

Assessing Alzheimer's disease in long-term care: an autoethnographic study of a proposed innovative tool

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Abstract

Purpose – *The Nordic region is projected to experience a substantial increase in the number of older adults diagnosed with dementia, reaching approximately half a million. Given this expanding demographic, the dissemination of innovative solutions developed by nurses is imperative to ensure the effective and continuous management of older adults in nursing facilities. This study aims to communicate the author's experience with the effective selection of an innovative concept, entitled the memory passport, with the goal of enhancing care services for older adults residing in nursing homes.*

Design/methodology/approach – *This study used the autoethnographic approach to recount the author's experiences in professional caregiving for residents and patients with Alzheimer's disease, grounding these experiences in self-reflexivity.*

Findings – *Drawing from autoethnographic observations, it is evident that nursing staff members have encountered significant challenges in implementing the physical, mental and social dimensions of health due to a prevailing nursing shortage. The onerous documentation requirements and the involvement of other health professionals, family members and next of kin have led to the development of a proposed innovative tool. The memory passport aims to address all the health dimensions and streamline nursing documentation while ensuring the implementation of a client-centered approach.*

Originality/value – *The memory passport as a proposed innovative tool considers a comprehensive, client-centered care approach to long-term care residents in nursing homes. It has also the potential to be used in home health services daily, integrated within the patient information system. The dissemination of innovative concepts by nurses, such as the memory passport, is of paramount importance, as it encourages nurses to explore avenues for enhancing the lives of older adults.*

Keywords Alzheimer, Care, Dementia, Memory, Nursing, Innovation, Tool, Documentation, Autoethnographic, Qualitative

Paper type Research paper

1. Background

The contemporary global shortage of nurses, compounded by an aging population with co-morbidities, has exerted significant challenges on healthcare workforces (Khan *et al.*, 2024). Annually, 10 million new cases of dementia are diagnosed (World Health Organization, 2023). Projections indicate that by 2050, the number of individuals affected by dementia will reach 139 million (World Health Organization, 2021). The Nordic region, which includes the countries of Finland, Sweden, Denmark, Norway, Iceland, the Faroe Islands, Greenland and the Åland Islands, is currently experiencing a significant increase in the number of individuals facing with dementia. This trend is of particular concern, as the number of cases is steadily rising, reaching approximately 500,000 individuals (Dahlström, 2024).

Projections indicate a surge in dementia cases in this region, primarily attributable to the aging population born in the 1940s. Projections indicate that the incidence of dementia will increase twofold by the year 2050 (Alzheimer Europe, 2019; Westman, 2024). Despite the

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Nordic region's reputation for its high-quality healthcare services, particularly in the domain of geriatric care, it is confronted with the challenge of recruiting personnel to maintain the viability of the healthcare and social care sectors (Hadnagy, 2019). This predicament has led to an increasing reliance on home-based services for older adults (Lindberg *et al.*, 2023), accompanied by a shift in responsibilities from physicians to registered nurses and, subsequently, from registered nurses to practical nurses (Danish Health Authority, 2021).

Innovation aimed at enhancing the quality of care provided to older adults is imperative to ensure that patient-centered care (Momeni *et al.*, 2022; Pakkonen *et al.*, 2024) is delivered through a multidisciplinary approach (Ellis and Sevdalis, 2019; Zucchella *et al.*, 2018). This innovation must also elevate the role of nurses in the context of quality improvement and patient safety (Bowles *et al.*, 2015). To cultivate innovative approaches, it is imperative to comprehensively understand older adults affected by Alzheimer's disease and their experiences, and to implement strategies in an empowering and affirmative manner (Quinn *et al.*, 2022). Furthermore, adopting a comprehensive approach to evaluate the requisites of individuals with dementia and discerning the factors influencing their well-being is of significant importance (Quinn *et al.*, 2022; Roberts and Shehadeh, 2021). The engagement of family members and the adoption of an interprofessional approach have also been identified as pivotal determinants contributing to favorable outcomes in their well-being (West *et al.*, 2022).

The nursing profession, particularly in the domains of gerontology and Alzheimer's disease care, continues to encounter persistent undervaluation (Birt *et al.*, 2023) of its critical role in the social and healthcare systems. The potential for innovation initiated by nurses to effect change in the healthcare system is considerable, contingent upon the presence of an organizational culture that fosters innovation. (Beaudet, 2024). Nurses as the frontline workers with older adult, witness, understand and bring solutions to ensure care is delivered with dignity and trust. However, innovations created and reflected by nurses based on experiences and professional judgment remain untold in the scientific community.

2. Objective

The aim of this study was to communicate the author's experience with the effective selection of an innovative concept, called the memory passport (MP), with the goal of enhancing care services for older adults residing in nursing homes.

3. Background of the tool and theoretical framework

The proposed innovative tool was developed based on a competition from the Queen Silvia Nursing Award, which is open to nursing professionals, including but not limited to nurses, nursing students and licensed practical nurses. Nursing educators, academicians, and leaders are also encouraged to participate in the competition. This annual program involves the selection of an awardee by juries across various disciplines, who will then be recognized as a laureate and scholar for the duration of the year. The laureate is awarded by Queen Silvia of Sweden in person at the Royal Palace (Swedish Care International, 2024).

The proposed tool was named the *memory passport*. The terms "memory" and "passport" are employed here to denote the former as the cognitive faculty responsible for the storage and retrieval of information, and the latter as a document evidencing the engagement in activities that facilitate cerebral activation. The development of this instrument was guided by four fundamental principles: First, a thorough definition of health is imperative (WHO, 2020). Second, a multidisciplinary approach is essential (Ellis and Sevdalis, 2019; Zucchella *et al.*, 2018). Third, a patient and family-centered care approach (Momeni *et al.*, 2022; Pakkonen *et al.*, 2024) is necessary. Finally, digitalization is crucial (Turjamaa *et al.*, 2023).

The theoretical framework of the tool is anchored by the definition of the World Health Organization (WHO, 2020), which encompasses the dimensions of physical, mental and social aspects, and not necessarily the absence of disease or infirmity. Addressing the salient issues associated with Alzheimer's disease necessitates a multidisciplinary approach. The effectiveness of a multidisciplinary team care approach in addressing patients' concerns is well-documented, ensuring a comprehensive and holistic approach to patient care (Ellis and Sevdalis, 2019; Quinn *et al.*, 2022; Zucchella *et al.*, 2018). It is imperative to prioritize the patient's well-being as the pivotal factor in all decision-making processes. In the case of a patient diagnosed with Alzheimer's disease, the involvement of a family member must be taken into consideration (Momeni *et al.*, 2022; Pakkonen *et al.*, 2024). Finally, when assessing the daily activities of the Alzheimer's patient (resident), nurses must be able to document their observations and evaluations with ease during the shift. The documentation of care should be digitalized and user-friendly.

4. Methodology

This study used the autoethnographic approach to recount the experiences of introducing innovative ideas aimed at enhancing public health awareness among individuals suffering from memory disorders, with a particular focus on Alzheimer's disease. The study also examined the development of the tool, which was informed by the researcher's professional experiences and interactions with colleagues and older adults. Autoethnography was used as a research method, leveraging personal experiences to describe and interpret cultural texts, beliefs and practices (Adams *et al.*, 2017; O'Hara, 2018; Ratnapalan and Haldane, 2022). The author used their narrative to both contribute to and address existing gaps in research (Adams *et al.*, 2017). Autoethnography, a qualitative research method, involves the use of personal experiences to understand the intricate layers of cultural, emotional, human social, political and theoretical practices (Poulos, 2021).

5. Results

The foundations of the MP are grounded in the principles of comprehensive care, encompassing the physical, psychological and social dimensions (see Table 1 on the autoethnographic approach of the study). This holistic approach attends to the individualized needs of the client, emphasizing the provision of care that addresses all three dimensions.

In 2023, researcher AA participated in a competition representing Finland and proposed an innovative concept named the MP. The conceptual foundation of this study is rooted in the researcher's clinical experience, which encompasses work with older individuals, teaching

Table 1 Autoethnographic approach from each dimension of the memory passport

<i>Dimension</i>	<i>Autoethnographic approach</i>	<i>Statement</i>
Physical	Personal experience	Clinical observations highlighted those older adults residing in nursing homes exhibited constrained mobility, a consequence of limitations in available resources. This observation led to the integration of physical aspects into strategies aimed at enhancing functional ability
Social	Observations and document	The author emphasized the critical importance of the social dimension in daily care routines, highlighting its role in activating memory and significantly enhancing the quality of life for older adults in nursing homes
Mental	Reading news, evidence-based data, and following the mainstream media on the current trend of older adult care in the Nordic region	The consideration of prevalent mental health challenges, particularly depression, among older individuals in nursing homes underscored the necessity to address the mental aspect in the creation of the innovative tool

students in gerontology nursing multidisciplinary health assessment courses, active observations and reading of news and research findings. During this period, researcher AA noted frequent instances of insufficient comprehensiveness in the care of older adults. This observation instigated a reflection on the absence of a coherent framework for older adult care, which culminated in the formulation of the MP.

First, the researcher, AA, reflected on their clinical experiences in nursing homes and assisted living facilities. A notable incident in the nursing home setting involved the failure to change the diaper of a bedridden older adult resident during the shift, despite the presence of soiled diapers. The researcher posited that older adults should not be regarded as mere routine tasks to be fed and left without proper care and assessment. This incident prompted a critical reflection on the part of the researcher, particularly because the assigned nurse appeared reluctant to change the diaper after the next shift.

In the researcher's clinical experience in a nursing home, the implementation of a morning program has been identified as a key component of the resident's well-being in a nursing home. This program involves a variety of activities, including physical exercises, morning care, and ensuring that residents receive adequate nutrition in a timely manner, along with medication as necessary. However, due to a shortage of nurses, as the researcher has observed, routine tasks may become the norm, potentially resulting in the neglect of the psychological and social aspects. The psychological dimension, as delineated by the researcher, encompasses mental well-being, emotional health, stress management and mental alertness. The social dimension, on the other hand, encompasses the social needs of the individual and their interactions with others. This dimension includes community support, social inclusion and the significance of one's social network.

The overarching objective of the MP is to integrate these dimensions, thereby providing healthcare professionals and older adults with a clear, comprehensive yet simple tool to guide the delivery of holistic care. The objective is to provide individualized, client-centered care that considers the unique needs of each older adult, promoting their well-being across all these dimensions. These dimensions can be documented and scored, and the results can be reported to relatives and analyzed by nursing management to improve care services.

5.1 Usage and interpretation

The MP (see [Figure 1](#)) is a proposed paper-based or electronic tablet form. It is initiated by presenting the older adult or resident with a form that is specifically designed to ensure ease of readability and comprehension. This form incorporates icons, clear text, and a larger font size to facilitate completion.

The resident or client is assigned the task of completing the form by indicating whether a specific task has been executed, based on three distinct domains. These domains relate to physical, mental and social aspects. For instance, within the physical domain, adherence to physical activities is a salient factor. Within the psychological domain, indicators of mood or cognitive stimulation should be activated. Finally, within the social domain, the necessity arises for the maintenance of social contacts or the engagement in community activities.

If the client or resident possesses the capacity to complete the form independently, they will execute this task autonomously. However, in cases where the client requires assistance or is unable to complete the form independently, the nurse is responsible for providing support and guidance. Where the client's immediate support system is unavailable, the nurse may seek assistance from relatives, friends, or other visitors. In the event that the documentation is initiated in a physical format, it is important that the relevant data, inclusive of the score, be transferred to the patient information system. It is imperative that the resident or client prioritize the completion of the form.

Figure 1 Memory passport tool

Component	Remembered (1)	Assisted (0)	Documentation
I remember/staff helps me remember:			
Physical			
1. Perform light physical movements.			
2. Carry out morning care.			
3. Eat on time and get good nutrition.			
Mental			
4. Participate in memory-enhancing activities, puzzles, games or memory therapy.			
Social			
5. Participate in group activities, discussions or joint events.			
Score			
			: Total
☐ I'll fill this in myself. ☐ Staff/family/relatives help me to fill this.			

5.2 Interpretation

1–2 (more activation needed): People scoring in this category may need more encouragement, reminders or support to actively participate in the MP activities. They may show occasional or low participation in physical, mental or social activities, indicating a need for improvement and more involvement in these areas.

3–4 (activated): Those in this category actively participate in the MP tasks but may occasionally need reminders or encouragement to keep up their participation. They show moderate levels of engagement and commitment in the physical, psychological and social domains, indicating generally good participation.

5 (highly activated): Older adult with a score of 5 are highly activated in the MP tasks. They consistently and excellently participate in all physical, mental and social activities. These individuals actively participate without frequent reminders or support, demonstrating a high level of commitment and a holistic approach to their overall well-being.

6. Discussion

The absence of a comprehensive evaluation tool and an interactive medium to assist nurses in delivering comprehensive care, while concurrently promoting active engagement from older adults, was identified as a significant gap in the caring science. To address this care gap, the author endeavored to develop an interactive assessment tool. The MP goes beyond a mere document or task list; it is designed to be an interactive tool that instructs nurses while motivating older adults to play a more active role in their care. The goal is not only to address current limitations in care but also to promote participation and collaboration in nursing practices.

The author of this study observed a colleague's failure to inspect the diaper of an older adult during a shift, which prompted the author to reflect on the professional identity of nursing in home care. This oversight has the potential to elevate the risk of pressure injury for the older adult, which can further compound the risk of the older adult becoming immobile. This observation served as the foundation for the author's reflection on the initial component of the

MP. Research has demonstrated that pressure injuries (PIs) are prevalent among older adults due to prolonged exposure to soiled diapers (Bender *et al.*, 2017; Institute for Quality and Efficiency in Health Care (IQWiG), 2022; Villela de Castro *et al.*, 2022). A study by Lund *et al.* (2024) revealed that a subset of nurses reported utilizing larger diapers due to constraints in time that precluded them from accompanying nursing home residents to the restroom. This practice has become a norm. The author of this study further reflected on the typical activities of older adults, which have been shown to stimulate brain activity. This stimulation is an integral component of the routine of older adults residing in nursing homes. This encompasses a range of activities, including physical exercise, morning routines and a nutritious diet. As indicated by the author's personal experience, numerous nurses have been characterized by their gentle and kind demeanor. They have also exhibited a commitment to enhancing the physical mobility of residents. However, limitations in staff availability and the numerous administrative responsibilities, such as medication administration and documentation, have hindered the full realization of this objective during work shifts.

A growing body of research has demonstrated the multifaceted impact of physical activity on the prevention of Alzheimer's disease (Iso-Markku *et al.*, 2022; Zhang *et al.*, 2023). In patients diagnosed with Alzheimer's disease, the implementation of physical activity has been shown to reduce neuropsychiatric symptoms and enhance daily living activities (Cass, 2017). Consequently, this has the potential to postpone the onset of Alzheimer's disease, which is regarded as a favorable non-pharmacological intervention (Ryan and Kelly, 2016). The author of this study emphasizes that even light physical activities of a resident in a nursing home, such as encouraging them to go to the bathroom or performing activities of daily living independently, can elicit brain activity even if the activities require a certain amount of time to complete and are not regarded as a mere routine task. Despite the nutritional quality of the food served in nursing homes, there is a notable prevalence of repetitive culinary offerings. In the realm of nutrition, Ahn *et al.* (2024) contend that the efficacy of a nutritionally balanced diet, replete with variety, in preserving cognitive function, particularly in the context of dementia prevention, has been substantiated.

The nursing shortage that is pervasive in many nursing homes, in conjunction with the rote nature of the work, has the potential to result in a failure to adequately consider the mental well-being of residents. The researcher noted that, following the administration of morning care, which was occasionally executed in a cursory manner, patients were seated in wheelchairs or remained in their rooms. While it is reasonable for nurses to prioritize other duties, nursing administration could implement a standard assessment or arrange for a clinical nurse specialist to periodically evaluate the cognitive abilities of the residents including depression. Considering these observations, the MP as a tool involves residents, with or without assistance from nurses, other health professionals, or family members, engaging in memory-enhancing activities, such as puzzles, games, or memory therapy. A substantial body of research has indicated that a considerable proportion of nursing home residents have been diagnosed with depression (Harris-Kojetin *et al.*, 2016; Simning and Simons, 2017; Yuan *et al.*, 2019). However, a recent study has demonstrated that contemporary digital interventions, such as serious games, have the potential to alleviate symptoms of depression (Kim *et al.*, 2022). Memory therapy, including reminiscence therapy, has been identified as a non-pharmacological intervention that can address depression and other neuropsychiatric symptoms in patients with dementia residing in nursing homes or long-term care facilities (Saragih *et al.*, 2022). The employment of clinical nurse specialists who have received training in dementia care has been demonstrated to possess the capacity to not only deliver clinical expertise but also to enhance the quality of life among patients with dementia. Additionally, these specialists can provide education and leadership support to staff and family members within a community setting (Duane *et al.*, 2015).

In terms of social engagement, the researcher noted that many residents in a nursing home appeared to be either in their rooms or in a common area, either sitting on a wheelchair or on a chair. However, the nurses present noted an effort to congregate the residents in a central area for social interaction. However, the initiative was hindered by limitations in time and resources, which also prevented the researchers from devoting additional attention to the residents. After the shifts ended, a sense of guilt was experienced by the author, as well as by nurses and staff members who were taking good care. This observation gave rise to a hypothesis proposing the necessity for the social dimension to be activated on a daily basis. In a previous study conducted by [Kang and colleagues \(2020\)](#), it was demonstrated that understanding social relationships among nursing home residents helps to cultivate a sense of belongingness within the community, facilitates recognition of their prior lives with family members and strengthens relationships between staff members and residents. The researcher recommends a series of activities, although it should be noted that these are not exhaustive: organizing discussion sessions, playing light games as a team or even calling family members on the phone or organizing a music event that engages their memory or reflects past experiences. [Chapman et al. \(2024\)](#) have proposed analogous activities, including facilitating introductions among residents, organizing outings and engaging family members and friends. The importance of a robust social life in promoting mental and physical well-being, particularly among long-term care residents, has been underscored by [Bethell et al. \(2021\)](#).

7. Study rigor

It is important to note that the study was part of the Queen Silvia Nursing Award competition, which was supported by Swedish Care International under the patronage of Queen Silvia of Sweden. This provided a platform for the author's insights and experiences. To enhance reflexivity, the author engaged in multiple dialogues with senior academicians and presented the winning innovative idea in classroom set-up during teaching sessions and in small discussions with colleagues to reflect on potential biases that may be present. The present study is founded on self-reflexivity, wherein the researcher actively engages in reflecting on past experiences ([Poulos, 2021](#); [Tracy, 2020](#)) in nursing homes and professional viewpoints. The study uses observational data from the researcher, incorporating emotions and feelings that are conducive to profound reflection ([Poulos, 2021](#)). In this case, the study draws from personal experiences in diverse healthcare settings that involve older adults.

8. Study limitations and strengths

While the researcher engaged in grounded self-reflexivity, the potential for bias emerged due to the observation period coinciding with specific instances when the author was engaged in part-time employment. Consequently, the nursing shortage influenced the dynamics among staff members, prompting a more expeditious execution of tasks. Despite the deliberate challenge of reflecting on these difficulties, they mirror the contemporary reality of nursing in nursing homes, a reality that necessitates heightened attention from healthcare management. The potential for bias has been addressed by presenting both positive and challenging experiences, supported by evidence-based data.

9. Conclusion

The MP as a proposed innovative tool that considers a comprehensive, client-centered care approach to long-term care residents in nursing homes. It has the potential to be used in home health services on a daily basis, integrated within the patient information system. The dissemination of innovative concepts by nurses, such as the MP, is of paramount

importance, as it encourages nurses to explore avenues for enhancing the lives of older adults. A comprehensive assessment of the physical, mental, and social dimensions of older adults' well-being, along with meticulous documentation, is imperative. However, the time demands of documentation should not be a significant encumbrance on nurses, who are already engaged in arduous tasks.

10. Ethical considerations

As no data has been collected from institutions, no ethics permit has been sought. However, the researcher's reflections on the [World Medical Association's \(2024\)](#) Declaration of Helsinki – ethical principles for medical research involving human participants – guided their actions. In this context, the principle of no harm was followed. Autoethnography is predicated on ethical and honest conduct in the description of events and the articulation of content ([Ellis, 2007](#); [Méndez, 2014](#)). The objective of this study was to develop a tool that would benefit older adults, family members, residents and staff members.

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