CHAPTER I

INTRODUCTION

“Chronic illness is like gravity. It always exists.”
Joan C. Barth, Ph.D. (1996)

Children are the most precious blessings given to family. There is nothing in this world that can be more important than own baby. The lives of the parents completely adjust upon the arrival of their child. All parents have hopes, dreams and expectations for their children. When disease strikes these expectations are shattered the moment the doctor utters the diagnosis. Some parents describe it as a physical blow, like being slapped. As the numbness wears off, parents are forced to begin to cope to accept the diagnosis, mobilize their emotions and get on with their lives. But their lives are forever changed. Taking care of a chronically ill child is one of the most draining and difficult task a parent can face.¹

A child’s chronic illness affects the lives of all family members emotionally and physically. Roles and routine change and the demands of care giving must be negotiated. Financial resources may be strained.²

Loss is an experience familiar to all individuals. Whether it is the loss of a job, skill, relationship, health finance, self esteem, trust freedom or ideals, it is something men and women encounter countless times throughout their life span. In recent years, interest in the area of “loss” in psychology has grown rapidly.
Encouraging this interest is the growing belief that the most severe events in life are loss events.\textsuperscript{3}

The area of loss that is the focus of this present study is that experienced by mothers who are informed that their child has a life threatening chronic illness. This type of loss is of interest because it involves grieving the loss of an “ideal”, not a tangible object. In this case ideal lost is that of the healthy child. When a woman is pregnant she is aware there are risks and problem may arise. Generally however, these thoughts are put aside and it is expected that she will give birth to a healthy child. During pregnancy it is also common for expectant mother to develop images and expectations of what their child will look and be like. When the child arrives and the parents are informed that he/she has life threatening chronic illness their image shattered. In turn rather than feeling the joy they had anticipated, parents are left in a state of shock and disbelief.\textsuperscript{4}

Past studies have looked at both parents of children suffering chronic illness and those suffering life threatening chronic illness. In general these studies have tended to focus on the stress the illness puts on the family unit and the burden of illness-related tasks, rather than the loss experienced. In recent years however, the loss these parents experience has been increasingly recognized. In looking at the grieving process questions such as “why are some better at coping with grief and others? And what determines a positive
outcome?. The answer to such questions lie in the fact that grief is a complex phenomenon, the effect of which are mediated by a wide range of variables.\textsuperscript{4,5}

It is decided to focus on a two specific chronic illness rather than generalize across different types of chronic illness. The chronic illness which will be the focus of this study is Leukemia and Thalassemia.

Leukemia is the most common malignancies in children with a prevalence of 129 in one million and the second cause of death among children aged 5-14 years.\textsuperscript{6} As per WHO, worldwide 15 million children have clinically apparent thalassemic disorders. There are about 240 million carriers of thalassemia worldwide and in India alone the number is approximately 30 million with a mean prevalence of 3.3. Every year approximately 100,000 children with thalassemia born world over of which 10,000 are born in India.\textsuperscript{7}

Despite advances in the cancer treatment a cure is still by no means certain. For parents, the diagnosis of cancer in one of their children is a psychological and existential challenge. As one parent explained “sometimes I think that I still live in some state of shock! I feel now that life is so unfair”. However a parent’s ability to manage his or her psychological distress during treatment of a child is vital not only for the consolation of the parent himself or herself, but it may also influence child’s well being.\textsuperscript{8}

Relaxation therapy is a systematic technique for achieving a deep state of relaxation. Relaxation therapy can take many forms and can
benefit most people. The best thing about this type of therapy is that it can be
done at no cost and can be practiced anywhere anytime. Gallagher - Thompson (2007) stated that there are various forms of individual and group therapies, and
teaching session have been used to treat the grief of parents with chronic
diseases. Raphoal and colleagues (2003) included that psychodynamic approaches,
behavioral therapies, and cognitive therapies are most useful in helping such individuals.

Worden (2006) suggested that providing adequate information,
addressing fears and anxiety providing reassurance that they are not to blame, listening
carefully and validating feelings are all essential components for managing the grief of
parents having children with chronic diseases.

Now a day’s science and technological advances have provided a wide
range of available interventions. Therefore both nurses and other health professionals
should pay attention to this process, in order to offer access to different kinds of
support to children with Leukemia and Thalassemia and their parents. Acknowledging
the actual support need of family members of children with these chronic diseases are
important for the coherent and adequate planning of nursing care, as well as to help
and direct intervention areas that need to be developed, tested in research and put in
to practice.
NEED FOR THE STUDY

Chronic illness is an illness that is long term and is either not curable or has residual features that results in limitations in daily living requiring special assistance or adaptation in function. Children with chronic illness may experience physical, psychological cognitive and neuropsychological effects. The caregiver is the main provider of physical and emotional support for the child when their younger one affected with chronic illness. Coping with chronic illness is very difficult circumstances for the child as well as the parent. Families face uncertainty when they are told that their child is having life threatening chronic conditions. They undergo phases of grief.\textsuperscript{13}

To overcome the grief people need to be educated, to help them realize grief does not need to be feared, and that even though it may seem impossible they can overcome grief, heal and even grow from experience. (Tatelbaum 2000)\textsuperscript{14}

Perception of grief explains why different people react to the same event in very different ways. It is also important to look at whether coping has an impact on the degree of grief experienced by mother of chronically ill children. Synder, Ford et.al (1997) defined coping as an attempt to lessen the physical and psychological pain associated with negative life events\textsuperscript{15}. Van Heck and Deridder (2001) added to this note that it is also used to regulate emotion and reduce the threat of loss. In all coping refers to the way one manages different situation\textsuperscript{16}.

Coping is a vital concept in nursing and its strategies can influence the nature of adaptation of a family. It is crucial for the nurse to take a long-term view of problems
and not to expect all of them to be solved quickly. Akbar Hussain and Ipshita Juyal reported that children and families, who were well adapted to diagnosis and treatment, would cope better with the stressors.\(^\text{17}\)

In a review and critique of the literature related to chronic illness, Mohalman Berge and Patterson (2004) found that mothers actually had more psychological distress, particularly depression and anxiety. This is consistent with literature that suggests a child’s illness has a greater psychological impact on the mother rather than father.\(^\text{18}\)

The focus on the mother in the present study was due to the fact that they were generally easy to contact, and as the primary care giver they tended to be the ones who attended hospital appointments with their child. It has been acknowledged; today that men and women do differ in their grief reactions. For these reason there is an increasing urgency to investigate the needs, perception and coping style of mothers. For a Mother, since the time of conception, life is completely dedicated to the all-round development and well being of her child. If the mother is anxious it will be transferred to the child and mother could not take care of the child.\(^\text{19}\)

It is decided to focus on a two specific chronic illness rather than generalize across different types of chronic illness. The chronic illness looked at in this study are leukemia and thalassemia that requires frequent medical treatment, blood transfusion, monthly hospital visit.
Leukemia is one of the most common cancers in children, comprising more than a third of all childhood cancers. The quality of life of children with leukemia is reduced by fear and anxiety of parents after diagnosis, lack of information about the disease, treatment and care of the child. F Hasheni, N Asadi, University of Medical Sciences Iran (2011) conducted a study to evaluate the effect of educating parents of leukemia children on quality of life. They have found that parent education successfully increased the quality of life of leukemic children, therefore parental consultation and educational programs are recommended.

Prasomsuk and all (2007) did a qualitative study explored the lived experience of fifteen mothers of children with Thalassemia in Thailand. A semi structured interview schedule was used. Six items were found namely lack of knowledge about Thalassemia, Psychological problems, concerns for future, affected social support system, financial difficulty and non effectiveness of health care services. These findings suggest that a holistic, culturally sensitive nursing approach should be considered when caring for children with Thalassemia.

Many stressful aspects of the mothers of illness of the children and hospitalization can be reduced or eliminated or avoided. In such cases, effective nursing care may involve teaching the relaxation technique that are thought to reduce the physical impact of stress on the body as well as providing the mothers with the means of physical or emotional control.
Self regulation therapies such as progressive relaxation and Jacobson relaxation technique have also been studied in patients undergoing cardiac rehabilitation. The result showed significant effects on diastolic blood pressure and lowered level of anxiety and depression.\textsuperscript{22}

Synder (1994) reviewed thirteen studies testing the outcomes of relaxation therapy on a variety of patients. Although significant differences were found between all test measurements before and after therapy, 12 out of 13 studies demonstrated positive outcome\textsuperscript{23}. Hyman et al (2004) analyzed 48 research studies on non-mechanically assisted relaxation technique and found that all therapies demonstrated evidence of effectiveness for people with anxiety, depression etc\textsuperscript{24}.

The investigator while working in pediatric ward found that mothers are confronting many difficulties, in caring their children with leukemia and thalaseamia had very less knowledge in looking after their children in performing their activities like giving medicines, keeping them clean, necessary nutrition to be provided etc. They also are having various types of grief.

Advances in medicine and ability to keep sick children alive have meant that today there are increasing number of children living with chronic illness. Looking at the grief experience of the parents of these children is important, because effective care of the child relies on their effective parenting. Helping parents recognize their loss not only enables them to be there for their child, it also helps them to better understand their pain, move through their grief, and get back upon their feel. Considering the above
factors the investigator decided to conduct the study on the effectiveness of planned interventions on perception of grief and coping strategies of mothers of children with selected chronic diseases.

**STATEMENT OF THE PROBLEM**

“A study to assess the effectiveness of planned intervention on perception of grief and coping strategies of mothers of children with selected chronic diseases in selected hospitals of Pune City.”

**OBJECTIVES**

- To assess the perception of grief of mothers of children having selected chronic diseases before and after planned interventions in the experimental group.
- To assess the coping strategies of mothers of children having selected chronic diseases before and after planned intervention in experimental group.
- To assess the perception of grief and coping strategies of mothers of children with selected chronic disease in control group.
- To correlate the findings with selected demographic variables.
- To assess the opinion of mothers regarding planned intervention.

**OPERATIONAL DEFINITION**

- Planned intervention:
In the present study planned intervention means information booklet regarding the chronic disease and protocol of relaxation therapy and demonstration of relaxation therapy to the mothers whose children suffering from thallasemia or leukemia.

- **Grief**

In the present study grief is the deep or intense sorrow or mourning of the mothers related to chronic illness (leukemia and thalasemia) of their children.

- **Perception**

In the present study perception is an interpretation or impression based on mothers understanding related to chronic illnesses of their children.

- **Coping strategies**

In the present study coping strategies refers to the specific efforts taken by the mothers of children with selected chronic illnesses (Thalassemia & Leukemia) to solve their problem and to master the situation, tolerate, reduce or minimize stress.

- **Chronic disease**

In the present study chronic disease is developing slowly and persisting for a long period of time often for the remainder of the lifetime of the individual which includes leukemia, and thalasemia.

- **Mother**
In the present study mother is a woman in relation to a child to whom she has given birth, with chronic disease (leukemia or thalassemia).

- **Children**

In the present study children are the young human being under 16 years.

**Hypothesis**

- **H₀₁ -** There is no significant difference between the perception of grief of mothers of children with selected chronic diseases of experimental group and control group at 0.05 level of significance.

- **H₀₂ -** There is no significant difference between the coping strategies of mothers of children with selected chronic diseases of experimental group and control group at 0.05 level of significance.

- **H₁ -** There is significant difference between the perception of grief of mothers of children with selected chronic diseases of experimental group and control group at 0.05 level of significance.

- **H₂ -** There is significant difference between the coping strategies of mothers of children with selected chronic diseases of experimental group and control group at 0.05 level of significance.
ASSUMPTIONS

The study was based on the following assumptions:

- Mothers whose children suffering from leukemia and thalassemia have various types of grief
- Mothers whose children suffering from leukemia and thalassemia use some coping strategies

DELIMITATION

- The study is delimited to mothers of children with selected chronic disease (leukemia and Thalassemia) and those children admitted in the selected hospitals of Pune city.
- Sample size is not large so findings cannot be generalized

CONCEPTUAL FRAME WORK

Conceptual models are used to guide theory based nursing practice. Models are tools to systematically examine client situations. They assist Nurses in organizing their thinking, observations and interpretations. Therefore, models are goal oriented and lead to efficient and effective nursing practice. Models serve as a link between nursing practice, Research and education. Conceptual frame work represents a less formal attempt at organizing a phenomenon.
The framework used for this study was adopted from Roy’s adaptation model (1984). Sister Callista Roy developed the adaptation model. The model is popularly known as RAM or Roy’s Adaptation Model. The major concepts of Roy’s model are briefly presented here.30

**Stimuli**

These are stressors from internal or external environment that act upon a person and the person responds to the stimuli by adapting as man is an adaptive person. The three major stimuli described are:

**Focal stimuli**- Immediate confronting stimuli demanding attention or relief. In the present study focal stimuli is the disease condition of the mothers of children having chronic illness in acute nature. This include feeling of loss, depression, anxiety, loss of confidence and unhappy.

**Contextual stimuli**- All other situational or surrounding stimuli contributing to the effect of focal stimuli. In the present study contextual stimuli include Effect of Hospitalization (confronting with other children with same disease condition), family support, and financial support and faith.

**Residual stimuli**- Ambiguous factors that may affect a person. In the present study Residual stimuli includes religious factors, beliefs, tradition and customs, Attitude change due to disease condition.
**Adaptation level**

Adaptation level of an individual is the ability to cope constantly and positively with the changing environment.

**Coping Mechanisms**

These may be in the form of routine and non routine behaviors. The two types of coping mechanisms described are

1. Regular or physiological coping mechanisms
2. Non regular or psychological coping mechanisms.

**Adaptive Modes**

An individual adapts by four modes in response to the changing environment.

1. Physiological Mode or adapting by a physiological response (Sweating, Insomnia, Irritability, Mood swing, Headache etc)
2. Self concept mode is an adaptation to one’s own self perception that may be personal or physical. Mothers may have queries related to child’s disease condition, treatment, prognosis and care of child at home.
3. Role function mode or adapting to a new role and behaviors associated with a role, performance, requirements associated with roles in order to maintain social integrity.
4. Interdependence mode or social adaptive modes i.e. a patients dependence on a nurse in varying degrees. In the present study Mothers Depends on spouse, relatives, God, Health care professionals. Mothers may have coping intolerance.
SUMMARY

This chapter has dealt with the background of the problem, need for the study, problem statement, objectives of the study, operational definitions, hypothesis, assumption, delimitation, and conceptual framework.