The challenges of communication with the late onset dementia patients

A nursing literature review.

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## Abstract:

The main goal of the study is to investigate the challenges of communication with the late onset dementia patients and also determine the responsibility of nurses in alleviating the challenges faced by the other nurses and caregivers of the late onset dementia patient in the society. The research questions posed for this study were; 1) what are the communication challenges of the late onset dementia (LOD) patients? And 2) in which ways can nurses assist in mitigating these challenges? Bonnie W Battey’s theory was used as the framework for this study. The research was carried out by use of qualitative method where literature review was used to collect data. Finally, the study selected 10 articles which were analyzed by use of matrix method.

## Keywords:

Dementia, late onset dementia, nurses, communication.
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1 INTRODUCTION

Alzheimer’s disease (AD) which is the main form of dementia is a degenerative disorder affecting the brain resulting in the loss of memory. The disorder affects 5.3 million people in the United States of America making it the seventh leading disease in the country. There two major forms of the Alzheimer’s disease which include the familial AD which affects persons whose age is less than sixty-five years and it accounts for 500,000 cases in the USA alone. However, the remaining proportion of cases affects adults who are aged above sixty-five years and are commonly referred to as sporadic AD. There are various factors that determine the prevalence of the disease which include the level of education, genetics, co morbidities as well as age. Presently, there is no other known method that can be used to diagnose the disease apart from an autopsy. Also, there is no known cure for the disease but there are promising researchers regarding early detection and treatment that is underway.

Dementia is a condition that leads to memory loss and deterioration of the behavior hence affecting the performance of day to day activities which includes communicating effectively with other people including nurses and caregivers. Inasmuch as this syndrome affects mainly older people, it should not be attributed to spontaneous conditions that occur at old age (WHO, 2015; Hoe & Thompson, 2010). WHO (2015) indicates that there are 47.5 million people globally who are suffering from dementia and there is also 7.7 million of fresh cases reported annually. The common known cause of dementia is Alzheimer’s disease which contributes to 60-70 percent of all the cases. The disease has been known to cause emotional, psychological as well as socioeconomic effect to the nurses, society and the family members. There is lack of understanding and awareness of early-onset dementia (EOD) among the members of the family which causes stigmatization and interference to diagnosis and care (Flynn & Mulcahy, 2013).
1.1 Background

The concept of my study is for future nurses to understand the importance of communication when in contact with the late Onset Dementia patients. Can a Late Onset Dementia patient understand a simple ‘‘YES or NO’’ in a nonverbal behavior. Since Dementia affects the process that involves in understanding, perceiving and responding to verbal and nonverbal communication, it is important to for nurses to have a clear form of communication. Through communication a greater chance of interaction between nurses and patients is initiated and goes well in establishing a good rapport at the work environment.

According to Flynn & Mulcahy (2013), there are many challenges faced by the nurses and caregivers especially when the caregiver is a close relative. In this case, taking care of the patient with dementia is an intimidating endeavor particularly when there is no reliable source of income in the family. In essence, family members are the ones bearing the cost of taking care of a patient (Ducharme, Kergot, Rene, Louis, Pascal & Florence, 2014). This, therefore, applies to the persons who are taking care of persons who are suffering from dementia. Regardless of who is responsible for taking care of the patients, it may cause resentment especially in the event where the nurse feels that the responsible bodies or other members of the family are not offering any support.

1.2 Research Questions.

Having a clear understanding of the healthcare experience when dealing with persons with dementia is becoming an important matter that should be given priority due to the increasing number of people affected by the condition. By understanding these challenges, it will give an opportunity to the nurses and other healthcare practitioners to better understand the appropriate ways to enhance the quality of care for the patient affected by dementia. The important things that the nurses will benefit from the understanding of the challenges are how to effectively communicate with the patient for a better healthcare delivery. Therefore, the primary objective of this study is to establish the challenges of communication with the late onset dementia
patients and also highlight the ways in which nurses can offer support to them to help them in the management that comes as a result of dementia. My research questions are two:

- What are the communication challenges of the late onset dementia (LOD) patients?
- In which ways can nurses assist in mitigating these challenges?
2 THEORITICAL BACKGROUND

This section explains more about Dementia and the type of Dementia I will be focusing on (The Late onset Dementia). In addition to this nursing skills are used to improve communication skills between the Late Onset Dementia patients and nurses.

2.1 Dementia

This is a type of disease that leads to the degeneration of the brain because of shrinking both in the sub cortical and cortical regions which give room for the cerebral ventricle to increase in size. According to (Engedahl and Hagen (2009), the main cause of the brain shrinking is the death of brain cells. Alzheimer disease is, therefore, the common form of dementia. This type of disease causes adverse effects on the patient which include the loss of memory which interferes with the process of learning, reasoning and thinking. This, therefore, leads to some conditions such as aphasia which are not in line with the place and time among those with this disorder (Warner et al., 2002; WHO, 2015).

2.2 Signs and symptoms of dementia

Dementia is presented differently among the individuals. This depends on the severity of the disease and the personality of the individual before getting ill. The signs and symptoms of dementia can be understood by subdividing the disorder into three stages as they have different presentation (Sandilyan & Dening, 2015).

a) The early onset stage- this is the initial stage that is gradual and is highly overlooked. Some of the common symptoms presented at this stage include losing track and getting lost in places that are familiar (Sandilyan & Dening, 2015=.

b) The middle onset stage- the common symptoms and signs at this stage could be much clearer as it advances. The patient at this stage can forget the names of familiar people and the latest events, getting lost at the homestead, develop communication difficulty, requires assistance with personal care and experiencing a change in behavior, repeating and wandering questions (Sandilyan & Dening, 2015).
c) **The late onset stage**- during this stage, the patient is fully dependent and unable to move which also include adverse memory loss. Further, both the physical symptoms and signs are evident in the patient. The common symptoms include disorientation in time and place, walking difficulty, hard to recognize close friends and relatives and aggression. According to the World health organization (2015) patients at this stage would require assisted care.

### 2.3 Prolonged Diagnosis

Based on the evidence, the psychological burden is sometimes caused by the questions that are not answered well or those whose response cannot make sense to help in the decision-making process. Nonetheless, other factors that cause frustrations include uncertainty and confusion as they anticipate getting the appropriate communication from the patient (Bakker et al, 2010; Potgieter & Heyns, 2006). Therefore, the spouses face a great challenge of addressing the issues affecting the patient hence the need to have interventions which will make them get prepared and appreciate their new responsibilities as the careers for the patients suffering from the late onset dementia. Nonetheless, Bakker et al (2010) assert that early detection, as well as diagnosis, will assist in containing most of these challenges hence enabling the spouses to fully get conversant with the changing behaviors shown by the patient. In so doing, it will help them seek the appropriate help from the healthcare practitioner which will assist them to understand their new responsibility.

### 2.4 The need to get informed

The need for conversation and information is vital to the relatives in the process of disease prognosis. In essence, providing information that is useful in educating the relatives make them accept the responsibility. The respondent indicated that this can be undertaken in any situation in the presence of relatives or any time the nurse is in contact with the patient or the relative. However, where the patient is not able to communicate effectively so that he or she can indicate the concerns, it makes it hard for the nurse and the relatives to understand the appropriate help that can help address the concerns (Ducharme et al, 2014). In this regard, the patient should be
able to provide the extended family members with some information which will guide them in making the right decision on the appropriate care. It is so because the careers are in a position to do about half the task that can be done by the nurses only if they are provided with the right information.

2.5 Emotional Burden

The outcomes indicate that the process of dementia is quite challenging as the disease advances since the patient is physically present, but the psychological abilities are lost which causes distressing factor to the careers (Bakker et al, 2010). Loss of companionship and personal feedback need to be seen as well as improved self-esteem are the main subthemes that emerged.

2.6 Loss if personal feedback and companionship

The closeness that was in existence before the patient was affected with dementia is lost since the caregiver and the patient is not able to communicate effectively. There arises a fight between the necessities to attain a closer psychological space to the caregiver which is tied with the greater urge to reestablish the previous relationships. The communication breakdown makes it hard to express love to the person loved before hence the person gets disconnected from the patient. This means that the patient may not get the necessary attention which causes distress. In this regard, when there is no opportunity for the meaningful exchange, natural meeting and personal stories tend to reduce drastically (Bauer, 2010). It so because no one can sit down and communicate with a man who is not responding. After familiar humorous comments are lost, the patient becomes silent without leaving feedback hence causing more distress to the caregivers. The opportunity of sharing the love and fun memories will change significantly among other important things such as decision making which reduces interaction between the patient and the caregiver. Nonetheless, the breakdown of the meaningful dialogue significantly creates a strong reaction emotionally among the informants. Some will thus speak majorly about the missing basics and the loneliness which takes place due to the absence of dialogue.
2.7 Self Esteem Improvement

The findings prove that self-esteem is an important ingredient in the well-being of the caregiver and the patient affected with late-onset dementia. Further, the improved behavioral support to the spouse or the career of the dementia patient assists in negating the effect of the adverse effects of becoming the main caregiver (Ducharme et al, 2014). This is due to the fact that the caregiver will forget to take care of herself as more of the time is taken addressing the issues affecting the patient. This affects the special orientation of the caregiver since they will not be able to enjoy their lives again. The caregiver is forced to constantly at the care of the patient and will be required to do the right things all through since if they do anything wrong it will hunger the patient who at this point is not in a position to communicate the discomfort (Bakker et al, 2010). Finally, the caregivers will not be able to take vacations since they will need to be close to the patient to monitor their behavior.

2.8 Personhood and Social Relationships

According to Ward et al. (2008), people dementia patients that live in the care homes attempts to interact with people around them. The study on the association between the caregivers and the residents indicated that they were carrying out their activities in a standardized way rather than taking part in a more social way with the individual. In as much as the social interaction of the people varies significantly, based on the level of engagement with the residents, the contact with the caregivers indicated a small proportion of variation.

Individuals with advanced dementia try to express their sense of self and also to comprehend their surroundings and environment (Clare 2008, Edvardsson & Nordvall 2007, Sabat 2010). In as much as the person suffering from dementia may not be in a position to use words in its communication, there other forms of communications which will need creativity and resourcefulness of those around the person to interpret the message (Allan & Killick 2010). This is quite challenging to the people caregivers since they may not be able to understand the non-verbal communication from the patient hence influencing the kind of care that patient will receive from the caregiver.
The respondent also found out that there is a need for the inclusive strategies in taking into consideration and responding to whatever may be seen as communication attempts by the patient. Some of these non-verbal communications that can be demonstrated by the patient include physical movement of the body parts, embodied gestures and sounds which can be observed among the patient as they try to communicate and express their selfhood (Allan & Killick, 2010). Furthermore, it is imperative to identify some ways that work effectively for the patients which will ensure the establishment of the meaningful link. These connections will go hand in hand in promoting various benefits regarding the welfare of the patient and the general quality of life.

In the figure above, it shows how psychological burden experienced by nurses with the late onset dementia patients. In regard nurses are affected psychologically because they are not able to communicate effectively to the patient. The researcher found out that without taking into
consideration the communication challenges faced by nurses makes it hard to attain quality care for the late onset dementia patients (Chioa.Wu & Hsiao 2015).

2.9 Ways in which dementia is presented among patients (Hoe & Thompson)

Understanding the way dementia is presented in a patient is important in the identification of various challenges a patient faces. It helps also in differentiating with other diseases which may be having the same symptoms as dementia. Due to this, healthcare professionals such as nurses can come up with a care plan which is geared to eliminating the symptoms through treatment or apply strategies that can help the patient cope with the condition effectively (Kovach et al., 2000). Therefore, the figure 1 below will be of great importance to the thesis in the sense that it highlights all the issues related to the late onset patients such as loss of memory, impaired judgment, faulty reasoning as well as difficulty with the abstract thinking. All these issues affect the communication ability of a patient since at some point it leads to communication breakdown. Thus, when a nurse is conversant with all these issues, it will form a basis in determining the type of communication that they can employ to ensure effective communication between the late onset dementia patient and the nurse hence helping in administration of quality care to the patient.
2.10 Relatives

Relatives refer to those persons who are close to the patient and it comprises the primary caregivers, those that contribute to the daily activities of the patient and help them perform some practical tasks (Helsedirektorat, 2010). As it regards to dementia, relatives are the family members who take part in daily life of the dementia patient and they include fathers, mother, wives, sons, daughters as well as unmarried partners who assist in the provision of prime care to the person suffering from dementia. However, the main concentration of the research is only confined to the spouse as they are mainly present to help in case of behavior change of the
partner. Due to forgetfulness and behavioral challenges with the late onset dementia, when relatives visit, they tend to go through so much difficulties in communicating to their moms and dads because of lack of communication. Through the help of the nurse’s communication can become easy thus paging way to the relatives. In this case relatives are affected in a way that, being that they sometimes come to visit their parents or spouses. They might get affected by the communication challenges. Nurses are supposed to assist the spouses by explaining to them the psychological effects that comes with the late onset dementia. The relatives might feel affected when they come to the hospital or homes and they cannot be recognized by their parents or spouses. Being that the nurses are the primary caregivers and thus the trust and communication level differs from that to the relatives, might affect the feelings of the relatives.

2.11 Nursing assistance to relatives

More than 60 percent of the patients suffering from dementia get assistance from the family members and in many cases receive the required care at their homes (Sarna & Thompson, 2008). Further, Sarna & Thompson indicated that there are undocumented facts which show that home-based cares save billions of dollars every year which is not paid by taking part in taking care of the patient. However, some studies indicate that the caregivers lag in the health due to caring roles which are bestowed unto them. Therefore, with the rise in the cases of dementia among the individuals as predicted by the world health organizations, it is evident that the number of people who take care of the dementia patients will significantly increase.

The best way to ensure that the caregivers of dementia patients remain sane is to offer them with professional assistance, advice and support. These ranges from the mental assessment and evaluations which can be given in different forms such as social care services as well as the provision of timely education as well as education which help them in making informed decisions regarding what is good for them to help the dementia patient.

The nurse needs require the application of various interventions for it to be successful (NICE, 2006). Some of these interventions include contacting support groups that deals with dementia patients, psychology education which must be directed to various persons based on the stage of
disease since every stage has its own unique requirements. There is also a need for training to be organized to give them an opportunity of solving some problems according to Paton et al (2004).

The professional nurse practitioner assists members of the family to cope with the challenges caused by dementia as well as the need to get meaning in their experiences. Without a proper understanding of the situation in which the member of the family is going through regarding provision of care to the dementia patient, it is hard to help the caregiver. Prigerson (2003) asserts that the situation in which the dementia patient can be described as “triple grief” based on the challenges they face while giving out care to the patients. In this case, the triple grief can be as a result of relationship changes, prolonged admission in the healthcare facility and finally the grief of losing a loved one due to dementia.

Nursing care is differentiated into four separate pillars which include treatment of the disease, support to the patient, treatment of the disease symptoms and finally giving support to the caregiver (Rabins et al., 2006). The study also argued that more focus should be on finding the right treatment for the patient and also accommodate the challenges that are faced by the caregivers. In so doing, it will imply that both the members of the family and the dementia patient are equally important as it relates to requirements of help.

Further, it was identified that speech communication dominates the social world. However, for the case of the people affected with dementia, as the disease progresses, there is diminishing of communication ability. This is because the patient may only be able to retain some few words or at some point, they may not be in a position to communicate at all. In this regard, the rising cognitive impairment that is associated with the advanced stage of the disease has devastating effects on the association of the people which include the caregiver and the nurses. In essence, effective communication play a significant role in comprehending various strategies to be used to address the issue affecting the person and make sure that they remain part of the shared social world.
3. THEORITICAL FRAMEWORK

Bonnie W. Battey theoretical framework was used for this study which is a humanistic nursing communication theory that concentrates on the interpersonal associations between the patients, peers, colleagues as well as the nurse. This theory can help in the reviewing of the appropriate literature and offers an opportunity for identifying the work of other researchers which help in the attainment of research objectives and answering of the research questions. Fink (2010) define review of literature as “a systematic, explicit, and reproducible method for identifying, evaluating, and synthesizing the existing body of completed and recorded work produced by researchers, scholars, and practitioners”. Due to this, the respondent will utilize Bonnie W Battey theory as a guide when carrying out analysis.

3.1 Bonnie W Battey View of Nursing

The theories of humanistic nursing communication and humanistic nursing communication were developed to bring the knowledge of human relations and communication to nursing. In this regard, both theories are believed to be in line with the humanistic and holistic theoretical paradigms are meant to be used alongside other theories. Therefore, the theory by Bonnie Battey put more emphasis on the relationships between colleagues, nurses, peers and patients. The theory has been used to different research which includes the job satisfaction communication importance (JSCI) and the nursing communication observation tools (NCOT).The NCOT research was used by Dunn (1987).The purpose of study was to test a selected relationship statement on Battey’s Humanistic Nursing Communication Theory by examining the effect of reminiscing on the communication behavior of elderly individuals in nursing homes the America specifically Northern Carolina. The theory of spiritual care for nursing practice is one of the theories that can be used alongside Bonnie Battey theory. I chose this theory because it talks about humanistic nursing communication. The reason as to why I chose this theory is because sometimes nurses might forget that the late onset dementia patients are still human being with rights and they do deserve respect just like any other human being.
The author (Bonnie W. Battey) emphasizes more on how nurses communicate to patients and also other colleagues. This is the theory that I chose to use because it implants more on communication. In her theory she explains how communication brings trust, dialogue, praises, support and encouragement. Nurses ought to remember that while communicating to the late onset dementia patient’s eye contact is important and also gentle touch. A message should be passed out in a gentle yet warm voice that is clear. That is what Bonnie W Battey emphasizes on.

Figure 3. Bonnie Battey Model

The aim of the author at this point was to seek a solution to the issues of establishing holistic care practice in the hospital as well as similar healthcare agencies and also in the education programs. Nonetheless, the spiritual care for the nursing theory was used to offer guidance and the structure of the effort. Presently, incorporating spirituality into nursing practice is one of the intangible tasks that should be addressed adequately. Therefore, this theory will be helpful in multicultural approaches and acts as a guide for the nurse leaders and educators to ensure that there is an effective communication between the late onset dementia patients and nurses (Sheldon & Ellington, 2008).
4 METHODOLOGY

The methodology section includes the overview of data collection, the way data was collected and the methods that were used. Further, the matrix is explained as well as the ethics that guide the study.

4.1 Research Method

The research method gives an overview of how the study should be undertaken to address the problem at hand by reaching new knowledge. According to (Dalland, 2007), the reason for selecting a specific method from the alternatives is to enable collection of appropriate data that ensures understanding of the problem at hand in a professional manner. There are various methods that can be used by a researcher to attain objectives of the study by answering the research questions. In essence, there are two main research methods which in this case are qualitative and quantitative methods. The method used varies from research to research. Therefore, this research employed qualitative research method.

4.2 Data Collection

Polit and Beck (2012) defined collection of data as gathering of necessary data which will be used in answering the research problem. In this regard, the data that was used in this study was collected from the articles which were obtained electronically in different web pages. The sites that were used include MEDLINE, Punmed, PsycINF, EMBASE and Cinahl, Cochrane databases. Keywords were used to identify the relevant article and journals from different sites. The keywords were: late-onset dementia, challenges of LOD, nurses of Late-onset dementia, and need for support. The articles that were written in English were selected for the study and those that were written in other languages were omitted.
Given many articles and journals that were found in the different websites, most of them were not relevant to the study. Some of the articles that were excluded were not written in the English language, were older than 15 years, were not available in full texts and/or were not peer reviewed. This means that they could not meet the inclusion criteria that were set out for this study. This was dependent on the criteria of exclusion and inclusion that were employed in choosing the articles to be used in the research. In this regard, articles that are older than 15 years were not included in the study. Also, those articles that were not peer reviewed were not
selected for the study including those that were not available in full texts. However, there are some other articles that were rejected after reading after considering its contents and the inclusion criteria that was put in place. Nonetheless, on the data collected in the clinical setting, the respondent made observations of the incidences and use it in the discussion section. This researcher ensured that the characters and the information were in line with the ethical responsibility in the sense that the privacy and protection of the patient were guaranteed.

The method that was used to model the design of this was the matrix. In this regard, the paper trail folder has all the required literature. This means that the matrix folder stored all the needed information while the document folder had downloaded files of all the articles and journals that were used for the study.

Table 1. Criteria that was used for exclusion and inclusion

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Articles that were available in the language understandable to the researcher (English)</td>
<td>Articles and journals that were published in other languages other than English</td>
</tr>
<tr>
<td>Articles available in full text</td>
<td>Articles which cannot be found in full text</td>
</tr>
<tr>
<td>The article was peer-reviewed.</td>
<td>The article was not peer-reviewed.</td>
</tr>
<tr>
<td>The articles were not older than 15 years</td>
<td>The articles were older than 15 years</td>
</tr>
<tr>
<td>Articles had relevant information to the study</td>
<td>The articles had no relevant information about the study.</td>
</tr>
</tbody>
</table>
4.3 Matrix Method Overview

Several ways exist in which literature review can be undertaken to obtain the necessary information for use in the scientific research. Garrard, (2011 asserts that “a review of the literature consisting of reading, analyzing, and writing a synthesis of scholarly materials about a specific topic” the matrix method therefore strictly follows a systematic process which entails 5 important concepts. Some of these important concepts include indicating the review purpose, selecting and screening of the scientific papers that are in line with the set criteria, careful screening the papers to authenticate their statistical procedures, scientific methods and validity of the data collected, summarizing the findings and finally coming up with a conclusion as per the gathered evidence (Garrard, 2011). Garrard further defined matrix method as the amalgamation of both processes and structures for easier and systematic review of the literature. The matrix method structure is given by the master folder in the literature appraisal in form of documents and notes that were collected by the respondent in the process of reviewing the literature. The components of the master folder as indicated by Garrard (2011) include the document folder, the paper trail folder, synthesis folder and review matrix folder.

4.3.1 The paper trailer folder

This is a research process record that was utilized by the respondent in the process of identifying materials that were relevant for the study (Garrard, 2011). It is, therefore, the collection of all the works of literature that were identified, appraised and important notes were made by the researcher about the materials in search of relevant materials to be used in the study. They comprise the databases obtained electronically, the keywords used in search of the information, personal records among other materials that were consulted by the researcher.

4.3.2 The Matrix Folder

This is one of the matrix method structures. Matrix folder is, therefore, a table or spreadsheet which has both rows and columns that were used by the researcher to collect summaries of all
the reviewed journal, articles, books, chapters of books or any other material that were incorporated in the literature review (Garrard, 2011). It is in the matrix folder that all the literature that was reviewed by the researcher was tabled in their order of relevance.

### 4.3.3 The document folder

Garrard (2011) asserts that the document folder comprises of the downloaded copies, links to books and journal that were found online, the PDFs files and book chapters that were collected in the literature review. It is in the document folder that the review matrix folder was created.

### 4.3.4 Synthesis folder

Synthesis folder refers to the respondent’s use of the matrix method to write the critical appraisal of the text collected depending on the abstract information obtained in the literature search. In this regard, the four matrix methods are important in the process of carrying out literature review using matrix method. Nonetheless, it is solely after matrix method process that the literature review can be said to be complete. The main reason as to why the matrix method was used in this study is that it is particularly designed for carrying a review of healthcare literature (Garrard, 2011). Due to this, it makes this method more suitable for this research that explores the challenges of communications with late-onset dementia.

Ten scientific articles were chosen for analyses were obtained from the Google Scholar and knell portal database. In this regard, the respondent read through various articles several times before they were analyzed using matrix method. Subsequently, the researcher noted down the words that were of great importance for the study. To assist in the visualization and show the connection of the research questions, diagrams were used to show the corresponding words on the notebook. The finding was then grouped into sub-themes depending on the similarities where it resulted in the other main themes. The main themes, therefore, gave a better platform to address the research questions which were raised in the study.
### Table 2. Themes

<table>
<thead>
<tr>
<th>Themes</th>
<th>Social challenges</th>
<th>Information-sharing challenges</th>
<th>Psychological challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sub Themes</strong></td>
<td>Lack of companionship and personal feedback</td>
<td>Prolonged diagnosis</td>
<td>Stress</td>
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<td></td>
<td>Lack of self-esteem and freedom</td>
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<td></td>
<td>Personhood and Social Relationships</td>
<td>Communication breakdown</td>
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<td>Nonverbal communication</td>
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<td>Poor decision making</td>
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#### 4.4.1 Social challenges

The outcomes indicate that the process of dementia is quite challenging as the disease advances since the patient is physically present, but the psychological abilities are lost which causes
distressing factor to the careers (Bakker et al., 2010). Loss of companionship and personal feedback need to be seen as well as improved self-esteem are the main subthemes that emerged.

### 4.4.2 Loss of personal feedback and companionship

The closeness that was in existence before the patient was affected with dementia is lost since the caregiver, and the patient is not able to communicate effectively. There arises a fight between the necessities to attain a closer psychological space to the caregiver who is tied with the greater urge to reestablish the previous relationships. The communication breakdown makes it hard to express love to the person loved before hence the person gets disconnected from the patient. This means that the patient may not get the necessary attention which causes distress. In this regard, when there is no opportunity for the meaningful exchange, natural meeting and personal stories tend to reduce drastically (Bauer, 2010). It so because no one can sit down and communicate with a man who is not responding. After familiar humorous comments are lost, the patient becomes silent without leaving feedback hence causing more distress to the caregivers. The opportunity of sharing the love and fun memories will change significantly among other important things such as decision making which reduces interaction between the patient and the caregiver. Nonetheless, the breakdown of the meaningful dialogue significantly creates a strong reaction emotionally among the informants. Some will thus speak majorly about the missing basics and the loneliness which takes place due to the absence of dialogue.

### 4.4.3 Lack of self-esteem and freedom

The findings prove that self-esteem is an important ingredient in the wellbeing of the caregiver and the patient affected with late-onset dementia. Further, the improved behavioral support to
the spouse or the care giver of the dementia patient assists in negating the adverse effects of becoming the main caregiver (Ducharme et al., 2014). This is because the caregiver will forget to take care of herself as more of the time is taken for addressing the issues affecting the patient. This affects the special orientation of the caregiver since they will not be able to enjoy their lives again. The caregiver is forced to constantly at the care of the patient and will be required to do the right things all through since if they do anything wrong it will hunger the patient who at this point is not in a position to communicate the discomfort (Bakker et al., 2010). Finally, the caregivers will not be able to take vacations since they will need to be close to the patient to monitor their behavior.

4.4.5 Personhood and Social Relationships

According to Ward et al. (2008), dementia patients that live in the care homes attempts to interact with people around them. The study on the association between the caregivers and the residents indicated that they were carrying out their activities in a standardized way rather than taking part more socially with the individual. In as much as the social interaction of the people vary significantly, based on the level of engagement with the residents, the contact with the caregivers indicated a small proportion of variation.

Individuals with advanced dementia try to express their sense of self and also to comprehend their surroundings and environment (Clare 2008, Edvardsson & Nordvall 2007, Sabat 2010). In as much as the person who has dementia may not be in a position to use words in its communication, there other forms of communications which will need creativity and resourcefulness of those around the person to interpret the message (Allan & Killick 2010).
This is quite challenging to the caregivers since they may not be able to understand the non-verbal communication from the patient hence influencing the kind of care that patient will receive from the caregiver.

The respondent also found out that there is a need for the inclusive strategies in taking into consideration and responding to whatever may be seen as communication attempts by the patient. Some of these non-verbal communications that can be demonstrated by the patient include physical movement of the body parts, embodied gestures and sounds which can be observed among the patient as they try to communicate and express their selfhood (Allan & Killick, 2010). Furthermore, it is imperative to identify some ways that work effectively for the patients which will ensure the establishment of the meaningful link. These connections will go hand in hand in promoting various benefits regarding the welfare of the patient and the general quality of life.

4.4.6 Prolonged Diagnosis

Based on the evidence, the psychological burden is sometimes caused by the questions that are not answered well or those whose response cannot make sense to help in the decision-making process. Nonetheless, other factors that promote frustration include uncertainty and confusion as they anticipate getting the appropriate communication from the patient (Bakker et al., 2010; Potgieter & Heyns, 2006). Therefore, the spouses face a great challenge of addressing the issues affecting the patient hence the need to have interventions which will make them get prepared and appreciate their new responsibilities as the careers for the patients suffering from the late onset dementia. Nonetheless, Bakker et al. (2010) assert that early detection, as well as
diagnosis, will assist in containing most of these challenges hence enabling the spouses to fully get conversant with the changing behaviors shown by the patient. In so doing, it will help them seek the appropriate help from the healthcare practitioner which will assist them to understand their new responsibility.

4.4.7 Poor Decision Making

The need for conversation and information is vital to the relatives in the process of disease prognosis. In essence, providing information that is useful in educating the relatives to make them accept the responsibility. The respondent indicated that this could be undertaken in any situation in the presence of relatives or any time the nurse is in contact with the patient or the relative.

However, where the patient is not able to communicate effectively so that he or she can indicate the concerns, it makes it hard for the nurse and the relatives to understand the appropriate help that can help address the concerns (Ducharme et al., 2014). In this regard, the patient should be able to provide the extended family members with some information which will guide them in making the right decision on the appropriate care. It is so because the careers are in a position to do about half the task that can be done by the nurses only if they are provided with the right information.

4.5 Psychological challenges

This is a common issue among the spouses of the late onset dementia patients. In this regard, these spouses are affected psychologically since they are not able to communicate effectively
with the patient to help them address the health concerns. The researcher, therefore, found out that without taking into consideration the communication challenges faced by the spouses, it will make it hard to attain quality care for the patient affected by dementia (Chiao, Wu & Hsiao, 2015). This is because in most cases the spouses are the primary caregivers for the late onset of dementia patients. Furthermore, it will be quite hard to deliver or obtain quality care to the spouses in the event they do not get the necessary help which will give them an opportunity to tackle the challenges that face them. The burden caused by psychological disturbances of the late onset dementia patients was further subdivided into two more subthemes which include the need to be informed and the prolonged diagnosis (Chiao, Wu & Hsiao, 2015)
5 DISCUSSION

The study objective was to establish the challenges of communication with the late onset dementia patients and also highlight the ways in which nurses can offer support to them to help them in the management that comes as a result of dementia. The theories of humanistic nursing communication and humanistic nursing communication were developed to bring the knowledge of human relations and communication to nursing. Bonnie Battey theory put more emphasis on the association between the patient, nurse and the colleagues as its paradigm. The theory, therefore, helps in the administration of holistic care for the patient and determines the roles of nurses in ensuring that the patients suffering from the late onset dementia get quality care through professional communication.

Addressing issues affecting the caregivers of the late onset dementia who are mainly spouses to comprehend the situation entails the creation of inter-human relationships that must act as the basis for the entire familiarity. In practice, it entails understanding particular situation and attempting to apply professional ethics as well as practical knowhow to pass exchange information with the caregivers and bring them to sense. Nonetheless, for the nurse to address issues affecting the spouses especially when it comes with issues of communication with the late onset dementia patient, the nurse should be well informed on the illness of the patient since the career is much concerned about the disease hence would be interested in getting more about it. Therefore, the nurse should be well positioned to address all queries that the career will have regarding the condition of the patient. In agreement with the Bonnie Battey theory, the career becomes distressed when there is a communication breakdown between the patient and the nurse or the caregiver since the concerns of the patient may not be addressed.

The study has therefore unraveled the major challenges that are faced with those who care patients affected with dementia, especially where there is no effective verbal communication with the persons who initially were good verbal communicators. According to Flynn & Mulcahy (2013), the career fell like they have been penalized for having their wives or husband diagnosed with dementia at old age. In this regard, the spouses got despaired as they face the reality of the challenge posed by losing effective communication with their loved ones to
something unknown. In life, there is a period when all things comes to a standstill for the relatives when they are not able to socialize freely and share their feelings and concerns or even make decisions regarding the family issues. This, therefore, prompts the need to have professionals who will help the spouses interpret the non-verbal communication signs which such as sound and bodily gestures which the patient with dementia used to communicate to the careers.

Furthermore, the careers expressed the need to be informed regarding the condition of the patient. In this case, the information will help them to widen their knowledge on the issue affecting the patient (Long et al. 2000). The careers who were mainly the spouses indicated how they rely on the information from the nurses to make decisions regarding the type of care they should give to the patient. This information assisted them to determine if they are supposed to look for professional help for their patient since the disease can be transmitted to the offspring through genetics (Ducharme et al. 2014). Since the patient is not able to communicate verbally, to the careers which affect their decision making, nurses need to constantly update themselves regarding the nursing care which includes how to effectively communicate with the patient with dementia. In so doing, it will make the nurses be conversant with the specific disease which will be translated to the career and eventually to the patient through inform decisions.

Spouses of patients suffering from the late Onset dementia automatically assume the role of being careers instead of being husbands or wives according to Ornstein et al. (2013). This is a great challenge since the family can no longer make decisions as a unit but decisions will be left to on member of the family which is distressing. In this regard, becoming a caregiver leads to a breakdown in the relationships with their loved ones as they are not able to discuss important things relating to their lives. Without effective communication due to dementia, the spouse loose companionship which is a vital component of the relationship. The situation worsens especially if the person that is sick is the one they loved since they will miss important conversation they used to enjoy. In essence, normal spouses share loving memories, deliberate on the important decisions but with dementia, they have despaired since they do not communicate effectively.
Knowing that one is suffering from dementia is coupled with the contradictory info due to lack of understanding of the illness among the people. Some of the communication challenges that are faced by the caregivers of the late onset dementia include social relationship breakdown, independent decision making and psychological stress for assuming new roles as the caregiver as well as lack of professional support. However, it is worth noting that society is much placed in handling the late onset dementia as compared to handling the early onset dementia.

Nurses should be fully aware that the late onset dementia does not only affect the patient but their affects many people. The theory by Bonnie Battey put more emphasis on the relationships between colleagues, nurses, peers and patients. Therefore, providing caregivers with adequate information about dementia, effective communication skills and referring the caregivers to the right professionals will help them to cope with the communication challenges affecting them while taking care of the late onset dementia patients. In so doing, it will make them get prepared hence avoid uncertainties which assist in reducing their psychological stress.
6 CONCLUSION

The study indicated that even though nurses understand what Dementia is all about, the challenges are bound to be there. According to the theory of Humanistic Nursing communication by the author Bonnie W Battey, where she emphasizes on how nurses can ease the communication between them and the patients. I chose that theory because when it comes to Dementia, it requires patience, understanding, tolerance, kindness, and nursing ethics. It might not be easy for nurses to understand the Late Onset Dementia patients due to the disease and it affects, but with time and putting into consideration that humanity communicating with the late onset Dementia patients might become easy.

Limitations and recommendations.

This study was educative and has the potential to be improved on with more research. However, the period of research was limited and there was limited information relevant to the research.

Recommendations for this study would be, to conduct personalized interviews among nurses working with late onset dementia patients as well as interview willing relatives of patients, to get their point of view with regards to how they cope with the patient situations. Additionally, more observation on late onset dementia patients could be done to improve the study.
REFERENCES


Helsedirektoratet, (2010).  
https://helsedirektoratet.no/Lists/Publikasjoner/Attachments/338/Parorende-en-ressurskonvertert-IS-1512.pdf


Table 3. Articles used in the study

<table>
<thead>
<tr>
<th>Author, title and Journals</th>
<th>Year</th>
<th>Aim</th>
<th>Results</th>
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<tbody>
<tr>
<td>Bauer, B. I gode og onde dager: om forhold av betydning for selvopplevelse og identitet hos ektefeller til personer som utvikler demens i yngre alder.</td>
<td>2010</td>
<td>The article examines the disparities with spouses due to development of dementia among their partners. It thus studies the aspects of disease process which are likely to affect the spouses of the patients suffering from dementia.</td>
<td>The outcomes were subdivided into two themes:</td>
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<td>1. Suspicion to recognition</td>
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<td></td>
<td>▪ Loss of companionship</td>
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<td>▪ The initial sign</td>
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<td>▪ Psychological consideration</td>
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<td>2. Adaptation to a different lifestyle</td>
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<td></td>
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<td>▪ Adversely affects reactions and feelings</td>
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<td>▪ Bolstering self esteem</td>
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<td>▪ Regaining own vision and activities</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>▪ Maintain your partner as long as possible.</td>
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<td>Cheung, J. &amp; Hocking, P. Caring as worrying: the experience of spousal carers. Journal of Advanced Nursing.</td>
<td>2004</td>
<td>The objective of the study was to examine the meaning of caring from the viewpoint of spouse or nurses among the people with the multiple sclerosis to help</td>
<td>The results indicated that the caregivers face emotional burden due to the responsibility in taking care of their spouses. Their main worry was facilities for care, lack of support from the government and their ending relationships with their spouses. The issue of</td>
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<tr>
<td>Author(s)</td>
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<td>Findings</td>
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<td>Madsen, R. &amp; Birkelund, R.</td>
<td>2012</td>
<td>The aim of the study was to determine the experience of the caregivers (spouses) that are suffering from dementia and evaluate if there is variation or relationships on their experiences.</td>
<td>The study found out that there was inadequate knowledge regarding the experiences of spouses suffering from the dementia, therefore it recommended for a better scientific knowledge that would help in accommodating the needs of dementia patients and their nurses especially due to communication challenges.</td>
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<td>Ott, et al. “Easing the Way” for Spouse Caregivers of Individuals with Dementia. A Pilot Feasibility Study of a</td>
<td>2010</td>
<td>This is a feasibility study (qualitative)</td>
<td>The results indicated that there are significant changes starting from the baseline to the end of the intervention for depression, anxiety, grief as well as positive states of kind measures.</td>
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<td>Grief Intervention. Gerontological Nursing</td>
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<td>2014</td>
<td>The study explores the provisions of the integrated late onset dementia care in the European nations and examines the contributions of effective healthcare viewpoint as the foundation for the reform.</td>
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<td>The study found out that for effective implementation of palliative care on the patients suffering from late onset dementia, there is need for the healthcare practitioners to be conversant with skills and knowledge to assist them deliver quality care especially in the poor setting.</td>
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<td>Flynn R. &amp; Mulcahy H. Early-onset dementia: the impact on family caregivers. British Journal of Community Nursing</td>
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<td>2013</td>
<td>The objective of this study was to determine how emotional, physical as well as financial burden impacts the process of caregiving by the relatives taking care of dementia patients.</td>
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<td>The results indicated that the effects of care giving include loneliness, social seclusion, difficult in planning important activities that assist the patient.</td>
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<td>There was also a challenge of obtaining the appropriate diagnosis for the dementia patient due to changes in the behavior especially poor communication. Nurses indicated both negative and positive relationships change when</td>
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The nurses expressed their concerns over lack of support from the community to address communication problems of the dementia patient. The study expressed the need for enhancement of community as well as specialized services for people suffering from dementia to help address the challenges faced by the nurses.

**Berglund, A. & Johansson, I. Family caregivers’ daily life caring for a spouse and utilizing respite care in the community. 2013**

The objective of the study was to show the challenges that are faced by the caregivers in their daily lives as they give care to their spouses and also when they utilize residential home care. The results indicated that nurses are susceptible to a huge burden when taking care of patient suffering from dementia. A major concern that was eminent is coping with the new role of taking care of the dementia patient. Nonetheless, the results indicated that nurses require persistent education as well as professional support for them to understand the needs of the dementia patient when it comes to communication. The needs of the caregivers were classified into two major parts which include social needs comprising fellowship with...
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<th>Date</th>
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| 2014  | Ducharme et al. Unmet support needs of early onset dementia family caregivers: a mixed-design study | The objective of the study was to highlight the needs that have not been met regarding the dementia patients among nurses. Ensuring that there is awareness will assist in facilitating involvement growth and provide services that meet their requirements. 70 percent of the nurses who took part in the study indicated that they required psychological education to help them cope with the conditions of their loved ones who are suffering from dementia. These are;  
  i. Those that will assist them reduce stress that is related with taking care of their relatives at such older age and condition that they cannot communicate well.  
  ii. They further indicated that the help offered to them should be given at appropriate time and it should be in line with the relative care of dementia patient.  
  iii. They desired to be given assistance especially with the fiancés to help them do things that could make the dementia patient happy since there's communication breakdown.  
  iv. Finally, they wished that the family members diagnosed with dementia should be treated with dignity and appropriate provision should be made for them to maintain their abilities if possible. |
| Hoe J. & Thompson R. Promoting positive approaches to dementia care in nursing |

| 2010 | The objective of the article is to offer the general concepts of the challenges which are relevant to dementia care for the nurses working in any environment. |

The results highlighted various interventions that can be used to address issues affecting dementia patients which include:

- Evaluation and comprehension of the dementia provision of leisure for the nurses which comprise social and physical.
- Further, the results indicated that nurses of the dementia patients are more stressed as compared to the caregivers of other illnesses due to communication breakdown.
- It also indicated that the responsibility of the nurse is to lead and develop some changes which surround caring of dementia patient in the clinical practice. In this case, the psychological action is meant to lower the burden on nurses of the dementia patients. These includes informing the nurses through education, training on various skills.
which include non-verbal communication and peer group as well as psychotherapy which helps in addressing the challenges affecting the late onset dementia patients.

| Elkins & Weatherhead. Dementia care: reducing carers Emotional burden. Journal Of Clinical Nursing | 2014 | The main objective was to highlight the necessity of the admiral nurses and their responsibility. | The role of admiral nurses is to offer psychological support. They do so by evaluating the needs of care and give professional and non-paid advice to the nurses on the appropriate ways of dealing with dementia patients by highlighting the possible challenges that might arise hence reducing the risk of crisis occurrence.

Admiral nurse also offers educational support which will be of great benefit to the professional nursing when dealing with patient suffering from the dementia.

It was also found that dementia is a neurology condition contrary to the previous view that it was a mental health condition.

Some of the ways that were recommended to help nurses address the challenges they face |
while dealing with the dementia patients include

Collaboration with other healthcare practitioners who will help these caregivers to get their desired needs.