Improving demeNtia care Through Self-Experience- INTenSE

Output Title 1 E-booklet on self-experience practices for dementia care

T1.1 – SCOPING REVIEW_Study protocol

Title

Scoping Review on the state-of-the-art of self-experience practices in dementia care

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1 Background

Neurodegenerative diseases such as dementia have a wide range of consequences for affected persons, their families and the healthcare system. In 2010, approximately 35.6 million people were living with dementia worldwide, and the number is expected to increase to 115.4 million by 2050 (Hugo, 2015; Prince et al., 2015). The majority of people with dementia are cared for in their own homes by relatives, with or without the support of professional services (BMFSFJ, 2017; DAIzG, 2011). Providing dementia care often represents a complex task for caregivers. People with dementia sometimes show symptoms like restlessness, anxiety, aggression, etc., which pose great challenges to family caregivers and nursing staff (Borsje et al., 2016; Sörensen, Duberstein, Gill & Pinquart, 2006). The coronavirus pandemic additionally leads to isolation due to the loss of care and respite services, thus exacerbating the situation (Geyer et al., 2020).

Against this background, it is becoming increasingly important to prepare professionals and family caregivers for any stressful situations. An improved understanding of the disease should help reduce the psychological stress of caregivers in the long term (Boots et al., 2014; Hepburn et al., 2001). In addition to understanding dementia, empathy skills and knowledge about the disease play an important role in better understanding people with dementia and thus minimizing psychological pressure for the caregivers (Wijma et al., 2017). Kirk (2007) describes empathy in caregiving as to „understand what it is like to be in someone else's position (what it is like to live that person's life) or, perhaps less ambitious, to understand what it is like to experience phenomena as someone else experiences them“. Therefore, empathy is one of the key competencies of nursing care in person-centred care for people with dementia (Wabnitz, 2020; Hirt et al., 2019; Mc Kinnon, 2018).

One way to improve the understanding of people with dementia is to try to experience for yourself what it is like to live with dementia and to see the world from the perspective of the person with dementia (Wijma, 2017; Hatting et al., 2015). For this purpose, innovative technologies such as virtual reality interventions (VR) and virtual dementia tours (VDT) are becoming increasingly important. Recent studies show that VR-based self-experience practices can contribute to a better understanding of and empathy for people with dementia (Peng et al. 2020; Wijma et al., 2017). To our knowledge, there are no reviews that focus on other dementia-specific self-experience practices such as role-playing games or theater labs. A further investigation that gives an overview of the current self-experience practices in the literature, and includes the barriers and facilitating factors in the development and implementation of these practices seems to be worthwhile.

Theoretical framework

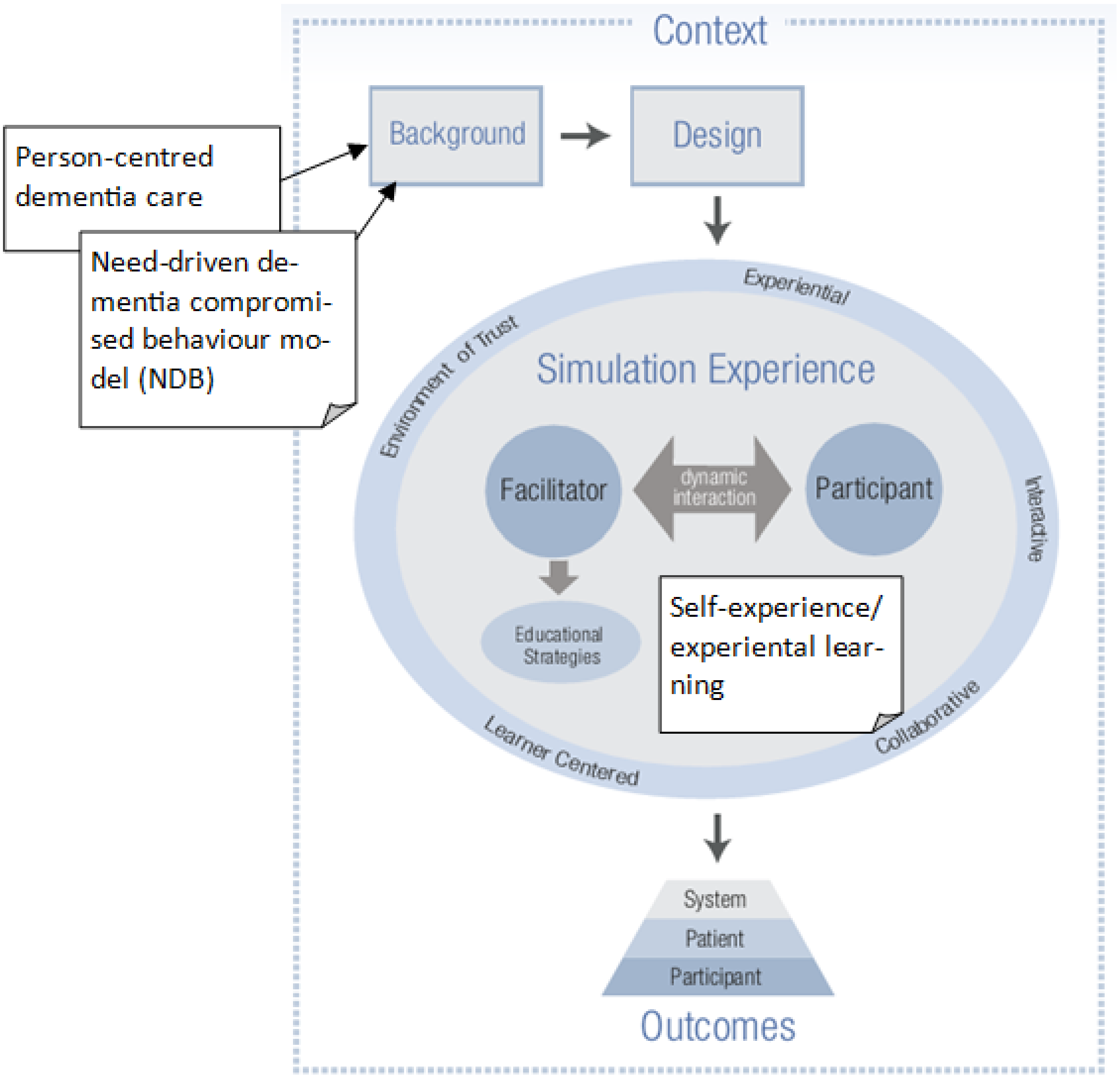
The topic of self-experience for improving dementia care requires a theoretical framework which links aspects of dementia care and self-experience learning. To the best of our knowledge, such an integrated theoretical framework does not exist. Therefore, we propose using an established framework of simulated learning, the Jeffries Simulation Framework (Jeffries et al., 2015), which was developed for nursing education. This framework relates to the context, background and design of the simulation experience, and to the outcomes. The context describes circumstances and settings of the simulation experience. Background aspects give information about the development and implementation of the intervention and its theoretical basics. The design describes the prerequisites, conditions and aspects of the involved participants or facilitators. Outcomes with regard to participants, patients and system aspects are considered. We will enhance this framework with characteristics of dementia care and self-experience learning (Figure 1). The concept of Person-centred dementia care and the Need-driven dementia-compromised behavior model (NDB) are background factors and may guide the design and evaluation of self-experience interventions. The concept of self-experienced/ experimental learning underlines the construct of simulation experience.

Person-centred care is a social-psychological concept developed by Tom Kitwood (Kitwood, 1997) that is based on both the dialogic principle by Martin Buber (Buber, 1923) and the client-centred therapy by Carl Rogers (Rogers, 1961). It aims at promoting the human being, the “personhood”, instead of focusing only on the disease-related aspects. According to Kitwood, the individual wellbeing depends essentially on the extent of which the individual need for “personhood” is met. “Personhood” is defined as the “standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997). Since in the context of dementia this personhood progressively is endangered, person-centred care aims at satisfying the individuals' psychological needs in order to increase the individuals' self-esteem (Kitwood, 1997). Kitwood postulates five fundamental psychological needs, namely inclusion, attachment, comfort, identity and occupation that influence each other and combine in the central need for love. Consequently, to understand these needs and to fulfill them represents a crucial point in person-centred dementia care.

With the basic assumption that our fundamental needs guide our behavior, Algase et al. (1996) and Kolanowski (1999) further developed the person-centred-care approach to the “need-driven dementia compromised behaviour model” (NDB), which not only explains the individuals’ feelings and needs, but also tries to understand and to interpret accordingly the behavior of people with dementia. It theorizes that the behavior of people with dementia should be understood as an expression of subjective needs, in a way that every behavior the person with dementia shows is directed towards a subjective goal. Therefore, the behavior can be explained by two different types of factors: background factors on the one hand and so-called proximal factors on the other hand. Background factors include aspects such as health status, physical and cognitive abilities, as well as characteristics of the person, personality traits or individual responses to stress. They can hardly be influenced by interventions, but may serve as risk predictors. Proximal factors comprise physiological needs, e. g. pain, hunger, thirst, and sleep disturbances, psychosocial needs, environmental stimuli such as light and noise, and also the social environment, e. g. continuity of the staff, the atmosphere etc. These factors can produce specific behaviors and are easier to influence.

Self-experience or *Experiential learning* as a method to reach these educational goals is defined as “the process whereby knowledge is created through the transformation of experience” (Kolb, 1984). It is derived mainly from constructivist approaches such as Piaget’s who considered learning processes as an interaction between the individual and the environment, in which, during socialization, the individual constructs specific expectations or schemes about the world that are constantly either confirmed or refuted through experiences (Piaget, 1970). Piaget introduced the concepts of assimilation and accommodation, in which assimilation is about integrating new information into pre-existing cognitive schemes whereas accommodation describes the modification of these pre-existing schemes once a discrepancy between the expectation and the actual outcome occurs (Piaget, 1985).

Figure 1: Integrated framework of dementia specific self-experience



The integrated theoretical framework can be used for conducting the scoping review (IO1) and also for developing and implementing the self-experience intervention (IO2).

2 Objectives

The objective of this scoping review is to provide an overview of the existing literature regarding self-experience practices in dementia care, such as virtual reality, virtual dementia tours, role-plays and theatre labs for professionals working or willing to work with people with dementia, in order to enhance their empathy and understanding for dementia-specific symptoms.

The research questions of the scoping review are:

- Which self-experience practices for evoking a deeper understanding of the experiences of people with dementia are described in the international literature?
- What are the possible barriers and facilitators in the development and implementation of self-experience practices in dementia care?

3 Methods

Methodological framework

The scoping review is guided by Arksey and O'Melley's methodological framework (Arksey & O'Melley, 2005) and the recommendations by Levac et al. (2010). This methodology allows for the inclusion of all study designs and grey literature, thus providing a broad overview of the topic. A scoping review is conducted in five steps: identifying the research question, searching for relevant studies, selecting studies, charting and collating the data, summarizing and reporting the results. Expert consultation is recommended as a facultative step. This is not part of this review, because of the methodological uncertainties of evaluating the statements and opinions of stakeholders in the field, as described by Levac et al. (2010).

4 Information sources

- PubMed
- CINAHL
- Web of Science
- Cochrane
- Reports by the World Health Organisation (WHO), the Organisation for Economic, Co-operation and Development (OECD), and the Alzheimer’s Disease International
- National reports, national dementia strategies (of Germany, Ireland, the Netherlands and Italy)

5 Search strategy

Inclusion criteria

- Study types: all types including systematic reviews, randomised controlled trials, controlled studies, observational studies, qualitative studies
- Topics: an overview of the state of the art and international experience on self-experiences in the context of dementia; identification of barriers and facilitators in the development and implementation of technology-based solutions

- Population: Professional adults working or willing to work with people with dementia (doctors, nurses, pharmacists, students, teachers etc.), family caregivers of people with dementia
- Setting: No restriction to a specific setting. The intervention can take place in nursing schools, workshops, universities, etc.
- Publications in English language / national languages of the INTenSE partners
- Publications between 2010 – 2020

Exclusion criteria

- interventions targeted at people with dementia
- Other interventions (pharmacological interventions, …)
- Self-experience practices in general or related to other conditions (e.g., Parkinson's disease, depression)

Search terms

Concept/complex	**Search Terms**	**MeSH Terms**
Dementia	dement* OR alzheimer* OR delir* OR „mild cognitive impairment“ OR „mental health“ OR „cognitive dysfunction“ OR „cognitive impairment“ OR neurodegenerative diseases OR neurodegenerative disorders OR “cognitive function”	Dementia
Simulation	„computer simulation*“ OR „virtual realit*“ OR „virtual tour*“ OR „virtual tour“ OR „augmented reali*“ OR simulation* OR VR OR „affective learning“ OR training OR practice OR approach OR mode OR intervention OR „web-based“ OR construct* OR “mixed reality” OR education	Computer simulation
Virtual dementia tour	„virtual dementia tour“ OR „virtual“	
Role-play	„role-play*“ OR „role game*“ OR „role playing game*“	
Theatre laboratory	„theatre laborator*“ OR drama OR theatre OR theater OR „theater laborator*“	
Self experience	„self-experience*“ OR „self experience*“ OR „self-awareness“ OR „self awareness“ OR „self-perception“ OR „self perception“ OR experien* OR „learning by doing“ OR „step into shoes“ OR „know-how“ OR knowhow OR workout OR empathy OR „social presence“ OR „embodied knowledge“ OR „being-there“ OR „experience-taking“ OR „compassion“ OR „person-centred attitude“ OR „person-centered attitude“	

Carers	„health personnel“ OR „health care professional“ OR „health professional“ OR nurse* OR physician* OR doctor* OR GP* OR „general practitioner*” OR psychologist* OR psychotherapist* OR caregiv* OR „family caregiver“ OR „informal caregiver“ OR carer* OR “nursing student*“ OR „medical student*“ OR „social care professional” OR „social worker*” OR physiotherapist* OR „occupational therapist*” OR family OR volunteer* OR therapist* OR professional*	Carer
Education	Education* OR learn* OR teach* OR instruct* OR train*	Education

Table 1: Search terms

6 Data management, selection process, and data extraction process

Two researchers will independently review the retrieved titles and abstracts (screen 1) and check whether they are eligible. To get a more detailed overview of the study interventions, the TIDieR (Template for Intervention Description and Replicatio) checklist will be used (Hoffmann et al. 2014). Bibliographic data will be downloaded to Rayyan bibliographic software and duplicates deleted. The full text of those citations deemed relevant by both reviewers will be obtained. Two researchers will independently assess the full texts (screen 2) to determine whether they meet the inclusion criteria. Any disagreements will be solved by consensus or by discussion with a third researcher.

If studies were reported in more than one publication, these publications will be grouped together and the publication with the most complete data will be used as the primary reference; the other publications describing the same study will be classified as associated papers.

Reviews will be screened with regard to their included studies, and those studies that fulfill the inclusion criteria will be included.

Each working group should conduct a search in the national grey literature, e.g. documents of the national Alzheimer societies. Relevant study reports should be analysed by using the data extraction sheet (Table 2) and forwarded to the IO1 team.

For quality assurance purposes, the data extraction process will be pilot tested by two researchers, discussed between the researchers, and modified if necessary. A data extraction form has been developed (Table 2), which will be modified after the testing phase, if necessary. The testing phase will be evaluated carefully.

category	subcategory	short description	informations/ comments

Reference	Authors		
	Year		
	Country		
	Aim		
Title			
Design			
Participants (nurses, caregivers etc.)			
Delivery method of the self-awareness practices (VR, role-play etc.)	Brief name		
	Why		
	What (materials & procedures)		
	Who provided		
	How		
	Where		
	When and how much		
	Tailoring		
	Modifications		
	How well (planned & actual)		
Context where study is conducted (hospital, community)			
Outcome measures/ data collection			
Main Results			
Barriers and Facilitators	Barriers		
	Facilitators		

Table 2: Data extraction form

7 Reporting of results

The data will be presented in tabular form based on the research questions of the scoping review. These include a comprehensive overview of the targeted participants, the content of the self-awareness practices, outcome measures, the main results as well as the barriers and beneficial factors in the development and implementation of self-experience practices. In addition to the tabular presentation, the results will be described narratively in detail.

Recommendations for developing the eBooklet

After the data evaluation has been completed, recommendations that serve as a basis for the INTenSE e-booklet will be derived. Ideally, it should be determined which intervention, e.g. VR or role play, has an impact on empathy skills, understanding and knowledge. In addition to this, the results are supposed to show what to consider when developing the intervention and how best to implement it.

References

Algase, D. L., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. American Journal of Alzheimer's disease, 11(6), 10-19.

Boots, l.M., De Vugt, M. E., Van Knippenberg, R. J. M., Kempen, G. I. J. M., Verhey, F. R. J. (2014). A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. Int J Geriatr Psychiatry 2014; 29: 331–344.

Buber, M. (1923). I and Thou, 2nd edn, trans. Ronald Gregor Smith, New York: Charles Scribner’s Sons. First published.

Bundesministerium für Familie, Senioren & Frauen und Jugend (BMFSFJ) (Hrsg.). (2017). Wir unterstützen Menschen mit Demenz deutschlandweit in 500 lokalen Hilfenetzwerken. 2. Auflage. Berlin: Bundesministerium für Familie, Senioren, Frauen und Jugend, Referat Öffentlichkeitsarbeit. https://www.bmfsfj.de/blob/77344/7ead93b422ad3af7dec9102a08e06f02/wirunterstuetzen-menschen-mit-demenz-data.pdf, Abruf: 23.08.2018.

Deutsche Alzheimer-Gesellschaft (DAIzG) (Hrsg.) (2011): Allein leben mit Demenz: Herausforderung für Kommunen. 2. Auflage. Berlin: Dt. Alzheimer-Ges. https://www.deutsche-alzheimer.de/fileadmin/alz/pdf/Handbuch_Allein_leben_mit_Demenz.pdf, Abruf: 23.08.2017.

Geyer, F., Böhm, F., Müller, J., Friedrichs, J., Klatt, T., Schiller, C., Kißlinger, V., Meyer, G., Heinrich, S. (2020). Die Lebenssituation von Menschen mit Demenz und pflegenden Angehörigen während der Coronavirus-Pandemie. Pflege, 33 (4), 189–197.

Hepburn, K.W., Tornatore, J., Center, B., Ostwald, S. W. (2001). Dementia Family Caregiver Training: Affecting Beliefs About Caregiving and Caregiver Outcomes. American Geriatrics Society, 49:450–457.

Hirt, J., Beer, T. (2019). Use and impact of virtual reality simulation in dementia care education: A scoping review. Nurse Education Today, Volume 84, 104207.

Hoffmann, Tammy C., Glasziou, Paul P, Boutron, Isabelle, Milne, Ruairidh, Perera, Rafael, Moher David et al (2014). Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ 348 :g1687.

Hugo, J. and Ganguli, M. (2015). Dementia and Cognitive Impairment: Epidemiology, Diagnosis, and Treatment. Clin Geriatr Med. 2014 August; 30(3): 421–442.

Jeffries, P.R.; Rodgers, B., & Adamson, K. (2015). NLN Jeffries Simulation Theory: Brief Narrative Description. Nursing Education Perspectives, 36(5), 292-293.

Kitwood, T. (1997). The experience of dementia. Aging & Mental Health, 1(1), 13-22.

Kolanowski, A. M. (1999). An overview of the need-driven dementia-compromised behavior model. Journal of Gerontological Nursing, 25(9), 7-9.

Kolb, D. A. (1984). Experiential Learning: Experience as the Source of Learning and Development. Prentice Hall.

Peng, X., Wu, L., Xiaoshu, W., Dai, M., Wang, D. (2020). Impact of Virtual Dementia Tour on empathy level of nursing students: A quasi-experimental study. International Journal of Nursing Sciences, 258e261.

Piaget, J. (1970). Psychologie et épistémologie (Vol. 73). Paris, Gonthier.

Piaget, J. (1985). The equilibration of cognitive structures: The central problem of intellectual development. University of Chicago Press.

Prince, M., Wirmo, A., Guerchert, M., Ali, G.-C., Wu, Y.T., Prina, M. (2015) World Alzheimer Report 2015 The Global Impact of Dementia. An analysis of prevalence, incid ence, cost and trends. Alzheimer’s Disease International (ADI), London, 3-87.

Rogers, C. (1961). Client centred therapy: on becoming human. London, Constable.

Sörensen, S., Duberstein, P., Gill, D., Pinquart, M. (2006). Dementia care: mental health eff ects, intervention strategies, and clinical implications. Lancet Neurol 2006; 5: 961–73.

Wabnitz, P., Rixe, J. (2020). Ohne Empathie geht es nicht. Heilberuge, 2.2020 /72, 32-33.

Wijma, E. M., Veerbeek, M.A., Prins, M., Margriet Po, M., Willemse, B.M. (2017). A virtual reality intervention to improve the understanding and empathy for people with dementia in informal caregivers: results of a pilot. Aging & Mental Health study, 22:9, 1121-1129.