INFORMAL LONG-TERM CARE FOR THE ELDERLY WITH DEMENTIA IN SLOVAKIA

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Abstract
Background: Dementia is one of the key reasons of disability and cause of the dependency of the elderly on another person. An elderly with dementia needs assistance in every aspect of their lives and their family members hold an important role as informal care givers. The complexity of the diseases and a wide range of life changes associated with long-term care in their homes provides a variety of physical, psychological, and also social and economic demands for them to cope with. Specific requirements and demands associated with dementia, high rates of workload carers, provided support and assistance from professionals are the factors that directly affect the quality of nursing care and thus the quality of life of the elderly with dementia.
Objective: The main objective is to provide a comprehensive perspective at the theme of long-term care for the elderly with dementia in their home environments. We focused on the quality of informal care provided by the closest relatives to people with special needs.
Method: The research method was a questionnaire of our own design. The part of it was a short knowledge test for informal carers and a test to assess the sufficiency of the elderly in ADL and IADL.
Sample: Research sample consisted of 96 respondents who took care of their loved ones in their social environment.
Results: Based on the analysis of the research results it is evident that the quality of long-term care in the social environment is relatively low. Informal care givers lack the theoretical knowledge and practical skills that are necessary for the implementation of quality and specific care for the elderly with dementia. There is not an integrated cooperation of experts from the health, social and legislative sectors, which would help them to improve the quality of informal care.
Conclusion: Providing informal care to people with dementia at their home environments is difficult, and evolving process. Physical demands and mental stress of everyday care elicit a high degree of congestion of informal carers. Management of long-term care in the social environment is weak and ineffective. There we need team, multidisciplinary and various spheres in the care of professionals who significantly affect the quality of informal care.

Keywords: Dementia. Elderly. Informal care. Long-term care (LTC). Quality.

1 Introduction

Dementia is such a serious problem that the WHO and other international organizations that deal with neurological diseases and mental health have developed several action programmes, strategic plans and recommended interventions to cope with it. According to the WHO, there are 47.5 million people with dementia in the world. An increase of 7.7 million new cases per year is estimated. Despite numerous clinical studies, there is currently no causal treatment to stop or reverse the development of dementia. There is only the care focused on its progressive course and on ensuring the maximum possible quality of life [1].

Most people with dementia live at home, and their family members are the key informal care givers. A quality care in the home environment is very demanding and difficult to assess. Different quality indicators are used in institutions, but in the home environment the use of these indicators is inappropriate and hardly used. Caring for people with dementia is very demanding and long-term in all aspects. The demands of daily care get informal caregivers beyond their physical and emotional burden.

The main objective of our study is to focus on the issue of long-term care for people with dementia provided by informal care givers in the natural environment of patients. A complex view of long-term care and its quality was reached by an analysis of research results, which was aimed at obtaining information on the current and real situation of care from the perspective of an informal care giver.

2 Informal care

Informal care is currently seen more as a substitute than as a complementary part of a holistic approach in LTC. This is often a gap filling or an emergency solution where the LTC service is not provided. Informal care is not free from a societal point of view. Some research has already confirmed that its costs are very high, sometimes unbearable, if we add all hours devoted to care, deteriorated quality of life and health of care givers, or difficulties connected with work and social employment in the long term [2].

Informal care is defined as *"care provided to persons who depend on the help of another person for normal daily activities due to severe disability, mostly by immediate family members in the home environment or by other persons living with the same household as a dependent person"* [3, p. 28]. The European Association for Care Givers EUROCARERS defines a care giver as *"a person who, outside a professional and formal framework, provides unpaid care to someone who has a chronic illness, disability or other long-term health or the need to be cared for"* [3, p. 11]. In our country the care givers are divided into formal and informal ones according to whether they receive a salary for their care. Unpaid care givers are family members who take care of their closest relatives most often are based on their close family relationships. Their care is provided without expectation of remuneration, in some cases they may receive social benefits as a compensation for the loss of income. In practice there are also informal carers who are not in a family relationship to a sufferer. In such cases, it is most of all a close friendship with the cared for person [3]. Many studies have shown that the most common group of informal carers is women aged 55, and this group is particularly vulnerable to a high risk of burnout, the possibility of abuse and social isolation [4].

The services provided by informal care givers can be divided into three main groups in terms of the intensity and extent of meeting the needs of a person with dementia: The first group is subsidiary care, which is physically and mentally relatively undemanding care including provision of repairs in households, accompaniment to the family doctor, or handling various official matters. The second group is referred to as impersonal care and includes activities that are mainly related to household care such as cooking, cleaning, and washing. The third group is considered the most demanding and is referred to as a personal care aimed at maintaining independence, autonomy and satisfying the needs of the cared for person [5].

3 Long-Term Care and its Impact on Informal Care Givers

According to the research made by National Family Caregiver Alliance, the common denominator of informal care is the emotional impact that it has on care givers. Informal care givers often deal with intense sadness and pain, often longing for a miracle and a normal life. They struggle with frustration at the changing family dynamics. They are disappointed by the lack of understanding from people who do not care about anyone. They suffer from social isolation due to stigmatism and deviation from the norm. An increased responsibility causes long-term stress and loss [6]. Prolonged physical, emotional, social, but also financial burden causes the overall burden on care givers. In their study Tabakova et al. define 5 most common areas that characterise the overload on a care giver overload as follows: Poor sleep, fatigue, lack of time to meet personal needs, stress, and depressed mood [7].

Pearlin et al. [8] list four areas of stressors that affect the care givers. The first area is the so-called background of the context to which belongs for example the level of support and the impact of other life events. The second area are the specific requirements of care referred to as primary stressors, which include the time devoted to care, the extent of care, the diversity and intensity of behavioural, cognitive and psychological symptoms. The third area are secondary stressors such as the secondary role of the care giver – childcare, work and career, caring for one's own household, family relationships and conflicts, but also social life. The fourth and last area includes intrapersonal stressors – the personality of the care givers, their competencies and roles [8]. Many studies show that family care givers are particularly prone to affective disorders such as depression and anxiety, with women being more prone to these disorders. The risk to develop affective disorders persists for many years during care and even after the end of care provision [1].

Many studies and research show that informal car givers who care for people with dementia are at greater risk of serious illness, general mortality. They have also been shown to be at higher risk of metabolic syndrome and cardiovascular disease, higher incidence of obesity and smoking, more likely to drink alcohol, more frequent sleep disorders, higher levels of stress hormones, impaired immunity, poorer vaccine responses, slower wound healing, more frequent over-the-counter medications, less interest in prevention and care for one's own health, but also loss of cognitive functions [8].

Care givers often lack social contact and support from their friends, neighbours, family members and they experience social isolation. They lose social contact especially after the decision to leave their jobs and devote their free time to caring for their closest relatives. Care givers tend to sacrifice their free time activities and hobbies, limiting their time spent with family and friends. It has been proven that care givers who have maintained their social contacts and continue to maintain various social interactions have lower negative psychological symptoms [8].

In addition to the impact on physical and mental health, informal carers also must deal with financial problems. The provision of care can become a full-time job without adequate financial support. It often happens that a family member must leave his or her job or find a less demanding one, but worse paid job, which is calculated as an indirect cost [1]. The direct payments for provided health and social services such as consultation with a doctor, emergency treatment, co-payments for medicines, or the purchase of over-the-counter medicines and various medical devices, fees for respite care in sanitary facilities are a huge burden for the budget of every household.

Despite the complexity of informal care, many care givers are motivated by several factors. Some caregivers feel proud of their role and can find many positives in their duties, such as feeling of importance and self-realization, feeling of love and reciprocity, spiritual fulfilment, and the sense of duty [8].

4 Support to Informal Care Givers

Informal care givers cannot be considered a natural source of care. Caring for people with dementia is demanding and requires a lot of time, and energy and often significant physical effort from care givers [2]. The risk of overload on the side of care giver increases if all care and responsibility is laid on exclusively one person. In their work, Tina and Karen point out the existence of the so-called triple model of nursing care. They emphasize that in LTC it is a mutual relationship of three active components – the care giver, the person that they are cared for and the public or private programme [9].

The support and assistance of carers by professionals, lead to a significant reduction of the burden, which is essential for them to be able to provide care for their loved ones for as long as possible. Support for informal carers must be complex and it should cover all the areas where problems occur such as the information to support understanding of dementia, the acquisition of skills needed to provide general care, relief services, but also financial support and legal aid.

Counselling and crisis intervention form the basis of psychosocial assistance. It is a long-term and permanent process in which a professional provides a care giver with guidance and support focused on their life goals and needs. They solve various problems and pass on information focused on the expertise and communication skills needed in day-to-day care. Telephone crisis intervention also has an important role in psychosocial support. It is easily accessible to informal care givers without having to leave a loved one. It offers fast help and support to informal care givers when they are in stress or mental discomfort [10].

Respite care is not often utilised service in Slovakia. However, there will always be time left when care givers need the help of formal services. Respite care includes a whole range of relief services, which can take place in the home environment, in day centres, but also in institutional care. The relief service may also vary in duration, where the services may be short from several hours to several weeks. Relief services can be planned, unplanned or emergency. The goal of respite care is to provide care givers with a break from his care responsibilities to such an extent that his stress, exhaustion, and also frustration and social isolation are removed. Of course, relief services should also benefit a person with dementia [1].

Certain form of support for care givers is provided by self-help groups. They are made up of informal care givers who meet at regular intervals under the guidance of an expert. They share their experiences in caring for their loved ones. Relationships between them are very important. They give each other hope, cohesion, provide each other with psychological support and share experiences with each other. Support groups are considered a form of support that significantly reduces the stress and overall burden of informal care givers [10].

Support for informal care givers should be ongoing, well-coordinated and multi-level with all stakeholders. And since people with dementia and their carers often have the most experience and unique views on dementia-related problems and needs, quality of life, and the overall burden of the disease, they should be involved in formulating policies, strategic plans, laws and services [1].

5 Quality of Services Performed by Informal Care Givers

Older persons who rely on LTC services have the right to an adequate degree of personal control over the care provided in terms of its scope, quality, financial demands, but also safety. In order to ensure the quality of LTC services, coordination and integration of individual services focused on the individual needs of a dependent elderly person must work. Informal care is traditionally considered a private matter in Slovakia, and therefore no special qualification requirements are expected for this performance. Some informal care givers undertake a nursing course and some of them receive, in a broader sense, professional instruction from health professionals [3].

6 Research Problem and Objectives

Based on theoretical knowledge, we formulated the following research problem:

“What is the level of quality of care for people with dementia provided by informal caregivers in the home environment?”

The main research objective was to obtain the most comprehensive view of the issue of healthcare provided for a person with dementia from the perspective of an informal care giver.

Partial objectives:

- Assess the complexity of care givers for the persons with dementia who live in their home environment and have the different stages of dementia.
- Determine whether informal care givers have sufficient theoretical knowledge and practical skills needed to care for people with dementia.
- Find out if informal care givers have the possibility of support and help and they cooperate with experts.

7 Methodology

The research method is a self-designed questionnaire that consists of 34 items that are divided into 5 sections. At the beginning of the questionnaire, the items focus on the demographic characteristics of the respondents – informal care givers. Other items focus on the issue of informal care. The third set of items focuses on care recipients. The fourth set of items consists of items focuses on the specifics of the care for elderly with dementia. At the end of the questionnaire, the items are aimed at supporting informal carers. The questionnaire includes a short knowledge test focuses on the theoretical knowledge of the respondents and a test to assess the self-sufficiency of the person in common daily activities and instrumental daily activities (ADL and IADL). Data collection took place from January to March 2017. The participation of respondents was voluntary. 100 questionnaires were distributed to direct and indirect contacts. 96 completed questionnaires were returned, which is a 96% return.

8 Sample

The research sample consists of 96 respondents addressed by deliberate selection. They are informal care givers who cared for their loved ones suffering from dementia in their natural environment. There is no restriction that would condition the age category of the respondent or the length of provided care.

The youngest respondent is 19 years old and the oldest 84 years old. The most frequent respondents are 47 years old (7.3 %). The median was 51 years old. In the examined group there is 10 (10.4 %) respondents in the age category over 65 years. Of the total number of the examined group, 74 (77.1 %) are women and 22 (22.9 %) men. The ratio of women to men is 3.36:

- Children (a daughter, a son) took care of their loved one most often. They are the largest group with 44 (45.8%) of the total number of respondents.
- The second group are grandchildren (a grandson, a granddaughter) with 16 (16.7 %) respondents.
- The third group consists of partners (a husband, a wife) with 14 (14.6 %) respondents.
- Siblings (a sister, a brother) and neighbours (a neighbour) form equal and quite large groups with 5 (5.2 %) respondents.
- In terms of housing conditions of the cared for person, up to 58 (60.4 %) respondents live in the same household as their close person, whom they care for.

9 Results and Discussion

In our study we present the perspective of an informal care giver who cares for a person with dementia in the home environment. We focus on the level of quality of care based on several indicators that are generally valid in the provision of services in LTC. The quality of services provided in LTC is extremely different. Many surveys and reports show great dissatisfaction and point out the shortcomings identified. The quality of services provided in LTC is not easily assessed. It is a challenging task in health or social care facilities and in their home environment it is almost impossible because there are no uniform mechanisms to assure quality and standard quality indicators are unsuitable for informal care [11].

Age and gender are a certain indicator of the quality of provided care. The average age of the respondents is 51 years. The oldest respondent is 84 years old. As many as 10.4 % of respondents are of retirement age (over 65 years). Repková states that family carers are aging, as demonstrated by the research project “Informal care givers in the long-term care sector” from 2008. This is confirmed by the results where up to 20 % of care givers receive a retirement pension, 47 % of care givers are aged between 51 to 64 years. In our research, women significantly outnumber them (77.1 %), while the group of men is represented only by 22.9 %. Similar age characteristics are mentioned in her research project by this researcher who reports 82 % is the participation of women in family care and only 18 % of involved in this kind of care are men [3].

Reconciliation of work, family and care responsibilities is another factor that directly affects the quality of care provided. Not only the time and physical demands of all responsibilities, but also the conflict of secondary roles of the care giver plays an important role in the care for a close family member. At the time of our research, up to 44.8 % of care givers took care of their close relatives and at the same time went to work full time. It is necessary to point out 12.5 % of this group of care givers who cared for their loved one in an advanced stage of dementia, when caring for these people is physically and emotionally exhausting. At the time of our research, 5.2 % of care givers had part-time work and 5.2 % of them were in the position of self-employed. 9.4 % of care givers were unemployed at the time of the research and 24 % of care givers were retired, so they could devote their time mainly to the care for their loved ones. This more flexible variant is also pointed out by Repková, who perceives the self-employed person as a care giver in up to 26.3 % of representations and the unemployed in up to 45 % of representations [3]. Care for close relatives represents a high degree of overload for the informal care giver due to the emotional bond, but also the time required. This is also proved by the results of our research, where caregivers stated in 77.1 % of cases that another person helps them in to care for their loved ones. 15.6 % of respondents stated that 3 or more people help them to care for their loved ones.

The complexity of care for persons with dementia is directly related to the progression of dementia and its individual manifestations. As many as 39.6 % of care givers cared for their loved one who had an advanced stage of dementia. Intermediate stage of dementia was reported by 32.3 % of care givers for their loved ones and the early stage of dementia by 16.7 % of care givers. From the stage of dementia, the dependency of the care for a person in the ADL and IADL also develops. That is also related to the time required to a provided care. According to our research results, up to 75.0 % of care givers provided seven-day care for their loved ones. The complexity of the care associated with the progression of dementia reflects the number of hours that informal carers spent with their loved ones. While less than 6 hours of care were sufficient for people with early-stage dementia, people with advanced dementia required 24-hour care.

The extent of burden of the care provided for persons with dementia is also confirmed by our results, which describe the scope and area of assistance that care givers should provide to their loved ones. The scope of care is mostly a “full help”, as expressed by 33.3 % of care givers. After reassessment the extent of dependency of the nursed persons in the ADL, we found that up to 41.2 % of care givers cared for a person with a “high dependence on another person” and 37.6 % of care givers provided care for their close relatives with a “mild dependence”. Similar results were obtained after reassessment the extent of dependency of the nursed persons in the IADL, where up to 54.1 % of respondents cared for their close relatives with a degree of burden “dependent on help from another person”. When assessing the intensity of care provided to the nursed persons, a certain degree of burden in the provision of care was demonstrated, as care givers had to apply daily interventions in almost all ADLs and IADLs.

Informal care, especially the care for a close relative with emotional attachment, is a great emotional burden. The irreversible progression of the disease is connected with specific manifestations that significantly affect the life of the whole family and represent various problem situations that they have to cope with. Behavioural and psychological symptoms (BPSD) are the main cause of emotional as well as social burden of informal care givers and become a decisive factor when home or institutional care comes to consideration [12]. As many as 78.1% of care givers assessed BPSD as a challenging situation. Of all the forms of BPSD, they most often encountered Sundowner's syndrome, in 42.7 % of respondents. Total of 29.2 % care givers described wandering and aggression as a challenging situation and 25 % of them considered hallucinations difficult to cope with. A frequently called as a “problem situation” for care givers was the replacement of the incontinent pad, which was reported by up to 27.1 % of care givers and the administration of medicines orally, was reported by 21.9 % of care givers.

Provision of help and care to close relatives at a time when they are no longer able to take care of themselves is a huge and long-lasting burden. This is also confirmed by the results of our research. 31.3 % of carers describes this care as “quite exhaustive” and 25.0 % of them as “maximum exhaustive”.

The quality of theoretical knowledge of dementia on the side of care givers is important when they care for people with dementia. As long as care givers perceive dementia as a hopeless situation, people with dementia will be very vulnerable. According to experts in the care of people with dementia, it is not possible to provide a high quality LTC without adequate and good theoretical knowledge and practical skills. Just understanding what is going on in the brain with dementia will help to manoeuvre the behaviour and the individual symptoms of the disease. With good knowledge our care can have impact and by proper responding to the needs of our close relatives, we can fundamentally improve their quality of life [13]. Therefore, we focused on the provision of professional information to informal care givers. Our results show that the vast majority (83.3 %) of informal care givers are provided with professional information necessary in the care for people with dementia. The family doctor was most often mentioned as the source of professional information (50.0 %). The second most common source of professional information was the Internet (30.2 %) and books from nursing practice (20.8 %). Based on a short knowledge test, we found out that more than a half of care givers has insufficient knowledge about dementia and the care for people with dementia. Only 7 care givers were assessed in the test for excellent knowledge and the knowledge of another 7 care givers were assessed as very good. 14 care givers had the good level of knowledge and 16 care givers reached only a sufficient level of knowledge.

In the care of persons with dementia, it is important to protect their cognitive performance from rapid decline, prevent their social isolation, ensure they have adequate social contact, and support their self-service skills in everyday activities at the maximum possible level. This requires great determination, strength, endurance, love, and also cohesion and empathy not only from the informal care giver, but from the rest of a family. Take hold of the role of an informal care giver changes the life habits, rituals and priorities of the whole family. As dementia progresses, care becomes more physically and mentally demanding [12]. Our results show that informal care givers lack the help and support of professionals. In seeking help and cooperation from experts, we found that the doctor who most often diagnosed dementia in a person was a neurologist, as stated by 39.6 % of care givers. However, we know from nursing practice that long-term care for persons with dementia is taken over by a psychiatrist. In practice, there is the lack of activity on the part of experts who focus on prevention, test cognitive functions, educate care givers and integrate cooperation with other experts. 56.3 % of care givers said they were not provided with the necessary information about the support. They also lack the help in sudden crisis. As many as 65.6 % of care givers stated that they have the opportunity to contact professional help, but at the same time we found out that it was their doctor's consultation, ambulance service, a first aid service and the intervention of a nurse from Home nursing agency. Park et al. states that the institutionalisation of a person with dementia was delayed by up to 329 days when the informal carer cooperated with an intervention group of professionals compared to persons whose care giver did not receive this help and support. Cooperation with support and self-help groups has been shown to improve caregivers' well-being, reduce their feelings of depression, and also burden and the overall impact of care [12].

Continuous and efficient help and targeted support provided by professionals is essential to eliminate the negative factors that cause overload for care givers. Fertaľová et al. state that the financial contribution for care and nursing service as the most frequently used form of support in the provision of care. It is also confirmed by the statistics of the Centre for Labour, Social Affairs and the Family. Another form of help and support that informal care givers are interested in is the care service provided by nursing professionals. According to other existing statistics, the social service in the day hospital is used only to a minimal extent in Slovakia [12].

The results of a special Eurobarometer from 2007 show that Slovak people prefer long-term care for their close family members at home and they rely less on professional social and health services. At present, there is also a network of various support services for dependent persons and informal care givers in Slovakia, but the problem is the lack of information about the possibilities of their use [12]. Our results also point to the lack of information about support and options for informal care givers. As many as 84.3 % of care givers use the help and support from professionals, but from all care facilitation services, care givers use food service (20.8 %), home nursing agency (18.8 %) and doctor's visits at home (16.7 %). Another problem that informal care givers must deal with on their own are compensatory aids. As many as 57.3 % of care givers depend on the use of compensatory aids to facilitate the care of their close relatives. The most frequently used compensatory aids are a shower chair, commode, positioning aids and a mechanical transfer device – a trolley. Only 39.6 % of care givers receive compensation aids through a contribution through Ministry of Labour, Social Affairs and Family of the Slovak Republic or a voucher from a health insurance company. 25.0 % of care givers buy the compensatory aid by purchase and 7.3 % of caregivers borrow it from their acquaintances [14].

The space we left at the end of the questionnaire to the observations, comments and suggestions of the respondents indicates that there in Slovakia care givers lack a satisfactory level of help and support from experts and the state. The requirements placed on them are too high and demanding to provide quality long-term care in home environment. The care and overall interest in informal care givers is also critical, mainly because of their burden and overall management of long-term care.

When we do not consider dementia to be a life-limiting condition, we do not provide adequate care to focus on the quality of life. Quality services and evidence-based care are the only key basis that reflects quality of life. Research shows that the quality of life of persons with dementia is threatened by the number of factors because informal care givers are unable to access services and needs adequately. In addition, the lack of understanding and stigma of society leads to what experts call the “social death of the family and carers” [13].

10 Conclusions and recommendations

Dementia is one of the most common and dreaded diseases of the elderly. It is a serious problem not only for individuals or families, but for our society. It is becoming a major threat and Slovakia does not have a National Plan to combat dementia, although the European Union has taken measures to combat neurodegenerative diseases since 2008. In our study, we point out the problems of informal care givers and their irreplaceable place in the long-term care system in the home environment. We assessed the complexity of care for persons with dementia and emphasised the specific problems that informal carers face on the daily basis.

Based on the theoretical background and evaluation of research results, we propose the following recommendations for practice with a focus on the following:

- Improve public awareness, amend legislation, set up support groups, improve awareness of the specific needs of persons with neurocognitive disorders in secondary and higher education (health, social work, and education), and implement programmes aimed at active aging and the age-friendly environment.
- Provide respite care services for informal care givers.
- Create an “informal care giver"” identity card, on the basis of which the care giver can use various forms of social assistance, support, relief, bonuses focused on the rest and relaxation (recreation, holidays, wellness, massages, season tickets for gym access, swimming pool).
- Make the form of “low-threshold help and assistance” [4]. A trained volunteer or employee will be able to support and supervise an assigned person with limited life abilities in performing his or her leisure activities. The day-to-day supervision of the informal care giver in social life of a dependent elderly person will be relieved and his role will be replaced by the so-called “Everyday companion” (for example a visit to a museum, theatre, board games, walks in the park), which will increase the quality of life of the dependent person. In cooperation with an expert, it will be possible to make a “biography” of a dependent elderly person (detailed CV describe the life story, highlight positive and negative events that significantly affected his life, define personal needs, rituals, daily routines). The care provided will be made and its quality can be

controlled. It will allow the interested to better plan leisure activities, services provided and care. Personal documentation will be applicable even in the case of placement in an institution.

- Organise free training of informal care givers for general public (personal participation, e-learning) to understand dementia as a disorder of brain function – training from the beginning – anatomy and physiology of the human body with the focus on the brain and nervous system, describe pathological conditions and their manifestations and context [13].
- Establish the “Palliative Care Letter”, the so-called “Living will”, where all attitudes, opinions are listed, the wishes of the persons being cared for at a time when he or she is still able to think and be concise, and can decide on themselves, on their lives, and finally on treatment and cure. If necessary, it will be possible to consult the individual decisions of the person with dementia, with an expert (doctor, nurse, and counsellor → individual alternatives, negative or positive consequences). The “Palliative Care Letter” will leave decisions and instructions that will be guided and defended in the future by an authorised legal representative for the benefit of the person with dementia (in case they refuse hospitalisation, refuse autopsy, and refuse artificial life extension).
- Select a legal representative, care giver (so-called third party) authorised to act in the field of health care. Based on the free decision of the guardian, a person will be elected to act on behalf of and defend the interests of the guardian when he or she is no longer able to verbalise his or her wishes and opinions (for example informed consent, refusal of examination, initiation of treatment). This will prevent ethical conflicts in problem issues, relieve the psychological burden of the care giver in decision-making in problematic situations [4].

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