

# **A map of long-term care for people with dementia at the level of local communities: The needs of people with dementia and the vision of care**

Jana Mali

*University of Ljubljana, Faculty of Social Work, Ljubljana, Slovenia*

---

## **Abstract**

Long-term care for people with dementia has been studied using the Rapid Assessment of Needs and Services method, which has been used to map long-term care needs in order to stimulate the development of care that effectively meets the needs of people with dementia. In this paper, we present the results of three focus groups with key stakeholders in long-term care for people with dementia in three selected communities, involving 29 people from a variety of organisations: social work centres, homes for the older people, health centres, general and psychiatric hospitals, municipalities and non-governmental organizations. Qualitative analysis of the empirical material showed that the following problems are prevalent in the communities: (i) acute and unmet needs of informal caregivers, (ii) a multi-tiered system of long-term care that puts people in an unequal position, (iii) a lack of community-based long-term care, and inadequate responses to the needs of people with dementia. Even in communities where there are various forms of support, both institutional and community-based, available across all service sectors, long-term care for people with dementia is based on informal care. We propose the development of a national strategy for family caregivers, with special attention to informal caregivers of people with dementia. The support offered by existing facilities is inadequate, poorly accessible, or nonexistent. Homes for older people are overcrowded, and people with dementia wait months or years to be admitted to a home. Home-based assistance is not evenly distributed across communities, and its scale (20 hours per week) in particular is insufficient to meet the needs of people with dementia. There is a lack of alternative forms of care that enable people with dementia to remain in their own home environment for as long as possible, for example in the form of personal assistance. We suggest that the development of long-term care for people with dementia should be based on the proposed research methodology.

*Keywords:* community care, older people, Rapid Assessment of Needs and Services

---

## 1. Introduction

Long-term care is driven by a number of social processes, the most prominent of which are: demographic change, ageing of population with concurrent decline in the share of young people, life extension, medical advances, a declining share of working age population, and an increasing share of people who are dependent on other people's help. The increase in life expectancy also brings with it various risks that are specific to older people (e.g., diseases, poverty, social exclusion). One of the risks that presents many changes for old people and their social networks is dementia. The consequences of dementia tackle health and social issues, since they affect the people who have the disease and all those around them, and therefore have a profound impact on people's daily lives and their relationships with each other.

Studying the social aspects of dementia has been present in international literature since the 1980s, while researching the social dimensions of dementia in the context of long-term care is still a novelty. In Slovenia, research on the social dimensions of dementia is lagging far behind that of other countries. In addition, there is no unified research on long-term care, as there is only partial research on age-related issues available that is scattered across various universities and institutes. In order to fill in both gaps, the research project Long-term care of people with dementia in social work theory and practice<sup>1</sup> has focused its scientific research on long-term care of people with dementia, based on the concepts of social work as a science and a discipline that operates at the intersection of two interdisciplinary themes—dementia and long-term care.

The situation of people with dementia is highly marginalised at various levels of social action—at the micro level of the social and political system, at the meso level of formal and informal forms of help in the community, and at the micro level, in relationships between people with dementia and social networks. The two pieces of research that were conducted in smaller municipalities in Slovenia on the needs and services of long-term care (Mali & Grebenc, 2019; Mali et al., 2019) have shown that the professionals—providers of long-term care—believe that the care for people with dementia is adequately provided only in institutions. The fact that the professionals are not the change catalysts in the situation of people with dementia raises concerns, as they see people with dementia as a special group for whom institutional care is foreseen. Such orientations are at odds with contemporary trends in the care of people with dementia, which are based on community care (Gauthier et al., 2022; World Health Organization, 2017).

Given that in Slovenia the system of long-term care is still under-developed, the current funding system, the culture of care and the lack of integrated service system make community care possible mainly for those with less intensive needs (Flaker et al., 2015), which, due to the characteristics of dementia as a disease does not involve people with dementia. The intensive personalised services that best respond to users' needs are either under-developed (personal assistance, personal plans and service packages), inadequately regulated or insufficiently intensive (home care, field work). In addition, the community services are over-typified (dominated by residential groups and day centres) or lack diversity. For these reasons, our project aimed to investigate the characteristics of long-term care for people with dementia. Using the Rapid Assessment of Long-Term Care Needs and Services (Mali & Grebenc, 2021a), the maps of long-term care have been developed that

---

<sup>1</sup>The project Long-Term Care of People with Dementia in the Theory and Practice of Social Work (Grant No. J5-2567) was co-financed by the Slovenian Research And Innovation Agency.

allow further development of long-term care for people with dementia. In the long-term care maps, the experiences of people with dementia and the experiences of formal and informal long-term care providers play a central role and have a relevance; they are used as a basis to improve existing long-term care and to develop new services and methods of help (Mali & Grebenc, 2021b).

In this paper, we present the research results in three selected municipalities, where, based on the focus groups with key players in the provision of long-term care for people with dementia, we have drawn up a map of long-term care that also provides a vision of long-term care and guidance for local authorities in taking responsibility for the development of long-term care.

## **2. The role of local communities in providing and developing long-term care for people with dementia**

In Slovenia, long-term care is not yet a system in its own right, although the long-awaited Long-Term Act has been in place since the end of 2021. For the implementation of long-term care, various strategic documents, such as resolutions or strategies, are still relevant. For the purpose of our research, the Resolution on the National Programme of Social Protection for the period 2022–2030 (ReNPSV22–30; Official Gazette of the Republic of Slovenia, 2022, p. 3026) has been examined, since the Strategy of Dementia Management in Slovenia (Petrič et al., 2016) expires in 2020, while a new one has not yet been adopted. Thus, this resolution is currently the most relevant strategic document in the field of long-term care for people with dementia.

The Resolution stipulates that the State gives local communities considerable powers in the area of old people's care. The introductory provision is of key relevance as it makes clear that in the context of social policy, the local authorities, along with the State, are responsible to provide help and support to individuals and families who are not able to provide social security for themselves. The central challenges of social policy (Official Gazette of the Republic of Slovenia, 2022, p. 3026) specify the ageing of population and, in this context, the rapid increase in the number of people with dementia—which has doubled in Slovenia over the last twenty years. The guidelines for developing forms of help for people with dementia have been set, such as day care, as well as guidelines for developing support for relatives and other informal carers. In addition, the support in developing new forms of accommodation is expected, since smaller residential units are to be developed next to old people's homes, providing accommodation for up to 24 users in a single unit. The specific role of local communities in this development has not been explicitly defined. It is likely that the municipalities will continue existing practice in the development and implementation of social home care, as the Rules on Social Services Price Formation Methodology (Official Gazette of the Republic of Slovenia, 2006, p. 9373) stipulate that the municipalities are obliged to finance this service at the rate of at least 50 % of the final price. In addition, the municipalities are obliged to pay extra for this service for those citizens who cannot financially afford it. The municipalities also pay up or pay in full for institutional care for the less financially able old people, including people with dementia.

Municipalities are also expected to play a role in the development of community-based forms of long-term care. The general guidelines of the 2030 Resolution establish a 1:1 ratio in users of community forms and institutional forms. This means that for every user of community forms, there will be one user of institutional forms of social care. People with dementia are not explicitly mentioned in this context, however, it is believed that they are included in this ratio as they are currently among the most institutionalised people in the

country. In this respect, Slovenia does not differ much from other countries. Charlesworth (2014), for instance, states that the institutionalisation of people with dementia increases with age, reaching 27 % in the 65–74 age group and 61 % in the 90+ age group. In the latter age group, there are very few opportunities for informal care of partners, therefore, care, particularly in the advanced stages of dementia, is taken over by formal care providers.

The Resolution's guidelines highlighting the development of community-based care are up-to-date, they follow the global guidelines of dementia care (World Health Organization, 2017) and the wishes of old people. Leichsenring et al. (2013) specify the results of a European research showing that the majority of Europeans see institutional care as the last in a series of forms of care that they would like to receive. They reject residential care because they want to live in a home environment for as long as possible, even if that means they will be dependent on other people's help. It is essential that people's wishes are respected and taken into account by decision-makers at the local and national levels, which will only encourage the development of new services and forms of long-term care in Slovenia as long-term care is highly institutionalised. Intermediate forms of help (between community-based and institutional care), such as day care and various forms of community care, need to be developed (Mali, 2013). At the national level, the changes are needed in terms of providing conditions for integrated health and social care, support for informal carers, various forms of rehabilitation, as well as proactive action to prevent long-term care (Fortinsky, 2014; Naiditch et al., 2013).

For some municipalities, such tasks will present new challenges, since they go beyond the current forms of financial support in some of the established services. It is not clear whether the authors of the Resolution wished to implement the Swedish model of care for old people, which, according to Trydegård and Thorslund (2010), has been transformed over the last twenty years into a separate system of rights, provided on the one hand by the state and on the other by a system of local, decentralised policies with services to help old people, based on local, cultural and historical traditions. Certainly, municipalities are confronted with new challenges that will be difficult to tackle without a proper analysis of the situation, needs and wishes of people with dementia and formal and informal care providers. Designing long-term care for people with dementia, based on the long-term care map as proposed by Mali and Grebenc (2021b) is a possible way forward for local authorities.

### 3. Methods

In this paper, the results of three focus groups with key actors in the provision of long-term care for people with dementia from three selected municipalities are presented. The selection of municipalities was based on the results of the research project Community-Based Care for Older People in Slovenia (Hlebec et al., 2014), in which five groups<sup>2</sup> of municipalities were defined with regard to institutional and community-based care, namely municipalities from Groups 2, 3 and 5. Group 2 consists of small rural municipalities with moderate quality of care for old people: no institutional care in the municipality with a moderate availability of social care at home (as this is more accessible also in the afternoon, during weekends and holidays). Group 3 consists of larger rural municipalities with a balanced quality of care for old people: institutional care is well-developed and the availability of social care at home is

<sup>2</sup>Group 1: higher welfare—high quality of care; Group 2: higher welfare—poor quality of care; Group 3: lower welfare—poor quality of care; Group 4: lower welfare—high quality of care; Group 5: Ljubljana and Maribor: high availability of care (favourable price)—no sufficient quality of care. See more on defining the groups of municipalities in Hlebec et al. (2014).

moderate. In Group 5, there is one municipality that is characterised by a good situation in the field of institutional care, as most of the residents stay in institutional care within the community due to the fact that there is so much institutional accommodation available that they do not need to move to other places. The residents of the municipality are also well placed in terms of financial contributions to social care at home.

The development of long-term care in the selected municipalities may be compared using other indicators than the methodology of Hlebec et al. (2014). Mali and Grebenc (2021a) propose designing a map of long-term care, as a result of research using the rapid needs and services assessment method. The map consists of four areas: (i) presentation of the municipality; (ii) existing forms and services of care; (iii) needs of long-term care; (iv) vision of long-term care. Below, a brief comparison of the first two categories is presented.

### *3.1. Presentation of municipalities*

All three municipalities are geographically close, located in the north-eastern part of Slovenia, in the Savinjska, Koroška and Podravska statistical regions. Two of the municipalities have the status of an urban municipality (Groups 3 and 5), characterised by the presence of a town with at least 20 000 residents and at least 15 000 employment positions, of which at least half are tertiary and quaternary activities. The town is the geographical, economic and cultural centre of a wider area (Official Gazette of the Republic of Slovenia, 2007, p. 12729).

A common feature of all municipalities is that the older population is growing at a very fast rate, on average faster than at the national level. In the municipality of Group 2, the share of people aged 65 and over was 15.3 % in 2008, rising to 17.6 % by 2014 and 21.4 % in 2021 (Statistical Office of the Republic of Slovenia, 2023). In the municipality of Group 3, there is an increase in the old population as follows: in 2008 the share was 13.7 %, by 2014 it was 15.6 % and by 2021 it increased to 20.4 %. The municipality in Group 5 had the highest share of people aged 65 and over in 2021, 23.3 % which is 2.4 % higher than the national average (Statistical Office of the Republic of Slovenia, 2023). The ageing index is higher for women in municipalities in Groups 2 and 5 and higher than the national average, which means that women in both municipalities are ageing faster than in Slovenia as a whole. In all three municipalities, the share of people aged 80 and over, who are usually the most frequent users of long-term care and who also have a higher prevalence of dementia, is increasing, which further indicates the relevance of the development of long-term care for people with dementia. The growth of this population group is expected to slow down in 2020 and even decrease in 2021, as a result of the high mortality rate due to the Covid-19 epidemic.

### *3.2. Existing forms and services of care*

In all three municipalities, long-term care services are found in three sectors—public, private and non-governmental. In addition to old people's homes, the public sector comprises social work centres, health centres, hospitals, centres of social care and day centres. The private sector is dominated by old people's homes and social services. In the non-governmental sector, there are various associations, ranging from pensioners' associations and associations of people with disabilities to the Red Cross, Caritas and various self-help groups. The municipality in Group 5 has the largest number of various long-term care providers from all three sectors, while the municipality in Group 2 has no old people's homes or hospitals. The municipality in Group 3 has a public old people's home and a few associations.

The remaining two categories from the map of long-term care, i.e. (iii) needs in long-term care and (iv) vision of long-term care, were identified in the focus groups meetings, where

the key players in long-term care from each municipality were invited to participate. The meetings were carried out in May and June 2022, as part of the research project Long-Term Care for People with Dementia in Social Work Theory and Practice. A total number of participants was 29 and they came from a variety of organisations: social work centres, old people's homes, health centres, general and psychiatric hospitals, municipalities and non-governmental organizations (NGOs; pensioners' associations, Spominčica—dementia support organisation, adult education organisations). The following questions were discussed with them:

1. What are the needs of people with dementia that you perceive in your work?
2. What are the trends in the amount of support for people with dementia in your municipality?
3. What is your vision of helping people with dementia?

The collected responses were analysed using a qualitative data analysis method by Mesec (1998), as it is the most established analysis of empirical material in social work. The analysis is partly based on the work by Glaser and Strauss (1967, as cited in Mesec, 1998) and Strauss and Corbin (1990, as cited in Mesec, 1998) and is a process in which the concepts are formulated by categorising and classifying the units of material, relating them to each other and formulating theoretical explanations (Mesec, 1998). It is also proposed for social work by Alstone and Bowles (2003).

Here below, the analysis of the empirical data collected from the three focus groups in the municipalities mentioned above are presented in order to demonstrate the characteristics of the needs of people with dementia and the vision of long-term care for them.

## 4. Results

### 4.1. *The needs of people with dementia and existing response within long-term care*

The *first* feature of the map of long-term care is the fact that high levels of care is on the part of the family members and close relatives. Long-term care is based on the informal sector of help, because the formal sector is not working or is in the process of breaking down. It was expected that the participants would discuss the needs of people with dementia and that we would gain insight into the real users' perspective. Unfortunately, our expectations were not met. The experts' narratives referred more to the response to the needs in terms of services and forms of help for people with dementia, rather than to the needs of people with dementia. There was a perceived shift away from directly addressing the distress and problems of people with dementia, as the narratives primarily focused on presenting the distress of family members and close relatives who provide care for people with dementia. The informal carers are perceived by the respondents as taking the lion's share of the care and coming to them for help when they are exhausted, at the end of their rope and in an urgent need of various forms of relief, including formal forms of long-term care such as residential care, home care, day care or forms of medical assistance, such as psychiatric hospital or old people's home. On the other hand, as people with dementia get older, so do their informal carers (partners, children and other family members), and they may already be in need of long-term care themselves.

Once again, informal care providers are being "discovered and recognised" as an indispensable part of long-term care, both in countries with a developed formal public care system (Northern European countries) and in countries where long-term care is based on informal care (Southern European countries) (Naiditch et al., 2013). Informal carers (most often partners, children and daughters-in-law) are not only co-players in long-term care, but also, as carers, have specific needs and requirements in their role (e.g., as employees

in long-term care). They are a highly heterogeneous group, consisting of vulnerable old people (partners and children) and still actively working people.

In the municipality of Group 5, there is a shortage of vacancies in all formal forms of long-term care, so informal providers of care, such as children, the representatives of the middle generation, are forced to leave their jobs and devote their time to providing care for a parent with dementia. The participants believe that such practices show that our long-term care system is clearly not working. According to Leichsenring et al. (2013), however, this is a feature of most existing long-term care systems. Long-term care is and will be based on informal care, and the differences between systems are in the help and support they have organised for them. Charlesworth (2014) argues that help and support intended for informal carers of people with dementia should be threefold: (i) informative (advice and knowledge), (ii) instrumental (concrete help, such as helping people with dementia with household chores, shopping, transport and personal assistance), and (iii) emotional (recruiting confidants). In the municipality at hand, there is a shortage of all three forms, so the relatives turn to professionals at a time when they are so exhausted from providing care for a family member with dementia that admitting a person with dementia to a psychiatric hospital is a crucial form of relief. Unfortunately, they show this by cutting off contact and care for the family member, resulting in the long-term hospitalisation of the person with dementia, which is not the purpose of psychiatric hospitalisation, as the places for longer-term hospitalisation are also extremely scarce. More capacity is needed in nursing facilities, which have proved to be a good solution for transferring people waiting for a more permanent form of care, such as old people's homes.

In all three municipalities the needs of relatives predominated and took precedence, even over the needs of people with dementia. The needs of the people with dementia were not in the foreground of our discussions, more present were the needs of the informal carers. Informal providers of care seek help in all forms of long-term care available in the municipality, ranging from special social care institutions to day care, and even in old people's self-help groups on how to help a person with dementia. Currently, in day care centres there are mostly people with dementia and it is observed that the relatives are not familiar with basic care skills, such as dressing, personal hygiene, feeding assistance, etc. Other forms of distress add up and they are related to the difficulty in coming to terms with dementia, denial of the disease, etc. Financial distress is not uncommon, as existing social care at home is not sufficient and they have to find and pay for additional forms of support if they want their family member with dementia to stay at home.

The experts observe that dementia is highly stigmatised; therefore, the informal providers of care cannot and do not want to recognise the signs of dementia. They hide the fact that their family member has dementia from themselves and others. Formal providers of care often have to first teach about the disease, its progression, seeking appropriate medical help, before they can offer the help that they do. The expectations of informal carers are most often not in line with the help offered, and there is a lack of acceptance of the disease. For instance, they expect 24-hour social care assistance at home, which can only be provided by institutional care. They also observe violent behaviour on the part of the relatives, most often in the form of tying their family member to a bed and preventing them from moving around the home so that they would not put themselves and other people at risk when they are away. The experts consider such behaviour to reflect the relative's distress as they are unable to find additional sources of help. Indeed, ignorance of the various forms of assistance is very high among the relatives in the municipality, and more attention should be paid to informing them about the forms of long-term care for people with dementia.

The *second* feature of the map of long-term care is multi-tiered system of long-term care. The respondents believe that long-term care for people with dementia needs to be developed in an integrated way, that currently, there are two systems that should work in harmony and coordination, but unfortunately this is not the case. The current two-tier care system is unfair, putting users in an unfair position, as their fundamental rights under health insurance are violated. A typical example is the financing of care in an old people's home and in a home, in the context of social care at home. "When old persons are admitted to an old people's home, they are entitled to all the available services—physiotherapy, occupational therapy, nursing. If old persons stay at home, they benefit from home care, while they need to pay for all additional services (Interview 11)", explains one of the respondents. In this way, we are not promoting community care, but rather directing people to institutions that are traditionally taken and where they wait for months or years for a vacancy (Association of Social Institutions of Slovenia, 2023). One of the respondents points out that "there are no services that would allow people to stay at home, in their home environment (Interview 18)." Social care at home is so time-limited that informal carers do not opt for it at all. Currently, a person with dementia is entitled to three or four hours of home help a day, twenty hours a week, which is significantly not enough for a person with advanced dementia.

The fact that the institutionalisation of long-term care is actually increasing is shown by the data of the Health Insurance Institute of Slovenia (2023), according to which the capacity of institutional care is expected to increase by 1129 places by the beginning of 2023, all of which are planned to be in the private sector, owned by the Austrian private companies. For users, this innovation does not bring about any change for the better in terms of accessibility to services, although the new capacities appear in the group of municipalities with the worst coverage of institutional services. Another problem is that over the last three years there has been a decline in interest in working in residential care because it is a low-paid job that is not valued in society. In 2022, with low unemployment, the situation has become so worrying that even employment in the planned new homes in 2023 is called into question.

There are not many organised forms of long-term care for people with dementia in the municipality of Group 3, but those that do exist are extremely diverse and fragmented. In addition, there is poor coordination between providers, leaving people with dementia and their informal carers feeling uncomfortable, abandoned and distressed. These characteristics point to a multi-tiered long-term care system (Flaker et al., 2008), which is no longer based on a sectoral division (public, private, NGO), but has added a division between social and health services, local and national providers, which adds to opacity and people's feeling of being ill-informed. In the municipality of Group 3, there are programmes for dementia education, social activities and volunteering, in addition to institutional care in the old people's home, health care in a general hospital, a patronage service, support from a social work centre and social care at home. The cooperation between the old people's home, which also provides social care at home, and the general hospital is very good. The cooperation between the centre of social work and the old people's home is also good. Other forms of cooperation should be further strengthened, as should the coordination of various forms of support, since this would create a clearer map of long-term care for people with dementia.

The *third* feature of the map of long-term care is the lack of community forms of care and inadequate response to the needs of people with dementia. The respondents agree that the current long-term care system does not adequately respond to the needs of people with dementia. There is a lack of alternative forms of care that would allow people with dementia to stay in their home environment as long as possible. Some respondents identified family carers (i.e., informal carers) as an alternative, which would allow the current informal



providers of care to be fully employed for the duration of the person with dementia's care in the home environment. Although the key motivations for informal carers to provide care are: the emotional bond of love and attachment between the users and the providers of care, the sense of duty to provide care for a family member (Naiditch et al., 2013), our respondents also highlight the financial aspect. Namely, the informal carers often face severe financial distress. Women are forced to leave their jobs, stay at home and care for a family member with dementia. Naiditch et al. (2013) argue that on average women provide twice as many hours of help as men, with a predominance of personal support, while men focus on administrative tasks and logistics, which require less time involvement. Women's informal long-term care is therefore already showing signs of becoming the dominant form of help in the selected municipalities.

There is also a growing need to provide care for certain groups of people with dementia who have specific needs and for whom new forms of support should be developed. In this context, there are people under 65 who suffer from dementia and for whom the current long-term care system does not provide adequate support. They are not adequately catered for in existing forms of long-term care and therefore their needs are not met. Social care at home with 20 hours of help a week is insufficient, the patients' partners are often still working and would need more hours of help. For people with alcohol-related dementia, dementia can occur before the age of 60, at an age when they are not eligible for institutional care and existing community care is not responding effectively to their needs. It is also not uncommon for people with dementia to be subjected to violence, therefore, crisis accommodation or similar solutions would be necessary. This is not available in any municipality, which is probably also a consequence of what Naiditch et al. (2013) observe in their analysis of European long-term care systems, when they conclude that the user perspective of old people and informal carers is often overlooked in policy orientations and in the implementation of concrete practical help by professionals. It is not taken into account in the planning and implementation of long-term care, even though it is often enshrined at a declarative level in various national guidelines. The role of social workers working in the field of long-term care for people with dementia is certainly relevant here. It is essential for them to advocate in order to guarantee human rights and decent treatment for people with dementia at the level of professionals and local communities' action, in order to create an inclusive society for all groups of people (Cahill, 2022).

New forms of help and methods of care also require more staff, and these have been a key problem in the development of long-term care in the municipality for some time. There is already a shortage of staff in existing forms of long-term care and it is difficult to imagine that new forms of long-term care for people with dementia could be developed with existing personnel structure. Thus, for a long time, there has been a system which, on the one hand, has drawn attention to the increased and unmet needs of people with dementia, while, on the other hand, the shortage of staff in existing long-term care system is so severe that its functioning is threatened. In many European countries, the solution to personnel problems is to recruit migrant workers. Bednarik et al. (2013) observe that while migrant workers complement the help of informal carers, the latter are still overburdened despite formal help. In 17 out of 23 European countries, family members reported that they rely on migrant workers at least from time to time to actually be able to provide continuous support and enable the person with dementia to live at home (Barbarella et al., 2016).

In the municipality of Group 2, there are various forms of help for old people available, both institutional and community-based, but they are all more or less organised as solutions for a heterogeneous group of older people, which includes people with dementia.

Unfortunately, the needs of people with dementia are very specific and help in existing forms of long-term care needs to be adapted. For instance, day care is recognised as a good form of help that prolongs the life of people with dementia in their home environment, but at the same time represents great distress for them. Every working day, they move from their home environment to a new one for the duration of the informal carers' working schedule, which is a big change for them and a huge stress that the staff at the centre have to deal with in their daily routines and rituals. The schedule of daily activities according to a well-defined timetable gives them a sense of security, stability and peace.

Social care at home is not sufficient to provide care for people with dementia, because it is limited to 20 hours a week. It is observed that the needs of people with dementia who do not have relatives and close family members to provide additional care alongside organised social care at home remain unmet. A person with dementia living alone at home does not even receive help with taking medication, as none of existing long-term care services provide such help. Nor, for instance, are they able to guide the person with dementia to purchase and use appropriate aids such as weekly medication boxes and similar medication dispensers. People with dementia who live alone or do not have family members or acquaintances to care for them are a particularly vulnerable group. They are 20 times more likely to be institutionalised than people with dementia living with relatives (Charlesworth, 2014).

Currently, the most pressing problem in the municipality of Group 3 is the provision of adequate nutrition at home for people with dementia. This need is perceived by all services in the area, since the only provider to deliver home-delivered meals is a caterer who provides home delivery, but not does not bother to check whether the person with dementia actually consumes the food. Food delivery service should be developed and feeding assistance provided for people with dementia. The solutions are seen in mobilising the social environment, particularly the volunteers from the neighbourhood and neighbours, who could take a very human approach to helping people with dementia. To tackle such a primary service as food distribution and feeding assistance, no large financial investments are needed, only the mobilisation of dormant resources and the promotion of human solidarity and help among people. Nevertheless, the first thing to do is to educate the community about dementia and work on the destigmatisation of people with dementia in society.

#### *4.2. Vision of long-term care for people with dementia*

The *first* feature of the map of long-term care: To make existing and known forms of long-term care fully operational so that new ones can be developed. The vision of long-term care for people with dementia is seen by respondents as a reinforcement of existing formal forms of help, so that people actually get help from services and facilities that they cannot get at the moment because they are waiting for them. There should be an increase in the number of social home care providers, more temporary care and day centres for people with dementia.

New forms of help should be developed along with new services and new methods of working with people with dementia. The new service that is most frequently mentioned is personal assistance for people with dementia. Legislation already provides for personal assistance for younger people with dementia, but this would be the most appropriate care for all age groups of people with dementia. This is prompted by the distress of relatives who come to professionals so exhausted that they need 24-hour, round-the-clock help from formal carers. If we want to strengthen the lives of people with dementia in their home environment, personal assistance is the best solution. Extending life in the home environment is also made possible by various information and communications technology

solutions that people are too little aware of. There is already a range of sensors on the market (e.g., smoke, water, motion, gas) that are affordable and provide a safe living environment for people with dementia. Tele-assistance should also be developed, but for people with dementia this can be a support in their home environment, as personal and direct human contact is irreplaceable for people with dementia.

The local authorities should take on a coordinating role, linking and integrating existing providers into a single long-term care system to eliminate the undue competition between NGOs for funding, as people with dementia need various forms of support. Solutions should also be systematised, as the long-term care system for people with dementia cannot be based on the voluntary sector.

The *second* feature of the map of long-term care: Personnel conditions do not allow long-term care to function and develop. Reflecting on a vision for long-term care for people with dementia cannot take place without finding solutions to the personnel constraints, which at the moment are very great indeed. There are no workers available to work in long-term care, and even fewer who want to work with people with dementia. The existing staff is overloaded with administrative tasks, which means that there is no time for direct contact with the users. Very soon, the solutions will have to be found to relieve existing staff of administrative work, otherwise even those who are currently employed will leave. The payment for working with people with dementia needs to be regulated, and decent wages need to be paid to staff to show that their work is really important and necessary. The employees must be given the opportunity to acquire the skills to work with people with dementia and be trained appropriately in this area of work.

The *third* feature of the map of long-term care is oriented towards the development of specialised forms of long-term care for people with dementia. In the municipality of Group 2, where there are currently few specialised forms of help for people with dementia, they are thinking in particular about how to strengthen the existing offer of help for old people with new services. There are two types of proposals: (i) forms of help and services that are familiar in other municipalities across Slovenia and (ii) new ones, based on solutions from abroad. The first type of new forms of help could be developed by existing providers who already provide long-term care for old people but have not yet developed specialised forms of help for people with dementia. One example is an NGO that organises self-help groups for old people. Two groups could be set up in a very short time, one self-help group for people with dementia and one group for relatives who provide help for people with dementia. There is a social care council at the municipality which could include long-term care for people with dementia as a new topic. The meeting promised to support the establishment of dementia-friendly points set up by the NGO Spominčica.

The second type is day care for people with dementia, which will have to become tailored to the needs of people with dementia and specialised only in providing help for them. Perhaps the existing day centre can become specialised in helping people with dementia. There is also a need for field work, for professionals to help people with dementia in their own home setting. Field teams would be made up of professionals in medical (general practitioner, neurologist), health (nurse, occupational therapist and physiotherapist) and social (social worker, social care worker) care.

There is no old people's home in the municipality and it is unlikely there will be one in the future, as the nearby special social care institution successfully covers institutional placements. The municipality will continue to fund the employments in this institution, provide care for the residents in need and promote the work of NGOs, including in the field of long-term care for people with dementia.

The special social care institution has the potential to develop long-term care for people with dementia. Within the institution, there are plans to reduce large wards and develop household communities, moving towards deinstitutionalisation. They also want to become a centre to provide care for old people in a geographically wider area and could also include people with dementia from the municipality in Group 2, especially those still living in their home environment. Such a vision can also be a model for other municipalities that do not yet have institutional care available.

Experience from social home care in all municipalities shows that the number of hours of home care for people with dementia is insufficient, the approach is inadequate, as it does not provide a sufficient level of personalised and individualised support, and the organisation is inadequate, as it does not provide permanent staff to ensure the routines needed in the lives of people with dementia. The time of uncertainty for both people with dementia and their relatives, from the first signs of dementia to the final diagnosis and continuing after diagnosis, which is pointed out by Fortinsky (2014), should be avoided. Moore and Jones (2012) add that less than half of people with dementia receive a diagnosis, meaning that there is a high risk of people living with dementia without adequate help and support. People with dementia receive a diagnosis when they experience a crisis, when an unpleasant event happens, when their ability to do their job is reduced, which are early warning signs of dementia. What is not resolved are the protocols for dealing with people diagnosed with dementia, which calls for integrated solutions between the health and social support systems and the creation of a new “long-term care” for people with dementia.

In all municipalities, there is a need to strengthen knowledge of the health and social security rights of people with dementia and to develop new rights aimed at informal carers, for instance by adapting the employment legislation to allow flexible employment, more leave for caring for a family member with dementia, etc. People need to be made aware of their rights and the procedures to exercise them. In addition, the role of social workers to communicate their knowledge of the needs of people with dementia and informal carers to relevant local and national policy makers needs to be strengthened. For such a role, they have the appropriate knowledge to act, as Gal and Weiss-Gal (2023) argue, based on their analysis of the political engagement of social workers at the global level, that social workers engage in political decision-making as citizens and as professionals with the purpose and goal of changing the organisations in which they work, as well as local and national policies.

New forms of help must be affordable. Existing ones are too expensive for many people in the municipality, even if they are time-limited, such as home help for 20 hours a week. For some people, home care is too expensive and unaffordable, and for this reason they are often hospitalised.

One of the new methods of help is long-term care planning. This should take place before people enter the long-term care system. People should be taught that it is a good idea to express their will in advance about how they want to be cared for when they need long-term care (Bartlett, 2014; Boyle, 2014; Manthorpe & Samsi, 2013). In the field of dementia, this is of course associated with general knowledge about ageing and dementia, therefore, educational programmes should be developed. These should also involve informal carers, as they need to be trained to care for family members with dementia. The most important results of the study are summarised in Table 1.

## 5. Conclusions

The analysis of the empirical material revealed the following characteristics of the long-term care maps in all selected municipalities: (i) acute and unmet needs of informal carers, (ii) a

**Table 1.** Map of long-term care (LTC) for people with dementia

Municipality	Status	65+	Sectors	<i>n</i>	N&R	Vision
1 (Group 2)	—	21.4	Public/private/non-governmental	16	Services not adapted to the needs	Vision of new services
2 (Group 3)	urban municipality	20.4	Public/private/non-governmental	8	not many organised forms of LTC	knowledge of existing rights, new methods of help
3 (Group 5)	urban municipality	23.3	Public/private/non-governmental	7	shortage of vacancies in formal forms of LTC	knowledge of existing rights, new methods of help

Notes: 65+ = Share of people 65+ in 2021 [%], Sectors = Sectors of LTC services, *n* = No. of participants in the focus group, N&R = The needs and response.

multi-tiered long-term care system, (iii) lack of community-based forms of long-term care and (iv) inadequate responses to the needs of people with dementia. Even in municipalities where there are different forms of help available, both institutional and community-based, which exist in all sectors of the services, long-term care for people with dementia is based on informal care. The cultural orientation of care, as well as the long-standing neglect of the development of long-term care, will probably mean that it will no longer be ignored, but that informal carers will have to be supported in a concrete way. In this respect, we can build on Crawford and Walker (2008) idea of developing a national strategy for kinship carers, with a particular focus on informal carers of people with dementia. The national strategy would define the forms of help and support, advice and information, crisis interventions, career programmes in which carers are recognised and supported to provide care. The national strategy would also define the role of municipalities in the development of these programmes, following the example of the Resolution on the National Social Protection Programme, which explicitly defines the role of municipalities. There is a need to develop a dyadic approach, one that responds to the needs of people with dementia and their relatives at the same time. Concrete support does not have to be for everyone involved in the care of people with dementia at the same time. It may be sufficient to help relatives to have a successful impact on the quality of life of people with dementia, or vice versa. There is research confirming that satisfaction of people with dementia has a positive effect on the well-being of relatives and vice versa (Charlesworth, 2014). It is also possible to develop support programmes that address all those involved in the support processes, as some research confirms that such involvement enhances the overall health of relatives, the mental health of people with dementia and prolongs the time of going to an old people's home.

The multi-tiered system of long-term care does not allow for transparency of the system, transparency of rights and transparency of how they are implemented. It hinders the development of community-based long-term care and reinforces institutionalisation. It is necessary to go beyond familiar patterns of practice and to put the needs of people with dementia at the centre, thus enabling the development of new forms of care that respond effectively to known needs, as well as to the specific needs of certain groups of people with dementia (e.g., under 65, people with dementia without relatives and informal care). At the same time, the needs of informal and formal carers in an integrated long-term care

system will need to be recognised. At the moment, the issue of staffing is very acute because there are no people to provide care for people with dementia. National measures should be coordinated with the needs at local level.

Research on long-term care for people with dementia, using the method of Rapid Needs and Services Assessment<sup>3</sup> in selected municipalities, showed that we have gathered relevant data for the development of long-term care for people with dementia in a rapid way. It demonstrated the usefulness of the method and its suitability for providing new solutions, both at local and national level.

### Acknowledgment

This paper was financially supported by the Slovenian Research And Innovation Agency within the research program Social Work as the Bearer of the Processes of Social Justice and Inclusion in Slovenia (Grant No. P5-0058) and the research project Long-term Care of People with Dementia in Social Work Theory and Practice (Grant No. J5-2567).

### References

- Alstone, M., & Bowles, W. (2003). *Research for social workers: An introduction to methods*. Routledge.
- Association of Social Institutions of Slovenia. (2023). *Pregled kapacitet in pokritost institucionalnega varstva starejših in posebnih skupin odraslih* [Review of capacities and coverage of institutional care for the elderly and special adult groups]. Retrieved May 10, 2023, from <https://www.ssz-slo.si/wp-content/uploads/Register-kapacitet-1.1.2023-ZA-OBJAVIT.pdf>
- Barbarella, F., Di Rosa, M., Melchiorre, M. G., & Lamura, G. (2016). The employment of migrant workers in Italy's elder care: Opportunities and challenges. In U. Karl & S. Torres (Eds.), *Ageing in context of migration* (pp. 159–171). Routledge.
- Bartlett, R. (2014). Citizenship in action: The lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, 29(8), 1291–1304. <https://doi.org/10.1080/09687599.2014.924905>
- Bednarik, R., Di Santo, P., & Leichsenring, K. (2013). The 'care gap' and migrant carers. In K. Leichsenring, J. Billings, & H. Nies (Eds.), *Long-term care in Europe: Improving policy and practice* (pp. 213–231). Palgrave Macmillan.
- Boyle, G. (2014). Recognising the agency of people with dementia. *Disability & Society*, 29(7), 1130–1144. <https://doi.org/10.1080/09687599.2014.910108>
- Cahill, S. (2022). Dementia: A disability and a human rights concern. In S. Torres & S. Donnelly (Eds.), *Critical gerontology for social workers* (pp. 146–160). Policy Press.
- Charlesworth, G. (2014). Living at home. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp. 303–314). Open University Press.
- Crawford, K., & Walker, J. (2008). *Social work with older people*. Learning Matters.
- Flaker, V., Rafaelič, A., Bežjak, S., Dimovski, V., Ficko, K., Fojan, D., Grebenc, V., Kastelic, A., Mali, J., Ošlaj, A., Pfeiffer, J., Ramovš, J., Ratajc, S., Suhadolnik, I., Urek, M., & Žitek, N. (2015). *Priprava izhodišč deinstitucionalizacije v Republiki Sloveniji* [Preparation of starting points for deinstitutionalisation in the Republic of Slovenia]. University of Ljubljana, Faculty of Social Work.

<sup>3</sup>For a better understanding of the characteristics of the method and its applicability to long-term care research, see Mali and Grebenc (2021a)

- Flaker, V., Mali, J., Kodele, T., Grebenc, V., Škerjanc, J., & Urek, M. (2008). *Dolgotrajna oskrba: Očrt potreb in odgovorov nanje* [Long-term care: Mapping needs and responses]. University of Ljubljana, Faculty of Social Work.
- Fortinsky, R. (2014). Diagnosis and post-diagnosis support. In M. Downs & B. Bowers (Eds.), *Excellence in dementia care: Research into practice* (pp. 273–289). Open University Press.
- Gal, J., & Weiss-Gal, I. (2023). The policy engagement of social workers: A research overview. *European Social Work Research*, 1(1), 47–64. <https://doi.org/10.1332/sgnp8071>
- Gauthier, S., Webster, C., Servaes, S., Morais, J. A., & Rosa-Neto, P. (2022). *World Alzheimer Report 2022: Life after diagnosis: Navigating treatment, care and support*. Alzheimer's Disease International. <https://www.alzint.org/u/World-Alzheimer-Report-2022.pdf>
- Health Insurance Institute of Slovenia. (2023). *Aneks št. 1 k Splošnemu dogovoru za leto 2022* [Annex no. 1 to the General Agreement for the contract year 2022]. Retrieved May 10, 2023, from <https://www.zzzs.si/?id=126&detail=1B54199D210FF236C12588530041BCAA>
- Hlebec, V., Mali, J., & Hrast, M. F. (2014). Community care for older people in Slovenia. *Anthropological Notebooks*, 20(1), 5–20.
- Leichsenring, K., Billings, J., & Nies, H. (2013). *Long-term care in Europe*. Palgrave Macmillan. <https://doi.org/10.1057/9781137032348>
- Mali, J. (2013). *Dolgotrajna oskrba v Mestni občini Ljubljana* [Long-term care in Ljubljana Municipality]. University of Ljubljana, Faculty of Social Work.
- Mali, J., & Grebenc, V. (2019). Rapid Assessment of Needs and Services in long-term care. *Revija za socialnu politiku*, 26(2), 171–187. <https://doi.org/10.3935/rsp.v26i2.1603>
- Mali, J., & Grebenc, V. (2021a). Researching long-term care for older people using the Rapid Assessment of Needs and Services method. *Advances in Methodology and Statistics*, 18(1), 1–15. <https://doi.org/10.51936/jfea4370>
- Mali, J., & Grebenc, V. (2021b). *Strategije raziskovanja in razvoja dolgotrajne oskrbe starih ljudi v skupnosti* [Strategies for research and development of community-based long-term care for older people]. University of Ljubljana Press.
- Mali, J., Grebenc, V., Kežzar, A., Buher, D., Fajković, L., Koželj, K., Štrancar, A., & Zupan, M. (2019). *Ocena potreb in storitev dolgotrajne oskrbe v Občini Žirovnica: Končno poročilo* [Assessment of needs and services for long-term care in the Municipality of Žirovnica: Final report]. University of Ljubljana, Faculty of Social Work.
- Manthorpe, J., & Samsi, K. (2013). 'Inherently risky?' Personal budgets for people with dementia and the risks of financial abuse: Findings from an interview-based study with adult safeguarding coordinators. *British Journal of Social Work*, 43(5), 889–903. <https://doi.org/10.1093/bjsw/bcs023>
- Mesec, B. (1998). *Uvod v kvalitativno raziskovanje v socialnem delu* [Introduction to qualitative research in social work]. Univerza v Ljubljani, Visoka šola za socialno delo.
- Moore, D., & Jones, K. (2012). *Social work and dementia*. Sage.
- Naiditch, M., Triantafyllou, J., Di Santo, P., Carretero, S., & Hirsch Durrett, E. (2013). User perspectives in long-term care and the role of informal carers. In K. Leichsenring, J. Billings, & H. Nies (Eds.), *Long-term care in Europe* (pp. 45–80). Palgrave Macmillan.
- Official Gazette of the Republic of Slovenia. (2006). *Pravilnik o metodologiji za oblikovanje cen socialno varstvenih storitev* (No. 87) [Rules on social services price formation methodology]. <https://www.uradni-list.si/1/objava.jsp?sop=2006-01-3814>
- Official Gazette of the Republic of Slovenia. (2007). *Zakon o lokalni samoupravi* (No. 94) [Local self-government act]. <https://www.uradni-list.si/1/objava.jsp?sop=2007-01-4692>

- Official Gazette of the Republic of Slovenia. (2022). *Resolucija o nacionalnem programu socialnega varstva za obdobje 2022–2030 (ReNPSV22–30)* (No. 49) [Resolution on the National Programme of Social Protection for the period 2022–2030 (ReNPSV22-30)]. <https://www.uradni-list.si/1/objava.jsp?sop=2022-01-0985>
- Petrič, D., Kogoj, A., Pirtošek, Z., Flisar, D., Zupan, B., Cvetko, T., Genorio, B., Lukič Zlobec, Š., Romih, J., Klančar, D., & Štrukelj, K. B. (2016). *Strategija obvladovanja demence v Sloveniji do leta 2020* [Strategy of dementia management in Slovenia until 2020]. Republic of Slovenia, Ministry of Health. [https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Preventiva-in-skrb-za-zdravje/nenalezljive-bolezni/Strategija\\_o\\_bvladovanja\\_demence.pdf](https://www.gov.si/assets/ministrstva/MZ/DOKUMENTI/Preventiva-in-skrb-za-zdravje/nenalezljive-bolezni/Strategija_o_bvladovanja_demence.pdf)
- Statistical Office of the Republic of Slovenia. (2023, February 2). *Population number and structure* [Data Set]. <https://www.stat.si/StatWeb/en/Field/Index/17/104>
- Trydegård, G.-B., & Thorslund, M. (2010). One uniform welfare state or a multitude of welfare municipalities? The evolution of local variation in Swedish elder care. *Social Policy & Administration*, 44(4), 137–152. <https://doi.org/10.1111/j.1467-9515.2010.00725.x>
- World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*. <https://iris.who.int/handle/10665/259615>