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Care of a Close Relative as a Change in the Carer's Lifestyle and Social Situation

ABSTRACT

Introduction: This paper focuses on providing social care to a close relative. It is crucial in social services. Design: qualitative methodology — method of semi-structured interviews. Methods: respondents were selected to satisfy specific criteria. Particularly, these criteria were the care of a close relative who was assigned level III or IV care benefits. Another criterion according to which we selected respondents was that the carer belonged to the age group in which a person is still usually economically active. The research sample consisted of 6 respondents. Results: Based on the data analysis, we created categories to present the content of semi-structured interviews. Needs focusing on the body carried over into maintenance of one's own physical and mental health are: the need for safety, the need for acceptance, the need for acknowledgement and respect, and the need for self-fulfilment and perspective. Conclusions: It is important to identify the care of a close relative, the specifics and needs, in the interests of configuring effective management of medical, psychological and social care, and creation of a system of social protection.

Keywords:

protection, needs, care, social work, carer

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INTRODUCTION

A situation when one realises that a close relative has some type of disability, has suffered an injury, has fallen ill or is so old that he or she can no longer take care of themselves may be considered a crisis. It may occur during any phase in life, and one is certainly never prepared for it. It is therefore understandable that such a person may subsequently feel threatened, confused and helpless, and it is in this situation that he or she becomes the focus of interest of social pedagogy, which Bakosova (2008) identifies as vital help. The need to care for people with a disability, ill or ageing people, and help for those who decide to take care of these people is indisputably becoming a social issue. Bakosova (1994, p. 22) defines a social issue as a situation in which a person is forced to choose the best solution out of multiple options, affecting specific groups or the entire society. Depending on the scope, this concerns global, regional, local or nationwide social issues, and another type is a social issue concerning values. Taking care of a close relative fulfils all these aspects. It is an issue that affects at least the so-called western countries, in relation to which the forecast indicates an ageing population, with which the individual countries, regions, municipalities and families will have to come to terms with, concerning their economic potential, moral and cultural models, and values. As in any other crisis, a situation in which an individual decides to personally care for a close relative has a specific social pedagogic aspect. It allows the person to learn to come to terms with the issue and be prepared for a new experience. It offers a specific self-knowledge definition of one's own limits, whether in empathy or relation to the degree of physical or mental stress, and leads to stabilisation or, on the contrary, to a rift in relations and bonds. One often has to draw on all of one's own inner strength to independently manage such a crisis, but it is often necessary to choose the option of asking for help or professional guidance.

THE NEEDS OF THE CARER

Many specialists have been engaged in human needs, and various theories arising from their motivation have originated based on their findings. The best-known of these is Maslow's hierarchical theory of needs. We can mention Frankl's logotherapy, which believes that the purpose of life is in carrying out the actions one designates, completion of commenced work and the enjoyment of the experience, which includes meeting and a feeling of love, can be mentioned as another theory that is closely linked to the issue of care of a close relative. McClelland, who states that human needs are derived from three basic requirements, these being able to achieve something, to belong somewhere, and the need for power conceived the theory of needs very interestingly. He divided people into three groups depending on which of these three needs predominates. According to his theory, the achiever is an individual who desires to distinguish himself and to be appreciated by others, but he or she avoids situations where the risk of failure is too great. On the contrary, an affiliation seeker is a person who seeks the feeling of belonging, a feeling of belonging somewhere and harmony with others. The power seeker desires power, control, or simply the achievement of a goal. He or she does not seek praise or appreciation; agreement with his or her requirements is sufficient. In order for a person to provide care for someone else, this person must primarily be healthy because caring for a close relative is an exhausting activity, not only physically but particularly mentally. There is a reason why the state examines whether the person providing care receives a care benefit himself or herself and, if so, what his or her state of health is, whether such a person is capable of providing care and in what scope. Whether formal or informal, care brings specific health risks arising from chronic stress. Krivohlavy (1994, p. 10) states that the carer is exposed to stress because he or she can feel threatened and also feels that he or she is not capable of effectively protecting himself/herself against such pressure, whereas the stress may be caused by the entire situation in which the carer finds himself/herself, and also by the sudden changes in the situation, for instance, bad news, the worsening state of health of the recipient of the care, or the condition of the carer's organism, which subjectively feels threatened. Informal carers, who provide care practically 24 hours a day, suffer from a lack of rest, including sleep, specific social isolation, lack of social appreciation and social contact, which may cause depression in case of absence of positive compensation (Krivohlavy, 1994, p. 25).

When caring for a close relative, the change in lifestyle, the common need to leave one's job, the need to learn nursing procedures and specific social downswing is particularly stressful. The effects of stress may manifest in sleep disorders, depression, worsening cognitive function and overall reduced performance, which may crystallise as somatisation in the form of headaches, joint and stomach pain, loss of appetite and overall exhaustion of the organism (Skarkova, 2016, p. 27). Burnout syndrome is frequently mentioned in relation to assisting professions, particularly nursing, in relation to the long-term effects of stress. Suppose we agree it is a state of physical, emotional, and mental exhaustion caused by remaining in a situation that is emotionally extraordinarily difficult for extended periods (Mlynkova, 2010, p. 38) and that people providing care subjectively bear the burden of responsibility for the state of the recipient of the care (Michalik, 2011, p. 98). In that case, even people providing informal care may be at risk of this syndrome, particularly if they care for a close relative for many years or even

decades. These problems may be relieved by specific relaxation techniques, which induce physical and mental relaxation and an active approach to life (Mlynkova, 2010, p. 45).

RESEARCH METHODOLOGY

The main research goal is to establish the methods for people caring for a close relative, who is dependent on the help of another person at levels III and IV, and to satisfy their own needs.

The research goals resulted from the research questions. The main research question is: What methods do people caring for a close relative dependent on the help of another person at levels III and IV use to satisfy their own needs? This main research question generated individual research questions: Vo1: How are carers themselves actively involved in satisfying their own needs? Vo2: What do carers consider the greatest obstacle to satisfying their needs? Vo3: Failure to satisfy which need do they consider the most significant?

During our research, we employed the qualitative methodology, namely the semi-structured interview method. The research took place from 2016 to 2017 within the Zlin Region. Research participants were selected to meet specific criteria. These criteria particularly concerned a close relative who had been awarded care benefits at level III or IV, who was not their own child. Another criterion according to which we selected respondents was that the carer belonged to an age category in which a person is still usually economically active, i.e., is not the recipient of an old age pension, and also that the care of a close relative had lasted for an extended period, at least 5 years for the requirements of this research.

The research sample in our qualitative research consisted of 6 respondents. The respondents were selected based on personal contact, and their friends were also recommended to us. The interviews took place in their natural environment.

The research provides more detailed information about the respondents. Respondent No. 1 (hereinafter R1F) Mrs Zita, female, age 51, completed secondary school. Zita worked as an operator in an industrial enterprise. She was unemployed just before she started providing care. She began providing care 3 years ago, first to her mother, who had suffered a serious stroke and had been assigned level IV dependence, and then her father had fallen seriously ill.

Respondent No. 2 (hereinafter R2M) Mr Filip, male, aged 55 years, graduated from a technical branch at secondary school and had worked in the machine engineering industry. As a result of providing care, he has been forced to change jobs several times, and currently, he works as a professional carer. He cares for his wife, who suffers from multiple sclerosis, at home.

Respondent No. 3 (hereinafter R3M) Mr Gustav, male, aged 52 years, graduated from secondary school in the machine engineering sector and had also worked in machine engineering in the past, has cared for his wife for 18 years and had known of her illness, multiple sclerosis before marrying her. It is also why the marriage remained childless.

Respondent No. 4 (hereinafter R4F) Kveta, female, aged 48 years. Initially cared for her father, who had suffered from a stroke and then senile dementia, and her older brother, whose basic diagnosis was cerebral palsy – quadriparesis, diabetes and cardiac issues. Her father died, and Mrs Kveta now cares for just her brother, with whom she lives in a joint household.

Respondent No. 5 (hereinafter R5M) Mr Pavel, male, completed primary school, aged 56 years, cares for his wife, who suffers from amyotrophic lateral sclerosis.

Respondent No. 6 (hereinafter R6F) Mrs Jitka, aged 46 years, secondary education. Cares for her husband, who suffers from multi-system muscular atrophy and Parkinson's disease.

RESULTS OF RESEARCH

Based on the data analysis, we centrally created categories in which we presented the content of the semi-structured interviews in outlines, whereas Maslow's hierarchy of needs inspired us.

- Needs focusing on the body, transmitted into maintaining one's own physical and mental health.
- The need for safety, in our case, means the feeling of financial security, the security of receiving sufficient information, and certainty in providing care.
- The need for acceptance, i.e., the general need for a relationship with people close to you.
- The need for acknowledgement and respect from people close to you and soci-
- The need for self-actualisation and a perspective with the prospect of future life.

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List of segments and codes		
1. DECISION TO PROVIDE CARE	2. WORSENING CONDITION	3. INITIATIVE
Money	Physical and mental aspects	Care of oneself
Need	exclusion	People close to me
Level of care	profession	

Table 1. List of segments and codes in the realised interviews

THE DECISION TO PROVIDE CARE

During the qualitative part of our research, we named the first segment "The decision to provide care". Three codes, which we monitored in the described interviews, arose from this category.

Level of Care

Placement in an accommodation facility was considered negative here, something the parents do not deserve and could cause them great harm in relation to their children's perceived ingratitude. We also feel that Kveta has the impression that she can provide the best care that her parents need. In the case of a partner being dependent, there is naturally no gratitude for being brought up, but the feeling of responsibility is as strong and important as in relation to the care of parents: "You mean a home? I would never do that. He is my husband and he is physically ill. His mind is fine and I don't know how I would explain to him that I can no longer take care of him, so I'm going to put him in an old people's home, I could never do that. That would be like laying him to rest right now?" (R6F). A strong desire to provide a close relative with care in his natural environment is also expressed here. Respondent Pavel accepts the situation as a fact and does not accept any other option. "I mean there is no decision to make. What decision? It is basically like it is, yeah?" (R5M).

Money

Another factor of the decision to provide care by oneself is the economic aspect, whereas the prices of an accommodation facility would exceed the acceptable limit of the carers' financial potential: "If I did not provide care myself, then we would not be able to cover the costs financially?" (R3M). Jitka also expressed her concerns about the financial shortage and the need to share the costs: "And I also don't know where we would find the money for it. Of course he has care benefits and a pension, but this would be quite expensive and I would be unable to cover all my expenses from just my own wages. This way I take care of him,

it doesn't matter whether I cook for one person or for everyone, it doesn't make much difference and I give him the best care I can". (R6F). In this sentence, Jitka also expressed the opinion that care of a family member, which consists of not iust physical work in relation to the dependent person, but also a concern for this person, the expressed relationship and accompaniment, is the best that can be provided to this close relative, even though it is not on a professional level. However, another factor that influences the decision to care for a close relative is the fact that the carer himself was unemployed before starting to provide care and therefore considers the provision of care a specific opportunity to secure himself financially, at least with regard to the need to pay health insurance (R3M): "...I was in a situation when I was without a job, so I said to myself, this is good....I won't have to go to the unemployment office?"

CATEGORY OF A WORSENING STATE OF HEALTH

Physical and Mental Aspects

All the informants mentioned a worsening state of health, particularly back problems, "I have quite a few problems with my back" (R1F), "Because I used to have problems with my back" (R2M), "... back pain? Well, unbelievable actually-" (R4F), "...well, whatever I do, my back, well it suffers really" (R3M). The previous research also mentions this issue and is related to the efforts expended mainly on manipulating a recipient of care with restricted mobility or completely immobile. However, as it was established, these difficulties with the loco-motor system are not caused by actually moving and positioning the person being taken care of. It was surprising that carers were very often not familiar with the techniques of care, which certainly caused unnecessary stress or unbalanced stress on some body parts: "when I simply always lifted or manipulated his right hand like this, the doctors said that that was the cause-" (R1F), whereas they usually considered it a minor thing that could have been prevented after receiving the proper instruction: "Such a small thing, like helping him move into the wheelchair. I didn't know how to do it and so I exerted myself unnecessarily" (R6F). Gustav also described the same problem: "after I taught her how to help me so my back didn't suffer so much. ... It doesn't sound very good, but it's no longer like lifting a sack of oats. She cooperates now. But I have to teach her how to work with me" (R3M). Pressure on the carer's psyche often also results in physical pain. As Jitka mentions: "Just the stomach, but its not as if I had to lie down or anything. It's just the nerve you know". (R6F), the mental burden is so great that it began to somatise. Another carer mentions the same difficulties with her stomach: "My stomach aches a lot

when I let my nerves get away with me". (R4F). Carers, particularly those caring for their partners, with whom they planned to experience a full and long life, find themselves uncertain about what tomorrow will bring and, particularly, what this will mean for their loved one: "You don't know what will happen tomorrow..if everything at least stays as it is, then things would be all right. But the illness keeps progressing, I am more and more tired, and the children are too. But we can't let him know, because he is the worst off. Well you can't just break down and cry and make out what a poor thing you are, when you know that he needs the support" (R6F). We find that their concerns are not actually about themselves and the future. However, they focus on the care recipient's condition and how he experiences the situation, particularly when this concerns an illness that is nearing its irrevocable end: "Yes, it is a incurable illness, as you know....it's not as if we simply have to grit our teeth for a while and things will get better. We know they won't. And that is what we are afraid of. All of us". At the same time, the carer also suffers the mood swings of his or her partner. However, he again endeavours to understand that the recipient of the care is in a worse situation than the carer himself and that he is naturally entitled to bad moods: "the individual is like, very, very nervous, unfriendly towards all others, because his life is changing" (R3M). Female respondents, who cared for ill parents, older siblings, or people with whom they had not linked their future closely in the past were negatively more sensitive to these mood swings: "Well sometimes it isn't easy. Because they have their guirks, they have their moods, and they just take it out on me. Basically he takes it out on you because he doesn't have anyone else at home, he's in a bad mood and you are there, basically" (R1F).

Exclusion and Profession

The decision to take care of a close relative also affects the professional life of the carer. Unless, as in the case of Zita, it is a specific solution to current unemployment, it forces the carer to consider how to combine care and work and whether these can actually be combined. Some carers have completely abandoned their jobs: "Unemployed... As a carer. You cannot care for someone and still go to work" (R6F), others accepted jobs that allowed them to remain in their profession with the help of an assistant and also provide care, even though it meant that their income fell considerably. "I used to work as a fitter abroad for many years, I used to travel the world, so the salary and the living standards were naturally completely different...! am happy with my job, but I have also had better offers, but I can't accept them due to my wife's state of health" (R3M). Mr Filip, who also had worked abroad before his wife became ill, expressed exactly the same thoughts: "I've travelled the world, it was no problem, whatever I needed I had...well, and then there was a period when I stopped travelling abroad and had to stay home...the worse my wife's health, the closer to home I had to work, and the closer to home, the worse the money" (R2M). Only Pavel did not leave the profession he had had a job in before his wife fell ill, but we can speculate that this only happened because her illness progressed more rapidly. As Pavel mentioned, the doctors "gave" her three years of life, even though the period of care lasted "only" five years, which was shorter compared to other respondents. Despite this, Pavel also had to formulate a specific plan, which he used to arrange immediate intervention if necessary: "When I needed them, if I was travelling somewhere for work for instance.... I simply called and they arrived" (R5M).

INITIATIVE CATEGORY

Care of Oneself

As stated, one of the key needs a carer has to provide the necessary care is his or her own physical and mental health. All respondents stated that a serious problem that arose when the recipient of the care ceased to be mobile was back pain caused by exertion. Pavel stated that he felt pain, but he didn't do anything about it because the progression of his wife's illness was fairly rapid, and the period for which his wife's immobility lasted was "only" three years. Jitka has also not provided care for more than 5 years, which is why her efforts are not as diligent. Rather this concerns the non-professional resolution of acute difficulties and her own feeling of well-being: "Well, I found some exercises in magazine. So I try. But not regularly, sometimes I can't make myself do it, but if I feel stiff, then I do. I don't know if it helps me, but at least I make an effort..afterwards I basically feel that I am doing something... for myself" (R6F). The difference between the attitudes of women and men can be seen in relation to the other informants. While both other women did visit the doctor with their problems, they do not regularly exercise for their backs, but rather, as Jitka also says, they exercise occasionally when their problems escalate or listen to the advice of friends who have similar difficulties: "well my friend, who also has problems with her back, she taught me sea lion-hare, if that means anything to you" (R4F). Zita and Kveta use massages, which they have at the recommendation of their doctor, or make appointments for themselves when necessary, or other therapeutic methods: "he'll prescribe some sort of electric therapy for me, or some sort of exercising..." (R1F), and, in the case of severe pain, they even take medication: "But, if nothing else works, then I take the pills" (R4F). Men were much more active in this aspect. Both stated

that they exercise regularly every day, specifically exercises intended for back pain, and also carried out other physical activity in order to maintain their overall fitness: "before I get out of bed, I've learnt some exercises, a few exercises, they take me about 10 minutes and just for stretching the back muscles..." (R2M). "So I exercise daily, I go swimming in the pool, in the summer I go for a bike ride if possible". (R3M). Gustav mentioned the effects of exercising and also as necessary prevention. "I don't suffer from any problems, because I take care of myself" (Gustav, 30). Changes in diet were also mentioned, even though again more with regard to the recipient of the care: "A low-sugar diet, because my brother has very bad diabetes, so I cook according to this also" (R4F), "I try to buy good quality food so my wife has enough minerals" (R3M). All respondents confirmed medical prevention in the form of preventive examinations.

People Close to Me

The mental part of the personality of someone providing care is also very strongly affected. The answers illustrate the situation and, in many aspects, providing care has worsened the carer's health. (R4F) "well, it's twenty-four hours, well not a full twenty- four hours, but you have 7 days a week basically....you finish a shift and you start another shift", or the constant responsibility when the carer does not ease up even when caring for a recuperating recipient of care, on the contrary, he takes care of additional people who do not have accompaniment. "I have to pay for absolutely everything. I have to work as a trainer and even transport the people, . instead of being able to relax in a room somewhere", (R3M) to the need to often tolerate the mood swings of the recipient of the care "if he takes care of someone like a close relative, then the patients always lay into them, they consider it a matter of course that the relative is taking care of them" (R3M). Two carers admitted to seeking professional help from a psychologist or psychiatrist "I've asked for help. from a friend who is a professional. From my doctor" (R4F) and (R3M), who accepted help within the terms of contact with a special interest group: "talking to a psychologist for example, that was several times really". Women carers discussed problems initially with friends or family, as represented by the people-close-to-me code: "I call my friend. Or my sister- in-law, to talk things out" (R6F). All three respondents appreciated the closeness of family members: "But if I feel really down I call my cousin. I'd rather call my cousin really" (R4F), "well, quite often my sister" (R1F), while the men practically did not mention the option of sharing their concerns or suffering, "my nephews and nieces really rejuvenate me" (R3M) which however does not mean that he shared his concerns with the children of his relatives, even though these children undoubtedly unconsciously gave him strength. We also registered the difference in relations within the close family, between women and men in relation to this sphere. Filip specifically stated that the close family of his wife was not very harmonic, so he did not expect or even require mental support from them, even though he did admit to receiving help from his wife's sister: "you could say that my sisterin-law occasionally helps me" (R2M), but the mother of his wife in particular is very reserved: "I can tell you that she called me by my surname only for a very, very long time, and although she does maintain contact with her relatives, due to the serious illness of one sister and the death of another, she doesn't share her problems or concerns with either her sister or her mother. So my mother..., but that doesn't mean she will come and help me, oh no" (R2M). Gustav also stated that his wife's relatives are not a source of support for him, similarly to Pavel.

RESEARCH FINDINGS AND RECOMMENDATIONS FOR PRACTICE

Our research allowed us to penetrate a highly topical and socially significant issue. The research instrument was chosen with respect to the sensitivity and focus of the topic. In the individual categories within the qualitative research evaluation, we analysed the findings, which prompted formulating recommendations for practice. The most important issue is the creation and reforming of the areas of social policy focused on family policy, social security, and the state's healthcare policy. Reforms must be in line with preserving the rights and interests of citizens protected by law – in this case, both the recipient of care and the caregiver. The social protection of vulnerable populations is a fundamental parameter for compliance with legislation and fundamental human rights (Neszmery, 2015).

Another critical step is effectively addressing measures and state support within the social security system in the context of income security in crises. Despite constantly appearing in various documents, this recommendation is not being successfully implemented. Basic counselling is a major challenge, with respondents repeatedly highlighting the lack of information or inability to obtain information. Changes for the better can be seen in specialised guidance, as the professionalisation, expertise, and continuous development of staff ensure that it is provided in an informed manner. As for financial security, there is a need to valorise benefits in light of the social and economic situation. It also covers another critical area, namely retirement provisions. Social services and care for dependent loved ones are topics that are seldom talked about in the media. It would surely help towards a better understanding and awareness of its importance and appreciation in society itself. Without caregivers, we are unable to provide care for the needy; yet the culture and maturity of a nation are measured by the parameters of its ability to provide, by the views, attitudes and appreciation of those who, in times of difficulty, change their career or personal life at the expense of another. Often, they do not even ask for what they are legally entitled to.

DISCUSSION AND CONCLUSIONS

Care of a close relative is a highly current topic we focused on in our study. It is the result of demographic changes (ageing population), various social events during a person's life (injury, invalidity, illness) and also current issues in relation to the protection of health and life (civilisational diseases, disability, viral infection - COVID-19, SARS, etc.). The dominant element is the carer, who is affected by significant changes to lifestyle and social situation as a result of changes to circumstances in life, work activities and status. Within the terms of preparation of the qualitative research, we defined research questions focusing on identifying the needs of carers, the definition of negative phenomena, and obstacles.

We considered it most important to establish: How are persons caring for a close relative involved in satisfying their own needs?

In the field of health, the carers felt the need to care for themselves at least by undergoing preventive medical examinations. They were aware that any worsening of their own health would affect the quality of the provided care, and they were also worried about the dependent person's future if they could not provide high-quality care. They admitted to adhering to prescribed medical procedures, particularly in relation to the back-pain that carers typically suffer from. This indisposition forces many carers to exert even more effort in the form of sport, most often swimming and specific exercises focusing on strengthening the back muscles and loco-motor system, which led one respondent to the idea of using his knowledge of physiotherapy exercises to work as a physiotherapy instructor for people with disabilities. Mental issues often manifest as stomach pain suffered by the carer and are dealt with by means of psychological therapy or talking to friends. Respondents avoided medication that would provide them with relief. Women were more inclined to assure the family's financial needs by implementing economic measures, working on their own smallholding or working for just several hours a week. Carers also showed a wide range of initiative in relation to the need for certainty when carrying out procedures linked to care, obtaining information and aid. However, we must admit that the carers were often confronted with the ignorance of medical experts, social workers, and insurance company agents, who they asked about the availability of aid. They were not disinterested in helping themselves because considerable activity was required in this area, which turned into a hobby in some cases, which was subsequently realised in the form of advisory services and assistance both individually to friends and acquaintances who informally asked the carers for advice in this area, and also by means of branches of the organisation established to help similarly affected individuals. We modified the need for love and the feeling of belonging to the need for closeness with others. Carers perceive the need for acknowledgement and respect, or the need to be appreciated through the quality of the care they provide. As the respondents mentioned, they (as partners to the persons they care for) particularly perceive fulfilment of this need in this person's appreciation of their care, despite occasional disputes and misunderstandings between them, which they consider completely normal disputes between partners, usual in every household. Women caring for parents, possibly siblings, do not receive this feedback as much in the form of appreciation. However, it can be observed in the specific dependence of the recipient of care on the carer because if the recipient considered the care insufficient, unpleasant, or annoying, they would certainly take the opportunities to spend time in another environment or the care of another family member. The carers are sympathetic to the frequent accusations and bad moods expressed by a person beset by illness, age or disability and try not to attach any importance to this phenomenon, even though they confided that they sometimes regret this behaviour and feel hurt. They often do not have the opportunity to evaluate the appreciation of friends and other people around them because they do not actively ask for any expression of appreciation. One of the carers even mentioned expressing some envy by people around her as a result of the fact that she received benefits for providing care. It means that actual care for oneself is insufficient, resulting in decline, frustration, dissatisfaction, and burnout. According to Novák (2013, p. 15), burnout syndrome occurs due to long-term stress, which can also mean insufficient thanks, appreciation and social support when performing the role of carer. Similarly to Novák, we consider the need to implement supervision for carers, who have a legitimate right to this service and to whom it will be provided free of charge, unavoidable in this area. Within this service, carers will be able to determine the type of supervision, and an annual limit will be set. The need for the opportunity for further education for carers, which would take place remotely and be provided free of charge or for a minimum payment, also appears essential. Their constant engagement again determines the need for self-fulfilment by carers. Carers endeavour to educate themselves by reading magazines or seeking information on the internet. Due to their care, two carers also visit various specialist training courses, even though one admitted that he participated in many of them as a formal carer, an employee of social services in the field. In their qualitative research study, Hanley and Morgan (2018) examined the topic of verified procedures by social workers when providing support of autonomy after the life of the cared-for person had ended. Eight social workers were selected in total. The results showed that the patient-family dynamics, education, progressive guidance and the social worker's role in healthcare and social services are also essential when determining systems, measures, needs and standards in the context of social policy. In their study, they give the unavoidability of carer realisation, creation and development, which directly affects their further employment and personal mental comfort when carrying out this demanding vocation.

We were also interested in "what carers consider the greatest obstacle to the satisfaction of their own needs?" The need for specific centralisation of information was confirmed in this aspect. It would prevent the circumstances one respondent mentioned, that many people never manage to obtain the required aid due to prolonged approval procedures or the lack of information about options. This situation, which forces carers to spend so much energy to resolve, also often exhausts them, making it very difficult to find moments for rest and their hobbies. We also considered the statement by one respondent, which we interpreted to mean that her love for her husband, whom she cares for, prevents her from meeting her need for rest because she does not consider the care that would be provided to him in a residential or out-patient social facility good enough, quite paradoxical. The lack of specialist physiotherapy centres, which would take full care of the patient, was also mentioned as an obstacle. Physiotherapy centres, social centres and day centres as we know them in various countries, play an enormously important role in providing the opportunity for the personal development of carers and the satisfaction of their personal needs. Day centres exist under our conditions, but these do not always provide personal care to the patient in the necessary scope and time. And it is practically impossible to ensure this care at a moment's notice. Therefore, institutional care is insufficient. Most respondents mentioned the need to spend several days without being required to provide care and the need for relaxation. However, they are unable to meet this need. Measures and services such as the position of the informal carer, which is unfortunately still not embedded in our legislation, are supposed to help. Just like relief services, one type of social service is defined by Act No. 108/2006 on social services in the Czech Republic. VEGA 1/0719/13 research under the title of "homelessness as an accompanying negative phenomenon of our time", under the management of Ilavska Haburajova (2012–2015), has shown the complicated application of this type of social care in practice due to insufficient personnel and also the insufficient readiness to provide specific services for various social work target groups and their specifics. The consequence is the constant provision of care by individuals or families, their mental and physical exhaustion and the impossibility of taking a holiday, which every employee is legally entitled to. Another issue, which appears serious, is the absence of research on the issue of the needs of carers and their subsequent application in legislation and proposal of measures for support of carers. In their study, Pickard, King, and Knapp (2015) focused their research on identifying the needs of carers. They based their research on and promoted research that has taken place in England. This concerns "Research on personal social services provided by adult carers in 2009-2010" and "Research of household carers in 2009-2010". The results focused on the carer's number of clients, the scope of services provided. working hours, environment, working conditions and client specifics (disability, identity-cultural, social...). Carers were successfully identified and categorised according to criteria. The key criterion was how many hours a carer permanently cared for the patient. It was found that in some cases, this concerns constant personal care, of a volume of over 20 hours. This category of carers deserves more attention and a compensation system that would allow them to draw benefits and increased assistance and financial compensation. The Care Act was adopted in 2014. It provides specialists with the option of providing more support to carers, not only because the claim for compensation of carers would be expanded, but also to implement the new duty to provide support during the satisfaction of the assessed needs of carers. Further research offers findings in the field of needs within terms of community care. Kuluski et al. (2017) directed their research on social needs titled "Community care of people requiring care Coimoplex". It is realised for a panel of experts from target groups, with 24 providers working in healthcare and social care throughout Toronto, Ontario, and Canada. Participants were given motorway coupons for patients, illustrating the significant need for health and social care. The motorway coupons were the basis for a discussion about how best to satisfy the complex need for care within the community and ii) the obstacles to providing care in this population. The categories concerning support of the need for care of complex patients and their families also included i) relations as the basis of care, ii) the required care processes and structures and iii) obstacles and solutions to the required care.

The research and findings are formulated within measures and assistance in strategic action plans, community social service plans, and legislation focusing on social security for carers. The study had the ambition of naming individual links, measures

and challenges and providing the opportunity for their elimination or potential resolution. The study has its limits, where the first limiting factor can be considered to be the research sample, which came from one region in our research. The compilation of data was limited. Thus, we know that the established findings cannot be generalised to the entire population. The situation in other regions can be partially different, during which time there could be a slight conflict in the findings.

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References

- Bakošová, Z. (1994). Sociálna pedagogika. Univerzita Komenského Bratislava.
- Bakošová, Z. (2008). Sociálna pedagogika ako životná pomoc. 3., rozš. a aktualiz. vyd. Univerzita Komenského Bratislava, Filozofická fakulta.
- Coface: confederation of family organisations of the European Union. European Charter for Family Carers. (2009). http://www.coface-eu.org/en/upload/07 Publications/COFACED isability%20CharterSK.pdf
- Colombo, F. (2011). Help wanted?: providing and paying for long-term care. OECD health policy studies.
- EUROPEAN FEDERATION FOR SERVICES TO INDIVIDUALS. White book on personal and household services in ten EU Member States. (2013). http://www.efsieurope.eu/fileadmin/MEDIA/publications/White book final dec ember 2013.pdf
- Gerzova, M. (2017). Potreby osob pečujících o osobu blízkou. Univerzita Tomáše Bati.
- Haburajova Ilavska, L. (2010). Konceptualizácia v oblasti sociálnych služieb. Hnutí R.
- Haburajova Ilavska, L., Baková, D., Mojtová, M., Tvrdoň, M., Vanková, K., & Krištofová, E. (2015). Bezdomovectvo ako sprievodný negatívny jav našej doby. Univerzita Konštantína Filozofa, Fakultra sociálnych vied a zdravotníctva.
- Hanley, M. (2018). Medical Social Workers' Best Practices in Supporting Autonomy at End of *Life.* https://sophia.stkate.edu/msw_papers/834
- Krivohlavý, J. (1994). Jakzvládat stres. Praha: Grada. Pro vaše zdraví, 190.
- Krivohlavý, J. (2006). Psychológie smysluplnosti existence: otázky na vrcholu života. Psyché (Grada).
- Kuluski, K., W. Ho, J., Parminder Kaur, H., & LA Nelson, M. (2017). Community Care for People with Complex Care Needs: Bridging the Gap between Health and Social Care. Int *J Integr Care*, 7(4). DOI: 10.5334/ijic.2944
- Michalík, J. (2011). Zdravotní postižení a pomáhající profese. Portál.
- Mlýnková, J. (2010). Pečovatelství: učebnice pro obor sociální péče pečovatelská činnost. Grada.

- Nakonečný, M. (1996). Motivace lidského chování. Academia.
- Neszméry, Š. (2015). In: Baková, D., Haburajová-Ilavská L., Vaňo I., a Neszméry, Š. *Vnímanie staroby a starnutia optikou súčasnej spoločnosti*. Hnutí R.
- Novák, T. (2013). The Beastess. Jak (pre)žít se stárnoucími rodiči. Grada.
- Pickard, L., King, D., & Knapp, M. (2015). *The 'visibility' of unpaid care in England*. PubMed. DOI: 10.1177/1468017315569645
- Šamánková, M. (2011). Lidské potreby ve zdraví a nemoci: aplikované v ošetrovatelském procesu. Grada.
- Scheyett, A. (2020). Thoughts in the Time of COVID-19. *Social work*, 65(3), 209–2011. DOI: 10.3390/su12208595
- Škarková, P. (2016). Hlavní úkol pečujících o osobu blízkou: Nenechat se zničit. *Sociální služby. Odborný časopis Sociální služby, XVIII*(3).
- Viereckl, M. (2015). Určité si poradíte: praktické rady pro životní situace, kdy potrebujete zdravotní a sociální služby. FM solutions.
- Zelnick, J., & Abramovitz, M. (2020). The Perils of Privatization: Bringing the Business Model into Human Services. *Social work*, 65(3), 231–224. DOI: 10.1093/sw/swaa024