Chapter I
INTRODUCTION
Egyptians and Indians were known to have been afflicted by some malignant growth, presumably cancer, over four thousand years ago. These rapidly growing swellings were named ‘Karkinomas’ by Hippocrates, the father of modern medicine, around 400 BC. And it is from this (Karkinoma) that the modern term ‘Carcinoma’ has originated. The term ‘Cancer’ was coined by Galen, personal physician to the emperor Marcus Aurelius. The term literally means ‘a crab’. He observed over 1,800 years ago that just as a crab’s feet are extended from every part of its body, so is this disease: the veins (later observed to be the lymphatic vessels) are distended and form a similar figure (Maroon, 1969).

Cancer and its treatment have a tremendous impacts on the patient and his/ her family: financial, psychological, social as well as physical. Right from the moment a physician makes the diagnosis of cancer and throughout the progressive stages of the disease, the patient along with the family members go through a lot of trauma- the shocks of being afflicted with one of the most dreaded illnesses, of enduring physical pain, the disability caused by the disease, of having to face the possibility of death, of losing the loved ones and, of changing relationships, equations, and of changing status etc.

Diagnosis of cancer, in the earlier part of the century, brought along with it a social stigma that both the patient and the family endured. It caused the person and the family to feel stigmatised, isolated and humiliated (Holland, 1989). Giving a historical perspective of the psychosocial issues in cancer, he traces that during the nineth century, families largely managed most of the cancer patients. Many others were taken care of by compassionate sisters who received support from the church. This marked the beginnings of the hospice movement in Europe. It was from these homes for people dying with cancer that many concepts of humanistic and comfort care took shape.

With the development of chemotherapy in early 1950’s, there was more scope for continuity of care, psychosocial support and greater attention to supportive and
palliative care. It was the paediatric oncology which was attuned to psychosocial issues well in advance of the adult oncology. In the 1950's, psychosocial support for cancer patients began to increase. Social workers in the United States were trained to assist patients with cancer, thus providing the first professional discipline to take care of these issues in cancer.

Meanwhile, important contributions were made in the field of cancer, by psychiatrists concerning patients' quality of life. With the change in attitude and increased awareness, psychosocial issues and aspects related to quality of life have received greater attention from the disciplines of oncology, psychiatry, social work, psychology, and nursing.

**Psychological Implications of Cancer:**

One of the most critical impact of concern is the acute psychological distress as the patient confronts the implications of cancer: possible death, dependence on others, disability, disfiguring changes in the body and loss of function (Ledersberg et al., 1993).

Cancer like any other serious and chronic disease stands as a symbol for the unknown and dangerous, for suffering and pain, for guilt and shame, for isolation and abandonment, for chaos and anxiety. It is often seen as a personal disaster, a crisis for both the patient and the family (Bolund, 1990). It is a crisis that evokes psychological responses from those affected. The initial response, according to Lederberg (1993) of an individual diagnosed having cancer is that of disbelief, a feeling of numbness. The next stage is that of anxiety and depression. The patient is pre-occupied with the implications of the illness, thoughts about the future and sense of helplessness. Attention and concentration are impaired, sleeping and eating patterns are disrupted. The two distinct phases involved are the shock phase and the reaction phase. The next phase is that of working through, where the patient with his/her coping skills tries to deal with the crisis.
Chaturvedi et al. (1994), Lederberg (1993), Holland (1989), have studied psychiatric morbidity in cancer patients and it is seen that anxiety and depression are the commonest psychiatric problems seen among cancer patients. Cancer patients have the same frequency of depression as other medically ill patients, when the level and severity of physical illness are controlled for (Lederberg, 1993).

Anxiety appears in cancer in all stages of the disease right from diagnosis, relapse and treatment failure, usually mixed with depression. Patients feel persistently on the edge, tense and are unable to relax. Panic attacks, irritability and poor concentration and autonomic symptoms are also present (Holland, 1990).

Social Implications of Cancer

The development of life-threatening and chronic disease like cancer has, apart from psychological consequences, profound social consequences also for both patients and those close to them. The onset of the disease tells upon various aspects of the patient’s life such as the activities of daily living, domestic life, social environments, working conditions, and general outlook on life itself.

One of the major consequences of cancer is the effect it has on the family and its structure. The burden of the care of the cancer patient, whether at home or at hospitals falls mainly on the family. More often, there is a loss of family income on the part of a family member due to his or her own illness or to having to limit working hours because of the illness of another family member. This creates an impossible burden for many families.

The family is part of the individual and individual is the part of the family (Richardson, 1940). Therefore any illness in one member of the family is most felt by the family. One of the direct effects of illness in the family is the change of roles within the family unit, which may be significant and sometimes permanent.

Role strain also sets in the family (Goods, 1960). The obligations that the role changes bring in are sometimes over-demanding for most people. They try to combat these strains using certain strategies aiming to reduce the effect this phenomenon.
The sick-role of the patient in the family is inevitable in most cases. Parson (1951) describes the concept of sick role as follows.

1. The sick person is exempt from “Normal” due to the individual’s illness, he or she gets exempted from performing his/her role and other social responsibilities.

2. The sick person is not responsible for his or her condition. Feeling sick usually thought to be a condition which is beyond one’s control. And to change this condition, personal will power, motivation and curative procedure are needed in good measure.

3. The sick person should try to get well. The sick person recognises that being sick is undesirable. He or she has an obligation to get well and resume normal responsibilities from which he or she was exempted.

4. The sick person should seek technically competent help and co-operation with the physician.

With the onus of responsibility to get well and to resume functions, the sick person has an obligation to get treated for his/her condition, and in that process of getting well, also co-operate with those treating. This ‘help seeking’ stage, when the patient and the family decide to seek medical intervention, heralds a lot of other problems. The family is in constant contact with illness. This induces in them the fear of the illness and its implications. They feel the need to break free of this uncomfortable situation, but are unable to do so. They are under pressure to carry out the expected roles assigned to them by the situation at hand.

For those who survive cancer, re-entry into the main stream can be difficult. The person and the family are both out of time with each other’s needs and capabilities. Re-adjustments and reallocation of roles take place, which again could
prove to be stressful, especially if members have started identifying with their newly assigned roles. This re-adjustment does not just stop at the home front. At the work place too, survivors must cope with altered co-worker attitudes. If the person is unable to do so, it may effect his career mobility (Lederberg et al., 1993).

Many cancer survivors tend to isolate from the society for the fear of rejection or they are actually isolated by their family and friends due to the continued social stigma of cancer. Cancer patient and the family have to learn to cope with the realities and learn to live with the reality, its probable implications, while trying to live together a friction free life and try to derive satisfaction from what is left in life. For this, what they need is a lot of understanding and support from their relatives, friends and professionals.

The present study is aimed to equip the social work professionals with empirically supported scientific knowledge and deeper understanding of the patient as a person in a psychosocial environment as the professional engages in the management of multitudes of psychosocial problems which crop up as patients and their families go through the different phases of the illness.

**Cancer: The Clinical Perspective**

The term 'tumor' was originally applied to the swelling caused by inflammation. Cornelius Celsus, a Roman writer of the first century AD, described the four cardinal signs of inflammation: rubor, toumer, calor and dolor (redness, swelling, heat and pain) Cotran et al. (1989). Neoplasia literally means "new growth" and the new growth is a neoplasm. Neoplasm also may induce swellings and by long precedent the non-neoplastic usage of tumor has passed into limbo. Thus the term is now equated with neoplasm. Cancer is the most common term for all malignant tumors.

The eminent British Oncologist Sir Rupert Wills (cit. Robins, 1989) defined neoplasm as ‘an abnormal mass of tissue, the growth of which exceeds and is uncoordinated with that of the normal tissues and persists in the same excessive
manner after cessation of the stimuli that evoked the change'.

Neoplasm can be divided into benign and malignant depending on the degree of differentiation, rate of growth, local invasion and metastasis. Benign tumors are well differentiated, usually progressive and slow, may come to a standstill or regress, mitotic figures are rare. They are cohesive and expansive, well-demarcated masses that do not invade or infiltrate the surrounding normal tissues and metastasis are absent. Malignant tumors on the other hand, show lack of differentiation. They show erratic growth, slow to rapid. Mitotic figures may be numerous and abnormal, locally invasive, infiltrating the surrounding normal tissues. Mitosis is usually present; larger and more undifferentiated the primary tumor, more likely the metastasis.

Grading of a cancer is based on the degree of differentiation of the tumor cells and the number of mitosis within the tumor. Thus cancers are graded as grade I to IV with increasing anaplasia (Cotran et al., 1989).

The progressive course of cancer is divided into four phases: malignant change in the target cell - referred to as transformation, growth of the transformed cells, local invasion and distant metastasis.

A review of literature shows that cancer is a disease that arouses a sense of horror and fear and the diagnosis of which cause the person and family to feel stigmatized, isolated and humiliated (Holland, 1982). Virtually no treatment existed until surgery came in as the first curative treatment of cancer. Cure of cancer was extremely rare. And cure depended on the early detection and diagnosis of the localisation of the disease which could be surgically removed.

It was thus essential and important to change public perception of cancer and its treatment. The earliest attempt at cancer education was in the 1890's in Europe, by a gynaecologist in East Prussia. In 1903, a newspaper campaign in East and West Prussia began, which publicised the early warning signs of cancer. In England too, similar efforts were started by Child to educate and inform the public about cancer and to lessen their fears. It was also advocated that national cancer control societies be established world-wide so as to create a more informed public. In the United States of America, the American Cancer Society was formed in 1923, mainly to
counter the public fears as to teach them that early diagnosis and treatment could be curative. This has helped to change public attitude considerably over the past few decades and make them aware of the types and signs and symptoms of cancer (Holland, 1989)

**Types of Cancer**

Cancer is not a single disease. There are over hundred types of cancer classified according to their site of origin and their appearance. All cancers are classified into four subgroups, each indicating the type of body tissue from which the cancer originated.

1. Carcinoma, a malignant tumor of epithelial or lining tissue. (Skin, various membranes and glandular tissues).
2. Sarcoma, a malignant tumor of connective tissue (Bone muscle and other ‘supportive’ tissues).
3. Lymphoma, a malignant tumor of lymphatic tissue (Hodgkin’s disease and lymphosarcoma).
4. Leukaemia, a malignant disease of the blood-forming tissues (often referred to as the cancer of the blood) (Maroon, 1969).

**Signs and Symptoms of Cancer**

The following signs and symptoms have been established over a period of time as indications of the onset of cancer:

1. Loss of appetite, loss of weight, an apparently undue amount of tiredness (Hodgkin et al, 1983).
2. Troublesome and persistent cough.
3. Lump in breast.
4. Jaundice, constipation and diarrhoea, blood or a mucous like discharge in faeces or urine.
5. Extreme changes of mood and mental attitude, epileptic-type of fits.
6. Haematuria.
7. Menorrhagia, irregular bleeding per vaginum or discharge per vaginum.

Carcinogenic Agents

The carcinogenic agents fall into following categories - chemical carcinogens, radiant energy and oncogenic virus. Aromatic amines and azodyes are implicated in human cancers. Acetyl aminofluorene and azodyes induce heptocellular carcinoma. Betanapthyamine induce bladder cancer. Aflatoxin B 1 produced by some strains of Aspergillus flavus is a potent hepatic carcinogen. Occupational exposure to asbestos has been associated with increased incidence of bronchogenic carcinomas, mesotheliomas and gastrointestinal cancers. Concomitant cigarette smoking heightens the risk of bronchogenic carcinoma many fold. Skin cancer associated with arsenic is also well established.

Cigarette smoking is seen to be directly associated with lung cancer as well as with cancer of the pancreas, kidney, urinary bladder and renal pelvis. Chewing of tobacco also increases the risk for cancers of the oral cavity and oesophagus. Consumption of alcohol is also a risk for developing cancers of oral cavity and oesophagus.

Diet has also seen to be one of the causative factors of cancer. Gastric cancer is seen to occur in population whose diets include large quantities of dried salted fish, pickled vegetables, smoked fish and low quantities of seasonal fresh fruits and vegetables. Colon and breast cancers are also linked with certain food habits.

Radiant energy, whether in the form of the ultraviolet (UV) rays of sunlight or as ionising electromagnetic and particulate radiation, has been found to transform virtually all cell types in vitro and induce neoplasm in vivo in both humans and experimental animals. UV light is clearly implicated in the causation of skin cancers.

Oncogenic viruses fall into two classes. They are the DNA and RNA viruses. Of the various DNA viruses, three of them are of particular interest, because they have
been implicated in the causation of human cancer. Human papilloma viruses (Benign squamous papilloma and squamous cell carcinoma) Eptein-Barr virus (Burkitis lymphoma) and Hepatitis B virus (Hepatocellular Carcinoma). RNA virus like Human T-cell leukaemia virus linked with causation of adult T-cell leukaemia/lymphoma. (Maroon, 1969).

According to Maroon, the exact mechanism that leads to the development of cancer is not known in spite of the tremendous amount of money being spent on research in this area. But the factors which may trigger the growth process in cancer have been delineated. Therefore prevention and/or early cure of many forms of cancer are effective if an awareness is created about these causative factors and necessary protective measures taken against them.

**Cancer Cachexia**

In the terminal stages of advanced cancer, patients commonly suffer progressive loss of body fat and lean body mass accomplished by profound weakness, anorexia and anaemia. This wasting syndrome is referred to as cachexia. Wasted patients with any form of chronic illness have immune deficiencies and are prone to infections, which could explain some of the debilitation and fever induced hypermetabolism. Ulcerative lesions may bleed, accounting in some part for anaemia and weakness. The grief and depression affect the physiological functions including sleep and appetite.

**Laboratory Diagnosis of Cancer**

Histologic and cytologic methods, immunocytochemistry for identification of cell products and surface markers, DNA probe analysis - Amplifications of N-myconcogene (neuroblastoma) and C-neungene (breast carcinoma), DNA flow cytometry are used in the study and diagnosis of tumor.
Karyotypic Changes in Tumors

With each passing year it becomes certain that the malignant cells of most types of human cancer have chromosomal abnormalities and that in many types of cancer the defects are consistent. Specific abnormalities have been identified in most leukaemia and lymphomas and an increasing number of nonhaemopoietic tumors.

Treatment of Cancer

Till about the middle of the nineteenth century, virtually no treatment for cancer existed. It was when general anaesthesia came into use that surgical treatment for cancer came to be widely used (Holland et al.). The medical treatment of cancer, that is, the conventional forms of treatment that offer significant levels of cure which have been successfully used are surgery and radiation.

Surgical treatment involves the excision of the tumor and of the tissues surrounding it which may have been affected by the disease. Sometimes surgical removal of tumors may involve the removal of all malignant tissue. This may result in the alteration or normal body functions.

Radiation is the form of treatment that is used to destroy the cancer tissues. Sometimes the adjacent normal tissues can be destroyed and devitalised due to exposure to radiation.

Both these forms of treatment emphasise an early diagnosis and are effective only if the malignant tissue/organ is removed or destroyed which otherwise spreads to other parts of the body.

Another form of treatment which has been recently discovered and has been effective in treatment of cancer and in relieving pain and management of symptoms is chemotherapy. Many of the drugs used in this form of therapy can bring serious side effects and no single drug is consistently reliable in putting a break in the advancing cancer growth (Smith et al. 1996).
Keeping in view, Devita (1993) has outlined three main types of therapeutic interventions. Psychopharmacologic, psychological and behavioural. Psychopharmacologic intervention involves the treatment of psychiatric disorders and patients with cancer are known to be prone to develop psychiatric disturbances which would need psychopharmacologic treatment.

Psychological interventions are mainly applied in the form of individual and group counselling, crisis intervention, psychotherapy. These interventions have proved effective as they have an educational function, encourage emotional learning and relieve anxiety and help patients to cope better.

Behavioural interventions have found an important place in the treatment of cancer patients as well (Redd, 1988, Devita, 1993). These authors have outlined the use of behavioural techniques such as relaxation, post hypnotic suggestion, autohypnosis, desensitisation and distraction. These are used to control and manage symptoms such as anxiety, pain, nausea and vomiting, eating disorders and some anxiety disorders.

Bouchier (1994), Devita (1993), Burish et al (1994) have all very clearly stated that the conventional treatments as surgery, radiation and chemotherapy alone do not suffice to meet the needs of the patient suffering from cancer and that treatment of cancer needs a multi-disciplinary approach since the problems related to cancer are multifaceted. And the behavioural and psychosocial issues of cancer receive a considerable attention in the prevention and management of symptoms. Mallette et al. (1994) too, in her views on cancer rehabilitation, talks about the need for multi-disciplinary team approach in the treatment of the physical, psychosocial and vocational disabilities of the cancer patients.

Cancer in the family involves the management of changes in and disruptions to the daily life of the family members as well as the patient necessiating them to make role adjustments and lifestyle adaptations, to meet the demands created by the illness (Mor et al., 1994). Role strain sets in the family, so do the financial burden, the burden of care giving, sense of guilt, helplessness, hopelessness, having to accept the progressive nature of the disease, and the eventual death in a majority of cases.
The psychological factors and their implications on patients and their families in the diagnosis of cancer have been increasingly acknowledged. There has also been a corresponding increase in the importance attached to psychological interventions, which in turn emphasises the role of social workers in the treatment and management of cancer. The number of social work professionals and the specific areas of their intervention in the management of cancer patients and their families is on the increase. So it is quite essential and proper that social workers become aware of the psychosocial implications that cancer and its treatment have on patients and their families. The researcher hopes to bring to focus the scientific awareness that would help the professionals in their interactions and interventions like counselling and family therapy when they deal with patients and their families.