Acta Univ. Sapientiae, Social Analysis, **14** (2024) 91–105

DOI: 10.47745/aussoc-2024-0006

# Role Construction of Family Caregivers in the Home Care of the Elderly Living with Dementia

Edith GAÁLNÉ SZABÓ

University of Sopron, Hungary
e-mail: szabo.edith@uni-sopron.hu

**Abstract.** Our research examines the home care of elderly people living with dementia as a sociologically scrutinized behaviour. Our goal is to understand how elderly people with special needs living with dementia are cared for in the families that care for them. Our empirical research used a qualitative method to examine how caregivers interpret their role as caregivers within the framework of the given context during the emerging constraints that motivate their actions, determining the family division of labour and the situation and well-being of the elderly. In our micro-sociological research, we were able to monitor the care process constructed through the joint life history of the cared-for elderly and their family caregivers, the care motivations, burdens, and struggles that show the development of care within the family and reveal the deficiencies.

According to our results, the individual variability of home care for the elderly is explained by the family caregivers' perception of care, their cultural background and social situation (tradition, health knowledge, material assets, nature of the relationship, etc.).

**Keywords**: demented elderly, social support, care, social constructionism

## Introduction

Care is a phenomenon that has always existed throughout history, which carries some kind of care-related knowledge and experience for the members of society. When care comes into focus as a sociological problem, we see that it has extremely diverse characteristics, in which macro-, meso-, and micro-social processes are connected. Among the various social contexts, I would like to understand in my study what meaning the people involved in care give to their caregiving role in a specific place and time, which also reflects on the shortcomings of care.

Understanding the care process presupposes that we examine what concrete care means to certain members of society.

Among the elderly, we can identify a dynamically growing group in need of care, whose care is a challenge for the current care policy in view of the multimorbidity characteristics of the dementia syndrome (Patyán 2017). According to the International Classification of Mental Disorders,[1] dementia is a psychiatric disease that means gradual mental and therefore physical deterioration to the state of complete incapacity. Although most people with dementia are elderly, it is not considered part of the normal aging process. In connection with epidemiological transitions, chronic, degenerative mental illnesses come to the fore (Bálint 2016). Considering the increase in the number of people with dementia (Gyarmati 2010), the high number of elderly people living alone (Monostori-Gresits 2018), as well as the need to develop care adapted to their care-related needs (Kostyál 2020), all resources must be disclosed in the care process that could be used to contribute to the well-being of those who are concerned.

## Research Aim and Questions

Our objective is, on the one hand, to understand how the care of demented elderly people in need of care takes place within the family, who undertakes care and why, and, on the other hand, following the interpretation of care, our aim is to reveal the care difficulties of families in order to shape policy intervention. It is necessary to understand the specific care process in order to provide adequate help for families caring for elderly people living with dementia.

Accordingly, our research questions are aimed at:

1. How are primary caregivers selected for care according to the interpretation of their own role?
2. What division of labour takes place in families when carrying out care tasks?
3. What losses and burdens do family caregivers bear when caring for elderly people with dementia at home?

## Theoretical Background of the Research

In aging societies, in the case of both North American and European countries, the number of people living with dementia is expected to increase simultaneously with the increase in the average life expectancy of the elderly population. According to demographic data, there were 55 million people living with

---

[1] https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/dsm-5-fact-sheets (downloaded: 23.05.2022).

dementia worldwide[2] in 2020, which could reach 139 million by 2050. The number of people with dementia in the European Union (EU27)[3] was estimated at 7,853,705 in 2018, which may double to 14,298,671 by 2050. According to the statistics of the World Health Organization (WHO), 60% of people with dementia live in middle- and low-income countries,[4] which are burdened by caring for people with dementia. The number of these seniors will continue to increase as they age. 15% of people over the age of 65 are affected by the disease, 20% over the age of 70, and 30% over the age of 80 in the age groups of the elderly (Gedeonné 2022).

The issues of caring for the elderly living with dementia poses a challenge to societies, which is why we are increasingly encountering models and programmes that deal with the exploration of resources that can be involved. Such a resource can be the family relationship system, which is essential in the care process and ought to be involved. Individuals in families have a common history, in which they are connected by common experience. The cultural background, patterns, and diversity of family forms have an influence on the development of the support relationships of the elderly, which influence their situation and well-being (Antonucci et al. 2013). Family relationships represent social capital for individuals. Within the multidimensional interpretation framework of these relationships, in addition to the skills, abilities, and profit-making opportunities that occur in a person’s life, Bourdieu (1978) interprets social capital as the totality of the current resources, in the framework of which relationships are also part of the individual’s wealth. Social capital means belonging to social groups, which depends on the individual’s network of relationships and its extent (Farkas 2013). In the case of a decrease in the self-sufficiency and ability to act of the elderly living with dementia, the closest family members are the most suitable supporters. During the disclosure of these resources, the caregiver network around the elderly person unfolds. The function and dynamic of this network is determined by the interpretation of the roles of those involved, as well as the cultural and political context of the given society.

A specific understanding of the social support network surrounding the elderly is the convoy model presented by Kahn and Antonucci (1980), according to which the supporters who influence the well-being of the elderly in the late life phase are selected from the network of relationships surrounding the individual. The motivation of these selected caregivers for their own role as caregivers can show the variety of care and care problems in the given social context. The

---

[2] https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/ (downloaded: 08.10.2024).

[3] https://www.alzheimereurope.org/sites/default/files/alzheimer_europe_dementia_in_europe_yearbook_2019.pdf (downloaded: 20.10.2021).

[4] https://www.who.int/news-room/fact-sheets/detail/dementia (downloaded: 08.10.2024).

concept of the convoy of care perceives care as dynamic, progressive, person- and family-specific, and influenced by different levels of factors. Events in the lives of families and individuals that determine the current situation of individuals must also be taken into account in the development of caregiving activities. Understanding this is aided by the lifespan and life path theories,[5] which are explanatory models for interpreting the convoy model. The Lifespan Theory is attributed to Batles (1987), according to whom the individual develops throughout his whole life. This development means not only losses but also gains. The main aspect is change, during which sociocultural and historical events all contribute to development. The events of the present become comprehensible through the events that take place in time – in our case, the care; we can say that they feed on the past, which does not mean that they are necessarily determined by it. The lifespan theory is complemented by the life course theory, which focuses on how social roles, structures, organizations, and resources influence the individual's situation (Elder 1985, Elder–Johnson–Crosnoe 2003, Hareven 2018, Fuller–Antonucci 2020). Life path means a set of socially determined circumstances, which includes the events and roles experienced by the individual over time. According to these, in our research we are looking for identifiable actors in the lifespan and life path of the elderly and their motivations for care.

We try to interpret the individual motivations of the people selected for care through a sociological point of view. This sociological theory is given by social constructionism, which examines the history of the formation of knowledge about a given social phenomenon (Szőllősi 2016). Based on the everyday experiences of social actors, in this case family caregivers, we interpret the social reality (Berger–Luckmann 2016) that determines their behaviour, that is, it becomes known why they care and what problems they struggle with. Weich's study presents in detail the process by which social discourse creates the persona of "the informal caregiver". According to his findings, care is based on a moral consensus maintained by public, social, and cultural discourse. This discourse creates the distinction between informal care and paid care; this creates the image of a "decent society" that properly cares for its elderly members. The function of the discourse is to contribute to the social order in which relatives are the primary caregivers of the elderly, which can be supplemented by institutional and (privately) paid care (Weich 2008). The established caregiver role perceptions determine caregiver actions, the main motivations of which are traditions and norms that feed on culture, behaviours based on religious values, the gender determination of care, and the availability of the formal institutional network (Zarzycki 2022).

---

[5] https://onlinelibrary.wiley.com/doi/full/10.1111/jftr.12376 (downloaded: 30.06.2023).

## Method and Sample Selection

We tried to reveal the history of care constructed through the interactions of the convoy of caregivers surrounding the elderly through qualitative data collection in the form of in-depth interviews. We conducted our research in a settlement in western Hungary in 2022 with 10 family caregivers, who presented the home care of an elderly family member through their own interpretations. Our interviewees were involved in the research through expert sample selection. We interviewed caregivers whose family members lived in a nursing home and who developed a trusting relationship with us during the joint work.[6] We considered it important to have shared experiences, a conversation, based on a supportive relationship and trust, because caregivers of elderly people with dementia often experience the mental deterioration of their elderly family members as a stigma and are reluctant to talk about it. We asked the family caregivers to tell the story of home care based on their memories. During the retrospective data collection, the caregivers often relived what was said, which was upsetting to them, but at the same time it also must be taken into account that these recollections have a distorting effect. The results of the research are not representative, but they still clearly reflect the burdens and difficulties of caring for elderly people with dementia in families. Prior to recording the interviews, those involved were informed about the purpose of the research and signed an anonymous consent form for data collection. The resulting conversations were confidential; in each case, they had a different duration (from 0.5 to 3 hours) in the family caregivers' own homes, and we recorded, transcribed, and analysed them thematically.

## Results

According to the interpretation of the convoy model, primary caregiver roles are formed during the organization of the caregiver network around the elderly, whose interpretations reveal the motivations of caregiving, the negotiation processes in the family, and the difficulties of caregiving. The average age of family caregivers participating in the interviews (N = 10) at the time of the research was 54.80 (± 9.750) years, women, mostly the daughters of the elderly (8 persons), and one daughter-in-law and one brother. According to the degree of dementia of the elderly cared for by family caregivers, 4 people had mild dementia, 4 people had moderate dementia, and 2 people had severe dementia[7] at the time of home care.

---

[6] The author and the therapist participating in the data collection used to work in the nursing home where the elderly family members lived and were cared for.

[7] According to family caregivers, based on a medical record or final report.

## Narratives of Becoming a Family Caregiver, Division of Family Work

### A Family Tradition

Insisting on home care, the family members either lived separately from the patient or made all the sacrifices together in order to be able to provide home care.

> My mother and I insisted on taking care of my father at home, so we took him home from the hospital and cared for him for 10 years. (46-year-old daughter)[8]

> We lived in the same household; it was natural for me to take care of my foster father in addition to my mother. (58-year-old foster daughter)

The children of the elderly took part in the care of the elderly depending on the extent to which they had the opportunity to do so. There were families where elderly spouses and siblings were available, but due to their illnesses, they only supplemented the primary caregiving tasks.

> I could very rarely rely on my younger brother, for he was also sick. My husband had a hard time bearing my absence, but after a while, he accepted the situation. (46-year-old daughter)

> I did not receive help during home care. As long as my mother was alive, she helped my father with the easier stuff: she prepared food, cut his nails; when he was able to walk, she helped him with the washing. My younger brother was rarely able to help me because of his illness. He usually took on the garden work and did not participate in carrying wood, care, and spiritual support. (63-year-old daughter)

### Compulsion

Some felt that no one else in the family was performing the care tasks, so they had to take care of it, as if drifting into an inevitable life situation. After family conflicts, there were no other caring family members left:

---

[8] The interview fragments cited in this paper were translated from Hungarian into English by the author.

> I couldn't count on my brother and my brother's children. Their relationship with my father was not good because of an inheritance case, so the grandchildren did not really visit him. (63-year-old daughter)

One of the family caregivers resents her mother for not being able to fulfil her role as a mother, and so it fell on her:

> Mom was introvert in her entire life, and her bad marriage with my father only deepened that. Dad was drinking constantly, chasing the girls, and mom fell into a complete depression. We are three girls and siblings, my older sister soon ran away from home, everything fell on me; I raised my sister and kept the family together, so it was also my task to take care of my parents. In the family, I was the one who paid attention to them. Actually, my caregiving duties were few; however, I struggled a lot with the fact that it was my duty to take care of them, regardless of the fact that there was not really an emotional bond between us. Maybe if mom had divorced and not run away into depression, our relationship would have been different. (65-year-old daughter)

## Solitariness and Professional Knowledge

One of the carers expresses ambivalent feelings and remembers the story of becoming a carer through his own painful life story. She interprets her singleness as meaning that she has to take care of her parents:

> I moved away from my parents when I was 25 years old. The main reason, however, was the circumstances at home, which left a deep mark on me up to this day. My grandfather molested me several times, and when my mother took notice of it, she didn't even say anything, not even to my father. I wasn't allowed to talk about it either. I moved away from my mother. Our relationship got from bad to worse; she was always a reserved, cold person, I never felt her love. When my parents' health began to deteriorate, my brother refused the caring tasks and did not help them. So, they moved here to the apartment on the floor below me. They often had lunch at my place, and I often did the shopping for them out of my own money. My father came home after his first stroke, and I nursed him for a year and a half. Due to my professional nursing qualification, it was not a problem. I could take care of him along with my work, and I could look after him in the evening or at night. My brother and I agreed that I would take care of him for I am single. (63-year-old daughter)

### End-of-Life Care

There was a caregiver who wanted to care for her dying father in home conditions, so she became a primary family caregiver. In this difficult end-of-life care, her younger sister did not help, but she was able to do it with the support of her husband:

> My father became sick, he got septicaemia due to a mistreated wound, the treatment of which caused him to spend a long time in the hospital. Because of the ongoing COVID-epidemic, I decided to bring him home. If he must die, he should go among his loved ones. My mother helped take care of him when I had to run errands or did the shopping. My current partner helped me financially. My younger sister couldn't bear mentally the sight of dad; she didn't even come to my aid. (41-year-old daughter)

## Detecting Symptoms of Dementia

Dementia begins with unusual forgetfulness that affects the entire behaviour of the elderly person. Members of the network of relationships surrounding the elderly do not always recognize the difference between forgetfulness that characterizes normal aging and pathological forgetfulness and behaviour change, and they are not prepared for the reserved manner of the elderly in this situation either.

> My mother-in-law's brother noticed something was wrong with my mother-in-law, as she was almost "out of her mind". There were days when she walked around her room and wailed and whimpered, even though she was not in any pain. About one year later, my father-in-law died, which further deepened this strange state: she forgot things more and more often, her money disappeared, or she was cheated, even though she used to be very organized. As a strong-willed woman, she was ashamed to ask for help, even though I visited her every day to buy her groceries. She was dismissive; we visited her daily. Thank God, we are a very close-knit family, my mother-in-law's family, the siblings constantly look out for each other. In fact, this period could be described by continuous visits and, apart from dementia, she had no other problems, which, however, worsened month by month. (67-year-old daughter-in-law)

According to informal caregivers, other signs of dementia were aggressiveness, disorientation, jealousy, and depression.

> We noticed that my foster father was getting lost on the street, he couldn't find his way home, and when me and my mother asked him, he aggressively replied that he didn't have a "home". However, he never raised his voice until then; he was a peaceful and calm person. I took him to psychiatry and neurology, and as a result of Parkinson's disease and dementia, a process of cognitive deterioration began. (58-year-old adopted daughter)

> My parents' marriage slowly fell apart; they had a hard time putting up with each other's deficiencies. Mom was extremely messy, they couldn't solve problems together. They eventually divorced; dad remarried shortly after their divorce. Later, mom also got married, and after 10 years, a high degree of jealousy and mistrust began to develop, which was not typical of her until then. At the same time, she began to be characterized by unusual arrogance and resentment for small things, which had never been seen before. One of mom's good friends took her to a neurologist, where, after many tests, more and more examinations followed. After one such examination, the doctor asked: How could you tolerate this paranoid behaviour? This is how the process of degradation began, and with it the burden of care falling on my shoulders. (47-year-old daughter)

> My father suffered a cerebral infarction, as a result of which he became paralysed on one side and his speech centre was damaged. Due to the lack of communication and awareness of the disease, he turned inwards and started to show signs of dementia. (46-year-old daughter)

## Losses, Difficulties

According to the recollections of family caregivers, the nursing tasks previously performed at home meant full nursing care in most cases. The 24-hour supervision and care of the elderly required them to reorganize their daily tasks, which in most cases entailed various losses.

### Staying Away from Your Family, Losing Your Job

> Dad was completely bedridden, he couldn't eat or drink on his own, he needed a diaper. I started doing exercises with him on a daily basis, which the physiotherapist showed me. He gradually got stronger, when he could be transferred into a wheelchair and stayed in it for a longer time. I was able to nurse him at home for one and a half year, and I was with him day and night, which brought results. He was able to eat on his own, sit

> out more and more, and move his legs to some extent. Even if not at full strength, I got my father back, whom the doctors had already given up on. My partner was extremely tolerant and understood that my place was next to dad. I had to leave a well-paying job in Austria because of home care. With 0–24 hours of observation, I could not undertake anything else. I took care of my father for a long time, it consumed all the time from my partner, and when my father got better, with his consent, we decided together to apply to the nursing home. (41-year-old daughter)

## Lack of Professional Nursing Help, Mental Strain

The worry felt due to the mental strain, and the lack of professional nursing knowledge led to the emergence of depression in the caregiver. Most family caregivers experienced mental stress, helplessness, and depression during home care; nevertheless, they did not receive external help to cope with it.

> I received no external help during home nursing care. I taught myself how to move him, e.g. to lift him up while changing diapers, move his hands so that he can hold the spoon, etc. There was a wound care nurse on one occasion, but by that time I had already watched videos for what it was for, how many times it should be bandaged, how to keep clean a decubitus.[9] (41-year-old daughter)

> I became depressed because of the constant anxiety and that I had to hold myself in readiness. Regarding his care, I had constant goals in front of me. The struggle to get my bedridden father on his feet and all the constant help with speech and articulation took a toll on me mentally, not to mention the constant doubt in myself: am I doing it right? There was no confirmation, not from anyone but dad. However, I was sure I had to take on the task, with or without help. (46-year-old daughter)

> I had a hard time admitting the fact that my mother is in need of care. I tried so hard to avoid it so that I wouldn't have to put up with my mother's condition every day. At work, I tried to cover it by being cheerful. Many people inquired about mom's condition; because of her work, she knew a lot of people (at the social welfare office) and helped everyone selflessly. It was also good for me that the outside world was concerned about her. (47-year-old daughter)

---

[9] Bed sores or pressure sores.

> It hurt me when I saw that he was in pain, suffering; it was mentally difficult. He was my foster father, but I loved him very much. (58-year-old foster daughter)
>
> Seeing his body failing was a tragedy, really. What comforted me, so to speak, was that he remained healthy and physically strong to this day. Now I have also accepted the fact that he doesn't recognize me, neither his grandson nor his brother. He had a difficult childhood in the orphanage, lost his son, and developed severe dementia... a heartbreaking fate. (67-year-old daughter-in-law)

## Summary

In our research, we tried to reveal the history of caring for elderly people with dementia in the families that care for them. In the interpretation of the convoy model, the caregiver network that surrounds the individual is primarily made up of family members, and the primary caregivers are selected from among them through the shared life history. Our research followed the selection processes of these caregivers, while we were able to learn from the interpretations of their own roles, who is/are additionally involved in the care besides them, and what kind of division of labour takes place in the family. According to the narratives of selection for primary care, the motivations of the caregivers' actions were examined through the perspective of social constructionism. The selection for care and the actions can take place: due to compulsion, tradition, reasons of conscience, professional nursing knowledge, etc. Primary caregiving roles are mainly taken on by women, which is also supported by evidence from previous research (Miller–Cafasso 1992). At the same time, secondary caregivers, such as elderly spouses, other male members of the family (sons and husbands), as well as friends also participate in care (supervision, chores around the house, accompanying to the doctor, etc.), without whose support the primary caregiver would not be able to provide long-term care at home. Therefore, the exploration of the roles of secondary caregivers can be of high priority in the care of the elderly with dementia.

Dementia, as a disease that affects the entire existence, is difficult to accept both by the patients and their caregivers, and they are less familiar with its treatment options, and their care skills are non-existent or incomplete. All questioned family caregivers reported that it was possible to identify the symptoms of dementia in the case of the elderly cared for. These were the following: aggression, wandering, mistrust, resentment, depression, and forgetfulness. Handling these negative habits posed a challenge for them. In the last phase of physical and mental deterioration, they turned to social institutional placement, sometimes after 10 years of home care. Due to the constant observing, family conflicts, and mental strain, family caregivers of the elderly often lose their jobs while struggling to provide care for the daily needs of someone that is unable to care for themselves in the severe stages of dementia.

## Discussion and Conclusions

Family caregivers of the elderly living with dementia explained their selection for care by their position in society, mobility opportunities, living conditions, and forced life situations. Examining these supportive relationships from a constructionist perspective revealed how family caregivers interpret care in each household. There are those who interpret their caregiving role as a filial or feminine obligation, or perhaps their decisions are motivated by an inner helping attitude, humanity or altruism, which, however, are culturally determined. According to Peeters et al. (2010), love and marital duty are strong motivations for care. Becoming a family caregiver is determined, on the one hand, by the personal characteristics of the elderly and their family caregivers (age, illness, self-sufficiency, financial resources, spatial proximity), their individual life path, and external social events. In addition, however, we must take into account the individual preferences of family caregivers, which shape the nature and content of care.

Caregiver actions and decisions are always influenced by the relationship between the elderly person and the family caregiver, which can be hostile. In such cases, the quality of the care activity and the well-being of the elderly may reveal the nature of the relationship. In his research, Shanas (1961) pointed out that the elderly who have caring children are in a more advantageous position in terms of organizing their care compared to those whose family network is weak or absent.

In some families, care for generations has meant care at home with a division of tasks between family members. In addition to cultural and socialization matters, the bargaining processes within the family were also influenced by other factors: spatial location of family members, financial opportunities, professional (nursing) experience, marital status, employment opportunities, health status, cohesion or conflicts between family members. Caring for elderly people with dementia is primarily managed by members within the family, sharing tasks among themselves (Kopasz 2020).

Examining the losses of family caregivers, the loss of job and family conflicts appeared as external losses; however, monitoring the deteriorated condition of the elderly, the mental and physical deterioration associated with dementia was a heavy internal and mental burden for them, which was considered more difficult than the burden associated with caregiving. Factors causing mental stress can be external and internal stressors (Pearlin et al. 1990).

During our research, it was proven that, as postulated by the convoy model, the examination of the selection process of primary caregivers and of the role of caregivers through social constructionism enables learning about home care for the elderly with dementia and thereby shaping policy. It would be important to enable family caregivers to receive mental health support, which is not available to them at all, long-term access to specialist care in their homes, and adequate financial support. The possibility of using formal systems in the care of elderly people with dementia requires further research.

## References

Antonucci, Toni C., Ajrouch, Kristine J., Birditt, Kira S. 2013. The Convoy Model: Explaining Social Relations from a Multidisciplinary Perspective. *Gerontologist* 54(1): 82–92.

Bálint, Lajos. 2016. Mennyire illeszkedik a magyar halandóság alakulása az epidemiológiai átmenet elméleteihez? [To What Extent Do Hungarian Mortality Patterns Are Consistent with the Theories of Epidemiologic Transition?). *Demográfia* 59(1): 5–57. DOI: https://doi.org/10.21543/Dem.59.1.1.

Baltes, Paul B. 1987. Theoretical Propositions of Life-Span Developmental Psychology: On the Dynamics between Growth and Decline. *Developmental Psychology* 23: 611–626. DOI: 10.1037/0012-1649.23.5.611.

Berger, Peter, Luckmann, Thomas. 2016. *The Social Construction of Reality.* Second edition. London: Routledge. eBook. ISBN: 9781315775357.

Bourdieu, Pierre. 1997. Gazdasági tőke, kulturális tőke, társadalmi tőke [Economic Capital, Cultural Capital, Social Capital]. In: Angelusz, Róbert (ed.), *A társadalmi rétegződés komponensei. Válogatott tanulmányok* [The Components of Social Stratification. Selected Studies]. Budapest: Új Mandátum. 156–177.

Elder, Glen H., Kirkpatrick Johnson, Monika K., Crosnoe, Robert. 2003. The Emergence and Development of Life Course Theory. In: Mortimer, J. T., Shanahan, M. J. (eds.), *Handbook of the Life Course.* Boston, MA: Springer. 3–19. DOI: 10.1007/978-0-306-48247-2_1.

Farkas, Zoltán. 2013. A társadalmi tőke fogalma és típusai [The Concept and Types of Social Capital]. *Szellem és Tudomány* 4(2): 106–133. (http://real.mtak.hu/26709/1/FarkasZ_Tarsadalmi_toke.pdf; downloaded on: 10 October 2022).

Fuller, Heather R., Ajrouch, Krisitine J., Antonucci, Toni C. 2020. The Convoy Model and Later-Life Family Relationships. *Journal of Family Theory & Review* 12: 126–146. https://doi.org/10.1111/jftr.12376.

Gedeonné Dallos, Rita. 2022. A demenciaellátás innovatív irányai [Innovative Approaches to Dementia Care]. *Máltai Tanulmányok* 4: 94–107. https://doi.org/10.56699/MT.2022.4.7.

Gyarmati, Andrea. 2010. Demensek a szociális ellátórendszerben (Demented Persons in the Social Care System). *Kapocs* 9(2): 36–47. (http://epa.oszk.hu/02900/02943/00045/pdf/EPA02943_kapocs_2010_2_04.pdf; downloaded on: 20 March 2021).

Hareven, Tamara K. 2018. *Families, History and Social Change: Life Course and Cross-Cultural Perspectives*. New York, NY: Routledge. DOI: 10.4324/9780429500572.

Kahn, Robert L., Antonucci, Toni C. 1980. Convoys over the Life Course: Attachment, Roles, and Social Support. In: Baltes, P. B., Brim, O. G. (eds.), *Life-Span Development and Behavior*. Vol. 3. New York: Academic Press. 253–286.

Kopasz, Marianna. 2021. „Van, amikor szakad a cérna.” Demenciával élő idősek családi gondozóinak terhelődése egy kvalitatív vizsgálat tükrében [“Sometimes We All Lose it.” The Burden on Caregivers of Elderly People with Dementia in the Light of a Qualitative Study]. *Socio.hu* 4: 47–68. https://doi.org/10.18030/socio.hu.2021.4.47.

Kostyál, L. Árpád. 2020. Demencia a családban – az informális gondozók támogatási lehetősége [Dementia in the Family – Support Possibilities for Informal Caregivers]. *Esély* 31(4): 97–116.

Miller, Baila, Cafasso, Lynda. 1992. Gender Differences in Caregiving: Fact or Artifact? *The Gerontologist* 32: 498–507. https://doi.org/10.1093/geront/32.4.498.

Monostori, Judit, Gresits, Gabriella. 2018. Idősödés [Ageing]. In: Monostori, Judit, Őri, Péter, Spéder, Zsolt (eds.), *Demográfiai portré* [Demographic Portrait]. 127–145. Budapest: KSH NKI.

Patyán, László. 2017. Családi (informális) gondozást segítő rendszerek Magyarországon [Systems of Support for Informal Family Care in Hungary]. *Magyar Gerontológia* 9: 34–48. https://dx.doi.org/10.47225/MG/9/33/8127.

Pearlin, Leonard I., Mullan, Joseph T., Semple, Shirley J., Skaff, Marilyn M. 1990. Caregiving and the Stress Process: An Overview of Concepts and Their Measures. *The Gerontologist* 30(5): 583–594. https://doi.org/10.1093/geront/30.5.583.

Peeters, José M., Van Beek, Adriana P. A., Meerveld, Julie H. C. M., Spreeuwenberg, Peter M., Francke, Anneke L. 2010. Informal Caregivers of Persons with Dementia, Their Use of and Needs for Specific Professional Support: A Survey of the National Dementia Programme. *BMC Nursing* 9: 1–8. https://doi.org/10.1186/1472-6955-9-9.

Shanas, Ethel. 1961. *Family Relations of Old People.* New York: Health Information Foundation. https://search.proquest.com/pao/docview/1297788929/fulltex tPDF/368AB2A653944C0EPQ/6? accountid=16746; downloaded on: 23 May 2020).

Szőllősi, Gábor. 2016. A társadalmi problémák szociológiai elmélete – a konstrukcionista nézőpont [Sociological Theory of Social Problems – The Constructionist View]. *Metszetek* 5(1): 64–78. DOI: 10.18392/metsz/2016/1/4.

Weicht, Bernhard. 2008. The Morality of Caring: The Discursive Construction of Informal Care. *Enquire* 1(2): 120–143.

Zarzycki, Mikolaj, Morrison, Val, Bei, Eva, Seddon, Diane. 2022. Cultural and Societal Motivations for Being Informal Caregivers: A Qualitative Systematic Review and Meta-synthesis. *Health Psychology Review* 17(2): 247–276. https://doi.org/10.1080/17437199.2022.2032259.