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THE SIGNIFICANCE OF FAMILY CAREGIVERS TODAY

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Abstract

Family care is defined as an informal type of lay care that is based on the principles of solidarity and love for the next of kin. The significance of this type of care is currently rising among the elderly in connection with the rising demographic increase in the number of older adults. Care for the elderly within families has a number of benefits, but there are also drawbacks that need to be eliminated. The major benefit for the elderly is being able to live at home in a stress-free environment. The major drawbacks lie in the physical and psychological strain for the caregiver, the financial burden for the family, a disrupted cohabitation, and disrupted relationships between the care provider, the care recipient and the family. Consequently, state social and health policy should support family care not only financially with available services, but also with moral appreciation. The system is still recipient-oriented rather than focusing on the family caregiver. Support for family caregivers has a positive effect, namely in long-term care on the overall health of the older person, as well as on the national economy. The information obtained was gathered from electronic databases: EBSCO, PubMed, BMČ, Google Scholar, etc. The inclusion criteria for the theoretical overview was a search period of 2005–2015 and availability of full texts. The keywords used were: family caregiver; role of caregiver; elderly; strain; burden. The exclusionary criteria were abstracts, articles related to childhood, etc. The aim of the article is to describe the current situation of family care and family caregivers in the Czech Republic. Summarized information can be useful for health and social services, and in particular for the necessary support and assistance to family caregivers.

Key words: *family caregiver; role of caregiver; elderly; strain; burden*

REVIEW ARTICLE

INTRODUCTION

Assistance to and care for a family member is based on the principle of solidarity. The first condition for caring for a close relative is social cohesion in the family (Jeřábek et al. 2005). Family cohesion can be described from six different perspectives: emotional, functional, normative, structural, solidarity of contacts and agreement. The combination creates the family environment (Pacáková and Trusinová 2012). Inter-generational solidarity is mostly demonstrated in providing care for an older family member. The need for care increases with age and the overall deterioration of health, alongside the impaired ability to perform the activities of daily living (Svobodová 2006). Family unity seems crucial, namely when providing complete care that involves several family members. Family members perform activities of care for a close relative with no entitlement for reward (Kotrusová and Dobiášová 2012). The responsibility for caring for parents should lie with the children (Svobodová 2006). The importance of family for an

older person increases with age. In a larger family, the elders play a significant role as a parent and grandparent. Care for older family members was an integral part of life in the past. There is currently a preference for independence and financial gain.

It is difficult for a family to adapt to the changed conditions and adjust to the needs of an older member. It is therefore more convenient for the majority of families to secure professional care for the elderly (Sladká and Machová 2008). Public opinion is, however, that family members should support one another across generations. More than half of adult children help their parents with serious housework and almost half of them help with running the household on an everyday basis. Two fifths of elders are accompanied by their children when seeing a doctor or going shopping. This kind of assistance is primarily reported by people aged around 75, and the need increases with a worsening health condition. Financial support is usually provided from the parents to the children. According to a public poll, elderly people with an income lower than the living minimum should be largely supported by the state. In a wider perspective, care for the elderly is understood as manual, economic and material help with emotional support seen as an expression of gratitude and love for one's family. The role of a caregiver is seen as a certain moral commitment and obligation which may have a negative effect on family relationships (Svobodová 2006).

The key factors for the provision of family care are financial income, occupation, vicinity and other aspects. Paid care services are available to dependent persons or relatives with a sufficient income. The majority of caregivers in the Czech Republic are women aged 35–64. A high proportion of caregivers have to combine the caregiver role with the role of a mother and an employed woman. The need to combine these roles is the reason why people of a productive age need support. With increasing years of care, the caregiver's financial inactivity becomes an issue. Almost one tenth of men and women are economically passive in the age group 55–64. This may be due to early retirement or unemployment. Caring activities are closely related to age and the stages of life. Certain family caregivers may see the care as challenging personal care, while others may only perceive it as intermittent assistance with everyday activities (Klímová Chaloupková 2013).

Formal care can be defined as a type of care provided by the state or another institution in the form of services performed by qualified staff. There is usually a formal contract between the caregiver and the care recipient with the obligations specified within the professional speciality, and the caregiver receives financial remuneration for the care provided. The activities of the formal care are defined by law. In contrast to formal care, informal care is provided by family relatives, friends or neighbours who are not expertly trained but may have taken a specialised course. They do not receive any wages for the care provided and the activities are not contractually specified. The activities provided by family caregivers may be divided into three areas based on the type of care. The first area involves the personal hygiene activities of daily living (bathing, dressing and feeding). The second area focuses on activities at home (e.g. tidying, cooking and shopping). The last area involves social activities, emotional support (e.g. listening, physical presence), supporting the social integration of the dependent person and activities dealing with administration (e.g. paying bills, contact with authorities). The informal care is relatively low in costs, but includes major hidden costs. These are connected with the overall impact on the caregiver's health and costs connected with interpersonal relationships between the caregiver, care recipient and the family. There is naturally a significant effect on the financial situation of the entire family (Triantafillou et al. 2010).

When performing the role of a caregiver, a series of new situations and problems arise and have to be dealt with, which involves psychological and emotional strain. These issues cause disagreements between the caregiver and the relative cared for and affect their cohabitation. It is therefore necessary to take these complications into consideration when assuming the role of a caregiver. The worsening health of the elderly person may result in less effective communication, which may also impact the relationship, as the dependence of the elderly person increases (Pacáková and Trusinová 2012). There are critical moments in various areas linked to the

demanding role of a caregiver. These problems may be reflected in the overall health of the caregiver, particularly when providing long-term care (Jeřábek et al. 2005).

The effects of home care on the family caregiver

Demanding long-term care has a negative consequence on family caregivers suffering from increased strain. The family has to adapt to the needs of the person cared for even if this means a considerable burden for the caregiver's family. A higher degree of psychological strain is recorded with a sole family caregiver. The more caregivers in the family there are, the more tolerable the conditions (Jeřábek 2009). Significant symptoms in nursing role overload can occur in just three months after the family member (e. g. after a stroke) is discharged from hospital to family care (Opara and Jaracz 2010). It has been confirmed that a significant strain on the caregiver can occur within 6 weeks of the discharge from a medical facility (Oosterveer et al. 2014).

The caregiver strain is perceived in the somatic, psychological, social and economic areas, as well as in interpersonal relationships, occupation, leisure time or family duties (Tabaková and Václaviková 2008). The caregiver develops a sense of insecurity, fear and anxiety, since a major part of his activities are connected with care. There are also the issues of lack of professional training and the amount of time devoted to care (Oliveira et al. 2013). This is particularly the case with older women who have to exert great physical effort when positioning the dependent family member. Psychological health is often disrupted by long-term stress, emotional exertion and other factors. Women are above all susceptible to psychological disturbance, particularly when they provide selfless, incessant care for a close relative. Another issue of importance amongst caregivers is their loneliness and even isolation from society. These caregivers do not know how to or are not able to obtain help. Insufficient state and municipal support for long-term care represents another significant aspect in lay family care. Lastly, the family suffers psychological trauma with a situation in which they are forced to commit the family member to institutionalised care once they are no longer able to sustain the role of a caregiver. Such a family may feel guilt and remorse with further negative consequences. In order to eliminate this crisis, effective state support is needed (Jeřábek et al. 2005).

In extreme cases family caregivers may develop burnout, which may lead to inappropriate or even harmful treatment of the elderly person. There are several contributing factors: work overload or the caregiver's chronic fatigue, which may lead to mistreating the relative. The caring person might be mistakenly convinced that he or she should use their power to control or to punish others. It is difficult to determine in practice if the caregiver's negative behaviour is intentional, or if it is an unconscious mistreatment of a family member. This is why there is a need to create suitable conditions for caregivers, in particular for those who wish to care for their relatives, but also for those who cannot provide the care needed (Bártlová 2006). Literature largely assesses the care performed by one main caregiver, but one should also take into consideration cases where more family members participate in care provision. This is a more realistic view of family care. Research in this area could bring significant information. A quarter of Czech families have had current or recent experience with caring for an elderly person. Three quarters of families, however, have no experience at all with this kind of care (Jeřábek 2009).

The advantages of family care

The demographic trend clearly demonstrates an increase in the number of older adults, which means more demands will be placed on the healthcare system and social services with the need to interconnect the facilities and services. State institutions were predominantly used to provide care for the elderly in the second half of the 20th century in care homes or other types of institutionalised care (such as long-term care facilities). Residents stayed in these institutions until the end of their life, in a strange, depersonalised environment, far away from their relatives and friends. Older adults were entitled to accessible, high-quality services that respected them as individuals. Caring for an elderly person in the home environment has many advantages, though there are some drawbacks that need be minimised since this kind of care is going

to be used more frequently. The reason for supporting home care is the increasing number of older adults dependent on other people's help, low economic demands and the limited capacity in care facilities. The advantage of home care is that it is provided in a home environment, which provides more effective cooperation among family members. The care is provided in a stress-free environment with more effective contact with the older family member. A substantial drawback lies in the distance from home to a healthcare institution (Tóthová et al. 2011).

Despite the transformation of the family social structure, such as fewer children in a family, a smaller number of dysfunctional families, a lower divorce rate, and women succeeding in professional careers, the willingness to care for an older family member is not decreasing. However, family care has little support from the state in terms of economic benefits or moral appreciation. The insufficient number of beds for the chronically ill and dependent elders has an effect on the number of families providing care in their home environment. From a long-term perspective, the care brings about significant strain on the family caregiver as well as on the entire family. The social and cultural habits of the family play a major role. The family witnesses change in the roles and their distribution, economic problems arise, the strain increases, conflicts occur and there are changes in the social area. It is important that family members who are close to the care recipient know his/her abilities and limitations. This aspect is important in relation to assisting the senior, not in terms of supervision. All of these aspects influence the caregiver's somatic and mental state and quite frequently lead to the unnecessary hospital or institutional admission of the elderly person. This is why it is important to care for the elderly person as well as for the caregiver (Bártlová 2006).

Promotion of family care

A large number of carers do not have the option to become a caregiver. This fact is associated with a higher degree of emotional stress, physical stress and other negative impacts on their health (Schulz et al. 2012). Therefore, family plays an invaluable role. Friends and hobbies are also important positive factors in coping with a caring role (Pierce et al. 2012). Caregivers have to be supported because only then can positive family ties be built upon reciprocal love and respect. Doctors, healthcare staff and social workers can help a care-giving family when all of them work together as a team and have a healthy relationship with the caregiver. Consequently social workers, and nurses in primary care and home care agencies have a great opportunity to cooperate. They carry out an assessment of the care recipient and the family. Healthcare professionals and social workers from hospitals, healthcare institutions, long-term care facilities and other institutions can significantly participate in the care during short-term admissions. The reason for a short-term admission is to relieve the caregiver and family of demanding care. Caregivers and their families have time to relax and recuperate. Nurses can provide caregivers with activities that will improve the dependent person's self-care (Bártlová 2006). It is necessary to remind caregivers of the importance of self-care and to offer alternative ways of help (Pierce et al. 2012).

Alternative help is respite care that can mitigate the risk of developing burnout and will prolong the home care period for the recipient. This is yet another reason for supporting home family care with respite services and short-term hospital admissions or stays in long-term care facilities. It is also important to raise awareness among caring families about the social and economic services available, which are often not utilised due to lack of information. Educating potential benefactors is an integral part of the job description of healthcare staff and social workers abroad. Caregivers have the opportunity to find and make use of information brochures on topics ranging from the elderly person's independence to sessions offered for individual or group discussions involving everyone who participates in care provision, including the GP. The caregiver should also be informed about various possible activities which involve providing care in the form of civic associations or interest groups. The above-mentioned activities are important for the prevention of social isolation of family caregivers (Bártlová 2006). When the family is not capable of providing care for their relative, immediate help is needed

in the form of private services. If the family maintains an active approach, responsibility and appropriate decision-making powers, this combined form of care could prove an effective way out of a crisis. However, if the responsibility for care is fully transferred to the state, possible problems in decisions about the extent and quality of care have to be considered. This responsibility would be passed on from the family to an institution. Relieving the family entirely of the care they provide holds significant perils that might not be obvious. The family adjusts to the extent and intensity of care for the family member based on current needs (Jeřábek 2009).

It is crucial to further develop alternative forms of care with flexible field services such as the respite service mentioned above. These services are needed when the family is not able to provide care or if no support is available. This is frequently the case with childless elders who might find themselves in a very difficult situation when they lose their independence. Apart from the provision of services for the elderly and their caregivers, there is a need to provide a safe environment: emergency care, low-floor transportation, wheelchair access to public buildings, barrier-free crossings and financial security. If institutionalised care is inevitable, the facility must be easily accessible. These facilities are currently scattered across the region and their capacity is limited (Svobodová 2006). Health and social care is currently focused on the care recipient rather than on the caregiver. There is a need to point out this fact and arrange for support that would relieve the psychological strain amongst caregivers. The number of elders in need of everyday care is increasing and the residential facilities are unable to supply the growing demand. The caregivers should be given support, which would help relieve the strain and have a positive effect on the provision of care (Jedlinská et al. 2009).

A direct positive effect amongst caregivers was reported in the areas of counselling, information provision, professional training and education, self-help and support groups, job support and financial benefits. There is an indirect effect on the lay caregivers when cooperating with professional caregivers in practical training. Direct service provides tools designed for care recipients in the form of financial benefits and services. The respite care, which is still unsatisfactory in the Czech Republic, falls into this category (Kotrusová et al. 2013). Health and social services offering professional care in the household, catering or lending medical aids or technical equipment are among the indirect tools designed for care recipients (Triantafillou et al. 2010, Kotrusová et al. 2013). As far as long-term care is concerned, the social and healthcare system in the Czech Republic relies mainly on families, and on women in particular. From an economic perspective, the caregivers report insufficient support for lay care from the state. The care benefit in higher degrees of dependence is insufficient not only for the procurement of professional services but also as a reward for the caregiver. Caregivers are of the view that provisions of services for the elderly are limited, particularly in respite services, psychological counselling and other social services. It is suggested that a new position of "care manager" be created who would provide complete and full information about all available services in the region. At present, the GP could take this role. A notable problem reported by caregivers is the limitation in career development and the narrow job offerings. Even though the current legal system allows part-time work contracts for caregivers, only a limited number of them are economically active. This may be due to a lack of job offers amongst employees, difficult harmonisation of care and occupation, or lack of respite care (Kotrusová et al. 2013).

Caregivers would welcome services that include psychological counselling, courses focused on working with seniors with depression, dealing with the topic of death and with effective communication. These services should also be flexible in terms of time and location (Kotrusová and Dobiášová 2012). For the development of a complete social and health network, there is a need for municipal and regional authorities to cooperate. The regional authorities should provide appropriate services that meet the needs of families and care recipients. Each municipal authority should provide publicity for these services and inform the public about social support and benefits (Formánková et al. 2012).

CONCLUSION

Education and the support of lay family care is the most effective investment for the long-term care of the elderly. The effectiveness of family caregivers will rise and will have a positive effect on the care itself. It will bring less health complications for the elderly and will lower health and social system expenses. Family care should be supported as much as possible with education, counselling, offering of respite care, financial benefits and improved conditions for caregivers on the job market. It is crucial to enhance geriatric care in professional care. In connection with the expected increase in older adults with dementia, there is a need to improve care for the elderly while maintaining their quality of life and independence. Care for the elderly should include a rich variety of services respecting the individual and his/her life situation. For this reason, counselling should be accessible and provide a high-quality service. Social services are also very much in demand amongst the elderly. It is therefore important that the health care and social systems cooperate (MPSV ČR 2014).

CONFLICT OF INTEREST

The authors have no conflict of interest to disclose.

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