



EARLY ONSET DEMENTIA

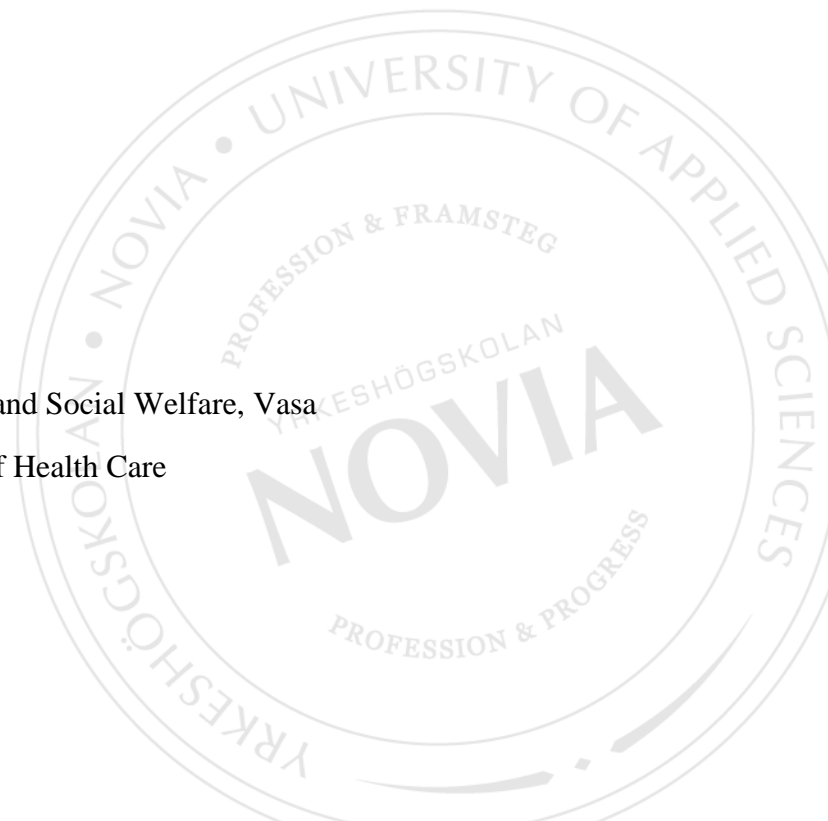
-the nurses role in supporting their relatives

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BACHELOR'S THESIS

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Summary

The aim of this study is to investigate the needs of carers' of EOD patients, roles of Nurses, particularly detailing roles they could play in order to alleviate some of the challenges that carers' of EOD patient face in today's society. Problems posed to be answered for this study were; what are the needs and challenges of EOD Spouses? And, how can Nurses help to mitigate these challenges? Travelbee's theory of human-to-human relationship was used as the framework for the study. This study was conducted with qualitative method and data was collected through literature review. 11 articles were finally selected and analyzed using The Matrix.

Three main categories emerged from the analysis; psychological burden, emotional burden and socio-economic burden. The results reflect on the challenges of spouses of EOD patients are faced with as their loved ones face the diagnosis of early onset dementia. There are several unmet needs from the perspective of spouses such as; informational, professional support etc. Moreover, spouses expressed how assuming the sudden role as caregiver to their loved ones brought a barrier between the companionship they once enjoyed.

Language: English

Keywords: Dementia, young age, relatives and dementia, early

onset, need for support.

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1 INTRODUCTION

Many studies have identified and uncovered the challenges that carers face, especially when the carer is a close relative, Ducharme, Kergot, Rene, Louis, Pascal & Florence (2014), Flynn & Mulcahy (2013) and Sarna & Thompson (2008) all discussed these challenges in their respective research papers. Taking care of someone with medical conditions could be a daunting task, especially when there is non-existence of any form of remuneration. As argued by Flynn & Mulcahy (2013), many relatives' caregivers pay a "penalty", i.e. health damages; a poorer financial situation; emotional strains and restrictions from everyday life. Although, it might be a difficult task to encapsulate the entire ordeal into these four perspectives, however it touches four main areas of everyday life.

Arguably, the core responsibility of taking care of a person with any health issues usually falls upon one family member's shoulders (Ducharme et al., 2014), at least this is true to a greater extent for a person suffering from e.g., "dementia". As argued by Gilleard, it often resolves to the elderly wife or adult daughter taking the mantle of a caregiver. Nonetheless, irrespective of who is responsible, it may engender resentment if carers' perceive other family members or even responsible bodies i.e. nursing home or municipalities as not being supportive.

Furthermore, Ornstein, Gaugle, Devanand, Scarmeas, Zhu, & Stern 2013), argued in their research that carers who automatically inherit caring role are most at risk of breaking down in their care giving role. This places dementia caregiver in this situation especially in the case of Young Onset Dementia [hereafter YOD or Early Onset Dementia (EOD)].

Dementia is a syndrome, which causes memory, thinking, and behavior to deteriorate thereby affecting the ability to perform daily activities. Although it affects older people, however, it cannot be attributed to part of ageing (WHO, 2015; Hoe & Thompson, 2010). According to the statistics provided by World Health Organization (WHO, 2015) worldwide, 47.5 million people have dementia and there are 7.7million new cases every year. The paramount known causes of dementia is Alzheimer's diseases and may contribute to 60-70% of cases. It has been established to have psychological, emotional and socio-economical impact on caregivers, families and society at large. There is often lack of awareness and understanding of EOD and their relatives,

resulting in stigmatization and barriers to diagnosis and care, (Madsen & Birkelund, 2013; Flynn & Mulcahy, 2013)

Families with older people with dementia probably had anticipated and hence gathered the required buffers to manage over a period of time, however when it comes to YOD it is a total different situation. As Ryan et al. (2000) clearly stated, the older ones are admitted to a nursing home and it is generally regarded as the termination of family care and the beginning of institutional care. In fact, Research has revealed that families are often relinquishing of their dependent older relative to the bureaucracy of the institution. Conversely, for the YOD family member, it marks the beginning of home care and it often relinquished their everyday routine.

1.1 Tale from clinical practice

This paragraph is a narration experienced by the respondent during practical training; this experience was a motivation to seek information, which will enable the respondent to be better prepared to address any similar situation.

A man of 59 years of age received interval placement to a nursing home because he was diagnosed with EOD. He has a wife who often visited him. Nursing management at the nursing had made an appointment in consultation with his wife that he was going to have a nursing personal staff per shift until he gets accustomed to his new surroundings. The patient's wife came to visit the patient, he was uneasy. He paced up and down the corridor in exasperation, the wife followed him. Suddenly he stood in front of his wife and tried to say something but could not express himself. He became more upset and started sobbing. The wife tried to console him but on the contrary she broke into tears. The patient suddenly turned to his wife; his facial expression looked as though he was going to say something to her. His facial color had changed, he had twinkle in his eyes. Suddenly he called the name of his wife and stroked her cheek with his hands and just walked on. The respondent's experience in this single situation was so impactful that the respondent developed the interest in researching into the role of support of the spouse of dementia patients.

2. AIM AND PROBLEM DEFINITION

There is a tendency that nurses do concentrate their care solely on the patient, and giving little or no attention to the ordeal the relatives of the patient especially what spouses might be going through as a consequence of the disease, (Ducharme et al., 2014). The aim of this study is to investigate the needs of carers' of EOD patients, roles of Nurses, particularly detailing what of role they could play in order to alleviate some of the challenges that is facing carers' in today's society and highlight how nurses can support them in order for them to enable them manage the challenges that come with the disease. Hence in specifics, problem definition;

- What are the needs and challenges of EOD Spouses?
- How can Nurses help to mitigate these challenges?

3. THEORETICAL FRAMEWORK

The theoretical Framework of this thesis is based on Travelbee nursing theory. The reviewing of literature provided the respondent with the opportunity of identifying the works of other researchers in order to identify ways by which the research objectives can be achieved and the research question can be answered. Fink (2010, p.3) describe literature review 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”. In the light of this, the respondent will use Travelbee theory as a guideline when analyzing.

3.1 Travelbee’s view of nursing

Travelbee (2007, p.29) defines nursing *as, an interpersonal process in which the professional nurse helps an individual, a family or a community to prevent or cope with experiences of illness and suffering and, if necessary, to make sense of these experiences*. According to Travellbee’s definition, nursing is a process which means that it is an "experience" or a series of events that occurs between a nurse and the people that needs the help or services provided by the nurse. With nursing as a process she emphasizes nursing as being dynamic and a continuous development. Travelbee believes that nurses always help the individual or family in need of nursing service. She further argues that one of professional nursing difficult task that should not be avoided is; to help individuals and their families to find meaning in the experiences that might be associated with the illness of the patient (Travelbee, 2007).

3.2 Human-to-human relationship

Human-to-human relationship is a fundamental part of the human experience and one of the relationships that expresses the normality of human beings. Hellier-Tinoco (2003, p.19) argues that human-to-human relationship involves experiencing people and revolves around human relationships and one-on-one encounter.

A human-to-human relationship in nursing is one or more lived experiences that are shared between the nurse, the sick or those in need of nurse’s services; significant others (Travelbee, 2007, p.41). Travelbee suggests that nurses combine their ability to use themselves

therapeutically and their professional ability to meet the individual's problems. By using itself therapeutically she believes that the nurse uses the learned behavior through theoretical knowledge and nursing training to treat each individual and their family members. She further argues that the individual should be considered unique to avoid stereotype such as; "helpless and dependent".

To explain the essence of human-to-human relationship in supporting spouses of demented patients, there are different phases that must take place. According to Travelbee (2007) there are phases that nurses and family caregivers should work through in order to maintain a reciprocal relationship:

- Phase one is the original encounter. This first phase is to have a preliminary meeting with the relative (spouse). The nurse establishes contact with the relative after mutual observations and assessments between the relative and the nurse. She believes that the nurse's role is to discover the unique human being in the role of relative.
- Identity emerges is the second phase. Travelbee postulates that the nurse has created a relationship and is now trying to find what makes the relative unique. In this phase, the nurse strives to have deeper understanding of the relative. Travelbee believes that this is very important and that it leads to the creation of a human-to-human relationship.
- The third phase is empathy. Travelbee explains that this is the ability to go into, share and understand the psychological status of the relative. She argues that the respect for the relatives is created in this phase.
- The fourth phase is sympathy. In this phase, Travelbee argues that the nurse's consistent actions to help the relative can be accomplished. She claims that the nurse's ability to reach this stage depends on his or her personality, lifestyle and values. In other to get to this phase both the nurse and the individual who's in need of the nurses care must have undergone and achieved the other phases mentioned above. Travelbee believes that phase crowns the efforts made by the nurse in other to have rapport and to establish and maintain a human-to-human relationship with the ill individual and their relative, (Travelbee, 2007).

- In the final phase rapport Travelbee states that, nurse consistent actions to help relatives is necessary to be able to reach. She claims that the nurse the opportunity to reach this phase depends on his or her personality, views of life and values. She also believes that this is the core of a human-to-human relationship (Travelbee, 2007).

The significance of establishing human-to-human relationship between nurses and relatives of dementia patients is based on several realities of the consequences of the impacts of the disease on relatives. Cheung and Hocking (2004) provided some essential reasons why this type of relationship is critical to relatives of dementia patients. First, spouse of dementia patients worry about their partner and their relationship; they worry about their partner's wellbeing because of their knowledge that the disease is progressive (Cheung and Hocking, 2004, p.478).

Secondly, the worrying about their relationship, the spouse worry is based on the fact that the patient personality changes with the progression of the disease making their partners a completely different person from who they once knew, (Cheung and Hocking, 2004, p.479).

Thirdly, spouse of dementia patients worry about their own future especially their own health. Spouse worry about something happening to them also as it had happened to their partner (Cheung and Hocking, 2004, p.479). Fourth, spouses of dementia patients worry about institutional care of their partners. The fifth and final worry that Cheung and Hocking (2004, p.479) identified was the worry that concerns requesting for support. Spouses of dementia patients in majority of circumstances worry about requesting for support themselves. These worries make human-to-human relationship between the nurse and the spouse of dementia patients critical.

3.3 Communication

Communication is a continuous process, an exchange of opinions or messages between two or more people. These opinions and messages can be expressed verbally and non-verbally (Travelbee, 2007). Travelbee refers to communication as behavior and a process because it involves mental and physical activity (Travelbee, 2007). Non-verbal communication, according to Travelbee is communicating without the use of words.

Travelbee (2007) argues that communication is the tool nurses use to search and communicate information to the sick and their relatives, and that it is a means by which the sick and their relatives use to accept help. Travelbee further claims that the interactions between the nurse and the patient cared for enables the nurse get to know that person on an individual basis. Enabling the nurse to determine what appropriate assistance that is tailored towards meeting specific needs of the patient as an individual, which might differ from the needs of other patients, and thereby establishing the human-to-human relationship and achieving the nurses' goals and purpose (Travelbee, 2007). In respect of the dementia patient, the goal of the nurse is sampling to support the relatives of the patient. In majority of cases the closest relative that is most affected by the condition of the dementia patient is usually the spouse. The main purpose of the nurse therefore is to support the spouse while proving the needed assistance to the patient as required. It is this human-to-human relationship that has been developed by the nurse, the spouse of the patient that enables the spouse to cope with dementia, (Travelbee, 2007).

3.4 To master the experience of illness and suffering

Travelbee claims in her definition of nursing that nursing practitioner helps the patient's family to cope with experiences of illness and suffering. This means that the family learns about how the disease manifests itself, the prognosis and what role they should take so that they have the feeling of being in control against the disease. She postulates that the ill individual is a member of a family, and that what affects one family member equally affects the others, and that the way the family reacts to the disease transmits meaningful messages to the sick (Travelbee, 2007).

If the sick mastered their disease, the relatives will also master their situation, and if the nurse looks after the families of the sick, the ill will benefit from better care. (Hertz, 1988, cited in Kirkevold and Ekern, 2001, s.96) has identified five families coping strategies that help the family to have control of the situation. These are openness and support – the family communicates and support each other. Silent family members do not discuss about the event. Guilt and conflicts – the family members accuse each other of the present situation and do not accept human differences in sorrow. The suffering individual - family members take into account

the most affected, splitting of the family - the ill individual's condition is what ties the family together (Hertz, 1988, cited in Kirkevold and Ekern, 2001, s.96). This clearly establishes the significant importance of mastering the experience of the illness to enable the ill and the relatives to be better served.

3.5 Hope

Travelbee defines hope as a mental state characterized by the desire to fulfill a given goal that what is desired is achievable (Travelbee, 2007). One may ask the question; how relevant is it to talk about hope in the case of an incurable disease such as dementia? Travelbee answered the question by describing a characteristic of hope, that hope is strongly related to dependence on others. Travelbee is suggesting that hope is related to the expectation that there is always someone else who will seek for help, especially when the individual's inner ability to cope is impaired (Travelbee, 2007).

3.6 Sympathy and Compassion

Sympathy and compassion is to be sensitive to or affected by someone else feelings and experiences, in particular sorrows. Travelbee tried to distinguish between empathy and sympathy by defining sympathy as the desire to alleviate suffering. She believes that this is a characteristic feature of sympathy and compassion. With this she believes that through sympathy and compassion one can take part in the others feeling. Compassion can be expressed as a facial expression, or the way the nurse performs their help. She went further to assert that one can have sympathy and compassion while maintaining the distance to the suffering. She related this to nursing by pointing out that sympathy and compassion reinforces and deepens the relationship between the nurse and the patient. When the nurse sympathizes he or she is emotionally involved, but not paralyzed in the involvement. The influence of sympathy and compassion care capacity is often communicated verbally and can sometimes be non-verbal (Travelbee, 2007).

4. THEORETICAL BACKGROUND

In this section, the respondent will define and provide a deeper meaning/explanation to some key words in this study.

Alzheimer

Alzheimer disease is one of the degenerative brain disease in which there is observed shrinking of the brain, both in the cortical and sub-cortical areas as allows the third cerebral ventricle increases. The shrinking of the brain is the result of cell death, (Engedahl and Hagen, 2009). Alzheimer's disease is the most common form of dementia. It leads to memory loss , inability to learn, think and reason , those with this disorder often have aphasia and are not oriented to time and place (Warner et al ., 2002, WHO, 2015) .

Young adult with Dementia

Young adult with dementia is dementia with early onset or when persons under 65 years receive a dementia diagnosis. The patient might look fresh and youthful, but the disease development gradually creeps in (Jakobsen and Homelien, 2011). According to Flynn & Mulcahy (2013), amongst the population of people living with dementia worldwide approximately 6-7% of them are suffering from EOD. In Finland statistics shows that there are about five to seven thousand young adults affected with memory loss. EOD cases also fall amongst this rating, (Alzheimer Europe, 2012).

The prevalence of the disease is commonly associated with people above the age of 65 years. Unlike older adult, these patient groups have peculiar challenges; they are in their prime, they are mostly working adults, dependent relative, (children, wives and probable parents). Misdiagnosis of these patients leads to burdens on their spouses, (Ducharme et al., 2014, Flynn & Mulcahy, 2013).

4.1 Signs and symptoms of Dementia

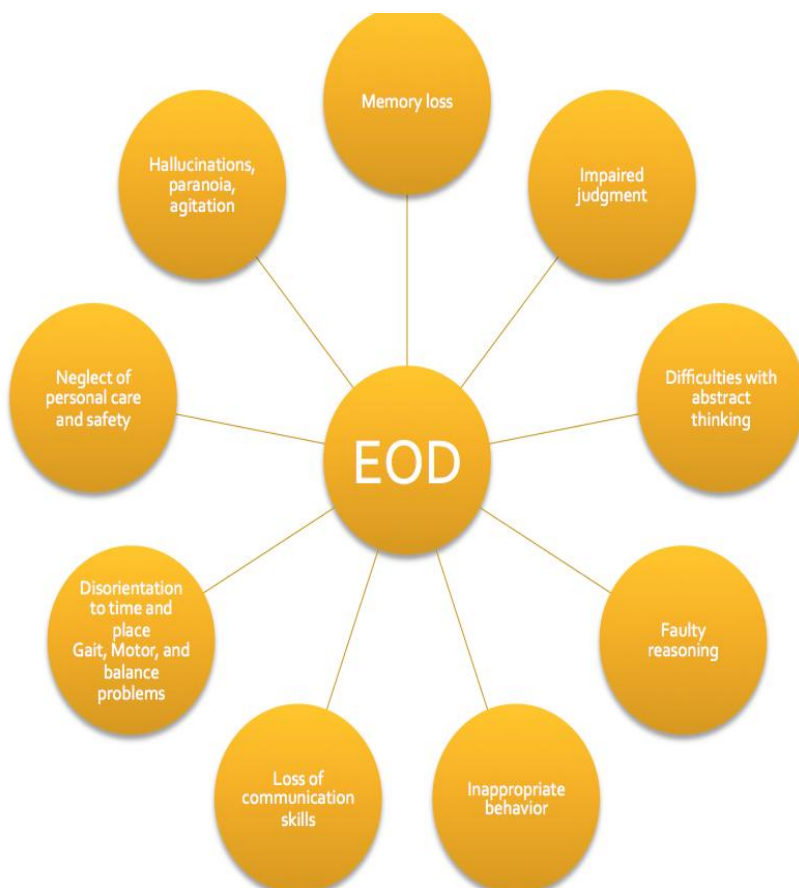
The way dementia affects individual varies, the severity depends upon the impact of the disease and the individual's personality prior to becoming ill. According to WHO, understanding the signs and symptoms can be understood in three stages;

- **Early Stage:** this stage is gradual and in most cases often overlooked. The common symptoms include: Forgetfulness, losing track of the time and becoming lost in familiar places.

- **Middle stage:** at this stage some of the signs and symptoms could be more cleared as it progresses. These include: forgetting familiar peoples' names and recent events, becoming lost at home, experiencing increase difficulty with communication, needing help with personal care and experiencing behavior changes, wandering and repeating questions.

- **Late stage:** at this stage, total dependence and inactivity is expected including serious memory disturbances and physical signs and symptoms are more evident. The symptoms include: difficulty in walking, disorientated to time and place, difficulty recognizing friends and relatives, aggression. At this stage there is high need for self assisted care (WHO, 2015), (Hoe & Thompson 2010).

Figure 1: Symptoms of dementia (concept derived from Hoe & Thompson 2010)



Relatives

The Norwegian Directorate of Health defines relatives as; those who often stay close to the patient including their main caregivers, the ones who often contributes to the patient's daily activities and assist them with practical tasks (helsedirektorat, 2010). When talking about relatives from the perspective of dementia, it is narrowed down to the people in the family who are involved in the dementia patient's everyday life, they listed relatives as including mothers, fathers, daughters, sons, wives, husbands, unmarried partners, and also in-laws all are involved in one way or another in providing primary care to the patient. The focus of the study however is limited to the spouse as already indicated above.

Nursing giving to relatives

According to Sarna & Thompson (2008) approximately two thirds of people suffering from dementia receives care from their family members, and often get the care they need at home. There are documented hard facts as stated by Sarna & Thompson, which estimated that carers save billions of dollars annually unpaid. In turn, studies shows that carers stand the risk of lagging in their health as a result of caring responsibilities bestowed upon them. Consequently, with the increase of dementia as predicted by WHO, it is inevitable that the number of people caring for dementia is on the rise.

Hitherto, the best panacea for keeping carers of dementia sane is to provide professional help, support and advice, these includes mental evaluations and assessments in the form of mental health and social care services, provision of timely information and education, access to adequate and necessary informations and to be deeply involved in decision making process.

According to National Institute for Health and Clinical Excellence (NICE, 2006), carers' needs should be address via range of interventions: firstly, individual or group psycho-education, secondly, peer-support groups with other carers, which should be fashioned to different individual needs depending on their stages of dementia. Finally, training should be organized for them giving them platform necessary problem solving tools and tips. Paton et al 2004 extends the later.

According to Rabins et al (2006) there is four distinctive pillars of dementia care i.e. treat the disease, treat the symptoms, support the patient and support the caregiver. As argued by Rabins (2006) focus should subtend more than the patients and finding the right treatments, instead it should also accommodate the carers. Furthermore an inclusion approach is important when it comes to dementia care delivery. This inclusion recognizes that both family carers and the victims are equally important and needs help.

Nursing in relation to this thesis is, the interpersonal process in which the professional nursing practitioner helps family members in coping with dementia, their experiences, difficulties and the need to find meaning in these experiences (Travelbee, 2001). The requirement of providing nursing assistance to relatives of dementia patients can be understood better when the situation of the relatives are completely understood. Prigerson (2003) described the situation of the relatives of dementia patients as “triple grief”. These triple griefs are due to firstly, changes in the relationship resulting from memory loss, secondly, grief at the long time of admission to a long-term care facility, and finally, grief after the dementia patient’s death (cited in Ott, Kelber & Blaylock, 2010, p.89).

5. METHODOLOGY

This section involves an overview of the collection of data, how data were collected, what method was used. A brief explanation of The Matrix, as well as ethics guiding writers in a study such as this.

5.1 Method

Method is a way that tells us something about how a study should go forward to solve the problems of reaching new knowledge. The rationale for choosing a particular method out of the numerous available to the respondent is therefore because of the possibility of enabling the collection of the appropriate research data that makes the illumination of the research problem in a professional and interesting way (Dalland, 2007, 83). There are several research methods as already mentioned that can be deployed by the respondent in achieving this study objective through answering of the research question of this study. There are two main research methods; qualitative and quantitative research methods, this study will be based on qualitative research.

5.1.1 Advantages and disadvantages of literature review

An advantage according to Forsberg and Wengstrøm (2003), by a literature review is that large amounts of data can be collected in a short amount of time to acquire knowledge that is relevant to the specific research problem. Moreover, the ability to go back to the source to re-read parts again to make sure that the respondent still have the same understanding of the content. If the read part is no longer relevant, the respondent can search for new articles or books from parts in different research information sources.

A disadvantage of the use of literature review is that it can be difficult to obtain the primary sources of the research data. Another disadvantage of the literature study is the fact that the respondent is forced to rely on the original authors' interpretation of research results that have been made. Literature study may also limit the respondent's choice of literature language.

5.1.2 Data collection

Polit and Beck (2012, p.725) defined data collection as “the gathering of information to address a research problem”. Articles used for this study was collected electronically through Nelli Portal in Novia’s web page. The respondent searched for articles and journals in, Bibsys, Cinahl database (Ebsco) and Google scholar. Keywords used were; *Dementia at a younger age, relatives of people with dementia, Early Onset Dementia, Challenges of carers of EOD, Spousal caregiver And need for support*. The respondent been a foreigner with a different language background then translated some keywords to Norwegian; *Yngre med demens, omsorg til pårørende med demens, sykepleie til demente og pårørende, omsorg til ektefelle av demens pasienter*.

Although there were many hits majority of the articles were not relevant to this research work. Inclusion criteria for article/journals were that chosen article will not be older than 15 years, only Full text and peer reviewed articles were chosen. Some of the articles were rejected after reading The respondent defines and limits her choice of sources to the aforementioned above. During clinical practice, the respondent observed an incident which will use in the discussion section. The incident will be related in such a way that the information and characters will remain anonymous in keeping with the required ethical responsibility of the respondent in ensuring the protection of the privacy of the patient and their spouse.

The Matrix Method was used to help structure the thesis design. Paper Trail Folder contains all searched literature; Document Folder contains downloaded/PDF files of the articles whilst Matrix Folder contains storage of all relevant articles.

Table 1: Inclusion and Exclusion criteria

The table below illustrates the selection criteria of the articles used in this study.

INCLUSION	EXCLUSION
Articles published in English & Norwegian language	Articles not published in English & Norwegian language
Published after year 2000	Published before year 2000
Available in "Full Text"	Not available in "Full Text"/ abstract
Peer reviewed	Not peer reviewed
Articles that are relevant to my study	Articles not relevant

5.2 Overview of the matrix method

There are several ways and manners in which literatures are reviewed in order to extract the most relevant information from them for the purposes of a scientific research. The Matrix method according to Garrard (2011, p.4) is "a review of the literature consisting of reading, analyzing, and writing synthesis of scholarly materials about a specific topic". The Matrix method is conducted through a step by step process that involves five basic elements. These elements includes: (1) Stating the purpose of the review; (2) screening and selecting scientific papers that meet specified criteria; (3) carefully reviewing the papers for excellence of the scientific methods, statistical procedures, and validity and reliability of the collected data; (4) carrying out a summary of findings across the studies; and finally (5) draw up conclusions based on the scientific evidence (Garrard, 2011, p.4 and 5).

The Matrix method is a combination of structure and process for systematically reviewing the literature (Garrard, 2011, p.17). The structural aspect of the Matrix method according to Garrard (2011, p.17) is provided by the literature review master folder that contains the documentations and notes that the respondent has accumulated in the course of reviewing the literature. This master folder is made up of four other folders, that is, (1) paper trail folder; (2) documents folder; (3) review Matrix folder; and (4) synthesis folder.

5.2.1 The paper trail folder

The paper trail folder is a record of the search process that the respondent used to identify relevant materials (Garrard, 2011, p.17). This folder is simply a collection of the entirety of the literatures searched, examined and the notes that the respondent made during the period of going through different materials in the quest for the relevant study data. These include keywords, electronic bibliographic databases, personal records of the respondent and others that the respondent consulted which can include materials as simple as the instructions for the making library and electronic searches.

5.2.2 Document folder

According to Garrard (2011, p.17) the documents folder includes the downloaded copy, the pdf file or links of the journal articles, books, book chapter and other materials gathered for the literature review. This is the folder in which the documents are organized to create a review matrix that will eventually go into the next folder.

5.2.3 Review matrix folder

The third folder in the structure of the matrix method is the review matrix folder. The review matrix folder is a spreadsheet or table with columns and rows that the respondent use to abstract selected information about each journal article, book, book chapter, or materials included in the literature review (Garrard, 2011, p.17). This the folder where every literature that the respondent considers to be relevant to the study is laid out in order of their relevance and impending utilization.

5.2.4 Synthesis folder

According to Garrard (2011, p.17) this is the outcome of the respondent's utilization of the Matrix method, that is, a written synthesis of the respondent's critical review of the literature based on the materials the respondent abstracted in the previous folder. The four folders of the Matrix method explained above are critical to conducting an effective Matrix method literature review. However, it is only after the process of the Matrix method uses the structure that a

reliable and valid literature review of the study can be considered completed. The reason why the Matrix method is the appropriate method for this type of study was provided by Garrard (2011, p.18) arguing “the Matrix method is specifically designed for the reviews health sciences literature”, making the Matrix method the most appropriate method for this study into the support for dementia patients spouses.

5.3 Ethical consideration

In the cause of conducting this study, ethical considerations adhered to in other to follow ethical guidelines for a quality study. The Finnish Advisory Board in research integrity ethical guidelines was used. This includes four sub-categories-fabrication, falsification, plagiarism and misappropriation.

Fabrication entails that the respondent did not develop her own words in order to support her study, or allow untold experiences to be presented.

Falsification simple means that the respondent did not change or present another author’s respondent’s work. The respondent abides with presentation of other authors’ work with absolute honesty by not fabricating or misrepresenting their findings, methodologies or conclusion in order to suit this thesis.

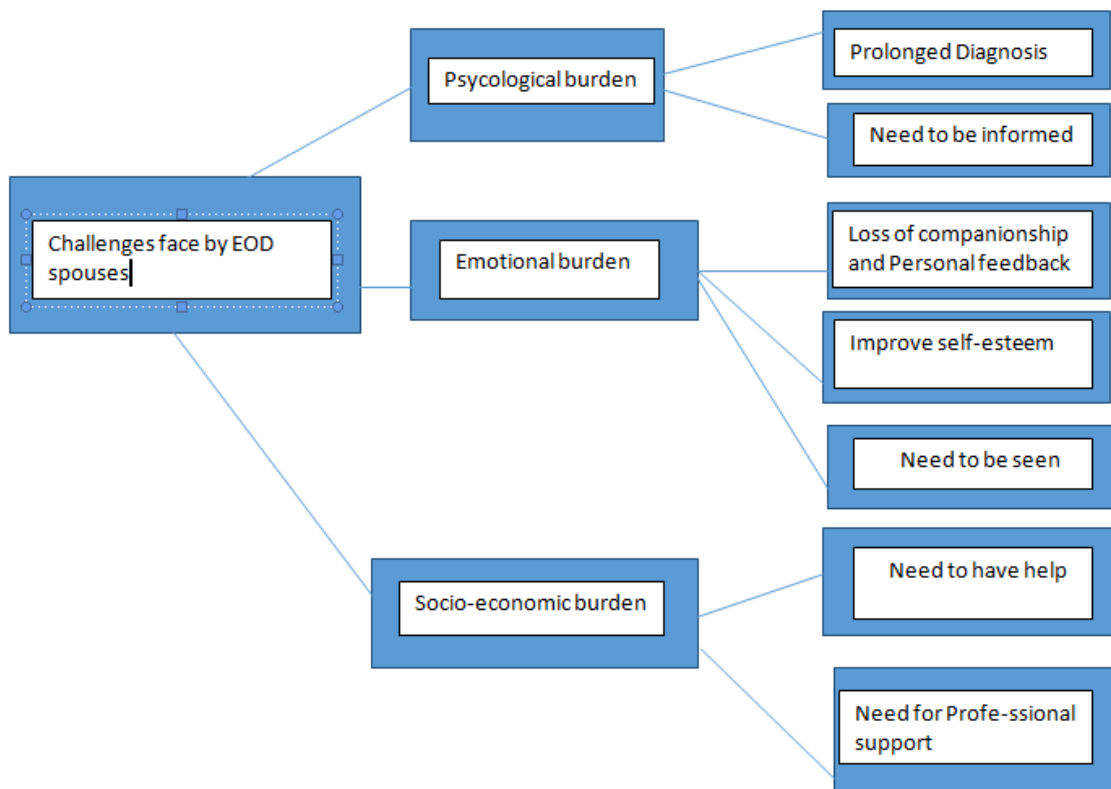
Plagiarism refers to the respondent copying another person’s work without acknowledging the original author or giving them credit.

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

6 RESULTS

Eleven scientific articles have been chosen to be analyzed from data collected through Nelli portal database. The respondent read through the articles severally and analysis was performed using The Matrix method. The next phase, that the respondent noted down words that were significant to this study. Diagrams were drawn on a note book to help visualize and sort out connection to the research questions. These findings were grouped into sub-themes based on similarities and later three main themes emerged from the analysis; *Psychological, Emotional and Socio-economic burden of the Spouse*. These three main themes tend to answer the questions earlier raised in the study.

Figure 2. This diagram shows the correlation between the themes and the subthemes.



6.1 Psychological burden of the spouse

Psychological burden emerged as one of the main themes spouses of EOD patient's faces. These spouses are faced with some proven factor that affects their psychologically. The respondent finds it obvious that without highlighting the needs of the spouses that it will make it difficult to render or achieve good quality care to spouses of EOD. Furthermore, it will be impossible to attain or rather deliver good quality care to spouses of EOD if they don't get the needed help to help them face the challenges that surfaces. The theme *Psychological burden* of spouses of EOD patients was alienated into two subthemes namely; *prolonged diagnosis and Need to be informed*

6.2 Prolonged diagnosis

Evidence shows that psychological burden sometimes includes unanswered questions that linger in the minds of these spouses because of some unusual behaviors shown by partner. Confusion and uncertainty also leads them to frustration. Clearly these Spouses need help to address these issues in other for them to be best prepared to endure and embrace their new role as young caregiver to their partners.

Cg: My husband went three times and the psychologist was more or less angry with me. I had to give my husband more space; there was no dementia, no brain tumor, only a minor concentration problem. I left and thought: maybe I am interfering with his life too much. I blamed myself, (Bakker et al., 2010 p. 636)

Cg: At that time, I did not know that he was ill. He did not want to see a doctor. I thought: If you are not ill, I will leave you . . .it could have ended in a divorce,(Bakker et al., 2010 p. 636)

That time is very confusing. One doesn't understand until you know what causes it... When he does little things that seem do deliberate.... I got very mad at him,(Potgieter & Heyns 2006, P 554)

Clearly early detection and diagnosis will help narrow down some of these challenges thereby enabling them understanding the behaviors displayed by their spouses. This hopefully will help them seek for the right assistance from healthcare to help them master their new role.

Cg: Finally, I had the answer to what had gone wrong in the past four, five years, (Bakker et al., 2010 p. 636)

That was the worst period... Something was wrong. He had not been himself, but I could not put my finger on the problem. The fact that I did not know exactly what was going on made me very unhappy. And when the diagnosis was made, the whole situation improved for me, (Potgieter & Heyns 2006, P 554)

When the diagnosis was made it came to me as a terrible shock, but now I knew who my enemy was. One cannot fight something or someone that doesn't have a face, that you do not know, (Potgieter & Heyns 2006, P 555)

Cg: Maybe I can talk to a psychologist who can alter my way of thinking. Maybe he can take away the guilt, (Bakker et al., 2010 p. 637)

How much further will I be able to go? My husband moves around all over the place all day long, he touches everything, he can't eat alone, and he often chokes on his food? (CG #13), (Ducharme et al, 2014, P 4)

Cg: When my husband gets in a different stage, I just want to know how others deal with that. I don't have to go every month, which would be too much. (. . .) I do not want to listen to their stories; I have enough on my mind as is. Bakker et al., 2010 p. 637

I knew that we were on our way to something unknown. What this unknown meant at that point, I didn't know. I cried because I knew the man who through many years had been my Peter, and whom I loved, I would lose bit by bit [...]. I felt like standing in front of a steep mountain and if I made my way up it was just to find another steep mountain to climb. (Older Fund 2002 cited in Madsen & Birkelund, 2013. P.3028).

6.1.1 Need to be informed

The need for information and conversation during prognosis of the disease is very important to the relatives. Evidently providing helpful information is to impart knowledge that relatives need

and are capable of accepting. Results also shows that this can be done in any situation the relatives are in or in any encounter the nursing practitioner has with relatives or patient.

Give the extended family some info. My husband has two brothers. They're afraid of this disease. Is it genetic? Hereditary?? (CG #32), (Ducharme et al, 2014, P 4)

We need information from the nurses...We rely on their information...We wouldn't be able to do half of what we do without them (Speech and Language Therapist). Long et al., 2000, P 74

6.2 Emotional burden

Result also shows that dementia process seems to be particularly challenging as the disease progresses, the fact that the partner is still physically present while individual psychosocial abilities are gone is a distressing factor on the emotional being of the spouse. Three subtheme emerged namely; *Loss of companionship and personal feedback, Improve self-esteem and Need to be seen*

Cg: When my husband was asleep, I was in the living room, crying and thinking, not knowing what the future might bring. (. . .) I was only just 50 years old. (. . .) How devastating for him . . . Bakker et al., 2010 p. 636

6.2.1 Loss of companionship and personal feedback

Partner in the same familiar environment as before and that opportunity for closeness has significantly changed. An ambivalent struggle between the need to achieve greater psychological distance to the partner, coupled with an underlying longing to recreate previous relationship, seems to emerge.

I found if I kept trying to look after the person I loved, it just made things worse – it presented barriers. I had to become disconnected to that part of it. You have to break away from the person who was a lover to a person that you're caring for, Cheung & Hocking 2004, P 479.

When the opportunity for meaningful exchange is absent, then there is reduction in personal stories and natural meeting points in everyday life.

You cannot sit and chat with a man that is not responding! What on earth will you be talking about!? You sit there and sort of push and push without getting anywhere, "as Lars puts it," then it becomes that you take a magazine instead, looking at it, even if you really have lots of unsaid things in your heart . Bauer, 2010. P30

Gradually the familiar and humorous comments subsided. Patients become more silent, leaving no feedback which puts a tool on their spouses.

I must say it is a huge change! Now he can stand there almost awkwardly in front of me, look across into the air and straight through me. That's how it feels indeed! Some I can almost feel invisible in a way. And less attractive too may be? It makes me sad. This really the same man, but at the same time it's not. Bauer, 2010. P32

Clearly there will be change in the opportunity to share fun loving memories and events, other changes like decisions making, putting together plans and making small talk about everyday events.

I had wished she could ask me how my day has been at work for example, helping to plan the visit of our daughter for the weekend, or simply comment on the things I tell her, Bauer, 2010. P30

The loss of meaningful dialogue also creates strong emotional reactions among informants. A majority speaks primarily about the basics missing and the loneliness that occurs in the absence of dialogue:

"we use to talk a lot together before, about our jobs, kids and things like that, It's like a vacuum in a way, filled with lots of emotions like longings and loneliness" Bauer, 2010. P30

6.3 Improve self-esteem

Findings supports the fact that improved self-esteem will be of essential benefits to the wellbeing of spouse of EOD patients. It claims further that increase behavioral support to spouse of dementia patients will help negate the impact of the negative effects of being a caregiver.

You forget to take care of yourself when you're a caregiver. You're in it up to your neck, you're completely consumed by the disease. That's a mistake [forgetting to take care of yourself]? (CG #2). (Ducharme et al, 2014, P 4)

Cg: I would like to be able to enjoy myself again, but I am not sure that I really can. (. . .) But I will have to try. Imagine that he will be at home for two more years. No vacation for two or three years with continuing care. When he's at home I constantly have to be on my guard. If I do something wrong, he gets angry, thus I do everything to keep him happy., (Bakker et al., 2010 p. 637)

Cg: I thought I will not take that vacation, but then I talked to the coordinator of the daycare centre and she said, 'If you never take a few days off, you will not be able to manage.' And that is true. (. . .) 'I am glad that she said that.' Bakker et al., 2010 p. 637

6.3.1 Need to be seen

Relatives of EOD patient's claims they perceived their experiences with healthcare workers was that they were not "seen" and further claim that they believe that it was because of the fact that they are not viewed as caregivers. They felt like the only ones that bore the caring responsibilities of the patient.

I liked being complimented on the fact that I'm doing a good job. That helps me go on the way I am. Ott et al. 2010, P 96

Home-help hours are also lacking and we are not being recognized Flynn & Mulcahy, 2013. P 603

It is [care-giving] hard work, draining, something you're not recognised for doing.[P6] Flynn & Mulcahy, 2013. P 603

6.4 SOCIO-ECONOMIC BURDEN

The Socio-economic aspect of the burden of EOD spouses are faced with can affect them negatively if not attended by professionals. It has dual effect on them in the sense that it affects both their financial status and for most of them it feels like the abolition of social life.

6.4.1 The Need to have help

Spouses of EOD sufferer's are exposed to several challenges that causes strains on their wellbeing. Caring for Dementia patients can be Physical demanding; Activities of Daly assistant living(ADL), assuming the role of two parent, taking care of and managing their finance. Caring for a demented person can also be time consuming. Above all this they still have to manage to live their life's as well. Clearly they need help to relieve them of some of these burdens.

"What we usually to do now is that I get a CD player and play some music. So we sit and listen to it while I hold her hand. She seems she is to like it. I can no longer carry the conversation alone. It's too tiring, even though I wish I could tell her about how I feel. (Bauer 2010, P 35).

'I take her everywhere; I do the cleaning, cooking, bathing and incontinence care...I help her in and out of bed, wash and dress her things like that.' [P7], (Flynn & Mulcahy 2013, P 603)

6.4.2 Need for professional support

The need to make life better for caregivers is viewed as one of their most unmet needs. Receiving support to reduce stress can act as a gate way to delivering the needed support. As needs changed, the availability of supportive professional caregivers was evident in the findings as another essential requirement all the way through the caring process.

Cg: You have to grow into each stage of the disease. But I do need the support of others, who you can call, whenever you need to. I have that now here at the daycare centre, I can call them. (. . .)We have a fine GP and neurologist, I can always call them, (Bakker et al., 2010 p. 637)

Cg: Friends do understand. I do know friends I can talk to about these things, but they are not professionals. (. . .), (Bakker et al., 2010 p. 637)

What I do need now is a professional I can talk to about the changes in my life. (. . .) You would think that would be possible at the nursing home where my husband is staying. Especially for partners of young patients with dementia who want to pick up their own lives again. They should be much more able to understand these kinds of issues (Bakker et al., 2010 p. 637-638)

It's hard for family and friends to realize that when I come home after dealing with problems all day at work, all I do is deal with more problems? I have no one to confide in anymore? No tenderness? No support ? I'm lonely! ? And all they (family and in-laws) have to say to me is ? Take care of yourself? (CG #26), (Ducharme et al, 2014, p 4)

Results also show that, carers' of EOD need the support of professional that are competent to help them map out strategies to help tackle their challenges. The right information and support will fizzle out uncertainty surrounding their relatives' illness. Knowing who and where to turn to for support, can be reassuring. These caregivers also expressed the need of having an organized support group where they can comfortable be around people with similar predicaments. They also wished to be educated so they can better manage and master their role as caregiver's.

I find that not enough is done to publicize the services offered? We learn about them bit by bit! A complete list or directory of the resources in the region should be drawn up and distributed? It's always up to us to dig things up, to scour the internet? (Caregiver (CG) #30). (Ducharme et al, 2014, p. 4)

People in their 50s are a band apart. My own aging parents get better services than we do [caregiver and care recipient]? (CG #9). Ducharme et al, 2014, P 6

I learned how I wanted to conduct a family meeting with my children..., (Ott et al. 2010. p. 96).

Nurses help to ensure careers look after themselves for their own wellbeing, so they can maintain their caring role. They also provide invaluable advice when a significant change in care is imminent, (Elkins & Weatherhead 2014, p. 66)

You represent the outside world and the fact that someone has an interest in this situation is a comfort. I need to have adult people to talk with me. I appreciated having the nurse come over and take a look at my wife to make sure that nothing was going on physically. (Ott et al, 2010, P. 96)

Stimulating, fun activities to pass the time, that's what's missing so much? Anything, outings just to get out of the house, picnics? Places for old folks, it's not for him! (CG #13), (Ducharme et al, 2014, p.4)

7 CRITICAL REVIEW

When the respondent of this study was thinking which of the materials that will be suitable for the nature of questions the respondent intend to investigate, one thought quickly comes to mind, i.e. choosing the right inter alia, articles, journals and books that contains dementia, Alzheimer's, dementia in young people, carers of dementia, early dementia and statistics on young people with dementia, since the main question is to see the challenges that EOD spouses i.e. care and how Nurses could help to mitigate these challenges.

Furthermore, relevant of each articles, books and journal has been put into perspective, for example, using an old research articles would arguably not qualify enough to explain the present phenomenon the author want to explain. Ideally, anything more than 15-year-old articles are considered not suitable enough. Nonetheless, in light of this, the respondent kept to this time frame and selected relatively recent articles and specifically articles that address the research aim. Furthermore, prior literature review, the author had some conception and subjective interpretations; however, the review has further refined the respondent's ideas and eradicate any form of subjectivism. This study tend to be transferable in the sense that, further studies can elaborate more on the impact of Early Onset Dementia focusing on family dynamics using result from this current study to expand the awareness EOD. More also, the external point of view from the supervisor has also been valuable in other to reduce ambiguities.

8 INTERPRETATION OF RESULTS

The aim of this study was to investigate the needs of carers' of EOD patients, roles of Nurses, particularly detailing what of role they could play in order to alleviate some of the challenges that is facing career in today's society. Travelbee's theory of human to human relationship with communication as a key point when the nurse comes in contact with a patient and their family was used as the framework for this study.

Helping an EOD spouse to make sense of its situation should involve creating a human-to-human relationship, which should serve as the platform for the whole experience. In short, this involves getting to know that cases are peculiar and trying to adapt professionalism and experience to communicate to the spouse and bringing them to realization. More also, for a nurse to help a spouse better, the nurse need to be grounded, particularly in the illness the patient is suffering from, because it is natural that the career will have a lots of questions and may demand answers in order to gain better knowledge of the illness. Hence a nurse should be in the position to answers considerable amounts of questions that the patients will have. In agreement with Travelbee, family or spouse will want to learn about how the disease manifests itself, the prognosis and the kind of role they would be expected to play.

This study has revealed the ordeal that dementia carers' could be subjected into. Flynn & Mulcahy (2013) explained how spouses often pay what they term "penalty" for having husbands or wives diagnosed with dementia at an early age; psychological, socio-economic and emotional penalties. For instance, spouses broke down and appeared to be in despair as they faced the realty of losing their loved ones to something unknown. It was expressed as standing in front of a steep mountain (Madsen & Birkelund, 2013). There comes a point in time when everything comes to a halt and for the spouses, this was the moment. This affirms to the need of professional help in helping spouses as they progress to another stage in their life.

Spouses expressed the need to be informed. Information helps one to widen their knowledge on issues (Long et al. 2000). Spouses clearly stated how they relied on the information they got from the nurses. It helped them to know if they had to seek professional help for their children since the disease is genetic (Ducharme et al. 2014). There is the need for nurses to constantly

update themselves when it comes to nursing care. Being well informed and educated about a particular illness of focused as a nurse has a multiplier effects, i.e. an informed nurse will lead to an informed carers' which will eventually lead to informed patients.

The spouses of EOD individuals automatically inherited this role as care givers rather than wives/husbands as argued by Ornstein et al. (2013). Becoming a caregiver created a kind of disconnection in their relationship with their loved one. They lost companionship; a vital part of their relationship. For the spouses, things worsened as they had to take care of the person they loved. They could no longer share loving memories, make decisions together and making small talks due to barrier created as a result of taking the role as a care giver. There is the need for the nurse to help theses spouses create coping strategies as they take the role as caregivers in other not to neglect their own needs.

Nurse's role can be felt also in the area of educating the caregivers on how to cope and master the challenges associated with EOD. Kirkevold & Ekern (2001) suggest family coping strategies like support from health caregivers as a way of which spouses of EOD patients can deal with their challenges.

8.1 Conclusion

The diagnosis of dementia is generally confronted with conflicting information's due to the low level of awareness of the disease in young adults. Some of the challenges which come about are having young wives or husbands and dependent children. Spouses are exposed to great level of burdens from psychological, socio-economical to emotional. Spouses who automatically assumed the role as caregivers had the tendency of breaking down, due to the untimely manners at which their spouses are diagnosed, insufficient information and inadequate professional support. One can argue that society is better placed in handling older people with dementia unlike the younger ones that is still in embryonic stage.

Nurses should understand that EOD does not only affect the patient but also have huge impact on their significant others. Travelbee discusses the need for nurses to acquire sufficient knowledge in order to be able to provide a well human-to-human relationship when they encounter spouses. Thus, providing more information about the disease, good communication skills, redirecting spouses to the right professionals in order to help them prepare well for what awaits them. Knowing what to expect helps prevent uncertainty which in turn ease up their burden.

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APPENDICES

Appendix 1, Paper Trail Folder

Data-base	Date Accessed	Search words	Hit	Relevant/ Trivial	Reason	Title of article
Bibsys	20.06.14	Ynge med demens And pårørende	10	1/10	The others did not meet my criteria	<i>I gode og onde dager – om forhold av betydning for selvopplevelse og identitet hos ektefeller til personer som utvikler demens i yngre alder.</i>
EBSCO	20.06.14	Spouse And dementia And suffering	9	2/9	I got some articles that I had already chosen	<i>Caring as worrying: the experience of spousal carers’</i> <i>‘The path through the unknown’: the experience of being a relative of a dementia-suffering spouse or parent</i>

EBSCO	01.09.14	Early Onset Dementia	24	1/24	I already have most of the article, so I choose those that more related to my topic	<i>Early-onset dementia: the impact on family care-givers</i>	
EBSCO	05.04.15	spousal caregiving And nursing Intervention	30	1	The rest articles did not coordinate with my topic	<i>Promoting positive approaches to dementia care in nursing</i>	
EBSCO	05.04.15	Need for support And caregiver And spouse And Dementia	5	2/5	I decided that the others did not fit my topic.	<i>Caring for a spouse with Alzheimer's disease: Stressors and strengths</i>	<i>"Easing the Way" for Spouse Caregivers of Individuals with Dementia. A Pilot Feasibility Study of a Grief Intervention</i>
EBSCO	06.04.15	Dementia And Challenges And Nursing role	16	2/16	The others did not meet my criteria	<i>The role of the nurse within the multi-professional rehabilitation team</i>	<i>Dementia care: reducing carers' Emotional burden.</i>

Google Scholar	06.04.15	Dementia carers burden	10	2/10	The other articles did not fit into what I was looking for.	<i>Unmet support needs of early-onset dementia family caregivers:</i>	<i>Family caregivers daily life caring for a spouse and utilizing respite care in the community</i>
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Appendix 2, The Matrix Method

Author, title & journals	Year	Aim	Participant	Result
Bauer, B. <i>I gode og onde dager: om forhold av betydning for selvopplevelse og identitet hos ektefeller til personer som utvikler demens i yngre alder.</i>	2010	To examine variations in self experience with spouses in the face of dementia development among its partner. To study which aspects of the disease process that particularly seems to affect the spouses' identity and experiences and to capture the procedural aspect of these experiences	11 spouses participated in this research. 7 women 5 men	The result of this stud was divided into 2 themes and several subthemes; 1. From suspicion to recognition Subtheme; ➤ The first sign ➤ Lost of companionship ➤ Psychological consideration 2. Adapting to a different life 5 subthemes ➤ maintain the person your partner has been for as long as possible ➤ suppress own feelings and reaction ➤ restoring own activities and visions ➤ strengthened self-esteem
Berglund, A. & Johansson, I. <i>Family caregivers' daily life caring for a spouse and utilizing respite care in the community.</i>	2013	The aim of this study is to unravel the day-day experiences of family careers when caring for their spouse at home and when they make use of residential respite care home.	18 Family care givers. 13 women & 5 men. All care-givers lived in their own homes with their spouses in rural or urban environments.	According to the results of the study careers are prone to burden when providing care to a spouse. Uncertainties of how to handle the new role as family caregiver was also a major concern. Result also shows that the career's needs continuous education & professional support. Their needs were classified into 2 major part; Social need; fellowship with friends and family Need of security; support of professionals

<p>Cheung, J. & Hocking, P. <i>Caring as worrying: the experience of spousal carers.</i> Journal of Advanced Nursing.</p>	<p>2004</p>	<p>The aim of this paper is to explicate the meaning of caring from the perspective of spousal carers for people with multiple sclerosis in order to shed light on and understand the challenges and demands these carers encountered.</p>	<p>10 multiple sclerosis spousal carers took part in the study.</p>	<p>These participants have emotional burden due to their responsibility in caring for their spouse. Their worrying includes; Their partners, their relationships with their partners and their future, Their own health, Care facilities, Deficient in support from government.</p>
<p>Ducharme et al. <i>Unmet support needs of early-onset dementia family caregivers:</i> a mixed-design study</p>	<p>2014</p>	<p>This study was aimed to elucidate the unmet support needs of Early Onset Dementia carers. Creating awareness will help facilitate and give room to growth of ground-breaking involvements and proficient services adapted to their exact needs.</p>	<p>32 Family carers in their between the ages of 50 participated in the study.</p>	<p>Up to 70% of carers that participated in the research indicated that they needed psycho education in order to enable them cope with the condition of their spouses these are; 1. They wish to be acquainted with obtainable help more especially on finance 2.They also that their diagnosed family member would be seen and respected as an individual and that provision should be made for them to uphold their outstanding abilities for as long as possible; 3. Which will help them diminish stress that is associated with them caring for their relative at such early age. 4. They also pointed out that they wish the rendered help should be given at appropriate time, and that it should adapt to their role relative of Early-Onset Dementia patient.</p>
<p>Elkins & Weatherhead. <i>Dementia care: reducing carers'</i></p>	<p>2014</p>	<p>Aim is to highlight the need for Admiral nurses and their roles.</p>	<p>Carers of Early Onset Dementia</p>	<p>Admiral Nurses render psychological support. The aim of Admiral nurses is to assess care need, reassure and render advise to carers (both professional and non-paid) on the way forward, with in depth care planning by identifying challenges that might arise,</p>

<p><i>Emotional burden.</i> Journal Of Clinical Nursing</p>				<p>thereby reducing the risk of crisis. Educational support Education that will benefit professional careers, non-paid careers and eventually the patient. Dementia is been seen as a neurology condition unlike before when it was viewed mental health. Social networking Collaborating with other health care personnel/association(s) to help these careers get the designed assistance needed.</p>
<p>Flynn R. & Mulcahy H. <i>Early-onset dementia: the impact on family care-givers.</i> British Journal of Community Nursing.</p>	<p>2013</p>	<p>The aim of this research was to investigate how physical, emotional, social and Financial burden affect care giving by relatives of Early Onset Dementia (EOD)</p>	<p>7 family carers of people with early-onset dementia (EOD).</p>	<p>Effect of caregiving <i>Theme 1.</i> Physical, Emotional; loneliness Social; social seclusion. Difficulties in arranging or planning social events for younger careers than for older careers Financial; majority were “breadwinners”. Shortage of pension and inadequate financial support <i>Theme 2.</i> Problem getting diagnosis for the patient. Relationship change; Careers expressed both positive and negative relationship changes from caring for their spouses. Lack of resources; they expressed insufficiency in knowledge, support and service from the community. <i>Theme 3.</i> The care-giving experiences identified in this study emphasizes the need for improvement in the provision of community and specialized services for people with EOD and family carers.</p>

Hoe J. & Thompson R. <i>Promoting positive approaches to dementia care in nursing</i>	2010	The aim of this article is to present a general idea of the issues relevant in dementia care for nurses working in any setting.		Intervention for Dementia includes; assessment and understanding of Dementia Provision of leisure activities for patients, Carers' burden includes; psychological, physical, social and finance. Result shows discrepancy between carers of Dementia and other carers', stress level is higher in Dementia carers' 1 of the roles of Nurses is to lead, develop and improve changes surrounding dementia care in clinical practice. Psychological action taken to reduce burden on Dementia carers'; Education and Information, skill training, peer groups and psychotherapy.
Long et al. The role of the nurse within the multi-professional rehabilitation team	2000	The aim of this investigation is to To pin point the input of nurses within the multi-professional rehabilitation team.	four groups: users, carers' and carers' organizations; nurses; members of the multi-professional team; and educationalists.	Result showed 6 Nurses roles which includes; assessment, co-ordination and communication, technical and physical care, therapy integration and therapy carry-on, emotional support, and involving the family. And lastly Creation of a supportive environment for the occurrence of rehab.
Madsen, R. & Birkelund, R. <i>The path through the unknown: the experience of being a relative</i>	2012	To distinguish amid the experiences of spouse or parent who suffers from dementia and examine if there are correspondence or discrepancies between	21 stories from 4 groups; 3 sons 3 husbands 7 wives 8 daughters	In their finding it was noted that there was lack of knowledge about the experiences of relatives of a spouse or parent suffering from dementia, furthermore the importance of producing scientific knowledge is required in other to accommodate the needs of dementia sufferers and their relatives.

<p><i>of a dementia-suffering spouse or parent.</i> Journal of Clinical Nursing</p>		<p>their experiences.</p>		
<p>Ott, et al. <i>“Easing the Way” for Spouse Caregivers of Individuals with Dementia. A Pilot Feasibility Study of a Grief Intervention.</i> Gerontological Nursing</p>	<p>2010</p>	<p>Feasibility study (this is qualitative)</p>	<p>20 spousal caregivers of individuals with dementia</p>	<p>Significant changes were found from baseline to the completion of the intervention for the measures of grief, depression, anxiety, positive states of mind, and self-efficacy.</p>