CHAPTER 2

What is not in the open street is false, derived, that is to say, literature... Henry Miller

Literature Review

This chapter aims to draw knowledge from the existing literature. The efforts are towards summarizing the empirical knowledge from studies conducted in different geographical contexts. The work done by health professionals focusing on needs and concerns of the parents of a child suffering from terminal stage of cancer and the methodology used for the same will help to understand the existing knowledge available in the field of cancer and also explain gaps in this literature. This review of studies is organized under following themes.

1. Global and Indian scenario of palliative care service
2. Experiences of cancer by patients and their care givers
3. The child’s perspective of the illness and its needs and concerns
4. Psychosocial, emotional, spiritual aspects of cancer
5. Role of professionals
6. Social support
7. Parenting styles

2.1 Global scenario of palliative care service:

Sepúlveda et al. (2002) describe the contribution of WHO (World Health Organization) to the development of palliative care. According to authors, “tens of millions of people worldwide are affected by life threatening illnesses such as HIV/AIDS and cancer, which cause them and their families’ great suffering and economic hardship. The majority of the cases occur in the developing world where quite often there is little accessibility to prompt and effective treatment for these diseases. The development of palliative care through effective, low cost approaches is usually the only feasible alternative to respond to the urgent needs of the sick and improve their quality of life (P.91)”

In the same article Sepulveda et al. (2002) mention that WHO advocated medication for pain relief, worked on availability of opioid (drugs for pain control) worldwide and published guidelines in various languages. The previous definition of palliative care, the importance or
relevance of this care was for the patients who do not respond to the curative treatment. So it was interpreted as the medication for the patients in the last stage of disease. The present definition emphasizes on applying the principles of palliative care as early as possible for the chronic and eventually fatal disease. The current efforts of WHO are towards spreading awareness about palliative care across the world and advocating it as a global health problem. Policy development, education and training, provision of good quality care (including home care) and drug availability are considered as key components of a comprehensive palliative care program. While describing the barriers for slow growth of this branch of medicine, the authors state that “Despite these substantial efforts and significant progress made in the development of palliative care worldwide in the last decade, there are still important gaps to be bridged. Many countries have not yet considered palliative care as a public health problem and, therefore, do not include it in their health agenda. Several initiatives have developed as “islands of excellence”. These initiatives have not, however, been well integrated into the country’s national health policies and, therefore, have not yet had a significant impact in the population of patients in need of palliative care (ibid.).”

According to study by Wright et al. (2008) palliative care is currently being regarded as a human right. Yet globally, palliative care development is not uniform. Comparative data about the distribution of services are generally unavailable. In total, 115 of the world’s 234 countries have established one or more hospice-palliative care services. Yet only 35 (15%) countries have achieved a measure of integration with other mainstream service providers together with wider policy recognition. Common challenges like the awareness of palliative care and its applicability, funding issues, coverage, access to opioid drugs, education, accreditation and government support impact a country’s rate of progress and level of development.

Clark et al. (2007) assessed the existing palliative care service across the continent of Africa, mapping existing ones and exploring the perspective of palliative care service. Africa is the second largest continent covering 22% of the land surface. The history of hospice development in Africa dates back to the late 1970s, when services first appeared in Zimbabwe and in South Africa. Island Hospice was founded in Harare in May 1979 and had developed 17 regional branches by 1997. In the late 1970s, hospice initiatives also developed in South Africa in
Johannesburg, Port Elizabeth, Cape Town, and Durban. After the start made in these two countries, it was another decade before hospice and palliative care developments began to occur elsewhere in Africa: in Kenya and Swaziland (1990), Botswana, Tanzania, and Zambia (1992), Uganda (1993), Sierra Leone (1994), Morocco (1995), Congo-Brazzaville and Nigeria (1996), Malawi (1997), Egypt (2001), and The Gambia (2004). In South Africa there are 37 organizations that have free-standing hospice inpatient facilities. 8 countries out of 15 with hospice palliative care in Africa have no such facility of inpatient, and in general, there is an emphasis on the development of home care services. The reason for limited development of palliative care stated in the study is the restricted availability of morphine and fear associated with morphine usage. This review of hospice and palliative care developments in Africa highlights the impact of individual, charismatically-led service initiatives, but also reveals some of their limitations. The report suggests that if the enormous needs in Africa are to be met, it will be necessary to harmonize hospice and palliative care with a variety of other structures and to reduce the risk that well-organized small-scale services fail to scale up and achieve wider impact. This requires engagement with the institutionalized health care system, as well as systems of family and community support. It highlights the necessity of palliative care in Africa. The service is provided in the form of hospice care as well as community based care. Every country has its unique need and culture specific provision of health care service which proves to be effective.

As per Brown et al. (2007) Nepal one of the poorest countries, having one third of population under poverty line is putting its efforts to develop palliative care services. In 2002, the Nepal branch of INCTR (International Network for Cancer Treatment and Research) requested help in developing a collaborative program in palliative care. A team of palliative care experts drawn from the United States, Canada, and Saudi Arabia is working closely with the ‘Nepal Palliative Care Group’. The efforts are based on the World Health Organization foundation measures for palliative care focusing on governmental policy, opioid availability, and education. Nepal Palliative Care group believes that home care service is a culturally suitable model of care of this country. A hospice was set up in 2000, and provision of care for palliative patients in hospitals and home care service underline the need of palliative care in Nepal.
Benini et al. (2011) conducted a study in Italy where Italian Parliament has already passed legislation that regulates the provision of palliative care and pain management for adults and children with an incurable illness. The study explores the understanding, awareness and attitude of Italians towards palliative care. 1897 Italians in the age group of 18 to 74, from four different geographical areas of residence (North-West, North-East, Centre, South and Islands) and having different levels of education (5 to 19 years of education) were interviewed. The number of inhabitants in the town (less than 10,000 to more than 10,000) was considered as one of the important factor to access the understanding of Italian population.

As per the study, awareness and perception of palliative care among the Italian population is inadequate; less of 60% of adults had heard of palliative care, but only 7% of them believed that they had a precise idea and another 16% thought that they had an adequate idea of palliative care. The study reveals that the perception of common population regarding this care was that this type of care alleviates pain and improves quality of life of patient. They expect to provide this care at home under the support of professional care givers. The concern attributed towards incurable patients was fear of suffering and death. The concern towards pediatric patients expressed was their separation from family, friends and toys which they face because of their illness. The authors emphasize the importance of palliative care and highlight the need of appropriate intervention to spread awareness among Italian population.

2.2 Palliative care in India

Seamark et al. (2000) discussed the importance of the development of palliative care set up, existing models of care and barriers to such services in India. Deficiencies in disease registration, communication difficulties and social stigma attached to diagnosis of cancer or HIV makes it difficult to estimate the exact requirement of palliative care. Traditional Western model of inpatient service was adopted in India by developing the first hospice, ‘Shanti Avedana’ in Mumbai, Goa and New Delhi. Initially it was not well received in the Indian culture as a hospice was seen as the ‘house of death’. Now the approach towards hospice service is changing. An effective pain management clinic at Trivandrum, Kerala was developed in 1986. Palliative Care Centre at Calicut is a regional service covering half the cancer patients in the district. This Calicut model is a WHO demonstrated project of delivering high quality, flexible, low cost service in collaboration with non government organizations and the government. Legislation is
being enacted in Kerala to simplify the licensing rules of buying, stacking and dispensing morphine. So other centers in Kerala are becoming models of care providing low cost high quality service to maximum number of patients.

The combined inpatient and training centre with the help of a funding from a pharmaceutical company is built in Pune. Seamark et al. (2000), mention that the Cipla Cancer and Palliative Care Centre at Pune, helps patients by admitting them for a short duration and they train the care givers (family members) for symptom management. In the Indian culture to let a person die at home is valued and hence trained care givers can offer them an improved quality of life. The centre organizes training for nursing and medical students in their colleges. This is helpful for these budding health professionals to serve better in the field of patient care. The cultural aspects are specific to various regions and the countries to be considered to develop new projects. Training for professionals and family members is an essential aspect of this care. India needs low cost, flexible and quality assurance care models for Oncology as well as non-Oncology set up. To summarize it can be said that need to attend to special needs of patients and their family members is emerging now in India. The health care professionals are now being trained to help them to deal effectively with the event of advanced stage of disease. Training programmes for multiple health care professionals such as doctors, nurses, social workers, counselors, psychologists, physiotherapists and occupational therapists are arranged; as a result service provision will go beyond metro cities. Considering the Indian culture and values and based on social, religious and regional norms need based services are currently being developed currently.

McDermott et al. (2008) conducted a study to assess the current status of palliative care in India, mapping the existence of services state by state, and documenting the perspectives and experiences of those involved. A multimethod review was used, which included synthesis of evidence from published and grey literature, ethnographic field visits, and qualitative interviews with 87 individuals from 12 states and collation of existing public health data. The review identified 138 hospice and palliative care services in 16 states and union territories. These are mostly concentrated in large cities, with the exception of Kerala, where they are much more widespread. Nongovernmental organizations, public and private hospitals, and hospices are the predominant sources of provision of palliative care services. Palliative care services in 19 states/union territories were not identified. Development of services is uneven, with greater
provision evident in the south than the north, but for the majority of states, availability of service is poor. Barriers to the development of palliative care services include: poverty, population density, geography, opioid availability, workforce development, and limited national palliative care policy. Availability of trained and skilled human power is needed to reach out to more of number of people. Successful models exist for the development of affordable, sustainable community-based palliative care services. These have arisen from adapting Western models of hospice and palliative care for implementation in the Indian cultural context.

According to Rajgopal and Palat (2002) fewer than 3% of the needy have access to palliative care in India. Kerala is one of the most thickly populated states of India having the highest literacy rate. Palliative care is becoming a known entity in this state. It is estimated that at least 15% of the needy in Kerala have access to quality palliative care today, compared to a national figure of less than 3%. The service can be said to have originated in the state of Kerala with the establishment of a pain clinic in the Regional Cancer Center in Trivandrum, the capital of the state of Kerala in 1986. This is one of the few Indian regional cancer centers to have made palliative care a priority. Kumar (2007) also mentions about the enormous progress of palliative care in Kerala. The credit to this progress is given to the network of community initiatives in palliative care in north Kerala. This network, called “Neighborhood Network in Palliative Care,” has more than 60 units covering a population of more than 12 million, and is probably the largest community-owned Palliative Care network in the world.

Koshy (2009) mentioned that “the message of palliative care in India has become a movement in several parts of India in a short span of time. The past two decades have seen palpable changes in the mindsets of health care providers, and policy makers with respect to the urgency in providing palliative care. With a population of over a billion spread over a vast geo-political mosaic, the reach and reliability of palliative care programmes may appear staggering and insurmountable. Nonetheless we have reasons to be proud in that we have overcome several hurdles and presently in a ‘consolidation mode’”. He is sure that every person will get access to good palliative care in short while (ibid).
2.3 Awareness regarding palliative care:

Among health professionals and common population

Sepúlveda et al. (2002) mentions that WHO has always emphasized on education and training for the professionals in the field of palliative care. The survey regarding checking the awareness of palliative care among medical residents was conducted by radiation department at New Delhi by Mohanti et al. (2001). The survey aimed to check awareness regarding palliative care, clinical knowledge, and education and training obtained during residency. The results of the survey concluded that 51% medical residents perceived that the training and skill imparted during the residency course was inadequate. According to this study, cancer care services most often do not meet the challenges of the advanced stages of disease. Cure-oriented approaches place an unnecessary burden on physicians, institutions, patients and their relatives. The budding professionals recommend that pain management, symptom control and alleviation of psychosocial distress should, therefore, form an integral part of training during residency, both for oncology as well as non-oncology clinical disciplines.

Joseph et al. (2009) conducted a cross-sectional study to check the awareness among the common population (lay people) regarding palliative care in Kerala. The senior-most member of the household present was interviewed using a questionnaire. The questionnaire included the questions assessing their awareness regarding palliative care and diseases such as cancer, HIV, heart disease, Central Nervous System disorders and respiratory ailments. If they have heard of this concept then the source of information (news paper, TV, friends, internet, health worker, and others) was assessed. The questionnaire also enquired about their understanding regarding their perceptions of the benefits (prolonged survival, quality of life, both) of palliative care. The preferred setting of care was inquired in the study. The study results showed that the level of knowledge regarding palliative care was significantly high among urban than rural participants. The study area, Ernakulum district has good level of literacy (93.2%) but still the level of awareness regarding concept of palliative care was poor. Most of the participants (53%) came to know about palliative care from news papers followed by television. The health care worker was recognized as a source of information in the rural areas. The preference to get this service at home rather than hospitals was expressed by participants. All the rural participants and 92.1% of
urban participants expressed that the treating doctor should honestly disclose the disease related facts. The marked difference is noted by the authors regarding ‘whom to disclose?’ Majority of rural participants 77.8% preferred disclosure ‘to family first’, while majority of urban participants 78.9% reported ‘to patient first’. The expectations of rural and urban population were different, which suggest that future programs should be tailor made, culture specific and suit the needs of the population.

Sadhu et al. (2010) conducted a nonrandomized population based study at Manipal University, Manipal, India. Undergraduate medical, nursing and allied health science students of Manipal University were included as subjects in the study. The result of the study highlights the inadequate knowledge and awareness of palliative care among medical, nursing and allied health science students. They are uncertain and unprepared in their approach of delivering the end of life care.

Karkada et al. (2011) conducted a study in Udupi district to assess the awareness and attitude of nursing students regarding palliative care by using a questionnaire. The study reveals that majority of students (79.5%) have poor awareness about the palliative care. The authors suggest that “to become competent, nursing graduates need to be prepared to take care of the terminally ill patient at the grass root level. They need to do home visits for patients who are ill and wish to be at home in their last stages of life. Home nursing should become part of nursing training which will promote a positive attitude among the nursing students (pg 23).”

To summarize it can be stated that still the development of palliative care service is not uniform across the countries. “More than 70% of all cancer patients in India require palliative care for relief of pain, other symptoms and psychosocial distress” (Mohanti, 2001; 102). The concept of palliative care is relatively new in India. It has been developing since the mid 1980s in India (http://www.palliativecare.in/servicesinindia.php dated 2nd March 2012). The service available in India needs to reach all states. The current service is not adequate to cater to needy patients suffering from a life threatening disease. The level of awareness among health professionals as well as general population is low. Efforts towards educating health care professionals and spreading awareness among the lay population are the current needs to reach palliative care to larger portion of society.
2.4 Experiencing event of cancer:

Stress experienced by patients with cancer and their care givers:

It is seen by the researcher that to be diagnosed with cancer or having a patient with cancer in the family provokes stress for patient as well as care givers. Entering the advanced stage of cancer is more stressful as the hope for cure diminishes. Milton (1973) describes the thoughts of cancer patients after interviewing 1000 cancer patients. According to the author, diagnosis of cancer initiates fear, doubt and suspicion. The patients expressed their loneliness, hopelessness and fear of unknown. Denial, by using the mask of jocular and cheerful nature, or by accepting the diagnosis but rejecting the consequences of the same are few of the coping strategies used by cancer patients while facing the disease. As per Poncar (1994) a cancer diagnosis evokes feelings of anxiety, fear, helplessness, depression, uncertainty, and hopelessness as the person tries to grasp the meaning of the disease. Cancer is generally seen as a life-threatening disease that creates a problematic and foreboding future.

Onyeka (2010) underlines the provision of special care to satisfy the needs of dying patients through palliative care. It helps to attend to the emotional needs and well being of patient and their care givers. It is essential to take care of their self esteem, social functioning and relationship when they make their efforts to adapt themselves to illness and its consequences. In the study, five different case studies are presented. Factors such as stigma, denial, depression associated with awareness of bad news, unresolved family conflicts and special needs of patients with cancer are expressed as reasons of stress.

While describing these points, the author mentions that disfigurement associated with cancer affects self-worth and interpersonal relationship of patients. They tend to withdraw from family and community. Denying diagnosis is observed which significantly elevates the stress level. The authors mention about adaptive and non adaptive denial. Awareness of bad news alters the future drastically as they lose the hope of cure. The diagnosis of cancer does not affect the patient alone but also his/her family members and other care givers so unresolved family conflicts affect the overall relationship. All these parties have unmet needs and baggage of old memories along with physical and psychological discomfort because of the current scenario of cancer diagnosis. The
interplay of these factors generates lots of moral obligations and responsibilities. Unresolved old family conflicts, unsettled disputes and disagreements play role in determining the quality of patient care.

Hoff (2007) studied the unmet needs for information of patients in his qualitative study. He interviewed twelve patients with malignant haematological diseases or lung cancer from diagnosis to recovery or into the terminal phase or at the most for two years. All patients described themselves as well informed from the start but in later phases of their disease some of them came to express a great uncertainty about the progressing disease and the approaching death. They expressed a wish to be well informed all through the disease trajectory though information was bad. Patients were happy about the straightforward way of informing about diagnosis, prognosis, treatment plans, possible side effects, complications, and a recurrence of the disease. They wished to listen to this information in a more cautious way. The patients in this study used different coping strategies to cope with the information they receive. The author concluded about the coping strategies adopted by the patients regarding awareness about the advanced stage of disease. The author categorizes the coping in four categories 1) Information-dependent and accepting; 2) Information-dependent but denying; 3) Medically informed and accepting; 4) Medically informed but denying.

Lipsman et al. (2007) interviewed 7 patients (brain tumor) and 22 caregivers and tried to understand the issues regarding death and dying. Most participants were able to describe lessons that they have learned as a result of dealing and coping with a terminal illness and some caregivers framed their experiences as challenges or opportunities to learn and grow. Caregivers seek strength from this experience. They mentioned about the importance of quality of life. Religion/spirituality played an important role in their coping. Talking or expressing themselves was used as a coping strategy. Having a malignancy is a unique experience for them. The result of the study emphasizes the importance that existential issues in terminally ill patients should not be underestimated. Importance to cognition, memory, and mental competence over motor functioning is given by the patients with brain tumor included in the study. The study highlights the importance of quality of life over prolongation of life.
In the study conducted by Faye et al. (2006), adult patients suffering from terminal stage of disease were interviewed and inquired about their stress and coping strategies used by them. The study reveals that physical symptoms, social concerns and existential issues are identified as major stress creating factors. The stressors of people who have a terminal illness are indeed complex and varied and they are not necessarily universal. Concern about being a burden to others was the most disturbing social issue. Pain was noted as a disturbing physical symptom for them.

Kim (2002) conducted a descriptive study in Korea by interviewing 257 hospitalized adult cancer patients who were either under active or palliative treatment. The study identified stress provoking factors. Stage of cancer was identified as the major factor to aggravate stress. The stress was higher in patients who were in the third stage of cancer as it was considered as the final stage of cancer and experience physical and psychological pain as they find fewer options of treatment. This study identified patients of both genders with cancer of reproductive system as higher risk subgroups that may be in greater need of stress-reduction intervention. According to authors, patients with cancer of reproductive system were more concerned about their family members and loved ones but had difficulty to communicate with them. In addition, they were worried about maintaining intimate relationship with loved ones as a result of impaired functioning of the reproductive system. Individuals with less education showed lower coping scores. The patients who were employed showed higher level of coping than those without occupation. Frequent use of emotion focused coping than problem-focused coping strategies was noted in this study. Individuals have been reported to use problem-focused coping more when they perceive they can alter the stress situation, and use emotion-focused coping when there are few modifiable personal factors to change the situation.
2.5 When a child is diagnosed:

Nowadays the medical technology is suitably advanced to extend the life span of the cancer affected children so their long term adjustment is an increasing concern. It is essential to understand the concerns of children with cancer during and after their treatment. As a result, the need of working on the disease related psychological burden of children is increasing. Gerali et al. (2011) conducted a prospective and comparative study with aim to evaluate the development of psychological problems in children with cancer during the initial 6-month period of intensive treatment in one of the largest Greek Oncology Pediatric Units in Athens. The parents and teachers of 132 children with cancer were interviewed. The Rutter scale was used to collect the data. They were asked to furnish the questionnaire and a short interview was conducted to assess the psychological problem during the first six months of treatment phase. 100 parents and teachers of healthy children were chosen as a control group. The parents of children with cancer were interviewed thrice. 1) one month after diagnosis, 2) 3 months after diagnosis (middle of intensive treatment) and 3) 6 months after diagnosis (at the end of intensive treatment). The teachers were interviewed only once after 6 months of intensive treatment. Also, the parents and teachers of participants in the control group completed the questionnaires only once.

The result of the study suggested that children with cancer might develop psychological problems during their treatment. These problems persist during the entire intensive period of treatment. Neurosis and hyperactivity were identified as psychological problems. No behavioral difficulties were reported by parents or teachers. The children with leukemia had higher scores in the beginning of treatment but in the following 6 months showed significant improvement in their psychological condition, contrary to the children with sarcoma and lymphoma. Similarly, younger children with cancer had higher scores in the end of the first month of treatment but showed the biggest improvement in the course of therapy.

The factors such as diagnosis of cancer, phase of treatment and related toxicity, bodily changes, and hospitalization challenge psychological adaptation of children. The children experienced stress and fear while undergoing treatment related painful procedures. Older children, especially teenagers were deeply affected by frequent hospital visits, body changes, resulting in lower self esteem and disappointment than younger children. Toddlers do not easily realize their body
alterations. They do not thoroughly understand the risks of disease and the complications of treatment, and, more importantly, they do not perceive completely the meaning of death. In addition, older children have the necessary cognitive abilities to interpret the health information provided, creating a greater pool of external stressors. Older children and adolescents have developed a larger variety of coping strategies to face challenges and have the maturity to deal with their disease anxiety. As the therapy progressed, the scores showed significant differences. Missing school and friends is noted as a stress provoking factor for ill children as compared with healthy children. The study suggests that the multidisciplinary team should identify these stressors and help them to deal with them effectively.

Patenaude and Kupst (2005) describe the emergence of pediatric psycho-oncology and to summarize research on psychosocial aspects of childhood cancer and survivorship. The literature focusing on communication, informed consent, procedural pain, late effects, psychological distress, coping and adjustment, and special risk populations is reviewed by the authors. In the past thirty years there is tremendous progress in the medical science resulting in higher survival rate in pediatric oncology.

The authors point out the emerging changes in last three decades such as change from avoidance of communication about cancer to an emphasis on straightforward discussion of diagnosis and prognosis. Behavioral research has led to interventions to reduce procedural distress. The involvement of child in assent and consent, communication patterns with family members and health professionals are observed to be changed over the period. The children are seen to be involved in discussions regarding diagnosis and even prognosis in the recent research. The study throws light on the strategies adopted by parents and children to cope with the situation. The study concludes that coping strategy varies from person to person. There is no single coping strategy that has emerged as an optimal coping strategy.

Dighe et al. (2008) conducted the study in India and highlighted the unmet needs of the children with cancer after interviewing 20 parents of these ill children. The study concluded that children are not involved in decision making process or no information regarding their disease is shared with them. They are not permitted to speak to the professionals care givers despite their wish as parents wish to protect them from the bad news. The study found that understanding of their fatal
illness provokes extremely high level of anxiety in children. These children experience loneliness, separation and can anticipate their death.

2.6 Experience of Care giving:

Linderholm and Friedrichsen (2010) studied experiences of family care giving of terminally ill patients. The study used purposive sampling to obtain a variation regarding demographic data such as age, sex, relationship to the patient, and the patient’s diagnosis. Fourteen family members from four different primary health care areas of Sweden were interviewed to understand their role, support and lived experience.

The study concluded that service of home care team was valued by care givers. According them care giving was not easy without the support of the professionals. The care givers expressed that they were expected to take care of their ill relatives/family members. The team as well as the ill person expected the same from them. They took the responsibility and control of the situation and accepted it as an obligation and moral duty. The feelings of doubt and anxiety about how to cope with the impending caring role were expressed. The care givers were not trained and even prepared to take care of patient’s needs such as dressing, medication and so on. When the feelings of care givers associated with insecurity and inexperience was not understood by the team, the care givers experience a feeling of powerlessness. The problems with communication and the lack of guidance from the nurses created feelings of frustration.

The caregivers experienced a demand for self-control toward their suffering relative. It was important not to show any insecurity, fear, and anger. The efforts of care givers were observed to project the feelings of strength and security to the dying patients. The care givers experience pain when they witness the complete transformation of an independent person to the completely dependent and helpless person. Care givers spend days and months caring for the ill family member. After the demise of the ill person, the care givers experience a vacuum as they remain with no role to perform. They experience loneliness, experience difficulty in eating, depression, isolation, insomnia and difficulty in concentration. Playing a role of care giver offers satisfaction and they feel proud of themselves for being a care giver of the ill person. During the period of
bereavement, the care givers expect the professional team to attend to their feelings and need the acknowledgment from the team for the role they performed. The study concluded that, a dying relative has a profound impact on his/her family members’ situation, including negative effects on roles, well-being and health. The need to recognize the needs of the care givers is essential.

2.7 Experience of Parents of children with cancer:

Norberg et al. (2005) conducted the study with an objective to compare the traumatic stress of parents of children with cancer during and after completion cancer treatment at two Swedish Hospitals. 423 parents (103 mothers, 78 fathers) of children furnished the questionnaire at home. A revised version of the Impact of Event Scale (IES-R) was used for assessing stress reactions. As per the study traumatic stress was more common among parents of children in treatment than in parents of children off treatment. Non-Swedish origin (immigrants) and low education of parents increased the risk for parental stress symptoms post treatment. Migrants having previous and concurrent experiences of discrimination, violence, and disrupted social networks also influence stress resiliency. Uncertainty about the success of treatment, fear of relapse and consequences of treatment were worry inducing stressors. In Sweden, mothers spend more time with the child in the hospital as they take the major responsibility of bed side caring. They carry a greater burden of memories of traumatic experiences and report intrusive thoughts. This study highlights the need to pay attention to the parental emotional needs as both of them experience stress when their child is diagnosed with the disease like cancer.

Kerr et al. (2004) analyzed 46 articles published in 1992-2002 related to pediatric oncology population and their supportive care needs from diagnosis to treatment. The focus of the study was to identify different stressors faced by the parents during the illness of child. The 49 studies were descriptive in design. Twenty-five used quantitative methods, 20 used qualitative methods, and 4 used mixed methods. Informational, emotional, psychosocial, practical, spiritual and physical needs were identified as the parental needs. Need for information is to reduce confusion, anxiety, and fear; better inform the patient’s or family’s decision making; and assist in skill acquisition. Emotional support is considered as help to sense comfort, belonging, and reassurance in times of stress and understanding. Psychological need is considered as related to one’s sense of self-worth, competence, and being valued; needs related to family relationships and community acceptance. To deal with treatment is difficult for parents. So help for direct
assistance to accomplish a task or activity and thereby reduce demands on the person is identified as support required. This is often fulfilled by the support system and the network that parents can access and utilize. Spiritual need is related to the meaning that life holds a sense of purpose and a relationship with a Higher Being. These above mentioned needs are in ascending order as expressed by parents of 49 articles analyzed by the authors. Socioeconomic status, age, gender, culture, education, religion, family form, urban rural location, social support, coping resources and personality are identified as the influencing factors. This observation reflects a summary of all the articles reviewed. The authors mention that no one study examined the entire range and types of supportive care needs from diagnosis to treatment. This knowledge is a key to planning appropriate care and services. This comment and observation underlines the need of conducting a study encompassing the entire range of needs, support services from diagnosis, treatment and even if the child enters the terminal stage of cancer.

The literature between 1997 and 2007 on parental stress reactions following the diagnosis of childhood cancer is reviewed by Vrijmoet-Wiersma et al. (2008). In the reviewed 67 articles, it is seen that parents seem relatively resilient, although a subset of parents report continuing stress even up to 5 years or more post diagnosis. Most emotional stress reactions are seen around the time of diagnosis. Compared to fathers, mothers of ill children have reported a greater amount of stress. According to the author, the reason for this difference of stress level might be because of following two reasons. Mothers take main responsibility of caring for the child and fathers are more peripherally involved in childcare and the style reporting differs according to the gender. Uncertainty associated with fear of relapse of death of the child and greater amount of anxiety was reported more at the time of diagnosis than anxiety recorded after some time of diagnosis. Stress related to cancer of their child is expressed and manifested differently by mothers and fathers. Several studies have focused on protective factors and on parental adjustment rather than parental stress. Family relations, social support are expressed as the factors helping coping strategies. The diagnosis and treatment leaves long lasting effect on parents. The parental needs, coping strategies vary as per the stage of disease and also the duration of diagnosis.

Dighe et al. (2008) conducted a study to explore the concerns of parents of children with advanced stage of cancer and their attitude towards revealing the diagnosis to their ill children at Tata Memorial Hospital-India. After interviewing twenty parents of children undergoing palliative care treatment, they identified their concerns such as financial constraints, anticipatory
grief of child’s death, usage of some alternate treatment, pain and symptoms of child and helplessness. Children with advanced, life-limiting illness have unique needs which are different from those of adults. As per the authors, the parents do not involve the ill children in the discussion regarding cancer. The parents are not comfortable to speak to child about the prognosis of her/his disease. Very few parents discussed the death with the child. Siblings of the ill child are also not involved or informed about the treatment of child. The siblings did not grumble about the special attention given by parents towards the ill child. They tried to help the parents by accompanying to the hospital and so on. The parents go through anticipatory grief and process of dying of child affects the parent and this impact is long lasting and complicated over the death of an adult patient. To deal with this event, parents reported the support of their family especially joint family members and their neighbors. *Karma* (faith/destiny) is identified as one of the parental coping strategy. Denial is used as a coping strategy which may not prove effective to prevent anxiety.

The study conducted by Hallstrom et al. (2002) focused on identification of the parental need when their child is hospitalized. 22 boys, 2 girls of different ages admitted at a pediatric department at a University hospital in the south of Sweden with different diagnosis and 35 parents were studied. Non participant observation was used as a tool to understand the parental needs. In the analysis nine themes of parental needs were identified. These were: need for security, mediating security to their child, communication, control, parental competency, to adjust in the given situation such as by not disturbing the staff, hiding feelings and so on, contact with family, releasing responsibilities, and satisfying practical needs such as sleep, food, travelling and so on. The need for security involves two themes, security for the parent and mediating security to the child. The caregivers expected to have treatment for their child from professionals with good education, experienced staff members, right medical and nursing treatment, parents being treated with respect, and the child being treated in an individual way and as a special person. Identifying the social, psychological and physical needs of the child also emerged as a need. Expectation from staff was to impart honest and understandable information through the professional’s effective skill of communication was expressed by parents. It was difficult for parents to spend longer duration at the as they were concerned about other members of family. The need to be replaced by other caregivers for some time was highlighted. Basic
parental needs like eating or sleeping were considered as secondary while the child was hospitalized. As per the parents, every person is different and has special needs so it is important to know the needs of children and their parents to be able to satisfy their needs as neither parents nor their children express them clearly. The study has included children with different diagnosis and focused on hospitalization. The parental needs which are influenced by diagnosis and prognosis might vary.

Grootenhuis and Last (1997) conducted a study to determine the emotional adjustment of parents of children with cancer. A total of 84 mothers and 79 fathers, of 84 children with cancer with different survival perspectives (in remission or with a relapse) participated in the study. The revealed that parents lacking positive expectation about the course of the illness were most strongly related to negative emotions. The stage of disease was identified as one of the factors which determined the emotional adjustment. The mothers of child with relapsed cancer reposted feelings of helplessness and uncertainty. The fathers of these (child with relapsed disease) children expressed the feelings of uncertainty. Age of the children was recognized as a factor of emotional stress for mothers. Younger (below 8 yrs) children were considered as to be more vulnerable by their mothers and they experienced greater depression. The family experiences helplessness and uncertainty when their child is diagnosed with cancer.

### 2.8 Coping to face the event of cancer:

Kim et al. (2002) assessed stress experience by 257 adult hospitalized cancer patients and the coping strategies used by them to deal with the event of cancer. The gender of patient was not identified as the factor influencing coping process. Employed patients showed higher level of coping. Female patients reported lower levels of college education than men, their level of coping showed a significant difference. The coping of patients having higher level of education was better than others. The results showed that stress was negatively correlated with both problem-focused coping and emotion-focused coping.

Shapiro et al. (2010) conducted a study in a non-profit organization that provides a wide variety of nonmedical services to people with cancer and their families located in midwestern part of U.S.A. 283 cancer patients filled the following questionnaires 1. Hospital Anxiety and
Depression Scale (HADS). 2. Center for Epidemiological Studies Depression Scale (CES-D) 3. Fordyce Emotions Questionnaire and 4. Quality of Life Questionnaire (QLQ-C30). The study enquired about a number of coping styles and strategies in people with cancer. Among the coping strategies, self-blame and behavioral disengagement were consistently associated with poor adjustment, while acceptance and humor were consistently associated with good adjustment. The patients who used humor as a coping strategy exhibited high levels of positive emotion, compared to patients who made little or no use of humor. Thinking about cancer related issues is associated with negative emotions and create greater level of distress. When the event of cancer is accepted as challenge then hopelessness is not observed and in contrast, when ill people give up they experience higher level of stress. Among the broader measures of coping styles, there were associations between poor adjustment and emotional processing, and between good adjustment and hope, benefit finding, and cancer-related social support. The coping is not universal and positive emotions such as hopefulness, using humor and fighting spirit help the patients to cope effectively. The ways people get adjusted with the event influence their coping.

The coping strategies studied by Faye et al. (2006) used most widely across the dimensions of stress were direct action, seeking instrumental support, perspective-taking, and resignation-acceptance. These strategies were reported by at least half of the participants for all three dimensions. The participants used combinations of coping strategies to deal with their stressors. However, there were broad differences across dimensions in the relative use of problem-focused and emotion-focused alternatives. Problem-focused coping was uncommon for existential issues, whereas emotion-focused approach and avoidance strategies were used less frequently for physical symptoms. The major finding of the study highlights that people cope with different problems in different ways.

From the literature it can be inferred that patients experience stress at the time of diagnosis of a life threatening disease such as cancer. The stress related to physical symptoms, becoming a burden on others, feelings of isolation, issues related to death and dying and many other factors is common among patients. It is seen that there is no coping strategy which can be identified as the unique and the best strategy to deal effectively with the disease. Every individual adopts a certain strategy of coping.
2.9 Support:

Slevin et al, (1996) conducted a study to understand importance of emotional support which cancer patients gain from different people and services. The study evaluated attitude of patients towards the sources of services and satisfaction. 431 cancer patients, who have been diagnosed of cancer at least for a three months period, furnished the questionnaire which gave the account of usage of different sources, including individuals, support groups and information sources. The questionnaire also incorporated validated measurements of anxiety, depression and locus of control. The study identified important sources of emotional support. Senior registrars (73%) and family (73%), followed by consultants (63%). They preferred doctor or nurse led support group than patients support group. The patients who were not satisfied regarding the amount of support they received experience greater amount of anxiety and depression. Having adequate information regarding the disease helped them gain control over the situation.

A study by Conrad and Altmaier (2012) evaluated the impact of social support received by children with cancer at the summer camp which they attended. The camp organized by a Non-profit organization for children who are either on treatment or on remission. A week duration camp which gave them an opportunity to mix up with others and joining activities such as riding, art, craft and so on. Following the camp, families were sent a Social Support Questionnaire (for the child to complete) and the Child Behavior Checklist (for parents to complete). The chance to mingle with other participants, experiencing the group spirit and forming new relationships were encourages at the camp. The study reveals that both genders reported receiving more support at camp than children in the general population. Girls reported receiving more support than boys.

Rajajee et al. (2007) conducted a prospective study, to assess the role of family structure in coping of parents of cancer affected children. Experiences of 34 parents (15 belonging to joint family and 19 belonging to nuclear family) regarding the support they received from family was evaluated. The study reveals the importance of emotional support besides sharing house hold responsibility and bedside caring. The study emphasised the importance of structure of Indian family over western nuclear family. The psychological support from own family members and contribition by them in bedside care giving help parents to cope effectively with the child’s
illness. Such support is helpful for well being of other children in family. Counselling sessions by professional health care givers aiming at emotional support also helps them to deal positively.

2.10 Role of heath practitioners

Seth, (2011) an Assistant Professor of Hematology, AIIMS, Delhi, comments on the practice of medical practitioners. She mentions that treating a child is an emotive experience for practitioners and failure or non response to the treatment by the child is considered as a personal failure. Few of the practitioners identify the patients with their own children of the same age. General conversation focuses on treatment protocol or next treatment and so on but not on emotional health of parents or patients. In the above mentioned study 25 parents of the children with Acute Lymphoblastic Leukemia, (a type of blood cancer) for at least six months were requested to fill a simple form which was furnished as per WHO guidelines and tested in the field. Then the parents were also interviewed. The parents mentioned that they are not comfortable discussing the disease related facts with the child. Shielding the child from painful information was the preferred strategy of parents. More time for counseling for parents was expressed as their need. Imparting knowledge regarding disease, therapy and side effects before starting the treatment of therapy was not advisable according to parents. They fear that after receiving such information a child might refuse the treatment. To break the bad news, the author suggests training workshops as the physicians are not comfortable and confident of delivering the bad news.

While describing communication as a vital component of palliative care, Seth (2011) mentions the importance of effective communication skill of the medical practitioner which helps to relieve the fear of parents related to the unknown and provided empowering information. Parents experience confusion when they lack the disease related information because of the improper communication. Abandonment of treatment or refusal to curative treatment options by patients is observed as a result of lack of information. As a result, confused parents get lost and sometime refuse further treatment. She expects the health care givers to provide adequate time to parents to deal with their stress and anxiety. The results of this study reinforce the traditional paternalistic role of physician.
Wolfe et al. (2002) focus on the philosophy of cancer care that facilitates communication between providers, patients (regardless of age), and parents throughout the illness, in a way that empowers parents, increases their knowledge of their child’s medical condition, and helps them to achieve continuity of care across treatment sites. The author mentions that the care of children with advanced cancer is multifaceted. The children and their families should have access to interdisciplinary care aimed at promoting optimal physical, psychological and spiritual wellbeing.

2.11 Collusion:

When two parties take strategic decisions to conceal the fact from third party, it is called as collusion. Facts such as poor prognosis or diagnosis of some life threatening disease are not revealed either from the patient or from other family members. In the health care Groopman (2005) mentions that in the past, people with an incurable cancer were not informed of the reality of their condition. Now the physicians work under the assumption that patients and their families deserve the truth.

A qualitative observational (ethnographic) study was conducted by The et al. (2000) in two stages over four years. The aim of the study was to discover and explore the factors that result in “false optimism about recovery” observed in patients with small cell lung cancer. The data was collected by four different sources such as observation of behavior of patient and staff within and outside consultation, by the researcher, interviews of the participants, notes obtained from medical record and diary maintained by the researcher about researcher’s behavior and feelings while interacting with staff and patients.

An important finding of the study was that the patients' false optimism about recovery is not only the result of the withholding of information from patients who are eager to know. According to the results of the study, the patients prefer not to focus on future and show concern about presence which includes treatments, tests and so on. Many cancer patients, when they fear that their prognosis is poor, they prefer not to ask for the precise information and do not listen to it even if provided by the doctor. The authors conclude that there are other factors which are responsible for collusion than tendency of professionals to withhold information or a lack of
communication skills of doctors. Along with these two reasons, even the patients are not willing to listen to the bad news as they are scared to face it.

Chaturvedi et al. (2009) discuss collusion as a challenge for professionals while discussing diagnosis or prognosis of diseases like cancer in western as well as non-western community. When the family members are involved in caring the ill person, the collusion occurs in various forms. The secrecy to hide the facts from the other occurs in different forms and with different intentions. In palliative care service, the focus of treatment shifts from cure to care. At this stage progression of disease and discussion on death and dying involve collusion. In India half of the patients taking treatment for cancer are unaware of their diagnosis. Care givers permit professionals to discuss the treatment protocol but not the diagnosis. According to the authors in the Indian family scenario because of the patriarchy system, family members/relatives involve themselves in patient care and direct or decide treatment related matters without involving the ill person. This affects the autonomy of patient and do not understand the factual details of disease/prognosis. The authors mention that collusion protects the ill patient because of the unawareness of the factual details and this minimizes their concerns. Professional care givers also go along with the concealment of prognosis and protect themselves from their own stress.

While discussing the implications of collusion, Bennett and Alison (1996), have mentioned that a conspiracy of silence can contribute to a lonely, isolated death if a patient is not given the opportunity of knowing his/her diagnosis. The strain on relatives of maintaining the 'secret' can be immense. The authors state their observation that usually the relative expresses fears that the patient will not be able to cope with the news and will 'give up' and they may be worried that the patient will be told bad news in a blunt manner. Different cultural groups having different attitudes to disclosure of medical information and language barrier (doctor not able to speak in the mother tongue of patient and care givers helping to translate for their patients) also play a role in concealing the bad news from the patient.

When the child is diagnosed of cancer, then the parents/caregivers show their concern by hiding the diagnosis or prognosis related facts from the child. Mack et al. (2006) conducted a study at the Dana-Farber Cancer Institute and Children’s Hospital (Boston, MA), which aimed to
determine parent preferences for prognostic information about their children with cancer and the results of receiving such information. To evaluate parents’ desire for prognostic information, its impact, and factors that might influence information preferences they were asked to furnish the questionnaire, based on literature review and seven exploratory interviews with parents of children with cancer, physicians, psychosocial providers, and a chaplain. The physicians were also asked to fill questionnaire which explored goals of care and likelihood of cure.

The result of the study throws the light on parent-clinician communication content and its impact. The clinician initiated the discussion and spoke about the prognosis of the child at some or other point of treatment and it was discussed numerically. Parents showed eagerness to understand diagnosis and treatment protocol in detail than a discussion of prognosis. The parents expressed ‘extreme upset’ when the prognosis was poor. Though upsetting, parents were keen to get more information regarding prognosis as it was necessary for them to take further decisions. The parents felt that clinicians were more sensitive when the child was present at the time of discussing diagnosis and treatment. According to the authors, the tendency of clinicians to avoid discussion about prognosis was observed. This type of collusion was noted because clinicians were compassionate towards care givers. These were efforts were to protect care givers from such a painful topic.

The findings of this study cannot be generalized as this study includes children from hematology as well as solid tumor cancers and both types of cancer have different prognostic levels. Secondly the opinions about communication were gathered through collecting the information from survey (questionnaire) form, so the complicity of the communication would not be covered.

In 1998, the American Society of Clinical Oncology (ASCO) surveyed its membership to assess the attitudes, practices, and challenges associated with end-of-life care of patients with cancer. All ASCO members in the United States, Canada, and the United Kingdom were mailed a survey, which was completed by 228 Pediatric Oncologists. While summarizing the report of above mentioned survey, Hilden et al. (2001) stated that Pediatric Oncologists reported a lack of formal training in pediatric palliative care, a strikingly high reliance on trial and error in learning to care for dying children, and a need for strong role models in this area. The lack of an
accessible palliative care team or pain service team was often identified as a barrier to good care. Communication difficulties exist between parents and Oncologists, especially regarding the shift to end-of-life care and adequate pain control. Wolfe et al. (2002) recommend an open and compassionate communication, as it can best facilitate meeting the goals of these children and families.

Harris (2004) mentions the reasons posing as barriers to delivery of adequate pediatric palliative care in his monograph. According to the author, diagnosis of cancer in children is that relatively rare. Second factor he mentions is there is lack of evidence based practice so clinicians are forced to use their personal experience and trial-by-error medical care. He recommends formal training in many areas of palliative care. The author mentions that pediatric oncologists should deal with the different physiologic and developmental stages encountered while caring for infants, children, and adolescents with cancer.

Onyeka (2010) while discussing the role of professionals in providing patient care, mentions the importance of multidisciplinary team work. The skilled person counseling the patient and involving the patient has his/her family members in support group promotes good interpersonal relationship. Provision of emotional support, frequent meetings, imparting information in a sensitive manner by a professional is advisable to deal with denial. Lack of skill of professionals in breaking bad news creates stress for patients as well as professionals. Patients lose interest, get depressed and distressed.

It is suggested that palliative care is still in its infancy and a full complement of multidisciplinary team and support service are inadequate and lacking. Members of this team should be well-equipped with advanced training in communication skills. Compassion and empathy should be the watchwords and should aim to make life comfortable till death.
2.12 Role of Culture, spirituality:

2.12.1 Spirituality:

While discussing the relevance and importance of spiritual care in the treatment of terminally ill cancer patients, Chaturvedi (2007) refers to the definition by W.H.O. which focuses on the spirituality as one of the essential aspects to address while dealing with death and dying issues of the patients. All aspects of the definition including cancer pain, morale, family, death and bereavement have a significant element of spirituality. Spirituality includes two main components: faith/religious belief, meaning and spiritual well being. These two constructs of spirituality have an important role in supportive care. Lunn (2004) mentions that spiritual care is an essential component of palliative care. According to the author spirituality is an important part of suffering and the relief of pain and suffering. It is especially important in the developing world where medical and comfort resources are limited. Reese (2011) feels that spirituality is the most important way of coping for many patients, families and their intimate network confronting a life threatening illness. Harris (2004) reported that there is an increasing awareness of the importance of spiritual well-being in patients of all ages.

Amoah (2011) who is a Chaplain, St Nicholas Hospice Care, England, highlights the relevance and importance of spirituality in palliative care setting. According to him, spirituality should be considered on an equal footing with other key themes in palliative care, like relieving pain and advance care planning. Any shade and form of spirituality help those who are facing terminal illness to make sense of the life. He suggests that spiritual care is not the whole responsibility of Chaplain but the staff and other health care providers should deliver the care sensitively and competently. The aim of this care provision should aim to improve the quality of life of patients and care givers.
2.12.2 Culture:

As stated by Sepúlveda et al. (2002) WHO believe that culture, tradition and availability of resource allocation for palliative care service influences country wide palliative care service. According to the report, “challenges in the near future include the validation of models for implementing effective and efficient palliative care programs in different resource settings. These programs need to be accessible to all patients and their families in need of this care (P.94).”

Whittam (1993) highlights the importance of having an open discussion with the child regarding his/her disease related facts. American Academy of Pediatrics (2000) describes the importance of helping the child to act familiar with the equipments, therapy, treatment and disease. Providing information to children and families and sharing accurate descriptions by child life specialists is given importance during the treatment span.

Chaturvedi et al. (2009) mention reasons responsible for collusion. Role of the patient in the family is observed as one of the reasons for collusion. In the Indian cultural context, head of the family (male person) is observed as a spokesman and women are considered as emotionally weaker. Most commonly the collusion observed between relatives and medical professionals is because of the relatives’ wish to keep the medical status away from patients. Relatives are concerned about the wellbeing of family and patients from whom the bad is hidden. Though this stems from cultural and traditional system of society, it affects the autonomy of patient. The study emphasizes on the importance of working on collusion by professionals.

The study by Dighe (2008) which is conducted in India, reveals exactly opposite findings. The parents are not ready to reveal the facts to their children. This attitude hinders open communication. The patients and their siblings are not involved in direct communication regarding diagnosis and prognosis. The cultural aspects of western and eastern countries influence the attitude of the parents towards disclosure of bad news to children. The study by Seth (2011) also supports the above mentioned finding regarding the parental discomfort while revealing the bad news to ill children. According to her, the Indian parents are unwilling to discuss the disease with the child. They do not wish to involve the child in any deliberation for treatment or palliation. Indian parents shield and protect the child from knowledge of cancer.
They prefer to avoid unpleasant discussion regarding prognosis or treatment. The author attributes this to the cultural impact. In western countries, the autonomy of child is given importance and his right to information is respected.

2.13 Parenting style:

Manne et al. (1993) investigated the prevalence of treatment adherence problems among children undergoing cancer treatment and explored the relationship of sociodemographic factors, child functional status, and parenting style to these difficulties. Seventy-seven patients and their primary caregivers (the individual primarily responsible for the child's cancer treatment) participated in the study. The sample of patients consisted of 45 boys and 32 girls. The caregivers consisted of 63 mothers, 13 fathers, and 1 grandmother. The study used scales to understand the adherence, cooperation, parental influence, SES of the family. (1)Lansky Play Performance Scale for Children-The PPSC was used to assess the child's level of functional status using restriction of play activities as the outcome measure. (2) Parenting Dimensions Inventory. The PDI (Power, 1989), was administered to primary caregivers to assess parenting style. (3) Adherence Measure. The pediatric nurse practitioner responsible for the medical care of each child completed a 7-item questionnaire

The results of the study reveal that younger children have more problems related to adherence. The influence of child rearing practices and attitude also influence the adherence. Lower socioeconomic status was found to be associated with more frequent appointment cancellations and delays, more frequent late arrival time for outpatient appointments, and more delays in the reporting of negative reactions to treatment to the physician. In contrast, parents with supportive parenting style have lesser adherence problems and cancellations. Such supportive parents encourage their child to express their needs and are more attentive towards emotional and physical reactions during treatment. As a result better care is provided by the parents to the child and the role of family in adherence to treatment. A physically active child has lesser problems in adherence. The role of parenting style influence overall adherence to regimen. As the treatment for cancer is of long duration, difficult, supportive parents encourage the child to undergo the protocol in the right way, adherence results in better prognosis.
The study conducted by Young et al. (2002) highlight a clear need for rigorous qualitative research on parents' accounts of having a child with cancer. Being the parents they need to work on their role as parents as the situation demands complex and overlapping roles as parents while providing bed side care to ill child. To be identified as parents of ‘cancer affected child or survivors’ is considered as threat to their parenthood. Parental realization that they could not fulfill the fundamental parental obligation of protection creates stress for them.

**Conclusion:**

From the above research findings, it is clear that caner is perceived as life threatening disease. The diagnosis and treatment of cancer is stressful for patients as well their care givers. The child with malignancy and his/her parents have special needs and concerns while experiencing this event. While facing the advanced stage of disease and to prepare for the eventuality, ill children and their parents seek various types of support. Pediatric Palliative Care is considered as one of the support systems which provide holistic care. The concept needs to be developed globally to provide effective patient care.

**Findings from literature review:**

- The global development of this branch of medicine is patchy
- The growth and acceptance of this concept is a recent picture in India
- Effective patient care models need to be developed after considering factors such as culture, belief and spirituality as these factors play a major role in coping process of ill people and their care givers
- Children with advanced stage of cancer have special needs and concerns to attend to
- To care for a child in an advanced stage of cancer is strenuous for parents and support from trained professionals can help them to deal effectively
- Training for health care professionals such as doctors, nurses, psychologist, social-worker and so on can provide improve quality of life to the ill people.
Context specific studies need to be conducted in India:

- There is contradiction among the findings of Indian and Western research as these issues are influenced by context specific cultural aspect
- The level of acceptance of this concept is not uniform globally. As a result, attitude towards provision and acceptance of service varies accordingly
- Field based grounded theory based study which is based on lived experience of parents of ill children need to be conducted
- In depth analysis of influence of own child’s life threatening stage on parents and their role as parent in India is lacking.