

**Sociodemographic Factors and Quality of Life (QoL) Among Family Caregivers of
Cancer Patients in Saudi Arabia**

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Master of Arts in Nursing

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Abstract

The current trend in cancer treatment involves inpatient hospital care and continuity of care in a home care setting; thus, the family caregiver plays an essential role in implementing the patient's treatment plan. The family caregiver provides support such as disease monitoring, management of signs and symptoms, pain management, home medication administration, emotional support, and personal assistance. These complex responsibilities of the family caregiver put them under stress that may affect their quality of life (QoL).

The findings of this study revealed that most family caregivers of cancer patients in Saudi Arabia have moderate QoL (55.71 %), while the rest have poor QoL (31.43%) or good QoL (12.86%). Results also showed that burden has low quality of life score and positive adaptation results in a higher quality of life score. Furthermore, male family caregivers have a more impaired quality of life than female family caregivers. Likewise, family caregivers of male patients and patients with metastatic cancer have poorer quality of life.

Several studies on the quality of life of family caregivers of cancer patients were conducted worldwide, but there is limited data and scarce literature that evaluates it in Saudi Arabian context. Thus, the results of this study may serve as baseline data in identifying the quality of life of family caregivers of cancer patients in Saudi Arabia and its relationship with sociodemographic factors. Moreover, the result may serve as a source for developing programs to improve the quality of life of family caregivers.

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Chapter I

INTRODUCTION

Background of the Research Problem

Quality of life (QoL) defines a person's highest mental, physical, role, and social functioning, including relationships and perceptions of health, fitness, life satisfaction, and well-being (Theofilou, 2012). Caregiving affects the quality of life of family caregivers due to the fear of losing their loved one, the impact of caring on their career stability and financial status, and the restrictions on their social life. Reports have identified that family caregivers experience health issues, domestic problems, psychological distress, depression, anxiety, and sleeping disorders. Moreover, caregiving changes their lifestyle, roles, relationships, and overall well-being. With the continuous provision of care and support, family caregivers tend to neglect their health and self-care needs. The patient's diagnosis of cancer challenges the family caregiver physically, emotionally, mentally, and socially. Thus, the quality of life of family caregivers is critical to consider because it will affect the quality of care received by the patient. Likewise, it is essential to identify the factors that influence the quality of life to prevent its decline (Maziyya, Rahayuwati, & Yamin, 2018; Turkoglu & Kihe, Mirsoleymani, Rohani, Matbouei, Nasiri, & Vasli, 2017; Maziyya et al., 2018; Turkoglu & Kihe, 2012; Tamayo, Broxton, Munsell, & Cohen, 2010; Uzar-Ozcetin & Dursun, 2020; Weitzner M.A., 1999).

Family caregiver (FC) is an unpaid informal caregiver who provides care for a sick relative or loved one (Guerriere, Zagorski, & Coyte, 2010). Reports show that family caregivers deliver 70-90% of care to patients with chronic conditions in the community and are considered essential partners in managing long-term diseases such as cancer.

The recent trends in cancer care involve not only inpatient treatment but also outpatient and home care settings; thus, the family caregiver is an essential element in the implementation of the patient's treatment plan. From the time of the patient's cancer diagnosis to the beginning of treatment and progression of the disease until end-of-life care, the family caregiver is involved throughout the caring process. The family caregiver assumes various responsibilities in providing support, such as disease monitoring, management of signs and symptoms, pain management, home medication administration, emotional support, and personal and economic assistance. Amid the cancer diagnosis, the family caregivers are suddenly confronted with the caregiving role with little or no training and limited resources. The responsibility of dealing with the physical demands of caregiving and providing emotional support for the patient while managing their health and self-care needs are among the family caregiver's demanding tasks. These complex responsibilities of the family caregiver put them to stress and burdens that may affect their quality of life (Maziyya et al., 2018; Turkoglu & Kihe, 2012; S.Y. Rha, Y. Park, S.K. Song, C.E. Lee, J. Lee, 2015, Uzar-Ozcetin & Dursun, 2020; Mazanec, Blackburne, & Daly, 2021; Parmar, Anderson, Abbasi, Ahmadinejad, Chan, Charles, Dobbs, Khera, Stickney-Lee, Tian, & Jain, 2021; Karabulutlu, E. 2014; Weitzner M.A., 1999).

Research shows that despite efforts of healthcare professionals to provide patient and family-centered care, the support needed by the family caregivers remains unmet. The unmet support needs identified by works of literature include social needs (e.g., financial aid), cognitive needs (e.g., support in decision-making and managing concerns about the disease), and psychological needs (e.g., support in mourning and addressing

fears) (Bijnsdorp et al., 2020). In the literature review of Maziyya, Rahayuwate, and Yamin (2018), it was reported that family caregivers of cancer patients have decreased quality of life, experienced burden with care, and suffered depression and psychological distress. These studies were conducted in Korea, Japan, China, Sweden, Greece, Italy, the United States of America, Canada, Colombia, and Taiwan. Results showed that most family caregivers are female (more than 60%) and have relationships as a patient's spouse and/or parents. Moreover, it was also identified that most caregivers were over 50 years. The literature review also recognized that the factors that influence the quality of life of family caregivers include the patient's age and condition; the family caregiver's relationship with the patient, age, sex, level of education, religiousness, income status, care period, changes in social life, emotional distress, caregiving burden and lack of social support and level of satisfaction with care. Subsequently, these factors are subdivided into the patient, family caregiver, and environmental factors.

Numerous studies on the quality of life of family caregivers of cancer patients were conducted worldwide, but there is limited data and scarce literature that evaluates it in Saudi Arabian context. In Saudi Arabia, the culture is primarily influenced by the Islamic religion, which reflects in the lives of the people in the Kingdom. According to Saudi culture, the family is held responsible for protecting and providing care to the patient. Moreover, the Saudi family has a significant role in patient treatment decisions (Wazqar, Kerr, Orchard & Regan, 2017). Thus, this research identified the quality of life of family caregivers in a different social and demographic setting specific to the Islamic and Arabic culture in Saudi Arabia as compared to the previous findings.

King Fahad Medical City (KFMC) is one of the most specialized and highly developed healthcare facilities in Saudi Arabia. Its comprehensive cancer center is one of the leading referral centers for hematology and oncology patients in the Kingdom. The center provides an array of cancer care services which includes intensive care units, consultation services, routine screening, cancer therapy, radiation therapy, rehabilitation, palliative care, supportive care (social services, dietary, occupational and physical therapy, wound care, patient and family education, and spiritual care), and home care programs. Its home care programs focus on patient and family-centered care to help the patient restore or regain lost functional abilities, ensure patient safety, and maintain their optimum health. Family caregivers are also taught about the disease process and treatment modalities such as chemotherapy, radiation therapy, and surgical treatments. Moreover, family caregivers are provided with a teaching process to improve their skills in providing safe and effective health care at home.

Although the pillars of care are centered toward person-centered care, the patient remains the focus of care, and family caregivers are not the center of priority. Caring for a sick relative is related to filial responsibility, and though it may give a sense of fulfillment, it can be overwhelming for the family caregiver. The diagnosis of cancer is sudden and places the family caregiver in a responsibility where they are unprepared and have no knowledge about it. Moreover, their commitment becomes bigger in providing care at home, especially in dealing with the symptoms and effects of the disease and treatment, such as pain, vomiting, fatiguability, anorexia, and others. With the responsibility of caring for the sick family, their own interest may be placed on hold, and their focus remains on the patient's needs.

Despite the support given to patients and family caregivers in the Kingdom, there is no active research related to the quality of life of family caregivers. Moreover, family caregivers are not evaluated on the quality of their life and the related sociodemographic factors. Family caregivers are increasingly taking responsibility for providing cancer care in the home care setting; thus, the broader impact of caregiving on their quality of life needs to be evaluated. In 1999, Dr. Weitzner developed the Caregiver quality of life index-Cancer (CQOLC), which assesses the family caregiver's physical, emotional, family, and social functioning. It measures the quality of life of family caregivers in four subscales: burden, disruptiveness, positive adaptation, and financial concerns. The CQOL-C has proven its reliability and validity, and it is one of the most utilized instruments to evaluate the quality of life of family caregivers of cancer patients across the world.

The incidence and prevalence of cancer in Saudi Arabia are rapidly increasing and are expected to double by 2030. With the increasing rate of patients diagnosed with cancer, the number of families living with and caring for a patient with cancer also arises. Thus, the general purpose of this study was to evaluate the sociodemographic factors and the quality of life among family caregivers of cancer patients in Saudi Arabia. Specifically, it aimed to identify the impact of caregiving on the quality of life of family caregivers of cancer patients in terms of burden, disruptiveness, positive adaptation, and financial difficulties. Furthermore, it sought to evaluate the patient and family caregiver sociodemographic profiles related to the quality of life of family caregivers of cancer patients. The result of the study may serve as baseline data in developing programs to improve the quality of life of family caregivers, foster their resilience, empower their role

as informal caregivers in the homecare setting and improve the efficiency of care received by the patients.

Statement of the Problem

1. What are the sociodemographic profiles of the family caregivers of cancer patients in Saudi Arabia in terms of:
 - a. Age?
 - b. Sex?
 - c. Level of education?
 - d. Employment status?
 - e. Marital status?
 - f. Relationship to the patient?
 - g. Financial status?
 - h. Duration of care?
2. What are the sociodemographic profiles of cancer patients in Saudi Arabia in terms of:
 - a. Age?
 - b. Sex?
 - c. Type of cancer?
 - d. Presence of metastasis?
 - e. Duration of illness?
3. What is the quality of life of family caregivers of cancer patients in Saudi Arabia in terms of:

- a. Burden?
 - b. Disruptiveness?
 - c. Positive adaptation?
 - d. Financial difficulties?
 - e. Total CQOLC (includes the above four aspects and general components)?
 - f. Four categories—good, moderate, poor, or very poor QoL?
4. What is the relationship of the patient sociodemographic factors with the quality of life of family caregivers of cancer patients in Saudi Arabia?
 5. What is the relationship of the family caregiver sociodemographic factors with the quality of life of family caregivers of cancer patients in Saudi Arabia?

Objectives

The study aimed to evaluate the relationship between the sociodemographic factors and the quality of life of family caregivers of cancer patients in Saudi Arabia. Specifically, it aimed to:

1. Identify the sociodemographic profiles of the family caregivers of cancer patients in Saudi Arabia in terms of:
 - a. Age
 - b. Sex
 - c. Level of education
 - d. Employment status
 - e. Marital status

- f. Relationship to patient
 - g. Financial status
 - h. Duration of care
- 2. Identify the sociodemographic profiles of cancer patients in Saudi Arabia
 - a. Age
 - b. Sex
 - c. Type of cancer
 - d. Presence of metastasis
 - e. Duration of illness
- 3. Identify the quality of life of family caregivers of cancer patients in Saudi Arabia in terms of:
 - a. Burden
 - b. Disruptiveness
 - c. Positive adaptation
 - d. Financial difficulties
 - e. Total CQOLC (includes the above four aspects and general components)
 - f. Four categories—good, moderate, poor, or very poor QoL.
- 4. Determine the relationship of the patient sociodemographic factors with the quality of life of family caregivers of cancer patients in Saudi Arabia.
- 5. Determine the relationship of the family caregiver sociodemographic factors with the quality of life of family caregivers of cancer patients in Saudi Arabia.

Significance of the Study

The diagnosis of cancer and how it is confronted affects the patient and their family caregivers. Moreover, the quality of life of family caregivers affects the quality of care for the patient and consequently affects the patient's quality of life (Turkoglu and Kilic, 2012). Hence, the healthcare team should treat the family caregivers as recipients and partners in providing care (Bijnsdorp et al., 2020). Furthermore, the nurses should be mindful of the potential factors related to family caregivers' quality of life to address their needs.

Several studies on the quality of life of family caregivers of cancer patients were conducted worldwide, but there is limited information that evaluates it in the Saudi Arabian context. Thus, the result of this study may serve as a source and baseline data in identifying the quality of life of family caregivers in Saudi Arabia. Additionally, the nurses will increase their awareness of the importance of looking into the factors that may impact the quality of life of family caregivers. The result of the research may also assist the nurses in developing a plan of care specific to the family caregivers and help them adapt to their caregiving roles both in the inpatient and outpatient setup. Moreover, the study will facilitate the development of programs, training, and educational resources for family caregivers to help them adjust to their responsibilities and prevent them from being overloaded and overwhelmed.

The needs and symptoms of the cancer patient change over time, and so as the needs and well-being of the caregiver. Hence, the family caregivers should be explicitly and continuously included in routine assessment and care planning. Lastly, assessing and evaluating the quality of life of family caregivers will accentuate the nurses' role in providing person-centered care for both patients and caregivers alike (Glajchen, 2012).

Scope and Limitation

The study respondents were delimited to the family caregivers of adult cancer patients with ongoing treatment in the Comprehensive Cancer Center (CCC) of King Fahad Medical City (KFMC). The participants were of Saudi nationality, believed in the Islamic religion, and had been family caregivers for at least one month. The family caregiver was identified by the patient and family as the primary person participating in the treatment plan for the patient. The research excludes caregivers who receive compensation for their caregiving role and family caregivers of pediatric cancer patients.

The study focused on the quality of life of family caregivers of cancer patients. Moreover, the study also identified the relationship of sociodemographic factors with the quality of life of family caregivers.

The study sought to evaluate the relationship of the quality of life of family caregivers with the patient and family caregivers' sociodemographic factors but not with the environmental factors, which is considered a limitation of this research. Moreover, the study included family caregivers of cancer patients regardless of the type and stage of the disease; thus, it limits the generalizability of the results. Lastly, although the related sociodemographic factors were identified and evaluated in their relationship with the quality of life of family caregivers, other aspects of caregiving, such as the functional status of the patient, caregiver preparedness, family function, and social support that may contribute to the quality of life were not considered in this study.

Definition of terms

1. Family Caregiver (FC)- a person caring for a patient with cancer without any return or compensation; lives with the patient; manages the patient treatment plan; and provides physical and emotional care and support to the patient.
2. Quality of life (QoL)- measured as the impact of caring on the family caregiver's physical functioning, emotional functioning, family functioning, and social functioning in terms of burden, disruptiveness, positive adaptation, and financial difficulties based on the Caregiver Quality of Life Cancer scale.
3. Sociodemographic-factors- pertain to the patient or family caregiver's social demographic profiles that may influence the quality of life of the family caregiver
4. Age- number of years from the date of birth to the present year
5. Sex- identity as male or female
6. Type of cancer- nature of the disease or primary organ inflicted with cancer
7. Presence of metastasis- refers to the spread of cancer to other parts of the body outside the primary diseased organ
8. Duration of illness- the period from the time of diagnosis of cancer to the present time
9. Level of education- highest educational attainment achieved by the family caregiver
10. Marital status- identifies whether the family caregiver is single, married, widow/widower, or divorced.
11. Relationship with the patient- defines how the family caregiver is related to the patient

12. Financial status- determines whether the current state of financial position meets the demand of economic needs

13. Duration of care- period identified from the time of starting to provide care for the cancer patient to the present time

Chapter II

REVIEW OF RELATED LITERATURE

The literature relating to the quality of life and family caregiver of a cancer patient or terminally ill patient was identified through electronic databases, including searching through PubMed, Science Direct, Google Scholar, Saudi Digital Library, EBSCO, and ProQuest. Key phrases and similar phrases were utilized in the subject search to maximize the amount of relevant literature. Initially, to collect the articles, the descriptors "quality of life," "family caregiver," "cancer patient," and "terminally ill patient" were used. Next, the intersections between terms were performed using the word AND; later, three and four descriptors were utilized. Articles written in English focused on family caregivers' quality of life were included; non-English articles were excluded.

Cancer and Cancer Care in the Kingdom of Saudi Arabia

Cancer is a leading global cause of morbidity and mortality, accounting for almost ten million deaths in 2020 (WHO, 2021). In Saudi Arabia, the incidence and prevalence of cancer are rapidly increasing and are expected to double by 2030. According to the 2016 Saudi Cancer Registry (SCR) report, 16,869 new cancer cases were registered, and it is projected to increase to around 40,000 by 2030 and may result in approximately 19,000 cancer deaths. The increase in incidence in Saudi Arabia (KSA) is attributed to the rise in life expectancy and lifestyle changes influenced by globalization, modernization, and economic and population growth. Like any other country around the world, the health-related behaviors of Saudis that have contributed to the increase in

incidence include increased use of tobacco, decreased physical activity, high sugar consumption, and unhealthy diets (Wazqar, Kerr, Orchard & Regan, 2017).

Specialized cancer care facilities in KSA are located in the urban areas where 80% of the Saudi population live—Jeddah, Riyadh, and Dammam. These specialized hospitals offer an array of services such as intensive cancer care management units, consultation services, routine screening, cancer therapy, rehabilitation, home healthcare programs, outpatient clinics, and supportive care services (diet center, physical therapy, patient education, pharmacy, and both institutional units of palliative care with translation and religious authorities to attend the spiritual needs of the terminally ill patients) including home-based care. Home-based care services in the KSA include cancer care programs that promote, restore, and maintain a person's optimum level of health, comfort, and function, including end-of-life care and towards a peaceful death.

According to a literature review, patients with cancer in KSA emerge in a more advanced stage and at a younger age than in Western Countries. Although advanced treatment and skilled hematologists and oncologists are available in KSA, many Saudis will only seek consultation when the cancer is in its advanced stage—when cancer has metastasized or spread to other sites of the body, such as the liver, lungs, bones, brain, or others. Furthermore, the delay of treatment and difficulty in managing patients' care plan decisions is influenced by Saudi culture, which includes the family's requests for non-disclosure of cancer diagnosis and prognosis to their family member who is sick with cancer.

In Saudi Arabia, the culture is primarily influenced by the Islamic religion, which reflects in the lives of the people in the Kingdom. According to Saudi culture, the family is

held responsible for protecting and providing care to the patient. Moreover, the Saudi family has a significant role in patients' treatment decisions. The Islamic belief of family members precedes them in assuming the responsibility of caring for their relatives in need by helping them live as comfortably as possible. They believe the patient should be withheld with the truth about their condition because it may lead to more harm and suffering. Thus, some family members of Saudi patients withheld the diagnosis and prognosis of cancer and proceeded with treatment without the patient consent because they believed that by doing so, they were protecting the patient (Wazqar, Kerr, Orchard & Regan, 2017).

Family Caregiver's Quality of life

Cancer is a chronic and life-threatening illness that needs long-term care. The diagnosis of cancer and how it is confronted affects not only the patient but also their family caregivers.

Family caregiver (FC) refers to an unpaid informal caregiver who provides care and assistance to a relative or friend with a chronic or disabling condition for a significant amount of time and often without previous training (Jablonski, Garcia-Torres, Zielinska, Bulat, & Brandys, 2020). As a person who lives closely with the patient, the family caregiver assumes the responsibility of providing care and support for the patient. With the increasing rate of patients diagnosed with cancer, the number of families living with and caring for a patient with cancer also arises. Family caregivers provide 70-90% of care to patients with chronic conditions in the community and are considered essential partners in managing long-term diseases. The recent trends in cancer care involve not only inpatient treatment but also outpatient and home care settings; thus, the family caregiver

is a significant element in the implementation of the patient's treatment plan. From the time of the patient's cancer diagnosis to the initiation of treatment and progression of the disease until end-of-life care, the family caregiver is involved throughout the caring process. The family caregiver assumes various roles in providing care and support, such as disease monitoring, managing signs and symptoms, pain management, home medication administration, emotional support, and personal and economic assistance. The diagnosis of cancer challenges the family caregiver suddenly with the caregiving role with little or no training and limited resources. The responsibility of dealing with the physical demands of caregiving and providing emotional support for the patient while managing their health and self-care needs are among the family caregiver's complex tasks. Thus, these complex responsibilities of the family caregiver put them to stress and burdens that may affect their quality of life (Maziyya, Rahayuwati, & Yamin, 2018; Turkoglu & Kihe, 2012; S.Y. Rha, Y. Park, S.K. Song, C.E. Lee, J. Lee, 2015, Uzar-Ozcetin & Dursun, 2020; Mazanec, Blackburne, & Daly, 2021; Parmar, Anderson, Abbasi, Ahmadinejad, Chan, Charles, Dobbs, Khera, Stickney-Lee, Tian, & Jain, 2021; Karabulutlu, E., 2014).

Caregiving affects the quality of life of family caregivers due to the fear of losing their loved one, the impact of caring on their economic and financial status, and the restrictions on their social life. The process of caregiving strains the marital or family life of family caregivers as well as their career stability, job performance, and social life. Reports have also revealed that most caregivers experience health issues, domestic problems, depression, anxiety, and sleeping disorders. The caregiving role also leads to physical problems such as hypertension, impaired immune system, indigestion,

unhealthy eating habits, headache, fatigue, altered body weight, muscle pain, and altered focus and concentration. Studies have also shown that caregiving affects caregivers' psychological, emotional, functional, and even physical health, and these may lead to a decline in their quality of life. (Uzar-Ozcetin & Dursun, 2020; Mirsoleymani, Rohani, Matbouei, Nasiri, & Vasli, 2017; Maziyya et al., 2018; Turkoglu & Kihe, 2012; Sercekus, Besen, Gunusen, & Edeer, 2014; Nemati, Rassouli, Ilkhani, Baghestani, 2017).

Quality of life is a broad and complex concept that identifies the highest level of mental, physical, role, and social functioning, including relationships and perceptions of health, fitness, life satisfaction, and well-being (Theofilou, 2012). Decades of literature have identified that family caregivers of cancer patients have a low quality of life. The decline in the quality of life of family caregivers is associated with the perception that cancer is a disease that equates with the threat of death (Weitzner et al., 1999). Studies have shown that family caregivers of cancer patients have decreased quality of life in all the domains of living life—physical, psychological, social, and environmental.

Sociodemographic factors affecting the Quality of life

In the literature review by Mazziya, Rahayuwati, and Yamin (2018), the factors that affect the quality of life are subdivided into the patient, family caregiver, and environmental factors.

The patient factors affecting family caregivers' quality of life are age and the patient's condition. Studies have shown that younger patients cause a decrease in the quality of life of family caregivers due to the increased burden of care. On the other hand, the patient's condition affects family caregivers' quality of life, including a decline in the patient's function and stress. Disease-related variables correlated to the caregiver's well-

being include the stage of cancer, the extent of the patient's disability, higher personal care needs of the patient, lack of patient mobility, patient dependency in doing activities of daily living, pain, and functional impairment (Bijnsdorp, Pasman, Boot, van Hooft, van Staa & Francke, 2020; Wen, Chen, Chang, Shen, Hsieh & Tang, 2018; S.Y. Rha, Y. Park, S.K. Song, C.E. Lee, J. Lee, 2015; Glajchen, M., 2012).

The family caregiver factors influencing their quality of life include age, educational and religious level, the relationship with the patient, and emotional stress. Studies have shown that family caregivers with older age, higher education, no religious belief, and emotional distress have decreased quality of life. In the literature review by Mazziya, Rahayuwati, and Yamin (2018), it was identified that most family caregivers are female and have a relationship as a spouse and/or parents of the patient. Moreover, it was also determined that most caregivers were over 50 years.

In a study conducted in Sweden, family caregivers' age is identified as a risk factor in their quality of life. The family caregivers of older age have decreased quality of life in the physical domain while younger family caregiver has declined in the mental health domain (Sjolander, Rolander, Jarhult, Martensson, & Ahlstrom, 2012 as cited by Mazziya et al., 2018).

Meanwhile, Korean studies showed that the demographic factors that influence the quality of life of family caregivers were the patient's age and the family caregiver's education. It was identified that family caregivers of younger patients have more burdens than older patients. On the other hand, the level of education of family caregivers positively influences their quality of life. Other factors that lead to lower quality of life of family caregivers were emotional distress, lack of family support, financial problems, and

decline in the patient's functional capability (Song et al., 2011 as cited by Mazziya et al., 2018; Choi et al., 2015 as cited by Mazziya et al., 2018; Lee et al., Mazziya et al., 2018; Rha et al., 2015).

In a study conducted in China, family caregivers with a lower quality of life were those who are older, with a higher level of education, believe in no religion, experience higher emotional distress, caregivers of younger patients, and those without insurance benefits (Yu et al. and cited by Mazziya et al., 2018).

A similar study by Lim et al. (2017) in Singapore identified that male family caregivers had more impaired QoL. This may be attributed to an experienced role strain when the male caregivers are obliged to balance the responsibilities at home and work to care for the family inflicted with cancer. In most Asian cultures like Singapore, the responsibility for family caregiving falls traditionally on women, while men are expected to provide for the family.

In the study of Araki in UAE (2019), the identified demographic characteristics of family caregivers that were significantly associated with their QoL were the caregiver's age, gender, and relationship with the patient. The results of her study also recognized the patient demographic variables that are significantly associated with the QoL of family caregivers: patient's age, gender, and type of cancer. Meanwhile, in Turkey (Turkoglu and Kilic, 2012), the caregiver characteristics and characteristics of the care situation that were identified that affect the quality of life of family caregivers were being under 35, being between 36 and 50, having low income, being the spouse and parent of the patient, and the patient having their room. A similar study by Uzar-Ozcetin and Dursun (2020) in Turkey also identified that married family caregivers have higher CQOLC scores.

Burden

The perceived burden of care, lack of social support, and level of satisfaction with healthcare services comprise the environmental factors affecting family caregivers' quality of life. Caregiver burden is the strain or distressful experiences related to caring for a chronically ill family member. It is important to note that being overloaded and overwhelmed with care work is the one considered stressful and not caregiving per se. The caregiver burden exists throughout the disease, from diagnosis, survivorship, and death until the process of grief. The time between one to three months after hospitalization is the most critical period when the spouses become worried about their health (Weitzner et al., 1999). The burden of care has a negative impact on the quality of life of family caregivers, and the level of social support and monthly income influences it. In the study by Sercekus, Besen, Gunusen, and Edeer (2014), it was revealed that the family of patients with cancers do not confide in their feelings and evade conversations related to the disease because they are afraid it will make the patient sad and uncomfortable.

Studies have shown that the quality of life of family caregivers of cancer patients declines as the patient's condition and level of independence deteriorate and the disease reaches its terminal stage. The presence of metastasis implies the complex reality of end-of-life care and the patient's mortality which adds stress to family caregivers. As the patient's condition worsens, the functional level declines, and the patient becomes more dependent; thus, more time is spent by the family caregiver caring for the patient. The increase in the physical needs of the patient suggests increased physical demands of caregiving from the family caregiver, which is associated with increased burden and

emotional stress (Bijnsdorp, Pasman, Boot, van Hooft, van Staa & Francke, 2020; Wen, Chen, Chang, Shen, Hsieh & Tang, 2018; S.Y. Rha, Y. Park, S.K. Song, C.E. Lee, J. Lee, 2015; Glajchen, M., 2012, Given et al., 2002; Ugur et al., 2014, Weitzner et al., 1999, Mazziya et al., 2017).

Financial difficulties

Patients and family members struggle with the patient's condition, the course of the disease, and treatment procedures. Family caregivers feel they are not ready and do not have enough resources for the life-long challenges of the disease. Moreover, issues in the treatment plan arise due to the healthcare system, transportation, and financial difficulties. Family caregivers with inadequate economic and social resources cannot afford home care and transportation facilities to lessen the caregiving stress, and families and friends may not be around to help due to their work and family responsibilities. In the study by Nayak, George, Vidyasar & Kamath (2014), it was revealed that most family caregivers had to stop working, lost their earnings, and expressed that 'financial burden' had a negative influence on the quality of life. These factors may present additional physical strain for oncology caregivers.

Disruptiveness

Despite efforts of healthcare professionals to provide patient and family-centered care, the support needed by the family caregivers remains unmet. The unmet support needs identified by literature include social needs (e.g., financial aid), cognitive needs (e.g., support in decision-making and managing concerns about the disease), and psychological needs (e.g., help in mourning and addressing fears). The support that the family caregiver receives is relevant to their quality of life and is significant in preventing

them from being overloaded and overwhelmed with responsibility (Bijnsdorp et al., 2020; Mazziya, Rahayuwati, & Yamin, 2018).

Caregivers were confronted with the challenges such as uncertainty, distress related to witnessing the disease progression, and the everyday battle with financial issues, own time, personal health, and sleep problems. They conveyed the need to be primed for their caring role, to be perceived by professionals, to obtain clear and specific information about the patient's condition, and to be supported emotionally (Harding, Epiphaniou, Hamilton, Bridger, Robinson, George, Beynon & Higginson, 2012).

Acute and chronic pain affects a patient's physical and psychological well-being, and it is one of the typical and unwanted symptoms among cancer patients. Ugur et al. (2014) found that caregivers have difficulty dressing the patient due to pain. Family caregivers assume the responsibility of pain management at home—making decisions on what to use to relieve pain, when to give the medication, monitoring side effects, reminding the patient about the medication, maintaining records, assessing the efficacy of pain control, and noting when and how to report negative result or ineffectiveness. It was reported that caregivers deal with difficulties in pain management, patient mobilization, activities of daily living, communication with the health care team, symptom management, home medication treatment, dealing with the emotional reactions of the patients, and often feel vulnerable and useless, especially when they cannot manage the patient's pain. It was revealed in the previous study by Nayak et al. (2014) that increasing the self-confidence of family caregivers in managing cancer pain is essential to the quality of life of both the patient and the caregiver. Literature has emphasized that family

caregivers should be supported, and their needs should be addressed for better health outcomes (Given et al., 2002; Ugur et al., 2014; Harding et al., 2012).

Positive adaptation

Othman et al.'s (2018) study identified that caregivers' coping strategies are positively accepting their fate and appreciating social support. Previous research also shows that attending support groups influences the caregiving experience positively. Moreover, caregivers have identified that religion provided strong tolerance for the caregiving process and aided in mediating strain. Meanwhile, caregivers who expressed a lack of support from family, especially siblings, had much anger and resentment (Lee et al., 2016; Ulidrich et al., 2018, as cited by Uzar-Ozcetin and Dursun, 2020).

In the qualitative study by Sharif et al. (2020) about the family caregiver experiences of burden and coping while caring for people with mental disorders in Saudi Arabia, it was reported that the effective coping strategies of family caregivers were: acceptance, religiosity, and spiritual-related coping techniques. Family caregivers believe that through praying and seeking refuge from God (Allah), all the experienced hardships would be reduced. This is consistent with the study of Alrashed (2017), which reported a high spiritual level among informal caregivers in Saudi Arabia. Accordingly, their religious principles catalyze dealing with the responsibilities of an informal caregiver. Saudis believe that health, illness, and death are all from God (Allah), and God's will is above all (Wazqar et al., 2017).

Summary and integration

Cancer is a chronic and life-limiting disease that affects the patient and family caregiver.

The family caregiver is a critical element in the patient's treatment plan. As someone who lives and stays close to the patient, the family caregiver assumes the responsibility of giving support and care. The family caregiver assists the healthcare team in managing the patient's condition and dealing with the courses of the disease and treatment procedures. With the diagnosis of cancer, the family caregiver is suddenly confronted with responsibilities without preparation and training and, most often, with limited resources. The demands brought by the disease precede them to adjust to the changes in their daily routines and modify their roles and responsibilities. Moreover, it is a considerable challenge for the family caregiver to deal with the demands of the caregiving role and provide emotional support for the patient while managing their health and self-care needs. Thus, these complex caregiver responsibilities put them under stress and burden and affect their quality of life.

Decades of literature have identified family caregivers' low quality of life. Quality of life defines the highest level of mental, physical, role, and social functioning, including relationships and perceptions of health, fitness, life satisfaction, and well-being (Theofilou, 2012). The patient's diagnosis of cancer challenges the family caregiver physically, emotionally, mentally, and socially. Nonetheless, it is essential to note that being overloaded and overwhelmed with care work is the one considered stressful and not caregiving per se. Caregiving affects the quality of life of family caregivers due to the fear of losing their loved one, the impact of caring on their economic and financial status, and the restrictions on their social life.

Numerous studies on the quality of life of family caregivers of cancer patients were conducted worldwide, but there is limited data and scarce literature that evaluates it in

Saudi Arabian context. In Saudi Arabia, the culture is primarily influenced by the Islamic religion, which reflects in the lives of the people in the Kingdom. According to Saudi culture, the family is held responsible for protecting and providing care to the patient. Moreover, the Saudi family has a significant role in patient treatment decisions (Wazqar, Kerr, Orchard & Regan, 2017). Hence, this research identifies the quality of life of family caregivers in a different social and demographic setting and with religious and cultural diversity as compared to previous findings.

King Fahad Medical City is one of the most specialized and highly developed healthcare facilities in Saudi Arabia. Its comprehensive cancer center provides an array of services, including intensive care management units, consultation services, routine screening, cancer therapy, rehabilitation, palliative care, supportive care, and home-based programs. Its programs focus on patient and family-centered care, and educational support is provided to family caregivers. Despite the support given to patients and family caregivers, there is no active research related to the quality of life of family caregivers.

The quality of life of family caregivers affects the quality of care for the patient and consequently affects the patient's quality of life. Moreover, the needs and symptoms of the cancer patient change over time, and so as the needs and well-being of the caregiver. The family caregiver is considered to be a provider and recipient of care. Hence, the family caregivers should be explicitly and continuously included in routine assessment and care planning.

Family caregivers need support to cope with the demands of continuous support and care; thus, this research is significant to identify their needs and enhance their capacity to provide care. Moreover, it is vital to identify the factors influencing the quality

of life to prevent its decline. Lastly, recognizing the need of family caregivers will also promote programs to support them and empower their role as informal caregivers in the homecare setting.

Theoretical Framework

This study was based on the Neuman Systems Model of Betty Neuman. The Neuman System Model is a nursing theory that focuses on a person as a whole and their reaction to stressors. The model has four major concepts of nursing: client, environment, health, and nursing (Nursing Theories, 2012, as cited by Howard, 2012). The Neuman Systems Model views the client as an open system that responds to environmental stressors. The client system has a basic or core structure protected by lines of resistance. The usual level of health is identified as the normal line of defense protected by a flexible line of defense. Stressors are intra-, inter-, and extrapersonal in nature and arise from internal, external, and created environments. When stressors break through the flexible line of defense, the system is invaded, the lines of resistance are activated, and the system is described as moving into illness on a wellness-illness continuum. Neuman emphasizes the prevention of primary stress response and adjustment to stress through secondary and tertiary prevention. Primary prevention occurs before the stressor invades the system; secondary prevention occurs after the system has reacted to an invading stressor; tertiary prevention occurs after the system has responded to an invading stressor.

Neuman proposes that a "flexible line of defense" is mounted against stressors. When stressors are persistent, such as in a caregiver's overwhelming role, a person's "lines of resistance" are activated to prevent damage to the "central core." This is a coping

mechanism that, if ineffective, can cause signs of stress related to caregiving, such as physical fatigue and emotional exhaustion. The Neuman Systems model illustrates that the quality of life of family caregivers of cancer patients can be influenced by the patient, family caregiver, and environmental factors by damaging the "central core."

According to Neuman, the family client system includes the family caregiver and the cancer patient. The caregiving role for the cancer patient is perceived to be a significant stressor for a family caregiver, which may influence their quality of life. Based on the Betty Neuman System model, the family caregiver's environment comprises intrapersonal, interpersonal, and extrapersonal factors identified by physiological, psychological, sociocultural, developmental, and spiritual variables. Intrapersonal factors that may be considered in evaluating the quality of life of family caregivers include sociodemographic profiles of the family caregiver and the physiologic symptoms brought by caregiving roles, such as increased anxiety, rapid heart rate, or increased blood pressure. Moreover, the Islamic belief that encompasses their faith, religion, and sociocultural beliefs are also included in the intrapersonal factors. Meanwhile, interpersonal factors include the sociodemographic profiles of the patient, the family caregiver's relationship with family, friends, and co-workers, and the support they receive from society. Lastly, the family caregiver's source of income, work stability, and ability to stay and live in a comfortable environment comprise the extrapersonal factors that may influence their quality of life.

The family caregiver is at risk for decreased quality of life; thus, preventing the strain brought by the caregiving role and responsibility is essential. The primary goal is strengthening the family caregiver's flexible line of defense. Thus, our role in nursing is to

strengthen the family client system—by strengthening the family caregiver's line of defense, the patient's line of defense is strengthened. Thru the Neuman system model, this research assesses the quality of life of family caregivers and evaluates its relationship with sociodemographic factors. The result seeks to develop programs to enhance the line of defense of family caregivers. Thus, the desired outcome goals are reducing or eliminating caregiver role strain, optimal health retention, and improved quality of life for family caregivers.

Applying the Neuman System model will assist this study in exploring the conceptual perspective on the quality of life of family caregivers of cancer patients in Saudi Arabia. Furthermore, the model will illustrate the relationship between sociodemographic factors on the quality of life of family caregivers of cancer patients in Saudi Arabia.

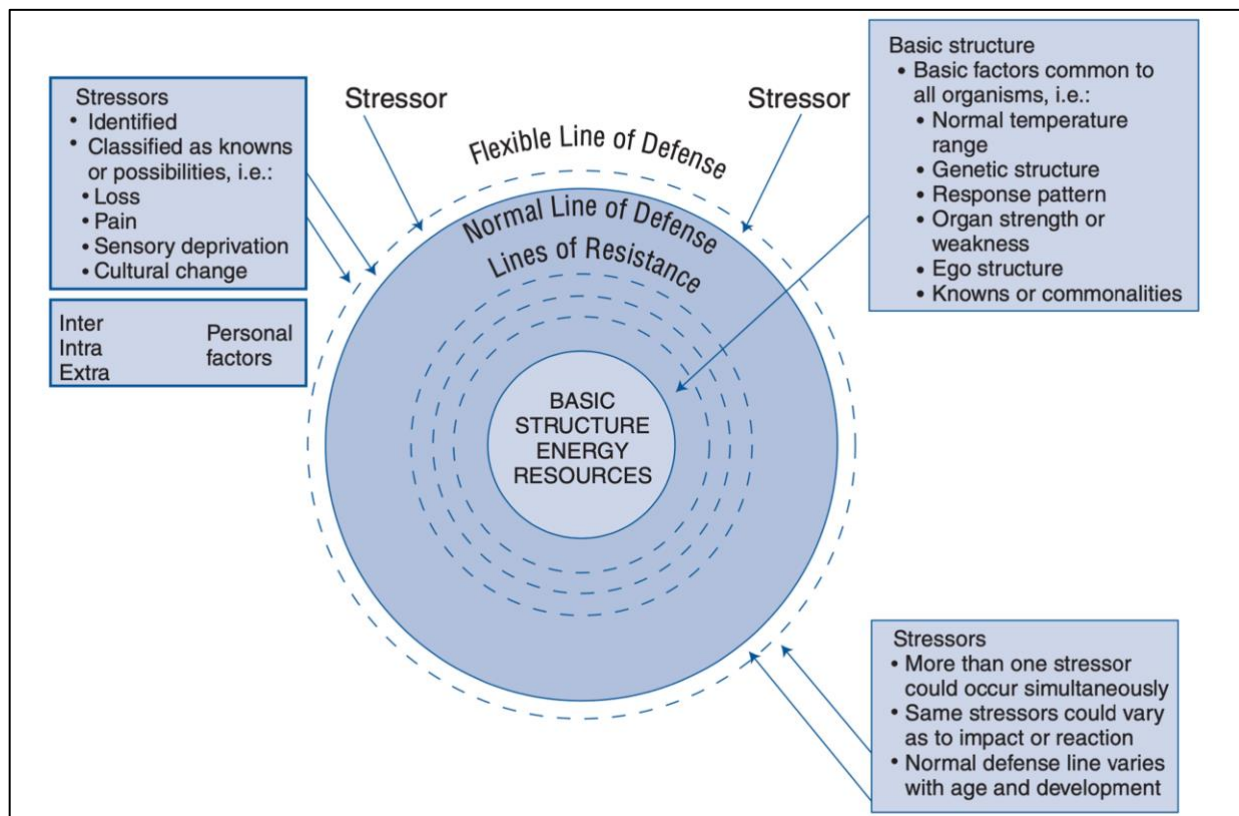


Figure 1. The Betty Neuman System

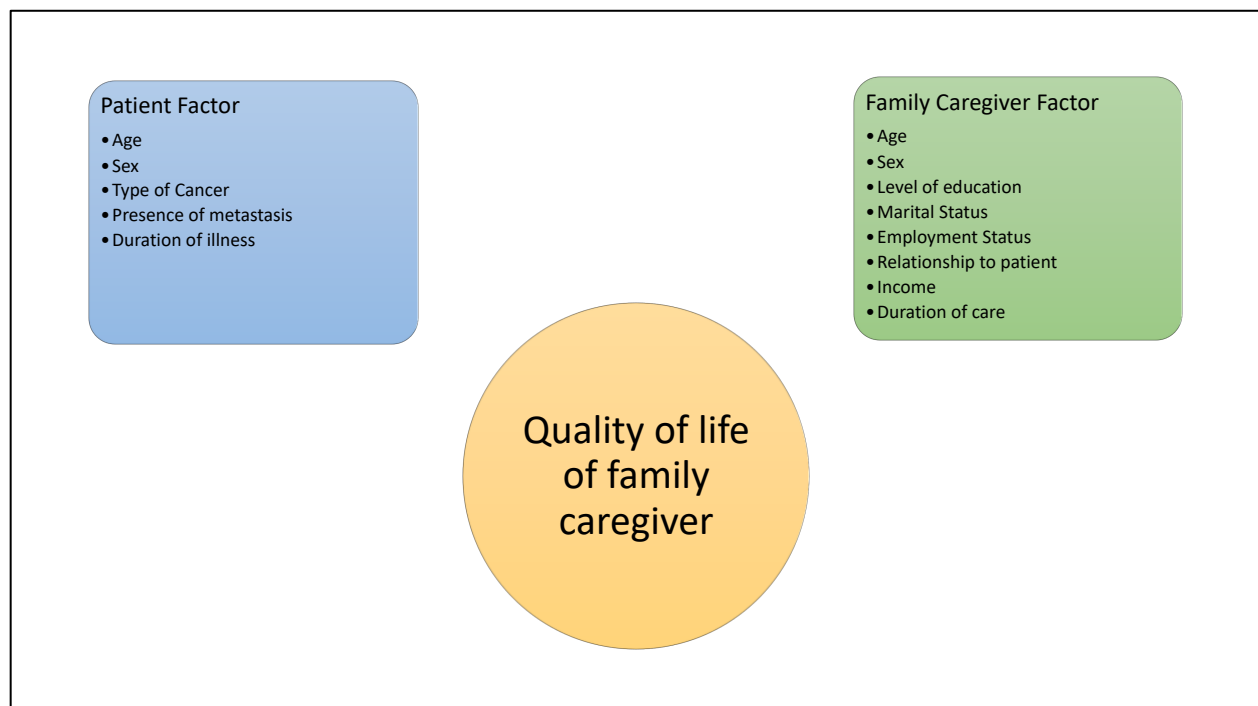


Figure 2. Application of Betty Neuman System on the Effects of Caregiver Burden on the Quality of life of family caregivers of cancer patients in Saudi Arabia

Conceptual framework

Figure 3 shows the research paradigm of the study. The study aimed to identify the relationship between the sociodemographic factors and the quality of life of family caregivers of cancer patients in Saudi Arabia. Specifically, it sought to identify the level of quality of life of family caregivers of cancer patients. Moreover, the study also determined the relationship of sociodemographic factors, subcategorized into patient and family caregiver factors, on the quality of life of family caregivers of cancer patients.



Figure 3. Paradigm of the Study

Hypotheses

1. There is no relationship between the quality of life of family caregivers of cancer patients and the patient sociodemographic factors in terms of:
 - a. Age
 - b. Sex
 - c. Type of cancer
 - d. Presence of metastasis
 - e. Duration of illness

2. There is no relationship between the quality of life of family caregivers of cancer patients and the family caregiver's sociodemographic factors in terms of:
 - a. Age
 - b. Sex
 - c. Level of education
 - d. Employment status
 - e. Marital status
 - f. Relationship to patient
 - g. Financial status
 - h. Duration of care

Chapter III

RESEARCH METHODOLOGY

Research Design

The study used the cross-sectional, descriptive correlational design to describe the relationship between sociodemographic profiles and the quality of life of family caregivers of cancer patients in Saudi Arabia. The design involves clear identification and definition of the variables involved. Moreover, the design involves forms of comparison and contrast and attempts to identify and evaluate the relationship among these variables. The method does not include manipulation and control of variables; however, it allows examination of variables in the study that already exists or is currently existing (Burns and Grove, 2011).

The proposed study aimed to evaluate the relationship between sociodemographic factors and the quality of life of family caregivers of cancer patients. In a cross-sectional design, the researcher divided the sample into various ways, such as male and female, age, level of education, marital status, employment status, relationship to the patient, and other sociodemographic factors; and performed statistical correlations. The identified dependent variable is the quality of life of the family caregiver, and the independent variables are the patient and family caregiver sociodemographic factors. This design aimed to define the quality of life of family caregivers. Moreover, it sought to identify and evaluate the relationship between the sociodemographic characteristics and the quality of life of family caregivers of cancer patients in Saudi Arabia.

Sampling design

A nonprobability sampling method, precisely the purposive sampling method, was used in the study. The randomization of the respondents was not possible in the study; thus, not every element of the population had the opportunity to be selected as a sample. In the purposive sampling method, the samples were chosen because they fit into the context of the study. Also known as “judgmental” or “selective sampling,” the investigator consciously selected specific participants included in the study. Purposeful or purposive sampling aims to pick information-rich subjects from which the researcher can get in-depth information needed for the study. All subjects who met the sample criteria were included until the desired sample size was reached. Through purposive sampling, the subjects were delimited to the eligible patients who met the inclusion criteria for the study.

The participants of the study consisted of family caregivers of cancer patients who came to King Fahad Medical City for emergency care, admission, follow-up, and treatment procedures. The family caregiver was identified by the patient and family as the primary person participating in the patient’s treatment plan. Family caregivers were invited and selected for the study based on the following inclusion and exclusion criteria:

Table 1. Subjects’ inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
• Saudi national and Muslim • Family caregiver of adult cancer patients with active treatment for inpatient and outpatient care • Aged 18 years old or above • Able to read and understand the English/Arabic language • Accompanies the patient during treatment procedures (admission, follow-up, consultation, surgical,	• Family caregiver of pediatric cancer patients • Family caregiver with chronic physical and psychological problems • A person who receives compensation for providing care

chemotherapy, or radiation therapy procedures) • Provides care to patients for at least one month and stays and lives with the patient during the caregiving process	
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The sample size was estimated based on the annual statistics record for in-patients and out-patients from January to December 2018. The number of patients treated in the out-patient and in-patient treatment unit during 2018 was 10316 and 2001, respectively. This study used Cochran's formula for the finite population to compute the sample size. The population in this study is 12317; thus, the target sample size is 373. The family caregiver sample (n=120) from a previous study in the United Arab Emirates (UAE) was used for comparison purposes.

Family caregivers who came to the hospital for their patient's treatment were approached in the emergency center, ambulatory, and inpatient care unit. A total of 175 agreed to join, and 140 samples completed the questionnaires in their complete form.

Research setting

The study was conducted in the Comprehensive Cancer Center of King Fahad Medical City (KFMC). King Fahad Medical City is one of the largest and most medically advanced hospitals in Saudi Arabia, with 1200 beds. The Comprehensive Cancer Center is considered one of the leading referral centers for hematology and oncology patients in the Kingdom. The center provides an array of services, including Radiation Oncology, Adult Hematology-Bone Marrow Transplant, Medical Oncology, Palliative Care, and Pediatric Oncology. The cancer center of KFMC comprises 120 clinical beds for

ambulatory and inpatient units. Based on the 2018 statistics, 2001 patients were admitted for in-patient care, and more than 10000 patients were treated in the outpatient treatment units. The center delivers high-quality treatment and therapies for cancer care to Saudi Arabia citizens and visitors from all over the region.

Research Instrument

A structured questionnaire checklist was utilized, considering the nature of the problems and the study's specific objectives. The structured questionnaire consisted of Part 1- Sociodemographic information and Part 2- Caregiver Quality of Life Index-Cancer (CQOL-C) instrument.

Sociodemographic information was collected via thirteen items and subdivided into patient and family caregiver factors. Patient factors include age, sex, type of cancer, metastasis presence, and illness duration. Family caregiver factors include age, sex, level of education, marital status, employment status, relationship to the patient, financial status, and duration of care.

The Caregiver Quality of Life Index-Cancer (CQOL-C) was developed by Dr. Michael Weitzner in 1999 and is commonly utilized to assess the quality of life of family caregivers of cancer patients. The instrument is multidimensional, with items that measure four conceptual domains of quality of life: physical functioning, emotional functioning, family functioning, and social functioning. It is a 35-item instrument that uses a 5-point Likert-type scale ranging from 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), and 4 (very much). It has four subscales: ten items related to burden, seven to disruptiveness, seven to positive adaptation, three to financial concerns, and eight single items to additional factors (disruption of sleep, satisfaction with sexual functioning, day-

to-day focus, mental strain, informed about illness, protection of patient, management of patient's pain and family interest in caregiving). A scoring algorithm was followed to evaluate the answer of the respondents, the highest score for each item is four, and the lowest is zero. The CQOLC scale is marked by adding up the score on each item to yield a score for the instrument, and the score can range from 0-140. The highest score possible is 140; a higher score means better quality of life. The level of caregiver quality of life (QoL) will be categorized into four categories as follows: Good QoL- If the total score is between (105-140); Moderate QoL- If the total score is between (71-104); Poor QoL- If the total score is between (36-70); and Very Poor QoL: If the total score is between (0-35).

The test-retest reliability and internal consistency of CQOLC psychometric properties were evaluated with 0.95 and 0.91, respectively. Moreover, the internal consistency of CQOLC psychometric properties subscales are as follows: burden- 0.89; disruptiveness- 0.83, positive adaptation- 0.73; and financial concerns- 0.81.

The instrument was translated into Arabic in the Mehad Mohammed Ahmed Araki study and tested for its reliability and validity. The instrument's internal consistency with the alpha coefficient was 0.9, and the correlation coefficient of the test re-test reliability was 0.94. On the other hand, the convergent validity of the physical component summary score was 0.10, and the mental component summary score was 0.69.

Permissions were taken from the original author, Dr. Michael A. Weitzner. For the Arabic version, Miss Mehad Mohammed Ahmed Araki was contacted, and she approved the utilization of the questionnaire.

Data Gathering Procedure

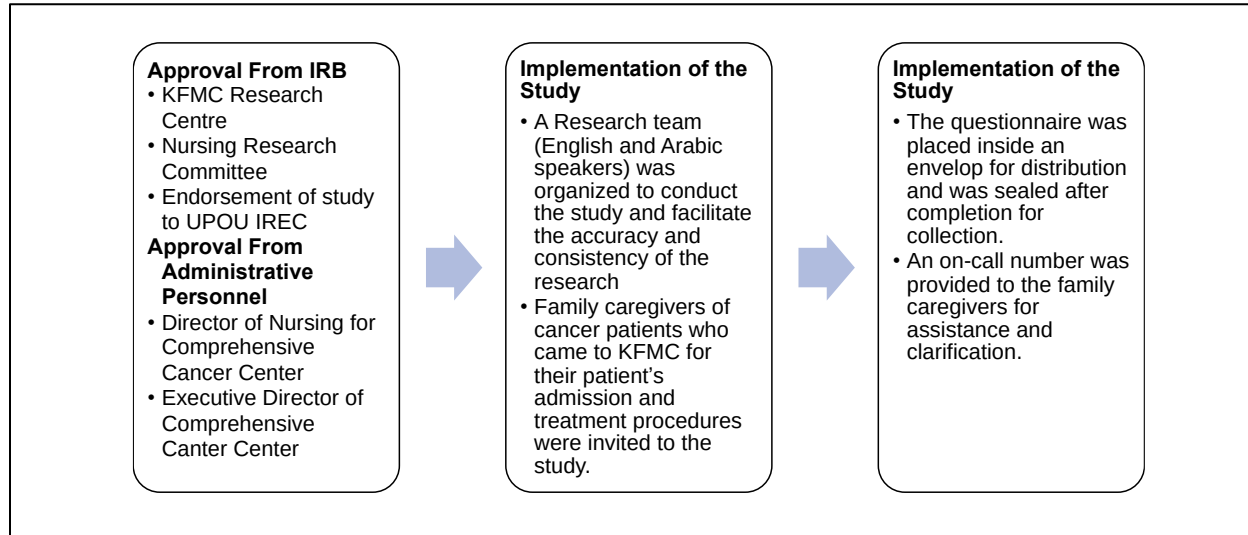


Figure 4 Data Gathering Procedure

The researcher sought permission from King Fahad Medical City's Institutional Review Board (IRB). Once approval was taken from the IRB, the approval of the nursing research committee of KFMC was acquired. After the approval of the nursing research committee was taken, the support of the quality team, nurse manager, and director of the Comprehensive Cancer Center (CCC) was acquired. After seeking their approval, the author presented the objectives and relevance of the study to the administrative personnel of CCC. Once the permissions were secured from the administrative personnel and the Institutional Review Board, the author organized a research team to conduct data collection of the study and facilitate the accuracy and consistency of the application of the research. Family caregivers of cancer patients were recruited for the study from February 20, 2022, to April 15, 2022.

Family caregivers of cancer patients who came to King Fahad Medical City for their patient's admission and treatment procedures were invited to the study. A structured questionnaire checklist was utilized for data collection. The structured questionnaire

consisted of two parts: Part 1 dealt with sociodemographic-clinical information, and Part 2 was allocated to assess the quality of life of family caregivers.

The research assistants, who were English and Arabic speakers, facilitated the data collection. Moreover, an on-call number was provided to the family caregivers for assistance and clarification. The data was collected during the patient's treatment procedures, such as chemotherapy, antibiotics therapy, blood transfusion, radiation therapy, and minor procedures in the ambulatory care (outpatient treatment unit and radiation therapy unit) and in-patient unit of KFMC. After explaining the study's aims, consent was given to the subjects for participation. The questionnaire can be completed in approximately 15 minutes. The sociodemographic profile of patients was taken as secondary data from the family caregiver since, in Saudi culture, some patients are hidden from the knowledge about their cancer diagnosis. The sociodemographic information and CQOL-C questionnaire are both available in Arabic and English.

The questionnaire was placed inside an envelope for distribution and was sealed after completion for collection. To maintain consistency in data collection, the investigator and the research team members monitored the data collection process.

Plan for data analysis and interpretation

The statistical software package for Windows, SPSS version 23, was used for data analysis.

Descriptive statistics such as frequencies, means, and standard deviations were utilized to characterize the sociodemographic data of patients and family caregivers and the quality of life of family caregivers. Meanwhile, the Fisher's exact test, chi-square test,

and Yates continuity correction were used to determine the relationship between patient and family caregiver sociodemographic factors and the quality of life of family caregivers of cancer patients. Fisher's exact test was used to determine whether the two variables were independent or related. Moreover, Fisher's exact test was used instead of the chi-square test because the sample size was too small and the expected value was less than 5. Lastly, Fisher's exact test was used to test the hypotheses at a 0.05 level of significance to reject or accept the null hypotheses.

Ethical Considerations

Before the data collection was initiated, the researcher sought King Fahad Medical City's Institutional Review Board (IRB) permission. Once approval was taken from the IRB, each potential participant received an invitational letter containing information about the study and informed consent. Confidentiality was guaranteed to the participant, and a signed informed consent form was obtained from the participants before data collection. The informed consent indicated the voluntary participation of the subjects and the risk and benefits of participating in the study. The study did not inflict any harm on the subjects since the result will serve as baseline data for improving the quality of life of family caregivers.

The research showed no conflict of interest. Moreover, it did not affect the patient's treatment plan and was not used to initiate sanctions or penalties. The result of the study will serve as baseline data in developing programs to improve the quality of life of family caregivers and improve the efficiency of care received by the patients. Lastly, it was

emphasized that even if the subject agrees to participate, they are free to withdraw from the study at any time, without penalty.

Plans for Dissemination

Plans for dissemination of the research proposal include submitting the result to UPOU, KFMC, and identified publishing research journals.

Table 2. Statistical Design Matrix

Objective	Statistical Test
Objective 1: Identify the sociodemographic profiles of the family caregivers of cancer patients in Saudi Arabia in terms of: a. Age b. Sex c. Level of education d. Employment status e. Marital status f. Relationship to patient g. Financial status h. Duration of care	Frequency Percentage
Objective 2: To identify the sociodemographic profiles of cancer patients in Saudi Arabia a. Age b. Sex c. Type of cancer d. Presence of metastasis e. Duration of illness	Frequency Percentage
Objective 3: To identify the quality of life of family caregivers of cancer patients in Saudi Arabia in terms of: a. Burden b. Disruptiveness c. Positive adaptation d. Financial difficulties e. Total CQOLC (includes the above four aspects and general components)? f. four categories—good, moderate, poor, or very poor QoL.	Mean Standard Deviation
Objective 4: To determine the relationship of the patient sociodemographic factors with the quality of life of family caregivers of cancer patients in Saudi Arabia.	Fisher's exact test Chi-square test
Objective 5: To determine the relationship of the family caregiver sociodemographic factors with the quality of life of family caregivers of cancer patients in Saudi Arabia.	Fisher's exact test Chi-square test Yates continuity correction

Chapter IV

RESULT AND DISCUSSION

Sociodemographic profiles of the family caregivers

The sociodemographic profile of the family caregivers of cancer patients in terms of age, sex, level of education, employment status, marital status, relationship to the patient, financial status, and duration of care is presented in Table 3.

Table 3. Sociodemographic profiles of the family caregivers

Family Caregiver's Sociodemographic Profile	Mean	Standard Deviation
Age, years	34.8	10.06
	Frequency	Percentage
Age, years		
18-40	98	70
41-60	42	30
Sex		
Female	57	40.71
Male	83	59.29
Level of education		
Illiterate	10	7.14
High School Certificate	57	40.71
Diploma Degree	11	7.86
Baccalaureate Degree	54	38.57
Master Degree	6	4.29
Ph.D. Degree	2	1.43
Employment Status		
Employed	62	44.29
Leave of Absence	9	6.43
Quit for Care	7	5
Not Employed	62	44.29

Marital Status		
Single	49	35
Married	77	55
Widow/Widower	6	4.29
Divorced	8	5.71
Relationship with the patient		
Wife	4	2.86
Husband	11	7.86
Father	5	3.57
Mother	6	4.29
Siblings (brother/sister)	37	26.43
Son	40	28.57
Daughter	34	24.29
Others	3	2.14
Financial Status		
Low (cannot meet financial demands)	41	29.29
Equal (can meet financial demands)	99	70.71
Duration of care		
1-3 months	33	23.57
3-6 months	23	16.43
6-9 months	12	8.57
9-12 months	16	11.43
Over a year	56	40

As gleaned in the table, most family caregivers' ages range from 18 to 40 years, and the rest are 41 to 60 years old. The family caregivers have a mean age of 35 years. This finding indicates that most family caregivers are in the early adulthood stage, and the rest are in the middle adulthood stage. According to Erickson's theory of development, early adulthood is the stage of developing intimate and loving relationships with other people. And middle adulthood is a stage of development that characterizes the period of

acquisition of care and concern for others. The result of this study indicates that most family caregivers are in the stage of development where duty, obligation, and responsibility for others' welfare are emphasized. The outcome of this study is different from the literature review by Mazziya et al. (2017) about the quality of life of family caregivers in Korea, Japan, China, Sweden, Greece, Italy, California, Canada, Colombia, and Taiwan. In her review, the characteristics of family caregivers are over 50 years. However, in the study by Turkoglu and Kilic (2012) in Turkey, 40% of family caregivers were under 35 years, and the average age was 42 years old. This is consistent with the study of Uzar-Ozcetin and Dursun (2020) in Turkey, which identifies family caregivers as primarily with a mean age of 40.

The table also reveals a greater number of male than female family caregivers, 59.29% and 40.71%, respectively. This outcome differs from studies in Korea, Japan, China, Sweden, Greece, Italy, California, Canada, Colombia, Taiwan, Singapore, UAE, and Turkey, whose family caregivers are primarily females. The result also contrasts with the study by Sharif et al., 2020 which evaluates the experiences of family caregivers for patients with mental disorders in Saudi Arabia. In her research, 77% of family caregivers were female and had varied relationships with the patient. Meanwhile, in the study by Alrashed (2017) about informal caregiving within Saudi society, female family caregivers of the elderly, individuals with a disability, and children aged five or younger were evaluated. Her study cited that women in Saudi society provide most caregiving. In the present study, a family caregiver is identified as someone who manages the patient treatment plan and provides physical and emotional care and support. The diagnosis of cancer is sudden and precedes the immediate initiation of treatment. In Saudi culture,

treatment decisions or consent for any medical procedures for the patient usually involve the male family members, who assume their role as the protector in preventing emotional distress to the patient.

Moreover, most critical decisions in Saudi families are carried out by or at least include the most senior male family member (Wazqar et al., 2017). Although the result of the study has a greater number of males than females, this cannot be generalized since the sex of the patient is also to be considered. In the hospital setting, most often, if the patient is male, the family caregiver is also male. Thus, the result signifies Saudi culture's influence on individuals' family caregiving roles.

The family caregivers are high school graduates and bachelor's degree holders, accounting for 40.71% and 38.57%. Others are illiterate or diploma holders or received Master's and Doctor's degrees. This indicates that family caregivers pursue higher education which is rational since education for girls was not entirely accepted by Saudi society until the first school for girls was established in 1964 (Alrashed, 2017). The result also implies that most family caregivers have formal education. In the study of Turkoglu and Kilic (2012), most family caregivers are primary school graduates. On the other hand, in the study of Araki (2019) in the United Arab Emirates, most family caregivers have high school certificates or acquired a baccalaureate degree.

This study has an equal rate of employed and unemployed family caregivers at 44.29%. Other family caregivers either quit their job for care or are on a leave of absence, indicating that family caregivers are challenged between balancing caregiving and work obligations. In the study of S.Y. Rha et al. (2015), most family caregivers received higher

education, but more than 50% of them either did not have a job or quit their job for caregiving.

More family caregivers are married (55%), followed in descending order of percentage by those who are single (35%), divorced (5.71%), and widowed (4.29%). This result denotes that family caregivers assume familial obligations regardless of marital status. The result of the study is consistent with the outcome of Araki (2019), Turkoglu and Kilic (2012), and Uzar-Ozcetin and Dursun (2020), which identify family caregivers as primarily married.

The table also shows the relationship of the family caregiver with the patient. More than half of the family caregivers were children of the patients, either son (28.57%) or daughter (24.59%). Meanwhile, more than a quarter are siblings of the patients (26.43%), and the others are spouses (husband/wife) or parents (mother/father) to the patient. This result implies that children of patients hold filial obligations in taking care of their parents, and siblings assume responsibility for caring for each other. Works of literature in the study of Alrashed (2017) reveal that caregiving in Saudi society is influenced by several attributes that define its unique identity—large family sizes in addition to extended families; adult family members living in the same household, particularly when unmarried; and individuals obligated by religion to care for their relatives in need and, above all, for their parents. The result of the present study is disparate from the result in the literature review of Mazziya et al. (2017), wherein most family caregivers had relationships with patients as spouses or parents.

The financial concern brought by cancer is also indicated in Table 3. Almost three-quarters, 70.71% of the family caregivers meet their financial demands, while 29.29%

reveal low financial status. This shows the extent of financial support received by families in the Kingdom. In Saudi Arabia, a significant amount of its finances is dedicated to improving healthcare services to provide free and accessible health services to every Saudi citizen (Wazqar et al., 2017).

Lastly, Table 3 shows the varied duration of care served by the family caregiver. Almost half of the family caregivers, 40%, have assumed the caregiving role for over a year. Of some family caregivers, 23.57% provided care at an early stage of 1-3 months. A few are providing care for 3-6 months (16.43%), 9-12 months (11.43%), and 6-9 months (8.57%). The result indicates that family caregivers have provided care at varied lengths of duration.

Sociodemographic profiles of cancer patients

Table 4 shows the sociodemographic profiles of cancer patients in terms of age, sex, cancer diagnosis, presence of metastasis, and illness duration.

Table 4. Sociodemographic profile of cancer patients

Patient's Sociodemographic Profile	Mean	Standard Deviation
Age, years	49.7	18.61
	Frequency	Percentage
Age		
14-40	43	30.71
41-60	51	36.43
>60	46	32.86
Sex		
Female	73	52.14
Male	67	47.86
Cancer diagnosis		
Head and Neck	16	11.43

Lung Cancer	8	5.71
Digestive tract and digestive organ Cancer	23	16.43
Breast Cancer	17	12.14
Blood Cancer (Lymphoma/Leukemia)	54	38.57
Female Genital	2	1.43
Male Genital	10	7.14
Renal Cancer	3	2.14
Bone/Muscle/Soft tissue Cancer	6	4.29
Skin Cancer	1	0.71
Other	0	0
Presence of Metastasis		
Yes	66	47.14
No	74	52.86
Duration of illness		
1-3 months	23	16.43
3-6 months	18	12.86
6-9 months	15	10.71
9-12 months	20	14.29
Over a year	64	45.71

As presented in table 4, almost forty percent of cancer patients range from age 41 to 60, and others are more than 60 or 40 years old or younger. The mean age of cancer patients is 50 years old. This result supports the literature in the study of Wazqar et al. (2017) that cancer in Saudi Arabia appears younger than in Western countries. In Saudi Arabia, breast cancer occurs earlier, with an average age of 50 years, compared to 61 years in Western countries such as the United States of America. According to the Saudi Cancer Registry (2016), the median age for cancer diagnosis was 57 years for males and 51 years for females. Among females, the highest number of cancer cases was reported

for 45-59 years, while among males, the highest number of cases were identified for the age group of 60-74 years.

This study also identified that cancer is more prevalent among females (52.14%) than males (47.86%). The result is supported in the 2016 report of the Saudi Cancer Registry (SCR), wherein the frequency of cancer is higher among women (55.9%) than men (44.1%), with a male-to-female ratio of 100:126. The crude incidence rate (CIR) of all cancers among Saudis was 56.6/100000 in males and 74.5/100000 in females.

As gleaned in the table, more patients have blood cancer (38.57%), followed in descending order of percentages by those with cancer in the digestive tract (16.43%), breast (12.14%), head and neck (11.43%), male genital (7.14%), and lungs (5.71%). This outcome is congruent with the most common cancers among Saudi nationals (SCR, 2016), including breast cancer, colorectal cancer, thyroid cancer, non-Hodgkin's lymphoma, leukemia, Hodgkin's lymphoma, uterine cancer, lung cancer, liver cancer, and prostate cancer.

The table also revealed a close rate between the absence of metastasis and the presence of metastasis, with 52.86% and 47.14%, respectively. This result accentuates the literature review that most Saudi patients with cancer are more likely to present at a more advanced stage. This indicates that most patients seek only treatment once cancer has spread to other body sites, for example, the liver, lungs, bones, brain, and other body parts (Wazqar et al., 2017).

Finally, Table 4 shows the varied duration of illness among cancer patients. Almost half of the patients, 45.71%, have been diagnosed for over a year. Of some patients, 16.43% have been diagnosed in the last 1-3 months and 14.29% for the previous 9-12

months. A few have been diagnosed within 3-6 months (12.86%) and 6-9 months (10.71%). The result indicates that patients have varying lengths of the duration of illness, which may be attributed to the availability and provision of appropriate cancer care.

Caregiver Quality of life of family caregivers of cancer patients in terms of burden, disruptiveness, positive adaptation, financial difficulties, and total CQOLC

The quality of life of family caregivers of cancer patients in terms of burden, disruptiveness, positive adaptation, financial difficulties, and total Caregiver Quality of Life-Cancer (CQOLC) are shown in table 5.

Table 5. The Caregiver Quality of life of family caregivers of cancer patients in terms of burden, disruptiveness, positive adaptation, financial difficulties, and total CQOLC

CQOLC Domains	Mean	SD
Burden		
I fear my loved one will die. (9)	1.07	1.50
My level of stress and worries has increased. (11)	1.59	1.43
I feel sad. (14)	1.99	1.42
I feel guilty. (17)	2.93	1.39
I feel frustrated. (18)	2.83	1.32
I feel nervous. (19)	2.19	1.52
I worry about the impact my loved one's illness has had on my children or other family members. (20)	1.61	1.63
I fear the adverse effects of treatment on my loved one. (25)	0.99	1.25
It upsets me to see my loved one deteriorate. (31)	0.76	1.20
I am discouraged about the future. (33)	2.41	1.49
Total	18.36	9.06
Disruptiveness		
It bothers me that my daily routine is altered. (1)	2.79	1.36
My daily life is imposed upon. (3)	3.21	1.15
It is a challenge to maintain my outside interests. (5)	1.92	1.39
I have difficulty dealing with my loved one's changing eating habits. (21)	2.19	1.43
It bothers me that I need to be available to chauffeur my loved one to appointments. (24)	3.01	1.4

My responsibility for my loved one's care at home is overwhelming. (26)	1.58	1.36
It bothers me that my priorities have changed. (29)	2.34	1.43
Total	17.03	5.57
Positive Adaptation		
I have more of a positive outlook on life since my loved one's illness. (10)	2.75	1.32
My sense of spirituality has increased. (12)	2.91	1.31
I get support from my friends and neighbors. (16)	2.73	1.39
I have developed a closer relationship with my loved one. (22)	2.81	1.28
I am glad that my focus is on getting my loved one well. (27)	3.59	0.97
Family communication has increased. (28)	3.26	1.13
I am satisfied with the support I get from my family. (34)	3.04	1.27
Total	21.09	5.75
Financial concerns		
I am under a financial strain. (6)	2.36	1.40
I am concerned about our insurance coverage. (7)	2.90	1.48
My economic future is uncertain. (8)	2.37	1.48
Total	7.63	3.59
Others		
My sleep is less restful. (2)	2.24	1.45
I am satisfied with my sex life. (4)	2.21	1.44
It bothers me, limiting my focus to day-to-day. (13)	2.11	1.34
I feel under increased mental strain. (15)	2.04	1.41
I feel adequately informed about my loved one's illness. (23)	2.94	1.23
The need to protect my loved one bothers me. (30)	2.43	1.63
The need to manage my loved one's pain is overwhelming. (32)	1.53	1.63
It bothers me that other family members have not shown interest in taking care of my loved one. (35)	2.21	1.35
Total	17.71	5.50
Total CQOLC	81.81	19.71

The Caregiver Quality of Life Index-Cancer (CQOLC) is commonly utilized to assess the quality of life of family caregivers of cancer patients. It has four subscales: ten items related to the burden, seven to disruptiveness, seven to positive adaptation, three to financial concerns, and eight single items to additional factors (disruption of sleep, satisfaction with sexual functioning, day-to-day focus, mental strain, informed about

illness, protection of patient, management of patient's pain and family interest in caregiving). The CQOLC scale is marked by adding up the score on each item to yield a score for the instrument, and the score can range from 0 to 140. The highest score possible is 140; a higher score means better quality of life.

In the present study, the highest acquired score was 135, and the lowest attained score was 43. The mean score of total CQOLC was 81.81 ± 19.71 . The result of this study is comparable with the result in Singapore, Turkey, and Taiwan; 83.5 ± 19.1 , 81.4 ± 17.3 , and 81.7 ± 19.6 respectively. However, this is significantly lower than the quality of life of family caregivers in the West. Literature has identified that the United Kingdom, the United States, and Canada have higher mean total CQOLC, 88.9 ± 24.4 ; 95.3 ± 16.3 , and 98.8 ± 15.8 , respectively. Meanwhile, the result in the present study is suggestively better compared to the mean of total CQOLC in Iran (71.8 ± 20.1) and South Korea (74.0 ± 18.7) (Lim et al., 2017). The result of this study identified the quality of life of family caregivers in a different social and demographic setting specific to the Islamic culture in Saudi Arabia as compared to the previous findings. Previous studies show that the experience of family caregivers is influenced by dynamic family systems, socio-cultural and religious beliefs, and the caregiver's resilience and ability to endure crises, adapt and cope. Moreover, literature on caregiving emphasized subjects of familial piety and obligatory care as motivations for caregiving, specifically in Asian and Muslim societies (Cancer, 2013, as cited by Lim et al., 2017).

In Saudi Arabia, the culture is primarily influenced by the Islamic religion, which reflects in the lives of the people in the Kingdom. According to Saudi culture, the family is held responsible for protecting and providing care to the patient. The Islamic belief of

family members precedes them in assuming the responsibility of caring for their relatives in need by helping them to live as comfortably as possible (Wazqar et al., 2017).

The table also reveals the quality of life according to the four domains of CQOLC; the mean scores for the following domains were—burden: 18.36 ± 9.06 ; disruptiveness: 17.03 ± 5.57 ; positive adaptation: 21.09 ± 5.75 ; and financial difficulties: 7.63 ± 3.59 . Based on the result, it was identified that burden yields a lower quality of life score, as illustrated with a mean score lower than 50% of the possible score. The highest possible score for burden is 40. Meanwhile, positive adaptation results in a higher quality of life score, as shown with a mean score of 75% of the maximum possible score. The highest possible score for positive adaptation is 28. A scoring algorithm was used to evaluate the answer of the respondents, the highest score for each item is four, and the lowest is zero. A higher score denotes better quality of life.

As gleaned in the table, the items of burden with low quality of life scores were: “It upsets me to see my loved one deteriorate.”; “I fear the adverse effects of treatment on my loved one.”; “I fear my loved one will die.”; “My level of stress and worries has increased.”; “I worry about the impact my loved one’s illness has had on my children or other family members.”; and “I feel sad.” On the other hand, items on disruptiveness that have low scores for quality of life include: “The responsibility I have for my loved one’s care at home is overwhelming.”; and “It is a challenge to maintain my outside interests.” And lastly, the item related to managing a patient's pain with low quality of life score is: “The need to manage my loved one’s pain is overwhelming.” These results indicate that the challenges of caregiving evoke a sense of fear and make the family caregiver feel stressed, sad, overwhelmed, worried, frustrated, and upset.

The family caregiver assumes various roles in providing care and support, such as disease monitoring; facilitating health care services according to the patient's condition; managing signs and symptoms; pain management; home medication administration; emotional support; and assistance in daily life activities, and personal and economic needs. With the cancer diagnosis, the family caregiver is confronted suddenly with the caregiving role with little or no training and limited resources. Family caregivers feel they are not ready and do not have enough resources for the life-long challenges of the disease. The family caregiver's complex tasks involve dealing with the physical demands of caregiving and providing emotional support for the patient while managing their health and self-care needs. These complex responsibilities of the family caregiver put them under stress and burden that may affect their quality of life. (Maziyya, Rahayuwati, & Yamin, 2018; Turkoglu & Kihe, 2012; S.Y. Rha, Y. Park, S.K. Song, C.E. Lee, J. Lee, 2015, Uzar-Ozcetin & Dursun, 2020; Mazanec, Blackburne, & Daly, 2021; Parmar, Anderson, Abbasi, Ahmadinejad, Chan, Charles, Dobbs, Khera, Stickney-Lee, Tian, & Jain, 2021; Karabulutlu, E., 2014).

Past studies showed that psychological factors such as distress, anxiety, and burden negatively influence family caregivers' quality of life (Maziyya et al., 2018). Moreover, the decline in the quality of life of family caregivers is also associated with the perception that cancer is a disease that equates with the threat of death (Weitzner et al., 1999). Caregivers were confronted with the challenges such as uncertainty, distress related to witnessing the disease progression, and the everyday battle with financial issues, own time, personal health, and sleep problems. They conveyed the need to be primed for their caring role, to be noticeable by professionals, to obtain clear and specific

information about the patient's condition, and to be supported emotionally (Harding, Epiphaniou, Hamilton, Bridger, Robinson, George, Beynon & Higginson, 2012). In the study by Sercekus et al. (2014), it was revealed that the family of patients with cancers do not confide their feelings and evade conversations related to the disease because they are afraid it will make the patient sad and uncomfortable.

Acute and chronic pain affects a patient's physical and psychological well-being, and it is one of the typical and unwanted symptoms among cancer patients. Ugur et al. (2014) found that caregivers have difficulty dressing the patient due to pain. Family caregivers assume the responsibility of pain management at home—making decisions on what to use to relieve pain, when to give the medication, monitoring side effects, reminding the patient about the medication, maintaining records, assessing the efficacy of pain control, and noting when and how to report negative result or ineffectiveness. It was reported that caregivers deal with difficulties in pain management, patient mobilization, activities of daily living, communication with the health care team, symptom management, home medication treatment, dealing with the emotional reactions of the patients, and often feel vulnerable and useless, especially when they cannot manage the patient's pain. Literature has emphasized that family caregivers should be supported, and their needs should be addressed for better health outcomes (Given et al., 2002; Ugur et al., 2014; Harding et al., 2012). In the study of Nayak et al. (2014), it was revealed that increasing the self-confidence of family caregivers in managing cancer pain is essential to the quality of life of both the patient and the caregiver.

Caregiver burden is the strain or distressful experiences related to caring for a chronically ill family member. It is important to note that being overloaded and

overwhelmed with care work is the one considered stressful and not caregiving per se. The caregiver burden exists throughout the disease, from diagnosis, survivorship, and death until the process of grief. The burden may occur due to increased caregiver demands that go with the progressive deterioration of the patient. Specifically, distress from symptoms (e.g., pain, dyspnea, nausea and vomiting, anorexia, constipation, and insomnia) and functional impairment or increasing level of dependency of terminally ill patients are associated with caregiver burden and decreased quality of life (Given et al., 2002; Ugur et al., 2014; Wen et al., 2019)

In the study of Tukoglu and Kilic (2012), the sub-scale score for family caregivers was 21.8 ± 5.3 for burden, 14.96 ± 4.8 for disruptiveness, 12.3 ± 3.9 for positive adaptation, and 5.69 ± 3.0 for financial difficulties. In their study, the burden is considered a significant predictor of the quality of life. However, a separate instrument was utilized to measure the burden's effect on family caregivers' quality of life. The result was also comparable with the study of S.Y. Rha et al. (2015) and Uzar-Ozcetin and Dursun (2020), which measured caregiver burden and quality of life using a separate instrument. Their analysis identified caregiver burden as a critical factor that influenced the quality of life of a family caregiver and accounted for a significant amount of variance in the quality-of-life score.

Table 5 also indicates that positive adaptation increases the score in the quality of life. As shown in the table, all items related to positive adaptation (items no.: 10, 12, 16, 22, 27, 28, and 34) have high mean scores. These items highlight the support received by the family caregiver from family, friends, and neighbors; better communication among family members; increased sense of spirituality; improved relationship with the sick family member; and a positive outlook in life with the emphasis and focus on the treatment of

the patient. Resilience and positive adaptation can positively affect family caregivers' quality of life. The study by Uzar-Ozcetin and Dursun (2020) reported that increased resilience led to improved quality of life of family caregivers.

Othman et al.'s (2018) study identified that caregivers' coping strategies are positively accepting their fate and appreciating social support. Research shows that attending support groups influences the caregiving experience positively. Likewise, caregivers have identified that religion provided strong tolerance for the caregiving process and aided in mediating strain. Meanwhile, caregivers who expressed a lack of support from family, especially siblings, had much anger and resentment (Lee et al., 2016; Ulidrich et al., 2018, as cited by Uzar-Ozcetin and Dursun, 2020).

In the qualitative study by Sharif et al. (2020) about the family caregiver experiences of burden and coping while caring for people with mental disorders in Saudi Arabia, it was reported that the effective coping strategies of family caregivers were: acceptance, religiosity, and spiritual-related coping techniques. Family caregivers believe that through praying and seeking refuge from God (Allah), all the experienced hardships would be reduced. This is consistent with the study of Alrashed (2017), which reported a high spiritual level among informal caregivers in Saudi Arabia. Accordingly, their religious principles catalyze dealing with the responsibilities of an informal caregiver. Saudis believe that health, illness, and death are all from God (Allah), and God's will is above all (Wazqar et al., 2017). Thus, religion plays a significant role in the coping process and positive adaptation of family caregivers in Saudi Arabia.

General QOL of the family caregivers of cancer patients

The general quality of life of family caregivers of cancer patients according to four categories is presented in Table 6. The level of caregiver's quality of life (QoL) was categorized as Good QoL if the total score is between (105-140); moderate QoL if the total score is between (71-104); poor QoL if the total score is between (36-70); and very poor QoL if the total score is between (0-35).

Table 6. The general QOL of the family caregivers of cancer patients

QOL	Frequency	Percentage
Good QoL: if the total score is between 105-140	18	12.86
Moderate QoL: if the total score is between 71-104	78	55.71
Poor QOL: if the total score is between 36-70	44	31.43
Very poor QOL: if the total score between 0-35	0	0

As gleaned in the table, the majority of the respondents have moderate QoL (55.71 %), followed by poor QoL (31.43%) and good QoL (12.86%). The result was lower than the study of Araki (2019) in UAE, wherein the majority of caregivers have moderate QoL (62.5%), followed by good QoL (35%) and poor QoL (3%). This result may indicate that the quality of life of family caregivers in Saudi Arabia needs continuous assessment and intervention to improve their situation.

The Comprehensive Cancer Center provides an array of cancer care services which includes intensive care units, consultation services, routine screening, cancer therapy, radiation therapy, rehabilitation, palliative care, supportive care (social services, dietary, occupational and physical therapy, wound care, patient and family education, and spiritual care), and home care programs. Its home care programs focus on patient and family-centered care to help the patient restore or regain lost functional abilities, ensure

patient safety, and maintain their optimum health. Family caregivers are also taught about the disease process and treatment modalities such as chemotherapy, radiation therapy, and surgical treatments. Moreover, family caregivers are provided with a teaching process to improve their skills in providing safe and effective health care at home.

Despite the support given to family caregivers, the result of the study shows only 12.6% of the family caregivers have a good quality of life. Although the pillars of care are centered toward person-centered care, the patient remains to be the focus of care, and family caregivers are not the center of priority. Caring for a sick relative is related to filial responsibility, and though it may give a sense of fulfillment, it can be overwhelming for the family caregiver. The diagnosis of cancer is sudden and places the family caregiver in a responsibility where they are unprepared and have no knowledge about it. The result of the study also shows that the average age of family caregivers is 35 years. This period defines a stage where an individual develops a career and engages themselves in building a family. With the responsibility of caring for the sick family, their interest may be placed on hold, and their focus may remain on the patient's needs.

Moreover, their responsibility becomes bigger in providing care at home, especially in dealing with the symptoms and effects of the disease and treatment, such as pain, vomiting, fatiguability, anorexia, and others. Although the treatment is accessible to all Saudis, comprehensive cancer care is available in the major cities. Thus, for patients seeking treatment from the provinces, family caregivers often put a hold on their work and responsibilities at home to focus on patient care in the cities. Furthermore, housing and means of transportation for patients from neighboring provinces are limited compared to

those living in the city. Although social support is provided, mobilization of social and health resources for these patients needs reinforcement.

Education and training are provided to family caregivers before the initiation of treatment, alleviating family caregivers' questions about patients and conditions and planned treatment. However, the needs of the patients change throughout the disease process; thus, the needs of the family caregiver should also be assessed routinely, and necessary intervention should be provided.

Caregiving affects the quality of life of family caregivers due to the fear of losing their loved one, the impact of caring on their economic and financial status, and the restrictions on their social life. Reports have revealed that most caregivers experience health issues, domestic problems, depression, anxiety, and sleeping disorders. The caregiving role also leads to physical problems such as hypertension, impaired immune system, indigestion, unhealthy eating habits, headache, fatigue, altered body weight, muscle pain, and altered focus and concentration. Furthermore, studies have also shown that the caregiving process affects caregivers' psychological, emotional, functional, and even physical health, leading to a decline in their quality of life. (Uzar-Ozcetin & Dursun, 2020; Mirsoleymani, Rohani, Matbouei, Nasiri, & Vasli, 2017; Maziyya et al., 2018; Turkoglu & Kihe, 2012; Sercekus, Besen, Gunusen, & Edeer, 2014; Nemati, Rassouli, Ilkhani, Baghestani, 2017).

In a concept analysis by Javison (2021), the vulnerabilities of family caregivers while caring for their patient and the idea of caring for them was emphasized. His dissertation highlights three defining attributes of caring for family caregivers for concept analysis. Firstly, the family caregivers have limited or no idea about the fundamentals of

patient care. Secondly, the family caregiver is susceptible to health hazards such as physical, mental, social, and safety. And thirdly, a collective effort between the family caregiver and the nursing team is essential to optimize their roles and avoid job-related hazards related to caregiving.

On the other hand, Bijnsdorp et al. (2020) identified four diverse profiles of family caregivers of patients at the end of life: (1) those who yearn for appreciation and need a contact person; (2) those who want or have a supportive relationship, (3) those who seek guidance, information and practical or medical support; (4) and those who want a day off from the caregiving role. These profiles identify the unique and varied support needs and experiences with caregiving that are relevant to improving the quality of life of family caregivers.

In 2019, Covenant Health in Canada developed the Caregiver-Centered Care Competency Framework to foster a collaborative relationship between families and healthcare professionals, emphasizing supporting the family in their caregiving role, making decisions about services, and managing care. This approach encourages the involvement of family caregivers in the planning and provision of support services. Moreover, this approach also identifies and tackles the needs and preferences of caregivers and incorporates family caregivers as partners in care.

The six competency domains of Caregiver-Centered Care are (a) awareness and understanding of the caregiver role; (b) interacting with family caregivers with emphasis on active listening, conveying empathy and equality, and providing emotional support; (c) partnering and connecting with family caregivers; (d) empowering and facilitating resilience in family caregivers; (e) piloting the health and social systems and accessing

resources by increasing health care workers awareness of health and community resources, and providing them with skills both to coach family caregivers to make learned decisions and to advocate for their needs.; and (f) enhancing the culture and context of care by promoting self-reflection, positive workplace behavior, and the interrelationship between healthcare providers and family caregivers. Each domain has competency indicators highlighting the knowledge, skills, attitudes, and values that structure caregiver-centered care practice (Fisher, R., Parmar, J., Duggleby, W., Tian, P., Janzen, W., & Anderson, S., & Bremault-Phillips, S., 2020).

Nurses play an essential role in promoting the health and safety of family caregivers and supporting their role in providing safe and effective care at home and in the community. The support the family caregiver receives is significant to prevent them from being overloaded and overwhelmed with responsibility. Moreover, recognizing their role and treating them with respect and dignity helps them enhance their confidence and attain their full potential. The needs and symptoms of the cancer patient are dynamic and may change over time, thus, so as the needs and well-being of the caregiver. Hence, the family caregiver is considered a provider and recipient of care. Consequently, the family caregivers should be included in routine assessment and care planning, explicitly and continuously. This could also be relevant for their quality of life and, ultimately, the quality of the patient's life (Bijnsdorp et al., 2020; Javison, 2021)

Relationship of the family caregiver's sociodemographic factors with their quality of life

The relationship between the family caregiver's sociodemographic factors with the quality of life is presented in Table 7.

Table 7. Association between the sociodemographic profiles of the family caregivers and the quality of life

Family Caregiver Sociodemographic Profile	Quality of Life	
	<i>Fishers Exact Test</i>	<i>Chi-square test</i>
Age	P value= 0.285 (>0.05)	5.236, $p>0.05$
Sex	P value= 0.003 (<0.05)	11.791, $p<0.05$
Level of Education	P value= 0.075 (>0.05)	
Employment status	P value= 0.815 (>0.05)	
Marital status	P value= 0.260 (>0.05)	
Relationship to patient	P value= 0.462 (>0.05)	<i>Yates correction factor</i> 1.552, $p>0.05$
Financial status		
Duration of care	P value=0.262 (>0.05)	

As gleaned in table 7, the results of the test of independence (no relationship) between the variables family caregiver's age and the quality of life using the Fishers exact test indicated no significant relationship between the two variables ($p=0.285$). The same result was found using the Chi-square test ($\chi^2 (4) = 5.236, p>0.05$).

On the other hand, the test of independence (no relationship) between the variables of family caregiver's sex and the quality of life using the Fishers exact test indicated a significant relationship between the two variables ($p=0.003$). The same result was found using the Chi-square test ($\chi^2 (2) = 11.791, p<0.05$). Thus, this indicates that the family caregiver's sex significantly influences their quality of life. The result shows male family caregivers have an impaired quality of life compared to their female counterparts.

Results of the test of independence (no relationship) between the family caregiver's level of education and the quality of life using the Fishers exact test indicated no significant relationship between the two variables ($p=0.075$). Also, results of the test of independence (no relationship) between the variables family caregiver's employment status and the quality of life using the Fishers exact test indicated that there is no significant relationship between the two variables ($p=0.815$). Furthermore, results of the test of independence (no relationship) between the variables family caregiver's marital status and the quality of life using the Fishers exact test indicated that there is no significant relationship between the two variables ($p=0.260$).

Analysis and results of the test of independence (no relationship) between the variables family caregiver's relationship to patient and quality of life using the Fishers exact test indicated that there is no significant relationship between the two variables ($p=0.462$). Also, results of the test of independence (no relationship) between the variables family caregiver's financial status and the quality of life using the Yates correction factor indicated that there is no significant relationship between the two variables ($\chi^2 (1) = 1.552, p>0.05$). Lastly, the test of independence (no relationship) between the variables of family caregiver's duration of care and the quality of life using Fisher's exact test indicated no significant relationship between the two variables ($p=0.262$).

Relationship of the patient sociodemographic factors with the quality of life of family caregivers of cancer patients in Saudi Arabia

The relationship of the patient sociodemographic factors with the quality of life of family caregivers of cancer patients in Saudi Arabia is presented in Table 8.

Table 8. Association between the sociodemographic profiles of the patients and the quality of life

Patient Sociodemographic Profile	Quality of Life	
	<i>Fishers Exact Test</i>	<i>Chi-square test</i>
Age	P value =0.371 (>0.05)	
Sex	P value =0.00 (<0.05)	23.203, p<0.01
Type of Cancer	P value =0.452 (>0.05)	
Presence of Metastasis	P value =0.00 (<0.05)	44.894, p<0.01
Duration of Illness	P value =0.648 (>0.05)	

The test of independence (no relationship) between the variables age of the patient and the quality of life of family caregivers using the Fishers exact test indicated no significant relationship between the two variables ($p=0.371$). On the other hand, the result of the test of independence (no relationship) between the variables patient's sex and the quality of life using the Fishers exact test indicated that there is a highly significant relationship between the two variables ($p=0.00$). The same result was achieved using the Chi-square test for independence of the two categorical variables ($\chi^2 (2) = 23.203$, $p<0.01$). Thus, this indicates that the patient's sex significantly influences the family caregiver's quality of life. The result shows that family caregivers of male cancer patients have a poor quality of life.

The test of independence (no relationship) between the variables patient's type of cancer and the quality of life of family caregivers using the Fishers exact test indicated that there is no significant relationship between the two variables ($p=0.452$).

However, results of the test of independence (no relationship) between the variables' presence of metastasis and the quality of life using the Fishers exact test indicated that there is a significant relationship between the two variables ($p=0.00$), with

those having no metastasis registering a higher quality of life. The same result was found using the Chi-square test ($\chi^2 (2) = 44.894, p < 0.01$).

Lastly, results of the test of independence (no relationship) between the variables duration of illness and the quality of life using the Fishers exact test indicated that there is no significant relationship between the two variables ($p = 0.648$).

The literature review by Mazziya et al. (2017) about the quality of life of family caregivers in Korea, Japan, China, Sweden, Greece, Italy, California, Canada, Colombia, and Taiwan identified factors that affect the quality of life and subdivided into three categories—patient factor, family caregiver's factor, and environmental factors.

The patient factors affecting family caregivers' quality of life are age and the patient's condition. Studies have shown that younger patients cause a decrease in the quality of life of family caregivers due to the increased burden of care. On the other hand, the patient's condition that affects family caregivers' quality of life includes a decline in the patient's function and stress. Disease-related variables correlated to the caregiver's well-being include the stage of cancer, the extent of the patient's disability, higher personal care needs, lack of patient mobility, patient dependency on daily activities, pain, and functional impairment. (Mazziya, Rahayuwati, and Yamin, 2018, Bijnsdorp, Pasman, Boot, van Hooft, van Staa & Francke, 2020; Wen, Chen, Chang, Shen, Hsieh & Tang, 2018; S.Y. Rha, Y. Park, S.K. Song, C.E. Lee, J. Lee, 2015; Glajchen, M., 2012).

On the other hand, the family caregivers' factors influencing their quality of life include age, educational and religious level, the relationship with the patient, and emotional stress. Studies have shown that family caregivers with older age, higher education, no religious belief, and emotional distress have decreased quality of life.

Moreover, family caregivers of older age have reduced quality of life in the physical domain, while younger family caregiver has diminished in the mental health domain (Mazziya et al., 2018, S.Y. Rha et al., 2015).

In a study conducted in Sweden, family caregivers' age is identified as a risk factor in their quality of life. The family caregivers of older age have decreased quality of life in the physical domain while younger family caregiver has declined in the mental health domain (Sjolander, Rolander, Jarhult, Martensson, & Ahlstrom, 2012 as cite by Mazziya et al., 2018).

Meanwhile, Korean studies showed that the demographic factors that influence the quality of life of family caregivers were the patient's age and the family caregiver's education. It was identified that family caregivers of younger patients have more burdens than older patients. On the other hand, the level of education of family caregivers positively influences their quality of life. Other factors that lead to lower quality of life of family caregivers were emotional distress, lack of family support, financial problems, and decline in the patient's functional capability (Song et al., 2011 as cited by Mazziya et al., 2018; Choi et al., 2015 as cited by Mazziya et al., 2018; Lee et al., Mazziya et al., 2018; Rha et al., 2015).

In a study conducted in China, family caregivers with a lower quality of life were those who are older, with a higher level of education, believe in no religion, experience higher emotional distress, caregivers of younger patients, and those without insurance benefits (Yu et al. and cited by Mazziya et al., 2018).

In the current study, the sex of the patient, the sex of the family caregiver, and the presence of cancer metastasis are the identified sociodemographic factors significantly

related to family caregivers' quality of life. Results show that family caregivers of male patients have a poor quality of life and that male family caregivers have a lesser level of QoL than their female counterparts. A similar study by Lim et al. (2017) in Singapore identified that male family caregivers had more impaired QoL. This may be attributed to an experienced role strain when the male caregivers are obliged to balance the responsibilities at home and work to care for the family inflicted with cancer. In most Asian cultures like Singapore, the responsibility for family caregiving falls traditionally on women, while men are expected to provide for the family.

Also comparable to the study of Lim et al. (2017), the result of the present study identified that family caregivers of patients with metastatic disease have a poor quality of life. Family caregivers of patients with advanced-stage cancer have impaired QoL in the domains of burden and social support. Moreover, the presence of metastasis implies the complex reality of end-of-life care and the patient's mortality which adds stress to family caregivers. Also, as the disease advances, patients may receive more treatment modalities and experience more functional impairment, thus requiring more time and support from the family caregiver (Weitzner et al., 1999, Mazziya et al., 2017).

Studies have shown that the quality of life of family caregivers of cancer patients declines as the patient's condition and level of independence deteriorate and the disease reaches its terminal stage. The patient's impending death may leave them with a feeling of grief. As the patient's condition worsens, the functional level declines, and the patient becomes more dependent; thus, more time is spent by the family caregiver caring for the patient. The increase in the physical needs of the patient suggests increased physical demands of caregiving from the family caregiver, which is associated with increased

burden and emotional stress (Bijnsdorp, Pasman, Boot, van Hooft, van Staa & Francke, 2020; Wen, Chen, Chang, Shen, Hsieh & Tang, 2018; S.Y. Rha, Y. Park, S.K. Song, C.E. Lee, J. Lee, 2015; Glajchen, M., 2012).

In contrast with the previous global studies (Mazziya et al., 2017), the present study did not find family caregivers' age and educational level as significant factors related to their QoL. In the study of Araki in UAE (2019), the identified demographic characteristics of family caregivers that were significantly associated with their QoL were the caregiver's age, gender, and relationship with the patient. The results of her study also recognized the patient demographic variables that are significantly associated with the QoL of family caregivers: patient's age, gender, and type of cancer. Meanwhile, in Turkey (Turkoglu and Kilic, 2012), the caregiver characteristics and characteristics of the care situation that were identified that affect the quality of life of family caregivers were being under 35, being between 36 and 50, having low income, being the spouse and parent of the patient, and the patient having their room. A similar study by Uzar-Ozcetin and Dursun (2020) in Turkey also identified that married family caregivers have higher CQOLC scores.

Previous studies show that family systems and socio-cultural and religious beliefs influence the experience of family caregivers. Moreover, literature on caregiving emphasized subjects of familial piety and obligatory care as motivations for caregiving, specifically in Asian and Muslim societies (Cancer, 2013, as cited by Lim et al., 2017). Familial piety implies that respect and support for parents is a virtue above all else. This norm promotes and provides assistance between generations through which children of all ages are expected to care for their parents.

Islam plays a significant role in Saudi's daily lives and impacts their attitudes and actions in work, family, relationships, and socialization. Family is seen as the primary social unit for human development, and members are expected to support and protect each other. The family structure in Saudi is patrilineal, and elders are highly respected. Children are raised to be dutiful, caring, and respectful toward their parents. Islamic traditions and Arabic cultural values structure the gender roles and responsibilities in Saudi Arabia. Both culturally and religiously, men are identified as the financial providers, while women have the functions of child-rearing, house chores, caregiving, and domestic work. Men are also expected to assume roles in protection and decision-making (Almalki, 2020).

In Saudi society, two desirable child and adult outcomes are emphasized in parenting practices: (1) "Al-Birr," which means full conduct and respect for parents, and (2) "Al-Wali," which identifies a male who will provide protection and has the legal responsibilities toward females in the household. Al-Birr implies children's responsibility to satisfy their parents' needs and requirements. These include providing physical and emotional care to their parents, which is expected from the females, and fulfilling financial and economic needs, which are expected from the males. Al-Wali emphasizes raising a male who takes the accountability of protecting the family, personally and financially. Moreover, male siblings are routed towards handling their sisters' needs by providing financial support and transportation (Almalki, 2020).

From a clinical perspective, the influence of Islamic tradition and Arabic culture on family caregivers in Saudi is both a benefit and a challenge. Caring for a sick family, especially among children who care for their sick parents, which is mirrored in the result

of the study, provides a sense of fulfillment. It gives them the motivation that they are doing what is expected of them. Moreover, this act conforms to the concept of loyalty based on the Islamic perspective that emphasizes trust, strong bonding, and support for the family. However, the sudden responsibility of caregiving may burden family caregivers, and their value of privacy prevents them from seeking professional help. Previous research shows that the act of professional help-seeking behaviors among Arab individuals and their families is limited (Al-Krenawi, Graham, Dean, & Eltaiba, 2004, as cited by Almalki, 2020). Among Arabs, seeking professional help can be stigmatized and affect the family's reputation in the community. The stigma of family failure inhibits many Saudis from seeking help from a therapist or psychiatrist for assistance in problem-solving; many Saudis do not want to be seen and identified as having a failed familial support structure (Algahtani, Buraik & Ad-Dab'bagh, 2017 as cited by Almalki, 2020).

The result of the study shows that male family caregivers and family caregivers of male patients have poorer quality of life. This may be attributed to the masculine sociocultural structure of the country. Men are seen as the protectors of the family and assume the responsibility for decision-making and supporting the family. Thus, the family structure is disturbed when sickness falls among males or when they take the caregiving role. Male caregivers may endure role strain when they are obliged to balance the responsibilities at home and work to care for the sick family.

This study's findings allow nurses and healthcare members to identify the vulnerable groups having low quality of life due to their caregiving role. The results also identified the support the family caregivers need to improve their quality of life. Thus, these results may assist the nurses in initiating care plans for family caregivers, including

developing programs, training, and educational resources to help them adjust to their responsibilities.

Chapter V

SUMMARY, CONCLUSION, RECOMMENDATIONS & IMPACT ON NURSING PRACTICE

Summary

This study aimed to evaluate the relationship between the sociodemographic factors and the quality of life of family caregivers of cancer patients in Saudi Arabia. Specifically, it aimed to identify the sociodemographic profiles of the family caregivers and the sociodemographic profiles of cancer patients in Saudi Arabia. It also aimed to determine the quality of life of family caregivers of cancer patients in Saudi Arabia in terms of burden, disruptiveness, positive adaptation, financial difficulties, and the total CQOLC (including the above four aspects and general components). Lastly, the study aimed to identify the overall quality of life (QoL) of family caregivers of cancer patients in terms of four categories—good, moderate, poor, or very poor QoL.

The study was conducted from February 20, 2022, to April 15, 2022. The respondents comprised 140 family caregivers of cancer patients in Saudi Arabia.

The salient findings of this study are the following:

1. Most of the family caregivers' ages range from 18 to 40 years, and the rest are 41 to 60 years old. The family caregivers have a mean age of 35 years. There is a greater number of male than female family caregivers. Although the result of the study has a greater number of males than females, this cannot be generalized since the sex of the patient is also to be considered. In the hospital setting, most often, if the patient is male, the family caregiver is also male. Most family caregivers are high school graduates and

bachelor's degree holders. Others are illiterate or diploma holders or received Master's and Doctor's degrees. There is an equal number of employed and unemployed family caregivers. Other family caregivers either quit their job for care or are on a leave of absence. The majority of family caregivers are married. More than half of the family caregivers were children of the patients, either sons or daughters. And more than a quarter are siblings of the patients. Almost three-quarters of family caregivers meet their financial demands. And lastly, there is a varied duration of care served by the family caregiver. Nearly half of the family caregivers have assumed the caregiving role for over a year.

2. On the sociodemographic profiles of patients, almost forty percent of cancer patients range from age 41 to 60, and others are more than 60 or 40 years old or younger. The mean age of cancer patients is 50 years old. This study also identified that cancer is more prevalent among females than males. The most prevalent cancers are blood cancer, cancer in the digestive tract, breast, head and neck, male genital, and lungs. Almost half of the cancer patients have identified the presence of metastasis. And nearly half of the patients have been diagnosed for over a year.

3. The Caregiver Quality of Life Index-Cancer (CQOLC) was utilized to assess the quality of life of family caregivers of cancer patients. It has four subscales: burden, disruptiveness, positive adaptation, and financial concerns. The CQOLC scale is marked by adding the score on each item to yield a score for the instrument. The highest score possible is 140; a higher score means better quality of life. In the present study, the highest acquired score was 135, and the lowest attained score was 43. The mean score of total CQOLC was 81.81 ± 19.71 .

In the quality of life according to the four domains of CQOLC, the mean scores for the following domains in the current study were—burden: 18.36 ± 9.06 ; disruptiveness: 17.03 ± 5.57 ; positive adaptation: 21.09 ± 5.75 ; and financial difficulties: 7.63 ± 3.59 . The result indicates that burden yields a lower quality of life score, and positive adaptation results in a higher quality of life score.

4. The general quality of life of family caregivers of cancer patients according to four categories was categorized as Good QoL if the total score is between (105-140); moderate QoL if the total score is between (71-104); poor QoL if the total score is between (36-70); and very poor QoL if the total score is between (0-35). Most respondents have moderate QoL, followed by poor QoL and good QoL.

5. Results of the test of independence (no relationship) between the sociodemographic profiles of the family caregivers and their quality of life using the Fishers exact test, chi-square test, and Yates test indicated that there is no significant relationship between the following variables: age, level of education, employment status, marital status, relationship to the patient, financial status, and duration of care with the quality of life of the family caregiver. However, the family caregivers' sex was significantly associated with their quality of life. Results of the study show that male family caregivers have a more impaired quality of life than female family caregivers.

6. Results of the test of independence (no relationship) between the sociodemographic profiles of the patient and the quality of life of family caregivers using the Fishers exact test and chi-square test indicated that there is a significant relationship between the patient's sex and cancer metastasis with the quality of life of the family caregiver. Family caregivers of male patients and those with metastasis have poorer

quality of life. On the other hand, the patient's age, type of cancer, and duration of illness are not associated with the quality of life of the family caregiver.

Conclusions

Based on the findings, the following conclusions are drawn:

1. Male family caregivers have a more impaired quality of life than female family caregivers of cancer patients in Saudi Arabia. Moreover, family caregivers of male patients and patients with metastatic cancer have poorer quality of life. Thus, this study identifies these profiles or groups of family caregivers needing more attention to improve their quality of life.

2. Most family caregivers have moderate QoL 78 (55.71 %), 31.43% have poor QoL, and 12.86% have good QoL. The mean score of total CQOLC was 81.81 ± 19.71 . The study identifies the quality of life of family caregivers in a different social and demographic setting and with religious and cultural diversity as compared to previous findings. Moreover, the result of this study marks the need for continuous assessment and intervention to improve the quality of life of family caregivers of cancer patients in Saudi Arabia. Thus, family caregivers should be openly and continuously included in routine assessment and care planning.

3. The caregiving experience confronts the family caregiver with challenges that evokes a sense of fear and makes the family caregiver feel stressed, sad, overwhelmed, worried, frustrated, and upset. They are overwhelmed with the pain management and caregiving responsibilities at home. Moreover, they are challenged to balance their caregiving responsibility and maintain their outside interest. Also, family caregivers are

worried, frustrated, and upset in witnessing the deterioration of their patients. They fear the concept of the death of their sick family. And lastly, family caregivers have worries and fears about the adverse effects of treatment and the impact of the patient's illness on their family. These results identify the support the family caregivers need to improve their quality of life. Moreover, these results may assist the nurses in initiating care plans for family caregivers, including developing programs, training, and educational resources to help them adjust to their responsibilities.

4. Positive adaptation increases the score of quality of life. These items highlight the support received by the family caregiver from family, friends, and neighbors; better communication among family members; increased sense of spirituality; improved relationship with the sick family member; and a positive outlook in life with the emphasis and focus on the treatment of the patient. The process of positive adaptation enhances the resilience of family caregivers and can be given focus to develop their quality of life.

Recommendations

1. Future studies with a more extended period (longitudinal study) and larger sample size to further identify and evaluate factors associated with quality of life. The study was conducted just after the global Covid pandemic, and there were restrictions on the availability of family caregivers in the hospital. Thus, a follow-up study will further reinforce the result and identify the support needed by the family caregivers.

2. Utilizing a separate instrument to evaluate the impact of burden and positive adaptation to the quality of life of family caregivers is recommended. Studies in Turkey

and Korea clearly defined the effects of burden and resilience on the quality of life of family caregivers with a separate instrument.

3. The study did not evaluate the functional status of patients with cancer which may determine the level of dependency of patients on family caregivers in completing their activities of daily living (ADLs). Moreover, the study includes family caregivers of cancer patients regardless of the type and stage of the disease, which limits the generalizability of the result. Thus, the results from this study opened doors for further research that will evaluate other aspects of caregiving, such as the patient's functional status, caregiver preparedness, family function, and social support that may contribute to the quality of life.

4. Family caregivers in KFMC are taught about the disease process and treatment modalities, such as chemotherapy, radiation therapy, and surgical treatments, during the treatment plan's initiation. Moreover, family caregivers are provided with a teaching process to improve their skills in providing safe and effective health care at home. However, the needs and level of care for cancer patients change over time, and so as the support needed by the family caregivers. Thus, nurses can develop a structure of intervention that supports the family caregiver's needs throughout the continuum of care. Moreover, a collaborative effort between the family caregiver and the nursing team should be emphasized to improve their roles and quality of life.

5. Utilize the result of recent studies to improve the quality of life of family caregivers. The current research results indicate that patients with metastasis have a poor quality of life. Bijnsdorp et al. (2020) identified four diverse profiles of family caregivers of patients at the end of life: (1) those who yearn for appreciation and need a contact person,

(2) those who want or have a supportive relationship, (3) those who seek guidance, information and practical or medical support; (4) and those who want a day off from the caregiving role. These profiles identify the unique and varied support needs and experiences with caregiving that are relevant to improving the quality of life of family caregivers.

Impact on Nursing Practice

The result of the study shows that male family caregivers and family caregivers of male patients and patients with metastatic disease have decreased quality of life. These findings identify the vulnerable groups that need support to improve their quality of life. The outcomes of this research may assist the nurses in initiating care plans for family caregivers, including developing programs, training, and educational resources to help them adjust to their responsibilities. The needs and level of care for cancer patients change over time, and so as the support needed by the family caregivers. Thus, nurses can develop a structure of intervention that supports the family caregiver's needs throughout the continuum of care.

Despite the support given to family caregivers, the result of the study shows only 12.6% of the family caregivers have a good quality of life. Although the pillars of care are centered toward person-centered care, the patient remains to be the focus of care, and family caregivers are not the center of priority.

Nurses play an essential role in promoting the health and safety of family caregivers and supporting their role in providing safe and effective care at home and in the community. The support the family caregiver receives is significant to prevent them

from being overloaded and overwhelmed with responsibility. Moreover, recognizing their role and treating them with respect and dignity helps them enhance their confidence and attain their full potential. Furthermore, a collaborative effort between the family caregiver and the nursing team should be emphasized to improve their roles and quality of life. The family caregiver is considered a provider and recipient of care. Thus, the family caregivers should be included in routine assessment and care planning, clearly and continuously. This could also be relevant for their quality of life and, ultimately, the quality of the patient's life (Bijnsdorp et al., 2020; Javison, 2021)

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APPENDICES

Appendix A

Letter of Request to Conduct the Study

February 17, 2022

Name of the Director of Nursing & Medical Director of Comprehensive Cancer Center
Administrator

Name of the Hospital
Riyadh, Saudi Arabia

Greetings! I am Jane Quinones, an ER/Hematology & Oncology Nurse from the Philippines and currently affiliated with King Fahad Medical City-Adult Emergency Department and formerly with Comprehensive Cancer Center. I am currently undertaking my Master of Arts in Nursing Degree at the University of the Philippine Open University (UPOU) and in the process of completing my research proposal. I am pursuing research relating to the sociodemographic factors and quality of life (QoL) among family caregivers of cancer patients in Saudi Arabia. In line with this may I ask your permission to conduct the research in Comprehensive Cancer Center.

Thank you very much for your support and rest assured proper documentation will be followed. Attached here is the IRB released by our hospital, the approval form from the nursing research committee, and the approval form from my research adviser and panels. Again, thank you very much for your support and understanding.

Kind regards,
Jane V. Quinones, RN
Researcher
KFMC ID: 010122

Appendix B

Letter Request to the Author of the Caregiver Quality of Life Index-Cancer (CQOL-C) Scale

September 22, 2021

Name of the Author
Author of the Caregiver Quality of Life Index-Cancer (CQOL-C) Scale

Dear Sir,

Greetings! I am Jane Quinones, an ER/Hematology & Oncology Nurse from the Philippines and currently affiliated with one of the hospitals in Saudi Arabia. I am currently undertaking my Master of Arts in Nursing Degree at the University of the Philippine Open University (UPOU) and in the process of completing my research proposal. In line with this may I ask your permission to have an access for the Caregiver Quality of Life Index-Cancer Scale. I am pursuing research relating to the sociodemographic factors and quality of life (QoL) among family caregivers of cancer patients in Saudi Arabia. Thank you very much and rest assured proper documentation will be followed.

Kind regards,
Jane V. Quinones
Researcher

Appendix C

Letter Request to the Author of the

Caregiver Quality of Life Index-Cancer (CQOL-C) Scale Arabic

August 2, 2021

Name of the Author

Author of the Caregiver Quality of Life Index-Cancer (CQOL-C) Scale Arabic

Dear Ma'am,

Greetings! I am Jane Quinones, an ER/Hematology & Oncology Nurse from the Philippines and currently affiliated with one of the hospitals in Saudi Arabia. I am currently undertaking my Master of Arts in Nursing Degree at the University of the Philippine Open University (UPOU) and in the process of completing my research proposal. In line with this may I ask your permission to have an access for the Caregiver Quality of Life Index-Cancer Scale Arabic Version. I am pursuing research relating to the sociodemographic factors and quality of life (QoL) among family caregivers of cancer patients in Saudi Arabia. I hope you understand my position. Thank you very much and rest assured proper documentation will be followed.

Kind Regards,
Jane V. Quinones

Appendix D

King Fahad Medical City Institutional Review Board Approval



IRB Registration Number with KACST, KSA: H-01-R-012
IRB Registration Number with OHRP/NIH, USA: IRB00010471
Approval Number Federal Wide Assurance NIH, USA: FWA00018774

February 6, 2022

IRB Log Number: 22-035

Department: Executive Administration of Nursing Affairs - Adult Emergency - Respiratory Zone-Triage

Category of Approval: EXEMPT

Dear Ms. Jane Viernes Quinones,

I am pleased to inform you that your submission dated January 25, 2022 for the study titled '**The relationship between sociodemographic factors and quality of life of family caregivers of cancer patients in Saudi Arabia**' was reviewed and was approved according to ICH GCP guidelines. Please note that this approval is from the research ethics perspective only. You will still need to get permission from the head of department or unit in KFMC or an external institution to commence data collection.

We wish you well as you proceed with the study and request you to keep the IRB informed of the progress on a regular basis, using the IRB log number shown above.

Please be advised that IRB for administrative purposes requires that you submit a progress report on your research every 6 months. You are required to submit any manuscript resulting from this research for approval by IRB before submission to journals for publication.

As a researcher you are required to have current and valid certification on protection human research subjects that can be obtained by taking a short online course at the US NIH site or the Saudi NCBE site followed by a multiple choice test. Please submit your current and valid certificate for our records. Failure to submit this certificate shall be a reason for suspension of your research project.

Sincerely yours,

Dr. Hussam Sakkijha, FCCP, FACP, Diplomat, ABSIM

Chairman Institutional Review Board-IRB

Consultant, Critical Care, Pulmonary & Sleep Medicine

Adult ICU Department

Critical Care Services Administration

King Fahad Medical City

P.O. Box. 59046, Riyadh 11525

Kingdom of Saudi Arabia

Mobile #: 053-941-7297 / E-mail: hsakkijha@kfmc.med.sa



Saudi Arabia - Riyadh
King Fahad Medical City
Faculty of Medicine
Phone:

المملكة العربية السعودية - الرياض
مدينة الملك فهد الطبية
كلية الطب
شؤون المساج
هاتف: 0112889999

Appendix E

King Fahad Medical City Nursing Research Committee Approval



KFMC NURSING RESEARCH COMMITTEE

NURSING RESEARCH APPLICATION FORM

Completed application form and submit it with your proposal to the KFMC Nursing Research Committee.

Principal Investigator: Name: Jane V. Quinones	Email: jquinones@kfmc.med.sa	Contact No.: 1111	Fax No:
Hospital: Emergency Center	Department: Adult Department	Section: Respiratory Zone/ Triage	
Research: Masters Degree ☒	PhD ☐ Institutional study ☐	Other ☐	
Study Title: The relationship between sociodemographic factors and quality of life of family caregivers of cancer patients in Saudi Arabia.			
Name of department/s where research will be conducted: Comprehensive Cancer Center			

Status of Principal Investigator: DON ☐ NMHN ☐ Charge Nurse ☒ Nurse Educator ☐ Staff Nurse 1,2,3 ☐ Other: ☐			
Co-Investigator(s):			
Study Supervisor/s:			
Approval letter from Institution/organization Yes: ☒ No: ☐			
Funding Information:	☐ Extramural	☐ Intramural	☒ No Funding
Funding Source(s):	☐ Government	☐ Industry	☐ Foundation
Study Sponsor:	Yes: ☐ No: ☒	Agency/Sponsor/Program	
Study Duration:	Start Date: February 2022	End Date: June 2022	

Study Description: State the objectives, value and necessity of the study. Include reasons why the proposed study should be undertaken in KFMC.

The current trend in cancer treatment involves inpatient hospital care and continuity of care in a home care setting; thus, the family caregiver plays an essential role in implementing the patient's treatment plan. From the time of the patient's diagnosis to the beginning of treatment until the end-of-life care, the family caregiver is involved throughout the caring process. The family caregiver provides support such as disease monitoring, management of signs and symptoms, pain management, home medication administration, emotional support, and personal assistance. These complex responsibilities of the family caregiver put them under stress that may affect their quality of life.

The act of caregiving changes the lifestyle, roles, relationships, and overall well-being of family caregivers. Studies have shown that the process of caregiving affects the family caregivers' psychological, emotional, functional, and even physical health and may decline their quality of life. Hence, the quality of life of family caregivers is critical to consider because it will affect the quality of care received by the cancer patient and consequently affects the patient's quality of life.

Several studies on the quality of life of family caregivers of cancer patients were conducted worldwide, but there is limited data and scarce literature that evaluates it in Saudi Arabian context. Thus, the result of this study will serve as baseline data in identifying the quality of life of family caregivers of cancer patients in Saudi Arabia and its relationship with sociodemographic factors. Furthermore, the result will serve as a source in developing programs to improve the quality of life of family caregivers.

KFMC

Appendix F

Certificate of Translation

Lexicology Translation Bureau

Certified Translation

C.R.: 1010845449 - Licence No.: 702

LTB

مكتب علوم المعاجم للترجمة

ترجمة معتمدة

س.ت: ١٠١٠٦٤٥٤٤٩ - رقم الترخيص: ٧٠٢

Certification

We, Lexicology Translation Bureau hereby certify that the text attached herewith in Arabic Language is a true and correct translation for the text attached herewith in English Language; and the translation was made from the original text. Furthermore we certify that the translator who has performed this translation is competent to translate.

In testimony whereof we set out hands and affixed the official seal of our office hereunto on this day 10/01/2022 in Riyadh, Kingdom of Saudi Arabia

مشهد

بهذا نشهد نحن مكتب علوم المعاجم للترجمة المعتمدة أن المستند الوارد باللغة العربية والمرفق بهذا هو ترجمة صحيحة ومطابقة للمستند باللغة الانجليزية للمرفق كذلك بهذا، وأن تلك الترجمة قد تمت من أصل المستند، وأن المترجم الذي قام بها هو مترجم مؤهل وكفاء.

وأثباتاً لذلك نضع هنا توقيعنا وختم مكتبنا في هذا اليوم الموافق ١٠/٠١/٢٠٢٢م في مدينة الرياض بالمملكة العربية السعودية

رقم العضوية: ٥٧٢٥٢٢

فايز صالح الياامي

Fayez Saleh Al-Yami

رقم العضوية: ٥٧٢٥٢٢

المملكة العربية السعودية - الرياض - شارع أبي بكر الرازي تقاطع شارع الضباب - جوال: ٠٥٥٤٢٣٧٨٢٦ - واتس اب: ٠٥٤٧٨٨٨١٨٧
Kingdom of Saudi Arabia - Riyadh - Abi Bakr Alrazi Street Intersection with Dabab Street - Mobile: 0554237826 - Whatsapp: 0547888187

E-mail: lexicologytranslation@gmail.com / darfeentranslation@gmail.com

Appendix G

Approval from Research Panels



UNIVERSITY OF THE PHILIPPINES
OPEN UNIVERSITY

FACULTY OF MANAGEMENT AND DEVELOPMENT STUDIES

26 November 2021

DR. PRIMO G. GARCIA

Dean, Faculty of Management and Development Studies
University of the Philippines Open University
Los Baños, Laguna

Through PROPER CHANNELS

Dear Dean Garcia:

We have the honor to inform you that the undersigned served in the oral examination of MS. JANE QUINONES/NA candidate who presented her thesis proposal with the final title "*The Relationship Between Sociodemographic Factors and Quality of Life of Family Caregivers of Cancer Patients in Saudi Arabia*" on 26, November, 2021, 1:30pm via Zoom and voted as follows:

PANEL MEMBERS	FOR APPROVAL	FOR DISAPPROVAL
ASST. PROF. QUEENIE R. RIDULME Adviser	_____	_____
MS. MARIA CECILIA E. PUNZALAN Co-adviser	_____	_____
MR. FRITZ GERALD JABONETE Member	_____	_____
ASST. PROF. RITA C. RAMOS Member	_____	_____
MS. IRENE KATE N. BAUTISTA Member	_____	_____

Committee's Decision:

(✓) PASSED

() FAILED

Additional Remark/s: Approved with minor revisions.

Very truly yours,

ASST. PROF. QUEENIE R. RIDULME
Adviser

ASST. PROF. RIA VALERIE D. CABANES
Program Chair, MAN

Appendix H

Informed Consent Form for the Respondents



University of the Philippines Open University

INFORMED CONSENT

موافقة مسبقة

Dear Sir/Ma'am: Greetings! I am Jane Viernes Quinones, an Adult Emergency Nurse, former Adult Hematology/Oncology Nurse, and a postgraduate student of the University of the Philippines Open University will be conducting a study entitled "The relationship between sociodemographic factors and quality of life of family caregivers of cancer patients in Saudi Arabia." In line with this, may I ask your kind involvement to be one of the participants of this research work.	سيدي العزيز / سيدتي العزيزة: تحياتي، أنا جين فيرنيس كينونيس، ممرضة طوارئ للبالغين، ممرضة سابقة بقسم أمراض الدم / الأورام للبالغين، وطالبة دراسات عليا في جامعة الفلبين المفتوحة، سأجري دراسة بعنوان "العلاقة بين العوامل الاجتماعية والديموغرافية ونوعية حياة مقدمي الرعاية للأسر مرضى السرطان في السعودية". استجابة لهذا، فإنني أطلب مشاركتك الطبية لتكون أحد المشاركين في هذا العمل البحثي.
PURPOSE: Family caregiver (FC) is identified as someone who provides care for a sick relative or loved one. This study aims to identify the relationship between the sociodemographic factors and the quality of life of family caregivers of cancer patients in Saudi Arabia. Specifically, it aims to identify the quality of life of family caregivers of cancer patients in Saudi Arabia. Furthermore, the research will identify the relationship of sociodemographic factors with the quality of life of family caregivers of cancer patients. Your participation is essential to us, and rest assured that all data will be kept strictly confidential.	الغرض: يُعرف مقدم الرعاية الأسري بأنه شخص يقدم الرعاية لقريب مريض أو أحد أفراد أسرته. تهدف هذه الدراسة إلى التعرف على العلاقة بين العوامل الاجتماعية والديموغرافية ونوعية الحياة الأسرية لمقدمي الرعاية لمرضى السرطان في المملكة العربية السعودية. على وجه التحديد، يهدف إلى تحديد نوعية حياة مقدمي الرعاية الأسرية لمرضى السرطان في المملكة العربية السعودية. علاوة على ذلك، سيحدد البحث علاقة العوامل الاجتماعية والديموغرافية بنوعية حياة مقدمي الرعاية الأسرية لمرضى السرطان. مشاركتك ضرورية لنا، وكن مطمئناً إلى أن جميع البيانات ستبقى سرية تماماً.
CHOICE OF PARTICIPANTS: As someone who lives closely and take care for a patient, I am inviting you to participate in the study. You will be among the 373 subjects who are invited to participate. Family caregivers of cancer patients who come to King Fahad Medical City for their patient's consultation, admission, follow-up, and treatment procedures are invited to join the study. An information questionnaire will be utilized to evaluate the quality of life of family caregivers of cancer patients.	اختيار المشاركين: بصفتي شخصاً يعيش بالقرب من ويعتني بمرضى، أدعوك للمشاركة في هذه الدراسة. ستكون من بين 373 تمت دعوتهم للمشاركة. تمت دعوة مقدمي الرعاية الأسرية لمرضى السرطان الذين يأتون إلى مدينة الملك فهد الطبية للاستشارة من أجل المريض وإدخال المريض للمستشفى والمتابعة وإجراءات العلاج للانضمام إلى الدراسة. سيتم استخدام استبيان المعلومات لتقييم نوعية الحياة لمقدمي الرعاية الأسرية لمرضى السرطان.
VOLUNTARY PARTICIPATION: The information in this consent form is provided to decide whether you wish to participate in our study. It is crucial that you understand that your participation is voluntary. This means that even if you agree to participate, you are free to withdraw from the study at any time, without	المشاركة التطوعية: يتم توفير المعلومات الواردة في نموذج الموافقة هذا لتحديد ما إذا كنت ترغب في المشاركة في دراستنا. من الضروري أن تفهم أن مشاركتك تطوعية. هذا يعني أنه حتى لو وافقت على المشاركة، فأنت حر في الانسحاب من الدراسة في أي وقت دون حرج.

penalty.	
PROCEDURE: Family caregivers of cancer patients who come to King Fahad Medical City for their patient's consultation, admission, follow-up, emergency care and treatment procedures will be invited to the study. A structured questionnaire checklist will be utilized for data collection. The structured questionnaire will consist of two parts: Part 1 will deal with sociodemographic information; Part 2 will be allocated to assess the quality of life of family caregivers. Consent will be given to the subjects for approval of participation after explaining the aims of the study. For family caregivers who cannot read, an interview method will be led by the research members by reading the questions and options to the participant, and then the patient will select the answer. The sociodemographic information questionnaire is in the English language, but the CQOL-C was translated into Arabic; thus, the sociodemographic information will be translated to the Arabic language. The completed questionnaires will be collected in a data collection box designated in the inpatient and ambulatory units of Comprehensive Cancer Center. To maintain consistency in data collection, the investigator and members of the research team will monitor the process of data collection.	الإجراء: سيتم دعوة مقدمي الرعاية الأسرية لمرضى السرطان الذين يأتون إلى مدينة الملك فهد الطبية للاستشارة من أجل المريض وإدخال المريض للمستشفى والمتابعة والرعاية الطارئة وإجراءات العلاج للدراسة. سيتم استخدام قائمة مرجعية للاستبيان منظم لجمع البيانات. سيتكون الاستبيان المنظم من جزئين: الجزء الأول سيتعامل مع المعلومات الاجتماعية الديموغرافية؛ بينما يخصص الجزء الثاني لتقييم نوعية حياة مقدمي الرعاية الأسرية. سيتم الموافقة على الموضوعات للموافقة على المشاركة بعد شرح أهداف الدراسة. بالنسبة لمقدمي الرعاية الأسرية الذين لا يستطيعون القراءة، سيقود أعضاء البحث طريقة المقابلة من خلال قراءة الأسئلة والخيارات للمشاركة، ثم سيختار المريض الإجابة. استبيان المعلومات الاجتماعية الديموغرافية باللغة الإنجليزية، ولكن تمت ترجمة CQOL-C إلى العربية؛ وعليه سيتم ترجمة المعلومات الاجتماعية الديموغرافية إلى اللغة العربية. سيتم جمع الاستبيانات المكتملة في صندوق جمع البيانات المخصص في وحدات المرضى الداخليين والمتقنين في مركز السرطان الشامل. للحفاظ على التناسق في جمع البيانات، سيقوم المحقق وأعضاء فريق البحث بمراقبة عملية جمع البيانات.
RISKS: The study will not be inflicting any harm to you since the result will serve as baseline data in improving the quality of life of family caregivers. Moreover, it will not affect your patient's treatment plan and will not be used to initiate sanctions or penalties.	المخاطر: لن تؤدي الدراسة إلى إلحاق أي ضرر بك لأن النتيجة ستكون بمثابة بيانات أساسية في تحسين نوعية حياة مقدمي الرعاية الأسرية. علاوة على ذلك، لن يؤثر ذلك على خطة علاج المريض ولن يتم استخدامها لبدء جزاءات أو عقوبات.
BENEFITS: King Fahad Medical City promotes Quality Improvement and Person-centered care. As part of quality improvement, the result of the study will serve as baseline data in developing programs to improve the quality of life of family caregivers and improve the efficiency of care received by the patients. Moreover, the result of the study will help the healthcare providers develop programs for family caregivers that will foster their resilience and empower their role as informal caregivers in the homecare setting.	الفوائد: تعزز مدينة الملك فهد الطبية تحسين الجودة والرعاية التي تركز على الفرد. كجزء من تحسين الجودة، ستكون نتيجة الدراسة بمثابة بيانات أساسية في تطوير البرامج لتحسين نوعية حياة مقدمي الرعاية الأسرية وتحسين كفاءة الرعاية التي يتلقاها المرضى. علاوة على ذلك، ستساعد نتيجة الدراسة مقدمي الرعاية الصحية على تطوير برامج لمقدمي الرعاية الأسرية من شأنها تعزيز مرونتهم وتمكين دورهم كمقدمي رعاية غير رسميين في بيئة الرعاية المنزلية.

CONFIDENTIALITY: You, the participant, will get access to the result of the study. We will not share information about you with anyone who does not work in the research study. While in this study, all information you will give will only be used in the research study and in my group's presentation. In case the study is published, respondents will be kept confidential.	السرية: أيها المشارك، سوف يتم تمكينك للوصول إلى نتيجة الدراسة. لن نشارك معلومات عنك مع أي شخص لا يعمل في الدراسة البحثية. أثناء إجراء هذه الدراسة، سيتم استخدام جميع المعلومات التي ستقدمها فقط في الدراسة البحثية وفي العرض التقديمي لمجموعتي. في حالة نشر الدراسة، سيتم الحفاظ على سرية المشاركين.
CONTACT INFORMATION: If you have questions or clarifications regarding the study, you may call me at 011 288 999 extensions 29779 or 29989 or thru my mobile at 0502721409 and look for Ms. Jane Viernes Quinones or call Mr. Mousa Saud Al-Mutairi at 0558481074 for assistance.	معلومات التواصل: إذا كانت لديك أسئلة أو استفسارات بخصوص الدراسة، فيمكنك الاتصال بي على الرقم 011288999 تحويله 29779 أو تحويله 29989 أو من خلال هاتفي المحمول على الرقم 0502751409 للتواصل مع السيدة / جين فيرنيس كينونيس أو الاتصال بالسيد / موسى سعود المطيري على الرقم 0558481074 للحصول على المساعدة.
DECLARATION OF WILLINGNESS TO PARTICIPATE IN THE STUDY I have read and understood the information stated above. I am giving my permission to participate ☐ Agree ☐ Disagree Date: _____ Witness: Name: _____ Signature: _____ Date: _____	إعلان الرغبة في المشاركة في الدراسة لقد قرأت وفهمت المعلومات المذكورة أعلاه. هنا أعلن موافقتي للمشاركة في هذه الدراسة. ☐ موافق ☐ غير موافق التاريخ _____ إسم الشاهد ورقم هويته _____ التوقيع _____ التاريخ _____

Appendix I

Research Tool



University of the Philippines Open University

Questionnaire

استبيان

Part 1	الجزء الأول
A. Patient' Profile (This section is sociodemographic-clinical information about the patient). Instruction: The items below area the desired profile of the patient which the researcher would need in her study. Kindly provide the correct information by writing or checking the blank space provided before each appropriate item. Please do not leave a blank unanswered. Age: _____ Sex: ☐ Male ☐ Female Type of Cancer ☐ Head and Neck Cancer ☐ Lung Cancer ☐ Digestive tract and digestive organ cancer ☐ Breast Cancer ☐ Blood Cancer (Lymphoma/Leukemia) ☐ Female Genital ☐ Male genital ☐ Renal Cancer ☐ Bone/Muscle/Soft Tissue Cancer ☐ Skin Cancer ☐ Other (Specify) Presence of Metastasis ☐ Yes (Cancer spread to other areas of the body) ☐ No Duration of illness: ☐ 1-3months ☐ 3-6 months ☐ 6-9 months ☐ 9-12 months ☐ over a year	أ. الملف التعريفي للمريض (هذا القسم عبارة عن معلومات اجتماعية وديموغرافية إكلينيكية عن المريض). تعليمات: العناصر أدناه تحدد الملف الشخصي المطلوب للمريض والذي ستحتاجه الباحثة في دراستها. يرجى تقديم المعلومات الصحيحة عن طريق الكتابة أو التحقق من المساحة الفارغة المتوفرة قبل كل عنصر مناسب. من فضلك لا تترك فراغ دون إجابة. العمر: _____ الجنس: ☐ ذكر ☐ أنثى نوع السرطان: ☐ سرطان الرأس والعنق ☐ سرطان الرئة ☐ سرطان الجهاز الهضمي وسرطان الأعضاء الهضمية ☐ سرطان الثدي ☐ سرطان الدم (سرطان الغدد الليمفاوية / اللوكيميا) ☐ الأعضاء التناسلية الأنثوية ☐ الأعضاء التناسلية الذكورية ☐ سرطان الكلى ☐ سرطان العظام / العضلات / الأنسجة الرخوة ☐ سرطان الجلد ☐ أخرى (يرجى التحديد) وجود ورم خبيث ☐ نعم (السرطان ينتشر إلى مناطق أخرى من الجسم) ☐ لا مدة المرض 1-3 أشهر ☐ 3 - 6 شهور 6 - 9 شهور ☐ 9 - 12 شهرا ☐ أكثر من عام



University of the Philippines Open University

Questionnaire

استبيان

B. Family Caregiver's Profile (This section is sociodemographic-clinical information about the Family Caregiver)

Instruction: The items below are the desired profile of the family caregiver which the researcher would need in her study. Kindly provide the correct information by writing or checking the blank space provided before each appropriate item. Please do not leave a blank unanswered.

Age: _____ Sex: ☐ Male ☐ Female

Level of Education:

- ☐ Illiterate ☐ High School Certificate
☐ Diploma Degree ☐ Baccalaureate Degree
☐ Master Degree ☐ PHD Degree

Employment status:

- ☐ Employed ☐ Leave of absence
☐ Quit for Care ☐ Not employed

Marital status:

- ☐ Single ☐ Married
☐ Widow/Widower ☐ Divorced

Relationship to patient:

- ☐ Wife ☐ Husband
☐ Mother ☐ Siblings (brother/sister)
☐ Son ☐ Daughter
☐ Others (Specify): _____

Income:

- ☐ Low
☐ Equal (Meet financial and economic demands)

Duration of care:

- ☐ 1-3months ☐ 3-6 months
☐ 6-9 months ☐ 9-12 months
☐ over a year

ب. الملف التعريفي لمقدم الرعاية الأسرية (هذا القسم عبارة عن معلومات اجتماعية وديموغرافية سريرية حول مقدم الرعاية الأسرية).

تعليمات: العناصر أدناه تحدد الملف الشخصي المطلوب لمقدم الرعاية الأسري الذي ستحتاجه الباحثة في دراستها. يرجى تقديم المعلومات الصحيحة عن طريق الكتابة أو التحقق من المساحة الفارغة المتوفرة قبل كل عنصر مناسب. من فضلك لا تترك فراغ دون إجابة.

العمر: _____ الجنس: ☐ ذكر ☐ أنثى

المستوى التعليمي:

- ☐ لمي ☐ شهادة الثانوية العامة

☐ درجة الدبلوم ☐ درجة البكالوريا

☐ ماجستير ☐ درجة الدكتوراه

الحالة الوظيفية:

☐ يعمل ☐ إجازة الغياب

☐ توقف للرعاية ☐ لا يعمل

الحالة الاجتماعية:

☐ أعزب ☐ إجازة الغياب

☐ أرمل / أرملة ☐ مطلق / مطلقة

العلاقة مع المريض:

☐ زوجة ☐ متزوج

☐ أم ☐ قريب (أخ / أخت)

☐ ابن ☐ ابنة

☐ غيرهم (يرجى التحديد): _____

الدخل:

☐ منخفض ☐ مساوي (يلبي المتطلبات المالية والاقتصادية)

مدة الرعاية:

☐ 1-3 أشهر ☐ 3 - 6 أشهر

☐ 6 - 9 أشهر ☐ 9 - 12 شهرًا

☐ أكثر من عام



University of the Philippines Open University

Questionnaire

Part 2:

استبيان

CAREGIVER QUALITY OF LIFE- CANCER

Below is a list of statements that other people caring for loved ones with cancer have said are important. By circling one number per line, please indicate how true each statement has been for you during the past seven days.

		0	=	Not at all	2	=	Somewhat		
		1	=	A little bit	3	=	Quite a bit		
		4	=	Very much					
1.	It bothers me that my daily routine is altered.	0	1	2	3	4			
2.	My sleep is less restful.	0	1	2	3	4			
3.	My daily life is imposed upon.	0	1	2	3	4			
4.	I am satisfied with my sex life.	0	1	2	3	4			
5.	It is a challenge to maintain my outside interests.	0	1	2	3	4			
6.	I am under a financial strain.	0	1	2	3	4			
7.	I am concerned about our insurance coverage.	0	1	2	3	4			
8.	My economic future is uncertain.	0	1	2	3	4			
9.	I fear my loved one will die.	0	1	2	3	4			
10.	I have more of a positive outlook on life since my loved one's illness.	0	1	2	3	4			
11.	My level of stress and worries has increased.	0	1	2	3	4			
12.	My sense of spirituality has increased.	0	1	2	3	4			
13.	It bothers me, limiting my focus to day-to-day.	0	1	2	3	4			
14.	I feel sad.	0	1	2	3	4			
15.	I feel under increased mental strain.	0	1	2	3	4			
16.	I get support from my friends and neighbors.	0	1	2	3	4			
17.	I feel guilty.	0	1	2	3	4			

18.	I feel frustrated.	0	1	2	3	4
19.	I feel nervous.	0	1	2	3	4
20.	I worry about the impact my loved one's illness has had on my children or other family members.	0	1	2	3	4
21.	I have difficulty dealing with my loved one's changing eating habits.	0	1	2	3	4
22.	I have developed a closer relationship with <u>my</u> loved one.	0	1	2	3	4
23.	I feel adequately informed about my loved one's illness.	0	1	2	3	4
24.	It bothers me that I need to be available to chauffeur my loved one to appointments.	0	1	2	3	4
25.	I fear the adverse effects of treatment on <u>my</u> loved one.	0	1	2	3	4
26.	The responsibility I have for my loved one's care at home is overwhelming.	0	1	2	3	4
27.	I am glad that my focus is on getting <u>my</u> loved one well.	0	1	2	3	4
28.	Family communication has increased.	0	1	2	3	4
29.	It bothers me that my priorities have changed.	0	1	2	3	4
30.	The need to protect my loved one bothers me.	0	1	2	3	4
31.	It upsets me to see my loved one deteriorate.	0	1	2	3	4
32.	The need to manage my loved one's pain is overwhelming.	0	1	2	3	4
33.	I am discouraged about the future.	0	1	2	3	4
34.	I am satisfied with the support I get from <u>my</u> family.	0	1	2	3	4
35.	It bothers me that other family members have not shown interest in taking care of my loved one.	0	1	2	3	4

Caregiver Quality of Life- Cancer Arabic Version

رقم الهوية: _____ التاريخ: ____/____/____

نوعية حياة مقدم الرعاية - السرطان

فيما يلي قائمة بالعبارات التي ذكر الأشخاص الذين يقدمون الرعاية لأحبائهم المصابين بالسرطان أنها مهمة، الرجاء اختيار مدى صحة هذه العبارات بالنسبة لك خلال الأيام السبعة الماضية وذلك بوضع دائرة حول رقم واحد في كل سطر:

0 = لا على الإطلاق 2 = نوعاً ما
1 = قليلاً 3 = كثيراً
4 = كثيراً جداً

خلال الأيام السبعة الماضية:

- | | | | | | |
|---|---|---|---|---|--|
| 4 | 3 | 2 | 1 | 0 | 1. يزعجني حدوث تغيير في نظام يومي المعتاد. |
| 4 | 3 | 2 | 1 | 0 | 2. نومي أقل راحة. |
| 4 | 3 | 2 | 1 | 0 | 3. تم التطفل على حياتي اليومية. |
| 4 | 3 | 2 | 1 | 0 | 4. أنا راضٍ عن الناحية الجنسية في حياتي. |
| 4 | 3 | 2 | 1 | 0 | 5. تشكل المحافظة على اهتماماتي الخارجية تحدياً بالنسبة لي. |
| 4 | 3 | 2 | 1 | 0 | 6. أعاني من صعوبات مالية. |
| 4 | 3 | 2 | 1 | 0 | 7. أشعر بالقلق فيما يتعلق بتغطية بوليصة التأمين الخاصة بنا. |
| 4 | 3 | 2 | 1 | 0 | 8. مستقبلي المالي غير واضح. |
| 4 | 3 | 2 | 1 | 0 | 9. أخشى موت من أحب. |
| 4 | 3 | 2 | 1 | 0 | 10. لدي نظرة أكثر إيجابية عن الحياة منذ أن مرض من أحب. |
| 4 | 3 | 2 | 1 | 0 | 11. لقد ازداد مستوى الضغوطات والهموم لدي. |
| 4 | 3 | 2 | 1 | 0 | 12. لقد ارتفع شعوري بالروحانية. |
| 4 | 3 | 2 | 1 | 0 | 13. يزعجني محدودية تركيزي على ما ينبغي فعله يوماً بيوم. |
| 4 | 3 | 2 | 1 | 0 | 14. أشعر بالحزن. |
| 4 | 3 | 2 | 1 | 0 | 15. أشعر بضغط عقلي متزايد. |
| 4 | 3 | 2 | 1 | 0 | 16. أتلقى الدعم من أصدقائي وجيراني. |
| 4 | 3 | 2 | 1 | 0 | 17. أشعر بالذنب. |
| 4 | 3 | 2 | 1 | 0 | 18. أشعر بالإحباط. |
| 4 | 3 | 2 | 1 | 0 | 19. أشعر بالقلق. |
| 4 | 3 | 2 | 1 | 0 | 20. أشعر بالقلق تجاه تأثير مرض من أحب على أطفالي أو أفراد العائلة الآخرين. |
| 4 | 3 | 2 | 1 | 0 | 21. أجد صعوبة في التأقلم مع تغير عادات الطعام لدى من أحب. |
| 4 | 3 | 2 | 1 | 0 | 22. لقد بنت أكثر قرباً ممن أحب/ لقد ازدادت علاقتي بمن أحب قريباً. |
| 4 | 3 | 2 | 1 | 0 | 23. أشعر بأنه تم إطلاعي بشكل جيد حول مرض من أحب. |

24. تزعجني ضرورة أن أكون متواجداً لأخذ من أحب إلى مواعيده. 0 1 2 3 4
25. أخشى الآثار الجانبية للعلاج على من أحب. 0 1 2 3 4
26. تتسبب لي المسؤولية الملقاة على عاتقي فيما يتعلق برعاية من أحب بشعور غامر. 0 1 2 3 4
27. أنا سعيد بتركيزي على تحسين صحة من أحب. 0 1 2 3 4
28. لقد ازداد التواصل العائلي لدينا. 0 1 2 3 4
29. يزعجني تغير أولوياتي في الحياة. 0 1 2 3 4
30. تزعجني الحاجة إلى حماية من أحب. 0 1 2 3 4
31. تضايقتني رؤية تدهور صحة من أحب. 0 1 2 3 4
32. تتسبب لي الحاجة إلى التعامل مع ألم من أحب بشعور غامر/ كاسح. 0 1 2 3 4
33. أنا محبط فيما يتعلق بالمستقبل. 0 1 2 3 4
34. أنا راضٍ عن قدر الدعم الذي أحصل عليه من عائلتي. 0 1 2 3 4
35. يزعجني عدم إظهار أفراد الأسرة الآخرين اهتماماً للمشاركة في رعاية من أحب. 0 1 2 3 4

Appendix J

Caregiver Quality of Life- Cancer Scoring Algorithm

Caregiver Quality of Life--Cancer

CQOLC Items	Scoring Algorithm
1 It bothers me that my daily routine is altered.	4 - ____
2 My sleep is less restful.	4 - ____
3 My daily life is imposed upon.	4 - ____
4 I am satisfied with my sex life.	0 + ____
5 It is a challenge to maintain my outside interests	4 - ____
6 I am under a financial strain.	4 - ____
7 I am concerned about our insurance coverage.	4 - ____
8 My economic future is uncertain	4 - ____
9 I fear my loved one will die.	4 - ____
10 I have more of a positive outlook on life since my loved one's illness.	0 + ____
11 My level of stress and worries has increased.	4 - ____
12 My sense of spirituality has increased.	0 + ____
13 It bothers me, limiting my focus to day-to-day.	4 - ____
14 I feel sad.	4 - ____
15 I feel under increased mental strain.	4 - ____
16 I get support from my friends and neighbours.	0 + ____
17 I feel guilty.	4 - ____
18 I feel frustrated.	4 - ____
19 I feel nervous.	4 - ____
20 I worry about the impact my loved one's illness has had on my children or other family members.	4 - ____
21 I have difficulty dealing with my loved one's changing eating habits.	4 - ____
22 I have developed a closer relationship with my loved one.	0 + ____
23 I feel adequately informed about my loved one's illness.	0 + ____
24 It bothers me that I need to be available to chauffeur my loved one to appointments.	4 - ____
25 I fear the adverse effects of treatment on my loved one.	4 - ____
26 The responsibility I have for my loved one's care at home is overwhelming.	4 - ____
27 I am glad that my focus is on getting my loved one well.	0 + ____

Appendix K

Research Timeline

Time schedule	
Time/Date	Task/Strategy
Week One-Two	Presentation of research to the Nursing Research Committee
Week Three-Six	Presentation of research to the Research Center and Institutional Review Board of King Fahad Medical City
Week Six- Eight	Presentation of research to the Nurse Manager, Director of Nursing of Comprehensive Cancer Center, and Director of Hematology, Oncology and Palliative Medicine
Week Nine- Fourteen	Data Collection
Week Fifteen-Twenty-Four	Analysis of Data; Writing of Report

Appendix L

Curriculum Vitae

JANE V. QUINONES, RN

Home Address: 153 Lower Fairview, Baguio City, Philippines, 2600
Current Address: King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia
Mobile No.:
Email: jane010122@gmail.com/janvique@gmail.com



Date of Birth	:	March 29, 1987
Place of Birth	:	Baguio City
Citizenship	:	Filipino
Civil Status	:	Single
Religion	:	Roman Catholic
Position Applied	:	Nurse (Emergency Department)
Language Spoken	:	English, Arabic, Filipino, Ilocano
PRC License No.	:	0459130 (Date of expiration: 29/03/2021)
Saudi Council ID No.	:	10-J-N-0330639 (Date of expiration: July 2023)
Objective	:	To seek a challenging and responsible position, which would effectively utilize prior experience, training and abilities, offering opportunities for professional growth and advancement.

EDUCATION

Postgraduate Education:

University of the Philippines Open University, *Los Banos, Laguna*
June 2013- Present
Master of Arts in Nursing: Major in Adult Health Nursing

College Education

Benguet State University, *La Trinidad, Benguet*
March 2007

Bachelor of Science in Nursing, *Cum Laude*

Awards: Outstanding Achievement in Academics (2007)
Outstanding Achievement in Clinical Practice (2007)
Outstanding Achievement in Sports (2007)
Academic Achiever of the Year- College Scholar (2004, 2005, 2007)

Secondary Education

Pines City National High School (Science Class), *Palma St., Baguio City*
March 2003

Award: 6th Honor

Elementary Education

Bonifacio Elementary School, *Bado Dangwa St., Baguio City*

March 1999

Awards: Valedictorian and Athlete of the Year

WORK EXPERIENCE

King Fahad Medical City

Staff Nurse (Adult Emergency Department)

Riyadh, Saudi Arabia

September 22, 2011- June 2018; March 2020-May 2022

Job Description

- Able to categorize & prioritize in rendering emergency treatment and observations (Triage);
- Performs physical assessment and obtains patient health history;
- Participates and assists in emergency treatment;
- Provides patient comfort and privacy;
- Provides health education to patients;
- Recognizes patient's cultural background as good source of rendering care;
- Admits/Discharges patients as per policies of the institution;
- Respects superiors and colleagues;
- Learns technical skills in relation of correct usage of medical machines;
- Able to adapt in hospital computerized system, i.e. clerical and computer works;
- Provides support to the health team;
- Maintains good attitude and relationship with hospital personnel.

King Fahad Medical City

Charge Nurse/Shift Manager (Comprehensive Cancer Center- Adult Department)

Riyadh, Saudi Arabia

June 2018- February 2020

Job Description

- Performs physical assessment and obtains patient health history for hematology and oncology;
- Provides comprehensive health education to hematology and oncology patients and their families regarding the disease, treatment plans and possible side effects;
- Evaluate and monitor physical and emotional status of patients;
- Administer medications related to cancer treatment like chemotherapy;
- Assist in the provision of supportive care and treatment for patient symptoms;
- Works with multidisciplinary team regarding patients treatment plan;

- Supervise and assist in performing daily activities of the assigned shift in accordance with the policies and procedures;
- Supervise and assist the implementation of all aspects of the nursing process, including assessment, diagnosis, plan and evaluation;
- Participate in the optimal management of hospital resources;
- Collaborate with Unit Manager to identify departments' required projects to meet future demands.

Dr. Adel Bahlas Medical Center
Staff Nurse (Emergency Room and OPD)

Jeddah, Saudi Arabia

February 2009- April 24, 2011

Nature of Work:

- Provides direct nursing care activities;
- Administers and records medications;
- Assumes responsibility in the preparation of procedures including gathering necessary equipment and organizing patients chart;
- Assists physicians in the treatment and administration of specialized procedures;
- Provides a holistic nursing care to homecare patients;
- Participates in the vaccination campaign during Hajj period (administers vaccines for meningitis and influenza)

St. Martin's Mission Hospital
Staff Nurse (Emergency Room and General Wards)

Sablayan, Occidental Mindoro, Philippines

November 2007- January 2009

Nature of Work:

- Provides direct patient care activities and professional nursing services required in the nursing care of patients;
- Administers and records medications, cognizant of reactions and reports harmful side effects to the physician;
- Adheres to nursing service policies and procedures in the performance of patient care activities;
- Documents in the patient's chart nursing observation and care provided according to problem-oriented record system;
- Maintains effective relationship with patients, visitors and other hospital personnel;
- Assists physicians in the treatment/or administering specialized therapy, utilizing equipment and instrumentation;
- Provides thorough health education to the Mangyan natives, the indigenous people of Mindoro;
- Assumes responsibility when referring patients to a tertiary level hospital;
- Participates in medical missions organized by the hospital;
- Delegates responsibilities to subordinates according to their nature of work;
- Performs other job related duties as directed.

TRAININGS/SEMINARS

Comprehensive Pain Management

Date attended: April 15, 2019

Adult Oncology Course

Date attended: March 19, 2019

Annual Saudi Hematology Research Group (SHRG) Meeting 2019

Date attended: February 16, 2019

Hematology Year Review

Date attended: February 15, 2019

Evidence Based Chemotherapy and Oncology Emergencies Nursing Course

Date attended: November 25, 2018

Motivation Sources Among Cancer Center Nurses

Date attended: November 3, 2018

Central Venous Catheters Care and Maintenance Course

Date attended: October 29, 2018

Adult Oncology Nursing Course: End of Life Care and Psychosocial Dimension of Care

Date attended: October 22, 2018

Adult Oncology Nursing Course: Treatment Modalities & Nursing Management of Common Side Effects

Date attended: October 15, 2018

Adult Oncology Nursing Course: Adult Specific Cancer Management

Date attended: October 08, 2018

Adult Oncology Nursing Course: Health Promotion, Cancer Prevention and Early Detection

Date attended: October 01, 2018

Saudi CTAS Course

Date attended: May 02, 2018

Triage in Real Action

Date attended: April 04, 2018

Surgical Site Infection Course

Date attended: May 16, 2017

Basic Life Support: Health Care Provider Course

Issue date: February 04, 2018

Renewal date: February 2020

Advanced Cardiac Life Support: ACLS Provider

Issue date: November 26-27, 2017

Renewal date: November 2019

Surgical Site Infection

Date attended: May 16, 2017

Preceptorship

Date attended: August 30-31, 2017

SPECIAL ACHIEVEMENTS:

- Quality Project: Strategic Intervention to deal with MERS-CoV Psychological Distress (Adult Emergency Department, 2016-2017)
- Quality Project: Emergency Center Website Improvement Project (ongoing)

REFERENCES:

Mohammed Al Awneh

Former Head Nurse, Emergency Center- Adult

King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia

malwaneh@kfmc.med.sa

Muawiyah Yaqub

Director of Nursing, Comprehensive Cancer Center

King Fahad Medical City, Riyadh, Kingdom of Saudi Arabia

myaqub@kfmc.med.sa

I hereby certify that the above information is true and correct to the best of my knowledge and belief.

Jane V. Quinones

Researcher