Nurses’ perceptions towards delivering care for patients with dementia
A literature review

Ho Lien Bao Hoan
Ngo Thi Man Khoi

Bachelor’s thesis
May 2019
Social Services, Health and Sport
Degree program in Nursing
Nurses’ perceptions towards delivering care for patients with dementia – A literature review.

Title of publication: Nurses’ perceptions towards delivering care for patients with dementia – A literature review.

JAMK University of Applied Sciences – School of Social and Health Services

Author(s):
Ho Lien Bao Hoan
Ngo Thi Man Khoi

Type of publication: Bachelor’s thesis

Date: May 2019

Language of publication: English

Number of pages: 33

Permission for web publication: x

Degree programme:
Nursing

Supervisor:
William Garbrah

Dementia is a global epidemic which targets aged populations in mainly developed countries. Patients with dementia are those with complicated needs and behavioral disturbances. This study aims to focus on nurses’ feelings towards the care for dementia patients in variable settings based on existing literature.

Three databases (CINAHL, MEDLINE, PUBMED) was browsed to obtain all relevant studies meeting the inclusion criteria. The literature search yielded 11 peers reviewed empirical studies published from 2008 – 2018. The chosen articles were analyzed through data reduction, data display, data comparison and then making conclusion and verification of data from the included articles.

The results of this literature review clearly showed nurses’ challenges in providing care for dementia patients. Challenges such as the lack of resources, time and support, negative attitude from other healthcare professionals and family members, stress from patient’s family and their own family, nurses’ personal feelings towards the patient were mentioned in the review. In addition, the results pointed out nurses’ inevitable need for further education and training in providing care for dementia patients.

Key word/tag: Nurses, perceptions, dementia, cognitive impairment, memory loss.

Miscellaneous: Thesis data sheet as an appendix from page 29 to 33.
1. INTRODUCTION

Dementia has been an increased incidence globally (Hardie & Smith, 2017) and the number is anticipated to double in the next 30 years. The primary affected population group of dementia is elderly people – who may have other age-related illnesses (Baillie, 2012). Many of whom are admitted to hospital for these non-dementia-related conditions and spent a great duration of time at acute care settings. (Borbast J., Lockwood, & Emden, 2006).

These patients with complicated needs and behavioral complications are becoming an immense headache for registered nurses working in medical-surgical units (Byers et al., 2008). Although nurses want to work from a holistic nursing perspective, they confide in shortage of knowledge regarding the demands of demented patient. (Odbehr et al., 2014). In fact, deficiency of dementia skills and staff education had been suggested by research in 1990s. (Tolson et al., 1999)

Thus, many of these nurses reported to experience exhaustion and frustration when providing care for patients with dementia (Berg, Hallberg, & Norberg, 1998; Hallberg & Norberg, 1995). Accompanied with these negative feelings are the lack of staffs, low self-confidence among nurses and absenteeism are leading to "burnout" and noxious situations in quality of care and patient safety. (Byers et al., 2008). Therefore, the aim of this study is to focus on nurse’s feelings towards the care for demented patients in variable settings based on existing literatures.
2. REVIEW OF THE LITERATURE

2.1. Dementia disease

Dementia is a decline of intellectual function in a medical term called the decline of cognition. The intellectual function has several components and the most important among them is memory; therefore, people define this disease as “memory loss”. (Vijay Chandra 2012). Around 47 million people all over the world suffer from this disease and nearly 10 million cases are diagnosed every year. Among other cognitive impairment diseases, Alzheimer could be seen as the most common cause of dementia and it contributes up to 60-70% of cases. (World Health Organization 2017).

Even though dementia disease has been taken into consideration since early civilizations, most of the ancient philosophers thought about it as a natural part of aging. Until the late 1800s, with more advanced medicine and science, they now had an ability to firmly look through a human’s brain and thus realized it as a cognitive impairment disease. The most common dementia type: Alzheimer disease was named in 1906 after Alois Alzheimer, a German psychiatrist after he figured out the microscopic plaques and tangles now known as primary suspect of dementia in the brain of an old woman with dementia symptoms. (The University of Queensland, Australia 2017.) Recently, US National Institute on Aging 2014 considered the third feature of dementia disease is the loss of connections between nerve cells in the brain.

Dementia has a supreme impact on human’s life as causing disability and dependency for elderly people globally. Moreover, it also affects to body normal
functions as memory, perception, behavior, language, and personalities. (The University of Queensland, Australia 2017.) Recognizing the important impact of dementia disease, World Health Organization has marked it as a public health priority. (World Health Organization 2017).

2.2. Causes of different types of dementia

According to National Institute on Aging in 2014, the causes of dementia are influenced by various factors and diseases which interfere and destroy neurons inside the brain and their functions. As pointed out by WHO (2017), a variety of diseases and injuries that primarily or secondarily affect the brain such as Alzheimer’s or stroke can precipitate dementia. There are different types of dementia disease such as Alzheimer’s disease, Vascular disease, Lewy body dementia, Frontotemporal disorder and Mixed dementia. (National Institute Aging 2017).

Among these types, Alzheimer’s disease is known as the most common type of dementia among elderly people. It generally happens to old population is called late-onset. In addition, a rare Alzheimer’s type which happens to young generation around 30s is termed early-onset. (National Institute of Aging 2017.) A combination of genetic, lifestyle and environmental factors that affect brain for a great period of time is believed to be one the influences of Alzheimer's disease. With Alzheimer’s patient, the size of the brain shrinks compared to normal brain size. According to Alzheimer’s Association, scientists are not entirely certain of the real reason for dementia disease. Yet, they considered plaques and tangles as hallmarks of Alzheimer. “The plaques”- the clumps of a protein called beta-amyloid bring damage and slowly destroy the neurons in various ways, including affecting cell-to-cell communication. “The tangles” – in a normal brain, contains a protein named “Tau”, which is the main internal support that carries and transports the nutrient to nourish the brain cells. However, in Alzheimer’s brain, “tau” protein appears to be an abnormal tangle that build up inside the brain cells, conducting the failure in
nutrition’s transportation to the brain, thus cause the decline and death of brain cells. (Mayo Clinic, 2017.) The demonstration of how the 'plaques' and the 'tangles' affect to brain cells is shown in a figure below.

![Image of Alzheimer's plaques and tangles](image.jpg)

Figure 1. The plaques and tangle inside an Alzheimer’s brain. (Alzheimer’s Association 2017).

Despite from Alzheimer’s disease, vascular dementia is known as the second most common form of dementia. Alzheimer’s Society categorizes three main types of vascular dementia including stroke-related dementia, post-stroke dementia, single-infarct and multi-infarct dementia. Stroke-related dementia is caused when the vessels supplying blood and nutrition to brain is cut off. Post-stroke dementia happens due to a severe stroke which occurs after the blood flow in a large vessel in the brain is abruptly and permanently blocked by a clot. However, it doesn’t mean that everybody would get vascular dementia after they experienced a stroke. There is about 20% of people who had stroke would develop into vascular disease within the following six months. Single-infarct and multi-infarct dementia appear during a smaller stroke where a large or medium-size blood vessel is temporary suspended by a clot for more than few minutes. It causes some parts of the brain to die or infarct. If
one infarct is developed in an important part of the brain, it leads to dementia which
known as single-infarct dementia. On the other hand, several infarcts spreading all
over the brain due to series of strokes over a long period will cause multi-infarct
dementia. (Alzheimer’s Association 2017.) The signs and symptoms of vascular
dementia are quite similar to Alzheimer’s disease. However, the symptoms develop
all of a sudden and condition can either exacerbate or mitigate during lifetime
(National Institute on Aging of USA). Moreover, nearly 10% of demented patients are
diagnosed with mixed dementia- a condition where both Alzheimer’s and vascular
disease are the reasons causing dementia (Alzheimer’s Association 2017).

The following type of dementia is Lewy Body Dementia (LBD), named after the
scientist Friederich H. Lewy who first discovered the abnormal protein deposits that
disturb brain’s functions in early 1900s. According to Lewy Body Dementia
Association (2016), LBD affects 1.4 million people and their family in the United
States. The symptoms of LBD are intently similar to Alzheimer’s and Parkinson’s
disease but likely to be more complex. Lewy Body Dementia is a brain disorder which
abnormal protein deposits called alpha-synuclein builds up in the brain’s parts that
generate individual’s behaviors, cognitive thinking and body functions. It alters one’s
thinking, memory, sleep patterns and causes changes in behavior. It disturbs
autonomic body functions including blood pressure control, body temperature
regulation, bladder and bowel function. More seriously, LBD could even create visual
hallucinations or severe sleep walking. Unfortunately, the cause for LBD is not yet
well-defined. Scientists believe that genetic, environmental risk factors together with
natural aging process can be potential risk factors for LBD. (Lewy Body Dementia
Association 2016.)

Lastly, Fronto-temporal Dementia (FTD), refers to a group of related conditions
proceeding from the progressive degeneration of the temporal and frontal lobe of
the brain. These places have vital roles in generating decision making, monitoring
functions, emotions and the use of language. (University of California San Francisco
FTD adds up to 10% of all dementia cases and commonly happens to people under 65 years old. Scientists estimate around 60% FTD's patients are from 45 to 64 years old (National Institute on Aging 2017). Unfortunately, the disease is progressive which means the symptoms would only get worse throughout life and currently no treatment is available for curing the disease. Therefore, it is difficult to predict the course of survival, patient with FTD can usually live up to 10 years or a bit longer after the diagnosis. (National Institute on Aging 2017.) The figure below shows the different damaged areas belonging to Alzheimer’s brain and Frontotemporal Dementia’s brain.

![Image of brain damage comparison]

Figure 2. The difference in damaged areas between Frontotemporal Dementia’s brain versus Alzheimer’s brain. (Hudson Valley News Network, 2015)

### 2.3. Overall signs and symptoms of dementia

Dementia affects each person in various ways, depending upon how severe the impact of the disease is and also the person’s personalities before affected by the disease. (World Health Organization 2017). Demented patients are likely to experience emotional disturbances such as depression or elevated mood. However,
making an accurate diagnosis of depression symptoms in dementia patient is quite difficult since they are not always able to express their own feelings such as sadness, hopeless, dismissed interest, or loss of self-esteem. In contrast, when dementia patients experience elevated mood, they would suffer from hypomania (eg: euphoric, quick speech, high self-esteem) to severe mania (eg: uncontrolled happiness, delusion and paranoia) (Mind for a better mental health UK, 2013). Moreover, they tend to be more irritated, restless in almost every situation, especially in case of hunger, sleepiness and pain. (National Institute of Health, 2012).

The National Institution of Health states that neuropsychological symptoms in dementia also include delusion and abnormal of thoughts. However, demented patients with delusion are commonly less complicated when compared to non-demented psychotic patients. Their typical thoughts of delusion are usually just suspiciousness, abandonment, and misidentification. Common examples are patients coming into one's home trying to hide or steal things; entering the house which is not the patient’s home, convicting that spouse is unfaithful, etc. If a demented patient has severe depression, their delusional thoughts can consist of guilt, worthlessness, reference and persecution. (National Institution of Health, 2012).

Disturbance in motor functions, on the other hand, could be precisely observed. There are two types of monitor disturbances relating to dementia: motor retardation and motor hyperactivity. A patient who is associated with motor retardation will perform slower movements and speech, reduced body tone as well as body movements. In contrast, motor hyperactivity is described as an amazingly increased energy level with more frequent body movements and rapid speech. (National Institution of Health, 2012.) Some common symptoms are wandering, purposeless behaviors, memory decline, etc.
Behavioral symptoms of dementia also include circadian rhythm (sleeping disturbance), changing in appetite or eating behavior. Although the change in sleep pattern is normal to aging people, it is more severe with dementia patients as they experience hypersomnia, insomnia, rapid eye movement sleep behavior disorder and pain. As a result of poor sleeping quality, dementia patients usually take naps during the day which eventually keep them wide awake at night. When having dementia, an individual’s appetite could either change into quantitative or qualitative. Quantitative refers to consuming an abnormally increased amount of food while qualitative refers to no change in taste or preference for a particular food. The desire for sweet particularly increases in frontotemporal dementia. Patients with dementia usually lose weight due to hyper-metabolism, inflammatory process or hormone disturbance. (National Institution of Health, 2012.)

2.4. Stages of dementia

World Health Organization divides dementia into 3 stages which are early, middle and late in order to help healthcare staffs select the most suitable care for patients.

In the beginning of the disease - the “early stage”, signs and symptoms are not clear enough due to the gradual onset. During this period, common symptoms are forgetfulness, losing track of time, becoming lost even in familiar places. (World Health Organization 2017)

When the disease has considerably developed during the “middle stage”, signs and symptoms become more apparent. The signs are specified as being forgetful of recent events, names, getting lost even at home, having difficulty in communicating, needing help with personal care, experiencing behavior changes such as wandering and repeating questions. (World Health Organization 2017)
In the “late stage” of dementia, patients become dependent and inactive. Severe memory loss, physical signs and symptoms appear remarkably obvious. They are becoming unaware of time and place, having difficulty in recognizing relatives and friends, increasing needs for daily basic care and having aggressive behavior. (World Health Organization 2017)

3. AIM, PURPOSE AND RESEARCH QUESTION

The aim of this study is to focus on nurses’ feelings towards the care for dementia patients in variable settings based on existing literature. The purpose is to support existing theories and provide additional knowledge on how to enhance the quality of care for patients with dementia. The objective is also to recognize challenges which nurses are compelled with while delivering care for dementia patient.

Research question: What are nurses’ perceptions of caring for dementia patients?

4. METHODOLOGY

4.1. Literature Review

Literature review helps enhancing the efficiency of evidence-based nursing science by summarizing different information available on any topics. Healthcare professionals are regularly required to update recent augmentation or research that apprises their practice. Literature review allows practitioners access to all this information in the form of only one report. (Aveyard, 2010) The importance of
literature review can be viewed as an analysis and interpretation of pre-existing results. In this way, it provides suggestions to new advantageous findings, research methods. (Rowley & Slack, 2004) Therefore, undertaking a literature review is a simple way to orchestrating data of clinical evidences. (Gray, 2016, 62) Nursing’s perceptions towards the care of dementia patient are paramount to recognize in contemplation of improving quality care and nurses’ experience. This is such a diversified theme which cannot possibly be explored in one study. In this regard, conducting a literature review will help gather and synthesis the findings of various researches about nurses’ experiences of caring for patient with dementia into a single report.

4.2. Literature research

In this thesis, two autonomous reviewers would conduct the literature review research based on predefined rigorous criteria to diminish all bias and ensure the reliability as well as the consistency of the research process. The reviewers firstly made a search protocol in advance of finding databases to minimize unrelated information and recapitulate the main themes. The search protocol also supports the readers to comprehend ideas and methods of the research.

Study eligibility:

Peer reviewed articles published in English language from 2008 to date, that are available in full-text with abstract on the selected databases, which answers the research question were included.

As the first step, the authors chose CINAHL, MEDLINE and PUBMED as databases to obtain all relevant studies meeting our inclusion criteria. Several
keywords combination were tested prior to the data search. The Boolean tools such as "and", "or" were practiced to link the database search. The combination which gave out the best results includes the following keywords "Nurses" AND perceptions" OR "attitudes" OR “opinion” OR "experience" AND "dementia” OR “Alzheimer’s” OR “cognitive impairment” OR “memory loss”. Articles were first chosen based on their titles and abstracts. Afterwards, two authors filtered down the number of articles according to the inclusion criteria. A table showing the process of choosing articles that matched inclusion criteria was created (Table 1.) Once this was done, the final step was to cross-examine each other’s work and decide on chosen articles used for the analysis. Eleven articles met the inclusion criteria and were therefore analyzed for this study. Detailed analysis of the reviewed articles is listed as a table which could be found at the last section of this paper.

<table>
<thead>
<tr>
<th>Database</th>
<th>Results</th>
<th>Chosen based on the basis of title and abstract</th>
<th>Relevant studies based on full text</th>
</tr>
</thead>
<tbody>
<tr>
<td>CINAHL</td>
<td>136</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>MEDLINE</td>
<td>35</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>PUBMED</td>
<td>33</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>204</td>
<td>17</td>
<td>11</td>
</tr>
</tbody>
</table>

Table 1. The process of chosen articles.

4.3. Data Extraction and analysis

In a literature review, data synthesis means the process of obtaining information from the findings, results and discussions of the selected articles in order to answer the research question. (Kiteley and Stogdom 2014.17). Therefore, eleven articles were read and analyzed by each researcher and then discussed precisely together in order to collect the most suitable information. The chosen articles were analyzed through data reduction, data display, data comparison and then making conclusion and verification of data from the included articles. First the articles were read several
times to get familiar with them. Then, a word document was created to gather and all the information from the selected studies which answer to this study’s question were extracted. The aim was to generate new and fresh interpretation among these studies rather than reading individual papers solely. Therefore, every selected information that was found in the abstract, result, findings and discussion section of the articles were divided into different categories according to their similarities. Thus, themes were formed by grouping extracted data that are similar together (Figure 3). In the end, papers were re-assessed to assure that the final themes fit the research question (Aveyard, 2014.)
5. RESULTS

After the data analysis, researchers identified three main categories, regarding the nurses’ responses towards the care for dementia patient which are 1) Challenges in providing care for dementia patients, 2) The need for additional education and training and 3) Nurses’ coping strategies towards caring for dementia patients. Table 2 demonstrates the main categories together with their sub-categories. The results are discussed more explicitly in the following text.

<table>
<thead>
<tr>
<th>Main categories</th>
<th>Sub-categories</th>
</tr>
</thead>
</table>
| Challenges in providing care for dementia patients. | ● Lack of resources, time and support  
● The attitude of other healthcare professionals and family members  
● Stress from patient’s family and nurses’ own family  
● Nurses’ personal feelings towards the patients |
| The need for additional education and training | ● Education and training |

Table 2. Main categories and their sub-categories.

5.1 Challenges in providing care for dementia patients

Despite coming from different healthcare systems, most nurses working in dementia care experienced strain during their work. The primary source of strain came from being prevented from delivering the best care for dementia patients due to environmental factors. Nurses indicated the system, the community, their own family and patient’s family as influencing components. (Edberg et al, 2008; Byers et al, 2008; Krupic et al, 2015)
Lack of resources, time and support

Nurses experienced frustration and anger resulting from not having enough resources, opportunities or abilities to perform quality care for dementia patient. (Edberg et al, 2008; Byers et al, 2008) Improper staffing ratio – based on lack of knowledge of the complex needs of dementia patients – were causing frequent emotional exhaustion for the nurses. Heavy patient load also prevented nurses to holistically caring for those with dementia and their families (Byers et al, 2008). Nurses were deeply concerned about inadequate caring time for dementia patient. Most nurses felt they were not given enough time to communicate with patients to help them understand their current health status. They stated that since dementia patient did not comprehend as well as other patients, it was more time-consuming to assess their needs (eg: pain identification) and give verbal as well as non-verbal communication (Byers et al, 2008; Lars et al, 2010 Krupic et al, 2015; Burns et al, 2015). Moreover, nurses indicated that time spent at the patient’s bedside was significant for certain safety reasons. (Byers et al, 2008) Especially in perioperative setting, many nurses felt that they did not have adequate time to provide the most advantageous conditions when the patient was agitated. (Krupic et al, 2015) In addition, nurses reported lack of qualified pain management tools, since the traditional models cannot be applied for those with dementia as they lack the ability to self-report. (Burns et al, 2015) Nurses also felt powerless and frustrated as management did not support their concerns and opinions. (Edberg et al, 2008 & Bryon et al, 2011). Some stated to be forced into a subjacent position and were ignored by the ward. (Bryon et al, 2011)

The attitude of other healthcare professionals and family members

Many nurses working in dementia care felt that their expertise was not acknowledged and appreciated. (Edberg et al, 2008 & Bryon et al, 2011). Lack of
knowledge about dementia created stigma and negative attitudes from other colleagues towards those working in this field. Many staffs voiced belittling opinions which caused nurses unnecessary distress (Edberg et al, 2008). Their expertise in viewing the patient beyond their medical condition based on the intimate nurse-patient relationship, was not recognized both by the physician and the family members. Thus, some nurses expressed frustration and even resignation as their effort was frivolous. Furthermore, disagreements about policy were indicated between members of the care-takers team – leading to serious conflicts such as incomprehension and mutual indignation (Bryon et al, 2011).

Stress from patient’s family and nurses’ own family

Dealing with the patient’s family was reported to cause weariness among nurses. (Edberg et al, 2008 & Bryon et al, 2011) In cases when family members’ viewpoint on the patient’s care did not come to terms with the nurses, a distant and sometimes hierarchical relationship was accidentally formed. (Bryon et al, 2011) According to Edberg et al (2008), many nurses felt resentful for being under the family’s suspicion of not doing their jobs properly. Other nurses reported exasperation towards the family due to lack of empathy and understanding as their opinions did not clash. (Bryon et al, 2011) Discussing about their own family, nurses asserted situation at home and at work mutually affected each other. On the one hand, it was difficult to work efficiently and deliver the “best” care for dementia patients while having problems at home. On the other hand, it was demanding to be a parent or partner after a stressful day at work. (Edberg et al, 2008)

Nurses’ personal feelings towards the patients
The direct encounter with dementia patient was reported to have affected the nurses personally. (Bryon et al, 2011) Many nurses indicated feelings of overload, lack of energy and the deterioration of emotional resources, along with the feeling of guilt. (Bryon et al, 2008 & Shinan-Altman et al, 2015) It exhausted them that the energy did not exist reciprocally between the professionals and their patients, since patients with dementia were unable to express their feelings. (Shinan-Altman et al, 2015) Furthermore, some were aware that communication with these patients was extremely difficult, making it almost impossible to guide patients through various situations (eg: personal hygiene). As a result, they felt remorseful as their actions of delivering care could affect patients in a negative way (Edberg et al, 2008 & Shinan-Altman et al, 2015). The caretakers expressed impotence as they failed to protect dementia patients in delicate situations resulting from the nature of the disease. (Edberg et al, 2008 & Shinan-Altman et al, 2015) They also found it difficult to keep balance between patient’s well-being against others such as other patients, family members and themselves. This contributed to their constant emotional exhaustion. (Edberg et al, 2008) Lastly, some nurses indicated feeling strongly empathized for dementia patients – which lead them to emotional difficulties seeing patients in such conditions. (Bryon et al, 2008)

5.2 The need for additional education and training

Deficiency in education and skills

The nurse’s knowledge specifically in pain management area for dementia patient was reported to be problematic. According to Burns et al. (2015), nurses were aware of deficits regarding pain assessment despite being main responsible for this particular task. The nurses agreed that they could not apply their formal knowledge into practice or used the traditional model of pain assessment for dementia patient. Therefore, they sometimes mistook patient’s physical pain with other psychiatric problems. It is asserted that they mostly observed the mood changes and behavioral
responses of the patient to identify pain. (Burns et al., 2015.) Lack of training and knowledge preparation in pain management were claimed to be reasons for this nurses’ poor pain management skills. (Burns et al., 2015 and Hirata et al., 2016).

### 5.3 Coping strategies

Providing adequate care for patients with dementia is demanding, according to Byers et al. (2008), nurses often experienced dilemmas while performing care due to patients’ complex needs and behavioral disturbances. This theme discussed about nurses’ perceptions on how to overcome the previously mentioned obstacles to enhance the quality of care towards dementia patients. Within this theme, 3 sub-themes were classified: Nurses professional values and knowledge, work experience and interpersonal relationships.

**Professional values**

The reviewed studies claimed that seeing the dementia patient as a person and providing a holistic care for them were two most important elements which positively improved the care (Krupic et al., 2015; Lars et al., 2010; Hirata et al., 2016; Bryon et al., 2011; Cowdell 2015 and Bryons et al., 2011). Moreover, considering patient’s autonomy and privacy while providing holistic care was viewed to be essential (Krupic et al., 2015; Hirata et al., 2016). Meanwhile, being professional in decision-making, accountability, confidence, and patience, being attentive and present for patients at all times could contribute to a better nursing care experience (Bryon et al., 2011; Krupic et al., 2015 and Edberg et al., 2008). Nurses seemed to empathize and sympathize with patient’s vulnerability and defenselessness not only as health care professionals but also as human beings. Thus, they were willing to reduce this hardship for the patients by providing care with dignity. These values
allow them to establish better interest in the well-being of the patients (Bryons et al., 2011.) and primarily improved the quality of care for dementia patients.

Professional knowledge and experience

Moreover, it is disclosed that nurses with satisfactory level of knowledge about dementia disease and its characteristics could provide better nursing interventions (Lars et al., 2010; Hirata et al., 2016; Nakanishi et al., 2016 and Burns et al., 2015). This individual’s knowledge was indicated to have developed through one’s clinical experiences (Burns et al., 2015). Additionally, nurses who had longer working period in this field were having more positive experiences in delivering care to dementia patients. (Nakanishi et al., 2016) Nurses indicated that having a long and persistent contact with dementia patients gave them the ability to realize patient’s pain and other needs through their behavioral symptoms, which is quite challenging for juniors, less experience workers or staffs with training deficiency. (Burns et al., 2015).

Interpersonal relationships

Achieving a safe and sound relationship with dementia patient was reported to be difficult, some nurses admitted that they saw and treated dementia patients without emotional involvement.

By keeping cognitive and emotional distance from their patients, nurses could preserve themselves from unnecessary involvements and decreased emotional consequences that were common while providing care for dementia patients. However, this was reported to have caused feeling of guilt afterwards. (Krupic et al., 2015 and Shinan-Altman et al., 2015.) Moreover, a receptive atmosphere and close cooperation with physicians could facilitate nurses’ professional confidence. The nursing team cooperation was reported to have created a positive energy among
caretakers. They felt that cooperative conversations inspire different perspectives towards patient care. The team also helped each other to overcome difficulties and trauma triggered from the care for dementia patients. In addition, receiving mutual support and understanding from patient’s family members helped enhance nurses’ experience during the care (Bryon et al, 2011).

6. DISCUSSION

6.1 Discussion on key findings

As reviewed by this study, nurses are consistently forced to carry a heavy workload and given inadequate time to perform the care for dementia patients, despite scientific based evidence showing that caring for these patients is more time-consuming than others. As a result, poorer health outcomes have been associated with deficient staffing ratio. In addition, nurses also reported to experience stress and frustration resulting in escalated job dissatisfaction and burnout (Byers et al., 2008; Lars et al, 2010; Krupic et al., 2015; Burns et al., 2015). According to Willis and Henderson (2018), modest daily tasks such as assistance during meal time or frequent position changing for bed-bound patients can affect greatly on the quality of dementia care. Problems such as malnourishment and pressure sores are regularly gravitated from the absence of such simple tasks. Furthermore, evidence has shown the inability to deliver the most advantageous care for agitated patients due to heavy workload and inadequate caring time results in frustration, anger and guilty among nurses. (Edberg et al, 2008; Byers et al, 2008; Bryon et al, 2011; Krupic et al, 2015). In connection to the earlier statements, Carayon and Gurses (2008) indicates that staffing and nurses’ workload should be well managed in order to increase safety and care’s qualification for both nurses and patient. Willis and Henderson (2018) agreed, stating that the implementation of minimum staffing or decreasing nurse-to-patient ratios could drastically improve health outcomes for patients and job satisfaction among nurses.
Another major finding of this study shows that nurses working in dementia care felt that their expertise was not acknowledged and appreciated by both physicians, the care team and patient’s family members (Edberg et al, 2008 & Bryon et al, 2011). According to Edberg et al. (2008) and Bryon et al. (2011), due to the lack of empathy and understanding from patient’s family, nurses often feel resentful for being under patient’s suspicion of not doing their jobs properly which accidentally, created a distance and sometimes hierarchical relationship between the family and care-givers. Furthermore, disagreements about policy were indicated between the healthcare team’s members and lead to serious conflicts. As a result, some nurses ended up experiencing frustration and even resignation as their effort was frivolous. (Bryon et al., 2011). Therefore, Bryon et al. (2011) reveals that a receptive atmosphere and close cooperation with physicians could facilitate nurses’ professional confidence. The nursing team co-operation was claimed to create a positive energy among caretakers. They felt that co-operative conversations inspire different perspectives towards patient care. The team also helped each other to overcome difficulties and trauma triggered from the care for dementia patients. In addition, receiving mutual support and understanding from patient’s family members helped enhance nurses’ experience during the care and primarily enhance the quality of care.

Nurses who empathized and sympathized with demented people were more likely to provide holistic care for these patients (Bryon et al., 2011). However, Edberg et al. (2008) and Bryon et al. (2008) indicated, some nurses who felt strongly empathetic for dementia patients usually experience emotional disturbances or even having an imbalance lifestyle between work and their own living environment. Webster D. (2010) stated that empathy should not be felt by the nurse alone but rather to be expressed in a mutual way between the nurse, the patient, and the patient’s family. In addition to this statement, Cunico L. et al. (2012) suggested two main categories
which help the nurse to deliver appropriate compassionate care, including education and support from working placement. Having an appropriate on-going education about dementia knowledge and clear communicating guidelines between the nurses and patient’s family resulted in a positive influence on nurse retention and an enhancement of nurses’ feeling towards the care for dementia patients, as they become more skilful in their expertise (Chenoweth L. et al., 2014 and Webster D., 2010). Furthermore, it is essential to ensure good emotional and physical support from the organization and other colleagues for nurses who are caring for dementia patients. (Clissett P. et al 2013). It is also recommended that ‘relational practices’ warrant a higher place on the educational and competency agendas in order to support nurses to deliver appropriate compassionate care (Dewar B. and Nolan M., 2013). Additionally, Baker et al. (2015) suggested a web-based mindfulness course which included meditation practices as well as group discussion about challenges and experiences of incorporating mindfulness into daily lives and stressful situations. This could help alleviate burnout among nursing staffs and increase job satisfaction.

According to Wang, Xiao and Luo et al. (2018), healthcare workers with an adequate level of dementia knowledge and positive attitudes are more likely to detect and treat dementia patient in a timely manner and demonstrate a better care approach in comparison to those with poor dementia knowledge and negative attitudes. In line with earlier statement, nurses in the reviewed studies recognize the importance of their role in pain management for dementia patients. However, there are limitations which challenge nurses in performing effective pain management. The inability to apply formal knowledge and traditional assessment tools to real life situation has been listed as a main barrier in carrying out effective pain management to dementia patients. Researchers support this showing that inapplicable knowledge and assessment tools affect the care outcomes given to dementia patients. Evidence shown are mistaking patient’s physical pain with other psychiatric symptoms or the identification of pain is mostly relied on patients’ behavioral and mood changes were found because of the lack of education (Burns et al., 2015). In connection to previous
statements, Acheterberg, Pieper and Dalen-Kok et al. (2013) implies the necessity in implementing a continuous education and training program to nurses, as well as evaluating these implementations to ensure the effective use of any updated tools. Furthermore, it is essential to provide support and clear guidance for nurses who are caring for people with dementia in order to enable them to make informed decision and remove the current reluctance in pain management. It is also advisable to establish a “pain management team” and increase the opportunities for the healthcare workers to consult with experts in all dementia care settings to achieve a collaborative decision which improves the effectiveness of pain management in dementia in the future. In addition, Handley et al. (2017) stated that developing evidence-based explanations and identifying interventions to a dementia-friendly environment could positively improve patient and career outcomes. A team of “Dementia champion” or dementia nurse specialist who expertise in dementia care were recommended as “advisors” or “tutors” to provide peer support and advice for staff on care practices, treatment and community services. Organizational and clinical authority were advised to communicate the priorities of dementia and address staff concerns around managing risks and workplace disruption in person-centered ways. In addition, it was necessary for staff to be supported by training and resources which improved decision-making process as well as safety of dementia patients.

As reviewed by this study, nurses who include a holistic and patient-centered care approach to dementia patient, could significantly improve the treatment outcomes (Burns et al., 2015). Moreover, according to Kim and Park (2017), dementia patients rarely express agitation and other disturbance behaviors when engaged in certain types of activities, including personal interests. Therefore, it would be logical to see that the care for demented patients could be advanced with the use of patient-centered care approaches, which including individual’ preferences and interests while delivering care.
6.2 Ethical Consideration, validity and reliability

The data used in this literature review was collected from three major databases for health science articles: CINAHL, MEDLINE and PUBMED. The authors achieved these materials securely on private computers and carefully check if the articles included informed consents from its interviewees. Moreover, the unambiguous and detailed description of the procedure here also contributed to the study’s reliability. Having predefined research protocol, with its thorough search of the literature and use of inclusion/exclusion criteria, documented search process, critical appraisal and data extraction and synthesis, made it possible to obtain a trustworthy and prevent plagiarism. (JBI Manual, 2014.)

To enhance the reliability of this study, the two researchers have done separately appraisal for all chosen articles, discussed them together and finally cross-checked the results. As mentioned, a clear planned of procedure was followed throughout the process to avoid any possible biases. However, the researchers have also acknowledged the limitations within this literature review such as the deficiency in language by using only English articles and the availability bias of articles.

6.3 Conclusion

In conclusion, the results of this literature review have shown that nurses face many different challenges while taking care of patients with dementia as well as their inevitable need for further training and education. Challenges such as heavy workload, lack of team support and patients’ family members support, emotional exhaustion while taking care of dementia patient as well as the knowledge deficiency in pain assessment are reported to have affected negatively on the care for dementia patients. Thus, another literature review is recommended to further evaluate the
challenges and need for further training as well as providing solutions to improve nurses’ perceptions towards the care for dementia patients.
REFERENCE


Appendix 1: A summary of the articles included in this study.

<table>
<thead>
<tr>
<th>Author(s) (year), Country</th>
<th>Purpose/Aim of study</th>
<th>Participants and sample</th>
<th>Methods/Instruments</th>
<th>Main findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bryon et al. (2011), Belgium.</td>
<td>The study was to analyze and describe Flemish nurses’ experiences in providing care for hospitalized patients with dementia, especially in case of artificial nutrition and hydration (ANH).</td>
<td>21 hospital nurses from nine different hospitals in Flanders’ regions.</td>
<td>Interview guided by a literature review.</td>
<td>Nurses are comprehensively participated and fulfill diverse roles within the care process of ANH towards demented patients. Nurses’ guiding principle in this area is “providing good care” which grounded in “being touched by the vulnerability of the patient”. And thus, nurses professionally and personally are greatly influenced and it plays an important role in their actions, emotions throughout the ANH care process.</td>
</tr>
<tr>
<td>Cowdell (2015), UK.</td>
<td>The study was to examine the experiences of both demented old patients and nurses in relation to the care delivered to and received by in an acute hospital setting.</td>
<td>11 old people, aged with dementia before hospital admission, 25 registered nurses and 33 nurse’s assistants who had worked with elderly between two months and 22 years.</td>
<td>Ethnographic observation in a total of 125 hours between 7am-8pm and interviews were used.</td>
<td>Providing to and receiving care by older people with dementia in acute hospital settings is not always adequate and satisfactory. Demented patients are ordinarily described the delivery of care and experience of being in the hospital is deplorable. Likewise, nurses aim to provide optimum care, however this is not always obtainable. Therefore, sub-optimum care could be understandable by considering the effect of empathy and Bourdieu’s theory of practice.</td>
</tr>
<tr>
<td>Hirata H., Harvath T. (2016), USA.</td>
<td>The purpose of this study was to analyze Japanese healthcare’s workers and their attributions, beliefs, cultural explanations towards physically and psychologically aggressive behavior</td>
<td>137 care workers in 10 nursing homes in both northern and western parts of Japan.</td>
<td>Three open-ended questions analyzed using a content analysis.</td>
<td>Most of the participants addressed that they believed physically and psychologically aggressive behavior symptoms of demented people came from their own stress. Around one-fourth of the participants agreed that Japanese values as loyalty and hierarchy</td>
</tr>
<tr>
<td>Study Authors and Year</td>
<td>Study Overview</td>
<td>Methodology</td>
<td>Findings</td>
<td></td>
</tr>
<tr>
<td>------------------------</td>
<td>----------------</td>
<td>-------------</td>
<td>----------</td>
<td></td>
</tr>
<tr>
<td>Krupic et al. (2015), Sweden.</td>
<td>The purpose of this study is to characterize the difficulties in anesthesia nurses’ experiences that related to perioperative care in hip fracture patients with dementia. Moreover, it also showed how communication could be maintained effectively in this setting.</td>
<td>10 anesthesia nurses (5 men and 5 women) from a university hospital in Individual interviews and the data were analyzed using qualitative content analysis.</td>
<td>Three main categories were discerned included “Communication”, “Dementia as a special issue” and “Practical issues”. Dementia was seen as one of the most difficult and shifting diseases an individual could suffer from. Therefore, during perioperative setting, nurses need to embrace patient with empathy, holistic, respectful and prepare themselves with a profound knowledge of how demented patients react to surgery. It includes allocated time to be able to explain clearly, patiently and enable patient participation. State-of-the-art analgesia and anxiolytic medications are mandatory.</td>
<td></td>
</tr>
<tr>
<td>Lars et al. (2010), Sweden.</td>
<td>To define care providers' opinions of and reasoning for oral care in nursing home with demented residents. Additionally, it described nurses' perceptions in relation to their responsibility for monitoring oral care.</td>
<td>Nine care providers and four nurses in nursing home units specialized in dementia. Two sub-studies were carried out: focus group discussion and interviews.</td>
<td>The discussion group revealed three main themes which were Art of caring, Barriers and Treatment strategies. Even though, it is very important to provide oral care to demented old people, however, after the discussion, three main findings were founded: unclear responsibilities of different staff members about providing oral care, lack of guidelines.</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Intervention Details</td>
<td>Research Methods</td>
<td>Findings</td>
<td></td>
</tr>
<tr>
<td>-------</td>
<td>----------------------</td>
<td>------------------</td>
<td>---------</td>
<td></td>
</tr>
<tr>
<td>Shinan-Altman et al. (2015), Israel.</td>
<td>Interventions within the basic caregiving routines which included in nursing home for patient with dementia.</td>
<td>The purpose was to study the relationship between Alzheimer's disease (AD) illness representations and burnout among social workers and nurses, based on the self-regulatory model.</td>
<td>The study indicated that emotional representations were associated with burnout while only some of the cognitive illness representations were associated with burnout. In other hand, cognitive illness representations were related directly to burnout while the relation between emotional representations and burnout was mediated by emotion-focused coping. The study found out that AD characteristics had an impact on both personal and professional levels of healthcare workers; the participants also showed negative feelings towards AD and revealed that these perceptions and opinions had led them to burnout.</td>
<td></td>
</tr>
<tr>
<td>Söderlund et al. (2015), Sweden.</td>
<td>The study aimed to illustrate the actions and reactions of demented people living in nursing homes in one-to-one conversations with nurses during one year of virtual machine (VM) training, while observed in videotapes.</td>
<td>Firstly, 327 social workers and nurses completed about AD. Secondly, interviewed with 8 social workers and nurses.</td>
<td>Through the videotaped conversations in the end of the VM training program, individuals with dementia had the opportunities to use their remaining communications skills and demonstrated signs of being confirmed. Moreover, after the experience, the nurses had enhanced their own communication skills, which gave the persons chance to communicate what was on their mind at the time. Accordingly, demented patients might also benefit from VM training program that spotting the communication.</td>
<td></td>
</tr>
<tr>
<td>Authors</td>
<td>Country</td>
<td>Aim of Study</td>
<td>Participating Population</td>
<td>Methodology</td>
</tr>
<tr>
<td>---------</td>
<td>---------</td>
<td>--------------</td>
<td>--------------------------</td>
<td>-------------</td>
</tr>
<tr>
<td>Nakanishi et al. (2016), Japan</td>
<td>The aim of this study was to examine factors affecting knowledge and attitudes of nursing home staff towards palliative care for advanced dementia in Japan.</td>
<td>Nursing home staffs recruited from long-term facilities across Shiga, Saga and Tottori.</td>
<td>A cross-sectional study design was applied in the study. Paper questionnaires were distributed to participating facilities.</td>
<td>Nurses who have longer tenures tend to be more positive towards palliative care. In addition, positive attitudes were observed among nurses with higher education levels. The facility policy on end-of-life care for patients was also associated with nurses’ knowledge and attitudes.</td>
</tr>
<tr>
<td>Burns et al. (2015), United Kingdom</td>
<td>The aim was to discover nurses’ knowledge and attitudes towards pain management for older people with dementia.</td>
<td>Registered nurses associated with pain assessment and management for older people with dementia in all healthcare settings.</td>
<td>A systematic review of peer-reviewed articles between the year 2000 to 2014.</td>
<td>Nurses highlighted the difficulty in recognizing pain for older people with dementia although pain is highly prevalent. Nurses also expressed not having adequate pain assessment tools. In addition, physicians and nurses’ communication and trust were paramount, leading to a hesitation in the physician’s medical decisions.</td>
</tr>
<tr>
<td>Edberg et al. (2008), United Kingdom</td>
<td>The study aimed to discover nurses’ experience towards the use of strain in the care for dementia patients.</td>
<td>35 nurses in Sweden, Australia, United Kingdom</td>
<td>The study conducted tape-recorded discussions and used qualitative approach for content analysis.</td>
<td>Nurses expressed constant strain and frustration while encountering patients with dementia. Working environment factors such as lack of resources, lack of time and poor management support were contributing to the negative experience. In addition, nurses felt the severe inability to communicate with the patients which forced them to carry out the care against patients’ will. Nurses also experienced frustration in trying to protect the patients against “reality” in different situations.</td>
</tr>
<tr>
<td>Byers et al. (2008), USA</td>
<td>The aim of the study was to discover registered nurse’s experience of caring people with dementia in acute care setting.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Registered nurses who frequently work in medical-surgical units and have been caring for dementia patients.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Tape-recorded open-ended interviews, field notes. Six steps of Van Manen’s hermeneutic phenomenological approach were applied in the study.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Nurses expressed frustration and remorse as they were unable to provide safe, holistic quality care for patients with dementia due to poor staffing ratios. The lack of perceived complex needs of these patients were mentioned as the reason. Nurses describe feelings of aggravation, time consuming, worrisome and frustration as well as general concern for dementia patients. Nurses also reported the need for full presence in knowledge and commitment with patients and families to provide quality nursing care.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>