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HARDSHIPS AND DIFFICULTIES OF INFORMAL CARERS SUPPORTING PEOPLE WITH DEMENTIA

Abstract

As the population ages, informal care is gaining increasing attention from both researchers and policymakers. The term *informal carers* refers to family members, friends, or neighbours of people with dementia who provide unpaid assistance and support. This article is based on research data collected as part of a larger research project conducted in Slovenia between 2020 and 2024. The aim of this article is to explore the challenges faced by informal carers supporting people with dementia in Slovenia and to identify the main characteristics of informal care in this context, in comparison to findings from studies in other countries. The data source for this study consists of five interviews with people with dementia and five interviews with informal carers, conducted in various regions of Slovenia over the project's duration. The findings of the study are consistent with those of research from other countries. For instance, in Slovenia informal caregiving for people with dementia is predominantly carried out by wives and daughters, highlighting a significant gender dimension to informal care. The interviewees reported experiencing similar challenges to those faced by caregivers in other countries. In particular, managing the demanding coordination of informal care with jobs and other responsibilities, such as household chores and family care, was highlighted. They also reported psychological strains associated with this role, noting that its time-consuming nature deprives them of opportunities to care for themselves.

Keywords: informal care of people with dementia, hardships of informal carers, community care, reproductive work, social work with people with dementia

Introduction

The aim of this article is to present the findings of a study conducted as part of the author's doctoral research, focusing on the characteristics of informal care for people with dementia and the associated hardships and difficulties faced by informal carers in Slovenia. The article also aims to identify the key characteristics of informal care for people with dementia in Slovenia and to compare these findings, with a focus on the struggles faced by informal carers, with those from studies conducted in other countries. The article first presents statistical data demonstrating the increase in the number of people with dementia, and the corresponding rise in the number of informal carers. The theoretical section presents the various types of informal carer based on classifications by different authors. It highlights the main characteristics of informal carers for people with dementia, which differ somewhat from those of informal carers for other marginalised groups. The article also addresses *reproductive work*, including domestic household duties and childcare, as well as the concepts of *emotional work* and *shadow work*. These concepts are closely related to informal care, as the challenges faced in informal care often overlap with issues in reproductive work, emotional work, and shadow work, and vice versa. The methodological section outlines the period during which the research was conducted and the methods used for data collection. The results section focuses on the findings of the research and contextualises them within the framework of studies conducted in other countries. Based on the analysis, it can be concluded that the issues associated with informal care are similar across different European countries. In the conclusion, the article summarises the findings and presents recent changes in Slovene legislation related to informal care.

Longevity is a defining phenomenon of 21st-century society, as various factors contribute to increasing human lifespans. However, with increasingly longer lifespans, various issues typical of older age – such as disease, social exclusion, and poverty – are also emergent. Dementia is a major risk factor, posing significant challenges not only for the elderly but also for the organisation of various services (Mali, 2022). Dementia can be defined as a syndrome associated with a progressive brain disease. It is characterised by impairments in cognitive functions, memory, language, and orientation. Among all known diseases, dementia is currently the seventh leading cause of death and a major cause of disability and dependency among older adults globally. As dementia progresses, individuals require increasing assistance from others (World Health Organization, 2021; Slovene Ministry of Health, 2023). Today, over 55 million people globally live with dementia, and each year over 10 million new cases are diagnosed. The ageing of the global population is contributing to this increase in the number of people with dementia. In Slovenia, the exact number of dementia cases is not made available, due to the absence of a register. According to some sources, today there are approximately 40,000 people with dementia living in Slovenia, with 5% in institutionalised care and the remaining 95% in their home environment. This highlights the prevalence of informal care and indicates that the number of informal carers is quite substantial (Slovene Ministry of Health, 2016, 2023; World Health Organisation, 2017; Mali, 2022). It is estimated that, due to intense demographic ageing, the number of people with dementia is set to increase by nearly 60% by 2035. Globally, the number of people with dementia is expected to rise from 47 million in 2015 to 75 million by 2050.

In Slovenia, services for people with dementia are predominantly focused on institutionalised care. Though there is a lack of available data on people with dementia amongst those receiving social welfare, the Slovene Ministry of Health (2016, p. 22) estimates that approximately 40 to 50% of residents in elderly care facilities have dementia. In the last decade, new and revised concepts of work have been introduced, with social work emerging as the leading expertise in Slovenian elderly care facilities, spearheading innovative forms of care (Mali, 2019; Mali & Grebenc, 2021). During this period, modern care concepts have been developed, focusing primarily on identifying and addressing the needs, wishes, and expectations of individuals receiving care. The new approach has a focus on treating people as individuals, while allowing them freedom of movement. Nonetheless, according to the Slovene Mental Health Act (Official Gazette of the Republic of Slovenia, 2023a), people with dementia are still placed in secure units, which are available in 30% of elderly care facilities in Slovenia (Slovene Ministry of Health, 2016). In the sphere of institutionalised care some progress has been made, with the most significant change being the introduction of holistic care that considers the person's individual needs (Mali, 2019; Mali & Kejžar, 2019). Despite these advancements, shortcomings in quality of treatment have been identified across various elderly care facilities. Many older facilities are not spatially adapted, and their personnel standards do not align with modern work practices (Mali, Flaker, Urek, and Rafaelič, 2018; Mali, 2019; Slovene Ministry of Health, 2023).

In contrast to institutionalised care, there is *community care*. This can be understood in two ways: firstly, as a range of community services, including various long-term care options available in non-institutional environments, such as health services and community social work. Secondly, however, the term *community care* can also be understood in a broader context, encompassing the daily assistance provided by family members and neighbours – commonly referred to as *informal care* (Hlebec, Mali, and Filipovič Hrast, 2014). The term *informal care* typically refers to unpaid care provided by family members, friends, or neighbours to individuals who need assistance due to age, illness, disability, or dependence. Estimates suggest that 10 to 25% of people living in Europe already provide informal care; however, the definition of a carer can vary depending on the context. Studies conducted in Great Britain suggests that at least 60% of people will become family carers at some point in their lives (Zigante, 2018; Jegermalm & Torgé, 2023).

Classification of Informal Carers

Informal carers are not a homogeneous group and the literature offers several ways of classifying and defining them. Many differences can be observed depending on factors such as the carer's location, the type of work they perform, as well as the age and other characteristics of the person they care for. Hvalič Touzery (2009, p. 111) cites that family carers are individuals who either live under the same roof as the person they care for or separately to them, who are providing unpaid care to their relative. He categorises informal carers into *primary* and *secondarycarers.* Primary carers are those who hold primary responsibility for the care of the individual, while secondary carers assist the primary carer. In addition to relatives, informal carers can include acquaintances, friends, neighbours, and other individuals. Milne and Larkin (2023) classify informal carers based on their own characteristics (such as age and occupational status) as well as the characteristics of the person they care for (e.g., whether or not they have dementia). They describe individuals who are employed while also providing care to someone who needs their assistance as *working carers*. People who provide informal care to two generations within their family – both their parents and their children – are referred to as *sandwich carers*. *Young carers* are informal carers who are under 18 years of age. The majority of these carers look after their mothers. The percentage decreases in the following order: caring for one's father, sibling, grandparent, other relatives, and individuals who are not related. Informal carers who are over 65 years of age are referred to as *older carers*. These carers predominantly look after their parents and life partners. *Former carers* are individuals who have previously provided care to someone but have ceased caregiving due to the person they cared for either recovering, moving to another environment, or passing away. The final group they mention is the focus of this article – informal carers of people with dementia, or *dementia carers*. This group is predominantly composed of women – either life partners or daughters of people with dementia – a finding confirmed by the research conducted for this article. Jegermalm and Torgé (2023) conducted a large-scale quantitative study on defining informal carers in Sweden in 2021 and found that informal carers can be categorised into three groups. The first group consists of individuals who live with the person they care for; these are referred to as *co-habitant family carers*. The second group consists of individuals who do not live in the same household as the person they care for but visit them several times a day, daily, weekly, or at other intervals. These individuals are referred to as *non co-habitant family carers*. They termed the third profile of informal carers *helpful fellowmen*. These are informal carers who provide assistance to individuals who are not their relatives and who do not require complex care.

It is clear, then, that informal carers can be categorised based on their own characteristics (such as age and family affiliation), the characteristics of the individual they care for, and whether or not they live with the person needing assistance. Informal dementia carers represent a specific subgroup of informal carers, but they can also be further defined according to various aspects and characteristics, as described by the aforementioned authors.

Characteristics of Informal Care for People with Dementia

For people with dementia who are not in institutionalised care, it is often the case that they live in a home environment, though this is not always the case. As a result, a significant portion of the caregiving responsibilities falls on informal carers, who are predominantly life partners and adult children of the person with dementia. Informal caregiving for people with dementia often differs from informal care provided to individuals with other illnesses or disabilities. Many informal carers experience difficulties and various forms of distress while caring for a person with dementia. The biggest issue is the lack of familiarity with the nature of dementia as a condition, and the associated challenges. Researchers (Joling et al., 2010) report a lack of awareness regarding the rights of people with dementia. People are either not informed about or lack understanding of the rights and services to which they are entitled. Furthermore, people with dementia may exhibit behavioural issues, including aggression; this can be common in certain types of dementia. Therefore, issues may arise in the relationship between the person with dementia and their carer, as well as more broadly within the family as a whole (Zwaanswijk et al., 2013). Last but not least, informal carers often face the difficult decision of whether to seek institutionalised care for their relative with dementia, even though this decision is primarily that of the person with dementia themselves. The decision to move to an elderly care facility should ideally be made in agreement with all parties involved. This can lead informal carers to feel weighed down by the pressure of their heavy responsibilities, as well as the difficulties in balancing work with caregiving, emotional and mental distress, and frequent issues with sleep. These burdens help explain why partners of people with dementia are four times more likely to suffer from depression than individuals of the same age living with a partner who does not have dementia (Francke et al., 2017).

The lives of people with dementia and their informal carers are also impacted by stigmatisation. Like any other disability, dementia itself can become a stigmatising label that society attaches to individuals. Stigma, as defined by Goffman (1963), remains prevalent despite substantial efforts to raise awareness and inform the public about the disease (Slovene Ministry of Health, 2023). This stigma can lead to the social isolation of both people with dementia and their informal carers, as well as to feelings of shame and other impacts of discrimination. The stigmatisation of dementia stems from false beliefs and stereotypes about people with the condition, who are often falsely perceived as being confused and incapable of independent living. Often, this incorrect perception means that people with dementia avoid seeking help and participating in social activities due to the fear of being criticised or negatively judged. Such isolation diminishes their quality of life and makes it more difficult to detect the disease early (Kitwood, 2005; Innes, 2009). Stigmatisation also has serious consequences for informal carers of people with dementia. Despite their crucial role in the dementia care system, informal carers often face stigmatisation stemming from misconceptions about their role. The social environment often labels them as victims of their family member's disease, portraying them as trapped in a difficult and hopeless situation. Feelings of shame, guilt, and isolation are often experienced by informal carers of people with dementia, exacerbating their existing challenges. Stigmatisation can mean that informal carers avoid seeking help, which can lead to physical and emotional exhaustion and result in broader social consequences. The lack of support for informal carers can directly impact people with dementia by diminishing the quality of their care, given the interplay between carer and care recipient (Mackenzie, 2006). Stigma can also discourage family members of people with dementia from assuming the role of informal carer (Innes, 2009). For these reasons, international strategic documents (Alzheimer Europe, 2014; World Health Organisation, 2017) recognise the importance of addressing the stigma associated with dementia and informal care. These documents highlight the need for educational and informational programmes to challenge and dispel stereotypes and misconceptions about dementia. Moreover, it is crucial to provide greater support for informal carers – particularly in managing stress and emotions – and to improve accessibility to resources, services, and financial assistance. The social discourse on informal dementia carers must become more inclusive and avoid labelling; this would likely improve the quality of life of both people with dementia and their informal carers. In working against stigmatisation, it is important to promote understanding and compassion towards informal dementia carers. It is important to emphasise that people with dementia must be allowed to retain their dignity, and that informal carers are an irreplaceable element of society, deserving, as such, greater recognition and support (World Health Organisation, 2013; 2017). According to Jane Mali (2022, pp. 138–139), social work with people with dementia needs to be focused on three key areas: researching the needs of people with dementia; destigmatisation and anti-discrimination; and ensuring the participation of people with dementia in care processes. Anti-discrimination is a fundamental principle of social work. It involves addressing prejudice, and negative, disparaging attitudes – which often manifest as exclusion, labelling, and stigmatisation. Miloševič Arnold (2007) describes the role of social work in preventing discrimination. She states that, "… dementia is not only a medical phenomenon. This is because its consequences affect the entire personality of the individual with dementia, including their ability to function socially and their social network. Therefore, dementia presents a challenge even in the field of social work, as it involves extensive direct work with individuals with dementia and their support networks, which are crucial for the care of people with dementia. An important mission of social work is to prevent social exclusion and to counter all forms of discrimination against individuals and social groups. When discussing the social exclusion of people with dementia, we must also consider the social exclusion of their informal carers. Due to being overburdened, these carers often neglect their social contacts and become increasingly isolated from everyday life. The social exclusion of people with dementia and their informal carers is a critical reason for social work to take an even more active role in this area."

Conceptual Framework of Informal Caregiving

The work of informal carers can be understood through various conceptual frameworks. *Reproductive work* encompasses tasks related to caring for family members, maintaining the household, and providing for children. Although it is often associated with child-rearing, the concept is broader than this in scope. In fact, it includes all activities necessary to meeting the basic needs of the family, such as cooking, cleaning, tidying, running errands, organising household chores, and so on. Thus, reproductive work is closely related to informal care. The meanings of these two terms, reproductive work and informal care, overlap significantly and address similar issues. Reproductive work generally pertains to the care of the entire family – such as children, the elderly, or multiple generations – as well as household maintenance. In contrast, informal care specifically refers to the support provided to elderly individuals or those in need due to illness, medical status, or other personal challenges. These activities are crucial for the functioning of the household/family as well as for society as a whole, as problems in the family, as the basic social unit, are reflected in the wider dysfunctioning of society. Reproductive work is also related to the concept of *sandwich carers* – individuals responsible for caring for two generations within a family, typically their own children and their parents. However, reproductive work remains undervalued and unpaid compared to productive work or paid employment (Hrženjak, 2007). Reproductive work is closely tied to gender roles, both within the family and in society. Both reproductive work and informal care are mostly carried out by women. Often invisible and unappreciated by society, this work is essential to the daily lives and well-being of individuals and communities (Federici, 1975). Humer (2007) explores the informal caregiving activities performed by men within the life of the family. She argues that men's caregiving roles within the family context are primarily centred on providing material support to family members. Symbolically, men are viewed as a source of stability and reliability, in alignment with the patriarchal image of the man as the primary breadwinner. It is generally considered that men view caregiving primarily in terms of duty and obligation, rather than as an activity involving emotion, or *emotional work*. *Emotional work* is a concept that applies to both professional and non-professional caregivers. Šadl (2002) describes it as the process whereby the individual performing the work – whether formal or informal – must manage their emotions to present a specific facial or physical demeanour. Informal care for people with dementia often requires caregivers to regulate their emotions in various ways. Primarily, this relates to masking negative feelings arising from disagreements with the person with dementia or their challenging behaviour. Flaker et al. (2008) discuss the concept of *shadow work*, which is of relevance to a discussion of informal care for people with dementia. Shadow work encompasses those tasks informal carers perform that remain unseen and unacknowledged by others. This concept includes not only daily caregiving and emotional support but also the coordination of health and social care services and various household chores. The concept intersects with related concepts such as reproductive work and emotional work. According to Flaker et al. (2008), shadow work is vital to the functioning of the long-term care system because informal carers assume a significant portion of the burden that would otherwise be managed by institutional or formal care services. Shadow work highlights an inequality in that caregivers, who are predominantly women, often find themselves in economically and socially vulnerable situations due to their unpaid caregiving roles. It is essentially work that is crucial to people's livelihoods and well-being, yet which remains invisible, unrecognized, and unsupported.

When describing their responsibilities in caring for a family member with dementia, interviewees often highlighted tasks that extended beyond informal care to include duties related to family care, child-rearing and household maintenance. They described tasks that overlap with the concepts of reproductive and shadow work, and sometimes also emotional work. This reflects the considerable burden borne by the interviewees, who invest significant effort into supporting their family members. This work is frequently overlooked or taken for granted by society. Consequently, the efforts of caregivers are often unacknowledged and unrewarded, leaving them without adequate support.

Methodology

The research material for this paper is drawn from the project *Long-term Care of People with Dementia in the Theory and Practice of Social Work*[3], conducted in Slovenia between 2020 and 2024 (Faculty of Social Work, n.d.; Mali, 2022a; Mali, 2022b)[4]. The research project employs the *rapid assessment of needs and*

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[3] The paper is part of the project Long-term Care of People with Dementia in the Theory and Practice of Social Work (No J5-2567), co-funded by the Public Agency for Research and Innovation of the Republic of Slovenia.

[4] The research data will be utilised for the author's PhD thesis and is employed, in part, in this paper,

services method, which was introduced to Slovenia by the Faculty of Social Work at the University of Ljubljana. This method has become the primary approach for research in long-term care and deinstitutionalisation in recent decades (Flaker et al., 2019; Mali & Grebenc, 2021). It is a fundamental method for exploring the needs of various groups of people, contributing to the development of theory and practice in social work through a holistic and interpretive approach, while also allowing users to actively participate in research (Mali and Grebenc, 2018). The main purpose of this research strategy is to provide policymakers and key organisations with practical and actionable information to effectively address the needs expressed by individuals (Stimson, Fitch and Rhodes, 1998). A key feature of this method is its speed; it allows for a quicker collection of information than traditional empirical research methods. The method has demonstrated its ability to yield appropriate and effective responses (Flaker et al., 2019). Accessing people with dementia and their informal carers is a challenging task. In the research project, firstly statistical data was compiled and catalogued covering all the services in specific local environments/municipalities that interact with people with dementia and their family members. This is typical of the rapid assessment of needs and services method. Such services included medical and healthcare workers in local health centres and hospitals. The social workers who participated in the survey were employed in various settings, including social work centres, elderly care facilities, day care centres, home care coordination, and intergenerational associations. There were also some survey participants who did not have direct contact with people with dementia in their professional roles. These included representatives from municipal administrations, mayors, and their staff. Staff at various institutions provided the research team, with prior explanation and consent, with contact details for people with dementia or their family members/informal carers. Each individual was contacted separately to schedule an interview and provided with additional explanations as needed. The interviews took place in the interviewees' home environments.

For this paper, the current author has utilised research data from five interviews with people with dementia and five interviews with informal carers. They have also incorporated data from six focus groups that included informal carers, specifically focusing on their responses. The interviews were conducted in 2021 and 2022. The participants had diverse profiles. They lived and worked in various local environments across the eastern, central, and northern parts of Slovenia. The informal carers involved displayed a variety of characteristics. The researchers spoke to both women and men of various ages. Some were still working, while others

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which is a required component of their PhD studies at the Faculty of Social Work, University of Ljubljana.

were retired. Some people with dementia were living in institutional settings, while others were in non-institutional settings. While searching for relevant literature and reviewing the transcripts of the interviews and focus groups, two key research questions in particular began to emerge: 1) What are the characteristics of informal care for people with dementia in Slovenia? 2) What are the hardships and difficulties faced by informal carers of people with dementia? The author sought to understand what the work of informal carers entails, including the nature of their tasks (such as reproductive work and emotional work), the challenges they encounter, and the hardships they endure. Every conversation and focus group session was carefully transcribed. The transcripts were used to conduct a text analysis of the conversations and focus groups, using the qualitative analysis method described by Mesec (2009; Mesec and Rape Žiberna, 2023).The transcriptions were thoroughly reviewed, with relevant parts of the texts underlined and categorized, and variables assigned to each category. Relevant concepts and categories were collected based on the research questions. The data gathered through the analysis were organized into themes, which are described in the following section.

Results and Discussion

Characteristics of Informal Care for People with Dementia

In accordance with the classification of informal carers, our interviewees belonged to the various groups described above. Women represented the vast majority of the interviewees. All the interviewees were life partners or children of people with dementia, especially wives or daughters. It seems probable that the gender disparity in the number of interviewees was not simply a matter of male informal carers being harder to reach or less responsive to interview invitations. It appeared to confirm the thesis that both informal care and reproductive work have a strong gender dimension (Oakley, 2000; Humer, 2007; Hrženjak, 2007). The care of family members and performing of household chores in Western society predominantly fall to women; this pattern is also evident in the author's own research. Mali, Rihter, and Mešl (2011) state that the care of an elderly person is seldom undertaken by the entire family. Rather, the family appoints a caretaker for this role. Caretaking is thus unevenly distributed and tends to be concentrated on a single individual. The team did interview some male informal carers, but their number was significantly smaller. Again, these were the life partners and adult sons of people with dementia. The interviews with men were not significantly different from those with women, and in some cases, they were even more emotional. The son of a woman with dementia demonstrated extensive knowledge about dementia and effective communication with people with dementia. This expertise was gained through active learning, research, and seeking information while caring for his mother. It would be incorrect to definitively state that the gender of the informal carer influences the quality of care, whether material or emotional, or affects communication and attitude towards the person with dementia. Humer (2007, pp. 80-81) reports that men have increasingly become involved in caregiving, with more equal division of labour in recent decades. Humer also highlights the scarcity of studies focusing on men's caregiving activities outside of the immediate family context, particularly within the broader kinship network, which involves caring for one's own or one's partner's parents. Almost all interviewees were primary carers, meaning they were directly responsible for the care of a family member with dementia. However, in the interviews they described individuals who support them in the caregiving – that is, *secondary carers*. Secondary carers are primarily the adult children of people with dementia and their life partners. When asked about who supported her, the wife of a man with dementia responded, *"My sons are always available"* (S_2Ž_1M_I_01). The husband of a woman with dementia said, "*For my daughters, it is easier to be with their mother than it is for my son"* (S_2Ž_1M_I_01). All primary carers identified their children or grandchildren as secondary carers. The daughter of a woman with dementia spoke about the secondary carers and the stress she had experienced: *"My husband, my sister, and my friend have stood by me. But at that time, I would have needed a professional every day to help me interpret and reflect on the situation, my emotions, my sadness, my anger"* (S_Ž_55_I_03). The daughter of a person with dementia identified her husband, her two children, her mother's sister, and her sister's husband as secondary carers: "*These are all people who've helped me, asked me how I was. They spend a day or so with my mother so that I can take care of my other tasks, have a change of environment, have some time off, and rest. These are the details that count"* (S_Ž_65_I_11). The interviewee spoke about the relief provided by secondary caregivers, which is crucial for the continuity of informal care. The participants in the study were from various age groups. Many were over 65 years of age and categorised as *older carers*, while some were under 65 and still working, thus classified as *working carers*. Those in the working carer group reported challenges in balancing work commitments with caregiving responsibilities. They frequently had to explain at work why they needed to leave early or needed to take time off to accompany their family member to medical appointments. A significant number of respondents described that they not only provide informal care but also care for their children and the household, reflecting aspects of reproductive work (Hochschild, 1997), shadow work (Flaker et al., 2008), and emotional work (Hochschild, 2012).

Interviews with people with dementia themselves varied widely according to the impact of their condition and their current mood. It is important to note that the interviews were conducted during a single visit; this meant that the people with dementia did not know or trust the researchers, with whom they had had no prior connection. Many of them talked about their past experiences, significant aspects of their lives, family, hobbies, work and so on. They recalled details of the past well, while questions about the present or recent past were challenging to answer. In terms of informal care, they mainly mentioned who assists them, rather than detailing how they help or identifying the specific tasks for which they need the most assistance. All interviewees with dementia reported that their life partner and children assist them with daily tasks. This was also true for those in institutional care settings. For example, a man living in a secure unit of an elderly care facility remarked of his wife, *“My wife does everything. My wife is a real treasure”* (ČD_M_85_I_03). Interviewees reported receiving help with daily chores, cooking, eating, hygiene/personal care, and being accompanied to doctors’ appointments. A man with dementia living with his spouse in a village in the Štajerska region, when asked who helps him with his daily chores and in what way, answered briefly: *“My wife takes care of everything. My wife and sons, because they live close by. Other people don’t help me. Every morning, she bathes me and dresses me”* (ČD_M_74_S_09). Similarly, a woman with dementia who lives with her daughter’s family said, *“B does everything. I just clean up after myself. Everything else is done by B”* (ČD_Ž_79_01).

In interviews with informal carers, much discussion centred on the initial signs of dementia and the journey to diagnosis. Participants gave details of the process, noting variations such as whether the person with dementia was referred to a psychiatrist or a neurologist by their general practitioner. Most were referred to a psychiatrist, fewer to a neurologist, and some chose to self-pay for a neurology consultation. The answers indicated that diagnosing dementia through a neurologist involves a longer process, with more examinations and tests, compared to a psychiatrist, who typically provides a diagnosis after fewer visits, or even just one. Many interviewees noted that the diagnostic process can be lengthy, often taking several months: *“It took eight or nine months in total”* (S_M_0_I_15). The data reveal that people seek professional help relatively late, often when signs of dementia are already visible and dementia is already advanced. This delay highlights the strong stigma associated with dementia and that of living with or having a family member with dementia. For initial information and assistance, individuals most frequently turn to health centres or their general practitioners, rather than social work centres. None of the interviewees first sought help or information from social workers. This suggests that dementia is predominantly perceived through a medical lens, despite the fact that anti-dementia medication is generally not successful, and it remains a progressive disease with no return to baseline (World Health Organisation, 2021). The impact of dementia is largely social, affecting not only the individual but also their family members and close contacts. The consequences of dementia are directly related to the everyday life of the person with dementia, their social network and their relationships (Little, 2022). Social workers in social work centres and elderly care facilities are typically contacted later, when individuals are seeking institutional care placements, day care services, home assistance, or other entitlements. Most of the interviewees reported receiving valuable information from various lectures organised in their locality. Lectures, often held in elderly care facilities (such as Alzheimer's cafés), community centres, or similar public spaces, are primarily aimed at individuals who interact with people with dementia. Most of the interviewees reported receiving particularly valuable information from a variety of sources, including brochures and lectures by the non-governmental organisation Spominčica – the only Slovenian organisation dedicated to supporting informal carers of people with dementia. Their activities include hosting lectures, talks and themed evenings on dementia in local communities. However, the organisation states that public awareness campaigns are their main activity. Raising public awareness on the topic of dementia is a significant recommendation of international organisations such as Alzheimer Europe and Alzheimer's Disease International, as it helps to reduce societal stigma (Spominčica, n.d.). An informal carer, the son of a woman with dementia, remarked: *"...That's why I went to the lecture organized by Spominčica There, they provided us with a toolbox full of knowledge, which comes in very handy"* (S_M_0_I_15). Many interviewees also obtain information by reading books and browsing the Internet. It was somewhat surprising to learn that the interviewees only began to educate themselves about dementia and consider care options once the disease's symptoms were already quite evident, rather than beforehand. Most families do not proactively plan for elderly care or discuss with their parents and grandparents the circumstances under which they would seek out an elderly care facility or other forms of assistance. Few of them apply for institutional care in advance. Typically, applications for institutionalised care are made at the last minute, often when the family urgently needs a placement for their family member due to caregiver burnout or other pressing commitments. In these situations, families may face delays in securing a placement, or they may have to accept a space in an institution located far from their home. This underscores the continued stigma surrounding dementia and residential care within society. Many families only start looking for a place in an elderly care facility when they reach breaking point, feeling the exhaustion and the physical and emotional toll of informal caregiving.

Informal care for people with dementia includes managing medical appointments with general practitioners, psychiatrists, or neurologists, which requires significant time, effort, and organisation. Carers often have to take time off work to accompany the person with dementia to the doctor during working hours. Furthermore, people with dementia need to be driven to outpatient clinics, given that they are no longer able to drive. This can be a major obstacle when the family lives in a rural area, far from the clinic. Furthermore, coordinating with different professionals and navigating the bureaucracy involved adds to the stress and time commitment. This is work that often goes unseen and unappreciated.

Hardships and Difficulties of Informal Carers

One of the most surprising findings from the research was that several interviewees with relatives in elderly care facilities or attending day care reported that the burden of care did not significantly decrease after their loved ones started receiving formal care. They tended to visit their relative daily or several times a week in the elderly care facility. This can require the adjusting of responsibilities and the arranging of transportation, which cannot be taken for granted (either for the elderly person or for carers who are still working) and can present a significant obstacle. Additionally, bringing in necessary supplies and clothing adds a financial strain, even though they are already paying for formal care. Some interviewees also took their relatives with dementia out for walks from the care facility because walks are not one of the services provided in an institutional care. This is a task performed out of love for the person with dementia, yet one that remains invisible to society at large (Hrženjak, 2007; Flaker et al., 2008). Furthermore, they must also ensure they can make ends meet because the financial burden of institutionalised care is immense: *"I am completely subject to the regime of the retirement home. I have to make additional payments to the retirement home, too, and the amounts are staggering considering my pension. It's hard for me to give up so much of my pension just to keep my mother safe"* (S_Ž_65_I_11). Most elderly people do not have enough income to cover the full cost of formal care. One respondent shared: *"I take him to day care in Žalec three times a week. Honestly, pensions are small, and we can't afford more care days than this. We receive €150 per month in attendance allowance, which doesn't even cover half of the cost. We can't afford it every day. This is a great shame. The doctor recommended various vitamins and supplements, but I had to carefully calculate what we could afford. Unfortunately, we can only manage day care three times a week"* (S_67_S_18). These seemingly small tasks represent a substantial commitment and responsibility, which naturally introduces stress into the lives of informal carers (Fauth, Femia and Zarit, 2016). The burden of informal caregiving does not end when the relative with dementia moves into institutionalised care or receives other forms of formal support, such as home care or day care. On the subject of home care, the interviewees stressed that it is insufficient, as despite receiving a few hours of help, they are still under a great deal of pressure. One woman whose husband has dementia described her experience with home care thus: *"When my sons started urging me to opt for home care, I couldn't make up my mind right away... Eventually they convinced me, and we accepted the help. But then we realized it was only three or four hours a day, and the rest of the time I was on my own"* (S_Ž_73_S_07). While interviewees generally expressed positive opinions about day care and home care, they also noted that the services provided were insufficient to fully meet their needs. Formal assistance is clearly of value and helps alleviate the burden on informal caregivers. However, there are still gaps, as support is often unavailable during certain times of the day or on weekends (home care is typically not provided on Saturdays and Sundays), leaving informal carers to manage on their own.

Numerous studies, from a variety of countries, have explored the impact of informal caregiving for people with dementia on both the mental (Pinquart and Sörensen, 2003, 2006; Savage and Bailey, 2004) and physical (Pinquart and Sörensen, 2007) health of caregivers. The psychological toll of informal caregiving is frequently highlighted in research – more so, in fact, than the physical effects. Anxiety is the most commonly reported psychological symptom, with challenging behaviours and aggression in people with dementia often linked to the onset of depression among informal carers. Researchers have noted that caregivers experience significant stress during the caregiving period, compared to their lives before the onset of their relative's dementia. Interviewees reported all of the aforementioned problems. One interviewee described how the emotional strain of caring for her mother with dementia had exacerbated her physical health issues: "*I became ill at the time and had three breast surgeries. My own trauma was so intense that my mother's diagnosis only worsened my condition. Her dementia made everything so much harder for me during that period"* (S_Ž_65_I_11). Pinquart and Sörensen (2007) found that the most prevalent physical impacts of informal caregiving are hypertension and related cardiovascular disease, with muscle and spinal injuries also being common.

While none of the interview questions specifically addressed stigma, it became apparent from the responses that both people with dementia and their caregivers face stigma, exclusion, and discrimination. Informal carers encountered disapproval from acquaintances and neighbours for deciding to place their relative with dementia in institutional care: *"Some people were very critical. These remarks affected me deeply because I truly want the best for my family"* (S_Ž_49_S_19). The son of a woman with dementia, who had also been the informal carer for his grandmother and father, shared: *"People blamed me for putting her in a care home. They said things like,* 'I could never do that to my family, but you've placed both of them in a care home'. *Yes, I did, because it was the right choice. People around you see things differently. Unfortunately, not everyone in this world will understand or like you. People still foster a negative attitude towards retirement homes" (S_M_0_I_15).* In addition to these criticisms, interviewees reported that old friends often distanced themselves after the dementia set in, leading to reduced socialisation both for people with dementia and their informal carers.

Conclusion

Similar challenges in informal care for people with dementia are also seen in other countries besides Slovenia, including Scandinavian countries and other developed European nations, all of which allocate significant resources to long-term care. In particular, the difficulties in balancing work commitments with informal care and the stress experienced by informal carers of people with dementia have been well-documented (Zwaanswijk, Peeters, van Beek, Meerveld and Francke, 2013; Francke, Verkaik, Peeters, Spreeuwenberg, Lange and de Pot, 2017). Informal carers undertake substantial work, deserving of greater recognition and reward from official institutions. In Slovenia, changes were introduced in 2024 with the new *Long-Term Care Act* (Official Gazette of the Republic of Slovenia, 2023b), which marks a significant shift in the social welfare system. This Act allows for *family carers* to be officially employed, formalising informal care as a job. This change represents the most substantial intervention to date in the sphere of social welfare mechanisms, public health, civil society, and voluntary networks involving families and individuals since Slovenia's independence. The rights of the family carer role are defined by the new long-term care system in Slovenia, but it is not entirely new, as Slovenia previously had *family assistants*. The status of family assistants did not constitute an employment relationship, however. Thus, it did not include employment benefits such as annual leave, holiday pay or paid sick leave. The new system allows family carers to leave the labour market to care for a family member with an impediment and limited independence, with renumeration provided. However, a family carer can only be a relative who lives at the same address as the person in need of assistance. This move from family assistants to family carers is a major step forward in acknowledging the importance of informal care. The transition to family carers is noteworthy, as the monthly payment exceeds the Slovenian minimum wage (it is financed under the new compulsory long-term care insurance) and includes 21 days of leave (during which institutional care is temporarily provided) and unemployment insurance benefits if the family carer status is lost (Hrženjak, Mali, & Leskošek, 2024). However, some controversies persist. The right to a family carer is limited to individuals in the fourth and fifth categories, defined in the Long-Term Care Act (Official Gazette of the Republic of Slovenia, 2023 b) as those who cannot take care of themselves any longer and are completely dependent on others. This restriction may seem irrational given the significant physical and psychological burden involved in caring for such individuals, which often requires skills similar to those of professional carers. Additionally, family carers must complete 30 hours of pre-service training and 20 hours of refresher training every five years. They also have to maintain a care diary. These requirements add an additional (bureaucratic) burden. To support informal carers, the state should perhaps explore additional relief measures or streamline bureaucratic processes. Solutions should be found that take into account both the physical and mental well-being of informal carers and that acknowledge their efforts.

This research identifies the main characteristics of informal care for people with dementia in Slovenia. It confirms the findings of international studies: that informal care has a strong gender dimension and remains predominantly the responsibility of women, who are expected to care for family members in need of assistance, including children, the sick and the elderly. Consequently, women engage in substantial work, in addition to their professional responsibilities, which can be described using various concepts such as informal care, reproductive work, shadow work, and emotional work. The research project uncovered how informal care for people with dementia begins, the path to diagnosis, and the nature of the professional help sought by informal carers. Individuals with dementia primarily discussed who assists them in their daily lives. Informal carers reported where they had obtained crucial information and how they had educated themselves about informal care and their rights. The study highlights the challenges faced in informal care, noting in particular that carers experience difficulties in balancing their multiple responsibilities alongside their provision of care. It was observed that informal care does not cease when a person transitions to an institutional setting or is in receipt of other formal care services. The findings also indicate a correlation between informal care and a deterioration in the health status of carers.

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