CHAPTER 3

“Life is like riding a bicycle. To keep your balance, you must keep moving.” Albert Einstein

Methodology

“Research is the systematic and rigorous process of enquiry which aims to describe phenomena and to develop and test explanatory concepts and theories. Ultimately it aims to contribute to a scientific body of knowledge” (Bowling, 2002:1).

The proposed study is to understand the life experience of the parents having children in the terminal stage of cancer and in palliative care. The researcher feels the need to understand their concerns and coping strategies. After understanding the issues in totality, it will be advisable to comprehend and inform the efficacy of the existing palliative care services. The focus of the study is to explore parental needs and concerns while their child is in the terminal stage of cancer. The study will help to identify their needs in totality. The literature underscores the gaps in the research focusing on the psychological aspect of the parents of children with advanced stage of disease in the Indian context. As factors like social realities, culture, community life play a major role in the human life, it is necessary to understand the context specific reality. In order to appreciate the influence of these aspects in a scientific way, a sound methodology needs to be implemented.

“Methodology is defined as a way of thinking about and studying social reality” (Strauss and Corbin, 1998:3). The methodology adopted in any research depends on the context, type of research and the rationale of the research question. The present study is conducted using a qualitative approach.

“The term ‘qualitative research’ means any type of research that produces findings not arrived at by statistical procedures or other means of quantification. It refers to the research about a person’s life, lived experiences, emotions, and feelings. It helps obtain the intricate details about phenomena such as feelings, thought processes, and emotions that are difficult to extract or learn about through more conventional research methods” (Strauss and Corbin, 1998:17). “They are
the ways of finding out what people do, know, think, and feel by observing, interviewing and analyzing documents” (Patton, 2002:94). The data generated by qualitative methods is all-inclusive and voluminous giving a sense of the whole.

This study aims to explore the stress and the coping strategies adopted by parents, when their child is diagnosed with cancer and has reached the terminal stage of disease and is in palliative care. The whole spectrum of issues related to emotional, psychological, social and spiritual aspects related to cancer in children is experienced by the parents. The acceptance towards the diagnosis of the disease such as cancer in their child becomes as painful as accepting the terminal stage of disease. The factors helping them deal with this life event is the primary concern of the study. The data gathered by using an explorative interview helps to identify the felt needs of the parents. The assessment of their needs and factors creating stress might help the existing support system to modify or change in order to facilitate appropriate and effective services.

The way children cope with the life threatening disease depends on factors like age, socioeconomic state, family structure, gender, understanding of the disease and prognosis. The coping of the children affects the overall coping strategy of parents which will be addressed by adopting a qualitative methodology. “Qualitative research explores people’s subjective understandings of their everyday lives” (Pope and Mays, 2006:6).

The proposed study seeks to locate the exploration of various domains of the study within field based realities which will help the researcher to observe, understand and record the parental perspective related to the experience of having a child in advanced stage of disease. In order to facilitate such an understanding, the qualitative paradigm lends itself appropriately for such exploration. This paradigm encourages a detailed and thorough exploration of variables that form the basis for such an enquiry. The study has included parents from varied demographic background, having their own unique values, ideas, experiences while facing a similar life event. “The quality of qualitative data depends to a great extent on the methodological skill, sensitivity, and integrity of the researcher. The skillful interviewing involves much more than just asking questions” (Patton, 2002:8).
This study adopts the grounded theory approach for knowledge building, which is a type of qualitative research methodology. The rich data will be useful to understand parental concerns and needs.

3.1 Grounded theory approach

Theory denotes a set of well developed categories (e.g. themes, concepts) that are systematically interrelated through statements of relationship to form a theoretical framework that explains some relevant social, psychological, educational, care giving or other phenomenon. The statements of relationship explain who, what, when, where, why, how, and with what consequences an event occurs. It is to build the theory and not to test the theory. “A theory is more than a set of findings: it offers an explanation about phenomena” (Strauss and Corbin, 1998:22). The approach emphasizes being “systematic and creative simultaneously.” The characteristics of grounded theory stated by Strauss and Corbin 1998:7 are:

1. The ability to step back and critically analyze situations
2. The ability to recognize the tendency towards bias
3. The ability to think abstractly
4. The ability to be flexible and open to helpful criticism
5. Sensitivity to the words and actions of respondents
6. A sense of absorption and devotion to work process.

As per Strauss and Corbin (1998) the term grounded theory means theory derived from data, systematically gathered and analyzed through the research process. In this method, data collection, analysis and eventual theory stand in close relationship to one another. The researcher does not begin a project with preconceived theory in mind. Rather the researcher begins with the idea of study and allows the theory to emerge from the data. Theory derived from data is more likely to resemble the ‘reality’ than is theory derived from putting together a series of concepts based on experience or solely through speculation. Grounded theory, because it is drawn from data, is likely to offer insight, enhance understanding and provide a meaningful guide to action.

The given study uses grounded theory as an approach for exploration. This approach begins with the basic description of the phenomenon under study and moves on to conceptual ordering and
then theorizing. Thus knowledge is generated from the data that emerges from such an exploration. The vast data collected through interviews when coded and classified will give meaning to the words, actions and expressions. The advantage of this approach is it tries to look for the unique and critical cases also. In the given study though the event (having cancer to their child) is same for all parents, the reactions or responses to the event may differ from person to person depending on other influencing factors. The relationship between the factors will be studied.

3.2 ‘Me’ in the research ……

- I have eleven years of work experience with the children with terminal stage of cancer and their parents. This made me curious about their emotional and psychological process related to their experience during the illness of their child.

- Working and interacting with patients and their caregivers in the capacity of a counselor helped me understand their experiences. I could recognize their worries and concerns. I could look at them not just as a patient but as a human being. My profession gave me a chance to go beyond their hospital case files. I could read between the lines their pain and discomfort. The ‘said’ and ‘unsaid’ words of the parents made me wonder about their psychological experience.

- I had an experience of cancer in my family. When I think about those stressful days, I feel professional intervention would have helped us deal with the difficult life event in a better manner. I could observe many issues experienced by my family members (I was not a primary care giver). I have seen them spending sleepless nights and struggling with anxiety, fear, and uncertainty. Memories of tears of my family members encouraged me to focus on the psychological and emotional aspect of pain along with the physical suffering.

- Being the member of professional multidisciplinary team of Tata Memorial Hospital- Palliative Care Unit since 2000, I am aware of the professional approach towards patient care. As I was actively involved in developing the patient care programs, I wish to
understand the efficacy of existing service at Tata Memorial Hospital-Palliative Care Unit. I was involved from foundation of the Unit. Based on the needs and concerns of patients and care givers, a few of the services are added in the due course of functioning of the Unit. I have been involved in planning and executing those new services. So I could witness the strategies used to modify the service.

- Tata Memorial Hospital arranges training program twice a year for medical and paramedical health care professionals. Psychosocial aspect of patient care is considered as one of the important component of training and I am involved as a faculty for this module. The participants are from different states and regions working in different set ups. Their experience related to their various set ups such as general Hospital, private hospital, Municipal Hospital. I could understand different issues attached to different treatment contexts.

3.3 Geographical context of the study:

Geographical context: The parents of children in the terminal stage of the disease of both genders, who are registered in the Pediatric Palliative Care Unit of Tata Memorial Centre. The geographic boundary will be Mumbai in which the parents who are local residents of Mumbai as well as those who are not citizens of Mumbai but staying currently in Mumbai seeking symptomatic care from Pediatric Palliative Care Unit of Tata Memorial Hospital.
3.4 Operational definitions:

**Child:** A child undergoing symptomatic treatment at Tata Memorial Centre – Pediatric Palliative Care Unit, when no chance of curative treatment is left.

**Terminal illness:** The advanced stage of disease when curative measures of treatment play no role or are ineffective.

**Stress:** The physical, mental or emotional strain or tension experienced by the care giver when their child reaches the terminal stage of cancer (as per the definition of stress from Webster’s dictionary).

**Coping:** Coping is a cognitive and affective response to the stressful situation of witnessing child in the terminal stage of disease (Folkman and Lazarus, 1988).

**Resilience:** is the ability of care giver of the terminally ill child to withstand and rebound from adversity. These are efforts of parents while trying to overcome the difficult life event.

**Parents:** Biological parents as well as other members of immediate family of the ill child who are involved as a primary care giver. The word parents and care givers is used interchangeably.

**Life situation:** The current situation in which the reality of terminal stage of disease is declared and parents experience this situation.

3.5 Methodology:

3.5.1 Research Design

This exploratory study will adhere to the paradigm of Qualitative Research Methodology. “A qualitative study is defined as an inquiry process of understanding a social or human problem, based on building complex, holistic picture, formed with words, reporting detailed views of informants, and conducted in a natural setting” (Cresswel, 1998:15).
The purpose of the research is to study the parental experiences of the event of cancer of child in the life of parents. The experience of having a child in the terminal stage of disease is the event and the coping, stress, and resilience of the parents at the time of this experience will be studied. The reliance of the study will be on the expressions of the parents describing their thoughts and feelings. As the exploratory design focuses on the characteristics, attitudes and conditions of group or individuals, the said design will help to understand the true picture. This design will be helpful to understand the process of the phenomena and not just an incidence. The process of coping or the stress which might have varied in terms of facing the event can be understood, as the study will focus on the process right from diagnosis of disease to the terminal stage of cancer. The descriptive details like the way of expression of the child, reaction patterns of parents, their general behavior, language, support system and even culture will be understood and they form the influencing key points of the study. Acknowledging the cultural aspect and social norms is important as it is the part of individual’s life. Describing and understanding the day today events is possible in this type of design. The metaphors, characters and symbols used by the individuals can also be understood and which helps researcher understand the research problem.
3.5.2 Aim:

The aim of the study is to explore the stress and the coping strategies adopted by parents, when their child is diagnosed with cancer and has reached the terminal stage of disease and is in palliative care.

3.6 Objectives and research questions:

I. To explore the understanding of parents about Pediatric Palliative Care Unit and related services.

   Research questions:

   1. What is the understanding and awareness of parents about pediatric palliative care unit and its availability?
   2. How do parental needs related to palliation match with the existing services?
   3. What expectations do they have from the Palliative Care Unit?
   4. Do they feel supported/helped after availing the services? If yes, how
   5. Do they feel the need for such services? In what way?
   6. What are some of the advantages and challenges faced by parents with regard to palliative care?

II. To understand the influence of child’s condition and stress experienced by the parents.

   Research questions:

   1. How does witnessing the suffering of the child impact parental coping?
   2. How does the child’s resilience influence coping?
   3. What creates stress for the parents?
   4. What kind of stress do they experience?
   5. How does the stress affect the overall event?
III. To explore the coping resources used by parents.

Research questions:

1. What factors play a major role in deciding parental coping strategies?
2. How does coping change in response to need of the situation?
3. Do coping strategies change with the changes in social, psychological and spiritual factors that are related to the stress?

IV. To investigate the influence of terminal illness on parenting style.

Research questions:

1. Do family interactions and relationships influence parental coping?
2. Does parenting style influence the overall family atmosphere?
3. Does past parenting behavior affect the current relationship?
4. Does openness, control, warmth of parents play a major role in child’s resilience?
5. Do parents and child perceive any change in the parenting style after diagnosis of terminal stage of disease?

3.6.1 Inclusion Criteria:

- Parents of cancer affected children with advanced stage of cancer registered at Tata Memorial Hospital under Paediatric Palliative Care Unit for symptomatic treatment.

- Parents who are able to communicate in English, Marathi or Hindi as researcher can speak and understand these languages.
3.6.2 Exclusion Criteria:

1. Children come for treatment from out of Mumbai. Few parents decide to return to their own native place when curative treatment is discontinued. Such parents having a plan to go back to their native place were excluded from the study.

2. Parents not able to communicate in English, Hindi or Marathi as the researcher can communicate in these three languages only.

3.7 Sampling Procedure:

3.7.1 Theoretical sampling:

“Data gathering driven by concepts derived from the evolving theory and based on concept of ‘making comparisons’, whose purpose is to go to places, people, or events that will maximize opportunities to discover variations among concepts and to densify categories in terms of their properties and dimensions” (Strauss and Corbin, 1998:201).

According to Glaser and Strauss (1967), theoretical sampling is the process of data collection, for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find them. The process of data collection is controlled by the emerging theory whether substantive or formal. “Sampling involves decisions not only about which people to observe or interview, but also about settings, events, and social processes. Qualitative studies calls for continuous refocusing and Redrawing of the parameters of the study during field work” (Miles and Huberman, 1991:30).

Theoretical sampling is a way of sampling which is based on principle of divergence and saturation. The principle of divergence helps to choose the deviant cases. The researcher can change the size of sample during the research by choosing the cases in terms of theory (Strauss and Corbin, 1998).
“In data collection for grounded theory research, the investigator selects a sample of individuals to study based on their contribution to the development of the theory. Often this process begins with a homogeneous sample of individuals who are similar, and, as the data collection proceeds and the categories emerge, the researcher turns to a heterogeneous sample to see under what condition the categories hold true” (Creswell, 2007:243).

“The sampling process gets over when researcher reaches the point of saturation that is no more divergence point is left is to be covered. This means that a) no new or relevant data seem to emerge regarding a category, b) the category is well developed in terms of its properties and dimensions demonstrating variation, c) the relationship among categories are well established and validated. Theoretical saturation is of great importance. Unless a researcher gathers data until all categories are saturated, the theory will be unevenly developed and lacking density and precision” (Strauss and Corbin, 1998:212). The adequate theoretical sample is judged on the basis of how widely and diversely the researcher chose the participants for saturating categories of the theory (Strauss, 1997).

In qualitative research the focus is to look for a variety of incidents that demonstrate dimensional range or variation of the concept and the relationship among the concepts. The researcher chooses the sites, persons, and documents that will maximize opportunities for comparative analysis (Strauss and Corbin, 1998).

In the given study, it is observed from the literature as well from the experience of the researcher that factors like gender of child, age, birth order, duration of treatment, unpleasant physical symptoms play an important role in the process of coping. The reactions of the parents to a similar life event differ as the whole process is influenced by these factors. The stress experienced by the parents while experiencing the event is influenced by above mentioned factors. The data collected by using these points intends to capture the varied aspects of the life event.
Following are the points of divergence:

1. **Gender of child:** In the current cultural context, it would be interesting to explore the differences between girls and boys, their upbringing and illness related issues may affect the parental reactions and coping.
   
   Family structure: Support systems available may be a factor which helps the parents to cope. So the type family structure - if joint family or nuclear family should be taken as the point of divergence.

2. **Duration of treatment:** Cancer treatment is a long duration treatment protocol. Few patients take the complete treatment like chemotherapy or radiation or surgery, either one of them, or in combination by spending months or even years. Few report in advanced stage of disease and do not receive a chance of curative treatment, as a result they spend hardly some time in hospital. Financial and psychological exhaustion of parents depend on the duration of treatment the child has availed.

3. **Birth order/number of siblings:** It is observed that when the child in the terminal stage is the only child of the parents, it is a major loss for them as they claim that they have nothing to look forward to in life. The number of children in the family, and number of male children in the family and birth order of the child can be a point of divergence. Parents having an only child (of any gender) go through severe stress. Losing the only child ends their role as parents. To lose a male child is difficult for family as the male child is considered as asset and support for family. First born child is precious for parents as they experience parenthood first time. Parents spend more time with last born child as elder children demand less attention (as they grow in age) of parents.

4. **Physical condition/symptoms of disease:** Child in the advanced stage of cancer experience pain, fatigue, weakness, or other unpleasant symptoms. To watch the child with severe symptoms creates stress for parents. Advanced stage of disease is associated with symptoms such as pain, swelling on body, nausea, fever, fatigue, cough and breathlessness. The type of symptoms and the usefulness of medicines to offer relief
affect the parental coping. Parents expect their child lives at least an improved quality of life when the chances of cure become difficult.

3.8 Data collection:

Qualitative research allows the researcher to use multiple tools, which helps us to get multidimensional and in-depth perspectives of all possible stakeholders. Different tools can be useful for different stakeholders, as the views/opinions differ. Analysis of varied and voluminous data helps the researcher to identify the factors affecting the overall event. This is a main and important advantage of using multiple tools.

“Interview guide ensures that the interviewer has carefully decided how best to use the limited time available in an interview situation” (Patton, 2002: 343). The list of questions or issues that are to be explored in the course of an interview are included in the interview guide. The probes in the initial part of the interview guide focused on the understanding of parents about the disease, stage and progressive nature of the disease of child. The awareness of the existing support system was checked for later. The factors influencing coping and stress were elicited in the form of detailed descriptions. The last part of the interview guide was to inquire about the relevance and efficacy of the existing support systems at Tata Memorial Hospital-Palliative Care Unit. The probes were framed in a way that the participants will get an opportunity to discuss and describe the challenges as well as the factors which helped them during the journey of the illness of their child. The interview guide was used at the time of in-depth interview session.

The interview guide (Appendix 1) included probes that covered the concepts of the conceptual map. The conceptual map was formulated based on the literature review and the experience of the researcher. The various concepts included are type of family, children as individuals, disease, parents, social support as the factors influencing the overall coping process of the parents having child in the terminal phase of the cancer. The support systems which include social, professional, and family support were considered as one of the domains. In the process of data collection it was noted that the spiritual support and belief system attached to the spiritual values play a major role. So the interview guide also was modified to include the spirituality as one of the topics to be discussed.
During the interview it was mentioned by the parents that collusion plays a major role in coping of parents. Based on this information probes related collusion, type of collusion, effect and reason of collusion were added in the interview guide. Another point that emerged during interviewing the parent is that they are not aware about the term and concept of ‘palliative care’. The existing service was a new concept for the parents. When the child was referred to Palliative Care Unit, the parents had no idea regarding the purpose of referral. To understand their perception regarding concept, awareness and expectation about this branch of medicine, probes were added in the interview guide.
Parental factors:
- Attribution, behaviour
- Parenting style: indulgent, authoritative, uninvolved, authoritarian

Illness
- Symptoms, stage, available curative options, palliative, hospitalization

Parents of terminally ill children and their coping

Family:
- Family structure, interpersonal relationship, support, access to information, education, culture, religion, socio economic pattern status, parents experience as child, experience of similar trauma, access to hospital

Support:
- NGO, Hospital staff, Home care team, workplace support, other sources of support

Children:
- Age, gender, birth order, number of siblings, understanding and perception regarding disease, other family members, physical discomfort
3.9 Conceptual map:

A concept map is a diagram showing the relationships among concepts. Based on experience of researcher and knowledge from literature the interrelation of concepts is presented in the map. The objectives and research questions then directly emerge from the elaboration of the conceptual framework (Miles and Huberman, 1984).

Different concepts attached to the event of having a child with terminal stage of cancer are listed in the map.

**Illness of the child:** The diagnosis of cancer is difficult to accept for parents. When the disease is diagnosed in the early stage, then parents focus on the possible available curative options. In the terminal stage of disease focus from curative treatment changes to symptomatic treatment. This stage of cancer generates physical symptoms like pain, edema (swelling), breathlessness, fatigue. To witness the child with multiple or severe symptoms affect the coping of parents. This is the time when parents need to understand and accept the option of palliative care. Hospital and medical professionals working in the Palliative Care Unit influence parental coping. Parental need for getting support in totality (physical, emotional, psychological, spiritual and social) becomes the priority.

**Family:** Family structure and family support influence the parental coping. Parents getting support from other family members in areas such as taking care of other children, assisting financially or contributing to bedside caring, affect the parental coping. Inter-personal relationship within family members, openness and type of collusion are also some of the major factors in overall coping. Past experience of parents as care giver affect the way they face the event.

**Support System:** Family, extended family members, neighbors, friends, well wishers, people from work place, spiritual groups, community, Non Government Organization influence the parental coping. Type of support they receive at this time from above mentioned factors decide the way parents cope. Provision of support in the form of material and non material by Palliative Care Unit and Home Care Team influence the coping of parents and children.
**Children:** Demographic details of the child such as age, birth order, gender, socioeconomic condition of family, awareness of the disease and prognosis determine coping. Perception of child regarding disease affects the coping of parents.

**Parenting Style:** Parents use different types of parenting styles to rear their children. The goal of parenting is to help the child to achieve success in their life. Different styles like authoritative, indulgent, uninvolved or authoritarian are adopted by them. The styles affect the family atmosphere. Parents providing freedom to child regarding taking their own decision (career, education, hobbies) create an open environment which affects the coping of ill child. Children express their needs and concerns openly when they are encouraged to share from beginning. In contrast, a few of the parents train and discipline their children. Low level of communication in such families affects the coping process of parents as well as children as ventilation of feelings/thought is restricted.

**Physical condition of the child affects the parenting style:** Parents adopt different coping strategies to cope with stress and helplessness related to anticipated eventuality. Availability of support system and demographic details of the family is one of the major aspects influencing the parental coping.

**3.10 Consent Procedure:**

The formal written permission (Appendix 2) was taken from the Hospital Scientific Research Committee as well as Hospital Ethics Committee of Tata Memorial Hospital to interview the parents of the children registered in the Palliative Care Unit. Secondly consent from the parents was taken.

To get the formal permission, certain documents were submitted for their review. 1. Consent form, 2. Information sheet, and 3. List of questions. All these documents were submitted in three languages- 1) Marathi 2) Hindi and 3) English.

1. **The consent forms:** These were prepared in English, Marathi and Hindi languages. The simple and short sentences were framed to make it easy to understand. The information about rights, risk, cost, time requirement for interview was given. (Appendix 3)
2. **Information Sheet**: Hospital Ethics Committee of Tata Memorial Hospital expects the researcher to draft a short information sheet written in a simple language (in three languages—Marathi and Hindi English). The document describes the purpose of the study and their role in it. (Appendix 4)

3. **List of questions**: This is to be given to clients before administration of the Informed Consent Form (Appendix 5). The Committees expect clients to clarify their doubts by asking questions like purpose of this study, name of investigator, duration of study and the reason for them to invite in the study. To help the clients to take the decision regarding their participation, questions are formed and they are expected to ask those questions to researcher.

**Ethical Considerations:**

As per the norms of the Hospital Ethics Committee, the information sheet of the study was handed over to parents. Then the researcher orally explained the idea behind the existing research to the parents in the language they understand. The consent form was handed over to them. At least twenty four hours sleep over time was given to them. If the interest was shown by the parents to participate in the research the day was fixed as per the mutual convenience of researched and researcher. The time was fixed on the days of their follow up visits as they could save an extra visit for this purpose. The right to opt out of the study was explained to them. A copy of the consent form was given to them for their information. Unless the child was taken care of by another care giver the interview was not conducted as the both child and parents would be uncomfortable. The interviews were conducted with one parent at a time (as other care giver was looking after the child).

- **Privacy and confidentiality**: Complete privacy and confidentiality was assured to them. The manuscript does not contain the real names of the children. The names are changed to protect their identity.
• **Convenience of interviewee:** In two cases the parents were uncomfortable in answering all questions in one sitting as it was emotionally stressful to them. In such case, the interview was terminated and another day was scheduled considering their emotional health. One of the mothers was interviewed in the ward as per her convenience as she was keen to be next to the bed of the child (the child was taken to another department for few tests by his father).

• **Duration of Interview:** The duration of interview varied from parent to parent. The average time of the interview was one and half hours.

• **Language of Interview:** Most of the interviews were conducted in Marathi and Hindi as the researcher and parents were comfortable in those languages. No interview was conducted in English.

• **Place of data collection:** Data was collected in hospital ward and Out Patient Department of Pediatric Palliative Care Unit-Tata Memorial Hospital as per the mutual convenience of researcher and researched.

• **Scheduling the interview:** To avoid extra time, energy and money, interviews were scheduled only on the day of follow up. The date and time was fixed up as per the mutual convenience of researcher and parents.

Conscious efforts were taken by the researcher to refrain from adopting the role of counselor. In few of the cases the need of in depth counseling was realized, so the parents were referred to the trained counselor of the Palliative Care Unit for further help.
3.11 Unstructured in-depth interview:

Unstructured in-depth interview was used as the method to collect data from the parents. The advantage of this method is that there is no limit on the duration and the number of interviews with the same participant. This gives an opportunity to maintain the rapport. Such a sensitive topic may demand more than two to three sessions as it may be difficult to speak about the all issues in one sitting. Duration of interview can be short or may long which can be decided by the availability and comfort level of the respondent.

By considering all these points suiting the current study demands, an interview guide was constructed on the basis of the conceptual framework of the study. This was to make the data collection more systematic and to avoid gaps in the data. One to one conversation proved to be the best tool to discuss sensitive and personal issues. As there was no rigid pattern of questions, the free flow of conversation can ease the respondents to ventilate the innermost concerns and feelings. The privacy, assured confidentiality and the flexible approach helped participants to open up easily.

The word ‘unstructured’ emphasizes the idea of researcher’s attempts to draw out information, attitudes, opinions, and beliefs around particular themes, ideas and issues without the aid of predetermined questions. The interview was conducted in a conversational style. The prompt, probe and questions which were framed on the spot helped to flow the conversation. By using the golden rule ‘speak less and listen more’ rich data was gathered.

3.12 Experience of researcher during interview sessions:

The researcher has worked at Tata Memorial Hospital for more than ten years as a counselor. Conscious efforts were taken by the researcher not to mix the roles of researcher and counselor. One of the mothers was going through severe anticipated grief and was in complete denial. So she was immediately referred to the Department of Psychology of Tata Memorial Hospital. A mother, who lost her first son few years ago, blames her negligence for the death of the child. Currently, her second son is suffering from life threatening disease. She experiences severe guilt
and blames her motherhood, parenting practices and destiny. Her expression of guilt and experience of trauma touched the researcher.

The researcher decided to help the mother to ventilate her feelings. The next meeting was schedule after finalizing the narrative to avoid the conflict between the roles of a researcher and counselor. The information gathered in next meeting was not included in the study. To help her to deal with her trauma, next session was scheduled as per her convenience. Her feeling of guilt and her self-blaming was attended to patiently. Two sessions with the mother and third session with couple were scheduled as per their convenience. Warm assuring words of her husband and catharsis of feelings help her cope with the past trauma. Then she decided to focus on care of the second child (who is suffering with life threatening disease). She said, “mere manka boj kam ho gaya. (I am feeling less burdened now).”

The researcher was deeply touched by this case. The researcher decided to debrief herself. Palliative Care Unit has a practice to help the members to deal with their stress. To avoid burn out, the help is given by other members of the Unit. After this incident, the researcher had a sharing session with other counselor. The sharing helped her lot to deal with the case related stress.

3.13 Secondary data collection:

The personal and demographic details of the researched were obtained by perusing the Demographic record file maintained by hospital. The Palliative Care Unit has a practice to maintain the cases papers of every visit of the patients. The case papers keep the detailed record of physical, psychological, spiritual, social and emotional aspects. Trained counselor and psychologist note their minute observations. These case papers were referred to understand the awareness level of the disease as well as process of the coping. The factors affecting stress and coping were gathered through the notes.
3.13.1 Non participant observation:

It was done using check list including following points of observation. Observation was supported by documented details by social workers, counselor, psychologist and doctor to understand the patient and care givers in detail.

- **Cleanliness and hygiene pattern**
- **Support system** (who accompanies the child every time): The number of care-givers accompanying the child and parent at the time of follow up visits was observed consciously. The interpersonal relationship was documented through observation as well as from the follow up record sheets of the clinic. Relationship pattern between extended family members as well as neighbors (if accompanied with) were noted.
- **Availability of support from community or Non Government Organization**: The role of NGO in the treatment phase of child was documented trough Medical Social Worker’s notes. Financial as well as support in form emotional, psychological, social and spiritual was observed. There are NGOs which help children to get free medicines, stay facilities and provide other facilities.
- **Availability of resources**: Availability and ability to get access to resources (material and non-material) was observed. Factors like literacy level, computer literacy level, networking with other NGOs, resource persons were documented.
- **Communication patterns, inter personal relationship within family members**: gesture, tone and body language was noted. Conscious efforts were made to understand the level and role of collusion within family.
- **Duty allocation and role of family members**: Few of the members in the family take charge of the situation and make treatment related decision such as whether to seek some other alternate treatments or whether return to their native place. Certain families make collective decisions. Certain members of family are bed side care givers and other choose to perform other duties like having a word with medical professionals, approaching support systems, arranging finance and other needs.
Regularity of treatment, punctuality of appointment, clinic case papers regarding regularity in follow up visits were referred. Telephone record was also studied to understand the incoming-out going phone calls (from and to the clinic) and reasons for their calls.

These points of observation are based on the experience of the researcher. She has noted that such observation give valuable information regarding their practices, routine, support system, interpersonal relationship and so on.

3.14 Recording interviews:

It is necessary to record the gathered data while interviewing the researched. A tape recorder was used with the prior permission of researched. If the consent was not given for recording the researcher used her skills of writing notes simultaneously with inquiring and listening. The important issues brought up in the conversation, the facial expressions, unsaid words, tears and even silence were noted in writing. The practice of going through the notes was followed so as to fill in the gaps in the notes as the memory used to be fresh immediately after the interview session. The data gaps were filled in the next interview session.

3.16 Writing Memos: "Memos are the theorizing write-up of ideas about substantive codes and their theoretically coded relationships as they emerge during coding, collecting and analyzing data, and during memoing" (Glaser, 1998:177). The researcher developed the habit of making notes simultaneously while speaking to the parents. Some parents permitted to record the interview. Recorder records verbal conversation but other observations, expressions, gestures were documented immediately. One of the parents was looking at the photograph of his daughter (who is in the terminal stage of cancer) while speaking. He was weeping when he spoke about the possible eventuality in the near future. These details were recorded as he spoke about his reactions to the anticipated grief. The interviews which were not recorded, as the parents did not permit the researcher to do so, were documented in detail. One of the sessions was conducted with both the parents as the paternal uncle was looking after the child. While taking the down the notes of interview, the relationship patterns observed between parents were noted. When the mother started crying, the father showed empathy by patting her back.
### 3.17 Analysis:

“The data collected by qualitative method is voluminous and rich. It is important to make sense out of the pages of interviews and files of field notes. Developing some manageable classification or coding scheme is the first step of analysis. The recurring regularities in the data reveal patterns that can be sorted into categories. The qualitative analyst’s efforts are towards uncovering patterns, themes, and categories”(Patton, 2002:463). In this way, the data collection helps to study the field reality and build the concepts and develop a web of hypotheses and ultimately ends with the field based theory which will be context specific. This is the process of induction which is used in qualitative research for knowledge generation. “It is important to maintain a balance between the qualities of objectivity and sensitivity when doing analysis. Objectivity enables the researcher to have confidence that his/her findings are a reasonable, impartial representation of a problem under investigation, whereas sensitivity enables creativity and the discovery of new theory from data” (Strauss and Corbin, 1998:53).

In qualitative data analysis, there is a common reliance on words and images to draw out rich meanings. The methods of qualitative analysis involve uncovering and discovering themes that run through raw data. The job of the researcher is to interpret the implication of those themes for the research questions. The raw data is processed to convert into integrated narratives, which will be identified as the unit of analysis. First step of data analysis is to sort the data on the basis of concept and sub concept. Sorting has to be according to stake holder position. So the term ‘narrative’ is used. The focus of sorting will be based on logic of chronology and logic of association. The narrative will be written separately for every unit of analysis. The data used will be chronologically ordered uncensored data.
Data Analysis process

The analysis followed the above mentioned model (Cresswell, 2007 p. 171).

“Open coding is the first step in the data analysis process for a grounded theorist. It involves taking data (e.g. interview transcriptions) and segmenting them into categories of information”(Strauss and Corbin, 1990 cited from Creswell, 2007:240). In this phase the researcher analyzed the narratives. The narratives are formed after translated and transcribed the interviews. The data gathered from secondary sources are a part of narratives. After reading line-by-line and paragraph-by-paragraph transcripts, the process of coding is done. After the completion of this line-by-line and paragraph-by-paragraph coding, the similar codes are clubbed to form concepts. Then these emerged concepts were clubbed to form subcategories and categories. The categories are composed of various subcategories that are properties (Creswell, 2007). Each category was saturated through constant comparison. This process is followed by axial coding. In this step, relationship between categories and subcategories is established.
“The researcher takes the categories of open coding, identifies one as a central phenomenon, and then returns to the database to identify (a) what caused this phenomenon to occur, (b) what strategies or actions actors employed in response to it, (c) what context (specific context) and intervening conditions (broad context) influenced the strategies, and (d) what consequences resulted from these strategies. The overall process is one of relating categories of information to central phenomenon category.” (Strauss, and Corbin, 1990 cited from Creswell, 2007:237). Qualitative analysis transforms data into findings. The themes running through metaphors were listed. The themes, concepts, sub concepts emerging from the data were noted. The efforts were towards making the sense as a ‘whole’. Significant patterns were noted along with its commonality and differences. Line by line coding through which categories, their properties, and relationships emerge automatically takes the researcher beyond description and puts us into conceptual mode of analysis (Strauss and Corbin, 1998). “Analysis has an obligation to monitor and report its own analytical procedures and processes as fully and truthfully as possible” (Patton, 2002: 434).

The finding of the study will help in training/knowledge development sector. As we can understand real need pattern, we can start training professionals, volunteers from different geographical areas and eventually this will help to spread the concept more widely in the country and reach many patients and care givers in an effective manner.

Parents were interviewed. Parents are considered as unit of analysis. Either both or one parent was interviewed. But narratives of father and mother were considered as one narrative. All interviews were either in Marathi or in Hindi. They were translated in English. Silences and pauses were also recorded. After translating and transcribing the interviews, the narratives were written. These narratives and information gathered through other sources like case files, notes of counselor and psychologist and notes of researcher through her observation was clubbed together to cover all possible aspects related to the event. Line by line coding was done. Sub themes were merged together under main theme. Similarities and differences were highlighted. Systematic grouping and summarizing descriptions were used to understand the lived experiences of parents. In the study, stress was identified as one of the themes. Then while coding line by line, it was understood that the stress is related to uncertainty of life, unpreparedness to face the death of
child, lack of medical facilities, other pending responsibilities, financial, minimal resources were identified as the sub category. It was found later that all these themes, categories, sub themes and sub categories which emerged through data are related to each other. As suggested by Corbin and Strauss (1990), causal condition are included that influence the central category, intervening and context factors surrounding it, and specific strategies and consequences (axial coding) as a result of it occurring.

As the analysis progressed it was realized that there was little content and information related to life situations of the parents and children suffering from cancer. Further the data generated yielded information related to stress and resources of coping from which inferences were drawn. From this data, resilience did not emerge as a major theme. Hence the conceptual map was revised right from the beginning of data collection to suit the data that emerged. Once the findings were compiled and was presented, there was a felt need to change the title that was mentioned in the original proposal, to suit the emerging findings of the study. Hence the research currently focuses only stress, coping resources and strategies.

3.18 Conclusion:
The study to understand the lived experience of the parents of the terminally ill cancer patients, within the larger framework of Qualitative research methodology, grounded theory approach was considered appropriate. The chapter provides the rationale of using qualitative approach and grounded theory methodology. The detailed description of data collection and data analysis is to explain the process of emerging field based theory. The detailed description of emerging theory is described in the subsequent chapter.