

Sensitive Memory Work in Finland

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This part of the monograph explores sensitive memory work for minority ethnic groups in Finland. The Finnish social and healthcare system emphasizes the rights of individuals with dementia to dignified care. Still, assessing individuals with different linguistic backgrounds poses significant hurdles, such as delayed diagnoses and cultural taboos surrounding dementia. The Alzheimer Society of Finland and the Finnish Centre for Cultural Diversity and Memory MUKES elaborate the initiatives for supporting linguistic and cultural diversity in memory care. Their projects, the Memory Guide Project and the *Jututtaja* Project, strive to empower ethnic minorities by training volunteers as memory guides and phone companions, respectively. The importance of cultural competence and flexibility is highlighted. Continued development, training, and collaboration is needed to enhance societal understanding of the diverse aging population in Finland.

Keywords: sensitive memory work, minority ethnic groups, volunteers

Introduction

Finland has an estimated 193 000 people with dementia, of which 100 000 have mild dementia and 93 000 have moderate or severe dementia. Of these, 7000 are of working age, under 65 years old. Every year, 14 500 new individuals are diagnosed with dementia [1, 2].

This overview discusses the support for people with dementia and their families in Finland, focusing on sensitive memory work with minority ethnic groups. It highlights the importance of language when dealing with dementia and considers factors to be mindful of in finding effective operational models for people with different linguistic and cultural backgrounds. Two dementia organizations in Finland, The Alzheimer Society of Finland and The Finnish Centre for Cultural Diversity and Memory MUKES, are introduced, and their activities are described through development project goals and expected results. A common theme in

these projects is recognizing the importance of receiving support in one's native language and the opportunities to reach individuals with different linguistic and cultural backgrounds through volunteers offering support.

1. People with dementia from ethnic minority groups

As of the end of 2022, there were 495 992 permanently resident individuals in Finland with a non-native language as their mother tongue. The proportion of non-native speakers in the total population is nine percent. The largest linguistic groups are those who speak Russian, Estonian, English, and Arabic. In Finland, there are 23 377 non-native speakers over the age of 65, with Russian, Estonian, English, and German being the most common language groups. This number increases by 4000 individuals annually [4]. The number of individuals with different linguistic and cultural backgrounds is growing continuously as dementia becomes more prevalent.

Language changes with dementia. The production and comprehension of language become difficult, and individuals with dementia may experience difficulties in finding words or understanding complex sentences. Therefore, it is essential to consider that good communication enhances the well-being of individuals with dementia. As dementia progresses, a language learned later in life may be forgotten, leaving only the native language, whose significance grows.

The initial assessment of dementia for individuals with a different linguistic or cultural background is often challenging because there are no adapted tests for those with weak literacy skills. Functioning as an interpreter in a memory test situation is a highly challenging and demanding task. It involves not only speaking two or more different languages but also requires considerable talent, skills, and training [3, 5].

2. Care and support services for people with dementia

Finland's social and healthcare system is publicly funded, with the responsibility for public services for people with dementia lying within the wellbeing services county. In addition to the public sector, services are provided by private companies. Finland also has a broad field of social and health organizations that provide both paid and unpaid services. The Funding Centre for Social Welfare and Health Organizations, operating under the Ministry of Social Affairs and Health, is a state aid authority that grants subsidies for activities promoting general well-being, health, and welfare. A significant portion of these subsidies goes to organizations supporting the well-being of people with dementia and their families [6].

Every person with dementia has the right to dignified and life-sustaining support and care. Support and assistance are available to help individuals with dementia and their families, such as various social security benefits and social and healthcare services. The care and rehabilitation of individuals with dementia is aimed at their well-being, meaningful life, slowing the progression of symptoms, and maintaining functionality. Medication is important, but non-pharmacological treatments and various forms of rehabilitation are often prioritized [1].

Working with individuals from different linguistic and cultural backgrounds, the importance of a sensitive approach is emphasized as clients come from increasingly diverse backgrounds. It is essential to be aware that each culture may perceive dementia and aging differently. The role of the family may also differ, likewise, the language and communication differences pose their own challenges.

A sensitive approach recognizes and respects these differences, seeking to understand the client's values and ways of life, and adapting the dementia care path accordingly. This requires openness, flexibility, and a willingness to learn from dementia care professionals. Asking, listening, and genuinely being present while interacting are crucial traits. This approach builds trust and fosters a shared understanding. Sensitivity in memory work improves the quality of memory services and customer satisfaction. It also promotes the participation and empowerment of clients [3, 5].

3. Working with people with dementia from ethnic minority groups

It is known that dementia occurs in both the majority population and minority groups. In the case of individuals with a different linguistic and cultural background, the diagnosis of dementia often gets delayed, posing a risk of them being left outside the service network. Lack of understanding or different perceptions of dementia, poor familiarity with the system, and a lack of proficiency in the Finnish language hinder initial assessments. Additionally, dementia is often considered a taboo in many cultures [3, 5].

Memory work with minority ethnic groups in Finland differs somewhat from other European countries and the Nordics due to the unique structure of immigration. The dissolution of the Soviet Union in 1991 significantly influenced this, leading to a new and large group of international immigrants from various Soviet countries in Europe. In Finland, it is primarily made up of Russian- and Estonian-speaking individuals, whose backgrounds are usually quite different compared to the immigrants from the countries outside Europe, such as those who speak Arabic or Somali.

The educational level of clients plays a crucial role in the initial assessment of dementia among ethnic minority groups. Immigrants from the former Soviet

Union are often highly educated compared to, for example, aging Somali speakers, where illiteracy is sometimes encountered. Literacy directly affects performance in memory tests.

People who have moved to Finland from various countries usually share the characteristic of having little information about dementia. Memory loss is not often interpreted as an illness, and discussions about it are avoided due to the fear of stigma [2].

4. Experiences of memory organizations in developing sensitive work

4.1 The Alzheimer Society of Finland and the Memory Guide Project

The Alzheimer Society of Finland serves as a public health, patient, and advocacy organization for people with dementia and their families. The organization aims to improve the quality of life and general well-being of this target group. The goal is to create a dementia-friendly society where people with dementia and their families can live a good life and receive the support and services they need. The Alzheimer Society of Finland is an industry pioneer that promotes brain health, supports those affected and their families, strengthens their voices, and defends their rights. Established in 1988, the Alzheimer Society of Finland has 42 local member associations throughout Finland, providing information, support, and activities for people with dementia and their families, as well as anyone interested in memory issues. Memory associations organize group activities for people with dementia and their families, hold lectures on dementia, and provide advice on memory issues [1].

The Alzheimer Society of Finland is developing new forms of activities to improve the well-being of people with dementia and their families. Currently, there are ongoing development projects related to the rehabilitation of people with dementia, mobility, support tools for communication, and support for people with different linguistic and cultural backgrounds. In the Memory Guide Project (2023–2025), the goal is to create a model that enables the support of people over 65 with different linguistic and cultural backgrounds and their families as part of their community's own activities. The target groups are German-, Russian-, and Estonian-speaking individuals.

The model involves training volunteers from ethnic minority groups as memory guides, acting as intermediaries of information about dementia and as contact persons in their own communities. The aim is for the memory guides' activities to strengthen the community's internal capabilities to discuss dementia and seek support for dementia-related challenges. It is essential that acting as a memory guide brings meaningful activity, new skills, and well-being to the volunteer. The project also focuses on developing collaboration between local memory

associations and multicultural actors, supporting sensitive memory work through training and materials [1].

Preliminary results indicate that the interest and the need for information in different ethnic minority groups varies significantly. In the German-speaking community, there is a desire to learn more about dementia, voluntary work in one's native language is found inspiring, and peer support for caregivers is considered important in the emotional language. Utilizing various flexible approaches in communication and offering volunteer tasks is beneficial. Collaboration between organizations is key to continued operation in each target area. Investment in professional training and encouragement to engage with immigrants with dementia is crucial. The importance of materials in different languages in customer work has also been emphasized.

4.2 The Finnish Centre for Cultural Diversity and Memory MUKES and the *Jututtaja* Project

MUKES is an organization established in 2020, functioning as an expert entity in sensitive memory work. Its purpose is to promote collaboration among various stakeholders to enhance the well-being of aging individuals with different linguistic and cultural backgrounds in Finland. MUKES supports these aging individuals, living with memory disorders, by promoting timely initial assessments of dementia within minority ethnic groups in Finland. MUKES participated in the Alzheimer Europe working group, where recommendations were formulated for the initial assessment, diagnosis, and needs of individuals with dementia from minority ethnic groups. The Alzheimer Europe (2018) report supports sensitive memory work in Finland [2].

In recent years, Finland has developed several successful practices in sensitive memory work, exemplified by the ETNIMU-activity/Society for Memory Disorders Expertise (2015–2020) and the Memoni Project/Salon Muistiyhdistys ry (2016–2019). ETNIMU produced information on sensitive memory work for professionals and developed multilingual materials to increase awareness of memory health among both immigrants and Finnish Roma populations. ETNIMU worked with aging individuals who spoke Estonian, Russian, Somali, Arabic, and Chinese. The ETNIMU activity was unique, originating from a project that responded to practical needs, eventually evolving into a nationwide initiative [2,3].

The Memoni Project by Salon Muistiyhdistys was a significant step toward promoting brain and memory health amongst working-age individuals with different linguistic and cultural backgrounds in Finland. The project aimed to provide information on brain health, dementia, and the risk factors for ethnic minority groups. The project focused on sharing information in different languages, with emphasis on maintaining brain and memory health. It produced sensitive multilingual materials, such as flyers, videos, and conversation starter cards. This

information empowered individuals to influence their brain health and prevent dementia [1]. All these experiences in the history of MUKES provided valuable tacit information about the diversity, needs, and knowledge of dementia in minority ethnic groups [2].

The *Jututtaja* Project is a developmental project by MUKES with the goal of creating guided phone companionship for individuals aged 55 and above with different linguistic and cultural backgrounds in their own native languages. In this project, volunteers, called “*Jututtajat*”, from the same linguistic and cultural background make weekly calls to elderly individuals to promote well-being, memory and brain health, as well as to reduce their loneliness and guide them to various services. The project particularly focuses on the largest non-Finnish-speaking groups: Arabic, English, Russian, and Estonian speakers. The necessity of the *Jututtaja* Project has arisen for various reasons, with recent challenges brought about by the pandemic further compromising the position of elderly individuals with different linguistic and cultural backgrounds in society. Language and cultural challenges have been significant barriers to participation, leading to social isolation, and services are often less accessible from the individual’s perspective [2].

The *Jututtaja* Project, like many others, has faced various challenges. For instance, immigrants who have moved to Finland engage less in volunteer work, and commitment may be a foreign concept. Some elderly individuals may hesitate to participate in new projects or services, especially if they differ from the familiar, and using technology may be challenging if systems are not user-friendly. Ensuring that individual needs and differences between the elderly and communities are considered in the project’s implementation and planning can be challenging. In some minority ethnic groups, everyone knows each other, and there may be family disputes. The expected outcome of the *Jututtaja* Project is an increase in societal understanding of the diversity of the aging population. Additionally, awareness of the importance of diverse memory work will rise, allowing for the provision of more suitable services to minority ethnic groups. It is crucial for society to address these challenges and create an inclusive and supportive environment for all elderly citizens, regardless of their language or culture [2].

The role offered to volunteers in the *Jututtaja* Project has, according to preliminary results, been an empowering experience. Volunteers feel that they are doing meaningful work, helping others, and providing companionship. Assisting and listening to others has enabled volunteers to feel a sense of community participation, and they have felt they are making an important contribution to the lives of the elderly. Sharing personal experiences and engaging in diverse and interesting conversations have helped maintain memory functions and brain health. Often, the calls have been long, discussing various aspects of life. One elderly participant noted in a concluding interview that the calls have helped sharpen and crystallize their past and envision their remaining future.

Conclusions. Through development, towards a good life for individuals with different linguistic and cultural backgrounds

The projects viewed above are expected to increase societal understanding of the diversity of the aging population and provide a model that can expand into other services. In further development, it is possible to extend a similar model to other age groups and backgrounds. Sensitive memory work and its promotion play a crucial role in a diversifying Finland. Meeting individuals from minority ethnic groups in dementia care requires sensitivity, flexibility, and the ability to empathize with the client. Understanding cultural backgrounds helps tailor services individually [3].

Good practices for sensitive memory work include using interpreter services, involving family members, utilizing visual and non-verbal communication methods, and providing training for professionals in the field [5]. Developmental needs include increasing training, considering diversity in recruitment, and fostering closer collaboration with the public sector, organizations, and communities. The Memory Guide Project and the *Jututtaja* Project are developmental initiatives supporting the understanding and consideration of diversity in memory work. It is essential to strive for new tools and work towards an equal and satisfying life for individuals with different linguistic and cultural backgrounds in Finland.

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