

Providing Support to Family Caregivers of Older Adults: A Scoping Review

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Abstract

Worldwide, as the population of older adults receiving palliative and hospice care increases so is the rise in family caregivers who play crucial roles in home support to loved ones. Sadly, they undergo some challenges such as physical, psychological, social, and financial setbacks which creates primary and secondary stressors that affect their quality of life and results in anger even after patients have passed away. The aim of this study was to find out the support methods healthcare providers particularly nurses employ to help relieve family caregivers of stress and enhance their overall well-being. Hence, the research question is "What kind of supports do nurses provide to assist family caregivers of older adults". This study was conducted as a scoping review, using an inductive content analysis approach for the 12 articles included to answer the research question.

The findings revealed some methods that nurses with the help of other healthcare providers implement to support family caregivers of older adults to ensure a peaceful and dignified death. Nurses educate caregivers by providing the necessary information concerning patients and coping skills to better handle the caregiving tasks to reduce caregiving burden and relieve stress. The result shows that the support methods had positive outcomes and should continue to be implemented.

Language: English Key words: Family Caregivers, Older Adults, End-of-Life Care, Nursing Support

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1 Introduction

Death is inevitable. It is evident throughout human existence on earth and has been a source of great sorrow to many. The wish for many people is to live in good health. Unfortunately, that is not the case as death can either occur suddenly or allow some people to linger while fading away gradually with deteriorating health. There comes a time in life when people lose dear ones in death such as, spouse and children, or begin to prepare the heart in advance to accept the rapid change of death that is about to occur. A point where most meet changes in lifestyle and deliberate on what is in store for them after the end of a loved one (Renee, 2013). Dying is natural and has become a part of life (Ferlay et al. 2007). This understanding positively affects the provision of palliative care to patients which begins soon after the diagnoses of a life-threatening or incurable disease, and their families who also experience difficult times as patients undergo care. Palliative care involves the services of healthcare professionals including nurses, and volunteers like family caregivers who help to reduce avoidable hospital admissions and limit the use of hospital services (WHO, 2020).

Worldwide, the number of family members rendering care and support to older patients at home is increasing. Studies have shown that most dying patients prefer to live and die at home, an environment that they are familiar with, amid close family members, friends, and neighbours. A place where they are supported by palliative staffs, with the hope of enjoying the rest of their lives before passing away peacefully and quietly (Munday et al., 2009). To such persons, the home is not just a physical space.

However, the burden of caring for older patients who are dying falls on family caregivers, starting from diagnoses through treatments and death (Bevans et al., 2012). Family caregiver's responsibilities include difficult tasks and challenges of family members suffering from different types of health diseases and those without ill health. These caregivers experience depression and distress in the process of providing care. This study highlights family caregivers' challenges and directs attention to present literature studies regarding the kind of support nurses provide to assist family caregivers of older adults.

2 Aim and Problem Definition

This study aims to examine the support methods that healthcare providers apply as interventions to ease and improve the well-being of family caregivers to older patients undergoing palliative care before and after death, and to know whether the support is enough or if there is need for more help due to the challenges that family caregivers experience.

The research question is:

- What kind of supports do nurses provide to assist family caregivers of older adults?

3 Background

The family is a place of comfort and has always been to many for centuries. Most people enjoy the privilege of belonging to families whose members provide care and support to one another in times of ill health. In every society, there are people of younger ages and older adults who suffer acute and chronic diseases, some of which are in the end-of-life and have chosen the home as a preferred place of death to spend the few months left before death comes (Gomes et al., 2010). Patients who are dying need care, support, and resources to help with coping, which in most cases, are provided by the primary health care team and family caregivers (Gott & Ingleton, 2011). A family caregiver is a partner, relative, friend, neighbour, and anyone who provides care and helps manage the condition of people who are seriously ill or with disabilities.

Caring for a dying family member can be distressing. The feeling of watching the health deteriorate can negatively affect the caregiver emotionally, psychologically, socially, and even cause shock before and after the patient dies, leading to grief and bereavement as caregivers are always present from the beginning to the end (Harding et al., 2011). Grief and bereavement are universal and occur in every culture in the world. It is an individualistic experience, different from each loss, and different from person to person regarding the same loss. However, there are different types of grief known as normal and

complicated grief. In this chapter, I will discuss about normal grief, bereavement, the role of family caregivers, the challenges they undergo, as well as their needs.

Grief is a strong overwhelming natural, emotional, cognitive, functional, and behavioral reaction when a loved one dies (Melinda et al., 2019). It is the way a person expresses loss outwardly, which could be psychologically, emotionally, and physically. That is a complete reaction to how we feel when we undergo loss (Audrey et al., 2012). The feeling of grief is a personal and universal experience. On the other hand, bereavement can be defined as "a period of mourning after a loss, especially after the death of a loved one" (Dictionary.com). Grief and bereavement bring extraordinary pain as they are both related to the act of loss. When individuals experience distress, they suffer emotionally, feel empty, hurt, sadness, sorrow, numb, anxiety, scared, lonely, helpless, regret, anger, guilt, disbelief, and disturbed. This type of suffering can make some individuals lose their minds, which could also affect the usual daily activities, thereby making life difficult, miserable, and not worth living. In most parts of the world, people view the feelings of grief and bereavement as a normal and natural way of reacting to loss (Melinda et al., 2019). These are part of the experiences of family caregivers.

The care for patients living alone without the help of a caregiver can be difficult. This is one reason why such patients may live or even die receiving care in other settings like in the hospital, with residential care facilities, assisted living facilities, or in a nursing home, which sometimes is against the patient's wish regarding the preferred place of death. However, with the availability of family caregivers, the situation is usually different as caregivers are present to have early discussions with healthcare professionals about patient's choice of place of death to enable adequate support (Funk et al., 2010). It shows that many patients will not have the privilege of living or dying at home according to their desire without the support from family caregivers.

The Institute of Medicine (IOM, 2008) reports presented a new view regarding family caregivers. It states:

"The definition of the healthcare workforce must be expanded to include everyone involved in a patient's care: healthcare professionals, direct care workers, informal caregivers (usually family and friends), and patients themselves. All of these individuals must have the essential data, knowledge and tools to provide high quality care". It went further to state "exactly when and how providers need to incorporate the family into the health care process is not yet well understood, but such incorporation is relevant across the full spectrum of institutional, ambulatory, and residential patient care settings".

This definition fits the fact that family caregivers have always supported relatives and handled more outstanding tasks given to them indirectly by health care providers. Sometimes, caring for a patient can take several years depending on the condition. The services of caregivers toward relatives throughout the world can over time become stressful to the extent that the family caregiver faces physical, psychological, social, and financial challenges, especially for those who do not receive help from the society (Funk et al., 2010; Hudson et al., 2011).

3.1 The role of Family caregivers

In a research study conducted by Schulz & Beach (1999), it was postulated that the level of task caregivers perform while caring for older adults every day can be physically stressful and emotionally demanding or draining for many family caregivers thereby making caregivers pay less attention to their health and care. This reduced physical health situation may have led and still leads to several deaths of some caregivers.

Caregivers handle multiple tasks and can provide up to 45 hours of care and support every week to palliative and hospice patients. Laura et al. (2012) gave a list of some of the tasks to include bathing, toilet use, dressing, grooming, home cleaning, laundry, meals preparation, feeding, taking medications sometimes several times a day, mobility, transportation, shopping, taking phone calls, handling finances, giving emotional supports. Caregivers are also involved in making decisions about patients, cooperating with healthcare professionals, discussing end-of-life care matters with the older adult, and making sure that the wishes of loved ones are granted (Kahana et al., 2004). For family caregivers who handle patients with dementia, the tasks include supervising and managing the patient's behavioural symptoms to ensure safety, thereby having the feeling of working around the clock everyday (Schulz et al., 2003). It is important to note that these tasks

increase in the final months of the patient's life, which also affects the wellbeing of caregivers.

3.2 Challenges of Family Caregivers

Family caregivers face many burdens and experience higher physical and emotional distress as they care for chronically ill, terminally ill, or senility loved ones. Due to the multiple demands, caregivers suffer reduced health resulting from the heavy care responsibilities (Shaji et al., 2012), although there are some benefits. Caregivers of elderly patients living at home, thus have a wide range of physical, psychological, social, and financial challenges (Harding et al., 2011).

3.2.1 Physical Challenge

Family caregivers are mostly middle-aged adult children and older spouses who provide care to either parents or spouses with functional disabilities and cannot perform daily routine. The role assumed by younger caregivers affects their normal daily activities, limits personal freedom, and suspends future plan. On the other hand, older caregivers are more affected by illness and are at a higher risk of death when under pressure to render care (Roth et al., 2009). Some researchers also agree that the weight of the burden and stress from the services of caring for older adults with functional limitations contributes to psychiatric morbidity caused by a high level of depression (Haley et al., 2004).

Harding et al. (2011) points out that people react to stress differently but that one common fact about caregivers is that they struggle to provide care to others, while neglecting themselves. It makes caregivers have increased health care needs, which affects the continuous provision of care to even patients in end-of-life care. The effects on health also resurface later in life due to the higher risk of frailty in the body (Centre on Aging Society, 2005). Research has it that caregivers have a high level of physical illness and weakened immune system, which opens the room for frequent infections, and places caregivers at high risk for cancer, high rate of heart disease, high blood pressure, high levels of cholesterol, diabetes, arthritis, stroke, chronic lung disease, and hypertension. The series

of missed doctor's appointment shows that most caregivers usually miss appointments due to the heavy tasks performed, while others hardly have time to go for medical check-ups.

3.2.2 Psychological Challenge

The mental and emotional health of family caregivers is also affected negatively in caring for dying patients. Studies have shown that caregivers have an increased rate of depression and other mental health problems than people who are non-caregivers (Pinquart et al., 2003). Some caregiver's level of depression has reached the height where it can be called "major depression" (Zarit, 2006). About 30-40% person of people caring for patients experience depression and emotional stress. Depression and anxiety disorder can also affect family caregivers to the extent that even when the loved one moves to other institutions for further care, the level remain high like when the patient was home (Schulz et al., 2003). High rate of stress, anger, and frustration can be found among caregivers so that they feel like a shadow of themselves, with low self-confidence, feel lost, not too sure about life, loss of self-identity, feel unnecessarily guilty and helpless, undergo emotional strain, always anxious, and full of fear.

Chronic fear can put caregivers at a higher risk for a short-term memory loss (Vitaliano et al., 2005). Feeling always weak and tired every day when retired to bed, and yet finds it hard to sleep off (Carter, 2002). It is also noteworthy that women experience more levels of depression and poor health compared to the male counterpart, and worse for older caregiver women.

3.2.3 Social Challenge

Family caregivers of dying patients are very busy most times, so that the time for recreational activities is cancelled, not even to embark on a vacation for relaxation and some refreshments. There is hardly time for leisure to maintain social connections as probably before, and this affects family relationship (Kesselring et al., 2001). Caregivers feel highly isolated, sad, lonely, and abandoned.

3.2.4 Financial Challenge

Worldwide most family caregivers do not work full time as caregiving always interferes with functioning, thereby causing them to make excuses and be off work without pay. Some may reduce the work hours each week, embark on early retirement, or even quit working to devote considerable time to interacting and caring for loved ones, while many others may empty their savings (Covinsky et al., 2001; Tilden et al., 2004). These can significantly affect the income of caregivers and their financial state.

3.3 Needs of Family Caregivers

Caregivers of chronically ill, terminally ill, or infirm elderly adults living at home experience physical, psychological, financial, and emotional burdens while providing care. They also have unmet needs for information, which when addressed, can help with the provision of appropriate care. The requirements include information need and sufficient communication needs.

3.3.1 Information Need

Different diseases appear at the end of a person's life. According to Lynn (2001), the three types of diseases are cancer, organ failure, and senility/dementia. The care period for cancer and organ failure can take between 2 to 6 months, while the care period for senility and dementia can take longer. It means that family caregivers need to acquire information regarding the condition of their loved ones, such as the evolution of the disease, symptoms, prognosis, medications, treatments, and how to deal with the abnormal behaviour of the elderly (Wackerbarth et al., 2002), depending on whichever category the older person may belong to as mentioned above that is, information about diseases, dying, and death.

Caregivers also need information concerning the services that are available for residential facilities, disease-specific services, including daytime activities for the elderly, as well as how to gain access to these services, guidance on care responsibilities, general guidelines regarding healthcare delivery, rehabilitation exercises, and use of equipment like fan, bath

chairs, nebulizer, and information on issues about the end of life (Yedidia et al, 2008). Caregivers likewise need information about their self-care, physical activities, and medical intervention for themselves.

3.3.2 Effective Communication

Family caregivers points out that effective communication is important as they closely collaborate with professionals to provide care to the frail ones (Wackerbarth et al., 2002). Communication is an instrument for opening the way to better interaction between caregivers and nurses, especially when it comes to decision-making. Through this means, caregivers can give suggestions which, when accepted, can make them feel like genuine partners and more comfortable (Levesque et al., 2010). Family caregivers, through communication, have the role of making physicians know more about patients. They facilitate the exchange of information between doctors and patients (Wolff et al., 2017).

3.4 Government Support for Family Caregivers

In Finland every year, about 15,000 patients are in need of hospice care. The order for hospice care recommendations started through the Citizens initiative and a debate in the parliament. There were concerns about the variability and inequality regarding the quality of care for dying people (Hyva Saattohoito Suomessa, 2010, pg. 7, 11). The purpose of the hospice care recommendations by the Ministry of Social Affairs and Health was to provide good and equal hospice care to people who are dying, plan and organize the care, and consider the competence of staff or healthcare professional's training. The government's proposal for healthcare law supports the implementation of good hospice care as it should relieve the suffering of dying patients.

Hospice care reduces the symptoms and suffering of dying individuals starting from when no prognosis for the cure is available, or the patient has refused to be treated and has limited time to live (Hyva Saattohoito Suomessa, 2010, pg. 11). Patients who choose home as the preferred place of death are mostly cared for by family members who act as caregivers. However, many family caregivers experience intense burden and stress due to

the responsibilities performed. It means that without support, these caregivers are overburdened and exhausted. Finland therefore practices a system in which some family caregivers get compensation. The support system is set up on legislation. However, to receive compensation the patient in need of care and support must apply for the caregiver. A written care and service plan or an agreement will be made between the caregiver and the municipality (Finnish Institute for Health and Welfare, 2019). The family caregiver can also apply by him or herself.

Many Finns care for family members who are ill, including the elderly. More than One Million Finns provide care and support to loved ones, and out of these number are 350,000 who act as primary caregivers, of which 60,000 of them are in more demanding situation often caring for the elderly. However, only about 47,500 out of the 350,000, primary caregivers receive support from the Municipalities based on the Act on Support for Informal Care. This means that the remaining caregivers do not get help from the government (Omaishoitajat.fi). Below is the figure of family caregivers in Finland.

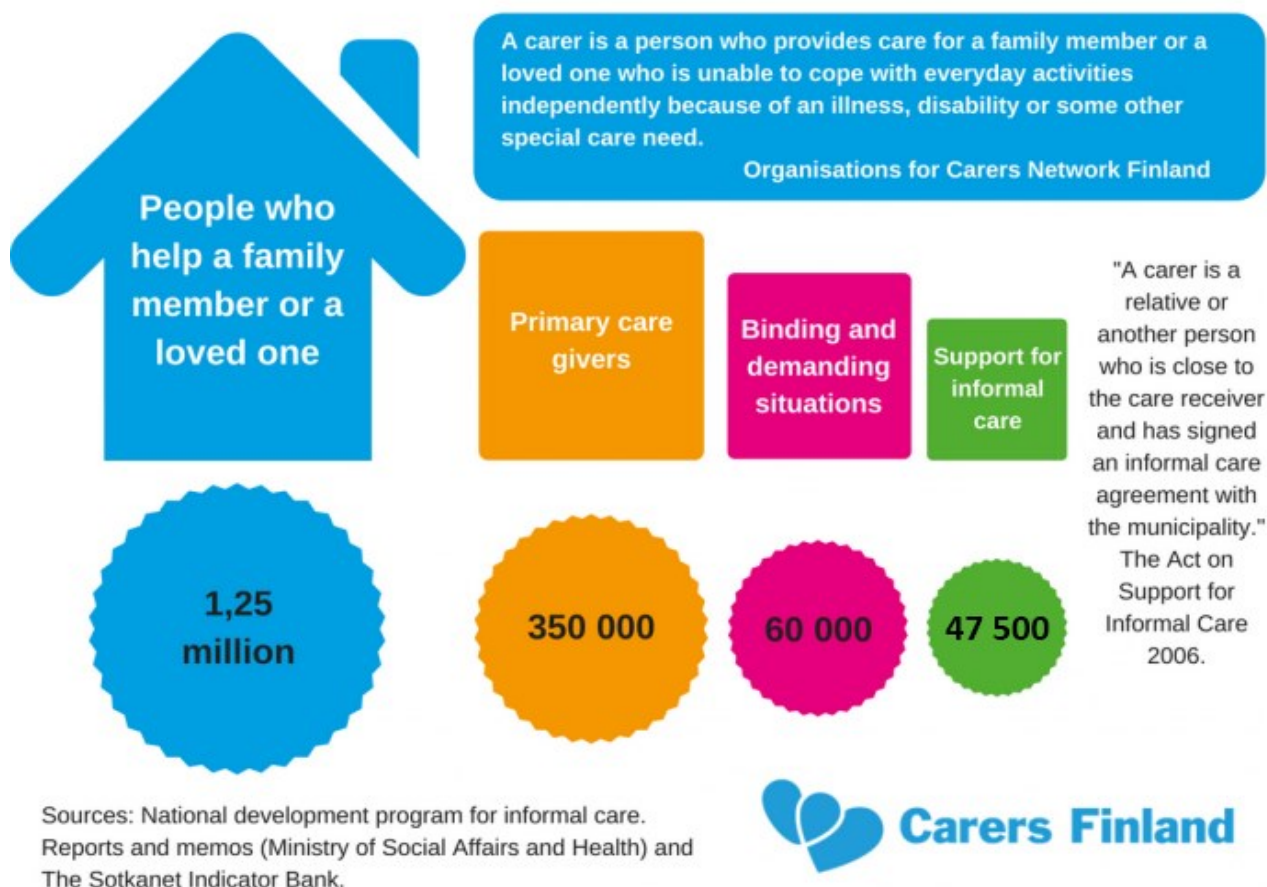


Figure 1: Informal Caregivers

Municipality, Social Insurance Institution of Finland, Kela, Associations, and Churches supports caregivers who receive help. The support comes in form of money paid to the caregiver, and the sum depends on the level of care and the municipality. Caregivers can also be given some days off or leave in which a substitute is arranged to be another member of the family, or a healthcare provider to care for the older patient while the caregiver is away. Caregivers can get support services like housekeeping services such as meal from the municipality. Insurance is also offered by the municipality to the caregiver in case if accident should occur whereby the caregiver gets injured (A Guide for Carers in Simple English, pg. 14-21).

It is important to note that certain conditions are to be reached for the municipalities to support family caregivers. The requirements for permission are; When the receiver of the care is sick or has a disability, which affects caring for him or herself; If the receiver can no longer care for himself or herself as before or cannot manage at home alone at all. In these situations, the person needs care from someone else. The family caregiver can then go forward to present and assume the responsibility of caring for the loved one and be healthy and do so as part of the criteria. The caregiver's amount of care should be enough regarding the health, wellbeing, and safety of the receiver. The home chosen as the preferred place of death should also be suitable for the care receiver, as the authorities will assess whether it is or not. Thus, the authorities will decide if the home is the best place for the patient or if the patient can be cared for elsewhere (A Guide for Carers in Simple English, pg. 15, 16).

4 Theoretical Framework

A theoretical framework guides and supports a research study. In this study, the stress process model has been chosen and will be used to examine stress and coping for family caregivers of older adults. This model will help to understand the experiences of caregivers in the end stage of caregiving.

The Stress Process Model

The model was developed by Pearlin et al. (1981). It was published in an article that focused on social structure and its outcomes for stress and psychological distress. The model is a framework that centre on the relationship between the experiences of caregivers and the stress process model (1990). According to the model, caregivers' quality of life is affected directly by health and socio-demographic features, the diagnosis of an illness, the manifestations, and the consequences of care demands. However, supports can play an important role by directly reducing the burdens of caregivers.

This model has been used in most research that examines stress and coping for family caregivers of patients who have dementia and can also be applied to caregivers of patients with other illnesses or senility. In a study of individuals providing care to other persons after a longitudinal survey of a demographically diverse sample of caregivers to close elderly family members suffering from Alzheimer's disease or a related dementia, Pearlin et al. (1995) showed that the stress process model can be applied to understanding the stress of caregiving. It was observed that the deteriorating and irreversible courses of these diseases generally resulted in family caregivers getting much immersed into their loved ones needs, including the consumption of the time and energy of these caregivers. According to Skaff and Pearlin (1992), this situation may have resulted in the caregiver's isolation, that is, the feeling of been unseen by members of the larger society and a firm conviction that no one knows or care about their suffering. It could be one reason why Pearlin et al. (1995) were received with open arms upon hearing that they were interested in learning about caregiving and the people who provide it, thereby giving caregivers the opportunity to express themselves and draw the attention of everyone to their existence.

During the study, Pearlin et al. (1995) also observes that it might be easy to offer to assist people whose needs are limited or transient in the beginning when care demands are not much and can easily be added in the regular daily routine. But as time goes by, due to the increasing tasks involved, the reverse may be the case as caring requires the sacrifice of the caregiver's wellbeing for the recipient's benefit.

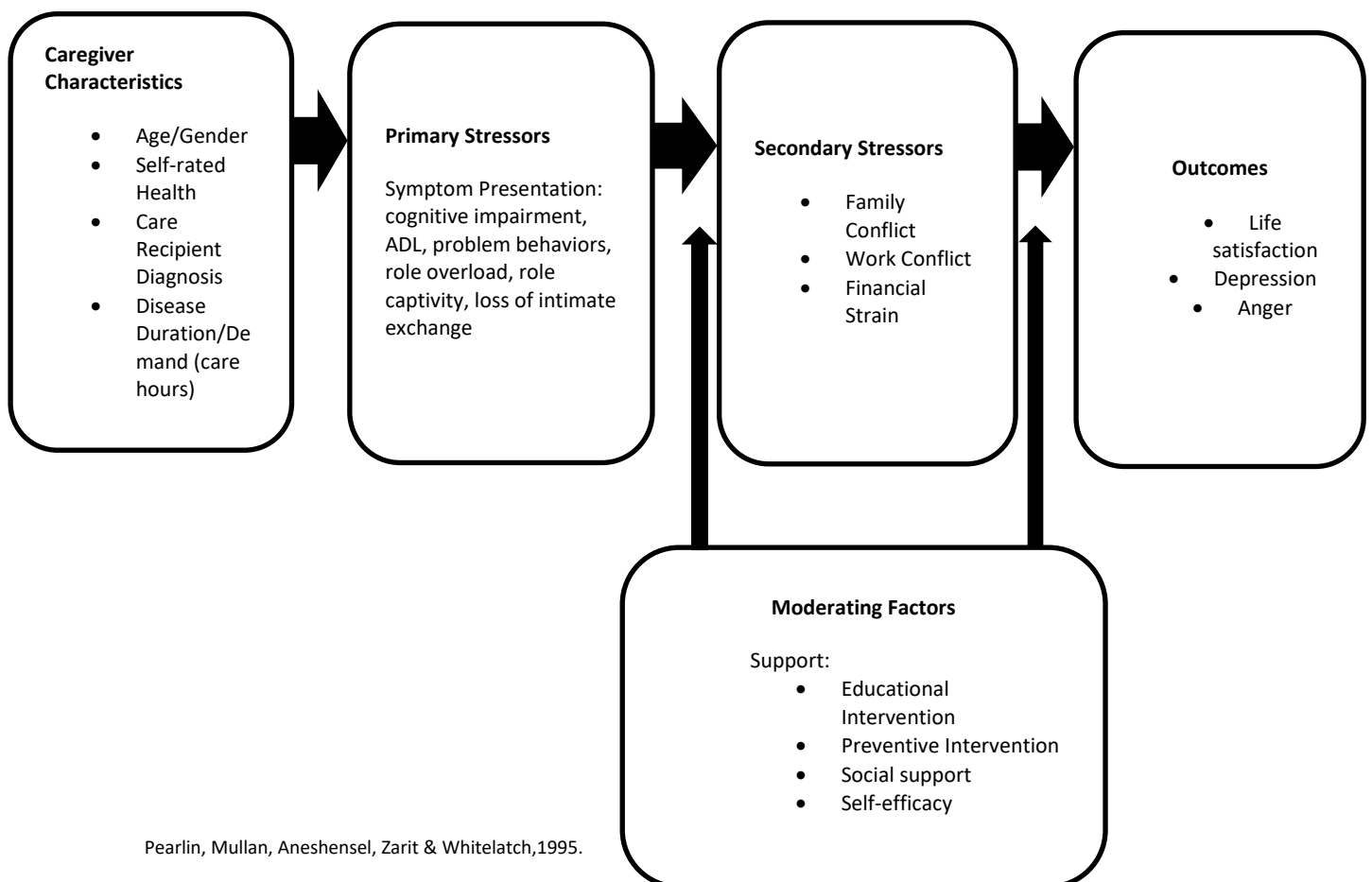
In the stress process model, Pearlin et al. (1995) pointed out five crucial elements based on caregiver's experiences: *background and context*, *primary stressors*, *secondary stressors*, *moderators (available resources to lessen caregiving stress)*, and *outcomes* (Pearlin et al., 1995). Stressors refer to "conditions, experiences, and activities that are problematic for people, threatening them, thwarting their efforts, fatiguing them, and defeating their dreams". That is, the negative symptoms carried along with illnesses and the strains and psychosocial effects that result from it. Caregiving stress thus arises mainly due to the level of tasks performed by caregivers based on the patient's condition, which in most cases collide with the caregiver's subjective ability to respond to the demands or when the need blocks the pursuit of other goals.

The *background* refers to the age and gender of caregivers, who in most cases are mainly female and old spouse, including the adults receiving care. Some caregivers are within the ages of 65 years and older. *Context* refers to the degree of the recipient's disabilities which also determines the type of help required concerning activities of daily living (ADL), the strain of the tasks performed by caregivers, and the duration of caregiving. Many older adults have physical and mental disabilities that make them need assistance with one or more daily living activities such as help with walking, dressing, feeding, sitting, and changing positions on the bed. Some others need help with shopping, cooking, laundry, budgeting, telephone calls, and driving.

Primary caregiving stressors are directly caused by caregiving activities between caregivers and care recipients. The stressors develop from the pressure that the needs, symptoms, or condition of patients produce such as functional, behavioural, cognitive impairment, role overload, role captivity, loss of intimate exchange, and the physical or level of care demands required by recipient's needs which makes many caregivers exceed the limit of their physical and emotional stamina (Pearlin et al., 1995, pg 69-77). These demands may present different phases during the end-stage. Caregiving activities that indirectly causes *secondary stressors* refer to the consequences of those strains encountered in roles or activities that happen outside of caregiving, and intra-psychic strains that affect a person's self-concept (Pearlin et al., 1995, pg 34). The secondary stressors for end-of-life caregiving can be a financial strain, family conflict, work strain, increasing expenses, unemployment,

and work reduction. However, through public health actions, these stressors may be resolved to reduce their effects.

Pearlin et al. (1995), proposed that *moderators* consist of social, personal, and available resources that help reduce or control the relationship between stressors and outcomes and are also referred to as "stress-buffering". Social support, mastery or self-efficacy can be considered moderators to manage the stress (Pearlin et al., 1995, pg 34,35). In many caregiving literature, social support and coping are the most highly researched resources identified. The consequences of stressors are known as *outcomes*. In providing care to terminally ill or senile family members for example, the caregiver's health and emotional wellbeing especially the mental health of caregivers, are affected over time as the effects of stressors and can result in depression and anger (Pearlin et al., 1995, pg 34). The stress process, hence, refer to those changes in life situations that are interconnected and affect an individual's wellbeing.



Pearlin, Mullan, Aneshensel, Zarit & Whitelatch, 1995.

Figure 2: The Stress Process Model

Pearlin et al. (1995), conceptualized caregiving as a "career". Caregiving career do not refer to caregiving as a job. Unlike an occupational career that keeps to a precise time plan through the ranks, caregiving career might begin caregiving slowly and subtly before the caregiver may even become aware of it or might begin suddenly with caregivers most times having little idea of what is happening. Caregiving is conceived to have multiple stages, which constitute considerable similarities in the caregiving experience. These stages are caregiver's preparation for the tasks and acquisition of caregiving role; the intensification of care-related jobs and control in the home or maybe in a formal institution; and the end of caregiving after patient's death, which most times involve bereavement, recovery, and reintegration to social life (Pearlin et al., 1995, pg 21-23).

5 Research Methodology

A scoping review method was used in this study. It requires the identifying all literatures relevant to the research topic regardless of the study design, and has the possibility to address broader topics, unlike a systematic review which provides the answer to questions from a somewhat limited or restricted scope of quality assessed studies (Arksey & O'malley, 2005). In a scoping review the result of the findings are generally presented in a narrative way and with little statistical language (Peterson et al., 2017). The Scoping method can be used on topics that are complex or diversified in nature or that have not yet been widely reviewed (Mays et al., 2001).

A scoping review method aims to map out available literatures that are pertinent to the field of interest or area of study in terms of the volume, nature, and features of the main research, that is, the topic area. This method provides a meticulous and transparent technique for mapping the areas of a research. It can be used as a study method on its own and as an introduction to a systematic review (Arksey & O'malley, 2005). A scoping review method allows the researcher to assess a wide range of published and unpublished articles, including grey materials. There are different reasons for using a scoping review. It can be undertaken to examine the extent, range, and nature of conducting research, and may not require a detailed explanation of the research findings but rather the mapping of the field of study; to ascertain the value, relevance, and cost of carrying out a thorough systematic

review; to sum up and possibly provide a detailed description of research findings to everyone interested; and to recognize gaps in the literature (Arksey & O'malley, 2005).

The scoping review in this study was conducted using Arksey & O'malley's adopted framework to assess the large quantity of literatures on family caregivers support, including qualitative and quantitative studies, grey materials, and articles. The framework of Arksey & O'malley outlined five stages for conducting scoping reviews. These stages are, to "Identify the research question; Identify relevant studies; Study selection; Charting the data; Collating, summarizing, and reporting the results" (Arksey & O'malley, 2005). This method will be used to answer the research question and find out about the various supports that are in place for family caregivers by healthcare providers, particularly nurses. Explanation of the five stages requirements for scoping review are the following:

5.1 Identify the Research Question

Identifying of the research question to be addressed from the outset of a study is the first step in a scoping review. It serves as a guide to the researcher in terms of the strategies to apply during a search. The use of keywords from the research questions for searching produces more option of literature to explore. Therefore, it is essential that the research questions are not too specific, and the definitions are not too broad either so as not to miss articles that are useful to the study (Arksey & O'malley, 2005). In this study, the research question is: "What kind of supports do nurses provide to assist family caregivers of older adults?". The research question is meant to acknowledge nurse's possible intervention towards the challenge family caregivers experience in their everyday lives.

5.2 Identify Relevant Studies

A thorough search is required to identify relevant articles in a study (Arksey & O'malley, 2005). This was achieved by carefully searching through different databases and grey materials that relates to the topic of this study. The Boolean connector method was applied to explore in full texts by combining keywords from the research question. The search was

conducted with the use of different databases. The following search words were used, "Nursing support and family caregivers or informal caregivers and older adults and end of life care and before death and after death", "Nursing support or nursing intervention and family caregivers or informal caregivers and end of life care", "support family caregivers", "Nursing intervention to family caregivers of older adults and end of life care", nursing intervention and family caregivers and older adults and end of life care. The table below shows the search strategy with the combination of keywords that forms the search phrases.

Table 1: Search Strategy

Source	Nursing Support and Family Caregivers or Informal Caregivers and Older Adults and End-of-Life Care and Before Death and After Death	Nursing Support or Nursing Intervention and Family Caregivers or Informal Caregivers and End-of-Life Care	Support Family Caregivers	Nursing Interventions to Family Caregivers of Older Adults and End-of-Life Care	Nursing Interventions and Family Caregivers and Older Adults and End of Life Care	Total
CINAHL	316	214	17	0	618	1,165
Academic Search Elite	512	381	436	0	227	1,556
Medline	10	16	4	0	0	30
SpringerLink	269	176	687	493	45	1,670
Pubmed	94	110	636	430	124	1,394
Google Scholar	0	0	912	1115	0	2027
Google	0	0	123	140	0	263

Total: 8,105

5.3 Study Selection

To identify relevant studies that answers the research questions, applicable words were used to search thoroughly through the Novia University of Applied Sciences Tritonia Library, Vaasa. The databases used were, Cinahl (Ebscohost), Academic Search Elite, Pubmed, Medline, Springer Link, Google Scholar, and Google. Details of the search process are shown in the PRISMA flow diagram (Appendix 1). The PRISMA flow diagram outlines the process of searching for articles in a systematic manner, showing the different stages of literature review, number of literatures identified, number of literatures included and excluded, and the reason behind the exclusions (Moher, Liberati, Tetzlaff & Altman, 2009).

The inclusion and exclusion criteria enable smooth gathering of the necessary information and adequately channel all study in the same direction by avoiding digression from the subject for consideration. The use of this criterion for selection served as a guide to the researcher and helped to direct all relevant articles to the study questions (Aveyard, 2014, p. 71). When applying the inclusion criteria in this study, important articles that answers the study research question were used. And such articles were written in English language, freely accessed, in full texts, are qualitative and quantitative studies, published between 2010 to 2020. For the exclusion criteria, articles that were irrelevant to the study topic were removed, such as articles that were published in languages not in English, and are published before the year 2010, to maintain credibility for the study (Lincoln & Guba, 1985). The search keywords and the hits that came up can be found in the following table.

Table 2: The Inclusion and Exclusion Criteria

Inclusion Criteria
Articles published between 2010-2020
Articles published in English Language
Articles in full texts

Articles with free access
Articles from different Countries
Qualitative, Quantitative, and relevant articles which answers the research question
Exclusion criteria
Articles not published in English language
Articles not relevant to answer the research question
Articles published before 2010
Articles not with free access
Articles not in full texts

5.4 Charting and Analysing the Data

According to Arksey & O'malley (2005), the essential information derived from the included studies is presented in a chart in this stage. The process involves the decision concerning a systematic arrangement of the type of data to take out from the primary studies and compare the various measures discussed in the form of charting. This is put forward in a narrative way to make it more helpful to readers who may be interested to act based on the findings of the study. The relevant studies selected are grouped in different categories and presented in "Appendix 2".

- Author
- Year of Publication
- Title
- Aim
- Material
- Methodology
- Result

- Conclusion

5.5 Collating, Summarizing, and Reporting the Results

This is the stage where data collected is summed-up, and the result is presented. That is, a point in a scoping review in which an overview of the results from the evaluation regarding the information derived from every material reviewed during the study is reported (Arksey & O'malley, 2005). A summary of the results on the information that is relevant to the research question of this study will be presented.

In this study, a content analysis method was used. This requires a personal interpretation of the contents contained in the data obtained from the various sources. The method is divided into two categories known as inductive and deductive. An inductive content analysis was applied to analyse the chosen articles. The selected articles were divided into smaller groups, carefully read through, marked in writing, and separated based on similarities thereby forming the categories and subcategories under the theme. The sentences that answer the aim of the study such as the types of support strategies and the effects on caregivers were highlighted with different shades of colour. These were then categorized in terms of similarities, differences, and effectiveness.

5.6 Ethical Consideration

The term "Ethical" is derived from the Greek word "Ethos", which relates to morals. It defines conduct to be either good or bad (Dewey, 2016). It refers to those values and beliefs that have an impact on how we approach research. Research ethics simply means "principles of right and wrong conduct" (Gallager, 2009, p.11).

In this study there were no participants, hence there was no formal consent required. However, during data collection, screening, and data analysis in this study, ethical consideration was implemented. Deception is an ethical issue that was avoided, as it could occur due to lack of enough data and insufficient time. A researcher may influence a part of the study, and this will be unethical. For qualitative research, original studies must not

be tampered with (Denzin & Lincoln, 2005). Different authors of various studies were acknowledged in this study, and the materials used along with all direct quotes were credited and rightly referenced for transparency of sources. Integrity is another aspect of research that is vital, which should be applied in nursing research and was applied in this study (The Finnish National Board on Research Integrity, 2019). This means that reports were well documented and trustworthy as required.

6 Findings

In this chapter, the findings that relates to the research question is presented and discussed in depth. The chosen articles for this study, shows the type of supports implemented to help family caregivers of older adults. The support methods according to the articles are divided into three main categories of educational support, coping strategy, and emotional support, under which are the subcategories which are darkened to answer the research question.

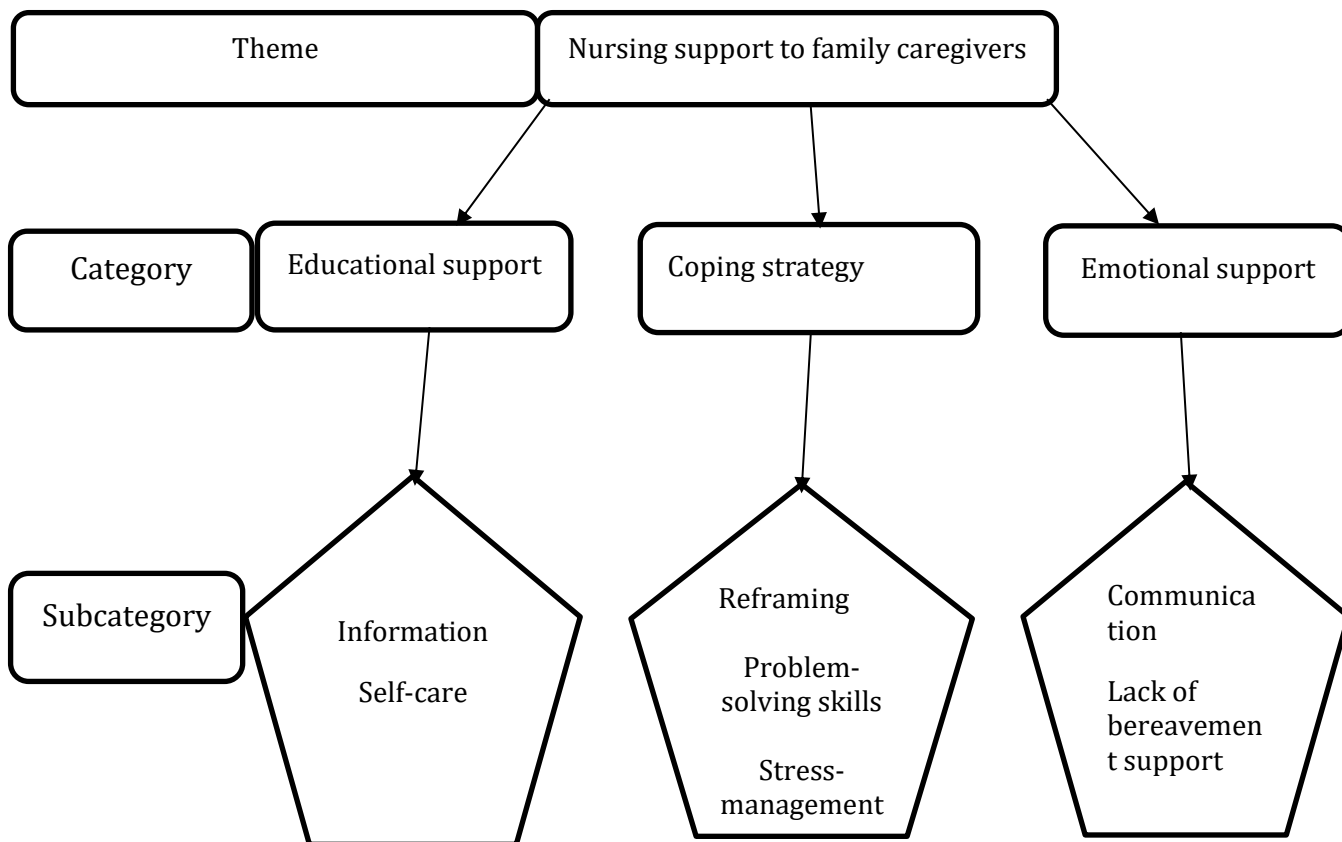


Figure 3: The main categories and subcategories

6.1 Educational support

In the educational support category, two subcategories were formed to understand the effects of such method use to increase the knowledge and skills in the care family caregivers provide to their relatives and friends. The two subcategories under the educational support provided by nurses are **Information, and self-care**.

Education and **Information** improve caregiver's knowledge, self-efficacy, preparedness, satisfaction, and reduce burden (Chi et al., 2015). Caregivers are provided with information about patient's disease, coordination of care needs, skill-building for care management, and how to cope with stress generally as they perform their caregiving role. The acquisition of information through knowledge about coping with care related stress can increase the mental health and has positive impact on caregiver's strategy and sense of control (Alves et al., 2016). Nurses share close link with the families of patients they care for especially the primary caregivers to the care recipients. They understand the stress and other challenges caregivers undergo and as such render individualized interventions based on individual needs which can be determined using different scales for caregiver's measurement such as the preparedness scale, caregiver burden scale, caregiver competence scale, anxiety, and depression scale (Al Daken and Ahmad, 2018). Nurses provide the necessary information required to keep their loved ones comfortable at home by educating them for better performance of their caregiving responsibilities to the best of their ability, empower and encourage self-care knowing that caregivers consider the needs of the dying family member to be more important than their own (Angelo et al., 2013).

According to Douglas and Daly (2014), and Schulz and Eden (2016), when the needs of family caregivers are first assessed and information and support are given to them early enough that extends throughout the course of patients care, caregiver satisfaction with end-of-life care increases. Nurses therefore consider the level of burden experienced by family caregivers by assessing their psychological well-being or quality-of-life and the situation of the care recipient, that is, how dependent he or she is, the amount of task performed, and the way the caregiver perceives the caregiving task such as the emotional response of him or her with regard to the experience of caring for a family member, as

these have effects on the health and behavior of caregivers considering the frequency and intensity of the emotional involvement (Rosell-Murphy et al., 2014).

The provision of information by nurses through the education of family caregivers can take various forms such as through face-to-face interaction, and group setting to help modify their cognitive abilities to face stressors (Demiris et al., 2019). The former is reported to have more significant effect than the group as it is directly delivered to caregivers with great intensity (Demiris et al., 2019). On the other hand, group sessions are arranged to enable caregivers deal with isolation by encouraging interaction and sharing of experiences with one another thereby giving way to share emotions and find some relief in supportive peers who have undergone and still undergo similar challenges (Alves et al., 2016).

Nursing education of family caregivers is an important support measure that have been provided to enable caregiver's better deal with various caregiving situations (Chi et al., 2015). The care of a loved one can result in mental difficulties that are manifested through stress, anxiety, and depression, thus affecting the well-being of family caregivers who in turn have specifically reported the need for information concerning patient care. Nurses like other health professionals provide supportive care to family caregivers, recognizing the important role they play in rendering optimal care. This support helps them to maintain good level of capability as they carry on with their caregiving responsibilities (Al Daken and Ahmad, 2018).

Nurses provides information regarding what to expect as the health of the family member deteriorates and are in good position to provide essential information regarding reference to resources and how to gain access to them such as how to locate respite services, and benefit from government assistance including opportunities for financial support. Family caregivers are also referred to where supportive services are provided and can obtain optimal end-of-life care (Angelo et al., 2013). Successful home care can be achieved by supporting and empowering family caregivers.

Empowerment through education and encouragement can help caregivers foster a sense of control over the caregiving situations. **Self-care** is empowering and considered important to caring for older adults (Schulz and Eden, 2016). The education of family caregivers includes counseling and encouragement to care for their physical, emotional, and spiritual

needs even as they care for loved ones, by taking time off for themselves to experience relief from stress, be refreshed, and acquire more skills to better care for their family members. Caregivers are also encouraged not to hesitate to accept help from friends and relatives as a way of practicing self-care, taking out time from their caregiving role, and reduce burden for themselves. As the needs of caregivers and patients increases so are the information provided by health care providers to enable them carry on well down to the end (Angelo et al., 2013). When caregivers attend to their own needs, it results in positive outcomes (Al Daken and Ahmad, 2018).

6.2 Coping strategy

Family caregivers experience stressors and require the use of coping skills to adapt to the changes that takes place in their lives. Under the coping strategy, three subcategories were created which explains the types of support measures applied by nurses to lessen caregivers psychological and emotional stress. The subcategories are **reframing, problem-solving skills, and stress-management**.

Caregivers are helped to examine the connection between their thought and behavior. The purpose is to change their behavior by altering their thoughts and beliefs. This **reframing** method has helped many caregivers to seek out ways to view their present situation and show positive attitude as they care for their loved ones (Ducharme et al., 2016). Family caregivers are encouraged to be attentive to the happenings around them at a particular time and in a non-judgmental manner. They are advised to focus more on the present that is, on what is happening in the moment thereby slowly separating themselves from disabling feelings and thoughts, helping caregivers to change their reasoning which improves their mood, mental, and physical well-being. Reframing help family caregivers to understand care situations that can be changed and those that cannot be changed, and to choose a coping strategy that is fitting to the situation. According to Ducharme et al. (2011), thinking about a stressful situation that cannot be changed can give way to painful thoughts. Although some caregivers find the reframing method to be difficult to apply as it involves sentiment and emotion, however, they still consider it much important to learn how to reframe things. It is better to alter dysfunctional thoughts by replacing them with more helpful thoughts, as not doing so can affect the quality of life.

Family caregivers are taught **problem-solving skills** which helps them identify or recognize situations that are considered stressful. By doing that, they understand exactly what is stressing them and resolve the problem by determining solutions. This skill enables caregivers handle major negative life events including those daily situations that makes them anxious and depressed (Demiris et al., 2019). Life situation or task that requires response for adaptive functioning but without the presence of an immediate effective response to the individual due to one or more obstacles is referred to as a problem. Coping strategy such as the problem-solving skills enable a more, smooth handling of daily stress situations that results from caregiving tasks placing them more in control of the caregiving situation. This can be implemented through friendly calls, face-to-face interaction by visits, and through video conferencing (Ducharme et al., 2011; Chi, Demiris et al., 2015; Schulz and Eden, 2016; Demiris et al., 2019). Such patterns especially the one-to-one conversation have proven to be effective allowing caregivers to take on positive attitude, are able to define problems, set goals for themselves, come up with solutions as well as assess the solutions (Demiris et al., 2019). The problem-solving skill reduces depression and increases social function.

Implementation of the **stress-management** skills encourages family caregivers to set aside little free time for themselves by engaging in relaxation activities where they practice techniques that help them remain calm, able to manage their stress and improve their general coping skills. Respite care makes it possible for caregivers to be provided with services that takes them away from their caregiving responsibilities for some time through the provision of older adults with daily medical and social services in form of adult day services. These services are offered in some communities for few hours per day or at weekends, enabling family caregivers the opportunity for respite. Sadly, many caregivers are not aware of the availability of such services. On the other hand, some who are aware find it hard to leave the care recipient to attend these activities. Yet, some others who know about the respite do not have access to the services (Schulz and Eden, 2016; Ducharme et al., 2011). The use of respite care improves caregiver's mood, and quality of life.

Family caregivers usually experience mental difficulties while caring for loved ones, caused by caregiving or role change due to stress, anxiety, and depression which in turn causes sleep deprivation, loss of appetite, fatigue, and even weight loss (Al Daken and Ahmad,

2018). Coping is however necessary in response to this psychological stress to maintain their mental health and emotional well-being. Coping strategies are applied to help caregivers adjust to the changes that takes place in their lives by changing their thoughts, behavior, and emotions. Supporting caregivers psychologically help them to avoid thinking about what has happened in the past and stop being anxious about what would happen in the future as well.

6.3 Emotional Support

Family caregivers need emotional support before and after the death of care recipients. In this method of support provided by nurses, two subcategories emerged which are **communication and lack of bereavement support**.

Communication at the end-of-life by patients, family caregivers, and healthcare providers is believed to be extremely critical. Families in palliative care rely a lot on healthcare providers especially nurses for guidance regarding care, and nurses in turn ensure that the needs of these families are met in a family-centred and quick manner (Angelo et al., 2013). Psychological and physical issues are mostly discussed, as well as social and spiritual aspects of care including care of the dying patients, and the structure and process of care. Nurses provide encouragement, give compliments, listen compassionately, encourage networking support to caregivers, and help to connect them to the actual services needed. They provide reassurance by addressing caregivers fear and concerns. Such conversations can ease caregivers fear and give them a good memory about their loved ones, and the day of patient's death. Issues pertaining to spirituality are discussed a little with caregivers who had religious affiliation but more with those who never had religious affiliation. This is an additional kind of caregiver support as required by the clinical guidelines (Clayton et al., 2017).

Nurses however reports that the effectiveness of their communication skills are lower than their general communication skills when discussing difficult topics (Clayton et al., 2017). Negative emotional statements are not easy to manage as they require that nurses make up correct and empathetic answers that meet the needs of patients and family caregivers, which means that patients-centred approach must be used by nurses to address end-of-life

communication concerns. Educational support and communication skills training programs can help to improve and make nurses communication skills effective and even to discuss caregiver's emotional burden on the day of patient's death (Clayton et al., 2017; Schulz and Eden, 2016).

In a study by Aoun et al. (2017), result shows that the relatives or friends of many bereaved family caregivers had from excellent to good care whereas they themselves did not receive optimal support before and after the care recipient's death. When compared to the experiences of support from the palliative services and the best clinical practice guidelines, a **lack of bereavement support** revealed that few of the bereaved were specifically asked about emotional or psychological distress prior to the death of their relative whereas others were asked more general questions about how they were coping. Clayton et al. (2017), also state that even on the day of patient's death not all caregivers and patients had a nursing visit including those whose relatives died on a Sunday, which greatly affects the caregivers regardless of the reason. After the death of their family members or friends, half of the bereaved population were given a follow-up contact by the palliative care services between three to six weeks while a quarter had follow-up six months after the death of patients. This shows that there is less end-of-life communication which also results in the lack of attention or bereavement support for family caregivers prior to death and after death. It was revealed that much attention is not directed to the links between pre-death and post-death experiences of caregivers, pointing that these links are connected to each other as preparatory or anticipatory grief (Aoun et al., 2017).

According to Holtslander and Susan (2011), six months into bereavement depression rated up to thirty four percent in caregivers due to unpleasant memories, uncontrolled pain, and the amount of stress experienced during caregiving which affected the grieving process. Nurses should be interested to know and see if normal grief has progressed into clinical depression or if complicated grief is being mistaken for normal grieving. If left unchecked the overall quality of life of caregivers will be negatively affected. It was also found that the relationship between depression, grief, and complicated grief are strong. This means that bereaved caregivers who undergo depressive symptoms also experience grief and complicated grief symptoms. Carefully assessing family caregivers before and after

patient's death is suggested to identify those who are more at risk, giving way to the provision of the most appropriate intervention needed. The international guideline for palliative care highlights the significance of family support through the illness and into bereavement. Nurses should always remember that grief is a normal process that it is expected in most cases three months into the death of a loved one, and especially after a stressful caregiving experience (Holtzlander and McMillan, 2011; Douglas and Daly, 2014).

As the population of older adults increases so is the need for family caregivers who play critical role in caring for their loved ones. Although they have good intention regarding the care of the recipients, however according to Clayton et al. (2017), they do not in most cases have any earlier experience or skills to render all kinds of supports caregivers provide, not even on the day of patient's death. One of the values of the nursing discipline is health promotion, and support is an integral part of the role of nurses (Ducharme et al., 2011). Nurses therefore render emotional, informational, and physical care supports to family caregivers, help them understand what is going on, make informed decisions, assist the caregiver to ensure that the patient is comfortable, inform them about the dying process, and what to do after patient's death. (Clayton et al., 2017). These can be achieved by means of communication and emotional support which is mostly directed to caregivers as many dying patients are unable to communicate in the end-of-life.

7 Discussion

In this chapter the method and findings of the study are discussed.

7.1 Method Discussion

The initial plan was to apply a qualitative literature review in this study. However, the decision was reconsidered to the use of a scoping review method which happen to fit more considering the research topic. The former intended method may have produced a limited amount of research articles than the present method while searching for literatures that relates to the study topic. A scoping review method was then used in this study which allows the author to include a wide variety of research articles such as quantitative, qualitative, and other relevant materials (Arksey & O'malley, 2005).

There were different databases and search words used to find studies that relates to the topic such as CINAHL, EBSCO, Medline, Pubmed, SpringerLink, Google Scholar, and Google. After searching and excluding irrelevant studies, 12 articles were finally selected and used in the study. The reviewed articles in this study basically assessed family caregivers of patients in the palliative or end-of-life care with specific and non-specific diseases who are dependent on the caregivers for care. 1 article is about family caregivers in the bereavement stage but without the mention of the specific ages of the deceased whether they were older adults in the end-of-life before passing away or not.

Researchers are to conduct a critical evaluation to examine the value of a research. Assessing the reliability and validity of a study require the researcher to ensure that the data used are suitable to report the facts. This refers to the trustworthiness regarding each phase in a study which can be assessed based on credibility, dependability, and confirmability (Lincoln and Guba, 1989, cited in Bitsch, 2005).

Credibility is the level at which data can be trusted (Bitsch, 2005). In the attempt to enhance the credibility of this study, data were rigorously read and carefully chosen by applying the inclusion and exclusion criteria to get the most suitable data. After which the chosen articles were reviewed.

Dependability is the stability of a study in terms of the similarity in the findings of a replicated study carried out in later times (Bitsch, 2005). However, a scoping review method was applied in this study which permits the use of data that contains different methodology that were combined in the findings. It is therefore noteworthy that this study is based on the review of current literatures, which means that some parts of the results may overtime become irrelevant as more research continues to be carried out and published for further improvements.

Confirmability shows the objective of the result of the data, which should be the exact description of the experiences of the informants from the reviewed studies rather than been bias based on the objective, opinion, or personal interpretation of the researcher

(Bitsch, 2005). Hence, explanation is given on the methodology and how the question in this study was answered, thereby making it more transparent.

7.2 Findings Discussion

The discussion of the findings from the chosen articles in answer to the research question is based on the stress process model. To get the answers to the question, the materials found which relates to the question were linked to the model and analysed.

This study highlights the challenges of family caregivers and reports the various nursing supports provided to help family caregivers of older adults in the end-of-life. Findings revealed that caring for older adults usually takes gradual process except it begins in the sequence of acute disease. At first family caregivers are present to help the care recipient with normal daily activities, however, progressively they assume more tasks. Alves et al. (2016) and Pearlin et al. (1995, pg 306), explains that when caregivers take on the caregiving role and responsibilities they mostly do so without sufficient education, training, and support. Alves et al. (2016) further stated that caregiving creates strain such as the stress of dealing with the poor behavior of some care receivers and the role change, all of which affects caregiver's health. This can be related to the stress process model by Pearlin et al. (1995, pg 26) which states that certain conditions, experiences, and activities known as stressors negatively affects family caregivers as they perform their caregiving roles.

According to the selected articles there are different support measures nurses implement to aid family caregivers of older adults. Almost all the articles used in this study found the application of the educational support to be of great method to provide help to family caregivers of end-of-life patients with relevant information and caregiving skills to equip them with the caregiving role, reduce family caregiver burden and improve their general well-being.

Family caregivers need educational support, strategies to cope with the caregiving situation, and emotional support. The education of caregivers is important to enable better performance of their roles (Pearlin et al., 1995, pg 306). It involves the provision of information, a need which caregivers have reported and activities such as counselling and

other supportive interventions (Chi et al., 2015). These interventions provide information about community services, healthy lifestyle, exercise, healthy diet, encourage group participation for caregivers, and prepare caregivers to face challenges by improving their coping skills and self-efficacy. According to Chi et al. (2015), these had positive outcomes on many caregivers by informing and properly training them to better care for their loved ones without so much stress.

In a similar study by Rosell-Murphy et al. (2014), the result shows that such interventions can reduce the burden of caregivers and improve their quality of life. Furthermore, the interventions by Chi et al. (2015) had no significant outcomes on few caregivers as the study also found that some factors can be responsible for that. All caregivers are believed to come from different backgrounds, have individual needs, possess distinct levels of functions, as well as different health literacy. These factors affect the possibility to detect the effectiveness or strength of the interventions on all caregivers. However, when caregivers are well informed on all that they require to know about the condition of their love ones, how to handle stress, how to properly care for the patients, what to expect as patients draw closer to death, and what to do on the day of patients death, such knowledge and information can increase their mental health, reduce stress, and place them in control of the care situation (Alves et al., 2016).

In the subcategory of self-care, the practice enables caregivers look after themselves. Studies found that family caregivers forget or neglect their personal care and rather concentrate on the care recipients. This negatively affects their quality of life or general well-being placing them on more health issues as many caregivers of older adults are also old and need care too. Counseling and continuous encouragement to practice self-care can have positive results (Angelo et al., 2013; Al Daken and Ahmad, 2018). According to Pearlin et al. (1995, pg 317), caregivers need help to understand when they are over-working themselves to take some breaks from caregiving. In the model it states that counseling may assist caregivers to recognize their limitation pertaining the provision of care and acknowledge that they cannot do everything alone. Caregivers are therefore advised by nurses to allow either close relatives, friends, or healthcare workers to relieve them of their duties for some time while they take some rest by engaging in other personal activities and hobbies (Angelo et al., 2013).

Under the reframing subcategory, data shows that the thoughts of many caregivers affect their behaviour toward care recipients. Nurses assess the psychological well-being of family caregivers and the level of dependence or condition of the care receiver. The amounts of tasks provided has effects on the way caregivers view the caregiving task. When the task performed is frequent and demanding, the health and behaviour of caregivers are affected making them feel like they are trapped (Rosell-Murphy et al., 2014). Most times they are angry at the situation they find themselves and that reflects in their behaviour so that sometimes they take to heart what their loved ones say or do (Ducharme et al., 2011).

This can be related to the explanation by Pearlin et al., 1995, pg 70-76) which says that caregiver health status, the type of illness diagnosed of the recipient, how long the patient has been diagnosed, and the number of hours required to provide patient care every day affects and creates primary stressors on caregivers. Resulting in pressure of the caregiving activities performed such as cognitive impairment, problematic behaviour, activities of daily living, role overload, role captivity, and loss of intimate exchange. However, by means of the reframing technique nurses help family caregivers view their caregiving situation from a different angle and to understand how to cope with situations that cannot be changed but rather to change their perception of the situation (Ducharme et al., 2011).

To successfully cope with the toughness of handling the day-to-day activities of patient care, the problem-solving skill which is one of the coping strategies is implemented to encourage family caregivers to take a pause, reflect and try to pinpoint what might be stressing them, the cause of the stress, possible solution to the problem causing the stress, and putting to use of the resolved solution (Demiris et al., 2019). Thus, reducing caregiver burden and improving the quality-of-life and psychological health. Supports on the acquisition of skills including the problem-solving skill can be offered via face-to-face meeting or videoconferencing. The method of internet intervention is applied to reach caregivers who cannot or do not want to be at a conventional support programs, and to help caregivers deal with their caregiving demands and promote their health. It is an approach that also support geographically isolated caregivers who most times are not able to get involved to benefit from support groups or counselling programs. Although family caregivers perform their caregiving tasks individually, through this medium they have the chance to interact with other caregivers online where nurses and other healthcare

providers are available to answer their questions, provide information, and refer them to resources (Ducharme et al., 2011).

The general well-being of family caregivers suffers as they undergo stress, anxiety, depression, psychological distress, and diminished physical health. The caregiving experiences of caregivers are uniquely individual even though they may share many similar experiences. It is important to note that each caregiver's role changes and depend on some factors such as individual availability, preparedness, and capability to take up and handle the caregiving responsibility. In the stress-management skills subcategory data shows that when caregivers of older adults receive quality assessment training, respite, and other supports, their well-being improves (Schulz and Eden, 2016). Pearlin et al. (1995, pg 316-319) explains that the use of respite care reduces caregiver's exposure to stressors.

However, based on the data there are obstacles to the use of respite care as result shows that some family caregivers do not know about the existence of such services, may feel it is their responsibility to provide all the care and not seek for assistance, the patient might refuse outside help, or caregivers may experience financial strain and cost strain that can serve as barrier to make use of the services. Nurses can help caregivers identify the right places where they can get assistance or money to pay for services. Douglas and Daly also find that caregivers derive satisfaction in caring for their frail family members when their needs are first assessed to know what and how to support them or properly manage their stress throughout the course of the patients care. Therefore, the assessment of caregiver needs, risks, soundness, and choices are important by nurses.

Families rely a lot on healthcare providers for guidance in caring for their loved ones more especially during end-of-life care, and communication is one way that nurses pass information across. In the communication subcategory, data shows that communication enables easy access of information from nurses to family caregivers. Nurses occupy a position where they must have experienced the death of many patients and understands the physiologic process of death, which enables them to provide reliable and right informational support to caregivers such as how to care for dying patients, the dying process, what to expect, and what to do after patient's death. A study by Clayton et al.

(2017), shows that this approach addresses the disturbing concerns of patients and their caregivers by giving positive emotional responses, to ask physical questions and obtain information, promotes healing relationship, give answers to emotionally concerned statements, assist in decision-making, cope with concerned statements, and help with self-management.

Clayton et al. (2017), also find the importance of communication between nurses and family caregivers to be crucial. Nurses discuss about cultural practices or spiritual support with patients and caregivers both for those with previously declared religious affiliation and those without, as caregivers may worry about what happens to their loved ones on the day of patient's death and after death. The result shows that such communication can create a lasting positive effect on caregivers, making that day a memorable one. In relation to the Stress Process Model, family caregivers also experience secondary stressors which creates family conflicts, work strain, unemployment, increased expenses, work reduction, and financial strain. Preventive Intervention can help to avoid such problems for caregivers before assuming the care giving role (Pearlin et al., 1995, pg 306), including family meetings even after role acquisition (Schulz and Eden, 2016). Hence, nurses are found to be in better position to enlighten and provide adequate information through proper communication in the beginning of care, before and after patient's death (Clayton et al., 2017).

In the subcategory of lack of bereavement support, some family caregivers reported after the death of loved ones that they lacked care and support by nurses even though their family members were well cared for before dying. Although many caregivers appreciated the bereavement follow-up that was carried out on them through phone calls and friendly visits after the death of the patients, some others did not receive any contact and feel like they were forgotten. Whereas few others who were contacted had the call from someone unfamiliar. Among all these family caregivers were those who were informed about bereavement services and contacted three to six weeks after patient's death, while some others were contacted about six months after death, and a few were contacted at other times. Nurses should pay attention to caregivers well enough before the death of the older adult, as such level of care will have effects after patient's death knowing that there is a relationship between pre-death and post-death regarding the level of depression and grief

(Aoun et al., 2017). Nurses are to examine and monitor family caregivers to identify their level of depression, grief, or complicated grief before and after patient's death (Holtlander and Susan, 2011). When the well-being is improved and caregiver burden is reduced, the level of depression of caregivers would also reduce even after patient's death.

Studies further reports that for caregivers of patients who had limited time interval between when the patient was diagnosed, and death suffered more depression. Caregivers explained that they experienced higher level of depression as patients draw closer to death. And the reasons for these was the feeling of abandonment, lack of family relationship, and the distress of patients. However, the interventions implemented by nurses including social support and self-efficacy, are interventions referred to as "moderators" according to Pearlin et al. (1995), that can drastically reduce the challenges of caregiving leading to life satisfaction instead of depression and anger by family caregivers (Pearlin et al., 1995, pg 34-36).

8 Conclusion

This study was to find out the kind of supports healthcare providers particularly nurses implement to assist family caregivers ease the stress of caregiving and improve their well-being. Findings show that family caregivers undergo challenges due to the level of tasks performed, which highly affects their health resulting to depression and anger even after patients pass away, rather than personal satisfaction. In line with the stress process model, interventions should be put in place to support family caregivers. The supportive measures provided by nurses ensure the education of family caregivers to reduce caregiving burden, practical skills to relieve stress, offering of solace and reassurance by means of adequate communication. Findings of this study also shows that the present intervention measures apply by nurses and other healthcare providers have positive outcomes. However, these methods should be carried out on a larger population of family caregivers to further prove the effectiveness.

Limitation

There is limited evidence regarding the effectiveness of the interventions found in this study to support family caregivers due to the small samples used. It is also possible that some relevant articles might have been missed during search. In attempt to find up-to-date data, the year of publication of the articles searched was limited to between 2010-2020, which means that other useful articles published before 2010 might have been missed. The articles searched were mainly in English language, which also means that some relevant articles which were written in other languages may have been lost. Few materials in the background were based on previous sources. Some other relevant articles did not grant the author free access.

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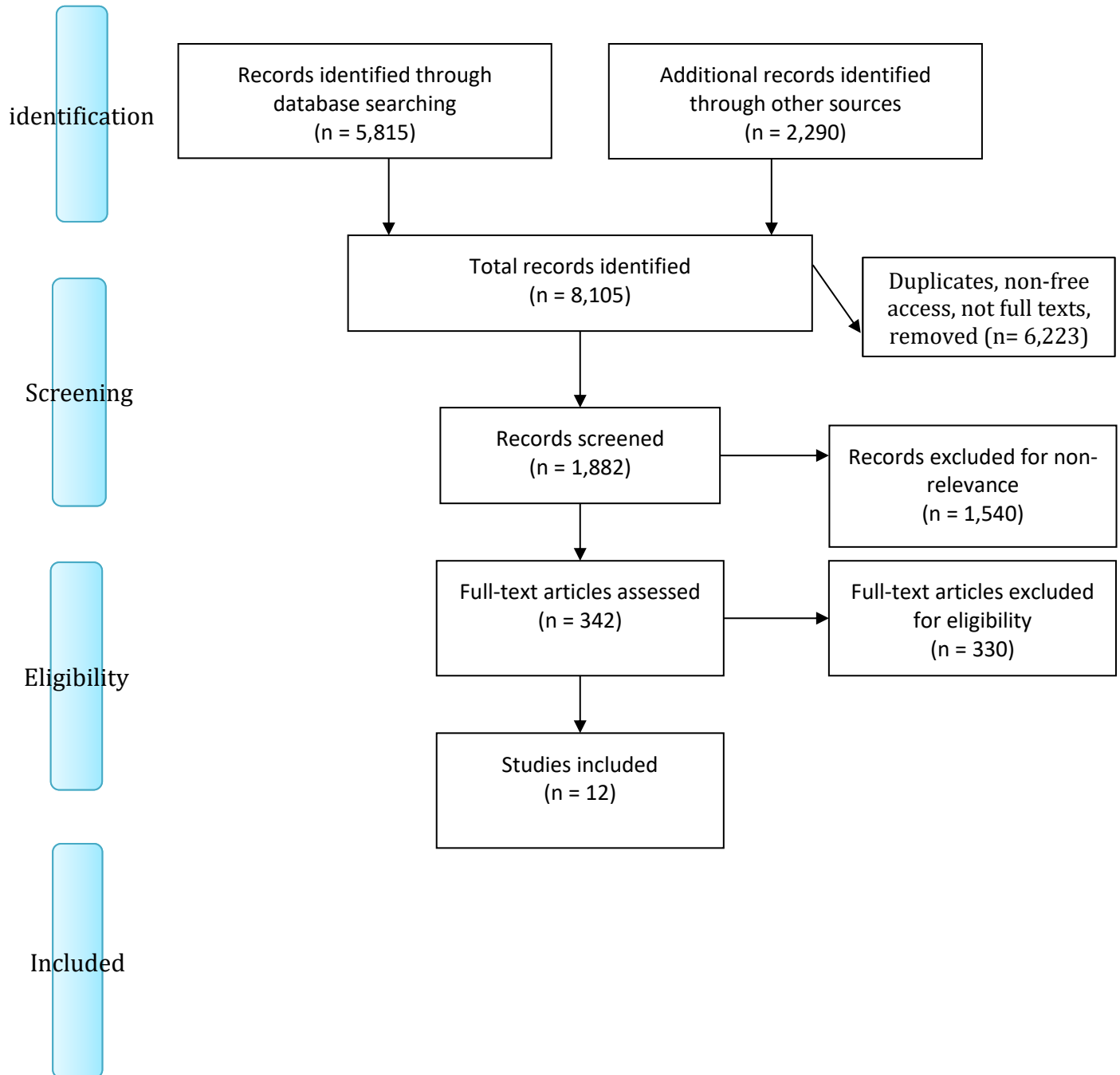
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Appendix 1: Prisma Flow Chart



Biographic Data	Aim	Material	Method	Result	Conclusion
<p>Chi, N., Demiris, G., Lewis, F., Walker, A. & Langer, S. (2015). Behavioural and Educational Interventions to Support Family Caregivers in End-of-Life Care: A Systematic Review. <i>The American Journal of Hospice and Palliative Care</i>, 33(9):1-15.</p>	<p>To combine educational, psycho-educational and cognitive behavioural therapy interventions that supports family caregivers of patients who are receiving end-of-life care.</p>	<p>Studies that contain educational and behavioural interventions to support family caregivers of terminally ill patients or palliative care and hospice care patients.</p>	<p>Systematic Literature Review</p>	<p>The result shows that the combined interventions improved family caregiver's outcomes. However, the cognitive-behavioral therapy had more positive outcomes than the educational and psycho-educational interventions.</p>	<p>There should be more randomized controlled trials to replicate interventions that are effective in larger samples. And more reliable and specific tools should be developed to measure family caregiver's outcomes effectively.</p>
<p>Alves, S., Teixeira, L., Azevedo, M., Duarte, M. & Paul, C. (2016). Effectiveness of a Psycho-educational Program for Family Caregivers of Older Adults. <i>Scandinavian Journal of Caring Sciences</i>, 30(1):65-73.</p>	<p>To assess how effective a psycho-educational program is to family caregivers of older adults without specific diagnosis.</p>	<p>60 informal caregivers of older adults in the north of Portugal.</p>	<p>Careers of Older People in Europe (COPE) Index. Informal caregivers filled a form with information about themselves and the care recipients.</p>	<p>The outcomes for the psycho-educational intervention proved positive, with improvement on the physical health, and reduced psychological distress and strain.</p>	<p>A deep knowledge regarding caregiving burden through a qualitative evaluation will help to improve the conclusions of the effectiveness of a psycho-educational intervention program for caregivers of older adults.</p>

<p>Ducharine, F., Dube, V., Levesque, L., Saulnier, D. & Ginoux, F. (2011). An Online Stress Management Training Program as a Supportive Nursing Intervention for Family Caregivers of Elderly Persons. <i>Canadian Nursing Informatics Journal</i>, 6(2). https://cjni.net/journal/?p=1344</p>	<p>To assess the effects of stress management training program provided online to family caregivers of elderly persons with weakened physical or cognitive independence.</p>	<p>26 caregivers of physically or cognitively vulnerable older adults.</p>	<p>Quantitative and Qualitative data collection.</p>	<p>Family caregivers no longer consider the caregiving role as a threat and difficult challenge due to the acquired self-efficacy ability to handle caregiving demands and control over their situations.</p>	<p>There are caregivers who cannot or probably do not welcome the idea to attend any conventional supportive program. By providing support through the internet as a method, nurses can still assist such caregivers.</p>
<p>Angelo, J., Egan, R. & Reid, K. (2013). Essential Knowledge for Family Caregivers: A Qualitative Study. <i>International Journal of Palliative Nursing</i>, 19(8):383-388.</p>	<p>To reveal the information nurses usually provide to family caregivers.</p>	<p>17 healthcare professionals from three community palliative care teams in New Zealand.</p>	<p>Nominal group technique, which is a type of focus group.</p>	<p>Majority of family caregivers do not have experience to perform the caregiving role. Nurses encourage personal care, skills acquisition, and provide adequate information about patients.</p>	<p>Home care for family members or close friends can be successful when family caregivers are empowered.</p>
<p>Al Daken, L. & Ahmad, M. (2018). The Implementation of Mindfulness-Based Intervention and Educational Intervention to Support Family Caregivers of Patients with Cancer: A Systematic Review. <i>Perspectives in Psychiatric Care</i>, 54(3): 441-452.</p>	<p>To find out the success of applying the mindfulness-based intervention and educational intervention to support family caregivers of patients with cancer.</p>	<p>Relevant studies that contain mindfulness-based intervention and educational intervention for family caregivers of patients with cancer in Jordan.</p>	<p>Systematic Review</p>	<p>The result revealed that mindfulness-based intervention has the possibility to increase the general well-being and reduce the burdens of family caregivers, while the educational intervention had</p>	<p>There were insufficient sample sizes used in the mindfulness-based intervention. Therefore, additional highly controlled trials with sufficient sample size are needed to verify the effects of the MBIs on the well-being and burden of family caregivers of patients with cancer. On the other hand, the educational intervention should continue to be applied as multiple studies have proved its effectiveness.</p>

				positive outcomes in the reduction of family caregiver burdens and improve the psychological well-being.	
Douglas, S. & Daly, B. (2014). Effects of an Integrated Cancer Support Team on Caregiver Satisfaction with End-of-Life Care. <i>Oncological Nursing Forum</i> , 41(4): E248-E255. doi:10.1188/14.ONF.E248-E255	To assess the effectiveness of an interdisciplinary comprehensive program on the psychological, social, and satisfaction outcomes on the family caregivers of patients with advanced cancer in the end-of-life.	106 family caregivers from two cancer centers in urban Cleveland, OH.	Quasi-experimental pre- and post-test design.	The meeting of nurses, caregivers and patients, assessment of the needs of caregivers, and the provision of appropriate supports on time and throughout the care of the patient leads to caregiver's high end-of-life care satisfaction.	The provision of social support to family caregivers may not change the feeling of an impending death of a loved one. However, the satisfaction of knowing and remembering that the patient was well cared for in the last phase of life has positive effect throughout the grieving process.
Clayton, M., Hulett, J., Kaur, K., Reblin, M., Wilson, A. & Ellington, L. (2017). Nursing Support of Home Hospice Caregivers on the Day of Patient Death. <i>Oncology Nursing Forum</i> , 44(4):457-464.	To describe hospice nurse-caregiver communication that occur on the day of patient's death.	42 caregiver-patient dyads, and 27 hospice nurses representing 9 hospices across 3 states in the U.S.A.	Descriptive Secondary Analysis of 44 Audio-recordings of home hospice nursing visits that took place on the day patients die.	In supporting family caregivers and patients, nurses mainly focus on the emotional, informational, and tangible care part of a dying patient, and address the aspects of spirituality and	Nurses should continue to provide a more holistic end-of-life care by following the National Guidelines of support.

				network of other support services.	
Rosell-Murphy, M., Bonet-Simo, J., Baena, E., Prieto, G., Bellerino, E., Sole, F., Rubio, M., Krier, L., Torres, P. & Mimoso, S. (2014). Intervention to Improve Social and Family Support for Caregivers of Dependent Patients: ICIAS Study Protocol. Biomed Central Family Practice, 15(1):53.	To find out if an intervention implemented by primary healthcare professionals on caregivers, and the self-help group will improve the social support as viewed by the caregivers, reduce caregiver burden, and improve caregiver quality of life. To also find out the population subgroups with the most effective result of the intervention, and the factors responsible for the effectiveness.	282 informal caregivers of patients who receive home healthcare from primary healthcare teams in 9 primary care centers from 2 regions of Catalonia, Spain.	Controlled, Multicenter, Community Intervention Trial, with randomized patients and their caregivers to the intervention or controlled group as assigned by their primary healthcare teams.	Different intervention strategies were applied such as individualized intervention, family intervention, and group educational sessions. The result shows that when the social support of primary caregivers is strengthened, the quality of life of caregivers will improve and their burdens reduced.	A new view should be adopted on home healthcare such as a new strategy which will center more on patients, caregivers, and on the family system. And through the primary care system, a complete support and greater planning should be given. This may improve care and strengthen preventive efforts.

<p>Holtslander, L. & Mcmillan, S. (2011). Depressive Symptoms, Grief, and Complicated Grief among Family Caregivers of Patients with Advanced Cancer Three Months into Bereavement. <i>Oncology Nursing Forum</i>, 38(1):60-65.</p>	<p>To describe the level of depressive symptoms, grief, and complicated grief of family caregivers three months after the death of patients with advanced cancer, and to find out the relationship among these variables.</p>	<p>280 family caregivers, three months after the death of family members with advanced cancer in West Central Florida, U.S.A.</p>	<p>Secondary Analysis</p>	<p>A third of the bereaved caregivers experienced high levels of depressive symptoms, and possibly experienced symptoms of grief and complicated grief.</p>	<p>There should be routine assessment of bereaved caregivers for symptoms of depression and complicated grief.</p>
<p>Aoun, S., Rumbold, B., Howting, D., Bolleter, A. & Breen, L. (2017). Bereavement Support for Family Caregivers: The Gap Between Guidelines and Practice in Palliative Care. <i>PLOS ONE</i>, 12(10): e0184750.</p>	<p>To point out the pattern of bereavement support in palliative services, according to the experiences of people who were bereaved from a population-based survey compared to the clinical practice guidelines.</p>	<p>298 individuals who had experience with palliative care services, and 208 individuals who did not have experience with palliative care services in 4 Australia States.</p>	<p>Postal Survey collection of information from clients of 6 funeral providers.</p>	<p>There was no sufficient attention given to some family caregivers of dying patients before and after death.</p>	<p>In accordance with the guidelines and practice of palliative care, more attention and concern should be placed on family caregivers.</p>
<p>Schulz, R. and Eden, J. (2016). <i>Families Caring for an Ageing America: Programs and supports for Family Caregivers of Older Adults</i>. National Academies Press, Washington DC. doi:10.17226/23606</p>	<p>To review the intervention strategies designed with the aim to support family caregivers of older adults with different conditions, and to conclude the</p>	<p>Literatures that contain caregiver's intervention for patients with dementia, cancer, stroke, and other conditions of older adults.</p>	<p>Systematic literature review.</p>	<p>The conduction of caregivers risks, needs, and preferences assessment enables the provision of the right support to meet their unmet needs and connect them to the</p>	<p>Different types of interventions especially the combination of interventions such as education and skills training, makes caregivers to better manage the daily caregiving challenges. Counseling, self-care, respite programs, and relaxation training also improves their quality-of-life thereby allowing care recipients the</p>

	interventions that are effective.			appropriate resources and services.	privilege of remaining at home instead of institutionalization.
Demiris, G., Oliver, D., Washington, K. & Pike, K. (2019). A Problem-solving Intervention for Hospice Family Caregivers: A Randomized Clinical Trial. Journal of the American Geriatrics Society, 67(7):1345-1352. doi:10.1111/jgs.15894	To assess the impact of a problem-solving intervention on the quality-of-life and anxiety of family caregivers and to examine the effectiveness when delivered through friendly calls, face-to-face, and videoconferencing.	514 home hospice caregivers consisting of male and female with a mean age of 60.3years.	A four years randomized clinical trial conducted with caregivers assigned to three groups.	The result shows that family caregivers of hospice patients have many needs as they struggle to manage with the stressful situations which affects their quality-of-life and creates anxiety. These needs include communication and emotional support. However, a problem-solving intervention prove to be effective to help caregivers handle major negative life events and everyday challenges that causes anxiety and depression.	The face-to-face group and the videoconferencing group were effective, although the face-to-face had more impact. This intervention should be implemented by nurses to meet the needs of caregivers as it requires direct contact and communication.