

Effect of Cancer Patients' Activity Level and Psychosocial Factors on Caregivers' Quality of Life

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DECLARATION

I, C Vanlalhrui, hereby declare that this thesis entitled “*Effect of Cancer Patients’ Activity Level and Psychosocial Factors on Caregivers’ Quality of Life*” submitted by me under the guidance and supervision of Dr. G. Padmaja is a bonafide research work which is free from plagiarism. I also declare that it has not been submitted previously in part or in full to this University or Institution for the award of any degree or diploma. I hereby agree that my thesis can be deposited in Shodganga/INFLIBNET.

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Further, the student has the following publications before submission of the thesis for adjudication and has produced evidence for the same in the form of the reprint in the relevant area of his research.

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ABSTRACT

Cancer as a disease affects the lives of millions across the globe. It is now clear that the cause of cancer is not due to one single event or factors but is multifactorial. In India, breast cancer is the most common cancer among women and is also the leading cause of death. Among men in India, lip, oral cavity cancer is the most common cancer. Head and neck cancer accounted for 30% of all cancers among males. The outcome of a cancer diagnosis can be atrocious. For patients diagnosed with breast cancer (BC) and head and neck cancer (HNC), the physical disfigurement as a result of the cancer treatment can be enormous. It can have a negative impact on the patients' psychological, physical, and social functioning. Cancer patients require assistance and caregiving at some point during their illness trajectory. The persons who assumes the role of caregiving are often family members who are underprepared for the task they need to carry out as caregivers. Hence, these family caregivers as a result of the physical and emotional assistance that they provide to their loved ones often experience negative psychological states (distress, depression, anxiety, and somatization). The upheavals may result in poor quality of life. During the cancer illness trajectory, interpersonal relationship which is open and supportive between patients and their caregivers plays an important role in reducing the negative psychological states and thus resulting in a good quality of life. The present study has the following objectives: 1) To assess the level of psychological states and perception of the interpersonal relationship among cancer patients (BC & HNC) and their family caregivers and assess the quality of life of family caregivers 2) To find out the differences in the levels of psychological states, interpersonal relationship, and quality of life among caregivers, categorized on the basis of patients' activity levels 3) To find out the agreement or disagreement in perception of the interpersonal relationship

between cancer patients (BC & HNC) and their family caregivers 4) To find out indicators of family caregivers' quality of life 5) To categorize family caregivers of cancer patients (BC & HNC) based on their levels of quality of life and to examine the differences in indicators of their quality of life. The study used between-groups design and included 248 pairs of cancer patients (breast cancer and head and neck cancer) and their family caregivers. Eastern Cooperative Oncology Group Performance Status was administered to the patients. Cancer-Specific Interpersonal Relationship- Form A and Form B and The Four-dimensional Symptoms Questionnaire were administered to both patients and their caregivers. Caregivers' quality of life was assessed using Caregivers Quality of Life- Cancer. Data were analysed using IBM SPSS and MATLAB programming. The results of the present study showed that patients had a higher mean score in psychological states such as distress, depression, anxiety, somatization than their caregivers. However, patients perceived a higher overall interpersonal relationship between them and their caregivers. The result of one-way ANOVA showed significant differences in distress and mutual communication among the three groups of caregivers based on the patients' activity level. The result of feature analysis showed disagreement between patients and their caregivers in their perception of their interpersonal relationship. The result of the hierarchical regression analysis showed that demographic details, specific dimensions of psychological states, and the interpersonal relationship were the predictors of caregivers' quality of life. Based on their quality of life caregivers were categorized into three groups and significant differences were found on dimensions of interpersonal relationship and psychological states. The present study proposed a SMILE model to address the psychological needs, improvement in interpersonal

relationship and thus enhance the quality of life of both patients and their caregivers.

Limitations of the study and future directions were also discussed in the study.

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ABBREVIATIONS

4DSQ	: Four-Dimensional Symptom Questionnaire
ACS	: American Cancer Society
ANOVA	: Analysis of Variance
BC	: Breast Cancer
CANSIRS	: Cancer Specific Interpersonal Relationship Scale
CHD	: Coronary Heart Disease
CQOLC	: Caregiver Quality of Life- Cancer
CT	: Computerized Tomography
DSM	: Diagnostic and Statistical Manual
EBV	: Epstein- Barr Virus
ECOGP	: Eastern Cooperative Oncology Group Performance Status
FNAC	: Fine Needle Aspiration Cytology
GLOBOCAN	: Global Cancer Incidence, Mortality and Prevalence
HADS	: Hospital Anxiety and Depression Scale
HBCRs	: Hospital Based Cancer Registry
HNC	: Head and Neck Cancer
HPV	: Human Papilloma Virus
HRQOL	: Health Related Quality of Life
IARC	: International Agency for Research on Cancer
MATLAB	: Matrix Laboratory
MRI	: Magnetic Resonance Imaging
NCCN	: National Comprehensive Cancer Network
NCDIR	: National Centre for Disease Informatics and Research
NCRP	: National Cancer Registry Programme
PBCRs	: Population Based Cancer Registry
PET	: Positron Emission Tomography
QoL	: Quality of Life
WHO	: World Health Organization

CHAPTER I

INTRODUCTION

Cancer as a disease affects the lives of millions across the globe. Globally, it was reported to be the second leading cause of death in the year 2015; out of which 70% of deaths by cancer occur in low-income and middle-income countries (World Health Organization, 2017). In the fifth Century B.C., Hippocrates coined the term ‘cancer’. He coined it to describe group of diseases which grows on tissue and spread throughout the body unrestrained.

Cancer is a disease in which abnormal cells multiply in an uncontrolled fashion and spread through the body. Cancer cells can arise from different tissues and organs (Kliensmith, 2006). As a result, there are more than hundred types of cancer described, whose properties and treatment are different (Pardee & Stein, 2009). Annually ten million cases of cancer are diagnosed worldwide, and by 2020, it is projected that the number of new cases will increase to 20 million. In just the past 50 years an individual’s chance of developing cancer in his/her lifetime has increased multifold. An individual’s risk for developing cancer depends on many factors such as genetic inheritance, background, smoking behavior and diet. However, it is now clear that the cause of cancer is not due to one single event but is multifactorial. Though the rate of developing cancer in the past 50 years had increased, there is also steady rise in the survival rate in the past 20 years (Spence & Johnson, 2001).

Based on the area of which it originates cancer is broadly classified. Carcinoma cancer arises from epithelial cells of the body and it forms covering layers over the external and internal body surface. A type of cancer called adenocarcinoma arises from

glandular tissue, Sarcoma originates in supporting tissues (bone, cartilage), Myeloma arises from bone marrow. Blastoma is cancer that arises from embryonic tissue of organs; Leukemia arises from tissue that forms blood cells and lymphoma arises from lymphatic tissue. Out of all cancers, cancer of the epithelial cells contributed 85%. Again, within the same type of cancer, there may be differences. Leukemia in early childhood differs from adult leukemia in properties and treatment (Pardee & Stein, 2009). Cancer may arise from any organ and usually follows a pattern where the cells become abnormal or anomalous and start to grow, then the cells will look abnormal (dysplasia). In cases where the abnormal cells originate in the organs with ducts such as breast and prostate, these abnormal cells hoard up and fill in the duct (carcinoma in situ) then cancer cells may invade the surrounding tissues (invasive cancer called metastasis). Metastasis is the foremost cause of death worldwide.

Medical advances made marked strides in treating cancer and dealing with several health aspects associated at several stages and advancement of disease. The branch of medicine which deals with prevention, diagnosis and the treatment of tumor or cancer is called Oncology. Physical examination and history are the first steps in cancer diagnosis; imaging studies which include X-ray, Computerized Tomography (CT), Magnetic Resonance Imaging (MRI), and Positron Emission Tomography (PET) are also used. Ultrasound, endoscopy and biopsy (where a sample of tissue or cells are taken from an individual's body and examined by pathologist) are also used in diagnosis of cancer. Most cancer types can be treated and some can be cured depending on the size of the tumor, stage, specific type and the location of the cancer. Cancer is treated mainly with

surgery, radiation therapy, chemotherapy, targeted therapy or through a combination of the mentioned treatments.

The effects of cancer on patients are not only physiological but also psychological. Negative reactions to cancer are considered common. For example studies show that psychological distress will be experienced by 35-45 % of all patients suffering with cancer regardless of the stage and type of cancer during the course of the disease (Carlson et al., 2004; Kissane et al., 2004).

Psycho-oncology is a multi-disciplinary professional subspecialty in oncology which mainly addresses two psychological dimensions in cancer. The first dimension is the psychological response/reaction of the patients, their family caregivers, and other members of the family at all stages of the disease. The second dimension is the psychosocial factors that may have impact on the disease process (Holland & Weiss, 2010). The role of the family, caregivers, and social networks in all stages of cancer continuum is an important aspect of this specialist discipline (Folkman, 1997). Given the uniqueness of the cancer experience, researchers feel that it is important that psychologists working in this area have extensive knowledge of the disease and its treatment, as well as the key supportive care issues that patients and their families face (Burney & Fletcher, 2013).

The role of the family, caregivers, and social networks in all stages of the cancer continuum is an important aspect of this specialist discipline (Folkman, 1997). “It combines the formal study, understanding, and treatment of the social, psychological, emotional, spiritual, quality of life, and functional aspects of cancer as applied across the cancer trajectory from prevention to bereavement”. Psycho-oncology aims in the

development and integration of knowledge and techniques which includes both psychosocial and biomedical care of cancer.

Cancer: Incidence and Prevalence

Cancer affects millions worldwide. Around the world, in 2012, out of a total estimation of 14.1 million cases of cancer, 7.4 million were reported among men and a 6.7 million among women. The International Agency for Research on Cancer (IARC, 2008) reported that out of 12.7 million new cases of cancer; countries which are economically developed contributed 5.6 million cases and the rest 7.1 million cases were contributed by economically developing countries. Cancer accounts for 8.8 million deaths worldwide in 2015 (WHO, 2017). By 2030 it is projected that cancer cases will rise to 21.4 million and death caused by cancer will rise to a raging number of 13.2 million. The rise in cancer cases and its mortality rate is contributed by growth of aging population and decrease in childhood mortality in developing countries. According to Global Cancer Facts and Figures (2011) by American Cancer Society (ACS), the most common cancer for males is lung & bronchus cancer and for females it is breast cancer (BC) worldwide. The most common cancers that lead to death worldwide for male are also lung and bronchus cancer and for female breast cancer. In developed countries prostate cancer has the highest occurrence in males and in females, BC. However, lung cancer causes more death in developed countries than prostate and BC. In developing countries lung and bronchus cancer are the most common cancer among males and have the highest mortality rate. BC is found to be the most common cancer among females and has the highest mortality rate among females in developing countries. In terms of incidence and mortality, the cancer of head and neck (HNC) is also reported to be at an alarming rate.

The incidence rate of HNC around the world is more than 550,000 cases and around 300,000 deaths annually (Jemal, Bray, Center, Ferlay, Ward & Forman, 2011). The ratio of male to female head and neck cancer ranges from 2:1 to 4:1 and HNC is the sixth leading cancer (Parkin, Bray, Ferlay, & Pisani, 2005). As reported by GLOBOCAN (2008) in South Central Asia, the estimated number of new cancer cases is 651100 in males and 772000 in females; the estimated death is 496800 in males and 483200 in females.

Cancer in India

In India, breast cancer is the most common cancer among women and lip, oral cavity cancer is the most common among men (National Institute of Cancer Prevention and Research, (2018). According to Population Based Cancer Registry (PBCRs) report (NCDIR-NCRP, 2016), the top five places in India that recorded the maximum cases in between 2012 to 2014 were Delhi, Thiruvananthapuram District (Kerala State), Mumbai (Maharashtra State), Chennai (Tamil Nadu State) and Kollam (Kerala State). Cancer cases in males were more in Delhi, Cachar District (Assam State), Dibrugarh District (Assam State), Kamrup Urban District, Mizoram State, Sikkim State, Ahmedabad Urban District (Gujarat State), Kolkata (West Bengal State), Kollam, Kollam District, Meghalaya State, Tripura State, Nagaland and Naharlagun (Arunachal Pradesh State) PBCRs. Female cancers were more in Bangalore (Karnataka State), Barshi Expanded (Maharashtra State), Bhopal (Madhya Pradesh), Chennai, Mumbai, Manipur State, Nagpur and Pune (Maharashtra State), Thiruvananthapuram District, Wardha (Maharashtra State) and Patiala (Punjab State) PBCRs. The first five highest Crude Rate (i.e. the number of new cases occurring in a specific population per year) per 100,000 population among males

was observed in Aizawl District, Thiruvananthapuram, Kollam, Mizoram State and Kamrup. Among females the first five highest Crude Rate were observed in Aizawl District, Thiruvananthapuram, Chennai, Kollam and Kamrup Urban District. In Age Adjusted Rates per 100,000 population in males the highest was Aizawl District of Mizoram state and for females it was Papumpare District of Arunachal Pradesh.

Among the eight Hospital Based Cancer Registry (HBCRs) during the 2012 to 2014 (NCDIR-NCRP, 2016), which were in places such as New Delhi, Bangalore, Mumbai, Chennai, Dibrugarh, Guwahati (Assam State), Thiruvananthapuram and Chandigarh (Punjab State), records from these hospitals showed that there were 1,17,358 new cancers cases among these 62,946 were males and 54,412 were females. HBCRs record the leading site of cancer among three age groups, such as the ages between 15 to 34; 35 to 64; and 65 years and above. Their records show that for age groups between 15 to 34 years of age, Myeloid Leukemia was the leading site in three among the eight Hospitals and was second leading site in two Hospitals among males. Among females, breast cancer was the leading site in six hospitals among the eight Hospitals where registry was done. For age group 35 to 64 years, among males the leading site in reference to cancer was mouth for three Hospitals among eight and was the second leading site for another three Hospitals. For female breast and cervix were the two most common sites of cancer in reference to cancer in all the registries. Mouth, tongue and stomach were among the leading sites of cancer among males in all registries. BC was also the leading site for three Hospitals and second leading site for another three Hospitals. Among females aged 65 and above mouth, oesophagus, lung and ovary were other important leading sites.

The number of cancer cases in India are likely to rise from 979,786 cases in the year of 2010 to 1,148,757 cases in the year of 2020 (Takiar, Nadayil & Nandakumar, 2010). According to census data in India, the mortality rate of cancer in the country was high and disquieting, about 806000 cases existed by the end of the last century (Ali, Wani, & Saleem, 2011). It is seen that lung cancer is most often reported among males and breast cancer and cervix cancer seem to be the most often reported among females. However, another cancer type which is often reported and the incidence of which is quite alarming, is head and neck cancer (HNC). Especially in India, in certain parts of the country its occurrence is very high, as reported in the following portions of the present chapter. Overall, 57.5% of world's HNC (excluding esophageal cancer) occur in Asia and India contributing a large portion, for both sexes. As a result of smoking, chewing of tobacco and chewing of betel nut, about 0.2 to 0.25 million cases of HNC are diagnosed in India every single year. In India HNC accounted for 30% of all cancers among males except Dibrugarh Assam, and 11 to 16% of all sites of cancer (Kulkarni, 2013). It accounts for one fourth of all cancers in males and one tenth of all cancers in females in India (Yeole, Sankaranarayanan, Sunny, Swaminathan, & Parkin, 2011). With these prevalence and incidence rates as background, though there are more than 100 types of cancer, present study focuses on two types of cancer namely breast cancer (BC) among women and HNC among men. Both of these cancer types seem to be of high incidence other than the lung cancer in males and cervix cancer in females in India. HNC may result in physical disfigurement of the patients and also may cause disruptions of essential functioning such as deficits or complication in eating, swallowing, breathing normally and forming speech as well as disfigurement causing change in appearance in

case of surgery. Also, in BC the treatment may result in certain change in physical appearance of the patients in cases of mastectomy and certain periods of treatment which can have negative impact on their self-image and femininity or sexuality. Thus, both HNC and BC, may contribute to changes in physical appearance which in turn may result in different psychological impact on the patients. The following part of this chapter discusses further about these two types of cancer in detail and also about the psychological dimensions related to patients and caregivers with these two types of cancers. This study attempts to assess the interpersonal relationship between the patients and their caregivers while studies seem to focus on psychosocial dimension of patients individually and certain dimension of caregivers as well. There seems to be scarcity in studies related to caregivers of men with HNC and women with BC.

Breast Cancer (BC)

BC is found to be the most commonly occurring cancer among women worldwide and is rapidly increasing in the developing countries. A vast majority of the cancer diagnoses in developing countries are in late stage (WHO, 2017). BC is the type of cancer which originates from breast cells. This cancer usually starts in the inner lining of the milk ducts or the lobules that supply milk. BC which starts from the ducts is known as ductal carcinoma and BC which starts from lobules is known as lobular carcinoma. BC is the second most common cancer among women in South Central Asia. BC is known to be more common among women in the developed countries than women in the developing countries. Age is found to be one of the risk factors for BC. With increased age, the incidence of BC also increases; women of age 80 are 20 times higher at risk for developing BC than those aged 30. Women who are at risk are those who start

menstruating early (less than 12 years) and women who undergo menopause late (Spence & Johnson, 2001). Other risk factors of BC include age at first full term pregnancy, lactation, weight and diet. It also includes the use of alcohol, exposure to radiation, early use of oral contraceptive pills, hormone replacement therapy, previous benign breast disease and family history.

Diagnosis of BC is done by collecting medical history of the patient, physical examination, mammography, ultrasonography, fine needle aspiration cytology (FNAC where needle is inserted into the lump), core and open biopsy. However, the cases of BC among males, amount to less than 1%, making it a highly uncommon phenomenon. According to ACS (2018) the following are types of BC:

Ductal carcinoma in situ- This type of BC is considered non-invasive/ pre-invasive BC.

Invasive ductal carcinoma- It is the most common type of BC which starts from milk duct and can metastasize.

Invasive lobular carcinoma- About 1 out of 10 patients with BC suffers from this type of BC. It starts in the lobules and can metastasize into other parts of the body.

Inflammatory breast cancer- Account for 1 to 3% of all BC. In this cancer cells block the lymph vessel on the skin making the skin on the breast look red and feel warm.

Paget disease of the nipple- This type of cancer starts in the breast ducts and spread to the skin of the nipple and then to the areola, the dark circle of the nipples. It accounts for 1% of all BC.

Phyllodes tumor- Usually benign but on rare occasions may be malignant and is a type of tumor that arises in connective tissue of the breast.

Angiosarcoma- It occurs rarely in the breast and usually develops as a complication of previous radiation treatment. It can develop about 5 to 10 years after radiation. This cancer tends to grow and spread quickly.

The prognosis and the response to treatment are very similar between the sexes (Spence & Johnson, 2001). Breast cancer can be clinically grouped into four categories such as i) operable BC, ii) large operable BC, iii) locally advanced BC and iv) metastatic BC.

Head and Neck Cancer (HNC)

In India, the highest occurring cancer among males is the HNC (IARC 2010). Aizawl district in the state of Mizoram has the world's highest incidence of cancer in men, which are cancer of the lower pharynx and the tongue (Ganapati, 2005). HNC are a heterogeneous group of tumors and can be divided based on the sites, namely, skin and lip, oropharynx, hypopharynx, nasopharynx, larynx, salivary glands, oral cavity, nasal cavity and the par nasal sinuses, and external auditory meatus and the middle ear. Cancer that occurs in the regions of the head and neck are called the squamous cell carcinomas, as the cancer cells begin in the surface region where the cells are flat and squamous. And when cancer is confined to the region in which it originates, it is referred to as the carcinoma in situ. Another type is the invasive squamous cell carcinoma, in which the cancer cells spread in to the deeper layer of the tissue. The disfigurement from the disease or treatment can be enormous and its impact on cancer patients' psychological, physical, and social functioning cannot be understated, although cosmetic surgery improves the

physical change (Spence & Johnson, 2001). Tobacco either smoking or chewing is the major risk factors for cancer, especially cancers that occur in the oral cavity, larynx, hypopharynx and the oropharynx, (Gandini et al., 2008; Boffetta, Hecht, Gray, Gupta, Straif, 2008). Around 90% of patients with HNC report history of smoking (Spence & Johnson, 2001) Alcohol, environmental factors such as air we breathe, food and drinks we consume, genetics, human papilloma virus (HPV), and the Epstein- Barr virus (EBV) are among the other factors which can cause HNC. It is diagnosed mainly by physical examination, history, endoscopy, imaging tests (which include, CT, PET, MRI) and biopsy. Cancer which arise from glandular cells, for example salivary glands are called adenocarcinomas. HNC mainly includes cancer of oral, laryngeal, nasal cavity and paranasal sinus, nasopharyngeal, oropharyngeal, hypo pharyngeal, salivary gland and thyroid gland.

Physical Effects of Cancer and Treatment

Based on the type, stage and location of cancer, patients undergo various treatments, which include—surgery, chemotherapy, radiation therapy, targeted therapy, stem cell therapy, hormone therapy, immunotherapy, and precision medicine. However, these treatments can result in physical discomfort for the cancer patients where they experience physical pain, fatigue, restriction in movements, dyspnea, headache, clothing problems and other various physical complications. Especially for patients with HNC, pain is often seen. For instance, chemotherapy may have side effects such as fatigue, easy bruising and bleeding, pain, hair loss, nausea and vomiting, anemia, problem with nerves and muscles, sores etc. (ACS, 2016)

Surgical treatment also has side effects such as pain, fatigue, appetite loss, swelling, bruising, numbness, bleeding, infections and organ dysfunctions (Cancer net, 2016). A case of BC and HNC surgery can result in physical disfiguration which may result in psychological issues such as body image, distress, depression and anxiety. For example, in lumpectomy, which is a type of breast-conservative surgery, based on various aspects, such as the size of the tumor, the location of the tumor and other important factors, a part of the breast that contains the cancer and its surrounding normal tissue is removed. On the other hand, mastectomy is a surgical procedure which involves the removal of the entire breast, and when the surgery involves the removal of both the breasts, it is called a double mastectomy (ACS, 2016). However, having done mastectomy or lumpectomy may have negative impact on woman's body image and her self-image (Kieszkowska-Grundny, Rucinska, Ciesak, & Wisniewska, 2017; Kocan Gursoy, 2016; Rosenberg et al., 2013). Radiation treatment can cause weakness or tiredness, sore skin, loss of hair in treatment, and the side effects of radiation may include change in skin color of the treatment area, infertility, breathing problem, and dry mouth (Cancer Research UK, 2016).

Another cancer treatment immunotherapy also has side effects such as soreness, rash, fever, chills, dizziness, muscle and joint aches, heart palpitations, sinus congestion, high or low blood pressure, nausea and vomiting etc. Targeted therapy has side effects such as risk of blood clot, stroke, bone loss, joint pains, gastrointestinal symptoms, pain and so on. Targeted therapy for cancer patients can also result in problems that involve skin, delay in blood clotting, wound healing and high blood pressure (National Cancer Institute, 2018).

It is now well established that patients suffer not only from physical complications and discomfort from the symptoms of cancer itself, but also from the treatment which they are undergoing. Most of these effects may result in psychological repercussions as well. Thus, this is the time where the patients need physical as well as psychological assistance. More often than not, it is the family members who provide this assistance to the patients apart from the care they receive from medical professionals. The role of caregivers in supporting the cancer patients is very important. While they provide care and support to the patient, they themselves undergo certain psychological issues and problems which may require enough attention as well.

Caregivers of Cancer Patients

Although some cancer patients may not require caregiving, most of them require caregiving at some point during the illness trajectory which is provided by their caregivers. These caregivers are often their immediate family members who are underprepared for the task they need to carry out as caregivers. Caregivers are defined as “individuals (eg. Adult children, spouses, parents, friends, and neighbors) who provide care that is typically uncompensated and usually at home, which involves significant amounts of time and energy for months or years and requires the performance of tasks that may be physically, emotionally, socially, or financially demanding” (Biegel, Sales, Schulz, 1991). Cancer research studies show several psychological outcomes of its diagnosis, progression and treatment not only in the patients suffering with cancer but also in their caregivers. Thus, another angle that researches need to look into is the caregivers’ health. Present research thus seeks to probe the caregiver’s angle.

There is growing recognition that in order to give comprehensive care for patient with cancer it is necessary to involve giving attention to the psychosocial and other various needs of their family caregivers who are also informal caregivers and the patients themselves (Applebaum & Breitbart, 2013). Definition of informal caregiver is given as “any relative, friend, or partner who have significant relationship with and provide assistance (i.e., physical and emotional) to a patient with life threatening, incurable illness” (Applebaum & Breitbart, 2012). Institute for Family Centered Care (2015) defines the term family as “two or more persons who are related in any way- biologically, legally or emotionally”. At home it is the family primary caregiver who is the main provider of physical and emotional support for the patients. The family caregivers of patient with cancer provide direct support to the patients which includes assisting in daily living, administering or monitoring medication to the patients, providing and assisting in transportation, managing finances, and emotional support. Approximately one-quarter of caregivers who are family members of the patients spend excess of 40 hours per week providing care to the cancer patients (National Alliance for Caregiving, 2009). Owing to the care extended to the cancer patients by their caregivers, the caregivers are also bound to experience physiological and psychological complications. Caring for a patient, medical and financial management, decision making and dealing with emotional aspects of the patients as well as themselves may create lot of stress and even anxiety for the caregiver. Family caregivers do not appear to have received much attention in published literature from India. Researchers point out this fact and say that it is surprising as the family forms the backbone of support in a collective society like India with limitations in terms of availability of tertiary support (Mehrotra, 2008).

Research studies show an array of concern with regard to the family caregivers of patients who are suffering with different types of cancer. One of the most common cited concerns of families of HNC are the meaning of caregiving, the hospital experience, treatment of the disease, disruption in social relations, and future placement (Mah & Johnston, 1993). A cancer diagnosis creates multiple challenges for the family caregivers which includes, physical demands for practical caregiving, emotional strain, adjustment to change in roles and responsibilities, and work/career schedule. From the very beginning of the diagnosis, to giving the patients a long-term care at home, family caregivers play an important and pivotal role. With an increase in the need for day care outside the hospital and decrease in hospital stay, the family caregiver's role and responsibilities in taking care of the patients at home increases. The caregivers are often termed as 'hidden patients' because they have to look after the patients and themselves. Dealing with their loved ones' diagnosis with cancer will also have huge emotional toll on the family caregivers. Sometimes the family caregivers while giving care and handling other roles and responsibilities may neglect their own health. Because of the mounting challenges and responsibilities in relation to caregiving, the family caregivers of cancer patients often report feeling depressed.

Cancer and Psychological Factors

"Psychological factors refer to an individual's thoughts, feelings and other cognitive characteristics that affect the attitude, behavior and functions of the individual." Various psychological factors including stress, depression, negative affect, repression or denial and social support can have an impact on the immune status and function (Cohen & Herbert, 1996). Various changes are induced into a patient's life after the cancer

diagnosis and its treatment. They bring about many changes in the personal lives of the patients, their daily activities, work-life, interpersonal relationships, and the roles they play within their family. These changes, most often than not, are associated with high levels of psychological stress among the patients. This stress manifests itself as anxiety and/or depression among them (Zabalegui, Sanchez, Sanchez & Juando, 2005). Patients suffering with HNC are reported to have a high risk of development of emotional disturbance after diagnosis of cancer and the treatment begun (Wood & Bisson, 2004). Anxiety, depression, fear of recurrence, concern related to body image, communication and other problems within the family are common among cancer patients suffering with cancer. In this background psychological needs of patient's family members cannot be neglected.

Diagnosis of life threatening illness such as cancer of loved one can create the fear of losing them and concern about their suffering. The psychological distress in family members can be as severe as the patients and sometimes far worse than the patients (Hodges, Humphris, Macfarlane, 2005). There is limited information about the physical and psychological symptoms in family caregivers during cancer illness trajectory. If the caregivers have pre-existing symptoms, this can interfere with the ability to carry out a caregiving role and to perform it effectively. The family caregivers can also develop new physical symptoms or their existing symptoms can get worse as a result of caregiving activities. The unrelieved or not lessened symptoms and demand of caregiving can have impact on the caregivers functional status and lead to poor quality of life (QoL). Caregivers' fatigue is found to have impact on care on the daily schedule (Jensen, & Given, 1991). The patients as well as family caregivers require good interpersonal

relationship with each other and also with other family members. As has been found in the studies discussed this far, psychological states of patients are likely to exert their influence on psychological states of caregivers as well. When situations continuously demanding the need to deal with patients undergoing such psychological states become a part of the life of the family caregivers over a period of time they develop certain psychological states themselves leading to overall negative impact possibly on their QoL. The present study makes an attempt to discuss such psychological states in patient, followed by discussion about similar psychological states in caregivers. As mentioned earlier good social support can help patients to better adjustment to their illness. On the other hand, we can also hypothesize that receiving good social support and mutual interpersonal relations will help the caregivers in giving care effectively to the patients.

Distress is one of the most commonly experienced psychological factors that affects both the patients suffering with cancer and their family caregivers. Distress, as defined by the National Comprehensive Cancer Network (NCCN, 2008) is “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that interferes with the ability to cope effectively with cancer, its physical symptoms, and treatment. Distress extends along a continuum, ranging from common, normal feelings of vulnerability, sadness, and fears, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis”. Distress is conceptualized as “the direct manifestation of the effort people must exert to maintain their psychosocial homeostasis and social functioning when confronted with taxing life stress” (Terluin et al., 2006). The prevalence of distress among patients suffering with cancer ranges from 22%-58%.

Mehnert, et al. (2014) reported that out of 2,100 patients suffering with cancer they interviewed, nearly one third experienced mental or emotional distress that includes anxiety, depressive symptoms and adjustment disorders. The prevalence of these psychological issues varied by cancer type. The highest prevalence was found among patients with BC (42%) and HNC (41%), which is followed by malignant melanoma (39%).

For BC, distress predicts depression and the predictors of distress includes gender, mixed cancer diagnosis, poor functional performance, problem with housing, dealing with children and partner. Post-treatment distress predictors include physical symptoms and side effects experienced during the course of treatment and distress is also found to be associated with mastectomy and hormonal treatment (National Cancer Institute, 2015). Iwamitsu and Buck (2005) suggested that patients who have suppressed negative emotion and have high trait anxiety experience greater emotional distress.

Studies show that HNC patients have significant level of general distress (Haman, 2008). Distress is common and understandable among cancer patients, because of this it is sometimes ignored by the medical professionals. However, to determine the levels of distress, it is important to ask about its persistency, and its disruption. Symptoms of distress may often appear as side effect of treatment, resulting in changes in mood, reduced activities, and withdrawal from people, maladaptive lifestyle, irritability and even noncompliance with treatment. The factors found to predict distress in cancer are education, being unmarried, living alone, stage of cancer and alcohol abuse (Kugaya et al., 2000). Such a distress in cancer patient may have its impact just the patients but also their caregivers who are family members. Thus, on the other hand, distress among

caregivers of cancer patients is also frequently seen with their prevalence ranging from 41% to 62% (Dumont, Surgeon, Allard, Gagnon, Charbonneau, & Vezina, 2006).

Many studies point to the fact that along with the patients, caregivers of cancer patients experience distress. Caregivers of cancer patients reported distress as high as 62% to 66.1% (Areia, Fonseca, Major & Relvas, 2018; Dumont, Surgeon, Allard, Gagnon, Charbonneau, & Vezina, 2006). Distress among caregivers was found to be significantly predicted by levels of education, lifestyle interference, (Cameron, Franche, Cheung, & Stewart, 2002) and taking care of children in case of spouse (Kim, Baker, Spiller, & Wellisch, 2006). A study done in India by Manjeet, Rathod, & Sainath (2014) on the prevalence of emotional distress on caregivers of cancer patients, found that 53% of the caregivers experienced emotional distress. Distress among the caregivers of cancer is often associated with the amount of assistance the patients need from the caregivers, duration of illness, caregivers' decline in work performance, financial concern and the amount of support the caregivers themselves received.

Depression is another psychological factor commonly experienced by patients suffering with cancer and their family caregivers. WHO (2017) defines depression is “ a common mental disorder, characterized by persistent sadness and a loss of interest in activities that you normally enjoy accompanied by an inability to carry out daily activities for at least two weeks”. The construct depression is not only theoretically challenging but is also complex diagnostically. Either in its clinical form or as transient mood depression is challenging and intriguing. Sadness, pessimism, grief denigration, along with loss of energy, motivation and concentration are the common symptoms of depression (Singh, 2006). Depression can range from sadness to major affective disorder. It is important to

note that treatment for cancer can result in various symptoms that are similar to depression, thus making it difficult to evaluate mood changes that occur during the course of the disease & its treatment. For example, fatigue, loss of appetite and disturbed sleep are all side-effects of the treatment as well as the symptoms of depression.

Depression approximately affects 15 to 25% of patients suffering with cancer and it affects both women and men equally (National Cancer Institute, 2015). Cancer types highly associated with depression are HNC, breast, lung, brain, pancreas, and gynecological cancers (Kissane, Maj & Sartorius, 2011). HNC and BC are highly associated with depression with HNC up to 42% and BC up to 37% (Massie, Llyod-Williams, Irving & Miller, 2011). Among patients suffering with BC, the prevalence of depression is reported to range from 3% to 34% (American Psychological Association, 2014). The various risk factors contributing to depression include age, social status, ethnicity, comorbidity, psychiatric history, physical functioning, smoking, alcohol use and body mass index (BMI).

Incidence of depression in HNC ranges from 5% to 50%, and it may develop at any given point in the course of treatment of the disease, and also during its initial diagnosis and therapy (Lydiatt, Moran & Burke, 2009). Social isolation as a result of unpaired verbal communication and other difficulties such as breathing and swallowing may contribute to the development of depression among patients with HNC (Paula, Sonobe, Nicolussi, Zago, & Sawada, 2012). Other factors that may cause depression in HNC patients include, lack of social support, inadequate information which leads to uncertainty, behavioral factors which include tobacco and alcohol cessation, personality traits and history of depression. In a study done by Morton, Davies, Baker,

Baker and Stell (1984) it was reported that 40% of their sample of patients suffering with HNC showed clinical symptoms of depression. Also, women with HNC patients with low social support and face disfiguring treatment are at highest risk for psychosocial dysfunction (Katz, Irish, Devins, Rodin, & Gullane, 2003). On the other hand, patients suffering from depression are more likely to have poor treatment outcome, poorer immune system, take more treatment breaks, and require longer time to complete prescribed therapy and poorer health related QoL than cancer patients without depression (Lydiatt, Moran & Burke, 2009).

On the other side, caregivers of cancer patients experience high level of depression (American Society of Clinical Oncology, 2016). Among the caregivers of patients suffering with cancer, a 14 to 82% experience depression (Jho et al., 2016; Park et al., 2013; Rhee et al., 2008), and in the same population, gender differences are also often seen (Oechsle, Goerth, Bokemeyer, Mehnert, 2013). Assessing and addressing depression among caregivers of patients suffering with cancer is necessary to prevent negative outcomes of caregiving such as decline in their physical and mental health. Depression among caregivers of patients suffering with cancer is associated with educational level of the caregivers, duration of the patients' illness (Ambigga Devi, Sherina, & Suthahar, 2005), gender, employment status and patients' anxiety (Nipp et al., 2015).

Anxiety is reported to be common among patients suffering with cancer and the family caregivers of the patients. Anxiety is defined as the "Apprehension, uneasiness, or worry we experience when we perceive threat to our security" (Vye, Scholljegerdes, Welch, 2007). "Anxiety is often a diffuse, unpleasant, and uncomfortable feeling of

apprehension, accompanied by one or more bodily sensation”, it may exist with fear simultaneously or follow each other. (Veeraraghavan & Singh, 2002). Anxiety is often manifested in patients suffering with cancer and their family caregivers at various stages during cancer screening, diagnosis, treatment and recurrence. Across cancer types, 19 % of patients showed anxiety of clinical levels and another 22.6% symptoms that are subclinical and women showed higher levels of anxiety than men (Linden, Vodermaier, Mackenzie, & Greig, 2012). Mitchell et al. (2011) in their international review of 94 interview-based studies reported that the prevalence of anxiety disorders was 10.3%. And the contributing risk factors of anxiety in patients suffering with cancer are age, gender and functional status. In BC patients the occurrence of anxiety disorder was reported to be 16.0%, while the occurrence of symptoms of anxiety was 19.0% (Lueboonthavatchai, 2007). The risk factors for anxiety disorder include presence of disturbing symptoms, fatigue, respiratory symptoms, pain and number of times of hospital admission. Psychological factors include social support, family relationship and functioning.

Studies report high prevalence of anxiety in patients with cancer. The prevalence of probable cases of anxiety among HNC patients was 20% (Neilson, Pollard, Boonzaier, Corry, Castle, Smith, et al., 2013), before treatment was found to be 30% and after treatment 17% among HNC patients (Neilson, Pollard, Boonzaier, Corry, Castle, Mead, Gray et al., 2010). Anxiety can result in delay or neglect of diagnosis and treatment of cancer.

Not only are the patients subjected to anxiety but their caregivers also experience anxiety. Apart from personal factors, the treatment decision, change in role, impending death of loved ones etc. can cause anxiety among caregivers. The prevalence of anxiety

among caregivers of cancer patients range from 11.5% (Din, Jaafar, Zakaria, Saini, Ahmad & Midin, 2017) to 45% (Katende & Nakimera, 2017). Among caregivers of cancer patients, anxiety was more common than depression and anxiety was even higher than the cancer patients (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013). Aspects such as caregivers sharing the role of caregiving with someone else and the type of treatment the cancer patients received predicted anxiety among caregivers (Din, Jaafar, Zarakiah, Saini, Ahmad, & Mindin, 2017). Age, gender, marital status of the caregiver and patients' anxiety were also found to be associated with anxiety among caregivers (Nipp et al., 2015). Anxiety can interfere with the QoL of patients and their families and should be evaluated and treated.

Somatization can be defined as “a tendency to experience and communicate psychological distress in the form of somatic symptoms and to seek medical help for them” (Lipowski, 1988). It is important to note that the etiology of somatization is not completely understood in cancer. The cause of somatization includes both the organic as well as psychological factors. The causes of these symptoms in cancer could be of a wide variety which can include depression, anxiety, somatization or a manifestation of illness behavior. Treatments for cancer, such as the radiation therapy or the chemotherapy can also give rise to many somatic symptoms. The presence of somatic symptoms can cause complications in the treatment procedures and in the overall outcome of cancer. The most common of these symptoms among cancer patients include pain, fatigue, anorexia, tiredness or exhaustion, weakness, reduced energy, lethargy, and tremors. Apart from the anxiety and panic attacks, various other symptoms such as breathlessness, muscle pain, dizziness, and palpitations have also been noted, in patients suffering with cancer

(Chaturvedi, Maguire, & Somashekar, 2006). Somatic concerns and preoccupation among cancer patients are also common. The presence of these symptoms in patient with cancer create difficulty in diagnosing depression and anxiety. Somatic symptoms in cancer can be addressed through counselling and psychopharmacotherapy. However, for better understanding of the somatization processes in patients suffering with cancer, extensive research is yet needed to be carried out.

Anxiety and depression could be related to somatic symptoms. Somatization, physical complaints and emotional factors may exaggerate the experience of somatic symptoms (Chaturvedi & Maguire, 2006). Various clinical implications of somatization and abnormal illness behaviour in cancer are given in the following passage, (Chaturvedi, 2012).

“Firstly, it is difficult to decide whether certain physical symptoms are due to cancer, chemotherapy, radiotherapy, surgery, psychiatric disorder, or illness behavior. Secondly, somatic symptoms magnify disability resulting from cancer and interfere with treatment adherence and decisions cause delay in recovery. Thirdly, these symptoms result in poor outcome and recurrence, and reduce overall wellbeing and quality of life (QoL). Lastly, it is known now that these physical symptoms in disease-free cancer patients respond to antidepressants and psychosocial intervention. It will become an error of clinical judgment, if these somatic symptoms and physical distress are treated as signs of progression of the disease with chemotherapy, radiation treatment, or opiates.”

Patients who had symptoms of somatization, among BC patients, i.e. those who were dissatisfied with their body showed lower levels of self-esteem and high comorbidity of depression (Serto, Doğanavsarqil, & Elbi, 2009). Studies show mutual as

well as differential impact of factors like distress, depression, somatization in cancer and vice versa. For example, somatization is found to be diagnosable in patients with cancer, and to have a negative influence on coping and QoL outcomes (Grassi, Caruso, & Nanni, 2013). Researchers feel that it is important for the psycho-oncologists or the medical professionals to identify the presence of problems such as somatoform disorders in cancer patients as they can create problems in management of cancer, by either delaying the process of treatment or by over treating somatoform symptoms (Chaturvedi, Hopwood, & Maguire, 1993; Chaturvedi & Maguire, 1998).

The somatization process in patients suffering with cancer is often a neglected area (Grassi, Caruso, & Nanni, 2013) which is why there is limited information regarding somatization of caregivers of cancer patients. However, one recent study indicated that the prevalence of somatization among caregivers of cancer patients as 50.9 % (Areia, Fonseca, Major, & Relvas, 2018).

Interpersonal Relationship

As fast and accurate diagnosis and timely treatment are an inevitable part of cancer care, understanding the psychosocial needs of patients with cancer, which call for social support is also important. Social support consists of support from people we can count on, to provide ongoing emotional support, affirmation, information, and assistance, especially during the time of crisis (Atchley, 2000). Studies indicate that there exists a positive relation between perceived social support and the psychological adjustment following the treatment for cancer (Usta, 2012). As a part of social support, relationship with family members and significant others with whom patients spend maximum of their time, becomes important. In this background it is noteworthy that cancer diagnosis and its

treatment may be a crisis not only to the patient but also to the caregivers. As a result of which the interpersonal relationship between the patients with cancer and their caregivers in some cases may be strained. Interpersonal relationship plays an important role in peoples' adjustment to crisis in life.

Interpersonal relationship can be understood as a strong, deep, or close social and emotional association or interaction between two or more people who share common interests and goals. An interpersonal relationship can range from a fleeting to an enduring one. These relationships may be based on factors ranging from love, inference, and solidarity, to regular business interactions, or some other type of social commitments. In the present study, interpersonal relationship is looked at as based on the family or kinship relations, friendship, marriage etc, as an interactional process between the patients and their family caregivers focusing on their mutual communication, mutual relationship, ways in which they deal together with certain situations, social support and its availability and the care for each other during illness. Research has shown that in the face of major illnesses, better psychological and physiological adaption was consistently linked to the perceived availability of social support (Wimberly, Carver & Antoni, 2008). On the other hand, low marital satisfaction, conflicts, high criticalness, hostility, low closeness or cohesiveness, low family coherence results in poor management of the disease and poor illness outcome (Fisher, 2006). In the context of cancer patients, studies show the importance of support. For example, in patients with BC, social support was found to be an important predictor of their psychological adjustment to the disease (Alferi, Carver, Antoni, Weiss, & Durán, 2001). Effect of interpersonal relationship as a part of and in the context of family social support therefore is important to cancer

patients. Many families see during illness an opportunity to increased communication within the family (Murray, Kelley-Soderholm, & Murray, 2007). However, on the other side of the picture, it is not very uncommon that patients may experience difficulty in their interpersonal relationship as a result of their disease. The higher the amount of unmet care and support needs of the patients, the more negative the caregivers' caregiving experience will be (Chen, Tsai, Liu, Yu, Liao, & Chang, 2009). Research studies have shown that problems such as communication problems were commonly cited by the patients (Abdelrahman & Abdelmageed, 2017; Reader, Gillespie, & Robert, 2013; Taylor, Wolfe, & Cameron, 2002). It is important to examine interpersonal relationship processes among people affected by cancer, as the social environments that they are in, play an important role in the face of adjustment to the disease (Thornton & Perez, 2007). Relationships provide the patient suffering with cancer opportunities to receive emotional as well as instrumental support from others, and it is noted to be associated with better adjustment to the disease. The primary source of this support is family members, especially their life partners (Robert, Lepore, & Helgeson, 2006; Helgeson & Cohen, 1996; Pistrand & Parker, 1995). The presence of a positive partner relationship can be understood as an important component that would lead to a successful adaptation to virtually all aspects related to the experience of cancer (Avis, Crawford, & Manuel, 2005; Quartana, Schmaus, & Zakowski, 2005). In the assessment of health-related quality of life, interpersonal relationship is widely regarded as critical component (Cella et al., 1993; Aaronson et al., 1991; Aaronson, 1991). Research related to interpersonal relationship in cancer patients and their caregivers appears to be sparse. This points to a need to focus on interpersonal relations aspect of cancer patients with

their family caregivers which is closely related to the healthy psychological functioning of both. “Interpersonal relationships are a missing dimension in models of delay. We need to know more about how to use relationships, in addition to traditional routes, to harness health promotion message”, (Forbat, Place, Hubbard, Leung & Kelly, 2014). For breast cancer patients, having good interpersonal relationship is important as lack of intimate confiding relationship was found to be associated with anxiety and depression (Burgess, Cornelius, Love, Graham, Richards, and Ramirez, 2005). For the present study, interpersonal relationship is operationally defined as an interactional process between the patients and their family caregivers focusing on their mutual communication, mutual relationship, ways in which they deal together certain situations, availability, support and care for each other during illness. Interpersonal relationship is called a process because it involves a series of actions between the patients suffering with the disease and their family caregivers. This process is interactional in nature as both patients and their family caregivers share mutual responsibilities and influence each other.

In the process, the additional burden of care, which they so far never had to show to this extent may create certain negative psychological states in caregivers too. In addition to that if patient’s psychological states show their impact on caregiver, it adds to the caregiver’s suffering. This may lead to further manifestation of psychological states such as distress. Thus, either or both of them may be influenced and /or may influence each other’s psychological states in turn. Thus, interpersonal relationship is very important between the patient and caregivers for mutual support. Research demonstrates several such outcomes as discussed in the preceding paragraph. In the present study the

psychological states of patients suffering with cancer and their caregivers along with the interpersonal relationship between them is considered as psycho-social factor.

Quality of Life

Regardless of its stage cancer diagnosis is a stressful predicament which have its impact on physical status, emotional, spiritual well-being, and relations. WHO (1998) defines Quality of Life (QoL) as “individuals’ perception 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. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (WHO, 1997). QoL is difficult to define. However, literature shows various authors proposing definitions. Gotay, Korn, McCabe, Moore, Cheson (1992) define QoL “as the state of well-being that is a composite of two components: the ability to perform everyday activities that reflects physical, psychological, and social well-being; and patient satisfaction with levels of functioning and control of the disease”. Whereas, Calman (1984) defines it as “the gap between the patient’s expectations and achievements. The smaller the gap, the higher the quality of life”. According to Schipper and Clinch (1988), “quality of life represents the functional effect of an illness and its consequent therapy upon the patient as perceived by the patient”. Also, according to WHO Quality of Life Group (1993) “quality of life is patient’s perception 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”.

Quality of life is a multidimensional concept which has no clear or fixed boundaries. The presence of distress, depression, anxiety and poor functional status are believed to lead to poor quality of life. This in turn affects the prognosis, recovery, treatment compliance of the patients with cancer. QoL includes the emotional, social and physical well-being of an individual's life. In terms of healthcare, quality of life includes the subjective perceptions of the positive as well as the negative aspects of the physical, emotional, social symptoms, cognitive functions, most importantly disease symptoms and side effects of treatment of the patients suffering with cancer (Leplege & Hunt, 1997). Health related quality of life (HRQOL) at an individual level includes physical and mental health perception; and at a community level includes resources, conditions, policies, and practices that influence a population's health perceptions and functional status. Centre for Disease Control and Prevention (2000) defined HRQOL as, "an individual's or group's perceived physical and mental health over time".

CHAPTER II

REVIEW OF LITERATURE

The number of cases being diagnosed with cancer seem to be alarming. Around the world, 14.1 million new cases in 2012 (IARC, 2012) and in India 7 to 8 lakh new cases of cancer are identified every year (Singh, Kaur, Banipal, Singh, & Bala, 2014). It is important to note that among cancer cases reported for diagnosis and treatment more than 70% were in advanced stage (Sajid, Tonsi, & Baig, 2008). In developed countries cancer of the breast is the most common type and in developing countries it is the second most common (Ali, Wani, & Saleem, 2011). As the incidence increased over the years, as many as 100,000 new patients are being detected every year (Michael, & Jernal, 2003; Yip, Taib, & Mohammed, 2006). While cancer diagnosis in itself is agonizing, across every phase of treatment thereafter, the patients seem to manifest several psychosocial issues. This may happen both during their treatment phase when admitted in the hospital and outside the hospital as well. Studies report that hospital stay in itself may lead to certain psychological states. During their stay in the hospital some patients may develop a sense of alienation, which often create stress, anxiety, loneliness, depression, dependency and pain that is both physical and psychological (Rana & Hariharan, 2015).

During the course of cancer illness, the patients' need both physical and psychological support. These supports are mainly from their family members and the role of informal caregivers is very important as a support system. More often than not, these family caregivers are unprepared for the task of caregiving (Family Caregiver Alliance, 2006; National Alliance for Caregiving & AARP, 2004) which involves giving physical and psychological support, decision making, changes in roles and so on. The caregivers

often make sacrifices that involves children, work, possible relationship and their normal activities in order to give care (Maree, Moshima, Ngubeni, & Zondi, 2018). The consequences of such prolonged caregiving have their psychological effects on the caregivers. Studies report that these caregivers are often having high level of stress (Pinquart & Sorensen, 2003), emotional strain, experience frustration (Health Policy Institute, 2005), often feel less acceptance, less in control of their lives (Marks, Lambert, & Choi, 2002; Pinquart & Sorensen, 2004). These caregivers also sometimes experience constant worry or feeling of less certainty (Health Policy Insitute, 2005) and caregivers are found to have higher depression and mental health problems than non-caregivers. Caregiving can also result in poor health outcomes, increased risk for heart disease, lower level of self-care behavior, and lower subjective well-being (Family Caregiver Alliance, 2018). In this context, the present study seeks exploration of psychological factors and QoL from the caregiver perspective. The caregivers of patients with breast cancer and head and neck cancer are considered for this.

Impact of Cancer on Patients and their Family Caregivers

The impact of cancer on the patients and their family is multidimensional and sometimes profound. Cancer effect is not only physical but also psychosocial and economic. In their study on elderly cancer patients, Stafford and Cyr (1997), have found that individuals with cancer reported poorer health, greater limitations of daily living and greater health care utilization than elderly individuals without cancer. The most common difficulty cited were getting out of chair, walking, heavy household work and shopping. In a study conducted by Zebrack, Yi, Petersen, & Ganz (2007) on 193 cancer survivors, they found that these survivors report low income and comorbidities which indicated

worse physical functioning. This study also found association between higher negative impact of cancer and reduced physical functioning, mental health and lower overall QOL. On the other hand, higher positive impact of cancer score was associated with better mental health and overall QoL.

Cancer diagnosis and treatment can lead to profound psychological impact on patients. Individuals diagnosed with BC are likely to experience distress related to treatment, fear, change in perception of themselves, body image and sexuality. It is therefore important to identify and address these issues. Being diagnosed with HNC can be devastating as its diagnosis may lead to change in the anatomy and function of the head and the face and they have a specific role within social and emotional expression and communication (Vickery, Latchford, Hewison, Bellew, & Feder, 2003). Although cancer is not considered universally a negative experience, the phenomenon known as posttraumatic growth is found among persons with cancer. The study of Cordova, Cunningham, Carlson, & Andrykowski, (2001) found that many cancer patients in their study reported improvements in relating to others, appreciation of life, and spiritual change. However, many patients diagnosed with cancer engage in search for meaning and consolation, philosophical explanation for illness, and loss of hope are common concerns (Burney, et al., 2013).

On the other hand, being diagnosed with cancer results in change in roles as the patients are unable to engage in their normal activities of daily living. Feeling of social isolation due to the place of treatment at a far distance and inability to work can result in lack of interaction with others. Communication problems are common owing to cancer diagnosis and treatment, and this can lead to strained relationship. Additionally, the

partners or caregivers of cancer patients may also experience same level of distress. So communication and relationship between them may be worse as a result of this. Both can have mutual impact thus worsening the state of well-being for both.

Not only do the cancer patients suffer the adverse effects of cancer psychologically but also their caregivers. Providing care to cancer patients is a dynamic and ongoing process. Caregivers of cancer patients experience disruption and changes in work situation as a result of caregiving. These changes include working for fewer hours, taking leave, quitting job and even losing job (Gropper, van der Meer, Landes, Bucher, Stickel & Goerling, 2016). The family caregivers of the cancer patients may also suffer psychological distress, depression, anxiety and physical symptoms. Some studies even reported that the caregivers have higher distress than the patients themselves (Vickery, Latchford, Hewison, Bellew, & Feber, 2003). Regardless of the stage of cancer, adult children or parents of cancer patients can experience high levels of emotional distress or affective disorders (Kissane, Bloch, Burns, McKenzie, Posterino, 1994). Caregivers of cancer patients experience different difficult emotional reactions to caring. These include feeling of fear, uncertainty, hopelessness, powerlessness and mood disturbances (Stenberg, Ruland, & Miaskowski, 2010). These result in poor QoL for the family caregivers which can cause hindrance in their caregiving role. Depression is frequently reported by caregivers of cancer patients. Adult children of cancer patients and employed caregivers reported high levels of depression (Given, et al., 2004). A study of Rhee et al., (2008) shows that out of 310 caregivers, 67% had high depression scores.

Caregivers of cancer patients play a vital role during the course of cancer journey, they are sometimes referred to as the hidden patients. While they need to take care of the

patients they themselves also have to cope with their loved one's illness, yet their focus is always needs to be toward the patients. These caregivers are mostly untrained and family members, because of this they are likely to experience distress and other psychological problems. It is suggested by Edward and Clark (2004) that patients and their families' depression, anxiety and distress were associated with patients' illness characteristics which includes type of cancer physical functioning, type of treatment taken, duration of the illness, and subjective concerns related to cancer illness. The fear of recrudescence of cancer is often experienced by them as well.

The way in which the caregiver of cancer patient appraises the situation, the demands of caregiving and how well they cope with these challenges related to caregiving of cancer patients is an important predictor of the caregiver's later psychological adjustment (Northouse, Templin, & Mood, 2001; Ey, Compas, Epping-Jordan, & Worsham, 1998; Carey, Oberst, McCubbin, & Hughes, 1991). Often the caregivers of cancer patients are their life partners or adult children. Giving care can have a profound effect on the physical as well as the psychological realms of the caregivers. Research has found significant negative effect of caregiving on the cells of the immune system, which also includes T cells and natural killer cells (Scanlan, Vitaliano, Zhang, Savage, & Ochs, 2001; Vitaliano, Scanlan, Ochs, Syrjala, Siegler, & Snyder, 1998; Pariante et al., 1997). Studies show that caregivers themselves may manifest chronic illness. Caregivers when compared to non-caregiver were found to have higher level of disease related to heart such as coronary heart disease (CHD) and metabolic syndrome (Vitaliano, Scanlan, Zhang, Savage, Hirsch, & Siegler, 2002). A study was conducted by Grov, Fossa, Sorebo and Dahl (2006) on 96 primary caregivers of cancer patients, where

they used path analysis. Their study modelled caregivers' burden as dependent variable and two different models were constructed. The first model, Model 1 shows that social support is associated with depression, symptoms of the patients also have association with caregivers' anxiety. In this model significant association of anxiety and depression with physical health was found. However, in this study pathway model 2 showed association between caregivers' physical health and patients' symptoms with anxiety was found but no association was found with depression. This study highlighted the importance of indirect association of caregivers' anxiety and physical health.

In another study, physical health of caregivers of chronically ill patients was explored by Chang, Chiou and Chen (2010). They used structural equation modelling to examine relationship among burden of the caregivers, mental and physical health. Their findings showed that with increase in age of caregiver, there is an increase in the number of chronic diseases. It was also found in this study that mental health had a stronger effect on physical health of these caregivers than did burden. Cancer experience resulted in physical, psychological, social, practical and spiritual concerns, it disrupted the everyday life of the patients and their relatives (van't Spijker, Trijsburg, & Durvenwooden, 1997; Zabora, Brintzenhoferjoc, Curbow, Hooker, & Piantadosi, 2001). Studies on impact of cancer mainly focus on individual psychological issues, health outcome or QoL. These studies rarely seem to focus on the impact of cancer on their quality of interpersonal relationship. Therefore, there is a need for studies that focus on this variable as well.

Patients' Performance Status and its Impact on Family Caregivers

Studies have explored and showed an association between patients' performance status and its impact on family caregivers, at the same time they emphasized on the need for more studies in the related areas. The study of Douglas, Daly, and Lipson (2016) found that patients physical status is the significant predictor of caregivers' moods such as anger, tension, depression, confusion, fatigue, and vigor. The study also highlighted that there is a lack of studies that incorporate both physical and psychological perspective for patients and caregivers in their analyses. Studies related to impact of patients' functional states gave some rather contrasting result. A study of Given, Stommel, Given, Osuch, Kurtz and Kurtz (1993) found that patients' physical limitations have an impact on the daily schedule of their caregivers. However, the caregivers' physical health is not impacted by patients' physical limitations. But in a later study done by Grunfeld (2004), it was found that as the patients' functional status declines, there is an increase in caregivers' depression and perceived burden. Research hence recommended that there is a need to assess the caregivers who report providing more help to patient in their daily living and give support to these caregivers (Hsu et al., 2017).

Studies have shown relationship between patients physical or performance status and the disruption in caregivers' routine or schedule. But there are hardly any studies found in the search for relevant literature which focus on the association between patients' physical activity levels and other caregivers' variables such as psychological states, their quality of life, interpersonal relationship between cancer patients and their caregivers. Therefore, research focusing on these areas is necessary for a holistic understanding of not only the cancer patients but also their caregivers who are their

family members experience during cancer illness trajectory. Thus, present study attempts to study not only psychological states such as distress, depression, anxiety and somatization but also the interpersonal relationship between them, as well as the QoL the caregivers.

Distress among Patients and their Family Caregivers

Distress is one of the psychological problems which is very common patients who are suffering from cancer patients. The overall burden of cancer diagnosis and its treatment often is referred to as distress' (Tuinman, Gazendam- Donofrio, Hoekstra-Weebers, 2008; National Cancer Control Programme, 2004; Carlson, Bultz, 2003). Distress was defined by Hess and Chen (2014) as "a multifactorial, unpleasant, emotional experience of a psychological (cognitive, behavioral, emotional) social, and/or spiritual nature that may interferes with the ability to cope effectively with cancer, its physical symptoms and its treatment." Distress in specific to cancer is defined by NCCN, (2000) as "an unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that interferes with the ability to cope effectively with cancer and its treatment. It extends along a continuum, ranging from common normal feelings of vulnerability, sadness and fear, to problems that can become disabling, such as depression, anxiety, panic, social isolation, and spiritual crisis".

Negative psychological states such as distress, depression and anxiety are no strangers to cancer patients. According to Srivastava et al., (2016), prevalence of psychological distress is high among patients with BC and they are at higher risk for developing anxiety and depression. In their study they assessed anxiety and depression among cancer patients who took treatment at Varanasi, India. They have also did an

investigation on associated factors such as socio-demographic, socio-economic background and the cancer stage. Their study showed that anxiety among patients with BC was 37% and depression was 28%. According to their findings anxiety has strong association with age group, levels of educational, monthly income and received financial support, whereas depression was associated with patients' marital status, monthly income, financial support and the person accompanying them to the hospital. Their regression analysis shows that among patients, those with factors such as being single, less income and less financial support are more likely to have anxiety and depression. Also, those that are below 50 years of age, low level of education or illiterate are more likely to have anxiety.

Studies not only show such results in patients with BC but also among HNC patients. Patients with HNC have high amount of emotional distress because of the possibility of physical disfigurement from the disease progression and treatment and also the possibility of impairment of functions such as eating, speaking, and breathing (Lewis, Salins, Kadam, & Rao, 2013). A study was conducted by Pandey, Thomas, Ramdas and Nandamohan (2005) to identify distress and its contributing factors among 103 cancer patients who were undergoing curative treatment. The results of multiple regression and One-way ANOVA show that distress was higher among lower income group. Distress was also higher among those who were divorced or without partner, whose living distance was 150 to 350 km from the cancer Centre. It was also high among those cancer patients with presence of pain and with advanced tumors. Distress score was also found to be correlated with patients who were not doing follow-up. Distress is also known to have its effect on the QoL of cancer patients. A study was done by Pandey, Devi,

Ramdas, Krishnan, & Kumar (2009) to investigate the effect of distress on the QoL in 123 patients with HNC. Their study found that distress in patients was predicted by education, occupation, tumor, and nodal stage and that patients with higher distress had poor QoL. In this study it was also found that financial security, understanding and support from the partner reduced distress, thus pointing to the importance of caregivers. This turns the focus on the caregivers, and thus, the perspective of caregiver distress also needs to be explored.

Research findings have suggested that psychological distress is not experienced only by cancer patients but also their caregivers. A meta-analysis was conducted with 21 independent samples of cancer patients and their caregivers by Hodges, Humphris and Macfarlane (2004) to quantify the relationship and difference between respective measures of psychological distress. Their analysis confirmed that there is a positive correlation between patient and caregivers' psychological distress which suggested that with the increase in psychological distress of a patient, the distress in caregiver also increases. This meta-analysis also indicated that patients and caregivers did not experience significantly less or more psychological distress than each other. Similar findings were given by Hagedoorn, Sanderman, Bolks, Tuinstra, Coyne, & James, (2008), who further noted that cancer patients and their partners react to the illness as an emotional system rather than individual. On the other hand, the study of Chambers et al., (2012) has shown that caregivers of cancer patients had higher distress ratings and intrusive thinking when compared with patients themselves.

In another study done by Sklenarova et al., where they assessed the distress of caregivers of cancer patients, results showed higher distress, and found that out of 188

caregivers 69.1% of them were screened positive with distress. This distress was found to be associated with unmet needs in areas such as health care services, informational, emotional, and psychological needs. A study of Huan, Sklenarova, Brechtel, Herzor and Hartman (2015) also found that the prevalence of distress among caregivers was higher than the patients they care for. In another study, caregivers' distress was found to be predicted by demographic, physical and emotional status, and behavioral characteristics of caregivers (Mathew, Baker, & Spillers, 2003). However, among caregivers of cancer patients, gender difference in experiencing distress was not found (Hagedoorn, Buunk, Kuijer, Wobber, & Sanderman, 2000).

An even higher distress was seen among caregivers of HNC patients where the distress was found to be 77% (Badr, Gupta, Sikora, & Posner, 2014). Such as distress may show its effect on caregivers which in turn may extend to the care they provide as well. Distressed caregivers may have difficulty in giving optimum care to the patients (van Ryn, 2011). Caregiver distress has negative effect on the patients' long-term adjustment (Northouse, Templin, & Mood, 2001). Studies thus have demonstrated that distress is high among cancer patients and their family caregivers. However, there are few studies that assessed distress among patient-caregiver dyads for specific cancer types such as HNC, breast cancer or any other specific cancer. Therefore, it felt necessary to understand not only psychological states of the cancer patients but also focus on their caregivers physical and psychological experience of cancer, with reference to specific cancer types considered for the present study that is BC and HNC.

Anxiety and Depression among Patients and their Family Caregivers

Anxiety and depression are no strangers among cancer patients. A study was conducted by Burgess, Cornelius, Love, Graham, Richards, and Ramirez (2005) to examine the prevalence of cancer and the risk factors for anxiety and depression among women with BC. In their study which used observational cohort study design, they interviewed 170 women with BC. These women with BC were recruited 8 weeks after their diagnosis. They were also interviewed after five months of diagnosis and then every 18 months up to five years. The interview focused on the symptoms of depression and anxiety, was used therefore shortened version of clinical structured interview was used. Their findings show that nearly 50% of the women with early BC had depression and anxiety or both in the first year after diagnosis, 25% in the second, third year of diagnosis, and fourth years of diagnosis, and 15% in the fifth year. They also found that factors such as previous psychological treatment, lack of intimate confiding relationship, younger age and severely stressful non-cancer life experience were associated with depression and anxiety. The relationship dimension identified along with other dimensions directs our focus once again to the caregivers' role.

The prevalence of anxiety among cancer patients was found to be around 30% (Stark, & House, 2000) while depressive disorder affect was found to be up to 38% among cancer patients (Honda, & Goodwin, 2000; Massie, 2004; Pirl, 2004). A cross-sectional study was conducted by Santre, Rathod and Maidapwad (2014) to assess the prevalence of anxiety and depression among cancer patients. Their study found that 23% of the participants have scores in moderate to severe category on both HADS subscales namely anxiety and depression. Their study also emphasized on the need of

psychological measures to cope with the emotional distress associated with cancer diagnosis.

In a study conducted by Singh, Singh, Singh & Kaur (2015) it was found that depression, anxiety and stress were more prevalent among patients suffering from HNC, BC and genital tract cancer. The aim of the study was to analyze and compare depression, anxiety, and stress levels and their impacting factors in homogeneous surviving cancer patients. The findings of their study highlighted a strong correlation between cancer and psychological disorder, it demonstrated a strong connection between psychological factors such as depression, stress, and social isolation with the disease progression.

On the other side, it was seen that not only among the cancer patients, such psychological states were found in caregivers too. Caregivers of cancer patients have high anxiety and depression (Nipp et al., 2016; Ratnakar, Banupriya, Doureradjou, Vivekanandan, Srivastava, & Koner, 2008; Chentsova-Dutton, Shuchter, Hutchin, Strause, Burns, & Zisook, 2000). Depression and anxiety among caregivers of cancer patients is as common as among patients and according to some studies they are higher. For example, in a study conducted by Grunfeld, et al., (2004) it was found that the caregivers of cancer patients were more anxious than patients and were also significantly more depressed than the patients. In this study it was also found that burden was the most important predictor of anxiety and depression among caregivers. A study of Sklenarova et al. (2015) also find similar results where anxiety among caregivers of cancer patients was higher than the patients themselves. The same study found depression as equally high among patients and caregivers.

Studies to assess the prevalence of anxiety and depression on caregivers of cancer patients have shown that the prevalence of anxiety ranges from 38% to 48.6% and the prevalence of depression ranges from 29% to 57.6% (Ambigga Devi, Sherina, & Suthahar, 2005; Jho et al., 2016). A study of Park, Kim, Shin, Sason-Fisher, Shin, Cho & Park (2013) found higher prevalence of anxiety but lower prevalence of depression among caregivers of cancer patients. In their study the prevalence of anxiety among caregivers was 38.1% whereas the prevalence of depression was 82.2%. This study also showed sociodemographic factors and quality of life as predictors of caregivers' anxiety and depression.

While study of Nipp et al., (2015) suggested that young female caregivers are at higher risk for the development of anxiety and depression, the study done by Oechsle, Goerth, Bokemeyer, and Mehert (2013) on caregivers of terminally ill cancer patients, found that more male caregivers have anxiety and depression when compared with female caregivers. In this study it was also found that caregivers' anxiety was associated with patients' shortness of breath, nausea, and frequency, intensity and distress due to anxiety. Caregivers' depression was found to be associated with patients' evaluation of distress due to constipation and frequency, intensity, and distress due to anxiety. Depressive symptoms among these caregivers include fatigue, insomnia, hypersomnia, indecisiveness, and lack of concentration. Caregivers suffering from depression may have a problem in meeting the caregiving needs of the multi-symptomatic cancer patients. The burden of caregiving, caregiver's anxious attachment, and marital satisfaction of the caregivers were the significant predictors of depression among the caregivers (Braun, Mikulincer, Rydall, Walsh, & Rodin, 2007). Caregivers levels of education and duration

of patients' illness were also found to be associated with depression (Ambigga Devi, Sherina, & Suthahar, 2005).

Studies show that caregivers who are more likely to experience depression are; female, spouse of the patients, and caregivers with poor health. In addition, caregivers who are adapting poorly, feeling burdened by caregiving, caring for patient with poor performance status are more likely to experience depression. A study used Korean Caregivers Quality of Life, measuring three variables such as burden, disturbance, and financial concern. It was seen that young family caregivers, caregivers who were caring for male patients, had a low quality of life (Park et al., 2013).

Somatization among Patients and their Family Caregivers

Apart from distress, depression, and anxiety somatization is also seen among cancer patients. Somatization is viewed as a “process in cancer patients which is a challenging and neglected area, for the extreme difficulty in differentiating and assessing the psycho (patho) logical components from those biologically determined and related to cancer and cancer treatment, as well as for the scarce usefulness of rigid categorical DSM criteria” (Grassi, Caruso, & Nanni, 2013). The study of Zimmerman, Story, Gaston-Johansson and Rowles (1996) found that there is an association between pain in cancer patients and their level of anxiety, depression, somatization and hostility. “The study of somatization in cancer patients is intriguing because there is a dual relationship—between cancer and somatic symptoms, and psychological problems and somatic symptoms” (Chaturvedi, & Maguire, 1998). Presence of somatic symptoms in cancer patients can complicate the course of the disease. And can also complicate the outcome of treatment. Somatization is also found to have negative influence on the QoL of cancer

patients. For example, Kirchhoff et al., (2011), found that male survivors of cancer who experience somatization and memory problem reported higher risk of health-related unemployment when compared with survivors with normal physical health. The most unmet supportive care needs for cancer patients were psychological which once again shift our focus to the major support providers who are caregivers. As seen in preceding section, while support is expected from the caregivers, support to caregivers remains a largely unexplored area.

As is seen with other psychological states, somatization needs to be explored not only in cancer patients, but also in the caregivers of cancer patients. Caregivers are found to have higher somatization than non-caregivers (Pakenham, Bursnall, Chiu, Cannon, & Okochi, 2006). Chambers et al. (2012) conducted study on 354 cancer patients and 336 caregivers, in which it was found that 53.4% of cancer patients have caseness in somatization or depression and anxiety. It was also found that cancer patients had higher somatization when compared with caregivers. Thus, studies on somatization of cancer patients and their caregivers gave mixed results. In the study of Gropper, van der Meer, Landes, Bucher, Stickel and Goerling (2016) on cancer patients and caregivers, it was found that both the patients and caregivers have no differences in psychosomatic complaints. On the other hand, a study by Areia, Fonseca, Major, and Relva (2018) also found an almost similar result where 50.9% of family caregivers of cancer patients reported high level of somatization. Presently, literature that focuses on somatization among caregivers of cancer patients appears sparse. Therefore, further studies on the symptoms, prevalence and intervention on somatization among cancer patients and their caregivers who are also their family members is required, as well as its impact on QoL.

Interpersonal Relationship between the Patients and their Family Caregivers

Studies have been pointing to the effect of cancer on patient diagnosed with it through the illness and treatment. It was also seen that there is a possibility that both the patient and the caregiver are affected, or one of them is psychologically affected. In such situations, the relationship between the patient and the caregiver may be affected too. It is well known that partners and family members play a supportive role for the cancer patients. Though there are those caregivers who cope well with their role as a caregiver, there are also caregivers who become highly distressed and develop affective disorder (Pitceathly, & Maguire, 2003). In their review Pitceathly & Maguire (2003) examined the psychological impact of cancer on partners of the patients and other key relatives and concluded that caregivers who are in conflicted relationships, those who view illness-related events negatively or view their caregiving role as negative impact in their lives are more likely to have problems. This is seen even more if support received is less and patient they care for is depressed. For patients, women and those with history of psychological problems prior to the diagnosis of cancer, and caregivers of patients who are nearing death are more vulnerable to psychological problems. The study suggested the requirement of a tailor-made model of adjustment, which incorporates risk factors of negative psychological states such as intrapersonal and interpersonal.

According to Pistrang and Barker (1995), interpersonal relationship plays a key role in adaptation to serious illness. In their study they interviewed 113 first time diagnosed breast cancer patients. Their interview was structured interview and includes items related to anxiety, depression, and hostility. Findings also showed that women who found talking to their partner more helpful reported less distressed, and also good

communication with partner was characterized by high empathy and low withdrawal. This study thus highlighted the important role the partner plays in BC patients' adaptation. Studies thus indicated importance of interpersonal relations between patients and their caregivers. However, the problem in communication among patients and their caregivers was found to be high in the study of Zhang and Siminoff (2003). It was reported that 65% of the couples who participated in their study experienced problem in communication.

Studies pointed that maintaining good communication and congruence between the patients with cancer and their caregivers is important. A review was done by Li and Loke (2013), to explore concepts of mutuality among spouse caregivers and cancer patients dyads. From 31 articles they have found that communication between the dyad, reciprocal influence of each other, and caregiver-patient congruence were interrelated and contribute to the spouse caregivers and patients' dyads' mutual appraisal of caregiving and role adjustment through the course of cancer. It is important to focus on the nature of relationship between the patients and their spouse in their coping with cancer. Their findings also suggested the importance of quality of communication between patients and their spouse.

During a chronic illness maintaining good interpersonal relationship between the patients and caregivers becomes important. In addition to illness, having a poor relationship with caregivers can have dire consequences for the dyads. Both illness and the uncertainties associated with physical health, life, finances, employment, and others may be discomfoting and worrying to both the patient and caregiver. All this may also affect their interpersonal relationship in terms of mutual communication and other

aspects of relationship. Both in the dyad require care and share mode of support. However, the patient being the sufferer may demonstrate certain states psychologically or expect certain support. The caregiver who is likely to be undergoing similar psychological states owing to the new roles and responsibilities is expected to provide the support. These undercurrents may influence the interpersonal relationship. One of the aspects of interpersonal relationship is communication. Being able to communicate or talk to the spouse or caregiver may be helpful in many ways. Relationship talk is an important aspect of good interpersonal relationship, it refers to “talking with a partner about the relationship, what one needs from one’s partner, and/or the relationship implications of a shared stressor” (Badr & Acitelli, 2005).

Having good communication between partners helps to define their relationship better, it helps in repairing the aspect of relationships that are not functioning well (Duck, 1995; Baxter & Bullis, 1986). Both these functions according to Badr, Acitelli and Taylor (2008) are relevant in cancer ‘as couples must adapt to new roles and responsibilities, incorporate the reality of the diagnosis of cancer in the patient in their everyday lives, and overcome constraints on spousal communication that may adversely affect relationship functioning’. These researchers conducted a study to examine the effects of relationship talk on lung cancer patients and their partners’ psychosocial adaptation to cancer. The results showed that couples who reported more frequent relationship talk had less distress and greater marital adjustment over time, regardless of gender. Communication is also observed to be an unmet need of the caregivers who are also family members (Sklenarova et al., 2015). The problem in communication among patients and their caregivers was reported by Zhang and Siminoff (2015) as high. Among their participants 65% of the

couples reported that they experienced problem in communication. Therefore, understanding the nature of relationship between the patients and their caregivers is necessary, as it is the first step to help improve interpersonal relationship and thus, better adjustment to the illness.

Quality of Life among Patients and their Family Caregivers

A review of literature pertaining to cancer patients shows multiple psychosocial consequences of illness diagnosis and treatment. Studies indicate several problems with respect to adjustment with life among the two groups of cancer patients considered for present study, BC and HNC. Studies have shown that one out of every three newly diagnosed patients with BC experiences significant difficulty in adjustment (Yeole, Kurkure, 2003; Kothari, et al. 2002; Walker, Lees, Webb, & Dearing, 1996). At the time of diagnosis patients experience confusion, uncertainty and even distress. Therefore, treatment is required beyond physical domain, as the diagnosis further affects the body image, sexuality and family life (Zabora et al., 1997; Schover, 1994). Rehabilitation is required for psychological, social, sexual, nutritional, financial and vocational aspects (Dunn & Steginga, 2000; Schover, 1994). In this era of cancer management, focus is more on the QoL than on the quantity of life; where attainment of total cure is not possible, measuring QoL and following it up may indicate acceptance, adaptation to the disease (McNeil, 2008; Sajid, Tonsi, Baig, 2008; Testa, Simonson, 1996) “Quality of Life is subjective and patients own judgement in this respect is a major determinant, in a way it is described as a quality of being” (Benner,1985). QoL has been defined by Morton and Izzard (2003) as “perceived discrepancy between the reality of what a person has and the concept of what the person wants, needs, or expects”.

In a study conducted by Pandey, Singh, Behere, Singh and Shukla (2000) on 50 BC patients (early and advanced carcinoma) at Varanasi, the objectives were to assess the QoL determinants in patients with BC and the impact of treatment on QoL. The results showed that among their participants, significant deterioration was seen in health-related index of QoL such as recreation, social life, mobility, physical activity, sleep and appetite. Their study also found that self-care and recreation were the most important indices that influence QoL.

Early effect of surgery on QoL among women with BC was explored by Pandey, Thomas, Ramdas and Ratheesan (2006). In this study, interview was conducted prior to and after surgery on 251 women with BC who were undergoing surgery. This study showed significant decrease in physical well-being and functional well-being after surgery, and QoL was significantly poor among women who had undergone mastectomy. QoL among patients with BC is determined and associated with various factors. For example, Kwan et al., (2010) found among patients recently diagnosed with invasive BC those that are at younger age at the time of diagnosis and those that were more at advanced stage of BC were associated with lower QoL and that social support had positive relationship with QoL. Pandey et al., (2005) in their study on 504 patients with BC undergoing curative treatment, also found that factors such as religion, stage, pain, spouse education, nodal status, and distance travelled to reach the treatment center influence patients' QoL. In this study they also found that women younger than 45 years of age, women having unmarried children, nodal and/or metastatic disease, and those currently undergoing active treatment showed significantly poorer QoL.

While all the above studies indicate the lowered QoL in cancer patients, studies also indicate the role of social support in QoL of patients along with other variables. A study was conducted by Yan et al., (2016), to evaluate the relationship between of support received from others, health insurance and clinical factors with the QoL of women with BC. Their findings showed that adequate social support from family, friends and neighbors, was associated with significantly improved QoL among the participants. Such findings once again direct our focus to the role of caregivers.

Among HNC patients swallowing, chewing, saliva, eating disruption, taste, and aesthetic deficit may persist (Rathod, Livergant, Klein, Witterrick, & Ringash, 2015). Though multimodal treatment such as surgery, chemotherapy, and radiation has increased disease control, it may also have side effects which impact the QoL of the patients. In a study done in India by D'Souza, Chakrabarty, Sulochana, & Gonsalves (2013), on patients with HNC receiving cancer specific treatment, it found that out of 89 sample 30% have poor quality of life. Positive correlation was also found between the domains of QoL and performance status.

Some studies suggested that QoL of cancer patients and their caregivers are known to be interdependent. One of such studies is the study conducted by Mellon, Northouse and Weiss (2006) where they examined the QoL of cancer patients and their caregivers. In their cross-sectional study, they included 375 Whites and African Americans who survived cancer and their caregivers were interviewed. Their study indicated that both the cancer survivor's and family caregiver's QoL independently contributed to the other's QoL. This suggested the importance of including the family caregivers in the program of cancer care.

Though the experience of caregiving may sometimes be a meaningful experience, it is also associated with declining of QoL (Schulz & Beach, 1999). And studies on impairments of QoL of family caregivers are mostly done in Western population (Lim, et al., 2017). Few studies done in India also suggested the association between cancer patients and their caregivers' QoL. In a study by Padmaja, Vanlalhrui, Rana, Tiamongla and Kopparty (2016) which included 206 pairs of cancer patients and their family caregivers from Aizawl and Hyderabad in India, explore the relationship between the QoL of cancer patients and their family caregivers. Their findings indicated that patients and their family caregiver QoL correlate highly and significantly. For example, with decline in patients' QoL on parameters such as global health status, emotional functioning, and social functioning there is an increase in the caregivers' difficulties related to quality of life. Studies on caregivers' QoL in relations with illness duration are inconclusive. A longitudinal study of Le et al. (2004) on caregivers of cancer found that at the conclusion of treatment for the patients, their caregivers QoL improved from the initial stage of treatment. On the other hand, the study of Borneman et al. (2003) reported worsened caregivers' QoL. Gender difference among caregivers of cancer patients in terms of QoL is not clear. While study of Iconomou et al., (2001) shows gender difference where wives of cancer patients have lower QoL than the QoL of the husbands of cancer patients quality of life. Contrasting results were seen in some other studies which report no gender difference in QoL among caregivers of cancer patients (Hagedoorn, Buunk, Kuijer, Wobbles, & Sanderman, 2000; Borneman et al., 2003).

Caregivers' QoL has many influencing factors. These factors include patients' factors such as stage of the disease and efficacy of the patients (Campbell et al., 2004;

Koot, Heer, Oort, Hulshof, Bosch, & de Haes, 2004; Mathew, Baker, & Spiller, 2004; Hahn, Dunn, Logue, King, Edwards, & Halperin, 2003). Among caregivers of other chronic illnesses, gender of the caregiver, age health status, duration of caregiving, levels of mobility and cognitive impairment were significant indicators of caregivers QoL (Morley, Dummett, Peters, Kelly, Hewitson, Dawson, Fitzpatrick & Jenkinson, 2012). Being primary caregiver is also found to be related with decrease in caregivers' QoL (Reis & Gomes, 2013). For caregivers of cancer patients, factors such as stress (Kim, Spillers, & Hall, 2012; Kim, Baker, & Spillers, 2006), depression, anxiety, characteristics of caregivers such as age, employment, personal attributes such as positive expectation, self-efficacy, and esteem (Kim, Baker, & Spillers, 2006), good health, appraisal of caregiving role, and social support, depression and anxiety effect their QoL of caregivers of cancer patients. In the study done by Gorji, Bouzar, Haghshenas, Kasaeeyan, Sadeghi, & Ardebil, (2012) it was found that caregivers of BC patients have poor quality of life.

Previous researches had their focus mainly on cancer patients, their psychological states, QoL and other experiences that they have gone through owing to cancer. It is not until recently that caregivers of cancer patients are given attention to. Considering the important role that they play during cancer illness trajectory and the importance of their inclusion in the health care system, there are still very few studies. Kitrungrrote and Cohen (2006) stated in their study that few researchers have explored QoL of caregivers of cancer patients. Though there are more research related to caregivers of cancer patients there is a scarcity of research related to QoL of family caregivers of cancer patients especially in India. Keeping in view of this scarcity the present study has its prime focus on QoL of caregivers of patients with BC and HNC.

The rate at which cancer diagnosis of cancer patients is increasing each year is alarming and patients diagnosed with cancer need physical as well as psychological support during their illness. It is the untrained, unprepared family caregivers which provide such support. Caregiving is a dynamic and on-going process, and role of caregiving can have negative impact on the caregivers. As mentioned earlier in this chapter, there is a disruption in daily routine, job, and social life for caregivers owing to the patient's diagnosis and treatment.

Patients levels of physical functioning or activities are often related to family caregivers' psychological states. The lower the patients' level of physical functioning or activities the more negative psychological states experienced by the family caregivers, and in turn the family caregivers may have poor QoL. Studies show that like patients, family caregivers of cancer patients experience distress, depression, anxiety and somatization, some studies even reported even higher distress among family caregivers of cancer patients. However, literature related to impact of patients' level of physical functioning or activities on their family caregivers gave contrasting results, hence there is a requirement of more studies related to this topic to find out the association between patients' levels of activities and their family caregivers.

During the cancer journey, the interpersonal relationship between patients and caregivers plays an important role. It involves open and proper communication between patients and family caregivers. It is also important that cancer patients and their family caregiver perceive the care and support that each of them gives to each other. Inability to perceive the effort that another person shows may result in strained relationship between the cancer patients and their family caregivers, thus resulting in poor outcome during the

illness journey and even in poor quality of life. However, the paucity of research related to interpersonal relationship especially from the perspective of both cancer patients and their family caregivers indicates the need for studies related to this area and its impact. Keeping in mind the above, the present study looks into the following research questions.

Research Questions

1. What is the level of psychological states and perception of the interpersonal relationship among cancer patients (BC & HNC) and their family caregivers?
2. What is the level of quality of life of family caregivers of cancer patients (BC & HNC)?
3. Are there any differences in the levels of psychological states, interpersonal relationship among caregivers, categorized on the basis of patients' activity levels?
4. Is there an agreement in the perception of the interpersonal relationship between cancer patients (BC & HNC) and their family caregivers?
5. What are the indicators of family caregivers' quality of life?
6. Can the family caregivers of cancer patients (BC & HNC) be categorized into groups based on their quality of life and are there any differences in the indicators of their quality of life?

Objectives

From the above research questions, the following objectives are formulated.

1. To assess the level of psychological states and perception of the interpersonal relationship among cancer patients (BC & HNC) and their family caregivers and assess the quality of life of family caregivers.
2. To find out the differences in the levels of psychological states, interpersonal relationship, and quality of life among caregivers, categorized on the basis of patients' activity levels.
3. To find out the agreement or disagreement in perception of the interpersonal relationship between cancer patients (BC & HNC) and their family caregivers.
4. To find out the indicators of family caregivers' quality of life.
5. To categorize family caregivers of cancer patients (BC & HNC) based on their levels of quality of life and to examine the differences in indicators of their quality of life.

Hypotheses

To address the objectives of the present study the following hypotheses were formulated. However, no hypothesis was formulated against the first objective.

1. There will be differences in the levels of psychological states, interpersonal relationship, and quality of life among caregivers, categorized on the basis of patients' activity levels.
2. There will be an agreement between cancer patients and their family caregivers in their perception of the interpersonal relationship.

3. Family caregivers' quality of life will be predicted by specific dimensions of patients' activity level, the interpersonal relationship, and psychological states of cancer patients and their family caregivers.
4. There will be differences in indicators of quality of life among family caregivers categorized on the basis of their quality of life.

CHAPTER III

METHOD

This chapter contains plan and design, description of the participants, and the measures used with their psychometric properties. This chapter also includes the procedure followed after obtaining the approval from the Institutional Ethics Committee of University of Hyderabad for the study. All measures and procedures of the study were approved by the committee.

Plan and Design

It was planned to approach Government and Corporate Hospitals where treatment for cancer is provided. It was planned to recruit women suffering from breast cancer and men suffering from HNC. It was also planned to recruit family caregivers of these patients' that is either spouse or blood relatives. It was planned to assess a) level of physical activity, b) psychological states, and c) perception of interpersonal relationship of the patients. It was also planned to assess a) assess psychological states, b) perception of the interpersonal relationship, and c) quality of life of family caregivers.

The study used between-groups design. And the main study was conducted on patients with breast cancer, head and neck cancer and their family caregivers.

Participants

The participants for the study included patients with Breast Cancer (BC), Head and Neck Cancer (HNC) and their family caregivers. These participants were selected from two cities in India i.e Aizawl in the state of Mizoram and Hyderabad in the state of

Telangana. The hospitals included in the study were two Government Hospitals and two Corporate Hospitals. The inclusion and exclusion criteria considered for recruitment of the participants are given below.

Inclusion criteria for cancer patients. The inclusion criteria for recruiting cancer patients were; i) Diagnosed with breast cancer (female), head and neck cancer (male), ii) Undergoing curative treatment, iii) Cancer stage below IV stage

Exclusion criteria for cancer patients. The following exclusion criteria were considered while recruiting the participants with cancer in the study: i) Patients with history of mental illness, ii) Patients age below 18 years

Inclusion criteria for Family Caregivers of cancer patients. The following criteria were considered for inclusion of caregivers of patients: i) Family member of the patient, either spouse or blood relative, ii) Primary caregiver of the patient, iii) Age above 18 years

Exclusion criteria for Family Caregivers of cancer patients. The following exclusion criteria were considered while recruiting the caregivers of cancer patients in the study: i) Caregiver undergoing treatment for chronic illness, ii) Caregiver with history of mental illness.

Informed Consent. Through a separate informed consent form, consent was obtained from the participants that is both patients and family caregivers of patients. The informed consent form included information sheet which includes description regarding the purpose of the study, the risk or discomfort that may be associated with the study, confidentiality of the data and the rights of the participants.

During the study, 270 pairs were approached. However, with respect to 27 of the pairs, either the patients or their caregivers or both declined to participate in the study. Another 4 pairs were also removed from the study due to patients' demise. In order to increase sample size, new pairs fulfilling the criteria were recruited. Data cleaning was done by computing Mahalanobis distance. The final sample consisted of 248 patients with breast cancer and head and neck cancer, and 248 of family caregivers of the mentioned cancer patients.

The age range of patients was 20 to 65 with mean age of 48.29 ($SD= 10.99$). Among the patients, 49.6% were men with head and neck cancer and 50.4% were women with breast cancer (Table 1). Among the patients 19.8% reported family history of cancer and the rest 80.2% were without family history of cancer. Majority of the patients that is 91.2% were married, whereas, 6% were unmarried, 0.8 % were divorced and 2% were widow/er. Among the patients 36.7% were employed, 6.5 % were self-employed, 55.6% were unemployed and 1.2% were retired.

Among all the participants and their family caregivers, 59.3% were from lower socio-economic background, 39.5% from middle socio-economic background and 1.2% from upper socio-economic background. Among the patients 24.6% reported to be smoking, 2.8% reported to be drinking alcohol, 7.3% were habituated to both smoking and drinking alcohol. Among 248 patients 2.4 % reported that they used to chew pan i.e. betel nut, 15.7% reported that they take tobacco other than smoking (e.g. chewing) and 47.2% reported that they reported to none of the above mentioned lifestyle issues. Among 248 patients 55.2% have their spouse as their caregivers and 44.8% of the patients had their blood relatives including siblings, children, and parents as their caregivers (Table 1).

The age range of the family caregivers were 18 to 65 with mean age of t 40.09 ($SD= 12.67$). Among Caregivers 35.2% were men and 64.8% were women (Table 2). Among the 248 family caregivers, 84.7% were married and 15.3% were unmarried. Among the 248 family caregivers 26.2% of patients were employed, 8.1 % were self-employed, 65.3% were unemployed and 0.4 % were retired. Among 248 family caregivers of patients 9.6% were smoking, 2.4% were drinking alcohol, 6.8 % reported that they chew pan i.e. betelnut, 6.8% reported that they take tobacco other than smoking (e.g. chewing) and 74.2% reported none of the above mentioned lifestyle issues (Table 2)

Table 1
Demographic details of patients with BC and HNC (n= 248)

Demographic Detail	Frequency	Percentage
Patients		
Breast cancer	125	50.4
Head and Neck cancer	123	49.6
Family history of cancer		
Yes	49	19.8
No	199	80.2
Marital status for patients		
Married	226	91.1
Single	15	6
Divorced	2	.8
Widower/widow	5	2
Occupation		
Employed	91	36.7
Self-employed	16	6.5
Unemployed	138	55.6
Retired	3	1.2
Socio economic status		
High	3	1.2
Middle	98	39.5
Low	147	59.3
Lifestyle issues		
Smoking	61	24.6
Alcohol	7	2.8
Smoking and alcohol	18	7.3
Pan	6	2.4
Tobacco	39	15.7
None	117	47.2
Nature of Relationship with caregivers		
Spouse	137	55.2
Blood Relatives	111	44.8

Table 2
Demographic details of Caregivers of patients with BC and HNC (n = 248)

Demographic Detail	Frequency	Percentage
Caregiver		
Male	87	35.2
Female	161	64.8
Marital status for caregivers		
Married	210	84.7
Single	38	15.3
Divorced	0	0
Widower/widow	0	0
Occupation		
Employed	65	26.2
Self-employed	20	8.1
Unemployed	162	65.3
Retired	1	.4
Socio economic status		
High	3	1.2
Middle	98	39.5
Low	147	59.3
Lifestyle issues		
Smoking	24	9.6
Alcohol	6	2.4
Smoking and alcohol	0	0
Pan	17	6.8
Tobacco	17	6.8
None	184	74.2

Research Instruments

In this study four measures were used along with the demographic data form of the participants. The measures were Eastern Cooperative Oncology Group Performance Status (Oken, Creech, & Tormey, 1982), The Four-Dimensional Symptom Questionnaire (Terluin et al., 2006) and Cancer Specific Interpersonal Relationship Scale (Caregivers' and Patients' Perception), developed for the purpose of the present study, The Caregiver

Quality of Life Index- Cancer (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). Those measures whose items are in English were translated into Mizo and Telugu by two experts for the participants' better understanding of the items. The translated version was then re-translated into English by another two experts, then this back translation was compared with English version to elude ambiguity of the items. The measures are appended (*Appendix B*). The descriptions of the measures are given below with their psychometric properties and scoring procedures.

Eastern Cooperative Oncology Group Performance Status (ECOGPS)

The ECOGPS was developed by Oken, Creech, and Tormey in 1982. It was used to measure the performance status of cancer patients. ECOGPS is used to quantify the functional status of cancer patients, it is also an important factor that determines the prognosis in a number of malignant conditions. ECOGPS describes the status of symptoms and functions with respect to patient's ambulatory status and need for care. The ECOGPS grades range from 0 to 5, where 0 grade indicates fully active and able to carry out pre-disease normal activity; grade 1 indicates presence of some symptoms but still near fully ambulatory; grade 2 means spends less than 50% on bed; grade 3 means spends more than 50% on bed; grade 4 means completely disabled and need care and grade 5 indicates dead.

The Four-Dimensional Symptom Questionnaire (4DSQ)

The 4 DSQ was used to measure the psychological state of the participants. The 4 DSQ was developed by Terluin, et al. (2006), and is a self-report questionnaire that has been developed to distinguish non-specific general distress from depression, anxiety and

somatization. The 4 DSQ comprises of 50 items that are divided into four dimensions such as distress, depression, anxiety and somatization. Each item has responses such as no, sometimes, regularly, often, and very often or constantly.

In the 4DSQ, distress has 16 items (e.g. During the first week, did you suffer from worry?). Depression dimension has 6 items (e.g. During the past week, did you feel that everything is meaningless?), while anxiety has 12 items (e.g. During the first week, do you suffer from a vague feeling of fear?). In 4DSQ somatization dimension in this scale has 16 items (e.g. During the past week, did you suffer from dizziness or feeling light-headed?)

Scoring. Scoring was done by summing up all the scores of items in each dimension. The response ‘no’ was scored as 0, response ‘sometimes’ was scored as 1 and for the responses such as ‘regularly’, ‘often’ and ‘very often’ score was 2. For distress dimension if the score obtained is more than 10, it was interpreted as ‘moderately elevated’ and if the score is more than 20, it was interpreted as ‘strongly elevated’. For the dimension depression if the score obtained is more than 2, it was interpreted as ‘moderately elevated’ and if the score obtained was more than 5, it was interpreted as ‘strongly elevated’. In anxiety dimension if the score obtained was more than 4, it was interpreted as ‘moderately elevated’, if the score obtained was more than 10, it was interpreted as ‘strongly elevated’. Lastly, for the dimension of somatization if the score obtained was more than 10, it was interpreted as ‘moderately elevated’ and if the score obtained was more than 20, it was interpreted as strongly elevated.

Psychometric Properties. The Cronbach's alpha of 4DSQ varied between 0.84 and 0.92 (Terluin, Smits, Brouwers & de Vet, 2016) and the criterion validity of the 4 DSQ was also established.

Cancer Specific Interpersonal Relationship Scale (CANSIRS)

The CANSIRS (Padmaja, Vanlalhruii, & Rana, 2018) developed for this study was used to assess the cancer patients and family caregivers' perspective on their interpersonal relationship with each other. The scale has 24 items which include positive and negative items. CANSIRS is measured on 5-point scale (1=never, 2= Rarely, 3=Sometimes, 4= Often, 5=Always). CANSIRS comprises of two forms Form A for Caregivers and Form B for Patients, the items in form A and Form B are parallel to each other. The scale CANSIRS also have five dimensions—mutual communication which is the first dimension consisted of nine items and included statements related to the communication between the dyad that is patients and their family caregivers (e.g. I talk openly with him/her about his/her illness- Form A; I talk openly with my caregiver about my illness- Form B). The second dimension is mutual relationship, this dimension consisted of six items related to the relationship between patients and family their caregivers (e.g. I receive his/her emotional support- Form A; I receive emotional support from my caregiver- Form B). The third dimension is attention and support which consisted of three items related to attending and being a support, the patients and their family caregivers are to each other (e.g. I see to it that he pursues his/her interest despite his/her illness- Form A; I see to it that my caregiver takes some time off to pursue his/her interests- Form B). The fourth dimension is availability and providing comfort which consisted of three items that are related to giving comfort to each other (e.g. I try to make

him forget about his/her illness- Form A; My caregiver makes me forget about my illness- Form B). Lastly, the fifth dimension is mutual care and have three items related to care given and received from each other that is between patients and their family caregivers. (e.g. The love that I have for him/her helps me in caring for him/her- Form A; I feel loved by my caregiver- Form B).

Scoring. The score of the scale was found by summing up the responses of the participants for each item. For negative items the scoring was reversed. CANSIRS total score range from 24 to 120. Higher the score better the relationship.

Psychometric Properties. The Cronbach Alpha for CANSIRS was found to be .93.

Caregiver Quality of Life - Cancer (CQOLC)

The CQOLC (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999) was used to measure the levels of Quality of Life of caregivers of cancer patients (e.g. My level of stress and worries have increased). It consisted of 35 positive and negative items which were scored on 5-point scale (0= Not at all, 1= A little bit, 2= Somewhat, 3= Quite a bit and 4= Very Much). Tamayo, Broxson, Munsell, and Cohen (2010), divided the CQOLC into four dimensions such as burden (e.g. I feel frustrated), disruptiveness (e.g. It bothers me that my daily routine is altered), positive adaptation and financial concern (e.g. My sense of spirituality has increased) and support (e.g. I get support from my friends and neighbors).

Scoring. Negative items are scored reversed. Total score was found by summing up the item scores and it ranges from 0 to 140. Higher the score, worse caregivers'

Quality of Life (Tan, Mollassiotis, Lloyd-Williams & Yorke, 2017, Ozer, Firat & Bektas, 2009; Carter, 2006).

Psychometric Properties. The test-retest reliability was 0.95 and internal consistency coefficient was 0.91, the scale also possesses adequate validity (Weitzner, Jacobsen, Wagner and Cox, 1999). The Cronbach alpha coefficient of burden was 0.9, disruptiveness was 0.84, positive adaptation and financial concern was 0.74 and support was 0.28 (Tamayo, Broxson, Munsell, & Cohen, 2010).

Demographic Data Form

This refers to patient and caregiver's demographic forms which sought information regarding demographic and medical details, relationship with patient or caregiver, and contact information that were relevant to the study.

Procedure

The procedure involved in the study has been described in the following paragraph.

Ethical Clearance and Permission. Before the commencement of the pilot study ethical clearance was obtained from the Institutional Ethics Committee, University of Hyderabad (*Appendix A*). In order to use the scale selected for pilot study, the investigator intended to ensure that permissions for all measures were sought. However, the scales used in this study were available in public domain and hence were used without needing any specific permission. The Four-Dimensional Symptom Questionnaire (4 DSQ) and the Caregivers Quality of Life Index- Cancer Scale were downloaded from Measurement Instrument Database for the Social Sciences. The sites for data collection

was finalized after two Government Hospitals and three corporate hospitals in two cities i.e. Aizawl and Hyderabad were approached and permissions were obtained from these Hospitals. The newly developed scales as well as the other scales deemed to be used in the study were translated into Telugu and Mizo which are regional languages and the procedure of back translation to ensure proper translation was done.

Pilot Study. Pilot study was also conducted to examine the effectiveness and feasibility of CANSIRS and other measures to be used in the main study. To examine the feasibility of the proposed design and to verify the accessibility and availability of the sample, pilot study was done. After the above mentioned conditions were met, main study was conducted. However, before pilot study was started, CANSIRS was constructed and the following phases were followed for the construction of the scale.

Phases of Construction and Development: The scale was developed through three phases—item writing, content evaluation and naming and establishment of psychometric properties and preliminary validation.

Phase 1: Item Writing. Before the items were constructed, extensive review of literature on interpersonal relationship was done. Four scales on the related areas were also referred, such as Fundamental Interpersonal Relationship Orientation- Behaviour (Schutz, 1958), Interpersonal Solidarity Scale (Wheelees, 1976), Relationship Assessment Scale (Vaughn & Baier, 1999), and Dyadic Adjustment Scale (Spanier, 1976). Multiple in-depth interview sessions were also conducted with cancer patients (diagnosed with breast cancer, head and neck cancer) and their family caregivers. Three psychologists and an oncologist having more than 10 years of experience were consulted during item writing phase. Basing on these, five major theoretical dimensions related to

interpersonal relationship were identified—mutual communication, mutual relationship, attention and support, availability and providing comfort, and mutual care. Subsequently, items were written for family caregivers of cancer patients. Initially, 50 items belonging to the five dimensions were generated. These items were revisited to increase the readability and were administered on the target group (n=20) and feedback was collected from each of the participants. Based on the feedback, some of the items were modified to improve clarity and simplicity. After modification, all 50 items were retained.

Phase 2: Content Evaluation and Naming. The scale underwent the standard process of content evaluation to find out if the scale captured the essence of interpersonal relationship. Therefore, 10 experts from the field of Psychology and Oncology were requested to read the scale. They were asked to mark each item if it was ‘essential’ or ‘non-essential’ to measure the interpersonal relationship between cancer patients and their family caregivers. Only items that were marked essential by all the experts were retained and in this way 35 items were retained as per the suggestion. A 5-point scale was adopted to rate each item (1= never to 5= always). The scale was named as Cancer Specific Interpersonal Relationship Scale-Caregiver/ Patients and abbreviated as CANSIRS.

Phase 3: Establishment of the Psychometric Properties and Preliminary Validation: After naming, the scale was ready for pre-test to assess its initial psychometric properties and to establish preliminary validation. The results of the establishment of psychometric properties and preliminary validation is appended (*Appendix D*)

Main Study

For the main study data were collected from 248 patients with breast cancer, head and neck cancer and their Caregivers.

Recruitment Process. A patient and his/her family caregiver who fulfilled the criteria for this study were approached in the hospitals where data collection were permitted. The investigator visited the potential participants at hospital wards or rooms and out-patients units. After brief introduction and rapport building, the patients and their Caregivers were given information sheet which includes information regarding the purpose of the study, the risk or discomfort that may be associated with the study, confidentiality of the data and the rights of the participants (*Appendix B*). After the doubts were clarified, and if both the patient and the caregiver agreed to participate in the study, they were asked to sign or give thumb impression on the consent form (*Appendix B*). Both the patient and his/her caregiver's details were collected using demographic data forms.

Administration of the measures. After the informed consent was signed by the participants, first Eastern Cooperative Oncology Group Performance status was administered to the patient only, then the measures—Four-Dimensional Symptom Questionnaire and Cancer Specific Interpersonal Relationship Scale Form B were given to the patients, while Caregivers Quality of Life- Cancer, Four-Dimensional Symptom Questionnaire and Cancer Specific Interpersonal Relationship Scale Form A were given to their family caregivers. Instructions were given on how to give response to the measures, after which the participants were requested to start answering the measures. Each measure took between 15 to 20 minutes to complete. For some participants,

measures were asked orally depending upon the comfort and when it was needed. Breaks were given between administration of the measures. Any question raised by the participants during the administration of the measures was clarified by the investigator, and after each assessment the participants were debriefed.

Data Analysis

The data were analyzed using the IBM SPSS version 20.0 to compute descriptive statistics (Frequency, Mean, and Standard Deviation), and inferential statistics such as One-way ANOVA, Tukey's HSD, Eta Squared, Pearson's Product Moment Correlation (r), hierarchical regression, and k-mean cluster analysis. MATLAB programming was also used in order to compute the agreement in the perception of the interpersonal relationship between patients with BC and HNC and their family caregivers. From this point on patients with BC and HNC will be referred to as patients and family caregivers will be referred to as caregivers.

CHAPTER IV

RESULTS

This chapter includes the description of the results. Quantitative data analysis was used to address the objectives of the study. The study essentially aimed at finding out the effect of patients' activity level on caregivers' Quality of Life (QoL). It also aimed to find out the effect of psychosocial factors of patients and their caregivers on caregivers' QoL. The first objective of the study was to assess the level of psychological states and perception of the interpersonal relationship among cancer patients (BC & HNC) and their family caregivers and assess the quality of life of family caregivers. Descriptive statistics such as mean, standard deviation, 95% *CI* and frequency was computed for patients and their caregivers.

Another objective of the study was to find out the differences in the level of psychological states, interpersonal relationship, and quality of life among caregivers, categorized on the basis of patients' activity levels. One-way between groups ANOVA was conducted across the groups on caregivers' psychological states, interpersonal relationship and QoL. The three groups of caregivers based on the patients' physical activity level acted as the independent variables, caregivers' psychological states, interpersonal relationship and QoL were the dependent variables. Post Hoc analysis was also done.

The study also planned to find out the agreement or disagreement in perception of the interpersonal relationship between cancer patients (BC & HNC) and their family caregivers. Feature analysis was done and it resulted in the development of three features

based on the agreement and disagreement between patients and their caregivers. The procedure followed for the development of feature is explained in this chapter.

Another objective of the study was to find out the indicators of caregivers' quality of life and its four dimensions. Pearson product moment correlation between caregivers QoL (with its four dimensions) and caregivers' demographic variables, patients' level of physical activity, quality of interpersonal relationship based on agreement in perception of patients and caregivers and psychological states of patients and caregivers. Hierarchical regression analysis was conducted for those variables that have significant correlation with caregivers' QoL and its four dimensions. Altogether, five hierarchical regression analyses were done. Criterion was caregivers' QoL and its four dimensions. The study also aimed to categorize family caregivers of cancer patients (BC & HNC) based on their levels of quality of life and to examine the differences in indicators of their quality of life.

As the focus is on caregivers' QoL and the scale—Caregivers QoL- Cancer (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999) did not have norm for scoring, the natural occurrence of group among caregivers based on their QoL is included. A cluster analysis method, *k*-means cluster analysis was done and three groups were identified. A one-way ANOVA was conducted to find out differences among the categories of caregivers on indicators of their QoL. From this point on patients with BC and HNC will be refer to as patients and family caregivers will be refer to as caregivers. Also, caregivers without lifestyle issues and caregivers not indulging in any of the lifestyle issues will be used interchange.

Levels of Interpersonal Relationship

The first objective of the study was to assess the level of psychological states and perception of the interpersonal relationship among cancer patients (BC & HNC) and their family caregivers and assess the quality of life of family caregivers. Patients and their caregivers' perception on their interpersonal relationship was assessed using Cancer Specific Interpersonal Relationship—CANSIRS, which is developed for the purpose of this study. The parallel scales which consist of Form A (Caregivers) and Form B (Patients) have five dimensions. Table 3 depicted the means, standard deviations, and 95% *CI* of the interpersonal relationship as perceived by patients. The mean score of patients on overall interpersonal relationship was 82.27 (*SD* = 19.04). The mean score of patients on the dimension of mutual communication was 31.29 (*SD* = 9.95), the mean score of patients on the dimension of mutual relationship was 22.67 (*SD* = 5.42). Also shown in Table 3, the mean of patients on the dimension of attention and support was 8.93 (*SD*= 2.22), on the dimension of availability and providing comfort the mean score of Patients was 10.72 (*SD* = 2.23). Lastly, on the dimension of mutual care patients mean score was 9.21 (*SD* = 2.38).

Table 3

Means, Standard Deviations, and 95% CI of interpersonal relationship of patients with BC and HNC

Variables	<u>Patients with BC and HNC</u>			<u>95% CI</u>
	<i>M</i>	<i>SD</i>	<i>LL</i>	<i>UL</i>
Interpersonal Relationship	82.27	19.04	80.01	84.61
Mutual Communication	31.29	9.95	30.18	32.48
Mutual Relationship	22.67	5.42	22.00	23.35
Attention and Support	8.39	2.22	8.11	8.68
Availability and Providing Comfort	10.72	2.23	10.43	10.99
Mutual Care	9.21	2.38	8.90	9.51

Note. *CI* = Confidence Interval; *LL* = Lower Limit; *UL* = Upper Limit

Table 4 depicted the means, standard deviations, and 95% *CI* of the interpersonal relationship as perceived by caregivers of patients. On the perception of interpersonal relationship caregivers of patients mean score was 76.57 (*SD* = 17.26), this mean score is lower than the mean score of patients (*M* = 82.27, *SD* = 19.04) on the same. This result indicated that the overall perception of caregivers on their interpersonal relationship was poorer than that of the patients to whom they give the care. On the dimension of mutual communication the mean score of caregivers of patients was 24.31 (*SD* = 7.51), this mean score is lower than that of the patients (*M* = 31.29, *SD* = 9.95). The result indicated that the caregivers of patients perceived lower mutual communication with patients, than the patients themselves.

On the dimension of mutual relationship, the mean score of caregivers of patients was 20.14 (*SD* = 5.86), this mean score is very close to the mean score of patients (*M* = 22.67, *SD* = 5.42) on the same. This indicated that the patients' perception of their mutual

relationship is slightly higher than their caregivers. The mean score of caregivers on the dimension of attention and support was 8.98 ($SD = 2.98$), this score is almost similar with the score of patients themselves ($M = 8.39$, $SD = 2.22$). This indicated that both the patients and their caregivers almost had a similar perception of their attention and support with each other.

On the dimension of availability and providing comfort the mean score of caregivers was 12.36 ($SD = 2.14$), this mean is higher than patients' mean score on the same dimension. This result indicated that the caregivers' perception in their availability and providing comfort ($M = 10.72$, $SD = 2.23$) is slightly higher than the patients to whom they give care. The mean score of caregivers on mutual care was 10.77 ($SD = 2.74$), this mean score is more than the mean of patients ($M = 9.21$, $SD = 2.38$) perception on mutual care. This result indicated that caregivers perceived greater perception of mutual care than the patients themselves.

Table 4

Means, Standard Deviations, and 95% CI of interpersonal relationship of caregivers of patients with BC and HNC

Variables	<u>Caregivers of Patients with BC and HNC</u>			
			<u>95% CI</u>	
	<i>M</i>	<i>SD</i>	<i>LL</i>	<i>UL</i>
Interpersonal Relationship	76.57	17.26	74.42	78.73
Mutual Communication	24.31	7.51	23.38	25.30
Mutual Relationship	20.14	5.86	19.36	20.87
Attention and Support	8.98	2.98	8.58	9.35
Availability and Providing Comfort	12.36	2.14	12.08	12.61
Mutual Care	10.77	2.74	10.41	11.11

Note. *CI* = Confidence Interval; *LL* = Lower Limit; *UL* = Upper Limit

Levels of psychological states

Psychological states of the patients along with their caregivers were assessed using Four-Dimensional Questionnaire which measures the psychological states such as distress, depression, anxiety, and somatization. The mean scores, standard deviation, and 95% *CI* of the four dimensions are depicted in Table 5. As shown in Table 5, the mean score of patients on the dimension distress was 10.79 (*SD* = 6.17). Among 248 patients 7.7% have strongly elevated distress whereas 42.7% have moderately elevated distress, and 49.6 % have low level of distress (Table 6).

Table 5

Means, Standard Deviations, and 95% CI of psychological states of patients with BC and HNC

Variables	<u>Patients with BC and HNC</u>			
	<i>M</i>	<i>SD</i>	<u>95% CI</u>	
			<i>LL</i>	<i>UL</i>
Distress	10.79	6.17	10.03	11.58
Depression	1.00	1.77	0.80	1.25
Anxiety	1.81	1.86	1.58	2.11
Somatization	5.57	4.50	5.05	6.13

Note. *CI* = Confidence Interval; *LL* = Lower Limit; *UL* = Upper Limit

Table 6

Frequency and percentages of psychological states of patients with BC and HNC

Variables	<u>Patients with BC and HNC</u>					
	Strongly Elevated		Moderately Elevated		Low	
	Frequency	%	Frequency	%	Frequency	%
Distress	19	7.7	106	42.7	123	49.6
Depression	6	2.4	38	15.3	204	82.3
Anxiety	0	0	28	11.3	220	88.7
Somatization	4	1.6	29	11.7	215	86.7

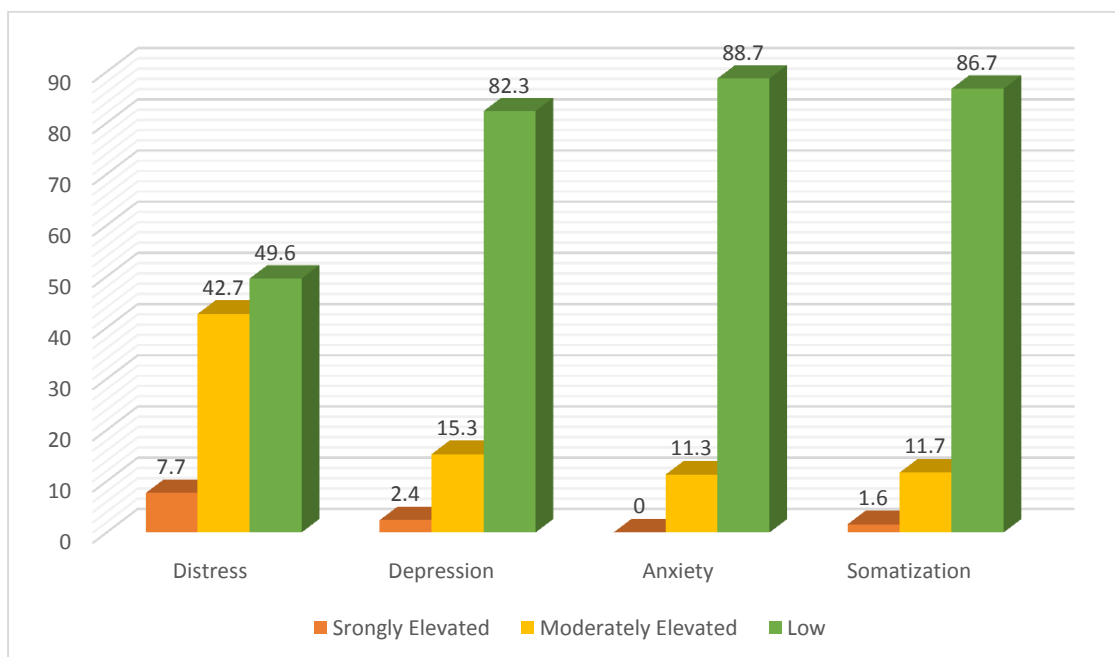


Figure 1. Frequency percentages of psychological states of patients with BC and HNC.

The mean score of patients on the dimension of depression was found to be 1 ($SD = 1.77$). From the 248 Patients, 2.4% have highly elevated depression, 15.3% have moderately elevated depression, and 82.3 % have low level of depression (Table 6). On the dimension of anxiety, the mean score of patients was 1.81 ($SD = 1.86$). Among 248 patients, 11.3% have moderately elevated anxiety whereas, 88.7 % have low level of anxiety (Table 6). The mean score of patients on the dimension of somatization was 5.57 ($SD = 4.50$). It was found that among 248 patients 1.6% have strongly elevated somatization, 11.7% have moderately elevated somatization, and 86.7% have low level of somatization. From the above results (shown in Table 5 & Table 6) of the four dimensions of psychological states distress was the highest among patients. Figure 1 demonstrated the frequency percentages of psychological states of patients.

The mean scores, standard deviation, and 95% *CI* of caregivers of patients on distress, depression, anxiety, and somatization are shown in Table 7. The mean score for

the dimension of distress of caregivers of patients was 4.92 ($SD = 4.35$). Among 248 caregivers of patients 14.9 % have moderately elevated distress, whereas 85.1 % have low level of distress (Table 8). On the dimension of depression, the mean score of caregivers of patients was 0.13 ($SD = 0.53$). Out of 248 caregivers of patients 2.4% have moderately elevated depression and 97.6% have low level of depression.

Table 7

Means, Standard Deviations, and 95% CI of psychological states of caregivers of patients with BC and HNC

Variables	<u>Caregivers of Patients with BC and HNC</u>			
			<u>95% CI</u>	
	<i>M</i>	<i>SD</i>	<i>LL</i>	<i>UL</i>
Distress	4.92	4.35	4.41	5.44
Depression	0.13	0.53	0.07	0.20
Anxiety	0.83	1.22	0.69	0.99
Somatization	1.21	1.69	1.01	1.43

Note. CI = Confidence Interval; LL = Lower Limit; UL = Upper Limit

The mean scores of caregivers of patients on the dimension of anxiety as shown in Table 7 was 0.83 ($SD = 1.22$). Among 248 caregivers of patients, 3.2 % have moderately elevated anxiety and 96.8 % have low level of anxiety. On the dimension of somatization, the mean score of caregivers of patients was 1.21 ($SD = 1.69$). None of the caregivers of patients reported strongly or moderately elevated somatization. Among four dimensions of psychological states assessed on caregivers of patients' distress was found to be the highest. Figure 2 demonstrated the frequency percentages of psychological states of caregivers of patients.

Table 8

Frequency and percentages of psychological states of caregivers of patients with BC and HNC

Variables	Caregivers of Patients with BC and HNC					
	Strongly Elevated		Moderately Elevated		Low	
	Frequency	%	Frequency	%	Frequency	%
Distress	0	0	37	14.9	211	85.1
Depression	0	0	6	2.4	242	97.6
Anxiety	0	0	8	3.2	240	96.8
Somatization	0	0	0	0	250	100

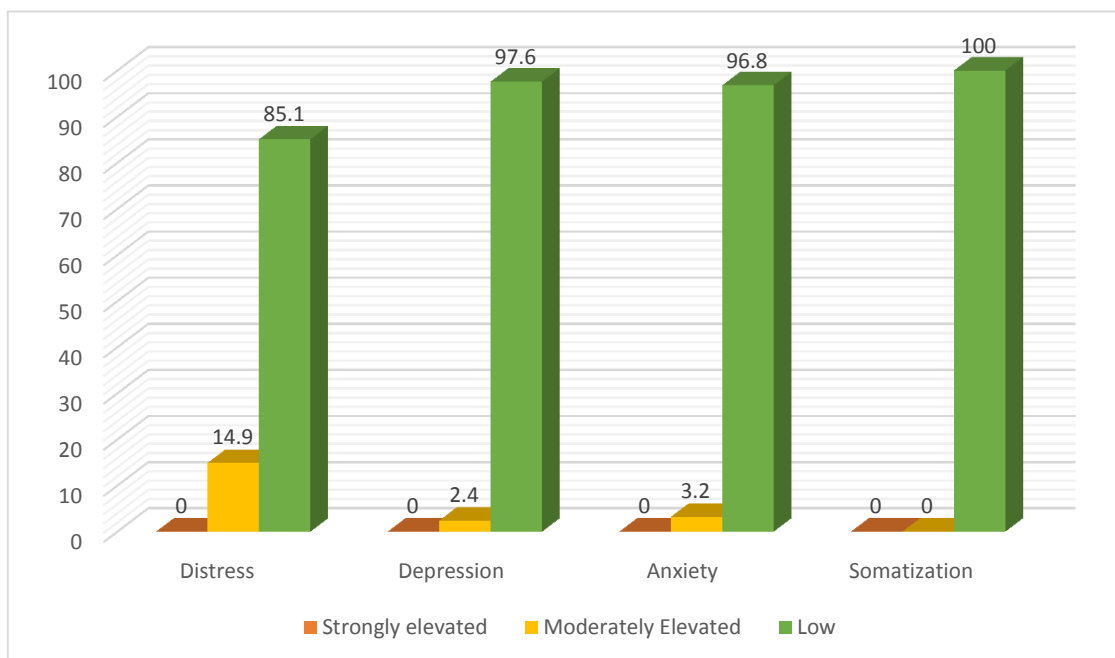


Figure 2. Frequency percentages of psychological states of caregivers of patients with BC and HNC

Levels of Quality of Life

QoL of caregivers was assessed using Caregivers QoL Index- Cancer (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). The scale was divided into four dimensions by Tamayo, Broxson, Munsell, and Cohen (2010). The mean, standard deviations, and 95% *CI* are presented in Table 9. The mean score of overall QoL of caregivers was 32.22 ($SD = 14.91$). The caregivers have good QoL as the mean score ($M = 32.22$) is lower than the mid-point 70 in the score range (0- 140) for the scale. The mean score of caregivers on the dimension of burden was 11.70 ($SD = 6.91$), the mean score for the dimension of disruptiveness was 4.58 ($SD = 4.29$). On the dimension of positive adaptation and financial concern the mean score of the caregivers was 12.56 ($SD = 4.81$) and on the dimension of support the mean score was 3.38 ($SD = 2.82$).

Table 9

Means, Standard Deviations, and 95% CI of QoL of caregivers with BC and HNC

Variables	Caregivers of Patients with BC and HNC			
	<u>95% CI</u>			
	<i>M</i>	<i>SD</i>	<i>LL</i>	<i>UL</i>
QoL	32.22	14.91	30.25	34.26
Burden	11.70	6.91	10.86	12.60
Disruptiveness	4.58	4.29	4.05	5.13
PAFC	12.56	4.81	11.92	13.19
Support	3.38	2.82	3.03	3.75

Note: PAFC- Positive Adaptation and Financial Concern

Difference in Caregivers' Interpersonal Relationship, Psychological States, and Quality of Life

The patients' performance status or ability to perform day to day task may play a role in their caregivers' psychosocial functioning. Therefore, the second objective of the present study was to find out the differences in the level of psychological states, interpersonal relationship, and quality of life among caregivers, categorized on the basis of patients' activity levels.

First, patients were divided into three groups based on their activity level and one –way between groups ANOVA was conducted. Eastern Cooperative Oncology Group Performance Status (Oken, Creech, & Tormey, 1982) was used to assess the physical activity level of the patients. Table 10 depicted the frequency and percentage of the physical activity level of the patients. Out of 248 Patients 22.2 % reported that they are capable of all self- care and carry out light or sedentary work but ambulatory and able to carry out work of a light or sedentary nature. On the other hand, 43.1% of the patients have reported that they are ambulatory and capable of all self-care but unable to carry out

any work activities; up and about more than 50% of waking hours. Lastly, 34.7% reported that they are Capable of only limited self-care; confined to bed or chair more than 50% of waking hours. Hence, the caregivers were then divided into three groups based on the physical activity level of the patients to whom they give care. Group 1 consisted of caregivers capable of all self-care and carry out light or sedentary work, Group 2 consisted of caregivers capable of all self-care, and Group 3 consisted of caregivers capable of limited self-care.

Table 10

Frequency and percentage of physical activity level of patients with BC and HNC

ECOG Performance Status	Frequency	Percentage
“Fully active, able to carry on all pre-disease performance without restriction”	0	0
“Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature”	55	22.2
“Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours”	107	43.1
“Capable of only limited self-care; confined to bed or chair more than 50% of waking hours”	86	34.7
“Completely disabled; cannot carry on any self-care; totally confined to bed or chair”	0	0
“Dead”	0	0
Total	248	100

Note: The statements in the above table are exact copy of the statements in the checklist. Hence, quotation is used.

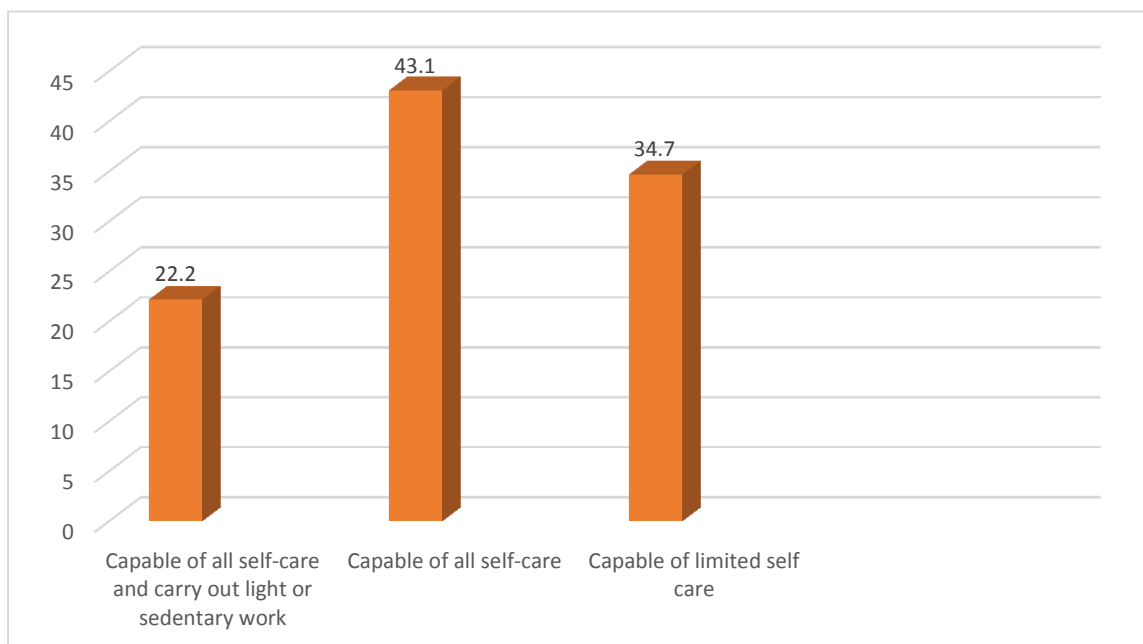


Figure 3. Frequency percentages of performance status (level of physical activity) of patients with BC and HNC

As mentioned, one-way between groups ANOVA was conducted to examine the impact of patients' performance status on caregivers' psychological states, interpersonal relationship, and QoL. Statistically significant differences were found in the dimension of caregivers' perception on mutual communication and caregivers' distress, but there was no statistically significant difference found in other dimensions. The following sections present the detail of analysis of results.

Interpersonal Relationship of Family Caregivers of Patients

There was a statistically significant difference on the dimension of mutual communication between the three groups of caregivers, $F(2,245) = 5.09$, $p < .01$. The effect size was small which is calculated using eta squared and was found to be 0.04 (Table 11). Post Hoc comparison using Tukey HSD test (Table 12) indicated that the

mean score of Group 1 ($M = 26.78$, $SD = 6.79$) did not have a statistically significant difference from Group 2 ($M = 24.32$, $SD = 7.72$). There was a statistically significant difference between Group 1 ($M = 26.78$, $SD = 6.79$) and Group 3 ($M = 22.71$, $SD = 7.32$). Group 1 have higher perception on mutual communication between them and the patients to whom they give care when compared with Group 3. Post Hoc comparison using Tukey HSD also indicated that there was no statistically significant difference between Group 2 ($M = 24.32$, $SD = 7.72$) and Group 3 ($M = 22.71$, $SD = 7.32$).

Table 11

Table showing Mean, Standard Deviation, and summary of one-way ANOVA for the three groups

Patients' Performance Status Variables	Group 1 (n= 55)		Group 2 (n= 107)		Group 3 (n= 86)		One-way ANOVA Mean Square			η^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	Between	Error	F (2,245)	
Caregivers' overall I.R.	80.95	16.80	76.01	18.01	74.47	16.26	733.81	294.34	2.49	-
Mutual Communication	26.78	6.79	24.32	7.72	22.71	7.32	278.20	54.58	5.09**	.04
Mutual Relationship	20.85	6.48	20.18	5.75	19.64	5.61	24.87	34.46	0.72	-
Attention and Support	9.60	2.94	8.67	3.19	8.98	2.69	15.61	8.84	1.77	-
Availability and Providing Comfort	12.55	1.91	12.22	2.32	12.42	2.04	2.08	4.59	0.45	-
Mutual Care	11.16	2.57	10.62	2.79	10.72	2.79	5.62	7.52	0.75	-
Psychological States										
Caregivers' Distress	3.71	3.85	5.05	4.19	5.53	4.74	57.44	18.65	3.08*	.03
Caregivers' Depression	.05	.29	.17	.64	.14	.49	0.24	0.28	0.85	-
Caregivers' Anxiety	.53	.90	.92	1.26	.92	1.34	3.25	1.49	2.19	-
Caregivers' Somatization	.98	1.46	1.07	1.73	1.53	1.70	7.09	2.84	2.49	-
Caregivers' Overall QoL	30.27	13.95	32.07	15.26	33.64	14.91	192.05	222.48	0.86	-
Caregivers' Burden	11.60	6.85	11.56	6.96	11.94	6.96	3.83	48.14	0.80	-
Caregivers' Disruptiveness	3.80	3.79	4.51	4.51	5.15	4.28	30.99	18.34	1.69	-
PAFC	11.35	4.90	12.55	4.96	13.35	4.45	67.33	22.83	2.95	-
Caregivers' Support	3.53	2.78	3.45	2.84	3.20	2.84	2.28	7.98	0.28	-

Note: * $p < .05$, ** $p < .01$; **Group1**- Capable of all self-care and carry out light or sedentary work, **Group 2**- Capable of all Self Care, **Group 3**- Capable of Limited Self Care; I.R.- Interpersonal Relationship, PACAREGIVERS- Positive Adaptation and Financial Concern

Table 12

Table showing mean comparisons using Tukey's HSD between the four groups of levels of activity of the variables under study

Variables	<u>Level of Physical Activity</u>		
	G1-G2	G1-G3	G2-G3
Caregivers' Interpersonal Relationship			
Mutual Communication	2.46	4.07*	-1.61
Caregivers' Psychological States			
Caregivers' Distress	-1.34	-1.83*	-.49

Note: * $p < .05$; **G1**- Capable of all self- care and carry out light or sedentary work, **G2**- Capable of all Self Care, **G3**- Capable of Limited Self Care.

Psychological States of Caregivers of Patients

There was statistically significant difference in the dimension distress scores for three groups of caregivers $F(2, 245) = 3.08, p < .05$. The effect size was small which is calculated using eta squared and was found to be 0.03 (Table 11). In order to determine where the group differences are, Post Hoc comparison using the Tukey HSD test was conducted. As shown in Table 12 the mean score for Group 1 ($M = 3.71, SD = 3.85$) was not significantly different from the mean score of Group 2 ($M = 5.05, SD = 4.19$). However, statistically significant difference was found between the mean score of Group 1 ($M = 3.71, SD = 3.85$) and Group 3 ($M = 5.53, SD = 4.74$). Group 3 have higher distress when compared with Group 1. Post Hoc comparison using Tukey HSD also indicated that the mean score of Group 2 ($M = 5.05, SD = 4.19$) was not different significantly from Group 3 ($M = 5.53, SD = 4.74$).

Agreement/ Disagreement in Perception of Interpersonal Relationship

In the advent of chronic illness like cancer the patient requires multidimensional support from others that includes their family members, friends, and neighbors. However, one of the most important support they receive is the support from their primary caregiver. These primary caregivers more often are the spouse, children, siblings, or parent(s) of the patient and are often themselves neglected at large as it is often considered more important give support to the patient. But it is important to note that the patients themselves can be the source of support for their caregivers and this can be achieved by maintaining good relationship with each other i.e. between patients and their caregivers. Therefore, the third objective of this study aimed to find out the agreement or disagreement in perception of the interpersonal relationship between cancer patients (BC & HNC) and their family caregivers. The feature analysis related to the present objective was addressed by using MATLAB programming. The procedure for manual calculation of feature development is explained below. The total sample comprise of 248 pairs of patients and their caregivers. Responses of each pair that is of patients and their caregivers on each of the items on CANSIRS have been noted down in a chart (sample chart shown in *Figure 4*). Then, the agreement and disagreement of responses of each pair have been charted out in a matrix. Sample matrix for one such pair indicating item wise match mentioning the item numbers and their agreement or disagreement between the pair are demonstrated in *Figure 5*. Thus, *Figure 5* shows that both the patient with cancer (BC & HNC) and their caregivers gave exactly the same response for item number 16, 4, 1, 3, 9, 19 and 24. For item number 16 the response of the pair has been 1, for item number 4 response of the pair has been 2 and so on. There was a total agreement between

patients and their caregivers in their perception on the above said item numbers. Thus, showing perfect match/ agreement in their responses.

A frequency matrix which is reflected in Figure 5 to demonstrate the agreement and disagreement by showing the item numbers is now reflected in Figure 6 without mentioning the item numbers but the frequency of agreement or disagreement. That is item number 16 shown in Figure 5 is represented as frequency of 1, similarly item no 4 also is written as a frequency of 1, however, item numbers 1, 3, 9, 19, and 24 are written together as frequency of 5 in Figure 6. Thus, the agreement frequencies have been plotted in terms of items numbers in Figure 5 and in terms of frequencies in Figure 6. Same was the case with disagreement. In figure 5, there was a disagreement on item number 22, where the responses have been different. That is while the caregivers response was 2, the patients response was 1 thus indicating disagreement in their perception on item no 22. There was no other item where this pattern of response was repeated. Hence, the frequency of this response combination is 1 as depicted in Figure 6. Similarly, for item numbers 5 and 11, Figure 5 shows the response combination for caregivers and patients that is 4 and 1 respectively indicating their disagreements in their perceptions and is represented as 2 in terms of frequency of same response in Figure 6.

We see both in Figure 5 and Figure 6 where the matrix tries to look at the agreement and disagreement between the responses of patients and their caregivers, the diagonal represents perfect match (complete agreement). This diagonal which is the perfect match in the responses of the pair and the frequency of such matched responses is named as f_2 . There are two more such categories, the category where the caregivers' response had greater value whereas patients' response has lesser value thus indicating

greater response score for caregiver but lesser response score for the patients and thus indicating disagreement is categorized as f_3 . That is f_3 category shows higher perception of specific dimensions of relationship by caregivers compared to cancer patients.

In Figure 5 on the upper side of the diagonal it is seen that item numbers 7, 12, 15, and 23 for all these items the score of the patients is 5 whereas score of the caregivers has been 1, similarly on items numbers 8, 13, 14, and 21 the response score of patient is 5 but the caregivers response is 3. Thus, this indicates a disagreement once again between the perception of patients and their caregivers. However here the patients' perception is higher than the caregivers' perceptions. Thus, the category of f_1 is where patients' perceptions are higher on specific dimension on interpersonal relation when compared to their caregivers.

F_1 and f_3 are reversal of the response value of patients and caregivers according to their perceptions of interpersonal relationship between them and both are indicative of disagreement in their perceptions. However, f_2 is indicative of complete agreement (perfect match) between the pair in their perception of interpersonal relationship. Figure 5 and Figure 6 are indicative of agreement and disagreement in terms of items and frequency respectively for one pair of patients and their caregivers for demonstration purposes. For all the pairs such matrixes have been generated.

Thus, f_2 represented by the diagonal reported complete agreement (perfect match) between patients and their caregivers. F_1 represented the disagreement in the responses between patients and caregivers, where patients are seen to be reporting greater perception of interpersonal relations whereas their caregivers are not perceiving as high as the patients did. So f_1 can be said to be higher perception by patients and hence the

disagreement. On the other hand, f_3 , the portion below the diagonal represented higher perception of interpersonal relations by the caregivers as compared to the patients and hence the disagreement. Thus, f_3 can be called higher perception of caregivers of interpersonal relationship.

Items	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Pt	5	5	5	2	1	5	5	5	2	1	5	5	5	5	1	1	5	5	5	5	1	5	5	
Cg	5	4	5	2	4	4	1	3	5	5	4	1	3	3	1	1	5	4	5	4	3	2	1	5

Note: Pt- patients; Cg- caregivers

Figure 4. Sample response of a pair of patients with BC and HNC and their Caregivers on interpersonal relationship

Caregivers	Patients					
	Pair 1	1	2	3	4	5
	1	Item No. 16				Item No. 7, 12, 15, 23
	2	Item No. 22	Item No. 4			
	3					Item No. 8, 13, 14, 21
	4	Item No.5, 11				Item No 2, 6, 18, 20,
	5	Item No. 17	Item No. 10			Item no. 1, 3, 9,19, 24

Note: Numbers written in the box are item number

Figure 5. Agreement and disagreement frequency matrix (item wise) of 1 pair (sample) response in CANSIRS

Caregivers	Patients					
	Pair 1	1	2	3	4	5
	1	1	0	0	0	4
	2	1	1	0	0	0
	3	0	0	0	0	4
	4	2	0	0	0	4
	5	1	1	0	0	5

Note: Orange= f_1 , Purple = f_2 , Yellow= f_3 ; Number in box are frequency of items

Figure 6. Agreement and disagreement frequency matrix 1 pair (sample) response in CANSIRS

Calculation of values of f_1 , f_2 and f_3

To find out the value of patients' higher perception of interpersonal relationship (f_1), complete agreement/ perfect match (f_2), and caregivers' higher perception of interpersonal relationship (f_3) the following procedure is followed. All the frequencies in f_1 , f_2 , and f_3 category have been summed up. Thus, the total frequency for f_1 is 12, total of the frequency for f_2 is 7 and the total of the frequency for f_3 is 5. And the sum total of f_1 , f_2 , and f_3 is 24 which is the total number of items in the scale. F_1 , f_2 , and f_3 frequencies are divided by the total number of items of the scale each respectively. Thus, $f_1 = 12/24$, $f_2 = 7/24$, and $f_3 = 5/24$. The sum total of f_1 , f_2 , and f_3 after division was equal to 1. As shown in Figure 7, the value of f_2 which is complete agreement is lower than both the f_1 i.e. higher perception of patients' interpersonal relationship and f_3 i.e. higher

perception of caregivers' interpersonal relationship. This indicated that there is more disagreement between patients and their caregivers than agreement.

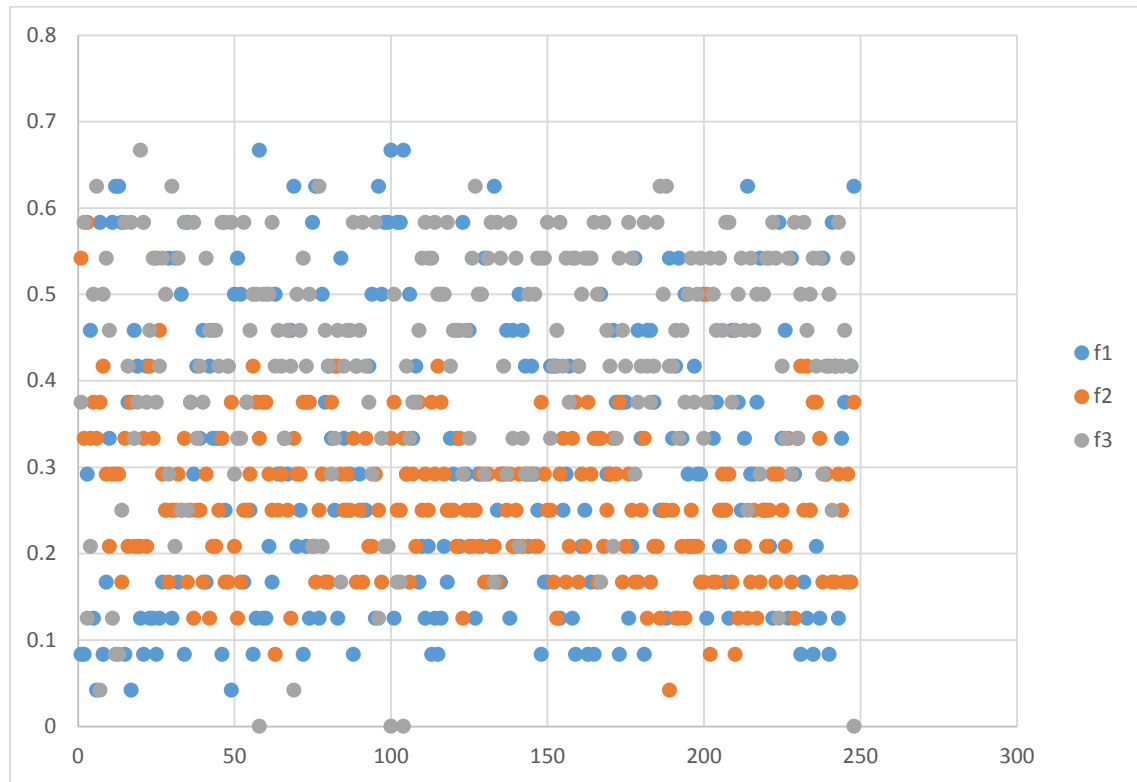


Figure 7. Plot of f_1 , f_2 , and f_3 (N= 248 pairs)

Indicators of Family Caregivers' Quality of Life

Taking care of one's family member who is suffering from chronic illness such as cancer by providing physical, emotional, social support and taking care of many aspects, sometimes take a toll on the caregivers resulting in poor or low QoL. Thus, it is important to understand what are the factors that contribute to caregivers' QoL. Hence, the fourth objective of the study was to find out the indicators of caregivers' QoL and its four dimensions. In the present objective, the impact of the following on caregivers' QoL was addressed. They are a) caregivers' demographic variables, b) physical activity levels of patients, c) interpersonal relationship of patients and caregivers, and d) psychological

states of patients and their caregivers. Firstly, Pearson Product-moment Correlation was ran for demographic variables, patients' physical activity level, quality of interpersonal relationship of both patients and their caregivers, psychological states of patients and their caregivers and caregivers' QoL (Table 13 & Table 13 contd.). Secondly, hierarchical regression analysis was done by taking caregivers' QoL as criterion (dependent variable) and all the other variable that have significant correlation with caregivers' QoL as predictors (independent variables).

Table 13 depicted the caregivers' QoL correlation with the demographic variables, patients' level of physical activity, interpersonal relationship and psychological states. Caregivers' QoL has significant negative correlation with caregivers' smoking ($r = -.21, p < .01$), chewing pan ($r = -.15, p < .05$), and taking tobacco such as chewing ($r = -.20, p < .01$) There is a significantly positive correlation between QoL and caregivers not indulges in any of the lifestyle issues ($r = .39, p < .01$). Caregivers' QoL has significant positive correlation with patients' higher perception on interpersonal relationship ($r = .34, p < .01$), caregivers' distress ($r = .53, p < .01$), depression ($r = .33, p < .01$), anxiety ($r = .35, p < .01$), somatization ($r = .18, p < .01$), and patients' distress ($r = .16, p < .05$), depression ($r = .19, p < .01$), anxiety ($r = .18, p < .01$), and somatization ($r = .13, p < .05$). Caregivers' QoL also have significant negative correlation with complete agreement (patients & caregivers) on interpersonal relationship ($r = -.14, p < .05$) and caregivers' higher perception on interpersonal relationship ($r = -.32, p < .01$).

Table 13

Summary of Product moment correlation of indicators of caregivers' QoL

Variables	Overall QoL	Burden	Disruptiveness	PACAREGIVERS	Support
Demographic Variables					
Age	-.02	.28	-.04	-.08	-.08
Gender	-.06	.09	-.02	.10	.09
Marital Status of Caregivers					
Married	-.03	-.01	-.08	.01	-.02
Single	.03	.01	.08	-.01	.02
Occupation of Caregivers					
Employed	-.11	-.11	-.08	-.03	-.14*
Caregivers					
Self Employed	-.02	-.03	.05	-.06	.03
Caregivers					
Unemployed	.12	.12	.06	.08	.12
Caregivers					
Retired	-.01	-.05	-.06	-.01	-.04
Caregivers					
Socio-economic Status					
High	-.002	-.07	-.01	.06	.08
Middle	-.12	-.009	-.14*	-.15*	-.11
Lower	.12	.02	.15*	.14*	.09
Lifestyle Issues of Caregivers					
Smoking	-.21**	-.09	-.18**	-.21**	-.23**
Alcohol	-.08	-.06	-.09	-.05	-.06
Smoking & Alcohol	-.11	-.06	-.07	-.14*	-.08
Pan Tobacco	-.15*	-.07	-.09	-.18**	-.18**
Not indulging in lifestyle issues	-.20**	-.13*	-.18**	-.18**	-.16*
	.39**	.21**	.32**	.39**	.39**

Note: * $p < .05$, ** $p < .01$, *** $p < .001$; PAFC- Positive Adaptation and Financial Concern; IR- Interpersonal Relationship

Table 13 contd.

Summary of Product moment correlation of indicators of caregivers' QoL

Variables	Overall QoL	Burden	Disruptiveness	PACAREGIVERS	Support
Patients Level of Physical Activity					
Restricted	-.07	-.01	-.09	-.14*	.03
Physically					
All Self Care	-.01	-.02	-.01	-.01	-.02
Limited Self Care	.07	.02	.09	.12	-.05
Levels of Interpersonal Relationship					
Patients' Higher Perception	34**	.16**	.34**	.40**	.22**
Higher perception on Interpersonal relationship					
Complete Agreement on Interpersonal Relationship	-.14*	-.07	-.13*	-.21**	-.03
Caregivers' higher Perception on Interpersonal Relationship	-.32**	-.15*	-.32**	-.34**	-.24**
Caregivers' Psychological States					
Distress	.53**	.58**	.34**	.38**	.19**
Depression	.33**	.33**	.34**	.13*	.16**
Anxiety	.35**	.45**	.25**	.18**	.06
Somatization	.18**	.27**	.15*	.03	.004
Patients' Psychological States					
Distress	.16*	.17**	.14*	.12	-.002
Depression	.19**	.23**	.19**	.07	.01
Anxiety	.18**	.18**	.22**	.08	.04
Somatization	.13*	.22**	.19*	-.04	-.07

Note: * $p < .05$, ** $p < .01$, *** $p < .001$; PAFC- Positive Adaptation and Financial Concern; IR- Interpersonal Relationship

There is a significant negative correlation between dimension of burden and caregivers' habit of chewing tobacco such as chewing, eating gutkha ($r = -.13, p < .05$) and caregivers' higher perception on interpersonal relationship ($r = -.15, p < .01$). The dimension of caregivers' burden had significant positive correlation with caregivers not indulging in any of the lifestyle issues ($r = .21, p < .01$), patients' higher perception on interpersonal relationship ($r = .16, p < .01$), caregivers' distress ($r = .58, p < .01$), depression ($r = .33, p < .01$), anxiety ($r = .45, p < .01$), somatization ($r = .27, p < .01$), and patients' distress ($r = .17, p < .01$), depression ($r = .23, p < .01$), anxiety ($r = .18, p < .01$), and somatization ($r = .22, p < .01$).

Caregivers' QoL dimension disruptiveness had significant negative correlations with caregivers' middle economic status ($r = -.14, p < .05$), caregivers' smoking ($r = -.18, p < .01$), caregivers' habit of chewing tobacco ($r = -.18, p < .01$), complete agreement (patients and caregivers) on interpersonal relationship ($r = -.13, p < .05$), and caregivers' higher perception on interpersonal relationship ($r = -.32, p < .01$). The dimension disruptiveness also had significant positive correlations with caregivers' lower economic status ($r = .15, p < .05$), caregivers not indulging in any of the lifestyle issues ($r = .32, p < .01$), patients higher perception on interpersonal relationship ($r = .34, p < .01$), caregivers' distress ($r = .34, p < .01$), depression ($r = .34, p < .01$), anxiety ($r = .25, p < .01$), somatization ($r = .15, p < .05$), and patients' distress ($r = .14, p < .05$), depression ($r = .19, p < .01$), anxiety ($r = .22, p < .01$), and somatization ($r = .19, p < .05$).

Positive adaptation and financial concern dimension had significant negative correlations with caregivers' middle economic status ($r = -.15, p < .05$), caregivers smoking ($r = -.21, p < .01$), caregivers doing both smoking and drinking alcohol ($r = -.14,$

$p < .05$), caregivers chewing pan that is betel nut ($r = -.18, p < .01$), and caregivers with habit of chewing tobacco ($r = -.18, p < .01$). Positive adaptation and financial concern dimension also have significant negative correlations with patients capable of all self-care and carry out light or sedentary work ($r = -.14, p < .05$), complete agreement (patients & caregivers) on interpersonal relationship ($r = -.21, p < .01$), caregivers' higher perception on interpersonal relationship ($r = -.34, p < .01$). Positive adaptation and financial concern dimension had significant positive correlations with caregivers' lower social economic status ($r = .14, p < .05$), caregivers not indulging in any of the lifestyle issues ($r = .39, p < .01$), patients' higher perception on interpersonal relationship ($r = .40, p < .01$), caregivers' distress ($r = .38, p < .01$), depression ($r = .13, p < .05$), and anxiety ($r = .18, p < .01$).

Caregivers' QoL dimension of support had significant negative correlations with caregivers being employed ($r = -.14, p < .05$), caregivers smoking ($r = -.23, p < .01$), caregivers with habit of chewing pan that is betel nut ($r = -.18, p < .01$), caregivers with habit of chewing tobacco ($r = -.16, p < .05$), and caregivers' higher perception on interpersonal relationship ($r = -.24, p < .01$). The dimension support has a significant positive correlation with caregivers not indulging in any of the lifestyle issues ($r = .39, p < .01$), patients' higher perception on interpersonal relationship ($r = .22, p < .01$), caregivers' distress ($r = .19, p < .01$), and depression ($r = .16, p < .01$).

To identify major indicators of QoL of caregivers of patients, hierarchical regression analysis was computed using IBM SPSS Statistic 20. In this analysis QoL and its four domains were taken as a criterion and demographic variables, patients' level of physical activity, interpersonal relationship between patients and their caregivers, and

psychological distress of patients and their caregivers were taken as predictors. The sequence of entry for the predictors in the model was demographic details, patients' level of physical activity, interpersonal relationship, and lastly, psychological states. Altogether five hierarchical regression analyses were ran.

Table 14 indicated the hierarchical regression analysis done by taking QoL as criterion. The analysis gave rise to three models. Model 1, with demographic variables of various lifestyle issues of caregivers as predictors explained 15% variance, and was significant, $F(4, 243) = 11.11, p < .001$. Caregivers without lifestyle (e.g. Smoking, drinking alcohol, pan etc.) issues ($\beta = .37, t = 3.01, p < .01$) that is caregivers not indulging in lifestyle issues was found to be significant predictor of QoL. In Model 2, patients higher perception on interpersonal relationship, complete agreement between patients on interpersonal relationship, and caregivers' higher perception on interpersonal relationship were added and the model significantly predicted more variance R^2 change was 0.10 $p < .001$. The model excluded patients' higher perception on interpersonal relationship and then explained 25% variance, and was significant, $F(6, 241) = 13.77, p < .001$. In Model 2, caregiver without lifestyle issues ($\beta = .39, t = 3.39, p < .01$), complete agreement between patients (BC& HNC) and their Caregivers ($\beta = -.12, t = -2.15, p < .05$) on care and caregivers' higher perception on interpersonal relationship ($\beta = -.29, t = -5.32, p < .001$) were found to be significant predictors of caregivers' QoL.

Table 14

Summary of Hierarchical Regression Analysis for variables predicting caregivers' QoL (N= 248 pairs)

Model and predictor variables	B	SE B	β	t	R ²	ΔR^2
Model 1 (C = 23.21, F = 11.11***)					.15	
Caregivers Smoking	-.18	4.81	-.004	-.04		
Caregivers Chewing Pan	-.67	2.38	-.022	-.23		
Caregivers Taking Tobacco	-2.04	5.22	-.06	-.39		
Caregivers without lifestyle issues	12.45	4.13	.37**	3.01		
Model 2 (C = 41.33, F = 13.77***)					.25	.10***
Caregivers Smoking	3.12	4.58	.06	.68		
Caregivers Chewing Pan	.28	2.27	.01	.12		
Caregivers Taking Tobacco	-1.52	4.92	-.03	-.31		
Caregivers without lifestyle issues	13.20	3.89	.39**	3.39		
Complete Agreement on interpersonal relationship	-20.74	9.64	-.12*	-2.15		
Caregivers higher Perception on interpersonal relationship	-31.99	6.02	-.29***	-5.32		
Model 3 (C = 29.87, F = 15.69***)					.48	.23***
Caregivers Smoking	1.14	3.93	.02	.29		
Caregivers Chewing Pan	-.09	1.92	-.003	-.05		
Caregivers Taking Tobacco	.03	4.21	.001	.008		
Caregivers without lifestyle issues	10.32	3.36	.30**	3.07		
Complete Agreement on interpersonal relationship	-14.23	8.53	-.08	-1.67		
Caregivers higher Perception on interpersonal relationship	-24.83	5.21	-.23***	-4.77		
Distress of caregivers	1.37	.26	.40***	5.22		
Depression of Caregivers	3.56	1.51	.13*	2.36		
Anxiety of Caregivers	.79	.78	.06	1.01		
Somatization of Caregivers	-.89	.52	-.10	-1.71		
Distress of Patients	-.15	.17	-.06	-.87		
Depression of Patients	.44	.53	.05	.82		
Anxiety of Patients	.45	.47	.06	.97		
Somatization of Patients	.45	.19	.13*	2.39		

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

In Model 3, psychological states (distress, depression, anxiety, & somatization) of both patients and their Caregivers were added and the model significantly predicted more variance R^2 change was 0.23, $p < .001$. The model then predicted 48% variance and was significant $F(14, 233) = 15.69, p < .001$. In Model 3, caregivers without lifestyle issues ($\beta = .30, t = 3.07, p < .01$), caregivers' higher perception on interpersonal relationship ($\beta = -.23, t = -4.77, p < .001$), distress of the caregivers ($\beta = .40, t = 5.22, p < .001$), depression of the caregivers ($\beta = .13, t = 2.36, p < .05$), and somatization of patients ($\beta = .13, t = 2.39, p < .05$) were found to be the significant predictors of caregivers' QoL.

Table 15 presents the results of hierarchical regression analysis done by taking the dimension caregivers' burden as criterion. The analysis gave rise to three models and in Model 1 caregivers' lifestyle issues was taken as predictor explained 5% variance of caregivers' burden and the model was significant $F(2, 245) = 6.07, p < .01$. Caregivers without lifestyle issues ($\beta = .19, t = 2.74, p < .01$), that is caregivers not indulging in any lifestyle issues was found to be significant predictor of caregivers' burden. In Model 2, patients higher perception on interpersonal relationship and caregivers' higher perception on interpersonal relationship were added and the model did not significantly predict more variance. Model 2 then explained 7% of variance in caregivers' burden and was significant $F(4, 243) = 4.57, p < .01$. Caregivers without lifestyle issues ($\beta = .17, t = 2.43, p < .05$) was the significant predictors of caregivers' burden.

Table 15

Summary of Hierarchical Regression Analysis for variables predicting caregivers' burden (N= 248 pairs)

Model and predictor variables	B	SE B	β	t	R²	ΔR^2
Model 1 (C = 12.27, F = 6.07**)					.05	
Caregivers taking tobacco	-1.24	1.92	-.04	-.64		
Caregivers without lifestyle issues	3.04	1.11	.19**	2.74		
Model 2 (C = 12.35, F = 4.57**)					.07	.02
Caregivers taking tobacco	-1.64	1.92	-.06	-.85		
Caregivers without lifestyle issues	2.69	1.11	.17*	2.43		
Patients' Higher Perception on interpersonal relationship	4.88	4.93	.12	.99		
Caregivers' Higher Perception interpersonal relationship	-2.01	5.80	-.04	-.35		
Model 3 (C = 4.48, F = 15.99***)					.45	.38***
Caregivers taking tobacco	-.21	1.52	-.01	-.14		
Caregivers without lifestyle issues	2.08	.92	.13*	2.27		
Patients' Higher Perception on interpersonal relationship	1.51	4.03	.04	.04		
Caregivers' Higher Perception interpersonal relationship	.52	4.67	-.01	-.11		
Distress of caregivers	.71	.12	.45***	5.71		
Depression of Caregivers	1.32	.72	.10	1.45		
Anxiety of caregivers	.84	.37	.15*	2.28		
Somatization of Caregivers	-.31	.25	-.07	-1.22		
Distress of patients	-.11	.08	-.09	-1.37		
Depression of patients	.51	.25	.13*	2.01		
Anxiety of patients	.11	.22	.03	.51		
Somatization of patients	.36	.09	.23***	4.01		

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

In Model 3, psychological states (distress, depression, anxiety and somatization) of patients with (BC & HNC) and their caregivers were added and the model significantly predicted more variance R^2 change was 0.38, $p < .001$. Model 3 explained 45% variance of caregivers' burden and was significant $F(12,235) = 15.99$, $p < .001$. In Model 3,

caregivers without lifestyle issues ($\beta = .13, t = 2.27, p < .05$), distress of the caregivers ($\beta = .45, t = 5.71, p < .001$), anxiety of the caregivers ($\beta = .15, t = 2.28, p < .05$), depression of patients ($\beta = .13, t = 2.01, p < .05$), and somatization of the patients ($\beta = .23, t = 4.01, p < .001$) were found to be the significant predictors of caregivers' burden.

In Table 16, the hierarchical regression analysis done by taking the dimension of caregivers' disruptiveness is presented. Caregivers' disruptiveness refers to disruptiveness that occurs in their otherwise regular work and daily routine as a result of caregiving to the patients. The analysis gave rise to three models. In Model 1 caregivers demographic variable such as economic status and lifestyle issues were taken as predictors and the model explained 12% variance of caregivers' disruptiveness and was significant $F(5, 242) = 6.59, p < .001$. In this model, the dimension of caregivers without lifestyle issues that is caregivers not indulging in lifestyle issues was found to be the significant predictor ($\beta = .27, t = 2.85, p < .01$). In Model 2, complete agreement between patients and their Caregivers on interpersonal relationship and caregivers' higher perception on interpersonal relationship were added into the model. Model 2 then significantly predicted more variance R^2 change was 0.10, $p < .001$. The Model then explained 22% of variance in caregivers' disruptiveness and was significant $F(7, 240) = 9.56, p < .001$. In this model, caregivers without lifestyle issues ($\beta = .26, t = 2.94, p < .01$) and caregivers' higher perception on interpersonal relationship ($\beta = -.30, t = -5.26, p < .001$) were found to be the significant predictors of caregivers' disruptiveness.

Table 16

Summary of Hierarchical Regression Analysis for variables predicting caregivers' disruptiveness (N = 248 pairs)

Model and predictor variables	B	SE B	β	t	R²	ΔR^2
Model 1 (C = 1.36, F = 6.59***)					.12	
Middle Economic Status	.77	2.39	.09	.32		
Low Economic Status	1.79	2.37	.21	.75		
Caregivers Smoking	-.42	1.19	-.03	-.35		
Caregivers Taking Tobacco	-.96	1.32	-.06	-.73		
Caregivers without lifestyle issues	2.64	.93	.27**	2.85		
Model 2 (C = 6.98, F = 9.56***)					.22	.10***
Middle Economic Status	.35	2.27	.04	.15		
Low Economic Status	1.35	2.25	.15	.59		
Caregivers Smoking	.23	1.13	.02	.20		
Caregivers Taking Tobacco	-1.05	1.25	-.06	-.84		
Caregivers without lifestyle issues	2.58	.88	.26**	2.94		
Complete Agreement on interpersonal relationship	-4.54	2.87	-.09	-1.58		
Caregivers higher Perception on interpersonal relationship	-9.38	1.78	-.30***	-5.26		
Model 3 (C = 3.30, F = 9.53***)					.38	.16***
Middle Economic Status	-.21	2.07	-.02	-.09		
Low Economic Status	.57	2.06	.06	.27		
Caregivers Smoking	-.62	1.05	-.04	-.58		
Caregivers Taking Tobacco	-.97	1.15	-.06	-.84		
Caregivers without lifestyle issues	2.12	.82	.22*	2.56		
Complete Agreement on interpersonal relationship	-5.13	2.72	-.11	-1.89		
Caregivers' higher Perception on interpersonal relationship	-7.72	1.65	-.25***	-4.67		
Distress of caregivers	.08	.08	.08	.95		
Depression of Caregivers	1.92	.48	.24***	3.97		
Anxiety of caregivers	.34	.25	.09	1.38		
Somatization of Caregivers	-.01	.16	-.003	-.04		
Distress of patients	-.09	.05	-.13	-1.65		
Depression of patients	.16	.17	.11	.93		
Anxiety of patients	.24	.15	.11	1.66		
Somatization of patients	.19	.06	.19**	3.20		

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

In Model 3 of the hierarchical regression analysis taking caregivers' disruptiveness as criterion, psychological states (distress, depression, anxiety, & somatization) were added to the model. The model then significantly predicted more variance R^2 change was found to be 0.16, $p < .001$. Model 3 explained 38% of variance in caregivers' disruptiveness and was significant $F(15, 232) = 9.53$, $p < .001$. Caregivers without lifestyle issues ($\beta = .22$, $t = 2.56$, $p < .05$), caregivers' higher perception on interpersonal relationship ($\beta = -.25$, $t = -4.67$, $p < .01$), depression of caregivers ($\beta = .24$, $t = 3.97$, $p < .001$), and somatization of patients ($\beta = .19$, $t = 3.20$, $p < .01$) were found to be the significant predictors of caregivers' disruptiveness.

In Table 17, results of hierarchical regression analysis taking caregivers' positive adaptation and financial concern dimension as criterion are presented. The analysis gave rise to four models. In Model 1, caregivers' economic status and lifestyle issues together predicted 17% variance of caregivers' positive adaptation and financial concern and was significant $F(7, 240) = 7.23$, $p < .001$. Caregivers without lifestyle issues ($\beta = .35$, $t = 2.87$, $p < .01$) that is caregivers not indulging in lifestyle issues was the significant predictor of caregivers' positive adaptation and financial concern. In Model 2, patients with restriction of physical activity which is patients' level of physical activity is added to the model but the model did not significantly predict more variance. The model explained 18% of variance and was significant $F(8, 239) = 6.54$, $p < .001$, and caregivers without lifestyle issues ($\beta = .36$, $t = 2.91$, $p < .01$) was found to be the significant predictor of caregivers' positive adaptation and financial concern.

In Model 3 of hierarchical analysis taking positive adaptation and financial concern as criterion, complete agreement between patients with patients and their Caregivers on interpersonal relationship and caregivers' higher perception on interpersonal relationship were added to the model. Model 3 significantly predicted more variance as R^2 change was found to be 0.13, $p < .001$. Then, this model explained 31% variance of caregivers' positive adaptation and financial concern and was significant $F(10,237) = 10.66$, $p < .001$. In Model 3, caregivers without lifestyle issues ($\beta = .38$, $t = 3.39$, $p < .01$), complete agreement between patients with patients and their Caregivers on interpersonal relationship ($\beta = -.17$, $t = -3.00$, $p < .01$), and caregivers' higher perception on interpersonal relationship ($\beta = -.33$, $t = -6.00$, $p < .001$) were the significant predictors of caregivers' positive adaptation and financial concern.

Table 17

Summary of Hierarchical Regression Analysis for variables predicting caregivers' positive adaptation and financial concern (N = 248 pairs)

Model and predictor variables	B	SE B	β	t	R²	ΔR^2
Model 1 (C = 11.48, F = 7.23***)					.17	
Middle Economic Status	-2.34	2.61	-.24	-.89		
Low Economic Status	-1.32	2.59	-.13	-.51		
Caregivers Smoking	.09	1.58	.01	.06		
Caregivers Smoking & Alcohol	-6.95	4.61	-.09	-1.51		
Caregivers Chewing Pan	-.29	.78	-.03	-.37		
Caregivers Taking Tobacco	-.33	1.69	-.02	-.19		
Caregivers without lifestyle issues	3.85	1.34	.35**	2.87		
Model 2 (C = 11.44, F = 6.54***)					.18	.01
Middle Economic Status	-2.07	2.62	-.21	-.79		
Low Economic Status	-1.21	2.59	-.12	-.46		
Caregivers Smoking	.29	1.59	.02	.18		
Caregivers Smoking & Alcohol	-7.34	4.61	-.09	-1.59		
Caregivers Chewing Pan	-.33	.78	-.03	-.42		
Caregivers Taking Tobacco	-.05	1.70	-.002	-.03		
Caregivers without lifestyle issues	3.89	1.34	.36**	2.91		
Patients capable of all self- care and carry out light or sedentary work	-.89	.71	-.07	-1.26		
Model 3 (C = 18.72, F = 10.66***)					.31	.13***
Middle Economic Status	-2.46	2.42	-.25	-1.02		
Low Economic Status	-1.69	2.39	-.17	-.71		
Caregivers Smoking	1.50	1.48	.09	1.02		
Caregivers Smoking & Alcohol	-6.98	4.25	-.09	-1.64		
Caregivers Chewing Pan	.06	.72	.006	.09		
Caregivers Taking Tobacco	.05	1.57	.003	.03		
Caregivers without lifestyle issues	4.19	1.24	.38**	3.39		
Patients capable of all self- care and carry out light or sedentary work	-.64	.66	-.05	-.97		
Complete Agreement on interpersonal relationship	-9.24	3.08	-.17**	-3.00		
Caregivers' higher Perception on interpersonal relationship	-.11.25	1.89	-.33***	-6.00		

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

Table 17 contd.

Summary of Hierarchical Regression Analysis for variables predicting caregivers' positive adaptation and financial concern (N = 248 pairs)

Model and predictor variables	B	SE B	β	t	R²	ΔR^2
Model 4 (C = 16.70, F = 11.20***)					.38	.07***
Middle Economic Status	-3.04	2.31	-.31	-1.31		
Low Economic Status	-2.27	2.28	-.23	-.99		
Caregivers Smoking	1.64	1.41	.10	1.16		
Caregivers Smoking & Alcohol	-7.14	4.05	-.09	-1.76		
Caregivers Chewing Pan	-.10	.69	-.01	-.15		
Caregivers Taking Tobacco	.54	1.50	.03	.36		
Caregivers without lifestyle issues	3.89	1.18	.35**	3.30		
Patients capable of all self- care and carry out light or sedentary work	-.36	.63	-.03	-.57		
Complete Agreement on interpersonal relationship	-6.60	3.01	-.12*	-2.19		
Caregivers' higher Perception on interpersonal relationship	-10.29	1.81	-.29***	-5.68		
Distress of caregivers	.36	.08	.33***	4.33		
Depression of Caregivers	-.39	.53	-.04	-.73		
Anxiety of caregivers	-.19	.27	-.05	-.69		

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

In Model 4 of hierarchical analysis taking positive adaptation and financial concern as criterion (Table 17 contd.), psychological states (distress, depression, anxiety, & somatization) were added. The model significantly predicted more variance as R^2 change was found to be 0.07, $p < .001$. Model 4 then explained 38% variance of positive adaptation and financial concern and was significant $F(13, 234) = 11.20$, $p < .001$. Caregivers without lifestyle issues ($\beta = .35$, $t = 3.30$, $p < .01$), complete agreement between patients and their family caregivers on interpersonal relationship ($\beta = -.12$, $t = -2.19$, $p < .05$) between patients and their Caregivers, caregivers' higher perception on interpersonal relationship ($\beta = -.29$, $t = -5.68$, $p < .001$), and distress of caregivers ($\beta =$

.33, $t = 4.33$, $p < .001$) were found to be the significant predictors of caregivers' positive adaptation and financial concern

Table 18 presents the results of hierarchical regression analysis taking caregivers' support as criterion. Caregivers' support includes the support received by caregivers from relatives, friends and neighbors. The analysis gave rise to three models and in Model 1, caregivers' demographic variables such as occupation and lifestyle issues predicted 16% variance of caregivers' support and the model was significant $F(5, 242) = 9.35$, $p < .001$. Caregivers without lifestyle issues ($\beta = .36$, $t = 2.92$, $p < .01$) that is caregivers not indulging in lifestyle issues was the significant predictor of caregivers' support.

Table 18

Summary of Hierarchical Regression Analysis for variables predicting caregivers' support (N = 248 pairs)

Model and predictor variables	B	SE B	β	t	R ²	ΔR^2
Model 1 (C = 1.84, F = 9.35***)					.16	
Employed Caregivers	-.47	.39	-.07	-1.22		
Caregivers Smoking	-.11	.91	-.01	-.11		
Caregivers Chewing Pan	-.29	.45	-.05	-.64		
Caregivers Taking Tobacco	.03	.98	.003	.03		
Caregivers without lifestyle issues	2.29	.78	.36*	2.92		
Model 2 (C = 3.97, F = 9.07***)					.21	.05**
Employed Caregivers	-.54	.38	-.08	-1.41		
Caregivers Smoking	.20	.89	.02	.23		
Caregivers Chewing Pan	-.26	.45	-.05	-.59		
Caregivers Taking Tobacco	.13	.96	.01	.13		
Caregivers without lifestyle issues	2.34	.77	.36**	3.05		
Patients' higher Perception on interpersonal relationship	-.38	1.88	-.02	-.20		
Caregivers' higher Perception on interpersonal relationship	-4.82	2.21	-.24*	-2.18		
Model 3 (C = 3.83, F = 9.89***)					.23	.02
Employed Caregivers	-.49	.39	-.07	-1.25		
Caregivers Smoking	.08	.89	.01	.09		
Caregivers Chewing Pan	-.27	.44	-.05	-.61		
Caregivers Taking Tobacco	.18	.96	.02	.19		
Caregivers without lifestyle issues	2.22	.76	.35**	2.92		
Patients' higher Perception on interpersonal relationship	-.53	1.89	-.03	-.28		
Caregivers' higher Perception on interpersonal relationship	-4.76	2.19	-.23*	-2.16		
Distress of caregivers	.03	.04	.05	.77		
Depression of Caregivers	.61	.35	.11	1.75		

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

In Model 2, patients' higher perception on interpersonal relationship and caregivers' higher perception on interpersonal relationship were added to the model. The model significantly predicted more variance as R^2 change was found to be 0.05, $p < .01$, Model 2 explained 21% variance of caregivers' support and was significant $F(7,240) = 9.07$, $p < .001$. In Model 2, caregivers without lifestyle issues ($\beta = .36$, $t = 3.05$, $p < .01$) and caregivers' higher perception on interpersonal relationship ($\beta = -.24$, $t = -2.18$, $p < .05$) were found to be significant predictors of caregivers' support. In Model 3, psychological states (distress & depression) of caregivers were added to the model. However, Model 3 did not significantly predict more variance but the model was significant $F(9,238) = 9.89$, $p < .001$ and the model explained 23% variance. Caregivers without lifestyle issues ($\beta = .35$, $t = 2.92$, $p < .01$) and patients' higher perception on interpersonal relationship ($\beta = -.23$, $t = -2.16$, $p < .05$) were found to be significant predictors of caregivers' support.

Categorization of Family Caregivers

As the scale used for measuring the caregivers' QoL does not have a norm, it was the interest of the investigator to find out if there were any categories of caregivers that may be seen based on their QoL. Therefore, the fifth objective of the study was to categorize family caregivers of cancer patients (BC & HNC) based on their levels of quality of life and to examine the differences in indicators of their quality of life. The present focus on the QoL of caregivers has been because the scale Caregiver Quality of Life- Cancer (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999) does not have a norm to categorize them into groups. Hence, cluster analysis was done based on the four

dimensions (Tamayo, Broxson, Munsell, and Cohen 2010) of QoL of caregivers. The cluster analysis used for this purpose was k-means cluster analysis.

Table 19 and Figure 8, represented the means, standard deviation and ANOVA values for the four dimensions of caregivers' QoL across the clusters that emerged in k means cluster analysis. Cluster 1, was characterized by higher levels of score across the four domains and was named '*poor quality of life*' ($n_1 = 36$), cluster 3 was characterized by low levels of scores on all the four domains and was named '*good quality of life*' ($n_3 = 109$). Cluster 2 was named '*moderate quality of life*' ($n_2 = 103$) as it was characterized by score that are neither high nor low. The mean score of poor QoL category (cluster) on burden was 23.58 ($SD = 4.49$), disruptiveness was 11.58 ($SD = 4.58$), positive adaptation and financial concern was 16.03 ($SD = 4.51$), and support was 5.69 ($SD = 2.71$). The mean score of moderate QoL category (cluster) on burden was 12.24 ($SD = 4.03$), disruptiveness was 5.62 ($SD = 2.29$), positive adaptation and financial concern was 15.40 ($SD = 2.89$), and support was 4.30 ($SD = 2.52$). The mean score of good QoL category (cluster) on burden was 7.27 ($SD = 4.49$), disruptiveness was 1.28 ($SD = 1.42$), positive adaptation and financial concern was 8.73 ($SD = 3.47$), and support was 1.74 ($SD = 2.11$).

One-way ANOVA was done for the three categories of caregivers (clusters) on four dimensions of QoL. The results showed statistically significant differences among the three categories of caregivers on the QoL dimensions such as burden ($F = 195.59$, $p < .001$), disruptiveness ($F = 252.44$, $p < .001$), positive adaptation and financial concern ($F = 122.04$, $p < .001$), and support ($F = 50.50$, $p < .001$).

Table 19

Mean value of three domains of caregivers' QoL by total and cluster (n= 248)

Patients’ Performance Status	<u>Sub-group</u>								<i>F</i> (2,245)
	Total (N = 248)		Cluster 1 (n= 36)		Cluster 2 (n= 103)		Cluster 3 (n= 109)		
Variables	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Burden	11.7	6.91	23.58	4.49	12.24	4.03	7.27	4.49	195.59***
Disruptiveness	4.58	4.29	11.58	4.58	5.62	2.29	1.28	1.42	252.44***
Positive Adaptation and Financial Concern	12.56	4.81	16.03	4.51	15.40	2.89	8.73	3.47	122.04***
Support	3.38	2.82	5.69	2.71	4.30	2.52	1.74	2.11	50.50***

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

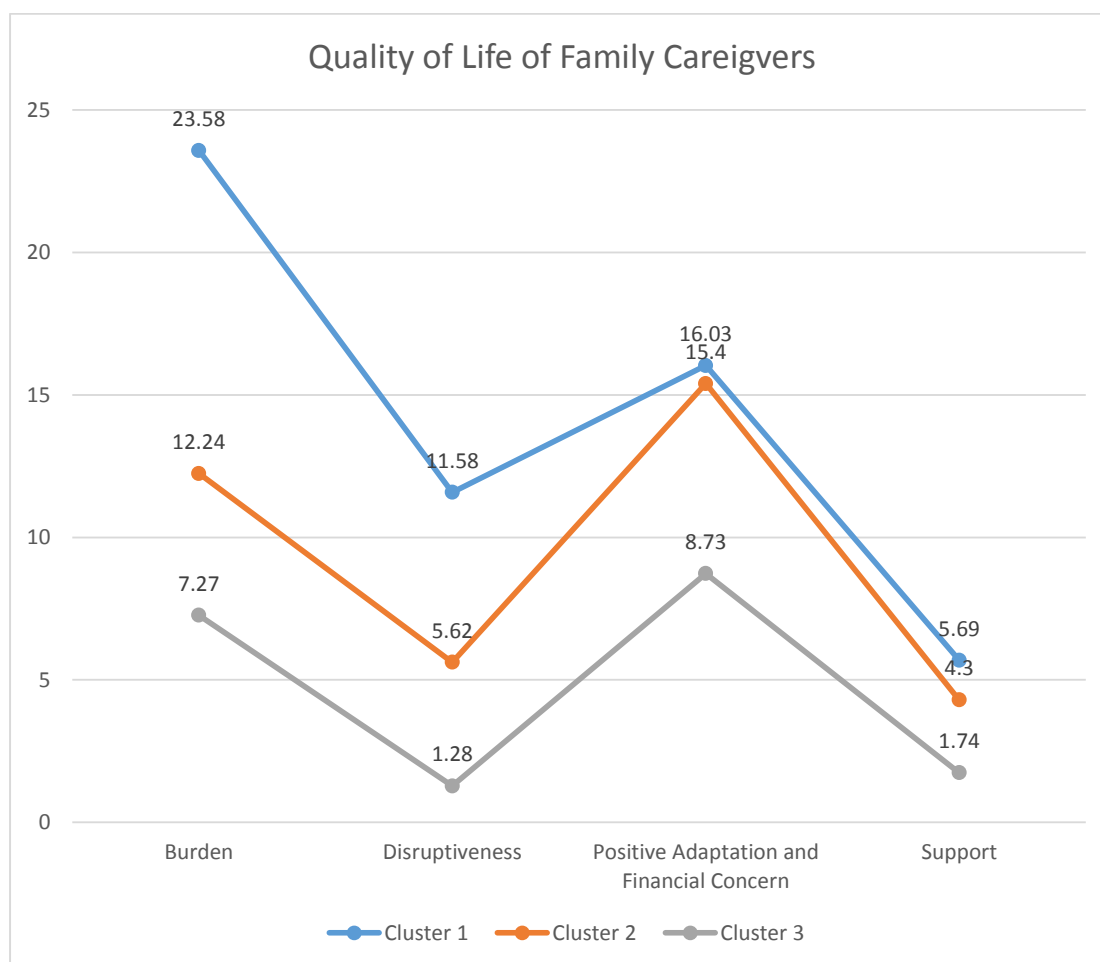


Figure 8. Line graph showing means values of three categories of family caregivers based on their QoL

Table 20 indicated the Relationship between the categories of caregivers based on their QoL and the categories based on patients' level of physical activity. Cluster 1 that is poor QoL category of caregivers consisted of 36 caregivers of patients. Out of these 36 caregivers, 9 caregivers were taking care of patients who are capable of all self-care and carry out light or sedentary works. While 16 caregivers were taking care of patients who are capable of all self-care, and 11 caregivers are taking care of patients capable of limited self-care.

Cluster 2 that is moderate QoL category of caregivers consisted of 103 caregivers and out of these 17 caregivers were taking care of patients who are capable of all self-care and carry out light or sedentary works. While 44 caregivers were taking care of patients capable of all self-care and 42 caregivers are taking care of patients capable of limited self-care. The third cluster that is good QoL category of caregivers, this group consisted of 109 caregivers. Among these 109 caregivers 29 caregivers were taking care of patients who are capable of all self-care and carry out light or sedentary works, 47 were taking care of patients capable of all self-care, and 33 caregivers were taking care of patients capable of limited self-care.

Table 20

Relationship between the categories of caregivers based on their QoL and the categories based on patients' activity level

		Categories based on patients' levels of Physical Activity			Total
	Groups	Caregivers of P.A. 1	Caregivers of P.A. 2	Caregivers of P.A. 3	
Categories based on caregivers' Quality of life	Cluster-1	9	16	11	36
	Cluster- 2	17	44	42	103
	Cluster- 3	29	47	33	109
Total		55	107	86	248

Note: **P.A.1**- Patients capable of all self-care and carry out light or sedentary work; **P.A.2**- patients capable of all self-care; **P.A. 3**- Patients capable of limited care.

To address the second part of the fifth objective that is to examine the differences in indicators of caregivers' quality of life. One-way between groups ANOVA was computed on predictors of caregivers' QoL, these are physical activity level of patients, interpersonal relationship and psychological states of patients and their caregivers. Results are shown in Table 21 and Table 22.

Patients Higher Perception on Interpersonal Relationship

There was as statistically significant difference in patients' higher perception on interpersonal relationship than their caregivers among the three categories of caregivers $F(2, 245) = 12.64, p < .001$ and the effect size was medium which is calculated using eta squared and was found to be 0.09 (Table 21). In order to determine where the group differences are Post Hoc comparison using the Tukey HSD test was conducted (Table 22). As shown in Table 21, the means score ($M = 0.41, SD = 0.19$) for category of caregivers with poor QoL was significantly different from the mean score ($M = 0.32, SD = 0.15$) of moderate QoL category of caregivers. Poor QoL category of caregivers have higher means score on patients' higher perception on interpersonal relationship than that of moderate QoL category of caregivers. Statistically significant difference was found between the means of poor QoL category of caregivers and good QoL category of caregivers ($M = 0.26, SD = 0.15$). The mean of poor QoL category of caregivers was higher than the mean of good QoL category of caregivers. Tukey HSD test (Table 22) also shown that there was statistically significant difference between the means of moderate QoL category of caregivers and good QoL category of caregivers on patients' higher perception on interpersonal relationship. The mean of poor QoL category of

caregivers' mean is higher than that of good QoL category of caregivers on patients' higher perception on interpersonal relationship.

Caregivers' Higher Perception on Interpersonal Relationship

Statistically significant difference was found on caregivers' higher perception on interpersonal relationship among the three categories of caregivers of cluster $F(2, 245) = 13.07$, $p < .001$. The effect size was medium which is calculated using eta squared and was found to be 0.09 (Table 21). Post Hoc comparison using Tukey HSD shows that there was a statistically significant difference between the mean score of poor QoL category of caregivers ($M = 0.34$, $SD = 0.16$) and moderate QoL category of caregivers ($M = 0.42$, $SD = 0.13$). Caregivers with moderate QoL had higher perception on the quality of their interpersonal relationship than poor QoL category of caregivers. Statistically significant difference was found between poor QoL category of caregivers and good QoL group category of caregivers on caregivers' higher perception on interpersonal relationship, the mean score of poor QoL category of caregivers ($M = 0.34$, $SD = 0.16$) is lower than the mean score of good QoL category of caregivers ($M = 0.46$, $SD = 0.12$). Post Hoc comparison Tukey HSD also showed that there was a statistically significant difference between the mean score of moderate QoL category of caregivers ($M = 0.42$, $SD = 0.13$) and mean score of good QoL category of caregivers ($M = 0.46$, $SD = 0.12$). The mean score of moderate QoL category of caregivers is higher than the mean score of low QoL category of caregivers on.

Table 21

Table showing Mean, Standard Deviation, and summary of one-way ANOVA for the three groups

Patients' Performance Status Variables	Poor (n= 36)		Moderate (n= 103)		Good (n= 109)		One-way ANOVA Mean Square			η^2
	M	SD	M	SD	M	SD	Between	Error	F (2,245)	
Restricted activity	.25	.44	.17	.37	.27	.44	.29	.17	1.66	-
Patients capable of all self-care	.44	.50	.43	.49	.43	.49	.004	.25	.02	-
Patients capable of limited Self-Care	.31	.47	.41	.49	.30	.46	.33	.23	1.45	-
Patients' Higher Perception on I.R.	.41	.19	.32	.15	.26	.15	.31	.02	12.64***	.09
Complete Agreement on I.R.	.25	.09	.25	.08	.26	.08	.01	.01	1.17	-
Caregivers' higher Perception on I.R.	.34	.16	.42	.13	.46	.12	.23	.02	13.07***	.09
Caregivers' Distress	8.42	5.47	5.62	4.21	3.10	3.01	425.76	15.64	27.21***	.18
Caregivers' Depression	.50	.91	.12	.53	.03	.21	3.04	.25	11.93***	.09
Caregivers' Anxiety	1.69	1.47	.75	1.17	.62	1.07	16.12	1.38	11.66***	.09
Caregivers' Somatization	2.25	2.45	1.01	1.42	1.06	1.52	22.84	2.72	8.41***	.06
Patients' Distress	13.5	6.92	10.92	6.08	9.77	5.76	189.73	36.87	5.15**	.04
Patients' Depression	2.14	2.88	.90	1.59	.72	1.25	28.24	2.94	9.62***	.07
Patients' Anxiety	2.44	2.21	1.94	1.83	1.48	1.72	14.18	4.17	4.17*	.03
Patients' Somatization	7.94	7.71	5.18	3.76	5.15	3.39	118.9	6.11	6.11**	.05

Note: * $p < .05$, ** $p < .01$, *** $p < .001$; I.R.- Interpersonal Relationship, PAFC- Positive Adaptation and Financial Concern

Table 22

Table showing mean comparisons using Tukey's HSD between the three groups of predictors of caregivers' QoL

Variables	<u>Level of Physical Activity</u>		
	G1-G2	G1-G3	G2-G3
Patients' Higher Perception on interpersonal relationship	.08*	.15***	.06*
Caregivers' higher Perception on interpersonal relationship	-.08**	-.13***	-.05*
Caregivers' Distress	2.79**	5.32***	2.52
Caregivers' Depression	.38***	.47***	-.09
Caregivers' Anxiety	.95***	1.07***	.12
Caregivers' Somatization	1.27***	1.19**	-.04
Patients' Distress	2.58	3.73**	-1.15
Patients' Depression	1.24**	1.42***	.19
Patients' Anxiety	.50	.97*	.46
Patients' Somatization	2.76**	2.79**	.04

Note: *** $p < .001$, ** $p < .01$ * $p < .05$; G1- Poor, G2- Moderate, G3- Good

Distress of Family Caregivers

On distress which is one of the dimension of psychological states, there was a statistically significant difference among the three categories of caregivers (QoL) $F(2,245) = 27.21$, $p < .001$ as indicated in Table 21. The effect size was medium which is calculated using eta squared ($\eta^2 = 0.18$). Post Hoc comparison using Tukey HSD was computed to address where the difference between the category of caregivers is (Table 22). Post Hoc comparison showed that there was a statistically significant difference between the mean score of poor QoL category of caregivers ($M = 8.42$, $SD = 5.47$) and moderate QoL category of caregivers ($M = 5.62$, $SD = 4.21$). This indicated that distress

is higher among caregivers with poor QoL than caregivers with moderate QoL. Statistically significant difference was found between the mean score of caregivers with poor QoL category of caregivers ($M = 8.42$, $SD = 5.47$) and caregivers with good QoL ($M = 3.10$, $SD = 3.01$). However, no statistically significant difference was found between moderate and good QoL categories of caregivers.

Depression of Caregivers of Patients

Statistically significant difference was found among the three categories of caregivers $F(2, 245) = 11.93$, $p < .001$ and the effect size was medium which is calculated using eta squared and was found to be 0.09. Post Hoc comparison (Table 22) also showed that there was statistically significant difference between the mean score of poor QoL category of caregivers and good QoL category of caregivers. The mean score of poor QoL category of caregivers ($M = 0.50$, $SD = 0.91$) was higher than the mean score of moderate QoL category of caregivers ($M = 0.12$, $SD = 0.53$). Statistically significant difference was found between the mean score of poor QoL category of caregivers ($M = 0.50$, $SD = 0.91$) and the means score of good QoL category of caregivers ($M = 0.03$, $SD = 0.21$). However, there was no statistically significant difference between the means score of moderate QoL category of caregivers and the means score of good QoL category of caregivers.

Anxiety of Caregivers of Patients

There was a statistically significant difference on the dimension of anxiety among the three categories of caregivers $F(2, 245) = 11.66$, $p < .001$. The effect size was medium which is calculated using eta squared ($\eta^2 = 0.09$). Post Hoc Tukey HSD (Table 22) test was conducted to determine where the group difference lies. As shown in Table

22, statistically significant difference was found between the mean score of poor QoL category of caregivers ($M = 1.69$, $SD = 1.47$) and moderate QoL category of caregivers ($M = 0.75$, $SD = 1.17$). Anxiety was found to be higher among caregivers with poor QoL than moderate QoL category of caregivers. Statistically significant difference was found between poor QoL category of caregivers ($M = 1.69$, $SD = 1.47$) and good QoL category of caregivers ($M = 0.62$, $SD = 1.07$). Caregivers with poor QoL have higher anxiety than caregivers with good QoL. There was no significant difference between the mean scores of caregivers with moderate QoL category of caregivers and good QoL category (Table 22).

Somatization in Family Caregivers

As shown in Table 21, there was statistically significant difference between the three categories of caregivers on the dimension of somatization $F(2, 245) = 8.41$, $p < .001$. Despite reaching statistical difference the actual difference in mean score was quite small, as it is seen in the Eta squared value which showed an effect size of 0.06. Post Hoc Tukey HSD comparison (Table 22) showed that there was a statistically significant difference between the mean scores of poor QoL category of caregivers ($M = 2.25$, $SD = 2.45$) and moderate QoL category of caregivers ($M = 1.01$, $SD = 1.42$) of caregivers. Caregivers with poor QoL have higher somatization than caregivers with moderate QoL. Statistically significant difference was found between poor QoL category of caregivers ($M = 2.25$, $SD = 2.45$) and good QoL category of caregivers ($M = 1.06$, $SD = 1.52$). Caregivers with poor QoL have higher somatization than caregivers with good QoL. No statistically significant difference was found between the mean scores of moderate and good QoL categories of caregivers.

Distress in Patients

In the present study ANOVA was run to see the impact of the three categories of caregivers on patients' psychological states and results are shown in Table 21 and Table 22. Statistically significant difference was found for patients among the three categories of caregivers $F(2, 245) = 5.15, p < .01$ on the dimension of distress. Though there was a statistically significant difference the actual difference in mean score between the categories of caregivers was quite small, which is calculated using eta squared and was found to be 0.04. Post Hoc Tukey HSD comparison (Table 22) between the three categories of caregivers showed that there was statistically significant difference between the mean score of poor QoL category of caregivers ($M = 13.5, SD = 6.92$) and good QoL category of caregivers ($M = 9.77, SD = 5.76$). Patients who are cared by caregivers with poor QoL have higher distress than patients who are cared by caregivers with good QoL. There was no statistically significant difference between cancer patients who are cared by caregivers with poor QoL and patients who are cared by caregivers with moderate QoL and between patients who are cared by caregivers with good QoL and patients who are cared by caregivers with moderate QoL.

Depression of Patients

There was a statistically significant difference between the three categories of caregivers on patients' depression $F(2, 245) = 9.62, p < .001$. However, the effect size was found to be low as reflected in the calculation using Eta squared which is 0.07. Post Hoc comparison using Tukey's HSD test (Table 22) was done and it showed that there was a statistically significant difference between the means of caregivers with poor QoL ($M = 2.14, SD = 2.88$) and caregivers with moderate QoL ($M = 0.90, SD = 1.59$).

Depression was found to be higher among patients whose caregivers have poor QoL than patients whose caregivers have moderate QoL. Statistically significant difference was also found between patients whose caregivers have poor QoL ($M = 2.14$, $SD = 2.88$) and patients whose caregivers have good QoL ($M = 0.72$, $SD = 1.25$). Patients whose caregivers have poor QoL have higher depression than patients whose caregivers have good QoL. There was no statistically significant difference between patients whose caregivers have moderate QoL and patients whose caregivers have good QoL.

Anxiety of Patients

There was a statistically significant difference between the three categories of caregivers on patients' anxiety $F(2,245) = 4.17$, $p < .05$. However, the effect size was found to be low as reflected in the calculation using Eta squared which is 0.03. Post Hoc comparison using Tukey's HSD test (Table 22) was done and it showed that there was no statistically significant difference between the means of caregivers with poor QoL ($M = 2.44$, $SD = 2.21$) and caregivers with moderate QoL ($M = 1.94$, $SD = 1.83$). Statistically significant difference was found between patients whose caregivers have poor QoL ($M = 2.44$, $SD = 2.21$) and patients whose caregivers have good QoL ($M = 1.48$, $SD = 1.72$). Patients whose caregivers have poor QoL have higher anxiety than patients whose caregivers have good QoL. There was no statistically significant difference between patients whose caregivers have moderate QoL and patients whose caregivers have good QoL on patients' anxiety.

Somatization of Patients

There was a statistically significant difference between the three categories of caregivers on the dimension on patients' somatization $F(2,245) = 6.11, p < .01$. However, the effect size was found to be low as reflected in the calculation using Eta squared which is 0.05. Post Hoc comparison using Tukey's HSD test (Table 22) was done and it showed that there was a statistically significant difference was found between the means of caregivers with poor QoL ($M = 7.94, SD = 7.71$) and caregivers with moderate QoL ($M = 5.18, SD = 3.76$). Somatization was found to be higher among patients whose caregivers have poor QoL than patients whose caregivers have moderate QoL. Statistically significant difference was also found between patients whose caregivers have poor QoL ($M = 7.94, SD = 7.71$) and patients whose caregivers have good QoL ($M = 5.15, SD = 3.39$). Patients whose caregivers have poor QoL have higher somatization than patients whose caregivers have good QoL. There was no statistically significant difference between patients whose caregivers have moderate QoL and patients whose caregivers have good QoL on the dimension of somatization.

An overview of the findings based on the results is as follows. The results based on the first four objectives in the present study showed that that some elements of demographic variables, interpersonal relationship between patients and their caregivers, as well as their psychological states predicted the caregivers' QoL. Patients who participated in the study were found to have higher distress, depression, anxiety and somatization than their caregivers who were taking care of them. Patients were found to perceived higher interpersonal relationship with their caregivers than the caregivers

themselves. It was also found that caregivers who have participated in the present study were obtained lower scores on their QoL which indicated that their QoL is good.

Caregivers who were taking care of patients capable of all self-care and can carry out light or sedentary work showed significant differences on certain dimensions from caregivers who were taking care of patients capable of limited self-care. The difference was seen on the psychological states dimension of distress with respect to psychological states; and mutual communication dimension with respect to interpersonal relationship. There were three features developed based on the agreement and disagreement in the perception of interpersonal relationship between the patients and their caregivers. Perception of interpersonal relationship of patients and caregivers were higher than complete agreement between patients and their caregivers in their perception interpersonal relationship. This indicated that the disagreement between patients and their caregivers was higher than agreement between patients and their caregivers.

Results of the present study showed that demographic variables related to caregivers such as not indulging in lifestyles issues such as smoking, drinking alcohol, chewing pan (betel nut) and tobacco were found to be significant predictors of caregivers' QoL and its four domains. Apart from this the significant predictors of caregivers' QoL were complete agreement between patients and their caregivers on interpersonal relationship and caregivers' higher perception on interpersonal relationship. Other significant predictors of caregiver's QoL were distress and depression of caregivers and somatization of patients.

The predictors of caregivers' QoL dimension burden were caregivers not indulging in lifestyle issues, dimensions such as distress and anxiety of caregivers, and

depression and somatization of patients. Caregivers' QoL dimension disruptiveness was predicted by caregivers not indulging in lifestyle issues, caregivers' higher perception on interpersonal relationship, dimensions such as depression of caregivers, and somatization of patients among the psychological states. The dimension positive adaptation and financial burden on caregivers' QoL was predicted by caregivers not indulging in lifestyle issues, complete agreement between patients and their caregivers in their perception of interpersonal relationship between them, caregivers' higher perception on interpersonal relationship, and distress of the caregivers. Caregivers' QoL dimension support was found to be predicted by variables such as caregivers not indulging in lifestyle issues and caregivers' higher perception on interpersonal relationship.

In the present study, the cluster analysis based on the caregivers' QoL gave rise to three categories of caregivers (three clusters). Based on the nature of the categories, these categories are named poor quality of life, moderate quality of life, and good quality of life. In each category of caregivers of patients capable of limited self-care were highest in number. Statistically significant difference was seen between the three categories of caregivers on patients' higher perception on interpersonal relationship, caregivers' higher perception on interpersonal relationship, psychological states (distress, depression, anxiety, somatization) of patients and psychological states of caregivers.

The result demonstrated that patients' physical activity level does not have an impact on caregivers' QoL. However, patients and their caregivers' psycho-social factors such as the interpersonal relationship between them and their psychological states did have impact on the caregivers' QoL.

CHAPTER V

DISCUSSION

The prime objective of this study was to find out the effect of patients' physical activity level and psychosocial factors on quality of life of their family caregivers. The present study tested four hypotheses on patients and their caregivers. It was observed that the mean scores of patients on all four of the psychological states that is distress, depression, anxiety, and somatization were higher than that of their family caregivers which indicated poor psychological states. Whereas, the overall perception of interpersonal relationship was higher among patients than their family caregivers.

Further observation showed that among the psychological states which include distress, depression, anxiety, and somatization, the frequency percentage of distress was for patients (Strongly Elevated = 7.7%; Moderately Elevated = 42.7%) was higher than their caregivers (Moderately Elevated = 14.9%). This finding is in contrast with studies which found similar level of distress for both patients and their caregivers (Gropper, van der Meer, Landes, Bucher, Stickel, & Gerling, 2015; Hodges, Humphries, & MacFarlane 2005). However, the present study is more in line with studies such as Ben-zur, Gilbar, and Lve, (2001) and Baider and Denour (1999) which found that patients have higher distress than their caregivers. It was also observed that the frequency of other dimensions of psychological states such as depression, anxiety, and somatization were higher for patients than their caregivers. The findings in the present study are also supported by a research study of Huan, Sklenarova, Brechtel, Herzog, Hartmann (2015) which also found that depression and anxiety among cancer patients were higher than their caregivers.

With respect to the perception of interpersonal relationship, patients demonstrated higher perception of interpersonal relationship with their family caregivers, than the caregivers themselves. The reason why patients perceived higher interpersonal relationship may be attributed to their caregivers providing them with physical and psychological support throughout their illness trajectory including treatment and its outcomes. On the other hand, the patients may not be able to reciprocate the same support as a result of their illness. While the caregivers give their best support possible to patients suffering with cancer, they themselves may be needing psychosocial support owing to their own negative psychological states and agony due to the illness of their dear one and the resulting changes in life from multiple perspectives. In their personal relationship, thus same support provided by the caregiver cannot be reciprocated by the patient. Also, owing to their own concerns of illness, patients may not show their understanding and recognition of support received from their caregivers. Thus, on all the components involved in the interpersonal relationship between patients and caregivers such as mutual communication, mutual relationship, availability and providing comfort, attention and support, and mutual care, reciprocation may not be practically possible. As a result, while patients perceive the above components and perceive better interpersonal relationship, family caregivers do not perceive the same to the same extent. The understanding related to the patient's receptivity of the support provided by the caregiver may not be clear and may be uncertain. The result shows that in perception of the interpersonal relationship, perception of patients is higher than their family caregivers on the dimension of mutual communication. While patients may perceive the quality of the interpersonal relationship with caregivers, there is a possibility that they may not actually communicate the same.

In addition, the concern of illness and treatment may be an overwhelming concern and thus the communication which should have been greater with caregiver may be altered in the process. The psychological states of distress, depression, anxiety, and somatization also may be the factors behind lower communication from patients if any. This result is again in line with the study of Huan, Sklenarova, Brechtel, Herzog, Hartmann (2015) where caregivers of cancer were found to have perceived lower communication in patients to whom they give care. These results indicated that more than the caregivers, the patients perceived more verbal expression, openness in conversation, and discussion related to their illness between themselves and their caregivers. Results also show that there was only slight difference between the mean score of patients and their caregivers in the dimension of mutual relationship and attention and support. Patients perceived slightly higher mutual relationship than their caregivers. However, on the dimension of attention and support caregivers' perception was slightly higher than the patients to whom they give care. This indicated that the family caregivers perceived themselves as giving more attention and more support to the patient compared to patients' perception of receiving attention and support. While mutual communication and mutual relationship dimensions have been higher in patients, at the same time their perception of receiving attention and support not being higher indicates to the patients' expectation of more attention and support. Their illness might have created a higher need for attention and support in them. The concern of illness, the negative psychological states they may be undergoing may also be the contributing factors for not giving enough importance to the attention and support provided or expecting more. On the other hand, the family caregivers who make many sacrifices as a part of their caregiving may also have felt

greater offering of attention and support from self to the patient (BC & HNC) to their best effort. It was also observed in the study that the family caregivers' perception was higher in the dimension of availability and providing comfort. This indicates that more than the patients the caregivers seemed to perceive greater availability of themselves to the patients and that they were providing comfort to the patients. The family caregivers also perceived higher mutual care than the patients to whom they give care. This shows that the care given and received between patients and family caregivers was perceived more by the family caregivers compared to patients.

Further, it was observed in this study that caregivers had good QoL. This could be because the patients in the study were undergoing curative treatment and not palliative treatment. The mean scores of the caregivers on all the four dimensions of psychological states such as distress, depression, anxiety and somatization were also found to be low. Some previous research studies show that caring for cancer patients increased the risk of poor psychological states such as high distress, depression, and anxiety which may results in low quality of life among caregivers (Gorji, Bouzar, Haghshenas, Kasaeeayan, Sadeghi, & Ardebil, 2012; Haley, 2003; Flaskerud, Carter, & Lee, 2000). But in the present study the result did not support previous research. Low levels of distress, depression, anxiety, and somatization among caregivers found in the present study may be the contributing factors to good QoL among caregivers, psychological states have association with QoL (Umadevi, Ramachandra, Varambally, Philip, & Gangadhar, 2013; Gorji, Bouzar, Haghshenas, Kasaeeayan, Sadeghi, Ardebil, 2012; Friðriksdóttir, et al., 2011; Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004). In the present study, as negative psychological states do not seems to be high we may say that QoL was found to be also

good. Factors impacting the caregivers' QoL will be discussed further in the discussion of successive objectives.

The second objective of the study was to find out the differences in the level of psychological states, interpersonal relationship, and quality of life among caregivers, categorized on the basis of patients' activity levels. It was hypothesized that there will be differences in the levels of psychological states, interpersonal relationship, and quality of life among caregivers, categorized on the basis of patients' activity levels. This hypothesis was partially accepted.

In the present study the physical activity level of patients was assessed using the ECOG Performance Status. The cancer patients who participated in the study fall into three categories of physical activity levels. The first category indicated that patient was capable of all self-care and can carry out light or sedentary work, the second category indicated that patient was capable of all self-care and the third category indicated patient was capable of limited self-care. There are studies which indicated indirect impact of patients' physical status or impairments on caregivers' distress and depression (Fang, Carolyn, Manne, Sharon, & Stephen, 2001; Kurtz, Kurtz, Given, & Given, 1995). Therefore, family caregivers of each patients were categorized based on these three-physical activity levels of patients. It was observed in the study that there was statistically significant difference among the category of caregivers on the dimension of distress in psychological states. In the interpersonal relationship, statistically significant difference was seen among the three categories of caregivers in the dimension of mutual communication.

Caregivers of patients who were more capable of all self-care and could carry out light or sedentary work had comparatively lesser distress and higher mutual communication because of self-reliance of the patients being cared for and lesser dependency on the caregivers. Thus, lesser responsibility of their care was expected from to be provided by the caregivers. It was observed in the study that caregivers of patients capable of limited self-care (Group 3) had higher distress than the caregivers of patients capable of all self-care and can carry out light or sedentary work (Group1). Statistically significant difference was also found on the dimension of mutual communication between caregivers of patients capable of all self-care (Group 2) and caregivers of patients capable of limited self-care (Group 1). The patients capable of only limited self-care require more assistance in day to day activity and are more dependent on caregivers than patients capable of all self-care and can carry out sedentary work. This could be the reason why the caregivers of patients in Group 3 have higher distress than the other two groups. While there was a statistically significant difference between Group 1 and Group 3, and between Group 1 and Group 2 (Caregivers of patients capable of all self-care), no such difference was evident between Group 2 – Group 3. The capability of the patients to take care of themselves on their own and being able to carry out work without dependence on caregiver thus appears to be the contributory factor. The lesser the self-dependence (which leads to greater dependency on others), greater the responsibility of the caregivers to take care and hence higher the distress. Studies also show that patients' physical status or physical dependency is the predictor of caregivers' mental health (Grunfeld et al., 2004; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999).

Between Group 2 and Group 3 no statistically significant difference was found on distress. Though in Group 2 self-care was not problematic, the limitation of this group of patients seems to be lack of capability to work; and in Group 3 both self-care and work being restricted may be contributing to greater distress among their caregivers. Thus, in both the groups, lack of capacity to work is commonly seen. This seems to have contributed to the nonexistence of significant difference. Group 2 showed no statistically significant difference both with Group 1 and Group 3. The self-care capacity not being thoroughly disrupted may have contributed to its similarity partially to Group 1, thus showing no significant difference between Group 1 and Group 2. On the other hand, the restricted capabilities to work for Group 2 makes it appear similar to Group 3. Thus, Group 2 shares partial commonality with Group 1 and also partial commonality with Group 3 on the other side. This seems to have contributed to lack of statistically significant differences between Group 1 and Group 2 as well as Group 2 and Group 3. The mean difference of distress between Group 1 and Group 2 and the mean difference of Group 2 and Group 3 were not high enough to be statistically significant.

Another observation made in the study with respect to interpersonal relationship was that caregivers of Group 1 showed greater perception of mutual communication than caregivers of Group 3. The capability of self-care and do work enables self-sufficiency in patients and two-way communication process between patients and caregivers. Thus, caregivers of this group need no special effort to maintain communication in particular. But the limitation in the capacity for both self-care and any possibility of work for the patients (Group 3), requires the caregivers to put in extra efforts to maintain the channel of communication mutually. The caregiver may need to enquire more, talk more, and

respond more as requirement of caregiver support and dependency on caregiver is larger. This must be the reason for greater perception of mutual communication in Group 1 compared to Group 3.

But no statistically significant difference was found between Group 1 and Group 2 and between Group 2 and Group 3. Here also, the self-care capacity not being thoroughly disrupted may have contributed to its similarity partially between Group 1 and Group 2. On the other hand, the restricted capabilities to work for Group 2 may have contributed to its similarity to Group 3. Thus, Group 2 does not seem to differ significantly from both Group 1 and Group 3 as it has common components with each group thus showing no statistical difference with either of them. Communication between patients and their family caregivers or significant others is important. Manne, Norton, Ostroff, Winkel, Fox & Grana (2007) wrote “the degree to which patients share their concerns with a significant other has been shown to play an important role in adjustment to cancer”. So far, literature is rich on emphasizing the need for communication between patients and medical professionals. It is seen that communication between patients and the caregivers with doctors or physicians is well researched (e.g. DeBenske, Gustafson, Shaw, & Cleary, 2010; Street, Makoul, Arora, & Epstein, 2009; Kimbelin, Brushwood, Allen, Radson, Wilson, 2004). However, research on communication between patients and their caregivers who are also their family members seems to be a sparsely researched area and appears neglected. Therefore, this result will contribute to the literature related to communication between patients and their family caregivers and may provide directions for future research.

The second hypothesis of the study was that there will be an agreement between cancer patients and their family caregivers in their perception of interpersonal relationship. This hypothesis was refuted as the results did not point to the agreement between patients and caregivers. Both for patients and their caregivers, individual perceptions were higher than complete agreement between their perceptions of the interpersonal relationship. In results section, Figure 7 shows greater concentration of responses in f_1 (patients' higher perception of interpersonal relationship). The results indicate that while patients are able to perceive greater interpersonal relationship, the agreement in perceptions between patients and their family caregivers was not seen. As those who are undergoing the suffering, the patients who have cancer may focus more on their interpersonal relationship particularly with their primary caregivers as they are a great source of immediate support to them. On the other hand, caregivers of the patients, who carry out the responsibility of caregiving, also have to distribute their energies and attention towards many other routine activities as well and hence may not match with the perception of the patients they care for. Thus, the f_1 value indicating the patients' perception of interpersonal relationship is higher than the agreement in perceptions of patients and their family caregivers. Disagreement between patients and their spouses was also found by studies such as Clipp and George (1992) in patients functioning and marital quality. Also, study has shown that when the patients perceived communication between them and their caregivers as a hindering communication, this will have negative affect on their perception on all other aspects of care (Kimberly, Brushwood, Allen, Radson, & Wilson, 2004).

The higher values of disagreement between patients and their caregivers indicate a need for development of greater understanding between the caregivers and the patients which contributes to better perceptions of interpersonal relationship mutually. A need to investigate further into the dynamics of the difference in the perceptions may be seen as an important angle which calls for further exploration. Factors contributing or are deterrents of interpersonal relationship between patients and caregivers need to be examined thread bare in future research. This would further add to the scope of development of psychosocial interventions which positively contribute to a greater interpersonal relationship between patients and their caregivers. Caregivers being the primary source of support, designing and providing supportive interventions will strengthen their perception of interpersonal relationship between them and the patients that they care for. This will further enhance the support system which would contribute a long way from a health-psychological perspective. If both the cancer patients and their caregivers have similar perception of interpersonal relationship between them, with such mutual agreement in perceptions, the bond sought by the patient and provided by the caregiver will be stronger. This in turn will enhance more realistic and mutual understanding. This further contributes to healthier and supportive life for both and may help reduce negative psychological impact of the disease and its course on the cancer patients as well as their caregivers. Thus, the findings related to the third objective show that psychosocial interventions need to be designed to strengthen and increase agreement on the perspectives of the interpersonal relationship of patients and their caregivers who are also their family members. This will further provide scope for new dimensions to the research in psycho-oncology.

The fourth objective, was to find out the indicators of family caregivers' quality of life. Results demonstrated that out of 35 specific variables 15 significantly correlated with caregivers' QoL. These are - lifestyle issues of caregivers (i.e. smoking, pan, tobacco, not indulging in lifestyle issues), patients' higher perception on interpersonal relationship, complete agreement on interpersonal relationship, caregivers' higher perception on interpersonal relationship, patients' and caregivers' psychological states (distress, depression, anxiety, somatization). From these fifteen variables that are significantly correlated with caregivers' QoL, five specific variables—caregivers not indulging in lifestyle issues, caregivers' higher perception on interpersonal relationship, caregivers' distress, caregivers' depression, and patients' somatization were the significant predictors of caregivers' QoL. Some earlier studies support these findings by showing similar results. Previous studies have demonstrated that distress of caregivers, and depression of caregivers were indicators of QoL (Kim, Kashy, Wellisch, Spiller, Kaw, Smith, 2008; Kitrungle, & Cohen, 2006; Northouse et al., 2002; Iconomou, Viha, Kalofonos, & Kardamakis, 2001). Among these five indicators, caregivers' higher perception on interpersonal relationship has significant negative correlation with QoL. This indicated that with increase in the score of caregivers' perception of quality of interpersonal relationship, there is a decrease in score of their QoL and thus indicating good QoL. This shows that the better the caregivers' perception of interpersonal relationship better is their QoL.

Caregiver's burden which is one of the dimensions of QoL is defined as "the distress that caregivers feel as a result of providing care, and this distress is different from depression, anxiety, and other emotional response" (Montgomery, Gonyea, & Hooyman,

1985). This dimension of burden in caregivers' QoL has significant correlations with 12 specific dimensions—caregivers chewing tobacco, caregivers not indulging in lifestyle issues, patients' higher perception on interpersonal relationship, caregivers' higher perception on interpersonal relationship and psychological states of cancer patients and their family caregiver (distress, depression, anxiety, somatization). From these 12 specific dimensions, four specific dimensions such as caregivers not indulging in lifestyle issues, distress of caregivers, anxiety of caregivers, depression of patients, and somatization of patients were the significant predictors of the caregivers' burden. These results are consistent with a study done by Mirsoleymani, Rohani, Matbouei, Nasiri and Vasli (2017), which shows family distress as predictor of caregiver's burden. Earlier studies also found relations between caregivers' burden and their anxiety and depression, and the latter two were found to be indicators of caregivers' burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2012; Grov, Dhal, Moun, & Fossa, 2005). However, caregivers' anxiety as indicator of burden is inconsistent with the results of the study done by Grov, Fossa, Sorebo, & Dahl, 2006. On the other hand, the dimension of burden in caregiver's QoL is also found to predict anxiety and depression in the caregivers of cancer patients (Grunfeld et al., 2004). Though the present study found depression in patients as predictor of caregivers' burden, the findings of Lou, Liu, Huo, Liu, & Ji (2015) were not consistent with these findings. Their research showed that in other chronic illnesses there is no correlation between depression of patients and caregivers' burden.

Lifestyle disruption among family caregivers of critically ill patients is not uncommon (Van Pelt et al., 2007), and may contribute to emotional distress (Cameron,

Franché, Cheung, & Stewart, 2000). The dimension of disruptiveness in caregivers' QoL has significant correlations with 16 specific dimensions—middle and lower socio-economic conditions, caregivers not indulging in any lifestyle issues, smoking, chewing tobacco, caregivers' not indulging in any lifestyle issues, patients' higher perception on interpersonal relationship, complete agreement on interpersonal relationship, caregivers' higher perception on interpersonal relationship, psychological states of patients and their family caregivers' psychological states (distress, depression, anxiety, somatization). Among these 16 specific dimensions, those such as caregivers not indulging in lifestyle issues, caregivers' higher perception on interpersonal relationship, depression of caregivers, and somatization of patients were the significant predictors of disruptiveness dimension.

When caregivers are depressed, some of them may resort to some avoidance mechanisms like some deviant lifestyle practices as a support to adjust to current crises. Such practices may include, drinking, alcohol, chewing pan and tobacco. On the other hand, some may not indulge in such lifestyle issues and get adapted to the current crisis on their own without resorting to deviant or avoidance behavior patterns. They may bear with an attempt to adjust with their negative psychological states they are currently experiencing. They thus do not run away from reality or seek the support of escape route which may give temporary escape from the reality but may harm self in the long run. The caregivers who feel depressed are less likely to want to indulge in daily activities such as work, or other roles. They may sometimes perceive that he/she had done more as compared to caregivers who are not depressed. This could be why the caregivers' depression predicted the QoL dimension disruptiveness.

As mentioned earlier in the first two chapters of this study, the patients' physical performance status is associated with caregivers' perception of lifestyle disruption. When the patients experience somatization and complain physical discomfort to the caregivers, the caregivers may be more concerned about the patients, resulting in the caregivers giving more attention and assistance to the patients. This may also probably lead to caregivers' perception of disruption in daily living as it involves time, physical, and psychological investment of efforts. Caregivers' higher perception of interpersonal relationship has a significant negative correlation with QoL, disruptiveness dimension of QoL, and is also a significant predictor of disruptiveness dimension of QoL. This indicated that when the caregivers perceived high interpersonal relationship between them and the patients, their reported feeling of disruptiveness on the QoL decreases. This result indicated that when the caregivers perceived themselves as having good interpersonal relationship with the patients they cared for, by maintaining good mutual communication, attention, mutual support, and so on, they neither feel that they have to give extra effort to care for the patients nor perceived caregiving as cumbersome. Thus, this may be the reason why they perceive less disruptiveness in their daily living.

The dimension positive adaptation and financial concern of caregivers' QoL has significant correlation with 14 specific dimensions—middle and lower socio economic status, smoking, smoking as well as drinking alcohol, chewing pan, chewing tobacco, caregivers not indulging in lifestyle issues, patients capable of all self-care and carry out light or sedentary works, patients' higher perception on interpersonal relationship, complete agreement on interpersonal relationship between patients and family caregivers and family caregivers' higher perception on interpersonal relationship. The dimension of

positive adaptation and financial concern also had significant positive correlations with caregivers' distress, depression and anxiety. From these fourteen dimensions three dimensions such as caregivers not indulging in lifestyle issues, caregivers' higher perception on interpersonal relationship, and distress of caregivers were the significant predictors of positive adaptation and financial concern. When caregivers do not resort to temporary escape through certain deviant lifestyle patterns, when they have higher perception of the interpersonal relationship between them and the patients they care for and their distress, predict their positive adaptation to their life and current situations they are facing and the financial concerns being encountered owing to the present illness of the patient they care for.

The results indicated that when the patients and their caregivers are in agreement with each other in regard to their perception of their interpersonal relationship, their positive adaptation and financial concern decreases. This result means that when the patients and caregivers perceived that the care and support they gave is in reciprocation and synchronizes with the care and support they received, they have lesser need to put in extra effort to deal with current situation. They also have lesser concern in spite of financial issues and need to positively adapt to those. In summary there may be lesser need to put in extra efforts. It is the same when the caregivers' perceived higher interpersonal relationship with the patients. The presence of distress on the other hand among the family caregivers results in the poor adjustment to the situation of cancer illness and increase in financial concern.

Support which is the fourth dimension of caregivers' quality of life had significant correlations with 8 specific dimensions—smoking, chewing pan, chewing tobacco,

caregivers not indulging in any of the lifestyles issues, patients' higher perception on interpersonal relationship, caregivers' higher perception on interpersonal relationship, caregivers' distress and depression. From these 8 specific dimensions, caregivers not indulging in lifestyle issues and caregivers' higher perception on interpersonal relationship were the significant predictors of caregivers' support. The results indicate, that when the caregivers perceived that the attention, care, and communication efforts that they provide are not only recognized by the patient, but also reciprocated from the patient, this will increase their perception of support.

The dimension of caregivers not indulging in any of the lifestyle issues such as smoking, drinking alcohol, chewing pan and tobacco was found to be the significant predictor of caregivers' QoL and all of its dimensions which include—burden, disruptiveness, positive adaptation and financial concern, and support. The dimension of caregivers not indulging in any of the lifestyle issues mentioned above had significant positive relationship with caregivers' overall QoL and was also its significant predictor. This finding indicted that by not resorting to smoking, drinking alcohol, and chewing pan or tobacco the caregivers did not resort to any escape/ avoidant behavior, are less distracted and are able to focus on the task of caregiving and other roles that they have to assume after the diagnosis of illness in their loved ones. Though previous research has shown that smoking and drinking alcohol are often included in recreational activities, and high level of stress often increases the risk of smoking (Ng & Jeffrey, 2003) and alcohol (Higley, Hasert, Suomi, & Linnoila, 1991) as a means of coping with the stress (Connell, 1994). The present study does not support the same. Caregivers not indulging in any lifestyle issues mentioned also have significantly positive relationship

with caregivers' quality of life dimensions such as burden and disruptiveness and it is also their significant predictor. This indicated that when the caregivers of cancer patients are not indulging in any of the lifestyle issues they have a lesser chance of getting distracted from their task of caregiving which makes them perceive themselves as doing more work as their attention will be towards the patients. This may make them perceive the burden and their regular schedule as more disrupted by the role and responsibilities of caregiving.

Caregivers not indulging in any of the lifestyle issues also have significant positive relationship with caregivers' QoL dimension of positive adaptation and financial concern and it is also their significant predictor. Not indulging in these maladaptive and health risk behavior patterns such as smoking and drinking alcohol may help the caregivers of patients to cope effectively with their loved one's illness and their role as caregivers. However, unlike some who escape from realities of life using these lifestyle patterns like drinking alcohol, smoking etc., caregivers who are not resorting to these life styles issues have to face the realities of financial concern most of the time. These concerns may be owing to medical expenses, lack of financial security, sensitivity to future financial status, uncertainty about escalation in the expenditure for the treatment, reduction of income owing to the increase in time for care and attention and existing resources depleting as they are being spent for the patient. This may be the case when both patients or caregivers is the. Source of income as well as both support the family with combined income. Thus, several areas of life may put them in position leading to financial concern.

Caregivers' QoL dimension of support also has significantly positive relationship with caregivers not indulging in any lifestyle issues. The dimension of caregiver not indulging in any of the lifestyle issues is also a significant predictor of the caregivers' QoL dimension of support. When the caregivers are not indulging in any of these lifestyle issues they may have less distraction from their caregiving thus making them seek or anticipate some help and support received from their others such as family members and significant others.

A study of Weitzner, McMillan, & Jacobsen, (1999) demonstrates contrasting findings compared to the present study. It said that lower QoL in caregivers indicated lower performance status of patients. But it is observed in the present study that patients' level of physical activity was not significant predictor of family caregivers' QoL and any of its four dimensions. This confirms the results found in objective two in the study where physical activity has no impact on the caregivers' QoL. All the patients in the study fall into three categories such as capable of all self-care and can carry out light or sedentary work, capable of all self-care and capable of limited self-care. The fact that all the patients were on some level able to take care of their basic needs makes them in some way a homogenous group. Thus, since all the groups including the group of patients who are capable of limited self-care are able to handle their basic self-care, this could be the reason why they are not significant predictors of caregivers' QoL. This finding of this study is in line with studies such as those of Tuinman, Fleer, Hoekstra, Sleijfer, and Hoekstra-Weeber (2004) and McMillan (1996) which found that patients' functional status was not correlated with caregivers' QoL. Thus, the third hypothesis, family

caregivers' quality of life will be predicted by specific dimensions of patients' activity level, the interpersonal relationship, and psychological states is partially accepted.

The fifth objective was to categorize family caregivers of cancer patients (BC & HNC) based on their levels of quality of life and to examine the differences in indicators of their quality of life. In the present study caregivers were categorized into three groups based on their quality of life. The k-means cluster analysis method was used for clustering the family caregivers of cancer patients. The goal of k-means cluster analysis was to find a structure in the given data. It allows the experimenter to build classification based on the experimental data. Therefore, k-means clustering method is mainly used in exploratory data analysis and creation of classification of data (Morissette & Chartier, 2013). In the present study k-means cluster analysis was used for this purpose. In k-means cluster analysis it is assumed that the researcher/ experimenter will have prior knowledge and is able to give the number of clusters (Zakharov, 2016). The review of literature done for the present study suggested that caregivers of cancer patients often have poor quality of life due to their role in caregiving. Therefore, it was assumed that caregivers of patients in this study will fall into three categories such as those with good, moderate, and poor QoL. Hence, the number of clusters was set as three.

The results of k-means cluster analysis gave rise to three clusters/ categories. As mentioned in results chapter, based on their characteristics these three categories were named good QoL, moderate QoL, and poor QoL. Studies were published where k-means cluster analysis was used which compared all the variables including the variables used for clustering (Zakharov, 2016). In the present study, ANOVA was computed to see the differences between the three categories of caregivers based on their QoL. The result

showed that there was a significant difference in caregivers' QoL and its four dimensions such as burden, disruptiveness, positive adaptation and financial concern, and support. This study is therefore in line with the other studies published earlier where k-means cluster analysis was used.

As shown in the results, statistically significant differences were found between the three groups of caregivers' such as those with poor QoL, moderate QoL and good QoL on specific dimensions such as patients' higher perception on interpersonal relationship, caregivers' higher perception on interpersonal relationship, caregivers' psychological states, and patients' psychological states.

It was seen that when patients had higher perception on the interpersonal relationship, the caregivers were having poor QoL. This indicated that their caregivers care for the patient to their best and may even do it to the point where they may not take care of several aspect of themselves, thus resulting in their poor QoL. It is found in the present study that as the caregivers' QoL increases, the patients' perception on interpersonal relationship (mean score) decreases. It may suggest that when caregivers pay more attention to themselves, patients may feel a lowered interpersonal relationship. As for the caregivers' higher perception on interpersonal relationship, among the three groups of caregivers those caregivers who perceive less interpersonal relationship have poor QoL. The fact that they perceived themselves as not having good quality of interpersonal relationship may enable them to apply greater attention and more effort in giving care and support to the patients which may lead towards having poor QoL. On the other hand, the lower perception of the interpersonal relationship may indicate an

uncertainty in the caregivers and lack of clarity in their understanding about their interpersonal relationship. As a result, there may be an effect on their QoL.

There was a statistically significant difference among the three categories of caregivers based on their QoL on their psychological states which include distress, depression, anxiety, and somatization. In the present study, those caregivers who had poor QoL have highest means on all the four dimensions of their psychological states scores, whereas caregivers belonging to good QoL category scored the lowest in all the four dimensions of psychological states. These findings indicated that there are associations between caregivers' QoL and their psychological states. In the present study when the caregivers have high scores on distress, depression, anxiety, and somatization their QoL deteriorates showing a poor QoL. There are studies such as Gorji, Bouzar, Haghshenas, Kasaeeyan, Sadeghi, and Ardebil, (2012); Kim, Spillers, and Hall, 2012; and Kim, Baker, and Spillers, (2006) which demonstrated findings where caregivers' distress, depression, and anxiety have effects on caregivers' QoL.

There was also a statistically significant difference among three categories of caregivers based on their QoL in all the four dimensions of patients' psychological states. These psychological states include distress, depression, anxiety, and somatization. It is observed in the present study that patients whose caregivers had poor QoL have the highest means in all the four dimensions of psychological states. On the other hand, those patients whose caregivers had to good QoL have the lowest means on all the four psychological states. This indicated the association between patients' psychological states and their caregivers' quality of life. Thus, the fourth hypothesis, there will be differences

in indicators of quality of life among family caregivers categorized on the basis of their quality of life is accepted.

The findings of the study point to the need for psychosocial interventions involving active participation and mutual care and support between the dyad of patients and caregivers. It also points to the support needed for both patients and caregivers for improvement of psychological states. Also, more exploration into the psychological states of caregivers and social support to the caregivers emerged to be important. While caregivers are expected to provide major support, they in turn may need support too as they are often overwhelmed with several physical, psychological additional states to manage.

The study thus proposes the following SMILE Model involving the dyad of patients and caregivers for enhancement of positive psychological states, healthy interpersonal relationship and enhanced QoL for both patients and the caregivers. SMILE Model intends to address the needs of patients and their caregivers in order to enhance their psychological states, interpersonal relationship and thus enhance the dyad QoL. SMILE is an acronym for '*Support for each other*', '*Mutual communication*', '*Integrative approach*', '*Life skill enhancement*', and '*Empathy and Empowerment*'. All these five elements are complementing each other. Giving support for each other is important as disruption in their daily routine occurs for both the patients due to their illness and for the caregivers due to their role in caregiving. Disruption in their job, social life and other areas of life can lead to frustration, financial concerns, and thus have negative impact in terms of their psychological states. The negative psychological states lead to poor health outcome for the dyad as well as poor quality of life. Therefore, it is necessary to provide

patients and their caregivers support and improve mutual support between them so that disruption in their lives as a result of cancer diagnosis can be minimized. As they are primary sufferers-with patient taking the blow of the illness and caregivers supporting the patient to face and deal with the challenges, both having a mutual understanding, communication, care, and concern for each other helps them face the challenges more boldly.

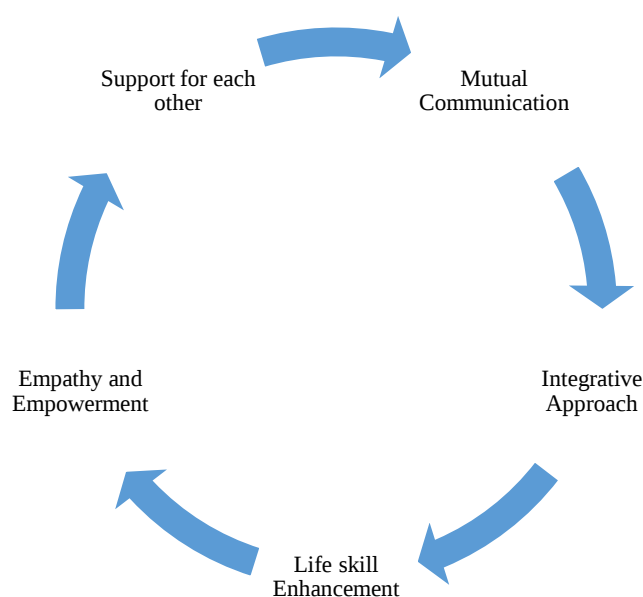


Figure 9. SMILE Model for the dyads Cancer patients and their Family Caregivers

Accordingly, it becomes important that both the patients and their caregivers have open and clear communication with each other. Mutual open communication clarifies many aspects which may go unnoticed or unattended to otherwise. It is important to train both the patients and their caregivers in communication as cancer diagnosis and its treatment is a complicated and dynamic process that involves large amount of resources

such as money, man power and investment of physical, psychological resources as well. It is important that the patients and their caregivers discuss mutually take decision so that each of them will not feel left out in the decision making process. Thus, communicating one's feelings and emotions between the dyad can be enhanced. The openness contributes to the factors of empathy which will be discussed shortly. The dyad may be provided with communication skill enhancement training so that each of them can give each other psychological support and thus reduce the negative impact of cancer on the psychological states.

For both the cancer patients and their caregivers it is important to consider an integrative approach as they deal with their life as a whole. Both the cancer patients and their caregivers have different needs and therefore require support during the time of the present crisis. In order to cater to these needs a holistic approach that balances various aspects of life such as psychological aspects, interpersonal relationship, approach to treatment required and, management of the disease, finances, family relationship and responsibilities and many other spheres of life. Such an integrative approach is possible with life skills enhancement and interventions may be designed for the same. Both the cancer patients and their Caregivers can be given life skills enhancement training. This may help in dealing with the cancer diagnosis and its journey better. The patients and their caregivers can be trained on aspects of management of caregiving, treatment, hospital stay, finances and other social life not only from the physical, financial point of view but from a psychosocial point of view. Life skills training will give both the patients and their caregivers a sense of balance of the situations and thus will help in better adjustment to the illness. For example, skills related to communication and interpersonal

aspect; awareness of self and empathy for others; assertiveness, problem solving, decision making, critical and creative thinking whenever situation demands are some of the aspects needed. In addition, balancing the emotions and coping with emotions and stress; and building up resilience in the face of adversity of disease together may help in dealing with the crisis in their lives owing to cancer diagnosis and treatment, both in terms of the experiences of patients as well as their caregivers.

In order to make the above mentioned elements to be effective it is important that the patients and their caregivers feel empathy for each other and gain a sense of empowerment together to deal with the current situation. This further enhances their confidence to move ahead and support as well as communicate with each other and deal with this journey through the combat with cancer. It will also help them in putting their life skills into action and thus resulting in good and open communication, better interpersonal relationship, improve on psychological states into a more desirable direction and thus, attain better quality of life. Thus, an intervention suitable to the dyad of patient and caregiver together as a unit both helps them deal with the current crisis as well as strengthens their mutual support system with combined strength and understanding. Thus, integration and synthesis of perceptions, perspectives, strengths, and efforts results a synergy which helps both of them. This dyad as a unit further needs to be supported by not just the health team but also the closer circles of society such as family, close relatives and friends.

Limitations

The present study is limited to only two cities in India such as Aizawl and Hyderabad. It would be beneficial to extend the study to other parts in India for better understanding such that interventions can be designed relevant to the findings thus obtained at a larger level bringing together greater diversity. The study is also limited to two cancer types prevalent in India. Other prevalent cancer types like cervix cancer and lung cancer also need to be explored. A more in-depth study on the interpersonal relationship which could not be done in the present study to understand the factors and dynamics of disagreement between the patients and their caregivers is needed. A quantitative analysis of factors contributing to agreement and disagreement in perceptions of patients and caregivers regarding their interpersonal relationship would possibly throw greater light on several hitherto unexplained areas in interpersonal relationship.

Future Directions

Future research on cancer should include greater diversity in terms of more types of cancer, more sample size, and include participants from other parts of India. This will also help in better understanding of the caregivers of various types of patients who are suffering from cancer. This benefits for not just the patients but also for the caregivers of patients with various types of cancer. It would be beneficial to work further on interpersonal relationship aspect between patients and caregivers. It is important to enhance mutual understanding, communication, and integration of several changes in a more realistic manner into adaptation to current situation, gain greater balance through application of relevant life skills and sense of empowerment for both patients and caregivers. Thus, an intervention model has been recommended based upon which

customized training modules/ programs may be designed to help the patient and caregivers dyad in dealing with current crisis situations. Tailor made psychosocial interventions after assessment of needs of patients and caregivers' dyad may be relevant to help enhance the QoL of both patients and caregivers.

Implications

The present study provides various implications for psychologists working in the area of health. The study assessed on the impact of patients' level of physical activities on the caregivers' on factors such as psychological states, their perception of interpersonal relationship with the patients and their QoL. This exploration among cancer patients in the Indian context is a contribution to the existing literature.

The understanding of relationship between the cancer patients and their caregivers which is carried out in the study provides a ground work for health psychologists and other professionals working in the field of oncology in better understanding of the relationship and the interpersonal dynamics between the dyad. The development of scale that is CANSIRS, Form A and Form B as part of the thesis contributed to the field of Health Psychology for use in the future.

India is a country rich with collective culture, where family member plays vital role in times of illness and crisis in terms of social support. However, the family members themselves face the repercussions of the patient's illness and may themselves undergo several psychosocial outcomes. Thus, the family caregivers are often referred to as hidden patients. The exploration and discovery of factors that indicated these family caregivers' QoL in the present study will help in understanding the family caregivers and

their needs during the illness trajectory. While the situations faced by the patients are viewed with sympathy by caregivers as well as others, the study shows a need to explore the caregiver needs, empathic understanding and support through psychosocial interventions involving counseling and enhancement of interpersonal personal skills for both patients and caregivers who are also their family member.

Lastly, from the findings and understanding about the cancer patients and their family caregivers in the present study, the study proposed a psychosocial model which can be used as intervention along with family counseling. The model proposed is holistic in nature and thus aims to address the needs of both patients and their caregivers as a unit. This is also a contribution to the field of health psychology to enhance the QoL of both patients and their caregivers.

Conclusion

The findings of the study thus conclude that, based on the patients' physical activity level their family caregivers differ in their experience of distress and mutual communication. It was also observed that there was a disagreement between patients and their caregivers in their perception of the interpersonal relationship between them. It can also be concluded from the study that caregivers' QoL was predicted by some of the caregivers' demographic variables, the agreement, and disagreement in perception between patients and their caregivers, and specific dimensions of psychological states of patients and their caregivers.

The present study pointed to the need for psychological interventions aimed to enhance the QoL of caregivers such that they do not succumb to the pressure of

caregiving and the psychological states of patients who are under suffering. The support of caregivers understandably is the most important to the patient who may be undergoing psychological upheavals owing to diagnosis of cancer and phases of treatment. Hence, psychosocial interventions to facilitate empowerment of caregivers to sustain efficiency in the heavy responsibility of caregiving seems to be imperative. Improvement in QoL of Caregivers may in turn contribute to enhanced support to the patients and help them deal with their psychological states. Enhanced interpersonal relationship between the cancer patients and their caregivers will contribute to greater agreement in their perceptions, which further will contribute to better quality of interpersonal relationship during the time of crisis. Thus, present study recommends customized psychosocial interventions and family counseling for caregivers alongside the cancer patients. Caregivers need to be trained in life skills to deal with current situation with greater integrative approach.

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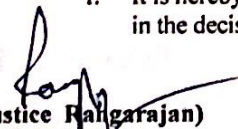
**Institute Ethics Committee
University of Hyderabad**

**Decision Letter of Institute Ethics Committee
University of Hyderabad**

IEC No Application No:	UH/IEC/2014/20	Date of review	21.4.2014
Project Title:	Anxiety, Depression and Quality of Life among cancer patients and their family caregivers		
Principal Investigator/ Co-PI:	Dr. G. Padmaja C. Vanlalhruii		
Participating Institutes if any	Citizens Hospital, Yashoda Hospital, Global Hospital, Retional Institute of Cancer, Indo-American Cancer Hospital, Omega Cancer Hospital	Approval from Participating Institute	Received approval of one hospital in Mizoram, other approvals pending
Documents received and reviewed	Protocol, ICF, Questionnaire/Tools		
In case of renewal, submission of update	--		
Decision of the IEC:	Conditional Approval Duration of Approval: One year from date of approval		
Any other Comments Requirements for conditional Approval	Approval granted subject to the condition that the study will not be commenced without obtaining administrative approval of the institution where the study will be made. A copy of such approval should be submitted to IEC along with the date of commencement of the study.		

Please note:

- Any amendments in the protocol must be informed to the Ethics committee and fresh approval taken.
- Any serious adverse event must be reported to the Ethics Committee within 24 hours in writing (mentioning the protocol No. or the study ID)
- Any advertisement placed in the newspapers, magazines must be submitted for approval.
- The results of the study should be presented in any of the academic forums of the hospital annually.
- If the conduct of the study is to be continued beyond the approved period, an application for the same must be forwarded to the Ethics Committee.
- It is hereby confirmed that neither you nor any of the members of the study team participated in the decision making/voting procedures.


(Justice Rajgarajan)
Chairperson


(Prof. Geeta K. Vemuganti)
Member Secretary
Member Secretary

Address: School of Medical Sciences, University of Hyderabad, O.R. Rao Road, Gachibowli, Hyderabad - 500 046.
Institutional Ethics Committee (IEC)
School of Medical Sciences
University of Hyderabad
Hyderabad-500046.

Dear sir/madam,

This is to collect information for the study mentioned above. The information collected herewith will be confidential and will be used only for the study related activities. Your support and contribution in this is solicited and greatly acknowledged.

Hospital Name:

Unit:

IP No:

Date:

Patient's Demographic Data Form (DDF)

Participant's Characteristics

1. Name:

2. Age : _____

3. Gender : Male / Female

4. Marital Status : Single Married Divorce Others

5. Occupation: Employed Self-Employed Unemployed

6. SES : USES MSES LSES

7. Religion: Hindu Muslim Christian Sikh Jain
Others

8. Language Spoken :

9. Place of Living : Urban Rural Semi-Urban

10. Category of Cancer :

11. Stage : I II IIIa IIIb IV

12. Lifestyle Issues if any: Smoking Alcohol Gutkha Others
None

Family Characteristics:

1. Caregiver : Spouse Parents Brother Sister Son
 Daughter none
2. Family history of illness,if any:
3. Address of correspondence

Phone or Mobile No:

E-Id:

_____Dear sir/madam,

This is to collect information for the study mentioned above.The information collected herewith will be confidential and will be used only for the study related activities.Your support and contribution in this is solicited and greatly acknowledged.

_____Hospital Name:

Unit:

IP No:

Date:

Caregiver's Demographic Data Form (DDF)

Participant's Characteristics

13. Name:

14. Age : _____

15. Gender : Male / Female

16. Marital Status : Single Married Divorce Others

17. Occupation: Employed Self-Employed Unemployed

18. SES : USES MSES LSES

19. Religion: Hindu Muslim Christian Sikh Jain
Others

20. Language Spoken :

21. Place of Living : Urban Rural Semi-Urban

22. Lifestyle Issues if any: Smoking Alcohol Gutkha Others
None

23. Relationship with Patient:

Address for Correspondence:

Phone or Mobile No:

E-Id:

INFORMED CONSENT FORM

University of Hyderabad

Centre for Health Psychology

Title of the Study: Anxiety, Depression and Quality of Life among Caregivers of Patients with Cancer

Investigator: C. Vanlalhruii, Research Scholar, University of Hyderabad.

Please read the details of the study carefully. In case you have any questions please feel free to ask the investigator all your queries. After understanding the whole study, if you are convinced to participate in the study you may sign the consent form.

Purpose of the Study

The investigator intend to study the levels of anxiety and depression; quality of Life among the primary caregivers of patients with cancer.

If you agree to participate in the study, it would involve filling out questionnaires. The filling of each questionnaire would take about 10 to 15 minutes of your time.

Risk and Discomfort

There are no risks associated with the study.

Protection of Confidentiality

All your information will be kept confidential; it will be used for research or academic purpose only.

Voluntary Participation

You are under no requirement to participate in this study and can decline. If you participate and decide against further participation you are free to withdraw anytime from the study. You will not be penalized for not participating or withdrawing.

Contact Information

Incase if you have any questions about the study you may contact the investigator of the study C.Vanlalhruii, phone

If you are satisfied with the information please sign the consent form.

PARTICIPATION CONSENT FORM

University of Hyderabad

Centre for Health Psychology

“Anxiety, Depression and Quality of Life among Caregivers of Patients with Cancer”

This is to state that I have read the information sheet carefully and understood the details of the study. I have been given the opportunity to ask questions related to this study.

I give my consent to participate in the study “Anxiety, Depression and Quality of Life among Caregivers of Patients with Cancer”. I am 18 years or above and am legally able to give my consent.

Investigator's Signature

Name of the Participant

Date :

Signature

ECOG Performance Status

These scales and criteria are used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis. They are included here for health care professionals to access.

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, e.g., light house work, office work
2	Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair
5	Dead

* As published in Am. J. Clin. Oncol.:

Oken, M.M., Creech, R.H., Tormey, D.C., Horton, J., Davis, T.E., McFadden, E.T., Carbone, P.P.: Toxicity And Response Criteria Of The Eastern Cooperative Oncology Group. Am J Clin Oncol 5:649-655, 1982.

Patient-Caregiver Interpersonal Relationship Scale

Caregivers' form (Form A)

Instructions: Please read each of the below given statements carefully. These statements talk about the interaction between you and the patient you are caring for. On the five point scale given beside each statement (always, often, sometimes, rarely and never) put a tick (✓) mark in the column which is relevant in terms of your interaction as appropriate to that particular statement. Please mention the relation with your care recipient: spouse/ parent/ son/ daughter/son-in-law/ daughter-in-law/others (specify)

S.No.	Statement	Never	Rarely	Sometimes	Often	Always
1	The love I have for him/her helps me in caring for him/her					
2	His/her illness does not stand in the way for his/her care towards me					
3	I freely express my feelings to him/her even after his/her illness					
4	I spend more time with him/her than others during his/her illness					
5	I do my best to make him/her feel comfortable in spite of his/her illness					
6	I talk openly with him/her about his/her illness					
7	I get appreciation from him/her for the care that I show					
8	I am closer to him/her after his/her illness					

9	I find him/her silent even in my company after his/her illness	Never	Rarely	Sometimes	Often	Always
10	I discuss and plan financial matters with him/her even after his/her illness	Never	Rarely	Sometimes	Often	Always
11	I receive his/her emotional support	Never	Rarely	Sometimes	Often	Always
12	He/she is hiding his/her feelings from me	Never	Rarely	Sometimes	Often	Always
13	I find it difficult to discuss with him/her about his/her illness	Never	Rarely	Sometimes	Often	Always
14	I am happy with the appreciation he/she shows for my care towards him/her	Never	Rarely	Sometimes	Often	Always
15	I avoid discussing and planning financial matters with him/her after his/her illness	Never	Rarely	Sometimes	Often	Always
16	I don't think in the way he/she thinks about his/her illness	Never	Rarely	Sometimes	Often	Always
17	After he/she became sick, it is difficult for me to communicate freely with him/her	Never	Rarely	Sometimes	Often	Always
18	I enjoy his/her company in spite of his/her illness	Never	Rarely	Sometimes	Often	Always
19	I try to make him/her forget about his/her illness	Never	Rarely	Sometimes	Often	Always

20	I have the ability to convince him/her to abide by Doctor's prescriptions related to illness	Never	Rarely	Sometimes	Often	Always
21	I see it that he/she pursues his/her interests despite his/her illness	Never	Rarely	Sometimes	Often	Always
22	Attending on him/her creates stress for me	Never	Rarely	Sometimes	Often	Always
23	I want him/her to be in the company of others more and more after his/her illness	Never	Rarely	Sometimes	Often	Always
24	Giving care to him/her during the illness is a burden to me	Never	Rarely	Sometimes	Often	Always

Patient-Caregiver Interpersonal Relationship Scale

Patient's Form (Form B)

Instructions: Please read carefully each of the below given statements which talk about the interaction between you and your caregiver. On the five point scale given beside each statement (always, often, sometimes, rarely and never), put a tick (✓) mark in the column which is relevant in terms of your interaction on that particular statement. Please mention the relation of the caregiver with you: spouse/ parent/ son/ daughter/son-in-law/ daughter-in-law/others (specify)

S.N o.	Statement	Never	Rarely	Sometimes	Often	Always
1	I feel loved by my caregiver	Never	Rarely	Sometimes	Often	Always
2	My illness does not stand in the way for my care towards my caregiver	Never	Rarely	Sometimes	Often	Always
3	My caregiver freely expresses his/her feelings to me even after my illness	Never	Rarely	Sometimes	Often	Always
4	I get more of my caregiver's time during my illness	Never	Rarely	Sometimes	Often	Always
5	My caregiver does his/her best to make me feel comfortable in spite of my illness	Never	Rarely	Sometimes	Often	Always
6	I talk openly with my caregiver about my illness	Never	Rarely	Sometimes	Often	Always
7	I appreciate my caregiver for his/her care	Never	Rarely	Sometimes	Often	Always

10	I am closer to my caregiver after my illness	Never	Rarely	Sometimes	Often	Always
11	My illness has made me silent even in his/her company	Never	Rarely	Sometimes	Often	Always
12	I discuss and plan financial matters with my caregiver even after my illness	Never	Rarely	Sometimes	Often	Always
13	I receive emotional support from my caregiver	Never	Rarely	Sometimes	Often	Always
15	I hide my feelings from my caregiver	Never	Rarely	Sometimes	Often	Always
18	I find it difficult to discuss about my illness with my caregiver	Never	Rarely	Sometimes	Often	Always
19	I am happy with the care I receive from my caregiver	Never	Rarely	Sometimes	Often	Always
22	My caregiver avoid discussing and planning financial matters with me after my illness	Never	Rarely	Sometimes	Often	Always
23	I don't think in the way my caregiver thinks about my illness	Never	Rarely	Sometimes	Often	Always
24	After I became sick, it is difficult for me to communicate freely with my caregiver	Never	Rarely	Sometimes	Often	Always
25	I enjoy the company of my caregiver	Never	Rarely	Sometimes	Often	Always

27	My caregiver makes me forget about my illness	Never	Rarely	Sometimes	Often	Always
28	My caregiver has the ability to convince me to abide by Doctor's prescription related to my illness	Never	Rarely	Sometimes	Often	Always
29	I see to it that my caregiver takes some time off to pursue his/her interests	Never	Rarely	Sometimes	Often	Always
30	Attending on me creates stress for my caregiver	Never	Rarely	Sometimes	Often	Always
31	My illness made me want to be in the company of the others more and more	Never	Rarely	Sometimes	Often	Always
34	I dislike being a burden on my caregiver	Never	Rarely	Sometimes	Often	Always

ID# _____ Day 01 _____ Day 16 _____ Day 30 _____

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 since my loved one's illness. | 0 | 1 | 2 | 3 |
| | 4 | | | | |
| 11. | My level of stress and worries has increased. | 0 | 1 | 2 | 3 |
| | 4 | | | | |
| 12. | My sense of spirituality has increased. | 0 | 1 | 2 | 3 |
| | 4 | | | | |

13.	It bothers me, limiting my focus to day-to-day. 4	0	1	2	3	
14.	I feel sad. 4	0	1	2	3	
15.	I feel under increased mental strain. 4	0	1	2	3	
16.	I get support from my friends and neighbors. 4	0	1	2	3	
17.	I feel guilty. 4	0	1	2	3	
18.	I feel frustrated.	0	1	2	3	4

(OVER ⇒)

0	=	Not at all	2	=	Somewhat
1	=	A little bit	3	=	Quite a bit
		4	=		Very much

19.	I feel nervous. 4	0	1	2	3
20.	I worry about the impact my loved one's illness has had on my children or other family members. 4	0	1	2	3
21.	I have difficulty dealing with my loved one's changing eating habits. 4	0	1	2	3
22.	I have developed a closer relationship with my loved one. 4	0	1	2	3
23.	I feel adequately informed about my loved one's illness. 4	0	1	2	3
24.	It bothers me that I need to be available to chauffeur my loved one to appointments. 4	0	1	2	3
25.	I fear the adverse effects of treatment on my loved one. 4	0	1	2	3

26.	The responsibility I have for my loved one's care at home is overwhelming. 4	0	1	2	3
27.	I am glad that my focus is on getting my loved one well. 4	0	1	2	3
28.	Family communication has increased. 4	0	1	2	3
29.	It bothers me that my priorities have changed. 4	0	1	2	3
30.	The need to protect my loved one bothers me. 4	0	1	2	3
31.	It upsets me to see my loved one deteriorate. 4	0	1	2	3
32.	The need to manage my loved one's pain is overwhelming. 4	0	1	2	3
33.	I am discouraged about the future. 4	0	1	2	3
34.	I am satisfied with the support I get from my family. 4	0	1	2	3
35.	It bothers me that other family members have not shown interest in taking care of my loved one. 4	0	1	2	3

పాల్గొనేవారి సమ్మతి పత్రం
యూనివర్సిటీ ఆఫ్ హైదరాబాద్
సెంటర్ ఫర్ సైకాలజీ

పరిశోధనాంశం: క్యాన్సర్ రోగులు, వారి సంరక్షకుల ఆందోళన, కుంగుబాటు, జీవన ప్రామాణ్యత

పరిశోధకురాలు: సి. వాన్లాల్ఘువాయి, సెంటర్ ఫర్ హెల్త్ సైకాలజీ, యూనివర్సిటీ ఆఫ్ హైదరాబాద్

క్రింద ఇవ్వబడిన వివరాలు జాగ్రత్తగా చదవండి. మీకేమైనా ప్రశ్నలుంటే సందేహించకుండా పరిశోధకురాలిని అడగండి. మొత్తం పరిశోధన గురించి అర్థం చేసుకున్నాక మీకు ఈ పరిశోధనలో పాల్గొనడానికి సమ్మతమైతే ఈ సమ్మతి పత్రంలో సంతకం చేయండి.

పరిశోధన యొక్క ఉద్దేశం:

ఈ పరిశోధన యొక్క ఉద్దేశం క్యాన్సర్ రోగులలోనూ, వారి సంరక్షకులలోనూ ఆందోళన, కుంగుబాటు, జీవన ప్రామాణ్యతల స్థాయి తెలుసుకోవడం.

ఈ పరిశోధనలో పాల్గొనేందుకు మీరు ఒప్పుకుంటే మీరు మీకిచ్చే ఈ ప్రశ్నావళిలో సమాధానాలు నింపవలసి ఉంటుంది. ప్రతి ప్రశ్నావళి (ప్రశ్నా పత్రం) నింపడానికి 10 – 15 నిమిషాల సమయం కేటాయించవలసి ఉంటుంది.

సమస్యలు, ఇబ్బందులు:

ఈ పరిశోధన వలన మీకు ఏ ఇబ్బందులు ఎదురు కావు.

వ్యక్తిగత సమాచార రక్షణ:

మీ సమాచారమంతా గోప్యంగా కాపాడబడుతుంది. కేవలం విద్యా పరంగా పరిశోధన కోసం మాత్రమే ఆ వివరాలు వాడబడతాయి.

స్వచ్ఛందంగా పాల్గొనటం:

మీరు ఈ పరిశోధనలో పాల్గొని తీరాలన్న నియమం ఏమీ లేదు. మీరు పాల్గొనటానికి మీ అనంగీకారాన్ని నిరభ్యంతరంగా తెలుపవచ్చు. అలాగే మీరు పాల్గొనడానికి ఒప్పుకున్నాక కూడా మధ్యలో ఎప్పుడైనా ఈ పరిశోధన నుండి తప్పుకోవాలనుకుంటే మీకు తప్పకుండా ఆ స్వేచ్ఛ ఉంది.

ఈ పరిశోధనలో పాల్గొనకపోవడం వలన కానీ, మధ్యలో దాని నుండి తప్పుకోవడంవలన కానీ మీకు ఏవిధమైన ఇబ్బందులు/శిక్షలు ఎదురు కావు.

మీ వద్ద ఏమైనా సమాచారం/ప్రశ్నలుంటే మీరు పరిశోధకురాలిని కింద ఇవ్వబడిన ఫోన్ నెంబరు పై సంప్రదించగలరు.

సి. వన్‌లాల్‌ఘవాని – 90892 53663

పైన ఇవ్వబడిన సమాచారంతో మీరు సంతృప్తి చెందితే, ఈ సమ్మతి పత్రంలో సంతకం చేయండి.

పాల్గొనేవారి సమ్మతి పత్రం
యూనివర్సిటీ ఆఫ్ హైదరాబాద్
సెంటర్ ఫర్ సైకాలజీ

“క్యాన్సర్ రోగులు, వారి సంరక్షకుల ఆందోళన, కుంగుబాటు, జీవన ప్రామాణ్యత” అనబడే ఈ పరిశోధనకి సంబంధించిన సమాచారాన్ని నేను జాగ్రత్తగా చదివి వివరాలను అర్థం చేసుకున్నాను. పరిశోధనకి సంబంధించిన ప్రశ్నలు లేదా సందేహాలుంటే వాటిని నివృత్తి చేసుకునేందుకు నాకు తగిన అవకాశమివ్వబడింది.

“క్యాన్సర్ రోగులు, వారి సంరక్షకుల ఆందోళన, కుంగుబాటు, జీవన ప్రామాణ్యత” అనబడే ఈ పరిశోధనలో స్వచ్ఛందంగా పాల్గొనేందుకు నేను నా అంగీకారం తెలుపుతున్నాను. నా వయస్సు 18 సంవత్సరాలకు పైబడి ఉంది అందువలన నేను చట్టపరంగా నా సమ్మతిని ఇవ్వగలుగుతున్నాను.

పరిశోధకురాలి సంతకం

పాల్గొనే వ్యక్తి పేరు: _____

తేదీ: _____

సంతకం: _____

Patients' Demographic Data Form (DDF)

Hospital Name :					
Unit:		IP No.:		Date:	

Participant's Characteristics:

1.	పేరు (Name)						
2.	వయస్సు (Age)						
3.	లింగం (Gender)	మగ (Male)		ఆడ (Female)			
4.	వివాహ పరిస్థితి (Marital Status)	ఒంటరి (Single)	వివాహం అయినది (Married)	విడాకులు (Divorced)	ఇతరులు (Others)		
5.	వృత్తి (Occupation)	ఉద్యోగి (Employed)	స్వయం ఉపాధి (Self-employed)	నిరుద్యోగి (Unemployed)			
6.	సామాజిక ఆర్థిక స్థాయి (SES)	ఎగువ (USES)	మధ్యమ (MSES)	దిగువ (LSES)			
7.	మతం (Religion)	హిందు (Hindu)	ముస్లిం (Muslim)	క్రిస్టియన్ (Christian)	సిక్కు (Sikh)	జైన్ (Jain)	ఇతరులు (Others)
8.	మాట్లాడే భాషలు (Language Spoken)						
9.	నివాస స్థలం (Place of Living)	నగరం (Urban)	గ్రామీణం (Rural)	సెమీ-గ్రామీణం (Semi-urban)			
10.	Category of Cancer						
11.	దశ (Stage)	I	II	IIIa	IIIb	IV	
12.	జీవన విధానంలోని సమస్యలు (చెడు అలవాట్లు ఏమైన ఉంటే) (Life style issues)	పొగ త్రాగడం (Smoking)	మద్యం (Alcohol)	గుట్కా (Gutka)	ఇతరులు (Others)		

కుటుంబానికి సంబంధించిన లక్షణం/లక్షణాలు (Family Characteristics):

1.	Caregiver	భార్య/భర్త (Spouse)	తల్లితండ్రులు (Parents)	నోదరుడు (Brother)	నోదరి (Sister)	కుమారుడు (Son)	కుమార్తె (Daughter)	ఇతరులు (Others)
2.	కుటుంబంలోని వారి పూర్వ అనారోగ్యం, ఏమైనా ఉంటే							

	(Family History of illness, if any)	
3.	ప్రస్తుత చిరునామా (Address for correspondence)	
	మొబైల్ నెం.: (Phone or Mobile No.)	ఈ-మెయిల్ (Email ID.)

Caregiver's Demographic Data Form (DDF)

Participant's Characteristics:

1.	పేరు (Name)																										
2.	వయస్సు (Age)																										
3.	లింగం (Gender)																										
		మగ (Male)			ఆడ (Female)																						
4.	వివాహ పరిస్థితి (Marital Status)																										
		ఒంటరి (Single)		వివాహం అయినది (Married)		విడాకులు (Divorced)		ఇతరులు (Others)																			
5.	వృత్తి (Occupation)																										
		ఉద్యోగి (Employed)		స్వయం ఉపాధి (Self-employed)			నిరుద్యోగి (Unemployed)																				
6.	సామాజిక ఆర్థిక స్థాయి (SES)			ఎగువ(USES)				మధ్యమ(MSES)				దిగువ(LSES)															
7.	మతం (Religion)																										
		హిందు (Hindu)		ముస్లిం (Muslim)		క్రైస్టియన్ (Christian)		సిక్కు (Sikh)		జైన్ (Jain)		ఇతరులు (Others)															
8.	మాట్లాడే భాషలు (Language Spoken)																										
9.	నివాస స్థలం (Place of Living)																										
		నగరం (Urban)			గ్రామీణం (Rural)			సెమీ-గ్రామీణం (Semi-urban)																			
10.	రోగితో గల సంబంధము (Relation with the Patient)																										
11.	ప్రస్తుత చిరునామా (Address for correspondence)																										
మొబైల్ నెం. (Phone or Mobile No.)														ఈ-మెయిల్ (Email ID.)													

రోగి/సంరక్షకుని వ్యక్తిత్వ సంభాషణ కొలమానము

సంరక్షకుని ఫారమ్ - [ఫారమ్-A]

సూచనలు: ఈ క్రింది వాక్యాలు మీ మరియు మీరు సంరక్షించే రోగి మధ్య పరస్పర అవగాహనల/పరస్పర వ్యక్తిగత సంబంధాన్ని గురించి ఇవ్వబడ్డాయి. అన్ని వాక్యాలను జాగ్రత్తగా చదివి వాటి కుడివైపు 5 స్థాయిలలో (ఎల్లప్పుడూ కాదు, అరుదుగా, కొన్నిసార్లు, తరచుగా, ఎల్లప్పుడూ) ఇవ్వబడిన స్పందనలలో మీకు వర్తించే సమాధానాన్ని టీక్ (✓) చెయ్యండి. రోగితో గల సంబంధాన్ని తెలపండి (జీవిత భాగస్వామి/తల్లి లేదా తండ్రి/కుమారుడు/కుమార్తె/కోడలు/అల్లుడు/ఇతరులు).

S.No.	వాక్యం (Statement)	ఎప్పటికీ కాదు	అరుదుగా	కొన్నిసార్లు	తరచుగా	ఎల్లప్పుడూ
1.	వారిని సంరక్షించేందుకు నాకు వారిపై ఉన్న ప్రేమానురాగాలే దోహదపడుతున్నాయి					
2.	వారి రోగ స్థితి, నేను అందించే సంరక్షణకు ఏమాత్రం అడ్డుగా నిలవదు					
3.	వారికి ఈ రోగం సంక్రమించినప్పటికీ, నేను వారితో నిస్సందేహంగా నా భావాలను వ్యక్తపరచగలను					
4.	వారి రోగ స్థితిలో నేను ఇతరులతో కంటే వారితోనే ఎక్కువ సమయం గడుపుతాను					
5.	వారు రోగస్థితిలో ఉన్నప్పటికీ వారికి అన్ని సౌకర్యాలు ఇవ్వాలని నేను శాయశక్తుల ప్రయత్నిస్తాను					
6.	వారి వ్యాధి గురించి వారితో బహిరంగంగా చర్చిస్తాను					
7.	నేను వారి ఎడల చూపే శ్రద్ధకు వారి నుండి ప్రశంసలను పొందుతాను					
8.	వారికి వ్యాధి సంక్రమించిన తరువాత నేను వారికి దగ్గరవ్వడం జరిగింది					

9.	వారికి ఈ వ్యాధి సంక్రమించిన తరువాత నేను సంరక్షిస్తున్నప్పటికీని వారిలో కలత/కలవరం చూస్తుంటాను					
10.	వారికి ఈ వ్యాధి సంక్రమించిన తరువాత కూడా నేను వారితో కుటుంబ ఆర్థిక పరిస్థితులను గూర్చి చర్చిస్తాను					
11.	వారి నుండి నేను మానసిక స్థైర్యాన్ని పొందుతాను					
12.	నానుండి వారు, వారి భావోద్వేగాలను దాస్తున్నట్లు అనిపిస్తుంది					
13.	వారితో వారి వ్యాధి గురించి మాట్లాడాలంటే నాకు చాలా ఇబ్బందిగా ఉంటుంది					
14.	నేను వారి ఎడల చూపే సంరక్షణ నిమిత్తమై వారు వ్యక్తపరిచే తృప్తి మరియు మెచ్చుకోలు నన్ను సంతోషపరుస్తాయి					
15.	వారి వ్యాధి సంక్రమణ తరువాత వారితో కుటుంబ ఆర్థిక పరిస్థితుల గురించి చర్చించడం మానివేశాను					
16.	ఈ వ్యాధి గురించి నా ఆలోచనాశైలి, వారి ఆలోచనాశైలి వేరుగా ఉండటం జరుగుతుంది					
17.	వారు వ్యాధిగ్రస్తులు అయ్యాక వారితో సంభాషించడం కష్టంగా ఉంటుంది					
18.	వారు వ్యాధిగ్రస్తులై ఉన్నప్పటికీని వారితో సమయం గడపడం నాకు ఆనందాన్ని కలిగిస్తుంది					
19.	వారి వ్యాధిని గురించిన విషయాలను మరిపించే ప్రయత్నం చేస్తాను					

20.	వారి వ్యాధిని గురించి డాక్టరుగారు సూచించిన వాటిని పాటించేలా చేసే సమర్థత ఉంది					
21.	వారు వ్యాధిగ్రస్తులై ఉన్నప్పటికీ వారికి ఇష్టమైన పనులు వారు చేసేలా నా మద్దతును ఇస్తాను					
22.	వారి సంరక్షకునిగా/సంరక్షకురాలిగా వారి అవసరాలు తీర్చడం నాకు ఒత్తిడిని కలుగజేస్తాయి					
23.	వారు వ్యాధిగ్రస్తులయ్యాక ఇదివరకటి కంటే వారు ఇతరులతో ఎక్కువగా సంభాషణ కలిగి ఉండాలని నేను కోరుకుంటాను					
24.	వారి అనారోగ్య స్థితిలో వారిని సంరక్షించడం నాకు చాలా భారంగా ఉంటుంది					

రోగి/సంరక్షకుని వ్యక్తిత్వ సంభాషణ కొలమానము

పీషంట్ (రోగి) ఫారమ్- [ఫారమ్-B]

సూచనలు: ఈ క్రింది వాక్యాలు మీ మరియు మీరు సంరక్షించే రోగి మధ్య పరస్పర అవగాహనల/పరస్పర వ్యక్తిగత సంబంధాన్ని గురించి ఇవ్వబడ్డాయి. అన్ని వాక్యాలను జాగ్రత్తగా చదివి వాటి కుడివైపు 5 స్థాయిలలో (ఎల్లప్పుడు కాదు, అరుదుగా, కొన్నిసార్లు, తరచుగా, ఎల్లప్పుడు) ఇవ్వబడిన స్పందనలలో మీకు వర్తించే సమాధానాన్ని టీక్ (✓) చెయ్యండి. సంరక్షకుడు/సంరక్షకురాలితో మీ సంబంధాన్ని తెలపండి (జీవిత భాగస్వామి/తల్లి లేదా తండ్రి/కుమారుడు/కుమార్తె/కోడలు/అల్లుడు/ఇతరులు).

S.No.	వాక్యం (Statement)	ఎప్పటికీ కాదు	అరుదుగా	కొన్నిసార్లు	తరచుగా	ఎల్లప్పుడు
1.	నా సంరక్షకుడు/సంరక్షకురాలు నుండి నేను ప్రేమ పొందుతాను					
2.	నేను రోగి స్థితిలో ఉన్నప్పటికీని నా సంరక్షకుని యెడల నాగున్న శ్రద్ధ ఏమాత్రం తగ్గలేదు					
3.	నా సంరక్షకుడు/సంరక్షకురాలు నాతో వారి భావాలను ఇదివరకటిలా పంచుకుంటున్నారు					
4.	నా రోగావస్థలో నా సంరక్షకుడు/సంరక్షకురాలు నుండి ఎక్కువ సమయం దొరుకుతుంది					
5.	నేను రోగావస్థలో ఉన్నప్పటికీని, నా సంరక్షకుడు/సంరక్షకురాలు నాకు ఎటువంటి ఇబ్బందులు కలగనీయకుండా చూసుకుంటారు					
6.	నా వ్యాధి గురించి నేను నా సంరక్షకుడు/సంరక్షకురాలితో బహిరంగంగా మాట్లాడతాను					
7.	నా సంరక్షకుడు/సంరక్షకురాలు నా యెడల చూపే శ్రద్ధకు నేను అతను/ఆమెని మెచ్చుకుంటాను					

8.	నాకు వ్యాధి సంక్రమించిన తరువాతే నేను నా సంరక్షకుడు/సంరక్షకురాలికి బాగా దగ్గరయ్యాను					
9.	నా వ్యాధి వల్ల నేను నా సంరక్షకుడు/సంరక్షకురాలితో సరిగ్గా మాట్లాడలేకపోతున్నాను					
10.	నాకు వ్యాధి సంక్రమించిన తరువాత కూడా నేను కుటుంబ ఆర్థిక పరిస్థితుల గురించి నా సంరక్షకుడు/సంరక్షకురాలితో ఇదివరకటిలాగే చర్చిస్తున్నాను					
11.	నేను వారి నుండి మానసిక స్త్రైయాన్ని పొందుతున్నాను					
12.	నేను నా భావోద్వేగాలను నా సంరక్షకుడు/సంరక్షకురాల నుండి దాస్తాను					
13.	నా వ్యాధి గురించి నా సంరక్షకుడు/సంరక్షకురాలితో చర్చించడం నాకు ఇబ్బందికరముగా ఉంటుంది					
14.	నా సంరక్షకుడు/సంరక్షకురాల నుండి పొందే శ్రద్ధ, సేవ నాకు ఎంతో సంతోషాన్ని కలుగజేస్తాయి					
15.	నాకు వ్యాధి సంక్రమించిన తరువాత నా సంరక్షకుడు/సంరక్షకురాలు నాతో కుటుంబ ఆర్థిక చర్చలు మానివేశారు					
16.	నా వ్యాధి గురించి నా ఆలోచనలు నా సంరక్షకుడు/సంరక్షకురాలి ఆలోచనలు ఒకే విధముగా ఉండవు					
17.	నాకు వ్యాధి సంక్రమించాక నా సంరక్షకుడు/సంరక్షకురాలితో మాట్లాడడం ఇబ్బందికరముగా ఉంది					

18.	నా సంరక్షకుడు/సంరక్షకురాలితో నాకు సమయం గడపడం ఇష్టం					
19.	నా సంరక్షకుడు/సంరక్షకురాలు నాకు వ్యాధి ఉన్న విషయము నేను మరచిపోయేలా నాతో వ్యవహరిస్తారు					
20.	డాక్టరు సూచించిన విషయాలను నేను సరిగ్గా పాటించేలా చేసే సమర్థత నా సంరక్షకుడు/సంరక్షకురాలకు ఉంది					
21.	నన్ను చూసుకోవడమే కాకుండా వారి వారి ఆసక్తులకు కూడా కొద్ది సమయం వెచ్చించేలా చూస్తాను					
22.	నన్ను సంరక్షిస్తున్నవారు చాలా ఒత్తిడికి గురవుతున్నారనిపిస్తుంది					
23.	ఈ వ్యాధి సంక్రమించిన తరువాత ఇదివరకటి కంటే ఎక్కువగా ఉండాలని, సంభాషించాలని అనిపిస్తుంది					
24.	నా సంరక్షకుడు/సంరక్షకురాలికి నేను భారంగా ఉండడం నాకెంతో బాధని కలుగజేస్తుంది					

సూచనలు:

ఈ క్రింది పేర్కొనబడిన అంశాలు మీ అనారోగ్యం తాలూకు లక్షణాలు, మీ ఫిర్యాదులకి సంబంధించినవి. ఇందులో ప్రతి అంశం గతవారం రోజుల్లో మీకున్న ఫిర్యాదుల, మీరనుభవించే లక్షణాలకు సంబంధించినది (అంటే ఇవాళ్టితో కలుపుకుని గత ఏడు రోజులు). గత వారానికి ముందున్న ఫిర్యాదులు పరిగణించబడవు.

గతవారం నుండి మీరు క్రింద ఇవ్వబడిన ఫిర్యాదులు, లక్షణాలు ఎంత తరచుగా మీరు అనుభవించారో ఆ వాక్యం పక్కన ఇవ్వబడిన బాక్సులో X గుర్తుతో (X) సూచించండి.

No	=	లేదు
Sometimes	=	కొన్నిసార్లు
Regularly	=	క్రమం తప్పకుండా
Often	=	తరచుగా
Very often	=	చాలా తరచుగా

క్రమ సంఖ్య	గతవారం రోజుల నుండి మీరు ఈ క్రింది వాటివల్ల బాధపడ్డారా?	లేదు	కొన్నిసార్లు	క్రమం తప్పకుండా	తరచుగా	చాలా తరచుగా
1.	మైకం లేదా తలలో తేలికగా అయిపోతున్న భావన					
2.	కండరాల నొప్పి					
3.	స్పృహ తప్పడం					
4.	మెడ నొప్పి					
5.	వెన్ను నొప్పి					
6.	ఎక్కువగా చెమటలు పట్టడం					
7.	గుండె దడ					
8.	తలనొప్పి					
9.	కడుపులో ఉబ్బరం					
10.	చూపు మసకబారడం లేదా మీ కళ్ళముందు చుక్కలు గాల్లో తేలుతున్నట్లుగా ఉండటం					
11.	ఊపిరి ఆడకపోవడం లేదా కష్టమవడం					
12.	వికారంగా అనిపించడం					
13.	కడుపు లేదా ఆ చుట్టుపక్కల ప్రాంతంలో నొప్పి					
14.	వేళ్ళలో జలదరింపు					

15.	ఛాతీలో ఒత్తిడి లేదా ఛాతీలో బిగువుగా అనిపించడం					
16.	ఛాతీలో నొప్పి					
17.	కుంగుబాటుగా అనిపించడం					
18.	కారణం లేకుండా ఉన్నట్లుండి భయం					
19.	దిగులు చెందడం					
20.	కలత నిద్ర					
21.	అస్పష్టమైన భయభావన					
22.	శక్తి హీనత					
23.	ఇతరులలో కలిసి ఉన్నప్పుడు వణుకు					
24.	ఆందోళన లేదా విపరీతమైన అలజడి					
25.	ఆందోళన					
26.	తొందరగా చికాకు చెందడం					
27.	భయభ్రాంతులవడం					
28.	ప్రతిదీ అర్థరహితమనే (అర్థం లేనిదనే) భావన					
29.	ఇకపై మీరు ఏమీ చేయలేరన్న భావన					
30.	జీవితానికి విలువ లేదన్న భావన					
31.	ఇకపై మీ చుట్టూ ఉన్న మనుషులు, వస్తువుల పట్ల ఏ ఆసక్తి చూపలేననే భావన					
32.	ఇకపై ఏదీ సమర్థవంతంగా ఎదుర్కొనలేదన్న భావన					
33.	మీరు చనిపోయి ఉంటే బాగుండేదన్న భావన					
34.	ఇకపై ఏదీ ఆనందించలేననే భావన					
35.	మీ పరిస్థితి నుండి తప్పించుకోవడానికి మార్గం లేదనే భావన					
36.	ఇకపై దేన్నీ ఎదుర్కోలేనన్న భావన					
37.	ఇకపై ఏదీ చేయాలని అనిపించకపోవడం					
38.	స్పష్టంగా ఆలోచించడం కష్టంగా అనిపిస్తోందా?					
39.	నిద్రపట్టడం ఇబ్బందిగా అనిపిస్తోందా?					
40.	ఇంటి నుండి ఒంటరిగా బయటికి వెళ్లాలంటే ఏమన్నా భయం అనిపిస్తున్నదా?					
41.	తొందరగా భావోద్వేగానికి గురయ్యారా?					

42.	నిజంగా భయపడాల్సిన అవసరంలేని ఏ విషయానికన్నా భయపడ్డారా? (ఉదాహరణకు: జంతువులు, ఎత్తు, చిన్న గదులు)					
43.	మీరు బస్సులో, కార్లో లేదై రైల్లో ప్రయాణించడానికి భయపడతారా?					
44.	ఎప్పుడైనా ఇతరుల ఎదురుగా మీరు సిగ్గుపడే/ ఇబ్బంది పడే సందర్భం కలుగుతుందేమోనని భయపడ్డారా?					
45.	ఎప్పుడైనా ఏదో తెలియని అపాయం కలుగవచ్చునని బెదిరినట్లు అనిపించిందా?					
46.	ఎప్పుడైనా 'నేను చనిపోయి ఉంటే బాగుండేది' అని అనుకున్నారా?					
47.	ఎప్పుడైనా ఇంతకు ముందు ఎదుర్కొన్న బాధకరమైన సంఘటనల దృశ్యాలు మీ కళ్ళ ముందు కదిలాయా?					
48.	ఎప్పుడైనా బాధాకరమైన సంఘటనల తాలూకు ఆలోచనలు పక్కనపెట్టడానికి మీ శక్తిమేరకు ప్రయత్నించవలసి వచ్చిందా?					
49.	భయం కలిగించాయన్న కారణం వలన ఏమైనా కొన్ని ప్రాంతాలకు దూరంగా ఉన్నారా?					
50.	ఎప్పుడైనా ఏదైనా పనిచేయాలంటే దానికంటే ముందు కొన్ని చర్యలను పడే పడే చేయడం జరిగిందా?					

క్యాన్సర్ వ్యాధిగ్రస్తుల సంరక్షకుల జీవన ప్రమాణం మా పని

ఈ కింది జాబితాలో ఉన్న వాక్యాలు క్యాన్సర్ వ్యాధిగ్రస్తుల ఆప్తులు వారిని సంరక్షించేవారు ముఖ్యమైనవిగా భావించే విషయాలకు సంబంధించిన ప్రకటనలు. ప్రతి వాక్యం ప్రక్కన కొన్ని అంకెలున్నాయి. ఆ అంకెల అర్థమేమిటో ఈ పేరా తర్వాత సూచించబడింది. గత వారం రోజులుగా మీ విషయంలో ప్రతి వాక్యం ఎంతవరకూ మీకు తగినదిగా అనిపించే అంకే చుట్టూ వృత్తం (o) చుట్టడం ద్వారా సూచించండి:

క్రమ సంఖ్య	గతవారం రోజులనుండి మీరు ఈ కింది వాటివల్ల బాధపడ్డారా?	ఏమాత్రమూ నిజం కాదు (o)	చాలా కొద్దిగా నిజం (1)	కొంతమేరకు నిజం (2)	బాగానే నిజం (3)	చాలా నిజం (4)
1.	నా దినచర్య మారినదన్న విషయం నన్ను కలవరపెడుతున్నది.					
2.	నా నిద్ర విశ్రాంతికరంగా లేదు.					
3.	నా రోజువారీ జీవితం నామీద రుద్దబడింది					
4.	నా శృంగార జీవితంలో నేను సంతృప్తిగా ఉన్నాను.					
5.	నా బయటి వ్యవహారాలను చక్కబెట్టు కోవడం నాకు సవాలుగా ఉంది.					
6.	నేను ఆర్థికపరమైన ఒత్తిడిలో ఉన్నాను					

7.	మా జీవిత భీమా ఎంతవరకు సహాయపడుతుందోనన్న కలతతో ఉన్నాను.					
8.	నా ఆర్థిక భవిష్యత్తు అనిర్భీతంగా ఉంది.					
9.	నా ఆస్తుడు/ఆస్తురాలు చనిపోతారేమోనని భయంగా ఉంది					
10.	నా ఆస్తుడు/ఆస్తురాలు జబ్బుపడినప్పటి నుండి నాకు జీవితం పట్ల సానుకూల దృక్పథమే ఎక్కువగా ఉంది.					
11.	నాలో ఒత్తిడి, చింతలు రెండు పెరిగాయి.					
12.	నా ఆధ్యాత్మిక ధోరణి పెరిగింది.					
13.	నా దృష్టిని ఏరోజుకి ఆరోజు వరకే పరిమితం చేయడం నన్ను కలవర పెడుతున్నది.					
14.	నాకు విచారంగా/దిగులుగా అనిపిస్తున్నది.					
15.	అధికమైన మానసిక ఒత్తిడికి లోనవుతున్నట్లు అనిపిస్తున్నది.					
16.	నాకు స్నేహితుల నుండి, పొరుగువారి నుండి సాయం లభిస్తుంది.					
17.	నేను అపరాధ భావనకి లోనవుతున్నాను.					

18.	నేను నిస్పృహకి లోనవుతున్నాను.						
19.	నాకు ఆందోళనగా అనిపిస్తున్నది.						
20.	నా ఆత్మని జబ్బు నా పిల్లలపై లేదై ఇతర కుటుంబ సభ్యులపై చూపిన ప్రభావాన్ని గురించి ఆందోళన చెందుతున్నాను.						
21.	మారుతున్న నా ప్రియమైన వ్యక్తి యొక్క ఆహారపు అలవాట్లలో వ్యవహరించడం నాకు కష్టంగా ఉంది.						
22.	నా ప్రియమైన వ్యక్తితో మరింత దగ్గర సంబంధాన్ని పెంచుకున్నాను.						
23.	నా ప్రియమైన వ్యక్తి జబ్బుని గురించి నాకు తగినంత సమాచారం ఇవ్వబడిందని భావిస్తున్నాను.						
24.	నా ఆత్మనికీ/ఆత్మరాలికి ఇవ్వబడిన అపాయింట్మెంట్లని తనను తీసుకెళ్ళడానికి నేను అందుబాటులో ఉండాలన్న విషయం నన్ను కలవర పెడుతున్నది.						
25.	నా ఆత్మనిపై/ఆత్మరాలిపై చికిత్స తాలూకు ప్రతికూల ప్రభావాలను గురించి నేను భయపడుతున్నాను.						
26.	ఇంట్లో నా ఆత్మని/ఆత్మరాలి సంరక్షణ యొక్క బాధ్యత నాపై అధికంగా ఉంది.						
27.	నా దృష్టి నా ఆత్మని/ఆత్మరాలి ఆరోగ్యం బాగుపడేట్లు చేయడంపై ఉండటం నాకు సంతోషాన్ని కలిగిస్తున్నది.						

28.	కుటుంబంలో ఒకరితో ఒకరం ఆలోచనలు/మాటలు పంచుకోవడం పెరిగింది.						
29.	నా ప్రాధాన్యతలు మారటం నన్ను అలజడికి గురి చేస్తున్నది.						
30.	నా ఆవుని/ఆవురాని రక్షించుకోవాల్సిన అవసరం నన్ను అలజడికి గురి చేస్తున్నది.						
31.	నా ఆవుడు/ఆవురాలు క్షీణించడాన్ని చూడటం నన్ను బాధ పెడుతున్నది.						
32.	నా ఆవుడు/ఆవురాని నొప్పి తగ్గేటట్లుగా చూడాల్సిన అవసరం నాపై అధికంగా ఉంది.						
33.	భవిష్యత్తుని గురించి నిరుత్సాహంగా ఉన్నాను.						
34.	నా కుటుంబం నుండి అందుతున్న సహకారం నాకు సంతృప్తికరంగా ఉంది.						
35.	నా ఆవుడు/ఆవురాని సంరక్షణ విషయంలో ఇతర కుటుంబ సభ్యులు ఆసక్తి చూపకపోవడం నన్ను కలవర పెడుతున్నది.						

Informed Consent Form
University of Hyderabad
Centre for Health Psychology

Zirlai thupui: Anxiety, Depression, and Quality of Life among Patients with cancer and their caregivers

Zirtu: C Vanlalhruii, Research Scholar, University of Hyderabad.

A hnuai a thu inziak te khu ngun takin chhiar la, zawhna I neih chuan I zawhna zawng zawng chu hemi research ti tu hi zawt ang che. A hnuai mite khu I hriathiam veka he research a tel I ram ti a nih chuan, I remtih na I kuta sign in I pe dawn nia.

Zirna in a tum

Hemi zirlai hian a tum ber chu cancer vanga dam lo te leh an chhungte anxiety, depression leh an nun pum bihchian a ni a. Hemi zirlaia tel ve rem I ti a nih chuan zawh na hetiang lam hawi hi zawh I ni ang. Heng zawhna chang chung hi minute 10 -14 vel theuh ni a ngaih a ni.

Hlahhawmna leh Intihnatna

He research ah hian I tan engmah hlahhawm leh in tih hliam theihna a awm lo.

Chhana te venhimna

Hemi research a zawhna channa zawng zawng hi tumah hnenah pek chhawn a ni lo ang. Tin, zawhna chhanna hi zirna lam leh research ah chauh hman a ni bawh ang.

Mahni duhthu a tel

Hemi research ah hian I tel duh lo chuan tel ve rem kan ti lo a tih theih. Tel I rem ti a, I lo tel a rokhawlhna avanga he research hi I bansan duh a nih chuan engtik lai pawn I bansan thei bawh a ni. I bansan avangin hremna pek I ni lo ang.

Zawt chiang duh tan

He research a I tel zawh hunah, hemi research buatsaihtu hnenah engtik lai pawhin a hnuaia number ah hian I be reng thei e.

C Vanlalhruii

Phone: 9089253663

A chungah thu inziak te khi I hrethiam a, hemi zirna a I tel ve du a nih chuan I remti tihna pheh leh lam ami ah sawn I sign dawn nia.

Informed Consent Form
University of Hyderabad
Centre for Health Psychology

“Anxiety, Depression, and Quality of Life among Patients with cancer and their caregivers”

He zirna/ research ah hian hriattirna siam te ngun takin ka chhiar a. Ka hriattirna chhiar te ka hrethiam vek a ni. Tin, research ti tu in zawhna min zawh pawh ka rem ti bawh e.

He research “Anxiety, Depression, and Quality of Life among Patients with cancer and their caregivers”, ah hian ka tel ve ka rem ti a, kum 18 aiin ka upa a, keimah ngei in tel ve remthihna nemnghet e.

Research ti tu signature.

I hming

Date:

Signature

Damlo Tan

Chibai le

Hei hi a chung a kan ziah a mi chunzawmna a ni a. Hemi bikah hi chu I chungchang zawhna lam a ni a. Helai a I thu ziah zawng zawnh hi midang hnenah hlan chhawng a ni lo ang. I puihna avangin in chhungah kan lawm hle ang.

Hospital Hming:

Unit:

IP No:

Date:

1. Hming:

2. Kum:

3. Gender: Mipa/ Hmeichhia

4. Nupui/ Pasal: La nei lo/ Nei tawh / Inthen / A dang

5. Eizawna: Hnathawk lai/ Mahnia eizawng / Hna nei lo

6. SES: USES/MSES/ LSES

7. Sakhua: Hindu/Muslim/ Christian/ Sikh/ Jain / A dang

8. Tawng hman:

9. Chenna: Khawpui/ thingtlang/khawpui bul

10. Ruitheihthil, zuk, leh hmuam: Meizial Zu. Sahdah Adang:

Chhungkua Lam

1. Enkawltu: Kawppui Nu/Pa Unaupa. Unaunu. Fapa Fanu

Adangte

2. Chhuangkua ah cancer vei dang an awm leh awm loh:

3. Biak pawh theihna

Phone :

Email Id:

Damlo Enkawltu Tan

Chibai le

Hei hi a chung a kan ziah a mi chunzawmna a ni a. Hemi bikah hi chu I chungchang zawhna lam a ni a. Helai a I thu ziah zawng zawnh hi midang hnenah hlan chhawng a ni lo ang. I puihna avangin in chhungah kan lawm hle ang.

1. Hming:

2. Kum:

3. Gender: Mipa/ Hmeichhia

4. Nupui/ Pasal: La nei lo/ Nei tawh / Inthen / A dang

5. Eizawna: Hnathawk lai/ Mahnia eizawng / Hna nei lo

6. SES: USES/MSES/ LSES

7. Sakhua: Hindu/Muslim/ Christian/ Sikh/ Jain / A dang

8. Tawng hman:

9. Chenna: Khawpui/ thingtlang/khawpui bul

10. Ruitheihthil, zuk, leh hmuam: Meizial Zu. Sahdah Adang:

11. Damlo nena inlaichinna:

12. Biak pawh theihna tur:

Phone:

Email ID:

ECOG PERFORMANCE STATUS

Grade	ECOG	
0	Nun pangngai a nung, dam loh hma a tih theih ang zawng zawng ti thei.	
1	Taksa hah taka hnathawh ngai ang chi thawk thei tawh lo, mahse ke a kal kual thei leh hna hahthlak lutuk lo thawk thei, entir nan in lama thawh chi harsa vak lo te, office lam hna te	
2	Ke a kal thei leh mahni in enkawl thei mahse eng hna mah thawk thei lo. A harh hun 50% chu kal kual thei.	
3	Mahni a inenkawl thei vek lo, a harh hun darkar 50% chu khum emaw thutthleng a khawsa deuh chawt.	
4	Mahni insaseng thei reng reng lo. Mahni a inenkawl thei lo. Khum emaw thutthleng a awm chawt.	
5	Thi.	

Cancer Specific Interpersonal Relationship- Form A (Damlo Enkawltu)

A hnuai a thu te khu ngun takin chhiar la, nangmah nen a a in mil ang zelin a sir a bawm ah khuan nangmah mi ber thai ang che. I damlo enkawl nen in inlai chin an khawngaih in ziah hmasa ang che: kawwppui/nu leh pa/ fapa/ fanu

Sl. No	Statement	Ngai lo	Ti ve zeuh	A changin	Ti reng	Engtiklai pawn
1	Ka hmangaih vanga enkawl ka ni.					
2	A damloh vang hian min duat loh phah loh					
3	A damloh hnu pawn inthlahrung lovin ka rilrua thil awmte ka la hrihl reng fo.					
4	Midang aiin keimah nen a damloh hnuin hun kan hmang tam zawk					
5	<i>Damlo mah nise a</i> nuamsa taka a awm theihnan ka theih tawp ka chhuah thin					
6	A natna/damlohna chungchang a bulah engmah ka zep ngailo					
7	Ka ngaihsakna avangin a lawm thu a sawi thin					
8	A damloh hnu hian kan in pawh sawt					
9	A damloh hnu hian keima bulah a ngawi tlat zel					
10	Sum leh Pai chungchangah amah nen remruatna a damloh hnu pawn kan siam dun thin					
11	Ka rilru hah na te min chhawk thin.					
12	A rilru zawng zawng hi min hrihl lo thin					
13	A natna chungchang a bula sawi hi nuam ka ti lem lo					
14	Ka ngaihsakna avanga a lawm thu ka hriat hian keipawh ka lawm a ni					
15	Sum leh Pai chungchanga remruatna a damloh hnu hian siampui loh hram ka tum thin					
16	A damlohnaa kan ngaihnan hi a in anglo in ka hria					
17	A damloh hnu hian inhawng taka inbiak hi a har ka ti thin					
18	Damlo mahse a bula awm hi nuam ka ti em em					
19	A damlohna te theihnghilh tir ka tum thin					

20	Doctor te thurawn zawm tur in ka ti thei					
21	Nuam a tih zawngte la tih tir zel turin hma ka la thin					
22	Amah enkawl hi a hahthlak ka ti					
23	Midang te bula awm tam turin a damloh hnu hian ka duh					
24	A damloh laia enkawl hi ka tan phurrit a ni					

Cancer Specific Interpersonal Relationship- Form B (Damlo)

A hnuai a thu te khu ngun takin chhiar la, nangmah nen a a in mil ang zelin a sir a bawm ah khuan nangmah mi ber thai ang che. Nangmah enkawltu che nen in inlai chin an khawngaih in ziah hmasa ang che: kawwppui/nu leh pa/ fapa/ fanu

Sl. No	Statement	Ngai lo	Ti ve zeuh	A changin	Ti reng	Engtiklai pawn
1	Min enkawl tu hian min hmangaih niin ka hria					
2	Min enkawl tu hi ka damloh vang hian ka duat loh phah lo					
3	Min enkawl tu hian a duh duh ka bulah a sawi thin					
4	Ka damloh hnu hian min enkawl tu hun tam zawk ka chang					
5	Ka nawmsak theih nan min enkawl tu hian theih tawp a chhuah					
6	Ka natna chungchang min enkawl tu hnenah ka zep lo					
7	Min enkawl danah ka lawm a ni					
8	Min enkawl tu nen hian ka damloh hnuah kan in pawh sawt					
9	Ka dam loh na hian min enkawl tu bulah pawh min ti tawng peih lo					
10	Ka damloh hnuah min enkawl tu nen pawisa chungchang kan sawiin remruatna kan siam dun thin					
11	Ka rilru hahna te min enkawl tu hian min chhawk					
12	Ka rilru a thil awm zawng zawng hi min enkawl tu ka hrilh vek lo					
13	Min enkawl tu bula ka natna chungchang sawi hi harsa ka ti					
14	Min enkawl tu chngah hian ka lawm a ni					
15	Ka damloh hnu hian min enkawl tu hian sum dinhmun sawi a ruah hmana siamte hi tih loh hram a tum					
16	Min enkawl tu nen hian kan thu leh thil ngaihtuah te a in ang lo					
17	Ka damloh hnuah hian min enkawl tu hi pawh taka biak harsa ka ti					

18	Min enkawl tu nena hun hmang dun hi nuam ka ti					
19	Min enkawl tu hian ka natna min chhawk					
20	Min enkawl tu hian Doctor te thurawn zawm turin min ti thei					
21	Min enkawl tu duh leh chak zawngte hi tih tir ngei ka tum					
22	Min enkawl tu hi ka ti hah					
23	Ka dam loh vang hian mi bulah ka awm chak lo					
24	Min enkawl tu phurrit nih hi nuam ka ti lo					

Cancer Specific Interpersonal Relationship- Form A (Damlo Enkawltu)

A hnuai a thu te khu ngun takin chhiar la, nangmah nen a a in mil ang zelin a sir a bawm ah khuan nangmah mi ber thai ang che. I damlo enkawl nen in inlai chin an khawngaih in ziah hmasa ang che: kawwppui/nu leh pa/ fapa/ fanu

Sl. No	Statement	Ngai lo	Ti ve zeuh	A changin	Ti reng	Engtiklai pawn
1	Ka hmangaih vanga enkawl ka ni.					
2	A damloh vang hian min duat loh phah loh					
3	A damloh hnu pawn inthlahrung lovin ka rilrua thil awmte ka la hrilh reng fo.					
4	Midang aiin keimah nen a damloh hnuin hun kan hmang tam zawk					
5	<i>Damlo mah nise a</i> nuamsa taka a awm theihnan ka theih tawp ka chhuah thin					
6	A natna/damlohna chungchang a bulah engmah ka zep ngailo					
7	Ka ngaihsakna avangin a lawm thu a sawi thin					
8	A damloh hnu hian kan in pawh sawt					
9	A damloh hnu hian keima bulah a ngawi tlat zel					
10	Sum leh Pai chungchangah amah nen remruatna a damloh hnu pawn kan siam dun thin					
11	Ka rilru hah na te min chhawk thin.					
12	A rilru zawng zawng hi min hrilh lo thin					
13	A natna chungchang a bula sawi hi nuam ka ti lem lo					
14	Ka ngaihsakna avanga a lawm thu ka hriat hian keipawh ka lawm a ni					
15	Sum leh Pai chungchanga remruatna a damloh hnu hian siampui loh hram ka tum thin					

16	A damlohnaa kan ngaihdaan hi a in anglo in ka hria					
17	A damloh hnu hian inhawng taka inbiak hi a har ka ti thin					
18	Damlo mahse a bula awm hi nuam ka ti em em					
19	A damlohna te theihngihl tir ka tum thin					
20	Doctor te thurawn zawm tur in ka ti thei					
21	Nuam a tih zawngte la tih tir zel turin hma ka la thin					
22	Amah enkawl hi a hahthlak ka ti					
23	Midang te bula awm tam turin a damloh hnu hian ka duh					
24	A damloh laia enkawl hi ka tan phurrit a ni					

Cancer Specific Interpersonal Relationship- Form B (Damlo)

A hnuai a thu te khu ngun takin chhiar la, nangmah nen a a in mil ang zelin a sir a bawm ah khuan nangmah mi ber thai ang che. Nangmah enkawltu che nen in inlai chin an khawngaih in ziah hmasa ang che: kawwppui/nu leh pa/ fapa/ fanu

Sl. No	Statement	Ngai lo	Ti ve zeuh	A changin	Ti reng	Engtiklai pawn
1	Min enkawl tu hian min hmangaih niin ka hria					
2	Min enkawl tu hi ka damloh vang hian ka duat loh phah lo					
3	Min enkawl tu hian a duh duh ka bulah a sawi thin					
4	Ka damloh hnu hian min enkawl tu hun tam zawk ka chang					
5	Ka nawmsak theih nan min enkawl tu hian theih tawp a chhuah					
6	Ka natna chungchang min enkawl tu hnenah ka zep lo					
7	Min enkawl danah ka lawm a ni					
8	Min enkawl tu nen hian ka damloh hnuah kan in pawh sawt					
9	Ka dam loh na hian min enkawl tu bulah pawh min ti tawng peih lo					
10	Ka damloh hnuah min enkawl tu nen pawisa chungchang kan sawiin remruatna kan siam dun thin					
11	Ka rilru hahna te min enkawl tu hian min chhawk					
12	Ka rilru a thil awm zawng zawng hi min enkawl tu ka hrih vek lo					
13	Min enkawl tu bula ka natna chungchang sawi hi harsa ka ti					
14	Min enkawl tu chngah hian ka lawm a ni					

15	Ka damloh hnu hian min enkawl tu hian sum dinhmun sawi a ruah hmana siamte hi tih loh hram a tum					
16	Min enkawl tu nen hian kan thu leh thil ngaihtuah te a in ang lo					
17	Ka damloh hnuah hian min enkawl tu hi pawh taka biak harsa ka ti					
18	Min enkawl tu nena hun hmang dun hi nuam ka ti					
19	Min enkawl tu hian ka natna min chhawk					
20	Min enkawl tu hian Doctor te thurawn zawm turin min ti thei					
21	Min enkawl tu duh leh chak zawngte hi tih tir ngei ka tum					
22	Min enkawl tu hi ka ti hah					
23	Ka dam loh vang hian mi bulah ka awm chak lo					
24	Min enkawl tu phurrit nih hi nuam ka ti lo					

CAREGIVER QUALITY OF LIFE- CANCER

A hmuai a thu inziak te khu cancer vanga damlo enkawl ve tuten a an sawi pawimawh tak tak an ni a. I tab a dik ve leh ve loh dan a zir in thu inziak zawna number te khu thai bial rawh. Tun ni 7 hun chhunga I tawn dan a ni tur a ni.

0	=	Ni miah lo	2	=	Ni ve deuh
1	=	Tlemte in	3	=	Ni ve nual
			4	=	Ni lutuk

During the past 7 days:

1.	Nitina ka thiltih thin a inthlak hian min tibuai. 4	0	1	2	3
2.	Ka mut a tui lo sawt. 4	0	1	2	3
3.	Ka nitin nun tihbuaiin a awm. 4	0	1	2	3
4.	Hmeichhiat mipatna ka hman thin ah ka lungawi . 4	0	1	2	3
5.	Pawnlama ka thiltih thin te tih reng a harsa. 4	0	1	2	3
6.	Pawisa lamah rilru hahna ka tawk. 4	0	1	2	3
7.	Insurance coverage chungchangin ka rilru a luah. 4	0	1	2	3
8.	Ka hmalam huna sum leh pai dinhmun a Chiang lo. 4	0	1	2	3
9.	Ka hmangaih tak hi a thih ka hlau. 4	0	1	2	3
10.	Ka hmangaih tak a dam loh atang hian nun ah thil a tha zawnga thlir ka thiam tan ta. 4	0	1	2	3
11.	Ka rilru hah leh lungkham a pung lehzual. 4	0	1	2	3
12.	Thlarau lam nun ka ngaihtuahna a pung. 4	0	1	2	3
13.	Nitin ni khat te te a thil ngaihtuah bek bek hian min tilungngai. 4	0	1	2	3

14.	Ka lungngai. 4	0	1	2	3
15.	Rilru hahna tam tak ka phurin ka in hria. 4	0	1	2	3
16.	Ka thian te leh ka thenawmten min chhawmdawl. 4	0	1	2	3
17.	Inthiamlohna ka nei. 4	0	1	2	3
18.	Engmah tih theih nei lo ah ka in ngai. 4	0	1	2	3

(OVER ⇒)

0	=	Ni miah lo	2	=	Ni ve deuh
1	=	Tlemte in	3	=	Ni ve nual
			4	=	Ni lutuk

19.	Ka hlauthawng.	0	1	2	3	4
20.	Ka hmangaih dam lohna hian ka fa te leh ka chhungte ah nghawng tha lo a nei ang tih ka hlau.	0	1	2	3	4
21.	Ka hmangaih in a thil ei dan a thlak hian min ti hrehawm.	0	1	2	3	4
22.	A hma aiin ka hmangaih nen a kan inkar a tha zawk tawh.	0	1	2	3	4
23.	Ka hmangaih dam lohna chungchang hi ka hre tha viauin ka hria.	0	1	2	3	4
24.	Ka hmangaih appointment a hruai tur hian motor khalhtu ka ni hian ka rilru a tinuam lo.	0	1	2	3	4
25.	Ka hmangaih treatment lak hian a hriselna a khawih nasa viau ang tih ka hlau.	0	1	2	3	4
26.	In lama ka hmangaih ka enkawl na a ka mawhphurhna hi a tam mah mah in ka hria.	0	1	2	3	4
27.	Ka insawrbingna hi ka hmangaih dam leh theih nan a ni hi ka lawm hle.	0	1	2	3	4
28.	Kan chhungkua kan inpawh tawna a tha lehzual.	0	1	2	3	4
29.	Ka thil ngaih pawimawh zawng te a inthlak ta hian ka rilru a tibuai.	0	1	2	3	4
30.	Ka hmangaih ka hualhim ngai hian rilru a tibuai.	0	1	2	3	4
31.	Ka hmangaih a awngrawp telh telh hian min tilungngai.	0	1	2	3	4
32.	Ka hmangaih natna enkawl hi a harsa thin.	0	1	2	3	4
33.	Hmalam hun thlir pawh hi ka phur lo.	0	1	2	3	4
34.	Ka chhungte min tawiamna ah hian ka lungawi.	0	1	2	3	4
35.	Ka chhungten ka hmangaih enkawl chungchang an Ngaihtuah ve lo lutuk hian ka rilru a tinuam lo .	0	1	2	3	4

Effect of Cancer Patients' Activity Level and Psychosocial Factors on Caregivers' Quality of Life

by C Vanlalhrui

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Cancer Specific Interpersonal Relationship Scale (CANSIRS): Construction and Preliminary Validation

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Cancer interrupts the life of the person diagnosed with the disease and their caregivers, it may also result in change in activities such as social and general stability of the life of both patients and caregivers. These changes have potential ramifications for relationship adjustment and the ways in which the patients and caregivers relate to and support one another. Therefore, our main objectives were to construct a self-report scale to measure the interpersonal relationship between patients with cancer and their caregivers and examine the different psychometric issues as well as to establish preliminary validation in the development of this scale. Two hundred and fifty dyads consisting of patient with breast cancer, head and neck cancer and their family caregivers were selected. Findings indicated that majority of the dimensions for both Form A and B of CANSIRS have high alpha coefficient. The results of factor analysis and preliminary validation were also discussed. The present study findings show that the scale developed with further factor analytic research, could become useful clinical tools.

Keywords: Interpersonal, Relationship, Scale, Cancer, Caregivers.

Cancer shows its effect not only in biological, but also in psychosocial aspects of a person's life. In addition to the patient, its effects are observed many times in the patient's family, friends, and close relations. Patients as well as their family members or caregivers must make many changes and adjustments in their lives to adapt to the new situation and its effects. Studies have shown that level of adjustment of patients with cancer tends to moderately correlate with the level of adjustment of their partners (Hodges, Humphris, & Macfarlane, 2005; Northhouse, Templin, Mood, & Oberst, 1998; Thornton, Perez, & Meyerowitz, 2004). The life of the patients and their caregivers are disrupted by cancer as it brings with it a complete alteration in their plans, priorities, identity, roles, responsibilities, needs, and day to day functioning (Padmaja, Vanlalhruii, Rana, Tiamongla, & Kopparty, 2017). Cancer may also result in change in social activities and general stability of the patient and partner, these changes have prospective ramifications for relationship adjustment and the ways in which they relate to and support one another (Burman & Margolin, 1992; Blanchard, Albrecht, & Ruckdeschel, 1997; Mane, 1998; Oberst & Scott, 1988).

For patients suffering from cancer, the social support is an important determinant for their ability to live with illness (Bernard, Zynarska, & Adamek, 2010). The providers of this support are more often their family members who are also their primary caregivers. These primary caregivers mainly include spouse and blood relatives. When the patients are diagnosed with disease such as cancer their focus is likely to be towards pain, death and time they have left for them, and so on. On the other hand, family caregivers need to take care of the patient, plan for the treatment, need to do financial planning, worry about the patient's health status and at the same time try to maintain a positive attitude as well as and relationship towards the patients while they themselves are trying to adjust with their loved one's illness. Therefore, it is imperative to examine the crucial role played by interpersonal process and relationship in patients with cancer and their caregivers' psychological adjustment to cancer (Thornton & Perez, 2007).

We are aware that human beings have a general need of belongingness. This is explained as "a pervasive desire to form and maintain at least a minimum quantity of

lasting, positive, and significant interpersonal relationship" (Baumeister & Leary, 1995). Feelings of loneliness, anxiety, anger, and even depression manifests in those people who are deprived of the feeling of belongingness (Cacioppo, Berntson, Larsen, Poehlmann, & Ito, 2000; Hagerty, William, Coyne, & Early, 1996). Berscheid and Ammazalorso (2004) explain relationship as 'two people whose behavior is interdependent in that a change in behavior in one is likely to produce a change in behavior of the other'. Interpersonal relationship is the social association, connection, or affiliation between two or more people (Ejifugha, 2011). Interpersonal relation is defined by Braken (1993) as "unique and relatively stable behavioral patterns that exist or develop between two or more people as a result of individual and extra individual influences". At present, the focus is on the measurement of interpersonal relationship between patients with cancer and their family caregivers. The interpersonal relationship has been conceptualized and operationalized as an interactional process between the patients and their family caregivers focusing on their mutual communication, mutual relationship, ways in which they deal together with certain situations, availability, support and care for each other during illness. Interpersonal relationship is called a process because it involves a series of action between the patients and their family caregivers. This process is interactional in nature as both patients and their family caregivers share mutual responsibilities and influence each other.

Interpersonal relationship is affected by personal factors, proximity, and similarity (Essay, UK, 2013). It was suggested by Berscheid and Regan (2016) that social environment (approval of social network and availability of alternative) and physical factors (proximity) are factors in the development and maintenance of interpersonal relationship. Research has shown a consistent link between perceived availability of social support with better psychological and physiological adaptation to major illness (Wimberly, Carver, & Antoni, 2008). It is also observed that the major source of their stress and interpersonal conflict is the social network (Rana & Hariharan, 2015). Communication problems are also commonly cited by the patients

(Gordon, et al., 1977). Patients diagnosed with cancer and their partners may have experienced significant reduction in emotion, social, and physical functioning depending on the patient's response to their cancer (Thornton, Perez, & Meyerowitz, 2004; Mane, 1998). Interpersonal relationship between patients with cancer and their caregivers is constructed as a multidimensional and complex construct. Measures such as Interpersonal Solidarity Scale (Wheeless, 1976), Interpersonal Support Evaluation List (Cohen & Hoberman, 1983), and Fundamental Interpersonal Relation Orientation-Behavior (Schutz, 1958; Waterman, 2004) are developed to measure interpersonal relationship among general population. Scales such as The Trust in Physician Scales (Anderson & Dedrick, 1990), Psychological and Interpersonal Relationship Scale, PAIR (Swindle, Cameron, Lockhart & Rosen, 2004) and 15-item short form of PAIR (Swindle, Cameron & Rosen, 2006) for erectile dysfunction patients have been found. However, in the context of patients with cancer and their family caregivers, specific scales which measure their interpersonal relationship has not been found in literature search.

The objectives of the present study was to (i) construct a self-report scale to measure the interpersonal relationship between patients with cancer and their family caregivers from the caregiver's perspective, (ii) construct a self-report scale to measure the interpersonal relationship between patients with cancer and their family caregivers from the patient's perspective (iii) examine the different psychometric issues and (iv) establish preliminary validation of these scales.

Phases of Construction and Development

The scale was developed through three phases—item writing, content evaluation and naming and establishment of psychometric properties and preliminary validation.

Phase 1: Item Writing. Before the items were constructed, extensive review of literature on interpersonal relationship was done. Four scales on the related areas were also referred, such as Fundamental Interpersonal Relationship Orientation- Behaviour (Schutz,

1958), Interpersonal Solidarity Scale (Wheelees, 1976), Relationship Assessment Scale (Vaughn & Baier, 1999), and Dyadic Adjustment Scale (Spanier, 1976). Multiple in-depth interview sessions were also conducted with patients with cancer (diagnosed with breast cancer, head and neck cancer) and their family caregivers. Three psychologists and an oncologist having more than 10 years of experience were consulted during item writing phase. Basing on these, five major theoretical dimensions related to interpersonal relationship were identified—mutual communication, mutual relationship, attention and support, availability and providing comfort, and mutual care. Subsequently, items were written for family caregivers of patients with cancer. Initially, 50 items belonging to the five dimensions were generated. These items were revisited to increase the readability and were administered on the target group ($n=20$) and feedback was collected from each of the participants. Based on the feedback, some of the items were modified to improve clarity and simplicity. After modification, all 50 items were retained.

Phase 2: Content Evaluation and Naming. The scale underwent the standard process of content evaluation to find out if the scale captured the essence of interpersonal relationship. Therefore, 10 experts from the field of Psychology and Oncology were requested to read the scale. They were asked to mark each item if it was 'essential' or 'non-essential' to measure the interpersonal relationship between patients with cancer and their family caregivers. Only items that were marked essential by all the experts were retained and in this way 35 items were retained. As per the suggestion, a 5-point scale was adopted to rate each item (1= never to 5= always). The scale was named as Cancer Specific Interpersonal Relationship Scale-Caregiver and abbreviated as CANSIRS.

Phase 3: Establishment of the Psychometric Properties and Preliminary Validation

After naming, the scale was ready for pre-test to assess its initial psychometric properties and to establish preliminary validation.

Participants

Initially 290 caregivers of patients with cancer who are also their family members were contacted from regional cancer centers located in two different cities in India –Hyderabad and Aizawl. Finally, 250 dyads were selected for the study. The selected patients with cancer included patients with breast cancer (50%) and with the head and neck cancer (50%). The age of the patients with cancer ranged between 20-65 years. The patients undergoing curative treatment and having no cases of mental illness were included in the study. The 250 patients included equal number of men and women. The family caregivers included their spouses, children, or blood relations. Their inclusion criteria include age between 18-65 years and without reported history of mental illness.

Measures

In addition to the newly developed scale, two other measures—European Organization for the Treatment and Research of Cancer Quality of Life Questionnaire-QLQ-C30, version 3.0. and Caregiver Quality of Life Index - Cancer (CQOLC)—were used for establishment of psychometric properties and preliminary validation.

Cancer specific interpersonal relationship scale (CANSIRS). This newly developed scale—CANSIRS—is a self-report psychological instrument to measure the degree and kind of interpersonal relationship between patients with cancer and their family caregivers. This scale has two parallel forms—Form A family caregivers and Form B for patients with cancer. Each form consisted of 35 items measure using a 5-point scale (1= never, 2 = rarely, 3 = sometime, 4 = often, 5 = always). Each form has five dimensions—mutual communication (e.g. I talk openly with him/her about his/her illness), mutual relationship (e.g. I am close to him/her after his/her illness), attention and support (e.g. Attending on him/her creates stress for me), availability and providing comfort (e.g. I try to make him/her forget about his/her illness), and mutual care (e.g. His/her illness does not stand in the way for his/her care towards me). The score of the items of a particular dimension are

to be added to calculate the dimensions score, whereas the scale score is to be calculated by adding the score of all the dimensions. The higher the score the better is the interpersonal relationship.

European organization for the treatment and research of cancer quality of life questionnaire-QLQ-C30, version 3.0. (EORTC QLQ-C30 v. 3.0). EORTC QLQ (Aaronson et al., 1993) was used to assess the quality of life of patients with cancer (BC and HNC). The questionnaire contains 30 items and is designed to cover a range of quality of life issues for patients with cancer. The questionnaire comprises of five functional scales (such as physical, role, emotional, cognitive and social), seven symptoms scales (such as fatigue, nausea and vomiting, pain, dyspnea, insomnia, appetite loss, constipation, diarrhea, and financial difficulties) and global health status /QoL. Except for global health status items, all other items were scored using 4-point scale (1 = not at all, 2 = a little, 3 = quite a bit, 4 = very much), whereas in global health status, items were rated in a scale of 1 to 7. EORTC QLQ- C30 includes items such as 'Have you had pain? Did you need rest?' A high score for functional scale represents a high or healthy level of functioning, a high score for the global health status/ QoL represents a high QoL. However, it should also be noted that a high score for a symptom scale represents a high level of symptomatology. Cronbach alpha coefficient of the questionnaire ranged from .54 to .86 (Aaronson et al., 1993).

Caregiver quality of life index-Cancer (CQOLC). CQOLC (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999) was used to measure the QoL of the family caregivers of patients with cancer. The questionnaire consisted of 35 items which were scored on a 5-point scale (0=not at all to 4= very much). CQOLC includes items such as I feel nervous, I get support from my friends and neighbors, I have developed a closer relationship with my loved one. The total score was found by addition of the item scores and the higher the score the poorer was the QoL. CQOLC was divided into four dimensions such as burden, disruptiveness,

positive adaptation and financial concern and support (Tamayo, Broxson, Munsell, & Cohen, 2010). The test-retest reliability was 0.95 and internal consistency coefficient was 0.91. In addition to this, the scale also has adequate validity.

Procedure

Before starting the study, approval of the Institutional Ethics Committee of the University where the authors work was obtained. In addition to this, permissions from the authorities of the three cancer specific hospitals were obtained. Basing on the inclusion and exclusion criteria, the participants (dyads consisting of patients and their family caregivers) were selected. During the process of selection, rapport was established, and informed consent was obtained from each member of the dyad. Such dyads were excluded, where informed consents were not given by either members or both dyad. After final selection of the participants, the measures were administered individually on each member of the dyad. The duration of the administration varied between 20 to 35 minutes (M = 25 minutes). During administrations, the doubts raised by the participants were clarified. At the end, the participants were debriefed.

Results

Reliability analysis. Data obtained were analyzed by means of reliability analysis with alpha model using IBM SPSS statistics for windows, version 20.0. Cronbach's Alpha for the total items for Form A (Caregiver's) i.e. was found to be .93. Those items where total correlation less than .30 were deleted which were item numbers 8, 21, 33, and 35.

Factor Analysis. Factor analysis using Principal Component Analysis and varimax rotation was run and those items with communality value less than .50 were deleted. These items were 14 (Communalities=.464), 16 (Communalities=.404), and 26 (Communalities=.422). After deletion of the above mentioned seven items, factor analysis using Principal Component Analysis and varimax rotation was run again and those items with communalities which had a value less than .50 were deleted. These items were item number 17 (Communalities=.385), and item no.32 (Communalities=.431). With the

remaining 26 items, factor analysis using the Principal Component Analysis and extraction method was done and five-factors were extracted. Item numbers 9 and 20 were deleted at this stage because in rotation component matrix their value in the five-factors was less than .50. The remaining 24 items were then retained.

Five-factors were identified from the remaining 24 items. The scale explains 63.66% of the total variance, where factor one is explaining 39.66%, factor two is explaining 8.57%, factor three is explaining 5.74%, factor four is explaining 5.50%, and factor five is

explaining 4.16%. Each item loaded .50 or higher on its expected factor. The CANSIRS items, pattern and structure coefficient (factor loadings), along with reliability estimates are presented in Table 1.

After the identification of factors from the remaining 24 items, the factors were named as per their contents. Factor 1 was named as 'Mutual Communication' as all the nine items loading in this factor emphasized on perception regarding communication between the caregivers and their patients with cancer. Further, the items in this factor refer to the perception of the caregiver

Table 1: Component matrix for principal component analysis with varimax rotation of CANSIRS Caregiver's perspective

CANSIRS Items: original item number	Component				
	1	2	3	4	5
Item 6	.782				
Item 18	.780				
Item 3	.748				
Item 24	.748				
Item 15	.724				
Item 11	.704				
Item 23	.636				
Item 22	.603				
Item 12	.543				
Item 19		.824			
Item 7		.797			
Item 10		.634			
Item 13		.633			
Item 25		.557			
Item 28		.515			
Item 31			.737		
Item 29			.612		
Item 30			.567		
Item 5				.695	
Item 4				.624	
Item 27				.533	
Item 2					.695
Item 34					.618
Item 1					.558
	Factor 1	Factor 2	Factor 3	Factor 4	Factor 5
Coefficient Alpha	.912	.867	.624	.695	.602
Number of items	9	6	3	3	3
Mean inter-item correlation	.534	.524	.361	.437	.345
Percentage of explained variance	39.67	8.58	5.75	5.50	4.16

in openness and sharing, it is the process and extent to which patients and their caregivers exchange information, ideas, feelings, news in relation to themselves and about the illness, about several facets of life like illness, financial planning, family matter etc., during the present period i. e. after the onset of illness.

Factor 2 was labeled as 'Mutual Relationship' as all the six items loading on this factor reflected on the caregiver's perception of relationship between him/her with his/her ward. The items in this factor reflected the caregiver's perception of the way in which caregivers and patients acknowledge the mutual support they share as well as trust, bonding, respect, acceptance, shared interest and values in the present situation i.e. after the onset of illness.

Factor 3 was labeled 'Attention and Support' as all three items in these factors refers to the caregiver's perception of self and partner's stress and ways of dealing with it. Factor 4 was labeled 'Availability and Providing Comfort' as the three items in this factor reflected the caregiver's perception of being available and supportive physically and emotionally during the course of the patient's illness. Factor 5 was named 'Mutual Care' as all three items in this factor reflected on the caregiver's perception of the feelings of care they give to and receive from patient being cared for.

As the investigators were interested in the perception of patients with cancer on the interpersonal relationship with their caregivers, parallel items were generated based on the 24 items retained. This patient's perspective on interpersonal relationship with their caregivers was named CANSIRS Form B (Patient's Perspective) while the caregiver's perspective was named CANSIRS Form A (Caregiver's Perspective).

Preliminary Validation of CANSIRS (Caregiver's Perspective). Pearson correlation r was run to establish correlation between the newly developed CANSIRS Form A and quality of life of family caregivers of patients with breast cancer and head and neck cancer (Table 2). Significant and negative correlations were found between CANSIRS Form A's mutual communication and caregivers' quality of life

dimensions such as burden [$r(248) = -.170$, $p < .01$], disruptiveness [$r(248) = -.336$, $p < .01$], positive adaptation and financial concern [$r(248) = -.322$, $p < .01$], and support [$r(248) = -.145$, $p < .05$]. This indicated that when the caregivers perceived increase in their mutual communication with the patient, he/she is caring for their scores in CQOLC dimension such as burden, disruptiveness, positive adaptation and financial concern, and their need of support from family and friends decreased.

CANSIRS Form A's mutual relationship was found to have significant and negative correlations with CQOLC dimensions such as disruptiveness [$r(248) = -.238$, $p < .01$], positive adaptation and financial concern [$r(248) = -.383$, $p < .01$], and support [$r(248) = -.169$, $p < .01$]. This indicated that when caregivers perceived increase in mutual relationship with the patients, their scores of disruptiveness, positive adaptation and financial concern, and their need of support from family and friends decreased.

In CANSIRS Form A, attention and support have significant and negative correlations with CQOLC dimensions such as burden [$r(248) = -.221$, $p < .01$], disruptiveness [$r(248) = -.312$, $p < .01$], positive adaptation and financial concern [$r(248) = -.519$, $p < .01$], and support [$r(248) = -.322$, $p < .01$]. This indicated with an increase in caregivers' perception of attention and support, their scores in CQOLC dimension such as burden, disruptiveness, positive adaptation and financial concern, and their need of support from family and friends decreased.

Significant and negative correlation was found between CANSIRS Form A's availability and providing comfort and CQOLC's burden [$r(248) = -.145$, $p < .05$], disruptiveness [$r(248) = -.235$, $p < .01$], and positive adaptation and financial concern [$r(248) = -.201$, $p < .01$]. This indicated that when the caregivers perceived increase in their availability and providing comfort for the patient, their scores in CQOLC dimension such as burden, disruptiveness, and positive adaptation and financial concern decreased.

In CANSIRS Form A mutual care have significant and negative correlations with

Table 2: Correlation between caregivers' perception of interpersonal relationship and their Quality of Life

Variables	Mutual Communication	Mutual Relationship	Attention and Support	Availability and providing comfort	Mutual Care
Burden	-.170**	-.101	-.221**	-.145*	-.132*
Disruptiveness	-.336**	-.238**	-.312**	-.235**	-.285**
PAFC	-.322**	-.383**	-.519**	-.201**	-.345**
Support	-.145*	-.169**	-.322**	-.121	-.190**

Note: **< .01, *< .05. PAFC-Positive Adaptation and Financial Concern

Table 3: Correlation between patients' perception of interpersonal relationship and their Quality of Life

Variables	Mutual Communication	Mutual Relationship	Attention and Support	Availability and providing comfort	Mutual Care
GHS	.063	.073	-.039	.022	.134*
Physical Functioning	.123*	.073	.059	.070	.166**
Role Functioning	.111	.072	.038	-.015	.074
Emotional Functioning	.112	.059	-.062	.027	.121
Cognitive Functioning	-.076	-.132*	-.140*	-.119	-.053
Social Functioning	.031	-.057	-.027	-.070	.140*
Fatigue	-.150*	-.134*	.054	-.060	-.132*
Nausea and Vomiting	-.045	-.036	.120	.072	-.046
Pain	-.179**	-.117	-.057	-.102	-.059
Dyspnea	-.079	.021	.163**	.013	-.028
Insomnia	-.056	-.031	-.002	.043	-.209*
Appetite Loss	-.146*	-.091	-.061	.001	-.160*
Constipation	-.083	-.080	.016	-.145*	-.041
Diarrhea	-.023	.027	-.054	-.008	.080
Financial Difficulties	-.030	.050	.067	.060	-.091

Note: **< .01, *< .05. GHS- Global Health Status

CQOLC's burden [$r(248) = -.132, p < .05$], disruptiveness [$r(248) = -.285, p < .01$], positive adaptation and financial concern [$r(248) = -.345, p < .01$], and support [$r(248) = -.190, p < .01$]. This indicated that when the caregivers perceived increase mutual care, their scores in CQOLC

dimension such as burden, disruptiveness, positive adaptation and financial concern, and their need of support from family and friends decreased.

Preliminary Validation of CANSIRS (Patient's Perspective). Pearson correlation r was run to establish correlation between CANSIRS Form B and quality of life of patients with breast cancer and head and neck cancer (Table 3). CANSIRS Form B which measures patients' perception of mutual communication has positive correlation with physical functioning [$r(248) = .128, p < .05$]. This indicated that with the increase in patient's perception of mutual communication there is an increase in physical functioning of the patients. Mutual Communication also has significant and negative correlations with fatigue [$r(248) = -.150, p < .05$], pain [$r(248) = -.179, p < .01$] and appetite loss [$r(248) = -.146, p < .05$]. As per the interpretation of EORTC QLQ-C 30, when score in physical symptoms items/dimension increases it indicates more problem. So, when patients perceived an increase in mutual communication with their caregivers, their fatigue, pain and appetite loss decreased.

Patients' perspective on mutual relationship negatively correlates with cognitive functioning [$r(248) = -.132, p < .05$] and fatigue [$r(248) = -.134, p < .05$]. This indicated that when patients perceived an increase in mutual relationship, their cognitive functioning decreased. This may be because when patients perceived themselves as having good relationship with their caregivers during their illness they may depend excessively on them in terms of reasoning, planning, decision making and so on, and on issues related to their illness. As mentioned earlier, when score in physical symptoms items/dimension increases it indicates more problem. Thus, when patients perceived an increased in mutual relationship with their caregivers, their fatigue decreased.

Patients' perspective on attention and support have negative correlation with cognitive functioning [$r(248) = -.140, p < .05$]. When the patients perceive an increase in attention and support there is decrease in their cognitive functioning. Positive correlation was found between patients' perspective on attention and support and dyspnea [$r(248) = .163, p < .01$].

When the patients perceived an increase in attention and support, dyspnea i.e. difficulty in breathing increased. This may be attributed to the physical state of the patient thus result in getting more attention and support from the caregivers. Significant and negative correlation was found between patients' perspective on availability and providing comfort with their constipation [$r(248) = -.145, p < .05$]. As mentioned earlier, when score in physical symptoms items/dimension increases it indicated more problem. So, when the patients perceived their caregiver as available and comfort is being provided to them the symptoms of constipation decreased.

Patient's perception of mutual care has significant and positive correlations with patient's global health status [$r(248) = .134, p < .05$], physical functioning [$r(248) = .166, p < .05$] and social functioning [$r(248) = .140, p < .05$]. This indicated that when the patients' perceived themselves as being loved, not being a burden and are caring towards their caregivers despite their illness their global health status, physical functioning and social functioning increased. Patient's perspective on mutual care was negatively correlated with fatigue [$r(248) = -.132, p < .05$], insomnia [$r(248) = -.209, p < .05$] and appetite loss [$r(248) = -.160, p < .05$]. As per the interpretation of EORTC QLQ-C 30, when score in physical symptoms, items/dimension increases it indicates more problem. So, when the patients' perceived themselves as being loved, not being a burden and are caring towards their caregivers despite their illness they experienced less fatigue, insomnia and appetite loss.

Discussion

A study conducted by Chung and Hwang (2012) reported that patients with breast cancer and their husbands cope through mutual help, support, concern, and sharing what is important for the patient. The same study also reported that husband tries to help their wives more actively by providing care. There are studies which suggested the need to focus on patients with cancer and their caregivers' open communication (Wittenberg, Borneman, Koczywas, Del Ferraro & Ferrell, 2017; Bachner & Carmel, 2009), the areas where improvement in

communication are needed (Ellington, Clayton, Reblin, Donaldson, & Latimer, 2017; Kimberlin, Brushwood, Allen, Radson, & Wilson, 2004) and exploration of mutual needs of patients and caregivers (Dobrina, Vianello, Tenze, & Palese, 2015). The present tools thus add value to these suggestions. The main objective of the present study was to construct a self-report scale to measure the interpersonal relationship between patients with cancer and their family caregivers from the caregiver's perspective. The finding of this study indicates that CANSIRS has established high internal consistency. Five-factor structure—mutual communication, mutual relationship, attention and support, availability and providing comfort and mutual care—has been identified with a substantial number of family caregivers of patients with cancer.

The constructed instruments are the first of its kind to measure the perspective of both caregivers and cancer patients. Though the scales have been developed using caregivers and patients with breast cancer and head and neck cancer dyads, the instruments can be extended to any caregivers and patients suffering from cancer and other chronic diseases and is designed for use with both men and women. The scales will clarify the relationship between patients and their caregivers, it will help the researchers and practitioners in quantifying the relationship between patient and their caregivers.

In this ongoing research work, though the scales show good preliminary psychometric properties, potential users need to be aware of the limitations. Confirmatory factor analysis or other approaches needs to be done to establish construct validity. It is also necessary to establish the norms of the scales for better interpretation and understanding of the caregiver and patient's perspective. Although the scales have few limitations, the findings in this study indicate that CANSIRS Form A and B have well defined structure and high reliabilities. As with any new self-report scale, range of psychometric properties can be established for the scale.

Conclusion

In conclusion, it may be said that a strong interpersonal relationship involving mutual

communication, mutual relationship, attention and support, availability and providing comfort and mutual care between patient with cancer and their caregiver may enhance the quality of care and support provided to the patients. The present scales may be useful for assessment of interpersonal relationship of patients with cancer and their family caregivers. Based on the results of this assessment if areas which need to be strengthened in their interpersonal relationship are identified, appropriate psychological interventions may be planned. This strengthening may in turn have a positive influence on several other facets of their lives.

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Quality of Life of Elderly Cancer Patients as Predictor of their Caregivers' Quality of Life

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ABSTRACT

The study was conceptualized to find out the association between quality of life of cancer patients and their caregivers and to assess whether patients' quality of life predicts their caregivers' quality of life. Sixty two dyads (N=124) of elderly cancer patients and their caregivers were selected through correlational design. Results showed that with an increase in the social functioning of the patient there is decrease in their caregivers' quality of life. Again, with an increase in cognitive functioning of the patients, there is an increase in their caregivers' quality of life. Stepwise regression analysis showed that social functioning and cognitive functioning of the patient predicted significant amount of variance in the quality of life of their caregivers.

Keywords: Cancer dyads, Social functioning, Cognitive functioning, Quality of life

Cancer as a disease has a life altering impact on the people affected by it. Both the patient and the primary caregiver are to brave the treatment and the survival phases. By the year 2026, India will witness an increase of 5.5 per cent (i.e. from 6.9% to 12.4%) cancer cases in the

age group of 60 years and above of the total population (D'Souza *et al.*, 2013). The incidence of cancer increases with age and more than 12 per cent–23 per cent of all cancers occur after the age of 65 years (Nand Kumar, 2001, and Agrawal, *et al.*, 2002). Cancer is reported to be 11 times more likely to develop in people above 65 years compared to younger people (Ries, LAG *et al.*,). Although more than 25 per cent of cancers are diagnosed in people over 60 years, this group is less extensively investigated and probably receives less appropriate treatment than younger patients (Sarkar and Shahi, 2013). Though the advancement in healthcare has contributed to the increased life expectancy, it also increases the number of people suffering from cancer, given the high prevalence of cancer in the older age group. Reduced DNA repairing ability, genetic instability, decreased carcinogen metabolism and decreased immune surveillance are some of the risk factors for developing cancer among the older people (Cicero, 2005).

Primary caregiver (PC) is the main provider of physical and emotional support for the patient. PCs are mostly the patient's spouse, partner or closest relatives, but significant others can also take on that role and function (Grover *et al.*, 2005). The role of caregiver is very challenging when it comes to giving support in terms of physical, psychological, spiritual and emotional, and in particular, care tasks over time, medical management, and decision-making (Goren, *et al.*, 2014). This alters the various aspects of their life, such as physical and mental health, quality of life, financial resources, change in roles, etc. The sudden challenge in the caregiving has been shown to have both positive and negative effects on their quality of life (Kim and Given, 2008). This takes a toll on their health (Ibid) and quality of life (Given and Given, 1992). Caregivers' burden, distress (Grunfeld, *et al.*, 2004) and poor quality of life have been closely linked with the cancer patient's physical health (WHO, 1947).

Quality of life of patients with cancer has been extensively researched. Patient's quality of life can also impact their caregivers' quality of life and vice versa. However, the caregivers' quality of life is often neglected. In fact, this lacuna is considered as a serious gap in health care system. Quality of life doesn't possess a means-end definition; it can rather be defined as a measure of how happy and healthy an individual feels within himself and his environment. It

correlates to his physical and psychological health, his social relationships, his environment, his spiritual beliefs and his expectations about himself and others (Ibid.).

Health-related Quality of Life (QoL) – both of the patients and their caregivers has been recommended as one of the hard end-points for clinical cancer research. In fact, their QoL are interdependent. Research also shows that family caregivers in cancer care experience higher levels of distress and depression as compared to the patients themselves, which can inversely impact the patients' QoL (Grov *et al.*, 2005). As the patients' QoL deteriorates, caregivers' quality of life also worsens. However, they may be reluctant to raise their own health issues, making their physical and emotional burden invisible to the professionals who can actually intervene. Assessment of the caregiver's well-being is not formally assigned to any one team member (Glajchen, 2012). Hence, they suffer as the hidden patient and thus, focusing on the family caregiver QoL becomes significant (Lim and Zebrack, 2004).

Impaired health related quality of life (HRQoL) is often associated with care giving in the context of cancer. Longitudinal studies have also indicated that when family caregivers are highly distressed, it has a negative effect on the patient's long-term adjustment (Hodges, *et al.*, 2005). Given the prevalence rate of cancer among the older population, geriatric oncology is going to become a major component of oncology and geriatric practice, and therefore appropriate consideration and support needs to be developed in public health, institutional and educative policies around the world.

The study objectives were to explore the relationship between the quality of life of elderly patients and their caregiver's quality of life and to examine if the quality of life of patients predicted the quality of life of the care givers.

Method

Sampling

The sample of this correlational study consisted of 62 dyads of elderly cancer patients and their caregivers. Among 62 cancer patients, 51 per cent were men and 49 per cent were women whereas among their family caregivers, 37.9 per cent were men and 62.1 per cent were

women. The age of cancer patients ranged from 60 to 80 ($M = 64.61$) whereas, the age of their family caregivers ranged from 18 to 74 ($M = 43.46$). The family caregivers included the spouse (52.4 %), children (32 %), siblings (12.2 %), in-laws (0.5 %), and relatives of the patients (2.9 %). The inclusion criteria of the study were – cancer in-patients below stage IV and their primary caregivers within the age range of 18–80, both without any history of mental ailment or cognitive impairment. Exclusion criteria included cases above stage III, any comorbid condition, mental ailment or cognitive impairment and cases above 80 years of age. Demographic details of both the patients and their family caregivers were also obtained.

Measures

European Organization for the Treatment and Research of Cancer Quality of Life Questionnaire-QLQ-C30, version 3.0. (EORTC QLQ-C30 version 3.0)

The EORTC-QLQ-C30 (Aronson *et al.*, 1993) was used to assess the HRQOL for cancer patients. It consists of 30 questions and is designed to cover a range of health-related QoL issues relevant to most cancer diagnoses. The questionnaire is organized into five functional scales (physical, role, emotional, cognitive, and social), three symptoms scales (fatigue, pain, and nausea/vomiting), a global health status and QoL (GHS/QoL) scale, and a number of single items assessing additional symptoms (dyspnoea, sleep disturbance, constipation, and diarrhea) and perceived financial impact. Each item has a 4-point response scale (1 – not at all, 2 – a little, 3 – quite a bit, and 4 – very much) with the exception of the two items measuring GHS/QoL, which have 7-point response scales such as 1 – very poor to 7 – excellent. The scoring was done as per the procedure prescribed in the manual. For the functional and global health, and QoL scales, a higher score indicates better functioning, while for the symptom-oriented scales and items, a higher score corresponds to a higher level of symptomatology. Cronbach's alpha of the questionnaire ranges from 0.52 to 0.89.

Caregiver Quality of Life-Cancer

The Caregiver Quality of Life-Cancer (Weitzner, *et al.*, 1999) was used to measure the levels of QoL of the family caregivers of cancer

patients (e.g., My sleep is less restful). It consisted of 35 items which were scored on 5-point scale ranging from 'Not at all' (0) to 'Very Much' (4). Total score was found by summing up the item scores and it ranges from 0 to 140. Higher the score, the better is the QoL. The test-retest reliability was 0.95 and internal consistency coefficient was 0.91; the scale also possesses adequate validity.

In addition to the measures, the demographic details such as age, gender, types of relation between the cancer patients and their family caregivers were obtained from the participants.

Procedure

Approval from the Ethics Committee of the University where the authors worked and the appropriate hospital authorities were obtained prior to starting of the study. The selected hospitals from the States of India (Mizoram and Telangana) were visited and rapport was established with the patients with cancer who were in-patients of the hospital and their family caregivers, who signed informed consent forms. Such cases were dropped where the informed consent forms were not obtained from the pair – the patient and their caregiver. Each participant – patient and caregiver – was also informed about the measures and how long it would take to complete them. The measures were administered individually on the participants. During administration, the doubts of the participants regarding any of the items of the measures were clarified. The average period of administration of the measure was 15 to 20 min per participant. After the completion of the administration of the measures, each participant was debriefed.

Results

Multiple stepwise regression analysis was run to identify the predictors of quality of life of caregivers' of patients with cancer. The analysis resulted in two Models, in the first Model social functioning of patients with cancer predicted 8.4 per cent of variance for caregivers' quality of life $F(1, 60) = 6.61, p < .05$. In Model 2, cognitive functioning dimension was added and the Model significantly predicted more variance, R^2 change was .062. Therefore, Model 2 significantly predicted 16.2 per cent of variance for caregivers' quality of life $F(2, 59) = 5.68, p < .01$.

Table 1
Summary of Multiple Stepwise Regression Predictors of Caregivers' Quality of Life

<i>Model and predictor variable</i>	β	<i>SEB</i>	β	<i>R</i> ²	ΔR^2
Model 1 (C = 52.83, F = 6.61*)				.084	
Social Functioning	-.19	.07	-.31*		
Model 2 (C = 30.83, F = 5.68**)				.162	.062*
Social Functioning	-.23	.07	-.37**		
Cognitive Functioning	.26	.12	.25*		

Note: * $p < .05$, ** $p < .01$

Discussion

The objective of the study was to find association between quality of life of patients with cancer and their respective caregivers. Result shows that in Model 1 social functioning is the predictor of caregivers' quality of life, this result suggested that with the increase in social functioning of the patient there is a decrease in quality of life. This finding contradicts the conventional thought that if the patients cope well with the disease and are able to have social interactions with others, their caregivers' quality of life will improve. However, in the current finding decrease in caregivers' quality of life could be due to fact that when the patients are up and about doing their own thing, the caregivers are worried about the patients. The caregivers expected that the patients being elderly and diagnosed with cancer will always need their assistance and attention. So when the patient appear independent and able to have social interaction with others which is the opposite of what the caregivers expected, they may feel that their role as a caregiver is not properly carried out which leads to decrease in their quality of life.

In Model 2, when cognitive functioning is added to the model there is significant increase in prediction of variance. Model 2 suggested that when there is an increase in cognitive functioning there is increase in caregivers' quality of life. This finding is in line with previous studies which suggested that with the increase in performance of the patients there is also an increase in the caregivers' quality of life. Literature also suggested mental functioning decline with age and considering that the sample is consisting of elderly patients 60 years and above, their caregivers may expect them to depend on them

in terms of cognitive functioning such as remembering things decision-making regarding issues related to their treatment and so on. But when the patient is independent to perform activities related to cognitive functioning this may reduce their anxiety and stress towards the patient's wellbeing this in turn results in increasing quality of life for the caregivers.

Conclusion

It is seen that social and cognitive quality of life of elderly cancer patients predicts the quality of life of their caregivers. With the recent rise of geriatric cancer population, research on these aspects is indicated. Geriatric population becomes dependent by default. On top of that, getting diagnosed with cancer is a major challenge both for the patients and their caregivers. Research has also shown the various negative impacts of cancer on the quality of both the patients and their caregivers. Hence psychological interventions are suggested. A more comprehensive, holistic approach is indicated, one that gathers to the biopsychosocial needs of the dyads.

Limitations and Future Directions

Larger sample size is suggested for higher generalizability. Qualitative approach could have given more insight into the perspectives of the dyad and hence a better understanding of the problem is assured.

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Quality of Life of Patients with Cancer: A Determinant of the Quality of Life of Their Family Caregivers

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Abstract Cancer disrupts the quality of life of both the patients and their family caregivers. This study attempted to explore the relationship between the quality of life of cancer patients and their family caregivers and to examine whether the quality of life, age, and gender of the patients contributed to the quality of life of their family caregivers. This correlational study involved 206 pairs of participants consisting of cancer patients and their corresponding family caregivers. The European Organization for the Treatment and Research of Quality of Life Questionnaire C-30 (version 3) was administered on the patients and the Caregiver Quality of Life-Cancer was administered on their family caregivers. The result revealed that social functioning, appetite loss, physical functioning, and gender of the patients contributed significantly to the quality of life of their family caregivers. Implications, shortcomings, and future directions were discussed.

Keywords Quality of life · Caregiver · Cancer · Correlational study

Getting diagnosed with cancer can be equally overwhelming and traumatic for both the patients and their family caregivers. Cancer disrupts the life of the dyad as it brings along a complete shift in their identity, roles, responsibilities, priorities, needs, plans, and daily functioning. These complexities can be a challenging adjustment for the dyad, not just during the time of

diagnosis but throughout the treatment and recovery process. In fact, cancer mars the quality of life of the dyad. Quality of life (QoL) is a multi-dimensional construct. It is the individual perception about their life in relation to their goals, expectations, standards and concerns, against their culture and value systems, which is affected by their biopsychosocial factors [1]. Extensive research has been done on the QoL of cancer patients, but much attention has not been given to the QoL of their family caregivers, which is the focus of this study.

Cancer debilitates a person so profoundly that its impacts linger even when its signs cease to exist [3]. Health-related QoL, thus progressively becomes paramount in measuring the potency of treatment in today's cancer care [2], because surviving a disease-free life from cancer is a critical factor [3]. Health-related QoL of cancer patients encompasses the positive as well as the negative subjective perceptions of the patient about various aspects of cancer symptoms—physical, mental, emotional, social, and cognitive functions—and importantly, disease symptoms, and side effects of treatment [4]. Thus, health-related QoL with its comprehensive dimensions becomes an ideal measure to assess the prognosis and effectiveness of the treatment—both for the patients as well as the clinicians. It also acts as a yardstick in assessing the results of any new therapeutic strategies and also to plan for cost-effective treatment choices [5].

The current cancer prevalence in India is estimated to be around 2.5 million, with 800,000 new cases and 550,000 deaths occurring each year [6]. The most common cancers in men are head and neck cancer, stomach cancer, and lung/bronchi cancer; while in women, they are cervix cancer, breast cancer, and head and neck cancer [6]. This statistics also implies distinctly, the number of their family members who become the untrained primary/informal caregivers, making the care giving process even more tasking. In India, family caregiver comprises of persons from both the primary and secondary social network, encompassing the parents, spouse,

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Original Article

Care givers' depression, anxiety, distress, and somatization as predictors of identical symptoms in cancer patients

ABSTRACT

Context: The critical condition of the cancer patient and the stringent medical procedures do not often warrant the accessibility of the patient for psychological evaluation. Therefore, the study is conceptualized to assess the psychological problems of caregivers, which in turn have their impact upon cancer patients.

Aims: The objective of the study was to explore the relationships between depression, anxiety, distress, and somatization in cancer patients and their caregivers along with age, gender, and relationship; and to measure whether these psychological problems of caregivers were predictors of the identical symptoms of the cancer patients.

Materials and Methods: Four-Dimensional Symptom Questionnaire was used to measure depression, anxiety, distress, and somatization of cancer patients and their caregivers. The sample had 200 participants, with 100 patients (male = 47 and female = 53) and 100 caregivers (male = 36 and female = 64) selected by purposive sampling method.

Statistical Analysis Used: The data were analyzed by using descriptive statistics, product-moment correlations, simple and multiple linear regression analyses.

Results: Significant correlations were found between cancer patients' depression and anxiety, and caregivers' depression, anxiety, distress, and somatization; patients' distress and somatization, and caregivers' anxiety and age, respectively. It was also found that anxiety was a significant predictor of distress in patients, and that caregivers' depression, anxiety, distress, and somatization significantly predicted depression and anxiety in cancer patients.

Conclusions: The association between depression, anxiety, distress, and somatization of caregivers and patients indicates the need for psychological interventions to manage these problems of caregivers, which would in turn help managing the identical symptoms in patients.

KEY WORDS: Anxiety, depression, distress, somatization

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INTRODUCTION

Cancer is the leading cause of death worldwide.^[1] Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. Cancer is caused by both external factors such as tobacco, chemicals, radiation, and infectious organism as well as internal factors such as inherited mutations, hormones, immune conditions, and mutation that occur from metabolism.^[2] The risk of developing cancer increases with the increase in age, especially middle age onward and in many countries the incidence rates of cancer are high in males than females.^[3] Cancer is affecting the lives of many, there were an estimated 14.1 million cancer cases around the world in 2012, of these 7.4 million cases were in men and 6.7 million cases were in women. As per Indian population census data, the rate of mortality due to cancer in India was high and alarming with

about 806,000 existing cases by the end of the last century.^[4] Cancer is the second most common disease in India, its prevalence in India is estimated to be around 2.0–2.5 million, with over 7–8 lakh new cases identified every year.^[5]

Whatever the type of cancer and the stage is, diagnosis of cancer creates psychological problems in not only cancer patients but also their caregivers. The connotation of psychological problem in the study is confined to four dimensions such as depression, anxiety, distress, and somatization. Psychological distress is common among cancer patients and their caregivers; this can in turn have a profound effect on their disease progression. Cancer patients rely almost always on family, friends, and significant others, in their journey of dealing with their illness. Carer, especially spouse often symbolically shared in the illness and presented the struggle with cancer as a joint one.^[6] One

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Enhancing the life skills in Patients with Cancer and Other Chronic Illness

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ABSTRACT

Chronic conditions account for the greatest mortality and morbidity internationally and among them, cancer is the most common. Cancer and other chronic illnesses can cause depression and anxiety among the patients. Due to physical limitations as a result of the illnesses, the patients may experience low self-efficacy, which in turn leads to low self-esteem among them. Interventions aimed at enhancing life skills and self-management to patients with cancer and other chronic illnesses can have positive impact on lives of the patients. In this review, with a specific focus on cancer patients in particular, an attempt is made to portray the psychosocial needs of the chronically ill patients as cited in several studies and the need for enhancement of certain life skills is emphasized to address the same.

Key words: Chronic illnesses, Cancer, Self-efficacy, Psychosocial needs

INTRODUCTION

Chronic illnesses: prevalence and effects

Chronic illness is defined as an illness that lasts for a long time and usually cannot be cured. But it can be managed through diet, exercise, lifestyle and medical care. Chronic illness is any disorder that persists over a long period and affects physical, intellectual, vocational, social and spiritual functioning. Chronic diseases, such as heart disease, stroke, cancer, chronic respiratory diseases and diabetes, are by far the leading cause of mortality in the world, representing 63% of all deaths. Out of the 36 million people who died from chronic disease in 2008, nine million were under 60 and ninety per cent of these premature deaths occurred in low- and middle-income countries (World Health Organization, 2013). In India, chronic diseases are projected to account for 53% of all deaths according to World Health Organization in 2005.

challenges in the life of the individual from multiple perspectives. Some of the challenges faced by chronically ill people include physical challenges which are associated with symptoms of illness or condition. Second is reduction in ability, i.e. chronic illness can result in certain physical limitations which in turn can result in increased fatigue levels, decreased strength and stamina. The third is financial, medical bills, transportation, follow up treatment and other care aspects which add to a significant burden on the patients and their families.

Psychological effects of chronic illnesses

Being chronically ill may result in the patient being dependent on others which causes discomfort to the patient and members of the family. It also has an immense impact on the patient's self-image and self-worth. As a result, the cumulative effect of these factors can lead to a significant burden on the patient and their families.

Do differences in place of living and gender affect the self-efficacy and quality of life of university students?

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Entering into university level education often poses challenges, both academics as well as life, especially when it demands people to leave their houses and stay in hostels. The present study was conceptualised to measure the general self-efficacy and quality of life of students who approached universities for higher study and to examine whether the differences in place of living and gender affect their self-efficacy and quality of life. Two hundred and forty university students were assessed on their self-efficacy and quality of life using General Self-efficacy Scale and World Health Organisation-Quality of Life BREF questionnaire. The data were analysed by means of descriptive statistics, 2 (place of living) X 2 (gender) between-subjects ANOVA, product moment correlation (*r*), and line graph. Both place of living and gender played significant role in the university students' self-efficacy and quality of life. The students who lived in their home and women were found to have greater self-efficacy as well as better quality of life compared to the students who lived in hostel and men respectively. It was also observed that women who stayed in hostel were more vulnerable to psychological health issues. The results demonstrate a need for designing interventions that target enhancing self-efficacy in hostel boarders as well as men students such that their quality of life be improved.

Keywords: place of living, university students, self-efficacy, quality of life

India with a total of 712 universities, 36671 colleges and 11445 standalone institutions, i.e., 48828 institutions under higher education, and a total enrollment of 29629 million students in higher education (Government of India, 2014), interstate academic migration has become a prominent trend in the educational trajectory today. Many students, in their pursuit of higher education, venture out of their homes to distant places. And as they adjust and adapt to the various inherent facets of a new environment, they undergo various psychological issues like- stress, anxiety, loneliness and even depression. Besides, as they transient from college to university level, they are also confronted with both career specific as well as common everyday life stressors, which put them under constant challenges and pressure. They also have to meet expectations both from 'self' and also from 'significant others'. Thus, this whole process of venturing out, adjusting and adapting in a new place demands an individual to be self-efficacious; because in certain cases, it even becomes essential for the students to stay on the campus of the higher educational institutions, either in the hostel or any other such facilities provided by the institution, depriving them of their home environment. Their mobility, primarily from homes to hostels, is observed to be one of the major sources of psychological and social stress, and subsequently influence their self-efficacy that gradually brings changes in their quality of life. Staying in hostels can also alter the quality of life of a person as it requires undergoing various changes in their normal lives.

A study has shown that students who stay at home have higher skill of managing emotional and social management as well as overall emotional intelligence compared to those who stay in hostels (Madhavi, Waddar, & Vijayalaxmi, 2010). This finding seems to

indicate that students who stay at home are better adjusted in life as compared to those who stay in hostels. Given the inherent challenges that every student staying in hostels has to tackle, a person requires to be self-efficacious, as is found that self-efficacy has a major influence in psychological adjustment of students when put in a new environment (Abdullah, 2014). Self-efficacy is an individual's self-evaluation of one's competence to successfully execute a course of action necessary to reach desired outcomes (Bandura, 1977).

Self-efficacy is also shown to have direct positive effect on pursued goals and academic achievements (Mavis, 2001; Vrugt, Oort, & Zebera, 2010; Carroll et al., 2008; Hsieh, Sullivan, & Guerra, 2007), and that it predicts students' motivation and learning (Schunk, 1989) which in turn, influences their quality of life. Self-efficacy also contributes to both psychological and interpersonal health related motives (Shen & Xu, 2008) and behaviors, (Zalewska-Puchal, Maida, Galuszka, & Kolonko, 2007) and predict unhealthy-addictive behaviors such as smoking (Chang et al., 2006) and heavy alcohol drinking among students (Choi, 2006). These psychological factors affect quality of life and adaptation to university mechanisms (Bray, 2007). Quality of life is individuals' perceptions 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 (Skevington, Lofly, & O'Connell, 2004). Research studies show not only significant positive relationship between self-efficacy and quality of life but that self-efficacy also predicts and has mediating effects on quality of life (Mukhtar & Hashim, 2010).

It is observed that while many studies describe self-efficacy as a salient construct, no recent studies examine the relevance of this construct with the quality of life among vulnerable university students who are in their crucial transition phase from late adolescence to early adulthood. Hence, this study attempted to answer three major research questions (i) What are the levels of