is characterized by uneven loss of intellectual functions, slowing down intellectual processes, reduced intelligence, and the predominance of various memory disorders. Often there is a violation of the criticality of thinking. The thinking of patients is not specific, since it does not rely on experience, and at the same time does not apply to abstract due to the lack of generalization. Thus, thinking in partial dementia, as well as in total dementia, is unproductive (Myagkov, Bokov, Chaeva, 2003).

The following types of partial dementia are distinguished:

1. Epileptic dementia is a consequence of an unfavorable epileptic disease. This type of dementia is characterized by a slowdown in mental processes, a decrease in the level of mental activity, pathological circumstance of thinking, amnesic aphasia. The main features of epileptic dementia are the viscosity of thinking (the extreme degree of circumstance, in which detailing to such an extent distorts the main direction of thought, which makes it almost incomprehensible), inertia, inability to switch to something new, inability to briefly formulate their ideas and progressive impoverishment of speech. Speech is depleted, stretched, filled with verbal stamps, diminutive words appear. Statements are shallow, poor in content and built on banal associations. The reasoning of patients is related to a specific situation from which it is difficult for them to distract. The range of interests narrows to concerns about your own health and well-being.

2. Vascular (atherosclerotic) dementia - occurs in atherosclerotic brain damage. The core of the personality with it remains relatively preserved for a long time. The initial signs of

vascular dementia are a violation of memorization with persistent criticism, as a result of which the patient tries to compensate for his defect with records or nodules for memory. Early there is emotional lability, explosives. Vascular dementia usually progresses gradually, with each subsequent cerebral tissue infarction. Neurological symptoms usually occur; intellectual disorders can be fragmented with partial preservation of cognitive abilities. If dementia develops after a stroke, then soon there are gross violations of memory, understanding, speech (aphasia), as well as neurological symptoms.

3. Traumatic dementia is a consequence of physical brain injury (noted in about 3-5% of patients who suffered a traumatic brain injury). The clinical picture depends on the severity and localization of the damage. In frontal-basal lesion, a clinical picture resembles progressive paralysis appears. The defeat of the anterior parts of the frontal lobes is manifested by apathy, asponence, akinesia, a decrease in thinking and speech activity, and behavior disorder. Temporal lobe lesions can lead to disorders resembling those in epileptic dementia. The main feature of traumatic dementia can be called a gradually increasing intellectual decline, while due to memory impairment, old information is lost and new information is not received, criticality to its state disappears.

4. Schizophrenic dementia - characterized by dissociation between the inability to capture the real meaning of everyday situations and a satisfactory state of abstract logical thinking. Knowledge, skills and combinatorial capabilities cannot be used in life due to autistic isolation from reality, as well as asponence and apathy. At the same time, gross memory violations are not detected, acquired skills, knowledge and judgments remain preserved. At the same time, uncritical thinking, violation of evidence, intellectual unproductivity and personality regression are observed.

5. Psychogenic dementia (pseudo-dementia) is the personality's reaction to a psycho-traumatic situation that threatens its social status, manifesting itself in the form of imaginary dementia with an imaginary loss of simple skills and an imaginary decrease in intellectual functions. In pseudo-dementia, the patient is characterized by ridiculous past-answers and past-actions in elementary situations. Despite the fact that patients cannot answer the simplest questions or answer them without falling, the answers are always in the plane of the given question. In addition, patients unexpectedly can answer a difficult question. Behavior is so demonstrably deliberate and does not lead to any benefit that it does not raise doubts about mental disorder. Psychogenic dementia - "flight to the disease" - usually the reaction of a weak or hysteroid person, if necessary, to be responsible for his behavior (for example, in a situation of prosecution for an offense). Pseudodementia is transient dementia, that is, a disorder in which, unlike previous dementia, symptoms subsequently disappear. The duration of the state is from several days to several months, after leaving the state, intelligent and other functions are fully restored (Myagkov, Bokov, Chaeva, 2003).

The most common diseases in this group are dementia in Alzheimer's and Peak's disease, which present particular challenges for differential diagnosis. Peak disease is a relatively rare primary degenerative dementia similar in clinical manifestations to Alzheimer's dementia. However, with Peak disease, more pronounced damage to the frontal lobes occurs, and therefore symptoms of relaxed behavior may appear at an early stage of the disease. In patients with this disorder, reactive gliosis is found in the frontal and temporal lobes of the brain. Diagnosis is confirmed by autopsy; computer and magnetic resonance imaging can also reveal a dominant frontal lobe lesion (Bleicher, Crook, Bokov, 2002).

Senile dementia (senile dementia and Alzheimer's disease in older age) are mental disorders that accompany brain degeneration in old age.

When studying psychopathological manifestations in diseases, Peak and Alzheimer are guided by the accepted division of diseases into three stages (Bleicher, Crook, Bokov, 2002):

1. The initial stage is characterized by changes in intelligence, memory and attention, without pronounced rough-focal symptoms;
2. The second stage is characterized by pronounced dementia and focal symptoms (aphasia, agnosia, apraxia);
3. The terminal stage takes place along with deep mental decay, patients lead a purely vegetative existence.

Dementia of the Alzheimer's type, which occurred both in presenile and senile age, is diagnosed when the patient has a decrease in memory, apathic, apractic, agnostic disorders or disorders of abstract thinking, which leads to a significant decrease in the previously available level of social and professional functioning.

In order to establish a diagnosis of dementia of Alzheimer's type at presenial age, it is necessary to exclude the condition of dementia with brain disease (for example, cerebral atherosclerosis), extensive hematoma, hydrocephalus, systemic disorder (for example, vitamin V12 or folic acid deficiency) (Karvasarsky, 2004).

#### Dementia in Huntington's Disease

Huntington's disease is a genetically determined degenerative damage to the central nervous system. The disease was first described by American neurologist George Gentington in 1872. The frequency of occurrence is approximately 5 cases per 100 thousand people. If one of the parents suffers from Huntington's disease, the risk of developing this disease in his children is

50%. The disease usually begins at the age of 30-50 years. However, there is also a so-called juvenile form with the onset of the disease up to 20 years old (5% of all cases). Noticeable behavioral disorders often occur several years before the appearance of detectable neurological signs. The disease is characterized by chronic progressive chorea (involuntary and disorderly sharp, twitching movements), as well as mental disorders. Dementia usually occurs in the later stages of the disease and, as a rule, with psychotic symptoms. Personality is characterized by psychopathic disorders: excessive excitability, explosives, Isterian-like capriciousness. In the clinical picture of the disease, low-systematized paranoid disorders are observed (in particular, delusions of jealousy or expansive delusional syndromes with obsessions of greatness and omnipotence), as well as acute psychotic episodes with disorderly psychomotor arousal. 90% of patients develop dementia, manifested in a general decrease in intellectual activity, deterioration of memory, acalculia, pathological distraction, reduced ability to reason and abstraction, impoverishment of speech and disruption of orientation. To a large extent, intellectual disorders of patients depend on gross disorders of active attention. Memory violations are expressed - in particular, retention and memorization (when memorizing 10 words, patients reproduce no more than 3-4 of the same words). Early violations of logical-semantic memory are found, expressed in the impossibility of reproducing simple stories. With the progression of the disease, the stage characterized by instability of attention and uneven intellectual performance is replaced by an increasing decline in intellectual activity and leveling of its manifestations. The course of the disease is usually slowly progressive, with a fatal outcome after 15-25 years (Dmitrieva, 1999).

#### Dementia in Peak Disease

Peak disease is a progressive neurodegenerative brain disease that begins, as a rule, in presenial age with gradually increasing personality changes and impaired speech. This disease

was first described by Arnold Peak in 1892. Peak disease is less common than early Alzheimer's disease. The disease takes place along with an early loss of criticism and social maladaptation and relatively quickly leads to the development of total dementia. In Peak disease, atrophy of the frontal and temporal lobes of the cerebral cortex is noted, the cause of which is unknown. The disease usually begins at the age of 45-50 years. The prevalence of Peak disease in our country is 0.1%. Women are more susceptible to the disease than men, the approximate ratio of cases is 1.7:1 according to Marilov (2004).

Moreover, Mavrilov (2004) states that the disease begins slowly and usually with personal changes. At the same time, there are difficulties in thinking, minor memory defects, mild fatigue and often characteristic changes in the form of weakening social inhibition. Changes in personality at the initial stage depend on the predominant localization of the atrophic process. Dmitrieva (1999) in her study of the clinical psychiatry mentioned that with the defeat of the frontal lobes, inactivity, lethargy, apathy and indifference gradually increase, motives decrease to their complete disappearance, emotions blunt, and at the same time the decline in mental, speech and motor activity progresses.

The author continues that with atrophy, pseudoparalytic syndrome develops in the basal cortex. In these cases, personal changes are expressed in the gradual loss of a sense of distance, tact, moral attitudes, and lower attractions, euphoria and impulsivity appear. At first, patients become extremely scattered, sleazy, untidy, stop coping with their usual work, lose tact, rude. In the future, they grow pronounced lethargy, indifference, inactivity. So-called standing turns appear in the speech - patients give the same answer to a variety of questions. Within the framework of pseudoparalytic syndrome in Peak disease, gross violations of conceptual thinking

(generalization, understanding of proverbs) usually occur early, and no distinct memory disorders or orientation are found (Dmitrieva, 1999).

With atrophy of temporal lobes or combined frontal-temporal atrophy, stereotypes of speech, actions and movements occur early. In this case, diseases in the early stages are also not characterized by memory impairment. Nevertheless, the most complex and differentiated types of thought activities - abstraction, generalization and interpretation, flexibility and productivity of thinking, criticism and the level of judgment - are steadily declining and collapsing (Dmitrieva, 1999).

As atrophy progresses, mental impairment worsens, and the clinical picture of Peak's disease is increasingly approaching senile dementia with memory destruction and disorientation. The second stage of Peak's disease is characterized by a typical picture of steadily and monotonously progressive dementia, affecting intelligence "from top to bottom," starting with its most complex manifestations and ending with the simplest, elementary, automated with the involvement of the prerequisites of intelligence. Dissociation of all higher intellectual functions occurs, their coordination is disrupted. Against the background of deep global dementia, a characteristic dynamics of speech disorders is revealed.

The nature of speech pathology is largely determined by the primary localization of the atrophic process. With the frontal version of Peak's disease, a drop in speech activity comes to the fore, up to the complete asponence of speech. The vocabulary is steadily scarce, the construction of phrases is simplified. Speech is gradually losing its communicative significance. In the temporal version of Peak disease, the stereotype of the development of speech disorders resembles a similar stereotype in Alzheimer's disease, but with some differences. There is a

simplification of the semantic and grammatical design of speech and the appearance of speech stereotypes (standing turns of speech).

Stereotyping in speech and behavior characteristic of Peak disease undergoes a certain dynamics. At first, standing turns of speech are used with unchanged intonations in the story (a symptom of a gramophone record), then they are increasingly simplified, reduced and reduced to a stereotypically repeated phrase, several words, become increasingly meaningless. Sometimes the words in them are so distorted that their original meaning cannot be determined.

The third stage of Peak's disease is characterized by deep dementia, patients lead a so-called vegetative lifestyle. Externally, mental functions come to a final decay, contact with the patient is completely impossible (Dmitrieva, 1999). Peak disease usually ends in death after 2-7 years.

#### Dementia in Alzheimer's Disease

Dementia in Alzheimer's disease was named after Aloise Alzheimer, a German neuropsychologist who first described the disease in 1907. Alzheimer's disease is primary degenerative dementia, which comes along with a steady progression of memory disorders, intellectual activity and higher cortical functions and leading to total dementia. In most cases (75 to 85%), this pathology begins at the age of 45-65 years, but it is possible an earlier (up to 40 years) and later (over 65 years) onset of the disease. The average duration of the disease is 8-10 years (Marilov, 2002).

Often, diagnosis of Alzheimer's disease is difficult and uncertain. The main reason for these difficulties is the inability to fully establish the presence of neuropathology characteristic of this disease in living patients. Diagnosis is usually made only after all other causes of dementia are excluded through the study of medical history and family history, various examination



methods and laboratory tests. Brain imaging techniques can provide further evidence of pathology in the case of the detection of enlarged ventricles or enlarged cortical folds of the large hemispheres indicating brain atrophy. Unfortunately, several other pathological conditions, as well as normal aging, are characterized by atrophy of a similar type, which currently makes it impossible to make a final diagnosis of Alzheimer's disease without performing an autopsy.

In older adults, Alzheimer's disease usually begins gradually, with a slow breakdown of the personality. In some cases, physical illness or other stressful events can be the trigger, but usually a person falls into dementia almost unnoticed, so it is impossible to accurately determine the onset of the disease. The clinical picture can vary greatly in different people depending on the nature and degree of brain degeneration, the premorbid personality of the patient, the presence of stressors and the support provided by others.

During the course of the disease, three stages are distinguished: the initial stage, the stage of moderate dementia and the stage of severe dementia.

At the initial stage of the disease, the first sign of the disease is often the gradual departure of a person from active participation in life. There is a narrowing of social activity and interests, a decrease in intelligence and mental adaptability, tolerance to new ideas and everyday problems. At this stage, initial signs of mnestic-intellectual decline are found, which manifest themselves in often repeated forgetfulness, incomplete reproduction of events, and easy difficulties in determining time relationships. At the same time, the adequacy of everyday functioning is fully preserved. At the beginning of this stage, patients, as a rule, manage to hide or compensate for their disorders. In the future, the phenomena of fixation amnesia, violation of orientation in time and place begin to increase. Difficulties arise in thought operations, especially in abstract thinking, generalization and comparison capabilities. Violations of higher cortical

functions appear and are progressively intensified - speech, praxis, optospacial activity. Distinct personality changes are also noted in the form of increased excitability, conflict, super-innocence, sharply expressed egocentrism. As a result, the patient's thinking and activity often revolves around himself and becomes childish (Dmitrieva, 1999).

At the initial stage of Alzheimer's disease, patients critically assess their condition and try to curb their growing insolvency.

At the stage of moderate dementia, the clinical picture of the disease is dominated by signs of the syndrome of disorders of higher cortical functions caused by damage to the temporo-parietal parts of the brain (symptoms of amnesia, apraxia and agnosia appear). Memory impairments, which are manifested in the inability to acquire new knowledge and remember current events, as well as the inability to reproduce past knowledge and experience, become more pronounced. Disorientation progresses in place and time. Intelligence functions are especially grossly violated - there is a pronounced decrease in the level of judgment, difficulties in analytical and synthetic activities, speech, praxis, gnosis and optospacial activities.

The listed disorders at the stage of moderate dementia do not allow patients to independently cope with any professional duties. Due to their status, they can only perform simple work at home, their interests are extremely limited, they need constant support even in such types of self-care as dressing and personal hygiene (Dmitrieva, 1999). However, at this stage of Alzheimer's disease, patients tend to retain basic personal features, a sense of their own inferiority and an adequate emotional response to the disease for a long time.

The stage of severe dementia is characterized by extremely severe memory decay. Patients retain only very scarce fragments of memory reserves, the expression of orientation is limited by fragmented ideas about their own personality. Thus, there is an incomplete orientation

even in one's own personality. Judgments and thought surgeries become essentially inaccessible to patients. They need constant help even in basic self-care (Dmitrieva, 1999).

At the final stage of severe dementia, a total decay of the patient's memory, intelligence and all mental activity occurs. Agnosia at the same time reaches an extreme degree - patients cease to not only recognize others or determine any substantive spatial relationships, but also distinguish between the direction from which the speech addressed to them is heard. In addition, they cannot fix their eyes on objects even with insistence from the outside, do not recognize their image in the mirror (Dmitrieva, 1999).

Apraxia also reaches a maximum. At the same time, patients are not able to perform any completed, purposeful movements, cannot walk, climb or go down the stairs, sit down. Usually they stand in some awkward unnatural pose, push in place, sit sideways, sometimes next to the chair, often hang over the chair, not knowing how to sit down (Dmitrieva, 1999).

Speech decay takes place along with the formation of total sensory aphasia with a loss of ability to word formation and with the loss of various speech automatisms. Sometimes violent speaking is noted, consisting of monotonous and monotonous repetitions of individual words or sounds. At this final stage of the disease, the decay of all cortical functions reaches a total degree. Such severe destruction of mental activity is rare in other atrophic processes or organic lesions of the brain. A typical Alzheimer's patient is an elderly person. Most patients are really in old age, but Alzheimer's disease is presenile dementia, sometimes begins at the age of 40-50. In such cases, the disease and associated dementia progress very quickly. Cases of early onset of the disease in relatively young and energetic patients show especially strongly the tragedy of Alzheimer's disease.

Many patients with Alzheimer's disease with appropriate treatment, which includes the use of drugs and maintaining a calm, encouraging and non-provocative social environment, show symptoms of improvement. However, destruction within months or years leads to death. Patients forget their relatives, find themselves bedridden and lead a plant-based existence. Resistance to disease decreases, and death usually occurs due to pneumonia or similar respiratory or cardiac diseases.

Moreover, the study of a number of scholars such as Dmitrieva (1999), Mendelevich (2001) and Mavrilov (2002) highlighted several critical periods during the course of dementia disease, when a patient's relative especially needs help. The stages related to the crisis, as well as measures for the prevention of mental disorders in caregivers during these periods in the provision of medical and psychological assistance, are summarized.

The duration of the course of dementia disease varies significantly: there are fast-progressing mainly early forms, in which two years after the formation of clinical manifestations of mild dementia, the patient goes to the stage of severe dementia and dies, whereas in later forms of the disease progression to severe dementia may take more than 10 years, and the life expectancy of the patient with good care even at the terminal stage can be several years. For this reason, it is not possible to distinguish the characteristic time frame or time range in which the crises of caregivers develop, this is individual in each family.

Encountering illness, pain, fear, coping experience is an indispensable part of our lives. A person has to get used to living with the disease, master the skills of patience and coping with it, accept the idea that doctors are necessary assistants in the fight against the disease. As a result, it is not the one who was able to "forget" that he is ill, but the one who learned to determine the first symptoms of exacerbations of the disease, take the necessary treatment in accordance with

the recommendations of the doctor and be patient and persistent in his fight against the disease, who learned to apply measures to prevent exacerbations of his disease.

Among a wide range of human diseases, mental disorders occupy a significant place. A person carrying a severe mental disorder often experiences unusual experiences, such as auditory hallucinations, which leads to inadequate behavior. In fact, he does not hear others, loses the right orientation, performs actions that are inadequate from the point of view of other people, due to his painful experiences and ideas. It is very important that during the exacerbation of the disease he loses his criticality - the intellectual ability to look at himself from the outside, to weigh his statements and actions from the point of view of common sense, to correct his inadequate behavior. Often the disease leaves imprints, changing the worldview of the person and her goals, depriving a person of normal energy and liveliness of reactions.

First of all, attention should be paid to the change in the nature of thinking, which we can judge by human statements and actions. For example, in ordinary events, a person begins to catch some hints, a hidden meaning. The phrase heard on TV, an article in the newspaper, an erroneous phone call is perceived by a sick person as having a direct relation to him. Often painful ideas arise that have a completely defined theme and do not receive any real confirmation. Most often, these are thoughts that such a person is being monitored, strangers are hostile, say something about him, or want to harm. Another common kind of painful ideas (psychiatrists use the term "nonsense" to refer to them) concerns the assumption that the patient is influenced by some kind of external influence, for example, hypnosis or telepathic influence. Many patients become confident in their exclusivity, attribute to themselves unique abilities - to treat, prolong life, manage world events. Their behavior changes accordingly.

Another sign of mental illness is unexpected changes in values and character. For example, a person suddenly begins to show interest and unusual absorption in mystical teachings or ufology. At the same time, he casts his daily life, his usual duties. Relatives notice an extraordinary change in his character, conclude that a person unexpectedly became "different." A frequent manifestation of mental distress can be depression - a stubbornly depressed mood that persists for several consecutive weeks. Such a person loses productivity, experiences lethargy, eats poorly and sleeps, experiencing feelings of longing, guilt or apathy. Thoughts about the worthlessness of one's life are characteristic, often ending in a desire to commit suicide. Other frequent symptoms of mental disorder are pronounced emotional imbalance, inadequate emotional responses, unprovoked hostility.

The symptoms of a severe mental disorder are very numerous and diverse, and often only a specialist, a psychiatrist, can understand them. But the main detail is usually reported to the psychiatrist by the patient's relatives themselves - a person has become socially inadequate due to a change in his mental state.

Usually, in the first collision with a mental disorder, a loved one experiences shock. At first, confusion and denial are characteristic ("this could not happen to us"). Then comes the phase of active search for help. Concerned about the condition of his loved one, a person begins to seek help from everyone who, it seems to him, promises quick healing. A particular danger is the appeal to charlatans and "healers." It is well known that attempts by such "therapists" to affect the "bioenergy" of mentally ill people led to a sharp deterioration in their condition. There have been cases where "specialists" offered "effective" help to mentally ill patients, who themselves have received treatment for severe mental disorder in the recent past. Another danger is that a mentally ill person becomes more dependent and potentially vulnerable to involvement

in various totalitarian sects. Devoid of will, but intuitively understanding that something is wrong with him, he often turns to authoritarian "gurus" for help, hoping to get support from them. In the future, he becomes a victim of abuse by sectarians, often loses his property. . It should be noted that representatives of official faiths are usually sufficiently aware of the manifestations of mental illness and do not advise the mentally ill to refuse the help of psychiatrists.

Due to the great diversity of mental pathology, it is very difficult to give any specific recommendations on how to behave with a mentally ill person. Only a highly qualified doctor can give them. But it is extremely important to remember - a person with a mental disorder needs, like all of us, support, respect, love. It is useful to look at a mentally unhealthy loved one as a sick child who requires an appropriate attitude. At the same time, each of us must be aware - sometimes a mentally ill person is uncontrollable, even dangerous, and then society must take responsibility for exercising control over his behavior.

The only correct way out in a situation where a person close to you has a mental illness is to contact a psychiatrist. During the course of a mental illness, spontaneous temporary improvements may be noted, but this never solves the problem. Modern treatment of mental disorders is based on the use of sophisticated knowledge-intensive technologies, which are implemented by qualified specialists. Over the past 50 years, a wide range of medicines and non-medicines have appeared at the disposal of psychiatrists, which make it possible to effectively combat various manifestations of mental pathology. Psychiatric care in our country is under the special attention of the state and is actively developing. In order to get quality and free help, you need to consult a psychiatrist at the place of residence. If your loved one detecting symptoms of a mental disorder rejects medical care, it is also useful to consult your doctor about the tactics of

further behavior. In most cases, timely therapy allows a mentally ill person to recover, restore the positions lost due to the disease, save his family and work. Assistance, support and understanding from other family members is also a prerequisite for recovery.

#### Dementia in the early stages

Before we talk about possible options for helping people with dementia, we should mention the original origins of the disease. There is a serious problem of insufficient diagnosis of dementia only in its initial stages, but this is the most important period in the development of the disease, since at this stage the therapeutic capabilities are greatest. The later the diagnosis is made and adequate treatment is begun, the less amenable the correction of the manifestation of this disease.

Dementia is in most cases a long process that begins many months before it becomes apparent to the loved ones and acquaintances of patients. The first signs of approaching dementia may be a weakening of interest in the environment, a decrease in initiative, social, physical and intellectual activity, increased dependence on others, a desire to shift responsibility for making decisions related to financial issues or housekeeping to the spouse and other loved ones. In patients, there is increased drowsiness during the daytime and evening, during conversations, interest and activity decrease, the conversation thread often slips away due to weakening attention. Often there is an oppressed mood, increased anxiety, a tendency to self-isolation, the circle of communication is sharply limited. Many of these changes have long been viewed by people around the patient as manifestations of aging. In order not to miss developing dementia, it is necessary to widely conduct a screening neuropsychological study in elderly patients who contact neurologists, therapists, general practitioners about certain complaints.



After the diagnosis is established, it will be possible to try to implement the treatment itself. Treatment of patients with dementia can be divided into three groups of activities: eliminating or compensating for the cause of dementia; pathogenetic therapy with modern drugs; individual symptomatic therapy.

#### Eliminating or compensating for the cause of dementia

Eliminating or compensating for the cause of dementia - there is an attempt to eliminate or regress "reversible" dementia. With potentially reversible dementia, it is possible to achieve complete or partial regression of cognitive impairment by curing the disease or achieving its compensation.

Although reversible dementia is rare, it is in the first place that they should be excluded primarily in patients with increasing cognitive impairment. A thorough somatic examination (it is important to pay attention to possible signs of liver, kidney, lung, heart or thyroid diseases) may help in diagnosing reversible dementia. Usually, the faster dementia develops and the younger the age of the patient, the higher the likelihood that it may be reversible dementia and the more active the examination should be.

#### Pathogenetic therapy with modern drugs

Pathogenetic therapy- The successes achieved in the 80-90s of the XX century in the study of the neurochemistry of cognitive disorders led to the development of effective methods of pathogenetic therapy of the main forms of dementia. The most promising area of therapy is currently considered the use of acetylcholinesterase inhibitors, such as, for example, galantamine (reminil), and NMDA glutamate receptor modulators (acatinol memantine). These drugs are widely used around the world, and in recent years have become available in Russia. Constant use of these drugs helps improve memory and attention indicators, increase the activity and

independence of patients, streamlines their behavior, improves self-care skills, slows down the progression of memory disorders. The drugs are usually well tolerated, can be used as the main treatment or in combination with other drugs.

It is important to emphasize that, like other drugs, these drugs have a positive effect only when prescribed by a doctor with the correct indications for use. Therefore, before starting their appointment, you need to consult a neurologist. Self-medication can be harmful to health, while properly chosen therapy allows you to significantly reduce the severity of disturbing symptoms and suspend the progression of forgetfulness.

#### Individual symptomatic therapy

Individual symptomatic therapy - includes primarily correction of affective, behavioral, vegetative disorders, sleep disorders, which can affect the state of adaptation of patients to almost a greater extent than the intellectual decline itself.

It is also necessary to emphasize the importance of the role of people around the patient. The socio-economic and emotional burden of dementia falls not only on the patients themselves, but also on their relatives, the closest and more distant environment, therefore, on the whole society. The fact is that in dementia, the patient reveals disorders that make him not completely independent in the performance of ordinary everyday household activities. Previously, professional skills suffer, the ability to independently effectively contact other people, perform financial transactions, use modern household appliances, drive a car or navigate the city. Domestic difficulties in self-care are formed at the stage of moderate and severe dementia, when diagnosis of this condition is no longer significant difficulties.

In the family of patients with emerging dementia, conflict situations can often arise related to the lack of understanding by relatives of the problems of a sick person. In particular,

the aggressive behavior of patients is a protective response and is due to the fact that they do not understand and cannot explain their condition to loved ones. Unfortunately, not so rarely do the patient's relatives, not understanding the essence of the disease, begin to accuse the patient of his forgetfulness, allow themselves unacceptable jokes or try to again "teach" him lost skills. The natural result of such activities is patient irritation and inevitable family conflicts. Therefore, having diagnosed the patient with dementia and prescribed adequate treatment, the doctor should conduct explanatory work with him and his relatives.

#### Burden of caregivers for dementia patients

The burden of disease is social, economic and medical damage from the disease, which is measured both in monetary, psychological, and life years lost to the disease. In the case of chronic progressive disabling diseases, in which the patient needs constant care, the concept of "burden" applies not only to the patient, but also to the person who cares for him.

The vast majority of dementia patients live in families, so to estimate the number of people constantly caring for patients with the disease, you can multiply the number of patients by at least two. At the same time, in most cases, the patient has one main caregiver who takes on most of the load. Undoubtedly, this caregiver is subjected to stress, which often becomes a cause that affects the decision to place patients in boarding schools (C.J. Gilleard, H. Belford, E. Gilleard, 1984.). For this reason, relieving the burden and reducing the stress of these individuals becomes an important medical, social and economic task.

They began to study the condition of persons caring for chronically ill patients from the 80s of the last century. A social prerequisite for this was the development of the health system in high-income countries, which contributed to an increase in life expectancy, as well as the critical "aging" of the population, in which it became necessary for a small number of young and

middle-aged people to care for an increasing number of relatives with dementia. Taking into account that by estimates of WHO and Alzheimer's Disease International, the number of people with dementia will double each 20 years, and by 2015 will be 115 million in the world, to the forefront in social and epidemiological researches there is a simplification of a burden on care for patients with dementia.

Globalization and the disintegration of the traditional, intergenerational family were additional factors. These processes have led a family member, in an environment of insufficient support from other relatives and the health and social care system, to assume all responsibilities to care for a patient with dementia, often at the expense of their own quality of life and health (Schölzel-Dorenbos et al., 2009).

In general, over the forty years of research, the perception of the role of the caregiver has changed significantly. The approach to this highly relevant issue has become more positive. The Alzheimer's International Association recommends that the consequences of acting as a caregiver should not be referred to as "care burdens," but rather as "care effects," emphasizing that they can be positive (such as a sense of pride or experience) (Beach, 2000). However, such changes in the perception of the role of the caregiver could occur only against the background of increased support for this group of the population by the state and public organizations: the creation of a system of assistance during, short-term institutionalization, self-help groups and the work of coordinators. (Cohen, Vernich, 2002.)

According to experts, on average, three quarters of the caregiver's time is devoted to the patient, and this indicator increases linearly as the disease progresses. When dementia goes into a difficult stage, the caregiver has an average of about two hours a week left on his own business (Aguglia, 2004). This can become one of the major reasons why the patient experience stress

during the caregiving process. Caregivers lose their personal boundaries and are forced to stop doing some of their favorite activities.

The condition of caregivers also plays a role in the treatment of a patient with dementia. Compliance is usually entirely dependent on the caregiver, and if the caregiver's cognitive function is below a certain level, adherence to therapy decreases (Boucher, 1996). This means that not only the patients with dementia need to be treated, but also, the caregivers should be given attention and special care so they do not become stressed and consequently ill.

In addition, even the symptoms of the disease may vary depending on the well-being of the caregiver. For example, some features of the caregiver's behavior can cause hyperactivity in the patient, and frequent criticism of the patient with dementia by the caregiver increases the severity of his behavioral disorders (De Vugt, 2004).

Caregivers are one of the most important participants in the research of new drugs. It is known that the vast majority of caregivers who provide patient participation in research are elderly spouses (Grill, 2013), often themselves suffering from forgetfulness and various somatic diseases. It is difficult for an elderly caregiver to fulfill all the requirements related to participation in the study (for example, keeping a diary, monitoring the regularity of the drug, bringing the patient to regular examinations), and this is a factor limiting the recruitment of patients, and therefore they are trying to attract younger caregivers to the studies. There are also large economic losses due to the care of dementia patients, as many people of working age are forced to reduce employment at work or retire prematurely.

Among caregivers, two social and age groups are distinguished: mature children of patients and elderly spouses of patients. Spouses of dementia patients who have reached retirement age usually leave work to care for the patient around the clock, although they often

want and could continue to work. At the same time, the elderly spouses of patients themselves often suffer from chronic somatic diseases that require careful observation, and due to their age, they have an increased risk of dementia and cardiovascular disasters (heart attacks and acute cerebral circulation disorders). Focusing all their attention on the condition of a patient with dementia, caregivers miss their own visits to the doctor, spend less resources on maintaining their health, which increases the risk of an adverse course of chronic diseases in them.

#### Health status of caregivers with dementia

One area of research is the study of the impact of care for patients with dementia on the health of caregivers. The topic of caregiver stress first appeared in the scientific literature in 1965 (Grad, 1965), but empirical research began in the 1980s when the burden of caregivers of dementia patients was first described.

The first phase of the research focused on what measures of the patient's condition affect caregiver stress. Then the researchers began to study the characteristics of the caregivers themselves (gender, age, social ties, attitudes to the patient's behavior, etc.) (Drinka, 1987).

Work has also been carried out to compare different designs of caregivers' research and to systematically review publications on the subject and to formulate recommendations for the survey and care of caregivers (Dunkin, Anderson-Hanley, 1998).

Most studies have shown that the health status of caregivers with dementia is worse than in the control group of peers not performing a care function (Baumgarten, 1994). In few studies, some health indicators in individual caregiver groups did not differ from those in the general population. In Jutras et al. (1995) no impact of patient care on physical health was found, but the deterioration of caregivers' mental health was confirmed.

The population of caregivers of elderly dementia patients is seen in many papers as a model of chronic stress in which the association of depression and somatic health should be studied (O'Rourke, Haverkamp, 1997). Caregivers of dementia patients are twice as likely to visit doctors and take 86% more drugs than their peers who are not caring (Katon, Kleinman, Rosen, 1982).

It should be noted that in Russia and Kazakhstan, comparison in the use of health resources by caregivers of patients with dementia and persons from the general population was not carried out. In our country, the demand for psychiatric care and the frequency of prescribed psychotropic drugs are obviously not comparable to data from the USA, Canada or Europe, and it would be more informative to assess the frequency of taking over-the-counter sedatives, but such studies have not been conducted.

Psychological stress is a proven risk factor for many somatic diseases. Everyday stress and depression, regardless of its structure, increase the risk of cardiovascular disease. Recent works have proven that psychological stress is a risk factor for the development of dementia, especially vascular, but also dementia disease. Against the background of stress and depressive symptoms in caregivers, there is a violation of immunity, which can also be the cause of increased mortality (Kiecolt-Glaser, Glaser, 1999).

Also among caregivers of AD patients, the effects of chronic stress on cognitive function were studied. Chronic lifelong stress has been shown to be associated with more pronounced cognitive decline in old age. In particular, it was found that older people caring for spouses have lower comprehensive attention and speed of information processing compared to those who do not perform the function of care.

The cause of cognitive impairment appears to be chronic stress, for which studies in humans show a negative effect on memory due to an increase in basal cortisol levels. It has been found that for older adults, everyday stress can be more traumatic than major life events (Lupien, Lecours, Lussier, 1994).

Longitudinal studies are used to confirm the impact of care function. The change in cognitive function in caregivers of dementia patients and in the control group during the year was compared. Caregivers lagged behind controls for verbal memory scores, and the deterioration was due to the caregiver's subjective competence and patient hyperactivity, but the nature of the causal relationship is unclear.

Studies were conducted comparing the health status of those caring for patients with dementia and those with severe somatic condition, but without cognitive impairment. According to the results of these works, caregivers of patients with dementia have worse physical health and are more likely to experience depression than caregivers of patients without dementia, as well as more impaired social functioning according to Canadian Study of Health and Aging Working Group, where patterns and health effects of caring for people with dementia were examined (Gerontologist, 2002).

Even after caregivers cease to perform the function of care, the incidence of sleep and appetite disorders as well as arterial hypertension is increased in this population, as well as depressive symptoms that appeared during the period of patient care persist.

Similar studies are conducted for persons caring for patients with mild cognitive disorder. According to the diagnostic criteria for mild cognitive disorder, these patients do not need care - they only need to help in the most difficult household tasks.



For this reason, the methodological validity of direct analogies with the concept of "caregiver" - a caregiver - seems dubious. However, one study identified a very high incidence of depression in individuals living with older adults suffering from mild cognitive disorder (depression rate 24.6%; confidence interval 21.5-27.7). In this case, it is possible that other social factors played a leading role in the high frequency of depression, in addition to caring for a relative. Depression was more common in unmarried individuals with lower levels of education. It has been shown that one of the factors influencing the results of studies on the frequency of depression is that among the children of patients, unmarried women become the most likely caregiver. They are more likely to experience depression regardless of the performance of the care function, i.e. the impact of the care function may be exaggerated (Hughes, Waite, 2002). At the same time, there is a justification for the appearance of depressive symptoms in those living together with persons suffering from mild cognitive disorder: this effect is explained by changes in the patient's personal characteristics and a violation of family relations. Depression in caregivers with mild cognitive disorder is seen more frequently than in the general population, but less frequently than in caregivers of dementia patients.

Particular attention was paid by the researchers to the development of clinically significant depression in the caregiver (Beeson, 2003). This indicator is extremely important, especially in older patients for whom subclinical and clinical depressive syndromes have been found to increase mortality (Penninx, Geerlings, 1999), possibly by various independent mechanisms. A number of studies have shown that the incidence of depression is higher in caregivers of dementia patients than in general. According to most studies, about one-third of caregivers with dementia suffer from depression. The incidence of depression in elderly caregivers of dementia patients reaches 83%. For comparison, in the general population of the

elderly in a foreign study, this figure is less than 7% (Blazer, Hughes, George, 1987), and according to a comprehensive study of the mental health of older people in one of the districts of Moscow, the incidence of depression is 11.6% (Kalyn, 2001).

One of the main topics of research on caregivers with dementia is the study of factors that increase or decrease caregiver stress and also increase or decrease the incidence of depression. In 1990 Pearlin and Mullan proposed a comprehensive model of caregiver stress in dementia patients. According to this model, a caregiver's well-being depends on three types of factors:

- 1) characteristics of the caregiver (education, sex, health and economic situation, relationship with the patient);
- 2) stressors;
- 3) mediators (social and medical support services).

Among stressors, primary ones are distinguished: symptoms of the disease in the patient (cognitive disorders, household disorders, behavioral and psychotic disorders), as well as secondary stressors - combining roles (for example, patient care and work activities or care for the patient and their children), conflicts with other family members or at work, financial problems. (Pearlin, Mullan, and Semple, 1990)

Factors affecting caregivers' stress

Factors associated with patient condition

Many studies have shown that the most significant factor worsening the condition of the caregiver is behavioral disorders in the patient. In addition, as a risk factor for mental disorders in a caregiver, low income, duration of the disease, and the age of the patient is under 65 years. Cognitive disorders (including memory impairment, gnosis) affect less. One study found a negative correlation of caregiver burden with the patient's MMSE rating of dementia severity,

however, in this case only families of patients with mild dementia in dementia disease were included in the examined group. In Raccichini et al. (2009) it has been shown that the greatest burden (burden) is caused by functional impairments in the daily activities of patients who act on this indicator more pronounced than cognitive and even behavioral disorders present in patients

Over time, research has begun to pay increasing attention not to external factors, but to the personal factors of the caregiver and the previous relationship between the caregiver and the patient. They began to take into account cultural and mental differences in the perception of the role of the caregiver. Belonging to a certain culture determines psychological protection, in particular, Kazakh society more often turns to family values and religion.

That is, cultures close to traditions, characterized by large families and community support, are inherent in attracting a large number of friends and relatives to help, which allows institutionalizing the patient only in rare cases. Representatives of such cultures, for example, caring for patients with dementia, are less likely to make complaints about insufficient care and later go to the doctor when signs of dementia appear in a relative. Compared with representatives of European culture, Russian and Kazakh society are more often of the opinion that it is children who should fully take on the role of caregiver. At the same time, it is suggested that stress in such cultures manifests itself in the form of psychosomatic disorders, and not affective disorders themselves.

According to a number of studies, caregiver stress does not decrease with institutionalization of the patient, therefore, physical activity in patient care itself is not the only factor that worsens the condition of the patient's family members (Zarit, Whitlatch, 2002).

The subject of some studies is the relationship between dementia knowledge, depression and anxiety. To assess knowledge about dementia in a caregiver, a special questionnaire has been

developed - Dementia Knowledge Questionnaire. It has been established that knowledge about dementia does not correlate with signs such as age, cohabitation with the patient and level of education. At the same time, a lower level of knowledge was associated with a higher incidence of depression and a lower incidence of anxiety conditions. The nature of the causal relationship with depression in this case is not clear. Both a low level of knowledge due to unrealistic expectations can provoke depression, and caregivers in a depressed state are less able to find information. The connection with anxiety is most likely due to the fact that during anxiety caregivers tend to look for information.

The concept of burnout syndrome is applied to caregivers of patients with dementia, which is more often studied as part of the professional activities of people "helping" specialties. One study found that burnout syndrome in caregivers of dementia patients was associated with their personal anxiety and the patient's low self-care capacity.

Attempts have also been made to evaluate the different coping strategies that caregivers use to address patient care issues. It was found that with non-functional ways of overcoming difficulties (for example, avoiding a problem), the load on the caregiver increases.

#### Social factors

Caregivers of dementia patients were found to have reduced quality of life. In this population group, the level of economic well-being is reduced and social isolation is more pronounced. Thus, caregivers need not only psychological, but also social support.

To develop measures to help caregivers with dementia, it is necessary to know the socio-demographic characteristics of caregivers. The nature of group formation in studies (mostly families of patients seeking medical care or participants in epidemiological studies) does not allow these groups to be considered fully representative, but general trends are traced. According

to studies conducted in different countries, the majority of caregivers are women (62-76%), mainly daughters (52-70.5%) and wives. According to a number of studies, the burden of women caring for dementia patients is greater than those caring for men, and there are differences in how older women and men respond to the role of caregiver. A significant proportion of caregivers aged 65 and over are themselves at risk for cognitive impairment (Graham, Ballard, Sham, 1997.)

It is necessary to take into account the characteristics of different countries and cultures, which, along with the methods of group formation, can influence the results of research. For example, in a study conducted in China, the burden associated with caring for a patient with dementia turned out to be higher in the spouses of patients than in children, while in Spain there was an opposite trend, but the researchers in this case do not explain such discrepancies.

It should be noted that in a society with strong ideas about the traditional family style, caregivers of dementia patients use little social care. According to Collins et al. (1991), caregivers are influenced by the opinion of others and the concept of family independence, along with this, the Russian study shows that most caregivers are not at all aware of what social assistance they can receive.

For example, the handbook prepared by the Alzheimer's association states that there are ten common problems connected with caregiving to patients with dementia. They are "denial, anger, social withdrawal, anxiety, depression, exhaustion, sleeplessness, irritability, lack of concentration and greater mental and physical health problems" ("Taking Care of Yourself", 2021, para 4). The list of the symptoms and negative results of taking care of dementia patients will definitely cause worsening of the caregivers' health at some point in future. What is more important, all of the mentioned problems inevitably affect psychological health of a person.

Without a proper and timely treatment, any of these will develop into a separate psychological disease and lead to worsening of the family situation. Some of the solutions proposed by the aforementioned association are to take occasional breaks from being a constant caregiver. If the patient is in safe conditions, caregivers ought to give themselves some time in a different environment, which will help them relax. Moreover, it is advisable for such people to engage in communities of similar caregivers. This way, people will be able to share information and practical advice. Moreover, communities help the people to ease their anxiety because of seeing people in a similar situation calms caregivers to some extent. Moreover, the Alzheimer Association advises the caregivers to seek information in order to stay informed regarding the most recent inventions and solutions to typical problems of dementia caregivers ("Taking Care of Yourself", 2021).

A prominent work has been prepared Berg-Weger & Tebb (2003). They have listed the articles dedicated to the caregiver burden in order to find gaps in the knowledge. This article has a practical importance for the present thesis, as the methodology part of the Berg-Weger & Tebb's (2003) serves as a good example of qualitative research in a field of psychology. The conclusions of the research are that at that time, the analysis were conducted having more bias such as gender and ethnic bias. Moreover, authors explain that for better understanding of the scope of the problem, evidence-based practices need to be employed.

There are number of scholarly papers that study the matter even deeper. For instance, Ferrara et al. (2008) have investigated the relationship between the depression, stress related diseases and caregiving to dementia patients. In order to do that, they conducted a linear regression. The population of the study has been asked to answer a number of questions, based on which a dataset have been created. The respondents were asked their age, gender, gender of

the patient with dementia, their education level, occupation, how they were related to the patient and their financial sufficiency. Moreover, the variables for the regression analysis were the examination of mental state and nervous system. Having conducted the research, Ferrara et al. (2008) concluded that the caregiver mental problem exists and needs solving.

De Cola et al. (2017) examine the extent to which caregivers are short of support in the example of Italian families. They have asked a number of questions from dementia patients (when they were able to answer) and their caregivers in order to reveal to what extent each of them thought no support has been received. Moreover, issues such as lack of information for the caregivers and absence of special medical treatment has been discussed as well. As a conclusion of their work, authors declare that in the case of Italian families caregiving involves a number of factors that worsen the physical, psychological and mental state of the caregivers. The authors explain that each of the caregiver spent long hours during a day supporting the patient. This support includes maintaining their personal hygiene, feeding them, helping them to take drugs and other direct support. In addition to that, caregivers were forced to keep a constant eye on the patient. This made them reorganize their own lives. De Cola et al. (2017, p. 5) conclude by stating that “spaces and roles required assisting the patient expose the entire family to stress and pressures that threaten to destabilize, even dramatically, their “equilibrium.”

Podgorski & King (2009) have examined the dynamics of the changes occurred after the patients were diagnosed with dementia. They have differentiated the changes in family lives based on stages of dementia. They are early-stage, middle-stage and late-stage dementia. The early stage is the stage before the disease is diagnosed and the signs of dementia did not prominently show. At this stage, the lifestyles of the entire concerned people are not affected. Podgorski & King (2009) citing the article of Logsdon, McCurry and Teri (2007) emphasize the importance of acquiring

needed knowledge about the disease progression and the timely medical tests. This means that the availability of full and understandable information for the dementia patients and their caregivers may affect their future state of mental and physical health. As the significance of raising awareness is high, the respondents for the present work should be asked if they are given enough informational support.

With the beginning of the middle stage, as Podgorski & King (2009) suggest, the dynamics within the family change greatly. The family members will begin to feel the distress. There are two sources for such a distress. On the one hand, they feel so-called “anticipatory grief” (Podgorski & King, 2009, p. 25). Anticipatory grief refers to a feeling of sadness related to anticipation of upcoming challenges and future changes in relative’s health. Sweeting & Gilhooly (1990) explains that people feeling anticipatory grief go through the same stages as a real grief. Thus, psychologically it is challenging for the patient and the caregiver. Overcoming this grief during the middle level progression of the disease can be difficult for some people and impossible for another (Relajo-Howell, 2020). The certain group of people will need to seek for specialist help. This includes both patients and caregivers. Thus, that is the stage where psychological distress of the caregivers is expected to start.

Moreover, in the middle stage of the dementia, the relationship between the family members may worsen. This is connected with the fact that dementia patients start needing continuous support and the family members will need to make a tough decision of giving up their jobs, hobbies, and spare time. At this stage, siblings or spouses may become annoyed at each other for not sharing the responsibility. There is an evidence based conclusion stating that “family conflict is most prevalent in cases of mild to moderate dementia, most often between siblings, who may make accusations of neglect or exploitation or fail to communicate entirely”



(Podgorski & King, 2009, p. 25). In other words, except being saddened by the fact of the illness of the relative, the caregivers are stressed by worsening of the relationship with the closest relatives. At this point, they may feel emotions such as disappointment, sadness, aggression, frustration and abandonment. Together with a newly emerged responsibility of constant surveillance over a dementia patients, these feeling lead to a substantial worsening of the mental health of the caregiver. Most of the times these problems are accompanied by sleep deprivation and insufficient diet (Gibson et al., 2014, Leggett et al., 2018). In fact, number of scholars emphasize the importance of healthy family relationships for future mental health of a main caregiver (Podgorski & King, 2009, Steadman, Tremont, and Davis, 2007, LoboPrabhu, Molinari & Lomax, 2006). Depression and anxiety are said to emerge from the initial conflict at the middle-stage dementia. Moreover, authors such as Podgorski & King (2009) and Steadman, Tremont, and Davis (2007) agree on the opinion that pre-existing understanding between the siblings and spouses helps to establish fare and adequate responsibility sharing. This helps to avoid many direct conditions that lead to a psychological distress. Thus, in order to examine the extent to which the studied group has healthy relations with the family members and how the responsibilities are shared between them, this need to be included in the questionnaire. Steadman, Tremont, and Davis (2007) list possible indices that can be used to measure the caregiver perception of his distress and discontent. They can also be used to anticipate future distress, depression and other mental diseases. These indices are “caregiver perceptions of current problems, satisfaction and amount of social support, available resources, coping skills, and feelings of self-efficacy” (Steadman, Tremont, and Davis, 2007, p. 116).

Steadman, Tremont and Davis (2007) have conducted an important work in the appraising the caregiver distress. They have studied 72 patient-caregiver pairs who lived

together. The focus area was the relationship satisfaction level before patient was diagnosed with dementia. In other words, the relationship quality that existed prior to finding out about the disease significantly influenced the consequent caregiver stress amount. This aligns with Podgorski & King's (2009) view of the family dynamics in the middle stage dementia. Nevertheless, Steadman, Tremont and Davis (2007) perform a statistical analysis of the variables such as the premorbid relationship satisfaction, burden survey and other questionnaires and checklists. The results have been regressed, and, the findings are as follows.

Caregivers with retrospective reports of low premorbid relationship satisfaction perceived greater burden than caregivers with retrospective reports of high premorbid relationship satisfaction. We also found that caregivers with less premorbid relationship satisfaction were more likely to negatively react to patients' behavior and have strained communication and problem solving skills (Steadman, Tremont, and Davis, 2007, p. 119).

The aforementioned can serve as a possible predictor of a caregiver burden after the dementia is diagnosed. The authors explain that if the perceptions of the caregivers were modified and relationship problems were worked out, the caregiver burden would decrease and the caregivers would feel themselves less stressed (Steadman, Tremont, and Davis, 2007, Kales, Gitlin & Lyketsos, 2014).

The last and the most severe caregiver psychological stress is connected with late stage dementia. At this stage, the patients' behavior deteriorates significantly and their functionality falls. At this stage, the relatives will need to constantly watch the patient and help with all necessities including personal hygiene. In some case, caregivers will have to carry the patient around. There are several stress triggers for caregivers at this point. The first, a certain category

of caregivers will need to quit their jobs and social life. This adds up to other stress stimuli as the person giving up his daily activities, routine and financial independence.

Another problem that the caregivers face at this stage is connected with making a decision to place a patient in a specialized geriatric care centers. However, Podgorski & King (2009) suggest that caregivers who had problems in relationship with the patient before the illness, and, those who did not receive any support are inclined to feel less stress at the moment of placing a patient in the specialized center. Other categories of caregivers may be exposed to stress for not bearing the challenges. They accept the case of institutionalization of the patients as an example of betrayal. As they fell guilt, they are likely to have psychological problems as well.

Drebing, McCarty & Lombardo (2002) investigate the level of stress that employees of geriatric centers were exposed to while working with late stage dementia. In the case of non-relative caregiver, not only disease related triggers affect the stress levels of the caregiver, but also the negative attitude and overly high expectations of the relatives.

All of the aforementioned mainly concerned siblings. However, there are cases when a caregiver is a spouse of the dementia patients. Kaizik et al. (2017) compare the caregiver burden of spouses versus other relatives. They found out that spouses felt more stressed and more miserable because their lives were out of control due to a spouse's disease. However, the surprising conclusion made by the Kaizik et al. (2017) is that overall level of stress was higher for children of dementia patients compared to spouses.

Having analysed the existing literature, the table has been created. The table summarizes the key features of studies conducted on the subject of psychological stress of dementia carers.

Table 1

*Summary of the existing researches on the subject of psychological distress of dementia caregivers*

<b>Year of publication</b>	<b>Author / authors</b>	<b>Data sample</b>	<b>Tested variables</b>
2008	Ferrara et al.	200 people	Stress, depression, disease connected with caregivers stress
2017	De Cola et al.	59 people	54 questions examining how respondents felt left out
2007	Steadman, Tremont and Davis	72 people	Relationship satisfaction
2017	Kaizik et al.	90 people	Spousal and children caregiver burden, caregiver stress of residing and non-residing caregivers

Table 1 presents a few studies which have similar objectives to the present thesis. The number of respondents varied from 59 people to 200 people. All of the mentioned scholarly works focused on evaluating to what extent the caregivers were experiencing distress, depression or had other mental and physical illnesses. Based on the studied literature, the author of the present thesis has developed her own objectives, chosen the means and tools of the study and have selected the research methodology, which are presented in the following two parts of the paper.

### **Objectives**

As have been mentioned above, the present thesis has a general aim of evaluating the existence and severity of psychological distress among the caregivers who take care of dementia patients residing in Russia and Kazakhstan. From the aim of the paper, the following objectives can be deducted:

- To classify the existing knowledge on the studied topic in order to build a basis for the research;
- To construct a survey and collect primary data from the people whose life is directly affected and who are involved in caregiving in Russia and in Kazakhstan;
- To revise the collected data and present findings that answer the research question;
- To draw conclusions and offer recommendations for future studies in the area of psychological distress of the caregivers involved in supporting the dementia patients.

To sum up, the aim is to identify whether the chosen group of people suffer from caregiver burden or experience other forms of psychological distress. All of the objectives align with the general aim and are consequently worked through in a thesis paper. As for the following part of the thesis, it presents the main features of the data used in the research and the methodology employed to carry the research out.

## **Material and methods**

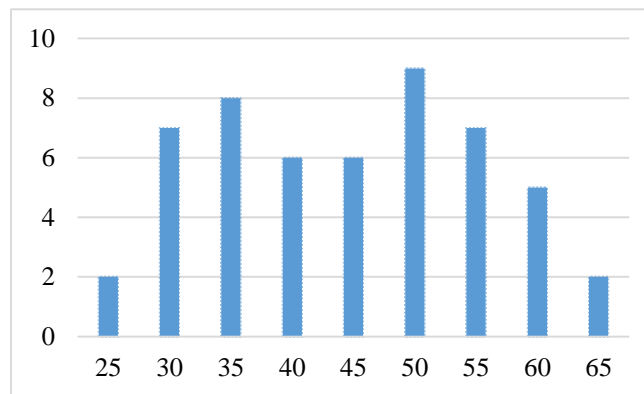
### **Material**

The data for the analysis was collected using the digital survey portal Google Forms. There were 23 questions of different forms (multiple choice, open end questions and scale questions). The author created all of the questions herself. Two questions are designed to describe the demographic image of the respondents such as gender and age. The data is collected to examine to what extent the caregivers of dementia patients from Russia and Kazakhstan feel the caregiver burden and to what extent they feel abandoned. The choice of geographical location of the caregivers have been made based on two reasons. The first, there are online communities, whose members were willing to take part in the research and answer the questions. They live in both countries. As Kazakhstan and Russia have many commonalities in social and economic state, then the decision to include respondents from both countries have been made. Second, the surveys were conducted in Russian and all of the respondents spoke Russian language freely. As the author of the thesis paper speaks Russian fluently as well, there was no need in interpreting services.

Moreover, the questions are designed to reveal to what extent they are supported financially. At the end, the questionnaire contains an open-end question, which allows the respondents share any thought they may want to share related to the subject of the research.

It is important to point out that personal information was not collected, and the respondents were not paid. All of the respondents have voluntarily answered the questions of the questionnaire. This allows the author to assume that all of the answers were given in a sincere way. Moreover, as no personal information is revealed, there was no need to sign an informed consent form. The caregivers are referred to as Caregiver 1, Caregiver 2 and so on.

There were 52 respondents living in various regions of the Russian Federation and the Republic of Kazakhstan. Regarding the gender, only 3 out of 52 respondents were man. Their ages differed greatly being 24, 43 and 67. The 49 respondents were females. Their average age was 44.89 years and the median age was 45. The mode of the ages of female caregivers was not taken into account, as it would not add value to the analysis. The average age of females and males together was 44.88, and the median age equalled 44 and 45. The indices are quite similar as the quantity of male respondents is low. The following graph illustrates the distribution of caregiver ages divided groups with a 5-year-step.



*Figure 1.* Number of respondent in age groups

It is evident that there are more than six people in each age group starting from 30 to 55. There are seven caregivers of 60 and over, and there are two caregivers of 25 and under.

The answers to the questionnaire is the main dataset that will be analysed to answer the main research questions. The tables in appendices B, C and D contain detailed answers of the respondents.

## **Methods**

Qualitative research is a research, which analyses non-numeric data in order to develop an understanding of the notions, attitudes, opinions, experiences and social phenomena.

Compared to quantitative research, which works with numerical data and reveals the trends and

patterns for existing or future phenomena, qualitative research allows the researcher gather and develop an insight that will broaden the research area for future studies. Qualitative research is widely used in psychology as explained by Willig (2013), Sullivan & Forrester (2018) and Camic et al. (2003). Willig (2013) asserts that applying qualitative research to psychology has advantages. It reveals the way studied group of people make sense of their experiences and the situation. The main purpose is to understand the situation from the perspective of the studied people or to understand how these people manage the issues and cope with the conditions arisen from the certain phenomenon. The author explains, “Qualitative researchers tend, therefore, to be concerned with the quality and texture of experience, rather than with the identification of cause–effect relationships” (Willig, 2013, p. 9). Moreover, the author argues that conducting qualitative research versus quantitative research, where variable are predefined, allows the researcher to avoid unnecessary limitations and boundaries. Thus, the conclusion in such research will reflect the real life situation in deeper and more profound way.

As an approach of the qualitative research, the author uses phenomenological research, which aims to appraise a phenomenon by investigating and interpreting subjective opinions and experiences of people living within the certain circumstances or a phenomenon (Heidegger, 2005). Phenomenological qualitative research has number of advantages compared to other approaches. First introduced by Husserl (1999) phenomenology seeks to explain the events or phenomena based on consciousness of people involved. In other words, it denied the idea that object and external world happened and evolved independent from each other (Groenewald, 2004). Moreover, Husserl (1999) explained that reality is the only pure data to begin the research with as it represents the phenomenon as it is. Groenewald (2004, p. 43) states: “to arrive at certainty, anything outside immediate experience must be ignored, and in this way the external



world is reduced to the contents of personal consciousness”. That is to say that in order to evaluate to what extent the caregivers are experiencing psychological distress, one would need to gather and analyze their perceptions, opinions, attitudes to the circumstances they live in.

As for the research methods, the present thesis will employ qualitative analysis based on a survey. Braun et al. (2020, p. 2) advocate to the usage of the surveys in qualitative studies, as they “harness the rich potential of qualitative data”. The authors examine the application of online surveys as a tool of conducting full and comprehensive study. Having compared the approaches and presenting practical examples, Braun et al. (2020) conclude that the newly emerging tendency to use online surveys can benefit to the faster development of new concepts in a number of social sciences. As for the present work, this method will allow drawing conclusions from the conducted semi-structured analysis (Appendix A). As the survey has options to choose from in some case and open questions, where respondents can answer using any amount of words, then the results are expected to provide answers reflecting the respondent experiences in-depth.

For the first part of the survey, where the answers are given in a form of predefined options, frequency and proportions will be analyzed across age groups, across number of years in caregiving and other parameters. This way, the author will attempt to find patterns in thinking of the respondent caregivers.

For the part with open questions, all of the answers will be collected in one place, translated from Russian into English, and, then categorized. For categorization, the author will code the meaningful sentences and code them using Microsoft Word and MaxQDA software for qualitative analysis.

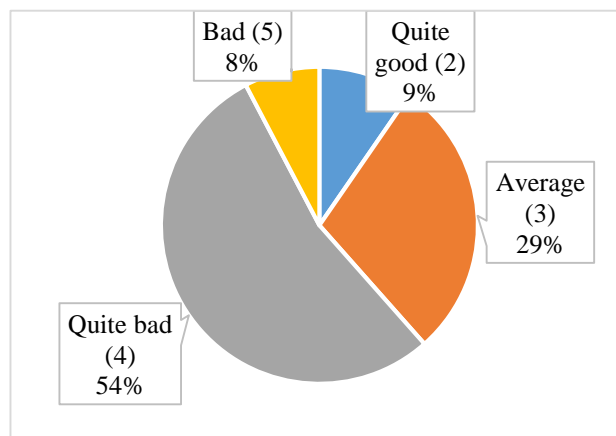
In conclusion, according to the information provided above, the present thesis will employ qualitative research with phenomenological approach based on online surveys with mixed structure.



## Results and discussion

The present part will display the core findings of the study carried out based on the methodology described above. The results will be presented without bias and in the order the questions are displayed in the survey. The questions will be grouped in order to deliver concise but informative findings.

Respondents were asked to evaluate their current health state including mental and physical health. The results of the survey is displayed below:



*Figure 2.* Self-evaluation of health state

The question asked respondents to choose from a scale an option that shows the state of their health. 28 people or 54% of respondents have indicated quite bad health state. 8% or 4 respondents thought their health was bad. Other 20 respondents thought that their health was average or quite good. The age and state of health was correlated using Microsoft Excel software, where the correlation coefficient was 0.02, which allows the author to conclude that the Simpson's paradox is not present in this case.

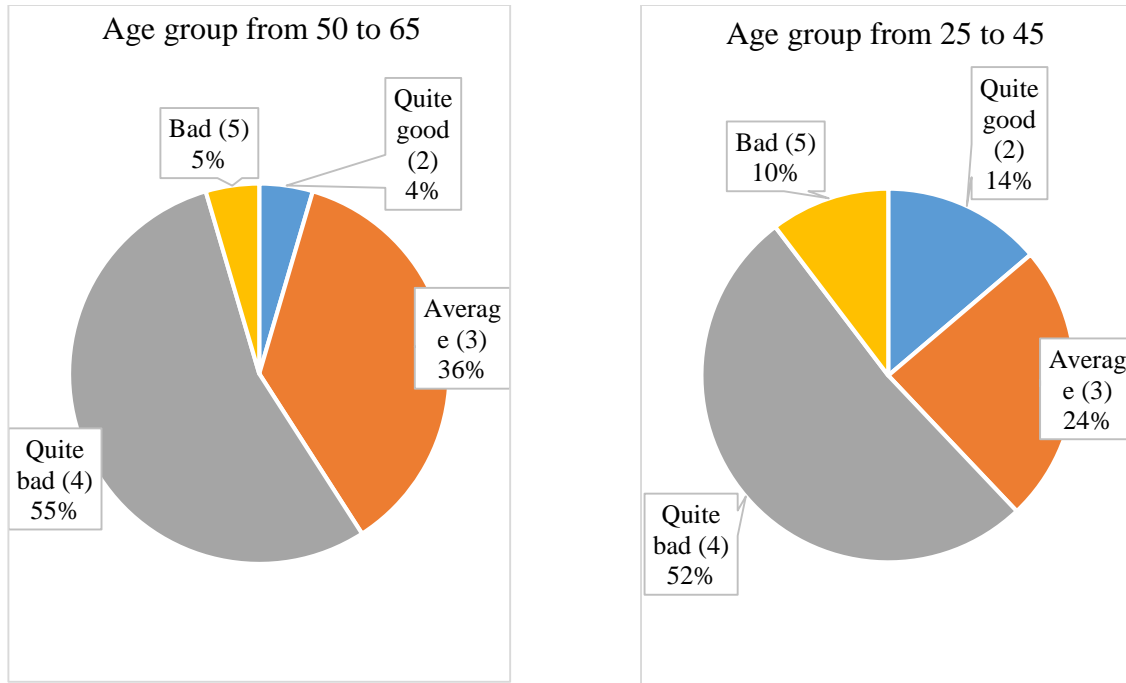


Figure 3. Self-evaluation of health state based on two age groups from 50 to 65 and from 25 to 45

As clearly seen from comparison of Figure 2 and 3, the general tendency is present and more than half are not satisfied with their health state regardless the age. Thus, one can assume that caregivers are generally not satisfied with their mental and physical health.

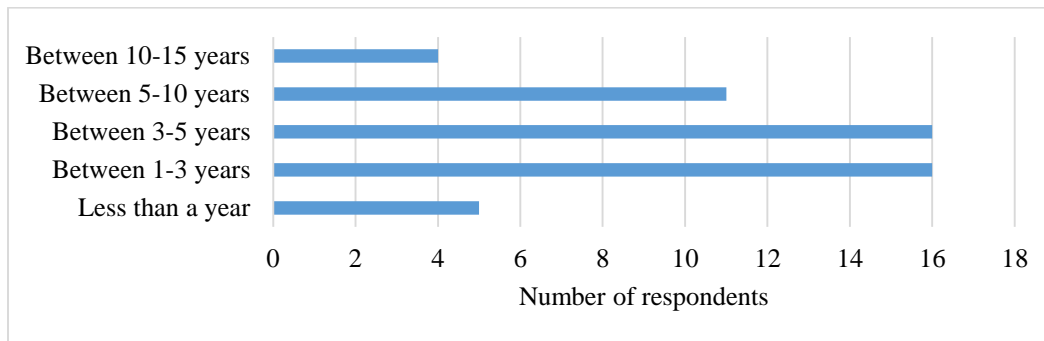


Figure 4. Number of years the respondents were involved in caregiving

As illustrated in Figure 4, the majority of respondents (31 people) have a caregiving experience of three and more years. 29 percent have five and more years of experience. Thus,

the effect of caregiving on the level of psychological stress can be traced as these people have been engaged in the caregiving activities for a long time.

Answers behind the reason why people are engaged in caregiving were distributed in the following way:

Table 2

*Answers to question 5 of the survey*

Options	Number of respondents	Share
Familial sentiment	46	87%
A hired caregiver	3	6%
There is nobody else except me who will do it	3	6%
Planning on inheriting the patient's belongings	1	2%

87% of the respondents are engaged in caregiving because the patient is their relative. In three cases the patient is not only a relative, but also the caregiver is the only relative of the dementia patient. Thus, 49 caregivers out of 52 were related to the patient as a child caregiver or a spouse. In four cases or in 8% of the cases the caregiver was not related to the dementia patient. Three of four were paid for their services, while one respondent had been promised to inherit the belongings of the patient after his death. To continue, 28 out of 52 respondents (54%) were the only people who cared for the patient. This meant that these people were continuously in charge of taking care, running errands and managing the needs of the patients with dementia, and did not have time for themselves. For instance, 13 out of 28 worked full time along with being an only caregiver. All of these 13 respondents indicated that they did not receive any help from neither the state nor the charities. Moreover, seven out of these 13 respondents indicated that they feel stressed more than several times a day. Thus, 13.5% of the studied population indicated that they were the only person who cared for the patient. They did not receive any

support and they were stressed during the daytime each day. What it more important, these people marked their health state being average or bad.

To continue, the proportion of people who were not the only caregiver for the patient was 46%. The occupation of the respondents was distributed in the following shares (Figure 5).

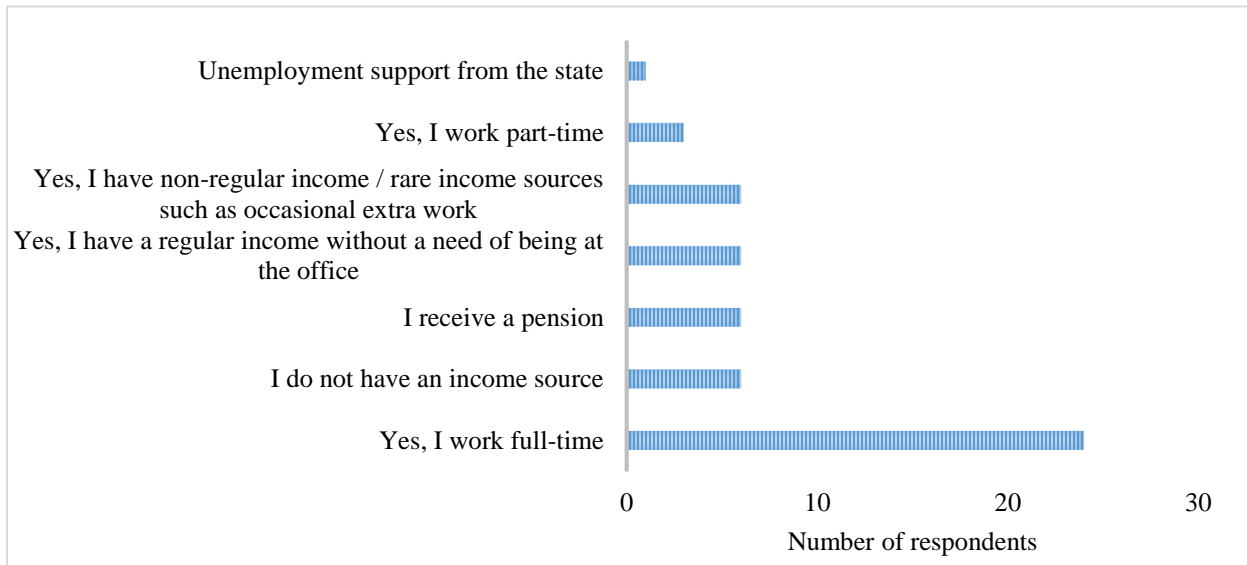


Figure 5. Occupation of the respondents

From the data displayed in the Figure 5 it becomes clear that almost the half of the respondents are employed full time, which adds to the stress experienced from being a caregiver. The average self-assessment of the health state of these people was equal to 3.7, which indicates that majority marked their health to be “bad” or “very bad”.

Moreover, the table below indicates the answers of people employed full-time to questions 11 and 12 (Appendices A, C).

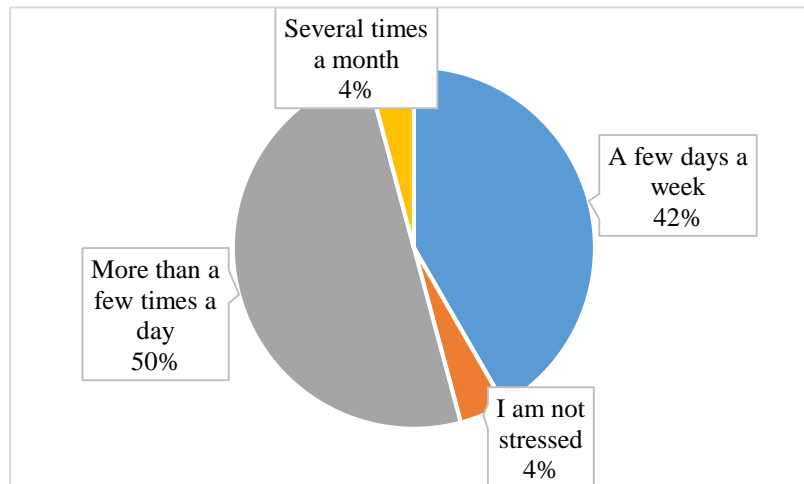
Table 3

Answers to questions 11 and 12 by respondents employed full time

	Yes	No
Do you have enough money for your needs?	11	13
Do you have enough time to solve your own problems / run errands?	6	18

It is clear that more than half are not able to satisfy their own needs despite the fact that they are employed full-time. Moreover, 18 of 24 full-time working caregivers were unable to take care of their own problems.

Moreover, only two respondents felt minor stress. They either had no stress or experienced it only in several occasions during a month (Figure 6).



*Figure 6.* Frequency of experiencing stress by respondents employed full time

At the same time, the table proves how stressed the people can be if they are engaged in 24/7 caregiving to dementia patient and in 40 hours a week job. 50% of the chosen respondents experienced stress during the day and 42% of the respondents were stressed during a week. This makes the proportion of the continuously stressed people equal to 92% of the working full-time respondents.

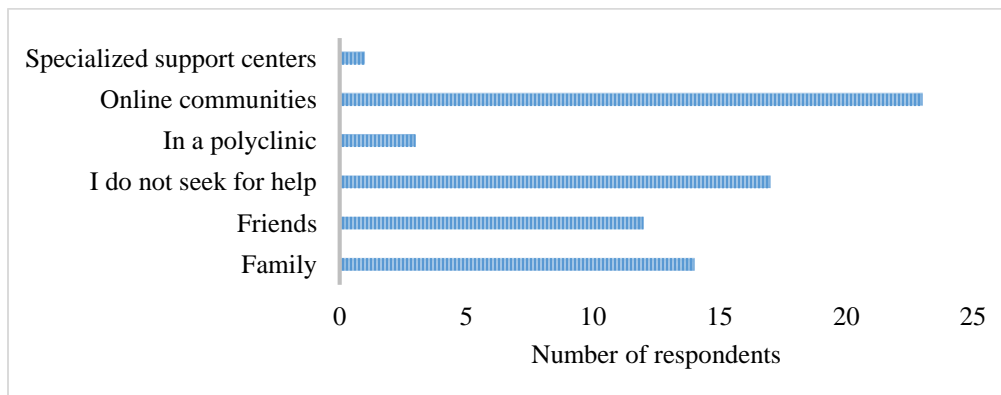
Moreover, six people were retired and served as a caregiver to their relatives. The frequency of experiencing stress was even higher for these respondents. Three people indicated that they were stressed several times a day, two of six were stressed few times a week and one respondent indicated that he was stressed constantly. Another caregiver who was constantly stressed was an unemployed caregiver, who received state funding due to an unemployment.



Four respondents who were stressed during the day were unemployed and did not have an income source. Only one person out of all 52 respondents felt no stress during caregiving.

From the data displayed above, one can conclude that people who worked full working hours and had to take care of dementia patients and retired caregivers were stressed highly. Unemployed full time caregivers marked similar stress levels. As for part-time working or out-of-office working caregivers, they have indicated moderate stress frequency (from several occasions a week to few times a month).

As for the existence of state support or support from charities or funds, six people have received state help as a caregiver, while only one caregiver received help from charities. This allows the author to conclude that neither state nor private organizations support caregivers residing in countries such as Russia and Kazakhstan. The caregivers, their needs and problems are ignored by the institutions, which also add to the stress levels of the named category of citizens.



*Figure 7.* Where the respondents look for support

From the given information (Figure 7), it becomes clear that the caregivers do not know or do not have specialized support. Only one person have received specialized support. 52 respondents have chosen 70 options. 37% receive information and support from friends and family, who are assumed to have none or minimal knowledge about the disease and the

psychological distress caused by it. 33% search for information and support online and 24% of the caregivers deal with their problems themselves. This means that no institutional organized support is available for the people engaged in continuous caregiving activities. Taking into account the fact that almost none of them receive financial support, the high stress levels are reasonable.

The questions 14-20 were constructed in a way to evaluate the severity of stress, the causes of stress and the opinions of the respondents on the situation they are in. The questions and answers are presented in Appendices A and C. For the analysis, the following table has been constructed in order to understand what the scale meant for the respondents.

Table 4

*Scales for the questions 14-20 and their interpretation*

Main focus of the question	Meaning of 1	Meaning of 10
Experiencing stress	No stress	Severe stress
Tiredness	Not tired	Severe tiredness
Expectations for future improvement	Optimistic	Pessimistic
Dementia symptoms influence (not recognizing)	Does not affect	Affects (saddens) greatly
Obligation to care rather a desire	More desire than obligation	More obligation than desire
Angry at patient for being sick	Not angry	Very angry
Breaking on at others sue to stress	Rarely	Frequently

Thus, the greater the number, the greater the stress is experienced by the respondent. The average for each caregiver has been calculated and presented in the bar chart below (Figure 8). It is evident from the bar chart that the number of people who have reported minimal stress levels or negative emotions from caregiving is extremely low. Three people had minimal stress (average 1 and 2 for all answers). Ten people's answers prove their stress levels to be average.

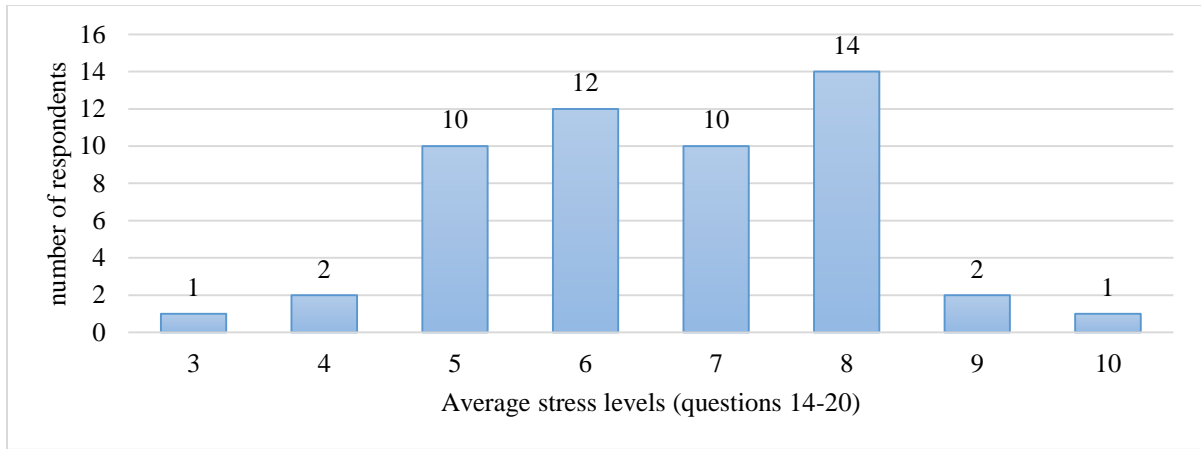


Figure 8. Number of respondents with various stress levels (average)

At the same time, other 39 respondents had experienced from average to severe stress.

Most of the respondents have marked 6, 7 and 8 out of 10, which is the highest possible level of stress included in the survey responses. Three respondents were severely stressed according to the survey.

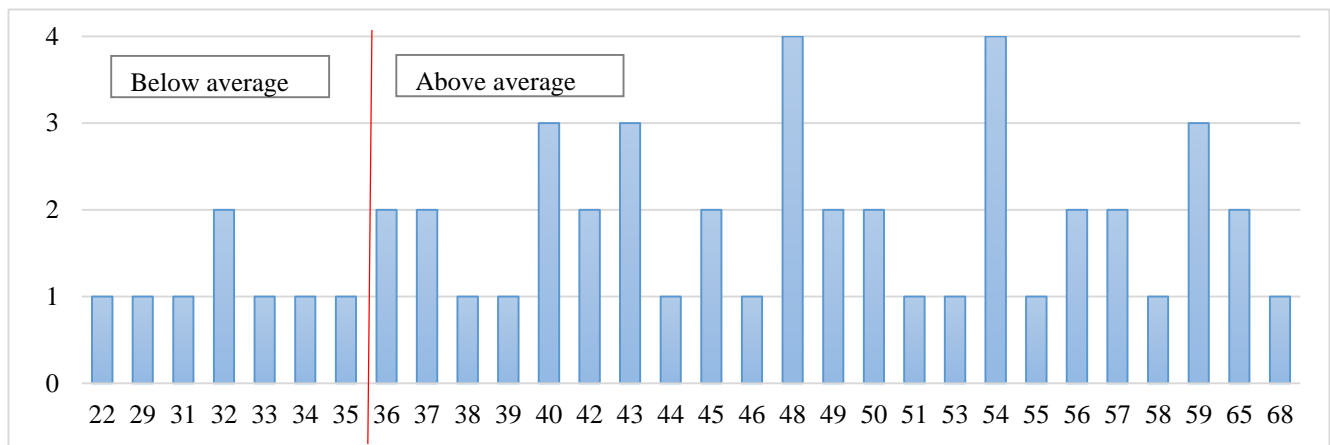


Figure 9. Number of respondents with various stress levels (total count)

The Figure 9 further investigates the psychological stress experienced by the respondents. Only a minority of respondents have answered the questions from 14 to 20 in a positive way, indicating low stress levels. Despite that, their total count for seven questions ranged from 22 to 35. In other words, their average mark was from 3 to 5. However, as it is evident from the Figure 9, the majority have experienced stress and stress related issues severely. The total count for

them for questions 14-20 varied from 36 to 68. Thus, the study of the survey results reveal the signs of severe stress in the majority of the respondents.

The following analysis has been conducted using a qualitative analysis software called MaxQDA, which has been used in a trial version. In order to conduct the analysis, the open-end answers of the respondents were extracted into a Microsoft Word document, and imported into the MaxQDA software. After that, the phrases from the transcript were coded based on nine codes classifying the type of problem mentioned by the respondents. All of the coding of the phrases in the form of the extract from the MaxQDA software is displayed in the Appendix E.

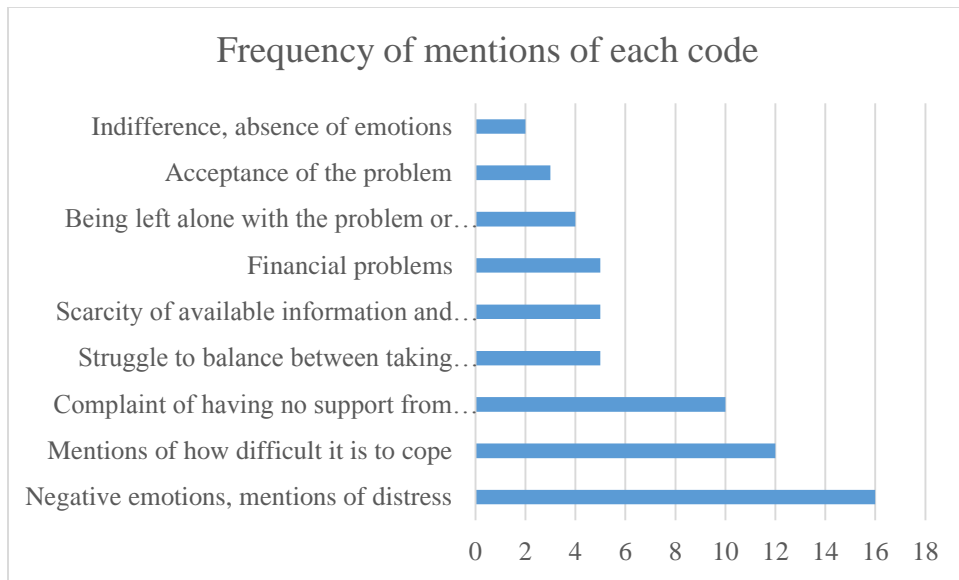
The results of the coding are displayed in Table 5 and Graph 10.

Table 5

*Frequency and percentage of mentions of each code*

<b>Type of a problem mentioned by the respondents</b>	<b>Frequency</b>	<b>Percentage</b>
Negative emotions, mentions of distress	16	26%
Mentions of how difficult it is to cope	12	19%
Complaint of having no support from government or NGOs	10	16%
Struggle to balance between taking care and other responsibilities	5	8%
Scarcity of available information and professional help	5	8%
Financial problems	5	8%
Being left alone with the problem or taking care alone	4	6%
Acceptance of the problem	3	5%
Indifference, absence of emotions	2	3%
<b>TOTAL</b>	<b>62</b>	

The majority of the problems mentioned by the respondents are different negative emotions the caregivers (16 mentions) and their discussing the difficulty of being around or taking care of the dementia patients. The third problem the majority of the respondents mentioned is the absence of institutional support. Other than that, respondents had other stressful factors in their lives such as being unable to maintain balance in their life or being forced to take care of their relatives.



*Figure 10.* Frequency of mentions of each code

Out of all respondents there were three people who had accepted the disease of their relative. This means that other 49 people feel stress with accepting the disease of the loved ones. They are not ready to accept the problem and feel various levels of stress due to the situation, their relation to the health problem of the relative.

### **Limitations**

The present thesis paper has some limitations that occurred due to Covid-19 pandemic consequences. Due to inconstant sanitary rules, the author was not able to meet the respondents in person in order to interview them. Moreover, the stress experienced by the respondents may be partially influenced by the lockdown and from the psychosis connected with the Covid-19 related concerns. However, the author does not include any of that into the research and has warned the respondents to avoid mentioning the Covid-19 related mental problems if that was possible.

**Bias**

The author has reconsidered the content of the survey questions in order to avoid design bias. That is to say, there was no purpose to convince the respondents to prove the author's point in purpose. Moreover, there was no participant bias, as all of the respondents took part in the survey voluntarily. Moreover, the author is aware about the analysis bias. Thus, she carried out the analysis without bias and with an aim of developing and delivering a properly conducted research.

**Conclusion**

In conclusion, the present thesis has examined the existence of psychological stress of caregivers for Dementia Patients residing in Russia and Kazakhstan. In this regards, 52 people living in the named circumstances were surveyed in order to find out if these people suffer from distress and what are the main causes of the stress. Moreover, the author aimed to find out to what extent the caregivers are supported by the governments or charities. All of the objectives were achieved and the author was able to conclude that majority of the respondents felt stressed from few times a day to few times a week. Moreover, the intensity of their stress was from average to high.

The importance of the present thesis is in evaluating the extent of the problem in two countries. The findings of the present thesis can be used by scholars to receive an insight regarding the caregivers of CIS counties, and could be used by specialized caregiver support centres.

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**Appendix A****Survey questions**

1. Indicate your gender
  - a. Male
  - b. Female
2. Indicate your age rounded to the full years
3. On a scale from one to five subjectively rate your health state, where 1 is “bad, I need a medical care” and 5 is “I am absolutely healthy”.
4. How long have you been taking care of a patient with dementia?
  - a. Less than a year
  - b. Between 1-3 years
  - c. Between 3-5 years
  - d. Between 5-10 years
  - e. Between 10-15 years
  - f. More than 15 years
5. What is the main reason why you care for a patient with dementia?
  - a. Familial sentiment
  - b. I am a hired caregiver
  - c. There is nobody else except me who will do it
  - d. I am planning on inheriting the patient’s flat and belongings
  - e. Other answer\*
6. Are you the only person who takes care of a patient with dementia?
  - a. Yes

- b. No
7. Do you work? Do you have an income?
- a. Yes, I work full-time
  - b. Yes, I work part-time
  - c. Yes, I have a regular income without a need of being at the office
  - d. Yes, I have non-regular income / rare income sources such as occasional extra work
  - e. I do not have an income source
  - f. Other answer\*
8. Do you receive any support from the state as a person who cares for a person with dementia?
- a. Yes
  - b. No
9. Do you receive any support from charities?
- a. Yes
  - b. No
10. How much money you spend on a patient's needs?
11. Do you have enough money for your needs?
- a. Yes
  - b. No
12. Do you have enough time to solve your own problems / run errands?
- a. Yes
  - b. No



c. Other answer\*

13. How often do you experience stress?

- a. More than a few times a day
- b. A few days a week
- c. Several times a month
- d. I am not stressed
- e. Other answer\*

10 scale questions	Evaluate the following from 1 to 10	Meaning of 1	Meaning of 10
14.	Experiencing stress	No stress	Severe stress
15.	Tiredness	Not tired	Severe tiredness
16.	Expectations for future improvement	Disagree	Agree
17.	Dementia symptoms influence (not recognizing)	Disagree	Agree
18.	Obligation to care rather a desire	Disagree	Agree
19.	Angry for being sick	Disagree	Agree
20.	To be irritated at others	Disagree	Agree

21. Where do you get counselling/psychological help? (multiple choices can be selected)

- a. Friends/Friends
- b. Family members
- c. In the polyclinic/hospital
- d. Online Communities

- e. In specialized centers
- f. I do not seek for help
- g. Other answer\*

## Appendix B

The survey answers – 1<sup>st</sup> part

Caregiver	Q 1	Q 2	Q 3	Q 4 min	Q 4 max	Q 5	Q 6	Q 7	Q 8	Q 9	Q 10 in Rub
Caregiver 1	Female	35	4	3	5	Familial sentiment	No	Yes, I work full-time	No	No	5000
Caregiver 2	Female	34	2	5	10	I am a hired caregiver	No	Yes, I work full-time	No	No	35000
Caregiver 3	Female	57	4	10	15	Familial sentiment	Yes	Yes, I work full-time	No	No	40000
Caregiver 4	Female	57	3	10	15	Familial sentiment	Yes	I receive a pension	No	No	15000
Caregiver 5	Female	51	4	3	5	Familial sentiment	No	Yes, I work full-time	No	No	The pension of the dementia patient covers the expenses
Caregiver 6	Female	32	3	5	10	There is nobody else except me who will do it	Yes	Yes, I work part-time	No	No	12500
Caregiver 7	Female	44	2	10	15	Familial sentiment	Yes	I do not have an income source	Yes	No	30000
Caregiver 8	Female	44	4	1	3	Familial sentiment	Yes	Yes, I have non-regular income / rare income sources such as occasional extra work	No	No	20000
Caregiver 9	Female	44	3	1	3	Familial sentiment	Yes	Yes, I work full-time	No	No	I do not count
Caregiver 10	Female	27	3	3	5	Familial sentiment	No	Yes, I have a regular income without a need of	No	No	20000

								being at the office			
Caregiver 11	Female	48	4	10	15	Familial sentiment	Yes	Yes, I have a regular income without a need of being at the office	No	No	25000
Caregiver 12	Female	63	4	1	3	Familial sentiment	No	I receive a pension	No	Yes	30000
Caregiver 13	Female	34	4	1	3	Familial sentiment	No	Yes, I work full-time	No	No	15000
Caregiver 14	Female	57	3	1	3	Familial sentiment	Yes	I receive a pension	No	No	I do not count
Caregiver 15	Female	35	4	3	5	There is nobody else except me who will do it	No	Yes, I work full-time	No	No	30000
Caregiver 16	Female	58	4	5	10	Familial sentiment, inheritance , payment after the patient's death	Yes	I receive a pension	No	No	17000
Caregiver 17	Female	59	4	3	5	Familial sentiment	No	I receive a pension	No	No	22500
Caregiver 18	Female	51	4	0	1	Familial sentiment	No	Yes, I work full-time	No	No	12000
Caregiver 19	Male	24	4	3	5	Familial sentiment	No	Yes, I have non-regular income / rare income sources such as occasional extra work	No	No	17000
Caregiver 20	Female	47	2	5	10	There is nobody else except me who will do it	Yes	I do not have an income source	No	No	17000

Caregiver 21	Female	32	3	1	3	Familial sentiment	No	Yes, I work full-time	No	No	20000
Caregiver 22	Female	58	5	1	3	Familial sentiment	Yes	Yes, I have a regular income without a need of being at the office	No	No	I do not count
Caregiver 23	Female	50	3	1	3	Familial sentiment	Yes	Yes, I work full-time	No	No	25000
Caregiver 24	Female	47	3	5	10	Familial sentiment	No	I do not have an income source	No	No	The pension of the dementia patient covers the expenses
Caregiver 25	Female	50	3	1	3	Familial sentiment	Yes	Yes, I work full-time	No	No	10000
Caregiver 26	Female	35	2	3	5	Familial sentiment	No	Yes, I work full-time	No	No	10000
Caregiver 27	Female	39	4	1	3	Familial sentiment	Yes	Yes, I work full-time	No	No	30000
Caregiver 28	Female	41	4	5	10	Familial sentiment	Yes	Yes, I work full-time	No	No	20000
Caregiver 29	Male	43	5	3	5	Familial sentiment	No	Yes, I have a regular income without a need of being at the office	No	No	20000
Caregiver 30	Female	41	5	1	3	Familial sentiment	Yes	Yes, I work full-time	No	No	5000
Caregiver 31	Female	53	4	3	5	Familial sentiment	Yes	Yes, I work full-time	No	No	15000
Caregiver 32	Female	42	3	3	5	Familial sentiment	Yes	I do not have an income source	No	No	15000
Caregiver 33	Female	28	4	3	5	Familial sentiment	Yes	I sell my belongings through an online market	No	No	12000

Caregiver 34	Female	55	4	5	10	Familial sentiment	No	Yes, I work full-time	Yes	No	25000
Caregiver 35	Female	48	3	1	3	Familial sentiment	Yes	Yes, I have a regular income without a need of being at the office	No	No	50000
Caregiver 36	Female	37	5	0	1	I am a hired caregiver	No	Yes, I work full-time	Yes	No	9000
Caregiver 37	Female	28	4	1	3	Familial sentiment	No	Yes, I work part-time	No	No	30000
Caregiver 38	Female	65	4	5	10	Familial sentiment	Yes	Yes, I work part-time	No	No	7000
Caregiver 39	Female	48	2	1	3	Familial sentiment	Yes	I do not work, but my mother supports me financially	Yes	No	All of my income goes to a patient support
Caregiver 40	Male	67	3	3	5	Familial sentiment	No	Yes, I have a regular income without a need of being at the office	No	No	20000
Caregiver 41	Female	28	4	1	3	Familial sentiment	No	Yes, I work full-time	No	No	15000
Caregiver 42	Female	52	4	3	5	Familial sentiment	Yes	Yes, I work full-time	No	No	22000
Caregiver 43	Female	38	4	1	3	Familial sentiment	No	I do not have an income source	No	No	15000
Caregiver 44	Female	58	3	3	5	I am a hired caregiver	Yes	Yes, I work full-time	No	No	The pension of the dementia patient covers the expenses
Caregiver 45	Female	56	3	3	5	Familial sentiment	Yes	Unemployment support from the state	Yes	No	20000

Caregiver 46	Female	56	4	5	10	Familial sentiment	Yes	Yes, I work full-time	No	No	20000
Caregiver 47	Female	32	4	5	10	Familial sentiment	Yes	Yes, I have non-regular income / rare income sources such as occasional extra work	No	No	25000
Caregiver 48	Female	35	4	0	1	Familial sentiment	Yes	Yes, I work full-time	No	No	15000
Caregiver 49	Female	36	4	5	10	Familial sentiment	No	Yes, I have non-regular income / rare income sources such as occasional extra work	Yes	No	250\$
Caregiver 50	Female	33	3	0	1	Familial sentiment	No	I do not have an income source	No	No	The pension of the dementia patient covers the expenses
Caregiver 51	Female	45	4	3	5	Familial sentiment	No	Yes, I work full-time	No	No	30000
Caregiver 52	Female	57	4	0	1	Familial sentiment	Yes	I receive a pension	No	No	20000

## Appendix C

## The survey answers – 2nd part

Caregiver	Q 11	Q 12	Q 13	Q 14	Q 15	Q 16	Q 17	Q 18	Q 19	Q 20	Q 21
Caregiver 1	No	No	A few days a week	7	10	8	7	2	3	8	I do not seek for help
Caregiver 2	No	No	More than a few times a day	9	10	10	2	1	1	5	Online communities
Caregiver 3	No	No	A few days a week	7	7	7	10	1	1	4	I do not seek for help
Caregiver 4	No	No	More than a few times a day	10	10	10	2	10	3	5	I do not seek for help
Caregiver 5	Yes	It differs each year	A few days a week	9	10	8	10	6	6	7	Friends Online communities
Caregiver 6	Yes	No	More than a few times a day	6	10	5	5	10	8	5	Friends Family Specialized support centers
Caregiver 7	No	No	A few days a week	10	9	10	10	6	1	8	I do not seek for help
Caregiver 8	No	No	I do not know	5	10	10	5	3	1	3	I do not seek for help
Caregiver 9	No	No	More than a few times a day	10	10	10	5	10	8	5	Online communities
Caregiver 10	Yes	Yes	A few days a week	8	8	6	10	1	1	8	Family Online communities
Caregiver 11	No	No	Several times a month	4	10	10	5	1	1	5	I do not seek for help
Caregiver 12	No	No	More than a few times a day	8	10	6	4	1	1	2	Family Online communities
Caregiver 13	No	No	More than a few times a day	10	10	10	10	10	8	10	Online communities
Caregiver 14	No	Yes	More than a few times a day	8	7	8	7	1	1	3	Family
Caregiver 15	No	No	More than a few times a day	9	10	6	10	6	1	8	Family In a polyclinic Online communities



Caregiver 16	Yes	Yes	Constantly when I care for a patient with dementia	5	4	1	2	10	7	2	Friends Online communities
Caregiver 17	Yes	I would n't be able without my husband and my son	A few days a week	7	9	10	10	6	8	9	Family Online communities
Caregiver 18	Yes	Yes	A few days a week	5	10	5	9	8	8	1	Family
Caregiver 19	No	No	Several times a month	5	8	5	10	4	1	1	I do not seek for help
Caregiver 20	No	No	More than a few times a day	10	10	5	2	1	1	10	Online communities
Caregiver 21	No	No	More than a few times a day	10	10	7	10	10	9	9	I do not seek for help
Caregiver 22	Yes	No	More than a few times a day	10	8	9	1	10	10	6	Family In a polyclinic
Caregiver 23	Yes	Yes	More than a few times a day	8	10	10	1	2	3	6	Online communities
Caregiver 24	Yes	If I was completely involved in caregiving, there will be no spare time for me and my family	More than a few times a day	7	9	8	10	8	5	6	Family
Caregiver 25	No	No	A few days a week	5	10	10	5	10	7	10	I do not seek for help

Caregiver 26	Yes	No	More than a few times a day	4	1	2	10	5	10	10	Friends Family
Caregiver 27	No	No	A few days a week	10	10	10	10	1	1	6	I do not seek for help
Caregiver 28	No	No	More than a few times a day	9	10	10	8	9	9	10	Friends
Caregiver 29	Yes	No	A few days a week	8	8	3	5	7	10	3	Online communities
Caregiver 30	Yes	Yes	I am not stressed	1	5	10	10	1	1	1	I do not seek for help
Caregiver 31	Yes	Yes	A few days a week	10	8	10	10	1	4	5	Friends Family Online community
Caregiver 32	No	No	A few days a week	8	8	9	8	10	6	7	I do not seek for help
Caregiver 33	No	Yes	A few days a week	10	7	9	6	9	9	9	I do not seek for help
Caregiver 34	Yes	No	Several times a month	7	9	4	9	2	4	8	Online communities
Caregiver 35	No	No	A few days a week	8	8	10	7	9	4	8	Online communities
Caregiver 36	Yes	Yes	A few days a week	7	10	8	3	10	1	9	Online communities
Caregiver 37	No	No	A few days a week	9	10	7	5	1	1	10	Friends
Caregiver 38	No	No	More than a few times a day	9	10	5	8	10	8	5	Family Online communities
Caregiver 39	No	No	A few days a week	9	9	7	1	5	7	2	Friends In a polyclinic Online communities
Caregiver 40	No	No	Several times a month	4	7	3	1	1	1	5	Online communities
Caregiver 41	No	No	More than a few times a day	8	9	10	6	8	7	1	Friends Family
Caregiver 42	No	No	More than a few times a day	10	10	10	10	10	1	8	Online communities
Caregiver 43	Yes	Yes	More than a few times a day	6	8	8	8	6	2	2	Friends Online communities
Caregiver 44	Yes	Yes	More than a few times a day	10	10	1	1	1	10	10	I do not seek for help
Caregiver 45	Yes	No	Constantly	8	8	3	5	2	2	8	Online communities
Caregiver 46	Yes	No	A few days a week	8	8	10	5	5	7	2	In primary care facility I received unsatisfactory

											treatment, thus, I did not look for another support source
Caregiver 47	No	No	More than a few times a day	9	10	10	7	2	2	8	Friends Family
Caregiver 48	No	No	More than a few times a day	10	10	1	10	10	5	8	Friends Online communities
Caregiver 49	No	No	More than a few times a day	10	10	10	9	3	7	8	Family
Caregiver 50	No	No	More than a few times a day	8	9	5	3	2	1	5	I do not seek for help
Caregiver 51	Yes	No	A few days a week	8	8	8	10	6	1	10	Friends
Caregiver 52	Yes	No	A few days a week	8	8	3	9	1	1	2	I do not seek for help

## Appendix D

## Survey answers the third part

Caregiver	Answer to an open question
Caregiver 1	For a long time she could not cope with the adoption of mother's disease. Resisted, angry and stuff, but when Mom fell ill in my head that something has changed and I was no longer so hard neither morally nor physically, I like to let go of everything and devote themselves to it. It lasted not for a long time, my mother was burned for 3.5 months.
Caregiver 3	Now I'm retired, but when I was working it was very hard and take care of and work to earn a pension. If I pay for the care that I would devote more time to care.
Caregiver 5	It is a pity that the many scandals in the family when a patient is between the children. Mom raised us four, but now the next two.
Caregiver 7	One hard to care if there was outside help, you can easy to handle ..
Caregiver 9	Mother died ... It became easier, but in 3 years that the child was in school and from elementary school the children were not controlled, and their progress equals 0 .... now working on a child, trying to catch up ....
Caregiver 12	I would like to receive more information from other sources and physicians. And it is a very lengthy process of registration of disability.
Caregiver 13	Our family was faced with Alzheimer's disease, ill mother. A few months ago she died. Mom was in '62. Support was not from anyone, neither the treating physician nor the state. Everybody just shrugged their shoulders and said, "Be brave, then worse ..." experienced all the circles of hell because of this disease. Especially hard it was getting the idea that this disease is incurable and any help we could not.
Caregiver 14	It is difficult to accept that a native person becomes so angry, understood nothing. Each day becomes a challenge. No one would not wish this experience .Very hard !!! If such tests are given, then I stand it !!! I'm strong ! I love my family and I will do everything so that they were good !!!!
Caregiver 15	It is a pity that there is no support for such people and no specialists
Caregiver 16	As for the question, I do not see problem solving. I did not understand. Whose problems did you mean? Or my patient? In terms of a patient getting better - there was nothing to decide just Living out. My problems are solved, until I move and think. There was also a question about aid from the state. Help in the form of tax free diapers and p / p mattress is, supplement the disability is. Personally, I aid was 1200 rubles / month, until I began to receive a pension. Now there is no help. I have it and not looking.
Caregiver 17	I would like more information from the doctors, when you know the diagnosis of a relative. Many have mistakes could have been avoided.
Caregiver 18	I take care of her mother 87let July 2020. I took to him from the village. 3 months was quiet horror. I did not know what to do. For information on dementia found on the Internet. I began to understand how to deal with such patients. Morally difficult. I was used to an active lifestyle. Now I spend more time at home. And it annoys me. It helps daughter. She is on maternity leave and her husband. Saves work. My mother is now two states from morning till evening, she thought it was at home and she nada go to feed chickens, cows. In the evening, she did not recognize me. And it seem that she was at work, and at night goes home.
Caregiver 20	At the legislative level to pay attention to caregivers, to increase pension to such patients.
Caregiver 22	Yeah I accustomed through the years, at first thought that can not stand

Caregiver 23	We need a program of state support for these caregivers. And in general, for the implementation of palliative care program.
Caregiver 25	My mother's mother had Alzheimer's. And now my mother is a strong possibility that I will have the disease myself. I do not want my children to suffer with me. I am a paramedic myself and I understand everything myself. There are so many similar patients. I do not understand why there are so many.
Caregiver 26	The worst thing is when the love of the loved one, it is hatred of empty shell where there is nobody and no way out except death.
Caregiver 29	1. there is a necessity to set up a forum for caregivers on state webpages. What to use someone else's already gained experience caring. 2. Another approach in the field of family policy to the maximum number of couples living out together (or less patients with their care)
Caregiver 31	For 5 years of care, we have adapted to each other, I am glad that she is no longer trying to escape to his home or somewhere to go. But sometimes I struggle to give her more communication than the daily care and mandatory procedures. I'm scared to communicate with her, there is no logic and it is a completely different person.
Caregiver 32	I would love to receive psychological assistance on a regular basis, at least once a month professionally trained specialists, to relieve the tension. I am a member in the group Vkontakte "Fondaltsrus" where I read the news and looking for tips on caring for dementia patients. But this to me is not enough. I would like to fill in a brief diary, which would reflect the course of the disease my mother every day, its activity, emotional state, etc., but this takes time. I would like to study the problem of dementia by analyzing the lifestyle, the patient's thinking and his family conflicts, in order to avoid such a diagnosis in their own old age. I would like to share their experiences with others to care for their elderly people. I would like to receive financial assistance from the state in the form of wages, like professional nurses, to receive benefits for expensive medication, treatment and patient transportation. Now none of this have not, since disability is not yet issued. I do not work myself due to constant supervision and care of the sick, living on a pension ill mother and her husband, the three of us. Husband earns very little, not always, works part-time. Interrupts as we can, to a full dose of medicine for a sick mother does not have enough funds.
Caregiver 36	Should not be allowed to care for patients with dementia of people "from the street". Need for special training, as well as help the caregiver psychologist.
Caregiver 37	Alzheimer's disease deserves more attention from scientists. I lost my dad in 2 years of illness, he passed away in '53. It is very hard physically and morally (especially when it is a close relative like a parent or children) to live with a person with a disease ... an incurable disease.
Caregiver 38	Difficult!
Caregiver 45	It is very hard physically and mentally especially because a person dies before our eyes, "a close relative.
Caregiver 46	It is very difficult when the person does not understand you, and constantly had to explain the same thing, and even degradation of the individual is very pressure on the psyche (in the past, successful, powerful, very competent man-now helpless creature)
Caregiver 47	I would like to receive support from the state
Caregiver 49	Are lacking in psychological help, I myself can not put up for 7 years with the disease, looking for outlets that are not. Friends do not accept why I do not go with them for a walk after my mother, and I mentally squeezed like a lemon, there is neither the desire nor the strength to go anywhere. I know it's bad, but nothing I can do about it. I started drinking beer, it relieves –I have gained weight as a result.... custody of his mother to me, pay benefits, at twice the shop go, nurses are very expensive. I very much want to find a job or his business open. But all the time it does not work, after stress with my mother, shaking for a long time, there were panic attacks, and more children want these 7 years have passed so quickly that the there was no time and I already am 36 (((

Caregiver 50	I'm mentally drained. Sometimes even physically. I look after the grandfather every day, seven days a week, and when mom comes home from work, then supper and rises to the second floor to rest. She wakes up early and prepare breakfast for him, is removed, if the grandfather went to the toilet is not there. And so I spent the whole day with him, and cook lunch and dinner, do cleaning, chores around the garden grandfather hygiene, too, for me, because my mother can not be - it protects the nerves. I can briefly wandered into the store. And yet. On Sunday, when my mother off, I want to really relax and spend the day away from home, but my mother finds some things. It is spring - will soon begin a vegetable garden. I completely lose my mind. Very tired. I want to do and what I personally like. Sometimes possible to play computer games before going to bed, when it's all gone to bed. But in the evening, basically, I was exhausted, and even on their own hobbies I do not have enough forces. I would like to learn a foreign language, walking more, find a new hobby, but it's almost impossible. I have nothing. Either there are no forces, or the time or mood. Notice of a continuous depressed mood. Mom did not even ask how my day was and how I feel. Not pulls me in the evening because it is tired after work. Grandpa really bad. It is aggressive. Sometimes it is not possible to remain calm. Sometimes I'm very angry. Very tired.
Caregiver 51	My mother's pension is allowed to hire a nurse, so on weekdays from 11 to 19, we can work. But every morning I go to feed and put in order my mother to nurse, and spend the night we took turns with his brother. Weekend sit by turns too. I was half asleep sometimes do not understand, or at home, I have my mother, and in the evening I can not remember right away - I spend the night, or a brother today, so tired of the bustle ..
Caregiver 52	I look after my mother recently, before that looked remotely, by phone, is now transported to yourself, BA yet often do not know in the middle stage (me, the hour and every day is going to go back, the memory holds event no more than 5 minutes, non-corrosive, she cannot be left alone but not more than 3 hours. This is so tiring and hard) her disease stopped at this stage and is not passed into the heavy form.

## Appendix E

### Extract from MAXQDA 2020

#### Summaries with Coded Segments - Dementia qa.mx20

Code	Coded segments
Scarcity of available information and professional help	I would like to receive more information from other sources and physicians transcript: 7 - 7 (0)
	I would like more information from the doctors, when you know the diagnosis of a relative. transcript: 14 - 14 (0)
	1. there is a necessity to set up a forum for caregivers on state webpages. transcript: 21 - 21 (0)
	would like to study the problem of dementia by analyzing the lifestyle, the patient's thinking and his family conflicts, in order to avoid such a diagnosis in their own old age transcript: 24 - 24 (0)
	Should not be allowed to care for patients with dementia of people "from the street". Need for special training, as well as help the caregiver psychologist. transcript: 26 - 26 (0)
Complaint of having no support from government or NGOs	And it is a very lengthy process of registration of disability. transcript: 7 - 7 (0)
	Support was not from anyone, neither the treating physician nor the state transcript: 8 - 8 (0)
	It is a pity that there is no support for people with asthma and no specialists transcript: 10 - 10 (0)

There was also a question about aid gtsudarstva

transcript: 12 - 12 (0)

At the legislative level to pay attention to caregivers, to increase pension to such patients.

transcript: 16 - 16 (0)

We need a program of state support for these caregivers.

transcript: 18 - 18 (0)

1. there is a necessity to set up a forum for caregivers on state webpages.

transcript: 21 - 21 (0)

"I would love to receive psychological assistance on a regular basis

transcript: 23 - 23 (0)

I would like to fill in a brief diary, which would reflect the course of the disease my mother every day, its activity, emotional state, etc., but this takes time.

transcript: 23 - 23 (0)

I would like to receive support from the state

transcript: 31 - 31 (0)

Being left  
alone with the  
problem

One hard to care

transcript: 4 - 4 (0)

Everything just shrugged their shoulders and said,

transcript: 8 - 8 (0)



Sometimes even physically. I look after the grandfather every day, seven days a week,

transcript: 33 - 33 (0)

I look after my mother recently, before that looked remotely, by phone, is now transported to yourself, BA yet often do not know in the middle stage (me, the hour and every day is going to go back, the memory holds event no more than 5 minutes, non-corrosive, can be left alone but not more than 3 hours) mol Lord to asthma stopped at this stage and is not passed into the heavy form.

transcript: 35 - 35 (0)

Acceptance  
of the problem

like to let go

transcript: 1 - 1 (0)

I love my family and I will do everything so that they were good !!!!

transcript: 9 - 9 (0)

Yeah I accustomed through the years, at first thought that can not stand

transcript: 17 - 17 (0)

Indifference,  
absence of emotions

no longer so hard neither morally nor physically

transcript: 1 - 1 (0)

I mentally squeezed like a lemon

transcript: 32 - 32 (0)

Struggle to  
balance between care  
and other  
responsibilities

in 3 years that the child was in school and from elementary school the children were not controlled, and their progress equals 0.

transcript: 5 - 5 (0)

I struggle to give her more communication than the daily care and mandatory procedure

transcript: 22 - 22 (0)

Friends do not accept why I do not go with them for a walk after my mother, a  
transcript: 32 - 32 (0)

I want to do and what I personally like.  
transcript: 33 - 33 (0)

But every morning I go to feed and put in order my mother to nurse, and spend  
the night we took turns with his brother.  
transcript: 34 - 34 (0)

Financial  
problems

If I pay for the care  
transcript: 2 - 2 (0)

Now there is no help.  
transcript: 13 - 13 (0)

At the legislative level to pay attention to caregivers, to increase pension to such  
patients.  
transcript: 16 - 16 (0)

I would like to receive financial assistance from the state in the form of wages  
transcript: 25 - 25 (0)

, nurses are very expensive.  
transcript: 32 - 32 (0)

Mentions of  
how difficult it is to  
cope

very hard  
transcript: 2 - 2 (0)

Especially hard it was getting the idea that this disease is incurable and any help  
we could not.  
transcript: 8 - 8 (0)

It is difficult to accept that a native person becomes so angry,

transcript: 9 - 9 (0)

Very hard

transcript: 9 - 9 (0)

In the evening, she did not recognize me. And it seem that she was at work, and at night goes home.

transcript: 15 - 15 (0)

Heavy

transcript: 28 - 28 (0)

It is very hard physically and mentally especially because a person dies before our eyes,

transcript: 29 - 29 (0)

It is very difficult when the person does not understand you

transcript: 30 - 30 (0)

Very tired

transcript: 33 - 33 (0)

I do not have enough forces

transcript: 33 - 33 (0)

Sometimes I'm very angry. Very tired.

transcript: 33 - 33 (0)

she cannot be left alone but not more than 3 hours. This is so tiring and hard.

transcript: 35 - 35 (0)

Negative  
emotions, mentions  
of distress

could not cope

transcript: 1 - 1 (0)

Resisted

transcript: 1 - 1 (0)

angry

transcript: 1 - 1 (0)

scandals

transcript: 3 - 3 (0)

Especially hard it was getting the idea that this disease is incurable and any help we could not.

transcript: 8 - 8 (0)

3 months was quiet horror.

transcript: 15 - 15 (0)

My mother's mother had Alzheimer's. And now my mother is a strong possibility that I will have the disease myself. I do not want my children to suffer with me. I am a paramedic myself and I understand everything myself. There are so many similar patients. I do not understand why there are so many.

transcript: 19 - 19 (0)

one, it is hatred of empty shell

transcript: 20 - 20 (0)

I struggle to give her more communication than the daily care and mandatory procedure

transcript: 22 - 22 (0)

I'm scared to communicate with her, there is no logic and it is a completely different person.

transcript: 22 - 22 (0)

in '53. It is very hard physically and morally

transcript: 27 - 27 (0)

It is very hard physically and mentally especially when a person dies before your eyes,

transcript: 29 - 29 (0)

after stress with my mother, shaking for a long time

transcript: 32 - 32 (0)

there were panic attacks

transcript: 32 - 32 (0)

I'm mentally drained. S

transcript: 33 - 33 (0)

Sometimes I'm very angry. Very tired.

transcript: 33 - 33 (0)