



**Business and
Management PhD
Programme**

THESIS SUMMARY

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**Social sustainability and well-being among informal carers of people with
dementia**

Ph.D. thesis

Supervisor:

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Motto:

„People start researching because they have a dream of adding something important to the world through their discretions and insights. However, it is not enough just to dream, we need to realize our dreams.”

*/Juliet Corbin – Anselm Strauss, 2015 – Basics of qualitative research;
L'Harmattan – SE-EKK – SAGE, first Hungarian edition, p.54./*

1. Goals and methods

My thesis is based on my three publications on chosen topic. The first involves a qualitative method, the second is based on a quantitative research method, while the last publication summarizes the information in the form of a study.

I focused my research on informal care, which is necessarily accompanied by an increase in the proportion of older people. Informal care provided voluntarily by family members and acquaintances has a growing role to play in many conditions, but dementia is one of the most prominent of these, which often puts caregivers, individuals or families in charge of these patients, for decades. My choice was based on my medical experience as well as expert opinion that medical, health technology and pharmaceutical developments in this syndrome, unlike many other chronic, degenerative conditions, will not necessarily be forthcoming in the near future or in the decades to come in treatment or care. Dementia, one of the leading causes of vulnerability in old age, is one of the primary determinants of informal care needs, with increasing incidence and prevalence, as life expectancy increases. Of the loss of function in old age that threatens social sustainability, the decline in cognitive function is currently the least successfully supported, counterbalanced, and corrected for impairment.

During the exploration and development of my research principles I have deliberately chosen to engage with, and develop relationships with people with dementia, in institutional or home care, and their family members. Since 2016, I have been involved in the interactions of communities that help people with dementia, and their families. All the information, impressions and experiences I have gained at community events, and the inspirational environment of caring families, professionals in the field or even lay people interested in helping have had an indisputable role in shaping my approach. For myself, enrichment is provided not only by the increase of knowledge, but also by the fact that I can contribute to the feeling of 'not being alone' by illuminating the broader social context or listening to individual problems, which is a good practical example of a community approach.

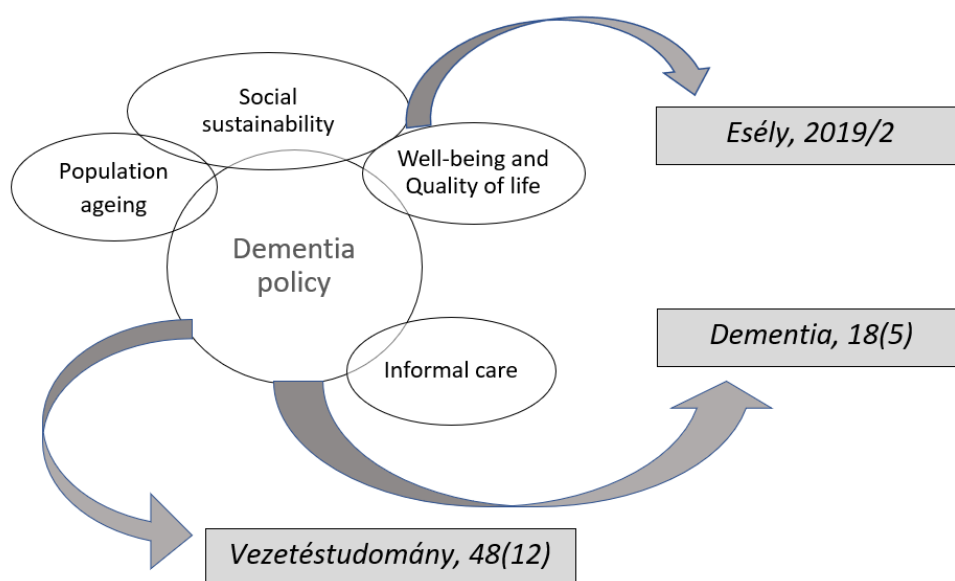
The social and economic importance of dementia has been recognized by many countries even before it was classified as a "priority disease" by the World Health Organization (WHO, 2008). This is evidenced by the national action plans that have been published since 2001 (for example, on the Alzheimer Europe website)¹ and serve as a model for those who are lagging behind. Hungary does not have a dementia strategy, despite the fact that the number of people living with dementia is expected to increase significantly due to both demographic processes

¹ <https://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies> (23/02/2019)

and the disease composition of the population - the high prevalence of cardiovascular diseases and cerebral vascular catastrophes. When mentioning the size of the patient population, it should be noted immediately that today we do not have reliable information on the number of people living with dementia in Hungary. Perhaps this is also the reason why, so far, there has been insufficient attention paid to the disease by decision makers. At the same time, the apparently large number of unrecognized cases also means that if the initial steps of an action plan - typically the presentation of the disease, raising awareness, 'finding' the affected - were successful, there would be a huge need for organised provision. Due to the lack of capacity in the health and social care systems, families may be overwhelmed in the short term. To solve the problem, alleviate it, and make sound policy decisions, there needs to be interdisciplinary collaboration for dementia.

The publications that form the basis of the dissertation are also linked by this aim, the means and role of gathering information needed for relevant policy decisions (Figure 1). My research focus is not solely on addressing the negative consequences of informal care activities. I have paid attention to the positive benefits of the activity, trusting that systemic support for caring relatives will also contribute to the well-being of informal carers through the presentation and awareness of these factors.

Figure 1. Relationship between research focuses and publications



My first article *Systems Mapping As a Potential Tool for Establishing Dementia Strategy*, published in *Budapest Management Review* (Fekete, 2017), presents a methodological experiment. My first authored English-language publication is the fruit of a three-month, self-organized study trip to New Zealand that explores the factors that influence the quality of life of caregivers of people living with dementia (Fekete, 2019a). I regard both publications as an

important milestone in my development as a researcher, not only because of the highly uplifting feeling of acceptance of papers for publication, but also because I have experienced them both as important feedback. The publication of a special edition of the journal *Budapest Management Review* with a qualitative focus provided an additional incentive to use the qualitative research methodology alongside the "learning-by-doing" difficulty. The processing of the New Zealand database from a completely personal point of view, on its own, gave the experience of researcher freedom and endless possibilities of research, as well as results that immediately prompted further research ideas and possibilities.

My third paper is a study, entitled *Dementia and Social Sustainability*, published in *Esély* (translated: opportunity), a journal of social and political science (Fekete, 2019b). In this, I summarize the economic and social implications of dementia as a relevant issue for social sustainability, and highlight, through international examples, what coordinated policy action can be taken to ensure the well-being of patients and their families.

The theoretical background is presented in five sections. The subject of the first chapter is *dementia*, since in publications underlying the dissertation there is less talk about the syndrome, I found it important to summarize current knowledge in order to related social and economic aspects. The topic of *social sustainability* that is most relevant to the doctoral specialization is also discussed in my book chapter entitled *Sustainable Society* - published in the Family Science Note of the Semmelweis University Faculty of Health Sciences (Fekete, 2018). It was an honour to have been called upon to write this chapter which was an important step in achieving interdisciplinary collaboration. In my dissertation I highlight the actuality of the formation and interpretation of the concept. In the context of the *ageing of society*, I also refer to the above-mentioned book chapter. In discussing the issues of *quality of life* and *subjective well-being*, I will focus particularly on the development of concepts, the interdisciplinary approach and the question of economic utilization. The concept of *informal care* is also a key element of my research work so far, and although all three publications contain basic information, I will briefly summarize it in the chapter on theoretical background.

2. Findings and results

2.1. Systems Mapping as a Potential Tool for Establishing Dementia Strategy

This article, published in Budapest Management Review (Fekete, 2017), presents the theoretical background, implementation experience and results of a qualitative research technique. Participatory systems mapping seemed to be an appropriate tool for initiating knowledge sharing among actors worthy of involvement in the development of a dementia strategy still to be developed in Hungary. As a central problem to be addressed, I have identified improving the quality of life of people living with dementia. In this article, I summarize the positive experiences of using the method and present the results of using the tool. Participatory system mapping, both from a moderator's point of view and from participants' feedback, proved to be appropriate for achieving the goal. Participants emphasized the immediate visibility of the results of their work, the rare experience of having a real answer to the question asked. The moderator gained a very positive experience with the method, which dispelled communication boundaries between the very hierarchical structure of health, social and academic systems.

The applicability of the method in policy is supported by the results, as the priorities identified were largely in line with the programs of the countries in the forefront of strategy development. In the complex causality diagram, four nodes emerged: specialist care, medical care, family background / informal care, and knowledge / information. After the research, and based on my experience at relatives' self-help meetings, it became clear that these are indeed critical points from the perspective of family members involved in care. As stated in the publication, I believe that the method is well suited to involving relatives, or those with mild syndromes, in developing a policy concept.

2.2. Older New Zealanders in caregiving roles: Psychological functioning of caregivers of people living with dementia

This article, published online in 2017 and in print in 2019 (Fekete et al., 2019a), explores the factors that influence the quality of life of caregivers of people living with dementia with a unique approach. The research was based on the Health, Work and Retirement Study database coordinated by the Health and Ageing Research Team at Massey University, Palmerston North, New Zealand. The database has been based on a biennial survey since 2006, and more

than 11,000 people in the country's population of 5 million participated in the survey over the first 10 years (HART, 2018)².

During the research, my methodological approach was person-centric, using the statistical tool of latent profile analysis. Based on the theoretical background, we assumed that the negative consequences of activity are predominant for some of the caregivers, while in the other group the balance is tilted towards positive effects, but identifying intermediate group(s) was also not excluded.

Psychological functioning was defined by four variables:

- mental health (based on SF-12 - Ware et al., 1998),
- symptoms of depression (not the same as clinical diagnosis of depression, measured by CESD-10 scale - Kohout et al., 1993),
- quality of life (measured by the CASP-12 instrument; Wiggins et al., 2008) and
- satisfaction with life (Inglehart et al., 2004).

In latent profile analysis, we tested the separation of 2, 3 and 4 groups, and best results were born for three profiles. Finally, the three profile groups were named optimal, suboptimal, and poorly psychologically functioning, based on standardized values for their characteristic variables.

Highlighting curiosity, the only demographic factor that showed correlation to profile membership was the age of the caregiver: carers in the poorly functioning group were younger than those in the other two profiles. Consistent with this, shorter care experiences were also common among malfunctioning groups. This clearly confirms that informal care can have positive benefits, for example through the acquisition of new knowledge, personality enrichment (Rozario et al., 2004), and the capacity for coping strategies to develop over time plays a role in this less expected outcome (Charlesworth et al., 2017; Greenwood and Habibi, 2014).

One of the strongest factors in belonging to a profile was the variables referring to social support, such as the extent of the relationship, the feeling of loneliness (here it is important to distinguish between the emotional type of loneliness, and isolation) and the availability of social care.

² Health and Ageing Research Team. 2018. The New Zealand Health, Work and Retirement Longitudinal Study 2006-2016 Massey University
http://www.massey.ac.nz/massey/fms/Colleges/College%20of%20Humanities%20and%20Social%20Sciences/Psychology/HART/publications/reports/NZHWR_10YearReport_2006-2016_LR.pdf?8010D8D175A2379138BF59C960D9025A (Accessed 08/08/2019)

The suggestions made in the research summary are still valid. Based on my experience since then, I believe that profiling should be the first step in adequately helping informal caregivers. To be able to provide the right support and to provide the support capacity effectively, we need to know the caregivers' psychological status and risk factors. As the article noted as a limitation, possibly change in the status of the respondents was not followed-up - those who participated in several waves of the survey took into account only their first responses. Given that dementia is a progressive disease, the condition of the patient as a primary stressor (Pearlin et al., 1990) can contribute significantly to the quality of life of the caregiver. Although, according to the present study, the burden and frequency of care did not correlate with the profile, only longitudinal studies can answer as to how the characteristics of informal care change as the disease progresses, the symptoms worsen, and the type of caring burden alters. This would also allow for the identification of risk factors specific to each profile, and for the informal carer to receive cost-effective and efficient community support throughout the carer's lifecycle, following a well-established scheme.

2.3. Dementia and social sustainability

In this paper (published in *Esély*, Hungarian language journal of social and political affairs), I sought to summarize why I consider it important that dementia should not be regarded as merely an incurable disease (Fekete, 2019b). As long as even professionals are not aware of the fact that dementia is a social problem, we can't expect that the majority of society, that is, lay people, to support families afflicted with dementia, or show tolerance on a daily basis.

The occurrence of dementia is closely related to the ageing of society. In this study I discuss the extent of disease burden on the community, and how the community's "caring capacity" will drastically decrease by half within a few decades. I emphasize the distortion that the increasing burden of care, for families, is not reflected in economic indicators. Thus, it is not known what value the welfare-related tasks of the state will attribute to the active or retired family members who take part in the care of their dementia-afflicted elders / loved ones. I also criticize the fact that the domestic public health and social care system is currently not ready to serve the ageing population. The design and financing of these systems must also adapt to changes that are already well under way, so policy decisions need to address this area as well.

The purpose of presenting international co-operation, advocacy and policy action is, primarily, to provide good examples and to emphasize that work does not have to start from

scratch, although analysing local conditions, socio-cultural and economic circumstances is strongly recommended.

3. Summary

According to the World Bank report based on United Nations' data (World Bank Group, 2016), the global demographic situation has reached a turning point in the current decade. The countries of the world were essentially divided into two groups. About half of the world's population lives in countries where the rate of population growth has slowed or become negative, and the proportion of older people has started to increase. Typical examples of these areas are North American and European countries, including Hungary. At the same time, the other half lives in "fertile", "young" countries, and the increase in population here is responsible for continuing global population growth. African countries are typical examples, but population growth is also true for the two giant nations, India and China, where challenges are faced due to the numerical dimension of an ageing population.

Both numerically, in absolute and structural terms, the ageing of society is leading to an increase in the importance of informal care. On the one hand, the lack of capacity for welfare services, on the other hand, the centralization of care tasks within the family, the involvement of one or a few family members, and changing societal roles place more burden on informal carers than ever before. And they need more support than ever.

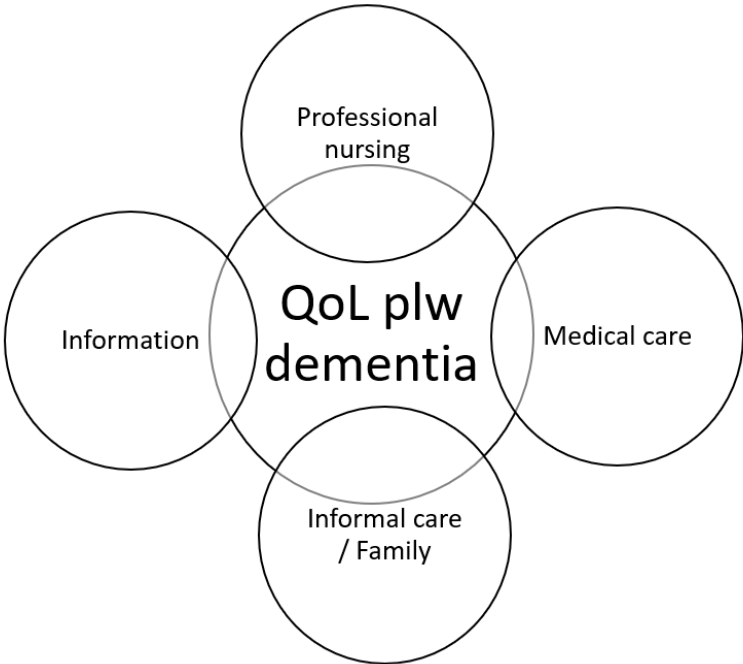
A special group of informal carers is the carers of people living with dementia. Dementia, a syndrome that gradually causes the affected patients to become unable to perform many daily activities, eventually results in functional disability, resulting in a total inability to self-sustain. In ageing societies, the number of people living with dementia will increase, making care of them an inevitable social issue. Given that the therapeutic potential of dementia-related disorders is strongly limited once the symptoms develop, they are not expected to disappear despite therapy, so the affected family and environment must be prepared for a task that can last up to decades. The institutional and service background that the welfare state can provide, in principle, is accessible without limits only in a few countries, so the extent of family caregiving is often not a matter of choice or conscious decision, but a constraint that affects the quality of life throughout society. Research has focused more on reviewing institutional care systems of ageing European countries, the so-called long-term care systems. An own, not yet published, research made with co-authors, justifies the distinction between specific types of European systems. This research, briefly summarized in Appendix 2, examined the relationship between quality of life and systems of long-term care. As a result of our research, we have typified slightly different, but not contradictory typing from previous

system partitions. According to this, systems can be minimizing, or can operate in an optimizing or maximizing manner depending on the degree of investment in the systems. Hungary and the other countries previously classified as 'family-based' or 'Central-Eastern European' have been placed in the 'minimizing' group based on the quality of life assessment of older people.

However, even with enough formal care capacity, support for 'accompanying' family members and friends is needed in difficult, painful psychological conditions. This support can take the form of providing information, providing the carer with respite day care or organizing a self-help community (Lamura et al., 2008).

The aim of my research entitled “Systems Mapping as a Potential Tool for Establishing Dementia Strategy” (Fekete, 2017) was to explore the factors that influence the quality of life of people living with dementia in Hungary by sharing knowledge based on a broad expert base. The complex causality diagram shows four main areas (Figure 6):

Figure 6. Factors influencing the quality of life of people with dementia (source: Fekete, 2017, Figure 4.)

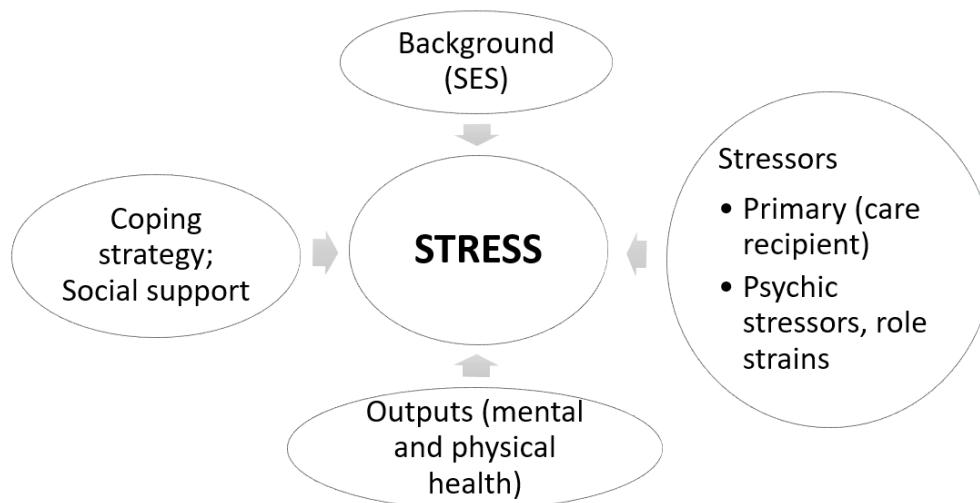


In addition to specialized nursing and medical care, information and relatives were identified as key factors. Compared with the main objectives set out in the action plans of countries with a dementia strategy, the result showed that a participatory system dynamic modelling approach is a good tool to prepare a solution to a problem requiring policy intervention, as described previously (Leischow and Milstein, 2006).

After identifying the role of relatives caring for people with dementia, I turned to the importance of informal care for dementia. Throughout my understanding of the role of informal care in a broader context, I followed the specialties of dementia throughout. Krol et al. (2015) argued in favour of the economic factor of informal care in tracking nursing tasks associated with conditions such as Alzheimer's disease, Parkinson's disease, rheumatoid arthritis, and metastatic colorectal cancer. Of the publications identified in the systematic literature research, and considered relevant, nearly two-thirds linked to Alzheimer's disease. Alzheimer Disease International (ADI), an international umbrella organization, also provides data on the financial burden on families (ADI, 2015).

However, caregivers of people with dementia do not only face financial burdens. Pearlin et al. (1990) summarized the factors affecting informal carers of Alzheimer's disease in a stress model (Figure 7).

Figure 7. Pearlin's Stress Model for carers of people living with Alzheimer's (Source: Pearlin et al., 1990, self-processing)



According to this model, the development of caregiver burden can be explained by four factors. The primary stressor is the patient in his or her current condition. Secondary stressors have been identified as psychic effects, as well as conflicts arising from the role of caregiver (including difficulty in paid-work and the consequent emergence of financial problems). The ability to cope with stressors and the existence, or lack of social support play a role in bearing the burden, as do the consequences of these, the evolving of physical and mental health.

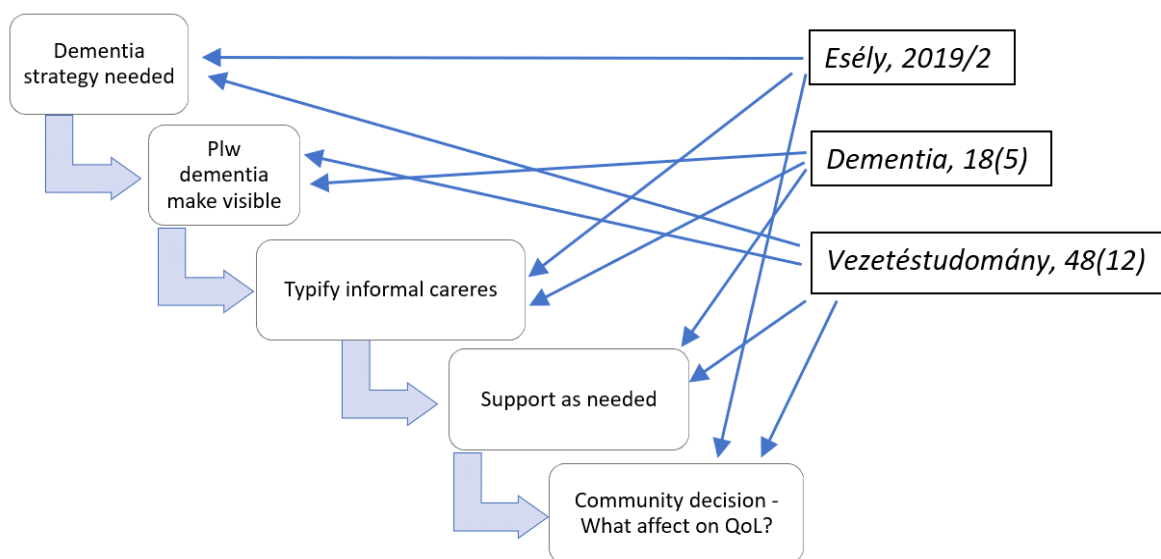
The motivation of my own research among the caregivers of people living with dementia was to discover the factors determining their well-being and psychological condition. As previous research has pointed out, some of the determinants of well-being can be influenced, while

some attributes are not, or are harder to influence (Alves et al., 2016; Gitlin et al., 2003; Pinquart and Sorensen, 2004; Wennberg et al., 2015).

Latent profile analysis in my research identified three types of caregivers. The approach of informal care as an exclusively burdensome activity is immediately contradicted by the group distribution of carers. In fact, 60% of caregivers were in the group with optimal psychological function, nearly 29% had suboptimal and 11% showed poor psychological functioning. Profiling was defined by four factors: quality of life, mental health, depression, and life satisfaction. According to our results, factors contributing significantly to better psychological functioning were: greater caregiver experience, longer nursing time, more active social life, and better financial conditions. These results highlight the factors that are worth targeting; interventions and support activities that lead directly to improvement in the well-being of carers.

Through research on the well-being of family members and informal carers who care for people living with dementia, my goal was to provide suggestions for possible intervention points (Figure 8).

Figure 8. Lessons from publications as a source of policy proposals



In addition to the results of my own research, I base my recommendations on strategic plans that have been made in other countries for many years, and on the principles of social sustainability.

1. It is needed to assess the number of people with mild to severe cognitive impairment and dementia, and obtain information about their support requirements. The call for support should be assessed not only at individual level, but also at family level, as the disproportionate burden on informal carers is often due to their invisibility in the care system. In most cases,

health and social care providers measure needs only of the patient concerned, as they are at the centre of their work. It would be important to know how many people requiring care live alone, as they will surely want institutional placement as their condition progresses and the requirement for place can be planned accordingly. All generations of the caring family should be known, and assessed as to who can or must take on the role of caregiver. Different types of support will be required by an active-age relative whose income earning ability is at risk as opposed to those who are retired caregivers.

2. It is exigent to develop forms of support appropriate to the types of domestic need known. For informal carers of active age, the primary goal is to secure a work income. Providing a choice on a spectrum from full-time job to full-time care for a family member in need would be ideal. Given that the need for care is gradually increasing for people with cognitive impairment, it would be desirable if the caregiver could move between the two ends of the spectrum gradually and as needed. For example, initially reducing working hours by one to two hours a day, either as a reduction in working hours or as part-time work, supplemented by a time-proportional care allowance. Today's social support system does not follow either grades or logic, and employers are not motivated to provide part-time employment, at least not for this reason.

3. Ensuring access to elaborated forms of support is the most critical aspect of social sustainability. If social sustainability is identified by creating justice and reducing social inequalities, then today we are light-years away from the hoped-for end. Today, access to services is often accidental. Referring again to the ability approach, the deprived state of a caregiver begins immediately with an inability to obtain information, which is further exacerbated by an inability to process and assert interests, but finally the quality of life of the caregiver will be modified by the social network.

4. It is exigent to assess the determinants of the quality of life of people living with dementia and caring family members. This assessment ideally will be carried out at the level of smaller communities: settlement, community-based advocacy, or communities defined by any principle. Ensuring participation in exploring the problem and seeking solutions is a factor that improves the quality of life (see Figure 3 on OECD well-being indicators). At the same time, involvement in the process will ensure that information on the topic is available to the affected person and thus there will be improved access to support services.

5. Dementia poses a major challenge to society, not just for families directly affected. An ageing society, such as Hungary has, must have a comprehensive action plan and strategy to prevent dramatic deterioration in the quality of life, especially due to the absence of adequate capacity in its welfare system. The role of informal carers will undoubtedly increase over the coming decades, not least due to the increase in the number of people living with dementia.

The ageing population is leading to an increase in other conditions associated with physical decline and deterioration of self-sustainability. From the point of view of social inequality, it is critical that volunteering within the family is truly "voluntary", dictated by choice, rather than forced, which, in fact, leads to a further increase in social disparity.

The aim of my research work so far and in the future is to present relevant background information and good practice for social policy decisions to ensure the well-being of informal carers of people living with dementia. At the moment, this commitment does not appear to be expedient or swift to implement, as we suffer from a huge lack of information here, in Hungary. However, it is already late for action, which is why research and intervention must go hand in hand and continuously develop the results and experiences of both activities.

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