CHAPTER - 1

INTRODUCTION

1.1 Background

The term psychosocial is understood as the dynamic relationship between psychological and social effects, each continuously interacting and influencing with the other. Psychological make-up is the product of an individual's experiences with self and others. The social aspect is the outside yet inseparable environment that helps to shape the psychological world of an individual. Both aspects cannot be isolated since an individual is the product of biological (body and function), psychological (built-up knowledge of self and others), and social (the other people and environment) factors.

Psychosocial factors constantly interact with each other bringing changes within the individuals in their daily functioning both at individual and interpersonal level. Psychosocial factors are changed for better or worse in a person suffering from cancer depending upon the duration and stage of cancer, type of treatment, and financial burden of the treatment. However, in cancer treatment, a person needs a long term and unconditional psychosocial care including support to deal with the health condition as well as to maintain social relationships.

Cancer has been considered a life threatening disease that leaves a life-long impact on the patient. A cancer patient commonly experience uncertainty that characterizes his/her life in the survival path following diagnosis and treatment. A person's reaction to cancer and one's own life depend on how s/he perceives cancer as disease. Majority of patients lose balance of life. Psychologically they are under enduring stress and feel helpless and hopeless. Socially, they feel being neglected, fear of losing job, have extra financial burden to the family and for not being able to get involved in social activities (Kapoor, 1998).

The cancer affects the quality of life (QOL), influencing physical and mental health, functional status, independence, general well-being, personal relationships and social functioning (Al-arabai, 2006). Quality of life of a person is possible to measure. The measures focus on subjective perception of functioning and well-being in their day-to-day living (Al-arabai, 2006).

World Health Organization (WHO) has defined quality of life as "individual's perceptions of their position in life in the context of the culture and value systems where they live and in relation to their goals, expectations, standards and concerns" (Testa and Simonson, 1996, P. 835). It is a broad concept incorporating in a complex way an individual's physical health, psychological state, level of independence, social relationships, personal beliefs and his/her relations to the silent features of the environment. Quality of life, among the cancer patient, encompasses the major dimensions such as physical, psychological, social and spiritual (Liu, 2005).

The physical dimension of QOL among the cancer patients encompasses pain, nutritional problems, anorexia, nausea, vomiting, insomnia due to development of cancer and adverse effects of treatment strategies (Liu, 2005). The psychological dimension of QOL among the cancer patients can be attributed to being beyond the control of one's body, changes in body image (alopecia and cachexia) and almost all aspect of life. For example, family members of patients, receiving palliative/supportive treatment, experience emotional turmoil that occurs at transition points along the clinical course of cancer (Liu, 2005). The social dimension of QOL among the cancer patients are often affected by withdrawal from work, social activities and one's role in the family. People's material conditions and their position in the social structure greatly affect their behavior, which in turn affects their health. In addition, culture is found to affect the behavior especially the pattern of eating, drinking and social relationships (Liu, 2005). Other factors related to sickness are also found to play major roles. 'Social rejection' for example, is found to play major role in the family of cancer patients in south Asian social life (Sotnik and Hasnain, 1998). Similarly, it was found especially to affect the marital relationship among the Muslim women (Sotnik and Hasnain, 1998). People are excluded when they are not a part of the networks which support most people in ordinary life- networks of family, friends, community and employment. Cancer patients may be at risk of social exclusion due to long term illness and for not being able to perform their social responsibilities (Sotnik and Hasnain, 1998). The spiritual dimension of quality of life among the cancer patients is related to the task of finding the 'meaning of cancer'. Meaning of cancer is different in different cultures. For instance, the Chinese largely view illness as a punishment for sins committed in past life by the ill person or the person's parents (Liu, 2005). The South Asians believe that cancer is caused due to the sins committed by their ancestors or extended family members, or by the patient in previous life. Being resigned to the belief that it is *Karma* (destiny, based on one's actions), or God's will, or even that the person is cursed with cancer, is a frequent way in which South Asian communities deal with the social impact of the disease (Liu, 2005).

Nepal is a land-locked country nestled in the foothills of the Himalayas. It occupies an area from 260 22' to 300 27' north latitude and 800 4' 880 12' east latitude with elevation ranging from 90 meters to 8,848 meters. The country is sandwiched between India to the East, South and West and China to the North. It has a rectangular shape and stretches 885 kilometers in length (east to west) and 193 kilometers in width (North to South). The total area of the country is 147,181 square kilometers. According to the 2001 census, the total population of Nepal is 23,151,423 (Central Bureau of statistics, 2006a).

Nepal is gifted with the combined beauty of cultural heritage and nature. The diversity in language, ethnic group, religion, geography, climate, natural environment, etc is the major feature of the country with 103 recognized indigenous nationalities and over 100 languages spoken in communities. However, most people understand the Nepali language. The country is spread across the plains (Terai), hills and the high Himalayas. There is uniqueness in the diversity in natural environment, culture and society. Geographical variations have been an obstacle to development of transportation and communication networks.

Even though the majority of Nepalese population is poor, the economic status is rising slowly yet large population within the society are still systematically disadvantaged or traditionally marginalized. Majority of the Nepalese are unable to maintain their normal relationships and activities in the economic, social, cultural and political field due to lack of resources, rights, goods and services. It has affected both quality of life of the individuals and their social harmony.

1.2 Statement of the Problem

Psychosocial factors are recognized to be a crucial issue of cancer patients during their treatment and rehabilitation. But there is a lack of evidence on the role of psychosocial factors in relation to quality of life among the cancer patients in Nepal. Therefore, this study aims to investigate the association between major psychosocial factors and the quality of life among Nepalese cancer patients.

1.3 Research Questions

Following research questions concerning the factors, which are expected to influence quality of life among Nepalese cancer patients:

1.3.1 What type of association exists between gender, age, education, marital status, economic status and role of cancer patient in the family in relation to their quality of life including its four domains among cancer patients in Nepal?

1.3.2 What type of association exists between stages of cancer, duration of cancer diagnosis, modalities of treatment received and facing financial problems for treatment in relation to their quality of life including its four domains among cancer patients in Nepal?

1.3.3 Do coping, social support and self-esteem associated with quality of life including all its domains among cancer patients in Nepal?

1.3.4 Do anxiety and depression associated quality of life including all its domains among cancer patients in Nepal?

1.4 Objectives of the Study

This research is empirically based on the perceived psychosocial factors (social support, self-esteem, coping, anxiety and depression) and the quality of life as defined by World Health Organization among Nepalese cancer patients.

1.4.1 To find out the association of selected demographic variables (gender, age, education, marital status, economic status and role of the patient in the family) with their quality of life including all its domains among the cancer patients in Nepal.

1.4.2 To find out the association of selected disease variables (duration of cancer diagnosis, stages of cancer, treatment modalities and facing financial problems during treatment) with their quality of life including all its domains among the cancer patients in Nepal.

1.4.3 To examine the association of selected psychosocial variables (coping, social support, self-esteem, anxiety and depression) with their quality of life including all its domains among the cancer patients in Nepal.

1.5 Rationale of the study

Looking at the world scenario, each year, more than 11 million new cases of cancer are diagnosed; more than 7 million people die of cancer, out of which over 70% are in low and middle-income countries and if the current trend continues, then in the year 2020, new cases will increase to 16 million per year and more than 10 million people will die due to cancer (UICC, 2008). In Nepal, approximately 50 thousand people are noted as suffering from the cancer and most common cancers include uterine cervix, lung, breast and head and neck cancer (Baduwal, 2009). Cancer is a medical problem and lay people believe it to be a fatal/non-curable disease. Cancer is an experience that touches all aspects of a person’s existence. It questions one’s life and threatens to disintegrate it (Liu, 2005). A detail study of the cancer patients in relation to quality of life of Nepalese cancer patient in their proper context is yet not made.

People with cancer are influenced by their psychological make-up, socio-cultural, and existing health care factors. Usually, a cancer diagnosis is a threat to life but preexisting perception of cancer and social stigma determines the social expectations, interaction, and way to deal with cancer. A person's struggle for survival continues even when recovered from cancer. Cancer survivors may confront a diverse range of psychosocial problems, including difficulty in re-integration into their family, social and work lives after treatment (Mehta, 1998). Studies have indicated that cancer survivors who had systematic psychosocial rehabilitation were found to engage in more social and recreational activities than who had no psychosocial rehabilitation (Wayne, 1978). A systematic study on psychosocial problems of different nature cancer patients’ face is yet to be recorded in Nepal.

More specifically, a cancer patient, if married and adult, have social and psychological concern. Socially, the person may experience concern about children and family, social deprivation, economic burden, loss of normal function and social control. Altered self-esteem, altered body image, powerlessness, loss, hopelessness, guilt, anxiety and mal-adjustment/coping cause the major psychosocial problems in cancer patients (Mehta, 1998). Mehta further indicates previous studies revealing that up to half of all the cancer patients face psychosocial problems (Mehta, 1998). Psychological well being and social consequences of cancer on patients in Nepal are not systematically examined.

Quality of life becomes an issue during survival of the cancer patients. Stanhope (1992) also indicated that both internal and external phenomena that are closely related to QOL are affected. Health and happiness are related to high QOL and among cancer patients such level of health and happiness may not exist. Thus, Stanhope (1992) insists that among cancer patients, quality of life has gained prominence as an important outcome of cancer treatment, encompassing those things that give worth, meaning, purpose and satisfaction to life. From the above studies it can be conclude that QOL conveys an overall sense of well being and includes happiness and satisfaction in their lives as a whole. It is a very complex concept as it involves satisfaction of emotional needs and social aspirations of the cancer patients.

Psychosocial care has been made available to the cancer patients in the developed countries since the beginning of last three decades, but it is not practiced in Nepal till date and no study is being done in this area. This study explores the major psychosocial factors such as level of social support, self-esteem, coping, anxiety and depression among cancer patients and associations of each factor with their quality of life according to the World Health Organization criteria. This study documents the baseline data in psychosocial factors and quality of life of cancer patients in the cultural context of Nepal, which contributes to health psychology. Health is a fundamental right of each individual. The study result provides data related to the types of care which the cancer patients needed to maintain their quality of life.

1.6 Limitation of the Study

This study was limited to the research participants, who were diagnosed cancer of head and neck, lung, breast and uterine cervix. This study was also limited to the people, who were aware about their diagnosis for more than a month. Cancer patients, who were mentally stable and able to communicate, were included in this study. This study adopted both qualitative and quantitative method during data collection. Out of these two, quantitative data was limited to the hospital settings. This study was limited to the perceived level of psychosocial factors (coping, social support, self-esteem, anxiety and depression).

1.7 Operational Definition of the Key Words

There are some key words, which were frequently used in whole dissertation report. These words/concepts were defined below according to their use in this study.

1.7.1 Cancer

The term ‘cancer’ refers to a diverse group of diseases, characterized by uncontrolled growth of abnormal cells, which have the ability to spread in the whole body or body parts and lead to a variety of pathological consequences. In this study, cancer of head and neck, lung, breast and uterine cervix was included.

1.7.2 Cancer Patient

Cancer patient refers to the person diagnosed with cancer of head and neck, lung, breast and uterine cervix whether undergoing/underwent treatment or not. Here the term 'patient' includes the person, who was under treatment or without treatment after a month of cancer diagnosis.

1.7.3 Psychosocial Factors

Here psychosocial factors refer to those factors, which influence an individual’s thinking, feeling, behavior and adaptation towards having diagnosis and treatment of cancer. Psychosocial factors, thus, include perceived level of social support, self-esteem, coping, anxiety and depression after having diagnosed with cancer.

1.7.4 Coping

Coping refers to the ways or means a person adopts to keep stress at manageable levels. Here, the cancer patient utilizes an active response to avoid stressful events due to cancer and its treatment. In this study, coping is used as an independent variable, which is measured by using Carver’s brief cope inventory.

1.7.5 Self-esteem

Self-esteem is patient's self-image, self-respect and self-worth. A multiplicity of variables can affect how cancer patient perceives the self, after having the disease cancer. In this study, self-esteem is used as an independent variable as measured by Rosenberg’s self- esteem scale.

1.7.6 Social support

Social support is the perceived availability of functional support, where functional support refers to the degree to which interpersonal relationships serve the cancer patient after having diagnosed with cancer. Here, the word social support is used as an independent variable as measured through Sherbourne and Stewart’s medical outcome study (MOS) social support survey scale. This scale constituted with four sub-scales viz. emotional/informational, tangible/instrumental, affective and positive social interactive support.

1.7.7 Anxiety

Anxiety is a condition of persistent and uncontrollable fear, nervousness, stress and worry that is triggered by anticipation of future events, memories of past events, that reflects over day-to-day events among cancer patients. Here, the word anxiety is used as an independent variable, which was measured through Hamilton anxiety scale (HAM-A).

1.7.8 Depression

Depression is a term used to describe a mood, a symptom and syndrome of affective disorders, which is characterized by negative feelings, attitudes, beliefs a person has about self and his/her environment, for example pessimism, helplessness, hopelessness, low self- esteem and feeling of guilt. Depression is a subjective reaction which occurs with or without a clear reason. It is a common response to cancer. Here, the word depression is used as an independent variable, which was measured through Beck depression inventory- II (BDI-II).

1.7.9 Quality of life

Quality of life refers to the subjective well-being of cancer patients. In this study, quality of life is used as dependent variable, which was based on WHO criteria and measured through the instrument named as World Health Organization Quality of Life- BREF (WHOQOL-BREF). WHOQOL-BREF constituted with four major domains namely physical, psychological, social relationship and environment. Along with four domains, there was two additional items in scale to measure the total quality of life.

1.8 Study Variables

Demographic characteristics of the research participants, disease related attributes and psychosocial factors were taken as independent variables. Quality of life and its four domains (physical, psychological, social relationship and environment) was endorsed as dependent variable in this study.

1.8.1 Independent Variables

1.8.1.1 Demographic variables: age, sex, education, marital status, socio-economic status and role in the family.

1.8.1.2 Disease variables: stages of cancer, duration of illness, modalities of treatment and facing financial problems for treatment.

1.8.1.3 Psychosocial variables: coping, social support, self-esteem, anxiety and depression.

1.8.2 Dependent variables: Quality of life

CHAPTER - 2

REVIEW OF LITERATURES

AN EXTENSIVE REVIEW OF THE LITERATURES WAS CONDUCTED MAINLY FOR THREE PURPOSES, TO ACHIEVE A DEGREE OF CONCEPTUAL CLARITY, CONSIDER MAIN ISSUES IN PSYCHOSOCIAL VARIABLES AND SOME RELEVANT ISSUES ON DEMOGRAPHICS AND ILLNESS VARIABLES; TO BUILD THE GIST OF FINDINGS BY EXPLORATION OF EMPIRICAL STUDIES RELATED TO THE VARIOUS DIMENSIONS OF PSYCHOSOCIAL FACTORS, QUALITY OF LIFE AND ITS RELATION WITH CANCER TO SUPPORT THE FINDINGS OF CURRENT STUDY; TO DEVELOP A THEORETICAL FRAMEWORK TO TRACK THE VARIABLES UNDER INVESTIGATION IN THIS STUDY. THE SELECTED LITERATURES REVIEWED STRETCHED TO LAST THREE DECADE'S WORK ON SPECIFIC TYPES OF CANCER. MOREOVER, AS HISTORY SHOWS ADVANCEMENT IN PSYCHOSOCIAL ONCOLOGY DURING THIS PERIOD. DIFFERENT BOOKS AND JOURNALS WERE SEARCHED WITH THE HELP OF CATALOGUE AND RECOMMENDATION OF PREVIOUS RESEARCHERS; NEWSPAPER READING WAS DONE TO GET AWARE OF THE RECENT FINDINGS OF NEPAL AND WEB SITES (GOOGLE, HINARI, BLACKWELL, SCIENCE DIRECT, MIDLINE, ETC.) WERE SEARCHED WITH KEYWORDS SUCH AS PSYCHOSOCIAL FACTORS, COPING, SOCIAL SUPPORT, SELF-ESTEEM, ANXIETY, DEPRESSION, QUALITY OF LIFE, AND CANCER.

THE AIM OF THIS STUDY WAS TO EXPLORE QUALITY OF LIFE OF THE CANCER PATIENTS IN RELATION TO THEIR CERTAIN DEMOGRAPHIC AND DISEASE VARIABLES, THE AMOUNT OF SOCIAL SUPPORT THEY PERCEIVED, LEVEL OF SELF-ESTEEM AND COPING, AS WELL AS PSYCHOLOGICAL CONSEQUENCES SUCH AS ANXIETY AND DEPRESSION IS ASSESSED. THE DIAGNOSIS OF CANCER CAN BE OVERWHELMING, BECAUSE OF THE THREAT OF THE NATURE OF DISEASE AND THE UNFRIENDLY NATURE OF MEDICAL CARE INSTITUTIONS THAT PATIENTS MAY ENCOUNTER DURING THEIR TREATMENT. PATIENTS ADJUST TO THE PROSPECT OF CANCER IN THEIR LIVES IN A NUMBER OF WAYS. THEY MAY SEE A CHALLENGE TO OVERCOME, A TEMPORARY INCONVENIENCE, OR EVEN "WAKE-UP CALL" TO A NEW LIFE OR IT MAY BE EXPERIENCED AS A DEATH SENTENCE, PRECIPITATING A TEMPORARY EMOTIONAL CRISIS OR MORE CHRONIC AND SERIOUS PSYCHOSOCIAL DISTURBANCES.

2.1 CANCER

CANCER IS NOT JUST ONE DISEASE, BUT A GROUP OF ALMOST HUNDRED DISEASES. ALL CANCERS BEGIN IN CELLS. CELLS MAKE UP TISSUES AND TISSUES MAKE UP THE ORGANS OF THE BODY. NORMALLY, CELLS GROW AND DIVIDE TO FORM NEW CELLS AS THE BODY NEEDS THEM. OLD CELLS ARE REPLACED BY THE NEW ONES. SOMETIMES, THIS ORDERLY PROCESS GOES WRONG. NEW CELLS ARE FORMED EVEN WHEN THE BODY DOES NOT NEED THEM, AND THE OLD CELLS DO NOT DIE WHEN THEY SHOULD. THESE EXTRA CELLS CAN FORM A MASS OF TISSUES CALLED A GROWTH OR TUMOR. ITS TWO MAIN CHARACTERISTICS ARE UNCONTROLLED GROWTH OF CELLS IN HUMAN BODY AND THE ABILITY OF THESE CELLS TO MIGRATE FROM THE ORIGINAL SITE AND SPREAD TO DISTANT SITES. IF THE SPREAD IS NOT CONTROLLED, CANCER CAN RESULT IN DEATH.

THE FIRST MEDICAL DOCUMENT TO DESCRIBE CANCER WAS THE EBERS PAPYRUS, WRITTEN AROUND 1500 B.C. THAT DOCUMENT BRIEFLY DEALT WITH THE DESCRIPTION OF THE SWELLINGS THAT ACCOMPANY SOME TUMORS. HIPPOCRATES TERMED IT AS CANCER AND DESCRIBED SEVERAL KINDS OF CANCERS. HE CALLED THE BENIGN TUMORS AS ONCOS, A GREEK TERM FOR SWELLING AND MALIGNANT TUMORS AS CARCINOS, GREEK TERM FOR CRAB OR CRAYFISH. THIS TERM COMES FROM THE APPEARANCE OF THE CUT SURFACE OF A SOLID MALIGNANT TUMOR (THE VEINS STRETCHED ON ALL SIDES LOOKED LIKE CRAB'S FEET). HE LATER ADDED THE SUFFIX-OMA, GREEK TERM FOR SWELLING, RESULTING IN THE NAME CARCINOMA. SINCE IT WAS AGAINST THE GREEK TRADITION TO OPEN A BODY, HIPPOCRATES ONLY DESCRIBED AND MADE DRAWINGS OF OUTWARDLY VISIBLE TUMORS ON THE SKIN, NOSE AND BREASTS. TREATMENT WAS BASED ON THE HUMOR THEORY OF FOUR BODILY FLUIDS (BLACK, YELLOW BILE, BLOOD AND PHLEGM). ACCORDING TO THE PATIENT'S HUMOR, TREATMENT CONSISTED OF DIET, BLOOD-LETTING AND/OR LAXATIVES. THROUGH THE CENTURIES, IT WAS DISCOVERED THAT CANCER COULD OCCUR ANYWHERE IN THE BODY, BUT HUMOR-THEORY BASED TREATMENT REMAINED POPULAR ONLY UNTIL 19TH CENTURY WHEN THE TYPICAL MALIGNANT CELLS WERE DISCOVERED (PAUL, 2007).

IN RECENT TIMES, CANCER TREATMENT INVOLVES FOUR MODALITIES WHICH MAY BE EMPLOYED SINGLY OR IN COMBINATION: SURGERY, RADIOTHERAPY, CHEMOTHERAPY OR A

GROUP OF LESS WELL-DEFINED TREATMENTS, OF WHICH IMMUNOTHERAPY IS THE CHIEF EXAMPLE. IT IS COMMON PRACTICE TO EMPLOY SURGERY WHERE APPLICABLE TO REDUCE THE TUMOR BURDEN, IF A SINGLE LARGE MASS HAS BEEN DETECTED BY THE X-RAYS OR MAGNETIC RESONANCE IMAGING. IT IS FOLLOWED BY LOCALIZED OR WHOLE-BODY RADIOTHERAPY TO ATTACK RESIDUAL DISEASE AND/OR CHEMOTHERAPY TO DEAL WITH DISTANT METASTASES. IF THE DISEASE IS ADVANCED, WITH OBVIOUS METASTASIS, CHEMOTHERAPY WITH A COCKTAIL OF THREE OR FOUR POWERFULLY CYTOTOXIC DRUGS MAY BE THE ONLY WORTHWHILE OPTION. MOST OF THESE DRUGS ARE DNA-REACTIVE CHEMICALS WHICH DIRECTLY ATTACK THE GENETIC BLUEPRINTS OF THE ROGUE CELLS. ALTERNATIVELY A MASSIVE DOSE OF WHOLE-BODY IRRADIATION MAY BE ATTEMPTED TO RESCUE THE PATIENT FROM DEATH BY DESTRUCTION OF HIS/HER BONE MARROW, FOLLOWED BY SUBSEQUENT RE-IMPLANTATION OF HIS/HER OWN MARROW CELLS, COLLECTED PRIOR TO TREATMENT AND 'CLEANED UP' IN VITRO (AUTOLOGOUS BONE MARROW TRANSPLANTATION) (PARK ET AL, 2008). DOCUMENTING AND UNDERSTANDING THE SYSTEMATIC APPLICATION OF VARIOUS FORMS OF BIOMEDICAL THERAPY TO TREAT THE CANCER, HOWEVER, IS NOT AIM OF THIS STUDY.

EARLY DETECTION AND CANCER PREVENTION DEPENDS LARGELY ON RESHAPING ATTITUDES AND BEHAVIORS THAT PUT PEOPLE AT GREATER RISK. IN THE PAST TWO DECADES, RESEARCH HAS CONTRIBUTED IN UNDERSTANDING OF THE PSYCHOSOCIAL REACTIONS THAT ACCOMPANY A CANCER DIAGNOSIS. PSYCHOSOCIAL APPROACHES WORK WITH THE IDEA THAT MIND AND EMOTIONS CAN PROFOUNDLY INFLUENCE THE CONDITION OF HEALTH AND DISEASES. MANY STUDIES HAVE ACKNOWLEDGED THAT MIND AND EMOTIONS PLAY A KEY ROLE IN CANCER AND IMMUNE FUNCTIONING (DOLBEAULT ET AL, 1999). PEOPLE SUFFERING FROM CANCER MAY SUCCESSFULLY MAKE MEANING FROM THEIR EXPERIENCE, WHICH, IN TURN, MAY INFLUENCE THEIR PSYCHOSOCIAL ADJUSTMENT. ONCOLOGISTS BETTER RECOGNIZE PSYCHOSOCIAL DISTRESS SUCH AS ANXIETY, DEPRESSION AND DELIRIUM (IN HOSPITALIZED PATIENTS) AS FREQUENT CO-MORBID DISORDERS (DOLBEAULT ET AL, 1999). NOW, OUTCOMES IN CONTROLLED TRIALS OF THE NEW TREATMENTS INCLUDE QUALITY OF LIFE AS WELL. THE FUTURE WILL CONTINUE TO BRING NEW CHALLENGES TO PSYCHO-

ONCOLOGY AS PATIENTS FACE NEW CHALLENGES IN TREATMENT. A MAJOR AIM OF THE 21ST CENTURY WILL BE TO BRING THIS INTEGRATED APPROACH TO ALL PATIENTS IN AN AFFORDABLE MANNER (DOLBEAULT ET AL, 1999).

THERE HAVE BEEN DIFFERENT OBSERVATIONS BY DIFFERENT RESEARCHERS REGARDING THE RELATIONSHIP BETWEEN CANCER AND PSYCHOSOCIAL FACTORS. PREVIOUSLY, CANCER WAS CONSIDERED ALMOST ALWAYS FATAL, BUT DUE TO RECENT ADVANCES IN TREATMENT, CANCER IS REACHING CURABLE RATES UP TO 80% (HARVEY ET AL, 1999; ACS, 2003). YET, MOST PEOPLE FEEL THAT THERE IS NO SCARIER DIAGNOSIS THAN THAT OF CANCER. CANCER IS OFTEN THOUGHT OF AS AN UNTREATABLE, UNBEARABLY PAINFUL DISEASE WITH NO CURE. HOWEVER POPULAR THIS VIEW OF CANCER MAY BE, IT IS EXAGGERATED AND OVER GENERALIZED. CANCER IS UNDOUBTEDLY A SERIOUS AND POTENTIALLY LIFE-THREATENING ILLNESS. HOWEVER, IT IS A MISTAKEN BELIEF THAT ALL FORMS OF CANCER ARE UNTREATABLE AND DEADLY. WHILE DIAGNOSIS OF CANCER MAY STILL LEAVE THE PATIENTS FEELING HELPLESS AND OUT OF CONTROL, IN MANY CASES THERE IS HOPE RATHER THAN HELPLESSNESS (PARKIN, 2001). FURTHERMORE, THE PATIENTS REPORT DISTRESS IN OTHER FAMILY MEMBERS, ADVERSE NEUROPSYCHOLOGICAL PROBLEM TO CHEMOTHERAPY, SEXUAL PROBLEMS AND DISRUPTION OF DAILY SOCIAL, PHYSICAL AND COGNITIVE FUNCTIONING. THE DIAGNOSIS AND TREATMENT OF CANCER THEREFORE HAVE LONG LASTING, PERVASIVE PSYCHOSOCIAL EFFECTS ON THE LIVES OF MANY PATIENTS (LEDERBERG, 1980). THE TRUTH IS THAT THERE ARE MULTIPLE TYPES OF CANCER, MANY OF WHICH CAN TODAY BE EFFECTIVELY TREATED TO ELIMINATE, REDUCE OR SLOW DOWN ITS IMPACTS. THE DURATION OF DIAGNOSIS AND TREATMENT CAN BE A SIGNIFICANT PSYCHOLOGICAL DISTRESS, WHICH CAN HAVE BOTH DIRECT AND INDIRECT EFFECTS ON HEALTH (GANZ, 2002). DIFFERENTIATION OF PSYCHIATRIC MORBIDITY RELATED TO CANCER AS SUCH OR FROM ITS TREATMENT IS RARELY CLEAR. PSYCHIATRIC MORBIDITY ASSOCIATED WITH CANCER TREATMENT RANGES FROM 18 TO 40% ACCORDING TO THE TYPE OF TREATMENT (VYAS ET AL, 2000).

LOSS AND DEATH ARE UNIVERSAL FOR ALL LIVING THINGS. YET, PEOPLE ARE AFRAID OF DEATH OR DYING OR OF THE THOUGHT OF SUFFERING AS THEY DIE. PEOPLE ALSO USUALLY

FEAR THAT THEY WILL BE A BURDEN TO OTHERS IN THEIR FINAL YEARS OF LIFE OR THAT THEIR SPOUSE OR CHILDREN WHO ARE LEFT BEHIND WILL SUFFER. SOME RESEARCHERS HAVE THEORIZED THAT WOMEN HAVE A GREATER WILLINGNESS TO EXPRESS FEAR (CAIRNS, 1997). YOUNG PEOPLE ARE MORE FEARFUL OF DEATH THAN THE ELDERLY. THE CLINICIAN APPLIES PAST EXPERIENCES OF LOSSES TO UNDERSTAND THE FEELINGS THAT COME WITH A LOSS (CAIRNS, 1997). LOSS IS ASSOCIATED WITH DEPRESSION, ANXIETY AND SOMATIC COMPLAINTS. PEOPLE, WHO LOST THEIR HOMES, SOCIAL AND CULTURAL ENVIRONMENT DEMONSTRATED HIGH LEVELS OF ANXIETY AND DEPRESSION (KONDIC AND MARVAR, 1992). A HUMAN'S SOCIAL DEVELOPMENT OFFERS A UNIQUE INTERPRETATION OF LIFE'S EXPERIENCE. DEATH IS AN OVERWHELMING EXPERIENCE THAT AFFECTS EVERYONE EMOTIONALLY ATTACHED TO THE INDIVIDUAL. ACCORDING TO PSYCHOLOGISTS, THE VALUE OF INDIVIDUALS IS A UNIQUELY LEARNED RESPONSE FROM A SPECIFIC CULTURE AND SOCIETY (BINSTOCK AND SPECTOR, 1997). AGE, GENDER, STATUS, RACE, RELIGIOUS BELIEFS, INTELLECT, ACHIEVEMENT, SELF-EXPRESSION AND CULTURAL OPPORTUNITY ARE THE BASIS FOR AN INDIVIDUAL TO DEFINE AND QUALIFY THE DEFINITION OF LIFE AND DEATH (CRESSY, 1997).

STUDIES HAVE DEMONSTRATED THAT A VARIETY OF EMOTIONAL AND PHYSICAL EXPRESSIONS ARE ASSOCIATED WITH BEREAVEMENT (RAPHAEL, 1983). GENERALLY, THE FEARS OF DEATH IS AN UNHEALTHY AND UNREALISTIC AND AVOID THE THINKING, IGNORE THE SUBJECT, DENY IT, OR ON THE OTHER HAND, GET MORBIDLY OBSESSED BY IT AND THINK THAT LIFE IS MEANINGLESS (WWW.FEAR-OF-DEATH, 2009). MAJORITIES OF THE PEOPLE ASSOCIATE CANCER WITH PAINFUL DEATH. MORE PEOPLE HAVE FEAR OF DEATH BY CANCER THAN DEATH BY HEART DISEASE (US DEPARTMENT OF HEALTH, EDUCATION AND WELFARE, 1979). SUCH CANCER-PHOBIA, EXISTS BECAUSE DYING OF CANCER IS BELIEVED TO BE SLOW, PAINFUL AND UNPLEASANT (US DEPARTMENT OF HEALTH, EDUCATION AND WELFARE, 1979).

THERE IS CULTURAL VARIATION IN UNDERSTANDING AND DEALING WITH DEATH, DYING, AND THE PATIENT. HOWEVER, MOST PEOPLE FROM DIFFERENT CULTURES WISH TO BE INVOLVED IN THE CARE OF A DYING FAMILY MEMBER (WWW.FEAR-OF-DEATH, 2009). SOME

CULTURES PERCEIVE DEATH AS A CONTINUUM OF LIFE AND THEY FOLLOW CERTAIN RITUALS, CUSTOMS AND PRACTICES. KLEINMAN (1988) POINTS OUT THAT HELPING PROFESSIONAL SHOULD FULLY BE AWARE OF THE SPECIFIC CULTURAL REQUIREMENTS ASSOCIATED WITH DEATH AND BEREAVEMENT. HE PROVIDES A DETAIL DESCRIPTION OF FEELINGS OF MR. GORDON STUART (WRITER) AND MR. SONG MINGYUAN (SENIOR PHYSICIAN), BOTH DIED FROM CANCER. MR. SONG, A DOCTOR, WHO SHOULD BE WELL AWARE OF THE DISEASE, ITS PROGNOSIS AND STAGES, WHEREAS MR. GORDON WAS UNFAMILIAR ABOUT HIS DISEASE PROCESS BUT HIS DEATH IS CONSIDERED AS CULTURALLY 'GOOD DEATH' EVEN THOUGH HE WAS VERY YOUNG (33 YEARS OLD), BECAUSE HE WAS IN HIS COUNTRY AND OTHERS KNEW ABOUT HIS CULTURAL EXPECTATIONS. BUT DR. SONG WAS OUT OF HIS NATION (TAIWAN), HAD ONLY ONE FRIEND, WHO WAS VERY BUSY WITH HIS WORK. THERE WAS NO ONE TO PROVIDE CLOSE CARE (TENDER LOVING CARE) ACCORDING TO HIS CULTURALLY ACCEPTED EXPECTATIONS. HIS DEATH IS CONSIDERED AS A BAD DEATH, BECAUSE HE WAS UNABLE TO MEET HIS DESIRES AT THE END OF HIS LIFE. DEATH IS A UNIVERSAL PHENOMENON; YET THERE IS DIVERSITY IN PERSONAL AND SOCIAL EXPECTATIONS. THAT'S WHY PROPER CARE AT THE END OF ONE'S LIFE IS NEEDED TO MAINTAIN RESPECT OF THE INDIVIDUAL (KLEINMAN, 1988). PSYCHOSOCIAL FACTORS PLAYS MAJOR ROLE IN THE PROCESS OF DIAGNOSIS, TREATMENT AND END-OF-LIFE CARE OF THE CANCER PATIENTS.

2.2 DEMOGRAPHIC VARIABLES

IN GLOBAL SCENARIO, IT IS NOTED THAT DEMOGRAPHIC CHANGES ALONE WILL INCREASE THE NUMBER OF NEW CANCER CASES PER ANNUM TO ALMOST 13 MILLION BY THE YEAR 2015. HOWEVER, TAKING INTO CONSIDERATION EXPECTED INCREASES IN INCIDENCE OF CANCERS IN MALES SUCH SITES AS LUNG, COLON, RECTUM AND PROSTATE, AND IN FEMALES OF BREAST, COLON AND LUNG, THE REAL FIGURES MORE LIKELY TO BE AROUND 19 OR EVEN 20 MILLIONS. THIS WILL HAVE ADVERSE ECONOMIC AND SOCIAL CONSEQUENCES FOR ALL THE COUNTRIES. THE NEGATIVE EFFECTS OF THESE CONSEQUENCES ON THE WORLD AND NATIONAL HEALTH SITUATION AND THEIR SUSTAINABLE DEVELOPMENT WILL EXPONENTIALLY INCREASE BEING AUGMENTED BY THE PROJECTED DEMOGRAPHIC CHANGES

AND FURTHER DETERIORATION OF HUMAN ENVIRONMENT (WHO. N. D.). THE IMPLICATION AND CHALLENGE OF THE CURRENT DEMOGRAPHIC AND SOCIOECONOMIC FORECASTS IS DRAMATIC INCREASE OF DISABLED PEOPLE DUE TO CANCER AND WORSENING OF QUALITY OF THEIR LIFE. CANCER CONTRIBUTES A LARGE PART TO THE GLOBAL MORTALITY (>13%) AND TOTAL GLOBAL BURDEN OF DISEASE [ALMOST 6%] (NICOLAI, 2007).

GOLDBERG ET AL (1985) REVEALED THAT THERE WAS NO CONSISTENT ASSOCIATION BETWEEN AGES, SEX, MARITAL OR SOCIO-ECONOMIC STATUS WITH PSYCHOSOCIAL PROBLEMS IN THEIR STUDY. THE ADAPTATION AND THE PATIENT'S PSYCHOLOGICAL SITUATION SUCH AS DEGREE OF PESSIMISM OR ANXIETY, PERSONALITY CHARACTERISTICS, PRIOR EXPERIENCE WITH THE DEATH OF A CLOSE FRIEND OR RELATIVE OR RELIGIOUS BELIEFS HAVE BEEN INDECISIVE (GOLDBERG ET AL, 1985). IN CONTRAST, ANOTHER STUDY CONDUCTED BY THE CRESSY (1997) STATED THAT THE AGE, GENDER, STATUS, RACE, RELIGIOUS BELIEFS, INTELLECT, ACHIEVEMENT, SELF-EXPRESSION AND CULTURAL OPPORTUNITY ARE THE BASIS FOR AN INDIVIDUAL TO DEFINE AND QUALIFY THE DEFINITION OF LIFE AND DEATH (CRESSY, 1997).

Bernadine, David and Gloria (2002) conducted a cross-sectional study among 105 long-term survivors of breast cancer to determine the relationship between life-stage variables (ie, age at diagnosis and years of survival) and quality-of-life. The Quality of Life-Cancer Survivors (QOL-CS) scale was used to assess QOL outcomes in the physical, psychological, social, and spiritual domains. The study revealed that long-term survivors of breast cancer who had received diagnoses at an older age (> 65 years) showed significantly ($P < .05$) worse QOL outcomes in the physical domain, while those who had received diagnoses at a younger age (27–44 years) showed worse QOL outcomes in the social domain than other age groups. A nonlinear relationship was observed, with long-term survivors who had received diagnoses in middle age (45–65 years) showing better QOL outcomes in the physical domain and in overall QOL. Age at diagnosis and years of survival were significant predictors of QOL outcomes. Walker, Kohler, Heys and Eremin (1998) stated the relationship between age and psychosocial problems. Their study result has shown that older people are less distressed by the diagnosis of cancer than their younger counterparts. This maybe because older people have fewer dependants and they are less likely to suffer financial difficulties and to experience disruption to their daily routine following the diagnosis (Walker, Kohler, Heys and Eremin, 1998).

A STUDY CONDUCTED BY GOODWIN ET AL (2004) AMONG OLDER WOMEN WITH BREAST CANCER, THE STUDY RESULT SHOWN THAT A RECENT DIAGNOSIS OF DEPRESSION WAS ASSOCIATED WITH NOT RECEIVING DEFINITIVE CANCER TREATMENT AND POORER SURVIVAL (GOODWIN ET AL, 2004). ANOTHER STUDY ALSO DONE AMONG BREAST CANCER PATIENTS, WHICH REVEALED THAT, THERE WERE VARIETY OF RESPONSES TO THEIR DIAGNOSIS AND DIFFERENT TRAJECTORIES IN ADJUSTMENT. MOST OF THE RESEARCH PARTICIPANTS IN THEIR STUDY SHOWED SOME IMPROVEMENT IN THEIR FUNCTIONING AFTER SOMETIME; ALONG WITH THE TIME GAP OLDER WOMEN DISPLAYED BETTER PHYSICAL ADJUSTMENT THAN THE YOUNGER BREAST CANCER PATIENTS (HELGESON, SNYDER AND SELMAN (2004) CITED IN BRANNON AND FEIST, 2007). PREVIOUS FINDINGS ARE SUPPORTED BY THE KLEINMAN (1988), WHICH ILLUSTRATED THAT YOUNG WOMEN ARE FEELING DEMORALIZED BY THE DISFIGURING WHO HAD DONE MAJOR SURGERY. YOUNG WOMEN FELT THAT THEY REMOVE THEIR SENSE OF SELF-ESTEEM ALONG WITH BREAST CANCER (KLEINMAN, 1988). INFORMATION COLLECTED BY THE MEDIA PEOPLE REPORTED THAT YOUNG PEOPLE ARE MORE FEARFUL OF DEATH THAN THE ELDERLY (BROTMAN, 2006).

ALTHOUGH THERE IS A RECENT TREND TOWARDS MORE ELDERLY PATIENTS PARTICIPATING IN ONCOLOGY TREATMENT TRIALS, YET, THERE IS A GREAT SHORTAGE OF INFORMATION ABOUT THE ACCEPTABILITY AND EFFECTIVENESS OF PSYCHOSOCIAL INTERVENTIONS IN ELDERLY PATIENTS (WALKER ET AL, 1998). OTHER HAND, YOUNG PEOPLE ARE UNDER SHADOW AND THERE IS LACK OF INFORMATION WITH REGARDS.

Stagno et al (2005) reported that women have higher risk of depression as compared to men. The study also mentioned that women reported more fear of death than men (Stagno et al, 2005). Kleinman (1988) revealed that females are generally more flexible under stress, have an easy-going temperament and a strong internal locus of control to cope with stress (Kleinman, 1988). The studies related to effects of social support are very less among men as compare to women with cancer. This phenomenon may be related to recurrent findings that males report not needing or wanting as much support as their female counterparts (Markwood et al, 2003).

A meta-analysis of existing evidence conducted by Tamre, Janicki and Helgeson (2002) suggested that men and women may indeed prefer different tactics for handling stress. Results of this careful study indicate that overall women use a wider range for coping strategies than men do, including both problem-focused (e.g. active coping, planning) and emotion-focused (seeking social support, positive reappraisal, venting, rumination) strategies. In addition, women are more likely to use strategies that involve verbal expressions to others or the self to ruminate about the contrast; men are more likely to use avoidance of problems or withdrawal from them than are women. Interestingly, there isn’t strong evidence that men are more likely to attack problems head-on than are women. Tamre, Janicki and Helgeson (2002) also suggested that the basis for gender differences in coping with stress may reflect contrasting gender roles. Women are expected by society to turn to others for support during times of stress, while men are not, and these expectations may become self-conforming. Another possibility, the one supported by some findings obtained in same study, is that women tend to perceive many stressors as more severe than men do (Baron, Byrne and Branscomble, 2008).

Low level of education can contribute to the development of depression among cancer sufferers (Somerset et al, 2004). High intelligence is positively associated to coping with stress (Kleinman, 1988).

NATIONAL CANCER INSTITUTE ALSO HIGHLIGHTED THAT THE IMPACT OF THE CANCER CAN ALSO COMPOUND THE CHALLENGES OF EVERYDAY LIFE, FOR INSTANCE, TO MARITAL RELATIONSHIPS AND DIFFICULTIES OR TO FAMILY COMMUNICATIONS ISSUES. KLEINMAN (1988) REPORTED THAT VARIOUS INDICATORS OF SOCIAL RELATIONSHIPS PREDICTED MORTALITY RISK. MARITAL STATUS IS A KEY COMPONENT OF MOST INDICES THAT SEEK TO MEASURE SOCIAL SUPPORT AND HAS BEEN THE MOST STUDIED ASPECT OF SOCIAL RELATIONSHIPS. MARRIED PEOPLE CONSISTENTLY HAVE LOWER DEATH RATES THAN UNMARRIED PEOPLE (KLEINMAN, 1988). THE PREVIOUS STATEMENT IS SUPPORTED BY THE FINDINGS OF CARTER AND GLICK (1970), IN THEIR STUDY THEY FOUND A LONGER LIFE

EXPECTANCY IN MEN, WHO WERE MARRIED THAN IN THEIR SINGLE COUNTERPARTS (CARTER AND GLICK, 1970).

In contrast, Saito-Nakaya et al (2004) suggested that marital status and social support are associated with survival in cases of lung cancer and that such an association may be mediated by several factors. Researchers were investigated the effect of marital status and social support on survival after curative resection for non-small cell lung carcinoma (NSCLC) in Japan from June 1996 to April 1999. The study result showed that there is no relation between marital status and social support (Saito-Nakaya et al, 2004). However, some positive influence of marital factor on cancer recovery rate, yet much study are not being done among cancer patients.

ILLNESS IS DEEPLY EMBEDDED IN THE SOCIAL WORLD, AND CONSEQUENTLY IT IS INSEPARABLE FROM THE STRUCTURES AND PROCESSES THAT CONSTITUTE THE WORLD. FACTORS THAT INCREASE THE ABILITY TO COPE WITH STRESS INCLUDE THE FAMILIES WITH A HIGH SOCIO-ECONOMIC STATUS (KLEINMAN, 1988). IN FACT, SOCIO-CULTURAL AND ECONOMIC ALONG WITH OTHER FACTORS ARE MANIFESTED IN MAKING ILLNESS A PART OF A FAMILY'S CONSTRUCTION OF REALITY.

EPIDEMIOLOGICAL STUDIES REGULARLY INCLUDE THE CATEGORY OF SOCIAL CLASS OR SOCIO-ECONOMIC STATUS WITH A LITTLE THOUGHT AS THE CATEGORY OF SEX. THE LARGE SOCIAL DIFFERENCES IN MORTALITY IN MANY SOCIETIES ANALYZED BY SOCIAL CLASS ARE CRUCIAL. THE SOCIAL FORCES AFFECTING HEALTH ARE EXPRESSED IN CLASS TERMS. THIS DIVISION INTO CLASSES ENCOMPASSES ECONOMIC, POLITICAL AND CULTURAL DIFFERENCES, ALL OF WHICH MAY AFFECT HEALTH. SOCIAL TIES CAN BE DESCRIBED IN TERMS OF THEIR CONTENT, WITH SOCIAL SUPPORT INVOLVING EXCHANGES OF EMOTIONAL CONCERN, INFORMATION AND INSTRUMENTAL ASSISTANCE, AND IS PROBABLY THE CENTRAL HEALTH-ENHANCING ASPECT OF RELATIONSHIPS. THERE ARE OTHER TWO COMPONENTS OF RELATIONSHIPS VIZ. SOCIAL CONFLICT AND SOCIAL CONTROL. FIRST, SOCIAL RELATIONSHIPS ARE OFTEN UNPLEASANT OR CONFLICTIVE, AND MODEST EVIDENCE INDICATES THAT THESE NEGATIVE ASPECTS OF RELATIONSHIPS ARE MORE STRONGLY LINKED TO PSYCHIATRIC MORBIDITY THAN IS SOCIAL SUPPORT. SECOND, SOCIAL TIES ALSO CONTROL PEOPLE SOCIALLY. THIS

REGULATORY OF RELATIONSHIPS CAN EITHER IMPROVE OR WORSEN HEALTH DEPENDING ON THE PARTICULAR BEHAVIOR THAT IS FACILITATED OR RESTRAINED. THE DISTRIBUTION OF HEALTH-ENHANCING SOCIAL RESOURCE IS SHAPED BY BROADER PROCESSES AND STRUCTURES. NEVERTHELESS, THE EVIDENCE AVAILABLE IN THE UNITED STATES STRONGLY SUGGESTS THAT THE QUANTITY AND QUALITY OF SOCIAL TIES ARE LINKED TO SEX, SOCIOECONOMIC STATUS AND RACE (MARMOT ET AL, 1991).

Family is considered as a small unit of social system and their problems are interlocking that means each family must make sense of their experience, and responsibility. The ability to cope with stress including the availability of adult members and their role in the family, who exhibit warmth, affection; and maybe bread earner for the family. If the cancer patients are earners have dependents, and they are likely to suffer financial difficulties and to experience disruption to their daily routine following the diagnosis. Schag et al (1994) reported that in comparison with other cancer survivors, lung cancer survivors had more problems, including difficulty working and disruptions in day-to-day activity (Schag, et al. 1994). Role of the cancer patient in their family is considered as vital in their day-to-day life, yet there is lacks of researches in this field.

2.3 DISEASE VARIABLES

CANCER IS NOT ONLY A MEDICAL PROBLEM; CANCER PATIENTS ARE CONFRONTED WITH A VARIETY OF PHYSICAL, EMOTIONAL, AND SOCIAL ISSUES THAT, IF LEFT UNCHECKED OR IGNORED, CAN RAPIDLY CONTRIBUTE TO DIMINISHED QUALITY OF LIFE. PSYCHOSOCIAL FACTORS HAVE BEEN FOUND TO BE CLOSELY LINKED WITH ILLNESS RELATED CONDITIONS. IT IS NOTED THAT ILLNESS REDUCES THE CONFIDENCE LEVEL OF THE PATIENT LEADING TO HOPELESSNESS (KLEINMAN, 1988) HOWEVER, THE PROCESS IS PROMINENT IN CHRONIC ILLNESS LIKE CANCER WHERE GENERALLY ONE STARTS LOSING CONFIDENCE IN ONE'S GENERAL HEALTH, ADAPTABILITY OF BODILY PROCESSES, AND SUBJECTIVE SENSE OF WELL-BEING. STUDIES INDICATE THAT PSYCHOSOCIAL DISTRESS IS AGGRAVATED BY DECLINING PHYSICAL ABILITIES (CASSILETH, 1985) AS WELL AS THE PROCESS OF TREATMENT (KLEINMAN, 1988; SOMERSET ET AL, 2004) WHICH MAY RANGE FROM TIME SPENT TRAVELING, APPOINTMENT, LABORATORY TESTS, AND HOSPITALIZATION TO MULTI-MODALITY

TREATMENT THAT RANGE FROM SURGERY, RADIO-THERAPY, CHEMO- THERAPY. SUCH PROCESSES ESPECIALLY THE LENGTH OF THERAPY IS NOTED TO INCREASE THE RISKS OF DEPRESSION (SOMERSET ET AL, 2004). IT IS FOUND, IN ONE STUDY, THAT 89% OF INDIVIDUALS UNDERGOING CHEMOTHERAPY REPORTED FATIGUE AND 71% REPORTED SLEEP DISTURBANCE WHICH CAN IMPAIR AN INDIVIDUAL'S ABILITY TO FUNCTION IN THEIR USUAL ACTIVITIES AND DIMINISH THEIR QUALITY OF LIFE DURING TREATMENT (BARSEVICK, DUDLEY, BECK, 2006).

2.4 PSYCHOSOCIAL FACTORS

The term psychosocial is stated as pertaining to the influence of social factors on an individual's mind or behavior and to the interrelation of behavioral and social factors (Simpson and Weiner, 1991). Psychosocial impression varies with the social, economic and cultural contexts of different countries and their social standards and value systems. These factors include cultural values, customs, habits, beliefs, attitudes, morals, religion, education, lifestyles, community life; health services, social and political organization (Park, 2007). While, personality characteristics, stressful life events and socio-cultural issues have been implicated both in pathogenesis of cancer and in attitudes in seeking care (Park, 2002). Psychosocial factors have become an area of increasing concern in cancer process as it has been found out that they have an impact at all stages of the cancer - prior to detection, at the time of detection, during treatment and rehabilitation in almost all cases in the care of the terminally ill patients (Park, 2002). However, the development process of cancer, diagnosis and treatment seeking behavior is not aim of this study as study is being done during and after treatment completed.

Risk factors for higher levels of distress have been identified and there is an emerging consensus on the psychosocial issues. Although clinical practice in this area is inevitably informed by work on the identification and management of psychosocial morbidity among the physically ill in general, there are some aspects of psychosocial studies of cancer that can be usefully isolated from the vast literature and applied in everyday practice on cancer patients (Mehta, 1998). Assessing and understanding the meaning of cancer is helpful in integrating an awareness of information provision, family support and coping strategy enhancement (White, 2006). Patients who approach their cancer with positive attitudes and peaceful acceptance have longer survival rates than those patients who react with negative emotions like depression, cynicism or helplessness (White, 2006).

Robert and others (2010) have conducted study on psychosocial and functional outcomes in long-term survivors of bone cancer patients. Researchers found that patients with more functional lower limbs had better quality of life than did those with less functional lower limbs regardless of types of surgery (Robert, et al., 2010).

PSYCHOSOCIAL PROBLEMS AND THEIR RESULTING CONSEQUENCES SUCH AS ANXIETY, DEPRESSION, WORRY, MARITAL/PARTNER DIFFICULTIES, SEXUAL PROBLEMS, AND INTERPERSONAL COMMUNICATION PROBLEMS OCCUR WITH CONSIDERABLE FREQUENCY IN CANCER PATIENTS. THESE PROBLEMS ARE LESS OBVIOUS THAN PHYSICAL DIFFICULTIES AND ARE LESS LIKELY TO BE ACKNOWLEDGED BY THE PATIENT AND/OR CARE PROVIDERS. PSYCHOSOCIAL PROBLEMS TEND TO FLUCTUATE WITH THE CLINICAL COURSE OF THE DISEASE (CASSILETH, 1985). SEVERAL OBSERVATIONS HAVE REVEALED THAT PEOPLE SUFFERING FROM CANCER REPORTED ADJUSTMENT PROBLEMS, LOW SELF-ESTEEM, FREQUENT WORK PROBLEMS, INCLUDING FEAR, SHAME, DISCRIMINATION, DEPRESSION, ANXIETY, AND A TENDENCY TO BE SECRETIVE ABOUT THEIR DIAGNOSIS (NYSMITH, 1983). THERE IS CONTRADICTORY VIEW REGARDING INFLUENCE OF PSYCHOSOCIAL FACTORS ON THE LENGTH OF SURVIVAL (DONAGAN, 1988) BUT IT IS POSITIVE THAT PSYCHOSOCIAL FACTORS WILL CERTAINLY MAKE IT EASIER TO COPE WITH TREATMENT AND IMPROVE THE OF QUALITY OF LIFE (ALLEN, 2002).

Morasso et al. (1996) has conducted a study on screening for psychological distress among 434 cancer patients by using Psychological Distress Inventory (PDI). The study result revealed that 62.6% of the patients diagnosed with a psychiatric distress according to the ICD-X criteria. Based on literatures, risk factors for higher levels of cancer distress depend upon: 1. Characteristics of the individual – patients who are young, single, separated, divorced or widowed, living alone or children younger than 21 years, having faced economic hardship, lack of social support or perceived poor social support, having poor marital or family functioning, history of psychiatric problems, cumulative stressful life events, and history of alcohol or other substance abuse have higher risk factors; and 2. Characteristics/stages of disease and treatment - risk factors are different at the time of diagnosis and recurrence, during advanced stage of the disease, poorer prognosis, more treatment side effects, greater functional impairment and disease burden, experiencing lymph-edema, experiencing chronic pain, and fatigue (Watson et al, 2003).

On the other hand, study of Goldberg et al (1985) has revealed existence of wide range of emotional reactions among cancer patients. Certain types/sites of cancer have been noted to be associated with psychosocial problems. For example, lung, pancreatic cancer, etc. have a specific biological basis for psychosocial problems. In addition, to types/sites of cancer, a number of chemotherapy agents are also now recognized as accounting for presumed symptoms of psychosocial problems (Goldberg et al, 1985).

Most of the cancer patients cope with their psychosocial difficulties. However, some need professional interventions (Derogatis, 1983). Ross et al. (2002) evaluated the scientific evidence for effect of psychosocial intervention on survival from cancer, their well-being, anxiety and depression. A literature search yielded 43 randomized studies of psychosocial intervention where a significant effect of anxiety and depression, though inconsistent, was noted and some of intervention strategies were found to affect the prognosis yet a large scale of study with sound method is suggested (Ross et al, 2002).

APART FROM COUNSELING INTERVENTION TO CANCER PATIENTS, A HORDE OF STUDIES ARE BEING CONDUCTED ON PSYCHOSOCIAL SUPPORT AND CARE. WORLD HEALTH ORGANIZATION (WHO) IS ALSO PAYING ATTENTION FOR SUPPORTIVE METHODS FOR GOOD PSYCHOSOCIAL CARE. THE FIRST PRINCIPLE IS THAT CARE IS FAMILY CENTERED, BASED ON THE FAMILY'S NEED. AN IMPORTANT ASPECT IS INVOLVEMENT IN DECISION MAKING AND IN PROVIDING COMFORT. CARE PROVIDERS NEED A RECEPTIVE ENVIRONMENT AND THEY MAY NEED INSTRUCTION IN HOW BEST TO HELP. THE IMPORTANCE OF FAMILY IS ENSURING THE GENERAL HEALTH AND WELL BEING OF THE CANCER PATIENT. ANOTHER ELEMENT OF FAMILY-CENTERED CARE IS MAKING THE CLINIC OR HOSPITAL ENVIRONMENT FRIENDLY TO FAMILIES. THIS WILL INCLUDE HAVING LIBERAL VISITING HOURS AND A PHYSICAL ATMOSPHERE WHICH IS CONDUCTIVE TO FAMILY PARTICIPATION. THROUGHOUT THE WORLD, CULTURALLY-SPECIFIC PAIN REDUCTION TECHNIQUES OR FOLK REMEDIES ARE USED (WHO, NO DATE). THEY REFLECT THE TRADITIONAL WISDOM, LOYALTIES, AND TRUST OF A FAMILY, AND THE SOCIAL SANCTUMS OF A COMMUNITY. IT IS IMPORTANT TO RESPECT FOLK REMEDIES AND TO ESTABLISH THEIR COMPATIBILITY WITH TREATMENT, TAKING CARE NOT TO ISOLATE THE FAMILY. IF THE FAMILIES ARE NOT ACCURATELY INFORMED ABOUT THE DIAGNOSIS AND TREATMENT PLAN, THEY CANNOT PARTICIPATE. INFORMATION IS ACCEPTED BEST IF IT IS TAILORED TO THE NEEDS OF THE PATIENT AND FAMILY. HEALTH CARE PROVIDERS SHOULD INDIVIDUALIZE THEIR APPROACH, DEPENDING ON THE FAMILY'S STYLE.

IT IS BEST TO PROVIDE INFORMATION EMPATHETICALLY, IN SMALL DOSES AND REPEATED FREQUENTLY AS NEEDED (WHO, NO DATE). THESE ARE THE FACTORS WHICH ARE TAKEN INTO CONSIDERATION IN THIS STUDY.

ALTHOUGH SCIENCE HAS MADE GREAT PROGRESS AGAINST CANCER, A CANCER DIAGNOSIS CONTINUES TO AWAKEN FEAR AND APPREHENSION. DIANE BLUM (1997),[1] EXECUTIVE DIRECTOR OF CANCER CARE, INC. SAID "PROVIDING SUPPORT TO THESE PATIENTS AND THEIR FAMILIES IS A CRITICAL STEP IN DEALING WITH CANCER AND A KEY COMPONENT IN THE QUALITY OF LIFE OF PATIENTS."

2.4.1 COPING

A BEHAVIORAL PATTERN FACILITATES ADJUSTMENT TO THE ENVIRONMENT FOR THE PURPOSE OF ATTAINING SOME GOAL. COPING MEANS THAT THE PERSON COMES TO THE TERM WITH STRESSES AND MAKES USE OF OPPORTUNITIES AND ALSO THE UNIQUE ORGANIZATION SUGGESTED BY THE VARIOUS MEANS EMPLOYED BY THE PERSON IN ADAPTIVE EFFORTS. WITH RARE EXCEPTIONS, THE CONSEQUENCES OF COPING ARE NOT INFLUENCED BY THE HANDLING OF A SINGLE ENCOUNTER, BUT RATHER ON THE EXTENT TO WHICH COPING HAS BEEN EFFECTIVE OVER THE LONG RUN IN MANY STRESSFUL ENCOUNTERS AND ARENAS OF LIVING. TO CONTRIBUTE TO DISEASE, INCOMPETENCE MUST OCCUR REPEATEDLY OR CHRONICALLY, AS IT WERE, AND PROBABLY OVER A LONG PERIOD OF TIME (LAZARUS AND FOLKMAN, 1984).

COPING IS THE PROCESS OF CONTENDING WITH DIFFICULTIES IN LIFE IN AN EFFORT TO OVERCOME OR WORK THROUGH THEM. COPING MECHANISMS ARE CONSCIOUS OR UNCONSCIOUS STRATEGIES OR MECHANISMS THAT A PERSON USES TO ADJUST WITH STRESS OR ANXIETY. COPING IS AN IMPORTANT INGREDIENT IN ABILITY OR INABILITY TO COPE WITH A STRESSFUL SITUATION. LAZARUS AND FOLKMAN (1984) DEFINED COPING AS "CONSTANTLY CHANGING COGNITIVE AND BEHAVIORAL EFFORTS TO MANAGE SPECIFIC EXTERNAL AND/OR

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[1] National Cancer Institute Press Office, Tuesday, April 22, 1997

INTERNAL DEMANDS THAT ARE APPRAISED AS TAXING OR EXCEEDING THE RESOURCES OF THE PERSON" (BRANNON AND FEIST, 2007 : 127)

THE TERM 'COPING' USUALLY SUGGESTS THAT THE SUBJECT IS REACTING AS ADAPTIVELY AS POSSIBLE TO A DIFFICULT SITUATION. COPING MEANS THE WAYS OR MEANS THE PERSON CAN ADAPT TO KEEP STRESS AT MANAGEABLE LEVELS. FOLLOWING SERIOUS LIFE EVENTS OR THREATS LIKE CANCER, EMOTIONAL EXCITATION INCREASES AND THE INDIVIDUAL MAY FEEL DISORGANIZED OR OUT OF CONTROL. TO AVOID EXCESSIVELY PAINFUL OR HELPLESS STATES OF MIND, VARIOUS SELF-REGULATORY PROCESSES OCCUR TO KEEP THE PERSON UNDER CONTROL. THE IDEAL COPING MECHANISM IS TO SOLVE THE PROBLEM AND THUS SURVIVE THE THREAT, BUT THE OPERATIONAL GOAL IS OFTEN TO MAINTAIN A SENSE OF EQUILIBRIUM WITHOUT BEING FLOODED WITH UNWANTED LEVEL OF EMOTIONS (GOLDMAN, 1988).

ATTITUDES AND PERCEPTIONS ARE MAJOR FACTORS THAT DETERMINE THE ABILITY TO COPE WITH STRESS. OTHER FACTORS INCLUDE GENETICS, A GOOD SENSE OF HUMOR, A WELL-BALANCED AND NUTRITIOUS DIET, REALISTIC GOAL SETTING, PLENTY OF SLEEP, THOROUGH JOB PREPARATION, FINANCIAL SECURITY, STABILITY AT HOME, AN UNDERSTANDING OF STRESS, AND USE OF RELAXATION SKILLS. MORE DOCUMENTED PROTECTIVE FACTORS INCLUDE HIGH SELF-ESTEEM, LEARNING TO BE FLEXIBLE AND INNOVATIVE IN SOLUTIONS, CLOSE PERSONAL RELATIONSHIPS, HAVING SUCCESS/MASTERY EXPERIENCES, SELF-DISCIPLINE (INCLUDING GOOD CONTROL OF TIME), POSITIVE EXPECTANCY (HOPE) AND HUMOR (KLEINMAN, 1988).

An adequate knowledge of the world, having inner resources and control over life events; and having social support, and a spiritual orientation to oneself and the world is proven to have a direct affect on mortality rate (Reddick et al, 2005). Coping skills are an individual's attempt to resolve life stresses and emotional pain.

THERE HAVE BEEN DIFFERENT OBSERVATIONS ASSOCIATED WITH POSITIVE PSYCHOLOGICAL STATES BUT ALL SHARED THE COMMON UNDERLYING THEME OF 'SEARCHING FOR AND FINDING POSITIVE MEANING'. PATIENTS MAY REPORT EVIDENCE OF STRENGTHENED

RELATIONSHIPS AND POSITIVE CHANGES IN PERSONAL CHARACTERISTICS, SUCH AS TOLERANCE, AND MODIFICATIONS TO LIFE GOALS AND PRIORITIES. POSITIVE MEANING SEEMS TO BE RELATED TO A NUMBER OF POSITIVE PSYCHOLOGICAL OUTCOMES IN TERMS OF LESS NEGATIVE AFFECT AND DISTRESS AND A FEWER INTRUSIVE THOUGHTS (FOLKMAN, 1984).

ADAPTING TO CHRONIC DISEASE INCLUDES DEALING WITH THE SYMPTOMS OF THE DISEASE, MANAGING THE STRESSES OF TREATMENT, LIVING LIFE AS NORMAL AS POSSIBLE AND FACING THE POSSIBILITY OF DEATH. ADJUSTMENT TO SOME CHRONIC DISEASES LIKE CANCER IS MORE DIFFICULT THAN OTHERS BECAUSE OF SYMPTOM SEVERITY AND THE DEMANDS OF COPING WITH SYMPTOMS (BRANNON AND FEIST, 2007).

JIM ET AL (2006) SUGGESTED THAT THE SEARCH FOR MEANING IN LIFE IS A PART OF THE HUMAN EXPERIENCE. A NEGATIVE LIFE EVENT MAY THREATEN PERCEPTIONS ABOUT MEANING IN LIFE, SUCH AS THE GENEROSITY OF THE WORLD AND ONE'S SENSE OF HARMONY AND PEACE. THERE HAVE BEEN OBSERVATIONS DONE TO EXAMINE THE LONGITUDINAL RELATIONSHIP BETWEEN WOMEN'S COPING WITH A DIAGNOSIS OF BREAST CANCER AND THEIR SELF-REPORTED MEANING IN LIFE. MULTIPLE REGRESSION ANALYSES REVEALED THAT POSITIVE STRATEGIES FOR COPING PREDICTED SIGNIFICANT VARIANCE IN THE SENSE OF MEANING IN LIFE-FEELINGS OF INNER PEACE, SATISFACTION WITH ONE'S CURRENT AND THE FUTURE LIFE. SPIRITUALITY, FAITH AND THE ABSENCE OF SUCH STRATEGIES PREDICTED REPORTS OF CONFUSION (JIM ET AL, 2006).

COSTANZO ET AL (2006), WHO EXAMINED THE USE OF ENGAGEMENT AND AVOIDANT COPING STRATEGIES AMONG ADVANCED-STAGE GYNECOLOGIC CANCER PATIENTS, WHO WERE FACING THE LONG-TERM STRESSORS OF EXTENSIVE CHEMOTHERAPY AND ADVANCED DISEASE IN USA. THEIR STUDY RESULTS SUGGESTED THAT COPING PATTERNS AND ITS OUTCOMES MAY BE MORE EVIDENT AMONG CANCER PATIENTS AS CHALLENGING WITH LIFE THREATENING DISEASE AND EXTENSIVE TREATMENT AND THAT AVOIDANT COPING STRATEGIES MAY BE PARTICULARLY HARMFUL WITH RESPECT TO THESE PATIENTS' QUALITY OF LIFE.

Wilkinson (2000) and De Raeve (1997) stated that there is little evidence regarding coping styles, which play an important part in survival of the cancer patients. This is an important finding because often there is a pressure on patients with cancer to engage in "positive thinking," and this may add to their psychological burden (Wilkinson, 2000; and De Raeve, 1997).

THERE HAVE BEEN SOME OBSERVATIONS RELATED TO PATIENT'S COGNITIVE AND BEHAVIORAL COPING RESPONSES TO THE DIAGNOSIS WHICH MAY ACCOUNT FOR INDIVIDUAL DIFFERENCES IN PSYCHOLOGICAL ADAPTATION. STUDIES ABOUT COPING WITH CANCER HAVE PRODUCED INCONSISTENT AND OFTEN CONTRADICTORY FINDINGS. AN EARLIER STUDY INDICATED THAT THE PSYCHOLOGICAL RESPONSES SHOWN BY PATIENTS FOLLOWING THE DIAGNOSIS AFFECTED THE LENGTH OF SURVIVAL FROM 5 TO 10 YEARS. SEVERAL OTHER STUDIES HAVE ALSO CONCLUDED THAT THE NATURE OF PSYCHOLOGICAL RESPONSE MAY AFFECT THE COURSE OF THE DISEASE AND IN PARTICULAR HAVE FOUND THAT AN "ACTIVE" RATHER THAN "PASSIVE" COPING STYLE IS CONDUCTIVE TO LONGER SURVIVAL (CITED IN VYAS ET AL, 2000).

STAVARKY ET AL (N.D.) FOUND THAT AN UNFAVORABLE OUTCOME WAS ASSOCIATED WITH HOPELESSNESS OR "GIVING UP", IN PATIENTS WITH A VARIETY OF CANCER TYPES. WEISMAN AND WORDEN (N.D.) STUDIED PATIENTS WITH MALIGNANT MELANOMA, HODGKIN'S DISEASE AND CANCER OF LUNG, BREAST AND COLON FOR 18 MONTHS AND FOUND THAT LONGER SURVIVORS HAD CLOSE PERSONAL RELATIONSHIPS, WERE LESS EMOTIONALLY DISTRESSED, COMPLAINED LESS AND COPED BETTER WITH ILLNESS- RELATED PROBLEMS THAN SHORTER SURVIVORS (CITED IN VYAS ET AL, 2000).

IN CONTRAST, DEROGATIS ET AL (1983) FOUND THAT LONGER SURVIVORS SHOWED MORE EMOTIONAL DISTRESS, A TENDENCY TO "EXTERNALIZE CONFLICTS" AND POORER ADJUSTMENTS THAN PATIENTS WITH RECURRENCE OR WHO DIED LATER. HOWEVER, CASSILETH ET AL (N.D.) FOUND THAT PSYCHOLOGICAL ADJUSTMENT IS NOT AN IMPORTANT CONTRIBUTORY FACTOR TO THE OUTCOME (CITED IN VYAS ET AL, 2000).

RECENT STUDIES SUGGEST AN ASSOCIATION BETWEEN MALADAPTIVE COPING STYLES WITH HIGHER LEVELS OF DEPRESSION, ANXIETY, AND FATIGUE SYMPTOMS. EXAMPLES OF MALADAPTIVE COPING BEHAVIORS INCLUDE AVOIDANT OR NEGATIVE COPING, NEGATIVE SELF-COPING STATEMENTS, PREOCCUPATION WITH PHYSICAL SYMPTOMS, AND CATASTROPHIZING. ONE STUDY CONDUCTED IN A GROUP OF 86 MOSTLY LATE-STAGE CANCER PATIENTS SUGGESTED THAT MALADAPTIVE COPING STYLES AND HIGHER LEVELS OF DEPRESSIVE SYMPTOMS ARE POTENTIAL PREDICTORS OF THE TIMING OF DISEASE PROGRESSION (REDDICK ET AL, 2005). ANOTHER STUDY EXAMINING COPING STRATEGIES IN WOMEN WITH BREAST CANCER CONCLUDED THAT PATIENTS WITH BETTER COPING SKILLS SUCH AS POSITIVE SELF-STATEMENTS HAVE LOWER LEVELS OF DEPRESSIVE AND ANXIETY SYMPTOMS. THE SAME STUDY FOUND RACIAL DIFFERENCES IN THE USE OF COPING STRATEGIES, WITH AFRICAN AMERICAN WOMEN REPORTING AND BENEFITING FROM MORE RELIGIOUS COPING STRATEGIES SUCH AS PRAYER AND HOPEFULNESS THAN CAUCASIAN WOMEN (EDWARDS AND CLARKE, 2004).

There have been some evidence regarding timeline/duration of illness and coping. A study was conducted among head and neck cancer (HNC) by using different psychological measurements (tools) which was focused on the relations between personality factors, coping styles, informational needs, illness representations, and outcomes using a longitudinal study design. Coping strategies employed and levels of satisfaction with information before treatment were significant predictors of several outcomes (Llewellyn et al, 2007).

THERE HAVE BEEN DIFFERENT OBSERVATIONS BY DIFFERENT RESEARCHERS REGARDING THE RELATIONSHIP BETWEEN RELIGIOUS/SPIRITUAL AND COPING WITH CANCER. ACCORDING TO THUNE-BOYLE ET AL (2006) PRESENTED THE PAPER OF SYSTEMATICALLY REVIEWED STUDIES EXAMINING THE POTENTIAL BENEFICIAL OR HARMFUL EFFECTS OF RELIGIOUS/SPIRITUAL ON COPING WITH CANCER. RELIGIOUS/SPIRITUAL COPING MAY ALSO SERVE MULTIPLE FUNCTIONS IN LONG-TERM ADJUSTMENT TO CANCER SUCH AS MAINTAINING SELF-ESTEEM, PROVIDING A SENSE OF MEANING AND PURPOSE, GIVING EMOTIONAL COMFORT AND PROVIDING A SENSE OF HOPE. OUT OF SEVENTEEN PAPERS MET THE INCLUSION CRITERIA OF WHICH SEVEN FOUND SOME EVIDENCE ON THE BENEFICIAL EFFECT OF RELIGIOUS COPING,

AND ONLY ONE OF THESE ALSO FOUND RELIGIOUS COPING TO BE NEGATIVE IN A SUB-SAMPLE OF THEIR POPULATION (THUNE-BOYLE ET AL, 2006). ANOTHER STUDY CONDUCTED BY KAPPELI (2005) ON RELIGIOUS COPING STYLES AMONG CHRISTIAN AND JEWISH PATIENTS SUFFERING FROM CANCER. THE ANALYSIS SHOWS THAT PATIENTS OF BOTH RELIGIOUS USED THE SAME FIVE COPING STRATEGIES. THIS RESEARCH DEMONSTRATES THAT FOR MOST PATIENTS-THOUGH NOT FOR ALL-RELIGIOUSNESS HAS GREAT POTENTIAL AS A RESOURCE TO HELP THEM COPE IN POSITIVE WAYS WITH CANCER (KAPPELI, 2005).

MANY STUDIES ON FAMILY STRESSES HAVE FOUND THAT FAMILY COPE BY THE SAME BASIC MEANS AS AN INDIVIDUAL DOES- BY TAKING ACTIONS AND CHANGING THEIR ATTITUDES, BOTH TO SOLVE THE PROBLEMS AND TO MAKE THEM FEEL BETTER (MEHTA, 1998).

THERE HAVE BEEN DIFFERENT STUDIES BY DIFFERENT RESEARCHERS REGARDING THE RELATIONSHIP BETWEEN COPING AND QUALITY OF LIFE. LITERATURES REVEALED THAT THE CANCER PATIENTS WHO WERE FACING THE LONG-TERM STRESSORS OF EXTENSIVELY-TREATED, ADVANCED STAGE OF DISEASE AND HAVING PHYSICAL DIFFICULTIES WERE FOUND TO BE DIFFICULT TO COPE. MAJORITIES OF THE CANCER PATIENTS WERE UTILIZED MORE FREQUENTLY BOTH ENGAGEMENT AND AVOIDANT STRATEGIES INCLUDING ACTIVE COPING, SEEKING SOCIAL SUPPORT, AND MENTAL DISENGAGEMENT, WHICH HAS SIGNIFICANT RELATIONSHIP WITH QUALITY OF LIFE.

2.4.2 SOCIAL SUPPORT

SINCE 1980S, DESPITE THE AGREEMENT ON THE VITAL ROLE OF SOCIAL SUPPORT ON INDIVIDUAL'S PSYCHOLOGICAL AND PHYSIOLOGICAL FUNCTIONING, RESEARCHERS WERE SKEPTICAL ON THE PROPER DEFINITION OF SOCIAL SUPPORT. TODAY, MANY ACCEPT ON CHARACTERISTICS FOUND IN SOCIAL SUPPORT. BASED ON IT, THEY HAVE AGREED ON ITS IMPLICATION FOCUSED ON SOME TYPE OF POSITIVE INTERACTION OR HELPFUL BEHAVIOR PROVIDED TO A PERSON IN NEED OF SUPPORT (HUPCEY, 1998). BROADLY SOCIAL SUPPORT CAN BE REFERRED AS A POSITIVE INTERACTION OR RELATIONSHIP THAT RESULTS INTO A POSITIVE OUTCOME. WILLS (1985) SORTED OUT THE MAIN FUNCTIONS OF SOCIAL SUPPORT

INTO FIVE CATEGORIES NAMELY I) ESTEEM SUPPORT OR EMOTIONAL SUPPORT II) INSTRUMENTAL SUPPORT III) SOCIAL COMPANIONSHIP IV) INFORMATIONAL SUPPORT AND V) MOTIVATIONAL SUPPORT.

THE EMOTIONAL SUPPORT PROVIDES REASSURANCE ABOUT A PERSON'S WORTH AND CAN BE LINKED WITH THE CONCEPT OF UNCONDITIONAL POSITIVE REGARD. EMOTIONAL SUPPORT IS OFTEN REQUIRED WHEN DOUBTS ABOUT ONE'S ABILITY OR WORTH ARE EXPERIENCED. THIS SUPPORT USUALLY PROVIDED BY RELATIONSHIPS THAT ARE FELT TO BE VERY CLOSE AND REASONABLY LONG-STANDING. MOST COMMONLY, THE RELATIONSHIPS THAT PROVIDE THIS FUNCTION WOULD BE A SPOUSE OR A PARTNER, A CLOSE RELATIVE OR A CLOSE FRIEND.

INSTRUMENTAL SUPPORT IS ALSO TERMED AS AID, PRACTICAL SUPPORT, TANGIBLE SUPPORT OR MATERIAL SUPPORT. IT DESCRIBES THE PROVISION OF DIRECT ASSISTANCE SUCH AS HELP WITH THE HOUSEWORK, ACTIVITIES FOR DAILY LIVING (ADL) OR CARE WHENEVER NEEDED AND OTHER FACILITIES SUCH AS THE PROVISION OF MONEY, TRANSPORT, ETC.

SOCIAL COMPANIONSHIP INVOLVES THE EXPERIENCE OF BEING IN THE GROUP OF KNOWN OTHERS WHILE ENGAGING IN ACTIVITIES WHICH ARE PARTLY OR SOLELY FOR THE PURPOSE OF PLEASURE, LEISURE OR RELAXATION.

EMOTIONAL SUPPORT, INSTRUMENTAL SUPPORT AND SOCIAL COMPANIONSHIP CAN BE REGARDED AS THREE CORE SUPPORT FUNCTIONS. IN ADDITIONS TO THESE THREE FUNCTIONS, WILLS (1985) ALSO DISCUSSES TWO OTHER SUPPORT FUNCTIONS. THESE ARE INFORMATIONAL AND MOTIVATIONAL SUPPORT.

INFORMATIONAL SUPPORT INVOLVES THE PROVISION OF INFORMATION, ADVICE AND GUIDANCE. SUCH INFORMATION MAY INVOLVE PROVIDING A MORE OBJECTIVE VIEW OF THE PERSON'S OWN SITUATION OR PROBLEM E.G. ADVICE ON HOW COMMONPLACE AN EXPERIENCE IS AND WHAT CAN BE DONE TO HELP. WILLS (1985) POINTED OUT THAT INFORMATIONAL SUPPORT OFTEN COMES FROM THE SAME SOURCE AS EMOTIONAL, INSTRUMENTAL AND SOCIAL COMPANIONSHIP SUPPORT (WILLS, 1985).

THERE IS DIFFERENT TECHNIQUES VIZ. RELAXATION TRAINING, HYPNOSIS, BIOFEEDBACK, COGNITIVE BEHAVIOR THERAPY (CBT), AND EMOTIONAL DISCLOSURE ARE AVAILABLE TO HELP THE CANCER PATIENTS TO COPE WITH STRESS AND PAIN (BRANNON AND FEIST, 2007).

MOTIVATIONAL SUPPORT IS ESSENTIALLY THEORETICAL AND THERE IS NO DIRECT RESEARCH EVIDENCE TO SUPPORT ITS EFFECT ON MENTAL HEALTH. HOWEVER, WILLS (1985) ARGUES THAT MUCH STRESS ASSOCIATED WITH PSYCHIATRIC DISORDER IS CHRONIC IN NATURE. SUPPORT THAT CONSISTENTLY HELPS TO MAINTAIN HOPE IN CHRONICALLY DIFFICULT CIRCUMSTANCES AND HELPS TO SUSTAIN A BELIEF IN A CHOSEN COURSE OF ACTION, ESPECIALLY IF THIS IS DEMANDING, MAY BE IMPORTANT IN PREVENTING PSYCHIATRIC DISORDER. WITH INFORMATIONAL SUPPORT, MOTIVATIONAL SUPPORT MAY BE APPROPRIATELY SUPPLIED BY PROFESSIONALS (TANTAM AND BIRCHWARD, 1994).

A DIAGNOSIS OF CANCER CARRIES A GREAT DEAL OF EMOTION AND FEAR OF UNCERTAINTY. SOCIAL SUPPORT IN THE FACE OF A DIAGNOSIS REGARDED AS A LIFE CRISIS CAN IMPACT THE COURSE OF THE DISEASE. CANCER AND ITS ASSOCIATED TREATMENTS MAY REQUIRE A FUNDAMENTAL CHANGE IN LIFESTYLE, WHICH PROMPTS THE PERSON TO QUESTION THEIR PERSONAL IDENTITY AND SELF WORTH. A CANCER PATIENTS' NEED FOR SUPPORT IS OFTEN EXTENDED BEYOND THE INITIAL DIAGNOSIS, DURING TREATMENT AND FOLLOW UP (PRICE, 2003). BERKMAN AND SYME (1979) DEMONSTRATED A CORRELATION BETWEEN HIGHER MORTALITY RATES AND LOW LEVELS OF SOCIAL SUPPORT. RESEARCHERS FURTHER SUGGESTED THAT A SOCIAL SUPPORT SYSTEM IS BENEFICIAL IN BUFFERING THE STRESS ASSOCIATED WITH ILLNESS AND LIFE CHANGING EVENTS THUS HELPING THE RECIPIENT OF THE SUPPORT TO BETTER COPE WITH PROBLEMS (BLIESE AND BRITT, 2001; CALDWELL, PEARSON AND CHIN, 1987; COHEN AND WILLIS, 1985; DEVRIES, GLASPER AND DETILLION, 2003). OTHER RESEARCHERS STATED THAT SOCIAL SUPPORT PLAYS AN IMPORTANT ROLE IN ADJUSTMENT TO A CHANGING LIFE AFTER DIAGNOSIS OF CANCER (KORNBLITH ET AL, 2001).

THE PRESENCE OF A SOCIAL SUPPORT NETWORK HAS A POSITIVE IMPACT ON LONGEVITY AND DECREASE IN MORTALITY (BERKMAN AND SYME, 1979 AND GLASS ET AL, 2000). SOCIAL SUPPORT APPEARS TO PLAY A ROLE IN LESSENING THE SEVERITY AND/OR PROGRESSION OF

PRESENT HEALTH PROBLEMS. PERSONS WHO ARE MORE ISOLATED AND LACK A SOCIAL NETWORK EMERGE AS A GROUP WITH HIGH MORTALITY AND MORBIDITY RATES (DURKHEIM, 1951). THIS DATA IS SUPPORTED BY THE BERKMAN AND SYME (1979), WHO WERE CONDUCTED LARGE-SCALE STUDY IN ALAMEDA COUNTY IN CALIFORNIA ON SOCIAL SUPPORT AND ESTABLISHED THAT PEOPLE WITH THE LOWEST LEVEL OF SOCIAL CONTACT HAD MORTALITY RATES GREATER THAN THOSE WITH STRONG SOCIAL NETWORKS (BERKMAN AND SYME, 1979). OTHER STUDIES ALSO REVEALED THAT THE EFFECT OF SOCIAL SUPPORT ON PERSONS ALREADY COPING WITH A DISEASE, ESPECIALLY A LIFE THREATENING ONE LIKE CANCER. SOCIAL SUPPORT CAN REINFORCE THE RECIPIENT'S FEELINGS OF BELONGING THUS GIVING THEM STRENGTH ON A PSYCHOLOGICAL LEVEL. SOCIAL SUPPORT MAY ALSO BE BENEFICIAL IN ALTERING THE DISEASE PROCESS ITSELF AND POSSIBLY AMPLIFYING THE RESPONSE OF THE IMMUNE SYSTEM (LUTGENDORF ET AL., 2002; UCHINO, CACIOPPO AND KIECOLT-GLASER, 1996; DEVRIES, GLASPER AND DETILLON, 2003).

DEVRIES ET AL (2003) DEPICTED THAT SOCIAL SUPPORT HAVE A POSITIVE IMPACT ON HEALTH AND DECREASE MORTALITY FROM MANY DIFFERENT CAUSES (DEVRIES ET AL., 2003). DEVRIES ET AL (2003) ALSO NOTED THAT THE LEVEL OF SOCIAL SUPPORT SIGNIFICANTLY CORRELATED WITH THE RATE OF PROGRESSION FROM ASYMPTOMATIC TO SYMPTOMATIC STAGES OF FATAL DISEASES LIKE HIV/AIDS, CANCER, ETC. THESE NOTIONS ARE RESTATED FREQUENTLY THROUGHOUT SOCIAL SUPPORT LITERATURES SUGGESTING THAT SOCIAL SUPPORT IS BENEFICIAL TO BUFFER THE EFFECTS OF STRESS AND IN THE PREVENTION OF ADVERSE HEALTH OUTCOMES (DEVRIES ET AL, 2003).

A STUDY CONDUCTED BY GLASS ET AL (2000) HAS BEEN SHOWN TO BE INFLUENTIAL IN MAINTAINING HEALTH AND PREVENTING DISEASES IN MEN AND WOMEN AS WELL AS HELPING TO COPE AND ADAPT TO A VARIETY OF MEDICAL PROBLEMS (GLASS ET AL, 2000). ANOTHER STUDY CONDUCTED TO SUPPORT INFLUENTIAL FACTORS BY GOODWIN, SAMET AND HURT (1996); WHICH BRIEFLY SUGGESTED THAT CHARACTERISTICS SUCH AS POOR SOCIAL SUPPORT, LIMITED ACCESS TO TRANSPORTATION AND IMPAIRED COGNITION CAN

DELAY TREATMENT AND INCREASED THE RISK FOR INADEQUATE TREATMENT ESPECIALLY FOR OLDER MEN (GOTAY AND BOTTOMLEY, 1998).

DIFFERENT RESEARCHES PRESENTING THE EXAMINATION OF SOCIAL SUPPORT POSITIVELY INFLUENCES A PATIENT'S STATE IN DISEASES LIKE CANCER, AS WELL AS DECREASING MORTALITY RATES ASSOCIATED WITH THE DISEASE (BOBBY, 1995; BUSH, 2005; BERKLEY, 2006; BRIAN ET AL., 2009 ETC.). PRICE (2003) STATED THAT A STRONG SOCIAL SUPPORT NETWORK CAN BUFFER SOME OF THESE FEELING AND SUCCESSFULLY HELP THE PATIENT DIAGNOSED WITH CANCER TO COPE AND PROGRESS THROUGH ILLNESS AND ITS TREATMENT. SOCIAL SUPPORT HAS BEEN SHOWN TO HAVE A POSITIVE AND IMPORTANT INFLUENCE ON A PATIENT'S ABILITY TO ADAPT TO THE CHANGES IN THEIR LIFE THAT ACCOMPANY A DIAGNOSIS OF CANCER (PRICE, 2003). MEHTA (1998) ALSO STATED ABOUT THE IMPORTANCE OF SELF EFFICACY IN SUPPORTING SOCIAL ADAPTATION AND HEALTH. THE QUALITY OF SOCIAL NETWORKS AND THE DEGREE OF PARTICIPATION HAVE SUBSTANTIAL EFFECTS ON COPING, HEALTH STATUS AND LONGEVITY (MEHTA, 1998). LACK OF SOCIAL SUPPORT CAN CONTRIBUTE TO THE DEVELOPMENT OF DEPRESSION AMONG CANCER SUFFERERS (SOMERSET ET AL, 2004).

DURKHEIM (1951) FOUND THAT THE LESS SOCIALLY INTEGRATED PEOPLE WERE MORE LIKELY TO COMMIT SUICIDE THAN THE MORE INTEGRATED PERSONS (DURKHEIM, 1951). ANOTHER STUDY FOUND A LONGER LIFE EXPECTANCY IN MEN WHO WERE MARRIED THAN IN THEIR SINGLE COUNTERPARTS (CARTER AND GLICK, 1970). PREVIOUS FINDINGS SUPPORTED BY ANOTHER STUDIES, LINK SOCIAL SUPPORT TO POSITIVE IMPACTS ON HEALTH INCLUDING REDUCING MORTALITY RATES AND IMPROVING RECOVERY FROM SERIOUS ILLNESS LIKE CANCER (BERKMAN AND SYME, 1979; BLIESE AND BRETT, 2001; CARTER AND GLICK, 1970; COHEN AND WILLIS, 1985; DEVRIES ET AL, 2003; GLASS, DYM, GREENBERG, RINTELL, ROESCH, AND BERKMAN, 2000; HOUSE ET AL, 1988).

BOLGER, ZUCKERMAN AND KESSLER (2000) FOUND THAT 'INVISIBLE' SUPPORT MAY BE THE BEST KIND. THESE RESEARCHERS STUDIED BOTH THE ACT OF PROVIDING AND OF RECEIVING SUPPORT IN COUPLES AND CONCLUDED THAT SUPPORT WHICH ONE PARTNER DOES NOT

NOTICE IS BETTER AT RELIEVING STRESS THAN THE MORE OBVIOUS TYPES OF SUPPORTIVE INTERACTIONS. RECEIVING SUPPORT ENTAILS OBLIGATIONS, WHICH MAY BE ESPECIALLY TROUBLING FOR PEOPLE WHO ARE ILL. THUS, PARTNERS WHO ARE SUPPORTIVE WITHOUT BEING OBVIOUS PROVIDE MANY ADVANTAGES TO THE CANCER PATIENTS (BOLGER, ZUCKERMAN AND KESSLER, 2000).

GOODWIN ET AL (1996) IDENTIFIED SOME FACTORS REGARDING SOCIAL SUPPORT AMONG OLDER MEN CANCER PATIENTS, WHO SUGGESTED THAT THE POOR SOCIAL SUPPORT, LIMITED ACCESS TO TRANSPORTATION, IMPAIRED COGNITION CAN DELAY TREATMENT AND ALSO INCREASED THE RISK FOR INADEQUATE TREATMENT (GOODWIN, ET AL 1996). OTHER FACTORS SUCH AS BEING UNCOMFORTABLE IN A GROUP OR INDIVIDUAL SETTING MAY HINDER MEN FROM PARTICIPATING IN SOCIAL SUPPORT GROUPS. IN SUCH SITUATIONS OTHER MEANS OF PROVIDING SUPPORT MAY NEED TO BE EXPLORED SUCH AS PROVIDING PSYCHOSOCIAL SUPPORT BY TELEPHONE (GOTAY AND BOTTOMLEY, 1998).

SOCIAL SUPPORT PROVIDED ESPECIALLY BY SPOUSES PLAYS A CRITICAL ROLE IN THE PSYCHOLOGICAL ADAPTATION. MEYER AND MARK (1995) REVEALED THAT A LACK OF EMOTIONAL SUPPORT FROM CLOSE ONES, A GREATER FREQUENCY OF NEGATIVE INTERACTIONS AND A TENDENCY NOT TO SHARE IMPORTANT CANCER-RELATED CONCERNS WITH THEM, ARE ASSOCIATED WITH INCREASED PSYCHOLOGICAL DISTRESS PARTICULARLY AMONG WOMEN IN LATE STAGE OF CANCER (MEYER AND MARK, 1995).

HURDLE (2001) PROJECTED THAT THERE WAS A SIGNIFICANT INCREASE IN THE UTILIZATION OF HEALTH PROMOTION AND DISEASE PREVENTION PROGRAMS WHEN THE PROGRAMS WERE INTRODUCED IN GROUP (HURDLE, 2001). SUPPORT GROUPS OFTEN PROVE USEFUL FOR CANCER PATIENTS. SUPPORT GROUPS VARY CONSIDERABLY IN THEIR STRUCTURE AND FORMAT [TIME LIMITED VS. ONGOING; DISEASE SPECIFIC VS. HETEROGENESIS; FAMILY VS. PATIENT ONLY] (HASKELL AND BEREK, 1995).

A STUDY CONDUCTED TO FIND OUT THE RELATIONSHIP BETWEEN FAMILY FUNCTIONING AND COPING AMONG ADULT CANCER PATIENTS AND THEIR ADULT RELATIVES SHOWED THAT

FAMILY FUNCTIONING IS AN IMPORTANT FACTOR THAT HAS IMPACT ON THE PATIENT AND FAMILY DISTRESS. FAMILIES THAT WERE ABLE TO ACT OPENLY, EXPRESS FEELINGS DIRECTLY, AND SOLVE PROBLEMS EFFECTIVELY HAD LOWER LEVELS OF DEPRESSION, AND DIRECT COMMUNICATION OF INFORMATION WITHIN THE FAMILY WAS ASSOCIATED WITH LOWER LEVELS OF ANXIETY (BERESFORD, 2006).

IN CONTRAST, THERE IS VERY LITTLE INFORMATION ADDRESSING NEGATIVE ASPECTS ASSOCIATED WITH SOCIAL SUPPORT; HOWEVER IT BEARS NOTING THAT THESE ASPECTS DO EXIST AND CAN HAVE A GREAT IMPACT ON A PERSON'S ABILITY TO GIVE AND RECEIVE SUPPORT (SHAH, SUBBA, AND SHAH, 2009). SOCIAL RELATIONSHIPS CAN BE VIEWED AS NEGATIVE ESPECIALLY WHEN THE RELATIONSHIP THREATENS THE INDIVIDUAL'S SELF-ESTEEM, AUTONOMY AND ABILITY TO MAKE CHOICES. IF THE SUPPORT PROVIDED IS MORE THAN WHAT IS RECIPROCATED, THE RECIPIENT MAY HAVE FEELINGS OF DEPENDENCY OR MAY FEEL AS THOUGHT THEY ARE BEING TREATED AS AN INFANT AND BELIEVED TO BE INCAPABLE OF DOING ANYTHING FOR THEMSELVES (HANDLEY, 2004). SOCIAL SUPPORT RELATIONSHIPS CAN ALSO HAVE A NEGATIVE EFFECT IN DEALING WITH CANCER, IF THE PROVIDER IS UNWILLING OR UNABLE TO DISCUSS THE DISEASE AND/OR THE TREATMENT IN FEAR OF UPSETTING THE PERSON WITH CANCER. WHILE THE BENEFITS AFFILIATED WITH SOCIAL SUPPORT ARE OF SIGNIFICANCE, IT IS ALSO IMPORTANT TO REMEMBER THAT GOOD INTENTIONS MAY BE PERCEIVED IN A NEGATIVE LIGHT (BOTTOMELY AND JONES, 1997).

HOWEVER, MAJORITY OF THE STUDIES RELATED TO SOCIAL SUPPORT REVEALED THAT IT IS AN IMPORTANT FACTOR DURING DIAGNOSIS, TREATMENT AND SURVIVAL FOR THE CANCER PATIENTS TO MAINTAIN THEIR QUALITY OF LIFE.

2.4.3 Self-esteem

Rosenberg (1989) stated that self-esteem is a positive or negative orientation toward oneself, an overall evaluation of one's worth or value. People are motivated to have high self-esteem, and having it indicates positive self-regard, not egotism. Self-esteem is only one component of the self-concept, which he defines as totality of the individual's thoughts and feelings with reference to himself/herself as an object (Rosenberg, 1989).

Self-esteem is a way one feels about oneself, including the degree to which one possesses self-respect, and self-acceptance. It is the sense of personal worth and competence that persons associate with their self-concepts. The self-esteem needs were reported by Abraham Maslow, in which self- esteem is related to the process of becoming a self-actualizing person. As might be expected, love, warmth, and acceptance have been demonstrated to be extremely important in terms of developing a high degree of self- esteem. This sense of trust becomes a major safeguard against anxiety in coping with the world. Self- esteem is a multi- dimensional concept, as it exists in degrees. It is a vitally important component of one’s self-concept (Abraham Maslow, 1934; Cited in Corsini, 1996).

Self-esteem refers to the evaluation of the self, an expression of attitude of approval or disapproval toward oneself (Rosenberg, 1986). The process of self-esteem formation is said to involve the principles of “reflected appraisal”, “social comparison” and “self attribution”. Reflected appraisal involves the individual’s interpretation of how he or she is viewed by others, whereas social comparison holds that “in the absence of objective information about themselves people judge themselves on the basis of comparison with others”. Self attribution refers to the tendency to draw conclusions about oneself by observing one’s own actions, including the success or failure of efforts. Sometimes other issues are ignored or overlooked due to an emphasis on body image and physical changes. Physical transformations are important and often a source of increase or decrease in self-esteem, but there are also other issues that affect self-esteem. Data shows that the other issues may be equally important or of even greater concern (Rosenberg, 1986). Feeling well, functioning adequately, having faith, experiencing hope, appreciating life, having effective coping skills, accepting the disease, achieving desired goals, and social characteristics such as feeling attractive, experiencing positive relationships and being independent were reported as issues that affect self-esteem (Brockopp et al, 1996).

SELF-ESTEEM MAY BE CONSIDERED AN ECONOMIC ANALYSIS OF ONE'S PLACE IN THE SOCIAL MILIEU AND SEXUAL MARKETPLACE, AND THUS, OF ONE'S FITNESS. SIMILARLY, SELF-ESTEEM MAY BE AN UNCONSCIOUS CALCULATION OF "RESOURCE HOLDING POTENTIAL", DEFINED BY SOCIO-BIOLOGISTS AS AN INDIVIDUAL'S ABILITY TO COMPETE FOR RESOURCES WITH OTHERS OF THE SAME SPECIES. MALES, ESPECIALLY, COMPETE WITH OTHERS TO OBTAIN RESOURCES, INCLUDING FEMALES. RATHER THAN ACTUALLY FIGHTING REPETITIVELY, INDIVIDUALS OFTEN KNOW THEIR RANK IN A DOMINANCE HIERARCHY AND CHOOSE CONTESTS THEY MIGHT WIN BASED ON THEIR SELF-ASSESSMENT. FEMALES COMPETE WITH OTHER FEMALES FOR ACCESS TO DESIRABLE MALES AND RESOURCES AND AGAIN INDIVIDUALS ARE MORE FIT IF THEY CAN ASSESS THE OUTCOME OF POTENTIAL CONFLICTS WITHOUT ACTUALLY ENGAGING IN COMBAT. HIGH SELF-ESTEEM CAN THUS BE CONSIDERED A CALCULATION OF ONE'S CAPACITY TO HOLD RESOURCES AND OBTAIN MATES. LOW SELF-ESTEEM THEN IS AN ANTICIPATED LOSING OUTCOME IN SOCIAL COMPETITION. IT IS ADAPTIVE TO ASSESS ONE'S SELF-WORTH ACCURATELY, SO AS TO AVOID UNNECESSARY LOSSES WITH FURTHER EROSION OF RESOURCES OR DANGER TO SELF (SADOCK, 2005). SELF-ESTEEM FLUCTUATES SOMEWHAT WITH SURROUNDING CONDITIONS, ALTHOUGH A BASIC CORE OF POSITIVE OR NEGATIVE SELF-ESTEEM REMAINS FAIRLY CONSTANT EVEN WITH CHANGING CIRCUMSTANCES.

THE ROOTS OF SELF-ESTEEM ARE IN EARLY PARENTAL AND SOCIAL RELATIONS AS WELL AS IN THE PERSON'S PERCEPTION OF GOAL ATTAINMENT AND HIS/ HER OWN IDEALS. ABRAHAM MASLOW (1934) PLACES SELF-ESTEEM AT A VERY HIGH LEVEL, INDICATING THAT THIS NEED CAN BE ACCOMPLISHED ONLY WHEN THE MORE BASIC NEEDS ARE FULFILLED. SELF-ESTEEM INCREASES AS THE INDIVIDUAL ACHIEVES PERSONAL GOALS. FEELING GOOD ABOUT ONE'S SELF INFLUENCES MANY ASPECTS OF LIFE, INCLUDING DEALING WITH OTHERS, MANAGING CONFLICTS, STANDING UP FOR ONE'S OWN BELIEFS, TAKING RISKS AND BELIEVING IN ONE'S ABILITY TO HANDLE ADVERSITIES. THROUGHOUT LIFE, BOTH INTERNAL AND EXTERNAL FACTORS INFLUENCE SELF-ESTEEM (ABRAHAM MASLOW, 1934; CITED IN CORSINI, 1996).

ILLNESS CAN REPRESENT A THREAT TO SELF- ESTEEM (ABRAHAM MASLOW, 1934; CITED IN CORSINI, 1996) SINCE ILLNESS AND DISABILITY OFTEN REQUIRE A PERSON TO ALTER OR EVEN ABANDON PERSONAL GOALS AND MAY STRONGLY INFLUENCE THE PERSON'S VIEW OF SELF. SOME MAY READJUST WITH NEW GOAL WHILE OTHER MAY FAIL TO REGAIN THE PREVIOUS LEVEL OF SELF-ESTEEM. SEROUS ILLNESS SUCH AS PROSTATE OR BREAST CANCER, HEART DISEASE, OR STROKE NOT ONLY REQUIRE ADAPTATION OF PERSONAL GOALS, BUT OFTEN DISTORT THE DEEPER SENSE OF SELF. THIS IS A MAJOR CONTRIBUTOR TO DEPRESSION. BUT A DESIRE TO MAINTAIN A STRONG SENSE OF SELF IS A POWERFUL DRIVE, AND OVER TIME MANY PEOPLE ADAPT TO THESE CHANGES IN HEALTH (GORMAN ET AL., 2002). PATIENTS AND FAMILIES COPE WITH A DAY-BY-DAY COURSE THAT ENCOMPASSES MANY INDIVIDUAL EPISODES AND EVENTS. THERE ARE SERIOUS CONSEQUENCES, SOME AVOIDABLE, OTHERS NOT. THE EXPERIENCE OF CANCER OFTEN CONVERTS THE ONCE BORN INTO THE TWICE BORN. FOR FAMILY MEMBERS AND PRACTITIONERS, MORAL INSIGHT CAN EMERGE FROM JUST PROVIDE SYMPATHY TO THE CANCER PATIENT; AND MAINTAIN EMPATHETIC RELATIONSHIP TO FIGHT WITH THE CANCER. IT IS THIS PARTICULAR SENSE THAT IS TAKEN TO BE THE INNER MORAL MEANING OF CHRONIC ILLNESS AND CARE (KLEINMAN, 1988).

CANCER, LIKE CHRONIC ILLNESS ALSO MEANS THE LOSS OF CONFIDENCE IN ONE’S HEALTH AND NORMAL BODILY PROCESSES. THE CYCLE OF SYMPTOMS BEGINS; THE SUFFERER LOSES FAITH IN THE DEPENDABILITY AND ADAPTABILITY OF BASIC BODILY PROCESSES THAT THE HEALTHY ONES RELY ON AS PART OF THEIR GENERAL SENSE OF WELL-BEING. THIS LOSS OF CONFIDENCE BECOMES GRIM EXPECTATION OF THE WORST AND, IN SOME, DEMORALIZATION AND HOPELESSNESS. A CLOSELY RELATED FEELING IS GRIEF AND UNHAPPINESS OVER LOSS OF HEALTH, MOURNING FOR THE BODILY FOUNDATION OF DAILY BEHAVIOR AND SELF-CONFIDENCE. CANCER AND ITS TREATMENT PROCEDURES CHANGE BODY IMAGES, LIFE PATTERNS, AND MAY ALSO INFLUENCE FEELINGS OF SELF-WORTH (KLEINMAN, 1988).

AN EMPIRICAL STUDY OF SELF-ESTEEM IN CANCER HAS BEEN DONE BY THE KATZ, AND OTHERS (1995) REVEALED THAT OF GLOBAL SELF-ESTEEM HAS GENERALLY REVEALED NO

DIFFERENCES BETWEEN CANCER PATIENTS AND CONTROLS, BUT ASPECTS OF MULTIDIMENSIONAL SELF-ESTEEM, PARTICULARLY BODY SELF-ESTEEM, APPEAR TO BE DISTURBED IN MANY PATIENTS WITH CANCER (KATZ ET AL., 1995).

VIRGINIA ET AL (2006) STUDIED THE EXISTENTIAL ISSUES OFTEN ACCOMPANYING A DIAGNOSIS OF CANCER WHICH REMAINS ONE ASPECT OF PSYCHOSOCIAL ONCOLOGY CARE WHICH NEEDS FOCUSED AND EMPIRICALLY TESTED INTERVENTIONS. THAT STUDY EXAMINED THE EFFICACY OF A NOVEL PSYCHOLOGICAL INTERVENTION SPECIFICALLY DESIGNED TO ADDRESS EXISTENTIAL ISSUES THROUGH THE USE OF MEANING-MAKING COPING STRATEGIES ON PSYCHOLOGICAL ADJUSTMENT TO CANCER. A CASE CONTROL STUDY WAS CONDUCTED IN EIGHTY-TWO BREAST OR COLORECTAL CANCER PATIENTS AND THE MEANING OF THE EMOTIONAL RESPONSES AND COGNITIVE APPRAISALS OF EACH INDIVIDUAL'S CANCER EXPERIENCE WITHIN THE CONTEXT OF PAST LIFE EVENTS AND FUTURE GOALS WERE EXPLORED. STUDY RESULT DEMONSTRATED SIGNIFICANTLY HIGHER LEVELS OF SELF-ESTEEM, OPTIMISM AND SELF-EFFICACY AMONG EXPERIMENTAL GROUP PARTICIPANTS AS COMPARED TO THE CONTROL GROUP. THE RESULTS WERE DISCUSSED IN LIGHT OF THE THEORETICAL AND CLINICAL IMPLICATIONS OF MEANING-MAKING COPING IN THE CONTEXT OF STRESS AND CANCER (VIRGINIA ET AL, 2006).

BROCKOPP AND CARPENTER (1996) REPORTED THAT SELF-ESTEEM AFFECTED ON WOMEN UNDERGOING CHEMOTHERAPY AND SERVES TO PROVIDE INTERESTING INSIGHT INTO THEIR REACTIONS. THERE WAS WIDE VARIANCE IN FACTORS THOUGHT TO INFLUENCE SELF-ESTEEM, WHICH WAS REPORTED BY CANCER PATIENTS INCLUDING PHYSICAL, SOCIAL, PSYCHOLOGICAL, AND/OR SPIRITUAL FACTORS (BROCKOPP, AND CARPENTER, 1996).

RECENT STUDIES (CITED IN MEHTA, 1998) ANALYZED THE EFFECTS OF CHEMOTHERAPY ON SELF-ESTEEM OF WOMEN AND SERVES TO PROVIDE INTERESTING INSIGHT INTO THEIR REACTIONS. RESEARCHERS FOUND THAT EACH AND EVERY PATIENT DIFFERED WHERE THEIR SELF-ESTEEM WAS CONCERNED. WHILE MOST OF THE PATIENTS WERE CONCERNED WITH SKIN CHANGE, HAIR LOSS, LOSS OF A BODY PART, OR OTHER PHYSICAL CHANGES, OTHER PATIENTS WERE PRIMARILY CONCERNED WITH QUESTIONS OF MORTALITY AND MISSED

OPPORTUNITIES FOR THE FUTURE. ALL PATIENTS HAD THE SAME PRIMARY CONCERNS AND REACTIONS TO CANCER WERE ALSO SIMILAR AND ITS TREATMENT LEADS TO AN INCORRECT ANALYSIS OF THE PSYCHOLOGICAL REACTIONS OF PATIENTS. WIDE VARIANCES IN FACTORS THOUGHT TO INFLUENCE SELF-ESTEEM WERE REPORTED BY THE WOMEN INVOLVED IN THE STUDY, INCLUDING PHYSICAL, SOCIAL, PSYCHOLOGICAL, AND/OR SPIRITUAL FACTORS.

A STUDY WAS DONE IN CHENNAI, INDIA AMONG THE CANCER PATIENTS TO FIND OUT WHETHER AND HOW RELIGIOUS TENDENCIES AFFECTED THE COURSE OF TREATMENT. THERE WAS LITTLE DIFFERENCE ON ISSUES SUCH AS LONELINESS AND RELIGIOSITY, BUT WHEN IT CAME TO SELF-WORTH, PEOPLE AFFLICTED WITH CANCER SCORED LOWER. ON TOP OF THAT, CANCER PATIENTS WERE ALSO EXPRESSED; THEY HAD NOT DONE ENOUGH FOR THEIR FAMILY. CANCER PATIENTS ALSO FELT THAT THEY WERE LOVED LESS BY THEIR FAMILY AFTER SUFFERING FROM CANCER. PALLIATIVE CAREGIVERS SAID THAT THE EMOTIONAL NEEDS OF A PATIENT WERE HIGHER THAN THAT OF NORMAL PEOPLE. THOUGH, MOST OF THEM COPED WITH THE DISEASE WELL, WHEN PAIN TOOK OVER, PATIENTS NEEDED HELP. THEIR SELF-WORTH FELL AND OFTEN THEY WERE NOT THINKING OF THEMSELVES BUT OF THE FAMILY AND OF UNRELATED THINGS (SUJATA, 2006).

CANCER AND ITS TREATMENT CAN NEGATIVELY CHANGE THE WAY ONE FEELS ABOUT ONESELF. THIS MAY BE BECAUSE OF THE PHYSICAL CHANGES TO BODY OR IT MAY BE ABOUT LESS OBVIOUS CHANGES. THE INTENSE EMOTIONS AMONG CANCER PATIENT CAN CAUSES LOWER THE SELF-ESTEEM. PATIENTS FELT HAVING LESS FREEDOM, BEING TRAPPED IN FRAGILE BODY, DEPENDENT, AND WITHOUT NO IMMEDIATE CLEAR FUTURE PLANS AND HOPES. THE PERCEIVED HELPLESSNESS SITUATION AND FEELING OF HOPELESSNESS CAN REDUCE THEIR LEVEL OF CONFIDENCE ABOUT WHO THEY ARE AND WHAT THEY CAN DO. HAVING CONFIDENCE AND A HEALTHY SELF-ESTEEM ARE VERY IMPORTANT FOR EVERYONE (GREER, 1987).

BASED ON THE ABOVE FINDINGS, IT CAN BE ASSUMED THAT THE MORE THE CHRONIC ILLNESSES SUCH AS CANCER, ARTHRITIS, ETC. INTERFERES WITH PATIENT'S ABILITY TO ENGAGE IN ACTIVITIES CONTRIBUTING TO FEELINGS OF WORTH OR SUCCESS, THE MORE IT

LOWERS THE FEELING OF SELF-WORTH AND CONFIDENCE THUS, DISTORTING THE SELF-IMAGE AND SELF-ESTEEM. SUCH LOW OR DECREASED SELF-ESTEEM IS FOUND TO BE INTERRELATED WITH POOR QUALITY OF LIFE.

DIMITRA, ET AL., (2005) CONDUCTED A STUDY ON EARLY STAGE BREAST CANCER AMONG SPANISH POPULATION, WHERE SELF-ESTEEM WAS MEASURED THROUGH ROSENBERG'S SELF-ESTEEM SCALE AND QUALITY OF LIFE WAS MEASURED BY USING GLOBAL DETERIORATION OF QUALITY OF LIFE, WHICH CONSTITUTED WITH SUBSCALES NAMELY FUNCTIONAL STATUS, PHYSICAL SYMPTOMS, PSYCHOLOGICAL DISTRESS, FAMILY AND SOCIAL PROBLEMS, SEXUAL PROBLEMS, SATISFACTION WITH MEDICAL CARE. THE STUDY RESULT FOUND THAT SELF-ESTEEM CORRELATED NEGATIVELY WITH QUALITY OF LIFE ($R = -0.296$, $P < .05$) AND ALL SUB-SCALE SCORES.

2.4.4 Anxiety

ANXIETY IS A FEELING OF APPREHENSION, UNCERTAINTY, FEAR AND DEFINED AS AN UNPLEASANT EMOTIONAL STATE OR REACTION THAT CAN BE DISTINGUISHED FROM OTHERS, SUCH AS ANGER OR GRIEF, BY A UNIQUE COMBINATION OF EXPERIENTIAL QUALITIES AND PHYSIOLOGICAL CHANGES (SPIELBERGER, 1985). THE PHYSIOLOGICAL MANIFESTATIONS GENERALLY INCLUDE INCREASED BLOOD PRESSURE, RAPID HEART RATE (PALPITATION, TACHYCARDIA), SWEATING, DRYNESS OF THE MOUTH, NAUSEA, VERTIGO, HYPERVENTILATION, AND MUSCULAR SKELETAL DISTURBANCES SUCH AS RESTLESSNESS, TREMORS, AND FEELINGS OF WEAKNESS. THOUGH THE MEANING OF ANXIETY DIFFERS FROM CULTURE TO CULTURE, IT IS GENERALLY ACCEPTED THAT INCREASED ANXIETY IS "NORMAL" IN SITUATION WHERE IMMEDIATE DANGER MIGHT RESULT IN PHYSICAL HARM. ANXIETY IS ALSO A NORMAL REACTION TO SOCIAL-EVALUATIVE SITUATIONS THAT POSE THREATS TO SELF-ESTEEM OR PSYCHOLOGICAL WELL BEING. HOWEVER, THE OCCURRENCE OF ANXIETY IN SITUATIONS IN WHICH THERE IS NO REAL PHYSICAL OR PSYCHOLOGICAL DANGER OR WHEN THE EMOTIONAL REACTION IS DISPROPORTIONATE IN INTENSITY TO THE ACTUAL DANGER, GENERALLY INDICATES TO THE PRESENCE OF NEUROTIC ANXIETY (SPIELBERGER, 1985). HOWEVER, IN HUMANS, THIS CAN BE DEFINED BY DESCRIPTION USING LANGUAGE. TESTS OF

ANXIETY IN MAN ARE THUS BASED ON SELF REPORT AND THESE MAY BE DIVIDED INTO FEATURES THAT CHARACTERIZE THE PERSON'S TEMPERAMENT (‘TRAIT’ ANXIETY) OR THAT DESCRIBE A CURRENT EMOTIONAL STATE (‘STATE’ ANXIETY). ‘FEAR’ CAN BE SUBSTITUTED FOR ‘ANXIETY’ IN MANY CONTEXTS. HOWEVER, ANXIETY IS NOT ONLY A BEHAVIORAL PHENOMENON.

ANXIETY IS A MULTI-SYSTEM RESPONSE TO A PERCEIVED THREAT OR DANGER. IT REFLECTS A COMBINATION OF BIOCHEMICAL CHANGES IN THE BODY, THE PATIENT'S PERSONAL HISTORY AND MEMORY AND THE SOCIAL SITUATION. AS FAR AS WE KNOW, ANXIETY IS A UNIQUE HUMAN EXPERIENCE. MOREOVER, A LARGE PORTION OF HUMAN ANXIETY IS PRODUCED BY ANTICIPATION OF FUTURE EVENTS. WITHOUT A SENSE OF PERSONAL CONTINUITY OVER TIME, PEOPLE WOULD NOT HAVE THE "RAW MATERIALS" OF ANXIETY. IT IS IMPORTANT TO DISTINGUISH BETWEEN ANXIETY AS A FEELING OR EXPERIENCE AND AN ANXIETY DISORDER AS A PSYCHIATRIC DIAGNOSIS. A PERSON MAY FEEL ANXIOUS WITHOUT HAVING AN ANXIETY DISORDER. ALSO A PERSON FACING A CLEAR AND PRESENT DANGER OR A REALISTIC FEAR IS NOT USUALLY CONSIDERED TO BE IN A STATE OF ANXIETY. IN ADDITION, ANXIETY FREQUENTLY OCCURS AS A SYMPTOM IN OTHER CATEGORIES OF PSYCHIATRIC DISTURBANCE.

ANXIETY CAN BE THE MOST CRUCIAL FORMATIVE INFLUENCE IN THE INTERPERSONAL FIELD, AND CAN ALSO BE THE ORIGINS OF PERSONALITY AND OF SELF. FOR INSTANCE, COMMON ROOTS LIE IN THE HELPLESS NATURE OF INFANTS, WHO SURVIVE ONLY IF NURTURED. A DISTRESSED INFANT CRIES. A CAREGIVER RESPONDS. THE CRY BECOMES A COMMUNICATION WITHIN A RELATIONSHIP AND THE FIRST TOOL OF NEED REDUCTION. OVER TIME, SUCH INTERACTIONS ACQUIRE TWO CONSEQUENCES: SATISFACTION ARISING FROM NEED REDUCTION AND SECURITY ARISING FROM THE PRESERVATION OF A NECESSARY RELATIONSHIP. THREATS TO BIOLOGICAL SURVIVAL BRING FEAR. THREATS TO SECURITY BRING ANXIETY, WHICH MAY BE DEVASTATINGLY POWERFUL FOR INFLUENCING THE LACK OF MATURITY AND EXPERIENCE TO MANAGE OR DAMPEN IT.

ANXIETY SYMPTOMS HAVE OFTEN BEEN OBSERVED AS A PART OF DEPRESSION IN CANCER PATIENTS. ANXIETY CAN ALSO BE A PART OF THE NORMAL STRESS RESPONSE, ADJUSTMENT

DISORDER AND DELIRIUM. GENERALIZED ANXIETY DISORDER IS NOT AS FREQUENT AS DEPRESSION IN CANCER PATIENTS. THE COMMON ANXIETY SYMPTOMS NOTED IN CANCER PATIENTS ARE PERSISTENT TENSION AND WORRYING, PANIC ATTACKS AND PALPITATIONS (VYAS ET AL, 2000).

REDEKER AND OTHERS (2000) HAVE CONDUCTED STUDY AMONG 263 CANCER PATIENTS WHO WERE UNDERGOING CHEMOTHERAPY TO EXAMINE THE RELATIONSHIPS BETWEEN THE ANXIETY AND DEPRESSION WITH QUALITY OF LIFE. THE STUDY REVEALED THAT ANXIETY IS NEGATIVELY CORRELATED WITH QUALITY OF LIFE OR IT LEADS TO POOR QUALITY OF LIFE (REDEKER ET AL., 2000).

SCHREIER AND SUSAN (2004) CONDUCTED A DESCRIPTIVE LONGITUDINAL STUDY AMONG 48 BREAST CANCER PATIENTS, WHO WERE RECEIVING EITHER CHEMOTHERAPY OR RADIATION THERAPY IN SOUTHEASTERN USA. ANXIETY WAS MEASURED THROUGH SPEILBERGER'S STATE-TRAIT ANXIETY INVENTORY (STAI) AND QUALITY OF LIFE WAS MEASURED THROUGH FERRANS AND POWERS QUALITY OF LIFE INDEX (QLI). THEIR STUDY REPORTED THAT CANCER PATIENTS, WHO HAD HIGHER LEVEL ANXIETY SCORES, RECEIVED THE LOWER LEVEL OF QUALITY OF LIFE.

IN NEPALESE CONTEXT A STUDY CONDUCTED AMONG 50 TERMINALLY ILL CANCER PATIENTS AT SHREE BIRENDRA HOSPITAL, KATHMANDU, NEPAL. HOSPITAL ANXIETY SCALE WAS USED TO COLLECT DATA, WHICH REVEALED THAT THE 40.0% OF CANCER PATIENTS HAD ANXIETY (THAPA, RAWAL AND BISTA, 2010).

IN MANY CASES, CANCER AND ANXIETY GO HAND-IN-HAND, AND ANXIETY IS CONSIDERED AS A NORMAL REACTION TO CANCER. CANCER PATIENTS MAY EXPERIENCE ANXIETY WHILE UNDERGOING A CANCER SCREENING TEST, WAITING FOR TEST RESULTS, RECEIVING A DIAGNOSIS OF CANCER, UNDERGOING CANCER TREATMENT, OR ANTICIPATING A RECURRENCE OF CANCER AND/OR FUTURE CONCERNS. ANXIETY ASSOCIATED WITH CANCER MAY INCREASE FEELINGS OF PAIN, INTERFERE WITH ONE'S ABILITY TO SLEEP, CAUSE NAUSEA

AND VOMITING, AND INTERFERE WITH THE PATIENT'S AND HIS OR HER FAMILY'S QUALITY OF LIFE. IF IT IS LEFT UNTREATED, SEVERE ANXIETY MAY EVEN SHORTEN A PATIENT'S LIFE.

2.4.5 DEPRESSION

DEPRESSION IS A STATE ASSOCIATED WITH THE MOOD OF A PERSON. IT IS A TERM USED TO DESCRIBE A MOOD, A SYMPTOM AND SYNDROMES OF AFFECTIVE DISORDERS. AS A MOOD, IT REFERS TO A TRANSIENT STATE OF FEELING SAD, BLUE, HOPELESS, CHEERLESS AND UNHAPPY. AS A SYMPTOM, IT REFERS TO A COMPLAINT THAT OFTEN ACCOMPANIES A GROUP OF BIO-PSYCHOSOCIAL PROBLEMS. IN CONTRAST, THE DEPRESSIVE SYNDROMES INCLUDE A WIDE SPECTRUM OF PSYCHOBIOLOGICAL DYSFUNCTIONS THAT VARY IN FREQUENCY, SEVERITY AND DURATION. NORMAL DEPRESSION IS A TRANSIENT PERIOD OF SADNESS AND FATIGUE THAT GENERALLY OCCURS IN RESPONSE TO IDENTIFIABLE STRESSFUL LIFE EVENTS. THE MOOD ASSOCIATED WITH NORMAL DEPRESSION VARIES IN LENGTH, BUT GENERALLY DO NOT EXCEED 7 TO 10 DAYS. IF THE PROBLEMS CONTINUE FOR A LONGER PERIOD AND IF THE SYMPTOMS GROW IN COMPLEXITY AND SEVERITY, CLINICAL LEVELS OF DEPRESSION MAY BE PRESENT. SOMETIMES, PROBLEMS ASSUME PSYCHOTIC PROPORTIONS AND THE DEPRESSED INDIVIDUAL MAY ATTEMPT SUICIDE AND/OR MAY EXPERIENCE HALLUCINATIONS, DELUSIONS, AND SERIOUS PSYCHOLOGICAL AND MOTOR RETARDATION.

THIS OBSERVATION IS SUPPORTED BY THE DATA PRESENTED ON WORLD MENTAL HEALTH DAY (2004) ABOUT THE INCIDENCE OF SUICIDE IN PEOPLE BEING TREATED FOR CANCER WHICH MAY BE AS MUCH AS 10 TIMES HIGHER THAN RATE OF SUICIDE IN GENERAL POPULATION.

DEPRESSION IS A MOOD DISTURBANCE CHARACTERIZED BY NEGATIVE FEELINGS, ATTITUDES AND BELIEFS THE PERSON HAS ABOUT SELF AND HIS ENVIRONMENT E.G. PESSIMISM, HELPLESSNESS, HOPELESSNESS, LOW SELF-ESTEEM, AND A GUILT FEELING (KAPOOR, 1998). CLINICAL DEPRESSION, AS AN ILLNESS, IS NOT A NORMAL REACTION, BUT CAN OCCUR EVEN WITHOUT A CLEAR REASON. IT IS MUCH MORE THAN AN OCCASIONAL SAD MOOD. IT GENERALLY INVOLVES QUITTING OR JUST PLAIN GIVING UP. FOR A DEPRESSED PERSON, PRESENT CONDITIONS AND THE FUTURE POSSIBILITIES ARE INTOLERABLE. A DEPRESSED

PERSON 'GOES ON STRIKE' FROM LIFE, DOING LESS AND LESS, LOSING INTEREST IN PEOPLE, ABANDONING HOBBIES AND GIVING UP AT WORK (HAFEN ET AL, 1996).

IN GENERAL, 1 IN 5 FOR WOMEN AND 1 IN 10 FOR MEN HAS PROBABILITY TO DEVELOP DEPRESSION. ABOUT 6% OF THE POPULATION MEET THE CRITERIA FOR DEPRESSIVE DISORDER OR DYSTHYMIA AT ANY TIME AND THUS MAKES IT A MAJOR PUBLIC HEALTH PROBLEM WORLDWIDE (NARAYAN, 2004). IT IS REPORTED THAT 4 OF THE 10 LEADING CAUSES OF THE DISABILITIES IN THE UNITED STATES AND OTHER DEVELOPED COUNTRIES HAVE MENTAL DISORDER INCLUDING MAJOR DEPRESSION, BIPOLAR DISORDER AND SCHIZOPHRENIA (WORLD MENTAL HEALTH DAY, 2004). DEPRESSIVE DISORDER AFFECTS APPROXIMATELY 19 MILLION ADULTS IN UNITED STATES (NATIONAL INSTITUTE OF MENTAL HEALTH [NIMH], 2002). DEPRESSION AS NOTED BY SCHOUTEN AND WILLIAMS (2000) IS BOTH AN IMPORTANT CAUSE AND CONSEQUENCE OF DISABILITY. WHO ESTIMATE HAS SHOWN THAT 121 MILLION PEOPLE WORLDWIDE ARE SUFFERING FROM DEPRESSION AND 60% OF THEM ATTEND GENERAL HEALTH CARE. TOTAL NUMBER OF DEPRESSED PATIENTS IN INDIA IS ABOUT 90 MILLION. ABOUT 15% OF THOSE WHO ARE CLINICALLY DEPRESSED DIE BY SUICIDE. NIMH NOTES THAT STRESSFUL LIFE EVENTS SUCH AS WORK-RELATED INJURIES MAY CONTRIBUTE TO RECURRENT EPISODES OF DEPRESSION IN SOME INDIVIDUALS (NIMH.NIH.GOV, 2007). THE INCIDENCE OF DEPRESSION IS ALSO HIGHER IN MEDICAL IN AND OUT PATIENTS, RANGING FROM 10 TO 15% (SMELTZER AND BARE, 2001).

Factors associated with adjustment disorders and/or major depression are younger age, longer education, lower performance status, severe pain, severe constipation, severe fatigue, greater concerns about financial issues, feeling of being a burden to others, loss of independence and dignity, less satisfaction with close friends and presence of past history of major depression. The logistic regression analysis showed that lower performance status, greater concern about being a burden to others and less satisfaction with close friends was the final significant factors associated with the presence of psychological distress at baseline. The factors underlying psychological distress are multi-factorial. Early intervention to treat sub-clinical anxiety and depression may prevent subsequent psychological distress (Tatsuo et al, 2004).

SYMPTOMS OF DEPRESSION OCCUR COMMONLY IN MEDICAL ILLNESS AND THERE IS A COMMON MISPERCEPTION THAT ALL DEPRESSION IS AN 'UNDERSTANDABLE' PSYCHOLOGICAL REACTION TO A SERIOUS ILLNESS. SUCH BELIEF MAY DENY THE PATIENTS THE DIAGNOSIS AND APPROPRIATE TREATMENT. DEPRESSION IN THE PHYSICALLY ILL HAS BEEN SHOWN TO HAVE A SIGNIFICANT IMPACT, WITH INCREASED SYMPTOM BURDEN, IMPAIRED FUNCTIONING AND REDUCED QUALITY OF LIFE (RUTTLEY AND REID, 2006). SINCE IT IS BELIEVED AS COMMON RESPONSE TO HEALTH PROBLEMS, IT IS OFTEN UNDIAGNOSED. PEOPLE MAY BECOME DEPRESSED AS A RESULT OF INJURY OR ILLNESS, OR MAY BE DUE TO SUFFERING FROM AN EARLIER LOSS THAT COMPOUNDED BY A NEW HEALTH PROBLEM (SMELTZER AND BARE, 2001).

COMMON REACTION IN CANCER DIAGNOSIS IS DEPRESSION. PEOPLE, WHO FACE A CANCER DIAGNOSIS, WILL EXPERIENCE MANY STRESSES AND EMOTIONAL DISTURBANCES. FEAR OF DEATH, INTERRUPTION OF LIFE PLANS, CHANGES IN BODY IMAGE AND SELF-ESTEEM, CHANGES IN SOCIAL ROLE, LIFESTYLE, AND MEDICAL BILLS ARE IMPORTANT ISSUES TO BE FACED (NIH, 2002). DEPRESSION IN CANCER MAY BE RELATED TO THE PHYSICAL DISABILITIES (CHATURVEDI ET AL, 2000).

EARLIER, DEPRESSION WAS CONSIDERED AS THE ONLY EMOTIONAL RESPONSE TO CANCER AS MOST OF THE EARLIER LITERATURE ON PSYCHIATRIC MORBIDITY OF CANCER WAS DRAWN FROM CLINICAL EXPERIENCE OR UNSTRUCTURED INTERVIEWS WITH PATIENTS AND WAS LARGELY ANECDOTAL. RECENT STUDIES REVEALED THAT THERE ARE CONSIDERABLE METHODOLOGICAL PROBLEMS IN ASSESSING THE PSYCHIATRIC MORBIDITY (ESPECIALLY DEPRESSION AND ANXIETY) AMONG CANCER PATIENTS. PEOPLE, INCLUDING MEDICAL PROFESSIONALS, VIEW CANCER AS A DREADED CONDITION, A CONDITION THAT 'TANTAMOUNT TO A DEATH SENTENCE' (DEROGATIS, 1983; LEDERBERG AND HOLLAND, 1989). THIS IS REFLECTED IN THE RESULTS OF STUDIES IN WHICH MEDICAL PROFESSIONALS WERE ALSO FOUND TO HAVE RATED CANCER AS A CONDITION WHICH IS 'MORE WORTHLESS THAN DEATH'. THIS LEADS TO UNDER-REPORTING OF PSYCHOLOGICAL MORBIDITY AMONG CANCER PATIENTS. DESPITE THESE DIFFICULTIES, A MAJORITY OF THE STUDIES HAVE

REVEALED A HIGH LEVEL OF PSYCHIATRIC MORBIDITIES AMONG CANCER PATIENTS. A STUDY CONDUCTED IN THE OUTPATIENT DEPARTMENT REPORTED THAT ONE THIRD (34%) OF THE CANCER PATIENTS HAVE A HIGH LEVEL OF PSYCHOLOGICAL DISTRESS AND ANOTHER STUDY AMONG ADMITTED CANCER PATIENTS IN THREE CENTERS OF USA ALSO REVEALED SIMILAR RESULTS (DEROGATIS, 1983; LEDERBERG AND HOLLAND, 1989).

FIRSTLY, DEPRESSION IS FOUND AMONG CANCER PATIENTS BUT THERE IS VARIATION IN POPULATION AND TYPE OF CANCER AND DEPRESSION. GENERALLY 4 TO 50% CANCER PATIENTS SUFFER FROM DEPRESSION BUT LARGE NUMBER OF STUDIES INDICATED AROUND 35% OF CANCER PATIENTS SUFFER FROM ADJUSTMENT OR MILD TO SEVERE DEPRESSION. CLARAMELLA (2001) REPORTED THAT 49% OF THE CANCER PATIENTS HAVE THE DEPRESSION USING DSM III-R CRITERIA, WHEREAS 29% OF CANCER PATIENTS HAVE DEPRESSION USING ENDICOTT CRITERIA AND 29% HAVE DEPRESSION USING BOTH CRITERIA; HOWEVER, THEY NEED TO BE INTERPRETED CAREFULLY IN THE LIGHT OF THE LIMITATIONS OF SELECTION BIAS. THEIR FINDINGS SUGGEST A HIGH PREVALENCE OF MAJOR DEPRESSION AND ADJUSTMENT DISORDERS IN TERMINALLY ILL CANCER PATIENTS (SIMON, 2002; WEISSMAN, 1996 AND HIBBELN, 1998). MCDANANIEL ET AL, (2000) REPORTED THAT PREVALENCE OF DEPRESSION VARY ON METHODOLOGICAL GROUNDS; HOWEVER, IT WAS FOUND TO VARY FROM 1.5 TO 50% (MEAN 24%; MEDIAN 22%). THE PREVALENCE OF DEPRESSION IN CANCER PATIENTS VARIES WITH CANCER SITE, CLINICAL COURSE, TYPE OF TREATMENT AND PRESENCE OF PAIN. THE PREVALENCE OF MAJOR DEPRESSION IN CANCER PATIENTS RANGES FROM 13% TO 40% (MCDANANIEL ET AL, 2000). THOUGH THERE ARE EVIDENCES OF HIGH LEVEL OF DEPRESSION AMONG ALL INDIVIDUALS WITH CANCER, VERY FEW CANCER PATIENTS RECEIVED TREATMENT FOR DEPRESSION (MCDANANIEL ET AL, 2000). IN INDIAN SETTING, 38% OF CANCER PATIENTS WERE FOUND TO HAVE IDENTIFIABLE DSM III-R ANXIETY OR DEPRESSIVE DISORDER (CHATURVEDI ET AL, 1994). IN NEPAL CASE, THERE IS NOT MANY STUDIES DONE ON CANCER AND DEPRESSION, A STUDY WAS CONDUCTED BY SHARMA AND DEO (2005) IN B.P. KOIRALA MEMORIAL CANCER HOSPITAL, BHARATPUR, CHITWAN, NEPAL AMONG 50 CANCER PATIENTS. THE STUDY RESULT SHOWED THAT 72% OF THE CANCER PATIENTS HAD MILD TO SEVERE DEPRESSION (SHARMA AND DEO, 2005). ANOTHER STUDY ALSO

CONDUCTED AMONG 50 TERMINALLY ILL CANCER PATIENTS AT SHREE BIRENDRA HOSPITAL, KATHMANDU, NEPAL. HOSPITAL DEPRESSION SCALE WAS USED TO COLLECT DATA. THEIR STUDY REVEALED THAT 28.0% OF CANCER PATIENTS HAD DEPRESSION (THAPA, RAWAL AND BISTA, 2010). YET, THERE IS LACK OF OTHER LARGE SCALE STUDY AMONG CANCER PATIENTS IN NEPAL AND REPORT OF 50 PATIENTS ARE NOT SUFFICIENT TO GENERALIZE THE WHOLE CANCER PATIENTS OF NEPAL.

DEPRESSION MAY OCCUR AT SEVERAL KEY-MOMENTS: AFTER DIAGNOSIS OR RELAPSE IN THE CONTEXT OF TREATMENT FAILURE. DEPRESSION IS CORRELATED WITH BIOLOGICAL FACTORS DUE TO ILLNESS ITSELF AND ITS TREATMENT (BAILEY ET AL, 2005).

DEPRESSIVE SYMPTOMS CAN BE CAUSED BY THE DISEASE PROCESS DIRECTLY OR BY THE VARIOUS CHEMOTHERAPEUTIC AGENTS USED FOR THE TREATMENT OF CANCER. DEPRESSION CAN ALSO OCCUR AS A FUNCTIONAL RESPONSE TO DISABILITIES. FEELING OF WORTHLESSNESS AND GUILT WERE FOUND TO BE POWERFUL IN DISTINGUISHING BETWEEN NORMAL SADNESS SEEN IN CANCER AND MAJOR DEPRESSION. RECURRENT THOUGHTS OF SUICIDE ARE COMMON IN CANCER PATIENTS. STUDIES BASED ON THE INPATIENT POPULATION SHOWED A HIGHER INCIDENCE THAN THAT IN OUTPATIENT POPULATION (CHATURVEDI ET AL, 2000).

DEPRESSIVE DISORDERS AND PSYCHOSOCIAL RELATED FACTORS WERE INVESTIGATED BY GRASSI ET AL (1997) AMONG 113 PATIENTS AFTER ONE YEAR OF CANCER DIAGNOSIS. PATIENTS WITH AN ICD-10 (INTERNATIONAL CLASSIFICATION OF DISEASE) DIAGNOSIS OF DEPRESSION (31% OF THE SAMPLE) SHOWED HIGHER EXTERNAL LOCUS OF CONTROL, POORER SOCIAL SUPPORT, AND HIGHER INCIDENCE OF UNDESIRABLE AND/OR UNCONTROLLABLE EVENTS THAN NON-DEPRESSED PATIENTS (GRASSI ET AL, 1997). THE RESULTS OF THE STRUCTURED PSYCHIATRIC INTERVIEW INDICATED THAT APPROXIMATELY ONE-FOURTH OF THE TERMINALLY ILL CANCER PATIENTS EXPERIENCED ADJUSTMENT DISORDERS AND/OR MAJOR DEPRESSION (GRASSI ET AL, 1997). THE RESULT OF A RECENT SYSTEMATIC REVIEW OF DEPRESSION IN TERMINALLY ILL CANCER PATIENTS IS HIGH, INCLUDING MAJOR DEPRESSION AND ADJUSTMENT DISORDERS (HOTOPF ET AL, 2002). IN A

REVIEW OF STUDIES OF CANCER PATIENTS AT VARIOUS TIMES DURING THEIR DISEASE, PREVALENCE OF DEPRESSION RANGED FROM 4.5 TO 50% (DANIEL AND NEMEROFF, 1993). STUDIES SUGGEST THAT PATIENTS ARE DEPRESSED AT THE TIME OF DIAGNOSIS OF CANCER AND FLOWING RELAPSE (SOMERSET ET AL, 2004). SPIEGEL AND GIESE-DAVIS (2003) LIMITED THEIR INTEREST TO CANCER AND DEPRESSION, TWO EXPERIENCES THAT OFTEN CO-OCCUR. THESE AUTHORS DISCUSSED SOME DIFFICULTIES IN SEPARATING DEPRESSION FROM A DIAGNOSIS OF CANCER, NOTING A RELATIONSHIP BETWEEN DEPRESSION AND SEVERITY OF CANCER. THEY SUGGESTED THAT SEVERE DEPRESSION MAY INCREASE CANCER PROGRESSION AND MORTALITY. THUS FOR SOME PEOPLE, RECEIVING A DIAGNOSIS OF CANCER MAY SPEED THE PROGRESS OF CANCER. THIS SPIRALING EFFECT MAY BE BUFFERED BY SOCIAL SUPPORT AND OTHER PSYCHOSOCIAL INTERVENTIONS (BRANNON AND FEIST, 2007).

FOR MANY PATIENTS SUFFERING FROM DEPRESSION RESULTING FROM CANCER, THE COGNITIVE-BEHAVIORAL COUNSELING INTERVENTION HAS BEEN SHOWN TO BE EFFECTIVE IN REDUCING EMOTIONAL DISTRESS AND CONTROLLING PHYSICAL SYMPTOMS IN CANCER PATIENTS (WEBB ET AL, 1966). HISTORY OF DEPRESSION, A WEAK SOCIAL SUPPORT SYSTEM (NOT MARRIED, FEW FRIENDS, A LONELY WORK ENVIRONMENT), EVIDENCE OF PERSISTENT IRRATIONAL BELIEFS OR NEGATIVISTIC THINKING REGARDING THE DIAGNOSIS, A MORE SERIOUS PROGNOSIS AND GREATER DYSFUNCTION RELATED TO CANCER IS NEEDED EARLY PSYCHOSOCIAL INTERVENTION. CANCER-RELATED DEPRESSION IS NOT SUBSTANTIALLY DIFFERENT FROM DEPRESSION IN OTHER MEDICAL CONDITIONS, BUT TREATMENTS MAY NEED TO BE ADAPTED OR REFINED FOR CANCER PATIENTS (PATRICK ET AL, 2002).

DEPRESSED PATIENTS NEED SUPPORTIVE CARE OR GROUP COUNSELING EITHER BY A MENTAL HEALTH PROFESSIONAL OR THROUGH PARTICIPATION IN A SELF-HELP SUPPORT GROUP (MEYER AND MARK, 1995). PRELIMINARY DATA SUGGEST A BENEFICIAL IMPACT OF SPIRITUALITY ON ASSOCIATED DEPRESSION, AS MEASURED BY THE FUNCTIONAL ASSESSMENT OF CHRONIC ILLNESS THERAPY-SPIRITUAL WELL-BEING (FACIT-SP) AND THE HAMILTON DEPRESSION RATING SCALE (NELSON ET AL, 2002).

REDEKER AND OTHERS (2000) HAVE CONDUCTED STUDY AMONG 263 CANCER PATIENTS WHO WERE UNDERGOING CHEMOTHERAPY TO EXAMINE THE RELATIONSHIPS BETWEEN THE ANXIETY AND DEPRESSION WITH QUALITY OF LIFE. THE STUDY REVEALED THAT DEPRESSION IS NEGATIVELY CORRELATED WITH QUALITY OF LIFE OR IT LEADS TO POOR QUALITY OF LIFE (REDEKER ET AL., 2000).

PEOPLE SUFFERING FROM CANCER AND DEPRESSION HAVE A VARIETY OF CHALLENGES TO FACE. THEY ARE DISTRESSED AND TEND TO HAVE TROUBLE WITH EVERYDAY TAKES AND THEY OFTEN FIND IT DIFFICULT TO FOLLOW MEDICAL ADVICE. VARIETIES OF THERAPIES SUCH AS CRISIS INTERVENTION; PSYCHOTHERAPY AND THOUGHT BEHAVIOR TECHNIQUE ETC ARE FOUND TO BE EFFECTIVE IN TREATMENT OF DEPRESSION RELATED TO CANCER. VARIOUS STUDIES HAVE SUGGESTED THAT APPROPRIATE TREATMENT OF PSYCHIATRIC ILLNESS AND POSITIVE ATTITUDE TOWARDS THOSE PATIENTS CAN PROLONG THEIR LIFE SPAN (BRAUNWALD ET AL, 1994).

THE COMMON NEEDS TO ALL TYPE OF CANCER PATIENTS ARE AN APPROPRIATE MANAGEMENT OF THEIR PSYCHOLOGICAL STRESS. DEPRESSION AFFECTS BODY, FEELINGS, THOUGHTS AND BEHAVIOR AND CAN CAUSE GREATER STRESS AND MAKE SOMEONE LESS ABLE TO FOLLOW NEEDED TREATMENT SCHEDULES. DEPRESSION IS A TREATABLE CONDITION, AND A VARIETY OF OPTIONS ARE EASILY AVAILABLE.

THE FINDINGS OF THIS STUDY SUPPORT THE MULTIDIMENSIONAL NOTION OF THE CANCER. QUALITY OF LIFE WAS INCLUDING A CANCER PATIENT’S SENSE OF WELL-BEING AND FUNCTION CAN BE AFFECTED BY DEPRESSION AND ANXIETY (GREISINGER ET AL. (1997) AND FERRELL ET AL. (1995). ANOTHER STUDY, ALSO CONDUCTED AMONG CANCER PATIENTS UNDERGOING RADIATION THERAPY, WHO WERE ASSESSED THROUGH HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS) IN GERMANY. THAT STUDY ALSO REVEALED THAT ANXIETY AND DEPRESSION WERE SIGNIFICANTLY CORRELATED WITH IMPAIRED QOL (FRICK, TYROLLER AND PANZER, 2007).

2.5 Quality of Life

WHO (ORLEY ET AL, 1996) HAS DEFINED QOL AS INDIVIDUAL'S PERCEPTION OF THEIR POSITION IN LIFE ACCORDING TO THEIR CONTEXT OF THE CULTURE AND VALUE SYSTEMS IN WHICH THEY LIVE AND IN RELATION TO THEIR GOALS, EXPECTATIONS, STANDARDS AND CONCERNS (ORLEY ET AL, 1996). QOL PROVIDES A MEASUREMENT OF FUNCTIONING AND WELL BEING RATHER THAN OF DISEASES AND DISORDERS, HENCE IS MORE COMPREHENSIVE AND COMPATIBLE WITH WORLD HEALTH ORGANIZATION'S CONCEPT OF HEALTH (I.E. HEALTH IS A STATE OF COMPLETE PHYSICAL, MENTAL AND SOCIAL WELL-BEING AND NOT MERELY THE ABSENCE OF DISEASE). IT IS BELIEVED TO BE A BROAD CONCEPT INCORPORATING IN COMPLEX WAY AN INDIVIDUAL'S PHYSICAL HEALTH, PSYCHOLOGICAL STATE, LEVEL OF INDEPENDENCE, SOCIAL RELATIONSHIP, PERSON BELIEFS AND HIS/HER RELATIONS TO THE SILENT FEATURES OF THE ENVIRONMENT. QOL IS ALSO MULTIDIMENSIONAL, INCORPORATING POSITIVE [E.G. FEELING HAPPY, CONTENDED, AND ENERGETIC] AS WELL AS NEGATIVE ASPECTS [E.G. NOT HAVING PAIN, SADNESS, AND SEXUAL DIFFICULTIES] (ORLEY ET AL, 1996).

QUALITY OF LIFE ASSESSMENT INVOLVES A CLASS OF MEASUREMENT FUNDAMENTALS TO MANY ASPECTS OF HEALTH CARE PLANNING AND OUTCOMES RESEARCH. IT IS RELEVANT FOR ASSESSING SYMPTOMS, SIDE EFFECTS OF TREATMENT, DISEASE PROGRESSION, SATISFACTION WITH CARE, QUALITY OF SUPPORT SERVICES, NEEDS THAT WERE NOT MET WITH AND APPRAISAL OF HEALTH CARE OPTIONS. PATIENT'S SELF-REPORTS IS THE MOST DESIRABLE AND OFTEN THE ONLY WAY TO OBTAIN THIS CRITICAL INFORMATION. THUS, ACCURATE AND MEANINGFUL MEASURES OF THE VARIOUS DIMENSIONS OF QUALITY OF LIFE ARE VITALLY IMPORTANT (RAPKIN AND SCHWARTZ, 2004).

The *Quality of Life Profile* was developed to provide a measure that considers both the components and determinants of health and well-being. It draws upon a conceptual model that is consistent with the recent definitions of health and health promotion as provided by the World Health Organization. The profile emphasizes individuals' physical, psychological, and spiritual functioning; their connections with their environments; and opportunities for maintaining and enhancing skills. Possibilities result from the opportunities and limitations each person has in his/her life and reflect the interaction of personal and environmental factors (*Brown* et al, 1993).

2.6 Summary of literature review

Psychosocial health helps a person to appreciate life that directly and indirectly contributes to his/her quality of life. Usually, a psychosocially healthy person has high resilience and can bounce back to struggle with cancer. Social supports are vital to increase resilience within an individual. The level of quality of life depends both on individual's coping level and on the social supports. The level of psychosocial health determines his/her ability to face cancer.

CANCER IS EMERGING AS CHALLENGING PROBLEMS IN SOUTH ASIA INCLUDING NEPAL. INTERVENING CANCER DISEASE WITH MEDICINES IS INADEQUATE SINCE BIO-PSYCHO-SOCIAL ASPECTS PLAY DYNAMIC ROLE IN TREATMENT OUTCOME AND RESILIENCE OF THE CANCER PATIENT. THUS, UNLESS THE CONSIDERABLE PSYCHOSOCIAL PROBLEMS OF CANCER PATIENTS ARE RECOGNIZED AND ATTENDED TO, THE RELIEF OF PAIN AND OTHER SYMPTOMS MAY BE DIFFICULT TO ATTAIN. THESE NEEDS MAY BE COMMON TO CANCER PATIENTS IN ALL CULTURES. MANY PATIENTS, HOWEVER, WILL NOT RAISE PSYCHOSOCIAL PROBLEMS UNLESS PROMPTED. THEREFORE, THERE IS A NEED TO ADDRESS AN AWARENESS OF PSYCHOSOCIAL CONCERNS, MAKING PEOPLE WILLING TO SPEND THE TIME THAT IS REQUIRED FOR ITS DETECTION, EVALUATION AND IMPROVEMENT. THIS STUDY IS DOCUMENTED IN THE FOUR DOMAINS OF QUALITY OF LIFE VIZ. PHYSICAL, PSYCHOLOGICAL, SOCIAL RELATIONSHIPS AND ENVIRONMENT AS DEFINED BY WORLD HEALTH ORGANIZATION (WHO), EXTENDING ACROSS THE CONTINUUM FROM ONE MONTH OF CANCER DIAGNOSIS TO PALLIATIVE CARE AMONG HEAD AND NECK, LUNG, BREAST AND UTERINE CERVIX CANCER.

THE MAIN AIM OF THIS STUDY IS TO GENERATE IDEAS APPLIED TO UNDERSTAND AND DRAW 'A VIVID PICTURE OF THE LIVED EXPERIENCE' COMPLETE WITH THE RICHNESS OF DETAIL AND CONTEXT THAT SHAPED THE EXPERIENCE OF THE PEOPLE AFTER DIAGNOSIS OF CANCER. THIS RESEARCH IS PARTICULARLY INTENDED TO VERIFY THE NEEDS AND CHALLENGES IN THE DELIVERY OF PSYCHOSOCIAL CARE TO THE CANCER PATIENTS FROM THE CULTURE-SENSITIVE POINT OF VIEW. TO PROVIDE A THEORETICAL FRAMEWORK FOR THIS RESEARCH, LITERATURES ON PSYCHOSOCIAL FACTORS AND QUALITY OF LIFE WERE REVIEWED.

ANXIETY AND DEPRESSION IS THE PSYCHOLOGICAL CONSEQUENCES, WHICH WERE RELATED TO MAJORITY OF THE CANCER PATIENTS EVERYWHERE. PRESENT STUDY RESULTS PROVIDED SEVERAL IMPORTANT IMPLICATIONS FOR UNDERSTANDING THE IMPACT OF CANCER AND ITS RELATED ANXIETY AND DEPRESSION ON PATIENTS' QUALITY OF LIFE.

FIGURE 2.1

CONCEPTUAL FRAMEWORK BASED ON MODIFIED HEALTH BELIEF MODEL

FIGURE 2.1 DEPICTS THE CONCEPTUAL FRAMEWORK OF THIS STUDY, WHICH IS BASED ON MODIFIED HEALTH BELIEF MODEL (BECKER, 1978); CONCEPT ON PSYCHOSOCIAL RESPONSE TO ILLNESS AND ITS TREATMENT (GORMAN, RAINES & SULTAN, 2002), AND WORLD HEALTH ORGANIZATION'S QUALITY OF LIFE MODEL, WHICH INCLUDES FOUR DOMAINS NAMED AS PHYSICAL, PSYCHOLOGICAL, SOCIAL RELATIONSHIPS, AND ENVIRONMENT (ORLEY, ET AL., 1996).

THIS STUDY ADOPTED MODIFIED HEALTH BELIEF MODEL, WHICH WAS FIRST DEVELOPED IN THE 1950S BY SOCIAL PSYCHOLOGISTS HOCHBAUM, ROSENSTOK AND KEGELS WORKING IN THE UNITED STATES (U.S.) PUBLIC HEALTH SERVICES. MODIFICATIONS WERE DONE TO THE MODEL BY DIFFERENT RESEARCHERS. THIS STUDY HAS ADOPTED MODIFIED HEALTH BELIEF MODEL, WHICH IS A PSYCHOSOCIAL MODEL THAT FOCUSES ON ATTITUDES AND BELIEFS OF THE INDIVIDUALS. ACCORDING TO HEALTH BELIEF MODEL, HEALTH-RELATED BEHAVIORS ARE INFLUENCED BY A PERSON'S PERCEPTION OF THREAT CAUSED BY A HEALTH PROBLEM AND THE VALUE ASSOCIATED WITH THE ACTIONS AIMED AT REDUCING THE THREAT (BECKER, 1978).

CANCER IS CONSIDERED AS A CHRONIC DISEASE IN DEVELOPED PART OF THE WORLD DUE TO ADVANCED TREATMENT AND COMPREHENSIVE CARE RECEIVED BY THE PATIENTS TO INCREASE THEIR SURVIVAL. HOWEVER, NEPALESE CANCER PATIENTS STILL PERCEIVED IT AS A LIFE THREATENS/FATAL DISEASE DUE TO LACK OF ADVANCE TREATMENT AND COMPREHENSIVE CARE PROVIDED TO THEM. DEATH IS UNIVERSAL PHENOMENA, BUT IT IS NEVER ACCEPTED BY ANY INDIVIDUAL IRRESPECTIVE OF THEIR AGE, SEX, EDUCATION, NATIONALITY, AND OTHER SOCIAL CHARACTERISTICS, AND DISEASE CONDITIONS. THIS STUDY ASSESSED THE THREATS PERCEIVED BY AN INDIVIDUAL DUE TO DIAGNOSIS OF CANCER AND ADVERSE EFFECTS OF DIFFERENT TYPES OF TREATMENT, WHICH IS AN INITIAL CONCEPT OF HEALTH BELIEF MODEL. THIS IS A SIMILAR CONCEPT, ANY CHRONIC ILLNESS HAS SOME PSYCHOSOCIAL IMPACT, WHICH THREATENS THE INDIVIDUAL'S LIFE AND EVOKES A WIDE ARRAY OF EMOTIONS, SUCH AS FEAR, SADNESS, ANGER, DEPRESSION, DESPAIR AND LOSS OF CONTROL. IN THE CASE OF CHRONIC ILLNESS, THERE ARE HIGHER CHANCES OF

HAVING SOCIAL DETACHMENT AND ISOLATION. EACH INDIVIDUAL, WHO FACES ILLNESS, RESPONDS DIFFERENTLY ACCORDING TO PERSONALITY, PREVIOUS LIFE EXPERIENCES AND COPING STYLE (GORMAN, RAINES, & SULTAN, 2002). THEREFORE, THE RESEARCHER DECIDED TO ASSESS THE PERCEIVED LEVEL OF PSYCHOSOCIAL FACTORS, WHICH IS MAINLY DIVIDED INTO TWO CATEGORIES VIZ. PSYCHOSOCIAL ADJUSTMENT FACTORS COPING, AND SOCIAL SUPPORT AND SELF-ESTEEM; AND PSYCHOLOGICAL CONSEQUENCES IN TERMS OF ANXIETY AND DEPRESSION. COPING STRATEGIES IS AN ADJUSTMENT FACTOR DURING PSYCHOSOCIAL HOMEOSTASIS IN RELATION TO DEFENSE MECHANISM. SOCIAL SUPPORT AND SELF-ESTEEM IS ANOTHER INDEPENDENT PSYCHOSOCIAL FACTOR TO STRENGTHEN QUALITY OF LIFE. ADOPTIVE COPING SKILLS OR ADJUSTMENT FACTORS HELP TO ENHANCE SOCIAL SUPPORT AND SELF-ESTEEM. THESE THREE COMPOSITE INDEPENDENT VARIABLES, COPING STRATEGIES, SOCIAL SUPPORT AND SELF-ESTEEM IS RELATED TO PSYCHOSOCIAL FUNCTIONING OF THE PERSON. ON THE OTHER SIDE, THERE ARE PSYCHOLOGICAL CONSEQUENCES NAMED AS ANXIETY AND DEPRESSION, WHICH ARE THE INDEPENDENT VARIABLES FOR THIS STUDY. ANXIETY AND DEPRESSION ARE UNAVOIDABLE CONSEQUENCES IN CANCER, AS IT IS A LIFE THREATENING AND NON-CURABLE DISEASE; ITS TREATMENT MAY CONTINUE FOR LONGER PERIOD AND MAY HAVE SEVERE ADVERSE EFFECTS, THUS AFFECTING THE QUALITY OF LIFE. ANXIETY AND DEPRESSION IS ALSO THE CONSEQUENCES OF FAILURE OF COPING STRATEGIES, LACK OF SOCIAL SUPPORT, AND LOW SELF-ESTEEM, WHICH IS DUE TO DESPERATE EFFORT OF COPE WITH SITUATION, ETC. AS WELL AS DURATION OF DIAGNOSIS, SEVERITY OF CANCER SYMPTOMS SUCH AS PAIN. DEMOGRAPHIC CHARACTERISTICS OF THE CANCER PATIENTS ALSO TAKEN IN TO CONSIDERATION AS IT MAY AFFECTS QUALITY OF LIFE DIFFERENTLY ACCORDING TO THEIR CONTEXT.

THIS STUDY WAS LIMITED TO THE ASSESSMENT OF PERCEIVED LEVEL OF PSYCHOSOCIAL FACTORS IN RELATION TO QUALITY OF LIFE AMONG CANCER PATIENTS. THEREFORE, RECOGNITION OF PSYCHOSOCIAL IMPACT (BOTH POSITIVE AND NEGATIVE); CUES FOR INTERVENTION AND LIKELIHOOD ACTION ARE DEPICTED WITH DOTTED LINES AS THEY WERE NOT INCLUDED IN THIS STUDY.

CHAPTER - 3

RESEARCH METHODOLOGY

3.1 Research Types and Design

This is an empirical study, adopted a cross-sectional descriptive research design, which was an exploratory in nature. Descriptive research design is a scientific method which involves observing and describing the behavior of the research participant/s without influencing it. Many scientific disciplines, especially social sciences, use this method to obtain a general overview of the research participants. The descriptive research design also helps to set an avenue for the hypothesis of the variables.

This study enrolled 300 samples, out of which 280 were utilized for quantitative analysis and were collected from cancer hospitals. Rest 20 research participants were enrolled from cancer hospitals as well as from their door-steps. This study adopted both quantitative and qualitative research method. Empirical research method is broadly divided into quantitative and qualitative research. These methods are designed to collect different types of data to answer the research questions (Yin, 1994). The qualitative method has large potentialities to explore the social phenomena and to reveal the actual behavior. Quantitative data is collected to generate measures that are reliable, generalizable, and unbiased (Steckler et al, 1992). Establishing causal relationships through statistical means between predetermined variables is basic in the quantitative research paradigm (Steckler et al, 1992).

Qualitative researches immerse in the culture and research the participative world of the informants. The goal in collecting qualitative data is to elicit an insider’s view towards the topic under study (Steckler et al., 1992). Qualitative method is intensive in approach and quality in response is the motto. Thus, qualitative studies generally rely on a smaller number of informants to obtain rich description of the phenomenon under study. Rich and detailed data are the advantages of qualitative method. It also provides a contextual understanding of health behavior (Steckler et al, 1992).

This study has adopted in-depth interview method as it is one of the most common qualitative methods and is frequently used in social and behavioral research. One of the reasons for its popularity is that it is very effective in giving a human face to research problems. In addition, conducting and participating in interviews can be a rewarding experience for participants and interviewers alike. Therefore, this study utilizes the qualitative method in addition to the quantitative method. A practice of combining both qualitative and quantitative method is known as methodological triangulation and is essential to explore psychosocial factors in relation to quality of life of cancer patients in Nepal.

The quantitative method is used in research by social scientists for a variety of reasons. This study adopted survey method under quantitative research, as it is designed to deal more directly with the nature of people's thoughts, opinions and feelings (Shaughnessy and Zechmeister, 1994) and interrelations among sociological and psychological variables (Kerlinger, 1983). Quantitative studies usually regard culture and human action from a narrow perspective and attempt to isolate the issue from the whole. This may limit the data quality from the informants' perspective. Some quantitative methods have not always yielded new information (Good, 1994).

Given the guiding conceptual model, the present study is designed to relate the major psychosocial factors such as coping, social support, self-esteem, anxiety and depression to quality of life of cancer patients. Data was collected using questionnaires available from World Health Organization (WHO) and other sources specifically for the research purpose. Dependent variable, the quality of life, was assessed through the scores obtained from WHOQOL-BREF, which is constituted with four domains viz. physical, psychological, social relationships and environment (Orley et al, 1996). Independent variable, the psychosocial factors was assessed through calculating the scores obtained from Carver's Brief cope, MOS Social Support Survey

Scale, Rosenberg's Self-esteem, Hamilton’s Anxiety scale, Beck Depression Inventory-II (BDI-II).

Some of the research problems of the present study cannot be addressed by the quantitative method due to lack of basic information on the psychosocial aspects of cancer patients in Nepal. Besides, general information and measurement obtained by the use of some standardized instrument which is essential for conducting quantitative study. Therefore, this study also adopted qualitative research method to support the data gathered through quantitative method and to obtain new original information that is not possible through quantitative tools especially subjective or insider's view on specific issue that is constructed and shared through socio-cultural practices. The researcher alone has collected whole information for this study. A methodological triangulation was done to conclude the results of this study.

A methodological triangulation involves using more than one method and may consist of within-method or between-method strategies. By combining multiple methods and empirical materials, a researcher can hope to overcome the weakness or intrinsic biases and the problems that come from single-observer (Webb, 1966). Triangulation research approach deals with the application and combination of several research methodologies in research of the same phenomenon or it also refers to the use of more than one approach to investigate a research question in order to enhance confidence in ensuring the findings. It can be employed in both quantitative (validation) and qualitative (inquiry) studies. The idea of triangulation frequently associated with measurement practices in social and behavioral research (Webb, 1966). The complexity of social phenomena sometimes demands triangulation so that data derived from the two methods meet and make the data more meaningful as a whole. The use of qualitative method as a preparation strategy for quantitative research is well established.

Figure 3.1

Schematic Representation of Research Design

Figure 3.1 depicts the research design and type, which shows that this is a descriptive cross-sectional research design and sample drawn from Nepalese cancer patients. This study describes the psychosocial factors of the cancer patients on the basis of their cognitive domain that is thinking and experiences; emotions that is their reaction to the cancer after diagnosis and their feeling towards social phenomena in relation to social support. Figure 3.1 also depicts demographic, disease and psychosocial factors; they are related with each others. Yet, this study was conducted with the aim of psychosocial determinants in relation to quality of life among the cancer patients in Nepal.

3.2 Sample area

The study is based on data collected from two hospitals namely B.P. Koirala Memorial Cancer Hospital (BPKMCH) and Bhaktapur Cancer Hospital (BCH); and community (door-step of the research participants) from 15th October 2008 to 15th June 2009. Nepal has only two cancer hospitals providing comprehensive services to the cancer patients. Altogether, 294 samples were registered from both hospitals, out of which 280 samples were utilized for quantitative study and 14 of them were utilized for qualitative study, as per the eligibility criteria. Rest 6 samples for qualitative study were registered from their homes.

Total of 601 patients attended BPKMCH from 15th October 2008 to 15th February 2009 (4 months) with final diagnosis of head and neck cancer, breast cancer, lung cancer and uterine cervix cancer, these patients were the population for this study. Of the total, 253 (42%) who met the eligibility criteria were registered for quantitative study. Among them 60 were diagnosed with breast cancer, 62 lung, 65 head and neck and 66 uterine cervix cancer. Eight samples from BPKMCH participated in qualitative study.

Total of 78 patients attended BCH from 17th February to 15th April 2009 (2 months) and were diagnosed of head and neck, breast, lung and uterine cervix cancer. Of the total, 27 (35%) samples who met the eligibility criteria (10 breast, 8 lung, 5 head and neck and 4 uterine cervix) were deployed for quantitative study. Six samples from BCH participated for qualitative study.

BPKMCH, Bharatpur is situated in the Central Development Region of Nepal and is the only government-supported specialized cancer hospital in the country, where comprehensive care is being provided to the cancer patients. Patients come for treatment from all over the country as well as from North India. BPKMCH is a referral center for cancer treatment. It is a 100 bedded hospital having surgical, medical, radiological and post-operative wards. This hospital is well equipped for cancer diagnosis and treatment such as surgery, chemotherapy, internal and external radiation therapy, immunotherapy, etc. It is also providing community services for awareness, screening programs; and training to the health workers and teachers. In addition to that, this hospital has a hospice center for providing palliative/supportive care. BCH, Bhaktapur, a private, but specialized cancer hospital with facility of diagnosis, surgery, chemotherapy and external radiation therapy, is located near central Kathmandu (Capital of Nepal). This is also a referral center for different hospitals in Kathmandu. Bhaktapur cancer hospital is a specialized hospital for cancer patients and it has capacity of 42 beds.

Both hospitals are specially designed to meet most of the medical and surgical needs of cancer patients including administration of chemotherapy when needed, laboratory sampling for blood counts, and ability to access blood products for administration. These hospitals have also been providing comprehensive care for most medical need that arises at any point of time to the any type of cancer patient. Along with the quantitative data, 20 cases were deployed for qualitative data through in-depth interview. Out of 20 cases, 14 cancer patients were deployed from both hospitals; whereas 6 cancer patients were deployed from their door step/community field during the month of May and June 2009. Total 8 months were spent in collecting data for this study.

3.3 Population and Sample Size

To draw the sample from study population, that is cancer patients of Nepal, the inclusion criteria were: all adults (18 years and above), diagnosed with head and neck, lung, breast and uterine cervix cancer for more than a month, able to communicate and mentally stable and willing to participate in the study. Cancer patients, who were unwilling to participate and having other problems like mental retardation, diagnosed with psychosis and unable to communicate properly were excluded from this study.

This type of study has not been conducted in Nepal and no data related to psychosocial aspect of cancer is available. Therefore, sample size estimation is done on the basis of observed prevalence rate (47%) of psychiatric disorders as defined in the Diagnostic and Statistical Manual of Mental Disorders III (DSM-III) in a cohort study of cancer sufferers (Razavi and Stiefel, 1983).

Formula used for sample size estimation (n) = Z^2PQ/d^2

$2^2*47*53/ (6.3)^2 = 251+ 26 = 277$

Here, Z value is set at 2, which is as per standard value (1.96) at 95% of confidence interval. Prevalence of psychiatric disorders, which is drawn from previous study (P= 47%), value of Q calculated on the basis of prevalence (100-P) =100-47=53; Power of ‘d’ is the percentage value of P (13.4%= 6.3), which is set by the researcher. In the descriptive study up to 40% difference (d) can be taken into consideration. Yet, lower percentage of ‘d’ value considered as more valid sample. Systematic and non-systematic error was covered by adding 10% of extra sample= 25.1

Sample size estimation was done on the basis of observed prevalence rate of previous researchers. Cohort study is considered as more reliable research method, and a DSM criterion is a valid measure for categorization of disease. While dealing with the human subjects, there is chances of having error as each individual are unique in nature, they might response of structured questions in different way. Therefore, 10% of sample was added to minimize systematic and non-systematic sampling error. Twenty samples were registered for qualitative study to support the data and justify the sample in this study.

This study covered 18 to 80 years old cancer patients. Altogether 300 cancer patients were enrolled in this study, out of which 280 research participants (Male 101 and Female 179) were enrolled for quantitative part of study; and 20 research participants (Male 6 and Female 14) were enrolled for qualitative part of the study.

3.4 Sampling Procedure

Non-random purposive samples of people, with age between 18 to 80 years diagnosed as selected cancer were deployed in this study. In purposive sampling method, a sample is chosen which is thought to be typical of the universe with regard to the characteristics under investigation. When the desired population for the study is rare or very difficult to locate and recruit for a study, purposive sampling may be the only option. The sample element was arbitrarily selected by the researcher, because by the researcher's judgment, this element represented the population most effectively. Research participants (sample) for this study were identified from the out-patient-department (Day care and radiation therapy unit) and in-patient-department (Medical, radiation, surgery, and palliative ward) of both hospitals by going through the out-patient-department (OPD) card/ in-patient chart; and the selected cancer patients were contacted for participation in the quantitative study.

3.5 DATA COLLECTION METHOD: QUALITATIVE AND QUANTITATIVE: TRIANGULATION

All the cancer patients who attended the selected hospitals or traced out from community during study period were contacted; and those who agreed to participate and met the eligibility criteria were enrolled for the study. Data was collected from the primary source, i.e. the people who were suffering from cancer at least for a month. Data collection for quantitative study was done through direct interview using standardized (Validated and Reliability checked) structured questionnaire.

Participants were given a quiet environment and ample time to complete the survey. After initial settlement and establishment of rapport with the cancer patients, the questionnaires were administered. All psychosocial and quality of life tools were administered to all patients. The research instruments were administered in two phases. In the first phase, structured questionnaire of Carver's Brief cope inventory, MOS social support survey, Rosenberg's self-esteem scale, Hamilton' Anxiety Scale, and Beck depression inventory-II, and in second phase and World health organization quality of life (WHOQOL-BREF) was administered. The first phase took approximately 1 to 1½ hours and second phase took another 1 to 1½ hours, which was planned and implemented in two separate sessions in two different days to minimize monotonous response between psychosocial factors and quality of life and exertion of the research participants. Total 280 research participants were enrolled for quantitative study. Quantitative data was collected from the hospitals to study present phenomena.

Data for qualitative study was collected through in-depth interview of those cancer patients, whose diagnosis was made one year before. Other eligibility criteria remained same as that of quantitative part of this study. Data was collected at their doorsteps or in the hospital to study the phenomena retrospectively. Qualitative data also collected in 2 separate sessions/phases as in quantitative study. Open-ended guidelines were prepared by the researcher for in-depth interview, which was related to same phenomena of psychosocial factors and quality of life of cancer patients.

An attempt was made to maintain the uniformity in the administration of the tools by filling up the questionnaire strictly according to the instructions by the researcher alone as all questionnaires were based on rating scale. Therefore, in this study, there is no inter-rater variability. Even though instruments used for this study were self-reported tools, yet, face-to-face interview technique was used, because most of the research participants were illiterate. As it was a direct interview, response rate was very high, that is, 98% research participants participated in the study or out of a total of 285 cancer patients, only 5 (2%) refused to participate in the study. Hence, final analysis for quantitative part of this study was done with 280 research participants. The reasons for refusal included the long length of the questionnaire and their denial to remember the bitter truth.

3.6 STANDARDIZED TOOLS AND RATIONALE

A standardized questionnaire was adopted for the quantitative study to measure psychosocial factors and quality of life. These standardized tools are most frequently used in health research for screening and diagnostic purposes. Several scales constructed to measure the research participants’ endorsement of psychosocial factors and their sense of relational quality of life. Procedures taken to construct standardized tools were almost identical for all the scales, which was adopted for the study.

Quantitative measurements have six-parts of questionnaires such as cope inventory, social support survey scale; self-esteem scale, anxiety scale, depression inventory and quality of life scale were utilized from the pre-existing tools accessed from the World Health Organization (WHO) and other sources. These tools were measured the psychosocial factors and quality of life of the cancer patients, which is also known as Likert's scale. Likert's scaling method is also known as the technique of summated rating. A number of statements, some in positive sense and some in negative sense, are constructed. Number of statements should be sufficiently large to include all shades of opinions in attitude continuum (Singh, 2007). Four to five points rating scales weight (1, 2,3,4,5 and 0, 1, 2, 3) were used in this study, which is enough to measure the psychosocial phenomena of the cancer patients. The basis for selection of these tools was based on their internal consistency (value of correlation coefficient) among sub-scales, which has been checked by different researchers during standardization process respectively. A rule of thumb was to select the scale items of loading factor less than one that means these items reduced the reliability coefficient alpha (DeVellis, 1991).

3.6.1 Coping Scale

This study adopted Brief-COPE Inventory to measure the level of coping among cancer patients. COPE inventory is mainly interested in how people respond when they confront difficult or stressful events in their lives. The COPE inventory has been validated in many languages such as Estonian, Croatian, Chinese, Italian, Spanish and French population (Muller and Spitz, 2003).

Brief COPE Inventory was developed based on concepts of coping skills (Lazarus and Folkman, 1984). Carver (1997) developed brief COPE inventory to measure the coping abilities of individuals and to assess a broad range of coping responses. The inventory includes some responses that were expected to be dysfunctional, as well as some that are expected to be functional. Brief-COPE Inventory was a widely used tool for academic and research purposes in different countries including Nepal and India. It was easy to use as coping measure was worldwide spread among health and psychological studies allows a better broadcast and comparison of results whatever the pathology and it had good psychometric properties too (Muller and Spitz, 2003). Despite the fact that individual coping pattern can be identified which is very useful for psychosocial counseling, the present researcher was only depict a general pattern of coping style, as not analyzing the individual coping pattern but a general picture that is easy to relate with psychosocial health and quality of Life.

Brief COPE was a measure used for many health-relevant such as drugs addiction, ageing, cancer, depression, AIDS (Cited in Muller and Spitz, 2003). The Brief cope inventory was used among the employee of society for social workers (SSWR), who were experiencing work-related stress resulting from working with traumatized individuals and groups (Jodi, 2005). Validity and reliability of brief COPE inventory was tested among Malay breast cancer patients, where internal consistencies ranged from 0.51 to 0.99. There was consistent result, the test-retest intra-class correlation coefficient less than 0.98. Sensitivity of the scale was observed in nearly all of the domains with effect size index less than 0.49 (Yusoff, Low and Yip, 2009). But, there is lack of evidence of standardization of brief COPE inventory among cancer patients in Nepal.

The Brief cope scale is a 28-item self-report measure of both adaptive and maladaptive coping skills. The scale was designed to yield fourteen subscales, comprised of two items each with no reversals of coding. The scale consists of self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Each item describes a particular way of coping. The scoring criteria of this tool indicated like 1=I haven't been doing this at all, 2= I've been doing this a little bit, 3=I've been doing this a medium amount and 4=I've been doing this a lot. The total score ranges from 1 to 112, and each subscale score is 1 to 8 (Appendix-II). Reliability score for each subscale ranged from 0.75 to 0.82.

3.6.2 Social Support Survey Scale

The level of social support among cancer patients was measured through medical outcomes study (MOS) social support survey scale in this study. MOS social support survey is a brief, multidimensional, self-administered survey that was designed to be comprehensive of various dimensions of social support. According to the MOS social support scale instrument, people sometimes seek companionship, assistance, or other types of support from others. This scale allowed an examination of mediation of events and other stressors by assessing the availability of perceived social support. The tool’s developers selected response items based on the current theory of the most important dimensions of social support, primarily the perceived availability of functional support (Sherbourne and Stewart, 1991). This tool is used among young adult cancer patients during camp experience (Handley, 2004). Though, there is lack of evidence of standardization of MOS social support survey scale among cancer patients in Nepal.

There were 19 items in this tool, out of those 18 items were divided into four subscales: tangible or instrumental support; affectionate; positive social interaction, including companionship in leisure and other recreational activities; and a combination category of emotional/informational support, including love and empathy, and providing feedback and guidance. Responses corresponded with a 5-point Likert scale ranging from 1 (none of the time) to 5 (all of the time). These support measures are distinct from structural measures of social support and from related health measures (Sherbourne and Stewart, 1993). Items from the MOS social support survey were randomized within the survey participants. The range alpha reliability for the subscales and overall support index is reported to from 0.91 to 0.97. A score on the original MOS social support survey scale is 1 to 95, yet percentage is calculated, created the lowest possible score was 0 and the highest possible score was 100, indicating more frequent availability of different types of support. The overall index of support was calculated using each of the subscale scores and one additional item (Appendix-II). A higher score for an individual scale or for the overall support index indicated more support.

3.6.3 Self-esteem Scale

Self-esteem of cancer patients was measured through Rosenberg’s self-esteem scale in this study. The scale have chosen to measure level of self-esteem among cancer patients in this study as it is most widely used tool to measure self-esteem in social sciences research. This tool was used in a variety of settings like in school (Adolescence), industries (Employee) and cancer patient as well (Maharjan, 2010, Monina, 2008, Sujatha, 2006, Dimitra, et al., 2005, & Karen, et al., 2004). This scale is the most widely used instrument to measure self-esteem despite certain negative criticism. There is lack of evidence of standardization of Rosenberg self-esteem scale among cancer patients in Nepal.

The self-esteem scale is now commonly scored as positive and negative form. The 10 items are answered on a four point scale ranging from strongly agree to strongly disagree. During coding of data, five statements were coded in reversed forms as those items were stated in negative statements such as for items 3, 5, 8, 9, 10 (which are reversed): Strongly Agree=1, Agree=2, Disagree=3, and strongly Disagree=4. Whereas, rest items 1, 2, 4, 6, 7: Strongly Agree=4, Agree=3, Disagree=2, and Strongly Disagree=1. The scale's score ranges from 10-40, with 40 indicating the highest score possible, which corresponds to a high self-esteem among cancer patients (Appendix-II). The scale appearance high reliability through test-retest correlations, which was ranges from 0.82 to 0.88, and Cronbach's alpha for various samples were ranges from 0.77 to 0.88. The scale has demonstrated both one-dimensional and two-factor (self-confidence and self-deprecation) structure.

3.6.4 Anxiety Scale

Hamilton's anxiety scale (HAM-A) was adopted for this study to measure the level of anxiety among cancer patients. Max Hamilton (1959) introduced an anxiety scale to measure the severity of anxiety symptoms such as anxious mood, tension, and depressed mood, palpitations, breathing difficulties, sleep disturbances, restlessness and other physical symptoms. HAM-A was one of the first rating scale developed to measure the severity of anxiety symptomatology. This is a widely used scale and an accepted outcome measure in clinical trials. A number of validation studies of the clinician HAM-A document its psychometric properties. Internal scale consistency (coefficient alpha) is high (0.92), the mean item-to-total scale correlation was .65, and the test-retest reliability was 0.96. This tool is used among infertile women attended to sub-fertility centers of selected hospitals in Kathmandu, Nepal (Mainali, 2010), and patients with panic disorders in BPKIHS, Dharan, Nepal (Amatya, 2005). However, there is lack of evidence of standardization of HAM-A tool among cancer patients in Nepal.

HAM-A consists of 14 items, each defined by a series of symptoms. Each item is rated on a 5 points scale, ranging from 0 (not present) to 4 (severe). Out of 14 items, 8 items (Item numbers 1 to 6, 12 and 14) are related to psychological symptoms, where as rest 6 (Item numbers 7 to11 and 13) are related to physical symptoms of anxiety. HAM-A score level of anxiety up to 17 corresponds to mild, scores 18-24 corresponds to moderate and score 25 and above corresponds to severe anxiety (Appendix-II).

3.6.5 Depression Inventory/Scale

Beck Depression Inventory- II (BDI-II) is adopted for this study to measure the level of depression among cancer patients. BDI-II was modified by Beck et al in 1996 from original BDI-I developed in 1978. The new edition of the Beck Depression Inventory is the most widely used instrument for measuring depression. BDI-II is used in a wide age range from 13 to 80 years. It is a widely used tool to assess level of depression among outpatients and short-term inpatients (Beck, Steer, & Brown, 1996).

BDI-II is designed as a standardized measure to calculate the depth of depression. Its items were based on observations of attitudes and symptoms characteristic of depressed patients. All significant symptoms and attitudes associated with depression were accounted for; since the number of reported symptoms were found to be associated with the depth of depression. It is an invaluable tool for screening and diagnosis and is also used extensively to monitor therapeutic progress. Twenty-one items assess the intensity of depression in clinical and normal individuals. Represented within the inventory are 21 categories of symptoms and attitudes: sadness, pessimism, sense of failure, dissatisfaction, guilt, sense of punishment, self- dislike, self-accusations, suicidal ideation, crying spells, irritability, social withdrawal, indecision, distorted body image, work inhibition, sleep disturbance, fatigability, loss of appetite, weight loss, somatic preoccupation, and loss of libido. Each symptom category consists of a series of statements referring to the intensity of each symptom, since this variable was also found to be associated with the depth of depression. Thus, the BDI score is the function of both the number of symptoms reported and their intensity. The reliability of BDI determined with split-half method and Spearman-Brown correlation was 0.93. Scores on the BDI were found to correlate well with other measures of depression also (Corisini, 1996).

This tool is also used in Nepalese context for psychological studies among poisoning cases (Lohani, 2004). BDI-II was used among geriatric admitted medical Nepalese patients with different medical diagnosis (Kumar, 2010). Nepali version of BDI first validated in OPD, teaching hospital, Kathmandu and rural community of Jumla, Nepal among healthy (no-psychiatric diagnosis) population. Despite cultural and linguistic differences, the instrument shows good sensitivity and specificity when compared with the gold standard of DSM-IV diagnoses. A cut-off score of 16/17 for the BDI is suggested if one wants comparable specificity

(0.86) and sensitivity (0.85) (Kohrt, et al., 2001). Yet, there is lack of evidence of validation of BDI-II among cancer patients in Nepal.

Each answers being scored on a scale value of 0 to 3 and the total score is ranged from 0-63. Higher scores correspond to higher level of depression. There are different classifications of BDI-II available to categorize the level of depression according to the settings. It is a well-known fact that cancer is a chronic and life threatening disease and having pain symptoms. Clinicians declared that among the cancer patients, there was some degree of depression exists. BDI-II score level of depression less than 15 corresponds to mild; 15 - 30 corresponds to moderate and more than 30 to severe depression (Appendix-II).

3.6.6 Quality of Life (QOL) Scale

WHOQOL-BREF was adopted to measure quality of life among cancer patients in this study. The WHOQOL-BREF is a shorter version of the original instrument that may be more convenient for use in large research studies or clinical trials. The World Health Organization Quality of Life (WHOQOL) project was initiated in 1991. The aim was to develop an international cross-culturally comparable quality of life assessment instrument. It assesses the individual's perceptions in the context of their culture and value systems and their personal goals, standards and concerns. The WHOQOL instruments were developed collaboratively in a 15 field centers worldwide including India (New-Delhi and Madras). The WHOQOL is now available in over 20 different languages and its development in further languages is progressing**.** The instrument was rigorously tested to assess its validity and reliability in centers and is currently being tested to assess responsiveness to change. It includes a generic English language version of the WHOQOL-BREF, containing instructions for administering, scoring and proposed uses for this short form of the WHOQOL (WHO, 2007). Validity, reliability, internal consistency, and dimensional structure of the WHOQOL-BREF were tested in a heterogeneous Iranian population too. Where, physical health domain contributed most in overall quality of life, while the environment domain made the least contribution. The WHOQOL-BREF had adequate psychometric properties and is, therefore, an adequate measure for assessing quality of life at the domain level in an adult population (Usefy, et al., 2006).

WHOQOL instrument was also used among cancer patients in Japan, with differences by gender, treatments and cancer sites were also found to be significantly different. The results of their study indicated that the WHOQOL core instrument was sensitive enough to evaluate the QOL of cancer patients as it had high reliability (Cronbach's alpha=0.96) and a high correlation within domains (Miyako, et al., 2010). Yet, there is lack of evidence of standardization of WHOQOL tool among cancer patients in Nepal.

The WHOQOL-BREF instrument comprises 26 items, which measure the following broad domains: physical health, psychological health, social relationships, and environment (Appendix-II). The instrument scores ranges from 1 to 130, higher score indicated higher quality of life.

3.7 TRANSLATION AND BACK TRANSLATION OF STANDARDIZED TOOLS

The standardized questionnaire was adopted in English and translated to Nepali by the researcher, who is bilingual. An effort was made to ensure that the translation carried the same meaning as the English version, at the same time being sensitive to the tone of Nepali language. To check on the researcher’s English translation, bilingual experts of Nepali language compared the version translated by the researcher, and provided comments on the differences between them. Another bilingual person was asked to review these differences in order to resolve the disagreements in the translation. In addition, meaning of any questionnaire item, which included typical colloquial English words or phrases, was cross-checked with a reliable English expert in order to ensure the meaning. Nepali version of the standardized tools also enclosed in this report (Appendix-VII).

Pre-testing of the standardized tool was done among 30 cancer patients from BPKMCH, BCH and B.P. Koirala Institute of Health Sciences (BPKIHS), Dharan, Sunsari, Nepal to find out the variation in use of different words and tones in eastern and western regions of Nepal (Appendix-VIII). Further correction was done to generate the meaning of original statement, as it is of importance for reliability and validity. Additional verification was also done by carrying both English and Nepali questionnaire with the investigator during interview to verify the information in case of confusion.

3.8 IN-DEPTH INTERVIEW GUIDELINES

In-depth interview is a technique designed to draw a vivid picture of the research participant's perspective of the psychosocial factors and quality of life. During in-depth interviews, the person being interviewed is considered the expert and the interviewer is considered the student. The researcher's interviewing techniques are motivated by the desire to learn everything the participant can share about the research topic. Researchers engage with participants by self-importance questions in a neutral manner, listening attentively to participants' responses, and asking follow-up questions and probes based on those responses. They do not lead participants according to any preconceived notions, nor do they encourage participants to provide particular answers by expressing approval or disapproval of what they say. In-depth interviews are usually conducted face-to-face and involve one interviewer and one participant (Kvale, 1996).

The in-depth interview was applied chiefly to get illness histories and personal experiences from the research participants. It helps to trace the past to understand the present and expected future behavior of the research participants. In-depth interview is suitable for investigating the perception of illness and factors associated with the quality of life of cancer patients. The self-designed open-ended guidelines about experiences of the research participants after having disease cancer were developed. In addition to the open-ended guidelines, personal diary of the researcher was used. By using this method the researcher was able to identify and uncover the factors, which was needed to maintain quality of life of cancer patients in the cultural context of Nepal.

Tuckman's (1972) cited in Cohen and Manion (1994) stated that in-depth interview should be completed in three phases, first phase being an introductory session to develop rapport as well as to give hints about the research matter. In second phase, detailed interview with probing questions is conducted. In the third phase, doubts, misinterpretations are clarified and the research participants are acknowledged. This study also followed the three phases during data collection. Tuckman's (1972) cited in Cohen and Manion (1994) also highlighted about interview time, which should be according to the convenience of the participants to get ideal information (Tuckman, 1972) cited in Cohen and Manion, 1994). Therefore, during data collection, cancer patients' convenience time was also taken into consideration.

A personal diary also maintained by the researcher to record non-verbal responses during interaction with the research participants. Podhisita (1993) stated that recording of non-verbal interactions have a meaning, which is helpful for reflection on the interviews. By noting non-verbal interaction during in-depth interviews, the researcher believes that the power and knowledge brought into play was identified and the researcher's position was understood. In a qualitative study, each action, object and gesture have a meaning and these are not openly expressed with other people due to culture and taboos (Podhisita, 1993).

3.9 ETHICS

Ethical clearance to conduct this research was obtained from Nepal Health Research Council (NHRC), Kathmandu, Nepal. Institutional administrative approval was obtained from B. P. Koirala Memorial Cancer Hospital, Bharatpur, Chitwan, Bhaktapur Cancer Hospital, Bhaktapur, and B.P. Koirala Institute of Health Sciences, Dharan, Sunsari, Nepal (Appendix- IX).

This research involved a lot of social and emotional effects as well as time consuming for the sample. Therefore, the researcher was aware of these issues and its direct negative impact on the research participants. All individuals have a right to maintain their confidentiality, privacy and personal situation. Specifically in qualitative research, the researcher searches the participants' personal situation. Cancer patients were explained about their full right to withdraw their participation from the study at any time during data collection, without hesitation. Informed consent was obtained from the each research participants. Therefore, cancer patients were asked to read and sign or listen (in case of illiterate) details which was written in informed consent form prior to completing the survey. A copy of the consent form has been attached (Appendix-I). Research is related to Nepali context; therefore researcher was well aware and paid attention to maintain the due respect of the research participants in relation to their values and social norms during collection. Confidentiality was maintained by excluded name and exact address of the research participants during analysis.

3.10 Statistics

The parametric and non-parametric tests were used to analyze the association between independent variables (demographic, disease and psychosocial factors) and dependent variable (quality of life). The collected data was handled by editing and documentation at each point of the analysis. The data cleaning was done in order to ensure that all the questions were answered. The researcher was rechecked all the collected data sheet immediately after administration, so that any missing questions and/or confusion were corrected with the research participants before s/he was discharged from the hospital or before leave research participants' house. Data was entered into the computer by using standard data entry system that is Microsoft Office Excel 2007 and then shift to Statistical Package for the Social Sciences (SPSS, Version 13.0) for the statistical analysis.

Data analysis for this study was organized in two ways. Data derived from the structured questionnaire was organized and entered into computer software for analysis. During data analysis in SPSS, univariate, bivariate and multivariate analysis techniques were used to conclude the result. Data derived from in-depth interview were scanned for commonalities and similar findings were added along with the description of the tables in this study.

The research objectives and questions were tested by using three inferential statistical tests such as chi-square, correlation and regression analysis to collected data. The first two research questions and objectives were tested through chi-square and Spearman's rank correlation to find out the association between demographic and illness related variables (independent variables) with quality of life (dependent variable) including its four domains. Chi-square test allowed the influence of independent variables on dependent variable, to be composed into its direct and indirect effects arbitrated by one variable another variable.

The third research question and objective was measured through Spearman's rank correlation, binary and multinomial logistic regression statistical tests. These tests were analyzed the direct effect of each psychosocial factors with every domains of quality of life or vice versa, which means while applying these tests on non-parametric/qualitative data, it gives inferences at micro level on two-ways (bivariate) and more than two (multivariate) of both independent and dependent variables. Endorsement of psychosocial factors and its critical values that were predicted to enhance quality of life were independent or interdependent and vice versa.

In this study, both psychosocial factors and quality of life had non-parametric data that was in the form of scores. Therefore, during analysis numerical as well as categorical forms of measurements were utilized to find out the associations of independent variables with dependent variables. Spearman’s rank correlation gave inferences of numerical values, which was applied with obtained open scores and shows the relationship either negative or positive forms.

Regression analysis statistical test also deployed to find out the relationship of psychosocial factors with quality of life. Regression analysis helps the researcher to understand how the typical value of the dependent variable (quality of life) changes when any one of the independent variables (psychosocial factors) is varied, while the other independent variables like socio-demographic and illness related variables were held fixed. In this study, regression analysis gave the inferences like effect of quality of life (Y) on psychosocial factors (X) in categorical form of data. Out of five psychosocial variables social support was measured in 5 points scale and rest four self-esteem, coping, anxiety and depression were measured in 4 points scales or in 4 categories. Quality of life was also measured in 5 point scales or 5 categories. Binary logistic regression analysis statistical test was utilized to find out the level of relationship of each psychosocial variables with quality of life or out of five psychosocial factors, which factor can be a strongest predictor to determine quality of life of cancer patients. Multinomial logistic regression analysis statistical test was deployed to examine the relationship of several predictors with quality of life and its four domains. Multinomial logistic/logit regression was applied to the selected independent variables, which have shown significant relationship in binary logistic regression test.

Multinomial logistic regression is useful for situations in which researcher wants to be able to classify subjects based on values of a set of predictor variables. This type of regression is similar to logistic regression, but it is more general because the dependent variable is not restricted to two categories. But the dependent variable should be in categorical form. Factors are optional and can be either numeric or categorical. Covariates are optional but must be numeric and continuous variables. A multinomial logistic model is fit for the full factorial model or a user-specified model (SPSS, version 13.0). Here, both independent and dependent variables were taken in categorical forms. During analysis 2 categories of quality of life including its four domains and two categories of selected psychosocial factors were taken to reveal the relationship. Type of associations between psychosocial factors and quality of life was concluded on the basis of multivariate regression analysis as it is more powerful statistical test for factors analysis.

The binary test procedure compares the observed frequencies of the two categories of a dichotomous variable to the frequencies expected under a binary distribution with a specified probability parameter. To change the probabilities, researcher can enter a test proportion for the first group. The probability for the second group is 1 minus the specified probability for the first group. The variables tested should be numeric and dichotomous. A dichotomous variable is a variable that can take on only two possible values: yes and no, or 0 and 1. If the variables are not dichotomous, researcher must specify a cut point. The cut point assigns cases with values greater than the cut point to one group and the rest of the cases to another group (SPSS, version 13.0). This study deployed cut off point at 75% as this test needed categorical data and scores obtained more than 75% was considered as high quality of life (dependent variable). Independent variables scores were taken in numeric and continuous form. The conditional forward method was entered for processing, where confidence interval was fixed at 95% and removal at 0.10 to find out stepwise level of associations of psychosocial variables with quality of life. Test result revealed the psychosocial predictor for QOL in different steps.

In all analyses P-value ≤ 0.05 was defined at the numerical level for significance. Yet, this is an empirical research and it had exploratory nature, P-value ≤ 0.01 were also noted.

CHAPTER - 4

Results and Interpretaton

THIS CHAPTER DEALS WITH THE RESULTS AND ITS INTERPRETATION, WHICH COVERS INFORMATION GATHERED ACCORDING TO THE QUESTIONNAIRE ITEMS AND RESPONSE GIVEN BY THE RESEARCH PARTICIPANTS. THIS STUDY HAD THREE MAJOR INDEPENDENT VARIABLES NAMED AS DEMOGRAPHIC, DISEASE AND PSYCHOSOCIAL. OUT OF WHICH ONLY TWO VARIABLES (DEMOGRAPHIC AND DISEASE) WERE COMPOSITE; WHEREAS THE THIRD, I.E. PSYCHOSOCIAL VARIABLE, WAS INSUBSTANTIAL INDEPENDENT VARIABLE AS IT CAN CHANGE ACCORDING TO THE SITUATION. THEREFORE, PSYCHOSOCIAL FACTORS OF THE CANCER PATIENTS WERE MEASURED THROUGH STANDARDIZED (VALID AND RELIABLE) TOOLS, WHICH MOST FREQUENTLY ARE USED IN PSYCHOLOGICAL AND SOCIAL STUDIES. ON THE OTHER HAND QUALITY OF LIFE WAS TAKEN AS A DEPENDENT VARIABLE IN THIS STUDY, WHICH ALSO WAS MEASURED THROUGH STANDARDIZED TOOL.

RESULTS OF THIS STUDY WERE ORGANIZED IN TWO PARTS. FIRST PART INCLUDES ALL DESCRIPTION OF DEMOGRAPHIC, DISEASE, PSYCHOSOCIAL CHARACTERISTICS AND QUALITY OF LIFE OF THE RESEARCH PARTICIPANTS. SECOND PART IS THE INFERENTIAL STATISTICS OR ASSOCIATIONS OF INDEPENDENT VARIABLES (DEMOGRAPHIC, DISEASE, AND PSYCHOSOCIAL VARIABLES) WITH THE QUALITY OF LIFE INCLUDING ITS DOMAINS.

4.1 DESCRIPTIVE STATISTICS

DESCRIPTIVE STATISTICS WAS USED TO ANALYZE THE DISTRIBUTION PATTERN OF THE RESEARCH PARTICIPANTS ACCORDING TO THEIR DEMOGRAPHIC FACTORS, DISEASE FACTORS,

PSYCHOSOCIAL FACTORS AND QUALITY OF LIFE INCLUDING ALL ITS DOMAINS. IT INCLUDED FREQUENCY, PERCENTAGE, MEAN, MEDIAN, STANDARD DEVIATION AND INTER-QUARTILE RANGE TO DESCRIBE THE SAMPLES. THERE WERE 300 SAMPLES IN THIS STUDY, OUT OF WHICH 280 RESEARCH PARTICIPANTS WERE ENROLLED FOR QUANTITATIVE ANALYSIS. REST 20 RESEARCH PARTICIPANTS WERE TAKEN FOR QUALITATIVE ANALYSIS, WHICH WAS USED TO SUPPORT QUANTITATIVE DATA IN THIS STUDY

4.1.1 Mean

The mean is the average, which we use to measure the data. To calculate mean, all the observations are added up and then divided by the number of observations (Stevens 1946).

4.1.2 Median

Median is described as the numeric value separating the higher half of a sample, a population or a probability distribution, from the lower half. The median of a finite list of numbers can be found by arranging all the observations from lowest value to highest value and picking the middle one. If there is an even number of observations, then there is no single middle value; the median is then usually defined to be the mean of the two middle values (Stevens, 1946). For example, the median of a uniform distribution in the interval $[a, b]$ is $(a + b) / 2$, which is also the mean.

4.1.3 Inter-quartile range

THE INTER-QUARTILE RANGE IS A MEASURE OF VARIABILITY, SPREAD OR DISPERSION. IT IS THE DIFFERENCE BETWEEN THE 75TH PERCENTILE (OFTEN CALLED Q3) AND THE 25TH PERCENTILE (Q1). THE FORMULA FOR INTER-QUARTILE RANGE IS THEREFORE: Q3-Q1. THE 'RANGE' IS JUST THE DIFFERENCE BETWEEN THE LARGEST AND SMALLEST VALUES (STEVENS, 1946).

4.1.4 STANDARD DEVIATION

STANDARD DEVIATION IS A WIDELY USED MEASUREMENT OF VARIABILITY OR DIVERSITY USED IN STATISTICS AND PROBABILITY THEORY. IT SHOWS HOW MUCH VARIATION OR 'DISPERSION' THERE IS FROM THE AVERAGE' (MEAN OR EXPECTED/BUDGETED VALUE). A LOW STANDARD DEVIATION INDICATES THAT THE DATA POINTS TEND TO BE VERY CLOSE TO THE MEAN, WHEREAS HIGH STANDARD DEVIATION INDICATES THAT THE DATA IS SPREAD OUT OVER A LARGE RANGE OF VALUES (SINGH, 2007).

4.1.5 DEMOGRAPHIC VARIABLES

Demographic variables are taken as independent variables in this study. A total of 300 cancer patients were enrolled in this study, among which 280 were enrolled for the first part which was the quantitative study. Of the 280 research participants, 145 (51.8%) were enrolled from outpatient departments (OPDs) and 135 (48.2%) from the indoors/wards (hospitalized patients). Majority (80%) of the cancer patients were villagers (from rural areas). This data matches with the national figure of Nepal, 2001 census, which showed 80% of cancer patients from rural areas and rest (20%) from the urban areas. Majority 242 (86.5%) of the research participants were Hindu by religion, which was more than the 2001 census data (81%). This study also revealed that 170 (60.7%) of the research participants belonged to joint families. This finding showed that joint family system still exists in Nepal. This study also revealed that more than one third (36.1%) of the research participants belonged to upper caste groups as per Government of Nepal classification (2007). Disadvantaged Janjatis 83 (29.6%) reported more than the percentage population proportion (21.5%) as per Central Bureau of Statistics (CBS, 2001). Disadvantaged non-dalit terai castes 40 (14.2%) also reported more than the percentage population proportion (10.4%). Very few 10 (3.6%) research participants were from religious minorities groups (*Muslims, Churoute*), which is less than the percentage population proportion (4.3%) and few 17 (6.1%), were dalit both from hill and terai, which was lower as compared to their population proportion (7.1%).

Second part was the qualitative study for which 20 cancer patients were enrolled from cancer hospitals as well as from their door-steps. Out of 20, 13 (65%) were from rural areas and rest 7 (35%) were from the urban areas. More than one third (40%) research participants were enrolled from upper castes category, one fifth (20%) from disadvantaged non-dalit terai castes and one fifth (20%) from relatively advantaged janjatis, some (15%) from disadvantaged janjatis and few (5%) from religious minorities. None of the research participants was reported from dalit caste/ethnic groups.

Disadvantaged Janjatis and Non-dalit terai castes/ethnic groups reported more than their population proportion, which could be due to the higher prevalence of cancer among these groups or high level of awareness about the disease and its treatment procedure among them or easy accessibility of cancer hospitals. But the reason cannot be specified as it was not investigated in the study.

TABLE 4.1

AGE AND GENDER DISTRIBUTION

N=280

AGE	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
YOUNG ADULT (18 TO 39 YEARS)	**10**	**9.9**	**25**	**14.0**	**35**	**12.5**
MIDDLE AGE (40 TO 59 YEARS)	**51**	**50.5**	**102**	**57.0**	**153**	**54.6**
OLD AGE (60 TO 80 YEARS)	**40**	**39.6**	**52**	**29.1**	**92**	**32.9**
TOTAL	101	100	179	100	280	100
MEAN AGE ± SD	58.7 ± 12.9		48.4 ± 12.8		52.2 ± 12.9	

CLASSIFICATION OF THE AGE GROUP OF THE RESEARCH PARTICIPANTS HAS BEEN DIVIDED ACCORDING TO BIOLOGICAL RHYTHM (SMELTZER AND BARE, 2001). TABLE 4.1 DEPICTS THAT OUT OF 280 CANCER PATIENTS, 35 (12.5%) BELONGED TO YOUNG ADULT (18-39 YEARS) AGE GROUP; AND 92 (32.9%) WERE FROM THE OLD (60 TO 80 YEARS) AGE GROUP. MORE THAN HALF (54.6%) OF THE RESEARCH PARTICIPANTS WERE FROM 40 TO 59 YEARS OF AGE. THE AGES OF THE RESEARCH PARTICIPANTS RANGED FROM 18 TO 80 YEARS AND MEAN AGE 52.2, AND STANDARD DEVIATION 12.9 YEARS. RESPECTIVELY, MEAN AGE OF MALE RESEARCH PARTICIPANTS 58.7 YEARS, AND STANDARD DEVIATION 12.9 YEARS AND FEMALE MEAN AGE 48.4 YEARS, AND STANDARD DEVIATION 12.8 YEARS. TABLE 4.1 ALSO DEPICTS THAT CANCER AMONG YOUNG FEMALES IS MORE COMMON THAN IN THE SAME AGE GROUP OF MALES.

QUALITATIVE DATA REVEALED THAT OUT OF 20 RESEARCH PARTICIPANTS, 14 (70%) WERE FEMALE AND 6 (30%) WERE MALE. MAJORITY (70%) OF THE RESEARCH PARTICIPANTS WERE FROM THE AGE GROUP OF 39 TO 59 YEARS. NONE OF THE CANCER PATIENTS WERE LESS THAN 28 YEARS; AND MORE THAN 69 YEARS.

TABLE 4.2

EDUCATIONAL STATUS AND GENDER DISTRIBUTION

N=280

EDUCATIONAL STATUS	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
ILLITERATE	**40**	**39.6**	**145**	**81.0**	**185**	66.1
LITERATE	**61**	**40.4**	**34**	**19.0**	**95**	33.9
TOTAL	101	100	179	100	280	100
LITERACY STATUS (N=95)						
PRIMARY & LOWER SECONDARY LEVEL	**37**	**62.7**	**22**	**37.3**	**59**	100
HIGH & HIGHER SECONDARY	**18**	**64.3**	**10**	**35.7**	**28**	100
GRADUATION AND ABOVE	**6**	**75.0**	**2**	**25.0**	**8**	100

TABLE 4.2 DEPICTS THE EDUCATIONAL STATUS AT MACRO LEVEL, WHICH WAS DIVIDED INTO TWO CATEGORIES VIZ. ILLITERATE AND LITERATE TO APPLY THE STATISTICAL TEST. OUT OF 280 RESEARCH PARTICIPANTS, MORE THAN HALF 185 (66.1%) OF THEM WERE ILLITERATE AND REST 33.9% OF THEM WERE LITERATE (JUST READ AND WRITE) TO EDUCATED. TABLE 4.2 ALSO DEPICTS THE LITERACY STATUS AT MICRO LEVEL. OUT OF 95 LITERATE RESEARCH PARTICIPANTS 8 (8.4%) OF THEM HAD COMPLETED GRADUATION AND ABOVE DEGREES. AMONG THE 61 MALE LITERATE RESEARCH PARTICIPANTS, MAJORITY (64.3%) OF THEM HAD COMPLETED HIGH AND HIGHER SECONDARY, WHEREAS 37 (62.7%) HAD COMPLETED PRIMARY AND LOWER SECONDARY LEVEL OF EDUCATION.

QUALITATIVE DATA FOUND THAT OUT OF 20 RESEARCH PARTICIPANTS, 5 (25%) WERE ILLITERATE AND REST 15 (75%) LITERATE TO EDUCATED. OUT OF 15 LITERATE RESEARCH PARTICIPANTS, 6 (30%) HAD COMPLETED GRADUATE DEGREE AND 9 (45%) OF THEM HAD COMPLETED HIGH SCHOOL LEVEL OF EDUCATION.

ILLITERACY AND LOW LITERACY WERE FOUND TO BE HIGHER AMONG THE RESEARCH PARTICIPANTS, WHICH COULD BE BECAUSE OF THE AGE DISTRIBUTION OF THE RESEARCH PARTICIPANTS. IN GENERAL POPULATION, YOUNGER PEOPLE ARE MORE EDUCATED THAN THE OLDER ONES AND IT IS SEEN THAT CANCER IS A DISEASE OF THE AGED, THUS, THE RESULT.

TABLE 4.3

MARITAL STATUS AND GENDER DISTRIBUTION

N=280

MARITAL STATUS	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
SINGLE	**9**	**8.9**	**38**	**21.2**	**47**	16.8
MARRIED	**92**	**91.1**	**141**	**78.8**	**233**	83.2
TOTAL	101	100	179	100	280	100
SINGLE (N= 47)						
UNMARRIED	**2**	**25.0**	**6**	**75.0**	**8**	100
SEPARATED/DIVORCEE	**2**	**18.1**	**9**	**81.9**	**11**	100
WIDOW/ER	**5**	**17.8**	**23**	**82.2**	**28**	100

TABLE 4.3 SHOWS THE MARITAL STATUS OF THE RESEARCH PARTICIPANTS, WHICH WAS DIVIDED INTO TWO CATEGORIES AT MACRO LEVEL, SUCH AS SINGLE VS. MARRIED, TO APPLY THE STATISTICAL TEST. THE REMARRIED RESEARCH PARTICIPANTS WERE ALSO INCLUDED IN MARRIED GROUP. OUT OF 280 RESEARCH PARTICIPANTS, MAJORITY 233 (83.2%) OF THEM WERE MARRIED AND REST 47 (16.8%) WERE SINGLE.

TABLE 4.3 ALSO DEPICTS THE MARITAL STATUS AT MICRO LEVEL, WHERE DETAILS OF THE SINGLES IS EXPLAINED. AMONG THE 47 SINGLES, 8 (17.1%) WERE UNMARRIED, 11 (23.4%) WERE DIVORCED OR WERE LIVING SEPARATELY FROM THEIR SPOUSE AND REST 28 (59.5%) WERE WIDOW/ER. MORE FEMALE CANCER PATIENTS WERE SINGLE AS COMPARED TO THEIR MALE COUNTERPARTS.

QUALITATIVE STUDY ALSO REVEALED THAT OUT OF 20 RESEARCH PARTICIPANTS, 14 (70%) WERE MARRIED, 3 (15%) WERE WIDOWED, 2 (10%) UNMARRIED AND 1 (5%) WAS DIVORCED FEMALE.

Table 4.4

Socio-economic Status and Gender Distribution

n= 280

VARIABLES	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
ECONOMIC STATUS*						
HIGH	**50**	**49.5**	**69**	**38.5**	**119**	42.5
LOW	**51**	**50.5**	**110**	**61.5**	**161**	57.5
TOTAL	101	100	179	100	280	100
FOOD SUFFICIENT FROM OWN LAND						
< 3 MONTHS	**44**	**43.6**	**58**	**32.4**	**102**	36.4
3 TO 6 MONTHS	**33**	**32.7**	**79**	**44.1**	**112**	40.0
7 TO 12 MONTHS	**24**	**23.8**	**42**	**23.5**	**66**	23.6
TOTAL	101	100	179	100	280	100
SOCIO-ECONOMIC STATUS**						
UPPER MIDDLE CLASS	**-**	**-**	**3**	**1.7**	**3**	1.1
LOWER MIDDLE CLASS	**21**	**20.8**	**22**	**12.3**	**43**	15.4
UPPER LOWER CLASS	**76**	**75.3**	**128**	**71.5**	**204**	72.9
LOWER CLASS	**4**	**3.9**	**26**	**14.5**	**30**	10.7
TOTAL	101	100	179	100	280	100

* **PER CAPITA INCOME PER DAY (MGD, 2000)**

** **KUPPUSWAMI SES SCALE (1986)**

TABLE 4.4 DEPICTS THE DIFFERENT WAYS TO CALCULATE THE SOCIO-ECONOMIC STATUS (SES) OF RESEARCH PARTICIPANTS AS IT IS TROUBLESOME TO CALCULATE IT ACCURATELY BY A SINGLE METHOD, PROVIDED THE CULTURAL CONTEXT OF NEPAL. STATISTICAL TEST WAS APPLIED TO ECONOMIC STATUS CALCULATED ON THE BASIS OF PER CAPITA INCOME PER MONTH. CHI-SQUARE TEST REQUIRED MINIMUM VALUE 5 IN EACH CELL, BUT IN THIS STUDY UPPER MIDDLE SOCIO-ECONOMIC STATUS HAVE CELL VALUE 3. OUT OF 280, MAJORITY 161 (57.5%) OF THE RESEARCH PARTICIPANTS HAD PER-CAPITA INCOME <2000 NEPALI CURRENCY

PER MONTH, WHO WERE CATEGORIZED AS HAVING LOW ECONOMIC STATUS AND 119 (42.5%) OF THEM HAD PER-CAPITA INCOME MORE THAN 2,000 PER MONTH. ACCORDING TO THE LAND MARK SET BY THE MILLENNIUM DEVELOPMENT GOAL (MDG, 2000), A PERSON HAVING PER DAY INCOME LESS THAN ONE U.S. DOLLAR (US$1) IS CONSIDERED TO BE AFFLICTED WITH HUNGER OR POVERTY. ACCORDING TO THIS CRITERION, MAJORITY OF THE RESEARCH PARTICIPANTS IN THIS STUDY HAD LOW ECONOMIC STATUS. PER-CAPITA INCOME OF THE RESEARCH PARTICIPANTS RANGED FROM 100 TO 15000, WHERE MEAN INCOME 1857.2, AND STANDARD DEVIATION 18.61 NEPALI CURRENCY.

Table 4.4 also depicts the food sufficiency for the research participants. The economy of Nepal is based on agriculture; therefore Government of Nepal (2007) has taken a basis to categorize economic status as per food sufficient to the family for a month from their own land. According to that criteria, more than one third 102 (36.4%) had sufficient food for less than 3 months; which is categorized as very poor. Forty percent (112) had sufficient food for 3 to 6 months; which is categorized as poor. No one had sufficient food for more than a year i.e. no one, according to the criterion, was affluent. According to the criterion, majority 214 (76.4%) of the research participants in this study were poor.

TABLE 4.4 ALSO DEPICTS THE SOCIO-ECONOMIC STATUS (SES) OF THE RESEARCH PARTICIPANTS CALCULATED ON THE BASIS OF PER CAPITA INCOME, EDUCATION AND OCCUPATION OF THE HEAD OF THE FAMILY. THERE WAS STANDARD SES SCALE, DEVELOPED BY KUPPUSWAMY (MAHAJAN, 1995). THIS SES SCALE WAS USED FOR SUB-URBAN POPULATION OF INDIA. THERE WAS NO SPECIFIC SCALE AVAILABLE TO CALCULATE SES IN THE CONTEXT OF NEPAL. THEREFORE, PRESENT STUDY ADOPTED KUPPUSWAMY SES SCALE (APPENDIX-V). THERE IS NO DEFINED SUB-URBAN POPULATION IN NEPAL, AND MAJORITY (80%) OF THE RESEARCH PARTICIPANTS WERE FROM RURAL AREAS IN THIS STUDY. OUT OF 280 RESEARCH PARTICIPANTS, NO ONE WAS FROM UPPER SES; WHEREAS MAJORITY 204 (72.9%) WERE IN UPPER LOWER SES AND SOME 43 (15.4%) IN LOWER MIDDLE SES. MORE FEMALE RESEARCH PARTICIPANTS BELONGED TO LOWER SOCIO-ECONOMIC STATUS AS COMPARED TO THEIR MALE COUNTERPARTS IN THIS STUDY.

QUALITATIVE STUDY ALSO REVEALED THAT MAJORITY (90%) OF THE RESEARCH PARTICIPANTS WERE FROM LOW AND MIDDLE SOCIO-ECONOMIC STATUS. HIGHER NUMBER OF POOR AND FEMALE CASES REPORTED AT THESE HOSPITALS COULD BE BECAUSE OF THE PREFERENCE OF THE RICH AND MALE CANCER PATIENTS TO BE TREATED AT OTHER CENTERS IN INDIA AND/OR OTHER COUNTRIES. THIS INFORMATION WAS SECURED THROUGH IN-DEPTH INTERVIEW FROM THE RESEARCH PARTICIPANTS.

Table 4.5

Role in the Family and Gender Distribution

n=280

ROLE IN THE FAMILY	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
EARNER	**44**	**43.6**	**78**	**43.6**	**122**	43.6
DEPENDENT	**57**	**56.4**	**101**	**56.4**	**158**	56.4
TOTAL	101	100	179	100	280	100

Table 4.5 shows the role of the cancer patients in their family, which was categorized in two major categories, namely earner and dependent, to apply statistical test. Out of 280 research participants, 122 (43.6%) were earners and rest 158 (56.4%) were dependent members for their family. Of the 122 earners, 102 (83.6%) were main earner and rest 20 (16.4%) were supportive earners.

Qualitative data found that out of 20 research participants, 12 (60%) were main and supportive earners for their family, whereas 8 (40%) were dependent on other family members.

Most of the research participants were found to be dependent which could be due to higher participation of housewives in this study. Also, majority of the research participants belonged to joint families where younger members have more earning role as compared to their elder counterparts.

4.1.6 DISEASE VARIABLES

OUT OF 300 CANCER PATIENTS, 73 RESEARCH PARTICIPANTS WERE DIAGNOSED WITH HEAD AND NECK CANCER, 70 OF WHOM WERE ENROLLED FOR QUANTITATIVE AND 3 FOR QUALITATIVE ANALYSIS. ALTOGETHER, 75 LUNG CANCER PATIENTS WERE ENROLLED IN THIS STUDY. OUT OF THOSE 75, 70 RESEARCH PARTICIPANTS WERE ENROLLED FOR QUANTITATIVE AND 5 FOR QUALITATIVE ANALYSIS. ALONG WITH THE HEAD AND NECK; AND LUNG CANCER, 76 BREASTS AND 76 CERVICAL CANCER PATIENTS WERE ALSO ENROLLED IN THIS STUDY. OUT OF THESE, 70 RESEARCH PARTICIPANTS WERE ENROLLED FOR QUANTITATIVE AND 6 WERE

FOR QUALITATIVE ANALYSIS. DISEASE VARIABLES ARE TAKEN AS THE INDEPENDENT VARIABLE IN THIS STUDY.

Out of 300 research participants, near about two third 193 (64.3%) of the cancer patients were female. Three months patients' record of BPKMCH (2008) showed that out of 601 cancer patients, 438 (72.8%) were female.

Table 4.6

Stages of cancer and Gender Distribution

n=280

STAGES OF CANCER	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
EARLY STAGE	**8**	**7.9**	**72**	**40.2**	**80**	28.6
LATE STAGE	**93**	**92.1**	**107**	**59.8**	**200**	71.4
TOTAL	101	100	179	100	280	100
EARLY STAGE (N=80)						
STAGE I	**-**	**-**	**9**	**100.0**	**9**	100
STAGE II	**8**	**11.3**	**63**	**88.7**	**71**	100
LATE STAGE (N=200)						
STAGE III	**58**	**48.7**	**61**	**51.3**	**119**	100
STAGE IV	**35**	**43.2**	**46**	**56.8**	**81**	100

Table 4.6 depicts stages of cancer, which was categorized into two to apply chi-square test. Among the 280 research participants, 80 (28.6%) of them were categorized under early stage and rest 200 (71.4%) were in late stage of cancer. Among the 4 stages of cancer, only few, 9 (3.2%) female cancer patients were diagnosed in 1st stage of cancer. Very few 8 (7.9%) among male and some 63 (35.2%) among female were diagnosed in 2nd stage of cancer. More than one third 119 (59.5%) cancer patients were diagnosed in 3rd stage. Near about one third 81 (40.5%) of the cancer patients were diagnosed in 4th stage of cancer.

This means that most of the patients come to the cancer hospitals in the late stage. Female research participants reported in the early stage (I and II) as compared to their male counterparts.

It could be due to the nature of disease. Cancers of breast and cervix have early warning signs like breast lump and abnormal discharges, whereas lung and head and neck cancer have no such warning signs in the early stages.

Qualitative study revealed that the reason for delay in seeking treatment from the cancer hospitals was due to the fear of the word ‘cancer’ attached to the name of the hospitals. Majority of the research participants verbalized during data collection that they first visited general health facilities before reporting to the cancer hospitals.

Table 4.7

Duration of Diagnosis and Gender Distribution

n=280

DURATION OF DIAGNOSIS	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
UP TO ONE YEAR	**88**	**87.1**	**155**	**86.6**	**243**	86.8
MORE THAN A YEAR	**13**	**12.9**	**24**	**13.4**	**37**	13.2
TOTAL	101	100	179	100	280	100
UP TO ONE YEAR (N=243)						
≤ 6 MONTHS	**62**	**35.0**	**115**	**65.0**	**177**	100
7 MONTHS TO 1 YEAR	**26**	**39.4**	**40**	**60.6**	**66**	100

Table 4.7 depicts the duration of cancer diagnosis at macro level, which was divided into two categories, i.e. up to one year and more than one year of duration of cancer diagnosis, to apply statistical test. Out of 280 research participants, majority 243 (86.8%) of them were diagnosed with cancer within one year. Some, 37 (13.2%), were diagnosed for more than a year.

Table 4.7 also depicts micro level of distribution of the research participants according to duration of diagnosis. Out of 280 cancer patients, 177 (63.2%) had cancer diagnosis before six months, out of which, 62 research participants were male and 115 were female. Nearly one fourth, 66 (23.6%), had been diagnosed for 6 months to one year. Duration of diagnosis ranges from 2 to 72 months. Mean duration of cancer diagnosis 7.7, and standard deviation 8.9 months. Qualitative study results revealed that out of 20 research participants, 11 (55%) were diagnosed as stage III and IV.

Table 4.8

Modalities of Treatment and Gender Distribution

n=280

MODALITIES OF TREATMENT	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
SINGLE	**41**	**40.6**	**44**	**24.6**	**85**	30.4
MULTIPLE	**60**	**59.4**	**135**	**75.4**	**195**	69.6
TOTAL	101	100	179	100	280	100
SINGLE TYPE OF TREATMENT						
CHEMOTHERAPY	**24**	**37.5**	**40**	**62.5**	**64**	**100**
RADIATION	**15**	**78.9**	**4**	**21.1**	**19**	**100**
SURGERY	**2**	**100**	**-**	**-**	**2**	**100**

Table 4.8 depicts the modality of treatment, which was categorized as single vs. multiple types of treatment to apply statistical test. Research participants who received either surgery or chemotherapy or radiation therapy fell under single modality of treatment and multiple modality of treatment included combination of more than one type of treatment either surgery and chemotherapy or radiation and chemotherapy or surgery and radiation or all.

Out of 280 cancer patients for quantitative analysis, majority 195 (69.6%) of the cancer patients were receiving multiple modalities of treatment which could be due to their reporting to the hospital in late stage. Less than one third (30.4%) of the sample were receiving single modality of treatment. Among the 85 research participants, 64 (75.2%) of them were receiving chemotherapy only.

A type of treatment is important in relation to quality of life among cancer patients. But this study has chosen modality of treatment as independent variable because majority of the research participants were receiving multiple modalities of treatment and they didn’t bother much about the type of treatment; which could be due to the similarity of side effects and tolerating difficulty associated with them.

Table 4.9

Facing Financial Problem during Treatment and Gender Distribution

n=280

FACING FINANCIAL PROBLEMS	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
YES	**55**	**54.5**	**120**	**67.0**	**175**	62.5
NO	**46**	**45.5**	**59**	**33.0**	**105**	37.5
TOTAL	101	100	179	100	280	100

Table 4.9 depicts the financial problems faced by the research participants during the period of treatment. Cancer patients, who took loan, sold land, collected fund/received donation and were treated under hospital aid/charity were included in the category of those facing financial problems for treatment.

Out of 280 cancer patients, majority 175 (62.5%) of the patients were facing financial problems during treatment. Among them, female patients were facing more financial problems than their male counterparts. The gender variation could be because of the preference of rich male patients to be treated in other centers or other countries. Also are being the decision makers and earners of the family male members usually get more preference than their female counterparts. Qualitative study result uncovered that the financial problem during treatment was due to long term expensive therapy. Some research participants were stated "*yo rog le dhoti nā topi bānāi diyo*" (this disease made me beggar).

4.1.7 PSYCHOSOCIAL VARIABLES

THIS SUB-SECTION DEALS WITH THE LEVEL OF SOCIAL SUPPORT, SELF-ESTEEM, COPING, ANXIETY AND DEPRESSION UNDER PSYCHOSOCIAL VARIABLES AMONG THE RESEARCH PARTICIPANTS ACCORDING TO THEIR GENDER DISTRIBUTION. PSYCHOSOCIAL VARIABLES WERE TAKEN AS THE INDEPENDENT VARIABLE IN THIS STUDY.

OUT OF FIVE PSYCHOSOCIAL VARIABLES, ONLY TWO VARIABLES (ANXIETY AND DEPRESSION) HAD CUT-OFF RATE TO DEFINE THE LEVEL OF ANXIETY AND DEPRESSION. THERE WAS '0'

VALUE TO EXCLUDE NON-ANXIETY AND NON-DEPRESSED RESEARCH PARTICIPANT. THEREFORE, MEAN AND STANDARD DEVIATION WERE ALSO CALCULATED TO FIND OUT THE AVERAGE ALONG WITH THE DISPERSION OR VARIATION OF THE DATA. REST THREE VARIABLES (SOCIAL SUPPORT, SELF-ESTEEM AND COPING) AND QUALITY OF LIFE SCALE HAD NO CUTOFF TO DEFINE RANK/LEVEL. THE SCORE FOR THESE 3 TOOLS WAS STARTED FROM 1, WHICH REFLECTS THAT 1ST QUARTILE (25%) SCORES FOR SELF-ESTEEM AND COPING CAN BE INTERPRETED AS NO SELF-ESTEEM AND NO COPING. ON THE OTHER HAND, UP TO 20% SCORES OF SOCIAL SUPPORT SCALE CAN BE INTERPRETED AS NO SUPPORT, BECAUSE IT HAS 5 POINTS SCALE. HERE, UP TO 25% SCORES WERE CATEGORIZED AS LOW SOCIAL SUPPORT. ORDINAL SCALE WAS USED TO CATEGORIZE THE SCORES AND GAVE RANK ORDERS OF SELECTED VARIABLES. OF THE ORDINAL SCALES, RANK ORDER WAS USED MOST WIDELY AND EFFECTIVELY BY THE PSYCHOLOGISTS.

THE ORDINAL SCALE DESCRIBES ORDER, BUT NOT RELATIVE SIZE OR DEGREE OF DIFFERENCE BETWEEN THE ITEMS MEASURED. IN THIS SCALE, TYPES OR THE NUMBERS ASSIGNED TO OBJECTS OR EVENTS REPRESENT THE RANK ORDER (1ST, 2ND, 3RD, ETC.) OF THE ENTITIES ASSESSED. WHILE USING AN ORDINAL SCALE, THE CENTRAL TENDENCY OF A GROUP OF ITEMS CAN BE DESCRIBED BY USING THE GROUP'S MODE (MOST COMMON ITEM) OR ITS MEDIAN (THE MIDDLE-RANKED ITEM), BUT THE MEAN (AVERAGE) CANNOT BE DEFINED (STEVENS, 1946). THEREFORE, THIS STUDY ADOPTED MEDIAN AND INTER-QUARTILE RANGE AND CALCULATED THE MIDDLE-RANKED ITEMS AND DIFFERENCES TO PUT THE DATA IN RANK ORDER. THE SCALE USED NAMES WITH AN ORDER SUCH AS HIGH, AVERAGE AND LOW OR HIGH, LOW AND NO.

TABLE 4.10

COPING AND GENDER DISTRIBUTION

N= 280

COPING	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT

High	23	22.8	39	21.8	62	**22.1**
Low	55	54.4	91	50.8	146	**52.2**
No	23	22.8	49	27.4	79	**25.7**
TOTAL	101	100	179	100	280	100
MEDIAN SCORE= 64				*IQR= 54-74*		

Table 4.10 depicts the level of coping and gender distribution. Coping among cancer patients were measured trough Carver's Brief COPE Inventory, which has no cut-off score to categorize the level of coping. Therefore, some modification was done by the researcher to categorize the level of coping. Median (64) and inter-quartile range (54 - 74) of the obtained scores were calculated by the researcher. Total scores of the tool were divided into 3 categories according to which scores up to 54 were labeled as no coping or maladjustment, whereas score 55 to 74 were labeled as low coping and score more than 74 were labeled as high level of coping or well adjusted with the cancer among research participants.

OF THE TOTAL 280 RESEARCH PARTICIPANTS, 79 (25.7%) HAD NO COPING; AND 62 (22.1%) HAD HIGH LEVEL OF COPING. THIS STUDY ALSO REVEALED THAT LOW LEVEL OF COPING WAS HIGHER AMONG THE MALE RESEARCH PARTICIPANTS AS FEMALES.

TABLE 4.11

SOCIAL SUPPORT AND GENDER DISTRIBUTION

N=280

SOCIAL SUPPORT	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
High	26	25.7	40	22.3	66	**23.6**
Average	51	50.5	100	55.9	151	**53.9**
Low	24	23.8	39	21.8	63	**22.5**
TOTAL	101	100	179	100	280	100
MEDIAN SCORE = 70			*IQR = 59-79*			

Table 4.11 depicts level of social support and gender distribution. Social support was measured through MOS social support Inventory, which has no cut-off score to categorize the level of

social support. Therefore, some modification was done by the researcher to categorize the level of social support. Median (70) and inter-quartile range (59-79) of the obtained scores were calculated. Total scores of the tool were divided into 3 categories, according to which the scores obtained up to 59 (25%) were labeled as low social support, whereas scores 60 to 79 were labeled as average social support and score more than 79 were labeled as high level of social support among the research participants.

OF THE 280 RESEARCH PARTICIPANTS, 63 (22.5%) RECEIVED LOW LEVEL OF SOCIAL SUPPORT; WHEREAS 66 (23.6%) OF THEM RECEIVED HIGH LEVEL OF SOCIAL SUPPORT. THIS STUDY ALSO REVEALED THAT THE MALE RESEARCH PARTICIPANTS RECEIVED MORE HIGH SOCIAL SUPPORT AS COMPARED TO THEIR FEMALE COUNTERPARTS.

TABLE 4.12

SELF-ESTEEM AND GENDER DISTRIBUTION

N= 280

SELF-ESTEEM	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
High	18	17.8	38	21.2	56	**20.0**
Low	52	51.5	94	52.5	146	**52.1**
No	31	30.7	47	26.3	78	**27.9**
TOTAL	101	100	179	100	280	100
MEDIAN= 24		*INTER-QUARTILE RANGE (IQR) =19-28*				

TABLE 4.12 DEPICTS THE LEVEL OF SELF-ESTEEM AND GENDER DISTRIBUTION. SELF-ESTEEM WAS MEASURED THROUGH ROSENBERG'S SELF-ESTEEM SCALE, WHICH HAS NO CUT-OFF SCORE TO CATEGORIZE THE LEVEL OF SELF-ESTEEM. THEREFORE, SOME MODIFICATION WAS DONE BY THE RESEARCHER TO CATEGORIZE THE LEVEL OF SELF-ESTEEM. MEDIAN (24) AND INTER-QUARTILE RANGE (19–28) OF THE OBTAINED SCORES WERE CALCULATED BY THE RESEARCHER. TOTAL SCORES OF THE TOOL WERE DIVIDED INTO 3 CATEGORIES ACCORDING TO WHICH THE SCORES OBTAINED UP TO 19 WERE LABELED AS NO SELF-ESTEEM, BECAUSE THERE WAS NO '0' VALUE IN TOOL AND UP TO 25% SCORE WAS CONSIDERED AS NO SELF-

ESTEEM. WHEREAS SCORE 20 TO 28 WERE LABELED AS LOW SELF-ESTEEM AND SCORE MORE THAN 28 WERE LABELED AS HIGH SELF-ESTEEM.

OUT OF THE 280 RESEARCH PARTICIPANTS, 78 (27.9%) HAD NO SELF-ESTEEM; AND 56 (20.0%) HAD HIGH LEVEL OF SELF-ESTEEM. THIS STUDY ALSO REVEALED THAT LOW SELF-ESTEEM WAS HIGHER AMONG THE MALE RESEARCH PARTICIPANTS, WHEREAS AVERAGE AND HIGH LEVEL OF SELF-ESTEEM WERE AMONG THE FEMALES.

TABLE 4.13

ANXIETY AND GENDER DISTRIBUTION

N= 280

ANXIETY	ALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
Mild	**19**	**18.8**	**27**	**15.1**	**46**	16.4
Moderate	**24**	**23.8**	**22**	**12.3**	**46**	16.4
Severe	**58**	**57.4**	**130**	**72.6**	**188**	67.1
TOTAL	101	100	179	100	280	100
OBTAINED SCORE RANGE = 2-54				*MEAN* ± SD= 29.6±10.9		

TABLE 4.13 DEPICTS LEVEL OF ANXIETY AND GENDER DISTRIBUTION, OUT 280 RESEARCH PARTICIPANTS, 46 (16.4%) OF THEM HAD MILD ANXIETY, HERE OBTAINED SCORES UP TO 17 (30.3%) AND 188 (67.1%) WERE SUFFERING FROM SEVERE ANXIETY, WHERE, OBTAINED SCORES MORE THAN OR EQUALS TO 25 (44.6%). CUT OFF SCORES FOR SEVERE ANXIETY WAS TAKEN TO UTILIZE STATISTICAL TEST AS PER STANDARDS OF THE TOOL. THIS STUDY ALSO REVEALED THAT MILD AND MODERATE ANXIETY WAS HIGHER AMONG THE MALE RESEARCH PARTICIPANTS AND SEVERE ANXIETY WAS HIGHER AMONG THE FEMALE RESEARCH PARTICIPANTS. THE QUANTITATIVE DATA WAS SUPPORTED BY THE QUALITATIVE INFORMATION IN THIS STUDY, WHICH MEANS FEMALE RESEARCH PARTICIPANTS VERBALIZED MORE SYMPTOMS OF THE ANXIETY AS COMPARE TO THEIR MALE COUNTERPARTS.

TOOL USED TO ASSESS LEVEL OF ANXIETY IN THIS STUDY SCORED 0-56, OUT OF THAT, MINIMUM OBTAINED SCORE WAS 2 AND MAXIMUM SCORE WAS 54. MEAN SCORE 29.6, AND STANDARD DEVIATION 10.9.

TABLE 4.14

DEPRESSION AND GENDER DISTRIBUTION

N=280

DEPRESSION	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
Mild	6	5.9	15	8.4	21	7.6
Moderate	21	20.8	39	21.8	60	21.5
Severe	74	73.3	125	69.8	199	70.9
TOTAL	101	100	179	100	280	100
OBTAINED SCORE RANGE = 4 - 56				MEAN ± *SD= 34.8 ± 11.4*		

TABLE 4.14 DEPICTS THE LEVEL OF DEPRESSION AND GENDER DISTRIBUTION. OUT OF THE 280 RESEARCH PARTICIPANTS, 21 (7.6%) HAD MILD DEPRESSION, HERE OBTAINED SCORES UP TO 14 (22.2%) WAS INCLUDED AND 199 (70.9%) HAD SEVERE DEPRESSION. WHERE OBTAINED SCORES MORE THAN 30 (47.6%) WAS INCLUDED. THE OBTAINED SCORE RANGE WAS 4 TO 56. MEAN SCORE 34.8, AND STANDARD DEVIATION 11.4. CUT OFF SCORES FOR SEVERE DEPRESSION WAS UTILIZED FOR STATISTICAL TEST AS PER STANDARDS OF THE TOOL. THIS STUDY ALSO REVEALED THAT MILD AND MODERATE DEPRESSION WAS HIGHER AMONG THE FEMALE RESEARCH PARTICIPANTS AND SEVERE DEPRESSION WAS HIGHER AMONG THE MALE PARTICIPANTS. THE REASONS FOR HIGHER LEVEL OF DEPRESSION AMONG MALE COULD BE DUE TO THE LACK OF ADDRESSING THEIR PROBLEMS FOR SOLUTION. ANOTHER REASON COULD BE RELATED TO THEIR RESPONSIBILITY TOWARDS THEIR FAMILIES AND SOCIETY WHERE, IN NEPALESE CONTEXT, THEY HAVE A DOMINANT ROLE AS THE EARNER, DECISION MAKER AND IN BUILDING ADDITIONAL SOCIAL NETWORKS. WHEN THEY HAD CANCER, THEY COULD NOT SHOULDER THEIR RESPONSIBILITIES EFFICIENTLY WHICH ADDED TO THEIR FEELING OF WORTHLESSNESS AND BEING STIGMATIZED, LEADING TO DEPRESSION.

QUALITATIVE STUDY REVEALED SIMILAR FINDINGS. OUT OF 6 MALE RESEARCH PARTICIPANTS, 2 (33.3%) EXPRESSED "*SHREEMĀTI KO ĀNKHĀ MĀ ĀNSHU DEKHNĀ SĀKDINA*" (CANNOT SEE TEAR OF MY WIFE'S EYES), "*MERO CHHORI SITĀ KĀSLE BIHE GĀRNE HOLĀ?,*"

***SĀMĀJMĀ MĀILE MUKH DEKHĀUNĀ SĀKINA*”** **(WHO WILL MARRY MY DAUGHTER?, I AM UNABLE TO SHOW MY FACE IN THE SOCIETY), MARNA PANI GAHRO BHAYO (IT HAS BECOME DIFFICULT EVEN TO DIE).**

4.1.8 QUALITY OF LIFE VARIABLE

OUT OF 300 CANCER PATIENTS, 280 RESEARCH PARTICIPANTS' QUALITY OF LIFE WAS MEASURED THROUGH WHOQOL-BREF, WHICH HAS FOUR FACETS/DOMAINS VIZ. PHYSICAL, PSYCHOLOGICAL, SOCIAL RELATIONSHIP AND ENVIRONMENT. THESE FOUR DOMAINS GIVEN DIFFERENT TABLE NUMBERS LIKE A, B, C, D AND SERIAL NUMBER OF QUALITY OF LIFE, AS THEY WERE THE PART OF THE QUALITY OF LIFE.

REST 20 RESEARCH PARTICIPANTS WERE ENROLLED FOR QUALITATIVE ANALYSIS, INFORMATION WAS GATHERED THROUGH IN-DEPTH INTERVIEW TO SUPPLEMENT THE INFORMATION FOR THE QUANTITATIVE ANALYSIS. QUALITY OF LIFE IS TAKEN AS THE DEPENDENT VARIABLE IN THIS STUDY.

WHOQOL-BREF tool also didn't have cut-off score to categorize the level of quality of life. Therefore, researcher had done some modification that is total obtained score was divided into 3 parts on the basis of median score (70) and inter-quartile range (62–79). This scale had 5 points rater and no '0' score to rate quality of life or unsatisfied with life. Therefore, up to 20% scores were considered as no quality of life. Yet, scores obtained up to 62 (25%) was labeled as low quality of life, whereas score 63 to 79 corresponded to average quality of life and score more than 79 were labeled as high quality of life in this study.

TABLE 4.15

QUALITY OF LIFE AND GENDER DISTRIBUTION

N= 280

QUALITY OF LIFE	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
HIGH	**30**	**29.7**	**37**	**20.7**	**67**	23.9
AVERAGE	**48**	**47.5**	**93**	**52.0**	**141**	50.4
LOW	**23**	**22.8**	**49**	**27.3**	**72**	25.7
TOTAL	101	100	179	100	280	100

MEDIAN SCORE = 70	*IQR = 62-79*

Table 4.15 depicts the level of quality of life and gender distribution. Of the 280 research participants, 72 (25.7%) had low quality of life; whereas 67 (23.9%) of the cancer patients had high level of quality of life. This study also revealed that the male research participants had better quality of life as compared to their female counterparts.

TABLE 4.15A

PHYSICAL DOMAIN OF QOL AND GENDER DISTRIBUTION

N=280

PHYSICAL DOMAIN OF QOL	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
HIGH	**27**	**26.7**	**38**	**21.2**	**65**	23.2
AVERAGE	**49**	**48.5**	**84**	**46.9**	**133**	47.5
LOW	**25**	**24.8**	**57**	**31.8**	**82**	29.3
TOTAL	101	100	179	100	280	100
MEDIAN SCORE = 18			*IQR = 15-20*			

Table 4.15a depicts the physical domain of quality of life and gender distribution of the research participants. Out of 26 items of WHOQOL-BREF tool, 7 were allocated for physical domain, which had score range 7 to 35. Median 18 and inter-quartile range (IQR) 15 to 20 was calculated to categorize the data. Total scores of the allocated items were divided into 3 categories according to which scores up to 15 were labeled as low physical quality of life, whereas score 16 to 20 were labeled as average physical quality of life and score more than 20 were labeled as high level of physical quality of life among research participants.

OF THE TOTAL 280 RESEARCH PARTICIPANTS, 82 (29.3%) HAD LOW LEVEL OF PHYSICAL QUALITY OF LIFE; AND 65 (23.2%) HAD HIGH LEVEL OF PHYSICAL QUALITY OF LIFE. THIS STUDY ALSO REVEALED THAT HIGH LEVEL OF PHYSICAL QUALITY OF LIFE WAS HIGHER AMONG THE MALE RESEARCH PARTICIPANTS AS COMPARE TO THEIR FEMALE COUNTERPARTS.

TABLE 4.15B

PSYCHOLOGICAL DOMAIN OF QOL AND GENDER DISTRIBUTION

N= 280

PSYCHOLOGICAL DOMAIN OF QOL	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
HIGH	**21**	**20.8**	**31**	**17.3**	**52**	18.6
AVERAGE	**48**	**47.5**	**97**	**54.2**	**145**	51.8
LOW	**32**	**31.7**	**51**	**28.5**	**83**	29.6
TOTAL	101	100	179	100	280	100
MEDIAN SCORE = 19			*IQR = 17-20*			

Table 4.15b depicts the psychological domain of quality of life and gender distribution of the research participants. Out of 26 items of WHOQOL-BREF tool, 6 items were allocated for psychological domain, which had score range 6 to 30. Median 19 and inter-quartile range (IQR) 17 to 20 was calculated to categorize the data. Total scores of the allocated items were divided into 3 categories according to which, scores up to 17 were labeled as low psychological domain of quality of life, whereas score 18 to 20 were labeled as average psychological quality of life and score more than 20 were labeled as high level of psychological domain of quality of life among research participants.

OF THE TOTAL 280 RESEARCH PARTICIPANTS, 83 (29.6%) HAD LOW LEVEL OF PSYCHOLOGICAL QUALITY OF LIFE; AND 52 (18.6%) HAD HIGH LEVEL OF PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE. THIS STUDY ALSO REVEALED THAT HIGH LEVEL OF PSYCHOLOGICAL QUALITY OF LIFE WAS HIGHER AMONG THE MALE RESEARCH PARTICIPANTS AS COMPARE TO THEIR FEMALE COUNTERPARTS.

TABLE 4.15C

SOCIAL RELATIONSHIPS DOMAIN OF QOL AND GENDER DISTRIBUTION

n=280

SOCIAL RELATIONSHIPS DOMAIN OF QOL	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
HIGH	**29**	**28.7**	**31**	**17.3**	**60**	21.4
AVERAGE	**49**	**48.5**	**79**	**44.1**	**128**	45.7
LOW	**23**	**22.8**	**69**	**38.5**	**92**	32.9
TOTAL	101	100	179	100	280	100
MEDIAN SCORE = 9			*IQR = 7-10*			

Table 4.15c depicts the social relationship domain of quality of life and gender distribution of the research participants. Out of 26 items of WHOQOL-BREF tool, 3 items were allocated for social relationship domain, which had score range 3 to 15. Median 9 and inter-quartile range (IQR) 7 to 10 was calculated to categorize the data. Total scores of the allocated items were divided into 3 categories according to which, scores up to 7 were labeled as low social relationship domain of quality of life, whereas score 8 to 10 were labeled as average social relationship and score more than 10 were labeled as high level of social relationship domain of quality of life among research participants.

OF THE TOTAL 280 RESEARCH PARTICIPANTS, 92 (32.9%) HAD LOW LEVEL OF SOCIAL RELATIONSHIP DOMAIN OF QUALITY OF LIFE; AND 60 (21.4%) HAD HIGH LEVEL OF SOCIAL RELATIONSHIP DOMAIN OF QUALITY OF LIFE. THIS STUDY ALSO REVEALED THAT HIGH LEVEL OF SOCIAL RELATIONSHIP DOMAIN OF QUALITY OF LIFE WAS HIGHER AMONG THE MALE RESEARCH PARTICIPANTS AS COMPARE TO THEIR FEMALE COUNTERPARTS.

TABLE 4.15D

ENVIRONMENT DOMAIN OF QOL AND GENDER DISTRIBUTION

N=280

ENVIRONMENT DOMAIN OF QOL	MALE		FEMALE		TOTAL	
	NO.	PERCENT	NO.	PERCENT	NO.	PERCENT
HIGH	**28**	**27.7**	**42**	**23.5**	**70**	25.0
AVERAGE	**47**	**46.5**	**83**	**46.4**	**130**	46.4
LOW	**26**	**25.7**	**54**	**30.2**	**80**	28.6
TOTAL	101	100	179	100	280	100
MEDIAN SCORE = 21			*IQR = 17-24.75*			

Table 4.15d depicts the environment domain of quality of life and gender distribution of the research participants. Among the 26 items of WHOQOL-BREF tool, 8 items were allocated for environment domain, which had score range 8 to 40. Median 21 and inter-quartile range (IQR) was calculated 17 to 24.75. Total scores of the allocated items were divided into 3 categories according to which, scores up to 17 were labeled as low environment domain of quality of life, whereas score 18 to 25 were labeled as average environment related quality of life and score more than 25 were labeled as high level of environment domain of quality of life among research participants.

OF THE TOTAL 280 RESEARCH PARTICIPANTS, 80 (28.6%) HAD LOW LEVEL OF ENVIRONMENT RELATED QUALITY OF LIFE; AND ONE FOURTH 70 (25.0%) HAD HIGH LEVEL OF ENVIRONMENT DOMAIN OF QUALITY OF LIFE. THIS STUDY ALSO REVEALED THAT HIGH LEVEL OF ENVIRONMENT QUALITY OF LIFE WAS HIGHER AMONG THE MALE RESEARCH PARTICIPANTS.

4.2 INFERENTIAL STATISTICS

INFERENTIAL STATISTICS WAS USED TO FIND OUT THE STATISTICAL ASSOCIATION OF DEMOGRAPHIC, DISEASE AND PSYCHOSOCIAL VARIABLES WITH THE QUALITY OF LIFE AND ITS FOUR DOMAINS. INTER-QUARTILE RANGE WAS CALCULATED FOR THE SCORES OBTAINED FROM QUALITY OF LIFE AND PSYCHOSOCIAL MEASUREMENT SCALES. THIRD QUARTILE OR 75

PERCENTILE (75%) WAS TAKEN AS CUTOFF FOR DEMARCATION OF HIGH QUALITY OF LIFE AND ALL PSYCHOSOCIAL VARIABLES, AND UTILIZED WHEREVER NEEDED DURING APPLICATION OF STATISTICAL TESTS. CUTOFF 75% IS STANDARD AND UNIVERSALLY ACCEPTED BY MANY RESEARCHERS. RESEARCH PARTICIPANTS, WHO SCORED MORE THAN 75, WERE CONSIDERED TO HAVE HIGH QUALITY OF LIFE, SOCIAL SUPPORT, SELF-ESTEEM, COPING. WHEREAS, CUT OFF FOR SEVERE ANXIETY AND DEPRESSION WERE TAKEN AS PER STANDARD SET IN TOOL. TO MEASURE THE ASSOCIATIONS BETWEEN INDEPENDENT AND DEPENDENT VARIABLES CHI-SQUARE TEST, SPEARMAN RANK CORRELATION (RHO), AND LOGISTIC REGRESSIONS (BINARY AND MULTINOMIAL) STATISTICAL TESTS WERE APPLIED.

THE LEVEL OF SIGNIFICANCE (THE POINT AT WHICH RESEARCH CAN SAY WITH 95% CONFIDENCE THAT THE DIFFERENCE IS NOT DUE TO CHANCE ALONE) IS SET AT .05 (THE STANDARD FOR MOST OF THE RESEARCH), BECAUSE OF THE CHANCES OF HAVING ERROR DURING DATA COLLECTION FROM THE HUMAN RESEARCH PARTICIPANTS. IN DESCRIPTIVE STUDY USUALLY CONFIDENCE INTERVAL (CI) IS SET AT 95%, WHICH MEANS THERE MAY BE HAVING CHANCE OF 5% ERROR.

STRUCTURED QUESTIONNAIRE TECHNIQUE WAS USED TO COLLECT DATA, BY WHICH ONLY RELEVANT INFORMATION FROM THE RESEARCHER'S PERSPECTIVE WAS GATHERED. THEREFORE, IN THIS STUDY, OPEN ENDED GUIDELINES (UNSTRUCTURED QUESTIONNAIRE) WERE ALSO USED TO COLLECT DATA FROM 20 CANCER PATIENTS TO ADD THE COMPREHENSIVE THOUGHTS OF THE RESEARCH PARTICIPANTS.

4.2.1 CHI-SQUARE TEST

Chi-square test (x^2) was applied to find out the association between demographic and disease variables with the quality of life and its four domains among cancer patients. In this study, chi-square test is used to determine whether there is a significant difference between the expected frequencies and the observed frequencies in one or more categories. The numbers of individuals or objects that fall in each category differ significantly from the number which is expected by the researcher. With the help of chi-square test, researcher would be able to find out if the difference between the expected and observed is due to sampling error, or is it a real difference (Singh, 2007). Chi-square test required quantitative data, one or more categories, independent observations, adequate sample size (at least 5 in each cell), data in frequency form, all observations must be used.

4.2.2 Spearman's Rank Correlation (rho)

Correlation coefficient (*r*) is applied for quantitative and normally distributed variables. The quantity *r*, called the linear correlation coefficient (*r*), measures the strength and the direction of a linear relationship between two variables. The linear correlation coefficient is sometimes referred to as the Pearson product moment correlation coefficient (PMCC) in honor of its developer Karl Pearson. [1]

IN CASES WHERE THE ASSOCIATION IS NON-LINEAR, THE RELATIONSHIP CAN SOMETIMES BE TRANSFORMED INTO A LINEAR ONE BY USING THE RANKS OF THE ITEMS RATHER THAN THEIR ACTUAL VALUES. USING RANKS RATHER THAN DATA VALUES PRODUCES TWO NEW VARIABLES (THE RANKS). THESE FULFILL THE CONDITIONS FOR THE USE OF THE DESCRIPTION "CORRELATION" SINCE THEIR RELATIONSHIP IS LINEAR BUT RESEARCHER CANNOT JUST USE THE PEARSON PRODUCT MOMENT CORRELATION COEFFICIENT (*R*) TEST ON THE RANKS BECAUSE THEY ARE NOT DRAWN FROM A BIVARIATE NORMAL POPULATION (ARMITAGE AND BERRY, 1994). IF THE DATA ARE NOT NORMALLY DISTRIBUTED OR HAVE ORDERED CATEGORIES, RESEARCHER CAN CHOOSE KENDALL'S TAU-B OR SPEARMAN, WHICH MEASURE THE ASSOCIATION BETWEEN RANK ORDERS.

Spearman's rank correlation provides a distribution free test of independence between two variables. It is, however, insensitive to some types of dependence. Here, Spearman's rank correlation coefficient (*r*) ranges in value from –1 (a perfect negative relationship) and +1 (a perfect positive relationship). A value of 0 indicates no linear relationship (SPSS Version 13.0).). Two-tailed test method was utilized during data analysis, which means at the 10% level of significance, the critical values separate off the 5% tail nearest to -1 and the equivalent 5% tail nearest to +1**.** Correlation '*r*' is interpreted as follows

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[1] http://www.mei.org.uk/files/pdf/Spearmanrcc.pdf

***R* FROM 0.00 TO ± 0.20 DENOTES INDIFFERENT OR NEGLIGIBLE RELATIONSHIP**

***R* FROM 0.20 TO ± 0.40 DENOTES LOW CORRELATION; PRESENT BUT SLIGHT**

***R* FROM 0.40 TO ± 0.70 DENOTES SUBSTANTIAL OR MARKED RELATIONSHIP**

***R* FROM 0.70 TO ± 1.00 DENOTES HIGH TO VERY HIGH RELATIONSHIP**

DATA COLLECTED DURING THIS STUDY WAS NOT NORMALLY DISTRIBUTED AND NON-LINEAR; THEREFORE SPEARMAN RANK BIVARIATE CORRELATION STATISTICAL TEST WAS UTILIZED TO FIND OUT THE ASSOCIATION OF INDEPENDENT VARIABLES WITH DEPENDENT VARIABLE (QUALITY OF LIFE INCLUDING ITS FOUR DOMAINS) AMONG THE RESEARCH PARTICIPANTS. THIS TEST WAS APPLIED WITH OPEN SCORES OBTAINED FROM BOTH INDEPENDENT AND DEPENDENT VARIABLES. THIS STUDY WAS DESCRIPTIVE, BUT EXPLORATORY IN NATURE. THEREFORE, RESEARCHER HAS CHOSEN THE SPEARMAN RANK CORRELATION TEST TO QUANTIFY THE RELATIONSHIP OR ASSOCIATION OF INDEPENDENT VARIABLES WITH QUALITY OF LIFE INCLUDING ITS FOUR DOMAINS. THIS STUDY RESULTS CANNOT BE INTERPRETED AS ANY CAUSE-AND-EFFECT RELATIONSHIP IN CONCLUSIONS, AS RELATIONSHIP DRAWN WAS NON-LINEAR.

4.2.3 Logistic Regression Analysis

Regression analysis includes any techniques for modeling and analyzing several variables, when the focus is on the relationship between a dependent variable and one or more independent variables. More specifically, regression analysis helps researcher to understand how the typical value of the dependent variable changes when any one of the independent variables is varied, while the other independent variables are held fixed. Most commonly, regression analysis estimates the conditional expectation of the dependent variable given the independent variables that is, the average value of the dependent variable when the independent variables are held fixed.[2] In restricted circumstances, regression analysis can be used to infer causal relationships between the independent and dependent variables. This study utilized the logistic regression

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[2] HTTP://EN.WIKIPEDIA.ORG/WIKI/LOGISTIC_REGRESSION

analysis to bring out the factor, among the five psychosocial factors, which has a stronger association and can be a predictor of quality of life including its four domains in micro form.

In this study, researcher wanted to understand how the quality of life and its domains among cancer patients changed when any one of the psychosocial factors varied. Conditional expectations of quality of life including its four domains relationship with selected psychosocial factors was calculated by using bivariate/binary and multivariate/multinomial regression analysis.

TABLE 4.16

ASSOCIATION OF DEMOGRAPHIC VARIABLES WITH QUALITY OF LIFE

N=280

DEMOGRAPHIC VARIABLES	CATEGORIES	QUALITY OF LIFE		TOTAL N (%)	P-VALUE
		HIGH N (%)	LOW N (%)		
AGE	18-39 years	**8 (22.9)**	**27 (77.1)**	**35 (100)**	0.889
	40-59 years	**38 (24.8)**	**115 (75.5)**	**153 (100)**	
	60-80 years	**21 (22.8)**	**115 (75.2)**	**153 (100)**	
GENDER	**MALE**	**30 (29.7)**	**71 (70.3)**	**101 (100)**	0.061
	FEMALE	**37 (20.7)**	**142 (79.3)**	**179 (100)**	
EDUCATION	**ILLITERATE**	**44 (23.8)**	**141 (76.2)**	**185 (100)**	0.524
	EDUCATED	**23 (24.2)**	**72 (75.8)**	**95 (100)**	
MARITAL STATUS	**SINGLE**	**12 (25.5)**	**35 (74.5)**	**47 (100)**	0.454
	MARRIED	**55 (23.6)**	**178 (76.4)**	**233 (100)**	
ECONOMIC STATUS	**HIGH**	**28 (23.5)**	**91 (76.5)**	**119 (100)**	0.504
	LOW	**39 (24.2)**	**122 (75.8)**	**161 (100)**	
ROLE IN THE FAMILY	**EARNER**	**28 (23.0)**	**94 (77.0)**	**122 (100)**	0.424
	DEPENDENT	**39 (24.7)**	**119 (75.3)**	**158 (100)**	

TABLE 4.16 DEPICTS ASSOCIATION OF DEMOGRAPHIC VARIABLES (AGE, GENDER, EDUCATION, MARITAL STATUS, ECONOMIC STATUS AND ROLE IN THE FAMILY) WITH QUALITY OF LIFE. CHI-SQUARE TEST WAS APPLIED, WHERE DEGREE OF FREEDOM FOR AGE GROUP WAS 2 AND FOR OTHERS VARIABLES 1. THERE WAS NO SUFFICIENT STATISTICAL EVIDENCE TO SAY THAT THERE WAS AN ASSOCIATION BETWEEN AGE, GENDER, EDUCATION, MARITAL, ECONOMIC STATUS AND ROLE IN THE FAMILY OF CANCER PATIENTS WITH THEIR QUALITY OF LIFE.

Yet, qualitative data revealed that when diagnosis of cancer is declared among young research participants, they expressed “*Kinā yo rog mālāi nāi, māile ke pāp gāreko thinye rā kun juni ko phāl ho yehi umer mā yāsto sāmsya bhognu pāryo*” (why this disease crabbed me?, why am I the one suffering?, Is it a sin or curse of someone?). But when same problem happened to aged research participants, they stated “*Pākeko phāl jhārna lāgeko mātra ho āru kehi hoinā”*(when fruit ripens, it falls down). Some research participants also stated “*belā bhāyo bhānera yāmrāj le khābār mātrā pāthāyeko ho āru kehi haina”* (it is nothing but a message from the God of death *(yāmrāj*, according to Hindu religion) because it is time to die). This means the younger patients diagnosed as cancer may face more problems with their settlement or due to the loss of hopes of fulfilling their dreams and aspirations because of the diagnosis of such a life threatening disease. Also, the expectations of the family members/relatives from patients or their financial issues could be contributing factors.

QUALITATIVE STUDY RESULT ALSO REVEALED THAT OUT OF 6 SINGLE RESEARCH PARTICIPANTS, 3 WERE WIDOW, 1 DIVORCED AND 2 UNMARRIED. MAJORITY OF THEM HAD MANY PSYCHOSOCIAL PROBLEMS LIKE SYMPTOMS OF DEPRESSION, AVOIDANT COPING, DEVELOPING STUBBORN NATURE AND GETTING WORRIED ABOUT CANCER STIGMA ATTACHED TO THEIR FUTURE PROSPECTS SUCH AS GETTING MARRIED, ETC; WHICH INFLUENCED THE QUALITY OF LIFE OF THE CANCER PATIENTS.

QUALITATIVE STUDY ALSO REVEALED THAT OUT OF 20 SAMPLES, TWO (10%) BELONGED TO LOW SOCIO-ECONOMIC STATUS. BOTH OF THEM WERE EXPRESSED “*MĀRNĀ PĀNI SĀKIYENĀ*” (COULD NOT DIE ALSO), “*MĀNĀ KO BĀHĀ KĀSĀLĀI KĀHĀ*?” (TO WHOM I CAN SHARE THIS BITTER FEELINGS OR PAIN), “*HĀSNĀ BIRSE KO JĀSTO LĀGCHHĀ*” (FORGET TO LAUGH), *DIKKA LAGCHHA*” (FED UP). OTHER THAN THESE PROVERBS THEY BECAME SAD, IRRITATED, ANGER, SILENT, ETC. THESE ARE THE SIGNS AND SYMPTOMS OF DEPRESSION, WHICH LEADS TO LOW QUALITY OF LIFE.

QUALITATIVE STUDY ALSO REVEALED THAT ROLE IN THE FAMILY COULD NOT BE A DETERMINANT FOR THE CANCER PATIENTS IN NEPAL. AS JOINT FAMILY SYSTEM STILL EXISTS IN NEPALESE SOCIETY, OTHER MEMBERS OF THE FAMILY SUPPORTED THE CANCER PATIENTS AS SUBSTITUTE IN THEIR ROLES FOR THE TIME BEING.

TABLE 4.16A

ASSOCIATION OF DEMOGRAPHIC VARIABLES WITH PHYSICAL DOMAIN OF QOL

N= 280

DEMOGRAPHIC VARIABLES	CATEGORIES	PHYSICAL DOMAIN OF QOL		TOTAL N (%)	P-VALUE
		HIGH N (%)	LOW N (%)		
AGE	18-39 years	10 (28.6)	**25 (71.4)**	**35 (100)**	0.477
	40-59 years	35 (22.9)	**118 (77.1)**	**153 (100)**	
	60-80 years	20 (21.7)	**72 (78.3)**	**92(100)**	
GENDER	**MALE**	**27 (26.7)**	**74 (73.3)**	**101 (100)**	0.184
	FEMALE	**38 (21.2)**	**141 (78.8)**	**179 (179)**	
EDUCATION	**ILLITERATE**	**43 (23.2)**	**142 (76.8)**	**185 (100)**	0.556
	EDUCATED	**22 (23.2)**	**73 (76.8)**	**95 (100)**	
MARITAL STATUS	**SINGLE**	**9 (19.1)**	**38 (80.9)**	**47 (100)**	0.303
	MARRIED	**56 (24.0)**	**177 (76.0)**	**233 (100)**	
ECONOMIC STATUS	**HIGH**	**25 (21.0)**	**94 (79.0)**	**119 (100)**	0.272
	LOW	**40 (24.8)**	**121 (75.2)**	**161 (100)**	
ROLE IN THE FAMILY	**EARNER**	**29 (23.8)**	**93 (76.2)**	**122 (100)**	0.478
	DEPENDENT	**36 (22.8)**	**122 (77.2)**	**158 (100)**	

TABLE 4.16A DEPICTS ASSOCIATION BETWEEN DEMOGRAPHIC VARIABLES (AGE, GENDER, EDUCATION, MARITAL STATUS, ECONOMIC STATUS AND ROLE IN THE FAMILY) WITH PHYSICAL DOMAIN OF QUALITY OF LIFE. PHYSICAL DOMAIN OF QUALITY OF LIFE COVERED ACTIVITIES OF DAILY LIVING, DEPENDENCE ON MEDICINAL SUBSTANCES AND MEDICAL AIDS, ENERGY AND FATIGUE, MOBILITY, PAIN AND DISCOMFORT, SLEEP AND REST; AND WORK CAPACITY. THERE IS NO STATISTICAL EVIDENCE TO SAY THAT THERE IS AN ASSOCIATION BETWEEN AGE, GENDER, EDUCATION, MARITAL, ECONOMIC STATUS AND ROLE IN THE FAMILY OF CANCER PATIENTS WITH THE PHYSICAL DOMAIN OF QUALITY OF LIFE.

QUALITATIVE STUDY REVEALED THAT, OUT OF THE 20 RESEARCH PARTICIPANTS, 14 (70%) WERE FEMALE AND AMONG THEM 9 (64.3%) CANCER PATIENTS HAD THE PHYSICAL PROBLEMS WITH THEIR DAILY ACTIVITIES, PAIN, DISCOMFORT, ANOREXIA. DURING IN-DEPTH INTERVIEW FEMALE USED TO HAVE MULTIPLE COMPLAINS. HENCE, QUALITATIVE DATA REVEALED THAT THE FEMALE HAVE UNEXPLAINED EXTENTS OF PROBLEMS, WHICH CAN GENERATE THE LOW PHYSICAL DOMAIN OF QUALITY OF LIFE AMONG THE CANCER PATIENTS.

QUALITATIVE STUDY ALSO REVEALED THAT OUT OF 14 MARRIED RESEARCH PARTICIPANTS, 6 (42.8%) REPORTED THAT THEY USED TO ENGAGE THEMSELVES WITH THEIR HOUSEHOLD WORKS, THEIR SPOUSE AND CHILDREN. SOMETIMES THEY USED TO GO TO THEIR PARENT'S/IN-LAWS HOME TO DIVERT THEIR MINDS AND GET SOME SUPPORT FROM THEIR FAMILY AND RELATIVES. THIS MEANS THAT THE MARRIED RESEARCH PARTICIPANTS HAD BETTER QUALITY OF LIFE IN PHYSICAL DOMAIN.

TABLE 4.16B

ASSOCIATION OF DEMOGRAPHIC VARIABLES WITH PSYCHOLOGICAL DOMAIN OF QOL

N= 280

DEMOGRAPHIC VARIABLES	CATEGORIES	PSYCHOLOGICAL DOMAIN OF QOL		TOTAL N (%)	P-VALUE
		HIGH N (%)	LOW N (%)		
AGE	18-39 years	**5 (14.3)**	**30 (85.7)**	**35 (100)**	0.921
	40-59 years	**31 (20.3)**	**122 (79.7)**	**153 (100)**	
	60-80 years	**16 (17.4)**	**76 (82.6)**	**92 (100)**	
GENDER	**MALE**	**21 (20.8)**	**80 (79.2)**	**101 (100)**	0.286
	FEMALE	**31 (17.3)**	**148 (82.7)**	**179 (100)**	
EDUCATION	**ILLITERATE**	**40 (21.6)**	**145 (78.4)**	**185 (100)**	0.045
	EDUCATED	**12 (12.6)**	**83 (87.4)**	**95 (100)**	
MARITAL STATUS	**SINGLE**	**7 (14.9)**	**40 (85.1)**	**47 (100)**	0.315
	MARRIED	**45 (19.3)**	**188 (80.7)**	**233 (100)**	

ECONOMIC STATUS	**HIGH**	**22 (18.5)**	**97 (81.4)**	**119 (100)**	0.551
	LOW	**30 (18.6)**	**131 (81.4)**	**161 (100)**	
ROLE IN THE FAMILY	**EARNER**	**27 (22.1)**	**95 (77.9)**	**122 (100)**	0.117
	DEPENDENT	**25 (15.8)**	**133 (84.2)**	**158 (100)**	

TABLE 4.16B DEPICTS ASSOCIATION BETWEEN DEMOGRAPHIC VARIABLES (AGE, GENDER, EDUCATION, MARITAL STATUS, ECONOMIC STATUS AND ROLE IN THE FAMILY) WITH PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE. PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE INCLUDED BODILY IMAGE AND APPEARANCE, NEGATIVE FEELINGS, POSITIVE FEELINGS, SELF-ESTEEM, SPIRITUALITY/RELIGION/PERSONAL BELIEFS; AND THINKING, LEARNING, MEMORY AND CONCENTRATION. THERE WAS SIGNIFICANT STATISTICAL ASSOCIATION (*P=< 0.05*) BETWEEN EDUCATIONAL STATUS AND PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE OF THE RESEARCH PARTICIPANTS. THE STUDY RESULT REVEALED THAT ILLITERATE CANCER PATIENTS HAD BETTER PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE AS COMPARED TO THEIR EDUCATED COUNTERPARTS. WHEREAS, THERE IS NO ADEQUATE STATISTICAL EVIDENCE TO SAY THAT THERE IS AN ASSOCIATION BETWEEN AGE, GENDER, MARITAL, ECONOMIC STATUS AND ROLE IN THE FAMILY OF CANCER PATIENTS WITH PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE.

OUT OF 20 RESEARCH PARTICIPANTS IN QUALITATIVE STUDY, 6 (30%) WERE ILLITERATE AND AMONG THEM 2 (33.3%) STATED “*PURĀNO PHOTO, RĀ AIENĀ HERNĀ MĀNĀ LĀGDĀIN*” (POOR BODY IMAGE); AND “*MĀRNA MĀNĀ LĀGCHHĀ”* (FEEL LIKE DYING). QUALITATIVE STUDY ALSO REVEALED THAT WHEN DIAGNOSIS OF CANCER WAS CONFIRMED AMONG ILLITERATE RESEARCH PARTICIPANTS THEY STATED “*JE LEKHEKO CHHĀ BHĀGYĀ MĀ TEHI NĀI HUNCHHĀ*” (WHATEVER HAS BEEN FATED WILL SURELY HAPPEN). BUT WHEN SAME THING HAPPENED TO THE EDUCATED RESEARCH PARTICIPANTS, THEY USED TO HAVE MANY QUERIES ABOUT THE PROGNOSIS/FORECAST OF DISEASE PROCESS, THEIR SURVIVAL, SIDE-EFFECTS OF THE CHEMOTHERAPY AND/OR RADIATION THERAPY, THREAT OF RELAPSE/REOCCURRENCE, ETC. AT TIMES, IT WAS BETTER TO KNOW ABOUT ONESELF BUT MOST OF THE TIME IT MADE THE RESEARCH PARTICIPANTS MORE SENTIMENTAL,

EMOTIONAL AND AROUSED NEGATIVE FEELINGS. THUS, EDUCATIONAL STATUS OF THE CANCER PATIENTS CAN BE A DETERMINANT FOR PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE.

THIS STUDY ALSO REVEALED THAT OUT OF 14 MARRIED RESEARCH PARTICIPANTS, 7 (50%) WORSHIPPED AND PRAYED TO THEIR 'GOD' ACCORDING TO THEIR RELIGION. AMONG THE MARRIED, ONE MUSLIM RESEARCH PARTICIPANT EXPRESSED THAT AFTER THE DIAGNOSIS OF CANCER HE USED TO PRAY 'NAWAJ' ON A MORE REGULAR BASIS. HINDUS WORSHIPPED AND PRAYED MORE, PAID REPENT TO GOD AND DONATED (*DĀN DĀKCHHINĀ*) TO RELIGIOUS PEOPLE (*PĀNDIT*) TO COPE WITH THE CANCER. THIS MEANS THAT MARRIED RESEARCH PARTICIPANTS HAVE BETTER QUALITY OF LIFE IN PSYCHOLOGICAL DOMAIN.

TABLE 4.16C

ASSOCIATION OF DEMOGRAPHIC VARIABLES WITH SOCIAL RELATIONSHIP DOMAIN OF QOL

N=280

DEMOGRAPHIC VARIABLES	CATEGORIES	SOCIAL RELATIONSHIP DOMAIN OF QOL		TOTAL N (%)	P VALUE
		HIGH N (%)	LOW N (%)		
AGE	18-39 years	**6 (17.1)**	**29 (82.9)**	**35 (100)**	0. 278
	40-59 years	**31 (20.3)**	**122 (79.7)**	**153 (100)**	
	60-80 years	**23 (25.0)**	**69 (75.0)**	**92 (100)**	
GENDER	**MALE**	**29 (28.7)**	**72 (71.3)**	**101 (100)**	0.020
	FEMALE	**31 (17.3)**	**148 (82.7)**	**179 100)**	
EDUCATION	**ILLITERATE**	**35 (18.9)**	**150 (81.1)**	**185 (100)**	0.102
	EDUCATED	**25 (26.3)**	**70 (73.7)**	**95 (100)**	
MARITAL STATUS	**SINGLE**	**9 (19.1)**	**38 (80.9)**	**47 (100)**	0.421
	MARRIED	**51 (21.9)**	**182 (78.1)**	**233 (100)**	
ECONOMIC STATUS	**HIGH**	**25 (21.0)**	**94 (79.0)**	**119 (100)**	0.502
	LOW	**35 (21.7)**	**126 (78.3)**	**161 (100)**	
ROLE IN THE FAMILY	**EARNER**	**30 (24.6)**	**92 (75.4)**	**122 (100)**	0.11
	DEPENDENT	**30 (19.0)**	**128 (81.0)**	**158(100)**	

TABLE 4.16C DEPICTS ASSOCIATION BETWEEN DEMOGRAPHIC VARIABLES (AGE, GENDER, EDUCATION, MARITAL STATUS, ECONOMIC STATUS AND ROLE IN THE FAMILY) WITH SOCIAL RELATIONSHIPS DOMAIN OF QUALITY OF LIFE. SOCIAL RELATIONSHIPS DOMAIN OF QUALITY OF LIFE COVERED PERSONAL RELATIONSHIPS, SOCIAL SUPPORT, AND SEXUAL ACTIVITY. THERE WAS SIGNIFICANT STATISTICAL ASSOCIATION (*P=< 0.05*) BETWEEN GENDER AND SOCIAL RELATIONSHIP DOMAIN OF QUALITY OF LIFE AMONG THE RESEARCH PARTICIPANTS, WHICH MEANS THAT MALE CANCER PATIENTS HAD HIGHER QUALITY OF LIFE IN SOCIAL RELATIONSHIP DOMAIN AS COMPARED TO THEIR FEMALE COUNTERPARTS.

EVIDENCES COLLECTED THROUGH IN-DEPTH INTERVIEW REVEALED THAT IN NEPALESE CONTEXT MALES ARE THE BREAD-EARNERS FOR THE FAMILY, WHEREAS FEMALES HAVE TO LOOK AFTER THEIR FAMILY, CARE FOR THEIR CHILDREN, PARENTS, IN-LAWS, ETC AND FULFILL THE SEXUAL NEEDS OF THEIR HUSBANDS, EVEN IF THEY WERE EARNERS. FEMALE USED TO HAVE MORE SOCIAL NETWORKS SUCH AS GATHERING, COMMUNICATION, ETC. AS COMPARED TO THEIR MALE COUNTERPARTS. MOST OF THE FEMALES STATED THAT WHEN THEY HAD CANCER, THEY COULD NOT PERFORM THEIR ROLE FOR THE FAMILY OR SOCIETY. OUT OF THE 8 MARRIED WOMEN, 2 (25%) VERBALIZED THAT THEY WERE FACING PROBLEMS RELATED TO SEXUALITY *"CHIDCHID GĀRNU HUNCHHĀ, RISĀUNU HUNCHHĀ"* (HUSBAND BECAME IRRITATED). MAJORITY OF THE FEMALE CANCER PATIENTS FELT DETACHED OR ISOLATED FROM THEIR FAMILY AND SOCIETY. GENDER OF THE CANCER PATIENTS CAN BE A DETERMINANT FOR QUALITY OF LIFE IN SOCIAL RELATIONSHIP DOMAIN.

TABLE 4.16C ALSO SHOWS THAT THERE IS NO SUFFICIENT STATISTICAL EVIDENCE TO SAY THAT THERE IS AN ASSOCIATION BETWEEN AGE, EDUCATION, MARITAL, ECONOMIC STATUS AND ROLE IN THE FAMILY OF CANCER PATIENTS WITH SOCIAL RELATIONSHIP DOMAIN OF QUALITY OF LIFE.

YET, QUALITATIVE FINDINGS REVEALED THAT OUT OF 7 AGED RESEARCH PARTICIPANTS, MORE THAN HALF, 4 (57.1%), STATED THAT THEY WERE UNABLE TO ATTEND SOCIAL FUNCTIONS, LOST JOB, HAD LOW SEXUAL ACTIVITY, AND HAD LESS SOCIAL SUPPORT, WHICH IS RELATED TO LOW SOCIAL RELATIONSHIP DOMAIN RELATED QUALITY OF LIFE.

TABLE 4.16D

ASSOCIATION OF DEMOGRAPHIC VARIABLES WITH ENVIRONMENT DOMAIN OF QOL

N= 280

DEMOGRAPHIC VARIABLES	CATEGORIES	ENVIRONMENT DOMAIN OF QOL		TOTAL N (%)	P VALUE
		HIGH N (%)	LOW N (%)		
AGE	18-39 years	**8 (22.9)**	**27 (77.1)**	**35 (100)**	0.629
	40-59 years	**42 (27.5)**	**111 (72.2)**	**153 (100)**	

	60-80 years	**20 (21.7)**	**72 (78.3)**	**92 (100)**	
GENDER	**MALE**	**28 (27.7)**	**73 (72.3)**	**101 (100)**	0.258
	FEMALE	**42 (23.5)**	**137 (76.5)**	**179 (100)**	
EDUCATION	**ILLITERATE**	**48 (25.9)**	**137 (74.1)**	**185 (100)**	0.360
	EDUCATED	**22 (23.2)**	**73 (76.8)**	**95 (100)**	
MARITAL STATUS	**SINGLE**	**11 (23.4)**	**36 (76.6)**	**47 (100)**	0.471
	MARRIED	**59 (25.3)**	**174 (74.7)**	**233 (100)**	
ECONOMIC STATUS	**HIGH**	**35 (29.4)**	**84 (70.6)**	**119 (100)**	0.093
	LOW	**35 (21.7)**	**126 (78.3)**	**161 (100)**	
ROLE IN THE FAMILY	**EARNER**	**26 (21.3)**	**96 (78.7)**	**122(100)**	0.133
	DEPENDENT	**44 (27.8)**	**114 (72.2)**	**158 (100)**	

TABLE 4.16D DEPICTS ASSOCIATION OF DEMOGRAPHIC VARIABLES (AGE, GENDER, EDUCATION, MARITAL, ECONOMIC STATUS AND ROLE IN THE FAMILY) WITH ENVIRONMENT DOMAIN OF QUALITY OF LIFE. ENVIRONMENT DOMAIN OF QUALITY OF LIFE COVERED FINANCIAL RESOURCES, FREEDOM, PHYSICAL SAFETY AND SECURITY, HEALTH AND SOCIAL CARE: ACCESSIBILITY AND QUALITY, HOME ENVIRONMENT, OPPORTUNITIES FOR ACQUIRING NEW INFORMATION AND SKILLS, PARTICIPATION IN AND OPPORTUNITIES FOR RECREATION/LEISURE ACTIVITIES, PHYSICAL ENVIRONMENT (POLLUTION/ NOISE/TRAFFIC/CLIMATE) AND TRANSPORT. THIS STUDY REVEALED THAT THERE WAS NO STATISTICAL EVIDENCE TO SAY THAT THERE IS AN ASSOCIATION BETWEEN AGE, GENDER, EDUCATION, MARITAL, ECONOMIC STATUS AND ROLE IN THE FAMILY OF CANCER PATIENTS WITH ENVIRONMENT DOMAIN OF QUALITY OF LIFE.

YET, THE FINDINGS OF QUALITATIVE STUDY REVEALED THAT OUT OF 7, 50 YEARS AND ABOVE AGED CANCER PATIENTS 5 (71.4%) EXPRESSED THAT SUFFICIENT MONEY, PEACEFUL HOME ENVIRONMENT, RECREATIONAL ACTIVITIES, EASY ACCESSIBILITY TO HOSPITAL AND AVAILABILITY OF TRANSPORT FACILITIES ARE ESSENTIAL TO MAINTAIN QUALITY OF LIFE. THEY ALSO STATED “DOCTOR *RĀ* NURSE *LE PĀNI MITHO BOLNU PĀRYO”* (DOCTORS AND NURSES SHOULD ALSO COMMUNICATE RESPECTFULLY).

DURING QUALITATIVE STUDY A 44 YEARS OLD MARRIED FEMALE RESEARCH PARTICIPANT ALSO EXPRESSED “E*UTĀ NURSE LE ‘KASTO LODDĀR BIRĀMI’, BHĀNEKO SUNDA UPCHĀR NĀI NĀGĀRI MĀRNĀ PĀYE HUNTHYO JĀSTO LĀGYO*” (WHEN I HEARD A NURSE CALLING ME “AN UNLUCKY PATIENT”, I FELT THAT IT WOULD BE BETTER TO DIE WITHOUT ANY TREATMENT). THIS MEANS THAT THE PROFESSIONALS WHO HAVE UNDERTAKEN THE NOBLE JOB OF HEALING SHOULD TAKE PRECAUTIONS WHILE COMMUNICATING WITH THE PATIENTS. AS A MATTER OF FACT, ANYONE IN CONTACT WITH THE PATIENT SHOULD NOT USE THE PHRASES WHICH HAVE NEGATIVE CULTURAL MEANING.

TABLE 4.17

ASSOCIATION BETWEEN DISEASE VARIABLES AND QUALITY OF LIFE

N=280

DISEASE VARIABLES	CATEGORIES	QUALITY OF LIFE		TOTAL N (%)	P VALUE
		HIGH N (%)	LOW N (%)		
CANCER STAGE	Early stage	**26 (32.5)**	**54 (67.5)**	**80 (100)**	0.026
	Late stage	**41 (20.5)**	**159 (79.5)**	**200 (100)**	
DURATION OF DIAGNOSIS	**≤ ONE YEAR**	**56 (23.0)**	**187 (77.0)**	**243 (100)**	0.244
	> ONE YEAR	**11 (29.7)**	**26(70.3)**	**37 (100)**	
MODALITIES OF TREATMENT	**SINGLE**	**24 (28.2)**	**61 (71.8)**	**85 (100)**	0.168
	MULTIPLE	**43 (22.1)**	**152 (77.9)**	**195 (100)**	
FACING FINANCIAL PROBLEM FOR TREATMENT	**YES**	**49 (28.0)**	**126 (72.0)**	**175 (100)**	0.026
	NO	**18 (17.1)**	**87 (82.9)**	**105 (100)**	

TABLE 4.17 DEPICTS ASSOCIATION OF DISEASE VARIABLES (STAGE OF CANCER, DURATION OF DIAGNOSIS, MODALITIES OF TREATMENT AND FACING FINANCIAL PROBLEM FOR TREATMENT) WITH QUALITY OF LIFE. CHI-SQUARE (2×2 TABLE) WAS APPLIED, WHERE DEGREE OF FREEDOM WAS 1 FOR ENTIRE DISEASE VARIABLES. THERE IS SIGNIFICANT STATISTICAL ASSOCIATION (*P=<0.05*) BETWEEN STAGES OF CANCER AND QUALITY OF LIFE. THE STUDY RESULT REVEALED THAT EARLY STAGE (STAGE I AND II) CANCER PATIENTS HAD BETTER QUALITY OF LIFE AS COMPARED TO THE LATE STAGE CANCER PATIENTS OR WITH THE INCREASE IN THE STAGE OF CANCER, QUALITY OF LIFE OF THE CANCER PATIENTS DECREASED.

QUALITATIVE STUDY ALSO REVEALED THAT OUT OF 20 CANCER PATIENTS, 11 (55%) WHO WERE DIAGNOSED AS STAGE III AND IV HAD WORSE QUALITY OF LIFE. THE DECREASE IN QUALITY OF LIFE WITH INCREASING STAGE OF CANCER COULD BE DUE TO INCREASING INTENSITY OF PAIN, DISCOMFORT, INABILITY TO WORK, LOSS OF JOB, INABILITY TO SHOULDER RESPONSIBILITIES. SOME RESEARCH PARTICIPANTS WERE STATED "*PĀISĀ*

***KHĀRCHĀ GĀRNU BHĀNEKO, BĀLUWĀ MĀ PĀNI HĀLEKO JĀSTO MĀTRĀ HO OR KHER JĀNU HO*" (EXPENDITURE ON TREATMENT IS JUST DO WASTAGE MONEY OR NOTHING ELSE). BECAUSE OF UNCERTAINTY OF LIFE, FEELING OF HOPELESSNESS AND HELPLESSNESS, AND STRUGGLING BETWEEN LIFE AND DEATH. THIS STUDY REVEALED THAT STAGE OF CANCER CAN BE A DETERMINANT OF QUALITY OF LIFE.**

TABLE 4.17 ALSO SHOWS THE ASSOCIATION OF FINANCIAL PROBLEMS DURING TREATMENT WITH QUALITY OF LIFE. THERE IS SIGNIFICANT STATISTICAL ASSOCIATION ($P=<0.05$) OF FACING FINANCIAL PROBLEM FOR TREATMENT WITH QUALITY OF LIFE. QUALITY OF LIFE WAS FOUND TO BE BETTER AMONG THESE SAMPLES IN SPITE OF FACING FINANCIAL PROBLEMS DURING THEIR TREATMENT. THIS COULD BE DUE TO THE PARTICIPATION OF THE SAMPLE I.E. ALL RESEARCH PARTICIPANTS FOR QUANTITATIVE STUDY WERE ENROLLED FROM THE HOSPITALS. THIS MEANS THAT THOSE WHO WERE COMING TO HOSPITALS WERE DEFINITELY CONTINUING THEIR TREATMENT SO HAD BETTER QUALITY OF LIFE. ANOTHER REASON COULD BE DUE TO AVAILING FREE OF COST TREATMENT, WHICH IS AVAILABLE FOR ECONOMICALLY MARGINALIZED CANCER PATIENTS OR RECEIVING FINANCIAL SUPPORT FROM OTHERS SUCH AS THE RELATIVES, EMPLOYER ORGANIZATION, DONATIONS FROM GOVERNMENT AND OTHER NON-GOVERNMENTAL ORGANIZATION LIKE CANCER SOCIETY, ETC., WHICH MAY BE THE CONFOUNDING FACTORS FOR BETTER QUALITY OF LIFE IN SPITE THEIR FINANCIAL PROBLEMS.

YET, QUALITATIVE STUDY REVEALED THAT OUT OF 20 CANCER PATIENTS, 7 (35%) HAD FINANCIAL PROBLEM. MOST OF THEM EXPRESSED "*JE SUKĀI HOS, KEHI GĀRNĀ SĀKINĀ JIWĀN MĀ*" (FEELING WORTHLESSNESS, FRUSTRATION AND GUILT). SOME OF THEM FELT PUNISHED AND CONSIDERED THEMSELVES AS BURDEN ON THEIR FAMILY, SOCIETY AND EARTH (*PRITHVI LĀI BHĀR BHĀYEIN*), WHEREAS FEW OF THEM HAD PLANNED TO DISCONTINUE TREATMENT, CRIED AT TIMES, WERE WORRIED AND HAD DEVELOPED INSOMNIA AND SUICIDAL TENDENCIES. THESE ARE THE SYMPTOMS OF DEPRESSION AND SIGNS OF AVOIDANT COPING WHICH ARE AN INDICATOR FOR LOW QUALITY OF LIFE. THIS MEANS THAT THOSE CANCER PATIENTS WHO ARE FACING FINANCIAL PROBLEM HAVE LOW

QUALITY OF LIFE. THUS, FINANCIAL PROBLEMS FACED DURING TREATMENT CAN BE A DETERMINANT FOR QUALITY OF LIFE.

TABLE 4.17 ALSO DEPICTS THAT THERE IS NO SUFFICIENT STATISTICAL EVIDENCE TO SUGGEST AN ASSOCIATION OF DURATION OF CANCER DIAGNOSIS WITH THE QUALITY OF LIFE. HOWEVER, QUALITATIVE STUDY WAS DONE AMONG THE CANCER PATIENTS WHO WERE DIAGNOSED FOR MORE THAN A YEAR. THE STUDY RESULT REVEALED THAT THE RANGE OF DURATION OF DIAGNOSIS AMONG THE RESEARCH PARTICIPANTS WAS 1 TO 6 YEARS. MAJORITY OF THEM STATED THAT ADDITIONAL CARE AND SUPPORT IS REQUIRED TO IMPROVE QUALITY OF LIFE. ON THE BASIS OF QUALITATIVE STUDY DURATION OF DIAGNOSIS CAN BE TAKEN AS A DETERMINANT FOR QUALITY OF LIFE.

TABLE 4.17 ALSO DEPICTS THAT THERE IS NO SUFFICIENT STATISTICAL EVIDENCE TO SUGGEST AN ASSOCIATION BETWEEN MODALITIES OF CANCER TREATMENT AND QUALITY OF LIFE. THIS FINDING IS SUPPORTED BY THE FINDINGS OF QUALITATIVE STUDY WHERE IT WAS FOUND THAT THEY DIDN'T BOTHER MUCH ABOUT THE MODALITIES OF TREATMENT, EITHER SINGLE OR MULTIPLE, AS THEY WERE EQUALLY TROUBLESOME FOR THE CANCER PATIENTS. THEREFORE, THIS STUDY DECLARED THAT TYPES OR MODALITIES OF TREATMENT COULD NOT BE A DETERMINANT FOR THE NEPALESE CANCER PATIENTS IN RELATION TO THEIR QUALITY OF LIFE.

TABLE 4.17A

ASSOCIATION BETWEEN DISEASE VARIABLES AND PHYSICAL DOMAIN OF QOL

N= 280

DISEASE VARIABLES	CATEGORIES	PHYSICAL DOMAIN OF QOL		TOTAL N (%)	P VALUE
		HIGH N (%)	LOW N (%)		
CANCER STAGE	Early stage	**22 (27.5)**	**58 (72.5)**	**80 (100)**	0.179
	Late stage	**43 (21.5)**	**157 (78.5)**	**200 (100)**	
DURATION OF	**≤ ONE YEAR**	**54 (22.2)**	**189 (77.8)**	**243 (100)**	0.209

DIAGNOSIS	**> ONE YEAR**	**11 (29.7)**	**26 (70.3)**	**37 (100)**	
MODALITIES OF TREATMENT	**SINGLE**	**23 (27.1)**	**62 (72.9)**	**85 (100)**	0.196
	MULTIPLE	**42 (21.5)**	**153 (78.5)**	**195 (100)**	
FACING FINANCIAL PROBLEM FOR TREATMENT	**YES**	**43 (24.6)**	**132 (75.4)**	**175 (100)**	0.293
	NO	**22 (21.0)**	**83 (79.0)**	**105 (100)**	

TABLE 4.17A DEPICTS ASSOCIATION OF DISEASE VARIABLES (STAGE OF CANCER, DURATION OF DIAGNOSIS, MODALITIES OF TREATMENT AND FACING FINANCIAL PROBLEM DURING TREATMENT) WITH THE PHYSICAL DOMAIN OF QUALITY OF LIFE. THE STUDY REVEALED THAT THERE IS NO STATISTICAL EVIDENCE TO SUGGEST AN ASSOCIATION BETWEEN STAGE OF CANCER, DURATION OF CANCER DIAGNOSIS, MODALITIES OF TREATMENT AND FINANCIAL PROBLEMS AMONG CANCER PATIENTS WITH THE PHYSICAL DOMAIN OF QUALITY OF LIFE.

TABLE 4.17B

ASSOCIATION BETWEEN CANCER RELATED AND PSYCHOLOGICAL DOMAIN OF QOL

N= 280

CANCER RELATED VARIABLES	CATEGORIES	PSYCHOLOGICAL DOMAIN OF QOL		TOTAL N (%)	P VALUE
		HIGH N (%)	LOW N (%)		
CANCER STAGE	Early stage	**19 (23.7)**	**61 (76.3)**	**80 (100)**	0.109
	Late stage	**72 (36.0)**	**128 (64.0)**	**200 (100)**	
DURATION OF DIAGNOSIS	**≤ ONE YEAR**	**46 (18.9)**	**197 (81.1)**	**243 (100)**	0.447
	> ONE YEAR	**6 (16.2)**	**31(83.8)**	**37 (100)**	
MODALITIES OF TREATMENT	**SINGLE**	**16 (18.8)**	**69 (81.2)**	**85 (100)**	0.532
	MULTIPLE	**36 (18.5)**	**159 (81.5)**	**195 (100)**	
FACING FINANCIAL PROBLEM FOR TREATMENT	**YES**	**34 (19.4)**	**141 (80.6)**	**175 (100)**	0.378
	NO	**18 (17.1)**	**87 (82.9)**	**105 (100)**	

TABLE 4.17B DEPICTS THE ASSOCIATION OF DISEASE VARIABLES (STAGE OF CANCER, DURATION OF DIAGNOSIS, MODALITIES OF TREATMENT AND FACING FINANCIAL PROBLEM FOR TREATMENT) WITH PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE. THE STUDY RESULT SHOWS THAT THERE IS NO STATISTICAL ASSOCIATION BETWEEN DURATION OF CANCER DIAGNOSIS AND MODALITIES OF TREATMENT OF CANCER PATIENTS WITH THE PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE.

TABLE 4.17C

DISEASE VARIABLES	CATEGORIES	SOCIAL RELATIONSHIPS DOMAIN OF QOL	TOTAL N (%)	P VALUE

ASSOCIATION OF DISEASE VARIABLES WITH SOCIAL RELATIONSHIPS DOMAIN OF QUALITY OF LIFE

N=280

		n (%)	n (%)		
CANCER STAGE	Early stage	**19 (23.8)**	**61 (76.3)**	**80 (100)**	
	Late stage	**41(20.5)**	**159 (79.5)**	**200 (100)**	0.327
DURATION OF DIAGNOSIS	**≤ ONE YEAR**	**48 (19.8)**	**195 (80.2)**	**243 (100)**	
	> ONE YEAR	**12 (32.4)**	**25 (67.6)**	**37 (100)**	0.066
MODALITIES OF TREATMENT	**SINGLE**	**20 (23.5)**	**65 (76.5)**	**85 (100)**	
	MULTIPLE	**40 (20.5)**	**155 (79.5)**	**195 (100)**	0.338
FACING FINANCIAL PROBLEM FOR TREATMENT	**YES**	**43 (24.6)**	**132 (75.4)**	**175 (100)**	
	NO	**17 (16.2)**	**88 (83.8)**	**105(100)**	0.065

TABLE 4.17C DEPICTS ASSOCIATION OF DISEASE VARIABLES (STAGE OF CANCER, DURATION OF DIAGNOSIS, MODALITIES OF TREATMENT AND FACING FINANCIAL PROBLEM FOR TREATMENT) WITH SOCIAL RELATIONSHIP DOMAIN OF QUALITY OF LIFE. THERE IS NO STATISTICAL ASSOCIATION BETWEEN STAGES OF CANCER, DURATION OF CANCER DIAGNOSIS, MODALITIES OF TREATMENT AND FACING FINANCIAL PROBLEM FOR TREATMENT OF CANCER PATIENTS WITH THE SOCIAL RELATIONSHIP DOMAIN OF QUALITY OF LIFE.

TABLE 4.17D

ASSOCIATION OF DISEASE VARIABLES WITH ENVIRONMENT DOMAIN OF QOL

N= 280

DISEASE VARIABLES	CATEGORIES	ENVIRONMENT DOMAIN OF QOL		TOTAL N (%)	P VALUE
		HIGH N (%)	LOW N (%)		
CANCER STAGE	Early stage	**29 (36.3)**	**51 (63.7)**	**80 (100)**	0.005
	Late stage	**41 (20.5)**	**159 (79.5)**	**200 (100)**	
DURATION OF DIAGNOSIS	**≤ ONE YEAR**	**57 (23.5)**	**186 (76.5)**	**37 (100)**	0.095
	> ONE YEAR	**13 (35.1)**	**24 (64.9)**	**37 (100)**	
MODALITIES OF TREATMENT	**SINGLE**	**24 (28.2)**	**61 (71.8)**	**85 (100)**	0.248
	MULTIPLE	**49 (25.1)**	**146 (74.9)**	**195 (100)**	

FACING FINANCIAL PROBLEM FOR TREATMENT	**YES**	**48 (27.4)**	**127 (72.6)**	**175 (100)**	0.142
	NO	**22 (21.0)**	**83 (79.0)**	**105 (100)**	

TABLE 4.17D DEPICTS ASSOCIATION OF DISEASE VARIABLES (STAGE OF CANCER, DURATION OF DIAGNOSIS, MODALITIES OF TREATMENT AND FACING FINANCIAL PROBLEM FOR TREATMENT) WITH THE ENVIRONMENT DOMAIN OF QUALITY OF LIFE. THERE IS HIGHLY SIGNIFICANT STATISTICAL ASSOCIATION (*P=0.05*) BETWEEN STAGES OF CANCER AND ENVIRONMENT DOMAIN OF QUALITY OF LIFE. THE STUDY RESULT REVEALED THAT EARLY STAGE CANCER PATIENTS HAD BETTER QUALITY OF LIFE IN ENVIRONMENT DOMAIN AS COMPARED TO LATE STAGE CANCER PATIENTS.

QUALITATIVE STUDY REVEALED THAT AFTER THE COMPLETION OF FIRST COURSE OF TREATMENT RESEARCH PARTICIPANTS FELT EXCITED, BECAUSE THEY HAD A FEELING OF BEING CURED. MAJORITY OF THE RESEARCH PARTICIPANTS' QUALITY OF LIFE WAS BETTER IN EARLY STAGE, BECAUSE THEY HAD NO PAIN OR DISCOMFORT AND WERE ABLE TO CONTINUE JOB/WORK AND TAKE RESPONSIBILITY.

TABLE 4.18D ALSO DEPICTS THAT THERE IS NO STATISTICAL ASSOCIATION OF DURATION OF CANCER DIAGNOSIS, MODALITIES OF TREATMENT AND FINANCIAL PROBLEMS FOR TREATMENT AMONG CANCER PATIENTS WITH THE ENVIRONMENT DOMAIN OF QUALITY OF LIFE.

HOWEVER, ALMOST ALL RESEARCH PARTICIPANTS OF QUALITATIVE STUDY, CONDUCTED AMONG 20 CANCER PATIENTS AFTER A YEAR OF DIAGNOSIS, STATED THAT SUFFICIENT MONEY, EITHER SELF-EARNED OR PROVIDED BY OTHERS, WAS REQUIRED TO MAINTAIN QUALITY OF LIFE.

TABLE 4.18

CORRELATION BETWEEN DEMOGRAPHIC VARIABLES AND QUALITY OF LIFE

N= 280

DEMOGRAPHIC VARIABLES	DOMAINS OF QUALITY OF LIFE	TOTAL QOL

	PHYSICAL	PSYCHOLOGICAL	SOCIAL RELATIONSHIP	ENVIRONMENT	
AGE	**-0.045^**	**-0.062^**	**0.044^**	**-0.009^**	**-0.033^**
EDUCATION	**0.030^**	**-0.066^**	**0.011^**	**-0.060^**	**-0.032^**
PER CAPITA INCOME	**-0.050^**	**-0.082^**	**-0.007^**	**-0.035^**	**-0.065^**

^SPEARMAN'S RANK CORRELATION IS NOT SIGNIFICANT AT 2 TAILED

TABLE 4.18 DEPICTS THE RELATIONSHIP BETWEEN DEMOGRAPHIC VARIABLES (AGE, EDUCATION, AND PER CAPITA INCOME) AND QUALITY OF LIFE AND ALL ITS DOMAINS. SPEARMAN'S RANK CORRELATION STATISTICAL TEST AT TWO-TAILED WAS APPLIED. NON-LINEAR RELATIONSHIP REVEALED THAT AGE HAS NEGATIVE RELATION WITH QUALITY OF LIFE AND ITS PHYSICAL, PSYCHOLOGICAL AND ENVIRONMENT DOMAIN, WHEREAS AGE HAS POSITIVE RELATION WITH SOCIAL RELATIONSHIPS DOMAIN OF QUALITY OF LIFE. AT THE SAME TIME, THERE IS NO SIGNIFICANT STATISTICAL ASSOCIATION OF AGE WITH QUALITY OF LIFE AND ALL ITS DOMAINS.

TABLE 4.18 ALSO DEPICTS THE CORRELATION OF EDUCATION WITH QUALITY OF LIFE AND ALL ITS DOMAINS. THIS STUDY REVEALED THAT EDUCATION HAS POSITIVE RELATION WITH PHYSICAL AND SOCIAL RELATIONSHIPS DOMAINS OF QUALITY OF LIFE. EDUCATION ALSO HAS NEGATIVE RELATION WITH QUALITY OF LIFE AND ITS PSYCHOLOGICAL AND ENVIRONMENT DOMAINS. AT THE SAME TIME, THERE IS NO SIGNIFICANT STATISTICAL ASSOCIATION OF EDUCATION WITH QUALITY OF LIFE AND ALL ITS DOMAINS.

TABLE 4.18 ALSO DEPICTS THE CORRELATION OF PER CAPITA INCOME WITH QUALITY OF LIFE AND ALL ITS DOMAINS. THIS STUDY REVEALED THAT PER CAPITA INCOME HAS NEGATIVE RELATION WITH QUALITY OF LIFE AND ALL ITS DOMAINS AMONG CANCER PATIENTS IN NEPAL. AT THE SAME TIME, THERE IS NO SIGNIFICANT STATISTICAL ASSOCIATION OF PER CAPITA INCOME WITH QUALITY OF LIFE AND ALL ITS DOMAINS. THIS IS BECAUSE THERE IS NO HEALTH INSURANCE POLICY FOR PATIENTS IN NEPAL AND TREATMENT FOR CANCER IS EXPENSIVE.

TABLE 4.19

CORRELATION BETWEEN DISEASE VARIABLES AND QUALITY OF LIFE

N= 280

DISEASE VARIABLES	DOMAINS OF QUALITY OF LIFE				TOTAL QOL
	PHYSICAL	PSYCHOLOGICAL	SOCIAL RELATIONSHIP	ENVIRONMENT	
STAGE OF CANCER	**0.011^**	**-0.024^**	**0.041^**	**0.089^**	**0.063^**
DURATION OF DIAGNOSIS	**-0.038^**	**-0.106^**	**-0.036^**	**0.004^**	**-0.035^**

^SPEARMAN'S RANK CORRELATION IS NOT SIGNIFICANT AT 2 TAILED

TABLE 4.19 DEPICTS THE RELATIONSHIP BETWEEN DISEASE VARIABLES (STAGE OF CANCER AND DURATION OF DIAGNOSIS) AND QUALITY OF LIFE AND ALL ITS DOMAINS. SPEARMAN'S RANK CORRELATION STATISTICAL TEST AT TWO-TAILED WAS APPLIED. NON-LINEAR RELATIONSHIP REVEALED THAT STAGE OF CANCER HAS POSITIVE RELATION WITH QUALITY OF LIFE AND ITS PHYSICAL, SOCIAL RELATIONSHIPS AND ENVIRONMENT DOMAIN, WHEREAS STAGE OF CANCER HAS NEGATIVE RELATION WITH PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE. AT THE SAME TIME, THERE IS NO SIGNIFICANT STATISTICAL ASSOCIATION OF STAGE OF CANCER WITH QUALITY OF LIFE AND ALL ITS DOMAINS.

TABLE 4.19 ALSO DEPICTS THE CORRELATION OF DURATION OF DIAGNOSIS WITH QUALITY OF LIFE AND ALL ITS DOMAINS. THIS STUDY REVEALED THAT DURATION OF DIAGNOSIS HAS POSITIVE RELATION WITH ENVIRONMENT DOMAINS OF QUALITY OF LIFE. DURATION OF DIAGNOSIS ALSO HAS NEGATIVE RELATION WITH QUALITY OF LIFE AND ITS PHYSICAL, PSYCHOLOGICAL AND SOCIAL RELATIONSHIPS DOMAINS. AT THE SAME TIME, THERE IS NO SIGNIFICANT STATISTICAL ASSOCIATION OF DURATION OF DIAGNOSIS WITH QUALITY OF LIFE AND ALL ITS DOMAINS. THE REASON FOR POSITIVE RELATION OF INCREASING DURATION WITH ENVIRONMENT DOMAIN OF QUALITY OF LIFE COULD BE THE BEGINNING OF

ADJUSTMENT WITH DISEASE PROCESS AND THE REDUCTION OF FEAR OF RELAPSE AND DEATH, ETC AFTER THE COMPLETION OF COURSE OF TREATMENT.

TABLE 4.20

CORRELATION BETWEEN PSYCHOSOCIAL VARIABLES AND QUALITY OF LIFE

N= 280

PSYCHOSOCIAL FACTORS	DOMAINS OF QUALITY OF LIFE				TOTAL QOL
	PHYSICAL	PSYCHOLOGICAL	SOCIAL RELATIONSHIP	ENVIRONMENT	
SOCIAL SUPPORT	**-0.383****	**-0.210****	**-0.485****	**-0.595****	**-0.644****
SELF-ESTEEM	**-0.149***	**-0.139***	**-0.233****	**-0.214****	**-0.246****
COPING	**0.303****	**0.148***	**0.509****	**0.624****	**0.610****
ANXIETY	**0.017^**	**0.007^**	**-0.104^**	**-0.126***	**-0.091^**
DEPRESSION	**0.016^**	**0.012^**	**-0.109^**	**-0.130***	**-0.095^**

****SPEARMAN'S RANK CORRELATION IS SIGNIFICANT AT THE 0.01 LEVEL (2 TAILED)**

***SPEARMAN'S RANK CORRELATION IS SIGNIFICANT AT THE 0 .05 LEVEL (2 TAILED)**

^SPEARMAN'S RANK CORRELATION IS NOT SIGNIFICANT AT 2 TAILED

TABLE 4.20 DEPICTS THE RELATIONSHIP BETWEEN PSYCHOSOCIAL VARIABLES (SOCIAL SUPPORT, SELF-ESTEEM, COPING, ANXIETY AND DEPRESSION) AND QUALITY OF LIFE AND ALL ITS DOMAINS. SPEARMAN'S RANK CORRELATION STATISTICAL TEST AT TWO-TAILED WAS APPLIED. NON-LINEAR RELATIONSHIP REVEALED THAT SOCIAL SUPPORT WAS NEGATIVELY CORRELATED WITH QUALITY OF LIFE (*R=-0.644; P=< 0.01*) AND ALL ITS DOMAINS (RANGE OF '*R*'=*-0.210 TO -0.595; P=< 0.01*). THIS MEANS THAT EVEN WITH HIGH LEVEL OF SOCIAL SUPPORT, THE QUALITY OF LIFE OF THE CANCER PATIENTS WAS LOW OR VICE VERSA.

YET, ALMOST ALL RESEARCH PARTICIPANTS OF QUALITATIVE STUDY EXPRESSED THAT STRONG SOCIAL SUPPORT IN TERMS OF FAMILY SUPPORT, SUPPORT FROM SPOUSE,

RELATIVES AND/OR FRIENDS HAVE VITAL ROLE IN MAINTAINING QUALITY OF LIFE BUT THE ATTITUDE OF THE CARE PROVIDERS HAD TO BE HELPFUL. SOME OF THE RESEARCH PARTICIPANTS STATED *"JO ĀĀYE PĀNI BICHĀRĀ BHĀNCHHĀ, GĀRNE CHĀHI KEHI HOIN, NĀRĀMĀILO MĀTRĀ LĀGCHHĀ"* (EVERYBODY SHOWS TOO MUCH OF SYMPATHY BUT DOES NOTHING, WHICH MAKES MORE DESPONDENT). THIS MEANS SOCIAL SUPPORT IS IMPORTANT TO IMPROVE QUALITY OF LIFE OF CANCER PATIENTS. AT THE SAME TIME, ESPECIALLY EMOTIONAL AND AFFECTIVE SOCIAL SUPPORT IS REQUIRED TO SOLVE THEIR PROBLEMS. BECAUSE, AFTER THE DIAGNOSIS OF CANCER, SOME OF THE RESEARCH PARTICIPANTS STATED "*CANCER BHĀYEKO THĀHĀ PĀYE PĀCHHI, LĀGYO KI MERO KHUTTĀ MUNI BHUIN CHHĀINĀ RĀ MĀTHI ĀKĀSH CHHĀINĀ, MĀ BICHĀ MĀ HĀLLIRĀHEKO CHHU, RĀ CHĀRĀITIRĀ ĀNDHĀKĀR NĀI ĀNDHĀKĀR CHHĀ KEHI DEKHINĀ, KEHI CHHIN KO LĀGI TĀ BEHOSH NĀI BHĀNYE"* (WHEN I HEARD THAT I HAVE CANCER, I FELT AS IF THERE WAS NO LAND UNDER MY FEET AND NO SKY OVER MY HEAD AND I WAS WAVERING SOMEWHERE IN BETWEEN; EVERYTHING SUDDENLY WENT DARK AND I BECAME DISORIENTED FOR A WHILE).

TABLE 4.20 ALSO DEPICTS THE RELATIONSHIP BETWEEN SELF-ESTEEM AND QUALITY OF LIFE INCLUDING ITS FOUR DOMAINS. NON-LINEAR RELATIONSHIP REVEALED THAT SELF-ESTEEM WAS NEGATIVELY CORRELATED WITH QUALITY OF LIFE (*$R=-0.246$; $P=< 0.01$*). SELF-ESTEEM WAS NEGATIVELY CORRELATED (*$R=-0.149$ AND -0.139; $P=< 0.05$*) WITH QUALITY OF LIFE IN PHYSICAL AND PSYCHOLOGICAL DOMAINS. SELF-ESTEEM WAS NEGATIVELY CORRELATED (*$R=-0.214$ AND -0.233; $P=< 0.01$*) WITH QUALITY OF LIFE IN SOCIAL RELATIONSHIPS AND ENVIRONMENT DOMAINS. THE GREATER THE WHOQOL-BREF OF THE QUALITY OF LIFE, THE LOWER THE CANCER PATIENT'S SELF-ESTEEM WAS, AND VICE VERSA. QUALITATIVE STUDY REVEALED THAT OUT OF 20 RESEARCH PARTICIPANTS, 16 (80%) WAS NOT SATISFIED WITH THEIR LIFE. WHEREAS, 4 (20%) OF THEM STATED 'WILLPOWER' TO BE AN IMPORTANT KEY IN THE MAINTENANCE OF QUALITY OF LIFE.

BOTH QUALITATIVE AND QUANTITATIVE RESULT INDICATED THAT THOSE RESEARCH PARTICIPANTS, WHO WERE NOT SATISFIED WITH ONESELF OR NOT RECOGNIZED SELF; COULD NOT DEFINITELY APPRECIATE THE QUALITY OF THEIR LIVES.

TABLE 4.20 ALSO DEPICTS THE RELATIONSHIP BETWEEN COPING AND QUALITY OF LIFE INCLUDING ITS FOUR DOMAINS. NON-LINEAR RELATIONSHIP REVEALED THAT COPING WAS POSITIVELY CORRELATED (*R=0.610; P=< 0.01*) WITH QUALITY OF LIFE. COPING WAS POSITIVELY CORRELATED (*R=0.303 TO 0.624*; *P=< 0.01*) WITH PHYSICAL, SOCIAL RELATIONSHIP, AND ENVIRONMENT DOMAIN, WHEREAS POSITIVELY CORRELATED (*R=0.148; P=< 0.05*) WITH PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE. THIS MEANS IN THE CASE OF INCREASED LEVEL OF COPING, THE QUALITY OF LIFE INCLUDING ALL ITS DOMAINS AMONG CANCER PATIENTS WAS ALSO INCREASED OR VICE VERSA.

AMONG THE 20 RESEARCH PARTICIPANTS, MAJORITY (75%) OF THEM HAD TAKEN UP ENGAGEMENT COPING STRATEGIES. THEY STATED THAT THEY WERE KEEPING BUSY WITH DIFFERENT ACTIVITIES LIKE ENGAGING THEMSELVES IN HOUSEHOLD WORKS, TAKING CARE OF THEIR CHILDREN, GOING TO PARENTS HOME, WORSHIPPING AND 'SUBMITTING THEMSELVES IN THE HANDS OF GOD'.

TABLE 4.20 ALSO DEPICTS THE RELATIONSHIP BETWEEN ANXIETY AND QUALITY OF LIFE INCLUDING ALL ITS DOMAINS. NON-LINEAR RELATIONSHIP REVEALED THAT ANXIETY WAS NEGATIVELY CORRELATED (*R=-0.126; P=0.05*) WITH ENVIRONMENT DOMAIN OF QUALITY OF LIFE. THIS MEANS THAT WITH THE DECREASE IN LEVEL OF ANXIETY, THE QUALITY OF LIFE IN ENVIRONMENT DOMAIN INCREASED. THIS STUDY RESULT ALSO SHOWED THAT THERE WAS NO SIGNIFICANT CORRELATION OF ANXIETY WITH QUALITY OF LIFE AND ITS PHYSICAL, PSYCHOLOGICAL AND SOCIAL RELATIONSHIP DOMAINS.

AMONG THE 20 RESEARCH PARTICIPANTS, HALF (50%) OF THEM VERBALIZED THAT THE ANXIETY SYMPTOMS APPEARED AFTER THE DIAGNOSIS OF CANCER. OF THE 20 RESEARCH PARTICIPANTS, 10 (50%) STATED THAT PAIN-FREE AND COMFORTABLE LIFE IS NEEDED TO MAINTAIN QUALITY OF LIFE, WHEREAS 8 (40%) STATED THAT 'ABILITY TO PERFORM DAILY ACTIVITIES OF LIVING' IS MOST IMPORTANT PART FOR QUALITY OF LIFE.

TABLE 4.20 ALSO SHOWS THE RELATIONSHIP BETWEEN DEPRESSION AND QUALITY OF LIFE INCLUDING ITS DOMAINS. NON-LINEAR RELATIONSHIP REVEALED THAT DEPRESSION WAS

NEGATIVELY CORRELATED(*R=-0.130; P= 0.05*) WITH ENVIRONMENT DOMAIN OF QUALITY OF LIFE. THIS MEANS THAT WITH THE DECREASE IN LEVEL OF DEPRESSION; QUALITY OF LIFE IN ENVIRONMENT DOMAIN INCREASED. THIS STUDY ALSO REVEALED THAT THERE WAS NO SIGNIFICANT CORRELATION BETWEEN DEPRESSION AND QUALITY OF LIFE AND ITS PHYSICAL, PSYCHOLOGICAL AND SOCIAL RELATIONSHIP DOMAINS.

AMONG THE 20 RESEARCH PARTICIPANTS, ALMOST ALL (90%) OF THEM EXPRESSED THE SYMPTOMS OF DEPRESSION LIKE FEELING LONELY, WORTHLESSNESS, HELPLESS, AND ALSO STATED "Ā*PHĀNO JIMMEBĀRI BĀHĀNĀ GĀRNĀ SĀKIN*" (COULD NOT SHOULDERED RESPONSIBILITIES), "*DIKKĀ LĀGCHHĀ*" (FED UP), WHICH HAD APPEARED AFTER DIAGNOSIS OF CANCER.

TABLE 4.21

MULTIPLE REGRESSIONS ON QUALITY OF LIFE SATISFACTION OVER PSYCHOSOCIAL FACTORS

N= 280

QOL DOMAINS	PSYCHOSOCIAL FACTORS				
	SOCIAL SUPPORT	SELF-ESTEEM	COPING	ANXIETY	DEPRESSION
PHYSICAL	**11.289***	**0.611^**	**0.003^**	**0.021^**	**0.541^**
PSYCHOLOGICAL	**6.751***	**0.293^**	**5.048***	**0.337^**	**0.474^**
SOCIAL RELATIONSHIP	**5.373***	**0.900^**	**14.226****	**0.350^**	**0.370^**
ENVIRONMENT	**10.914***	**0.194^**	**19.770****	**0.164^**	**0.138^**
TOTAL QOL	**9.551***	**0.004^**	**12.499****	**1.009^**	**0.012^**

PARAMETER ESTIMATES AT DEGREE OF FREEDOM= 1, HIGHER THE SCORES REFLECT HIGHER SATISFACTION WITH QOL

***P= < 0.05** ****P= < 0.01** **^ P= NOT SIGNIFICANT**

TABLE 4.21 DEPICTS MULTINOMIAL LOGISTIC REGRESSION ANALYSIS TO FIND OUT THE EFFECTS OF QUALITY OF LIFE AND ITS DOMAINS ON PSYCHOSOCIAL FACTORS. STUDY RESULT REVEALED THAT AMONG THE FIVE PSYCHOSOCIAL VARIABLES, COPING HAD HIGHLY SIGNIFICANT STATISTICAL ASSOCIATION (*P=< 0.01*) WITH QUALITY OF LIFE AND ITS SOCIAL RELATIONSHIP AND ENVIRONMENT DOMAINS; AND SIGNIFICANT STATISTICAL ASSOCIATION (*P=< 0.05*) WITH QUALITY OF LIFE IN PSYCHOLOGICAL DOMAIN. COPING HAD NO ASSOCIATION WITH QUALITY OF LIFE IN PHYSICAL DOMAIN. SOCIAL SUPPORT HAD STATISTICAL ASSOCIATION (*P=< 0.05*) WITH QUALITY OF LIFE AND ALL ITS DOMAINS. SELF-ESTEEM, ANXIETY AND DEPRESSION HAD NO SIGNIFICANT STATISTICAL ASSOCIATION WITH QUALITY OF LIFE AND ALL ITS DOMAINS.

TABLE 4.22

HIERARCHICAL MULTIPLE REGRESSION FOR PSYCHOSOCIAL VARIABLES ON QUALITY OF LIFE

N= 280

PSYCHOSOCIAL FACTORS	TOTAL QOL	DOMAINS OF QUALITY OF LIFE			
		PHYSICAL	PSYCHOLOGICAL	SOCIAL RELATIONSHIP	ENVIRONMENT
STEP 1					
COPING	**18.185****	**22.873****		**18.195****	**24.433****
SOCIAL SUPPORT			**8.268***		
STEP 2					
SOCIAL SUPPORT	**20.010****		**6.783***	**8.895***	**16.927****
COPING	**14.258****		**3.914***	**15.085****	**20.158****

BASED ON CONDITIONAL PARAMETER ESTIMATES (MODEL IF TERM REMOVED) *P= < 0.05 ** P= < 0.01

TABLE 4.22 DEPICTS BINARY LOGISTIC REGRESSION ANALYSIS BASED ON CONDITIONAL PARAMETER ESTIMATES (MODEL IF TERM REMOVED). AMONG THE FIVE PSYCHOSOCIAL FACTORS, THREE VARIABLES SUCH AS SELF-ESTEEM, ANXIETY AND DEPRESSION HAD NO SIGNIFICANT RELATIONSHIP WITH QUALITY OF LIFE AND ALL ITS DOMAINS DURING FACTOR ANALYSIS. ON THE BASIS OF CONDITIONAL FORWARD METHOD, THIS STUDY RESULT REVEALED THAT QUALITY OF LIFE WAS ASSOCIATED WITH COPING AND SOCIAL SUPPORT. AMONG THE TWO, COPING HAD STRONGEST ASSOCIATION WITH QUALITY OF LIFE AND ITS PHYSICAL, SOCIAL RELATIONSHIP AND ENVIRONMENT DOMAINS, WHEREAS SOCIAL SUPPORT HAD STRONGEST ASSOCIATION WITH PSYCHOLOGICAL DOMAIN OF QUALITY OF LIFE.

CHAPTER - 5

DISCUSSION AND CONCLUSION

5.1 Discussion

Despite the major medical advances made in diagnosis and treatment of cancer, it continues to be viewed with dread, a great deal of emotion, fear, apprehension and uncertainty attached to survival of the cancer patients. Living with cancer is not easy, even it is mentioned in the literatures that ‘cancer is not just a four letters word’; as it gives terrible experiences after diagnosis. Dealing with loss of function, changes in capabilities, and modifications in life style that accompany the diagnosis and treatment of cancer has valence for many individual. Yet, life management goals vary widely and may be influenced by each individual’s developmental level, life experiences, and personality characteristics. Psychosocial factors will certainly make it easier to cope with treatment and improve the quality of life (Allen, 2002). Social support in the face of a diagnosis regarded as a life crisis can impact the course of the disease. Diane Blum (1997)[3] said "providing support to these patients and their families is a critical step in dealing with cancer and a key component in the quality of life of patients”.

Psychosocial aspects of cancer care is an area of expertise concerned with the understanding and treatment of the social, psychological, emotional, spiritual, and functional aspects of cancer, at all stages of the disease pathway from prevention through to bereavement. Psychosocial cancer care involves a whole-person approach to address a range of human needs that can improve or optimize the best possible quality of life for individuals and their networks affected by disease. The individual suffering from cancer needs a long term care and unconditional psychosocial supports to alleviate suffering, maintain social relationships and fight with the disease.

As far as the demographic characteristics of the cancer patients is concerned, the quantitative result of this study indicates that more than half (54.6%) of the sample belonged to 40 to 59 years of age. Majority of the cancer patients were female (63.9%), Hindu (86.5%) by religion and belonged to joint families (60.7%). More than one third (36.1%) of the research participants belonged to upper caste groups as categorized by Government of Nepal (2007). Majority (66.1%) of the sample were illiterate and most (83.2%) of them were married. More than two

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[3] Executive Director of Cancer Care, National Cancer Institute Press Office, Tuesday, April 22, 1997

third of the research participants belonged to low socio-economic status, and more than half (56.4%) of them were dependent members for their family. Qualitative study also revealed that there are similar demographic characteristics of the research participants in this study.

The disease variables of cancer patients in the quantitative result of this study indicates equal percentage (25%) from each site covered such as head and neck, lung, breast and uterine cervix. Majority (71.4%) of the research participants were diagnosed as stage III and IV cancer and most (86.8%) were diagnosed with cancer for last one year. Majority (69.6%) of the cancer patients was receiving multiple modalities of treatment, and majorities (62.5%) were facing financial problems during treatment. Qualitative study also revealed that there are similar disease characteristics, except duration of cancer diagnosis of the research participants in this study.

As far as psychosocial factors of the cancer patients are concerned, the quantitative results of this study point out that less than one fourth (23.6%) of the research participants felt they received high level of social support. This study also revealed that the male research participants received higher social support as compared to their female counterparts. One of the five research participants (20%) perceived high level of self-esteem. This study also revealed that self-esteem is higher among the female research participants as compared to their male counterparts.

Present study revealed that less than one fourth (22.1%) of the research participants perceived high level of coping. This study also revealed that male research participants had better coping as compared to their female counterparts.

This study revealed that more than two third (67.1%) of the research participants were suffering from anxiety. Anxiety seems to be a natural reaction among the cancer patients both as an attempt to face the health situation and consequences of the failure to use adequate coping strategies. This study also revealed that severe anxiety was higher among the female research participants. This finding is supported by qualitative result, which revealed that female research participants verbalized more symptoms of the anxiety as compared to their male counterparts.

Present study revealed that more than two third (70.9%) had severe depression. There are similar findings in other studies; psychosocial and emotional distress, which is often experienced in the form of depression or other adjustment difficulties, was a significant problem for up to half of all cancer patients (Carlson and Bultz, 2004). Another study also reported that chronic illness, particularly illness that obstructs the daily functioning, like cancer, are especially susceptible to problems with depression (Taylor & Aspinwall, 1993) and this relationship has been reported across cultures (Ormel et al. 1994). Present study also revealed that severe depression was higher among the male participants. The qualitative study result also revealed that in Nepalese context the probability of males being depressed is more than the females, which could be due to the stress of not being able to shoulder their role and responsibility of their families and societies. On the contrary, women have higher risk of depression as compared to men (Stagno et al., 2005). Several studies have found such clear gender differences in the prevalence of depressive disorders (Meltzer et al., 1995). Similar psychosocial features were found among research participants in present qualitative study, yet without using any measurement scale researcher could not declare its valid percentage.

While addressing the research objectives and questions, the quantitative study result revealed that there were insignificant positive correlation between age and quality of life, which could be due to the nature of the sample distribution. However, qualitative result of present study revealed that majority of young research participants had worse quality of life in psychological and social relationship domains, while aged sample reported worse quality of life in physical and environment domains. Other similar result reported; younger research participants showed worse quality of life outcomes in the social domain, whereas those diagnosed at an older age showed significantly worse quality of life outcomes in the physical domain (Bernadine, David and Gloria, 2002).

Both qualitative and quantitative study result revealed that gender of the cancer patients was positively associated with quality of life in physical and social relationship domain. The quantitative study result revealed that there was no significant statistical association of current marital status of the sample with quality of life. Yet, qualitative study result revealed that one of the four (25%) married sample had worse quality of life in social relationship domain, which was mainly due to sexual problems. Present qualitative result also revealed that majority of married research participants reported better quality of life in physical domain because of the family support in performing the activities for daily living (ADL). Other similar study result also shows that marital status is associated with physical subscale scores of quality of life (Bernadine, David and Gloria, 2002).

Present study result indicated that educational status of the cancer patients was negatively associated with quality of life in psychological domain; which is consistent with other studies in which educational level of cancer survivors was inversely correlated with total quality of life (Bernadine, David and Gloria, 2002). This study also revealed that there is insignificant negative association between economic status and quality of life. The statistical test applied to this study is reliable, yet in Nepalese context qualitative result indicated that economic status is most important to continue treatment and improve quality of life of the cancer patients. Therefore, economic status can be a determinant for quality of life among the cancer patients in Nepal. This study also revealed that there is no association between role of the cancer patient in the family and quality of life. Qualitative result also supports this finding, as joint family system still exists in Nepal and there is a strong positive component to support them in relation to their quality of life.

Present quantitative study result revealed that the stage of cancer at diagnosis was positively associated with quality of life and its environment domain. However, insignificant negative correlation was found between the stage of cancer and psychological domain of quality of life. Qualitative study result revealed that with the increase in stage of cancer, quality of life decreased, which could be related to the increase in physical symptoms, hopelessness, feeling of social isolation/loneliness and separation anxiety from their family and shortage of resources/property due to long term and expensive treatment. There is insignificant negative correlation between duration of diagnosis and quality of life. However, qualitative result revealed that duration of diagnosis is important in terms of care and support in improving their quality of lives. Modalities of treatment are not associated with quality of life among cancer patients in Nepal.

Quantitative study result revealed that financial problem faced during treatment was negatively associated with quality of life among samples, i.e. those who were facing financial problems also had better quality of life as compared to their counterparts. Yet, qualitative study result revealed that suffering from cancer and not being able to afford treatment is a tragedy in life, even though it happened among minority of research participants. This finding is supported by a case report of 50 years old male cancer patient from Morang district of Nepal, who committed suicide because he could not afford the treatment of his cancer.[4] This is an empirical research so there is lack of evidence to rely only on statistical tests even though they are very reliable. In this situation, the findings of qualitative study could be considered to support research variables especially in social studies. This study also revealed that there is no association between modalities of treatment and quality of life among cancer patients in Nepal. Qualitative result also supports this finding, as Nepalese cancer patients appreciated that any kind of treatment is equally painful and troublesome.

Non-linear correlation revealed that social support was negatively correlated with quality of life including all its domains among the research participants. MOS social support survey scale was used to measure the level of social support, which constituted four sub-scales namely emotional/informational, tangible/ instrumental, affective and positive social interaction. On comparing the obtained scores of four sub-scales, tangible support had highest and emotional support had lowest scores.

Yet, qualitative study result revealed that social support is the most important factor to maintain the quality of life after suffering from cancer, but the attitude of helper and kinds of social support play a vital role. Emotional support can be encouraged by supporting counseling or psycho-education to the family members. Such provision does not exist in Nepal. Qualitative result revealed that the health professionals also need to be take precautions while communicating with their patients, while breaking bad news and providing care to the cancer patients. Besides the attitude of the person and kinds of social support provided, the relation of the patient to the person providing support is equally important. This could be the reason for negative correlation between social support and quality of life in quantitative study, but the relationship of the patient with the person providing social support was not investigated.

Present study result is consistent with other studies; higher social support was associated with better quality of life on all domains (Erika, Ying, Donna, 2010). Social support significantly correlated with the rate of progression from asymptomatic to symptomatic stages of cancer.

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[4] Cancer ko Upachar Garna NasakDa Aatmahatya. Gorkhapatra Daily Newspaper (Nepal). Published on 4th July 2001.

These notions are restated frequently throughout social support literatures suggesting that social support is beneficial to buffer the effects of stress and in the prevention of adverse health outcomes (DeVries et al., 2003). Husband's support showed significantly higher score in the high quality of life group as compared to low quality of life group (Eun, et al, 2010). Social support provided especially by spouses plays a critical role in the psychological adaptation. Lack of emotional support from close ones, a greater frequency of negative interactions and a tendency not to share important cancer-related concerns with them, are associated with increased psychological distress particularly among women in late stage of cancer (Meyer and Mark, 1995). Emotional support is most important as compared to other kinds of social support as people often struggle; feel isolated and alone in coping with significant issues, such as feeling vulnerable around their own mortality and in dealing with complex questions around the quality and quantity of their lives (CAPO, 2010). Cancer and its associated treatments may require a fundamental change in lifestyle, which prompts the person to question their personal identity and self worth. Cancer patient needs for support is often extended beyond the initial diagnosis, during treatment and follow up (Price, 2003). However, on the basis of this study researcher recommends to conduct an intensive study in relation to social support and quality of life.

Cancer, still considered as fatal disease, also means the loss of confidence in one’s health and normal bodily processes. The cycle of symptoms begins; the sufferer loses faith in the dependability and adaptability of basic bodily processes that the healthy ones rely on as part of their general sense of well-being. This loss of confidence becomes grim expectation of the worst and, in some, demoralization and hopelessness. A closely related feeling is grief and unhappiness over loss of health, mourning for the bodily foundation of daily behavior and self-confidence. Cancer and its treatment procedures change body images, life patterns, and may also influence feelings of self-worth (Kleinman, 1988).

Present study revealed that self-esteem was negatively correlated with quality of life and all its domains. The unique association of self-esteem with quality of life suggests that interventions are required to promote self-esteem, which is the influential factor for quality of life. Both qualitative and quantitative result indicated that those cancer patients, who are not satisfied with oneself or those who did not recognize self, could not definitely appreciate the quality of their lives. The findings of present study is consistent with other studies; self-esteem correlated negatively with quality of life and all sub-scale scores (Dimitra, et al. (2005). Patient's ability to engage in activities contributing to feelings of worth or success, the more it lowers the feeling of self-worth and confidence thus, distorting the self-image and self-esteem. Such low or decreased self-esteem is found to be interrelated with low quality of life. Low self-esteem then is an anticipated losing outcome in social competition. It is adaptive to assess one's self-worth accurately, so as to avoid unnecessary losses with further erosion of resources or danger to self (Sadock, 2005). An empirical study of self-esteem in cancer revealed that global self-esteem has no differences between cancer patients and controls, but aspects of multidimensional self-esteem, particularly body image, appears to be disturbed in many patients with cancer (Katz et al., 1995). Self-esteem affected women undergoing chemotherapy serves to provide interesting insight into their reactions. There was wide variance in factors thought to influence self-esteem, which was reported by cancer patients including physical, social, psychological, and/or spiritual factors (Brockopp, and Carpenter, 1996).

Adapting to life threatening disease includes dealing with the symptoms of the disease, managing the stresses of treatment, living life as normal as possible and facing the possibility of death. Adjustment to cancer is more difficult than other diseases, because of symptom severity and the demands of coping with symptoms (Brannon and Feist, 2007). An adequate knowledge of the world, having inner resources and control over life events; and having social support, and a spiritual orientation to oneself and the world is proven to have a direct affect on mortality rate (Reddick et al, 2005). Coping skills are an individual's attempt to resolve life stresses and emotional pain.

Present study revealed through non-linear relationship that coping was positively correlated with quality of life including all domains. The qualitative part of this study also revealed that there was higher level of engagement coping among Nepalese cancer patients, which was beneficial for individual's quality of life. The findings of current study was supported by other studies; suggested that avoidant coping strategies may be harmful for quality of life. The cancer patients who were facing the long-term stressors of extensively-treated, advanced stage of disease and having physical difficulties had difficulty in coping Majorities of the cancer patients utilized more frequently both engagement and avoidant strategies including active coping, seeking social support, and mental disengagement, which has significant relationship with quality of life (Costanzo et al., 2006).

Attitudes and perceptions are major factors that determine the ability to cope with stress. Other factors include genetics, a good sense of humor, a well-balanced and nutritious diet, realistic goal setting, plenty of sleep, thorough job preparation, financial security, stability at home, an understanding of stress, and use of relaxation skills. More documented protective factors include high self-esteem, learning to be flexible and innovative in solutions, close personal relationships, having success/mastery experiences, self-discipline (including good control of time), positive expectancy (hope) and humor (Kleinman, 1988). Search for meaning in life is a part of the human experience. A negative life event may threaten perceptions about meaning in life, such as the generosity of the world and one's sense of harmony and peace. A longitudinal study discovered the relationship between women's coping with a diagnosis of breast cancer and their self-reported meaning in life, researchers revealed that positive strategies for coping predicted significant variance in the sense of meaning in life-feelings of inner peace, satisfaction with one's current and the future life (Jim et al., 2006). Patients and families cope with a day-by-day course that encompasses many individual episodes and events. There are serious consequences, some avoidable, others not. The experience of cancer often converts the once born into the twice born. There is an association between maladaptive coping styles and higher levels of anxiety and depression symptoms. Examples of maladaptive coping behaviors include avoidant or negative coping, negative self-coping statements, preoccupation with physical symptoms, and catastrophizing.

Present study result revealed that anxiety is negatively correlated with quality of life in environment domain. Other studies with consistent result; higher level anxiety scores among cancer patients was associated with decreased quality of life (Schreier and Susan, 2004). Another study also reported that anxiety is negatively correlated with quality of life or it leads to poor quality of life (Redeker et al., 2000). Present study also stated that there was no significant correlation between anxiety and quality of life including its physical, psychological and social relationship domains. Quality of life is linked to psychological phenomenon. The tool which was used to measure the level of anxiety had two types of symptoms viz. psychological and physical. The sub-scale scores result has shown higher scores on physical as compared to psychological symptoms, which could be the reason for high level of anxiety. Physical symptoms of anxiety were higher among the sample. This could be a defense mechanism to cope with the cancer. This study also revealed distinctive indifferent correlation value for physical and psychological domains of quality of life, which threatens the quality of life. Researcher suggests for an intensive study in relation to anxiety and quality of life of cancer patients in Nepal.

In a study conducted among Indian cancer patients, majority of them expressed that they had not done enough for their family and felt that they were loved less by their family after having cancer. Palliative caregivers said that the emotional needs of a patient were higher than that of normal people (Sujata, 2006). Cancer and its treatment can negatively change the way one feels about oneself. This may be because of the physical changes to body or it may be about less obvious changes. The intense emotions among cancer patient can lower the self-esteem. Patients felt having less freedom, being trapped in fragile body, dependent, and with no immediate clear future plans and hopes. The perceived helplessness situation and feeling of hopelessness can reduce their level of confidence about who they are and what they can do (Greer, 1987). Cancer not only requires adaptation of personal goals, but often distorts the deeper sense of self. This is a major contributor to depression. But a desire to maintain a strong sense of self is a powerful drive, and over time many people adapt to these changes in health (Gorman et al., 2002).

Depression was negatively correlated with environment domain of quality of life. There is consistent result of other studies which revealed that depression is negatively correlated with quality of life (Redeker et al., 2000). Depression in the physically ill patients has been shown to have a significant impact, with increased symptom burden, impaired functioning and reduced quality of life (Ruttley and Reid, 2006). Another study conducted among late-stage cancer patients suggested that maladaptive coping styles and higher levels of depressive symptoms are potential predictors of the timing of disease progression (Reddick et al, 2005). Present study revealed unique indifferent correlation value for physical and psychological domains of quality of life because depression itself is an indicator of low quality of life. Qualitative result also revealed that depression is linked with indecisive thoughts, which may be the reason be for not being able to appreciate the quality of life Hence, the findings of this study recommend taking this matter seriously and intervening urgently to promote quality of life among cancer patients.

Quality of life, according to World Health Organization (WHO), is mainly related to physical, psychological, social, spiritual and environmental health. The definition for quality of life is quite similar to the definition of health given by WHO (1948). Present study outlined that among the five psychosocial factors (social support, self-esteem, coping, anxiety and depression), social support, self-esteem and coping is related to adjustment factors and the other two, anxiety and depression, are psychological consequences. On the basis of factors analysis, coping and social support proved to be the strongest predictors for determining quality of life. On ranking the psychosocial predictors, coping was found to be the first predictor for total quality of life and its physical, social relationship and environment domains. Social support was found to be the first predictor for psychological domain of quality of life. On the other hand, self-esteem, anxiety and depression remained indecisive predictors for determining quality of life among the cancer patients in Nepal.

5.2 Conclusion

The psychosocial context of cancer would seem to be important both in negative impact on the perception of cancer as a disease and its positive impact on potential therapeutic effects, either on cancer directly or its consequences. The implication of this research and findings in this chapter for researchers and clinical practitioners is that it is necessary to interrupt categorical view of psychosocial determinants with more delicate view of these concepts as a dynamic aspect of identity when targeting cancer patients with quality of life concerns. Psychosocial perspective is important not only in relation to developing and providing frontline health services but is also an important insight for quality of life through the patients' perspective. Information and interventions are of specific relevance to the quality of life of a cancer patient, which depends on a range of contextual factors that bring to the different aspects of their sense of belongingness.

The findings of both qualitative and quantitative study conclusively bring out that out of six demographic variables, age has insignificant positive correlation and education has negative insignificant correlation with quality of life in this study. Educated, and young cancer patients have worse quality of life in psychological domain, which could be considered as a serious matter. This study also revealed that female; and married cancer patients have worse quality of life in social relationships domain. Economic status of the cancer patients has insignificant negative correlation with quality of life. Yet, qualitative result indicated that economic status is most important to continue treatment thereby improving quality of life among cancer patients in Nepalese context. Role of the cancer patients in relation to their family is not associated with quality of life in Nepalese context.

Cancer patients at late stage have worse quality of life and its environment domain too. This finding is consistent with qualitative result, which anticipated that late stage of cancer need additional psychosocial care in relation to their quality of life. Duration of cancer diagnosis can be a determinant for quality of life. The research participants, who were facing financial problem for treatment, also had better quality of life. In the same context, qualitative result revealed that it is a serious matter related to quality of life among low socio-economic status cancer patients. Therefore, researcher recommends for the provision of health insurance policy or frees of cost treatment in relation to the improvement their quality of life.

The findings of this study also revealed that psychosocial status such as low level of social support, coping and self-esteem; and psychological consequences like high level of anxiety and depression reported by the cancer patients in Nepal were similar to those in other parts of the world. But the higher prevalence of depression among male cancer patients in this study is controversial.

Social support was negatively correlated with quality of life including all its domains. This study revealed distinctive association of social support with quality of life can be a serious matter in relation to quality of life. Qualitative result also revealed that the emotional/informational social support especially from close persons (spouse/ relatives/ friends) along with positive attitude of care providers is most important in relation to the quality of life. Hence, researcher recommends strengthening psycho-education components by interventions for family members and care givers to promote psychosocial adjustment, which is an influential factor for quality of life. Qualitative study also revealed that precautions should be taken by the health professionals while providing care. Therefore, researcher strongly suggests that the health workers (doctor, nurse, clinical psychologist, social workers, spiritual care, etc.), particularly those working for the cancer patients should have additional training on psychosocial care and communication skills in relation to the improvement of quality of life among cancer patients in Nepal.

Self-esteem was negatively correlated with quality of life and all its domains. This study revealed unique association of self-esteem with quality of life, which can be a serious matter in relation to quality of life. Factors analysis also revealed that it is a fragile psychosocial predictor for quality of life. Qualitative result also revealed that self-esteem is distorted very badly among cancer patients. Establishment of psychosocial care networks in terms of intervention is the felt need of the researcher, in relation to improvement quality of life of cancer patients.

Coping was positively correlated with quality of life including all its domains. Qualitative result also revealed that engagement coping is higher among Nepalese cancer patients, which is favorable for better quality of life. Yet, factors analysis revealed that there is a need to improve physical domain of quality of life. Hence, researcher advocates that psychosocial intervention is required to strengthen physical components of quality of life among cancer patients in Nepal.

Anxiety is negatively correlated with quality of life in environment domain. Yet, insignificant positive correlation of anxiety with quality of life in physical and psychological domain concluded that it could be a defense mechanism for coping with cancer and its sequelae. If the physical elements of quality of life among cancer patients are addressed, it will definitely help enhance the quality of life in Nepal too; qualitative results are also consistent with these findings.

Depression is negatively correlated with quality of life in environment domain. Yet, insignificant positive correlation of depression with quality of life in physical and psychological domain could be appreciated as low quality of life among Nepalese cancer patients. Timely management of depression, which is a sensitive psychological consequences related to quality of life among Nepalese cancer patients, is a burning issue.

On the basis of both qualitative and quantitative result, this study concluded that psychosocial factors determine the quality of life among cancer patients in Nepal. Social support and coping are the strong predictors for quality of life among the cancer patients. Self-esteem can be a predictor for quality of life, but it requires psychosocial intervention. Timely management of psychological consequences such as anxiety and depression is needed to enhance quality of life. On the other hand, qualitative data revealed that the emotional support especially from close persons along with positive attitude of providers, willpower, engagement coping, lessening the symptoms of anxiety and depression are the fundamental components for better quality of life.

Hence, researcher recommends an inclusion of psychosocial care services for cancer patients, and psycho-education for the care providers or family members of cancer patients to enhance quality of life in Nepal.

Figure 5.1

Conceptual Framework Based on Factors Associated with Quality of Life among Cancer Patients in Nepal

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Figure 5.1 depicts the factors associated with quality of life among cancer patients in Nepal. Present study revealed that perceived level of coping among Nepalese cancer patients is positively associated with quality of life. Perceived level of social support and self-esteem among Nepalese cancer patients is negatively associated with quality of life. Present study also revealed that perceived level of anxiety and depression among Nepalese cancer patients is negatively associated with quality of life in environmental domain. Age, education, economic status, gender (female), marital status is negatively associated with quality of life among cancer patients in the context of Nepal. Stage of cancer and duration of diagnosis is negatively associated with quality of life. Facing financial problem during treatment is positively associated with quality of life among Nepalese cancer patients. Role of the cancer patients in their family and modality of treatment is not associated with quality of life among cancer patients in the context of Nepal.

Besides the association between independent variables and quality of life, this study also revealed psychosocial problems and low quality of life among cancer patients in Nepal. Researcher strongly suggests that these are the cues for intervention in terms of psycho-education and psychosocial care services to improve quality of life of the cancer patients in Nepal.

5.3 Implications of the Study

The implication of this dissertation finding for researchers and clinical practitioners is that it is necessary to interrupt categorical outlook of psychosocial determinants with more delicate view of these concepts as a dynamic aspect of identity when targeting cancer patients with quality of life concerns. This is important not only in relation to developing and providing frontline health services. It is also an important insight for psychosocial cancer care activity through other professionals such as administrators, doctors, nurses, clinical psychologists, social workers, etc.

Cancer patient’s quality of life is relevant to them specifically of information or interventions, which depends on a range of contextual factors that bring to the different aspects of their sense of belongingness. The importance of assessing the psychosocial factors both positive and negative; and quality of life of cancer patients have provided an important baseline information from which future research can compare the rates of change in its prevalence. Future researchers can also be benefitted as this set avenue for hypothesis.

Present study is beneficial for screening of psychosocial factors as well as quality of life and their relationships among sampled population. The findings of this study revealed that the cancer patients in Nepal report low psychosocial status with respect to coping, social support and self-esteem. This study also revealed that the samples of this study have faced the psychological consequences such as severe grade of anxiety and depression; these factors adversely affect their quality of life.

This study explained the importance of regularly providing psychosocial care to the cancer patients and psycho-education to their family members for the improvement of their quality of life. Hence, this study is beneficial for the research participants also as it will help them further to seek support from their care providers when ever needed.

APPENDIXES

APPENDIX-I

INFORMED CONSENT FORM

Research participants were enrolled into the study with informed, verbal and/or written consent. Enrollment in or withdrawal from the study of subjects will not affect in access of medical care in any form. Dissertation entitled ‘Psychosocial factors determining Quality of life of Cancer Patients in Nepal’.

Purpose

You are being asked to participate in a study examining some of your feelings as they relate to a disease cancer. This may help us better understand how a diagnosis, treatment of cancer experience may impact a person.

Procedure

You have been chosen to participate in this study because you are attending treatment or suffering from disease. If you agree to participate you will be asked some questions related to psychosocial health. In addition to the questionnaire you will be asked to answer some questions about your personal background. This process will take approximately 2-3 hours to complete in 2 sessions.

Risks

Answering the questions may cause you to think about your feelings and could make you feel sad or upset. If you start to feel sad or upset please stop answering the questions.

Benefits

The potential benefit for you and/or others is a possible increase in the understanding of how a disease cancer experience impacts a person, especially persons dealing with a diagnosis, treatment and survival.

Participation

If you do not wish to participate in the study you can tell the researcher/interviewer, who asked you the questions that you do not wish to be involved. You may also continue to answer the questionnaire, however DO NOT sign the consent form or permission if you do not want your data to be included in the study. If you have any questions at this time please notify interviewer.

Confidentiality

The researcher was maintained confidentiality of data at all times and study documentation was stored in secure locked location accessibility only to the researcher. Ethical intervention was not compromised or prejudiced in way a participant’s right to anonymity, confidentiality, privacy, informed consent to participate or withdrawal from the study at any time for whatever reason.

If you choose to participate in this study your identity will be kept confidential. The investigator will treat your identity with professional standards of confidentiality. The information obtained in this study may be published in a health or psychology related journal, but your identity will not be revealed.

Authorization to Share Personal Health Information in Research

I am asking you to take part in the research described. To do this research, I will be collecting health information. For you to be in this research, I need your permission to collect and share this information.

Authorization:

I have read and/or heard the above and understand the purpose, procedure, risks, and benefits of this study. I, _________________, agree to participate in this research. I understand that I may later refuse to participate, and that I may withdraw from the study at any time.

Signature: _____________

APPENDIX-II

ENGLISH VERSION OF TOOLS

I. Demographic Variables

Serial No: …………...… Date of interview:…………

Name of Hospital: BCH/BPKMCH/BPKIHS

Ward/OPD: …………… Bed No………

Name: ……………… Caste/Ehnicity:……………

Sex: Male/Female Age (Year)…………

Religion: ……………………

Address: …………………. VDC/Municipality, District: ……………….

Education:
- a) Illiterate
- b) Literate: Year of education……..

Marital Status:
- a) Married
- b) Single: I) Unmarried II) Separated III) Widow/er

Role in the family:
- a) Earner: I) Main earner II) supportive earner
- b) Dependent : I)) Care provider II) just a member

Type of family: Nuclear/Joint/others…………

Food sufficient from own land: a) <3 months b) 3-6 months c) 7 to 12 months d) >12 months

Education of Head of Family (HOF):…………

Occupation of HOF:……………

Total No. of family members:………

Total family income/ month: NPR………

Per capita income (Per month): NPR…………

II. Disease Variables

Stages of cancer:
- a) Early stage: I) Stage I II) Stage II
- b) Late stage: I) Stage III II) Stage IV

Duration of illness: ………….. months

Modalities of treatment received:

a) Single: Surgery/Chemotherapy/Radiation therapy/Immunotherapy/Hormonal therapy/others……

b) Multiple: Combination of more than one therapy

Facing Financial Problems for Treatment: a) Yes
b) No

III. PSYCHOSOCIAL VARIABLES

Substance use

1. Brief Cope inventory

Scoring Criteria

1 = I haven't been doing this at all,	2 = I've been doing this a little bit
3 = I've been doing this a medium amount,	4 = I've been doing this a lot

S. No.	Inventory	Scoring Criteria			
Self-distraction					
1.	I've been turning to work or other activities to take my mind off things.	1	2	3	4
	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
Active coping					
2.	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
	I've been taking action to try to make the situation better.	1	2	3	4
Denial					
3.	I've been saying to myself "this isn't real."	1	2	3	4
	I've been refusing to believe that it has happened	1	2	3	4

Brief Cope inventory (Cont…..)

Behavioral disengagement					
7.	I've been giving up trying to deal with it.	1	2	3	4
	I've been giving up the attempt to cope.	1	2	3	4
Venting					
8.	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
	I've been expressing my negative feelings.	1	2	3	4
Positive reframing					
9.	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
	I've been looking for something good in what is happening.	1	2	3	4
Planning					
10.	I've been trying to come up with a strategy about what to do.	1	2	3	4
	I've been thinking hard about what steps to take.	1	2	3	4
Humor					
11.	I've been making jokes about it.	1	2	3	4

	I've been making fun of the situation.	1	2	3	4
Acceptance					
12.	I've been accepting the reality of the fact that it has happened.	1	2	3	4
	I've been learning to live with it.	1	2	3	4
Religion					
13.	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
	I've been praying or meditating.	1	2	3	4
Self-blame					
14.	I’ve been criticizing myself.	1	2	3	4
	I’ve been blaming myself for things that happened.	1	2	3	4

MOS Social Support Survey Instrument

S. No.	Items	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/informational support						
1.	Someone you can count on to listen to you when you need to talk	1	2	3	4	5
2.	Someone to give you information to help you understand a situation	1	2	3	4	5
3.	Someone to give you good advice about a crisis	1	2	3	4	5
4.	Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
5.	Someone whose advice you really want	1	2	3	4	5
6.	Someone to share your most private worries and fears with	1	2	3	4	5
7.	Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
8.	Someone who understands your problems	1	2	3	4	5
Tangible support						
9.	Someone to help you if you were confined to bed	1	2	3	4	5
10.	Someone to take you to the doctor if you needed it	1	2	3	4	5
11.	Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5

12.	Someone to help with daily chores if you were sick	1	2	3	4	5
Affectionate support						
13.	Someone who shows you love and affection	1	2	3	4	5
14.	Someone to love and make you feel wanted	1	2	3	4	5
15.	Someone who hugs you	1	2	3	4	5
Positive social interaction						
16.	Someone to have a good time with	1	2	3	4	5
17.	Someone to get together with for relaxation	1	2	3	4	5
18	Someone to do something enjoyable with	1	2	3	4	5
Additional item						
19.	Someone to do things with to help you get your mind off things	1	2	3	4	5

2. Rosenberg's Self-esteem Scale

S. No.	Items	Strongly Agree	Agree	Disagree	Strongly Disagree
1.	I feel that I'm a person of worth, at least on an equal plane with others.	4	3	2	1
2.	I feel that I have a number of good qualities.	4	3	2	1
3.	All in all, I am inclined to feel that I am a failure.**	1	2	3	4
4.	I am able to do things as well as most other people.	4	3	2	1
5.	I feel I do not have much to be proud of.**	1	2	3	4
6.	I take a positive attitude toward myself.	4	3	2	1
7.	On the whole, I am satisfied with myself.	4	3	2	1
8.	I wish I could have more respect for myself.**	1	2	3	4
9.	I certainly feel useless at times.**	1	2	3	4
10.	At times I think I am no good at all.**	1	2	3	4

** Negative items

4. Hamilton Anxiety Scale (HAM-A)

0= not present 1= mild 2= moderate 3= severe 4= greatly disabled

S. No.	Symptoms	0	1	2	3	4
1.	Anxious mood, including worry, insecurity, irritability, fear, dread and panic					
2.	Tension, including nervousness, muscle tension and trembling, frighten, cries easily, restless					
3.	Fears, such as fear of the dark, fear of strangers, fear of being alone, fear of animal					
4.	Lack of sleep or poor sleep, difficulty with nightmares					
5.	Poor concentration or trouble making decisions					
6.	Depression, including sadness, darkness (gloom) and hopelessness					
7.	Muscle pain or weakness					
8.	Trouble hearing or tinnitus (ringing in the ears), poor vision or blurred vision, unusual sensations on skin (such as prickling)					
9.	Symptoms of tachycardia (Check pulse), palpitations, chest pain or feeling faint					
10.	Trouble breathing (chest pressure, choking sensation, shortness of breath)					
11.	Constipation, diarrhea, nausea or other problems related to digestive system like dysphagia, constipation, weight loss, abdominal fullness,					
12.	Needing to urinate too often; abnormal periods (Urinary frequency or urgency, Dysmenorrhea, Impotence)					
13.	Nervous symptoms, such as sweating, dry mouth, flushing, pallor					
14.	Feeling anxious, nervous or agitated during interview such as restless, tremor, paces (rapidity)					

5. Beck Depression Inventory-II (Cont…...)

S. No.	**Inventory**	**Scoring criteria**	**Obtained score**
1.	**Sadness**		
	I do not feel sad.	0	
	I feel sad.	1	
	I am sad all the time and I can't snap out of it.	2	
	I am so sad or unhappy that I can't stand it.	3	
2.	**Pessimism**		
	I am not particularly discouraged about the future.	0	
	I feel discourage about the future	1	
	I feel I have nothing to look forward to	2	
	I feel that the future is hopeless and that things cannot improve.	3	
3.	**Past failure**		
	I do not feel like a failure.	0	
	I feel I have failed more than the average person.	1	
	As I look back on my life, all I can see are a lot of failures.	2	
	I feel I am a complete failure as a person.	3	
4.	**Loss of pleasure**		
	I get as much satisfaction out of things-as I used to.	0	
	I don't enjoy things the way I used to.	1	
	I don't get real satisfaction out of anything anymore.	2	
	I am dissatisfied or bored with everything.	3	
5.	**Guilty feelings**		
	I don't feel particularly guilty.		
	I feel guilty a good part of the time-		
	I feel quite guilty most of the time.		
	I feel guilty all of the time.		
6.	**Punishment feelings**		
	I don't feel I am being punished.		
	I feel I may be punished		
	I expect to be punished.		
	I feel I am being punished.		
7.	**Self-Dislike**		
	I don't feel disappointed in myself.	0	
	I am disappointed in myself.	1	

	I am disgusted with myself. I hate myself worse than anybody else.	2 3	
8.	**Self-criticalness** I don't feel I am any worse than anybody else. I am critical of myself for my weaknesses and mistakes. I blame myself all the time for my faults. I blame myself for everything bad that happens.	0 1 2 3	
9.	**Suicidal Thoughts or Wishes** I don't have any thoughts of killing myself. I have thoughts of killing myself, but I would not carry them out. I would like to kill myself. I would kill myself if I had the chance.	0 1 2 3	
10.	**Crying** I don't cry any more than usual. I cry more now than I used to. I cry all the time I used to be able to cry, but now I can't cry even though I want to.	0 1 2 3	
11.	**Agitation** I am no more irritated by things than I ever am. I am slightly more irritated now than usual. I am quite annoyed or irritated a good deal of the time. I feel irritated all the time now.	0 1 2 3	
12.	**Loss of Interest** I have not lost interest in other people. I am less interested in other people than I used to be. I have lost most of my interest in other people. I have lost all of my interest in other people.	0 1 2 3	
13.	**Indecisiveness** I make decisions about as well as I ever could. I put off making decisions more than I used to. I have greater difficulty in making decisions than before. I can't make decisions at all anymore.	0 1 2 3	
14.	**Worthlessness** I don't feel that I look any worse than I used to. I am worried that I am looking old or unattractive.	0 1	

	I feel that there are permanent changes in my appearance that make me look unattractive. I believe that I look ugly.	2 3	
15.	**Loss of Energy** I can work about as well as before. It takes an extra effort to get started at doing something. I have to push myself very hard to do anything. I can't do any work at all.	 0 1 2 3	
16.	**Changes in Sleep Pattern** I can sleep as well as usual. I don't sleep as well as I used to. I wake up one or two hours earlier than usual and find it hard to get back to sleep. I wake up several hours earlier than I used to and cannot get back to sleep.	 0 1 2 3	
17.	**Irritability** I don't get more tired than usual. I get tired more easily than I used to. I get tired from doing almost anything. I am too tired to do anything.	 0 1 2 3	
18.	**Changes in Appetite** My appetite is no worse than usual. My appetite is not as good as it used to be. My appetite is much worse now. I have no appetite at all anymore.	 0 1 2 3	
19.	**Concentration Difficulty** I haven't lost much weight, if any, lately. I have lost more than five pounds. I have lost more than ten pounds. I have lost more than fifteen pounds.	 0 1 2 3	
20.	**Tired or Fatigue** I am no more worried about my health than usual. I am worried about physical problems such as aches and pains or upset stomach, or constipation. I am very worried about physical problems and it's hard to think of much else. I am so worried about my physical problems that I cannot think about	 0 1 2 3	

	anything else.		
21.	**Loss of Interest in Sex** I have not noticed any recent change in my interest in sex. I am less interested in sex than I used to be. I am much less interested in sex now. I have lost interest in sex completely.	 0 1 2 3	

I. World Health Organization Quality of Life (WHOQOL) – BREF

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		VERY POOR	POOR	NEITHER POOR NOR GOOD	GOOD	VERY GOOD
1.	**HOW WOULD YOU RATE YOUR QUALITY OF LIFE?**	**1**	**2**	**3**	**4**	**5**
		VERY DISSATISFIED	DISSATISFIED	NEITHER SATISFIED NOR DISSATISFIED	SATISFIED	VERY SATISFIED
2.	**HOW SATISFIED ARE YOU WITH YOUR HEALTH?**	**1**	**2**	**3**	**4**	**5**

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		NOT AT ALL	A LITTLE	A MODERATE AMOUNT	VERY MUCH	AN EXTREME AMOUNT
3.	**TO WHAT EXTENT DO YOU FEEL THAT PHYSICAL PAIN PREVENTS YOU FROM DOING WHAT YOU NEED TO DO?**	**5**	**4**	**3**	**2**	**1**
4.	**HOW MUCH DO YOU NEED ANY MEDICAL TREATMENT TO FUNCTION IN YOUR DAILY LIFE?**	**5**	**4**	**3**	**2**	**1**
5.	**HOW MUCH DO YOU ENJOY LIFE?**	**1**	**2**	**3**	**4**	**5**
6.	**TO WHAT EXTENT DO YOU FEEL YOUR LIFE TO BE MEANINGFUL?**	**1**	**2**	**3**	**4**	**5**
7.	**HOW WELL ARE YOU ABLE TO CONCENTRATE?**	**1**	**2**	**3**	**4**	**5**
8.	**HOW SAFE DO YOU FEEL IN YOUR DAILY LIFE?**	**1**	**2**	**3**	**4**	**5**
9.	**HOW HEALTHY IS YOUR PHYSICAL ENVIRONMENT?**	**1**	**2**	**3**	**4**	**5**

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		NOT AT ALL	A LITTLE	MODERATELY	MOSTLY	COMPLETELY
10.	**DO YOU HAVE ENOUGH ENERGY FOR EVERYDAY LIFE?**	**1**	**2**	**3**	**4**	**5**
11.	**ARE YOU ABLE TO ACCEPT YOUR BODILY APPEARANCE?**	**1**	**2**	**3**	**4**	**5**
12.	**HAVE YOU ENOUGH MONEY TO MEET YOUR NEEDS?**	**1**	**2**	**3**	**4**	**5**
13.	**HOW AVAILABLE TO YOU IS THE INFORMATION THAT YOU NEED IN YOUR DAY-TO-DAY LIFE?**	**1**	**2**	**3**	**4**	**5**
14.	**TO WHAT EXTENT DO YOU HAVE THE OPPORTUNITY FOR LEISURE ACTIVITIES?**	**1**	**2**	**3**	**4**	**5**

WHOQOL-BREF (Cont……)

		VERY POOR	POOR	NEITHER POOR NOR GOOD	GOOD	VERY GOOD
15.	**HOW WELL ARE YOU ABLE TO GET AROUND?**	**1**	**2**	**3**	**4**	**5**
		VERY DISSATISFIED	DISSATISFIED	NEITHER SATISFIED NOR DISSATISFIED	SATISFIED	VERY SATISFIED
16.	**HOW SATISFIED ARE YOU WITH YOUR SLEEP?**	**1**	**2**	**3**	**4**	**5**
17.	**HOW SATISFIED ARE YOU WITH YOUR ABILITY TO PERFORM YOUR DAILY LIVING**	**1**	**2**	**3**	**4**	**5**

	ACTIVITIES?					
18.	**HOW SATISFIED ARE YOU WITH YOUR CAPACITY FOR WORK?**	**1**	**2**	**3**	**4**	**5**
19.	**HOW SATISFIED ARE YOU WITH YOURSELF?**	**1**	**2**	**3**	**4**	**5**
20.	**HOW SATISFIED ARE YOU WITH YOUR PERSONAL RELATIONSHIPS?**	**1**	**2**	**3**	**4**	**5**
21.	**HOW SATISFIED ARE YOU WITH YOUR SEX LIFE?**	**1**	**2**	**3**	**4**	**5**
22.	**HOW SATISFIED ARE YOU WITH THE SUPPORT YOU GET FROM YOUR FRIENDS?**	**1**	**2**	**3**	**4**	**5**

WHOQOL-BREF (Cont……)

23.	**HOW SATISFIED ARE YOU WITH THE CONDITIONS OF YOUR LIVING PLACE?**	**1**	**2**	**3**	**4**	**5**
24.	**HOW SATISFIED ARE YOU WITH YOUR ACCESS TO HEALTH SERVICES?**	**1**	**2**	**3**	**4**	**5**
25.	**HOW SATISFIED ARE YOU WITH YOUR TRANSPORT?**	**1**	**2**	**3**	**4**	**5**

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		NEVER	SELDOM	QUITE OFTEN	VERY OFTEN	ALWAYS
26.	**HOW OFTEN DO YOU HAVE NEGATIVE FEELINGS SUCH AS BLUE MOOD, DESPAIR, ANXIETY, DEPRESSION?**	**5**	**4**	**3**	**2**	**1**

APPENDIX-III

1. Measurement of the Psychosocial Tools

This sub-section deals with the description of the tools, which was used to measure the psychosocial factors (social support, self-esteem, coping, anxiety and depression) in this study. The sub-scale of the each tool is described by using median and inter-quartile range, which was used among 280 cancer patients.

Table 1.1

Median & Inter-quartile Range (IQR) of Four Sub-scales of MOS Social Support Survey Scale

n=280

S.N.	Subscales	Score range	Median	IQR
1.	Emotional/informational	8 - 40	31	26 - 37
2.	Tangible/instrumental	4 - 20	20	20 – 20**
3.	Affectionate	3 - 15	12	9 - 15
4.	Positive social interaction	3 - 15	6	3 - 9
Overall coping score		19 - 95	70	59-79

Higher scores indicate better social support. **Scales scores range from 0 to 100.*

** Mean and need to calculate standard deviation

Table 1.1 depicts MOS social support survey scale, which constituted four sub-scales viz. emotional/informational, tangible/instrumental, affectionate and positive social interaction, including companionship in leisure and other recreational activities. Median score of tangible/instrumental support was 20 and inter-quartile range was also 20-20 in this study which means out of the four elements, tangible/instrumental support received by the research participants were near to the center, which is considered as mean, therefore only standard deviation was to be calculated. Mean of the tangible support was 19.4 with the standard deviation of 1.7 (19.4±1.7), which reflected that there is not much variation in receiving tangible support among the research participants in this study. Emotional support received were the lowest (median= 31; inter-quartile range= 26 – 37). Affectionate and positive social interaction support were received by the research participants at medium level in this study.

Table 1.2

Median & Inter-quartile Range of Two Aspects of Rosenberg Self-esteem Scale

n=280

S.N.	Aspects	Score range	Median	IQR
1.	Positive	5 - 20	13	10-15
2.	Negative	5 - 20	11	8-13
Overall self-esteem scale score		10 - 40	24	19-28

Higher the score better the self-esteem

Rosenberg's self-esteem scale had 10 points, out of that 5 statements were formed in positive and rests 5 were available in negative form. This tool allocated lowest 1 and highest 5 score. During analysis for the negative items were codes in reversed score that means in spite of five; given score was one.

Table 1.2 depicts that among the positive and negative aspects, positive aspects had higher median (13) and inter-quartile range (10-15). This result can be interpreted that there is positive higher score received by the research participants in this study.

Table 1.3

Median & Inter-quartile Range of Fourteen Sub-scales of Brief COPE Inventory n=280

S.N.	Subscales	Score range	Median	IQR
1.	Self distraction	2 - 8	5	3 - 6
2.	Active coping	2 - 8	6	4 – 8
3.	Denial	2 - 8	2	2 – 2**
4.	Substance use	2 - 8	2	2 – 2**
5.	Use of emotional support	2 - 8	6	4 – 8
6.	Use of instrumental support	2 - 8	6	4 – 8
7.	Behavioral disengagement	2 - 8	2	2 – 2**
8.	Venting	2 - 8	4	4 - 6
9.	Positive reframing	2 - 8	6	4 – 8
10.	Planning	2 - 8	6	4 – 8
11.	Humor	2 - 8	2	2 – 2**
12.	Acceptance	2 - 8	6	4 - 6
13.	Religion	2 - 8	6	4 – 8
14.	Self blames	2 - 8	4	2 - 6
Overall coping scale score		28 - 112	64	54-74

Higher scores indicate better coping **Mean and need to calculate standard deviation

Table 1.3 depicts Carver's Brief COPE Inventory, which has 14 items, each item has two subscales and each item is allotted minimum 2 and maximum 8 score. Highest score was obtained by the research participants in the subscales like active coping, use of emotional support, use of instrumental support, positive reframing, planning and religion; for all of which sub-scales' median score was 6 and inter-quartile range was 4–8. These are the positive attributes of coping. Same score was obtained in the subscales like denial, substance use, behavioral disengagement and humor, that is median=2 and inter-quartile range also = 2. This means that all the values were near to the center, which is mean score, therefore only standard deviation needs to be calculated. Mean= 2.2 with standard deviation 0.9 of denial, mean=2.0 with standard deviation 0.12 of substance use, mean=2.1 with standard deviation 0.7 of behavioral disengagement, and mean=2.0 with standard deviation 0.4 of humor. There was no ‘0’ score in scale that was the reason to achieved mean score 2 in above sub-scale. Out of 14 subscales, 4 items (denial, substance use, behavioral disengagement and humor) were related to negative attributes of coping. This study revealed that majority of the research participants were trying their best to cope with the cancer than adopting negative attributes of coping.

Table 1.4

Median and Inter-quartile Range of Two Types of Symptoms of Anxiety

n=280

S.N.	Symptoms	Score range	Median	IQR
1.	Psychological	0 - 24	18	12 - 23.5
2.	Physical	0 - 18	13	8.25 - 16
Overall anxiety scale score		0 - 56	31	22 - 37

Higher the score higher the level of anxiety

HAM- A anxiety scale has 14 items, out of those 8 items are deployed for psychological symptoms, where as rest 6 items are related to physical symptoms of anxiety. There was ‘0’ at lowest and 3 in highest level of score in the tool. Therefore, mean 29.6 and standard deviation 10.8 (29.6±10.8) was calculated for anxiety scale.

Table 1.4 depicts that among the psychological and physical symptoms, highest score was achieved under the physical symptoms as compared to psychological symptoms of anxiety which means that the cancer patients have more physical problems especially bodily pain, discomfort and limitation of daily activities. Where median score 18 and inter-quartile range 12 - 23.5 was calculated for psychological symptoms and median score 13 and inter-quartile range 8.25-16 was calculated for physical symptoms of anxiety.

Table 1.5

Median and Inter-quartile Range of Two Types of Symptoms of Depression

n=280

S.N.	Symptoms	Score range	Median	IQR
1.	Psychological/affective	0 - 24	12	8 - 15
2.	Physical/Somatic	0 - 39	25	19 - 28
Overall depression scale score		0 - 63	36	27 - 42

Higher the score higher the level of depression

Beck depression Inventory- II (BDI-II) had 21 items, out of which 8 items were deployed for psychological/affective symptoms, where as rest 13 items were related to physical/somatic symptoms. There was ‘0’ at lowest and 3 in highest level of score in the tool. Therefore, mean 34.8 and standard deviation 11.4 (34.8±11.4) was calculated for depression scale.

Table 1.5 depicts the median score 12 and inter-quartile range 8-15 was calculated for psychological or affective symptoms and median score 25 and inter-quartile range 19-28 was calculated for physical or somatic symptoms of depression. Both symptoms had highest score, which means that the cancer patients have depression due to both physical and psychological problems especially loss of energy, changes in sleep pattern, changes in appetite, and feeling tired, etc. and other side having fear of relapse, side effects and death, which creates lack of concentration, irritability, lack of interest towards life, feelings of sadness, guilt, worthlessness, burden to their family, etc.

2. MEASUREMENT OF THE QUALITY OF LIFE TOOL

This sub-section dealt with the description of the tool, which was used to measure the quality of life in this study. The sub-scale of the tool is described by using median and inter-quartile range, which was used among 280 cancer patients.

Table 2.1

Median & Inter-quartile Range of Four Domains of WHOQOL-BREF
n=280

S.N.	Domains	Score range	Median	IQR
	Physical	7 - 35	18	15 - 20
	Psychological	6 - 30	19	17 - 20
	Social relationship	3 - 15	9	5 - 10
	Environment	8 - 40	21	17 - 24.75
Overall scale QoL score		26 - 130	70	62 - 79

Higher scores indicate better physical, psychological, social relationship and environment

WHOQOL-BREF tool had 26 items, out of that 24 items were allocated for four domains and rest 2 items were included in overall quality of life index. Table 2.1 depicts that the highest score was attained in the psychological domain (median= 19; inter-quartile range= 17-20) and second highest score was attained on physical domain (median= 18; inter-quartile range= 15-20). The lowest score was attained in social relationship and environment. Scores attained by the research participants reflected that subjective well-being related to physical and psychological domains were better than the social relationship and environmental well-being.

APPENDIX-IV

DOMAINS of WHOQOL-BREF

Domains	Facets incorporated within domains
1. Physical	▪ Activities of daily living ▪ Dependence on medicinal substances and medical aids ▪ Energy and fatigue ▪ Mobility ▪ Pain and discomfort ▪ Sleep and rest ▪ Work Capacity
2. Psychological	▪ Bodily image and appearance ▪ Negative feelings ▪ Positive feelings ▪ Self-esteem ▪ Spirituality / Religion / Personal beliefs ▪ Thinking, learning, memory and concentration
3. Social Relationships	▪ Personal relationships ▪ Social support ▪ Sexual activity
4. Environment	▪ Financial resources ▪ Freedom, physical safety and security ▪ Health and social care: accessibility and quality ▪ Home environment ▪ Opportunities for acquiring new information and skills ▪ Participation in and opportunities for recreation / leisure activities ▪ Physical environment (pollution /noise/ traffic/ climate) ▪ Transport

APPENDIX-V

SCORING INDICATORS OF SOCIO-ECONOMIC STATUS SCALE

Education was measured by asking respondents to indicate the number of years they completed in school. Occupation is categorized in seven groups. Per capita income was calculated on the basis of total family income. Their income was categorized and recoded as the directions given by Kuppuswamy’s socio-economic status scale (Mahajan, 1996). Ultimately, socioeconomic status was recorded on the basis of standard scoring indicators given in the table mentioned as below:

Classification of scores indicates SES

26 – 29 = Upper

16 – 25 = Upper middle

11 – 15 = Lower middle

5 – 10 = Upper lower

Below 5 = Lower

Scoring Indicators

	Items	Weightage
1.	Education of head of household	
	1. Professional degree, post-graduate and above	7
	2. B.A. or B.Sc. degree	6
	3. Intermediate or post high school diploma	5
	4. High school certificate	4
	5. Middle school completion	3
	6. Primary school or literate	2
	7. Illiterate	1
2.	Occupation of head of household (last occupation in case of retired persons)	
	1. Profession	10
	2. Semi-profession	6
	3. Clerk, shop owner, farm owner, etc.	5
	4. Skilled worker	4
	5. Semi-skilled worker	3
	6. Unskilled worker	2
	7. Unemployed	1
3.	Per capita income (Rs. per month in Nepali Currency)*	
	1. 26,847 or above	12
	2. 13,407 - 26,846	10
	3. 10,047 – 13,406	6
	4. 6,687 – 10,046	4
	5. 3,999 – 6,686	3
	6. 1,340 – 3,998	2
	7. Below 1,340	1

APPENDIX-VI

IN-DEPTH INTERVIEW GUIDE FOR CANCER PATIENTS

Serial No………….. Date of interview:…………

Place of Interview: Hospital/Community

1. Demographic and Disease Variables

Name:……………… Surname/Caste:…………

Sex: Male/ Female Age (Year)…………

Address:………………….

Education: …….. Marital Status:……….

Role in the family:…………………. Type of family…………

Food sufficient from own land: …………… in month.

Total number of family members:……………………………..

Total family income/ month: NPR…………………………….

Per capita income (Per month): NPR…………………………..

Stages of cancer: …………………

Duration of illness: …………..year.

Types of treatment received: …….

Facing Financial Problems for Treatment: ………………..

2. PSYCHOSOCIAL VARIABLES

Experience as a cancer patient……………..

Meaning of cancer as a survivor……………

Meaning of cancer in social context…………

Previous life experiences…………………….

Future plans of the cancer patient……………

Problems faced after having the disease cancer:

A. PHYSICAL………………………………….
B. PSYCHOLOGICAL……………………………
C. SOCIAL…………………………………….
D. SPIRITUAL………………………………….

Change in behavior……………………………………………………………………

Facing problem during communication………………………………………………..

Coping pattern/strategies after having cancer…………………………………………….

Any other newly adopted behavior after cancer………………………………………….

Types of social support received after having cancer…………………………………….

Feelings of received adequate social support…………………………………………..

Types of social support, do you expect from your providers:

A. SPOUSE………………………………………….
B. CHILDREN……………………………………..
C. OTHER RELATIVES/CARE PROVIDERS………………….
D. HEALTH PROFESSIONALS……………………………

Feelings regarding self respects after having treatment……………………….

3. QUALITY OF LIFE

Suggestions to improve quality of life of the cancer patients………………….

A. PHYSICAL……………….
B. PSYCHOLOGICAL………….
C. SOCIAL RELATIONSHIPS……
D. ENVIRONMENT…………..

Any other suggestions……………………………………………………………

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