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A SUPPORT PROGRAMME FOR CAREGIVERS OF CANCER PATIENTS IN THE PALESTINIAN CONTEXT

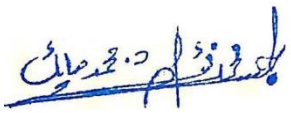
MOHAMMED F. A. HAYEK

A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, in fulfillment of the requirements for the degree of Doctor of Philosophy

Johannesburg, 2020

DECLARATION

I, Mohammed Hayek, declare that this thesis is my own work. It is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not previously been submitted for any degree or examination at this or any other university.

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PREVIOUES PUBLICATIONS

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4- Hayek M., Maree, J. E. 2018. Support care need for caregivers of cancer patients: Scoping the landscape of evidence at An Najah national university – faculty of medicine and health sciences research day - 22 of March 2018.

DEDICATION

Great is your faithfulness Allah, I am so grateful.

I dedicate this work to my little angels, Ameer, and dear Wife, Simon, for standing by me through this very tough journey and to my mother, brother and the rest of my family for their continuous support and sacrifices. This work is dedicated to all cancer patients and their caregivers who may have suffered from cancer. I hope that this work will contribute to evidence that will be used to develop interventions that could accelerate the ending of their suffering, enhancing their overall QoL and decline caregivers care burden as well as decline the cancer patients symptoms burden.

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My mum, my pillar of strength, the person l run to when I feel like it is all too much for me to take. Thanks for encouraging me and for never allowing me to give up. My dear brother and sister, thank you for your support and prayers.

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ABSTRACT

***Background**:* Caring for a cancer patient is not easy and caregivers receive little preparation, information, and support to carry out their caregiving role. Caregivers experience physical, psychosocial/spirituals, emotional, financial distress, which increase their risk for burden, poor quality of life (QoL), and burnout.

Aim: The study aimed to develop and pilot test a support programme for caregivers of cancer patients in Palestine.

Methods: The study was underpinned by Lazarus and Folkman's transactional model of stress and coping. A sequential multi-method study design which employed two scoping reviews, and an intervention design with pre-test post-test approach was used. Therefore, the study had four Phases. Phase One was a scoping review, to synthesise the evidence regarding the support needs of caregivers of cancer patients, Phase Two was the second scoping review in order to exhaust the viability of published support programmes for caregivers of patients diagnosed with cancer, Phase Three was a developed/adapted and validated a support programme for caregivers of cancer patients and Phase Four was pilot tested of the support programme. The primary outcome was caregiver QoL and secondary outcomes caregiver burden, patient pain, symptom burden and QoL. Sampling was convenience and fifty care givers (n=50) and (n=50) patients were recruited. The Caregiver QoL Index-Cancer (CQOLC) and Zarit Burden Interview (ZBI) measured caregiver outcomes and The Brief Pain Inventory (BPI), EORTC QLQ and Memorial Symptom Assessment Scale (MSAS) measured patient pain, QoL and symptom burden.

***Results**:* The first scoping review revealed that the caregivers had numerous unmet needs which were grouped in seven themes namely: information and emotional needs, cancer care services and physical, social, psychological/spiritual and financial support needs.

Different caregivers support programmes were investigated from included studies in the second scoping review, which are varied in the scope of interest. All the studies were conducted in developed countries. A shared theme in most of the works that offered

programmes was easy to understand and applicable to the participants, to facilitate the sharing of experiences as well as enhancing their role as caregivers in cancer care. In response to the support needs identified, a support programme was developed, validated by a group of experts and implemented. There was an improvement in caregiver burden and caregivers and patient QoL post intervention. There an improvement change in the patients' pain severity score post intervention. The worst pain and pain interference with daily activities also showed an improvements as well as the total symptom burden, the global distress index and psychosocial symptoms were improved post intervention.

Conclusion: The study provided evidence that the support program had a positive influence on the QoL of the caregivers and decreased their caregiving burden. In addition, the patients also benefitted as their QoL, symptom burden and pain improved. The positive results support the conclusion that the programme was successful and emphasizes the importance of such programs to improve the lives of cancer patients and their caregivers. However, this was a pilot study without a control group and a small number of participants. Therefore, the results should be not overemphasized and considered cautiously.

Keywords*:* Cancer, Care burden, Quality of life (QoL), Support program, Cancer symptoms burden.

ACRONYMS AND ABBREVIATIONS

ADLs	Activities of daily living
ACS	American Cancer Society
BPI	Brief Pain Inventory
CGEP	Carer Group Education Program
CEO	Chief Executive Officer
CBT	Cognitive Behaviour Therapy
CT	Computer Tomography
CR	Complete Response
COPE	(Creativity, optimism, planning, and expert information)
CQOLC	Caregiver Quality of Life Index-Cancer
ECOG	Eastern Cooperative Oncology Group
ENABLE	Educate Nurture Advise Before Life Ends
EFT	Emotionally Focused Therapy
ESMO	European Society of Medical Oncology
EORTC	European Organization for Research and Treatment of Cancer Quality of Life Questionnaire
EBT	Existential behavioural therapy
FOCUS	(Family involvement, Optimistic attitude, Coping effectiveness, Uncertainty reduction, and Symptom management)
HREC	Human Research Ethics Committee
IRB	Institutional Review Board
JBI	Joana Briggs Institute
IPC	Interdisciplinary palliative care plan
LNLW	Learn Now, Live Well
MRI	Magnetic Resonance Imaging
MSAS	Memorial Symptom Assessment Scale
m	Mean score
MMAT	Mixed Methods Appraisal Tool
NCI	National Cancer Institute

NCDs	Non-communicable diseases
NSAIDs	Non Steroids Anti Inflammatory Drugs
PC	Palliative Care
PR	Partial Response
PET	Positron Emission Tomography scan
PD	Progressive Disease
QoL	Quality of life
RCT	Randomize Control Trial
SD	Stable Disease
SD	Standard Deviation
SDT	Self-determination theory
TIP-C	Telephone interpersonal counselling
TNM	**T**umour, **N**ode, **M**etastasis staging system
WHO	World Health Organization
ZBI	Zarit Burden Interview

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CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

Chapter One provides the outline and significance of the current study. It begins by describing the challenges in providing care for a person with cancer, followed by analysing the knowledge gaps in quality of life, needs of caregivers and support interventions programmes. Thereafter, it describes the research questions, aim and objectives of the study, followed by the definition of terms used.

The majority of worldwide deaths have occurred due to non-communicable diseases (NCDs), and cancer probably ranks as the most important reason for loss of life and the greatest barrier to increasing life expectancy globally in the 21st era. According to recent estimations from the World Health Organization (WHO), cancer is the first or second main reason of death before the age of 70 years in 91 out of 172 countries, and considered third or fourth in another 22 countries (Cao *et al.*, 2017; Bray *et al.*, 2018).

The most popular health problem in Palestine is cancer. It is the second main reason of death (15%), and mostly discovered at an advanced stage (Abu-Rmeileh *et al.*, 2016; Palestinian Central Bureau of Statistics, 2016). According to the Al-Sadeel Society for Palliative Care (2017), there were 8106 new cancer patients between 2000 and 2016 in the West Bank, with 3471 (42.8%) people dying during the same period, which indicates a high mortality rate between cancer patients in Palestine. According to the Palestinian Ministry of Health (Abu-Rmeileh *et al.*, 2016), the most common cancer among the Palestinian population is breast cancer, which constitutes 17.8% of all cancers, followed by colon cancer (9.4%) and lung cancer (8.7%). However, the data of the National Cancer Registry in Palestine, a section of the Health Information Centre, shows that cancers of the breast, lung, colon and brain plus leukaemia constitute 58.6% of the cancers resulting in death among Palestinians (Palestinian Central Bureau of Statistics, 2016).

As mentioned, most cancer patients in Palestine (68%) are diagnosed with advanced cancer, thus too late to be cured. The improvement in cancer diagnosis and

management, which allows patients to live beyond five years after diagnosis, has shifted healthcare management from acute cancer centres such as hospitals and inpatient care to outpatient care taking place at homes and in community settings (World Health Organization, 2010; Hamid, 2014). Therefore, the care burden has moved from healthcare professionals to caregivers, who mostly work as primary caregivers (Bauer and Sousa-Poza, 2015; Friedemann and Buckwalter, 2016; Frambes *et al.*, 2017). Although family caregivers mostly provide care for patients at home, they also care for patients at the hospital, as 50% of cancer patients are not treated for their illness (Bakitas, Kathleen Doyle Lyons, *et al.*, 2009; LeSeure and Chongkham-Ang, 2015).

With the cancer patient's care gradually being moved to the home, providing care of such patients is a demanding physical and emotional experience, which results in a tremendous burden on caregivers (Ishii *et al.*, 2012; Kulkarni *et al.*, 2014; Grov and Eklund, 2016; Frambes *et al.*, 2017; Maree *et al.*, 2017). Advanced cancer has complex physical needs that pose a daily challenge to their caregivers (Qi and Leow, 2011; The National Cancer Institute, 2016). In addition to helping the person with their activities of daily living (ADLs), caregivers also have to control the person's pain and other symptoms; furthermore, the person's physical condition could fluctuate day-to-day, making it difficult for caregivers to cope with this constant change (Schulz and Eden, 2016).

The physical needs of the person increase significantly in the last three months of life as they become weak as death approaches (Hui, Dev and Bruera, 2015; Lim, 2016). Apart from coping with stress arising from the physical care of the person with advanced cancer, caregivers have to cope with their own emotions of having to face the imminent loss of their loved one and witnessing their deteriorating condition (Stajduhar *et al.*, 2010; LeSeure and Chongkham-Ang, 2015). Studies found that caregivers of people with advanced cancer stated increased levels of burden compared to those who care of frail elderly people, which was attributed to the terminal nature of the illness and the prospective occurrence of death (Baider and Surbone, 2014; Grov and Eklund, 2016; Ringer *et al.*, 2017).

Caring for a cancer patient is not easy and consumes many hours every day. For instance, Reinhard *et al.* (2008), in a study conducted in USA, found that caregivers can spend eight hours or more a day taking care of cancer patients. Most caregivers are not prepared to care for a person with cancer, but suddenly find themselves having to fulfil this role (Bevans and Sternberg, 2012; Chih *et al.*, 2013). During attempts to take care of their relative with cancer, caregivers neglect their needs, such as their health, exercise and sleep. Therefore, the caregiving has a negative influence on them and the sick person's QoL (Lapid *et al.*, 2016; Louis, 2017). Adding to this, Bakitas *et al.* (2009), in a study conducted in USA, revealed the caregivers of cancer patients who used palliative care have better mental wellbeing compared to those who have not, and most caregivers who have not received any form of supportive care have suffered from serious levels of anxiety and have had signs and symptoms of depression.

The significance of cancer care programmes focusing on caregiver needs as a fundamental part of excellence in cancer care, has been well documented (Glajchen, 2012; American Cancer Society, 2017). Unfortunately, researchers primarily give attention to the QoL, physical and mental difficulties of cancer patients and give less attention to the needs of caregivers (Fujinami *et al.*, 2012; Kent *et al.*, 2016). To decrease the burden of care imposed on the caregivers and enhance their QoL, supportive plans such as support programmes should be used (Bahrami and Farzi, 2014; Schulz and Eden, 2016).

1.2 RESEARCH PROBLEM AND QUESTION

The research problem for this study relates to the influence caring for a cancer patient has on the caregiver's life. As already mentioned, a cancer diagnosis does not only effect the person diagnosed with the cancer, but also those who care for him/her (Graves, 2009; LeSeure and Chongkham-Ang, 2015; Hamad and Abu-odah, 2016). Most cancer patients experience social, spiritual, emotional, and physical problems resulting from the cancer and its pharmacological treatment and suffer from symptoms such as pain and fatigue. These symptoms and problems have a deleterious influence on cancer patients' QoL and other functional activity daily living, and can lead to depression, hopelessness and distress (Omran *et al.*, 2014; Karunanithi *et al.*, 2018). In

addition, the long hours family members spend caring for the patients have a negative influence on the caregiver's QoL (Seir and Kharroubi, 2017). Girgis, Lambert and Lecathelinais (2011), in a study conducted in Australia, found both the patients and their caregivers often experienced emotional distress and other psychosocial symptoms.

Similar to the rest of the world, the prevalence of cancer is on the increase in Palestine (Abu-Rmeileh *et al.*, 2016; Hamadeh, Borgan and Sibai, 2017). Despite the various problems faced by caregivers of people living with cancer, limited attention has been given to their physical, social, and psychological wellbeing (Shin *et al.*, 2002; Yusuf, Adamu and Nuhu, 2011). Most interventions are focused on the cancer patients' treatment, with only a few on the caregiver (Given, Given and Sherwood, 2012; Northouse, *et al.*, 2012; Northouse *et al.*, 2014; Aubin *et al.*, 2017). Although literature emphasises the importance of caregiver support, such support programmes are not available in Palestine. This deficit is exacerbated by the fact that cancer patients and their families living in Palestine face various challenges. For instance, the Palestinian health structure functions under huge pressure because of the rapid population growth, absence of sufficient financial resources, scarcities in basic medical supplies, inadequate resources and absence of access to cancer care, which contribute to the fact that many cancer patients are detected with Stage III and IV cancer (Shawawra and Khleif, 2011; Ambrogio *et al.*, 2016).

The absence of health insurance plans and education, the lack of knowledge of the values and practices of cancer care between healthcare professionals, patients and their relatives, especially male caregivers (Maree, Wright and Makua, 2011), and the inaccessibility of drugs, mainly opioids, not only to add to the burden of the patient, but also to that of the caregiver (Hammoudeh, Hogan and Giacaman, 2016; Seir and Kharroubi, 2017).

According to the Italian study of Andersen (2013), there are knowledge gaps regarding the caregiving process among caregivers of cancer patients. The major gaps include scarce information about the needs of caregivers, little information on the experiences of caregivers especially males, and the influence of interventions on caregiver behaviours. Currently, there is no standardised support programme for caregivers of

patients with cancer found in Palestine, and because the caregiver plays a major role as the primary caregiver, this has led to questions in the effectiveness of the care provided. Additionally, there are no clinical guidelines available to guide the caregivers' caring process, which would enhance their QoL, lessen the care burden and increase the QoL of patients with cancer.

The proposed study is to add to the bulk of available knowledge by highlighting the support needs of cancer patient's caregivers, their burden of quality of life and care, before and after the implementation of a support programme. In addition, the study was investigate the symptom burden and QoL of patients cared for by the participants in this study.

To address the research problem, the following questions were formulated:

1. What evidence is available pertaining to the support needs of caregivers of cancer patients, and which support programmes exist.
2. Could the findings of the scoping reviews lead to a validated support programme for caregivers of cancer patients in the Palestinian context?
3. Would a support programme for caregivers of cancer patients have a positive influence on caregivers' care burden and QoL as well as cancer patients QoL, pain experience and symptom burden in the Palestinian context?

1.3 RATIONALE FOR THE STUDY

The literature review shows that both cancer diagnosed patients and their caregivers experience worries and difficulties including physical, financial, emotional, and psychosocial distress associated with the illness (Girgis *et al.*, 2013; LeSeure and Chongkham-Ang, 2015). There is therefore a need to deliver the caregivers with support programmes that improve their physical, social, and psychological wellbeing, as well as QoL. This study provides a support programme (Addendum A) for the caregivers of persons diagnosed with cancer who receive treatment at the An Najah National University Hospital in Palestine.

The main issues of quality of life and care burden are crucially significant in both the short- and long-term of cancer patient's management, but these stay unaddressed in the Palestine cancer care system. The current study strived to discover and focus on the existing status of the care burden amongst caregivers of cancer patients and quality of life in public and community settings. In addition, it aimed to examine the support programme for caregivers in terms of enhancing their quality of life and decreasing their burden.

The results from the current study contributed to teaching nurses, doctors, social workers, and other healthcare providers on the effects of giving care to cancer patients on their caregivers or families. In addition, the hope is it enhances the aforementioned professionals' understanding of the essential needs of their cancer patients as well as the care requirements of their caregivers. The results from the current study may be used as a model for establishing upcoming interventions to assist cancer patients' caregivers in the direction of refining resilience and satisfaction in giving care, decrease the care burden and elevate wellness and favourable caregivers' experiences. Moreover, results from the current study were a worthy reference for healthcare provider's policymakers and healthcare organisers in Palestine in planning, applying, and assessing the efficacy of supportive strategies and protocols for the caregivers taking care of patients with cancer and other chronic diseases.

1.4 AIMS AND OBJECTIVES OF THE STUDY

The study aims to develop and pilot test a support programme for caregivers of cancer patients in Palestine.

The study objectives are:

1. To explore literature to synthesise the support needs of caregivers of cancer patients as well as the exiting support programmes.
2. To develop/adapt and validate a support programme for caregivers of cancer patients in the Palestinian context.

3. To pilot test the support programme for caregivers of cancer patients in the Palestinian context in terms of the following outcomes: primary outcome of caregivers QoL and secondary outcomes of caregivers' care burden, as well as cancer patients' QoL, pain experience and symptoms burden.

Four Phases were conducted to fulfil the aims and objectives of the current study.

Phase 1: was consisted of a scoping review on how to synthesise the evidence regarding the support needs of caregivers of cancer patients.
Phase 2: was consisted of a scoping review to find support programmes available for caregivers of cancer patients.
Phase 3: was focused on the development/adaptation and validation a support programme for caregivers of cancer patients.
Phase 4: was a pilot test of the study to test the support programme using an intervention study design.

1.5 THEORETICAL MODEL

The theoretical model for this study was the Lazarus and Folkman transactional model of stress and coping. This model acknowledges personal, social, and illness-related factors as antecedent conditions that can constitute harm and effect the QoL of primary caregivers of cancer patients (Lazarus and Folkman, 1984).

1.6 RESEARCH DESIGN

This is a sequential multi-method study conducted in Phases, which involves:

1.6.1 Phase 1- Scoping review

Scoping review was used to synthesise the evidence regarding the caregivers of cancer patients support needs. The following research question was to guide the current review, What evidence is available pertaining to the caregivers of cancer patients' support needs?

To search the literature in a comprehensive manner, related peer-reviewed journal papers published between 1st January 2008 and 31 December 2017 were searched using the following electronic databases: PubMed, CINAHL, Science Direct, and Scopus. Using the mentioned inclusion criteria, 487 (n=487) papers were recognised through the databases; of these, 19 (n=19) were involved in this scoping review.

1.6.2 Phase 2- Scoping review

The second scoping review was to exhaust the viability of published support programmes for caregivers of patients diagnosed with cancer. This review was guided by the research question, What support programmes are available for caregivers for cancer patients?

To search the literature in a comprehensive manner, relevant peer-reviewed journal papers published between 1st January 2008 and 31 December 2017 were searched from the following four electronic databases: PubMed, CINAHL, Science Direct, and Scopus. Using the above inclusion criteria, no support programmes (n=0) were found, however the researcher searched Google and Google scholar for related reviews, (n=22) were found and included in the current literature review.

1.6.3 Phase 3- Developed/adapted and Validation Phase

Phase three was development/adaptation and validation of a support programme for caregivers of cancer patients. A draft of a support programme for caregivers of cancer patients was developed based on Phases 1 and 2, and the opinions of the expert panel in Phase 3. The support programme was presented to the expert panel for validation using a scoring sheet with a 5-point Likert scale and necessary changes were made to some statements. They were allowed to make comments, which informed the changes to be made to the support programme content.

1.6.4 Phase 4 – Pilot-Testing Phase

The proposed and validated support programme was pilot tested and the outcomes assessed; this was done by conducting interventions and pre-test post-tests of the caregivers' support programme. The intervention was assessed in terms of a primary outcome of caregivers QoL and secondary outcomes of caregivers' care burden as well as cancer patients' QoL, pain experience and symptoms burden. The methodology chapter of this study fully discussed each Phase with the corresponding research design.

1.7 OPERATIONAL DEFINITIONS

1.7.1 Cancer

According to the National Cancer Institute (2015d) and the World Health Organization (2017a), and for the benefits of the current study, cancer is well-defined as a broad term for a wide group of illnesses that can have an impact on every part of the human body; other terms used are malignant tumours and neoplasms. According to Seyfried and Huysentruyt (2013), one describing trait of cancer is the speedy formation of irregular cells that develop outside their normal limits, and which may then assault neighbouring cells and spread to additional structures and tissues; this end-Phase is known as metastasising. Advanced cancer is defined as end-stage cancer as the disease is incurable (Torre *et al.*, 2015; National Cancer Institute., 2017).

1.7.2 Caregiver

For the purpose of the study and pertaining to the American Cancer Society, (2016c), the cancer caregiver refers to any family member, friend, or former support individual who offers all type of support at any time through the cancer course (Mahendran *et al.*, 2015). This assistance is provided free of cost to the cancer patient. Caregivers are often not qualified in giving care but regularly assist the cancer patient. The caregiver's role is a lifeline for the cancer patient, as they fulfil many roles and the role changes as the needs of the patient change (Glajchen, 2004; Steinwedel, 2013)

1.7.3 Caregiver burden

For the purpose of this study, the burden of caregiving denotes a multidimensional reaction to the undesirable appraisal or judgement and experienced stress caused from offering cancer care to sick persons, or the suffering that caregivers' sense because of given care; it refers to the care and differs from being anxious or depressed as a result of other emotional and overall reactions (Kim *et al.*, 2012; Rha *et al.*, 2015; Gabriel and Mayers, 2019). Such response occurs as a consequence of the imbalance of care strains or demands with caregivers' private time, social duties, physical personal needs and emotional issues, economic concerns and proper care means, added to other numerous duties they fulfil (Applebaum, Kulikowski and William Breitbart, 2015).

1.7.4 Caregiving

Caregiving means providing care or assistance to the person suffering from some illness, or is disabled and needing help in terms of physical, social, emotional and psychological aspects, by healthcare providers, family members or friends. In this study it refers to cancer patients requiring care and specific attention and the person who cares for them (Hermanns and Mastel-smith, 2012; Roth, Fredman and Haley, 2015).

1.7.5 Quality of life (QoL)

According to the World Health Organization (1996), QoL is the conception or perception of persons of their own condition inside their beliefs, value and cultural framework or system; it takes into account the person's physical tasks, psychological or mental well-being, family and social relationships, environmental impacts, and values or beliefs (Alptekin *et al.*, 2010).

1.7.6 Supportive care

For this study's purpose, the Fitch, Porter and Page (2009) definition was applied. These authors defined Supportive care "as the providing of essential services for persons diagnosed or affected by cancer and living with it to provide access to "informational, emotional, spiritual, social, or physical needs" through their diagnostic,

cancer therapy, or follow-up stages, covering concerns of improving health and deterioration prevention, surviving, providing palliation, and mourning .

1.7.7 Palliative care

Palliative care as a method or attitude that recovers or enhances the QoL of sick persons and their caregivers in the face of the deadly disease, by the anticipation, prevention and release of distress and suffering in terms of early recognition and infallible evaluation and action of cancer pain and physical, psychosocial and emotional concerns (Eliot, 2017; World Health Organization, 2018).

1.8 OUTLINE OF THE STUDY

This study was structured as outlined below:

Chapter One: this chapter presents the background and the study rationale, the research problem, aim and study objectives, research question, and operational definition of terms related to the study. It concludes with the conceptual framework that guided the study.

Chapter Two: this chapter discusses the literature related to cancer patients, incidence of caregiver burden, caregiver burden and caregivers' QOL, and provides an overview of psychosocial interventions, effectiveness of such interventions, outcome measures reported, evaluations of the outcome measurement tools, and critical appraisal of study instruments used by reviewed articles.

Chapter Three: this chapter presents the methodology of the study, which includes the study design, study setting and population, inclusion criteria, sample, measurement instrumentation, pilot study, data analysis, and data collection procedures. The ethical considerations and issues of data management and storage conclude this chapter.

Chapter Four: this chapter presents the sample characteristics baseline and the study results.

Chapter Five: this chapter discusses the results, recommendations, study limitations, and conclusion.

1.9 SUMMARY

This chapter outlined the introduction and study background, rationale, research problem and question, aim and study objectives, hypothesis and definition of basic terms, as well as the conceptual framework used to guide the research.

Chapter 2 outlines the review of literature pertaining to influence of support interventions on the caregivers of patients diagnosed with cancer.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter will focus on study key concepts and will describe cancer as a worldwide health problem, followed by the cancer diagnosis and treatments, overview of palliative and support care, caregiver and incidence of caregivers' burden, caregivers' burden and QoL, psychosocial distresses, stressors and self-efficacy of caregivers, spousal caregivers and finally, the researcher will provide the theoretical framework for the study.

2.2 CANCER AS WORLDWIDE HEALTH PROBLEM

Cancer is a global health problem and affects people of all ages and walks of life (Ketlogetswe, 2018). The global cancer burden in 2018 was estimated at 18.1 million with 9.6 million deaths related to cancer (Bray *et al.*, 2018; World Health Organization, 2018b). Amongst five men and six women worldwide, one will experience cancer throughout their lifetime worldwide, and out of eight men and 11 women one will die from cancer (Roxanne Nelson, 2018; World Health Organisation, 2018b). The number of people who lived within five years of the disease diagnosis globally, is assessed to be 43.8 million (American Cancer Society, 2018a ;Kelland., 2018).

The number of those newly diagnosed with cancer is likely to increase by around 70% within the next two decades (World Health Organization, 2007; Torre *et al.*, 2015). The growing burden of cancer, due to various reasons such as the growing and ageing population, is greater than ever as well as the altering prevalence of some specific causes of cancer related to social and financial improvement (Michelle, 2010; Smetana *et al.*, 2016). This is evidenced in quickly rising economies, where a change is witnessed in cancers associated with poverty and infections to cancers linked to a way of life more typical of developed countries (Maree, Lu and Wright, 2012; World Health Organisation, 2018b).

In 1970, 85% of recently diagnosed cancer cases existed in developed countries and just 15% in developing countries (Brown *et al*., 2012; Naghavi, 2015; Azubuike *et al*., 2018). However by 2030, developing countries are likely to afford 70% of the burden of cancer globally (World Health Organisation., 2010; Moten *et al.*, 2014; Torre *et al.,* 2016). This significant shift relates to a rise in different risk factors in developing and newly developed countries, such as improved in people life growth, ageing populations, the use of a western regime, the increased consumption of tobacco, fat rich meals and lack of fibre in diets, as well as a decrease in physical activity (Bener *et al.*, 2010). In countries located in the Middle East, the amount of cases newly diagnosed with cancer is likely to rise by 50 to 70% by 2020 (Beaulieu *et al*., 2009; Folley *et al*., 2012) due to an increase in the ageing population (Al Mezan Center for Human Rights, 2018; Halahleh and Gale, 2018).

Similar to other Middle Eastern countries, in Palestine cancer is responsible for 14% of deaths and is considered the main reason of death (the seconed) next to cardiac disease (Abu-Rmeileh *et al.*, 2016; Halahleh and Gale, 2018). In 2005, the incidence of newly diagnosed cancer patients in the West Bank was 49.2 per 100,000 and 32.7 per 100,000 in the Gaza Strip, and the mortality rate was 27.8 per 100,000 for both locations (Abu-Rmeileh *et al.*, 2016; Awwad, 2016). In Palestine the burden of cancer is estimated to rise, and challenges in the economic and infrastructural purse of the existing healthcare system will worsen the problem (Halahleh and Gale, 2018).

Most cancers deaths in Palestine are due to lung cancer amongst men (22.8 %) and breast cancer (21.5 %) in females, prostate cancer (9.5 %) takes third place, followed by colon cancer in females (11.4 %) (Abu-Rmeileh *et al.*, 2016; Awwad, 2016; World Health Organization, 2018b). This trend is similler to the global trend where cancer of the lung and female breast are the most common, contrbuting to about 11.6% of the entire incidence burden of cancer (Bray *et al.*, 2018; World Health Organisation, 2018b).

Unfortunately, people living in Palestine present late and approximately 60 % of cancer patients are diagnosed at stages III or IV.

Culture, inadequate resources, and difficulties in using medical services contribute to the cancer late diagnosis (Silbermann, 2016). However, late presentation with cancer seems to be a worldwide phenomenon and has been reported in various countries (Forbes *et al.*, 2014; Murugan *et al.*, 2014; Asoogo and Duma, 2015). Late presentation has many causes and in addition to those mentioned, it is influenced by social and demographic aspects like age, gender, educational level, religions and cultural prescriptions, lack of knowledge, poverty, the absence of screening programmes and not using the screening opportunities available (Mbuka-Ongona and Tumbo, 2013; Dey *et al.,* 2015). Cancer diagnosis can also be delayed by healthcare providers and secondary care, such as misdiagnosis, a lack of examination, co-morbidity and patient characteristics. Delays caused by the health system are long waiting times for tests, referrals and follow up visits (Forbes *et al.*, 2014; Jansen van Rensburg, 2016).

People presenting with advanced cancer in the developing world face additional challenges to those of the developed world. Developing countries have additional challenges such as a high burden of infectious illnesses like HIV/AIDS and non-communicable diseases, poverty, insufficient government funding for healthcare and a shortage of healthcare providers, especially trained providers to take care of cancer patients, resulting in inadequate resources to diagnosis and treat cancer. Healthcare priorities in developing countries give preference to communicable diseases and treatment of non-communicable diseases is often not well structured (Maher, Ford and Unwin, 2012). A shortage of surgeons skilled in cancer surgery, radiation oncologists and medical physicists, as well as radiation equipment and cytotoxic drugs, compounds the lack of effective cancer treatment offered to the patients in developing countries. Palliative care available to cancer patients is insufficient in many developing countries and healthcare providers are not trained in effective pain control (Jansen van Rensburg, 2016).

According to the World Health Organization (2017a), between 30–50% of cancers could be prevented. Factors that increase the chance of the disease are increased smoking consumption, increased consumption of fat rich meals and the lack of fiber in diets, as well as a decrease in physical activity (Bener *et al.*, 2010; Maree, Lu and Wright, 2012).

Other cancer prevention strategies include regulations for limiting trans-fats and salt in foods, reduction of tobacco use by means of limiting advertising of smoking and restrictions on smoking areas, and elimination of infant feeding bottles containing bisphenol A (Jansen van Rensburg, 2016).

Cancer screening plays a significant role in lessening the burden of cancer through prevention and early detection (Maree, Wright and Makua, 2011; Cora *et al.*, 2012). Screening programmes vary in terms of their exposure to the population and areas, and the way in which they involve the community (Marcus *et al.*, 2016). Programmes that provide worldwide coverage for groups where appropriateness is dependent on an accurately measured population risk are typically categorised as population-based programmes (Walsh, Silles and Ciarán, 2011). Such programmes use a self-determining risk assessment as rules for persons' eligibility criteria, as well as implementing a systematic method for contacting those who are eligible to participate (Walsh, Silles and Ciarán, 2011; Frohlich, 2014). Opportunistic programmes depend on the subjective assessment of risk by the persons as well as the readiness and capability of the persons to take responsibility to organise a screening test (Walsh, Silles and Ciarán, 2011; Marcus *et al.*, 2016). Dissimilarities in the role given to the individual among the two programmes could contribute to the variances in screening, as the awareness of the risk, enthusiasm and capability of persons to organise screening will be different, such as social and economic characteristics (Walsh, Silles and Ciarán, 2011).

Various screening tests are available to detect cervical, breast, colorectal and prostate cancer. Cervical cancer screening is done by means of a Pap smear whilst a mammogram is used for breast cancer detection (Wirth *et al.*, 2014). Home testing kits are available for testing faecal occult blood, and if the result is positive, a colonoscopy is done for the screening of colorectal cancer. Prostate specific antigen (PSA) is done to check and examine the prostate for cancer as well as a rectal examination (Wirth *et al.*, 2014; Ferlay *et al.*, 2015). According to literature, screening individuals with a high risk of lung cancer using " low-dose, helical computed tomography (LDCT) scans"

decreased their chances of death due to lung cancer by 20% compared to individuals screened with classical chest x-rays (Maree, Lu and Wright, 2012; National Cancer Institute, 2014a; Masoudiyekta *et al.*, 2017).

Unfortunately, the lack of financial and infrastructure resources in developing countries often makes screening impossible. Not having screening services is especially negative considering the fact that the incidence of cancer in developing countries is increasing rapidly and an 85% increase is expected by 2030 (Jansen van Rensburg, 2016). Cancers can be treated with early detection but unfortunately in Palestine they are being diagnosed at advanced stages compared to developed countries (Ambrogio *et al.*, 2016; Halahleh and Gale, 2018). The only active programme individuals can find in Palestine is a breast cancer-screening programme. The Palestinian Breast Cancer Programme" is a nationwide programme using a portable mammography clinic and centralised film interpretation. Mammograms are provided free for females more than 40 years old, as well as for young women who are at high risk (Abu-Rmeileh *et al.*, 2016; Halahleh and Gale, 2018). The programme although successful needs significant enhancement. There are, of course, economical restraints, but there is a need for public awareness to cope with the cultural issues towards mammography, particularly in Gaza. There are no structured programmes for lung, colorectal or prostate screening (Halahleh and Gale, 2018).

2.3 CANCER DIAGNOSIS

To understand cancer survival, it is necessary to understand how cancer is diagnosed, graded, staged and treated. Establishing a cancer diagnosis starts with taking a holistic history and physical examination followed by diagnostic tests (Rosenzweig, Gardner and Griffith, 2015). Investigation includes assessments and tests to approve the existence of illness and recognise the precise tumour type, extent, location and stage (Jelovac and Armstrong, 2011; Levesque *et al.*, 2015). Various tests can be used to diagnose cancer, such as “physical examination, investigative tests like blood tests, x rays, Computer Tomography (CT), Magnetic Resonance Imaging (MRI), and Positron Emission Tomography scan (PET), however, a histopathological examination is critical

for confirming the diagnosis and to guide the treatment and management of the patients (Hamilton, 2010; Meads *et al.*, 2013; Wait *et al.*, 2017).

2.3.1 Cancer grading system

A grading system of tumour cells, shown in Table 2.1, was established to accurately describe the malignant characteristics of individual tumour diagnosis in humans (Avancini and Alves, 2017; American Cancer Society, 2018b). Grading is the assessment of the degree of malignancy of tumours by matching the cellular anaplasia, diversity and mitotic motion of the cells (Mendoza *et al.*, 2015). It compares cancer cells with their normal counterparts in terms of appearance and cellular activity (Fleming *et al.*, 2012; Newton, Hickey and Brant, 2017). Cancer cells that resemble their normal appearance and functions are considered low grade; others are more aggressive and treatment resistant and are classified as high-grade tumours (Galli *et al.*, 2017; Newton, Hickey and Brant, 2017). The cancer grading system is very important in planning treatment and the possible outcome (Lambin *et al.*, 2013; Riera *et al.*, 2013).

Table 2.1: Grading System for Malignancy

Grade	Definition
GX	Grade cannot be determined
G1	Cells are very much distinguished, much like the cells from where they emerge, indicted for a “low-grade tumour”
G2	Cells are reasonably distinguished, look like normal cells, but displayed other malignant traits
G3	Cells are not well distinguished, scarce usual cellular features are reserved, but the cells of source may still be developed .
G4	Cells are distinguished, certainly not usual cellular appearance, defining the source of cells is very hard.

American Joint Committee on Cancer, (2016)

In order to select the best treatment option for a specific tumour, the cancer stage must be determined. Tumour staging is to define the extent and site of the tumour, and the degree to which the cancer has spread is done as a step-by-step process (Galli *et al.*,

2017; American Cancer Society, 2018b). The smaller the tumour and the less it has spread at the time of diagnosis, the greater the potential for cure or control of the disease.

According to the American Joint Committee on Cancer (2016), the " Tumour, Node, Metastasis (TNM) staging system," as shown below in Table 2.2, is used to stage malignancies and define the prognostic variable, such as their pattern of growth and spread. **T** indicates the size or extent of the tumour, **N** indicates the existence or non-existence of lymph node envelopment, and **M** denotes the existence or non-existence of distant metastasis. The number assigned to any of these components (T3, N2, M1) indicates the degree of tumour size, nodal involvement, and metastasis spread (Galli *et al.*, 2017). Once the TNM staging has been determined, it is combined to define the stage of the cancer.

The TNM classification system serves several purposes: to stage the tumour at diagnosis, to examine the progress of disease related to the usual progress of cancer, to provide standardised data on which the base treatment options, and to specify prognosis (American Joint Committee on Cancer, 2016; Galli *et al.*, 2017).

Table 2.2 Tumors, Node and Metastasis classifications of cancer

Classification	Definition
TX	Primary tumour cannot be evaluated
T0	No evidence of primary tumour
Tis	Carcinoma in situ (early cancer that has not spread to neighbouring tissue)
T1–T4	Size and/or extent of the primary tumour
NX	Local lymph nodes assessment cannot be done
N0	No regional lymph node involvement (no cancer found in the lymph nodes)
N1-N3	Involvement of regional lymph nodes (number and/or extent of spread)
M0	No distant metastasis (cancer has not spread to other parts of the body)
M1	Distant metastasis (cancer has spread to distant parts of the body)

American Joint Committee on Cancer, (2016)

The majorities of tumours are divided into four stages, Stages I to IV, with Stage 1 being the least disease and Stage 4 disseminated diseases. Some cancers have a Stage 0 (zero), which refers to the cancer found only in ducts and lobules tissue of the breast and has not metastasised to the adjacent tissues. It is also known as non-invasive cancer (Galli *et al*., 2017; Newton, Hickey and Brant, 2017).

The stage of cancer at diagnosis will identify the treatment available and prognosis, and has a strong influence on the length of survival (Cetin *et al.*, 2015; Rivera-Franco and Leon-Rodriguez, 2018). If it is presented and diagnosed at an initial stage, as soon as the cancer is still limited (Stage1), the prognosis will almost be positive, but if it has spread or metastasised (Stage 4) to additional portions of the body, the survival or length of survival chances are low (Zhang *et al.*, 2012). Therefore, the earlier that cancer is screened and detected, the better chance cancer patients have of survival for 5 years after being diagnosed (Borneman *et al.*, 2015; Ghandourh, 2016).

However, cancer patients mostly discover and present to the hospital for treatment at a late stage (stage 3 or 4) of the disease when the individual is terminally ill, needs aggressive treatment strategies and has limited chances of survival (Montazeri, 2009; Ghandourh, 2016; Seir and Kharroubi, 2017).

2.4 CANCER TREATMENTS

According to the American Cancer Society (2015) and Matthews and Choi (2016), various treatment modalities are available to treat cancer patients.

The selection of treatment modalities are subject to the location, tumour grade and the cancer stage, and conversely, the patient's performance status (Kelly and Shahrokni, 2016). Performance status measures patients' general well-being and capability of carrying out daily living activities, as well as determining their ability to tolerate therapies such as chemotherapy, radiotherapy, etc. (Young *et al.*, 2015;

Kelly and Shahrokni, 2016). As shown in Table 2.3, the “Eastern Cooperative Oncology Group (ECOG),”, is the commonly used scoring system (Oken *et al*., 1982).

Table 2.3: Cancer patients ECOG performance status

Grade	ECOG
0	Fully active, able to carry on all pre-disease performance without restriction.
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, light housework, office work.
2	Ambulatory and capable of all self-care, but unable to carry out any work activities. Up and about more than 50% of waking hours.
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours.
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair.
5	Dead.

The Eastern Cooperative Oncology Group (ECOG) (Oken et al., 1982).

There are many ways that the cancer can be treated, by surgery, radiotherapy, chemotherapy and hormonal therapy or by using of different treatments in combination, all of which be determined by the stage of the cancer (Jelovac and Armstrong, 2011).

The major aims of the treatment of cancer are to cure or substantially extend the life of cancer patients and to safeguard the finest potential QoL for survivors (Balogh *et al.*, 2011; World Health Organization, 2018a). People presenting with advanced cancer should have access to curative treatment where their prognosis is good, as well as palliative treatment to prolong survival and maintain the best QoL for the cancer patient and their family (Kim *et al.*, 2013; Heckel *et al.*, 2015).

2.4.1 Cancer surgery

Cancer surgery is used for diagnosis, the staging of tumours, cure and palliation, and can be used in combination with chemotherapy, radiation and immunotherapy as part of multidisciplinary treatment, and for prophylaxis in case of genetic predisposition to certain cancers (Oncology Nursing Society, 2013).

Curative surgery, believed to be the primary treatment, is used when the cancerous tumour cells are localised to a certain body part (Bacchetti *et al.*, 2014). *Preventive surgery* is usually applied to eliminate tissue that does not include harmful cells but could change and grow into a malignant tumour (Matthews and Choi, 2016). *Diagnostic surgery* serves to decide if the cells have a carcinogenic feature, as well as used to take out a tissue for testing and evaluation to confirm a diagnosis, and to recognise the cancer type or define the cancer stage (Pedamallu *et al*., 2016). In *Debulking surgery* is where part of the tumour is removed. It is used in specific circumstances when eliminating the whole tumour might affect or cause harm to other body organs (Martinek and Kehoe, 2009; Tangjitgamol, Manusirivithaya and Laopaiboon, 2014).

Palliative surgery deals with cancer at late stages. It will not treat the cancer, but will relieve distress and discomfort, or manage further cancer problems in which related therapy might be generated (Fahy, 2013; Bacchetti *et al.*, 2014; Nthumba, 2014). *Restorative surgery* is occasionally applied to return the normal appearance of cancer patients after curative or other cancer surgeries, or to restore the function of a body part (Bacchetti *et al.*, 2014; Nthumba, 2014).

2.4.2 Cancer chemotherapy

Cancer disease can be managed by a single cytotoxic treatment as the primary treatment, but mostly commonly it is managed in combinations; chemotherapy can work together with other treatment modalities to enhance action and to prevent chances of resistance (Fowler, Mankoff and Joe, 2017).

Chemotherapy is defined as a systemic form of tumour therapy that uses cytotoxic treatments to cause damage to cancer cells (Raffaghello *et al.*, 2010; Palumbo *et al.*, 2013). The chemotherapy may destroy the cancer cells including those that have metastasised to other parts of the body. Chemotherapy is not specific to cancer cells only, as it targets all rapidly growing cells. Cancer cells are however unable to repair the deoxyribonucleic acid damage, whereas normal cells can (Pegg, 2012; Liu *et al.*, 2015). Due to absence of specificity, chemotherapy has the possibility of harming healthy tissue, especially those that have a high replacement rate, for example, cells in the mouth and those in the intestinal lining (Pegg, 2012).

Occasionally chemotherapy is the single therapy that patients need. More often, chemotherapy is applied together with surgery or radiation treatment, or both, for different reasons. It may be given to decrease the tumour size before surgery or radiation therapy; if applied in such a manner it is known as neoadjuvant therapy. Chemotherapy may be applied post-surgery or after radiation treatment to destroy any cancer cells remaining, in this instance it is known as adjuvant therapy. Chemotherapy can also be applied with other therapies if a patient's disease re-occurs (Carroll, 2015; World Health Organization, 2018).

2.4.3 Cancer radiotherapy

Radiotherapy is a significant and essential way of controlling cancer, commonly enhancing the survival benefit (Lutz, Jones and Chow, 2014). Radiation therapy damages the cancer by concentrating a "high-energy" beam of ionising radiation on the cancer tissue (Baskar, Yap, *et al.*, 2012; Baskar *et al.*, 2014). It is a localised therapy that uses ionising material to destroy cells of cancer and minimises the size of the tumors by destroying the cells' genetic makeup making it impossible for them to continue growing and dividing. The main aim of radiotherapy, which can be administered as external beam radiotherapy and as brachytherapy, is to kill as many cancer cells as possible and limit the harm to adjacent normal cells (Taleghani, Shahriari and Alimohammadi, 2017). To achieve this aim, fractionation is used, allowing the recovery of healthy tissues between fractions (Bamps, Dok and Nuyts, 2018). The

effects of therapy are localised and confined to the treatment region. Radiation therapy does not destroy the cancer cells immediately; it needs days of therapy before DNA is destroyed in an adequate way for cancer tissue to die. At that time, cancer tissue will keep dying for weeks or more, even after radiation therapy ceases (Baskar, Lee, *et al.*, 2012; Polanski *et al.*, 2016).

2.4.4 Cancer immunotherapy, targeted therapy, and hormonal therapy

Recently, the ability to distinguish a definite gene mutation in diverse cancers, and a better biological understanding of the cellular actions and the ways of motivating carcinogenesis, led to the evolution of targeted agents and immunotherapeutics (Palumbo *et al.*, 2013). These fresh therapies seem to provide substantial benefits in providing growth inhibitory or cytotoxic properties in a much more cell-specific style (Palumbo *et al.*, 2013; Riaz *et al.*, 2016).

Cancer immunotherapy includes using naturally or unnaturally generated ingredients to stimulate the immune system to identify and fight cancer cells (Tarkowski and Rzaca, 2014; Dine *et al.*, 2017). The immune system is stimulated to enhance its activities in attacking cancer cells, or the patient may be given some immune system ingredients such as “man-made” immune system proteins (Masoudiyekta *et al.*, 2017). This therapy has become a crucial up-to-date oncology option since first defined in 1985. Immunotherapeutic methods apply components of a cancer patient’s own immune system to selectively targeted cancer cells thereby modifying various side effects related with typical alternative treatment (Palumbo *et al.*, 2013; Koury *et al.*, 2018).

Targeted therapy targets the changes that are specific to cancer cells that help in their growth, division and spread. This therapy targets exact genes or proteins that are seen in cancer cells or in cells associated with cancer growth, such as cancer vascular cells (Newton, Hickey and Brant, 2017; Wilkes, 2018). Targeted therapies used in various kinds of cancer are currently being developed at a rapid pace (Bozic *et al.*, 2013). Such

therapy is pushing the boundaries to significantly improve patient outcomes and quality of life (Chan and Hughes, 2015).

Hormonal treatment is a form of systemic therapy, which is non-cytotoxic, prescribed for cancer patients whose cancer is influenced by hormones to inhibit tumour growth (Palumbo *et al.*, 2013). Hormonal treatment lowers the amount of body hormones, which prevent cancer progress, and play a vital role in the treatment or management of breast and prostate cancer (Nelles, Hu and Prins, 2011; Garay and Park, 2012). Hormonal therapy for breast cancer has enhanced disease survival by about 10% to 10 years (Dowsett *et al.,* 2010) and patients with advanced disease or metastatic disease respond well to hormonal therapy (Carducci *et al*., 2015; Abraham and Staffurth, 2016). Hormonal therapy is used as adjuvant therapy to help decrease the risk of recurrence as well as neoadjuvant (Wisniewska *et al*., 2016; Karunanithi *et al*., 2018).

Each of the modalities of treatment has its own effects and side effects, which may have a serious influence on the QoL of the patient and their family. It is not only the treatment, but also the cancer that has an effect on all aspects of a patient's life and that of their families. It not only causes physical symptoms, such as pain, fatigue, nausea and vomiting, but has an influence on mental and physical functioning, body image, psychological wellbeing, social and financial aspects, roles and spiritual life (Newton, Hickey and Brant, 2017).

Irrespective of the treatment used, the goal of treatment is curing the disease, prolonging cancer patients' lives and ensuring the best possible QoL (Rome *et al*., 2011; Davis, 2015; Newton, Hickey and Brant, 2017).

2.4.5 Goals of cancer treatment

There are three main goals for cancer - cure, control and palliation. Cure when the cancer cells are eradicated in the body. Control means containment of the growth of cancer cells without complete eradication and palliation when the possibility of cure is hopeless. Palliation means to comfort and relieve the symptoms, which is the major aim

of cancer treatment and includes any of the therapeutic modalities (Itano and Taoka, 1997).

Cancer care involves various treatment modalities, and is reliant on the stage of the disease. Irrespective of whether the goal of treatment is a cure, control of disease or palliation, patients need to be supported through the cancer experience to ensure the best QoL possible for the patient and family (Rome *et al.*, 2011). In the end, from a patients' rights is the availability of all types of treatment that the cancer patient needs (HPCSA, 2008; Mastaneh and Mouseli, 2014).

2.4.6 Response to cancer treatment

The effect of cancer treatment is measured in terms of response. Tumour size, performance status, and lymph node involvement are used in determining patients' response to treatment (Graham *et al.*, 2014; Tadayyon *et al.*, 2017).

Response to cancer treatment is indicated as follows: Complete Response (CR) meaning that all targeted lesions disappear, which is a localised change in a tissue or an organ that has been specifically measured; Partial Response (PR) means the sum of the targeted lesion's longest diameter decreases by 30% and takes the baseline sum of the longest diameter as reference as well as a 30% reduction in the longest diameter of target lesions in total; Stable Disease (SD) means there is no definite shrinking, which can define partial response; it uses the smallest diameter sum as the reference from the start of treatment. Progressive Disease (PD), which means the target lesion's longest diameter increases by 20% or more; the smallest sum of the longest diameter is noted from the time of treatment resumed or appearance of new lesions and used as the reference (Tahara *et al.*, 2005; Maree, 2011; Maas *et al.*, 2015; Fowler, Mankoff and Joe, 2017; Gordic *et al.*, 2019).

2.5 PALLIATIVE AND SUPPORT CARE

Services of Palliative Care (PC) do an essential role in the multidisciplinary care of cancer patients and their caregivers (Maciasz *et al.*, 2013). According to the World Health Organization, (2017b), palliative care is an approach that improves the QoL of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other distressing symptoms, physical, psychosocial and spiritual (Khleif and Dweib, 2015; Jansen van Rensburg, 2016).

The WHO specifies that palliative care is applied early in the course of sickness in concurrence with other treatments that are proposed to prolong patients' lives, like chemotherapy or radiation treatment modalities, and contains investigations or examinations to better recognise, manage and understand stressful clinical complications (Fadul *et al*., 2009; Lim, 2016). Early transfer to palliative care is of great significance in allowing healthcare providers to offer early relief of physical and psychosocial upset, start a relationship with cancer patients and their caregivers, as well as give the care providers the opportunity to discuss the concerns of discharge planning that may prevent a patient's death. Researchers agree with this definition, but with emphasis on symptoms management and spiritual and psychosocial issues of the patient, the caregiver and family as a whole (Mosher *et al.*, 2016; Nemati *et al.*, 2018).

According to International Association for Hospice and Palliative Care (2018), palliative care addresses patient and family needs, such as counselling and bereavement, through a team approach. It also emphasises that palliative care processes must be applied as soon as a life-threatening illness has been diagnosed, but becomes the focus of care when cure or life-prolonging therapies are no longer effective (Murphy, 2016; Narsavage *et al*., 2017).

Palliative care, as defined earlier, assists with decision making, improves the care quality and reduces the unnecessary use of medical and technological cancer services (Portenoy, 2016; Cotogni, Saini and De Luca, 2018). Until recently, it has been vague

as to why referrals to palliative care happen late in the illness course (Dalal and Bruera, 2017; Narsavage *et al*., 2017). Traditionally, palliative care was always delivered late to those hospitalised in specialised inpatient wards, or as a counselling service for those patients who encountered uncontrolled symptoms (Temel *et al.*, 2010; Chen and Glover, 2016). Previously, studies had suggested that referring patients for palliative care services just before death was insufficient to change the quality and conveyance of services offered (Caraceni *et al*., 2012; Epstein and Morrison, 2012). Palliative care should be provided early during the course of the disease and as soon as metastatic diseases are diagnosed so that meaningful effects on patients' QoL and end-of-life care can be achieved (Temel *et al*., 2010).

Specialised palliative care delivered parallel with usual oncology care decreases wearisome psychological symptoms, enhances QoL, reduces healthcare expenses near to death, enhances timing of treatments, and may prolong a patient's life (Bakitas, Kathleen Doyle. Lyons, *et al.*, 2009; Cherny *et al.*, 2010; Davis *et al.*, 2010). Palliative care asserts life and regards dying as a normal path; it aims to neither accelerate nor delay death, incorporates the psychological and spiritual aspects of cancer patient care, offers a support system to provide help to patients live as actively as possible until death, and a support system which allows caregivers to adapt through the patients sickness and their own grief. It uses a team method to recognise the patients' and their caregivers' needs, as well as mourning counselling, if desired, it will improve QoL, and may also positively affect the illness' course (Sepúlveda *et al.*, 2002). In some countries, the practicing of specialist palliative care occurs in units and run exclusively for palliative care by nurses and doctors who are qualified as palliative care specialists. Whether such specialisation is significant or vital is something that can only be argued in the perspective of national needs and resources. Effective and actual public health plans, covering community and home-based care, are crucial to release pain and other cancer-related symptoms and palliative care for cancer patients and caregivers in low-resource settings (Kim *et al.*, 2017). Enhanced access to oral morphine is obligatory for the treatment of cancer pain when it is rated from moderate to severe, which over 80% of cancer patients in late Phase suffer from (Simmons, MacLeod and Laird, 2012).

To date, the providing of palliative care services to cancer patients still inadequate. The informational, physical, financial, social and emotional, unmet support needs and needs are commonly unmet for patients with advance disease taking usual oncology care (Whitmer *et al*., 2006; Rainbird *et al*., 2009). One of the reasons for insufficient use of palliative care may be misunderstandings regarding the meaning and/or scope of palliative care services. Patients and healthcare providers may wrongly equate PC with hospice, or assume that palliative care services cannot be delivered concurrently with cancer treatment (Mahon and McAuley, 2010; Mosher *et al.*, 2014).

Conversely, Uchitomi *et al.,* (2007) study revealed the undesirable image of palliative care was the main obstacle to early referral of the patient to an inpatient palliative care department as perceived by the cancer patients, caregivers, and healthcare providers. While comparing the terms palliative care and supportive care, Boldt, Yusuf and Himelstein's (2006) study revealed that the term palliative care stimulates bad emotions and reduces hope, and was less preferred by caregivers or healthcare providers. Healthcare providers in Fadul *et al*., (2009) study during a discussion on patient's referral to palliative care services sensed the name palliative care as a source of distress and anxiety, not only for patients and their caregivers but also to themselves.

Fitch, Porter and Page (2009) defined support care as the provision of necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostics, treatment, or follow-up Phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement . The National Cancer Institute (NCI) defines support care as care provided to enhance the QoL of patients who have a severe or deadly disease (Hui *et al.*, 2012). The objective of support care is to stop or treat as quickly as possible the symptoms of the illness, treatments' side effects, and social, psychological and spiritual difficulties associated with cancer or its active therapy (Fadul *et al*., 2009; Molassiotis *et al*., 2011).

The European Society of Medical Oncology (ESMO) has documented the importance to integrate support care and palliative care to cancer patients care (Cherny *et al.*, 2010; Jordan *et al.*, 2018). Supportive care is defined by the ESMO as care that aims to

optimise the comfort, function, and social support of patients and their families at all stages of the illness, including those with curable cancer (Jordan *et al.*, 2018). However, Fitch, Porter and Page (2009) might clarify the conflicting interest between palliative care and support care through their description of support care, which is the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social, or physical needs during their diagnostic, treatment, or follow-up Phases encompassing issues of health promotion and prevention, survivorship, palliation, and bereavement . Figure 2.1 will describe the time of palliative and support care implementation through the cancer journey (Fadul *et al.*, 2009; Hui, 2012; Marrow, Secreted and Protect, 2014).

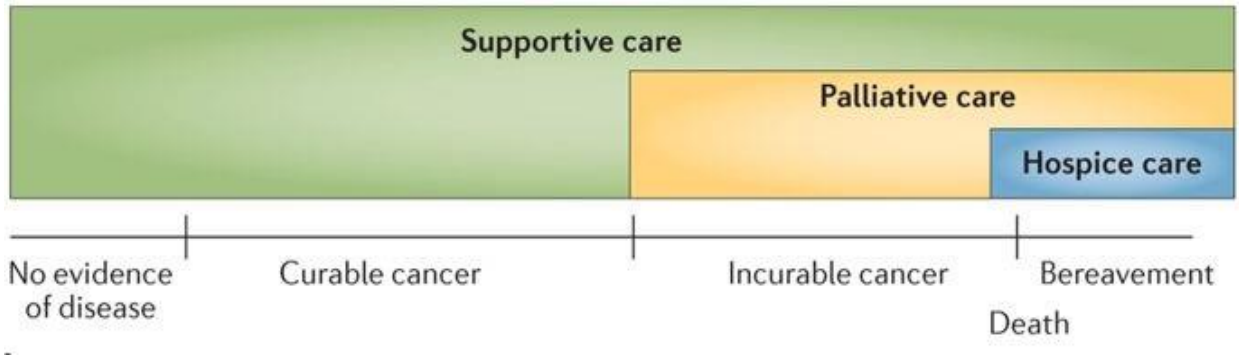


Figure 2.1: Integrating support and palliative care into the trajectory of cancer (Benz, 2016)

Uchitomi *et al.* (2007) revealed in their study that healthcare providers have a preference for using the term support care more than palliative care while discussing the referrals of cancer patients and caregivers regardless of healthcare provider age, years in practice, specialty or earlier training in palliative care. The study revealed an important variance in probability of referral of cancer patients receiving active therapy preferring a service with the name support care.

In addition, a study conducted in the USA by Fadul *et al.* (2009) revealed that oncologists prefer a service with the name support care for cancer patients who are actuality treated with curative intent. In instances where patients were beyond all anticancer treatment choices and those whose end of life was imminent, there was no

preference to whichever term. This outcome proposes that healthcare providers recognise the dissimilarity between the terms that are associated to clinical background.

Curable cancer patients have diverse needs and want diverse modes of care (Hui *et al.*, 2013). For patients with treatable cancer disease and dying patients, the perspective of imminent end-of-life makes these concerns more significant and fundamental to the whole clinical endeavour (Hudson, Aranda and Kristjanson, 2004; Benz, 2016). This uniqueness between palliative care and support care based on need and clinical context, necessitates a different method to provide care (Fadul *et al.*, 2009; Hui *et al.*, 2013). Although the provided services differ between those patients with treatable cancer and those with terminal disease, the offering of these services should be completed by the same team to give emphasis to continuity and stability of care and patient's QoL concerns, and to overcome healthcare delivery system challenges (Juhasz *et al.*, 2006; Fadul *et al.*, 2009; Park *et al.*, 2010).

From the above, it appears complicated and actually sad that there is no one definition regarding the services provided. The researcher supports the definition of supportive care as stated by Fitch, Porter and Page (2009), which actually says palliative care is part of supportive care. It would appear the definitions are the same, however there is a debate of when palliative care should be started; it is does not matter what it is called as long as it is done.

2.6 THE ROLE OF CAREGIVERS IN THE CARE OF CANCER PATIENTS

Every cancer patient's journey is shared by their family caregivers, who might be as influenced and affected by the diagnosis and its consequences or outcomes as the cancer patient. A caregiver is a person who provides assistance and care to anyone who needs it, especially those who can no longer do it independently (Hunt, 2004; Wilson *et al.*, 2012). According to the American Cancer Society (2016c), the caregiver of cancer patients refers to a family member, friend, loved one or other support person who lends physical, emotional or other support to someone at any time during the cancer journey (Mahendran *et al.*, 2015:1). This assistance is provided free of cost to the cancer patient. Caregivers are frequently not qualified in giving care, but regularly

assist the cancer patient. The caregiver's role is a lifeline to the cancer patient, and they fulfil many roles, which change as the needs of the patient change (Glajchen, 2004; Steinwedel, 2013).

As the needs of patients change, so do the roles of the caregivers (Mwangipowell, Pereira and Spence, 2003; Schulz and Eden, 2016). The many roles caregivers play result in them being involved in various activities, such as taking the patient for doctor visits, providing assistance with meals, providing nutritional support, feeding the patient, picking up medicines and ensuring that treatment is taken according to the care plan, symptom management especially pain management, wound care, hygiene, and running of errands, such as bill payments, as well as accessing health system resources. Other activities include coordinating care, monitoring use of electronic devices, such as oxygen concentrators, and communicating with healthcare providers (Park *et al.*, 2010; Ryn *et al.*, 2011; Woźniak and Izycki, 2014).

Caregivers have always been an extension of the professional workforce for cancer and play a serious and important part in cancer care and its components of care (Given, Given and Sherwood, 2012; Maree *et al*., 2017). Cancer care is shifting from longer to shorter hospital stays and outpatient treatment, such as homes and community settings to reduce the economic burden (Northouse, *et al.*, 2012; Ferrell *et al*., 2018). Due to this shift, most cancer patients are cared for at home and caregivers find themselves playing the role with little knowledge and without support and guidance from the healthcare system (Reinhard *et al.*, 2008; Hudson *et al.*, 2015; LeSeure and Chongkham-Ang, 2015).

Caring for a cancer patient is not easy; it is demanding and challenging as caregivers share the experiences of cancer with the patient (Jacobs, Clawson and Mynatt, 2014; Jacobs and Shulman, 2017). In addition, it is possible that a cancer diagnosis could have a greater impact on the caregivers compared to the patient (Northouse, *et al.*, 2012; Hudson and Aranda, 2014). Caregiving is linked with negative physical health difficulties such as pain, fatigue, impaired cognitive function, sleep problems, and burn out (Stenberg, Ruland and Miaskowski., 2010), as caregiving often results in other duties invading the caregivers' daily needs, and consuming the caregivers' time,

attention and energy leading to caregiver burden (Bevans and Sternberg, 2012; Sakakibara, Kabayama and Ito, 2015).

2.7 CAREGIVERS CARE BURDEN

According to Applebaum, Kulikowski and Breitbart, (2015) caregiver burden denotes a multidimensional reaction to the undesirable appraisal or judgement and experienced stress caused from offering cancer care to sick persons, or the suffering that caregivers sense because of given care. It refers to the care and differs from being anxious or depressed due to other emotional and overall reactions. Kim *et al*. (2012) agree with the multidimensionality of the burden and ascribe it to the negative appraisal and/or assessment of caregiving and the perception of stress as a result of caring that impends the psychological, physical, emotional and functional health of caregivers (Etters, Goodall and Harrison, 2008; Carretero *et al*., 2009).

Besides the caregiver burden being multidimensional, it also consists of objective and subjective burdens (Gabriel and Mayers, 2019). Objective burdens are caregivers' health and individual time away from providing care and contain privacy, salary, personal time and freedom, holidays, energy, and relationships with individuals. Subjective burdens are the perceptions of the impact of objective burdens on the caregiver arising from the process of caregiving. This aspect of the caregiving burden is the psychological dimension of caregiving, which is rooted in social support and coping ability. Subjective caregiver burdens deplete the psychological resources of the caregiver in the process of caregiving (Govina *et al.*, 2015). Although it is important and necessary to assess both the objective and subjective caregiver burden, the objective burden does not show how the caregivers carry out caregiving duties. Some caregivers might enjoy providing care for a loved cancer patient, while others may find it hard and not an easy duty, resulting in changes in subjective burden over time due to alterations in the caregiving condition, and the upcoming prospects of the patient (Sur *et al.*, 2002).

Lau *et al*., (2010) also identified self-confidence as an asset. Self-confidence assisted in reducing the high subjective caregiver burden, which impedes the caregivers'

performance. Other factors that increased subjective burden were negative emotional statuses, such as exhaustion and grief, physical impairments, low literacy level and poor communication skills. Competing responsibilities, such as occupation, housework, and care of other dependents, acted as obstacles to caregiving. The ability of caregivers to create and preserve a good relationship with their patient and the availability of support networks were positive in terms of social functioning.

Gabriel and Mayers (2019) investigated breast cancer patient's caregiver burden and focused on three broad perspectives of caregiver burden: psychological burden, occupational burden and economic burden. The study reported that the causes of psychological burden were caregiver burden, patient anxiety and patient physical functioning, resulting in caregiver anxiety and depression. In addition, the psychological, occupational and economic burdens related to caregiving increased as the patients' functional status declined, which led to caregiver anxiety and depression.

Various studies (Kim *et al.*, 2012; Glajchen, 2012; Datta and Kar, 2016 Abdullah *et al.,* 2019) support the belief that the caregiver burden increases as the patient's illness worsens. During deterioration, the patients' disability increases, they have higher personal care needs, lack mobility, have a greater dependency on their caregivers, and experience pain and functional impairment (Glajchen, 2012; Datta and Kar, 2016). The caregiver burden reaches its height through giving care to the terminal Phase cancer patients and existing with the patient experiencing high physical wellbeing impairment and needs, since the caregivers tend to offer more physical care to the cancer patients with less chances for respite (Glajchen, 2012; Abdullah *et al.*, 2019). Caregivers also have a tendency to experience major distress as they observe the suffering of their loved cancer patient, and at the end of life they tend to become unsociable (Glajchen, 2012; Northouse, Williams, *et al*., 2012).

Various factors influence caregiver burden. Kim *et al.,* (2012) study, which examined the predictors of caregiver burden among caregivers of dementia patients, established both correlations and predictors of caregiver burden. The study found that nine identified

factors, caregiver age, caregiver gender, marital status, living with the care recipient, daily activities, instrumental activities of daily living, number of carers, adaptation strategies, and number of hours were all predictors of caregiver burden, and were the greatest contributors to caregiver burden prediction, accounting for 18%, 34%, 27% and 32% respectively. By implication, patients with significant functional decline place serious demands on the caregiver in terms of time devoted to the care and increased help with daily activities, which in turn results in high levels of both objective and subjective caregiver burden. This finding supported those from other studies including Sussman and Regehr (2009) and Conde-Sala *et al.*, (2010) who reported similar findings on the predictors of caregiver burden of cancer patients, especially with regard to daily activities of caregiving.

In terms of cancer care, Stajduhar, Fyles and Barwich (2008) add to the list of predictors of the caregiver burden. When investigating the aspects manipulating family caregivers' capability to adapt to care provided to end-of-life cancer patients, the researchers identified five broad themes: (1) the approach of how the caregiver's perceive life, (2) the patient's sickness involvement or experience, (3) the person’s gratitude of the caregivers' support to cancer care, (4) the value or feature of the relationship between the caregiver and their sick person, and (5) and how safe the caregivers feel. Caregivers with a positive attitude to life tend to cope better with caregiving demands than those who do not, indicating that a positive attitude to life tends to reduce the subjective caregiving burden. In addition, the relationship between the care recipient and caregiver plays a significant role in creating an effective coping environment for caregivers. Social support was further shown to be an important element in caregiving as care recipients were grateful of the support received from family and friends. This boosted the caregivers' coping strength. Healthcare systems and institutions also act as caregivers to the caregivers when they provide support to them, strengthening the caregivers coping abilities in a positive way.

2.7.1 Caregivers burden assessment instruments

Caregiver burden instrument was initially developed in 1980 by Steven Zarit, a Professor of Pennsylvania State University (The Joanna Briggs Institute, 2007). The Zarit Burden Interview (ZBI), is used internationally (Kumar and Gupta, 2014; Bianchi *et al.*, 2016; Souza *et al.*, 2017), although numerous caregiver burden instruments are available to measure the burden of the caregiver (Frederick, 2018). Caregiver burden instruments repeatedly focus on the several disease courses of the individual being cared for (Reinhard *et al*., 2008; Mlinac and Feng, 2016; Molony *et al*., 2018). Several examples of how specific disease entities have impacted caregiver burden have been observed, these include: testing caregiver burden which is the outcome from caring with a prolonged physical illness (Lim and Zebrack, 2004; Reinhard *et al.*, 2008; Faronbi *et al.,* 2019); taking care for old persons with chronic disease (Stoltz, Udén and Willman, 2004), caring for cancer patients and in need of PC service's (Harding *et al*., 2004); taking care for dementia diagnosed patients (Thompson *et al.,* 2007); taking care of psychiatric illnesses (Östman and Hansson, 2004). Caregiver burden instruments have been used in a lot of countries and translated into other languages (Özer, Yurttaş and Akyıl, 2012; Bachner, 2013; Bianchi *et al.*, 2016; Iecovich, 2017; Souza *et al.*, 2017; Gratão *et al*., 2019). The Zarit Burden Interview instrument (ZBI) was used in the current study to measure the care burden of caregivers of cancer patients.

2.8 SPOUSAL CAREGIVERS

Special attention was applied to the spouse/dyad caregivers of cancer persons because they are a high risk population for caregiving burden, as well as diminished QoL due to the major role of caregiving they play as the primary source of cancer patients' support. The impact of cancer on caregivers is real when the cancer patient's caregiver is the patient's spouse, who takes on vigorous task of implementing treatment choices and delivers emotional, physical and psychological support to the cancer patient (Kayser, Watson and Andrade, 2007; Hagedoorn *et al*., 2008; Li and Yuen, 2014). It is stated that the support provided by the spouse of the cancer patient is of huge magnitude, and this support is greater than that provided from friends or other family caregivers (Li and

Yuen, 2014). However, by concentrating on giving, the spousal caregivers frequently fail to deal with their own needs and their emotional state (Chung, 2012; Lopez, Copp and Molassiotis, 2012; Li and Loke, 2014). Literature revealed that the spousal caregivers of cancer patients are at a high risk of concealed physical, mental and social illnesses, as a result of giving care (Li and Yuen, 2013; Li and Loke, 2014).

At different levels cancer has an emotional impact on patients and their partners as one component, instead of as isolated entities, causing partners to respond to a cancer diagnosis as an "emotional system" (Hagedoorn *et al.*, 2008). The diagnosis and management of cancer can adjust how the relationship moves among cancer patients and their close partners, which could have an effect on individual well-being and the ability to adapt to some concepts (Dankoski and Pais, 2007). The partners have a shared effect on their QoL, mental health, and amendment to their duties (Northouse *et al.*, 2000; Kim *et al.*, 2008).

These alterations and mutual effect may disturb the core of the relationship, duties and their responsibilities, causing unclear future plans (Dankoski and Pais, 2007). A cancer diagnosis causes the couple stress regarding "breaking the bad news," discussing the alterations in work-related issues, family title role, and handling home and childcare duties (Maughan, Heyman and Matthews, 2002; Lopez, Copp and Molassiotis, 2012). During the cancer's course, the couple must adapt with the everyday concerns and problems they may come upon (Dankoski and Pais, 2007). Spouses moreover have concerns about their capability to deliver emotional, financial and realistic support to their cancer patient, as well as the possible harm to their partner (Maughan, Heyman and Matthews, 2002; Li and Yuen, 2014).

To give attention to cancer care, studies have moved from the single involvements of "cancer patients or spousal/dyads caregivers to caregiver-patient dyads" (Fletcher *et al.*, 2012). It is recommended that in the future, the relations among caregivers and patients as care spouses/partners should be highlighted (Fletcher *et al.*, 2012; Li and Yuen, 2014). Two conceptual models were recognised that are based precisely on "caregiver-patient dyads" in the cancer inhabitants. One is the "relationship intimacy model," which reports the psychosocial coping of the patient and spousal caregivers to cancer (Manne

and Badr, 2008). This model highlights the significance of the relationship between the parties, and how much communication improves the relationship throughout stressful times.

The second conceptual model, proposed by Fletcher et al., (2012), “caregiver-cancer patient dyads” is hypothesised as a practical component with a shared concern over the three dyad concepts: “communication,” “reciprocal influence,” and “caregiver-patient congruence.” The idea is the emphasis and route of research on the process of caregiving, which must focus on the “caregiver-patient dyad” as a one unit (Fletcher *et al.*, 2012; Li and Yuen, 2014).

Worry of potential side effects, such as treatment addiction, tolerance and depression that could be happen, may affect the spouse’s judgment regarding administering analgesics (Savage, Kirsh and Passik, 2008; Prince *et al.*, 2011; Raff *et al.*, 2014). Non-adherence with pain treatments is aggravated by the fact that partner caregivers rarely receive information about the significance of complying and obeying treatment schedules (Brown and Bussell, 2011; Saifan *et al.*, 2015). Pain education programmes could provide support in refining pain management and controlling awareness among patients and their spousal caregivers (Kim *et al.*, 2013; Latter *et al.*, 2016; Lam *et al.*, 2017).

Pain context comprises various aspects and consists of how patients diagnosed with cancer and their spouse caregivers recognise, reply to, and assess pain and in what way that effects patient’s agreements with pain controlling approaches (Achterberg *et al.*, 2013; Lichtner *et al.*, 2016). Spirituality and beliefs are aspects surrounding this context. Such beliefs have an influence on symptom control, and the awareness of and the response to symptoms by the caregivers and cancer patients (Dedeli and Kaptan, 2013; Agorastos, Demiralay and Huber, 2014; Lichtner *et al.*, 2016).

Unrelieved cancer pain is an important health issue that negatively affects the QoL of cancer patients as well as their spouse caregiver (Sessle, 2011; Saifan, Bashayreh and

Saifan, 2015). The experience lived by cancer regarding cancer pain not only has an effect on the physical well-being of cancer patients, it also has an influence on spouse caregiver's mental well-being as well as other life aspects, causing both physical and mental illnesses for both parties. Physically distress occurs as a consequence of sleep deprivation, anorexia, weakness, and diminished functioning, thus causing additional medical illnesses (Sessle, 2011; Saifan, Bashayreh and Saifan, 2015).

2.9 CAREGIVER QOL

Caregiver QoL is an important outcome of the caregiver burden (Boyoung *et al.*, 2013; Gabriel and Mayers, 2019) as the caregiver burden negatively affects the QoL of caregivers (George and Gwyther, 1986; Collins and Swartz, 2011; Glajchen, 2012). There is no worldwide explanation for the QoL, however the World Health Organization, (1996) states that the QoL denotes for the persons' awareness of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. QoL consists of various domains or dimensions and authors differ in terms of these domains, for instance, QoL has various dimensions including health and physical functioning, economic, emotional, social, psychological and caregivers (Alptekin *et al.*, 2010:608). QoL in simpler terms is the individual's general feeling of wellness with regard to life (Salvador-Carulla *et al.*, 2014).

Various studies, by Sur *et al.* (2002), Northouse, Williams, *et al.* (2012), Belgacem *et al.* (2013) and Johansen, Cvancarova and Ruland (2018), agreed that the caregiver burden affects the caregiver's psychological, behavioural, physiological and psychological health as well as economic and financial resources. In addition, caregiver suffering and QoL have been strictly related to the cancer patients' physical health; if the patient's health worsens, the caregiver care burden increases and QoL of the caregiver worsens (Rutering *et al.*, 2016). The decrease in QoL of the caregiver affects the quality of care provided to the patients and thus the QoL of the patient (Ugur *et al.*, 2014; Krug *et al.*, 2016; Seyedeh, Ebadi and Seyed, 2017; Souza *et al.*, 2017).

QoL is hard to test or evaluate but it comprises the social well-being of the individual as well as the prevailing health condition (Cano and Hobart, 2011; Hand, 2016). This explanation of QoL varies and fluctuates from individual to individual, and expresses and articulates different meanings to the same individual through the disease course (Alptekin *et al.*, 2010; Svalastog *et al.*, 2018).

2.9.1 QoL assessment instruments

There are numerous QoL instruments available to investigators, but there is little guidance for the researcher to select between them (Hyland, 2003; Matthews and Choi, 2016). To choose between the QoL instruments it is not easy because in fact that experts who developed the instrument are commonly part of their own scales (Hyland, 2002, 2003). Even though the investigators may feel daunted in the need to select them, this task is amazingly straightforward as soon as the guidelines and rules underlying QoL scale performance are comprehended. This study used the “Caregiver Quality of Life Index-Cancer” (CQOLC) to measure the cancer caregivers QoL and the “ European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC)” to measure cancer patients QoL.

2.10 CANCER PAIN

Pain is a multifaceted phenomenon and refers to, unhappy “sensory and emotional” involvement ascending from real or possible tissue injury (International Association For The Study Of Pain, 2014) . According to Everdingen *et al.* (2007), more than 70% of cancer patients experience pain caused by their disease and/or treatment. However, 50% to 70% of cancer patients experience pain in some point, which usually increases as the disease aggregates (Kaila and Maree, 2018). Cancer pain can either be acute or chronic, based on duration of pain, which may trigger fear of cancer progression or recurrence, worsen anxiety, hopelessness and depression (Brant, 2018).

Cancer pain includes inflammation mechanisms, compression and ischemia producing nociceptive and neuropathic combination symptoms and this neuropathic component has been adjudged to affect, at minimum, 20% of all cancer patients (Yoon and Oh,

2018; Edwards, Mulvey and Bennett, 2019). According to Brant (2018), nociceptive pain consists of “somatic and visceral” pain. Somatic pain is produced by stimulation of “nociceptors” in the periphery arising from the bone, muscles, skin, joint or connective tissue and is described as localised, aching, gnawing, sharp or throbbing pain or pressure, and can be persistent or recurrent (Beinart *et al.*, 2012; Kaila and Maree, 2018; Yoon and Oh, 2018; Edwards, Mulvey and Bennett, 2019). Visceral pain results from stimulation of nociceptors in the abdominal or thoracic cavity, secondary to distension of viscera, compression or infiltration of the thoracic or abdominal tissue and is characterised by diffuse, aching or cramping sensations which are poorly localised, dull, aching or cramping (Sikandar and Dickenson, 2012; Kaila and Maree, 2018). Peripheral pain is neuropathic pain caused by peripheral nerve injury, often characterised by numbness and a tingling sensation, whilst centrally mediated pain is neuropathic pain characterised by radiating and shooting sensations within a background of burning and aching (Sikandar and Dickenson, 2012; Yoon and Oh, 2018).

Cancer pain can be acute or chronic. Acute pain is pain which typically lasts less than six months, the cause is often known and pain behaviours are more frequently exhibited (Brant, 2018; Kaila and Maree, 2018). Acute pain is one that has a sudden, well-defined onset, an identifiable cause and is subject to sympathetic output. Acute pain may be caused by diagnostic or treatment interventions including surgery, biopsy, reactions to anticancer therapies, such as chemotherapy or the infusion technique, radiotherapy such as mucositis in response to chemotherapy toxicity, hormonal therapy, immunotherapy and infection (McMahon *et al.*, 2006; Kaila and Maree, 2018).

Chronic pain continues for more than three months, or reoccurs over several months beyond the usual course of an acute illness or injury (Kwon *et al.*, 2013; Agboola *et al.*, 2015). Chronic pain is one of the main reasons of suffering and disability globally, and a shared symptom of both cancer and HIV/AIDS. Chronic pain is also associated with a collection of maladjustment of physical, psychological, family and social concerns and can be considered as a disease entity (Brennan, Lohman and Gwyther, 2018; Kaila and Maree, 2018). Chronic pain may be caused by the disease itself resulting in muscle

pain, chronic headache, peripheral neuropathic pain and pain syndrome of the viscera, and is also associated with cancer therapy, such as hormonal treatment, chemotherapy, or surgical therapy (Brown, Ramirez and Farquhar-Smith, 2014).

Persistent pain is devastating for the QoL of those having cancer (Brown, Ramirez and Farquhar-Smith, 2014; Stewart, 2014). Unrelieved pain results in many adverse effects that have a negative outcome on the patient's physical, psychological, social and economic status. Physically the patients elicit pathophysiologic neural alterations, including peripheral and neuronal sensitisation, which includes chronic pain syndromes. In addition, the physiologic and psychological impairments related to pain interfere with the patient's ability to function at work, whilst persistent pain affects their capability to sleep, eat, concentrate and deal with others (Sessle, 2011; Kaila and Maree, 2018). Emotional and psychological issues, such as mood, fear and worry or anxiety, as well as environmental issues, such as relationship with friends and families, influence the pain experience and is associated suffering (Cousins, 2007)

Unfortunately, cancer pain is not always well managed. Deandrea *et al.* (2008), in a systemic review focusing on the incidence of under-treatment pain of cancer, suggest that approximately one in two patients with cancer pain are undertreated. Despite several guidelines focusing on the management of cancer pain, including the WHOs recommendations developed over two decades, 70% to 90% of cancer patients experience pain even if effective treatment is available. Among cancer patients who experience pain, 42% report insufficient analgesia (Rannestad and Skjeldestad, 2007; Kaila and Maree, 2018). Unrelieved cancer pain is also related to sleep turbulences and feeling depressed, which is more often stated by young cancer survivors and those with co-morbidities (Syrjala *et al.*, 2014; Posternak *et al.*, 2016).

Inappropriate management of pain, due to barriers relating to patients and health care providers, contributed pointedly to the challenges of controlling cancer pain (Kaila and Maree, 2018). According to Oldenmenger (2009), patient and family barriers include false impression about anaesthetics medication and their side effects, which lead to non-adherence to treatment schedules and low communication of their distress to health professionals. Not reporting pain is also a barrier to effective management.

Campbell (2011), stated that patients might not report their cancer pain for many reasons, such as the desire not to bother the staff, fear that their pain is indicative of disease progression, fear of becoming addicted or tolerant to the pain medication and concern about the side effects (Omran *et al.*, 2014; Givler and Maani-Fogelman, 2019). Additional barriers include ignorance about pain medication, social, educational, economic and/or religious factors, family beliefs, culture and society's attitudes towards pain relief and the belief of patients that they can manage their own pain (Givler and Maani-Fogelman, 2019).

2.10.1 Pain assessment

A systematic assessment of cancer pain is the crucial first step in pain management and of little significance if the assessment is incorrect (Breivik *et al.*, 2008; Campbell, 2011; Kim *et al.*, 2012; Boekel *et al.*, 2017). According to Campbell (2011), the existing standard method of early cancer pain assessment comprises a comprehensive history and physical examination, assessment of the psychosocial conditions of the patient and a diagnostic work up considering what causes the pain and pain intensity. Brant (2018) suggests the `ABCDE` approach consisting of ask, believe the patient, choose an intervention and treatment, deliver treatment on time and empower the patient to have control of their situation to assess and treat pain. However, pain assessment usually includes two areas. the initial assessment that consists of the site of pain, pattern of pain, aggravating factors, relieving factors, patient´s description of pain and an ongoing assessment that includes the response to treatment (Campbell, 2011; Stewart, 2014).

2.10.2 Pain Assessment Instruments

Pain assessment instruments are important to perform a proper assessment and likely to be communicated constantly and sustained over any period of time (Hadjistavropoulos *et al.*, 2016; Lichtner *et al.*, 2016). Numerous assessment instruments and pain rating scales have been developed for different types and sub types of acute and chronic pain that are either one-dimensional or multidimensional. One dimensional instruments have one measure to rate pain, while multidimensional instruments measure numerous factors and its severity, such as behaviour, mood, how

pain impacts on life, activities of daily living and the treatment used before (Dansie and Turk, 2013; Brant, 2018). Pain measurement scales include verbal rating scales, word scales, nonverbal scales, face scales, behavioral pain scales and behavioral observation scales. Numerical rating scales are commonly used in adults (Hjermstad *et al.*, 2011; Pathak, Sharma and Jensen, 2018) and verbally administered numerical rating scales are favoured over visual analogue scales and word descriptor scales (Pathak, Sharma and Jensen, 2018).

Pain assessment instruments usually include a rating scale, and assess other factors such as the quality of the pain, the location of the pain, what alleviates and what aggravates the pain (Hjermstad *et al.*, 2011; Kaila and Maree, 2018). The brief pain inventory (BPI) (Ballout *et al.*, 2011) is an example of such an instrument and was used in this study.

2.11 THEORETICAL MODEL

There are a number of models relating to stress and coping with stress. The model selected for this study was Lazarus and Folkman's (1984) transactional model of stress, appraisal, and coping . According to Lazarus and Folkman, (1984, 1987), Shaw, (1999) and Hudson, (2003), this model has been broadly supported as a valuable model to direct caregiver research. This model recognises the significance of positive mental states and intervention outcomes related to caregiving. While this seminal body of research is important in the understanding of how caregivers react to and cope with stressors, it assumes that coping is the most efficient means for adaptation. This may be more useful as a model in short-term crisis events as opposed to long-term living with the outcome of cancer and its related treatment.

Lazarus and Folkman (1987) contended stress was a consequence of a transaction among a person and his/her environment. As such, stress incorporates a set of intellectual, perspective, affective, and coping factors . According to Lazarus and Folkman (1984), Serido *et al*. (2014) and Yao *et al*. (2017), stress is a consequence of an inequality between the caregivers and cancer care-related environment.

Personal appraisal of an event or condition provokes adapting and the ability to use available support resources and these reactions facilitate the existence of a stress response. To be precise, stress will take place once there is an apparent inconsistency among the needs of the situation and the sources existing to deal with the stressor.

Lazarus and Folkman's (1984) model proposes that cancer is a stressor in cancer patients and will affect the physical and psychosocial status of caregivers of cancer patients. In this perspective, stress includes cognitive, affective, and adaptive variables. In addition, the factors that influence appraisals of harm include a person's values, commitments, nature of the harm, social support, availability of resources, coping skills, and duration of harm.

This model described in figure 1.2 claims that the main facilitator of "person-environmental transactions" is appraisal. Three kinds of appraisal that define the emotions and coping behavior are: "primary, secondary, and reappraisal" (Lazarus and Folkman, 1984).

Primary appraisal is a judgment about how a person perceives a situation to be a potential source of harm, as well as what harm occurred because of the situation. This awareness of harm elicits the secondary appraisal. Secondary Appraisal is the procedure of defining what adaptive preferences or behaviours exist to deal with any harm and how effective these options might be. Frequently, primary and secondary appraisals happen simultaneously and interrelate with each other; factors that affect the appraisal involved in an individual's belief in personal control. Other factors affecting the cognitive appraisal comprised the volatility of an incident, how imminent an incident was and the incident duration. Reappraisal is the process of continuously evaluating and changing earlier primary or secondary appraisal as the situation progresses; what was firstly perceived as harm might now be observed as irrelevant. Often, reappraisal results in the cognitive elimination of an apparent risk (Shaw, 1999).

Use of the Lazarus and Folkman model

Figure 2.2 presents the Lazarus and Folkman's "transactional model of stress and coping" model to guide the current study.



Figure 2.2: Lazarus and Folkman's transactional model of stress and coping (Shaw, 1999).

According to this model, personal, social, and disease-associated factors are antecedent circumstances that can constitute harm and affect the QoL of cancer caregivers. The transaction between a person and his/her social or illness-related factors, such as cancer ,can influence how individuals appraise and cope with the illness (Shaw, 1999).

Lazarus and Folkman's " transactional model of stress and coping" is a conceptual model developed for evaluating the process of coping with numerous stressors, such as work stress, family stress, and the challenge of caregiving. The conceptual underpinning of the model is that when persons are confronted with a stressor such as cancer, they experience appraisal practices which point their coping to the stressor. If they are unable to cope, it will have an impact on their QoL.

This model offers a testable theoretical method for measuring the alteration in QoL. This theoretical model, as shown in figure 2.3, was used in this study to explain and expect alterations in QoL as consequences of the collaboration of mentioned factors.

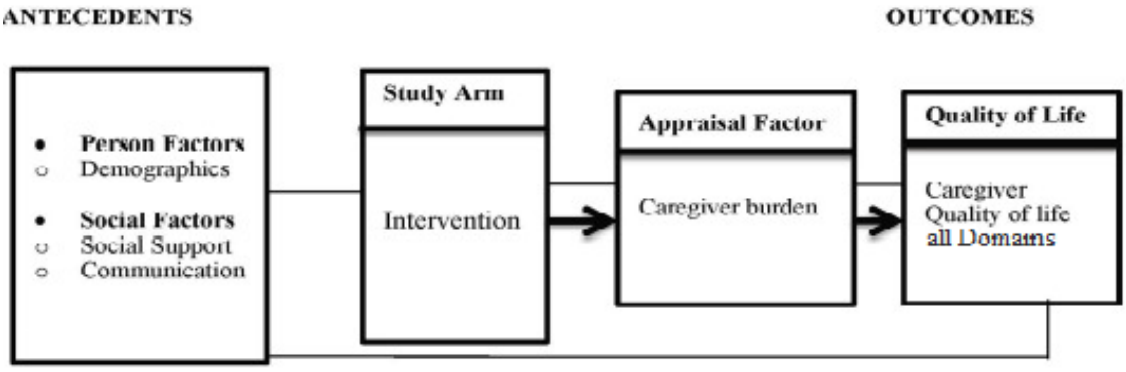


Figure 2.3: Theoretical framework of factors affecting Primary Caregiver QoL. Arrows (→) indicate the effects of the intervention on the outcome. Light lines (——) indicate significant relationships between variables of the study that observed from previous studies.

The variables identified in Lazarus and Folkman's "transactional model of stress and coping" are predictors of physical, emotional and psychosocial outcomes of cancer patient's primary caregivers. Therefore, they offer a solid theoretical source for an intervention to enhance QoL.

2.11.1 Stress

Lazarus and Folkman (1984), defined stress as an association among the individual and the environment that is appraised by the individual as exhausting, or greater than a person' resources and compromises an individuals' wellbeing . The decision that a certain "person-environment" correlation is stressful is a turning point for a cognitive appraisal . When threatened with a stressful event, an individual may react with a psychological or physical reaction (Lazarus, 1999). The existence of a stressful state does not mean that the individual would have a reaction, as stress was well-defined by the individual's reaction instead of the incident (Lazarus, 1999).

Stressful circumstances could possibly be classified into three areas: (a) great scale incidents including a lot of persons, such as "disasters or wars," (b) great incidents,

which have an influence on one or a few persons, such as decease of a precious one, and (c) day-to-day hassles or small annoyances which have an influence on responses to bigger stressors (Lazarus and Folkman, 1984). Caring for a cancer patient could position itself into the second or third areas, where the large-scale event involved a caregiving experience. Not everybody reacts to similar stressful conditions in a similar way, as the stressful incident and the features of the caregiver vary (Lazarus and Folkman, 1984).

2.11.2 Coping

Once an individual appraised an incident as stressful, the individual then identified what they might do to adapt to this incident (Lazarus and Folkman, 1984). Coping may possibly take two forms, either " problem-focused or emotion-focused strategies" (Lazarus and Folkman, 1984). "Problem-focused strategies" are coping strategies that include handling or modifying the trouble with the individuals or the environment. "Emotion-focused strategies" comprise an adaptable, expressive reaction to the incident. Persons might use both kinds of strategies to hand out the stressors. "Emotion-focused forms of coping," which consist of denial and avoidance can damage health by blocking or hindering the coping health and disease-related behaviour (Lazarus and Folkman, 1984). Once using the "emotion-focused strategies," individuals may succeed in depressing emotional distress, but during the course, have no success in pointing out the problem that could be receptive to appropriate action (Lazarus & Folkman, 1984).

2.12 SUMMARY

This chapter provided a brief history of cancer as a disease, cancer symptoms, diagnosis of cancer and treatment, the influence of caring of cancer patients on caregivers, the role of caregivers, palliative and support care, and then went further to discuss in detail the conceptual framework used. The next chapter describes the methodology and research design used in the study.

CHAPTER THREE

RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

This chapter focuses on the study design, study setting, population of the study and sample, instruments, recruitment, inclusion criteria, collection of the data procedures, management and analysis of the data and ethical considerations. The current study was aimed to develop and pilot test a support programme for caregivers of patients with cancer in Palestine. The intervention was measured in terms of a primary outcome and secondary outcomes; the primary outcome was caregiver QoL and secondary outcome, caregiver care burden, cancer patient QoL, pain experience and symptom burden.

3.2 STUDY DESIGN

The research design presents the process of enquiry and is the plan for solving research questions (Creswell, 2014; Adebiyi and Abayomi, 2016), and serves as the blueprint of a study guiding its planning and implementation in a way to achieve accurate results. The research design is a set of consistent steps, which the researcher takes in order to offer answers to the research questions (Byrne and Humble, 2007; Burns and Grove, 2009; Polit and Beck, 2012; Creswell, 2014).

The research design for this study was a sequential multi-method study conducted in Phases (Figure 3.1). According to Mafuba and Gates (2012), supported by Stange, Crabtree and Miller, (2006) and Byrne and Humble, (2007), sequential multiple methods comprise the use of outcomes and results obtained via one data gathering method to determine the implementation and direction of following Phases of a research plan. This design assisted the researcher in using all the available tools to gather extra comprehensive information, which offers outcomes that have a comprehensive perspective of the overall concern or the problem of the current research. Instead of just focusing on one style of research methodology, mixed methods encouraged the researcher to highlight or underline the research problem and use all methods available

in order to have a better understanding (Creswell and Plano Clark, 2007, 2011; Wium and Louw, 2018).

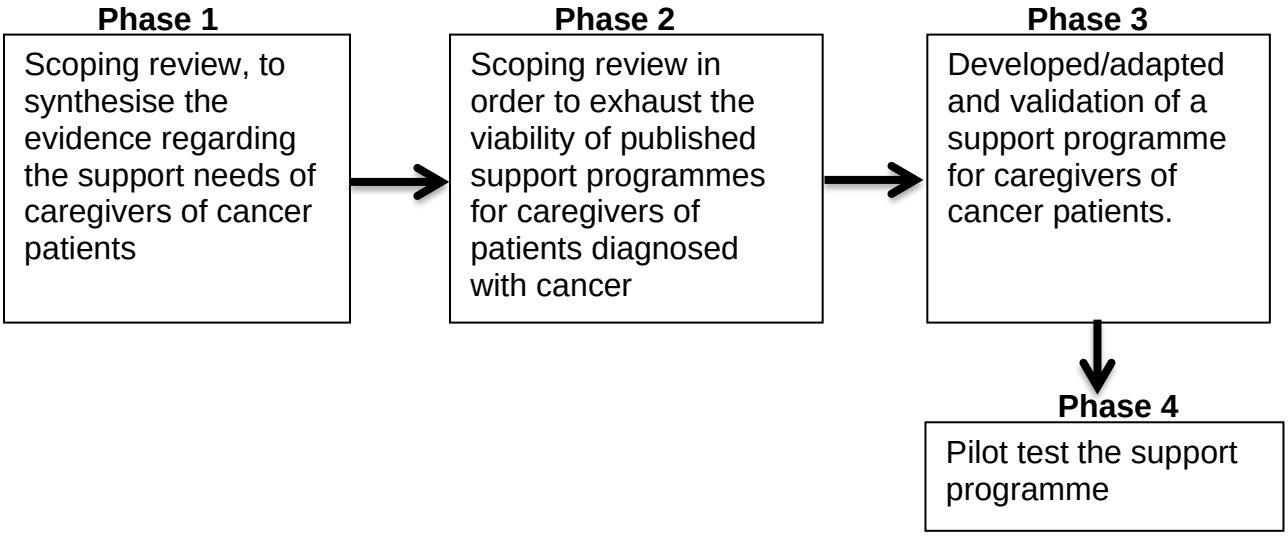


Figure 3.1: Summary of Steps of the Study

Development of a support programme for caregivers of cancer patients involves a scoping review and systemic search of the literature. In the current study, however, both of scoping reviews occurred prior to the implementation of the programme to allow the researcher to recognise the existing issues, improvement and challenges that the caregivers face in cancer care. It also allowed the researcher to formulate the intended support programme content that was found in the literature (Levac, Colquhoun and O'Brien, 2010). A scoping review includes a precise method of intensive literature review that categorises, critically appraises, chooses and synthesises all pertinent research evidence about a particular research question (Arksey and O'Malley, 2005). The scoping reviews should be used to search for evidence and the criteria for selecting the evidence and the strong point and limitations of the core of evidence must be undoubtedly described (Arksey and O'Malley, 2005; Levac, Colquhoun and O'Brien, 2010; Dijkers, 2011).

3.3 PHASES OF THE STUDY

3.3.1 Phase 1: Scoping review

The research question addressed in this scoping review was, “What evidence is available pertaining to the support needs of caregivers of cancer patients?

These questions were answered by obtaining evidence about the effects of support programmes on cancer patients’ caregivers’ QoL and care burden, as well as, cancer patients’ QoL, pain experience and symptoms burden according to the literature. The scoping reviews followed Arksey and O’Malley's (2005) guidelines. The method for the scoping reviews is discussed in detail.

Scoping reviews have become a common method for synthesising research evidence (Arksey and O’Malley, 2005; Levac, Colquhoun and O’Brien, 2010; Pham *et al.*, 2014). Scoping studies are an easier and faster method of gathering ideas and main perceptions that the research depends on and the type of evidence that is available. Scoping can be carried out as individual research particularly if the area under investigation is complicated or it is studied for the first time (Arksey and O’Malley, 2005; Emmerson *et al.*, 2009; Dijkers, 2011; Daudt, Van Mossel and Scott, 2013). The scoping review also strives to offer a general idea of a possibly great and varied body of literature relating to a comprehensive area (Arksey and O’Malley, 2005; Boldt, Yusuf and Himelstein, 2006; Drucker, Fleming and Chan, 2016; Aryal, 2017).

Scoping reviews are used to evaluate the research findings, identify the knowledge gaps in the research study, set the research agenda, identify implications for decision-making, identify articles that are used or designated scoping review approaches and give guidelines and quality for reporting scoping review studies (Burga and Rezania, 2015; Buchberger *et al.*, 2016).

The researcher selected Arksey and O'Malley's (2005) “five-stage framework,” which approves a rigorous or precise method of clearness, permitting duplication of the search plan and aggregating the consistency of the results for the scoping review. Arksey and O’Malley (2005) aim to inspire conversation about the worth of scoping reviews and

offer a starting point in the direction of a practical model. Since the development of Arksey and O'Malley, (2005) scoping review, a few researchers have depended on their experience with scoping reviews and applied an enhancement or refining to the core of the scoping review (Brien e*t al.,* 2010; Daudt, Van Mossel and Scott, 2013; Pham *et al.*, 2014).

To search the literature, relevant and related peer-reviewed journal articles published between 1st January 2008 to 31 December 2017 were searched from the following electronic databases; PubMed, CINAHL, Science Direct, and Scopus. The key words used were support needs + caregivers + cancer. The databases were chosen to be broad and to overlay a wide range of disciplines. In addition, reference lists of tracked papers were also used to track other related articles.

The review comprised the following five stages: (1) finding the initial question of the research, (2) detecting related studies, (3) study selection, (4) charting the information that the research obtained and (5) summarising and reporting the outcomes utilised in this review.

3.3.2 Phase 2: Scoping review

The researcher used a Scoping review to answer part two of the first research question: Which support programmes exist in literature? The second scoping review was used by the researcher in order to exhaust the viability of published support programmes for caregivers of patients with cancer. And the same method used in Phase 1 was used here in Phase 2.

For a wide-ranging search of the literature, publications of related and relevant peer-reviewed journal articles written in English were searched in the following four electronic databases; PubMed, CINAHL, Science Direct, and Scopus. The databases were chosen to be broad and to overlay a wide range of disciplines. Data were collected by repeatedly searching the selected databases with the key words: Support programme + Caregivers + Cancer.

Literature reviews, dissertations, editorials and letters to the editor, case reports, discussion papers, conference proceedings, and grey literature, as well as duplicate articles were not included. Shortlisting of the articles according to the criteria described was done by the researcher who checked the titles of all the identified work papers, picking those that related to the study, as well as evaluating the abstracts and reading the selected papers that appeared to answer the research question.

During phase 1 and 2 regular meeting with the supervisor was done to identify the relevant studies and to ensure study rigour. The abstracts were read in full to see whether they were suited to the inclusion criteria. If the abstract are not clear, the full texts were read.

3.3.3 Phase 3- Development/adaptation and validation of the support programme for caregivers of cancer patients.

This Phase refers to the second objective of this study, which was the development/adaptation and validation of the support programme for caregivers of cancer patients. During the programme development, the findings of the literature reviews conducted in Phases 1 and 2 guided the development of the support programme. The data were analysed according to the question asked during the reviews, “What evidence is available pertaining to the support needs of caregivers of cancer patients and which support programmes exist in literature? An expert group validated the proposed support programme.

The support programme was adapted from the work of numerous authors (Hudson *et al.*, 2008, 2009; Miyashita *et al.*, 2008; White *et al.*, 2008; Bakitas, *et al.*, 2009; Clarke and Seymour, 2010; Badger *et al.*, 2011; Meyers *et al.*, 2011; Porter *et al.*, 2011; Boele *et al.*, 2012; Ledderer *et al.*, 2013; Mclean *et al.*, 2013; Northouse *et al.*, 2013; Belgacem *et al.*, 2013; Clark *et al.*, 2013; Collinge *et al.*, 2013; Fegg, 2013; Badr *et al.*, 2015; Shaw *et al.*, 2015; Sun *et al.*, 2015; Dionne-odom *et al.*, 2015; Hendrix *et al.*, 2016), as well as publications of the National Cancer Institute, (2014), Department of Health and Human Services, including: “When Someone You Love is Being Treated for

Cancer," which is a programme focused on the caregiver who provides care to a critically ill person and cancer patients.

The findings from the two scoping reviews were triangulated, using an inductive approach to draw conclusions which were used to develop/adapt the new support programme (Addendum A).

Once developed, an expert group validated the programme; the purpose was to ensure the programme measured what it was supposed to. The hope was that during the validation, the expert group would subject it to face and content validity, and then it could be modified in line with the outcome of the exercise. The validation process was performed by disseminating the developed support programme and the self-designed scoring form with a Likert scale by the expert group.

Convenience sampling was used to select experts who validiated the programme. Convenience sampling, also known as accident sampling, is a type of nonprobability or non-random sampling where participants of the target population meet defined criteria, such as geographical closeness, availability or accessibility at a given time, or the willingness to take part for the objective of the current study (Farrokhi, 2012; Etikan, Musa and Alkassim, 2016). It is also denoted as the researching of participants within the population who are accessible without difficulty to the researcher (Zohrabi, 2013).

The expert group, who practiced in the field of cancer care, worked with the cancer patients and their families in inpatient and outpatient clinics at the target hospital, and had more than two years' experience. According to Guimarães *et al*. (2015), these two years of experience were enough to prepare experts who were nurses and physicians to be specialised in health fields with at least two years of practice. The expert group consisted of healthcare professionals (n=6): four senior oncology nurses (n=4) who had more than five years of experience, two of whom had post-graduate degrees in oncology, one oncologist (n=1) acting the Head of Oncology and Bone Marrow Transplantation Department and who had more than 15 years of experience with cancer patients, and one social worker (n= 1) with more than 15 years of experience with cancer patients, having worked 9 years in the private sector and 6 years in the target

hospital. All the experts worked in the oncology unit at the target hospital with cancer patients treated at the same facility. In addition, the chosen caregivers (n=4) had to have more than three months experience taking care of their cancer patients at home to make them eligible to be included as an expert to validate the proposed programme.

It is important to ensure content and face validity as these two measures build a strong foundation for an empirical measure. The expert group was asked to read the developed support programme, and use the self-designed scoring sheet form for feedback, recommendations, criticisms, suggestions to be analysed and to enhance the face and content validity, as well as incorporate it into best practice.

Face validity, is the extent to which a support programme is subjectively viewed as covering the concept it purports to measure (Elo *et al.*, 2014; Bolarinwa, 2019). At this stage, the expert group, who were familiar with the concept under investigation, were given the programme to review the support programme and conclude it measured the characteristic or trait of interest. Face validity involves the expert looking at the items in the programme and agreeing that it is valid to measure the concept being measured (Tsang, Royse and Terkawi, 2017; Bolarinwa, 2019). This means they are evaluating whether each of the measuring items in the proposed programme match any given conceptual domain of the concept; it is the most widely used form of validity in developing countries (Elo *et al.*, 2014; Bolarinwa, 2019). The expert group was required to evaluate the programme with respect to problems, ambiguity, relativity, proper terms and grammar, and understandability using the self-designed scoring sheet (Addendum C).

The content validity of the support programme refers to the degree to which a support programme is relevant to, and representative of the targeted construct it is designed to measure (Dahiru, Aliyu and Kene, 2006). Assessment of the content validity of the support programme was by asking the expert group whether they agreed that each heading and subheading, as referring text, was about that which it was supposed to be. The experts were asked to look for the sampling sufficiency of the content being

assessed to validate and refine the programme. The rating for the programme content was for relevance for the intended target group, the feasibility of the programme by means of applicability, adequacy or appropriateness of the intervention's acceptability and recruitment ways. The programme material, delivery, period and strength, as well as its support nature and comprehensiveness were also to be validated (Dalal and Bruera, 2017; Seltam, 2018). The support programme and self-designed scoring sheet were collected and analysed.

The procedure for validation in Phase 3 was as follows:

- The necessary permissions were obtained, and the expert panel group recruited.
- During the first visit, the nurse, oncologist and social worker who were on duty in the oncology department and caregivers accompanying the cancer patients were recruited by requesting their permission to take part in the study as an expert group, if they were eligible according to the inclusion criteria, after the explanation was provided regarding their role, goals and objectives of the study.
- When the researcher prepared the support programme, the programme and a self-designed scoring form with a Likert scale, which were translated and printed, were given to all members of the expert panel, one week before a scheduled group meeting. The self-designed scoring form with the Likert scale, agree, disagree and not sure what the expert believed, was to validate the programme and ensure familiarisation with the programme with the view to facilitate discussion of the same.
- The expert group was also given the opportunity to express their opinions or views, and make comments, notes and suggestions, or corrections and recommendations on the support programme after agreeing or disagreeing with the statement, and provide any comments they thought would enhance and strengthen the proposed support programme for caregivers' of cancer patients, as the process would lead to changes in the programme draft by restructuring, modification of sentences and reordering of statements. The researcher asked

the experts their opinion about whether the programme focused on the concept intended and the degree to which the objects in the tool sufficiently signified the whole content for the idea being assessed. To confirm anonymity, assessors were not asked to provide their names.

- The Likert scale, used for the validation, aimed to identify the ideas or attitude of a topic and cover a number of declarative declarations. Answer choices on a Likert scale usually state agreement, evaluation and frequency (Burns and Grove, 2009; Pearse, 2011; Lovelace and Brickman, 2013). The Likert scale assigns a numerical score to individuals to put them on a continuum with respect to the attribute being measured. Declarative statements expressing a viewpoint on the topic were developed and the panel was asked to indicate the degree to which they agreed or disagreed (Pearse, 2011; Hudson and Aranda, 2014). Data were analysed descriptively to determine whether or not the panel approved the content.

- One week later, permission was again obtained from the head of the department to meet with the expert group without affecting their daily duties by choosing the most suitable time and place. The time allocated was at 12 mid-day in the oncologist's office; the six healthcare experts were available as the department works until 5 pm daily, which enables the researcher to meet them any time in any day. The researcher agreed to meet the caregivers separately as they came with their sick persons on different days.

- The meeting with the expert group included discussion of their notes and recommendations. The researcher took the notes and discussed them with the supervisor to ensure the capturing of all their comments. The notes were added to those on the self-scoring sheet, and the expert group notes were also analysed to guide the refinement of the support programme.

- The researcher provided the expert group with the validated support programme before it was implemented for the final evaluation.

- The process was continued until the saturation level of the notes analyses was seen and no new notes were provided. At this point, the support programme (Addendum A) was validated and ready to pilot test.

3.3.4 Phase 4: Pilot testing the support programme

3.3.4.1 STUDY SETTING

The state of Palestine is divided into two geographical parts; the West Bank is located in the East close to Jordan, and the Gaza Strip is located by the Mediterranean Sea in the West. East Jerusalem is the capital of Palestine. The number of inhabitants in both parts is 5.148.809 as of March 23, 2019. Palestine includes 21 cities distributed in all lands controlled by Palestinian's government (Palestinian Central Bureau of Statistics, 2011; Al Mezan Center for Human Rights, 2019) and 73.7% of the population is urban (3.822.445). The median age of Palestinians is 19.6 years. Regarding religion, 93% of Palestinians are Muslim, while Palestinian Christians represent an important minority of 6% (Falk, 2012; Falah, 2014). Regarding education, the literacy rate was 96.3% according to a 2014 report by the United Nations Development Programme, which is high by worldwide criteria (Hugh *et al.*, 2019).

The study was conducted in An-Najah National University Hospital in Palestine, Nablus City in the West Bank, which is easily accessible to all patients and their families of the Nablus Province, and which forms part of the public health services, providing cost-free healthcare services to patients in Nablus City and surrounding provinces (Figure 3.2). The health service provided by the hospital is funded by the An-Najah National University and by the Government. The hospital has 120 beds plus 25 beds for oncology patients, has more than 500 staff members and serves more than 389,328 residents living in the city, and more than 200 000 from surrounding areas. This central hospital also serves the cancer patients from other referral governmental and private hospitals in Palestine. Cancer patients have access to surgery and cancer chemotherapy as primary treatment modalities. Treatment and care are delivered on an outpatient and inpatient basis by a multi-professional team (An Najah National University, 2019).

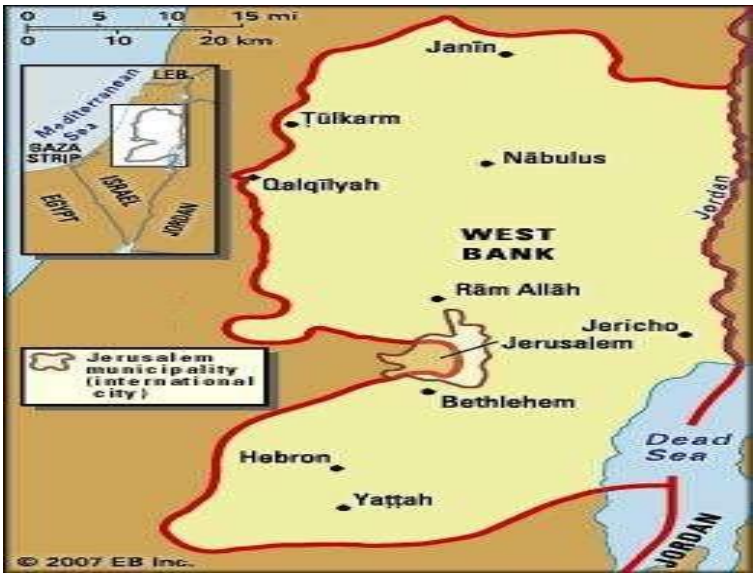


Figure 3.2: Map of Palestine/West Bank showing 10 states (Jardaneh, 2007).

3.3.4.2 RESEARCH DESIGN AND METHODS

Pilot study to test the support programme using an intervention study design and pre-test post-test approach to measure the outcomes. Nursing interventions are defined as "intentional cognitive, physical, or verbal actions accomplished with, or on behalf of, persons and their families that are directed in the direction of accomplishing specific therapeutic objectives relative to a individuals health and wellbeing (Wilson-Barnett, 2001; Burns and Grove, 2006; Reising, 2016; Butcher *et al.*, 2018). The nursing interventions was defined as a treatment, therapies, procedures, or actions applied by healthcare professionals toward clients, in a specific situation, to move the individual's condition to preferred health outcomes that are helpful to the individual (Wilson-Barnett, 2001; Burns and Grove, 2006; Reising, 2016; Butcher *et al.*, 2018).

Intervention research is a term occasionally used to speak of a unique practice of design, developing, applying, testing, analysing, distributing and disseminating interventions (Polit and Beck, 2004; Lobo, Kagan and Corrigan, 2017). Intervention studies test the influence of an intervention on a dependent variable or outcome (Burns and Grove, 2009; Thiese, 2014; Alla, 2016). As well as an intervention study, a research design is the process of specifying who will receive an intervention and how outcomes

were observed. In addition, its indicates when an intervention occurs and for what period it was provided (Fraser *et al.*, 2009; Alla, 2016).

Interventional study design, also named experimental studies, are those wherever the researcher acts as mediator as part of the design of the study, and are frequently prospective and explicitly tailored to assess the direct effects of treatment or protective actions on disease (Thiese, 2014; Adebiyi and Abayomi, 2016). According to Burns and Grove (2009), intervention research is a revolutionary new methodology that has great potential and promises as a more efficient way of interventions measurement and analysis. It swings the focus from causal connection to causal outcomes.

The intervention in the current study was the support programme for caregivers of cancer patients and it was developed based on findings of Phase 1 and 2 of the study. Intervention design used in current study was appropriate because it allowed the researcher to examine the effectiveness the proposed support programme, and to conclude that the support programme was responsible for an observed outcome that was not spuriously the result of some of other factor (Fraser *et al.*, 2009; Thiese, 2014). The intervention was introduced to observe the effect of independent variables, which was the support programme given to the caregivers' of cancer patients and the dependent variables, included the primary and the secondary outcomes.

The intervention study design was used to introduce the validated support programme in Palestine using a pre-and post-intervention method and products of the programme were assessed.

3.3.4.3 Pre-test Post-test approach

This involves implementing the intervention to some subjects and assessing that intervention before and after (Thiese, 2014; Krasny-Pacini and Evans, 2018). Pre-test post-test approach testing is an evaluation, assessment or measurement model planned to examine the alteration in overall critical thinking skills or dispositions in a group that took the test or the intervention (Valer *et al.*, 2015; Alessandri, Zuffianò and Perinelli, 2017). It includes the observation of the dependent variable, which is the

primary and secondary outcomes at two points in time pre and post the intervention (Polit and Beck., 2010; Marsden and Torgerson, 2012).

This Phase was conducted as follows:

Recruit intervention group → pre-test group → intervention → post-test group

Caregivers (n=50) and cancer patients (n=50) with different cancer types and disease stages were sampled using a convenience sampling method. The researcher first asked the patients to identify the primary caregiver. Those who fitted the inclusion criteria were enrolled into the current study, if available and willing; they could only participate if their cancer patients also agreed to participate in the study. The caregivers attended the intervention without cancer patients as this programme was established by means of the caregivers support needs.

3.3.4.4 Pre-test approach

Before the support programme was implemented, caregivers of cancer patients QoL, and care burden, as well as, cancer patients QoL, pain experience, and symptoms burden were assessed to determine the influence of the support programme would have on the outcomes.

3.3.4.5 Study Population

Population is all participants that conform to a set of specifications, which is the total group of people that are of concern to the researcher and to whom the research's results can be generalised (Eldredge, Weagel and Philip, 2014; Schuller *et al.*, 2014; Rudhumbu, 2015). A population is a whole set of persons or objects that share specific characteristics of interest to the researcher and can consist of objects, people, or places, such as schools, from which the sample is taken (Banerjee and Chaudhury, 2010; Asiamah, Mensah and Oteng-Abayie, 2017).

The target population differs from the population and, according to Byrne and Humble, (2007) is the total set of people about which the researcher would like to generalise the findings. The target population has to meet specific criteria, but may still be too large for

a study. Therefore, due to time, money and personnel constraints, the accessible population, which is available and meets the criteria of the target population, is used (Etikan, Musa and Alkassim, 2016; Asiamah, Mensah and Oteng-Abayie, 2017).

The population for this study was all cancer patients 311 (N=311) and their caregivers 311(N=311), who accompanied their cancer patients to the hospital**.**

3.3.4.6 Sampling

The method of sampling selects a fraction of the population, or members selected from the whole population, who represent the whole population to make inferences and conclusions about the population (Palinkas *et al.*, 1968; Omair, 2014; Rudhumbu, 2015; Seltam, 2018).

Convenience sample was used to select the participants. The participants were all accessible adult unpaid primary caregivers and cancer patients who receive cancer care and treatment at the setting at the time of the study, which represented different cultural groups in Palestine, both males and females and who lived in both rural and urban communities.

Thabane *et al.* (2010) stated that pilot studies can be used to assess treatment or interventions. The authors also stated there is no need for a sample size calculation in a pilot study. Cohen (1992) however stated that to achieve power (confidence level) for a pilot study, when expecting a medium effect in an intervention study, a sample size of approximately 50 (n=50) is adequate. For the purposes of this study however, 50 (n= 50) caregivers and 50 (n= 50) cancer patients, were included in the pilot study.

3.3.4.7 Inclusion criteria

The inclusion criteria for the participants in the current study was a cancer patient 18 years old and older, has an “ECOG performance status” of less than four and who agreed to participate in the study, and caregivers 18 years old and older who have more than three months experience of caring for a cancer patient, should identified by the patients as the primary caregivers and agree to participate in the study.

3.3.4.8 Recruitment

The researcher approached the nurses practicing in the oncology unit after data about the study was clarified to them in order for them to provide assistance to the researcher to organise the educational intervention for caregivers and to communicate with cancer patients to get them to identify the primary caregiver. As the cancer patients health status ‘was one of the main inclusion criteria for the study, the researcher, together with nurses, used the ECOG performance status to measure if the cancer patients’ health status made the patients eligible to be included in the study and if they were capable of answering the pre- and post- intervention questionnaires.

Caregivers were recruited conveniently when they accompanied their relatives or persons with cancer for whom they were caring to outpatient consultations. After the researcher recognised the caregivers, with assistance provided from the nurses and their cancer patients, caregivers was asked for their permission to participate in the study. Caregiver information leaflets (Addendum D) and informed consent (Addendum E) were posted in the department waiting sector and disseminated by the researcher himself.

Once the caregivers were recruited, the cancer patients were approached and asked whether they would be prepared to participate in the study. The caregivers were entered into the programme only if the sick person was willing to participate. An information leaflet was given to both caregivers and the patients and informed consent (Addendum F & G) to participate in the study was obtained from both parties.

3.3.4.9 Data collection

Data collection is the organised and structured collecting of data relevant or related to the research purpose or objectives and questions using the inclusion criteria of the study (Dahiru, Aliyu and Kene, 2006; Polit and Beck, 2012; Bhaskar and Manjuladevi, 2016). In addition, data may be collected from the participants by “observing, testing, measuring, questioning or recording, or a grouping of all these approaches” (Burns and

Grove, 2011; Bhaskar and Manjuladevi, 2016). The data collection process was as described bellow:

- The necessary approvals were obtained from the Department of Nursing Education, the School of Therapeutic Sciences Research Assessor Group and the Ethics Committee of the University of the Witwatersrand with reference No: M180115 (Addendum H). The Chief Executive Officer (CEO) of the hospital where the study took place also approved the application to conduct the research (Addendum I).
- The researcher approached the Head of Nursing and Head of Department to ask for permission to commence the data collection and to gain their support for the study. The researcher intended no disruption to the daily functions of the department.
- The patients were approached and recruited, using convenience sampling, to identify their primary caregivers. The researcher started to recruit the caregivers when they accompanied the sick person to the hospital or outpatient's clinic, and the caregivers were allowed to participate if their cancer patients were also willing to join in the study.
- Study descriptions were provided to all participants. The researcher explained that joining the study was voluntary and that participation could be withdrawn at any time without any penalty, and no names would appear at any point of the study.
- The researcher administered questionnaires to collect the data. This approach had the advantage of permitting the researcher to explain or rephrase the questions and include participants of all educational levels (Bolderston, 2012; Alshenqeeti, 2014; Practice, Carolina and Hill, 2015).
- Demographic data were gathered first by means of a pre-interview questionnaire using self-conducted sociodemographic data questionnaire.
- The researcher collected the data pre and post the intervention (Figure 3.3), and validated the Arabic questionnaires, ZBI, CQOLC, BPI, EQRTC and MSAS, used in previous studies (Ballout *et al.*, 2011; John, 2015; Shata, El-Kady and Ibrahim, 2015; Alawneh *et al.*, 2016; Taherdoost, 2016; Mohajan, 2017; Zarit *et al.*, 2019) served as data collection questionnaires. The questionnaires were selected because they were recommended standard questionnaires that have been used in studies of cancer

caregivers' burden and QoL, and have established validity and reliability (Tamayo *et al.*, 2010; Leow, Chan and Fai Chan, 2015).

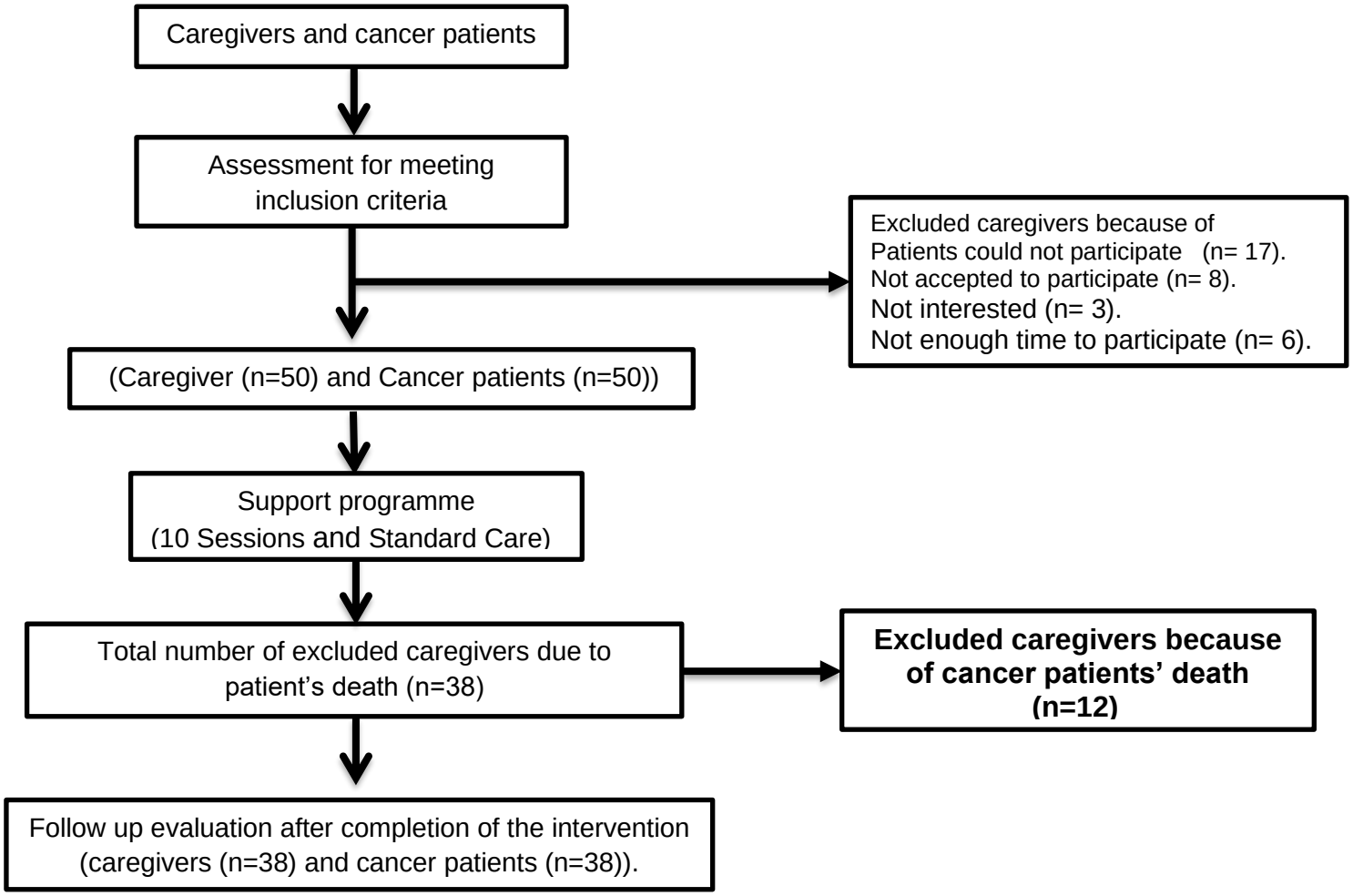


Figure 3.3: data collection process in Phase 4 adopted from (Arksey and O'Malley (2005)

3.5 STUDY INSTRUMENTS

Six instruments were used to collect the data. Five of the instruments were standard instruments that have been used in studies of cancer caregivers' burden and QoL, and have established validity and reliability (Shilling *et al.,* 2016; Bhardwaj, 2018). The sixth instrument was a researcher-developed sociodemographic questionnaire. In addition to the sociodemographic questionnaire, the ZBI and the CQOLC questionnaires were

completed by the caregivers and the BPI, EQRTC and MSAS were completed by the cancer patients. The questionnaires were:

3.5.1 Socio demographic data questionnaire

The researcher developed this closed-ended socio-demographic questionnaire (Addendum J). The questionnaire was guided from previous studies that had the same research interest and comprised 10 questions relating to age, gender, material status, level of education completed, employment status, relation to cancer patients, and the type of cancer the patient was suffering from, the anticancer treatment they received and the medication they use.

3.5.2 Zarit Burden Interview (ZBI):

The ZBI is most popular and regularly used to measure caregiver burden (Bédard *et al.*, 2001; Bachner, 2013; Valer *et al.*, 2015; Shilling *et al.*, 2016; Souza *et al.*, 2017; Tessitore *et al.*, 2018; Yu, Yap and Liew, 2018; Gabriel and Mayers, 2019). Initially established and validated three decades ago (Zarit, Reever and Bach-peterson, 1980), the ZBI has 22 items and is identified as a "one-factor scale," reflecting the following concern, namely "health, finances, social life, emotional well-being, personal life, and interpersonal relationships" (Bédard *et al.*, 2001; Özer, Yurttaş and Akyıl, 2012). A new meta-analytic study done by Yu *et al.* (2018) revealed that responses and replies to such scale are reliable on caregivers population's such as "spouses/partners, children, parents" and care receivers such as "cancer, dementia, physical illness, mental illness."

The original 22 item ZBI is scored on a "5 point Likert scale". Every item is scored from "0 to 4," where "0= never, 1= rarely, 2= sometimes, 3= quite frequently, and 4 = nearly always". The entire ZBI was achieved by calculating the scores for the 22 items with a range of 0 to 88, upper scores indicating more burden (Zarit, Reever and Bach-peterson, 1980). According to the interpretation of the scores, the ZBI has four levels: "0 - 20 little or no burden, 21- 40 mild to moderate burden, 41- 60 moderate to severe burden and 61- 88 severe burden". In the full 22-item scale, two different aspects were recognised, "personal strain and role strained," both representing sufficient internal

consistency (ά = 0.89 and ά = 0.77, respectively). The concurrent validity of replies was also proven (Bédard *et al.*, 2001; Harding *et al.*, 2004; Bianchi *et al.*, 2016).

The ZBI has been validated in many different countries, including Turkey, Singapore and China. In Turkey, it was used to measure the caregiving burden among family caregivers of inpatients in hospitals or clinics. It has an overall coefficient alpha of 0.82. The Cronbach alpha extended between 0.81 and 0.83 (Özer, Yurttaş and Akyıl, 2012). The ZBI was used to measure the level of caregivers care burden they experienced in Singapore (Seng *et al*., 2010); validity scores were very much associated with the "Burden Assessment Scale" score (correlation coefficient = 0.73, p<0.0001) (Seng *et al*., 2010; Taherdoost, 2016).

With time, abridged or condensed forms of the ZBI have been presented (Bédard *et al*., 2001). The abridged Arabic version of the (ZBI-A) was used to measure the caregiver care burden (Addendum K) after permission to use it was obtained (Addendum L). (ZBI-A) is comprised of 12 items, which are graded on a "5-point Likert scale from 0 (never) to 4 (almost always)", with an upper score expressing a higher care burden. Total scores range from "0 (low burden) to 48 (high burden)" (Zarit, Reever and Bach-peterson, 1980; Bachner, 2013). Pearson correlations were made to observe the validity of the ZBI-A. Important correlations were seen among caregivers' well-being, depression and emotion and the ZBI-A. As predicted, higher scores on the ZBI-A were linked with higher scores on the measure of caregiver depression ($r = 0.39$, $p < 0.001$) and emotional tiredness ($r = 0.22$, $p < 0.05$) and with low scores on the measure of well-being ($r = 0.37$, $p < 0.001$) (Bachner, 2013).

3.5.3 The Caregiver Quality of Life Index-Cancer (CQOLC):

CQOLC is commonly used and mostly recommended standard instruments to measure cancer caregivers' QoL (Weitzner *et al.*, 1999; Duan *et al.*, 2015; Shilling *et al.*, 2016; Diesbach *et al.*, 2018). The CQOLC scale is a 35-item "cancer-specific" instrument that measures "physical, social, emotional, financial aspects of well-being, and functioning" (Weitzner *et al.*, 1999; Shata, El-Kady and Ibrahim, 2015).

The CQOLC scale was established by Weitzner *et al*. (1999) using cancer patients and their caregivers in 1997 (Duan *et al*., 2015). CQOLC contains 35 items, and responses are counted from 0 (not at all) to 4 (very much) (Weitzner *et al.*, 1999; Lim *et al.*, 2017; Gabriel and Mayers, 2019). One hundred and forty is the entire potential score, with higher scores signifying improved QoL. In the first study conducted by Weitzner *et al.* (1999), suggestions were made for four subscales: “Burden, disruptiveness, positive adaptation, and financial concern” (Duan *et al.*, 2015; Lapid *et al.*, 2016). These four concerns contained 27 items, with eight extra items not fitting into these concern or factors. Sufficient internal consistency was established, with internal consistency values (Cronbach’s alpha) related to the four subscales being “0.89, 0.83, 0.73, and 0.81”, with a value of 0.90 for entire CQOLC scores (Weitzner *et al*., 1999; Lapid *et al*., 2016).

The CQOLC (Arabic version) Index (Addendum M) was translated by Halabi (2006) and used to measure the QoL of the caregiver of the cancer patient after permission was obtained (Addendum N). CQOLC has well recognised reliability and validity in both Arabic and English languages (Halabi, 2006; Turkoglu and Kilic, 2012). The Arabic version of the QoL Index is very reliable and has adequate content validity for measuring QoL of Arabic-speaking participants. The instrument has a ”test–retest reliability correlation coefficient of 0.95 and a Cronbach’s alpha coefficient of 0.91” (Halabi, 2006).

3.5.4 Brief Pain Inventory (BPI) (short form):

The BPI, was developed by Charles S. Cleeland in 1991 (Cleeland and Ryan, 1994; Ballout *et al.*, 2011; Poquet and Lin, 2016), and is a self-administered questionnaire that was initially planned to measure cancer pain. BPI exists in a short form (nine items) and the long form (17 items) (Saifan *et al.*, 2015) The BPI short form is most commonly used to measure cancer pain (Cleeland and Ryan, 1994; Wang *et al.*, 1996; Uki, Mendoza and Cleeland, 1998; Kapstad, Rokne and Stavem, 2010).

The BPI has primarily been applied to the measurement of cancer-related pain. It has been translated into different languages, including Arabic, and used throughout the world for cancer pain measurement (Cleeland *et al.*, 1988; Caraceni *et al.*, 1996; Wang

et al., 1996; Uki, Mendoza and Cleeland, 1998; Ger, Ho and Sun, 1999; Radbruch *et al.*, 1999; Rauch *et al.*, 2001; Klepstad, Loge and Borchgrevink, 2002; Ballout *et al.*, 2011). Kumar mentions that the BPI usage has been established in breast cancer, bone metastases and post-operative cancer patient populations in a diversity of languages (Kumar, 2011).

The instruments psychometric properties have been analysed in a variety of pain cancer and non-cancer patients. Adequate reliability has been stated in pain with advanced cancer patients studies (Pelayo-alvarez, Perez-hoyos and Agra-varela, 2013), osteoarthritis pain (Williams, Smith and Fehnel, 2006; Kapstad, Rokne and Stavem, 2010), and in patients with neuropathic and nociceptive chronic pain (Erdemoglu and Koc, 2013). Reliability test and retest for malignant pain was assessed and demonstrated a good reliability for intensity of pain (r = 0.8) and for the interference of pain (r = 0.8). The "internal consistency" of BPI severity scale is high <0.81 and <0.89 and "interference scale" <0.88 and <0.95. With regard to criterion validity, the "Spearman's correlation coefficient" among BPI "intensity and interference scales" and the "Short Form Survey Instrument SF-36 Bodily Pain displays a moderate relationship <0.47 to <0.65. The coefficient among "pain interference score" and the "Roland Morris Disability Questionnaire" was r = 0.57, presenting moderate correlation. Cronbach alpha reliability ranges from 0.77 to 0.91.

Permission was obtained (Addendum O) to use the short form of Arabic BPI (Addendum P) to measure the pain experienced by the cancer patients. This short form asks 16 questions, and measures two domains: pain severity and the effect pain have on a patient's life. Numerical scales are used to measure pain at its worst and least, on average, and pain experienced at the time of data collection. How pain interferes with daily life is measured in terms of normal activity, walking, employment, mood, life pleasure, relationships with others, and sleep. Numerical scales are once again provided (Ballout *et al.*, 2011). Every item is in a similar manner to the last score, extend from "0 to 40" (Chaudakshetrin, 2009; Ballout *et al.*, 2011). When investigating the reliability of the Arabic short form BPI, the values of the Cronbach coefficients were 0.82 for the severity objects and 0.92 for the interference objects. The interim

associations and correlation of the severity of objects were statistically significant and ranged between mild to strong, the values alternating between 0.37 (current pain and strongest pain) and 0.68 (minimum pain and tolerated pain) (Ballout *et al.*, 2011; Poquet and Lin, 2016; Tegegn and Gebreyohannes, 2017).

3.5.5 European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC)

The EORTC is a popular and most used instrument for assessment of the QoL of patients mainly in palliative care. Conversely, it is comprehensive and comprises items unrelated to palliative care services (Ozcelik *et al*., 2016). Consequently, the EORTC QOQ-C15-PAL is an abridged 15-item form of EORTC QLQ-C30. It contains four scales: “multi-item functional scales, physical (questions 1–3) and emotional (questions 13 and 14), multi-item symptom scales, fatigue scale (questions 7 and 11), and pain scale (questions 5 and 12), five single-item symptom scales (nausea and vomiting, dyspnea, insomnia, appetite loss, and constipation) and one global QoL item (question 15)”. This instrument has been translated to numerous languages, one of which is Arabic (EORTC, 2005; Shin *et al.*, 2011; Suárez-del-Real *et al.*, 2011; Arraras *et al.*, 2014; Natália and Nunes, 2014; Alawneh *et al.*, 2016; Zhang *et al.*, 2019). EORTC QLQ-C30 scoring manual was used in order to generate the scores of the different scales of the QLQ-C15-PAL (Groenvold *et al.*, 2006) was used. The functioning and symptom subscale item scores range from 0 to 100. A high scores for individually functional scales and the last question of the QLQ-C15-PAL, which describe the overall QOL perception of patient’s; signifies a positive response (Iwase *et al.*, 2015; Ahlam *et al.*, 2019).

Studies have been conducted to measure the “validity and reliability” of the EORTC QLQ–C15–PAL’s scale (Abu-Saad Huijer, Sagherian and Tamim, 2015; Ozcelik *et al.*, 2016). Internal consistency level of the scale items was tested with the intention of defining its level of reliability and lack of measurement errors. For this reason, “Cronbach’s internal consistency coefficients” were calculated for the entire scale, as

well as for the subscales. In calculations applied from the first information, Cronbach's alpha met the "0.7" criterion. In calculations applied using the entire dataset of the research, the values of Cronbach's alpha were found to vary among "0.93 and 0.98, equivalent to 0.90" for the entire scale. These results confirm that the EORTC QLQ–C15–PAL scale is a reliable instrument (Huijer, Sagherian and Tamim, 2013; Ozcelik *et al.*, 2016).

All EORTC QLQ–C15–PAL items are counted on "4-point Likert scales" that extend from "1 (not at all) to 4 (very much)", with the exclusion of one item on the global health/ QoL scale, which uses a revised "7-point linear analogue scale", one very poor to 7 excellent QoL (Shin *et al.*, 2011; Ahlam *et al.*, 2019).

The Arabic version of the scale (Addendum Q) was used to measure the patient's QoL with permission (Addendum R). Six investigators reviewed the Arabic version of the instrument and found no linguistic concerns. Cronbach's alpha coefficient encountered the 0.7 alpha criterions. Whole item-scale association coefficients exceeded the established value of 0.40, demonstrating acceptable convergent validity (Awad, Denic and El Taji, 2008; El Fakir *et al.*, 2014; Alawneh *et al.*, 2016). Construct validity was verified by point inter scale correlation coefficient. The entire constructs had correlation coefficient of <0.70. External validity was verified and significant differences (P value <0.05) were found in the entire scale (Huijer, Sagherian and Tamim, 2013; Alawneh *et al.*, 2016).

3.5.6 Memorial Symptom Assessment Scale (MSAS):

The MSAS was developed by Portenoy *et al.* (1994), contains a number of subscale scores: "a physical symptom or PHYS subscale" that contain the average of the "frequency, severity, and distress" related with 12 symptoms which are "lack of appetite, lack of energy, pain, feeling drowsy, constipation, dry mouth, nausea, vomiting, change in taste, weight loss, feeling bloated, and dizziness"; "a psychological or PSYCH subscale" that contain the average of "frequency, severity, and distress" scores for six symptoms which are "feeling sad, worrying, feeling irritable, feeling nervous, difficulty

sleeping, and difficulty concentrating"; and the "Global Distress Index (MSAS-GDI)", is used to measure the overall symptom distress. That includes the average of the only item dimension scores for 10 symptoms: the frequency scores for "feeling sad, worrying, feeling irritable, and feeling nervous, and the distress scores for lack of appetite, lack of energy, pain, feeling drowsy, constipation, and dry mouth" (Portenoy *et al.*, 1994; Lobchuk, 2003; Thiagarajan *et al.*, 2016). Each symptom's rate is rated as occurring "rarely," "occasionally," "frequently," and "almost constantly." Severity is assessed as "mild," "moderate," "severe," and "very severe." Symptom-related distress is rated using a 5-point Likert scale: "not at all," "a little bit," "somewhat," "quite a bit," and "very much." Every symptom score is an average of the three dimensions (Portenoy *et al.*, 1994; Abu-Saad Huijer, Sagherian and Tamim, 2015). The Global Distress Index is the rate of the incidence scores for "feeling sad," "worrying," "feeling irritable," and "feeling nervous," along with the distress scores for "lack of appetite," "lack of energy," "pain," "feeling drowsy," "constipation," and "dry mouth. The higher scores indicating more severity, greater frequency, and higher distress (Portenoy *et al.*, 1994; Oechsle *et al.*, 2013; Thiagarajan *et al.*, 2016).

The MSAS has established validity and reliability in a cancer patients in- and outpatient population (Portenoy *et al.*, 1994; Abu-Saad Huijer, Sagherian and Tamim, 2015).

In a Lebanese study conducted in 2015, the MSAS Cronbach's alpha coefficients and its subscales fluctuated from 0.71 to 0.83 (Abu-Saad Huijer, Sagherian and Tamim, 2015). Regarding convergent validity analysis, the universal distress key and psychological subscales were moderately related ($r > 0.50$; $P < 0.01$) with the emotional operative subscale of the related instruments (Thiagarajan *et al.*, 2016). Correlation coefficients among the MSAS items and chosen subscales from the EORTC QLQ-C30 suit the criteria of convergent validity ($r = -0.55$ to 0.81; $P < 0.01$) excluding the nausea/vomiting subscale (Howard-Ruben, 2014; Abu-Saad Huijer, Sagherian and Tamim, 2015).

The early step calculates a score for every symptom. If a symptom does not occur, all aspects are scored as 0, “the score for that symptom is 0”. If a symptom occurs, the score for that symptom is identified as the rate of the scores on the “severity, frequency and distress” scales, or if suitable, on the “severity and distress” scales only. Missing items are simply not entered in the calculation of the entire symptom score. If a symptom that is assumed to have all three scopes answered by the participants, but actually has two dimensions answered, the score is for the average symptom of the two objects instead of the three objects. Only a certain extent of data that is missed should be acceptable before excluding the patient from the overall calculation of MSAS scores; in the current study, this was subjectively recognised at 13% of the objects (Portenoy *et al.*, 1994; Heo *et al.*, 2016).

The MSAS has been translated into and validated in numerous languages, and Arabic is one such language (Cheng *et al.*, 2009; Yıidirim *et al.*, 2011; Browall *et al.*, 2013; Abu-Saad Huijer, Sagherian and Tamim, 2015). Reliability and validity were reported in all studies.

The Arabic version of the MSAS- Leb (Addendum S) with permission (Addendum T) was used to measure the patient symptom burden. The MSAS-Leb measures 32 associated symptoms in terms of cancer “occurrence, intensity, and distress,” and has adequate psychometric properties regarding its reliability and validity. This instrument is recommended for use in clinical practice as well as outpatient clinical settings to enable healthcare professionals to evaluate and have further follow-up regarding symptom burden of cancer patients (Abu-Saad Huijer, Sagherian and Tamim, 2015).
The MSAS-Leb and related subscales “PSYCH, PHYS, and GDI” met the criterions of reliability and internal consistency, with coefficients extended between “0.71 and 0.83”. The entire MSAS-Leb had a mean score of 2.30 (SD = .51); the maximum mean score between the three subscales was found to be in the MSAS-PSYCH (score = 2.46; SD = .68) (Abu-Saad Huijer, Sagherian and Tamim, 2015). Regarding validity, the “MSAS-PSYCH ($r = _0.59$; $P < 0.01$) and GDI ($r = _0.51$; $P < 0.01$)” had acceptable correlations with the emotional operational subscale only, thus fit the criterions of convergent

validity. Conversely, the associations among the “physical functioning and the MSAS-PHYS (r = _0.35; P < 0.01) and GDI (r = _0.27; P < 0.01)” subscales were lower than the set principles and did not maintain convergent validity. All correlation coefficients suit with the criterions of “convergent validity (r = _0.55 to 0.81; P < 0.01)” except for the “MSAS-vomiting” and the “nausea/vomiting (NV)” subscale. Powerful correlations were found among MSAS-“lack of energy” and the “fatigue subscale (r = 0.81; P < 0.01)” and “MSAS nausea with the NV subscale” (r = 0.73; P < 0.01) (Abu-Saad Huijer, Sagherian and Tamim, 2015).

3.6 PROCEDURE OF PRE-TEST APPROACH

The support programme of caregivers of cancer patients was developed and the intervention study design pre-test post-test approach was used to implement the support programme in Palestine, and the outcomes were evaluated.

- Once the caregivers were recruited, the cancer patients were approached and asked whether they would be prepared to participate in the study. The caregivers were entered into the programme only if the sick person was willing to participate.
- An information leaflet was given to the caregivers and patients and written informed consent to take part in the study was obtained from both parties.
- Caregivers (n=50) were requested to complete the self-developed sociodemographic questionnaire, as well as the pre-test CQOLC and ZBI questionnaires (10-15 every session).
- At the same time, the cancer patients (n=50), who met the inclusion criteria and agreed to participate in the study, were requested to complete the BPI, EQRTC and MSAS questionnaires (10-15 every session).
- After completing the questionnaires, the researcher placed them together with the informed consent forms into two sealed boxes, each labelled for its intent.

3.7 POST-TEST APPROACH

The researcher administered the support programme, which was continued for three months until the objectives of the programme was fully completed and the entire content of the programme was provided.

By using researcher administered questionnaires, and after three weeks from the completion of the support programme, the post-test ZBI and the CQOLC questionnaires were obtained from caregivers (n=38) as well as the post-test BPI, EQRTC and MSAS from patients (n=38). The reason for the 12 participants (n=12) who did not complete the intervention was because of cancer patients' deaths. The researcher observed 24% attrition. Sensitivity analysis was performed using multiple imputations in STATA 14 to ascertain if there were some substantial changes in the results attained from the complete case analysis. However, there were no substantial differences and the researcher proceeded with the complete case analysis, assuming missing data was completely at random (MCAR).

The researcher placed the questionnaires together with the informed consent forms into two sealed boxes, each labelled for its intent.

3.8 DATA MANAGEMENT AND ANALYSES

After data gathering was done, all the questionnaires were checked for quality. The questionniares were saved in a sealed box, numbered sequentially, cleaned and entered using Excel spread sheets and analysed by means of descriptive statistics with the assistance of the STATA 14 computer programme. When the data entry was completed, the data collected were stored in a locked cupboard to which only the researcher had access. Wilcoxon matched-pairs signed-ranks test was used also to test the statically differences between variables, and Spearman's correlation was a nonparametric test to the strength the correlation among the variables, the Chan, (2003); Akoglu, (2018), criteria of interpretations of the (r) value were used (+1 to -1 was perfect; +0.9 to -0.8 was very strong; +0.7 to -0.6 was moderate; +0.5 to -.03 was fair; +0.2 to -0.1 was poor and 0 was zero correlation among the variables).

As there was some substantial missingness (20% both groups) post intervention, the researcher performed some sensitivity analysis using multiple imputations in STATA 14 to ascertain if there were some substantial changes in the results attained from complete case analysis.

To attain the objectives of this study, different statistical methods were used, which are outlined below.

3.8.1 Level of significance

The level of significance is the probability that a detected relationship refers to the sampling error, also known as Type 1 error (Banerjee *et al.*, 2009). The specification of an alpha level enables the researcher to control the risk of a Type 1 error, which would lead to the rejection of a true null hypothesis. A $p \leq 0.05$ was used in this study to determine if the result was significant. A 5% level of significance was chosen as this is the conventional value employed in healthcare researches (Banerjee *et al.*, 2009; Burns and Grove, 2009).

3.8.2 Wilcoxon matched-pairs signed-ranks test

This test is a non-parametric equivalent of the paired t-test. It is generally used to examine the difference in the mean, or median, of paired explanations – whether those measurements occur in pairs of units or pre- and post-measurements on the identical unit. It could also be used on a "one-sample" test to examine whether a certain sample originated from a population with a quantified median (Byrne and Humble, 2007; MacFarland and Yates, 2016).

3.8.3 Management of missing data

Missing data frequently occurs in research and could occur at item-level, where individuals questions were not answered by the participants, or due to participant attrition for longitudinal research (Dong and Peng, 2013; Young and Johnson, 2015). In this study, there was no missing data at item level, as the researcher ensured that participants completed all survey questions, missing data only occurred due to participant attrition. As there was substantial absence of data (20%) post intervention,

the researcher performed sensitivity analysis using multiple imputations in STATA 14 to ascertain if there were some substantial changes in the results attained from complete case analysis. There were no substantial differences; therefore the researcher proceeded with the complete case analysis.

3.9 RIGOUR OF THE STUDY

Rigour is the striving for excellence in research using precision, precise pledge to detail and strict accuracy (Burns and Grove, 2009; Stewart, 2014; Shelton, Smith and Mort, 2014; Cypress, 2017). Strict rigour must be ensured in the study by making sure strict procedures are followed to guarantee quality of the findings (Charrois, 2015; Turner *et al.*, 2017). Each step in the research process was carried out with solicitous attention to detail and linked together in a logical way; this approach was followed to ensure rigour in this study.

The reviews in Phase 1 and 2 had a defined population and a main question to maintain focus. The main databases in health and nursing were included and a hand search of literature was carried out. Multiple databases were searched so that the risk of introducing database, source selection and publication bias would be reduced. The researcher appraised each study included in the study. A defined selection principle was adhered to by having an inclusion and exclusion criteria for studies included within the study, and the criterion for excluding studies was stated.

In Phase 3, content and validity of the support programme was evaluated by an expert panel (n=6) with more than two years of cancer care experience and (n=4) caregivers. All experts agreed it was a valid programme to implement.

In Phase 4, the data collection instrument for patients and their caregivers was validated and reliable for such purpose and used in literature on same population characteristics (Ballout *et al.*, 2011; John, 2015; Shata, El-Kady and Ibrahim, 2015; Alawneh *et al.*, 2016; Taherdoost, 2016; Mohajan, 2017; Zarit *et al.*, 2019). Validity is the extent to which a concept is accurately measured. It broadly ensures the soundness or accuracy of the study's evidence, which is whether the results are equitable or unbiased, cogent

and well-grounded (Kimberlin and Winterstein, 2008; Burns and Grove, 2009; Heale and Twycross, 2015). Reliability denotes to the amount of consistency or dependability with which an instrument assesses a specific trait (Kimberlin and Winterstein, 2008; Heale and Twycross, 2015). Simply, it is the consistency of the measure obtained (Burns and Grove, 2009; Heale and Twycross, 2015; Mohamad *et al.*, 2015). Reliability gives attention to the degree to which a measurement of a phenomenon supplies a stable and consist result. Reliability is also concerned with repeatability (John, 2015; Taherdoost, 2016; Mohajan, 2017).

To confirm validity and reliability of the research, the researcher ensured rigour and control throughout the research process. This was maintained in the study by ensuring that the same method of data collection and instrument were used throughout the study. All the data was collected by the researcher without influence from anyone.

Literature document the monitoring of intervention fidelity (completeness and consistency of the intervention implementation) during the conduct of the study (Mars *et al.*, 2013; Swanson *et al.*, 2013), to ensure consistency the intervention was implemented by the researcher. Gathering data was done in a structured way. Data gathering took place in the Department of Oncology at the hospital where the study was conducted and private rooms were available to ensure privacy, comfort and confidentiality. Data gathering in the current study was controlled by means of a good quality measurement instrument. Research outcomes can be influenced by respondents' knowledge of the study, for example the Hawthorne effect, which implies that being part of a study can have an influence on respondents' behaviour (Burns and Grove, 2009). During data gathering, respondents were informed about the study and that all data gathered would be anonymous, as questionnaires did not contain the respondents' names, only numbers. Respondents took part in the study voluntarily, with the assurance there would be no consequences should they refuse to take part. The researcher explained the rationale for conducting the study, based on the identification of a gap in the knowledge base according to the literature.

In addition, the data analysis process was described comprehensively, with graphs and tables labelled clearly. Interpretation of the results was explained and the researcher indicated whether the aims of the study were met, as well as what the implications of the research were for clinical practice (Yilmaz, 2013). The instrument used was well validated and used in literature (Mohamad *et al.*, 2015). The researcher used five validated instruments from other researchers of the same culture and population environments.

Sample sizes are usually large enough to indicate whether the intervention would work (Burns and Grove, 2009; Silva, 2011). In this study the sample size was 50 caregivers (n=50) and 50 cancer patients (n=50) recruited and entered into the study.

3.10 ETHICAL CONSIDERATIONS

The researcher in the current study made the effort to reduce risk especially when dealing with human participants. There are many ways to reduce risk, including informed consent, confidentiality, data protection, right to withdraw and informing participants about potential benefits and harm (Royal College of Nursing, 2009). The ethical principles outlined by the Health Professions Council of South Africa, (2016) was applied in the study.

- The proposal was submitted to Wits Human Research Ethics Committee (HREC) for approval, with ethics reference number: M180115, and the Ethical Review Committee at An Najah National University (Addendum V). Permission was also obtained from the Chief Executive Officer (CEO)/Medical Director of the hospital where the study was conducted.
- Informed, written consent was gained from all applicants before participating in the study.
- Participants should be fully aware of the research aims and any potential benefits and harms and should give their consent voluntarily without cohesion.
- The right to self-determination was upheld, as participation was voluntary and respondents were free to withdraw from the study without being harmed in any way.

- Confidentiality and anonymity were ensured by numbering the questionnaires sequentially and respondent's information was not discussed with other people.
- The survey questionnaires were numbered sequentially and the names of respondents did not appear on them. Participants could have access to research findings upon request.
- The right to fair treatment was maintained as participants were selected according to the inclusion criteria and all were treated with respect throughout the study.
- Autonomy, respect for dignity, justice and dissemination of results was maintained.
- The principle of non-maleficence applied, as respondents were not forced to disclose any information.
- Research participants were informed and reassured that their data would be kept safe and protected by the researcher.
- Participants in this study were informed that their data was kept safe and handled only by the researcher.

3.11 SUMMARY OF CHAPTER THREE

This chapter described the research methods used, outcomes, pre-post research design, population, sampling, sample size, recruitment data collection and instruments, data analysis and the procedure for all Phases, validity, reliability and the ethical considerations was described. Chapter 4 will present the findings of the Phases of the study.

CHAPTER FOUR

RESULTS OF PHASE 1 AND 2

4.1 INTRODUCTION

This chapter describes the results of the first two phases of the study – the scoping reviews.

4.2 Phase 1: For the **first scoping review** the researcher selected Arksey and O'Malley's (2005) five-stage framework to guide the study. This framework provides a rigorous, precise, permitting duplication of the search plan of the results for the scoping review. Scoping reviews are used to evaluate the research findings, identify the knowledge gaps in the research study, set the research agenda, identify implications for decision-making, identify articles that are used or designated scoping review approaches and give guidelines and quality for reporting scoping review studies (Burga & Rezania, 2015; Buchberger *et al.*, 2016).

4.2.1 Stage one: Identify the research question

This review was guided by the following research question,

- What evidence is available pertaining to the support needs of caregivers of cancer patients published between 1st January 2008 and 31 December 2017?

4.2.2 Stage two: Identify relevant studies

To search the literature, relevant and related peer-reviewed journal articles published between 1st January 2008 and 31 December 2017 were searched form the following electronic databases: PubMed, CINAHL, Science Direct, and Scopus. The key words used were support needs, caregivers and cancer. The databases were chosen to be broad and to overlay a wide range of disciplines. In addition, reference lists of tracked papers were used to track other related articles. Regular meetings with the supervisor was done to identify and find consensus on the relevant studies and to ensure study rigour.

4.2.3 Stage three: study selection

As the researcher wished to include empirical research only, studies had to be published in English, between 1st January 2008 and 31 December 2017, in a peer-reviewed journal. Literature reviews, editorials and letters to the editor, dissertations, discussion papers, case reports, conference proceedings, and grey literature were not included.

Content analysis, using an inductive approach, was used to analyse the data (Margarete Sandelowski, 2010; Elo *et al.*, 2014) to enhance the rigour of the study. Data gathering occurred simultaneously with data analysis to recognise the unmet needs support care domains of caregivers of cancer patients across studies. Descriptive statistics were used for the incidence of support care unmet needs. Content analysis is is a research method where the content of text data is subjectively interpreted through a classification process of coding and recognizing themes (Marvasti, 2019). This type of analysis classifies large amounts of text into a manageable number of categories representing a similar meaning (Elo *et al.*, 2014; Marvasti, 2019). Data are presented in words and themes, which allows the researcher to draw interpretations of the results. An inductive approach was used, and when using this type of approach, the text is analyzed with an open mind in order to identify meaningful subjects to provide answers to the research question (Bengtsson, 2016). The researcher and supervisor were involved in the coding of data; the data was confirmed after consensus was reached. The researcher used reflexivity whilst analysing the data to be aware of the possible influence to the study's findings. Reflexivity is a process where researchers reflect on themselves to provide a fair and impartial analysis. The researcher consciously acknowledges the preconceived thoughts and assumptions they bring into the research and therefore shape the outcome (Palaganas *et al.*, 2017).

The data were analysed as follows:

- The articles were read and reread, and notes and headings were made in the margins. This manner was repeated to make sure the headings labeling all the aspects of the content were written down.

- The categories belonging together were grouped as sub-themes, which were then grouped as themes. Higher order headings were allocated to the themes (Elo *et al.*, 2014).

The data were analysed according to the question asked during the review, “What evidence is available pertaining to the support needs of caregivers of cancer patients?” The themes were organised into topics by examining what was important and describing them. A new reading was done to start coding the data in a systematic way. Several readings of the data were done for complete coding of themes and subthemes together.

Data gathering started in August 2018 and ended in November 2018. Regular searches were done to enhance inclusion of the available work. In total, 487 (N=487) articles were identified across the databases: 39 (n=39) articles were found in PubMed, 53 (n=53) in Science Direct, 62 (n=62) in CINAHL and 374 (n=374) in SCOPUS. The lists of publications were printed and the duplicates were removed. Thereafter the researcher reviewed the titles to confirm the work examined some aspect of caregivers support needs; abstracts were used where the titles were not clear. Full texts were used to examine the latter if the abstracts did not offer the need information. Once the duplicated articles (n=32) were removed and 40 (n=40) were excluded because only the abstracts were available, 418 (n=418) remained. The researcher then excluded those that did not meet the inclusion criteria, leaving 19 (n=19) articles for inclusion in this review (Figure 4.1). Once this process was completed, a consensus meeting was held with the researcher’s supervisor.

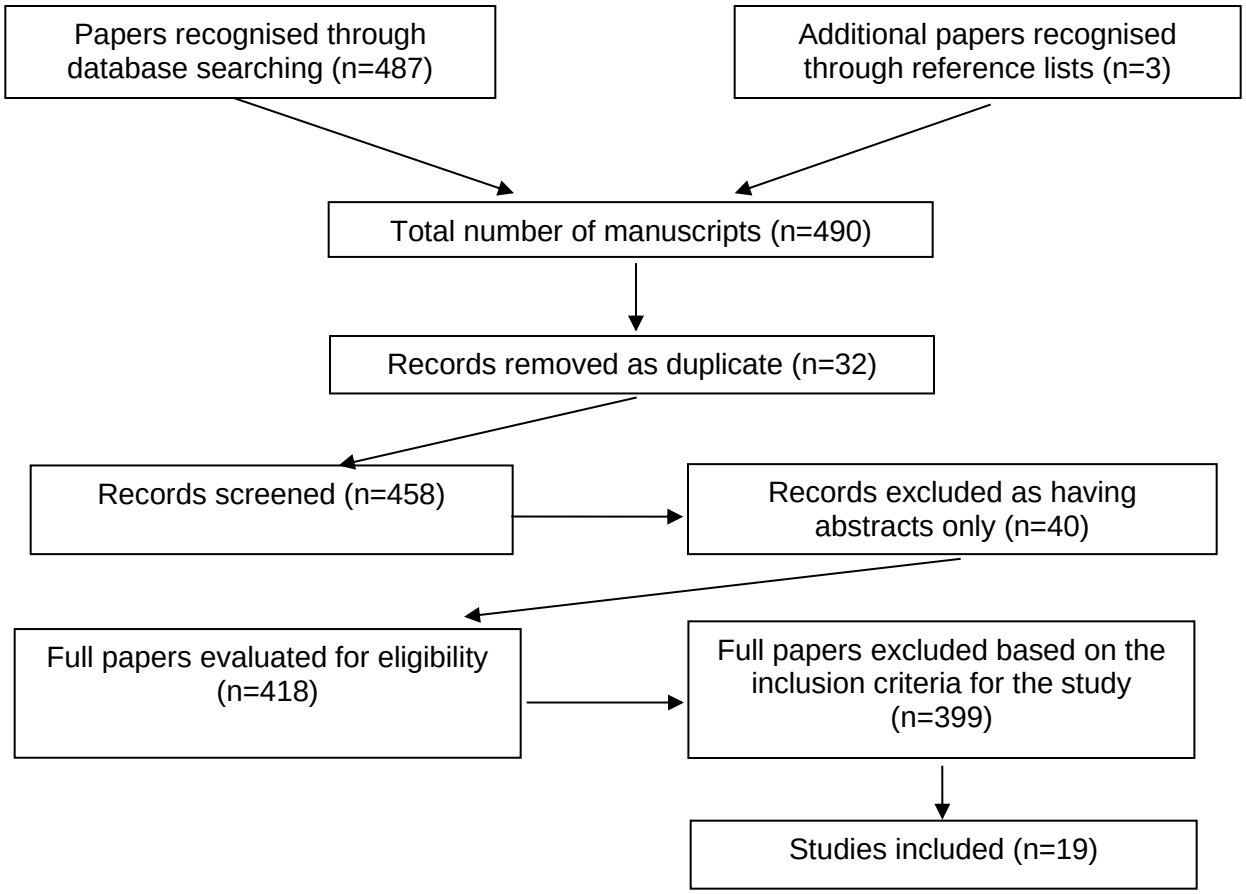


Figure 4.1: A flow diagram of the scoping review search process (Arksey & O'Malley, 2005)

4.2.4 Stage four: charting the data

In Stage Four, the researcher developed a data extraction sheet to chart the data (Table 4.2), which allowed the researcher to summarise it in a consistent way (Arksey & O'Malley, 2005) and combine results effectively. The data were charted in terms of author(s), year of publication, country of origin, studu aim, study design, population and sampling, data collection and instrument; the main findings were captured. To prevent the risk of bias, the first author extracted the data where after it was reviewed by the supervisor; a consensus meeting was held to promote rigour.

4.2.5 Methodological quality appraisal

The methodological quality of the articles included was evaluated by the researcher using the Mixed Methods Appraisal Tool (MMAT) (Hong *et al*., 2018), and confirmed by the supervisor. The MMAT (Addendum W) evaluates the quality of qualitative studies, mixed methods and quantitative studies, specifically quantitative randomised control trials, non-randomised studies and descriptive studies (Hong *et al.*, 2018). Two screening questions are asked, namely whether the study has clear research questions, and whether the data collected is suitable to answer the research question. Only studies with a "yes" answer to both the screening questions are assessed according to the research design used. For each research design, there are specific five questions and responses are "yes", "no" and "cannot tell" (Hong *et al.*, 2018).

When appraising the methodological quality of the studies included in this review, only one (n=1; 5%) qualitative descriptive study, by Al-Jauissy (2010), had clear research questions allowing a quality assessment, and according to the set of criteria in the MMAT, this study got one score. No study was excluded based on its quality (Dougherty, 2010; Evertsen & Wolkenstein, 2010; Khan Joad, Chaturvedi & Mayamol, 2011; Friðriksdóttir *et al.*, 2011; Harding *et al.*, 2012; Deshields *et al.*, 2012; Shaw *et al.*, 2013; Lee *et al.*, 2014; Butow *et al*, 2014; Chen *et al.*, 2014; Cui *et al.*, 2014; Aoun *et al.*, 2015; Borneman *et al.*, 2015; Heckel *et al.*, 2015; Richardson, Morton & Broadbent, 2015; Haynes-Maslow, Allicock & Johnson, 2016; Hazen, Lazar & Gennari, 2016; Gültaş & Yilmaz, 2017).

4.2.6 Results: summarising, and reporting the outcomes utilized in this review.

Descriptive statistics and content analyses were used to obtain the outcomes; seven themes or domains of caregivers support care need were recorded.

4.2.6.1 Support care needs

The highest support care needs (Table 4.1) were obtained from the included studies and according to need, the areas were:

- Information need was recorded in 18 (n=18; 95%), and was the most common need, and included providing sufficient information to caregivers on how to communicate with their cancer patients (Khan Joad, Chaturvedi & Mayamol, 2011) or with healthcare professionals (Dougherty, 2010; Shaw, Harrison, *et al.*, 2013; Butow *et al.,* 2014), provide information to family members to maintain active caregiver roles and how to deal with their own feelings and the cancer patient's needs (Al-Jauissy, 2010; Evertsen & Wolkenstein, 2010; Friðriksdóttir *et al.*, 2011; Deshields *et al.*, 2012; Harding *et al.*, 2012; Shaw *et al.*, 2013; Chen *et al.*, 2014; Lee *et al.*, 2014; Aoun *et al.*, 2015; Heckel *et al.*, 2015; Richardson, Morton & Broadbent, 2015), provide instruction in practices such as symptom management, provide information on cancer disease, benefit of treatment and the side effects, prognosis and outcomes (Al-Jauissy, 2010; Dougherty, 2010; Friðriksdóttir *et al.*, 2011; Harding *et al.*, 2012; Shaw *et al.*, 2013; Lee *et al.*, 2014; Butow *et al,* 2014; Chen *et al.*, 2014; Cui *et al.*, 2014; Aoun *et al.*, 2015; Heckel *et al.*, 2015; Richardson, Morton & Broadbent, 2015; Hazen, Lazar & Gennari, 2016; Haynes-Maslow, Allicock & Johnson, 2016; Gültaş & Yilmaz, 2017), information about hospice care (Al-Jauissy, 2010; Khan Joad, Chaturvedi & Mayamol, 2011; Cui *et al.*, 2014; Gültaş & Yilmaz, 2017), discharge plan (Dougherty, 2010), tracking health information and technology use (Khan Joad, Chaturvedi & Mayamol, 2011; Hazen, Lazar & Gennari, 2016), patient's care such as wounds, nutrition regimen and hygiene (Al-Jauissy, 2010; Friðriksdóttir *et al.*, 2011; Chen *et al.*, 2014; Lee *et al.*, 2014; Gültaş & Yilmaz, 2017) and provide information on alternative therapy (Heckel *et al.*, 2015).

- Emotional support needs were obtained from 11 (n=11; 58%) studies, and varied from friend, family and healthcare professionals' emotional support groups (Al-Jauissy, 2010; Evertsen & Wolkenstein, 2010; Harding *et al.*, 2012; Shaw *et al.*, 2013; Butow *et al*, 2014; Cui *et al.*, 2014; Lee *et al.*, 2014), coping (Deshields *et al.*, 2012), empathy from clinical staff, to emotional expression through starting communication with healthcare professionals (Evertsen & Wolkenstein, 2010; Richardson, Morton & Broadbent, 2015).

- Cancer care services support needs were also presented in seven (n=7; 37%) studies, and included managing the household, caring for others and childcare (Al-Jauissy, 2010; Deshields *et al.*, 2012; Chen *et al.*, 2014; Richardson, Morton & Broadbent, 2015), transportation support (Al-Jauissy, 2010; Haynes-Maslow, Allicock & Johnson, 2016; Gültaş & Yilmaz, 2017), follow up and comprehensive medical support services (Shaw *et al.*, 2013; Haynes-Maslow, Allicock & Johnson, 2016), and the availability of equipment used in cancer care (Aoun *et al.*, 2015).

- Physical support needs were described in four (n=4; 21%) studies, and included, fatigue (Borneman *et al.*, 2015), physical burden (Khan, Joad, Chaturvedi & Mayamol, 2011; Borneman *et al.*, 2015), and physical and mental wellbeing *(Butow et al*, 2014; Aoun *et al.*, 2015).

- Social support needs are shown in 13 (n=13; 68%) studies and include, time to socialise, family, spouse and children time, relationships and interaction (Evertsen & Wolkenstein, 2010; Khan Joad, Chaturvedi & Mayamol, 2011; Borneman *et al.*, 2015; Haynes-Maslow, Allicock & Johnson, 2016; Gültaş & Yilmaz, 2017), social support, isolation, communication and advance direct planning (Aoun *et al.*, 2015; Borneman *et al.*, 2015), social life activities (Khan Joad, Chaturvedi & Mayamol, 2011; Heckel *et al.*, 2015; Gültaş & Yilmaz, 2017), family and friends support (Al-Jauissy, 2010; Butow *et al*, 2014; Chen *et al.*, 2014; Richardson, Morton & Broadbent, 2015), healthcare professionals support (Chen *et al.*, 2014), cultural silence (Haynes-Maslow, Allicock & Johnson, 2016), patients' visits (Al-Jauissy, 2010; Dougherty, 2010), life change (Shaw, Harrison, *et al.*, 2013) and personal time (Aoun *et al.*, 2015).

- Psychological and spiritual support needs were recorded in 19 (n=19; 100%) of the studies and the concerns included, feelings of distress, upset, irritable, tense, anxiety, lost, alone, scared, overwhelmed, depression, exhaustion, frustration, uncertainty and worries because of health deterioration and the unfamiliarity with cancer care (Evertsen & Wolkenstein, 2010; Khan Joad, Chaturvedi & Mayamol, 2011; Deshields

et al., 2012; Shaw *et al.*, 2013; Butow *et al*, 2014; Chen *et al.*, 2014; Lee *et al.*, 2014; Aoun *et al.*, 2015; Borneman *et al.*, 2015; Heckel *et al.*, 2015; Hazen, Lazar & Gennari, 2016; Gültaş and Yilmaz, 2017), family support group (Al-Jauissy, 2010; Evertsen & Wolkenstein, 2010; Harding *et al.*, 2012; Shaw *et al.*, 2013; Butow *et al*, 2014; Richardson, Morton & Broadbent, 2015; Haynes-Maslow, Allicock & Johnson, 2016), funeral concerns (Harding *et al.*, 2012; Cui *et al.*, 2014), cognitive statues, purpose and meaning, and inner strength (Borneman *et al.*, 2015), hope (Friðriksdóttir *et al.*, 2011; H.-T. S. Lee *et al.*, 2014; Borneman *et al.*, 2015), witnessing patients' health status (Deshields *et al.*, 2012), coping strategies (Dougherty, 2010; Shaw *et al.*, 2013; Richardson, Morton & Broadbent, 2015), understanding the experience of patients with cancer (Chen *et al.*, 2014).

- Financial support needs were also described in 14 (n=14; 74%) studies, and these included financial and work life (Al-Jauissy, 2010; Dougherty, 2010; Khan Joad, Chaturvedi & Mayamol, 2011; Harding *et al.*, 2012; Shaw *et al.*, 2013; Chen *et al.*, 2014; Lee *et al.*, 2014; Aoun *et al.*, 2015; Richardson, Morton & Broadbent, 2015; Heckel *et al.*, 2015; Haynes-Maslow, Allicock & Johnson, 2016; Gültaş & Yilmaz, 2017), and medical insurance (Deshields *et al.*, 2012; Cui *et al.*, 2014). Table 4.1 lustrates the themes investigated in this review.

Table 4.1: Themes investigated between 2008 and 2017 in the articles included in this review (n=19)

Included studies research themes and subthemes	***n***	**%****
Information support needs		
Disease, treatment and prognosis, outcomes and symptom management	15	79
Hospice care	4	21
Alternative therapy	1	5
Actual role as a caregivers	11	58
Technology use	2	11
Patients' care, wound care and hygiene	5	26
Communication with patients' healthcare professionals	1	5

Communication with healthcare professionals	3	16
Discharge plan	1	5
Physical support needs		
Fatigue	1	5
Physical burden	2	11
Physical and mental well-being	2	11
Social support needs		
Family time, relationships and interaction	5	26
Social support, isolation, communication and advance direct planning	2	11
Social life activities	3	16
Family and friends support	4	21
Healthcare professionals support	1	5
Cultural concern	1	5
Patients' visits	2	11
Life changes	1	5
Personal time	1	5
Psychological and spiritual support needs		
Distress, upset, irritable, tense, anxiety, lost, alone, scared, overwhelmed, depression, uncertainty and worries.	12	63
Family support group	7	37
Funeral concern	2	11
Cognitive statues, purpose and meaning and inner strength	1	5
Hope	3	16
Patients' health status witnessing	1	5
Coping strategies	3	16
Understanding the experience of patients with cancer	1	5
Emotional support needs		
Emotional support groups from friend, family and healthcare professionals	7	37
Coping	1	5
Empathy and emotional expression	2	11

Cancer care services support needs		
House holding	4	21
Healthcare providers support, follow up and comprehensive medical support services	2	11
Transportation	3	16
Caregivers financial support needs		
Financial and work life	12	63
Medical insurance	2	11

** Some included studies have more than one theme and subthemes, therefor percentage are higher than 100%.

4.2.6.2 Characteristics of the studies

A summary of the characteristics of the studies will first be presented in Table 4.2, where after the specifics will be presented.

Table 4.2: The first scoping review data extraction sheet

	AUTHOR (DATE) **COUNTRY**	**STUDY AIM**	**STUDY DESIGN**	**POPULATION & SAMPLE SIZE**	**SAMPLING METHOD**	**DATA COLLECTION METHOD**	**DATA COLLECTION INSTRUMENTS**	**MAIN FINDINGS**
1	Khan Joad, Chaturvedi and Mayamol, (2011) *India*.	To evaluate the needs of caregivers of patients with advanced cancer.	Qualitative descriptive.	Caregivers of terminally ill cancer patients (n=60).	Not clear.	Interviews.	Researcher administered questionnaire.	Most of caregivers had unmet needs such as home care, psychological support, financial, medical, social and informational needs.
2	Harding *et al.*, (2012) *UK*.	To create evidence to inform a successive suitable intervention depending on the experiences of the caregivers.	Qualitative cross sectional.	Caregivers of cancer patients (n=20).	Purposive sampling.	Semi-structured interviews.	Not clear.	Caregivers required better preparation for their caring responsibilities. They needed information and physical, emotional, spiritual/psychological and financial support.
3	Borneman *et al.*, (2015) *USA*.	To report on the education content of a nurse-lead, tailored palliative care programme for caregivers and cancer patients.	Quantitative descriptive.	Lung cancer patients (n= 272) and caregivers (n=366).	Not clear.	Researcher administered questionnaire.	Self-developed interdisciplinary palliative care plan (IPC).	The topic chosen by the caregivers included worry, fatigue, fear, purpose and meaning of life and communication. A need for palliative care services was identified.
4	Deshields *et al.*, (2016) *USA*.	To study the observed needs in terms of the psychosocial responsibilities of caregiving and assess the relationship between demographic and clinical variables with care needs.	Quantitative descriptive.	Cancer patient and their caregivers (n=100).	Convenience sampling.	Self-administered questionnaire.	Questionnaire.	Caregiver's reported that they need for e emotional support as their patients need as well as for psychological and logistic issues need. The outcomes showed the patients may undervalue how hard the caregivers recognize the psychosocial aspects of caregiving.
5	Cui *et al.*,(2014) *China*.	To describe the needs of caregivers and the potential factors related with their needs.	Quantitative cross-sectional.	Caregivers (n=649).	Convenience sampling.	Self-report questionnaire.	Questionnaire.	Various support needs were identified. The needs included support from the health care providers, how to maintain health, treatment and prognosis informational need, hospice care, funeral support, symptoms management and psychological support. Hospital and treatments bills, the long-period caregiver care burden and the relationship with the cancer patient were also identified as needs.
6	Friðriksdóttir *et al.,* (2011) *Iceland*.	To evaluate the needs and unmet needs, QoL, anxiety & depression symptoms, and the association among those variables in a big sample of caregivers of patients with cancer in different points of illness.	Quantitative cross-sectional, descriptive & correlational.	Caregivers of cancer patients (n=223).	Not clear.	Self-report questionnaire.	Family Inventory of Needs (FIN). Quality of Life Scale (QOLS). Hospital Anxiety and Depression Scale (HADS).	The prevalence of anxiety and depression was high. There was a positive relationship between unmet needs and QoL. The significance of screening needs and spiritual/psychological distress were highlighted.
7	Hazen, Lazar and Gennari, (2016) *USA*.	To investigate the caregivers experiences, challenges, interests, and preferences for managing symptoms and health information.	Quantitative survey.	Brain cancer patients (n=7) and 6 caregivers (n=6).	Convenience sampling.	Semi structured interviews.	Demographic and Health and technology Use survey.	Although current technology use in health-related activities was minimal, participants reported being highly willing to use such technologies to capture and manage information, provided they were designed according to the needs, interests, and abilities of these users. Participants felt that such tools could benefit patient care activities, and help to address information challenges for both current and future patients and caregivers.
8	Gültaş and	To define the difficulties	Quantitative	Cancer	Not clear.	Face to face	Self-developed	Relatives experienced difficulties in maintaining the proper

	Yilmaz, (2017) *Turkey.*	experienced by caregivers who provide palliative care at home related to QoL.	survey.	patients and caregivers (n=100).		interviews.	questionnaire. Caregiver quality of life cancer index (CQOLC).	relationship with family members, not utilizing home care services, information about the disease, prognosis and treatment. The faced difficulties with managing symptoms such as pain, nausea, vomiting, defecation, and mobility.
9	Richardson , Morton and Broadbent, (2015) *New Zealand.*	To describe the psychological support needs of caregivers and cancer patients. The suitable timing, extent, design and content of education sessions were also examined.	Qualitative descriptive.	Head and neck cancer patients (n=83) and caregivers (n=73).	Convenien ce sampling.	Self-administered questionnaire.	Questionnaire.	The participants described their need to be acknowledged, and for empathy and practice support. They had informational, psychological support needs and face to face sessions. Interventions for caregivers and cancer patients should start as early as possible post diagnosis; person to person sessions should be held and true and realistic data about cancer and coping should be provided.
10	Butow *et al,* (2014) *Australian.*	To investigate QoL, burden and end of life unmet needs for caregiver of women diagnosed with ovarian cancer.	Quantitative prospective longitudinal.	Caregivers of ovarian cancer (n=99).	Not clear.	Self-report questionnaire.	12-item Short Form version 2 (SF-12v2). Hospital Anxiety and Depression Scale (HADS). Duke-UNC Functional Social Support questionnaire. Life Orientation Test-Revised (LOT-R). Supportive Care Needs Survey (SCNS)-caregivers version. Functional Assessment of Cancer Therapy-Ovarian scale (FACT-O-version 4).	The mental and physical QoL decreased over time but not for social support. Caregivers need help with controlling emotions regarding prognosis, matching their personal needs and the patient's needs, work, as well as decision-making while there is uncertainty.
11	Chen *et al*., (2014) *Taiwan*.	To recognize factors related to unmet supportive care needs of caregivers of cancer patient.	Quantitative cross-sectional.	Spousal caregivers of oral cancer patients (n=102).	Convenien ce sampling.	Self-administered questionnaire.	Partners and caregivers supportive care needs survey. Social Support Scale modified. Symptom Distress Scale modified for head and neck cancer. The Pittsburgh Sleep Quality Index. Hospital Anxiety and Depression Scale (HADS).	The caregiver's needs for supportive care in information domain and healthcare professional/healthcare services domain were highest. Caregivers who received less social support from other family members were associated with greater overall unmet supportive care needs. Caregivers report the need for more information and healthcare services.
12	Evertsen and Wolkenstei n, (2010) *USA*.	To explore women's interactions with physicians (primary care and urologist) and the support needs associated with the diagnosis and treatment of their partners' prostate cancer.	Qualitative focus group.	Female partners of patients diagnosed with prostate cancer (n=14).	Not clear.	Focus group interviews.	Open-ended trigger questionnaire.	A need for more emotional support in terms of providing opportunities to share experience, during the uncertainty of transfer process when the treatment has no longer benefit and changes in partner relationships emerged as main themes.
13	Haynes-Maslow,	This study focuses on the challenges that both African	Qualitative focus group.	Breast cancer survivors and	Not clear.	Focus group interviews.	Semi structured moderator guide.	Participants discussed five themes: (1) a culture that discourages the discussion of cancer; (2) lack of support

	Allicock and Johnson, (2016) *USA.*	American cancer survivors and caregivers face across the cancer continuum.		their caregivers (n=41).				services for African American cancer survivors; (3) lack of support services for cancer caregivers; (4) need for culturally appropriate cancer resources, including resources targeted at African American women; and (5) aspects that were helpful to cancer survivors and caregivers, including connecting with other survivors and caregivers, and having strong social support networks.
14	Hsin-Tzu Sophie Lee *et al.,* (2014) *Taiwan*.	To explore caregivers' experiences and their needs over a 1-year data gathering period in relation to the provision of home care to the advance patients with cancer in Taiwan.	Qualitative longitudinal.	Cancer caregiver's (n=44).	Consecutive sampling.	Semi structured interviews.	Open-ended questionnaire.	Participant interviews revealed 5 themes, hoping for a cure, experiencing fluctuating emotions, accepting the patient's dying, regarding the patient's death as a good death, and needing emotional support and information. Caregivers in hospice home care who experienced difficulties tended to seek emotional support and information throughout the entire caregiving process. Nurses play a major role in relieving the distress of caregivers.
15	Dougherty, (2010) *USA.*	To determine the specific needs of patients and family members during an inpatient oncology admission.	Qualitative descriptive.	Cancer patients and their caregivers (n=27).	Convenience sampling.	Self-administered questionnaire.	Questionnaire.	The main needs identified were cancer information, communication, environment cleanliness, pain control, and discharge information.
16	Shaw *et al*., (2013) *Australia*.	To explore the caregiver's experiences of upper GI cancer post-surgical intervention to (1) recognize the supportive care unmet needs and (2) examine how caregivers recognize their caregiving role during this point.	Qualitative longitudinal.	Patients with upper GI cancer caregivers (n=58).	Not clear.	Semi-structured telephone Interviews.	Not clear.	The participants reported a significant informational and support needs. Lack of care knowledge caused increased in caregiver distress. The caregivers access to the need support was restricted causing increasing anxiety and distress.
17	Aoun *et al.*, (2015) *Australia.*	To describe the caregivers support needs using the Care Support Needs Assessment Tool (CSNAT).	Preliminary stepped wedge cluster comparative.	Caregivers of patients with primary brain cancer (n=29).	Random sampling.	Semi-structured telephone Interviews.	Family Appraisal of Caregiving questionnaire. 12-item Short Form version 2 (SF-12v2). Care Support Needs Assessment Tool (CSNAT).	The caregivers of brain cancer had significantly higher levels of caregiver strain; lower levels of mental wellbeing and a higher level of ADL workload in comparable with other caregivers taking care with different cancer type. Their physical wellness also deteriorated significantly over time. This preliminary study has demonstrated that the CSNAT provides a practical and useful tool for assessing the support needs of family caregivers of patients with brain cancer.
18	Al-Jauissy, (2010) *Jordan.*	To explore health care and unmet needs of caregivers of cancer patients in Jordan.	Qualitative descriptive exploratory.	Caregivers of cancer patients (n=82).	Consecutive sampling.	Structured interviews.	Caregivers' medical information form. Caregivers need scale	Most of patients caregivers reported their need was "a very important need" such activity management, personal care, work, involvement with health care and social relationships.
19	Heckel *et al*., (2015) *Australia.*	To examine levels of unmet needs and depression among caregivers of people newly diagnosed with cancer and to identify groups who may be at higher risk, by examining relationships with demographic characteristics.	Multi-center RCT.	Dyads caregiver of cancer patients (n=150).	Random sampling.	Self-administered questionnaire.	Supportive Care Needs Survey (SCNS)-caregivers version. Centre of Epidemiologic-Depression Scale (CES-D).	All caregivers reported unmet needs; the most commonly endorsed unmet needs were in the domains of information and health care service needs. Because the relationship between depression and unmet support needs; 30% of caregivers at risk of clinical depression.

Among 19 studies, 14 (n=14; 74%) were conducted in developed countries such as USA, Australia, Iceland, Turkey, UK and New Zealand, while five (n=5; 26%) were conducted in developing countries, such as Taiwan, India, China and Jordan (Table 4.3).

Table 4.3: Countries contributing to the data collection listed on the selected data basis between 2008 to 2017 by country (n = 19)

Country	*n*	*%*
USA	6	32
Australia	4	21
Taiwan	2	11
India	1	5
Iceland	1	5
China	1	5
Turkey	1	5
Jordan	1	5
UK	1	5
New Zealand	1	5

Six studies (n=6; 32%) investigated the support needs of the caregivers and the cancer patients, whilst 13 studies (n=13; 68%) explored the support needs of caregivers only.

Various research designs were used; nine (n=9; 47%) were qualitative research design (Al-Jauissy, 2010; Dougherty, 2010; Evertsen and Wolkenstein, 2010; Khan Joad, Chaturvedi and Mayamol, 2011; Harding *et al.*, 2012; Shaw, Harrison, *et al.*, 2013; H.-T. S. Lee *et al.*, 2014; Richardson, Morton and Broadbent, 2015; Haynes-Maslow, Allicock and Johnson, 2016), which included descriptive study, focus groups, cross sectional and longitudinal studies, and ten (n=10; 53%) were quantitative research design (Friðriksdóttir *et al.*, 2011; Deshields *et al.*, 2012; Butow et al, 2014; Chen *et al.*, 2014; Cui *et al.*, 2014; Aoun *et al.*, 2015; Borneman *et al.*, 2015; Heckel *et al.*, 2015; Hazen, Lazar and Gennari, 2016; Gültaş and Yilmaz, 2017) including, descriptive study, cross-

sectional studies, survey studies, longitudinal studies, randomised control trials and preliminary steeped wedge clustral comparative studies (Table 4.4).

The sample size for qualitive studies ranged from 14 to 272, and the sample sizes for the quantitive research ranged from 13 to 649, with observation times ranging from 4 months to 24 month from baseline.

A non-probability sampling method was used for nine (n=9; 47%) studies, whilst two (n=2; 11%) used probability sampling and eight (n=8; 42%) did not state which approach was used (Table 4.4).

Questionnaires remained the common data collection instrument, as used in nine (n=9; 47%) of the studies, followed by eight (n=8; 42%) interview data collection methods; two (n=2; 11%) of the studies did not mention the methods they used to collect data (Table 4.4).

Table 4.4: Research designs and methods used in the studies included in this review.

Design	Method	*n*	%
Qualitative research design			
	Descriptive study	4	21
	Focus groups	2	11
	Longitudinal study	2	11
	Cross-sectional	1	5
Quantitative research design			
	Describtive study	2	11
	Cross-sectional	3	16
	Survey studies	2	11
	Longitudinal study	1	5
	Randomised control trials	1	5
	Preliminary, steeped wedge clustral comparative study	1	5

Sampling			
A non-probability sampling			
	Purposive	1	5
	Convenience	6	32
	Consecutive	2	11
Probability sampling	Random	2	11
Not stated		8	42
Data collection methods			
	Questionnaires	9	47
	Interviews	8	42
	Not stated	2	11

Pertaining to the diagnostic focus, 10 (n=10; 53%) studies focused on caregivers of patients with no specific cancer, while two (n=2; 11%) focused on the caregivers of patients with brain cancer, one (n=1; 5%) each focused on caregivers of patients with head and neck, oral, prostate, breast, upper GI, lung and ovarian cancer (Table 4.5).

Table 4.5: Cancer diagnostic focus of caregivers of cancer patients included in this review.

Cancer diagnostic focus	*n*	%
Mixed cancer site	10	53
Brain cancer	2	11
Head and neck cancer	1	5
Oral cancer	1	5
Prostate cancer	1	5
Breast cancer	1	5
Lung cancer	1	5
Ovarian cancer	1	5
Gastrointestinal cancer	1	5

Participants were recruited from various settings, two (n=2; 11%) were in Palliative care medicine department and hospices' home care and medical oncology outpatients clinic,

one (n=1; 5%) each were home cancer palliative care, head and neck outpatient clinics, GI surgery wards, otolaryngology head and neck surgery wards, urology clinic, outpatient chemotherapy clinic, and three (n=3; 16%) were in the oncology department (for full explanation of other details (Table 4.6).

Table 4.6: Settings and sources of information for studies included in this review

Sample source	***n***	**%**
Palliative medicine department	2	11
Hospices' and palliative home care	3	16
Medical oncology outpatients clinic	3	16
Radiation therapy centres	1	5
Head and neck outpatients clinics	1	5
GI surgery wards	1	5
Head and neck surgery wards	1	5
Urology clinics	1	5
Health service clinics	1	5
Oncology departments	3	16
Multi-cites and other places	1	5
Not mentioned	1	5

The data were collected during different times, ranging from 1 to 3 years after cancer diagnosis, in quantitative studies, and for qualitative studies the times ranged during the whole treatment course till the patient completed the treatment.

4.2.6.3 Instruments used in quantitative studies included in scoping review

The studies included in this review did not have the same sample sizes and methodical rigour. All tools were either previously validated or validated in the related study. Validated tools were used to evaluate the needs of caregivers of cancer patients using self-developed and validated instruments.

The quantitative work used 19 different questionnaires. The Khan Joad, Chaturvedi and Mayamol, (2011); Deshields *et al*., (2012); Cui *et al.*, (2014); Gültaş and Yilmaz, (2017) works used self-developed questionnaires for their aims and purposes. The Hospital Anxiety and Depression Scale (HADS) was the most commonly used in the included studies (Friðriksdóttir *et al*., 2011; Butow *et al,* 2014; Chen *et al.,* 2014), followed by 12-item Short Form version 2 (SF-12v2) of the Health Survey, which was used in two studies (Butow *et al,* 2014; Aoun *et al.*, 2015). The family Inventory of Needs (FIN) and the Quality of Life Scale (QOLS) were used in Friðriksdóttir *et al*, (2011) study, the Caregiver Quality of Life Index Cancer Scale –CQOLC was used in Gültaş and Yilmaz's (2017) study, the Duke-UNC Functional Social Support Questionnaire, Life Orientation Test-Revised (LOT-R), Supportive Care Needs Survey (SCNS)-caregivers version and Functional Assessment of Cancer Therapy-Ovarian scale (FACT-O-version 4) were used in Butow *et al,* (2014) study. The Partners and Caregivers Supportive Care Needs survey, social support scale modified, symptom distress scale modified for head and neck cancer, and the Pittsburgh Sleep Quality Index were used in Chen *et al.,* (2014), and finally, the Family Appraisal of Caregiving questionnaire and Care Support Needs Assessment Tool (CSNAT) were used in the study of Aoun *et al.* (2015), (See Table 4.7).

Table 4.7: The Instruments used in quantitative studies included in the scoping review

Instruments used in the first scoping review	**Friðriksdóttir *et al.* (2011)**	**Butow *et al.* (2014)**	**Chen *et al.* 2014)**	**Aoun *et al.* (2015)**	**Gültaş and Yilmaz, (2017)**	**Khan Joad, Chaturvedi and Mayamol (2011)**	**Deshields *et al. (2016)***	**Cui *et al. (2014***
Family Inventory of Needs (FIN).	+							
Quality of Life Scale (QOLS).	+							
Hospital Anxiety and Depression Scale (HADS).	+	+	+					
Technology used survey.								
Caregiver quality of life cancer index (CQOLC).					+			
12-item Short Form version 2 (SF-12v2).		+		+				
Duke-UNC Functional Social Support Questionnaire.		+						
Life Orientation Test-Revised (LOT-R).		+						
Supportive Care Needs Survey (SCNS)-caregivers version.		+						
Functional Assessment of Cancer Therapy-Ovarian scale (FACT-O-version 4).		+						
Partners and caregivers supportive care needs survey.			+					
Social Support Scale modified.			+					
Symptom Distress Scale modified for head and neck cancer.			+					
The Pittsburgh Sleep Quality Index.			+					
Care Support Needs Assessment Tool (CSNAT).				+				
Family Appraisal of Caregiving Questionnaire (FACQ-PC).				+				
Caregivers need scale.								
Centre of Epidemiologic-Depression Scale (CES-D).								
Self-developed questionnaires or survey.					+	+	+	+

4.3 SUMMARY OF THE FIRST SCOPING REVIEW

In total, 490 articles (n=490) were found through the database searches; 19 papers (n=19) met the inclusion criteria and were included in this review.

The aim of the Khan Joad, Chaturvedi and Mayamol (2011) qualitative study was to measure the caregivers (n=60) needs of critically ill cancer patients by using semi-structured questionnaires. The study revealed that the service of cancer care need is to identify psychological and technical need support.

To create evidence to develop a suitable intervention depends on experiences of caregivers. Harding *et al*, (2012) qualitative study was conducted in UK amongst 20 (n=20) caregivers of cancer patients, and used purposive sampling and flexible, open-ended, semi-structured interviews. The study showed that the caregivers noted the need for better preparedness for caring tasks as they needed more information and skills and physical, emotional, psychological and financial support. Conversely, a qualitative study conducted by Borneman *et al*., (2015), in USA, examined the effectiveness of an interdisciplinary palliative care intervention comprising of assessment of patient and education by nurses on (n=272) cancer patients and their caregivers (n=366) using a self-developed interdisciplinary palliative care plan (IPC). The result indicated that currently there is a big need for cancer care services during the cancer journey. The nurse plays a major role in integrating cancer care into the daily routine care.

The quantitative descriptive study of Deshields *et al.* (2012), was aimed at testing the observed needs concerning the psychosocial responsibilities of caregiving, as stated by patients and caregivers. They also assessed the relationship of demographics and caregivers self-reported clinical care needs, using convenience sampling to recruit 100 cancer patients and their caregivers. Their self-developed questionnaire was used to collect the data need, as their study revealed patients with cancer might undervalue how hard caregivers identify the psychosocial characteristics of the caregiving designate. It would appear that

caregivers have a tendency to undertake the psychosocial characteristics of caregiving, while patients do not want to report this need.

In China, a quantitative cross-sectional study using convenience sampling, conducted by Cui *et al.* (2014), was used to search caregivers'(n=649) needs and the potential related influences by completing data collection questionnaires. The results showed the factors such as medical bills payment and lacking of medical insurance increase burden on caregivers, as well as, giving care for long time also affect the caregiver's burden.

A quantitative cross-sectional study was conducted in Iceland by Friðriksdóttir *et al.*, (2011), using an emailed questionnaire to 233 (n=233) caregivers, to evaluate the support needs, QoL, anxiety and depression symptoms, as well as the association among those variables in diverse Phases of disease. After analysis, the study revealed there was an association among the significant needs and QoL, as well as among needs that were met and QoL; in addition, there was a major association between anxiety and support needs.

Convenience sampling was used to recruit the brain cancer patients (n=7) and caregivers (n=6) in the quantitative survey study conducted by Hazen, Lazar and Gennari (2016) in USA, and a semi-structured interview to collect the data. The study showed that although current technology uses in health-related actions were lacking, applicants stated being extremely ready to use such technologies to release and manage the data need regarding disease and treatment. By using the same research design in the study conducted by Gültaş and Yilmaz (2017), in Turkey, 60 (n=60) caregivers and cancer patients were interviewed face-to-face with the researcher to define the challenges that the relatives faced whilst giving palliative care at home, as well as their QoL; the result revealed that the palliative care team should take into consideration the caregivers needs as well and provide the support the caregivers need. The scope of palliative care needs to grow to increase the value of services provided.

To search the psychological support needs of patients diagnosed with head and neck cancer and their caregivers, the New Zealand qualitative descriptive study of Richardson, Morton and Broadbent (2015) was conducted using the convenience sampling method to recruit their sample, which included cancer patients (n=83) and their caregivers (n=73), and their self-developed questionnaire to collect the data. This study illustrated the importance of discussing the psychological support needs as early as possible to patients and their caregivers and provides all the information they need regarding the disease, prognosis and treatment and how they have to deal with other difficulties they may face.

In the quantitative prospective longitudinal study conducted in Australia by Butow *et al.* (2014), caregivers (n=99) of ovarian cancer patients were recruited to identify the support needs related to QoL and the care burden of caregivers of women with ovarian cancer using a self-reported questionnaire to collect the data. This study indicated that the caregivers' role was not to maintain patient QoL, but that of the caregiver and to minimise distress related to caregiving, as they need support in managing their emotional upsets and the imbalance between their personal and patients' needs.

To recognise the influences related to support supportive care needs in caregivers of patients diagnosed with cancer after an operation, the Taiwanese quantitative cross-sectional study, conducted by Chen *et al.* (2014), involving 102 (n= 102) caregivers was convenience sampled and used a self-administered questionnaire to gather the data. The study reported the need for information regarding the disease as well as the importance of implementing support programmes to answer all questions regarding caregiving concerns. Evertsen and Wolkenstein's (2010) qualitative focus group study investigated the relationships of female partners (n=14) of patients diagnosed with prostate cancer with doctors and the support needs related to their husband's prostate cancer in terms of diagnosis and treatment. The data collected via the interviews

was analysed and the result indicated the information needs among the caregivers as well as other support needs. They revealed the doctor's role in referring the patients as quickly as possible for support care, and the delay in referring increased the patients and caregivers' burden. The caregivers also reported the relationship between partners changed, as the husband became more dependent on his wife and she acted as the main communicator and caregiver. Another qualitative focus group study, conducted by Haynes-Maslow, Allicock and Johnson (2016), examined the challenges that the African American cancer patient and their caregiver faced through the cancer journey; semi-structured interviews were applied with breast cancer survivors and their caregivers (n=41). This study reveals the unlimited need for services that include cultural and traditional variances that are found in different races in providing the support care for the cancer patients.

To identify the caregiver's needs and experiences during hospice home care for patients with advanced cancer, a qualitative longitudinal study was conducted in Taiwan by Lee *et al.* (2014) amongst 44 caregivers (n=44) who were recruited by consecutive sampling, using semi-structured interviews to assemble the data. The result provided evidence that the caregivers faced difficulties in caring for the cancer patient; they try to seek the support needs regarding informational and emotional support in the caregiving process. The results indicated that nurses play a major role in alleviating caregiver's distress during giving care. Dougherty's (2010) qualitative descriptive study aimed to define the precise needs of patients and caregivers in clinical settings; cancer patients and their caregivers (n=27) were recruited via convenience sampling and a questionnaire was used to gathered the needs information. Many needs were identified by the participants; one need was for information and the communication process regarding care of cancer patients, as well as environmental cleanness and pain management concerns. In depth semi-structured telephone interviews were used with upper GI cancer caregivers (n=58) to evaluate their perceptions and needs during giving care to GI cancer patients after surgery in qualitative longitudinal study conducted in Australia by Shaw *et al.* (2013). The caregivers stated

important information and support needs were required, as their personal suffering was aggravated by the absence of care facts and information.

A preliminary stepped wedge cluster comparative study, conducted by Aoun *et al.* (2015), to discover brain cancer caregivers support needs used the self-developed CSNAT. Random sampling was used to recruits the caregivers (n=29) of patients with primary brain cancer; the data were collected using semi-structured telephone interviews. This study established a new tool, CSNAT, which is an applied and valuable way for evaluating the support needs of brain cancer caregivers. Conversely, a multi-centre RCT study was applied by Heckel *et al.* (2015) to test support needs and depression between caregivers of patients recently diagnosed with cancer; random sampling was also used to recruit the caregivers of cancer patients (n=150). The result of this study found it was important to develop a support programme especially for caregivers who take care of recently diagnosed patients with cancer. Finally, a qualitative descriptive exploratory Jordanian study used convenience sampling to recruit cancer patients' caregivers (n=82) to depict the needs, as well as support needs, of Jordanian caregivers of patients diagnosed with cancer. In this study, structured interviews were used to collect the data and the results of the data analyses indicated that when designing a plan for the caring of cancer patients, the education and support needs of caregivers should be taken in consideration.

This review informed the intervention of the support needs for caregivers of cancer patients identified from the included studies: information support needs, followed by physical support needs, social support, psychological and spiritual support needs, emotional support needs, cancer care services support needs, and finally, financial support needs used to develop the support programme.

4.4 RESULTS OF PHASE 2: SCOPING REVIEW

As already mentioned, Phase 2 of the study consisted of the second scoping review in order to exhaust the viability of published support programmes for

caregivers of patients diagnosed with cancer. This review was guided by the research question, ‘What support programmes are available for caregivers for cancer patients?’ and by Arksey and O'Malley's (2005) five-stage framework: (1) formulating the research question, (2) finding related studies, (3) study selection, (4) charting the information that the research obtaining, and (5) summarising and reporting the outcomes.

4.4.1 Stage one: Identify the research question

This review was guided by the following research question

- Which caregivers of cancer patients’ support programme is available published between 1st January 2008 and 31 December 2017?

4.4.2 Stage two: Identify relevant studies

To search the literature, relevant and related peer-reviewed journal articles, published between 1st January 2008 and 31 December 2017, were searched from the following electronic databases: PubMed, CINAHL, Science Direct and Scopus, using the key words Support programme + Caregivers + Cancer. The databases were chosen to be broad and to overlay a wide range of disciplines. In addition, Google and Google scholar were searched to track other relative works. Regular meetings with the supervisor were done to identify and find consensus on the relevant studies and to ensure study rigour.

4.4.3 Stage three: study selection

The researcher used the same methods and data analysis as in Phase 1.

The data were analysed as follows:

- The articles were read and re-read and notes and headings made in the margins. This process was repeated to make sure the headings describing all the aspects of the content were written down.
- The included works were read in full, the intervention or the caregivers support programmes were read in full and the main concepts and concerns were noted and used in this current research

- The data were analysed according to the question asked during the review, Which caregivers of cancer patients' support programmes are available?
- Data gathering started in March 2018 and ended in June 2018. Regular searches were done to enhance inclusion of the available work. In total, 257 (N=257) works were identified across the databases, however, 155 (n=155; 60%) were excluded by title or due to duplication, 81(n=81; 32%) were excluded as only abstracts were available, and 21(n=21; 8%) were excluded after the full reading as they did not answer the research question, which left no (n=0; 0%) suitable work. The researcher searched Google and Google Scholar for related reviews and 22 (n=22) were found and included in the current literature review. Therefore, Phase 2 of this study comprised 22 work papers issued between 2008 and 2017 (Figure 4.2). Once this process was completed, a consensus meeting was held with the researcher's supervisor.

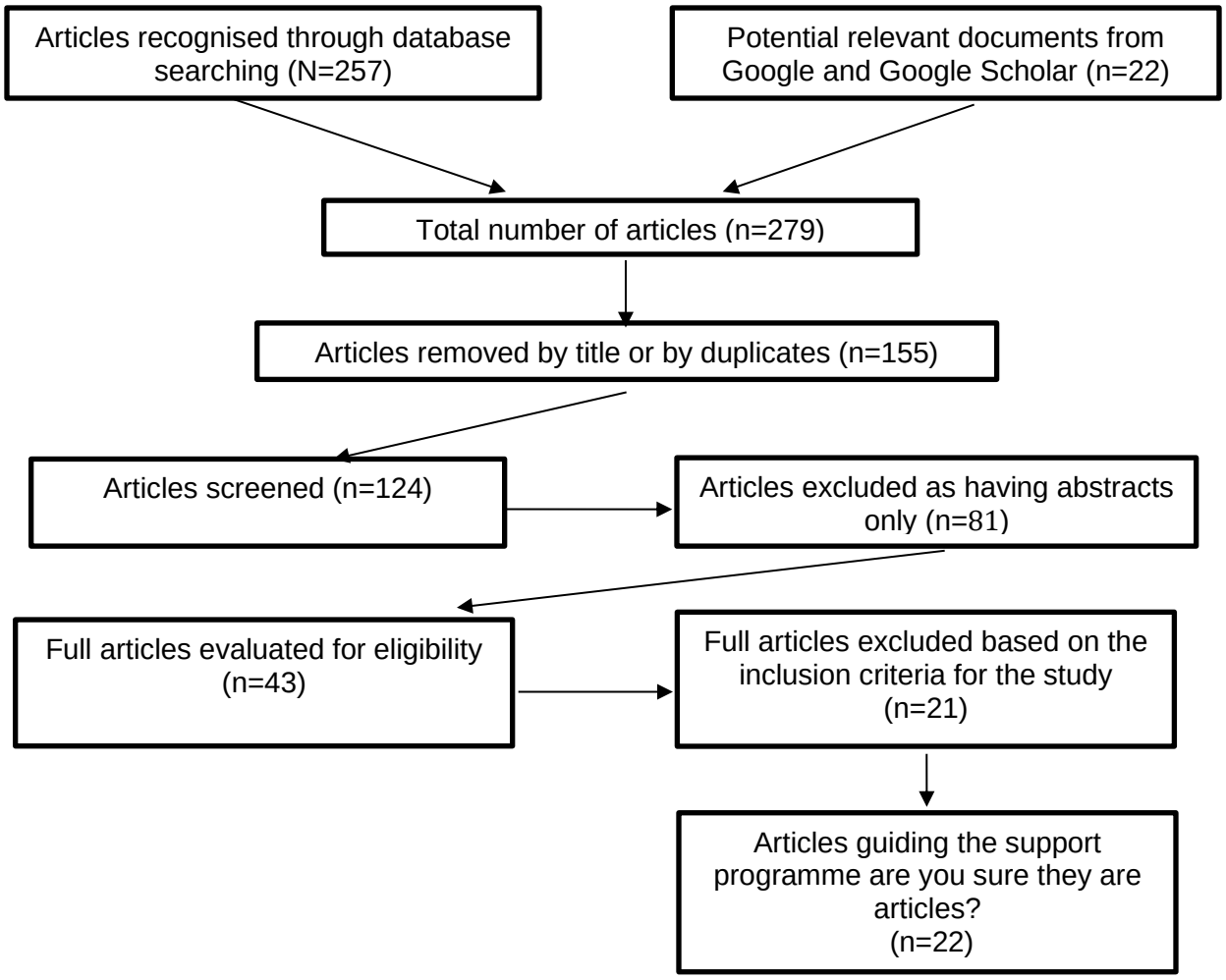


Figure 4.2: A flow diagram of the scoping review search process (Arksey and O'Malley, 2005).

4.4.4 Stage four: charting the data

The researcher developed a data capturing spread sheet (Table 4.8) to summarise the data of the included studies terms of the first author, year of publication and country, study aim, study design, population, sample size and source, name of intervention, duration and setting of the intervention, assessment instruments used in included studies and main findings of the interventions. To prevent the risk of bias and promote rigour the researcher extracted the data while it was reviewed by the supervisor for agreement.

Table 4.8: Support programmes available for caregivers (2008-2017), general characteristics (N=22)

	AUTHOR (DATE) **COUNTRY**	**STUDY AIM**	**STUDY DESIGN**	**POPULATION AND SAMPLE SIZE**	**NAME OF INTERVENTION**	**DURATION OF INTERVENTION**	**DATA COLLECTION INSTRUMENTS**	**MAIN FINDINGS**
1	Badger *et al*., (2011) *USA.*	To assess the effectiveness of two telephone-delivered psychosocial interventions for maintaining and improving QoL.	Experimental.	Prostate cancer (n=71) patients and caregivers (n=70).	Telephone Interpersonal Counselling (TIP-C).	8 weeks (4 sessions).	Centre for Epidemiological Studies-Depression Scale (CES-D). Positive and Negative Affect Schedule (PANAS). Perceived Stress Scale (PSS). Multidimensional Fatigue Inventory (MFI). Perceived Social Support- Family scale (PSS-FA). Quality of Life-Breast Cancer version questionnaire.	The psychosocial interventions were effective in preserving or enhancing the QoL of the caregivers and patients.
2	Badr *et al.*, (2015) *USA.*	To describe if the A dyadic Psychosocial Intervention Model is superior to the existing practices of typical medical care.	Randomized control trial.	Lung cancer patients and caregivers (n=39).	A dyadic Psychosocial Intervention Model.	6 weeks (6 sessions).	Patient Reported Outcomes Measurement Information System (PROMIS). Zerit burden inventory. Self-developed Autonomy Scale. Self-developed Competence scale.	Caregivers' level of depression, anxiety and care burden declined significantly. The results supported the intervention practicability, appropriateness, and preliminary efficacy.
3	Fegg, (2013) *Germany.*	To offer the need care to caregivers of patient using palliative in bereavement course.	Randomized clinical trial.	Caregivers (n=202) and cancer patients.	Existential Behavioral Therapy (EBT).	3-12 months (6 group sessions).	Brief Symptom Inventory. Satisfaction with Life Scale (SWLS). WHO Quality of Life-BREF scale. Numeric rating scale for QOL (QOL-NRS, range 0–10).	The programme seems to exert beneficial effects on caregiver's QoL and distress. Additional longitudinal evidence is needed to approve these findings.
4	Ledderer *et al.*, (2013) *Denmark.*	To examine the feasibility of the intervention in a randomized controlled trial (RCT) and to evaluate the impact on QoL.	Randomized clinical trial.	Lung and cancer patients and caregivers (n=42).	Psychosocial and Rehabilitation Intervention.	One year (2 sessions).	EORTC-QLQ-C30. WHO-Five Well-Being Index.	The QoL caregivers in intervention group as well as those in control group improved. However, no clinical significance difference was found between the groups. The study found it might be challenging to apply an RCT of psychosocial rehabilitation intervention for couple's intervention. The study highlighted the challenges experienced in terms of an RCT, inclusion and drop out.
5	Meyers *et al.*, (2011) *USA.*	To examine the importance of a consistent cognitive–behavioral problem-solving educational intervention on the caregivers and cancer patients.	Randomized clinical trial.	Caregivers (n=136).	(COPE) Problem Solving Model.	6 months (3 sessions).	City of Hope Quality of Life. Social Problem Solving Inventory-Revised.	The programme enabled caregivers to obtain a steady QoL post intervention but not for the patients.

6	Miyashita *et al.*, (2008) *Japan.*	To deliberate the worries and distresses related to end of life choices.	Intervention al.	Caregivers (n=607).	Population-based Educational Intervention.	One-hour educational lectures from April 2006 to March 2007.	Self-developed questionnaires.	This intervention was effective in shifting beliefs regarding feasibility and practicing cancer care at homes, preference for life-prolonging treatment and methods headed for end-of-life care. This programme changed the believes and attitudes about management cancer symptoms, the opioids use and it is misconceptions and practicing artificial hydration. Communication between caregivers and patients and health care providers also improved post intervention.
7	Sun *et al.*, (2015) *USA.*	To confirm the effectiveness of an interdisciplinary palliative care intervention for caregivers of patients cancer.	Quasi-experimental.	Caregivers (n=366).	Interdisciplinary Palliative Care Intervention.	12 weeks (4 educational sessions).	City of Hope QOL Tool (COH-QOL-FCG). Functional Assessment of Cancer Therapy-Lung tool. Functional Assessment of Chronic Illness Therapy-Spirituality Subscale. Distress Thermometer.	An interdisciplinary method to palliative care for patients with in lung cancer resulted in statistically significant enhancements in caregiver's social wellbeing as well as psychological distress and fewer caregiver care burden.
8	White *et al.*, (2008) *Australia.*	To offer the caregivers with daily need skills for caring of patients at home; increase awareness of current public means for caregivers; raise caregivers' confidence through the need information and knowledge; as well as support the concepts of palliative care.	Mix methods.	Caregivers (n=205).	Learn Now, Live Well (LNLW).	Six Modules carried out for over 3 Saturdays.	Self-developed questionnaire.	This programme effectively enhanced caregiver's access to support through a range of sectors, increasing assurance by education and support. By increasing knowledge and care confidence, a substantial decline of care isolation was obtained.
9	Porter *et al.*, (2011) *USA.*	To confirm the effectiveness of lung cancer patient's caregiver-assisted coping skills training protocol.	Randomized Clinical Trial.	Caregivers and lung cancer patients (n=233).	Caregiver-Assisted Coping Skills Training.	14 telephone sessions).	Brief Pain Inventory (BPI). Beck Depression Inventory (BDI). State Trait Anxiety Inventory (STAI). Functional Assessment of Cancer Therapy-Lung Cancer (FACT-L). Chronic Pain Self-Efficacy Scale. Profile of Mood States-B (POMS-B). Caregiver Strain Index (CSI). Modified version of a standard self-efficacy scale.	This psychosocial intervention was beneficial and can produce enhancements in a range of consequences for cancer patients. Pain, depression, QoL, and self-efficacy for cancer patients, and caregiver's anxiety and self-efficacy improved post intervention.
10	Clarke and Seymour, (2010) *UK.*	To comprehend the distresses related to the concerns of the end of life, providing information and inspiring reflection.	Qualitative.	Caregivers (n=74).	The Listening Events Help the Aged.	Four Workshops.	Self-developed anonymous questionnaire.	Three themes were observed through this programme; commination according end of life, death and dying concerns and development care planning. Additional community-based explanations to queries of quality of death should be available, supported by public education programmes.

11	Collinge *et al.*, (2013) *USA.*	To describe the effect of caregiver administered massages on patient symptoms and adverse effects and, on QoL of patients and stress points equally in caregivers and cancer patients.	Randomized controlled trial.	Caregivers (n=97).	Multimedia Caregiver Education Program.	4 weeks (listening 20 min session three times per week).	Perceived Stress Scale (PSS-10). Functional Assessment of Cancer Therapy-General (FACT-G, version 4).	Significant reductions in all symptoms occurred for patients after both activities: 12–28 % reductions after reading vs. 29–44 % after massage. Massage caregivers showed significant gains in confidence, comfort, and self-efficacy using touch and massage as forms of caregiving.
12	Bakitas *et al.*, (2009) *USA.*	To recognize the common methodological concerns that confront palliative care investigators.	Randomized controlled trial.	Caregivers and patients (n=322).	Project ENABLE II.	4 sessions.	Karnofsky Performance Scale (KPS). Edmonton Symptom Assessment Scale (ESAS). Centre for Epidemiological Study-Depression Scale (CES-D). Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal).	It is possible to overcome several of the methodological obstacles to applying a rigorous RCT in palliative care.
13	Shaw *et al.*, (2015) *Australia*.	To test the efficacy of a structured telephone intervention for caregivers of cancer patient who have a poor prognosis to raise psychosocial consequences similarly in both caregivers and cancer patients.	Randomized controlled Trial.	Caregivers (n=128).	Family Connect Individualized Intervention.	6 months.	Short Form (SF)-12v2. Partner and Caregiver Supportive Care Needs Survey (SCNS-P&C). Caregiver Reaction Assessment (CRA)—disrupted schedule. Distress Thermometer. Functional Assessment of Cancer Therapy—General (FACT-G). Supportive Care Needs Survey—Patient version (SCNS-34).	This programme reduced caregivers worry about finance and provided social support. However, the programme did not find any significant improvement in caregiver well-being. This programme decreased hospital consultations and unintended readmissions post-discharge period.
14	Northouse *et al.*, (2013) *USA.*	To study the influence of FOCUS Program on couples using the programme comparable with those who not use the programme.	Randomized clinical trial.	Cancer patients and caregivers (n=484).	FOCUS Programme.	6 months (6 sessions).	Appraisal of Illness Scale (patients). Appraisal of Caregiving Scale (caregivers). Mishel Uncertainty in Illness Scale. Beck Hopelessness Scale. Brief Cope scale. Researcher-developed scale to measure Healthy behavior. Social Support Questionnaire. Lewis Mutuality and Sensitivity Scale. Lewis Cancer Self efficacy Scale. Functional Assessment of Cancer Therapy (version 4).	Significant improvement in coping, self-efficacy, social and emotional QoL were found. However, these effects were sustained for three month only.
15	Hudson *et al.*, (2009) *Australia.*	To prepare the caregivers for the role of supporting a patient with advanced cancer.	Qualitative.	Caregivers (n=156).	Carer Group Education Program (CGEP).	3 sessions during 3 weeks.	Carer Competence Scale. Preparedness for Caregiving Scale. Family Inventory of Need. Rewards for Caregiving Scale.	This study confirmed that a group education program has positive effects on caregiver competence, rewards, information needs and preparedness to provide support at home.
16	Clark *et al.*, (2013) *USA.*	To maintain QoL for end stage cancer patients using radiotherapy, and their caregivers QoL during cancer.	Randomized controlled trial	Caregivers (n=131).	Cognitive Behaviour Therapy (CBT).	6 months (six 90-minute sessions).	Beck Depression Inventory-II (BDI-II)". Functional Assessment of Cancer Therapy-General (FACT-G, version 4). Caregiver quality of life cancer index (CQOLC).	Participating in this intervention was effective in maintaining the QoL of cancer patients.

17	Hudson *et al.*, (2008) *Australia.*	To examine the utility of a group family caregiver psycho-educational programme focused on preparing primary family caregivers for the role of supporting a relative with advanced cancer at home.	Mix method.	Caregiver (n=74).	Carer Group Education Program (CGEP).	3 sessions (1.5/h each) over a 3-week period.	Self-developed questionnaire.	This study confirmed that the programme was successful in preparing caregivers to provide support for dying patients at home and increased caregiving competence.
18	Mclean *et al.*, (2013) *Canada.*	To evaluate the effect of Emotionally Focused Therapy, modified for the advanced cancer population versus standard care, on marital functioning and psychosocial outcomes among distressed couples.	Randomized controlled trial.	Cancer and their caregivers (n=42).	A couple-based Emotionally Focused Therapy (EFT) intervention.	3 months (8 sessions).	Revised Dyadic Adjustment Scale. Beck Depression Inventory-II (BDI-II). Caregiver Burden Scale. Relationship-Focused Coping Scale (RFCS).	The efficiency of and adherence to the intervention were confirmed by this study. There was an improvement of marital functioning and patient experience of caregiver's empathic care.
19	Belgacem et al., (2013) *France.*	To examine the efficiency of a caregiver educational programme by evaluating the caregivers and cancer patients QoL and care burden.	Randomized clinical trial.	Cancer patients and their caregivers (n=67).	Caregiver Educational Program.	4 years.	Short form 36 of the Health Survey. Zerit burden inventory.	The educational programme improves the QoL caregivers and cancer patients alike and declines caregivers' burden.
20	Boele *et al.*, (2012) *Netherlands.*	To define the issues influencing caregivers QoL and their mastery of caregivers of cancer patients.	Randomized controlled trial.	Caregivers (n=56).	Cognitive Behaviour Therapy (CBT).	Two years (6 sessions).	Health related QoL questionnaire.	This intervention found efficient in preserving caregivers QoL, mental wellbeing and caregivers mastery as well as rise the sense of caring throughout the 8 months.
21	Dionne-odom *et al.*, (2015) *UK.*	To describe the effect of early versus delayed beginning of a palliative care intervention for caregivers	Randomized controlled trial.	Caregivers (n=122).	Grief counselling.	3 years	Caregiver quality of life cancer index (CQOLC). Center for Epidemiologic Study–Depression (CESD) Scale. Montgomery–Borgatta CG Burden (MBCB).	The caregivers in early group had lesser depression scores at 3 months and lesser stress burden.
22	Hendrix *et al.*, (2016) *USA.*	To test the influence of an improved informal caregiver training (Enhanced-CT) protocol in symptom of cancer and monitoring of caregiver stress.	Randomized controlled trial.	Caregivers (n=120).	Enhanced Caregiver Training Program.	One to two hours.	Self-efficacy Scale for Cancer Caregivers. Preparedness for Caregiving scale. Profile of Mood States (POMS). Center for Epidemiology Studies Depression Scale (CES-D). Caregiver Reaction Assessment (CRA).	Enhanced-CT protocols lead to temporary enhancements in self-efficacy in controlling symptoms and caregiver stress, and readiness for caregiving but not in psychological well-being of caregivers.

4.4.5 Methodological quality appraisal

The methodological quality of the work included works that were evaluated by the researcher and the supervisor by means of the Mixed Methods Appraisal Tool (MMAT) (Hong *et al.*, 2018).

When appraising the methodological quality of the works included in this review, only one (n=1; 5%) mix method study referred to Hudson *et al.* (2008) three sessions Carer Group Education Programme (CGEP) study was aimed to assess the efficiency of the proposed programmes allowing the caregivers caring for their cancer patient at home and have a clear research question allowing a quality assessment. and according to the set of criteria in the MMAT, this study got one score. As guided by MMAT, no further appraisals were done. No works were excluded based on their quality (Hudson *et al.*, 2008, 2009; Miyashita *et al.*, 2008; White *et al.*, 2008; Bakitas, *et al.*, 2009; Clarke & Seymour, 2010; Badger *et al.*, 2011; Meyers *et al.*, 2011; Porter *et al.*, 2011; Boele *et al.*, 2012; Ledderer *et al.*, 2013; Mclean *et al.*, 2013; Northouse *et al.*, 2013; Belgacem *et al.*, 2013; Clark *et al.*, 2013; Collinge *et al.*, 2013; Fegg, 2013; Badr *et al.*, 2015; Shaw *et al.*, 2015; Sun *et al.*, 2015; Dionne-odom *et al.*, 2015; Hendrix *et al.*, 2016).

4.4.6 Results: summarising, and reporting the outcomes utilised in this review.

Different caregivers support programmes were revealed from the investigated studies. The details will be described below.

All the studies were conducted in developed countries, indicating the lack of caregivers of cancer patients' support programmes in developing countries such as Palestine. The USA had the largest share of included works, followed by Australia (Table 4.9).

Table 4.9: Countries contributing to the data collection listed in the selected data basis between 2008 and 2017 (n = 22)

Country	*n*	*%*
USA	10	45
Australia	4	18
UK	2	9
Germany	1	5
Denmark	1	5
Japan	1	5
Canada	1	5
France	1	5
Netherlands	1	5

4.4.6.1 Programme designs and duration

Different designs and research methods were used: nine (n=9, 41%) randomised control trials (Bakitas, Kathleen Doyle. Lyons, *et al.*, 2009; Boele *et al.*, 2012; Clark *et al.*, 2013; Collinge *et al.*, 2013; Mclean *et al.*, 2013; Badr *et al.*, 2015; Dionne-odom *et al.*, 2015; Shaw *et al.*, 2015; Hendrix *et al.*, 2016), followed by six (n=6, 27%) randomised clinical trials (Meyers *et al.*, 2011; Porter *et al.*, 2011; Belgacem *et al.*, 2013; Fegg, 2013; Ledderer *et al.*, 2013; Northouse *et al.*, 2013), two (n=2, 9%) intervention study designs (Miyashita, Sato, Morita, *et al.*, 2008; Hudson *et al.*, 2009), two (n=2, 9%) mix method designs (Hudson *et al.*, 2008; White *et al.*, 2008), one (n=1, 5%) experimental (Badger *et al.*, 2011), one (n=1, 5%) quasi-experimental design (Sun *et al.*, 2015), and one (n=1, 5%) qualitative study design (Clarke & Seymour, 2010). The length of the programmes varied from 3 weeks to 4 years and the duration of the contact session was between 1-3 hours. All the programmes were executed by health experts.

4.4.6.2 Program themes

22 (n=22; 100%) reported the concerns allied with cancer care. Some of the programmes were conducted widespread with caregivers, cancer patients and the public.

Programmes applied to caregivers and widespread to the general public (Hudson *et al.*, 2008; Miyashita, *et al.*, 2008; Hudson *et al.*, 2009; Clarke & Seymour, 2010), proposed to raise conversation on general themes and assess the efficiency of programmes that would allow the public's input on caregiving and emphasise the ability to play the active role as a caregiver (Hudson *et al.*, 2008). They also hoped to increase the caregiver's capability in caregiving duties and maintain their wellbeing, raise awareness towards the available of public resources, which may be needed in cancer care, raise the caregivers' self-reliance through knowledge and information needed for caring, enhance the ideas of cancer care or in the last stage of disease bereavement (White *et al.*, 2008; Hudson *et al.*, 2009; Fegg, 2013), and measure the efficiency and level of influence of similar interventions on different life domains in caregivers of patients in the advanced disease stage.

A shared theme in most of the works that offered programmes was easy to understand and applicable to the participants, to facilitate the sharing of experiences as well as enhancing their role as caregivers in cancer care (Bakitas, Kathleen Doyle. Lyons, *et al.*, 2009; Badger *et al.*, 2011; Meyers *et al.*, 2011; Porter *et al.*, 2011; Boele *et al.*, 2012; Mclean *et al.*, 2013; Northouse *et al.*, 2013; Belgacem *et al.*, 2013; Clark *et al.*, 2013; Collinge *et al.*, 2013; Ledderer *et al.*, 2013; Badr *et al.*, 2015; Sun *et al.*, 2015; Dionne-odom *et al.*, 2015; Hendrix *et al.*, 2016).

4.4.6.3 Data collection instruments

In total, 56 (n=56) varied data collection instruments were used to measure the results of the programmes, the most common ones being the Center for Epidemiological Studies-Depression Scale (CES-D), which was used to measure depression among the participants (Bakitas *et al.*, 2009; Badger *et al.*, 2011; Dionne-odom *et al.*, 2015; Hendrix *et al.*, 2016), the Functional Assessment of Cancer Therapy-General (FACT-G, version 4) to evaluate the health-related QoL in cancer patients going through cancer treatment, the influences of cancer treatment in four domains, physical, emotional, social/family and functional as used in Clark *et al.*, (2013), Collinge *et al.*, (2013), Northouse *et al.*, (2013), Shaw *et al.*, (2015), followed by Beck's Depression Inventory (BDI) to assess the depression severity of individuals as used in the studies of Porter *et al.*, (2011); Clark *et al.*, (2013); Mclean *et al.*, (2013) (Table 4.10).

Table 4.10: The Instruments used in quantitative studies included in the scoping review (n=22)

	Badger et al., (2011)	Badr *et al.*, (2015)	Fegg, (2013)	Ledderer *et al.*, (2013)	Meyers *et al.*, (2011)	Miyashita *et al.*, (2008)	Sun *et al.*, (2015)	White *et al.*, (2008)	Porter *et al.*, (2011)	Clarke and Seymour, (2010)	Collinge *et al.*, (2013)	Bakitas *et al.*, (2009)	Shaw *et al.*, (2015)	Northouse *et al.*, (2013)	Hudson *et al.*, (2009)	Clark *et al.*, (2013)	Mclean *et al.*, (2013)	Belgacem *et al.*, (2013)	Boele *et al.*, (2012)	Dionne-odom *et al.*, (2015)	Hendrix *et al.*, 2016)
Centre for Epidemiological Studies-Depression Scale.	+											+								+	+
Positive and Negative Affect Schedule (PANAS).	+																				
Perceived Stress Scale (PSS).	+									+	+										
Multidimensional Fatigue Inventory (MFI).	+																				
Perceived Social Support- Family scale (PSS-FA).	+																				
QoL Breast Cancer version questionnaire.	+																				
Patient Reported Outcomes Measurement Information System (PROMIS).		+																			
Zerit burden inventory.		+															+	+			
Self-developed Autonomy Scale.		+																			
Self-developed Competence scale.		+																			
Brief Symptom Inventory.			+					+	+												
Satisfaction with Life Scale (SWLS).			+																		
WHO Quality of Life-BREF scale.			+																		
Numeric rating scale for QOL.			+																		
EORTC-QLQ-C30.				+																	
WHO-Five Well-Being Index.				+																	
City of Hope Quality of Life Instruments.					+	+	+														
Social Problem Solving Inventory-Revised.					+	+															
Functional Assessment of Cancer Therapy-Lung tool.						+	+	+	+												
Functional Assessment of Chronic +Illness Therapy-Spirituality Subscale.						+	+														
Distress Thermometer.						+	+						+								
Beck Depression Inventory (BDI).								+	+							+	+				
State Trait Anxiety Inventory (STAI).								+	+												

Chronic Pain Self-Efficacy Scale.								+	+													
Profile of Mood States-B (POMS-B).								+	+													+
Caregiver Strain Index (CSI).								+	+													
Self-efficacy Scale.								+	+													*
Functional Assessment of Cancer Therapy-General (FACT-G, version 4).											+		+	+		+						
Karnofsky Performance Scale (KPS).												+										
Edmonton Symptom Assessment Scale (ESAS).												+										
Functional Assessment of Chronic Illness Therapy-Palliative Care (FACIT-Pal).												+										
Short Form (SF)-12v2.													+									
Partner and Caregiver Supportive Care Needs Survey (SCNS-P&C).													+									
Caregiver Reaction Assessment (CRA)													+									+
Supportive Care Needs Survey (SCNS-34).													+									
Appraisal of Illness Scale														+								
Appraisal of Caregiving Scale.														+								
Mishel Uncertainty in Illness Scale.														+								
Beck Hopelessness Scale.														+								
Brief Cope scale.														+								
Social Support Questionnaire.														+								
Lewis Mutuality and Sensitivity Scale.														+								
Lewis Cancer Self efficacy Scale.														+								
Carer Competence Scale.															+							
Preparedness for Caregiving Scale.															+							+
Family Inventory of Need.															+							
Rewards for Caregiving Scale.															+							
Caregiver quality of life cancer index (CQOLC).																+				+		
Revised Dyadic Adjustment Scale.																	+					
Relationship-Focused Coping Scale (RFCS).																	+					
Short form 36 of the Health Survey.																		+	+			
Health related QoL scale.																			+			
Montgomery–Borgatta CG Burden (MBCB) Scale.																				+		
Self-developed questionnaires						+		+		+												

Participants were recruited from various settings. The sample sources of the reviewed studies varied from surgical and medical oncology clinical settings to community settings (Table 4.11).

Table 4.11: Settings and sources of information for studies included in this review (n=22)

Sample source	*n*	%
Surgical and medical oncology clinical settings	11	50
Community oncology clinics	4	18
Palliative and hospice care settings	2	9
Veterans medical centres	2	9
Radiation oncology department	1	5
Oncologists' offices	1	5
Not mentioned	1	5

4.4.6.4 Programs assessment

The interventions that were investigated in this review were varied in the scope of interest. Some of the interventions (n=13, 59%) focused on providing the proper skills the caregivers needed during taking care of their cancer patients (Hudson *et al.*, 2008, 2009; Bakitas *et al.*, 2009; Badger *et al.*, 2011; Meyers *et al.*, 2011; Porter *et al.*, 2011; Northouse *et al.*, 2013; Belgacem *et al.*, 2013; Clark *et al.*, 2013; Collinge *et al.*, 2013; Ledderer *et al.*, 2013; Badr *et al.*, 2015; Hendrix *et al.*, 2016), others (n=1; 5%) focused on "couple-based interventions" for married relationships (Mclean *et al.*, 2013), one (n=1; 5%) on clusters skill teaching (Fegg, 2013) and five (n=5; 23%) on interventions that provide training to sharpen the caregivers skills, such as the communication process with patients, providing daily need activities and managing cancer symptoms (White *et al.*, 2008; Boele *et al.*, 2012; Dionne-odom *et al.*, 2015; Shaw *et al.*, 2015; Sun *et al.*, 2015). Conversely, two interventions (n=2; 10%) focused on community individuals as well as the caregivers to apply the programme or training they established (Miyashita, Sato, Morita, *et al.*, 2008; Clarke & Seymour, 2010).

4.5 SUMMARY OF THE SECOND SCOPING REVIEW

In total, 490 articles (n=257) were found through the database searches, Google and Google scholar; 22 papers (n=22) met the inclusion criteria and were included in this review.

The eight sessions of telephone interpersonal counselling (TIP-C) in the experimental study of Badger *et al.* (2011), were conducted in USA on caregivers and cancer patients to evaluate the efficiency of two telephone-delivered psychosocial interventions for preserving and enhancing QoL for participants. The intervention showed its effectiveness on maintaining or enhancing the caregivers and cancer patients QoL. Besides this, a randomised control trial was also conducted in the USA by Badr *et al.*, (2015) to determine whether their six weeks intervention was superior to existing practices of usual medical care. This dyadic self-developed psychosocial intervention enabled the caregivers with the abilities to direct care and encounter the challenges of cancer care. Conversely, in a prospective, multi-institution, randomised clinical trial, three sessions of the COPE problem solving model was applied by Meyers *et al.* (2011), which allowed the caregivers to be much nearer to their established QoL over the 6-month follow-up.

The prospective, quasi-experimental study of Sun *et al.* (2015) was designed to implement the interdisciplinary palliative care intervention among American caregivers and lung cancer patients to verify the efficiency of four educational sessions for caregivers of patients with non-small cell lung cancer. The intervention indicated for the enhancements in caregiver's social wellbeing, psychological distress and decrease in the caregivers' burden. To verify the effectiveness of a caregiver-assisted CST protocol in patients with lung cancer, the Porter et al. (2011) randomised clinical trial was conducted. The findings of the 14 telephone sessions that used in the study indicated for an enhancement of the outcomes of cancer patients could be achieved by such psychosocial interventions. In their randomised control trial, Collinge *et al.* (2013) aimed to define the influence of a multimedia caregiver education programme on patient's

symptoms and side effects on patients' QoL, and stress points in patients and their caregivers. This 4-week programme may offer caregiver's practical resources for improving self-efficacy and satisfaction in caregiving even with declining patient pain, depression, and other symptoms. In addition, caregivers could learn and apply safe and simple ways to enhance the patient's comfort and decrease distress. Another randomised controlled trial of Bakitas *et al.* (2009) was conducted in the USA. This four-session ENABLE II project aimed to enhance palliative care for rural cancer patients; this project demonstrated the usefulness of a new model of palliative care for cancer that could be used in oncology settings. To measure the effect of the FOCUS Program on pairs comparable with those who did not use the programme, Northouse *et al.* (2013) conducted their randomised clinical study in the USA on 484 advance cancer patients and their caregivers. This 6-sessions FOCUS Program had positive outcomes for dyads, but few sustained effects; dyads benefit when viewed as a unit of care.

Another randomised control trial was conducted in the USA by Clark *et al.* (2013). The 6 months (six 90-minute sessions) Cognitive Behaviors Therapy (CBT) intervention aimed to sustain the QoL of end stage cancer patients who were receiving radiotherapy, as well as practical support for patients and caregivers' QoL during cancer course. The results displayed that participating in a 6-session multidisciplinary intervention was effective in sustaining the cancer QoL who were actively using radiotherapy. The QoL of this population as well as symptom burden is striking, making it significant to recognize the effective QoL approaches to implement in combination with cancer care. According to the last study conducted in the USA, the randomised control trial (Hendrix *et al.*, 2016) included a one to two hours Enhanced Caregiver Training Program, which was applied to test the influence of an improved informal caregiver training (Enhanced-CT) protocol in cancer symptoms and stress of caregivers of cancer patients in hospital, using 120 caregivers and cancer patients. This study revealed that the Enhanced-CT protocol caused a short-term enhancements in

self-efficacy for dealing with symptoms of cancer and caregiver stress, and readiness for caregiving but not in caregivers' psychological well-being.

White *et al.*(2008) conducted a mixed method study in Australia, which implemented the Learn Now, Live Well (LNLW) programme on 205 caregivers and cancer patients. The six modules carried out over three Saturdays in hospital and community settings, aimed to provide the caregivers with everyday skills needed for caring for patients at home, raise awareness of present public resources for caregivers, raise caregivers' confidence through information and knowledge and support the ideas of palliative care. The LNLW programme effectively enhanced access of caregivers to support through a range of sectors, improving confidence through education and support. Another randomised controlled trial in an Australian study conducted by Shaw *et al.* (2015), implemented a 6 months family connect individualised intervention to examine the efficiency of a structured telephone intervention for poor prognosis cancer patient's caregivers to increase psychosocial outcomes amongst 128 caregivers and GI cancer patients. The study did not indicated for any significant enhancements in caregiver well-being but did result in a lessening in unplanned patient emergency department visit and re-admissions in the immediate post-discharge period.

In Australia, Hudson *et al*. (2009) conducted the Carer Group Education Program, using a qualitative study design amongst 156 caregiver and their cancer patients, to develop the capability to improve the role of caregivers; this three session programme verified that a group education programme for caregivers to be ready for supporting a dying relative at home duties was effective. Hudson *et al.* (2008) also implemented the Carer Group Education Program (CGEP) over a 3 weeks period (three sessions) on 74 caregivers and cancer patients using mixed method research design to assess the efficiency of programmes that allow the caregivers to care for patients at home; the study verified that a group education programme to prepare family caregivers for the

role of supporting a dying relative at home was accessible, applicable and effective.

In a randomised controlled trial study conducted in the UK by Dionne-odom *et al.* (2015) to define the influence of early versus delayed start of a palliative care intervention for cancer patients' caregivers. In this trial, grief counselling and three structured weekly telephone-coaching sessions, ENABLE || programme, were applied on 122 caregivers and cancer patients. The study revealed that the early group of caregivers had lower depression scores at 3 months, and lower depression and stress burden in the terminal decline analysis. The study by Clarke and Seymour (2010) was conducted on community caregivers older than 60 years to comprehend the distresses of end-of-life concerns, providing data and inspiring reflection. This qualitative study used the 4 Workshops of Listening Events Help the Aged (guided by the booklet Planning for Choice in End-of-Life Care). The programme showed that more community-based solutions to questions of quality of death needed to be found.

Fegg (2013) conducted a randomised clinical trial, in Germany, on 81 caregivers and cancer patients to provide need maintenance to informal caregivers of patients using palliative care in the course of bereavement; the Existential Behavioural Therapy (EBT) was applied over 3 to 12 months (six group sessions). This trial showed the Existential Behavioural Therapy appeared to exert beneficial effects on distress and QoL of informal caregivers of palliative patients. Conversely, Ledderer *et al*. (2013) conducted a randomised clinical trial study in Denmark on 42 lung and gynaecological cancer patients and their caregivers; over one year, two sessions of psychosocial and rehabilitation intervention were applied to test the intervention feasibility of the randomised control trial as well as to assess the influence of the intervention on QoL. This trial showed it might be difficult to apply an RCT of a psychosocial rehabilitation intervention for pairs, and difficulties with inclusion and drop out have to be recognized.

The Japanese interventional (Miyashita *et al.*, 2008) study was implemented with 607 end-of-life home care community public caregivers and using a population-based educational intervention continuo for one year. The study showed that such population-based educational intervention was efficient in shifting beliefs concerning the possibility of home care, preference for life-prolonging treatment and attitudes to end-of-life care.

To assess the influence of 3 months (eight sessions) couple-based Emotionally Focused Therapy intervention versus routine care, and on married conditions and psychosocial consequences of distressed pairs, Mclean *et al.*, (2013) conducted a randomised controlled trial in Canada on 42 caregivers and cancer patients. This trial demonstrated the effectiveness of and adherence to the EFT couple intervention for patients facing advanced cancer. The Belgacem *et al*. (2013) French randomised clinical trial implemented the caregiver educational programme on 67 caregivers and cancer patients to measure the effectiveness of a caregiver educational programme by assessing two outcomes: caregivers and cancer patients QoL and care burden over 4 years. This educational programme for caregivers inspires the involvement of patients, informal caregivers and healthcare providers in a triangular relationship, which improves the QoL of patients and caregivers equally and declines caregivers' burden.

Finally, the randomised controlled trial of Boele *et al.* (2012) was conducted in Netherlands on 56 caregivers and cancer patients, over 2 years (6 sessions), using the Cognitive Behaviour Therapy (CBT) to define the issues that influence health-related QoL and mastery of caregivers of brain tumour patients, and examined if a structured intervention containing psych-education and cognitive behavioural therapy enhanced the mental component of health-related QoL and mastery of caregivers. This intervention helped caregivers to maintain a stable level of health-related QoL and enhanced the feelings of mastery over an 8-month period.

Programmes evaluated in Phase 2 identified possible learning activities, useful handouts and their presentation, and potential guiding questions for discussion. The programmes provided the researcher with a suitable framework to develop a support programme to encourage the caregivers to try to see positive characteristics in the caregiving experience, and offered access to spiritual guidance, to support self-care by inspiring caregivers to improve their physical and mental health. Such guidance included supporting regular 'time out,' pleasant experiences, adequate sleep, a healthy food, aerobics exercises, guidance on relaxation plans by providing caregivers the chance to recognize concerns and plan goals/strategies and counselling them of their rights and other aspects, such as coordinating care and maintaining communication to prevent misunderstanding and promote positive interaction, and how the caregivers' reactions to demands of care were adopted and implemented.

4.6 SUMMARY OF CHAPTER FOUR

This chapter describes the results of the first two phases of the study. The results started with the first scoping review, which synthesised the evidence regarding the support needs of caregivers, after content analysis seven themes were raised and analysed to be used in development of the support programme. Then the second scoping review data were analysed in order to exhaust the viability of published support programmes for caregivers. Different programmes pointed to the caregivers were analysed and used to develop the support programme.

CHAPTER FIVE

RESULTS OF PHASE 3 AND 4

5.1 INTRODUCTION

The results of the development/adaptation and validation of the support programme (Phase 3) and intervention study (Phase 4) are described in this chapter.

5.2 THE RESULTS OF PHASE 3: THE DEVELOPMENT/ADAPTATION AND VALIDATION OF THE SUPPORT PROGRAMME

The findings of the literature reviews conducted in Phases 1 and 2 guided the development of the support programme (Addendum A). As already mentioned, the data from the scoping reviews were analysed with an open mind in order to identify meaningful subjects to provide answers to the research questions. The researcher used reflexivity whilst analysing the data to be aware of the possible influence to the study's findings.

The inductive analysis of the aggregated conclusions revealed there was a need to address basic cancer knowledge and describing the role of caregivers. Some conclusions from the reviews are presented:

- There were a limited number of studies and programmes focusing on the care needs of family members caring for cancer patients.
- Most of the studies were conducted in developed countries and all the programmes studied were conducted in developed countries.
- Different research designs were used.
- The studies and the programmes used different sample sizes and caregivers of patients diagnosed with different cancers.
- The caregivers lacked knowledge about cancer and it is treatments as well as, the ability to access information to enhance their understanding of relevant issues and to provide a basis for skill acquisition.

- The caregivers lacked information about the meaning of support.
- The caregivers lacked knowledge about adjusting to being a caregiver, for instance how to manage common patient's symptoms /emotions.
- The caregivers lacked the ability to provide for their own needs and apply self care
- The support needs of the caregivers were grouped into seven themes:
    - Information support needs.
    - Physical support needs.
    - Social support needs.
    - Psychological and spiritual support needs,.
    - Emotional support needs.
    - Cancer care services support needs.
    - Financial support needs.

The support programme (Addendum A) was adapted from the work of numerous authors (Hudson *et al.*, 2008, 2009; Miyashita *et al.*, 2008; White *et al.*, 2008; Bakitas, *et al.*, 2009; Clarke and Seymour, 2010; Badger *et al.*, 2011; Meyers *et al.*, 2011; Porter *et al.*, 2011; Boele *et al.*, 2012; Ledderer *et al.*, 2013; Mclean *et al.*, 2013; Northouse *et al.*, 2013; Belgacem *et al.*, 2013; Clark *et al.*, 2013; Collinge *et al.*, 2013; Fegg, 2013; Badr *et al.*, 2015; Shaw *et al.*, 2015; Sun *et al.*, 2015; Dionne-odom *et al.*, 2015; Hendrix *et al.*, 2016), as well as from Publications of the National Cancer Institute, (2014), Department of Health and Human Services, including: "When Someone You Love is Being Treated for Cancer," which can be found at https://www.cancer.gov/publications/patient education/when-someone-you-love-is-treated.pdf".

The support programme was tested for readability, pilot-tested and adapted to be used in this study. The expert panel group validated the programme, and face and content validity were established. The expert group consisted of healthcare professionals (n=6); Four senior nurses (n=4), one oncologist (n=1), one social worker (n=1) and four caregiver (n=4) of cancer patients, who works in the

oncology unite at the target hospital with cancer patients who treated at the same facility, as well as four caregivers of cancer patients .

The programme was reviewed by the expert group for language, clarity, and validity to assess if the programme was developed to assess the caregivers QoL and care burden. Expert group also required to segregate the statements on different support care dimensions of QoL and care burden (Information, physical, psychological/ spiritual, emotional, social, and financial and cancer care services support needs).

Seven responses were retained and the expert group had agreements on the rest of the support programme.

The responses of the expert panel group (Addendum X) were as follows:

The main concerns revolved around the terminology used, as some of the words would not be easy for the community to understand; some advised changing the terminology to lay language or to include simple explanations. Some concerns were raised around the time needed to implement the programme. In addition, it was recommended that:

- The concept of end-of-life care should be used to a greater extent
- Caregivers and cancer patients should be advised to visit social workers and mental health clinics regularly
- Care should be taken when describing sexual problems; some experts said, “Please omit any things related to sexual intercourse, as may they refuse to continue and would lead to losing them.” They concluded that communication between patients or caregivers and healthcare providers, coupled with cultural beliefs and norms surrounding sex, may exacerbate concerns in this domain, as it does not suit the culture, beliefs and norms; sexual issues might have been ‘taboo’ with caregivers or patients.
- If the patient does not know about his/her disease do not include them (Table 5.1 presents the suggested changes).

Table 5.1: Changes suggested by the expert panel (n=10)

Suggested change	*n*	%
Limit the time of each of the session	2	20
Remove all information related to sexual issues	2	20
Patients who do not know their diagnosis should not be included in the study	1	10
Add text from Holy Quran (reading and listening)	1	10
Increase the attention given to end of life support	1	10
Change the terminology to lay language	2	20
Encourage the caregivers to visit social workers and mental health specialist clinics	1	10

On the basis of the remarks of the expert group, a response was then reworded for presenting clarity, avoiding ambiguity and suits the Palestinians culture. After the support programme was validated, the researcher begin preparing for programme implementation.

5.3 PROGRAMME IMPLEMENTATION

After validation of the support programme, the programme was finalised, and learning material was developed (Addendum Z). The researcher held a short meeting with the management and staff of the oncology department at the target hospital, at a convenient time, to organise the support programme, as well as to help the researcher assemble the caregivers recruited to attend the sessions.

Recognizing that caregivers had limited time, the support programme content was organized so it could be covered in ten sessions over a period of three months; this enabled the researcher to cover the content of the programme.

The researcher began with a small speech to welcome the participants, provided a brief introduction to caregivers' life, the described benefit of participants, and the purpose of the meeting.

Every session includes 10-15 participants, and each session was 60-100 minutes in length, using a PowerPoint presentation. The objectives described for each session were listed in the support programme.

The themes of the support programme were:

1. The introduction, the objective of the programme, and general information about cancer.
2. The meaning of support, the influence of disease on patients, caregiver demands, and providing support to the sick person
3. Patient illness-related needs: introduction to comfort and cure–symptom management, emotional support, administration of medications, assistance with mobility or bathing and indirect care, such as obtaining medications, transportation, errands, scheduling and coordinating appointments, assisting with the medical bills and finances, coordinating care and maintaining communication to prevent misunderstanding as well as promote positive interaction
4. Caregiver's needs: information, support, assistance and adjusting to being a caregiver
5. Caregivers' reactions to demands of care.

Every session began with caregivers discussing what they learned in the previous session and sharing their experiences.

The description of how the programme sessions were delivered and presented available in appendices (Addendum A).

5.4 RESULTS OF PHASE 4: PRE AND POST INTERVENTION

This section was described the five outcomes studied in Phase 4 of the study, the result of the outcomes measured, namely; caregivers QoL and care burden and cancer patients QoL, pain experience and symptoms burden

The total number of participants was for the group (n=50) that started the intervention and completed the questionnaires pre-intervention, and 38 participants remained (n=38) and completed the questionnaires post-intervention. The reason for the 12 participants (n=12) did not complete the intervention was because of cancer patients' deaths.. However, there were no substantial differences and the researcher proceeded with the complete case analysis, assuming missing data was completely at random (MCAR).

5.4.1 Socio-demographic characteristics of the caregivers

The ages of the caregivers ranged between 18 and 74 years; the mean was (*m*=39.44; SD±13.82) years. Males and females were equally represented (n=25; 50%) and most (n=37; 74%) were married. The greatest percentage of the caregivers (48%; n=24) were the child of the sick person, full time employed (n=16; 32%), and cared for the sick person between 1 and 2 years (n=26; 52%). As reported by the caregivers, the greatest percentage of patients (18%; n=9) had breast cancer and acute lymphatic leukaemia and took Step 2 pain drugs. Table 5.2 presents the details.

Table 5.2: Socio demographic characteristics of the caregivers (n=50)

Variable	***n***	**%**
Age		
18-29	18	36
30-39	5	10
40-49	13	26
50-59	10	20
60-69	3	6
70 years and above	1	2
Gender		
Male	25	50
Female	25	50

Marital status		
Married	37	74
Divorced	6	12
Single	4	8
Widowed	3	6
Education Level		
No formal education	2	4
Primary School	9	18
High School	25	50
Graduate School	12	24
Post graduate	2	4
Employment status		
Full time	16	32
Part time	13	26
Retired	3	6
Not employed	18	36
Relationship to the patient		
Parent	6	12
Spouse	12	24
Sibling	7	14
Child	24	48
Friend	1	2
Caregiver's period of caring		
< 1 year	9	18
1-2 years	26	52
> 2 years	15	30
Type of the treatment the cancer patients received**		
Chemotherapy	50	100
Radiotherapy	4	8
Surgery	30	60
No anti- cancer therapy	50	10
Cancer diagnosis of the patients reported by the caregivers		

Acute lymphatic leukaemia	9	18
Breast cancer	9	18
Prostate cancer	3	6
Chronic lymphatic leukaemia	4	8
Colon cancer	6	12
Oesophageal cancer	1	2
Liver cancer	2	4
Lung cancer	6	12
Multiple myeloma	2	4
Ovarian cancer	4	8
Pharyngeal cancer	2	4
Skin cancer	1	2
Stomach cancer	1	2
Medications reported by the caregivers		
Morphine, Oxycodone and Methadone	21	42
Paracetamol and NSAIDs	27	54
Not mentioned	2	4
ECOG Score of the patients as reported by the caregivers		
1	8	16
2	13	26
3	17	34
4	12	24
5	0	0

**** Some of patients received more than one type of cancer treatment therefore the percentages and frequencies are higher than 100%

5.4.2 Caregiver QoL

According to the Arabic CQOLC, the *lower the mean (m) scores are, the higher the QoL.* As illustrated in Table 5.3, there was an improvement in the QoL after the intervention according to the Wilcoxon matched-pairs signed-ranks test (p=0.0000). The pre-intervention mean score was (*m*=91.06; SD±5.33), compared to the post intervention mean score (*m*=75.47; SD±5.67).

Table 5.3: QoL of the caregivers pre (n=50) and post (n=38) intervention

QoL	Pre-intervention		Post-intervention		p-value
	m±SD	Range (0-140)	*m*±SD	Range (0-140)	
	91.06±5.33	80-105	75.47±5.67	62-85	0.0000*

* Significant change occurred p<0.05

When analysing the 35 individual QoL items, before the intervention, patient death had the highest mean score (*m*=3.50; SD±0.64), followed by management of patient's pain, (*m*=3.30; ±SD 0.73) and sadness (*m*=3.16; SD±0.54). Family communication had the lowest mean score (*m*=1.64; SD±0.57). After the intervention, guilt had the highest mean score (*m*=1.00; SD±0.77), followed by frustration (*m*=1.18; SD±0.45) and disruption of sleep (*m*=1.31; SD±0.66). Relationship with patient had the lowest mean score (*m*=3.84; SD±0.36). Of the 35 items, 26 (74%; n=26) showed an improvement change after the intervention (p<0.05). In contrast, nine items (26%; n=9) deceased in mean scores post intervention, which showed an improvement change (p<0.05). Table 5.4 describes the mean score of the individual items pre- and post-intervention.

Table 5.4: The mean of QoL items of the caregivers pre (n=50) and post (n=38) intervention

Caregivers CQOLC Items	Pre-intervention		Post-intervention		p-value
	m±SD	Range (0-4)	*m*±SD	Range (0-4)	
Alteration in daily routine	2.74±0.44	2-3	1.84±0.36	1-2	0.0000*
Disruption of sleep	2.50±0.54	1-3	1.31±0.66	0-2	0.0000*
Impact on daily schedule	2.76±0.55	2-4	1.55±0.64	0-3	0.0000*
Satisfaction with sexual function	2.88±0.93	1-4	1.65±0.81	0-3	0.0000*
Maintenance of outside activities	2.56±0.50	2-3	1.39±0.59	0-2	0.0000*
Financial strain	2.86±0.57	2-4	1.78±0.66	1-3	0.0000*
Concern about insurance	3.12±0.65	2-4	2.05±0.80	0-4	0.0000*
Economic future	3.02±0.68	2-4	1.89±0.68	0-3	0.0000*
Death of patient	3.50±0.64	2-4	1.97±0.85	1-4	0.0000*
Outlook on life	1.56±0.83	0-4	2.07±0.71	1-4	0.0001*
Level of stress	3.16±0.54	2-4	2.07±0.71	1-3	0.0000*

Spirituality	1.94±0.86	1-4	3.23±0.71	1-4	0.0000*
Day-to-day focus	2.74±0.44	2-3	1.63±0.75	0-3	0.0000*
Sadness	2.36±0.66	1-4	1.68±0.57	1-3	0.0000*
Mental strain	3.06±0.51	2-4	2.02±0.75	1-4	0.0000*
Social support	1.82±0.91	0-4	3.21±0.52	2-4	0.0000*
Guilt	2.20±0.69	1-3	1.00±0.77	0-2	0.0000*
Frustration	1.86±0.80	1-4	1.18±0.45	0-2	0.0000*
Nervousness	2.42±0.64	1-4	1.57±0.50	1-2	0.0000*
Impact of illness on family	2.86±0.72	1-4	1.44±0.60	0-3	0.0000*
Patient's eating habits	2.72±0.70	2-4	1.36±0.71	0-2	0.0000*
Relationship with patient	1.56±0.90	0-4	3.84±0.36	3-4	0.0000*
Informed about illness	2.2±0.83	0-4	3.52±0.60	2-4	0.0000*
Transportation	2.8±0.57	2-4	1.81±0.39	1-2	0.0000*
Adverse effect of treatment	2.76±0.71	2-4	1.65±0.74	0-3	0.0000*
Responsibility for patient's care	2.9±0.64	2-4	1.73±0.64	1-3	0.0000*
Focus of caregiving	1.54±0.64	0-4	3.71±0.51	2-4	0.0000*
Family communication	1.46±0.57	1-3	3.55±0.55	2-4	0.0000*
Change in priorities	2.72±0.70	1-4	1.55±0.82	0-4	0.0000*
Protection of patient	2.92±0.69	2-4	2.00±.95	0-4	0.0000*
Deterioration of patient	2.40±0.49	2-3	3.44±0.79	1-4	0.0000*
Management of patient's pain	3.30±0.73	2-4	2.18±0.80	1-4	0.0000*
Future outlook	2.80±0.83	2-4	1.65±0.70	1-4	0.0000*
Family support	1.66±0.55	1-3	3.34±0.53	2-4	0.0000*
Family interest in caregiving	2.82±0.43	2-4	1.34±0.66	0-3	0.0000*

* Significant changes occurred $p<0.05$

The QoL varied according to the different age groups. Caregivers within the age group of 40-49 years had the highest QoL pre-intervention (*m*=86.66), and the same age group had the highest mean score post-intervention (*m*=70.66), indicating an improvement change (p=0.0051). However, the biggest change occurred in the 60-69 age group pre intervention (*m*=92.18) and post intervention (*m*= 74.84); but this was not a significant change (p=0.1797) (Table 5.5).

Table 5.5: The mean of caregiver's QoL scores by age category, pre- (n=50) and post-intervention (n=38).

Caregivers QoL by age category	Pre-intervention	Post-intervention	P value
	m	***m***	
18-29	94.00	85.00	0.0014*
30-39	88.33	72.50	0.0341*
40-49	86.66	70.66	0.0051*
50-59	91.13	76.72	0.0180*
60-69	92.18	74.84	0.1797
70 and more	90.72	76.12	0.3173

* Significant changes occurred p<0.05

When comparing the caregiver's relationship to the patients and their QoL, it was found that friend (*m*=87.00) and Parent (*m*=89.50) had the highest QoL pre and post intervention. The QoL of all categories of caregivers improved from pre to post intervention; all except for friends indicating an improvement change (p<0.3173) (Table 5.6).

Table 5.6: The mean of caregiver's QoL scores by relationship, pre (n=50) and post intervention (n=38).

Caregivers QoL by relationship	Pre-intervention	Pre-intervention	P value
	m	***m***	
Child	91.29	75.00	0.0002*
Friend	87.00	69.00	0.3173
Parent	89.50	73.00	0.0431*
Sibling	91.14	77.00	0.0178*
Spouse	91.66	77.85	0.0180*

* Significant changes occurred p<0.05

5.4.3 Caregiver burden

The caregiver burden varied according to the different age group. In addition, the caregiver burden of all age groups increased except for those 50-59 and 60-69 age groups. Caregivers within the age group of 18-29 years had the highest care burden

(*m*=31.00) pre-intervention which was improved (p=0.0026) post-intervention (*m*=32.00). The biggest change occurred in the 60-69 caregivers age group pre-intervention (*m*=27.25) and post-intervention (*m*=26.30), which was not significant change (p=0.6547), (See Table 5.7).

Table 5.7: The mean of caregiver's care burden scores by age category, pre-(n=50) and post-intervention (n=38).

Caregivers care burden with age category	Pre-intervention	Post-intervention	P value
	m	***m***	
18-29	31.00	32.00	0.0026*
30-39	21.66	25.00	0.1797
40-49	21.00	23.33	0.0493*
50-59	25.00	24.72	0.2459
60-69	27.25	26.30	0.6547
70 and more	26.45	27.12	0.3173

* Significant changes occurred p<0.05

When comparing the caregiver's relationship to the patient and the care burden, it was found that friends had the highest care burden (*m*=29.00), followed by spouses (*m*=27.08) pre-intervention, while friends (*m*=28.00) and children (*m*=26.55) had the highest care burden mean scores post-intervention. However, only the category children showed an improvement change (p<0.0010), (See Table 5.8).

Table 5.8: Caregiver's care burden scores by relationship, pre (n=50) and post intervention (n=38).

Caregivers care burden with cancer patients relation	Pre-intervention	Post-intervention	P value
	m	***m***	
Child	25.62	26.55	0.0010*
Friend	29.00	28.00	0.3173
Parent	25.16	26.00	0.0556
Sibling	24.57	25.57	0.1405
Spouse	27.08	23.57	0.07984

* Significant changes occurred p<0.05

When calculating the caregiver burden, there was an improvement in care burden post intervention (Table 5.9).

Table 5.9: Care burden pre- (n=50) and post- (n=38) intervention

Care burden level	Pre-intervention		Post-intervention		p-value
	***m*±SD**	**Range(0-48)**	***m*±SD**	**Range(0-48)**	
	25.84±6.34	14-40	25.78±4.45	18-37	0.0003*

* Significant change occurred p<0.05

In terms of the 12 (ZBI) items individually, all items decreased post-intervention except for four items that did not have really differences (p>0.05), (See Table 5.10).

Table 5.10: The mean care burden items pre- (n=50) and post- (n=38) intervention

Caregivers ZBI Items	Pre-intervention		Post-intervention		P value
	***m*±SD**	**Range (0-4)**	***m*±SD**	**Range (0-4)**	
Do not have enough self-time	2.06±1.01	1-4	2.15±0.88	0-4	0.2188
Stressed between caring and other duties	2.10±1.16	1-4	2.10 ±1.06	0-4	0.2188
Angry when you are around your relative	2.86±1.06	1-4	2.89± 0.98	1-4	0.6250
Relationship with family was affected	1.92±1.20	1-4	1.89 ±0.89	0-3	0.0625
Strained when you are around your relative	2.02±0.93	1-4	2.00 ±0.80	0-3	0.5625
Caring for your relative affects your health	1.28±1.12	1-3	1.39 ±0.91	0-3	0.2891
Do not have privacy	2.26±1.08	1-4	2.10±0.95	0-4	0.0625
Caring of your relative affects your social life	1.96±0.96	1-4	1.94±0.89	0-3	0.3594
Lost control of your life	2.10±0.83	1-4	2.15±0.67	1-4	0.0625
Uncertain about what do about your relative	2.14±0.80	1-4	2.07±0.63	1-3	1.0000
You should be doing more for your relative	2.54±0.95	0-4	2.50±0.86	1-4	0.4375
Could do a better job in caring of relative	2.60±1.03	0-4	2.55±1.00	1-4	0.3750

5.4.4 Level of caregiver's care burden

Pre-intervention, a larger proportion of the participants (80%) reported having high caregiver burden, while 20% reported having a mild to moderate burden. Post-

intervention, most of the participants (92%) reported having a high caregiver burden, whilst 8% reported mild to moderate burden, (See Table 5.11).

Table 5.11: Care burden pre- (n=50) and post-intervention (n=38)

Care burden level	Pre-intervention		Post-intervention	
	Freq.	%	Freq.	%
No to mild burden				
Mild to moderate burden	10	20%	3	8%
High burden	40	80%	35	92%

5.4.5 General characteristics of the patients

The ages of the patient participants ranged between 20 and 86 years, with a mean of 60.22 (SD±13.82). Most (n=30; 60%) were male. All the participants (n=50; 100%) had received chemotherapy, 60% (n=30) had surgical interventions, and 8% (n=4) had received radiotherapy. Table 5.2 presents the general characteristics.

5.4.6 Cancer patients' QoL

When investigating the individual items measured, feeling nauseated was the most pressing problem (*m*=3.32), followed by pain (*m*=3.24), constipation (*m*=3.06) and walking outside (*m*=3.00). Only seven of the 14 items showed an improvement after the intervention ($p<0.05$), (See Table 5.12).

Table 5.12: Cancer patients QoL pre- (n=50) and post- (n=38) intervention.

Cancer patients EORTC items	Pre-intervention		Post-intervention		p-value
	***m*±SD**	**Range (0-4)**	***m*±SD**	**Range (0-4)**	
Walk outside	3.00±0.80	2-4	2.28±0.69	1-4	0.0000*
Stay in bed during day	2.36±0.85	1-4	1.84±0.76	1-3	0.0000*
Eating, dressing, or washing	2.42±1.03	1-4	2.23±0.99	1-4	0.1191
Dyspnea	2.68±1.01	1-4	2.36±0.71	1-4	0.0201*
Pain	3.24±0.74	1-4	2.36±0.75	1-4	0.0000*

Insomnia	3.24±0.68	2-4	3.07±0.78	1-4	0.6938
Weak	2.78±0.76	2-4	2.52±0.92	1-4	0.1108
Appetite loss	2.92±0.80	1-4	2.65±0.78	1-4	0.2534
Nausea	3.32±0.62	2-4	2.78±0.70	1-4	0.0018*
Constipated	3.06±0.76	1-4	2.68±0.84	1-4	0.0144
Tired	2.92±0.96	1-4	3.23±0.67	1-4	0.0217
Pain interferes with daily activities	2.86±0.94	1-4	2.44±0.82	1-4	0.0236*
Tense	2.94±0.81	1-4	2.60±0.88	2-4	0.0977
Depressed	3.36±0.74	2-4	3.73±0.50	1-4	0.0156*

* Significant changes occurred p<0.05

The global QoL and the functional scale, pain symptoms subscale, fatigue symptoms subscale and five items symptom subscales were measured. A poor global QoL was reported with a mean score (*m*=3.00; SD±1.03), however it showed improvement (*m*=4.02; SD±0.88) after the intervention (p=0.0000). The same trend was seen in the physical subscale but not the emotional subscale, which scored the lowest before the intervention and stayed the lowest after the intervention and with no actual change (p=0.6632).

The highest mean score for the EORTC QLQ-C15-PAL symptom items pre-intervention was for pain (*m*=68.33; SD±21.88), followed by fatigue (*m*=61.66; SD±20.27) and the five items symptom scales (*m*=18.13; SD±13.28); the mean of the pain symptoms subscale improved after the intervention (p=0.0000), (See Table 5.13).

Table 5.13: Cancer patients Global Health status/QoL and EORTC subscales pre- (n=50) and post- (n=38) intervention.

EORTC Global health status QoL and scales	**Pre intervention**		**Post intervention**		**p-value**
	***m*±SD**	**Range (0-100)**	***m*±SD**	**Range (0-100)**	
Global health status/QoL	3.00±1.03	10-50	4.02±0.88	20-60	0.0000*
Functional scale					
Physical Functioning	46.88±19.60	0-77	62.57±14.70	44-100	0.0000*
Emotional Functioning	28.33±18.21	0-66	27.63±15.63	0-66	0.6632
Symptoms scale					

Pain symptoms	68.33±21.88	0-100	46.92±21.17	0-83	0.0000*
Fatigue symptoms	61.66±20.27	17-100	62.71±17.93	33-100	0.9982
Five items symptom					
Dyspnea	2.68±1.01	1-4	2.36±0.71	1-4	0.0201*
Insomnia	3.24±0.68	2-4	3.07±0.78	1-4	0.6938
Appetite loss	2.92±0.80	1-4	2.65±0.78	1-4	0.2534
Nausea	3.32±0.62	2-4	2.78±0.70	1-4	0.0018*
Constipation	3.06±0.76	1-4	2.68±0.84	1-4	0.0144*

* Significant changes occurred $p<0.05$

5.4.7 Cancer patients' pain severity and interference

As already mentioned in Chapter Three, the BPI was used to assess the patients' pain. On asking the patients before the intervention whether they have pain everyday other than headaches, sprains and toothaches, all (n=50; 100%) responded positively. The same trend followed as all the patients experienced pain after the intervention (n=50; 100%). When asking the patients to indicate the location of their pain, the majority (62%; n=31) indicated their chest area, followed by the abdominal region (n=23; 46%). After the intervention, the same areas were commonly indicated, but to a lesser extent. Table 5.14 summarises the results.

Table 5.14: Pain location that was shaded by cancer patients using the BPI diagram

Pain location	**Pre intervention**		**Post intervention**	
	n**	**%****	***n*****	**%****
Whole body	1	2	1	3
Abdominal regions	23	46	17	45
Buttocks	6	12	5	13
Chest	31	62	29	76
Neck	9	18	8	21
Legs	3	6	3	8
Pelvis	10	20	9	24
Back	6	12	5	13
Arms	3	6	3	8

Head	8	16	8	21

** Some of patients had more than one body pain location, therefore the frequencies and percentages were higher than 100%

The pain severity compromised four questions - worst pain, least pain, average pain and pain right now. Pain at its worst was more than 7 pre-intervention therefore severe, but decreased to less than 7, thus moderate, after the intervention; this change was significant (p=0.0254). Similarly, improvements were found in the average pain, least pain and pain right now (p< 0.05), however, the pain remained moderate. Table 5.15 provides the details.

Table 5.15: Cancer patients' worst pain, least pain, average pain and right now pain pre- (n=50) and post- (n=38) intervention.

Pain severity	Pre-intervention		Post-intervention		p-value
	***m*±SD**	**Range (0-10)**	***m*±SD**	**Range (0-10)**	
Worst pain	7.22±1.23	5-10	6.86±1.06	5-9	0.0254*
Least pain	5.52±1.79	2-9	5.15±1.48	2-8	0.0313*
Average pain	6.88±1.30	5-10	5.94±1.01	5-9	0.0000*
Right now pain	6.42±1.29	4-9	5.71±1.01	3-7	0.0000*

* Significant changes occurred p<0.05

The pain severity was measured by the sum of the means of worst pain, least pain, average pain and pain right now. When comparing the pre- and post- intervention overall pain levels, an improvements of pain severity was found post intervention (p=0.000), (See Table 5.16).

Table 5.16: The cancer pain severity pre- (n=50) and post- (n=38) intervention.

Pain severity	Pre intervention		Post intervention		p-value
	***m*±SD**	**Range (0-100)**	***m*±SD**	**Range (0-100)**	
	26.04±4.34	17-33	23.68±3.47	16-30	0.0000*

* Significant change occurred p<0.05

When grouping the pain levels experienced into mild, moderate and severe pain, 26% (n=13) of the patients stated they experienced moderate pain pre-intervention and 32% (n=12) reported they had moderate pain post-intervention. However, most patients

(74%; n=37) reported having severe pain pre-intervention and 68% (n=26) had severe pain post-intervention, (See Table 5.17).

Table 5.17: Pain level pre- (n=50) and post- (n=38) intervention.

Pain level	Pain level	Pre-intervention		Post-intervention	
		n	**%**	***n***	**%**
Worst pain	No pain				
	Mild pain				
	Moderate pain	13	26	12	32
	Severe pain	37	74	26	68
Least pain	No pain				
	Mild pain	6	12	5	13
	Moderate pain	28	56	25	66
	Severe pain	16	32	8	21
Average pain	No pain				
	Mild pain				
	Moderate pain	21	42	27	71
	Severe pain	29	56	11	29
Pain right now	No pain				
	Mild pain			1	3
	Moderate pain	24	48	28	74
	Severe pain	26	52	9	24

When asking the patients to what extent their pain treatment provided pain relief during the past 24 hours using a numerical scale, a mean of less than 1 (*m*=< 1) was found both before and after the intervention, however, improved of pain relief was occur post intervention (p=0.0099), (See Table 5.18).

Table 5.18: Pain relief after using pain medication pre- (n=50) and post- (n=38) intervention.

Pain relief	Pre-intervention		Post-intervention		p-value
	***m*±SD**	**Range (1-10)**	***m*±SD**	**Range (1-10)**	
	0.48±0.131	2-8	0.52±0.131	2-8	0.0099*

* Significant change occurred p<0.05

When asking the patients which pain medication they took for pain, the greatest percentage (54%; n=27) used paracetamol and NSAIDs. The percentage increased

post-intervention to 78.9% (n=30). Interestingly, the use of strong opioids decreased from pre-intervention (42%; n=21) to post-intervention (19%; n=7), (See Table 5.19).

Table 5.19: Pain medication used for cancer pain pre- (n=50) and post- (n=38) intervention.

Pain medication used	Pre-intervention		Post-intervention	
	n	**%**	***n***	**%**
Morphine, Methadone, and Oxycodone	21	42	7	19
Paracetamol and NSAIDs	27	54	30	79
Not mentioned	2	4	1	2

When investigating how the pain interfered with the patient's general activity, mood, walking ability, normal work, relations with other people, sleep and enjoyment of life during the last 24 hours, the mean score for normal work scored the highest before the intervention (*m*=6.36; SD±1.41) and walking ability the highest after the intervention. In addition, pain interfered least with sleep before the intervention (m=5.18; SD±1.27) and with the relation with other people after the intervention (m=5.23; SD±1.36). There was an improvmrnts change was found in general activity, walking ability, normal work and sleep, (See Table 5.20).

Table 5.20: Pain interference with daily living activities pre- (n=50) and post-intervention (n=38).

Interference of pain during the last 24 hours	Pre-intervention		Post-intervention		p-value
	***m*±SD**	**Range (0-10)**	***m*±SD**	**Range (0-10)**	
General activity	6.14±1.59	2-9	5.65±1.30	2-8	0.0469*
Mood	5.78±1.59	2-9	5.36±1.45	2-8	0.0557
Walking ability	6.30±1.48	4-9	5.86±1.45	4-10	0.0001*
Normal work	6.36±1.41	3-9	5.70±1.27	3-9	0.0025*
Relation with people	5.66±1.52	3-10	5.23±1.36	3-9	0.1094
Sleep	5.18±1.27	3-8	4.78±1.14	3-8	0.0098*
Enjoyment of life	5.74±1.35	3-8	5.57±1.40	3-9	0.2668

* Significant changes occurred p<0.05

The mean of pain interference was calculated using the sum of the related items indicted above. Before the intervention, the mean of pain interference was (m=41.16; SD±7.12) compared with post-intervention (m=38.21; SD±6.10), which is an improvement's change (p=0.0000). Table 5.21 provides the details.

Table 5.21: Pain interference pre- (n=50) and post-intervention (n=38).

Pain interference	Pre-intervention		Post-intervention		p-value
	***m*±SD**	**Range(0-100)**	***m*±SD**	**Range(0-100)**	
	41.16±7.12	26-59	38.21±6.10	23-49	0.0000*

* Significant changes occurred p<0.05

5.4.8 Patient's symptoms burden

When calculating the total symptoms burden, an improvement was found from pre- to post-intervention (p=0.0000). In addition, a small change was observed in the global distress index before and after the intervention, this change was statistically significant (p=0.0119). The same trend was seen in the psychological symptoms subscale, however, the small difference in the mean score before and after the intervention of the physical symptoms subscale was not a really change (p>0.05), (See Table 5.22).

Table 5.22: MSAS global distress index, Physical and psychological symptoms subscales pre- (n=50) and post-intervention (n=38).

MSAS total symptoms burden global distress index and subscales	Pre-intervention		Post-intervention		p-value
	***m*±SD**	**Range (0-100)**	***m*±SD**	**Range (0-100)**	
Total symptoms burden	50.0±2.71	19-31	38.0±2.56	20-28	0.0000*
Global distress index	2.86±0.46	19-38	2.80±0.21	21-33	0.0119*
Physical symptoms subscale	2.75±0.47	18-32	2.56±0.34	18-32	0.1565
Psychological symptoms subscale	3.02±0.47	18-38	3.01±0.32	25-38	0.0000*

* Significant changes occurred p<0.05

When analysing the 24 individual symptoms measured, in terms of often, severe and bothering/distress symptoms occurring during the past week, the following was found:

pre-intervention, the lack of appetite had the highest mean score (*m*=5.52; SD±0.70) in the “often” group, followed by feeling sad (*m*=3.42; SD±0.60) and worrying (*m*=3.38; SD±0.56); sweats had the lowest mean score (*m*=1.72; SD±0.64). After the intervention, worrying had the highest mean score (*m*=3.68; SD±0.47), followed by feeling nervous (*m*=3.47; SD±0.68) and vomiting (*m*=3.18; SD±0.69), sweats had the lowest mean score (m=1.42; SD±0.64). Of the 24 symptoms mean scores, six were increased post-intervention, of which four showed an improvement change ($p<0.05$). However, the mean scored of 18 symptoms deceased post-intervention, 14 of which showed an improvement ($p<0.05$). According to the symptoms in the “severe” group, feeling sad had the highest mean score pre-intervention (m=3.34; SD±0.71), followed by difficulty sleeping (m=3.26; SD±0.69) and feeling nervous (m=3.24; SD±0.68); itching had the lowest mean score (m=1.56; SD±0.64). Of the 24 symptoms mean scores, eight were increased post-intervention, and seven of these symptoms showed an improvement change ($p<0.05$). However, 16 symptoms had a decreased in mean score post-intervention, with 15 symptoms showing showed an improvement change also ($p<0.05$).

When looking at the distress or bother symptoms group, feeling sad had the highest mean score (m=3.48 SD±0.57) pre-intervention, followed by worrying (m=3.44 SD±0.78) and difficulty sleeping (3.36±0.77); itching had the lowest mean score (m=1.44; SD±0.67). Of the 24 symptoms mean scores, eight were increased post-intervention, with two symptoms showing an improvement change ($p<0.05$). The mean of 16 symptoms decreased post-intervention, and 10 symptoms showing an improvement change ($p<0.05$). Table 5.23 provides the details.

Table 5.23: Symptoms experienced in the first group symptoms, pre- (n=50) and post-intervention (n=38)

Symptoms experienced	How OFTEN did you have?				P-value	How SEVER was it usually?				P-value	How much did it DISTRESS OR BOTHER you				P-value
	Pre-intervention		Post-intervention			Pre-intervention		Post-intervention			Pre-intervention		Post-intervention		
	***m*±SD**	**Range (1-4)**	***m*±SD**	**Range (1-4)**		***m*±SD**	**Range (1-4)**	***m*±SD**	**Range (1-4)**		***m*±SD**	**Range (0-4)**	***m*±SD**	**Range (0-4)**	
Difficulty concentrating	2.18±0.71	1-3	1.86±0.66	1-4	0.0005*	2.06±0.84	1-3	1.86±0.70	1-4	0.0039*	2.08±0.80	0-3	1.50±0.76	0-3	0.0001*
Pain	2.78±0.67	1-4	2.81±0.69	1-4	0.0000*	2.90±0.99	1-4	2.65±0.84	1-4	0.0001*	3.02±0.84	1-4	2.73±0.68	2-4	0.0018*
Lack of energy	2.54±0.86	1-4	1.86±0.81	1-4	0.0000*	2.56±0.90	1-4	2.89±0.89	1-4	0.0039*	2.48±1.01	0-4	2.84±0.78	1-4	0.0032*
Cough	2.56±0.99	1-4	2.47±1.00	1-4	0.0703	2.26±1.05	1-4	2.10±0.98	1-4	0.0002*	2.52±0.90	0-4	2.52±0.89	1-4	1.0000
Feeling nervous	3.20±0.63	2-4	3.47±0.68	3-4	0.0078*	3.24±0.68	2-4	3.57±0.50	3-4	0.0020*	3.12±0.79	1-4	3.31±0.66	2-4	0.0918
Dry mouth	2.64±1.00	1-4	2.31±0.90	1-4	0.0010*	2.46±0.97	1-4	2.21±0.74	1-4	0.0098*	2.54±0.90	1-4	2.21±0.70	1-4	0.0019*
Nausea	2.96±0.87	1-4	2.26±0.64	1-4	0.0000*	2.62±0.87	1-4	2.23±0.67	1-4	0.0001*	3.02±0.74	1-4	2.86±0.74	2-4	0.4049
Feeling drowsy	2.36±0.77	1-4	2.05±0.80	1-4	0.0001*	2.02±0.93	1-4	1.94±0.80	1-4	0.0078*	2.16±0.65	1-3	1.71±0.51	1-3	0.0000*
Numbness in hands/feet	2.02±0.71	1-3	1.94±0.61	1-3	0.0625	1.68±0.84	1-3	1.81±0.80	1-3	1.0000	2.12±0.52	0-4	1.71±0.51	1-3	0.0009*
Difficulty sleeping	3.12±0.79	2-4	3.00±0.77	2-4	0.0078*	3.26±0.69	2-4	2.65±0.84	2-4	0.0000*	3.36±0.77	1-4	3.02±0.75	1-4	0.0063*
Feeling bloated	2.68±1.00	1-4	2.65±0.99	1-4	0.1250	2.44±0.83	1-4	2.76±0.75	1-4	0.0039*	2.50±0.81	1-4	2.73±1.00	1-4	0.3914
Problems with urination	1.72±1.00	1-4	1.55±0.79	1-4	0.0039*	1.64±1.13	1-3	1.65±0.96	1-4	1.0000	2.08±0.94	0-4	1.89±1.00	0-4	0.0625
Vomiting	2.96±0.92	1-4	3.18±0.69	1-4	0.1094	2.90±0.93	2-4	2.78±0.81	1-4	0.0039*	3.22±0.88	1-4	2.89±0.72	1-4	0.0001*
Shortness of breath	2.40±1.00	1-4	2.39±0.87	1-3	0.0391*	2.12±1.08	1-4	1.86±0.87	1-3	0.0002*	2.32±0.99	0-4	2.31±1.01	0-4	0.2534
Diarrhoea	3.04±0.66	1-4	2.73±1.10	1-4	0.0005*	2.94±0.97	1-4	2.73±0.75	1-4	0.0010*	3.20±0.53	2-4	2.76±0.81	2-4	0.0000*
Feeling sad	3.42±0.60	2-4	3.02±0.78	3-4	0.0002*	3.34±0.71	2-4	3.65±0.48	3-4	0.0195*	3.48±0.57	2-4	3.68±0.47	3-4	0.1250
Sweats	1.72±0.64	1-3	1.42±0.64	1-2	0.0020*	1.76±0.55	1-3	1.44±0.50	1-2	0.0215*	1.76±0.62	1-3	1.42±0.50	1-2	0.0010*
Worrying	3.38±0.56	2-4	3.68±0.47	2-4	0.0078*	3.18±0.82	3-4	3.65±0.53	2-4	0.0001*	3.44±0.78	1-4	3.73±0.60	1-4	0.0039*
Sexual problems	2.94±0.71	1-4	2.71±0.89	2-4	0.2198	2.78±0.95	1-4	3.05±0.65	2-4	0.0005*	2.64±0.82	0-4	2.52±0.82	0-4	1.0000
Itching	1.96±0.75	1-4	2.00±0.56	1-2	1.0000	1.56±0.64	1-3	1.18±0.45	1-2	0.0054*	1.44±0.67	0-3	1.50±0.64	0-3	1.0000
Lack of appetite	5.52±0.70	1-4	2.42±0.59	1-4	0.0156*	2.62±0.69	1-3	2.44±0.82	1-4	0.0283*	2.16±0.86	1-4	2.31±0.84	1-4	0.7656
Dizziness	2.04±0.72	1-4	1.92±0.42	1-3	0.0625	2.08±0.66	1-3	1.81±0.56	1-3	0.0020*	2.18±0.62	0-3	1.97±0.67	1-3	0.0195*
Difficulty swallowing	2.10±1.00	1-4	1.97±0.85	1-3	0.0117*	1.94±0.71	1-4	1.60±0.59	1-3	0.0005*	2.10±0.70	1-4	2.05±0.69	1-4	0.0625
Feeling irritable	2.80±0.72	1-4	3.05±0.61	2-4	0.0215*	2.74±0.72	1-4	3.07±0.63	2-4	0.0313*	2.74±1.12	1-4	3.00±0.92	1-4	0.1875

* Significant changes occurred p<0.05

The MSAS also measured eight additional symptoms in terms of severity and distress occurring during the past week. According to the symptoms in the “severe” group, weight loss had the highest mean score (*m*=3.28; SD±0.70) pre-intervention, followed by constipation (*m*=3.04; SD±0.80) and change in the way food tastes (3.02±0.79); swelling of arms and legs had the lowest mean score (m=2.29; SD±0.64). Of the eight symptoms the mean scores of four were increased post-intervention, with three showing an improvement change ($p<0.05$). Four symptoms had a decreased mean score post-intervention with three having had an improvement change ($p<0.05$). When looking at distress or bother, constipation had the highest mean score (m=3.59; SD±0.50) pre-intervention, followed by hair loss (m=3.58, SD±0.49) and change in the way food tastes (m=3.46; SD±0.57); “I don’t look like myself” had the lowest mean score (m=2.52; SD±0.57). The mean of all eight symptoms decreased post intervention ($p<0.05$), (See Table 5.24).

Table 5.24: Symptoms experienced in the second different group, pre- (n=50) and post-intervention (n=38)

Symptoms experience	**How SEVERE was it usually?**				**P-value**	**How much did it DISTRESS OR BOTHER you**				**P-value**
	Pre-intervention		**Post-intervention**			**Pre-intervention**		**Post-intervention**		
	***m*±SD**	**Range (1-4)**	***m*±SD**	**Range (1-4)**		***m*±SD**	**Range (0-4)**	***m*±SD**	**Range (0-4)**	
Mouth sores	2.92±0.77	2-4	2.68±0.57	2-4	0.0020*	3.06±0.68	2-4	2.81±0.69	2-4	0.0215*
Change in taste	3.02±0.79	2-4	3.28±0.51	2-4	0.0391*	3.46±0.57	2-4	3.18±0.39	3-4	0.0034*
Weight loss	3.28±0.70	2-4	3.71±0.65	2-4	0.0001*	2.76±0.68	2-4	2.34±0.48	2-3	0.0023*
Hair loss	2.94±0.79	2-4	3.18±0.83	2-4	0.0078*	3.58±0.49	3-4	3.18±0.45	2-4	0.0002*
Constipation	3.04±0.80	2-4	2.42±0.72	2-4	0.0001*	3.59±0.50	3-4	2.97±0.54	2-4	0.0000*
Swelling of arms or legs	2.29±0.78	1-4	2.23±0.58	1-4	1.0000	3.24±0.71	2-4	2.52±0.76	2-4	0.0001*
"I don't look like myself"	2.48±0.81	1-4	2.13±0.47	1-3	0.0057*	2.52±0.57	1-4	2.18±0.39	2-3	0.0010*
Skin Changes	2.74±0.75	1-4	2.78±0.57	1-4	0.7539	2.94±0.54	2-4	2.39±0.59	2-4	0.0000*

* Significant changes occurred $p<0.05$

5.4.9 The correlation between the study outcomes

The Spearman correlation (r) tested the correlation between the outcomes studied. Outcome correlations ranged from “perfect” correlations to “none,” as mentioned in Chapter Three (Chan, 2003; Akoglu, 2018). All the “very strong” correlations among the outcomes were significant, such as the correlation between the care burden and cancer pain severity pre- and post-intervention. The same trend occurred for moderate correlations, however, the poor correlations were non-significant and varied between negative and positive, such as the negative correlation between cancer QoL post-intervention and cancer pain interference post-intervention, and the correlation between QoL pre- and post-intervention. The fair correlations varied between significant and non-significant, the significant correlation was between the QoL pre-intervention and care burden post-intervention, and non-significant between the cancer pain severity pre-intervention and cancer global distress index post-intervention. Only two fair correlations were found to be negative, (See Table 5.25).

Table 5.25: Correlation between outcomes measured

Correlations between outcome's	Caregivers QoL pre intervention	Caregivers QoL post intervention	Caregivers care burden pre intervention	Caregivers' care burden post-intervention	Cancer patients Global health status pre intervention	Cancer patients Global health status post intervention	Cancer patients QoL pre intervention	Cancer patients QoL post intervention	Cancer patients pain severity pre intervention	Cancer patients pain severity post intervention	Cancer patients Global distress index pre intervention	Cancer patients Global distress index post intervention	Cancer patients physical symptom's pre intervention	Cancer patients physical symptom's post intervention	Cancer patients psychological symptom's pre intervention	Cancer patients psychological symptom's post intervention	Cancer patients pain interference pre intervention	Cancer patients pain interference post intervention
Caregivers' QoL pre-intervention.	1																	
Caregivers' QoL post-intervention.	0.09	1																
Caregivers' care burden pre-intervention.	0.47*****	-0.04	1															
Caregivers' care burden post- intervention.	0.39*****	-0.03	0.89*	1														
Cancer patients' Global health status pre-intervention.	0.13	0.43*	0.23	0.15	1													
Cancer patients' Global health status post-intervention.	0.15	0.30	0.13	0.07	0.54*****	1												
Cancer patients' QoL pre-intervention.	-0.02	0.03	0.13	0.24	-0.16	-0.15	1											
Cancer patients' QoL post-intervention.	-0.27	0.05	-0.19	-0.03	-0.25	0.03	0.57*****	1										
Cancer patients' pain severity pre-intervention.	-0.07	0.03	-0.01	-0.29	0.09	0.01	-0.06	-0.10	1									
Cancer patients' pain severity post-intervention.	-0.06	-0.01	-0.01	-0.01	0.02	0.02	-0.02	0.02	0.92*	1								
Cancer patients' Global distress index pre-intervention.	0.06	0.06	0.10	0.04	-0.04	-0.05	0.07	0.21	0.14	0.20	1							

Cancer patients' Global distress index post-intervention.	-0.06	0.35*	-0.08	-0.13	0.10	0.01	-0.11	0.17	0.28	0.35*	0.78*	1						
Cancer patients' physical symptom's pre-intervention.	0.11	0.17	0.17	0.09	0.10	0.14	0.01	0.19	0.08	0.13	0.90*	0.68*	1					
Cancer patients' physical symptom's post-intervention.	-0.10	0.38*	-0.03	-0.14	0.20	0.08	-0.15	0.05	0.15	0.17	0.67*	0.77*	0.75*	1				
Cancer patients' psychological symptom's pre-intervention.	-0.13	0.05	-0.10	-0.07	-0.11	-0.10	0.11	0.26	0.15	0.25	0.70*	0.69*	0.53*	0.43*	1			
Cancer patients' psychological symptom's post-intervention.	-0.08	0.01	0.01	-0.02	-0.17	-0.14	0.12	0.26	0.05	0.15	0.86*	0.74*	0.70*	0.53*	0.87*	1		
Cancer patients' pain interference pre-intervention.	-0.17	-0.09	-0.06	-0.87	0.02	0.12	-0.01	-0.13	0.71*	0.66*	0.28	0.30	0.16	0.24	0.27	0.26	1	
Cancer patients' pain interference post-intervention.	-0.13	-0.11	-0.01	-0.02	-0.01	0.10	-0.05	-0.14	0.67*	0.67*	0.22	0.27	0.085	0.210	0.26	0.25	0.93*	1

***** Indicated for significant correlations occurred between the outcomes $p<0.05$

5.5 SUMMARY OF CHAPTER FIVE

This chapter described the results of the validation of the support programme and the results of the pilot test in terms of caregiver QoL and care burden and cancer patient QoL, pain experience and symptoms burden. The next chapter will discusses the findings of the study according to the Phases.

CHAPTER SIX
DISCUSSION

6.1 INTRODUCTION

This chapter discusses the findings of the study according to the phases.

- **Phase one:** there were seven caregivers' support needs identified from the included studies namely; information needs, physical, psychosocial/spiritual, emotional, and social needs. In addition, caregivers' financial support needs.

- **Phase two:** there were different programmes structures, learning activities, useful handouts, potential guiding questions for discussion were revealed from the studied programmes.

- **Phase three:** the conclusions and determining the overarching goals and objectives of the programme and a preliminary structure found in the studies of Phase 1 and 2 were used developed/adapted. The programme was validated in terms of the face and content validity by using expert group responses; related to the terminology used, the timing of the programme implementation, encouraging to visit sociologists and mental health clinics as well as the non-describing sexual issues.

- **Phase four**: The results of the pilot test of the programme were:

- An improvement of caregiver QoL and care burden post-intervention.
- An improvement of cancer patient QoL, pain experience, and symptoms burden post-intervention.

6.2 PHASE 1: FIRST SCOPING REVIEW:

The first scoping review was conducted to synthesise the evidence regarding the caregivers of cancer patients support needs.

The findings of the first scoping review provided evidence that 19 papers, focusing on caregivers of cancer patients support needs, were published over 10 years in the USA, Australia, Iceland, Turkey, UK, New Zealand, Taiwan, India, China and Jordan. Most of studies were conducted in developed countries with few in developing countries, as it may be possible they do not have advance research capability and therefore the absence of manpower or permitting environment to apply indigenous health research (Dye, Reeder and Terry, 2013; Obiora, Maree and Nkosi-Mafutha, 2020). The content analysis and synthesis of the results, the first scoping review highlighted seven themes the caregivers' support need namelly; information needs, physical, psychosocial/spiritual, emotional, and social needs. In addition, caregivers financial support needs.

The majority of the included studies were not of the highest quality because they did not have clear research questions. Conversely, in the same manner as the guidance of Hong *et al.*, (2018), only one (n=1; 5%) qualitative descriptive study by Al-Jauissy (2010) had clear research questions allowing a quality assessment. The researcher did not exclude any study according to it is own quality.

Various research designs were used. Most of studies (n=10; 53%) were a quantitative research design, including descriptive studies, cross-sectional studies, survey studies, longitudinal studies, randomised control trials and preliminary steeped wedge clustral comparative studies (Friðriksdóttir *et al.*, 2011; Deshields *et al.*, 2012; Butow *et al,* 2014; Chen *et al.*, 2014; Cui *et al.*, 2014; Aoun *et al.*, 2015; Borneman *et al.*, 2015; Heckel *et al.*, 2015; Hazen, Lazar & Gennari, 2016; Gültaş & Yilmaz, 2017), while nine (n=9; 47%) were qualitative research design (Al-Jauissy,

2010; Dougherty, 2010; Evertsen and Wolkenstein, 2010; Khan Joad, Chaturvedi and Mayamol, 2011; Harding *et al.*, 2012; Shaw, Harrison, *et al.*, 2013; Lee *et al.*, 2014; Richardson, Morton and Broadbent, 2015; Haynes-Maslow, Allicock and Johnson, 2016), which included descriptive study, focus groups, cross sectional and longitudinal studies. This was not similar to the Australian scoping review conducted by Pelentsov, Laws and Esterman (2015), which included four studies that used quantitative design, and 18 that used qualitative research design. Similar to the other Australian integrative review conducted by Alananzeh *et al.*, (2016), four of the studies employed quantitative methodology, but two qualitative studies were conducted. The studies included in the first scoping review used mostly convenience sampling method to recruits the participants, and this was similar to the Alananzeh *et al.* (2016) review, as most studies in their study were based on convenience or consecutive sampling.

Similar to the findings of Petricone-Westwood and Lebel (2016) and Heckel and Heynsbergh (2019), the first scoping review demonstrated that the peer-reviewed scientific data on caregivers' care and support needs and what it means to be a caregiver for a cancer patient is limited. According to the researcher's knowledge, the first scoping review is the first that includes a wide range of caregivers support needs, apart from one review conducted in Sydney exploring the unmet needs of Arab people affected by cancer (Alananzeh *et al.*, 2016).

The first scoping review provides evidence that spouses or adult children were the primary caregivers of cancer patients (Robison *et al.*, 2009; Deshields *et al.*, 2012). The researcher particularly encountered difficulties in the classification of the caregivers needs cited within the literature across the seven domains. The caregivers experienced a large number of complex challenges and had various needs, such as information needs, physical, psychosocial/spiritual, emotional, and social needs. In addition, their financial wellbeing was under threat; they faced health-related problems and high burdens related to caregiving as supported by Al-

Jauissy, (2010); Altamimi, (2013); Shaw *et al.*, (2013); Yi and Kim, (2015); Alananzeh *et al.*, (2016), as well as the prevalence of unmet needs being high (Butow *et al.*, 2011; Shaw, Butow, *et al.*, 2013; Alananzeh *et al.*, 2016). Some needs were found to fit quite well and some did not, while others the author felt fit across more than one domain, and this was reported by Kerr *et al.* (2007) in a mixed-method study and by Pelentsov, Laws and Esterman (2015) in an Australian scoping review study where they encountered difficulties categorising the needs of caregivers of cancer patients.

In the first scoping review, the prevalence of unmet needs ranged from 5.0% to 79.9%, depending on the domain. These prevalence rates are higher than those found in the study of Kim *et al.* (2010) who, in study conducted in the USA, reported prevalence rates ranging from 18.9% to 67.9% in Western country. This discrepancy could relate to differences in participants and backgrounds, and the availability of supportive care, as there is a huge difference between developed and developing countries in cancer care resources viability.

The result of the first scoping review was supported by two articles reported in Arab cancer caregivers' needs (Al-Jauissy, 2010; Altamimi, 2013), and one of them was included in first scoping review (Al-Jauissy, 2010). These studies, conducted in Jordan, highlighted the cultural commitment to caregiving, which places high expectations for fulfilling the caregiving role. However, these studies found that caregivers had unmet needs relating to information, health services and patient care, psychological and spiritual issues, and experienced a financial burden. Al-Jauissy (2010) recognised 68 needs across six domains, individual and self-care, management duties, contribution with cancer care, work, interpersonal collaboration and interaction, and finance. The highest ranked needs were, being informed about symptoms (97.6%), the need for home nursing (95%), the need for information about their patients' health condition (94.7%), help with the patients' emotional needs (87.8%), and help with supplementary expenses (85.4%). The study of Al-Jauissy

(2010), highlighted the negative influence caring for cancer patients had on Jordanian caregivers; fatigue was the most common (78.0%), followed by sleep problems (64.6%), anxiety (60.7%), financial constraints (58.5%) and mood problems (43.9%).

Osse *et al.* (2006), in a study applied in the Netherlands, included psychological/spiritual and emotional needs in the top 20 caregiver needs they presented. In addition, many caregivers needed care support regarding cancer symptom management information and cancer service care (Stenberg, Ruland & Miaskowski, 2010).

The first scoping review indicated the absence of reviews that span the cancer trajectory, as this was supported by previous studies of Stenberg, Ruland and Miaskowski (2010), Deshields *et al.* (2012), Petricone-Westwood and Lebel, (2016) and Revenson *et al.*, (2016). They emphasised the lack of evidence and highlighted a need for further research on this important area. These results map out certain essential outcomes that prospective researchers must appraise longitudinally within the population of cancer.

As seen from the synthesis of the results, the first scoping review highlighted caregivers' QoL domains, physical, psychosocial/spirituality, social and financial wellbeing and emphasised their importance. It was interesting to note that the QoL of caregivers was good and stable during the first 12 months of diagnosis, after that it declined in steady manner because of the patient remaining sick as well as the disease progression; in the last year before death, the caregivers QoL appeared to be much poorer. This was supported by Petricone-Westwood and Lebel (2016), in their study conducted in Canada, as well as by the Australian study of Butow *et al.* (2014), which indicated that worsening in QoL wellbeing and the escalation in suffering and distress was visibly determined in the last year before death.

6.2.1 Informational support needs

The first scoping review provided evidence that information seeking was highest immediately following diagnosis. The need for information has consistently been described as an unmet need (Harrison *et al.*, 2009; Fiszer *et al.*, 2014). This could be because of the patient's illness being serious and expected to need additional physical care, which induced more worries and concerns for caregivers (Cui *et al.*, 2014). According to Alananzeh *et al.* (2016), the strong need for additional information about the disease, treatment and symptoms may be indicative of how information is presented in the care environment. This is a mismatch in content between patient and caregivers and the information they are provided, and the degree to which high-quality educational materials are available within Arab countries.

Caregivers usually used all sources available; healthcare providers frequently searched for the information from family and friends as well as from the Internet. Conversely, caregivers gain experience and learn by trial and error, and by informal channels, such as a neighbour or friend. This is similar to what was reported in Schubart, Kinzie and Farace's (2008) study conducted in USA, their need was for the physicians to inform them of what to expect earlier, before the crisis. They needed to be ready to manage the neurocognitive alterations that were likely to occur and to know how to address the health needs of the patient and the behaviour alterations, how to manage the hostile or life-threatening behaviour, and at what time they would need to look for specialised assistance.

As observed in the first scoping review, various studies identified caregivers had high unmet needs with regard to needs for information about the disease, prognosis, outcomes, symptom management, hospice care, treatment, caregiver role and support from healthcare professionals (Schubart, Kinzie and Farace, 2008; Kim *et al.*, 2010; Friðriksdóttir *et al.*, 2011; Deshields *et al.*, 2012; Chen *et al.*, 2014; Cui *et*

al., 2014; Yi and Kim, 2015; Heckel *et al.*, 2015; Hazen, Lazar and Gennari, 2016; Gültaş and Yilmaz, 2017; Ashrafian *et al.*, 2018). A study conducted by Hydary (2015), focusing on breast cancer, supports this finding as receiving information about breast cancer, self-care and patient care were the main needs of the caregivers. Similarly, Cui *et al.* (2014), when investigating 649 caregivers in Shanghai hospitals in China, found the most prominent unmet needs included the need for the disease-related knowledge and its treatment and support from healthcare providers. This strongly indicates that both caregivers and cancer patients depend heavily on oncology healthcare providers for informational and educational support. Thus, it is necessary for oncology healthcare providers to be prepared to communicate effectively with caregivers by providing appropriate information in an empathetic manner. Furthermore, interventions such as support programmes would be helpful, not only to meet the unmet needs of caregivers but also to improve their QoL (Northouse *et al.*, 2012; Yi and Kim, 2015).

Informational support is particularly significant when cancer patients are discharged from hospital to be treated at home, as instruction and the provision of needed information at the time of hospital discharge is inadequate most times. This was supported by Schubart, Kinzie and Farace (2008), as they reported that caregivers need to be ready for the exact responsibilities they will expected to carry out for their cancer patient. Many of the caregivers who offered nursing care duties had very little, if any, preparation to accomplish what was needed. Home appointments by healthcare providers who were qualified to support caregivers with the need of cancer care, would, once the patient was discharged and at other critical transition points, enhance the value of this data and endorse improved patient care.

6.2.2 Emotional and psychological/spiritual support needs

The care support needs for caregivers were one of the most needed among caregivers who reported in the first scoping review, and this was similar to the result

of the study conducted on 188 caregivers of patients with cancer, which showed that emotional and psychological/spiritual support are the most prominent areas of caregivers' unmet needs (Sklenarova *et al.*, 2015). This was supported by Kim *et al.* (2010) in their study on three groups of caregivers who were either 2 months, 2 years, or 5 years into their patient's cancer diagnosis; their main needs included psychological/spiritual, among others. The differences observed in the caregivers' need priorities were anticipated, and could be attributed to the differences in research setting and context, as well as methodology; in other words, people from different countries may have different needs.

As seen in the first scoping review, caregivers were challenged continually to resolve difficulties and provide decisions according to the change of care needs. They regularly performed new jobs that they were not qualified to do, leaving their own emotional and spiritual needs unnoticed and unaddressed. The same concerns were reported in the study of Goldzweig *et al.* (2013) conducted in Jerusalem, which described the levels of emotional and spiritual/psychological suffering were approximately double for caregivers of older cancer patients. In the study of Sklenarova *et al.* (2015), it was reported that the caregivers had a considerably higher irritable, tense, anxiety, lost, alone, scared, and depression score compared to their patients, which agreed with their recurrently stated needs, and gave emphasis to the terror and probable threat of losing the one they love faced by caregivers with a cancer diagnosis.

6.2.3 Physical support need

The evidence regarding physical needs of caregivers was confirmed in the first scoping review; the caregivers experienced physical needs included sleep problems and fatigue. The same result was described in the Australian study conducted by Butow *et al*. (2014), as they reported that mental as well as physical wellbeing of

caregivers was compromised due to giving cancer care, mainly in the last 6 months of the cancer patient's life.

6.2.4 Social support needs

The first scoping review recognised caregivers' social wellbeing as essential and appeared to play a part in their overall wellbeing, which was similar to that reported in Petricone-Westwood and Lebel's (2016) study conducted in Canada, and many other studies (Arden-Close *et al.*, 2010; Frost *et al.*, 2012; Butow *et al,* 2014), reported that the social need for caregivers was one of the main needs during cancer caregiving. As well as social support, feeling socially isolated was one of the main social needs, as stated by caregivers in the first scoping review, at the beginning of the last year of life; this was mentioned in the studies of Koldjeski *et al.* (2007), Frost *et al.* (2012) and Petricone-Westwood and Lebel (2016). They reported that social support, including social life activities, isolation and personal time, was different but deteriorated from diagnosis to 3 years later, and then was steady over the last year before death. The first scoping review provided evidence that caregivers' social networks influenced the caregiving quality, as other members in the family and their friends were important to be supported, and the same result was reported in Robison *et al.* (2009) who found that when the community and care system support is lacking for caregivers, it will lead to work loss, feeling isolated and depressed, which in turn will lead to institutionalisation and burn out of caregivers.

In addition to sociality, communication with patients, family members and friends was one of the most important needs of the caregivers. As the findings of the first scoping review suggested, caregivers relied heavily on support from family and friends, but indicated poor communication, as a significant percentage of the caregivers had unmet needs in this domain. This was supported by Butow *et al.* (2014), as they reported the important support care need was lack of ability to deal with the issue of cancer in social sites and communication during the end-of-life

period. The result was similar to Khan Joad, Chaturvedi and Mayamol (2011), who reported that 42% of caregivers' care experience had a negative influence on the interactions with other family members and friends, as well as experiencing an interruption in personal habits and schedules and constraints on their leisure time.

6.2.5 Financial support needs

Financial concerns were one of the main caregivers' needs revealed in the first scoping review, Caregivers are still faced with great financial burden due to expensive medications and diagnostic and medical services; this was also reported in the studies of Zierhut and Bartels, (2012) Anderson, Elliott and Zurynski (2013) and Pelentsov, Laws and Esterman, (2015), who described that the high cancer indirect costs imposed, as well as potential unemployment following the patient's process of treatment and care, created a huge financial burden.

Caregivers in other studies described financial matters as a major source of stress and distress. A similar result was reported in the study of Pelentsov, Laws and Esterman (2015), as they described that many caregivers reported financial hardship associated with their patient's disease and ongoing care requirements. Caregivers in the first scoping review expressed their financial needs and unstable work life, the cost of medical bills and medical insurance coverage, and the consequences of this on their psychological and mental wellbeing; the same concept was described in the studies of Ashrafian *et al.* (2018) and Hashemi, Irajpour and Taleghani (2018). According to their results, the caregivers have extensive unmet needs, including financial needs, and they confirmed the financial unmet needs of caregivers were high.

Absence of sufficient continuing care services as well as financial trouble were obviously the hardest and most dependable predictors of the range of health and psychosocial outcomes deliberated. Even though conclusions from other

researchers supported the necessity of adequate revenue for caregiver wellbeing, lack of desired care services provided from within the community has not been studied with caregivers until now (Robison *et al.*, 2009).

6.2.6 CONCLUSION

The majority of the caregivers of patients with cancer have many unmet needs. Healthcare providers should attend to the care needs of patients with cancer, as well as the unmet physical, psychological, and social needs of their caregivers and other family members, by designing and implementing dynamic and holistic care programmes. It is important to note that although patients with cancer and their caregivers are regarded as one care unit, the patients' needs require attendance independently of the caregivers' needs, and meeting the patients' needs and their satisfaction does not equate to meeting the caregivers' needs and their satisfaction.

Nevertheless, part of the needs of the patients and caregivers may be beyond the ability or scope of responsibility of healthcare providers. Accordingly, the role of multidisciplinary care teams and other systems providing support and cancer care services becomes more vital, and they can play an effective role in reducing the caregivers' burden of care and improving their QoL by adopting the right strategies and interventions (Yi and Kim, 2015; Ashrafian *et al.*, 2018). The healthcare providers should always remember that the first responders to the problems of patients with cancer are their caregivers, and their value in the process of patient care should be further recognised.

In included studies, the caregivers of cancer patients and their cancer patients had lower QoL, thus, more attention must be given to these vulnerable groups, in order to encourage them to obtain adequate rest and not feel obligated to deal with the patient's condition at all times. Healthcare providers must pay attention to caregivers who have been providing care for a long period (Weitzner, McMillan and Jacobsen,

1999; Dumont *et al.*, 2006; Kim *et al.*, 2012; Romito *et al.*, 2013; Laws, 2014; Yi and Kim, 2015).

The extent of unmet needs was highly correlated to QoL. Higher unmet needs scores corresponded to lower QoL levels. However, as indicated in previous studies (Kitrungrote and Cohen, 2006; Kim *et al.*, 2010), QoL was influenced by unmet needs in the domains of "health/psychological problems," "practical support," and "caregivers/social support," which showed relatively low prevalence rates. This indicates caregivers may suffer from their own physical and psychological health problems, but do not feel able to discuss them because they are afraid to draw attention to themselves, thereby distracting from the care of the cancer patients they care for. These findings clearly suggest that it is necessary to include the physical and psychological health of caregivers when developing interventions (Schubart, Kinzie and Farace, 2008). Practical support and caregivers/social support requires reinforcement to improve the QoL of caregivers. In particular, low-income caregivers living with patients with advanced or terminal-stage cancer, and those who have been providing care for long periods, must receive support from other family members as well as oncology healthcare providers. Utilising respite care and self-help group activities would help to enhance the QoL of caregivers. For caregivers, sharing their experiences in self-help groups could relieve their feelings of being burdened. Identifying a "caregiver champion" (Northouse, *et al.*, 2012), would be an important step in empowering caregivers. As many authors have noted (Northouse *et al.*, 2010; Northouse *et al.*, 2012; Yi and Kim, 2015), such programmes must be designed to help caregivers, be tailored to their needs, and focused on their physical and psychosocial/spiritual, emotional and social care.

6.3 PHASE 2: SECOND SCOPING REVIEW:

The second scoping review was conducted to exhaust the viability of published support programmes for caregivers of patients diagnosed with cancer.

The majority of the included works were not of the highest quality because they did not have clear research questions. Conversely, similar to the guidance of Hong *et al.* (2018), only one (n=1; 5%) mixed method study (Hudson *et al.,* 2008) had clear research questions allowing a quality assessment. The researcher did not exclude any study according to it is own quality.

The findings of the second scoping review provided evidence that 22 support programmes for caregivers of cancer patients were published over a period of 10 years in the USA, Australia, UK, Germany, Denmark, Japan, Canada, France and Netherlands; all interventions were done in developed countries. The same result was reported in the systematic review study of Fu *et al.* (2017), as most of their included interventions applied to developed countries. This review also verifies the result of Reigada, Pais-ribeiro and Novellas' (2014) study, which indicated the lack of publications regarding programmes designed and developed to support caregivers of cancer patients in developing countries.

Different designs and research methods have been used, and in the last 6 years, according to Waldron *et al.* (2013), both the quality and quantity of research referring to cancer care had been enhanced significantly. The majority (41%; n=9) of work designs in the second scoping review were randomised control trials (Bakitas, Kathleen Doyle. Lyons, *et al.*, 2009; Boele *et al.*, 2012; Clark *et al.*, 2013; Collinge *et al.*, 2013; Mclean *et al.*, 2013; Badr *et al.*, 2015; Dionne-odom *et al.*, 2015; Shaw *et al.*, 2015; Hendrix *et al.*, 2016), followed by six (n=6, 27%) randomised clinical trials (Meyers *et al.*, 2011; Porter *et al.*, 2011; Belgacem *et al.*, 2013; Fegg, 2013; Ledderer *et al.*, 2013; Northouse *et al.*, 2013), and other works (n=7; 33%) distributed between intervention, mix method, experimental, quasi-experimental and qualitative study designs. The same study designs were used in the systematic review of Fu *et al.* (2017), as 91% of their review included interventions used RCT, two of which were of quasi-experimental design. Although the works delivered respected evidence, the caregivers of cancer patients benefitted from such support

intervention. Nonetheless, no such support programmes were found in developing countries or in Palestine.

The second scoping review indicated the importance to involve the caregivers and cancer in a cancer care system as soon as possible, in order to address their demands together and maintain quality of care. All types of educational or supports programmes acknowledged and studied by several authors may be an example of good practice observed in individual and group interventions (Tufan *et al.*, 2011; Reigada, Pais-ribeiro and Novellas, 2014). The second scoping review has shown that support programmes can reduce caregiver burden and improve their QoL (Witkowski and Carlsson, 2004; Miyashita, Sato, Morita, *et al.*, 2008; Miyashita, Sato, Morita, *et al.*, 2008; Bakitas *et al.*, 2009; Clarke and Seymour, 2010; Fegg, 2013; Badr *et al.*, 2015; Dionne-odom *et al.*, 2015; Sun *et al.*, 2015), nonetheless most of this education is done through verbal or written means.

The works included in the second scoping review offered three kinds of interventions of programmes focusing on cancer patients caregivers, containing psycho-educational, skills training, and/or therapeutic counselling. This was similar to the Chinese review study of Fu *et al.* (2017), as they reported the programme offering in their review was caregivers training, group training and paired-intervention. The paired intervention turned out to be a new style, and exposed a substantial influence on refining QoL. This was also reported in the RCT study of Belgacem *et al.* (2013), which aimed to measure the effectiveness of a caregiver educational programme by assessing two outcomes: caregivers and cancer patients QoL and care burden; the importance of this type of intervention in decreasing care burden was also described in the RCT study of Badr *et al.* (2015) conducted in the USA. Many interventions had broad scope and spoke of instructive and skills training activities by means of primary or secondary objectives. The common of these interventions contained educational material for caregivers that spoke of giving care to cancer patients, preserving family and spousal relationships, as well as self-caring, signifying some

agreement that these are important interventions focused on content and offered to caregivers. Some of the interventions were intended for and focused on caregivers' self-care (n=9; 40%). Most of them were provided together to caregivers and cancer patients (n=13; 59%), proposing the caregivers and cancer patients are influenced by cancer, conversely offering directed interventions to caregivers and cancer patients. Providing communication and emotional support had an obvious influence on both barites. Some works indicated that caregivers and cancer patients preferred to not receive all counselling or educational sessions together (Northouse *et al.*, 2010; Fu *et al.*, 2017), sometimes they wanted to be with their consultant by themselves. In this instance, they might better explicate their feelings, concerns and worries without swaying each other. Direct intervention led to better guiding contents on handling the symptoms, releasing emotional burdens and stress and self-adjustment was useful, practical and efficient for the caregivers. Conversely, the caregivers' traditional intervention approach also showed to be effective.

In addition, the second scoping review illustrated that the assessment of caregivers' skills and needs might help with their QoL, the result of which was likened to those stated by other systematic reviews (Waldron and Janke, 2013; Fu *et al.*, 2017). For caregivers getting an evaluation, they expected they could flexibly talk about feelings, concerns and worries, and that their speech would be heard and understood by healthcare providers, which in turn might decrease their strain. Even in interventions applied by the multidisciplinary healthcare team, social workers were mentioned in only six studies (Hudson *et al.*, 2008, 2009; Bakitas, Kathleen Doyle. Lyons, *et al.*, 2009; Clark *et al.*, 2013; Collinge *et al.*, 2013; Ledderer *et al.*, 2013), which indicates that the social worker role in support programmes had not been recognised and given full attention.

According to the contents of interventions, the mentioned support programmes focused on how the support programmes for caregivers could improve caregivers' and their cancer patients' QoL and reduce caregivers care burden (Waldron and

Janke, 2013). The second scoping review provided additional evidence to support the result of delivered information on cancer training and education on living a healthy life style might help in improving caregivers and cancer patients' QoL.

The studies in literature reported about caregivers' support needs, as well as the few programmes developed on the same target group, as the researchers primarily gave attention to the QoL, physical and mental difficulties of cancer patients and gave less attention to the needs of caregivers. There is little attention focused on caregivers' specific informational needs and preferences for diagnostic information or to caregivers' readiness or willingness to integrate this new medical information (Fujinami *et al*., 2012; Kent *et al.,* 2016). More attention needs to be devoted to the needs and support of caregivers in order to facilitate the caregiving tasks, minimising the caregiving burden and enhancing their QoL. Supportive plans such as support programmes should be used (Bahrami and Farzi, 2014; Schulz and Eden, 2016).

6.4 PHASE 3: DEVELOPMENT/ADAPTATION AND VALIDATION THE SUPPORT PROGRAMME

The results of Phases 1 and 2 were used to develop and adapt the programme, and the expert group validated the support programme.

In order to ensure the process of developing the support programme, one principle was taken into account, the content of the programme had to be empirically grounded in the caregivers support needs identified through content analysis of the studies included in Phase 1. Based on this, the researcher knew that caregivers often did not take time for themselves, and were at risk of their own health-related problems as a consequence (Khan Joad, Chaturvedi and Mayamol, 2011; Harding *et al.*, 2012; Gültaş and Yilmaz, 2017). Therefore, it was determined that the purpose of the programme would be to promote the health and well-being of caregivers.

Programmes evaluated in Phase 2 were drawn upon to identify possible learning activities, useful handouts and their presentation, and potential guiding questions for discussion. As the programme was developed, some natural combinations emerged and topics were combined. For example, the module on family caregiver needs for information support was combined with the module on the assistance and adjusting to being caregiver. The discussion on caregiver health was woven throughout all the modules rather than separating this content into a separate module.

Despite the strengths of many of the programmes, the evidence available to support caregivers' effectiveness in enabling them to manage their responsibilities through knowledge, skill development and self-efficacy enhancement, none of the programmes evaluated in Phase 2 addressed all the support needs identified during Phase 1. It became clear that a customised programme would be required.
The support programme was adapted to local practice patterns and resource availability. This programme seeks to improve caregivers' roles in Palestine and does not intend to repeat all that contained in international guidelines, but to state what is relevant and appropriate for the Palestinians caregivers' environment. Finally, in response to the conclusions and establishing guiding principles, determining the overarching goals and objectives of the programme and a preliminary structure, the support programme was developed to meet the identified caregivers support needs. This same approach was performed in a study conducted in the USA by Finlayson, Garcia and Preissner, (2008) to identify and develop a programme for caregivers.

The researcher used convenience sampling to recruit the expert group to validate the programme. Continuous meetings with them was discuss their notes and recommendations about the programme. The main concerns revolved around the terminology used, as some of the words would not be easy for the community to understand; some advised changing the terminology to lay language or to include

simple explanations. Some concerns were raised around the time needed to implement the programme. The concept of end-of-life care should be used to a greater extent. Caregivers and cancer patients should be advised to visit social workers and mental health clinics regularly. Care should be taken when describing sexual problems as may they refuse to continue, which would lead to losing them. They concluded that communication between patients or caregivers and healthcare providers, coupled with cultural beliefs and norms surrounding sex, may exacerbate concerns in this domain, as it does not suit the culture, beliefs and norms. Sexual issues might have been 'taboo' with caregivers or patients, and the same concern was addressed in study conducted in the USA by Attum and Shamoon (2018), in which the researchers indicated the Muslims tended to avoid discussing sexual issues, as they have a tendency to keep sexual matters private. Sexual relationships were not described in the study; if they had been the results may have differed. The recommendation was that training for caregivers on the importance of sexual relationships and ways to raise them in a culturally sensitive manner may help to address this potentially hidden need. The study conducted by Motsomi *et al*. (2016) to investigate the factors that affected effective communication concerning sexual issues, emphasised enhancing the awareness of sexual life among participants.

On the basis of the remarks of the expert group, a response was re-worded for presenting clarity, avoiding ambiguity, and which suited the Palestinian culture. After the support programme was validated, the researcher began preparing for programme implementation.

6.5 PHASE 4: PILOT TEST THE SUPPORT PROGRAMME

The CQOLC and ZBI was used to measure the caregivers QoL and care burden respectively, while the EORTC, BPI and MSAS measured cancer patients QoL, pain experience and symptoms burden respectively. The result indicated for the improvement in the outcomes was measured in intervention.

6.5.1 Socio-demographic characteristics of the caregivers

The results showed that participants' relationships with the patients ranged from friend to spouse, however, the greatest percentage of the participants (48%) were a child of the sick person. Gender was evenly distributed, and most (74%) were married. Gültaş and Yilmaz's (2017) Turkish study reported the same result with regard to the material status of the caregivers, as most of the caregivers in their study were married and had children. The same result was reported in LeSeure and Chongkham-Ang (2015), and included a child of the sick person, parents, spouses, and next of kin as the main caregivers for cancer patients. Of the participants, 50% were high school graduates and 28% had completed graduate and post graduate school, which is typical for the population in Palestine; the latest statistics show that 96.3% of the population of Palestine are literate (Palestinian Ministry of Education and Higher Education, 2014).

Caregivers' ages ranged from 18 to 74 years, with a mean of 39.44. Similar numbers were reported in the Jordanian study of Al-Jauissy, (2010), as the age of participants in the sample ranged between 21 and 62, with mean age 36.2.

6.5.2 Caregivers QoL

With respect to the caregivers' QoL pre-intervention, it was interesting to note that people between 40 and 49 years of age had the highest QoL; this was also reported in Shahi *et al.* (2014) in their study conducted in USA, as their result showed that older caregivers of cancer patients demonstrated better QoL than younger caregivers. And who had the poorer QoL were primarily spouses, children and siblings, whilst friends reported the highest QoL. As revealed in the current review, spouses played a major role in caregiving as the primary source of cancer patients' support, and got the poorer QoL score pre-intervention. This finding agreed with Li, Mak and Loke's (2013) review study reporting that spousal caregivers perceived

greater levels of negative and undesirable experience in caregiving, such as decreased mental health, decreased physical health, poorer health-related QoL, decreased life satisfaction and reduced marital satisfaction.

After the intervention, QoL showed an improvement for all age groups. These same findings were reported in Belgacem *et al.* (2013) in their French study, which reported that the support intervention enhanced the caregivers' QoL in all domains after intervention, for all different caregivers' ages. In the current review, the QoL ratings for caregivers with different relationships to the patients also improved. Friends and parents of patients with cancer reported the highest QoL. Parent caregivers had the better QoL post-intervention; this finding was the same as that of Helga Bragadóttir (2008) and Tang *et al.* (2014), who described that the support programme enhanced parent coping abilities, in a manner of decreased depression, anxiety, burden, stress, and negative mood and perceived bonding in cancer caregivers. The QoL rating for spouses who were caregivers was the lowest. The finding of the current review revealed that the spouses received the lowest QoL, before and after the intervention. Studies by Kayser, Watson and Andrade (2007), Hagedoorn *et al*. (2008) and Li and Yuen (2014) described that the influence of cancer on caregivers is real when the cancer patient's caregiver is the patient's spouse, who takes on the vigorous task of implementing treatment choices and delivers emotional, physical and psychological support to the cancer patient, and because of the tremendous duties they apply, their QoL is always compromised.

As seen in the results of Phase 4, the total score of CQOLC was 91.06 pre-intervention and 75.47 post-intervention. According to the literature, the total score of CQOLC of this study was above average, as the total score of CQOLC in other studies was 71.77 (Bektas and Ozer, 2009).

The study provided evidence that the support programme significantly enhanced the overall QoL post-intervention, maybe due to the programme contents that included a

large part to the domain of QoL. This is what can be expected after such an intervention, a pattern increase in reported QoL. The findings of the study were similar to studies that utilised intervention programmes such as CCP, FOCUS and COPE, which stated the effects of a support programme or intervention on caregivers QoL (McMillan *et al.*, 2006; Belgacem *et al.*, 2013; Northouse *et al.*, 2013; Leow, Chan and Fai Chan, 2015; Hendrix *et al.*, 2016).

Although QoL is the conception or perception of persons of their own condition inside their beliefs, value and cultural framework or system, it takes into account the person's physical tasks, psychological or mental well-being, family and social relationships, environmental impacts, and values or beliefs (Alptekin *et al.*, 2010). The interventions that integrate with features of support programmes that deal with caregiver spirits, feelings, perceptions, emotional state and experiences, possibly have a major influence on QoL. This is because the caregiver learns how to deal with distress that emanates from the real demands of the caregiver position as well as the emotional demands, and they are capable of looking out for and managing the care recipient; these concepts were also applied in previous studies (Badger *et al.*, 2011; Meyers *et al.*, 2011; Porter *et al.*, 2011; Boele *et al.*, 2012; Belgacem *et al.*, 2013; Clark *et al.*, 2013; Ledderer *et al.*, 2013; Northouse *et al.*, 2013; Shaw *et al.*, 2015).

6.5.3 Caregiver care burden

The reported caregiving burden differed with respect to the relationship of the caregiver to the patient before intervention; caregiving burden was highest for the friend caregiver followed by the spouse caregiver, child caregivers reported slightly less burden followed by parents, and the sibling caregivers experienced the least amount of burden (Table 4.17). This result was in concordance with Hong and Kim (2008), Pinquart and Sörensen (2011) and Revenson *et al.* (2016), who reported that the burden of caregiving was higher among spouses of patients with cancer.

This is explained by the fact that spousal caregivers provide more care and support to their cancer partners, as they are more likely to share household duties as well as the changes that occur in personal relationships, as well as the burden of economic hardship, which fell heavily on them. It was also reported that spouses of patients with cancer reported a significantly higher burden than the children (Lowenstein and Gilbar, 2000). Spouse's caregivers had the lower care burden post-intervention, which was similar to the studies of Northouse *et al.* (2010) and Litzelman and Yabroff (2015), due to the support programme for cancer caregivers emphasising how the spouses control patients symptoms and in the way they can cope with major psychological distresses near the time of diagnosis and treatment.

Other studies have observed the high incidence of caregiving burden as reported by patients' relatives before intervention in this review. It is clear that the caregiver's burden has a direct effect on caregivers. Parents, children, siblings and spouses are those directly involved in taking care of patients with cancer and therefore experience first-hand caregiving burden. The burden experience is attributable to factors such as financial burden, personal care, medical care and the general management of the patient. Patients with cancer, particularly in the late stages, require dietary management, lifestyle changes and management of medication, among others. It is the task of the caregiver to perform these effectively to ameliorate the effect of the illness on the patient. Lu *et al.* (2010) also reported that patients' relations are most likely to experience high caregiver burden.

The study provides evidence that support programmes improved care burden post-intervention. The findings are in accordance with those of McMillan *et al.* (2006), Belgacem *et al.* (2013) and Bahrami and Farzi (2014) who reported the care burden of the caregiver was significantly reduced because of the intervention. This finding is also in line with those who reported that the different support interventions had an effect on care burden, by expanding the way of caring, providing the need care, obtaining the need information and increasing the mastery (Hudson, Aranda &

Hayman-White, 2005; White *et al.*, 2008; Miyashita, Sato, Morita, *et al.*, 2008; Hudson *et al.*, 2009; Badger *et al.*, 2011; Porter *et al.*, 2011; Boele *et al.*, 2012; Belgacem *et al.*, 2013; Mclean *et al.*, 2013; Badr *et al.*, 2015; Sun *et al.*, 2015; Dionne-odom *et al.*, 2015; Hendrix *et al.*, 2016). In the present study, the performance of the intervention on the caregivers' burden followed a pre-expectation of a lessening of the burden and enhancing the experience of caregiving to be able to cope with the caregiver's role and provide care to cancer patients.

Cancer care, such as supportive and palliative care, is more informal than formal, and this has implications for the caregivers. More attention needs to be devoted to the needs and support of caregivers in order to facilitate the caregiving tasks and minimising the caregiving burden and enhancing their QoL.

6.5.4 Cancer QoL

The findings provide evidence that the QoL scores for cancer patients show a significant difference pre- and post-intervention, and this was expected after such support programmes. This was congruous with studies that utilised intervention programmes, and reported major effects of a support intervention on the QoL of cancer patients (Montazeri *et al.*, 2008; Saleha. *et al.*, 2010; Badger *et al.*, 2011; Ganz *et al.*, 2011; Zucca *et al.*, 2012; Ledderer *et al.*, 2013). The reason for better QoL in cancer patients was because the caregivers used the offered support programme and they gained the needed information about their health condition, social relationships and financial support, as well as being conscious about their health, and they have the need for information on how to manage symptoms as the caregivers obtain the needed information and skills on how to be a caregiver; all of this affects the cancer patients QoL positively.

A statistical significant difference was observed between the pre and post mean scores of Global health status/QoL, physical, pain symptoms scales and dyspnea;

these results also replicate previous research findings that confirm the effects of such support programmes on QoL, physical and symptoms scales (Allard *et al.*, 2001; Korstjens *et al.*, 2006; Borneman *et al.*, 2010; Badger *et al.*, 2011; Porter *et al.*, 2011; Clark *et al.*, 2013; Shabani *et al.*, 2014; Syrjala *et al.*, 2014; Koplin *et al.*, 2016; Kristanti, Setiyarini & Effendy, 2017). The influence of the current support programme was possibly due to numerous reasons. Firstly, in the study by McMillan and Weitzner (1998), it was advocated that the QoL of cancer patients in life-threatening illness reduced mostly due to the decrease in physical functioning. On the other hand, the enhanced global health status/QoL of cancer patients in Phase 4 could relate to the enhancement of physical aspects and lowering in pain levels, as well as the facilitation of symptom elevation during the support programme. Secondly, the support programme being developed/adapted was mostly to improve the caregivers' contribution in cancer care (So *et al.*, 2010; Kristanti, Setiyarini and Effendy, 2017). To be together with friends and caregivers is probably the most essential coping approach for persons facing imminent death from cancer (Sand, Olsson and Strang, 2009). Offering productive social and psychological support has proven valuable in decreasing pain and depressing all the depressive symptoms (Hughesa *et al.*, 2014; Kristanti, Setiyarini and Effendy, 2017). Thirdly, it is also likely that the caregivers practicing the relief measures, such as changing patients' positions and enhancing patient's hygiene, helps patients decrease their focus on their physical discomfort and makes them more able to remain socially, spiritually and emotionally involved. Caregivers also provide patients with the informational needs regarding their illness and treatment from the start (Wittenberg *et al.*, 2017). Enhancing knowledge will aid in their decision-making, thus reducing their stress and better their QoL (Shea-Budgell *et al.*, 2014; Wittenberg *et al.*, 2017). Literature also shows the effectiveness of support interventions on the emotional adjustment, physical condition, treatment and disease-related symptoms, or improving patients' information (Shabani *et al.*, 2014).

As seen in the findings of the Phase 4, emotional function mean scores did not improve post-intervention, but this result it is not congruous with most studies. Those of Barre *et al.* (2015), Larson, Rosen and Wilson (2018) and Villani *et al.* (2018), conducted to assess the cancer patients emotional wellbeing, revealed a significant difference between the pre- and post-intervention scores in respect of emotional functioning; this result may because of the nature of cancer disease. Even small improvements were observed in the means scores of nausea and vomiting, insomnia, appetite loss and constipation symptoms, although this improvement was non-significant. The non-significant increasing of the fatigue symptoms post-intervention was similar to Bower's (2014) study, as they described that cancer disease and the treatment mechanism were associated with elevated levels of fatigue.

6.5.5 Cancer pain severity and interference

The findings of Phase 4 regarding cancer pain severity and interference was significantly decreased post-intervention. This is consistent with other previous support and educational interventions (Miyashita, Sato, Morita, *et al.*, 2008; Bennett, Bagnall and Pain, 2009; Chan *et al.*, 2011; Porter *et al.*, 2011; Collinge *et al.*, 2013; Lee *et al.*, 2014; Nguyen, Alexander and Yates, 2018), which describe the crucial benefit from such programmes on cancer patients pain level. This result may be overshadowed by the influence of the intervention on improving physical symptoms and QoL of cancer patients (Given *et al.*, 2002; Lee *et al.*, 2014; Nguyen, Alexander nd Yates, 2018). The fact that patients in Phase 4 stated significant decreases in pain from the period before to the period after intervention may suggest that pain concerning issues treated in the support programme helps cancer patients by enhancing their pain and pain interference even in the face of the cancer's progressive nature and its treatments (Bennett, Bagnall & Pain, 2009; Porter *et al.*, 2011; Collinge *et al.*, 2013; Somers *et al.*, 2016). The support programme armed patients' caregivers with instructive information regarding cancer and its

management, and chances to ask questions and deliberate worries related to the patient's pain and other symptoms. The kind of detailed information that was delivered in this support programme may be helpful to participants by relieving their patients' worries that come from lack or misunderstanding (Porter *et al.*, 2011).

The mean of pain intensity level at its worst, least, on average in the last 24 h and at the time of intervention ("right now") reduced significantly after intervention. Conversely, the amount of patients who stated worst pain in severity in the last 24 h declined from 74% pre-intervention to 68% post-intervention. In the same way, the mean of pain interference in term of physical and effective functions also significantly declined; this result was in agreement with the studies of Bennett, Bagnall and Pain, 2009, and Lee *et al.,* 2014). They described the reduction of cancer pain can be attributed to enhanced pain controlling after the intervention.

The findings of Phase 4 showed the degree to which the caregivers of cancer patients received the essential basics of management cancer pain, pain evaluation and regular monitoring. By comparing with the cancer pain results pre-intervention, pain intensity level at present, at least, at worst, and on average, and the level of pain interference with activity daily function, significantly reduced after intervention. The results are in agreement with results from other previous related studies, including programmes for cancer pain management (Wells-Federman, Arnstein and Caudill, 2002; Germossa, Helles and Sjetne, 2019), pain educational programmes (De Rond *et al.*, 2000; Zhang *et al.*, 2008; Germossa, Helles and Sjetne, 2019) and pain management programmes (Germossa, Helles and Sjetne, 2019) on pain and its interference with activity daily function. Even though the findings of Phase 4 presented a significant positive influence on the mean pain intensity and functional interference level, the number of patients who stated pain in the last 24 h post-intervention was quite high when compared with the outcomes of prior prevalence studies in Germany (63%) (Strohbuecker *et al.*, 2005), and in Chicago, USA (59%) (Germossa, Helles & Sjetne, 2019).

The usually used medications for cancer pain were Non-Steroidal Anti-Inflammatory Drugs (NSAID), such as paracetamol and ibuprofen, and the reason for medication selection may be related to the intervention effect on decreasing pain severity and interference. Furthermore, taking pills to manage the cancer pain could be determined mainly on the direct orders from oncologists. While labours were made to enhance the caregivers communication and collaboration with healthcare providers, the influence was on enhancing pain severity of cancer patients when appropriate prescribing of pain medication is needed (Allard *et al.*, 2001; Nguyen, Alexander and Yates, 2018).

6.5.6 Cancer symptoms burden

The total symptoms burden, global distress index and the psychological symptoms subscale were significantly improved post-intervention. This result was similar to the study of McMillan *et al*. (2006), conducted in USA, which reported that the intervention was efficient in increasing the QoL of caregivers, decreasing patients' symptoms burden as well as caregiving burden. Despite the improvement in the mean score of the physical symptoms subscale, this improvement was non-significant. Notably, the global distress index is a combined measure of the most predominant physical and psychological symptoms that the cancer patients experienced. As cancer patients' experiences of their illness is mainly through symptoms, lowering distress of the most predominant symptoms is an essential and promising outcome (Deshields *et al.*, 2012; Ruland *et al.*, 2013).

The findings of Phase 4 measured the prevalence, frequency, severity and distress of symptoms the cancer patients experienced. The majority of studies have reported the pain N/V, fatigue and vomiting are the most frequent symptoms (Baggott *et al.*, 2010; Atay, Conk & Bahar, 2012; Torres *et al.*, 2019). Some of the symptoms recorded in Phase 4 were reported in previous studies, namely lack of appetite,

feeling sad, vomiting, worrying, feeling nervous and difficulty sleeping were recognised as the most dominant symptoms (Collins *et al.*, 2000; Hockenberry & Hooke, 2007; Yeh *et al.*, 2008; Yeh, Wang & Chiang, 2009; Walker, Gedaly-Duff, *et al.*, 2010; Miller, Jacob & Hockenberry, 2011). In this study and before intervention, the author found these symptoms were not only the most prevalent symptoms, but also the most severe and most bothersome or distressful of all symptoms. Gastrointestinal symptoms (lack of appetite, nausea, mouth sores and constipation) were also among the most frequently reported physical symptoms pre-intervention, and this is similar to other reports (Yeh *et al.*, 2008; Baggott *et al.*, 2010; Atay, Conk & Bahar, 2012). The existing literature about psychological symptoms in patients with cancer is scarce. Pre-intervention, psychological symptoms such as anxiety, fear and worries were amongst the most reported in this and previous studies (Ribeiro *et al.*, 2009; Baggott *et al.*, 2010; Torres *et al.*, 2019). Patients may have worries or concerns about treatment failure and fears of dying (Aparecida Garcia de Lima *et al.*, 2010; Torres *et al.*, 2019). Other negative emotions, such as feeling sad, angry, and sorry for oneself have been previously reported to be associated with fatigue (Walker, Johnson, *et al.*, 2010).

Yeh, Wang and Chiang (2009) stated that one of the most disturbing symptoms of Taiwanese cancer patients is lack of appetite. Inconsistencies among symptom experiences might be associated with culture, treatment modality differences, size of population, as well as the difficulty in measuring the symptom (Robinson & Carr, 2007; Miller, Jacob & Hockenberry, 2011). Similar to previous studies, the trend was for the poorest for symptoms to be of a more subjective nature, such as psychological distress - worrying, feeling sad and feeling nervous (Lobchuk & Degner, 2002; Mcpherson & Brajtman, 2008). Feeling nervous, worrying and feeling irritable did not improve post-intervention and symptoms were recorded mostly as sever pain, and distress in patients, such as pain, nausea, difficulty in sleeping, lack of appetite and feeling irritable improved post-intervention. Other patients' symptoms were significantly enhanced by the support programme and in a practical sense,

which means that caregivers were getting to use the information provided from the support programme, and they were now more skilled to deal with patient symptoms, or tasks such as providing personal care (McMillan *et al.*, 2006).

The caregivers experienced lower QoL and high level of burden because the influence of cancer care is a demanding and life-long job. Caregivers undertake the vigorous task of implementing treatment choices and delivering emotional, physical and psychological support to the cancer patient, and these tremendous duties run parallel with household duties if the caregivers are spouses, as well as the changes that occur in personal relationships.

The implemented support programme for cancer caregivers enhanced their QoL, and lowered their burden by enhancing their coping abilities, emphasising how the caregivers control patient's symptoms by providing the information of cancer care in a way they can cope with major psychological distresses, such as depression, anxiety, burden, stress, and negative mood, and perceived bonding in cancer caregivers near the time of diagnosis and treatment.

The programme integrates with features of support programmes that deal with caregivers' spirits, feelings, perceptions, emotional state and experiences that possibly have a major influence on QoL. This is because the caregiver learns how to deal with the distress that emanates from the real demands of the caregiver position as well as the emotional demands, and they are capable of looking out for and managing the care recipient; these concepts were also applied in previous studies (Badger *et al*., 2011; Meyers *et al.,* 2011; Porter e*t al.,* 2011; Boele *et al*., 2012; Belgacem *et al.,* 2013; Clark et al., 2013; Ledderer *et al.,* 2013; Northouse *et al*., 2013; Shaw *et al.,* 2015). Conversely, with the enhancing of the caregivers' QoL, this reflected on the cancer patients' QoL, and the information provided allows the caregivers to alleviate cancer patients' pain and other symptom burden (Shea-Budgell *et al*., 2014; Wittenberg *et al*., 2017).

6.6 JUSTIFICATION OF THE STUDY

The study will be justified in terms of the aims and its objectives. The aim for this study was to develop and pilot test a support programme for caregivers of cancer patients in Palestine. In order to achieve the aims of the study, the following objectives were developed:

- To explore the literature to synthesise the support needs of caregivers of cancer patients as well as the exiting support programmes.
- To develop/adapt and validate a support programme, suitable for the Palestinian context, for caregivers of cancer patients.
- To pilot test the caregivers support programme in the Palestine context in terms of the following outcomes: primary outcome of caregivers QoL and secondary outcomes of caregivers' care burden as well as cancer patients' QoL, pain experience and symptoms burden.

All the chapters of this study were geared towards achieving the study objectives through the four Phases described in the previous chapters.

6.7 LIMITATIONS

Despite several steps to ensure high validity for the study, such as using multiple methods and multiple data sources, various limitations were identified. This study had four phases, and different limitations for the different study phases were described.

The first two phases were the scoping reviews. These reviews had some limitations that require acknowledgement, as they were traditional scoping reviews focusing only on peer-reviewed articles. There could be some unpublished work on caregivers' support needs, or could have been disseminated through other venues,

and citations in the reference lists of the excluded studies may have been missed. Many of the studies had both patients and caregivers, or had patients identify their caregivers, which could introduce bias to the samples examined. A further limitation could be there were some articles missed because keywords were definitive for support needs, caregivers and cancer in the search terms.

According to the validation of the programme, the researcher aimed to ensure best practices during the validation, such as independent expert assessments and inputs before producing the final programme, however, the particular support needs of caregivers of cancer patients' across Palestine might not have been fully captured in the new programme.

As mentioned before, and according to the validation of the support programme, by using expert group opinion, their response and advice (n=2) was not to discuss the sexual life with the participants, as this did not suit the culture and would lead to losing them; they concluded that communication between patients or caregivers and healthcare providers, coupled with cultural beliefs and norms surrounding sex, may exacerbate concerns in this domain. As stated, this topic was possibly ‘taboo’ with caregivers or with their patients. If sexual issues had been described in this study, the results may have differed. However, the recommendation was that training for healthcare professionals on the importance of sexual relationships and ways to raise them in a culturally sensitive manner, may help to address this potentially hidden need.

Phase four was the pilot test of the support programme directed in the exact selected area using a convenience sampling method; consequently, the results cannot be comprehensive or generalised. Due to the lack of a comparable control group, it is not probable to appeal final decisions about the influence of the support programme, as it is likely that the influence achieved might be the effect of time. Similarly, the main study limitation was the lack of a randomised controlled trial

design, and there may have been some normal enhancement in the symptoms experienced regardless of the effect of the intervention (Chan, Wong and Lee, 2019). The small sample size of convenience, which may not have achieved the power required to detect a difference pre- and post-intervention, was a significant shortcoming, the caregivers' recruitment process was challenging, mainly when patients were diagnosed with a bad prognosis, the high level of withdrawal (24%) might have been caused by the recruitment methodology, and patients and caregivers needed to consent to participate in the study; the same percentages of withdrawal of participants was described in literature (Meyers *et al.*, 2011; Porter *et al.*, 2011; Boele *et al.*, 2012; Badr *et al.*, 2015; Dionne-odom *et al.*, 2015; Shaw *et al.*, 2015). Since the outcomes were conceptually reasonable, it is unlikely they were the result of accident or chance. The researcher observed 24% attrition. Sensitivity analysis was performed using multiple imputations in STATA 14 to ascertain if there were some substantial changes in the results attained from the complete case analysis. However, there were no substantial differences and the researcher proceeded with the complete case analysis, assuming missing data was completely at random (MCAR). There is a need for identification of outcome enhancement strategies, with greater appeal to caregivers and their cancer patients.

Another limitation was the administered questionnaire approach. Generally, multiple questions confuse the respondents (Zohrabi, 2013) and, according to the same researcher, "Leading questions reveal a bias or an assumption that the researcher is making, which may not be held by the participants. These set the respondent up to accept the researcher's point of view."

Literature recommends using research assistants to collect the data if the main researcher plans to implement the intervention (Hudson, 2011; Harding et al., 2012). The researcher funded this research and due to financial concerns, he collected the data himself, maintaining his neutrality.

Considering all possible confounding factors, there may nevertheless be some residual confounding factors that could explain the results obtained.

Furthermore, as this study was conducted in just one area of Palestine, cultural discrepancies in diverse areas could have had an effect on taking care of cancer patients, as well as caregiver QoL.

The evaluation of the project was restricted to a three-week post-education period. Further projects, if feasible, should be extended to undertake a longer post programme follow-up.

The researcher encountered some problems during the study:

- Some of the patients had no idea about their cancer diagnosis and were not included in the study, leading to minimising the sample size.

- Due to the session being 60-90 minutes long, the cancer patients had to stay at the department by themselves, and the researcher and the other staff working there had to take care of them until the caregivers returned.

- Sometimes the questionnaire required more than 15-20 minutes to complete as the participants paused the process to do other things and the researcher had to wait for them to return to complete the questionnaires.

- Sessions had to be postponed because the caregivers did not attend due to a change in the cancer patients' treatment regime.

- Some of the participants became emotionally distressed during the study and therefore referred to the mental health clinics for counselling.

6.8 SUMMARY

This chapter discussed the results of the study. In the final chapter, the study will be justified, the limitations presented, recommendations will be made and the study will be concluded. Finally, the researcher will reflect on his experiences when conducting this study.

The Lazarus and Folkman model chosen in the current study focused on how caregivers received the role of caregiving, as well as the impact on their loved one diagnosed with cancer. The developed programme added a different way to cope with the situation, and to deal with it in a good manner. The study follows the model of Lazarus and Folkman by providing long- and short-term coping strategies to reduce stress to a tolerable level. Creating a meaning of resilience and role satisfaction, as much as possible, assists caregivers to cope with their new role, as well as the effect of caregiving on their life, such as burden, fatigue, stress, change in life routine, social, psychological, financial, and physical alterations.

Because the stress was occurred as a consequence of inequality between the caregivers and cancer care-related environment, providing adequate information on the current situation to enhance the understanding of how caregivers react to and cope with stressors was applied through the implementation of the support programme.

CHAPTER SEVEN
IMPLICATIONS FOR PRACTICE AND RECOMMENDATIONS FOR FUTURE RESEARCH AND CONCLUSION

7.1 INTRODUCTION

This chapter will provide the conclusion to the study in terms of implications for practice and recommendations with regard to the purpose and aims of the study. The plan is to evaluate the study in terms of its positive influence to the body of scientific knowledge.

7.2 IMPLICATIONS FOR PRACTICE AND RECOMMENDATIONS FOR FUTURE RESEARCH

Guidelines currently recommend comprehensive care for cancer patients (Dionne-odom *et al.*, 2015), however, caregivers have received less attention and few interventions. In this study, the researcher provided the support programme directly to caregivers, which significantly improved their outcomes. It is important that investigators find means to support caregivers experiencing caregiving burden (Dionne-odom *et al.*, 2015).

Caregivers support programmes was developed in a way to lessen the sum of responsibilities and hours that the caregivers spend in caregiving, and focus on enhancing the physical health of caregivers. In addition, future studies might deliberately explore other features connected to the intervention. This study described the effectiveness of support programmes for caregivers of cancer patients, and literature also indicated the patients should be requested to attend some of the provided sessions alone, so that they would feel comfortable disclosing their distress without being concerned about burdening their or other caregivers. Other studies results proposed that when interventions are accessible for both

cancer patients and caregivers as the unit of care, caregivers and cancer patients coping skills, self-efficacy, and QoL aspects might be maintained, or even enhanced.

Additional intervention studies are required to provide the information about the complexity and diversity of the experiences of caregivers, and to contain their interactions with the healthcare professionals who provide care for cancer patients, to better realise and meet the needs of these significant providers to the healthcare process. Research is also required to evaluate the discrepancies among caregivers and patient's expectations and their real experiences to define the education and support needed to achieve ideal health and QoL outcomes.

A strong qualitative study in this field could add much to the body of knowledge by highlighting the support needs of cancer patient's caregivers and their burden of QoL and care, before and after the implementation of a support programme. In addition, the study should investigate the symptom burden and patients' QoL of those cared for by the participants in this study.

A multi-centre study and larger sample size would have provided a better result in identifying the influence of the support programme on caregivers and their cancer patients.

Once the support programme has been refined, the intervention should be pilot tested again before testing by means of a randomised controlled trail.

Before future implementation, this programme will be accessible for both cancer patients and caregivers as the unit of care, caregivers and cancer patients coping skills, self-efficacy, and QoL aspects might be maintained, or even enhanced. Had the sexual issues been added, the results may have differed, and training the healthcare professionals on the importance of sexual relationships and ways to raise

them in a culturally sensitive manner, may help to address this potentially hidden need.

7.3 CONCLUSION

This is the first study of its kind conducted in the Arab world and it explored the support care needs as well as exhausted the viability of published support programmes for caregivers of patients diagnosed with cancer. It pilot tested a caregivers of cancer patients support programme in terms of primary and secondary outcomes. From the first scoping review exploring seven themes, namely information, physical, psychosocial/spiritual, emotional, social, financial wellbeing and cancer as a service's needs, it became evident that the majority of caregivers of cancer patients have a variety of unmet needs that predicted their QoL. This review provided knowledge about the caregivers' need for consideration when developing appropriate future support programmes or interventions for cancer patient's caregivers.

The second scoping review explored the intervention programme conducted with the caregivers of cancer patients over 10 years. All the included programmes focused on caregivers of cancer patients, and indicated both the caregivers and cancer patients benefitted from the programmes. The programmes were effective in improving or maintaining the caregivers QoL and decreasing care burden, enhancing caregivers' preparedness, self-efficacy as well as cancer patients' QoL, and lowering their symptoms burden by empowering the caregivers with the skills and information to coordinate care and meet the challenges of caregiving. The programmes were conducted in developed countries, but unfortunately, such programmes are not available for use in developing countries such as Palestine. The general overview of the content of the available programmes, related to the caregivers of cancer patients, was studied and used to develop/adapt the current support programme. This caregiver support programme was tailored to meet the

needs and expectations of both caregivers and cancer patients. Both caregivers and cancer patients considered their overall QoL had improved significantly by providing the needed knowledge during implementation of the support programme. Caregivers considered their burden to be lessened and cancer patients' pain severity and the total symptoms burden declined. These enhancements can be related to the content delivered in the intervention to their caregivers. The outcomes of this study demonstrate that caregiver's support programmes are a need for caregivers, and that there are benefits from attending such programmes as it was noted that several cancer patients do not obtain any other cancer care, and it is likely that this support programme also may be supportive to them and caregivers.

According to the pilot test of the support programme of caregivers of cancer patients, the results showed an improvments of study outcomes measured in term of caregivers QoL and care burden as well as, cancer patients QoL, pain experience and symptoms burden.

7.4 REFLECTION OF THE STUDY

According to Helyer (2015), reflection is associated with "looking back" and examining the past in order to learn from what happened and not repeat mistakes. It is also a learning process, which involves revisiting one's thoughts, feelings or actions after an encounter with an event, with the purpose of making sense of the experience (Boud, Keogh & Walker, 2013). Therefore, I would like to look back at my experiences in order to learn from what happened and make sense of my experience. Eight years ago I started work in the oncology field, publishing my first paper in 2014 (Omran *et al.*, 2014). In general, the concept of support care for caregivers and for their cancer patients is still new in Palestine. The starting point of this PhD was a scoping review, to discover what was already known about this concept. The surprising results of lack of literature, and physical and emotional burden for both caregivers and cancer patients, persuaded me to do something about the support care for caregivers and cancer patients.

Reflecting on the experience of conducting this research, I truly enjoyed the process. I am person who is passionate about learning and writing research, mostly in the oncology field.

This study has been helpful in gaining a learning experience and understanding the research process and thinking beyond boundaries.

I have learnt how to put things into categories and explain them in detail so that the examiners would know what I had done, but also to provide them with key ideas.

Although at times it was hard to inspire myself to do the work, I enjoyed the research and writing, and found the work was much more manageable than I thought it would be. It was very difficult to match my ideas with what I wanted to write about with a relevant topic and information that actually existed. Doing a PhD can be boring and frustrating sometimes, however after realising what is required it can also be greatly exciting. After completion of my PhD, I feel more prepared and excited to write theses and articles in the upcoming years.

Finally, this research changed my knowledge of the concepts of cancer care, ways of caring, difficulties of caring, resources that should be available, support needs, and the effect of caring on individuals, enhancing my knowledge in such a way to be able to plan for future action according to cancer care in Palestine's health system.

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APPENDICES

ADDENDUM **A**

Support Programme for Caregivers of Cancer Patients.

- The training programme included the main domain of supportive and palliative care. The domains were physical, social, psychosocial, and spiritual needs.
- After recruiting participants, the programme was introduced and schedules of sessions and meetings clarified.
- A conducive room in the target hospital (Computer, LCD, board, markers, comfortable chair, paper, pins, refreshments drinks and junks) was prepared.
- The total training programme time was 7hr 60 minutes.
- Managerial administrative permission was received from the hospital.

The **objective** of the Training Programme of Caregivers for Cancer Patients was:

1- To prepare caregivers by providing them with information (verbal, written) about typical aspects and common issues associated with the caregiving role

2- To guide and educate by offering caregivers an opportunity to access information (verbal and written) to enhance their understanding of relevant issues and to provide a basis for skill acquisition

3- To support caregivers by focusing specific attention on their needs and reinforcing the role of the cancer care services, identifying services 'outside' the palliative care team and providing strategies to involve family/friends

4- To help caregivers make sense of and/or find meaning by normalising emotional reactions to the situation, encourage caregivers to try to see some positive aspects of their experience, and offer access to spiritual guidance

5- To promote self-care by encouraging caregivers to enhance their physical and mental health by promoting regular 'time out,' enjoyable experiences, enough sleep, healthy diet, exercise, and advice on relaxation strategies

6- To provide options by offering caregivers an opportunity to identify issues and plan goals/strategies, and advising caregivers of their rights

An interactive session was to follow every module for brainstorming and conversation.

MODULE ONE: INTRODUCTION AND INFORMATION ABOUT CANCER

	Time	Activity	Aim of activity	Equipment needed
Session 1	20 minutes	Welcome and Introduction of Participants	-Make them familiar with one another -Provide an opportunity to express their ideas, views, and experiences -Facilitate creating a working atmosphere	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins **Other**: Refreshments drinks and snacks
Session 2	10 minutes	Expectations and objectives of the training	-Understand the topics of the training -Explain the objectives of the training	
Session 3	60 minutes	Basic information about cancer and its treatment	- Know about cancer.	

MODULE TWO: CAREGIVERS SUPPORT

	Time	Activity	Aim of activity	Equipment needed
Session 1	30 minutes	Describe the meaning of support and the influence of giving care on caregivers	Expand the caregiver's capacities to respond to care demands to maintain the patient's comfort and enhance the patient's QoL, and to prevent or minimise unnecessary caregiver distress	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins **Other**: Refreshments drinks and snacks
Session 2	30 minutes	Educational and Informational support programme.	Provide the appropriate information for caregivers to provide care for patients	
Session 3	30 minutes	Participants express their experience concerning caregiving burden	Maintain coping and stress management	

MODULE THREE: PATIENT ILLNESS-RELATED NEEDS

	Time	Activity	Aim of activity	Equipment needed
Session 1	60 minutes	Practical care, how to deal with common patient symptoms / emotions, and introduce the term of comfort as well as the cure	Know about practical care. -Know what to do when patients experience certain symptoms and emotions	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins

Session 2	30 minutes	Patient needs for comfort	To ensure caregivers' perceptions are congruent with patient needs, and the addressing of direct and indirect care needs. Healthcare professionals need to provide caregivers with appropriate information to manage patients' symptoms	**Other**: Refreshments drinks and snacks
Session 3	30 minutes	Coordinating and keeping communication to prevent misunderstanding and promote positive interaction	Recognise the main communication technique, emphasising the importance of communication in caregiving Participants had the ability to get health information from patients and the health care providers	

MODULE FOUR: CAREGIVER NEEDS FOR INFORMATION, SUPPORT, ASSISTANCE AND, ADJUSTING TO BEING CAREGIVER

	Time	**Activity**	**Aim of activity**	**Equipment needed**
Session 1	90 minutes	Family caregiver needs for information support Assistance and adjusting to being caregiver	To gain a deeper understanding of caregiving Understand the basic concept and meaning of caregiving Helping the participants to adjust to being a caregiver	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins **Other**: Refreshments drinks and snacks

MODULE FIVE: CAREGIVERS' REACTIONS TO DEMANDS OF CARE

	Time	**Activity**	**Aim of activity**	**Equipment needed**
Session 1	30 minutes	Caregivers' reactions to the demands of care	To decrease the negative influence (caregiver burden) of caring on caregiver QoL	Computer, LCD, whiteboard, markers, comfortable chair, paper, and pins **Other**: Refreshments drinks and snacks
Session 2	40 minutes	Describe the importance of self-care and how the caregivers could practice self-care	To assist the participants to become familiar with self-care and how to practice self-care	

The researcher began with a small speech to welcome the participant's, provided a brief introduction on caregivers' life, the described benefit of participants and the purpose of the meeting.

Participants supporting the programme will learn basic information about cancer, its treatment and evolution, adjusting to being a caregiver, community resources that can help cancer caregivers, how to help families improve their emotion-management strategies, the variety of internal and external resources to assist caregivers in this role, amongst others.
The training includes 10 support programme modules/sessions; the duration of each daily session is 60–90 minutes (one session per week/group) that will last for three months.

Finally, the researcher declares the official opening of the training of caregivers on the outcomes of a support programme for caregivers of cancer patients. For a successful training programme over the next 10 weeks, all participants are encouraged to become actively engaged in the various course sessions and discussions on the subject matter. The researcher wishes all participants 10 fruitful weeks of an interesting and beneficial programme.

Before starting with the caregiver's support programme, the researcher will describe the following concepts.

Definition: Who Is the Caregiver?

Also referred to as *informal caregivers*, caregivers provide a complex array of support tasks that extend across physical, psychological, spiritual, and emotional domains. Generally, more women than men become caregivers, and most are related to the cancer patient.
Caregivers, whoever they are, play an important role in the management of cancer; enlisting their cooperation and including them as the unit of care from the outset are critical ingredients to effective cancer management. Most oncology teams recognise this and try to include caregivers in treatment planning, decision making and implementation. However, for a programme to be feasible, they must be appropriate within the constraints of busy oncology practices and service delivery environments. Short-term hospital admissions may also restrict the time available to implement supportive strategies for caregivers.

The Caregiver's Perspective: Across the Illness Trajectory

Caregivers have their emotional responses to patients' diagnoses and prognoses, and may require coaching and emotional support separate from that offered to patients. Caregiver's roles and burdens are affected by a patient's prognosis, stage of illness, and goals of care. The existing body of work on family caregivers of patients with cancer focuses primarily on a caregiver's adjustment during the acute survivorship Phase, from the time of diagnosis to 2 years post-diagnosis.

As open communication and diagnostic disclosure for patients have gained in popularity, studies have focused on the impact of truth-telling amongst patients, and guidelines for such communication have been developed. Although caregivers are sometimes included in these studies, little attention has been paid to their specific informational needs and preferences for diagnostic information or to their readiness or willingness to integrate this new medical information. Yet, a caregiver is expected to learn new illness-related terminology, enter the new treatment setting with the cancer patient, and participate actively in treatment decision making. For all of these reasons, caregivers experience a complex array of powerful emotions that may equal or surpass those experienced by the patient during diagnosis and treatment.

MODULE ONE: INTRODUCTION AND INFORMATION ABOUT CANCER

Session (1): Participants introducing ---------- (10.00-10.20).

Aim: Participants were familiar with each other, and provide the opportunity to express their ideas, views, and experience besides, creating a working atmosphere.

Materials: flipchart, markers, board, projector, and computer

Session (2): Objective and expectations of training programme ---------- (10.20-10.30)

Aim: After describing the training objective, participants understand their expectations, explain the objectives of the training, and the main topic of training.

Materials: flipchart, markers, board, projector, and computer

Session (3): Information about cancer, types, and methods of treatments, symptoms management, and trajectory of disease was provided ---------- (10.30-11.30).

Aim: Understanding the cancer disease and it is treatment.

Materials: flipchart, markers, board, projector, and computer

Objectives of Module One:

- Training objectives were clearly understood by the participants, the sharing of the overall views about training and the time of commencement. Provide all information needed about cancer disease.

Cancer key fact

Cancer is one of the leading causes of morbidity and mortality worldwide, with approximately 14 million new cases in 2012. The number of new cases is expected to rise by about 70% over the next two decades.

Cancer is the second leading cause of death globally, and was responsible for 8.8 million deaths in 2015. Globally, approximately one in six deaths is due to cancer.

Approximately 70% of deaths from cancer occur in low- and middle-income countries. Around one-third of deaths from cancer are due to the five leading behavioural and dietary risks: high body mass index, low fruit and vegetable intake, lack of physical activity, tobacco use, and alcohol use.

Tobacco use is the most important risk factor for cancer, and is responsible for approximately 22% of cancer deaths. Cancer-causing infections, such as hepatitis and human papillomavirus (HPV) are responsible for up to 25% of cancer cases in low- and middle-income countries.

Late-stage presentation and inaccessible diagnosis and treatment are common.

In 2015, only 35% of low-income countries reported having pathology services generally available in the public sector. More than 90% of high-income countries reported treatment services were available compared to less than 30% of low-income countries.

The economic impact of cancer is significant and increasing. The total annual economic cost of cancer in 2010 was estimated at approximately US$ 1.16 trillion. Only one in five low- and middle-income countries have the necessary data to drive cancer policy.

Cancer is a generic term for a large group of diseases that can affect any part of the body. Other terms used are **malignant tumours and neoplasms.** One defining feature of cancer is the rapid creation of abnormal cells that grow beyond their usual boundaries, and which can invade adjoining parts of the body and spread to other organs; the latter process is referred to as metastasising. Metastases are a major cause of death from cancer.

The problem

Cancer is a leading cause of death worldwide, accounting for 8.8 million deaths in 2015.

The most common causes of cancer deaths are cancers of the:

- Lung (1.69 million deaths)
- Liver (788 000 deaths)
- Colorectal (774 000 deaths
- Stomach (754 000 deaths)
- Breast (571 000 deaths)

What causes cancer?

Cancer arises from the transformation of normal cells into tumour cells in a multistage process that generally progresses from a pre-cancerous lesion to a malignant tumour. These changes are the result of the interaction between a person's genetic factors and three categories of external agents, including:

1. Physical carcinogens, such as ultraviolet and ionising radiation
2. Chemical carcinogens, such as asbestos, components of tobacco smoke, aflatoxin (a food contaminant), and arsenic (a drinking water contaminant)
3. Biological carcinogens, such as infections from certain viruses, bacteria, or parasites

Aging is another fundamental factor in the development of cancer. The incidence of cancer rises dramatically with age, most likely due to a build-up of risks for specific cancers that increase with age. The overall risk accumulation combines with the tendency for cellular repair mechanisms to be less effective as a person grows older.

Risk factors of cancers

Tobacco use, alcohol use, unhealthy diet, and physical inactivity are major cancer risk factors worldwide, and the four shared risk factors for other non-communicable diseases.

Some chronic infections are risk factors for cancer and have major relevance in low- and middle-income countries. Approximately 15% of cancers diagnosed in 2012 were attributed to carcinogenic infections, including Helicobacter pylori and Human papillomavirus (HPV), Hepatitis B virus, Hepatitis C virus, and Epstein-Barr virus. Hepatitis B and C virus and some types of HPV increase the risk for liver and cervical cancer, respectively. Infection with HIV substantially increases the risk of cancers such as cervical cancer.

Reducing the cancer burden.

Between 30–50% of cancers can currently be prevented, by avoiding risk factors and implementing existing evidence-based prevention strategies. The cancer burden can be reduced through early detection of cancer and the management of patients who develop

cancer. Many cancers have a high chance of cure if diagnosed early, and treated adequately.

Modify and avoid risk factors

Modifying or avoiding key risk factors can significantly reduce the burden of cancer. These risk factors include:

- Tobacco use including cigarettes and smokeless tobacco
- Being overweight or obese
- An unhealthy diet with low fruit and vegetable intake
- Lack of physical activity
- Alcohol use
- Sexually transmitted HPV-infection
- Infection by hepatitis or other carcinogenic infections
- Ionising and ultraviolet radiation
- Urban air pollution
- Indoor smoke from household use of solid fuels

Tobacco use is the single most important risk factor for cancer and is responsible for approximately 22% of cancer-related deaths globally.

Pursue prevention strategies. To prevent cancer, people may:

- Increase avoidance of the risk factors listed above
- Vaccinate against HPV and hepatitis B virus
- Control occupational hazards
- Reduce exposure to ultraviolet radiation
- Reduce exposure to ionising radiation (occupational or medical diagnostic imaging).

Vaccination against these HPV and hepatitis B viruses could prevent 1million cancer cases/year.

Early detection

Cancer mortality can be reduced if cases are detected and treated early. There are two components of early detection:

Early diagnosis

When identified early, cancer is more likely to respond to effective treatment and can result in a greater probability of surviving, less morbidity, and less expensive treatment.
Significant improvements can be made in the lives of cancer patients by detecting cancer early and avoiding delays in care.

1. Early diagnosis consists of three steps that must be integrated, and provided promptly:
Awareness and accessing care
Clinical evaluation, diagnosis, and staging
Access to treatment.

Early diagnosis is relevant in all settings and the majority of cancers. In the absence of an early diagnosis, patients are diagnosed at late stages, when curative treatment may no longer be an option. Programmes can be designed to reduce delays in, and barriers to care, allowing patients to access treatment promptly.

Screening

Screening aims to identify individuals with abnormalities suggestive of specific cancer or pre-cancer who have not developed any symptoms and refer them promptly for diagnosis and treatment.
Screening programmes can be effective for select cancer types when appropriate tests are used, implemented effectively, linked to other steps in the screening process, and when quality is assured. In general, a screening programme is a far more complex public health intervention compared to early diagnosis.

Examples of screening methods are:

- Visual inspection with acetic acid (VIA) for cervical cancer in low-income settings
- HPV testing for cervical cancer
- PAP cytology test for cervical cancer in middle- and high-income settings
- Mammography screening breast cancer

Treatment

A correct cancer diagnosis is essential for adequate and effective treatment, because every cancer type requires a specific treatment regimen that encompasses one or more modalities, such as surgery, radiotherapy, and chemotherapy. Determining the goals of treatment and palliative care is an important first step, and health services should be integrated and people-centred.

The primary goal is generally to cure cancer, or to prolong life. Improving the patient's quality of life is also an important goal, and is achievable by supportive or palliative care and psychosocial support.

Potential for cure among early detectable cancers

Some of the most common cancer types (breast cancer, cervical cancer, oral cancer, and colorectal cancer) have high cure rates when detected early, and treated according to best practices.

Potential for the cure of some other cancers.

Some cancer types, even when cancerous cells have travelled to other areas of the body, such as testicular seminoma and leukaemia and lymphomas in children, can have high cure rates if given appropriate treatment.

Palliative care

Palliative care is a treatment to relieve, rather than cure, symptoms caused by cancer and improve the quality of life of patients and their families. Palliative care can help people live more comfortably. It is an urgent humanitarian need for people worldwide with cancer and

other chronic fatal diseases and particularly needed in places with a high proportion of patients in advanced stages of cancer where there is little chance of cure.

Relief from physical, psychosocial, and spiritual problems is achievable in over 90% of advanced cancer patients through palliative care.

Palliative care strategies

Effective public health strategies, comprising of community and home-based care are essential to provide pain relief and palliative care for patients and their families in low resource settings.

Improved access to oral morphine is mandatory for the treatment of moderate to severe cancer pain suffered by over 80% of cancer patients in the terminal Phase.

Contact on routine bases with the social worker at hospitals or clinics as well as with the mental health specialist.

MODULE TWO: **CAREGIVERS SUPPORT**

Session (1): The meaning of support was described, and what the influence of disease affects patients and caregivers demands---------- (10.30-11.30)

Aim: Support from healthcare professionals, family, and friends can help family caregivers expand their capacities to respond to care demands. The goals of support should be to enable family caregivers to maintain the patient's comfort, enhance the patient's quality of life and prevent or minimise unnecessary caregiver distress. Support should balance the psychosocial needs of the caregiver and promote the caregiver's physical and emotional well-being so that he or she can effectively attend to the physical and emotional needs of the patient with cancer. **The needs:** To provide this support, a partnership and collaboration must be developed between health professionals and family caregivers around the patient's plan of care. Professionals should develop a patient-family member-focused plan for care that recognises the caregiver's capabilities. Such a plan should begin with a focus on illness-related patient needs.

Getting Support

Knowing Your Strengths and Limits

You may face new challenges and concerns now that your loved one has advanced cancer. If the illness has been going on for a long time, these challenges may wear you down. Many caregivers say on looking back, they took on too much themselves, or they wish they had asked for help sooner in sharing tasks or seeking support.

Take an honest look at what you can and cannot do. What things are you good at? What do you need to do yourself? What tasks can you give to or share with others? Be willing to let go of things that others can do.

Many people may want to help you, but are unsure of what you need or if you want help.

As the cancer progresses, you may see changes in the support you get from others, for example:

- People who have helped before may not help now
- Others who have helped before may want to help in new ways now
- People who have not helped before may start helping now

- Agencies that could not help before may offer services now

Remember that getting help for yourself can also help your loved one, as well as other friends and family.

- You may stay healthier
- Your loved one may feel less guilty about all the things that you are doing
- Some of your helpers may offer time and skills you do not have
- Having a support system is a way of taking care of your family. The idea is to remove some tasks so that you can focus on others
- Talk with someone you trust, such as a friend, member of your faith community, or counsellor. Other people may be able to help you sort out your thoughts and feelings. They may also be able to help you find other ways to get support

Planning and Implementing Patient Care

If healthcare providers are to be supportive of caregivers and facilitate quality care for patients with advanced disease, they have to implement programmes that address caregivers' priority needs, such as the need for information and education, have the ability to mobilise formal and informal sources of assistance, and strategies for maintaining physical health, positive attitudes, and well-being. In tailoring such programmes, providers must recognise that caregivers possess different levels of knowledge and skill, differ in their level of burden, experience different levels of care demands, and differ in the amount of support and assistance they receive from other family members.

Session (2): Educational and Informational support needs---------- (30 Minutes)

Aim: It is clear from a review of literature that education and information are essential if family caregivers are to participate effectively in the home care of patients. Families report providing much care through trial and error; this creates a sense of uncertainty that makes caregiving more time-consuming and stressful. Information that is tailored to the problems that caregivers face would provide them with guidance for implementing care but more importantly, would reduce the stresses of caregiving and the associated burdens and feelings of inadequacy and helplessness arising from ambiguity. Firstly, Therefore, the

support programme will be reviewed first, recognising that effective education will produce important secondary benefits for caregivers and reduce the necessity for such a programme. There are personal as well as structural reasons why caregivers of patients with advanced disease often do not have the appropriate information to care for their patients; moreover, in many instances caregivers are not perceived as partners in developing the patients' plans of care.

Needs (1): caregivers should be included in care plans; being overwhelmed by the care situation, they may not have prepared their questions or may be unaware of what questions should be asked. Additionally, patients with advanced disease may have wide fluctuations in disease and treatment status, and need for care.

Needs (2): Providing Specific Guidelines
Healthcare professionals need to establish a structured and ongoing dialogue with family members about treatment goals, plans of care, and expectations regarding patient outcomes. They may find it useful to develop protocols or "help sheets" to meet the informational needs of caregivers.

Having specific guidelines or suggestions for care provides caregivers with a sense of control, and monitoring patients according to specific limits, such as "report to the health care professional temperature of 101° that persists for 36 hours," helps them evaluate the need for assistance. Wherever possible, professionals need to distribute written, individualised guidelines that caregivers can follow, with specific actions when reaching a criterion.

Caregivers report that specific and tailored direction is supportive and reduces the uncertainty they experience as they provide care, but they do not want to be overwhelmed with massive amounts of nonspecific information.

Acquiring information regarding the disease and treatment-related expectations from healthcare providers can help caregivers plan care, anticipate possible problems and detect changes in the trajectory of the illness.

In general, the reasons caregivers give for their lack of sufficient information include:

1. The inability of family members to ask questions (they may lack social skills)
2. Inability to obtain specific information from providers
3. Limited contact with providers
4. Too many intermediaries between the treating oncologist, the patient and the caregiver
5. Primary care physicians who do not understand cancer, cancer treatment, or cancer care needs
6. Providers who talk only to the patient and do not relate to the family
7. Receiving only filtered information from providers
8. Being overwhelmed due to distress, and having attention or comprehension deficits

Customising information by addressing it

1. What family caregivers can expect about the patients' symptoms, disability, reactions to treatment, and disease trajectory
2. What patients and caregivers can expect from their healthcare provider
3. How different types of supportive and educational care services can assist them, as well as the situations in which these services are most useful

Needs (3): Clinicians need to be cognizant of how the course of the disease and treatment will affect caregiving situations, anticipate the problems and needs of family caregivers during these transitions, and provide anticipatory guidance to family members. Restrictions on time, personal activities and privacy may increase during the advanced disease Phase, and family caregivers need to be informed to anticipate these changes and restrictions. They need to know there are nine types of support services that may help caregivers challenged by multiple care demands. The areas identified were:

1. Diagnostic and medical treatment information
2. Interpretation of the course of illness and anticipatory guidance
3. Interpretation of patients' emotions to the caregiver
4. Interpretation of illness to school-aged children
5. The cognitive process of the meaning of illness
6. Access to services for physical care

7. Skill-building services
8. Problem-solving services
9. Referral services for distressed family caregivers

Session (3): Participants expressed their experience concerning caregiving burden --- (30 Minutes)

The design of the support programme for caregivers is to enhance morale, self-esteem, coping, sense of control and problem-solving abilities, and to decrease caregiver emotional distress while caring for patients at home. These support programmes are not designed to inform caregivers regarding specific aspects of delivering care, but focus on helping caregivers psychologically adjust to the demands of caring.

Aim: Problem-solving and stress management are important components of psychological support for caregivers and health professionals need to recognise when family caregivers may benefit from such support programmes (a problem-solving approach can help reduce a caregiver's sense of uncertainty and accompany feelings of stress and burden enhancing positive patient outcomes).

Needs: Family caregivers should be assessed periodically for psychological/emotional distress and the specific sources of this distress should be identified. The assessment of the quality of the family relationship and communication patterns is necessary if support programmes are to be effective. If warranted, a referral should be made to outside expert resources. e.g., counsellor, psychologist. During visits, healthcare providers need to devote time to candid discussions with caregivers to enable questions and concerns to be freely expressed.

Healthcare providers must plan patient care based on the assumption that the family is a system and that the behaviour and response of one member affects the family as a unit. Both the patient and the caregiver may need *cancer care support or caregiver classes*.
The emotional distress of the caregiver must be addressed. Although the support programme may be important for some family caregivers, most clinical oncology settings do not include such services. Nevertheless, *problem-solving and stress management* are

important components of the support programme for caregivers, and health professionals need to recognise when family caregivers could benefit from such.

MODULE THREE: PATIENT ILLNESS-RELATED NEEDS

Activity (1): The term of comfort**,** as well as the cure, were introduced ----(10.00-11.00)

Aim: Cancer team may refer the patients and family back to the primary care physician. These care transitions occur at a time when families may be experiencing not only the shock, anger and depression associated with realising that treatments are no longer effective, but also increased care responsibilities.

This may place family caregivers in a particularly difficult situation, without a consistent provider to turn to for advice and direction, regarding the plan of care for their patient. Patients' needs are influenced by age, the number of comorbid conditions, psychological disposition, cultural traditions, cancer stage, and Phase of treatment. Caregivers, in turn, may perceive this patient's needs as demands.

Helping your Loved One Cope with Cancer.

Your loved one may be struggling with advanced cancer or with a cancer recurrence. Doctors may be saying the cancer is not responding to treatment, that long-term remission is not likely, or your loved one may have decided to discontinue treatment and live out his or her days to the fullest.

This may be a time to make new decisions. Shifts in care may be needed, or may already be taking place. The burden of making these decisions together may seem heavier than it used to be. These choices often come with many emotions, such as sadness, anger and fear of the unknown. They may also come with questions about how much longer your loved one will live.

Thinking or talking about these issues may feel like you are giving up, but you are not; it does not mean giving up hope. People usually cope better when they have different options. Having information about how to deal with tough situations will help. Your loved one still deserves good medical care and support from the healthcare team even if the treatment changes.

Making Decisions Together.

You may have been caring for the cancer patient for a short or a long time. Most likely, you will be very involved in helping make choices about the next steps for care.

Some of these choices may include:

- Treatment goals
- When to use hospice care
- Financial decisions
- How to get support from family members

When dealing with advanced cancer, people have different goals for their care; some want to keep following aggressive treatments, others decide to choose other paths for care. You may wonder, “Have we done everything possible to treat cancer, or should we try another treatment?” It is natural to want to do all you can, but you should weigh these feelings against the positives and negatives for your loved one.

Questions to ask:

- What is the best we can hope for by trying another treatment?
- Is this treatment meant to ease side effects or slow the spread of cancer?
- Is there a chance that a new treatment will be found while we try the old one?
- What are the possible side effects and other downsides of the treatment? How likely are they?
- Are the possible rewards bigger than the possible drawbacks?

Asking these questions, may help the patient decide whether to continue or begin more treatment? It is best to work together on this process. It will help you figure out both of your needs and the needs of others close to you.

It is important to ask your healthcare team what to expect in the future. It is also important to be clear with them about how much information you and the patient want from them.

Understanding Your Loved One’s Wishes

For many families, your loved one must be in charge of making decisions. In some families and cultures, it is common for the caregiver to make many of the decisions, with or without the patient knowing, or sometimes the patient wants the caregiver to make all the decisions This may be hard, for many reasons:

- Your stress may make it hard to decide
- Your ideas about how to move forward may differ from the ideas of other family members or friends
- The patient may have different beliefs about care than you or other loved ones
- The opinions of your healthcare team may differ from your loved ones or yours

There may also come a time when you have to make decisions for your loved one because he/she is no longer able to. It is important to get a sense of how he/she feels about this before it happens. How would he/she like to deal with it? This may mean letting go of some opinions that you have about treatment (for example, you may want to keep your loved one alive, whatever it takes, but he/she may wish to stop receiving life-sustaining measures at a certain point.) Try to keep things in perspective by looking at the facts.

Palliative Care

All patients have a right to comfort and quality of life throughout their care. Care that makes patients feel better, but does not treat the disease itself, is **palliative care**, and includes treating or preventing cancer symptoms and side effects caused by treatment.

Comfort care can also mean getting help with emotional and spiritual problems during and after cancer treatment. People once thought of palliative care as a way to comfort those dying of cancer.

Doctors now offer this care to all cancer patients, beginning when the cancer is first diagnosed. Palliative care can go on through treatment, survival, advanced disease and the time when treatment no longer controls the cancer.

Members of the healthcare team may be able to provide comfort care, but a palliative care specialist may be the best person to treat some problems. Ask the doctor or nurse if there is a specialist your loved one can see.

Choices for Care

There are several options for your loved one's cancer care; these depend on the type of cancer and the patient's goals for care.

These options include:

- Clinical trials (research studies)
- Palliative radiation, chemotherapy, or surgery
- Hospice care
- Homecare

Many patients choose more than one option. Your loved one should base his/her decision on the risks and benefits of available treatments, as well as their feelings about life and death.

You both have to ask all the questions you need to. If he/she chooses *not* to get further active cancer treatment, it does not necessarily mean a quick decline and death, and they will continue to receive palliative care and be made comfortable. The healthcare team can offer information and advice on treatment options.

Palliative Treatment

Many of the same methods used to treat cancer, such as medicines and certain treatments, can be used to reduce pain or other symptoms and help a patient feel more comfortable. In advanced cancer, palliative treatment may be given to help a person feel better, even if it is not intended to treat cancer. For example, doctors may give chemotherapy to slow the growth of a tumour that is causing pain, or surgery to remove a mass that is pressing on certain nerves and causing pain.

Needs (1): *Participants should differentiate between Direct and Indirect Care.*

Care may be classified as “direct care” or “indirect care,” depending on its focus.

This classification affects the demands of caregiving. ***Direct care*** is carried out directly with the patient, such as symptom management, emotional support, administration of medications, and assistance with mobility or bathing. ***Indirect care*** is carried out on behalf of the patient, and includes activities such as obtaining medications, transportation, errands, scheduling and coordinating appointments, and assisting with the medical bills and finances.

Practical care

Information about your relative’s illness*.*

A person’s medical history is often a private matter, but there are usually a couple of people in our lives with whom we do not mind sharing this information. If possible, get your relative to write down the people who they will allow access to this medical information, and ask them to sign it and have someone sign as a witness.

If you are going to be the main caregiver for your relative, having their written permission to give and receive information about their medical situation may make it easier for you. This will make communication easier when you need to speak to nurses, doctors and other health professionals about your relative’s condition.

Providing practical care.

Your relative may be quite independent with some tasks or may require assistance. You will find it helps if you have some knowledge of these tasks, so you can assist when necessary. Remember, only do things you feel comfortable with; if you are unsure at any time, seek guidance from the palliative care team.

Helping with medications

Always double-check the label on containers to ensure you are giving the right medicine at the right time. Not all medicines are taken orally (by mouth), so check first; not all medicines

are in tablet form, some may be liquid and others may need to be given by injection or via a skin patch.

Sometimes people receive a list, from the hospital or GP, of what medicines are for and when to take them. If you have not got a list and would like one, speak with the GP or palliative care team

Some medicines need to be given at certain times; others are given ‘as required.’ For example, some pain medications are only taken when the person gets pain, whilst other pain medications are given regularly at specific times of the day or night.

Medicines should only be taken ‘as directed;’ if your relative is unsure about this, speak to the doctor or nurse.

If there are many tablets, consider using a dosette box, which allows tablets to be put into special compartments so that it is easier to remember which ones need to be given when. Dosette boxes are available at most chemists and can be filled by you, or the chemist. Alternatively, speak with your chemist, palliative care team or GP about a ‘webster’ pack; this is a weekly pack, made up by your chemist, of all the necessary medicines.

If using syringes and needles, ask about safe disposal via a ‘sharps disposal’ container available from the chemist or local council.

It is quite common for medicines to change. When medicine is no longer needed, it should be discarded to avoid accidental use. Unused medicines should be returned to the chemist for safe disposal. If there is a chance that medicine may need to be used again in the future, store it in a safe, cool and dry place, away from the medicines that are being used every day.

If you have only a few tablets (or other medicines) left, phone the GP to arrange for another prescription. Try not to leave this too late. Where possible, avoid having to arrange this on a weekend. Some chemists provide home prescription delivery services.

If swallowing is difficult, it is possible to crush some tablets give with food or fluids. Check first, with the doctor or nurse, as some tablets should not be crushed, and an alternative form of the medication may need to be prescribed.

Some people may need to take strong pain medicines, such as morphine. If strong pain medicine is required, the doctor, chemist or palliative care team can explain why, how, and when to use it; written information is also available.
In many cases, the palliative care team may arrange for some medicines, in the form of injections, to remain in a safe place within the home. Sometimes referred to as 'emergency medications,' these are prescribed 'just in case' your relative has discomfort that is not relieved by oral medicines. For example, if a person has nausea and is unable to take their pain medicine by mouth, the nurse or doctor may need to visit to give an injection to stop nausea or to prevent the pain.

Many drugs (medicines) given to relieve pain also have unwanted side effects; speak with your nurse about this, so you know what to look for. Most side effects wear off within 24 or 48 hours as the body gets used to the drug. However, it is much better to prevent the side effects where possible, for example, by giving laxatives regularly to prevent constipation or having anti-nausea medications on hand to prevent vomiting.

Some patients and families worry about the use of strong pain medicines (opioids such as morphine). They worry that the person may become addicted, or that the prolonged use of these powerful drugs may hasten death. You can rest assured that palliative care is based on the latest evidence. This shows that when given for pain, opioids do not cause addiction, and when used in prescribed doses, do not hasten death. Many patients feel so much better when their pain is relieved; their appetite improves, they can move about more freely and can often resume pleasurable activities.

Providing hygiene care

Assisting with hygiene care is possible in different ways; you might just be nearby to 'lend a hand,' you may offer to wash your relative's face and hands, you may want to assist with a complete shower or bed bath, your relative may also need help to move out of bed and to

the bathroom. The nurse can guide you with any of these tasks. If preferred, a nurse can provide hygiene care and/or you can do it together.

Safety is important. Consider having rails installed in the bathroom, where there are steps. Talk to your palliative care team about hiring a shower/bath chair so that your relative does not have to stand. A handheld shower hose may also make things easier. A health professional can assess the bathroom set up in your home to improve safety. Several other devices help people move safely if they are unsteady on their feet.

If incontinence, that is loss of control over passing urine or faeces, is an issue there are several aids or products that can help your relative feel clean and comfortable. Do not be afraid to talk about this to one of the palliative care team or your GP.

Assisting with eating and drinking

Many people with a life-threatening illness lose their appetite, possibly caused by the disease, or a side effect of treatment and/or medications, or by feeling sick, downhearted, constipated, tired, or having a sore or dry mouth. Unrelieved pain can also result in a loss of appetite.

Despite the reason, caring for a person who is not interested in food and is losing weight can be very hard.

Here are some suggestions you can offer:

- Regular smaller meals, rather than three big meals; serve food on smaller plates and do not fill drinks to the top of the glass
- New types of foods, as people's food desires may also change. For example, people may no longer like sweet tastes and may now prefer spicy food
- Nutritious drinks. These are available in chemists and some supermarkets. You can also make juices or smoothies. If a person is not interested in solid food, offer drinks regularly

- Good mouth care; keep the mouth moist by encouraging regular teeth cleaning, drinks, and mouth rinses. If you notice white ‘flaky’ spots in the mouth, let the doctor or nurse know. This is common and is easily treatable with a special medication
- As your relative’s illness progresses, you may notice they are eating less. It may not be so important at this stage to have ‘well-balanced meals’ every day, but to concentrate on what your relative enjoys.

Help with other ‘technical’ care

Some patients cared for at home require special management of various tubes, wounds, drainage systems, injections, etc. Many relatives develop significant skills in managing this complex care, but others are not so comfortable.

Use of special equipment

The equipment you need depends on your situation. The use of equipment can increase your relative’s independence, make it easier for you, and promote a safer environment.

The following types of equipment may be needed in the home:

- Shower chair – enables a person to sit down safely in the shower
- Commode – portable toilet, looks like a chair
- Bath/shower handrails – provides support for standing/sitting in a bath/shower
- Bath board – enables a person to safely get into and out of the bath
- Slipper pan/urinal – devices to allow toileting in bed
- Absorbent and plastic sheets – used on a bed or chair where incontinence (uncontrolled bladder or bowels) is an issue
- Dosette box – special medicine container that helps people to take the correct tablets at the right time • Syringe driver – a device used to deliver medications under the skin rather than by mouth
- Sharps container for used syringes and needles
- Call bell or intercom
- Disposable gloves

- Hospital bed – a bed that can be raised or lowered and has sides to prevent falls
- Bed stick – helps the person to sit up and get in or out of bed
- Urinary catheter – tube into the bladder to assist the passing of urine
- Pressure-relieving devices – special mattresses, sheepskins or cushions used for comfort in bed or a chair and to prevent bedsores
- Walking frame – a device used to help with walking
- Wheelchair – allows a person to be mobile if they are unable to walk easily
- Slide sheets –slippery sheets, make it easier to move your relative around when they are in bed

Dealing with common symptoms

The word symptom describes an issue related to an illness. When a person has a serious illness, and where curative treatment has stopped, the focus of care is on relieving symptoms that may arise.
Every person is different and so are the symptoms that might occur. It is important to highlight the common symptoms (pain, constipation, nausea, tiredness, breathlessness) and some basic ways of relieving them. Symptoms may not disappear completely, but in most cases, controlled to a comfortable level.

Your role in helping to recognise and manage the symptoms will depend on how independent your relative is, your relationship, and what you feel comfortable doing. Remember that relief of symptoms is one of the major aims of the palliative care team, so help is available.

If a symptom arises that is not mentioned here, then speak with the palliative care team and they will provide you with more information. It may help to keep a diary or a daily journal to jot down the time and the words used by your relative to describe a particular symptom.

Pain

Many caregivers worry about the comfort of their relatives. This is very understandable. The first thing to be aware of is that not all people who need palliative care suffer ongoing pain. It is also important to realise that a person's level of comfort is a very personal feeling.

We all feel discomfort in different ways and at different levels. People often associate discomfort with pain; however, we may also feel uncomfortable if we feel sick, tired, worried, or restless.

The important thing is that if your relative says they are in pain then the palliative care team can help. Despite advances in treatment, pain may not always be completely removed. The palliative care team will help you with various strategies to reduce the pain as much as possible.

The ways of dealing with pain vary from person to person.

Here are some common things you could do if your relative is in pain:

Assess the pain. You may want to ask your relative these questions and write down the answers. This will help you to describe the pain to the nurse or doctor and assist in the choice of treatment.

- Where is the pain? (Sometimes the pain may be in more than one area)
- What does the pain feel like? (e.g., sharp, throbbing, burning)
- How long has the pain has been there?
- Is this a new type of pain?
- How would you rate the pain on a scale of 1 to 10? (1 'no pain,' through to 10 'excruciating pain'). If the answer is 7 or 8 out of 10 this would be regarded as a considerable amount of pain
- Do you feel like vomiting?
- When did you last have your bowels open? (Constipation can cause pain)

Managing the pain:

- Ask your relative to lie on the bed or to sit down
- Ask your relative to take 10 deep breaths
- If your relative has medicines to take (which are for the pain they are feeling) give the medicine as directed on the container. Check first to see what pain medicines have already been taken that day. If your relative has had as much as they are allowed, phone the palliative care service
- Ask your relative to try to take their mind off the pain by reading, watching TV, or listening to some music
- Offer a massage of feet, hands, or shoulders
- If nausea (feeling like vomiting) or constipation (no bowel action for several days) is an issue, this may be a possible cause of the pain
- If the discomfort has not eased after 30 minutes phone the palliative care team, they will be able to review the problem and suggest other ways to reduce the pain

Concern about opioids and hastening death.

Opioids are very strong painkillers only prescribed if the pain is not managed with milder medicines. Some patients and relatives fear the use of opioids (like morphine for example) because they think it might hasten death.
It is important to remember that what causes death is the underlying disease, not the drug. The doctor will carefully reduce the medication if it is causing serious side effects. However, you must know about the effect of these drugs, and why they are used; ask your palliative care nurse for a brochure that explains all about opioids.

Nausea

This is the term used when someone feels the urge to vomit or feels sick at the thought or sight of food. The cause of nausea can be related to the disease, medications, chemotherapy, radiotherapy, constipation, or an imbalance of chemicals within the body.
If your relative has nausea:

- Ensure a bowl or bucket is within easy reach in case they vomit
- Ask how they rate nausea on a scale from 1 to 5 (1 being ‘very little’ nausea and 5 being ‘extreme’ nausea)
- If anti-nausea medicines are prescribed, check to see if they have been taken as directed. If the prescription allows, give the anti-nausea medication, unless the thought of trying to take a tablet makes your relative feel worse
- Some people prefer not to eat or drink anything until the nausea passes; others find small amounts of food or drinks helpful
- Ask when was the last time your relative had a good bowel motion. If it is longer than two days follow directions under the ‘constipation’ symptom below
- Encourage your relative to rest, suggest deep breathing, play some soft music, offer a foot or neck massage. If your relative feels up to it, a bath or shower may help
- If nausea is not relieved after one hour or if it gets worse, phone the palliative care team

Constipation

Constipation occurs when a person does not open their bowels for several days. This symptom can cause nausea, pain, and tiredness. The cause of constipation can be related to decreased fluid intake, limited mobility, poor diet, or a person’s illness, and often to the side effects of strong pain medicines. In most cases, constipation is preventable.

To prevent constipation:

- Encourage drinks such as water and juices
- If possible, have foods high in fibre, as well as plenty of drinks
- Suggest that your relative has a short walk each day, if they feel up to it
- Take note of the bowel actions: are they hard, soft, small, or liquid?
- Keep a record of when bowel actions occur
- If your relative is prescribed strong pain medicines (such as morphine), make sure that laxatives have been ordered
- There are many natural remedies for constipation that can be used in conjunction with prescribed medicines. Ask a member of the palliative care team for suggestions

- If there is no bowel action for 2 days, speak with the palliative care team who will set up a plan specific to your relative's needs
- Do not assume that if your relative is not eating they do not need to use their bowels – constipation can still occur even when little food is eaten

Breathlessness

Breathlessness or difficulty breathing can be an unpleasant symptom. It is usually caused by disease of the lung, or asthma, emphysema, chest infection, and pressure from other body organs, or anxiety.

While the specific treatment depends on the cause, here are some general tips that may help:

- Encourage your relative to sit in the upright position and stay with them.
- Put on a fan and/or open a window
- Suggest that your relative wear loose-fitting clothing
- Put on some calming music, maintain a gentle, reassuring presence, offer a foot, hand, or shoulder massage
- If medicines for breathlessness have been prescribed, ensure they are taken as directed.
- Oxygen via a mask or nasal prongs is not routinely needed and requires a doctor's order for use
- If breathlessness is not relieved and is causing distress, phone the palliative care team

Fatigue

Fatigue is very common in people with life-threatening illnesses. It is a feeling of extreme tiredness that can be quite frustrating or debilitating.

There are several possible causes of fatigue. These include lack of sleep, low oxygen in the blood, poor diet, depression, the effect of chemotherapy or radiotherapy, infection, or the effects of the disease itself.

Fatigue can be (not always) quite hard to manage.

The following strategies may help:

- Encourage short naps during the day
- Suggest regular gentle exercise
- Encourage nutritious food and drinks
- Plan to do the most energetic tasks (e.g., shower or bath) when energy levels are higher
- Encourage your relative to take up a hobby that does not require a lot of energy, for example board games, talking books, listening to the radio, and/or watching television or videos
- If you think that fatigue has become worse, speak with the palliative care team

Delirium

This is a change in a person's thinking, memory and behaviour, and is common in patients who are receiving palliative care. The changes are due a disturbance in brain function due to illness or sometimes medication.

Patients receiving palliative care, either in the hospital or at home, are often more ill than other patients, and are taking a variety of medicines.

We know that seriously ill patients, who take several different medicines and who may have infections or have had recent surgery, may develop delirium. Patients who are older, or who already have some memory problems are more likely to develop delirium.

Delirium can be very distressing for the person who has it, and for their family. People with delirium have difficulty remembering new information, trouble concentrating, and paying attention, and sometimes difficulty telling day from night.

The person with delirium may be confused and not recognise familiar people or they may become fixated on one thing, or suspicious. Sometimes delirium causes hallucinations when people see things that are not there.

The doctors and nurses looking after your relative will look for causes and try to treat the cause so that the delirium will settle. Sometimes the patient may be prescribed tranquilising medicine to help them to feel calmer and to make sure they are safe.

The changes in the person's thinking and behaviour when they have delirium are not usually permanent and do not mean that the person has an ongoing mental health problem. However, it is noteworthy that patients in a palliative care setting may be very ill and close to death, and in this situation, the thinking, memory, and behaviour problems of delirium may not settle completely.

The best way of helping your relative with delirium is to make sure you have eye contact with them, speak slowly and calmly and remind them who you are, where they are, and that you are there to help.

If your relative is in the hospital or another care facility, it is very helpful for staff if family and friends can stay with the patient whenever possible, as patients with delirium respond better to familiar people than strangers.

It is best for the person with delirium not to have too many visitors at once, nor to have too much stimulation, such as loud music or TV. It is also important to encourage them to drink fluids, as they may get dry, especially if they are restless and not wanting to eat and drink.

Please advise health professionals if you think there are changes in your relative that might mean they are developing delirium. It is also helpful to give the staff as much information as you can about your relative's previous history as this may be important in diagnosing the cause of the delirium and preventing delirium recurring.

Complementary therapies

Complementary therapies are treatments used together with conventional medicine. Alternative treatments are those used in place of conventional medicine and are sometimes referred to as unproven remedies.

Complementary physical and psychological therapies include massage, acupuncture, reiki, hypnosis, and guided imagery.

Complementary therapies can have beneficial outcomes in some circumstances; however, it is strongly recommended that you speak with a health professional for further information about what complementary therapy(s) might be suitable for your relative or you. Other examples include aromatherapy, music therapy, art therapy, pet therapy.

It is quite common for people with life-threatening illnesses to consider other medical treatments not routinely used by doctors. This is because people often want to explore all possible treatment options. It is highly recommended that before using alternative treatments you discuss these options with your relative's GP or medical specialist. While some of these alternative treatments may be promoted as being beneficial, some might be harmful. It is wise to talk with a medical specialist about the benefits of any alternative treatments.

Emotional care

It is very hard to provide precise tips on dealing with your relative's emotions, as every relationship is different. It may help to be aware that your relative will have 'highs and lows' throughout the illness. At times, they might feel angry, upset, grumpy, or irritable and may even blame you for some of their emotions, however, sometimes they may feel very positive.

Your relative may be thinking about several major issues about death and dying. Some of these things may be easier to talk about with someone else, perhaps someone from the palliative care team. The point is, you do not have to have all the answers.

Some things that may help include:

- Providing some time alone each day, if desired
- Asking if there is anything that you can do to make things easier
- Suggest some enjoyable things to do together
- Asking if there is anything they particular desire
- Remember that it is normal for your relative to feel downhearted from time to time
- Encourage involvement in ‘day to day’ things such as news and social activities
- Remind your relative of the skills and different roles of the palliative care team
- Tell them how much you care for them and want to help them

In some instances, patients and/or their caregivers become so worried about what is happening that they become depressed or anxious. Everyone has times where they feel a bit low or ‘flat.’ Depression usually means the person experiences the following symptoms for more than two weeks: feeling sad, down or miserable most of the time, lost interest or pleasure in most of their usual activities.

While there are many types of anxiety disorders and the symptoms for each disorder are different, some general signs and symptoms include:

- Feeling very worried or anxious most of the time
- Finding it difficult to calm down
- Feeling overwhelmed or frightened by sudden feelings of intense panic anxiety
- Experiencing recurring thoughts that cause anxiety, but may seem silly to others
- Avoiding situations or things that cause anxiety (e.g. social events or crowded places)
- Experiencing ongoing difficulties (e.g. nightmares/flashbacks) after a traumatic event

Spiritual care at the end of life is much broader than formal religious practices.

It refers to any support related to questions about life’s meaning, depending on the person’s values and beliefs. The kind of spiritual care required will differ for every person.

If you are unsure of your relative's spiritual needs, you (or someone else) can open up a conversation with questions such as:

- Is there any particular person, place, or object that gives you hope and strength at this stage of your illness?
- Is there a particular religious ritual with which you would like assistance?
- Do you have any particular concerns as death is approaching?
- Is there anyone you would like to talk to about spiritual matters?

If your relative is in the habit of attending religious services, and this is no longer possible, discuss the matter with the religious representative. For example, someone from the religious community may arrange to come to your home to support you and read the Quran together.

These religious contacts need to be maintained, as well as any familiar rituals.

These visits may help you and your relative feel less isolated, and to feel that you remain an important part of the religious community.

Opportunities to receive Holy Communion or to participate in other rituals, to make a confession or to seek religious 'counsel' are all a part of spiritual care, depending on your relative's wishes and familiar practices. In times of crisis, spiritual care can be very helpful.

Other spiritual matters may include reminiscing or conducting a 'life review' with you and/or with another family member or friend. This provides the opportunity to 'tie up loose ends,' to laugh and to cry, and to tap into the 'spirit' of your relative. Some people choose to write the life review down so that it can be available as a memoir.

Other ways of tapping into the 'spirit' or the 'whole person' maybe through music, art, literature, photos, or conversation. A way into this 'spiritual realm' may be to ask your relative, 'What's the most important issue for you at this time?' or, 'If you had one wish, what would it be?"

Cultural care

We all have certain values, beliefs, and customs, and these are usually associated with our cultural backgrounds. You must let the palliative care team know about any specific cultural practices that are important for you and your relative. These may include matters of diet, personal hygiene, clothing, special national or holy days, or other important rituals.

If you or your relative has difficulty understanding English, the palliative care service can arrange for an interpreter. Although family or friends may be able to help with interpreting from time to time, the recommendation is for professional health interpreters when discussing important information about healthcare.

If you or your relative would prefer not to discuss issues of death and dying because of your cultural beliefs, please let the palliative care team know, to prevent offense or embarrassment.

How much patients should be told about their illnesses

Your relative might have chosen not to be told of their serious illness, leaving you to obtain all the information and to make the decisions. Even though your relative may in fact 'know' that they have a life-threatening illness, they may avoid any discussion on the subject. This may place a great burden on you, and seeking help from the palliative care team is essential.

Depending on your relationship with your relative, and the way you have communicated difficult issues in the past, you may ask, 'Can we have a chat about this with someone else here?' A member of the palliative care team can help you with this discussion. Remember also, that some patients who have previously refused to speak about their terminal illness change their mind, so be prepared for the unexpected.

On some occasions, family carers think their relative should not be informed about their diagnosis. This could be because they think their relative will not cope with such news, or specific cultural reasons why it is not appropriate to talk about death and dying.

However, people with a life-threatening illness commonly want to plan and make decisions about their place of care, put their affairs in order, say their good-byes, and be protected from unnecessary medical interventions.

It is very difficult to keep information from relatives. As one person said, “Truth may hurt but deceit hurts more.” The palliative care teams are very experienced in having open discussions and answering family and patient queries about the impact of the illness.

Forgoing medical treatment

Many patients and carers are keen to pursue ‘just one more treatment’ in the hope of a cure, or in the desire to postpone the person’s death. Others think that ‘stopping treatment’ is ‘giving up’ or hastening the person’s death. You may find reassurance in the palliative care principle that treatments should only be offered if they are going to improve the person’s quality of life. This is why treatment such as pain management remains right until the end. Remember also, that palliative care focuses on comfort when cure is no longer possible. When no more specific medical treatment is likely to improve the person’s condition, all aspects of palliative care (physical, psychological, spiritual, cultural, and emotional) will continue, together with support for you and your relative.

Working with the Healthcare Team.

Your situation may be changing a lot; it is very important to keep asking questions. Some caregivers feel they received a great deal of information early on, but not as much later. Learning all the unknowns of the different care and treatment options can be stressful.

You and your loved one need to sit down with the healthcare team to talk about future steps and what to expect. You may be afraid of what you might hear, but other caregivers have felt reassured after learning their options - it made them able to plan.

Some people with cancer want to know everything. Others let their caregivers make decisions. Sometimes these differences are cultural, other times they are personal. The patient, your family, and you should decide who would be the primary contact for the healthcare team.

General Tips for Meeting With the Health Care Team

If you are going with the patient to medical visits, here are some general tips for meeting with the healthcare team:

- Make a list of questions before each appointment
- Take notes, or ask the doctor if it is okay to use a tape recorder
- Get a phone number of someone to call with follow-up questions
- Keep a file or notebook of all the papers and test results. Make sure it is taken to medical visits
- Keep records or a diary of all the visits. List the drugs and tests your loved one has taken
- Keep a record of any upsetting symptoms or side effects; note when and where they occur
- Find out what to do in an emergency; this includes who to call, how to reach them, and where to go

Activity (2): Patient Needs for Comfort---------- (30 minutes).

Aim: To ensure caregivers' perceptions are congruent with patient needs, and that direct and indirect care needs are addressed, healthcare professionals need to provide caregivers with appropriate information to manage patients' symptoms.

Symptom management for patient comfort is a fundamental need and becomes a major concern as the disease progresses and treatments become less effective.

Healthcare providers should assess family members' abilities to recognise symptoms and to gauge the circumstances under which the patient should be referred to the healthcare system.

Tailoring a plan of care involves providing information to enhance family caregivers' levels of knowledge so that they can identify symptoms early, manage them effectively and recognise

when to seek assistance from the formal system, i.e. when symptoms appear out of control or current measures are ineffective.

Additionally, family members need to know how to report symptoms in ways that are useful to healthcare professionals in making effective decisions. Symptom control can become a major struggle for patients with advanced disease and their family caregivers. Pain management, in particular, often becomes a pervasive and intractable problem for family caregivers, contributing to care demands as well as to their distress.

Pain Control as a Model:

Pharmacologic Pain Control*:* The pharmacologic-specific demands on the family caregiver relate to deciding what medication to use for pain relief, when to give the medication (around the clock versus as needed), monitoring for side effects, reminding the patient about medication keeping records, controlling dosage, assessing the efficacy of pain control, and noting when and how to report negative results or ineffectiveness.

Nonpharmacological Pain Management: Nonpharmacological activities related to pain management may include distraction, such as talking with the patient or playing music, emotional support, positioning or complementing drug therapy with heat or cold therapy.
Although healthcare professionals usually help family members understand pharmacologic issues and medication instructions, nonpharmacological strategies, such as distraction or complementary approaches, are not discussed as frequently.
Patients/caregivers report they learn these management skills through trial and error, and would like more assistance from the formal healthcare system.

Asking About Pain

People who have their pain managed can focus on enjoying life

Caregivers often worry about their loved ones being in pain. If they are preoccupied with pain, you may notice changes in their personality, such as being distant, not being able to sleep, or not being able to focus on daily activities they once enjoyed.

Your loved one does not have to be in pain or any discomfort

Some people assume there will always be severe pain with cancer. This is not true. Pain is manageable throughout treatment. The key is to talk regularly with the healthcare team about pain and other symptoms. You may want to ask if there is a pain specialist on staff as well.

Sometimes people with cancer do not want to talk to the healthcare team about their pain

They worry others will think that they are complaining, or that pain means the cancer is getting worse, or they think that pain is just something they have to accept. Sometimes people get so used to pain, they forget what it is like to live without it.
The medical team should ask about pain levels, but it is up to you and the patient to be open about any pain he/she is having. This is when you need to encourage him/her to speak up, or you can speak up for them. Be honest with the doctor about the pain and how it is affecting his/her routine. It may take more than one talk to feel comfortable about the pain medicines given.

Some caregivers worry that they will give their loved one too much medicine. This rarely happens, but you need to talk to the doctor about your fears and concerns.
Talk with the healthcare team about how to keep your loved one as comfortable as possible; make sure to include any hospice staff you may have. Some drugs can help treat pain, and can be adjusted or changed if they are not working, or have unpleasant side effects.

Do not be afraid to ask for stronger pain relievers or larger doses if needed by the patient; addiction is not an issue in people with advanced cancer, and they will help your loved one

stay as comfortable as possible. People with a history of addiction will want to talk to their doctor about any concerns.

Asking About Other Changes

Sometimes, as treatment continues, changes may take place in the person with cancer. These may be due to the side effects of treatment or cancer itself, or be caused by other drugs. Some caregivers have said they wished they had known about these changes sooner and had known what to expect.

Changes may occur in:

- Looks
- Personality or mood
- Memory
- Sleep
- Appetite or nutrition needs

The person you are caring for may or may not go through any of these changes, but you should ask the doctor if you need to be aware of them. At the same time, ask what you can do about them if they happen. It will help you to know that these changes are normal, and give you ways to be prepared.

Some caregivers who have lost their loved ones say they wished they had known the signs that death was near. They say this would have helped them be less afraid or worried.

Activity (3): Coordinating Care and Keep Communication to Prevent Misunderstanding and Promote Positive Interaction ---------- (30 minutes)

Among patients with advanced disease, an often unrecognised and complex demand relates to the coordination and structuring of care. Family caregivers must interact and negotiate with the formal care system to schedule appointments, report changes in condition, change medications, or ask for assistance.

Health professionals need to recognise that primary family caregivers often are gatekeepers themselves, and may be reluctant to seek assistance even when they feel inadequately prepared to provide care and report both informational and skill deficits.
Some caregivers cannot carry out the full range of care activities successfully, some have difficulty with making decisions and problem-solving, whilst others become stressed dealing with multiple healthcare providers and coordinating the tasks of both professionals and other family caregivers. All of this indicates the importance of coordination and communication between primary caregivers and other health professionals related to their patient's quality of life and health condition. Conversely, understanding of caregivers to communicate with patients will enhance the process of health information exchange.

Aims:

- Recognising main communication technique and emphasising the main role of communication in caregiving
- Participants will have the ability to get health information for their patients and keep the connection with others to collect relative information need

As a caregiver and advocate for a loved one, you play a central role in this partnership. You are likely to be the person who collects information, speaks to healthcare professions, transports the patient, ensures lab tests are done, picks up, prepares and gives medications, researches treatment options and risks, handles insurance, and fulfils many other related tasks. In this fact sheet, we offer some tips to remove barriers and encourage meaningful communication between you and any other healthcare practitioners.

Talking with Family and Friends.

Talking about serious issues is never easy. It is hard to face an uncertain future and the potential death of your loved one. Often people are uncomfortable talking about it, or just do not know what to say, but you will need to talk to your loved one or others about several issues. These might include the seriousness of cancer, preparing for the future, fears of death, or wishes at the end of life.

Some families talk openly about things, others do not. There is no right or wrong way to communicate, but studies show that families who talk things out feel better about the care they get and the decisions they make.

Talking with Your Loved One Who Has Advanced Cancer.

Likely, you and your loved one are both having the same thoughts and fears about the end of life. It is natural to want to protect each other. Talking about death does not cause someone to die, and keeping things to yourself does not make them live longer.

You and your loved one can still have hope for longer life or an unexpected recovery. It is a good idea to talk about what is happening, and the fact the future is uncertain; keeping the truth from each other is not healthy. Avoiding important issues only makes them harder to deal with later.

You may find that you both are thinking the same things, or you may find you are thinking very different things. This makes it important to get them out in the open. Talking over your concerns can be very healing for all involved.

Often the best way to communicate with someone is to just listen

This is one of the main ways of showing you are there for them; may be one of the most valuable things you can do. It is important to be supportive of whatever your loved one wants to say; it is their life and their cancer. He/she needs to process their thoughts and fears in their own time and way. You can always ask whether he/she is willing to think about the issue and talk another time. He/she may prefer to talk to someone else about the topic.

Bringing Up Hard Topics

Bringing up challenging subjects is draining. You may think, for example, that your loved one needs to try a different treatment or see a different doctor. They may be worrying about losing independence, being seen as weak, or being a burden to you.

What is important to remember is that your loved one has the right to choose how to live the rest of their life. Although you may have strong opinions about what he/she should do, the decision is theirs to make.

Here are some tips on how to bring up hard topics:

- Practice what you will say in advance
- Find a quiet time. Ask if it is an okay time to talk
- Be clear on what your aims are. What do you want as a result?
- Speak from your heart
- Allow time for your loved one to talk. Listen and try not to interrupt
- Do not feel the need to settle things after one talk
- You do not always have to say, “It’ll be okay.”

Some people will not start a conversation themselves but may respond if you start first. Ask other caregivers how they have handled hard topics.

If you continue to have trouble talking about painful issues, ask for professional advice. A mental health expert may be able to help you explore issues that you do not feel you can yourselves, but if your loved one does not want to go, you can always make an appointment to go alone. You may hear some ideas for how to bring up these topics. You can also talk about other concerns and feelings you are dealing with.

Keeping the Lines of Communication Open

Understand Your Patient's Actions and Feelings

Cancer caregivers of any age react to their loved one’s cancer in many different ways. They may:

- Seem confused, scared, angry, lonely, or overwhelmed
- Feel scared or unsure how to act when they see the treatment’s effects on the patient
- Act clingy or miss all the attention they used to get

- Feel responsible or guilty
- Get angry if they're asked to do more chores around the house
- Get into trouble at work and neglect their duties
- Have trouble eating, sleeping, keeping up with duty issues, or relating to friends
- Be angry that someone else is taking care of them now

No matter how your patient is reacting, it is usually easier to deal with their feelings before problems appear. If they do not open up to you, they may prefer talking to someone outside the family; if you notice changes or problems, you may want to ask for help from health professionals who know your family already. Any of these may be able to suggest a mental health professional for your patient if needed.

Other Behaviours.

It is normal for some cancer patients to show signs of regression. They may begin acting younger than their years, resuming behaviours they had stopped, or they may lose skills they had mastered recently. This is usually a sign of stress.

This is a way for them to express their feelings and, in their way, ask for support. Recognise they are needier right now. Be patient as you work with them to get them back to their normal behaviour. Do not hesitate to seek help from a social worker or other professional if you need more advice, or support.

Try to Ask Open-Ended Questions

For some families, talking about serious issues is very difficult. As challenging as it may be, *not* talking about it can be worse. Try to ask open-ended questions, instead of "yes" or "no" questions.
Here are some ideas you might want to share with cancer patients of any age:

- No matter what happens, you will always be taken care of
- Nothing you did caused the cancer, and there is nothing you can do to take it away either

- People may act differently around you because they are worried about you or worried about all of us
- You can ask me anything anytime
- Are you okay talking with me about this? Or would you rather talk to Mrs. Xxx
- It is okay to be upset, angry, scared, or sad about all this. You may feel lots of feelings throughout this time. You will probably feel happy sometimes, too. It is okay to feel all those things

Encourage Your Cancer Patient to Share Their Feelings and Questions

Let them know they are not alone, and that it is normal to have mixed emotions. Help them find ways to talk about their feelings. Young cancer patients may be able to show you how they are feeling by playing with dolls or drawing pictures. Other forms of art can help older patients express themselves.

Keep encouraging them to ask questions throughout caregiving. Keep in mind that young patients may ask the same question repeatedly. This is normal, and you should calmly answer the question each time.

Find Moments to Connect

Come up with new ways to connect. Make a point of tucking them in at bedtime, eating together, and reading to them, talking on the phone, or by email. Talk to them while you fold clothes or do the dishes.

Have a set time when your children do homework while you do something else in the same room. Take a walk together. Going to the grocery store can even be “together time.” Just 5 minutes alone with each child without interruptions can make a world of difference.

Communicating with Your Partner with Cancer

Some couples feel more comfortable talking about serious issues than do others. Only you and your partner know how you feel about it.

Some things that cause stress for you and your partner cannot be solved immediately, but sometimes talking about them can be helpful. You may want to say something like this upfront, “I know we can’t solve this today. But I’d like to just talk some about how it’s going and how we’re feeling.”

Topics to explore may include how each person:

- Copes with change and the unknown
- Feels about being a caregiver or being cared for
- Handles changing roles in the relationship or home
- Would like to be connected
- Sees what issues may be straining the relationship
- Feels, or would like to feel, cared for and appreciated
- Feels thankful for the other person

As your loved one becomes more ill, you may want to share issues that are more practical, such as what decisions you should share and which you should make alone. Along with this, you may want to talk about the different tasks you can each handle right now.

Find Ways to Say Thanks

Maybe your partner used to do a lot to keep your family going, and now, because he/she is sick, you are trying to get used to less help. It may be hard to notice the small things your partner is still doing to help as often too much is going on. When you can, try to look for these things and thank your partner for doing them.

Often it does not take much to put a bright spot in your loved one’s day. Bringing your partner a cool drink, giving him a card, or calling to check in can show that you care. Showing a little gratitude can make both of you feel better.

Spend Time Together

Many couples find that it helps to plan special time together. Some days may be better than others are, depending on how your partner feels; you may need to be okay with last-minute changes. You do not have to be fancy as it is about spending time together. It can mean watching a video, going out to eat, or looking through old photos. It can be whatever you both like to do. You also can plan occasions to include other people, if you miss that.

Communication Troupe

Studies show that open and caring communication works best. Yet often caregivers run into:

- Tension from different ways of communicating
- Lack of sensitivity or understanding about appropriate ways to talk and share feelings
- People who do not know what to say, will not communicate at all, or will not be honest

Talk about it. Choose a time when you both can talk. Focus on how you can renew your connection.

Try not to judge. If your partner is not performing, try not to read meaning into it. Let your partner tell you what he or she needs.

Make space. Protect your time together. Turn off the phone and TV. If needed, find someone to take care of the kids for a few hours.

Communicating with Other Family Members and Friends

Any problems your family may have had before the cancer diagnosis are likely to be more intense now. This is true whether you are caring for a young child, an adult child, a parent, or a spouse. Your caregiver role can often trigger feelings and role changes that affect your family in ways you never expected. Relatives you do not know very well or who live far away may be present more often, which may complicate things.

It is very common for families to argue over several things at this time.
These might include:

- Treatment options for their loved one, or whether to continue treatment at all
- When to use hospice care
- What treatment the patient desires
- Feelings that some family members help more than others

While everyone may be trying to do what is best for your loved one, some family members may disagree as to what this means. Everyone brings their own set of beliefs and values to the table, which makes these decisions hard. It is often during these times that families ask their healthcare team to hold a family meeting.

Family Meetings

Family meetings are necessary throughout cancer care. They become even more important as cancer progresses. In a family meeting, the healthcare team and family meet to discuss care. You can ask a social worker or counsellor to be there if needed. Talk with your loved one to see if he wants a family meeting. Ask if he would like to be involved.

Meetings can be used to:

- Have the healthcare team explain the overall goals for care
- Let the family state their wishes for care
- Give everyone an open forum in which to express their feelings
- Clarify caregiving tasks

If you need to, bring a list of issues to discuss. At the end of the meeting, ask the healthcare team to summarise decisions and plan the next steps.

How to Communicate When Support Is Not Useful

Sometimes people are eager to help you because they want to feel useful, but at times, you may not need the support, or you may simply want to spend time alone with your sick loved one.

If people offer help you do not need or want, thank them for their concern. Let them know that right now, you have things under control, but you will contact them if you need anything. You can tell them that it always helps to send cards, letters, and emails, or they can pray or send good thoughts.

Sometimes people offer unwanted advice on parenting, medical care, or any number of issues. It can be unpleasant to hear such comments.

For example, some caregivers have shared:

"We have a problem with a member of my husband's family. She doesn't live here and keeps questioning all our decisions. It's gotten so bad that we've had our doctor explain to her that she's not here all day, and, therefore, doesn't understand the situation. She has been a real pain."

"I feel like people want him to do the treatment they are suggesting, rather than what we feel is best. It's making this harder than it needs to be."

"People often offer unwanted advice because they aren't sure what else they can do. They may feel helpless to do anything, yet want to show their concern. While it may come from a good place, it can still seem judgmental to you."

" It's your decision on how to deal with these opinions. You don't have to respond at all if you don't want to. If someone has concerns about your kids that seem valid, talk to a counsellor or teacher about what steps to take. Or if the concerns are about your loved one, you can talk to the medical team. Otherwise, thank them. And reassure them that you are taking the necessary steps to get your loved one and family through this tough time."

Caring for Your Self.

Coping with Your Feelings

You have probably had a range of feelings as you care for your loved one. These emotions can be quite strong at times and less so at others. It takes a lot of energy to stay hopeful and cope with the ongoing waves of emotion. Now that the cancer has advanced, these feelings maybe even more intense.

Sadness or Worry

You may feel sad or worried as you watch your loved one struggle with cancer. You may be concerned with how he/she is coping with side effects or coping with fear. You may be worried about bills, your family, or ending up alone.

It is okay to cry or express your feelings when you are alone or with a trusted friend. You do not have to be upbeat all the time or pretend to be cheerful. Give yourself time to cope with the changes you and your loved one may be going through.

Depression is a persistent sadness that lasts more than two weeks. If any of these symptoms start affecting your ability to function normally, talk with your healthcare provider. Do not think you need to tough it out without any help as more than likely your symptoms can be eased.

Grief

Grief is the process of letting go and accepting and learning to live with loss. Part of the grieving process is feeling extreme sadness, as well as other feelings. You may feel sad about the losses you have experienced, including the loss of the life you used to have.

Grieving does not mean you have to feel a certain way

Everyone is different. Let yourself grieve in your way and time. For example, some people may not show as much emotion as others do when they grieve. They show their feelings by doing things, rather than talking about them. This does not mean they are not feeling “the right way,” or that they need to change how they react.

You may begin to feel the loss of your loved one even before he dies. This is **anticipatory grief**. It is normal to feel sad about the changes you are going through and the losses you are going to have. You may have expected your life with your friend or family member to be different to what you are going through. Feeling sad over what might have been or what is to come is expected. It is normal for you to have grief over the future loss of your loved one, and all the changes involved.

Understand that these feelings are normal, and grief can come up at times when you are not expecting it. Although it can come and go in intensity, grief can last for many months. It is important to seek help from hospice staff, a mental health expert, or a support group.

Anger.

Many things are going on right now that can make you angry. You may be angry with yourself, your family, God, or even the person you are caring for. At first, anger can help by moving you to take action. You may decide to learn more about different treatment options or get more medical opinions. However, anger does not help if you hold it in too long, or take it out on others.

It may help to pinpoint why you are angry. This is not always easy. Sometimes anger comes from feelings that are hard to show, such as fear, panic, or worry, or it may come from resentment. If these feelings remain, seek help from a counsellor or other mental health professional.

Denial

You may have trouble accepting that your friend or family member may not recover. You may think that if he/she keeps getting treatment, something may finally work, or there will be a discovery. There is nothing wrong with this, but try to listen to your loved one and the doctor to hear what they are saying.

Your way of coping may make the patient feel you do not understand what is happening. Again, it is okay to deal with things at your own pace, but be aware of the effect this may have on others.

Caring for Your Mind and Spirit

Find Comfort

Your mind needs a break from the demands of caregiving. Think about what gives you comfort or helps you relax. Caregivers say that even a few minutes a day without interruptions helps them to cope and focus.

Take 15–30 minutes each day to do something for yourself, no matter how small it is. For example, caregivers often find that they feel less tired and stressed after light exercise - try to make time for taking a walk, going for a run, riding a bike, or doing gentle stretches.

You may find it is hard to relax even when you have time for it. Some caregivers find it helpful to do exercises designed to help you relax, such as stretching or yoga. Other relaxing activities include taking deep breaths or just sitting still.

Look for Positives

Finding positive moments when you are busy caregiving can be hard. Caregivers say that looking for the good things in life helps them to feel better. Each day, try to think about something that you find rewarding about caregiving. You also might take a moment to feel good about anything else from the day that is positive — a nice sunset, a hug, or something funny that you heard or read.

Find Acceptance

You are on your path toward accepting the fact that your loved one may die. Although it may take time, acceptance can bring feelings of peace. You may find that cancer helps you value life more. You may feel that you live each day more fully, even though the future is unknown.

Feel Tankful.

You may feel thankful that you can be there for your loved one. You may be glad for a chance to do something positive and give to another person in a way you never knew you could. Some caregivers feel they have the chance to build or strengthen a relationship. This does not mean that caregiving is easy or stress-free, but finding meaning in caregiving can make it easier to manage.

Connect with Other People

Studies show that connecting with other people is very important for most caregivers. It is especially helpful when you feel overwhelmed. Sometimes you want to say things that you are just unable to say to your loved one.

Try to find someone you can open up to about your feelings or fears. You may find it helpful to talk with someone outside the situation. Some caregivers have an informal network of people to contact. Some also see a counsellor or therapist. If you are concerned about a caregiving issue, you may want to talk with your loved one's healthcare team. Knowledge often helps reduce fears.

Let Yourself Laugh

It is okay to laugh, even if your loved one has advanced cancer. It is healthy. Laughter releases tension and makes you feel better. You can read funny columns and comics, watch comedy shows, talk with upbeat friends, or remember funny things that have happened to you in the past. Keeping your sense of humour is a good coping skill.

Confront Your Anger or Frustration

You may find that you are getting angrier and frustrated as the person you are caring for becomes sicker. It may help to try to process these feelings as they happen, rather than hold them in. Ask yourself what is causing the anger. Are you tired? Frustrated with medical

care. Does your loved one seem demanding? If you can, try to let some time pass before bringing up your feelings. It may also help you to express your anger through exercise, art, or even hitting the bed with a pillow.

Let Go of Your Guilt

If you are feeling guilty, here are some things you can do:

Let go of mistakes. You cannot be perfect, no one is. The best we can do is learn from our mistakes and move on. Continue to do the best you can, and try not to expect too much from yourself.

Put your energy into the things that matter to you. Focus on the things you feel are worth your time and energy. Let the other things go for now. For example, do not fold the clothes when you are tired, go ahead and rest instead.
Forgive yourself and others. Chances are people are doing what they can; that includes you. Each new moment and a new day gives you a chance to try again.

Join a Support Group

Support groups can meet in person, by phone, or over the Internet. They may help you gain new insight into what is happening, give you ideas about how to cope, and help you know that you are not alone.

In a support group, people may talk about their feelings and experiences. They may trade advice with each other and help others who are dealing with the same kinds of issues.

Some people like to go and just listen, while others prefer not to join support groups at all. Some people are not comfortable with this kind of sharing.

If you feel you would benefit from outside support such as this but are unable to get to a group in your area, try a support group on the Internet. Some caregivers say websites with support groups have helped them.

Making Time for Yourself

You may feel your needs are not important right now, or maybe by the time you have taken care of everything else, you have no time left for yourself. You may feel guilty that you can enjoy things that your loved one is unable to right now.

Most caregivers say they have those same feelings. Caring for your own needs, hopes, and desires is important to give you the strength to carry on.
Taking time to recharge your own body, mind, and spirit can help you be a better caregiver. If you are sick or not feeling well, it is even more important that you take care of yourself, too. You may want to think about:

- Finding nice things you can do for yourself—even for a few minutes
- Finding nice things others can do or set up for you
- Finding new ways to connect with friends
- Taking larger chunks of time that are “off-duty”

Giving yourself an outlet to cope with your thoughts and feelings is important, too. Try to think about what would help give you a lift. Would talking with others help ease your load? Is quiet time by yourself what you would like best? You might want some of both, depending on what is going on in your life. It is helpful to take the time to think about your own needs.

Finding Meaning

Many caregivers find that cancer experience causes them to look for meaning in their lives. Taking time to think about your life and your relationship with your loved one may help you feel a sense of closure, accomplishment, and meaning. You may want to share your thoughts with your loved one or others, or you may just want to write them down or tape-record them for yourself.

Here are some questions to ask yourself or your loved one:

- What are the happiest and saddest times we have shared?

- What are the defining or most important moments of our life together?
- What have we taught each other?
- How has being a caregiver affected my life?

When you are ready, you may want to step back and take a further look at life together. When someone you love has cancer, you may begin to rethink the things that are important to you. Some caregivers and loved ones do things together that they had always planned to do. Others do not make many changes; instead they enjoy the life they have together much more. Life can become more about the person, not the disease.

Some things you and your loved one can do to celebrate your life together are:

- Make a video of special memories
- Review or arrange family photo albums
- Chart or write down your family's history or family tree
- Keep a daily journal of feelings and experiences
- Make a scrapbook
- Help write notes or letters to other friends and family members
- Read or write poetry
- Create artwork, knit, or make jewellery
- Choose meaningful objects or mementos together to give to others
- Write down or record funny or meaningful stories from the past

You, the patient, and other family members can do whatever brings joy and meaning to your lives. Your loved one may even decide to make an "ethical will." It is not a legal paper, it is something a person writes to share with people he or she cares about. Many ethical wills contain the person's thoughts on their values, memories, and hopes. They may also contain the lessons learned in life or other meaningful things.

Faith and Spirituality

Some find meaning in religion; others look to another kind of higher power.

Some caregivers wonder why they have to go through this experience, whilst others feel blessed by it; some caregivers feel both these things.

Being spiritual is very personal and means something different for everyone. As you look at life in new ways, you may find a spiritual path helpful.
Some ways to add spirituality to your daily life include:

- Reading religious or spiritual books, listening to spiritual music or watching related videos or TV programmes
- Keeping uplifting quotes handy
- Praying or meditating
- Talking with a member of your faith community or someone else with a spiritual nature
- Visiting a place of worship
- Finding a special place where you find beauty or a sense of calm
- Asking the hospital social worker or recreation therapist to suggest relaxing music

Caring for Your Body.

You may find yourself so busy and concerned about your loved one that you do not pay attention to your health. You must take care of yourself.

Taking care of yourself will give you the strength to help others. The added stress and daily demands often add to any health problems caregivers already have.
They also may have one or more of the problems below:

- Fatigue (tiredness)
- Sleeping problems
- Weaker immune system (poor ability to fight off illness)
- Slower healing of wounds
- Higher blood pressure
- Changes in appetite and/or weight
- Headaches
- Anxiety, depression, or other mood changes

Taking Care of Yourself.

These ideas for taking care of yourself may sound easy, but they are a challenge for most caregivers. You will need to pay attention to how you are feeling, in both body and mind. Even though you are putting your loved one's needs first, it is important to:

- Keep up with your check-ups, screenings, and other medical needs
- Try to remember to take your medicines as prescribed
- Ask your doctor to give you extra refills to save trips
- Find out if your grocery store or pharmacy delivers

Try to eat healthy meals.

Eating well will help you keep up your strength. If your loved one is in hospital, or has long doctor's appointments, bring easy-to-prepare food from home. For example, sandwiches, salads, or packaged foods and canned meats fit easily into a lunch container.

Get enough rest.

Listening to soft music or doing breathing exercises may help you fall asleep. Short naps can energise you if you are not getting enough sleep. Talk with your doctor if a lack of sleep becomes an ongoing problem.

Exercise

Walking, swimming, running, or bike riding are a few ways to get your body moving. Any kind of exercise (including working in the garden, cleaning, mowing, or going upstairs) can help you keep your body healthy. Finding at least 15-30 minutes a day to exercise may make you feel better and help manage your stress.

Make time for yourself to relax.

You may choose to stretch, read, watch television, or talk on the phone. Whatever helps you unwind, you should take the time to do it.

Reflection.

As a caregiver, you try to strike a balance each day. You have to care for your loved one while keeping up with the demands of family and work. Your focus tends to be on the patient's needs, but it is up to you to try to stay in tune with yourself. Remember the things you need to maintain a healthy mind, body, and spirit. If you can, try to find a quiet time for reflection each day; meditating, praying, or just resting may help you keep a sense of peace at this time.

Other have described caring for someone with advanced cancer as the toughest thing they have ever been through, yet they would not have given it up for the world.

Whether good or bad, life-changing situations often give people the chance to grow, learn, and appreciate what is important to them. Many people who care for someone with cancer describe the experience as a personal journey. They say it has changed them forever, much like the way people with cancer describe their experience. It is not a journey most caregivers would have chosen, but they can use their skills, strength, and talents to support their loved one while finding out more about themselves along the way.

<u>MODULE FOUR</u>: FAMILY CAREGIVER NEEDS FOR INFORMATION, SUPPORT, ASSISTANCE AND ADJUSTING TO BEING CAREGIVER

Provide information about the dimensions of care offered to gain a deeper understanding of caregiving and figuring out the basic concept and meaning of caregiving which help participants to adjust to being caregiver, such as information and assistance regarding the disease, physical care, comfort measures, what symptoms to expect, their causes, and how to manage them, treatment regimens, expectations for future care, patients' emotional responses, household management procedures, finances and community resources. Provide assistance about how to structure such care activities as transportation, monitoring, and reporting symptoms, providing personal care (bathing, walking, and dressing), nutritional considerations, coordination of care (scheduling appointments and calling a physician), monitoring disease status, and financial activities.

Aim: Continued guidance and support from healthcare professionals will assist caregivers in coping with these aspects of care, which, in turn, will help to alleviate some of the stress, burden, and depression that caregivers experience and reassuring patients with decreased energy, as well as about managing other symptoms.

Needs: Patients with advanced disease require direct and indirect care, which involves coordination with health professionals and healthcare systems that may not be receptive to the needs of families. The number of required tasks, of which many are unpredictable, influences the complexity of caregiving. These tasks may require insights and abilities that caregivers do not possess, adding to caregivers' anxiety and frustration. The information thus becomes a key resource for family caregivers.

Session (1): Family Caregiver Needs for Information, Support, Assistance and Adjusting to Being Caregiver---------- (10.00-11.30)

Participants will receive information and assistance regarding the disease; physical care; comfort measures; what symptoms to expect, their causes, and how to manage them; treatment regimens; expectations for future care; patients' emotional responses; household management procedures; finances; community resources. Assistance about how to

structure such care activities as transportation, monitoring, and reporting symptoms, providing personal care (bathing, walking, and dressing), nutritional considerations, coordination of care (scheduling appointments and calling a physician), monitoring disease status and financial activities (Table 1).

Table 1 Demands of Caregiving

Demands of Caregiving

Direct Care: (1) Administration of Medications; (2) Wound Care and Dressings; (3) Bathing; (4) Dressing; (5) Assistance with Mobility; (6) Emotional Support

Indirect Care: (1) Obtaining Medications; (2) Scheduling Appointments and Coordinating Care; (3) Assistance with Medical Bills and General Finances; (4) Observing for Side Effects

Symptom and Comfort Management: (1) Nonpharmacological Approaches; (2) Administration of Medications; (3) Titrating Doses of Medication; (4) Observing for Side Effects

Information Needed: (1) Disease; (2) Treatment; (3) Symptom Management; (4) Expected Trajectory of Illness; (5) Emotional Distress Management; (6) Coordination of Care

Programme content

Definition:

Who Is the Caregiver?

Also referred to as *informal caregivers*, family caregivers provide a complex array of support tasks that extend across physical, psychological, spiritual, and emotional domains.

Caregivers of cancer patients generally undertake **multifaceted responsibilities** for tasks, such as:

- Administrative tasks (case management, management of insurance claims, bill payment)

- Instrumental tasks (accompanying the cancer patient to medical appointments, running personal errands, managing cooking, cleaning, and other housekeeping tasks)
- Navigation tasks (seeking information that may be difficult to find, finding a doctor)
- Social support activities (providing companionship, socialising)
- Decision maker; advocate; communicator; hands-on care provider

The caregiver burden commonly describes multiple dimensions of distress that result from an imbalance between care demands and the availability of resources to meet those demands.

- Physical Impact
- Social Impact
- Financial Impact
- Psychological Impact
- Spiritual Impact

Home Care Services for the Cancer Patient

Home care services provided for the cancer patient generally include caregiver support as part of the plan of care.

Hospice Care for the Cancer Patient

Family caregivers of home-based palliative care patients need coaching in practical care skills and more access to professional advice to increase their self-confidence and ability to perform the practical aspects of home-based care. Caregivers assisting patients in the final stages of life experience as much distress as patients do, if not more.

Adjusting to Being Caregiver

Changing Roles

Whether you are younger or older, you may find yourself in a new role as a caregiver. You may have been an active part of someone's life before cancer, but perhaps now the way you support that person is different. It may be in a way in which you have not had much experience, or in a way that feels more intense than before.

Even though caregiving may feel new to you now, many caregivers say they learn more as they go through their loved one's cancer experience.

Common situations they describe:

- Your spouse or partner may feel comfortable with only you taking care of him
- Your parent may have a hard time accepting help from you (her adult child) since he/she has always been used to caring for you
- Your adult child with cancer may not want to rely on his/her parents for care
- You may have health problems yourself, making it hard physically and emotionally to take care of someone else

Whatever your roles are now, accepting the changes may be tough. It is very common to feel confused and stressed at this time. If you can, try to share your feelings with other loved ones or join a support group, or seek help from a counsellor or psychologist. Many caregivers say that talking with a counsellor helped them; they felt they were able to say things they were unable to say to their loved ones.

Coping with Your Feelings

You have probably felt a range of feelings as you care for your loved one. They can be quite strong and may come and go as you go through treatment with the patient. Many caregivers describe it as being "like a rollercoaster." You may feel sad, afraid, angry and worried. There is no right or wrong way to feel or react. **These feelings are all normal.**
You may relate to all of the feelings described, or just a few. You may feel them at different times, with some days being better than others are. It may help to know that other caregivers have felt the same way you do.

One of the first steps in coping with feelings is to recognise they exist and that having them is normal. Try to give yourself time to understand and work through your range of emotions.

Anger

Many caregivers say they often feel angry with themselves, their family members, or the patient. Sometimes anger comes from feelings that are hard to show, such as fear, panic, or worry; or it may come from resentment of all that you are going through. If you can, try to avoid lashing out at others because of these emotions.

Anger can be healthy if you handle it the right way. It can help motivate you to take action, find out more, or make positive changes in your life. If these feelings persist and you remain angry with those around you, seek help from a counsellor or other mental health professional.

Guilt

Feeling guilty is a common reaction for caregivers. You may worry you are not helping enough, or that your work or distance from your loved one is getting in the way. You may even feel guilty that you are healthy.

You may feel guilty for not acting upbeat or cheerful, but know that it is okay. You have reasons to feel upset, and hiding these feelings may keep other people from understanding your needs.

Grief

You may be mourning the loss of what you hold most dear, your loved one's health or the life you had with each other before cancer. It is important to permit yourself to grieve these losses. It takes time to work through and accept all the changes that are occurring.

Anxiety and depression.

Anxiety means you have extra worry, you are unable to relax, you feel tense, or you have panic attacks. Many people worry about how to pay bills, how cancer will affect the family, and of course, how their loved one is doing.

Depression is a persistent sadness that lasts more than two weeks. If any of these symptoms start affecting your ability to function normally, talk with your healthcare provider. Do not think that you need to tough it out without help; there are ways of easing your symptoms during this hard time.

Loneliness

You can feel alone in your role as a caregiver, even if you have people around you. It is easy to feel like no one understands what you are going through. You may feel lonely because you have less time to see people and do things that you used to. Whatever your situation, you are not alone.

Other caregivers share their feelings.

Hope or hopelessness

You may feel hope or hopelessness to different degrees throughout your loved one's cancer treatment and this may change over time. You may hope for a cure most of all, but you may also hope for other things, such as comfort, peace, acceptance, and joy.

If you are not able to get rid of a feeling of hopelessness, talk to a trusted family member, friend, health provider, or spiritual or a faith leader. As a caregiver, feelings of hope can get you through the next 5 minutes or the next 5 days.

Other Ways to Cope

Let go of mistakes. You cannot be perfect, no one is. The best we can do is to learn from our mistakes and move on. Continue to do the best you can. Try not to expect too much from yourself.

Cry or express your feelings. You do not have to be upbeat all the time or pretend to be cheerful. Give yourself time to cope with all the changes you are going through. It is okay to cry and show that you are sad or upset.

Put your energy into the things that matter to you. Focus on the things you feel are worth your time and energy. Let the other things go for now. For example, do not fold the clothes when you are tired. Go ahead and take time to rest.

Understand where anger comes from. Your loved one may get angry with you. It is very common for people to direct their feelings to those who are closest. Their stress, fears, and worries may come out as anger.

Try not to take it personally. Sometimes patients do not realise the effect their anger has on others. So, it may help to share your feelings with them when they're calm. Try to remember that the anger is not really about you.

Forgive yourself. This is one of the most important things you can do. Chances are that you are doing what you can at this moment. Each new moment and day gives you a new chance to try again.

Knowing Your Strengths and Limits.

One way that caregivers cope is to focus their energy on things they can control. This can mean:

- Helping schedule doctor visits
- Helping with daily needs such as meals and errands
- Taking on your loved one's tasks
- Learning more about cancer and treatment options
- Doing whatever else you can do

Many caregivers say that looking back, they took on too much themselves, or they wish they had asked for help sooner. Take an honest look at what you can and cannot do. What things

do you need or want to do yourself? What tasks can you give to or share with others? Be willing to let go of things that are not essential for you to do.

Setting Your Priorities

Make a list of your weekly tasks and activities. Figure out how much time you spend on each one and how important it is. Scratch things off your to do list if they are not important. That will give you more time for the things you want and need to do. This may mean disappointing someone else, but you need to take care of what is important to you, regardless of what others may think.

Most people will understand if you tell them what is going on. “You have to learn that if people offer, let them do something. Ask for what you need, because they don’t know. You have to be willing to let go of your pride and let them help you.”

Why Getting Help Is Important

Accepting help from others is not always easy. When tough things happen, many people tend to pull away. They think, “We can handle this on our own.” However, things can get harder as the patient goes through treatment.

- You may need to change your schedule and take on new tasks. As a result, many caregivers have said, “There’s just too much on my plate.”

Remember that getting help for yourself can also help your loved one because

- You may stay healthier
- Your loved one may feel less guilty about all the things you are doing
- Some of your helpers may offer time and skills that you do not have

How Can Others Help You?

Would you find it helpful if someone made dinner for you or ran some of your errands? If so, you may benefit from having people help with the tasks for which you do not have time. People want to help, but many do not know what you need or how to offer it.

It is okay for you to take the first step.

Ask for what you need and for the things that would be most helpful to you. For example, you may want someone to:

- Help with household chores, like cooking, cleaning, shopping, yard work, and childcare or eldercare
- Talk with you and listen to your feelings
- Drive your loved one to appointments
- Pick up a child from school or activities
- Set up a website where people can find out what support you need or receive updates on your loved one
- Look up information that you need
- Be the contact person and help keep others updated on your loved one's situation

Who Can Help?

Think about people who can help you with tasks. Think of all the people and groups you know, including family, friends, neighbours, and co-workers. Members of your faith community, civic groups, and associations may also be able to help. The hospital or cancer centre may also be able to tell you about the services they offer or have a list of agencies to call.

Finding Respite Help

Respite helpers spend time with your loved one. They can be paid or volunteer their time. Many caregivers say they wish they had gotten respite help sooner. It can leave you free to rest, see friends, run errands, or do whatever you would like to do. Respite caregivers can also help with physical demands, such as lifting the patient into a bed or a chair.

If this service appeals to you, you may want to:

- Talk with your loved one about having someone come into your home to help from time to time
- Get referrals from friends, healthcare professionals, or your local agency
- Ask respite helpers what types of tasks they do. You can get respite help from family and friends, but also government agencies or non-profit groups. Whatever you do, remember that it is not a failure on your part as a caregiver if you need some help and time to yourself.

Be Prepared for Some People to Say No

Sometimes people may not be able to help. This may hurt your feelings or make you angry. It may hard coming from people whom you expected to help. You might wonder why someone would not offer to help you.

Some common reasons are:

- Some people may be coping with their problems, or a may not have the time
- They are afraid of cancer or may have already had a bad experience with cancer They do not want to get involved and feel pain all over again
- Some people believe it is best to keep a distance when people are struggling
- Sometimes people do not realise how hard things are for you; or they do not understand that you need help unless you ask them for it directly

Some people feel awkward because they do not know how to show they care. If someone is not giving you the help you need, you may want to talk to them and explain your needs; or you can just let it go. If the relationship is important, you may want to tell the person how you feel, as this can help prevent resentment or stress from building up. These feelings could hurt your relationship in the end.

Tips on How to Ask for Help

- “His cancer is a private thing. I would have to tell people about it to get any support”

You and your loved one can decide who to tell, what to tell them, and when and how. Some options are to:

- Tell only a few people close to you for now
- Limit specifics about what you share. You can say, “He’s sick,” or “She isn’t feeling well today.”
- Ask another family member, friend, or member of your faith or spiritual community to share the news
- Get help from services or agencies in your area instead of from people you know
- “Everyone has a lot going on. I don’t want to bother them or put them out”

If you are worried about being a burden to others, here are some things to think about:

- Many people probably want to help
- If you let more people help, it can ease your workload
- Would you want to help someone else who was in a similar situation? Would you mind if they asked you to lend a hand?

“I can’t explain it, but I just don’t feel up to reaching out right now.
”

- Many people do not want support when they need it most. You may often back away from your regular social life and people in general. You may feel that it is just too much work to ask for help
- Talk with someone you trust, such as a friend, member of your faith community, or counsellor. This person can help you sort out your thoughts and feelings. They can also help you find ways to get support

“I have to take care of my family not someone else’s.”

- Having a support system is a way of taking care of your family. Giving some tasks to others lets you focus on those that you feel you should do yoursel

MODULE FIVE: CAREGIVERS' REACTIONS TO DEMANDS OF CARE

Session (1): Describe how the caregivers react with their responsibilities and tasks (10.00-10.30)

Caregivers' reactions to the demands of care stem from the ambiguity and uncertainty associated with organising and addressing multiple tasks and responsibilities in the face of increasing patient disability.

Aim: To decrease the negative influence (Caregiver Burden) of caring on caregiver's QoL.

Patients' dependencies in tasks of daily living, symptom severity, and immobility had a direct effect on the burden and depression experienced by family members providing care. Caregivers with a low socioeconomic status report more problems because of limited resources and a reduced capacity to provide adequate care.

Caregivers report fatigue and inadequate time for sleep and self-care. Compared with non-caregivers, family members involved in high levels of care have significantly increased odds of not getting enough rest, not having time to exercise, not having leisure activities, and forgetting to take prescription drugs.

Caregiver distress to the level of physical care demands, this may be due to increasing demands as caregivers assume more responsibility for family and social functioning.

Needs: Serious assessment of the family caregiver's support needs should be documented, and the capacity to care for the patient evaluated.

Appropriate support from healthcare providers and others may help families to prioritise and manage patients' problems, while at the same time lowering the burdens associated with the uncertainty of caring. If families can acknowledge the value of their care, their sense of burden is likely to be lower.

Session (2): Describe the importance of self-care and how caregiver's practice self-care (10.30-11.10)

Aim: Participants will be familiar with self-care and practice self-care

How do I look after myself?

Looking after yourself is important, so you should take the time to do something for yourself every day. Do not feel guilty caring for yourself – you are important and deserve to be looked after. Your relative will also benefit if you are feeling a bit better about yourself. Even if it feels selfish to you, many patients feel less of a burden if they can see that the person caring for them is getting some enjoyment and rest. It may not be possible to take away all the stress, but here are some things that might help:

Get some exercise

Do something physical. Go for a walk and/or do some bending and stretching. There are exercise videos, DVDs, and podcasts available for you to use at home if you find it difficult to leave the house. Exercise will help you maintain your energy. Try to choose an exercise you enjoy.

Get enough sleep

It is common for carers to have trouble sleeping. Limit coffee and alcohol in the evening. Consider herbal teas, a warm bath, and/or some relaxing music to help you get off to sleep. If you are unable to fall asleep, get up for a little while, try to do something relaxing and then attempt to fall asleep again. If your night-time sleep is disturbed, try to get a brief rest during the day.

Most of us can manage with less sleep from time to time, but if you are finding it hard to sleep regularly, discuss this with your nurse or doctor.

Maintain a healthy diet

This can be hard at times, particularly if your relative has lost their appetite. You need your strength, so eat a balanced diet. Do not forget to ‘treat’ yourself, from time to time, with the food you enjoy.

Do something just for yourself every day

Make a list of 10 things you enjoy that would give you a short break and replenish your energy. Do at least one of these things each day. You may feel as though you are managing quite well; however, looking after yourself also helps prevent stress.

Try to remain in contact with your friends as much as possible.

Depending on your religious or spiritual beliefs and practices, you may find help in prayer, meditation, or discussion with a trusted pastoral counsellor. It may also be important for you to continue your involvement with your religious community or other community involvement.

How do I maintain hope when the situation seems hopeless?

Maintaining hope while expecting the worst is a 'tough call' and your feelings of hopefulness and hopelessness may change many times. Some people have found help in hoping for small things, even in the face of death and loss.

- "I know I can't hope for him to be cured, but I can hope that he will have a good day today."
- "I hope I can keep my sense of humour even when things get pretty bad."
- "I hope he knows I'm here even though he's not able to talk."

Accepting help

Some former caregivers did not seek help for themselves because they felt their relative's needs were more important, or that the palliative care team was too busy to offer additional assistance.

Remember your well-being is a vital part of being able to support your relative. It is the palliative care team's responsibility to help you, so do not be afraid to let them know if you need more support.

If you have relatives or friends who are willing to help, use them. Their assistance may take some of the strain off you. Keep handy a list of things that other people could do for you, such as preparing a meal, being with your relative while you go to an appointment or do some shopping, making phone calls or taking messages. That way, if you are talking to someone and they offer to help, you can make suggestions from your list.

Asking for help does not mean you have failed or that you are not coping; it means that you are being smart, sensible, and acting on your feelings.

Family meetings

The palliative care team can arrange family meetings, which usually involves the patient (if well enough to attend), family carer(s), and relevant healthcare professionals. The purpose of a family meeting is to involve you in developing a 'care plan' for your relative and clarifying the 'goals of care.'

The care plan is based on your relative's specific needs and your needs. The care plan is regularly reviewed by the team, especially when your needs change, or your relative's needs change. Having a plan can help you to 'keep on track.'

Juggling your needs, your relative's needs and life's usual duties

Some days you may feel as though all you have done is provide care and had no time for other things. Despite your relative's needs, life goes on around you and you may find it hard to manage.

You may feel as though you are not in control. These are normal responses. You are reacting to a great deal of change and having to try to adapt quickly. Here are some suggestions that may help you gain a greater sense of control of the situation:

Priorities tasks into lists:

'Must do,' 'would like to do,' 'if I get a chance I'll do.' You may like to write down a list of things you would 'like to' achieve today, but do not make the list too long. Remind yourself that it is okay if you do not get everything done. At the end of the day think about the things you achieved rather than the things you did not.

Take one day at a time

It is normal to think about the future but try to take the challenges of caring one day at a time.

Consider writing care-related issues down in a diary

You can keep track of things as they occur and you can use it as a reminder when asking questions or giving details to the palliative care team or other caregivers.

Keep all written information about your relative in one place

For example place medication charts, palliative care team information, useful phone numbers, and this guidebook all in one place.

Get an answering machine

You do not have to pick up the phone if you are busy or having some time to yourself. Use this opportunity to have private time with your relative, time for an uninterrupted meal, or just for a time out.

Get a mobile phone if finances permit

You can go out of the house knowing that if there is an urgent issue with your relative you are contactable.

Make a list of friends/relatives you know you can ask for help

If no one is willing to help, speak with the palliative care team about a volunteer, or see the social worker.

Consider asking a friend/relative to stay overnight

This may allow you to get a good night's sleep and you might appreciate the extra company.

Get someone else to do the household chores (unless you find these chores relaxing)

Access the local council, private services in your local newspaper, or ask a friend or relative to help.

Ask your relatives/friends to bring over some prepared meals (soups, casseroles, etc.)

If this is difficult, consider 'meals on wheels' or other home delivery food services.

Ask one of your relatives/friends to phone or accept calls from 'others' who need or want to know the latest information related to your relative. This saves you repeating the story.

If your work outside the home is making it stressful trying to juggle both roles, discuss the issue with your employer (or other people involved) to see how much flexibility you can have. You may also need to consider taking special leave.

Consider sending a regular email to friends and families to keep them updated

This allows you to ensure relevant people are aware of how things are, but saves you making numerous phone calls.

Control the number of visitors

Relatives/friends may want to visit often; however, it is okay to say that the person you are caring for is very tired. You could put a note on the front door to say they are resting. If required, ask visitors to please always phone first.

It may help to set up visiting hours to avoid a constant stream of visitors. Do not feel as though you always need to be the host, ask others to make you a cup of tea.

If there is more than one person caring

Try to set up a roster system to share the load. Get family and friends together and ask what they would prefer to do, for example, one person may prefer to offer emotional support rather than physical care. Another may want to act as the key contact with health professionals.

Give yourself regular rewards

Take a break, have some nice food, do something special for yourself that makes you feel good and lifts your spirits.

Feeling overwhelmed? It is time to relax

People respond to caring in different ways. Please understand it is very common to feel any or many of the following: anxious, down, angry, upset, grumpy, guilty, or confused. Do not ignore how you are feeling. Some caregivers also feel the strain physically; they might get very tired or get headaches from time to time.

People deal with tension in different ways, there is no right or wrong way of managing the difficult emotions that arise.

Here are some things that may help:

- Plan to do something you enjoy within the next few hours

- Discuss your feelings with someone you feel comfortable with (a relative/friend, religious/spiritual professional or someone from the palliative care team)
- Look for the positive and find some benefits within your situation
- Plan to give yourself a big reward in the next couple of days, for all your hard work so far
- Maintain hope – that, even in the context of serious illness, things can get better
- Think of something funny that you have experienced or heard, or tell some jokes
- Listen to a relaxation tape

Remind yourself that: You are doing the best you can; there are options (even if you are unable to see them clearly at the moment); you are not alone; your feelings are normal; there is help available and you will feel better. *Try this relaxation exercise: '10 steps to feeling calm'. It may take some practice, but it gets easier*.

- Find yourself somewhere where you know you can have peace for at least 20 minutes
- Take 10 deep breaths
- Find a comfortable place: lie down on the floor. You may need to put something soft underneath you
- Loosen your clothes and take your shoes off
- Close your eyes
- Take a deep breath and slowly breathe out
- Tense all your body muscles; count to five and then slowly release (do this three times)
- Begin tensing then relaxing muscles at the top of your head and work your way to your toes (take your time)
- Keep your eyes closed and imagine a real or fantasised place that is peaceful Imagine pleasant sounds or sights. Stay in this place until you feel ready to return
- Count from 1–10 slowly, open your eyes. When you are ready stand up slowly

برنامج تدريبي لمقدمي رعاية مرضى السرطان.

المرضى والعائلات والأصدقاء يواجهون السرطان معا

محمد فؤاد حايك. دكتوراه © 2020

جامعة فتسفاتراند – جوهانسبيرغ

جامعه النجاح الوطنيه / كليه الطب وعلوم الصحه

المستشفى النجاح الوطني - قسم الأورام

سوف يشمل برنامجنا التدريبي المجال الرئيسي للرعاية التلطيفيه. سيكون مجالات البرنامج هي الاحتياجات المادية والاجتماعية والنفسية والاجتماعية والروحية.

بعد تحديد المشاركين ، سيتم توضيح البرنامج وجداول الدورة والاجتماع.

سيتم إعداد الغرفة المناسبة في المستشفى المستهدف (الكمبيوتر ، شاشات الكريستال السائل ، البلاكوورد ، العلامات ، الكرسي المريح ، الورق ، الدبابيس ، مشروبات المرطبات والبسكويت) من قبل الباحث.

سوف يتم أخذ الإذن الإداري الإداري من المستشفى.

الهدف العام من برنامج التدريب لمقدمي الرعاية لمرضى السرطان سيكون.

-1إعداد مقدمي الرعاية من خلال تزويدهم بالمعلومات (شفهية ، مكتوبة (حول الجوانب النموذجية والقضايا المشتركة المرتبطة بدور الرعاية.

- 2توجيه وتعليم من خلال تقديم مقدمي الرعاية فرصة للوصول إلى المعلومات (اللفظية والكتابية) لتعزيز فهمهم للقضايا ذات الصلة وتوفير أساس لاكتساب المهارات.

- 3دعم مقدمي الرعاية من خلال تركيز اهتمام خاص على احتياجاتهم وتعزيز دور خدمة الرعاية الملطفة. تحديد الخدمات "خارج" فريق الرعاية الملطفة ؛ وتقديم استراتيجيات لإشراك الأسرة / الأصدقاء.

- 4لمساعدة مقدمي الرعاية على فهم و / أو العثور على معنى عن طريق تيسير ردود الفعل العاطفية للوضع ، وتشجيع مقدمي الرعاية في محاولة لمعرفة بعض الجوانب الإيجابية لتجربتها ، وتوفير الوصول إلى التوجيه الروحي.

- 5تعزيز الرعاية الذاتية من خلال تشجيع مقدمي الرعاية على تحسين صحتهم الجسدية والعقلية من خلال تعزيز "الإجازة" المنتظمة ، والتجارب الممتعة ، والنوم الكافي ، والنظام الغذائي الصحي ، والتمارين ، والمشورة بشأن استراتيجيات الاسترخاء.

- 6توفير الخيارات من خلال تقديم مقدمي الرعاية فرصة لتحديد القضايا وتخطيط الأهداف / الاستراتيجيات وتقديم المشورة لمقدمي الرعاية من حقوقهم.

سوف تتبع الدورة التفاعلية كل وحدة نمطية لتبادل الأفكار والمحادثة.

تعريف: من هو مقدم الرعاية؟

كما يشار إلى مقدمي الرعاية غير الرسميين (من غير الطاقم الطبي)، يوفر مقدمو الرعاية مجموعة معقدة من مهام الدعم التي تمتد عبر المجالات البدنية والنفسية والروحية والعاطفية. وبوجه عام ، يصبح عدد النساء اللواتي يعانين من مرض السرطان أكثر من الرجال ، ويتصل معظم مقدمي الرعاية بالشخص المصاب بالسرطان.

يلعب مقدمو الرعاية ، بغض النظر عمن يلعبون ، دوراً مهماً في إدارة السرطان ؛ يعتبر إدراج تعاونهم وإدراجهم كوحدة للرعاية منذ البداية من المكونات الأساسية للإدارة الفعالة للسرطان. تدرك معظم فرق الأورام هذا وتحاول تضمين مقدمي الرعاية في تخطيط العلاج وصنع القرار والتنفيذ. ومع ذلك ، لكي تكون التدخلات مجدية ، يجب أن تكون مناسبة في حدود القيود المفروضة على ممارسات الأورام المزدحمة وبيئات تقديم الخدمات. قد يقيد دخول المستشفى لفترات قصيرة الوقت المتاح لتنفيذ الاستراتيجيات الداعمة لمقدمي الرعاية.

وجهة نظر مقدم الرعاية: عبر مسار المرض

لدى مقدمي الرعاية استجاباتهم العاطفية الخاصة لتشخيصات المرضى وتوقعاتهم ، وقد يحتاجون إلى تدريب ودعم عاطفي منفصل عن ذلك المقدم للمرضى. تتأثر بشكل كبير أدوار مقدمي الرعاية وعبء الرعاية من قبل تشخيص المريض ، مرحلة المرض ، وأهداف الرعاية.

ويركز الجزء الحالي من العمل على مقدمي الرعاية للأسر من المرضى الذين يعانون من السرطان في المقام الأول على التكيف مع مقدمي الرعاية خلال مرحلة البقيا الحادة ، من وقت التشخيص إلى تشخيص بعد 2 سنة.

مع اكتساب المعرفة المفتوحة والكشف التشخيصي عن المرضى في شعبية ، ركزت الدراسات على تأثير قول الحقيقة على المرضى ، وتم تطوير إرشادات لمثل هذا التواصل. على الرغم من أن مقدمي الرعاية يتم تضمينهم في بعض الأحيان في هذه الدراسات ، إلا أنه لم يتم الاهتمام إلا بالاحتياجات المعلوماتية المحددة لمقدمي الرعاية والتفضيلات الخاصة بالمعلومات التشخيصية أو استعداد مقدمي الرعاية أو استعدادهم لدمج هذه المعلومات الطبية الجديدة. ومع ذلك ، فمن المتوقع أن يتعلم مقدم الرعاية مصطلحات جديدة مرتبطة بالأمراض ، ويدخل في وضع العلاج الجديد مع مريض السرطان ، ويشارك بنشاط في اتخاذ القرارات العلاجية. لكل هذه الأسباب ، يواجه مقدمو الرعاية مجموعة معقدة من المشاعر القوية التي قد تساوي أو تفوق تلك التي يمر بها المريض أثناء التشخيص والعلاج

الوحدة الأولى: معلومات عامة عن مرض السرطان.

نشاط (1): يقدم المشاركون.

الهدف: سيكون المشاركون على دراية ببعضهم البعض ، ويوفرون فرصة للتعبير عن أفكارهم ووجهات نظرهم وخبراتهم بجانبها ، مما يخلق جواً من العمل.

نشاط (2): هدف برنامج التدريب.

الهدف: بعد وصف هدف التدريب ، يدرك المشاركون توقعاتهم الشخصية ، بالإضافة إلى موضوع التدريب الرئيسي.

النشاط (3): تقديم معلومات عن السرطان ، وأنواعه ، وأساليب العلاج ، وإدارة الأعراض ، ومسار المرض.

الهدف: فهم مرض السرطان ومن العلاج اقترب.

الوحدة الثانية: دعم مقدمي الرعاية:

النشاط: يصف معنى الدعم ، وما تأثير تأثير المرض على المرضى ومقدمي الرعاية.

الهدف: يمكن أن يساعد الدعم المقدم من المتخصصين في الرعاية الصحية ، والعائلة ، والأصدقاء ، مقدمي الرعاية للعائلات على توسيع قدراتهم للاستجابة لمتطلبات الرعاية. يجب أن تكون أهداف الدعم تمكين مقدمي الرعاية العائليين من الحفاظ على راحة المريض وتعزيز نوعية حياة المريض ، ومنع أو تقليل ضائقة الرعاية غير الضرورية. وينبغي أن يوازن الدعم الاحتياجات النفسية لمقدمي الرعاية وأن يعزز الرفاهية الجسدية والعاطفية لمقدم الرعاية حتى يتمكن من تلبية الاحتياجات الجسدية والعاطفية للمريض المصاب بالسرطان بشكل أكثر فعالية. الاحتياجات: لتوفير هذا الدعم ، يجب تطوير شراكة وتعاون بين المهنيين الصحيين ومقدمي الرعاية للعائلات حول خطة رعاية المريض. يجب أن يقوم المحترفون بتطوير خطة تركز على أعضاء الأسرة المريض للعناية التي تعترف بقدرات مقدمي الرعاية. يجب أن تبدأ هذه الخطة بالتركيز على احتياجات المريض المتعلقة بالأمراض

الوحدة الثالثة: الاحتياجات المتعلقة بالمرضى:

النشاط: قدم مصطلح الراحة والعلاج.

الهدف: قد يحيل فريق السرطان المرضى والعائلة إلى طبيب الرعاية الأولية. تحدث تحولات الرعاية هذه في وقت قد لا تعاني فيه الأسر فقط من الصدمة والغضب والاكتئاب المصاحب للاعتراف بأن العلاجات لم تعد فعالة ، بل زادت أيضًا من مسؤوليات الرعاية. هذا قد يضع مقدمي الرعاية الأسرية في وضع صعب بشكل خاص ، دون وجود مزود ثابت يلجأ إليه للحصول على المشورة والتوجيه فيما يتعلق بخطة الرعاية لمريضهم. تتأثر احتياجات المرضى من حيث العمر وعدد الحالات المرضية النفسية والتخلص النفسي والتقاليد الثقافية ومرحلة السرطان ومرحلة العلاج. يمكن لمقدمي الرعاية ، بدورهم ، إدراك احتياجات هؤلاء المرضى كطلبات.

الاحتياجات (1): يجب على المشاركين التفريق بين الرعاية المباشرة وغير المباشرة.

يمكن تصنيف الرعاية على أنها "رعاية مباشرة" أو "رعاية غير مباشرة" ، حسب تركيزها. يؤثر هذا التصنيف على متطلبات تقديم الرعاية. الرعاية المباشرة هي الرعاية التي تتم مباشرة مع المريض ، مثل إدارة الأعراض ، والدعم العاطفي ، وإدارة الأدوية ، والمساعدة في الحركة أو الاستحمام. يتم تنفيذ الرعاية غير المباشرة نيابة عن المريض وتشمل أنشطة مثل الحصول على الأدوية ، والنقل ، والمهمات ، وتحديد المواعيد وتنسيق المواعيد ، والمساعدة في الفواتير الطبية والمالية.

الاحتياجات (2): احتياجات المرضى للراحة.

ولضمان توافق تصورات مقدمي الرعاية مع احتياجات المريض ، ومعالجة احتياجات الرعاية المباشرة وغير المباشرة ، يحتاج اختصاصيو الرعاية الصحية إلى تزويد مقدمي الرعاية بالمعلومات المناسبة لإدارة أعراض المرضى. إدارة الأعراض لراحة المريض هي حاجة أساسية ويصبح مصدر قلق كبير مع تقدم المرض وتصبح العلاجات أقل فاعلية. ينبغي لمقدمي الرعاية الصحية تقييم قدرات أفراد الأسرة على التعرف على الأعراض وقياس الظروف التي يجب فيها إحالة المريض إلى نظام الرعاية الصحية.

المعلومات لتعزيز مستويات المعرفة لدى مقدمي الرعاية الأسرية حتى يتمكنوا من تحديد الأعراض في وقت مبكر ، وإدارتها على نحو فعال ، والتعرف على وقت البحث

المساعدة من النظام الرسمي ، أي عندما تظهر الأعراض خارج نطاق السيطرة أو أن التدابير الحالية غير فعالة. بالإضافة إلى ذلك ، يحتاج أفراد العائلة لمعرفة كيفية الإبلاغ عن الأعراض بطرق مفيدة للعاملين في الرعاية الصحية في اتخاذ القرارات الفعالة. يمكن أن تصبح السيطرة على الأعراض صراعا رئيسيا للمرضى الذين يعانون من مرض متقدم ومقدمي الرعاية الأسرية وتصبح إدارة الألم ، على وجه الخصوص ، مشكلة منتشرة ومستعصية بالنسبة لمقدمي الرعاية العائليين ، مما يسهم في تلبية متطلبات الرعاية فضلاً عن ضغوطهم الخاصة.

الاحتياجات (3): تنسيق الرعاية والحفاظ على التواصل لمنع سوء الفهم وتعزيز التفاعل الإيجابي.

بين المرضى الذين يعانون من مرض متطور ، فإن الطلب غير المعترف به والمعقد في كثير من الأحيان يتعلق بالتنسيق وتنظيم الرعاية. يجب على مقدمي الرعاية العائليين التفاعل والتفاوض مع نظام الرعاية الرسمي لجدولة التعيينات أو الإبلاغ عن التغييرات في الحالة أو تغيير الأدوية أو طلب المساعدة. يحتاج العاملون في مجال الصحة إلى إدراك أن مقدمي الرعاية الرئيسيين للأسر هم في الغالب حراس بوابات أنفسهم وقد يترددون في طلب المساعدة حتى عندما يشعرون أنهم غير مستعدين بشكل كافٍ لتقديم الرعاية والإبلاغ عن حالات العجز في المعلومات والمهارات. لا يملك بعض مقدمي الرعاية القدرة على تنفيذ مجموعة كاملة من أنشطة الرعاية بنجاح. البعض الآخر يجدون صعوبة في اتخاذ القرارات وحل المشكلات. لا يزال البعض الآخر يتعرض للتوتر ويتعامل مع العديد من مقدمي الرعاية الصحية وينسق مهام كل من المهنيين وغيرهم من مقدمي الرعاية العائليين ، وكل ذلك سيشير إلى أهمية التنسيق والتواصل بين مقدمي الرعاية الأساسيين وغيرهم من المهنيين الصحيين الذين لهم صلة بنوعية حياتهم الخاصة وصحة المرضى من ناحية أخرى ، سيعزز فهم مقدمي الرعاية للتواصل مع المرضى عملية تبادل المعلومات الصحية

الوحدات الرابعة: مقدمي الرعاية يحتاجون للمعلومات والدعم والمساعدة والتعديل على مقدمي الرعاية.

النشاط: تقديم معلومات عن أبعاد الرعاية التي سيتم تقديمها. مثل المعلومات والمساعدة المتعلقة بالمرض ؛ الرعاية الجسدية تدابير الراحة ما هي الأعراض المتوقعة ، وأسبابها ، وكيفية إدارتها ؛ نظم العلاج. توقعات للرعاية المستقبلية. استجابات المرضى العاطفية إجراءات إدارة الأسرة ؛ المالية. وموارد المجتمع. المساعدة في كيفية تنظيم أنشطة الرعاية مثل النقل والمراقبة وأعراض الإبلاغ ، وتوفير الرعاية الشخصية (الاستحمام ، والمشي ، وارتداء الملابس) ، والاعتبارات التغذوية ، وتنسيق الرعاية (جدولة المواعيد واستدعاء الطبيب) ، ومراقبة حالة المرض ، والأنشطة المالية.

الهدف: سوف يساعد التوجيه المستمر والدعم من أخصائيي الرعاية الصحية مقدمي الرعاية في التعامل مع هذه الجوانب من الرعاية ، والتي ، بدورها ، ستساعد على التخفيف من حدة التوتر ، العبء ، والاكتئاب الذي يعاني منه مقدمو الرعاية وطمأنة المرضى الذين يعانون من نقص الطاقة ، وكذلك حول إدارة الأعراض الأخرى.

الاحتياجات: لا يحتاج المرضى الذين يعانون من مرض متقدم إلى الرعاية المباشرة فحسب ، بل إلى الرعاية غير المباشرة ، والتي تتطلب التنسيق مع المهنيين الصحيين وأنظمة الرعاية الصحية التي قد لا تتقبل احتياجات العائلات. يتأثر تعقيد تقديم الرعاية بكمية المهام المطلوبة ، والتي لا يمكن التنبؤ بالعديد منها. قد تتطلب هذه المهام رؤى وقدرات لا يمتلكها مقدمو الرعاية ، مما يزيد من قلق وإحباط مقدمي الرعاية. وبذلك تصبح المعلومات موردا رئيسيا لمقدمي الرعاية للأسر.

الوحدات الخامسة: ردود فعل مقدمي الرعاية على طلبات الرعاية

النشاط: صف كيف يتجاوب القائمون بالرعاية مع مسؤولياتهم ومهامهم ، تتبع ردود فعل مقدمي الرعاية من متطلبات الغموض من الغموض وعدم اليقين المرتبط بتنظيم ومواجهة المهام والمسئوليات المتعددة في مواجهة زيادة عجز المريض.

الهدف: لتقليل التأثير السلبي (Caregiver Burden) من الاهتمام بجودة الرعاية لمقدمي الرعاية.

تؤثر اعتمادية المرضى في مهام الحياة اليومية وشدة الأعراض وعدم الحركة تأثيراً مباشراً على العبء والاكتئاب الذي يعاني منه أفراد الأسرة الذين يقدمون الرعاية. يفيد مقدمو الرعاية ذوو الحالة الاجتماعية والاقتصادية المنخفضة عن المزيد من المشاكل بسبب محدودية الموارد وانخفاض القدرة على توفير الرعاية الكافية. يقوم مقدمو الرعاية بالإبلاغ عن الإرهاق والوقت غير المناسب للنوم والرعاية الذاتية. مقارنة مع غير مقدمي الرعاية ، زاد أفراد الأسرة المشاركين في مستويات الرعاية بشكل كبير احتمالات عدم الحصول على قسط كاف من الراحة ، وليس لديهم وقت لممارسة ، وليس لديهم أنشطة ترفيهية ، ونسيان تناول العقاقير التي تستلزم وصفة طبية. ويخشى مقدم الرعاية من مستوى الرعاية الجسدية يتطلب ذلك زيادة الطلب ، حيث يتحمل مقدمو الرعاية المزيد من المسؤولية عن العمل الأسري والاجتماعي.

الاحتياجات: ينبغي توثيق التقييم الجاد لاحتياجات مقدمي الرعاية الأسرية ، وتقييم القدرة على رعاية المريض. يمكن أن يساعد الدعم المناسب من مقدمي الرعاية الصحية وغيرهم الأسر في تحديد أولويات مشاكل المرضى وإدارتها ، مع تقليل الأعباء المرتبطة بعدم اليقين في الوقت نفسه. إذا استطاعت العائلات الاعتراف بقيمة رعايتها ، فمن المرجح أن يكون إحساسها بالعبء أقل.

الوحدة الأولى: معلومات عامة عن مرض السرطان.

نشاط (1): المشاركون يدخلون ..... (10- 10.20 صباحًا)

الهدف: سيكون المشاركون على دراية ببعضهم البعض ، ويوفرون فرصة للتعبير عن أفكارهم ووجهات نظرهم وخبراتهم بجانبها ، مما يخلق جواً من العمل.

نشاط (2): هدف برنامج التدريب ..... (10.20- 10:30 صباحًا)

الهدف: بعد وصف هدف التدريب ، يدرك المشاركون توقعاتهم الشخصية ، بالإضافة إلى موضوع التدريب الرئيسي.

نشاط (3): تقديم معلومات عن السرطان ، أنواعه ، طرق العلاج ، إدارة الأعراض ، ومسار المرض ..... (10.30- 11.30 صباحًا)

الهدف: فهم مرض السرطان ومن العلاج اقترب.

الهدف من الوحدة الأولى:

ستكون أهداف التدريب مفهومة بشكل واضح من قبل المشاركين وتقاسم وجهات النظر العامة حول التدريب ووقت البداية.

نشاط (1): المشاركون يدخلون ..... (20 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

بعد الترحيب بالمشاركين ، كن على دراية ببعضهم البعض وإتاحة الفرصة للتعبير عن مشاعرهم وأفكارهم وآرائهم وخبراتهم ، وسيتم خلق جو من العمل.

نشاط (2): هدف برنامج التدريب ..... (20 دقيقة).). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط.(

الهدف والموضوع والتوقع الشخصي للتدريب سيتم وصفه وفهمه من قبل المشاركين.

نشاط (3): تقديم معلومات عن السرطان ، أنواعه ، طرق العلاج ، إدارة الأعراض ، ومسار المرض ..... (ساعة واحدة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

حقائق رئيسية عن السرطان

يعد السرطان أحد الأسباب الرئيسية للمراضة والوفيات في جميع أنحاء العالم ، مع ما يقرب من 14 مليون حالة جديدة في عام 2012. ومن المتوقع أن يرتفع عدد الحالات الجديدة بنسبة 70 ٪ على مدى العقدين المقبلين.

السرطان هو السبب الرئيسي الثاني للوفاة على مستوى العالم ، وكان مسؤولاً عن 8.8 مليون وفاة في عام 2015. على الصعيد العالمي ، ما يقرب من 1 من كل 6 حالات وفاة بسبب السرطان. ما يقرب من 70 ٪ من الوفيات الناجمة عن السرطان تحدث في البلدان المنخفضة والمتوسطة الدخل. ويعزى حوالي ثلث الوفيات الناجمة عن السرطان إلى المخاطر السلوكية والغذائية الرئيسية الخمسة: ارتفاع مؤشر كتلة الجسم ، وانخفاض استهلاك الفاكهة والخضراوات ، ونقص النشاط البدني ، وتعاطي التبغ ، واستخدام الكحول.

يعد استخدام التبغ أهم عامل خطر للإصابة بالسرطان وهو مسؤول عن حوالي 22٪ من وفيات السرطان. السرطان المسبّب للعدوى ، مثل التهاب الكبد وفيروس الورم الحليمي البشري (HPV) ، مسؤول عن 25٪ من حالات السرطان في البلدان المنخفضة والمتوسطة الدخل.

العرض في مرحلة متأخرة والتشخيص والمعالجة التي لا يمكن الوصول إليها شائعة.

في عام 2015 ، ذكرت 35٪ فقط من البلدان منخفضة الدخل أن خدمات الأمراض متاحة بشكل عام في القطاع العام. أفاد أكثر من 90٪ من البلدان ذات الدخل المرتفع أن خدمات العلاج متاحة مقارنة بأقل من 30٪ من البلدان منخفضة الدخل.

التأثير الاقتصادي للسرطان مهم ويتزايد. وقدرت التكلفة الاقتصادية السنوية الإجمالية للسرطان في عام 2010 بنحو 1.16 تريليون دولار أمريكي. هناك بلد واحد فقط من بين كل 5 بلدان منخفضة الدخل ومتوسطة الدخل يمتلك البيانات اللازمة لسياسات مكافحة السرطان.

السرطان هو مصطلح عام لمجموعة كبيرة من الأمراض التي يمكن أن تؤثر على أي جزء من الجسم. المصطلحات الأخرى المستخدمة هي الأورام الخبيثة والأورام. إحدى السمات البارزة للسرطان هي الخلق السريع للخلايا غير الطبيعية التي تتخطى حدودها المعتادة ، والتي يمكن أن تغزو الأجزاء المجاورة من الجسم وتنتشر إلى الأعضاء الأخرى ، ويشار إلى هذه العملية الأخيرة بأنها إنتشالية. الانبثاث هي سبب رئيسي للوفاة من السرطان.

المشكلة

يعد السرطان أحد الأسباب الرئيسية للوفاة في جميع أنحاء العالم ، وهو ما يمثل 8.8 مليون حالة وفاة في عام 2015. وأكثر أسباب وفاة السرطان شيوعًا هي:

الرئة (1.69 مليون حالة وفاة) الكبد (788000 حالة وفاة) كولوركتال (774000 حالة وفاة المعدة (754000 حالة وفاة) الثدي (571000 حالة وفاة)

ما الذي يسبب السرطان؟

ينشأ السرطان من تحول الخلايا الطبيعية إلى خلايا ورمية في عملية متعددة المراحل تتطور بشكل عام من آفة ما قبل السرطان إلى ورم خبيث. هذه التغييرات هي نتيجة للتفاعل بين العوامل الجينية للشخص و 3 فئات من العوامل الخارجية ، بما في ذلك:

-1المواد المسرطنة الفيزيائية ، مثل الأشعة فوق البنفسجية والإشعاعات المؤينة.

-2المواد الكيميائية المسببة للسرطان مثل الأسبستوس ومكونات دخان التبغ والأفلاتوكسين (ملوث غذائي) والزرنيخ (ملوث بمياه الشرب).

- 3المواد المسببة للسرطان البيولوجية ، مثل العدوى من بعض الفيرو الشيخوخة هي عامل أساسي آخر لتطور السرطان. ترتفع نسبة الإصابة بالسرطان بشكل كبير مع تقدم العمر ، ويرجع ذلك على الأرجح إلى تراكم مخاطر الإصابة بسرطانات معينة تزيد مع تقدم العمر. يتم الجمع بين تراكم المخاطر الكلي مع ميل آليات الإصلاح الخلوي لتكون أقل فعالية مع نمو الشخص.

عوامل الخطر للسرطانات

يعد تعاطي التبغ ، واستخدام الكحول ، والنظام الغذائي غير الصحي ، وعدم النشاط البدني من أهم عوامل اختطار الإصابة بالسرطان في جميع أنحاء العالم ، وكذلك عوامل الخطر الأربعة المشتركة للأمراض غير المعدية الأخرى.

بعض الأمراض المزمنة هي عوامل خطر للسرطان ولها أهمية كبيرة في البلدان المنخفضة والمتوسطة الدخل. كان ما يقرب من 15 ٪ من أنواع السرطان التي تم تشخيصها في عام 2012 تعزى إلى العدوى المسببة للسرطان ، بما في ذلك Helicobacter pylori ، فيروس الورم الحليمي البشري.(HPV)

فيروس التهاب الكبد B وفيروس التهاب الكبد C وفيروس ابشتاين بار. فيروس التهاب الكبد B و C وبعض أنواع فيروس الورم الحليمي البشري يزيد من خطر الإصابة بسرطان الكبد وعنق الرحم ، على التوالي. العدوى بفيروس نقص المناعة البشرية تزيد بشكل كبير من خطر الإصابة بسرطان الثدي مثل سرطان عنق الرحم.

تقليل عبء السرطان.

بين 30-50 ٪ من السرطانات يمكن الوقاية منها حاليا. ويمكن تحقيق ذلك عن طريق تجنب عوامل الخطر وتنفيذ الاستراتيجيات الوقائية القائمة على الأدلة. يمكن أيضا تقليل عبء السرطان من خلال الكشف المبكر عن السرطان وإدارة المرضى الذين يصابون بالسرطان. العديد من أنواع السرطان لديها فرصة عالية للشفاء إذا تم تشخيصها مبكراً ومعالجتها بشكل كافٍ.

تعديل وتجنب عوامل الخطر

تعديل أو تجنب عوامل الخطر الرئيسية يمكن أن يقلل بشكل كبير من عبء السرطان. عوامل الخطر هذه تشمل:
استخدام التبغ بما في ذلك السجائر والتبغ الذي لا يدخن
زيادة الوزن أو السمنة
نظام غذائي غير صحي مع انخفاض استهلاك الفاكهة والخضار
نقص في النشاط الجسدي
استخدام الكحول
عدوى فيروس الورم الحليمي البشري المنقولة جنسيا
العدوى عن طريق التهاب الكبد أو غيره من الأمراض السرطانية
الإشعاعات المؤينة والأشعة فوق البنفسجية

تلوث الهواء في المناطق الحضرية
الدخان الداخلي الناتج عن الاستخدام المنزلي للوقود الصلب.

يعد استخدام التبغ أهم عامل خطر للإصابة بالسرطان وهو مسؤول عن حوالي 22٪ من الوفيات المرتبطة بالسرطان على مستوى العالم.سات. البكتيريا ، أو الطفيليات..

متابعة استراتيجيات المنع.
لمنع السرطان ، يمكن للأشخاص:
زيادة تجنب عوامل الخطر المذكورة أعلاه.
تلقيح ضد فيروس الورم الحليمي البشري وفيروس التهاب الكبد.B

السيطرة على المخاطر المهنية.
تقليل التعرض للأشعة فوق البنفسجية.
تقليل التعرض للإشعاع المؤين (التصوير التشخيصي المهني أو الطبي).
التطعيم ضد فيروسات فيروس الورم الحليمي البشري وفيروس التهاب الكبد البائي يمكن أن يمنع 1 مليون حالة سرطان / سنة.

الكشف المبكر

يمكن خفض معدل وفيات السرطان إذا تم اكتشاف الحالات وعلاجها في وقت مبكر.

هناك مكونان للاكتشاف المبكر:

التشخيص المبكر

عندما يتم التعرف في وقت مبكر ، من المرجح أن يستجيب السرطان للعلاج الفعال ويمكن أن يؤدي إلى احتمال أكبر للبقاء على قيد الحياة ، أقل اعتلال ، وأقل تكلفة العلاج.

يمكن إجراء تحسينات كبيرة في حياة مرضى السرطان من خلال الكشف المبكر عن السرطان وتجنب التأخير في الرعاية.

يتكون التشخيص المبكر من 3 خطوات يجب دمجها وتقديمها في الوقت المناسب:

(1)الوعي والحصول على الرعاية. (2) التقييم السريري والتشخيص والتدريج. (3) الوصول إلى العلاج.

التشخيص المبكر ذو صلة في جميع الظروف وغالبية أنواع السرطان. في غياب التشخيص المبكر ، يتم تشخيص المرضى في مراحل متأخرة عندما لا يكون العلاج العلاجي خيارًا. يمكن تصميم البرامج للحد من حالات التأخير والحواجز التي تحول دون توفير الرعاية ، مما يسمح للمرضى بالوصول إلى العلاج في الوقت المناسب

تحري.

يهدف الفحص إلى التعرف على الأفراد الذين يعانون من تشوهات توحي بسرطان معين أو ما قبل السرطان الذين لم تظهر عليهم أية أعراض وإحالتهم على الفور للتشخيص والعلاج.

يمكن أن تكون برامج الفحص فعالة لأنواع السرطان المختارة عند استخدام الاختبارات المناسبة ، وتنفيذها بفعالية ، وربطها بالخطوات الأخرى في عملية الفرز وعند التأكد من الجودة. بشكل عام ، برنامج الفحص هو تدخل صحي عام أكثر تعقيدًا مقارنة بالتشخيص المبكر.

أمثلة على طرق الفحص هي:

التفتيش البصري مع حمض الخليك (VIA) لسرطان عنق الرحم في الإعدادات ذات الدخل المنخفض.

اختبار فيروس الورم الحليمي البشري لسرطان عنق الرحم.
اختبار علم الخلايا PAP لسرطان عنق الرحم في إعدادات الدخل المتوسطة والعالية.
فحص الثدي الشعاعى سرطان الثدي.

العلاج .

يعتبر التشخيص الصحيح للسرطان ضروريا للعلاج المناسب والفعال لأن كل نوع من أنواع السرطان يتطلب نظام علاج محدد يشمل طيفا واحدا أو أكثر مثل الجراحة والعلاج الإشعاعي والعلاج الكيميائي. يعد تحديد أهداف العلاج والرعاية الملطفة خطوة أولى مهمة ، ويجب دمج الخدمات الصحية والتركيز على الناس.

الهدف الأساسي هو علاج السرطان أو إطالة العمر بشكل كبير. تحسين نوعية حياة المريض هو أيضا هدف مهم. ويمكن تحقيق ذلك عن طريق الرعاية الداعمة أو الملطفة والدعم النفسي الاجتماعي.

إمكانات العلاج بين السرطانات التي يمكن اكتشافها مبكرًا: بعض أنواع السرطان الأكثر شيوعًا (سرطان الثدي وسرطان عنق الرحم وسرطان الفم وسرطان القولون والمستقيم) لها معدلات شفاء عالية عند اكتشافها مبكراً ومعالجتها وفقًا لأفضل الممارسات.

ممكن لعلاج بعض أنواع السرطان الأخرى.

بعض أنواع السرطان ، حتى عندما تنتقل الخلايا السرطانية إلى مناطق أخرى من الجسم ، مثل الورم النخاعي الخصوي وداء اللوكيميا والأورام اللمفاوية عند الأطفال ، يمكن أن يكون لها معدلات شفاء عالية إذا تم توفير العلاج المناسب.

الرعاية التلطيفية

الرعاية الملطفة هي علاج لتخفيف الأعراض التي يسببها السرطان ، بدلاً من علاجها وتحسين نوعية حياة المرضى وعائلاتهم. الرعاية التلطيفية يمكن أن تساعد الناس على العيش بشكل مريح أكثر. إنها حاجة إنسانية ملحة للناس في جميع أنحاء العالم المصابين بالسرطان وغيره من الأمراض المميتة المزمنة والمطلوبة بشكل خاص في الأماكن ذات نسبة عالية من المرضى في مراحل متقدمة من السرطان حيث توجد فرصة ضئيلة للشفاء.

يمكن تحقيق الإغاثة من المشاكل البدنية والنفسية والاجتماعية والروحية في أكثر من 90 ٪ من مرضى السرطان المتقدمين من خلال الرعاية الملطفة.

استراتيجيات الرعاية الملطفة

إن استراتيجيات الصحة العامة الفعالة ، التي تشمل الرعاية المجتمعية والبيتية ، ضرورية لتخفيف الألم وتوفير الرعاية الملطفة للمرضى وأسرهم في البيئات منخفضة الموارد.

يعد الوصول المحسن إلى المورفين عن طريق الفم أمرًا إلزاميًا لعلاج ألم السرطان المعتدل والشديد ، الذي يعاني منه أكثر من 80٪ من مرضى السرطان في المرحله النهائيه من المرض

الوحدة الثانية: تقديم الدعم لمقدم الرعاية الأسري:

النشاط: يصف معنى الدعم ، وما يتطلبه تأثير المرض على المرضى ومقدمي الرعاية من ..... (30 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

الهدف: يمكن أن يساعد الدعم المقدم من المتخصصين في الرعاية الصحية ، والعائلة ، والأصدقاء ، مقدمي الرعاية للعائلات على توسيع قدراتهم للاستجابة لمتطلبات الرعاية. يجب أن تكون أهداف الدعم تمكين مقدمي الرعاية العائليين من الحفاظ على راحة المريض وتعزيز نوعية حياة المريض ، ومنع أو تقليل ضائقة الرعاية غير الضرورية. وينبغي أن يوازن الدعم الاحتياجات النفسية لمقدمي الرعاية وأن يعزز الرفاهية الجسدية والعاطفية لمقدم الرعاية حتى يتمكن من تلبية الاحتياجات الجسدية والعاطفية للمريض المصاب بالسرطان بشكل أكثر فعالية. الاحتياجات: لتوفير هذا الدعم ، يجب تطوير شراكة وتعاون بين المهنيين الصحيين ومقدمي الرعاية للعائلات حول خطة رعاية المريض. يجب أن يقوم المحترفون بتطوير خطة تركز على أعضاء الأسرة المريض للعناية التي تعترف بقدرات مقدمي الرعاية. يجب أن تبدأ هذه الخطة بالتركيز على احتياجات المريض المتعلقة بالأمراض.

الحصول على الدعم

معرفة نقاط القوة والحدود الخاصة بك.

قد تواجهك تحديات واهتمامات جديدة الآن بعد أن كان شخص عزيز لديه سرطان متقدم. إذا استمر المرض لفترة طويلة ، فقد تزعجك هذه التحديات أكثر. يقول العديد من مقدمي الرعاية إنهم ، بالنظر إلى الخلف ، أخذوا الكثير من أنفسهم. أو يرغبون في أنهم طلبوا المساعدة في وقت أقرب في مشاركة المهام أو طلب الدعم.

يمكنك إلقاء نظرة صادقة على ما يمكنك فعله وما لا يمكنك فعله. ما هي الأشياء التي أنت جيد في؟ ماذا تحتاج أن تفعل بنفسك؟ ما المهام التي يمكنك تقديمها أو مشاركتها مع الآخرين؟ كن على استعداد لترك الأشياء التي يمكن للآخرين القيام بها.

قد يرغب العديد من الأشخاص في المساعدة ولكنك لا تعرف ما تحتاج إليه أو ما إذا كنت تريد المساعدة. ومع تقدم السرطان ، قد ترى تغييرات في الدعم الذي تحصل عليه من الآخرين. فمثلا:

الناس الذين ساعدوا من قبل قد لا يساعدون الآن.
-1قد يرغب آخرون ممن ساعدوا من قبل في المساعدة في طرق جديدة الآن.
- 2الناس الذين لم يساعدوا من قبل قد تبدأ المساعدة الآن.
-3الوكالات التي لا يمكنها المساعدة من قبل قد تقدم خدمات الآن.
تذكر أن الحصول على مساعدة لنفسك يمكن أن يساعد أيضًا حبيبك ، وكذلك الأصدقاء والعائلة.
-1يمكنك البقاء أكثر صحة.
-2قد يشعر حبيبك بالذنب من كل الأشياء التي تفعلها.
-3قد يقدم بعض مساعديك بعض الوقت والمهارات التي لا تملكها.
-4وجود نظام الدعم هو وسيلة لرعاية عائلتك. تكمن الفكرة في إزالة بعض المهام بحيث يمكنك التركيز على المهام التي يمكنك القيام بها. تحدث مع شخص تثق به ، مثل صديق ، أو عضو في مجتمعك الإيماني ، أو مستشار. قد يتمكن أشخاص آخرون من مساعدتك في تفصيل أفكارك ومشاعرك. قد يكونوا أيضًا قادرين على مساعدتك في العثور على طرق أخرى للحصول على الدعم.
تخطيط وتنفيذ رعاية المرضى.

إذا كان مقدمو الرعاية الصحية داعماً لمقدمي الرعاية ولتيسير الرعاية الجيدة للمرضى المصابين بأمراض متقدمة ، فعليهم تنفيذ التدخلات التي تلبي الاحتياجات ذات الأولوية لمقدمي الرعاية ، مثل الحاجة إلى المعلومات والتعليم ؛ القدرة على تعبئة مصادر المساعدة الرسمية وغير الرسمية ؛ واستراتيجيات للحفاظ على الصحة البدنية والمواقف الإيجابية والرفاهية. من أجل تفصيل مثل هذه التدخلات ، يجب أن يدرك مقدمو الرعاية أن مقدمي الرعاية يمتلكون مستويات مختلفة من المعرفة والمهارة ، ويختلفون في مستوى العبء ، ويواجهون مستويات مختلفة من متطلبات الرعاية ، ويختلفون في مقدار الدعم والمساعدة التي يتلقونها من أفراد العائلة الآخرين.

النشاط: التدخلات التعليمية والإعلامية. (30 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

الهدف: يتضح من مراجعة الأدبيات أن التعليم والمعلومات ضرورية إذا كان مقدمو الرعاية الأسرية سيشاركون بفعالية في الرعاية المنزلية للمرضى. تقارير العائلات توفير الكثير من الرعاية عن طريق التجربة والخطأ. وهذا يخلق شعوراً بعدم اليقين يجعل تقديم الرعاية أكثر استهلاكا للوقت ومجهدا. المعلومات التي تتناسب مع المشاكل التي يواجهها مقدمو الرعاية ستزودهم بتوجيهات لتطبيق الرعاية ، ولكن الأهم من ذلك ، أنها ستقلل من ضغوط الرعاية وما يصاحبها من أعباء ومشاعر عدم الكفاءة والعجز الناجمة عن الغموض. لذلك ، ستتم مراجعة التدخلات التعليمية أولاً ، مع الاعتراف بأن التعليم الفعال سينتج فوائد ثانوية مهمة لمقدمي الرعاية ويقلل من الحاجة إلى التدخلات العلاجية النفسية. هناك أسباب شخصية وكذلك هيكلية لماذا مقدمي رعاية المرضى الذين يعانون من مرض متقدم في كثير من الأحيان لم يكن لديك معلومات مناسبة لرعاية مرضاهم. علاوة على ذلك ، غالباً ما لا يُنظر إلى مقدمي الرعاية على أنهم شركاء في تطوير خطط رعاية المرضى.

الإحتياج (1): يجب أن يشمل مقدمو الرعاية في خطط الرعاية ، قد يكونون غارقين في وضع الرعاية وقد لا يكونون قد قاموا بإعداد أسئلتهم أو قد لا يكونوا على علم بما يجب طرحه. بالإضافة إلى ذلك ، قد يكون للمرضى الذين يعانون من مرض متقدم تقلبات واسعة في الأمراض وحالة العلاج واحتياجات الرعاية .

الاحتياجات (2): توفير إرشادات محددة.

يحتاج أخصائيو الرعاية الصحية إلى إقامة حوار منظم ومستمر مع أفراد الأسرة حول أهداف العلاج ، وخطط الرعاية ، والتوقعات المتعلقة بنتائج المرضى. وقد يجدون أنه من المفيد تطوير بروتوكولات أو "أوراق مساعدة" لتلبية الاحتياجات الإعلامية لمقدمي الرعاية.

توفر إرشادات أو اقتراحات محددة للرعاية لمقدمي الرعاية إحساسًا بالسيطرة ، ومراقبة المرضى وفقًا لحدود محددة (مثل "إبلاغ خبير الرعاية الصحية بدرجة حرارة تبلغ 101 درجة تستمر لمدة 36 ساعة") يساعدهم على تقييم مدى الحاجة إلى مساعدة. كلما كان ذلك ممكنًا ، يحتاج المحترفون إلى توزيع إرشادات كتابية فردية ، يمكن لمقدمي الرعاية اتباعها مع إجراءات محددة عند الوصول إلى معيار معين.

يفيد مقدمو الرعاية أن الاتجاه المحدد والمخصص هو داعم ويقلل من عدم اليقين الذي يواجهونه أثناء تقديمهم الرعاية. لكنهم لا يريدون أن يكتظوا بكميات هائلة من المعلومات غير النوعية.

يمكن أن يساعد الحصول على المعلومات المتعلقة بالأمراض والتوقعات المتعلقة بالمعالجة من مقدمي الرعاية الصحية مقدمي الرعاية في تخطيط الرعاية ، وتوقع المشاكل المحتملة ، واكتشاف التغيرات في مسار المرض. بشكل عام ، تشمل الأسباب التي تدفع مقدمي الرعاية إلى نقص المعلومات الكافية ما يلي:

1. عدم قدرة أفراد الأسرة على طرح الأسئلة (قد يفتقرون إلى المهارات الاجتماعية).
2. عدم القدرة على الحصول على معلومات محددة من مقدمي الخدمات.
3. اتصال محدود مع مقدمي الخدمات.
4. الكثير من الوسطاء بين أخصائي علاج الأورام ، والمريض ، ومقدم الرعاية.
5. أطباء الرعاية الأولية الذين لا يفهمون السرطان ، وعلاج السرطان ، أو رعاية مرضى السرطان.
6. مقدمي الخدمات الذين يتحدثون فقط للمريض ولا يرتبطون بالعائلة.
7. تلقي المعلومات التي تمت تصفيتها فقط من مقدمي الخدمات.
8. الغمر بسبب الشدة والانتباه أو العجز.

قد يتم تخصيص المعلومات عن طريق معالجة.

1. ما الذي يمكن أن يتنبأ به مقدمو الرعاية للعائلات حول أعراض المرضى ، والإعاقة ، وردود الفعل على العلاج ، ومسار المرض.

2. ما يمكن أن يتوقعه المرضى ومقدمو الرعاية من مقدم الرعاية الصحية الخاص بهم.

3. كيف يمكن لأنواع مختلفة من خدمات الرعاية الداعمة والتعليمية أن تساعدهم ، وكذلك الحالات التي تكون فيها هذه الخدمات أكثر فائدة.

الاحتياجات (3): يجب أن يكون الأطباء على دراية بكيفية تأثير مسار المرض والعلاج على حالات الرعاية ، وتوقع مشاكل واحتياجات مقدمي الرعاية الأسرية خلال هذه التحولات ، وتوفير التوجيه التوقعي لأفراد الأسرة. قد تزداد القيود المفروضة على الوقت ، والأنشطة الشخصية ، والخصوصية خلال مرحلة المرض المتقدمة ، ويجب إبلاغ مقدمي الرعاية العائليين بتوقع هذه التغييرات والقيود. وعليهم أن يعرفوا أن تسعة أنواع من خدمات الدعم التي قد تساعد مقدمي الرعاية يتحدون مطالب الرعاية المتعددة. المناطق التي تم تحديدها هي:

1. معلومات التشخيص والعلاج الطبي.
2. تفسير مسار المرض والتوجيه الاستباقي.
3. تفسير مشاعر المرضى إلى مقدم الرعاية.
4. تفسير المرض للأطفال في سن المدرسة.
5. العملية الإدراكية لمعنى المرض.
6. الوصول إلى خدمات للرعاية البدنية.
7. خدمات بناء المهارات.
8. خدمات حل المشكلات.
9. خدمات الإحالة لمقدمي الرعاية الأسرية.

تدخلات العلاج النفسي

النشاط: المشاركون يعبرون عن تجربتهم فيما يتعلق بعبء تقديم الرعاية ..... (30 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

تم تصميم التدخلات العلاجية النفسية لمقدمي الرعاية الأسرية لتعزيز الروح المعنوية واحترام الذات والتعامل مع الشعور بالسيطرة ، وقدرات حل المشكلات ، ولتقليل الكرب العاطفي لمقدمي الرعاية أثناء رعاية المرضى في المنزل. هذه التدخلات ليست مصممة لإبلاغ مقدمي الرعاية بشأن جوانب محددة من تقديم الرعاية ؛ بدلا من ذلك ، تركز هذه التدخلات على مساعدة مقدمي الرعاية على التكيف نفسيا مع متطلبات العناية.

الهدف: حل المشكلات وإدارة الإجهاد مكونان هامان من عناصر الدعم النفسي لمقدمي الرعاية ويحتاج المهنيون الصحيون إلى إدراك متى يمكن أن يستفيد مقدمو الرعاية العائليون من مثل هذه التدخلات (يمكن أن يساعد نهج حل المشكلات في الحد من مقدمي الرعاية

الشعور بعدم اليقين ومرافقة مشاعر التوتر والعبء تعزيز نتائج إيجابية المريض).

الاحتياجات: يجب تقييم مقدمي الرعاية العائليين بشكل دوري للضيق النفسي / العاطفي

وينبغي تحديد المصادر المحددة لهذا الضائقة. بالإضافة إلى ذلك ، يعد تقييم جودة العلاقة الأسرية وأنماط الاتصال ضروريًا إذا أريد للتدخلات أن تكون فعالة. إذا كان هناك ما يبرر ذلك ، ينبغي أن يتم إحالة إلى موارد الخبراء الخارجية (على سبيل المثال ، مستشار ، أخصائي نفسي). خلال الزيارات ، يحتاج مقدمو الرعاية الصحية إلى تخصيص وقت لإجراء مناقشات صريحة مع مقدمي الرعاية حتى يمكن التعبير عن الأسئلة والمخاوف بكل حرية.

يجب على مقدمي الرعاية الصحية تخطيط رعاية المرضى على أساس افتراض أن الأسرة هي نظام وأن سلوك أحد الأعضاء واستجابته يؤثر على الأسرة كوحدة واحدة. قد يحتاج كل من المريض ومقدم الرعاية إلى الدعم النفسي أو دروس مقدمي الرعاية.

يجب أن تعالج الضيق العاطفي لمقدم الرعاية. على الرغم من أن التدخلات العلاجية النفسية قد تكون مهمة لبعض مقدمي الرعاية الأسرية ، إلا أن معظم إعدادات علم الأورام السريرية لا تشمل هذه الخدمات. ومع ذلك ، فإن حل المشكلات والسيطرة على الإجهاد مكونان هامان من عناصر الدعم النفسي لمقدمي الرعاية ويحتاج المهنيون الصحيون إلى إدراك متى يمكن أن يستفيد مقدمو الرعاية من الأسرة من مثل هذه التدخلات.

الوحدة الثالثة: الاحتياجات المتعلقة بالمرضى:

نشاط (1): قدم مصطلح الراحة وكذلك العلاج ..... (60 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

الهدف: قد يحيل فريق السرطان المرضى والعائلة إلى طبيب الرعاية الأولية. تحدث تحولات الرعاية هذه في وقت قد لا تعاني فيه الأسر فقط من الصدمة والغضب والاكتئاب المصاحب للاعتراف بأن العلاجات لم تعد فعالة ، بل زادت أيضًا من مسؤوليات الرعاية.

هذا قد يضع مقدمي الرعاية الأسرية في وضع صعب بشكل خاص ، دون وجود مزود ثابت يلجأ إليه للحصول على المشورة والتوجيه فيما يتعلق بخطة الرعاية لمريضهم. تتأثر احتياجات المرضى من حيث العمر وعدد الحالات المرضية النفسية والتخلص النفسي والتقاليد الثقافية ومرحلة السرطان ومرحلة العلاج. يمكن لمقدمي الرعاية ، بدورهم ، إدراك احتياجات هؤلاء المرضى على أنها مطالب.

مساعدة أحب الخاصة بك واحد التعامل مع السرطان.

قد يكون محبوبك يعاني من سرطان متقدم أو مع تكرار الإصابة بالسرطان. قد يقول الأطباء أن السرطان لا يستجيب للعلاج. قد يكون قيل لك أن مغفرة على المدى الطويل ليس من المرجح. أو ربما قرر أحد أحبائك التوقف عن العلاج وعيش أيامه على أكمل وجه.

قد يكون هذا وقتًا يجب فيه اتخاذ قرارات جديدة. قد تكون هناك حاجة للتحولات في الرعاية أو قد تحدث بالفعل. قد يبدو عبء اتخاذ هذه القرارات معًا أثقل بكثير مما كان عليه من قبل. هذه الخيارات تأتي في كثير من الأحيان مع العديد من العواطف ، مثل الحزن والغضب والخوف من المجهول. قد تأتي أيضًا مع أسئلة حول المدة التي ستعيش فيها حبيبتك.

قد يبدو التفكير أو التحدث عن هذه المشكلات وكأنك تستسلم. لكنك لست كذلك. هذا لا يعني التخلي عن الأمل. عادة ما يتعامل الناس بشكل أفضل عندما يكون لديهم خيارات مختلفة. وجود معلومات حول كيفية التعامل مع المواقف الصعبة سيساعد. لا يزال أحباءك يستحق رعاية طبية ودعمًا من فريق الرعاية الصحية حتى لو تغير العلاج.

اتخاذ القرارات معا.

ربما كنت ترعى مريض السرطان لفترة قصيرة أو طويلة. على الأرجح ، ستشارك كثيرًا في المساعدة في اتخاذ خيارات حول الخطوات التالية للرعاية.

بعض هذه الخيارات قد تشمل:

أهداف العلاج
متى تستخدم رعاية المسنين
القرارات المالية
كيفية الحصول على الدعم من أفراد الأسرة

عند التعامل مع مرض السرطان المتقدم ، يكون لدى الناس أهداف مختلفة لرعايتهم. يريد البعض الاستمرار في اتباع علاجات أكثر قوة. يقرر آخرون اختيار طرق أخرى للرعاية. أنت قد تتساءل: "هل فعلنا كل ما هو ممكن لعلاج السرطان ، أم يجب أن نحاول علاج آخر؟" من الطبيعي أن تريد أن تفعل كل ما تستطيع ، ولكن يجب أن تزن هذه المشاعر ضد إيجابيات وسلبيات أحبائك.

أسئلة لطرحها:

ما أفضل ما يمكننا أن نأمل به من خلال تجربة علاج آخر؟
هل هذا العلاج يهدف إلى تخفيف الآثار الجانبية أو إبطاء انتشار السرطان؟
هل هناك فرصة أن يتم العثور على علاج جديد بينما نحاول القديمة؟
ما هي الآثار الجانبية المحتملة والجوانب السلبية الأخرى للعلاج؟ ما مدى احتمالية ذلك؟
هل المكافآت الممكنة أكبر من العيوب المحتملة؟

قد يسأل طرح هذه الأسئلة المريض أن يقرر ما إذا كان سيستمر في العلاج أو يبدأ. من الأفضل العمل معًا في هذه العملية. وسوف تساعدك على معرفة كل من الاحتياجات الخاصة بك واحتياجات الآخرين بالقرب منك.

من المهم أن تسأل فريق الرعاية الصحية ما تتوقعه في المستقبل. ومن المهم أيضًا أن تكون واضحًا معهم حول مقدار المعلومات التي تريدها أنت والمريض منها.

فهم رغباتك المحبوبة

بالنسبة إلى العديد من العائلات ، من المهم أن يكون أحد أفراد عائلتك مسؤولاً عن اتخاذ القرارات. ولكن في بعض العائلات والثقافات ، من الشائع أن يقوم مقدم الرعاية بالعديد من القرارات. ويجوز لهم جعلها مع أو بدون علم المريض. أو في بعض الأحيان ، يرغب المريض في أن يتخذ مقدم الرعاية كل القرارات.

قد يكون هذا صعبًا ، وذلك لأسباب عديدة:

الإجهاد الخاص بك قد يجعل من الصعب تحديده.
قد تختلف أفكارك حول كيفية المضي قدمًا من أفكار أفراد العائلة الآخرين أو الأصدقاء.
قد يكون للمريض معتقدات مختلفة عن الرعاية منك أو مع أحبائك الآخرين.
قد تختلف آراء فريق الرعاية الصحية الخاص بك عن حبيبك أو شخصك.

قد يكون هناك أيضًا وقت عندما يتعين عليك اتخاذ قرارات لأحبائك لأنه لم يعد بإمكانه. من المهم أن تشعر بما يشعر به قبل حدوثه. كيف يود التعامل معها؟ هذا قد يعني ترك بعض الآراء التي لديك حول العلاج. (على سبيل المثال ، قد ترغب في إبقاء أحباءك على قيد الحياة ، مهما كان ما يتطلبه الأمر. لكنه قد يرغب في التوقف عن تلقي إجراءات الحفاظ على الحياة عند نقطة معينة.) حاول أن تبقي الأمور في نصابها من خلال النظر إلى الحقائق.

الرعاية التلطيفية

جميع المرضى لديهم الحق في الراحة ونوعية الحياة طوال رعايتهم. الرعاية التي تجعل المرضى يشعرون بتحسن ، ولكن لا يعالج هذا المرض نفسه غالباً ما يسمى الرعاية الملطفة. ويشمل علاج أو منع أعراض السرطان والآثار الجانبية الناجمة عن العلاج. يمكن أن تعني الرعاية المريحة أيضًا الحصول على المساعدة في المشكلات العاطفية والروحية أثناء وبعد علاج السرطان. اعتقد الناس ذات مرة أن الرعاية الملطفة هي وسيلة لتهدئة أولئك الذين يموتون من السرطان.

يقدم الأطباء الآن هذه الرعاية لجميع مرضى السرطان ، بداية من تشخيص السرطان. يمكن أن تستمر الرعاية التلطيفية من خلال العلاج ، والبقاء ، والأمراض المتقدمة ، والوقت الذي لم يعد فيه العلاج يسيطر على السرطان.

قد يتمكن أعضاء فريق الرعاية الصحية من توفير رعاية مريحة. ولكن قد يكون أخصائي الرعاية الملطفة هو أفضل شخص لعلاج بعض المشاكل. اسأل الطبيب أو الممرضة إذا كان هناك أخصائي يمكن أن يراه أحد أفراد عائلتك.

اختيارات الرعاية

هناك عدد من الخيارات للعناية بسرطان الشخص الذي تحبه. هذه تعتمد على نوع السرطان وأهداف المريض للرعاية.

هذه الخيارات تشمل

التجارب السريرية (الدراسات البحثية)
الإشعاع الملطفة أو العلاج الكيميائي أو الجراحة
رعاية المسنين
رعاية منزلية

اختيار العديد من المرضى أكثر من خيار واحد. يجب أن يقوم أحد أفراد أسرتك على أساس قرارها بشأن مخاطر وفوائد العلاجات المتاحة بالإضافة إلى مشاعرها الخاصة حول الحياة والموت.

يجب عليكما طرح كل الأسئلة التي تحتاج إليها. إذا اختارت عدم الحصول على علاج أكثر فعالية من السرطان ، فهذا لا يعني بالضرورة حدوث انخفاض سريع وموت. وستستمر في تلقي الرعاية الملطفة وجعلها مريحة. يمكن لفريق الرعاية الصحية تقديم المعلومات والنصائح حول خيارات العلاج.

المعالجة الملطفة

يمكن استخدام العديد من الطرق نفسها المستخدمة لعلاج السرطان ، مثل الأدوية وبعض العلاجات ، لتقليل الألم أو الأعراض الأخرى ، ومساعدة المريض على الشعور بمزيد من الراحة. في حالات السرطان المتقدمة ، يمكن إعطاء علاج ملطّف لمساعدة الشخص على الشعور بتحسن ، حتى لو لم يكن الغرض منه علاج السرطان. على سبيل المثال ، قد يعطي الأطباء العلاج الكيميائي لإبطاء نمو الورم الذي يسبب الألم. أو يمكن إجراء عملية جراحية لإزالة كتلة تضغط على أعصاب معينة وتسبب الألم.

الاحتياجات (1): يجب على المشاركين التفريق بين الرعاية المباشرة وغير المباشرة.

يمكن تصنيف الرعاية على أنها "رعاية مباشرة" أو "رعاية غير مباشرة" ، حسب تركيزها.

يؤثر هذا التصنيف على متطلبات تقديم الرعاية. الرعاية المباشرة هي الرعاية التي تتم مباشرة مع المريض ، مثل إدارة الأعراض ، والدعم العاطفي ، وإدارة الأدوية ، والمساعدة في التنقل أو الاستحمام. يتم تنفيذ الرعاية غير المباشرة نيابة عن المريض وتشمل أنشطة مثل الحصول على الأدوية ، والنقل ، والمهمات ، وتحديد المواعيد وتنسيق المواعيد ، والمساعدة في الفواتير الطبية والمالية.

رعاية عملية

معلومات عن مرض قريبك.

غالبًا ما يكون التاريخ الطبي للشخص هو مسألة خاصة. ومع ذلك ، عادة ما يكون هناك شخصين في حياتنا لا نمانع مشاركة هذه المعلومات معهم. إذا كان ذلك ممكنًا ، اجعل قريبك يكتب الأشخاص الذين سيسمحون لهم بالوصول إلى هذه المعلومات الطبية ، واطلب منهم التوقيع عليها وتسجيل شخص ما كشاهد.

إذا كنت تعتقد أنك ستكون مقدم الرعاية الرئيسي لأقاربك ، فإن الحصول على إذن كتابي لإعطاء وتلقي المعلومات حول وضعهم الطبي قد يجعل الأمر أسهل بالنسبة لك. هذا سيجعل التواصل أسهل عندما تحتاج للتحدث إلى الممرضات والأطباء وغيرهم من المهنيين الصحيين حول حالة قريبك من وقت لآخر.

توفير الرعاية العملية.

قد يكون قريبك مستقلاً تمامًا مع بعض المهام ، أو قد يتطلب المساعدة. سوف تجد أنه يساعد إذا كان لديك بعض المعرفة من هذه المهام ، حتى تتمكن من المساعدة عند الضرورة. تذكر ، لا تفعل سوى الأشياء التي تشعر بالراحة معها. إذا كنت غير متأكد في أي وقت ، فاطلب توجيهات من فريق الرعاية الملطفة.

مساعدة مع الأدوية

تحقق دائماً من الملصق على العبوات للتأكد من أنك تعطي الدواء المناسب في الوقت المناسب. لا تؤخذ جميع الأدوية عن طريق الفم (عن طريق الفم) ، لذلك تحقق أولا. ليست جميع الأدوية في صورة أقراص ، وقد يكون بعضها سائلاً ، وقد يحتاج البعض الآخر إلى الحقن عن طريق الحقن أو عن طريق رقعة جلدية.

في بعض الأحيان يتم إعطاء الناس قائمة ، من المستشفى أو الممارس العام ، بماهية الأدوية وموعد أخذها. إذا لم تكن لديك قائمة وترغب في الحصول على قائمة ، فتحدث مع طبيب العائلة أو فريق الرعاية التلطيفية.

يجب إعطاء بعض الأدوية في أوقات معينة ؛ يتم إعطاء الآخرين "حسب الحاجة". على سبيل المثال ، يجب تناول بعض أدوية الألم فقط عندما يشعر الشخص بالألم ، في حين يتم إعطاء أدوية الألم الأخرى بانتظام في أوقات محددة من النهار أو الليل.

يجب أن تؤخذ الأدوية "حسب التوجيه" فقط. إذا كان قريبك غير متأكد من ذلك ، تحدث إلى الطبيب أو الممرضة.

إذا كان هناك العديد من الأجهزة اللوحية التي يجب أخذها ، ففكر في استخدام صندوق dosette ، والذي يسمح بوضع الأجهزة اللوحية في حجرات خاصة بحيث يسهل عليك تذكر أي منها يجب إعطاؤه متى. تتوفر صناديق دوتسيت في معظم الكيميائيين ويمكن ملؤها من قبلك ، أو من الصيدلي. أو تحدث مع الصيدلي أو فريق الرعاية الملطفة أو GP حول حزمة "webster". هذه هي حزمة أسبوعية ، يتألف منها الكيميائي الخاص بك ، من جميع الأدوية التي يتم تناولها.

في حالة استخدام المحاقن والإبر ، اسأل عن التخلص الآمن من خلال حاوية "التخلص من الأدوات الحادة" المتوفرة من الصيدلية.

من الشائع جدا أن تتغير الأدوية. عندما لا تكون هناك حاجة إلى الدواء ، يجب التخلص منه لتجنب الاستخدام العرضي. يجب إعادة الأدوية غير المستخدمة إلى الصيدلي للتخلص الآمن منها. إذا كانت هناك فرصة لاستخدام دواء مرة أخرى في المستقبل ، فقم بتخزينه في مكان آمن وبارد وجاف ، بعيداً عن الأدوية التي يتم استخدامها يوميًا.

إذا لم يكن لديك سوى عدد قليل من الأجهزة اللوحية (أو أدوية أخرى) ، فاتصل بالطبيب العام لترتيب وصفة طبية أخرى. حاول ألا تترك هذا بعد فوات الأوان. حيثما أمكن ، تجنب الاضطرار إلى ترتيب ذلك في عطلة نهاية الأسبوع. يقدم بعض الكيميائيين خدمات توصيل الوصفات المنزلية.

إذا كان البلع صعبًا ، يمكن سحق بعض الأقراص وإعطائها بالطعام أو السوائل. تحقق أولاً ، مع الطبيب أو الممرضة ، حيث أن بعض الأقراص لا يجب أن يتم سحقها ، وقد يتطلب الأمر وصف نوع بديل من الدواء.

قد يحتاج بعض الأشخاص إلى تناول أدوية قوية للألم ، مثل المورفين. إذا كان هناك حاجة إلى دواء قوي للألم ، يمكن للطبيب أو الكيميائي أو فريق الرعاية الملطفة شرح لماذا وكيف ومتى يتم استخدامها. المعلومات المكتوبة متاحة أيضا.

في كثير من الحالات ، قد يرتب فريق الرعاية الملطفة بعض الأدوية ، في شكل الحقن ، ليترك في مكان آمن داخل المنزل. ويُشار إلى هذه أحيانًا باسم "أدوية الطوارئ" ويتم وصفها "فقط في حالة" وجود قريب لك يشعر بعدم الراحة ولا يعفى من الأدوية التي يتم تناولها عن طريق الفم. على سبيل المثال ، إذا كان الشخص مصابًا بالغثيان ولا يمكنه تناول أدوية الألم عن طريق الفم ، فقد تحتاج الممرضة أو الطبيب إلى زيارة لإعطاء حقنة لوقف الغثيان أو لمنع الألم.

العديد من الأدوية (الأدوية) التي تعطى لتخفيف الألم لها أيضا آثار جانبية غير مرغوب فيها. تحدث مع الممرضة الخاصة بك عن هذا ، حتى تعرف ما الذي تبحث عنه. معظم الآثار الجانبية تلبس في غضون 24 أو 48 ساعة حيث يعتاد الجسم على الدواء. ومع ذلك ، من الأفضل بكثير منع الآثار الجانبية حيثما أمكن ؛ على سبيل المثال ، من خلال إعطاء المسهلات بانتظام لمنع الإمساك أو تناول الأدوية المضادة للغثيان في متناول اليد لمنع القيء.

يقلق بعض المرضى وعائلاتهم من استخدام أدوية الألم القوية (المواد الأفيونية مثل المورفين). انهم قلقون من أن الشخص قد يصبح مدمن ، أو أن الاستخدام المطول لهذه الأدوية القوية قد يعجل الموت. يمكنك أن تطمئن إلى أن الرعاية التلطيفية تعتمد على أحدث الأدلة. وهذا يدل على أنه عندما يعطى للألم ، لا تسبب المواد الأفيونية الإدمان ؛ وعندما تستخدم في جرعات محددة ، لا تعجل الموت. في الواقع ، يشعر العديد من المرضى بتحسن كبير عندما يتم تخفيف الألم ؛ تتحسن شهيتهم ، يمكنهم التحرك بحرية أكبر ويستطيعون في كثير من الأحيان استئناف الأنشطة الممتعة.

توفير الرعاية الصحية

يمكن أن يتم المساعدة في العناية بالنظافة بطرق مختلفة: قد تكون قريبًا من "تقديم يد المساعدة" ، قد تعرض غسل وجه قريبك ويديك ، أو قد تحتاج إلى المساعدة في حوض استحمام كامل أو حوض استحمام كامل. قد يحتاج قريبك أيضًا إلى المساعدة في الخروج من السرير والحمام. يمكن للممرضة إرشادك في أي من هذه المهام. إذا كنت تفضل ، يمكن للممرض تقديم الرعاية الصحية و / أو يمكنك القيام بذلك معا.

السلامة مهمة. فكر في وجود قضبان مثبتة في الحمام ، وحيث توجد خطوات. تحدث إلى فريق الرعاية الملطفة بشأن استئجار كرسي استحمام / حمام حتى لا يضطر قريبك إلى الوقوف. قد يجعل خرطوم الدش المحمول باليد الأشياء أيضًا أكثر سهولة. يمكن للطبيب الصحي تقييم الحمام الموجود في منزلك لتحسين السلامة. هناك العديد من الأجهزة الأخرى التي تساعد الأشخاص على التحرك بأمان إذا كانوا غير مستقرين على أقدامهم.

إذا كان سلس البول ، أي فقدان السيطرة على البول أو البول ، هو مشكلة هناك عدد من الوسائل المساعدة أو المنتجات التي يمكن أن تساعد قريبك على الشعور بالراحة والراحة. لا تخف من التحدث إلى أحد فريق الرعاية الملطفة أو طبيبك العمومي حول هذا الأمر.

مساعدة في الأكل والشرب

كثير من الأشخاص الذين يعانون من مرض يهدد حياتهم يفقدون شهيتهم قد يحدث هذا بسبب المرض أو أحد الآثار الجانبية للعلاج و / أو الأدوية أو من خلال الشعور بالمرض أو الانزعاج أو الإمساك أو التعب أو وجود التهاب في الفم أو جفاف الفم. الألم غير المرغوب فيه يمكن أن يؤدي أيضًا إلى فقدان الشهية.

على الرغم من السبب ، فإن رعاية شخص غير مهتم بالطعام وفقدان الوزن يمكن أن تكون صعبة للغاية.

إليك بعض الاقتراحات التي يمكنك تقديمها:

- وجبات أصغر ، في أغلب الأحيان ، بدلاً من ثلاث وجبات كبيرة. يمكنك تقديم الطعام على أطباق أصغر وعدم ملء المشروبات في الجزء العلوي من الزجاج.
- أنواع جديدة من الأطعمة. قد تتغير رغبة الناس في بعض الأذواق. على سبيل المثال ، ربما لم يعد الناس يحبون الأذواق الحلوة وربما يفضلون الآن الطعام الحار.
- مشروبات مغذية. ويمكن شراؤها من الكيميائيين وبعض محلات السوبر ماركت. يمكنك أيضًا صنع العصائر أو العصائر الخاصة بك. إذا كان الشخص غير مهتم بالأطعمة الصلبة ، فقم بتقديم المشروبات بانتظام.
- كوب من النبيذ أو كحول آخر قبل الوجبة يمكن أن يساعد على تحفيز الشهية. لا ينبغي أن يؤخذ الكحول مع بعض الأدوية لذلك تحقق مع الطبيب لمعرفة ما إذا كان على ما يرام.

- رعاية الفم الجيدة. حافظي على رطوبة الفم عن طريق تشجيع تنظيف الأسنان بانتظام ، والمشروبات وشطف الفم. إذا لاحظت وجود بقع بيضاء "غير مستساغة" في الفم ، فليعلم الطبيب أو الممرضة بذلك. هذا أمر شائع وعادة ما يتم علاجه بسهولة باستخدام دواء خاص.
- مع تقدم مرض قريبك ، قد تلاحظ أنهم يأكلون أقل. قد لا يكون من المهم في هذه المرحلة أن يكون هناك "وجبات متوازنة بشكل جيد" كل يوم. قد يكون أكثر أهمية التركيز على ما يستمتع به قريبك ، كما يظهر المثال التالي.

المساعدة في رعاية "تقنية" أخرى

يحتاج بعض المرضى الذين يتم الاعتناء بهم في المنزل إلى إدارة خاصة لمختلف الأنابيب والجروح وأنظمة الصرف والحقن وما إلى ذلك. ويطور العديد من الأقارب مهارات كبيرة في إدارة هذه الرعاية المعقدة. ومع ذلك ، فإن الآخرين ليسوا مرتاحين.

استخدام معدات خاصة

تعتمد المعدات التي تحتاجها على وضعك. يمكن أن يزيد استخدام المعدات من استقلالية قريبك ، ويسهل عليك الأمر ويروّج لبيئة أكثر أمانًا.

قد يلزم استخدام أنواع المعدات التالية في المنزل:

- كرسي الاستحمام - تمكن الشخص من الجلوس بأمان في الحمام.
- مرحاض - مرحاض محمول ، يشبه الكرسي
- قضبان استحمام للحمام / الدش - توفر الدعم للوقوف / الجلوس في الحمام / الدش
- لوحة الاستحمام - تمكن الشخص من الدخول والخروج من الحمام بأمان
- مقلاة النعال / المبولة - الأجهزة للسماح بمرحاض في السرير
- أوراق ماصة وبلاستيكية - تستخدم على السرير أو الكرسي حيث سلس البول (المثانة أو الأمعاء غير المنضبط) هي قضية
- صندوق Dosette - حاوية أدوية خاصة تساعد الأشخاص على أخذ الأقراص الصحيحة في الوقت المناسب • سائق الحقنة - وهو جهاز يستخدم لتوصيل الأدوية تحت الجلد بدلاً من الفم
- حاوية الأدوات الحادة للحقن والإبر المستعملة
- دعوة الجرس أو الداخلي
- قفازات يمكن التخلص منها
- سرير المستشفى - سرير يمكن رفعه أو خفضه وله جوانب لمنع السقوط.
- عصا السرير - يساعد الشخص على الجلوس والدخول أو الخروج من السرير
- القسطرة البولية - أنبوب في المثانة للمساعدة في تمرير البول
- أجهزة تخفيف الضغط - المراتب الخاصة أو جلود الغنم أو الوسائد المستخدمة للراحة في السرير أو الكرسي ولمنع قرح الفراش

• إطار المشي - جهاز يستخدم للمساعدة في المشي
• كرسي متحرك - يسمح للشخص أن يكون متنقلاً إذا كان غير قادر على المشي بسهولة
• صفائح شرائح - صفائح شجرية ، يجعل من الأسهل تحريك قريبك عندما يكون في السرير.
التعامل مع الأعراض الشائعة

يتم استخدام كلمة أعراض لوصف مشكلة تتعلق بمرض. عندما يكون الشخص مصابا بمرض خطير ، وحيث يتوقف العلاج العلاجي ، يكون تركيز الرعاية على تخفيف الأعراض التي قد تنشأ.

كل شخص مختلف وكذلك الأعراض التي قد تحدث. من المهم تسليط الضوء على الأعراض الشائعة (الألم ، والإمساك ، والغثيان ، والتعب ، وضيق التنفس) وبعض الطرق الأساسية للتخلص منها. قد لا تختفي الأعراض تمامًا ، ولكن في معظم الحالات يمكن التحكم في الأعراض إلى مستوى مريح.

يعتمد دورك في المساعدة على التعرف على الأعراض وإدارتها على مدى استقلالية قريبك وعلاقتك وما تشعر به مرتاحًا. تذكر أن تخفيف الأعراض هو أحد الأهداف الرئيسية لفريق الرعاية الملطفة ، لذلك تتوفر المساعدة.

إذا ظهرت أعراض غير مذكورة هنا ، تحدث مع فريق الرعاية التلطيفية ، وسوف يزودك بمزيد من المعلومات. قد يساعدك الاحتفاظ بدفتر أو يومية يومية لتدوين الوقت والكلمات التي يستخدمها قريبك لوصف أعراض معينة.

الالم

العديد من مقدمي الرعاية تقلق بشأن الراحة من قريبهم. هذا أمر مفهوم للغاية. أول شيء يجب أن تعرفه هو أن ليس كل الأشخاص الذين يحتاجون إلى رعاية ملطفة يعانون من ألم مستمر. من المهم أيضًا إدراك أن مستوى راحة الشخص هو شعور شخصي للغاية.

نشعر جميعنا بعدم الراحة بطرق مختلفة وعلى مستويات مختلفة. غالبًا ما يربط الناس بعدم الراحة بالألم. ومع ذلك ، قد نشعر أيضًا بعدم الارتياح إذا شعرنا بالمرض أو التعب أو القلق أو القلق.

الشيء المهم هو أنه إذا قال قريبك إنهم يشعرون بالألم ، فإن فريق الرعاية التلطيفية يمكن أن يساعد. على الرغم من التقدم في العلاج ، قد لا يتم دائمًا إزالة الألم تمامًا. سيساعدك فريق الرعاية الملطفة في استراتيجيات متعددة لتقليل الألم قدر الإمكان.

طرق التعامل مع الألم تختلف من شخص لآخر.
إليك بعض الأشياء الشائعة التي يمكنك فعلها إذا كان قريبك يعاني من الألم:
تقييم الألم. قد تريد أن تسأل قريبك هذه الأسئلة ، وتكتب الإجابات. سيساعدك ذلك على وصف الألم للممرضة أو الطبيب والمساعدة في اختيار العلاج.
(1) أين الألم؟ (في بعض الأحيان قد يكون الألم أكثر من منطقة واحدة).
(2) كيف يشعر الألم؟ (على سبيل المثال ، الخفقان الشديد ، الحرق).
(3) كم من الوقت كان الألم موجودًا؟
(4) هل هذا نوع جديد من الألم؟
(5) كيف تقيم الألم على مقياس من واحد إلى عشرة؟ (1 "عدم الشعور بالألم" حتى 10 يعانون من "ألم مبرح"). إذا كان الجواب 7 أو 8 من 10 ، فسيتم اعتبار ذلك كمًا كبيرًا من الألم).
(6) هل تشعرين بالتقيؤ؟
(7) متى أخرت فتحاتك؟ (يمكن أن يسبب الإمساك الألم).

إدارة الألم:

(1) اطلب من قريبك الاستلقاء على السرير أو الجلوس.
(2) اطلب من قريبك أن يأخذ 10 نفسا عميقا.

(3) إذا أعطيت قريبك بعض الأدوية التي يجب تناولها (والتي هي للألم الذي يشعرون به) اعط الدواء كما هو محدد على الحاوية. تحقق أولا لمعرفة ما هي الأدوية التي اتخذت الألم بالفعل في ذلك اليوم. إذا كان قريبك له نفس القدر المسموح به من الاتصال بخدمة الرعاية الملطفة.
(4) اطلب من قريبك أن يحاول إبعاد أذهانك عن طريق القراءة أو مشاهدة التلفزيون أو الاستماع إلى بعض الموسيقى.
(5) عرض تدليك القدمين واليدين والكتفين.
(6) إذا كان الغثيان (الشعور بالتقيؤ) أو الإمساك (لا يوجد عمل أمعاء لعدة أيام) هو مشكلة ، فقد يكون هذا سبب محتمل للألم.

(7) إذا لم يتم تخفيف الانزعاج بعد 30 دقيقة من الاتصال بفريق الرعاية الملطفة. سيكونون قادرين على مراجعة المشكلة واقتراح طرق أخرى لتقليل الألم.

قلق حول المواد الأفيونية.

المواد الأفيونية هي قاتلة قوية للغاية للألم والتي لن يتم وصفها إلا إذا لم يتم علاج الألم باستخدام أدوية أكثر اعتدالا. يخشى بعض المرضى والأقارب من استخدام المواد الأفيونية (مثل المورفين على سبيل المثال) لأنهم يعتقدون أنه قد يسرع الموت.

من المهم أن تتذكر أن سبب الوفاة هو المرض الأساسي ، وليس العقار. سيقوم الطبيب بتقليل الدواء بعناية إذا كان يسبب آثارًا جانبية خطيرة. ومع ذلك ، من المهم أن تعرف عن تأثير هذه الأدوية ولماذا يتم استخدامها. اسأل ممرضة الرعاية الملطفة لكتيب يشرح كل شيء عن المواد الأفيونية.

غثيان

هذا هو المصطلح المستخدم عندما يشعر شخص ما بالرغبة في التقيؤ أو الشعور بالمرض عند التفكير في الطعام أو مشاهدته. يمكن أن يكون سبب الغثيان للمرض ، والأدوية ، والعلاج الكيميائي ، والعلاج الإشعاعي ، والإمساك أو خلل في المواد الكيميائية داخل الجسم.

إذا كنت قريبًا لديك غثيان:

(1) تأكد من سهولة الوصول إلى وعاء أو دلو في حال تقيؤهم.
(2) اسأل عن كيفية تقييم الغثيان على مقياس من 1 إلى 5 (1 يكون غثيانًا "قليل جدًا" و 5 غثيانًا "شديدًا").
(3) إذا تم وصف الأدوية المضادة للغثيان ، تحقق مما إذا كان قد تم أخذها حسب التوجيهات. إذا سمحت الوصفة الطبية ، اعط الدواء المضاد للغثيان ، إلا إذا كان التفكير في محاولة أخذ قرص يجعل قريبك يشعر بأنه أسوأ.
(4) يفضل بعض الناس عدم تناول أو شرب أي شيء حتى يمر الغثيان ؛ يجد آخرون كميات صغيرة من الطعام أو المشروبات مفيدة.
(5) اسأل متى كانت آخر مرة كان فيها قريبك حركة أمعاء جيدة. إذا كانت مدتها أكثر من يومين ، فاتبع التوجيهات أسفل عرض "الإمساك" أدناه.
(6) شجع قريبك على الراحة. أقترح التنفس العميق. العب بعض الموسيقى الناعمة. تقديم تدليك القدم أو الرقبة. إذا كنت تشعر بالراحة نسبياً ، قد يساعدك الحمام أو الدش.
(7) إذا لم يتم تخفيف الغثيان بعد ساعة واحدة أو ازدادت الحالة سوءًا ، فاتصل بفريق الرعاية الملطفة.

الإمساك
يحدث الإمساك عندما لا يفتح الشخص أحشاءه لعدة أيام. هذا العرض يمكن أن يسبب الغثيان والألم والتعب. يمكن أن يرتبط سبب الإمساك بانخفاض مدخول السوائل أو محدودية الحركة أو سوء التغذية أو مرض الشخص. يرتبط الإمساك أيضًا بالآثار الجانبية لأدوية الألم القوية. في معظم الحالات ، يمكن منع الإمساك.
لمنع الإمساك:

(1) شجّع المشروبات مثل الماء والعصائر.
(2) إن أمكن ، تناول أطعمة غنية بالألياف ، بالإضافة إلى الكثير من المشروبات.

(3) أقترح أن قريبك لديه مسافة قصيرة كل يوم إذا كانوا يشعرون بذلك.
(4) يحيط علما بالأمعاء: هل هي صلبة أو ناعمة أو صغيرة أو سائلة؟
(5) الاحتفاظ بسجل عندما تحدث إجراءات الأمعاء.
(6) إذا وصف قريبك بأدوية قوية للألم (مثل المورفين) ، تأكد من أنه تم طلب أدوية مسهلة.

(7) هناك العديد من العلاجات الطبيعية للإمساك التي يمكن استخدامها جنبا إلى جنب مع الأدوية الموصوفة. اطلب من أحد أعضاء فريق الرعاية التلطيفية للحصول على اقتراحات.
(8) إذا لم يكن هناك عمل أمعاء لمدة يومين ، تحدث مع فريق الرعاية الملطفة الذي سيقوم بإعداد خطة خاصة لاحتياجات قريبك.
(9) لا تفترض أنه إذا كان قريبك لا يأكل أنه لا يحتاج إلى استخدام أحشاءه - فالإمساك لا يزال يحدث حتى عندما يتم تناول القليل من الطعام.

ضيق في التنفس.

يمكن أن يكون ضيق التنفس أو صعوبة التنفس أحد الأعراض غير السارة. عادة ما يكون بسبب مرض الرئة ، أو الربو ، وانتفاخ الرئة ، وعدوى الصدر ، والضغط من أعضاء الجسم الأخرى ، أو القلق.
بينما يعتمد العلاج المحدد على السبب ، إليك بعض النصائح العامة التي قد تساعد:
(1) شجع قريبك على الجلوس في وضع مستقيم والبقاء معه.
(2) وضع على مروحة و / أو فتح نافذة.
(3) تشير إلى أن ملابسك النسبية ارتداء ملابس فضفاضة.
(4) ضعي بعض الموسيقى الهادئة ، حافظي على وجود لطيف ، مطمئن ، قدمي تدليك القدم أو اليد أو الكتف.
(5) إذا تم وصف أدوية لضيق التنفس ، تأكد من أنها قد اتخذت حسب التوجيهات.
(6) لا يحتاج الأكسجين عبر قناع أو شوكات الأنف بشكل روتيني ويتطلب الأمر باستخدام طبيب. (7) إذا لم يتم تخفيف ضيق التنفس وتسبب الضيق ، اتصل بفريق الرعاية الملطفة.

إعياء

التعب شائع جدًا لدى الأشخاص المصابين بمرض يهدد حياتهم. إنه شعور التعب الشديد الذي يمكن أن يكون محبطًا تمامًا (أو موهنًا).

هناك عدد من الأسباب المحتملة للإرهاق. وتشمل هذه قلة النوم ، نقص الأكسجين في الدم ، سوء التغذية ، الاكتئاب ، تأثير العلاج الكيميائي أو العلاج الإشعاعي ، العدوى ، أو آثار المرض نفسه.

يمكن أن يكون التعب (ليس دائمًا) أمرًا صعبًا للغاية.

قد تساعد الاستراتيجيات التالية على:

(1) قم بتشجيع القيلولة القصيرة خلال اليوم.
(2) تشير إلى ممارسة التمارين الرياضية المنتظمة.
(3) تشجيع الأطعمة والمشروبات المغذية.
(4) خطط للقيام بأكثر المهام حيوية (مثل الاستحمام أو الحمام) عندما تكون مستويات الطاقة أعلى.
(5) شجع قريبك على أخذ هواية لا تتطلب الكثير من الطاقة. على سبيل المثال: ألعاب اللوح ، والكتب الناطقة ، والاستماع إلى الراديو و / أو مشاهدة التلفزيون أو الفيديو.
(6) إذا كنت تعتقد أن الإرهاق قد أصبح أسوأ ، تحدث مع فريق الرعاية الملطفة.

هذيان

هذا هو تغيير في تفكير الشخص والذاكرة والسلوك وهو شائع في المرضى الذين يتلقون الرعاية الملطفة. تحدث هذه التغيرات بسبب اضطراب في وظائف المخ بسبب المرض أو في بعض الأحيان العلاج.

المرضى الذين يتلقون رعاية ملطفة في المستشفى أو في المنزل غالباً ما يكونون أكثر مرضاً من المرضى الآخرين ؛ واتخاذ مجموعة متنوعة من الأدوية.

نحن نعلم أن المرضى الذين يعانون من مرض خطير ، ويتناولون العديد من الأدوية المختلفة ، والذين قد يكونون مصابين بالعدوى أو أجريت لهم جراحة حديثة ، قد يتطور لديهم الهذيان. أيضا المرضى الذين هم كبار السن ، أو الذين لديهم بالفعل بعض مشاكل الذاكرة هم أكثر عرضة لتطوير الهذيان.

الهذيان يمكن أن يكون محزنًا جدًا للشخص الذي لديه ، ولعائلته. الناس الذين يعانون من الهذيان يجدون صعوبة في تذكر المعلومات الجديدة ، صعوبة في التركيز والاهتمام ، وفي بعض الأحيان يجدون صعوبة في إخبارهم من الليل.

قد يكون الشخص المصاب بالهذيان مرتبكًا ولا يتعرف على الأشخاص المألوفين ، أو قد يكون مثبتًا على شيء واحد ، أو يصبح مشبوهًا. أحيانا الهذيان يسبب الهلوسة عندما يرى الناس أشياء غير موجودة.

سيبحث الأطباء والممرضون الذين يبحثون عن قريبك عن الأسباب ويحاولون علاج السبب حتى يستقر الهذيان. في بعض الأحيان قد يوصف المريض الدواء المهدئ لمساعدته على الشعور بالهدوء والتأكد من أنه آمن.

إن التغييرات في تفكير الشخص وسلوكه عندما يكون لديهم الهذيان ليست دائمًا دائمة ولا تعني أن الشخص يعاني من مشكلة صحية عقلية مستمرة. ومع ذلك ، يجب الإشارة إلى أن المرضى في بيئة الرعاية الملطفة قد يكونون مريضين جدًا وقريبًا من الموت ، وفي هذه الحالة قد لا تتم تسوية مشاكل التفكير والذاكرة والسلوك عند الهذيان تمامًا.

أفضل طريقة لمساعدة قريبك مع الهذيان هو التأكد من اتصالك بالعين ، والتحدث ببطء وهدوء وتذكيرهم بما أنت عليه ، وأين هم ، وأنك موجود هناك لمساعدتك.

إذا كنت قريبًا في المستشفى أو مرفق رعاية آخر ، فمن المفيد جدًا للموظفين إذا كان بإمكان العائلة والأصدقاء البقاء مع المريض كلما أمكن ، حيث يستجيب المرضى الذين يعانون من الهذيان بشكل أفضل للأشخاص المألوفين من الغرباء.

من الأفضل للشخص الذي يعاني من الهذيان ألا يكون لديه الكثير من الزوار في وقت واحد ، أو أن يكون لديه الكثير من التحفيز مثل الموسيقى الصاخبة أو التلفزيون. من المهم أيضا تشجيعهم على شرب السوائل لأنها قد تجف ، خاصة إذا كانوا لا يهدأوا ولا يرغبون في تناول الطعام والشراب.

يرجى تقديم المشورة للمهنيين الصحيين إذا كنت تعتقد أن هناك تغييرات في قريبك قد يعني أنهم يطورون الهذيان.

من المفيد أيضًا تزويد الموظفين بأكبر قدر ممكن من المعلومات عن تاريخ قريبك السابق حيث قد يكون هذا مهمًا في تشخيص سبب الهذيان ومنع الهذيان المتكرر.

العلاجات التكميلية

العلاجات التكميلية هي العلاجات المستخدمة مع الطب التقليدي. غالبًا ما تُعتبر العلاجات البديلة تلك المستخدمة بدلاً من الطب التقليدي ويُشار إليها أحيانًا على أنها علاجات غير مثبتة.

تشمل العلاجات البدنية والنفسية التكميلية التدليك والوخز بالإبر والريكي والتنويم المغناطيسي والصور الموجهة.

يمكن أن يكون للعلاجات التكميلية نتائج مفيدة في بعض الظروف. ومع ذلك ، فمن المستحسن بشدة أن تتحدث مع أخصائي الرعاية الصحية للحصول على مزيد من المعلومات حول ما قد يكون العلاج (العلاجات) التكميلية مناسبًا لأقربائك أو لك. تشمل الأمثلة الأخرى العلاج العطري والعلاج بالموسيقى والعلاج بالفن والعلاج بالحيوانات الأليفة.

من الشائع جدا للأشخاص الذين يعانون من مرض يهدد حياتهم أن يفكروا في علاجات طبية أخرى لا يستخدمها الأطباء بشكل روتيني. هذا لأن الناس غالبا ما يرغبون في استكشاف كل خيارات العلاج الممكنة. يوصى بشدة قبل أن يستخدم قريبك علاجات بديلة تناقشها مع طبيبك أو طبيبك المختص. في حين أن بعض هذه العلاجات البديلة قد يتم الترويج لها على أنها مفيدة إلا أن بعضها قد يكون ضارًا في الواقع. من الحكمة التحدث مع أخصائي طبي حول فوائد أي علاجات بديلة.

الرعاية العاطفية

من الصعب جدًا تقديم نصائح دقيقة حول التعامل مع مشاعر قريبك ، حيث تختلف كل علاقة. قد يكون من المفيد أن تكون على علم بأن قريبك سيحصل على "قيعان وقيعان" طوال فترة المرض. في بعض الأحيان قد يشعرون بالغضب ، أو الغضب ، أو الغضب أو الانفعال ، بل وربما يلومونك على بعض مشاعرهم.

ومع ذلك ، في بعض الأحيان قد يشعرون بإيجابية كبيرة.

قد يفكر قريبك في عدد من القضايا الرئيسية المتعلقة بالموت والموت. قد يكون من الأسهل التحدث عن بعض هذه الأشياء مع شخص آخر ، ربما شخص من فريق الرعاية الملطفة. النقطة هي ، ليس لديك للحصول على جميع الإجابات.

بعض الأشياء التي قد تساعد في:

(1) توفير بعض الوقت وحده كل يوم ، إذا رغبت في ذلك.
(2) طلب ما إذا كان هناك أي شيء يمكنك القيام به لجعل الأمور أسهل.
(3) اقتراح بعض الأشياء الممتعة للقيام بها معًا.
(4) طلب ما إذا كان هناك أي شيء لديهم رغبة خاصة ل.
(5) تذكر أنه من الطبيعي أن يشعر قريبك بالانزعاج من وقت لآخر.
(6) تشجيع المشاركة في أشياء "يومية إلى يوم" مثل الأخبار والأنشطة الاجتماعية.
(7) تذكير قريبك بالمهارات والأدوار المختلفة لفريق الرعاية الملطفة.
(8) أخبرهم كم تهتم بهم وتريد مساعدتهم.

في بعض الحالات ، يصبح المرضى و / أو القائمين على رعايتهم قلقين بشأن ما يحدث أنهم يصابون بالاكتئاب أو القلق. كل شخص لديه أوقات يشعر فيها بانخفاض قليل أو "مسطح". عادةً ما يعني الاكتئاب أن الشخص يعاني من الأعراض التالية لأكثر من أسبوعين: الشعور بالحزن أو الإزعاج أو التعاسة في معظم الأوقات أو فقدان الاهتمام أو المتعة في معظم أنشطته المعتادة.

في حين أن هناك العديد من أنواع اضطرابات القلق وأعراض كل اضطراب مختلفة ، بعض العلامات والأعراض العامة تشمل:

- الشعور بالقلق الشديد أو القلق في معظم الوقت
- يجدون صعوبة في تهدئة
- الشعور بالإرهاق أو الخوف من المشاعر المفاجئة من قلق الذعر الشديد
- تجربة الأفكار المتكررة التي تسبب القلق ، ولكن قد تبدو سخيفة للآخرين
- تجنب المواقف أو الأشياء التي تسبب القلق (مثل الأحداث الاجتماعية أو الأماكن المزدحمة)
- تعاني من صعوبات مستمرة (مثل الكوابيس / ذكريات الماضي) بعد حدث مؤلم.

الرعاية الروحية في نهاية الحياة الرعاية الروحية أوسع بكثير من الممارسات الدينية الرسمية.

يشير إلى أي دعم متعلق بالأسئلة المتعلقة بمعنى الحياة ، اعتمادًا على قيم ومعتقدات الشخص. يختلف نوع الرعاية الروحية المطلوبة لكل شخص.

إذا لم تكن متأكدًا من الاحتياجات الروحية لضيفك ، فيمكنك (أو شخص آخر) **فتح محادثة مع أسئلة مثل:**

هل هناك أي شخص أو مكان أو شيء معين يمنحك الأمل والقوة في هذه المرحلة من مرضك؟
هل هناك طقوس دينية معينة ترغب في الحصول عليها؟
هل لديك أي مخاوف خاصة عندما يقترب الموت؟
هل هناك من تود التحدث إليه حول الأمور الروحية؟

إذا كان قريبك معتادًا على حضور الخدمات الدينية ، ولم يعد ذلك ممكنًا ، فقم بمناقشة الأمر مع الوزير المحلي أو الكاهن أو الحاخام أو أي ممثل ديني آخر. على سبيل المثال ، قد يقوم شخص من المجتمع الديني بالترتيب للقدوم إلى منزلك.

من المهم للحفاظ على هذه الاتصالات الدينية ، وكذلك أي طقوس مألوفة.

قد تساعدك هذه الزيارات وأنت قريبًا على الشعور بالعزلة ، وتشعر بأنك جزء مهم من المجتمع الديني.

إن فرص الحصول على المناولة المقدسة أو المشاركة في طقوس أخرى ، أو للاعتراف أو السعي للحصول على مشورة دينية ، كلها جزء من الرعاية الروحية ، اعتمادًا على رغبات قريبك وممارساته المعتادة. في أوقات الأزمات ، يمكن أن تكون الرعاية الروحية مفيدة للغاية ، كما في المثال التالي.

قد تشمل المسائل الروحية الأخرى ذكرك أو إجراء "مراجعة الحياة" معك و / أو مع فرد آخر من أفراد العائلة أو صديق. وهذا يوفر فرصة "لربط الأطراف الضيقة" والضحك والبكاء والاستفادة من "روح" قريبك. يختار بعض الناس كتابة مراجعة الحياة حتى يمكن أن تكون متاحة كمذكرات.

هناك طرق أخرى للاستفادة من "الروح" أو "الشخص الكامل" قد تكون من خلال الموسيقى أو الفن أو الأدب أو الصور أو المحادثة. قد يكون أحد الطرق للوصول إلى هذا "المجال الروحي" هو أن تسألك عن قريب: "ما أهم مسألة بالنسبة إليك في هذا الوقت؟" أو "إذا كان لديك أمنية واحدة ، فماذا ستكون؟

الرعاية الثقافية

لدينا جميعًا قيم ومعتقدات وعادات معينة ، وعادة ما ترتبط بخلفياتنا الثقافية. من المهم أن تدع فريق الرعاية الملطفة بمعرفة أي ممارسات ثقافية معينة مهمة بالنسبة لك ولقريبك. قد تشمل هذه المسائل من النظام الغذائي ، والنظافة الشخصية ، والملابس ، والأعياد الوطنية الخاصة أو الأيام المقدسة ، أو غيرها من الطقوس الهامة.

إذا واجهت أنت أو قريبك صعوبة في فهم اللغة الإنجليزية ، يمكن أن تقوم خدمة الرعاية التلطيفية بترتيب مترجم شفوي. على الرغم من أنه قد تكون هناك أسرة أو أصدقاء يمكنهم المساعدة في الترجمة من وقت لآخر ، يوصى باستخدام مترجم صحي محترف عند مناقشة معلومات مهمة حول الرعاية الصحية.

إذا كنت تفضل أنت أو قريبك عدم مناقشة قضايا الموت والموت ، بسبب معتقداتك الثقافية ، يرجى إعلام فريق الرعاية الملطفة ، بحيث لا يحدث أي مخالفة أو إحراج.

كم من المرضى يجب أن يقال عن مرضهم؟

ربما اختار قريبك عدم إخباره بمرضه الخطير ، وتركك للحصول على جميع المعلومات واتخاذ القرارات. على الرغم من أن قريبك قد "يعرف" حقيقة أنه يعاني من مرض يهدد حياته ، فقد يتجنب أي مناقشة حول هذا الموضوع. قد يضع هذا عبئًا كبيرًا عليك ، ويسعى للحصول على المساعدة من فريق الرعاية الملطفة.

اعتمادًا على علاقتك مع قريبك ، والطريقة التي أخبرت بها المشكلات الصعبة في الماضي ، يمكنك أن تسأل ، "هل يمكن أن نجري دردشة حول هذا الأمر مع شخص آخر هنا؟" يمكن لعضو فريق الرعاية الملطفة مساعدتك في هذا الأمر نقاش. تذكر أيضا ، أن بعض المرضى الذين رفضوا في السابق التحدث عن مرضهم الوراثي يغيرون رأيهم ، لذا كن مستعدًا لما هو غير متوقع!

في بعض الحالات ، يعتقد مقدمو الرعاية العائليون أنه لا ينبغي إبلاغ قريبهم عن تشخيصهم. قد يكون هذا لأنهم يعتقدون أن قريبهم لن يكون قادرا على التعامل مع مثل هذه الأخبار. أو قد تكون هناك أسباب ثقافية محددة لعدم ملاءمة الحديث عن الموت والموت.

ومع ذلك ، فإن الأشخاص الذين يعانون من مرض يهدد حياتهم عادة ما يريدون التخطيط واتخاذ القرارات بشأن أماكن الرعاية الخاصة بهم ، وتنظيم شؤونهم ، والقول عن مساعدينهم والحماية من التدخلات الطبية غير الضرورية.

من الصعب للغاية الاحتفاظ بالمعلومات من الأقارب. وكما قال أحد الأشخاص: "قد تؤذي الحقيقة ، لكن الخداع قد يؤلم أكثر". إن فريق الرعاية الملطفة له خبرة كبيرة في إجراء مناقشات مفتوحة والإجابة على استفسارات حول الأسرة والمريض حول تأثير المرض.

العلاج الطبي المستمر

يحرص العديد من المرضى ومقدمي الرعاية على متابعة "علاج واحد فقط" على أمل العلاج ، أو الرغبة في تأجيل وفاة الشخص. يعتقد آخرون أن "التوقف عن العلاج" هو "التخلي" أو تعجيل موت الشخص. قد تجد الطمأنينة في مبدأ الرعاية الملطفة بأنه يجب تقديم العلاج فقط إذا كان سيعمل على تحسين نوعية حياة الشخص.

هذا هو السبب وراء بقاء العلاج مثل إدارة الألم حتى النهاية. تذكر أيضا ، أن الرعاية الملطفة تركز على الراحة عندما لم يعد الشفاء ممكنا. عندما لا يكون هناك علاج طبي محدد يحتمل أن يحسن حالة الشخص ، ستستمر جميع جوانب الرعاية الملطفة (الجسدية والنفسية والروحية والثقافية والعاطفية) مع دعم لك ولقريبك.

العمل مع فريق الرعاية الصحية.

قد يكون وضعك يتغير كثيرًا الآن. من المهم جدًا الاستمرار في طرح الأسئلة. يشعر بعض مقدمي الرعاية أنهم قد حصلوا على الكثير من المعلومات في وقت مبكر ، ولكن ليس بعد ذلك بكثير. وتعلم جميع المجهول من خيارات الرعاية والعلاج المختلفة يمكن أن يكون مرهقا.

من المهم بالنسبة لك ولعزيزك الجلوس مع فريق الرعاية الصحية. تحتاج إلى الحديث عن الخطوات المستقبلية وما يمكن توقعه. قد تكون خائفًا مما قد تسمعه. لكن مقدمي الرعاية الآخرين قالوا إنهم شعروا بالاطمئنان بعد تعلم خياراتهم. جعلهم قادرين على التخطيط للمستقبل.

بعض الأشخاص المصابين بالسرطان يريدون معرفة كل شيء. البعض الآخر يسمح لمقدمي الرعاية لهم باتخاذ القرارات. في بعض الأحيان تكون هذه الاختلافات ثقافية. في أوقات أخرى تكون شخصية. يجب أن يقرر المريض وعائلتك وأنت الشخص الذي سيكون جهة الاتصال الأساسية لفريق الرعاية الصحية.

نصائح عامة للاجتماع مع فريق الرعاية الصحية

إذا كنت ستذهب مع المريض إلى الزيارات الطبية ، فإليك بعض النصائح العامة للاجتماع مع فريق الرعاية الصحية:

تقديم قائمة من الأسئلة قبل كل موعد.
دون ملاحظات. أو اسأل الطبيب إذا كان من الأفضل استخدام جهاز تسجيل.
احصل على رقم هاتف لشخص للاتصال به مع أسئلة المتابعة.
احتفظ بملف أو مفكرة لجميع الأوراق ونتائج الاختبارات. تأكد من نقلها إلى الزيارات الطبية.
الاحتفاظ بسجلات أو يوميات لجميع الزيارات. أدرج الأدوية والاختبارات التي اتخذها الشخص الذي تحبه.
احتفظ بسجل لأية أعراض مزعجة أو آثار جانبية. لاحظ متى وأين تحدث.
معرفة ما يجب القيام به في حالات الطوارئ. ويشمل ذلك من يجب الاتصال به وكيفية الوصول إليهم وإلى أين يذهبون.

نشاط (2): حاجات المريض للراحة ..... (60 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

ولضمان توافق تصورات مقدمي الرعاية مع احتياجات المريض ، ومعالجة احتياجات الرعاية المباشرة وغير المباشرة ، يحتاج اختصاصيو الرعاية الصحية إلى تزويد مقدمي الرعاية بالمعلومات المناسبة لإدارة أعراض المرضى.

إدارة الأعراض لراحة المريض هي حاجة أساسية ويصبح مصدر قلق كبير مع تقدم المرض وتصبح العلاجات أقل فاعلية.

ينبغي لمقدمي الرعاية الصحية تقييم قدرات أفراد الأسرة على التعرف على الأعراض وقياس الظروف التي يجب أن يحال فيها المريض إلى نظام الرعاية الصحية.

يتضمن تصميم خطة الرعاية توفير المعلومات لتعزيز مستويات المعرفة لدى مقدمي الرعاية للأسرة حتى يتمكنوا من تحديد الأعراض مبكرًا وإدارتها بشكل فعال والتعرف على وقت طلب المساعدة من النظام الرسمي ، أي عندما تظهر الأعراض خارج نطاق السيطرة أو التدابير الحالية غير فعالة.

بالإضافة إلى ذلك ، يحتاج أفراد العائلة لمعرفة كيفية الإبلاغ عن الأعراض بطرق مفيدة للعاملين في الرعاية الصحية في اتخاذ القرارات الفعالة. يمكن أن تصبح السيطرة على الأعراض صراعا رئيسيا للمرضى الذين يعانون من مرض متقدم ومقدمي الرعاية الأسرية. وتصبح إدارة الألم ، على وجه الخصوص ، مشكلة منتشرة ومستعصية بالنسبة لمقدمي الرعاية العائليين ، مما يسهم في تلبية متطلبات الرعاية فضلاً عن ضغوطهم الخاصة.

السيطرة على الألم كنموذج:

التحكم بالعقاقير: التحكم في العقاقير الخاصة بمتلازمة الأسرة فيما يتعلق بتحديد الدواء الذي يستخدم لتخفيف الألم. متى تعطي الدواء (على مدار الساعة في مقابل الحاجة) ؛ رصد الآثار الجانبية ؛ لتذكير المريض بالأدوية الاستمرار في التسجيل؛ السيطرة على الجرعة تقييم فعالية السيطرة على الألم. ولاحظ متى وكيف يتم الإبلاغ عن النتائج السلبية أو عدم الفعالية.

إدارة الألم غير المناظب للأدوية: قد تتضمن الأنشطة غير المتعلقة بالأدوية المرتبطة بإدارة الألم التشتيت ، مثل التحدث مع المريض أو عزف الموسيقى. دعم عاطفي وضع؛ أو استكمال العلاج بالعقاقير مع العلاج الحراري أو البارد.

على الرغم من أن أخصائيي الرعاية الصحية عادة ما يساعدون أفراد العائلة على فهم القضايا الدوائية والتوجيهات الدوائية ، فإن الاستراتيجيات غير المناسلية ، مثل التشتيت أو الأساليب التكميلية ، لا تتم مناقشتها بشكل متكرر.

يفيد المرضى / مقدمي الرعاية أنهم يتعلمون مهارات الإدارة هذه من خلال التجربة والخطأ ويودون الحصول على مزيد من المساعدة من نظام الرعاية الصحية الرسمي.

يسأل عن الألم

يمكن للأشخاص الذين يعانون من آلامهم التركيز على الاستمتاع بالحياة.

غالباً ما يقلق مقدمو الرعاية من أن أحباءهم يعانون من الألم. إذا انشغلت بالألم ، فقد تلاحظ تغيرات في شخصيتهم ، مثل كونهم بعيدين ، أو عدم القدرة على النوم ، أو عدم القدرة على التركيز على الأنشطة اليومية التي كانوا يتمتعون بها في يوم من الأيام.

لا يجب أن يكون أحد أحبائك في حالة ألم أو في أي إزعاج

يفترض بعض الناس أنه سيكون هناك دائمًا ألم شديد مع السرطان. هذا ليس صحيحا. يمكن علاج الألم خلال العلاج. المفتاح هو التحدث بانتظام مع فريق الرعاية الصحية عن الألم والأعراض الأخرى. قد ترغب في التساؤل عما إذا كان هناك أخصائي ألم في الموظفين أيضًا.

في بعض الأحيان ، لا يرغب الأشخاص المصابون بالسرطان في التحدث إلى فريق الرعاية الصحية حول آلامهم.

إنهم قلقون من أن الآخرين سيعتقدون أنهم يشكون أو أن الألم يعني أن السرطان يزداد سوءًا. أو يعتقدون أن الألم هو شيء عليهم قبوله. في بعض الأحيان يعتاد الناس على الألم ، وينسون ما يشبه العيش بدونه.

يجب أن يسأل الفريق الطبي عن مستويات الألم ، لكن الأمر متروك لك وللمريض لكي يكون منفتحًا على أي آلام تواجهها. عندما يكون من المهم بالنسبة لك أن تشجعها على التحدث. أو يمكنك التحدث عنها. كن صادقًا مع الطبيب حول الألم وكيف يؤثر على روتينها. قد يتطلب الأمر أكثر من كلمة واحدة أن تشعر بالراحة حيال أدوية الألم الممنوحة.

يقلق بعض مقدمي الرعاية من أنهم سيعطون أحبائهم الكثير من الأدوية. نادرًا ما يحدث هذا ، ولكن من المهم أن تتحدث مع الطبيب حول مخاوفك ومخاوفك.

تحدث مع فريق الرعاية الصحية حول كيفية إبقاء حبيبك مريحًا قدر الإمكان. تأكد من تضمين أي موظف ضيافة قد يكون لديك. هناك أدوية يمكن أن تساعد في علاج الألم. يمكن أيضًا تعديل هذه الأدوية أو تغييرها إذا لم تكن تعمل أو كانت لها آثار جانبية غير سارة.

لا تخف من طلب مسكنات ألم أقوى أو جرعات أكبر إذا احتاجها المريض. الإدمان ليس مشكلة في الأشخاص المصابين بالسرطان المتقدم. بدلاً من ذلك ، سيساعدون حبيبك على البقاء مريحًا قدر الإمكان. سيحتاج الأشخاص الذين لديهم تاريخ من الإدمان إلى التحدث إلى طبيبهم حول أي مخاوف.

السؤال عن التغييرات الأخرى.

في بعض الأحيان ، مع استمرار العلاج ، قد تحدث تغيرات في الشخص المصاب بالسرطان. قد يكون هذا بسبب الآثار الجانبية للعلاج أو السرطان نفسه. أو قد تكون ناجمة عن أدوية أخرى. وقد قال بعض مقدمي الرعاية أنهم يرغبون في معرفتهم بشأن هذه التغييرات سريعاً. تمنوا لو كانوا يعرفون ما يمكن توقعه.

قد تحدث التغييرات في

شخصية أو مزاج
ذاكرة
ينام
شهية أو احتياجات التغذية
قد يخضع الشخص الذي تعتني به أو لا يخضع لأي من هذه التغييرات. ولكن يجب عليك أن تسأل الطبيب عما إذا كنت بحاجة إلى أن تكون على علم بها. في الوقت نفسه ، اسأل ما يمكنك فعله حيال ذلك إذا حدث ذلك. سيساعدك ذلك على معرفة أن هذه التغييرات طبيعية ، وتعطيك طرقًا للتأهب.

يقول بعض مقدمي الرعاية الذين فقدوا أحباءهم إنهم يودون أن يكونوا قد عرفوا علامات الموت بالقرب. يقولون أن هذا من شأنه أن يساعدهم على أن يكونوا أقل خوفا أو قلقا.

نشاط (3): تنسيق الرعاية والحفاظ على التواصل لمنع سوء الفهم وتعزيز التفاعل الإيجابي ..... (60 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

بين المرضى الذين يعانون من مرض متطور ، فإن الطلب غير المعترف به والمعقد في كثير من الأحيان يتعلق بالتنسيق وتنظيم الرعاية. يجب على مقدمي الرعاية العائليين التفاعل والتفاوض مع نظام الرعاية الرسمي لجدولة التعيينات أو الإبلاغ عن التغييرات في الحالة أو تغيير الأدوية أو طلب المساعدة.

يحتاج العاملون في مجال الصحة إلى إدراك أن مقدمي الرعاية الرئيسيين للأسر هم في الغالب حراس بوابات أنفسهم وقد يترددون في طلب المساعدة حتى عندما يشعرون أنهم غير مستعدين بشكل كافٍ لتقديم الرعاية والإبلاغ عن حالات العجز في المعلومات والمهارات.

لا يملك بعض مقدمي الرعاية القدرة على تنفيذ مجموعة كاملة من أنشطة الرعاية بنجاح. البعض الآخر يجدون صعوبة في اتخاذ القرارات وحل المشكلات.

لا يزال البعض الآخر يتعرض للتوتر ويتعامل مع العديد من مقدمي الرعاية الصحية وينسق مهام كل من المهنيين وغيرهم من مقدمي الرعاية العائليين ، وكل ذلك سيشير إلى أهمية التنسيق والتواصل بين مقدمي الرعاية الأساسيين وغيرهم من المهنيين الصحيين الذين لهم صلة بنوعية حياتهم الخاصة وصحة المرضى من ناحية أخرى ، سيعزز فهم مقدمي الرعاية للتواصل مع المرضى عملية تبادل المعلومات الصحية.

الهدف للنشاط (3):

1. التعرف على تقنية الاتصال الرئيسية والتأكيد على الدور الرئيسي للاتصال في تقديم الرعاية.

2. سيكون لدى المشاركين القدرة على الحصول على المعلومات الصحية من مرضاهم والحفاظ على التواصل مع الآخرين لجمع المعلومات النسبية.

بصفتك أحد مقدمي الرعاية والدعوة لأحبائك ، تلعب دورًا محوريًا في هذه الشراكة. من المحتمل أن تكون الشخص الذي يجمع المعلومات ، ويتحدث إلى مهن الرعاية الصحية ، وينقل المريض ، ويضمن إجراء الفحوصات المختبرية ، والالتقاط ، والإعداد ، وإعطاء الأدوية ، وخيارات علاجية للمخاطر والمخاطر ، والتعامل مع التأمين ، وتحقيق العديد من المهام الأخرى ذات الصلة. . في ورقة الحقائق هذه ، سنقدم بعض النصائح لإزالة العوائق وتشجيع التواصل المفيد بينك وبين أي ممارسين آخرين في الرعاية الصحية.

التحدث مع العائلة والأصدقاء.

الحديث عن القضايا الخطيرة ليس سهلا أبدا. من الصعب مواجهة مستقبل غامض والوفاة المحتملة لأحبائك. غالبًا ما يكون الناس غير مرتاحين يتحدثون عنها ، أو لا يعرفون ماذا يقولون. ولكنك ستحتاج إلى التحدث مع حبيبك أو آخرين حول عدد من المشكلات. قد تشمل هذه خطورة السرطان ، والاستعداد للمستقبل ، ومخاوف من الموت ، أو رغبات في نهاية الحياة.

بعض العائلات تتحدث بصراحة عن الأشياء. لا يفعل الآخرون. لا توجد طريقة صحيحة أو خاطئة للتواصل. لكن الدراسات تظهر أن العائلات التي تتحدث عن الأمور تبدو أفضل بشأن الرعاية التي تحصل عليها والقرارات التي تتخذها.

التحدث مع من تحب الذي لديه سرطان متقدم.

من المحتمل أن يكون لك ولأحبائك نفس الأفكار والمخاوف بشأن نهاية الحياة. من الطبيعي أن تريد حماية بعضها البعض. لكن الحديث عن الموت لا يتسبب في موت شخص ما. وحفظ الأشياء لنفسك لا يجعلها تعيش لفترة أطول.

لا يزال بإمكانك أنت وأحبائك الحصول على أمل لحياة أطول أو انتعاش غير متوقع. ولكن من الجيد أيضًا التحدث عما يحدث وحقيقة أن المستقبل غير مؤكد. والحفاظ على الحقيقة من بعضنا البعض غير صحي. تجنب المشكلات المهمة يجعل من الصعب التعامل معها في وقت لاحق.

قد تجد أنكما تفكران في نفس الأشياء. أو قد تجد أنك تفكر في أشياء مختلفة جدًا. هذا يجعل الأمر أكثر أهمية لإخراجهم في العراء. يمكن أن يكون التحدث عن مخاوفك شفاءًا للغاية لجميع المعنيين.

غالبًا ما تكون أفضل طريقة للتواصل مع شخص ما هي الاستماع فقط.

هذه إحدى الطرق الرئيسية لإظهار أنك هناك من أجلهم. قد يكون من أهم الأشياء التي يمكنك القيام بها. ومن المهم أن تكون داعمًا لأي شخص يحب أن يقوله. انها حياته وسرطانه. يحتاج إلى معالجة أفكاره ومخاوفه في وقته الخاص وطريقته الخاصة. يمكنك دائمًا أن تسأل ما إذا كان راغبًا في التفكير في المشكلة والتحدث مرة أخرى. قد يفضل حتى التحدث إلى شخص آخر حول هذا الموضوع.

إظهار المواضيع الصلبة

استنزاف الموضوعات صعبة هو استنزاف. قد تعتقد ، على سبيل المثال ، أن الشخص المحبوب يحتاج إلى تجربة علاج مختلف أو رؤية طبيب آخر. أو قد تكون قلقة بشأن فقدان الاستقلالية ، أو النظر إليها على أنها ضعيفة ، أو كونها عبئًا عليك.

ما هو مهم أن تتذكر أنه من حق حبيبك أن يختار كيف يعيش بقية حياته. على الرغم من أنه قد يكون لديك آراء قوية حول ما يجب أن تفعله ، فإن القرار هو الذي يتعين عليها اتخاذها.

فيما يلي بعض النصائح حول كيفية طرح المواضيع الصعبة:

تدرب على ما ستقوله مقدمًا.
العثور على وقت هادئ. اسأل إذا كان الوقت مناسبًا للتحدث.
كن واضحًا بشأن أهدافك. ماذا تريد كنتيجة؟
تكلم من قلبك.
إتاحة الوقت لأحبائك للتحدث. الاستماع ومحاولة عدم المقاطعة.
لا تشعر بالحاجة إلى تسوية الأمور بعد كلام واحد.
لا يجب عليك دائمًا قول: "ستكون بخير".
لن يبدأ بعض الأشخاص المحادثة بأنفسهم ، ولكن قد يستجيبوا إذا بدأت أولاً. أيضا ، يمكنك أن تسأل مقدمي الرعاية الآخرين كيف تعاملت مع الموضوعات الشاقة.
إذا كنت لا تزال تواجه مشكلة في التحدث عن المشكلات المؤلمة ، فاطلب نصيحة مهنية. قد يتمكن خبير الصحة العقلية من مساعدتك في استكشاف المشكلات التي لا تشعر أنك تستطيعها. ولكن إذا كان أحد أفراد أسرتك لا يريد الذهاب ، يمكنك دائمًا تحديد موعد للذهاب بمفردك. قد تسمع بعض الأفكار حول كيفية طرح هذه المواضيع. يمكنك أيضًا التحدث عن مخاوف ومشاعر أخرى تتعامل معها الآن.

الحفاظ على خطوط الاتصال مفتوحة

فهم أفعال المرضى والمشاعر
السرطان في أي عمر يتفاعل مع سرطان شخصه بعدة طرق مختلفة. انهم قد:
يبدو مرتبكًا أو خائفًا أو غاضبًا أو وحيدًا أو مكتظًا
أشعر بالخوف أو غير متأكد من كيفية التصرف عندما يرون آثار العلاج على المريض
قانون clingy أو يغيب عن الاهتمام الذي اعتادوا الحصول عليه
يشعر المسؤول أو مذنب
تغضب إذا طلب منهم القيام بالمزيد من الأعمال المنزلية في المنزل
الدخول في مشاكل في العمل وإهمال واجباتهم
تواجه مشكلة في الأكل ، أو النوم ، أو مواكبة مشاكل الواجب ، أو تتعلق بالأصدقاء
كن غاضبًا من أن شخصًا آخر يعتني بهم الآن
مهما كان رد فعل المريض ، فمن الأسهل التعامل مع مشاعره قبل ظهور المشاكل. إذا لم يفتحوا لك ، فقد يفضلون التحدث إلى شخص خارج العائلة ، إذا لاحظت تغييرات أو مشاكل ، فقد تحتاج إلى طلب المساعدة من المهنيين الصحيين الذين يعرفون عائلتك بالفعل. أي من هذه قد تكون قادرة على اقتراح المهنية الصحة العقلية لمريضك ، إذا لزم الأمر.

سلوكيات أخرى.

من الطبيعي أن يُظهر بعض السرطان علامات الانحدار. قد يبدأون في العمل أصغر من سنواتهم ، واستئناف السلوكيات التي توقفت. أو قد يخسرون المهارات التي أتقنها مؤخرًا. هذا هو عادة علامة على التوتر.

إنها طريقة لهم للتعبير عن مشاعرهم ، وطُلبوا ، بطريقتهم الخاصة ، الدعم. الاعتراف بأنهم في حاجة الآن. تحلى بالصبر أثناء العمل معهم لإعادةهم إلى سلوكهم الطبيعي. لكن لا تتردد في طلب المساعدة من أخصائي اجتماعي أو أي محترف آخر إذا كنت بحاجة إلى المزيد من النصائح أو الدعم.

حاول طرح أسئلة مفتوحة النهاية

بالنسبة لبعض الأسر ، فإن التحدث عن القضايا الخطيرة أمر صعب للغاية. على الرغم من الصعوبة التي تواجهها ، لا يمكن أن يكون الحديث عن ذلك أسوأ. حاول طرح أسئلة مفتوحة ، بدلاً من الأسئلة "نعم" أو "لا"

فيما يلي بعض الأفكار التي قد ترغب في مشاركتها مع مرضى السرطان من أي عمر:

"بغض النظر عما يحدث ، ستظل دائمًا مهتمًا بك."
"لم تتسبب في السرطان. وليس هناك ما يمكنك فعله لإزالته أيضًا. "
"قد يتصرف الناس بشكل مختلف من حولك لأنهم قلقون بشأنك أو قلقون منا جميعًا".
"يمكنك أن تسألني أي شيء في أي وقت."
"هل أنت بخير تتحدث معي عن هذا؟ أو تفضل التحدث إلى السيدة XXX
"من المقبول أن تكون منزعجًا أو غاضبًا أو خائفًا أو حزينًا من كل هذا. قد تشعر بالكثير من المشاعر طوال هذا الوقت. ربما تشعر بالسعادة أحيانًا أيضًا. لا بأس في أن تشعر بكل شيء

هذه الأشياء."

شجع مرضى السرطان على مشاركة مشاعرهم وأسئلتهم.
أخبرهم بأنهم ليسوا بمفردهم ، ومن الطبيعي أن يكون لديهم مشاعر مختلطة. مساعدتهم في العثور عليها
طرق للحديث عن مشاعرهم. قد يتمكن مرضى سرطان الشباب من إظهار شعورهم باللعب بالدمى أو رسم الصور. يمكن أن تساعد أشكال أخرى من الفن المرضى كبار السن على التعبير عن أنفسهم.

استمر في تشجيعهم على طرح الأسئلة خلال تقديم الرعاية. ضع في اعتبارك أن المرضى الصغار قد يسألون نفس السؤال مرارًا وتكرارًا. هذا أمر طبيعي ، ويجب عليك الإجابة على السؤال بهدوء في كل مرة.

العثور على لحظات للاتصال

ابتكر طرقًا جديدة للاتصال. جعل نقطة من الدس منهم في وقت النوم ، وتناول الطعام معا ، والقراءة لهم ، والتحدث عبر الهاتف أو عن طريق البريد الإلكتروني. تحدث معهم أثناء طي الملابس أو القيام بالأطباق.

حدد وقتًا محددًا عندما يقوم أطفالك بأداء الواجبات المنزلية بينما تقوم بشيء آخر في نفس الغرفة. أو قم بالمشي معا. الذهاب إلى محل البقالة يمكن أن يكون "وقتًا معًا". يمكن أن يحدث اختلاف في الخمس دقائق مع كل طفل دون انقطاع.

التواصل مع شريكك مع السرطان.

بعض الأزواج يشعرون براحة أكبر في التحدث عن قضايا خطيرة أكثر من الآخرين. أنت وشريكك فقط تعرفان شعورك حيال ذلك.

لا يمكن حل بعض الأمور التي تسبب لك الضغط النفسي وشريكك في الوقت الحالي. ولكن في بعض الأحيان يمكن أن يكون الحديث عنهم مفيدًا. قد ترغب في قول شيء من هذا القبيل في المقدمة ، "أعلم أننا لا نستطيع حل هذا اليوم. لكنني أود فقط أن أتحدث عن كيفية سيرها وكيف نشعر بها. "

الموضوعات التي يمكن استكشافها قد تتضمن كيف يمكن لكل شخص:

تتواءم مع التغيير والمجهول
يشعر عن كونه مقدم رعاية أو يتم الاعتناء بهم
يتعامل مع الأدوار المتغيرة في العلاقة أو المنزل
يود أن يكون متصلا ببعضها البعض
ترى ما هي القضايا التي قد توتر العلاقة
يشعر ، أو يود أن يشعر ، والرعاية والاهتمام
يشعر بالامتنان على الشخص الآخر

عندما يصبح مريضك مريضًا ، قد ترغب أيضًا في مشاركة المزيد من المشكلات العملية. قد تتضمن هذه القرارات التي يجب عليك مشاركتها معًا ، والتي يجب عليك اتخاذها بمفردك. بالإضافة إلى ذلك ، قد ترغب في التحدث عن المهام المختلفة التي يمكنك التعامل معها في الوقت الحالي.

العثور على طرق لنقول شكرا

ربما كان شريكك يفعل الكثير للحفاظ على عائلتك مستمرة. والآن ، نظرًا لأنه مريض ، فأنت تحاول التعود على قدر أقل من المساعدة. قد يكون من الصعب ملاحظة الأشياء الصغيرة التي ما زال شريكك يقوم بها للمساعدة. هناك كثيرًا ما يحدث كثيرًا. ولكن عندما تستطيع ، حاول أن تبحث عن هذه الأشياء وشكر شريكك على القيام بها.

غالبًا لا يتطلب الأمر الكثير لوضع نقطة مضيئة في يوم أحد أفراد أسرتك. إن جلب شرابك إلى مشروب بارد ، أو إعطائه بطاقة ، أو الاتصال لتسجيل الدخول يمكنه أن يظهرك أنك تهتم. عرض القليل من الامتنان يمكن أن يجعل كل واحد منكما يشعر بتحسن.

قضاء بعض الوقت معا.

يجد العديد من الأزواج أنه يساعد على تخطيط وقت خاص معًا. قد تكون بعض الأيام أفضل من غيرها ، اعتمادًا على شعور شريكك. لذلك قد تحتاج إلى أن تكون على دراية بتغييرات اللحظة الأخيرة. ليس عليك أن تكون محبوبًا. إنها تتعلق بقضاء الوقت معًا. قد يعني ذلك مشاهدة مقطع فيديو أو الخروج لتناول الطعام أو البحث في الصور القديمة. يمكن أن يكون كل ما تحب القيام به. يمكنك أيضًا تخطيط مناسبات لتشمل أشخاص آخرين ، إذا فاتك ذلك.

فرقة الاتصالات

تشير الدراسات إلى أن التواصل المفتوح والرعاية هو الأفضل. ومع ذلك ، غالبًا ما يواجه مقدمو الرعاية ما يلي:
التوتر من الطرق المختلفة للتواصل
عدم وجود حساسية أو فهم حول الطرق المناسبة للتحدث ومشاركة المشاعر
الأشخاص الذين لا يعرفون ماذا يقولون ، لن يتواصلوا على الإطلاق ، أو لن يكونوا صادقين.

العثور على طرق لتكون حميم

قد تجد أن حياتك الجنسية مع شريكك مختلفة عما كانت عليه من قبل.

أشياء كثيرة يمكن أن تؤثر عليه:

شريكك متعب ، في ألم ، أو غير مريح.
انت متعب.
علاقتك تبدو بعيدة أو متوترة.
قد لا تكون أنت أو شريك حياتك مرتاحًا للطريقة التي يبدو عليها.

قد تكون خائفا من إيذاء شريك حياتك.
قد يؤثر علاج شريكك على اهتمامه بالجنس أو القدرة على الأداء.
لا يزال لديك علاقة حميمة على الرغم من هذه القضايا. العلاقة الحميمة ليست بدنية فقط. كما ينطوي على مشاعر.

فيما يلي بعض الطرق للحفاظ على علاقتك الحميمة:

تكلم عنه. اختر وقتًا يمكنك فيهما التحدث معًا. ركز على كيفية تجديد الاتصال.
حاول ألا نحكم. إذا كان شريكك لا يعمل ، فحاول عدم قراءة المعنى به. دع شريكك يخبرك ما يحتاج إليه.
اجعل الفضاء. حماية وقتك معا. قم بإيقاف الهاتف والتلفزيون. إذا لزم الأمر ، ابحث عن شخص لرعاية الأطفال لبضع ساعات.
إعادة الاتصال. خطط لساعة واحدة أو أكثر لتكن معًا دون محاولة ممارسة الجنس. على سبيل المثال ، قد ترغب في تشغيل موسيقى خاصة أو المشي. على مهلك. هذه المرة حول إعادة الاتصال.

جرب لمسة جديدة. يمكن لعلاج السرطان أو الجراحة تغيير جسم شريكك. المناطق التي يكون اللمس فيها معتادًا قد يكون الآن خدرًا أو مؤلمًا. في الوقت الحالي ، يمكنك معرفة ما نوع اللمس الذي يشعر بالارتياح ، مثل الإمساك والعناق والحضن.

التواصل مع أفراد الأسرة الآخرين والأصدقاء

من المحتمل أن تكون أي مشاكل تواجهها عائلتك قبل تشخيص السرطان أكثر حدة الآن. هذا صحيح سواء كنت ترعى طفلًا صغيرًا أو طفلًا بالغًا أو ولي أمر أو زوجًا. دور الرعاية الخاص بك يمكن أن يؤدي في كثير من الأحيان مشاعر وتغييرات الدور التي تؤثر على عائلتك

طرق لم تكن تتوقعها. والأقارب الذين لا تعرفهم جيدًا أو الذين يعيشون بعيدًا قد يكونون في كثير من الأحيان ، مما قد يعقد الأمور.

من الشائع جدًا أن تجادل العائلات حول عدد من الأمور في هذا الوقت.

قد تشمل هذه:

خيارات العلاج لأحبائهم ، أو الاستمرار في العلاج على الإطلاق
متى تستخدم رعاية المسنين
ما العلاج الذي يرغبه المريض
الشعور بأن بعض أفراد العائلة يساعدون أكثر من غيرهم
في حين أن الجميع قد يحاول أن يفعل ما هو أفضل من أجل حبيبك ، قد يختلف بعض أفراد العائلة حول ما يعنيه هذا. الجميع يجمع مجموعة من المعتقدات والقيم الخاصة بهم إلى الطاولة ،

مما يجعل هذه القرارات صعبة. وغالبًا ما تكون العائلات في هذه الأوقات تسأل عن صحتهم

فريق رعاية لعقد اجتماع عائلي.

اجتماعات عائلية.
الاجتماعات العائلية ضرورية خلال رعاية مرضى السرطان. تصبح أكثر أهمية مع تقدم السرطان. في اجتماع عائلي ، يلتقي فريق الرعاية الصحية والأسرة لمناقشة الرعاية. يمكنك أن تطلب من أخصائي اجتماعي أو مستشار أن يكون هناك إذا لزم الأمر. تحدث مع حبيبك لمعرفة ما إذا كان يرغب في اجتماع عائلي. اسأل ما إذا كان يرغب في المشاركة.
الاجتماعات يمكن استخدامها ل:
اطلب من فريق الرعاية الصحية شرح الأهداف العامة للرعاية
دع الأسرة تذكر رغباتها للرعاية
منح الجميع منتدى مفتوح للتعبير عن مشاعرهم
توضيح مهام الرعاية

إذا كنت بحاجة إلى ذلك ، قم بإحضار قائمة بالمشكلات لمناقشتها. في نهاية الاجتماع ، اطلب الرعاية الصحية فريق لتلخيص القرارات وتخطيط الخطوات التالية.

كيفية التواصل عندما لا يكون الدعم مفيدًا

في بعض الأحيان يتوق الناس لمساعدتكم لأنهم يريدون أن يشعروا بأنهم مفيدون. ولكن في بعض الأحيان قد لا تحتاج إلى الدعم ، أو قد ترغب ببساطة في قضاء بعض الوقت بمفردك مع حبيبك المريض.

إذا كان الأشخاص يقدمون المساعدة التي لا تحتاجها أو لا تريدها ، فشكرهم على مخاوفهم. أعلمهم هذا الآن لديك أشياء تحت السيطرة ، ولكنك ستتصل بها إذا كنت بحاجة إلى أي شيء.

يمكنك إخبارهم أنه يساعد دائمًا على إرسال البطاقات والحروف ورسائل البريد الإلكتروني. أو يمكنهم الصلاة أو إرسال أفكار جيدة.

في بعض الأحيان يقدم الأشخاص نصيحة غير مرغوب فيها حول الرعاية الأبوية أو الرعاية الطبية أو أي عدد من المشكلات. قد يكون من غير المريح سماع مثل هذه التعليقات.

على سبيل المثال ، شارك بعض مقدمي الرعاية:

لدينا مشكلة مع أحد أفراد عائلة زوجي. هي لا تعيش هنا وتواصل استجواب جميع قراراتنا. لقد أصبح الأمر سيئًا جدًا لدرجة أننا قد أوضحنا لطبيبنا أنها ليست هنا طوال اليوم ، وبالتالي لا تفهم الموقف. لقد كانت ألم حقيقي.

أشعر أن الناس يريدونه فعلاً أن يفعل العلاج الذي يقترحونه بدلاً من ما نشعر به هو الأفضل. إنها تجعل هذا الأمر أصعب مما يجب.

غالبًا ما يقدم الأشخاص نصيحة غير مرغوب فيها لأنهم غير متأكدين مما يمكنهم فعله. قد يشعرون بالعجز لفعل أي شيء ، ولكن يريدون إظهار قلقهم. في حين أنه قد يأتي من مكان جيد ، إلا أنه لا يزال يبدو حكميًا عليك.

إنه قرارك بشأن كيفية التعامل مع هذه الآراء. لا يتعين عليك الرد على الإطلاق إذا كنت لا تريد ذلك. إذا كان لدى أحدهم مخاوف بشأن أطفالك تبدو صحيحة ، تحدث إلى مستشار أو المعلم حول الخطوات التي يجب اتخاذها. أو إذا كانت المخاوف حول حبيبك ، يمكنك التحدث إلى الفريق الطبي. خلاف ذلك ، شكرا لهم. وأطمئنهم على أنك تتخذ الخطوات اللازمة

للحصول على حبيبك وعائلتك في هذا الوقت الصعب.

رعاية نفسك.

التعامل مع مشاعرك

ربما كان لديك مجموعة من المشاعر بينما تهتم لأحبائك. يمكن أن تكون هذه المشاعر قوية جدًا في بعض الأحيان وأقل عند الآخرين. يتطلب الأمر الكثير من الطاقة للحفاظ على الأمل والتعامل مع موجات العاطفة المستمرة. الآن بعد أن تقدم السرطان ، قد تكون هذه المشاعر أكثر حدة.

الحزن أو القلق.

قد تشعر بالحزن أو القلق عندما تشاهد حبيبك يعاني من السرطان. ربما قد تكون تشعر بالقلق إزاء كيفية تعامله مع الآثار الجانبية أو التعامل مع الخوف. أو قد تكون قلقًا بشأن الفواتير أو عائلتك أو ينتهي بك الأمر وحدك.

من المقبول البكاء أو التعبير عن مشاعرك عندما تكون بمفردك أو مع صديق موثوق به. لا يجب عليك التفاؤل طوال الوقت أو التظاهر بالبهجة. امنح نفسك الوقت للتعامل مع التغييرات التي قد تمر بها أنت وأحبائك.

الاكتئاب هو الحزن المستمر الذي يستمر لأكثر من أسبوعين. إذا بدأ أي من هذه الأعراض يؤثر على قدرتك على العمل بشكل طبيعي ، فتحدث مع صحتك مقدم الرعاية. لا تظن أنك بحاجة إلى حلها دون أي مساعدة. من المرجح أن لديك

يمكن تخفيف الأعراض.

حزن

الحزن هو عملية الاستقالة وقبول وتعلم العيش مع الخسارة. جزء من الحزن عملية تشعر بالحزن الشديد ، فضلا عن مشاعر أخرى. قد تشعر بالحزن بشأن الخسائر التي تعرضت لها ، بما في ذلك فقدان الحياة التي اعتدت على ممارستها.

لكن الحزن لا يعني أن عليك أن تشعر بطريقة معينة. كل شخص مختلف. دع نفسك تحزن بطريقتك الخاصة. على سبيل المثال ، قد لا يُظهر بعض الأشخاص الكثير من العاطفة مثلما يفعل الآخرون عندما يحزنون. يظهرون مشاعرهم من خلال القيام بالأشياء ، بدلاً من التحدث عنها. هذا لا يعني أنهم لا يشعرون "بالطريقة الصحيحة" أو أنهم بحاجة إلى تغيير طريقة تفاعلهم.

قد تبدأ في الشعور بفقدان حبيبك حتى قبل موته. وهذا ما يسمى الحزن الاستباقي. من الطبيعي أن تشعر بالحزن تجاه التغييرات التي تمر بها والخسائر التي ستواجهها. ربما تكون قد توقعت أن تكون حياتك مع صديقك أو أحد أفراد عائلتك مختلفًا عما تمر به. الشعور بالحزن على ما كان يمكن أن يكون أو ما هو متوقع. من الطبيعي أن تشعر بالحزن تجاه فقدان حبيبك في المستقبل وجميع التغييرات التي ينطوي عليها.

افهم أن هذه المشاعر طبيعية ، ويمكن أن يصل الحزن في بعض الأحيان عندما لا تتوقع ذلك. على الرغم من أنه يمكن أن يأتي ويزداد حدة ، يمكن أن يستمر الحزن لأشهر عديدة. من المهم طلب المساعدة من الموظفين في المستشفيات أو خبير الصحة العقلية أو مجموعة الدعم.

الغضب.

هناك الكثير من الأشياء التي تحدث الآن يمكنها أن تجعلك غاضبًا. قد تغضب من نفسك ، عائلتك ، أو الله ، أو حتى الشخص الذي ترعاه. في frst ، يمكن أن يساعد الغضب عن طريق نقلك إلى أبدي فعل. قد تقرر معرفة المزيد عن خيارات العلاج المختلفة أو الحصول على المزيد من العلاج الطبي الآراء. لكن الغضب لا يساعدك إذا احتفظت به لفترة طويلة أو أخرجته للآخرين.

قد يساعد على تحديد سبب غضبك. هذا ليس سهلا دائما. في بعض الأحيان يأتي الغضب من مشاعر يصعب إظهارها ، مثل الخوف أو الذعر أو القلق. أو قد تأتي من الاستياء. إذا تبقى هذه المشاعر ، طلب المساعدة من مستشار أو غيره من أخصائيي الصحة العقلية.

إنكار.

قد تواجه صعوبة في قبول أن صديقك أو أحد أفراد عائلتك قد لا يتعافى. يمكنك أعتقد أنه إذا استمرت في الحصول على العلاج ، فقد ينجح شيء ما في النهاية ، أو سيكتشفه اكتشاف جديد مصنوع. لا يوجد شيء خاطئ في هذا. ولكن حاول أن تستمع إلى حبيبك والطبيب

حقا سماع ما يقولون.

طريقتك في التعامل قد تجعل المريض يشعر أنك لست كذلك حقا فهم ما يحدث. مرة أخرى ، لا بأس في التعامل مع الأشياء حسب سرعتك الخاصة. ولكن كن على علم من تأثير هذا قد يكون على الآخرين.

رعاية عقلك وروحك
البحث عن الراحة
يحتاج عقلك للخروج من مطالب الرعاية. فكر في ما يعطيك الراحة
أو يساعدك على الاسترخاء. يقول مقدمو الرعاية أنه حتى بضع دقائق في اليوم دون انقطاع يساعد
لهم للتعامل والتركيز.
خذ ما بين 15 إلى 30 دقيقة كل يوم للقيام بشيء ما لنفسك ، مهما كان صغيراً. على سبيل المثال ، غالباً ما يجد مقدمو الرعاية أنهم يشعرون بتعب أقل وشدة بعد ممارسة التمارين الخفيفة. حاول أن تخصص وقتًا للتنزه أو الركض أو ركوب الدراجة أو التمدد اللطيف.

قد تجد أنه من الصعب الاسترخاء حتى عندما يكون لديك وقت لذلك. يجد بعض مقدمي الرعاية أنه من المفيد القيام بتمارين مصممة لمساعدتك على الاسترخاء ، مثل التمدد أو اليوجا. وتشمل أنشطة الاسترخاء الأخرى أخذ نفس عميق أو الجلوس فقط.

ابحث عن ايجابيات

قد يكون من الصعب العثور على لحظات إيجابية عندما تكون مشغولاً بتقديم الرعاية. يقول مقدمو الرعاية ذلك
البحث عن الأشياء الجيدة في الحياة يساعدهم على الشعور بتحسن. كل يوم ، حاول التفكير في شيء ما أنك تجد مكافأة على تقديم الرعاية.
قد تأخذ لحظة أيضًا لتشعر بالرضا
أي شيء آخر من اليوم الذي هو إيجابي - غروب جميل ، عناق ، أو أي شيء مضحك لك سمعت أو قرأت.
البحث عن القبول.

أنت على طريقك نحو قبول حقيقة أن حبيبك قد يموت. برغم من قد يستغرق الأمر بعض الوقت ، القبول يمكن أن يجلب مشاعر السلام.
قد تجد أن السرطان يساعد أنت تقدر الحياة أكثر. قد تشعر أنك تعيش كل يوم بشكل كامل ، حتى لو كان المستقبل غير معروف.
يشعر بالشكر.

قد تشعر بالامتنان لأنك يمكن أن تكون هناك لمن تحب. قد يكون من دواعي سرورك فرصة القيام بشيء إيجابي وإعطاء شخص آخر بطريقة لم تعرفها أبدًا. يشعر بعض مقدمي الرعاية أنه قد تم منحهم الفرصة لبناء أو تقوية العلاقة. هذا لا يعني أن تقديم الرعاية سهل أو خالٍ من الإجهاد. لكن العثور على معنى في تقديم الرعاية يمكن أن يسهل التعامل معه.

تواصل مع أشخاص آخرين

تُظهر الدراسات أن التواصل مع الأشخاص الآخرين مهم جدًا لمعظم مقدمي الرعاية. انها مفيدة بشكل خاص عندما تشعر بالإرهاق. في بعض الأحيان تريد أن تقول أشياء أنك فقط لا يمكن أن تقول لأحد أحبائك.

حاول أن تجد شخصًا يمكنك فعلًا فتحه حول مشاعرك أو مخاوفك. قد تجدها من المفيد التحدث مع شخص خارج الوضع. بعض مقدمي الرعاية لديهم شبكة غير رسمية من الناس على الاتصال. يرى البعض أيضا مستشار أو معالج. إذا كنت قلقًا بشأن مشكلة تقديم الرعاية ، فقد تحتاج إلى التحدث مع فريق الرعاية الصحية التابع لمن تحب. المعرفة في كثير من الأحيان يساعد على تقليل المخاوف.

دع نفسك تضحك

من المقبول أن تضحك ، حتى لو كان أحد أفراد عائلتك مصابًا بالسرطان المتقدم. في الواقع ، إنه صحي. ضحك يطلق التوتر ويجعلك تشعر بتحسن. يمكنك قراءة الأعمدة والمجلات الهزلية المضحكة أو مشاهدة العروض الكوميدية أو التحدث مع الأصدقاء المتفائلين. أو تذكر الأشياء المضحكة التي حدثت لك في الماضي. الحفاظ على حسك الفكاهي هو مهارة جيدة للتعامل.

مواجهة غضبك أو الإحباط قد تجد أنك غاضب ومحبط لأن الشخص الذي ترعاه يصبح مريضًا. قد يساعدك في محاولة معالجة هذه المشاعر أثناء حدوثها ، بدلاً من الاحتفاظ بها. اسأل نفسك ما الذي يسبب الغضب فعلاً. هل أنت متعب؟ بالاحباط مع الرعاية الطبية؟ هل يبدو حبيبك متطلبًا؟ إذا كنت تستطيع ، حاول أن تدع بعض الوقت يمر قبل إظهار مشاعرك. قد يساعدك أيضًا على التعبير عن غضبك من خلال التمرين أو الفن أو حتى ضرب السرير بوسادة.

اترك ذنبك
إذا كنت تشعر بالذنب ، فإليك بعض الأشياء التي يمكنك القيام بها:
ترك الأخطاء. لا يمكنك أن تكون مثاليًا. لا احد. أفضل ما يمكننا القيام به هو التعلم من أخطائنا والانتقال. استمر في القيام بأفضل ما يمكنك. وحاول ألا تتوقع الكثير من نفسك.
ضع طاقتك في الأشياء التي تهمك. التركيز على الأشياء التي تشعر بها تستحق وقتك وطاقتك. دع الأشياء الأخرى تذهب الآن. على سبيل المثال ، لا تضع الملابس عند التعب. المضي قدما والراحة بدلا من ذلك. اغفر لنفسك والآخرين. من الجيد أن الناس يفعلون ما بوسعهم. هذا يشملك. كل لحظة جديدة ويوم جديد يمنحك فرصة للمحاولة مرة أخرى.

انضم إلى مجموعة الدعم

يمكن أن تلتقي مجموعات الدعم شخصيًا أو عبر الهاتف أو عبر الإنترنت. قد يساعدك ذلك في الحصول على إحصاءات جديدة حول ما يحدث ، وإعطاء أفكارك حول كيفية التعامل ، ومساعدتك في معرفة أنك لست وحدك. في مجموعة الدعم ، قد يتحدث الناس عن مشاعرهم وما مروا به. هم قد يتاجرون بالنصائح فيما بينهم ويساعدون الآخرين الذين يتعاملون مع نفس النوع من القضايا. بعض الناس يحبون الذهاب والاستماع فقط. والبعض الآخر يفضل عدم الانضمام إلى مجموعات الدعم على الإطلاق. بعض الناس غير مرتاحين لهذا النوع من المشاركة.

إذا كنت تشعر أنك ستستفيد من الدعم الخارجي مثل هذا ولكن لا يمكنك الوصول إلى مجموعة في منطقتك ، فجرّب مجموعة دعم على الإنترنت. يقول بعض مقدمي الرعاية أن مواقع الويب التي بها مجموعات دعم قد ساعدتهم كثيرًا.

اجعل الوقت لنفسك

قد تشعر أن احتياجاتك ليست مهمة في الوقت الحالي. أو ربما بحلول الوقت الذي تعتني فيه بكل شيء آخر ، لن يبقى لديك وقت لنفسك. أو قد تشعر بالذنب لأنك تستطيع الاستمتاع بالأشياء التي لا يمكن لأحبائك فعلها الآن.

يقول معظم مقدمي الرعاية أن لديهم نفس هذه المشاعر. لكن الاهتمام باحتياجاتك وآمالك ورغباتك هو أمر مهم ليعطيك القوة للاستمرار.

إن أخذ الوقت لإعادة شحن جسدك وعقلك وروحك يمكن أن يساعدك في أن تكون مقدم رعاية أفضل. و إذا كنت مريضًا أو لا تشعر بحالة جيدة ، فمن المهم جدًا أن تعتني بنفسك أيضًا. قد ترغب في التفكير في:

العثور على أشياء لطيفة يمكنك القيام بها لنفسك - حتى لبضع دقائق
العثور على أشياء لطيفة يمكن للآخرين القيام بها أو إعدادها لك
العثور على طرق جديدة للتواصل مع الأصدقاء
أخذ أجزاء أكبر من الوقت "خارج الخدمة"

إن إعطاء نفسك متنفسًا للتعامل مع أفكارك ومشاعرك أمر مهم أيضًا. حاول التفكير في ما قد يعطيك المصعد. هل التحدث مع الآخرين يساعد في تخفيف العبء؟ أو هل الوقت هادئ بمفردك لما تفضله على أفضل وجه؟ قد تريد بعضًا من الاثنين ، اعتمادًا على ما يحدث في حياتك. من المفيد تخصيص بعض الوقت للتفكير في احتياجاتك الخاصة.

العثور على المعنى

يزعم العديد من مقدمي الرعاية أن تجربة السرطان تجعلهم يبحثون عن معنى في حياتهم.

إن أخذ الوقت للتفكير في حياتك وعلاقتك مع حبيبك قد يساعدك على الشعور بالإغلاق والإنجاز والمعنى. قد ترغب في مشاركة أفكارك مع حبيبك أو الآخرين ، أو قد ترغب فقط في كتابتها أو تسجيلها بنفسك.

فيما يلي بعض الأسئلة التي تطرح على نفسك أو على شريكك:

ما هي أسعد الأوقات وأكثرها حزناً التي شاركناها معًا؟
ما هي أهم لحظات حياتنا أو أهمها؟
ماذا علمنا بعضنا البعض؟
كيف يؤثر تقديم الرعاية على حياتي؟

عندما تكون مستعدًا ، قد ترغب في الرجوع إلى الوراء وإلقاء نظرة أخرى على الحياة معًا. عندما يكون شخص ما تحبه مصابًا بالسرطان ، يمكنك البدء في إعادة التفكير في الأشياء التي تهمك. يقوم بعض مقدمي الرعاية وأحبائهم بأشياء معًا كانوا يخططون دائمًا للقيام بها. البعض الآخر لا يقوم بالكثير من التغييرات. بدلا من ذلك ، يتمتعون بالحياة التي لديهم معا أكثر من ذلك بكثير. يمكن أن تصبح الحياة أكثر عن الشخص ، وليس المرض.

بعض الأشياء التي يمكنك أنت وأحبائك القيام بها للاحتفال بحياتك معاً هي:

اصنع مقطع فيديو من ذكريات خاصة.
مراجعة أو تنظيم ألبومات صور العائلة.
رسم أو كتابة تاريخ عائلتك أو شجرة عائلتك.
الحفاظ على مجلة يومية من المشاعر والتجارب.
جعل سجل القصاصات.
مساعدة في كتابة الملاحظات أو الرسائل إلى الأصدقاء وأفراد الأسرة الآخرين.
قراءة أو كتابة الشعر.
خلق عمل فني ، متماسكة ، أو جعل المجوهرات.
اختيار كائنات ذات معنى أو تذكارات معا لإعطاء للآخرين.
اكتب أو سجل قصصًا مضحكة أو ذات مغزى من الماضي.

يمكنك أنت والمريض وأفراد العائلة الآخرين القيام بأي شيء يجلب الفرح والمعنى لحياتك. قد يقرر أحد أحبائك حتى جعل ما يسمى "إرادة أخلاقية". إنها ليست ورقة قانونية. إنه شيء يكتبه شخص ما لمشاركته مع الأشخاص الذين يهتم بهم. تحتوي العديد من الوصايا الأخلاقية على أفكار الشخص حول قيمه وذكرياته وآماله. قد تحتوي أيضا على الدروس المستفادة في الحياة أو أشياء أخرى ذات مغزى.

الإيمان والروحانية

بالنسبة للبعض ، يمكن العثور على المعنى في الدين. ينظر آخرون إلى نوع آخر من القوة العليا.

يتساءل بعض مقدمي الرعاية عن سبب خضوعهم لهذه التجربة. يشعر آخرون أنهم تم المباركة به. يشعر بعض مقدمي الرعاية بكل من هذه الأشياء.

أن تكون روحيًا شخصيًا جدًا ويعني شيئًا مختلفًا للجميع. عندما تنظر إلى الحياة بطرق جديدة ، قد تجد مسارا روحيا مفيدا.

بعض الطرق لإضافة الروحانية إلى حياتك اليومية تشمل:

قراءة الكتب الدينية أو الروحية أو الاستماع إلى الموسيقى الروحية أو مشاهدة مقاطع الفيديو ذات الصلة
أو البرامج التلفزيونية
الحفاظ على أسعار النهضة مفيد
الصلاة أو التأمل
التحدث مع أحد أفراد مجتمع إيمانك أو شخص آخر ذي طبيعة روحية
زيارة مكان العبادة
العثور على مكان خاص حيث تجد الجمال أو الشعور بالهدوء
طلب المساعدة الاجتماعية أو المعالج الترفيهي في المستشفى للإشارة إلى موسيقى الاسترخاء.
رعاية جسمك.

قد تجد نفسك مشغولاً للغاية وتشعر بالقلق حيال حبيبك الذي لا تولي اهتماما لصحتك الخاصة. لكن من المهم جدًا أن تعتني بنفسك.

إن العناية بنفسك ستمنحك القوة لمساعدة الآخرين. الضغط الإضافي والطلبات اليومية غالباً ما تضيف إلى أي مشاكل صحية يملكها مقدمو الرعاية بالفعل.

قد يكون لديهم أيضًا مشكلة أو أكثر من المشكلات أدناه:

التعب (التعب)
مشاكل النوم
ضعف نظام المناعة (ضعف القدرة على محاربة المرض)
تباطؤ الشفاء من الجروح

ارتفاع ضغط الدم
التغييرات في الشهية و / أو الوزن
الصداع
القلق أو الاكتئاب أو تغيرات مزاجية أخرى

الاعتناء بنفسك.

هذه الأفكار لرعاية نفسك قد تبدو سهلة. لكنها تمثل تحديًا لمعظم مقدمي الرعاية. ستحتاج إلى الانتباه إلى شعورك ، في الجسم والعقل.

على الرغم من أنك تضع احتياجات حبيبك أولاً ، فمن المهم: مواكبة الفحوصات الخاصة بك ، والفرز ، وغيرها من الاحتياجات الطبية.

حاول أن تتذكر أن تأخذ الأدوية الخاصة بك على النحو المنصوص عليه. اطلب من طبيبك أن يعطيك عبوات إضافية لتوفير الرحلات. معرفة ما إذا كان لديك متجر البقالة أو الصيدلة يسلم.

حاول أن تتناول وجبات صحية. الأكل الجيد سيساعدك على الحفاظ على قوتك. إذا كان أحد أفراد أسرتك موجودًا في المستشفى أو لديه مواعيد طويلة للطبيب ، فعليك بإحضار طعام سهل التحضير من المنزل. على سبيل المثال ، السندويشات أو السلطة أو الأطعمة المعلبة واللحوم المعلبة يمكن وضعها بسهولة في حاوية الغداء.

الحصول على ما يكفي من الراحة. قد يساعدك الاستماع إلى الموسيقى الناعمة أو تمارين التنفس على النوم. يمكن أن تنشط الغفوة القصيرة إذا لم تحصل على قسط كافٍ من النوم. لكن تحدث مع طبيبك إذا كان قلة النوم مشكلة مستمرة.

ممارسه الرياضه. إن المشي أو السباحة أو الجري أو ركوب الدراجة ليست سوى طرق قليلة لتحريك جسمك. أي نوع من التمارين الرياضية (بما في ذلك العمل في الحديقة أو التنظيف أو القص أو الذهاب

(صعود الدرج) يمكن أن تساعدك على الحفاظ على صحة الجسم. إن العثور على ما لا يقل عن 15-30 دقيقة يوميًا للتمارين الرياضية قد يجعلك تشعر بالتحسن وتساعد في التحكم في التوتر.

خصص وقتا لنفسك للاسترخاء. يمكنك اختيار التمديد أو القراءة أو مشاهدة التلفزيون أو التحدث على الهاتف. مهما كان يساعدك على الاسترخاء ، يجب أن تأخذ الوقت الكافي للقيام بذلك.

انعكاس.

بصفتك مقدمًا للرعاية ، تحاول تحقيق توازن كل يوم. عليك أن تعتني بأحبائك في حين مواكبة مطالب العائلة والعمل. ينصب تركيزك على احتياجات المريض.

لكن الأمر متروك لك أيضًا لمحاولة التوافق مع نفسك.

تذكر الأشياء التي تحتاجها للحفاظ على العقل والجسم والروح السليمة. وإذا استطعت ، حاول أن تجد وقتًا هادئًا لإعادة التأهيل كل يوم. قد يساعدك التأمل أو الصلاة أو الراحة فقط على الحفاظ على إحساس بالسلام في هذا الوقت.

وقد وصف آخرون رعاية شخص مصاب بالسرطان المتقدم بأنه أصعب شيء مر به. ومع ذلك ، لم يكن من الممكن أن يعطوها للعالم.

سواء كانت جيدة أو سيئة ، غالباً ما تعطي مواقف الحياة المتغيرة الفرصة للناس للنمو والتعلم والتعلم

نقدر ما هو مهم بالنسبة لهم. كثير من الناس الذين يهتمون بشخص مصاب بالسرطان يصفون التجربة بأنها رحلة شخصية. يقولون أنها غيرتها إلى الأبد. يشبه إلى حد كبير الطريقة التي يصف بها مرضى السرطان تجربتهم. إنها ليست بالضرورة رحلة اختارها مقدمو الرعاية لأنفسهم. ولكن يمكنهم استخدام مهاراتهم وقوتهم ومواهبهم لدعم أحبائهم أثناء اكتشاف المزيد عن أنفسهم على طول الطريق.

الوحده الرابعة: مقدمي الرعاية الأسرية يحتاجون للمعلومات والدعم والمساعدة والتعديل على مقدمي الرعاية.

تقديم معلومات عن أبعاد عرض الرعاية لاكتساب فهم أعمق للرعاية ومعرفة المفهوم الأساسي والمعنى لتقديم الرعاية التي تساعد المشاركين على التكيف ليكون مقدم الرعاية ، مثل المعلومات والمساعدة المتعلقة بالمرض ؛ الرعاية الجسدية تدابير الراحة ما هي الأعراض المتوقعة ، وأسبابها ، وكيفية إدارتها ؛ نظم العلاج. توقعات للرعاية المستقبلية. استجابات المرضى العاطفية إجراءات إدارة الأسرة ؛ المالية. وموارد المجتمع. المساعدة في كيفية تنظيم أنشطة الرعاية مثل النقل والمراقبة وأعراض الإبلاغ ، وتوفير الرعاية الشخصية (الاستحمام ، والمشي ، وارتداء الملابس) ، والاعتبارات التغذوية ، وتنسيق الرعاية (جدولة المواعيد واستدعاء الطبيب) ، ومراقبة حالة المرض ، والأنشطة المالية .

الهدف: سوف يساعد التوجيه المستمر والدعم من المتخصصين في الرعاية الصحية مقدمي الرعاية في التعامل مع هذه الجوانب من الرعاية ، والتي ، بدورها ، ستساعد على التخفيف من حدة التوتر والعبء والاكتئاب الذي يعاني منه مقدمو الرعاية وطمأنة المرضى الذين يعانون من نقص في الطاقة ، وكذلك حول إدارة الأعراض الأخرى.

الاحتياجات: لا يحتاج المرضى الذين يعانون من مرض متقدم إلى الرعاية المباشرة فحسب ، بل إلى الرعاية غير المباشرة ، والتي تتطلب التنسيق مع المهنيين الصحيين وأنظمة الرعاية الصحية التي قد لا تتقبل احتياجات العائلات. يتأثر تعقيد تقديم الرعاية بكمية المهام المطلوبة ، والتي لا يمكن التنبؤ بالعديد منها. قد تتطلب هذه المهام رؤى وقدرات لا يمتلكها مقدمو الرعاية ، مما يزيد من قلق وإحباط مقدمي الرعاية. وبذلك تصبح المعلومات موردا رئيسيا لمقدمي الرعاية للأسر.

الهدف العام للوحدة الرابعة:

توفير معلومات عن أبعاد الرعاية التي يتم تقديمها للحصول على فهم أعمق للرعاية ومعرفة المفهوم الأساسي والمعنى للرعاية التي تساعد المشاركين على التكيف ليكون مقدم الرعاية.

النشاط: يحتاج مقدم الرعاية للعائلة للحصول على المعلومات والدعم والمساعدة والتكيف مع مقدم الرعاية ... (ساعتان). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

سيحصل المشارك على معلومات ومساعدة بخصوص المرض. الرعاية الجسدية تدابير الراحة ما هي الأعراض المتوقعة ، وأسبابها ، وكيفية إدارتها ؛ نظم العلاج. توقعات للرعاية المستقبلية. استجابات المرضى العاطفية إجراءات إدارة الأسرة ؛ المالية. وموارد المجتمع. المساعدة في كيفية تنظيم أنشطة الرعاية مثل النقل والمراقبة وأعراض الإبلاغ ، وتوفير الرعاية الشخصية (الاستحمام ، والمشي ، وارتداء الملابس) ، والاعتبارات التغذوية ، وتنسيق الرعاية (جدولة المواعيد واستدعاء الطبيب) ، ومراقبة حالة المرض ، والأنشطة المالية . (الجدول 1)

الجدول 1 طلبات تقديم الرعاية

مطالب تقديم الرعاية.

العناية المباشرة: (1) إدارة الأدوية ، (2) العناية بالجروح والضمادات ، (3) الاستحمام ، (4) خلع الملابس ، (5) المساعدة في التنقل ، (6) الدعم العاطفي.

الرعاية غير المباشرة: (1) الحصول على الأدوية ، (2) تحديد المواعيد وتنسيق الرعاية ، (3) المساعدة في الفواتير الطبية والمالية العامة ، (4) المراقبة من أجل الآثار الجانبية.

الأعراض والراحة الإدارة: (1) المناهج غير الدوائية ، (2) إدارة الأدوية ، (3) المعايرة الجرعات من الأدوية ، (4) المراقبة من أجل الآثار الجانبية.

المعلومات المطلوبة: (1) المرض ، (2) العلاج ، (3) إدارة الأعراض ، (4) مسار المرض المتوقع ، (5) إدارة استغاثة عاطفية ، (6) تنسيق الرعاية.

محتوى تعليمي.

تعريف: من هو مقدم الرعاية؟

كما يشار إلى مقدمي الرعاية غير الرسميين ، مقدمي الرعاية الأسرة توفر مجموعة معقدة من مهام الدعم التي تمتد عبر المجالات المادية والنفسية والروحية والعاطفية.

1. يتولى مقدمي رعاية مرضى السرطان عمومًا مسؤوليات متعددة الأوجه للقيام بمهام مثل:

2. المهام الإدارية (إدارة الحالة ، إدارة مطالبات التأمين ، ودفع الفواتير).

3. المهام الآلية (المصاحبة لمريض السرطان إلى المواعيد الطبية ؛ إدارة المهمات الشخصية ؛ إدارة الطهي والتنظيف ومهام التدبير المنزلي الأخرى).

4. مهام الملاحة (البحث عن المعلومات التي قد يكون من الصعب العثور عليها ، والعثور على طبيب).

5. أنشطة الدعم الاجتماعي (تقديم الرفقة ، التنشئة الاجتماعية).

6. صانع القرار ، المحامي ، التواصل ، مقدم الرعاية العملية.

يستخدم عبء الرعاية الصحية بشكل شائع لوصف الأبعاد المتعددة للضيق الناتج عن عدم التوازن بين متطلبات الرعاية وتوافر الموارد لتلبية تلك المطالب.

الأثر المادي
تأثير اجتماعي
التأثير المالي
التأثير النفسي
الأثر الروحي

خدمات الرعاية المنزلية لمرضى السرطان:

تشمل خدمات الرعاية المنزلية المقدمة لمريض السرطان بشكل عام دعم الرعاية كجزء من خطة الرعاية.

رعاية المسنين لمرضى السرطان

يحتاج مقدمو الرعاية الأسرية لمرضى الرعاية التلطيفية في المنزل إلى التدريب على مهارات الرعاية العملية والحصول على المزيد من المشورة المهنية لزيادة ثقتهم بأنفسهم وقدرتهم على تنفيذ الجوانب العملية للرعاية المنزلية. بالإضافة إلى ذلك ، يقوم مقدمو الرعاية الذين يساعدون المرضى في المراحل النهائية من تجربة الحياة بالضيق مثلما يفعل المرضى ، إن لم يكن أكثر.

التكيف مع كونها مقدم الرعاية

تغيير الأدوار.

سواء كنت أصغر أو أكبر سنًا ، قد تجد نفسك في دور جديد كمقدمي الرعاية. ربما تكون جزءًا نشطًا من حياة شخص ما قبل الإصابة بالسرطان ، ولكن ربما تكون الطريقة التي تدعم بها هذا الشخص مختلفة. قد يكون ذلك بطريقة لم تكن لك فيها خبرة كبيرة ، أو بطريقة تبدو أكثر كثافة من ذي قبل.

على الرغم من أن تقديم الرعاية قد يبدو جديدًا بالنسبة لك الآن ، فإن العديد من مقدمي الرعاية يقولون إنهم يتعلمون أكثر أثناء خضوعهم لتجربة سرطان شخصهم.

المواقف الشائعة التي يصفونها:

قد يشعر زوجك أو شريكك بالارتياح تجاهك فقط.
قد تواجه والدك صعوبة في قبول المساعدة منك (طفلها البالغ) لأنها
كانت دائما تستخدم لرعاية لك.
قد لا يريد طفلك البالغ المصاب بالسرطان الاعتماد على والديه للحصول على الرعاية.
قد تكون لديك مشاكل صحية بنفسك ، مما يجعل من الصعب جسديًا وعاطفيًا القيام بها
رعاية شخص آخر.

مهما كانت أدوارك الآن ، قد يكون قبول التغييرات أمرًا صعبًا. من الشائع جدًا أن تشعر بالارتباك والتوتر في هذا الوقت. إذا كنت تستطيع ، حاول مشاركة مشاعرك مع الأحباء الآخرين أو الانضمام إلى مجموعة دعم. أو يمكنك اختيار طلب المساعدة من مستشار أو طبيب نفسي. يقول العديد من مقدمي الرعاية أن التحدث مع أحد المستشارين ساعدهم. يشعرون أنهم قادرون على قول أشياء لم يتمكنوا من قولها لأحبائهم.

التعامل مع مشاعرك

ربما شعرت بمجموعة من المشاعر أثناء رعايتك لأحبائك. يمكن أن تكون قوية جدًا وقد تأتي وتذهب أثناء العلاج مع المريض. يصفها العديد من مقدمي الرعاية بأنها "مثل الأفعوانية". قد تشعر بالحزن ، والخوف ، والغضب ، والقلق. لا توجد طريقة صحيحة أو خاطئة للشعور أو التفاعل. هذه المشاعر كلها طبيعية.

قد ترتبط بكل المشاعر في الصفحة التالية ، أو القليل منها. قد تشعر بها في أوقات مختلفة ، مع بعض الأيام تكون أفضل من غيرها. قد يكون من المفيد معرفة أن مقدمي الرعاية الآخرين قد شعروا بنفس الطريقة التي شعرت بها.

واحدة من الخطوات الأولى في التعامل مع المشاعر هي إدراك أنها موجودة وأن وجودها أمر طبيعي. حاول أن تمنح نفسك الوقت لفهم وعمل مجموعة من العواطف.

غضب

يقول العديد من مقدمي الرعاية إنهم غالبًا ما يشعرون بالغضب من أنفسهم أو من أفراد عائلتهم أو من المريض. أحيانًا يأتي الغضب من المشاعر التي يصعب إظهارها ، مثل الخوف أو الذعر أو القلق. أو قد يأتي من الاستياء من كل ما تمر به. إذا استطعت ، حاول أن تتجنب انتقاد الآخرين بسبب هذه المشاعر.

يمكن أن يكون الغضب صحيًا إذا كنت تتعامل معه بالطريقة الصحيحة. يمكن أن يساعدك في تحفيزك على اتخاذ إجراء ، أو معرفة المزيد ، أو إجراء تغييرات إيجابية في حياتك. ولكن إذا استمرت هذه المشاعر وكنت غاضبًا من حولك ، فاطلب المساعدة من مستشار أو غيره من أخصائيي الصحة العقلية.

الذنب

الشعور بالذنب هو رد فعل شائع لمقدمي الرعاية. قد تقلق أنك لا تساعد بما فيه الكفاية ، أو أن عملك أو بعدك عن حبيبك يعيق الطريق. قد تشعر حتى بالذنب لأنك بصحة جيدة.

أو قد تشعر بالذنب لعدم التصرف بالتفاؤل أو البهجة. لكن اعلم أنه بخير. لديك أسباب للشعور بالضيق ، وقد يؤدي إخفاء هذه المشاعر إلى منع الآخرين من فهم احتياجاتك.

حزن

قد تكون حزينًا لفقدان ما تحبه أكثر من شخص عزيزًا فأنت تحب صحة المرء أو حياته كان لديك مع بعضها البعض قبل السرطان. من المهم أن تمنح نفسك الإذن لتحزن هذه الخسائر. يستغرق الأمر بعض الوقت للعمل من خلال قبول كافة التغييرات التي تحدث.

القلق والاكتئاب.

القلق يعني أن لديك قلق إضافي ، لا يمكنك الاسترخاء ، أو تشعر بالتوتر ، أو لديك نوبات الهلع. يقلق الكثير من الناس حول كيفية دفع الفواتير ، وكيف سيؤثر السرطان على العائلة ، وبطبيعة الحال ، كيف يفعل أحباءهم.

الاكتئاب هو الحزن المستمر الذي يستمر لأكثر من أسبوعين. إذا كان أي من هذه الأعراض يبدأ في التأثير على قدرتك على العمل بشكل طبيعي ، فتحدث مع مقدم الرعاية الصحية الخاص بك. لا تظن أنك بحاجة إلى حلها دون أي مساعدة. هناك طرق يمكن تخفيف أعراضك خلال هذا الوقت العصيب.

الشعور بالوحدة

يمكنك أن تشعر وحدك في دورك كمقدم رعاية ، حتى لو كان لديك الكثير من الناس من حولك. من السهل أن تشعر أنه لا أحد يفهم ما تمر به. قد تشعر بالوحدة لأن لديك وقتًا أقل لرؤية الأشخاص والقيام بالأشياء التي اعتدت عليها. مهما كان وضعك ، فأنت لست وحدك. مشاركة مقدمي الرعاية الآخرين مشاعرك.

الأمل أو اليأس

قد تشعر بالأمل أو اليأس إلى درجات مختلفة . وما قد ترجوه قد يتغير بمرور الوقت. قد تأمل في علاج أكثر من أي شيء آخر. ولكنك قد تأمل أيضًا في أشياء أخرى ، مثل الراحة والسلام والقبول والفرح.

إذا لم تكن قادرًا على التخلص من شعور باليأس ، تحدث إلى أحد أفراد العائلة الموثوق بهم ، أو صديق ، أو مقدم رعاية صحية ، أو قائد روحاني أو إيماني. بصفتك مقدمًا للرعاية ، يمكن أن تحقق لك مشاعر الأمل خلال الخمس دقائق القادمة أو الأيام الخمسة المقبلة.

طرق أخرى للتعامل

ترك الأخطاء. لا يمكنك أن تكون مثاليًا. لا احد. أفضل ما يمكننا القيام به هو التعلم من أخطائنا والمضي قدما. استمر في القيام بأفضل ما يمكنك. وحاول ألا تتوقع الكثير من نفسك.

صرخة أو التعبير عن مشاعرك. لا يجب عليك التفاؤل طوال الوقت أو التظاهر بالبهجة. امنح نفسك الوقت الكافي للتعامل مع جميع التغييرات التي تمر بها. من المقبول البكاء وإظهار أنك حزين أو منزعج.

ضع طاقتك في الأشياء التي تهمك. ركز على الأشياء التي تشعر بأنها تستحقها. وقتك وطاقتك. دع الأشياء الأخرى تذهب الآن. على سبيل المثال ، لا تضع الملابس عند التعب. امض قدما واخذ وقت للراحة.

فهم من أين يأتي الغضب. قد يغضب من تحب. من الشائع جدًا أن يوجه الأشخاص مشاعرهم إلى أولئك الأقرب. قد يخرج التوتر ، والمخاوف ، والقلق من الغضب.

حاول أن لا أعتبر شخصيا. في بعض الأحيان ، لا يدرك المرضى تأثير غضبهم على الآخرين. لذلك قد يساعدك ذلك على مشاركة مشاعرك معهم عندما يكونوا هادئين. حاول أن تتذكر أن الغضب لا يتعلق بك حقًا.

اغفر لنفسك هذا هو واحد من أهم الأشياء التي يمكنك القيام بها. هي احتمالات أنت يفعلون ما تستطيع في هذه اللحظة. كل لحظة ووقت جديد يمنحك فرصة جديدة للمحاولة مرة أخرى.

معرفة نقاط القوة والحدود الخاصة بك.

إحدى الطرق التي يتعامل بها مقدمو الرعاية هي تركيز طاقتهم على الأشياء التي يمكنهم التحكم بها. هذا يمكن أن يعني:

مساعدة جدولة زيارات الطبيب
المساعدة في الاحتياجات اليومية مثل الوجبات والمهمات
التعامل مع مهام حبيبك
معرفة المزيد عن السرطان وخيارات العلاج
القيام بأي شيء آخر يمكنك القيام به

يقول العديد من مقدمي الرعاية إنهم ، بالنظر إلى الخلف ، أخذوا الكثير من أنفسهم. أو يرغبون في أنهم طلبوا المساعدة في وقت أقرب. يمكنك إلقاء نظرة صادقة على ما يمكنك فعله وما لا يمكنك فعله. ما الأشياء التي تحتاجها أو تريد القيام بها بنفسك؟ ما المهام التي يمكنك تقديمها أو مشاركتها مع الآخرين؟ كن على استعداد للتخلي عن الأشياء التي لا تعتبر ضرورية بالنسبة لك.

تحديد أولوياتك

قم بعمل قائمة بالمهام والأنشطة الأسبوعية. معرفة مقدار الوقت الذي تقضيه في كل واحد ومدى أهمية ذلك. أخذ الأشياء من قائمة المهام إذا لم تكن مهمة. سيعطيك ذلك المزيد من الوقت للأشياء التي تريدها حقًا وتحتاج إلى القيام بها. هذا قد يعني مخيبا للآمال شخص آخر. ولكن عليك أن تهتم بما هو مهم بالنسبة لك ، بغض النظر عما قد يعتقده الآخرون.

سيتفهم معظم الناس إذا أخبرتهم بما يجري. "عليك أن تعلم أنه إذا كان الناس يقدمون ، دعهم يفعلون شيئًا. اسأل عن ما تحتاجه ، لأنهم لا يعرفون. يجب أن تكون على استعداد للتخلي عن كبريائك والسماح لهم بمساعدتك. "

لماذا الحصول على مساعدة مهم

لا يعد قبول المساعدة من الآخرين أمرًا سهلاً دائمًا. عندما تحدث أشياء صعبة ، يميل كثير من الناس إلى الانسحاب. يعتقدون ، "يمكننا التعامل مع هذا بمفردنا". لكن الأمور يمكن أن تزداد صعوبة أثناء خضوع المريض للعلاج.

قد تحتاج إلى تغيير الجدول الزمني الخاص بك والقيام بمهام جديدة. نتيجة لذلك ، قال العديد من مقدمي الرعاية: "هناك الكثير على طبقتي".

تذكر أن الحصول على مساعدة لنفسك يمكن أن يساعد أيضًا شريكك لأنه:

قد تبقى أكثر صحة.
قد يشعر أحد أفراد عائلتك بالذنب حيال جميع الأشياء التي تقوم بها.
قد يقدم بعض مساعديك بعض الوقت والمهارات التي لا تملكها.

كيف يمكن للآخرين مساعدتك؟

هل تجد أنه من المفيد إذا قام أحدهم بإعداد العشاء لك أو ركض بعض مهماتك؟ إذا كان الأمر كذلك ، فقد تستفيد يو من مساعدة الأشخاص في المهام التي ليس لديك وقت للقيام بها. يريد الأشخاص تقديم المساعدة ، لكن الكثير منهم لا يعرفون ما تحتاجه أو كيفية تقديمه.

لا بأس من أن تأخذ الخطوة الأولى. اسأل عن ما تحتاجه وعن الأشياء التي ستكون أكثر فائدة لك. على سبيل المثال ، قد ترغب في أن يقوم شخص ما بما يلي:

المساعدة في الأعمال المنزلية ، مثل الطهي والتنظيف ، والتسوق ، والعمل في الفناء ، ورعاية الأطفال أو رعاية المسنين

التحدث معك والاستماع إلى مشاعرك

دفع شخص عزيز على المواعيد

تلتقط الطفل من المدرسة أو الأنشطة

قم بإعداد موقع على شبكة الانترنت حيث يمكن للناس معرفة الدعم الذي تحتاجه أو تلقي التحديثات على الخاص بك محبوب

ابحث عن المعلومات التي تحتاجها

كن الشخص الذي يمكن الاتصال به وساعد في إبقاء الآخرين على علم بآرائهم.

من يستطيع المساعدة؟

فكر في الأشخاص الذين يمكنهم مساعدتك في المهام. فكر في جميع الأشخاص والمجموعات التي تعرفها ، بما في ذلك العائلة والأصدقاء والجيران وزملاء العمل. قد يتمكن أعضاء مجتمعك الإيماني والمجموعات المدنية والجمعيات من المساعدة أيضًا. قد يكون المستشفى أو مركز السرطان قادرين على إخبارك عن الخدمات التي يقدمونها ، أو لديك قائمة بالوكالات للاتصال بها.

العثور على مساعدة الراحة

يقضي المساعدين الذين يقضون أوقات فراغهم بعض الوقت مع أحبائكم. يمكن أن تدفع أو تتطوع بوقتهم. يقول العديد من مقدمي الرعاية إنهم يرغبون في أن يحصلوا على المساعدة البديلة في وقت أقرب. يمكن أن يترك لك الحرية للراحة ، أو رؤية الأصدقاء ، أو إدارة المهمات ، أو القيام بكل ما تريد القيام به. يمكن لمقدمي الرعاية الذين يعانون من الراحة أيضًا المساعدة في تلبية المتطلبات البدنية ، مثل رفع المريض إلى سرير أو كرسي.

إذا كانت هذه الخدمة مناسبة لك ، فقد ترغب في:

تحدث مع شريكك عن وجود شخص ما يدخل منزلك لمساعدته من وقت لآخر.

الحصول على إحالات من الأصدقاء أو المتخصصين في الرعاية الصحية أو الوكالة المحلية بشأن الشيخوخة.

اطلب المساعدة من المساعدين حول أنواع المهام التي يقومون بها. يمكنك الحصول على مساعدة راحة من العائلة والأصدقاء ، ولكن أيضًا الوكالات الحكومية أو المجموعات غير الربحية. مهما فعلت ، تذكر أنه ليس فاشلاً من جانبك كمقدم رعاية إذا كنت بحاجة إلى بعض المساعدة والوقت لنفسك.

كن مستعدا لبعض الناس أن يقولوا لا

في بعض الأحيان قد لا يكون الناس قادرين على المساعدة. هذا قد يضر مشاعرك أو تجعلك غاضبا. قد يكون صعبًا على وجه الخصوص من الأشخاص الذين توقعت المساعدة منهم. قد تتساءل عن سبب عدم عرض شخص ما مساعدتك.

بعض الأسباب الشائعة هي:

قد يكون بعض الناس يتعاملون مع مشاكلهم الخاصة ، أو قد لا يكون لديهم الوقت.

إنهم يخافون من السرطان أو قد يكون لديهم بالفعل تجربة سيئة مع السرطان. لا يريدون التورط ويشعرون بالألم من جديد.

يعتقد بعض الأشخاص أنه من الأفضل الاحتفاظ بمسافة عندما يكافح الناس.

في بعض الأحيان لا يدرك الأشخاص مدى صعوبة الأشياء بالنسبة لك. أو أنهم لا يفهمون أنك تحتاج إلى مساعدة إلا إذا طلبت منهم ذلك مباشرة.

يشعر بعض الأشخاص بالحرج لأنهم لا يعرفون كيفية إظهار أنهم يهتمون. إذا لم يقدم لك أحد المساعدة التي تحتاجها ، فقد تحتاج إلى التحدث إليهم وتوضيح احتياجاتك. أو يمكنك فقط تركها تذهب. ولكن إذا كانت العلاقة مهمة ، فقد ترغب في إخبار الشخص بما تشعر به. هذا يمكن أن يساعد في منع الاستياء أو الإجهاد من بناء. هذه المشاعر يمكن أن تؤذي علاقتك على المدى الطويل.

نصائح حول كيفية طلب المساعدة

"سرطانه هو شيء خاص. يجب أن أخبر الناس عن ذلك للحصول على أي دعم "يمكنك أنت وأحبائك أن تقرروا من ماذا ستخبرهم

ماذا أخبرهم ، ومتى وكيف. بعض الخيارات هي:

■ أخبر عدد قليل من الأشخاص القريبين منك في الوقت الحالي.

■ يحدد الحد حول ما تشاركه. تستطيع أن تقول، "إنه مريض" أو "إنها لا تشعر جيدًا اليوم".

■ اطلب من فرد آخر من أفراد العائلة ، أو صديق ، أو عضو في إيمانك أو مجتمعك الروحي لمشاركة الأخبار.

■ احصل على المساعدة من الخدمات أو الوكالات في منطقتك بدلاً من ذلك من الناس الذين تعرفهم.

"كل شخص لديه الكثير من العمل. لا أريد أن أزعجهم أو أخرجهم منها "إذا كنت قلقًا من أن تكون عبئًا على الآخرين ، فإليك

بعض الأشياء للتفكير فيها:

■ ربما يريد الكثير من الناس المساعدة.
■ إذا سمحت لمزيد من الناس بالمساعدة ، فيمكنه تخفيف عبء العمل.
■ هل ترغب في مساعدة شخص آخر كان في حالة مماثلة؟ هل تمانع لو سألوك لتقديم يد العون؟
لا يمكنني شرح ذلك ، لكنني لا أشعر بالوصول الآن في الوقت الحالي "كثير من الناس لا يريدون الدعم عندما يحتاجون إليه
عظم. قد غالبًا ما تتراجع عن اجتماعيتك العادية
الحياة ومن الناس بشكل عام. قد تشعر أنها عادلة
الكثير من العمل لطلب المساعدة.
تحدث مع شخص تثق به ، مثل صديق وعضو
مجتمعك الإيماني أو مستشارك. يمكن أن يساعد الشخص تيس
يمكنك فرز أفكارك ومشاعرك. هم ايضا يستطيعون
مساعدتك في العثور على طرق للحصول على الدعم.

"من واجبي الاعتناء بأسرتي وليس شخص آخر". وجود نظام دعم هو وسيلة لرعاية الخاص بك . يتيح لك منح بعض المهام للآخرين التركيز عليها تلك التي تشعر أنك يجب عليك القيام بها بنفسك.

الوحدات الخامسة: ردود فعل مقدمي الرعاية على طلبات الرعاية

النشاط (1): صف كيف يتفاعل مقدمو الرعاية مع مسؤولياتهم ومهامهم ..... (30 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، الصبوره ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

تنبع ردود فعل مقدمي الرعاية تجاه متطلبات الرعاية من الغموض وعدم اليقين المرتبط بتنظيم ومواجهة المهام والمسؤوليات المتعددة في مواجهة زيادة عجز المريض.

الهدف: لتقليل التأثير السلبي (Caregiver Burden) من الاهتمام بجودة الرعاية لمقدمي الرعاية.

تؤثر اعتمادية المرضى في مهام الحياة اليومية وشدة الأعراض وعدم الحركة تأثيراً مباشراً على العبء والاكتئاب الذي يعاني منه أفراد الأسرة الذين يقدمون الرعاية. يفيد مقدمو الرعاية ذوو الحالة الاجتماعية والاقتصادية المنخفضة عن المزيد من المشاكل بسبب محدودية الموارد وانخفاض القدرة على توفير الرعاية الكافية.

يقوم مقدمو الرعاية بالإبلاغ عن الإرهاق والوقت غير المناسب للنوم والرعاية الذاتية. مقارنة مع غير مقدمي الرعاية ، زاد أفراد الأسرة المشاركين في مستويات الرعاية بشكل كبير احتمالات عدم الحصول على قسط كاف من الراحة ، وليس لديهم وقت لممارسة ، وليس لديهم أنشطة ترفيهية ، ونسيان تناول العقاقير التي تستلزم وصفة طبية.

ويخشى مقدم الرعاية من مستوى الرعاية الجسدية يتطلب ذلك زيادة الطلب ، حيث يتحمل مقدمو الرعاية المزيد من المسؤولية عن العمل الأسري والاجتماعي.

الاحتياجات: ينبغي توثيق التقييم الجاد لاحتياجات مقدمي الرعاية الأسرية ، وتقييم القدرة على رعاية المريض.

يمكن أن يساعد الدعم المناسب من مقدمي الرعاية الصحية وغيرهم الأسر في تحديد أولويات مشاكل المرضى وإدارتها ، مع تقليل الأعباء المرتبطة بعدم اليقين في الوقت نفسه. إذا استطاعت العائلات الاعتراف بقيمة رعايتها ، فمن المرجح أن يكون إحساسها بالعبء أقل.

النشاط (2): وصف أهمية الرعاية الذاتية وكيف يمارس مقدم الرعاية الرعاية الذاتية ..... (40 دقيقة). سيتم استخدام جميع المواد المتاحة (الكمبيوتر ، شاشات الكريستال السائل ، بالملل ، علامات ، كرسي مريح ، والورق ، ودبابيس ، والمشروبات المرطبات والهبوط).

الهدف: يكون المشارك على دراية بالرعاية الذاتية ويمارس الرعاية الذاتية.

كيف أعتني بنفسي؟

إن العناية بنفسك أمر مهم ، لذا يجب أن تأخذ وقتًا لفعل شيء لنفسك كل يوم. لا تشعر بالذنب برعاية نفسك - أنت مهم وتستحق أن يتم الاعتناء بها. سوف يستفيد قريبك أيضًا إذا كنت تشعر بشيء أفضل عن نفسك. حتى إذا شعرت بأنك أناني ، فإن العديد من المرضى يشعرون بقدر أقل من العبء إذا تمكنوا من رؤية أن الشخص الذي يعتني بهم يحصل على بعض المتعة والراحة. قد لا يكون من الممكن التخلص من كل الإجهاد ، لكن في ما يلي بعض الأمور التي قد تساعد:

قم ببعض التمارين

افعل شيئًا ماديًا. الذهاب للمشي و / أو القيام ببعض الانحناء وتمتد. هناك أشرطة فيديو للتمرينات الرياضية ، أقراص فيديو رقمية وبودكاست متاحة للاستخدام في المنزل إذا واجهت صعوبة في مغادرة المنزل. سوف تساعدك التمارين الرياضية على الحفاظ على طاقتك. حاول اختيار التمرين الذي تستمتع به.

الحصول على قسط كاف من النوم

من الشائع أن يعاني مقدمو الرعاية من بعض المشاكل في النوم. الحد من القهوة والكحول في المساء. فكر في شاي الأعشاب ، والحمام الدافئ و / أو بعض الموسيقى الهادئة لمساعدتك على النوم. إذا كنت لا تستطيعين النوم ، استيقظ لفترة قصيرة ، حاول أن تفعل شيئًا يبعث على الاسترخاء ثم حاول أن تغفو مرة أخرى. إذا انزعج نومك أثناء الليل ، حاول الحصول على قسط من الراحة أثناء اليوم.

يمكن لمعظمنا أن يتعامل مع قلة النوم من وقت لآخر ، ولكن إذا كنت تجد صعوبة في النوم بشكل منتظم ، ناقش ذلك مع الممرضة أو الطبيب.

الحفاظ على اتباع نظام غذائي صحي

قد يكون ذلك صعباً في بعض الأحيان ، خاصة إذا فقد قريبك شهيته. ومع ذلك ، فأنت تحتاج إلى قوتك ، لذا يجب أن تتناول نظامًا غذائيًا متوازنًا ولا تنس أن "تعامل" نفسك من وقت لآخر مع الطعام الذي تستمتع به.

افعل شيئًا لنفسك كل يوم

اصنع قائمة من 10 أشياء تستمتع بها والتي ستمنحك استراحة قصيرة وتجديد طاقتك. قم بأحد هذه الأمور على الأقل كل يوم. قد تشعر كما لو كنت تدير جيدا. ومع ذلك ، فإن الاعتناء بنفسك يساعد أيضًا على منع الإجهاد.

حاول البقاء على اتصال مع أصدقائك قدر الإمكان.

استنادًا إلى معتقداتك وممارساتك الدينية أو الروحية ، قد تجد المساعدة في الصلاة أو التأمل أو المناقشة مع مستشار رعوي موثوق. قد يكون من المهم أيضًا مواصلة مشاركتك مع مجتمعك الديني أو مشاركة المجتمع الأخرى.

كيف أحافظ على الأمل عندما يبدو الوضع ميئوسًا؟

إن الحفاظ على الأمل مع توقع حدوث الأسوأ هو "دعوة قاسية" وقد تتغير مشاعرك من الأمل واليأس عدة مرات. بعض الناس قد وجدوا المساعدة في تأمل الأشياء الصغيرة ، حتى في وجه الموت والخسارة.

"أنا أعلم أنني لا أستطيع أن أتمنى أن يتم شفاؤه ، ولكن يمكنني أن أتمنى أنه سيحظى بيوم جيد اليوم."

"آمل أن أتمكن من الحفاظ على حس الفكاهة حتى عندما تسوء الأمور."

"آمل أن يعرف أنني هنا حتى رغم أنه غير قادر على التحدث".

قبول المساعدة

بعض مقدمي الرعاية السابقين لم يطلبوا المساعدة لأنهم شعروا بأن احتياجات قريبهم أكثر أهمية أو أن فريق الرعاية الملطفة كان مشغولاً للغاية لتقديم مساعدة إضافية.

تذكر أن رفاهتك هي جزء حيوي من قدرتك على دعم قريبك. تقع على عاتق فريق الرعاية الملطفة مسؤولية مساعدتك ، لذلك لا تخشى أن تخبره إذا كنت بحاجة إلى المزيد من الدعم.

إذا كان لديك أقارب أو أصدقاء مستعدون للمساعدة ، استخدمهم! مساعدتهم قد تأخذ بعض الإجهاد عنك. حافظ على سهولة الحصول على قائمة بالأشياء التي يمكن أن يقوم بها الأشخاص الآخرون لك ، مثل إعداد وجبة ، أو مع قريبك أثناء زيارتك لموعد أو القيام ببعض التسوق ، أو إجراء مكالمات هاتفية أو تلقي رسائل. بهذه الطريقة ، إذا كنت تتحدث إلى شخص ما وتقدم المساعدة ، يمكنك تقديم اقتراحات من قائمتك.

لا يعني طلب المساعدة أن تكون قد فشلت أو أنك لا تتعامل معها ؛ فهذا يعني أنك ذكي وحساس وتتصرف على مشاعرك.

اجتماعات عائلية

قد يتم ترتيب اجتماع عائلي من قبل فريق الرعاية الملطفة وعادة ما ينطوي على المريض (إذا كان جيدا بما فيه الكفاية للحضور) ، ومقدم الرعاية الأسرة (ق) والمتخصصين في الرعاية الصحية. الغرض من اجتماع العائلة هو إشراكك في تطوير "خطة الرعاية" لأقربائك وتوضيح "أهداف الرعاية".

تعتمد خطة الرعاية على احتياجاتك الخاصة من قريبك وتتضمن احتياجاتك الخاصة. يتم مراجعة خطة الرعاية بشكل منتظم من قبل الفريق ، خاصة عندما تتغير احتياجاتك ، أو تتغير احتياجات قريبك. يمكن أن يساعدك وجود خطة على "الاستمرار في المسار".

التلاعب باحتياجاتك واحتياجات قريبك وواجبات حياتك المعتادة

في بعض الأيام قد تشعر كما لو أن كل ما قمت به هو توفير الرعاية وليس لديك وقت لأشياء أخرى. على الرغم من احتياجات قريبك ، تستمر الحياة من حولك وقد تجد صعوبة في إدارتها.

قد تشعر كما لو كنت لا تسيطر. هذه استجابات طبيعية. أنت تتفاعل مع قدر كبير من التغيير وتحتاج إلى محاولة التكيف بسرعة. فيما يلي بعض الاقتراحات التي قد تساعدك على اكتساب حس أكبر من السيطرة على الموقف:

أولويات المهام في القوائم:

"يجب أن يفعل" ، "تود أن تفعل" ، "إذا سنحت لي الفرصة سأفعل". قد ترغب في تدوين قائمة بالأشياء التي ترغب في تحقيقها اليوم ، ولكن لا تجعل القائمة طويلة جدًا. ذكّر نفسك أنه لا بأس إذا لم تنجز كل شيء. في نهاية اليوم فكر في الأشياء التي حققتها بدلاً من الأشياء التي لم تحققها.

خذ يومًا واحدًا في كل مرة

من الطبيعي أن تفكر في المستقبل ولكن حاول أن تأخذ تحديات العناية بيوم واحد في كل مرة.

فكر في كتابة المسائل المتعلقة بالرعاية في دفتر يوميات يمكنك تتبع الأشياء فور حدوثها ويمكنك استخدامها كتذكير عند طرح الأسئلة أو إعطاء تفاصيل لفريق الرعاية الملطفة أو مقدمي الرعاية الآخرين.

احتفظ بكل المعلومات المكتوبة عن قريبك في مكان واحد

على سبيل المثال المخططات الدوائية للمكان ، ومعلومات فريق الرعاية الملطفة ، وأرقام الهواتف المفيدة ، وهذا الدليل في مكان واحد.

الحصول على جهاز الرد على المكالمات

ليس عليك التقاط الهاتف إذا كنت مشغولاً أو لديك بعض الوقت لنفسك. استخدم هذه الفرصة للحصول على وقت خاص مع قريبك ، أو وقت لتناول وجبة غير متقطعة أو لمجرد انتهاء الوقت.

الحصول على الهاتف المحمول إذا التصاريح المالية

يمكنك الخروج من المنزل مع العلم أنه إذا كانت هناك مشكلة ملحة مع قريبك ، فيمكنك الاتصال بك.

قم بإعداد قائمة بالأصدقاء / الأقارب الذين تعرف أنه يمكنك طلب المساعدة

إذا لم يكن هناك أحد على استعداد للمساعدة ، تحدث مع فريق الرعاية الملطفة بشأن أحد المتطوعين أو شاهد الأخصائي الاجتماعي.

فكر في أن تطلب من صديق / قريب أن يبقى بين عشية وضحاها

قد يسمح لك ذلك بالحصول على ليلة نوم جيدة وقد تكون ممتعًا للشركة الإضافية.

احصل على شخص آخر للقيام بالأعمال المنزلية (ما لم تجد هذه الأعمال المنزلية مريحة)

قم بالاتصال بالمجلس المحلي والخدمات الخاصة في جريدتك المحلية أو اطلب من صديق أو قريب المساعدة.

اطلب من أقاربك / أصدقائك إحضار بعض الوجبات الجاهزة (الحساء ، الأوعية المقاومة للحرارة إلخ)

إذا كان ذلك صعبًا ، ففكر في "وجبات الطعام على العجلات" أو في غيرها من خدمات توصيل الطعام إلى المنازل.

اطلب من أحد أقاربك / أصدقاءك الاتصال بالهاتف أو قبول مكالمات من "أشخاص آخرين" ممن يحتاجون أو يريدون معرفة أحدث المعلومات المتعلقة بقريبتك. هذا يوفر عليك تكرار القصة مرارا وتكرارا.

إذا كان عملك خارج المنزل يجعله مجهولاً في محاولة التوفيق بين الدورين ، فقم بمناقشة المسألة مع صاحب العمل (أو الأشخاص الآخرين المعنيين) لمعرفة مقدار المرونة التي يمكن أن تتمتع بها. قد تحتاج أيضا إلى النظر في أخذ إجازة خاصة.

فكر في إرسال بريد إلكتروني منتظم إلى الأصدقاء والعائلات لإبقائهم محدثين

يتيح لك ذلك التأكد من أن الأشخاص ذوي الصلة على دراية بكيفية حدوث الأمور ، ولكنك توفر الكثير من المكالمات الهاتفية.

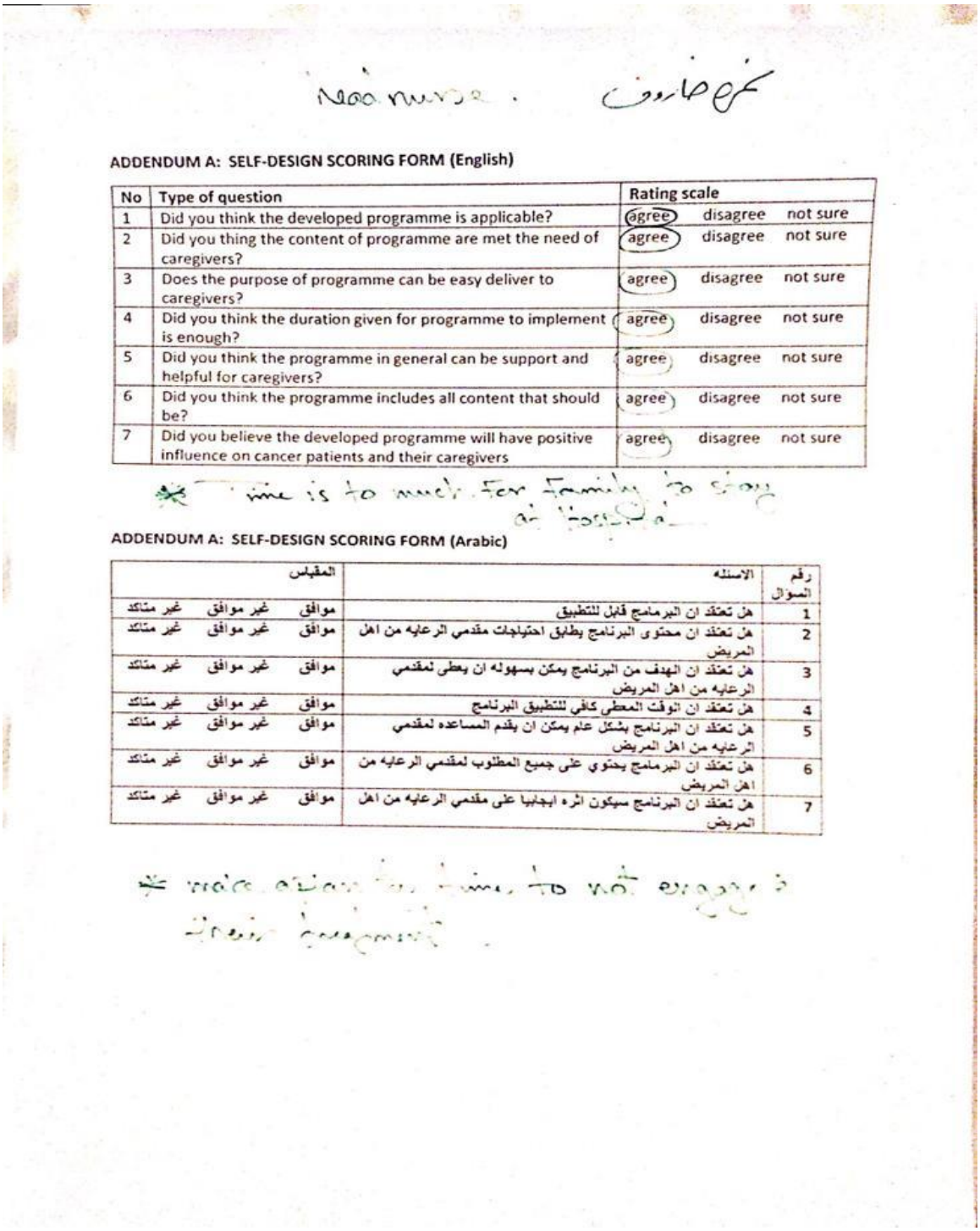
السيطرة على عدد الزوار

قد يرغب الأقارب / الأصدقاء في زيارة كثيرًا ؛ ومع ذلك ، لا بأس من القول بأن الشخص الذي ترعاه متعب للغاية. يمكنك وضع ملاحظة على الباب الأمامي لتقول أنها تستريح. إذا لزم الأمر ، اطلب من الزائرين إرضاء الهاتف دائمًا أولاً.
قد يساعدك على إعداد ساعات الزيارة لتجنب التدفق المستمر للزائرين. لا تشعر كما لو كنت دائمًا بحاجة إلى أن تكون المضيف. اطلب من الآخرين تقديم فنجان من الشاي لك.
إذا كان هناك أكثر من شخص يهتم حاول إعداد نظام القائمة ومشاركته لمشاركة الحمل. اجمع العائلة والأصدقاء معًا واسألهم عما يفضلون القيام به ، على سبيل المثال قد يفضل شخص واحد تقديم الدعم العاطفي بدلاً من الرعاية الجسدية. قد ترغب أخرى في العمل بمثابة الاتصال الرئيسي مع المهنيين الصحيين.
امنح نفسك مكافآت منتظمة
خذ استراحة ، وتناول بعض الطعام اللذيذ ، وافعل شيئًا مميزًا لنفسك يجعلك تشعر بالارتياح وتزيد من معنوياتك.
اشعر بالارهاق؟ حان الوقت للاسترخاء
يستجيب الناس لرعاية بطرق مختلفة. يرجى تفهم أنه من الشائع جدا أن تشعر بأي أو الكثير من الأمور التالية: القلق أو السقوط أو الغضب أو الغضب أو الغضب أو الذنب أو الارتباك. لا تتجاهل كيف تشعر. يشعر بعض مقدمي الرعاية أيضًا بالضغط النفسي ؛ قد يشعرون بالتعب الشديد أو يصابون بالصداع من وقت لآخر.
يتعامل الناس مع التوتر بطرق مختلفة. لا توجد طريقة صحيحة أو خاطئة لإدارة المشاعر الصعبة التي تنشأ.
فيما يلي بعض الأشياء التي قد تساعد:
خطط للقيام بشيء تستمتع به في غضون الساعات القليلة القادمة.
ناقش مشاعرك مع شخص تشعر بالراحة تجاهه (قريب / صديق ، شخصيات دينية / روحية أو شخص من فريق الرعاية الملطفة).
ابحث عن الإيجابي واعثر على بعض الفوائد في موقفك.
خطط لإعطاء نفسك مكافأة كبيرة في اليومين المقبلين ، على كل ما تبذلونه من العمل الشاق حتى الآن.
الحفاظ على الأمل - حتى في سياق مرض خطير ، يمكن أن تتحسن الأمور.
فكر في شيء مضحك عايشته أو سمعته أو أخبر بعض النكات.
استمع إلى شريط الاسترخاء.
ذكّر نفسك بما يلي: أنت تبذل أقصى ما في وسعك ؛ هناك خيارات (حتى إذا كنت لا تستطيع رؤيتها بوضوح في الوقت الحالي) ؛ انت لست وحدك؛ مشاعرك طبيعية هناك مساعدة متاحة وسوف تشعر بتحسن.

جرّب تمرين الاسترخاء هذا: "10 خطوات للهدوء". قد يتطلب الأمر بعض الممارسة ، لكن الأمر يصبح أسهل.

(1) تجد نفسك في مكان تعلمين أنه يمكنك التمتع بالسلام والهدوء لمدة 20 دقيقة على الأقل. (2) خذ 10 نفسا عميقا. (3) العثور على مكان مريح: الاستلقاء على الأرض. قد تحتاج إلى وضع شيء ناعم تحتك. (4) قم بفك ملابسك وخلع حذائك. (5) أغمض عينيك. (6) خذ نفسا عميقا وتنفس ببطء. (7) قم بتوتر جميع عضلات جسمك ؛ العد إلى خمسة ثم تحرير ببطء (القيام بذلك 3 مرات). (8) ابدأ بالتوتر ثم استرخى العضلات في أعلى رأسك وعمل طريقك إلى أصابع قدميك (خذ وقتك). (9) ابق على عينيك مغلقة وتخيل مكان حقيقي أو تخيل ، وهو أمر سلمي. تخيل أصوات أو مشاهد ممتعة. ابق في هذا المكان حتى تشعر بالاستعداد للعودة. (10) عد من 1-10 ببطء ، افتح عينيك. عندما تكون مستعدًا ، قف ببطء

ADDENDUM **B & C**



ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale
1	Did you think the developed programme is applicable?	agree disagree not sure
2	Did you thing the content of programme are met the need of caregivers?	agree disagree not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree disagree not sure
4	Did you think the duration given for programme to implement is enough?	agree disagree not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree disagree not sure
6	Did you think the programme includes all content that should be?	agree disagree not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree disagree not sure

* Time is to much for family to stay at hospital

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السؤال	الاسئله	المقياس
1	هل تعتقد ان البرنامج قابل للتطبيق	موافق غير موافق غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق غير موافق غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
6	هل تعتقد ان البرنامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد

* more than time to not engage in their assignment

Oncology Nurse

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale		
1	Did you think the developed programme is applicable?	agree	disagree	not sure
2	Did you thing the content of programme are met the need of caregivers?	agree	disagree	not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree	disagree	not sure
4	Did you think the duration given for programme to implement is enough?	agree	disagree	not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree	disagree	not sure
6	Did you think the programme includes all content that should be?	agree	disagree	not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree	disagree	not sure

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السؤال	الاسئله	المقياس		
1	هل تعتقد ان البرنامج قابل للتطبيق	موافق	غير موافق	غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق	غير موافق	غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
6	هل تعتقد ان البرنامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد

Oncology Nurse

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale		
1	Did you think the developed programme is applicable?	agree	disagree	not sure
2	Did you thing the content of programme are met the need of caregivers?	agree	disagree	not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree	disagree	not sure
4	Did you think the duration given for programme to implement is enough?	agree	disagree	not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree	disagree	not sure
6	Did you think the programme includes all content that should be?	agree	disagree	not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree	disagree	not sure

Brief Scale Concept.

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السوال	الاسئله	المقياس		
1	هل تعتقد ان البرنامج قابل للتطبيق	موافق	غير موافق	غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق	غير موافق	غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
6	هل تعتقد ان البرنامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد

caregiver مقدمي الرعاية

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale		
1	Did you think the developed programme is applicable?	agree	disagree	not sure
2	Did you thing the content of programme are met the need of caregivers?	agree	disagree	not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree	disagree	not sure
4	Did you think the duration given for programme to implement is enough?	agree	disagree	not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree	disagree	not sure
6	Did you think the programme includes all content that should be?	agree	disagree	not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree	disagree	not sure

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السؤال	الاسئله	المقياس		
1	هل تعتقد ان البرمامج قابل للتطبيق	موافق	غير موافق	غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق	غير موافق	غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
6	هل تعتقد ان البرمامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد

Caregiver Female

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale		
1	Did you think the developed programme is applicable?	agree	disagree	not sure
2	Did you thing the content of programme are met the need of caregivers?	agree	disagree	not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree	disagree	not sure
4	Did you think the duration given for programme to implement is enough?	agree	disagree	not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree	disagree	not sure
6	Did you think the programme includes all content that should be?	agree	disagree	not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree	disagree	not sure

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السؤال	الاسئله	المقياس		
1	هل تعتقد ان البرمامج قابل للتطبيق	موافق	غير موافق	غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق	غير موافق	غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
6	هل تعتقد ان البرمامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد

social worker Cancer

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale		
1	Did you think the developed programme is applicable?	agree	disagree	not sure
2	Did you thing the content of programme are met the need of caregivers?	agree	disagree	not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree	disagree	not sure
4	Did you think the duration given for programme to implement is enough?	agree	disagree	not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree	disagree	not sure
6	Did you think the programme includes all content that should be?	agree	disagree	not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree	disagree	not sure

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السوال	الاسئله	المقياس		
1	هل تعتقد ان البرمامج قابل للتطبيق	موافق	غير موافق	غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق	غير موافق	غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
6	هل تعتقد ان البرمامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد

Plus —
Focus On God of life & giving more.

Encourage the pt & their family to not feel shame if they need to go to visit Mental care specialist (Shrink)

Oncology Nurse

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale
1	Did you think the developed programme is applicable?	agree disagree not sure
2	Did you thing the content of programme are met the need of caregivers?	agree disagree not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree disagree not sure
4	Did you think the duration given for programme to implement is enough?	agree disagree not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree disagree not sure
6	Did you think the programme includes all content that should be?	agree disagree not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree disagree not sure

Brinto Seoul Concept.

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السوال	الاسئله	المقياس
1	هل تعتقد ان البرنامج قابل للتطبيق	موافق غير موافق غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق غير موافق غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
6	هل تعتقد ان البرنامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد

Oncology Nurse طاني

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale
1	Did you think the developed programme is applicable?	(agree) disagree not sure
2	Did you thing the content of programme are met the need of caregivers?	(agree) disagree not sure
3	Does the purpose of programme can be easy deliver to caregivers?	(agree) disagree not sure
4	Did you think the duration given for programme to implement is enough?	(agree) disagree not sure
5	Did you think the programme in general can be support and helpful for caregivers?	(agree) disagree not sure
6	Did you think the programme includes all content that should be?	(agree) disagree not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	(agree) disagree not sure

Bint Sea all Concept.

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السوال	الاسئله	المقياس
1	هل تعتقد ان البرنامج قابل للتطبيق	موافق غير موافق غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق غير موافق غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
6	هل تعتقد ان البرنامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق غير موافق غير متاكد

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale		
1	Did you think the developed programme is applicable?	agree	disagree	not sure
2	Did you thing the content of programme are met the need of caregivers?	agree	disagree	not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree	disagree	not sure
4	Did you think the duration given for programme to implement is enough?	agree	disagree	not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree	disagree	not sure
6	Did you think the programme includes all content that should be?	agree	disagree	not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree	disagree	not sure

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السوال	الاسئله	المقياس		
1	هل تعتقد ان البرمامج قابل للتطبيق	موافق	غير موافق	غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق	غير موافق	غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
6	هل تعتقد ان البرمامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد

Caregiver

ADDENDUM A: SELF-DESIGN SCORING FORM (English)

No	Type of question	Rating scale		
1	Did you think the developed programme is applicable?	agree	disagree	not sure
2	Did you thing the content of programme are met the need of caregivers?	agree	disagree	not sure
3	Does the purpose of programme can be easy deliver to caregivers?	agree	disagree	not sure
4	Did you think the duration given for programme to implement is enough?	agree	disagree	not sure
5	Did you think the programme in general can be support and helpful for caregivers?	agree	disagree	not sure
6	Did you think the programme includes all content that should be?	agree	disagree	not sure
7	Did you believe the developed programme will have positive influence on cancer patients and their caregivers	agree	disagree	not sure

Caregiver Supply & Validated Program.

ADDENDUM A: SELF-DESIGN SCORING FORM (Arabic)

رقم السوال	الاسئله	المقياس		
1	هل تعتقد ان البرنامج قابل للتطبيق	موافق	غير موافق	غير متاكد
2	هل تعتقد ان محتوى البرنامج يطابق احتياجات مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
3	هل تعتقد ان الهدف من البرنامج يمكن بسهوله ان يعطى لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
4	هل تعتقد ان الوقت المعطى كافي للتطبيق البرنامج	موافق	غير موافق	غير متاكد
5	هل تعتقد ان البرنامج بشكل عام يمكن ان يقدم المساعده لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
6	هل تعتقد ان البرنامج يحتوي على جميع المطلوب لمقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد
7	هل تعتقد ان البرنامج سيكون اثره ايجابيا على مقدمي الرعايه من اهل المريض	موافق	غير موافق	غير متاكد

ADDENDUM **D**

CAREGIVER INFORMATION LEAFLET

PROJECT TITLE

THE OUTCOMES OF A SUPPORT PROGRAMME FOR CAREGIVERS OF CANCER PATIENTS.

Dear Madam/Sir,

Good day! My name is Mohammed Hayek and I would like to invite you to participate in a study that will lead to obtaining a PhD in Nursing. The title of my project is: **A support programme for caregivers of cancer patients in the palestinian context**. This information leaflet will help you to decide whether you would accept this invitation or would prefer not to take part in the study. Before you agree to take part, you should fully understand what is involved. You should not agree to take part unless you are completely satisfied with all aspects of the study.

WHAT IS THE STUDY ALL ABOUT?

The study focuses on identifying the effectiveness of a support program for caregivers of cancer patients specifically in terms of the caregivers' quality of life and care burden as well as the patient's quality of life and symptom burden and the support program will be continue until the content of the programme will be completed which is need for three months.

WHAT WILL YOU BE REQUIRED TO DO IN THE STUDY?

If you decide to partake in this study, the following will be required:

- You will have to sign an informed consent form,
- Complete a demographic data and two other questionnaires in the Arabic language all types of questionnaires may need 10-15 minutes to be completed. Questioners will includes questions regarding caregivers of a cancer patient's quality of life, that is, some of the physical, social, emotional, and financial aspects of well-being, and functioning and other questions to examines burden associated with functional/behavioural impairments and the home care situation.
- You will attend the support programme as agreed with, and you will complete two (2) different questionnaires before the programme and you also complete the same questionnaires after the programme once again in the Arabic language. You will receive the support program after the data of the study have been collected and it would not be required of you complete any additional questionnaires.

ARE THERE ANY CONDITIONS THAT MAY EXCLUDE YOU FROM THE STUDY?

You may participate:

If you are 18 years and older, have more than three months experience of caring for a cancer patient and agree to participate in the study.

CAN ANY OF THE STUDY PROCEDURES RESULT IN PERSONAL RISK, DISCOMFORT OR INCONVENIENCE?

Due to the sensitive nature of the topic, some emotional discomfort may be experienced during the study. Should you become emotionally distressed, the researcher will refer you to a counsellor with your permission. This service will be rendered free of cost to you.

WHAT ARE THE POTENTIAL BENEFITS THAT MAY COME FROM THE STUDY?

The result of the study will allow the researcher to see whether a support programme for caregivers of cancer patients had a positive influence on the quality of life and caregiver burden and whether it assisted the patients in terms of experiencing less symptoms and improve their quality of life. This knowledge will assist the researcher to improve the proagramme if needed before implementing it as part of the standard care of caregivers and cancer patients.

WILL YOU RECEIVE ANY FINANCIAL COMPENSATION OR INCENTIVE FOR PARTICIPATING IN THE STUDY?

You will not be financially compensated for participation in the study.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY?

Your participation in this study is entirely voluntary. You are under no obligation to participate and you have the right to withdraw at any stage. You don't even have to provide the reason/s for your decision and be sure that standard care provided for your cancer patient will not effected in any way if you refuse to participate in this research.

HOW WILL CONFIDENTIALITY AND ANONYMITY BE ENSURED IN THE STUDY?

All information obtained during the course of this study is strictly confidential. The study data will be coded so that it will not be linked to your name. Your identity will not be revealed while the study is being conducted or when the study is reported in scientific journals. All the data sheets and questionnaires that have been collected will be stored in a secure place for 3 years. Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. The information received during the study will only be used for research purposes.

IS THE RESEARCHER QUALIFIED TO CARRY OUT THE STUDY?

The researcher is registered with the Palestinian Nursing Council as a nurse and has 5 years' experience working in the oncology environment. Furthermore, the researcher is in possession of a Master's degree in Nursing (Acute Cases) and has published the results of his dissertation. This study forms part of the researcher's doctoral degree and is supervised by an experienced oncology nurse practitioner and researcher.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

The research proposal has been approved by the University of the Witwatersrand Research Ethics Committee. All parts of the study will be conducted according to internationally accepted ethical principles.

WHO CAN YOU CONTACT FOR ADDITIONAL INFORMATION REGARDING THE STUDY?

The primary investigator, Mr. Mohammed Hayek, can be contacted on his moblie phone at 009725685994527 or via e-mail: 1805123@students.wits.ac.za. The study supervisor, Prof JE Maree, can be contacted during office hours at Tel (011) 488 4272/4196 or at Lize.maree@wtis.ac.za.

Should you need information about the ethics of the study and if you would like to report complaints / problems, please contact Prof Peter Cleaton-Jones at peter.cleatonjones@wits.ac.za

DECLARATION: CONFLICT OF INTEREST

This study is funded by the Researcher. No publication prohibitions, conditions or limitations were placed on the researcher.

A FINAL WORD

Your co-operation and participation in the study will be greatly appreciated. Please sign the informed consent below if you agree to participate in the study. In such a case, you will receive a copy of the signed informed consent from the researcher

ADDENDUM **E**

CAREGIVERS OF CANCER PATIENTS INFORMED CONSENT

I hereby confirm that I have been adequately informed by the researcher about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information. I am aware that the results of the study will be anonymously processed into a research report. I understand that my participation is voluntary and that I may, at any stage, without prejudice, withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

Research participant's name: _____ (Please print)

Research participant's signature: _____

Date: _____

Researcher's name: _____ (Please print)

Researcher's signature: _____

Date: _____

موافقة مسبقة

وأؤكد هنا أن الباحث قد أطلعنا بشكل كاف على طبيعة الدراسة وسلوكها وفوائدها ومخاطرها. وقد تلقيت أيضا، وقرأت وفهمت المعلومات المكتوبة أعلاه. وأنا على علم بأن نتائج الدراسة سوف تتم معالجتها بشكل مجهول في تقرير بحثي. إنني أدرك أن مشاركتي طوعية وأنني قد أسحب موافقتي ومشاركتي في الدراسة في أي مرحلة دون تحيز. كان لي فرصة كافية لطرح الأسئلة وإرادتي الحرة تعلن نفسي على استعداد للمشاركة في الدراسة.

اسم المشارك بالبحث _____(طباعه)

توقيع المشارك بالبحث _____(طباعه)
التاريخ_____

اسم الباحث _____(طباعه)

توقيع الباحث _____(طباعه)
التاريخ_____

ADDENDUM **F**

CANCER PATIENTS INFORMATION LEAFLET

PROJECT TITLE

THE OUTCOMES OF A SUPPORT PROGRAMME FOR CAREGIVERS OF CANCER PATIENTS

Dear Madam/Sir,

Good day! My name is Mohammed Hayek and I would like to invite you to participate in a study that will lead to obtaining a PhD in Nursing. The title of my project is **A support programme for caregivers of cancer patients in the palestinian context**. This information leaflet will help you to decide whether you would accept this invitation or would prefer not to take part in the study. Before you agree to take part, you should fully understand what is involved. You should not agree to take part unless you are completely satisfied with all aspects of the study.

WHAT IS THE STUDY ALL ABOUT?

The study focuses on identifying the effectiveness of a support program for caregivers of cancer patients in terms of their quality of life and care burden as well as the patient's quality of life and symptom burden. If the programme is found to be effective, it would in future assist other cancer caregivers to maintain and improve their quality of life and care burden as well as the quality of life and symptom burden of the person in their care.

WHAT WILL YOU BE REQUIRED TO DO IN THE STUDY?

If you decide to partake in this study, the following will be required:

- You would have to sign a separate informed consent form.
- You would have to complete three different questionnaires in Arabic before the start of the support programme that your caregiver would follow.
- You will have to complete the same three questionnaires in Arabic after the final session of the support programme all types of questionnaires may need 10-15 minutes to be completed.
- Questioners will includes questions that used to assessing the severity of pain and its impact on functioning, other questions used to assess your symptom burden while the others used to assess the your quality of life (QOL)
- You will not attend the support program that your caregiver will do, offering the programme will continue until the contents of programme will be completed which may take three months.

ARE THERE ANY CONDITIONS THAT MAY EXCLUDE YOU FROM THE STUDY?

You may participate:

- If you are 18 years old and older
- Are not bedridden; and
- Agree to participate in the study.

CAN ANY OF THE STUDY PROCEDURES RESULT IN PERSONAL RISK, DISCOMFORT OR INCONVENIENCE?

Due to the sensitive nature of the topic, some discomfort may be experienced when the researcher ask you certain questions. Should you become emotionally distressed, the researcher will refer you to a counsellor with your permission. Counselling will be free of cost.

WHAT ARE THE POTENTIAL BENEFITS THAT MAY COME FROM THE STUDY?

The result of the study will be used to improve a support programme for caregiver of cancer patients which will enable caregivers to better support and care for the patients with cancer not only during treatment phase, but also during the follow-up phase and subsequent years.

WILL YOU RECEIVE ANY FINANCIAL COMPENSATION OR INCENTIVE FOR PARTICIPATING IN THE STUDY?

You will not be financially compensated for participation in the study. However, through your participation, you will help the researcher improve cancer care in Palestine.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS STUDY?

Your participation in this study is entirely voluntary. You are under no obligation to participate and you have the right to withdraw at any stage. You don't even have to provide the reason/s for your decision and be sure that your standard care will not effected in any way if you refuse to participate in this research.

HOW WILL CONFIDENTIALITY AND ANONYMITY BE ENSURED IN THE STUDY?

All information obtained during the course of this study is strictly confidential. The study data will be coded so that it will not be linked to your name. Your identity will not be revealed while the study is being conducted or when the study is reported in scientific journals. All the data sheets and questionnaires that have been collected will be stored in a secure place for 3 years. Any information that is obtained in connection with this study and that can be

identified with you will remain confidential and will be disclosed only with your permission or as required by law.

IS THE RESEARCHER QUALIFIED TO CARRY OUT THE STUDY?

The researcher is registered with the Palestinian Nursing Council as a registered nurse and has 5 years' experience working in the Oncology environment. Furthermore, the researcher is in possession of a Master's degree in Nursing (Acute Care). The researcher also published the results of his study. The current study forms part of the researcher's doctoral degree and he is supervised by an experienced oncology nurse practitioner and researcher.

HAS THE STUDY RECEIVED ETHICAL APPROVAL?

The research proposal has been approved by the University of the Witwatersrand Research ethics committee. All parts of the study will be conducted according to internationally accepted ethical principles.

WHO CAN YOU CONTACT FOR ADDITIONAL INFORMATION REGARDING THE STUDY?

The primary investigator, Mr. Mohammed Hayek, can be contacted on his mobile phone at 009725685994527 or via e-mail: 1805123@students.wits.ac.za. The study supervisor, Prof JE Maree, can be contacted during office hours at Tel (011) 488 4272/4196 or Lize.maree@wits.ac.za. If you would like to know more about the ethics of the study and should you wish to report complaints / problems, please contact Prof Peter Cleaton-Jones at peter.cleatonjones@wits.ac.za

DECLARATION: CONFLICT OF INTEREST

This study will be funded by the Researcher. No publication prohibitions, conditions or limitations were placed on the researcher.

A FINAL WORD

Your co-operation and participation in the study will be greatly appreciated. Please sign the informed consent below if you agree to participate in the study. In such a case, you will receive a copy of the signed informed consent from the researcher.

ADDENDUM **G**
CANCER PATIENTS INFORMED CONSENT

I hereby confirm that I have been adequately informed by the researcher about the nature, conduct, benefits and risks of the study. I have also received, read and understood the above written information. I am aware that the results of the study will be anonymously processed into a research report. I understand that my participation is voluntary and that I may, at any stage, without prejudice, withdraw my consent and participation in the study. I had sufficient opportunity to ask questions and of my own free will declare myself prepared to participate in the study.

Research participant's name: _____ (Please print)

Research participant's signature: _____

Date: _____

Researcher's name: _____ (Please print)

Researcher's signature: _____

Date: _____

موافقة مسبقة

وأؤكد هنا أن الباحث قد أطلعنا بشكل كاف على طبيعة الدراسة وسلوكها وفوائدها ومخاطرها. وقد تلقيت أيضا، وقرأت وفهمت المعلومات المكتوبة أعلاه. وأنا على علم بأن نتائج الدراسة سوف تتم معالجتها بشكل مجهول في تقرير بحثي. إنني أدرك أن مشاركتي طوعية وأنني قد أسحب موافقتي ومشاركتي في الدراسة في أي مرحلة دون تحيز. كان لي فرصة كافية لطرح الأسئلة وإرادتي الحرة تعلن نفسي على استعداد للمشاركة في الدراسة.

اسم المشارك بالبحث _____(طباعه)

توقيع المشارك بالبحث _____(طباعه)
التاريخ_____

اسم الباحث _____(طباعه)

توقيع الباحث _____(طباعه)
التاريخ_____

ADDENDUM **H**

UNIVERSITY OF THE
WITWATERSRAND
JOHANNESBURG

R14/49 Mr Mohammed Hayek

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M180115

NAME: (Principal Investigator)	Mr Mohammed Hayek
DEPARTMENT:	Nursing Education An Najah National University Hospital, Palestine, West Bank
PROJECT TITLE:	The outcomes of a Support Programme for Caregivers of Cancer Patients
DATE CONSIDERED:	26/01/2018
DECISION:	Approved
CONDITIONS:	South African Human Research Ethics Committees (HRECs) have no standing outside South Africa. Ethics approval is also required from local HRECs in Palestine
SUPERVISOR:	Prof Lize Maree
APPROVED BY:	Professor CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	26/04/2018

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the Third Floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in **January** and will therefore be due in the month of **January** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

DECLARATION:

Adherence to HREC (Medical) Ethics Application Terms and Conditions

I, the undersigned, hereby declare that I have not collected data/ done secondary data analysis or other form of research, prior to obtaining clearance certificate from the HREC (Medical) for study no: M180115

I have read and understood the terms and conditions on section 9 of HREC (Medical) application fo confirm that it is my responsibility to ensure that I have received final HREC (Medical) Clearance b commencing any research.

Mohammed Hayek

Name, Surname and Signature

Student/Staff no if applicable: 1805123

Date: 26 - 2 - 2018

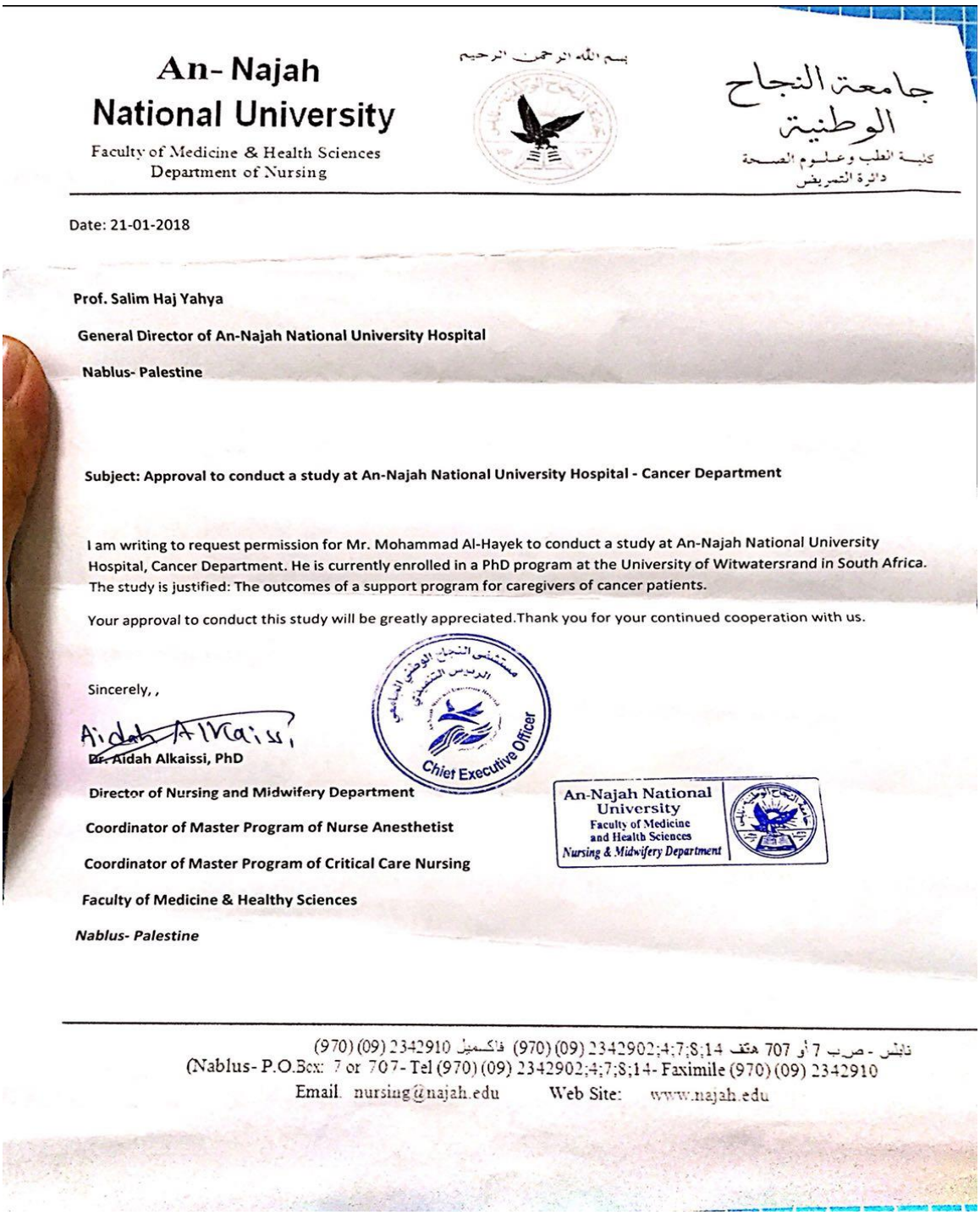
Professor Lize Mavee

Name, Surname and Signature

Supervisor (if applicable)

Date: 5/3/2018

ADDENDUM **I**



An- Najah National University

Faculty of Medicine & Health Sciences
Department of Nursing

بسم الله الرحمن الرحيم

جامعة النجاح الوطنية
كلية الطب وعلوم الصحة
دائرة التمريض

Date: 21-01-2018

Prof. Salim Haj Yahya

General Director of An-Najah National University Hospital

Nablus- Palestine

Subject: Approval to conduct a study at An-Najah National University Hospital - Cancer Department

I am writing to request permission for Mr. Mohammad Al-Hayek to conduct a study at An-Najah National University Hospital, Cancer Department. He is currently enrolled in a PhD program at the University of Witwatersrand in South Africa. The study is justified: The outcomes of a support program for caregivers of cancer patients.

Your approval to conduct this study will be greatly appreciated.Thank you for your continued cooperation with us.

Sincerely, ,

Aidah Alkaissi

Dr. Aidah Alkaissi, PhD

Director of Nursing and Midwifery Department

Coordinator of Master Program of Nurse Anesthetist

Coordinator of Master Program of Critical Care Nursing

Faculty of Medicine & Healthy Sciences

Nablus- Palestine

Chief Executive Officer

An-Najah National University
Faculty of Medicine and Health Sciences
Nursing & Midwifery Department

نابلس - ص.ب 7 أو 707 هاتف (970) (09) 2342902;4;7;8;14 فاكسميل (970) (09) 2342910
(Nablus- P.O.Box: 7 or 707- Tel (970) (09) 2342902;4;7;8;14- Faximile (970) (09) 2342910
Email. nursing@najah.edu Web Site: www.najah.edu

ADDENDUM **J**

1- How old are you? _____

2- Gender

Male	Female	Other

3- Material status

Married	Divorced	Single	Widowed

4- Level of education completed

No formal education	Primary school	High school	Graduate studies	Post graduate studies

5- Employment status

Full time	Part time	Retired	Not employed

6- Relation to cancer patients

Parent	Spouse	Sibling	Child	Friend	Other
					……

7- What kind of cancer does the person you care for suffer from? ----------

8- How long have you been caring for this person? ----------

9- What treatment do they receive?

Chemotherapy	Radiotherapy	Surgery	No anti-cancer therapy

10- Which medication are the person you are caring for using? ----------

1- العمر ----------

2- الجنس

ذكر	انثى	نوع اخر

3- الحاله الاجتماعيه

متزوج/ه	مطلق/ه	اعزب /عزباء	ارمل/ه

4- مستوى الدراسه

لم تلتحق بالدراسه ابدا	المرحله الابتدائيه	المرحله الاعداديه	بكالوريوس	درايات عليا

5- العمل

تعمل بدوام كالمل	تعمل بدوام جزئي	متقاعد	عاطل عن العمل

6- علاقتك مع المريض

اب / ام	زوج / زوجه	اخ / اخت / نسيب / قريب	احد الابناء	صاحب او صديق	غير ذلك

7- ما نوع المرض امرض الذي يعاني منه المريض----------

8- ما هي المده وانت تقدم العنايه للمريض----------

9- ما نوع العلاج الطبي المقدم للمريض (يمكنك الاختيار اكثر من اجابه)

علاج كيماوي	علاج جراحي	علاج اشعاعي	لا شيء

10- اذكر انواع الادويه التي يتناولها المريض----------

والمشرف على الدراسه البروفيسور ليز ماري هذا المحتوى تم انشائه من قبل الباحث

ADDENDUM **K**

capc Center to Advance Palliative Care

Short Form Zarit Burden Interview (ZBI-12)

	"Never" (0)	"Rarely" (1)	"Sometimes" (2)	"Quite frequently" (3)	"Nearly always" (4)
Do you feel…?					
That because of the time you spend with your relative that you don't have enough time for yourself?					
Stressed between caring for your relative and trying to meet other responsibilities (work/family)?					
Angry when you are around your relative?					
That your relative currently affects your relationship with family members or friends in a negative way?					
Strained when you are around your relative?					
That your health has suffered because of your involvement with your relative?					
That you don't have as much privacy as you would like because of your relative?					
That your social life has suffered because you are caring for your relative?					
That you have lost control of your life since your relative's illness?					
Uncertain about what to do about your relative?					
You should be doing more for your relative?					
You could do a better job in caring for your relative?					

→ Short form ZBI-12 validated as screening tool in advanced illness including dementia and cancer
→ Total ZBI-12 score: summation of 12 items (0 to 4 points per item, total score range 0 to 48)
→ Copyrighted, but available for free use by clinicians and for non-funded academic research
→ Suggested guidelines for scoring:
- 0-10: no to mild burden
- 10-20: mild to moderate burden
- >20: high burden

ضغط العناية بالمريض: الأسئلة هذه هي بخصوص علاقتك مع قريبك الذي تعتني به. لكل سؤال يوجد خمس امكانيات أجوبه تبدأ من0 –بالمرة لا وحتى 4- تقريبا دائما. اشر إلى الإجابة الأكثر ملاءمة لإحساسك.

.1 هل تشعر انه بسبب الوقت الذي تقضيه مع قريبك ليس لديك وقت كافي لنفسك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.2 هل تشعر بالصراع والضغط بين القلق على قريبك وبين واجبات اخرى مثل عملك أو عائلتك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.3 هل تشعر انك غاضب عند تواجدك بجوار قريبك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.4 هل تشعر ان قريبك يؤثر على علاقاتك مع ابناء العائلة الاخرين بطريقه سلبيه؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.5 هل تشعر بالتوتر بجوار قريبك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.6 هل تشعر ان صحتك تضررت بعد مشاركتك في عناية قريبك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.7 هل تشعر انه ليس لك خصوصيات بقدر كافٍ بسبب قريبك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.8 هل تشعر ان حياتك الاجتماعية تضررت بسبب قريبك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.9 هل تشعر انك فقدت السيطرة على حياتك منذ مرض قريبك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.10 هل تشعر بعدم الثقة بخصوص العلاج الصحيح لقريبك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.11 هل تشعر انك بحاجه لأن تفعل أكثر من اجل قريبك؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً
.12 هل تشعر انك كنت تستطيع ان تهتم بقريبك بصوره افضل؟	0 بالمرة لا	1 لأوقات متباعدة	2 في بعض الأحيان	3 في أوقات متقاربة	4 تقريبا دائماً

ADDENDUM **L**


Close Reply Reply to All Forward Delete Spam Actions

ePROVIDE™: Your User Agreement - Zarit Burden Interview - 9331

From: eprovide

To: Mohammed Hayek

UA-ZBI-mohammed...-20171207_9331.pdf (42.5 KB) Download | Briefcase | Remove

Dear User,

Thank you for using our online distribution form on https://eprovide.mapi-trust.org.

Please find attached the completed user agreement.

Should you have any questions, please contact us at eprovide@mapi-trust.org.

Best regards,

ePROVIDE™

Online Support for Clinical Outcome Assessments

User agreement

Special Terms

Mapi Research Trust, a non-for-profit organisation subject to the terms of the French law of 1st July 1901, registered in Carpentras under number 453 979 346, whose business address is 27 rue de la Villette, 69003 Lyon, France, hereafter referred to as "MRT" and the User, as defined herein, (each referred to singularly as a "Party" and/or collectively as the "Parties"), do hereby agree to the following User Agreement Special and General Terms:

Mapi Research Trust
PROVIDE™
27 rue de la Villette
69003 Lyon
France
Phone: +33 (0)4 72 13 66 66

Recitals

The User acknowledges that it is subject to these Special Terms and to the General Terms of the Agreement, which are included in Appendix 1 to these Special Terms and fully incorporated herein by reference. Under the Agreement, the Questionnaire referenced herein is licensed, not sold, to the User by MRT for use only in accordance with the terms and conditions defined herein. MRT reserves all rights not expressly granted to the User.

The Parties, in these Special Terms, intend to detail the special conditions of their partnership.

The Parties intend that all capitalized terms in the Special Terms have the same definitions as those given in article 1 of the General Terms included in Appendix 1.

In this respect, the Parties have agreed as follows:

Article 1. Conditions Specific to the User

Section 1.01 Identification of the User

User Name	mohammed hayek
Legal Form	Student
Address	Johannesburg city / south Africa 7 yourk street gouting 0027 Johannesburg
Country	Palestinian Territory, Occupied
Email address	m.hayek@najah.edu
Telephone number	0097256859427

Section 1.02 Identification of the Questionnaire

© Mapi Research Trust. The unauthorized modification and use of any portion of this document is prohibited.

,Dear Mohammed

.I hope this mail finds you well

.As requested attached please find the abridged Arabic version of the Zarit Burden Interview
I'm also attaching an Arabic translation of the Hamilton Depression Scale (Hamd-6). Maybe you can use it as well in your .studies

.Please feel free to use both scales

Good luck with your research

Yaacov

Prof. Yaacov G. Bachner, Ph.D

M.A. Program in Gerontology

Department of Public Health

Faculty of Health Sciences

Ben-Gurion University of the Negev

Beer-Sheva, Israel

Tel: +97286477425 Fax: +97286477635

Cel: 0545492177

bachner@bgu.ac.il

מ: Mohammed Hayek [m.hayek@najah.edu]
נשלח: יום שני 20 נובמבר 2017 09:58
אל: יעקב בכנר
נושא: The abridged Arabic version of the Zarit Burden Interview (ZBI-A)

Dear professor Yaacov G Bachner

.I hope my email finds you very well

Am Mohammed Hayek from Palestine - a Najah National University - Faculty of Medicine and Health .Sciences

I do my Ph.D. at Witwatersrand University in Johannesburg - South Africa

.The title of my Ph.D. will be developing and testing a support programme for caregivers of cancer patients

My professor, Lize Maree and I decide to use the abridged Arabic version of the Zarit Burden Interview (ZBI-A) among other in our study, so can we use your Arabic version of The abridged Arabic version of the Zarit Burden Interview (ZBI-A) published in 2013 (Preliminary assessment of the psychometric properties of the abridged Arabic version of the Zarit Burden Interview among caregivers of cancer patients), if yes can you send ?it back to me

Thank you for understanding

Thank you, in advance

ADDENDUM **M**

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 7 days.

0 = Not at all **2** = Somewhat
1 = A little bit **3** = Quite a bit
4 = Very much

During the past 7 days:

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 sinc	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	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 my 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 my 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 atisfied with the support I get from my 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

ADDENDUM **N**

Dear Dr. Mohammed,
Thanks for your interest in my publication. I would like to inform you that I agree on using the Arabic version of QoL-AD scale I developed, providing that a citation of the reference is ensured in your thesis.
Kindly, find attached Arabic scale as well as the paper of its validation.
Wishing you all the best in your PhD thesis, and if possible I will be happy to receive a copy of your thesis after publication.

Regards,
Dr. Zeinab Shata
Associate Professor of Mental Health
Alexandria University, Egypt
e-mail: zeinab.shata@yahoo.com
On Sunday, November 26, 2017 04:09:36 PM +03, Mohammed Hayek <m.hayek@najah.edu> wrote:

Dear professor Zeinab Nazeeh Shata

I hope my email finds you very well

Am Mohammed Hayek from Palestine - An Najah National University - Faculty of Medicine and Health Sciences

I do my Ph.D. at Witwatersrand University in Johannesburg - South Africa

.The title of my Ph.D. will be developing and testing a support programme for caregivers of cancer patients

My professor, Lize Maree and I decide to use the Arabic version of Quality of Life Index, among other .in our study

So can we use your Arabic version of Quality of Life Index published in 2015 (Reliability and validity of (Arabic version of quality of life Alzheimer disease in Alexandria, Egypt
if yes can you please send it back

Thank you for understanding
Thank you, in advance

Mohammed F. A. Hayek
RN, CNE, CNS, HP, Ph.D. Candidate
Acute Cases Specialty
Teaching Staff
Faculty of Medicine and Health Sciences
An Najah National University
New Campus|Building: 17|Office: 2060
Phone: +970 9 2345113 ext. 88-2754
Home : +970 9 2370924
Fax: +970 9 2342910
Mobile: +970 568594527
Email: m.hayek@najah.edu

ADDENDUM **O**

الجامعة الأميريكية في بيروت

Arabic Brief Pain Inventory (Short Form)

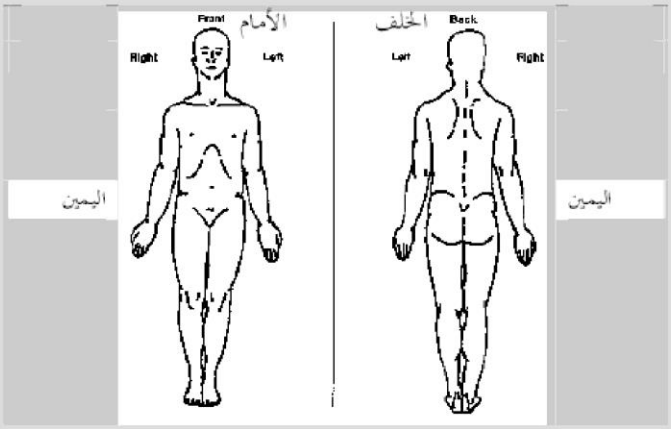
Patient Initials: _____ **Date:** _____

Patient No. _____ **Time:** _____

١. خلال حياتنا ، نعاني من بعض الآلام بين حين وآخر (كالصداع البسيط أو التواء عضلة أو ألم الأسنان).
هل عانيت خلال الأسبوع الماضي من ألم يختلف من هذه الأنواع من الآلام العادية؟

١. نعم ٢. لا

٢. على الرسم التالي, **حدد مواضعَ الألم** الذي تشعر به. ضع علامة X في الموضع الأشدّ ألماً.



٣. قيّم ألمك بوضع دائرة حول الرّقم الذي يصف ألمك في **أسوأ** حالاته خلال الأربع والعشرين ساعة الماضية.

٠ ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠

لا أشعر بألم **أسوء ما يمكن تصوره من ألم**

٤. من فضلك, قيّم ألمك بوضع دائرة حول الرّقم الذي يصف ألمك في **أدنى** حالاته خلال الأربع والعشرين ساعة الماضية.

٠ ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠

لا أشعر بألم **أسوء ما يمكن تصوره من ألم**

٥. قيّم ألمك بوضع دائرة حول الرّقم الذي يصف **معدّل الألم** الذّي تشعر به **إجمالاً**.

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا أشعر بألم										**أسوء ما يمكن تصوره من ألم**

٦. حَدِّد درجة ألمك بوضع دائرة حول الرقم الذي يصف درجة ألمك **الآن**.

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا أشعر بألم										**أسوء ما يمكن تصوره من ألم**

٧. ما هي أنواع العلاجات أو الأدوية التي تتلقاها لمعالجة ألمك؟

_____

٨. خلال الأربع والعشرين ساعة الماضية, كم كانت **درجة الأرتياح من الألم** لديك بعد تناولك الأدوية أو العلاجات للألم؟ من فضلك, ضع دائرة حول النسبة المئوية التي تصف مدى **ارتياحك**.

٪ ٠	٪ ١٠	٪ ٢٠	٪ ٣٠	٪ ٤٠	٪ ٥٠	٪ ٦٠	٪ ٧٠	٪ ٨٠	٪ ٩٠	٪ ١٠٠
لم يحصل أي ارتياح										ارتياح كامل

٩. ضع دائرة حول الرقم الذي يصف مدى التأثير السلبي أو العرقلة التي سبَّبها لك الألم خلال الأربع والعشرين ساعة الماضية في النواحي التالية:

أ. نشاطك العام

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا عرقلة										**عرقلة كاملة**

ب. مزاجك

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا عرقلة										**عرقلة كاملة**

ج. قدرتك على المشي

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا عرقلة										**عرقلة كاملة**

د. العمل العادي (يشمل ذلك العمل خارج المنزل و العمل المنزلي)

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا عرقلة										عرقلة كاملة

ه. علاقاتك مع الآخرين

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا عرقلة										عرقلة كاملة

و. نومك

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا عرقلة										عرقلة كاملة

ز. إستمتاعك بالحياة

٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠
لا عرقلة										عرقلة كاملة

مقياس الألم البصري (Visual Analog Scale)

الخط أدناه مقياس يمثّل درجة الألم الذّي قد تشعر به.

من فضلك, ضع علامة | على الخط أدناه محدِّداً المكان الذّي يصف درجة ألمك **الآن**.

لا يوجد ألم — **أسوء ألم يمكن تصوره**

نشكرك لملئ هذه الإستمارة!

1903

Date: ☐☐ / ☐☐ / ☐☐
(month) (day) (year)

Subject's Initials : _____

Study Subject #: ☐☐☐☐

Study Name: _____

Protocol #: _____

PI: _____

Revision: 07/01/05

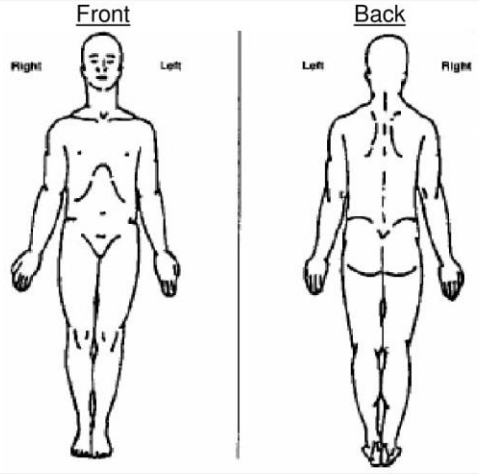
PLEASE USE BLACK INK PEN

Brief Pain Inventory (Short Form)

1. Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?

☐ Yes ☐ No

2. On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.



3. Please rate your pain by marking the box beside the number that best describes your pain at its worst in the last 24 hours.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

No Pain — Pain As Bad As You Can Imagine

4. Please rate your pain by marking the box beside the number that best describes your pain at its least in the last 24 hours.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

No Pain — Pain As Bad As You Can Imagine

5. Please rate your pain by marking the box beside the number that best describes your pain on the average.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

No Pain — Pain As Bad As You Can Imagine

6. Please rate your pain by marking the box beside the number that tells how much pain you have right now.

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

No Pain — Pain As Bad As You Can Imagine

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Pain Research Group
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1903

Date: (month) / (day) / (year)

Subject's Initials : _____

Study Subject #:

Study Name: _____

Protocol #: _____

PI: _____

Revision: 07/01/05

PLEASE USE BLACK INK PEN

7. What treatments or medications are you receiving for your pain?

8. In the last 24 hours, how much relief have pain treatments or medications provided? Please mark the box below the percentage that most shows how much relief you have received.

0%	10%	20%	30%	40%	50%	60%	70%	80%	90%	100%
☐ No Relief	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐ Complete Relief

9. Mark the box beside the number that describes how, during the past 24 hours, pain has interfered with your:

A. General Activity

☐ 0 Does Not Interfere ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 Completely Interferes

B. Mood

☐ 0 Does Not Interfere ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 Completely Interferes

C. Walking ability

☐ 0 Does Not Interfere ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 Completely Interferes

D. Normal Work (includes both work outside the home and housework)

☐ 0 Does Not Interfere ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 Completely Interferes

E. Relations with other people

☐ 0 Does Not Interfere ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 Completely Interferes

F. Sleep

☐ 0 Does Not Interfere ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 Completely Interferes

G. Enjoyment of life

☐ 0 Does Not Interfere ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 Completely Interferes

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ADDENDUM **P**

Hi Mohammed,

Please find attached the Arabic BPI.

Good Luck!

Best,

Suha

Suha Ballout, PhD, RN

Assistant Professor
College of Nursing and Health Sciences
University of Massachusetts Boston

100 Morrissey Blvd.
Boston, MA 02125-3393
E-mail: suha.ballout@umb.edu
Mobile: 305-505-8672

http://www.umb.edu/academics/cnhs
https://www.facebook.com/UMassBostonCollegeofNursingandHealthSciences

---

From: Samar Noureddine <sn00@aub.edu.lb>
Sent: Monday, November 20, 2017 4:45:29 AM
To: Suha Ballout
Subject: FW: Arabic Brief Pain Inventory

Dear Suha,

How are you doing? Can you answer the email below?

Samar Noureddine, PhD, RN, FAHA, FAAN
Professor
Assistant Director for Academic Affairs
Hariri School of Nursing
American University of Beirut
Maamari Street
Beirut 1107 2020, Lebanon
Tel: 961-1350000
Fax: 961-1744476
Email: sn00@aub.edu.lb
Adjunct faculty: Johns Hopkins University School of Nursing
President, nurses' Chapter, World wide Alumni Association of the American University of Beirut (WAAAUB)

From: Mohammed Hayek [mailto:m.hayek@najah.edu]
Sent: Monday, November 20, 2017 11:23 AM
To: Samar Noureddine <sn00@aub.edu.lb>
Subject: Arabic Brief Pain Inventory

ADDENDUM **Q**

ARABIC



EORTC QLQ-C15-PAL (Version 3)

نحن مهتمون بمعرفة بعض المعلومات عنك و عن صحتك. الرجاء الإجابة بنفسك عن كل من الأسئلة التالية و ذلك بوضع دائرة حول الإجابة الأكثر ملائمة لك. لا يوجد جواب "صحيح" أو "خطأ". جميع المعلومات ستعامل بسرية تامة.

الرجاء إدخال الحروف الأولى من اسمك: |_|_|_|_|

تاريخ ميلادك (اليوم، الشهر، السنة): |_|_|_|_|_|_|_|_|

تاريخ اليوم (اليوم، الشهر، السنة): |_|_|_|_|_|_|_|_|

	إطلاقاً	قليلا	بما فيه الكفاية	كثيرًا جدًا
1. هل لديك صعوبة بالمشي لمسافة قصيرة خارج البيت؟	1	2	3	4
2. هل تحتاج للبقاء في السرير أو الكرسي خلال اليوم؟	1	2	3	4
3. هل تحتاج للمساعدة في الأكل أو ارتداء الملابس أو الاغتسال أو استخدام المرحاض؟	1	2	3	4

خلال الأسبوع الماضي :	إطلاقاً	قليلا	بما فيه الكفاية	كثيرًا جدًا
4. هل شعرت بضيق بالنفس؟	1	2	3	4
5. هل شعرت بأي ألم؟	1	2	3	4
6. هل عانيت من مشاكل في النوم (أرق/ صعوبة في النوم/ نوم متقطع)؟	1	2	3	4
7. هل شعرت بالضعف؟	1	2	3	4
8. هل فقدت شهيتك للطعام (القدرة على الاكل)؟	1	2	3	4
9. هل شعرت بالغثيان (اللعيان)؟	1	2	3	4
10. هل عانيت من إمساك؟	1	2	3	4

انتقل إلى الصفحة التالية من فضلك

خلال الأسبوع الماضي:	إطلاقاً	قليلا	بما فيه الكفاية	كثيرا جدا
11. هل كنت متعبًا؟	1	2	3	4
12. هل عانيت من ألم أثّر سلبيًا على نشاطاتك اليومية؟	1	2	3	4
13. هل شعرت بالتوتر؟	1	2	3	4
14. هل شعرت بإكتئاب ؟	1	2	3	4

في السؤال التالي الرجاء الإشارة بدائرة حول الأرقام بين 1 - 7 الاكثر ملائمة لك

15.كيف تُقيّم /جودة حياتك عمومًا/ مستوى حياتك عمومًا خلال الأسبوع الماضي؟

1	2	3	4	5	6	7
سيء جدا						ممتاز

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EORTC QLQ-C15-PAL (version 1)

We are interested in some things about you and your health. Please answer all of the questions yourself by circling the number that best applies to you. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

Please fill in your initials: |_|_|_|
Your birthdate (Day, Month, Year): |_|_|_|_|_|_|
Today's date (Day, Month, Year): |_|_|_|_|_|_|

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
2. Do you need to stay in bed or a chair during the day?	1	2	3	4
3. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
4. Were you short of breath?	1	2	3	4
5. Have you had pain?	1	2	3	4
6. Have you had trouble sleeping?	1	2	3	4
7. Have you felt weak?	1	2	3	4
8. Have you lacked appetite?	1	2	3	4
9. Have you felt nauseated?	1	2	3	4

Please go on to the next page

During the past week:	**Not at All**	**A Little**	**Quite a Bit**	**Very Much**
10. Have you been constipated?	1	2	3	4
11. Were you tired?	1	2	3	4
12. Did pain interfere with your daily activities?	1	2	3	4
13. Did you feel tense?	1	2	3	4
14. Did you feel depressed?	1	2	3	4

For the following question please circle the number between 1 and 7 that best applies to you

15. How would you rate your overall quality of life during the past week?

1	2	3	4	5	6	7
Very poor						Excellent

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ADDENDUM **R**

Dear Sir/Madam,

Please find below the links where you can download the documents you requested.

Best regards,

Your data:

Title: mr
Firstname: mohammed
Lastname: hayek
Hospital/Institution: an najah national university
Address: nablus city
County/State: palesine
Postal Code: 00972
Country: West Bank
Phone: 00972568594527
Fax:
Email: m.hayek@najah.edu
Protocol: EORTC QLQ-C15-PAL

Documents requested:

QLQ-C15-PAL Core Questionnaire in Arabic
QLQ-C15-PAL Core Questionnaire in English
QLQ-C15 Scoring Manual
Reference Values: All cancer sites

URLs:

http://www.eortc.be/qol/files/C15/QLQ-C15-PAL%20Arabic.pdf
http://www.eortc.be/qol/files/C15/QLQ-C15-PAL%20English.pdf
http://www.eortc.be/qol/files/SCManualQLQ-C15-PAL.pdf
http://www.eortc.be/qol/files/RV/RV02_all_cancers.pdf

If the links don't work, you can copy and paste the entire URL (so with .pdf included) into your browser and that should work.If you are having other technical difficulties please contact us by email: qlqc30@eortc.be

Dear Mohammed,

Thank you very much for your email. Yes, sure you can use it.

Do you need me to send you the translated tool or do you already have it in our article?

Best wishes,

Alia

Sent from my iPhone

On Nov 6, 2017, at 10:41 PM, Mohammed Hayek <m.hayek@najah.edu> wrote:

> Dear Dr. Alia Alawneh
>
> I hope my email finds you very well.
>
> Am Mohammed Hayek from Palestine - a Najah National University - Faculty of Medicine and Health Sciences.
>
> I do my Ph.D. at Witwatersrand University in Johannesburg - South Africa
>
> The title of my Ph.D. will be developing and testing a supportive educative programme for caregivers of cancer patients in Palestine.
>
> My professor, Lize Maree and I decide to use the Arabic version of the EORTC QLQ-C15- PAL among other in our study, so can we use yours validated one in (Psychometric properties of the Arabic version of EORTC QLQ-C15-PAL among cancer patients in Jordan) 2016, if yes, can you send back to me to use in my research.
>
> Thank you, in advance

Mohammed F. A. Hayek
BsN, RN, CNE, CNS, HP
Acute Cases Specialty
Teaching Staff
Faculty of Medicine and Health Sciences
Nursing & Midwifery Department
An Najah National University
New Campus|Building: 17|Office: 2060
Phone: +970 9 2345113 ext. 88-2754
Home : +970 9 2370924
Fax: +970 9 2342910
Mobile: +970 568594527
Email: m.hayek@najah.edu

ADDENDUM **S**

الحروف الاولى من اسم المشترك_____ **التاريخ** _____

التعليمات: وضعنا أدناه 30 عارض. إذا حدث انك إشتكيت خلال **<u>الأسبوع الماضي</u>** من احداها، أخبرنا كم مرة أصبت به، كم كانت حدّته، والى اي حدٍّ <u>أزعجك أو أوجعك</u>، وهل تلقيت علاجاً لهذا العارض وكم كان هذا العلاج ناجحاً.

خلال **<u>الأسبوع الماضي</u>**: هل أصبت بأي من الحالات التالية؟	لم أصب بهذا العارض	إذا نعم، كم مرة أصبت به؟				إذا نعم، كم كانت حدة العارض؟				إذا نعم، كم أزعجك العارض؟				هل خضعت لعلاج مخصص للسيطرة على هذا العارض؟		إذا خضعت لعلاج، إلى أي مدى كان العلاج فعالاً في السيطرة على هذه العوارض؟		
		نادراً	أحياناً	تكراراً	تقريباً باستمرار	خفيف	متوسط	حاد	حاد جداً	أبداً	قليلاً جداً	بعض الشيء	كثيراً	كثيراً جداً	نعم	لا	لم ينجح	نجاح بسيط	نجاح
1. صعوبة في التركيز		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	3	2	1
2. الشعور بالتوتر		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	3	2	1
3. الشعور بالحزن		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	3	2	1
4. القلق		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	3	2	1
1. "أنا لا أشبه نفسي" 2.		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	3	2	1
6. قلة النشاط		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	3	2	1
7. خدر/وخز في اليدين/القدمين		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	3	2	1

| | | |

خلال **الأسبوع الماضي**: هل أصبت بأي من الحالات التالية؟	لم أصب بهذا العارض	إذا نعم، كم مرة أصبت به؟				إذا نعم، كم كانت حدة العارض؟				إذا نعم، كم أزعجك العارض؟					هل خضعت لعلاج مخصص للسيطرة على هذا العارض؟		إذا خضعت لعلاج، إلى أي مدى كان العلاج فعالاً في السيطرة على هذه العوارض؟		
		نادراً	أحياناً	تكراراً	تقريباً باستمرار	خفيف	متوسط	حاد	حاد جداً	أبداً	قليلاً جداً	بعض الشيء	كثيراً	كثيراً جداً	نعم	لا	بنجاح	بنجاح بسيط	لم ينجح
22. الحكاك		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3
23. تقرح الفم		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3
24. تساقط الشعر		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3
25. تغيّر في الجلد		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3
26. الشعور بالانتفاخ		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3
27. مشاكل في التبوّل		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3
28. إسهال		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3
29. إمساك		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3
30. مشاكل في الرغبة أو النشاط الجنسي		1	2	3	4	1	2	3	4	0	1	2	3	4	1	2	1	2	3

	إذا نعم، كم أزعجك العارض؟					هل خضعت لعلاج مخصص للسيطرة على هذا العارض؟		إذا خضعت لعلاج، إلى أي مدى كان العلاج فعالاً في السيطرة على هذه العوارض؟		
	لا يزعجني على الإطلاق	يزعجني إلى حد ما	يزعجني إلى حد كبير			لا	نعم	لا يساعد على الإطلاق	يساعد إلى حد ما	يساعد إلى حد كبير
إذا أصبت بأي حالة أخرى خلال الأسبوع الماضي، من فضلك دوّن أدناه كم أزعجتك أو آلمتك هذه الحالة.										
عارض:	0	1	2	3	4	1	2	1	2	3
عارض:	0	1	2	3	4	1	2	1	2	3
عارض:	0	1	2	3	4	1	2	1	2	3

MEMORIAL SYMPTOM ASSESSMENT SCALE

Name Date

Section 1

Instructions: We have listed 24 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how OFTEN you had it, how SEVERE it was usually and how much it DISTRESSED or BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."

DURING THE PAST WEEK Did you have any of the following symptoms?	DID NOT HAVE	IF YES How OFTEN did you have it?				IF YES How SEVERE was it usually				IF YES How much did it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not at all	A Little Bit	Somewhat	Quite a Bit	Very Much
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness/tingling in hands/feet		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4

Section 2										
INSTRUCTIONS: We have listed 8 symptoms below. Read each one carefully. If you have had the symptom during this past week, let us know how SEVERE it was usually and how much it DISTRESSED or BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE."										
DURING THE PAST WEEK, Did you have any of the following symptoms?	DID NOT HAVE	IF YES How SEVERE was it usually?				IF YES How much did it DISTRESS or BOTHER you?				
		Slight	Moderate	Severe	Very Severe	Not at all	A little bit	Somewhat	Quite a bit	Very much
Mouth sores		1	2	3	4	0	1	2	3	4
Change in the way food tastes		1	2	3	4	0	1	2	3	4
Weight loss		1	2	3	4	0	1	2	3	4
Hair loss		1	2	3	4	0	1	2	3	4
Constipation		1	2	3	4	0	1	2	3	4
Swelling of arms or legs		1	2	3	4	0	1	2	3	4
"I don't look like myself"		1	2	3	4	0	1	2	3	4
Changes in skin		1	2	3	4	0	1	2	3	4
IF YOU HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND INDICATE HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOTHERED YOU.										
Other:						0	1	2	3	4
Other:						0	1	2	3	4
Other:						0	1	2	3	4

ADDENDUM **T**

Here it is. Good luck

Dr. Huda Abu-Saad Huijer RN, PhD, FEANS, FAAN
Professor of Nursing Science
Director Hariri School of Nursing
American University of Beirut
Tel: +961-1-374374 extension 5952/3
Fax : +961-1-744476
E-Mail: huda.huijer@aub.edu.lb
http:/www.aub.edu.lb/~webson/

American University of Beirut
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From: Mohammed Hayek [mailto:m.hayek@najah.edu]
Sent: Sunday, November 05, 2017 12:25 PM
To: Huda Huijer Abu-Saad <hh35@aub.edu.lb>
Subject: Memorial Symptoms Assessment Scale

Dear Dr. Huda

I hope my email finds you very well.

Am Mohammed Hayek from Palestine - a Najah National University - Faculty of Medicine and Health Sciences.

I do my Ph.D. at Witwatersrand University in Johannesburg - South Africa

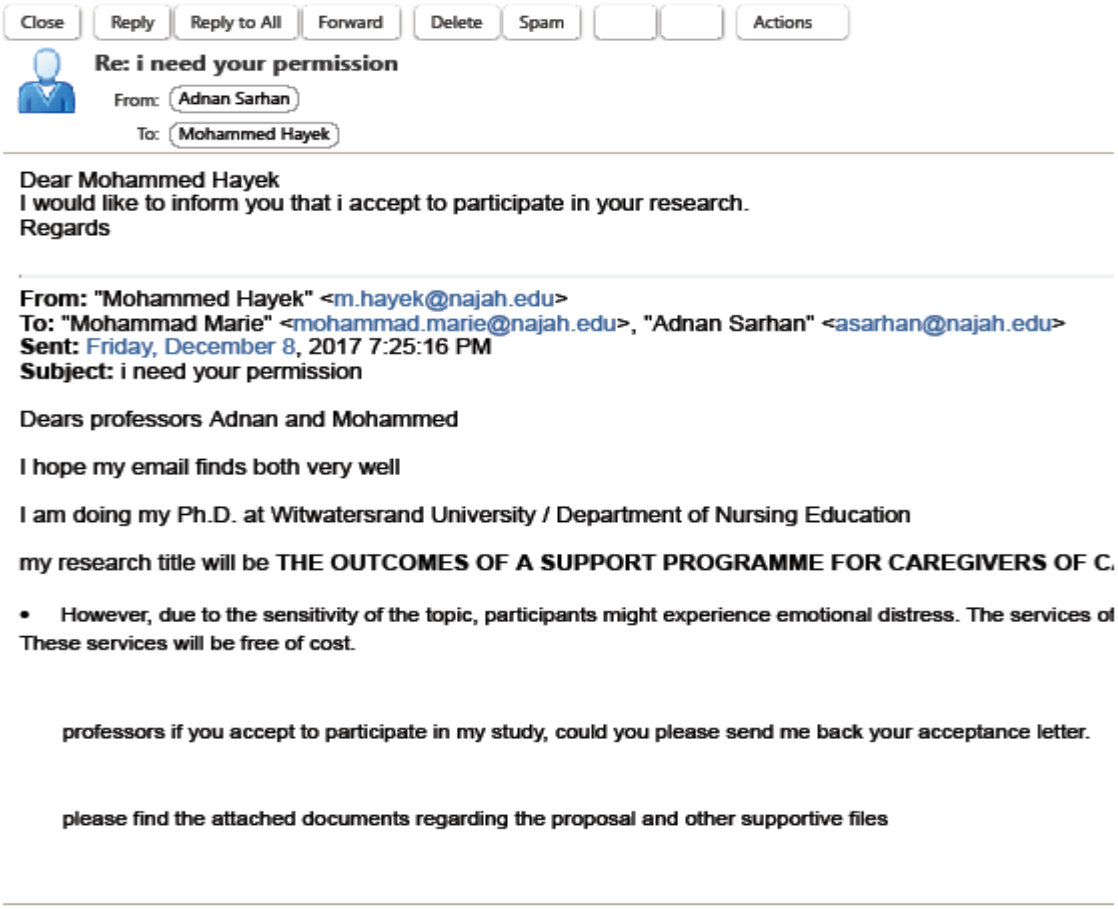
The title of my Ph.D. will be developing and testing a supportive educative programme for caregivers of cancer patients in Palestine.

My professor, Lize Maree and I decide to use the Memorial Symptoms Assessment Scale among other in our study, so can we use your Arabic version of Memorial Symptoms Assessment Scale, if yes from where can I download to be used.

Thank you, in advance

Mohammed F. A. Hayek
RN, CNE, CNS, HP, Ph.D. Candidate

ADDENDUM **U**



Close | Reply | Reply to All | Forward | Delete | Spam | Actions

Re: i need your permission

From: Adnan Sarhan

To: Mohammed Hayek

Dear Mohammed Hayek
I would like to inform you that i accept to participate in your research.
Regards

From: "Mohammed Hayek" <m.hayek@najah.edu>
To: "Mohammad Marie" <mohammad.marie@najah.edu>, "Adnan Sarhan" <asarhan@najah.edu>
Sent: Friday, December 8, 2017 7:25:16 PM
Subject: i need your permission

Dears professors Adnan and Mohammed

I hope my email finds both very well

I am doing my Ph.D. at Witwatersrand University / Department of Nursing Education

my research title will be **THE OUTCOMES OF A SUPPORT PROGRAMME FOR CAREGIVERS OF C.**

- However, due to the sensitivity of the topic, participants might experience emotional distress. The services of

These services will be free of cost.

professors if you accept to participate in my study, could you please send me back your acceptance letter.

please find the attached documents regarding the proposal and other supportive files

Dear Mr Hayek

It seems ur are doing very important and interesting research.
Please to let you know that I am happy to help and please to consider this as formal confirmation that It will be my pleasure to offer help as mental health consultant at Annajah National University Hospital.

I wish you the best with your study

Best Regards

Dr. Mohammad Marie RN, BSc (Hons), MSc, CMHP, M.H. Consultant, PhD

Assistant professor | Department of Bio-Medical Sciences | Faculty of Medicine and Health sciences | An-najah National University
Nablus city | West Bank | Palestine | PO.Box 7
www.najah.edu
Personal page :http://staff.najah.edu/mmarie
Facebook page: Mental Health Clinic عيادة الصحة النفسية للدكتور محمد مرعي
Mobile: 00972 (0) 595960100

UK-Address: Cardiff University -School of Health Care Sciences- 12th Floor, East Gate House -35-43 Newport Road- Cardiff CF24 0AB- United Kingdom
Skype: mohammad.marie772
http://www.cardiff.ac.uk/sonms/contactsandpeople/postgraduatestudents/marie-mohammad-mr-overview_new.html

---

From: "Mohammed Hayek" <m.hayek@najah.edu>
To: "Mohammad Marie" <m.marie@najah.edu>
Sent: Friday, December 8, 2017 7:35:32 PM
Subject: Re: i need your permission

Dears professors Adnan and Mohammed

I hope my email finds both very well

I am doing my Ph.D. at Witwatersrand University / Department of Nursing Education

my research title will be **THE OUTCOMES OF A SUPPORT PROGRAMME FOR CAREGIVERS OF CANCER PATIENTS**

- However, due to the sensitivity of the topic, participants might experience emotional distress. The services of your professors as a counseling for participants who might become emotionally distressed. These services will be free of cost.

professors if you accept to participate in my study, could you please send me back your acceptance letter.

APPENDIX V

An-Najah
National University
Faculty of medicine
&Health Sciences
Department of Graduate
Studies

جامعة النجاح
الوطنية
كلية الطب وعلوم الصحة
دائرة الدراسات العليا

IRB Approval Letter

Study Title:

The Outcomes of a Support Program For Caregivers Of Cancer Patients

Submitted by:

Mohammed Hayek, Lize.Maree

Date Reviewed:

17 December, 2017

Date Approved:

27th December, 2017

Your Study titled "**The Outcomes of a Support Program For Caregivers Of Cancer Patients**" with achieved number (20)September 2017 was reviewed by An-Najah National University IRB committee and was approved **28th December, 2017**

Hasan Fitian, MD

IRB

IRB Committee Chairman

An-Najah National University

(970) (09) 2342910 تلكس || (970) (09)2342902/4/7/8/14 هاتف 707 ص.ب 7 أو 707 نابلس - فلسطين

Nablus - P.O Box 7 or 707 | Tel (970) (09) 2342902/4/7/8/14 | Facsimile (970) (09) 2344910 | E-mail : hqs@najah.edu

APPENDIX W

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

Category of study designs	Methodological quality criteria	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. Is the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5 Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

2

ADDENDUM **X**

Responses of the expert panel group in validation of the support programme

- The oncologist (head of oncology department with more than 15 years of experience with oncology patients, he got his speciality from UK since 1995) says “you have to be careful about the time you give for the participant, because they are coming from very long distances and they are tired and please omit any things related to sexual intercourse, as may they refuse to continue in the research because they refuse to speak on this specific issues and finally, if the patient does not know about his disease don’t tell him/her, that’s mean you have to be sure that you speak with family if their patient know about he/she diagnose”. The score of the self-design scoring sheet for the oncologist (7 question – 7 agree).
- The first oncology nurse (High diploma of oncology nursing from Bethlehem university since 2014 with 14 years of experiance) says” as the oncologist says, I prefer to remove the sexual issues and please speak with patients and their caregivers while they not receiving the treatments” as well as changing the terminology to lay language or to include simple explanations. The score of the self-design scoring sheet for the Oncology nurse (1) (7 question – 7 agree).
- The second oncology nurse (Bachelor degree of nursing with 10 years of experience) says” everything is good and he offer if the researcher need for research assistance”. The score of the self-design scoring sheet for the Oncology nurse (2) (7 question – 7 agree).
- The third oncology nurse (Bachelor degree of nursing with 9 years of experience) says” the time is too much to meet the family in hospital if you can meet them also at homes and please if you can our culture in the programme like Holy Quran reading and listening ”. The score of the self-design scoring sheet for the Oncology nurse (3) (7 question – 7 agree).
- The fourth oncology nurse (master degree of oncology nursing with 6 years of experience) says” everything is good but you can translate the programme to Arabic”. The score of the self-design scoring sheet for the Oncology nurse (4) (7 question – 7 agree).

- Social worker with bachelor degree and experience larger than 15 years, says" focus on the end of life support, encourage the patient and the caregivers to visit the social worker in need and please show them the location of health clinics of social workers and mental health specialist". The score of the self-design scoring sheet for the social worker (7 question – 7 agree). -

Gill Smithies

Proofreading & Language Editing Services

59, Lewis Drive, Amanzimtoti, 4126, Kwazulu Natal

Cell: 071 352 5410 E-mail: g-tech@mweb.co.za

Work Certificate

To	Prof L. Maree, RN DCUR (Pret)
Address	Wits Dept of Nursing Education
Date	19/03/2020
Subject	Thesis: A SUPPORT PROGRAMME FOR CAREGIVERS OF CANCER PATIENTS IN THE PALESTINIAN CONTEXT.
Ref	LM/GS/071

I, Gill Smithies, certify that I have proofed the following for language, grammar and style,

Thesis: A SUPPORT PROGRAMME FOR CAREGIVERS OF CANCER PATIENTS IN THE PALESTINIAN CONTEXT.

To the standard as required by Wits Dept. of Nursing Education.

Gill Smithies