DOCTORAL (PhD.) THESIS

László Patyán

“The System of Relationships between the Professional and Family Caregivers in the Home Care of the Elderly People”

ELTE TáTK Doctoral School of Sociology

Social Policy Program

Mentor:

Zsuzsanna Széman PhD
Professor

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1. History of the research, problem raising

The fact of demographic aging has been widely recognized in modern societies. In the countries of the European Union, including the newly acceded member states with worse indicators, the number and proportion of elderly people is growing rapidly. The percentage of the population aged 65 and over 65 was 19.2% in 2016, 0.3% higher than the figure for the previous year. According to demographic estimations the proportion of people over the age of 65 will reach 29% by 2060, followed by a slowing increase, however, the proportion of the elderly will remain high in the population. By 2080, the percentage of people over the age of 65 may reach the 29.2%.

Significant changes can also be expected in the composition of the elderly population. The rate of the population over the age of 80 is expected to be 5.9% among the population by 2020. This rate is expected to double and to reach 12.1% by 2060 (EUROSTAT, 2017). The prolonged lifespan and the growing proportion of the very elderly will challenge the welfare systems of the nation-states. One of the challenges will affect the systems of long-term care, due to the constantly increasing care loads. In maintaining daily lives 39.5% of people over the age of 85 require some help, while 35.6% require intensive support and care (Carretero et al., 2012).

A closer cooperation between the formal care systems and the caring family members as well as the involvement of family carers (their support, their provision with services, using co-operation methods) provide a higher level of care, enhance the competency of the actors and their feeling that they have control over the care process, and in addition reduce the distance between formal and informal systems (Carretero et al., 2012) (Lamura et al., 2008).

According to the results of international research (Ward-Driffin, 2000) (Schwarz-Woelzl, 2009) (Triantafillou et al., 2011) (Jakobs et al., 2014) (Hlebec, 2015) helping family carers is an important resource, as they play a major role in the caring process of the elderly even in welfare states with well developed institutional support systems. The recognition of family care, the support of care without payment and shifting from institutional care to family and community care have now become an important element of the European care policies (Blusi et al., 2013) (Stoltz et al., 2004) Mestheneos - Triantafillou, 2006).

Family care seems to be the so-called "blindfold" of the Hungarian care policy. In the Hungarian care practice, family members do not appear as actors, even though, in cases requiring partial care, presumably (as the system assumes) there are assistants who support the elderly in their lifestyle1. There is no protocol for professional helpers when the participation of the assistance of a family member is obvious and necessary in the home care process not even when intensive care is provided.

In the operation of the care system and in the development of the professional content a greater emphasis is given to the regulation of the formal system, which has many disadvantages. One of them is the appearance of the professional roles and how the professionals can accept and can follow these protocols during the everyday care processes. The "top-down profession" can create special situations in care policy.

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1 I deal with the regulation of home help and the analysis of the service in the theoretical part. The service basically relies on an existing or not existing support system (service does not have to be provided at weekends or holidays) that surrounds the elderly.
The strengthening and spreading of service-management lobbies directly push the service-related policy decisions towards the sustainability of the institutional services and the regulation of capacities (Patyán, 2013) (Krémer, 2013). This could be a real obstacle to the recognition and prioritization of family care, as policies have recently been trying to comprehend and regulate institutional structures.

Policy, recognizing the activity, the risks and the social rights of family carers to a lesser extent, provides only a few tools to support caregivers. The two-year-unpaid leave available for caring in Hungary, makes the caregiver be the bearer of the social risks during the process of caring. As no statistical data are available, it can only be estimated how many family members have undertaken the non-subsidized lifestyle and the risk of a permanent absence from the world of work.

Transfer allowances for the period of care are not intended to cover the risk of caring but for the loss of earnings for active people. The assistance thus carries the characteristics of the subsidy-type benefits.

In my opinion, these factors also confirm that in Hungary family care is not recognized, and even the existing subsidies have been strongly curtailed. Further centralization of the areas of provisions and services can only strengthen the shift from family care and from informal directions.

Another consequence of the operating - regulatory mechanisms is the development of the "learned ineffectiveness" of the professionals". Its result is that their “applied task executioner” role increases while their professional competences decrease, which results in the increase of their frustration with professional activities. In this regard the situation of nurses and social carers is particularly interesting. As the most populous group of people working in the social field, they have the lowest qualification and they are the lowest-paid employees in the sector.

Nevertheless, social problems and needs become a "problem" (a need that the system acknowledges and recognizes and triggers a reaction to it) through this system and the helpers working in the system. This is true of the care needs of the elderly and of the role and needs of the family member involved in the care process. In this case, the caring activities, defined in the regulation of the sector and recognized by the state, determine what kind of care activities should be provided to the elderly in different levels of needs and risks.

Meeting the needs not acknowledged in the system may be the responsibility of other caregivers. It is questionable which area is significantly burdened by the tightening of the regulatory process. In the absence of the recognition of the carer's role in the family, the formal system does not recognize the efforts of the family carer in the caring process, it does not recognize the tensions of reconciling work and care and cannot focus on the support of the family carer when the burden of care exhausts the family member.

The re-interpretation of care risks and the tightening up of the state-recognized care needs are well-known processes in international care policy (Kröger - Leinonen, 2012), which cannot avoid Eastern European care regimes either. Access requirements for care and procedures regulating the content of activities (2008, 2011, 2015, 2016, 2017) have been set in Hungary as well.

The fair care allowance was intended to support a close relative caring the elderly family member - with modest income support (29.500 HUF in 2014). In 2005 support was given to 20.540 family caregivers, while the number of recipients had halved by 2012 (10.514).
2015, 2016) have practically led to the tightening of the access and to the better targeting of care, thus they affected the relationships of both the carer and the recipient of the care and of the family as well.

These changes, for example the more difficult or limited access to certain care activities as well as changes and limitations in the content and time of care activities may increase the responsibilities of family care or may develop new relations in cooperation. Care activities, defined in the regulation of the sector and recognized by the state, determine what kind of care activities should be provided to the elderly in different levels of needs and risks.

Meeting the needs not included in the protocol may be the responsibility of other care providers, namely the task of the elderly, the family or the formal and informal market. It is questionable which area is significantly burdened by the tightening of the regulatory process. Limited access to home help services, limitations of care in time and activity, and the inadequacy of support functions for family care may lead to the overlap of professional roles, which generates mechanisms to substitute or displace family roles.

This process leads to the downsizing of the professional role of professional caregivers on the three sides, namely in the relation of the family, the carer and the aged elderly. This process can be extremely damaging because a professional caregiver can exclude the family from its caregiving or family member role by not recognizing or supporting the caring family member as a caregiver.

For a professional caregiver it results in conflicts of roles that can worsen the efficiency of the care work and can easily lead to the emotional involvement of low-skilled practitioners. Additionally it may strengthen the caregiver's emotional transfer towards the family member, and may ultimately lead to faster fatigue and burn-out.

According to my knowledge, the cooperation of formal and informal helpers, the nature of their relationship, the existing and mappable co-operation schemes have not been studied in Hungary, and even little research has been conducted in this topic in Eastern Europe either (Hlebec, 2015).

In my research I study how the formal care system and the formal carer relate to the family caregiver. How do professionals see the role and problems of family carer, and what forms of co-operation can develop? What are the challenges of the cooperation of the formal and informal systems?

The aim of my research is to get to know the opinion of the experts working in this field about the home help service and its professional challenges. I wanted to get a picture of how family care appears in everyday practice and what methods have been developed to deal with each situation? Experience with caring family members help to know more about home care and the caregiving tasks of the family members, as well as the improvement of the cooperation between systems and of the development of care strategies supporting family care.
The theoretical framework of the dissertation

In my dissertation the challenges of the long-term care of the elderly people and responses to these challenges are presented through the analysis of long-term care and European care systems, focusing on the relationship between family care and formal care systems. I more specifically deal with the issue of how caring turns to be goods, the gender approaches of family care the effects of care policies that strengthen family involvement, and the policy impacts of institutionalization and deinstitutionalisation in elderly care.

2. Methodology

Research questions

The research examines three major topics that provide an overview of the conditions of formal and informal care, the role and place of the actors in the care process.

1. What is the role of the family caregiver and where is his/her place in the caring process of home care according to carers?
   - How does the caring family member appear in the caring process?
   - What kind of care and how much care can they take? Does this kind of care substitute or replace the personal services provided by the formal care system, and despite the regulatory anomalies, can co-operative solutions based on the mutual and useful sharing of resources be developed?
   - How does the change in family formations affect community care services?
   - Do formal care providers recognize the care burden of the caring family member? How are these situations handled? Can the “informal care of the informal carer” be realized in Hungary?

2. What is the impact of the changes in the service environment and competences of home care services to professional and family carers?
   - How does the change in the regulatory environment affect the work of professional carers?
   - Did the changes in the service competences of home care strengthen or weaken the professional role of caregivers? Does this process affect the relationship between professionals and family carers?
   - How does the change in the regulatory environment affect family carers?

3. How does the professional role in care appear and how does it affect the relationship between professionals and family carers?
   - Does the formal caregiver's role in home care strengthen or weaken the professional form of care?

The research was conducted with a complex qualitative analysis. One of its elements was to record the interviews of experts, professionals working in home care who coordinate and organized tasks. The second step was to interview formal caregivers working in home care with a focus group interviewing method. The combined technique of expert interviews and focus group method was successfully applied by an international research
team in the framework of the Mobilising the Potential of Active Aging in Europe (MoPAct) program (Széman-Tróbert, 2017a). I used the methodology of this research protocol in my study focusing on social home care workers.

I interviewed 20 experts and I held 6 focus groups altogether. I analyzed expert interviews with content analysis, while the focus group interviews were analyzed by the method of structural analysis of the discursive field (Glózer, 2007).

3. Results

3.1 The place and the role of the caring family member in the care process according to the opinion of social home care workers

In the care of the elderly, home care service as long-term care in the elderly home is of great significance. The recent regulation and funding of this service brings professionals into situations that are leading to the overlap of professional boundaries, the involvement of the private sector and the dilution of the areas of caregivers' competences. Unspecified competences reinforce the female and lay characteristics of caring, and it affects the workers in this system as a disadvantageous circle. Unrealistic care protocols simply cannot be kept. In addition to their senselessness, however, they generate a dual activity and administration system, which results in increasing the burden on caregivers.

At community care services there is a need to face with the growing need for care. The current system solves it with the overload of formal carers, the illegal employment of carers after the official working hours or with the involvement of other illegally employed carers, or with using residential care. However, the quality, quantity and outcome of care greatly depend on the financial situation of the elderly and the elderly’s family.

In this situation, people working in home care do not perceive the burdens of the caring family members and their risk of being exhausted. Substitutional care provided by carers is the only activity that can be included in the caregiver protocol. In the concept system of family care, elderly family caregivers cannot be interpreted, thus they are taken into formal systems as recipients of care, and they are also treated like recipients of care.

Cases requiring intensive care are challenging for both the family and the formal care system. Mental illness and the addictions of caregivers as well as the mental decline of the recipient of the care are regarded as the biggest problems by the experts.

The fact that the carers have no tools in their hands may lead to the exhaustion of the professionals, that might result in the projection of their emotions and frustrations on the family carers, which does not help to establish a proper professional relationship.

3 http://mopact.group.shef.ac.uk/research-activities-8/
The perception and treatment of the presence, care activity, efforts and care-related problems of the caring family member cannot be found either in the caring need assessment or in the service elements of the professional protocols of the service. Thus the existence or the absence of the family care cannot formally be brought to the attention of the caregiver, as the caregiver should typically focus on the recipient of the care. This kind of the individualization of caring work leads to confusing situations in the relationship with the family members of the elderly.

According to the opinions of the experts, two roles can be distinguished for the members of the family: the role of the "relative" and the role of the "caring family member". In relation to the relative, the rules require the promotion of the relationship of the recipient of the care and the relative as a professional task, but according to the professionals, they can do the least in this regard. The relationship determines rather the effectiveness of the caring activity. If the relationship between the recipient of the care and the relative is good, the relationship is harmonious thus caring can also be more effective. Otherwise, the professional may get into a conflict. This is critical in situations where the state of the elderly is suddenly deteriorating and the actors' opinions about care responsibilities are not the same. According to the opinions expressed in the focus groups, the caregiver can have a harmonious relationship with the family members even if they do not undertake any kind of caring activity, but they are interested in the condition of the elderly person or they help with important issues, or approve the caregiver's decisions.

In contrast, the role of the "caring family member" appears in other dynamics. The professionals are most likely to accept the activities of caregivers who are looking after their elderly parents with high care needs and therefore they make great efforts (e.g. they move to them and provide full-time care and supervision). In such cases, the care burden of the caring family member is also perceived and better understood.

The most important feature of the cooperation between the caregivers working in formal care system and the family caregivers is that the professionals are able to better accept the relationship if the family caregiver:

- does not take the controlling role (e.g. does not tell the carer what to do, does not supervise the caregiver’s job, etc.);
- let them do professional tasks relating to personal care, while the family members are more concerned with the cleaning and the upkeep of the house and with shopping;
- carry out the caring tasks together under the direction of the professional.

Professionals basically do not think that caring may be burdensome for the family members. In the everyday life, in the co-operation of the formal and family care the focus is on the substitution of a family member, on joint work together with the family carer, or sometimes on the mental support of the family member.

In this respect, the opinions of the professionals working in formal care are different by the spheres of activity.

Senior caregivers, who were the subjects to expert interviews in the research, consider cooperation with the family important primarily at the beginning of the care process, as long as the frameworks of caring and the caring activities have been clarified for each party.
Caregivers substituted the family members providing intensive care most often for the period of formal care. This tool was consciously used to help the family carers relax, or manage their tasks. Formal caregivers regarded the isolating, exhausting family carers asking for assistance in a different way. Some of them felt it as a burden, others felt the exhaustion of the family member disturbing, because it predicted the increasing burden of the caregiver’s tasks and responsibilities. In other cases, a supportive relationship developed between the family member and the caregiver, which can be regarded ideal.

Professional caregivers did not consider elderly family members who cared and supported their spouses as caregivers. However, if they encountered such a situation, they started to take care of both of the old-age persons, thus the person who was caring for the spouse was not treated as a family caregiver but as a person who needed care.

To sum up, it can be stated that caregivers have very little time for supporting the family members, they are burdened by their daily work and they are not prepared to provide professional activities for family caregivers in a proper way.

Cooperation in care is a dynamic process. Changes in the state of the elderly can lead to the overruling of the original role sharing, thus formal caregivers consider situations associating with the aggravation of the conditions and the symptoms (e.g. stroke, dementia) of the recipient of the care critical. In such cases, a new balance of cooperation should be developed between the family member and the formal caregiver. If it goes together with the family caregiver's resistance, professional carers often experience it as questioning of their professional knowledge.

It can be difficult if family carers cannot perform their duties. This is most commonly caused by the family members' mental illness, alcoholism, or neglected, abusive behaviour. Formal caregivers try to provide extra attention and take more responsibilities in the care process.

### 3.2. The impact of the changes in the environment and competences of home care services to the professional and the family carers

Home care service represents more than two-third of people in personal care services. It is a personal service that helps people in need of care to continue living in their own home if their self-sufficiency is reduced. In the Hungarian practice, the intimacy of care activity is decisive, which means carers have long-term, personal relationship with the elderly.

The sector largely depends on changes in sectoral regulation and this affects the working conditions of the caregivers, both the time and content characteristics of caring. However, the regulation of professional work does not take many factors that can determine the quality, availability and funding conditions of the service into consideration. Experts say that the system is not sensitive either to territorial differences or the differences in metropolitan and small-town caring conditions or to the access of clients.
A further problem is the lack of sector-neutral funding. As a consequence, some service providers may provide the same services with higher state support and thus they gain a competitive edge, while the supply obligation for the provision of the service burden the local governments operating under more disadvantaged financial conditions.

Frequent changes in professional regulatory and financing conditions are a source of uncertainty for service providers since they have to comply with the legal requirements and must provide secure, predictable care for the elderly at the same time.

According to experts the competitive position of service providers did not always lead to the development of the quality in the service. This is mainly due to the obligation to provide standard service elements, thus the service providers tried to keep their competitive position by reducing fees.

The cost-effective operation of the sector was solved by strict regulation of care activities and payment directly related to the amount of time care is provided. It increased the administrative burden on caregivers, but did not contribute substantially to raising the standard of the service, on the contrary, the rigid regulation resulted in a complete breakdown between the practical activities and the accounting administration.

After measuring the care needs the new ruling system makes it possible to conclude individual agreements for the caring activity and the time of care. According to the professionals’ experience, the fee in case of compulsory care leads to the under-care of the socially disadvantaged elderly or to their exclusion from the care system. It can be noticed even if the fee can amount to maximum the 25% of the income. The pressure to properly care for the elderly with low income and with the need of minimal care is one of the reasons of increasing the scope of the job or providing care.

There are no professional and ethical rules in home care that address the caring family member, and therefore, the Code of Ethics for Social Work has been consistently applied to caregiving practice. However, this code in its current form does not apply to social caregivers or nurses or to the caregivers’ activities.

Activities related to the regulation of the sector tend to make home care service more targeted and to raise its professional level. This regulatory process expected the prospective results completely from the transformation of the internal elements and the capacities of the formal sector. Despite the fact that several policy concepts have drawn attention to the complete reform of service organization and funding, policy decisions still regard the over-regulation of the procedures and the administration as the key to more efficient operation. However, in the course of the research all participants reported that the administration was practically unrelated to the professional activities carried out.

The place and role of caring family members and the relationship of formal carers to family care has so far been unclear either in the regulation or in the professional protocols.
3.3 Professionality in caring and its effect on the relationship of professionals and family carers

According to the interviews with the professionals and with focus groups the framework and competences of formal care often overlap in practice, and caregivers take on too much work and become exhausted. It regards to working longer than the compulsory working time on weekdays, at weekends and holiday as well. One of the causes of this extra work is the lack of a caring family (member).

Home care service means an activity done during a certain period of the day, assuming that the remaining tasks of caring are carried out by the family for the remaining part of the day. In the absence of a family background, the professional responsibility and the human attitudes of home caregivers make them feel responsibility for the proper care of the elderly, even at the expense of exceeding their competencies determined by formal care.

The close caregiver - recipient of care relationship strengthens this professional responsibility of formal careers. Anomalies related to the regulation of care (e.g. at weekends or holidays no activity should be done) also lead to the extension of their professional boundaries. Providing care in the evenings, at weekends, during vacation, or while being on sick list, giving loans to recipients of care lead to the downgrading of the professional role in a situation where formal carers replace families.

In situations where a family caregiver has to share his/her daily life between work, family and the elderly family member, the care responsibility can easily be loaded to the formal caregiver. Legal, professional, and liability issues beyond the formal borders can seriously risks the life of the formal carer (e.g. what rights he/she has in an extraordinary event, etc.) and additionally they can lead to the overlapping of the professional roles. Caregivers can be called at any time, can perform and solve any tasks, sometimes even the tasks of the family.

The trustworthiness of the caregiver – recipient of care relationship strengthens the emphasis of personal roles and attachments against professional relationships. This particular milieu of caring puts pressure on the private life of the formal carers. Reconciliation of work and family life is a major challenge for formal carers. The professionals themselves usually come from an age group that also experience the need for family care in their own life, however, due to their caring job, they are unable to provide the care to their own family members. This situation puts emotional pressure on formal carers.

Middle-aged women performing low prestige caring activities must struggle with the social judgment of care as a traditional female role. These signs appear in the caregiver's relationships. On the one hand, formal carers often feel that their work is devalued or degraded (e.g. cleaning women, chairwomen, servants, etc.) on the other hand, the activity is paid for, so the relatives or the elderly people themselves often put pressure on the caregivers saying work for your money.

The professional responsibility for the work of formal caregivers can easily lead to the transfer of family roles and care responsibilities to the professionals. These situations are especially difficult for carers when they exceed their professional boundaries when they do not have to perform tasks belonging to the caregivers' responsibilities (e.g. harvesting corn, sour cherry, or plucking hens) and, in addition, professionals assume the presence of caring family members and their unused caregiver capacity. The general behaviour of the caregivers, the nature of the work, the exceeding of the framework and the content of their work, in many cases, the exceeding of their own
formal framework is similar to the role of the "hero worker" (Ward-Driffin, 2000). It is characteristic of this role that the professionals gain the recognition of the family members through their experience, dedication in care, even in cases where the family is not essentially involved in caregiving tasks.

In contrast, they can identify with the role of "consumerization" the least when the consumer dimension of the care service appears in the co-operation, that is, the emphasize is put on the already provided services instead of the personal relationship. The caregivers experience these situations emotionally overheated and with anger. For caregivers, the dissonance is evidently caused by the completely distinct division and opposition of these two roles, since the carers often feel that they involve more into the caring process than compulsory.

3.4 Discussion

3.4.1 Care policy considerations

One of the most important questions among the Hungarian policy issues regarding support given to family caretakers and the recognition of family care is whether there have any steps be taken to recognize the caring role of the family.

Familization or refamilization, that is the strengthening or re-strengthening of family roles in Hungary is one of the not appropriately discussed professional discourses.

For the sustainability of the care system, it would be important to see where we are in this process. Many authors mention the underdevelopment of the Hungarian institutional forms of care (Lamura, 2007) (Kraus et al., 2011), which urges more intensive support for informal (family) engagement. According to several researches the strengthening of the role of family care, however, may easily bring the state's declining role in care. In the absence of adequate support schemes, it takes care to the direction of "negative family role policy" (Michon, 2008). This policy might be harmful to middle-aged women who have no choice but to get out of the world of work in order to be able to care for their old family members, elderly people with insufficient level of care and poor people who have to care for their family members from minimum care allowance.

The required provision for elderly parents is included into the Constitution of Hungary. However, it does not mean the right of caring the family member, it only means the obligation to take care of the parents. The current situation cannot be sustained for a long time. Despite the previous policy ideas, there is no visible change to recognize and support family care. The social and administrative reforms of the recent years have either deliberately or not deliberately resulted in a kind of appreciable shrinking of the support system of the caring family members, thus ignoring an important part of the care sector.

According to the OECD report, about 80% of the elderly family member's care is provided by an informal carer, predominantly by the family member or the relative of the elderly (OECD, 2011).

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4 Negative familisation
The required provision for elderly parents was regulated in the past\(^5\), thus including this obligation in a higher level of legislation did not bring any substantive change in the field of care. Nonetheless, the relevant Hungarian practice of legislation is regarded by some authors as the suppression of the roles of the state (Rubovszky, 2017).

Unfortunately, the Hungarian policy discourses and decision-making processes are less transparent regarding the role of the family in caring elderly people. The required provision for elderly parents can either include efforts to maintain formal systems or to strengthen the possibility to focus on family care.

In the former case, the suppression of the roles of the state does not appear in the regulation of the services or in the guarantee of their standard, but in the financing of the costs of the operation. In this case, the responsibility of the relatives who can be obliged to take care of the parents is to finance the costs of formal services. This approach is more likely to serve the purpose of maintaining the formal system. Its biggest threat is, and it can be found in the funding of the existing Hungarian care systems, that the elderly members of lower income families who are unable to pay the institutional contributions can be excluded from the formal provisions. This risk can be treated by including the social need into the system.

The family can, of course, care for the elderly. The question in this case will be how the state supports the family in this role. In the absence of the adequate support systems, family care will not be a solidarist expression of the family (member), but a kind of compulsion that involves the risk of social exclusion of family carers (Leitner, 2003).

At a conference on aging, a Deputy State Secretary spoke about the future plans. According to it the formal care system should give provision to the elderly whose family members are working. Women who retire early with a retirement pension based upon Hungarian law can care for their elderly relatives. The policy response to the challenges of care seems logical at first hearing, as those who are still in the labour market cannot care for their family members but retired women can do it.

This idea, however, raises a number of questions. In addition to the fact that in this case the formal care system would provide care for the elderly parents of employees with better labour market positions, logic assumes a widespread prevalence of multi-generational coexistence in the Hungarian society. The approach of the policies in connection with the family and the formal care systems based exclusively on the reconciliation of the world of work and the world of care has serious risks. Family care policies need to take many factors into consideration at the same time. First of all, it is perhaps necessary to clarify that the nation state considers care for the elderly a right and to what extent (in case of what risks) the state guarantees these rights. Thereafter, the actors of the "care sector\(^6\)" and their degree of engagement can be identified.

It is very difficult today to apply general regulatory principles to the caring role of families. Family forms are very diverse, and the patterns of caring for the elderly must also be characterized by this diversity.

\(^{5}\) 1952. évi IV. tv. a házasságról, a családéról és a gyámságról

\(^{6}\) The actors of the care sector or the "care diamond" are the state, the market, non-profit providers and the family (Razavi, 2007).
Actually, in a modern state it is advisable to use refamilization and defamilization tools at the same time, which are not each other’s counterpositives. Defamilization may mean that the elderly people can get caring in their home. The strengthening of the required provision for elderly parents does not necessarily have to be linked to the refamilization policy. Recognizing and the more intensive support of family care should not necessarily mean the ruin of the formal system or the suppression of the care groups from the system.

3.5 Suggestions

3.5.1 A stronger separation of professional competence levels in care

One of the important elements of developing community care services is the integration of care activities and its provision according to competence elements. In Germany first three then later five levels of competence were defined in community care services. In the Netherlands seven levels of competence were defined. These competency levels extend the range of care needs recognized by the nation state as a problem. Need for company or need for transportation can be the need of the elderly people as well as cleaning, personal care, or intensive care in a home environment. Community care services are provided in the form of service packages in accordance with their elderly needs.

During my research, people working in home care have reported several times that the care process has become exclusive for the caregivers. One of its reasons is the personal, intimate nature of the care and the other reason is the confidential relationship between the caregiver and the recipient of the care that has developed for a long time. This situation can be handled by involving case managers (Szabó, 2015). These professionals coordinate professional activities and they personally lead and organize the care process, they are in contact with the family and the elderly.

The use of low-skilled and low-prestige carers in the current situation results in the overloading of the caregivers and virtually due to the system’s own regulatory problems, the system takes advantage of its own caregivers.

Previous attempts to separate competency levels have been partly successful. The separation of social assistance and personal care led to the situation that public employees with low qualification can care for those receiving only social assistance. In practice, however, these roles overlap together. Further separation of competency levels provides an opportunity to expand and extend community care services, which is essential for reducing caregivers’ overload. Thus, it would be possible to handle situations that are exceed caregivers’ competence (eg, care for the elderly with dementia, cases requiring intensive care, etc.).

3.5.2. Strengthening person-centred care

Person-centred care makes it possible to customize the caring process, the follow-up of the sudden change in the condition of the recipient of the care. The current protocol provides less opportunity for it. In the planning of care, based on the request of the elderly, the family members of the recipient of the care should be involved, and the family’s commitments in the care process need to be clarified. In case of a change in the state of the elderly, sharing of roles can be re-discussed.
3.5.3. Clarification of the role of the caring family members and the role of the relatives

In order to have family care recognized by professionals, it is necessary to define and clarify family roles in professional rules properly, in a way that the family member who performs caring activities and the activity performed by the family member should be well defined. In major cases or in cases that require intensive care (that can be defined in the rate of the daily care), the caregiver should be involved in the planning process of caring, the caring activity should be helped through counselling, education, and various services (support groups, day care or temporary substitute care, stress management, counselling).

Care protocols should be developed according to the degree of the participation of the family in care. If the family members of the elderly are not available or the family cannot participate in the care, a more intensive level of formal services should be provided.

The situation of the different aged caregivers (active, employed, elderly) and their different needs should be taken into consideration in the planning of the support of the family carers.

3.5.4. Caring Time and Care Financing Considerations

Territorial differences of caring, differences in the social situation and in the incomes of recipients of the care urge solutions to the financing system of the service. Differentiated service financing can reduce territorial access disparities and access inequalities. Regulating of the need for care in the use of care services reduces the proportion of those who are being excluded from care due to financial reasons or the number of caregivers who undertake inadequate caring tasks. It would be advisable to organize the service according to the principles of sector-neutral funding, especially in the case of service providers as required by law. Additional funding should be provided for tasks, eg. for those requiring special care tasks.

Interviews with professionals and focus group discussions clearly considered the extension of the caring time per one recipient of the care and the reduction in the number of the recipient of the care considered to be the most important task for the more efficient work. The entire time spent on care must be taken into consideration, and this should include the overtime work and situations requiring occasional and periodic care (e.g. the supervision and the support of the caregiving until the time the emergency medical services arrive). In adapting the caring time to the local needs more competence should be given to senior caregivers.

By expanding the scope of the funded care activities, it is possible to count the time spent on supporting, preparing and "caring for" the family caregiver. Flexible extension of the funded care period and the special support of family members can be the responses to cases providing intensive care (e.g. serious illness, dementia).

In cases where the family is unavailable or unable to participate in caring and when it would be necessary due to the state of the elderly, an adequate level of home care should be made available at weekends and on public holidays.
3.5.5. For the protection of the professional caregivers

The prerequisite for high-quality care is the availability of well-trained professionals. It is useful to think about the curricula of nursing and caring programs in social care and to focus on practical competences. While conducting this research, several professionals mentioned labour shortages and the poor quality of workforce in the care sector. Training programs should be matched to competence levels. According to international comparative analyzes (Genet and Boerma, 2013), the training of employees in the lowest competency services (e.g. satisfaction of needs for having company, activities around the house) is based on practical skills and based on the principles of treatment and ethics in the elderly in many countries.

For caring and nursing activities, caring dementia or other tasks of higher competence level (e.g. family consultation), highly trained specialists should be available. In training programs, carers should be familiar with the concept of family care, their characteristics, the situation of caregivers, and the methodology of how they can work with family carers and how they can support family carers during their work.

The financial recognition of carers should be raised to the level of the remuneration provided in similar sectors (e.g. healthcare), in order to reduce the migration of skilled workers from the area.

Special emphasis should be placed on the targeted advanced studies of caregivers. Over the past 7 years, the number of caregivers has virtually doubled. Many of them had no qualifications, they have obtained vocational qualifications in parallel with working. Emphasis should be put on preventing exhaustion, burning-out, and on supporting professional staff.

Consultations with the representatives of the profession and targeted research in this field provide further assistance to the viable regulation of the sector. It is advisable to involve professionals in the development, in the decision-making mechanisms, in the development and testing of new solutions, and in methodological developments.

3.5.6. Financial support dilemmas in family care

The appropriate support for family carers consists of two important elements. One is the recognition of care or being in need for care recognized by the state. The draft of the National Social Policy Concept (Czibere et al., 2011) dealt with the idea of introducing care support. The support, based on care need analysis, is provided to the elderly or the carer (in a form of cash or service) due to the risk of care, when the income situation of the household justifies the use of state subsidies. The concept therefore acknowledged the care of the family's care, but support would only be provided to the caring family member in the case of social need.

Providing the right amount of care support in case of specific risks (based on the intensity of care, or on being eligible for care based upon a low income) reduces the vulnerability of family carers and helps their activities.

Another form of subsidy is the allowance with income replacement function (e.g. nursing fee). The extent and duration of the allowance determines how much it encourages the caregiver to choose family care. One of the
problems in eastern European countries is that subsidies are low, they do not have substitute force, so care will put more pressure on formal systems.

The amount of financial support of family caregivers should be adjusted to support the child’s long-term care or the care of disabled persons following the Hungarian family policy guidelines (with taking the intensity of care into account).

**3.5.7. Provision of services for family carers**

It is also important to support caregivers who cooperate with the formal system and also caring family members who do not use the services of the formal system with different services. It is important for caregivers to have the *right information* in order to be aware of their roles and tasks, to know the *possibilities of the care system* and to turn for help. They should know the *risk of caring, the process of the exhaustion of the caregivers* and they have to know where to turn for help.

While developing services organized for caring family members, the nature of care (e.g. long-lasting, intensive activity leading to the caregiver's isolation) should be taken into consideration. Services can accordingly be provided in *service packages* (e.g. supportive group of family caregivers, providing substitute caregivers for the time of the courses) and the availability of *online or phone-based consultations and information services* should be improved.

In the social care system, there are *several services* in Hungary that are widely available, accessible and, in case of appropriate preparation of the helpers, are able to provide supportive services and counselling to the caring family members.

The main tasks of the *senior caretakers* working in home care are to organize care work, to supervise the tasks of the administration based on the accounts, to establish legal care relations. In addition the law has obliged them to "monitor the basic needs of the population" and to promote the "practical efficiency and effectiveness of social work".

By increasing the number of these professionals, the person-centred care approach, the professional and methodological background of the care activity performed together with the family carers and the ways and practice of assisting and supporting family carers could be strengthened.

Another important area of basic services is the family support and child welfare services. The availability of family support should be organized in each municipality. Due to the nature of the work *family is the basic unit of professional work*. According to the services, 16.4% of the client circle was older than 62 (KSH, 2015). By targeted preparation of these professionals, it would be more effective to support caring family members and families.

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7 Subjects of expert interviews of this research
8 1/2000 (I. 30) SzCsM decree 26.§.
Unfortunately, day care for elderly with dementia is not an available service in many places. Day care for people with dementia can be seen as an indirect form of substitute care that supports caregivers, as it can be assumed that there is a family caregiver around the elderly who organizes home care and transportation for the elderly suffering from mental retardation. Day care provides an excellent opportunity to organize targeted help activities with family carers (e.g. information, lectures on dementia, counselling, care management, treating acute situations).

It can be seen, that the elements that have been developed so far for the provision of personal social services may become eligible for family carers without involving significant resources. For more effective work, it is necessary to develop an approach focused on supporting family care and on developing professional methods.

Even when drawing conclusions and suggestions, I do not forget that some of my suggestions may have serious cost implication for the system. According to the experience in the development of quality community care services (Swinkels et al., 2015), the extension of services has not reduced the extent of welfare expenditure that can be spent on the field. It is therefore necessary to define the services related to care and social risk, as well as to introduce new techniques and methods to help them maintain quality.

References:


Hlebec, Valentina (2015): Care arrangements among social home care users in Slovenia, Studia Socioloczne 2015, 2. 75 – 96 ISSN 0039-3

Jeneiné dr. Rubovszky Csilla (2017): Az idősgondozás megoldatlanságának áldozatai. A gondozó családok helyzete a mai Magyarországon (Doktori disszertáció ELTE TáTk)


Szociális Statisztikai Évkönyv 2015: Kiadja: Központi Statisztikai Hivatal, 2016. ISSN: 1585-8499


4. Publication activity relating to the topic

- Patyán László (2017): Családi (informális) gondozást segítő rendszerek Magyarországon Magyar Gerontológia 33. sz. 34 – 49. magyargerontologia.foh.unideb.hu
- Patyán László: The family carers’ support systems is Hungary (Megjelenés alatt Poland)

See the entire publication list on: https://tudoster.idea.unideb.hu/tudomany/LSKXJ2
Conference presentations relating to the PhD thesis:

- **Providing care and supporting carers in the Central and Eastern European Countries.** Előadás elhangzott: „Ember a társadalomban és az egészségügyben” c. konferencia, Magyar Tudomány Ünnepe, Debreceni Egyetem Egészségügyi Kar, Nyíregyháza, 2017. 11. 29.
- **Családi gondozás támogatása a kelet – európai országokban.** Előadás elhangzott: Ártó – védő társadalom konferencia, Semmelweis Egyetem, Budapest, 2017. 06. 08.
- **Current changes in the Hungarian care system and its effects to the formal and informal care.** Előadás elhangzott: Growing Old in Central and Eastern Europe – the challenges and the opportunities, Oxford Institute of Population Ageing: East Network, Cluj Napoca 2017. 06. 23. https://www.ageing.ox.ac.uk/events/view/322
- **Házi segítségnyújtásban dolgozók munkafeltételei.** Előadás elhangzott: A munkafeltételek és az innováció hatása a foglalkoztatásra. MTA Társadalomtudományi Kutatóközpont, Szociológiai Kutatóintézete, MTA, Budapest, 2016. 11. 3.
- **Aktív időskor, időskorúak aktivitásának dimenziói.** Előadás elhangzott: European Seniors’ Union és a Robert Schulman Intézet közös konferenciája, Budapest 2016. 05.27.