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Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

By

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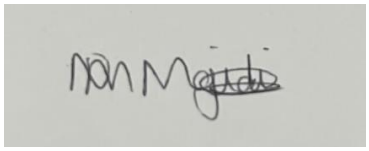
DECLARATION

I declare that this work, titled “Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.” has been composed by myself. It has not been submitted previously in other research reports. This thesis is submitted for a Maters of Arts in Speech Pathology, in the faculty of Humanities at the University of the Witwatersrand in Johannesburg.



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LIST OF TERMINOLOGY

Medication administration: The process of giving out medication, either orally or intravenously (Kim & De Jesus, 2021).

Care facility: Facilities such as nursing, and residential homes that offer a variety of services such as rehabilitation, and nursing care that is continuous and trailoured for each individual based on their health, and personal needs (Kalideen et al., 2022).

Polypharmacy: Taking five or more medications daily (Halli-Tierney et al., 2019).

Caregiver: An individual who offers assistance with daily activities, provides care to the care recipient, and also assists with the general health and social needs of the care recipient (Schulz et al., 2016). Caregivers are classified into formal caregivers and informal caregivers. Formal caregivers are professionals in the heath care sector such as nurse assistants, and community healthcare workers (Ku et al., 2013). For the purpose of this Masters Dissertation, the term caregiver will be used when making reference to formal caregivers.

Registered nurse: An individual that is qualified to practice nursing care independently and also account for the practice (Nursing Act, 2005).

Patient tailored care: Care that is collaboratively tailored with the patient by prioritising the patient's needs, beliefs, and culture (Bolton et al., 2020).

Aspriration: Breathing in contents from the oral cavity or the stomach into the larynx or the lungs (Almirall et al., 2021).

LIST OF APPENDICES

ABBREVIATIONS

PWD	People with dementia
ADL	Activities of daily living
WHO	World Health Organization
RNs	Registered nurses
CHW	Community healthcare worker
SOP	Standard Operating Procedure
MND	Major Neurocognitive Disorder

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Abstract

Introduction: Provision of care to people with dementia is a rapidly growing field in healthcare. Challenges regarding medication administration to people with dementia have been reported in studies. While the literature identifies how some of the challenges are mitigated, there remains a notable gap in understanding how these challenges influence the experiences of the registered nurses and caregivers during this important task. **Objectives:** The main aim of the current study was to investigate and document the experiences of registered nurses and caregivers when they administer medication to people with dementia in a care facility in Johannesburg. **Methodology:** Using a qualitative phenomenological research design, purposive sampling was used to recruit eleven participants in a care facility for dementia in Johannesburg. Data collection took place in three phases: observations, semi-structured interviews, and focus groups. The collected data was then analysed using thematic analysis with an inductive approach. **Results:** Five themes emerged from the study: a) Cognitive decline b) Behavioural challenges c) Patient tailored care d) Training needs e) Different perspectives. The caregivers tailored their strategies to ensure continuity of medication administration to PWD, depending on their cognitive status and the behaviours they exhibited. Different training needs and perspectives were expressed by the caregivers. Lastly, the results show the different perspectives on providing care to people with dementia. **Implications:** The results show that caregivers will benefit from training workshops on how to understand and manage behaviours, and cognitive decline exhibited by people with dementia affecting medication administration. The need for support groups is evident as the caregivers require advice on the some of the challenges they face on care provision to people with dementia. The results also show the need for the development of Standard Operating Procedure (SOP) that caregivers can use to safely administer medication to people with dementia.

Keywords: Dementia, medication, care facilities, cognitive decline, caregivers.

Chapter 1: Introduction

Providing care to people with dementia (PWD) is a growing field in health care (Helgesen et al., 2020). Statistics by the World Health Organization [WHO] (2019) show that there are approximately fifty-five million people diagnosed with dementia worldwide. Statistics further show that about 60% of people diagnosed with dementia are from low as well as middle-income countries (WHO, 2019). This is applicable to the South African context as it is listed as an upper-middle income country (Mncube & Kaulihowa, 2022). According to Global Burden of Diseases (2022), there were approximately 241 937 cases of dementia in South Africa in 2019. This is expected to increase to a number of 680 045 cases of dementia in 2050 (Global Burden of Disease, 2022).

Dementia or Major Neurocognitive Disorder (MND), is a medical condition characterized by a progressive decline in cognition that ultimately reduces the individual's ability to carry out activities of daily living (ADLs) (Emmady, 2020). For the purpose of the current study, the term dementia wil be used, reflecting its common use in medical literature and in the society. An individual with dementia may have difficulties with memory, eating, attention, language, orientation, and other cognitive skills such as executive functioning skills such as planning, self monitoring, organization, and time management (Arvanitakis & Bennett, 2019). As dementia progresses from mild to severe, the individual experiences difficulty with social interactions and independently completing of activities of daily living (ADL) (Adedeji et al., 2022).

The process of aging involves a gradual deterioration of physiological functions, which increases the risk of developing non-communicable diseases such as dementia (Xia et al., 2018). For most individuals, old age is associated with a burden of health related problems which often impact the individual's physical and social aspects of life (Ahmad-Zubaidi et al., 2020). These difficulties may be debilitating, requiring the need for medically directed support, which can ultimately lead to admission to a care facility (Temedda et al., 2025). The

literature states that as people age, the likelihood of taking multiple medications increases (Ahmad Zubaidi et al., 2020). The common conditions prevalent in the elderly population include hypertension, diabetes, arthritis, and osteoporosis (Ahmad Zubaidi et al., 2020). In addition to taking medication for the chronic conditions listed, some elderly individuals also require vitamin supplements (Ahmad-Zubaidi et al., 2020). It is estimated that some PWD in care facilities consume about seven to ten tablets daily, with some of them taking up to twenty-two tablets (Sefidani-Forough et al., 2021). Polypharmacy is common in PWD as they have other chronic conditions that require medication (Özsürekci et al., 2022). It is important to ensure that PWD take their medication, with the correct dosage and at the correct time, and that the tablet is completely swallowed to ensure that the current functioning status of the individual is prolonged (Jennings, 2017).

This research contributes to the existing literature on the experiences of the caregivers and registered nurses (RN) regarding medication administration and their overall perception of caregiving to PWD.

1.2: Literature Review

1.2.1 Dementia: Sub-types and Symptoms

Dementia is a broad term that encompasses a variety of symptoms that are characterised by cognitive deterioration, with its subtypes named based on the underlying causes (Duong et al., 2017). Among the subtypes, Alzheimer's dementia is the most common form. The type of dementia the individual presents with depends on the site of neuronal and connection damage in the brain (Coupe et al., 2019). Dementia is acquired and the likelihood of being diagnosed with this condition has been associated with factors such as genetic makeup, advancing age, and vascular disorder (Coupe et al., 2019). Dementia results in various changes to the brain. One of the changes is cortical atrophy, which leads to loss of neurons and damage to the connections (Coupe et al., 2019). Individuals diagnosed with dementia

experience progressive, and gradual changes that affect how they complete ADL, their behaviour, and cognition. Table 1 shows the different stages of dementia and the associated symptoms as the condition progresses. The clinical signs of dementia vary from one individual to another and the cognitive fallouts associated with dementia result in language impairment, apraxia, behavioural difficulties, loss of memory, motor (fine and gross) challenges, agnosia, swallowing difficulties, as well as executive function difficulties (Hildreth & Church, 2015).

Table 1:

Different stages of dementia and the associated symptoms (Duong et al., 2017).

Dementia stage	**Examples of symptoms associated with the stage of dementia**
Mild dementia.	i) Memory problems e.g. anomia. ii) Difficulties carrying out ADL. iii) Executive function difficulties.
Moderate dementia.	i) Agitation. ii) Refusing to do some ADL. iii) Severe memory problems. iv) Personality and behavioural problems. v) Incontinence.
Severe dementia.	i) Difficulties engaging in coversations. ii) Declining mobility and swallowing abilities. iii) Increased risk for opportunistic illnesses.

Behavioural difficulties are one of the most common changes in PWD, especially in the late stages (Jung et al., 2021). The most frequent changes in PWD include hallucinations, aggression, sleep disorders, delusions, wandering, agitation, incontinence, and vocalisations

(Jung et al., 2021). Eating problems have also been associated with behavioural difficulties resulting from dementia. The eating problems that some PWD may present with include leaving food unfinished, hunger, and eating non-food objects (Fostinelli et al., 2020). Other behavioural difficulties are restlessness and walking around during mealtimes, and personality changes which alters the attitude PWD have towards meals (Fostinelli et al., 2020). There is limited research on how behavioural difficulties such as aggression affect medication intake among PWD globally (Lim & Sharmeen, 2018). The present study provides insights into this gap.

Communication is another factor that is affected in PWD. Dementia can cause damage to the areas in the brain that are responsible for language such as Wernicke's or Broca's area and result in aphasia (Krein et al., 2019).

It was also found that some PWD had to be reminded to swallow their tablets in their mouths due to reduced oral sensitivity (Richardson et al., 2020). Reduced oral sensitivity results in not being able to feel when there is something on their tongue and diminished taste. For individuals with reduced oral sensitivity, the RNs giving out the tablets has to remind them to swallow their medication as it can remain unswallowed and the medication not taken as prescribed (Richardson et al., 2020). This is another aspect that is affected in the population with dementia, more especially taste (Richardson et al., 2020). This is due to the areas of the brain responsible for taste being affected.

1.2.2 Burden of dementia

Dementia imposes a significant impact on the individuals, family members, and society. This impact extends beyond medical problems to social and economic burdens (Szpryngel, 2023). The social impact of dementia is profound and can be felt by both individual and the society. The deterioration in cognition leads to behavioural and emotional changes, which ultimately causes a decline in the quality of life of the individual and increases caregiver burden (Szpryngel, 2023). PWD often experience stigma, social isolation, and feeling

unsupported. These factors result in less participation in hobbies and social activities, further exacerbating disconnection from the society (Szpryngel, 2023). Moreover, the emotional toll on caregivers of PWD is significant, with depression; feeling overwhelmed; and frustration being more common.

The increase in dependence on caregivers for assistance results in decreased productivity for both PWD and their caregivers. This has financial implications due to job loss, reduced income, and the increased costs of healthcare (Szpryngel, 2023).

1.2.3 Swallowing in dementia

Challenges with swallowing and the need for assisted feeding become more apparent as the dementia progresses (Payne & Morley, 2018). Dysphagia signs that may be present at the early to moderate stage of dementia include a decline in lingual movement, anterior spillage, pocketing food along the buccinator muscles, oral residue, delayed pharyngeal swallow, inability to clear the pharynx, challenges with opening of the upper oesophageal sphincter, or aspiration (Winblad et al., 2016). Dysphagia signs such as pocketing food and oral residue may lead to complications such as dehydration, and malnutrition as the individual takes reduced amounts of food and water while aspiration may lead to aspiration pneumonia (Winblad et al.,2016). PWD may also present with neurocognitive fallouts including swallowing apraxia and oral agnosia (Murphy et al., 2017). Swallowing apraxia is a dysfunction that occurs in the oral phase of swallowing caused by discoordination of the lingual, labial, and mandible movements (Yun et al., 2019). The end stage of dementia is characterised by oral agnosia (Gupta, & Mamidi, 2020), where the individual with dementia has difficulties with recognising food, and liquids in the oral cavity (Perrotta, 2020).

Payne and Morley (2018) conducted a study looking at the presence of eating challenges in seventy-three patients with dementia from an institution. Four different results of eating challenges were identified. At the end stage of dementia, 24% of patients ate independently

with supervision while 18% were assisted with eating. Regarding the rest of the patients, 26% refused to eat while 32% choked when eating. Some of the common deficits seen with eating behaviours included refusing food, swallowing apraxia, food pocketing, swallowing big portions, inability to recognize food, eating quickly, spitting food, swallowing without chewing food, and a delay in the trigger of swallow (Payne & Morley, 2018). Eating is a process that requires an individual to be cognitively aware, with the ability to recognize food, followed by the action of taking the food, planning, and executing the skills required (Rogus-Pulia et al.,2015). However, as noted; some of these processes are affected in an individual with dementia as they have impaired orientation, attention, recognition abilities, executive functioning, and apraxia (Rogus-Pulia et al.,2015).

1.2.4 Professionals responsible for medication administration

Medication administration is a process where a trained professional gives out medication through an injection, or oral intake (Sefidani-Forough et al., 2021). This process involves six steps: prescription, transcription, medication dispensation, preparation of the medication, administration, and documentation of side effects (if any) (Carayon et al., 2014).

In healthcare setting, RNs play an essential role in ensuring safe medication administration as part of their wide responsibilities. According to Brandburg (2012), RN have various roles, including educating, caregiving, healing, advocating, and coordinating care. As healers, RNs help the residents cope with or overcome illness as well as maintaining quality of life. In their caregiver role, RNs help the residents with their ADL. Additionally, RNs educate residents about their health and coordinate services from other professionals as needed (Brandburg, 2012).

The Nursing Act (2005) stipulates that the South African Nursing Council (SANC) may authorise RNs, enrolled nurses, and midwives to conduct assessments, diagnose, and prescribe medication. During medication administration in care facilities, RNs are required to

prepare the medication trolley by first ensuring that it is clean followed by putting the record for medication that will be administered to the residents in the trolley. The RNs then have to locate the residents within the care facility, get the medication from the medication trolley, prepare the resident to take medication, administer the medication, and document that medication was administered (Qian et al., 2018).

In contrast, caregivers have different responsibilities in care facilities. According to Ling and Song (2019), caregivers assist residents with ADL, meal preparation, and mobility. The importance of the role played by caregivers is evident in the care of PWD as highlighted by Lamotte et al. (2017). As cognitive abilities deteriorate, the involvement of the caregiver increases. Caregivers can be broadly classified into formal and informal caregivers. Oh et al., (2024) defines formal caregivers as individual that are medically trained and paid to provide care to those in need, whereas informal caregivers are unpaid individuls, typically family members, friends, relatives, and neighbours, who provide care.

Care facilities differ in terms of the staff members who can administer medication to the residents. In most care facilities in South Africa, RNs are responsible for administering day to day medication and medical procedures that require training such as providing oxygen, and injecting insulin (Odberg et al., 2019). In some facilities, junior members such as nurse assistants can also be given the task by the RNs to administer medication to the residents. However, it is the responsibility of the RNs to ensure that the junior member is well trained and able to administer medication to the resident safely and properly (Odberg et al., 2019). Even though the medication administration task may be delegated to junior members, the accountability lies with the RNs.

There are however care facilities where caregivers are delegated to administer medication to the residents (Solberg et al., 2022). The delegation only takes place when the caregiver has received training in administrating medication and approval from the care facility management. However, the care facility management is responsible for ensuring that the

healthcare professionals administer medication safely. This delegation occurs globally (Solberg et al., 2022).

Given the important role played by the RNs and caregivers in administrating medication to PWD, it is important to examine their level of preparedness, confidence, and training needs in this context. This is supported by several studies highlighting that dementia carers have inadequate skills, and knowledge

Given the above roles and responsibilities of RNs and caregivers, their experiences with these roles and responsibilities within the South African are not clearly documented. The current study thus captures how RNs and caregivers perceive one of their most important tasks, medication administration to PWD.

1.2.5 Medication intake among PWD

There is currently no cure for dementia; however, there is medication prescribed to manage the associated symptoms (Porter, 2019). It is important to consider the form of medication and how it is administered to PWD due to the cognitive, communicative, and behavioural challenges noted earlier (Sefidani-Forough et al., 2021). Various medication administration methods such as capsule opening or crushing tablets are widely used in care facilities that accommodate PWD to facilitate swallowing medication for those with swallowing difficulties (dysphagia) and medication adherence. If not done correctly, medication modifications have the potential to cause drug toxicity, detrimental effects such as heart attack, gastric irritation, or death (Sefidani Forough et al., 2021). Medication adherence refers to following a prescription based on the recommended dosage, time, and how often the medication should be taken (Cramer et al., 2008). Dispensing medication to PWD who have difficulties taking their medication, either due to behavioural or swallowing difficulties, is considered an area that is challenging due to time limitations and communication breakdowns between the person administering the medication and PWD (Sefidani Forough et al., 2021).

The relationship the RNs and the caregivers have with PWD has also been found to have an impact on medication adherence. It has been found that RNs and caregivers with good rapport with PWD (in the early stages) adhered to their medication. On the other hand, poor rapport with PWD led to poor medication adherence (Richardson et al., 2020). This was also seen in a study conducted in care facilities in London by Alsaeed et al. (2021). This study looked at ways of improving medication adherence as dementia progressed and recommended strategies that can be used by RNs and other professionals administering medication to PWD in care facilities. Building rapport and having a positive relationship with the residents was found to be an effective strategy that facilitated the process of medication administration in care facilities. In addition, familiarity with the individual residents assisted the RNs in detecting, monitoring, and communicating problems experienced by the residents to their doctors and relaying information back to the residents. However, this may not be the case with PWD in the end stages of dementia due to the significant cognitive decline as they may not be able to recognise individuals they know and have the cognitive capacity to understand the feedback (Coslett, 2018). This may result in PWD not wanting to take their medication.

In contrast, a study conducted in Australia by Gillespie et al. (2015) looking at the barriers during the process of medication administration found that the relationship the caregivers had with PWD did not improve medication administration. According to Gillespie et al. (2015), caregivers of PWD observed that the gradual decline in cognitive skills resulted in the individuals not wanting to take all their medication as they perceived some of the medication not benefiting them. This raised concerns about some of the chronic conditions that are left untreated as PWD choose the medication they want to take. The caregivers looking after the individuals with advanced dementia were also faced with challenges as the residents appeared to have forgotten how the tablets were taken. Instead of swallowing the tablets, the individuals chewed or spat them out as they believed that the medication would kill or poison them (Gillespie et al., 2015). In ensuring medication administration, the

caregivers resorted to altering the formulation of tablets by crushing and putting them on the residents food. However, altering the formulation of medication by crushing the tablet or opening the capsule raised some concerns for some of the caregivers as they worried that changing the original formulation of the medication may prolong the rate at which it is absorbed. On the other hand, some caregivers were not cognisant of the potential problems of changing the original formulation of medication (Gillespie et al., 2015).

Certain factors that were found as barriers and those that facilitate medication administration to PWD have been highlighted. However, these studies were not done in South Africa and thus it cannot be confirmed whether these barriers and facilitators are applicable to the South African context.

Rogers et al. (2014) state that finding ways to administer medication effectively could improve the experience of caring for a person with dementia. This is important as giving medication is a challenge on its own and could prolong the time taken to do medication rounds. Accrording to McGrattan et al. (2017) various policies and research have highlighted the importance of improving medication administration for PWD. However, there is not enough evidence advising on how to accomplish this with people who have dementia. One of the studies highlighting the need to improve medication administration is a study by Gillespie et al. (2016). This study was conducted in Australia and was done to develop an information document to help caregivers better administer medication to PWD.

PWD may experience changes in their medication regimen, including the potential addition of new medications temporarily or permanently, further complicating their their existing complex medication schedule. This may lead to some medication not being taken due to the amount of prescribed medication or as a result of preferences due to changes in their cognition.To deal with these challenges and ensure that all the prescribed medication is taken, the caregivers may resort to strategies such as persuading or placating the residents (Alsaeed et al., 2021). The caregivers also found that communicating with the resident's doctors was very helpful as alternative forms of medication would be prescribed, thus

ensuring continuity of medication administration. In addition to these strategies, understanding and working around the resident's mood was found to be of great assistance (Alsaeed et al., 2021). The caregivers highlighted that sitting down with the residents and explaining why they needed to take the tablets was important and thus very helpful. Another important factor to be cognisant of is the type of information given to residents with dementia, how that information is said to them, and the stage of dementia they are in (Alsaeed et al., 2021).

The type of tablet formulation was another factor mentioned by the caregivers at the care facility. The features of medication formulations refer to the size, type, colour, quantity, shape, and taste of the prescribed medication (Alsaeed et al., 2021). A study conducted by Shariff et al. (2020) highlighted the impact of the different features of medication formulations on medication adherence as some PWD had preferences regarding the size, shape, coating, and colour of tablets they would take. The study also highlighted the challenges of the size of some tablets as PWD would not be able to feel the tablet in their mouth and therefore remain unswallowed.

Although the RNs at the care facility mentioned medication formulation as an important facilitator of medication administration, a swallowing assessment was also seen as crucial as it would inform the RNs on the type of medication suitable for the individual and also ensure that it is received safely (Alsaeed et al., 2021).

Given the difficulties and the risks associated with medication administration in PWD, including modifying the original form of medication and adherence difficulties, it is essential to assess the level of preparedness, confidence, and training needs of the RNs and caregivers who administer medication to PWD. Several studies (Smythe, et al., 2014; Turner et al., 2017) highlight this importance as they found that carers of PWD have inadequate skills and knowledge regarding dementia and its care.

1.2.6 Care facilities in South Africa

Care facilities are designed to mimic a homely setting that is both conducive and safe (Cohen-Mansfield & Meschiany, 2022). Ideally, a care facility should have staff that includes a manager, administrative personnel, RN; caregivers, social workers, psychologists, speech therapists, audiologists, doctors; dieticians, pharmacists, general workers, and kitchen staff (Cohen-Mansfield & Meschiany, 2022).

Care facilities are also known to be flexible in terms of the services they offer. There are units such as the hospice, which offer palliative care, and other units that cater to individuals who require assistance with their ADL (Cruz-Oliver et al., 2020).

According to the mid-year population estimates of 2022, the elderly comprised 9,2% of South Africa's population (STATSSA, 2022). The historical provision of care for the elderly in South Africa is different compared to other developed countries such as the United Kingdom. In South Africa, care was historically provided at home by family members (Lloyd-Sherlock, 2019). However, things have changed as most people requiring assistance with ADL are now admitted to care facilities instead of receiving care at home from friends and family (Van Biljon & Roos, 2015).

1.3 Rationale

Medication administration is one of the most important and complex activities done in care facilities. Most of the existing literature has focused on the clinical aspects of medication administration such as adverse medication reactions, or modifying the dosage formulation in care facilities (Garratt et al., 2024). To date, there are no studies done to synthesize research on how RNs and caregivers perceive administering medication to PWD, especially in the presence of the challenges associated with dementia. There is a need for studies to investigate the experiences and perceptions of care facility workers regarding medication administration (Garrett et al., 2024). The current study served to contribute evidence to the

existing research gap. In doing so, the study considered various factors that impact medication administration that ultimately affect how medication administration is perceived. The initial step was to investigate the challenges arising during medication administration, and how the staff administrating medication dealt with the challenges. The challenges (if any) experienced with medication administration due to behavioural or swallowing changes will assist with creating awareness as well as bring in the relevant healthcare professionals such as speech therapists and/or the treating doctors to assess and also consider the presenting changes when prescribing medication to ensure continuity of medication administration (Alsaeed, 2018). The level of preparedness, confidence, and training needs of the RNs and caregivers were also considered, as competency also impacts how the RNs and caregivers would view medication administration. A systematic review conducted by Kang and Hur (2021) looking at the experiences of RNs when providing care to PWD found that the RNs inadequate knowledge and skill or helplessness hinders basic nursing care such as feeding or giving PWD medication. It has been documented that caregivers who are confident and have knowledge of dementia are able to manage the behavioural changes that come with dementia and thus provide high quality care (Gerritsen et al., 2019). Information on their level of preparedness and confidence will be used to advocate for continuous education and further training.

Problem statement

Understanding how RNs and caregivers experience medication rounds in the presence of the changes associated with dementia is crucial for the safety of PWD and for improving quality of care. The existing literature highlights the importance of medication intake in dementia as well as the challenges experienced by RNs and the caregivers during medication administration and how they overcome these challenges. Despite the increasing prevalence of dementia, there is limited research focusing on the perceptions of the RNs and caregivers in the context of medication administration. This qualitative study employed observations, semi-structured interviews, and focus groups with eleven caregivers from a

private care facility in Johannesburg over a period of two weeks. Insight on the RNs and caregivers experiences will benefit these professionals as the findings were used to advocate for further training and the development of guidelines for safe medication administration. PWD will also benefit as further training and the development of guidelines will improve quality of care and safety.

Chapter 2: Methodology

2.1 Research question

What are the experiences of RNs and caregivers regarding administrating medication to PWD in a care facility in Johannesburg, South Africa?

2.2 Main Aim

To explore the experiences of RNs and caregivers during medication administration to PWD in a care facility in Johannesburg, South Africa.

2.3 Sub-Aims

I. To explore barriers experienced by the RNs and caregivers when administrating medication to PWD.

II. To explore the strategies used by the RNs and caregivers to administer medication to PWD.

III. To document the perspective of the RNs and caregivers on caregiving to PWD in terms of their training, confidence, and preparedness.

2.4 Research Design

The current study utilised a qualitative approach, with a descriptive phenomenology design. Qualitative research entails asking research participants' questions about their experiences regarding certain things that occurred in their lives (Austin & Sutton, 2014). This type of research design allows the researcher to have a better understanding of what it feels like to be another person and further understand the investigated phenomenon as it is experienced by the individual participating in the study. Descriptive phenomenology aims to capture a detailed understanding of lived experiences of individuals without trying to attribute the experiences to external factors or imposing frameworks (Kudale & Kotte, 2024). Data obtained using qualitative research design can be used to demonstrate a sequential flow, understand which actions led to which results, and lastly produce rich descriptions (Austin et

al., 2014). However, qualitative research as an approach has its weaknesses. The data obtained is highly personal and may be difficult to present. It was also found that qualitative research can be difficult to replicate (Rahman, 2017). To account for the weaknesses, the participants were given codes and information that could identify the participants was removed in the write up of this research report. To ensure the replication of the current study, the different steps taken to conduct this research are stated in the methodology below, and raw data is available for audit trail. The processes applied to minimise the weaknesses of qualitative research will be explained further in the sections below. By utilising this research design and the various data collection tools (observations, semi-structured interviews, and focus groups), the researcher was able to gain insight into the experiences of the caregivers on medication administration to PWD, and their overall perception of caregiving these individuals.

2.5 Sampling

Not only is it important to choose participants with the required knowledge or experience, the participants must also be prepared or eager to share their knowledge or experiences in the topic of interest. Therefore, recruiting participants who have the knowledge or the experience and are also prepared to share those experiences or knowledge forms the core of the research (Acharya et al., 2013). The current study made use of purposive sampling to recruit participants. This is a widely used type of sampling for identifying and choosing cases with in-depth information. Purposive sampling entails identifying and choosing participants who have both the knowledge and the experience regarding the phenomenon being researched (Cresswell & Plano, 2011). In the current study, the participants were recruited directly from the chosen care facility through the distribution of research information letters.

It is important to select participants who meet the required criteria as they will be able to provide information that is rich regarding the topic of interest. Forming criteria for inclusion in qualitative research is imperative as it confirms that participants forming part of the study have the experience/skills or the knowledge needed to answer the questions (Marczyk et al., 2010). The following is the inclusion and the exclusion criteria that was used for recruiting participants:

Inclusion criteria:

i. RNs and caregivers administering medication to the residents.
ii. Employed at the selected care facility.
iii. Providing care to people with dementia.
iv. Providing care to people with dementia at the care facility for more than six months. Participants who have worked for six months or more would have the experience required to provide in-depth information which will assist with answering the main research question.

Exclusion criteria:

i. RNs and caregivers who are not involved with medication administration.
ii. RNs and caregivers who administer medication to residents without dementia.
iii. RNs and caregivers who have not provided care to people with dementia for more than six months.

2.6 Sample Size

Semi-structured Interviews

DeJonckheere et al. (2019) states that there is no set number of participants recommended for interviews as data collection should stop once thematic saturation is reached. Eleven participants who fit the inclusion criteria participated in the semi-structured interviews. The sample size was determined by the number of eligible participants who could be recruited, rather than reaching data saturation.

Focus Group

With regards to the number of participants making up the focus group, Basnet (2018) recommends eight to twelve participants as having a larger focus group could result in difficulties in controlling the discussions and equal participating opportunities for all the participants. A total of six participants consented to take part in the focus groups. Due to the availability of the participants, two separate focus groups took place. The first focus group had four participants and the second focus group had two participants. The limited availability of the participants led to the second focus group having a smaller sample size, with two participants being within the acceptable range according to Kamberelis and Dimitriadis (2005). Participation in the semi-structured interviews was not a prerequisite for participating in the focus groups.

2.7 Study Setting

The WHO (2008) defines a care facility as a facility serving a special purpose by providing accommodation, and other forms of support such as assisting with ADL, intensive care, and promoting independence to the residents who are fragile and old. For the purpose of the current study, this definition will be used.

The study was conducted at a private care facility located in Johannesburg. The care facility provides care to PWD, Parkinson's Disease and those who are frail. The care facility offers 24 hour nursing care as well as day care for those who only require care for a few hours in a day. Assistance is provided with carrying out ADL such as bathing or showering, dressing, grooming, and eating (Care centre name redacted for ethical reasons, 2023).

The care facility has caregivers providing assistance to the residents with the RN being the owner of the facility. The RN is only responsible for the day-to-day running of the care facility and does not assist the residents with their ADL. There are no medical doctors or allied healthcare professionals on site. Residents requiring medical attention and allied healthcare services are either taken to the nearest clinic or hospital or they are seen by private professionals (Care centre name redacted for ethical reasons, 2023).

This site was chosen because it caters for PWD and therefore had professionals who met the inclusion criteria.

2.8 Study Participants

As seen in Table 2, eleven participants who administer medication to PWD at the care facility were recruited. All the recruited participants were female caregivers with varying work experience ranging from eight months to sixteen years.

Table 2

Demographic information of the study participants.

Participant Number	Gender	Age	Type of qualification: Registered Nurse or Caregiver	Work experience (in years)

1	Female	55	Caregiver	8
2	Female	26	Caregiver	6
3	Female	50	Caregiver	16
4	Female	30	Caregiver	1.3
5	Female	39	Caregiver	6
6	Female	25	Caregiver	0.8
7	Female	37	Caregiver	12
8	Female	22	Caregiver	1
9	Female	40	Caregiver	14
10	Female	37	Caregiver	0.9
11	Female	35	Caregiver	3

As can be seen in Table 2, no RN were participants in the study. The chosen facility had caregivers who are responsible for medication administration to PWD.

2.9 Data Collection

The following are steps that were taken by the researcher for data collection.

1. Ethical clearance was obtained from the University of the Witwatersrand Human Research and Ethics Committee (Medical): M230334 MED23-03-018 (Appendix 1).
2. An information letter (Appendix 2) was given to the site manager and permission was obtained to access the site to do the observations, to approach the caregivers and RN to participate in the study and to collect data (Appendix 3).
3. Thereafter, permission was sought from the caregivers. The researcher conducted an information sharing session where information about the study was provided to all the caregivers. This information session was also an opportunity for the caregivers to ask any questions they had.

4. The participant information sheets for semi-structured interviews and focus groups (Appendix 4 and Appendix 5 respectively) and consent forms (Appendices 6, 7, 8, and 9) were left at the site, in an easily accessible location. The caregievrs were given three weeks to consider their participation and provide consent. Signed consent forms were placed in a sealed box which only the researcher had access to.
5. Permission was also sought from the legal guardian of the residents for observation of medication rounds. The information sheets (Appendix 10) and consent forms (Appendix 11) were left at the site. Signed consent forms were placed in the sealed box accessible to the researcher.
6. The researcher conducted a pilot study with two participants to evaluate the relevance of the semi-structured interview questions in answering the research question. The data from the pilot study was included in the main study as the contents of the questions of the pilot study were not changed for the main study.
7. Commencement of data collection:
    a. Observations: Observations were conducted over a period of three days. The researcher observed the process of medication administration and recorded field notes on the self designed observation sheet (Appendix 12).
    b. Semi-structured interviews: The semi-structured interviews took place at the care facility at a time that was suitable for the participants, this was before, during, or after their shift. The interviews were guided by the interview schedule (Appendix 13) and were audio recorded.
    c. Focus groups: The focus groups were conducted at the convenience of participants who provided consent. The focus group discussions were guided by the focus group schedule (Appendix 14). The focus group discussions were audio recorded.

2.10 Pilot Study

According to Lowe (2019), the purpose of a pilot study is to assess the different aspects of the methods that will be used in a larger scale study. For the current study, questions that were that used for semi-structured interviews with the larger sample size were piloted. Two participants were chosen for the pilot study from the list of caregivers who consented to participate in the study. The pilot study was conducted in a way that the semi-structured interviews would be implemented in the main study. This was necessary to inform whether adjustments or changes needed to be made before conducting the study with a larger sample size. No changes were made to the semi-structured interview questions following the pilot study. Due to identical sampling frame and methodology, data from the pilot study was included in the main study dataset (Thabane et al., 2010).

2.11 Research Instruments

The study utilized observations, semi-structured interviews, and focus groups to answer the research question. The three data collection tools were used to confirm, and supplement data that could have been missed or not gathered when using one research tool (Honorence, 2017).

Observations

Observations form part of the various tools used in qualitative research (Allan, 2020). Observations were chosen as part of the research tools as they allow for an in-depth collection of data, thus giving rich results about the situation being studied. Observations were also chosen as information is obtained in its natural state without any changes to the environment (Nixon & Odoyo, 2020).

The researcher utilised an observation sheet (Appendix 12) that was self-developed for conducting observations. The inclusion of the different observations aspects in the

observation sheet was guided by the sub-aims of the study. This helped the researcher focus on the following specific details that are relevant to the study:

- The type of medication formulations taken by the residents and how medication is administered.
- Behaviour of the residents during medication administration.
- How the RNs and caregivers solved the challenges (if any) as they administered medication.

Observations took place in different places within the care facility, as some residents sat around a big table to have their meal in a dining room, other residents preferred sitting in a lounge and have their meals while watching television. The observations took place for over three days, in the mornings and afternoons. Field notes were taken while observing the medication administration process from a distance without participantion in the medication administration process. Non-participant observation refers to observing the participants without being actively involved in what is being observed (Sirris et al., 2022). Non-participant observation allowed the researcher to avoid influencing the partipants behaviour (Cheek et al., 2024). Although the aim of the researcher was to observe the caregivers in a natural state without interfering in the administration of medication, the behaviour of the caregivers could have been affected by being observed (Perera, 2021). This is referred to as the Hawthorne Effect. Oswald et al. (2014) proposed steps that could be used by reseachers to overcome the possibility of Hawthorne Effect. These steps included: non-threatening presentation, introduction of the reseracher, and building rapport. Non-threatening presentation entails dressing casually and behaving in a non-formal manner while the researcher introduced herself and building rapport entails having conversations about the participants roles and other general topics that will create a non-threatening and relaxed environment (Oswald et al., 2014). The researcher had already introduced herself during the recruitment process to all the staff caregivers that she came across throughout the different

shifts. Building rapport with the caregivers was facilitated by their friendly demeanor, which allowed for easy engagement in casual conversations such as current weather or events.

Semi-structured Interviews

The second research tool was semi-structured interviews. This type of research instrument was chosen as it allowed the researcher to gather rich data, to probe the feelings, and to explore the matters that are sometimes personal and sensitive (DeJonckheere & Vaughn, 2019). However, this type of interview may result in interview effect as well as demand characterists. Interviewer effect refers to the effect of the characteristics of the researcher on the responses of the participant while demand characteristics refers to how the responses of the participants are influenced by what they think the situation needs from them (DeJonckheere & Vaughn, 2019).

Semi-structured interviews were selected for the current study as rapport was already made with participants during the recruitment process and during observations with some of the participants. This helped to make participants who conseted to participate in the study comfortable enough to share information that could not be shared in a group setting (Brown & Danaher, 2019). Semi-structured interviews also selected as they provide confidentiality, allowing participants to share personal feelings and experiences that may not shared in other types of data collection tools (Schmid et al., 2024).

The semi-structured interview schedule (Appendix 13) used for data collection was self-developed and the following are factors that were considered during the development of the schedule:

- The demographic information of the participants. This would give more information on whether the qualification type as well as the work experience of the participants plays a role in the perceptions of providing care to PWD.
- Thorough process of how medication is administered.
- Challenges that arise during medication administration and how these are solved.

The semi-structured interviews were conducted at the research site with the eleven recruited participants. These interviews were conducted over a period of two weeks at a time that was suitable for the each participant. The interviews were audio recorded and transcribed for analysis. Information that could lead to the identification of the participants was removed during analysis.

Focus Groups

Focus groups are defined as an interview consisting of a group of participants ranging from three to twelve (Nyumba et al., 2018). This research tool was chosen as it would allow for collaborative construction of meaning and knowledge (Kook et al., 2019). A self-developed focus group schedule (Appendix 14) was used to guide the discussions during the focus groups. The focus group schedule included topics that provided information on the general perception of providing care to PWD, the skills or experience required to be employed as a caregiver of PWD, and the training needs (if any). Two focus groups were conducted at a time that suited the participants. The researcher facilitated the group discussions to ensure that all participants participated equally (Nymba, et al., 2018). Howevever, a disadvantage of conducting focus groups is lack of confidentiality. This is highlighted by Sim and Waterfield (2019) who stated that confidentiality and anonymity is breached in focus groups where the individuals know each other. This was shared with the partipants in the focus group information sheet (Appendix 5). The focus group discussions were audio recorded for data transcription and analysis.

Audio recording

Audio recording is another tool recommended when conducting semi-structured interviews (DeJonckheere & Vaughn, 2019). In the current study, a built-in voice recorder on a mobile phone was used to record the semi-structured interviews and focus groups. This helps the interviewer with focusing on the interview or focus group and also build rapport with the participants as taking down notes may be distracting. An audio recording assists with

capturing all the responses, which were later transcribed word for word for analysis. DeJonckheere and Vaughn (2019) further state that participants should be informed of the audio recording that will take place. Participants were required to provide consent to be audio recorded (Appendix 3).

2.12 Data Analysis

Thematic analysis was used used to analyse data collected from observations, semi-structured interviews and focus groups. The following six phases by Clarke and Braun (2013) were used to analyse data and generate themes:

1. *Familiarisation with data:*

In the first phase of thematic analysis, the researcher familiarised herself with the raw data from the observation notes and the transcription of the audio recordings for the semi-structured interviews and the focus groups and active reading of the raw data more than once (Kiger & Vario, 2020).

2. *Coding:*

In the first step of coding, data pieces of interest or linked pieces were highlighted. In this phase, an Excel Spreadsheet with the participants responses was used to create codes. A code is defined as a vital piece of the raw data that is labelled (Kiger & Vario, 2020). Each code was defined and clearly demarcated to prevent overlapping with other codes that were highlighted. The creation of codes was linked to meanings of data pieces of interest (Kiger & Vario, 2020). Inductive analysis was used to come up with up with codes. Inductive analysis is defined as an analysis approach whereby the researcher goes through the raw data and highlights codes that emerge (Bingham, & Witkowsky, 2022). Creating codes based on the meaning of the data pieces is important as it forms part of audit trail, which will serve as proof of trustworthiness during the interpretation and analysis of the data (Kiger & Vario,

2020). The use of inductive analysis allowed for similar codes to be identified throughout the transcribed data and grouped together (Kiger & Vario, 2020).

3. *Searching for themes:*

In this phase, the collated and coded data was examined to look for themes that are of great significance (Kiger & Vario, 2020). It is important to note that themes do not come from the data; instead, they are made by analysing, collating, comparing, and mapping out the relation of different codes (Kiger & Vario, 2020).

4. *Reviewing the themes:*

In this phase, the researcher repeatedly read through the codes and the themes that were created from the data. This was done until all the data pieces were given codes and the themes were consistent (Kiger & Vario, 2020). The researcher and the supervisors collaboratively discussed and agreed on the names of the codes and themes. This ensured consensus through a mutual review and revision.

5. *Defining and naming the themes:*

For this phase of data anaylysis, the researcher came up with definitions and brief descriptions of all the themes that were derived, including their importance to the main study question (Kiger & Vario, 2020). Thereafter, the names of the themes were reviewed, and the important features of the themes were refined with focus on how the themes play a role in understanding the main research question (Kiger & Vario, 2020). This is the phase where the researcher extracted certain data items such as quoting the participants responses and including them in the final write up.

6. *Writing up the results:*

This is where the process of the writing began. In the write up of the current study, processes that were done in the previous phase such as introducing and describing the themes that emerged, and including certain extracted data pieces were included (Kiger &

Vario, 2020). When compiling the final report, the aim of the researcher was to present a clear and consise narrative of how and why the data interpretation and the themes are accurate and important. Furthermore, the narrative and the extracted data pieces were used to argue for why data interpretation and themes that emerged are used to answer the research question (Kiger & Vario, 2020).

2.13 Trustworthiness

Trustworthiness is a way that researchers convince their rearders that their research is legitimate and therefore deserves attention (Nowell et al., 2017). The following are different elements of trustworthiness that were applied in the current study:

Credibility

Credibility refers to showing the truthfulness of the research by llinking the research findings with reality (Nowell et al., 2017). To ensure credibility, triangulation and member checking were applied in the current study. Triangulation refers to the use of several data collection tools with the aim of answering the research question (Jensen et al., 2022). The current study made use of three data collection tools: observations, semi-structured interviews, and focus groups.

Member checks entails sharing the data, interpretations, and the conclusion with the participants so that they can check the accuracy of the information they provided before a final report is written (Jensen et al., 2022). The data and the interpretations for the observations, semi-structured interviews and focus groups were shared with the participants to validate the information they shared and how it was interpreted.

Transferability

Transferability refers to the ability to generalise the research findings (Nowell et al., 2017). This element of trustworthiness was applied in the current study by providing thick

descriptions of the phenomenon being studied, context of the study, and methods used to collect data (Nowell et al., 2017). To ensure transferability, the different processes taken to collect data were thoroughly discussed.

Confirmability

Confirmability refers to proving the research findings with the interpretations being derived from the data set. The researcher has to show how the interpretations and the conclusions have been made (Nowell et al., 2017). To ensure confirmability in the current study, an audit trail was done. Audit trails help with establishing confirmability as it highlights all the steps taken in analysing data to provide justification of the decisions made and this ensures that findings of the study accurately portray what the participants said (Nowell et al., 2017). In this report, the six steps of thematic analysis were applied with a thorough explanation of what the researcher did in each of the six steps.

Dependability

Dependability refers the consistency and the repeatability of the research findings. This can be done by ensuring that the process of gathering data is coherent, traceable, and well documented (Nowell et al., 2017). Dependability was ensured through an audit trail. Raw data such as audio recordings and transcripts, and observation notes are available for audit trail purposes.

2.14 Ethical Considerations

It is important to protect participants in any type of research and this can be done by applying ethical principles (Arifin, 2018). The following ethical principles were applied in the current study:

- *Informed consent*:

The researcher obtained consent from the site to have access to recruit the participants. This was followed by obtaining another consent from the participants to observe the medication administration process, conduct semi-structured interviews, and focus groups. Consent was also obtained for PWD as they were part of the observations, even though the focus was on the caregivers.

- *Anonymity:*

Anonymity entails removing details that may reveal the identity of the participants (Saunders et al., 2015). The name of the care facility in which the study took place is not disclosed in this masters dissertation. Information that could possibly reveal the identity of the participants such as quotations obtained during the semi-structured interviews and focus groups was anonymised during the reporting of the results.This was done through assigning codes to the participants. The identity of PWD was also not revealed in the reporting of the results obtained from observations. The participants and PWD will still remain anonymous if the study is to be published. This will be done through the use participant codes that were already assigned. Although anonymity could not be guaranteed in the focus group, the participants were informed about this in the focus group information sheets and they were also requested that the discussions and the information shared during the focus groups cannot be shared outside of the group.

- *Confidentiality:*

Saunders et al. (2015) defines this ethical principle as protection of the identities of the participants and data collected.The data collected is kept on a laptop that is protected by a password and only the researcher has access to the data. Confidentiality of the participants who participated in the focus groups could not be guaranteed. This was explained to the paticipants and stated in the focus group information sheet (Appendix 5).

- *The right to withdraw*:

The participants were assured in the participant information letter (Appendix 2), that they have the right to withdraw from the study at any stage in the research process without any consequences. This was explained to the participants during the information session.

- *Coercion:*

The manager was not directly involved in the recruitment process; however, she was requested to make reference to the current study when the caregivers changed shifts. There were no rewards or incentives offered for participation.

Chapter 3: Results

This section looks at the results obtained from the observations, semi-structured interviews, and focus groups. Data obtained from the observations are explained according to the aspects observed at the care facility and was used to verify data obtained from the semi-structured interviews and focus groups. Following the observations section is data from the semi-structured interviews and focus groups. Data from the semi-structured interviews and the focus groups was analysed thematically following the steps proposed by Clarke and Braun (2013) as discussed in the data analysis section.

3.1 Observations

Medication administration was observed for a period of three days in the mornings and afternoons. As the aim was not to interfere with the administration of medication, the researcher conducted the observations from a distance while taking notes. The researcher would, however, move around with the caregivers as they administered medication to the different residents in the different rooms in the care facility. The following items were observed and the observations were recorded on a observation recording sheet (Appendix 11):

i) Preparation of the medical administration process by the registered nurses and caregivers.
ii) Medication formulations taken by PWD.
iii) General behaviour of PWD during the administration process.
iv) How medication is administered by the registered nurses and caregivers.
v) Registered nurses and caregivers response to challenges experienced during the medication administration process.

i) Preparation of the medical administration process by the registered nurses and caregivers:

Residents' weekly medication was packed in medication trays at the beginning of each week by the manager of the care facility, who is a RN. The medication trays were kept in the medication cupboard. For ease of identification, medication trays were labelled with the resident's names. The preparation of medication administration was a quick process for some caregivers. The caregivers would wash their hands first, prepare meals, and ensure that the residents ate before medication was administered. However, this was different for some residents as they had to take medication before having their meals. Immediately after each meal, the caregivers collected the medication for the residents from the medication cupboard and administered it to residents. Some caregivers were observed crushing the tablets using a motar and pestle or opening the capsules in preparation for administrating medication to residents who required the modifications. The modification of medication was done in the room where the medication was kept with no use of personal protective equipment such as gloves or plastic aprons.

ii) *Medication formulations taken by PWD:*

It was observed that all the residents at the care facility took a variety of medication daily, including vitamins and supplements in addition to their chronic medication. All the residents took solid forms of medication (tablets and/or capsules) only. For those that were able, tablets or capsules were taken before or after meals, depending on the instructions given by the doctor. However, the medication formulation was altered for residents who either had swallowing difficulties or refused to take their medication. In this case, the tablet was crushed or the capsule opened and the contents mixed with the food or tea before given to the individual. This aligned with the strategies reported by the participants (described below).

iii) *General behaviour of PWD during the medication administration process:*

Various reactions were seen among the residents during medication administration. Some residents cooperated fully and understood that they had to take medication. These individuals were able to take their medication independently. However there were also some residents who did not want to take their medication. It was observed that these residents refused to take medication without any reason stated. One of the residents was seen refusing to open his mouth as soon as the caregiver approached him with his tablets and a glass of water. Another resident appeared confused and did not understand what the medication was for. These observations are consistent with the challenges reported by the participants during the semi-structured interviews and focus groups.

iv) *How medication is administered by registered nurses and caregivers:*

The medication was administered the same way for most of the residents. Some of the residents took their medication (tablets and/or capsules) with water while those that required their medication formulation to be altered, had their medication mixed with food or something to drink. It was noted that medication was only mixed with a small portion of the food and given to the residents as they were fed by the caregivers. Doing this ensured that the residents got the medication they needed to take even if they did not finish the rest of the meal. Therefore, the medication dosage is administered as required. It was observed that residents who took their medication independently had to do so in the presence of the caregivers, after which the caregivers would check inside their mouths to ensure that they swallowed the medication.

v) *Registered nurses and caregivers response to challenges experienced during the medication administration process:*

The participants responded differently to the different challenges they came across while administering medication. Some of the challenges stated below are consistent with the

information provided by the participants in the semi-structured interviews and the focus groups. How the participant responded depended on what the challenge was. Residents who did not want to take their medication would have the formulation of their medication altered. Having certain caregivers administer medication to specific residents was another strategy used in response to residents who had preferences regarding caregivers who would provide care to them. There was one case where one of the residents appeared to have aspirated on his medication. The resident had to take multiple tablets in their original formulation after breakfast with water. The resident coughed immediately after swallowing his medication and the supervisor who was around rushed to attend to the situation. Upon arrival, the supervisor gave the resident back blows for a few seconds until he stopped coughing.

3.2 Semi-structured interviews and focus groups.

Data analysis of the responses obtained during semi-structured interviews and focus groups led to five themes emerging as illustrated below in table 3. The themes are unpacked below. Additionally, the following are three minor themes that emerged, which are explored in this chapter: Ubuntu, Knowledgeable, and Facility driven process.

Table 3

Major themes that emerged from the study.

Sub-aims	**Theme/s**
Sub-aim 1: To explore barriers experienced by the RNs and caregivers when administrating medication to PWD.	Theme 1: Non-compliance due to cognitive decline. Theme 2: Behavioural challenges

Sub-aim 2: To explore the strategies used by the RNs and caregivers to administer medication to PWD.	Theme 3: Patient tailored care. Sub-themes: 1. Altering the normal formulation of medication. 2. Allowing the residents time to calm down. 3. Caregiver familiarity.
Sub-aim 3: To document the perspective of the RNs and caregivers on caregiving to PWD in terms of their training, confidence, and preparedness.	Theme 4: Training needs. Theme 5: Different perspectives.

Theme 1: Non*-compliance *due to decline in cognition.

One of the challenges experienced by the participants during medication admnistration to the residents was refusal of medication. This was also observed as one of the residents refused to open his mouth when he had to take his medication. However, some of the residents appeared not to understand why they had to take medication. This was another incident that was observed and also a challenge reported by six participants. While some residents had no reason for not wanting to take the medication, other residents refused taking medication when their prescription changed. These individuals often thought that they are being poisoned and therefore refuse taking medication. The quotes below highlight the above mentioned challenge.

P1: *"It's those ones who…it's like the other one, they refuse sometimes but when they're like that…"*

P4: *"The challenge is that some don't want to take medication."*

P5 (Focus group): *"Ehh…like XX (resident name), she won't take the medication when gets it from someone else. She only wants to be given by me. If the clinic changes her medication, she will not drink it, because she will think they are trying to poison her."*

P5: *"Even him, he is like that but we just make the same thing but he is better he doesn't want to swallow when we give him, he just spits and throw away."*

Theme 2: Behavioural challenges.

Changes in behaviour resulting in aggression from some of residents was another challenge reported by ten participants. The aggressive behaviour from some of residents ranged from the physical use of force towards the participants to intentionally breaking crockery (tea cups) when offered tea with medication. This appeared to be a defense mechanism for some residents as participants 1, 3, and 7 reported that some of the residents became aggressive as they thought they are being poisoned and when their prescription changed.

P1*: "…If I see that the person is aggressive and does not want to take the medication, then I will give them space and after a while I will come back."*

P3: *"One of the patients here, she knows everything but sometimes she is very aggressive and won't take the medication because she thinks it is poison and fight."*

P7: *"Okay, sometimes he can be aggressive, not that aggressive but he can be aggressive..."*

Knowing the residents and what triggers their aggressive behaviour was also mentioned as an important factor by one participant. This is seen in the statement below. Identifying the triggers not only reduced the occurences of aggressive behaviour but also helped the caregivers to avoid being on the receiving end.

P9: "…*or like, even if you are sitting and see her, because she's always trying to run away, I know how, I'll be sitting here and be like "Ahh gogo…", how to talk to her, to bring her back,*

not to make her angry but if I see her coming back angry, I know okay, stand up, get ready to…you know? Calm her down or conf…like that."

Theme 3: Patient tailored care.

A variety of responses emerged from the participants as they explained the techniques they used to ensure that medication is administered to the residents. Notablly, all the participants reported that their role was to administer medication that was already packed in medication trays. The different responses showed that there is no specific strategy that would cater for all the residents with dementia as some require assistance with taking medication while others can take the medication independently. This then requires the participants to tailor the strategies they use to administer medication for each individual with dementia, depending on whether they require assistance or they present with other challenges that make medication administration a difficult process to carry out. Below are the different strategies used by the participants to administer medication.

Altering the normal formulation of medication:

Modification of the normal formulation of medication and mixing it with the food or tea was one of the techniques mentioned by all the participants. Three participants were observed crushing tablets for some of the residents using a mortar and pestle. The modification of the normal formulation of medication was done in response to the challenges that participants reported when administering medication such as refusal to take medication. However, this appeared to be a standard practice for some of the caregivers as two participants reported that they modify the normal formulation of medication for all the residents they assisted with mealtimes. This included residents who did not present with any swallowing, behavioural, and other difficulties that made medication administration a challenge. This is seen in the responses below:

P1: *"So to make sure that they take their medication, we mix it with something. We can mix it with porridge, we can crush it and put it on tea to make sure they get the medication because some of them don't want to have it at all."*

P7*: "That's why I mix with porridge because if he can feel it's a medication, he can…"*

P11: "*Sometimes the patient doesn't want to drink medication. Sometimes they have problems of swallowing the medication, so we need to crush it then mix it with something they like the most then we give them the medication."*

Out of the eleven participants, three participants further stated that the crushed the tablets or the contents from the capsules would be poured on a small portion on the meal rather than pouring it all over the meal and mixing it with the food to be had. The small portion containing the altered medication would be given to resident first before they have the rest of the meal. This was done to ensure that the residents get all their medication as some of them would not finish their meals. One of the three participants explains below.

P6: "*Sometimes the…like others like XX (patient name)… uh when you give him the medication, he doesn't want to take it unless you put it in the food and then one spoon then you give him, when he starts chewing, he becomes more (mimics the resident's facial expression)."*

In some cases, the modified medication would be mixed with tea. This was done for some residents who are independent and therefore do not require to be assisted with meals but still did not want to take medication. Challenges like these required some form of flexibility and thinking out of the box from the participants as they needed to ensure that the residents still get their medication. Offering tea, juice, or even yoghurt mixed with medication to the residents, depending on what they wanted, was another strategy used, as described by participant 9, to ensure continuity of medication admnistration.

P9: *''…for some of them that have to take it, we'll make another plan, offer them tea, juice or something they want to eat."*

Allowing the residents time to calm down:

The participants reported behavioural difficulties from the residents, which often made medication admnistration challenging. Some residents would respond with aggression when the caregivers offered medication. In response to this, three participants reported giving the residents a few minutes alone to allow them to calm down and returned to offer them the medication again, this time mixed with something the individual with dementia loved or wanted to eat. This is seen in the statements below.

P4: "*It also depends on the patient's mood. Sometimes the patients take their medication and don't give us problems but sometimes they refuse. Uhmm…like with XX, sometimes he will take the medication when you give him, but some days he will give you problems and not want to take it. When he does that, I give him a few minutes then come back to try him again and then he takes."*

P9: *"And like with this lady, sometimes she can just go…tea gone, medication gone. In such cases we would leave her to calm down, talk to her nicely, we give her time alone, let her relax, then go back and offer her tea with medication. Uhmm…some of them will leave the food and we'll try again lunch time. For some of them that have to take it, we'll make another plan, offer them tea, juice or something they want to eat."*

P5: *"…If she don't want the medication, I just give few minutes and come back begging her with tea, I make the tea for her and I crush my medication, she don't want to see any medication so that's why I crush it and I pour put it inside the tea..."*

Caregiver familiarity:

Caregiver preferences based on familiarity was reported by two participants during the interviews and the focus groups. The two participants reported that some residents at the care facility agreed to take their medication when it was administered by certain caregivers. This was attributed to the lack of trust the residents had towards some of the caregivers at the care facility. To ensure continuity of medication intake, the participants resorted to having

specific caregivers who would administer medication to specific residents with dementia. However, this would be a challenge when a caregiver preferred by a certain resident would not be at work due to the shifts changing. One participant during a focus group reported that she was once called when she was off duty to help talk to one of the resident who was normally given medication by her as she was refusing to take medication from other caregivers. This is seen in the statement below:

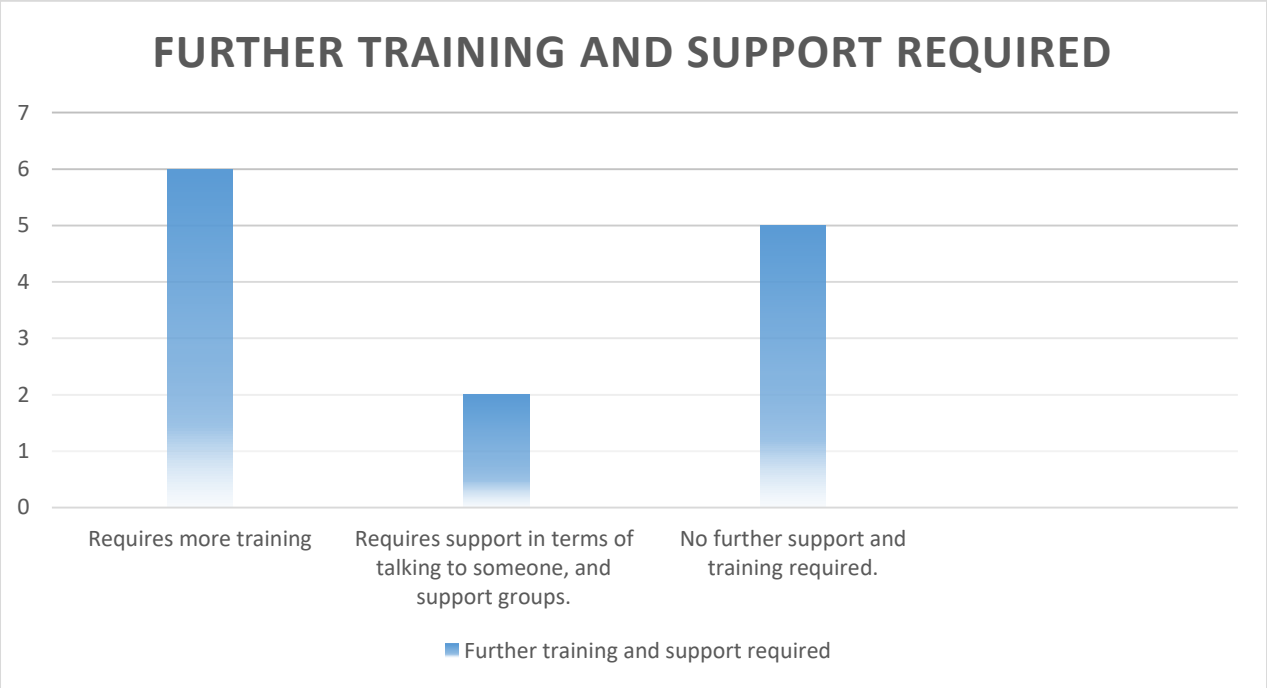
P11: *"…uhmm like there is someone who will be like "I don't want you to give me" but we know the person they like the most, you know there are people like that. So, that person will be their weakness, so we try to take the person so that she will explain the most and calm them down and give them medication…"*

P5 (Focus group): *"Ehh…like XX (resident name), she won't take the medication when gets it from someone else. She only wants to be given by me. If the clinic changes her medication, she will not drink it, because she will think they are trying to poison her."*

Theme 4: Training needs.

Figure 1

Further training and support required



Looking at the training needs and support of the participants at the care facility as illustrated in the figure above, only six participants indicated that they require further training in dementia as they want to know more about the condition.

P10: *"Me, I'm that kind of person who still want to know more. So like I want to know more about these people, like more of it, to go deeper."*

P6: *"Ehh for me, I want more training. I still want to know…more about dementia. You know ehh…you learn until you are old. Yes, I have been working with people who have dementia, but I still want to know more, know everything."*

P11: *"Hmm, in training I can say yes, I can say yes because I just believe I need to upgrade myself for upgrading myself, I can say yes but for taking care of people, I know I do can do this (laughs)."*

Another training need mentioned by one participant was having a professional like a physiotherapist, who could teach the caregivers how to do basic exercises such as stretching and massaging the residents.

P9: *"…How to go and exercise her legs, to…stretch her…almost like a physio but not a physio but to just know the basics of how to do it, know the body structure. The other gentleman, his leg gives him problems, know how to massage his leg and manage it.*

Participant 9 went on to mention that she also wants to know how to protect herself in a situation where one of the residents gets aggressive.

P9: Like the other one, the other one who lives here, his dementia since I've been here has actually gotten worse, and he's got a very strong, strong grip. Know when to protect yourself, how to protect yourself because they do lose it and do want to hit you."

On the other hand, two participants stated that they require more support regarding having someone to talk to. One of the participants reported that she would love to be in a support group with other caregivers whereby they talk about the challenges they come across as caregivers and also give each other advice. The caregivers reported the importance of social support in the form of sharing experiences of the challenges they experience as colleagues and also seek advice. This is seen in the quote below.

P9: *"Yes, especially if your patient is like this lady here. The further they go, the worse they become. Yes we do need a support group, where you can go and sit and talk to other caregivers… So like, where we'll come together and say…okay, this one did that, you know?! Just to have an outlet, so it doesn't bottle up, and then you explode."*

Five participants stated that they do not require any training or support. Some participants reported that they already know how to take care of PWD.

P6: *"No... I'm good."*

P5: *"I'm also fine. I know how to look after them."*

P7: *"No, I feel to be managing it, yes (unintelligible)."*

Theme 5: Different perspectives

Interestingly six participants reported that they loved and enjoyed providing care to the residents. The participants mentioned a few factors that made them love or enjoy caregiving for PWD. Six participants stated that they enjoyed or loved providing care to PWD due to innate qualities such as passion. Participant 6, 8 and 11 stated that their role as a caregivers goes hand in hand with passion, hence they enjoy what they do at the care facility.

P6: "Uhmm, its something that I enjoy doing. Yeah, its something that I like, I have passion about."

P8: *"I believe when it comes to that it has to do with you as an individual right?! Because we are different, you will get a person who will be like this is very difficult for them but you get another person who enjoys working and finds passion in that. So I think it comes hand in hand with passion. So with me for example, I enjoy doing it and I love being here."*

P11: *"To me, uhh caregiving is not a job (laughs). So to me, I believe I enjoy it, I really love it, what I'm doing, I really love it, I believe it's my passion."*

While some participants attributed loving their role of caregiving to being passionate, three participants stated that the reason why they love or enjoy looking after PWD was because they already understood dementia and knew what to expect from PWD.

P4: *"As for me, I enjoy doing my work, I don't find it difficult. It's only that you have to learn that sometimes people with dementia are difficult but you have to find a way of dealing with them…"*

P10: *"You need to have the…Okay, I think the first thing you need to know, like what kind of sickness is dementia?"*

One participant reported that she enjoys caregiving PWD because she has been working with them for a number of years.

P5: *"I'm enjoying it because I've already been with them for a few years..."*

Only one participant reported that she finds caregiving to PWD difficult due to some behavioural difficulties that are stated above in sub-aim 2.

P7: *"Uhh, I'm gonna say it's hard…But the thing you must tell, I tell myself I'm going to do it and this thing, I will never be like her or him. If he is aggressive or he's doing something wrong…"*

In addition to the major themes discussed above, three minor themes that are relevant to the current study also emerged from the data analysis: a) Ubuntu b) Knowledgeable c) Facility driven process. Ubuntu and knowledgeable emerged when the participants were asked about the skills and experience required in care provision for PWD. Love, passion, and patience were the innate qualities mentioned by six participants. Training on caregiving and dementia was also mentioned by two participants as an important factor. Lastly, the participants explained the process of medication administration. They first had to prepare the meals of the residents, assist with feeding for those who require assistance, and administer medication. However, there were residents who were given their medication before or with the meals. This led to the theme: facility driven process. Following the question of the detailed process of medication administration, the participants were further asked how many times they administer medication in a day and the responses were one to three times a day while some participants reported that it varied from one patient to another.

Chapter 4: Discussion

The results found in the current study reflect the perceptions of medication administration of caregivers only as no RNs were recruited. The facility gave the responsibility of medication administration to the caregivers. This finding contrasted with findings from the global literature where only qualified RNs could administer medication (Kuppadakkath et al., 2023). According to (Kalideen et al., 2022), care facilities are required to have sufficient RNs among other staff members that are required to provide care to the residents. This was not the case at the chosen research site as there was only one RN, who was the manager. The absence of RNs who provide care to residents at the care facility could be attributed to the shortage of RNs in South Africa. Statistics done in 2005 show that appromaximately thirty-five thousand South African RNs were practicing outside South Africa or left the health care system (Oosthuizen & Ehlers, 2007). By 2015, South Africa experienced a significant need for about 22 121 RNs (Reardon & George, 2014). The active recruitment of South African RNs by other developed countries that experience nursing shortages is one of the causes leading to many RNs leaving for other countries (Oosthuizen & Ehlers, 2007). Other factors that lead to the migration of South African RNs to other countries are dissatisfaction with salaries, huge caseloads, crime rate, and limited opportunities for career growth (Oosthuizen & Ehlers, 2007). In addition to insufficient RNs, the finding from the current study raises an important issue of potential dangers and concerns around whether caregivers have adequate training to be given the responsibility of medication administration especially with a vulnerable population i.e. PWD. It challenges existing certification for caregivers and questions whether the two to three months training certificate is sufficient or it needs to be extended and whether there should be compulsory component of the certification specifically around medication prepapration and administration which would be especially relevant for the South African context.

Literature focusing on RNs in care facilities found that RN providing care to older people found their work to be emotionally and physically challenging (Benadé et al., 2017).

Furthermore, the literature highlights that these RNs experience violence in the workplace (Benadé et al., 2017). Providing care to PWD increases the pressure on the RNs as more time and knowledge is required (Benadé et al., 2017). These challenges result in the RNs being stressed, ultimately affecting their health and work productivity, leading to burnout. These factors push the RNs in care facilities to resign, thus contributing to the shortage of RNs (Benadé et al., 2017).

The current study found that how the caregivers perceived their role of caregiving PWD influenced how they approach medication administration. While many caregivers expressed their love and enjoyment for caring for PWD, one caregiver perceived caregiving difficult, which can be attributed to limited experience. Regardless of these perspectives, the caregivers demonstrated flexibility, finding ways to ensure contuinity of medication administration. The current study found that regardless of the challenges that arise during medication administration, the caregivers find a way of ensuring continuity of medication administration. The results show that the caregivers use different strategies to administer medication to the residents and this is dependent on the type of challenges the caregivers are faced with during medication administration. The work experience of the caregivers also plays a role in how they respond to the challenges. The findings from the study reveal that the medication prescribed for PWD takes the form of a tablet or capsule and that many PWD require the medication to be altered in some way for them to consume it. Solberg et al. (2021) found that altering the formulation of medication was a common practice in care facilities. The caregivers reported crushing the tablets or opening capsules as part of medication administration. A study by Mc Gillicuddy et al. (2017), found that crushing tablets was the most common modification in care facilities. The study further states that RNs in care facilities viewed medication modification as an unavoidable process in medication administration due to reasons including dysphagia, and dementia. The benefits of modifying medication stated by the RNs were ensuring that important medication is administered, and reducing the risk of medication aspiration (Mc Gillicuddy et al., 2017). This is in line with the

findings in the current study as the caregivers emphasised the need to ensure that medication is administered, this included modifying the medication and mixing it with something the residents loved to eat or drink. In other instances, the medication is modified for residents who are known to present with behavioural difficulties which affect how medication is administered. Similar findings were highlighted in a study by Ganzetti et al. (2021) which found that medication was modified in care facilities to mitigate the behavioural difficulties (i.e.not wanting to take medication) which is characteristic of dementia.

However, it was found that some caregivers alter the formulation of medication for all the residents they assist during mealtimes in the absence of challenges or reluctance to take medication. This appeared to be a standard practice for these caregivers as they did not tailor the administration process based on the challenges or the needs of the residents. This is in line with results from a study by Mc Gillicuddy et al. (2017), which found that RNs reported crushing tablets as a standard routine. On the other hand, this appeared to be a routine that saves the caregivers time as they still needed to administer medication to other residents. A few studies (Farner & Hicks, 1976; Hamrick et al., 2007; Kaasalainen et al., 2010; McCloskey et al., 2015; Vogelsmeier et al., 2007) highlighted time pressure as a challenge that many caregivers were faced with in care facilities during medication administration. These studies further compared medication administration to a race, whereby the caregivers have to prepare the medication for administration (race preparation); administer the medication accurately and quickly (run the race); and record that the medication was administered (complete the race).

Although altering the formulation of medication appears to be a common practice, the literature highlights the dangers of this practice. According to Daibes et al. (2023), not all solid formulations of medications can be crushed, split, or opened. In some cases, this process may lead to toxicity to the individual being given the medication, or complete failure of treatment. Daibes et al. (2023) further state that administering the altered formulation of medication results in the medication being received all at once rather than being slowly

digested by the body. This then results in toxicity and can further lead to outcomes that may threaten the individual's life.

Contamination and lack of good hygiene are also problems linked to altering medication, which may affect safe medication administration (Abdrabba et al., 2021). Lastly, changing the original formulation of medication does not pose a risk to the recipients, but also to the caregiver as there is a high risk of inhaling the medication as they are being crushed or opened without wearing appropriate protective gear such as masks and gloves (Abdrabba et al., 2021). This was observed in the current study during the preparation of medication for residents who required their medication to be altered. The caregivers, despite use of a uniform, did not use disposable gloves or face masks but were involved with crushing tablets or opening capsules and mixing the contents with the food. Although the risk of crushing tablets has been highlighted, there are currently no suggestions regarding the ideal personal protective equipment for care facility staff members who administer medication (Amiri et al., 2023). In addition, there are no guidelines informing the RNs in care facilities about protecting themselves and other people around them from the residual particles in the air from crushing tablets. This also forms an important part of medication administration as prolonged exposure to crushed tablets is linked to illnesses in RNs (Amiri et al., 2023). For example, a case study by Lewis et al. (2012) found that a pharmacist was diagnosed with pneumonitis following crushing tablets for several months in an enclosed space without consistently wearing a mask. However, the symptoms that led to the diagnosis stopped as soon as the pharmacist was no longer exposed to the crushed tablets.

Giving the residents space and time to calm down is another strategy mentioned by the caregivers. This is done in response to the behavioural challenges or the changes in mood of the residents. The caregivers reported leaving the individual for a few minutes before coming back to offer medication again. It appeared that most caregivers offered the medication on their return in an altered form, mixed with something the resident loved to drink or eat. These findings are similar to a study by Watson and Hatcher (2021) which

found that PWD who were aggressive were given time to calm down by the caregivers. The caregivers followed the five minutes rule which meant they removed themselves from the vicinity of the aggressive resident for a few minutes and returned with something the resident loves such as tea or a different caregiver.

Having specific caregivers administer medication to certain residents is another strategy used by the caregivers at the care facility. This is done in response to the preferences some residents have regarding who would administer medication to them. A study conducted by Backhouse et al. (2022) looking at how caregivers cope with refusal of assistance from PWD with their ADL found similar results. The authors found that the caregivers relied on each other for support when one of the PWD refused care. This was done by swapping with other caregivers who had a good relationship with and knew the individual well.

Medication non-adherence attributed to cognitive decline is one of the two challenges reported by the caregivers at the care facility. Some of the residents refuse medication from the caregivers. For some of the residents, there are no reasons stated for refusing medication. On the other hand, other residents appear not to understand why they have to take medication, while others raise fears of being poisoned. This is a common challenge that caregivers of PWD face due to confusion, and lack of insight leading to unintentional non-compliance with medication (Lim & Sharmeen, 2018). Few studies (Maxwell et al., 2014; Arlt et al., 2008) have highlighted lack of insight into dementia leading to medication non-adherence. PWD who are not aware of their condition due to the nature of dementia have been found to default on their medication as they do not see the reason for taking medication.

Furthermore, it has been stated that individuals who are not aware of their medical condition may express their frustration through anger and being physical (Tondelli et al., 2021). This is consistent with the study findings as the caregivers reported that some residents responded with aggression when they were offered medication or as soon as they saw medication. However, this is not the case with all the residents who refuse taking medication from the

caregivers. Some residents only refuse to take medication or show signs of confusion as they asked why they have to take medication in the absence of behavioural difficulties such as aggression. It was also observed that residents who did not want to take medication refused to open their mouths without being aggressive.

Refusing medication due to fears of being poisoned also emerged as another reason stated by some PWD. The caregivers are faced with this challenge when the prescription of the individual changes or when the medication is administered by a caregiver not preferred by the resident. Similar findings were found in a study by Kaasalainen et al. (2011) which highlighted the same challenge as PWD refused to take medication due to being delusional or having suspicions of possible harm from the caregiver. Lindauer et al. (2017) found that PWD in care facilities with declining cognitive skills, delusion, visual difficulties, depression, and pain resisted care from the caregivers, including medication administration. These symptoms affect how PWD perceive care, leading to misinterpretation of the intentions of the caregivers, and refusing medication.

In cases where the prescription of the resident changed, the caregivers reported having to communicate with the resident and explain what each tablet is for and how it will help the resident.

As already stated in the literature review, communication is one of the affected areas in dementia, thus attempting to convince the residents to take medication may not always be a success for a number of reasons. Volkmer et al. (2023) looked at the impact communication difficulties have on daily conversations. Lack of insight as explained above may result in communication with some PWD being null. Reasoning or explaining the importance of medication to some PWD may not result in medication adherence as the individuals are unaware of their condition and therefore do not see the need to take medication. This leads to alteration of the formulation of the medication as most of the caregivers do at the care facility since some residents do not present with swallowing problems but rather question the need to take medication while others spit out the tablets. Lack of rapport between some

residents and the caregivers as well as the misconceptions PWD have about the caregivers make communication regarding the importance of medication futile. This is due to fears of being harmed as expressed by some residents thus medication will be refused. Lastly, short attention span and memory difficulties also make communication with PWD not effective. A decline in these cognitive skills results in the individuals not following through with the instructions or the explanation as they are easily distracted by other activities in the background. Furthermore, these individuals may forget what was communicated to them due to memory problems (Coleman & Asiri, 2017). In addition to the reasons stated above making communication with PWD not a useful tool to encourage medication adherence, Lindauer et al. (2017) advised against convincing PWD to take medication as this can prolong the tension and result in aggressive behaviour.

Hiding the tablets under the tongue and spitting them out as soon as the caregivers were not around or not looking is another challenge encountered during medication administration. This could be attributed to a decline in cognition, lack of insight, or fear of being harmed (poisoned). Kaasalainen et al. (2011) found similar results as the caregivers had to ensure that the tablets given to PWD were swallowed and not spat out.

Behavioural problems are the second challenge mentioned by the caregivers. It is already known that PWD present with behavioural problems as the condition progresses. During medication administration, the behavioural problems are triggered by the fear of being harmed by the caregivers and not wanting to take medication. This is consistent with the literature as previous studies show that aggression in PWD is a common challenge that caregivers experience (Schnelli et al., 2023). Aggression in PWD has been found to be a way in which these individuals express anxiety (Carrarini et al., 2021). However, Saina (2021) found that there are two causes of aggression in PWD, namely: physical, and emotional. The physical causes include pain and illnesses. Since communication is one of the areas that is affected in PWD as the condition progresses, the individual's ability to express that they are experiencing pain is impaired. In addition to pain and illnesses causing

aggression, some of the medications prescribed for PWD has been found to result in side effects such as fatigue, which further result in distress and eventually trigger aggression Saina (2021). The emotional causes of aggression in PWD include boredom and loneliness as the individuals may feel secluded or confined to their rooms. The confinement and seclusion leads to feelings of frustration and lashing out at the caregivers (Saina, 2021).

The environment has also been found to be a major cause of aggression. Environments that are too busy, noisy, too bright, dark, or with no activities to do trigger aggression. These factors trigger aggression as PWD, more particularly Lewy-body dementia, experience hallucinations, and delusions (Saina, 2021).

Identifying and knowing the triggers for aggressive behaviour in PWD is imperative as it can assist the caregivers in reducing the occurrences of aggressive behaviour (Holst & Skär, 2017). This was reported by one of the caregivers as she mentioned the importance of knowing what triggers aggression in PWD as it prepares her to act swiftly by keeping her distance from that particular resident for some time until the resident has calmed down.

Several studies (Janzen et al., 2013; Ostaszkiewicz et al., 2015; Zeller et al., 2011) identified person centred care as an approach that caregivers in care facilities can utilize to prevent and calm aggression in PWD. These studies highlight the importance of knowing the individual's history and personality as this can assist the caregivers with preventing and calming aggression and agitation. According to Holst and Skär (2017), recognizing the uniqueness of each individual and tailoring care and activities based on the needs of each individual has been one of the most effective strategies for lowering the occurrences of aggression and agitation in PWD. This approach is similar to the findings of the current study. The caregivers at the care facility employ techniques that are specific to each individual to ensure that medication is administered without triggering the residents. A few techniques were mentioned by the caregivers as there is no universal care strategy for PWD. Some of the techniques are stepping back, and modifying the original formulation of medication for residents who do not want to take medication or become aggressive during

medication administration. The caregivers know the residents and how they would react when they are offered medication, or their prescription changes, this allows them to be flexible and tailor how they administer medication based on the individual. The caregivers know who requires their medication to be modified and those who need to be given some time alone before they could be given medication again.

Various training needs emerged as the caregivers expressed their confidence and training needs regarding providing care to PWD. Some caregivers expressed that they still required further training in dementia, however, they did not mention any specific areas they required the training in. Some of the caregivers reported they require further training so that they could be updated with the latest research and practices relating to care provision to PWD. Learning how to exercise the residents and keep them fit was another training need mentioned by one of the caregivers at the care facility. This is an important training need that is highlighted in a study by Hirt et al. (2024), which found that caregivers or RNs, as primary carers of PWD, required training in physical exercise. The study also states that physical activities have been highlighted as an important factor that would promote and maintain independence in ADL in PWD.The last training need mentioned by one of the caregivers was learning how to protect themselves from the aggression of residents. Interestingly, this was required by a caregiver who has worked with PWD for fourteen years. However, the caregiver reported the need to be taught how to protect themselves as she sometimes finds herself with PWD who have a strong grip, making it difficult for her to keep a safe distance until the resident has calmed down. This training need is supported by a review that found training focusing on behavioural challenges in PWD to be beneficial as the caregivers were able to manage the patients better (Spector et al., 2016).

Other caregivers reported that they do not require further training and support. This was mostly seen in caregivers with work experience ranging between twelve to sixteen years and perhaps learnt more about the individuals and the coping skills over the years as caregivers.

Further support is also required by some of the caregivers in the form of support groups consisting of other caregivers of PWD for the purposes of sharing experiences and seeking advice. This is consistent with the findings of a study by Küçükgüçlü et al. (2018), which found that support groups provide a safe space for caregivers to share their challenges and emotions, thus decreasing their level of stress and improving their coping skills in the workplace and welfare. The need for support services for caregivers of PWD became more apparent after several studies found that caregivers of PWD were hardly coping and as a result were burdened and had poor quality of life (Küçükgüçlü et al., 2018). This is similar to the study findings as some of the caregivers expressed challenges pertaining to care provision to PWD and how talking to other caregivers would help with the emotional buildup from the challenges and also help them find coping skills.

The participants at the care facility appear to have found strategies that work with each of the PWD during medication administration. While others have learnt what to expect from dementia and how to address the challenges that come with the condition, other participants seem to use one strategy for all PWD. Further training needs were also expressed by some of the participants. The participants underwent training in dementia, however, they still require thorough training in this field as there are constantly new developments being made in dementia. Another training need that was mentioned was additional support in the form of counseling or debriefing sessions with other caregivers of PWD. The need for counseling or debriefing was due to the challenges the participants experience as they provide care to PWD. Only one participant requested training in physical exercise for PWD as well as to be taught how they can protect themselves as caregivers from PWD who are aggressive. Lastly, different perspectives were expressed regarding care provision to PWD. Some participants reported that they enjoyed providing care to PWD, others found it to be challenging but they embraced it, while a few found it quite challenging.

Chapter 5: Conclusion

This research has contributed to the existing literature on dementia care in the South African context. The caregivers responses have shed some light on the overall experience of medication administration to PWD. Various experiences emerged based on several factors, including the strategies used by the caregivers to administer medication; the barriers experienced during medication administration; and the preparedness and the training needs of the caregivers regarding care provision to PWD. Although RNs could not be recruited, it would have been great to get insight into how they perceive medication administration to PWD and whether these perceptions differ based on the qualification type. One mostly mentioned strategy used by the caregivers to administer medication was modifying the natural formulation of the medication. Other strategies included giving the residents some time to calm down, and having specific caregivers administer medication to specific residents. These strategies were specific to each individual as the caregivers knew the residents and what challenges they should expect when they administer medication. This demonstrated patient centrered care as care was tailored to suit the individual needs of the residents. All these strategies were used to ensure continuity of medication administration regardless of the challenges the residents presented with. The challenges mentioned by the caregivers included medication refusal which in some cases was attributed to fears of being poisoned and behavioural challenges, which were common among the residents. Additional support was required by some of the caregivers. Support in the form of further educational training in dementia was mentioned by some of the caregivers. The caregivers also expressed the need for a platform consisting of other caregivers for expressing their emotions, getting advice, and other challenges they may be experiencing regarding care provision to PWD.

The current study also found different perspectives towards caregiving to PWD and this was attributed to various factors. Most of the caregivers enjoyed looking after PWD. For some of the caregivers, this was due to innate qualities while other caregivers enjoyed providing care

to PWD as they already understood the condition and knew what to expect. Other caregivers found care provision to PWD challenging and embraced the challenge.

In addition to the findings answering the research question, the study also found additional results pertaining to medication administration. Ubuntu and knowledgeable emerged from the responses of the caregivers when the study sought the skills and knowledge required to provide care to PWD. The study findings also showed that qualification at the care facility determined the role played by staff regarding medication administration as the caregivers only fetched and administered medication that was already prepared for the residents by the RN. Lastly, the study sought the detailed process of medication administration. Although the study has provided insight into the experiences of caregivers regarding medication administration in PWD in one care facility, similar experiences of caregivers can be expected in other care facilities in the South African context.

5.2 Limitations

There were four limitations that were identified in the current study. The first limitation was not having RNs as part of participants in the current study as they could have shared their experiences from a perspective of a RN. This limits the study's ability to generalise the results across the different types of caregivers. The second limitation was lack of generalisability of the results to other care facilities within Johannesburg, and South Africa as data was collected at one research site. The experiences of RN and caregivers in other care facilities in South Africa may differ from those at the research site. The third limitation is the potential volunteer effect as there may be differences between the participants and the non-participants in terms of their perceptions which may affect the representativeness of the results obtained in the current study. The last limitation is the range of years of the participants. The work experience range of the recruited participants might not capture the spectrum of the experience of caregiving as most of the participants in the current study

have many years of working experience versus the other participants with limited work experience. This might limit depth of understanding the experiences of the caregivers.

5.3 Strenghths

There are three strengths in the current study. The first strength is the use of various data collection tools. This provided a rich data set that allowed for a thorough understanding of the caregivers experiences, and perceptions of medication administration. The second strength identified is that the current study addresses the gap in knowledge on the caregivers perceptions of medication administration to PWD, specifically in the South African context. The third strength is the study's transferability. The current study provided thick descriptions for applicability to other contexts.

5.4 Implications

Clinical Implications

Results obtained from the current study show that the caregivers at the care facility experienced challenges regarding medication administration to PWD. As a result, the caregivers resorted to modifying the formulations of medication to ensure that medication is administered. However, some caregivers have embraced the challenges that come with administrating medication. This calls for a training in safe admnisitration techniques and the implications of modying tablets as not all tablets can be modified (crushed) and capsules opened. Continuos education for care facility staff has been advocated for in previous studies (Eide & Schjøtt, 2001; Kolcu & Ergun, 2020; Lau et al., 2003) as it improves the competency of the staff and therefore facilitates safe medication administration (Garratt et al., 2024)

The results also show the need for further training as the caregivers require in depth information regarding dementia as there is new research and developments being done in this field. Similar results were found in a study by Prince et al. (2016) as they highlight the

importance of continuous education and further training for caregivers to provide more knowledge on dementia and improve the ongoing care.

Support in the form of a support group is also required as some of the caregivers reported being occasionally overwhelmed by some of the events between them and the residents. The need for meeting and engaging with other caregivers, particularly caregivers of PWD, was mentioned as expressing their emotions and seeking advice from those who have had similar experiences was necessary to avoid build up of mixed emotions. This is supported by studies that have shown that providing support, socially and emotionally, to caregivers of PWD mitigates burden on the caregivers and improves their wellbeing, and overall confidence (Kerpershoek et al. 2018; Cross et al., 2018). Therefore, support groups sessions may have a positive impact on the mental/emotional health of the caregivers.

Research Implications

There is paucity of research done in medication administration and how this process is affected in PWD as studies have focused on other areas or topics in dementia. This gap in literature is highlighted in a study by Alsaeed (2018). Results obtained from the current study will help close the gap in literature regarding understanding how cognitive decline and other changes that result from dementia affect medication administration in this population in the South African context. The results also show the techniques the caregivers have come to use through understanding the residents and learning what works for each individual.

Future research can focus on the emotional or mental wellbeing of the caregivers of PWD as they have to deal with the different manifestations of dementia such as mood swings, aggression, and cognitive decline. The results from the current study show that some caregivers require some form of support as they experience different emotions while taking care of PWD. Existing literature advocating for this type support for caregivers has already been discussed above in clinical implications.

Future research can also focus on investigating the specific training needs of the caregivers using the aspects identified in the current study. It is highlighted in a study by Rasmussen et al. (2023) that caregivers of PWD express feelings of inadequacy regarding providing specialised care and therefore require more education on dementia.

Lastly, future research can explore the differences in experiences of the different types of formal caregivers with diverse qualifications, and experiences regarding their roles and responsibilities.

Policy Implications

The current study shows the need for guidelines or Standard Operating Procedures (SOP) that will assist the caregivers in administrating medication safely. The importance of ensuring safe medication administration has been emphasised by Cotter et al. (2012). The guidelines can include the types of tablets or capsules that can be crushed or opened as not all medication can be altered and also include the implications of altering medication and other techniques that can be used to ensure continuity of medication administration.

5.5 Contributions of study

The results from the current study give insight into what transpires during medication administration on a daily basis. The current study also shows the various perceptions caregivers have towards administering medication to PWD. The findings of the current study narrows the existing gap in the literature, as most of the existing studies have focused on dementia and other areas related to this condition and not on care provision to PWD in care facilities.

References

Abdrabba, F., Salama, R., Fallah, G., Almahd, A., & Salem, S. (2021). Knowledge, Attitudes and Practices of Health Care Practitioners regarding Crushing or Splitting Oral Solid Dosage Forms in Benghazi Medical Centre, Libya. *Lebda Medical Journal*, *7*(1), 252-258.

Acharya, A. S., Prakash, A., Saxena, P., & Nigam, A. (2013). Sampling: Why and how of it. *Indian Journal of Medical Specialties*, *4*(2), 330-333.

Adedeji, I., Ogunniyi, A., Henderson,D. C., & Sam-Agudu, N. A. (2022). Experiences and pracices of caregiving for older persons living with dementia in African countries: A qualitative scoping review. Dementia, 14713012211065398.

Ahmad Zubaidi, Z. S., Ariffin, F., Oun, C. T. C., & Katiman, D. (2020). Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross sectional study. *BMC palliative care*, 19(1), 1-15.

Alexander, C. M., Martyr, A., Clare, L., & IDEAL Programme Research Team. (2022). Changes in awareness of condition in people with mild-to-moderate dementia: Longitudinal findings from the IDEAL cohort. *International Journal of Geriatric Psychiatry*, *37*(4).

Allan, G. (2020). Qualitative research. *In Handbook for research students in the social sciences* (pp. 177-189).

Almirall, J., Boixeda, R., de la Torre, M. C., & Torres, A. (2021). Aspiration pneumonia: A renewed perspective and practical approach. *Respiratory Medicine*, *185*, 106485.

Alsaeed, D. J. (2018). *Optimising medication use for people living with dementia and their caregivers* (Doctoral dissertation, UCL (University College London)).

Alsaeed, D., Orlu, M., & Smith, F. (2021). Optimising Medication Use Along Dementia Progression: Recommendations from a Qualitative Study. *In Healthcare* (Vol. 9, NO. 8, p. 982). Multidisciplinary Digital Publishing Institute.

Amiri, A., Guess, L., Gilder, R., Showalter, D., Hart, L., & Sattler, B. (2023). Using Fume Hood to Reduce Nurses' Exposure to Particulate Matters Dispersed Into the Air During Pill Crushing. *Workplace Health & Safety*, *71*(9), 412-418.

Arifin, S. R. M. (2018). Ethical considerations in qualitative study. *International journal of care scholars*, *1*(2), 30-33.

Arlt, S., Lindner, R., Rösler, A., & von Renteln-Kruse, W. (2008). Adherence to medication in patients with dementia: predictors and strategies for improvement. *Drugs & aging*, *25*, 1033-1047.

Arvanitakis, Z., & Bennett, D. A. (2019). What is dementia?. *Jama*, *322*(17), 1728-1728.

Austin, Z., & Sutton, J. (2014). Qualitative research: Getting started. *The Canadian journal of hospital pharmacy*, *67*(6), 436.

Basnet, H. (2018). Focus group discussion: A tool for qualitative inquiry. *Researcher: A Researcher Journal of Culture and Society,* 3(3), 81-88.

Benadé, P., Du Plessis, E., & Koen, M. P. (2017). Exploring resilience in nurses caring for older persons. *health sa gesondheid*, *22*, 138-149.

Bingham, A. J., & Witkowsky, P. (2022). Deductive and inductive approaches to qualitative data analysis. In C. Vanover, P. Mihas, & J. Saldana (Eds.), *Analyzing and interpreting qualitative data: After the interview* (pp.133-146). SAGE Publications.

Backhouse, T., Jeon, Y. H., Killett, A., & Mioshi, E. (2022). How do family carers and care-home staff manage refusals when assisting a person with advanced dementia with their personal care?. *Dementia*, *21*(8), 2458-2475.

Blanchard, M., Somme, D., Charras, K., & Corvol, A. (2022). Caregivers facing violence in long-term care setting: A cross analysis of incident reports and caregivers speech. *Journal of Nursing Management*, *30*(6), 1768-1776.

Bolton, R. E., Bokhour, B. G., Hogan, T. P., Luger, T. M., Ruben, M., & Fix, G. M. (2020). Integrating personalized care planning into primary care: a multiple-case study of early adopting patient-centered medical homes. *Journal of general internal medicine*, *35*, 428-436.

Brandburg, G. (2012). Nursing roles in health care and long-term care. *Encyclopedia of health & aging. SAGE, Thousand Oaks, CA*, 423-425.

Brown, A., & Danaher, P. A. (2019). CHE principles: Facilitating authentic and dialogical semi-structured interviews in educational research*. International Journal of Research & Method in Education,* 42(1), 76-90.

Brown, C. M., & Segal, R. (1996). The effects of health and treatment perceptions on the use of prescribed medication and home remedies among African American and white American hypertensives. *Social science & medicine*, *43*(6), 903-917.

Carayon, P., Wetterneck, T. B., Cartmill, R., Blosky, M. A., Brown, R., Kim, R., & Walker, J. (2014). Characterising the complexity of medication safety using a human factors approach: an observational study in two intensive care units. *BMJ quality & safety*, *23*(1), 56-65.

[Care centre]. (2023). Care facility description. Johannesburg.

Carrarini, C., Russo, M., Dono, F., Barbone, F., Rispoli, M. G., Ferri, L., & Bonanni, L. (2021). Agitation and dementia: prevention and treatment strategies in acute and chronic conditions. *Frontiers in neurology*, *12*, 644317.

Cheek, C., Austin, E., Richardson, L., Testa, L., Ransolin, N., Francis-Auton, E., ... & Clay-Williams, R. (2024). Non-Participant Observations in Experience-Based Codesign:

An example using a Case Study Research approach to explore Emergency Department Care. *International Journal of Qualitative Methods*, *23*, 16094069241289278.

Clark, N. M., & Dodge, J. A. (1999). Exploring self-efficacy as a predictor of disease management. *Health Education & Behavior*, *26*(1), 72-89.

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The psychologist,* 26(2).

Cohen-Mansfield, J., & Meschiany, G. (2022). Israeli nursing home staff perspectives on challenges to quality care for residents with dementia. *Geriatric Nursing*, *44*, 15-23.

Coleman, D. J., & Asiri, N. A. S. (2017). A person-centred communication approach to working with older people who have dementia. *British Journal of Healthcare Assistants*, *11*(11), 548-552.

Coslett, H. B. (2018). Apraxia, neglect, and agnosia. *Continuum: Lifelong Learning in Neurology*, *24*(3), 768-782.

Coons, S. J., Sheahan, S. L., Martin, S. S., Hendricks, J., Robbins, C. A., & Johnson, J. A. (1994). Predictors of medication noncompliance in a sample of older adults*. Clinical Therapeutics: The International Peer-Reviewed Journal of Drug Therapy.*

Cotter, M., Donlon, S., Roche, F., Byrne, H., & Fitzpatrick, F. (2012). Healthcare-associated infection in Irish long-term care facilities: results from the First National Prevalence Study. *Journal of Hospital Infection*, *80*(3), 212-216.

Coupe, P., Manjón, J. V., Lanuza, E., & Catheline, G. (2019). Lifespan changes of the human brain in Alzheimer's disease*. Scientific reports*, 9(1), 1-12.

Cramer, J. A., Roy, A., Burrell, A., Fairchild, C. J., Fuldeore, M. J., Ollendorf, D. A., & Wong, P. K. (2008). Medication compliance and persistence: terminology and definitions. *Value in health*, *11*(1), 44-47.

Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions.* Thousand Oaks, CA: Sage Publications.

Cresswell, J. W., & Plano, C. (2011). Designing and conducting mixed method research. *Thousand Oaks*, CA

Cross, A. J., Garip, G., & Sheffield, D. (2018). The psychosocial impact of caregiving in dementia and quality of life: a systematic review and meta-synthesis of qualitative research. *Psychology & health*, *33*(11), 1321-1342.

Cruz-Oliver, D. M., Reuda, A. P., Viera-Ortiz, L., Washington, K. T., & Oliver, D. P. (2020) The evidence supporting educational videos for patients and caregivers receiving hospice and palliative care: a systematic review. *Patient education and counselling*, 103(9), 1677-1691.

Daibes, M. A., Qedan, R. I., Al-Jabi, S. W., Koni, A. A., & Zyoud, S. E. H. (2023). Nurses' knowledge and practice regarding mixing medications with food: a multicenter cross-sectional study from a developing country. *Journal of Health, Population and Nutrition*, *42*(1), 52.

de Jager, C. A., Msembri,W., Pepper, K., & Combrinck, M. I. (2017). Dementia prevalence in a rural region of South Africa: a cross sectional community study. Journal of Alzheimer's Disease, 60(3), 1087-1096.

DeJonckheere, M., & Vaughn, L. M. (2019). Semistructured interviewing in primary care research: a balance of relationship and rigour. *Family medicine and community health*, 7(2).

de Munck, V. C., & Sobo, E. J. (1998). Participant observation. *H. Russell Bernard (Ed), Handbook of methords in cultural anthropology.*

Duong, S., Patel, T., & Chang, F. (2017). Dementia: What pharmacists need to know. *Canadian Pharmacists Journal/Revue des Pharmaciens du Canada,* 150(2), 118-129.

Eide, E., & Schjøtt, J. (2001). Assessing the effects of an intervention by a pharmacist on prescribing and administration of hypnotics in nursing homes. *Pharmacy World and Science*, *23*, 227-231.

Emmady, P. D., Schoo, C., & Tadi, P. (2020). Major neurocognitive disorder (dementia). In *StatPearls*. StatPearls Publishing.

Farner, J., & Hicks, C. I. (1976). The impact of drug distribution systems on nurses' time involvement in medication related activities in long term care facilities. *Drug Intelligence & Clinical Pharmacy*, **10**(8), 458–462.

Fincke, B. G., Miller, D. R., & Spiro, A. (1998). The interaction of patient perception of overmedication with drug compliance and side effects. *Journal of general internal medicine*, *13*(3), 182-185.

Fostinelli, S., De Amicis, R., Leone, A.,Guistizieri, V., Binetti, G., Bertoli, S., & Cappa, S. F. (2020). Eating behavior in aging and dementia: the need for a comprehensive assessment. *Frontiers in Nutrition,* 7, 604488.

Ganzetti, R., Logrippo, S., Sestili, M., Caraffa, A., Cespi, M., Pelliccioni, G., & Bonacucina, G. (2021). Tablet splitting in elderly patients with dementia: The case of quetiapine. *Pharmaceutics*, *13*(9), 1523.

Garratt, S., Dowling, A., & Manias, E. (2024). Medication administration in aged care facilities: A mixed-methods systematic review. *Journal of Advanced Nursing*.

GBD 2019 Dementia Forecastig Collaborators. (2022). Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *The Lancet Health.*

Gerritsen, D. L., van Beek, A. P. A., & Woods, R. T. (2019). Relationship of care staff attitudes with social well-being and challenging behaviour of nursing home residents with dementia: a cross sectional study. *Aging & mental health*, 23(11), 1517-1523.

Gillespie, R. J., Harrison, L., & Mullan, J. (2015). Medication management concerns of ethnic minority family caregivers of people living with dementia. *Dementia,* 14(1), 47-62.

Gillespie, R., Burns, P., Harrison, L., Baker, A. A., Win, K. T., Traynor, V., & Mullan, J. (2016). Medication management for people living with dementia: development and evaluation of a multilingual information resource for family caregivers of people living with dementia.

Gupta, K., & Mamidi, P. (2020). Dementia, delirium & neuropsychiatric conditions in Charaka indriya sthana. *Pharm Pharmacol Int J*, *8*(5), 297-310.

Halli-Tierney, A. D., Scarbrough, C., & Carroll, D. (2019). Polypharmacy: evaluating risks and deprescribing. *American family physician*, *100*(1), 32-38.

Hamrick, I., Nye, A. M., & Gardner, C. K. (2007). Nursing home medication administration cost minimization analysis. *Journal of the American Medical Directors Association*, **8**(3), 173–177.

Helgesen, A. K., Larsen, D. W., & Grøndahl, V. A. (2020). Quality of Care in Nursing Home as Experienced by Patients with Dementia. *Journal of Multidisciplinary Healthcare,* 13, 1947.

Hildreth, K. L., & Church, S. (2015). Evaluation and management of the elderly patient presenting with cognitive complaints. *Medical Clinics*, 99(2), 311-335.

Hirt, J., Vetsch, J., Weissenfels, I., & Heinrich, S. (2024). Nurse-led physical activity interventions for people with dementia in nursing homes: A systematic review on intervention characteristics and implementation facilitators/barriers. *International Journal of Nursing Studies*, 104756.

Holst, A., & Skär, L. (2017). Formal caregivers' experiences of aggressive behaviour in older people living with dementia in nursing homes: A systematic review. *International journal of older people nursing*, *12*(4), e12158.

Honorence, J. (2017). Understanding the role of triangulation in research. *Scholarly research journal for the interdisciplinary studies,* 4(31), 91-95.

Horne, R., & Weinman, J. (1999). Patients' beliefs about prescribed medicines and their role in adherence to treatment in chronic physical illness. *Journal of psychosomatic research*, *47*(6), 555-567.

Janz, N. K., & Becker, M. H. (1984). The health belief model: A decade later. *Health education quarterly*, *11*(1), 1-47.

Janzen, S., Zecevic, A. A., Kloseck, M., & Orange, J. B. (2013). Managing agitation using nonpharmacological interventions for seniors with dementia. *American Journal of Alzheimer's Disease & Other Dementias®*, *28*(5), 524-532.

Jennings, L. A., Palimaru, A., Corona, M. G., Cagigas, X. E., Ramirez, K. D., Zhao, T., & Reuben, D. B. (2017). Patient and caregiver goals for dementia care. *Quality of Life Research*, *26*(3), 685-693.

Jensen, L. X., Bearman, M., Boud, D., & Konradsen, F. (2022). Digital ethnography in higher education teaching and learning- a methodological review. *Higher Education,* 1-20.

Jung, D., Lee, K., De Gagne, J. C., Lee, M., Lee, H., Yoo, L., & Choi, E. (2021). Eating difficulties among older adults with dementia in long-term care facilities: a scoping review. *International journal of environmental research and public health*, 18(19), 10109.

Kaasalainen, S., Agarwal, G., Dolovich, L., Papaioannou, A., Brazil, K., & Akhtar-Danesh, N. (2010). Nurses' perceptions of and satisfaction with the medication administration

system in long-term-care homes. *Canadian Journal of Nursing Research*, **42**(4), 58–79.

Kaasalainen, S., Dolovich, L., Papaioannou, A., Holbrook, A., Lau, E., Ploeg, J., & Emily, A. (2011). The process of medication management for older adults with dementia. *Journal of Nursing and Healthcare of Chronic Illness*, *3*(4), 407-418.

Kalideen, L., Govender, P., & van Wyk, J. M. (2022). Standards and quality of care for older persons in long term care facilities: a scoping review. *BMC geriatrics*, *22*(1), 226.

Kalideen, L., van Wyk, J. M., & Govender, P. (2022). Perspectives of Nurses and Managers on the Standards and Quality of Care in eThekwini District's Long-Term Care Facilities, South Africa: A Qualitative study.

Kamberelis, G., & Dimitriadis, G. (2005). Focus groups: strategic articulations of pedagogy, politics, and inquiry.

Kang, Y., & Hur, Y. (2021). Nurses' Experience of Nursing Workload-Related Issues during Caring Patients with Dementia: A Qualitative Meta-Synthesis. *International Journal of Environmental Research and Public Health,* 18(19), 10448.

Kerpershoek, L., de Vugt, M., Wolfs, C., Woods, B., Jelley, H., Orrell, M., & Actifcare Consortium. (2018). Needs and quality of life of people with middle-stage dementia and their family carers from the European Actifcare study. When informal care alone may not suffice. *Aging & mental health*, *22*(7), 897-902.

Kiger, M. E., Varpio, L. (2020). Thematic analysis of qualitative data: AMEE Guide No. 131. *Medical teacher*, 42(8), 846-854.

Kim, J., & De Jesus, O. (2021). Medication routes of administration.

Kolcu, M., & Ergun, A. (2020). Effect of a nurse-led hypertension management program on quality of life, medication adherence and hypertension management in older adults: A

randomized controlled trial. *Geriatrics & gerontology international*, *20*(12), 1182-1189.

Kook, R., Harel-Shalev, A., & Yuval, F. (2019, January). Focus groups and the collective construction of meaning: Listening to minority women. In *Women's studies international forum* (Vol. 72, pp. 87-94). Pergamon.

Krein, L., Jeon, Y. H., Amberber, A. M., & Fethney, J. (2019). The assessment of language and communication in dementia: a synthesis of evidence. *The American Journal of Geriatric Psychiatry*, *27*(4), 363-377.

Ku, L. J. E., Liu, L. F., & Wen, M. J. (2013). Trends and determinants of informal and formal caregiving in the community for disabled elderly people in Taiwan. *Archives Gerontology and Geriatrics*, *56*(2), 370-376.

Küçükgüçlü, Ö., Söylemez, B. A., Yener, G., & Işık, A. T. (2018). The effects of support groups on dementia caregivers: A mixed method study. *Geriatric Nursing*, *39*(2), 151-156.

Kudale, K. M., & Kotte, M. R. (2024). Exploring Phenomenology in Literary Analysis: A Novel Theoretical Framework. *Literary Voice*, 1-9.

Kuppadakkath, S. C., Bhowmik, J., Olasoji, M., & Garvey, L. (2023). Nurses' perspectives on medication errors and prevention strategies in residential aged care facilities through a national survey. *International Journal of Older People Nursing*, *18*(6), e12567.

Lamotte, G., Shah, R. C., Lazarov, O., & Corcos, D. M. (2017). Exercise training for persons with Alzheimer's disease and caregivers: a review of dyadic exercise interventions. *Journal of motor behavior*, *49*(4), 365-377.

Lau, W. M., Chan, K., Yung, T. H., & Lee, A. S. (2003). Outreach pharmacy service in old age homes: a Hong Kong experience. *Journal of the Chinese Medical Association: JCMA*, *66*(6), 346-354.

Lewis, A., Gibbs, A., & Hope-Gill, B. (2012). Probable occupational pneumonitis caused by inhalation of crushed clozapine. *Occupational medicine*, *62*(5), 385-387.

Li, J., Song, Y. (2019). Formal and Informal Care. In: Gu, D., Dupre, M. (eds) Encyclopedia of Gerontology and Population Aging. Springer, Cham.

Lindauer, A., Sexson, K., & Harvath, T. A. (2017). Medication management for people with dementia. *AJN The American Journal of Nursing*, *117*(5), S17-S21.

Lim, R. H., & Sharmeen, T. (2018). Medicines management issues in dementia and coping strategies used by people living with dementia and family carers: a systematic review. *International Journal of Geriatric Psychiatry*, *33*(12), 1562-1581.

Liu, J., Meyer, K., Glassner, A., Gonzales, M., Bartlett Ellis, R. J., Park, H., ... & Wang, J. (2024). Thematic Analysis of Alzheimer's Medication Management Discussion in a Non-Moderated Online Forum. *Western Journal of Nursing Research*, *46*(4), 307-314.

Look, K. A., & Stone, J. A. (2018). Medication management activities performed by informal caregivers of older adults. *Research in Social and Administrative Pharmacy*, 14(5), 418-426.

Lowe, N. K. (2019). What is a pilot study? *Journal of Obstreric, Gynecologic, & Neonatal Nursing,* 48(2), 117-118.

Lloyd-Sherlock, P. (2019). Long-term care for older people in South Africa: The enduring legacies of apartheid and HIV/AIDS. *Journal of Social Policy*, *48*(1), 147-167.

Marczyk, G., DeMatteo, D., & Festinger, D. (2010). Essentials of research design and methodology (Vol. 2). John Wiley & Sons.

Maxwell, C. J., Stock, K., Seitz, D., & Herrmann, N. (2014). Persistence and adherence with dementia pharmacotherapy: relevance of patient, provider, and system factors. *The Canadian Journal of Psychiatry*, *59*(12), 624-631.

McCloskey, R., Donovan, C., Stewart, C., & Donovan, A. (2015). How registered nurses, licensed practical nurses and resident aides spend time in nursing homes: An observational study. *International Journal of Nursing Studies*, **52**(9), 1475–1483.

McDonald-Miszczak, L., Maki, S. A., & Gould, O. N. (2000). Self-reported mediation adherence psychosocial factors on medication adherence in cardiovascular disease. *Patient Education & Counseling*, *60*, 187-193.

McDonald-Miszczak, L., Maris, P., Fitzgibbon, T., & Ritchie, G. (2004). A pilot study examining older adults' beliefs related to medication adherence: the BERMA survey. *Journal of aging and health*, *16*(5), 591-614.

Mc Gillicuddy, A., Crean, A. M., Kelly, M., & Sahm, L. (2017). Oral medicine modification for older adults: a qualitative study of nurses. *BMJ open*, *7*(12), e018151.

McGrattan, M., Ryan, C., Barry, H. E., & Hughes, C. M. (2017). Interventions to improve medicines management for people with dementia: a systematic review. *Drugs & Aging*, *34*(12), 907-916.

Mncube, Z., & Kaulihowa, T. (2022). Financial Innovation and Income Inequality in Upper-Middle Income Countries. *African Journal of Development Studies*, *12*(3).

Moser, A., & Korstjens, I. (2018). Series: Practical guidance to qualitative research. Part 3: Sampling, data collection and analysis*. European journal of general practice*, 24(1), 9-18.

Murphy, J. L., Holmes, J., & Brooks, C. (2017). Nutrition and dementia care: developing an evidence-based model for nutritional care in nursing homes. *BMC geriatrics*, *17*(1), 1-14.

Nayak, S. K. (2021). Attitude towards Drug Compliance of Indoor and Follow-up Outdoor Psychiatric Patients.

Nixon, A., & Odoyo, C. O. (2020). Ethnography, Its Strengths, Weaknesses and Its Application in Information Technology and Communication as a Research Design.

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International journal of qualitative methods,* 16(1), 1609406917733847.

Nicholson, E. C., & Damons, A. (2022). Is medication administration in the elderly influenced by nurses' demographics in South Africa?. *Health SA Gesondheid*, *27*, 1750.

Noureldin, M., & Plake, K. S. (2017). Correlates of caregivers' involvement in the management of older adults' medications. *Research in Social and Administrative Pharmacy,* 13(4), 840-848.

Nursing Act, 2005 (Act 33 of 2005). Government Printers, Pretoria.

Nyumba, T., Wilspon, K., Derrick, C., & Mukherjee, N. (2018). The use of focus group discussion methodology: insights from two decades of application in conservation. *Methods in Ecology and evolution*, 9(1), 20-32.

Odberg, K. R., Hansen, B. S., & Wangensteen, S. (2019). Medication administration in nursing homes: A qualitative study of the nurse role. *Nursing open*, *6*(2), 384-392.

Oh, E., Moon, S., Chung, D., Choi, R., & Hong, G. R. S. (2024). The moderating effect of care time on care-related characteristics and caregiver burden: differences between formal and informal caregivers of dependent older adults. *Frontiers in public health*, *12*, 1354263.

Oosthuizen, M., & Ehlers, V. J. (2007). Factors that may influence South African nurses' decisions to emigrate. *Health SA Gesondheid*, *12*(2).

Ostaszkiewicz, J., Lakhan, P., O'Connell, B., & Hawkins, M. (2015). Ongoing challenges responding to behavioural and psychological symptoms of dementia. *International Nursing Review*, *62*(4), 506-516.

Opdenakker, R. (2006). Advantages and disadvantages of four interview techniques in qualitative research. In *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* (Vol. 7, No. 4).

Orsulic-Jeras, S., Whitlatch, C. J., Szabo, S. M., Shelton, E. G., & Johnson, J. (2019). The SHARE program for dementia: Implementation of an early-stage dyadic care-planning intervention. *Dementia,* 18(1).

Oswald, D., Sherratt, F., & Smith, S. (2014). Handling the Hawthorne effect: The challenges surrounding a participant observer. *Review of social studies*, *1*(1), 53-73.

Özsürekci, C., Ceylan, S., & Halil, M. G. (2022). Evaluation of Polypharmacy and Potentially Inappropriate Medication Use in Older Adults with Dementia Using the TIME Criteria. *European Journal of Geriatrics & Gerontology*, *4*(1).

Painter, V., Le Couteur, D. G., & Waite, L. M. (2017). Texture-modified food and fluids in dementia and residential aged care facilities. *Clinical interventions in aging*, *12*, 1193.

Palese, A., Bressan, V., Kasa, T., Meri, M., Hayter, M., & Watson, R. (2018). Interventions maintaining eating Independence in nursing home residents: a multicentre qualitative study. *BMC geriatrics*, 18(1), 1-10.

Paranji, S., Paranji, N., Wright, S., & Chandra, S. (2017). A nationwide study of the impact of dysphagia on hospital outcomes among patients with dementia. *American Journal of Alzheimer's Disease & Other Dementias®*, *32*(1), 5-11.

Payne, M., & Morley, J. E. (2018). Dysphagia, dementia and frailty. *The journal of nutrition, health & aging*, *22*(5), 562-565.

Perera, A. (2021). What is the Hawthorne effect. *Simply Psychology*.

Perrotta, G. (2020). Agnosia: definition, clinical contexts, neurobiological profiles and clinical treatments. *Archive of Gerontology and Geriatrics Research*, 5(1), 031-035.

Porter, B. (2019). *Understanding multiple medication use in people with dementia. A pharmacoepidemiology study of prevalence, intervention and associated harms (Doctoral dissertation, Univeristy of East Anglia).*

Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality, and costs now and in the future.

Qian, S., Yu, P., Hailey, D., Wang, N., & Bhattacherjee, A. (2018). Medication process in a residential aged care home: An observational study. *Journal of Nursing Management*, *26*(8), 1033-1043.

Rahman, M. S. (2017). The Advantages and Disadvantages of Using Qualitative and Quantitative Approaches and Methods in Language" Testing and Assessment" Research: A Literature Review. *Journal of Education and Learning*, *6*(1), 102-112.

Rasmussen, B. M., Andersen, P. T., Waldorff, F. B., & Berg-Beckhoff, G. (2023). Effectiveness of dementia education for professional care staff and factors influencing staff-related outcomes: An overview of systematic reviews. *International journal of nursing studies*, *142*, 104469.

Reardon, C., & George, G. (2014). An examination of the factors fueling migration amongst Community Service practitioners. *African Journal of Primary Health Care and Family Medicine*, *6*(1), 1-9.

Reitz, C. (2015). Genetic diagnosis and prognosis of Alzheimer's disease: challenges and opportunities. *Expert review of molecular diagnostics*, 15(3), 339-348.

Richardson, L., Morrissey, H., & Ball, P. (2020). Critical review of the determinants of medication adherence in patients with dementia.

Rönnefarth, M., Hanisch, N., Brandt, A. U., Mähler, A., Endres, M., Paul, F., & Doss, S. (2020). Dysphagia affecting quality of life in cerebellar ataxia A large survey. *The Cerebellum*, *19*(3), 437-445.

Rogers, S., Martin, G., & Rai, G. (2014). Medicines management support to older people: understanding the context of systems failure. *BMJ open*, *4*(7), e005302.

Rogus-Pulia, N., Malandraki, G. A., Johnson, S., & Robbins, J. (2015). Understanding dysphagia in dementia: The present and the future. *Current physical medicine and rehabilitation reports*, *3*(1), 86-97.

Saina, J. (2021). Triggers and management of aggression in dementia patients.

Saunders, B., Kitzinger, J., & Kitzinger, C. (2015). Anonymising interview data: Challenges and compromise in practice. *Qualitative research*, *15*(5), 616-632.

Schnelli, A., Karrer, M., Mayer, H., & Zeller, A. (2023). Aggressive behaviour of persons with dementia towards professional caregivers in the home care setting—A scoping review. *Journal of clinical nursing*, *32*(15-16), 4541-4558.

Schmid, E., Garrels, V., & Skåland, B. (2024). The continuum of rapport: Ethical tensions in qualitative interviews with vulnerable participants. *Qualitative Research*, *24*(5), 1253-1271.

Schulz, R., Eden, J., & National Academies of Sciences, Engineering, and Medicine. (2016). Family caregiving roles and impacts. In *Families caring for an aging America*. National Academies Press (US).

Seçil, Y., Arıcı, Ş., İncesu, T. K., Gürgör, N., Beckmann, Y., & Ertekin, C. (2016). Dysphagia in Alzheimer's disease. *Neurophysiologie Clinique/Clinical Neurophysiology*, *46*(3), 171-178.

Sefidani-Forough, A., Lau, E. T., Steadman, K. J., Kyle, G. J., Cichero, J. A., Serrano Santos, J. M., & Nissen, L. M. (2021). Factors that affect health-care workers'

practices of medication administration to aged care residents with swallowing difficulties: an Australia-wide survey study. *Australasian Journal on Ageing*, *40*(1), e79-e86.

Shariff, Z. B., Dahmash, D. T., Kirby, D. J., Missaghi, S., Rajabi-Siahboomi, A., & Maidment, I. D. (2020). Does the formulation of oral solid dosage forms affect acceptance and adherence in older patients? A mixed methods systematic review. *Journal of the American Medical Directors Association*, *21*(8), 1015-1023.

Sharkness, C. M., & Snow, D. A. (1992). The patient's view of hypertension and compliance. *American journal of preventive medicine*, 8(3), 141-146.

Sheehan, B. (2012). Assessment scales in dementia. *Therapeutic advances in neurological disorders*, 5(6), 349-358.

Siegel, K., Karus, D., & Schrimshaw, E. W. (2000). Racial differences in attitudes toward protease inhibitors among older HIV-infected men. *AIDS care*, *12*(4), 423-434.

Sim, J., & Waterfield, J. (2019). Focus group methodology: some ethical challenges. *Quality & quantity*, *53*(6), 3003-3022.

Sirris, S., Lindheim, T., & Askeland, H. (2022). Observation and Shadowing: Two Methods to Research Values and Values Work in Organisations and Leadership. In *Researching Values: Methodological Approaches for Understanding Values Work in Organisations and Leadership* (pp. 133-151). Cham: Springer International Publishing.

Smith, F., Francis, S. A., Gray, N., Denham, M., & Graffy, J. (2003). A multi-centre survey among informal carers who manage medication for older care recipients: problems experienced and development of services. *Health & social care in the community*, 11(2), 138-145.

Smythe, A., Jenkins, C., Harries, M., Atkins, S., Miller, J., Wright, J., & Oyebode, J. (2014). Evaluation of dementia training for staff in acute hospital settings. *Nursing Older People*, *26*(2).

Smythe, A., Jenkins, C., Galant-Miecznikowska, M., Bentham, P., & Oyebode, J. (2017). A qualitative study investigating training requirements of nurses working with people with dementia in nursing homes. *Nurse education today*, *50*, 119-123.

Solberg, H., Devik, S. A., Bell, H. T., Zeiss, D. H., & Olsen, R. M. (2021). Drug modification by nurses in Norwegian nursing homes: A cross-sectional study. *Geriatric Nursing*, *42*(2), 351-357.

Solberg, H., Devik, S. A., Bell, H. T., & Olsen, R. M. (2022). The art of making the right exception to the “rule”: Nurses' experiences with drug dispensing in nursing homes. *Geriatric Nursing*, *44*, 229-236.

Sorensen, L., Stokes, J. A., Purdie, D. M., Woodward, M., & Roberts, M. S. (2005). Medication management at home: medication-related risk factors associated with poor health outcomes*. Age and Ageing,* 34(6), 626-632.

Spector, A., Revolta, C., & Orrell, M. (2016). The impact of staff training on staff outcomes in dementia care: a systematic review. *International journal of geriatric psychiatry*, *31*(11), 1172-1187.

Stats sa. (2022). Mid-year population estimates. Retrieved from https:// statssa.gov.za/?page_id=1854&PPN=P0302&SCH=73305

Suzuki, H., Furuya, J., Hidaka, R., Miyajima, S., Matsubara, C., Ohwada, G., & Minakuchi, S. (2021). Patients with mild cognitive impairment diagnosed at dementia clinic display decreased maximum occlusal force: a cross-sectional study. *BMC Oral Health*, *21*(1), 1-9.

Swanlund, S. L., Sherck, K. A., Metcalfe, S. A., & Jesek-Hale, S. R. (2008). Keys to successful self-management of medications. *Nursing science quarterly*, 21(3), 238-246.

Szpryngel, C. (2023). The Social and Economic Impact of Dementia. *Available at SSRN 4881032*.

Tamanini, I., Castro, A. K. D., Pinheiro, P. R., & Pinheiro, M. C. D. (2009). Applied neuroimaging to the diagnosis of alzheimer's disease: a multicriteria model. In *World Summit on Knowledge Society* (pp. 532-541). Springer, Berlin, Heidelberg.

Temedda, M. N., Garnier-Crussard, A., Moutet, C., Mouchoux, C., & Dauphinot, V. (2025). Association between comorbidity indices and nursing home admission in patients with Alzheimer's disease: a longitudinal observational study using the MEMORA cohort. *BMC geriatrics*, *25*(1), 254.

Thabane, L., Ma, J., Chu, R., Cheng, J., Ismaila, A., Rios, L. P., & Goldsmith, C. H. (2010). A tutorial on pilot studies: the what, why and how. *BMC medical research methodology*, *10*, 1-10.

Tondelli, M., Galli, C., Vinceti, G., Fiondella, L., Salemme, S., Carbone, C., ... & Zamboni, G. (2021). Anosognosia in early-and late-onset dementia and its association with neuropsychiatric symptoms. *Frontiers in Psychiatry*, *12*, 658934.

Travis, S. S., Bernard, M. A., McAuley, W. J., Thornton, M., & Kole, T. (2003). Development of the family caregiver medication administration hassles scale. *The Gerontologist*, 43(3), 360-368.

Turner, A., Eccles, F. J., Elvish, R., Simpson, J., & Keady, J. (2017). The experience of caring for patients with dementia within a general hospital setting: a meta-synthesis of the qualitative literature. *Aging & mental health*, *21*(1), 66-76.

Urquhart, J. (1995). Patient compliance with prescribed drug regimens: overview of the past 30 years of research. Clinical Measurement in Drug Evaluation, Nimmo WS, Tucker GT, Ed., John Wiley & Sons, 213-227.

Van Biljon, L., & Roos, V. (2015). The nature of quality of life in residential care facilities: the case of white older South Africans. *Journal of Psychology in Africa*, *25*(3), 201-207.

Van der Poel, R., & Heyns, P. (2012). Algorithmic case prediction in relation to local clinician diagnosis in an indigenous South African population. In 27th International Conference of Alzheimer's Disease International (ADI). London, England.

Vogelsmeier, A., Scott-Cawiezell, J., & Zellmer, D. (2007). Barriers to safe medication administration in the nursing home–exploring staff perceptions and concerns about the medication use process. *Journal of Gerontological Nursing*, **33**(4), 5–12.

Volkmer, A., Bruns, C., Zimmerer, V., Varley, R., & Beeke, S. (2023). Giving voice to people with dementia and their carers: the impact of communication difficulties on everyday conversations. *International Journal of Qualitative Methods*, *22*, 16094069231171096.

Volicer, L., Seltzer, B., Rheaume, Y., Karner, J., Glennon, M., Riley, M. E., & Crino, P. (1989). Eating difficulties in patients with probable dementia of the Alzheimer type. *Topics in geriatrics*, *2*(4), 188-195.

Watson, K., & Hatcher, D. (2021). Factors influencing management of agitation in aged care facilities: A qualitative study of staff perceptions. *Journal of clinical nursing*, *30*(1-2), 136-144.

Winblad, B., Amouyel, P., Andrieu, S., Ballard, C., Brayne, C., Brodaty, H., & Zetterberg, H. (2016). Defeating Alzheimer's disease and other dementias: a priority for European science and society. *The Lancet Neurology*, *15*(5), 455-532.

World Health Organization. (2008). *International health regulations (2005)*. World Health Organization.

World Health Organization. (2019). Risk reduction of cognitive decline and dementia: WHO guidelines.

Xia, X., Jiang, Q., McDermott, J., & Han, J. D. J. (2018). Aging and Alzheimer's disease: comparison and associations from molecular to system level. *Aging cell*, *17*(5), e12802.

Yun, Y. J., Na, Y. J., & Han, S. H. (2019). Swallowing apraxia in a patient with recurrent ischemic strokes: A case report. *Medicine*, 98(39).

Zeller, A., Dassen, T., Kok, G., Needham, I., & Halfens, R. J. (2011). Nursing home caregivers' explanations for and coping strategies with residents' aggression: a qualitative study. *Journal of Clinical Nursing*, *20*(17-18), 2469-2478.

APPENDIX 1: ETHICS CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

R14/49 Miss Nompumelelo Mgidi

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M230334 MED23-03-018

NAME: (Principal Investigator)	Miss Nompumelelo Mgidi
DEPARTMENT:	School of Human and Community Development Sasonah Lodge Care Centre
PROJECT TITLE:	*Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia*
DATE CONSIDERED:	31/03/2023
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - Nicoleen.Potgieter@wits.ac.za
SUPERVISOR:	Miss Kelly-Ann Kater and Dr Jaishika Seedat
APPROVED BY:	Professor Paul Ruff, Chairperson, HREC (Medical)
DATE OF APPROVAL:	18/09/2023 **EXPIRY DATE:** 18/09/2028

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions.Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **March** and will therefore be due in the month of **March** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX 2: SITE INFORMATION LETTER

Date:

To whom it may concern,

Re: Permission to conduct research at the care facility.

My name is Nompumelelo Mgidi and I am doing a Masters of Arts in Speech Pathology at the University of the Witwatersrand. As part of the Masters degree, I am required to conduct research. I will be doing a research study looking at the experiences of registered nurses and caregivers, in care facilities, when giving the residents with dementia medication. The tittle of the study is **Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.** This study will be conducted under the supervision of Ms Kelly-Ann Kater and Associate Prof. Jaishika Seedat.

Conducting this study will help to better understand the process of medication administration, whether there are any challenges that arise during this process, and the strategies used by the registered nurses and the caregivers should there be challenges when administering medication. Furthermore, this study will look at the overall experience of registered nurses and the caregivers regarding providing care to people with dementia. Obtaining permission to conduct this study at this care facility is important as the results obtained from this study can be used to advocate for more support such as further training for the registered nurses and caregivers or support from speech therapists or any other required health care professional.

Why has your care facility been chosen as a study site?

The care facility was chosen for my study because it provides specialised care for people with dementia. Thus the registered nurses and the caregivers working at the facility have experience working with persons with dementia and they will be best placed to participate in the study and share their experiences. As noted, their specific experience during the medication routine at different times of the day, the strategies they may use when getting the

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residents with dementia to have their medication, the challenges they may experience and their overall level of confidence during the medication routine can be understood first-hand.

Will there be potential benefits or harm for the registered nurses and the caregivers who will be involved in the study?

No monetary benefits will be obtained by the registered nurses and caregivers for their participation in the study. The findings will contribute towards understanding how healthcare professionals such as speech therapists, dieticians, etc., may provide better support for persons with dementia to ensure that they take their medication safely. Furthermore, no harm will be done to the participants. The participants and their responses will be kept confidential, and no personal information that could potentially identify the participants will be revealed during the reporting and presentation of the results of the study. Also, the name of the research site will not be revealed in any of the reporting or publications. Lastly, participation in the study will be voluntary and the participants are free to withdraw from the study at any time if they feel uncomfortable without any consequences.

What will happen in the study?

After obtaining permission to conduct the study at your care facility, I will begin the process of recruiting participants by giving brief talks about my study for the registered nurses and caregivers during tea breaks then I will leave two boxes in the staff room: one box with information letters and consent forms while the other box will be for signed consent forms. I will also obtain consent from the residents with dementia or their next of kin for observing the medication administrating process. Having recruited participants, I will commence the study by firstly doing observations during medication time for three days. This will entail observing the participants giving out medication to the residents. Please note that more focus will be on the participants more than the residents. Following the observations will be semi-structured interviews whereby I will do one on one interviews with the participants at a place and time that is convenient for them. The participants can expect to spend at least 30-45 minutes doing the interview. Lastly, I will do focus groups whereby two to three group discussions will take place. The group discussions will focus on the different topics that will be covered by this research and will take place at a place and time that suits the participants. The expected time length for the group discussions is 30-60 minutes each.

Upon completion of this study, I will return to give feedback of the results.

Having stated the above, I therefore ask for permission in writing to conduct my study at your care centre.

Should you require any information, please feel free to contact me or my supervisors. If you have any concerns regarding how this study is being conducted, please feel free to contact the chairperson of the Human Research Ethics Committee (Medical), Professor Clement Penny, on 011 717 2301 or at Clement.Penny@wits.ac.za. I am looking forward to your response.

Yours sincerely,

Nompumelelo Mgidi

(MA Student)

Email Address:
1611508@students.wits.ac.za

Contact no.: 062 882 8554

Ms Kelly-Ann Kater

(Supervisor)

Email Address:

Kelly-ann.Kater@wits.ac.za

Contact no.: 011 717 4937

Associate Prof. Jaishika Seedat

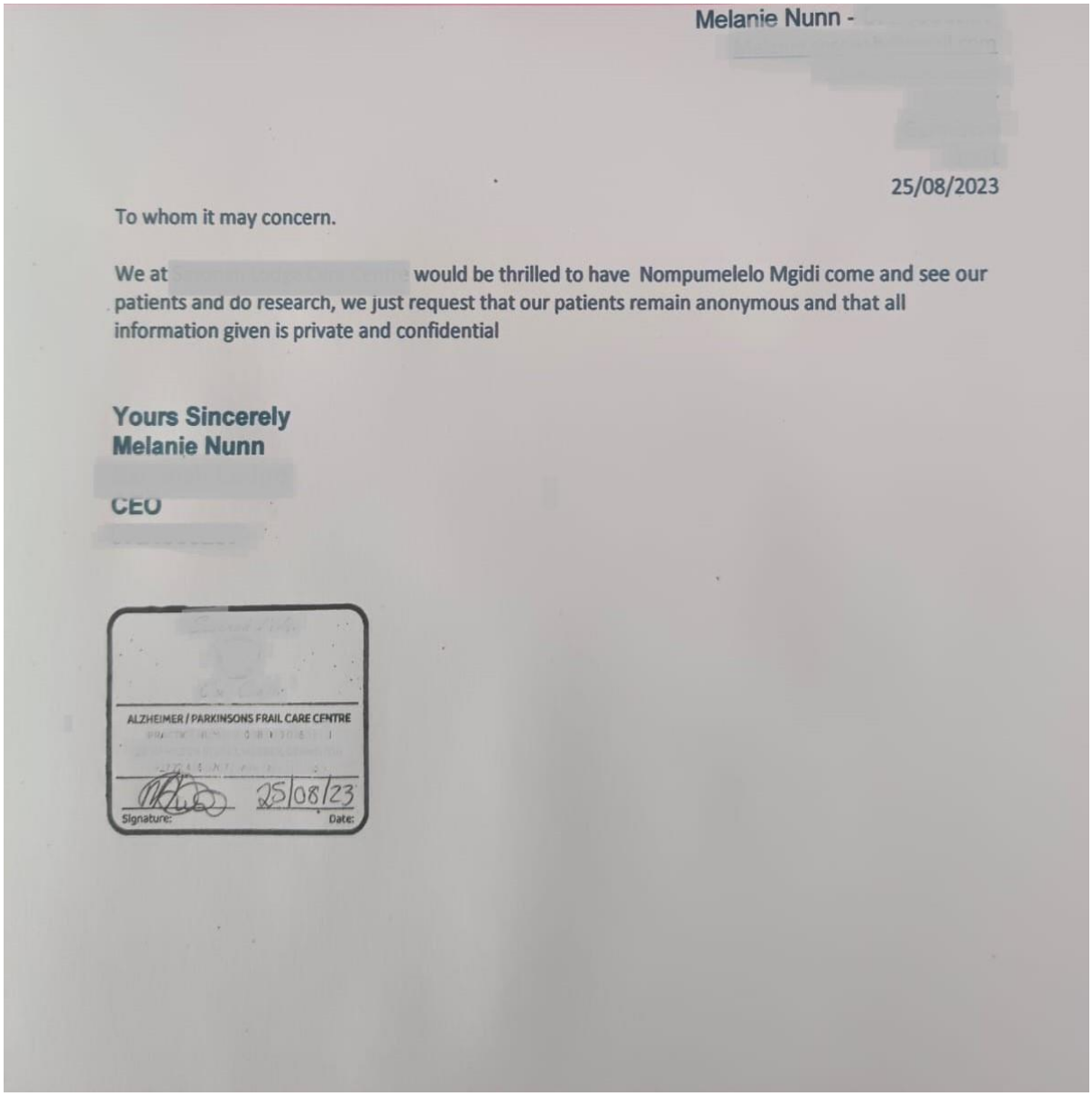
(Co-supervisor)

Email Address:

Jaishika.Seedat@wits.ac.za

Contact no.: 011 717 4576

APPENDIX 3: RESEARCH SITE CONSENT



Melanie Nunn -

25/08/2023

To whom it may concern.

We at would be thrilled to have Nompumelelo Mgidi come and see our patients and do research, we just request that our patients remain anonymous and that all information given is private and confidential

Yours Sincerely
Melanie Nunn

CEO

ALZHEIMER / PARKINSONS FRAIL CARE CENTRE

Signature: 25/08/23 Date:

APPENDIX 4: PARTICIPANT INFORMATION LETTER

Study Title: Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

Dear Potential Participant,

My name is Nompumelelo Mgidi and I am a Speech Therapist and Audiologist. I am currently doing my masters in speech pathology at the University of the Witwatersrand. I am inviting you to participate in my study whereby I will be looking at the registered nurses and caregivers experiences when giving the residents with dementia their medication. Conducting this study will help to better understand the process of medication administration, whether there are any challenges that arise during this process, and the strategies you use should there be challenges when administering medication. Furthermore, this study will look at your overall experience of providing care to people with dementia.

What will happen in the study?

Before you can participate in this study, you will be required to sign a consent form for observations, and semi-structured interviews. The study will be done in three parts:

1. Observations: this is the first part of the study where I will be observing you give medication to the residents with dementia. I will be observing from a distance, and you may not even know that I am around. The purpose of observations is to better understand the environment and get a clearer picture of what happens during medication time. The information obtained from observations will be used to supplement the information obtained in other parts of this study.
2. Semi-structured Interview: this will be the second part of this study whereby I will be conducting an interview with you alone and will be asking you questions. The interview will take place at a time that is convenient for you at the care facility. An audio recorder will be used to record all your responses to ensure that I do not forget any important response when I transcribe and analyse the data. You will be required to give consent for the semi-structured interviews to be audio recorded.
3. Focus group: this a group discussion that will be held after the semi-structured interviews are done. You can choose to participate in the interview and the focus

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group, or you can choose to participate only in the interview. In order to participate in the focus group, you need to have participated in the interview. For more information, please see the focus group information letter.

Participation in this study:

Participation is voluntary. This means you can withdraw any stage in the study process without any consequences.

Benefits for the participants:

You will not obtain any monetary benefits will be for your participation in the study. The findings will contribute towards understanding how other healthcare professionals such as speech therapists, dieticians, etc., may provide better support for persons with dementia to ensure that they take their medication safely.

Confidentiality and Anonymity:

The data gathered will only be accessed by myself and my research supervisors and it will be stored in a password protected computer. Any identifying personal information such as your name will not be included in the write up and presentation of the research.

Furthermore, the data collected will be retained at the University of the Witwatersrand for two years if it will be published and 6 years if it will not be published.

If you have any questions before or after the study, please feel free to contact me at 062 882 8554 or email me at 1611508@students.wits.ac.za or contact my supervisors on 011 717 4576/Jaishika.Seedat@wits.ac.za (Associate Prof. Jaishika Seedat) or 011 717 4937 /Kelly-ann.Kater@wits.ac.za (Ms Kelly-Ann Kater).

Yours sincerely,

Nompumelelo Mgidi

Speech Therapist and Audiologist

Master's Student

Ms Kelly-Ann Kater

(Supervisor)

.....

Associate Prof. Jaishika Seedat

(Co-supervisor)

.....

APPENDIX 5: PARTICIPANT INFORMATION LETTER FOR FOCUS GROUP

Study Title:

Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

Dear Potential Participant,

My name is Nompumelelo Mgidi and I am a Speech Therapist and Audiologist. I am currently doing my masters in speech pathology at the University of the Witwatersrand. I am inviting you to participate in my study whereby I will be looking at the registered nurses and caregivers experiences when giving the residents with dementia their medication. Conducting this study will help to better understand the process of medication administration, whether there are any challenges that arise during this process, and the strategies you use should there be challenges when administering medication. Furthermore, this study will look at your overall experience of providing care to people with dementia.

What will happen in this part of the study?

This is the last part of the study, called focus group. A focus group is a discussion that will involve other registered nurses and caregivers who are participating in this study. The discussion will be related to the different areas that I will be focusing on in this study and will take place a time that is chosen to be convenient by all the participants who will be in the focus group. For the purposes of data transcription and analysis, an audio recorder will be used to record the discussion. You will be required to sign the consent form for focus group before you can participate in this part of the study.

Participation in this study:

In order to particicpate in the focus group, you need to have participated in the interview. Participation in the focus group is voluntary. This means you can withdraw any stage in the study process without any consequences.

Benefits for the participants:

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You will not obtain any monetary benefits will be for your participation in this part of the study. The findings will contribute towards understanding how other healthcare professionals such as speech therapists, dieticians, etc., may provide better support for persons with dementia to ensure that they take their medication safely.

Confidentiality and Anonymity:

The data gathered will only be accessed by myself and my research supervisors and it will be stored in a password protected computer. Any identifying personal information such as your name will not be included in the write up and presentation of the research. Confidentiality cannot be guaranteed regarding the focus group as there will be other partcipants taking part in the discussion. However, you are requested not to share information that will be discussed in the focus group with other participants who will not participate in the group discussion.

Furthermore, the data collected will be retained at the University of the Witwatersrand for two years if it will be published and 6 years if it will not be published.

If you have any questions before or after the study, please feel free to contact me at 062 882 8554 or email me at 1611508@students.wits.ac.za or contact my supervisors on 011 717 4576/Jaishika.Seedat@wits.ac.za (Associate Prof Jaishika Seedat) or 011 717 4937 /Kelly-ann.Kater@wits.ac.za (Ms Kelly-Ann Kater).

Yours sincerely,

Nompumelelo Mgidi

Speech Therapist and Audiologist

Master's Student

.....

Ms Kelly-Ann Kater

(Supervisor)

.....

Dr Jaishika Seedat

(Co-supervisor)

.....

APPENDIX 6: OBSERVATION CONSENT FORM

Name of Department: Speech-Language Pathology and Audiology

Tittle of the study: Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

By signing below, I agree that I have read and understood the information letter and give consent to be observed. I confirm that I understand why I will be observed. I allow the researcher to take down notes of the aspects that will be observed. I understand that I will be kept anonymous in the writing of the results obtained from observations.

……..	……
Participant's signature	Date
…….	……..
Researcher's signature	Date

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APPENDIX 7: PARTICIPANT CONSENT FORM FOR INTERVIEW

Name of Department: Speech-Language Pathology and Audiology

Tittle of the study: Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

By signing below, I agree that I have read and understood the information letter and therefore give consent to participate in the interview.

1. I confirm that I understand the reason why I have been selected to be part of this study. The role of my participation has been explained to me.
2. I was given enough information regarding this study and everything was explained to me.
3. I understand that my participation in this study in voluntary, meaning I can withdraw from study anytime without any consequences.
4. I allow the researcher to take notes during the interview.
5. I was assured by the researcher that any information identifying me as an interviewee will not be revealed in the results of this study.

.....
Participant's signature

.....
Date

.....
Researcher's signature

.....
Date

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APPENDIX 8: PARTICIPANT CONSENT FORM FOR FOCUS GROUP

Name of Department: Speech-Language Pathology and Audiology

Tittle of the study: Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

By signing below, I agree that I have read and understood the information letter and therefore give consent to participate in the focus group.

1. I was given enough information regarding focus group and everything was explained to me.
2. I understand that my participation in this study in voluntary, meaning I can withdraw from study anytime without any consequences.
3. I allow the researcher to audio record the discussion in the focus group.
4. I allow the researcher to take notes during the focus group.
5. I will not disclose information discussed in the focus group to anyone outside the focus group.
6. I was assured by the researcher that any information identifying me will not be revealed in the results of this study.

Participant's signature

.....

Date

.....

Researcher's signature

.....

Date

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APPENDIX 9: AUDIO RECORDING CONSENT FORM

Name of Department: Speech-Language Pathology and Audiology

Tittle of the study: Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

As mentioned in the information letter, I will be audio recording your individual interview as well as the focus group (which you may be part of). The audio recording will allow the researcher to accurately transcribe the data collected. Your name or any other identifying information will not be associated with the audio recording or the transcription. The researcher and the supervisors will have access to the audio recordings.

Once the transcriptions have been verified for accuracy, the audio recordings will be deleted. The transcriptions of your interview and/or focus group discussion may be used for the write up of the results of this study, articles, or presentations. Your name or any other identifying information will not be used in the write up or presentations.

By signing this form, I am giving the researcher consent to audio record the interview and the focus group discussion.

.....

Participant's signature

.....

Date

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APPENDIX 10: INFORMATION LETTER FOR RESIDENT'S GUARDIAN

Date:

To whom it may concern,

Re: Permission to observe resident with dementia.

My name is Nompumelelo Mgidi and I am doing a Masters of Arts in Speech Pathology at the University of the Witwatersrand. As part of the Masters degree, I am required to conduct research. I will be doing a research study looking at the experiences of registered nurses and caregivers, in care facilities, when giving the residents with dementia medication. The tittle of the study is **Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.** This study will be conducted under the supervision of Ms Kelly-Ann Kater and Associate Prof Jaishika Seedat.

Conducting this study will help to better understand the process of medication administration, whether there are any challenges that arise during this process, and the strategies used by the registered nurses and the caregivers should there be challenges when administering medication. Furthermore, this study will look at the overall experience of registered nurses and the caregivers regarding providing care to residents with dementia. Obtaining permission to observe the residents being given medication is important as it will provide better understanding of what unfolds between the registered nurses, caregivers and the residents during medication administration. Although the residents with dementia will be observed, the focus will be on the registered nurses and caregivers.

What will happen in the study?

Before the residents with dementia can be observed during medication administration, their legal guardian will be required to sign a consent form.

I will be observing the registered nurse or caregiver giving the residents with dementia medication. I will be observing from a distance, and they may not even know that I am around. The purpose of observations is to better understand the environment and get a clearer picture of what happens during medication time. The information obtained from observations will be used to supplement the information that will be obtained in other parts of this study that the residents will not be part of.

Participation in this study:

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Participation is voluntary. This means the legal guardian of the resident with dementia can withdraw any time without any consequences.

Benefits for the participants:

The residents will not obtain any monetary benefits will be for their participation in the study. The findings will contribute towards understanding how other healthcare professionals such as speech therapists, dieticians, etc., may provide better support for the residents to ensure that they take their medication safely.

Confidentiality and Anonymity:

The data gathered will only be accessed by myself and my research supervisors and it will be stored in a password protected computer. Any identifying personal information such as the residents name will not be included in the write up and presentation of the research.

Furthermore, the data collected will be retained at the University of the Witwatersrand for two years if it will be published and 6 years if it will not be published.

If you have any questions before or after the study, please feel free to contact me at 062 882 8554 or email me at 1611508@students.wits.ac.za or contact my supervisors on 011 717 4576/Jaishika.Seedat@wits.ac.za (Associate Prof Jaishika Seedat) or 011 717 4937 /Kelly-ann.Kater@wits.ac.za (Ms Kelly-Ann Kater).

Yours sincerely,

Nompumelelo Mgidi

Speech Therapist and Audiologist

Master's Student

.....

Ms Kelly-Ann Kater

(Supervisor)

.....

Associate Prof. Jaishika Seedat

(Co-supervisor)

.....

APPENDIX 11: CONSENT FORM FOR RESIDENT WITH DEMENTIA

Name of Department: Speech-Language Pathology and Audiology

Tittle of the study: Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

By signing below, I agree that I have read and understood the information letter and therefore give consent for the resident with dementia at the care centre to be observed.

1. I confirm that I understand the reason why the resident with dementia has been selected to be observed.
2. I was given enough information regarding this study and everything was explained to me.
3. I understand that I can withdraw on having the registered nurse and caregiver being observed when with the resident with dementia at the care centre without any consequences.
4. I allow the researcher to take notes of the how the registered nurses and caregivers interact with the resident with dementia during the observations.
5. I was assured by the researcher that any information identifying the resident with dementia at the care centre will not be revealed in the results of this study.

Legal guardian's signature

.....

Date

.....

Researcher's signature

.....

Date

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APPENDIX 12: OBSERVATION SHEET

Study Title:

Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

Venue:

Date:

Time:

Researcher:

Aspects that will be observed:

1. Preparation of the medical administration process by the registered nurses and caregivers.
2. Medication formulations taken by PWD.
3. General behaviour of PWD during the administration process.
4. How medication is administered by the registered nurses and caregivers.
5. Registered nurses and caregivers response to challenges experienced during the medication administration process.

APPENDIX 13: SEMI-STRUCTURED INTERVIEW SCHEDULE

Study Title:

Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

Venue:

Date:

Time:

Researcher:

Participant's code:

1. Opening

- Welcoming the participant.
- Introduction of the researcher.
- Purpose of the interview.

2. Body

Areas to be discussed:

A. Demographic information:

- Gender
- Age
- Education: Type of qualification (RN or caregiver).
- Number of months/years working with PWD.

The demographic information will provide more data about the recruited participants and will also assist in determining whether the participants in this study are representing the

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sample of the targeted population. Information pertaining to the role played by the RN and caregivers medical administration process, and the behaviour of PWD will help with better understanding the events that occur from the time the medication is being prepared up to the end of the medication administration process.

B. Role played by the RN and the caregivers at the care facility:

- Do they fetch the medication, and dispense it to PWD?
- Do they only dispense the medication to PWD?
- Do they monitor for symptoms after giving medication?

C. Detailed process of medication administration.

D. Number of medical administrations in a day.

E. Behaviour of PWD when given medication:

- Any challenges arising.

F. RN and caregivers reactions to the behaviour of PWD when taking medication.

G. General perceptions of providing care to PWD.

H. Support or further training.

3. Closing

We have come to the end of the interview. Thank you for taking your time to be part of this study. If you want to ask questions or need clarity on anything regarding this study, you are more than welcome to ask.

THE END OF SEMI-STRUCTURED INTERVIEW

APPENDIX 14: FOCUS GROUP SCHEDULE

Study Title:

Medication time: The experiences of registered nurses and caregivers in a care facility for people with dementia.

Venue:

Date:

Time:

Researcher:

Participants' codes:

1. Opening

- Welcoming the participants.
- Introduction of the researcher.
- Purpose of the focus group.
- Ice breaker: Can everyone tell me something about themselves without revealing any personal information?

2. Body

Areas to be discussed:

- General perceptions of providing care to PWD.
- Role of healthcare professionals regarding medication.
- Challenges experienced by PWD during medication rounds.

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- Experience or skills required to provide care to PWD.
    - Skills required to provide care to PWD in care facilities.
- Support or further training.

3. Closing

We have come to the end of the focus group. Thank you for participating in this study again. Now that I have gathered the data that we discussed, I am to going to transcribe and analyse it. After compiling the research report I will come back to give feedback on what I have found and what the results mean. If there is anyone who would like to ask a question, they have the platform to ask.

THE END OF FOCUS GROUP