

Challenges experienced by nurses in delivering care to patients suffering from dementia

A systematic literature review

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Summary

Nurses play an important role in providing care to people with dementia. However, little attention is paid to the challenges nurses experience in their effort to provide care to people with dementia. This study seeks to explore challenges experienced by nurses in their effort to provide nursing care to people with dementia.

The study is done using qualitative literature review as a method with a deductive approach to analyze the data. Eight peer-reviewed articles were selected and analyzed. The study used Jean Watson's theory of human caring to understand the nurse's challenging experiences.

Presented in categories and sub-categories, the study establishes that nurses experience both mental, organizational and physical challenges which hinder their effort to provide care and improve on the nurse-patient relationship.

Language: English Key words: Dementia care, challenges to dementia nurses,
Nursing care, Nurses experiences/Barriers/ challenges, Difficulties in administering care

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1. Introduction

There is an interest in dementia in the health sciences and in healthcare. This is as a result of the steady increase in cases of dementia over time. The role of health care professionals has become indispensable in Medical care. And considering that ageing is an inevitable phenomenon, the interest in the nursing care of the aged and those with dementia only becomes natural. The risk of developing dementia increases with age, as does the risk of developing long term conditions such as arthritis, diabetes and cerebrovascular or respiratory problems (Akushevich, Kravchenko, Ukraintseva, Arbeev & Yashin, 2013). Nursing care is therefore very important and critical to managing patients with dementia. At any time, 25% of patients in hospital may have dementia and this group is at high risk of re-admission and death than other patients admitted with the same conditions (department of Health, 2013). Identification and care of people with dementia is therefore a crucial responsibility for nurses (Jenkins, C., Ginesi., & Keenan, 2017).

The proliferation of people suffering from dementia as a health condition is such that requires attention. Furthermore, the difficulty in handling dementia patients stems from the different ways the disease manifest which demands maximum patience and caring from nurses more than most health conditions. It is not possible for nurses to care appropriately for patients with dementia without the vital ingredients of empathy (Digby, Williams and Lee, 2016) This is very important as has been seen overtime that nurses caring for patient with dementia are at risk of getting frustrated. Frustration and emotional exhaustion are common among nurses. Furthermore, nurses' strain has been shown to negatively impact on the behavior of people with dementia (Edberg, Bird, Richards, Woods, Keeley and Davis-Quarrell, 2008).

The steady increase in the number of people suffering from dementia of any sort ranging from Alzheimer's disease or any other secondary sources places dementia as a major public health priority. The nature of this health condition and the very exacting challenges it poses on nurses and health care professionals saddled with caring for these patients forms the motivation of this thesis. This work explores the diverse challenges nurses experience in caring for dementia patients and unravels discussion and possible ways these challenges can be managed. This is as a result of the delicate nature and peculiarity of the ailment which comes with symptoms that presents real hurdle to nurses in their desire to administer quality care to patients suffering from dementia (Eriksson and Saveman, 2002).

2. Background

This chapter introduces dementia as a health condition, what it entails and its symptoms and how patients manifest them. It also contains notable researches on the different diseases that result in the experience of dementia and delves into the challenges it poses to the nurses caring for these dementia sufferers.

2.1 Dementia

The World Health Organization (WHO) defines dementia as “a syndrome due to disease of the brain – usually of chronic or progressive nature – in which there is disturbance of multiple higher cortical functions including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement” (WHO, 2012, p. 7). Dementia is also seen as a term used to describe a range of cognitive and behavioral symptoms that can include memory loss, problems with reasoning and communication and change in personality and a reduction in a person’s ability to carry out daily activities, such as shopping, washing dressing and cooking (NCE guidelines, 2018). Dementia UK further notes that dementia is an umbrella term for a range of progressive conditions which are all associated with an ongoing decline of brain functioning. This may include problems with memory loss, thinking speed, mental sharpness and quickness, language, understanding, judgement, mood movement, and difficulty in carrying out daily activities (Alladi , Mekala, Chadalawada, Jala, Mridula & Kaul, 2011).

There are several subtypes of dementia, but dementia is not a disease of its own, but a syndrome that have several causes (Alladi et al., 2011). It is the result of different diseases. It is a clinical syndrome – that is, a collection of symptoms and other features that exist together and form a recognized pattern (Sandilyan & Dening, 2015, p. 39).

The common forms of dementia are;

2.1.1. Alzheimer’s Disease

Alzheimer’s disease is the most common form of dementia and is responsible for about 75% of cases, either on its own or with other forms of pathology (in which cases we refer to mixed dementia). Alzheimer’s disease is thought to be caused by an abnormal build up of proteins in the brain (Alladi et al., 2011).

In the early stages of Alzheimer's disease, memory loss in relation to recent events and words finding difficulties are the most common features (Jellinger, 2013). As the disease progresses, greater memory loss and language difficulties become apparent. This causes difficulty in everyday activities such as shopping, handling money, and navigating routes. There may be other symptoms like anxiety and lack of motivation (Jellinger, 2013).

There are certain brain changes caused by Alzheimer's disease. There is abnormal disposition of insoluble 'plaques' of fibrous protein called amyloid and twisted fibres called neurofibrillary tangles in the brain (Jellinger, 2013). These abnormal plaques and tangles interfere with normal functioning of brain cells (Sandilyan & Dening, 2015).

1.1.2. Vascular Dementia

Vascular dementia the second most common type of dementia after Alzheimer's disease. It occurs when blood supply to the brain is compromised by Arterial disease, which results in reduced neuronal function and eventually the death of brain cells. (Sandilyan & Dening, 2015). Numerous vascular risk factors can contribute including hypertension, hyperlipidemia, diabetes, smoking, diet and obesity (Sandilyan & Dening, 2015).

Attacks (TIA's), which cause areas of cell damage in the brain. Vascular dementia may have many manifestations depending on the nature and local of the pathology (Román, 2003).

2.1.3 Dementia with Lewy Bodies

Dementia with lewy bodies is the third most common type of dementia accounting for around 10% of cases (Sandilyan & Dening, 2015). It is closely associated with Alzheimer's and Parkinson's diseases because it shares several characteristics with these conditions. Lewy bodies are small aggregations of a protein called alpha-syncline that occurs in cells in various areas of the brain including the cerebral cortex in dementia with lewy bodies (Jellinger, 2013).

The clinical features of lewy body dementia may include memory loss as seen in Alzheimer's disease. There is difficulty in maintaining alertness, disorientation to space and difficulty in planning (Sandilyan & Dening, 2015).

2.1.4 Fronto Temporal Dementia

Frontotemporal dementia is a relatively uncommon type of dementia and the term covers a range of conditions that affects regions in the front of the brain responsible for planning, emotion, motivation and language (Sandilyan & Denning, 2015). Clinical features include behavioral changes in about half of cases and the other half with problems in speech and language (primary progressive aphasia). Behavior changes might be quite profound and may affect the personality, for example lack of inhibitions, lack of empathy, the adoption of rigid routines because of lack of mental flexibility and difficulty in planning (Sandilyan & Denning, 2015).

2.1.5 Mixed Dementia

This refers to a condition where more than one type of dementia exists. The most common type is mixed Alzheimer's and vascular dementia, where there are clinical characteristics and brain changes common to both conditions. These become much more common with advanced age, beyond 80 years or so (Sandilyan & Denning, 2015).

Mixed dementia is often characterized by a gradual decline in abilities, as in Alzheimer's disease, but with additional mini-strokes or strokes contributing to the overall picture. Alternatively, the person has a history of vascular disease or vascular risk factors, for example is ischemic heart disease, hypertension, diabetes, raised lipid levels or smoking (Sandilyan & Denning, 2015).

2.2 Nursing Care

The nurses who care about people with dementia try to manage the suffering of their patients. Their experience could be understood as a desire to do the best for the people in their care by trying to alleviate their suffering and enhance their quality of life (Edberg, Bird, Richards, Woods, Keeley & Davis-Quarrell. 2008; 236). A few issues have been identified in residential care of people with dementia (Edberg, et al 2008; 236). There also seems to be a relationship between the wellbeing of staff and the quality of care they provide for example, Rodney (2000) found that resident aggression was significantly related to an increase in nurse stress, but also that perceiving the possibility of aggressive behavior was a source of stress. (Edberg, et al, 2008, 236). Studies have also shown that variables other than the person with dementia and the behavior itself can influence the experience of nursing staff. (Edberg, et al, 2008, 236).

Nursing care for people with dementia is very challenging. Dealing with different kinds of disorderly conduct has been described as the main cause of burnout among nursing staff with the field of geriatric care (Eriksson & Saveman, 2002, 79). For the encounter between nursing staffs and patients to be experienced as positive, the staff have to attain a balance between on the one hand, the expressed and unexpressed demands that are placed on them and on the other, their own competence (Eriksson & Saveman, 2002, 79). Disorderly conduct in patients suffering from dementia also gives rise to ethical conflicts which in turn give the nursing staff a feeling of powerless and meaninglessness which can lead to feelings of hatred towards the patients and themselves (Eriksson and Saveman, 2002, 79).

The nurses also described that they experienced several ethically difficult situations in the care of dementia patients' situations that caused frustration (Eriksson & Saveman, 2002, 81). They also observed that they had a feeling of powerlessness when observing a certain kind of fear of these patients, both among fellow patients and among nursing staff. (Eriksson and Saveman, 2002, 81). Some of the dementia patients used physical violence against the staff or accused them of stealing. (Eriksson & Saveman, 2002, 81). They observed that when these patients had outbursts of rage, they became extremely strong, which made it impossible for the nursing staff to approach them or to carry out an examination or a treatment. (Eriksson & Saveman, 2002, 81). They felt frustrated that the goal of co-operation between patient and caregiver could not be reached (Eriksson and Saveman, 2002, 81).

In nursing care, providing nutrition and hydration is important feeding is often seen as a basic caregiving activity (Bryon, Diercxx de casterle & Gastmans, 2011, 286). It is however, important that parallel education and training accompany any caring model (Rowlands & Rowlands, 2012, 36). Educating the Public and Healthcare professional, about dementia as an illness, palliative care as an approach and how they work together could combat the opinion that dementia is not a terminal illness and could raise awareness about the lack of services available (Rowlands and Rowlands, 2012, 36).

3. Aims and problem definition

The aim of this study is to identify challenges experienced by nurses in their effort to provide care and improve the quality of life of people with dementia.

The study seeks to answer the following questions:

1. What are the challenges that nurses experience in their effort to deliver quality care to patients with dementia?

4. Theoretical Framework

The theory used for this work is Jean Watson's Theory of Human Caring. This theory emphasizes on human caring and healing environment both of which can be provided by the nurse. Watson believes that caring encompasses a humanitarian, human science orientation to human caring process, phenomena and experiences (Watson, 2007).

Overview of Jean's Watson's Theory of Human Caring as a starting point for nursing as a field of study, offers a distinct disciplinary foundation for the profession. It provides an ethical, moral, values-guided meta narrative for its science and its human phenomena, its approach to caring – healing-person-nature-universe (Watson, 2008, 15). She adds that caring is the essence of nursing and effective caring promotes healing, health, individual/family growth and a sense of wholeness, forgiveness, evolved consciousness and inner peace that transcends the crises and fear of disease, diagnosis, illness, trauma, life changes and so on, (Watson, 2008, 15).

The broad concept of "caring" has long been associated with the nursing profession (Sitzman & Eichelberger, 2007, 8). Florence Nightingale described trained nurse caring behaviors as deliberate, holistic actions aimed at creating and maintaining an environment to support the natural process of healing (Sitzman & Eichelberger, 2007, 8). Watson goes on to assert that caring is the stable core of all nursing activities with specific time-space limited tasks and activities comprising the continually changing trim of the profession (Sitzman & Eichelberger, 2007, 8).

The theory of human caring proposes that professional nurses regardless of specialty area have awareness of the inter connectedness of all beings and share common intentional goal of attending to and supporting healing from both scientific and philosophical perspective (Sitzman & Eichelberger, 2007, 8). Jean Watson talks about some basic assumptions of caring science in her book *Nursing: The Philosophy and science of caring* and notes the following:

- Caring science is the essence of nursing and the foundational disciplinary core of the profession.

- Caring consists of curative factors/caritas processes that facilitate healing, honor wholeness, and contribute to the evolution of humanity.
- Effective caring promotes healing, health, individual/family growth and a sense of wholeness, forgiveness, evolved conciseness, and inner peace that transcends the crisis and fear of disease, diagnosis, illness, traumas, life changes and so on.
- Caring responses accept a person not only as he or she is now but as what he or she may become, is becoming.

The theory of Human Caring provides nurses with increased awareness and knowledge needed for compassionate and transpersonal caring relationships that are necessary in quality and of life care (Watson, 2007, 17).

Watson developed 10 clinical caritas processes to describe fully engaged nursing practice. These processes are based on intention and mindfulness in the moment and can be effectively applied in any specialty area during any nursing activity (Sitzman and Eichelberger, 2007, 9).

She also talked about transpersonal caring relationship which consists of connections that embrace the spirit or soul of the other through the process of full, authentic, caring/healing attention in the moment (Sitzman & Eichelberger, 2017, 9). The ten clinical caritas processes are:

- Practicing loving-kindness within the context of an intentional caring consciousness.
- Being fully present in the moment and acknowledging the deep belief system and subjective life world of self and other.
- Cultivating one's own spiritual practices with comprehension of interconnectedness that goes beyond the individual.
- Developing and sustaining helping-using, authentic caring relationships.
- Being present to and supportive of the expression of positive and negative feelings arising in self and others with the understanding that all of these feelings represent wholeness.
- Creatively using all ways of being, knowing, and caring as integral parts of the nursing process.

- Engaging in genuine teaching-learning experiences that arise from an understanding of interconnectedness.
- Creating and sustaining a healing environment at physical/readily observable levels and also at nonphysical, subtle energy, and consciousness levels, whereby wholeness, beauty, comfort, dignity, and peace are enabled.
- Administering human care essentials with an intentional caring consciousness meant to enable mind body spirit wholeness in all aspects of care, tending to spiritual evolution of both other and self.
- Opening and attending to spiritual mysterious and existential dimensions of existence pertaining to self and others.

These 10 caring caritas are based on the notion that all of life is interconnected. Each self/other exchange is made up of shared energy between all who are present during the interaction. The caring nurse recognizes the evolving physical/spiritual being in the other and also recognizes and nurtures the physical/spiritual being in the self, for it is not possible to provide authentic caring to another without first being able to care for self (Sitzman and Eichelberger, 2017).

5. Methodology

5.1 Systematic Literature Review

A literature review is an objective, thorough summary and critical analysis of the relevant available research and non-research literature on the topic being studied (Cronin, Ryan & Coughlan, 2008, 39). Its goal is to bring the reader up to date with current literature on a topic and form the basis for another goal, such as the justification for future research in the area (Cronin et al., 2008, 39). The types of literature review are traditional or narrative literature review which critiques and summarizes a body of literature and drawing conclusion about the topic in question (Cronin et al., 2008, 39).

A systematic literature review in contrast to any other traditional or narrative review uses a more rigorous and well-defined approach to review the literature in a specific subject area (Cronin et al., 2008, 39). Systematic reviews are used to answer well focused questions about clinical practice.

Praho (2006) suggests that a systematic review should detail the time frame within which the literature was selected, as well as the methods used to evaluate and synthesize findings of the studies in question (Cronin et al., 2014, 39).

Unlike traditional reviews, the purpose of a systematic review is to provide as complete a list as possible of all the published and unpublished studies relating to a particular subject area. While traditional reviews attempt to summarize results of a number of studies, systematic reviews use explicit and rigorous criteria to identify, critically evaluate, and synthesize all the literature on a particular topic. (Cronin et al., 2008, 39).

High quality review should have the following characteristics. It should be comprehensive, thorough and up to date. Secondly it should be clear. Finally, it should be consistent so that another reviewer can implement same rules and criteria and produce similar conclusions about the evidence (Polit & Beck, 2017). Under systematic literature review, we have meta-analysis and meta synthesis.

Meta – Synthesis is the non-statistical technique used to integrate, evaluate and interpret the findings of multiple qualitative research studies (Cronin et al., 2008, 39). Such studies may be combined to identify their common core elements and themes (Cronin, et al 2008, 39). Unlike meta-analysis where the ultimate intention is to reduce findings, meta synthesis involves analyzing and synthesizing key elements in each study with the aim of transforming individual findings into new centralizations and interpretations (Polit & Beck, 2006). This work adopts Meta – synthesis as it is basically a qualitative review.

5.2 Qualitative Content Analysis

Although qualitative content analysis is commonly used in nursing science research, the trustworthiness of its use has not yet been systematically evaluated (Elo, Kääriäinen, Kanste, Pölkki, Utriainen & Kyngäs, 2014, 2). A more focused discussion about the quality of qualitative content analysis findings is also needed (Elo et al., 2014, 2).

Qualitative content analysis is one of the several qualitative methods currently available for analyzing data and interpreting its meaning (Scheier, 2012). Quoting Downe-Wambolt, Elo notes that as a research method, it represents a systematic and objective means of describing and qualifying phenomena (Elo et al., 2014, 2). A prerequisite for successful content analysis is that data can be reduced to concepts that describe the research phenomenon (Elo et al., 2014, 2). In qualitative analysis, the abstraction process is the stage during which concepts are created. Usually some aspect of the process can be readily described, but it also partially

depends on the researcher's insight or intuitive action which may be very difficult to describe to others (Elo and kyngäs, 2008).

Content analysis is used in many studies in nursing and it has a long history. (Elo and kyngäs 2007, 107). Content analysis is a method of analyzing written, verbal or visual communication messages (Cole 1988). It was first used as a method of analyzing hymns, newspaper and magazine articles, advertisement and political speeches in the 19th century (Elo and kyngäs, 2008).

Content analysis as a research method is a systematic, and objective means of describing and quantifying phenomenon. It is also known as a method of analyzing documents (Elo & Kyngäs, 2007, 108). It allows the researcher to test theoretical issues to enhance understanding of the data (Elo and kyngäs, 2007, 108). Through content analysis, it is possible to describe words into fewer content related categories (Elo and Kyngäs, 2007).

Content analysis is a research method for making replicable and valid inferences from data to their context, with the purpose of providing knowledge, new insights, a representation of facts and a practical guide to action (Elo & Kyngas, 2007). The aim is to attain a condensed and broad description of the phenomenon and the outcome of the analysis is concepts or categories describing the phenomenon (Elo and kyngas, 2007, 108). It is a method that may be used with either qualitative or quantitative data. It may be used in an inductive or deductive way (Elo & kyngas, 2007, 109). Which of these is used is determined by the purpose of the study (Elo & kyngäs, 2007, 109, 18). If there is not enough former knowledge about the phenomenon or if this knowledge is fragmented, the inductive approach is recommended. On the other hand, deductive content analysis is used when the structure of analysis is operationalized on the basis of previous knowledge and the purpose of the study is theory testing (Elo & kyngäs, 2007, 109). An approach based on inductive data moves from the specific to the general, so that particular instances are observed and then combined into a larger whole or general statement (Elo & kyngas, 2007). A deductive approach is based on an earlier theory or model and therefore it moves from the general to the specific (Elo and kyngäs, 2007).

This study employs a deductive approach as it draws from previous research on the topic. It also makes use of the qualitative content analysis as methodology. Eight articles were read and analyzed deductively, and a structured matrix created where the contents were sorted and grouped into sub categories. This stage followed the principle of inductive approach where the data was analyzed, and the essence was extracted.

Applying the concept of qualitative content analysis as described by Elo and Kyngäs, 2007, the collected data was broken down into smaller categories which were named based on the content they presented. Texts with similar content were coded and sub-categorized using headings that mirror the contents of respective text e.g. "lack of required knowledge and low skills base" was coded as education and training....."Role burden and lack of professional development" was coded as self-worthiness and dignity. Lack of time was a general feature in most articles so did not need coding. Using a deductive approach, a structured matrix was constructed and contents of the analysis were sorted and grouped accordingly. A deductive approach allowed for usage of the most current data available and also to effect the aim of the study. The data analysis was done and categorized and only contents that match with the matrix were chosen and explained in sub-categories by abstraction process as described in inductive approach (Elo & Kyngäs, 2008, 110).

Table 1: Phase of content analysis study

| | |
|--------------------------|---|
| Preparation phase | Selecting unit of analysis and making sense of it |
| Organising phase | Coding, grouping, categorization and abstraction |
| Reporting phase | Reporting results and analysis process |

5.2.1 Data Collection

Data Collection is defined as the gathering of information to address a research problem. (Polit & Beck, 2012, 725). The respondent gathered data for this study using a systematic literature review. The data materials, with full text, were searched from Google Scholar, EBSCOhost and CINAHL databases. In using the qualitative method of research, this work consulted reliable scientific articles that are recent and updated. The articles used falls majorly within the ranges of 2013-2019. These articles are very relevant to the thesis topic and enhance the study in concise fashion. The articles used were limited to between 2013-2019, as priority is paid to the articles that meet the inclusion / exclusion criteria.

The key words searched were *Dementia care, challenges to dementia nurses, Nursing care, Nurses experiences/Barriers/ challenges, Difficulties in administering care.*

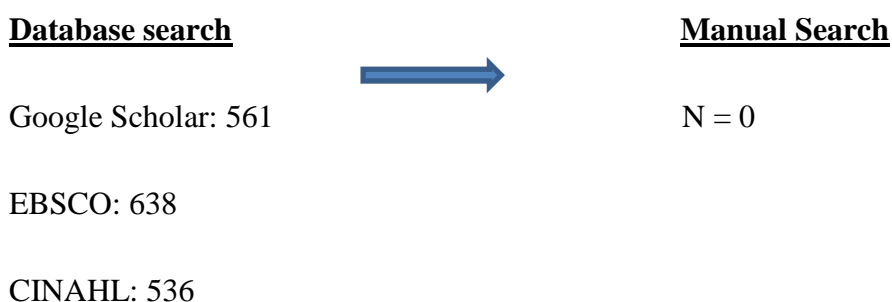
All keywords were based on dementia, nursing home/long-term care and care challenges using also synonyms. The search year was limited to 6 years aimed at getting access to the most current results with enough relevant data as expressed below in table 2.

Table 2: Results of literature search

| Keywords | Results: Google Scholar | Results: EBSCO Host | Results: CINAHL |
|---------------------------------------|------------------------------------|--------------------------------|----------------------------|
| Dementia care | 201 | 199 | 176 |
| Challenges to dementia nurses | 98 | 109 | 99 |
| Nursing care | 92 | 134 | 98 |
| Nurse experiences/barriers/challenges | 98 | 127 | 76 |
| Difficulties in administering care | 72 | 69 | 87 |
| TOTAL | 561 | 638 | 536 |

The selection process for the reviewed articles used for this work was entirely based on inclusion and exclusion criteria as illustrated in the table below. The major purpose of using this criterion in the article selection process is to highlight the relevance of the articles in relation to the topic of study and to answer the literature review questions.

5.2.2 Flow chart of selection process



**Duplicate articles removed**

Google Scholar: 241

EBSCO: 200 N = 635

CINAHL: 194

**Inclusion and Exclusion criteria considered (Year, peer-reviewed, language etc.)**

Google Scholar: 23

EBSCO: 12

CINAHL: 11

**Relevance of Title considered**

Google Scholar: 6

EBSCO: 3

CINAHL: 6

N = 15

**Relevance of Abstract considered****Excluded articles**

Google Scholar: 5

EBSCO: 3

CINAHL: 3

N = 11



Google Scholar: 1

EBSCO: 1

CINAHL: 1

N = 3



Relevance of full text considered

Google Scholar: 4

EBSCO: 2

CINAHL: 2

N = 8



Appraised Articles

Google Scholar: 4

EBSCO: 2

CINAHL: 2

5.2.3 Analysis matrix

Table 3: The analyzed results of the contents of the articles are grouped and explained in subcategories are presented below

| | Threats to continuity | Obstacles to effective care | Psychological wellbeing of nurses |
|--|-----------------------------------|-------------------------------|-----------------------------------|
| Challenges experienced by nurses when providing nursing care to people with dementia | Lack of resources / low workforce | Time pressure | Burnout / Strain |
| | End-of-life transitions | Communication / Understanding | Self-worth / Identity |
| | Care planning | Staff Training / Education | Role conflict |

5.2.4 Inclusion and Exclusion Criteria of the literature review

After data had been searched, relevance of the studies was assessed by reviewing the articles under inclusion and exclusion criteria. Articles that fell under the inclusion criteria were considered relevant to the study and these included articles with full text access, answered the research questions, were peer reviewed and are related to the study topic. Furthermore, articles published within 2013-2019, are scientifically based and uses English language were used. Articles that were not relevant to the study fell under the exclusion criteria and were excluded from the study as illustrated in table 4 below

Table 4. Inclusion and exclusion Criteria of the literature

| Inclusion Criteria | Exclusion Criteria |
|--------------------|--------------------|
| | |

| | |
|---|---|
| Articles with full text access | Care settings other than nursing home, long-term care or geriatric care setting |
| Articles that answer the research questions | Duplicate copies |
| Articles that are peer reviewed | Publications before 2013 |
| Articles that are related to the research topic | Literature not relevant to the research study |
| Articles published between 2013-2019 | Publications not available online as full text |
| Articles that are scientific-based | Publications that are not scientific or peer reviewed |
| Articles in English Language publication | Articles in other languages besides English language |

6. Findings

This chapter presents the results of the qualitative analysis. The categories are created and presented according to the research question “What are the challenges that nurses experience in their effort to deliver quality care to patients with dementia?”

6.1 Challenges experienced by Nurses when Providing Nursing Care to People with Dementia.

The health sector is saddled with an important responsibility of providing proper care for patients suffering from dementia. The numerous demands that characterizes care for dementia patients, is a result of the nature of the ailment, as it is one that demands extra patience and care because of the nature of dementia symptoms and the effects of the ailment on the patients. There are therefore very notable challenges when caring for people living with dementia. The categories are presented as **Threats to consistency**, **Obstacles to effective care** and **Mental wellbeing of nurses and caregivers**. The subcategories of Threats to consistency are **lack of resources / low workforce**, **palliative transitions** and

Plan of care . The subcategories of Obstacles to effective care are **pressure of time, communication / understanding** and **staff training / education**. The subcategories of psychological wellbeing of nurses are **burnout / strain, self-worthiness / identity** and **conflict of responsibility**

6.1.1 Threats to consistency

This chapter with its subsequent subcategories comes with some actual quotations lifted directly from articles that gives a clear view of caregiver's experiences when caring for people with dementia.

Lack of resources / Low workforce

Nurse 1: *"We work like robots.... we need more time with the residents"*. (Midtbust, Alnes, Gjengedal & Lykkeslet, 2018, p. 5).

Nurse 2: *"We are few, the resources are scarce, but we give priority to the residents who need it. This is at the expense of the others, who receive less attention. If someone demands that we be here all day, we are"*. (Midtbust et al., 2018, p.5).

The above quotes were made by nurses working with people with dementia in palliative care. Midtbust et al., 2018, had noticed that many long-term care facilities are characterized by a culture of business first with tough priorities. Nurses here noted the increasing ill-health conditions of the residents coupled with the dementia, which on its own, poses great care challenges and need increasing amount of assistance. They noted that the resources available to them to provide effective care does not increase as the resident's health problems and tasks increases (Midtbust et al., 2018). The nurses are required to be innovative and perform demanding tasks while adhering to the economic measures put in place.

These nurses complained of experiencing pressure and guilt over time towards the residents as they are always in a hurry and cannot provide adequate care to the patient as they must also fulfil other obligations as nurses (Midtbust et al., 2018).

One other major issue posing a challenge to caregivers in care for people with dementia is low workforce (Monthaisong, 2018, 4). With the statistics showing that there is a steady geometric increase in patients suffering from dementia, in addition to the fact that it is an ailment related with aging, the need for an increased workforce becomes very indispensable (Monthaisong, 2018, 4). A possible reason for reduced staffs is the fact that the nurses and

care givers are usually over stressed due to the aggressive and un-cooperative behavior of the patients. This could make nurses withdraw from such duty. And with the increased number of people with dementia every year, there is an even greater need for more care givers and nurses (Monthaisong, 2018, 4).

Palliative transition

Relocation of residents among different wards / care units is seen as an obstacle to providing effective care to people with dementia by a group of nurses who were part of a focus group of professionals who work with residents with dementia (Midtbust et al., 2018). They observed that most people with dementia are moved between nursing homes / units mostly due to a progression of the diseases or a loss of bodily functions and thus, require more extensive care. This movement means that the patient loses access to nurses who they are familiar with and possibly, their relatives over some periods. The challenge here is that a lot of important information is lost during transition meaning nurses and caregivers need to start learning from beginning about the patients who are very ill with dementia, are motion impaired and can no longer express their needs and wants (Midtbust et al., 2018).

Below are quotes from two nurses from the focus group.

Nurse 1: *“And I think a lot of information disappears when a resident moves from one ward to another”*.

Nurse 2: *“Yes, and we have to start all over again to build trust”*.

Nurses and caregivers observed that it can be stressful to relocate severely demented people across units where they are met with unfamiliar faces and this can be damaging to people with dementia (Midtbust et al., 2018).

Plan of Care

The continuous and extensive use of temporary nursing staff, mainly due to staff shortage, is considered an obstacle to care planning by nurses and healthcare professionals. This affects and threatens continuity of care offered by nurses to residents with dementia (Midtbust et al., 2018). Most temporary nurses and caregiving staff possess the necessary education and skills, but over time, their lack of knowledge and competence in understanding and translating the body language of each resident may interfere with facilitating an effective care planning for people with dementia (Midtbust et al. 2018).

Another challenge observed and emphasized upon was the knowledge of the local language as some temporary caregivers are foreigners and are still struggling with the local language (Midtbust et al., 2018). Below is a quote from a licensed nurse:

Nurse 1: *“As long as you have the right title, it is fine., but it can be very frustrating when the resident perhaps has lost parts of his language and has hearing loss as well, when the nurse caring for him is incapable of conveying the language...it is not easy...And people with dementia are suffering the most”*.

6.1.2 Obstacles to Effective Care

Pressure of Time

The role of a nurse caring for people with dementia is time pressured in nature and is widely believed to reflect directly on staff shortages, which in turn, impacts their ability to deliver appropriate and effective individual care to people with dementia (Talbot & brewer, 2015). The daily individualized care routine environment leaves nurses and caregivers with little time to actively spend with the residents (Talbot & brewer, 2015).

Communication / Understanding

One of the major challenges of caring for people with dementia is communication. It is even more challenging to access symptoms and concerns in people who are verbally compromised (Ellis-Smith, Higginson, Daveson, Henson & Evans, 2018, 2). Even the behavioral disturbances associated with dementia make it a herculean task for nurses and carers to get appropriate diagnosis and help patients. The aggressive behavior displayed by some patients impedes free flow of communication, as the care giver is grossly limited, owing to the fact that he or she deals with a patient who is mentally troubled. Baber and Murphy, 2011, notes that a systematic review carried out by Koch and Iliffe identified diagnostic uncertainty and disclosing the diagnosis as the main barriers in giving a diagnosis of dementia (Barber & Murphy, 2011, 587). Davies, Maio, Vedavanam, Manthorpe, Vernooij-Dassen & Iliffe, 2013, notes that people with dementia experience communication problems with professionals, particularly in the advanced stages of dementia, which often makes the receipt and provision of care difficult (Davies, Maio, Vedavanam, Manthorpe, Vernooij-Dassen & Iliffe. (2013, 386). Awareness of this communication deficit necessitates efforts to share decision-making with families and carers, but families also report being given little information about what is happening and likely to happen to their relatives. (Davies, et al., 2013).

Participants on a particular study also identified that a narrow understanding of dementia has also led to the quality of care offered as this lack of understanding has most often than not, led to uncertainties in the minds of the families of persons with dementia as they approach dementia care (Talbot & Brewer, 2015).

Education and Staff training

Another major challenge that faces nurses in helping dementia patients is limited education. There is need for more training and advanced education for professionals and care givers who take care of dementia patients. Previously, studies have argued that more education is needed for both professionals and the wider community to improve awareness of dementia, together with more training for professionals to improve the delivery of palliative care for dementia (Davies, et al., 2013, 392).

Care assistants occupy a pivotal role in the care of persons with dementia, yet despite the demanding nature of their role they receive little training and are often underappreciated, lack support and experience heavy workloads (Barbosa, Nolan, Sousa & Figueiredo, 2016, 222). Barbosa et al, notes that psycho-education of care assistants would be beneficial in equipping them for proper care giving. Psycho-educational (PE) interventions holds promise as a means of driving forward benefits for care assistants and care provision as they incorporate both illness-specific education and support to foster coping with concrete strategies for problem-solving and stress reduction (Barbosa, et al., 2016, 222). Putting more effort in training and educating carers, nurses and care givers, become very instrumental in helping them understand their shared struggles and equips them with the knowledge needed when further confronted with the challenges of patients with a chronic ailment. It helps them learn better how to combat these challenges when they come (Barbosa et al., 2016, 222).

It is also observed that there is a significant lack of training in the area of palliative care delivery. Rowlands and Rowlands quoting Sachs, notes that, it is therefore important that parallel education and training accompany any model of care (Rowlands & Rowlands, 2012, 36). Dementia care specialist services have a responsibility for educating and training generalist NHS staff to meet standards and needs (Kosteniuk, Morgan, O'Connell, Dal Bello-Haas and Stewart, 2016, 609). Therefore, in the light of the growing importance of home care services for individuals with dementia, the need for properly trained providers of dementia care is particularly apparent in rural communities (Kosteniuk et al., 2016, 609). Compared to home care providers with a lower level of dementia specific training, home

care providers with more dementia-specific training have a better understanding of the tools required to offer quality care and greater confidence in care delivery (Kosteniuk et al., 2016).

However, in the midst of all these, there is need for rural health givers to also engage in more training. This is because continuing education participation among rural home care staff is not supported to the same degree as among urban staffs because this requires a critical mass of patients to justify the development of new skills and releasing staff in short supply to develop these skills (Kosteniuk, et al, 2016, 609). There is also the need to provide more resources for continuing education of carers, nurses and caregivers. Knowledge is power, and more knowledge is needed in care giving especially considering the demanding nature of dementia as an ailment (Kosteniuk, et al., 2016, 609).

6.1.3 Mental wellbeing of nurses

Nurses Strain

Frustration and emotional exhaustion are common among nurses caring for people with dementia. Flawed organizational priorities can also be blamed for the frustration and workplace suffering generated by the gap between what nurses are able to do in terms of care and treatment and what they feel they should do (Digby & Lee, 2016, 54). Nurses may be distressed by the needs of the person with dementia while faced with organizational constraints which prevent them from delivering appropriate care (Digby & Lee, 2016).

Caring for people with dementia is demanding and becomes burdensome without the right things in place. One example is the needs to provide physical care and safety, which may be against the patient's will, another is the conflicts that arise because of difficulty communicating and, accordingly, difficulty in understanding the person's core needs. It was found that resident aggression was significantly related to an increase in nurse stress, but also that perceiving the possibility of aggressive behavior was a source of stress (Digby & Lee, 2016).

Nurse 1: *she kept saying to me. "I have to go home, I'm saying to her "you need to sit down, you've had a fall"*.

Burnout

The role of nurses as caregivers to people with dementia is particularly challenging and demanding, both physically and emotionally however, the caring and empathic nature of

these caregivers, which is manifested in the caregiver-patient relationship was the main motivation to remain in such physically and emotionally draining role (Talbot & Brewer, 2015). Caregivers tend to hide their emotional and physical fatigue when at work and this leads to an increased labour (emotional and physical) and the chance to suffer burnout and exhaustion and thus, has a direct impact on their health and ability to carry out their caring role (Talbot & Brewer, 2015).

Self-worthiness and identity

Nurses and care assistants tend to identify their roles as caregivers shaped by their relationship with the residents and this relationship is by far one of the main reasons why they stick to the job as caregivers (Talbot & Brewer, 2015).

Nurse 1: *“At the end of the day, as long as they are smiling then I am happy”*

Nurse 2: *“I like it for the residents. That`s the reason why I have stuck in the job this far”*

Conflict of responsibility

Combining other responsibilities and tasks like paperwork, was identified as a barrier to time spent with people with dementia in a nursing home (Talbot & Brewer, 2015). Paperwork, medication preparation amongst others is considered to consume a substantial amount of time that could be channeled towards care to the residents (Talbot & Brewer, 2015).

Nurse 1: *“I am too tired to be able to handle medication right now”*

Nurse 2: *“All they do, they come and go ”this paperwork needs doing”. Well, my job isn` t paperwork, i` m a nurse”.*

7. Discussion

This chapter focuses on the result discussion where key findings relating to the study will be reviewed and connected to the background and theoretical framework of this particular study.

7.1 Discussion of main results

The challenges experienced by nurses in their daily working life as caregivers to people with dementia were identified in three main categories and sub-categories. These sub-categories are supported by different points from the caritas processes as proposed by the human caring theory. The first challenge identified was consistency in care offered which was sub-categorized into low workforce / lack of resources, palliative transition and care planning. Understaffing and being made to work with minimal resources can be challenging, exhaustive and reduce the moral of nurses as caregivers to people with dementia. The increasing demand to work under restricted economic resources prevents nurses from offering effecting palliative care to people with dementia. Also, a lot of patient information can be easily lost during patient transfer which subsequently affects care planning. These are supported by caritas processes 1, 2,5,9 and 10.

The second category deals with obstacles to effective care which was sub-categorized into pressure of time, understanding and communication as well as education and training. With limited resources, increased workload and the employment of temporary care personnel who barely know the conditions of the residents with dementia, there could be an increase in frustration on nurses which in turn affects the quality of care offered. Extra time is spent by the nurses training the temporary staff instead of using it to learn new skills themselves. Temporary nursing personnel may have the nursing education but lack dementia-specific education and such lack of dementia knowledge and skills easily leads to frustration when providing care to people with dementia. Routine tasks like documentation limits the companionship that should be expected from a nurse to persons with dementia. These are supported by caritas processes 4,6,7 and 9.

The third and final category of challenge has to do with the mental wellbeing of the nurses. This also was sub-categorized into strain, burnout and self-worthiness / identity. Strain and burnout are direct negative impacts from understaffing and extra workload. Resistance to care and aggression are direct symptom of dementia, which itself is challenging. This becomes even more challenging when nurses as caregivers to people with dementia tend to endure such resistance and in the effort to do this, are worn out and stressed. These are supported by caritas processes 3,4,5 and 9.

This study used Watson's theory of human caring to illustrate the challenging experiences of nurses as they provide care to people with dementia. The theory explains that human caring is connected with skills, knowledge, values, empathy and relational interaction. Due to working under demanding conditions and emotions, nurses experience many challenges

due to the possibility of having limited education on dementia care. Most nurses agreed that nurses working with people with dementia need specialist education and skills. Due to this absence of dementia specific education and skills, as well as limited communication, this study identifies the challenges prevalent and experienced by nurses in providing care to people with dementia. The need for emotional and organizational backing especially visible in nurses caring for people with dementia.

7.2 Limitations

There are significant limitations to this study. The first being limited availability of free to access articles as many articles that could have been very useful to the study were inaccessible. Second limitation registered nurses, nurses or carers by different articles, thus making it difficult to focus the challenges to just nurses as different countries use different terms. The third limitation is that not all appraised articles were qualitative as few were actually mixed methods. The final limitation is that the study is focused nursing home and long-term care settings as other care settings could pose different challenges to nurses. Nonetheless, despite these limitations, this study is crucial in amplifying the scope of know-how from already existing facts in dementia care and it's challenges to nurses.

7.3 Ethical considerations

This work maintains originality as every information gotten from other sources were duly referenced. The work adhered to the ethical principles of research and as much as possible avoided plagiarism, fabrication and falsification. The Finish Advisory Board in research integrity ethical guidelines was used and this includes four sub-categories –fabrication, falsification, Plagiarism and misappropriation (Finnish Advisory Board and Research Integrity, 2012, 32-33).

Fabrication entail that the respondent did not develop his own words in order to support his study on allow untold experiences to be presented.

Falsification simply means that the respondent did not change or present another author's work. The respondent abides with presentation of another author's work with honesty by not fabricating or misinterpreting their findings to suit thesis.

Plagiarism refers to copying another person's work without acknowledging the original author.

Misappropriation refers to illegal adoption of all methodology from another study into his or her work without appropriate consent from approved sources (Finish Advisory Board and Research Integrity, 2012, 32-33).

8. Conclusion and Own reflections

The steady increase in patients suffering from dementia is a clear indication that the health sector is in need of the necessary knowhow and caregivers with the right disposition in combating the accompanying challenges facing nurses in caring for those suffering from this ailment. The need for true patience borne out of a sincere care and love (*caritas*) for patients as well as empathy for those suffering from dementia becomes very vital in health care. Therefore, the major challenges experienced by nurses as caregivers become a major hindrance to providing the best environment and health care for these patients. This paper therefore engages in these challenges with the aim of enhancing knowledge in this area towards providing viable solutions to these present challenges facing nurses as caregivers in their care for people with dementia.

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Appendices

Appendix 1.

| Author, Year & Title | Aim | Methods | Results |
|--|--|----------------------|--|
| Kosteniuk et al., 2016, Focus on dementia care: Continuing education (CE) preferences, challenges and catalysts among rural home care providers. | To determine whether the professional role of home care staff in a predominantly rural region was To determine whether the professional role of home care staff in a predominantly rural region was associated with preferences for delivering formats dementia specific continuing education (CE) programs and challenges, and catalysts to | A qualitative study. | Nurses recognize the value of CE but their participation in it is constrained by low staff levels, heavy workload, and insufficient work/personal. |

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| | attending CE on any topic. | | |
| Monthaisong. J, 2018, Nurses experiences providing care for people with dementia | Seeks to review experiences of registered nurses providing care for people with dementia | Integrative literature review of 19 articles | Nurses experienced struggling with painful emotions and working under difficult circumstances and there was the need for meeting spiritual needs of patients. Nurses identified that lack of knowledge of dementia and the need for improved effective communication when they provided care for a group of these patients and their families |
| Digby et al., 2016, Nurse Empathy and care of people with dementia, | To find out the relationship and relevance of nurse's empathy and care of people with dementia. | A qualitative and explorative study | Empathy is recognized as an essential element of being a nurse and is greatly needed when caring for people with dementia but the barriers to express this is multi-factoral. Nurses require |

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|--|---|--|--|
| | | | organizational backing to express empathy as people with dementia already pose challenging problems. |
| Davies et al., 2014, Barriers to the provision of high-quality palliative care for people with dementia in England. | To explore perceived barriers to the delivery of high-quality palliative care for people with dementia using semi-structured interviews | A qualitative study | Four major themes are identified describing the barriers to high-quality palliative care for people with dementia. Ambivalence towards the systemization of palliative care. Disconnection between services, Different assumptions about training needs and negotiation of risks |
| Ellis-Smith et al., 2018, How can a measure improve assessment and management of symptoms and concerns for people with dementia in care homes? | To explore perceived barriers to the delivery of high-quality palliative care for people with dementia using semi-structured interviews | Qualitative study with quantitative components | Key mechanisms of action are: improved observation and awareness of residents collaborative assessment, comprehensive systematic record |

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|--|---|--|--|
| | To understand the mechanisms of action of a measure to support comprehensive assessment of people with dementia in care homes; and its acceptability, feasibility and implementation requirements | | keeping, improved review and monitoring, care planning and changes to care provision, and facilitated multi-agency communication. |
| Barbosa et al., 2017, Implementing a psycho-educational intervention for care assistants working with people with dementia in aged-care facilities: facilitators and barriers. | To explore the facilitators and barriers to the implementation of a psycho-educational (PE) intervention for care assistants working with people with dementia in aged-care facilities | Mixed qualitative and semi-structured quantitative study | Divided into three levels, both care assistants and nurse managers considered the intervention useful, interesting and relevant. They are agreed on high job satisfaction levels that could be gained from PE intervention. They however, stressed on lack of time and heavy workload as a constraint. |
| Midtbust et al., 2018. Perceived barriers and | To examine care assistant experiences of | Qualitative descriptive study | Healthcare professionals experience a lack of |

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|---|---|-----------------------------------|---|
| <p>facilitators in providing palliative care for people with severe dementia: the healthcare professionals' experiences.</p> | <p>dementia care in British long-term residential and nursing environments</p> | | <p>continuity as the main barrier to facilitating palliative care. Time pressure and increased efficiency requirements especially affect the weakest and bedridden residents with dementia.</p> |
| <p>Talbot, R., & Brewer, G. 2016. Care assistant experiences of dementia care in long-term nursing and residential care environments. Dementia.</p> | <p>To examine care assistant experiences of dementia care in British long-term residential and nursing environments</p> | <p>Semi-structured interviews</p> | <p>The study revealed important deficiencies in understanding and varying levels of dementia training.</p> |