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.[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.[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. [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 Thallassemia.

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.[6] As per WHO, worldwide 15 million children have clinically apparent thallasemic disorders. There are about 240 million carriers of thallassemia 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.[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. [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 [9]. Raphoal and collegues (2003) included that psychodynamic approaches, behavioral therapies, and cognitive therapies are most useful in helping such individuals.[10]

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.[11]

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.[12]

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.[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)[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[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 [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.[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.[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.[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 thallssemia 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[6]. 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 been found that parent education successfully increased the quality of life of leukemic children, therefore parental consultation and educational programs are recommended.[20]

Prasomsuk S ,wt all (2007) done 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.[21]

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.[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[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[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 assess the perception of grief and coping strategies of mothers of children with selected chronic diseass 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 thallasemia) 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 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

- $H0_1$ - 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.
- $H0_2$ - 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.
- H_1 - 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.
- H_2 - 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 thallassemia have various types of grief
- Mothers whose children suffering from leukemia and thallassemia use some coping strategies

DELIMITATION

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

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[29].

The frame work 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 sourrending stimuli contributing to the effect of focal stimuli. In the present study contextual stimuli include Effect ofHospitalization (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 , Head ache 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 frame work.

CHAPTER II

REVIEW OF LITERATURE

“ Review of literature does for us what a map does for a traveler”

The reviewed literature for the present study is organized under following headings.

Section I deals with perception of grief, and evidence of grief in mothers of children with chronic illness.

Section II deals with coping strategies observed in mothers of children with chronic illness.

Section III deals with relaxation therapy, effect in reduction of grief in mothers of children with selected chronic illness.

Section IV deals with importance of information to be given to the mothers of children with chronic illness.

Section V deals with Nursing and role of Nurse in implementation of relaxation therapy and information booklet.

Perception of grief, and evidence of grief in mothers of children with chronic illness.

The notion that men and woman grieve losses other than death was mentioned as early as 1917 in a paper by freud entitled “ Mourning and Melancholia” . In this paper Freud wrote that follows upon every loss, whether it to be the death of a loved one , a material possession, or an ideal such as particular philosophy, religious conviction or patriotic dream [8,32].

It is important to mention Freud's writing from the outset when talking about theories of grief as it contains a number of important features that have influenced later descriptions and assumptions about the nature of this subject[33]. Freud believed the one thing certain regarding grief was that the individual was affected by the experience. On saying this he noted that the symptoms of grief vary among individuals and that the outcomes of grief could be either positive or negative[32].

Freud viewed grief as an active process. One that involved a struggle to give up the emotional attachment one has to an object (Archer 1999). Intially it was thought that recovery from bereavement was achieved when one reached a final detachment. After the death of his daughter , however Freud acknowledged that " although we know that after such a loss the acute state of mourning will subside , we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap , even if it be filled completely , it never the less remains something else.[33] (Written in a letter to Bainswagner 1929, cited in Rubin & Malkinson, 2001)

From the observations of Lindemann grief consisted of a syndrome of five components: somatic distress, preoccupation with image of diceased, guilt, hostility and disorganized behavior. Not stopping at this Lindemann went on to describe the grief experience in more detail. Reporting , for example the physical symptom one may feel such as tightness in throat, or an empty feeling in the abdomen. He also noted a desire to withdraw from others, a tendency towards heightened irritability and anger , and an intense subjective distress. Lastly he noted that many attempt to avoid the pain connected with grief by a flight in to activity that helped one to keep their mind off what had happened [34].

There are many different theories on grief, all of which have implications for how grief should be approached and considered. Amongst these theories run several common threads. One of these being that theories typically stress the challenges individuals face when bereaved and the tasks they must address in grieving. (Attig 1996). Most commonly mentioned is that individuals must accept the reality of their loss , and work through the pain of grief [35].

Another is that grief is a multi-dimensional phenomenon, involving more than just sadness and depression. In this light, it is thought that grief consists of a series of distinct periods that can be identified and described by particular features. Although there is some variations in what these are, those typically mentioned are shock and disbelief followed by somatic distress and acceptance where one sees a reduction in the intensity of emotion, and a reestablishment of social contacts. (Attig 1996)[35]. In terms of these different stages, Parkes and Kubler- Ross note they are not fixed and may overlap. Thus an individual does not necessarily move in an orderly progression from stage 1-5. Supporting this , Peppers and Knapp (1980, cited in Toedter etal. 1988) noted there are various routes one may take when grieving. This in turn means that although individual may ultimately have the grief score, the way they reached these scores may be very different [36].

A third common thread is the acknowledgment that everyone grieves differently. It could be expected that everyone grieves the same, especially if they have suffered the same loss. This, however, is not the case, with there being a great amount of individual variation when it comes to grieving. As individuals men and women place different levels of importance on different losses.[37]

Stages of grief (Geldard, Fortier) are commonly mentioned when someone suffers a loss. Stages of grief include shock, denial, guilt , anger, sadness , anxiety, symptoms, physical and emotional and psychological idealization, acceptance, re-adjustment and finally personal growth. Grief responses are explored further within the context of symptoms, stages and grieving process. The American academy of Bereavement identifies five dimensions of the human system being emotional, physical, intellectual, social and spiritual. A few example are offered from the reading, emotional (feelings): numbness, guilt and disbelief. Physical effect: crying, change in appetite, sleep and muscle twitching. Intellectual: Confusion, absent minded , denial. Spiritual: Loss of faith, angry at God, spiritual rebellion. Social: Loss of identity, isolation, withdrawal, leading to vulnerability [38].

Grieving is seen as process of mourning the loss, grieving may be either a quick process or one that takes many months or years to move through. Parents experiences wide range of feelings and reactions. Eg: jealousy, frustration, irritability, sleeplessness, withdrawal and isolation, hostility, abandonment, embarrassment, fear, blame and marital conflict. Offering an example of a family with a child who has suffering from chronic illness, although aspects of the above feelings reflect a grieving responses, they can also represent a realistic response or concern about their child's future, the lack of appropriate and responsive services and inappropriate reaction of family and social network to the loss.[39]

A review by the center for advancement of health (2003) illustrates that complicated grief is a potentially distinct clinical entity with decreased mental health, wellbeing and functioning in life roles. The terms complicated grief and traumatic grief (Jacobs and Prigerson 2000) appear to be becoming more widely used to cover a range of terms and grief reactions, such as pathological, unresolved , exaggerated, delayed and chronic[40].

It is generally accepted that the death of a child (regardless of age) is the most devastating of all bereavements and one of the most difficult losses an individual will experience. (Cleiren 1993)[41] . The reason for this is that children are seen as an extension of their parent and as such represent the future of their family line . (Sprang 1995). In this lightit follows that the birth of a chronically-ill child may result in a similarly strong feeling of grief for parents. This grief originates from the loss of the " healthy child" expected. It is then added to by the grief that accompanies the realization of the constant care the child requires, and the impact that the illness will have on normal family functioning. Lastly it is fuelled by the uncertainty sourrending their child's quality of life and life expectancy.[36,40]

The majority of the research on grief focuses on parents coping with children who live with Mental retardation or physical disability. However grief may also be experienced by parents of children with chronic illness. Both Damorsch and Perry (2001) found that it is common for parents of children with disabilities to feel grief because the expectation of each parent has for the child are no longer being met, and the hope for a " whole" or normal child is fantasy [41]. Grifin and Kearney's (2005) found that pain and sorrow were integral to the experience of being a parent of child with chronic illness and were angry that their experience of optimism were interpreted as maladaptive[42.]

Lowes and Lyn's (2002) illustrated in the study that critical appraisal of grief reactions in parents of children with Leukemia provided support for the presence of grief in relation to children who do not have developmental disability[43]. Lowes and Lyne (2002) believed that Leukemia to be an ongoing loss, and hypothesized that parents of children with Leukemia would periodically experience feelings of sadness and guilt due to daily reminders of loss of Health, change in life style and uncertain future. Several finding standout 1) Parents adapted overtime practical aspect of management. 2) The persistence of emotions associated with grief like anxiety, isolation, and guilt could sometime be renewed during critical times 3) Parents of children with Leukemia described continuing periods of upset, guilt, fear, concerns and sadness associated with developmental change[44].

Chronic illness in a child alters the life situation of the family and implies stressors of varying duration, predictability and impact. In addition to concerns about the child's prospects of being cured from chronic illness , the strain relate to demand and changes in everyday life. These demands include , for example accepting the intensity of one's own reaction, and dealing with the reaction of others , witnessing the child in pain ,concerns about child's future, quality of care negative employment and financial consequences and supporting the siblings of the child.[45]

Hobfoll (2004) conducted a research on parental grief after diagnosing the child as leukemia suggest that depression could be a dimension of grief. Result of the study revealed the following. 1) Parents reported a high intensity of acute grief and sadness. 2) 86% of the participants experienced chronic sorrow, with mothers reporting more sorrow than fathers. 3) Data demonstrated a statically significant relationship between grief and depression.[46]

Parents whose children are diagnosed with Thallassemia have been found to experience an initial grief reaction similar to that usually associated with bereavement (Kovas etal 2005). They described a range of emotions at diagnosis such as shock, denial, anxiety, sadness, anger, guilt and frustration and have been found to experience a number of lossess incurred by the diagnosis, such as loss of spontaneity, loss of freedom and loss of their child's health up to 5 year after diagnosis[47].

Several studies have indicated that presence of a patient or disabled child leads to stress and depression in parents. Mothers usually take active roles in the care of their ill children and even might avoid their favorite activities. Thus, they bear greater stresses than fathers bear and are at higher. Divorced mothers had higher depression score than the other two groups (married mothers and widows) Married mother and living with husband can be related with lower depression scores[48].

As part of the personal experience of this investigator, and also as witnessed among parents of thalassemia children , the level of stress were distressing lending to many physical and psychological problems like anxiety, depression, Insomnia, weight loss which leads them to unable to cope with others, failures and low achievements[49].

Belinda Barton et al. (2006) done a study to assess the experience of parents of children with chronic illness. Result of the study revealed that chronic grief the parents experienced in relation to their child's condition, which often recurred at various stages of child's illness. The child's initial diagnosis was found to be most stressful part of the grieving process, with most feeling their voices are parents were not being heard or valued by health professionals at this time. The finding illustrate that the grief experienced by these parents can be exacerbated by their dealings with health professionals.[50]

The study conducted by Karson et.al 2008 describes that parents of children with chronically ill shared the strife of caring for a child with chronic illness. Parents felt helpless when their child was discharged from the hospital. They were often overwhelmed by the care of the child requires everyday. They expressed the immense responsibility for the complex care for the child.[51]

As per the study conducted by Leo (2008) the experience of parenting children with chronic illness evoked strong emotions in the parents to protect their child mixed with the desire to withdraw from the situation. Parents shared the examples of feeling these emotions. The following are examples of the range of emotions they were feeling. Sadness was mentioned by several mothers. One mother of a child with thallasemia said initially " I could not do anything initially but weep for a week". Some parents talked of emotional detachment, " I almost had to detach myself emotionally in order to deal with it. Anger emerged as an emotion expressed by some of the parents. The parents often focused their anger and frustration on the health profession caring for their child. One mother shared her frustration as the lab technicians made repeated attempts to draw blood. Another mother of child with Thalassemia explained " you go through feelings of anger or sometimes sadness, you go through whole thing. The first year was just dreadful.[49]

Lotta Dellve et al (2005) conducted a study to assess stress, well-being and supportive resources experienced by mothers and fathers of children with rare disabilities, and how these variables were affected by them. Parents from all parts of Sweden visiting national centre for families of children with rare disabilities were consecutively selected (*n* = 136 mothers, 108 fathers). Instruments of parental stress, social support, self-rated health, optimism and life satisfaction and perceived physical or psychological strain was used.

The studies revealed high parental stress, physical and emotional strain among mothers, especially among single mothers. Fathers showed high stress related to incompetence, which decreased after the intervention. Decreased strain was found among full-time working mothers and fathers after the intervention. Parents, especially fathers and full time working parents, may benefit from an intensive family competence program[52]

Jerrett 2006 conducted a study to assess the experience of mothers of children with leukemia. In that study parents described staying in struggle by devising the “tricks of the trade”. These tricks were developed as strategies for improving their ability to assess their child’s condition… Gallo and Knafi 2006 suggest that mothers have to develop “tricks of the trade” to manage their child’s chronic illness day to day and maintain family routines. Their tricks of the trade are in the parents thought daily as a part of the routine.[53]

Jean Sherrng, Cofee et.al had done a metasynthesis study of parenting a child with chronic illness. During the literature search the focus was on keyword parenting, not mother / father role. Seven of the 11 article reported that mother was primary care giver and caring the burden as stated by mothers themselves. One mother shared “ my husband was alone with my child once. And that was it. He’s never stayed with her again”(Ray & Ritchare 2003).[52] This places the burden of all the care on the mother and does not allow her to have a break from the routine and the responsibility.

The mother as a primary care giver often experienced exhaustion. In the research of Hatton et.al 2005 one group of mothers shared their frustrations with the loss of an ideal mother child relationship due to the need to provide complex care to the child. Clements & colleagues reported that 30 % of the 30 families in their study reported that they called mother centered pattern. In this pattern the mother assumed responsibility for the care of the house hold as well as the care of the chronically ill child. [28,54]

In all, the studies cited above in relation to parents of children with leukemia, Thalassemia and other chronic illness are important in that they suggest parents are grieving for the loss they have experienced. The importance of studying this loss and the grief experienced is in turn realized when one become aware of just how long lasting this grief can be.

Coping strategies observed in mothers of children with chronic illness.

Coping is thought to be another important factor affecting grief experience, with the way men and women cope likely to influence the intensity of their grief, as well as their overall adjustment. In regards to the current study , coping is defined as specific strategies (both cognitive and behavioral) that people use to master, reduce or minimize the external and internal demands of a particular stressful situation.[55] (Carver, Scheier 2002)

Several general characteristics regarding coping are noted in the literature. First, is the fact that coping is contextual and thus influenced by appraised characteristics of a person, environment relationship (Folkman 2001). This in turn means that a strategy that works for one individual may not work for another. Second, coping is a process that changes as a situation unfolds (Folkman) with strategies varying over the course of a particular situation, just as they do between situation. Carver et al 1989)[35.56]

Coping is part of transaction between the person and the environment where that transaction is appraised as stressful (Latack & Havlovic, 1992). Coping means adjusting to or solving internal or external challenges. Coping is a persons attempt to control, manage or live with a stressful situation. (Folkman 1984)[56]

Coping strategies can be either problem focused or emotion focused. Problem focused coping involves an effort to solve the problem or meet the demand directly. Emotion focused coping occurs when nothing can be done and the people turns to cognitive process such as distancing, wishful thinking or self blame. Folkman 1984). Coping efforts include several behavioral and cognitive strategies . these fall in to two categories: strategies aiming at eliminating the stressor, and those focusing on the reduction of the stress response. The first category is typically referred to as problem focused or primary control strategies, while the latter are called emotion focused or secondary control strategies. Adaptive coping produces a reduction of the stress reaction.[55,56]

Coping behavior is considered successful, if when reappraised, the stressor or threat is absent or more manageable. Common indications of effective coping are perceived helpfulness, reduction of anxiety and emotional distress, and reduction or elimination of problem[57].

There is another distinction in the type of coping: active and avoidant coping strategies. Active coping strategies are either behavioral or psychological responses designed to change the nature of the stressor itself or how one thinks about it. Avoidant coping strategies lead people in to activities such as alcohol use or mental states such as withdrawal. Generally speaking , active coping strategies , whether behavioral or emotional are thought to be better ways to deal with stressful events, while avoidant coping strategies appear to be psychological risk factor or marker for adverse response to stressful life events. (Folkman 2001). In all, this is important as it helps the individual realize they do have some control in that they have the power to make the choices about what they do. In regards to mothers of children with chronic illness, for example, while they cannot change the fact their child has chronic illness, they do have control over their child's treatment, and can choose to be active when it comes to thing such as medication, chemotherapy, blood transfusion which help to improve their child's health and assist in holding back the progression of the disease. [55,56]

Patterson & McCubbin (2002) noted that mothers experiencing stressful events such as a child's chronic illness tended to use more coping behaviors than parents experiencing less stressful events[58]. Furthermore, Katz (2004) noted the severity of the child's illness appears to have a differential impact on coping, with parents of children who have life threatening conditions evidencing a larger repertoire of coping behaviors than parents whose children had non life threatening conditions.[54]

Pradeep Rao et al (2007) Conducted study on psychopathology and coping in parents of chronically ill children in Mumbai, North India. 30 parents whose children who had thalassemia were randomly selected from the thalassemia day care centre of a teaching general hospital. The parents were interviewed on a semi-structured performa and rated on stress and mechanisms of coping scales. Chronic illness in children affects the psychological health of the parents. Active coping strategies are associated with fewer distress indices and thus if inculcated may improve the ability to bear the burden of the illness without becoming themselves affected by psychiatric illness.[57]

Brown Ronald et al (2001) Conducted a study on analysis of parenting problems for caregivers of children with thalassemia. A situational analysis of problematic situations was conducted for 37 caregivers of children with thalassemia who ranged in age from 5-13 years. Participants responded to a semi-structured interview related to caring for a child with thalassemia. The interview included the domains of medication adherence, nutrition, minimizing and coping with pain episodes, social problems, academic difficulties and children's expression of negative feelings related to having thalassemia. Caregivers described 356 problems. Almost all caregivers reported experiencing problems with their children's nutrition, minimizing pain episodes and their children expressing feelings about having thalassemia. Moderately challenging and emotionally upsetting problems were reported for coping with symptoms. Nutrition issues were more frequently reported for younger children. Findings have salient clinical implications for the care of children with thalessemia.[59]

In regards to use of specific strategies, Katz (2004) found that those most used by mothers and fathers to help them cope and adapt to their child's chronic illness were family problem solving coping behavior. These included maintaining and promoting the cohesiveness of the family unit, sharing time and experiences together, and sharing the daily chores. In concluding Katz (2004) noted that these findings were in turn supported by the research literature that noted the importance of integration and cohesiveness in enhancing adaptation to a chronic illness.[54]

Coping may be monitored by way of a number of specific strategy clusters. For instance Hardy and her coworkers (2004) have studied the eight separate subtypes of engagement and disengagement coping. Problem avoidance, wishful thinking. Social withdrawal, self criticism (Disengagement coping) and problem solving, cognitive restructuring social support and express emotion (engagement coping). Alternatively a Dutch research group have used a taxonomy , according to which emotion focused as well as problem focused strategy include the four types of predictive, vicarious, illusory, and interpretive control strategies. Another set of strategies include seven strategy clusters, active problem focusing, palliative reaction patterns , avoidance behavior , passive reaction pattern ,expression of emotions and comforting cognition and social support seeking.[60]

After interviewing 100 families of children with Thallassemia (1998 cited in McCubbin) concluded that there were two major coping strategies that appeared to promote a high level family functioning. These were coping by sharing the burdens of illness, and coping by using an existing philosophy about life held by the family to endow the illness with meaning and make sense of what happened[61]. The importance of this strategy is supported by Saunders (2002) who suggested that one of the most difficult yet important tasks for those who are bereaved is to find some meaning in the situation. Furthermore, Macintosh, Silver and Wortman (2203) found greater participation in religious activities and social support enabled who had lost a child to find meaning of their child’s death. This in turn enhanced their well-being[61,62].

Coping involves psychological resources and coping strategies that help to eliminate, modify, or manage a stressful event or crisis situation . Having a child with special needs creates a crisis event, how mothers respond to the stresses of raising their child with special needs depends on a wide variety of factors influencing their ability to cope, such as their interpretation of the crisis event, the family’s sources of support, community resources, and family structure .The personality characteristics of the family members, their financial status, educational level, problem-solving skills, and spirituality all influence a family’s ability to cope. Strong marital relationship and social support also help determine mother adjustment (Emerson, 2003 & Fazil, Wallace & Singh,2004)[63]. The goal of coping strategies is to strengthen or maintain family resources , reduce the source of stress or negative emotions , and achieve a balance in family functioning . Strategies directly aimed at coping with the source of stress, such as problem solving and seeking information are more adaptive strategies than those effortsto deny or minimize the situation [64]

Annika Lindahl Norberg (2005) conducted a study examined 395 parents (224 mothers and 171 fathers) of children with cancer in Sweden in terms of coping, assessed using the Utrecht Coping List. The use of each of seven coping strategies among parents of children with cancer was compared with data from parents of children with no serious or chronic diseases. In addition, the relationship between coping strategies and anxiety/depression was examined. No differences in the frequency of using the seven coping strategies were found between the study group and the reference group. Neither did the use of coping strategies differ among parents of children with various types of cancer, nor among parents at various points in time after the child's cancer diagnosis. A more frequent use of active problem-focusing, and a less frequent use of avoidance behavior and passive reaction pattern, was related to lower levels of anxiety and depression in parents of children with cancer and in reference parents. Analyses of parents of children at different time points after diagnosis and in different diagnostic groups indicated that contextual demands influence the relation between coping and anxiety/depression.[65]

Vasundhara Kumari, ,& Vineeta Gupta, Department of Pediatrics, Institute of Medical Science, Banaras Hindu University (2011) conducted a study *to assess* Parental Stress and Coping Techniques in Parents of Children with Bronchial Asthma. The objective of this study was to examine the stress in parents of children with bronchial asthma and to assess coping technique used by them to meet their stress. Sixty parents of children with bronchial asthma were selected from Asthma Clinic, Department of Pediatrics, I.M.S., B.H.U, Varanasi and sixty parents of children suffering from minor illness were selected from Pediatrics Out-patient Department. Parenting-stress-index and Ways-of-coping questionnaire were administered on these parents. Socio-economic details were collected by using Kuppuswamy's socio-economic status scale. The mean scores of parents of children with bronchial asthma on Parenting Stress Index scale were significantly higher as compared to their matched controls (Pd"0.001). Regression analysis showed that emotion focused coping like escape avoidance (Pd"0.05) and positive reappraisal (Pd"0.01) were the main coping techniques used by these parents. Parents of children with bronchial asthma had higher level of stress and maladaptive coping techniques. Proper intervention may help these parents in improving their coping skills to meet stressful situation.[66]

Doris J. Heaman College of Nursing, The University of Alabama in Huntsville USA (2011) conducted a study to assess Perceived stressors and coping strategies of parents who have children with Leukemia: A comparison of mothers with fathers. The purposes of this study were to describe perceived stressors and coping strategies of parents who have children with developmental disabilities and to examine similarities and differences of mothers and fathers in their perceptions of stressors and coping. A sample of 203 parents of children with developmentally disabilities, ages two through five years, participated in the study. Hymovich's Parent Perception Inventory: Concerns (Hymovich, 1988) and the Ways of Coping Questionnaire (Folkmann & Lazarus, 1988) were used for data collection. Stressors and coping strategies were identified. The stressor reported by the largest number of both mothers and fathers was concern about the child's future. There were fewer differences between mothers and fathers in reporting of stressors than in reporting coping strategies. The importance of recognizing parental individuality in family coping is addressed within the context of implications for nursing practice and research.[67]

Hae-Ra Han, Eun Joo Cho (2012) done a study to assess the coping strategies and psychosocial adjustment in Korean mothers of children with cancer. A total of 200 Korean mothers of children with cancer participated in the study. Coping strategies were measured by the Coping Health Inventory for Parents in the following three categories: Maintaining Family Integration and an Optimistic Outlook for the Situation, Seeking Social Support, and Seeking Information. Maternal psychosocial adjustment was measured by psychological distress, family relationship, and social relationship subscales from the Psychosocial Adjustment to Illness Scale. Korean mothers reported coping strategies related to Maintaining Family Integration and an Optimistic Outlook for the Situation as being most helpful. More frequent use of coping pattern, Maintaining Family Integration and an Optimistic Outlook for the Situation, and less frequent use of coping pattern, Information-Seeking were significantly associated with lower psychological distress and better family relationship after children's medical and maternal characteristics were controlled for. Coping pattern, Seeking Social Support was only predictive of social relationships.[68]

In all , the findings cited above suggest that parents of children who are chronically ill will make use of a wide range of coping strategies. In particular, those that seem most beneficial are those that focus on integration, cohesiveness, finding meaning in their situation, gathering information, and enlisting social support.

Relaxation therapy, effect in reduction of grief in mothers of children with selected chronic illness.

What we think and feel can change our physiology. Our thoughts and emotions are transduced in to neural messages that are converted in the brain to neuro hormonal messenger molecules that move through the body to communicate directly with the autonomic endocrine , immune and neuro and peptide system. (Dossey & Guzzetta 1992) . People who participate in relaxation therapy are capable of changing negative imagery , thoughts, and feelings in to positive and healthy neural messages [69].

Relaxation therapy is a widely used approach to treat symptoms of general anxiety disorder (GAD). The goal of relaxation therapy is to help an individual be more tolerant of their worrying behaviors, thus decreasing the negative psychological and physical symptoms of GAD (Donegan, E., Dugas, M. J. (2012). CBT is an alternative approach that is used for various mental health problems, including GAD. It focuses on the somatic symptoms of tension and physical discomfort associated with anxiety, with the goal of reducing worry. Both CBT and AR have been shown to be effective at diminishing the symptoms of GAD in individuals who struggle with emotional and somatic symptoms. However, few studies have compared the dynamics that cause the symptom reduction in each of these treatment approaches.[70]

The therapeutic effects of relaxation are increasingly being recognized. It has been demonstrated to be effective in the control of Asthma (Erskine & Schonell 1981), regression of Cancer (Meares 1981), treatment of depression, treatment of anxiety conditions where it has been demonstrated to be effective in training patients to cope without the use of anxiolytic drug (Sinner 1984)[71]

Eleanor Donegan of the Department of Psychology at Concordia University in Montreal sought to identify the mechanisms by which AR and CBT worked and also to determine if one was more effective than the other at maintaining long-term symptom reduction. For her study, Donegan evaluated 57 individuals who underwent either AR or CBT over a period of 12 weeks. She found that for both groups, the amount of time they spent worrying each day decreased from approximately 36% of the time to 20%. Additionally, both AR and CBT reduced the amount of daily anxiety by nearly 50% [72].

Michelle Y. Kibby .The University of Memphis USA (2011) conducted a meta analysis to find out the effectiveness of psychological intervention for parents of children with chronic medical illness. Outcomes from 42 studies of psychological interventions for parents of children with chronic medical conditions were analyzed using meta-analysis. Studies were divided into the four intervention categories suggested by LaGreca and Varni (1993), Disease Management, Emotional/Behavioral Problems, Health Promotion, and Prevention. Results supported overall effectiveness of psychological interventions, with an effect size (ES) of 1.12, as well as maintenance of treatment gains for at least 12 months post treatment. Psychological interventions directed at disease-related or emotional/behavioral problems were both found to be effective, although too few studies of health promotion or disease prevention interventions were identified to be included in the analysis. Effectiveness of behavioral interventions, which were most heavily represented in the sample, demonstrated similar effects for disease management (ES = 1.20) and emotional/behavioral (ES = 1.03) problems. Although disease type, severity, and duration did not affect intervention effectiveness, some influences of patient age and gender were noted across studies. Recommendations for further intervention studies and improvements in study design are discussed.[73]

Simon et al. (2006) conducted a study to determine the effectiveness of relaxation technique on parents of children with Thallassemia. 60 parents were assigned to an experimental group with relaxation therapy and 50 parents were assigned to control group without relaxation therapy. The degree of grief was measured by means of a scale questionnaire and the quality of life was measured by means of a SF 36 health questionnaire. The result showed that 70 % of the parents in the experimental group practiced the relaxation technique and their grief reduced significantly at 3, 6 and 12 months. Their quality of life scores were better.[74]

Uzma Ali, and Shazia Hazan Institute of Clinical psychology Karachi (2010) conducted a study to assess the effectiveness of relaxation therapy in the reduction of grief related symptom. The study revealed that relaxation techniques are very effective in the reduction of grief and depressive symptom. Relaxation therapy replaces arousal , the client gains therapeutic outcome that involves a sense of control over disruptive emotional- physiological arousal which help them in restoring social occupational functioning [75]

Importance of information to be given to the mothers of children with chronic illness

Parents of chronically ill children overwhelmingly report that health care providers frequently contribute to their feelings of sadness, frustration and isolation. When health care providers do not recognize or understand the chronic grief it may add to the parents ongoing stress. According to various research parents feel that medical professionals do not provide enough information about their Childs condition. They also want more practical information about how to care for their child and deal with the child's condition. This lack of information along with poor communication and insensitive comments, may contribute to parents sense of frustration.[76]

Fatemeh Hashemi, Maryam Sedghi Nursing and Midwifery College, Shiraz University of Medical Sciences, Shiraz, Iran.2007) conducted a study to assess the impact of educating parents of leukemic children. The study suggests that the educational intervention for the parents was effective in the improvement of general QOL and all its dimensions among the healthy siblings of leukemic children. In this study, implementing educational intervention for their parents resulted in the improvement of the QOL in physical complaints and motor functioning dimensions. Another study also noted that holding interventional programme for cancer children and their parents caused the improvement of QOL dimensions .The current study also indicates that educational programmes for the parents improved the QOL of healthy siblings of children with leukemia in the dimensions of cognitive aspect and positive and negative emotions. A study stated that the parents of children with cancer reported a high level of anxiety and depression (negative psychical dimension) among the healthy siblings of their sick children and that carrying out educational sessions reduced such signs and symptoms significantly.˙ Other researchers also indicated that interventional programmes in the form of a peer support camp for the healthy siblings of a child with cancer will lead to decrease in their distress. Furthermore, a study reported that implementing a psychological supporting intervention is effective in reducing stress and anxiety and increase of self-esteem of leukemia.[77]

The quality of life of children with leukemia is reduced by fear and anxiety of parents after diagnosis, lack of information about the disease, treatments, and care of the child. F Yusaf (2011) conducted a study to evaluate the effect of educating parents of leukemic children on the patients' quality of life. sixty parents of ALL children who met inclusion criteria were selected using simple random sampling method, and assigned to the experimental and control groups. The study tool included a valid and reliable questionnaire (TNO-AZL), that was filled in through interview by parents before and two months after the intervention for both groups. The first part of the questionnaire included demographic items and the second part (7 dimensions, each with 8 sections) contained questions related to the quality of life. The scores could range between 56 and 280 and a higher score represented a better quality of life. The intervention included three one-hour classes composed of lecture and question-answer sessions which were held for groups of 4-6 participants, accompanied by a booklet. The result revealed that parent education successfully increased the quality of life of leukemic children; therefore, parental consultation sessions and educational programs are recommended.[78]

David Issacs et al (2003) conducted a study on coping mechanisms that can be adopted

by parents of chronic ill children. They found that almost 300 000 Australian children (7.5%) had a disabling chronic illness. Chronic conditions put increased stress on the child and the parents. Due to the illness the parents become exhausted and develop psychological problems such as anger and depression. Interventions that have been shown to be beneficial include family therapy, supportive counseling of parents, and the use of supportive protocols. Overall adjustment is better with family-centered interventions and when needs are met in the home. Families need clear communication, with healthcare professionals and with each other; opportunities for choice of supports; and practical assistance with finances, transport, respite care and recreation. Many parents report benefits from involvement in self-help groups.[79]

Shukir Saleem Hasan (2011) had done a study to assess home care management for caregivers having leukemic adolescent patients. The study shows that knowledge of the specific diagnosis and details of treatment can help care givers to provide good caring, and implement appropriate interventions.The study proved that majority of care givers have poor practice regarding home care management of leukemia. 92.5% of care givers have deficit practices to encourage their leukemic children from brushing teeth.[80]

Afran Shargli et al (2007) Conducted a study on lived experiences of mother carrying for children with thalassemia major in Thailand. This quantitative study explored the lived experiences of 15 mothers of children with thalassemia major by conducting semi-structured interviews; the data were analyzed utilizing content analysis. Six themes were identified: lack of knowledge about thalassemia, psychosocial problems, concerns for the future, social support systems, financial difficulty and the effectiveness of health services. These findings suggested that a holistic, culturally sensitive nursing approach should be considered when carrying for children with Thalassemia[81].

D'Souza , A (1996) done a descriptive evaluative approach for development of a booklet for parents of neonates admitted to neonatal intensive care unit, based on the information needs. The sample consisted to thirty mothers whose neonates were admitted to neonatal intensive care unit and questionnaire was used for data collection. The result of the study indicated that all parents were in need of information, but they did not know what kind of information they were entitled to, whom and when to approach for obtaining information or what response they would get their queries. The booklet helped the parents in getting the information of neonates care.[82]

Lalrinhlui , conducted a study to develop an information booklet for care givers on care of a child with Mental retardation. A descriptive approach was used.

The study consisted of 50 samples. The care givers existing knowledge were analyzed. The care givers needed information regarding care of a child with mental retardation. The care givers lacked the knowledge about the various aspect of care of their children. The information booklet was prepared and was given to the care givers. They felt the content was adequate in all the areas of care and the care givers appreciated it.[83]

Parents of young children with life threatening illness receive the most benefit from intervention associated with the role of teacher. (Eakesetal 2000) including the provision of accurate, situation specific information in a manner that can be both heard and understood and practical tips for dealing with the challenges of care giving.

Nursing role in the implementation of planned intervention

The real essence of nursing, as any fine art, lies not in the mechanical details of execution, not yet in the dexterity of the performer, but in the creative imagination, the scientific spirit and the intelligent understanding of the techniques and skills, without these nursing may become a highly skilled trade , but it cannot be a profession or a fine art. [84]

The nurse as a key member of the health care team, share responsibility for educating clients in a variety of health related settings. However the challenge associated with increasing client autonomy necessities a shift in the thinking of many nurses. Nurses are in a unique position to maximize the health potential of the client so it is imperative that is responsibility is recognized as an inherent aspect of professional practice.

Grief and anxiety are important concerns for nurses who adhere to Virginia Henderson's view of nursing: Nursing is to assist the individual, sic or well in the performance of those activities contributing to health or its recovery or to peaceful death. To maintain health or recover from an illness one has to learn to handle stress; if nurse can teach people measures to handle stress people will be free to channelize their energies for recovery.[85]

Grief and anxiety are natural or instinctive responses to events in which individuals feel threatened and insecure. The awareness of the threat may be perceived consciously or unconsciously. Because health is so highly valued, any threat to health and well being can precipitate grief and anxiety. Since the nurse care for people with various health and illness related concerns, nurse must be prepared to deal with stress and anxiety in any patient at any time. In fact nurses diagnose anxiety more frequently than any other conditions except pain.[44]

Nurses and other health care professionals should recognize that chronic grief is commonly experienced by individuals across the life span who has encountered significant loss or experience ongoing loss. Further it is important that they view the recurring periodic episodes of sadness and other emotions characteristics of grief , normal response to the ongoing disparity created by the loss and provide needed support when chronic sorrow is triggered.[86]

Specific actions by health care professionals have been identified as helpful in reducing the emotional pain of chronic sorrow. These interventions can be categorized as roles that Nurses can assume in their contacts with individuals experiencing grief. (Handsworth et al 2005). For Parents of children diagnosed with chronic illness or life threatening illness, intervention demonstrative of an empathetic presence and caring professionals are most helpful. (Burke 2005). The interventions are typify the role of empathetic presence include taking time to lsten, offering support and reassurance, recognizing and focusing on feelings and appreciating the uniqueness of each individual and family. [87]

The Nurse can play care for the child and family that include built in support system and recognition of the stress felt by the parent. Based on the finding , the nurse can be proactive to provide support system for families, respect their full range of emotions and prepare to work with them as team members in the management of their child’s care. Special emphasis must be placed on the mother because she is identified as the one who “ carries the burden” of care for the child with chronic illness. Future research may look at understanding the role of the Nurse in support of this group of parents, these parents may look to the Nurse for help with technical care as well as coping strategies. The Nurse may find herself in the unique role of care provider.[88]

Nurses can better assist parents to deal with chronic sorrow by offering internal and external management methods of coping, as illustrated in the mid-range theory of chronic sorrow (Eakes et al., 1998). Successful application of individualized management methods is achieved when a parent is able to balance the emotional and mental stress associated with the day-to-day demands of caring for a child with chronic illness or disability. On the contrary, if management methods are ineffective and proper intervention is not offered, the disparity created by the loss will continue to intensify and may progress to a pathological grief state, such as depression (Eakes et al., 1998).[84]

Nurses have a role in helping people to reduce the tension and grief. Nurses should assess patients abilities to recognize symptoms of stress and their usual methods of coping. In helping patient's use indirect coping , nurses actions are aimed at reducing the psychological and physiological disturbances resulting from grief. Patients can be taught techniques such as deep breathing, relaxation therapy which help them cope more effectively with grief.[85]

Patistea E Babatsikou F. (2003)Conducted a study to identify parents perception of the child's leukemia. 41 mothers and 30 fathers were interviewed to examine their perceptions of (a) The type and amount of information provided to them (b) The sources of information (c) Their level of satisfaction. The results revealed that health care professionals represented the main source of information and was centered primarily on the bio–medical aspects of the child's condition and also parents reported that they needed additional information related to psycho social situation.[89]

D Theofanidis, M. Sc**,** Clinical collaborator ATEI discussed with particular reference to the nurses' role in children with chronic illness. Both the child and the parents need to adapt to the situation from its early stages. The nursing personnel should be able to help and alleviate not only the physical problems, but also the psychological consequences to the child, as well as reducing the parents' stress and their possibly overprotective attitude towards the child. Without nursing support, a family can find itself in crisis and its members may try inappropriate methods of coping which can be detrimental to the short or long-term adaptation to the child's illness. However, even if an early phase nursing intervention is missed, later support can still be of enormous value.[104]

In recent studies Psychological interventions have been shown to be the most promising an popular approaches. Martire et.al (2004) state that such interventions can include patient education various types of relaxation therapy support group etc. Nurses can play a vital role in implementing such programmes.

Rempel et al. (2013) conducted a study to find out the need for implementation of nursing care to the chronically ill children concluded that nurses have a responsibility to provide parents with as much information as possible about their child's diagnosis. The unknown can cause anxiety or fear and nurses need to have discussions with the parents explaining all of the implications for the diagnosis, including what the illness actually is, how it happened, the medical care, differentiation between healthcare professional responsibilities and parental responsibilities, and treatment for this particular After giving the family the basic, initial details, the nurse should be sure to answer all parents' questions to the best of his or her knowledge whenever a question arises and if he or she is unable to answer the question, someone who can should be contacted as soon as possible

In this research the researcher is interested in finding out whether planned interventions (information booklet and relaxation therapy) will have an effect on grief and coping strategies of mothers of children with selected chronic disease.(Leukemia, Thallassemia)

Summary

This chapter has dealt with the review of literature related to the problems of the present study. The review of literature has been organized under five sections. This in depth review helped the researcher in the development of research instrument , data collection procedures, and plan for data analysis.

CHAPTER III

RESEARCH METHODOLOGY

This chapter deals with the research approach, research design, variables under study, schematic representation of the design, research hypothesis proposed, setting of the study, population, sample, and sampling technique.

It also describes the data collection tool, its selection and development, and scoring of content validity and reliability.

The chapter records details about the pretesting, pilot study, procedure of actual data collection, plan for data analysis and actual data collection.

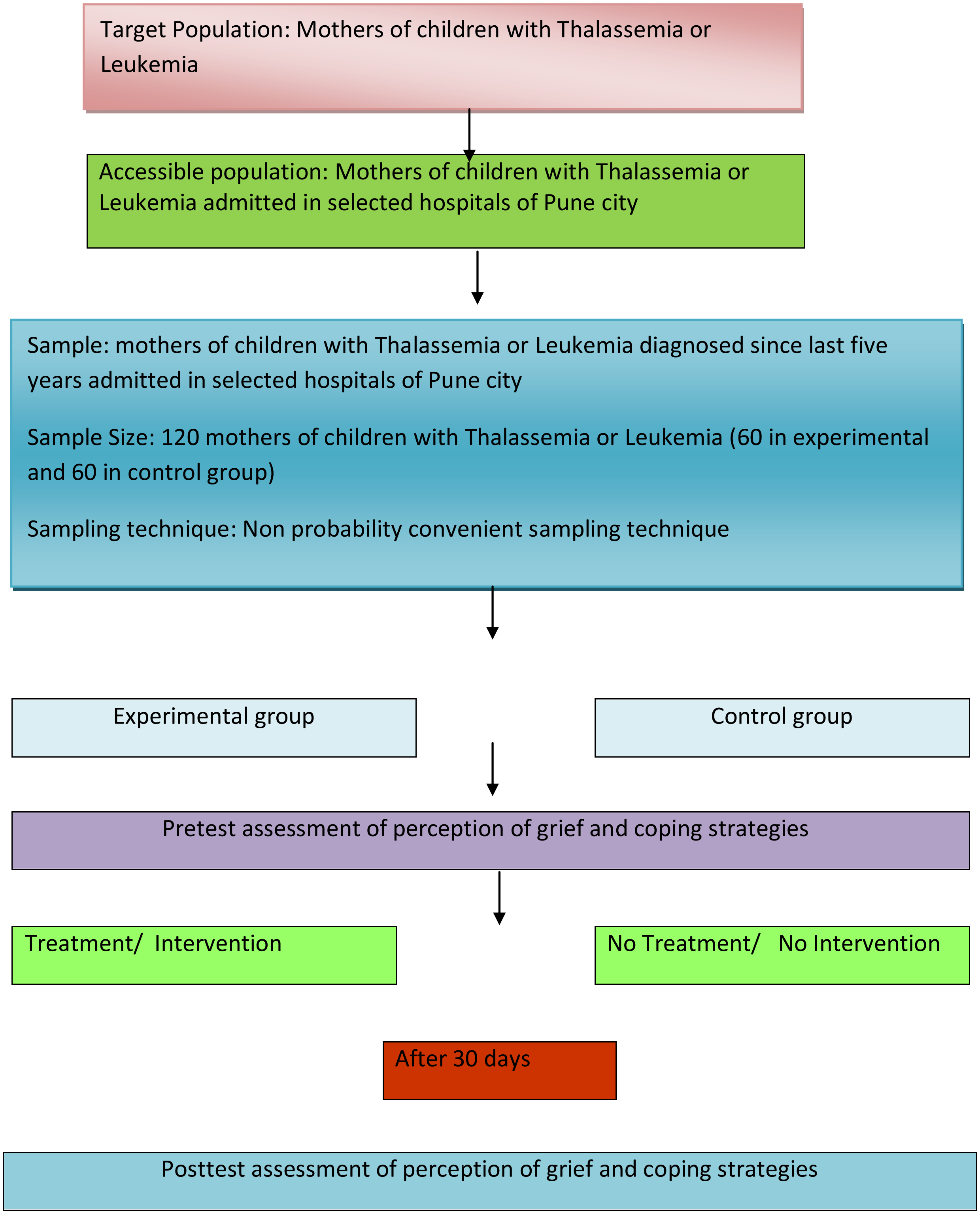
Research Approach

The study uses the quantitative research approach. A quasi experimental approach was considered best suited to the study, which aims to find out the effect of selected planned interventions on grief and coping strategies of mothers of children with selected chronic diseases.

Research Design

This study uses a non equalent control group design with one experimental and one control group

Fig no-2 Diagrammatic representation of the Research Design



Target Population: Mothers of children with Thalassemia or Leukemia

Accessible population: Mothers of children with Thalassemia or Leukemia admitted in selected hospitals of Pune city

Sample: mothers of children with Thalassemia or Leukemia diagnosed since last five years admitted in selected hospitals of Pune city

Sample Size: 120 mothers of children with Thalassemia or Leukemia (60 in experimental and 60 in control group)

Sampling technique: Non probability convenient sampling technique

Experimental group

Control group

Pretest assessment of perception of grief and coping strategies

Treatment/ Intervention

No Treatment/ No Intervention

After 30 days

Posttest assessment of perception of grief and coping strategies

Variables

- **Independent Variable:**

  In this study the Independent Variable is the planned intervention (information booklet and relaxation therapy) given to the mothers of children with selected chronic diseases.

- **Dependent variable:**

  In this study the dependant variable is the perception of grief and coping strategies of mothers of children having selected chronic diseases

Setting of the study

The study was conducted in four settings. The following hospitals were included in the study as per the number of children admitted in these hospitals.

Setting description.

Bharati Hospital- It is a private hospital located in Katraj area of Pune city. At the time of this study this Hospital had 830 functional beds. Out of which Pediatric ward is of 60 beds. 46 children are registered for the treatment of Leukemia, they are coming regularly for the follow up. 38 children are registered for the treatment of Thallasemia, coming regularly for Blood transfusion.

Red Cross Society- Indian Red cross Society Pune Branch is situated in Rastapeth area of Pune city. It has got a well- equipped Thallassemia Unit. Around 65-70 children with Thalassemia are receiving blood transfusion every month.

Nawale hospital- It is a private hospital located in Sinhgad Road. Pediatric ward consist of 50 beds. 46 children are registered for the treatment of Leukemia, they are coming regularly for the follow up. 38 children are registered for the treatment of Thallasemia, coming regularly for Blood transfusion.

Yashoda Hematological clinic- It is a private clinic run by Dr Vijay ramanan in Deccan area of Pune city. Around 42 children with leukemia and 24 cases of thallassmia are taking regular treatment from this clinic.

Population, Sample and sampling techniques.

Population

The population of the present study comprised of mothers of children with Leukemia and Thalassemia admitted in the selected hospitals from March 2013 to November 2013. Only those mothers who fulfilled the sample criteria were selected for the study.

Sample

In the present study sample consist of mothers of children with selected chronic diseases (Leukemia and Thalassemia) from four settings as per the inclusion criteria

Sampling Criteria

Inclusion criteria

- Mothers who are having children with selected chronic diseases (Thalassemia and Leukemia)
- Mothers whose children diagnosed with Thallassemia or Leukemia from the last 5 years
- Mothers who understand English and or Marathi.

Exclusion criteria

- Mothers who are not willing to participate in the study

Sampling Technique

Non probability purposive sampling technique is used in the study.

Sample size

The sample size consisted of 120 mothers of children with selected chronic diseases admitted in selected hospitals of Pune city. Out of 120 mothers 60 were in control group and 60 in experimental group

Data Collection Technique and tool

Description of Data Collection Tool

Based on the objective of the study the data collection tool had the following sections:

Section I : Demographic variables Performa

Section II- Revised grief experience inventory to assess the grief of mothers of children with selected chronic disease.

Section III - Modified tool to assess the coping strategies of mothers of children with selected chronic diseases.

Section IV- Opinion of mothers regarding planned intervention.

Section I : Demographic variable

One of the objectives of the present study was to find out the correlation between grief and coping strategies and background variables. The purpose was to find out whether background variables , which are treated as independent variables in this study , affected grief and coping strategies. Section I included items on background variables such as number of children, diagnosis, duration after diagnosis, occupation.

Section I- Revised Grief Experience Inventory.

The second objective of the study was to determine the perception of grief of mothers of children with selected chronic disease. Hence this tool was adopted. This tool was developed by Lev, Munro & McCorkle 1993. The revised grief Experience Inventory (RGEI) is a 22 item self reported measure that assess the experience of grief and bereavement. This scale was chosen because it is both a concise and valid measure that is sensitive to the grief experience.[91]

The RGEI was developed for use with adults, and contains four subscales. As grief is a multidimensional process a questionnaire that outlined the different aspect of grief in its subscale was important because it ensured one was measuring more than just depression. It also allowed more of an insight in to how people grieve and enabled one to be more accurate in identifying where help may be needed. For example, an individual may only be having difficulty with one particular area of grief[91].

The RGEI was revised using Parkes (1972) theory of grief. Its 22 items were chosen because they had corrected item total correlations of 0.35 or above, and its four subscales are based on a principal components factor rotation which yielded a four factor solution. The four subscales in this inventory are: existential concern, depression, tension and guilt, and physical distress. Responses are scored in a 3 point scale ranging from 1-3. Each answer is recorded, and then summed to get a score of each subscale. The subscale scores are then summed to get a total score. Overall higher scores indicate higher levels of grief .[91,92]

The RGEI was translated in to Marathi for better understanding by mothers. The instrument was shown to experts; however experts made no changes on this scale. This scale was pilot tested on 12 mothers for practicability, feasibly and reliability. The tool was found to be easily understandable.

Since this tool is introduced for the first time in Indian setting, the reliability of the tool was checked with Cronbach's Co-efficient alpha and found to be 0.92.

Section III- The coping strategies scale

The third objective of the present study was to determine the coping strategies used by the mothers of children with selected chronic diseases. Hence this tool was created after reading literature on coping strategies. The tool had 24 items, of which 12 were problem solving coping strategies and 12 were emotion coping strategies. The scoring of this tool was based on the 3- point Likert scale- 0 being the patients never used the strategy , 1 meant patients sometimes used the strategy, and 2 indicated that the patients often used the strategy.

The review of literature clearly identifies both strategies as effective and useful. The items were mainly taken from Rahe and Moos, Lazarus and Folkman's coping strategies instruments.[93]

The coping strategy scale was translated in to Marathi for better understanding by mothers. The instrument was shown to experts , however experts made no changes on this scale. This scale was pilot tested on 12 mothers for practicability, feasibility and reliability. The tool was found to be easily understandable.

The reliability of the tool was checked with Cronbach's coeffient alpha and found to be 0.82.

Section IV- Opinion of mothers regarding planned intervention.

One of the objectives of the present study is to assess the opinion of the mother of children with selected chronic disease regarding planned intervention. Five point likert scale is used to assess the opinion of mothers regarding relaxation therapy and information booklet which ranging from Strongly agree, Agree, neutral, disagree, strongly disagree.

Planned Intervention.

Relaxation Therapy.

The researcher underwent a certified relaxation therapy. Relaxation is a behavior therapy technique wherein clients are taught to keep their body and mind calm, as a result of which they will be able to handle situations more effectively. Relaxation programme aims at teaching the clients methods to produce the basic relaxation responses so that she can eliminate tension from her body and feel a deep sense of relaxation.[94]

Experts in the field of psychology were consulted for approval of the relaxation therapy. Experts validated the researcher's use of the relaxation therapy. A Marathi translation of the technique was given to the mothers to read and understand. The researcher demonstrated the techniques after obtaining the pretest. Every third day contacted the mothers and supervised the relaxation therapy for one month. Instructed the mothers to do the relaxation therapy every day.

Information booklet

Based on the objectives Information booklet was prepared which was handed to the mothers of children with Leukemia and Thalassemia and discussion was encouraged on all aspects of the care of children with leukemia and Thalassemia. It includes meaning, treatment, care of the child, Sources of support, ways to reduce the stress.[6,95,96,97] Experts validated the information booklet.

Validity

The tool was given for content validity to experts in the field of nursing, Medicine and psychology. (List given in Appendix.) . Their valuable suggestions were incorporated in the final tool.

Reliability

In the present study reliability was done in Bharati Hospital of Pune city. The tool was administered to 12 samples by split half method .The reliability of the tool was established using Cronbach's coefficient alpha formula. The scores were entered on a data sheet, and total mean and variance calculated using Cronbach's formula.

The reliability of section II was 0.92 ; and section III was 0.82

Pilot Study

The pilot study was conducted on 12 patients from November 2012 to February 2013 in Bharati Hospital Pune. Its purpose was to ensure the feasibility and practicability of the design. The researcher contacted the mothers with selected chronic diseases in the pediatric ward, and explained the purpose of the study. Their consent was taken after assuring them that their responses would be kept confidential and used for the research purposes only. The demographic variable, RGEI scale, and coping strategy scale were collected on the first day of admission. For experimental group information booklet was given to the mothers with brief discussion. Relaxation therapy was taught to the mothers. Every third day contacted the mothers and supervised relaxation therapy for one month. After one month post test taken .Opinion of mothers regarding planned intervention is also taken. For control group the RGEI scale, and coping strategy scale is measured on the first day of admission and post taken after one month.

Analysis of the pilot study

The pilot data analysis included both descriptive and inferential statistics. Descriptive statistics such as mean, standard deviation were used to describe the RGEI scale and coping strategy. Frequency and percentage were computed. A student t test was used to find out the effect of intervention.

Result of the Pilot study

The mothers easily understood the RGEI scale and coping strategy scale. The findings on stress and coping responses observed and reported showed significance at 0.5 level for experimental group. The findings were tabulated and presented to the guide. The final study was undertaken only after obtaining approval from the guide.

Actual Data Collection

Data collection started in March 2013 after obtaining the required permission from the hospital authorities and the subjects. Samples of 120 subjects were completed after nine months of data collection. The demographic variable, RGEI scale, and coping strategy scale were collected on the first meeting with the mothers of children with leukemia and thalassemia. For experimental group information booklet was given to the mothers with brief discussion. Relaxation therapy was taught to the mothers. Every third day contacted the mothers and supervised relaxation therapy for one month. Total 10 sessions were conducted. After one month post test was taken .Opinion of mothers regarding planned intervention is also taken. For control group the RGEI scale, and coping strategy scale is measured on the first day of meeting and post test was taken after one month. .

The data collection schedule was as follows

S.N	Setting	Group	Period of data collection	Selected conditions	Number of samples	Time
1	Yashoda Hematological Clinic	Control group	25/03/13-28/6/13	Leukemia Thalassemia	30 10	5-7pm
2	Nawale Hospital	Control group	20/4/13-10/6/13	Thalassemia	20	12-2 pm
3	Red cross society	Experimental group	1/7/13-28/8/13	Thalassemia	30	12-2 pm
4	Bharati Hospital	Experimental group	1/9/13-26/11/13	Leukemia	30	12-2 pm

Plan for Data analysis

The data analysis would be done based on the objectives and hypothesis to be tested.

It was decided that tests of descriptive and inferential statistics would be used to derive the necessary results.

Summary

This chapter deals with the research methodology adopted for the study and includes descriptions of the research approach, design, setting, sample, sampling technique, data collection tools, their information, validity, reliability, proposed plan of data collection and actual data collection.

CHAPTER IV

ANALYSIS AND INTERPRETATION OF DATA

This chapter deals with analysis and interpretation of data collected from 120 mothers whose children suffering from leukemia and Thalassemia in selected hospitals of Pune city to determine the effect of selected planned interventions on their perception of grief and coping strategies.

Data analysis was based on the objectives and hypothesis of the study, which were as follows.

- 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 assess the perception of grief and coping strategies of mothers of children with selected chronic diseass in control group
- To correlate the findings with selected demographic variables.
- To assess the opinion of mothers regarding planned intervention.

HYPOTHESIS:

- H_{01} – 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.
- H_{02} – 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.
- H_1 – 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.
- H_2 – 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.

During the analysis, the data was reduced to an interpretable form to summarize the findings, test the hypothesis, and establish the relationship between variables. In order to achieve the above, both descriptive and inferential statistics were computed.

The analysis of data is organized and presented under the following headings.

Section I: The frequency and percentage of demographic variables in experimental and control groups.

Section II:

A) Analysis of Perception of grief of mothers of children having selected chronic diseases in experimental and control group.

B) Analysis of Perception of grief of mothers of children having selected chronic diseases after planned intervention in experimental group.

C) Analysis of data regarding the areas of grief in experimental group control group.

D) 'Z' test for effectiveness of planned intervention on perception of grief of mothers having children with selected chronic diseases in experimental group.

F) Two sample 'Z' test for the comparison of the change in perception of grief of mothers having children selected chronic diseases in experimental and control group.

Section II:

A) Analysis of data related to the coping strategy of mothers of children having selected chronic diseases in experimental and control groups.
B) Analysis of data related to the coping strategy of mothers of children having selected chronic diseases after planned intervention in experimental group.

C) Analysis of data related to problem solving and emotional solving strategies in experimental and control group.

D) ‘Z’ test for effectiveness of planned intervention on coping strategies of mothers of children having selected chronic diseases in experimental group.

E) Two sample ‘Z’ test for the comparison of the change in coping strategies of mothers having children selected chronic diseases in experimental and control group.

Section IV:

A) Analysis of data related to association of perception of grief and selected demographic variables.

B) Analysis of data related to association of coping strategies and selected demographic variables.

Section V: Analysis of opinion regarding planned intervention.

Section I:

The frequency and percentage of demographic variables in experimental and control group are presented in table 1

Table 1:

Description of samples (Mothers of children with selected chronic diseases) according to Demographic characteristics by frequency and percentage

N = 60, 60.

Demographic variable	**Experimental group**		**Control group**	
	Freq	**%**	**Freq**	**%**
Number of children				
One	13	21.7%	10	16.7%
Two	30	50.0%	34	56.7%
Three	14	23.3%	11	18.3%
More than three	3	5.0%	5	8.3%
Diagnosis of the child				
Thalassemia	30	50.0%	30	50.0%
Leukemia	30	50.0%	30	50.0%
Duration of illness				
0-1year	29	48.3%	24	40.0%
1-3years	25	41.7%	24	40.0%
3-5years	6	10.0%	12	20.0%
Age of the child				
0-3 years	18	30.0%	24	40.0%
4-8 years	35	58.3%	27	45.0%
8-12years	5	8.3%	8	13.3%
12-15 years	2	3.3%	1	1.7%
Gender				
Male	34	56.7%	34	56.7%
Female	26	43.3%	26	43.3%
Occupation of mother				
Non-working mother (House wife)	45	75.0%	46	76.7%
Laborer	7	11.7%	9	15.0%
Service	8	13.3%	5	8.3%

In experimental group, 21.7% of them had one child, 50% of them had two children, 23.3% of them had three children and 5% of them had more than three children. In control group, 16.7% of them had one child, 56.7% of them had two children, 18.3% of them had three children and 8.3% of them had more than three children.

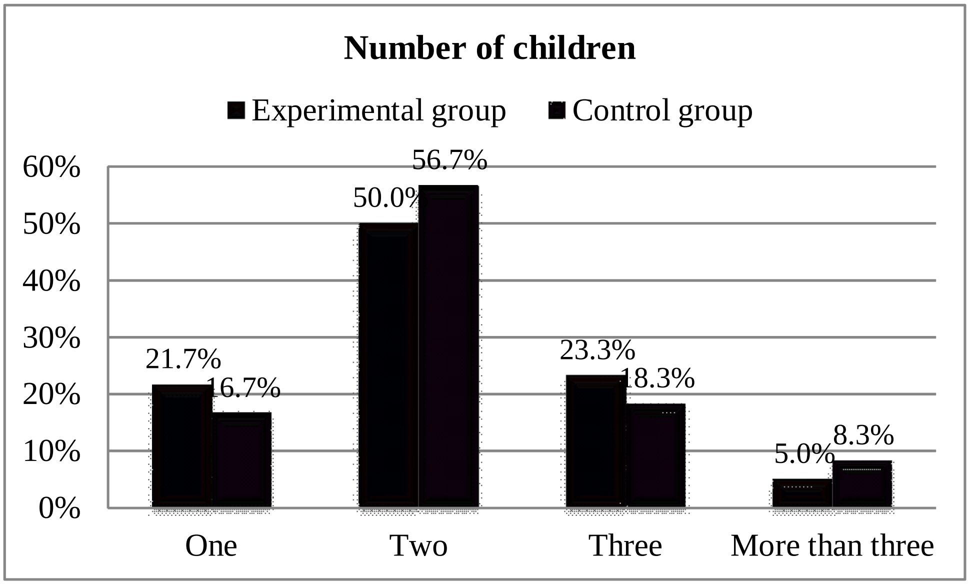


Fig. 3: Bar diagram showing the number of children.

In experimental group, half (50%) of them had their child having Thalassemia and another 50% of them had their child having Leukemia. In control group, half (50%) of them had their child having Thalassemia and another 50% of them had their child having Leukemia.

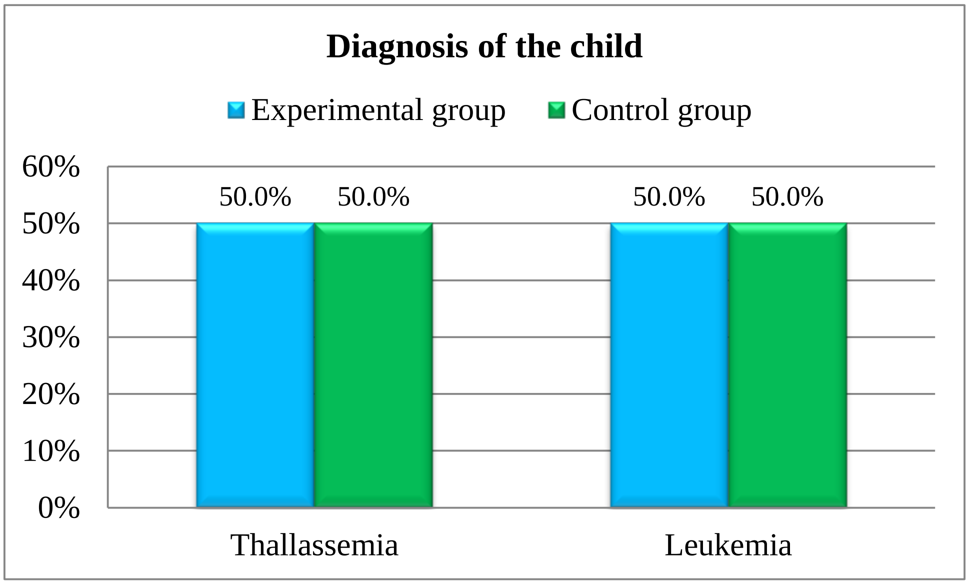


Fig. 4: Bar diagram showing the diagnosis of the child

In experimental group, 48.3% of the children had illness for less than one year, 41.7% of them had illness for 1-3 years and 10% of them had illness for 3-5 years. In control group, 40% of the children had illness for less than one year, 40% of them had illness for 1-3 years and 20% of them had illness for 3-5 years.

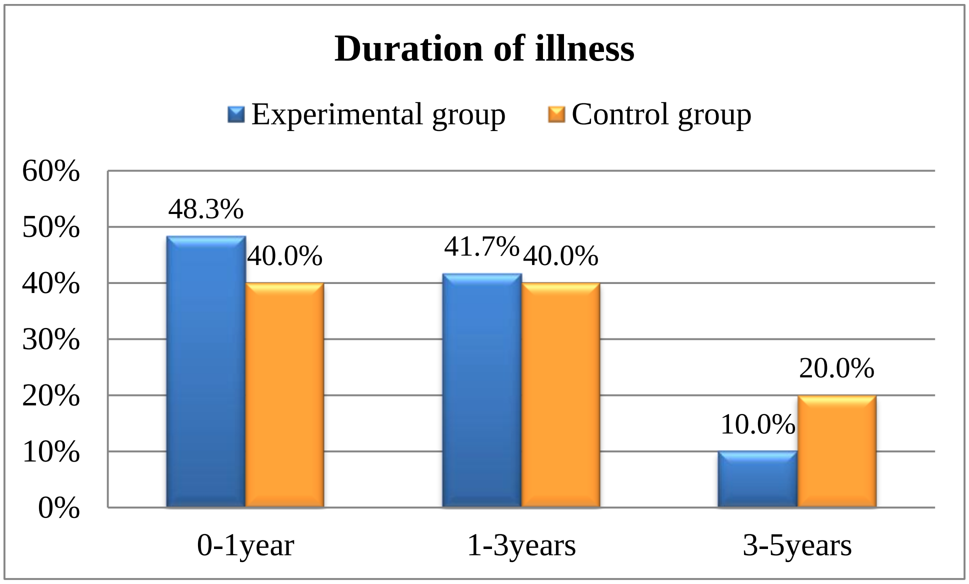


Fig.5: Bar diagram showing the duration of illness

In experimental group, 30% of the children had age 0-3 years, 58.3% of them had age 4-8 years, 8.3% of them had age 8-12 years and 3.3% of them had age 12-15 years. In control group, 40% of the children had age 0-3 years, 45% of them had age 4-8 years, 13.3% of them had age 8-12 years and 1.7% of them had age 12-15 years.

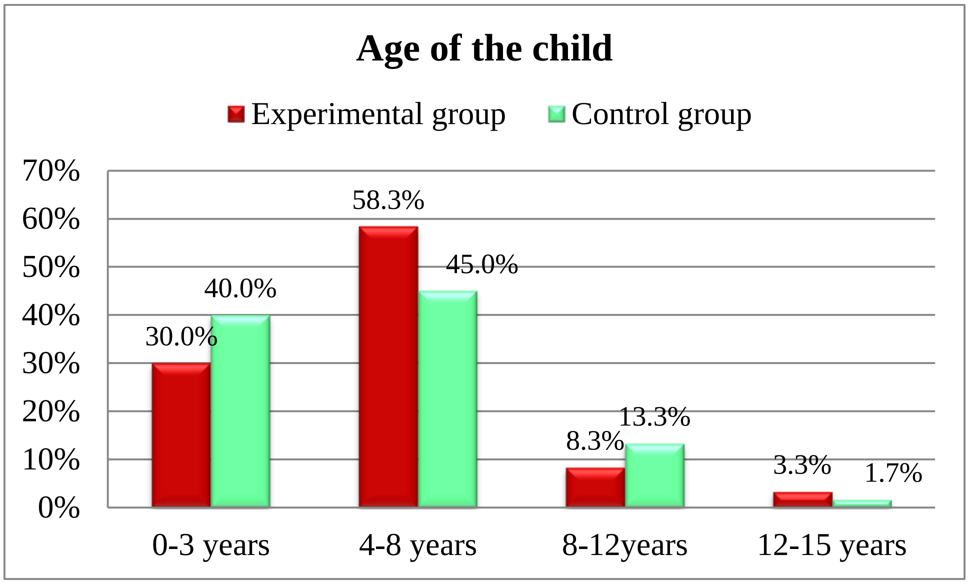


Fig.6: Bar diagram showing the age of the child

In experimental group, 56.7% of them were males and 43.3% of them were females. In control group, 56.7% of them were males and 43.3% of them were females.

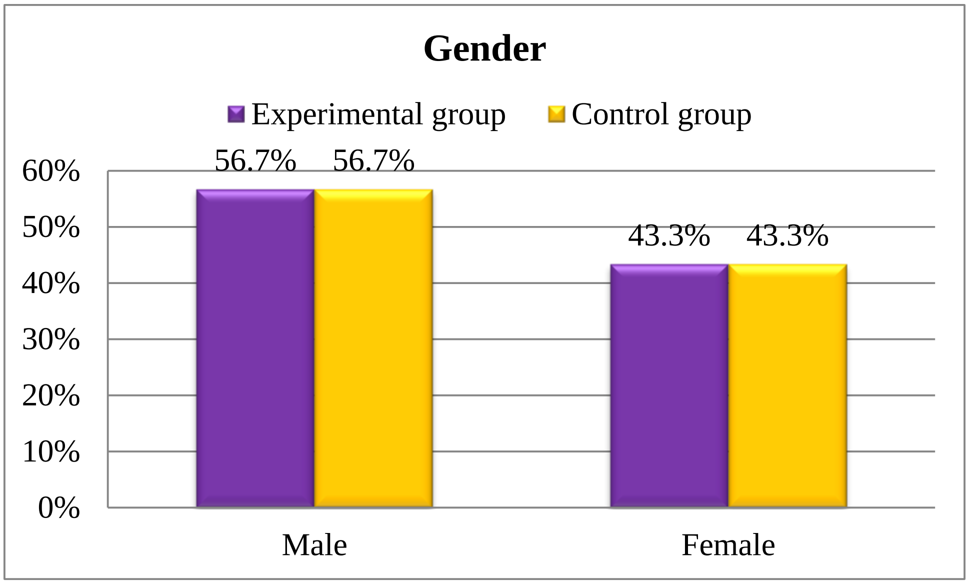


Fig.7: Bar diagram showing the gender of the child

In experimental group, 75% of the mothers were not working, 11.7% of them were laborers and 13.3% of them were doing service. In control group, 76.7% of the mothers were not working, 15% of them were laborers and 8.3% of them were doing service.

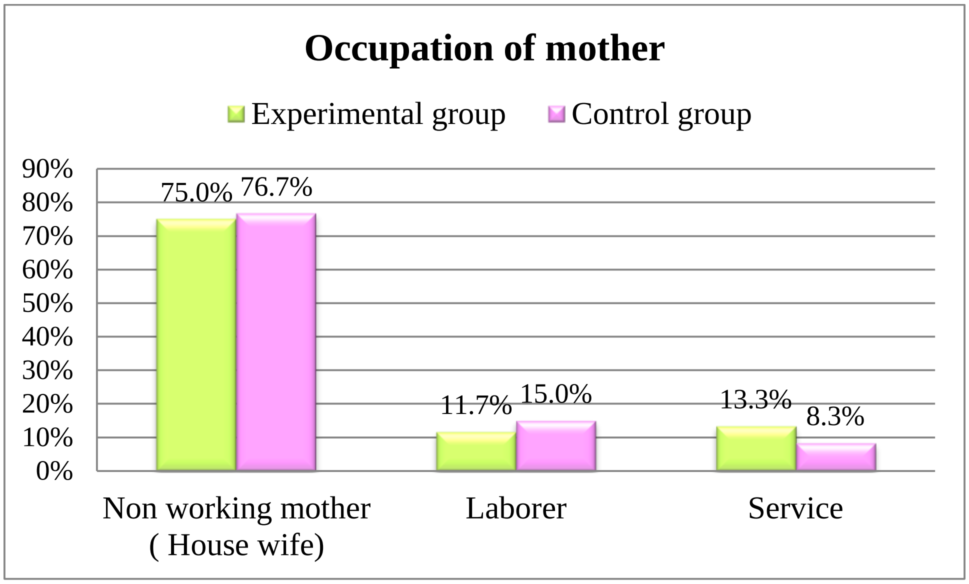


Fig.8: Bar diagram showing the occupation of mothers

Section II:

The objective of section II is to determine the perception of grief of mothers of children with selected chronic disease and the effect of planned interventions on perception of grief. The modified Revised Grief Experience inventory is used to determine the perception of grief of mothers. The assessment of perception of grief was done on the pre-intervention and post intervention days.

The frequency, percentage, mean, SD scores and effect of intervention on perception of grief using ‘Z’ test are presented in the tables and figures.

Section II C reports the results for the four subscales, i.e. existential concerns, Depression, Tension and guilt and physical distress.

Section II (A):

This section presents the findings of data related to the perception of grief of mothers of children with selected chronic diseases in experimental and control group.

Table 2:

Frequency and percentage of Perception of grief of mothers of children with selected chronic diseases in experimental and control group

N = 60, 60

Perception	**Experimental group**		**Control group**	
	Freq	**%**	**Freq**	**%**
Mild	1	1.7%	1	1.7%
Moderate	12	20.0%	11	18.3%
Severe	47	78.3%	48	80.0%

In pretest, in experimental group majority of 78.3% of the mothers of children having selected chronic diseases had severe perception of grief 20% of them had moderate perception of grief and 1.7% of them had mild perception of grief. In control group, in pretest, majority of 80% of the mothers of children having selected chronic diseases had severe perception of grief, 18.3% of them had moderate perception of grief and 1.7% of them had mild perception of grief.

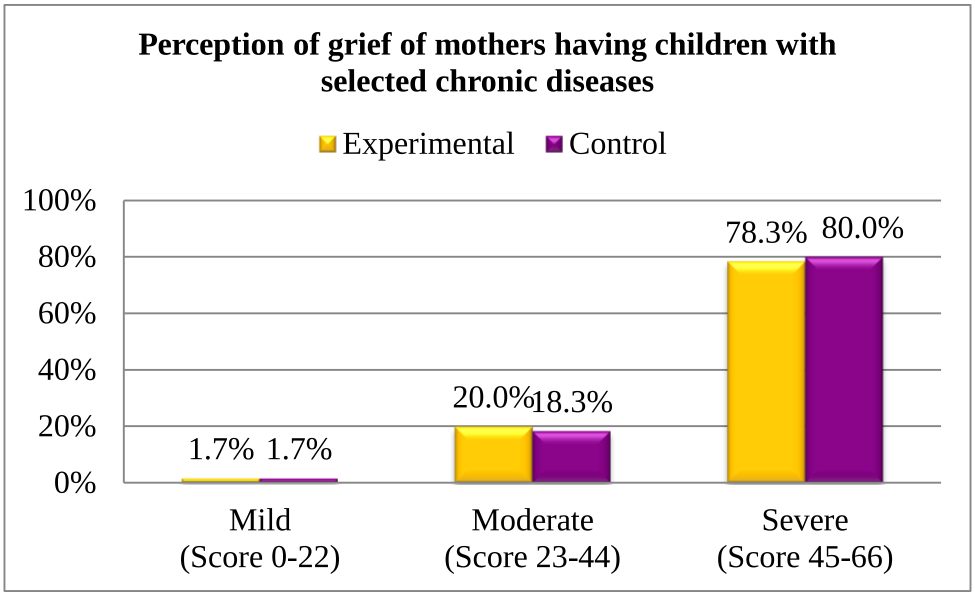


Fig. 9: Bar diagram showing the perception of grief of mothers having children with selected chronic diseases.

SECTION II (B):

This section present the analysis of data related to the perception of grief of mothers of children having selected chronic diseases after planned intervention in experimental group

Table 3:

Frequency and percentage of Perception of grief of mothers of children having selected chronic diseases after planned intervention in experimental group

N = 60

Perception	Pretest		Posttest	
	Freq	%	Freq	%
Mild	1	1.7%	9	15.0%
Moderate	12	20.0%	51	85.0%
Severe	47	78.3%	0	0.0%

In pretest, in experimental group majority of 78.3% of the mothers of children having selected chronic diseases had severe perception of grief, 20% of them had moderate perception of grief and 1.7% of them had mild perception of grief.

In posttest, majority of 85% of the mothers of children having selected chronic diseases had moderate perception of grief (Score 23-44), 15% of them had mild perception of grief (Score 0-22) and none of them had severe perception of grief (Score 45-66).

This indicates that the perception of grief of mothers decreased remarkably after planned intervention.

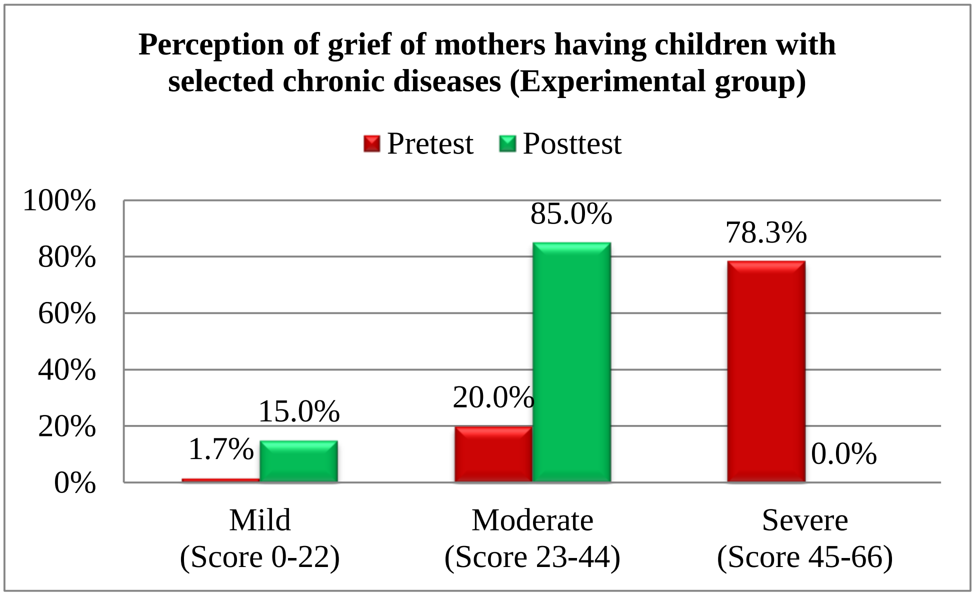


Fig. 10: Bar diagram showing the perception of mothers of children with selected chronic diseases before and after planned interventions in experimental group.

Section II (C):

Mean and standard deviation of mothers score regarding the areas of grief on RGEI, Experimental group

Table No: 4

N = 60

Scale	Pretest Mean & SD	Post test Mean & SD
Existential concerns	15.2 (2.96)	5.1 (0.81)
Depression	13.3 (2.81)	6.0 (0.97)
Guilt	11.5 (3.01)	10.4 (1.44)
Physical distress	12.3 (2.22)	6.1(0.98)

The data shows that in experimental group the pre intervention mean score of existential concern area is 15.2 with SD of 2.96, and the post intervention means score is 5.1 with SD of 0.81. The pre intervention depression mean score was 13.3 with SD of 2.81 and post intervention mean score is 6 with SD of 0.97. The pre intervention guilt mean score was 11.3 with SD of 3.01 and post intervention mean score is 10.4 with SD of 0.98. The pre intervention physical distress means score was 12.3 with SD of 2.22 and post intervention mean score is 6.1 with SD of 0.98. The findings suggest that there is major change in the area of existential concern, depression and physical distress.

Mean and standard deviation of mothers score regarding the areas of grief on RGEI, control group

Table 5: **N = 60**

Scale	Pretest Mean & SD	Post test Mean & SD
Existential Concerns	15.9 (2.16)	12.2 (1.96)
Depression	14.6 (2.81)	13.0 (1.97)
Guilt	12.1 (3.01)	11.2 (1.44)
Physical Distress	11.8 (2.22)	10.1 (1.98)

The data shows that in experimental group the pre-intervention mean score of existential concern area is 15.9 with SD of 2.16, and the post-intervention mean score is 12.2 with SD of 1.96. The pre intervention depression mean score was 14.6 with SD of 2.81 and post intervention mean score is 13 with SD of 1.97. The pre-intervention guilt mean score was 12.1 with SD of 3.01 and post-intervention mean score is 11.2with SD of 1.44. The pre-intervention physical distress mean score was 11.8 with SD of 2.22 and post-intervention mean score is 10.1 with SD of 1.98.

Section II (E):

Analysis of effectiveness of planned intervention on perception of grief of mothers of children having selected chronic diseases in Experimental group:

The effectiveness of the planned intevention was done by comparing the pretest and posttest perception of grief scores of mothers. This comparison was done using ‘Z’ test. Following table gives the summary of the ‘Z’ test results:

Table 6:

N = 60,60

	Mean	SD	Z	df	p-value
Pretest	52.3	11.0	24.3	59	0.000
Posttest	27.6	4.2			

Researcher applied ‘Z’ test for comparison of pretest and posttest perception of grief scores of mothers. The average perception of grief score in pretest was 52.3 which was reduced to 27.6 in posttest. The average perception score reduced remarkably after planned intervention in experimental group mothers. The ‘Z’ value was 24.3 at 59 degrees of freedom. The corresponding p-value was small (of order of 0.000 which is less than 0.05). Therefore, the null hypothesis was rejected. This indicates that the reduction in the perception of grief score is statistically significant. Planned intervention is proved to be significanly effective in reducing the perception of grief score.

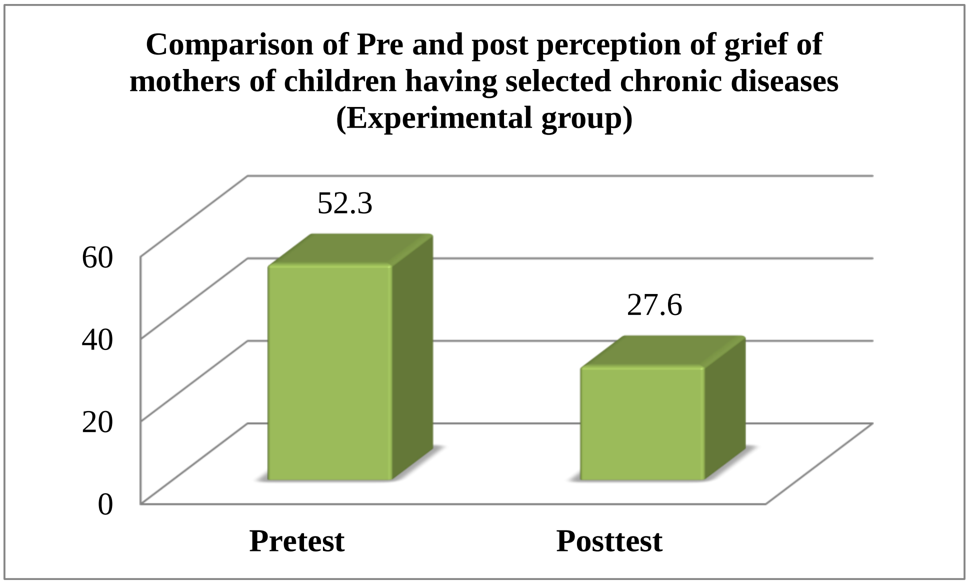


Fig.19: Bar diagram showing the comparison of pre and post perception of grief of mothers of children having selected chronic disease. (Experimental group)

Section II (F):

Analysis of comparison of the change in perception of grief of mothers in experimental and control groups:

The comparison of the change in perception of grief was done by comapring the differences between pretest and posttest perception of grief scores of mothers in experimental and control groups. This comparison was done using two sample ‘Z’ test. The following table gives the summary of the two sample ‘Z’ test:

Table 7:

N = 60,60

Group	Mean	SD	Z	df	p-value
Experimental	24.7	7.9	13.5	118	0.000
Control	7.9	5.6			

Researcher used two sample ‘Z’ test for comparing the change in perception of grief of mothers in experimental and control groups. Average change in perception of grief score for experimental group was 24.7 which was 7.9 in control group. ‘Z’ value was 13.5 at 118 degrees of freedom. Corresponding p-value was small (of the order of 0.000 which was less than 0.05). Null hypothesis is rejected. Experimental group had the significantly higher change in perception of grief of mothers as compared to that for control group mothers. Planned intervention is proved significantly effective in reducing the perception of grief.

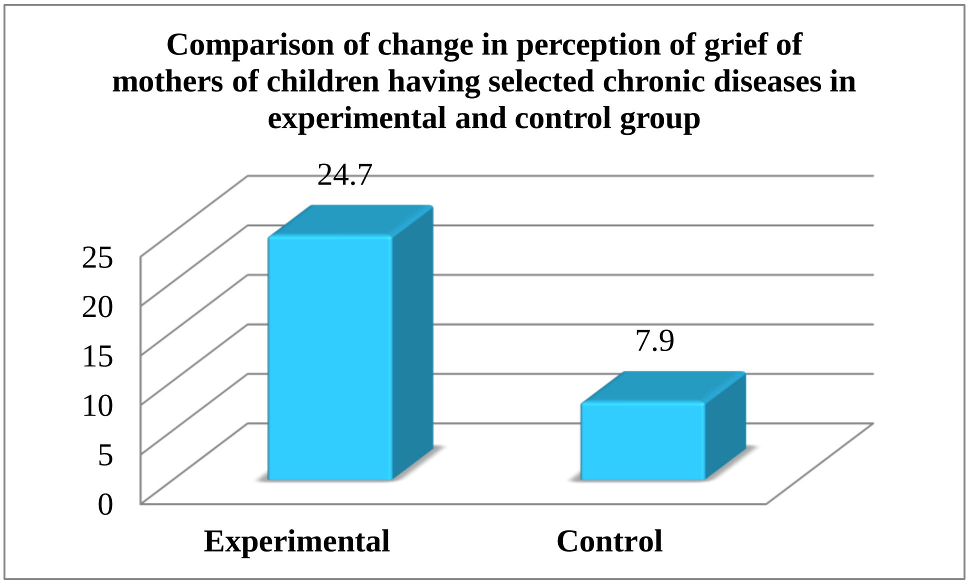


Fig.20: Bar diagram showing the comparison of change in perception of grief of mothers of children having selected chronic diseases in experimental and control group.

Section III:

The objective is to determine the coping strategies used by the mothers of children with selected chronic disease and the effect of interventions on coping strategies are presented in figures or tables.

Coping strategy scale was made consisting of 24 items, with two types of coping strategies; Problem solving and emotional strategies. The two strategies each featured 12 items. Mothers were asked to rate the strategies they had adopted to cope with the grief. The assessment of coping strategies was done on the pre intervention and post intervention days.

The frequency, percentage, mean, SD scores and the effect of intervention on coping strategies using the inferential statistics are presented in the tables and figures. Mean and SD of problem solving and emotional strategy are presented separately to see which coping strategy have been adopted more after the intervention.

Section III (A):

Analysis of data related to the coping strategies of mothers of children having selected chronic diseases in experimental and control group

Frequency and Percentage of coping strategies of mothers of children with selected chronic diseases in experimental and control group

Table 8: **N = 60, 60**

Coping	Experimental group		Control group	
	Freq	%	Freq	%
Never used the strategy	43	71.7%	11	68.3%
Sometimes used the strategy	16	26.7%	44	24.3%
Often used the strategy	1	1.7%	5	7.4%

Above table depicts, In experimental group, majority of 71.7% the mothers of children having selected chronic diseases had never used coping strategies, 26.7% of them had sometimes used coping strategies and only 1.7% of them had often used coping strategies whereas in control group, 68.3% the mothers of children having selected chronic diseases had never used coping strategies, 24.3% of them had sometimes used coping strategies and only 7.4% of them had often used coping strategies.

Section III (B):

Analysis of data related to the coping strategies of mothers of children having selected chronic diseases after planned intervention in experimental group

Frequency and percentage of coping strategies of mothers of children having selected chronic diseases after planned intervention in experimental group

Table 9: **N = 60**

Coping	Pretest		Posttest	
	Freq	**%**	**Freq**	**%**
Never used the strategy	43	71.7%	0	0.0%
Sometimes used the strategy	16	26.7%	19	31.7%
Often used the strategy	1	1.7%	41	68.3%

Above table describes, in Pretest, majority of 71.7% the mothers of children having selected chronic diseases had never used coping strategies, 26.7% of them had sometimes used coping strategies and only 1.7% of them had often used coping strategies while in posttest, majority of the mothers (68.3%) had often coping strategies and 31.7% of them had sometimes used coping strategies. This indicates that the planned intervention improved the coping strategies of the mothers remarkably.

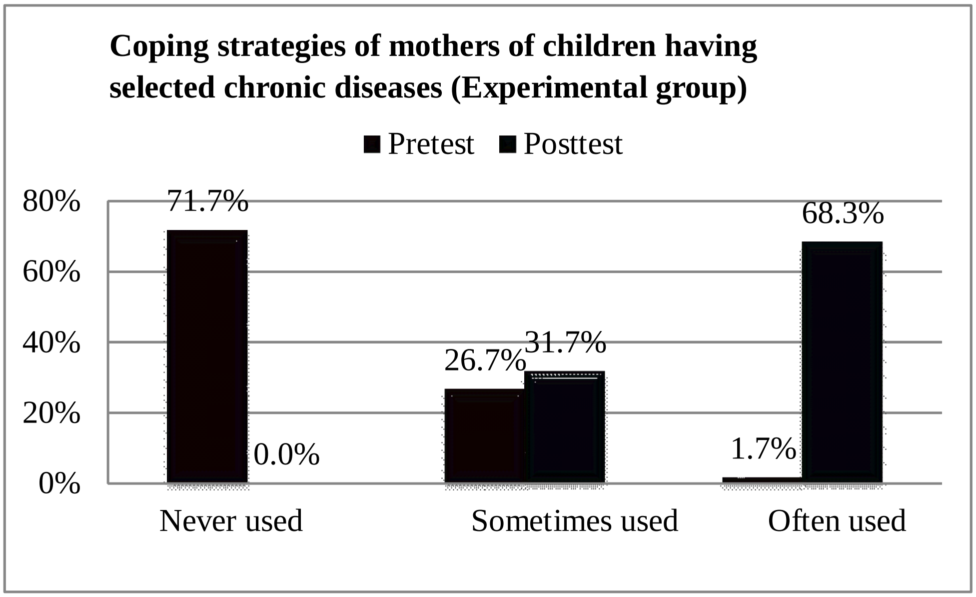


Fig.21: Bar diagram showing the coping strategies of mothers of children having selected chronic disease in experimental group

Section III (C):

Analysis of data related to problem solving and emotional solving strategy in experimental and control group

Table:10

Mean and SD of scores of coping strategies of experimental group

N = 60

Coping strategies	Mean& SD pre-intervention	Mean& SD post-intervention
Problem solving strategy	6.96 (1.98)	18.02(2.01)
Emotion strategy	6.24(1.72)	15.06 (2.1)

The data from the above table indicates that in the pre-intervention period experimental group mothers mean score of problem solving strategy is 6.96 and post-intervention, mean score is 18.02.The mean score of emotion strategy in the pre-intervention period is 6.24 and post-intervention mean score is 15.06 From the above table it is clear that before interventions mothers used problem solving and emotional startegy equally. At the post-intervention mean score of problem solving strategy is comparatively more than emotion strategy.

Table:11

Mean and SD of scores of coping strategies of control group

N = 60

Coping strategies	**Mean & SD** **pre-intervention**	**Mean & SD** **post-intervention**
Problem solving strategy	7.29 (1.85)	9.1(2.01)
Emotion strategy	6.84(1.7)	8.2 (1.98)

The data from the above table indicates that in the pre-intervention period experimental group mothers mean score of problem solving strategy is 7.29 and post-intervention, mean score is 9.1.The mean score of emotion strategy in the pre-intervention period is 6.84 and post-intervention mean score is 8.2.

Section III (D):

Analysis of effectiveness of planned intervention on coping strategies of mothers of children having selected chronic diseases in Experimental group:

The effectiveness of the planned intevention was done by comparing the pretest and posttest coping strategies scores of mothers. This comparison was done using z test. Following table gives the summary of the z test results:

Table :12

	Mean	**SD**	**Z**	**df**	**p-value**
Pretest	13.08	6.4	20.1	59	0.000
Posttest	34	4.0			

Researcher applied paired 'Z' test for comparison of pretest and posttest coping strategies scores of mothers. The average coping score in pretest was 13.8 which was increased to 34 in posttest. The average coping score increased remarkably after planned intervention in experimental group mothers. The 'Z' value was 20.1 at 59 degrees of freedom The corresponding p-value was small (of order of 0.000 which is less than 0.05). Therefore, the null hypothesis was rejected. This indicates that the increase in the coping score is statistically significant. Planned intervention is proved to be significanly effective in improving the coping strategies.

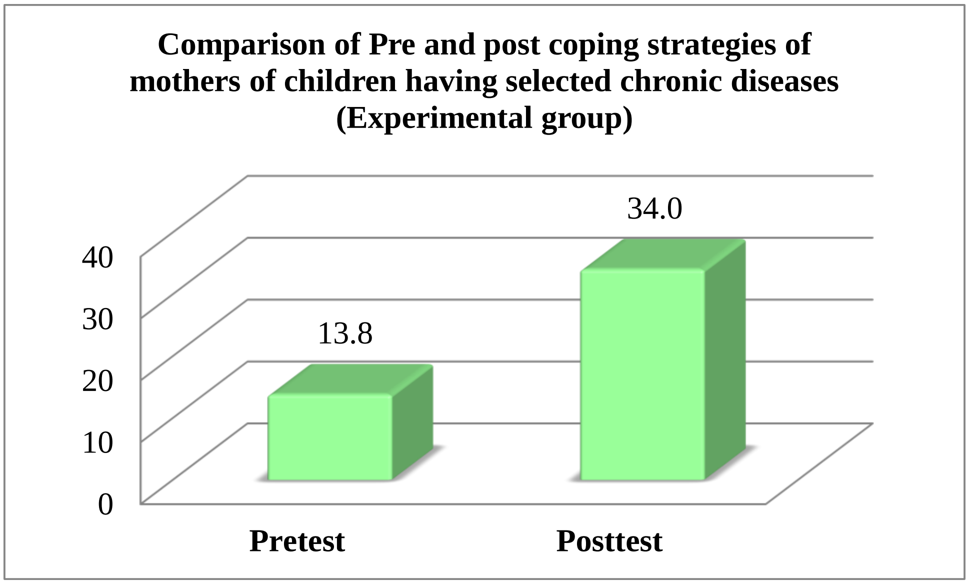


Fig.22: Bar diagram showing the comparison of pre and post coping strategies of mothers of children having selected chronic diseases in experimental group.

Section III (E):

Two sample ‘Z’ test for comparison of the change in coping strategies of mothers in experimental and control groups:

The comparison of the change in coping strategies was done by comapring the differences between pretest and posttest coping scores of mothers in experimental and control group. This comparison was done using two sample ‘Z’ test. The following table gives the summary of the two sample ‘Z’ test:

Table 13

	Mean	**SD**	**z**	**df**	**p-value**
Experimental	20.2	7.8	15.6	118	0.000
Control	3.7	5.1			

Researcher used two sample ‘Z’ test for comparing the change in coping strategies of mothers in experimental and control groups. Average change in coping score for experimental group was 20.2 which was 3.7 in control group. ‘Z’ value was 15.6 at 118 degrees of freedom. Corresponding p-value was small (of the order of 0.000 which was less than 0.05). Null hypothesis is rejected. Experimental group had the significantly higher change in coping scores of mothers as compared to that for control group mothers. Planned intervention is proved significantly effective in improving the coping strategies of the mothers of children having selected chronic diseases.

In general mothers of children with selected chronic diseases have been found to use a combination of problem focused and emotion focused coping strategies. Walker (1999) studied the effect of relaxation training and imagery v/s standardized care on 96 women with newly diagnosed breast cancer. The women were grouped in to experimental and a control group. He found that patient in the experimental group with relaxation therapy and imagery interventions were more relaxed, had a good coping strategy and a better quality of life[98].

Dr. Meena Ganpati (2006) studied the effect of selected bio behavioral interventions on stress and coping responses of adult hospitalized patients. The patents were divided in to three experimental groups and one control group. She found that combined interventions (Progressive muscle relaxation and breathing technique) are more effective in improving coping strategies.[93]

From the above studies and findings, it may be stated that planned interventions are more effective in improving coping strategies.

Section IV:

Analysis of correlation of perception of grief and coping strategies with selected demographic variables.

The sixth objective of the research is to find out the correlation between the above mentioned dependent variables with selected demographic variables, which includes number of children, diagnosis, duration of illness, age of the child, gender of the child and occupation of mother. The association between perception of grief and demographic variables assessment was done using Fisher's exact test. The findings are presented in the tables and figures.

Section IV (A):

An analysis of data related to association of perception of grief and demographic variables of mothers

The association between perception of grief and demographic variables assessment was done using Fisher's exact test. The summary of the results of Fisher's exact test are tabulated below:

Table 14: N = 120

Demographic variable	Perception			p-value
	Mild	Moderate	Severe	
Number of children				
One	0	4	19	0.283
Two	0	13	51	
Three	1	4	20	
More than three	1	2	5	
Diagnosis of the child				
Thalassemia	2	19	39	0.000
Leukemia	0	4	56	
Duration of illness				
0-1year	1	8	54	0.013
1-3years	0	9	30	
3-5years	1	6	11	
Age of the child				
0-3 years	0	12	30	0.189
4-8 years	2	7	53	
8-12 years	0	3	10	
12-15 years	0	1	2	
Gender				
Male	0	18	50	0.014
Female	2	5	45	

Occupation of mother				
Non-working mother (House wife)	0	19	72	0.125
Laborer	1	2	13	
Service	1	2	10	

p-values corresponding to demographic variables diagnosis, duration of illness and gender were less than 0.05. The null hypothesis is rejected. Diagnosis, duration of illness and gender are the demographic variables which were found to have significant association with perception of grief.

Mothers of the children who are being diagnosed for leukemia were found to have higher perception of grief scores as compared to those who are diagnosed for Thallassemia. Duration of illness are also found to have significant association with perception of grief. It has been found that perception of grief is more with in one year after diagnosis. It has been found that gender is also associated with perception of grief. Mothers of the male child were found to have severe perception of grief as compared to those those with female child.

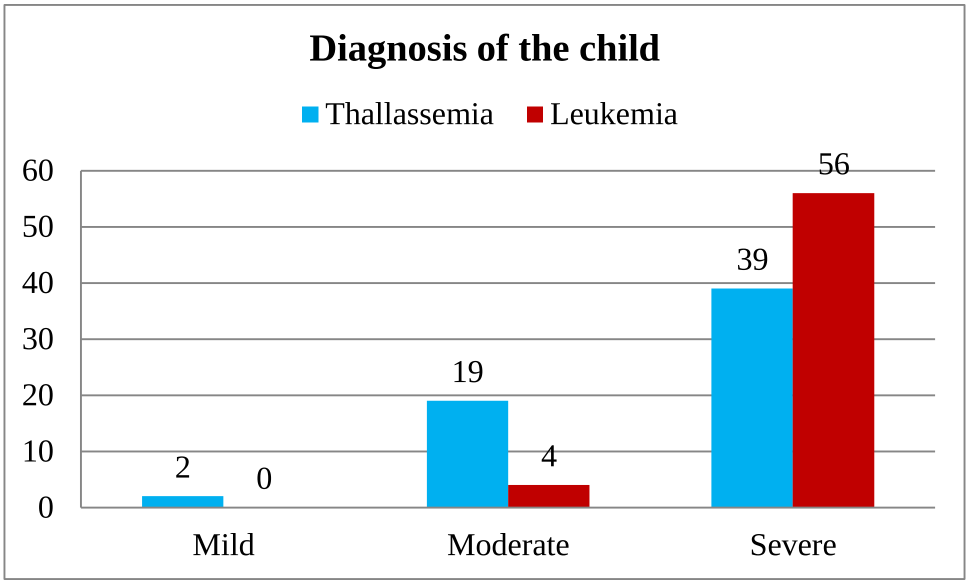


Fig.23: Bar diagram showing the average perception score Vs Diagnosis

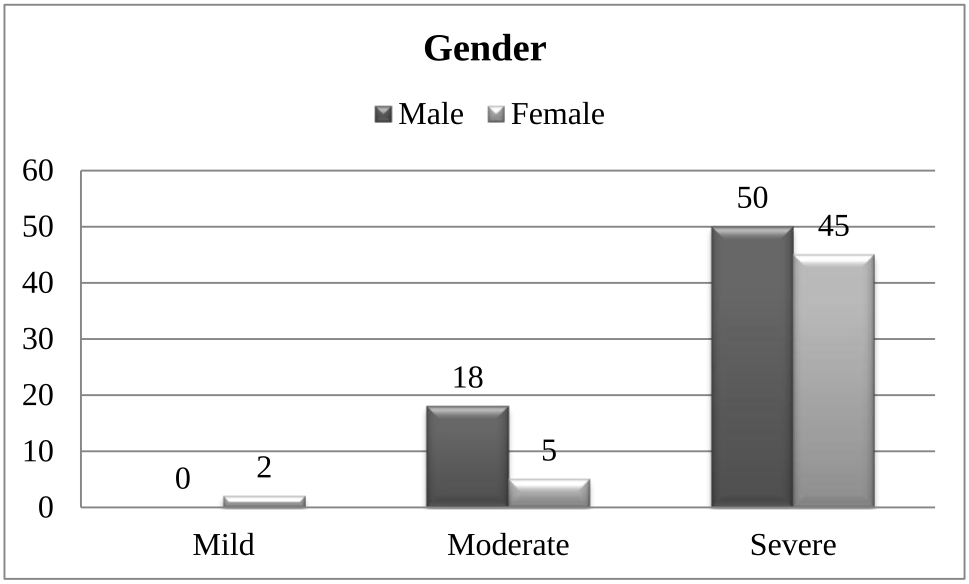


Fig.24: Bar diagram showing the average perception score Vs gender.

Section IV (B):

An analysis of data related to association of coping strategies and demographic variables of mothers

The association between coping strategies and demographic variables assessment was done using Fisher's exact test. The summary of the results of Fisher's exact test are tabulated below:

Demographic variable	Coping strategies			p-value
	Never used	Sometimes used	Often used	
Number of children				
One	11	10	2	0.309
Two	27	36	1	
Three	13	10	2	
More than three	4	3	1	
Diagnosis of the child				
Thalassemia	28	29	3	1.000
Leukemia	27	30	3	
Duration of illness				
0-1year	39	21	3	0.041
1-3years	10	28	1	
3-5years	6	10	2	
Age of the child				
0-3 years	19	21	2	0.441
4-8 years	32	26	4	
8-12years	3	10	0	
12-15 years	1	2	0	
Gender				
Male	30	36	2	0.397
Female	25	23	4	
Occupation of mother				
Non-working mother (House wife)	39	48	4	0.550
Laborer	9	6	1	
Service	7	5	1	

p-values corresponding to demographic variables, duration of illness was small. The null hypothesis is rejected. Duration of illness are the demographic variables which were found to have significant association with coping strategies. F Hashemi , S Razavil done a study to assess the coping strategies used by the parents of children with cancer. A total of 72 parents including 28 couples, 8 single mothers and 8 single fathers were participated in the study. They found that there is significant relation between duration of illness of their child and coping strategies. As the days passess parents have improvement in the coping strategies.

In the present research also it can be interpreted that there is significant correlation between duration of illness and coping startegies. Coping strategies were poor within one year after diagnosis. As the year passes mothers have good coping strategies.

Section V:

The fifth objective of the research is to assess the opinion of mothers regarding the planned intervention in the experimental group. At the end of interventions the subjects were asked to fill the opinnionnare. Separate opinnionnare is given for relaxation therapy and information booklet. This was analyzed using descriptive statistics.

PART IV

OPINION REGARDING THE INFORMATION BOOKLET ON LEUKEMIA AND THALLASSEMIA

Table no: 16 **N = 60**

Sl. No.	CRITERIA	STRONGLY AGREE		AGREE		NEITHER AGREE OR DISAGREE		DISAGREE		STRONGLY DISAGREE	
		Frequency	%	Frequency	%	Frequency	%	Frequency	%	Frequency	%
1	**Content**										
1.1	Appropriate	40	67%	20	33%	---	----	----	----	----	----
1.2	Adequate	39	65%	20	33%	01	2%	----	----	----	----
1.3	Useful	42	70%	17	28%	01	2%	----	----	----	----
1.4	Comprehensive	31	52%	28	46%	01	2%	----	----	----	----
2	**Language**										
2.1	Clear	38	63%	22	37%	----	-----	----	----	----	----
2.2	Accurate	34	57%	26	43%	----		----	----	----	----
2.3	Easy to understand	35	58%	25	42%	----		----	----	----	----
3	**Presentation**										
3.1	Simple	33	55%	26	43%	01	2%	----	----	----	----
3.2	Informative	28	47%	32	53%	----	----	----	----	----	----
3.3	Attractive	41	68%	18	30%	01	2%	----	----	----	----
3.4	Interesting	41	68%	19	32%	----	----	----	----	----	----

PART IV

OPINION REGARDING RELAXATION THERAPY

Table no: 17 **N = 60**

Sl. No.	CRITERIA	STRONGLY AGREE		AGREE		NEITHER AGREE OR DISAGREE		DISAGREE		STRONGLY DISAGREE	
		Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**	**Frequency**	**%**	**Frequency**	**%**
01	Relaxation therapy should be given to all the mothers whose children suffering from leukemia or thallassemia	51	85%	09	15%	----	----	----	----	----	----
02	Relaxation therapy will help to reduce the grief and ale to cope up with the situation	45	75%	14	23%	01	2%	----	----	----	----
03	Relaxation therapy enhances the positive thinking.	37	62%	23	38%	----	----	----	----	----	----
04	Extra time is required to do the relaxation therapy.	06	10%	13	22%	05	8%	34	57%	02	3%
05	According to me everyone should learn relaxation therapy.	50	83%	10	17%	----	----	----	----	----	-----
06	By this therapy person get self satisfaction	33	55%	23	38%	----	----	04	07%	----	----

SN	Content	Good		Better		Best	
		Frequency	**%**	**Frequency**	**%**	**Frequency**	**%**
07	Overall what is your opinion regarding relaxation therapy	04	07%	06	10%	50	83%

Opininon of mothers regarding planned intervention was obtained at the end of intervention by opinionnare. Regarding information booklet 70 % of the mothers strongly agreed that it was useful 65% strongly agreed that the content was adequte and appropriate,regarding the language 63% strongly agreed that it is clear 58 % strongly agreed that accurate and easy to understand. Regarding the presentation of information booklet 55% strongly agreed that it is simple and 47% strongly agreed that it is informative 68% strongly reported that it is attractive and interesting.

Regarding the relaxation therapy, 85% of the mothers strongly felt that Relaxation therapy should be given to all the mothers whose children suffering from leukemia or thallassemia. 75% of the mothers strongly agreed that Relaxation therapy will help to reduce the grief and able to cope up with the situation. 62% of the mothers reported that it will help to enhance the positive thinking. 83% strongly agrees that everyone should learn the relaxation therapy. 55 % strongly agrees that it will helps to increases the self satisfaction. 57% disagree in the statement of extra time required to do the relaxation therapy. Overall 83% of the mothers reported that relaxation therapy is a best method to decrease the grief and increase the coping strategies. The mothers also reported that they experienced a sense of relaxation, enjoyed good sleep and experienced reduced grief because of the intervention.

CHAPTER V

SUMMARY, MAJOR FINDINGS OF THE STUDY, DISCUSSION, CONCLUSION, IMPLICATIONS, LIMITATIONS AND RECOMMENDATIONS

This chapter contains a summary findings of the study, discussion, conclusion, implications to nursing, limitations and recommendations for future study.

SUMMARY:

The purpose of the present study is to find out the effect of planned intervention on the grief and coping strategies of mothers of children with selected chronic diseases admitted in selected hospitals of Pune City.

The objectives of the present study are thus following:

- 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 assess the perception of grief and coping strategies of mothers of children with selected chronic diseass in control group
- To correlate the findings with selected demographic variables.
- To assess the opinion of mothers regarding planned intervention.

HYPOTHESIS:

- H_{01} – 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.
- H_{02} – 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.
- H_1 – 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.
- H_2 – 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.

SCOPE OF THE STUDY:

This study highlights simple relaxation therapy and information booklet and their effects to

1) Provide scientific knowledge to the field of Nursing.

2) Provide independent nursing diagnosis and intervention.
3) Provide a new pathway for future researchers in to independent nursing interventions on different medical conditions.
4) Give a sense of satisfaction to nurses in providing care to their patents and care takers.

ASSUMPTIONS:

The study was based on the following assumptions:

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

VARIABLES UNDER STUDY:

The planned interventions and back ground variables were considered as independent variables. The perceived grief and coping strategies were considered as dependant variables.

Purpose of the study:

Nurses spend a large amount of time taking care of patients. Giving information regarding how to take care of the child and bio behavioral interventions such as relaxation therapy are inexpensive, feasible and can be easily thought by nurses to the mothers of children who have chronic illness. These interventions may provide a sense of inner self control that will help patients and care takers to cope with the grief experience because of their child’s disease condition.

Methodology:

The study has made the use of quasi experimental design. The study was conducted in four settings. The sample consisted of 120 mothers of children suffering from leukemia or thallassemia were taking treatment from the selected four setting during the data collection period, and those who fitted the sampling criteria.

Data collection Instruments:

The researcher prepared data collection instruments, including Demographic variable Performa, Grief assessment scale, coping strategy scale, and opinion scale. Validity and reliability has done before using the instrument for data collection. Data collection was done from March 2013 to November 2013.

Both descriptive and inferential statistics were used for data analysis. Frequency and percentage were calculated for describing demographic variables, level of grief coping strategies used and opinion regarding planned intervention. Mean and SD were calculated in the area of coping strategies. The data was analyzed using ‘Z’ test and two sample ‘Z’ test. Fisher’s exact test was used to find out the association between the grief and coping strategies reported with selected demographic variables.

Major findings of the study:

Demographic variables:

It was observed that there was almost equal distribution in number of children, diagnosis, duration after diagnosis, age of the child, gender of the child and occupation of the mother in experimental and control group.

The finding suggests that 50% of the mothers have two children in the experimental group and 56.7% of the mothers have two children in the control group. 50% of the children diagnosed with leukemia and another 50% of the children diagnosed with Thallassemia in experimental and control group. 48.3% of the children in the experimental group, duration of illness were 0-1 year and 40 % of the children in the control group duration of illness were 0-1 year.

It was observed that 58.3% children were in the range of 4-8 years in experimental group and 45% of children were in the range of 4-8 years in the control group. Regarding the gender of the child 56.7% were male child in experimental group and control group. 75 % percentage of the mothers in experimental group was non-working mothers (House wife) and 76.7 of the mothers in control group were non working mothers (House wife).

Perception of grief of mothers of children with selected chronic disease:

The overall grief, its subscale and effect of interventions on grief were computed using frequency, percentage, mean, SD, ‘Z’ value and two sample ‘Z’ value. The pre intervention grief score revealed that 80% of the mothers of children with selected chronic disease were having severe grief. After the intervention 85% of the mothers were in moderate grief and no one was there in the severe grief. This finding clearly indicates that intervention resulted in significant reduction in the intensity of grief. Exposure to a grief over a period of time will reduce its impact on the subject. It was observed that grief did reduce for the control group even without any interventions. However they reduced even more significantly for the experimental group with interventions. This indicates that interventions added to the reduction of stressors.

The grief experience inventory was consisting of four subscales, i.e. Existential concern, tension and guilt, depression and physical distress. Analysis was done separately to find out which area of grief is used by the mothers of children with selected chronic diseases. The frequency and percentage were calculated on the four areas of grief. Findings of the study shows that in experimental group the pre-intervention mean score of existential concern area is 15.2 with SD of 2.96, and the post-intervention mean score is 5.1 with SD of 0.81. The pre-intervention depression mean score was 13.3 with SD of 2.81 and post-intervention mean score was 6 with SD of 0.97. The pre-intervention guilt mean score was 11.3 with SD of 3.01 and post-intervention mean score was 10.4 with

SD of 0.98. The pre-intervention physical distress means score was 12.3 with SD of 2.22 and post-intervention mean score was 6.1 with SD of 0.98.

The data shows that in control group the pre-intervention mean score of existential concern area was 15.9 with SD of 2.16, and the post-intervention mean score was 12.2 with SD of 1.96. The pre-intervention depression mean score was 14.6 with SD of 2.81 and post-intervention mean score was 13 with SD of 1.97. The pre-intervention guilt mean score was 12.1 with SD of 3.01 and post-intervention mean score was 11.2with SD of 1.44. The pre-intervention physical distress mean score was 11.8 with SD of 2.22 and post-intervention mean score was 10.1 with SD of 1.98.

The findings suggest that there was major change in the area of existential concern, depression and physical distress.

‘Z’ test is used for comparison of pretest and posttest perception of grief scores of mothers. The average perception of grief score in pretest was 52.3 which was reduced to 27.6 in posttest. The average perception score reduced remarkably after planned intervention in experimental group mothers. The ‘Z’ value was 24.3 at 59 degrees of freedom The corresponding p-value was small (of order of 0.000 which is less than 0.05). Therefore, the null hypothesis was rejected. This indicates that the reduction in the perception of grief score is statistically significant. Planned intervention was proved to be significanly effective in reducing the perception of grief score.

The two sample ‘Z’ test was used for comparing the change in perception of grief of mothers in experimental and control groups. Average change in perception of grief score for experimental group was 24.7 which was 7.9 in control group. ‘Z’ value was 13.5 at 118 degrees of freedom. Corresponding p-value was small (of the order of 0.000 which was less than 0.05). Null hypothesis is rejected. Experimental group had the significantly higher change in perception of grief of mothers as compared to that for control group mothers. Planned intervention is proved significantly effective in reducing the perception of grief.

Coping strategies of mothers of children with selected chronic diseases:

The coping strategies and the effect of planned interventions of experimental group were computed by using frequency , percentage, mean, standard deviation, ‘Z’ test and two sample ‘Z’ test. In the pre intervention period, 71.7% of the samples never used any of the coping strategies but after post intervention the score which changed into 68.3% of them have often used coping strategy. This finding clearly indicates that intervention resulted in significant improvement in the coping strategies of mothers of children with selected chronic diseases.

In this research, the mothers used problem solving and emotional coping strategy equally. After the intervention a slight increase in the problem solving area of coping strategy occurred in the experimental group.

‘Z’ test was used for comparison of pretest and posttest coping strategies scores of mothers. The average coping score in pretest was 13.8 which was increased to 34 in posttest. The average coping score increased remarkably after planned intervention in experimental group mothers. The ‘Z’ value was 20.1 at 59 degrees of freedom The corresponding p-value was small (of order of 0.000 which is less than 0.05). Therefore, the null hypothesis was rejected. This indicates that the increase in the coping score is statistically significant. Planned intervention is proved to be significanly effective in improving the coping strategies.

The two sample ‘Z’ test was used for comparing the change in coping strategies of mothers in experimental and control groups. Average change in coping score for experimental group was 20.2 which was 3.7 in control group. ‘Z’ value was 15.6 at 118 degrees of freedom. Corresponding p-value was small (of the order of 0.000 which was less than 0.05). Null hypothesis is rejected. Experimental group had the significantly higher change in coping scores of mothers as compared to that for control group mothers. Planned intervention is proved significantly effective in improving the coping strategies of the mothers of children having selected chronic diseases.

Correlation between dependant and demographic variables:

Demographic variables like number of children, diagnosis, duration of illness, age of the child, gender of the child, and occupation of mothers were co-related with dependant variables such as perception of grief and coping strategies reported and observed at 0.05 level. The co-relations were computed using Fisher’s exact test.

It was found that diagnosis, duration of illness and gender were corelated with perception of grief. Diagnosis duration of illness and gender are the demographic variables which were found to have significant association with perception of grief as p-values corresponding to demographic variables ofdiagnosis (0.000) duration of illness (0.013) and gender (0.014) were small.

Mothers of the children who are being diagnosed for leukemia were found to have higher perception of grief scores as compared to those who are diagnosed for Thallassemia. Duration of illness are also found to have significant association with perception of grief. It has been found that perception of grief is more with in one year after diagnosis. It has been found that gender is also associated with perception of grief. Mothers of the male child were found to have severe perception of grief as compared to those those with female child.

Duration of illness are the demographic variables which were found to have significant association with coping strategies as p-values corresponding to demographic variable duration of illness (0.041) were small. Coping strategies were poor in the one year after diagnosis.

Opinion of mothers regarding planned intervention:

Opininon of mothers regarding planned intervention was obtained at the end of intervention by opinionnare. Regarding information booklet 70 % of the mothers strongly agreed that it was useful 65% strongly agreed that the content was adequte and appropriate,regarding the language 63% strongly agreed that it is clear 58 % strongly agreed that accurate and easy to understand. Regarding the presentation of information booklet 55% strongly agreed that it is simple and 47% strongly agreed that it is informative 68% strongly reported that it is attractive and interesting.

Regarding the relaxation therapy 85% of the mothers strongly felt that Relaxation therapy should be given to all the mothers whose children suffering from leukemia or thallassemia. 75% of the mothers strongly agreed that Relaxation therapy will help to reduce the grief and able to cope up with the situation. 62% of the mothers reported that it will help to enhance the positive thinking. 83% strongly agrees that everyone should learn the relaxation therapy. 55 % strongly agrees that it will help to increases the self satisfaction. 57% disagree in the statement of extra time required to do the relaxation therapy. Overall 53% of the mothers reported that relaxation therapy is a best method to decrease the grief and increase the coping strategies. The mothers also reported that they experienced a sense of relaxation, enjoyed good sleep and experienced reduced grief because of the intervention.

Discussion:

The result of this study confirmed the presence of grief in mothers of children with leukemia or thallassemia. These findings are in agreement with prior studies such as that by Quttener et al (1998) who identified the presence of grief in parents of children with leukemia. Also by J E M Betman (2006) who found the presence of grief in mothers of children with cystic fibrosis.[6,93]

These findings have important implications for parents, researchers and health care professionals. Validating the presence of grief in mothers and acknowledging that grief is a natural response to such a diagnosis would appear to be important, in that it would put mothers and fathers in a better position to understand and address their feelings. It may also assist in enhancing the predictability of one's' behavior which would in turn help in reducing any fears that one will lose control. Similarly, ensuring that medical practitioners are aware of this loss and its impact would also appear important, in that not only would give them a greater understanding of what mothers experience, it would encourage greater empathy. This in turn would put them in a better position to provide the support and help needed.

Such thinking is supported in the literature with Worthington (2001) suggesting that caring may be closest the medical team can come to curing in regards to many of the difficulties associated with chronic-illness. That is when a condition cannot be cured, one's ability to help parents through the difficult times is the type of healing that may be most helpful, with there being a great deal that can be done to improve the psychological and social consequences of a condition that will, in turn, assist parents as they continue to live and work though the more difficult stages of reoccurring grief [94].

The result of the study shows that interventions can reduce the grief and coping strategies. Kennedy (2004) studied the effect of relaxation exercise including meditative breathing on anxiety levels of mothers whose children with cerebral palsy. A convenience sample of 39 subjects was studied. Anxiety levels were measured prior to and post interventions with the State Trait anxiety inventory. Progressive muscle relaxation, Jackobson relaxation technique, guided imagery and soft music was employed to promote relaxation for one month. A significant reduction in anxiety level was obtained on the post test.[99]

The above findings support the findings of the present study, which indicates that perception of grief and coping strategies can be reduced over a period of one month.

Implications also arise in the area of simply acknowledging this loss, with Kennedy (1970, cited in Fortier & Wanlass 1984) noting that although an individual may be aware of their grief, they may hide their feelings due to the lack of understanding they feel from the environment. Studies such as this one, which highlights the presence of grief, would therefore seem important in helping to increase understanding in society which could in turn make it easier for individuals to feel their pain rather than feeling that they have to hide it.[34]

The role of parenting a child with chronic illness has been examined in many studies using both quantitative and qualitative methods. Based on these findings, the clinical nurse can be proactive to provide support systems for families, respect their full range of emotions, and prepare to work with them as team members in the management of their child's care. Special emphasis must be placed on the mother because she is identified as the one who "carries the burden of care for the child with chronic illness." [38]

Mothers of children with leukemia and thallassemia use both problem solving and emotional coping strategies. The result revealed that giving information and relaxation technique will help to improve the coping strategies. Stroebe & Schut (1996) found that bio-behavioral interventions like guided imagery, progressive muscle relaxation, and breathing exercise will help to improve the coping strategies of caretakers of mentally retarded child. Information seeking also seems an important coping strategy for parents [100]. Levers and Drotar (2000) noting that studies have identified mothers desire more information about thallassemia. Interestingly these information parents were after here was not just that concerning various aspects of the disease, such as progression, diet, physical care, and physical development but also information about how to raise Thalassemia children in general, the emotional and social development of these children, what to do when they become ill. With this Levers and Drotar also noted that in receiving information mothers wanted a positive hopeful emphasis from their health care provider[101].

In all findings cited above and the present study suggest that mothers of children with leukemia and Thalassemia make use of wide range of coping strategies. Planned intervention is effective to improve the coping strategies.

The diagnosis, duration of illness and gender are correlated with the perception of grief. The result revealed that the mothers of children with leukemia are having more grief than the mothers of children with Thalassemia. This may be because of the fear of word cancer or perceiving the concept that cancer is not curable. Oathman (2009) found in his study that parents are having more severe grief and coping problem with in one year after diagnosis[102]. Later on they will try to sdjust with the situation.Nusrat ara (2012) stated in her article that preference for a male child is a known fact in India.The family need son to carry on their name[103]. Rakhi adhiti Ghosh (2012) found that mothers too turn away from girl child.The report shows that 22.4% of women look forward to have sons' rather than daughters as against 20% of men in India wanting a male child [102].

With the above reference and the findings of the present study shows that mothers are having severe grief with one year after diagnosis and grief because of loss of male child will be more rather than a female child.

Duration of illness is also correlated with coping strategies. Perception of grief is more within one year after diagnosis and coping strategies are poor within one year after diagnosis. Exposure to a stressor over a period of time will reduce its impact on the subject.

When the mother's opinion about planned intervention (relaxation therapy & information booklet) was asked, none of the mothers denied the positive effect of relaxation therapy and information booklet. They all accepted that every mother should learn relaxation therapy. It was observed by the investigator that all mothers took active part in doing relaxation therapy and shown interest to read the information booklet.

Findings of the study indicate that planned intervention helps to decrease the grief and improve the coping strategies of mothers of children with selected chronic diseases.

Conclusion:

The conclusion drawn from the findings of the study are as follows:

Mothers of children with leukemia and thalassemia experience severe grief. Higher levels of grief are observed in all four areas of grief. The 't' test and 'Z' test is used to find out the effect of planned intervention on perception of grief and coping strategies at 0.000 level of significance. The result revealed that there is a significant reduction in the grief in the experimental group at 0.000 level. Hence the null hypothesis is rejected and alternate hypothesis is accepted.

Mothers of children with leukemia and thalassemia have never used coping strategies. Mothers have used both problem solving and emotional coping strategy equally before intervention. After the intervention slight increase in the problem-solving coping strategy is noted. The ‘t’ test, and ‘Z’ test is used to find out the effect of planned intervention on coping strategies at 0.000 level of significance. The result revealed that there is a significant reduction in the grief in the experimental group at 0.000 level. Hence the null hypothesis is rejected and alternate hypothesis is accepted.

The correlation findings was done using Fisher’s exact test to find out the association between demographic variables and perception of grief and coping strategies at 0.5 level of significance. The result revealed that significant correlation with diagnosis, duration of illness and gender with perception of grief. The average perception score of leukemia is more than the thallaseemia. Duration of illness are also found to have significant association with perception of grief and coping strategies. It has been found that perception of grief is more with in one year after diagnosis and coping stareties are poor with in one year after diagnosis.The study also revealed that gender is also associated with perception of grief. Mothers of the male child were found to have severe perception of grief as compared to those those with female child.

From this reaserch, it is very clear that planned interventions (Relaxation therapy and information booklet) reduce the grief and improve the coping strategies of mothers of children with leukemia and thalassemia.

Implications:

The findings of the study have implications for nursing practice, nursing education, nursing administration and nursing research.

Nursing practice:

The results of the study are highly significant to nursing practice because it provides a detailed description of the grief and the subscales of grief of mothers of children with leukemia or thallassemia. The information will help the nurses and nurse administrators to understand this grief and take measures to prevent those can be prevented.

The coping strategies vary from person to person. This highlights the fact that each person needs individual attention. Nurses can help the patient and care takers to improve their coping strategies by discussing the strength and weakness of the adopted strategies.

Validating the presence of grief in mothers and acknowledging that grief is a natural response to such a diagnosis would appear to be important, in that it would put mothers and fathers in a better position to understand and address their feelings. It may also assist in enhancing the predictability of one's' behavior which would in turn help in reducing any fears that one will loss control. Similarly, ensuring that medical practitioners are aware of this loss and its impact would also appear important, in that not only would give them a greater understanding of what mothers experience, it would encourage greater empathy. This in turn would put them in a better position to provide the support and help needed.

These findings will be very useful to nursing practice because nurses can give information regarding the disease condition and more over how to take care of the child at home. She can encourage the mothers to ask doubts and clarify those doubts. She can teach the relaxation therapy to the care takers of chronically ill children to reduce the grief and stress related to their child's disease condition and hospitalization. Nurses are with the patient at all the time. So the children and the caretakers feel comfortable enough with nurses to express enquire about and clarify doubts regarding their experiences. The intervention like relaxation therapy may provide a sense of inner control that will help the children and care takers to cope with grief they experience because of the disease condition.

Another striking finding which has implication for health care and nursing is opinion of mothers regarding planned intervention. Most of them expressed a strong agreement regarding planned intervention .So it is nurse's responsibility to assess the grief and coping strategies and provide effective intervention.

Nursing Education:

The nursing curriculum should include the learning experiences for the students to assess, plan, implement and evaluate nursing intervention based on the felt needs of the mothers of children with chronic diseases. Also should include learning experience in developing and testing self-learning materials, teaching modules, and programmed instructions for teaching mothers regarding care of the chronically ill child at home.

Nursing education across the world is progressing very rapidly. A significant amount of nursing and other research have been conducted on the effect of various alternative therapies on different conditions. While all these are specialty areas, a student nurse learns her clinical skills in a general set up. Hence these research findings will be very useful to nursing education- not only by adding to the theoretical base, but also to help teach nursing students simple complimentary interventions.

Nursing administration:

Nursing administration is the vital force in hospital administration. The findings of the research will help nurse administrators to conduct ongoing or in-service education on simple interventions to minimize the grief in self, subordinates and to the patient and care takers.

Research findings like these are of immense help to nursing administrations who can use them to prove to policy makers the role of nurses in reducing grief and coping strategies. The nurse administrator may conduct periodical in-service education on use of alternative therapies and information booklet to reduce the grief and coping strategies of mothers of children with chronic diseases.

Nursing research:

Health care environment today is dynamic and more demanding, there is a need to promote research based practice and the use of evaluated methods to measure and document the quality and cost effective care.

Results of the present study can encourage the nursing personnel to utilize the intervention in providing care to children with selected chronic diseases. More nursing research should be conducted on the effect of alternative therapies in various hospital settings and in various diseases condition.

Limitations:

1. The study was confined to purposive sample of mothers were able to communicate in Marathi or English which limits the generalization.
2. The study findings are limited to the selected hospitals and the study data were limited to the verbal responses of mothers. No observations were made.
3. The researcher did not have any control over the hospital treatments.

Recommendations:

On the basis of the findings of the study it is recommended that:

1. Similar studies can be conducted to assess the perception of grief of mothers and fathers separately.

2. Similar studies can be conducted to using other types of bio behavioural interventions such as progressive muscle relaxation, guided imagery, music therapy etc.
3. An explorative and detailed descriptive study may be undertaken to assess the coping strategies of care takers of chronically ill children
4. A qualitative study can be conducted to assess the perception of grief of mothers of children with selected chronic diseases.
5. The present study can be done with mothers of children with other chronic disease also.
6. A study can be conducted on effectiveness of planned interventions on different stages of grief of mothers of children with chronic illness.
7. A study can be conducted on effect of child's improvement on mothers health.

Summary:

The chapter contained a summary of the findings, discussion, conclusions, implications, limitation and recommendations for future research.

REFERENCES:

1. Best M, Streisand R, & Kazak A E (2001) “parental distress during pediatric leukemia and post traumatic stress symptoms after treatment ends”. Journal of pediatric psychology, 26(5), 299-307.
2. Cincolta N (1993) “Psychological issues in the world of children with cancer” Journal of pediatric Cancer, 71 (10), 3251-3260.
3. Hobfoll, Feedy & Solomen (2006) Parental stress when their child is diagnosed with chronic illness”, Journal of pediatrics, 145(3), 373-379
4. JEM Betman (2006), “Parental grief when a child is diagnosed with a life threatening chronic illness” Journal of Pediatric Psychology 18 (3) ,365-376 .
5. Berk. L E (2001) Development through the life span, Botson, London, Toronto, Allyan and Bacco 232-240

6. JASCAP, Child hood acute lymhocytic leukemia, Leukemia and lymphoma research, beating blood cancers, Booklet by Jeet Association for support to cancer patients, Mumbai, India.
7. Muhammad Shah, (2012) Beta thalassaemia major- a public health problem in Asia, Impacts, and coping strategies. Journal of public health, 12 (1), 22-24
8. Annika Lindhahl Norberg (2004) "Stress and coping in parents of children with cancer", European journal of cancer 33 (8), 1250-1255
9. Gallagher - Thompson (2007) Helping the people to learn relaxation therapy, Journal of psychology, 24(1)
10. Raphoal et al (2003) psychosocial consequences of parents of children with Thalassemia and its management, Journal of pediatric psychology 20 (5), 567-587
11. Wiedebusch, Silva (2010) Health related quality of life, psychosocial strains and coping in parents of children with chronic renal failure. Pediatric Nephrology 25 (8) 1477
12. Copeland L G & Clement D B (2003) Parental perceptions and support strategies in caring for a child with chronic condition. Issues in Comprehensive pediatric Nursing,16, 109-121
13. Saunders (2000) symtomatology and management of acute grief. American Journal of Psychiatry, 23 , 141-148.
14. Tatelbaum (2000) Welcome to Holland , In Cystic fibrosis news September 2005, Cystic fibrosis association of New Zealand.

15. Shrley. A. Hill. Cognitive Coping Strategies among Mothers of Children with Thalassemia. Wings Of Gause Wayne State University Press Publishers; 79-89
16. Akbar Hussain and Ipshita Juyal. Stress Appraisal and Coping Strategies among Parents of Chronic ill Children. Journal of the Indian Academy of Applied Psychology, July 2007; Volume 33: 172-182
17. Sucursala. Dr. Felix, Str. Dr. Romanian Thalassemia Association Contact Information. Romanian Institute Of Hematology And Blood Transfusion; Extension 2006
18. Williams P D Williams, A R Graph et al. (2002) Interrelationship among variables affecting well siblings and mothers in families of children with chronic illness Journal of behavioral medicine 25(5) 414-417
19. Yeh C H (2002) Gender differences of parental distress in children with cancer Journal of advanced Nursing 36 (1) 78-88
20. Rund.D. and Rachmilewitz. E, Thalassemia New England Journal Of Medicine. 2005 September; Volume 353:1135- 1146
21. M.Sengupta, Ph.D. Thalassemia Among The Tribal Communities Of India, The Internet Journal of Biological Anthropology. Volume 1: 2008
22. Gyan Mudra. A Study of Perceived Stress, Impact and Coping Strategies. The International Journal of Interdisciplinary Social Sciences. Volume 2; Issue 4 : 325-334
23. Booklet published by National center for complementary and alternative Medicine (NCCAM)

24. Shervin S. Churchill, Nanci L. Villareagle, Teresa A. Monaghan, Parents of children with special health care needs who have better coping skills. Journal of maternal and child health. Nov2008.Volume 18; Issue 5: 2008, 122 – 130.

25. Paul chodoff, Stanford B.Friedman, and David A. Hamburg,Stress,Defense and coping behaviour in parents of children with chronic disease. Journal of family nursing. Jan 2005. (1) 19 – 27.

26. Karen.M.Gill, Ph.d, Kelly K.Antony, BS, James W.Carson, MA, Rupa Reddig-Lalliger, MD, Charles W. Daeschner, MD And Russell E.Ware, D, PhD Daily Coping Practice Predicts Treatment Effects In Children With Thalassemia Disease. Journal of Pediatric Psychology. December 2006; Volume 26: 163-173

27. Saviolo-Negrin, N. Cristante, F. Zanon,E Canclini, M. Stocco,D.Girolami,A.A Psychology Parents with a Hemophilic Child; A Quantitative approach. Hemophilia. 1999; 5: 63-68.

28. Olsson.M.B; Hwang.C.P, Depression in Mothers And Fathers of Children with Intellectual Differences. Iranian Institute Of Health sciences Research, 2001; 45:535-543.

29. Marilyn E Parker, Nursing theories and Nursing practice, second edition, Jaypee publication 268-280

30. Afaf Ibrahim Meleis, Theoretical Nursing, Development and progress, Third edition,Lippincott publication 291-301

31. Polit F.D, Beck T.C & Hungles P.B (2001). essentials of nursing research : Methods, appraisal and utilization (5th edition), Lippincott, Philadelphia

32. Lotta Delve,Samuelson, Lena Tallborn, Stress and Wellbeing among parents of children with rare diseases; Journal of advanced nursing. Feb 2006 Volume 53;(4) 145-148.
33. Rubin, S. S., & Malkinson, R. (2001). Parental response to child loss across the lifecycle: Clinical and research perspectives. In M. S. Stroebe, R.O. Hansson,W. Stroebe, & H. Schut (Eds.), Handbook of Bereavement Research. Consequences, Coping and Care (pp. 219-240). Washington D.C.: American Psychological Association.
34. Lindemann, E. (1944). Symptomatology and management of acute grief. American Journal of Psychiatry, 101, 141-148.
35. Attig, T. (1996). How we Grieve: Relearning the World. Oxford, New York: Oxford University Pres
36. .Parkes, C. M. (1972). Bereavement: Studies of Grief in Adult Life. London: Tavistoc Publications
37. Parkes, C. M. (2001). A historical overview of the scientific study of bereavement. In M. S. Stroebe, R.O. Hansson, W. Stroebe, & H. Schut (Eds.), Handbook of Bereavement Research. Consequences, Coping and Care (pp. 25-45). Washington D.C.: American Psychological Association.
38. Fortier, L. M., & Wanlass, R.L. (1984). Family crisis following the diagnosis of a handicapped child. Family Relations, 33(1), 13-24.
39. McCubbin, H. I., & Figley, C.R. (1983). Bridging normative and catastrophic family stress. In H. I. McCubbin, & C.R. Figley (Eds.), Stress and the Family. Volume I:

40. Coping with Normative Transitions (pp. 218-228). New York: Brunner/ Mazel Jacobs, S., Kasl, S., Ostfeld, A., Berkman, L., & Charpentier, P. (2000). The measurement of grief: Age and sex variation. British Journal of Medical Psychology, 59, 305-310
41. Cleiren, M. (1993). Bereavement and Adaptation. A Comparative Study of the Aftermath of Death. Washington, Philadelphia, London: Hemisphere Publishing Corporation.
42. Grifin, Ferguson, P. M. (2005). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. Journal of Special Education, 36(3), 124-131.
43. Wes Lyn's, E., (2002). A shortened measure of an instrument measuring bereavement. International Journal of Nursing Studies, 30(3) , 213-226.
44. Levers, C. E., & Drotar, D. (1996). Family and parental functioning in cystic fibrosis. Developmental and Behavioral Pediatrics, 17(1), 48-55.
45. Nezu, A. M., Ronan, G.F., Meadows, E.A., & McClure, K.S. (Eds.) (2000). Practitioner's Guide to Empirically Based Measures of Depression. New York, Boston, Dordrecht, London, Moscow: Kluwer Academic, Plenum Publishers.
46. Hobfoll, S. E., Freedy, J.R., Green, B.L., & Solomon, S.D. (2004). Coping in reaction to extreme stress: The roles of resource loss and resource availability. In M. Ziedner,& N.S. Endler (Eds.), Handbook of Coping. Theory, Research, Applications (pp. 322-349). New York, Chichester, Brisbane, Toronto, Singapore: John Wiley and Sons Inc

47. Suksiri Prasomsuk, Arunee Jessrisuparp,Thawalwong Ratanasiri,and Amornrat. Lived Experiences Of Mothers Caring For Children With Thalassemia Major In Thailand, Journal For Specialist In Peadiatric Nursing, January 2007;Volume 12: (1).
48. Afran Shargli, Mogan Karbakhsh, Bhrooz abaei, Alipas. Depression In Mothers Of Children with Thalassemia Blood Malignancies: A Study From Iran, Clin Pract Epidemol Mental Health.October 2006; Volume 2,
49. Sapountzi- KrepiaZ. Roupa, M. Gourni,F, Mastorakou, E.Vojiata, A.Kouyioumtzi, S.Van Sheel, A Qualitative Study On The Experience Of Mothers Caring For Their Children with Thalassemia In Athens, Greece, Journal Of Pediatrics Nursing, 2004; Volume 21; (2) 142-152.
50. Belinda Barton et al. (2006) Parental perceptions and support strategies in caring for a child with a chronic condition. Issues in Comprehensive Pediatric Nursing, 16, 109-121.
51. Karson et al. (2008). Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. Family Relations, 33(1), 67-77
52. Lotta Dellve et al (2005) child rearing practices , Parents of children with selected disabilities, a prospective longitudinal study, Journal of Pediatric Psychology, 26 (4), 224-239
53. Jerrett 2006 Parent’s perceptions of the information provided to them about their child’s leukemia: European Journal of oncology nursing 2003. September; 7(3): 172 – 81.

54. Katz, S. (2002a). Gender differences in adapting to a child's chronic illness: A causal model. Journal of Pediatric Nursing, 17(4), 257-269.

55. Carver, C. S., Scheier, M.F., & Weintraub, J.K. (2002). Assessing coping strategies: A theoretically based approach. Journal of Personality and Social Psychology, 56(2), 267-283

56. Folkman, S. (2001). Revised coping theory and the process of bereavement. In M. S.Stroebe, R.O. Hansson, W. Stroebe, & H. Schut (Eds.), Handbook of Bereavement Research. Consequences, Coping and Care (pp. 563-584).Washington D.C.: American Psychological Association.

57. Pradeep Rao, Prakash V. Pradhan and Henal Shah. Psychopathology and Coping in Parents of Chronically ill Children, Indian Journal of Pediatrics October 2007; Volume 71.

58. Patterson, J. M., Budd, J., Goetz, D., & Warwick, W.J. (1993). Family correlates of a 10-year pulmonary health trend in cystic fibrosis. Pediatrics, 9(2), 383-389.

59. Brown Ronald T. PhD, Ivers-Landis, Carolyn. PhD, Drotar, Dennis PhD, Bunke, Vicki PhD, Lambert, Richard G. PhD, Walker, A. Adrienne M.A. Factors Associated with The Attitudes and Expectations of the Patient’s Suffering from Thalassemia; Scandinavian Journal Of Caring Sciences. May 2004; Volume 18; (2) 177-187

60. Hardy et al. (2004), assessing coping strategies, a theory based approach. Journal of personality and social psychology, 22(3), 45-50

61. McCubbin, H. I., McCubbin, M.A., Nevin, R. & Cauble, E. (1981). Coping health inventory for parents (CHIP). In H. I. McCubbin, A.I. Thompson, & M.A. McCubbin

(Eds.) (1996), Family Assessment: Resiliency, Coping and Adaptation. Inventories for Research and Practice (pp. 444-447). Madison, Wisconsin: University of Wisconsin Publishers.

62. Saunders, C. M., Mauger, P.A., & Strong, P.N. (1975). A Manual for the Grief Experience Inventory. Palo Alto, California: Consulting Psychologists Press Inc.
63. Emerson, 2003 & Fazil, Wallace & Singh,2004, Coping and psychosocial adjustment of parents of Pediatric cancer , a longitudinal study, In parental adaptation to Pediatric Cancer, PhD Thesis
64. Latack .J.C & Havlovic .S.J (2002), coping with job stress:- a conceptual framework for coping measures, journal of organizational behavior, 13, 479-508
65. Annika Lindahl Norberg (2005) Parent coping when the child is diagnosed as Leukemia, Journal of Pediatric Oncology Nursing, 16(1). 3-12
66. Vasundhara Kumari, ,& Vineeta Gupta (2011) Stress Appraisal and Coping Strategies among Parents of Chronic ill Children. Journal of the Indian Academy of Applied Psychology, July2011;Volume 33: 172-182.
67. Doris J. Heaman (2011) Perceived stressors and coping strategies of parents who have children with Leukemia: A comparison of mothers with fathers. The International Journal of Interdisciplinary Social Sciences.Volume 2; Issue 4 : 325-334
68. Hae-Ra Han, Eun Joo Cho (2012) coping strategies and psychosocial adjustment in Korean mothers of children with cancer. . Journal of family nursing.. (1) 19 – 27.

69. Barnason.S, Zimmerman. L & nieveen (1995). The effect of music intervention on anxiety in the patient after coronary artery bypass grafting, heart and lung, journal of acute and critical care 24, 124-132
70. Bijlani , RL et al (2005). A comprehensive lifestyle education programme based on yoga. Journal of Alternative complimentary medicine, 11(2), 267-274.
71. Cheung .Y.L, molasscotis A, Chang A.M (2001). A pilot study on the effect of progressive muscle relaxation training of patients after stoma surgery, European journal of cancer care, June, 10(2), 107-114.
72. Eleanor Donegan, mechanisms by which AR and CBT worked and also to determine if one was more effective than the other at maintaining long-term symptom reduction British Journal of Medical Psychology, 67, 37-52.
73. Michelle Y. Kibby, Effectiveness of psychological intervention for parents of children with chronic medical illness.
74. Cheung .Y.L, Molasscotis A, Chang A.M (2001). A pilot study on the effect of progressive muscle relaxation training of patients after stoma surgery, European journal of cancer care, June, 10(2), 107-114.
75. Uzma Ali, and Shazia Hazan, Effectiveness of relaxation therapy in the reduction of grief related symptom. Journal of family nursing, Jan 2005. (1) 19 – 27.
76. Elliot, G.R & Esidorfer C (1982). Stress and human health, Analysis and implications of research, A study by the institute of median national academy of science. New York : Springer.

77. Fatemeh Hashemi, Maryam Sedghi, impact of educating parents of leukemic children. Iranian Red Crescent Medical Journal, 2007; 9(3):124-128

78. Hahn . Y.B et al (1993). The effect of thermal biofeedback and progressive relaxation training in reducing B.P in patients with essential hypertension, Journal of nursing scholarship 25, 204.

79. David Issacs et al (2003) coping mechanisms that can be adopted by parents of chronic ill children, Journal of Pediatric Psychology. December 2003; Volume 26: 163-173

80. Shukir Saleem Hasan (2011) home care management for caregivers having leukemic adolescent patients European Journal of oncology nursing 2011. September; 7(3): 172 – 81. Afran Shargli, Mogan Karbakhsh, Bhrooz abaei, Alipas. Depression In Mothers Of Children with Thalassemia Blood Malignancies: A Study From Iran, Clin Pract Epidemol Mental Health.October 2006; Volume 2,

81. D'Souza , A development of a booklet for parents of neonates admitted to neonatal intensive care unit, based on the information needs, Journal Of Pediatrics Nursing, 2004; Volume 21; (2) 142-152.

82. Lalrinhlui et al. develop an information booklet for care givers on care of a child with Mental retardation, Clinical Child psychology psychiatry. 2007, April; 12(2): 281 – 93.

83. Yama Zaki Shin, Sokejima Shigeru. Health related quality of life of mothers of children with leukemia. Vol 14. No.4. May 2005.

84. E.A. Earie, Eiser C. Clinical Child psychology psychiatry. 2007, April; 12(2): 281 – 93

85. E Patistea, F Babatsikou. Parent's perceptions of the information provided to them about their child's leukemia: European Journal of oncology nursing 2003. September; 7(3): 172 – 81

86. Bruce, E. J., Schultz, C.L., & Smyrnios, K.X. (1996). A longitudinal study of the grief of mothers and fathers of children with intellectual disability. British Journal of Medical Psychology, 69, 33-45.

87. Gennaro.S, brooter. D, Roncoli .M (2003); Stress and health outcomes among mothers of children with leukemia, Western journal of nursing research 15 , 97-113.

88. Patistea E Babatsiko, Health related quality of life of mothers of children with leukemia. Vol 14. No.4. May 2005

89. Kothari .C.R (2004); Research methodology methods and techniques (2nd edition), New Delhi, New age international limit edition publishers.

90. Lev, E., Munro, B.H., & McCorkle, R. (1993). A shortened measure of an instrument measuring bereavement, International Journal of Nursing Studies, 30(3), 213-226

91. Parkes, C. M. (2001); A historical overview of the scientific study of bereavement, M. S. Stroebe, R.O. Hansson, W. Stroebe, & H. Schut (Eds.), Handbook of Bereavement Research. Consequences, Coping and Care (pp. 25-45). Washington D.C.: American Psychological Association.

92. Dr. Meena Ganapati, (2006) Effectiveness of selected bio-behavioral interventions on stress among hospitalized patients , PhD thesis

93. Anto Augestine(2010), A retreat before doom, relaxation therapy, Chaitanya Mental health care center, Pune. 79-82

94. V care foundation, Coping with chemotherapy, support and hope for those touched by leukemia.
95. John Walter (2012) Coping with childhood leukemia and lymphoma, Leukemia and Lymhoma Society.
96. Shivashankara. A. R. Jailkhani R, Kini A. Hemoglobinopathies in Dharwad, North Karnataka: February 2008; Volume 21: (1)593-599.
97. Walker (1999) of relaxation training and imagery vs. standardized care among patients with breast cancer, British Journal of Medical Psychology, 67, 37-52.
98. Kennedy (2004) effect of relaxation exercise including meditative breathing on anxiety levels of mothers whose children with cerebral palsy. Journal of health and social behavior, 21, 219-239.
99. David Issac and Jill R. Sewell,Children with chronic condition.Australian Institute of Health and Welfare.May 2003.179(5): 235-236.
100. Gennaro. S, brooter. D, Roncoli. M (2003). Stress and health outcomes among mothers of children with leukemia, Western journal of nursing research 15, 97-113.
101. Othman, Azizah; Blunden, Sarah Psychological Interventions for Parents of Children who have Cancer: A Meta-Analytic Review. Current Pediatric Reviews; 2009, Vol. 5 Issue 2, p118
102. Nusrat aura, Preference for a male child is a known fact in India, Women's news network, Jan 18, 2012.
103. Rashi Aditi Ghosh ,Mothers too turn away from girl child, DNA, Nov 24 2012 .