CHAPTER I – Introduction

Support for caregivers is an essential part of good cancer treatment. They make the cure of their loved one possible.

Across the globe, psycho-oncology research dates back to the 1950s and it has been recognized as a scientific field within the field of oncology recently (Holland, 1992).

The terms psycho-oncology refer to diverse psychological, social, behavioural, and psychiatric factors related to all aspects of cancer like cancer prevention, cancer illness and treatment and survivorship (Breitbart & Chochinov, 1998). Psycho-oncology studies the emotional responses of patients at all stages of illness, the patients' family members, the patients' caregivers as well as their psychological aspects, behavioural factors, and social factors that may influence cancer morbidity and its end (Holland, 1992).

Caregiver is an important member of oncology team but many times the caregiver has been ignored or overlooked. Most often the family member of the patient like spouse, parent, son, daughter, friend or other close relatives become the caregiver and the caregiver play an important role in the care and recovery of the patient. The very presence of a cancer patient and its associated pain is known to greatly affect not only the patient but also the caregiver. The demands placed on the caregiver are many and these demands significantly affect caregivers' quality of life (Ferrell 2005).
Caregivers provide the care, love, hope, encouragement, understanding, knowledge, and appreciation of the patient which the medical team cannot provide.

Caregivers become the advocates of the patient when the patients are unable to manage their day to day activities.

**Cancer**

The cause of cancer is the multiplication of cells in the body, and when cell multiplication grows beyond control or out of control it results in cancer. There are many kinds of cancer, but all cancer start because of out-of-control growth of abnormal cells in the body.

It is found that cancer is the second leading cause of death in the United States. In United States about one-half of all men and one-third of women in the US will develop cancer during their lifetimes. Today, millions of people are cancerous or had cancer.

**Oldest descriptions of cancer**

It is recorded throughout the history that cancer has affected not only human beings but animals also. The oldest description of cancer, was discovered in Egypt (3000 BC) and is called Edwin Smith Papyrus in the text book on trauma surgery. The textbook describes eight cases of tumours of the breast which was treated with a tool called the fire drill. The book says that the illness cancer has no treatment.

**Origin of the word cancer**

Hippocrates the Greek physician the "Father of Medicine" (460-370 BC), is credited with the origin of the word cancer. Tumours refer to a crab in Greek, because of the finger-like spreading projections from a cancer called to mind the shape the shape of a crab. He used the terms carcinos and carcinoma to describe non-ulcer forming and
ulcer-forming tumours. Tumours refer to a crab in Greek, because of the finger-like spreading projections from a cancer called to mind the shape the shape of a crab.

The Greek term was later translated into cancer by another Roman physician Celsus (28-50 BC), the Latin word for crab. Galen (130-200 AD), used the word oncos (Greek for swelling) to describe the tumours. The name for cancer specialists – oncologists is now used which is Galen’s term.

Nineteenth century

The birth of scientific oncology was in 19th century with modern microscope used to study the diseased tissues. The tissues removed were examined under microscope and a precise diagnosis was made possible. The pathologist was able to confirm whether the cells were completely removed or not.

CANCER CAUSES: Theories throughout History

From the earliest times, there is no particular cause for cancer which can be pointed out to a particular factor and physicians have puzzled over the causes of cancer. In Ancient days Egyptians blamed the gods for illness cancers.

Humoral theory

Hippocrates believed that the human body had 4 humors and believed that excess or deficient of any of the humors in the body caused disease. Over secretion of black bile in different body sites was thought to be the cause for cancer.

Lymph theory

Lymph theory is one of the theories that replaced the humoral theory of cancer which believed that formation of cancer is by body fluid, called lymph. Life was believed
to consist of continuous and appropriate movement of the fluid, through the solid part of
the body, the most important was blood and lymph. Stahl and Hoffman thought that the
fermenting and degenerating lymph caused cancer and the lymph varied in the density,
alkalinity and acidity.

**Blastema theory**

In 1838, German pathologist Johannes Muller opposed the lymph theory and
demonstrated that cancer is made up of cells and not lymph, and believed that cancer
cells was not from normal cells. Muller proposed that the cause for cancer were the cells
that developed from budding elements (which is called blastema) between normal tissues.
However, his student, Rudolph Virchow (1821–1902), the famous German pathologist,
believed that the cells of the body including cancerous cells were derived from other
cells.

**Trauma theory**

Despite advances in the understanding of cancer, from the late 1800s until the
1920s, some thought trauma was the cause or reason for cancer. This belief continued
even in the absence of injury in animals which was brought under experimentation.

**Infectious disease theory**

The two doctors from Holland, Zacutus Lusitani (1575–1642) and Nicholas
concluded at almost the same time that cancer was a illness and is contagious. Their
conclusion was based on their experiences with breast cancer in members of the same
household and throughout the 17th and 18th centuries, it was that cancer was contagious
disease.
Cancer is not just one disease but many diseases with more than 100 different types of cancer. Most cancers are named based on the organ it originated from or type of cell in which the cancer cell start.

All cancers begin in cells the basic unit of body’s life. There are many types of cells in the body and these cells grow and divide in a programmed and controlled way to produce more cells as they are needed to keep the body healthy. When cells starts getting old or degenerated, they die and those cells are replaced with new cells which is natural.

However, sometimes this orderly process goes wrong when the genetic material (DNA) of a cell can become damaged or changed, thus producing mutations and start affecting the normal cell growth and division. When this process happens, the cells do not die which is supposed to, thus leaing to extra cells which may form a mass of tissue called a tumour.

In common medical usage the neoplasm is referred to as tumour and the study of tumour is called oncology (from oncos, ōti/mourō and logos, ōti/study of). The division of neoplasm into benign and malignant categories is important in the field of oncology and this categorization is based on a judgment of a neoplasm’s potential clinical behaviour.

In oncology a tumour is said to be benign when the microscopic observation and gross characteristics of the tumour are considered to be relatively less dangerous, meaning that the tumour will remain localized, cannot spread to other sites or parts of the body and is amenable to local surgical removal. A patient with benign tumour generally survives however, it should be noted, that benign tumours can produce more than
localized lumps and sometimes they are responsible for serious disease if untreated for a longer period of time.

Tumours are called malignant tumours if they adhere to any part of the body that they seize in an obstinate manner and are collectively referred to as cancers, derived from the Latin word for crab or crabs behaviour. The Malignant, as applied to a tumour, implies that the lesion can invade and destroy adjacent structures and spread to distant sites (metasize) or different parts of the body to cause death. Not all cancers pursue such a deadly course. Some are less aggressive and are treated successfully, but the type malignant shows a red flag which needs to be treated at the earliest.

Cancer types can be grouped into broader categories depending on the tissue cells. The main categories of cancer include:

Carcinoma: is the cancer that begins in the skin or in tissues that line or cover the internal organs of the body. There are several subtypes of carcinoma, including adenocarcinoma and transitional cell carcinoma.

Sarcoma: The cancer that has origin in bone, cartilage, fat, muscle, blood vessels or other connective or supportive tissues are sarcoma.

Leukemia: is seen in the blood-forming tissue such as the bone marrow which causes large number of abnormal blood cells to be produced and enter the blood.

Lymphoma and Myeloma: The origin of Myeloma is in the cells of the immune system.

Central nervous system cancers: cancers that begin in the tissues of the brain and spinal cord.
Stages of cancer

The stage of a cancer is used by oncologists to help plan treatment and predict a person's chance of recovery. Stage is usually decided by three factors namely, the size and growth of the tumour, whether cancer has spread to the near or surrounding lymph nodes and whether it has spread to other parts of the body. Staging is a way of describing where a cancer is located, if located, whether it has spread to other parts of the body, and extent of damage the cancer has or is affecting the functions of other organs in the body.

The staging system of the tumour is called TNM staging.

Global Cancer Facts & Figures

According to estimates from the International Agency for Research on Cancer (IARC), it was found 12.7 million new cancer cases in 2008 that is worldwide. Of 12.7 million new cases 5.6 million occurred in developed countries, and 7.1 million in countries that is on the way of development. At the same time the corresponding estimates for overall total cancer deaths in 2008 were 7.6 million (around 21,000 cancer deaths per day), 2.8 million in developed countries, and 4.8 million in developing countries worldwide.

Table 1.1
Global cancer Facts and figures

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<tr>
<th>Sites</th>
<th>All ages</th>
<th>Younger than 45</th>
<th>45 and older</th>
<th>Younger than 65</th>
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*Projected cases are based on 1995-2009 incidence rates from 49 states and DC as reported by the North American Association of Central Cancer Registries (NAACCR) representing about 98% of the US population.*

*American Cancer Society, Surveillance Research, 2013*
**Breast, women**

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**Prostate**

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*American Cancer Society, Surveillance Research, 2013*

Table 1.3

**Cancer problem in India**

<table>
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<th>Estimated Population</th>
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<tbody>
<tr>
<td>Estimated new cancer cases</td>
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<td></td>
<td>4.3 males</td>
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<tr>
<td></td>
<td>5.2 females</td>
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<tr>
<td>Estimated Tobacco Related Cases</td>
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<tr>
<td>Estimated Breast Cancer</td>
<td>1,15,251</td>
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<td>Estimated cervix cancer</td>
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</table>

27% of world Burden

Source: KMIO

**Estimated Tumour Burden in India**

- One Million incident (new) cases of cancer
- About three million prevalent cancer cases
- About 6 lakh cancer deaths occur each year
Common cancer in India

<table>
<thead>
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<th>MEN</th>
<th>WOMEN</th>
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<tr>
<td>Pharynx</td>
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<tr>
<td>Oesophagus</td>
<td>Oral cavity</td>
</tr>
<tr>
<td>Stomach</td>
<td>Oesophagus</td>
</tr>
</tbody>
</table>

Source: KMIO, 2013

TREND OF CANCER IN INDIA

Cancer of Breast, Ovary, and Endometrial cancer is showing significantly rising trend among urban women and cervical cancer incidence is gradually decreasing.

Increasing trend in incidence of Lung cancer among women in Indian Urban Registries is glaring (Source: KMIO, 2013).

TOBACCO RELATED CANCERS

Tobacco related cancers constitute half of all cancers in males and one third in females, i.e., overall about 35-40% of cancers are related to the use of tobacco (Source: KMIO, 2013).

TUMOUR BURDEN IN KARNATAKA

Over 50,000 new cases were estimated to have occurred in Karnataka during the year 2010 and about 1, 50,000 prevalence cancer causes. About 7,000 new cancer cases per year are Tobacco related (Source: KMIO, 2013).
In future the estimated burden can be much larger than given above due to the adoption of western lifestyles, such as smoking, poor diet, physical inactivity, and reproductive factors, in economically developing countries.

There are several types of cancers which are considered as difficult or easier to treat depending on the stage of cancer. The following are few types of cancer that are either easier or difficult to treat and also the symptom management of the patient is either difficult or not very difficult to manage by the care giver such as Lung cancer, esophageal cancer, Gastrointestinal cancer, breast cancer, cervical cancer and Lymphoma.

**CAUSES OF CANCER:**

**Heredity:**

There are evidences which indicate that for many types of cancer hereditary predispositions are found such as cancers related to colon, ovaries, cancer of kidney, cancer related to thyroid, pancreatic cancer and skin melanoma. Family history of cancer is not nearly as common as the spontaneous cancer. The hereditary cause for cancer is less than 15% of all cancers.

Geographic and Environmental variables: Environmental factors that give rise to somatic mutations are the predominant cause for the most common sporadic cancers. There is no paucity of environmental carcinogens. The carcinogens can lurk in conducive environment, workplaces, food that we have and in personal hygeines or practices also (eg., carcinogens).
Genetic Basis:

Scientists discovered 2 particularly important families of genes during 1970s related to cancer, the oncogenes and tumour suppressor genes.

Oncogenes: These genes cause cells to grow out of control and become cancerous cells. They are formed by changes or mutations of certain normal genes called the proto-oncogenes. The Proto-oncogenes normally controls how often a cell divides and the degree to which it differentiates the cells (or specializes in a specific function in the body).

Tumour suppressor genes: These are normal genes that slow down cell division, corrects or repairs the errors found in DNA, and inform cells when to die. They are programmed in their function. When tumour suppressor genes don’t work properly, the cells multiplies and can grow out of control, which can lead to cancer death.

A proto-oncogene helps the cell to grow and divide. An oncogene causes the cell to divide out of control or multiply. A tumour suppressor gene normally keeps the cell under control from dividing very quickly and if anything goes wrong with the gene, which can be a failure of mutation then cell division can get out of control.

Viruses

One of the herpes viruses, the Epstein-Barr virus, which cause infectious mononucleosis is been linked to non-Hodgkin lymphomas and nasopharyngeal cancer. Kaposi sarcoma and non-Hodgkin lymphoma is seen in people with human
immunodeficiency virus (HIV) and are at greater increased risk of developing several cancers.

**Other causes:**

The other contributing causes of cancer can be U V radiation, poor physical activity, obesity, and lifestyle, alcohol, and Tobacco consumption.

**SIGNS AND SYMPTOMS**

The cancer symptoms are divided into types depending on the symptoms.

Local Symptoms: unusual lumps or swelling (tumour), hemorrhage (bleeding), pain and/or ulceration. Compression of local tissues may cause symptoms such as jaundice.

Symptoms of Metastasis (spreading): enlarged lymph nodes, cough and hemoptysis, hepatomegaly (liver enlargement), pain in bone, fractures in the bones affected, bones and other symptoms of neurology. Can causes pain especially in last stages but it is often not the first symptom of cancer.

Systemic symptoms: weight loss, anaemia, poor appetite, fatigue and cachexia (wasting), excessive sweating (sweating during night), paraneoplastic and specific phenomena, due to an fast spreading cancer, like thrombosis or hormonal changes.

Diagnosis/symptoms of cancer include the following:

Biopsy, blood test, cancer imaging, cancer staging, fine needle aspiration, pathology reports (laboratory reports), sentinel lymph Node Biopsy, tumour grade, tumour markers.
**Treatment overview:**

The most common treatment for cancer involves surgery, radiation and chemotherapy. Only one therapy may be used either alone or in different combination with other therapies involved.

Surgery: is the surgical removal of the tumour and the tissues surrounding. Surgery can be the first line of treatment for many type of cancer, and in some cancers the tumours and its tissues can be completely removed with surgery alone.

Radiation: Radiation therapy is the use of high energy X-rays or other particles to kill cancer the cells. Radiation therapy is not free from side effects like fatigue; reactions on skin reactions, stomach upset, and loose diaharrea.

Chemotherapy: chemotherapy uses drugs to kill cancer cells, usually by stopping the cancer cells growth, to divide and metasise to other or nearing body parts. Chemotherapy is generally administered through IV to the blood stream to reach cancer cells throughout the body.

Chemotherapy is not free from side effects but the adverse effects of chemotherapy depend on the patient’s ability to tolerate the side effects and the dose used. The adverse effect can commonly be fatigue, diarrhea, nausea, hair loss, infection and low immune. These side effects usually disappear after few days of stopping treatment.

Other therapies include Targeted therapy and this therapy is decided by the oncologist, a treatment that targets the genes which are specific to cancer, type of proteins, or the type of tissue that contributes to cancer growth and survival.
Immunotherapy is designed to boost the body’s natural defences to fight against cancer. Hormonal therapies are used to treat several types of cancer. Hormonal therapy functions by lowering the amounts of hormones in the body.

**Palliative Care**

In addition to treatment to slow, stop or eliminate the cancer (also called-directed treatment), the advanced stage of cancer care involves relieving a person’s symptoms and side effects specifically at the end of life. It includes supporting the patient with his or her physical, emotional, spiritual, and social needs, an approach called palliative or support care. People often receive disease-directed therapy and treatment to ease symptoms at the same time at the end of life. Palliative care focuses on improving quality of life and supporting patients and their families to maintain quality of life.

The goal of palliative care includes:

- Treating symptoms if illness including pain, nausea, breathlessness, insomnia and other physical symptoms caused by cancer illness and its treatment.

- Treating patient’s emotional and social needs, including psychological symptoms such as anxiety and depression.

- Helping with family relationship of the patient

- Addressing a patient’s spiritual needs or other concerns

- Addressing a patient’s practical needs, such as transportation to hospital and financial concerns

- Providing additional support for the patient’s family, friends, and caregivers.
Talking about cancer and its treatment, and patient’s family needs is an important part of palliative care because it helps to clarify expectations of the patient and their family members and also for both patients and caregivers to understand the diagnosis and prognosis of cancer (chance of recovery) and to be a part of the medical decision-making process.

End-of-Life considerations:

Recovery from cancer is either difficult or may lead to patients health deterioration and finally death. If treatment is not successful, the disease may be called advanced, last stage or terminal cancer. The focus of treatment changes to palliative care if people are diagnosed with advanced cancer, where the quality of life can be maintained since the cancer treatment no longer helps cure the cancer illness.

Treatment decision at the end of life should be the highly patients personal choice. Some people would like to go on with the treatment till the end though it leads to many of the side effects of treatment, while others want to have possible comfort and relief from pain even if that means stopping cancer treatment because these decisions are different for each patient, and it is crucial for patients to think about what is most important to them and talk about it openly with the medical care team and their families. The conversation of the patient with the family may help family members to understand the patient, reaffirm love, and promote proximity, which may lead to ease the pain
INTERVENTION:

Caregivers usually define the onset of care giving at the time of the patient’s diagnosis of first cancer. Ideally, interventions for the caregiver should begin after the diagnosis of cancer.

Generally speaking, interventions for the caregiver include the following:

Education and information

Counselling and psychotherapy

The family meeting

Psycho education

Education and Information

Information tailored to a caregiver’s situation provides guidance for implementing care and generally the oncologist or clinicians agree on the value of providing the information of patient to caregivers. The information from clinicians may also help reduce the stress of care giving and its associated feelings of inadequacy and helplessness (Given B, 2001). Information about the patient’s disease trajectory, anticipated course of disease, the treatment involved and the range of emotions experienced by families helps normalize the experience and enhances a caregiver’s sense of control.

In the area of pain management, caregivers need to understand pharmacological issues and medication instructions like which medications to use for pain relief, when to give a medication, how to assess the efficacy of pain control, how to monitor for side
effects, how to identify negative results or ineffectiveness and operating the medical equipment.

A caregiver’s knowledge of and attitudes about symptoms such as pain, side effects and fatigue may influence the patients quality of life. A caregiver who harbors fears of the patient getting into medically prescribed addiction, overdose of medication, or resulting in discomfort for the patient may guard the medication supply, limit its use, and under medicate the patient thus leading to more distress (Juarez.G., 1996). Caregivers need to be trained in managing the side effects of treatment because the experience of side effects can cause cancer patients to abandon their treatment regimens and give up hope.

The cancer-related situation falls into a multilevel hierarchical pattern consisting of the disease, the patients overall well-being, the person with cancer, the patients family, and the community. Each level is a self-contained entity and cannot be reducible to simpler components. The cancer related system emerges when the patient, the family, and the community come together in response to the effects of the malignancy in the patient’s body. Influences from each level combine to and contribute to produce the cancer-induced threat. These range from medical treatment to loss of relationships or painful interchanges between the patient and to patients family members. In each phase of the illness the family is in acute stress arising from the threat of the reduced functioning of the patient, the alteration of the patient’s roles as spouse, parent, and so forth, reduced day to day functioning of the patient and reduced economic capacity side by side with increased medical expenses (Watson, 1994).
With this, the family constitutes one of the primary and important external coping resources in chronic or terminal illness generally and for cancer patients specifically. The main care giving member of the family is expected by others to be able to contain and control personal feelings arising from the threat of cancer and its side effects. From this point onward, the caregiver is forced to take responsibility for the patient’s medical treatment, the patients daily routine and day to day activities. This individual becomes the primary caregiver. The caregiver is perpetually involved in monitoring the patient’s medical condition, often going to great lengths to self-educate and evaluate a mass of new and complex information and also to emotionally support the patient. Not only is the caregiver willing, but has a deep need to receive information and share in the decision-making process which becomes more burdensome (Lederberg, 1998).

The background characteristics of the caregiver that may influence caregiver outcomes include age and gender of caregiver, living with present situation, socio-economic status and type and quality of the relationship between the care recipient and the caregiver. Findings regarding gender, (Barush, 1989, Miller B 1992) age, (Moo V 1991, Montgomery 1985) co residence and the type of relationship between the care recipient and caregiver (George 1986, Young R F, 1989) were relatively consistent.

Studies have shown that women of younger age, have the tendency to perceive the role of caregiving more negatively than (older) men and report higher levels of psychological distress, (Blood G W, 1994) even when the quality of the patient’s health and/or amount of care provided is controlled for or manageable. Horowitz.A. (1985) investigation found that compared with other informal caregivers, partners or spouses in particular are expected to bear a large proportion of the stresses and burdens that follow
in the course of cancer. A high quality of patient-caregiver relationship (i.e., the absence of a distressed relationship) can be conceived as a necessity (Northouse, L. 1987) when care is provided over a longer period or different phases of illness. Less consistent findings were reported for the association between social and financial status and caregiver outcomes (Triemstra, M. 1999). Although caregivers with a relatively low socio-economic status can be assumed a higher burden, Bielgel (1991) findings were contradictory.

Patient characteristics that have been cited in the literature as having an influence on caregiver outcomes include disease-related and treatment-related characteristics, physical and psychological dependency, (Carey, I. J., 1991) and its associated symptoms. However, no consistent research findings have been found, with results of few studies showing that the characteristics of patient are related to negative outcomes in caregiver (George, 1986, Carey I.J. 1991) and others reporting no such relation. Based on their research among caregivers of cancer patients, Given et al (1993) in their study reported that a patient’s dependency and symptoms specifically have a negative impact on the caregiver’s day to day schedule. Another oncologic study regarding care giving revealed that only patient characteristics, like illness treatment or the adverse side effects of treatment, were not the main related factors with caregivers experiences of psychological health (e.g., mood) (Seigel, K. 1991)

Care characteristics of the care giving may include duration of care, (Gilhooly, M.L. 1984) intensity of care, and different types of care or treatment. The more confining the care tasks are, the more likely they are to create negative consequences on caregiving. Because providing care demands the caregivers time, and the allotted time for
other activities such as household chores, leisure activities and visiting family and friends, leisure and social activities may be expected to decrease (C Zarey.I.J. 1991).

**Burden of Caregiving**

While health and burden may be viewed as opposite sides of the same coin in caregiving (George & Gwyther, 1986), research illuminates the importance of distinguishing between the two in the context of the impact of caregiving (Stull, 1994). Burden appears to represent a unique domain of the caregiving situation and is considered as being created by specific care giving demands, whereas health is considered to be an overall outcome that can be viewed as the end result of the caregiving process to a cancer patient. Evidently, burden and health are factors that are interrelated, although whether the impact of care giving burden leads to an effect on health or whether health leads to an effect on burden is still unclear (Nijboer, 1998) and more research needs to be done.

In addition to treating the patient’s cancer symptoms, diagnosis, and its associated treatment, the caregiver-specific symptoms to reduce their burden are essential. This is an integral part of Palliative Care. While underscoring the importance of caring for the caregiver by the oncology team, Lederberg (1998) introduced the concept of the primary caregiver as psychologically a patient in the second order, that is next to the cancer patient. The patient's illness has its effect on the caregiver that can cause emotional and functional distress at levels equal to or even greater than that of the patients themselves which goes unrecognised (Bishop, 2007). Caregivers of cancer patients frequently feel that they must contain their own emotional responses to the diagnosis of their loved one, to be a source of emotional and physical support, and retain their own strength. Several
factors may result in many of the caregivers either directly or indirectly to quit their careers, take over the role of the spouse to their children especially if a spouse is affected by cancer, alienate themselves from social support systems, and participate in critical treatment decision process. Clearly, the concept of treating family caregivers psychologically as second-order patients can be appropriately applied which assessing the burden of caregiving.

As a direct consequence of assuming the role of caregiver, cancer family caregivers in the palliative phases are at increased risk for physical and psychological morbidity. Very often, the burden of the caregiver, specifically psychological burden while caring for the patient exceeds that of the critically ill patient. It is possible that the psychologically distressed caregivers have a deleterious influence on patient well-being and the patient hope of recovery (Williams, 2011). In a study by Grunfeld (2004) burden was the most important predictor of both anxiety and depression among caregivers. Of employed caregivers, 69% reported some form of adverse impact on work and in the terminal period 77% reported missing work because of increased caregiving roles. The drugs prescribed by the oncologist during the intense and unpredictable course of treatment contributed to financial burden. The caregiver's burden is complex and complicated by multiple competing priorities especially as the patient condition shifts from treatment phase to palliative phase. Because caregivers are often faced with multiple concurrent stressful events and experiencing greater intensity of stress, they may experience negative health effects, poor quality of life mediated in part by immune and autonomic dysregulation (Bevans, 2012).
Greater the caregiver objective burden and stress, lower is the patient quality of life, greater intensity of symptom, and greater mood disorder like depression. Studies have indicated that caregivers who perceived that patients were not treated with respect and had unmet needs at end of life and reported more objective burden, and higher demand burden (O'Hara, 2010).

**Quality of life**

Caring for a patient with cancer affects the family caregiver's quality of life. The caregivers who do not have experience of caregiving task begin their role without training and are expected to meet many demands without much help from other family members. Caregiver often neglects his or her own quality of life by putting the patient's needs first. Today, many health care teams watch for signs of caregiver distress during the course of the patient's cancer treatment. The patients well being gets affected when the caregiver strain negatively influences the quality of caregiving and their role as caregiver. As the intensity of caring increases the psychological and physical well being of the caregiver's gets affected. The others areas that gets affected are social financial, and spiritual area.

**Psychosocial Issues**

The caregivers quality of life is affected more commonly by psychological distress experienced by the caregivers and it is seen that caring is the most difficult and stressful job and caregiver distress comes from the practical demands of the caregiver role as well the emotional ones, such as seeing the patient suffer. The family members feel more distressed than the patient while seeing a loved one suffer with cancer.
Distress is usually worse when the cancer is advanced and the patient is no longer being treated to cure the cancer but to give comfort to patient. Caregivers who have health issues of their own or responsibilities from other parts of their lives may enter the caregiving role grudgingly. The role of caregiving becomes harder or difficult to handle or manage the patient for an older adult caregiver, problems that are a part of aging. The personality of the caregiver like being hopeful or positive influences his or her ability to cope with distress.

Physical Issues
Cancer patients often need a lot of physical help during their stages of illness. The dependency of the patient on the caregiver may result in the caregiver feeling that the patient is physically demanding for the caregiver, who need constant attention, and help the patient with many daily activities during the day such as: taking the patient to toilet, eat, change position in bed, move the patient from one place to another, such as from bed to toilet, and use medical equipment.

The amount of physical help a patient needs varies - whether the patient can do normal activities of daily living, like dressing and walking, the amount of fatigue the patient has, the stage of the cancer, the management of symptoms, side effects of the cancer and the treatment.

As caregivers try to meet the physical demands of caregiving, they may suffer from lack of sleep, do not get enough rest and may ignore their own health. Their lifestyle changes where the regular habits such as exercise, consuming nutritious food or healthy diet, and regular medical follow ups may be pushed to the side. The health
problems the caregiver already may have become worse, or they may be diagnosed with other new health issues.

**Social Issues**

Caregivers often have less time to spend for social activities with friends and in the community as their days are filled with caring for the cancer patient. If there are misunderstandings or miscommunication in the relationship between the caregiver and the patient, the caregiver may feel even more lonely and burdened. In the beginning of caring for the patient, the caregiver gets lot of support from friends which helps the caregiver to continue working and keep up work relationships. As cancer care continues for a long duration, the caregiver may need to stop working and friends may call or visit less often. As the caregivers struggle continues to meet the ongoing demands of caregiving, they may want more help from family and friends.

**Financial Issues:**

There are many financial costs of cancer. Families must pay for medicines, transportation to specialized hospitals, and other medical checkups. Some caregivers give up their jobs and income so they can stay home with the patient, which makes it harder to pay for everything.

**Spiritual Issues**

Feelings of spiritual well-being may help lower the caregiver's stress. Keeping faith and finding meaning and hope have been shown to decrease the effect of caregiving stress on mental health. Spiritual well-being may help some caregivers be more hopeful, find meaning in the cancer experience, and be more accepting of what is.
Caregivers become caregivers for many different reasons. Some feel it is natural to care for someone they love. Sometimes there are practical reasons, such as no insurance or money to pay for other help. Whatever the reasons, giving care and support during cancer isn't easy.

Caregiver perceived quality of life is related to four variables, perceived mastery, symptom distress, age, and years of education, with mastery being the strongest predictor. Overall symptom distress and education are found to be the best predictors of the patient's quality of life. However (Moody and colleagues 2007) mastery of the caregivers is found to be an important predictor of the patient's quality of life.

Mellon.S. (2006), in their study found that cancer survivors report significantly higher quality of life, less fear of cancer recurrence, and more support than their family caregivers. The strongest predictors for cancer survivors' quality of life were family stressors, social support, meaning of the illness, and employment status, whereas the strongest predictors for family caregivers' quality of life were fear of recurrence and social support. Both the survivor's and family caregiver's quality of life independently contributed to the other's quality of life.

There are a number of studies that have documented the mutual effect that people with cancer and their family caregivers have on one another. Baider and Kaplan De-Nour 1988 reported a significant relationship between the number of adjustment problems reported by survivors and their spouses. Couples, rather than just survivors, are at risk after a cancer diagnosis. Investigators Northhouse 1995, oberst 1988, and lewis F M 1992 also have reported a significant relationship between cancer survivors' and their family
caregivers' levels of distress, depression, and/or adjustment although this relationship is not consistent across all studies. This relationship seems to be stronger when measures of role adjustment (i.e., ability to carry out domestic, work, and family roles) are used to assess psychosocial adjustment than when measures of emotional distress are used (i.e., anxiety, depression) (Northhouse 2007).

Park B (2013) found that burden, disruptiveness, and financial concerns were identified as factors affecting the caregivers' quality of life and management of the patients. There are indications to suggest that high levels of distress place caregivers at risk of experiencing psychosocial problems. Earlier studies have focused on depression as the topic of concern when examining the health of caregivers.

Caregivers described three key challenges (Mosher, 2013) in coping with their family member's lung cancer. The most common challenge, identified by 38% of caregivers, was a profound sense of uncertainty regarding the future as they attempted to understand the patient's prognosis and potential for functional decline. Another key challenge, identified by 33% of caregivers, involved time-consuming efforts to manage the patient's emotional reactions to the illness. Other caregivers (14%) characterized practical tasks, such as coordinating the patient's medical care, as their greatest challenge.

Study by Williams (2011) on cancer family caregivers during the palliative, hospice, and bereavement phases showed that as a direct consequence of assuming the caregiver role, cancer family caregivers in the palliative, hospice, and bereavement phases are at increased risk for physical and mental morbidity. Often, the psychological
burden of the caregiver exceeds that of the critically ill patient. It is possible that distressed caregivers have a deleterious influence on patient well-being.

Mosher (2013), study on Economic and social change among distressed family caregivers of lung cancer patients indicated that seventy-four percent of distressed caregivers experience one or more adverse economic or social changes since the patient's illness. Common changes included caregivers' disengagement from most social and leisure activities and, among employed caregivers, reduced hours of work. In other cases, a family member quit work or makes another major lifestyle change due to caregiving. Additionally, caregivers report losing the main source of family income, and report losing most or all of the family savings. Loss of the main source of family income and disengagement from most social and leisure activities predicted greater caregiver distress. The lung cancer caregivers experience high rates of adverse economic and social changes that warrant clinical attention as lung cancer is the most difficult cancer to treat.

**Symptoms of stress**

Cancer diagnosis and treatment can be very stressful for patients and their families. One is thrust into a world of testing and treatments while coping with the emotional and physical demands of the experience. Caregiver stress is the emotional and physical strain of caregiving. It can take many forms like feeling frustrated, guilty, angry, lonely and exhausted. Caregiver stress appears to affect women more than men. Unlike professional caregivers such as physicians and nurses, informal caregivers, typically family members or friends, provide care to individuals with a variety of conditions including advanced age and cancer. This experience is commonly perceived as a chronic stressor, and caregivers often experience negative psychological, behavioural, and
physiological effects on their daily lives and health. About 75 percent of caregivers who report feeling very strained emotionally, physically, or financially are women.

Although most caregivers are in good health, it is not uncommon for caregivers to have serious health problems like symptoms of depression or anxiety, are more likely to develop a long-term medical problem, such as heart disease, cancer, diabetes or arthritis, higher levels of stress hormones, spend more days sick with an infectious disease, have a weaker immune response to the influenza, or influenza, or flu, vaccine, have slower wound healing, higher levels of obesity, higher risk for mental decline including problems with memory and paying attention.

Part of the reason that caregivers often have health problems is that they are less likely to take good care of themselves. For instance, women caregivers, compared with women who are not caregivers, are less likely to: Get needed medical care, fill a prescription because of the cost, get enough sleep, cook healthy meals and get enough physical activity. The symptoms of increased stress experienced by caregivers are feeling overwhelmed, sleeping too much or too little, gaining or losing a lot of weight, feeling tired most of the time, loss of interest in activities they used to enjoy, becoming easily irritated or angered, feeling constantly worried, often feeling sad, frequent headaches, bodily pain, or other physical problems and abuse of alcohol or drugs, including prescription drugs.

Study by Pinquart.M, (2002) demonstrated that care recipients' behaviour problems showed stronger associations with caregiver outcomes than other stressors did. The size of the relationships varied by sample characteristics: amount of care provided
and care receivers' physical impairments were less strongly related to burden and depression for dementia caregivers than for caregivers of nondemented older adults. For spouse caregivers, physical impairments and care recipients' behaviour problems had a stronger relationship to burden than for adult children. Furthermore, evidence showed the association of caregiver burden with the number of caregiving tasks, perceived uplifts of caregiving, and the level of physical impairment of the care receiver were stronger.

Greater caregiving stress and lack of social support are significant predictors of greater depressive symptoms (Kim Y, 2013). Family caregivers share the strain of cancer and are at risk of physical and psychological symptoms in relation to caregiver stress. The study by Chan (1999) demonstrated that more stress symptoms are experienced by caregivers who reported increased difficulty in managing caregiver tasks. The caregiver's psychological stress, rather than their physical symptoms, overwhelmed most of the caregivers. There are significantly more negative responses to stress by caregivers who have a shorter duration of experience in providing care. In addition, caregivers who have less education are at higher risk of developing stress.

Duration of caregiving, sharing of caregiving burden, patients' age, and patients' functionality are found to be significantly associated with stress (Raynuha Mahadevan, 2013). A high proportion of the family caregivers experience stress during the phases of cancer.

**Anxiety and Depression**

Anxiety is an frequent accompaniment of depression and is seen up to 15% of cases (Malhotra, 1992). Depression is a co morbid disabling syndrome that affects approximately 15% to 25% of cancer patients (Tatsuo, 2002, Stefan Feitenl, 2013).
Depression is believed to affect men and women with cancer equally, and gender-related differences in prevalence and severity have not been adequately evaluated. Individuals and families who face a diagnosis of cancer will experience varying levels of stress and emotional upset. Depression in patients with cancer not only affects the patients themselves but also has a major negative impact on their families.

A survey in England of women with breast cancer showed that among several factors, depression was the strongest predictor of emotional and behavioural problems in their children (Michel.P, 2001). Fear of death, disruption of life plans, changes in body image and self-esteem, changes in social role and lifestyle, and financial and legal concerns are significant issues in the life of any person with cancer, yet serious depression or anxiety is not experienced by everyone who is diagnosed with cancer.

In recent years, there has been an increase in research studies undertaken on family caregivers of individuals living with cancer beyond the initial phase of the illness.

There is considerable evidence demonstrating the negative effects of caregiver burden particularly in the areas of psychological well-being and quality of life of family caregivers of patients with cancer (Turkoglu, 2012).

The influence of family environment plays a role while caring for a lung cancer patient. The family environment and blaming the patient during times of illness can affect both patient and caregiver depression. Quality of the family dynamic is important for patients but may be particularly influential for caregivers (L.A.Simroff, 2010).

Grunfeld (2004), in their investigation on a longitudinal study of the psychosocial, economic, and occupational impact of caring for a terminally ill breast cancer patient
reported that the prevalence of anxiety and depression in cancer family caregivers was 30% and 35%, respectively, and exceeded that of the patient with cancer.

Recent studies also found that caregiver burden was the most important predictor of anxiety and depression (Bevans M, 2012). Work with partners of patients with myeloma shows that partners have high levels of anxiety and depression (48.7% and 13.6%, respectively) that are higher than those of patients. Partners are also more engaged with the illness than patients, provide practical and emotional support, and "filter" negative information in an effort to protect the patients, which all lead to a heightened sense of illness burden and difficulties with coping.

Furthermore, Grov et al (2004) found that the depression level of caregivers are significantly high, whereas Wang et al (2011) highlighted that the most frequently reported issues are emotional adjustment, changes in personal plans, and feeling upset, particularly in relation to changes observed in patients as a result of their disease process. It is also found that spouse caregivers are twice as nonspouse caregivers to experience family adjustments and changes in personal plans. Moreover, caregivers who are older need more information and education about the patients' disease and clinical prognosis.

Study on health-related quality of life of patients and their caregivers by investigator Vrettos, 2012, demonstrates that female patients more frequently experience anxiety and depression than male patients. Male and higher-education caregivers experience greater anxiety and demographic factors do not seem to influence patient's health-related quality of life.
Grov E K 2005, in their study on anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase found that the physical quality of life was higher in both genders and mental quality of life was lower in male, primarily caregivers. The anxiety is higher in both genders but not depression.

Regarding Health Risk Factors in Caregivers of Terminal Cancer Patients (Alice Corà, 2012) caregivers experience higher levels of depression, state anxiety, and more sleep dysfunctions than normal healthy people. Elevation of heart rate is associated with caregiving length. The caregiving stressor is associated with considerable psychological vulnerability, sleep disorders, and risk of alterations in the cardiovascular system, which seems to be modulated by caregiving characteristics.

The investigation by Grov E K (2006) supports the finding that caregiver's depression has a direct significant association with caregiver burden. Not only caregivers' depression is the main factor associated with caregiver burden, but also an important mediator of indirect associations of caregivers' anxiety and physical health.

In a study on Depression and Anxiety among Family Caregivers of cancer patients probable depression was significantly associated (Ambigga Devi, 2005) with education level of the caregiver and duration of illness of the patient. Where as probable anxiety was significantly associated with age of caregivers.

Caregivers report the highest level of depressive symptoms, and caregivers who are between the age group of 35-44 years feel the strongest sense of abandonment. Caregivers who are the adult children of patients with cancer and those who are employed report high levels of depressive symptoms. Feeling abandoned (a portion of
Caregiver burden) is more prevalent in female, nonspouse, and adult children caregivers, and adult children caregivers of patients with early-stage cancer and patients with multiple symptoms report a high perception of disruption in their schedule because of providing care (Given. B. 2004). Caregivers whose patients died early following diagnosis report the highest depressive symptoms, burden, and impact on schedule.

**Self-efficacy**

The concept of self-efficacy lies at the center of psychologist Albert Bandura’s social cognitive theory. Bandura’s theory emphasizes the role of observational learning, social experience, and reciprocal determinism in the development of personality. According to Bandura, a person’s attitudes, abilities, and cognitive skills comprise what is known as the self-system. This system plays a major role in how we perceive situations and how we behave in response to different situations. Self-efficacy plays are an essential part of this self-system. Self-efficacy is "the belief in one’s capabilities to organize and execute the courses of action required to manage prospective situations." In other words, self-efficacy is a person’s belief in his or her ability to succeed in a particular situation. Bandura described these beliefs as determinants of how people think, behave, and feel (1994).

As Bandura and other researchers have demonstrated, self-efficacy can have an impact on everything from psychological states to behaviour to motivation.

Virtually all people can identify goals they want to accomplish, things they would like to change, and things they would like to achieve. However, most people also realize that putting these plans into action is not quite so simple. Bandura and others have found
that an individual’s self-efficacy plays a major role in how goals, tasks, and challenges are approached.

People with a strong sense of self-efficacy view challenging problems as tasks to be mastered, develop deeper interest in the activities in which they participate, form a stronger sense of commitment to their interests and activities, recover quickly from setbacks and disappointments.

People with a weak sense of self-efficacy, avoid challenging tasks, believe that difficult tasks and situations are beyond their capabilities, focus on personal failings and negative outcomes, and quickly lose confidence in personal abilities.

Pain is a major concern not only for cancer patients, but also for their partners and caregivers. Providing care for a cancer patient with severe or persistent pain is one of the most challenging and stressful tasks anyone can face; seeing a loved one suffer can be extremely emotionally demanding for caregiver of cancer patients. Caregivers of cancer patients who experience pain have much higher levels of tension, depression, and mood disturbance than caregivers of cancer patients who are pain-free. In addition to dealing with the emotional and physical demands of providing care, partners and caregivers must adjust and cope with disruptions in their own daily lives. People vary in their ability to cope with the demands of the caregiving role. Some partners and caregivers are able to master caregiving tasks and seem to cope well with the challenges involved. Others, for a variety of reasons (e.g., child care and work responsibilities, health problems, and emotional distress), have more difficulty coping with these demands and report higher levels of depression and strain. Unfortunately, cancer caregivers often lack the skills and
resources they need to help the patient manage their treatment and the negative consequences of their disease and its management.

Factors that contribute to lower levels of self-efficacy include (Porter. S. 2002) low patient-rated self-efficacy, female gender of the patient, high patient psychological distress, and high caregiver strain. Caregivers are evenly split in their tendency to overestimate versus underestimate the patient's self-efficacy. A poorer quality of relationship between the caregiver and the patient (as rated by the patient), high levels of patient-rated symptoms, and high levels of caregiver strain are associated with caregivers overestimating patient self-efficacy.

Patients undergoing chemotherapy experience many symptoms that they may be able to manage with the support of an activated caregiver. The readily available technology to improve patient caregiver communication about symptoms and caregiver knowledge of symptom management may help the caregiver to have better physical function, fewer outpatient visits and hospitalizations related to symptoms, and greater adherence to chemotherapy. Silveira (2011) reports that if successful, it could substantially improve the quality of life of veterans and their families during the stresses of chemotherapy without substantially increasing the cost of care.

Patient and caregiver self-efficacy for managing pain, symptoms, and function may be important factors affecting adjustment. There are significant associations between self-efficacy and adjustment. Patients low in self-efficacy report significantly higher levels of pain, fatigue, lung cancer symptoms, depression, and anxiety, and significantly worse physical and functional well being, as do patients whose caregivers are low in self-efficacy.
efficacy. When patients and caregivers both have low self-efficacy, patients report higher levels of anxiety and poorer quality of life than when both are high in self-efficacy. There are also significant associations between patient and caregiver self-efficacy and caregiver adjustment, with lower levels of self-efficacy associated with higher levels of caregiver strain and psychological distress (Laura S. Porter, 2008).

Alice cora (2010), investigated Health Risk Factors in Caregivers of Terminal Cancer Patients and found that the caregiving stress is associated with considerable psychological vulnerability, sleep disorders, and risk of alterations in the cardiovascular system, which seem to be modulated by caregiving characteristics.

Sharan.P., (1995), in a investigation on Coping and adaptation in parent caregivers of children suffering from acute lymphoblastic leukemia using Thematic apperception test found that emotional distress was evident in the stories of 83%, and only 37% maintained an expectation of a positive outcome. Parent caregiver psychiatric morbidity was found to be associated with the gender of the parent, employment status. The parent caregiver expected an unfavourable outcome, feelings of lack of self efficacy and emotional distress, particularly depression. Significant association between the presence of psychiatric disturbance in the children and the parents is also found.

NEED FOR THE STUDY
Caregivers have received very little attention in the published literature from India. The literature shows that little is known about Indian family member's experiences of being caregivers, as well as their expectations of the palliative care services. The transition of a cancer patient from curative to palliative stage is one of the more difficult and challenging phases of cancer care, both to the physician and family caregiver.
Although family caregivers are the long-term care providers to people with cancer, they receive little preparation, information, or support to perform their vital role. Family caregivers often are expected to navigate an increasingly complex and fragmented health care system on their own and to find whatever help that may be available. In recent years, the caregiving responsibilities of family members have increased dramatically, primarily because of the use of toxic treatments, the decline in available health care resources, and the shortage of health care providers and lack of social support in semi urban and rural areas of India. Family caregivers have psychological needs that must be addressed so they can maintain their own health and provide the best care possible to the patient.

Recapitulating the main factors that have been explored so far it could be synthesized that psychological issues of a caregiver is the final sum of social, psychological, and physiological variables.

The correlates of psychological factors of caregiver have an impact on the quality of life of the patient. The behaviourial manifestation of long term caring from curative to palliative stage is show in various behavioural manifestations like burden, guilt, depression, anger, anxiety, poor quality of life, and physical stress. The distress experienced over a period of long term caring disturbs the psychological balance or emotions of the caregivers which in turn has an effect on their role as caregiver. Cancer symptoms in case of lung, gastrointestinal and esophageal cancer is difficult to manage, especially if the caregiver is sandwiched between caring of his/her family and the patient. The financial cost involved for medicine and the treatment leads to additional worry, depression, and anxiety. The self efficacy of caregiver in managing the symptoms of the
patient during palliation depends on the availability of health care services, preparedness to assume the role of a caregiver and information about medication schedule. The lack of knowledge to manage the pain of the patient during the end phase of life contributes to psychological distress of caregivers which in turn leads to low self efficacy.

From factors that have been explored and mentioned so far, it could be synthesized that the level of psychological functioning of caregivers of different types of cancer patients varies across different types of cancer. The relationship of caregiver with patient as a spouse, daughter, son, or others involves emotional component while caring for the patient which in turn has an impact on care giving role. The patient dependency on the caregiver for physical needs such as day to day care, providing psychological support for the patient’s anxiety and depression and arranging finance for treatment, does have a psychological effect on the caregiver which in turn affects the quality of life.

When caregivers’ needs are not addressed, their mental and physical health is at risk, and patients are denied the opportunity to obtain optimal care from a well-prepared family caregiver.

The present chapter is an introduction to the present study, providing a framework from the perspective of psychological and quality of life of caregivers as well as associated concepts of the topic of the present study, largely basing on the empirical research finding. The next chapter is the literature review that has been done with regard to the significance of the present study.