Dissertation

Title: What do nursing home staff understand about dementia and the palliative approach to dementia care?

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To my friends and family who understood why I had to ‘go to ground’ and put social activities on the back burner for periods of time, and who checked in regularly to offer encouragement and support, thank you.

DECLARATION

I, Aileen Sandra Forbes, hereby declare that the work in this dissertation is my original work (except where acknowledgments indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university. I empower the university to reproduce for the purpose of research either the whole or any part of the content in any manner whatsoever.

Signature:

Signed by candidate

Date: 19.1.2025

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Glossary

COPD	Chronic obstructive pulmonary disease
CW	Care worker
DKAS	Dementia Knowledge Assessment Scale
DSD	Department of Social Development
EN	Enrolled Nurse
EOL	End-of-life
HCP	Health care professional
HIV	Human immune-deficiency virus
HREC	Human Research Ethics Committee
IPOS	Integrated Palliative Outcome Scale
LMIC	Low to middle-income countries
LTCF	Long-term care facility
NH	Nursing home
NGO	Non-governmental organisation
NPO	Non-profit organisation
PANA	Palliative Approach for Nursing Assistants
PN	Professional Nurse
QOL	Quality of life
SA	South Africa
SANC	South African Nursing Council

Abstract

Background: Globally, the number of people diagnosed with dementia is set to continue to rise, and in the advanced stage of this disease, many patients require nursing home (NH) care. The symptom burden of advanced dementia suggests that a palliative approach to care is not only appropriate but necessary, and NH staff need a sound understanding of dementia and the role palliative care plays in alleviating suffering. Little is known about the knowledge held by NH staff in South Africa in these areas.

Aim: The purpose of this study was to determine what NH staff know and understand about dementia and palliative care.

Methods: The study used a concurrent mixed methods design, with quantitative data obtained by 184 participants completing questionnaires on dementia and palliative care, and qualitative data from the interviews of 14 NH staff. The quantitative and qualitative data were then merged through a narrative discussion.

Results: The findings of this study indicate that knowledge gaps exist in dementia and palliative care across all categories of staff in the NHs that participated in this study. It also highlights reliance on intuition and personal experience rather than on the education of NH staff to deliver high-standard care and draws attention to unmet training needs and the impact end-of-life care has on NH staff.

Conclusion: The knowledge gaps seen consistently across facilities not only identify training needs but highlight the untapped potential of NH staff to provide quality palliative care to patients with advanced dementia. Further research looking at the specific unmet needs of patients with advanced dementia in NHs in South Africa, and how best to maximise the potential of NH staff through education and training would be valuable.

Chapter 1: Introduction

Dementia is an umbrella term for a neurological syndrome characterised by a cluster of signs and symptoms associated with progressive neurocognitive decline (1). In the advanced stages of dementia, patients experience a significant symptom burden not dissimilar to that of cancer patients and face extensive end-of-life (EOL) challenges (2).

Diseases causing neurocognitive decline, such as Alzheimer's disease and other dementias, rank 7th as the cause of mortality globally (3). As people live longer, the risk of developing dementia with advanced age increases, such that by 2030, it is anticipated that the number of people living with dementia will exceed 78 million (4). In 2017, dementia was added to the Global Atlas of Palliative Care as a diagnostic group needing palliative care, with dementia accounting for 12.2% of the worldwide need for palliative care (5).

Palliative care is an approach aimed at improving the quality of life (QOL) of patients with a life-limiting illness. It is well recognized for its benefit to patients diagnosed with metastatic cancer. Over time, palliative care has extended to include the provision of care to people with other progressive, serious illnesses. Still, research highlights that dementia patients remain a vulnerable population group that has not had the benefit of a palliative care approach. (2, 6) The reasons for this include: the prolonged disease trajectory of dementia, prognostic challenges, dementia not being seen as a terminal illness, and a lack of staff knowledge about the palliative care needs of dementia patients in long-term care facilities/nursing homes (LTCF/NHs) (7-11).

Over 75% of patients residing in NH's have cognitive impairment (12), with advanced dementia being described as the primary reason for dependency and disability in older people (13). In the advanced stage of dementia, there is a profound level of dependence on others to have basic needs met due to progressive physical symptoms and severe cognitive loss. Swallowing difficulty, loss of mobility, pain, and infection are commonplace, and psychological symptoms such as depression, anxiety, and irritability are frequently experienced (14). The advanced stage of dementia can last up to two years, with an average survival of 1.3 years and a six-month mortality rate of 25% (15), but there are few significant clinical events to indicate a prognostic shift, thereby triggering a palliative approach to care.

The European Association for Palliative Care (EAPC) issued a white paper in 2020, which advocates for the improvement of palliative care for all older people living in NHs, regardless of diagnosis, and recommends that all NH staff have core competencies in palliative care (16). In SA, primary care in NH aims to be comprehensive, and generalist palliative care is part of the care provided; however, access to specialized palliative care services remains the exception rather than the norm. To implement educational programmes, the knowledge gap of staff in NHs needs to be identified, but research on care in nursing homes in SA is absent, or at best, limited, particularly from a palliative care perspective with a focus on dementia patients. Little is known about how the knowledge of staff in NHs in SA compares to other countries.

This study aims to explore the level of understanding and knowledge that NH staff in six facilities in KwaZulu-Natal have about dementia and palliative care.

Chapter 2: Literature Review

2.1 Epidemiology

Globally, it is estimated that over 56.8 million people need palliative care every year. Within that number, people over the age of fifty comprise 67.1% of those with palliative care needs, and according to the Worldwide Hospice Palliative Care Alliance, Africa has the highest number of adults in need of palliative care (5). Trends indicate that death from heart disease, HIV, and strokes have declined steadily, but death from advanced dementia increased substantially by 145% from 2010-2019 (17).

Recent estimates are that 60% of people with dementia live in low- or middle-income countries (LMIC), and the Global Burden of Disease report cites a prevalence rate of 4.4% of people in Africa over the age of sixty-five have dementia (18, 19). However, research suggests that the earlier stages of dementia may go undetected or not be reported, and studies highlight that this figure is likely to be a lot higher (20). This is in part due to a lack of awareness that dementia is not a normal part of aging (19).

In SA, as in many LMICs, there is little research on dementia prevalence, although it is recognised that factors such as diabetes and heart disease (which contribute to dementia risk) are increasing (19, 20). Using dementia screening tools in population samples of people over the age of 60 to estimate dementia prevalence, the figure varies from 2.1 to 8.5%. In SA, however, one study used culturally adapted language-specific interviews and identified dementia based on a cluster of clinical symptoms typical of dementia. Prevalence was found to be as high as 14.3%. (19, 21)

Hospital-based studies have led to results reflecting the lowest dementia prevalence in Sub-Saharan Africa, and yet in a study in Nigeria, diagnostic criteria for dementia were met in 48% of NH residents sampled (19, 22).

2.2 Care of dementia patients in NHs

Nursing homes accommodate a vulnerable population group, many of whom have palliative care needs in the protracted, advanced stage of dementia (19). Research into NH staff knowledge of dementia as a terminal illness and the benefits of a palliative care approach is fundamental to evaluating the provision of quality EOL care. As Stevenson et al stated in an article on improving palliative and EOL care in NHs, it is "time to renew our commitment." (23).

Due to the high symptom burden associated with advanced dementia, a substantial number of people are cared for in NHs (19). In the USA, approximately 1 in 9 people over the age of 65 have Alzheimer's, and it is estimated that 75% of dementia sufferers are being cared for in long-term care facilities, at a cost of over $321 billion in 2022 (17, 19).

In LMIC, however, access to NH care may not be readily accessible or accessed, and many dementia sufferers are looked after at home by family members. A study conducted in Cape Town found that 79% of the clients attending a memory clinic were being cared for at home by family members (20), and one-fifth of these were living in vulnerable circumstances (19).

While awareness of the benefits of a palliative care approach for NH patients is growing in many countries, research is scarce on this topic in SA (19). A scoping literature review conducted in 2022 by Kalideen et al on the quality of care provided to patients in NHs found that just 16 studies on this topic had been carried out between 1989 and 2017 and that

most of these studies took place in Europe and the United States. They also found that there was a clear lack of research that incorporated the psychosocial care of this patient group (19, 24).

It has been suggested that one possible reason for the lack of demand for placement in NHs is that dementia is viewed by many to be a normal part of aging, and is poorly understood in rural and peri-urban communities (19, 25).

In a paper on Dementia in Africa, Akinyemi et al, found that stigmatization stemming from cultural and supernatural beliefs was a frequent problem for people living with dementia and influenced the care received. Aside from dementia often being seen to emanate from bewitching, community leaders did not generally recognise dementia as a disease (26). The stigma associated with dementia means it is often kept secret, and in Nigeria, for example, about one-third of people believe that even those who have dementia would prefer that their diagnosis is not known to others (26). It has been found that these perspectives (influenced by culture and religious beliefs), lead to a negative attitude to formal care, irrespective of economic status.

Another example of the placement of dementia sufferers in NHs being influenced by culture and religion can be found within the Muslim community of SA, which makes up 2% of our total population. The Muslim belief is that there is a duty and a moral obligation for children to care for their parents. Stigma, guilt, and a negative view of formal care provision outside of the family home means that relatives diagnosed with dementia are seldom placed in nursing homes, despite significant caregiver burden (27).

In SA, it was estimated in 2021 that there were 1150 NHs, of which only 415 were registered with the Department of Social Development (DSD), and only 8 were fully subsidised or state-managed (19, 28). This may in part be attributed to the fact that the policy on aging in SA (based on the Older Persons Act of 2006) continues to promote deinstitutionalization, or "aging in place", resulting in just 2% of the population requiring full-time nursing care being catered for (19, 29). State oversight of registered homes would appear to be very limited, with compliance assessments of just 14 of the registered NHs having been undertaken between 2012 and 2015 (30).

2.3 Barriers to adopting a palliative care approach in advanced dementia.

A palliative approach to care is appropriate when someone is diagnosed with a life-limiting condition, and/or when clinical events indicate that prognosis is poor (19). In advanced dementia (which is frequently not recognised as a terminal disease), almost 50% of patients are only likely to be referred to palliative care services due to clinical event triggers, less than ten days before death (19, 31). Falls and fractures are commonplace due to impaired mobility, however, admission to hospital for traumatic injuries is unlikely to lead to the patient being identified as needing palliative care despite this being an indicator of 'impending mortality' (8) Other clinical events such as pneumonia, dehydration (resulting in electrolyte imbalances), febrile episodes, urinary tract infections, septicaemia, and seizures are frequently experienced in advanced dementia, and may also serve as a prognostic indicator.

Typically, HCPs rely on known disease trajectories and patterns of functional decline to determine when referral to palliative services would be appropriate (19), and the Supportive and Palliative Care Indicators Tool (SPICT) which was developed to aid in

identifying people who would benefit from a palliative approach is useful in this regard (19, 32).

There is a protracted functional decline in dementia patients, with the time from diagnosis until death taking anything from two to twenty years, which contributes to a lack of consensus on when best to initiate a palliative care approach (33). This, in combination with the lack of awareness of dementia being a progressive life-threatening illness by staff in NHs, is a significant barrier to the provision of palliative care for dementia patients, not just at a physician-based level, but also by family, care staff and the health care system (19, 33).

The National Institute for Health and Care Excellence (NICE) guideline in England recommends that a "flexible, needs-based" approach is taken for people with dementia from the time of diagnosis due to the unpredictable progression of dementia (34), but in reality, initiation of palliative care largely rests with the HCP's perception of dementia as a terminal illness, and agreement on when it is appropriate to implement a palliative care approach (33). It remains common practice that referral to palliative care services is based on dementia staging, with one systematic review of the literature citing that 84% of articles recommended palliative care only in the advanced stage of dementia, and just 2% advocated for referral at the point of mild cognitive impairment (19, 35). A significant consequence of this late referral practice is that the window of opportunity to formulate an advance care plan, document care and treatment preferences, appoint health care proxy decision-makers, and discuss end-of-life issues and preferred place of death closes as the disease progresses (19).

2.4 NH staff knowledge of dementia and palliative care.

The largest study to date on the palliative care knowledge of NH staff was carried out in 2018 across six countries in Europe, in which 2275 nurses were surveyed (36). The findings showed suboptimal knowledge on basic palliative care issues across all participating countries.

Robinson et al conducted a smaller survey study of 279 staff members working in NHs in Australia and found that approximately 50% of the care staff lacked the understanding that dementia was a terminal illness (8, 19). This knowledge deficit was seen in a subsequent Australian study, in which a limited understanding of dementia was shown by nursing home employees, with an average score of 32/50 for dementia knowledge (10). This lack of prognostic awareness extends to informal caregivers (family members) as well, with a USA study concluding that just over 50% of those surveyed understood the prognosis of people with dementia and the role of palliative care (9).

In SA, Van Wyk et al focused their research on the challenges NH staff face when dealing with behavioural issues in dementia patients, and training on dementia was identified as an unmet need (37), again indicating a lack of knowledge in this field. The same findings have been identified in other parts of Africa, where suboptimal clinical practices are found among healthcare workers, with inadequate training for the assessment of dementia (26).

It is clear from the literature that there is little understanding of the importance of palliative care for dementia patients in NHs, and a failure to identify dementia as a terminal illness has consequences for the patients and their families and impacts on quality of life.

2.5 Impact of poor staff awareness of Palliative Care in dementia on the patient and their family.

Symptoms commonly seen in advanced dementia such as pain, swallowing difficulties, immobility, weight loss, poor oral intake, and dehydration (6), may not be recognised by NH staff as factors indicating disease progression, poor prognosis, and likely mortality (8). Burdensome interventions, hospitalization, and poor care decisions potentially affect patients negatively and are often the result of a failure to recognise the prognostic indications of advanced dementia.

Missed opportunities to discuss disease trajectory timeously with family members can lead to unrealistic expectations and poor decision-making on treatment options in times of crisis.

Research confirms the need to discuss the clinical course of dementia with family members and facilitate advance care planning (9), but this relies on the NH staff having insight, knowledge, and awareness of the terminal nature of dementia (19). One study involving over 323 NH residents with dementia found that over 40% were subjected to at least one intervention that could be viewed as burdensome (15), and that the likelihood of (for example) hospital admissions and parenteral treatments was far less likely if family members understood the common clinical complications experienced in dementia (19).

The undertreatment of pain in NH patients is well documented (38), and is partly due to a poor understanding of the needs of dementia patients and the principles of palliative care. This has a direct impact on patient suffering and quality of life, with research showing that over 39% of NH patients experience pain (15), and as many as 63% of patients with advanced dementia have high levels of suffering (39). Assessing pain in non-verbal patients

is challenging, and without adequate knowledge of the clinical course of dementia and awareness of validated tools available to assess pain and suffering, it is likely to go undetected. This is borne out in the previously cited study, in which it was found that pain (and other physical symptoms) were identified in more than 50% of the patients, despite caregivers reporting that dementia patients experienced fewer physical symptoms than those without dementia (39).

Rationale for the study

The early recognition of palliative care needs can prevent burdensome or aggressive treatments and improve QOL of the patient (40). Failing to recognise dementia as a terminal illness, an inability to assess symptoms in non-verbal dementia patients, and being unaware of EOL preferences early in the disease trajectory can lead to physical, psychosocial, and spiritual needs not being identified and addressed. To better equip NH staff with the knowledge, skills, and insight to address the unmet palliative care needs of dementia patients, their knowledge and understanding of palliative care in a dementia context need to be explored.

Aim and Objectives

Aim

The aim of this study is to evaluate the knowledge and understanding of staff in nursing homes on dementia and a palliative approach to care.

Objectives

- To determine the NH staff members' knowledge and understanding of dementia.
- To assess the NH staff members' awareness and understanding of the concept of palliative care.
- To identify the educational needs of the nursing staff.

Chapter 3: Research Methodology

3.1 Study design

This study made use of a mixed-methods research methodology. The quantitative and qualitative findings of the study were integrated using a concurrent approach and then woven together in a narrative format.

The convergent design brings together the quantitative and qualitative phases (data for which was collected and analysed within the same timeframe), so that the results can be compared, and a more redundant understanding of the study findings is reported (41). It also allowed for the triangulation of the qualitative and quantitative data to check the validity and reliability of both (42).

3.2 Study sites

The study sites were selected using purposive, convenience sampling. Purposive in that three non-profit organisations (NPOs), and three private NHs in KwaZulu-Natal Natal which provide long-term care to the elderly, were selected and convenience as they were all located within easy travelling distance of the researcher, with the private homes being in the Upper Highway area (inland), and the NPOs were in the greater Durban area. Several facilities were initially contacted informally to explore management's receptivity to participation in the study once ethical permissions had been obtained. The private facilities accommodate a population of primarily middle to upper-class persons, while the NPOs are state-funded and accommodate patients from middle to lower socio-economic groups. These sites were selected as they are some of the larger facilities providing long-term care to the elderly and those with dementia and are staffed by caregivers and HCPs. Stratified sampling by incorporating facilities from both private and public sectors allowed for a broader representation of views in different contexts.

Inclusion criteria of the study sites:

- The NH must be registered with the Department of Social Development.
- The NH must accommodate and provide care to patients with dementia.
- Employees must be contracted to the NH, either directly or through an agency.

Exclusion criteria of the study sites:

- Lack of formal registration with the Department of Social Development
- NHs who do not provide care to dementia patients
- NHs who exclusively use agency workers who may be working at more than one of the study sites.

3.3 Study Population

The participants include qualified professional nurses (PNs), enrolled nurses (ENs), and carers. In SA, PNs undertake a four-year bachelor's degree in nursing at an accredited school, ENs undergo a three-year diploma course, and nurse auxiliaries complete a one-year Higher Certificate in Nursing. These qualifications are all regulated by the South African Nursing Council (SANC) and require practitioners to register with and maintain their certification through the SANC. There is no regulatory body overseeing carers.

3.3.1 Study Population – Knowledge Questionnaires

In SA, NHs are typically staffed by carers who have taken a short course in basic caregiving skills and are overseen by a PN or EN. This study aimed to examine the knowledge and understanding of NH staff, so stratified sampling incorporating all categories of staff was used. This allowed for data comparisons between participants with varying qualifications who perform distinct roles in the care of dementia patients.

3.3.2 Study Population – Semi-structured interviews

Purposive sampling was used to select interview participants, and NH management were relied on to identify members of their teams who they felt would be good candidates to participate. This was based in part on years of experience in their role, but also on communication skills and a desire to participate. The interviews included carers as well as enrolled nurses and one professional nurse.

3.4 Sampling

3.4.1 Nursing Homes

There is no specific register of NHs in KwaZulu-Natal (KZN), but the researchers' investigation identified 46 NHs in the Durban and Upper Highway area of KZN. Of these, thirty-nine were privately owned, and seven were NPOs, three of which received subsidies from the government. The accommodation capacity of the NHs varied between ten to three hundred patients.

Based on the number of employees at each home, purposively selecting three private NHs and three NPOs allowed for representative participation sufficient to allow for stratification of results, as explained in point 3.4.2 below. It also ensured that the research was representative of both the State and private sectors.

3.4.2 Nursing Home Staff

According to the Democratic Nursing Organisation of South Africa (DENOSA), there are no clearly defined or regulated nurse-to-patient ratios in South Africa (43), so nonprobability sampling was utilized and based on estimated numbers provided by the management of the selected facilities. This was extrapolated to include all 46 NHs identified

in the defined area. Based on an 85% confidence level and allowing for a 5% margin of error, a statistically significant sample size would be 189.

3.4.2.1 Sample size for quantitative data - knowledge questionnaires:

The total NH staff complement of each facility was invited to complete knowledge questionnaires if the inclusion criteria were met. This equated to a total of 272 potential participants.

3.4.2.2 Sample size for qualitative data – semi-structured interviews:

Prior determination of sample size in a mixed-methods study holds uncertainty and is largely determined by the scope and nature of the study, and practical considerations (44). The qualitative data in this study aimed to substantiate the quantitative findings and analysis through the merging and comparison of data added additional insights. Fourteen interviews were judged sufficient: after coding and analysing twelve transcripts, data saturation was likely achieved (44). Similar sample sizes have been shown to reach saturation in both South African palliative-care contexts and international qualitative research (45, 46). Transcription and initial data analysis were conducted simultaneously to data collection, with further analysis through coding and thematic identification allowing for the recognition of data saturation.

3.5 Recruitment

Once the required ethical permissions had been obtained for the proposed study, the selected facilities were contacted telephonically. Having established that the inclusion criteria were met, a request was made for an appointment to explain the purpose of the study in person and confirm the potential number of participants.

3.5.1 Knowledge Questionnaires

All employees meeting the inclusion criteria were invited to complete knowledge questionnaires. Awareness of the study was generated through an invitation to participate, which was displayed on notice boards in the NHs. A video presentation explaining the purpose of the research and what it would require of participants was made in both English and isiZulu. This was shared with NH management who were asked to present it to potential participants before signing consent and completing questionnaires so that they were accurately informed.

Once NH management had provided anticipated participant numbers and confirmation of language preference for the questionnaires to the researcher, envelopes labelled with a predetermined numbering system containing a demographic form, consent form, and two questionnaires were delivered by hand to the facilities, along with snack bags for the participants. All except one participant opted to complete the questionnaires in English, but isiZulu copies were provided in case they wanted to refer to these.

3.5.2 Semi-structured interviews

Employees known to management as having a particular interest in the care of dementia patients or those who had been employed by the facility for several years and worked with dementia patients were identified by management. Confirmation of a willingness to be interviewed was obtained from potential interviewees, and the researcher then met with each one in person before the interview to explain what would be required of them, the distress protocol, and the availability of a translator should they prefer to be interviewed in isiZulu.

3.6 Data Collection

3.6.1 Demographic details

Demographic details such as age, education level, qualification, home language, etc were captured by participants completing a tick-box form, allowing demographics to be described accurately and form part of the data analysis.

3.6.2 Quantitative data collection tools – Knowledge assessment questionnaires

To assess NH staff members' knowledge and understanding of dementia, the Dementia Knowledge Assessment Scale (DKAS) was used. This is a validated 25-item True/False questionnaire which is a reliable and valid measure of dementia knowledge (45). It covers four domains: 1) Causes and Characteristics, 2) Communication and Behaviour, 3) Care Considerations, and 4) Risks and Health Promotion. Research shows that DKAS demonstrates good discrimination between groups with different levels of knowledge, education, and experience in dementia (45). Considering the SA context, lack of formal training of carers, and language barriers, further explanations of certain words and phrases were used to support the participant. Examples of such modifications include the word "uncharacteristic" being more easily explained as "acting in a way that is unusual for that person," and a definition of vascular dementia was provided.

The Palliative Approach for Nursing Assistants (PANA) validated questionnaire was used to explore the level of understanding of palliative care. This questionnaire was designed and developed for nursing assistants and comprises True/False questions in three domains with 17 knowledge questions, 13 skills questions, and 10 attitude questions (46, 47). For this study, only the knowledge section of the questionnaire was used. PANA is based on a framework of residential aged care guidelines and has been demonstrated to be a valid and

reliable instrument that accounts for varying levels of education, knowledge, and skill in carers providing services to patients who require a palliative approach to their care (47). It intends to identify the educational needs of nursing assistants.

3.6.2.1 Translation of questionnaires

Both questionnaires were translated from English into isiZulu and then back-translated. This was done by four bilingual speakers independently of each other, with two translating from English into isiZulu and two from isiZulu into English. At least one of the translators was familiar with the topics of dementia and palliative care. The translations were closely scrutinized for consistency, and any discrepancies were addressed through consultation with the translators.

3.6.3 Qualitative data collection – Semi-structured interview guide

The interviews were conducted using an interview guide, which was developed with consideration of the Integrated Palliative Care Outcome Scale for Dementia tool (IPOS-Dem) as a framework for the questions. This tool was developed from the Integrated Palliative Care Outcome Scale (IPOS) and was chosen as it is designed to be used by carers without a professional qualification (48), and it focuses on symptoms common in the elderly population, including dementia-specific concerns. As the IPOS-Dem relies on check-box answers to comprehensively assess symptoms across a specified period, it was adapted for interview so that open-ended questions could be asked, which allowed for conversational, narrative responses but still encompassed the broader biopsychosocial elements contained in the IPOS-Dem.

3.7 Pilot Study

A pilot study of the DKAS and the PANA questionnaires was conducted, in which the same ethical standards and procedures outlined in 3.5.1 were considered and implemented. Six carers from a facility not taking part in the research were included in the pilot study.

Written consent was obtained from facility management and those who volunteered to take part, and an overview of the proposed research was presented in person to willing participants at the facility. The individual participants chose whether to complete the knowledge questionnaires in either English or IsiZulu, and in agreement with facility management, determined a suitable time for completion of the questionnaires. A follow-up meeting to obtain feedback was held on the completion of the questionnaires. This allowed for the identification of any questions that needed additional information or examples, confirmed the accuracy of the translated questionnaires, and provided an approximate average completion time. It also highlighted the potential issues of participant collaboration and the need for a video presentation to accurately convey study information if the researcher was not there in person.

One semi-structured interview was conducted with a senior (qualified) member of staff to determine if the interview guide elicited the depth of information sought. This was not included in the study sample or analysis but allowed the researcher to gauge how long each interview may take and aided in identifying any questions that needed to be refined, added or omitted. It was also an opportunity to ensure audio recording using the researcher's mobile device was suitable.

3.8 Data collection process

3.8.1 General Preparation

a) An initial meeting was held with NH management to introduce the project, give an overview of the intended research, and estimate approximate participation numbers. Distribution of an information package on the proposed research was then presented to each participating facility, and a PowerPoint presentation was given by the researcher if requested by the ethics committees, management, or decision-makers of the participating NHs. An opportunity was given to all participants and NH management to ask questions before consenting to participate.

b) Participants were advised that no financial compensation would be offered for taking part, but that refreshments would be provided, and measures taken to ensure no personal costs were incurred.

c) Assurance was given as to safeguarding privacy and confidentiality.

d) Information was provided on how data would be collected and analysed, and how results would be disseminated.

e) An opportunity to comment on the accuracy, validity, and reliability of the study will be afforded to participants.

3.8.2 Quantitative data collection process – Knowledge Questionnaires

a) Due to the rostering system used in NHs and the fact that some participants were on night duty or working split shifts, the knowledge questionnaires were given to senior management at each site for completion at a time that suited the facility and the participants.

b) Questionnaires in both languages were labelled before distribution using a coding system and placed in envelopes with matching codes.

c) Each participant was asked to sign a written consent form before completing the questionnaire. This was available in both English and isiZulu.

d) Participants were asked to complete a survey to capture demographic information, using the same coding as on the questionnaires. These codes were linked to their name in a password-protected format for auditing purposes if needed.

e) The managers were asked to ensure the following:

1. Questionnaires were not to be distributed before they were scheduled to be completed.
2. Measures were to be taken to ensure that there was no collaboration between participants, as this could affect the study results.
3. The questionnaires were to be placed back in the labelled envelopes and sealed on completion by each participant.

The sealed envelopes were collected in person by the researcher, after a 7–14-day interval, to ensure all participants had had an opportunity to complete the questionnaires.

3.8.3 Qualitative data collection process – semi-structured interviews

a) The individual interviews took place on-site at the various facilities by a previously agreed appointment.

b) Language preference for interviewing was determined so that an interpreter could be made available if required. The participants were asked to provide signed consent to be interviewed and to be audio recorded during the interview. They were also required to complete the demographic form.

c) The distress protocol was provided in writing and explained before the interview commenced.

d) The interviews were scheduled at a time agreed with the participants and in consultation with facility management, to ensure the interviews did not affect the smooth running of the facility or the duties of the participant.

e) The interviews were held in a private room or in an area that allowed for privacy and minimal disruption to the patients as well as to the interview process. The interviews were recorded using a voice recorder application on the researcher's password-protected mobile device.

3.9 Data management

3.9.1 Quantitative data – knowledge questionnaires

a) A coding system was used to protect the identity of facilities and participants to ensure confidentiality.
b) No participant names or identifying characteristics were used on knowledge questionnaires.
c) Data was stored on a password-protected computer.

3.9.2 Qualitative data – interview transcripts

a) The recorded interviews were uploaded onto a secure server and transcribed verbatim using a voice-to-text software program called Maestro AI. The transcript was read while the researcher listened to the recordings to ensure accuracy.

b) In the transcripts, any reference to the participant's name, place of employment, and names of colleagues or patients was anonymized or redacted so as not to affect or compromise the reporting of data.

c) Recordings of the interviews were saved to secure cloud storage once transcribed and then deleted from the mobile device. The transcriptions were saved to a password-protected computer and backed up to secure cloud storage as specified by the university research ethics guidelines.

3.10 Data analysis

3.10.1 Data analysis – Quantitative data

a. Participant numbers by facility were entered into an Excel spreadsheet, and note was taken of any exclusions and the reasons for exclusion. For example, an unsigned consent form.
b. Demographic details were entered into an Excel spreadsheet, and descriptive statistics were summarised using VLOOKUP. This is an Excel function that allows the user to search across multiple columns and worksheets to find specific values.
c. The individual questionnaire results were also captured on an Excel spreadsheet and VLOOKUP was used to summarise the data. An executive summary check was conducted to ensure accuracy and that all data had been captured.
d. A Likert scale scoring system was used, with one point given for each correct answer. Answers that were incorrect, don't know, or had been omitted were allocated a zero score. For this study, a higher score was interpreted as indicating greater dementia knowledge, but no absolute cut-off was applied to define a participant as "knowledgeable." Instead, results were analysed in terms of mean scores and comparisons between groups
e. Various data extractions were done manually and transferred to different Excel sheets for analysis purposes. This included numerical figures and percentage calculations of

both questionnaires per facility, qualification, and correct scores, as well as isolating specific questions or subscales for more in-depth analysis.

f. Graphs and tables were drawn up in Excel to present the data findings.

3.10.2 Data analysis – Qualitative interviews

a. Participant numbers and demographic details of interviewees were entered into an Excel spreadsheet.
b. Interviews were analysed using an inductive content analysis (48). Initially, NVivo software was used for iterative coding to extract meaning from the content, and sixteen codes were initially identified. From the sixteen codes generated by Nvivo, four primary themes were identified, encompassing eleven subthemes.
c. However, due to the risk of losing meaning contributed by language and cultural nuances, the researcher ultimately analysed the interview transcripts manually so that the depth and richness of the data could be better extracted.
d. The data were organised into an Excel workbook, following the identification of words, phrases, thoughts, and opinions expressed by the interviewees, which emerged as potentially significant themes by iterative processing.
e. Some subthemes were subsequently incorporated into broader themes, and final themes and sub-themes were determined based on their alignment with the research question.

A mixture of closed category and open category analysis was used, in that two of the four main themes (understanding of dementia and understanding of palliative care) were chosen to address the research question directly, and the additional two main themes emerged organically through analysis.

As a PN in SA with an awareness of the typically hierarchical structure of NHs, the empathy I felt for participating carers who appeared anxious during the interview process may have resulted in leading questions being asked as a way of helping them to understand and contextualize the scenarios presented. During analysis of the qualitative data, this was reflected on to ensure it had not influenced data analysis.

3.11 Mixed methods integration through merging

The quantitative data derived from the knowledge questionnaires and qualitative data derived from the interviews were integrated and merged into a narrative discussion of the significant findings of the study in Chapter 5. Initially, it was intended that the researcher collect and analyse the two sets of data in parallel and not do a mixed-methods analysis; however, a mixed-methods concurrent approach was ultimately adopted, and only once the quantitative data had been analysed and tabulated was it merged with the qualitative findings, which had been separately analysed and organised into themes. All data were carefully screened to protect the identity of individual participants and participating NHs during the collection, analysis, and dissemination phases of the research.

3.12 Ethical considerations

The Declaration of Helsinki, compiled by the World Medical Association, provides researchers with ethical guidelines within which to conduct research involving human subjects and informs researchers of sound ethical principles to be adhered to (49).

Ethical approval for this study was obtained from the Human Research Ethics Committee (HREC) of The University of Cape Town, (See Appendix D), and permission was obtained from all relevant stakeholders/managers of the participating facilities using a memorandum of understanding, which confirmed acceptance of the provisions contained in the UCT HREC approval. (See Appendix E) There were some challenges in establishing

which organization held the authority to grant ethical permission for research conducted in NHs, as the DSD is only tasked with administering the register for NGOs, which is voluntary. Ultimately, the UCT HREC considered the DSD committee's position and approved that it was fine to proceed. (See Appendix C)

Opportunity costs were considered, and accommodations were made to ensure there was minimal disruption to the participants' daily routine which affected their duties and responsibilities. Participants retained the right to amend any arrangement regarding dates and times of participation if there was a risk of the study impacting on patient care. Participants were not expected to incur any personal costs. The researcher bore all costs associated with conducting of the study. (See appendix P)

Participating facilities may have had concerns about reputational risk based on the research outcome. Emphasis was placed on the researcher's ethical responsibility to ensure confidentiality and assurance given that the identity of individual participants as well as the nursing home would be protected. A coding system was used when distributing questionnaires and during the data analysis phase for the presentation of findings.

The risk of deductive disclosure, whereby participants could potentially be identified or traced to a specific facility by the collection of uniquely identifiable information, was addressed by redacting or otherwise altering details in such a way that the substance of the information was not lost but confidentiality was maintained.

Participating nurses may have had concerns that the outcome of the knowledge tests will impact on their current employment or future employability. The aims of the research were carefully explained to reassure participants that only consolidated results would be analysed and reported, and that confidentiality and privacy would be protected.

Consideration was given to participants' feeling unduly pressurised to participate, so emphasis was placed on the voluntary nature of their participation and the right to withdraw without prejudice. They were also assured of support and provided with the contact details of the researcher. The distress protocol was also explained at this stage.

3.12 Dissemination of Findings

Telephonic contact will be made with the managers of all participating facilities, and a summary of the findings will be provided. An offer will be extended to them for the researcher to present in person, and to include a short training session based on the knowledge gaps identified in the study. This will allow the researcher to thank all the participants and to reiterate the value of the work they are doing. The presentation will include a short training session based on the knowledge gaps identified in the study, and the NH staff will be encouraged to carry this knowledge forward into their communities to raise awareness of both palliative care and dementia. A full copy of the study will be provided on request.

Chapter 4 – Research Findings

4.1 Quantitative Results

4.1.1 Introduction

Participant and demographic details, as well as the findings of the DKAS and PANA questionnaires, are tabulated below and will be discussed in Chapter 5.

4.1.2 Participation and Demographics

The total potential number of participants across the six facilities was 272, with final participation in the study of 212 HCPs (Carers, ENs, PNs). This equates to an 87% participation rate before exclusions, with 184 being included in the final analysis.

The importance of individual signed consent appears not to have been well understood by all facilities, resulting in several completed questionnaires having to be excluded as the participants' signature was missing on the consent form or had been signed on their behalf by facility management. Participation and socio-demographics details are presented below in tabulated format.

Table 4.1.2a – Participation

		Facility A (n)	Facility B (n)	Facility C (n)	Facility D (n)	Facility E (n)	Facility F (n)	TOTAL (n)
Total population	Carers	54	56	48	28	29	20	235
	EN's	7	4	5	2	2	2	22
	PN's	2	4	3	2	2	2	15
Participants	Carers	47	34	42	28	27	13	191
	EN's	7	2	2	1	1	1	14
	PN's	2	2	2	0	1	0	7
Excluded	Unsigned consent	4	0	16	0	9	0	29
	Not returned	0	0	0	0	0	0	0
	Withdrew	0	0	0	0	0	0	0
Final	Carers	43	34	26	28	19	13	163
	EN's	7	2	2	1	1	1	14
	PN's	2	2	2	0	1	0	7

The participation table represents a typical NH structure in SA, with the majority of participants being carers, fewer ENS and a maximum of 4 PNs in each facility.

Table 4.1.2b Socio-demographics

		Number (n)		
	VARIABLES	**CARERS (n)**	**EN'S (n)**	**PN'S (n)**
GENDER	Female	151 (93%)	10 (71%)	7 (100%)
	Male	2 (1%)	0	0
	Omitted	10 (6%)	4 (29%)	0
AGE	18 - 25	11 (7%)	0	0
	26 - 35	48 (29.5%)	1 (7%)	0
	36 - 45	57 (35%)	4 (29%)	1 (14%)
	46 - 55	33 (20%)	7 (50%)	1 (14%)
	56 - 65	13 (8%)	1 (7%)	4 (58%)
	Over 65	0	1 (7%)	1 (14%)
	Omitted	1 (0.5%)	0	0
HOME LANGUAGE	English	11 (7%)	1 (7%)	4 (57%)
	isiZulu	144 (88%)	12 (86%)	2 (29%)
	Other	6 (4%)	0	1 (14%)
	Omitted	2 (1%)	1 (7%)	0
EDUCATION	High school	38 (23.5%)	1 (7%)	0
	Grade 12	66 (41%)	0	0
	Higher Certificate	46 (28%)	5 (36%)	0
	College diploma	10 (6%)	8 (57%)	6 (86%)
	University degree	1 (0.1%)	0	1 (14%)
	Omitted	2 (1%)	0	0
EXPERIENCE	0 - 1 years	21 (13%)	0	2 (29%)
	2 - 5 years	46 (28%)	5 (36%)	2 (29%)
	6 - 10 years	43 (26%)	3 (21%)	3 (42%)
	Over 10 years	51 (32%)	5 (36%)	0
	Omitted	2 (1%)	1 (7%)	0
CURRENT POSITION	0 - 1 years	41 (25%)	4 (29%)	2 (29%)
	2 - 5 years	37 (23%)	2 (29%)	2 (29%)
	6 - 10 years	41 (25%)	4 (21%)	3 (42%)
	Over 10 years	40 (25%)	4 (21%)	0
	Omitted	4)2%)	0	0
DEMENTIA TRAINING	Yes	128 (78.5%)	10 (71%)	4 (57%)
	No	29 (18%)	4 (29%)	3 (43%)
	Omitted	6 (3.5%)	0	0
PALLIATIVE CARE TRAINING	Yes	112 (69%)	8 (57%)	3 (43%)
	No	45 (28%)	6 (43%)	4 (57%)
	Omitted	6 (3%)	0	0

Participants were predominantly female (93% of carers), and isiZulu-speaking (88%), with almost two-thirds having not had any tertiary education.

4.1.3 Dementia Knowledge Assessment Scale (DKAS) results

This tool is made up of 25 statements about dementia, which are either true or false, and has four subscales. Namely: Causes and characteristics of dementia, communication and behaviour, care considerations, and risks and Health Promotion (45, 50). Each correct answer was given a score of one and calculated as a percentage. (Table 4.1.3a on the following page) 7 PNs, 14 Ens, and 163 carers completed the questionnaire.

Table 4.1.3a DKAS results by item number (Correct answers)

		PNs		ENs		Carers		Total	Ave
ITEM	**STATEMENTS**	**(n)**	**(%)**	**(n)**	**(%)**	**(n)**	**(%)**	**(n)**	**(%)**
1	Most forms of dementia do not generally shorten a person's life *(false)*	2	28.6	3	21.4	36	22.1	41	22.3
2	Blood vessel disease (vascular dementia) is the most common form of dementia *(false)*	3	42.9	2	14.3	22	13.5	27	14.7
3	People can recover from the most common forms of dementia *(false)*	6	85.7	8	57.1	106	65.0	12	65.2
4	Dementia is a normal part of the aging process *(false)*	5	71.4	1	7.1	31	19.0	37	20.1
5	Dementia does not result from physical changes in the brain *(false)*	5	71.4	8	57.1	106	65.0	119	64.7
6	Planning for end-of-life care is generally not necessary following a diagnosis of dementia *(false)*	6	85.7	8	57.1	82	50.3	96	52.2
7	Alzheimer's disease is the most common form of dementia *(true)*	5	71.4	12	85.7	146	89.6	163	88.6
8	It is impossible to communicate with a person who has advanced dementia *(false)*	5	71.4	6	42.9	78	47.9	89	48.4
9	A person experiencing advanced dementia will not generally respond to changes in their physical environment *(false)*	5	71.4	7	50.0	69	42.3	81	44.0
10	It is important to correct a person with dementia when they are confused *(false)*	3	42.9	4	28.6	42	25.8	49	26.6
11	People experiencing advanced dementia often communicate through body language *(true)*	5	71.4	11	78.6	133	81.6	149	81.0
12	Uncharacteristic behaviours in a person experiencing dementia are generally due to unmet needs *(true)*	5	71.4	11	78.6	130	79.8	146	79.3
13	Medications are the most effective way of treating behavioural symptoms of dementia *(false)*	2	28.6	1	7.1	22	13.5	25	13.6
14	People experiencing dementia do not usually have a problem making decisions *(false)*	7	100	9	64.3	103	63.2	119	64.7
15	Movement is generally affected in the later stages of dementia *(true)*	6	85.7	13	92.9	134	82.2	153	83.2
16	Difficulty eating and drinking generally occurs in the later stages of dementia *(true)*	7	100	11	78.6	128	78.5	146	79.3
17	People with advanced dementia may have difficulty speaking *(true)*	7	100	14	100	124	76.1	145	78.8
18	People experiencing dementia often have difficulty learning new skills *(true)*	7	100	13	92.9	150	92.0	170	92.4
19	Daily care for a person with advanced dementia is effective when it focuses on providing comfort *(true)*	7	100	13	92.9	135	82.8	155	84.2
20	Having high blood pressure increases a person's risk of developing dementia *(true)*	2	28.6	9	64.3	106	65.0	117	63.6
21	Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia *(false)*	1	14.3	12	85.7	73	44.8	86	46.7
22	Symptoms of depression can be mistaken for symptoms of dementia *(true)*	3	42.9	12	85.7	137	84.0	152	82.6
23	The sudden onset of cognitive (mental deterioration) problems is characteristic of common forms of dementia *(false)*	1	14.3	2	14.3	28	17.2	31	16.8
24	Exercise is generally beneficial for people experiencing dementia *(true)*	5	71.4	12	85.7	132	81.0	149	81.0
25	Early diagnosis of dementia does not generally improve the quality of life for people experiencing the condition *(false)*	5	71.4	7	50.0	71	43.6	83	45.1
		65.7		**59.7**		**56**		**57.6**	
	TOTAL % SCORE OF CORRECT ANSWERS								

Average dementia knowledge was low at 57.6%, with a poor understanding that dementia may be classified as a terminal and life-limiting condition.

Subscale analysis (Section 4.1.3) revealed variation in performance by qualification. PNs scored highest in the 'Causes and Characteristics' domain, suggesting stronger clinical knowledge of dementia. However, their scores were lower than those of ENs and carers in the 'Risk and Health Promotion' subscale, pointing to possible gaps in preventive and health-promotion knowledge. These findings are explored further in the discussion chapter.

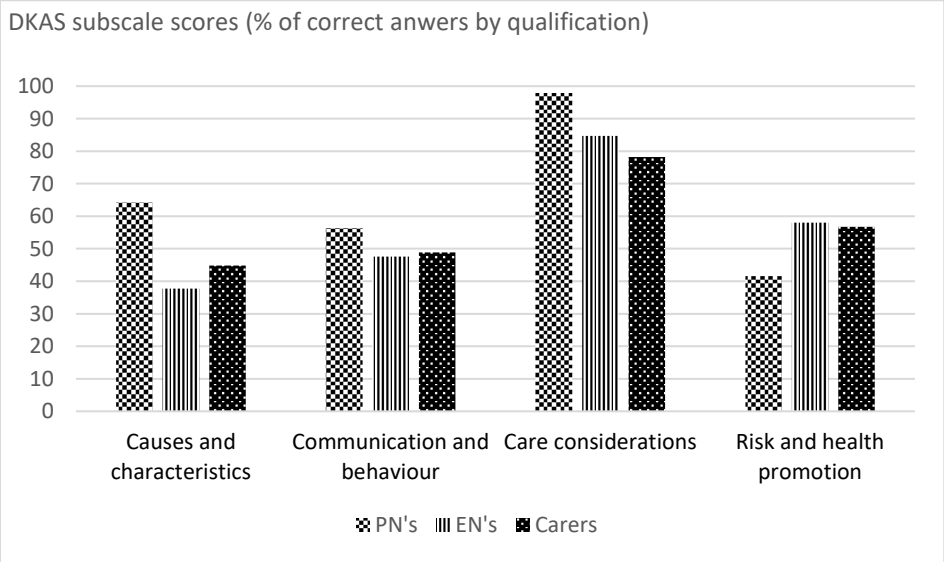

Figure 1 DKAS subscale scores by NH staff category

Participants scored highest on care considerations and lowest on causes and characteristics, with PNs performing best overall, except for the risk and health promotion questions.

Table 4.1.3b DKAS subscale scores by NH staff category in percentages

		Causes & characteristics (Questions 1 - 7)	**Communication & behaviour (Questions 8 - 13)**	**Care considerations (Questions 14 - 19)**	**Risk & health promotion (Questions 20 - 25)**
	Total Participants	Number of participants holding various positions/qualifications who answered subscale questions correctly			
	(n)	(n)	**(n)**	(n)	(n)
PNs	7	5 (66%)	4 (60%)	7 (97%)	2 (55%)
Ens	14	6 (43%)	7 (48%)	12 (87%)	9 (64%)
Carers	163	76 (46%)	79 (49%)	129 (79%)	91 (56%)

Scores were also examined across all six participating facilities, and the results highlight a difference of just 5.4% between the highest and lowest-scoring facilities. The care considerations subscale received the highest number of correct answers across all facilities.

Table 4.1.3c provides the total average scores per facility and a breakdown of the subscale scores. Each correct answer was allocated 1 point.

Table 4.1.3c DKAS correct score averages and subscale scores by facility

		Causes & characteristics (Questions 1 - 7)		**Communication & behaviour (Questions 8 - 13)**		**Care considerations (Questions 14 - 19)**		**Risk & health promotion (Questions 20 - 25)**	
	Total Participants	Number and percentage of participants from each facility who answered subscale questions correctly							
	(n)	(n)	**(%)**	**(n)**	**(%)**	(n)	**(%)**	(n)	**(%)**
FACILITY A	52	25	49	25	49	43	83	28	55
FACILITY B	38	17	41	6	50	31	82	21	56
FACILITY C	30	14	48	14	47	25	83	15	50
FACILITY D	29	10	54	14	47	21	74	16	56
FACILITY E	21	10	50	11	52	18	83	11	59
FACILITY F	14	6	44	7	64	10	74	9	63

Knowledge gaps are present across all facilities with minor score variations between sites.

The questions with the lowest correct DKAS scores per qualification are tabulated below (Table 4.1.3d) and highlight two questions that show a marked difference in score between PNs and ENs as well as carers.

Table 4.1.3d Lowest DKAS scores by question and NH staff category

			PNs 7 Participants		Ens 14 Participants		Carers 136 Participants	
			Questions answered correctly expressed in participant number and percentage					
Q	**Item**	**Subscale**	**(n)**	**%**	**(n)**	**%**	**(n)**	**%**
1	Most forms of dementia do not generally shorten a person's life *(false)*	Causes and characteristics	2	28.6	3	21.4	36	22.5
4**	**Dementia is a normal part of the aging process *(false)***	Causes and characteristics	5	71.4	1	14.3	31	22.8
13	Medications are the most effective way of treating behavioural symptoms of dementia *(false)*	Communication and behaviour	2	28.6	1	14.3	22	16.2
20**	**Having high blood pressure increases a person's risk of developing dementia *(true)***	Risk and health promotion	2	28.6	9	64.3	106	78
21	Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia *(false)*	Risk and health promotion	1	14.3	12	85.7	86	63.2
23	The sudden onset of cognitive (mental deterioration) problems is characteristic of common forms of dementia *(false)*	Risk and health promotion	1	14.3	2	14.3	28	20.6

*** Signifies the two questions with the largest variance in score between the groups*

The most misunderstood items relate to whether dementia shortens life, the link between lifestyle risks and dementia, and the onset of dementia. These findings show poor prognostic awareness and limited health promotion knowledge.

4.1.4 The Palliative Approach for Nursing Assistants (PANA) Results

The PANA questionnaire was selected for use in this study as it allows for the assessment of palliative care knowledge across various levels of education (46). As with the DKAS assessment tool, participants completing the PANA questionnaire were made up of PNs, ENs, and carers. The knowledge portion of the PANA questionnaire comprises seventeen true or false statements. One point is given to each correct answer and a zero value for incorrect, "don't know" or omitted answers. The following tables demonstrate the results

of the 184 participants who completed the PANA questionnaire. The average total score across all qualifications is 76% correct answers, as opposed to the dementia questionnaire (DKAS) which showed an average score of 57.6%.

Table 4.1.4a Summary of PANA score averages by qualification

CORRECT			INCORRECT			DON'T KNOW			OMITTED		
P/N	E/N	CARERS	P/N	E/N	CARER	P/N	E/N	CARER	P/N	E/N	CARER
82.0%	78.5%	76.2%	14.0%	14.5%	17.7%	1.0%	4.0%	4.0%	3.0%	3.0%	3.0%

Overall, dementia knowledge was higher than palliative care knowledge, but the score variation between different qualifications is negligible, as is the differences seen between facilities in the total scores with just two of the four facilities (B and D) falling 0.5% and 3.4% respectively below the average of 76% (Table 4.3b).

Table 4.1.4b PANA results by facility

TOTAL ITEMS SCORED CORRECTLY BY FACILITY (%)					
A	**B**	**C**	**D**	**E**	**F**
83%	75.6%	77.5%	72.6%	79.4%	79.2%

Questions 4 and 8 scored lowest across all facilities and question 6 pertains specifically to dementia patients in a palliative care context. (Table 4.1.4c) These questions will be explored further in the discussion chapter.

Table 4.1.4c PANA results by item number (Correct answers)

		PNs		ENs		Carers		Total	Ave
ITEM	**STATEMENTS**	**(n)**	**(%)**	**(n)**	**(%)**	**(n)**	**(%)**	**(n)**	**(%)**
1	Palliative care aims to improve the quality of life when people have an illness or a condition that affects how long they will live. *(true)*	6	85.7	14	100	143	87.8	163	77.6
2	A palliative approach supports comfort but does not provide a cure. *(true)*	7	100	14	100	139	85.3	160	87
3	Palliative care may be required by some people for months or years, while for others it may be required for hours or days. *(true)*	7	100	13	92.8	123	75.5	143	77.7
4	The needs of people requiring a palliative approach are all the same. *(false)*	4	57.1	7	50	81	49.7	92	50
5	A palliative approach is offered when treatment will not help the person to live longer. *(true)*	4	57.1	12	85.7	107	65.6	123	66.8
6	People who have advanced dementia benefit from a palliative approach. *(true)*	4	57.1	9	64.3	100	64.3	113	61.4
7	Families can often experience grief before the death of their family member.	5	74.4	12	85.7	140	85.9	157	85.3
8	It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English. *(false)* *(i.e.: No matter what language they speak or what their culture is.)*	4	57.1	4	28.6	44	27.0	52	28.3
9	The reason why a person receives nutrition through a PEG tube is because he/she can no longer swallow safely. *(true)* *(A PEG tube is a tube that goes directly into the stomach and the person is fed through that tube)*	7	100	14	100	157	96.3	178	96.7
10	Identifying symptoms (physical signs) is the first step in being able to manage symptoms. *(true)*	7	100	13	92.8	139	85.3	159	86.4
11	Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable. *(true)*	7	100	14	100	148	90.8	169	91.8
12	When a person is receiving pain relief medication, they no longer feel pain. *(false)*	6	85.7	8	57.1	104	63.8	118	64.1
13	Families or carers who know the person best are usually the first to notice changes in a person's condition. *(true)*	7	100	14	100	157	96.3	178	96.7
14	Bladder and bowel problems can cause discomfort when a person approaches the end of life. *(true)*	6	85.7	13	92.8	141	86.5	160	86.9
15	When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness. *(true)*	5	74.4	12	85.7	107	65.6	124	67.4
16	Signs that death is near can be present hours to days before death occurs. *(true)*	5	74.4	13	92.8	138	84.7	156	84.8
17	People's tolerance of pain is lowered by anxiety or fatigue. *(true)* *(i.e.: If someone is anxious or tired, they don't cope as well as they usually would with pain)*	4	57.1	12	85.7	139	85.3	155	84.3
AVERAGE SCORE PER QUALIFICATION		**80.3%**		**83.2%**		**76.2%**		**76%**	

Ens scored 3% higher than PNs overall, but across all three groups, high scores are seen in understanding the role of family and correctly identifying why PEG feeding may be used.

Table 4.2.4d PANA lowest scoring questions by NH staff category

		PN		EN		Carers		Average	
ITEM	QUESTION	(n)	(%)	(n)	(%)	(n)	(%)	(n)	(%)
4	The needs of people requiring a palliative approach are all the same. *(false)*	4	57.1	7	50	81	49.7	92	50
8	It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English. *(false)*	4	57.1	4	28.6	44	27.0	52	28.3

Table 4.1.4e Results of PANA question on dementia

		PN		EN		Carers		Average	
ITEM	QUESTION	(n)	(%)	(n)	(%)	(n)	(%)	(n)	(%)
6	People who have advanced dementia benefit from a palliative approach. *(true)*	4	57.1	9	64.3	100	64.3	113	61.4

Only 61.4% correctly identified that dementia patients benefit from palliative care, highlighting a possible lack of understanding of the role palliative care plays in advanced dementia.

4.2 Qualitative findings of in-person interviews

4.2.1 Introduction

Participants were purposively sampled with the intention of including a range of professional qualifications. While only one PN and three ENs ultimately participated in the interviews, this was proportionate to the overall demographic composition of the study sample (7 PNs, 14 ENs, and 163 carers). The only sampling criterion was professional qualification, as this was most directly aligned with the study objectives.

The aim was to explore the participants' opinions and understanding of palliative care and issues commonly affecting patients with advanced dementia. Questions adapted from the IPOS-dem assessment tool included (but were not limited to) the physical symptoms of patients with advanced dementia; communication; nutrition and hydration; assessing pain; depression and anxiety; and family interactions. Additional questions were added to the

interview guide so that the participants' understanding of palliative care and dementia as a terminal illness could be explored (See appendix J for full interview guidelines).

However, despite their qualifications, training, and experience, many interview participants found it difficult to understand the interview questions. The researcher adapted her approach to allow for a more conversational exploration of their thoughts and opinions, based on the case histories of some of the residents they had cared for. This led to additional questions being asked that had not initially formed part of the planned interview guide, thereby allowing for potentially pertinent themes to emerge organically.

The socio-demographic surveys found that ten of the fourteen interview participants had received training on both dementia and palliative care, nine participants had over six years' experience working with older people in nursing homes, with the remaining five had between two and five years of experience.

Four main themes were identified while conducting an iterative process of reading, coding, and analysis. Namely: 1) Understanding of palliative care, 2) understanding of dementia, 3) the impact end-of-life care has on care providers in NHs, and 4) training needs. Several sub-themes emerged from these broader themes and are presented in an illustrative diagram on page 39 and will be discussed in more detail in Chapter 5.

The coding used when presenting qualitative data findings from the interviews allows for the recognition of the position held by the participants in the NH through the last letter. P (participant), participant number (1 – 14), then qualification. (P - professional nurse, E - enrolled nurse, and C – carer).

4.2.2 Interview participation and demographics

Tables 4.2.2a and 4.2.2b below provide information on participant numbers and the demographic details associated with the interview participants.

Table 4.2.2a Interview participation numbers per facility

	FACILITIES					
Staff Categories	Facility A (n)	Facility B (n)	Facility C (n)	Facility D (n)	Facility E (n)	Facility F (n)
Carers	3	2	2	0	1	2
EN's	1	0	1	0	1	0
PN's	0	1	0	0	0	0

Table 4.2.2b Socio-demographic details of interview participants

	VARIABLES	TOTAL (n)	CARERS (n)	EN'S (n)	PN'S (n)
GENDER	Female	14	10	3	1
AGE	26 - 35	4	4		
	36 - 45	4	3	1	
	46 - 55	5	2	2	1
	56 - 65	1	1		
HOME LANGUAGE	English	1			1
	isiZulu	12	9	3	
	Other	1	1		
EDUCATION	High school	2	2		
	Grade 12	4	4		
	Higher Certificate	4	3	1	
	College diploma	3	1	2	
	University degree	1			1
EXPERIENCE	2 - 5 years	5	2	2	1
	6 - 10 years	4	4		
	Over 10 years	5	4	1	
CURRENT POSITION	0 - 1 years	2	1	1	
	2 - 5 years	3	1	1	1
	6 - 10 years	7	6	1	
	Over 10 years	2	2		
DEMENTIA TRAINING	Yes	10	7	2	1
	No	4	4		
PC TRAINING	Yes	10	7	2	1
	No	3	2	1	
	Omitted	1	1		

* Higher certificate information not specified on demographic survey.

The majority of participants were female (n=14) and isiZulu-speaking (n=12), with carers making up the majority. Over 70% of participants reported receiving both dementia and palliative care training, although no further detail about this training was collected.

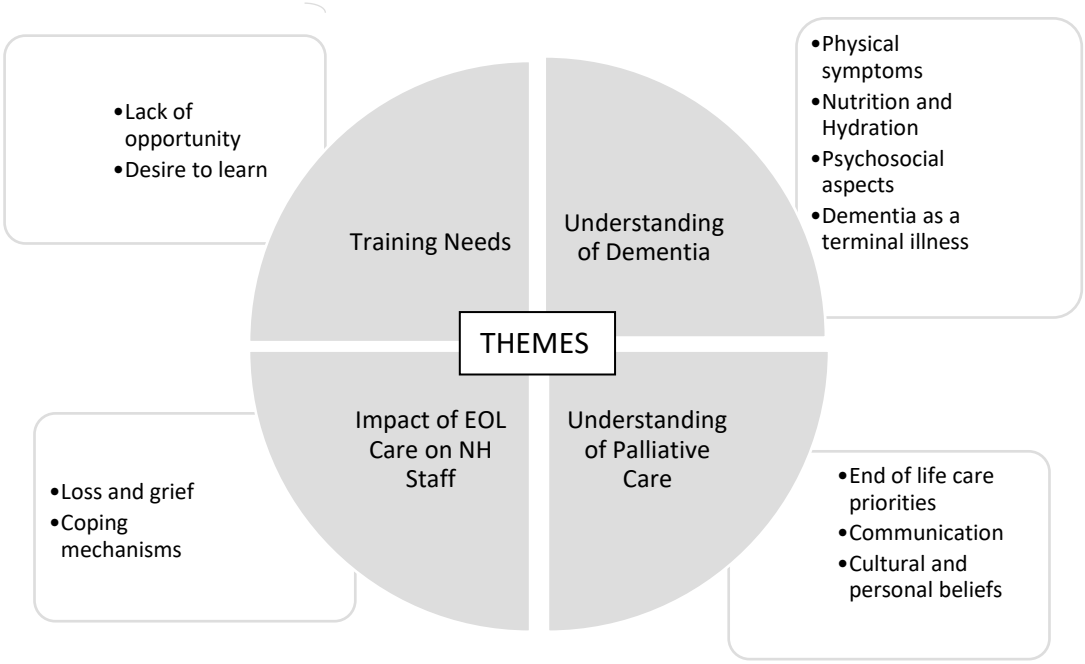

Figure 1: Themes and subthemes identified in the semi-structured interviews

4.2.3 Theme 1: Understanding of Dementia

Ten of the fourteen interview participants marked on the socio-democratic survey that they had had training on dementia. They did not have to furnish the researcher with details of the training in terms of duration, content and certification.

What is clear from the interviews is that most participants understood that dementia was a neurological condition, causing memory loss and confusion.

"They affect the brain, so when you look at them, the brain, they are totally damaged because they end up not knowing what is going on." (P11E)

"As the time goes by, they ended up really battling with all those things, (walking, talking, eating) because the mind can't, there's no control." (P1C)

"Because sometimes their mind will like come back, they'll talk to you. I think that you see that you can respond, you have a good chat. After five minutes, they forgot." (P2C)

4.2.3.1 Physical symptoms of dementia

There was difficulty during most interviews for participants to identify any physical symptoms commonly associated with disease progression of dementia, aside from a deterioration in mobility. Two participants referred to weight loss and eating difficulties, and two cited aggression as a physical symptom.

"Some do by bending, you know, bending too much, without putting their head up when they walk, they like facing down, but others are fine." (P14C)

"Because sometimes their bodies become stiff. She told you that she can't move the hands or the body, it's numb, something like that." (P13C)

"The ones who walk, they're walking nicely, but it's just that we have to support them. I'm not sure about the dementia that can affect the walking." (P3C)

"Even if they're eating food, they're eating slowly because they've got a problem with their oesophagus line, and even they're walking, they can't walk, like, steady, they're shaking. Sometimes you can see that this one, she will fall at any time, she can't balance." (P6C)

Opinions offered on cause of cognitive decline in dementia included stress, aging and abuse.

"I think it's abuse. It starts from abuse, then stress, yeah. (P4E)

"I think they think too much. Sometimes they lost their mind." (P10C)

"I think when they're old, it normally happens to them. Yeah, because I never saw a young person with dementia. It's not common." (P3C)

4.2.3.2 Nutrition and hydration

Several participants cited having no experience of dysphagia in patients with advanced dementia, and most interviewees were inclined to continue trying to maintain oral intake, without forcing a patient to eat. Numerous responses also centred around adjusting the patient's diet in line with changes in swallowing abilities. I.e. From a normal to a soft diet, then pureed food followed by meal-replacement supplements.

"The thing is I never give up into eating, it doesn't matter how bad the situation is. Even if it's like, for example, it's just like Ensure, things like that, those food replacements, just continue with that until the end, because I don't believe that you stop the patient from eating." (P1C)

"If you are talking to them and say, please swallow, they do swallow, even if they're not going to answer you. they do swallow. I never had a problem with someone who never listened to me even if she's not talking they do swallow." (P3C)

"That thing we can't, we can't just relax. As you notice that's an end, that is end of life. We treat till its end of the life. We can't just say okay, now she can't eat or he can't eat. We can't just relax. We have to try with all means till the end of life." (P11E)

"We have to, because they are living, but a small portion, if she says no I can't, I can't, I am not allowed to force her to say it, but at least she must have something." (P6C)

There was an awareness by many participants that patients ceasing oral intake was indicative of EOL, but the importance of "pushing fluids" was expressed by many and tube feeding as a last resort was mentioned by both carers and qualified staff.

"Then that's when it really gets to the point where it's real difficult. The only thing you can do at that point is to push the liquid into the person just to, yeah, because you have to get her or him something. And I think by that time it's already at the end, it's the end, the end is very near." (PC1)

"I think the food is not helping them when it's the end of their life." (P5C)

We can't, sister, try to force them to eat, maybe we can try like peg feeding, yeah." (P4E)

Interestingly, several comments were made regarding respecting the family's wishes around nutrition/feeding and opting for tube feeding, but more than one participant stated they would not like that for themselves or their loved ones.

4.2.3.3 Psychosocial aspects

Depression was mentioned frequently during interviews in the context of understanding the behaviours of dementia patients. In isiZulu, there is no direct translation for the word 'depression,' and it is interpreted rather as a low mood or sadness. However, signs commonly associated with depression were recognised.

"Besides crying, maybe you can notice the mood changes. The resident maybe doesn't want to be with others, wants to be alone, as if there's something that is troubling him."(P8E)

"They've been quiet and try to be on their own. Like to be in their rooms every day. They don't like to chat. They're quiet. Do you want to watch the TV? No. Do you like to take a walk? No." (P3C)

"Just starts crying without any response. The response will be just tears." (P14C)

Of interest during the interviews was that a lot of carers associated the cause of depression with being separated from family/loved ones by being placed in a NH. This may be indicative of cultural influence and will be explored further in the discussion chapter.

"I think it does depress to be with other people not with your family. It's a lot of depression. You don't know all these places, you don't know all these people, but you end up dying with them." (P6C)

"They have no families and then now they had to come here to us. So sometimes they feel like we're strangers. They don't know us. That could make them be depressed." (P12C)

In addition to NH staff noting self-isolation, crying, social withdrawal, loss of appetite, and increased somnolence, several interviews also cited anger and irritability as being symptoms of depression.

4.2.3.4 Dementia as a terminal illness

While some carers understood and described the progressive nature of dementia, many attributed the actual cause of death to aging, underlying conditions or cessation of eating which was not associated with dementia.

"Maybe they die from other diseases that they've got and dementia is also included into that, but I don't think that dementia would be the cause of death. I don't think so." (P14C)

"From my thinking, some they don't want to eat, Yeah, that might end up dying because of not eating and associated with some or other, some illnesses." (P4E)

"I think as we grow the body doesn't function well. Not actually dementia, just old age." (P6C)

Qualified members of staff who were interviewed were more aware that dementia was a terminal illness, with one EN saying:

"They get thin and thin and so on. Until they passed away. I've once noticed that the dementia patient can go to a terminal stage, and they die of dementia." (P8E)

4.2.4 Theme 2: Understanding of Palliative Care

Despite many participants seeming to lack a clear understanding of palliative care, most believed it involved additional care and support for patients, and a professional nurse felt that care staff instinctively adopted a palliative approach:

"So actually, our staff in care homes know a whole lot about palliative care they just don't know what the label for it is. But they do amazing palliative care, like I was just blown away when I came here. They pick up when people are dying, they will sit with them and hold their hand and be with them and it's all classic palliative care stuff." (P7P)

Thoughts on what palliative care was varied amongst participants. More than one carer believed the aim was to extend life, and others correctly stated it involved the care of patients who were terminally ill, with the majority citing cancer as a diagnosis related to palliative care. Enrolled and professional nurse participants held a better understanding on the broader concept of a palliative care approach, but opinions varied across all categories of staff on when a palliative care approach should be adopted.

"Palliative care, I remember, if I'm not mistaken, it's when now they need machines next to them to help them maybe to live a little bit longer." (P14C)

"Palliative care, I think you have to be there a lot for that person, you must understand him or her, you must understand him a lot. Maybe what he or she goes through while she's in pain or something. But you must be in her shoes. Be there. Just be there for him a lot." (P2C)

"Because I read a lot, so I think I came across that. But I was doing it, but I didn't know it was a palliative care until when I come out on this." (P1C)

4.2.4.1 End-of-life care priorities for NH staff

A high degree of empathy for terminally ill patients was expressed by participants, and this was often accompanied by a sense of pride and responsibility in their role of the care of patients near the end-of-life.

"For that I think the most important thing is to show love. There's nothing more about love because like, you know, it's nearly her time now to go, then she must get love from all of us." (P9C)

"I mean they still need that care, that special care, I mean you are in your bed, in your bed dying, you need all the support, all that, you know, you don't want to be totally alone there, you don't want to feel so alone." (P1C)

"I feel, to see them, to look after them until they die, I feel like I've done a huge thing, just to be there for them." (P12C)

With regards to the physical care of patients at the EOL, the focus of all participants was on providing good quality basic nursing care. Whilst most carers expressed an understanding that patients are generally no longer able to eat at this point, frequent mention was made of continuing to try to give oral fluids. This was not raised by any ENs and PNs who were interviewed.

Recognizing the spiritual needs of patients and the inclusion of family was referred to by one participant.

4.2.4.2 Communication with the families of terminally ill patients.

Participants across all qualification categories alluded to the need for more and improved communication with the family members of patients, in part so that the job of a caregiver was better understood, but also so that families knew what to expect.

"It helps them come to peace with it, I think. And it's also helped the staff because then there's less blame also. If you've had that conversation, is that they're more open, okay, this is a natural thing, it's nobody's fault."(P7P)

"Because some of the family, they always have that faith that she is still going to survive. So it is good to speak with them and give them understanding. That that person is going to pass away." (P11E)

"I'm sure the family needs to be told the truth what is happening and so that they understand everything like what's going on and especially then some of them they love to be there at the end." (P1C)

Despite acknowledging the need for EOL conversations, many participants expressed a lack of confidence and reluctance to initiate this communication (particularly when a patient was near the EOL) and would rely on senior members to staff. However, two senior

staff members also expressed discomfort in holding EOL conversations and one felt the patient's doctor should have talked to families.

"Maybe I can even say, you know, it looks like your mum, today it won't last. But you see, it's so hard to tell a person that thing. You can't say that to a person. So I don't think it's a good thing to say some things like that." (P14C)

"They have all those questions, but the big question is going straight to sisters. Sometimes we're not going to answer right, you know?" (P9C)

"As a nurse, even though I can see that the patient is on a terminal stage, but the doctor needs to confirm it, then I can do the counselling. If the doctor has told them, it's easy for me to reinforce it."(P8E)

4.2.4.3 Cultural, religious and personal beliefs

There were no specific questions about cultural, religious, or personal beliefs in the interview guide, but when discussing EOL issues, the personal beliefs of participants, and how these shaped the care of patients, emerged as a theme. Responses highlighted a deep respect for individual preferences and trying to meet the patient's spiritual needs.

"Yes, yes. It's very important to me to know because I need to respect them until their last days. If they believe in Christianity, I need to respect that." (P12C)

"I think that is also important because if the person was religious obviously then you know that you can pray for the person." (P1C)

Numerous participants mentioned using visual clues to determine a patient's religious leanings, with just two of the interviewees referring to having prior knowledge of their spiritual beliefs.

"Others the Bibles are there in their rooms and then you can see okay this is a Christian because the Bible is there, she knows the verses and sometimes she can even preach it to you. So yeah, this is the way I find out." (P14C)

"Some, they've got their bibles, their photos, all these things. Because we are cleaning their cupboards, they've got the stuff. You can know. That it's a religious person." (P6C)

Some participants referred to their own spiritual or religious beliefs in terms of coping strategies when working with patients near the EOL. As one carer said:

"As I'm doing this job for so many years, I feel bad for the family, but for the patient that is dying, sometimes I pray for her to just go so that the pain will go. But I'm not telling her that I'm praying for you. But on my mind, I keep on saying, oh God, please help her to go." (P3C)

4.2.5 Theme 3: The Impact of EOL Care on NH staff

This subtheme emerged strongly in the interviews. As seen in the socio-demographic information of interview participants, many have worked in the facilities they are currently employed in for many years. Evidently, strong bonds and relationships are built between NH patients and staff, and a sense of reciprocity was expressed by more than one carer.

"When you're working this kind of job, you bond with these people. You become like you are family. These old people, they're like now they're your own granny, you know. They know you when you sad." (P14C)

"It's very difficult because sometimes we get bond of this person, so yeah, obviously it's very difficult for us when they pass away." (P5C)

"It's painful. It's painful. It's painful, but sometimes you say, but she was suffering. At least she's in peace now. But it's painful because I used to be there personally. You get to know them over a long period of time. Yeah, it's not like easy." (P6)

NH staff process and experience the loss of patients not just on duty, but when they are at home as well. Several participants expressed this.

"We lost a patient recently, on Friday. And then when I was at home I couldn't sleep. I was just thinking, thinking about her, thinking about everything that we used to say, thinking about when I got her up in the morning." (P14C)

"As for me personally, what I do is when I go through that process, I always switch off when I get home, read a book, it helps me a lot to, yeah. Just to take a break from that and not even think about it because it's done and finished so I must try to you know." (P1C)

"Sometimes it's sad. Because sometimes you think about that person, even when you're at home, like, oh, maybe someone passed away and I loved him so much. Because sometimes this is a person that talks a lot. We will say, Mrs Whoever - we miss you. She will be laughing. She will be dancing." (P2C)

4.2.6 Theme 4 - Training needs

A strong desire to learn more about both dementia and palliative care was expressed by all participants. Many caregivers felt it would be beneficial to "go back to basics" and master skills such as routine observations.

"Caregivers need training, like even the especially those simple things. You know, they don't think they are important, but they are very important." (PC1)

One care felt that the institutions providing caregiver training did not prepare them for the reality of caring for dementia patients.

"If you go to most schools that we study at, they don't tell us, like, real things that we will face when you are working. But when you come here and start working you will see what is dementia but when they are teaching us it's just so easy." (P2C)

Care of terminally ill patients was mentioned by many carers and echoed by senior staff who felt that there was a need to be better educated on the progressive "end stages" of dementia.

"So just to be able to give them that confidence, okay, this is a normal thing and it does look like this person is going to die".(P11E)

"The end stage of the dementia, we don't understand, we only understand the cancer patient, that they can go to the end stage." (P8E)

4.3 Mixed methods integration

The table below brings together the qualitative and quantitative data and has been organised according to the four main identified themes. The impact of EOL care on NH staff and their training needs was not measured quantitatively using the DKAS or PANA questionnaires but emerged as an important consideration during the interviews and are discussed further in Chapter 5.

Table 4.3 – Summary of mixed methods findings

	Quantitative Findings	Qualitative Findings	Integrated Conclusions
Understanding of Dementia			
Physical Symptoms	Relatively high scores on DKAS for questions on physical symptoms (Qs 15, 15,16 & 17). 40% did not believe that dementia caused changes to the brain (DKAS Q5).	Good awareness that dementia is neurological. Immobility and postural changes are cited frequently, but fewer references to other physical symptoms.	Disparity between data sets on dementia as a neurological disease. Physical manifestations of advanced dementia are poorly understood, which may preclude timely prognostic discussion and impact symptom management.
Nutrition and Hydration	An average score of 82.3% on DKAS Q16 (difficulty eating/drinking) and a good understanding of the purpose of PEG feeds. (PANA Q9)	Some participants identified eating challenges, but didn't attribute this directly to dementia progression. PEG feeding was quite strongly supported.	Weight loss and reluctance to eat is identified by NH staff but not clearly linked to disease trajectory. General inclination that feeding cessation meant failing the patient.
Psychosocial Aspects	Low DKAS scores on Qs 8,9 & 10 show poor knowledge regarding communication.	Participants often mention sadness and withdrawal. Find aggression the biggest challenge. Many participants used communication and compassion as an effective intervention.	Staff are attuned to some psychosocial symptoms, but assumptions are made about causative factors. Quantitative data conflicts with qualitative data around communication with dementia patients.
Dementia as a Terminal Illness	22.3% recognized that dementia shortens life (DKAS Q1). 52.2% understood that planning for EOL care is needed (Q6) 61.4% believed a palliative approach for dementia was beneficial. (PANA Q6)	Several participants were unsure if dementia leads to death.	The terminal nature of dementia is not well understood, delaying the implementation of a palliative approach to care.
Summary	Average DKAS score: 57.6% with notable misconceptions on basic dementia facts (e.g., only 20% knew dementia isn't a normal part of aging)	Staff affiliates dementia primarily with memory loss, but not physical symptoms. Rely on intuition and understanding of individual patients, not formal knowledge	Knowledge gaps were identified in the theoretical understanding of dementia, especially disease progression and symptom management. Palliative care, as a concept, was not readily linked to dementia patients.
Understanding of Palliative Care			
End-of-Life Care Priorities	PANA Q1 (average score 77.6%) & Q2 87%, show an understanding of comfort-focused care and the non-curative nature of palliative care.	Many equated palliative care with cancer, EOL, or bedridden patients, but had clear care priorities that met physical and psychosocial needs. Many emphasized continued nutrition/hydration at EOL.	Limited understanding of when to adopt a palliative approach. Despite high scores on the questionnaire, the qualitative data indicated limited knowledge of the scope of "comfort care".
Communication	PANA Q7 & 13 (75–93%) on family involvement.	Interviews highlighted inconsistent communication with families.	Planned prognostic conversations are lacking.
Cultural and Personal Beliefs	PANA Q8: Only 28.3% disagreed with using English only for diverse patients. 88% of carers spoke isiZulu	Cultural norms shape perceptions of palliative care. NH placement is viewed by many as abandonment and the cause of psychosocial distress.	Cultural beliefs and language barriers may hinder full understanding of palliative care. The language appropriateness of questionnaires needs to be considered.

Chapter 5: Discussion

5.1 Introduction

Dementia is a progressive, terminal disease with a high symptom burden in the advanced stages and warrants a palliative approach to care. The aim of this study was to explore the knowledge and understanding NH staff have about dementia and palliative care using questionnaires and interviews.

The results concur with the findings of similar research in other countries, in that knowledge deficits are seen across all facilities, regardless of professional qualification (36, 51). PNs are found to score higher than ENs and carers in both dementia and palliative care, but there is a trivial difference between the knowledge and understanding held by ENs and carers.

Awareness of dementia as a terminal illness is lacking, and although there are indications that aspects of a palliative approach to care are being adopted, this is generally right at the EOL of patients with advanced dementia and relies on the intuitive and caring nature of NH staff, rather than a sound knowledge of palliative symptom management.

This study also describes the unique local perspective of the South African context and how cultural and personal beliefs influence care. The demographic profile of most patients in the participating facilities of this study is white, middle-class older people who are being cared for primarily by Zulu HCPs. Values, beliefs, stereotypes, and biases are all shaped by culture, and cross-cultural understanding and awareness are likely to play a role in understanding and interpreting the behaviours of dementia patients and influence the approach to palliative care.

5.2 Dementia knowledge based on DKAS findings

The average dementia knowledge score of NH participants in this study is consistent with the findings of other studies using the same assessment tool (51, 52). In Australia, Robinson et al had a similar demographic profile of participants to this study and also found that PN's achieved a higher average score in dementia knowledge with only a marginal difference between the scores of ENs and carers (8). In contrast to the Australian study, however, carers who answered the questionnaire in this study showed a better understanding than those with higher qualifications in understanding behaviours typical of dementia patients. One plausible explanation for this is that almost half the carers completing the questionnaire had been in their current position for over six years.

The prolonged trajectory of dementia makes it likely that an intuitive awareness of and insight into the behaviours and communication styles of individual patients with dementia develops progressively over time. This concept of accumulated knowledge being gained over time and the link between care experience influencing care decisions has been described by Handly et al and others (8, 53) and is confirmed in this study. The following quote supports the idea of accumulated knowledge gained from experience and length of service, despite a lack of formal qualification: *"Because sometimes their mind will like come back, they'll talk to you… After five minutes, they forgot."* (P2C)

Carers also scored higher than their counterparts on the risk and health promotion subscale of dementia. The age demographic of the participants may explain this outcome in part, in that in South Africa in the late 1990s, the HIV/AIDS epidemic was at its peak, and large numbers of home-based carers were enrolled in short training courses for the care and

support of HIV positive people in the community. ARVs were only rolled out in 2003, therefore HIV-related dementia was commonplace (54, 55), and these carers will not only have been involved in the care of patients presenting with dementia but would have been educated on general health promotion and risk reduction.

As projected figures for dementia diagnoses are set to continue to rise, the WHO blueprint for dementia research has emphasized that there is a need for more research to focus on risk evidence and reduction (4).

5.3 Recognising pain and other physical symptoms of dementia

Identifying physical pain in non-verbal dementia patients relies substantially on the interpretation of body language. This concept is challenging to interpret in isiZulu as it translates to 'physical communication' with examples such as touching hands and faces. The DKAS tool asks if 'uncharacteristic behaviours' can be attributed to unmet needs (such as pain) in dementia patients, and both carer and EN groups scored significantly higher on this than PN's, again reinforcing the concept that carers build up knowledge and understanding of patients over time.

"Because we're close to them, you can see the actions because we know them very well."(P6C)

Robinson et al found that NH staff 'struggle to identify that pain can be assessed in persons with advanced dementia' (8), however, the evidence from interviews in this study confirmed that NH staff (particularly carers) were acutely aware of nuanced changes in the body language of dementia patients, which aided in identifying pain. Six of the 10 carers interviewed made specific reference to facial expression, with some demonstrating what they saw in patients' faces (grimaces, scrunching eyes, facial changes) and others referring to

vocalizations and the expression of pain through body language such as protective movements or guarding.

Facial expression, vocalizations, and behavior changes were all considered when assessing patients' needs, with six of the 10 carers interviewed made specific reference to facial expression, with some demonstrating what they saw in patients' faces (grimaces, scrunching eyes, facial changes), and others referring to vocalizations and the expression of pain through body language such as protective movements or guarding.

This is echoed in Van Wyk's findings when he noted that "without exception" care workers in his study intuitively adopted a person-centered approach to the care of dementia patients, and an understanding of each patient assisted in their management (37).

5.3.1 Delirium

With over 80% of the participants who completed the DKAS questionnaire incorrectly believing that the sudden onset of cognitive decline is a characteristic of dementia, there is evidently a lack of knowledge or clarity on the difference between delirium and dementia. Delirium is commonly seen in patients with advanced dementia due to their susceptibility to infections, but an inability to differentiate between dementia and delirium has been found in other studies in equally high numbers (8, 51), and clearly identifies a need for focused training to differentiate the neurodegenerative trajectory of dementia from acute delirium and other causes of confusion.

5.4 Management of behavioural symptoms

Behavioural symptoms in dementia patients such as aggression or agitation can be challenging for NH to manage, and in the DKAS questionnaire results of this study, more than two-thirds of participants felt that medication was the most effective way to treat these

behavioural symptoms. This contrasts with the findings of other studies, in which NH staff were reported to prefer to manage such behaviours with an interpersonal approach (37, 56). However, a distinction must be drawn between the terms 'treating' versus 'managing,' as in the qualitative interviews of this study, participants described person-centred, interactive, and de-escalating tactics to manage (as opposed to treating) behaviours such as agitation or aggression, which aligns with the research cited above.

The recognition of psychosocial and emotional pain in dementia patients displaying atypical behaviours also emerged as a strong theme amongst interview participants, with participants associating behaviours like aggression or withdrawal with psychosocial causes, including loneliness: *"They've been quiet and try to be on their own… They don't like to chat."* (P3C)

This was an encouraging finding, as the importance of not dismissing these aspects of care has been identified in research (24), and is one of the cornerstones of palliative care.

5.5 Recognition of dementia as a terminal illness

The qualitative findings of this study show an almost equal split between interview participants who believe the cause of death in dementia patients is due to an underlying condition or old age, and those who associate the death with advanced dementia, primarily due to not eating. Interview data revealed varied understanding of dementia as a terminal illness:

"Maybe they die from other diseases that they've got… but I don't think that dementia would be the cause of death." (P14C)

"I've once noticed that the dementia patient can go to a terminal stage, and they die of dementia." (P8E)

The majority of ENs and carers believed that dementia did not impact the longevity of the dementia patient, as evident in the qualitative data, with many interviewees attributing progressive functional decline in dementia to general aging, and the death of patients with advanced dementia to underlying conditions such as diabetes.

Failing to recognize the life-limiting nature of dementia, and poor awareness of dysphagia and a loss of mobility as prognostic indicators, is not unique to this study (2, 8, 9, 12), and may influence when a palliative care approach is adopted, but does not appear to negatively affect the quality of care delivered at the EOL.

5.6 Understanding of Palliative Care

A generally poor understanding of the concept of palliative care was demonstrated in this study, as was recognising when to implement a palliative approach to care in dementia patients. This is in keeping with other NH studies across both high-income countries (9, 12, 36), and LMICs (57-59). However, most participants recognized that palliative care involved providing "extra" care and support, and high scores achieved on the DKAS subscale for care considerations, PANA items relating to symptom management, and opinions expressed in the interviews, all indicate that NH staff meet many of the goals of palliative care. It is encouraging to note that this extends not only to meeting the physical needs of the patient but also in offering psychosocial support, which contrasts with research showing that less emphasis is generally placed on these aspects as opposed to physical needs at the EOL (14).

Despite uncertainty about terminology, several interview responses illustrated how palliative care is often intuitively carried out, even when the concept is misunderstood, and empathy for patients during EOL care was expressed: *"You are in your bed dying… you don't want to be totally alone there."* (P1C)

5.7 Lack of access to information

Of concern is that this study highlighted the perspective of carers that they were generally not provided with relevant medical and personal information pertinent to the individuals in their care. A considerable number of participants stated that they were not aware of the patient's primary diagnosis or comorbidities, except for diabetes due to diet specifications. As a result, the readings of cues, behaviours, and body language extends past the physical aspects of care to include assessment of psychosocial and spiritual needs, with carers relying on environmental and behavioural clues to (for example) determine a dementia patient's religious or spiritual beliefs and the strength of family relationships.

"Some, they've got their bibles, their photos... we are cleaning their cupboards... you can know." (P6C)

Studies in England and Australia noted that care planning relied to some extent on sharing the unique life stories of patients with care staff, and Handley et al. describe a discrepancy between what carers were expected to know and do, and the training and information they received (53). In the SA context, Van Wyk noted that potentially valuable background information was not shared with NH staff (37), indicating that the hierarchical structure of NHs and lack of access to information needs to be considered.

5.8 Cultural and personal beliefs

Cultural beliefs can play a role in people's perception and understanding of dementia and how it is managed (60). This was reported on by Mkhonto et al. who found that belief in witchcraft contributed to a fear of dementia amongst trained healthcare workers in SA (61). This did not emerge as a theme in the qualitative data of this study, although a carer who was interviewed highlighted the fact that at her local clinic, trained health professionals did not know or understand dementia and were therefore unable to support or advise community members. As she explained:

"That's why I'm helping my community a lot because they don't know what dementia is. They'll just say they're mad or maybe the witchcraft. So we African people are suffering from that."(P2C)

The influence of cultural beliefs and practices amongst isiZulu NH staff was highlighted in their interpretation of perceived depression and "suffering" amongst dementia patients. In traditional Zulu culture, elders remain at home as they age and are cared for by family (30), and this may account for several participants associating depression in dementia patients with having been abandoned by their families in a care facility. Furthermore, two interview participants were reluctant to talk about death due to their cultural fear of death.

"*You can't say that to a person. So I don't think it's a good thing to say some things like that."* (P14C)

5.9 Training needs identified

As evidenced in the quantitative data of this study, knowledge gaps are seen across all categories of staff and in all the participating NH facilities. Furthermore, NH staff who were interviewed were cognisant of their need for further training and education in both dementia

and palliative care, and all expressed a strong desire to learn more. The need for education of NH staff has been recognized in other studies (7, 62), and in 2023 the WHO advocated for more research into the training needs of HCPs working with dementia patients (4).

In a SA context, this study highlighted that for many, economic hardships have meant that study opportunities and tertiary education to further their education and careers have been cost-prohibitive. As one carer said: “And it's not like we didn't want to do that. We tried, but it didn't happen. And you can't force things.”

Ongoing specific knowledge deficits were identified in the causes, characteristics, and disease trajectory of dementia; nutrition and hydration at the EOL, and the basic principles of palliative care. Self-identified training needs by carers included: taking routine observations, care of a dying patient, and managing challenging behaviours, while qualified members of staff expressed a need for further education in palliative care and advanced dementia. One NH manager described their in-house training of NH care staff as “reactive” and based on a need for improved performance, rather than proactive to expand learning.

The demographic surveys show that approximately 68% of the participants received training in dementia and 56% in palliative care. While this suggests a relatively strong baseline of exposure to training in these areas, no additional information was collected about the nature of this training. This lack of detail limits interpretation, as it is unclear whether the training was formal, structured, and comprehensive, or more informal and ad hoc. However, some of the carers interviewed expressed disappointment in training institutions:

"They don't tell us real things that we will face when you are working… but when you start working, you will see what is dementia." (P2C)

A need to be better trained on basic nursing skills was also expressed:

"Even those simple things… they are very important." (PC1)

A carer who was interviewed highlighted the fact that at her local clinic, trained health professionals did not know or understand dementia and were therefore unable to support or advise community members.

Limitations

In this study, there was a degree of reliance on NH senior staff, who acted as facilitators in the research process. They were responsible for ensuring the completion of signed consent forms and monitoring that participants completed questionnaires independently. Such reliance introduced potential barriers: incomplete consent forms resulted in the exclusion of numerous questionnaires, and the possibility of collaboration between participants cannot be ruled out. Furthermore, this dependency raises the possibility of selection bias, particularly in the qualitative data collection, where staff members who were more willing, available, or perceived as suitable by managers may have been more likely to participate. This consideration was not felt to affect the outcomes significantly, but is noted for completeness.

Although all documentation was translated into isiZulu and participants had the option of completing the questionnaires in either language, only one participant elected to do so in isiZulu, despite this being the home language of almost all participants. The reason for this is unclear, as is the influence it had on the questionnaire results. Similarly, all interviews were conducted in English at the request of participants. In some instances, the researcher had to provide several scenarios/practical examples to explain the topics being explored, and further insights and understanding into NH staff experiences could have been gleaned if they were expressing themselves in their home language.

In some facilities, the same participants completed both the questionnaire and an interview. With the questionnaire being administered first, it is possible that this primed participants' thinking and influenced the way they reflected on certain issues during the

interview. While this potential bias cannot be entirely excluded, there was sufficient richness and variability in responses to support the validity of the findings.

This study was limited to six NHs in the province of KwaZulu-Natal and may therefore not be representative of the knowledge and understanding NH staff in other provinces have on dementia and palliative. In addition, the perceptions of the fourteen individuals interviewed for this research may differ from other NH employees and draw into question the transferability of the data.

Another limitation of this study was that no details were asked of participants regarding the prior training they had received in dementia and palliative care. If future research explored the duration, content, and quality of training provided, a sub-analysis as to the efficacy of such further education could be explored.

Chapter 6: Conclusion

The findings of this dissertation show that NH staff have gaps in their knowledge and understanding of both dementia and palliative care, but it also highlights an absolute dedication to the work that they do; a desire and willingness to learn more; and a commitment to providing the best possible care they can within the limitations of their training. Specifically, there is a need for further training of NH staff in understanding the progressive trajectory of dementia and the management of patients in the advanced stages of dementia.

A solid grounding in the principles of palliative care and how these might be used to minimize suffering and improve the quality of life of dementia patients in their care would positively impact both staff and patients alike. NH management needs to recognize the benefits of empowering their workforce with knowledge and skills and commit to prioritizing training that benefits the patients and their families and will bring even greater job satisfaction to this valuable cohort of healthcare workers.

In a white paper on palliative care for dementia patients, the EAPC identified three domains that constitute what 'physical comfort' encompasses in the care of dementia patients. They asserted that person-centred care, communication, and shared decision-making which affect the care of dementia patients, was a priority for research (63)The findings of this study suggest that shared decision-making is an area not actively practiced in NHs, and further exploration of its impact on dementia patients would be valuable.

This dissertation adds to the body of knowledge on palliative care for dementia patients in that it highlights that a person-centred approach is intuitively adopted into the care

of NH residents and that despite a lack of theoretical knowledge, many of the core principles of palliative care are met at the EOL of patients with advanced dementia. As stated by Stevenson et al. ‘any effort to improve the quality of nursing home care must include a focus on palliative and end-of-life care’ (23).

Conducting research with a vulnerable cohort, such as those who are frail and have dementia, can be challenging, particularly when the focus is on the advanced stages of the disease. However, this should not preclude quality research from taking place.

Recommendations for future research include:

Evaluating existing practice: Assessing the current provision of palliative and dementia care within SA NHs, to determine whether what is offered constitutes quality palliative care, and to identify strengths, gaps, and areas for improvement.

Training interventions: Designing and testing training programs for NH staff on dementia-specific palliative care, including pain and symptom assessment tools adapted for low-resource settings.

Collaboration approaches: Assessing the impact of partnerships between trained palliative care specialists and NHs on quality EOL dementia care.

Given that palliative care is gaining momentum as a recognized field in South Africa, now is an opportune time to raise the profile of dementia care through research in NHs. Such studies could provide a vital evidence base to inform national policy, and the development of contextually appropriate standards of care.

In the South African context, this work is particularly urgent given the current limited access to specialist services, the shortage of trained professionals, and the reliance in NHs on care staff with minimal formal training.

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Appendix A - DSD Research application letter

Practice No: 0818534
6 Milbank Road
Assagay
3610

22.1.24

Dear Mrs NI Vilakazi,

Re: Application to conduct research.

I am a UCT student doing my MPhil in Palliative Medicine and am seeking your approval to conduct research in 6 care homes in KZN, which are registered with the Department of Social development.
I have attached my research protocol for your perusal, in addition to ethical approval letters from UCT, and signed memoranda of understanding (MOU) from 4 of the 6 care homes who have agreed to participate. I anticipate that the final two MOU's will be in hand by the end of January.
Please note the research focuses on the knowledge and skills of the nursing home staff and does not involve the patients.

Please advise if there is any additional documentation you require.

I look forward to hearing from you with a positive response.

Many thanks.

Kind regards,

Aileen Forbes
076 1415 118

Appendix B - Letter to HREC regarding DSD consent to conduct research

13 February 2024

To
Prof Marc Blockman
Chair HREC
UCT

Dear Professor Blockman,

Re: **HREC Ref 619/2023** Research site approval delay due to Department of Social Development (DSD) Student Ms Aileen Forbes FRBAIL002

Ms Forbes is a postgraduate student at UCT and is conducting a project in part fulfilment of the requirements of an MPhil (Palliative Medicine) at UCT. Her application to HREC was approved (reference HREC Ref 619/2023) Please can you advise on an issue with regards to obtaining governance approval from the Department of Social Development (DSD) to conduct this MPhil research study in nursing homes KZN. Following an initial email enquiry to DSD, the student was asked to submit a formal letter of request, along with the study protocol and the MOUs from participating facilities, all of which was done.

A subsequent letter requested a presentation, subsequently given to a panel from DSD on the 1st of February 2024. Having presented the proposal, Ms Forbes was advised by the panel that DSD is not mandated to oversee Nursing Homes, and that as she was not including Social Workers in the study, the research was not of any relevance to them. As per the below link, it does appear that DSD do have a mandate to oversee old age care facilities, but in view of their opinion that they do not have authority to give consent for this study, would like to please request the guidance of HREC in this matter. https://www.dsd.gov.za/index.php/about/legislative-mandate All participating facilities have followed their own internal processes; and have given written agreement to take part in the study by way of signing Memoranda of Understanding (MOUs), which are attached.

The following points summarize the study briefly: - The proposed research is aimed at employees of the nursing homes, all of whom will have the capacity to sign informed consent. - The study is focused solely on assessing the knowledge and understanding of nursing home employees, by means of questionnaires and interviews. - No residents/patients residing at the participating nursing homes will be involved in or impacted by the carrying out of the proposed research.

In summary, the UCT HREC has approved this study from an ethics point of view, and it seems that the remaining barrier is a governance one, which the DSD says that it is not mandated to cover.

Since these homes act autonomously in terms of management and governance, and that Ms Forbes has obtained MOUs from each, could this be considered to be sufficient evidence of due diligence in both ethics and governance for the study to proceed?

Warm regards, and thank you.
Alan Barnard (supervisor and principal investigator)

Appendix C - HREC Approval Letter from Professor Marc Blockman

Subject: FW: Research delay due to Department of Social Development (DSD) approval. Ref 619/2023
Date: 2024-02-16 14:38
From: Marc Blockman <marc.blockman@uct.ac.za>
To: abarnard <abarnard@intermail.co.za>
Copy: HREC Enquiries <hrec-enquiries@uct.ac.za>

Hi

Hope well

Thank you

From the description, it would seem that you have gone to great lengths to get permission and approached the Department of Social Development (DSD), who claim not to have no oversight of old-age facilities, which are the sites of the research. It seems that the facilities to be included are NGOs and therefore may not necessarily fall under DSD jurisdiction anyway.

You have secured permission from each of the individual institutions where research will take place and there are signed MOUs in place.

From the internet, it seems that the DSD has a role in administering the register of NGOs but that it is not mandatory for NGOs to be part of that so it sounds like a tenuous link *"Contained within the DSD is the Nonprofit Organisations Directorate, which was established in 1997. It is tasked with administering the Register for Nonprofit Organisations. This register is voluntary. It seeks to increase credibility and transparency by having nonprofit organisations report details of their operations.[ref given as https://www.dsd.gov.za/index.php/npo/about-us]. The DSD plays a significant role in helping administer the South African non-profit sector."*

As the DSD has been approached and indicated that it is not the overseer, the researchers have permissions and MOUs from the sites, and the research itself has already been approved by the HREC, I cannot see why you should not be reasonably allowed to proceed.

The HREC are happy; thank you and wish you much success

Be well

Marc

Professor Marc Blockman
Director of the WHO Collaborating Centre for Medicines Information
Division of Clinical Pharmacology
Faculty of Health Sciences | University of Cape Town and Groote Schuur Hospital
Room K45.43 | Old Main Building | Groote Schuur Hospital
Main Road | Observatory | 7925 | South Africa
Email: Marc.Blockman@uct.ac.za
Telephone: +27 21 406 6496
http: www.medicine.uct.ac.za

Appendix D - Ethics Approval Certificate

UNIVERSITY OF CAPE TOWN

FACULTY OF HEALTH SCIENCES
Human Research Ethics Committee

FHS016: Annual Progress Report / Renewal

HREC office use only (FWA00001637; IRB00001938)			
This serves as notification of annual approval, including any documentation described below.			
☑ Approved	Annual progress report	Approved until/next renewal date	30.12.2025
☐ Not approved	See attached comments		
Signature Chairperson of the HREC/ Designee		Date Signed	19/12/2024

Note: Please email this form and supporting documents (if applicable) in a combined pdf-file to hrec-enquiries@uct.ac.za.

Please use the latest form found on our website:
http://www.health.uct.ac.za/fhs/research/humanethics/forms

HUMAN RESEARCH ETHICS COMMITTEE
19 DEC 2024
HEALTH SCIENCES FACULTY
UNIVERSITY OF CAPE TOWN

Comments to PI from the HREC

Principal Investigator to complete the following:

1. Protocol information

Date (when submitting this form)	17.12.24		
HREC REF Number	619/2023	Current Ethics Approval was granted until	30.11.24
Protocol title	What do Nursing Home staff know and understand about dementia and a palliative approach to dementia care?		
Protocol number (if applicable)			
Are there any sub-studies linked to this study?		☐ Yes	☐ X No
If yes, could you please provide the HREC Reference number for all sub-studies? Note: A separate FHS016 must be submitted for each sub-study.			
Principal Investigator	Dr Alan Barnard		

Appendix E – Memorandum of Understanding

MEMORANDUM OF UNDERSTANDING

Between

_____

(Organisation)

AND _____ (Research Applicant)

This research opportunity is provided to the applicant for academic purposes in terms of the following conditions:

1 **Details of the research is declared in full by submission of a study information sheet.**

2 The research is relevant to the organization and directly or indirectly benefits the organization and/or its residents.

3 The completed research protocol is to be made available to the organization after verification by the academic institution and approval from research ethics committee.

4 Research may only commence after management reviews the relevant documents and provides written consent.

5 The researcher is responsible for obtaining individual written informed consent from study participants.

6 On completion, the researcher may be asked to present their findings to management.

8 Researchers are requested to give feedback to the participants on their findings.

9 Prior written consent is required prior to publication of the research conducted.

10 No financial or other compensation will be exchanged in respect of this research.

Roles and Responsibilities:

a) _____ (organisation) agrees to make resources and information required for the completion of the research available to the applicant.

b) Minimum reliance should be placed on our staff for the implementation of the project.

c) The Applicant agrees to comply with the regulations and restrictions of the POPI Act.

d) The Applicant agrees to conduct the research in an ethical manner.

e) The personal identities of staff and or residents will remain confidential unless special written consent is obtained by mutual agreement.

I_____ (ID) _____ enrolled at

_____ (Student number)_____, understand and accept the terms of the Agreement.

Applicant signature: _____ Date:_____

Organization Representatives signature: _____

Name: _____Designation: _____

Date: _____

Appendix F - Letter of confirmation from translation services

Simply Marketing (PTY) LTD T/A Simply Translate
Registration #: 2016 / 387890 / 07
Phone: 011 568 9824
Mobile: 071 565 9727
www.simplytranslate.co.za
11th December 2023

To Whom It May Concern:

This is to confirm that Aileen Forbes made use of Simply Marketing (PTY) LTD T/A Simply Translate to have their English document translated into IsiZulu by our Qualified Translator – Tusani Gumede.

For any further inquiries, please do not hesitate to contact me on the details provided below.
Kind Regards,

Carryn

Chiapperini

Accounts Manager
carrync@simplytranslate.co.za
071 565 9727

Appendix G1 - Invitation to participate in research

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Study Title: What do nursing home staff know and understand about dementia and a palliative approach to dementia care?

KNOWLEDGE QUESTIONNAIRES

You are invited to take part in research exploring the knowledge and understanding employees working in nursing homes have about dementia and palliative care, by completing a questionnaire on dementia containing 25 True/False questions, and a separate questionnaire of 17 True/False/I don't know questions on palliative care. The approximate time it will take to complete both questionnaires is 45 minutes.

Participation is completely voluntary, and you will be provided with a detailed description of what the study entails; and be asked to provide signed consent should you wish to take part.

The questionnaires will be completed during work hours, and refreshments will be offered.

Qualified nurse participants must hold current registration with the South African Nursing Council, and all participants need to have been employed in their current position for more than three months.

Your contribution to this study will be most valued and will add to the body of knowledge about a palliative care approach to patients with dementia.

Your participation would be greatly appreciated.

I will be following up on this initial invitation, but please contact me on 076 1415 118 or reply via email to aileen@palcareservices.com should you have any immediate questions.

With much appreciation,

Aileen Forbes (P/N)

Appendix G2 - Invitation to participate in research interviews

INVITATION TO PARTICIPATE IN A RESEARCH STUDY

Study Title: What do nursing home staff know and understand about dementia and a palliative approach to dementia care?

IN-DEPTH INTERVIEWS

You are invited to participate in interviews being held as part of a research study exploring the knowledge and understanding nurses working in nursing homes have about dementia and palliative care.

Participation is voluntary and full details about the study will be supplied. The interviews will be conducted during work hours; will be audio recorded for analysis purposes and will take approximately 30 - 45 minutes. You will be required to sign a consent form to take part.

Qualified nurse participants must hold current registration with the South African Nursing Council and need to have been employed in their current position for more than three months.

Your contribution to this study will be most valued and will add to the body of knowledge about a palliative care approach to patients with dementia.

I will be following up on this initial invitation, but please contact me on 076 1415 118 or reply via email to aileen@palcareservices.com should you have any immediate questions.

With much appreciation,

Aileen Forbes (P/N)

Appendix H1 - Study information sheet: Knowledge Questionnaires

STUDY INFORMATION DOCUMENT

Study Title: **What do nursing home staff know and understand about dementia and a palliative approach to dementia care?**

Knowledge Questionnaires

Introduction: As part of my Master of Philosophy degree in Palliative Medicine, I am carrying out a study into the knowledge and understanding that nursing home staff have about palliative care and dementia patients. I am inviting all professional nurses, staff nurses and care givers working in your facility to participate in this.

What is involved for participants:

- The researcher and a translator will visit your facility to explain in person what will be required of you for the study, and to answer any questions you have.
- After these meetings, anyone who would like to take part in the study will be asked to sign a consent form. Consent forms will also be left with the manager for distribution to staff members working on night duty or who are not on duty that day. These will be collected by the researcher.
- Once consent is signed, and at a time convenient to you and your manager, you will fill in a short demographic survey with details such as your age, qualification, years of experience.
- There will be two questionnaires to be completed by each participant. One questionnaire is on dementia, and the other is on palliative care. It will take approximately 20 minutes to complete each one using True and False answers.
- The questionnaires will be delivered to your manager, who will allow you time to fill them in during your shift. You will also be provided with an envelope to place your completed questionnaires and demographic survey in when you have finished. You will then seal this envelope and give it back to your manager for the researcher to collect.
- The sealed envelopes will be collected from your manager by the researcher two weeks after distribution.
- To ensure anonymity and confidentiality, you will be assigned a code. No names will be used on the data being collected.
- All forms and questionnaires will be available in both English and isiZulu.
- You will not be paid to take part in this research, but refreshments will be provided.

Potential Risks and Benefits

The questionnaires will take place during working hours, which may disrupt your usual daily routine. The researcher will be guided by you and your manager to find a time which is suitable for everyone and does not impact negatively on your duties and responsibilities.

Participants may feel nervous or stressed about taking tests. However, the process will be explained in person, you will have time and opportunity to ask any questions, and you will not be using your names on the questionnaires and anonymity is guaranteed.

Thinking about end-of-life issues and advanced dementia might be distressing for some of you, especially if you have had experiences in your personal lives in these areas. Support will be available for you, and contact details of the researcher provided. Participants can also withdraw from the study at any time without giving a reason.

Facility management may be concerned about their reputation if the study finds significant knowledge deficits amongst their staff. However, the facilities will not be named or described in any way which may reveal who they are.

All participating facilities will be provided with feedback on the outcome of the research and be given details on how to access the full research paper.

By taking part in this research, nurses will be reminded of the important role they play in the care of patients who have extensive needs such as in advanced dementia; and that participating in a study which contributes information on what is not known in this area, benefits society at large.

Important Points:

1. Participation is completely voluntary and can be withdrawn at any time.
2. Consent forms must be signed by all participants.
3. Personal information will be treated in the strictest confidence.
4. Anonymity of the questionnaires is guaranteed.
5. Facilities and individual participants will not be named in the study.
6. Data collected will be securely retained.

This research has been reviewed and approved by the University of Cape Town Human Research Ethics Committee and permission given by The Department of Health to conduct the study.

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Research Supervisor:
Name: Dr Alan Barnard
Tel: 021 713 1414
Email: abarnard@intermail.co.za

Researcher:
Name: Aileen Forbes
Tel: 076 1415 118
Email: aileen@palcareservices.com

Contact Details of UCT Human Research Ethics Committee: Tel: 021 650 6346 Email: hrec-enquiries@uct.ac.za

Appendix H2 - Study information sheet: Interviews

STUDY INFORMATION DOCUMENT

Study Title: **What do nursing home staff know and understand about dementia and a palliative approach to dementia care?**

Interviews

Introduction: As part of my Master of Philosophy degree in Palliative Medicine, I am carrying out a study into the knowledge and understanding that nursing home staff have about palliative care and dementia patients. I am inviting a limited number of professional nurses, staff nurses and care givers working in your facility to participate in this through individual interviews between selected participants and the researcher.

What is involved for participants:

- The researcher and a translator will visit your facility to explain in person what will be required of you for the interviews, and to answer any questions you have.
- After these meetings, you will be asked to sign a consent form.
- Once consent is signed, a date and time convenient to you and your manager will be agreed upon for the interview to take place.
- You will fill in a short demographic survey with details such as your age, qualification, years of experience prior to the interview starting.
- The interviews will be held on-site and will take approximately 45 minutes - 1 hour. Your knowledge and understanding of dementia and palliative care will be explored in a conversational way, and the interview audio recorded and transcribed afterwards. No names will be used when writing up the interviews.
- A translator will be available if you have confirmed with the researcher beforehand that you would prefer for the interview to be conducted in isiZulu.
- The interviews will be transcribed into a written document and analyzed by the researcher at a later date, and some individual contributions may be quoted without revealing the identity of any participants.
- Once the interviews have been transcribed, the audio recordings will be deleted.
- To ensure anonymity and confidentiality, you will be assigned a code to be used on the transcribed interview document. No names will be used on the data being collected.
- You will not be paid to take part in this research, but refreshments will be provided.

Potential Risks and Benefits

The interview will take place during working hours, which may disrupt your usual daily routine. The researcher will be guided by you and your manager to find a time which is suitable for everyone and does not impact negatively on your duties and responsibilities.

Participants may feel nervous or stressed about being interviewed. The researcher will give you plenty of time to ask questions before starting, and the interview can be stopped at any time if you are finding it difficult to continue for any reason.

Talking about end-of-life issues and advanced dementia can be distressing, especially if you have had experiences in your personal lives in these areas. Support during and after the interview will be available for you.

Facility management and individual participants may be concerned about their reputation based on the possible study findings. However, neither you or the facility you work for will be named or described in any way which may reveal your identity.

All participating individuals and facilities will be provided with feedback on the outcome of the research and be given details on how to access the full research paper.

By taking part in these interviews, you will be providing rich insights into the knowledge and understanding nurses working in nursing homes have about advanced dementia and palliative care.

Important Points:

1. Participation is completely voluntary and can be withdrawn at any time.
2. Consent forms must be signed by all participants.
3. Personal information will be treated in the strictest confidence.
4. Anonymity is guaranteed in the transcribed interviews.
5. Facilities and individual participants will not be named in the study.
6. Data collected will be securely retained.

This research has been reviewed and approved by the University of Cape Town Human Research Ethics Committee and permission given by The Department of Health to conduct the study.

.

Research Supervisor:
Name: Dr Alan Barnard
Tel: 021 713 1414
Email: abarnard@intermail.co.za

Researcher:
Name: Aileen Forbes
Tel: 076 1415 118
Email: aileen@palcareservices.com

Contact Details of UCT Human Research Ethics Committee: Tel: 021 650 6346 Email: hrec-enquiries@uct.ac.za

Appendix I - Video presentation on the study

https://youtu.be/Il6BhheqLvQ

Appendix J - Interview guideline

INTERVIEW QUESTIONS GUIDELINE (Based on Ipos-Dem)

1. When thinking about these patients who have dementia, what do you think the main physical problems are that they experience?
    - Explore pain/bladder and bowel issues/mobility/swallowing/skin breakdown
2. Of the patients you are currently caring for, do you worry that they are in pain?
    - Explore likely causes/frequency of pain/treatment
3. Thinking specifically about pain, can you tell me a bit about how you assess and treat dementia patients for pain?
    - Explore assessment tools/reporting methods/medical approach/practical approach
4. Communication can be difficult for people with dementia. How do you assess their symptoms?
    - Explore body language/behaviour changes/facial expression
5. Mobility often deteriorates when people have dementia. What impact do you feel this has on their quality of life?
6. Thinking specifically about swallowing problems; patients who are prone to choking; those that just don't want to eat, how do you manage this?
    - Explore thoughts on nutrition/hydration/artificial feeding
7. Something else we see quite often in patients with dementia, is restlessness, agitation, and behavioural issues. What do you feel might be the possible causes of these issues, and how do you manage them?
    - Explore correlation between physical symptoms and behaviours/chemical restraint/family understanding/approach
8. Considering all the things we have discussed in terms of the physical impact dementia has on patients, what do you think about the possible emotional or psychological impact on them?
    - Explore depression/anxiety/fear
9. What do you do if you are worried a patient with dementia might be depressed or anxious?
10. When family members visit, what sort of things are they worried about?
    - Explore families understanding of dementia progression
11. How do you feel about talking to families about their relative's deterioration, especially if you are worried they might be near the end of life?
12. Would you say that dementia is a terminal illness and why?
13. What is your understanding of what palliative care is?

Appendix K1 - Consent forms: Knowledge Questionnaire

CONSENT TO PARTICIPATE IN A STUDY

KNOWLEDGE QUESTIONNAIRES

Study Title: What do nursing home staff know and understand about dementia and a palliative approach to dementia care?

Facility Number:

Participant Identification Number:

Name of Researcher:

Please initial box

1. I confirm that I have read the information sheet for the above study. ☐
2. I understand that my participation is voluntary and that I am free to withdraw my participation at any time without adverse consequences or giving any reason. ☐
3. I confirm that I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
4. I have been provided with the researchers contact details and been advised of what to do should I feel distressed at any point during the study. ☐

Signing this document means that the research has been explained to you orally and in writing, and that you are agreeing to participate in the study. ☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person seeking consent	Date	Signature

Appendix K2 - Consent Form: Interview Guide

CONSENT TO PARTICIPATE IN A STUDY

INTERVIEWS

Study Title: What do nursing home staff know and understand about dementia and a palliative approach to dementia care?

Facility Number:

Participant Identification Number:

Name of Researcher:

	Please initial box
1. I confirm that I have read the information sheet for the above study.	☐
2. I understand that my participation is voluntary and that I am free to withdraw my participation at any time without adverse consequence or giving any reason.	☐
3. I confirm that I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
4. I consent to being audio recorded during the interview, and have been informed how recorded data is managed and safe-guarded	☐
5. I have been provided with the researchers contact details and been advised of what to do should I feel distressed at any point during the study.	☐
Signing this document means that the research has been explained to you orally and in writing, and that you are agreeing to participate in the study.	☐

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person seeking consent	Date	Signature

Appendix L - Demographic survey

DEMOGRAPHIC SURVEY

Study Title: **What do nursing home staff know and understand about dementia and a palliative approach to dementia care?**

Facility Number: Participant Identification Number:

Name of Researcher:

GENDER	☐Male ☐Female
AGE	☐18 – 25 ☐26 – 35 ☐36 – 45 ☐46 – 55 ☐56 - 65
WHAT IS YOU HOME LANGUAGE?	☐isiZulu ☐English ☐Other
WHAT IS YOUR LEVEL OF EDUCATION?	☐High School ☐Grade 12 ☐Higher Certificate ☐College Diploma ☐University Degree
HOW LONG HAVE YOU WORKED IN NURSING HOMES OR WITH OLDER PEOPLE?	☐0 – 1 year ☐2 – 5 years ☐6 – 10 years ☐Over 10 years
HOW LONG HAVE YOU WORKED IN THIS NURSING HOME?	☐0 – 1 year ☐2 – 5 ☐6 – 10 years ☐Over 10 years
HAVE YOU RECEIVED TRAINING ON DEMENTIA?	☐Yes ☐No
HAVE YOU RECEIVED TRAINING ON PALLIATIVE CARE?	☐Yes ☐No

Appendix M1 - Dementia Knowledge Assessment Tool (English)

DEMENTIA KNOWLEDGE ASSESSMENT SCALE (DKAS)

Facility no: _____ Participant no: _____

The purpose of these questions is to learn about your knowledge of dementia

Instructions for completing the questionnaire

1. Please answer each question True, False or Don't Know.
2. Please answer ALL questions.

		TRUE	FALSE
1	Dementia does not shorten a person's life		
2	Vascular dementia is the most common type of dementia. ***(Vascular dementia is caused by blocked or decreased blood flow to the brain, for example when the blood vessels are too narrow, or blood clots block the flow of blood to the brain)***		
3	People can recover from most types of dementia		
4	Dementia is a normal part of the ageing process ***(As people get older it is normal to develop signs of dementia)***		
5	Physical changes in the brain don't cause dementia		
6	Planning for end-of-life care is usually not necessary after being diagnosed with dementia		
7	Alzheimer's disease is the most common form of dementia		
8	It is not possible to communicate with a person who has advanced dementia		
9	A person with advanced dementia will not usually react to changes in their physical environment ***(Their behaviour will stay the same no matter where they are or what is happening around them)***		
10	It is important to correct a person with dementia when they are confused ***(For example, if they think they are living in another town, or that they have to find a lift to work)***		
11	People experiencing advanced dementia often communicate through body language ***(Body language means communicating using, hand/body movements or facial expressions rather than with words)***		
12	Uncharacteristic behaviours in a person with dementia are generally due to unmet needs ***(Acting in a way that is unusual for that person, because there is something that they need)***		

DEMENTIA KNOWLEDGE ASSESSMENT SCALE (DKAS)

Facility no: _____ Participant no: _____

		TRUE	FALSE
13	Medications are the most effective way of treating behavioural symptoms of dementia ***(Behavioural symptoms might include pacing; restlessness; being agitated or aggressive)***		
14	People with dementia do not usually have a problem making decisions		
15	Movement (mobility) is generally affected in the later stages of dementia		
16	Difficulty eating and drinking generally occurs in the later stages of dementia		
17	People with advanced dementia may have difficulty speaking		
18	People with dementia often have difficulty learning new skills ***(For example: learning how to use a new TV remote or phone)***		
19	Daily care for a person with advanced dementia is effective when it focuses on providing comfort		
20	Having high blood pressure increases a person's risk of developing dementia		
21	Maintaining a healthy lifestyle does not reduce the risk of getting dementia ***(Examples of a healthy lifestyle: having a good diet; exercising; not smoking; staying active)***		
22	Symptoms of depression can be mistaken for symptoms of dementia		
23	The sudden onset of mental deterioration/decline is characteristic of most types of dementia		
24	Exercise is generally beneficial for people with dementia		
25	Early diagnosis of dementia does not usually improve quality of life for people with dementia		

Appendix M2 – Dementia Knowledge Assessment Tool (IsiZulu)

ISILINGANISO SOKUHLOLA ULWAZI MAYELANA NESIFO SOKUDUKELWA UMQONDO (DEMENTIA) (DKAS)

Ikhasi 1

Inombolo Yesikhungo: _____ Inombolo Yombambiqhaza: _____

Inhloso yale mibuzo iwukuthola ukuthi unolwazi olungakanani ngesifo sokudukelwa umqondo (dementia)

Imiyalelo yokuphendula le mibuzo

1. Sicela uphendule umbuzo ngamunye ngokuthi Iqiniso, Amanga noma Angazi.
2. Sicela uphendule YONKE imibuzo.

		IQINISO	AMANGA
1	I-d*ementia* ayiyifinyezi impilo yomuntu		
2	I-*Vascular dementia* iwuhlobo oluvame kakhulu lwe-*dementia*. ***(I-Vascular dementia ibangelwa ukuvaleka noma ukuncipha kokugeleza kwegazi eliya ebuchosheni, isibonelo, lapho isikhala emithanjeni yegazi sincipha kakhulu, noma amahlule egazi evimba ukugeleza kwegazi eliya ebuchosheni)***		
3	Abantu bangalulama ezinhlotsheni eziningi ze-*dementia*		
4	I-*dementia* iyingxenye evamile yokuguga ***(Njengoba abantu bekhula bavamile ukuba nezimpawu ze-dementia)***		
5	Izinguquko ezingokoqobo ebuchosheni aziyibangeli i-*dementia*		
6	Ukuhlelela ukunakekelwa phakathi nesikhathi lapho umuntu esezoshona akudingekile ngemva kokutholakala ukuthi une-*dementia*		
7	Isifo i-*Alzheimer* siwuhlobo oluvame kakhulu lwe-*dementia*		
8	Akuxhumaneki nomuntu one-*dementia* eseyibucayi		
9	Umuntu one-*dementia* eseyibucayi ngokuvamile ngeke asabele ezinguqukweni ezenzeka endaweni akuyo ***(Ngeke ashintshe indlela enza ngayo izinto kungakhathaliseki ukuthi ukuphi noma ukuthi kwenzekani eduze kwakhe)***		
10	Kubalulekile ukulungisa umuntu one-*dementia* lapho edidekile engqondweni ***(Isibonelo, uma ecabanga ukuthi uhlala kwelinye idolobha, noma uthi kufanele athole into ezomyisa emsebenzini)***		
11	Abantu abane-*dementia* eseyibucayi bavame ukuxhumana ngothintana kwemizimba ***(Ukuxhumana ngokuthintana kwemizimba kusho ukuxhumana kusetshenziswa ukunyakaziza izandla/umzimba noma isimo sobuso kunokukhuluma ngamazwi)***		
12	Ukuziphatha okungavamile komuntu one-*dementia* ngokuvamile kubangelwa ukungatholi into ethile asuke eyidinga ***(Ukwenza kwalowo muntu izinto ezingavamile, kubangelwa ukuthi kusuke kunokuthile akudingayo)***		

ISILINGANISO SOKUHLOLA ULWAZI MAYELANA NESIFO SOKUDUKELWA

UMQONDO (DEMENTIA) (DKAS)

Ikhasi 2

Inombolo Yesikhungo: _____ Inombolo Yombambiqhaza: _____

		IQINISO	AMANGA
13	Imithi iyindlela ephumelela kakhulu yokwelapha izimpawu ze-*dementia* ***(Izimpawu zayo zingase zibe ukuhamba kancane; ukungahlaliseki; ukucasuka noma ukuba nolaka)***		
14	Abantu abane-*dementia* abavamile ukuba nenkinga yokwenza izinqumo		
15	Ukunyakaza (ukuhamba) kuvame ukuthinteka ezigabeni zokugcina ze-*dementia*		
16	Ukudla nokuphuza kanzima ngokuvamile kwenzeka ezigabeni zokugcina ze-*demetia*		
17	Abantu abane-*dementia* eseyibucayi baba nenkinga yokukhuluma		
18	Abantu abane-*dementia* bavame ukuba nenkinga yokufunda amakhono amasha ***(Isibonelo: ukufunda indlela yokusebenzisa irimothi entsha ye-TV noma ifoni)***		
19	Ukunakekelwa kwansuku zonke komuntu ono-*dementia* eseyibucayi kusebenza kahle uma kugxila ekumenzeni azole.		
20	Ukuba nomfutho wegazi ophakeme kwandisa ingozi kumuntu yokuba ne-*dementia*		
21	Ukunakekela impilo akuyinciphisi ingozi yokuba ne-*demantia* ***(Izibonelo zokunakekela impilo: ukudla okunempilo; ukuvivinya umzimba; ukungabhemi; ukuhlala umatasa)***		
22	Izimpawu zokucindezeleka engqondweni zingathathwa ngephutha njengezimpawu ze-*dementia*		
23	Ukuqala okuzumayo kokuwohloka/ukuncipha kokusebenza kwengqondo kuwuphawu lwezinhlobo eziningi ze-*demantia*		
24	Ukuzivocavoca ngokuvamile kunenzuzo kubantu abane-*dementia*		
25	Ukuhlonzwa kwe-*dementia* isesekuqaleni akuvamisile ukuyenza ngcono impilo yabantu abane-*dementia*		

Appendix N1 - Palliative Approach for Nursing Assistants (English)

PANA - KNOWLEDGE QUESTIONNAIRE

The purpose of these questions is to learn about your knowledge of a palliative approach. All questions concern the care of a person receiving a palliative approach and his/her family in the place where you work.

Instructions for completing the questionnaire

1. Please answer each question True, False or Don't Know.
2. Please answer ALL questions.

		TRUE	FALSE	DON'T KNOW
1	Palliative care aims to improve quality of life when people have an illness or a condition that affects how long they will live.			
2	A palliative approach supports comfort but does not provide a cure.			
3	Palliative care may be required by some people for months or years, while for others it may be required for hours or days.			
4	The needs of people requiring a palliative approach are all the same.			
5	A palliative approach is offered when treatment will not help the person to live longer.			
6	People who have advanced dementia benefit from a palliative approach.			
7	Families can often experience grief before the death of their family member.			
8	It is better to provide information about a palliative approach to people from culturally and linguistically diverse backgrounds in English. ***(ie: No matter what language they speak or what their culture is.)***			
9	The reason why a person receives nutrition through a PEG tube is because he/she can no longer swallow safely. ***(A PEG tube is a tube that goes directly into the stomach and the person is fed through that tube)***			
10	Identifying symptoms (physical signs) is the first step in being able to manage symptoms.			
11	Pain relief before providing physical care, such as dressing a wound, can help a person experiencing pain feel more comfortable.			
12	When a person is receiving pain relief medication, they no longer feel pain.			
13	Families or carers who know the person best are usually the first to notice changes in a person's condition.			
14	Bladder and bowel problems can cause discomfort when a person approaches the end of life.			
15	When a person has experienced a deterioration over time, it is a sign that they are approaching the end stage of their illness.			
16	Signs that death is near can be present hours to days before death occurs.			
17	Peoples' tolerance of pain is lowered by anxiety or fatigue ***(ie: If someone is anxious or tired, they don't cope as well as they usually would with pain)***			

Appendix N2 – Palliative Approach for Nursing Assistants (IsiZulu)

PANA - IMIBUZO YOLWAZI

Inombolo Yesikhungo: _____ Inombolo Yombambiqhaza: _____

Inhloso yale mibuzo iwukuthola ukuthi unolwazi olungakanani mayelana nokunakekela abantu abanesifo esibulalayo. Yonke imibuzo imayelana nendlela abanakekelwa ngayo abantu abanesifo esibulalayo kanye nemindeni yabo, lapho wena usebenza khona.

Imiyalelo yokuphendula le mibuzo

1. Sicela uphendule umbuzo ngamunye ngokuthi Iqiniso, Amanga noma Angazi.
2. Sicela uyiphendule YONKE imibuzo.

		IQINISO	AMANGA	ANGAZI
1	Inhloso yokunakekelwa komuntu onesifo esibulalayo iwukwenza ngcono ukuphila kwakhe lapho enesifo esinomthelela ebudeni besikhathi asazosiphila.			
2	Ukunakekelwa komuntu onesifo esibulalayo kusiza umuntu azole kodwa akuselaphi isifo esimphethe.			
3	Abanye abantu abanesifo esibulalayo kungase badinge ukunakekelwa izinyanga noma iminyaka, kanti abanye bangase badinge ukunakekelwa amahora noma izinsukwana.			
4	Abantu abanesifo esibulalayo abadinga ukunakekelwa banezidingo ezifanayo bonke.			
5	Ukunakekelwa komuntu onesifo esibulalayo kwenziwa uma imithi yokumelapha ingeke imsize ukuba aphile isikhathi eside.			
6	Abantu abanesifo sokudukelwa umqondo (*dementia)* esesibucayi bayazuza ekunakekelweni kwabantu abanesifo esibulalayo.			
7	Ngokuvamile umndeni ungaba lusizi ngaphambi kokushona kwelungu lomndeni wawo.			
8	Kungcono ukuyichaza nesiNgisi indlela anakekelwa ngayo umuntu onesifo esibulalayo kubantu bazo zonke izinhlanga nabazo zonke izilimi. ***(Okusho ukuthi: Kungakhathaliseki ukuthi bakhuluma luphi ulimi noma bangaboluphi uhlanga.)***			
9	Isizathu esenza umuntu adle ngeshubhu le-PEG yingoba usuke engasakwazi ukugwinya ngokuphepha. ***(Ishubhu le-PEG yishubhu elingena ngqo esiswini futhi umuntu udliswa ukudla ngalelo shubhu)***			
10	Ukubona izimpawu (izimpawu zomzimba) kuyisinyathelo sokuqala sokukwazi ukulawula izimpawu.			
11	Ukudambisa izinhlungu ngaphambi kokunakekela okuthile emzimbeni, njengokubopha isilonda, kungasiza umuntu ozwa ubuhlungu ukuba azole kakhudlwana.			
12	Uma umuntu ethola imithi yokudambisa izinhlungu, akabe esabuzwa ubuhlungu.			
13	Imindeni noma abanakekeli abamazi kangcono umuntu imvamisa kuba yibo ababa ngabokuqala ukubona izinguquko esimweni somuntu.			

PANA - IMIBUZO YOLWAZI

Ikhasi 2

Inombolo Yesikhungo: _____ Inombolo Yombambiqhaza: _____

14	Izinkinga esinyeni nasemathunjini zingabangela ukungakhululeki lapho umuntu esezoshona.			
15	Uma isimo somuntu siya siba bucayi ngokuhamba kwesikhathi, kusuke kuwuphawu lokuthi useya ngasekushoneni.			
16	Izimpawu zokuthi ukufa sekuseduze zingaba khona emahoreni kuya ezinsukwini ngaphambi kokufa.			
17	Amanga omuntu okubekezelela ubuhlungu ayehliswa wukukhathazeka noma ukukhathala ***(Okusho ukuthi: Uma umuntu ekhathazekile noma ekhathele, akakwazi ukubhekana nobuhlungu ngendlela evamile abezobhekana ngayo nabo)***			

Appendix O - Distress Protocol

Distress Protocol

The protocol for managing distress in the context of research interviews with nurses in long term care facilities.

If a participant expresses that they are feeling very stressed or emotionally distressed, or if their behaviour/body language indicates that this might be the case:

1. Stop the interview.
2. Offer support and explore how the participant is feeling.
3. Establish if they feel they can continue with the interview. If so, the interview can resume.
4. If the participant feels unable to continue:
    a) Ensure they are aware that you have discontinued the interview.
    b) Ask permission to notify a colleague or senior member of staff that they are distressed.
    c) Allow time and a safe space in which the participant can debrief.
    d) Encourage the participant to contact the researcher if she continues to feel distress in the days to come.
    e) With the consent of the participant, offer to hand over to the support structure of the NH and to follow up with them.

Appendix P - Study Budget

RESEARCH BUDGET

RESEARCHER: Aileen Forbes (FRBAIL002)

NO OF PARTICIPANTS 184

DATE	ITEM	COST	TOTAL
30.12.23	Professional translation of documents	1429 words @ 0.95c/word	1561.18
27.1.24	Informal back translation by Kwanele - EFT		400
9.2.24	Informal back translation by Wendi - flowers		350
5.3.24	Printing of questionnaires x 600	R2.50/page	1500
5.3.24	Printing of consent forms x 300	R2.50/page	750
5.3.24	Printing of demographic forms x 300	R2.50/page	750
6.3.24	Envelopes x 50		80
7.3.24	Printing of isiZulu documents x 640		443.5
15.3.24	Snack packs x 16		200
16.3.24	Printing of documents x 480		260
16.3.24	Envelopes 4 x 50		320
16.3.24	Snack pack paper bags		180
16.3.24	Snack packs x 54		985
20.3.24	Snack packs x 24		409.8
3.4.24	Snack packs x 36		671.8
6.4.24	Snack packs x 18		335.75
14.2.24	Maestro AI transcriptions x 8		390.18
20.4.24	Maestra AI transcriptions x 5		788
			10375.21

Appendix Q – Plagiarism Declaration

This thesis/dissertation has been submitted to the Turnitin module (or equivalent similarity and originality checking software). I confirm that my supervisor has seen my report, and any concerns revealed by it have been resolved with my supervisor.

During the Turnitin review process with my supervisor, it was noted that numerous similarities had been drawn from my literature review assignment. This was a planned and required assignment activity to guide the literature review for my dissertation, and as such, my supervisor deemed it acceptable.

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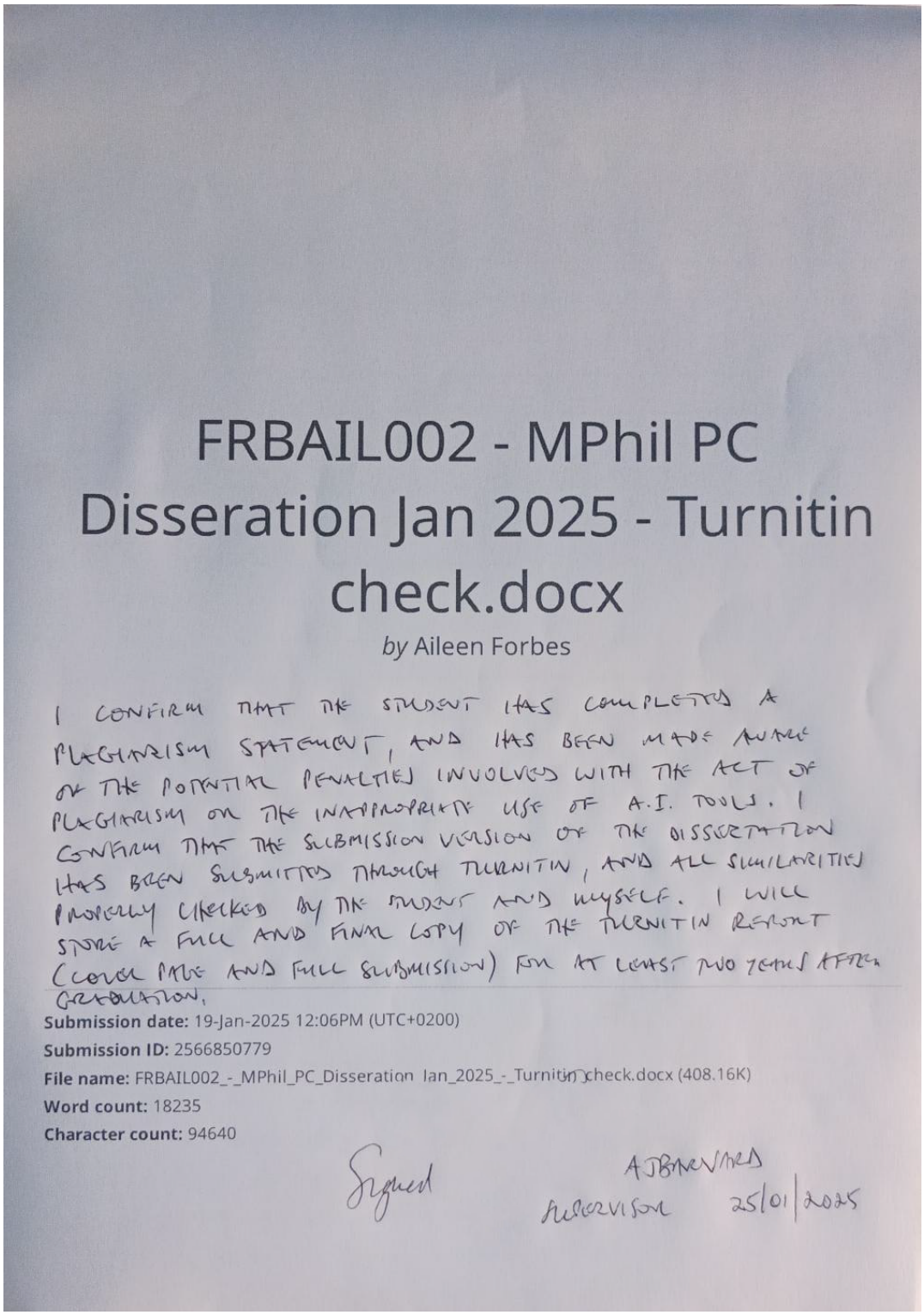
Appendix R – Plagiarism Declaration by Supervisor



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by Aileen Forbes

I CONFIRM THAT THE STUDENT HAS COMPLETED A PLAGIARISM STATEMENT, AND HAS BEEN MADE AWARE OF THE POTENTIAL PENALTIES INVOLVED WITH THE ACT OF PLAGIARISM OR THE INAPPROPRIATE USE OF A.I. TOOLS. I CONFIRM THAT THE SUBMISSION VERSION OF THE DISSERTATION HAS BEEN SUBMITTED THROUGH TURNITIN, AND ALL SIMILARITIES PROPERLY CHECKED BY THE STUDENT AND MYSELF. I WILL STORE A FULL AND FINAL COPY OF THE TURNITIN REPORT (COVER PAGE AND FULL SUBMISSION) FOR AT LEAST TWO YEARS AFTER GRADUATION.

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Signed

AJBrennan

Supervisor 25/01/2025