Propositions of the Ph.D. Dissertation

Victims of Unsolved Problems in Elderly Care
The Current Situation of Family Caregivers in Hungary

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1. Introduction to the topic of the dissertation, antecedents of research, raising problems

Fast changes in post-industrial societies have led to several new social risks (underemployment, rise in inequalities, migration etc.). Due to demographic processes and the quickly transforming family structure, ageing society and the disappearance of a significant part of traditional family caregiving have emerged as parallel tendencies in the developed world, creating one of the biggest social challenges of our age (Myles 2007). In the past decades both literature and the public were concerned with devising transfer systems that were to guarantee old age security for the elderly, and paid less attention to the equally important problem of who was going to care for the ever-growing number of old people. Although the „caregiving chain” is already global in scale (Yeates 2012), in my dissertation the focus was directed to an important domestic aspect of this challenge, namely the situation of family caregivers in Hungary.

The first step to provide old age security for the elderly in the second half of the 20th century was the integrated pension system covering all citizens, which had been implemented until the end of the 1960s. This pension system was supposed to protect against elderly poverty. Since the 1970s, however, with the income improvement of pensioners and along with demographic ageing, it was not only the risks of elderly poverty that welfare systems in the developed welfare states had to manage, but also the problem of meeting the growing needs in long-term care, due to the significant rise in the number of the oldest old (Myles 2007).
Compared with the age structure of the world where 8 percent of the population belongs to the group 65 or above, age indicators in the European Union are excessively high: the population group in the 65 or above category reaches or exceeds 19 percent of the population.\(^1\) Simultaneously, there is another significant change within the group of elderly population: the number of „the oldest old” (meaning those above 80) is rising twice as fast as the younger old (OECD 2015). In this age group particularly, there is a dual risk of sudden health deterioration and the subsequent need in long-term care\(^2\). These two risks together lead to the five well-known old-age risks\(^3\), completed with a sixth one: feeling lonely.

\(^1\) World Bank (2015) The proportion of the population aged 65 or above (expressed in percentage of the total population) - http://data.worldbank.org/indicator/SP.POP.65UP.TO.ZS?name_desc=true

\(^2\) A good example for the connection between health deterioration due to demographic ageing and the subsequent rise in the need for long-term care can be found in the 2012 comprehensive study of the Global Agenda Council on Ageing Society expert group that examines the global effects of ageing in extensive international comparative analyses. Table 6 in this study (pp.136-137) shows the related proportion of life expectancy and the years spent in good health.

\(^3\) The five risks of old age are: physical and mental deterioration, physical or mental dependence on family members or caregivers, elderly depression, frailty and ailment.
The change in family structure resulted in a huge decrease in informal care capacity (Hantrais 2004), foreshadowing the aggravation of problems in care provision where responsibilities originally rested on family caregiving. Post-industrial economy facilitated the employment of women (Beck 2003). Wherever heavy industry has given way to service industry, opportunities for female employment have increased (Somlai 2014). The instability of relationships, the growing numbers of divorce and one-parent families, the spread of atypical cohabitation forms all indicate a fast transformation of the family structure. Developed western welfare states had already taken into consideration in their social policies that women – who are the primary informal caregivers – are unable and unwilling to undertake alone all the recreational functions needed in the nuclear family (Beck 2003). Thus, growing attention has been paid to socio-political efforts that aim at harmonizing the double function of women as employees and caregivers. In Hungary, it took a slightly different turn: although women were emancipated during Kadar’s regime, the socio-political changes of 1989 mostly resulted in a conservative turn, preserving the dominance of traditional female roles.

Traditional female roles show more significant changes in economically developed cities (Esping-Andersen 2006), and the double burden will let women fulfil the roles of traditional caregiving only partially (Török 2014). As a result, three quarters of traditional capacities for elderly care have simply disappeared (Myles 2007).

The role of traditional caregiving may affect a female caregiver’s life at different stages in her life course. The period of raising children might overlap caring for the elderly, or caregiving may distract women from their
tasks as grandparents. The increase in care need may hamper the presence of women on the labour market, or, in the younger generation, the willingness to childbearing. Family caregivers are often forced to choose between employment and caring for their elderly relative, especially if there is a lack in flexible problem-oriented, state-supported personal and public social services that would facilitate harmonization. The coexisting presence of the above two problems (demographic ageing and instability of the nuclear family) causes insufficiency in traditional forms of elderly care.

Literature investigating elderly care concentrate mostly on care receivers, and pay much less attention to caregivers. In order to alleviate the burden of family caregivers, we have to evaluate the capacity of further pillars of the welfare mix. To provide for the growing need in care, a new balance is needed between the roles the state, the market, and the family play in the process. On the other hand, a market that is to provide for the needs of solvent demand would certainly be socially insensitive. If we are to devolve the lack in caregiving capacity that has emerged due to the transformation of the family structure to the market, we will be faced with further increase in – already significant – social inequalities. On the other hand, we will also be faced with unwillingness from the state, since it seems that the state is unable or unwilling to give a substantive response to this seemingly marginal problem. Varied challenges in elderly care have sprung various governmental responses that would support the principle of path-dependency, which indicates that a way-seeking approach is still dominant in this field. It seems, however, certain that the role of the family in elderly care remains significant. The important question is how the state – with its own measures – could promote the provision of this task in the most satisfactory way.
The Hungarian state has not yet reacted sufficiently to the changes in family structure. There can be plenty of reasons why – including that no independent research has been conducted to explore the sociological and demographic characteristics of family caregivers. With no actual surveys we can only hypothesize the ways a Hungarian family caregiver is similar or different from those living in other member states of the European Union.

From the 1950s up to the conservative turn at the change of regime in 1989, Hungary had been practising defamilization. During the period of state socialism the family was increasingly disencumbered from elderly care, as it is proven by cases where elderly people between 60 and 70 were segregated by force in residential homes in the countryside (Horváth 2012). After 1989 a refamilization process started parallel with the disimprovement of social services, leaving the altered family relations out of consideration. This, together with the lack of affordable market services, often resulted in the need for elderly care being partially unprovided for.

As far as the future is concerned, we may well forecast that it is fundamental to create a new, long-term balance between welfare pillars. It is also necessary to reconcile traditional care and employment, which first of all would mean that the double burden on women is decreased to a tolerable level, especially if we are unable to find other possible actors in this field.

In the thought process of present dissertation, I have chosen to investigate the living conditions and particular aspects and viewpoints of the family caregiver instead of the system or the care receiver, in a context of the needs
of the elderly care receiver. On the one hand, with this empirical research I wanted to explore the actual situation and standpoints of the family caregiver in the caregiving process as it appears in present-day Hungary. On the other hand, I also wanted to contribute to finding ways to disencumber the family caregiver, while at the same time facilitate their employment. The detailed elaboration of the Hungarian situation and possible response options may add important value to the theoretical path seeking in this subject.

2. Methods

I have analysed different documents, laws and regulations in the context of Hungarian and international policies in order to get closer to the needs of the elderly and the family caregiver. To achieve the most reliable data, in a pre-research I first had to define the concept of the possible Hungarian family caregiver as they would appear in the filter questionnaire, using a set of questions of a research conducted about elderly people over 65. Secondly, in the conceptualization process of my main research I combined qualitative and quantitative methods. When compiling the questionnaire, I used 15 semi-structured interviews as a pre-research, with participants selected from one large and one small settlement in seven different Hungarian regions, as well as from a district of Budapest. For the precise conceptualization of service expansion, focus group interviews were carried out.
2.1. Semi-structured interviews

15 semi-structured interviews were conducted with primary family caregivers, in seven different regions of Hungary. The selection of the interviewed family caregivers was made according to the recommendations of social institution leaders. The interviews used guidelines to keep the actual topics in focus, however, due to the particular characteristics of the semi-structured interview, interviewees were able to shape or define the process of the given topics, constructing their answers with relative flexibility. With the help of this method we could get closer to the given problems and their significant elements from the interviewees perspective. Out of the 15 interviewed family caregivers two live in Budapest, five in county seats, six in small towns, and two of them live in small settlements. Cases were equally divided from the regional aspect: three of the interviews were made in Central Hungary, while two interviews were carried out in each of the other six regions, with a family caregiver from one large and one small settlement in each region. Semi-structured interviews are of an explorative nature, and are able to give a deeper presentation of a relatively small number of hypothetically typical cases. In order to give a more vivid illustration some details were highlighted when analysing the interviews.

2.2. A national representative survey research

Between April 29th and May 25th, 2016, a national representative phone survey was conducted on a national sample, with the implementation of a
standard filter questionnaire\(^1\), in 30 minutes of length each. The themes of the questionnaire were constructed partly on the basis of the results obtained from the semi-structured interviews that had been analysed during the pre-research, while at the same time searching for answers to the central and sub research questions already referred to in the introduction of present dissertation.

The initial sampling frame of the research was the mobile or landline phone owners part of the Hungarian population (since more than 95 percent of the Hungarian population can be reached through the above two ways, the initial sample can be used as a good way to access the whole Hungarian adult population). Calls were made by a random number generator. Therefore, as everyone possessing either landline or mobile phones in Hungary had an equal chance to get into the sample, the sample of people called can be regarded as representative of the Hungarian population sampling frame.

Family caregivers who were asked to answer the total length of the survey had been selected using a filter questionnaire with the following criteria: they had to be a relative of the care receiver, as defined by the Civil Code (spouse, direct relative, adopted, step-, or foster child, adopting-, step or foster parent or sibling, as well as life partner, spouse of direct relative, direct relative and sibling of spouse, and spouse of sibling) – supplemented by the category of niece/nephew and cousin, on the basis of the results obtained about the family caregiver from the pre-research on the elderly. Another criterion was that

\(^1\) Questionnaires were surveyed by ARIOSZ Kft, as ordered by Barankovics Foundation.
caregiving activities continue for more than three months, at least in 8 hours a week, which can either be squeezed in one day or spread to a little more than one our per day. Since we have no knowledge base population and statistics about family caregivers, small corrections were made by weighting on the initial calls – that is, the total Hungarian population – after finishing the survey. Thus the proportion and number of family caregivers as compared to the Hungarian population could be well assessed from the research. On the basis of the research, the proportion of family caregivers according to above definition is 25.5 percent among people over 18, meaning 1 971 743 persons in Hungary (plus-minus sampling error). Owing to the perfectly random selection methods, sample spreads well approach values characteristic of knowledge base population.

2.3. Focus group research

In this qualitative part of the research there were three focus groups involved, one in Budapest, and two others in the country. A focus group in Budapest seemed obvious due to the fact that almost one fifth of the population live in the capital, with one of the highest rates of people aged 65 or above. The two other focus groups were selected from a disadvantaged settlement in North-Eastern Hungary and from a developed county town in Western Hungary, where the proportion of people over 65 is above the 17% national average. In the disadvantaged small settlement, due to the different living conditions, this proportion is significantly lower, 13.9%.2

2 Source: KSH http://www.ksh.hu/nepszamlalas/tablak_teruleti_00 [last downloaded on 21st December, 2016.]
The aim of these focus group interviews with family caregivers was to collectively define and evaluate possible service options as answers to the needs identified in the survey. The content of the focus group interviews was based on the results of the survey, thus developmental options and possibilities for the needs mentioned there created the backbone of this part of the research. Moreover, during the focus group research we were able to raise topics that had proved to show interesting or surprising results according to survey data.

On the basis of the results of the national representative standardized survey we assembled focus groups of 6-8 people, where the basic filter criterion was – similarly to the survey – that the interviewees had to take care of a family member aged 65 or above, in at least 8 hours a week. To map different needs, there were other filter criteria defined on the basis of the experience of the survey:

- gender aspect: 2 men and 6 women
- age group spread: 4 people under 50, 4 people over 50
- education aspect: 4 people with max. 8 grades of primary education or skills without secondary education, 4 people with secondary education or degree
- labour-market aspect: 4 people in full or part time employment, 4 people without employment
- cohabitation aspect: 4 people live together with care receiver, 4 live separately
• child rearing aspect: out of the 8 focus group members, at least one but maximum 2 people should have no children
• family status aspect: at least 4 people of the 8 group members should have a spouse or a life partner

Within **Budapest**, family caregivers were selected from the following districts:

• city centre (districts 5-9) – 2 people
• inner part of Buda (districts 1-2, 11-12) – 1 person
• inner part of Pest (districts 10, 13-14) – 1 person
• outer districts 1 (districts 3-4, 15) – 2 people
• outer districts 2 (districts 16-19) – 1 person
• outer districts 3 (districts 20-23) – 1 person

In order to reach my goals the central research questions of my dissertation were the following: under the given welfare system and family structures who take over personal caregiving, who are the actual family caregivers to elderly family members? What are their family connections, relationships and sociocultural characteristics? What kind of personal and community services would significantly contribute to the facilitation of their caregiving? To be able to answer the central research questions, the following sub questions were defined:

• **Sub question 1** What are the social attitudes to caregiving and who are the actual family caregivers?
- **Sub question 2** How can a typical family caregiver be characterized, what are his/her sociocultural-demographic indicators (with respect to education, employment, number of children, etc.)?
- **Sub question 3** What is the content and possible categories of informal care?
- **Sub question 4** How does the start of caregiving affect the living conditions of the family caregiver?
- **Sub question 5** What are the options of coordinating labour market and caregiving tasks?
- **Sub question 6** What state transfers or benefits do they get, are there any that are connected to providing care (such as local support given under the title of care provision)?
- **Sub question 7** What available public services do they know (even if it is obtained or used by the care receiver) and how much can they use/implement that in their caregiving?
- **Sub question 8** Does the elderly family member give any kind or type of help, financial support for the caregiving family member?
- **Sub question 9** What necessities and actual services (either personal or community services) are lacked or required according to the experience and opinion of those affected?
- **Sub question 10** What kind of help would the use of info communication tools provide in the mitigation of the care burden?

3. **Results**

To sum up my research it can be declared that – justifying my initial presumptions and along with international tendencies – a family caregiver in
Hungary can be described as a middle-aged woman with children, with a below-average income, living in a disadvantaged settlement together with the family member she is taking care of. Therefore, the tendency of their employment dropping from two-thirds to fifty percent due to their caregiving cannot be ignored – especially because one in four of the female caregivers is also struggling with deteriorating health state. More than 40 percent of family caregivers give personal care (such as changing diapers) or social care (such as cleaning) on a daily basis, while four in every five also provide psychological care, and they spend more than 28 hours a week with caregiving. Because of the heavy burden of care, one-sixth of family caregivers have not even a theoretical option for short-time recreation, which in extreme cases, may add up to a total social exclusion. Less than 10 percent get any kind of benefit for their care, even though they attend to highly burdensome tasks, since most of the elderly they care for are women over 78, disabled or struggling with long-term conditions. It can be stated then that there is a 70 percent predominance of women in informal elderly care.

More than 30 percent of female family caregivers have already been doing such activities for about 4 years on average, and most of them are supposed to have already been exposed to leaving the labour market earlier – at least once –, because of child-rearing. Therefore, their life chances in the future can be significantly lower than those of their male peers.

If we suppose that those with below-average income or wealth spend the longest time looking after their family member (36.9 hours per week on average), we may consider the question whether family caregiving should be respected and supported the same way as child-rearing, and caregivers should
be provided a state-guarantee benefit with service time, because instead of placing the solution of caregiving tasks in the equity jurisdiction of municipalities with discretionary rights, they attend to such tasks themselves. My research has supported the fact that elderly care – similarly to child-rearing – is a valuable activity in case of unemployment.

Among the new results of the dissertation we must mention the presentation of the dual regulation in coordinating family caregiving and female employment in the context of international law, and also the conceptualization of the family caregiver by identifying their socio-economic characteristics and at the same time defining some new service elements that can potentially help their caregiving activities.

The coordination of female employment and traditional caregiving, as examined in my dissertation, can partly be encouraged by the strict application of the prohibition of gender discrimination, and partly by creating positive social laws that would ensure the extensive social protection of the working mother and her child. Nevertheless, other caregiving activities of women, such as elderly care, are thematically split off this structure, which may seriously raise the question of possible coordination if it is still kept exclusively within the female life course. Hungarian legislation is in no way behind international legal practice, since Hungary has signed all relevant and significant international agreements and has been a member of the European Union since 2004. The problem is caused by the fact that all over the EU coordination between elderly care and employment still belongs to „issues to be solved in the future“. 
My research outlines the extension of care supply system; if from 2023 present care facilities could only be operated as long-term residential homes, the creation of interim or temporary residential institutions would be also needed, where old patients can stay for a period of one weekend up to three months. Short-term, less-than-a-week stays in such institutions may support and enhance the leisure time and social relations of the informal caregiver, while a longer residence with professional caregivers may facilitate the rehabilitation of the elderly after a hospital treatment, and at the same time promote the perpetuation of workplace and general health of the family caregiver. Basic service for all elderly patients who need long-term care could include accessible home care, home health care signalling systems, meal and food delivery, the extension of support service to the elderly and the state-guaranteed rent of medical aid devices – these would disencumber the informal caregiver from their daily tasks. Family caregivers can be supported by providing information, advice on caregiving and crisis support services. The specialization of residential homes and the transformation of present care facilities into long-term residential homes can be regarded as good tendencies, since specialization in different diseases and conditions may facilitate the decision of the family caregiver to claim the service of such institutions.
4. References


Somlai, Péter (2013): Család 2.0. Együttélési formák a polgári családtól a jelenkorig (Family 2.0. Cohabitation Forms from the Bourgeois Family to the Present Day), Napvilág Kiadó, Budapest


5. Related publications


