

Márta Fekete

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

Department of Decision Sciences

Supervisor:

György Pataki, PhD

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Corvinus University of Budapest

Business and Management PhD Programme

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people living with dementia**

doctoral dissertation

Dr. Fekete Márta

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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. Introduction

When I started my doctoral studies in 2014, I focused on researching ageing. I wanted to deal with the social and economic effects of the ageing process and to search for solutions. Recognizing the diverse nature of the topic in business science, 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.

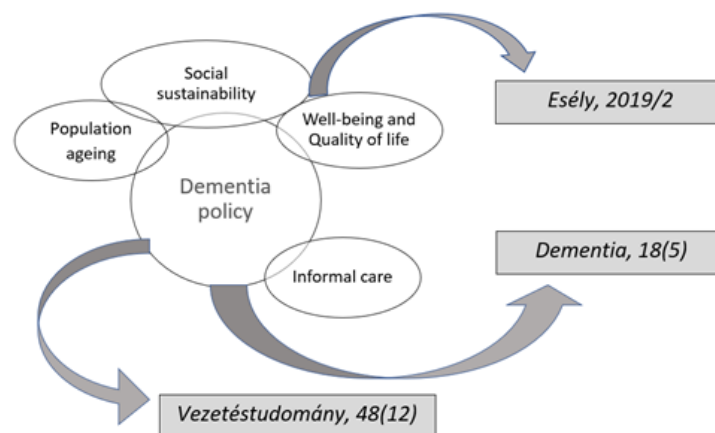
During the exploration and development of my research principles I have deliberately chosen to engage with, and develop relationships with people with dementia, in institutional or home care, and their family members. Since 2016, I have been involved in the interactions of communities that help people 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 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



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

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 of the dissertation introduces the concepts of social sustainability, ageing, well-being and quality of life, and dementia and informal care. My practical approach is strongly determined by my volunteering in community activities, which has increasingly influenced my theoretical research focus. The central element of my future research plans is the issue of social sustainability, the realization of citizen science (Szabó, 2013) and interdisciplinarity, especially the promotion of cooperation and communication between health sciences and social sciences.

1. Theoretical background

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 relate 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.

a. Dementia

i. Definition of dementia

Dementia is not a disease, but a syndrome which can be associated with multiple diseases, of different types, due to different pathologies. The internationally accepted and applied system of mental disorders was established by the American Psychiatric Association in 1921. The organisation compiled the Diagnostic and Statistical Manual of Mental Disorders (DSM), which was first published in 1952². The history of the classification of mental disorders is worthy of a brief review because it partially explains the medical profession's stance towards the syndrome, which has had and continues to have a strong impact on the social perception of dementia.

DSM is part of the International Classification of Diseases (ICD), which is a coding system used in everyday practice, in any medical documentation to record an established diagnosis. The predecessor of the ICD was the International List of Causes of Death, which in 1948, under the auspices of the World Health Organization (WHO), expanded

² <https://www.psychiatry.org/psychiatrists/practice/dsm/history-of-the-dsm> (07/08/2019)

to include the Classification of Diseases. ICD-6 was released as the first version. Currently, version 10 of the disease classification system, launched in 1990, is used by over 100 countries worldwide in 43 languages and serves health and statistical systems, including Hungary³. Version 11 of the code system was released in June 2018⁴. The significance of this step is well illustrated by the fact that this version was the first which contains the labelling of "gambling addiction", the point at which this disease "exists" for statistical purposes, meaning that data can be collected around the world.

DSM was first integrated into the International Classification of Diseases (ICD) system in 1952. DSM was the first clinical-oriented guide to mental illness. The subsequent development of the classification system was marked by the formulation of precise diagnostic criteria, which, however, neglected the causes as category-forming considerations. In this respect, DSM is much more complex and meaningful than the BNO system, since the latter is not intended to give a precise definition of a disease. So, the BNO and DSM systems are constantly evolving, but their refreshment is not fully coordinated, periodically, for example, the general system of disease coding does not follow the psychiatric professional consensus on classification of diseases and conditions. This leads to documentation disharmony and, consequently, difficulties of data collection and analysis.

Prior to the first publication of DSM, there was already evidence in the United States of categorization of psychiatric disorders and targeted data collection based thereon. The first classification was for administrative purposes only and was intended to measure the number of people with mental illness in the censuses. During the 1880 census, seven mental illnesses were singled out and, in addition to dementia, there were six other illnesses, also named differently than today, commonly referred to by the professional classification system.

The release of DSM Version 5 in 2013 is of great importance for dementia (Nemeroff et al., 2013). Dementia is categorized by a new entry, "neurocognitive disorder", into the new classification system, including "major neurocognitive disorder". At the same time, the term "dementia" (e.g. Alzheimer's dementia, Parkinson's dementia, Lewy body dementia) has been retained to identify different forms of origin. A new feature in the

³ <http://www.who.int/classifications/icd/en/> (07/08/2019)

⁴ <https://icd.who.int/en/> (07/08/2019)

classification system is the less severe form of dementia, the so-called "mild neurocognitive disorder". Constructing this concept is very important because it expresses that dementia is not a sudden onset condition, but that there is an actual anterior hall where the subject can spend a very long time without recognizing abnormal cognitive functioning. Mild cognitive impairment has been used in clinical and research applications well before the release of DSM Version 5, the most common being the mild cognitive impairment (MCI) (Petersen et al., 1999; Petersen, 2004; Hugo and Ganguli, 2014; Volosin et al., 2013; Penke et al., 2016). This new definition, which is gaining entry into the grading system, expresses that although loss of function is less pronounced in a person with this condition, it already requires the development of "compensation strategies", "tricks of adaptation" to maintain independence in daily activities (Sachs-Ericsson & Blazer, 2013).

Given that dementia, or severe cognitive impairment, is not a curable condition at this time, recognition of mild stage would be one of the most important tasks to focus on today, both clinically and socially. In patients with mild cognitive impairment, current drug therapies can be expected, at most, to cause the condition to stagnate or to slow progression, thus ultimately delaying the onset of the more severe condition. Although the borderline between mild to severe disorder is difficult to define - and this is consistent with the finding of a relative and an absolute deprived situation - the distinction between the two groups is extremely important as they differ widely in terms of care needs. While with mild disorder the focus is on exploring the underlying cause of the condition, initiating targeted therapy as soon as possible, and preparing for future care decisions, in the event of severe disorder, active treatment is of secondary importance, whereas assessing the need for care and support is of primary concern for the family involved. Medical professionals try to give a strict definition to a condition, in which the start and progression is not absolutely strict, and strongly depends on an individual's circumstances. If your circumstances are better, you will function better despite the severity of the disease.

As Hugo and Gangulin (2014, p. 421) state:

"Dementia is typically diagnosed when acquired cognitive impairment has become severe enough to compromise social and/or occupational functioning."

Mild cognitive impairment (MCI) is a state intermediate between normal cognition and dementia, with essentially preserved functional abilities."

The classification system for mental illness has not changed significantly regarding the etiology of dementia. However, the background is particularly important in patients with mild stage because, although in most cases the process is not reversible, in a smaller group, improvement in the condition can be achieved by timely treatment. The most common cause of dementia, Alzheimer's disease, responsible for 60-70% of cases, is incurable (WHO, 2018). However, dementia may appear as a symptom of other neurodegenerative pathologies (such as Parkinson's disease) and other specific forms (Lewy-body dementia, frontotemporal dementia), which are variants of the underlying mechanism or caused by impact on specific brain parts.

ii. Prevalence of dementia

Only estimates are known of the prevalence and incidence of dementia, and even if we have accurate information, we cannot be sure that we get a true picture of the occurrence of the condition (Perera et al., 2018; Prince et al., 2013). On the one hand, the definition and classification conditions detailed in the previous section, and on the other hand, the discipline and uniformity of the country's health records, strongly influence the quality of the data available. It is thought-provoking that direct domestic data on Hungary is not known. An important, scientifically relevant basis for estimating the number of people with cognitive impairment was published in 2013 by Prince et al. (2013), in which literature from three decades was systematically summarized and meta-analyzed.

The research also served as a source for the publication entitled "Dementia: A Public Health Priority" (Wortmann, 2012), co-authored by WHO and ADI; in fact, the commission of these two organizations initiated a summative research, the data and forecasts of which are often quoted. Despite the extensive summary work in this article, the limitations of the results are illustrated by the fact that regions defined by the international organization (Global Burden of Disease - GBD regions) are characterized by incongruous amounts of data. Thus, for example, data for Central Europe totalled 4, but there was only one set of data for Eastern Europe. Another weakness of the summary

is that most papers were published in the 1990s. This is especially true for data sources of high-income countries, although while low/middle-income countries also have the most articles from the 1990s, at least they show more activity in the new millennium. This publication dynamic, that can be interpreted as recognizing the seriousness of the problem, was more rapid in developed countries and this issue began to be addressed at a scientific level, while in developing countries the threshold for stimulus was reached later. The data gap for Central and Eastern Europe also applies to Hungary. According to its regional classification, based on demographic and epidemiological characteristics, Hungary is a member of the Eastern European group of European Region C⁵, with partners such as Belarus, Estonia, Kazakhstan, Latvia, Lithuania, Republic of Moldova, Russia and Ukraine, which have low infant mortality and high adult mortality. Most European countries, except our neighbours Romania and Slovakia, have been rated A (also referred to as Western European countries) with very low infant and adult mortality. Intermediate Group B (Central European) countries are characterized by low infant and adult mortality. Thus, Hungary is amongst those countries with the worst demographic ranking in Europe. In the course of systematic literature research of 2017 publications, it emerged that 135 met all criteria. Evaluating the quality of the publications selected, only 43% mentioned dementia as a multidimensionally diagnosed condition. These were measuring not only the degree of decline in cognitive function, but also the multi-spectral assessment of abilities, and associated psychopathology. As I will explain later in my dissertation, these are essential factors for care.

Based on weighted estimates, 5.7% to 5.8% of the population over the age of 60 in Europe's middle and eastern regions, is affected by dementia.

iii. Dementia as an economic factor

The "formula" of health economics about the costs of the condition to the community and society, also can be applied for dementia. The literature divides costs into direct and indirect groups (Gulácsi et al., 2012). Direct health care costs are all costs that are directly related to health care, whereas direct non-health care costs include costs that are related

⁵ http://www.who.int/choice/demography/euro_region/en/ (01/06/2018)

to medical treatment but not incurred within the health care system. The cost of informal care is also an indirect cost. The components of the cost of informal care are broadly defined by Krol et al. (2015). Based on their definition, informal care cost comes not only from the time spent on volunteering and unpaid work as a caregiver, but also the "side effect" of this activity, such as the costs of protecting and restoring one's health and well-being, or even counts informal payments.

The World Alzheimer Report (ADI, 2010) discusses costs in three groups:

- direct health care costs (hospital and outpatient care, medicines),
- direct social costs (costs of non-health care, formal social care, including community care, such as home care, meals, transportation, nursing home care),
- the cost of informal care is the third unit, where the time spent by the informal care on various activities is the basis for the calculation.

Dementia, like other diseases requiring care, imposes a significant financial burden on families, but this burden differs significantly from one country to another, mainly due to the different structure and support potential of the overall welfare system and the social welfare system in particular. Families first of all have to face a significant loss of income due to a total or partial loss of work of a person living with dementia, or a family member caring for them, but in Hungary we have no estimation of its sum.

A 2015 study led by Martin Prince (ADI, 2015), commissioned by Alzheimer Disease International (ADI), found that families in the low- and middle-income countries, because of the inadequate functioning of the welfare system, have a greater financial burden. While in high-income countries, the cost of informal care is slightly higher than that of formal social care, in low- and middle-income countries, only about one-sixth of the cost of dementia emerges in formal social care.

iv. Dementia as a social factor requiring strategic planning

Some European countries are two decades ahead of our country in recognizing and addressing the social problem of dementia. France, which launched its first action plan for dementia in 2001, is already implementing its fourth action program and, recognizing

the benefits of concerted action, has extended its application to other neurodegenerative disorders besides dementia. My publication in the journal *Esély* (Fekete, 2019b) discusses the available examples in detail, so I will not go into details here.

Based on the examples presented, the professional basis for the preparation of the strategy took many forms, but their common feature was that they sought to involve as wide a range of agents as possible. My first publication in the *Budapest Management Review* (Fekete, 2017) presents an experiment comprising many stakeholders, in which participatory system mapping explored the determinants of the quality of life of people living with dementia. This experiment also confirmed that participation and a system mapping tool can reveal the priorities of a given community, which, in other examples (Király et al., 2016), also provided a credible background for policy decisions.

b. Social sustainability

The birth of the concept of sustainability is linked to a report published in 1987 entitled "Our Common Future" (WCED, 1987), also referred to as the Brundtland Report, after Ms Gro Harlem Brundtland, who was responsible for managing it. In 1984 the United Nations (UN) mandated the World Commission on Environment and Development to clarify the situation between environment and economy. The original text defines sustainable development as follows:

"Humanity has the ability to make development sustainable to ensure that it meets the needs of the present without compromising the ability of future generations to meet their own needs." (paragraph 27.)

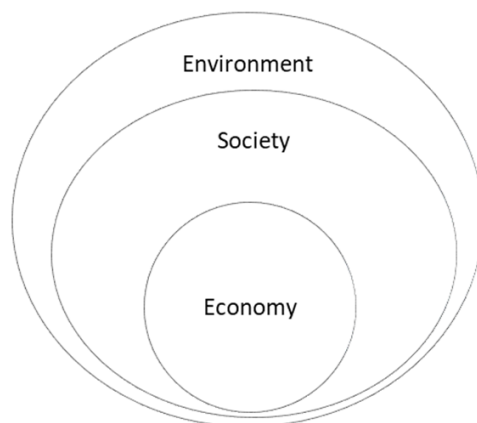
The increase in environmental and economic disarray between the two areas since the mid-20th century has led to the need to define what the task really is. It was also necessary to identify actions that could be adapted to countries with different levels of development and ability, since it was clear from the outset that we were facing a global challenge.

The report identified three dimensions along which thinking and ensuring harmony and sustainability should be addressed. In addition to the environment and the economy, the third dimension is society, that is, humanity itself, the survival of which must be the final

goal behind harmonizing efforts. The key to ensuring sustainability is thus the balancing of priorities of the competing economy, the environment and society (Boyer et al., 2016).

Given my research focus, I take the social dimension out of this triple unit, yet still recognizing their close connection. The basis of my approach as such is the relationship between the environment / ecosystem, the society and the economy in which they serve each other as a kind of background or as a receiving system (Figure 2) (Kerekes, 2009; McKenzie, 2004). This embeddedness as a representation expresses that the environment is the most comprehensive system that encompasses the social system and only within that, is the economic system justified. There is constant interaction between the systems, and these back-and-forth effects drive their evolution. All these processes and results take place within the global framework of the environment and the ecosystem, so their impact will show up sooner or later, since the operation of the systems is inseparable. It can also be deduced from this representation that the damage or unsustainability of any element leads to the collapse of the entire system.

Figure 2. Relationship of the system of environment - society - economy (Source: own editing)



The interpretation of the social dimension of sustainability is still open today, even though the role of society has already been raised in the decades preceding the Brundtland Report. In its first report, *The Limits to Growth* (Meadows et al., 1972), The Club of Rome, founded in 1968, dealt with the unsustainability of economic growth and its negative aspects. Examining exponential, unlimited growth, the factors of limits were divided into two categories: physical and social. Physical needs for growth, such as food, fresh water, forests, oceans, and various raw materials, have been grouped as one of the basic conditions for physiological and industrial functioning. These things are mostly tangible,

countable, and keeping track of their numbers is easy from a methodological point of view. The other set of growth needs were social needs such as peace, social stability, education, employment and technological progress, for which specific measurement methods with well-defined variables are less applicable, and forecasting can be more uncertain.

Based on his literature review, Murphy (2012) provided a conceptual framework for defining the third dimension, that is, the social pillar of sustainable development, and for defining its relationship to the environmental pillar. The four emerging policy approaches to the social pillar are: public awareness, equity, participation and social cohesion. Murphy (2012), summing up his predecessors' notions about social pillar as being vague and abstract, felt the need to help define the social dimension alongside the other two pillars. He points out that the social approach in most of the concepts so far has been confined to the objectives of the welfare of present generations, whereas intergenerational and international relations would also be a worthwhile policy approach.

Boyer et al. (2016), in their work summarizing different approaches to social sustainability, also sought an explanation for the topic's perceived stigma. On the one hand it has been explained by the historical tradition of identifying sustainability primarily as "green", i.e. the environmental problem, on the other hand by the fact that the complexity of social reality makes it impossible to make objective statements. It is certainly true that this aspect, the social pillar, was the latest as a part of the discussion on sustainability, and thus the discourse has long been focused on the relationship between the environment and the economy. Although for today, many have now made social sustainability the central issue.

Just as sustainability theories are not uniform, there is no uniformly accepted concept when looking for a definition of social sustainability. There are holistic, comprehensive and reductionist, simplistic approaches. The holistic approach is characterized by interdisciplinarity, but it is also characterized by an approach through the filter of the disciplines involved, even by exploration of topics along presupposed contexts.

In their summary work, Boyer et al. (2016) identified five interpretive approaches based on an overview of currently available scientific sources (Fekete, 2018, p. 285-6)⁶. Thus, according to the five approaches, social sustainability can be interpreted as:

1. a separate goal
2. an obligation under the control of economic and environmental factors
3. a prerequisite for environmental and economic sustainability
4. the cause of economic and environmental change
5. place-centric, process-oriented sustainability.

Putting social sustainability as a separate goal implies a transformation of the original 3-pillar model into a 1-pillar model, which is detrimental because it makes economic, environmental, and social processes independent of one another and ignores the legitimate relationships and interactions within the system (Griessler and Littig, 2005) (1). In another approach, the three systems keep each other under control but, as some authors point out, this approach does not necessarily lead to the survival of the original goal, the ecosystem. Through the example of business sustainability reports, Milne and Gray (2013) deduce that there is a risk that it is precisely to serve unsustainability, since obscuring the border of the three concepts, it becomes an attempt to combine environmental, economic and social goals (2). The theory that puts social capital at the forefront sees social sustainability as a prerequisite for environmental and economic sustainability and considers social capital as an essential element of social sustainability. In the interpretation of social sustainability in the built environment, attention is paid to social equity, justice and community sustainability (Dempsey et al., 2011) (3). Another theory puts social sustainability as a direct causal factor, where the final goal is ensuring economic and environmental sustainability. It cites a series of initiatives stemming from social needs, as well as alternative thinking and approaches, such as community initiatives to reduce unsustainable consumption or to conserve water. This interpretation emphasizes the need to stimulate research and development based on the formulation of new needs (Seyfang and Smith, 2007), and the role of social relationships, organization of society

⁶ Following 5 paragraphs are based on the author's textbook chapter "Social Sustainability" (in Feith, HJ ed. 2018. Society, Family, Health - Basics of Family Sciences. Semmelweis University Faculty of Health Sciences, pp. 285-286).

and culture. Local decision-making emerges as a solution for the issue of social sustainability (4). The final theory summarized also emphasizes the "local" approach (Cowling et al., 2008), which seeks to advance local issues, local motivation and local action in the field of sustainability. By considering the overlap of the three systems of sustainability as a basic thesis, a multi-focus, interdisciplinary approach stands out (Raymond et al., 2010) (5).

Thus, the concept of social sustainability is complex. Its description and definition cannot be compressed into a few lines. Many consider the area of social sustainability as the least studied and scientifically rigorous of disciplines, perhaps because it is the least concrete. In any case, the scope of the issues to be addressed is less specific than for the environmental, ecological branch. There the threat and the final goal are clear. Social sustainability is the most holistic, interdisciplinary approach, which, from a concept and research point of view, also means that there is untapped potential in the subject. The imminent or ongoing social crisis also calls for a solution as much as the environmental emergency.

Just as the Club of Rome study described social conditions of development as elusive and incalculable, this approach is consistent with the belief that social sustainability must be about maintaining, preserving and developing community and political values. Social values, norms, language, education and authority all have a significant impact on social relationships. Social, or rather, community and individual development can thus be interpreted also individually and collectively within the framework of social sustainability.

In their summary of interpretations of social sustainability Boyer and his colleagues (2016) show that the community has a prominent role in several approaches. There are cases where it is considered to be the primary causal factor, so the community's activity has led to the pursuit of economic and environmental sustainability. Elsewhere, the way society is organized is the key element for development based on handling local issues and involving local communities in local decision-making. My own work also deals with this aspect, both in terms of practical implementation (Fekete, 2017) and theoretical background (Fekete, 2019b).

Through my research focus, I see social sustainability as a community responsibility. Informal care and caring within the family make a significant contribution to the widening

of social gaps, as informal caregiving becomes a necessity for those with less earning ability. The issue of social justice will be a growing problem for ageing populations, with an increasing number and proportion of people with any functional limitation. Differences are also expected in the case of well-being, which is considered as a method of measuring social development, discussed in the next chapter. It is of paramount importance to explore determinants of well-being at an individual level and to identify and successfully apply community and social intervention.

It is worth noting that in recent decades, communities are playing an increasingly important role in shaping their lives. Their members, as citizens, are no longer merely involved in implementing community-led changes through external initiative and governance. As has emerged among the interpretative possibilities of social sustainability, society, a community, has become a catalyst for demand-shaping actors. The community can act as a catalyst, not only by raising needs-awareness, but also by participating in research and development. An example of citizen science for dementia is described in Appendix 1.

c. Well-being and quality of life

Not only about the social dimension of sustainability and sustainable development can it be said that its interpretation and conceptual definition is highly goal-oriented, but it is equally true of the economic dimension. Consequently, it is also problematic to simply define what is to be pursued. In any case, in addition to differences in approach, the consensus says it is a vision, it is about what to preserve and maintain for the future (Gébert, 2015).

From an environmental perspective, it is perhaps easiest to define this in a few words: the final goal is maintaining the entire ecosystem. Of course, those working on the topic will be able to set goals in a much more colourful way along the lines of the United Nations Sustainable Development Goals (United Nations, 2015; KSH, 2015).

From an economics point of view, the key concept of sustainable development again seems to be relatively straightforward, as some measure of development must be found. However, different schools of economics and trends have different approaches to

development, and thus determine the factor to be measured differently (Gébert, 2015). Of the measures of economic prosperity, the most criticized - perhaps just because it is the most commonly used - is Gross Domestic Product (GDP). Criticism from social development practitioners is particularly strong because, as I will discuss later, many value-added activities that are important to the individual and the community remain invisible under the GDP approach.

It's worth mentioning the so-called "capability approach" of Amartya Sen, a 1998 Nobel laureate economist, who considers the existence of capabilities and opportunities as a parameter worth monitoring for change, rather than capital-based development or growth (Gébert, 2015). Sen published his work on the individual approach to social and economic development, in which capacity was identified as the primary policy objective, in 1970. By expanding abilities, individuals are given a certain freedom of action because they are able to do things that are valuable to them and to achieve states of being that are valuable to them. All this also results in equity at the community level if equal access to valuable skills is assured (Pataki, 1998). It is undisputed that the possession of material goods also provides a degree of freedom in our society, since it gives the individual the ability to acquire additional goods. In this sense, however, economic growth - as measured by GDP - is only a tool. A tool to create a better quality of life. Permissions and capabilities are needed to use tools to achieve a valuable goal.

For a moment, while discussing the theoretical background, it is worth stopping to consider that dementia is just characterized by the loss of a key ability. An ability that prevents the individual concerned, and the family members involved in their care, to exercise their other abilities, their theoretical freedom. Sen presents the concept of ability through poverty as a deprived status, its definitions seem to be directly applicable to this disadvantaged group - those with dementia and their carers as a common interest group. All the statements in their case are true, for example, which Sen formulates in relation to the problem of poverty (Sen, 1999), ranging from the distinction between absolute and relative, through the definition of boundaries in the absolute approach, to the blurring of boundaries between absolute and relative. In the end, in Sen's words, "oversimplification" can be applied also to dementia, on the one hand it is "an absolute category", given the more sophisticated medical definitions. On the other hand, it is very often a "relative term" because the circumstances strongly affect the abilities remaining for the person living with this condition: for example, those living in a metropolitan area,

with a solid financial and social safety net, and with a supportive family. Living without any support, completely isolated, naked to the sensitivities and responsibilities of those in his or her immediate environment is a totally different situation.

From the perspective of social dimension, the currently accepted approach to measuring sustainability and development is the result of several decades of process. Given that the social dimension of sustainability was not immediately of central interest, economists had time to become interested in the subject, and during this time, other social science practitioners took initial steps to find appropriate measurement tools and methods. Basically, following people's mental development and well-being, which can be identified as an evident sustainability goal, is the field of psychologists. The process of forming the concept of well-being from a sustainability perspective was a long time coming, but it represents a good example of interdisciplinary collaboration.

As Frey and Stutzer (2002) explain (p. 402):

“Happiness is generally considered an ultimate goal of life; virtually everybody wants to be happy.”

Happiness is thus an understandable economic goal, but for a long time it has been a problem to measure. An important step is related to Ed Diener's name, who, recognizing the need for measurement, created the current conceptualization of the concept of subjective well-being in the mid-1980s (Diener, 1984). He broke dogmas, such as that young people, or those who are healthier, are happier. In line with those espousing positive psychology, later defined as a trend, he saw it as a problem that psychology has a fundamentally negative approach, since it focuses on the cause of “unhappiness”.

Martin Seligman, considered the founder of positive psychology, and Mihaly Csikszentmihalyi, who was also thinking in an optimistic way, summarized their thesis in a special issue of the journal *American Psychologist*, named Millennium Special Issue on Positive Psychology as a New Emerging Trend (Seligman and Csikszentmihalyi, 2000). They said that, after World War II at the centre of psychology was the alleviation of suffering, the pathological approach to psychology, and the neglected positive individual and community processes. Psychology worked as a subdivision of the health system that played the role of "victim". They believed that the goal of positive psychology is to change focus and develop an approach that focuses on strengthening positive

attributes. Diener was also featured in this Millennium issue, but later also co-authored with Seligman (Diener and Seligman, 2004). In their paper, they advocate the use of well-being as an economic indicator. They draw attention to the shortcomings of commonly used economic indicators (such as GDP). As they write, only economic indicators were of great importance at the start of economic development, when the aim was to measure basic needs, but since then this simple goal, as a measuring instrument has needed to be changed. By way of example, there is an increasing number of people with mental illness whose well-being is not helped by an improvement in economic indicators, and paradoxically, the service and consumption generated by the treatment of the disease are economically positive. In their view, ensuring well-being is important, not only because of the "feel good" factor, but also because of its positive consequences, such as in employment. Thus, welfare objectives should have a political role and an influence on policy, and to facilitate this, they propose the development of a national welfare index. Their vision for the indicator system can be summarized by the following: the indicator system should include questions relevant to decision-making; represent different interest groups; display a broad interpretation of well-being such as life satisfaction, purpose and meaning of life, trust, commitment, depression, and positive and negative emotions; include information on specific aspects of everyday life such as work, health, family, community, leisure; include issues related to standing and current action plans; and use both depth-of-field and sub-section longitudinal tracking for sub-samples.

However, up to the consensus of the measurement of well-being, even more scientific discourse was needed, on the one hand the "defensibility" of subjectivity and on the other hand the difference between emotional vs. cognitive content. The perspectives of hedonic and eudaimonic well-being are discussed by Ryan and Deci as opposing but complementary approaches (Ryan and Deci, 2001). The authors summarize the concept of well-being as "optimal psychological functioning". In the background of the hedonic and eudaimonic approaches, many authors refer to ancient Greek philosophical roots. The definition of hedonic well-being is traced back to several, including Plato, but the eudaimonic view is typically attributed to Aristotle (Diener, 1984; Ryan and Deci, 2001). The hedonic approach is a kind of deliberation, where falling in a positive direction results in a feeling of joy exceeding sorrow and pain (Wiseman and Brasher, 2008), or simply the cause of happiness is that desire is fulfilled (Ryan and Deci, 2001). Other illuminations suggest that maximizing pleasurable experiences over bad experiences

ensures the highest possible level of well-being (Vanhoutte, 2012). The concept of hedonic well-being is complex. It has an affective or mood branch, and a cognitive or thought-driven branch (Vanhoutte, 2012). The assessment of feeling depressed or of general health is attributed to the mood, whereas the expression of satisfaction with life is the result of a more conscious reflection process. The eudaimonic approach is more complex, and can be traced back to Maslow's hierarchy of needs, where self-actualization is a human need, meaning "living" a meaningful, purposeful life is itself a source of happiness (Vanhoutte, 2012). It is not merely a result that is achieved, but the way to it is evaluated. However, it is also possible that a fulfilled desire does not cause one to feel good, if the process leading to it was not good (Ryan and Deci, 2001). A special elderly-fitted quality of life questionnaire, CASP (Control, Autonomy, Self-realization, Pleasure) (Hyde et al., 2003), a tool used in my own work, is also a construct aiming to differentiate between the end result (well-being) and the status that leads to it.

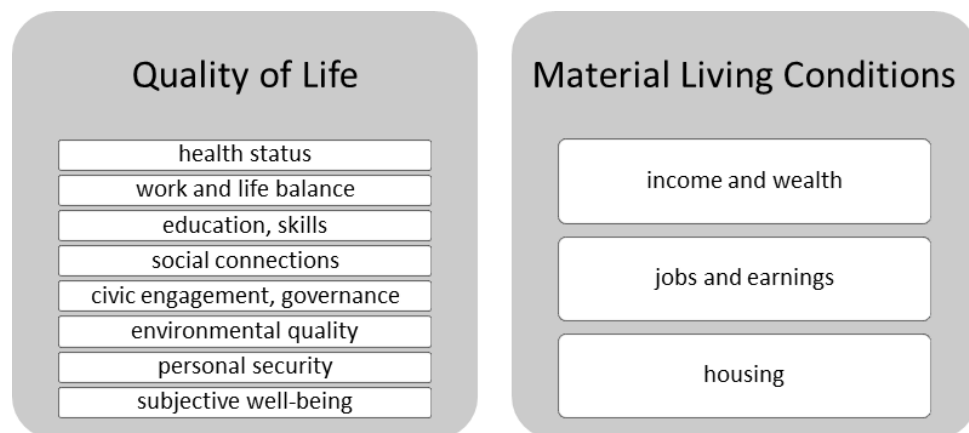
Today, the debate between the two approaches has come to a standstill, as it has been accepted that the components of the hedonic and eudaimonic interpretation of well-being are simultaneously influential (Ryan and Deci, 2001). At the same time, it cannot be said that the justification of "measuring subjective data" has been reassuring to everyone. In addition to subjectivity, Kahneman and Krueger (2006) highlight that this data was obtained directly from an individual recording experience and feeling. However, its role is outlined in the traditional utility-based concept as a new set of motivating factors for human choice. It is predicted that subjective well-being will also influence the way in which well-being is determined, and that the growth of social relationships rather than consumption, will be a driver to maximizing well-being.

Thus, after the turn of the millennium, there was no doubt that economic development, material prosperity, and welfare could not be directly matched to the happiness of individuals. By that time a newly created definition emerged: well-being. An important milestone was the Fitoussi Report (Stiglitz-Sen-Fitoussi, 2010)⁷, which was based on a calling from French president, Nicholas Sarkozy. The participants of this team, the Commission on Measuring Economic Performance and Social Progress, were asked to identify the constraints on GDP as an indicator, and propose the use of indicators and

⁷ Report by the Commission on the Measurement of Economic Performance and Social Progress. (Online accessible: <http://ec.europa.eu/eurostat/documents/118025/118123/Fitoussi+Commission+report> Downloaded: 05/08/2018)

statistical analyses that bring economic performance and social performance closer to better follow social development, in order to develop appropriate policy plans to influence them positively. However, the report was intended to be widely used by: politicians, decision-makers, members of the scientific community and non-governmental organizations, and indeed, all members of society - not just in France. The Organization for Economic Cooperation and Development (OECD) report about the well-being indicators (OECD, 2011) was also based on this work. This summary divided the factors determining human well-being into two groups (Figure 3). One contains the components of “material living conditions” that describe the income and wealth situation, while the other provides a more colourful source for describing well-being under the generic term “quality of life”. In this group there are many subjective state descriptors, as well as factors that determine the individual's well-being in society, role in the family, but also the characteristic of the interaction between the environment and humans.

Figure 3. Determinants of Well-Being - OECD Well-Being Indicators (Source: Compendium of OECD Well-Being Indicators, 2011; self-edited)



As social sustainability deals with how communities survive and develop, we need to outline appropriate measurement methods to follow. The well-being of individuals cannot be summed up mathematically in order to derive a measure of the development of a given community. Of course, this requires first defining what is meant by community well-being. According to Wiseman and Brasher (2008, p. 358):

“Community wellbeing is the combination of social, economic, environmental, cultural, and political conditions identified by individuals and their communities as essential for them to flourish and fulfil their potential.”

Thus, community well-being is much more complex than the definition of individual well-being, and cannot be measured on a consumption basis by the traditional welfare approach. However, individuals' well-being is expected to be modified by their role, their situation in the community. Several studies in this field have shown that the well-being of the individual and of the community has a reciprocal effect (Theodori, 2001).

d. Ageing of society

The ageing of society is a key factor in social sustainability. Changes in the age structure play a role in influencing social processes both globally and locally, at the level of local communities.

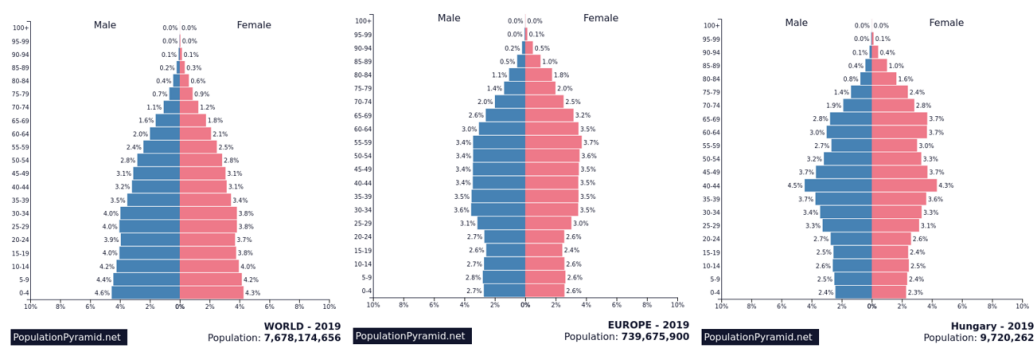
In Hungary the most used terminology of "ageing" (population ageing) is "ageing of the society", already a well-known, often referred to term. However, it is important to look a little behind the concept, because the concept of old age cannot be simply defined or given a value on a numerical scale. Jackson (2007) describes the ageing of society as a phenomenon, featuring four dimensions:

1. Numerical ageing, ie the absolute increase in the number of older people;
2. Structural ageing, that is to say an increase in the proportion of older people in society;
3. Natural decline, which occurs when the number of deaths exceeds the number of births - a process that is accompanied by numerical ageing, as no one can live forever;
4. Absolute decline occurs when population decreases due to falling birth rates and increasing deaths not being offset by migration.

These four dimensions are related to the development of three factors: fertility, life expectancy and migration, which determine the age composition of a given population.

Numerical ageing is a direct consequence of the increase in life expectancy, which is a feature not only of developed countries, but also of developing countries. In addition to increasing life expectancy, significant reductions in infant and child mortality also contribute to numerical growth. The shift in age-group ratios, that is, structural ageing, is primarily the consequence of changes in fertility and birth rates. After the Second World War, many countries witnessed an increase in population (baby boom), but this population tsunami was sometimes of different origins, and consequently of a different course and duration. Within this period, the birth rate increase in Hungary, linked to an aggressive population growth policy measures package (the so-called Ratkó era) of short duration - just over 1 year - having a decongesting effect within a further 2-3 years (Tárkányi, 1998; Bódy, 2017). Children and grandchildren of the Ratkó era leave a clear mark on the domestic age-tree (Figure 4).

Figure 4. Age-tree of the World, Europe and Hungary, in 2019 (source: <https://www.populationpyramid.net/hungary/2019/>)⁸



One of the cornerstones of population growth in the twentieth century was the fertility surge post Second World War, that has characterized many countries, albeit not at the same rate. According to English terminology, the baby boomer generation provided the human resources for economic development, which in turn transformed into retirement for the current decade and could soon increase the number of people in need of care due to the decline in their health. The ageing of the baby boomer group is expressed by the 2012 demographic turning point (World Bank Group, 2016), when the working-age group (age group 15-64) reached its peak in the global population with a ratio of 65.8%. Briefly

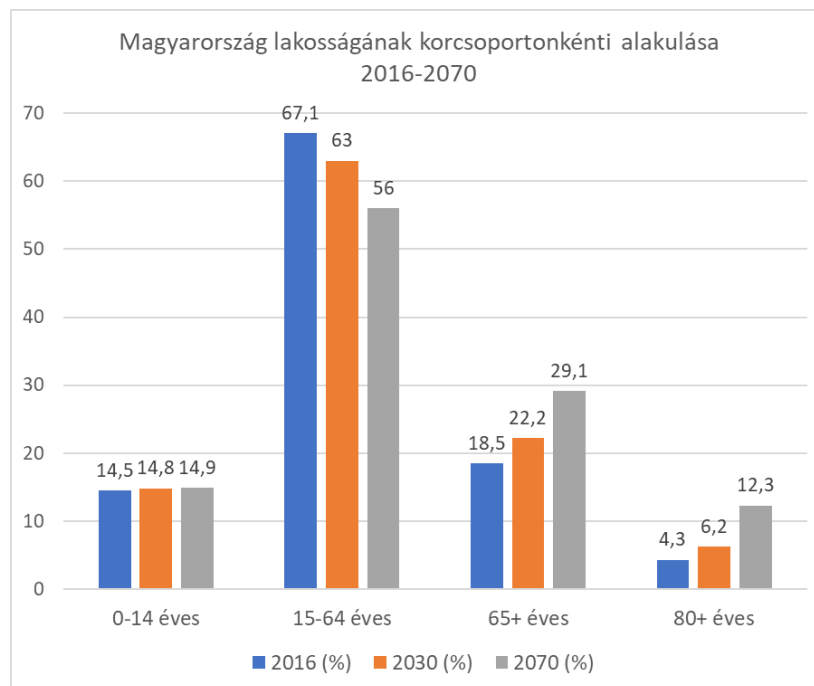
⁸ Downloaded: 01/09/2019

summarizing the demographic trends from the 1950s to the present, fertility was at half (5 / 2.5), mortality decreased significantly, so life expectancy became extended by about two and a half decades (1950: 46.8 years / 2015: 71.7 years).

The prominence of baby boomers comes from their upcoming or ongoing retirement, and their need for nursing care. Jackson (2007) considers the distinction between numerical and structural ageing to be important because the former is inevitable and rapid, whereas structural change is somewhat slower, so that policy could be prepared for change. For informal care, changes in proportions, expressed by structural ageing, are particularly important. Numerical ageing and the increase in the absolute number of older people are crucial to the capacity planning of welfare systems.

The domestic demographic tendency is illustrated in Figure 1 of my study published in the journal *Esély* (Fekete, 2019b) (Figure 5).

Figure 5. Population of Hungary by age group 2016-2070 (based on EUROSTAT - EUROPOP 2015⁹, own processing)



⁹ <https://ec.europa.eu/eurostat/web/population-demography-migration-projections/population-projectionsdata> Downloaded: 25/02/2019

In Hungary too, there is a trend as in other developed countries, whereby the decline in the proportion of the active population is accompanied by an increase in the proportion of the elderly. Due to the increased incidence of dementia or other neurodegenerative disorders, and other conditions requiring care, the significant increase in the proportion of those over 80 deserves special attention. Up to 10% of this age group may be affected by dementia (Prince et al., 2013), and this is only one of the factors prompting need of care.

e. Informal care

Informal care is the term used to describe an activity in which a non-expert or non-professional cares for a family member or friend of a chronic or terminally ill person (Van den Berg et al., 2004). Janet Heaton (1999) traces its origins back to the 1970s and, as a result of many processes, basically highlights a change in philosophy: “from care in the community to care by the community” (p. 759). This was primarily due to the ongoing decrease in the operational efficiency of health care facilities - the reduction in the number of hospital beds - which necessitated the care of patients at home. The volunteering and civic initiatives, as well as developing communication and technical tools, helped this activity. It is also an interesting background to the "age-in-place" movement, which is desirable for all seniors today. In addition to its many benefits, in fact, this is a necessity stemming from the growing proportion and absolute number of older people.

Thus, in the early decades of the concept's emergence, informal care was essentially described as a voluntary, unpaid, charitable activity (Heaton, 1999). Further research on this activity has revealed new dimensions. During studies with social focus, it was recognized that caring for a family member, friend, or neighbour was not necessarily a voluntary activity, but simply an obligation. At that time, opinions that highlighted the negative effects of caring life became stronger (Zarit et al., 1998; Pearlin et al., 1990; Kálmán et al., 2008). Concurrently, the important social and economic impact of the activity was highlighted after being praised as a substitute and complementary form of formal care (Van den Berg et al., 2004). The recognition of informal care as an economic factor was still missing. As Krol et al. in the title of their 2015 summary article provocatively asked: "Does Including Informal Care in Economic Evaluations Matter?"

(Krol et al., 2015, p. 123). On the one hand, the authors' answer is in the affirmative, as they mark informal care as an important determinant of social well-being. On the other hand, barely a quarter of the 100 relevant cost-review publications reviewed in this study dealt with the costs or other effects of informal care.

The idea of community-based care has been influenced by a new development since the turn of the millennium, emphasizing the positive benefits that this caring activity brings, along with undeniable difficulties and burdens (Rozario et al., 2004). Emphasizing the positive aspects of the caregiving role and helping to recognize and develop them will increase the well-being of the caring family, friend, neighbour and community. In the case of carers of people living with dementia, studying the positive effects is an orphan area of research. Following a systematic literature study, Lloyd et al. (2016) attempted to define a conceptual framework by analysing 14 qualitative studies. In their summary, the positive consequences fall into two groups: one is the "gains" from the care activity itself, and the other is the consequence of the dynamics between carers and care recipients. For example, caring activities have positive effects such as role satisfaction, personality development, and the enjoyment of new knowledge and competences. Relationships can be improved by experiencing the possibility of compensation or unconditional care, or a sense of duty that, along with satisfaction with the role, leads to a sense of internal reward. Caregiver support services and communities should facilitate the access to these outputs on a personalized basis.

3. Presentation of articles

3.1 Brief description of publications

3.1.1. *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.

3.2. 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)¹⁰.

¹⁰ 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 (Downloaded: 08/08/2019)

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.

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.

3.3. 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 "carrying 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.

3.2 Full text of publications

3.2.1. *Rendszertérképezés alkalmazása a hazai demenciastratégia megalapozásához*¹¹

Systems mapping as a potential tool for establishing dementia strategy

Abstract

The population ageing poses challenges in sustainability to the nations. An increasing number of people living with dementia is one reason for this, because dementia is an incurable health condition, needs long-term care, and is one of the key factors leading to vulnerability and declining quality of life in the elderly. Such an important challenge of social sustainability requires strategic planning, preparation, and setting up an action program. Many European countries already have a dementia strategy to tackle the problem.

This article presents an experiment using a qualitative methodology, participatory systems mapping, as a potential tool for knowledge summary, and as an initial step in the process of establishing a dementia strategy. With the combination of systems mapping and participation methodologies, a lot of benefits arise, especially in the field of developing policy, long-term programs, and short-term intervention plans.

With a focus on improving the quality of life of people living with dementia, participants created a complex causal loop diagram. This work revealed topics which are worth prioritization. Participants also experienced positive impacts of participation, and visual representation led to the objective of supporting communication. Based on these experiences and results, the combined methodology of participatory systems mapping is stimulating for further application.

Key words: systems mapping, participation, population ageing, dementia, strategy

¹¹ At the request of BCU Doctoral School, the full text of the article is embedded - in unlectored translation of Fekete, M. (2017). Rendszertérképezés alkalmazása a hazai demenciastratégia megalapozásához. Vezetéstudomány, 48 (12), 24-32.

Hungary is particularly affected in population ageing, which is a global problem. According to projections for Hungary, the age composition of the population will change dramatically by 2060. According to Eurostat data (Eurostat, 2014)¹², proportion of people over 65 years in Hungary will increase by 12 %, and the proportion of people over 80 years will increase by nearly 16 % by 2060. At the same time, the active population (15-64 years) will decrease by 12 %, while the proportion of children will not change. Expressing in a more plastic way, while in 2013, there were 16 active-age people "behind" every person over 80, by 2060 there will be less than 5 people behind them. This demographic process, referred to in literature as ageing, puts nations facing sustainability challenges, as new solutions are needed, among others, in retirement, health care and social care systems. One of the challenges - the importance of which is not yet recognized in Hungary - is spreading dementia.

Increase of life expectancy is accompanied - based on logic and experience - by increase of years spent with disease, although development of the disease is mostly multifactorial. Thanks to improvements of healthcare in developed countries, older populations do not have to expect increased functional impairment, deterioration in quality of life, despite increasing incidence of chronic diseases – such as cardiovascular, respiratory or metabolic – illnesses (Christensen et al., 2009). Dementia is a special case, since it is accompanied primarily by functional limitations that make up the components of the syndrome, so that they do not occur as a consequence but as a primary indicator of the disease.

Dementia is a process associated with decline in cognitive and thinking functions, which most prominent feature is loss of memory function. It is now obsolete, but earlier this disease was referred to as “senile dementia” or “senility” which nomenclature also indicated the condition was considered to be a natural part of ageing. This misconception may also have played a role in insufficient attention being paid to the extent of the problem. Dementia can occur as a result of a variety of conditions, but in most cases, it cannot be cured, and today’s therapeutic options are only hoped to reduce symptoms and slow down progression. As the syndrome progresses, vulnerability of patients gradually increases, eventually becoming incapable of independent living and requiring nursing for up to 10 years (Aguero- Torres et al., 1998). International estimates (EUROCODE Project: Dementia in Europe Yearbook 2006), based on worldwide prevalence data, suggest that at least 110-130,000 patients are living with dementia in Hungary. Other experts estimate that up to 2-300,000 people are affected, and estimate a proportion of people living with dementia to be 30 % in age group over 85 years (Kovács, 2016). In view of the trend toward population ageing, we must expect a significant increase in the number of people living with dementia, and be prepared to deal with this burden in time. With such a major challenge for social sustainability, the question rightly arises: how to plan strategically, and prepare for what is likely to happen. This article presents an experimental qualitative method, participatory systems mapping, which can be a tool in creation of dementia strategy. The system mapping method is capable of involving a wide range of stakeholders and structuring their thinking. Participation ensures that varied aspects, knowledge and experience are brought to the same scene. The jointly created

¹² Eurostat, 2014; http://appsso.eurostat.ec.europa.eu/nui/show.do?dataset=proj_13npms&lang=en

causal structure, mapped as such, provides participants with instant feedback on main elements of their work, relationships between elements, and points of intervention that are effective.

Background – Social significance of dementia

As a result of the projected tendency of ageing, dementia soon will be a serious social problem in Hungary due to the mass of patients affected by the syndrome (EUROCODE Project: Dementia in Europe Yearbook 2006). Complexity of the problem is partly due to characteristics of disease, so it is advisable to review it briefly. Besides numerous contradictory medical sources, we may rely on a consensus-based study of experts (Annear, 2015). Mentioning dementia, Alzheimer's dementia, Alzheimer's disease, most people think of memory impairment and loss of memory. However, deterioration of thinking function is not only a problem in the field of memory, dementia has several other manifestations. Thus, symptoms may include loss of attention or decision-making, confusion in planning, organization and problem-solving, being uncertain in judgment or even having difficulty expressing oneself or speaking. All these immediately bring to mind several everyday situations that require help and support for a person living with dementia. It should be noted that dementia is affecting not only elderly, but possibly people of active age. At primary form, early detection would be the most important step, while in case of secondary type, prevention should be given more prominence after the occurrence of cerebral thrombosis (also known as stroke) (Kling, 2013).

Working on preparation of an action plan, to address a problem, it is important to identify those who are primarily affected, because through targeting, intervention will be the most effective. In addition, if we consider participation as a methodological opportunity for knowledge integration, involvement of those primarily concerned should be considered. Not only people living with dementia, but also family members or another volunteer carer is the primary stakeholder. In most cases, an informal carer is a family member, who for reasons of compulsion or rarer but luckily, has volunteered for this role. Informal caring is in the focus of several researchers' interests (Etters et al., 2008; Fonareva et al., 2014; Krol et al., 2015): psychological, quality-of-life, economic aspects, and several other focuses emerge in research. Alzheimer's Disease International, an organization with more than 80 members worldwide, has been working with the World Health Organization (WHO), and has been publishing the World Alzheimer Report since 2009. In 2010 published this report with a focus on economic impacts, then returned to this topic in 2015. During this time, social costs raised with 35%. Distribution between three main cost drivers appears to be relatively constant: direct health care costs represent 20%, social care costs and informal care costs represent approximately 40-40%. Complexity of costs also indicates the complexity of the problem of dementia.

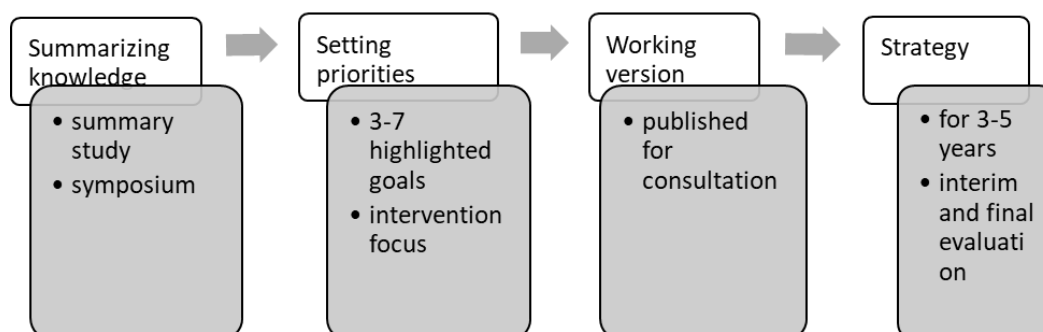
European Dementia Strategies – Why and how

In 2002, Council of Europe stated recommendations¹³ in reference to social policy challenges of ageing society and mentioned dementia as one of the chronic diseases and conditions that lead to an increased vulnerability and affect quality of life of elderly. WHO raised dementia as a priority disease in 2008, and in 2013 published a list of 24 conditions and diseases in its WHO Priority Medicines for Europe and the World – A Public Health Approach to Innovation (WHO, 2013) program, which pose such a significant social burden that it is of significant importance to achieve improvement in therapeutic options.

Given the complexity and scale of the problem represented by dementia, a national strategy is needed. This was recognized first by France, where the first action plan was adopted in 2001 and is now running its 4th program. As every program that relies heavily on the social and health care system, it requires uniqueness that the action plan should adapt to the existing care system - at least as a first step. In addition, another source of national distinction comes from socio-cultural traditions, which cannot be overlooked, especially in an area where interventions that have an impact on family and wider social relationships are needed. Today, 21 European Member States have a dementia strategy. In 2016, four countries – Czech Republic, Greece, Slovenia, Spain – reached the government's announcement of the strategy as a result of a multi-year preparatory process. In most cases, health and social action plans take the initiative of a self-organizing group of experts and, after varying degrees of involvement and intervention by governmental bodies, move forward as a program announced by governments. Experts are usually delegated or invited to work together by the organization or organizations representing people living with Alzheimer's and other dementias in the country. First step is usually creating a forum where experts can share their knowledge. This is somewhere in the form of a book of study, a summary report, elsewhere in the framework of a conference or symposium. This is usually followed by the formulation of general objectives to be set, tasks to be performed. The working version of a strategy document prepared by the experts is usually published, debated and, based on reflection, the final version is published and adopted at the level of government. Action plans usually set out tasks for 3-5 years, so those in the forefront of strategy development announce several programs based on an evaluation of the achievement goals set above. Therefore, it is of great importance that priorities should be measurable and evaluable (Figure 1).

¹³ Doc. 9615, 31 october 2002, Challenges of social policy in our ageing societies – Report: <http://assembly.coe.int/nw/xml/XRef/X2H-Xref-ViewHTML.asp?FileID=9911&lang=EN>

Figure 1. Process of developing a dementia strategy in international practice



Hungary does not have a strategy, not even a plan version, so our backlog can be measured in years. It is needed to shape the Hungarian approach. Dementia, which affects more and more people and places an increasing burden on the health and social care system, is not included in strategy for health (Healthy Hungary 2014-2020)¹⁴ nor mentioned in general strategy of social care (National Social Policy Concept 2014-2020; 2011)¹⁵, in contrast to diseases of much less social and budgetary importance.

Methodology – Applying a qualitative approach to knowledge aggregation

System mapping and participation as methodologies are relatively new approaches (Király et al., 2015). There are many policy areas that can get benefits by using a combination of these methods, such as developing a strategy, formulating longer-term plans, or developing shorter-term intervention programs. Based on system mapping and system dynamics approach, reveals possible points of intervention that may be the target of decisions needed to solve any problem by depicting negative and positive feedback and loops (Vennix, 1996). As can be seen in oeuvre of the creator of method, J. W. Forrester, engineering technology development led to the creation of a leadership theory achievement in the late 50s, which has been used extensively over the past decades (Lane, 2007). After engineering, system dynamics modelling worked in the field of management sciences, it seemed to be suitable for clarifying the context of complex social systems. As such, it was first used by Forrester himself to map the operational dynamics of a city, and then in 1970, he was asked to analyse global development of the world system dynamically, during which he explored sustainability factors of development with the method. As a continuation of this work, method was applied to research on systems related to the natural environment. Later, this method of analysis was used in many other disciplines. There are also few examples in health sciences. It has been found to be suitable for exploring public health issues, including dementia, because a transdisciplinary approach is needed to simultaneously enforce biological, organizational,

¹⁴ <http://www.enkk.hu/index.php/hun/kepzesi-kozpont/233-egeszseges-magyarorszag-2014-2020> (Accessed 01/12/2016)

¹⁵ Nemzeti Szociálpolitikai Konceptió 2011-2020; 2011, Czibere Károly, Sziklai István, Mester Dániel, Dr. Vörös Gyula, Sidlovics Ferenc, Skultéti József, Beszterczey András

and political principles, and the method is appropriate to ensure meeting this expectation (Leischow, 2006).

The need to ensure participation in social policy decisions has been formulated as an expectation at the beginning of millennium, with a lack of clarity what is meant "participation" (Bishop, 2002). Governments and decision makers often detect everyday events and functioning of social systems through a kind of a filter, so it is impossible to map them without involvement of real stakeholders. Involvement can differ from several levels, ranging from using it as a source of information to involvement in decision-making.

These "recommendations" were the starting point for experimental strategy-based reflection presented in this article. This experiment is unique in several aspects: in Hungary, strategy-making in the field of health and social policy has few traditions, and it is even less common to involve a professional or lay audience in a problem assessment or in making an action plan. Even in an international context, examples of system mapping based on the involvement of stakeholders are difficult to find in these specialty areas.

Given the proven benefits of combined methodology in Hungarian practice (Király, 2014), a decision was made on the method of this research. Firstly, the method of this kind is exploratory and in particular, depiction of reasons supports a deeper understanding of the problem. Secondly, in the process of thinking together, discourse focuses on so-called variables and their interrelationships, which allows for neutral communication, since the exchange of views is not about ideologies, complex opinions, but about specific factors and their relationships. All of this also helps participants to work together with a significantly different knowledge base, focus or level of knowledge. Thirdly, as usual, documentation is facilitated by visual techniques. Visualization of results in thinking and summarizing knowledge, whether we would like to follow the process or to record and analyse the final result. Graphics and analysis are supported by freely available softwares. It is also important, and perhaps of primary importance for the choice of method, that technique is easy to learn and teach, that is, technique is transferable.

These key methodological benefits contributed to choosing a participatory, dynamic tool system for knowledge synthesis to underpin the development of a dementia strategy. To take into account other benefits of this method, it is worth a while to separate attendance and system mapping elements for a while. Benefits of participation, especially in Hungary, still need to be emphasized (Király, 2014). Perhaps the easiest acceptable argument is that if more people have more knowledge, each participant potentially adds something to collective knowledge. However, it is important to look a bit behind it. Ensuring participation is a psychologically satisfying, need-based method, and thus contributes to improving the well-being of participants, making them more motivated. If participation is provided for a decision-maker, hopefully a more informed, better decision emerges, through more information the person receives. Participation also provides an opportunity for people in different status to meet directly, which enables them to deal with existing or potentially emerging conflicts, ideally, giving a chance to prevent them. Any way to reduce the "democratic/ democracy deficit" for society, this tool offers benefits. Ordinary distance between a decision-maker and a person whose life is

influenced by him/her is a major problem. Ensuring participation can strengthen direct communication between intermediaries. It is significant to choose the right person as a participant, as well as the way and form of participation, so that people involved may enjoy enough freedom during the process. In order to avoid false expectations, it is advisable to clarify the outcome of participation and final goal of the process in advance, so that, neither later disappointment nor low motivation develops.

One critical element of system mapping is the so-called use of internal perspective (Richardson, 2011). According to this, among factors influencing operation and behaviour of the system studied, those that are an integral part of the model, play a role in its dynamics by providing feedback and formation of closed loops formed by interactions. Consequently, its application can also be considered as a step toward interdisciplinary collaboration, as it illustrates the interaction of factors from different disciplines within the system studied. Combining it with participation, we can achieve the level of transdisciplinarity that not only gives possibility for different disciplines to emerge, but possibility for interactions of different views and types of knowledge. It can also be considered as a kind of common learning process, since everyone's existing knowledge will be enriched, and their attitude will develop. As nobody has a comprehensive knowledge of the problem discussed, it is essential summarizing the knowledge of individual actors. Participatory system mapping provides an appropriate opportunity to do so, which aims after collection of knowledge, identifying points of intervention and even building action programs of different perspectives. Limitations of the method also need to mention, as participants can influence outcome significantly, based on our own experience. While communication between participants of different levels of knowledge is for real greatly facilitated by the technique of representation, and linking of variables really simplifies complexity, recognizing the importance of system mapping requires a more abstract thinking. Participants with higher mental performance can overdrive the process and modify focuses. For a similar reason, concentrated thinking will not lead to the same level of fatigue among researchers, theoretical and operational practitioners. Thus, moderator has an important role in structuring properly the workflow and ensuring balanced expression in discussion.

Modelling Participatory System Dynamics for Knowledge Summarization – From Organization to Implementation

Along with above theoretical foundations, organizing was started involving an organization, Social Cluster¹⁶, which brings together nursing homes, institutions taking care of elderly, and individual members. Social Cluster was admitted in Alzheimer Europe¹⁷ umbrella organization in October 2016. According to their recent report, it closes 39 organizations of 34 countries as full members, and 4 other organizations from

¹⁶ Acknowledgments: The author would like to thank leader of association, Dr. Ágnes Egervári, and her colleague, Dr. Norbert Vajda, for their help in carrying out research, their supportive and encouraging suggestions, and to all participants for their cooperation.

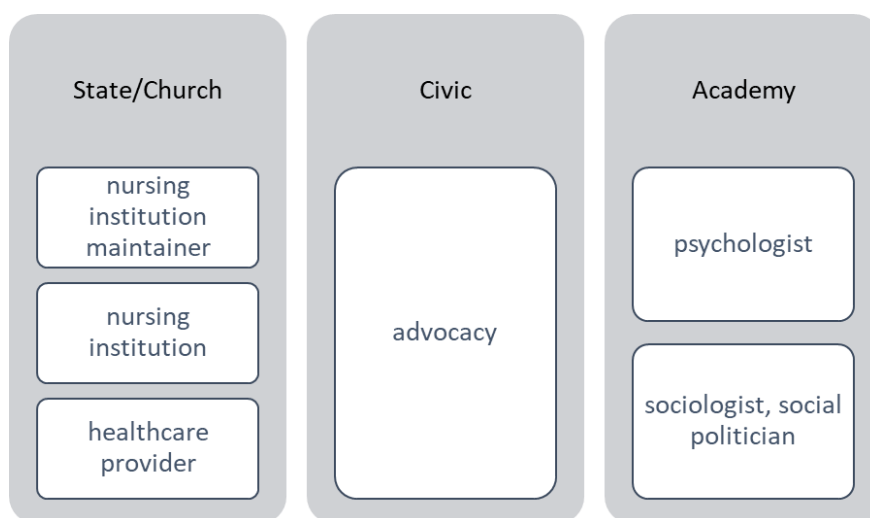
¹⁷ <http://alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Our-members> (Accessed: 12/12/2016)

4 countries - including Social Cluster, first from Hungary – are listed as prospective members.

Social Cluster has a decade-long history of supporting communication and advocacy between institutions and professionals involved in care of elderly and care for people living with dementia. This fact was a guarantee that invitation for participation would be successful.

At the same time, the association's network defined the range of actors to be involved, which was partly a limitation, but multilateralism was successfully enforced (Figure 2). Main limitation was the lack of a business sphere, which, however, does not currently play a significant role in Hungary in caring for people living with dementia. However, it would be worthwhile to involve private providers who are not currently active in this field, as their experience in other areas could be useful. Social Cluster is the only civil participant in this circle, which represents both maintainer of an institution (as a church organization) and as an institution operator, so their appearance is not emphasized by civilian approach. Presence of an informal caregiver support forum (for example Alzheimer Cafe) (Morrissey et al., 2006), which already exists in Hungary, would represent real civil representation.

Figure 2. Actors involved in system mapping to establish a dementia strategy



Social Cluster made suggestions for participants to be invited. Primary goal was to involve practitioners and theorists alike in the thinking process. This implies, however, that the scale of participants can range from academically advanced to mid-level graduates. For this reason, we have put a strong emphasis on visualization as we were based on its role in facilitating communication. Among representatives of practitioners we invited a head of a nursing institution, a care provider, a neurologist, a general practitioner representing primary care, a sociologist with experience in social services,

and from a theoretical basis, specialists in psychology and in sociology. Finally, together with moderator¹⁸ 12 people participated in the experiment.

Dementia strategies to help people living with dementia and to their carers are needed, not only because of international expectations, but because of its impact on society is significant, heavy burden on care systems and poor efficiency in financial or in-kind state care support. An interdisciplinary approach is particularly important, because of the complexity of the problem. Assembling strategic points is considered as a preparatory step for strategy-making, as it provides guidance on which newer and newer areas of expertise in iterative process are needed to call in develop the most comprehensive, consensual, feasible and sustainable program.

As we have already seen in completed national strategies about dementia in Europe, beside dementia as a major topic, action plans have been built on one of a few key issues. With prioritizing, steps of completing the entire program can be better tracked, its success may be better measured, but it does not exclude attention and resources for secondary goals. Typically, it is a primary or defined goal, to improve the starting of diagnosis of people living with dementia, that is, to recognize disease, since without identified participants, the program would be meaningless. Number of new cases and change in proportion of early-stage patients can be measured and monitored among identified patients. Often one of the main goals is to assess and build the necessary spectrum of care systems and to improve the quality of life of people living with dementia and their families, as the most important parameter of its operational efficiency.

Following this pattern, our working group decided as a key concept, both for future strategy development and for thinking together, improving the quality of life of people living with dementia.

In order to speed up the process and overcome initial difficulties expected due to the novelty of methodology, the author compiled an initial glossary based on guiding principles that could be incorporated later into the system map before collaborative work, with associating involvement of participants. Principal source was the Maltese Dementia Strategy, which also focuses on improving quality of life, and secondly an EU-funded programme named INDA (Inter Professional Dementia basics)¹⁹. The INDA programme was developed and implemented by Roman Catholic Church Charity Service in cooperation with Social Cluster. Moderator formulated a total of 45 variables/expressions related to quality of life of people living with dementia. These were introduced to participants after a theoretical introduction and a lecture on methodology. Participants were asked to identify some terms they considered to be the most important in the list, and these were summarized by the moderator. Moderator wrote down on a post-it the most frequently mentioned factors (by at least 5 participants), so the process of representation started with 15 variables. Location of the meeting was well-known by all participants and was a scene of several previous association meetings, which could also be an important factor in achieving a sense of dissolution in thinking together. Based on

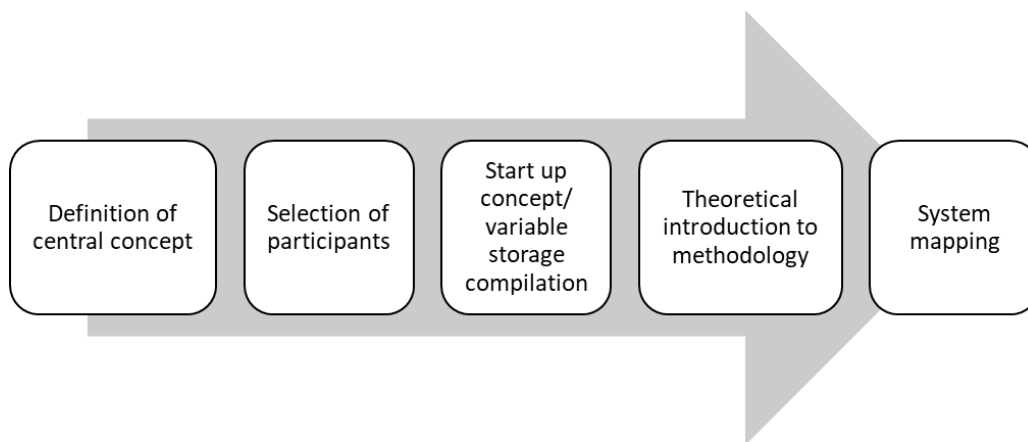
¹⁸ Moderator was the author, and the inventor of the experiment. In course of her medical activities, the author meets active people living with dementia and their caring relatives, and as a member supports the activity of Social Cluster.

¹⁹ <http://inda.info.hu/>

plans, in the first half an hour, the author of this article introduced the basics of methodology. We briefly reviewed potentials of participatory processes, modelling system dynamics and visual language. Subsequently, trigger concepts were selected as described above and resulted in 15 variables available in a ready-to-map format greatly facilitated first steps but were not forced to use variables provided in this way.

As a result of 2.5 hours of intensive work, the diagram was finally completed with 42 concepts (Figure 3.). These formed nodes that were connected by 88 relations, so-called causal relations. Of 88 connections, 79 were positive and 9 were negative, and one was negative on both sides. Nodes and variables resulted in a minimum of 1 and maximum of 11 and an average of 4.2 connections. All these statistics, as well as sophisticated representation, archiving and further analysis are facilitated by use of a software. In this case, VUE (Visual Understanding Environment)²⁰ open-source software helped in this part of the working process. Result of system mapping was recorded primarily on photographs and paper-based map was of manageable size. Using all of these, content was recorded by using software later, but not soon after the events. VUE software would also be suitable for in-process recording, especially if there is a participant who has knowledge in methodology and does not have a moderator role and who can participate in the event as an external observer or merely an administrator.

Figure 3. Steps of organizing and conducting a system mapping process



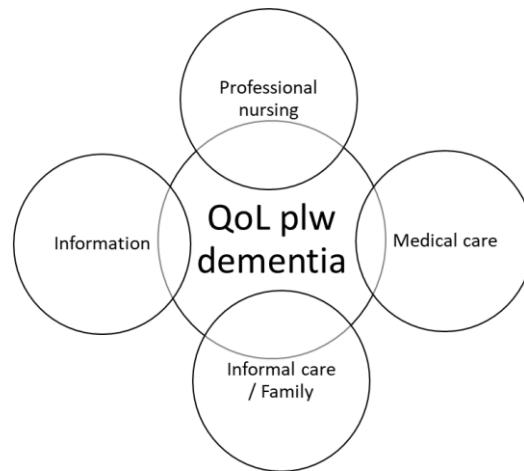
Results of participatory system mapping

The map created during cooperative thinking, so called complex causal diagram was already superficially analysed with participants on the spot. It was already at this point that most concepts relate to four main topics (Figure 4.). 31 out of 42 variables belonged to following:

- (Specialist) nursing factors (9),
- Background of medical care (8),
- Factors of relatives (8),
- Information- knowledge- awareness (6).

²⁰ <http://vue.tufts.edu/>

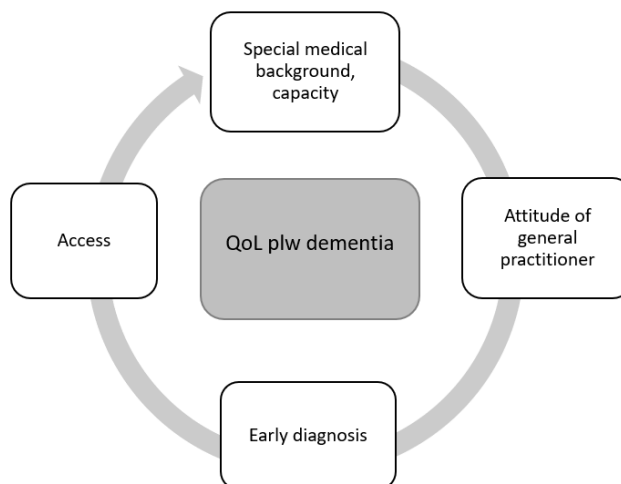
Figure 4. Identification of 4 main areas influencing quality of life of people living with dementia



Given the composition of participants' professional background, emerging of nursing and medical care as an important aspect is perhaps not surprising. The primacy of the nursing aspect is certainly due to the fact that professionals of dementia are aware of the fact that quality of care will be a decisive factor in a patient's quality of life. The main factor expressing social involvement is the idea of "information-knowledge-awareness", which is based on a separate central concept, stigmatization. Concepts that do not range into four main themes made further reference to the necessity of an interdisciplinary approach, as they raised, for example, funding, legal and research aspects. However, while focus reflects areas of participants' competency and proficiency, search for context over those too is clearly evident.

When constructing a complex causal diagram, representation of positive and negative relations makes connections clear between variables (Sedlacko et al., 2014). Given that the variable placed in the centre is essentially of output kind, feedback loops can be set up easier within and between different prioritised topics (Figure 5.).

Figure 5. Example of a positive feedback loop - Within the topic of Medical Care



Based on four main areas outlined, action to improve quality of life of people living with dementia should primarily be initiated in areas of medical care and nursing, support for relatives and dissemination of all types of information related to dementia. Identifying these four topics could be even a primary step in developing a strategy (see Figure 1.)

Conclusions

Based on the experiment, participatory system mapping and complex causal diagram seem to be an appropriate tool to help initial stage of framing an action plan by addressing a complex social problem, and by identifying key intervention points. Dementia was an ideal topic for experiment, as a problem to health and social policy, it is reliably predictable by demographic processes. Compared to other European countries, Hungary is lagging in developing a strategy to solve this problem, so every step which can be integrated into a strategy-making process accelerates achievement of goal. Participatory system dynamics modelling is expected to be applied in new fields in the future, because based on experience so far it can define long-term goals and identify concrete intervention points. Its application in the health and social field is rare, even on an international level. Our research for a large, comprehensive database of health science and economics (Medline and EconLit) yielded only 12 results²¹.

We have tried to reduce potential reluctance and need of time to adopt the novel approach, building on existing consultative relationships that already exist. Participants provided a number of positive feedbacks immediately after the experiment and later during informal meetings. Several participants emphasised the importance of experiencing their participation. This confirms adequacy of methodology. Participation was both clearly motivating, and it indeed provided a communication channel between academic researcher and practitioner involved in care of elderly. At the end of the exhausting discussion, many people explained their good feelings with seeing the fruits of their work, literally tactile and real products that everyone felt as their own. They could read their own handwriting or thoughts which became one of the nodes in figure.

It is a moderator's experience that there is a real need for careful selection of participants, as it may limit the review of a problem that is intended to be global if the professional/subfield wins too much importance due to level of representation or communication habits. Moderator must be ready to intervene actively, to convey the word, if the situation requires so. Although the task of depiction may seem simple, participants had to be reminded repeatedly to find and depict all causal relationships, trying to consider the complexity of the problem. This ability is improvable by practice or more detailed theoretical preparation.

It would also be possible or expedient to break down four identified key factors into further elements, and to explore sub-processes deeper. Seeing that in some areas complex overview was over detailed in exploring variables and causes, a possibility came up that mind-mapping focused on a particular area could be implemented with involvement of

²¹ keresési módszer: via EBSCOhost: ("systems thinking" OR "system dynamics approach" OR "causal loop diagram") AND (policy OR strategy) AND (health OR social) AND (participation OR participatory)

actors, experts of certain areas. Overcoming complexity in such cases would serve as a motivation for utilizing system mapping for other purposes, like identifying “good practices” in health and social care fields or ensuring participation.

Prominent role of relatives in care of people living with dementia has been demonstrated by the results of this research. Positive and negative effects of caregiving on family members are actively researched themes, and in addition to quantitative methodology, qualitative methods are also appearing. Applying participation as a methodology in this type of research, definitely should be considered as a next step and it is not an unrealistic goal to involve caring relatives, and people with early stage of dementia. There are examples of other qualitative methodologies applicable for working with people living with dementia in literature (Clare et al., 2008), thus it is possible to draw on their experience. In this case, special preparation is certainly needed, which should include knowing symptoms of the condition, gaining practical experience and understanding day-to-day difficulties of people living with dementia.

Discussion

Our experience, summarized in conclusion, substantiated our hypothesis based on literature research, in terms of participatory system dynamic modelling can be a suitable tool for exploring some public health problems to support health policy decisions and strategies (Leischow, 2006). From the perspective of participation, it has been proven that choice of participants determines outcomes, including type of involvement (Bishop, 2002). Our case was most similar to a “partnership” type of participation, whereby invited experts could even play a role in the advisory board alongside policy makers. Selection of participants served to achieve a holistic approach and knowledge synthesis, which are critical aspects of exploiting the decision support function of this method. Our experience also confirmed predecessors’ view that system dynamics is a problem driven approach and system mapping should focus on a particular problem (Sedlacko et al., 2014).

The central issue in our research was “improving quality of life of people living with dementia”. Our aim was to identify factors that influence this. The experiment was successful from this point of view, it had succeeded in displaying and exploring endogenous factors with feedback within the area represented by participants (Richardson, 2011). According to our map, factors determine and influence the quality of life of people living with dementia belong to four areas. Within these topics, many feedbacks and connections were discovered and there were also links between main topics, but to a smaller extent. Exogenous factors, such as financing, legal and research aspects are out of four main topics. According to our results, the quality of life of people living with dementia is determined by nursing, medical care, family background, and many aspects of information. It is in line with other countries’ dementia strategies²², which have been updated several times, which often include dissemination of clear and professional knowledge on dementia (information), fight against stigma (information),

²² <http://alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies> (Accessed: 27/02/2017)

support for caring families (relatives), developing quality of care (nursing and medical care background).

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World Alzheimer Report 2010: The Global Economic Impact of Dementia. Alzheimer's Disease International

World Alzheimer Report 2015: The Global Impact of Dementia. Alzheimer's Disease International

3.2.2 Older New Zealanders in caregiving roles: Psychological functioning of caregivers of people living with dementia²³

Abstract

Research suggests that caregiving can have both positive and negative effects on psychological functioning. It is, however, less understood how these positive and negative effects interact within individuals. The present study aimed to identify different patterns of psychological functioning and their correlates among caregivers of dementia patients. The sample included 336 older caregivers. Latent profile analysis revealed three distinct profiles. The optimally functioning profile was characterized by high levels of positive outcomes and low levels of depression. Those with a suboptimally functioning profile reported low levels of positive outcomes and increased depression symptoms. The poorly functioning profile displayed extremely high levels of depression symptoms and extremely low levels of positive outcomes. Differentiation among groups was driven by differences in social support and to a lesser extent by socio-demographic factors and caregiving experience. Results suggest that caregiving is not necessarily a burdensome role and highlight the role of social relationships.

Keywords: Alzheimer's disease, caregiver, dementia, depression, latent profile analysis (LPA), mental health, psychological functioning, social support, wellbeing

²³ At the request of BCU Doctoral School, the full text of the article is embedded: Fekete, M., Szabo, A., Stephens, C., Alpass, F. (2019a). Older New Zealanders in caregiving roles: Psychological functioning of caregivers of people living with dementia. *Dementia*, 18(5), 1663-78.

New Zealand, like other developed countries, has an ageing population. According to the most recent census (Statistics New Zealand, 2013), 14.3% of the New Zealand population were aged 65 years or older and the proportion of the 65+ population is expected to double in the next 50 years. Prevalence of dementia is growing parallel with population ageing (Prince et al., 2013). In 2016, the estimated number of people living with dementia in New Zealand was more than 62,000. It is predicted that, by 2050, this number will be around 170,000. As dementia progresses, patients require higher levels of care, which can pose significant challenges for the caretaker. Consequently, promoting pathways to caregiver wellbeing to better support people living with dementia is a key objective of the New Zealand Framework for Dementia Care (Ministry of Health, 2013).

The strains and gains of caregiving

Caregiving of people living with dementia can be a challenging and burdensome role in life. The consequences of providing care for somebody who is suffering from a chronic illness have long been one of the major foci of caregiving research (Wennberg, Dye, Streetman-Loy, & Pham, 2015). Studies have shown that caregiving burdens are associated with a wide range of negative health outcomes, including depression and related mood disorders (Joling et al., 2010), cognitive impairment (Vitaliano, Murphy, Young, Echeverria, & Borson, 2011), and poor physical health (Fonareva & Oken, 2014).

Despite the strains and challenges involved in caring for dementia patients, the caregiving experience can also present personal gains. In recent years, there has been increasing interest in understanding the positive effects of caregiving on psychological wellbeing (Kramer, 1997). For example, caregivers have been shown to derive psychological benefits from their caregiving-related responsibilities, such as increased life satisfaction, a more positive outlook on life, self-affirmation, and personal growth (Rozario, Morrow-Howell, & Hinterlong, 2004; Sanders, 2005; Tarlow et al., 2004). These studies suggest that, although caregiving can contribute to mental and physical health decline, not all caregivers would necessarily experience negative consequences. In contrast, adopting caregiving as a productive and meaningful role provides an opportunity for personal growth and to achieve a sense of mastery (Rozario et al., 2004; Sanders, 2005).

The dynamic interplay of positive and negative factors involved in caregiving can lead to vastly different individual experiences. However, previous investigations focussed mainly on establishing associations among key variables that characterize entire samples as opposed to trying to shed light on subgroups of people who experience caregiving in unique and distinctive ways. This type of inattention to divisions within the caregiver population and relevant differences across groups has been highlighted as one of the main methodological problems in the caregiving literature (Kramer, 1997).

Caregiver profiles

There has been a handful of studies exploring caregiving profiles in dementia based on caregiver characteristics and responsibilities. For example, Kraijo, Brouwer, de Leeuw, Schrijvers, and van Exel (2012) examined caregivers' motivations to provide care, burdens associated with caregiving, perceived social support and needs for support, and coping strategies. Using Q-analysis, they identified five distinct profiles with increasing subjective burden and decreasing ability to cope with strains. In a more recent study, Janssen et al. (2017) investigated caregiver profiles based on two dimensions: (1) caregiver and care-recipient characteristics, such as age or severity of dementia and (2) the strain or burden associated with the caregiving responsibilities. They differentiated among 'older low strain', 'older intermediate strain', 'older high strain', 'younger low strain', and 'younger high strain' profiles. They found that quality of life was lower in profiles characterized by higher strain.

Although these investigations used a person-oriented approach, they created profiles based on the burdens or stressors involved in caregiving for persons living with dementia. However, previous research shows that not every caregiver reports poor health outcomes or perceive this responsibility as burdensome or stressful (Kramer, 1997; Rozario et al., 2004; Sanders, 2005; Tarlow et al., 2004). Some caretakers report positive outcomes and high quality of life, even when they spend long hours taking care of someone with severe dementia and experience enormous challenges. To address this gap, the present study aimed to explore different profiles of psychological functioning in a sample of older caregivers of dementia patients. A second objective of the paper was to identify risk and protective factors that foster or hinder psychological wellbeing of dementia caregivers.

Present study

We adopted a person-oriented approach (using LPA) to identify groups of caregivers with similar patterns of psycho-social functioning. Based on previous research findings with respect to the strains of caregiving, we expected to find a vulnerable or ‘at risk’ group who display negative psycho-social outcomes, such as high levels of depression, low levels of quality of life and life satisfaction, and poor mental health. On the other hand, drawing on research emphasizing the gains associated with caregiving, we predicted that a second group would emerge characterized by resilience and healthy psychosocial functioning, i.e. low levels of depression, high levels of quality of life and life satisfaction, and good mental health. As our investigation was exploratory, we did not rule out the possibility of other caregiving profiles to be present in our sample. Additional profiles could display a combination of positive and negative psycho-social markers or they might occupy an intermediate position demonstrating moderately high levels of positive/negative outcomes.

The emerging caregiving profiles were examined in relation to socio-demographic factors, caregiving responsibilities, and social support to gain a better understanding of the factors that contribute to or hinder positive psychological functioning. Female gender, younger age, and spousal relationship to the care-recipient have been previously identified as risk factors for poor wellbeing among caregivers for dementia patients (Etters, Goodall, & Harrison, 2008; Fonareva & Oken, 2014; Wennberg et al., 2015; Zanetti et al., 1998). With respect to the circumstances of caregiving, research findings are rather inconclusive with some studies suggesting no or minimal effects, while others emphasizing the significant role of caregiving factors, such as intensity and frequency of care or the characteristics of the care-recipient (e.g. age), on psychological outcomes (Vellone et al., 2011; Wolff & Kasper, 2006).

Finally, changes in the quality and quantity of social interactions have been documented as important factors contributing to psychological outcomes in caregivers. For example, loneliness and poor access to social support have been found to be key predictors of depression symptoms and caregiving burdens among caregivers of people living with Alzheimer’s disease (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000; Beinart, Weinman, Wade, & Brady, 2012).

Method

Design and sample

Data were collected between 2010 and 2014 as part of the New Zealand Health, Work, & Retirement Study (Towers, Stevenson, Breheny, & Allen, 2016). The sample included 336 caregivers of people with dementia (70.2% female, 37.2% of Maori descent). The average age of caregivers was $M=65$ years (range: 49–88, $SD=8$ years). The average age of care recipients living with dementia or Alzheimer's disease was $M=82$ years (range: 47–101, $SD=9$ years). One-third (31.5%) of caregivers were living with the care recipient. More than half of the dyads were based on parent–child type relationships (52.4%; mother-in-law and father-in-law were counted as parents); 19% were spousal connections, 7.7% of caregivers provided care to other relatives including son/daughter or brother/sister, and 17.9% to non-relatives (friends or others). The remaining 3% did not answer this question. In terms of marital status, 69.94% of caregivers were married or lived in a de facto relationship. Of all respondents, 21.73% worked full-time, 25.30% were employed part-time, and 30.36% indicated that they were retired. The remaining 22.62% did not answer this question.

Procedure

Participants received a postal survey along with a free-post return envelope. The survey included questions pertaining to health and wellbeing, work and retirement, social support and participation, income and financial wellbeing, and demographics. For the analyses reported in the current paper, we included participants who provided care for someone living with Alzheimer's disease or dementia at any stage over the course of the study. As it is a longitudinal data set, some of the caregivers appeared in this role more than once. These people were enrolled only once, using the data from their first appearance.

Measures

Caregiving responsibilities. Caregiving responsibilities were measured in terms of frequency of caregiving (anchored by 1=every day, 2=several times per week, 3=once a

week, 4=once every few weeks, 5=less often), length of caregiving (measured in years), living arrangements, and relationship to the care recipient.

Socio-economic status (SES). SES was assessed with the Economic Living Standards Index (ELSI; Jensen, Spittal, Crichton, Sathiyandra, & Krishnan, 2002). ELSI assesses restrictions on ownership of assets (eight items; e.g. 'heating in main rooms'), restrictions due to cost in social participation (six items; e.g. 'visit hairdresser once every three months'), economizing behaviour (eight items; e.g. 'cut back on shopping'), and self-reported satisfaction with standard of living (three items). Item scores are combined into a composite measure (range: 0–31) where higher scores reflect higher economic living standards.

Social support. Three instruments were used to measure social support and the quality and quantity of social relationships: The Practitioner Assessment of Network Type (Wenger, 1991) measures frequency of contact with family, friends, and neighbours (three items; sixpoint scale ranging from daily to never). The Social Provisions Scale (Cutrona & Russell, 1987) examines six relational provisions, such as attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance. Respondents have to rate two positive and two negative statements regarding all six provisions using a four-point scale ('strongly disagree' to 'strongly agree'). Sample items for the 'guidance' relation are 'I have someone to talk to about decisions in my life' and 'There is no one I can turn to in times of stress' (reverse scored). Items can be summarized to form a composite measure where higher scores indicate greater degree of perceived support. The De Jong Gierveld Loneliness Scale was used to measure emotional and social isolation (Gierveld, van Groenou, Hoogendoorn, & Smit, 2009). Participants rated statements, such as 'I miss having a really close friend' (emotional loneliness) and 'There are enough people I feel close to' (social loneliness), on a three-point scale (anchored at 1= no, 2=more or less, and 3=yes).

Psychological functioning. Psychological functioning was operationalized in terms of self-rated mental health (SF-12; Ware, Keller, & Kosinski, 1998), depression symptoms (CESD-10; Kohout, Berkman, Evans, & Cornoni-Huntley, 1993), quality of life (CASP-12; Wiggins, Netuveli, Hyde, Higgs, & Blane, 2008), and life satisfaction (Inglehart, Basanez, Diez-Medrano, Halman, & Luijkx, 2004). The SF-12 is a generic health-related quality of life instrument. Participants were asked to give responses to statements, such

as ‘How much time during the past 4 weeks have you felt calm and peaceful?’ on a five-point scale (‘none of the time’ to ‘all of the time’). Total scores can range between 0 and 100 with higher scores indicating better mental health status. Self-reported depression symptoms were examined using the 10-item version of the Center for Epidemiologic Studies Depression Scale. Items, such as ‘I felt hopeful about the future’ (reverse scored), were rated on a four-point scale (‘rarely or none of the time’ to ‘all of the time’). Scores can range between 0 and 30, where a total score of 10 or higher indicates depression symptomology. The CASP-12, an instrument specifically designed for the older population, was used to assess quality of life. It consists of four domains (Control, Autonomy, Self-realization, and Pleasure) measuring different aspects of quality of life with statements, such as ‘I enjoy the things that I do’ (Pleasure), on a four-point scale (‘often’ to ‘never’). Total scores can range from 0 to 36, where higher scores represent a higher level of quality of life. Life satisfaction was assessed by one item adapted from the World Value Survey: ‘All things considered, how satisfied are you with your life as a whole these days?’. Responses were given on a five-point scale (‘very dissatisfied’ to ‘very satisfied’).

Data analysis

LPA was conducted in Mplus (www.statmodel.com; Muthén & Muthén, 2012) on responses to measures of psychological functioning. The Bootstrap Likelihood Ratio Test (BLRT), the Bayesian information criterion (BIC), the entropy, and the probability of class membership were used to compare models with increasing profile numbers. A significant BLRT indicates that the model with k number of profiles has an improved fit to the data than the model with $k-1$ number of profiles. Models with lower BIC score, higher entropy, and posterior class membership demonstrate better fit to the data. The recommended threshold for entropy and probability of class membership is .80. Emerging profiles were also expected to account for at least 10% of the total sample (Bauer & Curran, 2004; Clark & Muthén, 2009; Muthén & Muthén, 2012). Profiles were compared based on demographic characteristics using inferential statistics. Three multinomial logistic regression models were tested to identify sociodemographic, caregiving and social support variables distinguishing across profiles. The Nagelkerke’s pseudo R^2 and the Bayesian Information Criterion (BIC) were used to compare the fit of the three

domain-specific multinomial logistic regression models. The Nagelkerke's pseudo R^2 can range between 0 and 1 with higher values indicating a better fit. Smaller BIC indicates better model fit and a difference of 10 is considered to indicate improved fit (Raftery, 1995).

Results

Latent profile analysis

Models with profiles ranging from 2 to 4 were contrasted. The four-profile model produced a non-significant BLRT indicating that the three-profile model provided a better fit to the data with entropy and posterior profile membership probabilities higher than .80 (Table 1). The first profile (n=202, 60.3% of the sample) was characterized by optimal psychological functioning. Mental health, quality of life, and life satisfaction in this group were high, whereas self-reported depression symptoms were low. Participants in the second profile (n=96, 28.7%) displayed suboptimal psychological functioning with increased levels of depression symptoms and lower than average levels of mental health, quality of life, and life satisfaction. The final profile (n=37, 11%) included respondents with very high levels of depression symptoms and very low levels of mental health, quality of life, and life satisfaction indexing poor psychological functioning (Figure 1).

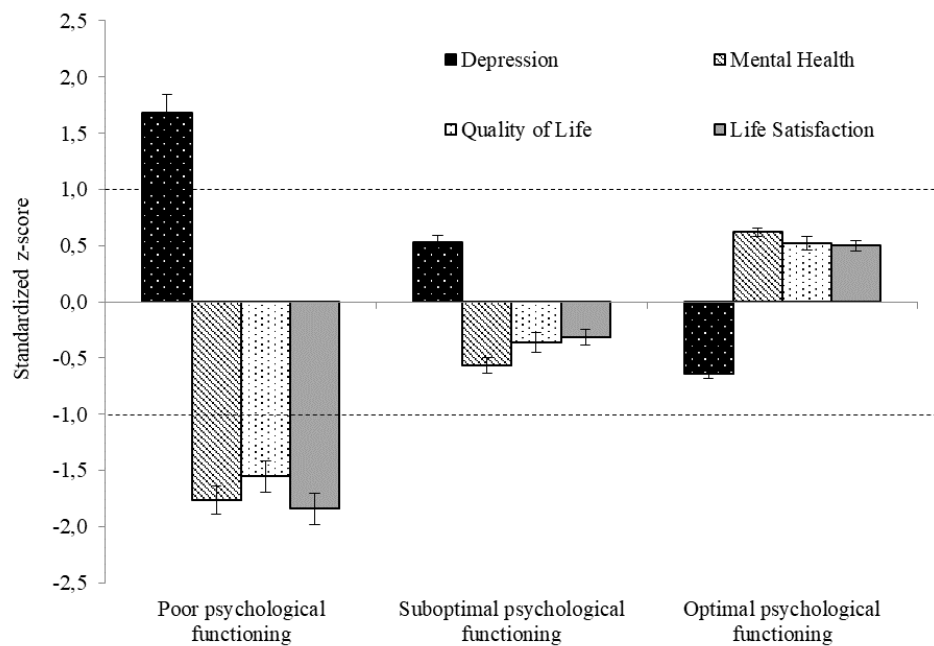
Table 1. *Latent Profile analysis model fit statistics*

Number of profiles	BLRT	BIC	ABIC	Entropy	Posterior membershi
2 profiles	373.73*	5771.27	5730.03	.856	.92-.97
3 profiles	123.74*	5672.35	5615.25	.800	.88-.94
4 profiles	50.40	5649.29	5576.33	.853	.88-.97

Note. * $p < .05$; BLRT; Bootstrap Likelihood Ratio Test, BIC; Bayesian information criterion; ABIC; Adjusted BIC

Figure 1. Prototypical profile structures.

Scores on the Y axis are z-scores ($M=0$, $SD=1$). The direction of the bars indicates whether participants scored above or below the mean. Longer bars represent greater deviation from the mean. Higher scores indicate more depression symptoms, better mental health, higher levels of quality of life, and higher levels of life satisfaction. Error bars indicate standard error of the mean.



Demographic characteristics of caregiving profiles

Analyses indicated no significant differences across profiles based on ethnicity, gender, marital status, and work status (Table 2). However, participants in the poorly functioning profile were significantly younger ($M=61.57$, $SD=7.55$) than those in the suboptimally ($M=66.39$, $SD=8.55$) and optimally ($M=64.87$, $SD=7.81$) functioning profiles; $F(2,332)=4.86$, $p=.008$, $\eta^2=.03$.

Table 2. *Demographic Characteristics of Caregiving Profiles*

	Poor functioning		Suboptimal functioning		Optimal functioning	
	<i>N</i>	<i>Column %</i>	<i>N</i>	<i>Column %</i>	<i>N</i>	<i>Column %</i>
Gender						
Female	21	56.8%	69	71.9%	145	71.8%
Male	16	43.2%	27	28.1%	57	28.2%
Ethnicity*						
Not of Māori Descent	24	64.9%	52	54.2%	134	66.3%
Māori Descent	13	35.1%	44	45.8%	68	33.7%
Marital status						
Not married nor de facto	12	33.3%	29	30.5%	53	26.4%
Married or de facto	24	66.7%	66	69.5%	148	73.6%
Work status						
Full-time	7	25.9%	22	28.2%	52	29.1%
Part-time	11	40.7%	16	20.5%	60	33.5%
Retired	9	33.3%	40	51.3%	67	37.4%

Note. * Māori are the indigenous population of New Zealand.

Prediction of profile membership based on socio-demographic caregiving and social support variables

Three domain-specific multinomial logistic regressions were performed. Results (Nagelkerke's pseudo R^2 , BIC, and odds ratios with confidence interval) are reported in Table 3.

Table 3. *Fit Statistics and Odds Ratios of the Domain-specific Multinomial Logistic Regressions*

	Poor vs Optimal		Suboptimal vs Optimal		Suboptimal vs Poor	
	<i>Exp(B)</i>	95% <i>CI</i>	<i>Exp(B)</i>	95% <i>CI</i>	<i>Exp(B)</i>	95% <i>CI</i>
<i>Model 1: Socio-demographics</i>						
Age	0.95	(0.90; 1.01)	1.01	(0.97; 1.04)	1.06	(0.99; 1.13)
ELSI	0.83***	(0.79; 0.88)	0.93***	(0.89; 0.97)	1.12***	(1.06; 1.18)
Gender	0.43	(0.18; 1.02)	1.00	(0.56; 1.79)	2.33	(0.95; 5.70)
Ethnicity	1.59	(0.64; 3.93)	0.74	(0.44; 1.23)	0.47	(0.19; 1.17)
Marital status	1.02	(0.41; 2.55)	0.94	(0.52; 1.68)	0.92	(0.36; 2.34)
Working status	1.35	(0.53; 3.41)	1.77	(0.98; 3.21)	1.31	(0.51; 3.39)
<i>BIC = 587.42</i>						
<i>R² = .25</i>						
<i>Model 2: Caregiving factors</i>						
Frequency of care	1.00	(0.70; 1.43)	1.06	(0.81; 1.39)	1.06	(0.72; 1.58)
Age of the person cared for	0.98	(0.94; 1.02)	0.99	(0.97; 1.03)	1.01	(0.97; 1.06)
Length of caregiving in years	0.85*	(0.75; 0.97)	1.00	(0.97; 1.04)	1.18*	(1.03; 1.34)
Living arrangements	1.39	(0.53; 3.63)	0.96	(0.50; 1.83)	0.69	(0.25; 1.92)
Relation to care recipient	0.49	(0.15; 1.54)	0.83	(0.40; 1.73)	1.70	(0.50; 5.91)
<i>BIC = 574.16</i>						
<i>R² = .05</i>						
<i>Model 3: Social support</i>						
Social Contact	0.42***	(0.28; 0.78)	0.66*	(0.46; 0.94)	1.57	(0.88; 2.80)
Social Provisions	0.86***	(0.80; 0.93)	0.92***	(0.88; 0.96)	1.07	(0.99; 1.14)
Loneliness	2.08***	(1.52; 2.84)	1.53***	(1.23; 1.90)	0.74*	(0.56; 0.97)
<i>BIC = 382.42</i>						
<i>R² = .44</i>						

Note. CI = confidence interval; BIC = Bayes Information Criterion; Gender (0 = female, 1 = male); Ethnicity (0 = non-Māori, 1 = Māori); Marital status (0 = not in a relationship, 1 = in a relationship); Working status (0 = retired, 1 = working); Living arrangements (0 = not living with the care recipient, 1 = living with the care recipient); Relation to care recipient (0 = not relative, 1 = relative). * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Distinguishing the optimally and poorly functioning profiles

Poorer economic living standards, less caregiving experience, higher levels of loneliness, less frequent social contact, and lower levels of social provisions were predictive of the poorly functioning profile. Specifically, one standard deviation increase in economic living standards was associated with a 1.20 increase in the odds of being assigned into the optimally functioning profile as opposed to the poorly functioning profile. Similarly,

given a one standard deviation increase in the year spent in the caregiving role, the odds of having an optimally vs. poorly functioning profile are 1.18 times more likely. One standard deviation increments in social provisions and social contact were associated with a 1.16 and 2.38 increase in the odds of being characterized by an optimally functioning profile as opposed to a poorly functioning profile. Finally, a one standard deviation increase in loneliness was associated with a 2.08 increase in the odds of having a poorly functioning psychological profile compared to an optimally functioning profile.

Distinguishing the optimally and suboptimally functioning profiles

Comparison of the suboptimally and optimally functioning profiles revealed economic living standards, social provisions, social contact, and loneliness as significant predictors. One standard deviation increase in economic living standards was associated with a 1.08 increase in the odds of being assigned into the optimally, as opposed to the suboptimally, functioning profile. One standard deviation increments in social provisions and social contact were associated with a 1.09 and 1.52 increase in the odds of being characterized by an optimally functioning profile compared to a suboptimally functioning profile. One standard deviation increase in loneliness, on the other hand, was associated with a 1.53 increment in the odds of having a suboptimally, as opposed to an optimally, functioning profile.

Distinguishing the poorly and suboptimally functioning profiles

Economic living standards, length of caregiving experience, and loneliness significantly differentiated between the poorly and suboptimally functioning profiles. One standard deviation increase in economic living standards was associated with a 1.12 increase in the odds of being assigned into the suboptimally functioning profile as opposed to the poorly functioning profile. One standard deviation increase in the length of caregiving experience was associated with a 1.18 increase in the odds of having a suboptimally vs. poorly functioning profile. Finally, a one standard deviation increase in loneliness was associated with a 1.35 increase in the odds of being in the poorly functioning profile compared to the suboptimally functioning profile.

Model fit

Both the BIC and the Nagelkerke's pseudo R^2 suggest that the social support domain model has the best fit.

Discussion

Although caregivers of dementia patients might face very similar difficulties, no two caregivers will be affected by these challenges the same way. The primary goal of the present study was to explore different patterns of psychological functioning among dementia caregivers by investigating differences in mental health, depression symptoms, quality of life, and life satisfaction. In addition, we aimed to elucidate some of the socio-demographic, caregiving, and social support factors that might contribute to differences in psychological wellbeing among caregivers of dementia patients.

The analysis revealed three distinct groups of caregivers based on their psychological functioning. In line with our hypothesis, we identified a poorly functioning or at risk subgroup, characterized by adverse psychological outcomes. In addition, and as expected, a subgroup with an optimally functioning or resilient profile emerged expressing high levels of wellbeing and low levels of psychological problems. Finally, the third group occupied an intermediate position with moderately low levels of wellbeing. The majority of the sample belonged to the optimally functioning group, reporting high levels of wellbeing. A smaller proportion (approximately 11%) of the participants was characterized by negative psychological outcomes. This confirms previous research showing that caregiving can have both positive and negative effects on caregivers' wellbeing (Kinney & Stephens, 1989; Kramer, 1997). In addition, 28.7% of the sample reported suboptimal functioning with lower levels of mental health, quality of life, and life satisfaction and increased depression symptoms. The psychological wellbeing of this group was below an optimal level, which could indicate caregivers who are at risk for compromised mental health.

Next, we examined differences across profiles in demographic, caregiving, and social support variables to identify potential risk and protective factors for older dementia caregivers. Of the demographic variables, economic living standards had significant effects. The optimally functioning group was characterized by significantly better

economic conditions than the other two profiles. Higher SES has been generally linked to better mental health (Glymour, Avendano, & Kawachi, 2014) and caregivers with more resources tend to find their responsibilities less stressful (Pearlin, Mullan, Semple, & Skaff, 1990; Schulz, Obrien, Bookwala, & Fleissner, 1995).

Length of caregiving experience was the only caregiving factor that significantly predicted profile membership. Specifically, participants in the poorly functioning group had less caregiving experience than caregivers in the optimally or suboptimally functioning profiles. Adjusting to the caregiver role can be challenging. New caretakers might cope less effectively with the difficulties involved in looking after a person with dementia. It has been shown that caregivers with more experience attain more psychological benefits (Hogstel, Curry Cox, & Walker, 2005), as they develop more adaptive strategies to combat stress associated with caregiving (Charlesworth et al., 2017; Greenwood & Habibi, 2014).

Finally, results indicated a clear pattern across groups in social support indicators: the optimally functioning group reported the most extended social network, most social provisions, and the lowest level of loneliness. The poorly functioning profile was characterized by the lowest value on all social support variables, whereas the suboptimally functioning group scored in-between. According to the conceptual model of Alzheimer's caregivers' stress, social support is a key mediator in the psychological adjustment of caregivers (Pearlin et al., 1990). Social support not only acts as a buffer but also prevents the development of secondary stressors. Our results provide support for the model showing that dementia caregivers with optimal psychological functioning have a wider network and access more social provisions. Although the poorly and suboptimally functioning groups could not be distinguished based on social contact and provisions, loneliness emerged as a significant predictor. Results indicated that caregivers with poor psychological functioning were more isolated and lonelier than those in the suboptimally functioning group.

In sum, of the three domains tested in this study, social support (measured in the form of contact, provisions, and loneliness) was the best predictor of psychological profiles. Caregiving factors had a weak predictive power with only caregiving experience significantly differentiating among profiles. Socio-demographic characteristics were better at predicting profile membership but this was driven mainly by differences in SES.

Implications for interventions

The relatively high ratio of participants reporting poor or suboptimal psychological functioning highlights the importance of developing interventions to distinguish between different profiles of caregivers, and, thus, identifying vulnerable or ‘at risk’ groups within the caregiver population. Former publications have emphasized the importance of identifying factors impacting wellbeing that are changeable, as they can be the target of effective interventions (Alves, Teixeira, Azevedo, Duarte, & Paul, 2016; Gitlin et al., 2003; Pinquart & Sorensen, 2004; Wennberg et al., 2015). While SES is hard to influence, recognizing its effect on wellbeing outcomes is important to find the best-fitted way for support.

Caregiving responsibilities had the weakest influence on psychological functioning. The only factor that significantly differentiated among profiles was caregiving experience. Neither frequency of caregiving nor care-recipient characteristics were predictive of profile membership. This suggests that it is not the intensity of caregiving that can be harmful but the lack of experience dealing with the associated burdens and challenges. One way to enhance the wellbeing of new caregivers is by providing them with necessary information about the difficulties and challenges they might encounter, by helping them develop adaptive strategies, and by ensuring they set realistic expectations.

Seeking instrumental and emotional social support has been shown to be effective coping strategies to deal with the burdens associated with dementia caregiving (Beinart et al., 2012). Our results indicated personal contact, loneliness, and strong social provisions as the most important contributing factors to psychological functioning. Development and mobilization of social networks should be emphasized as core facets of interventions for dementia caregivers. They can incorporate psycho-educational and training elements, along with more informal forms of provision. Dementia is still a stigmatizing condition, which might discourage caregivers to participate in intervention programmes (de Vugt & Verhey, 2013; MacRae, 1999; Werner, Mittelman, Goldstein, & Heinik, 2012). Support groups can be helpful by reminding caregivers that they are not alone in their challenging role. Previous studies have highlighted that interventions should be delivered based on the individual needs of caregivers (Schulz et al., 2003). Our person-centred analysis aimed to contribute to this approach. By profiling caregivers based on psychological and social characteristics, tailored interventions can be offered.

Limitations and strengths

Firstly, dementia is a progressive disease and we had no information about the clinical stage of the care recipient's condition, which can have a substantial influence on the caregiver's wellbeing. Secondly, our analyses were cross-sectional; therefore, we cannot make conclusions regarding causality. Although social support is likely to predict better health outcomes, it is also likely that those with higher levels of wellbeing can mobilize their social networks more effectively. Longitudinal studies are needed to better understand the directionality. In addition, follow-up qualitative investigations with individuals from each profile could provide valuable insights into the role of social support and other potential protective or risk factors not assessed in the present study. Finally, caregiving can be a chosen or forced role. Self-selection for any volunteering activity, such as being an informal caregiver, has been shown to have positive effects on wellbeing (Charlesworth et al., 2017; Morrow-Howell, 2010).

In this study, we focussed on three domains that previous research has investigated in relation to dementia caregiving: socio-demographic, caregiving, and social support factors. Individual difference variables, however, might also play a significant role in caregivers' psychological wellbeing. For example, in the New Zealand context, Dulin and Dominy (2008) have demonstrated that the mental health of caregivers of people living with dementia was predicted by their attitudes toward the caregiving role. Having a prosocial orientation predicted more positive affect in older caregivers.

The main strength of the study lies in its person-centred approach, which allowed us to differentiate between vulnerable and healthy groups of dementia caregivers and provide a more comprehensive picture of their different experiences. In addition, the study provides further evidence for the role of social support above and beyond demographic, socioeconomic, and caregiving-related variables. Our study was limited to older caregivers living in New Zealand. The way people experience and cope with being a dementia caregiver can be influenced by social climate, cultural values, or policies around aging, health, and care. It is possible that research conducted in other socio-political and cultural contexts would explore different configurations or identify additional psychological profiles of dementia caregivers. However, our study highlights that by exploring subgroups of individuals with similar psychological profiles, we can gain a better understanding of the heterogeneity of the caregiving experience.

Conclusions

Although the idea that providing care is not necessarily harmful for wellbeing is not new (Kinney & Stephens, 1989), research investigating the positive and negative effects of caregiving simultaneously is very limited. We believe that our person-oriented approach to identifying different patterns of psychological functioning and their correlates in dementia caregivers contributes to a better understanding of the mental health impact of caregiving and to the development of tailored interventions. Three distinct psychological profiles emerged based on dementia caregivers' self-reported mental health, life satisfaction, depression symptoms, and quality of life. These profile configurations suggest diversity in not only how individuals appraise their caregiving role but also in the ways caregiving difficulties impact people's mental health and wellbeing. How to provide appropriate care for the growing number of dementia patients has become a key question for policy in countries with ageing populations. Our study highlights that we need to be cautious with one-size-fits-all solutions when tackling the issue of caregiver mental health and wellbeing.

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3.2.3. Demencia és társadalmi fenntarthatóság²⁴

Dementia and social sustainability

Abstract

Dementia is a group of symptoms leading to the complete loss of ability to perform everyday activities, and it's affecting more and more people in aging societies like Hungary. Considering that it is not a curable disease, caring for people living with dementia is not primarily the responsibility of the health care system, but rather the social care system and the families. This is reflected in the cost ratios for the various forms of supply. However, from the perspective of society, not only economic factors are relevant. Dementia, as well as the challenge caused by other neurodegenerative diseases - although apparently affecting only one family - affects the whole society, and many countries have already drawn up an action plan and even evaluated the results of the first programs. An indispensable part of maintaining individual and social well-being is a systematic, experience-based treatment of the problem of a disadvantaged community, especially if it has an intergenerational effect, as in the case of dementia.

Introduction

Dementia is a syndrome, which can be caused by several diseases, pathological processes. The well-known element about this syndrome is forgetfulness but in fact it is a complex disorder of the ability of thinking, which continuously leads to the mutation of making decisions, judgments, paying attention, the decline of learning skills, as well as the morbid change of one's behaviour and personality, followed by physical decline, a disabled lifestyle and finally leads to a complete loss of self-sufficiency. In most cases Alzheimer's Disease is the cause of symptoms, but also stroke or chronic cerebral blood flow disorders can stand behind development of dementia. It may be associated with a neurodegenerative (characterized by the decline of nervous system) pathway (for example Parkinson's disease), in addition it may have other origins. As in the international classification system of mental disorders (DSM - Diagnostic and Statistical Manual of Mental Disorders²⁵) marked in its fifth version, released in 2013, the clinical approach – beside etiology – focuses on symptoms and their severity. Dementia, according to the latest classification, belongs to a new group, called “neurocognitive disorders”. Cases with mild symptoms belong to another group of conditions, which expresses the viewpoint that dementia is not a syndrome which appears without antecedent (American Psychiatric Association, 2013). Changes in clinical nomenclature reflect the efforts to show that symptoms are on a severity spectrum, where transitions between levels are not strict, at the same time the severity of the condition has the major importance in determining the required level of

²⁴ At the request of BCU Doctoral School, full text of article is embedded - in unlectored translation of Fekete, M. (2019b). Demencia és társadalmi fenntarthatóság. *Esély*, 30 (2), 31-53.

²⁵ <https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/dsm-5-fact-sheets> (2019. 03. 26.)

care. In case of mild cognitive impairment, the aim is to recognise the condition as early as possible, thereby identifying the possibly treatable cause, however in the case of the severe form, the purpose is assessing the need for care. Initially, the daily routine is even sustainable with compensatory tricks through the progression of dementia or rather the advance of cognitive disorder till then the associated behavioural, psychological, and physical symptoms, the deterioration of physical condition lead to the loss of self-sufficiency (Gustafson, 1996).

There is a potential increase in the incidence of dementia as age increases, as follows: ageing societies - such as Hungary - must expect an increase in the number of people living with dementia. The status accompanied with cognitive dysfunction among the elderly is not correctable with aids, against the other functional - sensory and moving - limitations, therefore missing functions lead to a gradual increase in the need for care. All of this is a great challenge for social sustainability, as maintaining quality of life means great difficulties for both people living with dementia and their family members, all those who care for them, the informal carers.

Societies face a foreseeable, predictable and consequential challenge, related to dementia. Countries with a similar ageing rate to Hungary, possess strategy to handle this issue. France, which is a leader on this topic, announced their first „Alzheimer Plan”, at that time, the proportion of the population over the age of 65 was 16 percent²⁶. Nowadays in Hungary, people over the age of 65 account for 19 percent of the population.

The word of “strategy”, inherited from the military, refers to plans developed to deal with challenges. Action plans are characterized by analysing the situation (confirmed by research), defining milestones, monitoring and measuring achieved results. The development of a credible, convincing theoretical background and the collaboration between specialties, decisions made on the basis of continuous consultation and consensus, lead to results. In case of dementia, beside the medical and social area, the societal and economic considerations also play a significant role, in order to let the social sustainability prevail.

Demographic background of dementia

Incidence of dementia, along with other processes with functional limitations affecting the elderly, is increasing with age. According to researchers, not excluding the role of other factors, dementia is considered to be one of the most common coefficients in the loss of self-sufficiency among older people (Wübker, 2015). Ageing populations, such as Hungary, should follow the needs of elderly with high priority, as their proportion in society gradually increases. The involvement of the whole society comes from not only the natural connection between generations, from the family ties, but also the new challenges that need to be accomplished on a social level, caused by the drastic change in proportions of age groups.

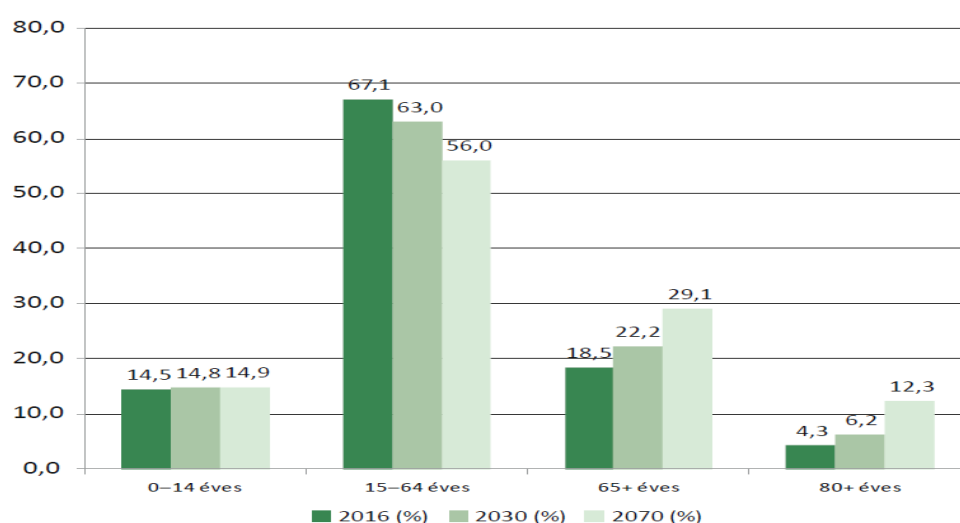
The latest European Commission study published in 2018, investigates the ageing of the population on the level of projections, is based on Eurostat’s 2015 demographic forecast

²⁶ Source: OECD (2019), Elderly population (indicator). doi: 10.1787/8d805ea1-en (2019.03.01)

(EUROPOP 2015)²⁷. The 2018 Ageing Report: Economic and budgetary projections for the 28 EU Member States (2016-2070), affecting five areas, provides economic and budgetary forecasts - based on demographic trends – for 28 members of the European Union, till 2070. These are retirement benefits, health care, long-term care (LTC), topics of education and unemployment which are directly or indirectly attached to social sustainability. The issue of healthcare and long-term care is directly linked to the issue of dementia, since it is a condition that constantly deteriorates and can be hardly influenced by medical treatment, it's a condition requiring regular monitoring and decades of care may be required. At the same time, due to the serious case of dementia, it affects the micro-communities of society and families. Living conditions and quality of life of those who look after a family member living with dementia, even if they are in employment or who have already retired, are exposed to a possibility of significant changes.

Even the most optimistic forecasts describe Hungary's population as decreasing: by 2040 the population will fall below 9.5 million, and by 2070 it is expected to be below 9 million. As the result of three determinants - fertility rate, migration, life expectancy - estimates are made, in connection with the population. Although the fertility rate is expected to increase sharply, expectedly it will not reach the minimum level which is necessary to maintain the population. Population growth due to migration is projected to be low in Hungary. The increase in life expectancy is estimated to be significant: over the next half century, men are expected to have an 11-year, while women a 9-year increase in life expectancy, by 2070. Life expectancy growth is also expected among the older population. While nowadays, when a man reaches the retirement age, has 14.9 more years expected to live, a woman has 18.7 additional life expectancy at that age. By 2070, members of this age group will live on average for another 22 or more than 25 years. Thus, the real demographic challenge also in Hungary - as in many countries of the European Union - will be caused by a significant change in the age distribution (Figure 1.).

Figure 1. Population of Hungary by age groups 2016-2070



²⁷ <https://ec.europa.eu/eurostat/web/population-demography-migration-projections/population-projections-data> (2019. 02. 25.)

Tendency shows a significant decline in the proportion of active age group, opposed to an increase in the proportion of the elderly. Even with an increasing fertility rate, the proportion of youth class is expected to stagnate. In terms of dementia, also relevant information, that rate of people over the age of 80 will increase from 4.3 percent to nearly three-times, 12.3 percent, as the prevalence rate of dementia in this age group may exceed 10 percent (Prince, 2013).

The relationship between the extents of different age groups is an economically and socially important predictor of demographic trends. Dependency rate shows the proportion of people aged 65 or more, and those who support them, so-called active population or people at working age (15-64 years). This rate provides important information on the sustainability of the functioning of social welfare systems and the possible burden on the potential working age population in connection with the „dependency”. According to the European Commission’s forecast, in the case of Hungary, this dependence increases from 27.5 percent to 52 percent, nearly double. Dependency rate of the oldest old population (over age of 80) – their proportion compared to the active population (aged 15-64) - shed light on more formal and informal care needs. It is thought that the 6.4 percent rate marked in 2016, will increase to 22 percent by 2070. Looking at the predictable change in the age structure from the issue of dementia there are two ways to look at it in terms of „dependency”. On the one hand, the person affected by the disease will not be an active revenue-generating, even if he or she belongs to the active age group. However, this loss of income often affects not only the person suffering from the disease but also his or her relatives – husband, wife or grown-up child. On the other hand, an active-age person who gives care for a person, suffers limitations in working ability. It is not uncommon that with older generations, a family member who is already retired takes part in care. In this case, „dependency” is turning into the opposite direction. Furthermore, there is a question of the obligation of monetary redemption of care, or the redemption of spare time, while this activity substitutes public duty of the state. The distorted macroeconomic perception of informal care is not only highlighted by personal cases. As an example of the „ruthlessness” and "fail" of GDP, informal care can be cited (Kerekes, 2009), as household activities - child rearing, washing, cooking, cleaning, etc. - that are invaluable to the family, are not functioning on a market basis, and do not generate income, as follows these are not included in the GDP calculation. Thus, this usually unpaid, but at the same time extremely important, burden-saving, voluntary activity for the society, does not appear in this macroeconomic indicator.

The urge of adaptation of health system

Increased incidence of dementia or mild cognitive impairment, together with other neurodegenerative conditions are merely some of the reasons why care systems must correspond to new challenges due to ageing populations. Exact data on the number of people living with dementia is not available, as early diagnosis is not accessible to all people affected, even in developed countries. A comprehensive study based - in part - on quantitative meta-analysis, estimates that 5.7 to 6.92 percent of people over the age of 60 may be affected by dementia in Europe (Prince, 2013). Incidence over age of 80 is more than 10%, over age of 90 at least one third of men and nearly half of women live with

cognitive disorder. Based on pan-European and regional estimates, the number of people living with dementia in Hungary may be at least 150,000. Alzheimer Europe²⁸ 'umbrella' organization's report, published in 2013 (Alzheimer Europe, 2013), was the last, when they reported concrete, country-specific prevalence data, which also converges to 150,000. Experts estimate 150-300,000 people living with dementia in Hungary (Kovács, 2016), so the number, at least 150,000 can be considered as well-established and confirmed data in several ways. It should be noted that Alzheimer Europe's latest published yearbook, named *Dementia in Europe Yearbook 2018 – Comparison of national dementia strategies in Europe* (Alzheimer Europe, 2018), highlighted that a significant proportion of dementia strategies support research, and determining the prevalence is one of the first tasks. The real incidence of the syndrome and the severity of the problem are still not clear, and probably underestimated. Ageing and the consequent decline of functions, on the one hand must shift the focus of acute care to chronic care, on the other hand must enforce closer cooperation with the social care system. Hungary does not need to invent fundamentally new concepts when it comes to developing health policy principles and action plans on ageing, as it can build on the achievements of those ahead of us in recognizing the need for action. Reasonable adaptation can take advantage of elsewhere established right practices, experience in operating customized systems. For example, Japan, known as the "oldest country", was confronted with the result of the demographic boom after World War II, the problem of increasing caring needs of elderly, by the end of 1980s. As an answer, increasing institutional capacity for nursing care, and funding of nursing insurance was introduced in 2000 (Campbell, 2000a), based on the model of Germany implemented in 1994 and the Scandinavian care structure. Both in Germany and Japan, when special social insurance was launched, the proportion of people over the age of 65 did not reach 16 percent (Campbell, 2010b). In Hungary, as mentioned earlier, the proportion of the age group is currently 19 percent.

Therefore, care systems must face new challenges, as the proportion of older people and life expectancy increases. Diseases and conditions that indicate care, which emerge in older age - such as femoral neck fractures, tumours, brain events (stroke) or dementia - is increasing (Rechel, 2013). Consequently, the structure and financing of care needs to be modified. At the same time, it is not clear why the increase in life expectancy will lead to an increase in health expenditure. The Lancet study cited earlier (Rechel, 2013), also presents three theories that differently assess how the increase in life expectancy affects the incidence of disease and mortality, or whether the number of years spent in health or illness increases, or whether elderly live longer in a better quality. Different studies confirm different theories, which are due to the distinction in the variables and measurement methods chosen. We can expect answers from panel surveys of older population (for example ELSA²⁹, SHARE³⁰, TILDA³¹), where data collected on several occasions, provided the opportunity to answer the above questions. As there is no clear concept for determining the development of morbidity, the impact of the population

²⁸ <http://www.alzheimer-europe.org/>

²⁹ English Longitudinal Study of Ageing

³⁰ Survey of Health, Ageing and Retirement in Europe

³¹ The Irish Longitudinal Study on Ageing

ageing on health expenditure is not clear. According to De Meijer and his co-workers (2013), population ageing, to a large extent, indirectly leads to an increase in health expenditure through so-called social factors such as growing national income, medical technology, prices and wages. However, increased willingness to pay for care can also contribute to an increase in costs, which is not necessarily a problem if it is based on the principle of solidarity and serves to improve the health status. Technological development - even with increasing costs - can also be particularly beneficial if it results in reducing or eliminating the functional limitations of elderly. As a result, lower-cost home care can be prolonged, or even labour market activity could be extended. The direct impact of health care costs on the acute care side is moderately influenced by the ageing population, its impact on chronic care is more significant. The increasing demand for chronic care and long-term care also leads to higher costs, as labour-intensive services are less substitutable with developing technology. This can lead to cost increases but can also have a reducing effect, thus intensely determining the price of care, which will surely increase. The costs of social services, along the above logic, are mainly due to their labour-intensive nature, and the increased need for care. Of the primary care activities, people with dementia can access most of them only with the active involvement of informal caregivers, for example meals or help at home. Day care would be an exceptionally good option for relatives and informal carers of people living with dementia, for partial relief or to maintain their labour or community activity, and for preventing illnesses and burnout. The main block is the need of specialists - providing day care -, but also services specialized to people living with dementia, licensed institutional capacity, or rather the need for a particularly high proportion of qualified carers, as well as the lack of appropriate environmental conditions, and appropriate funding. People living with dementia and their carers – mostly after the depletion of informal caregivers -, need institutional long-term care, where high labour-intensive care and demand for more complex infrastructure lead to increase of charge. Access to social provision is also influenced by a special circumstance: the deployment of service is often not demand driven, but the operators and maintainers (municipalities, churches, NGOs) determine the capacity, and they try to operate an effective economic process (Goldmann-Gyetzvai-Mester, 2016).

The economic effects of dementia

Dementia, on one hand, has a significant economic impact, due to the increasing demand for care based on the principle of social solidarity and, on the other hand, to the financial losses suffered by the invalids and their families. The previous entails an increase in the cost of maintaining, operating and providing care facilities, while those people with dementia and the families caring for them may suffer a fall in their income and an increase in the case of financial burdens. Both approaches are relevant from the point of view of social sustainability, since in addition to the subjective perception of individual well-being, material living conditions are also determinative (OECD, 2011). The outlined whole cost spectrum is decisive, because it must be covered by society, on the principle of solidarity. In determining the desired, preferred form of care, such as whether providing more expensive institutional or lower-cost home care, careful consideration, a

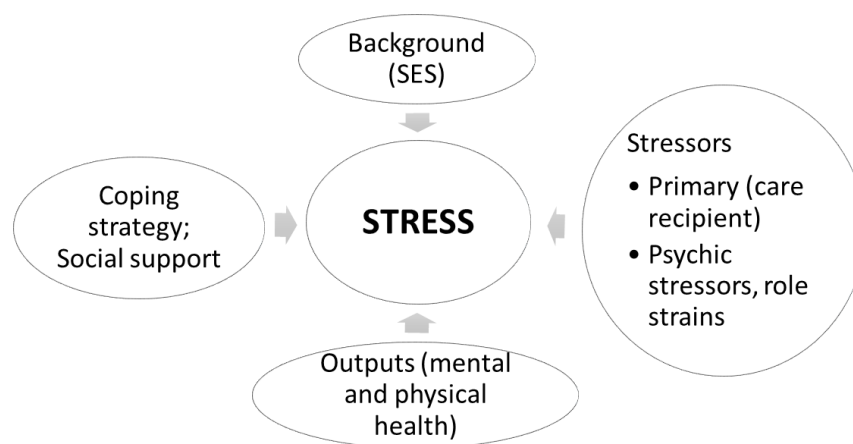
policy decision based one calculation should play a role alongside individual needs and capabilities. Within a service structure, governing policy must reflect the empowering of economic rationality, through regulators. To make decisions, knowledge of cost parameters is essential, thus the concept of burden of disease and cost-efficiency must prevail in case of dementia too (Gulácsi, 2012).

Costs can be divided into direct and indirect types according to how directly measurable they are. Direct costs are typically linked to official or formal care systems, accordingly, attached to health and social care, and are mostly based on official funding, therefore they can be calculated. Within this, the evolution of health care – primary care, outpatient and inpatient care - costs at different levels of progressivity and the different types of social – basic, specialized or institutional - care can be analysed in detail. However, indirect costs are related to informal, individually - not formal - organized care, so their definition is based on benchmarking or estimation, and influences the extent to which they can interpret related activities. In the case of people living with dementia, direct health care costs link to the use of the healthcare system, so the costs of inpatient or outpatient care, and the price of medicines are the main components. Given that there is currently no active substance in treatment of dementia, the overall treatment of dementia with medicines cannot be considered a significant cost factor, even if dementia is appearing as a symptom of another neurodegenerative disease. Dementia, as a leading diagnosis in inpatient and outpatient care, does not entail significant costs, given that only a small number of potentially affected patients are diagnosed. Most of the direct costs associated with dementia are costs of direct social care. These include the cost of formal services, provided by the social welfare system, such as the cost of catering, transport, living or nursing home care. Several home care services are funded in Hungary by the health insurance fund, while in other countries, this form of care is funded as direct social care, which makes the international comparisons problematic. Similarly, the classification of medical care costs varies. Caring for people with dementia is a typical example of the fact that health care and social care are often inseparable, not only at the funding, but also at the institutional level. It stems from the origin of establishing the solidarity-based welfare systems, where social security goes beyond the provision of health care. The need to take account of indirect costs has now been confirmed by numerous studies (Krol, 2015; Jönsson, 2009). A significant part of indirect costs is attributable to the informal care, provided by family members, acquaintances or other non-experts. This form of care is an increasingly important “contributor” to the welfare systems of aging societies, in which costs are made up indirectly of:

- Unpaid carer’s work - time-based approach: during which the carer cannot engage in any gainful activity; cannot do other work which is unpaid (for example housekeeping); but this also includes the cost of redeeming leisure time.
- Health damage caused by the carer’s voluntary nursing activities, or the cost of medical care or merely the costs of maintaining health.
- In connection with caring activity, the direct and indirect costs, from the purchase of supplies, the cost of providing consumable materials, supplies or even appropriate special meals, or any unofficial expenses where the “necessity” has not been considered, but the expenditure is complete.

Beside indirect costs emerging from individual perspective, societal costs are significant too, due to the dropout from labour market, and taxes and work-based contributions will drop away. Thus, the method of determining costs can vary, as it may be based on measuring the time spent on the activity, the intensity of care activity, in the level of mental strain, assessment of burden is not indifferent in measuring. The intensity of care can range from helped self-control to the more active help, from administration, through supporting the fulfilment of personal, everyday needs, or nursing-level activities. The theory developed about mechanisms of stress for caring for people living with dementia, takes these factors as unmodifiable, since these stressors are determined by the patient (Figure 2) (Pearlin,1990).

Figure 2. Components of stress caused by caring activity (Source: own edited; based on Pearlin,1990)



Krol's (2015) research confirms that informal care is a significant cost and points out that the caregiver may suffer not only financial but also physical and mental health burden and damage. They have also been found to have progressive neurodegenerative disorders (such as most conditions leading to dementia) characterized with an increasing need of care from time to time. Moreover, the care process often takes decades, making informal care particularly a challenging task, opposite to other diseases that cause shorter caring time. Informal care is a complement to well-being systems and characterized by intent and need. For today it has been proven that informal care contributes significantly to social well-being (Krol, 2015). Given its impact on those who care for people living with dementia, welfare systems must include their protection. Considering that people with dementia need the help of one or more informal caregivers daily - if they don't partake in permanent institutional care -, they must get a prioritized role in any action plan for dementia. The range of people who meet people with dementia, and whose quality of life is affected, is even wider. Relationships are extensive, and may be worth exploring at a regional, community level (Fekete, 2017a). Besides the not-surprisingly important social and medical care, family background, as well as the availability of information, amount of available knowledge, related to this, stigmatisation, exclusion, rejection facing the disease/patient proved to be a pronounced factor determining individual well-being.

International organisations, interests, and sharing of knowledge

The World Health Organization (WHO) declared in 2008, dementia is a condition which “deserves priority” (WHO, 2008). The diseases that need attention appear as typically high mortality or costly, emerging in the developed world, or affecting a lot of people in the developing world, usually infectious diseases, often of high mortality. The reason for listing dementia is the fact that the majority of cognitive disorders do not have a therapy which can lead to healing. Medical treatment expected only to reduce the deterioration of the condition. These would be of great importance if, in this way, the autonomy of the person with dementia could be preserved for a longer period of time in as many parts of functions as possible. In June 2018, the WHO published a paper, titled "Toward a Dementia Plan: a WHO guide" to help Member States act (WHO, 2018a). Prior to that, the action plan adopted in May 2017, entitled “The Global Action Plan on Public Health Response to Dementia 2017-2025” (WHO, 2017), identified seven areas that should be the focus of action:

- Dementia, as a priority of public health
- Raise awareness - awareness of dementia, “dementia friendly” approach
- Reduce the risk of dementia
- Diagnosis of dementia, treatment – caring and assistance
- Supporting carers
- Informing
- Research and innovation

The guidance of WHO aims to implement first the focus on action, prioritization. “The Global Dementia Observatory” - which is also the work of WHO (WHO, 2018b) - is related to this initiative, and was created with the intent of sharing data and knowledge in 2018 to assist decision makers. The action plan also takes into account the sustainable development objectives (Sustainable Development Goals – United Nations General Assembly resolution 70/1³²). According to this, all human beings must be given the same opportunity of dignity and equality. It is also in line with “United Nations’ Convention on the Rights of Person with Disabilities”³³. Extensive consultation has taken place to work on an action plan: with WHO member countries, UN organizations, NGOs, the delegates of private sector, charities, academic institutions, and with people living with dementia, their carers and family members. In line with sustainability efforts, it takes a summative and multisectoral approach, including the phasing of social and health care systems, with the specific objective of ensuring well-being and taking a holistic view of prevention, treatment, rehabilitation and care. The plan defines concrete actions and proposes indicators and targets. It sets out guidelines that can be used to develop dementia policies at country level, helping to align them with given health care structures, non-communicable diseases, in the case of elderly and disability strategies. To produce a

³² United Nations, 2015. Transforming our world: the 2030 Agenda for Sustainable Development <https://documents-dds-ny.un.org/doc/UNDOC/GEN/N15/291/89/PDF/N1529189.pdf?OpenElement> (2019. 03.31.)

³³ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities>. (2019.03.31)

‘dementia plan’, it sets out three practical steps that are considered necessary, beside the theory and specific practices of countries. Activities of each section:

- Section A - Preparation of the plan
There are two main steps in the planning phase. One is analysis of the situation, other is identification of priorities. Analysis of the situation should include an assessment of the needs, demands and health of those living with dementia and their caregivers, family members and all who is involved, as well as an assessment of the defects in care, systemic capabilities, resources and procedures. This is followed by prioritization based on the exploratory work of situational analysis to determine in which order the topics and objectives should follow each other due to importance.
- Section B - Improvement of the plan
Development phase is based on the facts collected during the planning process, which serve as a basis for defining the scope and expansion of the plan, so that priorities in effect form a unitary whole. Defining a frame means recording what to call for, what is the plan and what it can or cannot achieve. At this stage, 3 steps follow each other: outline the strategic framework of the plan, identify resource impacts, and approve stakeholders and policies.
- Section C - Realization of the plan
Realization is based on previous steps, accordingly the definition of areas of action and resources allocated to it. Three steps of this section follow the classic management functions: operational planning, cost allocation, monitoring and evaluation.

WHO aims to help all its member states promote dementia by moving forward a directive effectively, for countries with or without dementia plans and strategies, for those considering a separate action plan on dementia only, and for those who wish to integrate and implement related activity in an existing (for example health, social) program.

Alzheimer’s Disease International (ADI)³⁴, which was established in 1984 and connected with WHO, plays a very important coordinating and informative role in relation to dementia. They currently³⁵ have 94 member organizations, including Hungary, represented by the Society of Relatives of Persons Living with Alzheimer’s and other Dementia³⁶. The organization laid down the following objectives as an example in its 3-year strategic plan, issued in 2016: support for dementia globally and within member states to handle dementia as a priority health issue; reducing stigmatisation for dementia and carers by raising awareness attention towards dementia; supporting members to help better for those people involved; support research as well as in prevention, treatment and care. The organization first published its World Alzheimer Report in 2009, which has been published annually since then. Alzheimer Disease International (2010), in a report entitled The Global Economic Impact of Dementia, has already addressed the global

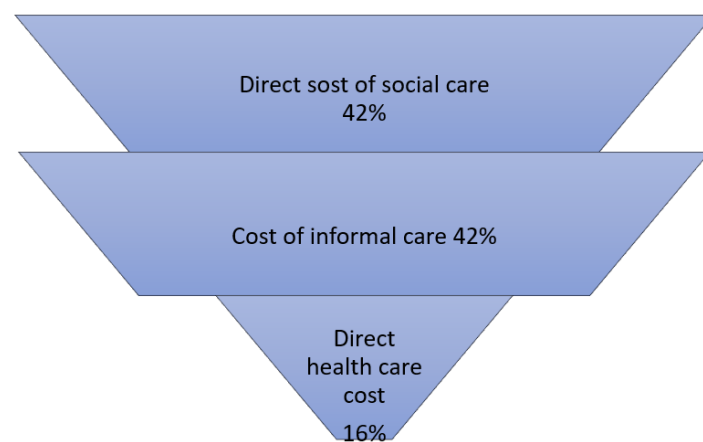
³⁴ <http://www.alz.co.uk/>

³⁵ <https://www.alz.co.uk/associations> (2019. 02. 23.)

³⁶ <http://www.alzheimerweb1.hu/> (2019. 02. 23.)

economic impact of dementia, and the conditions in countries with different economic status. The report identified dementia as a progressively increasing economic burden and highlighted that states must improve the access to provision and support therapeutic research. The report pointed out that while the most basic problem in lower-income countries is the lack of recognition of dementia, the higher-income countries are better off in recognizing the condition, however, the increased need for care and attendance is insufficient, and more and more patients remain without help. The importance of informal care was also highlighted when it comes to estimating the distribution of costs (Figure 3). While the cost of informal care is estimated to be the same as the cost of social care, the proportion of health care expenditure is minuscule.

Figure 3. Distribution of costs of dementia (Source: World Alzheimer Report, 2010.; own edition)



They also reported that according to their estimates, the share of informal costs is extremely high in low and middle-income countries, it can reach up to 58-65% of total cost, while social care costs are on a minimum level.

Alzheimer's Disease International makes seven recommendations in its cost-focused 2010 report to improve cost-effective care for people living with dementia. They raised governments to make a national program, an action plan to treat the problem of dementia. They remind decision makers and all-time governments to their obligations under international conventions to people with disabilities (Convention on the Rights of Persons with Disabilities³⁷) and to elderly (Madrid International Plan of Action on Ageing³⁸). The implementation of WHO's Mental Health Gap Action Programme³⁹, which aims to bridge the gap between care needs and opportunities, among others, could have the chance to improve the attendance for people with dementia. Also on the initiative of WHO (Innovative Care for Chronic Conditions⁴⁰), it is proposed to shift the focus of the healthcare system from acute care to treatment of chronic diseases, in view of, among other things, the ageing population, as required by the modified structure of the disease

³⁷ <http://www.un.org/disabilities/convention/conventionfull.shtml> (2019. 03. 31.)

³⁸ <http://undesadspd.org/Ageing/Resources/MadridInternationalPlanofActiononAgeing.aspx> (2019.03.31.)

³⁹ http://www.who.int/mental_health/mhgap/en/ (2019. 03. 31.)

⁴⁰ <http://www.who.int/chp/knowledge/publications/iccreport/en/> (2019. 03. 31.)

spectrum. In addition to treatment, it is needed to prepare for the increasing need for long-term care, and to develop plans, considering the circumstances of caring families. Furthermore, they recommend reviewing the social protection system to ensure that it serves adequately the needs of those living with dementia and those who care for them. They also encourage increased research funding for dementia, including the assessment of its social and economic impact.

In 2016 the issue of cost was again highlighted as one of the global effects of dementia (The Global Impact of Dementia: An analysis of prevalence, incidence, cost and trends. Alzheimer's Disease International, 2016). The cost increase was explained by three factors: the boost in the number of people living with dementia – due to the extension of life expectancy; rising the cost of care; and the growth in reaching diagnosis, which will eventually lead to an increase in the number of those affected. One possible way to control costs is so-called “task-driven care”, when the focus is not on specialized care, but on strengthening primary care to optimize the system and make it more efficient. The person responsible (case manager) for organizing care is also responsible for helping people with dementia, elderly people or anyone with a chronic condition. Organizing care that addresses needs preferably at primary level, will also be more person-centric, holistic, comprehensive and integrated, thereby will ensure better quality of care overall.

Another umbrella organization, Alzheimer Europe has 42 members from 37 countries (based on data updated in November 2018⁴¹), and contacts candidate organizations from another 5 countries, including Social Cluster from Hungary⁴². Since 2006 the organization has been publishing its summary, named “Dementia in Europe Yearbook”⁴³ which focuses on a different theme every year. The organization publishes national dementia strategies of many European countries on its website, which can serve as lessons and examples for those, who are even before this work.

Dementia Strategies – Patterns ahead

Besides WHO and international dementia umbrella organizations, the institutions of the European Union are also promoting to deal with dementia, as a strategic importance issue. In its July 2009 communication on “Initiative for Alzheimer's Disease and other dementias”⁴⁴, the European Commission encourages member states to develop a dementia strategy. The Alzheimer Europe publishes National action plans (National Dementia Strategies⁴⁵) on its website. According to the November 2018 update of the website, the umbrella organization is currently affiliated with 42 organizations from 37 countries, 36 of which are full members in 32 countries and 1-1 organization in 5 countries and a second organization in Bulgaria stands before the membership. The website provides information on dementia strategies or its preparations in 31 member states – of which four member states of the United Kingdom individually, and Belgium

⁴¹ <https://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/Our-members> (2019.02.23.)

⁴² <http://www.szocialisklaszter.hu/>

⁴³ <http://www.alzheimer-europe.org/Publications/Dementia-in-Europe-Yearbooks>

⁴⁴ <http://eur-lex.europa.eu/legal-content/HU/TXT/HTML/?uri=CELEX:52009DC0380&from=HU> (2019.02.23.)

⁴⁵ <https://www.alzheimer-europe.org/Policy-in-Practice2/National-Dementia-Strategies> (2019.02.23.)

of which Flemish and Walloon region is separate - , although data updates are highly variable, some have not been updated for 6 years.

The first European country to have made its dementia strategy was France. A 4-year strategy was announced in 2001, followed immediately by a 3-year program, which was adopted in 2008 for a 5 years program. Detailed evaluation of the third plan and the formulation of recommendations was followed in 2014 by the publication of the fourth, more comprehensive plan on neurodegenerative diseases. So, Alzheimer's Disease, Parkinson's disease and sclerosis multiplex were also included. The three key objectives identified here are: improving diagnostics and patient management; improving quality of life of people with disease and their carers; increasing and coordinating research activities. A new trend is the extension of action plans beyond dementia to other neurodegenerative disorders. This solution was chosen by Spain, which announced its first program in 2016, and England, which renewed its program in 2015: inspired research is not only extended to dementia but extends to all neurodegenerative disorders.

France was followed by the Netherlands in 2004, and their third program dedicated to 2020 is in progress. After two years of preparatory work, strategy, called Delta Plan Dementia, was announced in 2013. This name expresses recognition of the importance of the problem, as the "delta plan" was formerly known as a program designed to prevent a next natural disaster, such as the Great Flood in the Netherlands that happened in 1953. Next "wake" was Norway in 2007, a longer-term, 7-year program was already launched, and the focus on the current second 2020 strategy has appeared a creation of a new concept, which is increasingly referred to today, the creation of 'dementia- friendly' conditions. Norway has set itself the goal of creating a 'dementia-friendly society' just as Wales, most recently launched in 2018, already in its second plan. Malta, which announced its first program in 2015, has been applying the dementia-friendly attitude in practice, as it has published its eight-year program in a simplified, dementia-friendly version.

Countries launching their first strategy between 2009 and 2011 – Belgium, Denmark, Scotland, Wales – are already working on at least their second program. Finland uniquely defined its first plan, started in 2012, to a longer period of 8 years. Countries that came to proclaim their action plan in 2013 or thereafter – Austria, Czech Republic, Greece, Luxembourg, Italy, Ireland, Israel, Slovenia, Switzerland and Sweden – have already learnt a lot from those on the road, which is shown in targets. Thanks to Alzheimer Europe, we have access to dementia strategies of 22 countries and information on preparations in nine more countries. According to this, Bosnia and Herzegovina, Bulgaria, Cyprus, Gibraltar, Poland, Portugal, Romania, Turkey, Germany do not have a dementia strategy – although federal states (Bavaria and the Saarland) have announced programs with territorial scope in 2013 -, but some preparation could already be documented. In many countries these preparations have been going on for 5 or even 8 years. Information on work in other member states or candidate countries is not available through this source. Canada announced in summer of 2017 that it would soon develop a national dementia strategy. On this occasion, a summary has been published aiming to compare and review the previous 29 action plans to inform all those involved in dementia (Chow, 2018). Authors collected information from the Alzheimer Disease International

umbrella organization's website, including information⁴⁶ on dementia strategies. It should be noted that using other sources would have already led to more data about existing dementia strategies. At the same time, this was an exemplary work: collecting systematic information through overcoming language barriers, systematically sought information and revealed and communicated in detail. Thus, not only the date of implementation of the action plan, but also their main objectives and activities are described. As well as information on actors involved, contributors, the way which plan is implemented, and in a limited number of cases, financial resources allocated to such implementation were also registered, if these items were available.

Beyond Europe, most countries have come up with strategies after 2010. South Korea was one of the first in 2010, followed by the United States in 2012 with a specifically long-term program till 2025. Mexico, Australia, Cuba, Indonesia, Japan, Puerto Rico and Taiwan created their program between 2013 and 2016. Since then, Chile and Qatar have been among countries with strategies, based on the source of information for the Canadian summary. By the way, Canada has no government strategy - it seems to be completed by the winter of 2019. There is also a non-governmental ageing program in New Zealand. Also, there is a programme in India, which is young but has huge absolute numbers of older people.

The summary paper (Chow, 2018) identified five priorities that appeared in most strategies: raising awareness of dementia, developing support services, improving quality of care, improving professional training and promoting research. Reducing disease-related stigmatization/condemnation has also proved to be a priority and recurrent goal. Authors searched for information on which resources are assigned to implement the program and how it is realized. Both factors play a major role in ensuring that plans and if they might realize. It is also evaluated as a guarantee element if strategy includes milestones, target deadlines and if it prescribes how achievement and results are measured and evaluated. Furthermore, it was noticed, that out of 25 detailed action plans examined, only half (13 countries) have earmarked financial resources, and only six have marked specific funding for implementation. The "how to", the way of implementation, was the subject of a program only in 16 countries. Authors also explain that it is unclear why Canada has not yet developed a strategy for people with dementia. (In Canada, according to the 2016 census, proportion of the population over age of 65 was 16.9 %)⁴⁷. Raised as a background: counter-interests, political considerations, compete with other sources because of constrained sources of funding, potential role of stigmatization. Other potential cause can be the "ageism", age discrimination. My own work and the Canadian announcement summing up that there is now a well-established process for developing dementia as a social issue. In addition to governmental actors – central, regional, territorial – there is also a need for extensive cooperation between professional organizations, particularly health and social care providers. Participants from the civil sphere are interpreters of everyday problems of affected patients and families, and play essential roles in implementation of support activities, which are often identified as a priority in strategies.

⁴⁶ <https://www.alz.co.uk/dementia-plans> (2019. 03. 01)

⁴⁷ <https://www12.statcan.gc.ca/census-recensement/2016/rt-td/as-eng.cfm> (2019. 03. 01.)

Summary

Hungary is undeniably lagging behind in treating dementia as a social problem. Hungary does not have a government strategy in place. The awareness of world organizations is clear and not new. All countries, especially those that are more severely affected by the ageing of society, like Hungary, must have an action plan in place to ensure an aging society with a decent quality of life and a long life. Conditions that lead to dementia and other dysfunctions, consequent dysfunction of self-sufficiency, and then incapacity, can accompany the elderly for a long time, up to one and a half decades. Missing functions and abilities can usually be replaced by personal caregivers, technical tools only to support certain sub-activities - e.g. bathing, moving - are available, but in the course of everyday activities, the human factor, the "human voice", the deciphering, processing, reflection of emotions, and the justification of the meaning of everyday life are not possible without human consent. Caregiving, whether expert or lay, requires perseverance; research confirms the negative effects and their consequences. However, there are positive aspects to formal and informal caring activities, but for the latter they require special emphasis, recognition and support, while informal carers do not choose the job as a profession, but often they accept the situation and the role. The situation and quality of life of family members, caring relatives, informal carers are not accidentally highlighted in several action plans. The well-being of a caring family member also determines the quality of life of the cared for, so the impact of the care system is twofold. Given that different types of caregivers can be identified, in order to live their role well, they need different types of support, different interventions should be applied to address known stressors (Fekete, 2017b). This also means that not only people with dementia, but also those who care for them, must be "diagnosed", assessed, and given personalized, family-based support.

Recognizing the social importance of dementia and developing an action plan to ensure a dignified life for those affected is therefore of paramount importance to those who care for people living with dementia. Leaving them alone or providing them with adequate support and assistance in the caring role and their coordination with other roles have at least as much impact on the socio-economic situation of the country as the impact of the number of people living with dementia.

Existing strategies can provide guidance to countries that are lagging in many respects. In addition to designing programs, international knowledge sharing helps to monitor implementation, evaluate results, and set new milestones. Sharing research results can be a good example for policy makers and can act as a catalyst for the dissemination of good practices across countries. At the same time, interdisciplinary cooperation needs to take place in each country, even within its regions, as this will ensure that activities that truly serve the people and stakeholders concerned are defined and then launched. Complex support for families with dementia is key to social sustainability, and it is imperative that the improvement in the recognition of neurocognitive disorders, as a common strategic priority, results in a multiplication of needs toward the health and social care system.

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4. 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.

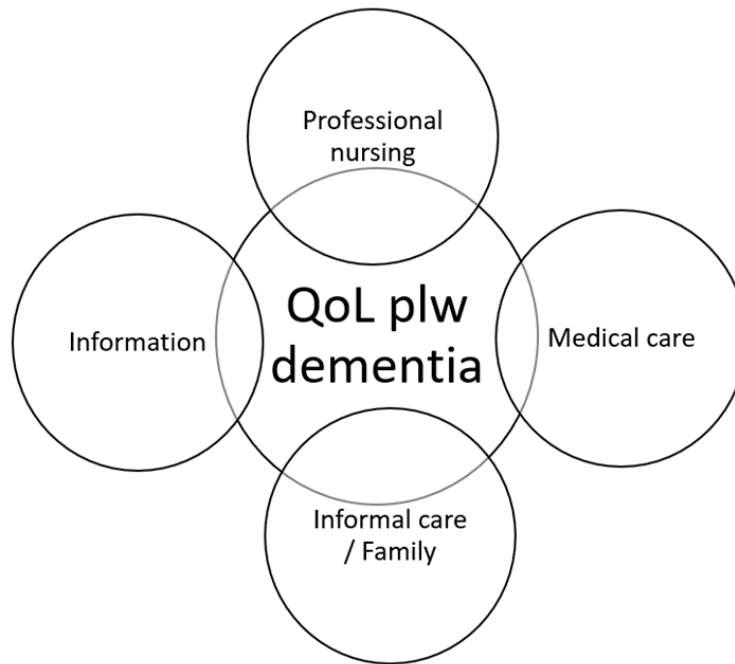
A special group of informal carers is the carers of people living with dementia. Dementia, a syndrome that gradually causes the affected patients to become unable to perform many

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.)

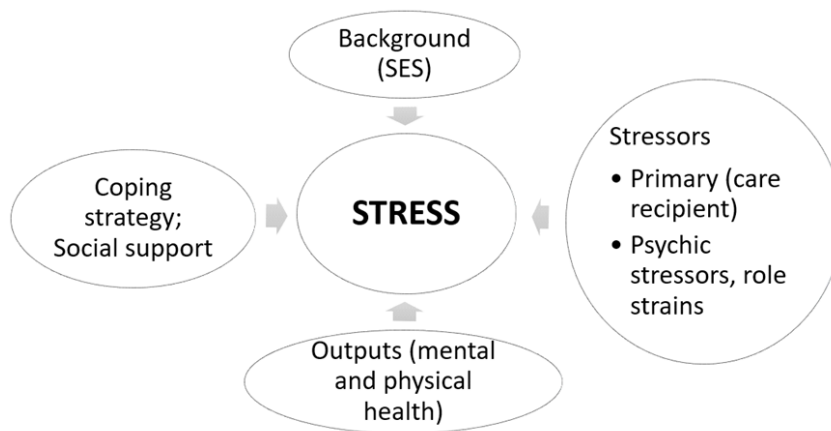


In addition to specialized nursing and medical care, information and relatives were identified as key factors. Compared with the main objectives set out in the action plans of countries with a dementia strategy, the result showed that a participatory system dynamic modelling approach is a good tool to 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.

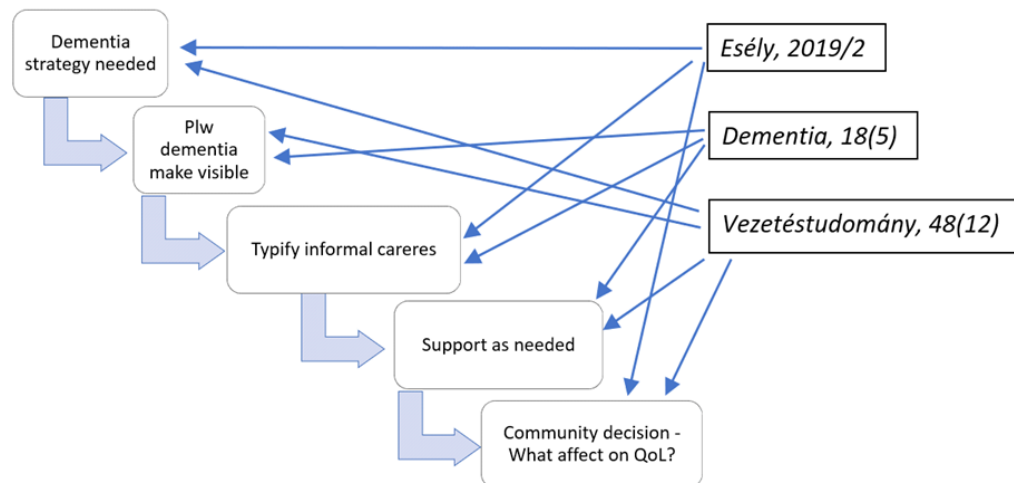
The motivation of my own research among the caregivers of people living with dementia was to discover the factors determining their well-being and psychological condition. As previous research has pointed out, some of the determinants of well-being can be influenced, while some attributes are not, or are harder to influence (Alves et al., 2016; Gitlin et al., 2003; Pinqart 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, 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.

Appendix I. – Citizen science and dementia

In her publication, Katalin Szabó (Szabó, 2013), describes the domestic definition of citizen science discovering international history, and discusses the definition of both "citizen" and "science". According to this, a civic participant can be either absolutely or relatively lay: absolutely / totally lay who has no university degree at all or, if any, a qualification that is irrelevant to the research being undertaken. Relatively lay people are defined as those who have professional experience in the field of research but have no scientific achievement, and who have never received scientific training. The field of research is usually one that requires a lot of "researchers" and many participants, as it seeks to collect, process and analyse large amounts of data. An example of citizen science from the field of dementia is the EyesOnALZ project⁴⁸, which began in early 2016 through collaboration with research centres hosted by, among others, Princeton, Cornell and Berkeley Universities, thus guaranteeing scientific background. In the same year, the game called Stall Catchers⁴⁹ was launched, which is a tool in citizen science. The aim of the project is to utilize the processing power of the lay crowd to find a way to treat dementia. Data analysis is thus "disguised as a game". Short videos of the blood flow of the cerebral blood vessels of mice are viewed by the "racers", who are lay scientists. Their task is to decide whether the blood flow of cerebral vessels is blocked, or not. The basis of citizen science⁵⁰ in this game is the fact that the development of Alzheimer's disease and other types of dementia is known to be associated with cerebral blood flow. However, the mechanism by which reduced blood flow leads to dementia is not well known. Researchers already have multiple databases with huge amounts of data, but their analysis is often not automated, so a lay researcher can play a role here. The player / researcher also receives so-called "practice" and "research" footage. The former has already been evaluated by experts, so if the competitor gives the correct answer, he or she will receive a very high score. At the same time, there is little reward for images being researched, not yet evaluated by an expert. Once the player has made a decision, they will see what the

⁴⁸ <https://stallcatchers.com/about#eyesonalz-1> (23/08/2019)

⁴⁹ <https://stallcatchers.com/about#stall-catchers> (23/08/2019)

⁵⁰ <https://stallcatchers.com/about#science-1> (23/08/2019)

"mass decision" is at that point in time. Based on the achievements so far, 7 lay answers are needed for a reliable "mass decision".⁵¹

It is estimated that the analysis of currently available data by professional researchers would take several decades, with the involvement of the masses of citizens by "crowdsourcing" (Szabó, 2013), this period can be reduced to years. This is of immense importance in researching a disease where the treatment target is currently unclear. As is known from the "game" online interface, there is no age limit for participation, and currently (August 2019) players are between the ages of 6 and 88⁵² and their numbers are over 20,000. According to project promoters, the speed of data analysis has already been doubled by participants in the game, which has led to the optimistic conclusion that this could even halve the time needed to develop an effective drug against dementia. Thus, several decades of waiting can be reduced to 15 years, but once the number of participants reaches 30,000, therapy may be available within 2-3 years. Unfortunately, this estimation is unrealistic due to the complexity of drug development and the huge amount of time needed to step after finding the target (Kaitin, 2018).

⁵¹ As a registered competitor until August 26, 2019 (in 4.36 hours of play / lab time), I scored 83,287 points in the evaluation of 158 training and 183 researcher videos, during which I identified a total of 26 blockings. With this performance, achieving the 979th best result out of 20,430 users. The total score of competitor in the lead on this day is 1,764,763,232.

⁵² In my own experience, my minor children also enjoyed watching while I "played" and, with less inhibition than me, expressed an opinion more quickly as to whether blood flow was blocked on that particular detail.

Appendix II. – Relationship between type of care system and quality of life

The results of an own research with co-authors⁵³ - just before publishing - also confirm that correlation between public spending on long term care and quality of life values measured with the CASP tool (Higgs et al., 2003; von dem Knesebeck et al., 2005, 2007), used the measures of SHARE (Survey of Health, Aging and Retirement in Europe) study (Börsch-Supan & Jürges, 2005).

Three groups emerged when examining the relationship between long-term care expenditure per capita and quality of life. This three-partition differs somewhat from, but does not contradict, the four (Nies et al., 2013; Ilinca et al., 2015) or the two (Lamura et al., 2008) previously described by other authors. The difference is due to the coincidence of the so-called Central-Eastern Europe, which includes Hungary in earlier analyzes, and the family-based care system typical of the Southern European countries, and the formation of a common group. There is a sharp distinction between the higher income countries of the Northwest, which are characterized by 'universal care' and countries with 'standard care-mix'. The former is distinguished by the high level of formal care, where informal care plays a small or medium role, as opposed to mixed care, where informal care is somewhat more important (Ilinca et al., 2015). As a result of our research to explore the relationship between the quality of life of older people and the system of long-term care, three systems emerged: minimizing, optimizing or maximizing types were identified, and named after 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 "minimizing" group based on the quality of life assessment of older people. By the term "optimizing" we mean a mixed care system, while a "maximizing" system is a universal system providing the highest level of formal care with the most investment.

⁵³ László Patyán, Lajos Hüse, Éva Huszti, Péter Takács – all from University of Debrecen, Faculty of Health Sciences

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And finally, as a reminder, my motto, which I chose not only for the sake of the dissertation:

„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./*

I feel like I did it! Thank you for making it possible!