Chapter 5

“I may not have gone where I intended to go, but I think I have ended up where I needed to be.” ……. Douglas Adams

Emerging theory from the findings

The analysis of the data reveals that parental experience of having the child with advanced stage of cancer is stressful. The lived experience of parents of children registered in Pediatric Palliative Care Unit of Tata Memorial Hospital is described using the paradigm of grounded theory by Strauss and Corbin (1990), a) causal conditions that underline the stress experience by parents while witnessing the worsening of physical symptoms of child and the efforts by parents to cope with anticipated death of child and coping strategies appointed by parents; b) the phenomenon that arises from the causal conditions; c) context that pertains to the phenomenon and influences strategy development; d) intervening conditions that influences coping strategy development, and flexibility of parents to change/modify them by seeking various sources and types of support. e) actual coping strategies and f) consequences of those strategies.

5.1 Grounded theory story line:

Accepting the diagnosis of cancer of their child is difficult for parents. In a few of the cases, the child does not respond to the curative treatment and shows poor prognosis and a few cases report with advance stage of disease and have limited scope of cure. Children belonging to both these categories develop unpleasant and painful symptoms. To witness their child in a poor physical condition is strenuous for parents. Parents seek support from various sources to deal effectively when they understand about the poor prognosis of child. After accepting the anticipated loss of the child, they willingly work on their unique parenting style to make the child happy. Parental wish is to make the child happy influences their parenting style and which affect their coping as well. This story line of ‘parental coping with advanced stage of cancer of their child’ is explored in the study.
“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). Well being of child and providing comfortable life to children is accepted as a duty by the parents. When a child having a normal and healthy survival is diagnosed with cancer, it is shocking and difficult for parents to accept this event of life. When the cancer enters the advanced stage of cancer, the ray of hope diminishes and parents experience stress related to the life threatening condition of their child. “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, the transition to ill heath may be viewed as loss, the loss of the healthy child and all the hopes, dreams and aspiration that go with it” (Hynson, 2006). This is the core phenomenon under which the theory of parental coping while experiencing the life threatening condition of their child.
5.2. Emerging conceptual map:

- **Context:**
  - Awareness
  - Physical Deterioration of child

- **Causal Conditions:**
  - Child variable
  - Parents Variable

- **Parental Coping**

- **Strategies by Parents, child**
  - Healthy coping
  - Unhealthy coping

- **Intervening conditions:**
  - Experiencing anticipated loss
  - Witnessing the child’s pain
  - Event specific parental needs
  - Involvement in bed side caring
  - Child’s age, gender, discomfort, birth order, number of children
  - Professional Behavior (PPCU/HCT)

- **Consequences**
  - Acceptance:
    - Parenting style-Reinforce, Change, Modify, emphasis of quality of life
  - Non-acceptance:
    - deny, burdened, lack of catharsis, false ray of hope
Parental coping:

Parents experience stress when their child is diagnosed with the terminal stage of cancer. Current symptoms, and anticipated grief related to loss of the child in the near future creates anxiety. “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). At this stage parents have various types of needs, pertaining to the child, his/her illness, their role as parents and their own role in the family. Getting adjusted to the added responsibility of being the care givers of ill children and to cater to the needs of other children become challenging. As parents need to accompany the child in hospital, it affects their employment and earning; in addition to that they need to bear the cost of cancer treatment. These factors are a financial burden to them. In addition to this stress, they experience emotional, psychological, social and spiritual stress when they are informed about the poor prognosis of the child. To deal with challenging event, they seek various types and sources of support to help them to cope with the event.

Phenomenon resulting from causal conditions: Parental coping is the core phenomenon of the study. To face the life threatening condition of the child, parents adopt various coping strategies. The entire phenomenon is influenced by causal conditions and the factors which intervene in the current situation. The strategy suiting the individual in the given context is chosen by them with ultimate aim of effective coping in the given condition. Current stressful condition, aggravating physical symptoms and anticipated loss influence the coping of ill children and their parents. The resilience of parents and ill children influence the mutual coping.

Causal conditions:

Causal conditions refer to the events or incidents that lead to the occurrence or development of a phenomenon (Strauss and Corbin, 1990). Causal conditions emerged from data, which ultimately led to certain phenomena related to parental coping identified in this study are divided in two categories. 1) Child variables and 2) Parent variables
(1). **Child Variable** includes a) Child’s awareness about the diagnosis and prognosis of the disease, b) Worsening of unpleasant painful symptoms, and c) parental understanding of experience of guilt and isolation of their child.

(2). **Parent Variable** includes a) Difficulty while performing multiple roles b) difficulty in balancing resources, c) Social stigma, d) fear of unknown, e) Hopelessness f) helplessness

1.a) **Child’s awareness about the diagnosis and prognosis of own disease:**

**Awareness regarding diagnosis:** Children perceive a disease like cancer based on their own experience and understanding. Generally the disease is perceived as ‘big, painful, scary and life threatening’. Diagnosis such as cancer is not accepted easily. It is seen that cancer is perceived as a life threatening disease. The children are inquisitive to know about their illness (“I am not a fool. This is Tata Memorial Hospital and only cancer is treated here. I am being treated for almost 2 years and you are expecting me to believe that this is not cancer” said Mehru). Tata Memorial Hospital is a name which is used as a synonym for cancer. The perception regarding cancer is painful, scary and life threatening disease. The fear and uncertainty related to future is generally seen to be attached to the diagnosis of cancer.

**Awareness regarding prognosis:** Children expect clear and factual information regarding their disease. They make efforts to gather it from parents, family members. health-care professionals, case records or from other patients. The experience of children is influenced by their awareness, understanding and their perception of disease. (“I have seen my mother crying many times. So I guess, this is a disease which is difficult to cure” states Vijaya). Children use their intuitive ability to guess the prognosis. Facial expressions and gestures of parents are used by children to guess the poor prognosis.

1.b) **Worsening of unpleasant painful symptoms:**

Children experience short and long term side effects while undergoing curative treatment. Experiencing weakness, nausea, weight loss, hair loss, darkening of skin, a few need to face the
surgical amputation. When the disease like cancer enters the advanced stage of cancer, it provokes difficult and unpleasant symptoms such as breathlessness, fatigue, nausea, wounds and so on. (“Disease related discomfort like breathlessness is difficult to bear for me” said Neeta). The nature and type of symptoms changes and they need to attend to it frequently. As a result, fear associated with decreasing quality of life is difficult for children to bear and difficult for parents to helplessly watch their child’s experience.

1.c) Parental understanding of their child’s experience of isolation, social rejection and guilt:

Child’s experience of isolation: Children are forced to be away from their daily routine to avoid opportunistic infections during curative treatment. As a result children experience isolation (“I don’t like Mumbai. I want to be back to my place. I miss my school and friends”). The children who come from out of Mumbai for their treatment are away from their place, school, friends, siblings and other family members (“We are missing our school and especially our friends” mentioned Neeta, Vijaya, Bhavana). Experiencing physical discomfort and additional emotional stress of being away from their own environment is difficult for children.

Child’s experience of social rejection: A few of the children experience rejection from friends or neighbors as a result of social stigma. Children show eagerness to be with their friends and peer group but the friends are not allowed to play with ill child by their parents. As a result the ill child experiences social rejection which is painful for them (“As people came to know about the diagnosis, no friend of Ajmal came to play or speak to him. The people who used to be my friends started hiding their children from us. Jamana bahut kharab hai. (world is really bad) father of Ajmal narrated his experience”)

Child’s experience of guilt: Because of the bed ridden condition, children are being cared for by their parents. The children who are little older in age wish to be a support for their family and when their bed ridden condition forces them to be looked after by their parents they experience stress. Accepting this type of role reversal is stressful for children. Witnessing children in physical as well as emotional pain influences parental stress. A few of the children develop disease related dependency (“I am becoming burden
on them than a support” Santosh). Children who undergo amputation become dependent. Along with physical limitation, their dreams are affected negatively. A child with amputation of lower limb feels sorry for his condition says; “Now I cannot be Sachin Tendulkar”. The parents feel helpless for themselves and sorry for their children (“I am his mother but I am unable to share his pain and his sufferings” Mother of Tarun).

Awareness of life threatening disease, worsening of symptoms, devastating dreams, anticipated eventuality, and fear of unknown and leaving the dear ones behind provokes stress in children. At the same time, it is stressful for parents to watch their child in a lonely and bed ridden condition.

(2). **Parent Variable** includes a) difficulty while performing multiple roles b) difficulty in balancing resources, c) social stigma, d) fear of unknown, e) hopelessness and f) helplessness

2.a) **Difficulty while performing multiple roles:** The parents are expected to perform multiples roles such as caring for the ill child, accompanying him/her at the time of hospitalization, follow up visits, taking care of other children, responsibility of older family members. For the parents who come for their child’s treatment from out of Mumbai, they experience additional difficulties such as lodging, boarding, getting adjusted with strange environment, and so on. Father of Sagar describes about multiple responsibilities and multiple roles which parents have to play in the given situation, (“I am having tough time handling his mother, taking care of financial arrangement, looking after office work, handling routine and in addition hide the true picture from the mother” father of Sagar).

2.b) **Difficulty in balancing resources:** When there is imbalance in needs and availability of resources, stress is experienced (Lazarus & Cohen, 1977). The parents need support in multiple areas to handle this demanding situation. The needs such as getting financial support for expensive treatment such as cancers, getting help to share responsibility of other children, help in bed side caring, getting information and so on. The non availability of resources such as support from charitable trusts, family, friends and lack of access to information creates stress for parents (“I need to be with my child in the hospital then I have to take off from my job. As a result, I lose my one day payment as I do not have a permanent job. If this happens frequently, then who will take care of needs of my other family members” (father of Tarun.)
2.c) Social Stigma: Parents experiencing social rejection or social bitterness, go through stress (“I have decided not to reveal her diagnosis to others as she has a sister to be married. Who will marry my other daughter, if people come to know about having the disease in the family?” Nihita’s father). Parents show their concerns towards other children by protecting them from social bitterness. Anticipated worry regarding seeking marriage alliances for siblings of ill child is a major concern of parents. To conceal the fact from others is stressful for parents. Parents avoid giving details about the name of the hospital to others as the mention of ‘Tata Memorial Hospital’ reveals the diagnosis. The usage of the word cancer is avoided. As a result parents prefer to use word ‘sathi gath (simple tumor)’ or ‘khunki bimari’ for ‘blood cancer’.

2.d) Fear of unknown: Discussion regarding cancer and its prognosis is avoided frequently by the parents. This daunting subject is kept aside to avoid the thoughts related to anticipatory worry. Parents experience fear associated with unknown. They are concerned about the process of death and dying. Disease such as cancer is perceived as a painful disease. The parents are uncomfortable when their child experiences symptoms such as breathlessness. ‘Will he/she choke up at end? How we will recognize the last moment of our child’ is the anxiety expressed by the parents when they listen to the poor prognosis of the disease.

2.e) Parental hopelessness and helplessness: Awareness of limitation of curative treatment, creates hopelessness for parents. To accept the diagnosis of cancer is difficult for parents though the medical science offers a ray of hope of cure. Parents prepare themselves to face the crisis of diagnosis with a positive attitude but when cure becomes difficult, the level of anxiety goes up (“I tried my best initially and still I was not tired. But now I am exhausted as I have lost all my savings and I have lost the battle” stated father of Sagar). To witness the child with advanced cancer and watch him/her helplessly is stressful for parents. Parents express that “we feel sorry for the child but we are not able to share his/her sufferings. We just watch them helplessly”. The role of the parents is considered to protect the child and take care of their well being. But when the illness is not under control, they feel guilty for not performing their role as a protector.
Context in which coping strategies are developed:

“A context represents the specific set of properties that pertain to a phenomenon; that is, the location of events or incidents pertaining to a phenomenon along a dimensional range. It is also the particular set of conditions within which the action/interaction strategies are taken to manage, handle, carry out, and respond to a specific phenomenon” (Strauss and Corbin, 1990, p. 101). These are specific in nature and close to the actions and interactions (Creswell, 2007). To cope with the stressful event, parents seek different coping strategies. These strategies are context specific.

The contextual markers in the study include 1) Awareness of advance stage of disease and, 2) Deteriorating condition of child.

1) Awareness of advanced stage of disease: The parents are informed about the status of their child from the parent unit. The same information regarding the child’s poor prognosis is clearly conveyed to them by the trained professional team of the Pediatric Palliative Care Unit. In addition to these sources, parents guess the poor prognosis through the deteriorating physical condition of child.

2) Deteriorating condition of child: The child presents various symptoms and the pain level goes up (“I cry looking at him and his symptoms. I am his mother but I am unable to share his pain and his sufferings” Mother of Tarun). The parents wish to share child’s physical pain and offer some level of comfort. Just to watch child’s struggle is emotionally painful for parents and they experience helplessness. “God, either cure him or take him back” becomes ultimate wish of parents. Awareness of the unavoidable eventuality and aggravating symptoms of child initiate the process of seeking coping strategies. The aim of treatment changes from cure to care. This paradigm shift becomes the context to plan the coping strategy.

Intervening conditions influencing coping strategies:

The data identified the following six intervening conditions which influence the coping strategies of parents. 1) Parental helplessness while witnessing deteriorating physical condition of child, 2) experiencing stress related to anticipated loss of child, child in pain, 3) parental needs, 4) Age, gender, birth order of the child, number of children in the family, symptoms 5) involvement in
bed side care giving and 6) professional behavior and help offered by Pediatric Palliative Care Unit

The event specific parental needs, painful circumstances and physical condition of child become intervening condition which influences the coping of parents. The demographic details such as age, gender, number of children and child’s distressing physical symptoms influence coping. Anticipating the loss of an only child irrespective of the gender of the child is not easy.

**Single child of family:** This creates vacuum in their life and terminates their role as parents (“He is my only child. I always wanted to have one more child. But my husband was against this idea. He used to feel, that we are not financially well off people. We have gone through extreme financial stress during our childhood so I don’t want my children go through the same. So I want to have only one child. My life revolves only around this child. I have no one to whom I am close to as I am to this child. If anything happens to him, then I will have no reason to live” mother of Shashi). Women who willingly make a choice to be at home over their career, experience stress as their life revolves around their child (“Now when this intelligent and precious son of ours is on the death bed, it is very difficult for us to think about our life after him”). Their dreams and aspirations suddenly come to an end when they understand the terminal stage of disease (“the homeliness will go away with her”) is fear of Hiral’s mother.

**Gender of child:** In the social context, male children are preferred over daughters. Son is valued more because of the social norms. They are considered as the support for parents in their old age. The daughters are ‘somebody’s property’ so they are expected to support their parents. If the parents have only son in the family then a major concern expressed is “who will continue the family name after us?” However when it comes to the loss of the child due to death, the gender of the child does not matter, as the loss is intense irrespective of gender.

**Birth order of the child:** The birth order of the child influences the type of attention and time provided by parents to their children. Parents providing quality time to their children result into more attachment (“We could spend lot of time with these children as there were no other younger children. Though we were occupied with older children still the youngest child grabs
First born child is precious for parents as their parenthood begins with that child ("Being a parent for the first time is special").

**Involvement in bedside caring:** The parents who involve themselves in actual bedside caring experience satisfaction. Parents achieve satisfaction. ("I have done my job and I am happy for that" father of Sagar). They feel that they have done their duty as parents and this helps them cope with the loss of child. Accompanying child in the hospital helps them spend more time together and strengthen the bond of love and trust. The parents who cannot contribute to actual bedside caring feel rejected and sorry. ("Now I feel, as I am financially not sound so I am not involved. They stay with her in the hospital. I hardly come here. I feel rejected. I feel sorry for not contributing in any aspect" father of Komal). This affects the coping negatively. The age, gender or birth order of ill child does not influence the bedside caring. The parents love and care for the children of both genders. The child is considered as the gift of God.

**Help offered by Pediatric Palliative Care Unit:** To deal with situation in a positive manner, parents accept the help by Pediatric Palliative Care Unit and Home Care Team of Tata Memorial Hospital. The Pediatric Palliative Care Unit intervenes to identify, understand, acknowledge their needs and makes attempts to address them with the help of a multidisciplinary professional team and the Home Care Team. The help by the Unit provides support in totality that is for physical comfort for child, psychological, emotional, social and spiritual support for parents. The Unit tries to help the entire family by understanding needs of parents and siblings ("I am happy as my other children are getting fees for their school. Otherwise they could have not continued their education” said father of Ajmal). The Palliative Care Unit tries to arrange vocational training for parents and helps them set up a small scale business. Their rehabilitation is planned as per the skill they have and the training they have already received. Siblings of the ill child are helped by providing school/college fees, school fees and so on.

**Communication by Pediatric Palliative Care Unit:** The Team members of the Unit are particular about selection of right words to convey factual information regarding prognosis of the child. Professional health care givers communicate with parents and children by taking care of pitch and tone of their voice, facial expressions and usage of simple sentences without medical jargons. The trained health care workers attend to the parental concerns, worries and feelings by
listening and observing them. The reliance is on understanding unsaid words, reading between the lines and acknowledging the pauses between the sentences to understand parental experiences. One of the major issues which the Unit deals is to break the bad news to the patient and care givers.

Breaking bad news:

The parents listen to the factual information regarding poor prognosis of the disease of their child from the Team members. The news is broken in an empathetic way (“Every word of the doctor was very compassionate but still difficult to digest” Mother of Lalita said). The parents express their satisfaction about the approach of breaking bad news. The emotional and psychological impact of the understanding of eventuality however does not change. The trained professional health care givers provide a listening ear to their feelings, concerns and thoughts. The Unit understands the difficulty of parents to accept the poor prognosis. The empathetic approach of the team members focuses on providing care in totality to patients.

The disease like cancer influences the entire family due to expensive and long duration of treatment. The Unit provides material and non-material aid to the family. The Unit provides medicines which improves the quality of life of child. Adequate time, patient ear, privacy and space are offered to parents by trained professionals to parents to ventilate their feelings and thoughts (“We received enough time and space to speak and even to ventilate. Her mother kept crying throughout her first conversation at the Palliative Care Unit, however, she felt better later” Lalita’s mother shares her experience). Special efforts are taken to converse in the mother tongue of the ill child and parents to help them to express easily. Home Care Team of the Unit tries to reach out to the ill children at their residence which helps parents to save their time, energy and money (“We are happy about the Home Care concept. Children like Tarun should be seen at home as it is difficult for parents to bring the child who is in a vegetative stage to the hospital”).

Special efforts are taken by the Unit to understand the needs and concerns of the child. The ill children have special needs to be attended to. They are helped to resume their daily activities such as school, college and so on. This helps them to mingle with their friends and influences positive coping. Empathetic way of conversation helps them to ventilate their concerns (“The
child spoke to one of the counselors for a long time. She was alone when the conversation took place. We were scared about the information the girl might have received by the counselor. We were hoping that this session should not affect the mental condition of the child. Later we realized that the child is much more open and composed” express the parents of Lalita). The Unit tries to assess the needs of the ill child, parents and other family members and need based support is provided to them. Children who are willing to return to their native place are helped by giving a reference letter to the local General Physician, contact numbers of doctors and counselors are provided to them. The assurance of continued help is offered to them.

Strategies for coping with advanced stage of cancer of child:
In the presence of above mentioned context and intervening conditions, the parents appoint strategies to help them to deal with child’s terminal illness. The coping strategies are adopted by parents and ill children to deal with the terminal stage of cancer. The strategies adopted to cope with the event by both (parents and children) can be broadly classified as 1) healthy coping, and 2) unhealthy coping.

Healthy Coping by Parents: 1) Initiating ventilation of feelings, thoughts and concerns 2) Preparation of eventuality 3) Accepting support from various sources 4) Parental resilience 5) Parenting style

Initiating ventilation of feelings, thoughts and concerns: A few of the parents take a strategic decision to protect their dear ones from bad news related harm by concealing the factual information and fear of social rejection because of the stigma attached to the disease. The rationale to hide the news from family members generally mentioned is ‘she is very soft at heart’, ‘he is already burdened with various responsibilities then why to bother him more?’ , ‘currently she is physically unwell and this news will collapse her completely’, ‘I have to think about the future of my other daughters, who will marry them if people understand the diagnosis of cancer of their sister/brother?’. These in vivo quotes highlight their sincere wish to guard their spouse or other family members from subsequent sorrow and social stigma.

Though the poor diagnosis is not verbally revealed to the spouse, non verbal expressions of their anxiety and stress is observed by their family members. As a result, the bad news can be guessed
(“I tried to hide the report of malignancy from my wife for almost ten days but she kept asking me after witnessing my anxiety, my stress and my behavior. At last I told her everything and I felt better” father of Hiral). To handle the burden of stress single handedly becomes strenuous and then the primary care giver decides to share the stress with someone (“I felt better when I shared everything with my wife. I felt supported” father of Bhavana). Sharing of feelings help to them cope effectively.

**Preparation of eventuality:** Though difficult, parents prepare themselves for the ultimate loss of their child. They plan the funeral arrangement according to their own religion and rituals. The parents who come to Mumbai for treatment wish to take the child back to their native place. At the same time they worry about possibility of sudden death of the child in Mumbai. (“If anything happens to my child in Mumbai, will he get a place to be buried? The Maulavi understood my concern and gave me assurance that he will take care of the child’s last rites. It is so difficult but I need to think. As we do not stay in Mumbai I am scared that if anything goes wrong on the way, or if he dies during the journey then what would I do? Whether I continue on the journey home, or do I rush to hospital? How do I get access to perform his last rites? It will be difficult for me to handle everything by myself alone. We need to think about the worst. It is certain that one day or the other, he has to be buried” Grandfather of Shoeb). They start working on making decisions like shifting the child back to the native place, to call some relative/family member to be with the child (“I have already spoken to the General Physician (practicing in his locality) and he has agreed to sign the death certificate. It is definitely sad for me to start the preparation of my own child’s funeral but it is inevitable” father of Tarun). These plans help them to prepare for the death of the child which results in effective coping.

When the parents prepare themselves to accept the eventuality they make efforts to speak to the ill child regarding death and dying. The father of Naresh was informed about the life threatening stage of the child. He decided to speak to the child regarding the same. After a while, he initiated the topic of eye donation which was difficult for the child to react on this sensitive issue. The father spoke to him (“As you have understood the poor prognosis of your disease, why don’t you think of eye donation? It should be your decision. I want you think over the same. You can discuss with any professional to clarify your queries. You should do some good deed in this life”). He assured that the child’s wish will be honored (it might be refusing eye donation). This
is an example of practicing healthy interpersonal relationship even after understanding the eventuality. Such healthy and open communication is considered helpful to accept the eventuality and cope healthily.

**Accepting support from various sources:** To cope with this stress, parents look for possible resources providing support. To receive the support from one’s own family members helps them to be motivated to cope with the event. Extended family members, friends, well wishers, community, spiritual groups and belief system, parents/care givers of other ill children and professional care givers are considered as the support systems. They seek various types of support from various sources.

- **Support from family and extended family members:** Family and extended family is considered as one of the pillars of support. Siblings of the ill child try to help the parents by sharing their responsibilities. They come forward to take care of other family members or look after family business in the absence of parents and so on. This helps to strengthen the mutual bond of love and trust (“*My other daughter of six years who herself is a kid, takes care of her two year old younger sister along with her granny*” mother of Naresh). When the parents come to Mumbai, they worry about earning an income as they need to run their house along with bearing the cost of child’s treatment (“*My elder son was taking care of the shop in my absence which kept the money rolling and business remained as it was*” father of Lalita). The parents who need to come to Mumbai for treatment are concerned and worried about the well being of other children. In such a case, the extended family members come forward to share the responsibility of children. (“*My mother who stays at Thane went back to Orissa to take care of my younger son. I am staying at Thane at my parents’ house. I am mentally relaxed as there is someone to take care of my little one who is hardly 5 years old*” mother of Shekhar). Joint family is valued in India as family members receive support from each other. At the time of crisis the entire family tries to help the person in problem (“*As we were part of joint family, my wife could concentrate better on this ill child. My vahini (sister-in-law) looks after the entire house work and our younger child*” father of Sameer).
✓ **Friends- a source of support:** Not only family and extended family members but even friends are recognized as the source of support. The parents feel comfortable sharing their grief and sorrow with their friends because of their close relationship (“I have a friend who is very close to me and I can share everything to him. I used to cry and share my every concern and worry. He used to listen to me. I used to feel supported” father of Komal).

✓ **Support from neighbors, well wishers and employers:** Well wishers are also considered as the source of support; they might be teachers, employers and so on. (“One of the teachers of my daughter is my support system. She was with us from the time of Neeta’s diagnosis” father of Neeta). The support parents receive is of different types. *Mandals* or a group of private donors come forward to help the deserving parents financially. (“Amount was not sufficient to treat the child but the love they showed was encouraging. I felt supported and cared” father of Sagar). ‘Someone is with me’; ‘someone is ready to support me’ is the thought which encourages stressed parents and help them to cope effectively.

✓ **Religious and spiritual belief:** The concepts such as wish of God, destiny, power of Almighty are accepted as a part of belief system. When they understand the limitations of the medical science they rely on these beliefs. To accept the stressful event as a part of God’s wish helps them to cope with the situation (“If Allah has decided to take the child away from me, then He will take her but without troubling her” mother of Sabina). Father of Neeta, accepts the power of God and accepts God’s decision (“If God has decided to take her back then we should not grumble. I must understand that she was never mine. I was appointed just to look after her for a short span”). The event of a life threatening disease is connected with punishment for bad deeds. ‘God is punishing me’; ‘I must have done bad to others in this life or in last life’. When the parents feel helpless they either bargain with God or surrender themselves. Prayers, observing fasts, donating or promising certain amount to some religious place or visiting temples/church or mosque is done with strong belief. They expect God to listen to their sincere request. When the parents accept the eventuality they surrender
themselves to God and accept it as wish of destiny. Parents belonging to religious self help group receive support from other members.

✓ Caregivers of other patients: Parents need to spend time in the ward or OPD with the child. During that period, they become friendly with caregivers of other ill children. (“His age, his religion, his language never became barriers as we were going through the similar problems. We used to cry, share with and support each other” father of Neeta). The parents feel comfortable sharing their concerns with other caregivers in the hospital. The common thread of having a patient in the family helps them to connect. As they form a bond of mutual trust they start helping each other. The help is generally in the form of material or non material help or emotional support as they can relate with each other.

Parental resilience: The event of crisis is considered as challenge and parents face it bravely by using own inbuilt capacities. They focus on the problem and try to seek probable and possible solutions (“My strength multiplies when I am under stress” father of Sameer). The past successful experiences of brave fight over crisis help them to gain confidence. This is irrespective of gender of caregivers; a female caregiver, reported, “My capability multiplies when I am in crisis. I feel brave and confident while fighting with the problematic life events”.

Parenting style: Witnessing the child in the terminal stage of cancer with physical discomfort is agonizing for parents. The responsibility of parents is considered as to educate, discipline and to teach the household chores to their children. They consider these tasks as their duty in the normal course. Being aware of the life limiting condition of the child, parents willingly change or modify their behavior not only towards their ill child but also towards other children. The parents have their unique parenting style to nurture their children. The own parenting style is reviewed once aging and the effectiveness is checked at the time of crisis.

✓ Valuing healthy inter-personal relationship with family: Being aware of the life threatening condition of the child, parents willingly change or modify their behavior not only towards their ill child but also towards other children. (“Previously he used to hardly communicate with the child. Overall behavior of the father has changed now. He tries to spend more time with both the children. He is more soft and loving now” mother
of Shekhar narrated her observation about her husband). Valuing inter-personal relationships over discipline or the importance of open communication within family members, spending more time with children are a few of the strategies that parents willingly implement as changes in their parenting style (“I feel sorry that I was busy worrying about feeding them. I never had enough time to communicate with any of them” father of Komal). Anticipated loss of the child makes the parents realize the importance of investing in healthy relationships and they try to compensate the gaps by providing quality time to ill and healthy children.

✓ Becoming more loving, tolerant and getting involved in bed side caring: The unique parenting style of parents is influenced by the terminal stage of cancer. Loving, pampering and being involved in bed side care giving help parents to deal with the life threatening disease of their child. The goal of parents shifts from ensuring discipline to make the child happy (“I have understood uncertainty of life during this episode. When life is uncertain then what kind of disciplinary patterns can you demand from your children?” father of Neeta expressed his changed thoughts). Parents become more tolerant and caring towards a child suffering from an advanced stage of disease and they make all efforts to keep the child happy. Spending time with each other, letting them ventilate disease related fears by initiating communication regarding issues of death and dying, anxieties and concerns help both children and parents to initiate the process of coping. The parents who are not involved in actual bed side care giving as they need to attend to other family members, busy with job, financial constraints or not being involved by other care givers experience greater amount of stress. It becomes difficult for them to cope with the situation as they carry guilt for not being involved and blame themselves for the same. The parents try and willingly get involved in bed side caring of the ill child.

✓ Enforcing existing parenting style: The parents practice their unique parenting style and the parents who feel that the existing parenting style is helping to cope positively at the time of crisis, make efforts to reinforce it. The parents of Sameer who believed that the child should be brave enough to handle any tough situation. The child had recently
undergone a surgery (lower limb amputation) and was experiencing severe fatigue. The school was considerate and offered a special concession to the child. The school made a special seating arrangement for the child on the ground floor so that he does not need to climb the stairs as the school does not have a lift facility. The child refused the offer and climbed up to second floor with the help of crutches. He appeared for the examination regardless of his disease and passed with flying colors. The parents were proud of their son (“We would have not liked him taking special concession. He has lost just a part of his leg and a human being can survive without that. We are happy that he is ready to face the difficult life situation”). According to the father, such fighting spirit which they encouraged while rearing him is helping the child currently.

**Healthy coping: by ill children**

**Preparation of eventuality:**

The ill children at any age have inherent ability to guess about their illness. The indicators such as growing physical discomfort help them to understand the terminal phase of their disease. It is seen that they prepare themselves for face the eventuality. The children who initiate the process of acceptance show concern for their parents. (“Baba (dad), I know I am not going to survive. But I promise to take rebirth in the same family and choose you as my parents and make both of you happy in the next life” said Sameer). This helps both of them to perceive the death as ‘temporary separation’. The hope of reunion with the family helps coping.

**Expressing the awareness by using metaphors:** A child discussing the death and dying issues is not considered age appropriate. The conversation is not encouraged as death is taboo subject. In such condition the child expresses the self by using metaphors. If the direct verbal communication is not encouraged by the parents, then the children other forms of communication such as sending text messages on mobile, writing notes and so on (“life is a question which has no answer; the death is an answer to which you can’t question, take care dad” Lalita sent a text message to her father).

**Expressing concerns, fear and anxiety:** The ill children worrying about unknown are seen commonly. The concerns such as possible physical discomfort, the process of death and dying
are difficult to anticipate and which create stress. (“Disease related discomfort like breathlessness is difficult to bear for me” said Neeta). The children such as Lalita, little older in age and are able to put their anxiety in words (“I am not scared of death but I am worried about the process. The journey towards death will be painful and I am scared of that”, She expressed her death related fear.) Ventilation of feelings related to fear and anxiety help them to initiate the process of acceptance of eventuality.

**Showing concern towards their parents:** The children anticipate their absence in the near future and try to help their parents to deal effectively with loss. (“Ma, let my clothes remain in cupboard in good condition, so that you can touch them and feel that I am around when I will not be alive” said Charu). Children equally feel sorry for parents. Both of them try to protect each other from the grief and help mutually to cope positively.

When children take initiative to discuss their concern, the communication between them and their parents become more meaningful and open. It helps them to face the event positively.

**Unhealthy Coping by parent:**

**Denial:** Parents refuse to believe the factual information regarding the poor prognosis of the child. Denial is one of coping strategies adopted by parents. Such parents hope for some miracle to take place. (‘I know these are experts and they are informing about the advanced stage of disease but I also know they are wrong and miracles take place. My child will definitely survive’ said father of Naresh). It is seen that the parents try to rely on the false hope. Their thoughts such as ‘everything will be fine’, *nothing can wrong with our child* are sufficient to explain their complete denial.

**Collusion:** As the parents deny the facts, they prefer to avoid the topic of illness of their child. They try and reduce the interaction with their friends, neighbors, or other family members. This non acceptance and false hope of cure negatively affect the process of coping.

**Unhealthy coping by ill children:**

**Change in overall behavior: Getting angry, throwing tantrums and so on:** A few of the children start behave differently. The child known for his/her friendly, sweet and active
nature suddenly starts behaving differently. They prefer to be isolated and willingly withdraw themselves. They get upset when friends/well wishers come to see them. They get angry when are referred to as ‘patient’ (‘She behaves differently at home. She is always angry. She throws tantrums even for small things. She verbally abuses her father. She throws things around” parents of Bhavana shared their observation) Being lonely and isolated created stress for children and if they do not get a chance to express their fear and concerns, it affects their process of coping negatively.

Consequences:

Ultimate goal of selecting various strategies of coping is to face the event effectively. The consequences of using various types of strategies can be divided into two broad types. 1) Parental readiness to understand and accept the poor condition and, 2) Parents having poor understanding of prognosis

Parental readiness to understand and accept the poor prognosis: Those parents who have understood and accepted the disease after the intervention of the staff of Pediatric Palliative Care Unit, have been able to come to terms with the disease/illness and made plans of action to suit the poor prognosis and thus cope with the disease. The material and non material help by Palliative Care Unit helps them to take care of ill child as well as other family needs. They accept service offered by Home Care Team which helps them to save their time, energy and time. Factors influencing good understanding are parental readiness to accept the illness, willingness on their part to plan for the eventuality and also prepare themselves and others for this. Parents prepare themselves to shift the focus from cure to care and focus on the improvement of quality of life. They try to make the child happy. The moments which they want to remain with them even after the demise of child are such as fulfilling the child’s desires by cooking and feeding favorite dish, spending more time with child for more time, and fulfilling the desires of child irrespective of financial constraints. The child from Bengal had a wish to visit few of the places in Mumbai and dine at some five star hotel. The parents recollected her desire and completed them irrespective of financial constraints. They reported, (“her uncle booked a taxi for a day and she enjoyed one day picnic. We took her for dinner in 5 star hotel. Her smile is our goal now”). The parents from out of Mumbai go back to native place so that the
child might get a chance to be with his/her entire family, friends, and siblings and so on. They put in their efforts to encourage the child to resume activities that they pursued prior to their illness. Children are helped to resume their school if their physical condition permits them. This interaction with teacher and friends help them to relive the old good school days and this helps the child to cope effectively with her/his illness. The coping of child influences the parental coping. The parents who accept the child’s life limiting disease, offer symptom control medicines, improved quality of life and happy moments.

The parents having a poor understanding of the prognosis: Such parents expect a complete cure of disease for their child. The ray of hope compels them to deny the poor prognosis of disease of their child. They tend to hide the prognosis from others as it is not accepted by the parents. They hesitate to accept the help from Home Care Team as fear that neighbors, friends or community might understand regarding disease. They lack of ventilation suffocates them. Handling stress alone affects their physical and mental health.

Collusion: As the acceptance is poor, they deny and prefer to keep mum regarding disease or prognosis. Strategic decision of hiding the factual information from patients, other family members, and neighbors continues resulting in additional stress.

Discussion:

The parents who willingly accept the role of protector, when understand the life limiting condition of the child, experience stress. They feel helpless when they anticipate the loss of the child and to witness their aggravating physical discomfort. Parents and the ill child have their own event related needs which affect the selection of coping strategies. To cope with the situation, they seek various types and resources for support. Parents receiving adequate support cope effectively. Imbalance in needs and resources create excess amount of stress and it affects the process of coping. Parental involvement in bed side care giving helps them to cope in health manner. They willingly work on their existing unique parenting style to make the child as they understand the paradigm shift of treatment (cure to care). When the focus of the treatment remains to provide improve quality of life, parents work toward make their child by fulfilling his/her desires. Expressing own concern and encouraging child to ventilate, support provided by Pediatric Palliative Care Unit and other resources help them to cope in positive manner.
The awareness, perception and coping of children influence the parental coping. The mutual love and concern for each other affect the process of healthy coping. Collusion, poor understanding of factual information, and denial are a few of the factors which are responsible for unhealthy coping of both (parents and children).

**Hypothesis developed after generation of the field based grounded theory and which can be empirically tested are as follows:**

- When parents are aware of the poor prognosis of their child’s illness, they experience stress, as the normative role of parents of being a protector is affected.
- When the parents are supported by various network resources they are better prepared to face the eventuality.
- Parents willingly change, modify or reinforce the existing parenting styles to make the child happy when they are aware of their child’s poor prognosis.
- When parental needs are adequately addressed by Pediatric Palliative Care Unit, they are better prepared to deal with the poor prognosis of child as well as to accept the eventuality.
- Healthy and unhealthy coping by parents and ill children is influenced by parental experience of stress, intervention of Pediatric Palliative Care Unit and child related variables such as age, gender, birth order and current symptoms, thus encouraging parents to adopt healthy strategies of coping.
- Consequences of coping strategies are demonstrated by parental preparedness, acceptance, efforts and readiness to deal with eventuality.