CHAPTER: 4

“Life is what happens to you while you’re busy making other plans.” — John Lennon

Findings and Analysis

The chapter aims to analyze the collected data to understand the experience of parents while facing the life threatening condition of their child. The awareness of poor prognosis of the child’s disease, stress experienced by the parents and coping strategies adopted by them is analyzed by using the grounded theory approach. The way the child understands his or her disease, current condition and deals with the crisis are also considered as an important aspect of the data as it influences the parental coping.

The chapter is divided in six sections. Section 4.A describes the participants’ demographic description. This part of the chapter describes the family and social details. Lived experience of parents and children while facing the crisis are described in section 4.B; which explores the needs of parents as well their ill children. Their awareness and understanding of diagnosis and prognosis is discussed in the same section.

The understanding of concept of palliative care is discussed in 4.C and it includes the functioning of the Pediatric Palliative Care Unit (PPCU) of Tata Memorial Hospital.

This is followed by Section 4.D, which contains the description of experience of parental and child’s stress while facing the event.

Section 4.E, describes the various types and sources of support systems used by parents of children to face the event of terminal illness in a positive manner. The next section 4.F, identifies the role of parenting styles in parental coping.

The last section 4.G discusses the effect of various coping strategies on the overall parental coping.
**Section 4.A**

**Demographic Profile of participants (parents) and their ill children**

The data is collected at Tata Memorial Hospital, Mumbai by interviewing the parents of the children in the terminal stage of cancer. Table 1 describes the demographic details of the ill children. The names of the children are changed to protect their identity.

Table 1

<table>
<thead>
<tr>
<th>Sr No</th>
<th>Patients’s name</th>
<th>Age</th>
<th>Gender</th>
<th>Education</th>
<th>No. of siblings</th>
<th>Birth order</th>
<th>If local resident</th>
<th>Diagnosis</th>
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<tr>
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<td>F</td>
<td>7th</td>
<td>3</td>
<td>3rd</td>
<td>No</td>
<td>PNET</td>
</tr>
<tr>
<td>2</td>
<td>Charu</td>
<td>10</td>
<td>F</td>
<td>5th</td>
<td>1</td>
<td>0</td>
<td>No</td>
<td>Soft tissue</td>
</tr>
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<td>6</td>
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<td>1st</td>
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<td>0</td>
<td>Yes</td>
<td>Glioma</td>
</tr>
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<td>Komal</td>
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<td>F</td>
<td>7th</td>
<td>3</td>
<td>2nd</td>
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</tr>
<tr>
<td>5</td>
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<td>19</td>
<td>F</td>
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<td>2</td>
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<td>Yes</td>
<td>osteo sarcoma</td>
</tr>
<tr>
<td>6</td>
<td>Mehru</td>
<td>17</td>
<td>F</td>
<td>9th</td>
<td>3</td>
<td>youngest</td>
<td>No</td>
<td>PNET</td>
</tr>
<tr>
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<td>Neeta</td>
<td>8</td>
<td>F</td>
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<td>12</td>
<td>M</td>
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</tr>
<tr>
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<td>18</td>
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</tr>
<tr>
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<td>Ajmal</td>
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<td>3</td>
<td>2nd</td>
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</tr>
<tr>
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<td>Sagar</td>
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<td>M</td>
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<td>9</td>
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<tr>
<td>13</td>
<td>Shashi</td>
<td>14</td>
<td>M</td>
<td>9th</td>
<td>0</td>
<td>0</td>
<td>No</td>
<td>Liver</td>
</tr>
<tr>
<td>14</td>
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<td>10</td>
<td>M</td>
<td>2nd</td>
<td>4</td>
<td>eldest</td>
<td>No</td>
<td>PNET</td>
</tr>
<tr>
<td>15</td>
<td>Sameer</td>
<td>11</td>
<td>M</td>
<td>5th</td>
<td>1</td>
<td>eldest</td>
<td>Yes</td>
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</tr>
<tr>
<td>16</td>
<td>Shekhar</td>
<td>6</td>
<td>M</td>
<td>KG</td>
<td>1</td>
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</tr>
<tr>
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<td>Sandhya</td>
<td>15</td>
<td>F</td>
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<td>3</td>
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<tr>
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<td>youngest</td>
<td>Yes</td>
<td>Osteo sarcoma</td>
</tr>
<tr>
<td>19</td>
<td>Tarun</td>
<td>6</td>
<td>M</td>
<td>1st</td>
<td>2</td>
<td>youngest</td>
<td>No</td>
<td>Brain stem Glioma</td>
</tr>
<tr>
<td>20</td>
<td>Vijaya</td>
<td>11</td>
<td>F</td>
<td>5th</td>
<td>2</td>
<td>youngest</td>
<td>Yes</td>
<td>PNET</td>
</tr>
</tbody>
</table>
Parents of these children, either the mother or father have been interviewed as they are primary care givers. Faizal and Seema are not cared for by their parents so their paternal grandparents and paternal aunt have been interviewed respectively. Mother of Faizal is busy in taking care of his four younger sisters (2 yrs to 8 years of age) at their native place and his father, being the only earning member of the family (rickshaw driver) cannot afford to come to Mumbai. In such a difficult situation, his paternal grandparents willingly came forward to take care of the ill child. They accompanied the child from the inception of the disease. In the case of Seema, though willing, her father is not physically fit to take care of her. He has been paralyzed for the past few years and is currently bedridden. Her mother lacks the confidence to travel independently to Hospital, meet with the doctors and handle all responsibilities related to the disease. Her aunt, who is their next door neighbor, has proved to be helpful and has been actively involved from the beginning.

Table 1 mentions the gender, age, the number of children in the family and type of cancer the child has. The age of children ranges from 6 years to 19 years. The data includes parents of 11 female and 9 male ill children. The way children perceive the disease and prognosis depend on their age and understanding. Based on their knowledge, they cope with their illness.

Figure 1: Age wise classification of children

![Age wise classification of children](image)
All children are enrolled in the general category of Tata Memorial Hospital for cancer treatment. All of them are referred from the parent unit of the Hospital to the Palliative Care Unit, except one who was referred from the Lokmanya Tilak Medical General Hospital-Sion, Mumbai. Out of 20 children, 11 children are not from Mumbai and have come for treatment of their cancer.

Table : 2

<table>
<thead>
<tr>
<th>No</th>
<th>Name</th>
<th>Father's occupation</th>
<th>Mother's occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Bhavana</td>
<td>Cobbler</td>
<td>Homemaker</td>
</tr>
<tr>
<td>2</td>
<td>Charu</td>
<td>Private company</td>
<td>Homemaker</td>
</tr>
<tr>
<td>3</td>
<td>Hiral</td>
<td>Rickshaw driver</td>
<td>Homemaker</td>
</tr>
<tr>
<td>4</td>
<td>Komal</td>
<td>daily wages</td>
<td>Homemaker</td>
</tr>
<tr>
<td>5</td>
<td>Lalita</td>
<td>Shop</td>
<td>Homemaker</td>
</tr>
<tr>
<td>6</td>
<td>Mehru</td>
<td>Retired-private company</td>
<td>Homemaker</td>
</tr>
<tr>
<td>7</td>
<td>Neeta</td>
<td>Tea stall</td>
<td>Homemaker</td>
</tr>
<tr>
<td>8</td>
<td>Naresh</td>
<td>daily wages-farm</td>
<td>Homemaker</td>
</tr>
<tr>
<td>9</td>
<td>Ramesh</td>
<td>Retired-teacher</td>
<td>Retired-teacher</td>
</tr>
<tr>
<td>10</td>
<td>Ajmal</td>
<td>Barber</td>
<td>Homemaker</td>
</tr>
<tr>
<td>11</td>
<td>Sagar</td>
<td>compounder/clerk</td>
<td>Homemaker</td>
</tr>
<tr>
<td>12</td>
<td>Sabina</td>
<td>diamond cutter</td>
<td>Homemaker</td>
</tr>
<tr>
<td>13</td>
<td>Shashi</td>
<td>Private Company</td>
<td>Homemaker</td>
</tr>
<tr>
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<td>Faizal</td>
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<td>Homemaker</td>
</tr>
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<td>Sameer</td>
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<td>Homemaker</td>
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<td>16</td>
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<td>Homemaker</td>
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<tr>
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<td>Sandhya</td>
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<td>domestic work</td>
</tr>
<tr>
<td>18</td>
<td>Seema</td>
<td>Unemployed</td>
<td>domestic work</td>
</tr>
</tbody>
</table>
Table 2 describes the occupation details of the family of ill children. The parents of children are engaged in various types of occupations ranging from daily wage earners to those employed in the private sector. Besides one, all other families have a single earning member. Two families have female bread earners as the male members of the family are bedridden and therefore not in a position to earn a livelihood. Furthermore, parents of two families are retired and do not have any other source of income.

The number of children in the family ranges from only child to five children. Four families have (4.20%) only one child. To anticipate the loss of their only child is a threat to the parenthood, as the parents remain with no role as parents. 5 (5.25%) are first born children of their family. 3 (3.15%) are second born and 1 is third born children respectively in the family of interviewed parents. 7 children are the youngest in the family.
Tata Memorial Hospital, being a well known hospital, people from different religions and states of India come for treatment. They have different cultural and linguistic back ground which affects the overall process of adjustment in the strange place such as Mumbai.
Section 4.B

Experiencing cancer

This section addresses parental experiences at the time of diagnosis of cancer and poor prognosis. It also includes parental perceptions regarding the child's understanding of cancer, and their experiences with the Pediatric Palliative Care Unit at the Tata Memorial Hospital, Mumbai.

4.B.1- Parental Perception of the Child's understanding and experiences of cancer:

A disease such as cancer is perceived as a life threatening disease by adults as well as children. It is observed by the researcher that when the person is referred to Tata Memorial Hospital by a General Physician, the first striking thought is ‘oh, I am finished.’ The perception towards the disease influences the degree of coping.

Ill children and their parents experience disease related stress. The way children cope with the disease affects the overall coping of their parents. Factors such as age, understanding, perception, communication patterns and availability of resources influence the coping of the ill child.

Child’s awareness /understanding the disease

According to the mother of 20 year old Mehru who told her, ”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.”

Tata Memorial Hospital is synonymous with cancer. To even get a referral to this Hospital is daunting for people. Generally, patients guess the diagnosis as soon as they start their treatment at the Hospital.

Mother of 11 year old Vijaya quoted her daughter, “I have seen my mother crying many times. So I guess this is a disease which is difficult to cure.”

When the information is not disclosed to them by their parents, they then make attempts to gather information about their own disease through various sources such as doctors, nurses, case files, and other patients.
Father of 19 years old Sagar said, "My son of 19 years reads the file and asks about the difficult words to the doctor and tries to get complete picture of his disease."

Children show a keenness to understand the truth. The children have an intuitive ability to read between the lines, observe the parental facial expressions, and also the non verbal communication between their parents. Children develop a habit to observe and sense the overall behavior of their parents and other family members when they feel that some fact is concealed from them. Few of the children who witness anxiety and stress of the parents in their behavior come forward and attempt to find out the reasons for the same. When the parents do not confide in their children about their concern, the children then take the initiative to procure the correct information by discussing it directly through various sources at the hospital. It is noted by the researcher that questions like, 'what was the doctor speaking to you about?', 'which disease do I have?', 'why was mom upset after receiving my reports?' and so on are asked by children to their parents. It is seen that the parents face problems while answering these uncomfortable questions. Hence efforts are made to hide the information. In one of the cases, the child read the diagnosis of ‘Leukemina’ (a type of blood cancer) and asked a direct question, "do I have blood cancer?"

The parents thought for while and said, “nahi beta. Ye sadhi khun ki bimari hai (no, this is a simple blood disease)”. When they do not get satisfactory answers from their family members, then they try to seek information from other sources. They try to get the information from files, by speaking to doctors, nurses and other paramedical people. Their need to know is evident through their actions and words.

Theme: The children intuitively observe parental verbal and non verbal cues and guess about the seriousness of their condition then they attempt to seek information about their disease from various sources.

4.B.2 Children’s desire and attempts to discuss:

It has been observed that the children convey their willingness to discuss the topic of the disease openly. Children use different means to communicate their knowledge and awareness of the disease and prognosis. They understand the worry of their parents and they express their concern towards them.
The father of 20 year old Lalita received the message on his mobile phone from her “life is a question which has no answer; the death is an answer to which you can’t question, take care dad.”

Older children feel sorry for their parents as they witness the helplessness of their parents. If the disease and probable death is not discussed openly in the family they choose alternative ways of communicating their thoughts. Writing a note, sending SMS on mobile phone are some of the few ways used to express themselves.

**Parental understanding of child’s perception of disease**

The researcher attempted to understand the perspective of the child regarding his/her disease from various sources such as parents, counselors and doctors of the Palliative Care Unit. According to these sources, the children think about their disease, gather information and create a picture of the disease in their mind. This picture is based on their understanding and awareness. Their perception influences their coping process. The general perception of the children towards cancer is “it is a fearful, painful and a bad disease which takes you towards death.”

According to her mother, Mehru feels, “it is something which is incurable and definitely painful.”

Vijaya expressed her thought regarding the disease to her mother, “this is something which is very painful.”

The counselor of the Unit noted the perceptions of Naresh, Charu and Komal, they said, “it is a BIG disease.”

While having a conversation with the counselor, twenty year old Lalita initiated discussions regarding her prognosis. According to her, she is aware of her poor prognosis.

Lalita said, “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,”

Neeta shared her concern with the doctor by saying, “disease related discomfort like breathlessness is difficult for me to bear.”
The researcher has noted that patients of all ages perceive this disease as fearful, life threatening and a painful disease. One of the patients said, “Going to Tata (Tata Memorial Hospital) means saying tata (good bye) to the world.”

When the patients articulate their experiences related to physical pain, they use metaphors to express their ideas of death as death is perceived differently by them. They are concerned about pain associated with both, illness and death. The physical pain and discomfort are issues that they anticipate to contend with. However they do not openly discuss their emotions related to death.

The researcher has observed that in the Indian context, death is taboo. The subject of death and dying is avoided by the ill as well as healthy persons. The children who grow in this environment also tend to avoid the use of the word ‘death’. They prefer to use metaphors and express their concern regarding the eventuality. Quotes such as ‘I will not be there for my next birthday’, or ‘touch my clothes when I won’t be around’ are self explanatory. The children avoid the word ‘death’ and still convey their understanding of the eventuality.

The parents experience dilemma while addressing the issues of death and dying, and the child also avoids the usage of the word ‘death’. Advanced stage of the disease aggravates the physical symptoms. It is noted by the researcher that it is equally difficult for parents to see their child suffering. The parents feel helpless as they cannot share the physical pain with the child. The child suffering from unpleasant physical symptoms such as pain, breathlessness, wounds and edema creates stress for patients as well as parents and hence affects their coping.

Theme: when children are unable to talk openly about their death they use metaphors to discuss death and cope with it.

Theme: The negative perception of cancer as being life threatening, painful and a scary disease influences the coping of children and therefore that of parents too.

4.B.3 Child experiencing isolation and rejection

A disease like cancer needs treatment for a long duration. The chances of opportunistic infections are high if the child is exposed to others. The children are separated from their friends,
family and siblings to avoid these infections. It restricts the child from being with friends to play, to attend school, classes and participate actively in school or college events. Frequent hospitalization and difficult therapy administration upset their routine. The children go through the trauma of isolation along with the accompanying physical discomfort. They start missing their friends, school and teachers. Children, who come to Mumbai for their treatment leaving their siblings behind, miss them a lot as they do not get a chance to meet them for several months. This loneliness adds to their distress. “If adolescents are unable to attend school or join in social activities this can leave them socially isolated and lonely” (Amery et al. 2009:293).

Two younger sisters of Naresh are at their native place with their grand-mother. He misses them a lot.

*Neeta, Vijaya, Bhavana* mentioned to their parents that, “*we are missing our school and especially our friends.*”

*Vijaya* said to the counselor, “*I used to feel better in the school as that environment would take me away from the disease related thoughts.*”

*Shekhar* spoke to his mother and expressed his wish to be taken back. To that he said, “*I don’t like Mumbai. I want to go back to my place. I miss my brother, school and friends.*”

It becomes difficult for children to get acquainted with an entirely new environment when they come to Mumbai for treatment. Long duration of treatment, need for frequent hospitalization and various side effects of therapy create stress for children. The sudden change in routines and being subjected to difficult cancer treatment is a rude shock for them. It is seen by the researcher that when the children (and even parents) come to Mumbai, they are not aware of the duration of treatment. When they are asked to extend their stay for months, it comes as a shock to them. Witnessing one’s own children being taken away from their familiar surroundings and the isolation experienced by the child influences the coping of parents.

Side effects of cancer treatment such as hair loss due to chemotherapy, darkening of skin due to radiation, amputated body part (surgery), loss of appetite, weight loss, vomiting, and being unwell makes them uncomfortable. The researcher has noted the following observations. Forced
isolation, deteriorating physical condition and change in routine creates distress. As a result, the children become confused and their relationship with their parents, neighbors, friends, siblings is affected. Children often use their own ways to deal with this situation by avoiding strangers, visitors. They also get angry, irritated and express this anger by throwing tantrums.

Father of Ajmal narrated his experience after his child was diagnosed with cancer. Ajmal is friendly by nature and he likes to be a part of his group of friends. When his diagnosis of cancer was revealed to his friends, suddenly they started avoiding him. He had no one to play with. He used to feel lonely as he was advised not to attend his school and his friends staying in his neighborhood started avoiding him. Gradually he started preferring to be aloof from others. He became close to his elder brother after experiencing isolation and rejection from his own peer group. The father used to feel sorry for the child and used to spend more time with him. The children who get a chance to be with their friends cope effectively with the disease.

Komal’s father narrated an experience. One of the friends of Komal suddenly stopped visiting and playing with her. According to the father, Komal must have revealed about the diagnosis to her as she is very close to that friend. The father feels that the child might not have thought about the after effect of disclosing the news, hence, she might have shared her concerns. The father feels sorry to see the child being alone at home.

Theme: When children have to be away from school, friends and family they experience isolation and this influences the coping of children.

Theme: When children experience social rejection, parents feel helpless as it is difficult for them to witness the child’s experience of loneliness. This affects parental coping negatively.
4.B.4 Child’s experiences of disease related dependency, guilt and sorrow

Along with temporary side effects of therapy, few children need to go through amputation.

**Sameer and Shekhar** said, “amputation was the biggest issue to face than the entire cancer treatment.”

**Sameer** who had a dream to be a cricket star like Sachin Tendulkar, was subjected to lower limb amputation and at that time he said, “now I cannot be Sachin.”

“The loss of body parts can give rise to grief for loss of body image or function or both. Anxiety, depression and sexual problems are related to the magnitude and type of loss as well as the personal vulnerability of the patient”(Maguire and Parkes, 1998: 1086). Amputation limits their routine activities. Daily activities such as walking, running or even moving around at home is restricted if the lower limb is amputated. It becomes difficult for a child to be on the bed all the time. Prosthesis is not an option which suits all children after amputation. Factors such as stage of disease, overall condition of the child and type of amputation determine the usefulness of prosthesis. Children who have been amputated and who have a keen interest in sports or outdoor activities, go through added trauma. Their amputation is not restricted only to their body image but also to the consequent physical disability which takes them away from their dream.

Vijaya had a surgical procedure as a curative therapeutic intervention. As a result of this treatment her face became distorted. Disfigurement is the biggest worry for her. Her face is affected and eyes are protruded. Vijaya being a female child, her mother is also concerned about this. According to the mother, “a girl needs to look beautiful”.

Sandhya is concerned about the partial blindness which she has developed due to the disease. Her vision is becoming weak day by day. She is scared of becoming totally blind.

Functional ability is severely affected in the case of Sabina. This active and naughty child is becoming dependent gradually. Her parents are worried and concerned about her. They do not let her move alone as she might fall down as her motor control is affected.

While expressing her concerns to the physician of Palliative Care Unit, 9 year old **Sabina** said, “I get angry with my parents as they do not let me be alone. But at the same time I
get irritated because I have to accept that if I decide to be alone I cannot. I am becoming dependent and need them. I don’t know how to handle this.”

“The perception of the loss of personal control is exacerbated by illness and worsened by the tendency of parents to become overprotective at such traumatic times” (Amery et al. 2009:293). Children experience severe fatigue and therefore it becomes difficult for them to move around because of the advanced stage of cancer. They need to depend on others even for little movements. This deteriorating physical ability and increasing dependency creates stress. The researcher’s observation has noted that for an adolescent patient to become dependent is the biggest distress for them. It is difficult for them to accept the deteriorated functional ability. The adolescent children experience stress related to their future. They express their concern regarding finding a life partner. According to ill children as well as their parents, it is difficult for them to find a life partner even if the person survives the cancer. No one will come forward to accept the cancer patient as their spouse.

Currently Mehru is staying with the family of her aunt in Mumbai. She is close to her cousin as both of them are of same age and frequently shares her anxiety related to her future.

While conversing with her cousin Mehru, a girl of marriageable age said, “even if I am cured, who will marry me? It is alright to be in the family till the parents are alive but after them I will be a burden on the shoulders of my bhai and bhabhi (brother and sister-in-law).”

She experiences stress associated with guilt of being a burden to others. This guilt is not associated with actual bedside care giving but the accompanying uncertainty and distress of being dependent on others in the future.

Children go through guilt. They feel that they are burden to their family members. Adolescent children like Sagar, Lalita and Sandhya feel sorry as they are not able to perform their duty towards their parents because of their disease.

Sagar in his bed ridden condition feels, “I am becoming a burden to them than a support.”
As per the notes of the Counselor of Palliative Care Unit, Lalita had a dream to become a support to her parents. She is an intelligent girl with excellent academic progress. Her desire was to find a good job and achieve financial security to support her parents in their old age.

*Lalita* feels, “I had a dream to offer a comfortable life to my parents in their old age but…”

*Sandhya* feels, “my father is bed ridden, my brother is not concerned about us so I was hoping to give some comfort to my mother but I am dependent now. I am increasing her problems and worries.”

Adolescents feel sorry and guilty for not performing their duty as a ‘grown up’ child of the family towards their parents. They express their guilt for being cared for by their parents. Their wish to become a support system for the family and especially to their parents is unfulfilled because of their poor physical condition.

According to parents the diagnosis of this disease comes as a shock for children as well as for parents. The hope of cure diminishes as the child enters the advanced stage of cancer. If the child becomes bed ridden and dependent because of the life threatening condition, parents experience stress and helplessness. Adolescent children find it difficult to accept the disease related dependency and feel sorry for themselves and their parents. This role reversal is hard to accept for adolescent children.

*Theme: When the disease condition worsens, children become dependent on their family members. This role reversal is stress inducing for them.*

4.B.5 Understanding of needs of terminally ill children and their parents:

**Parental Needs:**

The patients and care givers go through a range of problems at the time of diagnosis. Most of parental needs are similar, still few of the needs differ from case to case based on their demographic details like their place of residence, type of family support available, additional responsibilities of family, other children and so on. They need support in the form of getting material and non material help. They need to receive non-material help such as, proper and
timely information regarding the disease, side effects and details regarding working system of the hospital. To get financial assistance to bear the expensive medical treatment becomes one of the major needs. Emotional support is also expressed as a parental need. “Many families are affected emotionally, financially and physically by the burden of caring for children with life threatening or chronic conditions requiring complex care at home” (Monterosso, 2007:690). To deal effectively with this life event, parents need empathetic behavior from others. A well trained professional system taking care of their issues is value by the parents.

**Getting access to right information:**

12 year old Bhavana was treated at a private nursing home for a while immediately after diagnosis. The charges were heavy for this lower middle class family to bear. Because of the financial stress, the family decided to shift the child to the Tata Memorial Hospital. The father spoke about the experience he had at the time of curative treatment phase at the Tata Memorial Hospital. The father was called by the Oncologist to discuss the treatment protocol. While narrating that incident,

> her father said, “the treatment protocol was discussed with me, which included chemotherapy, radiation and surgery. The estimated cost of treatment was almost one and half lakhs. I was scared. It was impossible for me to arrange such a huge amount. I could not think anything other than making financial arrangement at that time.”

Father of Naresh was informed about the advanced stage of disease. He was stressed and his brother came all the way from his native place for his sake.

> The father said, “my brother came forward to support me in this difficult situation in life. It is important to have one’s own people around. When my brother came for me, I felt very good as he could recognize my need.”

Faizal was diagnosed with cancer at his native place and he was brought to Mumbai for treatment. The grand-parents, who are primary care givers of the child, were confused. They requested one of the relatives to help them. They paid for tickets, food and stay in Mumbai.

> The grand father said, “he explained to me about the registration, making file and where and how to get treatment. As and when I felt confident, he went back.”
The initial period of hospitalization for treatment and to understand the procedure of registration, getting appointments of doctor, carrying out different tests of child create stress for parents. They express the need for proper and timely sharing of information.

Diagnosis or poor prognosis of cancer is difficult to accept. It is noted by the researcher that parents need emotional support. The support received from family, professionals and friends is valued by the parents. Stress and anxiety has been observed amongst the care givers due to the presence of the fear of the known and unknown.

*Theme: Parental stress can be mitigated if their needs of emotional and or financial support and access to right information are provided at the early stage of hospitalization.*

**Needs of parents from out station:**

Some of the patients coming for their treatment to Tata Memorial Hospital are not from Mumbai. These people go through a different set of problems like arranging for their lodging, boarding facilities. They have to stay away from their family as it is not possible to shift to Mumbai with the entire family. It is seen that either of the parents and some other family members accompany the child. It is expressed by the parents that though these issues are difficult to handle, they try their best to adjust. Strong hope for cure helps them fight positively with these hurdles. But as soon as the hope of cure is minimized they lose interest to continue to be in Mumbai. In such a condition parents as well children prefer staying in their own environment amongst their own people. Along with the urge to go back to their native place, they start worrying about the management of possible symptoms such as pain, wounds, breathlessness, vomiting and so on. It becomes difficult for them to take the decision to shift back to their native place. Getting assurance of extended support even after leaving Mumbai helps them feel supported.

*Parents of Lalita said,* “we are very keen to go back to our native place. We are missing our family members for months. The mobile numbers of doctor and counselor are given to us by this department along with the reference letter to the local physician. These assurances are supporting us psychologically.”
Mother of Naresh said, “I am waiting to go back to my place. I am missing my daughters. I am sure that they are also missing us. Naresh might feel better when he will see his sisters after a long time.”

Mother of Mehru said, “my daughter-in-law is looking after our family very well. I am not worried about them, still we both (mother and child) are eager to go back. If needed, we will call the doctor of the Unit.”

To deal with this problem, a referral letter by Palliative Care Unit is given to their local physician (not an oncologist) along with the mobile numbers of doctors and counselor. It becomes easy for local General Physician to treat the symptoms. The physician can have a word with the doctor of Palliative Care Unit in case of any need or emergency. This arrangement helps the child and parents, as the child can be shifted to the native place and the parents thus feel supported. The phone call facility was acknowledged as a pillar of support as they felt connected. This service helps parents cope with the stress.

Theme: Additional help by Palliative Care Unit team helps care givers to cope better when the patient returns to the native place.

Needs of the parents and patients from different culture and language:

To express the self and especially about a stressful event like having a terminally ill child is the need of the parents. Being a premier and a well known hospital, patients from India as well as outside India are treated in the Tata Memorial Hospital. People belonging to different cultures, language, religions, regions, countries and states are treated here. Due to the different linguistic backgrounds, the patients experience a barrier in communication as it restricts their expression of thoughts, feelings and concerns in an effective way.

Parents of Shashi and Shekhar (both having Bengali as their mother tongue) said, “We were comfortable speaking in our mother tongue. Of course we know Hindi but we don’t think speaking in any other language than mother tongue is comfortable.”

Father of Charu having Bengali as his mother-tongue spoke about the volunteer who is from Assam and can communicate very well in Bengali. That volunteer was a great help to this
Bengali family from the time of curative treatment. He used give explanation regarding disease, side effects and treatment protocol and so on to the parents of Charu.

*Father of Charu said*, “I know and understand Hindi. But it is easy to understand information regarding disease in one’s own mother tongue.”

Mother of Shekhar (having Bengali as her mother tongue) also narrated an incident underlining the communication gap because of the language barrier. When the child was undergoing curative treatment, the treating Oncologist spoke about the follow up dates. Mother was the only attendant at that time with the child in OPD. As is not much comfortable with Hindi, she could not understand this important information. She missed the next follow up visit. Afterwards one of the family members checked with the file entry and came to know about their misunderstanding. Then the child was brought immediately for further treatment management. According to her not only prognosis but follow ups dates, protocol status has to be informed in the mother tongue of patients/care givers. Currently the child is in the advanced stage of the disease and his mother blames herself for delaying one follow up visit because of lack of understanding.

The need to express their feelings and emotions is acknowledged by the patients as well as care givers. It is easy for a person to express himself or herself in her/his mother tongue. In the Palliative Care Unit, conscious efforts are taken to allocate a health professional speaking the same language as the patient and care giver. The counselor who knows to communicate in Bengali will receive the case files of the patients who speak Bengali. It is observed that the communication becomes easy and effective resulting in early rapport building.

**Theme: Caregivers feel comfortable communicating in the mother tongue when professionals make extra efforts to speak in the language of the patient and care givers to create better trust and build rapport.**

To be attended to and getting enough time by professionals satisfies the patients and care givers. It is seen that parents have specific expectations from the health professionals such as doctor, social worker, nurses, and counselor and so on. Being attended patiently by giving adequate time, privacy helps them to develop the mutual bond of trust. As a result it becomes easier for them to clarify their doubts. It is observed that the care givers need the expected behavior of
treat ing health care professionals as it help them to cope effectively with the disease of their child.

Need for empathy, privacy, time and a listening ear:

**Parents of Naresh, Sagar, Komal, Sandhya, Lalita, Sameer and Ajmal said** “we were feeling homely as enough time was given to us. Even the doctor madam was not in hurry to finish the pile of files. She never hinted us to ‘go’ from her body language.”

**Father of Lalita said,** “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.”

**Father of Ajmal said,** “my child is under treatment since last 3 years. The parents get hardly two minutes from the doctor as they are very busy with many patients. Even we as care givers feel awkward to ask our doubts or express ourselves. Madam never grumbles here. The people here are ready to talk, listen and answer. It is something that I appreciate.”

The parents feel satisfied when enough time is given to them in the Palliative Care Unit. It is difficult for busy clinics to devote more time for the patients and their care givers because of a heavy patient load. In such clinics or Out Patient Departments their physician cannot spare ample time for patients and care givers. So while comparing these over loaded departments, Units like the Palliative Care Unit makes them feel satisfied and happy as they can address and thrash out their queries.

It is difficult for the parents to express themselves in front of other family members, their child or other people. Providing enough privacy for the parents to ventilate their concerns and worry is essential. This helps parents cope with their stress.

**Father of Sameer said,** “I am happy that my concerns are well acknowledged by the doctor. I was alone in the room and could speak about my worries. The child was attended to by a counselor. Once I cried in front of her but I never felt embarrassed as I know I will be accepted here as I am.”
Parents of Naresh are not comfortable sharing their feelings in the presence of each other. According to them, every individual needs space and privacy to express the self.

_Father of Naresh feels_ , “the need to talk separately with mother and father is recognized in this Unit. Both of us have different mind sets. It is difficult to express in front of the spouse for both of us. My wife is happy about the Palliative Care Unit as she feels that less educated people like her are also treated with dignity. The first interaction with the doctor was very soothing. When she came to see the child in ward the first time, the child was fast asleep. She never disturbed him at that time. Once again she came to see him when he was awake.”

Parents feel happy about such sensitive behavior displayed by professionals and this helps to build a strong rapport.

_Parents of Neeta said_ , “Madam was looking relaxed and was not in hurry to finish the files. She was ready to answer all my queries.”

The body language of the medical professionals is also observed closely by the parents. The relaxed and welcoming gesture of the doctor assures them. The parents expressed their satisfaction with the type of response they received from the respective doctors treating their child.

_Mother of Sandhya said_ , “my daughter has many symptoms which keep troubling her frequently. Generally I receive the medicines for fifteen days but I need to attend the OPD frequently as she gets different types of symptoms every time. But I am happy that though I come frequently no one grumbles and treats me in the same way as I was treated the first time.”

In general every hospital practices the appointment based patient care. The protocol plans are fixed and patients follow those dates. The Palliative Care Unit does not expect the patient to attend the clinic as per the appointments. Medicines are given for a specific period (15 day or 1 month) as per their physical condition. At the same time, they are informed about open door policy of the Unit. It means that they can approach the Unit any time even before completing the given course of medicines. The service is availed to patients as per the needs of patient. In the
advanced stage of disease, the symptoms are generally unpleasant and unpredictable. The open-door-policy of the Unit helps them feel confident that they can approach the Unit whenever they need the medicines or any other help. This assurance of availability at the time of need helps the patients and parents to feel supported.

**Parents of Sameer said,** “the experience in the Palliative Care Unit was very pleasant for both of us. A talk with a counselor in this unit was very assuring. At some places you are considered special in the first meeting and then you become one of many. But this place is full of warmth and it is same for all. “

The need of the parents and children to ventilate is acknowledged by the Unit. The multi-disciplinary professional team tries to provide a conducive atmosphere that permits free expressions of thoughts and feelings. This encourages them to speak about their concerns, needs and issues.

The care givers often have many doubts and queries. Many of the doubts might be ‘silly’ for the professional but are very important to the care givers. They feel satisfied when all their queries are attended to and explained in easy and comprehensible words. The care givers are satisfied when professionals spare enough time for them without grumbling. Body language, tone, pitch and selection of words used by Palliative Care Unit Team members are consciously noted by the care givers. These gestures create rapport between the care givers and health professionals. They feel comfortable and can express themselves without hesitation. It is seen that just to get answers is not sufficient for care givers but the way they are attended to, is important to them.

**Theme: Devoting more time, undivided attention and offering timely assistance by the Palliative Care Unit is acknowledged as a support system by parents.**
Parental need to get emotional support while listening to bad news:

The care givers and the patients who step into the hospital hope for complete cure. They make all attempts to see their child in the best of health. The hope of complete cure makes them go through financial, social, psychological, emotional and spiritual stress.

The moment they are informed about either the poor prognosis of the child or the advanced stage of the disease of the child, the bad news breaks their heart. In the Palliative Care Unit the bad news is broken either by a psychologist, trained counselor or a doctor. The reactions of care givers at the time of breaking the news differ from one care giver to the other.

It is essential to make the care giver aware of the prognosis of the child. Awareness of the fact though bitter, helps them to cope with the eventuality. Parents get enough time to accept the poor prognosis. It is seen by the researcher that, parents try and use this time thereafter to make the child happy. They make efforts to be with the child, and satisfy the child by fulfilling his/her wishes. Many children have wishes such as going back to the native place, spending some time in school or with friends. If the physical condition of the child permits, efforts are towards fulfilling these needs. For example if the child is keen to attend school, then a special request call or a letter is sent to the Principal. The child is allowed to attend school as per his/her wish and physical ability. It is seen that rules of the school are relaxed. This arrangement is possible as the school also wishes the best for their student. If the child wishes to visit some specific religious or historic place, then necessary arrangements are made either with the help of some NGO or some private donors. It is seen that this time is used to strengthen the bond of love and affection between the child and parents. Not only parents but also grand parents, siblings and other family members also come forward to make the child happy. The grieving parents expressed that these moments satisfy them. These memories are expected to help the parents cope with the loss of their children eventually.

This situation is handled in an empathetic manner. The knowledge of the care givers or patients is assessed before disclosing the bad news. Speaking to care givers and seeking permission from them to speak to the patients is practiced in the Unit. As per the experience of the researcher, care givers try to hide the painful facts from the patient. In such a case, counselors intervene and try to explain the importance of revealing the truth to the patient. If they consent to disclose the
information then the meeting with the patient is scheduled. Some caregivers wish to be present at the time of patient-counselor/doctor meeting. Their wish is respected. The feelings of patients are acknowledged. Some patients or their caregivers refuse to listen to the disease related facts. In such case, the information is not forced on them. Enough time is provided to them to register the news. Generally the news is broken in parts. Based on the knowledge and comfort level of parents more than one counseling sessions are scheduled.

Demographic details like type of family, current physical symptoms, age group of children, and available support influence the overall acceptance of bad news. It is noted by the researcher that parents having strong family support show a readiness to listen to the bad news. It is difficult for parents to witness the child suffering with difficult physical symptoms. Severity of symptoms indicates the terminal stage of disease which initiates the process of accepting the eventuality. It is noted that parents are worried about quality of life of the child as well the estimated life span. Sentences such as, ‘I do not know how many days or months he/she has to suffer.’ or ‘God should either cure him or end his suffering’ indicate their willingness to listen to the disease related facts. It is frustrating for parents to see their child in pain. The parents prefer death of the child over his/her painful suffering. This finding is also supported by Hunt et al. (2006:567) who mentioned that “The inability of the child with severe malignancy to communicate increases the likelihood of mothers thinking that death would be best for the child, while longer duration of the child’s illness increases the occurrence of this thought among fathers.”

The parents residing out of Mumbai and having responsibilities of other children, or elderly parents show eagerness to listen to bad news as they need to take a decision about their stay. Some parents hesitate to listen to the news initially as they are scared to hear about the poor prognosis of their child. It is observed that after some time, they come forward to listen to the news. Parents change their mind to end the uncertainty and understand disease related facts.

Few caregivers are informed about poor prognosis of the disease by their treating Oncologist prior to entering the Palliative Care Unit. Few of them guess the advanced stage of the disease as the symptoms progress indicating poor response of the body to the curative treatment. In this Unit they are given a clear understanding of the prognosis in simple words. It is seen that the parents who are aware of the poor prognosis also expect a ray of hope (cure) from the Unit. It becomes difficult for the parents to listen to the bitter facts.
Parents of Bhavana said, “I was scared though the advanced stage of disease was not news for me. I was aware of her condition but still the last ray of hope was taken away. The focus of treatment was changed from cure to care.”

Parents of Vijaya, Seema and Tarun said, “though the condition was explained to me by the doctor of the parent unit, still I was hopeful. I thought that the doctor from the parent unit may not be aware of new curative measures and the doctors from this Unit might be more qualified and will try to cure my child.”

The important aspect of care giving by the Palliative Care Unit is the way in which sad news is disclosed. The parents with high hopes and expectations come here and poor prognosis of the disease is explained to them. Sometimes care givers deny the poor prognosis. In such a condition enough time is given to help them understand the reality. They clarify many doubts and queries. Medical professionals and trained counselors attend to their needs. Repeatedly asked queries are addressed politely. The extent of the disease is explained only after checking their knowledge about the disease. Their wish to ‘know’ or ‘do not want to know’ is respected. The information is not forced on the parents or on the patient. They are helped to organize and plan their future by assuring the extended support to the child as well as the parents. Emphasis is on the feelings experienced by the parents. Prompts are used to help them speak their concerns. Instead of forcing information in direct words, questions such as ‘what do you think about the disease?’, or ‘do you think that the child is improving now?’ or, ‘was the child in a better condition at the time of diagnosis or now?’ are used to help the parents think and lead to an understanding of the diagnosis or the current condition. According to the experience of the researcher, it is observed that parents have the ability to guess the bad news. Deteriorating condition of the child, unbearable fatigue, paleness on the face and other symptoms act as indicators of the advanced stage of the disease to the parents.

Many parents adopt denial as a form of coping but some where they are prepared to face the eventuality. Hope of cure remains strong even after understanding the advanced stage of diagnosis. They hope for some sort of miracle when they understand the limitation of medical science.
Father of Naresh said, “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.”

Many times it is observed that the parents get frustrated and angry with doctors, spouse and even God when the prayers with their full faith are not answered by God. Diminishing hope, helplessness and hopelessness of parents associated with terminal stage of disease of their child result in irritation. This irritation is expressed as anger.

Mother of Lalita, a middle aged Hindu lady said, “I think my trust in God is reducing now. He is not ready to help good people than why pray? I am extremely angry on Him. He has cheated me.”

Bargaining is observed when parents listen to bad news. As a part of spiritual or religious belief, a person promises the practices such as fasting, prayers, mannats, navas, visiting specific prayer place (temple, darga, church). Navas is a religious practice of the Hindu community and mannat is that of the Muslims. This ritual is a commitment to God if a request is answered by God. For example, parents promise to keep a fast on certain days of the week, or to visit a religious place or to offer certain amount of money or some material to their place of prayer if their child is cured of the disease. Some of the promises observed are such as to be helpful to others, being good to others/society or promising some helpful task. The researcher has observed that people develop a certain philosophy such as ‘if I help others, God will be pleased and will grant me my wishes’. It is noted that parents start believing whatever friends or their well wishers suggest. They begin to have faith in religions other than their own. They follow certain rituals from other religions with strong faith.

Mother of Sandhya said, “I am Hindu by religion but I go to the church regularly as one of my friends asked me to trust Jesus. I am sure that Jesus will cure my child. I follow Hindu rituals such as going to the temple of Ganapati, performing pooja, praying, keeping a fast and so on. Akhir meri apani bacchike liye sab kuch kar rahi hu ( I am doing everything for my child).”
Father of Charu said, “we are Hindu by birth. Of course we have been to all possible temples for our child. We have been to church, Haji Ali Darga, ISKON temple and many more religious places. We used to feel at peace at such places. We used to pray to God and request him/her to cure the child.”

Reaction of parents to bad news:

Different parental reactions are observed when the parents are subjected to the bad news. They get angry, start bargaining or deny the facts as they are prepared to accept the fact. The news is broken in an empathetic way. Their thoughts and feelings are valued.

A trained counselor, psychologist, medical social worker or doctor of Pediatric Palliative Care Unit breaks the bad news. After getting oral consent of the primary care giver, the news is disclosed to the patient. Primary care givers listen to the news before the patient. Complete privacy and confidentiality is assured to his/her care giver before the bad news is revealed to them. As a first step of breaking the bad news, their level of awareness is checked. Then their willingness to listen is enquired. If they are prepared to listen to the true facts related to disease, then the information disclosed in parts. For example, the diagnosis and treatment given to the patients is discussed initially. Their reactions at that time and awareness help to build the foundation of further conversation. Then they are informed about the treatment given to their patient. Then they are told about poor response of the patient to the treatment. Then advanced stage of disease is disclosed to them. At every point, their receptiveness is checked by asking simple questions and summarizing the information. Their feelings, thoughts and concerns are valued and respected. When the news is broken to the patients, they are helped to assess, organize and prioritize their unfinished jobs. They are helped to fulfill their wishes and take decision regarding their future. Decision is never taken on behalf of the patient or care givers and they are encouraged to take control of their life. The scheduled intervention by the Unit is discussed after assuring the improved quality of life. Duration and number of sessions are planned as per the convenience of the care givers and patients. The intervention plan of the Unit varies as per the need of the patient and care givers,

Adequate time is given to the patients and care givers. Emphasis is on listening to them than speaking. Communicating bad news in sensitive manner is essential as it helps them to cope
effectively. This does not mean that communicating in effective way helps them to accept the reality. This finding is supported by Eden et al. (1994:105) who quotes that “Communication of bad news is a two-way process requiring skilled medical staff, but also a receptive audience. The emotional state of the parent determines his or her ability to hear and comprehend the information given”.

*Mother of Lalita* said, “every word of the doctor was very compassionate but still difficult to digest.”

*The mother of Mehru* said, “the way the bad news was broken was very good and empathetic. But still bad news remains bad only. It was like listening to a death sentence not only of my daughter but also of mine.”

*Father of Hiral* said, “people were good to me. Madam spoke to me very nicely but I was not able to speak as I was stressed and not able to gather my feelings/words.”

*Mother of Tarun said,* “you might do many things for us, you might try to help us with good intention but you cannot help us reduce our stress, sorrow and the biggest loss of life.”

It is observed by the researcher that it is not easy for the parents to accept the advanced stage of the disease of their child. Conscious efforts are taken by the Palliative Care Unit to understand caregivers, their stress, their discomfort and their feelings.

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 sorrow related to the news is acknowledged and free ventilation of feelings and thoughts is encouraged.

*Theme: Despite the sensitive and empathetic way of breaking bad news to help parents understand the reality, their pain persists.*

**Need to receive material support**

The treatment for cancer is of a long duration and is expensive. It is observed that parents spend 3 to 4 lakhs for cancer treatment of the child. They spend almost 1 to 3 years for curative
treatment. As a result, parents are financially exhausted. There are certain facilities offered by Palliative Care Unit to help them deal with the financial stress.

_Mother of Sandhya_, who is the only female earning member in a family of five said, “my daughter suffers from many physical symptoms like mouth ulcers, pain, swelling etc. The medicines which are free of charge are really helpful. Otherwise it was difficult for us to spend so much. She is much better now. We are also getting monthly rations and few other things from Palliative Care Unit which is helping me run the house.”

_The father_ of 19 year old bed ridden _Sagar_ said, “at present my child is at our native place with his mother but I am in Mumbai. I come here and get the free bandage material and other medicines from the Unit which I send to him through somebody or by courier. Because of free bandage material his bed sores are healing now.”

Free symptom control medication

It is noted by the researcher that it becomes difficult for parents to spend on symptomatic medication. It becomes difficult for the parents to manage the expenditure after spending lakhs of rupees on curative treatment. The lack of financial resources in the family might prove to be a threat to the compliance of the treatment. The medicines for controlling symptoms like pain and other opportunistic infections are generally expensive. Their need to get free medication is fulfilled by giving symptomatic treatment free of charge by the Palliative Care Unit. It is observed that the parents from lower economic strata cannot afford to buy these expensive medicines. As a result the child goes through painful physical symptoms. Receiving free medicines supports parents and offers an improved quality of life to the children. In short, the inability to provide expensive medication for symptom control might subject the child to a lowered quality of life. The Unit tries to offer physical comfort to the child.

_The father_ of _Ajmal_ said, “I am happy as my other children are getting fees for their school. Otherwise they could have not continued their education.”

_Parents of Komal, Vijaya, Sandhya, Seema and Tarun_ said, “because of the health drink received from the Palliative Care Unit, the child feels energetic. Otherwise we would have not managed to pay for such an expensive drink.”
The help offered to the family is not limited only to the free medication but also in kind. The researcher has observed that the siblings of the ill child suffer because of the inadequate financial support. The major flow of the money or savings is diverted to the treatment and other needs like school fees, classes and other needs of the siblings are side tracked. The Unit tries to help the family by providing the school fees for siblings. Food, clothes, health-drink for ill child and other need based materials are some of the examples which help the family cope with the financial burden.

Some parents lose their job as the need to attend to the child at the hospital frequently. 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. The researcher has seen some of the care givers becoming financially independent. Palliative Care Units donates sewing machines, grinding machines (*ghar ghanti*) to become self sufficient and to support the family. Working from home is generally a preferred option of female care givers. This allows them to take care of family members and earn simultaneously.

*Theme: When under financial stress, offering material help to parents of children with cancer is perceived to be supportive.*

*Need to understand the distress of ill children:*

As the focus of the Palliative Care Unit is to cater to the needs of the patient in totality, it is important to understand the efforts taken by the Unit towards helping the child. The age of the child registered at the Palliative Care Unit varies from few months up to the age of 19/20 years. The level of understanding the disease and prognosis varies as per their age. Each of them has a different way of expressing their concern, worry, fear and anxiety. The resilience of the child definitely affects the overall coping of the parents.

*12 year old Bhavana,* known for her friendly behavior has changed a lot after understanding the advancing stage of her disease. According to her mother,

> “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.”
After acknowledging the diagnosis of cancer, 7 year old Hiral changed her overall behavior. While describing her changed behavior her father said, “she was a good student in the 2nd standard. She is friendly by nature. She had so many friends. She never used to keep quiet. But suddenly her behavior has changed. She stopped going to school. Her friends used to come to her but she started behaving differently. She used to avoid them. She started saying ‘no’ to playing. She stopped going out also.”

Bhavana and Hiral showed a marked difference in their behavior after the disease started showing painful symptoms. Both of them are aware about their disease and poor prognosis. They speak regarding their disease to their parents but are not willing to share their concerns and worries to other family members or friends. Both of them were cooperative while undergoing cancer treatment. The awareness of advanced stage of the disease has influenced their overall behavior. They tend to stay away from others, even from their friends.

It is noted that the children express their stress by throwing tantrums. They try to distance themselves from their own people. Relatives and neighbors come to enquire about the child and his/her health. The children get irritated when the same topic is discussed by the family members. Because of the irritation, children back answer or abuse them. They try to stay away from their friends. Significant changes in their behavior are observed. The children in the adolescent age group react in a different way.

19 year old Sagar who is completely bed ridden, is dependent on his mother as he has lost sensation of the lower part of his body having no control on his bladder and bowel movement. Sagar said,

“Baba (father), I am feeling so bad for both of you. I am a young man who should have eligibility to take over your responsibilities but I am feeling so bad for not fulfilling my duties as a son. Please ask God to cure me or to end my life. I am tired of this bed ridden dependent life. I am losing my patience. I can’t see you stressed and running around for me.”
The adolescents go through the emotional pain as they regret not performing their duty. This is the age when they start growing up and want to play the role of being a support system especially for the parents. It becomes difficult to accept their dependency on the parents. Their concerns are not only limited to their duties towards their parents when they become adults, but also in terms of depletion of family resources due to their illness. It is seen that, children observe their parents spending in lakhs for their treatment. They understand the financial constraints borne by their families. Children are witness to their parents borrowing money from friends, relatives and other sources. They see them struggling to get help from different charitable trusts. When curative treatment does not prove fruitful, despite such struggles and efforts of the parents, children feel sad for their parents. Their worry regarding financial needs of their family, future of their siblings, burden of loan and so on create stress. They feel guilty as they blame their disease and expensive treatment.

19 year old Lalita has always seen herself as an achiever in life and the primary support system for her parents.

She said, “I dreamt of offering maximum comfort and care to my parents but today they are caring for me. They have exhausted all their resources, they are left with nothing. They spent everything on me and at last I will die and leave them with financial burden.”

Sagar is in a bedridden condition for a long duration with persistent pain. His main concern is his inability to help his parents. Beginning or increase of painful symptoms is an expected incident when the child enters the advanced stage of the disease. Children observe other symptomatic children in the Out Patient Department. They compare their disease and symptoms with other children. Lalita is one of the patients, currently not facing painful symptoms. She is scared as the understanding of poor prognosis evokes in her anticipated worry. When she witnesses other children with severe symptoms, she starts worrying about her future. According to her, understanding of prognosis is responsible for her anticipated grief.

Demographic details like age, type of family and financial status of family influence the level of stress and coping strengths of children. Adolescent children go through frustration and anger. They witness, understand and feel sorry for the struggle of their parents. Devastating dreams, anticipated grief of loosing dear ones create more stress. In contrast, children younger in age are
concerned more about their symptoms. Once the symptoms are controlled by medication, they are happy.

Child receiving enough support from the family/friends copes positively. Children belonging to a supportive family receiving love and security are more comfortable with their immediate family members. It is seen that such children opt to be aloof from other than immediate family members. They experience a sort of discomfort to discuss the disease related facts with people other than own family members. When children witness other family members providing help to their parents, they feel happy.

Socio economic condition of the family is one of the influencing factors of coping and stress. The parents who are included in the study belong to either the middle class or lower middle class families. Children feel sorry for the financial burden of their parents. They blame themselves and their illness for the resulting stress.

It is observed by the researcher that children from all age groups are against discussing their disease with extended family members, relatives or neighbors. To be labeled as an ‘ill child’ is not accepted by them. To visit the patient is considered as a social norm. When relatives pay a visit and ask about the condition of the patient, he/she gets irritated. Discussing the disease repeatedly is painful for them. Parents feel sorry when genuine well wishers of the family are also not attended to properly by the child. At such moments, parents do understand and accept the behavior of their child to be away from others. At the same time, they understand and recognize the concern of well wishers. While working with the parents of ill children the researcher has noted the parents saying that, “We become like a sandwich. We understand the condition of child and also the concern of others.” Such incidents result into excess stress for parents.

Father of Sameer narrated an incident. One day some relatives called up and asked about the child. The child was listening to the call. When the parents asked him, if they could come to see him, he refused immediately saying, “I am not a patient. Don’t disturb me.”
Attempts made by Palliative Care Unit to help the child to express

When the Unit understands the child’s need of being heard or listened to, enough privacy and an attentive ear is offered to them. Few children find it difficult to express themselves in words. Different ways of communication like art, painting and so on are used by the Unit for such children. Sometimes, children are encouraged to write about their emotions, concerns and needs. Children have shared that after expressing into them they feel less burdened.

Parents of 20 year old Lalita, were aware of the disease and prognosis. One day the child insisted on having a meeting with the counselor from the Palliative Care Unit. She had a long discussion with the counselor. The parents were worried and concerned about her reaction. While narrating this incident,

  her father said, “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.”

Ventilation of feelings and concerns help the children cope positively. According to the children, it is difficult for them to share their worries with parents as this might make their parents sad. Witnessing sorrow of parents is difficult for them. They are comfortable in engaging in the conversation with the counselor who is empathetic and still outsider.

Theme: The overall behavior of the ill children is generally influenced by the extent of their awareness about their physical condition.

Need to receive multiple professional services under the same roof

The multidisciplinary team system is the special feature of the Palliative Care Unit. The team consists of doctors, nurses, psychologists, social workers, trained volunteers and physiotherapists. Home Care Team is a part of this Unit to provide care at the patient’s home. The team aims to offer improved quality of life to the patients. Professionals specialized in their discipline serve the patients. The team intends to control physical symptoms and provide
emotional, psychological, social and spiritual support to the patients. Efforts are made towards helping care givers to cope with the event.

**Mother of Sabina said**, “we are happy about this idea to get help from a team. More people, more attention is given to the patient”.

**Father of Sameer said**, “I am satisfied about the multi disciplinary team approach. My son has received many gifts, love and pampering.”

**Mother of Mehru said**, “I am satisfied about the multi disciplinary team approach. I want such a structure to be copied in all departments too. According to me all experts can render their skills in the interest of the patient.”

**Father of Ajmal said**, “the multidisciplinary team is useful to the patients. They can save their time and money.”

**Father of Charu** who is from Bengal said, “it is like a joint family. Good to have more people in the team to love and help. This is really needed at this point.”

It is observed that parents are satisfied with this multi disciplinary team approach. Parents expressed their satisfaction because they save their time as multiple professionals are available under the same roof. Few children need to attend physiotherapy for treating lymphedema (swelling on any body part). Few children need nursing help to get their wound bandaged. All these services are available to the children, without spending extra time, energy and money. Assurance of support from all members of the team helps to enhance the mutual bond of trust.

**Theme:** The multidisciplinary team approach, which emphasizes multiple services under one roof is free of cost, is preferred by care givers as it ensures support by experts in a comprehensive manner.

**Need for professional care at home**

Parents while sharing their event related experiences emphasized the importance of the Palliative Care Unit as a support system. The children with an advanced stage of cancer become physically weak and are not in a condition to travel to the hospital. Financial constraints to spend on travel (home to hospital) or to take a day off from work to accompany the child to hospital becomes
difficult for parents. Getting help at home by the Home Care Team becomes convenient for children as well as their parents.

**Father of Bhavana** said when the Home Care Team of the Unit went to visit the child and her family, “because of the empathetic approach of the team and especially the counselor, I could share my concerns. After this I felt so relieved. I think such help is needed not only for me but all other parents like me.”

**Parents of Tarun** said, “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. The team should expand the area of their working as this is the need of such children and their parents.”

**Aunt of Seema** who is a primary care giver of the child (the father of the child is bed ridden) said, “I am happy about such visits. As a result of such visits, the father of the child could understand the picture in detail. The counselor of the Home Care Team was very empathetic and spent lot of time with the family.”

**Mother of Shashi** who is unhappy about prescription of medicines through the phone.

She feels, “unless the doctor sees the patient, how can the medication be prescribed? Home Care is the best solution to all the problems. I am happy that the doctor himself comes home. Other people with him are also very nice and speak sweetly. The counselor listened to me for a long time and then I felt better. I am all alone at home and feel like talking about my problems to someone.”

Parents recognize the necessity and availability of such a system which tries to help not only patients but the care givers. Many parents expressed the need of patients being treated at home. According to them it becomes difficult to bring the child to the hospital because of her/his deteriorating physical condition. Getting medicines at home proves helpful as it curtails the commute of the child. Among the interviewed parents, majority of them do not have a permanent and secure job. They depend on daily wages. Such parents lose their pay when they spend an entire day to bring the child to the hospital. If the need to attend the hospital arises frequently due to the severe physical symptoms of the child, then they lose the existing job or lose the
opportunity to get another job. Loss of pay and fear of probable unemployment is averted because of the facility of the Home Care Team.

**Theme:** Parents value the service of the Home Care Team as they can express themselves better in their own home environment.

**Conclusion:**

To deal effectively with the event of having a child with advanced stage of cancer, parents need support in different forms. Parents from Mumbai and those who come from outstation for treatment have a different set of difficulties, concerns and needs. To recognize their need and concerns, and attend to them, helps parents to cope positively with the situation. The patients who come for treatment from out of Mumbai belong to different regional and linguistic backgrounds. It is difficult for them to access resources such as lodging, boarding, commuting by local transport and so on. The human power or family support is comparatively less in their case as one of the parents attends to the ill child and other looks after the needs of remaining family members at their home. These parents feel lonely as they have no one from their family to share their emotions and experiences with. They experience stress related to the child’s illness and this is compounded by hassles resulting from lack of resources.

Parents from Mumbai and other cities have similar expectations and needs from the Unit. Besides getting timely information related to the illness, parents are at ease while communicating in their mother tongue, which facilitates building a strong patient-clinician alliance. This alliance is instrumental in providing a conducive atmosphere for the parents to ventilate their emotions. The professional behavior and demeanor adds value to this alliance and experience of parent satisfaction.

Disclosing the poor prognosis and the impending death of the child requires skill, which the Pediatric Palliative Care Unit is trained in. Hearing the bad news, even though it is communicated in a sensitive manner, is painful for the parents. The bad news ends their hope of cure. Their anticipated loss, sorrow and grief cannot be reduced by professionals but the assurance of extended support helps them to cope with the news. The Team helps them to accomplish an improved quality of life of the child. The Unit recognizes their concern and fulfills their need by providing symptom control medication, nursing and physiotherapy.
assistance if required. The service is available under the same roof as a result it helps the parents to save their time, energy and money.

The parental stress multiplies as they are concerned about other family members also. The long duration of treatment forces the parents to shift to Mumbai and this affects their employment. Parents lose their jobs or daily wages as they need to accompany the child frequently to the hospital. They go through financial constrains, which the Unit attempts to address by providing material and non-material help to them. Thus another source of stress is taken care of by the Unit. The children who are ill not only experience pain and associated feelings related to the poor prognosis, but also grieve about their inability to fulfill their normative roles in life. Accepting the role reversal create stress to them. Their communication with their parents is affected to the extent that they hide their feelings in order to protect their parents from witnessing their pain. Expressing the self and showing concern for parents help them to cope with their life threatening condition.
Section 4.C

Awareness regarding concept of Palliative Care

Medical science aims to cure ill patients. Treatment options, therapies and treatment protocols have changed because of advancement in medical science. Though medical science struggles to cure the patient, few patients do not respond to curative treatment and the advanced stage of disease becomes a hurdle to cure the disease. At this stage adopting a compassionate way of treating the patient becomes important. The focus of treatment shifts its paradigm from cure to care. Death is inevitable and it is still a taboo subject. When the patients are nearing death it becomes extremely important to deal effectively with physical, spiritual, social, psychological and emotional aspects of the patient and other family members.

Taking care of patients is not new to any culture. “The care of suffering and dying patients is part of human history. In the past quarter century, a revolution in terminally ill patients is seen” (Bennahum, 2003: 1). “The emergence of deep concern for the welfare of the patient dying of cancer has had significant impact on the medical community during the past decade. Many factors have contributed to the development of sometimes ‘cultish’ movements regarding patients' rights: death with dignity, right-to-die, and even efforts to protect the patient lest he fall into the hands of the “insensitive” physician.” (Leone, 1982: 141). “In Roman times, the concept of private hospitality was codified and legally defined. The hospital was considered as the temporary place for the patients while they receive their treatment and hospice was the permanent residence for poor, infirm, crippled, insane and incurable patients” (Bennahum, 2003: 2).

Hospice care and palliative care are comparatively newly introduced terms in medical science but the concept is definitely not absolutely new. Helping the dying patients, to take care of their needs has been part of every culture. Bennahum (2003) noted the historical root of the concept of hospice takes us back to the Greek world, the patients who were not cured by the physician used to seek the help by the God of medicine by staying in the temple. Tracing the history of such care, “In Western culture the specific concept of the hospice emerged during the Middle Ages, when "houses of guests" were built on the side of the roads to tend to the crusaders”
(Echeverri and Acosta, 1996). “The word "hospice" stems from the Latin word "hospitium" meaning guesthouse. It was originally used to describe a place of shelter for weary and sick travelers returning from religious pilgrimages. During the 1960's, Dr. Cicely Saunders, a British physician began the modern hospice movement by establishing St. Christopher's Hospice near London. St. Christopher's organized a team approach to professional care giving and was the first program to use modern pain management techniques to compassionately care for the dying. The first hospice in the United States was established in New Haven, Connecticut in 1974” (http://www.hospicefoundation.org/pages/page.asp?page_id=47055 retrieved on 27th June 11). Dame Cicely Saunders is acknowledged as the pioneer of the modern day palliative care and the hospice movement. Her efforts have been to improve the quality of living and dying with cancer.

To help ill people and take care of their needs is part of religious values. Offering services and satisfying their needs is linked with service to God. “The roots of modern palliative care are of course to be found in religious orders concerned with the care of the dying. These orders had a conception of a ‘good death’ which involves an acceptance of human mortality and recognition that human weakness and sin could be forgiven and that death itself could be seen as the signature of meaningful life. Moreover, death was seen in an earlier age to be a family or a community event rather than a medical event” (Randall and Downie, 2006:5).

Palliative medicine is the study and management of patients with active, progressive, far-advanced disease, for whom the prognosis is limited and the focus of care is the quality of life (Steven, 2005). In India, Palliative care is a newly introduced branch of medical science. As mentioned in the official site of Shanti Avedana Sadan, this hospice is the first Hospice of India established in 1986 at Bandra, Mumbai. This is an institute which takes care of terminally ill cancer patients. It is neither a hospital nor a home, but is in fact both, offering the specialized care of a hospital together with the love of a home. http://www.shantiavednasadan.org/about.htm# retrieved on 27th June 2011).

In 2002 the first Palliative Care Unit specifically for children in India was established in Mumbai at the Tata Memorial Hospital. Two days in a week are reserved for out-patient services, which is dedicated for children and their care givers. The Unit adopts a multi disciplinary approach as the focus of care is holistic. The multi disciplinary team includes doctors, nurses, psychologists,
trained counselors, physiotherapists and social workers. The primary aim of the Unit is to help the parents and children to deal effectively with the terminal stage of disease.

Figure 5: Statistics of patients at Pediatric Palliative Care Unit of Tata Memorial Hospital

![Graph showing statistics of patients at Tata Memorial Hospital Palliative Care Unit](image)

It is noted from the data collected after interviewing the parents that the clarity of the concept of palliative care has been differently understood by the patients. The aim of treatment is considered as curative. The care givers showed less amount of knowledge about the current system of palliative services. This in-house service of the Tata Memorial Hospital is new for patients and their care givers. The system is equipped to take care of possible unpleasant symptoms and help to deal with emotional, psychological, spiritual and social issues. The patients are referred to the Palliative Care Unit by their parent unit. Parent unit is the department where the possible curative treatment is given. It is witnessed that the patients and their care givers are comfortable with their parent unit. Since they need to visit the same department frequently they get acquainted with their working. Doctors, nurses and other health care professionals working in the parent unit become friendly because of the frequent interaction with parents. Hence the patients are more comfortable with their parent unit and are more receptive to their services.
Except one, all other patients have been referred to the Palliative Care Unit by their parent unit and not from any other hospital. Ajmal was referred by Lokmanya Tilak Municipal General Hospital, located at Sion where he was a registered for curative treatment.

The father of Ajmal said, “because the madam of Sion hospital asked me to come to the Palliative Care Unit, I came. She asked me to continue the medicines simultaneously. I also like the people of this department. So I continued.”

The reason for the referral for all children in this study has been either due to the relapse of the disease or the locally advanced site of the disease. The concept of palliative care is attached to the terminal or advanced stage of the disease. Sometimes the care givers are informed about the condition of the disease of their child in their parent unit. Only few caregivers are referred without much briefing about the poor prognosis of the disease and about the Unit. It is observed by the researcher that parents who have some knowledge regarding terminal stage of the disease or are ignorant about the prognosis expect curative treatment from the Unit and hope for the best. Some sort of treatment is expected as it becomes very difficult to accept the final word from the doctor. They express the hope of cure and expect the unit to help to provide comfortable and symptom free life to their child.

The parents who were interviewed said, “we thought that this might be some different new department of Tata Memorial Hospital. This department might be having some therapy to cure the disease.”

Parents of Sameer and Shekhar said, “when my child was referred to Palliative Care Unit though I was aware of the deteriorating condition of the child, I thought of some new possible curative treatment. I was expecting some oral medicines which might be used to control the disease if not cure.”

Father of Neeta said, “when our doctor (Parent Unit) referred her to Palliative Care Unit, I was hopeful about some curative treatment though I was aware of her poor prognosis. I was informed by the doctor that the disease has relapsed and now it has reached her lungs.”
The parents have no idea about this type of care which is available for their child at the same hospital. They are hopeful and look forward to cure rather than just care.

**Father of Bhavana said,** “then they referred my child to Palliative Care Unit. The word was totally new for me. I thought that our doctor wants us to show the reports to this new department.”

**Parents of Hiral and Sagar said,** “the word palliative care was heard of for the first time”

**Mother of Komal said,** “people like us, those who don’t understand the working of hospital, then how we would know about palliative care?”

Not only the concept but even the terminology is new for the patients. When they are referred to Palliative Care Unit, they are confused and keep guessing about the function of this new department. The focus of their hospital visit is cure. Then to make a paradigm shift from cure to care becomes a tough challenge for parents. Palliative care is a complex concept which needs emotional acceptance. “There is still a poor understanding of palliative care even among the medical profession” (Leong, 2003: 82).

It is necessary to spread awareness about this branch of medicine which focuses not only on the physical aspect but also takes care of the patient and his/her care givers in totality. As and when the curative treatment proves ineffective, then role of caring becomes prominent. It is necessary to increase the awareness of not only the patients but even among professionals. The word ‘treatment’ is associated with hope of cure. It is very hard for parents to accept the poor prognosis of their child. The hope of cure makes them struggle for any sort of curative treatment.

**Theme:** When the child reaches the advanced stage of the disease, it becomes more difficult for parents to accept the poor prognosis and the paradigm shift from cure to care.

**Theme:** The information and awareness about this new branch of medicine needs to reach the care givers, patients as well as all health professionals.
**Conclusion:**

‘Palliative care’ is a still strange concept for general population as well as health care professionals. The ill person expects complete cure from the medical treatment. Along with the medical treatment, the ill person has other needs to attend to. When the holistic care is provided by using empathetic approach, it facilitates the effective coping.

The Pediatric Palliative Care Unit (PPCU) of the Tata Memorial Hospital put the efforts to identify the needs of the ill children and their parents. The experiences that parents of ill children go through may also cause emotional, psychological, financial stress. The Unit strives to cater to the parental needs and help them to cope with the event of advanced stage of cancer of their child. Multidisciplinary team and Home Care Team of Palliative Care Unit provide care in totality only to patients but also to the entire family.
Section 4.D

Experiencing Stress

4.D.1 Stress related to witnessing and anticipating life threatening condition of child:

A child suffering from a life threatening disease goes through physical as well as emotional, psychological, social and spiritual pain. The researcher has noted that, the experience of the child during her/his illness develops the understanding of disease. Other factors like age, awareness, involvement of child in the discussion about the disease and the treatment influence the overall event. To face this stressful event, every child adopts different strategies of coping.

The researcher has observed that, children are inquisitive regarding the disease related facts. “Seriously ill and dying children are much more aware of their illness and prognosis than it is comfortable to acknowledge. They are known to harbor anxiety about their situation and are helped by the provision of age-appropriate information. Equipped with the knowledge, the caregiver can certainly be more attentive to the child’s verbal and non-verbal communication and seek, where possible, to lessens the child’s anxiety” (Stevens, 2005).

The findings from literature and the experience of the researcher reiterate that at any age a child has the capacity to understand or make sense of the situation. The age, education level and awareness regarding the disease help the child to understand the situation completely. The stress they observe on the face of parents and obvious changes at home make them wonder about their illness. They use their intuition and guess the reason of their parents’ stress. Newly developed or aggressive symptoms such as physical pain, swelling, wound, cough, and breathlessness affect the quality of their life. These symptoms also help the child to guess the severity of their disease.

A common trend seen is that cancer patients are keen to learn and gather information about the disease related facts. The expressions, gestures, or non verbal communication of either professionals or the primary care givers and their own intuition helps them to understand the status of the disease. Children try to gather clues and understand the diagnosis or even prognosis. The child at any age can guess the severity of diagnosis. “The most important factor in a child’s
understanding of illness, death and dying is the child’s own experience. A child who has been sick for some time will have a far more advanced understanding of health and illness than healthy children of his or her own age” (Amery et al. 2009).

**4.D.2 Parental perceptions regarding the Child's discomfort related to parents**

Parents have noticed the child's concern about their anticipated concerns and worries regarding his or her illness. Witnessing their child's concern compounds parental stress. The acceptance of the life threatening condition and fear to separate from parents create stress to the children. The children try to pacify themselves and their parents by finding alternatives which are hope inducing. The concept of re-birth might be a way they choose to re-connect with their dear ones. According to father of Sameer, they recognize the child’s need to express his feelings, anger or even fear. The parents have developed the habit of discussing and sharing their thoughts and feelings with family members from beginning. According to the father this habit of sharing makes him comfortable talking about the disease. Though the child is aware of the fact, he is scared and worried about the eventuality and anticipated separation from the family. The family believes in the concept of cycle of ‘birth-death-rebirth’ and hence the child uses it as a coping strategy.

*12 year old Sameer spoke to his father, “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.”*

Concept like taking rebirth in the same family helps the child as well as the parents to cope with the event. Both of them perceive the death as ‘temporary separation’. The hope of reunion helps coping. Children cannot see their parents in pain. The mutual love and concern for each other is expressed in this way. The way parents feel sorry for child’s sorrow, the children also experience the same. The child’s awareness about the advanced stage of disease and his/her readiness to face the eventuality becomes the one of the influencing factors of the parental coping. When children openly express their feelings and thoughts regarding the advanced stage of disease, it helps their parents to accept the event. It is observed that the children show their concern towards the
parental worry and grief. A few of the children try and help their parents to cope with the anticipated loss.

8 year old Neeta said to her mother, “Aai (mom), don’t cry. This disease (cancer) is a guest in my body who is troubling me. I know that the end is imminent now. Both of you don’t cry. If I see you in pain, I feel bad.”

Lalita on her birthday said, “Aai, Baba (mom and dad), Make me happy this year. I will not be there for my next birthday.”

A 10 year old girl Charu, who is fond of new clothes said, “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.”

8 year old Neeta said, “Baba, I want you to laminate my enlarged photograph. So that when you will remember me after my demise you will look at my picture hanging on the wall and that poster will make you happy.”

It is observed by the researcher that children prefer an open conversation. Difficult topics like death and dying are also tackled well by them. “The most important factor in understanding of illness, death and dying is the child’s own experience. A child who has been sick for some time will have a far more advanced understanding of health and illness than healthy children of his or her own age. Within Africa even the healthy child will have experience of illness, death and dying far above children of his/her age in other societies” (Amery et al. 2009).

Children show an eagerness to speak about the uncertainty of the life. They try and convey the inevitability of death to their parents. They express their concern for their parents as they understand and anticipate the parental grief. They try and convey their message emphasizing the eventuality. However if the child uses it as a coping strategy, the parents are also encouraged to adopt a similar coping strategy.

**Theme: When children understand the concept of death, they try to help their parents to face the eventuality and express their concern for them.**
4.D.3 To witness the child’s physical discomfort- provokes stress in parents.

It has been expressed by parents that they find it extremely difficult to see their child in pain. As the child enters an advanced stage of cancer, he/she starts developing different types of physical symptoms like pain, breathlessness, swelling, weakness, cough, fever or wounds. According to the parents interviewed, to witness the child suffering helplessly is the greatest sorrow for them. Though the Palliative Care Unit attempts to minimize the symptoms, the fear of probable death, weakness of child and aggravating symptoms raise the anxiety of the parents.

Parents of Sameer have accepted the advanced stage of disease of their child.

His mother said, “I am aware of the condition of my son. I cannot bear to see him in pain. To witness a child without a leg was a true suffering for me. I cry when I am alone.”

Mother of Ramesh said, “It is agonizing for the parents to see the child in pain and just watch helplessly.”

Tarun is in a vegetative state for a long duration. His mother is the primary care giver as his father is a rickshaw driver and cannot take breaks from his job as he might lose his wages.

Tarun’s mother said, “My biggest worry at this point is the inability of my child to speak or even express himself. I keep crying as I feel that he might be in pain but he is not able to express himself verbally- what is happening to him. At present we are trying to address and treat the symptoms, which we feel he might be suffering from. It is a heart breaking experience for us. I am not able to control my tears. I cry looking at him and his symptoms. I am his mother but I am unable to share his pain and his sufferings.”

Neeta is going through severe breathlessness as secondaries (spread of disease) are growing in her lungs. She has continuous cough and she has to spend many sleepless nights.

Her parents said, “Currently the child is suffering from a continuous cough. She is not able to sleep at night. She becomes breathless and it is difficult for us to watch her suffering. We feel bad for the child and cannot bear to see her in such a situation. We, especially her mother, cry a lot.”
Parents feel helpless about the condition of their child. Tarun is almost semi conscious and in a vegetative state, unable to express or tell his symptoms and the parents go through severe stress. Few parents feel it is better that the child dies soon rather than suffer. Few parents pray to God to end their child’s life. A mother (whose child was in hospice for a very long duration and was going through severe symptoms) said, “I cannot bear to see him in pain because I love my child a lot, so I will prefer to lose him forever than watch him suffering.”

**Theme: To witness their own child suffer is the biggest sorrow for the parents.**

**4.D.4 Discomfort of discussing poor prognosis with spouse:**

The parents watching their child in the terminal stage of disease, experience helplessness and go through stress. When this stress is shared with someone particularly a spouse it can ease the problem. Some couples share healthy relationship in their marriage. They are comfortable in sharing their happiness, sorrow and stress. This type of interpersonal relationship helps them to cope effectively when their child enters the terminal stage of disease. They try and involve the spouse in the disease management, bedside caring or decision taking. In contrast some individuals try to hide the painful facts from their spouses. In other couples, they maintain secrecy as they are not comfortable in discussing their child’s illness.

It is observed by the researcher that female care givers are considered as sensitive and vulnerable. Bad news is rarely shared with mothers or grandmothers. The rationale behind concealing the bad news from female family members is “it might harm them emotionally”, “they will not be able to face it as they are very soft at heart”. It is observed that female care givers hardly attend the meetings with doctors. As a result the filtered information reaches them. They are mostly expected to be involved in bedside caring.

*Father of Sagar said,* “I am having tough time handling his mother, taking care of financial arrangement, looking after office work, handling routine matters and in addition to this hide the true picture from his mother.”

Every family has its unique situation. The father of Neeta is preoccupied with responsibilities such as arrangement of finance for the child’s treatment, taking care of other children and
looking after his bed ridden wife. According to him, it is not possible to share the bad news with his ill wife as it might prove to be harmful to her. Awareness of poor prognosis of the illness might deteriorate the physical condition of her. Then it would be more stressful for him to handle the situation. These possible consequences deter him from revealing the facts to his wife.

_Father of Neeta said_, “I am already burdened with the problem and take additional stress is to hide the disease from others. I cannot share the same with her mother, as she is already bed ridden for years.”

The parents prefer to hide the bad news from each other due to their mutual concern.

_Father of Ajmal said_, “we (father and elder brother of patient) do not discuss much with the mother of the child. She is a soft hearted lady. She has the problem of low blood pressure and low sugar. As and when she gets stressed, her blood pressure goes down. Once she fainted down because of the stress. So we (father and elder brother of ill child) feel it is advisable not to discuss disease related facts with her.”

As a result, both parents experience the stress. One who is aware and hides from other goes through burden of bearing the pressure single-handedly. At the same time, other parent lacks the true information, as a result keeps wondering and suspecting about the poor physical state of the child. This aggravates the stress of both parents.

4.D.5 When one of the parents stays at Mumbai and other at their native place:

The children who come for treatment from out of Mumbai are sometimes accompanied by one of the parents. It is observed by the researcher that the couple divides their responsibilities. One of them takes care of ill child and other takes care of other responsibilities such as caring for other children, earning for family, looking after aged members of family and so on. Parents residing in their native place are informed about the child’s condition on phone or by letters. It is seen that bad news is not conveyed on phone or by letter. Sentences such as “don’t worry”, “I am there for our child” or “he/she will be fine soon” are conveyed to other parent. The intention behind not portraying the true picture is due to the concern or love for the spouse. The parents who are in Mumbai feel, “what can he/she do for the ill child staying at native place?” or “my spouse is shouldering entire responsibility of house then why to tell her about distressing facts?”

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Mother of Mehru is a primary care giver for her daughter and her husband stays at the native place.

She said,” I understand my husband very well. He is not tough at heart and cannot see his children in pain. That might affect his health. Then there will be more worries for us. So I have decided to keep everything to myself. Why to bother one more person?”

Parents of Sabina are aware of the poor prognosis of the child. Both of them try their best to avoid this topic. They speak to each other a lot but stay away from the topic of disease.

Mother of Sabina, a member of joint family feels, “If I cry, he (husband) will be more tensed. Then what’s the point in making him sad? Any way he is already burdened with lots of stress. He is taking care of such a huge family”

The father of Sabina feels, “she is taking care of the ill child beyond her normal capacity. Then why discuss the same thing again and again to make her stressed?”

Various factors such as protecting each other, way of expressing the love and concern for spouse, one of the parents is occupied with other family or job responsibilities or physically unwell to take care of child are observed to be considered as rationale to conceal the bad news from spouse. The conscious decision to hide the information is generally with a good intention. Male members conceal the fact from mothers as the females are considered as vulnerable. The decision is taken with intention to protect them from emotional distress. The same strategy is adopted by the female primary care giver but the reasons are different. According to them, male members are already loaded with other responsibilities such as earning for family, arranging funds for treatment, accompanying the child frequently to the hospital. “The basis for such a decision is the desire to protect the third party from anxiety or hurt as a result of being told bad news”(Finegan and McGurk, 2007).

Theme: The deliberate choice of the family members to withhold the bad news from each other in order to protect their dear ones from stress thereby expressing their concern for each other, helps in dealing with the burden of the disease and this influences coping negatively.
4.D.6 Stress because of stigma

Multiple reasons are responsible for the parental stress. Stigma is one the reasons for creating stress. The researcher has observed that the parents experience discomfort while sharing the diagnosis with others. Fear associated with anticipated rejection is found to be a reason to hide the facts from society, friends and extended family members.

The parents hesitate while verbalizing the name of the disease. They use an alternative words such as like ‘disease of blood’ or ‘sadhi gath (simple tumor)’ and so on for cancer.

Mother of Vijaya is a community health care worker by profession. She has complete knowledge of disease. She prefers to hide the fact from the people of the village. This mother has knowledge of disease, symptoms, treatment protocol, side effects and so on. She delivers lectures and shares information with villagers about diseases like cancer and HIV. She feels, “It is easy to preach others”. According to her if the villagers understand the diagnosis of her daughter, then her family might have to face the social rejection. Vijaya’s parents are concerned about the marriage of other children as they fear that no one will marry them as they have a sister who is suffering from cancer.

Mother of Vijaya said, “one day when we were at TMH we came across few people from our village. I fear that they might have guessed the diagnosis. Then I tried to cover it by saying “She is undergoing some treatment which will prevent her from any type of cancer in future.”

It is essential to note that the person having adequate knowledge about the disease opts not to reveal the diagnosis because of the fear of social rejection. The parents expressed that majority of village community lacks the scientific information regarding such diseases. They fear that disease might be contagious or hereditary. They recommend delivering scientific information regarding such life threatening diseases in simple language. Distribution of leaflets, information in pictorial form might help the people to get rid of wrong perceptions. The parents are equally concerned and worried about their other children and their future. The parents are worried about the marriage of other daughters.
Father of Neeta said, “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?”

Ajmal’s family is friendly by nature. His father experienced the change in the behavior of the neighbors and friends when Ajmal had a diagnosis of cancer. While sharing his observation,

The father of Ajmal said, “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).”

The people who face the bitterness of the society experience rejection. They prefer to be away from others. The strategy of hiding and keeping the things within family is adopted by the parents. The concern towards future of other children is also one of the important reasons to conceal the facts from society. Fear of being rejected by others becomes a reason to increase the parental anxiety. One of the observations of the researcher regarding stigma is as below- Home Care Team of Palliative Care Unit has a practice of making a telephone call to patients before confirming the home visit. The patients requested the team to park the vehicle of Tata Memorial Hospital at some distance from their place of residence. They fear that other people from society, chawl or community might understand the diagnosis of cancer as the name of the hospital is displayed on the vehicle. This awareness of neighbors might affect the social relationship is the apprehension that patient and care givers have.

Theme: Those who face social rejection by friends and members of community experience stigma and this causes stress in the family.
4.D.7 Stress related to using a brave mask to portray the picture that ‘everything is fine’

It is noted by the researcher that caregivers try and hide their stress from the patient and they put on brave mask on their face. The efforts are towards projecting the fact that they are not stressed. ‘Everything will be fine’ is the message which they try to convey through their expressions. As a result, caregivers suffer additional anxiety.

The interviewed parents expressed that they are worried about the physical as well as mental health of the child. Their efforts are towards encouraging the child to keep his/her fighting spirit strong. They avoid expressing the disease-related anxiety and sadness in front of the child. The brave mask is used to guard the child from disease-related stress. According to parents, stress on the face of parents might influence the coping of the child negatively.

_Aunt of Seema said_, “I never cry in front of her as my tears might upset her and affect her coping."

_Father of Naresh said_, “I am wearing the brave mask on my face as my tears might affect his overall resilience and he might lose his courage. I don’t cry but it does not mean that the reality does not pinch me.”

_Grand-father of Faizal said_, “If we cry, in front of the child then he will break down.”

**Theme:** When the parents fear that verbal expression of their sorrow or their tears might affect the coping of the child negatively they put on a brave mask which increases their experience of stress.

4.D.8 Stress – by anticipating non-availability of existing support system

**Palliative Care Unit:**

Assurance of support from professionals is helpful for healthy coping. But when the parents anticipate lack of support they experience stress. At present, the Home Care Team reaches to the door steps of the ill people up to a certain geographical area. When the decision of shifting the ill person to native place is taken by caregivers/ill person, they worry about not getting help by
Home Care Team. The Unit works for eight hours a day (9 am to 5 pm), the anticipation of need of medical help even after working hours create stress.

Following are the challenges for Palliative Care Unit. These challenges are stress provoking factors. The Palliative Care Unit is acknowledged as a necessary service by the patients and their care givers. It is necessary to extend the service to many geographical areas since it is not sufficient to serve only the patients from Mumbai. Patients from different regions of the country come to the Tata Memorial Hospital. It is not possible for them to stay at Mumbai to avail the palliative care service. So it is a challenge for the Unit to spread awareness about this concept. Complete palliative care set up should be established at different cities and regions. People getting treatment from hospitals other than the Tata Memorial Hospital will benefit from this service. As and when the possibility of cure becomes difficult then this type of holistic caring approach is perceived to be helpful to patients.

The Home Care Team is appreciated by the patients as it helps to receive support at the doorstep of patients. This service helps to save time and energy of parents as well as patients. Currently this service is available for certain geographic areas only. The patients from Mumbai and its suburbs receive this service but remaining patients are not included. So there is a need to build up multiple teams working in different geographical areas.

Along with the above mentioned challenges, Palliative Care Unit of Tata Memorial Hospital needs to extend its timing. As the patients have good rapport with the team of the Unit, they are more comfortable getting help from the team members compared to other General Physicians. The need to extend the timing of the clinic is one of the challenges for the Unit and is an expressed need of care givers. The existing service is available only till 5 pm. The patients in terminal stage of disease may need expert opinions or professional services at any time of the day. At present, the help is rendered telephonically. To extend the service hours of the Unit and make it available for twenty four hours is a challenge for the Unit. Few of the care givers wished to have this service all twenty four hours.
Conclusion:

Disease such as cancer is perceived as dangerous, scary, painful and life limiting illness by majority of people. The parents who find their child in the terminal stage of cancer experience grief and stress related to the fear of unknown. To witness their pain and gradual deterioration generates the feeling of helplessness in parents. Despite their efforts to help the child survive, when parents see them approaching death, they blame themselves. Financially and emotionally exhausted parents experience stress. Their decision of keeping the stress to themselves, create even more anxiety. Concern and love for each other, fear of repercussion of disclosure of bad news and acknowledging the burden of responsibility of other person become reasons to conceal the news from others. Social stigma attached to this disease force the parents to hide the diagnosis from others. Possible social rejection and concern for future of other children are observed to stress provoking factors for parents. Lack of ventilation of feelings and handling the situation single handedly with a brave mask hampers the parental coping.

Children with cancer show willingness to listen to the disease related facts. The sad facial expressions of family members, their body language, and own physical state indicate the advanced stage of cancer to children. They give a hint to their parents regarding their awareness and their wish to verbalize their feelings. Discussing the issues related to death and dying openly with ill child is not easy for parents. Parents and children try to mutually protect each other from discussing bad news related to the illness. They show their concern towards financial constraints and unmet needs of sibling due to own illness. When bed ridden children are cared by their parents, they (children) develop guilt. They feel sorry for their parents and blame themselves. Devastated dreams, being isolated and experiencing social rejection make the children suffer emotionally. Children experience isolation as they are forced to be away from school and daily activities to avoid opportunistic infections. Few children face rejection because of the social stigma attached to this disease. When ill children experience loneliness, guilt, social rejection, deteriorated physical condition and witness parental sorrow, their stress increases. The parents and ill child experience stress related to the current condition as well as anticipated eventuality. The strategies of coping adopted by parents and ill children are based on the current situation and context. Condition leading to stress facilitating current coping may or may not be adaptive.
Section: 4.E

Various types and sources of support

When parents face the event of having a child with the advanced stage of disease, they need support as it helps them to cope positively. The awareness of poor prognosis, frequent hospitalization, unpleasant distressing physical symptoms and life limiting conditions of the child’s illness add to the existing complexity and parents adopt certain coping strategies. It is noted that the factors like available support system, capacity for arranging resources, resilience of self and child, collusion pattern within family and community, spiritual belief system affect the overall coping of parents.

The support system such as getting support from family and extended family members, friends, community, NGOs, care givers of other patients, employers, well wishers, professionals help the parents to cope with the life threatening condition of their child.

Support Resources

To cope effectively with the life event, parents try to receive the support from possible resources. As per the study conducted by Slevin et al. (1996) emotional support is important for most cancer patients during their illness and can be gained from different people and services. Shumaker and Brownell (1984:11), define social support as “an exchange of resources between two individuals perceived by the provider or the recipient to be intended to enhance the well-being of the recipient.”

Support from family members:

In the Indian context it is observed that emotional and psychological support is available from the family members, relatives, friends, community and spiritual groups. The coping becomes positive as the feeling of being supported encourages one to face the difficult life event effectively. The help available from the near and dear ones might not be only in terms of material help, but other forms of support is appreciated by the parents.
Tata Memorial Hospital being a well known hospital treats many patients not only from Mumbai but also from out of Mumbai. The parents come to Mumbai with the expectation of short term treatment. They wish to seek a remedy for the existing symptoms of their child. In a few cases, children come to the hospital for consultation. After necessary investigations they are diagnosed with cancer. After diagnosis and other preliminary check up, they understand the need for prolonged stay in Mumbai for curative treatment. Arrangement for their boarding and lodging becomes their primary concern. It is seen that they are equally worried about other family members residing at their native place. It is not easy for them to handle both the sides. In this critical condition some of family member or some friend comes forward and offers his/her help to look after the children at the native place. The parents therefore feel relieved and can focus better on bed side care of the ill child.

**Mother of Shekhar said**, “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.”

**Father of Sameer said**, “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.”

**Mother of Mehru said**, “my son is newly married and my daughter-in-law has willingly accepted the responsibility of household chores. She never grumbled about taking over the entire responsibility immediately after her marriage at such a young age.”

**Mother of Naresh said**, “I was breast feeding my youngest child till we came to Mumbai. Now that small baby is staying with my old mother as we are not allowed to accommodate the kid in the hospital. My other daughter of six years who herself is a kid, takes care of her two year old younger sister along with her granny.”

**The father of Naresh said**, “it was so good that my brother was with me at the time of listening to the bad news from the doctor. I could deal with the difficult fact (relapse) only because of my brother who was with me to support.”
Mother of Sabina said, “in our community we generally marry within the family so we have common set of relatives. As a result it becomes easy to get help and cooperation from all the relatives.”

Family members generally pose as a support system. It is observed by the researcher that the immediate family members and extended family members try to help the primary care givers. The mother feels relieved as one of the members takes over the responsibility of other children. This helps the mother concentrate well on the treatment of the ill child.

Father of Lalita said, “my elder son was taking care of the shop in my absence which kept the money rolling and business remained as it was.”

It is seen that the older children of the family handle their family business in the absence of father/mother. Parents feel supported when their children try to share the parental burden.

Aunt of Seema said, “I am her (patient) aunt (father’s sister). As my brother is bedridden and my vahini (sister-in-law) is not capable to attend the hospital, I have taken the responsibility of this lovely child. She is more than a daughter to me.”

A few of the parents cannot participate in bed side caring or in accompanying the child to the hospital. The parents who themselves are ill, cannot engage themselves in child care. Some parents are loaded with other responsibilities such as looking after elder members of family, having other younger children to take care of, dealing with financial constraint and so on. In such a situation, it is seen that other family members come forward and willingly take over the responsibility for the treatment. It is observed that this is done out of love and concern and not as a mere duty.

Mother of Sabina said, “we have a practice to go back to our native place for a month after our children finish their exam. The entire family gathers together. I am looking forward to be with my people as it will support me emotionally and psychologically.”

Psychological support offered by family and extended family members at the time of crisis is valued. Assurance of being there proves as the support system. In India joint family structure is commonly seen. The members of the joint family share the sorrow of each other. The parents value and appreciate financial, emotional and psychological support offered by family members.
It is seen that a helping hand is offered by taking responsibility of either care of other children of the family, or involving in bed side caring of the ill child. Help to mobilize necessary resources such as locating funding trusts, identifying a place to stay and so on is offered to the parents. Parents feel proud when their children come forward to support their parents to cope with the disease of their sibling. Not only elder siblings but younger ones also contribute as per their capabilities. They share household responsibility or take care of family business and so on. This helping gesture is acknowledged and appreciated by parents. It is observed by the researcher that when siblings of the ill children willingly come forward to help the parents, the parents experience immense support and develop a sense of ‘we as family, for each other’. This helps them strengthen the bond of trust and love with each other.

**Theme: Receiving financial, emotional and psychological support from one’s family and extended family members, help the parents to cope effectively with their child’s illness.**

**Support from neighbors:**

The community or the place where we stay becomes a part of our family. Chawl is the residential place where a number of families live for many years. This type of dwelling accommodates several families. Chawls still exist in Mumbai at places like Girgaon, Parel and so on. Families stay at the same place for many years. As the association continues from generation to generation, interpersonal relationship bond between the residents is strong. The chawl is considered as one big family. The relationships like ‘aunt, uncle, brother, sister’ are developed during the course of time. Healthy and loving interpersonal relationship within different families is observed to be powerful. The researcher has observed that when there is an established bond of mutual trust and love, the care givers are comfortable to disclose the diagnosis to others as they are not worried about negative response from the community. This helps parents to accept the diagnosis without being worried about the social stigma related to the illness such as cancer.

*Father of Sameer said,* “I am a part of the chawl since my birth. We share every moment of happiness and sorrow with each other. I am sure that other members of chawl also must have gone through the similar stress when they came to know about the diagnosis of Sameer.”
Father of Seema is bed ridden and her mother is reported to be incapable to take care of her ill daughter. Seema’s paternal aunt willingly accepted the role of primary care giver during Seema’s treatment.

_Her Aunt said_, “Seema’s parents are not in a condition to take care of her during her illness. Along with me all our community members came forward and tried to help as per their capacities. There was never a day when she missed her hospital visit because of lack of attendant. They even try to help the family by providing ration and other necessary material to carry on their daily life.”

The interviewees residing in the chawl mentioned that every resident of chawl comes forward to offer help like their own family member could. They try and help the needy members in kind such as by providing ration, spending time with the patient, accompanying the patient to hospital, taking care of other children or by providing cooked food for them.

_Father of Hiral said_, “I had a bad reputation in the community. I was recognized as the ‘dada’ (goon) of the ‘basti’ (community). I misbehaved with many of the people. They used to avoid me. We were not on talking terms with each other in those days. Now when my child is unwell, I am amazed to see that the same people come forward to help us with extreme love.”

The above mentioned care giver was amazed by the goodness of the community towards his child. He was labeled as a ‘bad man’ because of his antisocial behavior and poor reputation. But when the time of need arose, people did not recollect those memories and whole heartedly came forward to help his daughter. The father admires the behavior of the community as the old memories did not interfere with the concern they showed towards his child. He mentioned that he was recognized as a man behind spreading terror in the community. After experiencing the kindness of the community he has understood the importance of ‘being good’ to others.

Father of Sagar shared his experience regarding the support he received at the time of crisis. The child was diagnosed at their native place. The father thought of coming to Mumbai for getting second opinion. The father was worried about financial arrangement after exhausting his savings. His neighbors, well wishers and Ganapati Mandal actively working in the community pitched in to provide financial support.
The father said, “amount was not sufficient to treat the child but the love they showed was encouraging. I felt supported and cared.”

Support from friends:

After confirming the diagnosis of cancer in Bhavana, her father decided to treat the child at Mumbai as he had strong belief on Tata Memorial Hospital. According to father it was necessary to bring the mother to Mumbai as they can share their responsibilities. The mother decided to take charge of bed side caring and the father was to take responsibility of arranging funds, approaching various trusts and so on. After discussing with all family members, the father decided to shift the entire family to Mumbai as other siblings of ill child would be taken care of. The next worry was to arrange a place to stay for the family of six members. The father was in Mumbai some time ago and had a good relationship with few of the people working at the same place. Those friends were informed about the disease of the child. All of them came forward to help the family. They helped him financially in the initial stage of treatment. To find a place for the family to stay is considered as the valuable help for father of Bhavana.

Father of Bhavana said, “as my friends stood by me I could get the child to Mumbai for her treatment. They helped me in finding a place to stay as the entire family decided to shift to Mumbai. I am lucky to have good friends in my life.”

Fathers of Hiral and Komal spoke about their childhood friends. According to both the fathers, they are close to their friends as they know each other for years.

Fathers of Hiral and Komal said, “we have a friend who is very close to me and I can share everything to him. We used to cry and share my every concern and worry. He used to listen to me. We used to feel supported.”

When the friends stand by the needy at the time of crisis, it is appreciated. The caregivers expressed their gratitude towards their friends as they became a support system at the time of need. The need ‘to be listened to’ is satisfied by the friends. The caregivers were open to ventilate their feelings to their friends. A few of the issues which were not disclosed or discussed with spouse were discussed with the friends. It was observed by the researcher that parents were comfortable sharing their feelings with the friends. Both the parents go through similar type of
stress. Parents are comfortable to share their feelings. The parents can cry, speak and share their concern about the illness of their child.

Mother of Sabina spoke about the support they received from the well wisher of the family during the illness of the child. ‘Sethji’ is the owner of the factory where grandmother of the ill child worked for number of years. He was the support system at every time when the family was in need.

*She said*, “Sethji came forward to support us not only financially but also provided psychological support.”

Mother of Sandhya works as a domestic help for a family. She acknowledged the support she received from that family.

*Mother of Sandhya said*, “the people in the family are like God for me. That is the only place where I can cry, share and express. They never treated me just as the domestic help but loved me as the member of their family.”

The employers of the care givers were considered as a support. Not only financial but even emotional support is provided to them at the time of need. Parents expressed their gratitude towards their employers. At the time of crisis the relationship of employer–employee goes beyond a professional one. At such a time, help received in the form of money, need based material or emotional support goes a long way.

*Father of Neeta said*, “one of the teachers of my daughter is my support system. She was with us from the time of Neeta’s diagnosis. She tried to raise the funds for curative treatment. Currently when the child is in the terminal stage of disease and I am totally broken, she helps me to face the difficult life event. I feel very comfortable while sharing my sorrow.”

Support from community, friends and other well wishers is acknowledged by the parents. They value the emotional support which they receive from them along with financial aid needed for the treatment. These relationships help them to ventilate and as a result they feel less burdened. It is noted that old rivalry and misunderstandings are kept behind as the current crisis is considered important and help is offered.
It is noted by the researcher that when the parents accept their child’s illness, they do not hesitate to reveal the facts to others. In contrast, lack of parental acceptance forces them to conceal the diagnosis from others. Factors such as past experience associated with stigma, rejection by society and denying the bad news compel the parents to hide the facts from others. As a result, they experience the burden of bearing the stress single handedly and also cannot request or look for any external support. The families who accept the situation cope effectively with child’s illness. They seek help from various sources such as friends, family, community, neighbors, and well wishers and so on.

**Theme: Neighbors, friends and well wishers are considered as an important support system, which helps parents to deal positively at the time of the critical life event.**

**Spiritual or Religious Support:**

Respecting and relying on God’s wish and destiny is generally used as a coping strategy. When the parents understand the poor prognosis of the child, they feel hopeless and helpless. Awareness of the eventuality helps them accept the limitation of complete cure. At this stage they attribute the event to destiny or God’s wish.

In the study conducted in South Carolina (Silvestri et al. 2003), one hundred patients with advanced lung cancer, their caregivers, and 257 medical oncologists were interviewed to understand the factors influencing the treatment decision. The study concluded that patients and their caregivers seemed to rely heavily on their faith to help them decide on treatment for their cancer.

*Father of Neeta said* “I am a part of a spiritual group. Our swamiji teaches us to deal effectively with the problems in the life. The likeminded devotees have formed a group and we help each other spiritually.”

The spiritual self help groups are recognized as a helpful source to cope effectively with the stress. According to caregivers the faith helps them to accept the difficult reality. Sharing and ventilating among the like-minded people is encouraged in such groups. Such a group believes in the power of God. Every difficult moment is attributed to the wish of God. Few of the parents expressed that praying together for the child helps them face the event positively.
Mother of Sabina said, “my child is very religious from her childhood. She keeps insisting on attending the namaz (mass prayer). Then I try to attend the same with her. Being a part of big group helps me emotionally”

She added by saying, “If Allah has decided to take the child away from me, then He will take her but without troubling her.

Mother of Mehru, a mother of 20 years old Muslim female patient said, “she is Allah’s property. His wish is the final word and I need to accept and respect His wish. I have a strong belief that He will not do anything wrong to anyone.”

Father of Neeta said, “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.”

As parents have no control over the situation, they prefer to surrender their burden to the Almighty. The child is considered as God’s property or a gift offered to the parents for a while. The faith in the Almighty initiates the process of acceptance. To rely on destiny or to accept the painful incidence as the wish of God is generally the way of coping. As and when the limitation of human efforts is accepted, power of God is viewed as the ultimate hope. The groups of devotees and the preaching of the religious leaders help parents gather their courage to face the eventuality. Rituals such as pooja, namaz, mass prayers, mannat, fasting are used as a tool to deal effectively with event related anxiety and fear. These rituals are considered as tool to convey their wish to God. ‘Sincere prayers are attended by God’ is the belief noted by the researcher while interviewing the parents. Parents belonging to a family having a strong religious or spiritual background accept the event relatively faster than others as it is considered as the wish of God.

Theme: Strong spiritual background, belief in the destiny, devotion towards the Almighty, and accepting God’s help enable parents to cope with the difficult situation.

Support from caregivers of other patients:

One of the factors mentioned by the parents as the support system is caregivers of other patients from the same hospital. The researcher has noted her observation while working with patients
that people in the same boat understand each other better. It is seen that parents or other care
givers become friends when they accompany their patients in hospital or when they spend their
time in waiting hall of the Out Patient Department and so on. Without formal introduction they
come close to each other. Sharing information regarding funding agencies, side effects of
therapy, diet and hygiene become main topics of their conversation in the initial stage of their
friendship. Gradually the relationship focuses on providing emotional support to each other.
Along with this valuable information, they find in them a good friend to share their feelings and
concerns. According to parents, the process of sharing is easy with other caregivers as they can
relate and empathize with them better. The researcher has seen parents sitting outside the ward
and expressing their concerns to other parents. There are parents who continue to remain friends
even after they go back to their respective native places. They maintain contact with each other
and continue to offer their support. This relationship is observed to go beyond the boundaries of
religion and age.

When Neeta was admitted in the hospital, her father became friendly with an elderly Muslim
gentleman who was the primary care giver of his son also suffering from advance stage of
cancer. His son and Neeta were admitted in the same ward.

Father of Neeta said, “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 Ajmal said, “by end of the first chemotherapy of Ajmal, we all care givers in
the ward became a part of a big family. We used to help and support each other.”

It is noted during the interviews of the parents that they 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. It is observed that they start sharing
responsibilities by getting reports for each other, submitting blood/urine samples, replacing the
bed care giver to offer a break to him/her. The informal support group is developed by the care
givers as they comprehend the severity of life event.
Theme: When parents go through similar difficult events of life, they understand and relate to each other, which enhance their coping.

Support from Health Professionals:

Experience of the researcher has noted that professionals from the medical field influence the process of coping of patients and care givers. Medical professionals are valued as the ultimate life savers in the Indian society. Overall behavior and response given to the patients and their care givers matter to them. It is observed that personality, gesture, tone and the body language of medical professionals are few of the aspects which are observed carefully by the patients and care givers. Their opinions regarding doctors are based on these observations. Care givers are specific about the certain expected behaviors of doctor and they compare the treating professionals with the image they have in their mind.

It is an expectation of every care giver to receive information about the diagnosis and prognosis of the disease, reports of investigations and condition of their child. The care givers feel satisfied if they are involved in the discussions with medical professionals. As per the interviewers, the care givers who were involved or at least informed about the possible treatment protocol feel that they are a part of the system. When the parents were informed about the disease, possible duration of treatment and side effects of therapy, they were prepared and the process of coping became relatively easy.

Father of Hiral said, “the reports mentioning her advanced stage of cancer were discussed with me on the same day. So my anxiety was not raised and I could save myself from the fear of unknown.”

Parents of Vijaya, Seema, Tarun and Sabina mentioned about the professional’s efforts to explain the necessity of tests. These parents are happy as the reports of MRI and CT scan were explained to them.

It is noted that medical terminologies such as MRI, scan, blood marrow, blood counts and so on are difficult and strange for the common person. When the reason or the need for conducting these tests and results of the test are discussed with parents, their fears associated with ‘why these tests’, ‘why only for my child’ is reduced.
After conformation of the diagnosis of cancer, the treating doctor spoke to the father of Bhavana. He told him that the estimated treatment cost will be Rs.1.5 lakh. It was a huge amount for this family. The father appreciated the way this information was shared by the doctor. While narrating this incident,

_Father of Bhavana said, “our doctor told us that estimated treatment cost will be not less than 1.5 lakhs. But don’t worry. This amount is not required immediately. This amount will be needed over next 2 years of treatment.”_

According to Bhavana’s father, this factual information helped him in two ways. One he had a good idea of the treatment and secondly he was relaxed as he came to know that entire amount is not needed immediately. He has enough time to gather the funds.

Accurate information given at right time in simple words helps the care giver to prepare the self for future. The above mentioned statement stands true for almost all cases. The fear associated with diagnosis and expensive treatment protocol builds distress. When all doubts are clarified and important information is imparted in advance, the care givers get time to prepare themselves to cope with the future.

_Mother of Vijaya said, “the job of a professional is to create confidence in the minds of people.”_

_Father of Naresh said, “the doctors are the experts, they should try different drugs but the care givers and patients should be taken into confidence.”_

The knowledge regarding the child’s disease is expected to be imparted to parents by the professional. The warm gesture, tone and body language of the professional helps parents feel supported. It is seen that the doctor is considered as the ultimate life saver. The child is handed over to the doctor with complete faith. Repetitive investigations, lack of awareness about the disease and multiple opinions of the different doctors create confusion in the mind of care givers and hamper positive coping. It is observed that patients and care givers belonging to the lower social economic strata or having a language barrier experience difficulty in communicating with doctors. Because of such difficulties, it becomes difficult to develop and maintain the rapport with the doctors. Those professionals, who understand these barriers, try and involve the parents
by giving them information at every stage of disease and treatment. Empowered parents can cope effectively as the uncertainty is minimized because of the awareness.

**Theme: Sharing accurate information regarding treatment protocol, duration, cost, need of hospitalization and involving them in decision making helps the parents to cope with the illness of their child.**

**Resilience and confidence to face the event**

It is observed by the researcher that some of the individuals have different types of strengths. He or she might have strong coping abilities as the part of personality. According to few parents, the event helps them to gather courage and face the situation bravely. The past experiences of their life also help them to boost their confidence and they cope positively. Few of the parents mentioned about their inbuilt strong resilience.

*Father of Sameer said,* “I have an inbuilt capacity to fight back. My nature is to answer vigorously to the problem.” He added by saying, “My strength multiplies when I am under stress.”

*Mother of Sandhya,* who is illiterate and absolute stranger to Mumbai said, “I am illiterate. But I don’t think, I experience any problem in my life because of my illiteracy. I always feel that if I would have not gathered the confidence and courage then my daughter would have not received the treatment. I always use one sentence ‘ho jayega’ (will be done.) and that helps me. I am happy about the way I did for my child. I think I performed my duty very well.”

*Mother of Vijaya* said, “my capability multiplies when I am in crisis. I feel brave and confident while fighting with the problematic life events.”

*Father of Sagar said,*” I never blame my low financial status for not getting proper treatment to my child. I did my best and used all possible resources to arrange the money for treatment. I found a job in Mumbai (originally he is not from Mumbai) and started fighting the battle from all fronts.”
Lindtrom and Eriksson (2005) mention that according to Antonovsky’s original idea it was more important to focus on peoples’ resources and capacity to create health than the classic focus on risks, ill health, and disease. The key elements in the salutogenic development are, firstly, the orientation towards problem solving and, secondly, the capacity to use the resources available.

The researcher also confirms the same observation in the current study. The event of having a terminally ill child is same for all parents but the way they cope depend upon the above mentioned two key factors. The parents can deal effectively with the event as they focus on problem and identify the supportive resources. They accept the problem as challenge and face it bravely. These individuals mention about their inborn ability to deal effectively with the difficulty.

*Theme: When parents are able to accept life’s problems as a challenge and resolve it by deflecting them into opportunities for growth, they cope better.*
Support Systems used by parents

Support sources:
Family, extended family, friends, spiritual belief, self help group, community, neighbours, well wishers, work place, caregivers of other patients, professional health care workers

For:
Catharsis, Financial aid Information Satisfy basic needs Bedside caring Taking care of other family responsibilities-business,

Strategies to cope:
• Accepting help
• Ventilation of feelings
• Identifying resources
• Accepting poor prognosis
• Preparation for eventuality
• Convert problem into challenge (Resilience)
• Parental participation in discussion regarding medical treatment
• Flexibility and openness to listen. Readiness to change own belief, values, opinions
Section 4.F

Influence of parenting style on coping

Each family has its unique way of rearing their children. This style of rearing children has a profound influence on the way parents groom their children and how the children interpret and understand how to live life and face its challenges. While parents may provide similar contexts of parenting to children, the latter learn to make meaning of these contexts and learn lessons that they carry with them for life. Hence children of the same family create meanings of that vary from each other. Child rearing styles serve as a foundation for families to pass down to generations and perpetuate interaction patterns and family characteristics that make this family unique. Some parents provide their child the space to take independent decisions, while others provide guidance and encourage their child to choose the best suited option. Parenting style often influences the overall family atmosphere.

Parenting

It was observed while interviewing the parents that they take completer responsibility for their children’s growth. Few factors such as their financial condition, job stability, their own experiences as children and their respective parents’ attitude and behavior towards them influence their parenting style. Parents dream for their child a good and secure future with a good education and job. Parenting style of mothers and fathers differ. The gender of the child influences the rearing patterns. The parenting style between mothers and fathers differs and the gender of the child influences their rearing pattern.

Father of Sagar belongs to an economically challenged category. He could not pursue his education due to poverty. He was forced to earn at an early age to provide financial support to his family. Hence, the father was keen to see his only son progressing well in studies. His dream was to see him pursuing a career in the corporate sector or in government service. However, Sagar was not interested to study but he was keen to earn and support his family. He did not pursue his education after he failed to clear the 10th standard board level examination. Though it distressed his father, he never compelled Sagar about academic pursuits.
Father of Sagar said, “my son has grown up now and let him decide the best suitable thing for himself. We as parents never try to force our wishes on our children.”

Since Sagar was their son, his parents were hoping for the best. While his father displayed keenness to educate him despite financial challenges as parents, they never imposed their dreams on him. The parents believe in sharing everything with the family members. Father used to initiate a discussion on every small happening during the day. The child used to speak about school, friends and teachers amongst other things. They would share their success, rewards and even punishments received in school. According to the father, this inculcated a habit of open communication which also enabled the child to discuss the advanced stage of cancer. Moreover, it helps him talk about his feelings and thoughts regarding his illness.

According to the father of Sameer, as parents they are concerned about the discipline and educational progress of children. The parents have dreamt of having intelligent sons doing well in their studies. But they were not harsh if the child could not meet their expectations.

The parents said, “we never pressurized our children for good marks, grades or ranks. We always encouraged them to accept the challenge. We are concerned about the efforts they put from their side. In fact I (father) always encouraged them to face defeat. This is nothing but the lesson of life.”

Father of Sameer believes that, this type of nurturing is helping Sameer face current event of life. He narrated an incident describing the fighting spirit in Sameer. The child was preparing for a scholarship examination. He 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 father said, “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.”
Both the parents are happy and satisfied about the way child is coping with the disease. According to them it was remarkable to see the way child faced the surgery (amputation). His composure and resilience to face/cope with the situation can be attributed to parenting styles and the family values imparted by his parents.

**Mother of Mehru** has four daughters and one son. She is keen to guide and discipline her children so that society should admire them. The father does not allow the daughters to watch television, sing songs or stand in front of a mirror. The mother is happy and feels the need for such discipline.

*She said, “for both of us discipline is the necessity as it is the foundation for a well groomed family. I am proud of being respected in the society and I want to maintain the same reputation. Bahu beti gharki ijjat hoti hai.”*

The four girls in the family are not allowed to sing or dance even at home. They are scared of their father. Mother narrated an incident which she links to the pattern of discipline. When the child was explained about the poor prognosis she became very much restless. One day when she was alone in the consulting room which has a CCTV camera attached to it. As soon as the doctor came out to get some reports, her mother saw her dancing inside the room. She was jumping and singing till the doctor entered the room. According to her mother this might be her way to ventilate, express her stress, or she might be fulfilling her desires. After watching this, the mother felt bad for the child. Despite her need of being strict with daughters she felt that the child never got a chance to fulfill her wishes and now she has no time for completing her wishes because of her life limiting illness. Still she has strong opinion that parents have to demand discipline and be stricter while nurturing the female child.

Mother of Neeta is bed ridden for the last four years. The two elder siblings of the child take care of their mother by feeding and cleaning her. Her father feels that he has to play the dual role of mother besides his own as a father. According to him, his children have seen him struggling in life without grumbling. The family has a good interpersonal relationship with each other. According to him, he has not tried to hide the reality from his children. He communicates about the stress he is experiencing while handling his bed ridden wife, household responsibilities, earning for family, looking after growing children and taking care of the ill child.
While describing the family atmosphere the father of Neeta said, “*We speak, we share, we try to involve all family members and so we understand each other. As a result, we have a good healthy atmosphere at home.*”

*Parents of Neeta* are devout followers of swamiji (a spiritual guru) and they said, “from the beginning we both never compelled the children to study. We feel that there is much more than studies in life. We are particular about their behavior. We never could tolerate children using abusive words in conversation or misbehaving with friends/neighbors etc. We are followers of swamiji and good disciplinary values should be learned by all. Be loving to all, be helpful to all, be good to all, are the values which we are trying to inculcate in their life.”

According to the father of Neeta, he is able to face this difficult period of his life because of *Swamiji*. As per his observation, their belief and spiritual value is the one of the major sources of support which is helping them to cope effectively. The child has grown seeing them following the preaching of Swamiji, so even the child has also imbibed it.

Every parent has a unique style of parenting. They have the desire to raise their children well, in the process proving themselves to be good parents. Few of the parents are very particular about the behavior of their child. They want them to behave according to their expectations. Few of the parents give freedom to children to choose their path. Parents like to provide continuous guidance to their children and give prime importance to education as it is considered an important asset to a more secure future in later life. They pay attention to the child’s behavior and disciplining. They have set expectations from their children and wish that these expectations be fulfilled. Parents are also open to give freedom and space to their child to choose their own path. The study reveals diverse experiences of parenting a child. The style of parenting is one of the factors that influence the coping process for both the children as well as the parents. It has reflections of the faith, values and opinions of the parents which help them to face the stressful situation.

*Theme: Parenting style influences the way they deal with the child’s illness.*
Certain demographic details like gender, number of children, and birth-order influence the coping in the family. In the study, four families having only one child are included. When the only child is on the death bed, the parents find it difficult to cope with the situation. It becomes difficult for them to deal with the anticipated loss in the family.

Parents of only child:

The parents of Hiral took a conscious decision about planning only one child.

Father said, “we spoke to each other about planning a second child, but we realized that to bring up a child is not just to provide food, shelter and clothes. But it demands much more than that. It needs money, time besides so many other things. So it was our conscious decision to have only one child.”

Today when the only child aged eight years is on the death bed, the parents are not happy about the decision they had consciously taken in the past to have only one child.

The mother of Hiral said, “sometimes I feel, if we would have had second child, then we would have had somebody to look for. To plan a second child it is too late now. I don’t think we are mentally prepared for one more child at this stage. We now feel that if anything goes wrong with our daughter then the feel of home, the homeliness will go away with her.”

Mother of 15 year old Shashi willingly decided to stay at home. Her desire to play the role of a mother twenty four hours a day was accepted and appreciated by her husband and other family members.

Mother of Shashi said, “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 the extreme financial stress during our childhood. Our child should not go through the same. So I want to have only one child. My life revolves 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.”
In the cases mentioned above, financial constraint was one of the factors to plan for one child only. Both parents had a dream to satisfy the desires of the child. Parents in both cases are financially not well off. They went through financial problems in their childhood and witnessed their parents struggling with poverty. Both fathers said they witnessed their own parents’ struggle with poverty, working hard to satisfy family needs. This past experience influences their dreams for their child and hence their parenting style.

Ramesh was born after almost sixteen years of marriage. Both parents underwent Ayurveda treatment for infertility problem. The parents never thought of adopting a child as they had immense faith in Ganapati and Saibaba and were sure that they would be definitely blessed by God.

_Father of Ramesh said_, “God blessed us with this child after sixteen years of marriage. Our life revolved around him. Our only wish was to have a child at home. 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.”

Ramesh’s mother is happy and satisfied about her rearing style. Both the parents being the teachers could give sufficient attention to his studies. The child is also an extra ordinarily brilliant student who has a cupboard full of his merit certificates, trophies and medals.

_Mother said “we are happy as parents to have child at home and satisfied that our child is so intelligent. I am afraid to imagine our life without him. We are retired people. All the time at home without the child will make us mad.”_

To witness a life threatening disease of the child is a difficult proposition for the parents. The parents who have an only child go through relatively greater stress. The efforts are towards providing a comfortable life to the child. Their life and their dreams revolve around the child. The thought of not having their child in the near future is frightening for the parents.

According to them they will have no motivation to live if they lose their child. It is difficult for them to conjure images of the prospective death of the child. When their role as parents comes to an end then they would remain with nothing to look forward to. Mothers, especially the home makers would face tremendous stress as they cannot imagine themselves without their child. It is
seen that their life revolves around the child and they are more conscious about the well being of the child. Generally the parents expect excellence from their child in all fields from their children and success is considered as a reward for their careful and dedicated parenting.

**Theme: Since parents of only children invest in their child, they tend to experience anticipatory grief and loneliness of the loss of their only child.**

**Parents of male child**

Experience of the researcher reveals that in the Indian context even in the 21st century, a male child is considered as an asset and a female child as a liability. A son is treated as a precious gift from God and sons are showered with more love and pampered as they are considered to be the support system for the parents in later years.

In the given study nine parents of male children have been interviewed. The concern which has been expressed frequently is the sorrow related to losing a solid support system of old age. If the parents have only son in the family then a major concern expressed is “who will continue the family name after us?”

Parents of Sagar have 2 daughters. Sagar is the only son in their family. His parents are approaching their old age.

They said, “he is our only son. As soon as a son is born, parents feel that they will be well taken care of during their old age. Now we will be alone when we need someone to take care of us. We might be in a poor physical and financial shape in our old age. We will miss him at that time. Our two married daughters are busy with their own lives and their families. We would be a burden to them. The daughters may feel like supporting us but they can’t decide unless they are permitted to help us.”

Middle aged mother of two daughters and Tarun said,

“To lose a male child is always difficult. Now we will have no one who will continue our family name. The girls will get married and will go to other families. We will remain by ourselves. We are losing our only support of our old age.”

Faizal is the only brother among four sisters. He is the only male child of the family.
His grandfather said, “of course it makes a difference when the only son of the family is on the death bed. God has given us 4 daughters. He is the only male child in our family. If anything goes wrong with our grandson then we have no one to carry our family. We have built a huge house at our native place. Our grand-daughters will get married and will shift to their in-law’s place. Who will stay in that huge house? We will be all alone. It is definitely very sad to lose a male child. The son is the only support of the parents in their old age. I am concerned about my son as he will be all alone in his old age.”

In a family, sons are preferred over girls. They are expected to look after their old parents. It is an accepted social norm that daughters are not considered as old age support systems of their parents. Parents want their daughters to get married and look after their own marital families. When the daughters get married, their maiden name changes and they start using their husband’s name. A son is valued more as he carries the family name. With a few exceptions, parents expressed their desire to have a son to enable them to keep their family name alive. Few of the mothers said, “women having sons are respected more in the society than those having daughters.”

To accept the help from a daughter especially a married one is considered an obligation. The girls in all cases (if diseased or healthy) are considered a property of someone else. The parents do not expect any monetary help from them and most of the girls accept and subscribe to these social norms.

**Theme: Parents of male child with a life threatening disease go through anticipated grief and loss as they perceive a loss of support during their old age.**

**Birth order:**

Mehru, Neeta, Bhavana, Sagar, Seema, Tarun and Sandhya are the youngest among the siblings.

Mothers of these children said, “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 the highest attention.”

Father of Bhavana and Neeta said, “as she is last in the birth order she is always considered as a child despite her age.”

Sameer, Naresh, Sabina, Faizal and Shekhar are first in birth order. First born child is considered as precious, as parenthood begins with that child.

Father of Sameer said, “being a parent for the first time is special.”
Parents of Naresh said, “being the first born male child, he is precious to both of us.”

When parents reflect and recollect their memories of their first child, they are observed to be very happy.

They said, “first child gives different meaning to the life.”

Their love towards the child remains unchanged irrespective of birth order of the child. Birth order does not necessarily alter the experience of parental stress and the way they cope with the event.

Gender of the child

There are a few parents among those interviewed who have only daughters with advanced stage of cancer. The researcher tried to inquire about their perception having an only daughter.

Charu’s parents took a conscious decision of planning only child.

The father of Charu said, “she is the first female child of our family. All my brothers have sons and we were so happy have Laxmi (Goddess of wealth) in the family. Her birth was a moment of celebration. Both of us decided to have only one child, gender was not the issue for us and even for the entire family.”

Father of Hiral said, “we have less number of daughters in the family. We were happy to have a girl child as our first child. My parents and other family members were also happy about this. She is considered as the Goddess Laxmi’s blessings.”

Father of Hiral who was dragged into anti social activities a few years ago gives the entire credit to his daughter for his complete makeover from ‘dada’ (goon) to a genuine family man.

According to father of Hiral, “I will not dare to step in to that black world as every time I would remember her face and it reminds me of my responsibilities as a father. Such miraculous changes can take place only because of a daughter.”

The parents mentioned above decided to have an only child irrespective of the gender. First born daughters are greeted with happiness in the family. Their parents nurtured them with love and care. It is worth noting that not only parents but the entire family is happy to have a first girl child in their family. There is no discrimination based on gender while rearing them.

The parents have their own unique ways of nurturing the child. Among the parents interviewed, all of them were conscious and keen about education of their child. Their desire to have an educated, qualified and a well placed son or daughter is expressed.
Few of them said, “we are aware about their behavior in the school. We punish them if they are not up to the mark.”

It is observed as well as expressed by the interviewed fathers that most of the girl children share a special kind of relationship with their fathers. With cancer being diagnosed, it provides an opportunity to the parent (father) to spend more time with the daughter, involving numerous trips to the hospital for treatment. These interactions in turn help in strengthening the bond between them.

**The father of Bhavana** who is always happy to speak a lot about his daughter said, “I have 4 daughters but I love this child the most. Not because she is ill but she is always preferred over all. She is a lovable child and we share a special relationship with each other. She is ‘Papa’s daughter’. She will never eat any special dish without sharing it with me.”

**Father of Hiral**, who regularly accompanies her to the hospital said,” From the beginning she is her father’s daughter. Now she keeps insisting on being with me in the hospital and I feel good about it. She is closer to me than her mother and now we are coming closer so the bond is only strengthening”

**Father of Lalita** said, “being the only daughter among our 3 children of ours she is always preferred over the sons. She proved her intelligence and sincerity in her studies so she is favored even more.”

Parent of Sabina shared their parenting practices. The mother does not scold the children. The father who is 12th pass is particular about studies and the school performance of his children.

**Mother of Sabina** said, “I try and make the daughters learn house hold chores. That is what girls should know. We expect the girls to do well in the Madarasa, to learn the house hold chores, to read the Quran etc. The knowledge gained should help them to do well after their marriage. Boys need education. If they fail to perform well then they deserve to be reprimanded. However, we never scold the girls regarding their performance in school.”

Mother of Sabina also wants her daughters to be trained considering their anticipated role of daughter-in-law in the future. They should be good in cooking, besides conducting other household duties. She would be tolerant if her daughter is not doing well in studies. According to
parents, ultimately girls should be trained to prove themselves as good home makers. The duty of running the house is that of boys.

_Father of Komal said_, “there is some gender specific differentiation in treating the children. For example, regarding access to education. We want our son to be well qualified. If the son is well educated he will be a strong support system to us in our old age. If we educate our daughters, we need to spend on their fees and books etc and eventually some different family will be benefited of that expense. Ultimately girls have to marry and spend their life not with parents but with parents-in-law. Then why should we spend on them?”

Mother of Vijaya has four daughters. The family belongs to the lower socioeconomic strata. She blames her low financial status for not being able to provide a comfortable life. One of her daughters is adopted by her brother. The mother is happy for that child as she feels that at least one of the daughters is leading a comfortable life. According to her, education is the only key to achieve a better quality of life.

_Vijaya’s mother said_, “I cannot compromise on discipline. Certain rules and regulations have to be followed by the daughters. I am a loving and caring mother if my children are a well behaved and doing well in studies. If I find them not studying well then I punish them. They are scared of me but I do not mind as I am doing this for their well being,”

Currently when Vijaya is in her terminal stage of cancer, her mother is not as strict as she was. She tries to discipline other daughters than Vijaya. According to mother is more tolerant and loving towards ill child. She wants to see her child happy.

The discrimination between girls and boys regarding selecting the school, assigning the house hold chores amongst other things is observed. Disciplining differs based on the gender of the child. It is essential to note that daughters also accept this favoritism without grumbling as it is inculcated in early childhood.

_Parents of Tarun said_, “my daughters go to a Marathi medium school but my son is in an English medium school. We are more concerned about the overall growth of my son”
Both parents love their children and perform their duties towards their children. According to them they try to educate the children. Parents always dream to see them grow well and be well settled in life. According to parents of Komal and Tarun, no parent would discriminate between their sons and daughters if they have adequate resources to satisfy their needs. In the given circumstances, since they need to make a choice considering the limited resources, parents, often tend to show preference to their sons over their daughters as the former are seen as support systems of old age.

**Gender of the child and care giving**

A significant observation regarding the care giving approach is observed in the study. The parents preferring sons over daughters feel equally sad to lose their daughters. The gender of the child makes no difference in caring and loving the child. The child is valued as a gift from God. The parents emphatically state that, “When our own child is on the death bed then gender of the child becomes immaterial and love is showered.”

*Shekhar’s mother said*, “gender makes no difference in care giving. At last it is our child who will be taken away from us. I don’t think I would have done less than this for my daughter.”

*Father of Komal* admits that there is discrimination based on gender while rearing the children. Preference is given to sons for education or getting other facilities. But when it comes to caring, he said,

“both of us love our daughters and son equally. I would have done the same for my son. I will not think twice before I do anything to save her life. She is my own child, God’s gift.”

*Neeta’s father said*, “girl or boy, this is the gift of God. Why should we discriminate? Who are we? If we do so then God will punish us. I don’t think that sorrow of witnessing the sick male child is more than that for a girl child. To me, my daughter is God’s blessing so she is precious.”

*Parents of Ajmal* have only one daughter and three sons (one of them is ill). They have a soft corner for their only daughter. The father believes that his sister has taken a re-birth through her in their family.
The parents said, “unfortunately if our girl child would have been diagnosed with cancer, we would then have done even more than whatever we have done for Ajmal. Every child is the gift from God and it is our duty to take care of the gift.”

**Aunt of Seema**, while commenting on caring for the bedridden girl said,

“Gender does not affect caring. I think people from the community must be laughing at me for spending so much money and time for helping a girl to survive. I would have been encouraged and appreciated by the community if I was caring for a male child. I think we are taught to value the life of a male child over that of a female child. The sorrow/grief of losing a son is definitely more than that of losing a daughter.”

**Parents of Shekhar** have two sons and no daughters.

The mother said, “gender makes no difference in care giving. I don’t think I would have done less than this for my daughter. I would have gone through the similar level of stress for her sake.

Even though parents prefer sons due to cultural norms as mentioned earlier, the gender of ill child does not alter bedside care giving. According to parents, their grief is about losing their own child. At that stage gender of the child becomes immaterial. The imminent loss of their child occupies primacy as compared to other parameters that otherwise would be significant in their lives.

**Theme: Gender of child does not influence bedside care giving by parents.**

**Care giving by family members other than biological parents**

Two children included in the data are not cared for by their own parents. Seema is being looked after by her paternal aunt in the course of her treatment as her father is bedridden. The aunt has been a great support to the family. She stays next door and is concerned about her paralyzed brother (child’s father).

According to the observations of the Home Care Team and Counselors, the mother does not enquire about the disease or prognosis, despite their keenness to share the same with her. Mother of the child is not involved in the treatment phase of her daughter. She sits in a corner of the room, makes no eye contact with anyone and does not utter a word. According to the aunt, the
mother of three daughters does not involve herself in family affairs. She keeps herself busy in her day to day house hold chores. She rarely speaks, neither does she comment or argue. There is hardly any dialogue between mother and other family members. As a result, children are more attached to their aunt and share everything with her.

*Aunt said, “I consider her as my own daughter. When she is in good health, I try to teach her, I taught her house hold chores as I always wished to see her married and making her family happy.”*

Second case is of Faizal. He belongs to a joint family. He is looked after more by his paternal-grandparents than his own parents. His father works as a rickshaw driver in a metro city. He is the only earning member of the joint family. He comes occasionally to visit the family.

*According to grandfather, “he is doing his duty to earn for us. So it is our responsibility to take care of his wife, four daughters and Faizal. When we are there to take care of him then why his parents are needed?”*

Mother of the child is not involved in care giving since the inception of treatment. According to the grandfather, she may not even be aware of the diagnosis. She has never accompanied the child for his treatment. Most of the decisions are taken by the eldest male member of the family as per the accepted family norms. All other family members listen to and follow his instructions. Currently the child is able to meet his mother when he goes to his native place. When enquired about her wish to be involved in the bed side caring,

*Grandmother said, “mother is always occupied with the house hold task like cleaning, washing clothes and utensils. She is busy cooking and feeding her children. When she finishes her work, it is late night. She has no time even to love her children.”*

As the researcher could not speak to the mother, she could not gather her opinions and desires. While answering the query of the researcher, “do the mother and child miss each other since they are away from each for a long time?”

*Grandfather thought for a while and answered, “why would she (mother) think of coming to Mumbai leaving her four daughters behind? Why the child will miss his parents? We are much more than parents for him. His grandmother has looked after Faizal immediately after his mother delivered this premature, low weight child.”*

The care givers from the extended family are caring and trying to provide the best from their end. They take the entire charge of the situation and they make decisions regarding treatment options.
They hardly involve parents of the child in entire process. However, when they think about the eventuality, they feel sorry for the parents of the children. According them, parents will go through the trauma of facing a major loss in their lives. These extended family members will feel sad to lose the child, but they have their own life to live. Moreover, the parents would have to face and experience the distressful event.

Father of Komal who is hardly involved in the child care from the beginning. While speaking to him one point emerged is ‘he is missing the role of bed side care giver and is feeling bad and neglected’. According to him, his family is financially challenged from beginning. Many times, the couple used to spend days without food. The children also did not grumble about the same. Poverty is the part of their life. His wife is well supported by her siblings. Since diagnosis to treatment, Komal’s maternal relatives took charge of her health related issues and other responsibilities in the hospital.

He said, “initially I felt good thinking that there is someone to support us. Now I feel, as I am financially not sound, I am not involved. My elder son and his mama (maternal uncle) do all running around. They speak to doctor. They stay with her in the hospital. I hardly come here. I feel rejected. I feel sorry for not contributing in any aspect.”

The father feels he is going through a stage of rejection. According to him, the lack of financial stability is limiting him from getting satisfaction of caring for his daughter. Monetary constraints restrain him from expressing his opinions, concerns and desires regarding his daughter’s treatment. This feeling of rejection impacts his coping patterns and feels frustrated at his inability to contribute meaningfully despite desiring to, in the entire process of treatment. Furthermore, he regrets his unstable financial condition and holds himself unreasonably and entirely responsible for this present state.

When extended family members are primary care givers, they give love, provide care and perform their duties, but the emotional need related to child-parent relationship is sometimes ignored. In the cases mentioned above, parents are not actively involved, but still care is well provided for, by other family members. Being away or opting to be away from the sick child may be an influencing factor in coping for both, the child as well as the parents.

Theme: Direct provision of care helps both, child and parents to cope positively.
Preparation for death of the child

To prepare for the death of one’s child is difficult but it is noted by the researcher that parents start preparing themselves for the inevitable event of death of the child. They think about the procedures pertaining to the last rites as per their religion. The concerns like what to do after the child passes away, whom to call, whom to approach for a death certificate, deciding the place for the funeral to take place and so on are considered. The parents of children who do not live in Mumbai are worried and scared. The worry related to issues such as, ‘if the child dies in a strange place like Mumbai, then what is to be done?’, ‘do we take the body all the way to native place’, or ‘do we call family members to attend the funeral of the child,’ are generally discussed amongst the close family members or at least given a serious thought, if not explicitly discussed.

Few of the parents wish to take their child back to their native place after understanding the terminal phase of the disease. Such parents often worry regarding the possibility of the death of the child during the journey. They anticipate possible complications related to this issue. Concerns emerge about ‘whether we should call the police in such cases?’ or ‘whether we should carry the dead body to the native place?’ and these are expressed by these caregivers.

Grandparents of Faizal who are from Bihar are worried about his poor prognosis and anticipate his death anytime soon. Besides being saddled with the sorrow of anticipated loss of the child, they are also concerned about the possible hurdles they might have to face if the child dies in Mumbai. To tackle this situation, the grandfather approached a Maulavi (priest in a mosque).

*He spoke to the Maulavi, “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.”*
Father of Tarun is worried about handling the child during the last 48 hours.

He said, “Palliative Care Unit has proven to be of great help to me as I am aware and well informed about handling the child in the last stage. They apprised me about the papers that are required to procure the death certificate. 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”.

Though it is difficult, parents prepare themselves for the death of the child and plan the rituals to be followed afterwards. Preparing themselves for this eventuality is a part of their coping mechanism. This also helps them to grieve as the impending loss of the child becomes a near reality. This works as a form of healthy coping as it helps them to initiate the process of accepting the eventuality.

When parents find it difficult to think about the anticipated loss of the child, they go through severe stress. Though bitter, as when they see child approaching towards the death, they start prepare for the moment. At this point they start worrying about necessary arrangements after the death of the child. They inquire about procedure to get death certificate, deciding funeral/burial place. It is observed by the researcher that parents deny the situation but at the same time start preparing themselves to accept the fact.

Theme: Parental preparation and planning for the death of their child, however difficult, aids healthy coping.

Efforts towards saving the child

It is an observation of the researcher that parents, irrespective of their financial limitations, struggle to save their child. These efforts are considered as their duty. They feel it is their responsibility to offer a better life to their child. They are not deterred even when the poor prognosis is discussed with them and they understand the eventuality of death. They try to achieve the satisfaction of performing the role of good parents. Few of them feel that if they give up these efforts, then they will carry this guilt and regret till the end of their lives.
Father of Sagar is trying his best and he is struggling alone. He is satisfied about his effort in child care.

The father who is aware of an advanced stage of the disease said, “there are many people who lose their lives in accidents. The accident-victim’s families often do not get a chance to even be care givers for a short while. In contrast I am fortunate that I have an opportunity to care for him and I did my best to help him survive. I did my job with complete honesty and sincerity. It is fine that I have lost everything, all my savings are drained. I have a big loan to repay, I have lived with severe stress and ultimately I would be losing my child. Yet I have the satisfaction of putting in my best efforts. I can face God as I have performed my best as a father.”

Parents of Mehru have spent a lot on their daughter’s treatment. Despite understanding her poor prognosis, the mother feels that if there is any remote chance of her being cured we do not mind arranging money at any cost.

She said, “almost all our savings have been drained by now. We would definitely try to arrange some money if any possible treatment is offered to or suggested to us.”

Parents of Naresh have a different stand on spending for the treatment of their child. According to the mother, enough money has been spent for the child and no positive outcome has resulted. Instead of incurring further expenses they feel it is their duty to save it for the future of their other children. His mother is concerned about their two daughters and worried about their old age.

The mother of Naresh feels, “in our old age, we will have no money to survive, nor our son to look after us. Hence we need to be practical.”

The father of Naresh said, “he is more valuable to me than any amount of money. I have borrowed more than a lakh of rupees from my relatives. I don’t mind borrowing even more if somebody ensures cure.”

The father values the child over his own future, while the mother thinks rationally. She not only thinks about the sick child, but about her other children and also about her husband’s and her own future. According to the father, using savings or even getting a loan from friends or relatives is all right if the money can save their son’s life. The assurance of cure is considered as the motivating factor for parents to struggle. Naresh’s mother understands the importance of helping
their child to survive. However, as and when the chances of cure diminish, they try and focus on other aspects like well being of other children or their own future.

**Theme: The parents believe that their duty is to help the child survive and attempt their best, as this gives them immense satisfaction.**

Parental sensitivity towards the needs of ill children

During the illness of the child most of the parents admitted that they became little extra sensitive towards their needs. Their usual parenting style is modified willingly to make the child happy. Each and every interviewed parent is struggling to make the child smile and happy.

**Father of Bhavana said,** “our parenting style has been altered but not changed completely. The efforts are towards making her happy. We tolerate her tantrums. We are little extra sweet and compassionate towards her. She is excused for her misbehavior.”

**Parents of Charu and Lalita said,** “our parenting style has not changed much. She is a loving child who always grabbed all love and attention from all the members of the family. The love is more now. We are focusing on fulfilling her desires. We try to fulfill her wish immediately.”

**Grandfather of Faizal said,** “as the child was diagnosed with cancer our parenting style has changed. When we got to know that he is a guest for a few days, since then we never scolded him. Whatever maybe his life span - may be 2/4 years let him survive. We give him whatever he asks for. We give money to him to fulfill his every wish. He was a pampered child from the beginning but now we love him more. Previously, when he would play truant from school, being naughty in the school, we would punish him. Now as we have understood about his disease none of the family members have ever scolded him or punished him.”

**Parents of Sabina** who are very particular about the way children behave said, “we are becoming softer towards her than the other children. When they fight with each other, then we support the ill child and scold the other children.”

**Mehru’s mother said,** “we have started loving her a little more. I try to give whatever she demands. I have kept some gold ornaments for her. The dream was to give her at the time of her marriage. But now I have decided to give them to her immediately after we go back. If she wants to wear them or change the existing design we will let her do so.”
Parents make sincere efforts to keep their child happy. When they have accepted the short life span of their child, they start fulfilling their wishes. Most of the parents prefer to let their child be happy. The parents feel satisfied when they offer a happy moment to the child. Parents of Komal or Vijaya try and fulfill their daughter’s wish irrespective of their financial crisis. Fear is associated with predictable death of the child, which makes the parents struggle to fulfill every wish of the child.

**Theme:** Parents become more tolerant and caring towards a child suffering from an advanced stage of disease and then make all efforts to keep them happy.

**Change in parenting style: more tolerant, considerate and loving**

The parents change their parenting approach. Their behavior changes do not remain restricted only towards the ill child but even towards other children. The child’s illness helps them revisit their parenting styles and make amends wherever possible. They start picking flaws or try to improve their relationship with their children.

*Father of Neeta feels, “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 Shekhar is strict and expects his child to listen to him. According to him, it is the duty of parents to discipline the children which in turn helps them to pursue a bright future in life. Following this episode, the mother has observed that his father’s parenting style has improved and changed for the better. In her view, he is more caring and loving now than before.

*As per the observation of Shekhar’s mother, “previously he used to hardly communicate with the child. His overall behavior has changed now. He tries to spend more time with both the children. He is more soft and loving now.”*

Komal’s family is economically challenged. As per the father it is not strange/ unusual for them to spend a couple of days without food. Father struggles hard by accepting all type of jobs to feed the family of five members.

Today, when the daughter is in an advanced stage of the disease, he feels,
“Poverty is a part of our life. I feel sorry that I was busy worrying about feeding them. I never had enough time to communicate with any of them. Poverty affects every aspect of life. “

In this case, father feels sorry about not being able to spend enough time with them. In his view, it is too late to prove himself as a good father. Social and economic factors affect the communication within family members. An earning person or elders of the family get exhausted while struggling to satisfy basic needs of the family members. The entire focus remains on providing food, clothing and shelter. In this busy and hectic life, the emotional aspect of the relationship is rarely considered.

Parents use their own unique style of parenting while rearing their children. They might be using both rewards and punishment method to guide and facilitate their children’s growth. They often adopt a combination of discipline, affection and love to aid in the growth process.

It is seen that children with life threatening disease motivate the parents to re-look at their current parenting practices. Spending quality time with children, building and maintaining a rapport and developing a bond of trust is considered valuable when they look at their past in retrospect. They try to change or modify their behavior. An event of having a child with a life threatening disease influences the overall parenting style. The parents become more tolerant and start the introspective process. When they find a flaw in their parenting style, they try and improve the same. They are willing to change their parenting style and try to play the role of ideal parents.

Reinforce existing styles:

A few of the parents experience the efficacy of their unique parenting style while dealing with event. When they understand its benefit, they reinforce it. The father of Sagar, who believed in giving space to the child and encourages him to take his decisions, is happy about the same. He feels that the imbibed openness within interpersonal relationship and habit of sharing is helping the child to express his disease related concerns. He actively participates in the decision taking procedure regarding treatment protocol. Father of Sameer, who had a dream to see his son fighting with the difficult life situation, is witnessing the son fighting with the advanced stage of disease and related discomfort. When Sameer refuses special concessions offered to him because of his illness and prefers to act just as healthy individuals, his parents feel satisfied. When the
child says, “please don’t refer me as a patient.” they experience happiness and attribute this strong and brave behavior of their child to their pattern of rearing.

Theme: Parents who value their relationship with their children and become more tolerant and sensitive to the needs of children in general and readily meet wishes of the ill child.
Influence of terminal illness on parenting style.

Child variable:
Child with cancer, Age, Gender, Birth order, number of children in family, Symptoms.

Parent's variable:
Own experience of childhood, upbringing of child, disciplinary style

Parental coping to awareness of advanced stage of child's illness

Reinforces existing parenting style:
Self reliance of child, openness, sharing, healthy relationship within family

Changes in parenting style:
Spending more time, Valuing interpersonal relationship over discipline, More tolerant, Sensitive, Caring toward ill and other children, Efforts to make the child happy by getting favourite gifts, cooking and feeding dishes of choice
Conclusion:

Parenthood is considered precious as a different role in the life of a couple is initiated. The parents willingly take responsibility of the well being of their children. Parents select their own style of rearing their children. Parenting is aimed towards the welfare of the child. Educating the child is generally observed as the goal of the parents. They try their best to provide education to their children irrespective of their socio economic condition. Parents are observed to be concerned about the child adhering to social norms. Parents feel responsible for the overall growth and health of the child. Rearing is influenced by gender. Efforts by parents of a girl child are towards training her in household chores and preparing her to be a good daughter-in-law in future. A son is preferred over a daughter because of the cultural norms. Parental affection towards children remains same for children of any birth order and of both genders.

Parents go through stress while experiencing the advanced stage of cancer of their children. To accept this fact becomes difficult for them. They react in different ways to this event. They try their best to offer treatment to their child. They readily use their savings for the treatment and even take a loan from friends and family. To witness the child in advanced stage of disease and undergoing severe physical symptoms is painful for parents. Anticipated eventuality provokes stress and anxiety in them. They start preparing themselves to face the eventuality and also plan for last rites as per their own religion and respective culture.

Bed side caring is considered as one of the factors influencing their coping. Parents who are involved directly achieve satisfaction. Being with the child or accompanying them, being there at the time of hospitalization helps them to strengthen the bond between them mutually. In some cases, parents are not involved directly in bed side caring since they have other responsibilities, physical inability, and financial constraints or have not been involved by other caregivers. Such parents experience guilt and feel rejected. Bed side caring helps them cope better with the event.

Gender of the child does not influence the type of bed side caring. Anticipated grief of losing the child or the sorrow of witnessing a child with difficult symptoms is the same for both genders. To lose one’s own child is agonizing for parents.

The event of cancer influences the overall behavior of the child. The parents observe child’s disease related anxiety. The children throw tantrums, get angry or abuse other people. The
children, known for their friendly behavior suddenly start fighting with others or avoid social contact. Some parents object certain activities such as dancing or watching television as a part of their disciplinary mode of parenting. Such children perform those activities despite their parental objection. When the parents witness efforts of children to fulfill their pending wishes, they realize the adverse effect of their discipline. They feel sorry for children for not giving a chance to complete their desires. Such realization helps them to change their parenting style.

The parents make efforts to make their child happy when they become aware of the poor prognosis of their child. Parents become more sensitive towards the needs of the sick child and efforts are towards fulfilling every wish and demand of the child. The parents from lower economic status also put their best to satisfy the wish of child. It is seen that to indulge the child by feeding and cooking child’s favorite dishes give immense satisfaction to parents. Parents become more tolerant and caring towards the ill child.

Parents prefer to spend more time with children. Parents regret that they have not spent enough time or money while rearing the child. They feel sorry for that and then they start working towards changing their parenting styles. These changes are not only towards ill child but also percolate to other children. 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 implement as changes in their parenting style.

These modifications in parenting style take place consciously by the parents. It is seen that the overall family atmosphere get affected positively when parents spend more time with family members and communicate especially with their children strengthens the bond of love and affection. Parents involve themselves in daily activities of the children.

The unique parenting style which they practiced in the past influences the current event and their coping. The parents encourage their children to take their own decisions or help them to take their own stand. The children get enough chance to share their thoughts and feelings as they are permitted to choose their own path or take decision. This parenting helps children as well parents to cope with the event. They initiate the open and healthy conversation with each other resulting
in healthy interpersonal relationship. This catharsis helps them deal effectively with the stress. For such parents, hitherto parenting styles have proved helpful.

Authoritarian parents are strict and disciplined while rearing their children. These children do not get a chance to behave as per own ideas or wishes. The children of such parents hesitate to express their stress and fear related anxiety as they are used to follow the parental instructions. These children feel uncomfortable to express their disease related concerns. When the parents understand the effect of their parenting pattern, they willingly opt to modify it. They become more tolerant and try to spend more time to develop warm relationship for not only ill child but also for other children. Their efforts are seen towards creating conducive atmosphere for children to ventilate. This positive change is the parenting style influences the overall family atmosphere.
Section 4.G
Parental Coping

4.G.1 Decision to disclose the bad news-to reduce the stress

In some cases, the information is kept away from the spouse. After several attempts and with depleting energy to deal with the issue all alone, they begin to feel more burdened. Further their nonverbal behavior tends to be a clear give away. And then they take a conscious decision to disclose the fact to their spouses. Expressing their sorrow helps them to cope with the stress.

Father of Bhavana said, “I felt better when I shared everything with my wife. I felt supported.”

Father of Hiral said, “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 Harshda spoke about the stress he experienced when the poor prognosis of his daughter was revealed to him by the Palliative Care Unit. He was alone when the news was informed. He was stressed at that time. He missed his spouse at that moment. After he reached home, his wife enquired about the child and suspected bad news from his expressions. When they got some privacy and enough time he shared the news with his wife.

He said, “After I spoke everything to her, I felt emotionally ventilated. I felt as if I have done a great job by sharing the news with her. I felt emotionally supported as I was tired of carrying the entire burden on my shoulder. I felt that the decision to disclose the fact to her was wise. “

Father and elder brother of Ajmal were involved as primary care givers from the time of diagnosis and treatment. It was difficult for them to hide the facts behind a brave mask. Then they decided to disclose the fact to other family members.

Father of Ajmal said, “After few months, we (father and brother of child) decided not to hide the fact from each other. We felt that it is better to have an open discussion
regarding every problem within the family. That might help gaining support from each other and which actually happened.”

When both the parents openly discuss the facts, they feel good. Sharing of sorrow helps them to reduce their stress. Open conversation within family members and especially with the spouse, helps parents cope effectively with the stress.

**Theme: Sharing and catharsis in the family is an effective way to deal with the stress.**

4.G.2 Coping-by respecting and accepting right of patient

There are a few parents who accept the patients’ right to information. They develop the skill to open up the topic and discuss the issues related to death and dying. While interviewing the parents a few of the points were emphasized such as ‘It is their life so they have a right to know’, ‘when none of us can help them cure then at least help them resolve their queries and satisfy them’.

*Father of 8 year old Neeta* said, “She is going through the problem then it is her right to have an access to the information.”

A surgery for limb amputation was scheduled for the 12 year old Sameer. The parents explained the importance of amputation along with other consequences. They spoke about the chances of relapse as the child enquired about the same. They encouraged him to speak about his worries and concerns.

His mother said, “Beta (child), your opinions will be valued. You need to express yourself as you are the one who will go through the physical and psychological pain. If you want to ask, speak or even to cry please feel free. We are there with you.”

The families which respect the right to know reveal the truth to the child. It helps both (parents and child) to discuss and share their thoughts and feelings. In such conversations the child receives an assurance that parents are willing to listen. This enhances inter personal relationship.

After understanding the advancing stage of disease,
Father of Naresh told 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.”

Very few parents are comfortable about initiating the topic of death and dying. When the father of Naresh spoke about this idea of eye donation, the child was upset for some time. Then the discussion was initiated again by the father and the professionals were involved to solve child’s queries. The doctor helped the child to understand the eye donation procedure. The doctor explained the painless, bloodless and stitch less procedure of eye donation. After clarifying his doubts Naresh said, “It means even I can do something for others.”

Father of eight year old Neeta said, “My daughter and I discuss about the death and dying as I feel that it is her life, her disease and she should be given a chance to discuss.”

The families practicing healthy pre illness relationship facilitates open communication. Such parents take initiative to discuss the facts with children, help them to clarify their queries and attend to their concerns regarding death and dying. The bond of trust strengthens when children get a chance to ventilate their feelings and thoughts to their parents. This healthy and open communication addressing mutual needs and understanding expectations help both (child and parents) to cope effectively with the terminal stage of cancer.

Parents who take strategic decisions to hide the truth experience stress. This is associated with the fear attached to ‘someone else’ might reveal the bitter facts to the child. To hide the truth from one’s family and to bear the burden of advanced stage of disease of one’s child creates anxiety, which in turn, influence the parental coping in negative way.

Theme: Healthy relationship within the family makes the communication easy and gives opportunity to an individual to express better; this further enhances communication within the family.
4.G.3 Flexibility, openness and impact of social, spiritual condition on coping

Parental flexibility and openness

It is seen that the care givers are flexible to choose the coping strategy as per the demand of the situation.

Father of Ajmal narrated an experience when the child was recently diagnosed of cancer and was admitted for his first chemotherapy. The father was worried and preferred to be aloof. He was stressed and used to share his feelings with his elder son. They mutually decided to support each other in all aspects such as being the bed side care giver, arranging medicines and funds for treatment and so on. According to him from the day of diagnosis, he was not interested to speak about the same to any one as he was scared that others might react in negative manner. When the child was in the ward, he witnessed other patients of the similar age of the Ajmal undergoing same treatment. He could relate himself with other parents. He saw them helping each other by getting reports from laboratory, to look after the child when his/her parents need the break and so on. He saw ward sister taking care of each child’s medication, hygiene and diet. Her empathy towards parents and affection for the ill children was observed by him. Few days in the ward changed his mind and he willingly became a part of the group of parents. He said, “Soon I became a part of them. It was like a big family.”

The father of Neeta also shared a similar same change. The mother of Naresh developed a healthy relationship with her husband after both of them started sharing their worries and concern. The eldest son of this couple has passed away few years ago when he was just a few months old. He was born as a premature low weight baby. He was treated for almost 3 months in a General Hospital. Physically tired and emotionally stressed mother was breast feeding the child when he was brought home from the hospital. While feeding she could not control her sleep and the child suffocated under her breast. Mother blames herself for this incident. According to mother, her negligence killed her child. When her second son is in the terminal stage of disease, she recollects the memory of that day frequently and experiences guilt. She shared all her worries, guilt related to past experience with her husband which she hardly did in the past. Her husband supported her by saying, “do not think about the past. It is over. Don’t blame yourself. It was destined for us. I know you have not done this purposefully. It was God’s wish.” The
mother felt relieved as after many years she could openly speak about her emotional pain. Words of assurance from her husband helped to strengthen the bond of trust. She said, “*Now I am more comfortable to share my feelings with my husband.*” In this incident, the current illness triggered her previous stress and she decided to express herself and share with her husband. She ventilated her feelings, thoughts, guilt, sorrow and additional stress due current event she felt relieved and then helped her to cope effectively with the past as well as current grief.

Mother of Lalita, a Hindu lady was strong believer of God. *Pooja* (prayer) or observing fast was considered as an important ritual by her. She used to follow all traditional religion related rituals as she had strong faith in God. When she understood about the advanced stage of disease of her daughter, she lost her faith in God. She felt that by not listening to her sincere prayers, God has cheated her. When parents of Sandhya and Charu, both Hindu by religion, heard about the life limiting condition of their children, they started believing in other religions also. According to them, crisis forces you to changes your religious or spiritual belief.

The awareness of terminal stage of the disease of the child and an ultimate wish to see the child in good health influence parental views, opinions or faith. When their friends or well wishers advice any religion related ritual they show openness to accept it as they have strong wish to see their child in good health. The parents willingly change their views as per the demand of event. These changes help them to cope effectively with the event of their child’s cancer.

*Theme: When parents demonstrate an openness to learn from each other and willingly change or modify their views or opinions regarding religious and spiritual belief, they tend to cope better with the stress.*

**Impact of social context on coping**

Mother of Vijaya who is a paramedical health care provider by profession motivated people to accept any disease diagnosis. The moment she realized the probable social rejection, she changed her mind and decided not to disclose the diagnosis and name of the treating hospital. According to her it is a strategic and wise decision considering the future of her other daughters.

Father of Hiral, used to feel proud to be called as ‘dada’ (goon) in his community. He said, “*After the birth of my child, I tried to change my behavior but I used to feel awkward to mingle*
with them because of my bad reputation.” He used to avoid others. Initially he did not think of sharing the disease related stress to any of them. But when the people from the same community came forward to help him to save the life of his daughter, their gesture changed his opinion. He recognized in importance of being good to others.

He said, “Now I am trying to become a good person by helping others. I share my worries to one of the persons from the same ‘basti’ (community) who is a good friend of mine. Now I believe in being good to others.”

Theme: Society’s current and anticipated responses influence their coping.

4.G.4 Coping of terminally ill children

Coping of child-religious belief

In this distressed stage children start finding reasons for having this disease. Most of the children attribute this event to God’s wish.

Naresh said, “God is punishing me.”

Sagar requests God by saying, “Please God, either cure me or just end my life.”

Mehru feels, “I leave it to God as cure is not within the human power.”

Trust in Almighty God and the spiritual beliefs are used by the children to cope with this life event. The belief system of parents influences the children in this matter. Awareness of poor prognosis and limitation of curative treatment force these children to surrender themselves to the wish of God. Losing hope of cure is stressful for children so the belief on ‘God’s wish’ helps them to deal effectively with eventuality. A few of them perceive this situation as punishment by God. Sentences such as ‘I must have behaved badly with others’, or ‘I did not hurt anyone purposefully in this life but might be in last life’ convey the belief they have about the power of Almighty. The researcher has observed that ill children or adults accept this punishment as they respect God’s power.

Such belief system helps them to accept their illness and poor prognosis effectively.
Theme: Faith in God and power of destiny is accepted and used to cope with event of advanced stage of cancer by ill children.

It is noted during interviews of parents, that the children have the ability to express their concerns. They develop a picture of disease and death in their mind. As per the experience of the researcher working with children, she could understand their opinions and concepts. It is seen that concept of death is related to losing the dear ones. The fear of unknown is expressed as an anxiety provoking factor. The children experience grief related to loss. The disfigurement influences the self image in a negative manner. Shattering of dreams is considered as the biggest grief. To fail to perform the duties towards their parents is considered as a personal failure. Social stigma is attached to the disease. Acceptance by the society means a lot to children. They look for the acceptance from neighbors, teachers, friends and community members. If they sense any sort of rejection they try to hide from others. This strategy is used as one of the coping strategies. They are concerned about the financial burden of their parents. Generally the question which bothers them is “Is it worth spending so much if eventuality of death is imminent?” God is accepted as the Power which cannot be questioned and many times considered as the support system.

Child’s efforts to protect parents from stress

Mother of Shashi is interviewed by the researcher. She is in complete denial. She denies the diagnosis of cancer. She avoids any discussion regarding poor prognosis. She is positive about his cure and healthy life. Shashi is a 14 year old child studying in 9th standard. As per the notes of counselor, the child is aware of diagnosis as well as the prognosis.

**Shashi said to the counselor,** “If I speak about the disease to my mother, she may not be able to digest that truth. So I prefer to say, “don’t worry ma, I will be alright and will be back to school.”

In this case, the child tries to protect his mother from the trauma. He takes care of her mental health and requests the team not to reveal the truth to his mother as she will be not able to deal with it. This depicts the immense concern and love of child towards his mother.
Theme: Mutual love and concern for each other helps both children and parents to cope with the stress related to the event.

When parents understand poor prognosis and terminal nature of disease of their child, they go through emotional turbulence. Fear related to uncertainty, current physical discomfort of child and shouldering family and work responsibilities generate stress for parents. Every individual makes efforts to face the event in his/her own ways. Level of awareness and acceptance of advanced stage of disease of the ill child plays a major role in determining the stress as well as coping of parents. Both help each other to face the event in an effective manner. Open and healthy communication initiates the process of acceptance. Expressing and understanding concerns of each other help them to cope positively.
PARENTAL STRESS AND FACTORS INFLUENCING THE COPING PROCESS

**Parental stress:**
- Stigma,
- Child’s suffering—physical, emotional,
- Social rejection,
- Bed ridden condition of child,
- Dependency,
- Difficulty in accepting eventuality/loss
- Multiple roles
- Balancing resources

**Parental coping**

**Strategy: Healthy coping:**
- Reveal prognosis
- Sharing feelings
- Initiating and responding to direct discussion about death and dying issues
- Preparing the self for eventuality

**Strategy: Unhealthy coping:**
- Collusion,
- False hope,
- Usage of brave mask
**Conclusion:**

The event of cancer of own child help the parents to change their opinions and views towards specific issue. They willingly change their coping strategies according to their changed outlook. The ultimate aim of every parent is to cope effectively with the stressful situation. The strategy which works well at the moment is considered as the best strategy for them.

The awareness of terminal nature of the disease and eventuality causes distress for them. To face this situation they try to locate different support systems that they can depend upon.

The primary care givers look for support from family, extended family members, friends, neighbors, group of likeminded people, religious beliefs, health-care professionals from the hospital, employers, well wishers and care givers of other patients.

When the parents enter the hospital with their ill child, they are stressed because of the anticipated diagnosis and treatment. The parents who come from out station for their child’s treatment are worried about the arrangement of accommodation, food, local transport, lack of human power, lack of other resources and so on. In this situation, family members come forward to share some of the responsibilities. They try and contribute to actual bed side caring, or take care of other responsibilities such as looking after siblings of the ill child or elderly family members and so on. Taking over the responsibility of family business in the absence of parents helps them financially and psychologically. The care givers value the family support when they can share their feeling and concerns. The parents who share their responsibility and concerns with their spouse feel supported.

Friends and other community members come forward to support the parents of the ill child by gathering funds for the treatment or providing material and non material help such as arranging loading, boarding, commuting and so on to satisfy family needs. Some parents who belong to a self help group (based on religion, belief and so on) receive strong support from the group. Catharsis within group members helps the person to cope effectively. Spiritual belief, belief on destiny, God, Power of Almighty helps the parents to accept the crises. Well wishers or employers help the deserving family financially as well as emotionally. Care givers of other ill children understand illness related stress and empathize with them as they can identify themselves with other parents. They help each other by providing useful information related to
disease, treatment therapy and sources of fund raising. The help from health care professionals in
terms of provision of information regarding the child’s illness, prognosis helps the parents to cope effectively. The information and assurance of extended support helps them to accept the situation positively. Some parents look at the event as challenge and put in their efforts to fight the event bravely. They use their inherent capacity to face and identify possible resources to deal with the crisis effectively.

As the physical condition of the child changes the strategies adopted by parents need to change or modify. The paradigm shifts from cure to care force them to identify other support system. When parents who struggle to gather funds for curative treatment understand the poor prognosis of their child, they experience helplessness. They wish to share their concerns with someone. In such case, the parents prefer to receive psychological support than financial aid. In case of some parents, they recollect their past stressful event and the strategies they used to cope at that time. Sometime they feel that the strategies which they appointed in the past were not adequate then they willingly identify new options to cope with current event.

The type of support they receive from friends or community influences their perceptions towards them. Parents seek different type of support from different sources at the same time. They identify charitable trusts to fund the treatment cost, they accept the help of neighbors/family members to share the house hold responsibilities and share their concern with their friend. Some parents get multiple types of support from the same source. When both parents involve themselves equally to deal with the event of child’s life limiting stage, they contributed in bed side caring, share other family responsibilities and ventilate their feeling to each other and so on. Various types and sources are chosen by parents as per the demand of the situation and which help them cope effectively with the crisis.

The children appoint various strategies to cope with the stress. Believing the concepts such as destiny, God’s wish, Power of Almighty and hope of taking rebirth in the same family help the children to deal effectively with their illness. They try to share their concern with their family members as catharsis proves helpful to reduce the stress. They use metaphors to express themselves and give a message of their willingness to initiate the discussion related to their illness. It is difficult for them witness the grief of their parents therefore they try to pacify their parents.
Summary:

The event of child’s advanced disease is stressful for ill children as well as their parents. The parents who perceive themselves as responsible for child’s development, growth and health, experience guilt when they understand the poor prognosis of the child. To accept the eventuality and prepare for anticipated loss is not easy for them. To see the child with unpleasant symptoms make them helpless. To face this event they (child and parents) appoint coping strategies. Parental strategies to cope with anticipated loss are based on the current situation, influenced by past experience of parents (parents as a children and their relationship with their parents). The coping of children is influenced by the factors such as understanding of disease, perception, age, access to information and level of openness within family and so on.

The coping strategies adopted by ill children and their parents are with an intention of effective coping. If they experience ineffectiveness of the selected strategy they show readiness to switch to other.

To summarize, no strategy is good or bad. The strategies are seen to be fluid in nature. Strategies are changed or modified as per the demand of the situation. Intervening factors and context influences the overall process of coping.