



**Supporting the Mental Health Of Palliative
Caregivers
A Literature Study**

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<p>Caregiving is a considerably challenging role, Palliative caregivers have responsibilities to provide optimal care services that otherwise would be received from the/a health care center. Therefore, caregiving comes with its challenges Family caregivers aren't always prepared for these challenges ahead, thus leading to more psychological difficulties and isolation of caregivers during the care. There has been considerably much research on palliative care patients however, not as much on the caregivers hence the aim of the research is to shed light on the psychological effect of informal palliative caregivers, emphasizing on how they manage or cope with the emotional strains. Furthermore, what kind of support they require and is available to them from health care, especially nurses. The research questions in focus are (1) What are the psychological difficulties experienced by palliative care givers? (2) What support is available for promoting Palliative care giver's mental well-being? (3) What is the nurses' role in supporting informal palliative caregivers? The study was a literature review with an inductive content analysis.</p> <p>The theory of Transactional model of Stress & coping and cognitive appraisal by Lazarus & Folkman was used to explore the connection between palliative caregiver's psychological distress and the appraisal and coping mechanism.</p> <p>Results indicate that caregivers display psychological problems and their mental well-being is impaired also there is availability of support to some degree but caregivers may lack the information and the knowledge on how to access the support needed.</p>	
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1 INTRODUCTION

The reality of dying at home is identified as a more comfortable and respectable experience than dying in a hospital even though the vast majority of patients die in a hospital. In addition, it is cost effective for many families as opposed to keeping their loved one in a hospital, hence the promotion of home-base care by health care services. Therefore, families are choosing to accept the responsibility of caring for their loved-ones during end of life instead of the alternative, hospitalization. Even with the benefits attached to family caregivers it comes with its challenges and problems. Often times these challenges lead to caregivers neglecting their own well-being due to the perceived level of responsibility and care duties of their loved-one. (Harding, Epiphaniou, Hamilton, Bridger, Robinson, George, Beynon and Higginson. 2011; Ventura, Burney, Brooker, Fletcher and Ricciardelli. 2014).

Though the focus lies on the patient, the caregiver should not be forgotten, as it is a natural part of the care process. It is recommended by The National Comprehensive Cancer Network (2013) that in palliative care, support for family members should be incorporated as an essential part. The guidelines written by The National Comprehensive Cancer Network (2013) are essential to nurses when supporting informal caregivers in palliative care, since they give recommendations and aid in assisting and improving the support (Grant et al., 2013).

It's very rewarding to care of a family member or a loved one during end of life, nevertheless it is also indicated that caregivers experience fatigue. Especially when their support network becomes strained as time passes. In palliative care family caregivers aren't always prepared for the challenges ahead, thus leading to more psychological difficulties and isolation during the care. Relatively little research has been done in developing different interventions to address the different needs of palliative caregivers. Research has shown that there is a lack of communication and information to informal palliative caregivers, which is a key issue that could be addressed and

avoided with support from health care staff. The lack of supportive interventions leads to caregivers being under prepared for challenges ahead. Yet informal caregivers often lack information and what to expect while caring for a dying person (MacLeod et al., 2011).

2 BACKGROUND

Palliative care is an approach aimed at improving the quality of life of patients and their families facing the problem associated with life-threatening illness. Palliative care is the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2015).

Today most countries have an increase in the elderly population, due to the generation known as the "baby boomers" have reached retirement age. As a result of stupendous progress in health care, life expectancy has increased. The opportunities are broader both in home- and hospital environments for terminally ill people to receive care. Terminally ill patients require both physical and psycho-social care. Thus, emphasizing the essential in effectively functioning health care systems and competent care givers. Furthermore, patients wish to spend their last days at home with their loved ones. Nowadays, more than often caregivers for terminally ill patients are family members (Williams et al., 2010).

There has been considerable research on palliative care patients however, not as much on the caregivers. Furthermore, a large amount of previous research is focused on cancer patients. Home based caregiving for palliative patients encompasses considerable financial, physical, social and not to mention emotional strain. There are about 100 million family caregivers in Europe, whose contribution to caring for their loved ones is likely to exceed the financial cost for formal nurses providing care (Aoun et al., 2015; Morris et al., 2015).

Family caregivers play a crucial role and undertake multiple tasks, including being the patients advocate, assessing symptoms and managing the patient's hygiene and medication. This exposes caregivers to considerable challenges, which they don't receive much support for. The focus is usually on the patient's needs and care, which often leads to the family caregivers being forgotten. Hence, the focus in this review is mainly on highlighting the psychological effects of palliative

caregivers and emphasizing on available support for palliative caregivers (Hudson et al., 2008; Funk et al., 2010).

Research suggests that family caregivers often have limited information and support to prepare themselves for their caregiving role. Thus, family caregiving is usually associated with unfavorable physical, social and psychological issues. Therefore, the focus in this review is how informal caregivers are effected by the caregiving process and what support is available to them, nevertheless what support nurse can provide and how they can be implemented. Caregivers often experience difficulties when caring for their loved one, be it physical, emotional, financial or social, it often impacts their psychological wellbeing. Hence the questions in focus are what are the psychological difficulties informal caregiver experience and what support is available for promoting their mental wellbeing.

2.1 Palliative care

Palliative care offers support for the patient and carers to live as actively, pain free and comfortably as possible, moreover dealing with both the patient and the caregivers' needs. In other words, the aim of palliative care is to enhance the quality of life for the patient and help the family and others involved to understand the situation at hand. Palliative care uses a multidisciplinary approach and offers support to the patient and carers to live as actively as they can for as long as possible. (Ventura et al., 2013).

According to (WHO, 2015) "Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." Furthermore, it is stated that: "Palliative care involves relief from pain and distressing symptoms that a dying patient might have. In palliative care death is regarded as a normal process, without hastening or postponing death. It is simply to make it more comfortable by any means for the dying person. It involves

physical, psychological and spiritual aspects of the patients' care. Further-more, it offers support for the family to cope during the patients' journey. It is a holistic view of the patients care with including the family. Palliative care is to enhance the patients' quality of life and help all parties understand the situation better" (WHO, 2015).

Palliative care services are provided in hospitals and in home settings. Palliative home care has become the dominant model in end of life care. In this review the focus is on home-based palliative care, which has become one of the main models of palliative care. In home base palliative care the patient stays at home and usually a family member, who is their caregiver, cares for them. The aim is to live as normally, pain free and comfortably as possible. The patient receives the same care as in a hospital, only that they can be more comfortable and have their own routines. Home-based palliative care offers many benefits including making own decisions, comfort and having choices. It is also regarded as a more dignified experience to die at home, although most of the patients don't die at home in the end (Ventura et al., 2013).

Additionally, home-based palliative care is more cost-effective compared to hospital care, which is why it is promoted by hospitals and healthcare facilities. Although there are many advantages with home based palliative care, challenges remain in implementing optimal services. In home-based palliative care the caregiver is usually a family member. Thus the care and services for the patient depend on the contributions of the family caregivers to make home-based palliative care possible (Ventura et al., 2013).

Research shows that in home-based palliative care family bonds were developed with the dying person. Caregivers could assess the patients comfort better, due to much time spent together in the home setting. The home was also viewed as a more comfortable setting and patients would feel more secure being at home. Family caregivers also felt more in control with the situation, since they were able to set routines, home settings also gives the family more time with the dying person and with each other. It also took away the stressful factor of separating which happens in a hospital due to visiting hours. Family caregivers also didn't worry as much when the dying person was at

home as oppose to being hospitalized. Furthermore, the home environment helped to maintain a sense of peace for the bereaved caregiver (Morris et al., 2015).

2.2 Palliative caregiver

Caregivers are health care workers that provide care for patients, however ‘caregiver’ in the review it is referred to as informal caregivers that care for their family member at home. Informal caregivers are essential for the care of patients with physical or mental impairments. Caregivers perform essential tasks that are day-to-day chores, such as buying groceries, cooking, cleaning the house or doing laundry, helping to get dressed, showering and providing medical care. Also, coordinating care with different health care providers and making medical appointments. When it comes to finances the caregiver arranges bills and manages both their economics and legal matters for them. Caregivers are also there for the patient to help them cope with their situation. A caregiver experience might be positive which helps them to cope with the illness or condition of a loved one. However, most of the time it is demanding, mind consuming and it may have a negative effect on the caregiver (Herbert et al., 2007). Family caregivers play a critical role in the patients’ care, not only do they undertake the different tasks mentioned above, but also symptom assessment, managing symptoms at home and medication administration. The caregiver experience is very diverse and it often presents unique challenges (Hudson et al., 2008).

According to (omaishoitajat.2015) a caregiver is a person who provides care for a dying person or someone with a chronic condition, disability or other special needs of assistance due to not being able to cope with their daily lives and chores independently that requiring care.

The concept of caregiver has only been recognized since the 1990s even though caregivers have always been there. In Finland informal caregivers have been carrying an invisible responsibility. In the past two decades’ informal caregivers have become more visible and their everyday life caring for their loved one has become more apparent (Omaishoitajat. 2015). There are also different cultural approaches regarding caregivers. In today’s society there is a great diversity and families from different cultures bring their own tradition and rituals to the caring process. In many

cultures there are expectations for family members to care for their own and in some cultures daughters or daughters-in-law are expected to take the primary caregiver role (Pavia et al., 2015).

An informal caregiver can be a spouse, a daughter, a son, grandchildren, and daughter- and son in-laws. It may also be a friend, a loved one, a partner, a relative or any other person who takes care of a loved one in need. As mentioned earlier, a caregiver can be a nurse or other official health care workers who get payed. Informal ones are often unpaid and without a medical background (Ratkowski et al., 2015).

The level of burden informal caregivers experience is very high. This brings forward the significance of the nurses' role in palliative care. When informal caregivers take care of their loved ones they need assistance in different ways. They need guidance and someone they can turn to for help. Nurses play an important role here. Considering the high burden level, there is a critical need to develop and implement support and intervention methods necessary for nurses to comprehend. Health care professionals should make sure that the caregivers get the appropriate and suitable support and resources available to help them manage with caring for their loved one. Caregivers also feel positive about caring for their loved one, positive features include normalcy and sense of pride. It also gives the opportunity to show their love and affection. Furthermore, it gives a sense of relief, accomplishment and inner peace. (Grant et al., 2013; Funk et al., 2010).

There is an abundant amount of caregivers and the number keeps growing with the aging population. There is, however not an exact number of how many family caregivers there are. Due to the large amount of informal caregivers there is necessary need to understand implications better. Morris et al. write that The National Institute for Health and Clinical Excellence (NICE) describes family caregivers as people with a close social and emotional relationship, not merely those related by kinship or marriage. Nowadays it is more common for patients to be at home with their family member taking care of them. There are numerous tasks that informal caregiver do, including providing medication, managing symptoms, feeding the patient and so on. Therefore, it is necessary for health institutions to be able to assist them in managing at home (Morris et al., 2015).

There is a growing recognition of the essential role family caregivers' play. However, there still remain knowledge gaps regarding how to best support caregivers when their loved one is dying. It is also important for health care personnel to understand how the home environment for palliative patients might affect family carers. (Morris et al., 2015).

2.3 Mental well-being

Mental health or mental well-being is challenging to define accurately, in that, there is no universal definition. However, the large consensus on these terms are that if an individual is able to function properly and perform their role in society with an appropriate behavior that is approved or is a norm in a given society then they are mostly deem as mentally healthy. On the contrary if a person behaves inappropriately and is unable to carry out their role in society or function properly. They are regarded as mentally unhealthy or even mentally ill (BT Basvanthapa., 2011).

Often mental health is referred to as a "state of well being" There are many aspects to be considered when speaking of mental healthiness that will encompass a total health. These aspects are satisfaction, accomplishment optimism or positive outlook and so forth, suggesting that physical health alone is not viewed as an individual being healthy. Moreover, mental well-being is a positive combination of intellectual, emotional physical and spiritual element of an individual. Mental health is usually also seen as an absence of a psychological disorder or having some level of intellectual and emotional well-being, furthermore it is an individual's possession of a positive traits that enables them to enjoy life and to harmonize their daily living and psychological resilience (BT Basavanthapa., 2011). According to (WHO 2014) mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to her or his community.

In the review of palliative caregiver's mental well-being, the focus was mainly put on the emotional status of caregivers. The effect and strain of caring for a dying loved one has on the mental

well-being of caregivers. Even though there is a considerable amount of research done on the caregiver, especially on their hardship or the physical strain. There is however a limited comprehensive knowledge on their psychological well-being (Neena and Colin 2002). Palliative caregivers may go through physical and psychological reactions as a result they do require various supportive care as highlighted by World Health Organization. They assume many different roles for instance physical role which includes giving medication, personal assistance like bathing, dressing, monitoring symptoms. Emotional role, these constitutes listening, talking, reading, giving love and companionship and practical role such as handling financial matters (P Hudson et al., 2008).

In addition to these responsibilities caregivers have to deal with the fact that their loved ones are in much pain, not to mention the impending death of someone they care about. These aspects pose an exclusive challenge no matter how experienced and hardy a caregiver may be. The emotional, social, physical and financial consequences of caring for a loving family member is hefty. These impact are manifested in caregiver as exhaustion, fatigue, anxiety, sleeplessness, weight loss, depression and burn out, hence affecting the mental well-being (P Hudson et al., 2008). Caregivers experience more psychological distress, develop anxiety and show signs of depression advancement that are in accordance with the progression of the patient's condition. These stressors not only pose threat to the caregiver's mental and physical well-being but also endangers the patient, hence the recognition and consideration of caregiving stressors remain essential for not only the caregiver but also the patient (Ratkowski et al., 2015).

2.4 PSYCHOLOGICAL DIFFICULTIES

Mental health, psychological difficulties or emotional strain emerged as a main theme in the study. The psychological impact of palliative caregiving is evident in the data collected. Psychological need in caregiver was more extensive than physical need. There was availability of physical support to some degree and what carers have voiced concerns on is the scarcity of psychological support for instance a counselor or a peer support. The indication of the findings is also that caregivers are susceptible to impaired mental health (Ventura et al., 2014; Song et al., 2011). There

has also been a correlation between patient's poor psychological well-being and the caregivers increased psychological distress and burden (Ratkowski et al., 2015). Most of caregivers are not mentally prepared for the responsibility ahead and have an unclear understanding of the meaning of being a caregiver (Munck et al., 2008). In a study done in Quebec Canada about family caregiver's burden, it has been found that 41-62% of family caregivers experience high level of psychological distress compared to the general population (Stajduhar., 2013). Caregivers struggle with their own health both physical and psychological health and they show problems such as depression, back pain, ulcers and even heart disease (Harding et al., 2011).

The difficulties experienced by caregivers are further explained through various psychological aspects such as stress and depression, anxiety and physical and emotional burden.

- Stress and Depression; As caregiver's burden increase so is their stress, there is evidence of direct proportion between the two. Even the availability of support it may not help with demanding nature of the caregiving role which affirms the existence of stress within caregivers (Hudson et al., 2008). Caregivers reported depressive episodes also a higher prevalence of depression among caregivers was noted (Song at al., 2011) Patients or loved one's sadness or worrying seems to be the most stressful issue for caregivers, also other issues that has been found to effect stress level in caregivers are physical aspects like Patient's lack of appetite, pain and weight loss. (Ratkowski et al., 2015) The unpredictability nature of the care giving process not to mention the disruption of life and the feeling of isolation pose a great emotional stress on caregivers. Caregivers also show levels of depression identical to that of the patient and higher than the general population (Stajduhar, 2013; Totman et al., 2015). In a qualitative study about caregivers challenges it was noted that caregivers experience distress as the patient condition deteriorates since caregiver have no control over the deterioration of the patient's condition and despite their effort to minimize it (Harding et al., 2011).
- Anxiety; Caregivers show a rise in the level of anxiety (Hudson et al., 2008; Song at al., 2011) A constant worrying about the patient even when they are not in their presence (Munck et al., 2008). In some study they found out that many family caregivers show

higher anxiety level than the dying patient (Stajduhar, 2013). Caregivers find themselves in constant alertness situation, they mention being in a state of hypervigilance and being anxious (Totman et al., 2015).

- Burden; Caregivers face a great deal of responsibilities which bring about physical problems that increase caregivers burden, among these burdens are financial burdens which is associated with risk of developing depression hence causing mental health impairment (Hudson et al., 2008). The great physical burden comes as an addition to the existing psychological challenges which is manifested in fatigue and sleep deprivation. The burden is so great that some family caregivers stop taking care of themselves, they do not eat properly and many times it even affects their occupations or work and their financial status (Stajduhar, 2013; Harding et al., 2011).

3 THEORETICAL FRAMEWORK

When discussing theory, it usually refers to how we explain facts. The word theory comes from the Greek *theoria*, which means "contemplation or speculation", according to Vocabulary.com. It's essential to support or hold a theory of the research study when researching, a theoretical framework is structured to do such. Theories are developed to explain, grasp and foresee phenomena. Furthermore, to challenge and enhance the knowledge we have within the limits of critical bounding hypothesis. The theoretical framework is a frame of references that illustrates and introduces the theory that explains why the research problem under study exists (University of Southern California, 2015).

The theory used in this review is a "Transactional model of Stress & coping and cognitive appraisal" by Lazarus & Folkman. This theory states that there is a transaction (communication, interaction) that takes place between an individual and an environment, and stress comes from an imbalance between the demand of life and the recourses available to a person. Thus we become stressed when the demand or the pressure exceeds our recourses and ability to cope. Also the meaning of stressful event is more important than the event itself. Two appraisals, primary and secondary, are central to Lazarus' cognitive theory of stress which affect how an individual cope through his or her perception of personal control over stressful situation. Emotions of an individual depends on cognitive appraisals of the relationship between the individual and the environment and available options for coping. Therefore, the primary and secondary appraisal process causes emotion (Lazarus and Folkman, 1984, 1987).

The transactional model of stress is a plan that combines aspects like stress, appraisal and coping theories. It explains how these aspects will relate to a person's reaction to psychological issues like stressful situations. This theory can be effectively used in the estimation and evaluation of an individual's psychological stress and coping responses. Although the transactional model is continually used in a great amount of stress research, the current focus is rather on the stressor (Perrewe and Zellars, 1999).

The theoretical Framework is believed to be suitable since the review is about mental health (stress, depression) of palliative caregivers and the coping strategies or support. The articles used mostly mention the stress palliative caregivers endure in the caregiving process. According to (Lazarus and Folkman, 1984) the interpretation of stress and the availability of resources to cope are considerable aspects of Stress. In the research it has become apparent that palliative caregivers do not have much support or they lack resources to meet the demand of caring for a dying person. This leads to stress and even depression.

The transactional model of stress and coping by Lazarus and Folkman (1984) has laid out a ground for understanding caregivers and families' responses to supporting a terminally ill person (P. Hudson, 2003). This model has been previously used to understand the issues' related to end-of-life care from the psychological point of view. It has been used to detect stressful events impacts on caregivers. It has also been encouraged to be used in palliative care research for it brings forth the stressors for caregivers which are diverse (e.g., taking up on a huge role, financial strains and end of life decision making) and their various appraisals, which how they perceive their caregiving role and the recourses available to them (Hebert et al., 2007).

4 AIMS AND RESEARCH QUESTIONS

The aim of this review is to shed light on the psychological effect of informal palliative care givers, emphasizing on how they manage or cope with the emotional strains. Furthermore, what kind of support they require and is available to them from health care, especially nurses. Nursing implications will also be brought forth through the nurses' role in supporting informal care givers.

The research aims at answering the following questions;

- 1 *What are the psychological difficulties experienced by palliative care givers?*
- 2 *What support is available for promoting Palliative care giver's mental wellbeing?*
- 3 *What is the nurses' role in supporting informal palliative caregivers?*

5 METHODOLOGY

Literature review is the method used in this study with inductive analysis as the method of analyzing the data. A literature review should be able to show a reader that the main aspect concerning the topic or the questions has been understood and that it is not a description of what others have published in a summary form, instead it should be of a critical discussion of the acquired knowledge. Furthermore, it is a synthesis of a published work. (Birmingham city university.2011)

In a literature review the author situates the research focus with the context of the academic community and reports the critical review that is relevant literature and furthermore, fills in the gaps within the literature that the research attempts to address. A Literature review is going through previous research and understanding, interpreting and analyzing, clarifying and developing an argument for or against it. The process of conducting and reporting a literature review helps clarify thoughts regarding the study, not to mention establishing a framework to help present and analyze the findings. In a literature review one becomes aware of relevant work of others, what is already known and understood and if the research question and research is relevant. When conducting a literature review one simply searches for articles or any literature data that regards the research question being asked, and re-views them (University of Leicester, 2009).

It is resourceful to do a literature review with small scale writing project, especially for beginners, since one reads about how others have done research and gets ideas and understands how much data there is regarding the research question, to name but a few. A literature review can establish the con-text and rationalize the study and confirm the choice of research question/focus (University of Leicester, 2009).

5.1 Data collection

Prior to data collection research questions were formulated and agreed upon by the authors. Subsequently Arcada University of Applied Sciences databases were accessed. Which include

EBESCO, SCIENCE DIRECT, SAGE and PUBMED. The articles found in these databases provide pre-existing information and knowledge about the topic and research questions. The key words used for the search were set, which are “palliative care”, “caregiver”, “stress”, “mental health”, “quality of life”, “coping strategies” and “mental stress”. The search strategy used was Boolean search operator with the connecting word “AND” This data collection process is further demonstrated clearly in the following table.

Table 1: Articles retrieval

Data bases	Search Category	Number of Hits	Relevant Articles	Selected Articles
EBESCO	Palliative care at home AND mental health AND caregiver.	126	24	6
	Palliative caregivers AND coping strategies.	6	2	2
	palliative care AND stress	658	178	4
	Palliative caregivers AND mental health	18	8	1
	Quality of life AND palliative care AND caregivers	315	91	3
	Quality of life AND caregivers	3,240	863	2
PUBMED	palliative caregiver AND stress	283	3	1
SAGE	Palliative medicine journal: palliative caregivers AND coping strategies	2	2	1
	Palliative medicine journal: family caregivers AND end of life	213	1	1
SCIENCE DIRECT	palliative caregivers AND mental stress	1,497	34	2

In EBESCO six searches were carried out, with the manipulation of the search words mentioned above. First search, search words used were: palliative care at home AND mental health AND caregiver. The second search, search words used: palliative caregivers AND coping strategies. The third search: palliative care AND stress, the fourth search: Palliative caregivers AND mental health. The fifth search: Quality of life AND palliative care AND caregivers. The sixth search: Quality of life AND caregivers. In PUBMED one search was carried out with the use of Palliative caregiver AND stress as the search words, this was followed by SAGE database in which two searches were carried out. In both searches Palliative Medicine journal was accessed and searched words palliative caregivers AND coping strategies was used in the first one, and in the second search the words used were family caregivers AND end of life. Finally, the Science direct database was accessed and one search carried out with search words, palliative caregivers AND mental stress.

Preceding the search, criteria were set and research questions formulated with an aim of only selecting article that would meet the standards. The selected articles must have been published in English. They must have been free to access with no price on them, since the review was not funded or sponsored and the articles must have been full text available. All the articles had to have been published from the year 2005 - 2015. These criteria were set in order to have recent and updated material for the study. In addition, due the abundance of articles published prior to the year set, it had to be limited.

To ensure the reliability of the review, criteria were set to exclude articles. In this criteria all the articles that contained irrelevant information and are deemed unscientific were not considered. Articles below the year 2005 were removed, also anything published in any language other than English was dismissed. Articles that required payment were excluded, also in the exclusion criteria were articles that were not full text. Following these criteria nineteen articles were considered and selected for the review. The selected articles are further demonstrated clearly in the table below.

Table 2: Summaries of the articles used in analysis

Article Number	Title	Year	Methods used	Results/Conclusions
Article 1 Adriana D Ventura, Susan Burney, Joanne Brooker, Jane Fletcher and Lina Ricciardelli	Home-based palliative care: A systematic literature review of the self-reported unmet needs of patients and carers	2014	Systematic literature review	The focus of the study is improving aspects of patient care, such as communication. Health professionals need to be more efficient to prevent or reduce suffering in areas such as psychosocial domains.
Article 2 Sara M Morris, Claire King, Mary Turner and Sheila Payne	Family carers providing support to a person dying in the home setting: A narrative literature review	2015	Narrative literature review	Better understanding of issues affecting family care givers at home can help to improve community services.
Article 3 Samar Aoun, Kathleen Deas, Chris Toye, Gail Ewing, Gunn Grande and Kelli Stajduhar	Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial	2015	a stepped wedge cluster trial	The Carer Support Needs Assessment Tool was found to be an easy assessment process. Key themes were identified: suitability and efficiency of the systematic estimation.
Article 4 Jong Im Song, Dong Wook Shin, Jin Young Choi, Jina Kang , Young Ji Baik, Hana Mo, Myung Hee Park ,Sung Eun Choi, Jeong Ho Kwak & Eun Jin Kim	Quality of life and mental health in family caregivers of patients with terminal cancer	2011	Study design	Findings affirm a compelling negative interaction between “impact on health” and health-related quality of life.
Article 5 P Hudson, K Quinn, T Thomas M Braithwaite, J Fisher, M Cockayne	Evaluation of a psycho-educational group programme for family caregivers in home-based palliative care	2008	Interviews and questioners	The study establishes that a group education programme was to prepare family caregivers for the role of supporting a dying relative at home was handy, applicable and efficient.
Article 6 Samar M Aoun, Linda J Kristjanson WA, David C Currow Peter L Hudson	Caregiving for the terminally ill: at what cost?	2005	literature review	Research indicates caregivers having significant unmet needs associated to their caregiving role.

Article 7 Siggi Zapart, Patricia Kenny, Jane Hal, Betty Servis and Sharon Wiley	Home-based palliative care in Sydney, Australia: the carer's perspective on the provision of informal care	2007	Cross sectional descriptive study	The study contributes findings for Australia that are consistent with previous research regarding informal carers of palliative care patients
Article 8 Ann MacLeod, Mark W. Skinner and Eleanor Low	Supporting hospice volunteers and caregivers through community-based participatory research	2011	Community-based participatory research	Research added to the social support for palliative caregivers. The study brought forth challenges faced and diversity in the available resources among family caregivers
Article 9 R. S. HEBERT, E. WEINSTEIN, L. M. MARTIRE & R. SCHULZ	Religion, spirituality and the well-being of informal caregivers: A review, critique, and research prospectus	2006	Narrative review	This study brings forth a summary of the research on religion/spirituality and caregiving outcomes. Results show that religion/spirituality is central in many caregivers' lives as a support.
Article 10 Kristy L. Ratkowski, Karla T. Washington, Kevin W. Craig and David L. Albright	The Stress of Sadness: The Most Stressful Symptoms for Hospice Family Caregivers	2015	Study case	This study shows that a problematic degree of stress in family caregivers of palliative patients illustrate symptoms to many patients.
Article 11 L Funk, KI Stajduhar, C Toye, S Aoun, GE Grande and CJ Todd	Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008)	2010	Literature review	Purpose of the review was to determine significant gaps in existing literature and areas for conceptual and empirical work for the future.
Article 12 Bianca Sakamoto Ribeiro Paiva & André Lopes Carvalho & Giancarlo Lucchetti & Eliane Marçon Barroso & Carlos Eduardo Paiva	“Oh, yeah, I’m getting closer to god”: spirituality and religiousness of family caregivers of cancer patients undergoing palliative care	2015	Exploratory and descriptive qualitative study	This study presents that spirituality and religion are coping strategies often used by family caregivers of patients with advanced cancer
Article 13 Kelli I. Stajduhar	Burdens of Family Caregiving at the End of Life	2013	Literature review	If the patient wishes to stay at home, providing care is mainly on family members.

Article 14 Jonathan Totman, Nancy Pistrang, Susan Smith, Susan Hennessey and Jonathan Martin	You only have one chance to get it right': A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer	2015	Qualitative study	Professionals' awareness on caregivers' can have a strong effect in alleviating anxiety, stress and diminishing isolation.
Article 15 Richard Harding, Sally List, Eleni Epiphaniou, Hannah Jones.	How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness	2011	literature review	Evidence proposes a fast increase in the amount of prosperous intervention studies. However, the amount of intervention models remain limited concerning caregivers' needs.
Article 16 R. Harding & E. Epiphaniou & D. Hamilton & S. Bridger & V. Robinson & R. George & T. Beynon & I. J. Higginson	What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention	2011	Qualitative interviews	Intervention ought to be brief and should aim to intensify their visibility for family caregivers, due to restricted amount of time. Information giving, preparing them for their caregiver role and emotional support is essential.
Article 17 Marcia Grant, Virginia Sun, Rebecca Fujinami, Rupinder Sidhu, Shirley Otis-Green, Gloria Juarez, Linda Klein, and Betty Ferrell,	Family Caregiver Burden, Skills Preparedness, and Quality of Life in Non-Small Cell Lung Cancer	2013	Case study	The study implies that caregivers experience high levels of caregiver burden and noted worsening in psychological wellbeing and quality of life.
Article 18 Randy S. Hebert, Robert M. Arnold, and Richard Schulz	Improving well-being in Caregivers of Terminally Ill Patients. Making the Case for Patient Suffering as a Focus for Intervention Research	2007	Literature review	The caregivers' well-being is often worsened in the caregiving process. The review shows that alleviating patient suffering physical, psychological, social or spiritual can improve caregiver well being.
Article 19 Berit Munck, Bengt Fridlund & Jan Ma ^o rtensson	Next-of-kin caregivers in palliative home care – from control to loss of control	2008	Case study	Informal caregivers can have much discomfort in observing the physical and psychological changes that occur during the end of the patients treatment.

5.2 Data Analysis

Data analysis is essential in determining the reliability for a review. It is a summary and description of collected data which is attained by using various methods. Depending on the researchers' approach and research question data analysis can differ (Seaman and Verhonick., 1982). The method used in this study for analyzing data is qualitative content analysis. Qualitative content analysis is a method that describes, summarize or examines contents and themes found in data by interpreting and summarizing the material at hand. It is interpretive and theoretical in nature. It is summarized as ratios, percentages and proportions (Chesnay., 2015).

Qualitative content analysis is the method used to analyze data and translate its context. It can be used in both inductive and deductive means. Inductive and deductive content analysis consist of three essential phases, first being the preparation phase. This phase involves collecting relevant data and understanding the raw data. The second phase is organization phase which for instance in the inductive approach involves coding and building categories. Whereas in deductive approach the organization phase involves developing matrix categories. Finally, the third phase is the reporting of the result whereby the findings are described phenomenon by the content of the developed categories using either deductive or inductive approach (Elo et al., 2014).

Based on the description of the inductive and deductive approach and the content analysis it was agreed that content analysis using inductive reasoning is the best method to analyze data for this study. The data collected was assessed in relation to the research questions and the aim of the study. The research questions "What are the psychological difficulties experienced by palliative care givers, what support are available for promoting Palliative care giver's mental wellbeing and what is the nurses' role in supporting informal palliative caregivers" have been used as guidance to obtain data that was then made sense of by understanding as per the preparation phase of the inductive approach.

The articles selected were then organized by using open coding process. Firstly articles were numbered in the following way [1], [2], [3]..... [19], in order to use numbers as representatives of the

articles when referencing the text. In the analyzation of data open coding applied through which the researcher begins the process by first reading the material carefully and pinpointing key words that are associated with the research questions. The open coding process then continues by the researchers making notes and headings in the reviewed material (Elo et al., 2014).

Therefore, this requires the articles being read repeatedly and thoroughly, which was done. The articles were categorized into categories and subcategories, that were specific to the research questions, which were then assigned separately to the writers. Notes of relevant information to the research questions were highlighted. The highlighted portions were re-read again and the various information listed to establish categories and subcategories suitable for the research questions.

5.3 ETHICAL CONSIDERATIONS

Ethical issues are encountered in any kind of research. There are code of conducts to be followed in the world of writing. In order to avoid violations of thesis principles various aspects were put into considerations. These are the principles essential to the review which began with discussing the topic with commissioning party (Vård I Hemmet Ekenäs) before starting the study. The Finnish Advisory Board on Research Integrity have three main ethical principal: Respecting the autonomy of research subjects, avoiding harm, and privacy and data protection. The writers read through these principles carefully and conducted the study accordingly (Finnish Advisory Board on Research Integrity, 2012). The material used in the study were retrieved from an official academic data bases of which the writers had rights to access through being students at the Arcada University of Applied Science. The quotations in this study came from the articles and are not directly quoted to avoid plagiarism. Also not misquoting or mis-presenting an author's information during paraphrasing Themes, concepts and ideas in all the journals used were not fabricated by the authors in any way. The writers also managed to remain objective and that the evidence based ideas weren't affected by any emotions. Arcada University of Applied Science's good scientific practices in research study were observed.

5.4 WORK DIVISION

The bulk of the work was done together in order to achieve a well-researched quality study. However, there was division of work in some areas of the research. In the background part of the study, there were two essential keywords to be written about, these were; **Palliative care**, **Palliative caregiver** and **Mental well-being**. These key words were shared between the Authors. Author 1 (Zahra Muhamed) wrote about Mental well-being while Author 2 (Tavga Zahir) wrote about Palliative care and Palliative caregiver. Both Authors have agreed to share in finding the answers to the research questions. Author 1 (Zahra Muhamed) focused on the first research question (*What are the psychological difficulties experienced by palliative care givers?*) whereas Author 2 (Tavga Zahir) handled the second research question (*What support is available for promoting Palliative care giver's mental wellbeing?*) The third research question (*What is the nurses' role in supporting informal palliative caregivers?*) was answered together. The Authors brought forth their respective findings and discussed it together to arrive at a conclusion.

6 RESULTS

This chapter is designed to answer the research questions by looking at the data collected from the articles. After the articles were read and analyzed two major themes emerged, these are; the psychological effect of palliative caregivers and the intervention/support available (through a nurses looking glasses). Development of themes and the provision of answers to the research questions were possible through the analysis of the data gathered from the articles. Categories and subcategories were made based on the research questions. The themes and categories were arranged in the result section in accordance with number of the research questions.

The categories formulated for the study are further illustrated in this section and the data acquired is used to answer the following questions; what are the psychological difficulties experienced by palliative care givers? Which was answered in the background. What supports are available for promoting Palliative care giver's mental wellbeing? and What is the nurses' role in supporting informal palliative caregivers?

6.1 SUPPORTIVE INTERVENTIONS

Research indicates that there are relatively few interventions and those existing are mostly underdeveloped but aim to assist caregivers cope with both physical and psychological issues. Interventions are usually group sessions, respite care, educating caregivers, helping them cope with emotional and physical strains, how to provide care and more. Interventions can focus on the relief of patient suffering or supporting the caregiver. They go hand in hand since research shows that the patients' relief of pain eases the caregivers' psychological burden. To address the unmet needs of both the patient and caregiver, implications for interventions could be developed. The unmet needs can be addressed separately depending on the caregiver's needs [1, 2, 5, 8, 15, 18].

There are supportive interventions that can be used to assist family caregivers in with their situation. Erwing and Grande developed a comprehensive and evidence based tool, Carer Support Needs Assessment Tool (CSNAT) that is applicable to use in all parts of palliative home care. It

includes psychological, physical, social, spiritual and more aspects. This supportive intervention tool is used to evoke caregivers concerns in a systematic way when caring for their loved one. Caregivers fill out a format and the results will indicate in which domain they need more support. It also encompasses support that family caregivers learn how to provide care at home for the dying person. This includes understanding the diagnosis, knowing what they can expect to come, how to manage symptoms and providing medication and more. Also who they can contact when they need more support. Furthermore, if the results indicate that the caregiver needs more direct personal support in their caring role, they can receive supportive interventions on how to look after their own physical health, dealing with their emotional burdens or supporting their spiritual concerns. Depending on what sort of support they need the supportive intervention changes. Health care professional can use tools such as this to support caregivers and thoroughly go through all domains. Following then with open communication and giving support where it is needed [3].

The various supportive interventions caregivers need are as follows:

- **Information and training interventions:** Studies show that communication from health care staff to informal caregivers has a positive outcome. There is a need for enhancement in social support for palliative caregivers. There is emphasis in conducted studies that supportive interventions reduce family caregivers' psychological distress. Caregivers also feel more prepared and confident with their role and that they have more support from health care professionals. Available evidence of meta-analysis points to that home death is more possible in correlation with family caregivers ability and chances of receiving support. Skill preparedness is associated with better quality of life for caregivers and better mental health. Measures such as Preparedness for Caregiving scale can be used to detect how much skill training caregivers need [2, 5, 8, 11, 15, 17, 18].

Research shows that information or arrangement session interventions can help both the patient and caregiver benefits them simultaneously. An immense issue experienced by caregivers and patients was that the health care staff were not com-

municating effectively within themselves and with the caregiver and patient. Patients and caregivers often needed to talk about the illness and situation with someone, which was not offered. More communication needs to be implemented for both patient and caregiver to effective services and interventions [1, 15, 17, 18].

- **Psychological interventions:** Both psychoeducational and emotional support have reported to have a more positive caregiving experience and better quality of life with less burden. It is identified that there is a need for better support for caregivers through already existing evidence-based interventions [2, 5, 8, 15, 18]. Psychoeducational skill training and intervention methods are found to have effect on improving the caregivers coping, overall better quality of life and reducing their burdens [17]. Psycho-educational interventions such as Cognitive Behavioral therapy have presented caregivers burdens becoming less and better quality of life for the caregiver and patient symptom management easier [3, 5, 18]. Coping strategies documented in reviewed literature included maintaining hope, taking one day at a time, maintaining control and keeping a positive outlook on the situation [11].
- **Support group interventions:** Family caregivers often rely on family members and friends for support, following health care personnel and hospital staff. Sharing their feelings help caregivers deal with the stress they might experience. Supporting the caregivers emotionally by having support telephone lines 24/7, to share their pain and discuss any difficulties experienced has shown to benefit them. Informal caregivers being aware of hospice services that can assist them, is considered to be a great support for them. Support groups indicate that given the familiarity of the same group offers support and reassurance to the caregivers participating [8].

There are several forms of support groups. A support group can exist of several participant that meet once in a while. It can also be one-on-one with a professional worker and it can also be sessions for the entire family among others [8, 11, 15]. Weekly support sessions with debriefings have shown to be productive. To clarify and assist in navigating health systems, information support sessions with

the staff showed to be productive. Some informal caregivers required more emotional support than others. Not only do the informal caregivers find support within the group participants but also information packages were perceived helpful. The information packages could contain information regarding hospice services and other community services available to informal caregivers. This helps to raise awareness of services and also what can be expected when being an informal caregiver [8, 15]. Group interventions are different depending on how often they meet and for how long. In the sessions the participants share their concerns and difficulties. Not only do they receive support from the professional health care worker but also from each other. The open environment benefits emotional support and a sense of belonging and normality. It also helps the caregiver prepare for their role and ease their anxiety, stress and depressive symptoms [15].

Research demonstrates that group education programmes for caregivers, preparing them for their roles is effective, available and suitable. It is highly recommended that palliative caregiver families receive this form of support, as it is viewed as a valuable and effective strategy to support them and give them information. Also giving them a Caregiving Guidebook prepares them for their caregiving role. It should provide information, how to think positively, coping and relaxation strategies that can be used both during a support group programme and at home. Research shows that caregivers felt that group education programmes provided them with the opportunity of having their anxiety, unmet needs and experienced normalized, confirmed and supported. The time spent with professionals was valuable to caregivers [5, 8, 15].

- **Religion and Spirituality:** Informal caregivers experience significant changes in their lives on several fronts concerning their daily activities, social life and more. Research shows that religiousness and spirituality provide informal caregivers with the strength to cope their stress and suffering associated with caring for their loved one. Spirituality and religion represent one of the most used strategies to help both informal caregivers' and the patient to cope as best as possible with the situation at

hand. A study conducted shows that participants considered spirituality, religiousness and other issues as a source of strength and was a coping strategy for them. The results emphasize that having a higher being was comforting for the informal caregivers and made them feel at peace with the situation and themselves. Study also shows that both informal caregivers and patient's spirituality or religiousness increased as their loved one became more ill. Not only does it help them to cope, it is also significant when dealing with depression, burden, social well-being, mental health and life satisfaction to name but a few [4, 9, 12].

Studies show that religion and spirituality is a well-used coping strategy for caregivers in palliative care. It is used to ease their pain and deal with their loved ones illness and end of life. It can offer a sense of security and hope. Both religious and spiritual well-being is correlated with greater overall psychological, social and physical well-being and not to mention caregivers expressed that religion/ spirituality was associated with them having a better and healthier relationship with the dying person. It gave them the strength to keep going, a sense of comfort and provided meaning to their situation [4, 9, 11, 12]. Nevertheless, it is very important for health care professionals to be aware of cultural differences and recognize the multi-dimension of religion and spirituality depending on how it is operationalized and how the family caregiver feel about it [4, 9, 12].

- **Physical and respite intervention:** Research has shown that physical interventions with methods such as yoga as an exercise or long walks has marked reduction in caregiver's stress levels. This leading them to feel more relaxed and a general sense of well-being [15]. Caregivers felt satisfied when receiving respite care and it gives them opportunity to rest and also have time for themselves which leads to better quality of life and better mental health [11, 15].

6.2 NURSES ROLE IN SUPPORTING INFORMAL CAREGIVERS

In palliative care healthcare professionals are involved differently depending on the patient and family caregivers needs and wishes. Nurses play an essential role in supporting both the patient and the family caregiver. Not only do they care for the dying person, they educate and support the caregiver in several forms. It is good to bear in mind that the caregiver is not only helping the dying person to prepare for their death but also themselves to for the death of their relative [8, 15].

Nurse's role in supporting caregivers include the following aspects;

- **Communication:** Studies showed that navigating healthcare systems can be difficult. Therefore, communication between nurses and informal caregivers is truly important. Family caregivers often rely on family members and friends for support following health care personnel and hospital staff. Sharing their feelings helps them deal with the stress and anxiety they might experience [8, 15]. Communication is an extremely sensible issue for informal caregivers. Research indicates that there is often a lack of it. For caregivers to receive support, communication with health care personnel needs to be available to them. Thus, nurses should coordinate the care for the patient with the informal caregiver and also be available to them at any time. Studies have shown that informal caregivers experience more stress due to lack of communication. Medication changes that the family caregiver did not know of increased their stress, thus the communication needs to be open and the information should be available and shared with the family caregivers at all-time [8, 11, 17].

Nurses should always inform the informal caregiver and family of any medical changes and gives more information, as study shows caregivers often lack this and feel left outside of the caring process. Thus, leading to more stress and worry. Is it essential for nurses to have an open dialogue with the family and information going both ways. Informal caregivers perceived needs has shown in studies conducted that they also need more information about what to do at the time of death [1, 15].

Nurses and health care workers need to listen to the caregiver and try to answer their questions as good as possible. Rapport also shows that nurses need to communicate more with themselves. Caregivers often felt they weren't answered and that health care workers often answered differently, indicating poor communication [1, 15]. Communication is one of the most frequent unmet needs. Open communication with nurses and other health care workers is essential and regular talks with both nurses and doctors is needed [1].

- **Emotional support:** Supporting the caregivers emotionally by having support telephone lines 24/7, to share their pain and discuss any difficulties experienced has been appraised. Caregivers being aware of hospice services that can assist them, is considered to be a great support for them [8, 15]. It is very important for nurses to enhance existing coping strategies during their limited time with family caregivers. The main aspect of supporting caregiver emotionally listening to them and giving them time [5, 11, 8].

Caregivers also needed more support in receiving information as mentioned above. Family caregiver often lacked emotional support from nurses, which can be provided by taking the time to communicate more with them. Of course all family caregivers are different and require different support, therefore it is essential for nurses to make a care plan with the family to know what support they need [2, 17].

- **Religion and spirituality:** Both caregivers and patients often put on a "brave face" not to upset others, thus their spirituality or religiousness needs were not recognized. It's essential for nurses to ask the patient and family about they believe, as to know how to help them or how they might receive help [1].
- **Educating and informing caregivers:** Caregivers often feel unprepared and that they need more support from health care personnel. Research indicates that managing symptoms is a proceeded a difficulty for informal caregivers, therefore it is of necessity for nurses to educate them on how to manage symptoms and administer

pain relief medication. This whilst understanding the seriousness and ethical concern related to giving and managing medication. Depending on what disease the dying person has it is necessary for the nurse involved to explain what symptoms there might be. Also explaining the side effects of some medications for example opiates [2, 11, 15].

Numerous reviews have conducted that what is essential in helping family caregivers is actively being part of the care. Studies show that nurses who provide care for the dying person at home with a positive attitude and providing a holistic patient care, who give clear and timely information regarding the patient's condition and care, medication and management whilst recognizing the family carer's important role. Studies have shown that caregivers feel that a good holistic care from health care workers helps them to maintain a normal life and feel less burden. This leads to reduced feelings of isolation [2, 15]. Research shows that some caregivers needed respite from their caregiving role by having palliative home care services to help them. Caregivers also wanted more help with everyday functioning such as mobility [1, 11, 17].

A study has shown that one in four caregivers wanted more professional attention concerning providing care and their competence for it. More than half of caregivers wanted more information during the caring process, this included information about alternative medicine, caring process and euthanasia. Furthermore, the study shows that informal caregivers wanted more information, financial assistance, advice and respite care from formal services. They also wished that formal services such as home care would offer more respite and some wished that they would offer the patient activities to help both the patient and caregiver [15]. Caregivers and patients wanted more information about the disease and the progression of it and how to manage with symptoms. Caregivers often required more information about what to do when the patient passes away. A critical point was that carers expressed that they wanted all the information in writing, since it's hard to remember everything [1, 15].

Caregiver often want support and more information regarding what to monitor and how to interpret symptoms when giving medication. Learning this they feel more confident about when they need to contact professionals. This is essential support for family caregivers. Studies has also found that family caregivers need support in practical assistance, how to manage at home. With relief meaning to ease the burden by family member having more time for themselves when formal caregivers can assist in the care [2, 17].

Nurses can offer supportive interventions in different ways, such as providing counselling, spiritual care, personal care and respite. In cases where nurses don't have resources to provide any of the mentioned supports it's preferable to contact those who can, for example social worker or psychological nurse [3].

7 DISCUSSION

The Finding of the research confirm that caregivers indeed have numerous challenges. They face great deal of responsibilities which impacts not only their physical well-being but more importantly their mental health. All the finding however, cannot be identified as grounded, comprehensive understandings of the informal caregiver's experience, as several studies were guided by researches targeting particular aspects of caregiving.

Family caregivers have shown to have increased level of anxiety, stress and depression. Caregivers often suffer from sleep deprivation and social isolation that in turn lead to high psychological distress. When caring for a loved one, caregivers often forget to take care of themselves in terms of not eating healthy and on time, forgetting their doctors' appointments and not resting enough. This has an impact on their overall psychological well-being and quality of life (Stajduhar et al., 2013; Ventura et al.,2014; MacLeod et al., 2011).

Research indicates that informal caregivers need to be supported in different ways. Palliative caregiving needn't undoubtedly be stressful. Depending on how the caregivers' personal coping resources are, it varies what form of support and how much support they need. This includes preparedness for the caregiving role, capabilities, having information and being able to focus on positive aspects of being a caregiver. Therefore, strategies that aim to these domains are intended to be included in supportive interventions that has positive psychological outcomes (Ventura et al.,2014; Hudson et al., 2008; MacLeod et al., 2011; Hebert et al., 2007).

Caregivers have mentioned the need for support and counsellor which is a suggestion that there is a reception of relief and psychological ease from confiding in someone (Ventura et al.,2014). Psychoeducational interventions which involved family caregivers attending group education programme has shown to demonstrate increased level of preparedness which in turn lowered their anxiety levels (Hudson et al., 2008).

Supportive interventions is also reassuring since the nurse can show their support for the family caregiver. Meaning the caregiver wouldn't feel alone and the interventions made the family caregivers' role more manageable and easier. Evidence shows that interventions can help caregivers

with appraising the stress factors they experience with their caregiving role and view them not as threatening. Interventions targeting several stressors of caregiving are more likely to achieve greater effect than interventions that are narrow focused. It is also evident however, that these interventions aren't always attainable for caregivers to participate in due to lack of time and support. Therefore, it is suggested that one on one sessions with caregivers in their home can be more suitable for them. Caregivers are also ambivalent sometimes regarding receiving support and usually put the dying persons' needs before themselves. It can be difficult to target caregivers' needs, therefore it is suitable to have several options of supportive interventions and communicate more regarding what the family caregivers need (Aoun et al.,2013; Hudson et al., 2008; MacLeod et al., 2011).

Herbert et al. (2007) suggest nursing intervention as a method to help caregivers assess the stressors that influence them and less threatening. There are different studies presented in the article about interventions and how they may help caregivers. There are group interventions and interventions within a family or just with a nurse. With these interventions, the caregiver or caregivers discuss different matters they find difficult or need assistance in and the group or the nurse might offer guidance.

Nurses play an essential role in palliative care where the focus mostly lies on the patient. However, caregivers also need support from nurses to able to handle their caregiving role better and be well prepared. Caregivers often lack communication with health care professionals, therefore communication enhancement is required between caregivers and health care professionals. It has been found that caregivers lack preparedness and understanding in their caregiving role and wish to have more information and knowledge regarding disease and the progression of it. Furthermore, how to manage symptoms, giving medication and how to handle the overall caring aspect of palliative care. Therefore, the need for nurses' supportive intervention is apparent (Ventura et al., 2014; Hudson et al., 2008; MacLeod et al., 2011).

7.1 Relating findings to the theoretical framework

The theoretical viewpoint used in the study presents understanding into the psychological aspect of caregiving role and how caregivers cope through creation of cognitive appraisals. The positive correlation between the mental health of caregivers and the support available show the importance of the transactional framework of caregiver stress and coping, which affirms that intervention may increase positive perception in caregivers hence shielding them against negative psychological effect of caregiving role. It is reported that family caregivers that attended psychoeducational group program show encouraging improvement in terms of preparedness, competence and emotional status, thus supporting the transactional model of coping in which caregivers evaluate their available coping resources (Hudson et al., 2008).

Caregivers display emotional distress as seen in the findings. According to Lazarus and Folkman (1987) emotions depend hugely on the cognitive appraisal of the relationship of an individual and the environment and the available coping mechanism. These emotions do not arise from an environmental demand or a situation but rather how the event is construed or understood by caregivers as either a harm or benefit.

Appraisals do play an important role in caregiver's mental well-being. Caregivers are faced with a great demand which they need to overcome. In doing so caregivers appraise the situation by assessing the nature of the demand as to whether it pose a threat to their well-being or not and whether they possess sufficient resources to cope with the demand. Often time caregivers feel unable to cope with caregiving demands and as a result they are manifested in their emotion and behavioural reactions thus affecting their well- being. Given the significance of appraisals in caregiver's well-being, it can be used in interventions and caregiver support. It was founded that caregivers who appraise their loved one's suffering as inevitable and felt powerless to do anything to alleviate it were more stressed whereas those who felt otherwise experienced less stress. Thus

showing that the view that pain is controllable positively paralleled with the caregiver's psychological well-being. Therefore, intervention can be designed to help caregivers appraise their caregiving stressors as less threatening (Hebert et al., 2007).

8 CONCLUSION

Caregivers face complex emotional challenges and high level of responsibility. Psychological distress was an emerging theme in the study, seeing how palliative care affects mental well-being of caregivers. Therefore, caregivers' need of support is evident. Depending on caregivers' personal coping resources, the form of needed support from health care professionals varies. There are various supportive intervention available for health care professionals to implicate. Due to lack of resources and time caregivers often don't receive the supportive interventions necessary for their mental well-being. Furthermore, caregivers lack the information on how to access these available interventions. It has been noted that there is a correlation between the caregivers' mental well-being and reception of support. Caregivers show a great deal of improvement when receiving support from health care professionals.

8.1 STRENGTHS, LIMITATIONS AND RECOMMENDATIONS

Strengths of qualitative research is that it helps in understanding diversities and individual variations. Mostly the studies reviewed in this study provided general summaries of most frequent themes. A vast amount of scientific articles, from different data bases were used to have diversity in cultural geographical aspects and different settings for caregiving. Two writers enabled integrating two perspectives, supporting each other in remaining objective and being able to cover much in short period of time through sharing the workload. Not to mention being thorough.

This study faced several limitations. Firstly, some useful scientific articles were not accessible or could not be found from Arcada database, which might have been relevant to the study. Secondly, it was expected to be easier to find more articles focusing on informal caregivers psychological difficulties, which was not the case. It was also challenging to find scientific articles about supportive interventions in palliative care from nursing perspective.

Finally, it is recommended that future studies could focus on the psychological difficulties experienced by caregivers within different cultures and how mental wellbeing in palliative care is affected within cultural, social and economic contexts. Future studies could also focus on the nurses' intervention in palliative caregivers' mental well-being. Also why caregivers feel unprepared for their role.

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