

Caregiving Stress and Health of Family Caregivers: A Literature Review

Zahra 'a Hassan Saimaldaher¹, Dr.Ohood Othman Felemban².

Master Student of Medical Surgical Nursing Faculty of Nursing King Abdulaziz University

Vice Dean of Nursing College Assistant Professor in Community and Primary Health Nursing Faculty of Nursing King Abdulaziz University

Corresponding Author: Zahra 'a Hassan Saimaldaher.

Date of Submission: 24-03-2019

Date of acceptance: 08-04-2019

I. Introduction

This literature review provides a background of previous research related to the impact of caregiving stress on the health of family caregivers of adult patients with cancer. The review covers the following topics: cancer epidemiology, caregivers of patients with cancer, caregiving stress, and the effects of caregiving stress on mental and physical health.

Data search strategy: The search strategy adopted was designed to retrieve published studies related to family caregivers of adult patients with cancer, caregiving stress, and the impact of caregiving stress on mental and physical health. Searches were conducted using the following electronic databases: CINAHL, MEDLINE, PUBMED, and PsycINFO. The following keywords were used in combination: 'caregiving stress', 'family caregivers', 'mental health', 'physical health', and 'adult patients with cancer'. This search was limited to English-language publications and included studies over a 5-year period from 2013 to 2018. Studies that focused on caregiving stress, the mental and physical health of nurses and other formal caregivers, and family caregivers of paediatric patients with cancer were excluded from the search.

Cancer Epidemiology: The Kingdom of Saudi Arabia, which is the largest country in the Middle East, derives its official name from the first king, Abdul Aziz al-Saud. Saudi Arabia is an Islamic country, and the constitution governing law in Saudi Arabia is the Holy Qur'an and the Sunnah (Ismail, Lai, Ayub, Ahmad, & Da Wan, 2016). Saudi Arabia's population is 31,540,000 and 10,690,000 are under 18 years old (Wazqar, Kerr, Regan, & Orchard, 2017). Oil was discovered in Saudi Arabia in 1936 and 25% of the world's current oil reserve is located in Saudi Arabia, which has become a current international leader in the oil industry. Saudi Arabia is one of the fastest growing economies in the world and the strongest Arab economy. It has achieved notable success in developing its economy by initiating the first stage of improvements through the development of transportation, which was followed by the second phase, consisting of improvements in education, health, and social services (Ismail et al., 2016).

Over the last 30 years, Saudi Arabia has made extensive progress in its socioeconomic development, and the government has used its vast resources to improve medical care. In a ranking of the world's healthcare systems by the World Health Organization (WHO), Saudi Arabia earned the 26th position (Chen, 2017). Healthcare in Saudi Arabia has improved dramatically over the past three decades and consists of three major sectors: the Ministry of Health (MOH), the private sector, and other government sectors. The major government provider of healthcare services is the MOH, which covers 60.2% of all healthcare services in the country, with a total of 268 hospitals (38,970 beds) (Aljuaid, Mannan, Chaudhry, Rawaf, & Majeed, 2016). The MOH in Saudi Arabia provides primary, secondary and tertiary levels of care. Primary care centres provide health-promotion, disease-prevention, and curative services. Patients requiring more advanced care are transferred to secondary-care facilities (general hospitals), and patients requiring more complex levels of care are referred to tertiary-care facilities (centres or hospitals providing specialised care) (Mohamed, Sami, Alotaibi, Alfarag, Almutairi, & Alanzi, 2015). The private sector provides 22.1% of all healthcare services in Saudi Arabia, with 136 hospitals (14,310 beds). The third sector, which includes other government agencies, covers 17.7% of the country's total healthcare services and operates 39 hospitals (11,497 beds). These facilities (e.g. the King Faisal Specialist Hospital and Research Centre) provide services for defined groups, usually employees and their dependents, such as medical personnel in the security and armed forces, and employees of the National Guard Health Affairs, ARAMCO hospitals, the Royal Commission for Jubail and Yanbu Health Services, the Red Crescent Society, and the Ministry of Education Hospitals (university hospitals). The university hospitals include

King Abdul-aziz University Hospital in the western region of Saudi Arabia, King Fahd University Hospital in the eastern region, and King Khalid University Hospital in the central region (Aljuaid et al., 2016).

The rates of some diseases, such as type 2 diabetes, hypertension, arthritis, hypercholesterolemia, and cancer have increased significantly in recent years among the Saudi population (Wazqar et al., 2017). Based on these increases, the Saudi government has developed healthcare services targeted for each of the diseases. For example, the Al-Wazarat Healthcare Center, located in Riyadh, Saudi Arabia provides services for most chronic diseases, such as diabetes (Al Harbi, Tourkmani, Al-Khashan, Mishriky, Al Qahtani & Bakhiet, 2015). More than 15 facilities provide oncology care, including the Oncology Center at King Faisal Specialist Hospital (Wazqar et al., 2017), the King Abdullah Medical City Holy Capital (Alsirafy, Raheem, Al-Zahrani, Mohammed, Sherisher, -Kashif, & Ghanem, 2016), and the King Khalid National Guard Hospital (Shaheen Al Ahwal, Al Zaben, Khalifa, Sehlo, Ahmad, & Koenig, 2015). Some centres have been established through donations, including the Abdul Lateef Charitable Screening Center in Riyadh (Abulhair, Al Tahan, Young, Musaad, & Jazieh, 2010), the Colorectal Cancer Chair at King Abdul-aziz University (Shaheen Al Ahwal et al, 2015), and the Sheikh Mohammed Hussein Al-Amoudi Breast Cancer Centre of Excellence at King Abdul-aziz University in Jeddah (Al-Zaben, Sehlo & Koenig., 2015).

Cancer is a 'disease process that begins when an abnormal cell is transformed by the genetic mutation of the cellular DNA'. When the immune system fails to destroy abnormal cells, they grow too large to be controlled by normal immune mechanisms (Brunner, 2010, p.337). Cancer is the second leading cause of death after heart disease (Chen, 2017). In 2012, the estimated number of new cancer cases was approximately 14.1 million, and cancer deaths reached 8.2 million worldwide (Torre, Siegel, Ward & Jamal, 2016). In 2015, there were 17.5 million cancer cases globally and 8.7 million deaths. Cancer cases have increased by 33%, with aging of the population contributing 16%, population growth contributing 13%, and changes in age-specific rates contributing 4% (Fitzmaurice, Allen, Barber, Barregard, Bhutta, Brenner & Fleming, 2017). In 2018, the International Agency for Research on Cancer published cancer incidence and mortality rates with a focus on cancer's geographic variability across 20 regions worldwide. An estimated 18.1 million new cancer cases (17.0 million, excluding non-melanoma skin cancers) and 9.6 million cancer deaths (9.5 million excluding non-melanoma skin cancers) are expected. Lung cancer is the most commonly diagnosed cancer (11.6% of all cases) among females and males combined, and it is the leading cause of cancer deaths (18.4% of all cancer deaths), followed by female breast cancer (11.6%), prostate cancer (7.1%), and colorectal cancer (6.1%) (for incidence), and colorectal cancer (9.2%), stomach cancer (8.2%), and liver cancer (8.2%) (for mortality). Breast cancer is the most commonly diagnosed cancer and the leading cause of cancer deaths among females, followed by colorectal and lung cancer (for incidence), and vice versa (for mortality). Cervical cancer ranks fourth for both incidence and mortality. Lung cancer is the most frequently diagnosed cancer among males, and the leading cause of cancer deaths, followed by prostate and colorectal cancer (for incidence), and liver and stomach cancer (for mortality) (Bray, Ferlay, Soerjomataram, Siegel, Torre, & Jemal, 2018).

In addition to an increase in the aging population and the growth of the total population, the adoption of certain lifestyles and high-risk behaviours have led to increases in cancer-related morbidity and mortality rates in low- and middle-income countries (Goren, Gilloteau, Lees & da Costa Di Bonaventura, 2014). The causes of cancer include gene mutations, hormone homeostatic dysregulation, chemical carcinogens, radiation, and epigenetic abnormalities (Chen, 2017). Several risk factors for cancer, including smoking, alcohol consumption, low physical activity, and unhealthy food have been identified by the WHO Global Status Report. Widespread use of tobacco in low- and middle-income countries will exert major cancer-related effects on these countries in the coming decades. In relation to diet, obesity, and physical inactivity, more people are currently overweight than are underweight worldwide. Obesity is one of the risk factors for breast (post-menopausal), endometrium, pancreatic, oesophageal, colorectal, and renal cancers. Consumption of processed foods and red meat and a low-fibre diet have been reported to be associated with colorectal cancer. Low physical activity is a major risk factor for colon, breast, and endometrial cancers. Alcohol consumption is a leading risk factor for liver, upper respiratory, digestive tract, colorectal, and breast cancer. Other risk factors for cancer are occupational and environmental carcinogens; exposure to asbestos, aromatic amines, benzene, and other carcinogens has been found to lead to some cancers (e.g. bladder cancer due to exposure to aromatic amines). Air pollution, aflatoxin, arsenic, and radon are examples of environmental carcinogens. Another environmental and risk factor for skin cancer is excessive exposure to sunlight (Vineis, & Wild, 2014). After nutritional factors and smoking (tobacco), infectious disease is the third leading cause of cancer worldwide (De Flora & La Maestra, 2015). Infectious agents also are responsible for many types of cancers, such as the hepatitis B and C viruses, the human papillomaviruses (HPV), and helicobacter pylori, which causes a large proportion of liver, cervical, and stomach cancers. Liver and gastric cancers account for more than 80% of cancers in men and cervical cancer accounts for approximately half of the burden of infection-related cancers in women. Approximately 30% of infection-attributable cancers occur in individuals younger than 50 years of age (Vineis, & Wild, 2014).

The International Agency for Research on Cancer (IARC) has reported that by 2030 the incidence of cancer cases is expected to increase by more than 75% globally. The burden of cancer will continue to increase worldwide as the figure reaches 22 million new cases annually over the next two decades (IARC, 2014). Bray (2016) reported that by 2030, 2.3 million Americans in the USA will be diagnosed with cancer annually, and most of them will live longer than five years after the diagnosis (Hendrix, Bailey, Steinhauser, Olsen, Stechuchak, Lowman & Tulsky, 2016). In France, cancer remains the leading cause of overall mortality and is responsible for 29.6% of all deaths (Belgacem, Auclair, Fedor, Brugnon, Blanquet, Tournilhac & Gerbaud, 2013). In Indonesia, the incidence of cancer has reached 240,000 persons annually. Studies have reported that two out of three patients are diagnosed with advanced stage cancer when they visit the hospital for treatment (Effendy, Vernooij, Dassen, Setiyarini, Kristanti, Tejawinata, Vissers, & Engels, 2015). The number of deaths is expected to increase over the next two decades by 70%, of which 60% will be in developing areas, where 70% of all cancer deaths now occur (Burnette, Duci & Dhembu, 2016). Currently, cancer causes one in three early deaths from non-infectious diseases worldwide (Bray, 2015).

In Saudi Arabia, cancer is expected to increase 5- to 10-fold by 2030 (Alshammary, Abdullah, Duraisamy & Anbar, 2014). Most patients with cancer have an advanced stage of the disease and at a younger age. In 2016, the Saudi Cancer Registry reported the total numbers of patients in the country with cancer of Saudi and non-Saudi nationality were 11,645 (77.6%) and 3,356 (25.4%), respectively, in 2013. Cancer cases were more widespread among women (8,294, 53%) than among men (7,359, 47%). The overall age-standardised incidence rate for all Saudis, using a world standard population reference, was 79.1/100,000 cases in males and 89.4/100,000 cases in females (Wazqar, Kerr, Regan & Orchard., 2017). In 2012, the Saudi Cancer Registry reported the total number of cancer cases was 14,336, with 7,545 (52.6%) cases among females and 6,791 (47.5%) cases among males. Saudi patients comprised 11,034 cases (76.9%) of the total number. Among Saudi females, the overall age-standardised rate (ASR) (incidence) for all cancer sites was 86.7 per 100,000, and for males, it was 78.1 per 100,000. The incidence differed by region, with Riyadh and the Eastern region showing the highest ASRs for both females and males and Jazan and Hail showing the lowest ASRs. Incidence varied by gender, with breast (25.8%), thyroid (11.7%), and colorectal cancers (9.3%) being the most common types of cancer among females, and colorectal cancer (13.3%), non-Hodgkin's lymphoma (8.4%), and leukaemia (8.2%) being the most common cancers among males (Bazarbashi, Al Eid, & Minguet, 2017).

Cancer is usually a long-term disease; therefore, as the number of cancer cases and survivors increase, more support from family members, supervisors, and care providers for cancer patients will be needed to assist them on their treatment journeys. This demand will increase the caregiving burden on the patient's family, including their level of stress. High stress levels will most likely have a negative effect on the family's physical and mental health. Therefore, it is important to understand the effects of caregiving stress on the physical and mental health of family caregivers of patients with cancer. Caregivers and caregiving stress are discussed in detail in the next section.

Caregivers and caregiving stress

Cancer is a chronic disease associated with constant, substantial, and unpredictable needs of patients and their caregivers (Rha et al., 2015). The term caregiver refers to 'anyone who routinely helps others who are limited by chronic conditions' (Amankwaa, 2017, p.92). A family caregiver is 'any relative, partner, friend, or neighbour who has a significant personal relationship with patients' (Sherman & McMillan, 2015, p.1). Illness is 'a highly personal state in which a person's physical, emotional, intellectual, social, developmental, or spiritual functioning is diminished'. Illness affects both patients and families and changes both of them; these changes depend on the severity, duration, and nature of the illness, and the financial needs and changes in usual responsibilities. The patient may experience emotional and behavioural changes, including: changes in body image, low self-esteem, disturbances in self-concept, and lifestyle changes. The patient might become irritable and tired or experience fear, anger, weakness, anxiety, depression, denial, and a desire to withdraw from others (Kozier, Erb, Berman, Snyder, 2012, p.311). One family member's illness can change an entire family, for example, role changes of members, reassignments of tasks, and anxiety about illness outcomes, which can lead to increased stress, conflict over unfamiliar responsibilities, financial problems, changes in social customs, and separation and pending loss leading to feelings of loneliness (Kozier et al., 2012, p.312).

A diagnosis of cancer especially affects the individual who provides care for the patient. Most patients with cancer depend on their families to provide care and assist them with their activities of daily living (Sherman & McMillan, 2015). Hence, a family caregiver is an individual who provides unpaid care for a patient, and might be an adult, child, spouse, parent, friend, or neighbour (Kent, Rowland, Northouse, Litzelman, Chou, Shelburne, & Huss, 2016). The most common relationship of the caregiver to the care receiver is an adult child who cares for an elderly parent, followed by a spouse, who is most often an elderly wife or husband (Deshields, Rihanek, Potter, Zhang, Kuhrik, Kuhrik & O'Neill, 2012).

When a person is diagnosed with cancer, their relatives, family members, and friends, frequently assume new responsibilities as caregivers by providing a broad range of voluntary assistance (Kessler, Moss, Eckhardt, Laudenslager, Kilbourn, Mauss, & Kutner, 2014). In the USA, cancer is considered a family issue, as family members provide more than half of the caregiving. The estimated number of people caring for a family member with cancer at home is 4.6 million (Mosher, Adams, Helft, O'Neil, Shahda, Rattray, & Champion, 2016). Moreover, the thirteen million patients diagnosed with cancer also have advanced stage disease, which requires the assistance of family caregivers (Dionne-Odom, Azuero, Lyons, Hull, Tosteson, & Hegel, 2015). Family caregivers also play an important role in the care of patients with cancer in Arab society. The family unit in Arab cultures places a high value on the expectation of family members to care for one another and maintain strong relationships. For Arabs, being cared for by family members is one way to maintain confidentiality and avoid the stigma related to having a cancer diagnosis (Alanzeh, Levesque, Kwok, & Everett, 2016).

The role of the family caregiver begins immediately at diagnosis and continues throughout the patient's illness journey. The need for information related to the patient's disease and treatment options varies according to the stage of the patient's illness (Effendy et al., 2015). The family caregiver is important during hospitalisation; this person provides uncompensated care and health-related assistance to the family member who has cancer. When cancer is untreatable because it is in an advanced stage, the physical and emotional demands of the family caregiver increase (Effendy et al. 2015). Most hospitals in Arab countries allow one caregiver to accompany the patient during the hospitalisation period to provide support, perform daily tasks, and assist hospital staff in providing care (e.g. help the nurse to transfer the patient from the bed to a wheelchair, use the toilet, or bathe or feed the patient) (Al-Zahrani, Bashihab, Ahmed, Alkhodair, & Al-Khateeb, 2015). Caring for patients with cancer is routinely limited to the hospital setting, but it continues outside the hospital when patients are discharged to their homes and the burden of care for advanced cancer shifts from the health professionals to the patients and their family caregivers (Kershaw, Ellis, Yoon, Schafenacker, Katapodi & Northouse, 2015).

Most family caregivers are not professional practitioners in the healthcare field; however, they assist relatives who are diagnosed with cancer in coping with physical, emotional, medical, and social challenges, and they communicate with professional caregivers and coordinate care (Kulkarni, Ghooi, Bhatwadekar, Thatte, & Anavkar, 2014). Family caregivers assume responsibility for many aspects of cancer care, usually without preparation or training on how to deal with cancer cases, and with limited resources (Rha et al., 2015). Moreover, family caregivers provide a broad range of assistance for these individuals, including practical assistance, symptom management, housekeeping, transportation (Sherman & McMillan, 2015), supervision, spiritual and emotional support, individualised care, assistance with activities of daily living, communication, and coordination of care management with clinicians (Dionne-Odom et al., 2015). Family caregivers assist adult patients with cancer with essential tasks, such as preparing meals, bathing, dressing, shopping, and medication administration (Amankwaa, 2017).

Care for patients with cancer may take precedence over normal family activities. Therefore, family caregivers have to reschedule tasks that they regularly perform, such as activities related to their own household, professional job, or care for others who depend on them, such as their children (Effendy et al., 2015). For example, in the USA, an estimated 65.7 million people serve as family caregivers, providing care for a relative diagnosed with cancer that is often combined with other work or family tasks (Sherman & McMillan, 2015). The responsibilities and roles of these caregivers are difficult, requiring them to rearrange their schedules to fulfil other responsibilities and commitments, which leave them fatigued and at risk for health problems. It is apparent that caring for patients with cancer is burdensome and a source of fatigue, which affects the health of caregivers (Hu, Kung, Rummans, Clark, & Lapid, 2015).

As mentioned above, caregivers usually help patients by providing emotional support, assisting with physical care, managing medications, scheduling appointments, and/or providing financial support. Therefore, they must have the intellectual ability and physical strength to oversee multiple care processes. Unfortunately, caregivers often lose track of their own needs, putting themselves at risk for increased workloads and possible psychosocial impairment (Kessler et al., 2014). These caregivers may experience psychological suffering that is equivalent to, and sometimes surpasses that of the patient with cancer (Dionne-Odom et al., 2015). The effort involved in caring may lead to caregiver burden (Belgacem et al., 2013), which is considered a 'multi-dimensional biophysical reaction resulting from an imbalance of care demands relative to a caregiver's personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other roles they fulfil' (Lukhmana, Bhasin, Chhabra, & Bhatia, 2015, p.146). The humanistic burden of cancer care is well documented; family caregivers provide serious instrumental and emotional support for patients with cancer throughout the duration of the disease (Goren et al., 2014).

Family caregivers of patients with cancer, who provide free long-term voluntary care, are increasingly responsible for supporting patients (Goren et al., 2014). Family caregivers often accompany these adult patients to all diagnostic and treatment-related activities during hospitalisation, and they may feel guilty about

leaving a family member during these times. This feeling may have a similar impact on the mental and physical health of both patients and family caregivers (Belgacem et al., 2013). Family caregivers provide care that is typically uncompensated, involves significant amounts of time and energy for months or years, and requires the performance of tasks that may be physically, emotionally, socially, and/or financially demanding (Kent et al., 2016). A study was conducted by Yabroff and Kim (2009) of 600 caregivers of patients with cancer from 2003 to 2006 to estimate the time spent providing informal caregiving during the 2-year period after the patient's diagnosis. That study found the average amount of time spent providing care was 8.3 hours per day, with 25% of caregivers providing care for more than 16 hours per day. Approximately 74% of caregivers live with their loved ones and provide an average of 20 hours of care every week (Sherman & McMillan, 2015).

Living with cancer causes distress for caregivers and patients; patients suffer from the illness burden as their caregivers strive to ease their suffering while continuing their work, despite the stress of having a relative with a life-threatening disease (Hendrix et al., 2016). Patients' families are usually distressed after receiving a diagnosis of cancer for one of their members, and they become overwhelmed with coordinating care for their family member (Belgacem et al., 2013). The evidence shows that providing family care affects several dimensions of a person's life: reduced quality of life (QOL), increased morbidity and mortality, psychological distress, and other sources of stress, such as lost time and productivity (Goren et al., 2014). Lack of preparedness and confidence in delivering complex care that is needed by the patient may increase a caregiver's distress. The term stress describes a 'state of physiologic and behavioural responses to a stressor with the brain being the critical interpreter of what is stressful' (Oken, Chamine & Wakeland, 2015, p.148). Lazarus and Folkman (1984) define stress as a 'transactional process between the person and the environment, whereby the individual appraises the environmental demands as outweighing his or her ability to meet those demands' (Gloria & Steinhardt, 2016, p.145). According to Lazarus and Folkman (1984) and Pearlin et al. (1990), stress occurs when family caregivers face a specific circumstance that is determined to be demanding beyond their resources, thereby increasing their risk for physical and mental health problems. Therefore, caregiving stress is 'the extent to which a caregiver [feels] overwhelmed by the duty of caring and responsibilities for a disabled or chronically ill individual' (Kim, Carver, Shaffer, Gansler, & Cannady, 2015, p.304).

Caregiving responsibilities can lead to high levels of distress in family caregivers of patients with advanced cancer (Rumpold, Schur, Amering, Kirchheiner, Masel, Watzke & Schrank, 2016). A considerable amount of distress is experienced by family caregivers related to their efforts to provide care for patients with cancer (Rha et al., 2015). Family caregivers are distressed by several acute health conditions experienced by the patient, such as chemotherapy, radiation therapy (e.g. managing patients' symptoms of fatigue or emesis), and surgery.

Patients' well-being is also closely linked with caregivers' well-being, particularly as the performance status of patients and their QOL decline over time and caregiver distress restricts the provision of optimal care (Sherman, & McMillan, 2015). The days and weeks following a hospital discharge is the most stressful time for caregivers (Hendrix et al., 2016). Patients with advanced cancer and their family caregivers experience greater disruptions in their daily lives and poorer mental and physical health (Kershaw et al., 2015). The responsibilities associated with caring for a patient with cancer entail major life changes, which have been identified as stressors resulting in a strain on the family as well as a burden (Kim et al., 2015). A stressor is 'an environmental event that significantly perturbs the entire human dynamical system away from the optimal attractor resulting in a state of lower utility' (Oken, Chamine & Wakeland, 2015, p.147). Family caregivers frequently face a range of stressors, including disrupted routines, family role changes, financial and occupational strain, and their own physical and mental health problems. The stress of caregiving may be the result of an unmet need for caregiver training, inadequate social or economic resources, or difficulty managing several roles (Mosher et al., 2016). Family caregivers face concurrent and continuous challenges aside from caring for the patient; they also have to fulfil their work commitments and family responsibilities, and perform household duties (Govina, Kotronoulas, Mystakidou, Katsaragakis, Vlachou, & Patiraki, 2015). Patients and their families encounter stressful situations, and the stress of such situations has been reported to have substantial negative effects on family caregivers (La, & Yun, 2016). These effects included **feeling helpless** when they did not know how to take care of the patient or they could not protect the patient from suffering. Some caregivers expressed feelings of helplessness when they were unable to help patients suffer from side effects of treatments. Another negative effect was **feeling overwhelmed** by the work of caregiving; after three months, caregivers were exhausted physically and emotionally. The caregivers reported that their lives became more restricted and their living routines changed because of the expansion of their caregiving role, accompanied by additional caregiving tasks both outside and inside the home. Many caregivers also reported **feeling inadequate** because the information they received about cancer and its treatment from healthcare providers was inadequate. Without training and knowledge, caregivers felt they could not provide appropriate or adequate care for patients. Caregivers also reported **feelings of uncertainty about the future**, which they initially experienced while waiting for confirmation of a cancer diagnosis, and these feelings continued throughout the patient's course of illness and

life. The caregivers found this very stressful, as they did not know how to deal with the situation. Nevertheless, they also reported several positive effects of their caregiving experiences: (1) **developing closer relationships with spouses and relatives**, which brought meaning to their lives and strengthened their family relationships; (2) **receiving support from family and friends**, which included alternating time spent with patients and receiving help with daily tasks, which allowed caregivers to continue their normal activities, such as caring for their children and returning to work; and (3) **having 'God watching me'**, because, for some caregivers, religion was their foundation for psychological and spiritual strength. They had faith in their religious beliefs and they applied 'God watching' to their present lives, as well as to the afterlife. Having faith helped caregivers regulate their emotions (LeSeure & Chongkham-Ang, 2015).

As mentioned previously, advanced cancer has psychological, physical, and social significance for patients and for all persons close to them, especially those who assume responsibility as the family caregiver on a long-term basis. Family caregivers give up past activities and may be forced to make changes in their own lives when they assume new roles and responsibilities (Govina et al., 2015). Family caregivers have been reported to experience high levels of emotional stress, physical strain, and financial need. The increasing effects of social, economic, emotional, and physical stressors on family caregivers often result in physical problems, worsening of co-morbid conditions, and increasing the risk of their own mortality. The stress increases as the time draws closer to the patient's forthcoming death (Sherman, & McMillan, 2015). The emotional physical, financial, and social stress that caregivers face in this role may result in neglect of their personal needs, and therefore, increase their exposure to infection and physical illness (Govina et al., 2015). The impact of caregiving stress on the mental and physical health of family caregivers is discussed in greater detail in the next section.

Impact of caregiving stress on mental health

The support of family caregivers is essential for patients with advanced cancer during the course of treatment (Mosher et al., 2016). Cancer is a feared diagnosis and life-threatening illness, and is therefore, a cause of great distress in patients. High levels of emotional distress for prolonged periods in patients with cancer may lead to depression, anxiety, or both. This mixed symptomatology is very common; two thirds of patients with cancer who have depression also have clinically significant levels of anxiety. Depression leads to a poorer QOL and compromises patient outcomes, and the mortality rate of cancer increases with depression (Smith, 2015). As mentioned above, patients with cancer depend on their caregivers for assistance with most of their activities of daily living, such as transportation to medical appointments, treatments, financial and emotional support, and assistance with personal care and symptom management (Nissen, Trevino, Lange, & Prigerson, 2016). The role of caregivers is difficult and challenging, which increases caregivers' risk for developing mental health problems (Mosher et al., 2016). An investigation of the impact of caregiving on caregivers' mental health found that family caregivers for patients with advanced cancer were at high risk for depression, poor QOL, heightened social isolation, and sleep impairment (Nissen et al., 2016). Studies have also found that caregivers feel a great emotional burden, a common characteristic of patients with cancer and their families, which impairs their psychological stability and increases their psychological stress (La, & Yun, 2016). Long-term monitoring of patients with cancer increases caregivers' burden and the risk for decline in their mental health (Burnette et al., 2016).

Caring for patients with chronic diseases, such as cancer, requires considerable time, effort, and emotional expenditure, which can be highly stressful and burdensome for caregivers; thus, most of them are likely to have significant levels of anxiety and depression (Almutairi, Alodhayani, Alonazi, & Vinluan, 2017). A comparison of family caregivers with non-caregivers of the same age showed family caregivers had higher levels of depression and stress and fewer personal interests than non-caregivers (Mosher et al., 2016). A study by Goren, Gilloteau, Lees, and DiBonaventura (2014), which was conducted in five European countries (France, Germany, Italy, Spain, and the United Kingdom) with adult populations, compared caregivers of patients with cancer and non-caregivers. They found that the caregivers had significantly greater impairment on all health outcomes (mainly mental health) than the non-caregivers. The incidence rates of psychological distress, depression, and anxiety among caregivers is often higher than that of the general population, and in some cases, the rates exceed those reported by the patients (Lambert, D., Levesque, J. V., & Girgis, 2016). Family caregivers of patients with cancer experience higher rates of caregiver burden and stress than the general population (Harvey-Knowles, Sanders, Ko, Manusov, & Yi, 2017).

Family caregivers are also at high risk for psychiatric morbidities, specifically anxiety and depression (Burnette et al., 2016). The most common mental health problems experienced by caregivers for patients with cancer are psychological distress, depression, and/or anxiety; 40.1% report anxiety (range = 25.4–55.9%) and 26% report depression (range = 18.4–35.0%) (Lambert, 2016). Negative outcomes of psychological distress include elevated risks for clinical depression, complex grief, sickness, and occupational, social, and job-related impairments, which can negatively affect caregivers' quality of care (Burnette et al., 2016). A cross-sectional, multi-institutional study conducted by Rumpold et al. (2016) screened 345 caregivers of patients with advanced

cancer for psychiatric disorders, such as depression and anxiety, and found that 52% of the participants had one or more of the suspected psychiatric disorders, with anxiety being the most prevalent. Approximately 50% of family caregivers of patients with cancer report significant depressive symptoms or anxiety, and these symptoms frequently persist during the initial months and years after the diagnosis of cancer (Mosher et al., 2016). Hence, it is important for family caregivers of adult patients with cancer to care for their own mental health. Aside from the psychological issues discussed here, family caregivers also experience physical health problems related to caregiving stress, which is described in the next section.

Impact of caregiving stress on physical health

Physical wellness is characterised by 'the ability to carry out daily tasks, achieve physical fitness, maintain adequate nutrition and proper body fat, avoid abusing drugs and alcohol and using tobacco, and generally practice positive lifestyle habits' (Kozier et al., 2012, p.305). The relationship between physical and psychological health has been well documented. Psychological (emotional) factors influencing health include self-concept and mind-body interactions. The mind-body interaction can affect health status negatively or positively. Emotional responses to stress affect bodily functions, and long-term emotional distress may lower a person's defences against organic diseases or cause them to occur suddenly. Emotional distress may affect the immune system through the central nervous system, and endocrine alterations in the immune system are associated with the occurrence of autoimmune diseases, infections, and cancer (Kozier et al., 2012, p.305).

The worldwide tendency to provide care at home for patients with advanced cancer places a considerable burden on family caregivers due to increases in their responsibilities for providing physical care, as well as emotional and financial support (Rumpold et al., 2016). The physical functioning of patients with advanced cancer declines at the same time their family caregivers' physical health declines, which might affect patients' health negatively and lead to physical impairments of family caregivers, and subsequently affect patients' health adversely (Kershaw et al., 2015). A large epidemiological study using a Swedish cancer registry reported that caregivers are at high risk for poor physical health. The study confirmed that spouses of patients with cancer, compared with unaffected spouses, were more likely to experience poor cardiovascular health, including stroke (26% increase), and have an increased risk for coronary heart disease (13% increase) 20 years after their spouses were diagnosed with cancer. Spousal caregivers were more likely to have chronic back pain and arthritis, and many stressed caregivers were more likely to have heart disease years after beginning their caregiving experience (Kim et al., 2015).

The stress associated with caregiving can have other negative effects on the physical health of caregivers, including increased heart rate and blood pressure, and it can affect the functioning of the immune system, and increase the mortality rate. Caregiving for patients with cancer also has physiological effects, including skeletal injury, muscle strain, aggravation of some chronic illnesses, physical discomfort and pain (Amankwaa, 2017), sleep deficits, lack of personal care, and fatigue (Almutairi et al, 2017). Chronic physical illnesses that are common among caregivers include heart disease, hypertension, arthritis, high cholesterol, and chronic back pain, with the most caregivers reporting more than one chronic illness. Stress increases the risk of health problems and leads to neurologic diseases, such as epilepsy, Parkinson's disease, and multiple sclerosis (Oken et al., 2015). A study by Ji et al., (2012) found spouses of patients with cancer had a higher risk for stroke and coronary heart disease after their spouse was diagnosed, compared to those without a spouse with cancer. A review by Stenberg et al., (2010) reported that caregivers' main physical health problems included loss of appetite, weight loss, and loss of physical strength. Dhruva et al., (2012) found that approximately 40–60% of caregivers experienced disturbances of sleep with a similar proportion reporting moderate levels of fatigue, which may lead to multiple health problems.

Gaps in the literature

This study is important because the number of cancer cases is increasing, and so, there is a greater need for complex care by hospital staff and family members, which is likely to continue until the patient's death. After the patient's discharge from the hospital, family members are solely responsible for providing care for the patient. Furthermore, the current health policy reflects the new trend in decreased healthcare costs by shifting care to outpatient clinics to integrate the informal care system of patients with cancer. Given the shortage of oncology and home care services in Saudi Arabia, the burden of the responsibility for the family caregivers of patients with cancer has increased. Most family caregivers suffer from high levels of stress that sometimes exceeds the level of stress experienced by the patients themselves, which has a negative impact on the mental and physical health of the family caregiver. Until now, research investigating the impact of stress on family caregivers of patients with cancer has been limited worldwide, and consequently, evidence-based knowledge of this topic is lacking. Research studies on stress related to family caregiving and its impact on the physical and mental health of family caregivers in Saudi Arabia are scarce. The present study will assess both the physical and

mental health of family caregivers of adult patients with cancer and investigate the relationship between caregiving stress and the health of family caregivers of these patients.

II. Summary

This literature review described the impact of caregiving stress on family caregivers of adult patients with cancer, and how caregivers' emotional and physical health are affected by their caregiving responsibilities. Caregiving stress negatively affects caregivers' health and leads to mental health problems, including anxiety, depression, emotional burden, poor QOL, social isolation, and impaired sleep. Physical health problems experienced by family caregivers include heart disease, hypertension, arthritis, high cholesterol, fatigue, and chronic back pain, loss of appetite, weight loss, and loss of physical strength. This literature review presented findings of studies on the stress of caregiving that affects family caregivers' QOL. The researcher discussed evidence from various studies on the roles of family caregivers, their emotional, physical, and general health, and possible factors leading to stress.

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Zahra 'a Hassan Saimaldaher.. "Caregiving Stress and Health of Family Caregivers: A Literature Review." *IOSR Journal of Nursing and Health Science (IOSR-JNHS)*, vol. 8, no.02 , 2019, pp. 17-25.