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SUPPORT AND EXPERIENCE OF FAMILIES CARING FOR A SENIOR WITH DEMENTIA

APOIO E EXPERIÊNCIA DE FAMÍLIAS CUIDANDO DE UM IDOSO COM DEMÊNCIA

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Abstract: The public, experts and government programs agree on the importance of supporting life in a natural social environment at all stages of life. Family care allows patients to live in a familiar environment, with close people, and minimizes the loss of closer and wider social ties and favorite activities. Compared to residential facilities, it is cheaper, preserves the patient's quality of life and prolongs the activity and self-sufficiency of such patients. Caring for a loved one suffering from dementia is in most cases a significant burden for the caregiver with negative consequences in the psychological, somatic, social and financial areas. This paper aims to highlight the importance of family carers and to reflect on questions and topics which have risen from the research conducted.

Keywords: A support group. Dementia. Family. Help. Home care. The burden of family careers.

Resumo: O público, especialistas e programas governamentais concordam com a importância de apoiar a vida em um ambiente social natural em todas as fases da vida. O cuidado familiar permite que os pacientes vivam em um ambiente familiar, com pessoas próximas e minimiza a perda de laços sociais mais próximos e mais amplos e atividades favoritas. Em comparação com instalações residenciais, é mais barato, preserva a qualidade de vida do paciente e prolonga a atividade e a autossuficiência desses pacientes. Cuidar de um ente querido que sofre de demência é, na maioria dos casos, um fardo significativo para o cuidador com consequências negativas nas áreas psicológica, somática, social e financeira. Este artigo tem como objetivo destacar a importância dos cuidadores familiares e refletir sobre questões e temas que surgiram a partir da pesquisa realizada.

Palavras-chave: Um grupo de apoio. Demência. Família. Ajuda. Atendimento domiciliar. O fardo das carreiras familiares.

1. INTRODUCTION

The demographic changes influence the age structure of society, and we notice society's ageing and the growing number of people in seniors' age. Mainly, older seniors require a more specific approach and support. In the context of this paper, is important for us to mention the topic of multidisciplinary cooperation. With regards to seniors living with dementia, multidisciplinary cooperation is crucial as the medical and social support must intensively cooperate. The doctor, general doctor or specialist must know the family environment of a client to be able to provide general information about options which the client and their family have to ensure quality services for a quality life.

In the context of the state's authority approach mainly in self-managing sectors (city parts, towns, and towns with extended rights), there has been a diverse approach toward people living with dementia. If dementia is noticed as an international priority, it is important to approach this phenomenon with a diverse attitude. Several types of questions are opened and solved questions such as financial resources, quality of provided services for people living with dementia, the support of field workers and ambulant services, the building of specialized houses for housing services dedicated to people with dementia, availability and sufficiency of mentioned services … Therefore, we can notice a significant change in society's attitude towards people with dementia who are an integral part of our life since we meet them daily or we are providing or securing sufficient care for them.

Alzheimer's disease significantly changes the life of a person who is diagnosed with it. Similarly, it influences the life of their family, friends, and the care given must consider whether they can provide adequate care. Also, they must evaluate their abilities and skills. A caregiver must evaluate their knowledge and if it is needed to extend it, chart their contacts and further contacts that they might need. Most families who can want to look after the senior in the home environment. According to Pidrman (2007), the role of a caregiver is crucial during care provision. Attitudes, relationships, ability to cope with unseen situations and emotional load of care provision are the factors which determine whether the seniors will be able to stay in their home environment, or whether they should be placed in housing service. The required care for a person with Alzheimer's disease must be provided 24/7.

With the spread of Alzheimer's disease, there is a growing tendency for family members to take care of their seniors. Nowadays, the potential of communication and family members' support is underestimated. The family caregivers should feel and be aware of the interest and support. The long-term and daily care for an ill person is influencing the health and psychological condition of a caregiver. The role of a family member as a caregiver is stressful, it influences the family mood, and is for caregiver physically and psychologically demanding. Also, we cannot forget that the caregiver cannot have a job, so it could be talked about negative financial influence as well.

2. DEMENTIA DISEASE IN THE CONTEXT OF NUMBER AND DEMOGRAPHIC CHANGES

The World Health Organization – WHO published in their action plan (Global action plan on the public health response to dementia 2017-2025) these alarming numbers. In 2015 there were 47 000 000 people diagnosed with dementia disease, which is 5 % world population. The future perspective is that in 2030 it will be 75 000 000 people and in 2050 it could be 132 000 000 people. It is estimated that every year dementia disease will be diagnosed in 9,9 000 000 people. Now there are 60 % of people living with dementia lives in countries with low and medium incomes and it is believed that most new cases (71 %) will be diagnosed in these countries. This assumption is clarified by Alzheimer's Disease International Organization whose data was used by Mátl, Mátlová and Holmerová (2016) … most people with dementia (58 %) live in less developed countries or countries with medium incomes. Also, it shows that in the region of middle Europe where is the Czech Republic the presence of people with dementia lower than is average anywhere else in the world. It could be argued that countries who joined the European Union with the Czech Republic in 2004 have a lower prevalence of dementia disease than is average in European union. Further, is important to mention that dementia disease does not occur only in older people. Dementia disease in younger age (under 65 years) afflicts 9 % people from the whole group of people with dementia.

Therefore, dementia becomes a crucial risk factor in everyone's life but in an economical context as well. The clinical picture of dementia has its meaning in the global economics' picture, not only within people as individuals but within society as a whole and it is economical as well. In 2015 the resources related to dementia disease were reckoned at 818 milliards USD which is 1,1 % of global GDP, in the range from 0,2 % in countries with low and medium income to 1,4 % in countries with high incomes. It is estimated that by 2030 the global cost of care for people with dementia will be 2 billion USD (WHO, 2017).

Further, the WHO (2017) together with the World Bank reckon that by 2030 there will be a global need for new 40 000 000 job positions in medicine and social services, and around 18 million in social care, mainly in countries with low incomes to achieve and provide good and accessible health care for people living with dementia.

In the Czech Republic, seniors are one of the largest groups which has their specifics and needs, and which need to be introduced into social care services. Even though we can assume that future seniors will be longer able to take care of themselves, the growth of this group will significantly influence whole society (Ondrušová, Krahulcová et all., 2019). In the context of prognosis and statistical data … the year 2040 will be for the Czech Republic era when the generation of baby boomers from 70' of 20th century will reach the seniors' age. The change in numbers of residents will not be significant as the assumed number of citizens older than 65 will be more than 2,75 million that will make 25 % of Czech's population (Ondrušová, Krahulcová et all., 2019). Every year the number of people living with dementia grows, in the Czech Republic and in general in Europe the growth is 5,4 %. Every 20 or 25 years this amount doubles (Holmerová, Horecký and Hanuš, 2016).

The average age for Czech men is 40,8 years and for Czech women, it is 43,6 years. The rate of people above 60 years is approximately 25 %. Demographic predictions show that in the following 30 years there will be significant growth in the number of people above 60 years. Thus, it is believed that with this growth there will be more ill elderly people. Thus, the population models about this age growth show that there will be expected growth of seniors with neurodegenerative illnesses – such as diverse forms of dementia (NAPAN, 2021).

With regards to worldwide trends, it is obvious that the growth of the number of people living with dementia will meet the Czech Republic as well. In historical context as stated by Mátl, Mátlová and Holmerová (2016). Prevalence of dementia was for 60' estimated half higher than are current number, during the change political system in 1989 it was 73-81 thousands of people, during begging of the new millennium it was 89-98 thousands of people, and in 2015 it was almost 156 thousands of people. If we use the projection of people in the middle variant from 2013 and we apply the last prevalence study by Alzheimer Europe, we can say that in 2020 there will be 183 thousand people with

Alzheimer's disease or any form of dementia living in the Czech Republic, and in 2050 it will be 383 thousands of people.

The Czech Alzheimer's society published 2006 a strategy called P-PA-IA (Kolektiv autorů, 2018), in the strategy they describe the diverse needs of people living with dementia in diverse stages of illness. The strategy aims to ensure the highest possible quality for people living with dementia. The strategy is divided into three parts while each part reflects one stage of illness.

In term of Slovakia (Slovakia Republic), there live around 5 500 000 inhabitants, has dementia around 50-60 000 people. It is reckoned that the light form of dementia has 15 % of the population over 65 years. It is also estimated that only 5-10 % of people living with dementia are undertaking adequate treatment meaning moderating the symptoms and improving quality of life. Slovakia does not have enough information about the illness. Based on assumptions (there are no official statistics because there is not enough diagnosis) Alzheimer's disease and other forms of dementia have 1,07 % of the population, whereas in the Czech Republic it is 1,365 (Antalová, Kaššaiova, Plichtová, 2020).

In Poland where lives 38 000 000 citizens, similarly as in other countries, dementia presents a huge and serious challenge to the health and social system. By diagnosis and treatment of this illness the neurosurgeon, psychiatrist, and geographic are a concern. From the available resource is obvious there is no accurate geriatric care available. For 100 000 inhabitants, there is not one specialist for dementia illness (0,8). In contrast in the Czech Republic, it is 2,1 specialists, in Slovakia, it is 3,1 specialists, and in Sweden, it is 8 specialists. In the last decade, Poland made an effort to improve diagnostics and treatments of all diseases related to ageing especially dementia. Nowadays, there is 14,7 % of people older than 65 years, and in 2035 it will grow up to 24,5 %, and in 2050 it will overcome 30 %. With dementia lives, there are over 300 000 people and a lot of them are without a diagnosis. This is a huge number, and it is important to mention that this illness has many people who work as caregivers. By 2050 the number of people living with dementia will triple to almost 1 million people. In 2015 there was research conducted which showed that 90 % of a caregiver are family members, 32 % are husbands and 62 % are children of people living with dementia (Szczudlik, 2016).

In Germany, where lives more than 83 000 000 inhabitants, the number of elderly people grows, and the lowering of the population is slowing down. The reason for this is extending the length of life and the longer-term stagnation in reproductivity. There is a lower number of people around the age of 20 years, the assumption is that by 2030 there will be less than one-third of young people and children than it was in the first decade of the new millennium. In the context of elderly people and seniors, there will be 40 % more seniors than is there now (Pohlmann, 2011). Neither Germany will avoid the growing trend of seniors with illnesses related to their age.

Germany has the fifth highest number of people living with dementia, with a similar number have Brazil, above them are China, the USA, India, and Japan. Specialists reckon there are 1,6 million people living with dementia in Germany. Most of them were diagnosed with Alzheimer's disease. Due to demographic changes, there are more new patients with dementia than bereavements in one year. Around two third of patients living with dementia are women and only one-third are men. If there will not be a change in prevention and therapy it is assumed that by 2050 there will be 2,4-2,8 million people living with dementia. This is equal to a year's growth by 25 000-40 000 people diagnosed with dementia. The number of people who have not reached the age of 65 years and were diagnosed with dementia is more than 25 thousand. This growth will slow down after the last generation of baby boomers reach higher age. In relation to the future development of the average length of life this could be reached after the year 2050 or 2060 (Deutsche Alzheimer Gesellschaft e. V., 2019).

In Austria live 9 000 000 inhabitants. Problematic of dementia is there an open topic which is one of the key aspects of focus in health care, providing social care, and constantly evolving care for people living with dementia, their families, and their caregivers. All provided services for people living with dementia, their families, and their caregivers are available for them all the time. Nevertheless, these services cooperate with each other including health care and social care. The Austrian Ministry for Social agenda, Health, Care and Safety of Consumers (Bundesministerium für Soziales, Gesundheit, Pflege und Konsumentenschutz) cooperates with individual regions, cities, towns, institutions for social security, societies, science, people living with dementia, their families, and their caregivers throughout the National Strategy for Dementia (Demenzstrategie Angebote für Angehörige von Menschen mit demenziellen Beeinträchtigungen, 2021). This National Strategy for Dementia aims to popularise the topic of dementia to wider society. Further, it urges all cooperating parts to do prevention and educate in their sector of responsibility.

In 2000 in Austria there were 90 500 women and men living with dementia. In 2016 the number of people living with dementia has grown to 130 00. Based on the current projections the number of people living with dementia by 2050 will be 270 000 (Kojer, Schmidl, Heimerl, 2022).

In the Netherlands, live 17 740 000 citizens and in 2021 there were 290 000 people living with dementia. Of this number 12, 000 people are younger than 65 years. In the context of age structure, the data about dementia evolution are that only 10 % are older than 65 years, and 40 % are older than 90 years. These numbers will dramatically grow in the next years. It is assumed that the number of people living with dementia in the Netherlands will be by 2050 half million (Alzheimer Nederland, online, citace, 2022-03-15). However, scientists do not agree on the pace of the growth. Nevertheless, there is still an open question about the amount of provided service when we know that we can either overestimate or underestimated it. So, we can either have too many providers, or we can have an insufficient number of providers.

With regards not only to already mentioned data and numbers but to the situation in European Union when we can observe the generation growth in last decades. Together with North America and East Asia, the European Union is heading towards an older society, with low reproduction, and higher education. Based on this observation new questions arise: Who will live and work in Europe in the next decade? How many people and with what skills? The research focused on migration, birth rate, death rate, level of education, and workability can predict possible future. The demographic changes present significant changes and challenges not only for the social sphere but for all aspects of society.

Every year the percentage of seniors in the inhabitants' structure grows. Therefore, we can observe descent in children and young people. This happens due to the rise in average age. The prognosis assumes the number of older people in Czech society will grow. Nowadays the group of people older than 65 years belong to people born after the second world war (Sak, Kolesárová, 2012).

3. METHODOLOGY

The main aim of this research is to investigate to what extent is the person taking care of a family member with Alzheimer’s disease in a home environment informed about the disease, and the possibilities to use the support system. Further, we researched how the care for a family member living with dementia influences their family, relationships, and mainly the health condition of the caregiver.

Methodology

To gain as much data as we needed, we used a questionnaire, which was prepared on basis of theoretical knowledge about the presented problem. The questionnaire is often used in pedagogical, sociological, and psychological research. This method is mainly used for data collection, personal opinions, and thoughts about problems. According to Chráska (2016), a questionnaire is a written form of asking questions and receiving written answers. It is a carefully prepared system of questions, their order is thoughtful, and respondents answer in written form. The structure of a questionnaire is based on the research's aim. Our questionnaire was anonymised. There were several reasons for our choice of the questionnaire. For example, the questionnaire is not time-consuming as other methods, respondents had enough time and privacy to answer questions properly. The questions were prepared with regard to the personal experience of people living with Alzheimer's disease and home caregivers who we met during social research. The information is always collected with an oral agreement, and it is noted in the questionnaire as well. The questionnaire's questions were prepared to collect the most exact answers, and they are related to the topic of the research. The questions are clear and in the context of the researched issue. The respondents were offered consultation to clarify the meaning of some questions. The questions were focused on changes in the period of care provision for a family member or an individual in their home environment, the extent of provided information, coping level of abilities related to changed life situations, and level of awareness about accessible help and support.

Overall, we have distributed 60 questionnaires to respondents. This group includes family members and providers of care for people with Alzheimer's disease in the middle stage of the illness. The return ratio was 90 % and we have received 54 filled questionnaires. For questionnaire distribution, we used an online website for non-formal caregivers. Of course, we carried out a pilot study to verify the questionnaire.

4. Results and Discussion

This part focused on diverse parts of the questionnaire and these parts are evaluated.

What relationship do you have with the person living with dementia? Of the whole number of 54 participants, 15 have answered there are either sons or daughters. The next largest group were wives who were represented by 12 respondents. The last groups were represented by a similar number of participants. There were 6 husbands, 6 daughters-in-law, or sons-in-law. From different research appears diverse data, according to Zveřinová (2016), the largest number of family members looking after a family member with dementia were wives/husbands. Stein (1998), claims on their intergenerational sample that with a difference in gender within the group of adults, there is a higher feeling of need to take care of parents in families where was only one parent. However, if we should draw a picture of a typical caregiver, it would be a woman looking after her husband on her own (Jeřábek, 2005). Based on another resource, in 64 % of couples, it is a woman who is taking care of the man. The second model would be an ageing person looking after their parents. The ideal solution to this situation is the cooperation of the whole family so the care is divided among more people. Thus, the demand for psychological and physical severity is divided as well.

The long-term provision of care for a person living with Alzheimer's disease is influencing the **health condition of the caregiver**. Often, the caregiver's health condition is worsening, and they might become another ill person in the family as well (Zvěřinová, 2017). Of all respondents, 42,60 % discovered that by the time they were providing care for an ill person, their health condition was impairing as well. In the questionnaire, this answer was interpreted as "not too good". Similarly, this is reflected by Hájková (2016) in her research …the care providers they evaluate as time-consuming, isolating, and causing health issues. This is often belittled as caregivers prioritise the senior. The long-term care provided is the source of stress and tension, health issues related to sleep poverty or sleep deprivation, physical and psychological exhaustion. There is a hood body of data on the relationship between non-formal caregivers and the deterioration of their health condition (Glendinning et al., 2009).

Did your family change relationships since you are taking care of a person with dementia or Alzheimer's disease? The diagnose of a serious illness for a family member can change the way of family functioning, negatively influence the quality of life (Kurucová, 2016). This question was answered by 25 respondents from a total of 54 respondents. These 25 participants answered that the relationship in their families has become a bit worse. The realisation of fact the person taking care of the senior could be isolated could damage the relationships not only in a family. The caregiver recognizes the need for care, and often they do not prioritise their own hobbies and leisure time. The current approach is that caregivers could be helpful to meet other people who are caregivers as well. Thus, they would be able to share their problems, and worries, and gain support and energy from each other.

The last part is focused on the financial situation. **Did your family the financial situation changed since you look after a family member with Alzheimer's disease?** The financial situation changes when a caregiver cannot work because they have to look after a family member with Alzheimer's disease, thus they become financially dependent on the other family members (Regnault, 2011). These answers have clarified this as 40,74 % of respondents agreed that the financial situation in their family become worse. Therefore, the worry about the financial poverty of caregivers and care receivers is well-founded. As the caregiver is considered a person who had to quit or partly quit their job to be able to provide care. According to quantitative research results conducted by Fond for Further Education (project Support for non-formal caregivers), 23 % of caregivers said they strongly felt the lowering of their standard of living when they started to provide care. 60 % of respondents said they are not able to the unexpected expense of 9 600 CZK (again 42 % of the population). The research found significant differences between caregivers based on who they take care of. In the best position were people who take care of seniors, and the worst situation was for single mothers taking care of a child with a health handicap.

5. CONCLUSION

The family caregivers in the system of long-term care for people with dementia are a crucial part. However, often they are underestimated and overlooked, and their job seems an automagical responsibility. On the other hand, society is not trying to ease their situation for them. The family caregiver often must provide exhausting 24/7 care for a family member, and solve other issues such as how to handle care via financial situation, how to take care of a person with limited movement ability, how to transport a family member to doctors, where to place a family member when a caregiver is undertaking a surgery, and many others. The caregivers are often confronted with indifferent and discreditable approaches from doctors and officers, with deficiency of information which they must find out on their own, and with holdouts during securing the financial supplies. Plus, they still have to face the fact that the health condition of their family member is not improving, that often they cannot communicate together, and sometimes the family member does not recognize them. The support of families who decide to look after their family members in the home environment should be from the state and society platitude.

This research has clarified that taking care of a family member is exhausting. Even though it does not look like it at first sight. When caregivers are considered whether to take care of their family members in the home environment they often decide based on their current feelings and their opinion. However, they do not recognize the extent of the demands and consequences of their decision. This was proved by this research as well. Therefore, it is important to think about how caregivers and wider society show the extent of care, so they would be aware of the demands of care for people living with dementia.

It is true that the home environment is often better for patients with Alzheimer's disease. However, it has been proved that in some cases insufficient information from family members and family carers is lead to the provision of inadequate care which could lead to deterioration of the patient's condition.

Most participants stated that at the moment of diagnosing their family members, they have been provided with an adequate and sufficient amount of information about home care. As the participants said the care of an ill person is significant ballast, which influences their health condition. Similarly, the respondents said that during the care of a family member the relationships in the family worsen. Plus, the financial situation of the family has changed and that is caused by the need for a family member to quit their job to be able to look after the senior living with dementia. Also, the caregivers have noticed that if the home care should be manageable for them, they should be able to relax and ask for help from other family members. More than one-half of participants 51,85 % relaxed by observing what is happening to the care receiver.

For practice we would recommend:

- better support system for a caregiver that would include an offer of psychological help;
- highlighting the need for relaxation of a caregiver, and better usage of support systems;
- support of education for caregivers with emphasis on multidisciplinary, so the education would include psychological aspects, pedagogical aspects, law, and social aspects;

- edification in the terms of support provided by the state – mainly at the Employment office of the Czech Republic, so the caregiver would know what they might be able to get from the state.

It is important to share emotions and mutual conversation in helping groups for non-formal caregivers is an example. When it is needed by the participants in these psychotherapeutic help groups is offered. Participation in these groups helps to overcome feelings of isolation and helplessness, and it learns them to notice their own limits. One of the principles of helping groups says, "there is not a perfect caregiver", and a group is guiding their members even when the care is over (Ondrušová, Krahulcová et all., 2019).

In the Czech Republic, there needs to be an interest in a specialist who is often a social worker. According to the need of participants, the other specialists invited to the meetings such as psychiatrists, psychologists, and lawyers. Often these meetings have an atmosphere of psychoeducation.

Meanwhile, the helping groups are focused on emotional support the psychoeducation programs are focused on psycho-hygiene. So, they are focused on teaching habits of psycho-hygiene, illness, and treatment. Originally psychoeducation was meant for a family member of people with psychotic illness when the family member learnt to understand the illness, high signs, and correct communication. This was discovered that a similar or higher level of psychoeducation needs family members of a person living with dementia. Psychoeducation helps caregivers in the home environment to reduce stress and extend the time for a person living with dementia in a home environment. So, psychoeducation helps to reduce the financial resources need for health care. However, it is not well known.

In conclusion, we can say that caregivers face serious problems which disrupt their psychological and health conditions. Sometimes, they cannot evaluate their strength properly, the length of needed care, or the demands that the care involves. Therefore, it is needed to change system settings – to identify the non-formal caregivers as specific target groups with their own rights and needs.

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