Burden of family carers of older people

Ph.D. thesis

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Introduction

In my study I address a topic of long-term care of increasing importance: the burden on family carers nursing elderly relatives. The need for care has increased as a result of the difference between life expectancy and expected healthy life span as well the growing proportion of the elderly within the population, while the ratio of working age population providing care to the elderly has been shrinking in the society. The burdens on the health and social care systems are increasing, and there are doubts as to their sustainability. Family as a natural care resource has come into the foreground again. In spite of family members shouldering a significant part of care tasks, care systems focus nearly exclusively on serving the care recipients, while there are no services for the family members. In addition to providing supporting services, it would be necessary for the care systems to acknowledge family carers as their partners (Wolff and Roter 2008, Lavoie and Guberman 2009, UNFPA 2011, Gillick 2013 Szabó 2013, 2014, Roth et al. 2015, Hlebec 2015, Tróbert 2015). Care provided by the family results in heavy burdens which may have serious consequences going as far as total exhaustion.

I define burden as a condition resulting from the provision of care and affecting both physical and mental health (Zarit 1980), which develops as a result of several factors. The two most important components of the factors jointly inducing this condition are the segment of objective and subjective burdens i.e. the objective "requirements" of the care and, on the other hand, the subjective perception of the care situation (Hoenig and Hamilton 1966, Thomson and Doll 1982, Montgomery et al. 1985). The tools used in my research were determined by Pearlin's concept (1990) combining background factors of the caring process, the interactions of objective and subjective burdens as well as stress factors resulting from the latter. This concept, which somewhat widens the focus of burden studies, highlights the process character of burden. Interpreting the phenomenon as a stress process, Pearlin and his colleagues emphasise the role of combating strategies and support (i.e. resources) in the development of burden and its consequences. Accordingly, the framework of the study was provided by focal points such as background factors, objective burdens, resources, subjective perception of the carer's situation and major consequences of the care.

Objectives

Until now, there were few surveys made in Hungary regarding the situation of family members nursing elderly relatives (e.g. Szabó 2014, Jeneiné Rubovszky 2017, Patyán 2018). My research is of an explorative character, its goal is to get acquainted with the situation of family carers participating in the survey, to identify their main problems with a special focus on topics related to burdens and burn-out as well as connections with the long term care system and the general practitioner (family doctor).

In this explorative research, I addressed three dimensions:

I. Burdens of family carers

II. The role of the social long term care system in decreasing the family carers' burden

III. The role of general practitioners in the family care of the elderly

The research was carried out in three successive phases relying on each other:

1) In-depth interviews with family members caring for elderly relatives (2015, N=10)

2) On-line questionnaire-based survey involving general practitioners (2016, N=145)

3) On-line questionnaire-based survey with family members caring for an elderly relative (2018, N=205)

Methods

To investigate research dimensions I used a *mixed* method applying both qualitative and quantitative approaches. In the first phase of the research (in-depth interviews) I used a semi-structured questionnaire. I used content analysis to process the material of the interviews (10). The second phase, a survey involving general practitioners (N=145) relied on an on-line questionnaire consisting of 19 questions. The questionnaire aimed at the assessment of the family carers' situation (N=205) and contained 89 questions compiled on the basis of the two previous research phases. The questions included two

measuring tools that had not been used in Hungary earlier: these were the COPE Index assessing burden (McKee et al. 2003) and the OLBI questionnaire measuring burn-out (Demerouti 1999, Demerouti and Nachreiner 1998, Demerouti et al. 2003). Data obtained in the second and third phases were analysed with the help of the SPSS program, using descriptive statistical and interdependence tests (Chi square test, F test).

Findings

Significant role of background factors: lack of information and preparedness, forced situation and resistance resulting from conflicting roles

In the course of in-depth interviews, general lack of care-related information surfaced as a significant, frequent stress factor for the family carers (e.g. they had no information about care-related difficulties, care tasks, available services, allowances they are eligible to). The problem of the information gap was quite evident in the on-line questionnaire, too: more than the half of respondents (58%) had not received information about the available services. Another important lack is shown by the experience that in most cases carers were not prepared for the care tasks. As the role of the carer implies high pressures and requires exceptionally good adaptation skills in many life situations, the burdens of family carers are still increased by their unprepared confrontation with the challenges.

The evaluation of the care tasks is significantly influenced by the motivation of its acceptance (Caradec 2009). Besides 'children's obligation' and 'norm of reciprocity', the expectation of the cared person and external coercion appeared as important motifs. The compulsion of accepting the role of the carer may have a negative impact on experiencing the carer's role, for in forced situations it may happen more often that the family carer cannot make a free decision and so-to-say just endures the caring role. The conflicting child role arising in connection with the cared person was mentioned by the interviewed persons as a source of frustration: for many of them, it implied a strong shock and internal tension that they had to nurse and physically care for their parent.

Significant objective and subjective burdens: long care process, lack of care competences, role conflicts, dementia

In-depth interviews indicated that, for the family carers, significant objective care burdens included prolonged care period, frequent care needs and physical distance from the person in care. As for the subjective stress factors, the most important ones were the revival of former conflicts with the person in care, care-related conflicting roles, distress resulting from the lack of care competences as well as psychical burdens arising when caring for a dementia patient relative.

The on-line sample shows an exceptionally high ratio of dementia patents in care (48.8%), what puts a significant surplus burden on family carers (Dunkin and Anderson-Hanley 1998, Donaldson et al. 1998, Hawranik and Strain 2000, Pinquart and Sörensen 2003, 2006, Schiffczyk 2013, Berwig et al. 2017, Coe et al. 2018). However, the on-line sample did not show the impact of dementia on the burden.

More than half of the family carers lived in the same household or building with the person they cared for. Several studies identified that co-living with the care recipient is a risk factor for high levels of burden (e.g. Brodaty and Hadzi-Pavlovic 1990, IPA 2002). In connection with the distance from the nursed person, the respondents evaluated physical proximity partly positive, as it facilitated for them to nurse their relative. On the other hand, proximity had a negative feature, too, as it made for them nearly impossible to get out from the care situation. In view of the secondary, negative private life impacts of the care (e.g. drastic shrinking of leisure time, narrow scope for maintaining external relationships), such a "locked-up" situation is an extremely heavy burden.

Availability and lack of resources

In nearly all cases, interviewed persons were assisted in their work by other members of the family or other helpers, while nearly one third of on-line questionnaire respondents received no help. Providing care alone is more typical for elderly family carers – in spite of the fact that, due to their own health situation, they probably perform this with more difficulties. Formal care diminishes the burden, so it may be a significant resource (Havens 1999, Mollard 2009). In spite of this fact, family carers do not use this possibility

in many cases. In the interviews, the nursed person's rejection seemed to be the most common explanation for the refusal, but lack of professionalism was also mentioned, e.g. the service could not provide an appropriate, safe care for the family member living with dementia, or they did not request this service due to former bad experiences. In the on-line survey, more than one third of the respondents requested help to their home care work, and their relation to the professionals providing such care was evaluated as good in the great majority of cases. As to the refusal of such care, on-line respondents emphasised their own self-expectations (as family carers) to provide full-scope care and the ethical constraint of "it's the correct thing". In a small percentage we found fear of social disapproval. Lack of information in case of care services and lack of resources to finance such care are essential motifs, too. More than one tenth of "refraining" respondents do not trust in care system staff; in some cases they mentioned bad experiences as a hampering factor. Rejection by the patient, insecure care of the dementia patient and inadequate care were significant restraining factors among on-line respondents, too.

As for the care systems, the respondents experienced a number of difficulties: among these, excess workload on the system, structural and operational problems, lack of partner relations with family carers and lack of professional support to family carers were the most significant. The survey made with general practitioners confirms the necessity of service roll-out and the need to adjust these to real care demand by setting up adequate services. Both interviews, general practitioner survey and on-line survey with family carers highlighted the total lack of certain services as a substantial gap (e.g. inaccessibility of hospice care and mental health support in the service system).

A large part of the interviewed persons evaluated their relation to the general practitioner as positive, but it surfaced as a significant problem that the general practitioner did not visit the person in care and undertook no responsibility for him/her as an attending physician, what implies serious extra burdens for the carer. In the course of the on-line survey, more than two thirds of the respondents evaluated their relationship with the general practitioner as good. However, not much more than two thirds of the respondents has regular consultations with the general practitioner about the patient. In the majority of cases the carers having no regular contact with the general practitioner do not deem it

necessary. Many respondents mentioned the excessive workload of general practitioner or problems and negative experiences related to the doctor. In the great majority of cases, the general practitioner's visits are very rare and not systematic.

In the second phase of the research, the great majority of general practitioners evaluated their relationship with the patients and their relatives as good. In spite of their great workload, very few of them mentioned lack of time as the reason for not keeping regular contacts with the relatives. They mentioned lack of interest by the relatives as the most important reason (in much more than two thirds of the responses). It is important to note that more than one tenth of the doctors in the sample thinks they have to inform the relatives only in serious cases. Nevertheless in their proposals regarding the development of elderly care they categorically emphasise the clarification and strengthening of the relatives' roles in the caring process, and the support to be provided to their care work. Accordingly, they also formulated a proposal to train family carers as well as to develop partnerships with family carers and care system staff.

Both in the interviews and the on-line survey, social support (and, within that, family) was mentioned as the most important resource (cf. Mockus Parks and Novielli 2000, Markowitz et al. 2003, Dos Anjos et al. 2015, Bermejo et al. 2015, Rodríguez-Pérez et al. 2017); other factors included leisure time activities and internal resources, especial spirituality and supporting atmosphere at the workplace. Care is a time-consuming task, so an additional extra tension may arise when resources get quasi inaccessible or, as a result of exhaustion, can be "activated" with more difficulty.

Both interviews and on-line survey indicate that positive relationship with the person in care is an important resource for the carer (cf. Nolan 2001, Mollard 2009, Szabó 2015), while relations perceived as negative imply a heavy burden. The care situation may revive previous conflicts or it may happen that the nursed parent forces the carer into an "unhealthy" child role. On the level of relationship, dementia is a surplus burden, as the personality of the nursed person slowly changes and the patient so to say "ceases to be present in the relationship". As a result of the excess workload connected to dementia, there is a higher chance for the carers to develop an illness, get socially isolated and their life quality deteriorates more frequently (Schulz et al. 2006, Torti et al. 2004, Etters et al. 2008).

The on-line survey highlights the significant resource potential hidden in Internet (cf. Jackson et al. 2016, Schaller et al. 2016, Martínez-Alcalá et al. 2016, D'Onofrio et al. 2017, Wasilewski et al. 2017), as the great majority of family carers makes use of it when care-related dilemmas arise.

Subjective perception of the care process

According to former research on the *negative impacts of care*, the role of subjective burden is more significant than that of objective factors (e.g. Fekete et al. 2017, Roth et al. 2015, Kajiwara et al. 2018). However, the significance of objective burdens was paramount in our sample. The *frequent experiencing of the negative impacts of care* (perception of care-related negative experiences in the following areas: excess workload, relationship with family and friends, financial difficulties, emotional well-being, physical health) correlated in the sample with objective burdens such as the nursed person's ability to care for himself/herself (p=0,003, Cramer V: 0,215), frequency of the care activity (p=0,000; Cramer V: 0,364), duration of care work per occasion (p=0,006, Cramer V: 0,202). In case of subjective factors, there was a correlation with the perception of being supported (p=0,000; Cramer V: 0,312) and the quality of the relationship with the nursed person (p=0,008; Cramer V: 0,232). The *perception of the positive care values* (carer's competence, valuable task, positive relationship with the nursed person and the frequency of esteem perceived) correlated with educational level (p=0,015 Cramer V: 0,232; is more typical of persons with a primary or secondary level education) as well as with the feeling of being supported (p=000, Cramer V: 0,444) and with the help available in care activities (p=0,006, Cramer V: 0,259). Interestingly, *the perception of being supported* did not correlate with requesting formal home care help.

However, the perception of care was dominated by subjective burdens in the interviews: significant factors included the burdensome nature of conflicts experienced with the nursed person, the parents' unrealistic requirements surfacing in the course of the care, revival of former conflicts with the person in care and the nursed person's forcing the carer into a child role.

Experiencing the lack of being esteemed appeared as a factor still increasing the carers' objective and subjective burden, as this dimension may have an impact both on the

external and internal resources of the carers (e.g. financial situation vs. self-esteem, valuable nature of care work, significance of carrying out the task).

Detrimental effects of the care process

The great majority of family carers have already experienced care-related detrimental effects. Frequent excessive workload was typical of more that two thirds of the online sample. We found a high ratio of cases (nearly the half of the carers) where they experienced the negative impact of care on their emotional well-being. In case of the negative impact on the physical condition the picture was more favourable, nevertheless this was also frequently experienced by one third of the sample.

The respondent evaluated their health status as good or satisfactory nearly in the same proportion, but nearly one fifth of the sample characterised it as poor. The evaluation of the health status correlated with age (F test: 6,106, p=0,003), the duration of care (p=0,003; Cramer V: 0,199), with the availability of help for the carer (p=0,035; Cramer V: 0,182) as well as the frequency of experiencing excess workload (p=0,004; Cramer V: 0,224), physical and emotional burdens (p=0,003: Cramer V: 0,229 and p=0,002; Cramer V: 0,239).

In case of family carers having a job, nearly one fourth of them experienced difficulties and nearly one tenth of them was thinking about finding another job (cf. Havens 1999, Jenson and Jakobzone 2000, Gimbert and Malochet 2012). The compulsion of constant double compliance was a significant source of stress for the family carers. The interviews have shown that care work may even facilitate the carers' burn-out within in their original job. As a result of the insufficient filling out of the burn-out questionnaire, I was not able to assess this effect in the on-line sample.

However, the protecting effect of a workplace was evident both in the interviews and the sample of the questionnaire: it represented an important resource and supporting medium. On the other hand, employment status correlated with experiencing less frequently negative care impacts as such and negative impacts on emotional well-being – negative experiences were felt more frequently by the unemployed and part-time workers. The negative impact on physical status was experienced in a higher percentage by retired persons, most likely this was due to their age.

As a result of the care work, private life suffers serious damages (Semple 1992, Aneshensel et al. 1995). A part of the interviewed family carers complained that their private life completely ceased to exist, and care-related family conflicts (cf. Semple 1992, Malonebeach and Zarit 1995) were also mentioned as well as strong restrictions on their leisure/rest opportunities. The online sample indicated a significant decrease of 'recharge'; much more than half of the respondents have no leisure time and cannot go for a holiday. Nearly one fifth of the respondents mentioned problems arising in their family life and partnerships.

Based on the sample, research highlighted the seriously burdensome character of care work, what is in strong contrast to the lack of resources experienced by family carers as well as problems connected to available formal care services. The results verify the theory of Pearlin et al. (1990) stating that the background of the care situation, its objective and subjective stress factors as well as role conflicts arising in the carers' private life and the negative consequences of the care are elements of a coherent stress process, the development of which is substantially influenced by available resources. As the exhaustion arising as a consequence of care activities may have not only serious individual, but social consequences as well (e.g. family carers may leave the labour market, their eventual illness puts an increased workload on the health care system and the substitution of their care work may incur serious problems), so it is a burning necessity to reach a deeper understanding of and investigate further the burden process, and to provide for the social support of the family carers.

Conclusions

Significance of social innovation

The ageing of societies raises serious challenges in elderly care, too. Parallel to an increasing demand for care we face limited resources, and it is always more difficult to sustain the long term care systems. We have to find new ways to treat social problems that cannot be solved with the previous structures; we need social innovation (Murray et al. 2010). Both interviews and on-line surveys indicate that *it is of a primary importance*

to acknowledge and esteem the family carers' role. When being ready to care for an elderly relative, family members accept significant burdens – if the cannot fulfil their role as a family carer, these burdens ought to be shouldered by the society. For this reason, it is of a social interest, too, that (whenever such a need arises) family carers should be able to appropriately fulfil this role also on the long run.

In the course of my research, lack of information and unpreparedness for care tasks/challenges were identified as significant background factors influencing the care process, what raises *the necessity to create care-related information bases and to train the family carers.* Unexpected challenges experienced in the course of their care work and their perception of competence gaps are serious stress sources for the carers, what also indicates their work has to be "mentored" and professionally followed up.

This research highlights that the care system does not function as a sustaining network for a significant part of family carers. When starting the care process, family carers often get into a sort of "vacuum": as a result of inadequate services and lack of partner relationships they cannot get connected to the care system. It is a compelling task to assess needs, requirements of the cared and caring persons and to develop adequate services in line with the demand. Accordingly, it is inevitable to coordinate the health and social services, to connect these two spheres – to establish an integrated, long-term care system where family carers are not mere "connecting links" or "exploitable resources", but function as partners with special competences.

Research has found that it is a major task to use resources to decrease the burden. In case of burdens and challenges resulting from care work, the efficient mobilisation and identification, development of resources and the safeguarding of psychical health are tasks in which many carers may need to be assisted. In addition to that, the care situation may be the source of conflicts between the cared and the caring person, the family carer and his/her family as well as his/her workplace. In order to appropriately handle the conflicts, efficient combating strategies are to be presented and learnt. *Research has confirmed the necessity of providing mental health support both to family carers and the persons they care for.* This service is not available at all in the present long term care system.

The findings of my research confirm that we need complex social strategies which rely on social innovations if we want to decrease the burdens of family carers. As a result of demographic processes and new challenges resulting from these (e.g. a large increase in the frequency of dementia cases) highlight the burning necessity of urgently transforming the elderly care system, of connecting social and health care systems working separately until now and to establish new services. Parallel to the increasing social expectations family carers have to face, it is inevitable to provide for their support.

List of own publications

Publications related to the thesis

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