

**NURSE ROLE IN SUPPORTING FAMILY CAREGIVERS WITH ALZHEIMER
PATIENTS: A LITERATURE REVIEW**

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<p>Abstract:</p> <p>This thesis studies entails the roles that nurses play in supporting family caregivers of patients with Alzheimer’s disease. The aim was to investigate the role nurses play in supporting family caregivers of patients with Alzheimer’s disease. The research questions were as follows: 1) What are the nurses’ roles in supporting family caregivers of patients with Alzheimer’s disease? 2) What are the challenges nurses face in supporting family caregivers of patients with Alzheimer disease? 3) How can the challenges nurses face in supporting family caregivers of patients with Alzheimer’s disease be mitigated? The method used was a Qualitative integrative content analysis. Data was collected from 14 articles from different academic database to answer the research questions. The result shows that as much as family caregivers of patients with Alzheimer’s disease face challenges, there is significant support offered to them as well as mitigation measures towards those challenges. The study reviewed that nurses are provided with current and relevant material concerning best practices in supporting family caregivers of patients with Alzheimer’s disease such as the intervention strategies including assessment, training, coordination, and information dissemination. These ultimately translate into better understanding of family caregivers’ roles and responsibilities towards those suffering from Alzheimer’s disease. About challenges that nurses face in supporting family caregivers, the study revealed that these challenges can be mitigated through patient-centered comprehensive care from physical, psychological, and social aspects. The study suggests that nurses should follow holistic healthcare intervention that includes developing joint strategies with families who are likely to feel less prepared for their caregiving role at different points in the caregiving. Strengths of this study included the identification of a large volume of relevant publications on the research topic. Since this was a systematic and procedural approach of literature review, there is a possibility that some important articles have been overlooked.</p>	
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ACRONYMS

AD	Alzheimer's Disease
AMED	Allied and Complementary Medicine
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DOH	Department of Health
NI	Narrative Inquiry
RN	Registered Nurse
TENK	Finland Advisory Board & Research Institute
US	United States
WHO	World Health Organization

1. INTRODUCTION

Alzheimer's disease (AD) occurs when the brain cells responsible for memory and other functions start to die. The Alzheimer's disease is the most common and well-known form of dementia affecting the increasingly elderly population, including families of those afflicted. Characterized by behavioral, psychological, and cognitive degeneration, including memory loss, the disease affects the lives of patients and their families. According to Ballard, Gauthier, Gorbett, Brayne, Aarsland, and Jones, (2011), an estimated 24 million people worldwide have dementia, the majority of whom are thought to have Alzheimer's disease. Thus, Alzheimer's disease represents a major public health concern and has been identified as a research priority.

In 2016, nearly 9,200 Finns died of dementia and Alzheimer's disease, which is almost 600 persons more than in 2015. The number of deaths from dementia has more than doubled over the past ten years (OFA, 2016). People with Alzheimer's disease and related dementias are usually cared for by family members or friends. According to Brodaty and Donkin, (2009), the majority (80%) of people with Alzheimer's disease and related dementias are receiving care in their homes. More than four in ten (43%) caregivers of people with Alzheimer's and related dementias provide care for one to four years, and more than three in ten (32%) are caregivers for five years or more. For other types of chronic conditions that require care, more than three in ten (33%) caregivers provide care for one to four years, and almost three in ten (28%) are caregivers for five years. The involvement of nurses is crucial to the marginal improvements in healthcare initiatives (Brook, 2014b) hence, this thesis shall be vital in the nursing profession to improve nurses' knowledge in enhancing healthcare delivery. The idea of proposing this study is an observation from practice where family caregivers are not adequately prepared to manage Alzheimer patients who are transitioning from institutionalized care to home care.

Following this introduction, chapter two addresses the background of the study by providing a critical analysis of the literature on nurses' roles in supporting family caregivers with Alzheimer patients. Chapter three describes the identified theory that is used to guide the study. Chapter four focuses on the aim of the study and the three research questions. Chapter five provides a detailed explanation of the research methodology including: the research design, data collection, inclusion and exclusion criteria, data analysis, and coding schematic. Chapters six and seven present the findings and discussions respectively in the light of evidence from the literature review and focus on issues related to each of the research questions. Chapter eight delve on the ethical value in the

research study. Chapter nine summarizes the main findings of the study and identifies its original contribution to knowledge reflections. It also proposes recommendations and gaps identified for further research. Finally, chapter ten considers limitations and strengths of the research.

2. BACKGROUND

The demands of caregiving can limit a caregiver's ability to take care of themselves (Schulz and Eden, 2016). Family caregivers of people with Alzheimer's and related dementias are at greater risk for anxiety, depression, and poorer quality of life than caregivers of people with other conditions. This is because, caregivers of people with Alzheimer's and related dementias provide care for a longer duration than caregivers of people with other types of conditions (Brodaty and Donkin, 2009). This chapter will therefore explore relevant contemporary research related to nurse role in supporting family caregivers of Alzheimer patients. It will explore the epidemiology of Alzheimer and Dementia; overview of Alzheimer and Dementia care; policies and guidelines on Alzheimer and Dementia care; and integration of the role of nurses and family caregivers towards Alzheimer and Dementia patients.

2.1 Epidemiology of Alzheimer

The Alzheimer Disease International was commissioned in 1985 by an international group of experts to reach a consensus on dementia prevalence and estimated incidence in 14 World Health Organization regions, based on epidemiological data acquired over recent years (Mayeux and Stern, 2012). The global prevalence of dementia has been estimated to be as high as 24 million and is predicted to double every 20 years until at least 2040. As the population worldwide continues to age, the number of individuals at risk will also increase, particularly among the very old. The global prevalence of dementia has been estimated to be as high as 24 million, and is predicted to double every 20 years until at least 2040

Compared with Africa, Asia and Europe, the prevalence of AD appears to be much higher in the US, which may relate to methods of ascertainment. The prevalence may be higher among African American and Hispanic populations living in the US, but lower for Africans in their homelands, for reasons that remain uncertain (Ballard, et al., 2016). According to report, Finland is one of the European countries with alarming aging population. Finland is said to have about 80,000 elderly people from age of 65 years and above who suffer from moderate to severe dementia. Said memory and Dementia study and 13,000 of the population suffer slight state of Dementia. An estimate of 11,000 people over the age of 65 are affected by dementia every year. However, dementia is common with patients with age of 80 and above (Dubale, 2016).

2.2 Overview of Alzheimer Care

The main elements of good care are appropriate medical treatment, suitable rehabilitation, the necessary supportive measures, and regular planned follow-up and support. The main aims of care are to predict changes and manage risks, to maintain a good quality of life, and to extend the period that patients can stay at home (Foebel, Hirdes, and Heckman, 2013).

The European parliament 2008 state that, people having memory disorder are supposed to have national care and treatment programmed to address public health. According to the declaration, Finnish Ministry of Social affairs and health has designed a national plan to addresses the challenge of dementia Alzheimer s type. According to the Finish Ministry of Political Affairs and Health report (2013), it was shown that memory disorders have a great national cost as the country population is rapidly increasing in the number of aging people.

The Finnish Medical Journal Supplement 10/2008 recommendations describe treatments and modes of rehabilitation related to the chain of care of patients with memory disease that have been shown to be effective, maintain the patient's functional capacity, help the patient to cope at home, and improve the quality of life of both patients and their relatives. A realistic proactive care and rehabilitation plan should be drawn up together with the patient and his/her relative. The person responsible for the treatment should make sure that every possibility is utilized, with consideration for the patient's and family's wishes and needs.

2.3 Policies and Guidelines on Alzheimer and Dementia Care

According to Krueger and Casey (2018), though there has been much work done on the legal aspects of mental health, not much has been done on dementia conditions. The key legal frameworks include the Human Rights Acts 1998, Care Act 2015, Equality Act 2010, Mental Capacity Act (2015) and Adults with Incapacity Act (2000), (Griffith, 2015). These legislations are geared towards strengthening advocacy while protecting the rights of adults with dementia to make decisions that put their interests first (Creswell, 2014). Furthermore, dementia is not usually seen as a 'rights issue' and securing these rights has been a long and difficult struggle (Murphy, 2018). However, a lot of advocacy and adoption of the social model of dementia practice through dementia-friendly communities are set to change the narrative (Department of Health (DoH), 2015). Social reengineering is meant to alter stereotyping and provide a conducive physical

environment and appropriate housing for people with dementia to be responsive and adapt to challenging situations (Aveyard et al., 2016).

The European Parliament adopted a written declaration in 2008 which highlighted the increasing importance of memory disorders from the perspective of public health and the national economy and the need for national dementia strategies as one means of preparedness. Finland's national programme was produced by a committee set up by the Finnish Ministry of Social Affairs and Health. On 8 May 2012, Finland launched a national dementia plan called the "National Memory Programme 2012-2020". Among the four areas of activity that the plan has, there is a particular focus on the entire care chain. The program helps the country to have a clear care and treatment strategies to help check the national public health problem. This program was also useful because it helped both the national and local policy designers to see the importance of reaching the aging population with memory disorders. Ways of lowering the dementia cost, the program suggest that, early preventions, diagnosis and supportive measures should be carried out at patient's home. Home care is the best approach of cost-effective care with dementia patients. Beside the intervention care mechanism recommended was to limit the prevalence and incidences of dementia. In Finland rehabilitation is the most common care aspect focus on which could be done either homes of patients or in rehabilitation centers near the patients. Another important care plan Finland uses is the palliative care which focuses on the patients comfort and their wellbeing couple with their family till end of life.

2.4 Integrating the Role of Nurses and Family Caregivers towards Alzheimer's Disease Patients

Research has proven that, majority of patients receive some level of care and support from their family members. This informal care can be important in scope, intensity and duration to older adult and those with chronic disabilities of all ages (Cook, Snellings, Cohen, 2018). Family caregiving raises safety issues in three ways (Tong, Sims-Gould, & Martin-Matthews, 2016): physical, spatial, and interpersonal that are largely multi-dimensional and intersectional. However, the promotion of safety in home care involves the roles, responsibilities, and perspectives of everyone including workers, clients, and their caregivers.

Caregivers always interact with their care recipients thereby spending a substantial amount of time with them providing care in a vast range of activities. While nurses on the other hand have a shallow view of this interaction because they spend limited time with their care recipients. Caregivers can only last for a short-acute care time especially after hospitalization of a person with ongoing chronic care need. Averagely informal caregivers spend 4.3 years this work (Foebel, *et al.*, 2013). In every 10 caregivers four spend 5 or more years providing support, while out of ten 2 spend a decade or more of their lives taking care of their family members which is a day- in day-out responsibility. Above half of the family caregivers provide 8 hours or more of care every week while one out of 5 provide more than 40hours per week (Family Caregivers Allisance, 2019). Over the past decades, there has been a growing appreciation and recognition of services provided by health volunteers and how their support has brought tremendous relief to patients (Deery et al., 2017). There has also been a rise in the use of volunteers as a supportive adjunct for caring for patients with dementia (Cronin et al., 2016). According to Rasheed & Wood (2015), volunteering reduces dependence on all health and social care services, reduces hospital admissions or readmissions, and increases capacity within healthcare systems

There is strong evidence that multicomponent intervention strategies that are supported by volunteers or family members can help manage the conditions of dementia patients, since they can present unique challenges to staff who care for them (Rahman, 2016; Jenkins, 2015). Support from volunteers is key to helping to restore a patient's independence, which is considered most relevant by patients, service users, caregivers, and their families (Marshall and Rossman, 2015). Volunteers must have good communication skills, must be reliable and flexible, have relevant work experience, and be equipped with emotional skills to support dementia patients during mealtimes (Green et al., 2018).

Caregiver role identity serves as interpretive frames and sets of standards used by individuals to make sense of personal experiences, actions, and emotions, as well as guide subsequent behavior (Funk, 2019). Basic to the idea of caregiver identity theory is the idea that caregiving is a dynamic process (Savundranayagam and Montgomery, 2010). Caregiving role thus emerges out of an existing role relationship, usually a familial role such as a daughter, wife, or husband. Caregiving is a systematic process of identity change in which the caregiving role emerges out of an existing role relationship (Eifert, Adams, Dudley, & Perko, 2015). The theory suggests that roles and responsibilities is a significant factor related to family caregiver identity development (Eifert, et

al., 2015). In a nutshell, caregivers, interacting with the care recipients undergo a self-appraisal and determine to what extent that caregiver role agrees with their understanding of self (Friedemann & Buckwalter, 2015).

Empirical studies Savundranayagam and Lee (2017) and Montgomery, Kwak, Kosloski, & Valuch, (2011), employ the model of family caregiver role that is grounded on caregiver identity theory which includes caregiver identity discrepancy, relationship burden, stress burden, and depression variables. All the mentioned variables relate to roles and responsibilities significant to family caregiver identity development.

3. THEORITICAL FRAMEWORK

The theoretical framework in this paper will attempt to bring knowledge about nursing role in supporting family caregivers of Alzheimer patients by taking the significant academic works on care by professor of nursing and sociology, Dr. Afaf I. Meleis. The transition theory was mainly developed in the mid-1960s when Meleis, in her Master's and PhD dissertation research, investigated phenomena of planning programmes and processes involved in become a new parent and meeting parental roles. Therefore, this theory has been used on this study to provide a framework in nurses' actions on developing interventions and defining outcomes, and in the process, generates research questions that serves as a guide to nursing care before, during, and after the transition.

Dr. Meleis' transition theory focuses on a framework that acknowledges universal aspects of nursing, enhances nurses' potential in supporting emerging identities and life patterns, supports nurses' concerns about changing systems and societies, and challenges nurses to develop therapeutics supportive of positive experiences and healthy outcomes. To date, this challenge has not been satisfactorily met. This study seeks to identify elements of interventions necessary during the transition from a nursing care to a family caregivers' model. Dr. Meleis highlights that during this transition, there are critical points, and milestones for which appropriately congruent care is required. This is a great area of investigation to ascertain when these milestones should occur.

Meleis (2010) avers that milestones need to be identified and defined models of care in tandem with different transition phases developed with actions that make a difference for such outcomes as quality of life, sense of well-being, integration of roles and healing cultivated and tested. Therefore, it is expected that the transition theory will lead to developing health care policies that insure healthy transition processes and outcomes. This study shall analyze Meleis' (2010) proposal that the 'nature of the transition' can facilitate or hinder the persons 'pattern of response' in the context of the research questions.

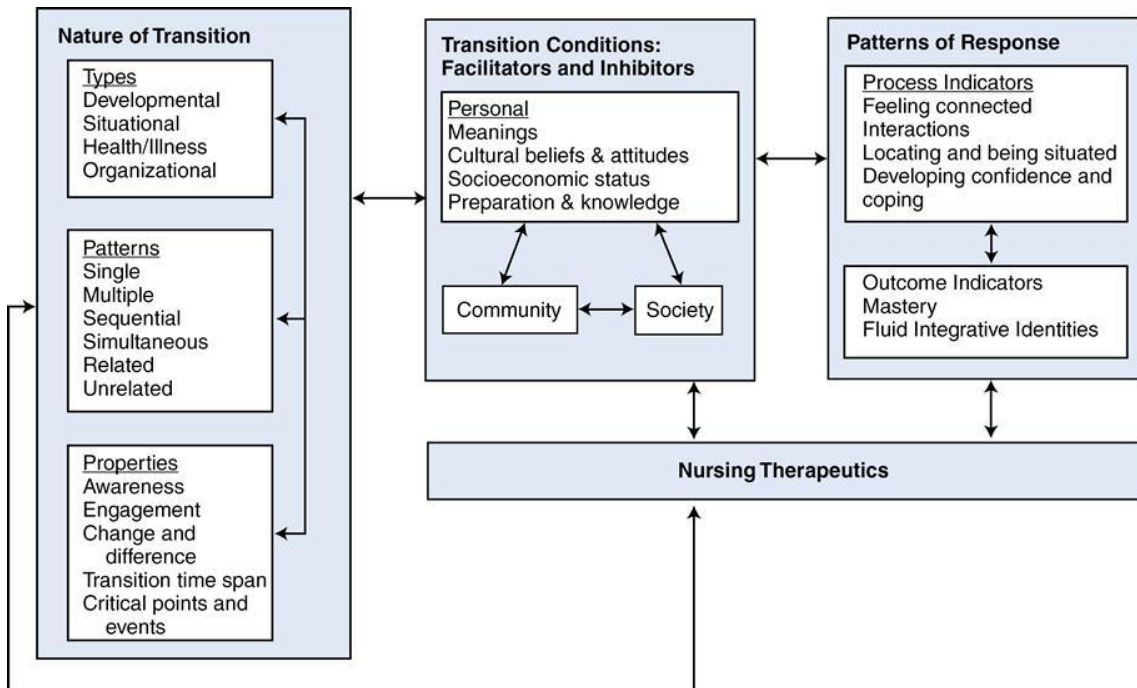


Fig.3.1: Meleis Transition Theory: Published with reusable license by Rhonda Misfeldt (June 3, 2016)

4. AIM AND RESEARCH QUESTIONS

Caregivers often strive to meet all the health and personal needs of the person with Alzheimer but neglect their own. Studies continue to uncover that Alzheimer and other chronic diseases can be managed in partnership with primary caregivers while employing effective strategies for helping friends and family cope with the stress of caring for those with Alzheimer's disease (Vroomen, Mierlo, Ven, Bosmans, Dungen, Meiland, Dröes, Charante, Horst, Rooj & Hoot, 2012). Informal caregivers include spouses, adult children, grandchildren, other relatives, and friends of non-institutionalized people with Alzheimer who provide unpaid care at home.

The aim of this study is to investigate the role nurses play in supporting family caregivers of patients with Alzheimer's disease. This will be guided by addressing the following research questions;

1. What are the nurses' roles in supporting family caregivers of patients with Alzheimer's disease?
2. What are the challenges that nurses face while supporting family caregivers of patients with Alzheimer disease?
3. What are the mitigation measures available in addressing challenges that nurses face while supporting family caregivers of patients with Alzheimer disease?

5. METHODOLOGY

This section will highlight research design employed, the data collection method and data analysis used to answer the research questions.

5.1 The Research Design:

This study employed a systematic literature review methodology that ensured that data was captured from all studies that are relevant to the research question. The qualitative content analysis was to investigate the role nurses play in supporting family caregivers of patients with Alzheimer's disease. This research method played a great role in ensuring the fidelity of the selected publications and ensuring that they are able to answer the target research question. The systematic literature review methodology followed a rigorous process of first, developing literature around the research questions, and secondly, coming up with a sound literature search strategy that included the selection of a diverse and peer-reviewed publications towards answering the research question. The third step was to review the quality of the articles selected and retain that ones that meet the criteria inclusion for further analysis. The final step was the process of synthesizing the information from the selected articles using exploratory and descriptive forms that describe the role nurses play in supporting family caregivers of patients with Alzheimer's disease.

5.2 Data collection.

In order to conduct a document analysis, relevant documents were accessed through various databases such as; EBSCO host and CINAHL. The articles were selected using the Boolean or phrases like: Nurses role in supporting caregivers, family caregivers of patients with Alzheimer; dementia and Alzheimer care and management; and challenges faced by nurses and family caregivers. CINAHL, Pub Med and Medline produced well defined and peer reviewed literature concurring with Creswell, (2014) who regards them as the leading databases for healthcare related literature searches. The initial number of searches obtained were over 616 however this was filtered down to 65 by applying limitations. Selecting years of publication reduced hits; full texts, peer reviewed and English language articles were used. To get current up-to-date literature on the subject matter, the searches were confined to the period between 2009 and 2019. The research was conducted using the abstract/title of the article and only articles with full texts available were included, reducing selected articles related to the research topic to 14 which were chosen for this study.

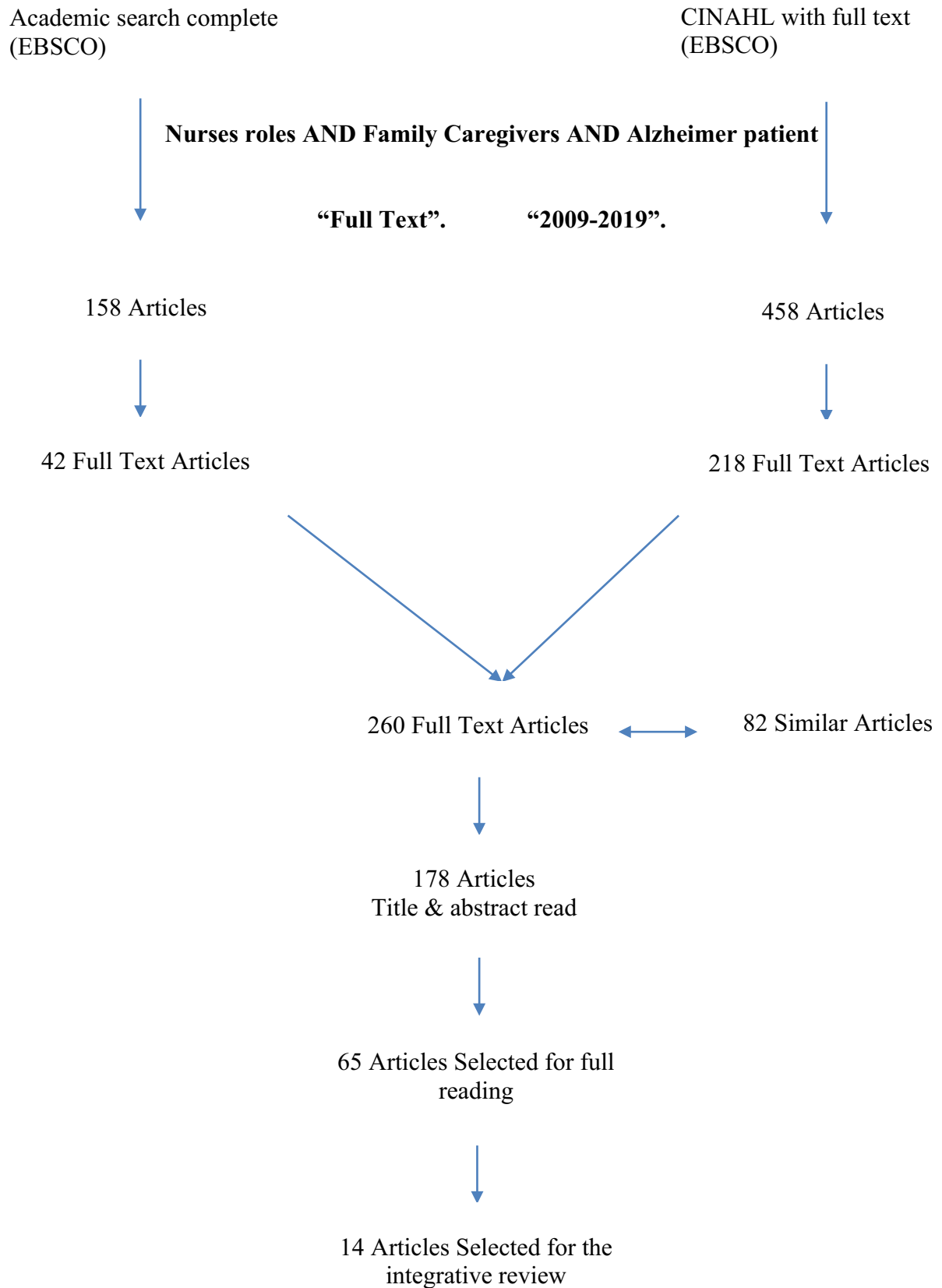
5.3 Inclusion and Exclusion Criteria

The Inclusion criteria are the boundaries set when selecting participants for the research Polit and Burns (2010). Therefore, the inclusion criteria in selecting articles for this study included, peer-reviewed, relevance to Alzheimer, less than 10 years (2009-2019), relevant to nurses and caregivers. Exclusion criterion included the participants who were not suitable and could produce bias, which could cause the study to be invalid (Burns and Groves 2011). This included articles; older than 10 years, not peer-reviewed, not English language, not full-free text, not relevant to research. In addition, doctors, and other healthcare workers apart from the identified group were excluded.

Table 5: Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Literature published in English language.	Literature published in language other than English
Full text articles with citations.	Articles with only abstract available
Published in 2009 or later	Published before the year 2009
Published literature	Non-published literature
Available free for Arcada University students	Doctors and other healthcare workers

Fig.5.1: Illustration on chosen articles for the study



5.4 Chosen Articles for the Research Study

The following articles have been chosen to conduct the research study, which is mentioned above in inclusion and exclusion criteria.

1. Bunn, C.G., Pinkney, E., and Drennan, V.M., (2015) Specialist nursing and community support for the carers of people with dementia living at home: an evidence synthesis. *Health and Social Care in the community*. Vol.24(1): 48-67. <https://doi.org/10.1111/hsc.12189>.
2. Dawson, A., Bowes, A., Kelly, F., Velzke, K., and Ward, R., (2015) Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic appraisal (online). *BMC Geriatr*: vol.15(59). doi:10.1186/s12877-015-0053-9 [Accessed on 30.10.2019]
3. Cola, M.C.D., Buono, V.L., Mento, A., (2017) Unmet needs for family caregivers of elderly people with dementia living in Italy: what do we know so far and what should we do next? (online). *INQUIRY: The Journal of Health Care Organization, Provision, and Financing*. SAGE. <https://doi.org/10.1177/00469558017713708>.
4. Fang, X., Chen, F., and Ye, C., (2016) Prevention of dementia and care of dementia patients from nursing perspective – Best practices and development needs. Bachelor's Thesis submitted to the Turku University of Applied Sciences.
5. Hansen, J.A., (2016) The nurse as a family caregiver: their experience, their story. Theses and dissertations. 1089. <http://openPrairie.sdstate.edu/etd/1089>
6. Hirschman, K.B., and Hodgson, N.A., (2018) Evidence-Based interventions for transitions in care for individuals living with dementia. *The Gerontologist*. Vol.58(1): S129-S140. <https://doi.org/10.1073/geront/gnx152>.
7. Hughes, S., Shuman, S.B., Wiener, J.M, and Gould, E., (2017) Research on supportive approaches for family and other caregivers. Research Summit on Dementia Care. <https://aspe.hhs.gov/national-research-summit-care-services-and-supports-person-dementia-and-their-caregivers>.
8. Montgomery, R.J., Kwak, J., Kosloski, K., Valuch, K.O., (2011) Effects of the TCARE intervention on caregiver burden and depressive symptoms: preliminary findings from a randomized controlled study. *The Journal of Gerontology Series B: Psychological Sciences and Social Sciences*. 66B(5): 640-647. Doi:10.1093/geronb/gbr.088.
9. Moreno-Cámara, S., Palomino-Moral, P.A., Moral-Fernandez, L., Frins-Osuna, A., Parra-Anguila, L., del-Pinto-Casado, R., (2019) Perceived needs of the family caregivers of people

- with dementia in a Mediterranean setting: a qualitative study (online) *Int. J. Environ. Public Health*. 16(6): 993. <https://doi.org/10.3390/ijerph16060993>
10. Sansoni, J., Anderson, K.H., Varona, L.M., Varela, G., (2013) Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some consideration on existing literature. *25*: 235-246. Doi:10.7416/ai.2013.1926
 11. Toye, C., Slatyer, S., Quested, E., Bronson, M., Hill, A., Fountaine, J., Uren, H.V., Troeung, L., Maher, S., (2019) Obtaining information from family caregivers to inform hospital care for people with dementia: A pilot study. *Wiley Online Library*. 14(1): e12219. <https://doi.org/10.1111/opm.12219>
 12. White, C.L., Overbaugh, K.J., Pickering, C.E.Z., Piernik-Yoder, B., James, D., Patel, D.I., Puga, F., Ford, L., Cleveland, J., (2018) Advancing care for family caregivers of persons with dementia through caregiver and community partnerships. *Research Involvement and Engagement*. SpringerLink. 4(1). Doi:10.1186/s40900-018-0084-4.
 13. Wijngaarden, E.V., Wedden, H., Henning, Z., Komen, R., The, A., (2018) Entangled in uncertainty. The experience of living with dementia from the perspective of family caregivers. *PLOS ONE*. <https://doi.org/10.1371/journal.pone.0198034>
 14. Wisneski, J.L., (2018) Social support, gender and burden in caregivers & patients with Alzheimer's disease. *Walden Dissertation and Doctoral Studies*. <https://scholarworks.edu/dissertations>.

5.5 Data Analysis.

In this qualitative study content analysis was used for document analysis to systematically identify relationship in data. Content analysis is a kind of interpretation, which is aimed to reveal common aspects of text, intended for classification and construction the common aspects through generalization quantification (Merriam, 2013). Articles selected were read carefully and categories were developed based on the research problem by revealing similarities and common aspects. In research, unit of analysis helps determine what data should be collected as it answers the question of 'what' and 'who' is being studied (Kumar, 2018). The unit of analysis for this study was the articles extracted from the literature review that identified with emerging themes.

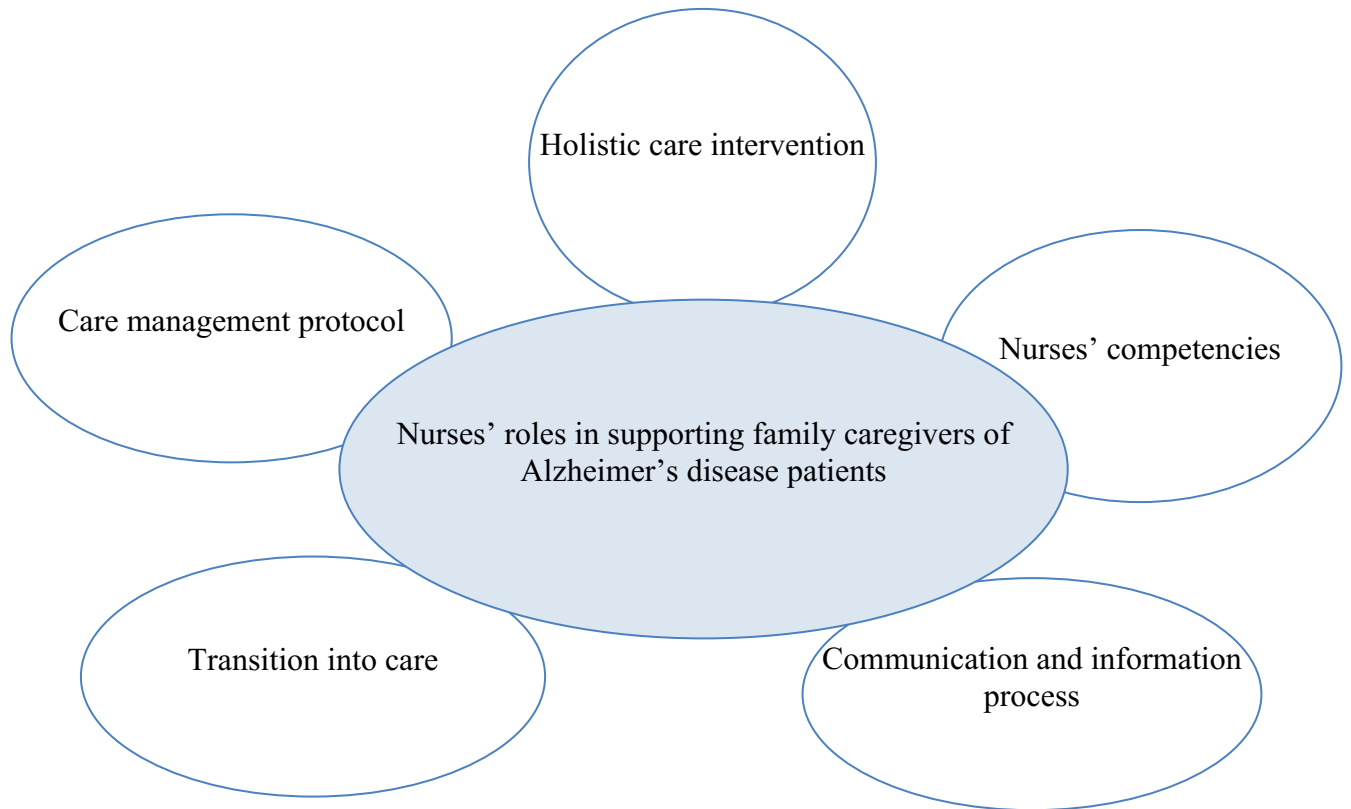
This analysis consisted of different phases; first, the researchers familiarize themselves with the data by reading of the whole data set actively and repeatedly and interpretation was shared within the peers. The second phase of analysis involved the development of a list of codes that identified any feature of the data that was interesting and noteworthy. An integrative review was undertaken

for themes related to the research question that sought to investigate the role nurses play in supporting family caregivers of patients with Alzheimer's disease. The text elements was coded, the codes was compared, combined, and summarized in main themes. The themes were then clearly defined in terms of what they represented.

The first theme identified was "nurses' role in supporting family caregivers of patients with Alzheimer's disease. The major evidence-based factors found in the literature was from at least five articles. Namely: Hughes, S., et al., 2017. Toye, C., et al., 2019; Bunn, F., et al., 2015; Hansen, J.A., 2016; and White, C.L., et al., 2018. The second theme identified was "needs and challenges faced by family caregivers of patients with Alzheimer's disease where the evidence-based factors from the literature were found from at least six articles. Namely; Sansoni, J., et al., 2013; Wijngaarden, E.V., (2018); Cola, M.C.D., et al., 2017; Wisneski, J.L., 2018; White, C.L., et al., 2018; and Hansen, J.A., 2016. The third theme identified was "nurse's responsibility in mitigating challenges faced by caregivers of patients with Alzheimer's disease." The major evidence-based found in the literature was from at least three articles. Namely; Hirschman, K.B., and Montgomery, R.J.V., et al., 2011; Dawson, A., et al., 2015; and Moreno-Cámara, S., et al., 2019. Familiarization with the overall content was achieved through reading and rereading each transcript. During this time, notes were made about potential codes.

Writing did not take place at the end, as it was an integral part of analysis, as the writing process itself deepened our understanding, clarified meanings, and highlighted layers and polarities in the data. Findings were equally shared within peers. Intersubjective reliability was sought throughout the analysis process. From analysis of the presented studies, five thematic areas emerged, as illustrated in Figure 5.2: holistic care intervention; nurses' competency; care management protocol; transition into care; communication and information.

Fig.5.2: Thematic Areas of Integrative Review



6. FINDINGS

6.1 Nurse's Role in Supporting Family Caregivers of Patients with Alzheimer's Disease

Findings of study done by Hughes, et al (7) revealed that nurses, social workers and other health care professionals deliver training in appropriate skills for caregivers of patients with Alzheimer's disease. Fang, et al., (4) posit that nurses play a major role in providing holistic intervention towards dementia care. They add that nurses can work with families and physicians to develop strategies towards effective interventions. In addition, involving nurses as change leaders motivate them to fully engage and increase their understanding on the need for high-quality care (12). Bunn, et al (1) identify nurses' role to include assessment of caregivers' needs, offering relevant skills training, offering information, and providing therapeutic interventions.

The essential elements of interventions for caregivers of dementia patients include assessment, education and skills training, care coordination, counselling and support groups, and registry and referral to other resources (7). These elements can improve quality of life and delay institutionalization of care recipient (7). Besides, nurses feel emotional connection when they provide support (5) while the family caregivers value the support that nurses provide (1). White, et al., (13) suggest a systematic approach towards the care of dementia patients and their family from diagnosis to the time of providing respite services. They also emphasize on the need for an up-to-date registry as well as community-based education.

6.2 Challenges faced by nurses while supporting family caregivers of patients with Alzheimer's disease

Caregivers face a myriad of challenges as a result of the burden of caring for patients suffering from Alzheimer's disease. These include negative impact on personal health, strain on interpersonal relationships, and financial drain (15). Wijngaarden (14) identified loneliness and exhaustion as some of the challenges faced by the caregivers. White et al (13), also agreed that there are limited resources to support families during the diagnostic phase. Caregivers face difficulty in getting a diagnosis. More so, caregivers from rural area have less access to healthcare facilities and medical specialists (13).

Caregivers experience emotional toll that result in detachment related to the stressful situation, anger, frustration, guilt, and grief (5 and 11). White, et al., (13) explain that caregivers hardly self-

identify with their role as they consider caregiving as part of their normal role as spouse or children. Caregivers' lack of awareness on the severity of Alzheimer's disease being a terminal illness limit their ability to plan and access resources to support them and their loved ones during advanced stages of dementia (13). In addition, caregivers also experience lack of streamlined system of disseminating information about resources (3 and 13). Their choices are also limited to the availability of healthcare system policies.

6.3 Mitigating challenges faced by Nurses while supporting family caregivers

Moreno-Cámara, S., et al (9) aver that there is need to develop comprehensive intervention. Key elements of successful interventions include caregiver education on likely transition and ways to delay the transition, provision of timely communication to the care team of Alzheimer's disease, involving the patient and caregiver in person-centered care, building a strong interagency team, and implementing good healthcare (6).

Family careers of patients with Alzheimer's disease require multi-component interventions that comprise of education, cognitive stimulation, cognitive training, and cognitive rehabilitation (2). Pyscho-education intervention helps family caregivers with increased knowledge and skills in the care of patients with dementia (9).

Moreno-Cámara, S., et al (9) suggest the training of caregivers in family negotiation skills as well as training intervention in care planning and time management skills. Findings from a study done my Montgomery et al (8) revealed that the use of TCARE[®] protocol shall promote the well-being and mental health of Alzheimer caregivers.

7. DISCUSSION

Most of the findings from the fourteen (14) articles reviewed agree with the aim of this study; to investigate the role nurses play in supporting family caregivers of patients with Alzheimer's disease.

In the process of integrative content analysis of each article to answer question one (1): "what are the nurses' roles in supporting family caregivers of Alzheimer's disease patients?", all articles reviewed mention support offered to family caregivers of patients with Alzheimer's disease. This was emphasized by the major role that nurses play in providing holistic intervention to the family caregivers, the benefits of emotional connection and better understanding on the need for high-quality care, while the family caregivers feel gratitude when they receive support (4, 5, 7, and 12). Others mentioned strategies and elements including assessment, training, coordination, and information dissemination that nurses apply to support family caregivers (article 1, 7, and 13).

To answer research question two (2): "what are needs and challenges faced by nurses in supporting family caregivers of patients with Alzheimer's disease?", each article reviewed, attempted to deduce such needs and challenges that nurses face. These needs and challenges have been grouped into different categories of personal wellbeing like poor health, strained interpersonal relationship, loneliness, exhaustion, emotional toll, stressful situation, anger, frustration, guilt and grief; financial like family financial drain/reduction, lack of access to information and resources; and institutional policies in the care and management of Alzheimer's disease (articles 3, 5, 11, 13, 14 and 15).

In question three (3): "how can the challenges faced by nurses while supporting family caregivers of patients with Alzheimer's disease be mitigated?" Most studies reveal care and management interventions for Alzheimer's disease by nurses supporting family caregivers such as education and training on transition, provision of timely communication and information, and interagency collaboration in care and management (2,6 and 9). There was also a suggestion on the use of TCARE[®] protocol to promote the well-being and mental health of caregivers (8).

7.1 Theoretical Discussion

This study was viewed through the scope of transition theory as established by Dr. Afal L. Meleis (2010). Based on the concepts of transition theory, it was hypothesized that establishing goals and educating caregivers about likely transition are effective approaches in improving care transition

for persons with dementia and their caregivers (Hirschman and Hodgsum, 2018). The results of this study confirm what was expected based on transition theory. It is possible that a strong inter-professional team that is competent in caring for patients with dementia can be created when timely communication is given about the patient with dementia. Secondly, based on the concepts of transition theory it was expected that nurses are able to prepare children, families and communities to navigate through and adapt to transition experience that enhance health outcomes (Smith and Parker, 2015; Bradway, *et al.*, 2012). The results of this study support the expectation that transition theory has been used as a conceptual framework for health-care providers to understand the caregivers' beliefs, views, unique experience and desired outcomes. One explanation for the nurses' understanding of patient caregiver transition may lead to the development of nursing therapeutics, interventions and resources that promote successful and healthy responses to transition.

Lastly, family caregivers were expected to provide care and management interventions for Alzheimer's diseases. This is because as the need for care recipient increases in quantity and intensity, there is need for the realization of caregiver identity (Eifert, *et al.*, 2015). As expected, when nurses support family caregivers' roles and responsibilities, there is significant development of caregiver's identity. These findings support the theoretical propositions that the level of stress or burden experienced by caregivers depends on the caregivers' personal expectation of the care tasks. Due to this approach to the task of caregiving, there were discrepancies of illness related stressors and other forms of burden experienced by spousal and caregivers of patients with Alzheimer's diseases (Savundranayagam and Montgomery, 2010). This approach showed that effective communication skills are essential in enhancing caregiving experience.

8. ETHICAL VALUES IN RESEARCH STUDY

Ethics is significant in researching. Therefore, the author considered the ethical aspects throughout. Furthermore, the materials which were chosen for literature review has already considered the ethics in their articles and the ethical values was also indicated. Hence fore, based on the ethics of original literatures, this thesis is been ethical and moral. Finish Advisory Board on Research Integrity (TENK, 2012), outlines the ethical process for a researcher's role in acknowledging other researchers' achievements in citing their publications appropriately. The due process outlined in Arcada guidelines on good scientific practices were also followed while conducting this research.

9. CONCLUSION AND RECOMMENDATION

Guided by the transition theory and caregiver identity theory, nurses' role in supporting family caregivers was conceptualized as a process indicator of healthy caregiving to patients with Alzheimer's disease. The study focused on literature that touches on the nurses' roles, needs and challenges faced by family caregivers, and nurses' support in mitigating the challenges. The evidence and result gathered in this thesis demonstrate that as much as family caregivers of patients with Alzheimer's disease face challenges, there is significant support offered to them as well as mitigation measures towards those challenges.

The information given in this literature review give nurses current and relevant material concerning the best practices in supporting family caregivers of patients with Alzheimer's disease such as the intervention strategies including assessment, training, coordination, and information dissemination. These ultimately translate into better understanding of family caregivers' roles and responsibilities towards those suffering from Alzheimer's disease. About needs and challenges that family caregivers face, the standing point is that Alzheimer's disease is a terminal disease, so family caregivers are burdened during the caregiving. These needs and challenges are grouped in the categories of caregivers' personal wellbeing, financial burden, and government policies. Even though the nurses have a crucial role in the care of patients with Alzheimer's disease, it is not clear on how they support family caregivers and mitigate challenges faced by the family caregivers of patients with Alzheimer's disease. Holistic nursing care offers an important role in patient-centered comprehensive care from physical, psychological, and social aspects.

The findings of this study suggest that nurses should follow holistic healthcare intervention that includes developing joint strategies with families who are likely to feel less prepared for their caregiving role at different points in the caregiving trajectory. At the beginning of the caregiving trajectory, nurses should play greater attention to the family caregivers' depressive symptoms and the relationship quality when targeted interventions are to be undertaken. In addition, available information and medical service available in the early stage of the disease will improve the prognosis and decrease the complication of disease. Hence, the health education of Alzheimer's disease to both the patients and family caregiver is useful and relevant in improving the quality of life of patients. This is because the development and prognosis of Alzheimer's disease are related to the quality of care provided by family caregivers or professionals. Currently Alzheimer's disease is incurable, however, nurses can use various mitigation methods that support family caregivers to prevent and prolong the process of this disease.

Future research should include looking at nurse-specific roles in mitigating challenges that family caregivers of patients with Alzheimer's disease face so that more sensitive interventions that involve close working relationship between the nurses and family caregivers could be tailored.

10. LIMITATIONS AND STRENGTHS OF OUR RESEARCH

Since this was a systematic and procedural approach of literature review, there is a possibility that some important articles have been overlooked. In addition, the literature reviewed had a presentation of broad themes in nurses' roles and family caregiving. In this study, the research questions, the search selection and sources as well as the inclusion and exclusion criteria employed, contributed to the identification of a large volume of relevant publications on the research topic. Furthermore, this study has strengthened the authors knowledge in research development and scientific writing.

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