Experiences and challenges of family caregivers of people with Alzheimer’s disease

Författare: Gloria Matovu
Handledare: Barbro Wadensten
Examinator: Katarina Hjelm

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ABSTRACT

Background: A family caregiver is a person living close to an individual in need of care. Being a relative of an Alzheimer’s patient involves switching roles from being a family member to a care giver. Studies have shown that it’s usually spouses and children especially daughters who offer care to their love ones in their homes. Family caregivers are faced with physical, psychological, emotional, social, and financial strain.

Aim: The aim of this literature study was to describe the experiences and challenges of family caregivers of people with Alzheimer’s disease.

Method: A literature study was conducted, and 11 original articles were selected from the databases PubMed and CINAHL; the selected articles went through a quality analysis with the help of a protocol for quality assessment of qualitative articles.

Results: Caregivers viewed their needs as irrelevant and secondary to the needs of the person with dementia. The challenges that come with the role put a lot of strain on the caregiver. Caregivers weren’t prepared to carry out their roles due to lack of support from formal care. A lack of awareness and knowledge about dementia in the community was the leading cause of social stigmatization.

Conclusion: With help from formal care, the caregiver doesn’t have to feel like their needs are secondary to their relative’s needs. Nurses, family caregivers and people with Alzheimer’s disease are required to work hand in hand in order to achieve their common goal of good health.
Nyckelord: Alzheimers sjukdom, familj vårdgivare, demens, upplevelser, utmaningar

SAMMANFATTNING


Syfte: Syftet med denna litteraturstudie var att beskriva erfarenheter och utmaningar av familj vårdgivare av personer med Alzheimers sjukdom.

Metod: En litteraturstudie genomfördes, 11 original artiklar hämtades från PubMed och CINAHL och genomgick en kvalitetsgranskning med hjälp av en checklista för kvalitativa artiklar.


BACKGROUND

According to Carlsson and Larsen (2014), a family caregiver is a person living close to an individual in need of care. It can be someone with direct company for example a friend, neighbor or a person from an extended family. It’s often spouses and children especially daughters who offer care to relatives in their homes. Growing in the role of a family caregiver is often considered a long process. The risk of burnout is relatively high; 17 out of 46 family caregivers were at risk of getting burned out. The emotional strain is perceived as the heaviest because the caregiver takes on both his/her and the patient’s emotional needs. Family caregivers of people with dementia were also linked to depression, anxiety and many other heart diseases. However, Jansson and Grafström (2011) mentioned that the role of caregiving is also known to be one of support, love, joy, satisfaction, companionship and help with daily needs as foreseen. Caregivers were given a sense of meaningfulness in helping someone they were closely connected to. Being appreciated, desired and needed made caregivers feel positive about their roles. It’s demonstrated that family caregivers are faced with emotional, physical, psychological, social, and financial challenges. Family caregivers are often referred to as ‘invisible second patients (Novais, Dauphonit, Salmon & Mouchoux, 2017).

Based on population surveys, 20 percent of women and 16 percent of men over the age of 18 are reported to regularly take care of family members with dementia. The care received from family caregivers consists of several different categories i.e. daily life activities, personal hygiene, transportation, emotional support, health and medical care needs. Being a relative of an Alzheimer’s patient involves switching roles from being a family member to a care giver. Adequate information and education about the disease as well as coping strategies are considered to be effective in dealing with the unpredictable outcomes of caring for a relative (Carlsson & Larsen, 2014).

Alzheimer’s disease

Alzheimer’s disease is a degenerative brain disease and the number one cause of dementia. Dementia is a name given to diseases that affect the brain (Edberg, 2014). Alzheimer's disease is a type of dementia in which brain tissue is damaged and nerve cells begin to die abnormally. The disease affects the brain, but above all the cerebrum and the tinning lobes. The brains of people with Alzheimer's disease are reduced in volume. The symptoms
differentiate depending on where the damage is in the brain. In Sweden there’s about 140 000-150 000 people who have dementia where 50-60 percent have Alzheimer’s disease. Alzheimer’s disease is not a normal part of aging, even though most people with it are 65 years and older. Only up to 5 percent of people with the disease have early onset Alzheimer’s, which often appears when someone is in their 40s or 50s (Swedish Dementia Center, 2016).

Alzheimer’s symptoms may vary according to different individuals. The most common early symptom is a gradually worsening ability to remember new information; this is because the first neurons to be destroyed in the brain are usually regions involved in forming new memories. Other symptoms include agitation, lack of sleep, delusions, and decline in cognitive and functional abilities (Basun, 2013). These difficulties worsen as the disease progresses; the final stages of the disease are bedridden and require ongoing care. There is no cure for Alzheimer’s, the treatment only focuses on relieving the symptoms brought on by the disease (Swedish Dementia Center, 2016).

According to the Swedish Dementia Center (2016), the basis for the clinical diagnosis of Alzheimer's disease is a clinical medical examination, the patient’s history, along with other clinical tests and cognitive functions test. The clinical diagnosis is done by a doctor for the person to know if they have dementia; it usually takes between 4-6 weeks. The clinical diagnosis includes i.e. medical history, interviews with relatives, assessment of physical and mental state, structured assessment of functional and activity ability (done by occupational therapists or sometimes physiotherapists to assess the person's ability to cope with various everyday activities), cognitive/memory test (MMSE, MMT and Clock test), blood samples and computer tomography on the brain.

**Nurse’s role**

For nurses to be able to intervene successfully, they need to have enough knowledge about dementia and the experiences of family caregivers. Nurses should create teaching opportunities about Alzheimer’s disease and how to handle people with the disease. Family caregivers should be encouraged to talk about their feelings and experiences as caregivers. This will help caregivers normalize their reactions towards the different challenges (Grafström, 2013). In order to reduce the negative effects of the caregiving role, the nurse
should present family caregivers with the different types of support available. Nurses should come up with different ways on how to reduce psychological and physical stress for family caregivers by helping them create time for their own needs. Support and care for family caregivers should be based on their specific needs (Carlsson & Larsen, 2014).

**Theoretical reference frame**

To understand the patients’ needs and the role of a family care giver, Watson’s theory of caring from 1975 will be applied to this study. According to Alligood (2014), Watson refers to the human being as "a person worth being cared for, respected, nourished, accepted and comforted. In general, Watson sees an ideological perspective of a human being as an entirely useful, unified individual.

According to Watson (Peptrin, 2016), the theory involves treating oneself and others with kindness; listening honestly, accepting and respecting others as they are and honoring both one’s and others’ human dignity. The theory supports a relationship built on empathy, helping, trust and warmth. A nurse’s strongest ability is her manner of communication, which involves listening, verbal and non-verbal communication. By promoting and allowing both good and bad feelings in a caring connection; the nurse and patient are aware and understand the causes and actions that come with these feelings.

Watson means that (Peptrin, 2016) caring can be adequately shown and practiced involving personal relations. It’s made up of ways that support the wellbeing of certain human needs. Sufficient caring should advocate for individual or family growth, the patient should be seen for where they are now but also where they could be. A safe surrounding is one that offers potential progress while still giving the patient a possibility to decide the best alternative for himself. In summary, the Alzheimer’s patient, their family and environment are dependent on each other to achieve the goal of wellbeing.

**Problem formulation**

Family caregivers were faced with emotional, physical, psychological, social, and financial challenges (Novais, Dauphonit, Salmon & Mouchoux, 2017). Caring for a family member with Alzheimer’s disease is a role that has been defined as straining and one that’s
accompanied with very many challenges (Carlsson & Larsen, 2014). There is need for more knowledge and information about the caregiver’s role. This study will help place the purpose of investigating the challenges and experiences of family caregivers in relation to what other researchers have published on the topic before. By investigating these experiences and challenges, nurses can be able to offer help and support to family caregivers.

**Study’s aims**

The purpose of this literature study is to describe the experiences and challenges of family caregivers of people with Alzheimer’s disease.

**Study questions**

1. What are the experiences of family caregivers of people with Alzheimer’s disease?
2. What challenges do family caregivers of people with Alzheimer’s disease encounter?

**METHOD**

**Design**

A descriptive qualitative design was used with a literature study as the data collection method to answer the questions for this study. A literature study is a collection of selected studies on a certain subject whose purpose is to clarify what is already known about an area (Forsberg & Wengström, 2016).

**Selection**

*Inclusion criteria*

The articles used in this study were original research articles with a qualitative method of data collection. Participants included both men and women. Only articles that provided free full texts were selected. The participants categorized as family caregivers had to be 18 years and above. The participants categorized as patients had to be diagnosed with dementia but particularly Alzheimer’s disease. Articles which had headings with dementia in general were also included in the study.
Exclusion criteria

Articles published in any language other than English were excluded from this study. Articles that weren’t approved by the ethics committee were excluded from the study. Low quality articles were also excluded from the study.

Search strategy

Article selection was made using PubMed and CINAHL databases. The articles were limited to the period 2013-2018. Search words included: caregivers, family, Alzheimer’s disease, dementia, challenges, experiences. These search words were then used to form sentences to make it easier to find the most relevant articles for the study. The sentences included; “family caregivers and Alzheimer’s patients”, “family caregivers of people with dementia”, “experiences of family caregivers of Alzheimer’s patients”, “experiences of family caregivers in dementia”. A minimum of 11 original qualitative articles were chosen for the study. Table 1 shows an overview on how the search in the chosen databases was carried out.

Table 1: Article search in PubMed and CINAHL

<table>
<thead>
<tr>
<th>Database</th>
<th>Search word</th>
<th>limitations</th>
<th>Search date</th>
<th>Number of articles found</th>
<th>Number of read abstracts</th>
<th>Chosen articles</th>
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Analysis

Quality analysis
First, articles with titles that fit the purpose of the study were selected. The abstracts of the same articles were read. After reading the abstracts, articles that were to be read in full text were chosen. After reading each article thoroughly well, the author then proceeded to a quality assessment. Qualitative analysis was conducted using a protocol for quality assessment of qualitative literature studies from Forsberg and Wengström (2016), see appendix 2. The protocol examined the quality of the articles used in the study. It determined whether the article had high, average or low quality. Quality assessment included the purpose and questions of the study, design, selection, measuring instruments, analysis and interpretation. 11 articles were analyzed in the study; an overview of the articles with medium to high quality was then briefly described in appendix 1, see appendix. Articles with high quality possessed a well-defined purpose and question, valid and interpretable results, clear description of materials and methods. The research in high quality articles was up to date i.e. published in the last three to five years. In general, the articles were credible and reliable. Articles with low quality had limited patient data, inadequate descriptions and evaluations with doubtful statistical methods. They had more deficiencies than merits i.e. an article had a well described purpose but then had insufficient data collection methods, unreliable results, published 10 years ago etc. Articles with average quality possessed more high-quality characteristics than low quality. With help of the protocol for quality assessment of qualitative literature studies, the author evaluated the articles based on yes and no questions. Questions

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<td>2013-2018 English language</td>
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that were answered with “yes” answers were considered to have met that criteria for that specific question. Articles with a score of 80-100% yes answers were considered high quality, 70-79% yes answers were considered average quality, and articles with less than 70% yes answers were considered low quality (Forsberg & Wengström, 2016).

**Results analysis**

Article analysis was carried out based on Forsberg och Wengströms (2010) method of content analysis. The articles were read and analyzed thoroughly well, relevant information that answered the study’s purpose was selected and sorted out according to the two study questions. Seven sub categories were then created under the study questions i.e. the feeling of not being in control, the change it brings in a relationship, the demands that come with the caregiving role, the strains of family caregiving on mental health, being unable to engage in social activities, caregiver’s inability to focus on their own needs, and lack of support from healthcare professionals. Information from the different articles was then placed under the headings author, year, country, purpose, method, results, research group, and article quality, see appendix 1 in appendix.

**Ethical considerations**

The articles included in this study indicated that they followed the ethical guidelines i.e. they mentioned that they acquired authorization from an ethics committee and were critically reviewed by other authors. They also stated that the participants’ rights were respected, and all participants deliberately agreed to participate in the studies without coercion. The selection of articles was objective (Forsberg & Wengström, 2016).

**RESULTS**

The results were divided according to the two study questions, which were then split into seven sub categories i.e. the feeling of not being in control, the change it brings in a relationship, the demands that come with the caregiving role, the strains of family caregiving on mental health, being unable to engage in social activities, caregiver’s inability to focus on their own needs, and lack of support from healthcare professionals. The results highlighted
out the experiences and challenges of family caregivers and the deficiencies in the healthcare professionals’ role of support.

**Experiences of family caregivers**

*The feeling of not being in control*

Tatangeloa, McCabea, Macleoda, and Youb (2018) believed that the quality of relationship between the caregiver and the person with dementia played a huge role in the caregiver’s desire to take on their roles and cope with the challenges of the disease. Many adult children taking care of their parent with dementia felt that it was their obligation and duty to provide care for their parent. Some caregivers didn’t identify themselves as “caregivers”, but rather viewed their role as a natural extension of their relationship. In the study Lethin, Hallberg, Karlsson, and Janlöv (2016), caregivers focused on how they could improve their relatives’ quality of life by becoming more aware of the disease. Caregivers were interested in preparedness through knowledge about dementia. Being prepared for future responsibilities and challenges protected them from the negative outcomes of being a caregiver. Without information and advice, caregivers experienced self-critical thoughts about themselves and their abilities to care effectively. Other studies (Melunsky et al., 2015; Lian et al., 2017; Myhre, Tonga, Ulstein, Høye & Kvaal, 2017) stated that some caregivers felt more secure about their roles after seeing other caregivers prospering. Caregivers described how their relatives were discouraged from seeking help due to the incurable nature of the disease. Alzheimer’s disease was described as being similar to a cancer diagnosis. Both the caregiver and the person with dementia wanted to avoid the psychological distress that came with the disease. Caregivers felt that they had no control over how the disease progresses.

*The change it brings in a relationship*

Studies (Malthouse & Fox, 2014; Melunsky et al., 2015) displayed how dementia led to a change in the quality of relationship bond between two people. Couples felt that they were unable to participate in activities together like they did before. Partner caregivers reported a lack of emotional support from the person with dementia. Most partner caregivers considered their health needs as irrelevant. The needs of the person with dementia came first. It was also discovered that partner caregivers had difficulty identifying and discussing their own health needs. Tatangeloa et al. (2018) noted that partner caregivers regarded their role as them
fulfilling their marital duty which must be fulfilled without assistance. The demands and burdens of being a spousal caregiver for a person with dementia affected the caregiver’s values, identities and perceptions of how they viewed themselves. However, Melunsky et al. (2015) concluded that the style of living between spouse caregivers and their relatives was improved when they maintained shared activities.

According to Malthouse and Fox (2014), switching roles within the couple relationship was often linked to the progression of dementia. Switching roles affected the amount of responsibility that each spouse took on. All participants described an awareness of becoming more of a caregiver and less of a significant other. Taking on more or all the household tasks and caring roles left partner caregivers feeling tired and less energetic. Other studies (Nay et al., 2015; Pik Yi, Yuk Lai, Ching Sum, Kin Kwan, & Ching Lai, 2016; Tatangeloa et al., 2018) with the similar findings mentioned that the loss of freedom associated with dementia affected activity levels for caregivers and their relatives. The constant fear of leaving the house alone and getting lost affected their personal freedom and reduced opportunities to outdoor activities. For caregivers, the ‘loss of freedom’ was associated with fear of leaving their spouse. People with Alzheimer's disease rarely participated in any activities due to their limited cognitive abilities. Progression of the disease also came with increased physical demands and decreased activity levels for the caregiver and the person with Alzheimer's disease.

The demands that come with the caregiving role

According to Myhre et al. (2017), the responsibilities of providing care to a person with dementia at home were considered burdensome. Caregiving involved looking out for someone else’s overall wellbeing. Some caregivers stated that taking care of a person with dementia consumes one’s physical energy and creates a heavy emotional burden. Most caregivers were linked to sleep deprivation and exhaustion. Many caregivers thought of quitting the task of providing care because it was too demanding. Based on the findings of Spigelmyer, Hupcey, Smith, Loeb, and Kitko (2017), caregivers expressed a lack of confidence in their roles. Caregivers reflected negatively on their abilities and questioned whether they were doing the right thing. Some caregivers weren’t certain if they made the right decision to take on the role of caregiving. One of the major responsibilities of being a caregiver was the change in roles
between the caregiver and the person with dementia. Young caregivers taking care of a parent with dementia had to take on the parenting role. According to (Pik Yi et al., 2016), young adults who observed their parents taking care of a relative termed it as “emotional work”.

**Challenges encountered by family caregivers**

*The strains of family caregiving on mental health*

Tatangeloa et al. (2018) mentioned that self-sacrifice and self-neglect were necessary within the role of a caregiver. The caregiver’s mental health needs weren’t met due to lack of time for themselves. Most caregivers seemed not to have knowledge about their psychological support options. Lethin et al. (2016) demonstrated that young caregivers had a higher risk of suffering from depression. Caregivers complained about the different roles and responsibilities they combined. High levels of depression were associated with low self-worth, loss of social relationships and networks. In relation to Lethin et al. (2016)’s findings, Pik Yi et al. (2016) stated that caregivers felt alone and isolated because formal care was not supportive as expected. Taking care of a person with dementia consumed caregivers’ physical energy and also created a heavy emotional burden. The caregiver’s independence became compromised as they adapted to the new situation. The change in perception of how care receivers viewed themselves was distressing. During the final stages of the Alzheimer’s disease, more caregivers were connected to depression, fatigue, sleep deprivation, and stress. Caregivers were prone to externalize their negative emotions to the person with dementia and vice versa.

*Being unable to engage in social gatherings*

Different studies (Greenwood, Smith, Akhtar, & Richardson, 2017; Malthouse & Fox, 2014; Myhre et al., 2017; Nay et al., 2015) concluded that many caregivers expressed a major loss of social participation since becoming a caregiver. Caregivers were not able to socially participate in activities as they desired. The outgrowing needs of the person with dementia and social stigmatization made it impossible to plan social events. Family members had difficulties in relating to the person with dementia due to the change in behavior from the person with dementia. Based on Lian et al. (2017)’s findings, the lack of awareness and knowledge about dementia in the community was the leading cause of social stigmatization. The person with dementia chose to withdraw from social situations themselves to avoid
scenarios where their memory was questioned. Lack of knowledge on how to communicate with the person with dementia also contributed to social isolation. Social stigma from the society caused people with dementia to deny they had dementia.

Lian et al. (2017) and Nay et al. (2015) reported that a lot of stress came from negative attitudes towards dementia in the community. People had negative attitudes towards dementia. Due to stigma from society, the caregiver and person with dementia lacked opportunities to socialize. The rate at which caregivers participated in different activities was reduced. Caregivers and their relatives were also restricted from the types of activities they participated. The loss of social participation caused caregivers to reflect on how important their social needs were. Caregivers felt miserable because they had no time or space for themselves. Caregivers were also unable to entertain people at home which resulted into loss of friendships. As the care needs of the person with dementia increased, the ability to plan social events ahead of time became less likely. According to Melunsky et al. (2015), when people with dementia couldn’t participate in social interactions, caregivers experienced a reduction in social network. Caregivers acknowledged the importance of doing things together with their relative.

*Caregiver’s inability to focus on their own needs*

Studies (Pik Yi et al., 2016; Tatangeloa et al., 2018) showed that almost all adult and young caregivers showed awareness on the importance of maintaining their own health. Caregivers felt that their own health was of great importance if they were to continue caring for their relatives. However, the caregiving role consumed their lives and left no room for their health needs to be met. Caregivers were forced to shift their focus to the relative’s needs every hour of the day. According to Spigelmyer et al. (2017), resistiveness to care contributed to an increase in their duties and responsibilities. Caregiving led to limited personal time and increased emotional work, the caregiver’s needs became irrelevant.

Most of the carers had no employment because they needed to take care of their relatives. The loss of employment resulted into increased social isolation. Caregivers reported feelings of loneliness and frustration. There was trouble trying to balance employment and taking care of the person with dementia. With or without employment, the caring role required a long period
of adjustment. Working caregivers who had other responsibilities such as careers and children, experienced role conflicts. Being unable to take a break from the person with dementia was a major burden for many caregivers. Most caregivers were unable to put emphasis on their own needs or have sufficient time for themselves (Greenwood et al., 2017; Melunsky et al., 2015).

Lack of support from healthcare professionals

Based on Smith et al. (2014)’s findings, caregivers had difficulty contacting or asking for information and advice from health professionals. Healthcare professionals did not involve caregivers in decisions concerning prescriptions or changes in their patient’s treatment. Caregivers were not well informed and experienced difficulties in interpreting and applying information about medications. Lethin et al. (2016) showed that support from formal care was a very important aspect in transitioning in to the role of a caregiver. The lack of support from formal care made it difficult for caregivers to provide care. Caregivers had a problem finding who to contact in healthcare when they needed help. Lack of support from formal care, family and friends left family caregivers feeling alone and isolated.

DISCUSSION

The purpose of this study was to gather knowledge from the 11 different articles about the experiences and challenges of family caregivers. All studies (Greenwood et al., 2017; Lethin et al., 2016; Liana et al., 2017; Malthouse & Fox, 2014; Myhre et al., 2017; Nay et al., 2015; Pik Yi et al. 2016.; Smith et al., 2014; Spigelmyer et al., 2017; Tatangeloa et al., 2018) showed that caregivers viewed their needs as irrelevant and secondary to the needs of the person with dementia. The challenges that came with the role put a lot of strain on the caregiver. Caregivers weren’t prepared to carry out their roles due to lack of support from formal care. A lack of awareness and knowledge about dementia in the community was the leading cause of social stigmatization.

Results discussion

Studies (Lian et al., 2017; Myhre et al., 2017) showed that an Alzheimer’s diagnosis was stressful but focusing on the positive was a good strategy to handling the challenges that came
with it. The quality of relationship between the caregiver and the person with dementia was associated with how caregivers felt about their roles. Carlsson and Larsen (2014) mentioned that the relationship bond between the caregiver and the person with dementia played a huge role during the caring period. Findings from Jansson and Grafström (2011) viewed that the positive aspects of being a caregiver made it easier for caregivers to continue with their roles for a much longer time. Some caregivers felt they had learned a lot as people and were proud of their efforts; if their loved ones were happy, they also felt happy and important. According to Lethin et al. (2016), Melunsky et al. (2015) and Tatangeloa et al. (2018), caregivers were still connected to having trouble integrating into their roles despite the few positive outcomes.

This was due to lack of enough information and support from the formal care and the community. The caregivers who received support felt secure and were more positive about their roles. The support received included; emotional support, financial support, education etc. Caregivers preferred to have received education and information about who to ask for help from the beginning of the diagnosis. Caregivers showed that they needed to be prepared for their roles through support and education about dementia. Through support and education, caregivers were able to transition into their roles successfully. This also helped caregivers understand what to expect and how to deal with negative outcomes such as stress and depression. Some caregivers however didn’t want support, they preferred to continue on their own for as long as they could; others considered their roles as loyalty. This belief made caregivers more exhausted and overwhelmed by their roles. Accepting the situation and focusing on what to do to improve both the caregiver and care recipient’s lifestyles was a healthy way to deal with their challenges.

Malthouse and Fox (2014) stated that the challenges and responsibilities that came with the caregiving role put a strain on the relationship between two people. Switching roles in the relationship was inevitable; the person with dementia became dependent on the caregiver for everything. As the disease progressed, it caused an inevitable change in the relationship leading to more challenges and unmet needs. The final stages of Alzheimer’s disease also limited both the caregiver and the care recipient’s social activities; caregiving became a 24-hour job. In relation to Malthouse and Fox (2014), Jansson and Grafström (2011) stated that spouse caregivers mentioned how everything was hanging on them; they took on their responsibilities and their partner’s responsibilities. These responsibilities included bills, house work, driving their partner to meetings and appointments and many more. Tatangeloa et al.
(2018)’s findings showed that caregivers were unable to receive emotional support from their partners because of their diagnosis; lack of emotional support was linked to mental illnesses like depression. More worries came about when the disease progressed, there was hardly enough time to participate in other activities except caring for the person with dementia. Most spouse caregivers didn’t want to receive support from formal care because they didn’t trust someone else taking care of their partners. Melunsky et al. (2015) made some important discoveries on how having shared activities helped maintain a healthy relationship between the caregiver and the person with dementia. Having shared activities as a couple was also viewed as a coping strategy for spousal caregivers during the challenges that came with their roles. Some shared activities included taking walks, going to the café, traveling, attending social events etc.

Becoming a caregiver to a person with dementia leads to a complete change in one’s life, everything is planned around the care recipient i.e. the caregiver’s needs become secondary to those of the person with dementia (Carlsson & Larsen, 2014). According to Pik Yi et al. (2017), the challenges that come with the role put a lot of strain on the caregiver and made it impossible for them to focus on their own personal needs. This led to negative side effects such as sleep deprivation, depression, fatigue, social isolation, resisting care etc. The negative experiences of being a family caregiver made caregivers question their abilities to do their jobs. Spigelmyer et al. (2017) and Tatangeloa et al. (2018) showed that most young caregivers taking care of their parents were conflicted on if they were the parent or the child, some claimed that they didn’t want to be parents to their parents. When the parent with dementia started resisting care, young caregivers felt that they had to take on the parenting role. It considered it stressful, physically and emotionally challenging for them; they were put in a position where they had to teach their parents what’s right or what was accepted by society. All caregivers agreed that when they experienced the sudden change in behavior from the person with dementia, they felt their roles getting harder and more demanding.

Family caregivers noticed how their responsibilities put on a strain on their mental health; this strain was mainly due to lack of support, progression of the disease and the never-ending demands. Self-sacrifice was a requirement in the caregiving role, this meant that the caregiver’s needs were taken care of after the care recipient’s needs (Pik Yi et al., 2016). Carlsson and Larsen (2014) described that young caregivers had other roles like careers but
taking on the role of caregiving made it impossible for them to maintain their careers. The burden of caregiving was reflected on their daily life commitments such as parenting or working. Based on Lethin et al. (2016)’s findings, lack of support from formal care and the community had caregivers facing every challenge by themselves. Caregivers found themselves unable to continue their roles due to negative side effects like mental depression, exhaustion, fatigue, sleep deprivation and many more. In comparison to Lethin et al. (2016) Nay et al. (2015) suggested that family caregivers needed to take care of themselves in order to be able to take care of their relatives. (Melunsky et al., 2015) mentioned that increased responsibilities for the caregiver led to loss of social contact and stress for the caregiver. All the side effects of having juggled many roles also contributed to mental illness and aggressive behavior from the caregiver.

Studies (Lian et al., 2017; Malthouse & Fox, 2014; Melunsky et al., 2015; Nay et al., 2015) stated that all the responsibilities that came with being a caregiver made it impossible for the caregiver to make any plans or social events spontaneously. Most caregivers who were unable to participate in any social events were most likely the ones who received little to no help from formal care and the community. The stigma from the society also made the caregiver and the person with dementia feel isolated. Most people in the community didn’t know how to treat the person with dementia, people had very little knowledge about Alzheimer’s disease and had trouble co-relating with the person. Despite of their decreased cognitive abilities, people with Alzheimer’s disease were still aware of the stigma they received from the community. Progression of the disease led to increased responsibilities and therefore leaving caregivers with no time for social gatherings. Lack of personal space and independence also led to social isolation for the caregiver; the caregiver shared their home with the care recipient and therefore unable to host people at home as they pleased. Caregivers stated that the loss of friendships and social contacts led to feelings of isolation and loneliness. Grafström (2016) described that even if it was beneficial for caregivers to meet others in the same situation; caregivers either had difficulties leaving their relatives alone at home or didn’t have time for meetings. Other caregivers felt uncomfortable discussing their own problems with people they were unfamiliar with.

Despite caregivers being aware of their health problems, the increased demands of their roles left no room for them to put their needs first. Caregivers regarded their needs as second to the
person with dementia. Most caregivers gave up their jobs, social events and many more other activities to take on this role; Self-sacrifice led to feelings of frustration, loneliness, stress, and isolation. Caregivers expressed a need for help and support on how to manage their roles without breaking down. They also showed a major interest in continuing their roles as caregivers, but their unmet mental, social, physical and emotional needs made them question if they had the vigor to continue. Taking care of a relative with dementia was a 24-hour job that required a lot of dedication and left family caregivers with no possibilities to simple luxuries such as rest or sleep. The expectations which caregivers placed on themselves in terms of their care-giving role were very high, this made them feel like failures when things didn’t turn out as they expected (Greenwood et al., 2017; Melunsky et al., 2015).

Grafström (2016) stated that according to the Social Services Act, the Social Services Board in Sweden is supposed to provide support to people caring for their relatives. It’s the role of municipalities to find out the kind of support family caregivers need and how this support can be improved. However, studies (Lethin et al., 2016; Smith et al., 2014) showed that there were caregivers who reported having little to no support from formal care. Caregivers mentioned having difficulties contacting health care providers and even when they did, they were still left with unanswered questions. Carlsson and Larsen (2014) also mentioned that caregiver burden was related to the relative’s needs not being met by formal care. Some caregivers didn’t identify themselves as caregivers and therefore their needs weren’t recognized by formal care. Healthcare professionals also expected the caregiver to initiate contact regarding their needs and those of the care recipient. Grafström (2013) suggested that educating caregivers was necessary to understand the disease and its consequences. Education contained information on dementia, causes, symptoms and how the disease was expected to progress. Education helped prepare family caregivers for the future and reduced the fear and stress that came with them having to face caregiving challenges by themselves.

According to Watson (Peprtin, 2016), a nurse’s strongest ability is her manner of communication. By promoting and allowing both good and bad feelings in a caring connection; the nurse and patient are aware and understand the causes and actions that come with these feelings. In relation to this study, Grafström (2013) mentioned that caregivers and care recipients should be given a platform where they’re allowed to express both their negative and positive feelings. Emotional support through counselling is one way a nurse can
get the caregiver and the person with dementia to reflect on their emotions. Getting family caregivers and their relatives to meet other people in the same situation could be another way for them to express their positive and negative emotions.

Watson mentions that (Peprin, 2016) caring can be adequately shown and practiced involving personal relations. The nurse should try to involve other relatives in caregiving so that the stress isn’t put on just one person. By doing this, the caregiver isn’t left to bare all the responsibilities by themselves. Chances for empathy are increased if the whole family has an insight on the situation and might even offer to help in whatever way they can. Based on Carlsson and Larsen (2014), caregivers who don’t have other relatives can be helped by finding ways for them to be relieved from their duties occasionally. This means that someone else takes care of the person with dementia for some time while the caregiver gets time to rest and cater for his or her needs.

Watson describes (Alligood, 2014) that the patient, environment and personal relations are dependent on each other to achieve the goal of wellbeing. In relation to this study, the caregiver needs to take care of themselves to be able to care for the person with dementia. A safe surrounding is one that offers potential progress while still giving the patient a possibility to decide the best alternative for himself. The nurse should see that the caregiver and person with dementia are in a safe surrounding, have access to health care and their autonomy rights are respected. Significantly Grafström (2013) tells us that nurses should strive to promote care that provides caregivers with preservation of their self-image, self-reliance, self-respect and dignity. An important aspect is to protect the person with dementia from being aware that he or she is ill. The person with dementia is also entitled to feel independent.

**Method discussion**

The author began with searching for articles from 2013–2018. 11 articles were selected for the study. The databases PubMed and CINAHL used in this study were credible and also had a large sample of articles to choose from. All the articles used in the study provided the relevant information needed and answered the study’s purpose. One of the strengths of the study was that the participants were diverse in their social backgrounds, relationships and family caregiver experiences hence favorable for generalization. The articles used in the study
focused on different challenges and experiences of family caregivers i.e. social participation and physical activity, experiences of partner caregivers and offspring caregivers, caregivers’ experiences of formal care, coping strategies of caregivers etc. This helped provide a variety of information on the different challenges and experiences of family caregivers. Another strength in the study was that the study topic was a broad search area with many articles to choose from; however, this was also a weakness since it was difficult to sort out the most relevant articles from the databases. Another weakness in the study could have been that it was the first time for the author to review research articles, the chances for an insufficient assessment of the articles was high (Forsberg & Wengström, 2016).

The author’s aim was to choose articles that had participants with Alzheimer’s disease; however, articles that had participants with dementia in general were also included. Since the author was focusing on original articles that provided full free texts with a qualitative method of data collection, focusing on participants with Alzheimer’s disease would have provided very few articles for the study. Forsberg and Wengström (2016) indicate that including articles that didn’t specify which type of dementia the participants were diagnosed with could affect the validity of the study. However, all articles came up to similar conclusions about family caregivers’ experiences and challenges.

All Studies showed need for further research and interventions focusing on how to help and support family caregivers cope with the challenges and responsibilities that came with their roles.

CONCLUSION

Taking care of a relative with Alzheimer’s disease has proven to come with a lot of challenges and responsibilities. Family caregivers were proven to set unrealistic expectations and goals for themselves. Caregivers showed a need for more help and support on how to care for their relatives. More people will be willing to take on the role of caregiving if they’re aware that they have assistance from formal care and the community. There’s need for more awareness about dementia in the community. It’s important for nurses to remember that family caregivers are also patients who need assistance and empathy. With help from formal care, the caregiver doesn’t have to feel like their needs are secondary to their relative’s needs. Nurses,
family caregivers and people with dementia are required to work hand in hand to find solutions on how to achieve their common goal of good health.

REFERENCES


**APPENDIX**

### Appendix 1: An overview of the included articles

<table>
<thead>
<tr>
<th>Authors, year, Country</th>
<th>Title</th>
<th>Purpose</th>
<th>Method</th>
<th>Research group</th>
<th>Dropout</th>
<th>Results</th>
<th>Quality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greenwood N, Smith R, Akhtar F, &amp; Richardson A, 2017, England</td>
<td>A qualitative study of carers’ experiences of dementia cafés: a place to feel supported and be yourself</td>
<td>To understand carers’ experiences of Alzheimer’s, dementia or memory cafés</td>
<td>semi-structured interviews</td>
<td>11 caregivers</td>
<td>None</td>
<td>benefits included peer support from other carers, information provision and support from the volunteer café coordinators. Despite diversity in how the cafés were run and, in the activities, offered, there were many reported similarities amongst carers in the value ascribed to attending the cafés.</td>
<td>Medium</td>
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<td>Lethin C, Hallberg R I, Karlsson S, Janlöv C A, 2016, Sweden</td>
<td>Family caregiver’ experiences of formal care when caring for persons with dementia through the process of the disease.</td>
<td>To investigate family caregivers’ experiences of formal care when caring for a person with dementia, through the stages of the disease.</td>
<td>Focus group interviews</td>
<td>23 spouses and adult children</td>
<td>None</td>
<td>Family caregiving requires collaboration with formal care to get support adjusted to needs specific to the stages of dementia.</td>
<td>High</td>
</tr>
<tr>
<td>Liana Y, Xiao D L, Zeng F, Wu X, Wang Z &amp; Ren H, 2017, China</td>
<td>The Experiences of People with Dementia and Their Caregivers in Dementia Diagnosis</td>
<td>The aim of the study was to understand the experiences of people with dementia and their caregivers in engaging in dementia diagnosis.</td>
<td>Focus group interviews</td>
<td>23 participants</td>
<td>35 participants</td>
<td>The findings illuminate a social ecological perspective of improving early detection and timely diagnosis of dementia in the community settings.</td>
<td>Medium</td>
</tr>
<tr>
<td>Malthouse, R &amp; Fox, F, 2014, England</td>
<td>Exploring experiences of physical activity among people with Alzheimer's disease and their spouse</td>
<td>To improve understanding about the barriers and facilitators to physical activity for people with Alzheimer's disease and their spouse carers</td>
<td>semi-structured interviews</td>
<td>5 people with Alzheimer's disease and their spouse carers (10)</td>
<td>None</td>
<td>The findings illustrate the complex interplay between the overarching themes ‘self’, ‘others’ and ‘couple’ that affect physical activity for both people with Alzheimer's disease and their spouse carers, and which are linked to the progression of dementia</td>
<td>High</td>
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<tr>
<td>Study Title</td>
<td>Research Question</td>
<td>Methodology</td>
<td>Participants</td>
<td>Findings</td>
<td>Score</td>
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<tr>
<td>Melusky N, Crellin N, Dudzinski E, Orrell M, Wenborn J, Poland F, Woods B, Charlesworth G, 2015, England</td>
<td>The experience of family carers attending a joint reminiscence group with people with dementia: A thematic analysis.</td>
<td>Semi-structured interviews</td>
<td>18 Participants</td>
<td>More targeted research within subgroups of carers is required to justify the continued use of joint reminiscence groups in dementia care.</td>
<td>High</td>
<td></td>
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<tr>
<td>Myhre J, Tonga B J, Ulstein D I, Høye S, &amp; Kvaal K, 2017, Norway</td>
<td>The coping experiences of spouses of persons with dementia</td>
<td>Semi-structured in-depth interviews</td>
<td>Six spouses</td>
<td>Caregivers had gained increased awareness of coping strategies in everyday life 6–12 months after the intervention. Caregivers who experienced fewer neuropsychiatric symptoms in their spouses with dementia benefitted most from the intervention.</td>
<td>High</td>
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<tr>
<td>Authors</td>
<td>Title</td>
<td>Methodology</td>
<td>Design</td>
<td>Participants</td>
<td>Findings/Implications</td>
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<tr>
<td>Nay R, Bauer M, Fetherstonhaugh D, Moyle W, Tarzia L, &amp; McAuliffe L, 2015, Australia</td>
<td>Social participation and family carers of people living with dementia in Australia</td>
<td>This paper reports on a study exploring the experiences and meaning of social participation for family carers of people living with dementia.</td>
<td>semi-structured face-to-face and/or telephone interviews</td>
<td>Participants were 33 family carers (17 spouses and 16 adult children) of older adults</td>
<td>Carers went through a process whereby the ways in which they had previously participated socially were compromised, which often prompted an exploration of new ways in which to remain socially engaged.</td>
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<td>Pik Yi H, Kam Yuk C L, Ching Sum C, Kin Kwan A S, Ching Lai Y, 2016, Hong Kong</td>
<td>Young adults' experiences of their parents caring for a relative with dementia</td>
<td>The aim of the present study was to explore the experiences and perceptions young adults had of family members who are caring for a relative with dementia</td>
<td>Semi-structured interviews</td>
<td>24 young adults</td>
<td>None</td>
<td>The findings showed that caring for a relative with dementia was perceived as a time-consuming, exhausting and long-term task. Despite their negative perceptions of the task, they were willing to take on the responsibility of becoming a primary caregiver in the future.</td>
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<tr>
<td>Smith F, Grijseels P, Tobiansky R R, 2014, England</td>
<td>Assisting people with dementia with their medicines: experiences of family carers.</td>
<td>This study examined the experiences of family carers when providing medicines-related assistance for a person with dementia</td>
<td>Semi-structured interviews</td>
<td>14 carers and 5 care recipients</td>
<td>66 participants</td>
<td>Carers reported difficulties in maintaining supplies and accessing health professionals; and they made some recommendations for service improvements. Carers’ difficulty in obtaining information and advice about medicines was compounded by their desire to allow the care-recipient to retain autonomy over their medicines as long as possible.</td>
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<tr>
<td>Spigelmyer C P, Hupey E J, Smith A C, Loeb L S, &amp; Kitko L, 2017, USA</td>
<td>Resistiveness to care as experienced by family caregivers providing care for someone with dementia</td>
<td>This research explored family caregivers’ lived experiences of resistiveness to care when they provided care for people with dementia</td>
<td>Caregiver interviews</td>
<td>Descriptive phenomenology</td>
<td>8 participants</td>
<td>2 participants</td>
<td>The identified general meaning structure contained five essential constituents. These included self-questioning of abilities; signal for increased future caregiver responsibilities; changed perception of personal self; unexpected emotional responses; and seeing a changed person, not the disease.</td>
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<td>Tatangeloa G, McCabea M, Macleoda A, Youb E, 2018, Australia</td>
<td>“I just don’t focus on my needs.” The unmet health needs of partner and of spring caregivers of people with dementia: A qualitative study</td>
<td>The aim of this study was to examine the health needs of partner and of spring caregivers of older people with dementia, including the barriers they experience in meeting their needs.</td>
<td>Semi-structured interviews</td>
<td>Qualitative study</td>
<td>24 family caregivers</td>
<td>None</td>
<td>Partner caregivers had a difficulty in acknowledging their needs. Offspring caregivers’ unmet health needs were easily identified and were focused on their unmet mental health needs and feeling socially isolated.</td>
</tr>
</tbody>
</table>

**Appendix 2: Protocol for qualitative articles**

A. Purpose of the study?

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..............................................................................................................................

a With help of the protocol for quality assessment of qualitative literature studies, the author evaluated the articles based on yes and no questions. Questions that were answered with “yes” answers were considered to have met that criteria. Articles with a score of 80-100% yes answers were considered high quality, 70-79% yes answers were considered average quality, and articles with less than 70% yes answers were considered low quality (Forsberg & Wengström, 2016).
Which qualitative method was used?

Is the design of the study relevant to answer the study questions?
Yes □ No □

B. Research Group
Are the selection criteria for the research group clearly described? (Inclusion and exclusion criteria should be described)
Yes □ No □

Where was the survey conducted?

Selection - is it described where, when and how the survey group was contacted?

Which selection method was used?
□ Strategic selection
□ Snowball selection
□ Theoretical selection
□ No specified description

Describe the survey group (age, gender, social status, and other relevant demographic background).
Is the research group appropriate?
Ja □ Nej □

C. Method for data collection
Is the field work clearly described (where, by whom and in which context did data collection occur)?
Yes □ No □


Describe:
..................................................................
..................................................................
..................................................................

Are the methods of data collection clearly described (what kind of questions are used?)
Describe:
..................................................................
..................................................................
..................................................................

Enter data collection method:
□ Unstructured interviews
□ semi-structured interviews
□ focus groups □ observations
□ video / tape recording
□ written texts or drawings
Are data systematically collected (are there interviews / study protocols)?
Yes □ No □

D. Data analysis
How are concepts, themes and categories developed and interpreted?
...............................................................

Please re-enter:
☐ Themes are developed as concepts
☐ there are episodically presented quotes
☐ The individual answers are categorized, and the width of the categories is described
☐ The answers are encoded

Results description
...............................................................
...............................................................

Is analysis and interpretation of results discussed?
Yes □ No □

Are the results credible (sources should be specified)?
Yes □ No □

Are the results reliable (the credibility of the research and researcher)?
Yes □ No □

Is there stability and consistency (is the phenomenon consistently described)?
Yes □ No □
Are the results reversed and discussed with the study group?
Yes □ No □

Are the theories and interpretations presented based on collected data (there are quotes of original data, summarizing data included as proof of interpretation)?
Yes □ No □

E. Evaluation
Can the results be returned to the original research question?
Yes □ No □

Does data gathered support the researcher’s results?
Yes □ No □

Do the results have clinical relevance?
Yes □ No □

Are methodological deficiencies and risk of bias discussed?
Yes □ No □

Is there a risk of bias?
Yes □ No □

What is the conclusion of the author?
..................................................................
..................................................................
..................................................................

Do you agree with the conclusions?
Yes □ No □

If no, why not? .................................................................
Should the article be included?
Yes □ No □