



HOLISTIC HOME CARE FOR DEMENTIA PATIENTS

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ABSTRACT

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Nurses play a vital role in the care of people living with dementia. The most are cared for in a home-based setting, so it is important to understand the challenges that nurses face that affect the holistic care they can provide. This study aims to answer the question: How nurses can provide a holistic home-based care for dementia patients. The study also intends to provide nursing care teams with evidence-based research that is beneficial in effectively caring for patients living with dementia in a home care setting.

This study used a descriptive literature review method where data were analysed from existing scientific journals and articles from four databases, namely: CINAHL, MEDLINE, JOANNA BRIGGS and PUBMED. The articles were narrowed down using inclusion and exclusion criteria to yield 10 peer reviewed empirical studies conducted in English between the year 2011-2024. The studies were analysed using a qualitative content analysis conducted in three phases: reduction phase, clustering phase and categorization.

The results revealed five key categories that should be incorporated into the implementation of a holistic care approach for patients with dementia. These included a patient-centered care approach, with nurses recognizing the importance of treating patients based on their individual cognitive and emotional needs rather than solely focusing on their disease. Additional categories were interdisciplinary collaboration among various healthcare teams, ongoing training and education to ensure the delivery of quality care, and comprehensive pain management and palliative care that prioritizes the dignity, comfort, and quality of life of patients living with dementia. The research also showed the need to address gaps in training and education, particularly in pain management and palliative care. The further implementation of interdisciplinary collaboration was identified as a key factor in improving and enhancing the holistic approach to home-based care for patients with dementia.

Key words: home care, dementia, memory disorder, nurses' perspective.

1 INTRODUCTION

Nurses play a vital role in the care of people living with dementia; most are cared for in a home-based setting, so it is important to understand the challenges that nurses face that affect the quality of care they can provide. It is important to first understand what dementia is, how it affects those living with it and how to approach caring for them.

According to WHO guidelines, (2012) dementia is not necessarily a normal part of ageing. Despite improvements in the past century to help people live healthier and longer lives, prevalence and incidence projections indicate that the total number of people living with dementia worldwide is expected to double every twenty years, to an estimate of 65.7 million in the year 2030. (WHO, 2012)

According to Arvanitakis, Shah and Bennett (2019), Dementia is an acquired loss of cognition in multiple cognitive domains that is sufficiently severe enough to affect one's social or occupational function. It further leads to behavioural symptoms that can include memory loss, lack of communication, personality disorders and cognitive decline.

There are several types of dementia, however, Alzheimer's Disease is the most generic form of dementia. It is further associated with the cerebrovascular pathology of the different neurologies of dementia. (Arvanitakis et al 2019.)

As Dementia is a progressive condition, it may gradually get worse depending on the individual and the different symptoms they experience. Yanfel, Xiuxia, Rui, Nan et Kehu (2021) further state that dementia can thus, not only affect the individual but is a disease that has a massive impact on not only the individual, but the individual's family, their primary caregiver and healthcare providers. (Yanfei et al 2021.)

According to NICE (2018) due to the substantial number of people living with Dementia and the variation in the symptoms that each person faces, providing care and support can be overly complex. Staff training needs of support carers and coordinating care and support between different services are some of the challenges caregivers and practitioners go through in supporting care for dementia clients.

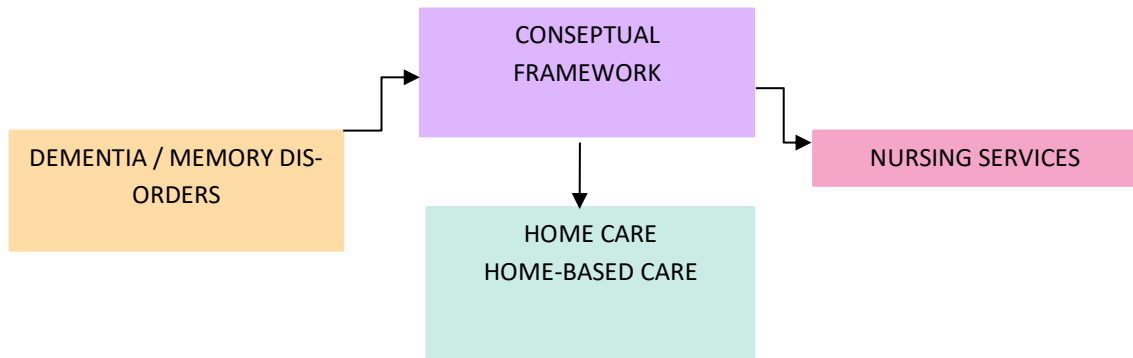
Home Based Care (HBC) services or Home Care further includes a wide range of services that can be provided in a home rather than a care community. As the condition progresses, HBC thus allows a person with dementia to receive assistance through a variety of different services provided to their home (Yanfei et al 2022.)

According to NICE 2015, Home Care for dementia patients is the planning and delivery of person-centred health and medical services that are provided at the client's home. (NICE, 2015)

Handley, Bunn, and Goodman (2017) state that nursing interventions used when dealing with patients living with dementia highlight that there is a widespread need of developing the knowledge skills and information in ensuring there is continuous progress ongoing in the improvement of treating clients with dementia. (Handley et al 2017.)

According to Beck, C., & Heacock, P. (1988) extensive research is done about the causes and deficits of patients with Dementia and Alzheimer's and the problems related to the family and the caregiver. However, it is also important to see patients with dementia as holistic individuals and develop more knowledge on how nurses can incorporate interventions that also pertain to the patients physical, emotional, intellectual, and social dimensions. Exploring this will ensure that dementia clients are receiving high quality, patient centred home based care

2 CONCEPTUAL FRAMEWORKS



2.1 Dementia / Memory Disorders

According to the World Health Organization, “Dementia is not a disease but a syndrome that can be caused by several diseases that over time destroy the nerve cells and damage the brain which over time leads to the deterioration of cognitive function. It is commonly preceded or accompanied by mood changes, lack of emotional control, behavioural and personality changes.” (WHO, 2023) It is important to note that dementia can occur in persons below the age of 65, it is uncommon, but it does happen and according to Dementia Australia, the term “younger onset dementia” is used to describe this.

Symptoms of dementia are categorized into two: Cognitive symptoms and non-cognitive symptoms.

Cognitive symptoms include:

- Memory loss
- Confusion about dates, time, and places
- Inability to follow a conversation
- Difficulty concentrating
- Difficulty carrying out daily familiar tasks (NHS, 2023)

Cerejeira J, Lagarto L, Mukaetova-Ladinska (2012) note that non-cognitive symptoms affect the person’s behaviour and personality refer to the Behavioral and Psychological Symptoms of Dementia (BPSD) or Neuropsychiatric symptoms and they include:

- Agitation
- Irritability
- Anxiety
- Elation
- Depression

- Apathy
- Delusions and Hallucinations

It is estimated that BPSD affects 90% of dementia patients and although these symptoms can occur individually, it is quite common that these symptoms occur concurrently (Cerejeira J, Lagarto L, Mukaetova-Ladinska 2012).

Dementia Australia (2024) also notes that there are over 100 diseases that cause dementia, with the most common ones being Alzheimer's disease, Vascular dementia, Lewy bodies dementia, Parkinson's disease, cerebrovascular disease, and frontotemporal degenerations. (Dementia Australia 2024)

The THL states that memory disorders are diseases that cause a decline in memory and other cognitive functions, it is another term for dementia and as earlier mentioned can be caused by many different diseases. (THL, 2023)

The THL also noted that in 2015 globally there were about 50 million people living with memory disorders and according to the national register in Finland 2021, there are about 150,000 people living with memory disorders, it is estimated that by 2040, there will be about 247,000 people living with memory disorders in Finland. (THL, 2023)

World Health Organization (2023) states that more than 55 million people have dementia worldwide, over 60% of whom live in low-and middle-income countries. Every year, there are nearly 10 million new cases, and that dementia is currently the seventh leading cause of death and one of the major causes of disability and dependency among older people globally.

2.2 Home Based Care / Home Care

In this thesis, we will use home care in equivalence to home based care.

According to the National Institute of Health and Excellence (2015) Home care is the planning and delivery of person-centred care for persons living in their own homes. It aims to promote client's independence and to ensure clients safety and quality of their wellbeing. (NICE, 2015)

The Finnish Institute for Health and Welfare (2023) suggests that in Finland, a percent of those aged 75 or over were covered by regular home care and the daily number of home care clients has gradually been increasing. The personnel involved in home care include practical nurses, nurses and public health nurses,

formal and informal caregivers, social care workers, therapists, and other special caregivers. (THL, 2023)

Home care services include the medical, social and health care services that are provided to a client's home on a temporary basis according to their health care needs. According to Stoddart, Whitley, Harvey et Sharp (2002) the provision of homecare services varies between and within countries' social and community care services and are organised and depending on how their health is financed. The range of support received from homecare services from personal activities of daily living to social care to technology services, to changes in the home and even assistance devices. Stoddart et al (2002)

2.3 Nursing Care Services

According to the National Institute of Aging (2023) nursing care services regarding dementia include providing information, care and support to the clients and the family members involved with the disease. This includes providing education about the disease, taking assessments, providing care planning, ethical consideration, and constant communication with both the client and their family members. (NIA, 2023)

According to Watanabe, Nakumara, Yoshiyama et Takahashi (2019) increasing use of nursing care services resulted in increased client independence and reduced homecare workers' burden.(Watanabe et al 2019.)

3 PURPOSE, OBJECTIVE & RESEARCH QUESTION

The purpose of this study is to gather evidence-based information for home care nurses to use to provide high quality, patient centered care for people who are living with dementia by using a descriptive literature review.

The objective of this study is to provide nursing care teams with evidence-based research that will be beneficial in effectively caring for dementia patients at home.

The research question that we intend to answer during this study is:

- How can nurses provide holistic home care to patients with dementia?

4 METHODOLOGICAL FRAMEWORK

This section of the study explains how relevant information and concepts were retrieved by searching appropriate databases. It begins by explaining the data collection process, then accounts for the inclusion and exclusion criteria, reduction process, clustering, categorization and analysis before concluding with the ethical considerations that were ensured in the study.

4.1 DATA RESEARCH PROCESS

Griffin (2005) highlights the importance of training on research methods for academics to better understand the topic one is undertaking in their chosen topic. According to Jonasson et Silen (2018) nurses are meant to be consumers of research as they are required to strive towards using evidence-based practice in their daily work. Having conducted a descriptive study of research methods in nursing student's bachelor's thesis in Sweden, Jonasson et Silen (2018) noted that literature reviews were the most common methods used among nursing students when partaking in a thesis. (Johansson et Silen., 2018, p 379)

There are a variety of research methods that can be used to evaluate and answer research questions posed. Dixon et Cusack (2016) quotes a literature review as, "a process to identify relevant material from both peer-reviewed and grey literature information that falls outside the mainstream of published journals and monographs, reading through the material, and analysing the information in the material." (p.286) This research will focus on a qualitative literature review method which in turn is a literature review that focuses on literature based on qualitative studies. It will include certain steps such as identifying our research question, displaying our search strategy, our inclusion and exclusion criteria, data extraction and our final reporting on our research question. (Elo S., Kääriäinen M., Kanste O., Pölkki T., Utriainen K. & Kyngäs H. 2014.)

4.1.0 Inclusion & Exclusion Criteria

The authors of this study sourced information from credible scientific databases to ensure that only reputable, peer-reviewed information was used. Five databases were chosen to primarily be used during this literature review, and they include: CINAHL, PubMed, Joanna Briggs, Theseus, and Google Scholar. Arti-

cles searched were then analysed under the inclusion and exclusion criteria. Articles that fell under the inclusion criteria were considered relevant; peer reviewed, answered our research question, with full access texts, Abstracts and were published in English between 2011 – 2024.

The tables below display an example the searches that were conducted, and the inclusion and exclusion criteria used. More detailed analysis of the articles can be found at the end of this paper.

Table 1: Search strategies

| Date | Database | Search phrase | Limitations | Re- sult | Evalu- ate |
|----------------|---------------------------|---|---|---------------------|----------------------------|
| 12.2.24 | <i>CINAHL (Ebsco)</i> | <i>Home care ser- vices AND de- mentia patients OR people with dementia</i> | <i>Peer Reviewed, Date: 2011- 2023 Language: English References available Academic Jour- nals</i> | 385 | <i>Mostly relevant</i> |
| 12.2.24 | <i>CINAHL (Ebsco)</i> | <i>Home care ser- vices AND de- mentia patients OR people with dementia AND best care prac- tices OR quality care</i> | <i>Peer Reviewed, Date: 2011- 2023 Language: English References available Academic Jour- nals</i> | 14,529 | <i>Not rele- vant</i> |
| 22.2.24 | <i>CINAHL (Ebsco)</i> | <i>Home care AND dementia OR memory disorder</i> | <i>Peer Reviewed, Date: 2011- 2023 Language: English</i> | 2,773 | <i>Relevant</i> |

| | | | | | |
|----------------|----------------|--|---|----|------------------------|
| | | | <p><i>References available</i></p> <p><i>Academic Journals</i></p> | | |
| 22.2.24 | CINAHL (Ebsco) | Nursing services AND Home-based care AND dementia patients OR people with dementia | <p><i>Peer Reviewed, Date: 2011-2023 Language: English</i></p> <p><i>References available</i></p> <p><i>Academic Journals</i></p> | 7 | <i>Relevant</i> |
| 26.2.24 | PubMed | Pain management for dementia patients | <p><i>Peer Reviewed, Date: 2011-2023 Language: English</i></p> <p><i>Text Availability: Free full text and Abstract</i></p> | 58 | <i>Mostly relevant</i> |
| 26.2.24 | PubMed | Challenges to providing high quality care to dementia patients | <p><i>Peer Reviewed, Date: 2011-2023 Language: English</i></p> <p><i>Text Availability: Free full text and Abstract</i></p> | 22 | <i>Relevant</i> |

Table 2: Inclusion and exclusion criteria

| INCLUSION CRITERIA | EXCLUSION CRITERIA |
|--|--|
| Articles based on home care | Articles based on other nursing settings other than home care. |
| Articles that answer the research questions | Articles that are not relevant to the research questions |
| Articles that are scientific and peer reviewed | Articles that are not peer reviewed and scientific |
| Articles published between 2011 - 2024 | Articles published before 2011 |
| Articles written in English | Articles written in other languages other than English |
| Articles with full text access | Articles that are not available online as full access texts |
| Articles relevant to the research topic | Articles that are not relevant to the research topic. |

After conducting our search in accordance with the inclusion and exclusion criteria, we were able to narrow down our results to 10 articles which are listed in table 3 in Appendix 1.

4.2 QUALITATIVE INDUCTIVE DATA ANALYSIS

According to Elo S., Kääriäinen M., Kanste O., Pölkki T., Utriainen K. & Kyngäs H. (2014.) qualitative content analysis which is commonly used for analysing data depends on the trustworthiness implemented in every phase of the analysis process. They further state that qualitative content analysis can either be inductive, deductive or both. All processes involve three main phases. These are preparation, organisation, and reporting of results. (Elo S. et al 2014)

This thesis will implement qualitative inductive data analysis. This is led by a search of patterns in the data provided and then further reasoning which is done

by moving the data to a theoretical understanding, i.e., from the concrete and specific to the abstract and general. (Granheim, Ulla, Lindgren et Lundan, 2017) The three phases of qualitative inductive content analysis include the reduction phase, the clustering phase and the abstraction or categorization phase. (Huuskonen, 2024)

4.2.0 Reduction Phase

According to the National Science Foundation (2025) when analysing qualitative data, the data reduction phase includes choosing which aspects of the assembled data should be emphasized, minimized, or set aside to answer the research question or purpose. It also includes picking and cutting the results into simpler pieces. (Huuskonen, 2024)

| MAIN RESULTS | REDUCTION |
|---|---|
| <p>The results of this study showed that non-pharmacological practices that can be used to address behavioural and psychological symptoms of dementia.</p> <p>These practices were considered patient-centred and required minimal to moderate investment to implement (1)</p> | <p>1. Non-pharmacological practices are patient-centred and integral in addressing some symptoms of dementia. (1)</p> <p>2. Non-pharmacological practices are noted to be easy to implement. (1)</p> |
| <p>This study raised concerns about addressing the palliative needs of their clients living with dementia such as comfort, verbal or non-verbal communication, challenging behaviour, and familiarity. There was also a need for training and interdisciplinary collaboration</p> | <p>1. Palliative care is an important aspect of caring for people with dementia. (2)</p> <p>2. Training is needed to provide home care for dementia patients. (2)</p> <p>3. Interdisciplinary collaboration is needed to provide home care for dementia patients. (2)</p> |

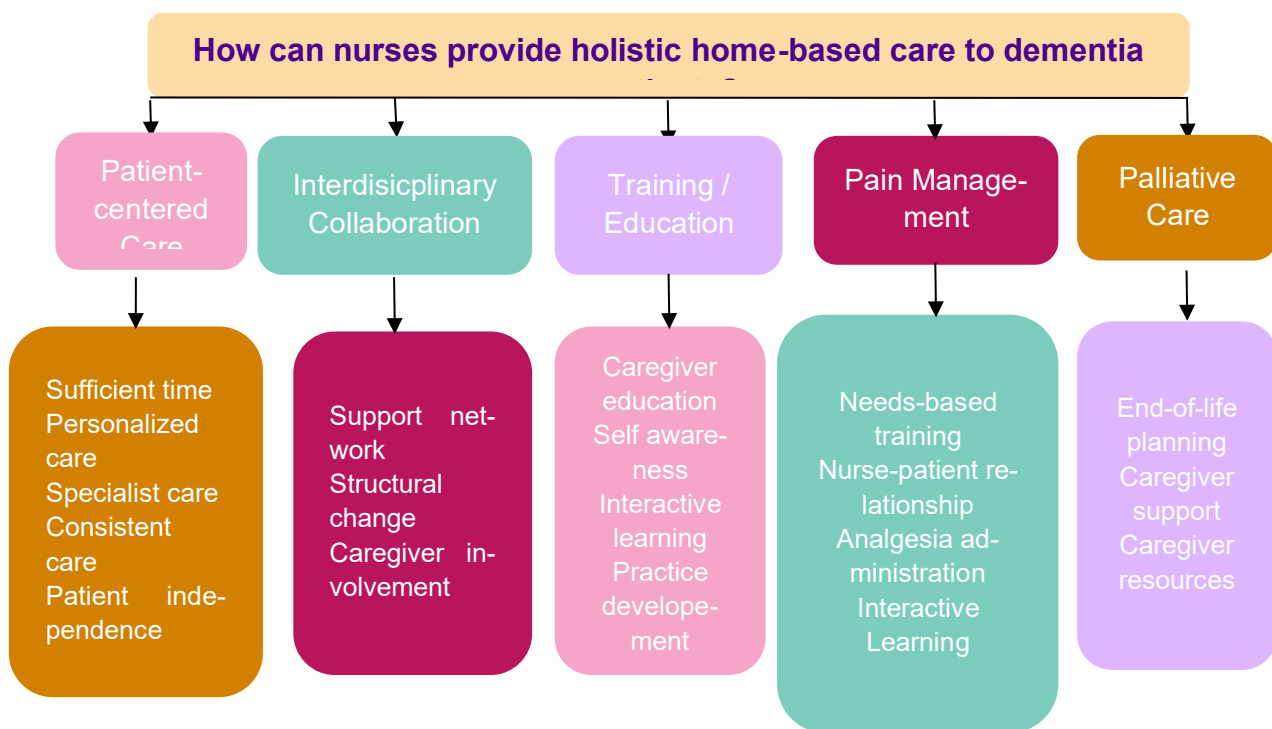
4.2.1 Clustering

The Miles and Huberman model (1994) describes this process of data display as going a step beyond data reduction to provide a compressed organized assembly of the information collected. At this stage additional higher order categories or themes emerge from the data. (NSF, 2025)

| Clustered Articles | Related Subject |
|---|-----------------------------|
| <p>Lack of time to spend with clients is a barrier to care. (4)</p> | <p>Patient-centred care</p> |
| <p>Person-centred care is essential in LTC settings. (5)</p> | |
| <p>Personalized activities that match the interests and abilities of people with dementia reduce behavioural symptoms and improve functioning. (6)</p> | |
| <p>Specialist care at home for people with dementia is mostly handled by general doctors and home care workers. (7)</p> | |
| <p>Key problems with informal caregivers include inconsistent care, lack of expertise, limited planning for end-of-life and reduced patient independence. (7)</p> | |
| <p>Improving the relationship needs of the patient was important to promote dignity preserving care for the dementia patient in a relationship-centred nursing network. (9)</p> | |

4.2.2 Categorization

According to Huuskonen (2024) this phase includes conceptualising the categories and forming them into a more general level. This includes considering what the final analyzed data means and assessing their implications to the research question at hand. (NSF, 2025)



5 RESULTS

Patient-centred care (PCC) is vital for dementia care, ensuring dignity, respect, and personal needs. Research highlighted challenges and solutions. (4) Found that temporary staff disrupted care consistency. (5) Emphasized the importance of adequate staffing, training, and communication for quality PCC. (6) Found non-exercise methods improve memory and well-being. (7) Noted that caregivers need better support. (9) Stressed the importance of social inclusion and identity for dignity. These studies confirm that PCC is important and called for better staffing, caregiver support, and dignity-focused care.

Interdisciplinary collaboration was a key theme in the studies reviewed. (2) Highlighted that nurses need to work closely with other healthcare professionals to address the complex needs of dementia patients, such as communication, comfort, and managing challenging behaviour. (3) Demonstrated how nurses rely on their support networks and stress the need for changes within the healthcare system to enhance teamwork. (6) Pointed out that effective dementia care involves a range of approaches, and collaboration between professionals is essential for improving patient outcomes. These studies emphasised on teamwork and communication between healthcare workers which are crucial for delivering high-quality dementia care, especially in home and long-term care settings.

The need for better training and education in dementia care was a common issue in the studies reviewed. (2) Emphasised the need for better training for nurses in palliative care for dementia patients, focusing on communication, comfort, and behaviour management. Similarly, (6) and (7) pointed out that both caregivers and healthcare workers often struggle to manage dementia symptoms and provide the best care because they are not adequately trained. (8) Noted that structured palliative care required skilled staff to manage the complex needs of dementia patients. (9) Emphasised that understanding how to preserve dignity for dementia patients requires the right training to implement a person-centred care approach. Additionally, (10) highlighted that nurses face challenges in managing pain for individuals with advanced dementia due to a lack of proper training and resources.

Managing pain in people with advanced dementia is difficult for nurses, as (10) highlighted. Key challenges included administering pain relief, limited medication options, poor communication with doctors, and insufficient training. Homecare nurses particularly struggled to assess pain in patients who cannot speak. The

study emphasised the need for better training, teamwork, and ongoing learning to improve pain management and care.

Palliative care for people with dementia was also a key focus in the studies reviewed. (2) Highlighted the challenges nurses face when providing palliative care, emphasised the importance of understanding each person's comfort, communication needs, and behaviour, as well as building close relationships. (7) Illustrated the emotional and practical challenges faced by caregivers, noted that there were gaps in support despite the availability of palliative care. (8) Suggested that a more structured approach to palliative care can reduce the burden on caregivers and improve the quality of life for dementia patients. These studies indicated that a holistic, patient-centred approach to palliative care, with better communication, training, and tailored services, is essential for meeting the complex needs of dementia patients at the end of life.

6 DISCUSSION

The reviewed articles recognized the importance and need of nurses to be able to provide a holistic healthcare approach when caring for dementia patients in home-based settings. It is important to note that improving the lives of people living with dementia is seen as both a moral necessity and an economic imperative (OECD, 2018). Findings showed that focusing on patient centred care, interdisciplinary collaboration, training and education, pain management and palliative care were all integral for nurses to provide holistic home based care that can enhance the quality of life and care received by dementia patients.

Patient centred care was a constant theme in most articles when discussing a holistic approach to caring for patients with dementia. This included treating the patients as individuals and invoking the person-centred care model. According to Kim and Park (2017) person centred care is an integrative and holistic approach designed to maintain wellbeing and quality of care for people with dementia by including different elements of care, the individual, the caregivers, and the family. Recognizing and addressing the client's needs such as comfort, verbal and non-verbal communication, challenging behaviours, and familiarity, knowing and understanding the person living with dementia and building close care relationships were also argued as a concern that needed to be raised and improved when providing holistic dementia care (Bolt SR et al, 2019)

Personalized activities that matched the interests of the patients living with dementia were also seen to both reduce behavioural symptoms and improve functioning whereas lack of adequate time spent with individual clients was seen as a barrier to care (Tan DGH et al, 2022: Midtbust MH et al, 2018)

Morgan et al, (2022) also noted that specialized care being handled at home-based setting by trained healthcare givers ensured a more patient centred care approach whereas care given by informal caregivers highlighted a decline in the ability for the patients to receive patient centred care. Fang et al (2024) also used the person-centred model to explore the factors that tend to preserve the patient's dignity and autonomy. These factors included improving the patient's external environment, the patients' relationship needs and the need of construction of self-awareness of the patient to improve their quality of life. (Fang et al, 2024)

This study also revealed that interdisciplinary collaboration, which included a dedicated support network, structural change and caregiver involvement was seen as a critical component in providing holistic care to people living with dementia.

According to the World Health Organization, interprofessional collaboration is “when multiple health workers from different professional backgrounds work together with patients, families, carers and communities to deliver the highest quality of care across settings” (WHO,2010)

Bolt et al (2019), Hoe J et al (2023) and Tan DGH et al (2022) all demonstrated how collaboration between other healthcare professionals, reliance on support networks for advice and caregiver involvement in nursing interventions was very essential for improving patient outcomes and the quality of life of people living with dementia.

Alzheimer’s Society (2024) expresses how both quality and evidence-based training has numerous benefits for both healthcare staff and patients living with dementia. The research however revealed that lack of training and education was a major issue that needs to be addressed when providing quality holistic care to patients living with dementia. Both Bolt Sr et al (2019) and Mogan et al (2022) recognized the need for caregiver training when providing palliative care for people living with dementia. Studies conducted further highlighted that adequate training could help ease the emotional and practical burden bereaved caregivers sometimes faced while caring for people with dementia at the end of life in domiciliary settings. (Mogan et al, 2022) Adequate training interventions on non-exercise strategies such as cognitive stimulation in managing dementia within home settings, symptom management, communication, and advanced care planning were seen as methods that could improve cognitive function, quality of life and daily function of patients living with dementia by also effectively decreasing caregiver burden. (Tan DGH et al, 2022: Cole et al 2023)

De witt Jansen et al (2017) also argued that significant gaps in differences in experiences of training development, lack of interactive learning and practical development were key challenges nurses experienced when providing pain management to patients at end-of-life dementia. The studies highlighted that continuous needs-based training and learning and providing opportunities for sharing knowledge and skills were imperative and benefited and supported both caregivers and patients.

The need for palliative care, which focuses on care, comfort and quality of life may increase while caring for patients with advanced dementia. Mogan et al (2002) highlighted the emotional and practical challenges caregivers may expe-

rience at this stage and that improvement of communication, training and personalization of services could enhance the care experience for the dementia patients at the end of life. Furthermore, Cole et al (2023) added that integrating palliative care models including proactive end of life planning, caregiver support and caregiver resources can enhance the quality-of-life for patients while simultaneously reducing the burdens experienced by carers.

The study also revealed pain management as a critical key role in meeting the patients' needs when. The Department of Health (2009) states that optimal palliative care for people with dementia, including the management of pain, is highlighted as a priority in health policy globally. De Witt Jansen et al (2017) thus argues that it is critical to understand the barriers nursing and healthcare professionals have when meeting the patient's needs. The barriers include troubles in administering analgesia, constricted routes of administration of pain medication, lack of proper communication between nurses and physicians, lack of interactive learning, lack of practice development and lack of needs-based training to support and promote development in pain management in end of stage dementia. Nurses also expressed challenges in assessing pain in nonverbal dementia patients and the need to rely on non-verbal cues to assess pain.

According to Warden, Hurley and Volicer, (2003) use of the Pain Assessment scale (PAINAD) had a good construct validity and reliability and helped successfully measure pain while treating patients with advanced dementia. This was done by observing the patients for a while in different conditions before and after pain medication and then scoring their behaviours. The behaviours included body language, facial expression, consolability and both breathing independent of vocalization and with negative vocalization. The score would then be tallied from 0-10 points with 1-3 being mild pain, 4-6 moderate pain and 7-10 severe pain (Warden et al 2003)

The overall reviewed findings of the study suggested that multidimensional approaches that included incorporating the person-centred care model, specialized and continued training and education, effective interdisciplinary collaboration, comprehensive pain management and structured approaches to palliative care are imperative for nurses to be able to provide holistic home-based care to patients with dementia.

The need for improvement in delivery of holistic care can further be implemented by providing nurses with proper support, training, and resources that they need to care for dementia patients and enhance their well-being. As suggested by Warren (2023) a multidisciplinary approach addressing several care needs that include psychosocial, physical, and emotional avenues can lead to optimized care for people living with dementia.

7 RELATED TOPICS & RESEARCH ETHICS

The overall reviewed findings of the study suggested that multidimensional approaches that included incorporating the person-centred care model, specialized and continued training and education, effective interdisciplinary collaboration, comprehensive pain management and structured approaches to palliative care are imperative for nurses to be able to provide holistic home-based care to patients with dementia. The need for improvement in delivery of holistic care can further be implemented by providing nurses with proper support, training, and resources that they need to care for dementia patients and enhance their well-being.

Further research topics can also be implemented to discuss the various organisational and structural barriers that nurses and healthcare professionals face while administering holistic home-based care to clients and more research on how long-term use of the patient centred model has improved outcomes on patients' well-being especially when applied over an extended period.

As suggested by Warren (2023) a multidisciplinary approach addressing several care needs that include psychosocial, physical, and emotional avenues can lead to optimized care for people living with dementia.

The reliability and trustworthiness of this study was based on the reliability of the peer reviewed articles selected. This work maintains originality as every information gotten from other sources were duly referenced. The work adhered to the ethical principles of research and as much as possible avoided plagiarism, fabrication, and falsification. (Finnish Advisory Board and Research Integrity, 2012, 32-33)

According to Khalid Ahmed, (2024) the nursing research community has constantly embraced qualitative research approaches as it heavily emphasizes on credibility, transferability, and dependability. This study ensured that those key factors were incorporated when researching on articles that consistently supported the theme of the research question. However, it is important to note that reliability of the study could be affected by the variability of methodologies used in the studies collected. There is also a possibility as well for potential bias by only choosing articles that only supported the main theme of the research question according to patient and caregiver experiences.

7.1 LIMITATIONS AND TRANSFERABILITY

Ahmed (2024) states that transferability pertains to the extent that the research findings can be applied in different settings and situations. While the study provided valuable research on the best way to provide holistic care for patients in home-based settings, the transferability of the information obtained may be affected by cultural differences in different health care settings, patient-client relationships, and availability of resources in the health care facilities. The articles also focused on research articles from all around the world which may have results that are not applicable in a Finnish health care setting.

Other limitations of the study include the fact that the articles focused only on English speaking articles published in the last ten years thus a lot of material and information may have been excluded. A limited number of databases and key words were also utilised. Articles reviewed were also primarily only based on existing research which may present a limited picture of the area being studied that is only a reflection of the surface. (Johnson, 1953)

Overall, while the articles reviewed presented reliable findings on holistic care of dementia in a home-based setting, reliability and transferability should be taken into careful consideration when analysing the overall results of the study.

8 CONCLUSION

In conclusion, this literature review has shown that nurses face barriers in the care for patients with dementia at home such as lack of time and resources to facilitate consistent and specialized care resulting in person-centred care, a need for staff, and caregiver training and education, a lack of interdisciplinary collaboration that would allow for a more holistic and well-rounded care, the study highlighted a need for pain management training for both caregivers and staff and the importance of palliative care planning and support for caregivers.

The study also noted numerous cases of nurses feeling unsupported by their organization and how all these took a toll on them emotionally. Our literature review concluded that addressing these challenges and working to resolve them would facilitate a more holistic approach to homecare for dementia patients. Thus, further research is recommended to evaluate further how nurses can provide holistic homecare for dementia patients.

9 REFERENCES

- Arvanitakis Z, Shah RC, Bennett DA. Diagnosis and Management of Dementia: Review. *JAMA*. 2019;322(16):1589–1599. doi:10.1001/jama.2019.4782
- Beck, C., & Heacock, P. (1988). Nursing interventions for patients with Alzheimer's disease. *Nursing Clinics of North America*, 23(1), 95-124
- Bolt SR, van der Steen JT, Schols JMGA, Zwakhalen SMG, Pieters S, Meijers JMM. Nursing staff needs in providing palliative care for people with dementia at home or in long-term care facilities: A scoping review. *Int J Nurs Stud*. 2019 Aug; 96:143-152. doi: 10.1016/j.ijnurstu.2018.12.011. Epub 2019 Jan 3. PMID: 30928183.
- Cerejeira J, Lagarto L, Mukaetova-Ladinska EB. Behavioral and psychological symptoms of dementia. *Front Neurol*. 2012 May 7;3:73. doi: 10.3389/fneur.2012.00073. PMID: 22586419; PMCID: PMC3345875.
- Chen, N., & Yang, K. (2022): Home-based care for people with dementia: A systematic review. *Campbell Systematic Reviews*, 18, e1285. 10.1002/cl2.1285
- Cole CS, Dafoe A, Tietbohl CK, Jordan SR, Huebschmann AG, Lum HD, Jones CD. Care challenges of home health patients living with dementia: a pathway forward with palliative care. *BMC Palliat Care*. 2023 Aug 29;22(1):122. doi: 10.1186/s12904-023-01247-9. PMID: 37641096; PMCID: PMC10464392.
- Dementia Australia 2024 <https://www.dementia.org.au/about-dementia> retrieved: 13.3.2024
- De Witt Jansen B, Brazil K, Passmore P, Buchanan H, Maxwell D, McIlfactrick SJ, Morgan SM, Watson M, Parsons C. Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study.
- Dixon, B. E., & Cusack, C. M. (2023). Measuring the value of health information exchange. In *Health Information Exchange* (pp. 379-398). Academic Press.
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K., & Kyngäs, H. (2014). *Qualitative Content Analysis*. SAGE Open, 4. <https://doi.org/10.1177/2158244014522633>
- Fang, S., Zhi, S., Song, D., Sun, J., Gao, S., Wang, Y., ... Dong, W. (2024). Dignity-preserving care of people with dementia in different nursing environments: a qualitative systematic review
- Finnish National Board on Research Integrity (TENK). (2023). Responsible conduct of research. Retrieved: 07.04.2025. [Responsible conduct of research and procedures for handling allegations of misconduct in Finland | Finnish National Board on Research Integrity TENK](#)
- Griffin, G. (2013) *Research methods for English studies*. Second edition. Gabriele Griffin (ed.). [Online]. Edinburgh, Scotland: Edinburgh University Press.

Hoe J, Trickey A, McGraw C. Caring for people living with dementia in their own homes: A qualitative study exploring the role and experiences of registered nurses within a district nursing service in the UK. *Int J Older People Nurs.* 2023 Jan;18(1):e12491. doi: 10.1111/opn.12491. Epub 2022 Jul 18. PMID: 35851749.

Johansson, L. & Silén, M. (2018) Research methods in nursing students' Bachelor's theses in Sweden: A descriptive study. *Nurse education today.* [Online] 66187–193.

Midtbust MH, Alnes RE, Gjengedal E, Lykkeslet E. Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professionals' experiences. *BMC Health Serv Res.* 2018 Sep 12;18(1):709. doi: 10.1186/s12913-018-3515-x. PMID: 30208872; PMCID: PMC6134769.

Mogan C, Harrison Denning K, Dowrick C, Lloyd-Williams M. Health, and social care services for people with dementia at home at the end of life: A qualitative study of bereaved informal caregivers' experiences. *Palliat Med.* 2022 Jun;36(6):976-985. doi: 10.1177/02692163221092624. Epub 2022 Apr 23. PMID: 35466787; PMCID: PMC9174574.

National Health Service UK. (2023). Symptoms of Dementia. <https://www.nhs.uk/conditions/dementia/symptoms-and-diagnosis/symptoms/> retrieved: 23.3.2024

Responsible Conduct of Research (RCR) | Finnish National Board on Research Integrity TENK
<https://tenk.fi/en/research-misconduct/responsible-conduct-research-rcr/> retrieved:15.3.2024

Scales K, Zimmerman S, Miller SJ. Evidence-Based Nonpharmacological Practices to Address Behavioural and Psychological Symptoms of Dementia. *Gerontologist.* 2018 Jan 18;58(suppl_1): S88-S102. doi: 10.1093/geront/gnx167. PMID: 29361069; PMCID: PMC5881760.

Tan DGH, Boo BMB, Chong CS, Tan MML, Wong BS. Effectiveness of home-based, non-exercise interventions for dementia: A systematic review. *Front Aging Neurosci.* 2022 Aug 11;14:846271. doi: 10.3389/fnagi.2022.846271. PMID: 36034133; PMCID: PMC9403464.

THL 2023. Muistisairaudet. <https://thl.fi/aiheet/kansantaudit/muistisairaudet/> retrieved:15.3.2024

Travers JL, Wittenberg GF, Gifford DR, Reddy A, McLaughlin MM, Baier RR. Providers' Perspectives on High-Quality Dementia Care in Long-Term Care. *J Am Med Dir Assoc.* 2022 Dec;23(12):2030.e1-2030.e8. doi: 10.1016/j.jamda.2022.07.025. Epub 2022 Sep 2. PMID: 36058295; PMCID: PMC11307288.

National Institute of Ageing. 2023. Caregiving Services for Older People Living at Home. <https://www.nia.nih.gov/health/caregiving/services-older-adults-living-home> retrieved 05.9 2024

Warden V, Hurley AC, Volicer L. Development, and psychometric evaluation of the Pain Assessment in Advanced dementia (PAINAD) SCALE. J Am Med Dir Assoc. 2003;4(1):9-15.

Watanabe, Mitsunori et al. "Analyses of Natural Courses of Japanese Patients with Alzheimer's Disease Using Placebo Data from Placebo-Controlled, Randomized Clinical Trials: Japanese Study on the Estimation of Clinical Course of Alzheimer's Disease." *Alzheimer's & dementia: translational research & clinical interventions* 5.1 (2019): 398–408. Web

World Health Organization. (2023). Dementia <https://www.who.int/news-room/fact-sheets/detail/dementia/> retrieved: 22.3.2024

World Health Organization. (2012). Dementia a Public Health Priority. *Retrieved: 22.02.2024*

10 APPENDICES

Appendix 1. Included Articles

| Author, Title, Journal, Publication year, Country | Purpose of the research | Method Study population | Main results |
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| <p>1. Scale K, Zimmerman S, Miller SJ. Evidence-Based Non-pharmacological Practices to Address Behavioural and Psychological Symptoms of Dementia. <i>Gerontologist</i>. 2018 Jan 18;58(suppl_1): S88-S102. doi: 10.1093/geront/gnx167. PMID: 29361069; PMCID: PMC5881760</p> | <p>The purpose of this study is to identify, describe and critique non-pharmacological practices that can be used to address behavioural and psychological symptoms of Dementia and to provide evidence-based recommendations that would be useful to caregivers and healthcare workers</p> | <p>A search of systematic literature reviews between 2010-2017</p> | <p>Nonpharmacological practices are person-centered, and their selection can be informed by considering the cause and meaning of the individual's behavioural and psychological symptoms. These practices include sensory practices (aromatherapy, massage, multi-sensory stimulation, bright light therapy), psychosocial practices</p> |

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| | | | (validation therapy, reminiscence therapy, music therapy, pet therapy, meaningful activities), and structured care protocols (bathing, mouth care). Most practices are acceptable, have no harmful effects, and require minimal to moderate investment. |
| 2.Bolt SR, van der Steen JT, Schols JMGA, Zwakhalen SMG, Pieters S, Meijers JMM. Nursing staff needs in providing palliative care for people with dementia at home or in long-term care facilities: A scoping review. <i>Int J Nurs Stud.</i> 2019 Aug;96:143-152. doi: 10.1016/j.ijnurstu.2018.12.0 | This study's purpose was to investigate the need to provide palliative care to people living with dementia from the nurses' perspective who | The authors used a scoping review method combined with thematic analysis methods | There were concerns raised about recognizing and addressing the clients' needs such as comfort, verbal or non- |

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| <p>11. Epub 2019 Jan 3. PMID: 30928183.</p> | <p>worked in home care or in long-term facilities.</p> | | <p>verbal communication, challenging behaviour, and familiarity. There was also a need for training and interdisciplinary collaboration</p> |
| <p>3.Hoe, J., Trickey, A. and McGraw, C. (2023) 'Caring for people living with dementia in their own homes: A qualitative study exploring the role and experiences of registered nurses within a district nursing service in the UK', <i>International Journal of Older People Nursing</i>, 18(1), pp. 1–13. doi:10.1111/opn.12491</p> | <p>The main purpose was to gain insight on the role and experiences of nurses caring for people with dementia at home and the challenges they face.</p> | <p>The study was informed by a descriptive phenomenological approach. Semi-structured interviews were conducted with a purposive sample of ten nurses working in DNS. Data were analysed thematically.</p> | <p>The study revealed the experiences of delivering care for dementia patients at home, it revealed how the health care team adapted and responded to the complexity of the needs of dementia patients, it also reflected on the unpredictability of dementia patients' needs</p> |

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| | | | and how this affected their workload, it detailed the networks that the nurses used to get advice and support, it also identified the need for structural changes and resources needed to allow for the nurses to better provide the care needed. |
| 4.Midtbust MH, Alnes RE, Gjengedal E, Lykkeslet E. Perceived barriers and facilitators in providing palliative care for people with severe dementia: the healthcare professionals' experiences. BMC Health Serv Res. 2018 Sep 12;18(1):709. doi: 10.1186/s12913-018-3515-x. PMID: 30208872; PMCID: PMC6134769. | This study explores the barriers in providing care to palliative dementia patients. | A qualitative research review was used, and semi-structured interviews were used as well | The study described various structural and organisational challenges that nurses' and other health care professionals face in providing care to palli- |

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| | | <p>ative dementia patients. They pointed out issues such as a lack of continuity of care which can be attributed to the extensive use of temporary professionals instead of employing more permanent ones. They also pointed out the time pressures they feel and the efficiency requirements they are expected to meet which affects the care they provide. There was also a mention of an internal strug-</p> |
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| | | | <p>gle of wanting to spend sufficient time with each client versus the pressure to have enough time to care for everyone</p> |
| <p>5.Travers JL, Wittenberg GF, Gifford DR, Reddy A, McLaughlin MM, Baier RR. Providers' Perspectives on High-Quality Dementia Care in Long-Term Care. J Am Med Dir Assoc. 2022 Dec;23(12):2030.e1-2030.e8. doi: 10.1016/j.jamda.2022.07.025. Epub 2022 Sep 2. PMID: 36058295; PMCID: PMC11307288.</p> | <p>The purpose of the study was to understand dementia care providers' views on delivering high-quality, person-centred care for people living with dementia in long-term care settings.</p> | <p>Five listening sessions on dementia care models and practices were held. Researchers mapped the data to the HATCh(Holistic Approach to Transformational Change) model, identified themes, and coded data with input from others to reach agreement. Follow-up sessions were</p> | <p>The study found that high-quality dementia care in long-term care (LTC) should focus on understanding and prioritising the preferences of persons living with dementia (PLWD). The study highlighted the need for person-centred care</p> |

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| | | done to ensure data accuracy. | in LTC (Long Term Care) settings. |
| 6.Tan DGH, Boo BMB, Chong CS, Tan MML, Wong BS. Effectiveness of home-based, non-exercise interventions for dementia: A systematic review. <i>Front Aging Neurosci.</i> 2022 Aug 11;14:846271. doi: 10.3389/fnagi.2022.846271. PMID: 36034133; PMCID: PMC9403464. | Dementia causes cognitive decline and increased dependency, with most people living with dementia (PLWDs) staying at home. While many studies focus on exercise interventions, less is known about the effects of non-exercise home-based interventions. This review examines how these interventions impact the behaviour, function, cognition, and | A search was conducted on multiple databases, including CINAHL, PubMed, and Web of Science, up to June 2020, with a manual search of article bibliographies. The review included studies meeting these criteria: (i) participants diagnosed with dementia, (ii) living at home, (iii) home-based interventions excluding physical exercise, (iv) RCTs or quasi-experi- | Eighteen studies (14 RCTs and 4 quasi-experimental) were included, covering various interventions like occupational therapy, cognitive rehabilitation, and music therapy. Results were mixed, but key features emerged. Personalised activities aligned with the interests and abilities of people with dementia (PLWDs) re- |

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| | mood of PLWDs, and the quality of life, burden, and mood of their caregivers. | mental designs, and (v) full-text studies published in English in peer-reviewed journals. | duced behavioural symptoms and improved function. |
| 7.Mogan C, Harrison Dening K, Dowrick C, Lloyd-Williams M. Health, and social care services for people with dementia at home at the end of life: A qualitative study of bereaved informal caregivers' experiences. <i>Palliat Med.</i> 2022 Jun;36(6):976-985. doi: 10.1177/02692163221092624. Epub 2022 Apr 23. PMID: 35466787; PMCID: PMC9174574. | The study aimed to explore informal caregivers' experiences with health and social care services while caring for individuals with dementia and Alzheimer's disease at home during end-of-life. By identifying their needs and challenges through qualitative interviews and thematic analysis, the research | This qualitative interview study involved thematic analysis of data collected from twenty-nine bereaved informal caregivers who cared for a person with dementia at home during the last six months of life. | The study revealed that specialist palliative care for individuals with dementia at home is rare, with most care managed by general practitioners and domiciliary care workers. Four key themes were identified: poor continuity of care, lack of expertise, limited advance care planning, and loss of pa- |

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| | sought to enhance caregiver support and improve care services for dementia patients. | | tient autonomy. The findings underscore the need for proactive end-of-life planning and highlight the importance of improving the qualifications and training of domiciliary care services in this context. |
| 8.Cole CS, Dafoe A, Tietbohl CK, Jordan SR, Huebschmann AG, Lum HD, Jones CD. Care challenges of home health patients living with dementia: a pathway forward with palliative care. BMC Palliative Care. 2023 Aug 29;22(1):122. doi: 10.1186/s12904-023-01247-9. PMID: 37641096; PMCID: PMC10464392. | The study aimed to explore how palliative care could be integrated into home health care (HHC) to better support people with dementia and their family caregiver. This research | The study included older adults with dementia receiving home health care (HHC) after hospital discharge, along with their family caregivers. Participants were selected to explore | Caregivers needed to plan, not just focus on daily tasks. Adding palliative care provided better support and resources. Overall, the findings underscored the need for |

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| | <p>focused on understanding the needs and experiences of patients and caregivers to improve care quality and help manage the emotional and practical challenges of caregiving.</p> | <p>their experiences and needs, focusing on how integrating palliative care into Home Health Care (HHC) could improve support for both patients and caregivers.</p> | <p>guidance on safety, care planning, and emotional support to help caregivers manage their challenges to provide improved home-based care to dementia patients.</p> |
| <p>9. Fang, S., Zhi, S., Song, D., Sun, J., Gao, S., Wang, Y., ... Dong, W. (2024). Dignity-preserving care of people with dementia in different nursing environments: a qualitative systematic review. <i>Contemporary Nurse</i>, 60(3), 300–317.</p> | <p>This study's aim was to systematically identify, evaluate and put together qualitative evidence about the dignity-related nursing experiences of people with dementia in families and nursing homes, it also aimed to analyse the</p> | <p>A combination of qualitative studies retrieved from 8 databases published before September 2022. Inclusion criteria was established through the PICOS principle and Quality assessment was guided by Joanna Briggs Institute's Qualitative</p> | <p>Three key elements that affected dignity preserving care included, the living environment, the relationship needs and improving the self-awareness of patients with dementia to promote dignity. These were connected in</p> |

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| | causes and influencing factors of providing this kind of care. | Assessment and Review Instrument | focusing on improving the dementia-centred nursing environment and meeting the needs of the relationship-centred nursing network. |
| 10. De Witt Jansen B, Brazil K, Passmore P, Buchanan H, Maxwell D, McIlfactrick SJ, Morgan SM, Watson M, Parsons C. Nurses' experiences of pain management for people with advanced dementia approaching the end of life: a qualitative study. <i>J Clin Nurs</i> . 2017 May;26(9-10):1234-1244. doi: 10.1111/jocn.13442. Epub 2017 Feb 7. PMID: 27324751. | This study aimed to explore hospice, acute care, and nursing home nurses' experiences of pain management for people with advanced dementia in the final month of life and to identify the challenges, facilitators and practice areas requiring further support. | A qualitative study using semi-structured interviews and thematic analysis to examine data | Three themes were identified, i.e. challenges administering analgesia, the nurse-physician relationship, and interactive learning and practice development. Patient-related challenges to pain management were universal across |

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| | | | care settings. In conclusion, achieving pain management in practice was highly challenging and Needs-based training to support and promote practice development in pain management in end-stage dementia is required |
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Appendix 2. Reduction Phase

| MAIN RESULTS | REDUCTION |
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| <p>The results of this study showed that non-pharmacological practices that can be used to address behavioural and psychological symptoms of dementia.</p> <p>These practices were considered patient-centred and required minimal to moderate investment to implement (1)</p> | <ol style="list-style-type: none"> 1. Non-pharmacological practices are patient-centred and integral in addressing some symptoms of dementia. (1) 2. Non-pharmacological practices are noted to be easy to implement. (1) |
| <p>This study raised concerns about addressing the palliative needs of their clients living with dementia such as comfort, verbal or non-verbal communication, challenging behaviour, and familiarity. There was also a need for training and interdisciplinary collaboration</p> | <ol style="list-style-type: none"> 1. Palliative care is an important aspect of caring for people with dementia. (2) 2. Training is needed to provide home care for dementia patients. (2) 3. Interdisciplinary collaboration is needed to provide home care for dementia patients. (2) |
| <p>The study revealed the experiences of delivering care for dementia patients at home, it revealed how the health care team adapted and responded to the complexity of the needs of dementia patients, the unpredictability of dementia patients' needs and how this affected their workload, the networks that the nurses used to get advice and support, and the need for structural changes and resources needed to allow for the nurses to better provide the care needed.</p> | <ol style="list-style-type: none"> 1. The needs of dementia patients, their unpredictable behaviour requires their health care team to adapt to respond effectively. (3) 2. Nurses use their network of support for advice. (3) 3. Structural changes are needed to better provide care for dementia patients at home. (3) |
| <p>The study described various structural and organisational barriers that nurses' and other health care professionals face. They pointed out issues such as a lack of continuity of care. They also pointed out the lack of time and the efficiency requirements they are expected to meet which affects the care they provide. There was also a mention of an internal struggle of wanting to spend sufficient time with each client versus the pressure to have enough time to care for everyone</p> | <ol style="list-style-type: none"> 1. Lack of continuity of care is a barrier to providing care to dementia patients. (4) 2. Lack of time to spend with clients is a barrier to care. (4) |
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| <p>The study found that high-quality dementia care in long-term care (LTC) should focus on understanding and prioritizing the preferences of persons living with dementia (PLWD). The study highlighted the need for person-centred care in LTC (Long Term Care) settings. (5)</p> | <ol style="list-style-type: none"> 1. Effective dementia care in LTC should prioritise the preferences of PLWD. (5) 2. Person-centred care is essential in LTC settings. (5) |
| <p>The study covered various interventions like occupational therapy, cognitive rehabilitation, and music therapy. Results were mixed, but key features emerged. Personalized activities aligned with the interests and abilities of people with dementia (PLWDs) reduced behavioural symptoms and improved function. Caregiver involvement enhanced intervention effectiveness and improved quality of life, especially when not too demanding. Caregiver education also reduced burden, particularly when the PLWD's functional status improved. (6)</p> | <ol style="list-style-type: none"> 1. Personalized activities that match the interests and abilities of people with dementia reduce behavioural symptoms and improve functioning. (6) 2. Caregiver involvement in interventions enhances their effectiveness and improves the quality of life for people with dementia. (6) 3. Caregiver education decreases burden, especially when the functional status of the person with dementia improves. (6) |
| <p>The study revealed that specialist palliative care for individuals with dementia at home is rare, with most care managed by general practitioners and domiciliary care workers. Four key themes were identified: poor continuity of care, lack of expertise, limited advance care planning, and loss of patient autonomy. The findings underscore the need for proactive end-of-life planning and highlight the importance</p> | <ol style="list-style-type: none"> 1. Specialist care at home for people with dementia is mostly handled by general doctors and home care workers. (7) 2. Key problems with informal caregivers include inconsistent care, lack of expertise, limited planning for end-of-life and reduced patient independence. (7) |

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| <p>of improving the qualifications and training of domiciliary care services in this context. (7)</p> | <p>3.Proactive end-of-life planning is needed, along with better training for domiciliary care services. (7)</p> |
| <p>Caregivers needed to plan, not just focus on daily tasks. Adding palliative care provided better support and resources. Overall, the findings underscored the need for guidance on safety, care planning, and emotional support to help caregivers manage their challenges to provide improved home-based care to dementia patients. (8)</p> | <p>1.Caregivers must plan, not just focus on daily tasks. (8) 2.Palliative care improves support and resources for caregivers (.8) 3.There is a need for guidance on safety, care planning, and emotional support for caregivers of dementia patients. (8)</p> |
| <p>Three key elements that affected dignity preserving care included, the living environment, the relationship needs and improving the self-awareness of patients with dementia to promote dignity. These were connected in focusing on improving the dementia-centred nursing environment and meeting the needs of the relationship-centred nursing network.</p> | <p>1. Improving the living environment of the patient was important to promoting dignity preserving care for the dementia patient in a dementia-centred nursing environment. (9) 2.Improving the relationship needs of the patient was important to promote dignity preserving care for the dementia patient in a relationship-centred nursing network. (9) 3.Improving the self-awareness of the patient was important to promoting dignity preserving care for the dementia patient. (9)</p> |

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| <p>Three themes were identified as problem areas, i.e. challenges administering analgesia, the nurse-physician relationship, and interactive learning and practice development. Patient-related challenges to pain management were universal across care settings. In conclusion, achieving pain management in practice was highly challenging and Needs-based training to support and promote practice development in pain management in end-stage dementia is required</p> | <p>1.Administering analgesia was a challenge for many nurses when administering pain administration in end stage dementia. (10)</p> <p>2.Nurse-Physician relationship was a challenge for many nurses when administering pain administration in end stage dementia. (10)</p> <p>3. Interactive learning and practice development was a challenge for many nurses when administering pain administration in end stage dementia. (10)</p> <p>4. Needs-based training to support and promote practice development in pain management in end-stage dementia is required. (10)</p> |
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Appendix 5. Clustering Phase

| Clustered Articles | Related Subject |
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| <p>Lack of time to spend with clients is a barrier to care. (4)</p> | <p>Patient-centred care</p> |
| <p>Person-centred care is essential in LTC settings. (5)</p> | |
| <p>Personalized activities that match the interests and abilities of people with dementia reduce behavioural symptoms and improve functioning. (6)</p> | |

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| <p>Specialist care at home for people with dementia is mostly handled by general doctors and home care workers. (7)</p> <p>Key problems with informal caregivers include inconsistent care, lack of expertise, limited planning for end-of-life and reduced patient independence. (7)</p> <p>Improving the relationship needs of the patient was important to promote dignity preserving care for the dementia patient in a relationship-centred nursing network. (9)</p> | |
| <p>Palliative care is an important aspect of caring for people with dementia. (2)</p> <p>Key problems with informal caregivers include inconsistent care, lack of expertise, limited planning for end-of-life and reduced patient independence. (7)</p> <p>Proactive end-of-life planning is needed, along with better training for domiciliary care services. (7)</p> <p>Palliative care improves support and resources for caregivers (8)</p> | Palliative care |
| <p>Interdisciplinary collaboration is needed to provide home care for dementia patients. (2)</p> <p>Nurses use their network of support for advice. (3)</p> | Interdisciplinary collaboration |

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| <p>Structural changes are needed to better provide care for dementia patients at home. (3)</p> <p>Caregiver involvement in interventions enhances their effectiveness and improves the quality of life for people with dementia. (6)</p> | |
| <p>Training is needed to provide home care for dementia patients. (2)</p> <p>Caregiver education decreases burden, especially when the functional status of the person with dementia improves. (6)</p> <p>Proactive end-of-life planning is needed, along with better training for domiciliary care services. (7)</p> <p>There is a need for guidance on safety, care planning, and emotional support for caregivers of dementia patients. (8)</p> <p>Improving the self-awareness of the patient was important to promoting dignity preserving care for the dementia patient. (9)</p> <p>Interactive learning and practice development was a challenge for many nurses when administering pain administration in end stage dementia. (10)</p> <p>Needs-based training to support and promote practice development in pain management in end-stage dementia is required. (10)</p> | <p>Need for training and education</p> |
| <p>Administering analgesia was a challenge for many nurses when administering pain administration in end stage dementia. (10)</p> | <p>Pain management</p> |

Nurse-Physician relationship was a challenge for many nurses when administering pain administration in end stage dementia. (10)

Interactive learning and practice development was a challenge for many nurses when administering pain administration in end stage dementia. (10)

Needs-based training to support and promote practice development in pain management in end-stage dementia is required. (10)

