Chapter 1

Introduction

“There are only two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle.”

...Albert Einstein

When a child is diagnosed with cancer, the entire family goes through severe stress. Advanced stage of cancer of the child is stressful for parents as the hope of cure is limited. Parents feel helpless and try to face the event by adopting varied coping strategies. The Palliative Care Unit attempts to understand the parental needs and offer care not only to the ill child but also to care givers in totality.

Brief Introduction to Cancer:

Cancer is the name given to a large group of diseases, all of which have one thing in common: cells that are growing out of control. Normally, the cells that make up all the parts of our bodies go through a predictable life cycle. Old cells die, and new cells arise to take their place. Occasionally, this process goes awry, and cells begin to multiply out of control. The end result is a mass of cells, called a tumor. A benign tumor is one that does not spread, or metastasize to other parts of the body. It is considered noncancerous. A malignant tumor, on the other hand, can spread throughout the body and is considered cancerous. When malignant cells break away from the primary tumor and settle into another part of the body, the resulting new tumor is called either a metastasis or a secondary tumor. (http://www.tatamemorialcentre.com/cancerinfo/cancer/cancer.htm retrieved on 23rd Mar 2011)

There are several major types of cancers: 1. Carcinoma 2. Leukemia is found in the blood, the bone marrow, and the spleen; and 3. Lymphomas are found in the lymphatic system
**Carcinoma:** Carcinomas form in the cells that cover the skin or line the mouth, throat, lungs and organs; sarcomas are found in the bones, muscles, fibrous tissues and some organs. ([http://www.tatamemorialcentre.com/cancerinfo/cancer/cancer.htm retrieved on 23rd Mar 2011](http://www.tatamemorialcentre.com/cancerinfo/cancer/cancer.htm)).

"Carcinoma", "Adenocarcinoma" or, "Sarcoma" are actually very broad classes of cancer cell types, rather than particular cancers, and are not nearly specific enough to allow one to research treatment. Sarcomas are cancers of the connective tissue, cartilage, bone, muscle, and so on. Carcinomas are cancers of epithelial (lining) cells. Adenocarcinoma refers to carcinoma derived from cells of glandular origin. One can have an adenocarcinoma of the pancreas, or an adenocarcinoma of the lung. ([http://www.cancerguide.org/basic.html retrieved on 23rd March 2011](http://www.cancerguide.org/basic.html)).

**Leukemia:** Leukemia is cancer that originates in the bone marrow, the soft, spongy inner portion of certain bones, and in which the malignant cells are white blood cells (leukocytes). Leukemia develops when a leukocyte undergoes a transformation into a malignant cell, one capable of uncontrolled growth. Leukemia cells begin to multiply in the marrow, and as they do so, they crowd out the normal blood cells those that carry oxygen to the body's tissues, fight infections, and help wounds heal by clotting the blood. Leukemia can also spread from the marrow to other parts of the body, including the lymph nodes, brain, liver, and spleen.

Leukemia is ten times more common among adults than among children. Leukemias are evenly split between the acute and chronic forms, but among children, acute lymphocytic leukemia accounts for about two-thirds of cases. Acute myeloid leukemia and chronic lymphocytic leukemia are the most common types in adults.

A malignant transformation can happen at any stage of blood cell development. The leukemia cells that carry many characteristics of the cell from which they began. Most leukemias fall into one of two general groups: myeloid leukemia and lymphocytic leukemia. Physicians also classify leukemias according to whether they are acute or chronic. In acute leukemias, the malignant cells, or blasts, are immature cells that are incapable of performing their immune system functions. The onset of acute leukemias is rapid, and, in most cases, fatal unless the disease is treated quickly. Chronic leukemias develop in more mature cells, which can perform some of
their duties but not too well. These abnormal cells also increase at a slower rate, so the disease develops more slowly than in acute leukemia, and in many cases it is more difficult to cure. (tatanemorialcentre.com/cancerinfo/leukemia/leukemia.htm retrieved on 29th Dec10)

**Lymphoma** – Lymphoma is a general term for cancer in the lymph system. The lymph system is made up of many cells and organs, including the lymph nodes, thymus gland, spleen, and liver. This system produces B-Cells and T-Cells, which make up human body’s immune system. Since these cells travel between the lymphatic and circulatory system while fighting infections and viruses, lymphomas are blood-related cancers. There are two main categories of lymphomas: Hodgkin’s lymphoma (aka Hodgkin’s disease or Hodgkin lymphoma) and Non-Hodgkin’s lymphomas (NHL). Hodgkin’s disease is a very specific type of cancer that involves a mutation in Reed-Sternberg cells. Non-Hodgkin’s Lymphomas involve mutations in the body’s B-Cells and T-Cells. B-Cell Lymphomas account for over 80% of all NHL. T-Cell Lymphomas make up the rest of NHL. ([http://www.lymphomainfo.net/lymphoma/whatis.html](http://www.lymphomainfo.net/lymphoma/whatis.html) retrieved on 23rd March 2011)

**Treatment for cancer:**

The aim of cancer treatment is to cure the patient and save life. The cases where complete cure is not possible, treatment aims to control the disease and to keep the patient normal and comfortable as long as possible. The treatment of each patient is designed to suit an individual and depends on the age of the patient, stage and type of disease. There may be only one treatment or combination of treatments. There are five main modalities of treatment: 1. Surgery, 2. Radiation therapy, 3. Chemotherapy, 4. Hormone therapy and 5. Immunotherapy.

**Surgery:** aims at eradicating the disease at the primary site (site of origin) of cancer. Surgery is the most important part of the cancer treatment. Surgery attempts to remove cancer cells from the body by cutting away the tumor and any tissues surrounding it which may contain cancer cells. It is a simple, safe and effective method when cancer is small and confined to the site of origin. It is best suited for certain type of cancers such as, breast cancer, head and neck cancers, early cancers of the cervix and lung, many skin cancers, soft tissue cancers and gastrointestinal

**Radiotherapy:** Radiotherapy has become the pre-eminent form of cancer treatment since the beginning of this century and now it is used for fifty percent of patients. Improvements in radiotherapy equipment, technique and applications, have led to an increasing role both in local treatment and also in its use as a whole-body treatment, as part of bone marrow transplantation techniques for leukaemia and other malignant diseases. (http://www.tatamemorialcentre.com/cancerinfo/cancer/cancer.htm#treat dated 29th Dec 2010)

**Radiation** is a special kind of energy carried by waves or a stream of particles originating from radioactive substances and delivered by special machines. These radioactive x-rays or gamma rays can penetrate the cell wall and damage the nucleus of the cell which prevents growth and division of cells. This also affects the normal cells but these cells recover more fully than cancer cells. (http://www.tatamemorialcentre.com/cancerinfo/cancer/cancer.htm#treat dated 29th Dec 2010)

**Chemotherapy** uses drugs which interfere with the growth and division of malignant cells. Once the drugs are administered, they circulate throughout the body. It is advantageous over surgery and radiation for treating cancer that is systemic (spread throughout the body). Chemotherapy is very useful in treating cancers like leukemia, lymphomas, testicular cancer. Chemotherapy can be given as the primary treatment, or following surgery or radiotherapy to prevent reappearance of cancer.

The side-effects of the chemotherapy include nausea, vomiting, hair loss and fever, which are temporary and completely reversible. Hormone therapy has limited use in cancer treatment since only a small minority of tumors are hormone sensitive e.g. breast and prostate cancer. This therapy provides systemic means of treatment, i.e. to the whole body, but without the side effects of chemotherapy. It is misconception that all cancers are incurable. Current methods of treatment are effective for many cancers. A large number of cancer patients are cured and more patients could be cured if their cancers were detected early and treated promptly (http://www.tatamemorialcentre.com/cancerinfo/cancer/cancer.htm dated 28th Dec. 2010)
**Immunotherapy:** Immunotherapy is treatment that uses body's own immune system to help fight cancer. (http://www.cancer.org/Treatment/TreatmentsandSideEffects/TreatmentTypes/Immunotherapy/index dated 1st Nov 2011).

**Hormone therapy:** Hormones are chemicals produced by glands, such as the ovaries and testicles. Hormones help some type of cancer cells to grow, such as breast cancer and prostate cancer. In other cases, hormones kill cancer cells, make cancer grow more slowly, or stop them from growing. Hormone therapy as a cancer treatment may involve taking medications that interfere with the activity of the hormone or stop the production of the hormones. Hormone therapy may involve surgically removing a gland that is producing the hormones. (http://cancer.stanford.edu/information/cancerTreatment/methods/hormone.html dated 1st Nov 2011).

Immunotherapy and Hormone therapy are used generally for adult cancer patients.

**Global Burden of cancer:**

As per the American Cancer Society, it is estimated that there will be worldwide 12 million new cases in 2007. Of which 5.4 million will occur in economically developed countries and 6.7 million in economically developing countries. The corresponding estimates for total cancer deaths in 2007 are 7.6 million (about 20,000 cancer deaths a day) 2.9 million in economically developed countries and 4.7 million in economically developing countries. By 2050, the global burden is expected to grow 27 million new cancer cases and 17.5 million cancer deaths simply due to growth and aging of population. (http://www.cancer.org retrieved on 31st Dec 10). “Of the 2 to 2.5 million cases of cancer in the country over 70% of cases are detected late and report for treatment in very advanced stages. The emphasis on early detection would go a long way to dealing with the large numbers as well as to mitigate avoidable suffering and a financial burden” (http://www.tatamemorialcentre.com/misc/aboutus.htm#cp retrieved on 10th Aug 2011).

“Worryingly, it is not only in the number of new cases that will increase, the proportion of new cases from the developing world will also rise to around 70%. The magnitude of the problem of cancer in the Indian sub-continent in terms of sheer numbers is the most alarming. From the
population census data for India in 1991, 609,000 new cancer cases were estimated to have been diagnosed in the country. This figure had increased to 806,000 by the turn of the century. The estimated age standardized rates per 100,000 were 96.4 for males and 88.2 for females. The most common cancers found in males were cancers of the lung, pharynx, oesophagus, tongue and stomach while among females cancers of the cervix, breast, ovary, oesophagus and mouth were common” (Bobba and Khan, 2003).
Table 1: Average Annual Number (AAN) of cases of cancer* and cancer incidence rates standardized for world population (ASR) in children 0 to 14 years of age†

<table>
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<th>Population based cancer registry</th>
<th>AAN**</th>
<th>% of all cancer</th>
<th>ASR††</th>
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<td>119</td>
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<td>51</td>
<td>59</td>
<td>1.6</td>
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*All neoplasms with a behavior code of '3' as defined by the International Classification of Diseases - Oncology, (3rd edition) and ICD 10 disease codes C00-C75 and C81-C95. †Data derived from the reports of the Indian Council of Medical Research, National Cancer Registry Program[16,18]. ‡These cover 4.3% of India's population and 0.5% of the geographical area. §Ahmedabad District other than Ahmedabad Urban. ‖North East comprises six PBCRs - Alizaw District, Dibrugarh District, Kamrup Urban District, Silchar Town, Imphal West District, and Sikkim State. **Average annual number calculated for Bangalore, Barshi, Bhopal, Delhi, and Mumbai PBCRs for period 2001-2003, for North East PBCRs for period 2003-2004, and for Ahmedabad for period 2004. ††Expressed per million children per year.
Cancer in Children:

Generally cancer is considered as the disease of adults. In England only 0.5% of all cancer occurs in children less than 15 years of age. However in India this proportion appears higher at 1.6-4.8% with variation across place of residence (Arora, Eden and Kapoor, 2009). The prevalence of cancer in children is increasing steadily. According to the International Union Against Cancer (2008) an estimated number of 160,000 children around the world are diagnosed with cancer every year, (retrieved from nationalchildrenscancersociety.com/page.aspx?pid=463 on 31st Dec.10). The exact number of new cases is probably much higher, say experts, because this data is not recorded in many countries. As per the cancer facts and figures of American Cancer Society (2010) 10,700 new cases are expected to occur among children aged 0 to 14 years in 2010. Childhood cancers are rare, representing less than 1% of all new cancer diagnosis. An estimated 1.340 deaths are expected to occur among children aged 0 to 14 years in 2010, about one-third of these from leukemia. Although uncommon, cancer is the second leading cause of death in children, exceeded only by accidents (retrieved from http://www.cancer.org/acs/groups/content/@epidemiologysurveilance/documents/document/acspc-026238.pdf on 1st March 2011). As per the Medical Record of Tata Memorial Hospital, approximately 20,000 patients are registered in a year. 5% of the total registered patients are paediatric patients (Joshi, 2010, personal communication).

“The diagnosis of fatal illness in a child strikes at the very core of what it is to be a parent. The role of a parent as a nurturer and protector is fundamentally challenged by the development of a condition over which they have no control. For parents, transition to ill health may be viewed as loss, the loss of the healthy child and all the hopes, dreams and aspiration that go with it” (Hynson, 2006:21). The parents of cancer affected children undergo a variety of experiences, including psychological challenges, illness related and other issues. The side effects, anticipated poor prognosis and chances of relapse add distress to the parental stress level. Cancer is considered as a disease which affects the whole family and not just the person. The entire family goes through a whole spectrum of psychosocial issues. The daily functioning of the entire family is affected because of the diagnosis of cancer and its treatment. To accept the painful diagnosis of cancer and act on it positively becomes the challenge. Financial, emotional, psychological, physical and spiritual burden creates stress. Inadequate resources, lack of support system are few
of the factors which add to the existing stress. They take a while to adapt to the new life event and maintain the equilibrium by accepting the new roles in the life. “Most commonly, stressors are defined as those life events or occurrences of sufficient magnitude to bring about change in the family system” (Hill, 1949 cited from McCubbin et al.1980).

“Of the 2 to 2.5 million cases of cancer in the country, over 70% of cases are detected late and report for treatment in very advanced stages” (http://www.tatamemorialcentre.com/misc/aboutus.htm retrieved on 16th June 2011). Such cases with reasons such as reporting in advanced stage to medical practitioners, recurrence of disease, no regular follow up, inability to complete the treatment can make the option of cure difficult to achieve.

Few of the children either reporting late or not responding well to the treatment protocol reach advanced stage of cancer. After awareness of the advanced stage of disease of their child, it becomes hard for parents as the entire focus of treatment changes from cure to care. The researcher has experience of working with children with advanced stage of disease and their parents at Palliative Care Unit of Tata Memorial Hospital as a counselor. The researcher has observed that anticipated loss, fear of unpleasant physical symptoms, possible short life span of the child disturbs the parents. Children from outside Mumbai, generally wish to go back to their family. In this situation, parents and other family members also show their keenness to bring the child back to their home. But at the same time they are scared to take the child away from the hospital. If they have to move to a place which is a remote village having minimal access to medical facilities, then they start worrying about the management of anticipated physical symptoms. So the dilemma in choosing the option of returning to their native place and being away from the treating hospital creates great amount of uncertainty.

As and when the child does not respond to the curative treatment of cancer then symptomatic medication remains the only option. At this stage of disease the focus of the treatment changes drastically. Symptom control and looking after the child in a holistic manner becomes the primary aim of the treatment protocol. The psychological, emotional, social and spiritual needs are considered as important as physical needs. Palliative care approach recognizes the unique needs of the children in the terminal stage of disease in a holistic manner. The needs of the parents are also recognized. It is difficult for parents to watch a child in pain helplessly. “The
death of a child is considered as one of the greatest stresses a parent can experience. It has been suggested that death from childhood malignancies is more stressful for parents than death due to other chronic diseases” (James and Johnson, 1997:83).

According to the experience of researcher, each individual has his/her own coping strategies to deal with the event of having a child with cancer. To accept the diagnosis of cancer in a child is generally a difficult moment for the parents. Their reactions to such a life event differ from person to person. “To date, no study has explicitly tested whether the normal course of adjustment to a natural death progresses through stages of disbelief, yearning, anger, depression, and acceptance” (Maciejewski et al. 2007:716).

Along with diagnosis related stress, parents go through other difficulties. Factors like accessibility of medical services, availability of funding required for the medication, hospitalization and other disease related needs, emotional support from family, community, friends and work place also determine the regularity in treatment follow up along with medical compliance. The patients who come from another city/village go through a different set of problems. Searching for a place to stay in an unknown city becomes a major difficulty. It is seen by the researcher that the child who is used to home cooked food does not enjoy outside meals. The different language and different culture of a new place and using local conveyance pose as additional stressors. Generally treatment for cancer needs a long duration. Being away from one’s home and family members may affect coping adversely. It is observed through the experience of the researcher that additional expenses for stay for a long duration along with costly medication for treatment become difficult to manage. Most of the patients are helped by different Charitable Trusts in Mumbai but to access them in an unknown place, and apply for aid becomes difficult for them. They lack the human-power for assistance as their family members and friends stay at the native place. So to manage the frequent hospitalization of child, mobilization of funds, getting adjusted to new place becomes a complex task with its own set of concerns and worries.
**Brief introduction of Palliative care**

The definition of palliative care is “an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for family and includes the management of distressing symptoms, provision of respite and care through death and bereavement” (cited from Lenton, Goldman, Eaton and southall, 2006).

The word ‘Palliative’ is derived from ‘pallium’, the Latin word for cloak, and reflects the fact that, when the underlying disease cannot be cured, it is often possible to ‘cloak’ the symptoms – such as by ‘cloaking’ pain with analgesics and so on (Twycross, 2003). The difference in curative treatment and palliative treatment is the approach towards disease. Palliative care aims towards comfort than cure. It is the technical term for comfort care at the end of life. Pediatric palliative care is the support system specifically for recognizing, acknowledging and addressing the felt needs of children as well their parents.

The palliative care support system follows these principles to provide quality of life to patients in totality:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends to neither hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.
A need based approach is used to help the patients and their care-givers to face and cope healthily. Many factors are responsible for coping. Social support system, family structure, available treatment options, existing unpleasant physical symptoms and their own resilience are the important aspects of parental coping. The types of adaptive measures used by parents or the consequent adjustments are also indicative of coping.

Avoidant strategies may be most effective as an initial response to a stressor when emotional arousal is high and when the situation is uncontrollable. Stressors are defined as those life events or occurrences of sufficient magnitude to bring about change in the family system (Hill, 1949 cited from McCubbin, et al. 1980).

The World Health Organization in 2003 has affirmed that palliative care should be incorporated into the care of all children with cancer, irrespective of geographic location (http://www.whocancerpain.wisc.edu/?q=node/120 retrieved on 9th May 2011).

According to WHO (2003), multi disciplinary team approach can deliver palliative care in the most successful way. Every member of the team puts in the best of their skills and knowledge to provide maximum quality of life to the child at the critical stage of the disease. WHO affirms the preference of the parents to treat the child at home than in hospital; caring in the presence of family members and at their own place. Therefore, pediatric palliative care requires a flexible, coordinated and a multidisciplinary approach. The preference of the child and family members is given importance than the rigid medical protocols. The efforts are towards providing the need based service to the child and parents. According to a recent study on children who die from cancer in England, 52% of children and adolescents and 30% of young adults die at home. This suggests that primary care and community services are critical to the provision of pediatric palliative care services (Higginson and Thompson, 2003).
**Brief introduction of Pediatric Palliative Care:**

“Palliative care for children and young people with a life limiting condition is an active and total approach to care embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for children and support for family and includes the management of distressing symptoms, provision of respite and care through death and bereavement” (Down and Symons, 2006:28).

“All over the world the children are living with and dying from life threatening illnesses in a wide variety of social, economic and health environment. Pediatric palliative care with its broad approach to symptom management, psychosocial, spiritual and practical care has the potential to help enormously in the care and relief of the suffering of these children and their families, particularly as it is inexpensive and low-tech” (Lenton et al. 2006:3). It is very clear that the approach is towards care and not cure. The unique feature of this relatively new branch of medicine is to provide care in totality which tries to encompass different aspects offering comfort to the patient as well as care givers. This is person centered approach of providing symptomatic treatment.

According to the experience of researcher, the needs and expectations of the patients of any age suffering from a life threatening condition are almost the same. Anticipated worry, fear of unknown, current physical symptoms and concern for family is common across all age groups. The disease related symptoms are treated when there is no hope of cure. It is essential to understand the similarities as well as differences in the caring approach adopted by the palliative care concept towards caring for adults and children.

As described by Lenton et al. (2006), the common features in both adult and children’s palliative care includes ,

- threat to life
- impact of symptoms on activities of daily living
- emotional impact
- distress to family
- need for a co-ordinated agency approach.
There are however, significant differences.

- Death in childhood is relatively rare in well resourced countries.
- The range of illness is different- wide range, often rare, often genetic, serious learning difficulties are common, varied time course and crisis can be rapid and unpredictable.
- Developmental factors influencing physiology and pharmacokinetics fluid, nutrition, choice of medication, doses and side effects.
- Developmental factors influencing cognitive and emotional understanding, special skills in communication, assessment, art, music, play, education.
- Family care, working alongside parents as primary care givers, parent education, parent support, siblings, grandparents.

As per Lenton et al. (2006), the four broad groups of children which have been delineated are those with,

1. “Life threatening condition for which curative treatment is feasible but can fail. Children in long term remission or following successful treatment are not included (cancer or organ failure)
2. Condition where premature death is inevitable, where there may be long periods of intensive treatments aimed at prolonging life and allowing participation in normal activities (Cystic fibrosis)

3. Progressive condition without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years (batten disease, mucopolysaccharidoses)

4. Irreversible but non progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death (cerebral palsy)

The above mentioned four categories discuss the different types of groups of children with a range of diseases. Some of them fall into life threatening or life limiting or irreversible diseases. Few genetic or progressive diseases also are included in the list seeking symptomatic care. It is essential to provide care to children so that they can live their life with maximum degree of quality. Life threatening diseases like cancer or organ failure demand the holistic care. Administration of good palliative care to the child in the terminal stage of cancer helps to lead an improved quality of life.

From the above discussion it can be summarized that the diseases which proves a threat to life and disturb the quality of life should be supported by providing palliative care. This approach helps them and their care givers to deal effectively with the life event.

The current study will focus on the issues faced by the parents of the children with terminal stage of cancer. “There is no easy way for parents to learn that their child is seriously ill. Their sense of shock, numbness and disbelief is much like the experience of bereavement, of mourning for the loss of the healthy child they had known or hoped for. Denial, anger, guilt and despair in varying degrees may all play a part in this initial period. A sense of isolation and loneliness may also be experienced” (Lewis and Prescott, 2006:160). “The diagnosis of childhood cancer and its treatment can be devastating for patient and family. Early psychological assessment of their ability to master tasks relative to the stage of the disease, their socioeconomic vulnerability, the degree of psychopathology and coping capacity, the cohesiveness of the family unit, and personal or family history is crucial to our ability to anticipate problems” (Adams-Greenly,
1986). The purpose of the study is to understand the linkage between coping strategies adopted by the parents while dealing with the significant life event.

The researcher has worked as a counselor for the past eleven years with cancer patients. Her job profile involved counseling the patients as well as the care givers and conducting the support groups for them. The researcher has acknowledged the special needs of the ill children and their care givers.

To highlight the learning from the eleven years of experience it is essential to mention that needs, stress and coping differ from person to person though they suffer from the same disease. It is difficult to see a child suffering from life threatening disease like cancer for the parents. They feel helpless when the child progresses to the advanced stage of disease. During the counseling sessions of parents and diseased children, she could understand their need to acknowledge their psychological pain. The coping strategies adopted by them to deal with this life event varied from person to person. Many demographic factors like age of the patient, gender, type of family structure, number of siblings, socio-economic status of family affect the coping of the family. Other factors like availability of support system, resource management capability, access to information and treatment, cooperative work atmosphere, pattern of interpersonal relationship were noted as important factors that determine their need and coping. Along with these above mentioned factors, the person as an individual has his/her own internal strength or ability to deal with the significant life situation. Care givers go through the range of psychological reactions like guilt, denial, shock and anger. Resilience of patient varies as per their age, understanding, interpersonal relationship, communication within the family members. Parenting style, parent’s childhood patterns are also significant key factors. The relationship of parents as a couple also determines the coping. Supportive, complementary relationship helps to create the warm atmosphere to face the difficult life event.

The above mentioned observations are drawn from the clinical experience of researcher. However these need to be validated through a scientific study of lived experience. Efforts will be directed towards exploring if the above mentioned factors affect the overall resilience. Parenting style, the role of parents in the life of child will be understood in the light of the overall coping process.
**Concept of Stress:**

As per Websters dictionary (2009) stress is “physical, mental or emotional strain or tension – a situation, occurrence or factor causing this”. Generally strain is considered as a resultant effect of external stimulus. Selye (1957) defines stress as “stress is the non specific response of the body to any demand made on it’. Even though every demand made on the body is specific, all of them have the increase in demand for readjustment for performance of adaptive functions which re-establish normalcy in common. In that case response is non-specific. This concept of non specificity is explained better by Selye after he noted his observation of a group of symptoms common to all sick people. General Adaptation Syndrome (GAS) in Selye’s model is to describe the biological reaction of an organism to a sustained and unrelenting stressor. It is important to understand that the different people respond in different ways though each individual is exposed to a similar or same type of stress. The parents of the cancer affected children respond in a different way though they have the same issue to face. Few take this life event as challenge and few break down. The above mentioned theory of Selye cannot explain the psychological stress as the theory is based on the physiological reaction premise.

If we look at the parental stress in the light of cancer affected children, the responses of parents fall under the realm of general adaptation syndrome. After the initial shock and counter shock phase, the efforts are towards finding a balance and minimizing distress. The type of stress, duration of stress affects the overall family equilibrium. When the resources are inadequate then an unpredicted event creates crisis. Chronic strain is persistent objective conditions that require continual readjustment, repeatedly interfering with the adequate performance of ordinary role-related activities (Pearlin et al. 1981 cited from Wallander and Varni, 1998).
**Stress in the context of family issues** is defined by McCubbin in 1980 as “not the event itself but a function of response of the distressed family to stressor and refers to the residue of the tensions generated by stressors which remain unmanaged”. Stress has generally been viewed as a set of neurological and physiological reactions that serves an adaptive function affecting overall equilibrium (Franken, 1994). Stress is viewed as a failure in adaptation. If the demands of the given event at that moment are not attended to then stress is experienced.

**Burr model of Hill’s ABCX Model (McCubbin, 1980)**, depending upon amount of change or type of crisis, family becomes vulnerable. But overall adaptability or regenerative power of the family varies from family to family. The capacity of family and family members to adapt to the given situation determines the regenerative power.

**Cognitive activation theory (Eriksen, 2004)** of stress defense and coping are distinguished phenomenon. Coping in this theory is defined as positive outcome expectancy (Ursin and Eriksen, 2004). Cognitive formulation of stress is a model in which Brown (1980) talks about the cognitive activities between stressor and the behavior opted by an individual. Parents expect to offer a good sound healthy life to their children but when these expectations are not likely to be fulfilled because of the poor prognosis of cancer then stress develops. In such condition, the way parents perceive the event is important. Few take this as a challenge and few consider them as victims of life’s situations. Uncertainty related anxiety, worry, concern for the child and helplessness are experienced by parents. At this point, they take their own decision. This decision is based on their available resources, capabilities, ability to adapt or adjust to restore the equilibrium. Few parents under stress think and try to focus on problem, find possible solutions as per the available resources and act accordingly. Few feel helpless and start blaming self, family, situation and even God sometimes. The study is to understand the stress related behavior of the parents and the strategies they adopt to cope.
Concept of Coping:

“Coping is cognitive and affective response to the stressful situation” (Folkman and Lauzarus, 1984). Lazarus emphasized 2 types of appraisal. 1. Primary appraisal and 2. Secondary appraisal.

1. Primary appraisal: Evaluation of the significance of a stressor or threatening event. This evaluates potential threat. At this stage, constant evaluation of the risk to the self, relationship, resources takes place.

2. Secondary appraisal: Evaluation of the controllability of the stressor and a person’s coping resources. At this stage, the process of ‘how to react?’, ‘if to react?’ ‘at what time to act?’ starts. The evaluation of existing and potential resources is carried.

For the parents to face the diagnosis of cancer, awareness of poor prognosis, resource constraints, frequent hospitalization and aggravated physical symptoms of the child pose as stressors. To face the complex life event parents adopt a certain coping strategy. Problem solving ability, mobilization of possible resources and cognitive ability are few of the factors of an individual determining the coping.

According to Freud’s psychoanalytic theory, defense mechanism is also coping used to distort reality to manage the distressing feelings. Many parents try to guard themselves as well as the child from the bad news. They try to adopt the mechanisms that help them run away from the life situation. Denying the reports, questioning the usefulness of the treatment protocol are few of the factors used as the coping strategy.

Transactional model of stress and coping (Lazarus and Folkman, 1984) pays less attention to ‘good’ coping or ‘bad’ coping and emphasizes on how the situation is judged. This may be a challenge for few and threat for others. The action or behavior of a person depends upon the given situation. The action changes as the threat changes with time as an ongoing cognitive behavior (process). Successful coping depends upon the context and environment relationship. Few individuals who adopt problem focused coping try to define problem and generate ways to solve it. They can think rationally about the cost and benefit and accordingly action is taken. This evaluation is ongoing process. Many parents look at the issue very practically and try to deal with it in the best positive manner. In short focus is not on “poor me” but on “let’s fight and
win”. Those who focus on emotions try to reduce their stress by adopting the measures like distancing, avoiding, selective attention, blaming, venting emotions and seeking social support (Lazarus, 1984).

In the given context of study, it is observed by the researcher that parents try to run away from situations, they cry, blame themselves, others and even God. They blame past life, bad deeds done by them, sins and so on. “Coping is inseparable from life strain experienced by people and from the state of their inner emotional life” (Pearlin and Schooler, 1978:3). Some parents perform better under stress. Anxiety which is an emotional experience is not same for all. As per anxiety-trait theory, people who are high on trait will show greater anxiety under stress (Bolger, 1990). Few of the parents of ill children feel that their capacity to perform is improved during the difficult span. They take the control of situation and not let the event drive them. They revise the coping strategy and they are flexible to change as per the demand of the situation. The stress does not stop them but helps them perform with the maximum ability.

**Cognitive coping (McCubbin, 1980)** strategies refer to the ways in which individual family members alter their subjective perceptions of stressful situations. Many factors determine the coping at a given life situation. The ability of networking, process of managing family resources or resource exchange helps them look at the situation in a more manageable way. The problem solving capacity of an individual helps as a tool to fight positively. Coping of an individual is by altering the subjective perceptions of stressful event or by manipulating social environment or by changing stressful event. The coping strategy helps them to decrease the presence of vulnerability factor by strengthening the family resources. Automatically this results in reduced stressor event or hardship. They feel empowered as they are actively involved in changing their environment (McCubbin, 1980). A few of the parents have ability to gather material and material help, to tap useful resources. They help themselves to get support from various sources. Such people believe in putting their efforts to solve the immediate problem. For example, when the child needs expensive medication at curative phase of treatment, they work to network with charitable trusts than worrying about other issues. To focus on one thing at one time help parents to deal effectively with stress.
The parents having cognitive control think rationally and act accordingly. They prefer to discuss, gather information and take decision suiting the current event. The researcher in her experience has witnessed the parents sharing the knowledge with other caregivers to help each other.

**Process oriented approach of coping** ((Lazarus, 1993) believes that there is no good or bad coping. What a person does depends upon the situation and the action changes as the threat changes with time. This process is an ongoing cognitive process. Generally 2 ways of coping are witnessed, 1. Problem focused and 2. Emotion focused coping.

Few of the parents adopt the problem focused coping. They begin with defining the problem. They constantly try and think over the possible solutions to the problem. The cost and benefit ratio of problem and possible solution is evaluated at every point. According to the situation they take the decision. The constant efforts are towards solving the problem. It is observed by the researcher that parents tend to partition or break the problem and try to focus on part by part. The process is generally ongoing and they keep trying different alternatives.

In emotion focused coping, the efforts are towards decreasing emotional stress, distancing, avoiding, selective attention, blaming, wishful thinking, venting emotions or by seeking social support (Lazarus, 1984). Few of the parents try to help themselves by crying, sharing, blaming, denying and so on. This is a way to cope with the situation by adopting the emotion focused coping.

At this point it is important to understand that every individual tries to interpret their environment to maintain a positive self-image. Human beings have a tendency to attribute success to their own intelligence and efforts. The failure is attributed to the factors which are beyond human control like bad luck and destiny (Weiner, 1972). In order to truly understand the components of the stress process, the primary focus should be on how individuals interpret objective conditions rather than simply relating stressors to strains.

Few of the parents go back to their old habits like alcohol, excessive smoking and so on. They consider this behavior as the way to cope with the situation. The researcher has observed this in few cases. Parents consume alcohol as helps them face the life crisis. When male care giver opts to consume alcohol, female care givers hardly object to their behavior. According to them, “if these habits are helping them to cope with the difficult situation, then how can we object?” But at
the same time they admit that their entire family experiences the additional stress because of this. Excess financial burden and disturbed family atmosphere adds to the existing burden of stress. “Certain coping strategies result as additional source of stress” (McCubbin, 1980). They can damage the family system directly or indirectly.

**Parenting style:**

“Parenting may be defined as purposive activities aimed at ensuring the survival and development of children. It derives from Latin verb ‘parere’ to bring forth, develop or educate” (Hoghughi, 2004:5). Firstly models of parenting have evolved from exclusively from person centered to ecologically based views that consider how certain circumstances or contexts contribute to parenting (Belsky, 1984). Secondly model has progressed from unidimensional to multidimensional paradigm, which takes into account the complex interactions among the elements (Belsky, 1984). Then thirdly models have progressed from a focus on parents as the sole agents of socialization to a focus on the joint contributions of parents and children (Belsky, 1984).

Parenting is a complex activity in which specific behavior is less important than broad patterns of parenting. Child’s behavior/outcome is influenced by specific behavior of parents individually and together. Rather than a linear combination of responsiveness (warmth) and demandingness (control), each parenting style is more than and different from the sum of its parts (Baumrind, 1991; Weiss & Schwarz, 1996; Miller et al. 1993 cited from Darling, 1999). Many factors like interpersonal relationship patterns, openness in relationship with parents are significant factors.

Learning Model (Darling, 1993) emphasizes on the behavior of parents than attitude. The parents who report experiencing low levels of nurturance during their childhood have been found to sanction the use of physical punishment. Similarly greater rejection in their childhood produces higher negative affect toward their own children (Belsky, Herzog, & Rovine, 1986; Belsky, Youngblood, & Pensky, 1989 cited from Bluestone and Tamis-LeMonda, 1999). The parents who had positive and secure relations with their mothers during childhood are likely to be responsive to their infants, and their infants are more likely to be securely attached (Gara, Rosenberg, & Herzog, 1996; Main & Goldwyn, 1984 cited from Bluestone and Tamis-LeMonda, 1999).
Warm caring parents create a healthy family atmosphere resulting in open discussion regarding disease or disease related issues. Sharing and open communication helps both (child and parents) to cope better. If a disturbed and disrupted relationship exists because of the parental withdrawal and rejection then anxiety, depression or any other somatic complaints may be observed. Overt behavior problems can interfere with positive coping.

**Applying theory to this study:**

**Transactional Model of stress and coping:**

As the Transactional Model, suggests the stress is neither in the person or the environment but a product of their interplay. Stressors are demands made by the internal or external environment that upset balance, thus affecting physical and psychological well-being and requiring action to restore balance (Lazarus & Cohen, 1977). The Transactional Model of Stress and Coping is a framework for evaluating the processes of coping with stressful events. Stress can be thought as resulting from an imbalance between demands and resources or as occurring when pressure exceeds one’s perceived ability to cope (Lazarus & Folkman, 1984).

In the current study, declaration of poor prognosis of cancer of the child is the stressor for the care givers and this is completely unexpected. This event creates an imbalance in all aspects like emotional, psychological, social as well as financial. The individual is not prepared for this and it comes as a shock. As a result, it affects the physical as well as psychological well-being of the care giver. Helplessness attached to the current physical condition of child and non-availability of the curative treatment gives rise to excessive stress. “Parents consider themselves to be responsible for their children and their children’s health”(Clarke and Fletcher, 2003:188). Parental awareness of poor prognosis of their child takes away the ray of hope of cure.

The experience of the researcher has revealed that the parents are not prepared to listen to the bad news about the poor prognosis of the child, failure of the treatment protocol or advanced stage of the current disease and this create more stress. The parents undergo multiple transitions during this period. To accept non-curative nature of disease and face the anticipated loss of the child’s life becomes the challenge for them. The situation becomes uncontrolled and helplessness
increases. Then the interplay between the unexpected, uncontrolled environment and the person ensures. The response of the care giver to the similar event is different. The resultant of the interplay of event and person is responsible for the level of the stress.

Second point which is observed frequently is the imbalance between the needs of resources (material as well as non material resources) and the available support system. To be equipped with the needed resources help the parents better with the situation. Few of the care givers do not have access to the resource system. Basic needs like shelter, food, clothes and local transport facilities become additional distress for the families coming from other places. To witness the child in pain and to accept inability to provide comfort produces guilt and which results in stress. The Medical Social Work Department of Tata Memorial Hospital and other Non Government Organizations try to help the patients by arranging for basic needs like food and temporary shelter. Few of the parents do not approach social work department after their registration or do not maintain regular follow up visits with social workers. Few of the reasons like, being engrossed with physical discomfort of the child or busy handling hospital and other responsibilities keep them away from these important resources. As a result, they spend more time and energy to get adjusted with the resource scarcity.

In the first type of coping an individual tries to work on his/her feelings and emotions. It observed that some care givers fight the situation with strong will power and try to eliminate their negative feelings. They are very positive about their success. Their strong determination to fight with the cancer is considered as the challenge. They struggle hard to prove their capability. It is observed that they try and select the different measures like spiritual/religious belief/value system, getting family/social support, by improving inter personal relationship and ventilating the distressing feeling. The direction of the thought process is influenced by the positive emotions. “I will and I can” is the strategy used by the care givers to face the stressful event in this type of care givers. A few care givers pray and get the strength to face the event. Few choose to ventilate their fear, concerns, needs and worries. The catharsis of negative feelings makes them strong. Few of them are observed to have such experiences in the past.

Each one has his/her experience as a child. Parenting style of an individual is seen to be influenced by these childhood memories. The way they were reared affects their current
parenting. It is observed by the researcher that the parents, who had warm experience as a child, tend to offer a comfortable atmosphere. They encourage open discussion within family.

One more observation is noted by the researcher. The parents, who had experience as a caregiver of the cancer patient, can handle the similar situation with better confidence. The knowledge they gathered while caring for the patient in past helps them to cope with the disease of the child. Their awareness regarding disease or possible side effects of therapy is observed to be better. The knowledge helps them to cope effectively as their knowledge reduces the anxiety.

The experience of cancer survivors helps parents to create perception about cancer. Patients leading disease free life/survivors become role models for parents. Parents initiate discussion on issues such as side effects of therapy, how they managed financial burden, other factors that helped them to cope.

The second category of caregivers try and explore possible ways of treatment. Their efforts are towards finding answers to the situation. Generally their efforts begin with the focused thought processes. Then the different ways to achieve the goal are planned. They try and find different available resources and all possible helping hands. Different options are tried and tested. Those might be finding different medical expert or different alternative medical treatment options like Ayurveda, Homeopathy, Unani and so on. They try to get access to internet or books to understand the situation clearly. They initiate discussion and try to explore the options. Their efforts are towards understanding the situation and finding the solution to that. They think rationally and anticipate the future condition. Few of the parents get busy discussing with other caregivers. They try to accumulate and understand their experiences and learn from them. They prefer multiple treatment options and they take initiative in discussing with medical professionals, nurses, other health professionals and try to gather information even through files. They feel strong as they are equipped with information. The process of coping is ongoing as per the demand of the situation. The strategy to cope varies as the situation changes.
**Theory of learned helplessness (Seligman, 1975):**

According to this theory when the failure is attributed to internal factors, individuals develop more helplessness. If this type of attribution remains stable for a longer time then the helpless is severe. The lack of control over the situation is observed. The interplay of cultural belief, value-system; faith, karma and destiny are noted by the researcher in her experience. The tendency to blame the unknown is observed. Few of the parents consider this situation as a punishment to them by the Almighty God. According to them their misbehavior from this life or from the last life is responsible for the current event. They try to recollect their behavior in the past and judge themselves. Behavior like hurting someone, especially parents or siblings is generally recalled. Deviation from the social norms creates guilt in parents. The current situation is viewed as the punishment for their misconduct. They feel ashamed of their behavior. The guilt which they carry results into helplessness. Harassing old parents, misconduct with other family members, misbehaving with neighbors or community, cheating or robbing others are generally considered as the reasons to be punished by God. It is noted by the researcher that the moment they realize their mistakes, they decide to work on those mistakes and correct it in the future.

They attribute this phase to the ‘karma’. The questions which have no answers are answered only with one word “karma”. The entire event is attributed to “God’s wish”. Destiny is considered as the ruling factor and the individuals accept that they have no control over it.

Few caregivers attribute this difficult stage of disease to their decision. They feel responsible for the child’s condition. Selection of wrong medical expert or starting the late treatment, or consuming more time in home remedies are the common factors which they attribute and take the responsibility of the same.

Few of them blame their own child care patterns. Few female parents blame their cooking patterns; type of their motherhood, irresponsible behavior. The caregivers feel guilty and blame themselves as they take sole responsibility of condition of the child. They feel lonely; get depressed as the helplessness is the dominant feeling in the entire process. They become more vulnerable as they blame themselves, feel guilty, depressed and helpless.
Model of Parenting

Parents feel responsible for the well-being of the child. The warmth and control are observed as two elements which parents use to rear their children. Rather than a linear combination of responsiveness and demanding-ness, each parenting style is more than and different from the sum of its parts (Baumrind, 1991). To see the child in pain or being diagnosed with life threatening disease like cancer is considered as their own failure.

As per the Learning Model (Darling, 1993) the emphasis is on the behavior of the parents than attitude. It is noted by the researcher while working with the cancer patients that children are very much vigilant about the overall behavior of their parents. The way parents react to the diagnosis of the cancer of their children or the behavior and even the change in the behavior is observed carefully by the parents. Most of the children mention about the changes in the behavior of the parents towards children after the diagnosis of the cancer. The level of warmth is experienced more and demandingness of parents is minimized. The efforts are toward making the child happy so the discipline is kept apart. Enforcement of rules is reduced than earlier.

Conclusion:

Cancer is the name given to the group of diseases. This disease is for all age groups and gender. Different types of cancer need different types of treatment options. Generally the treatment protocols are expensive and needs a long duration. Patients go through moderate to severe side effects. Number of cancer cases is increasing globally. There is considerable increase in the number of pediatric cases.

When the child is diagnosed with the life threatening disease like cancer then the entire family goes through a spectrum of emotional, psychological, social, and spiritual burden along with financial and physical stress. In few of the cases when the cancer reaches the advanced stage or the body does not respond to the curative treatment. In such a condition, the child needs symptomatic care which is recognized as the palliative care. The approach of this type of treatment is to provide holistic care to the child and the parents. The need based care is provided by involving the child and parents in the decision making process. Each individual has his/her own way to cope with the difficult situation in the life.
The parents react to the similar situation in different manner. Anger, depression, denial, bargaining and acceptance are the stages which are observed in the fluid form. The factors like age of the child, gender, number of siblings, structure of family, physical discomfort, stage of the disease at the time of diagnosis, availability of resources, financial condition of the family, other responsibilities of the parents, access to the medical treatment are few of the factors determining the overall coping of the parents. The age, understanding level of the child regarding the disease, interpersonal relationship with the family members and openness within the family members are few of the factors influencing coping of the children which affect the parental coping. They adopt different types of coping strategies which they feel are suitable for the given situation. The physical condition of the child and life limiting condition increases the warmth in the relationship and the efforts are made toward making the child happy.