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.
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. 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.

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). Initially 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.” (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 deceased, 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 into activity that helped one to keep their mind off what had happened. 

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.

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). 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.
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.\textsuperscript{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\textsuperscript{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.\textsuperscript{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\textsuperscript{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)\textsuperscript{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 light it 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 surrounding their child’s quality of life and life expectancy.\textsuperscript{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. 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.

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. 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.
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 et al 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 losses 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.\textsuperscript{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 thalassemia 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”.\textsuperscript{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.

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.

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). 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 situations. Carver et al. (1989)  

Coping is part of the 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 person's attempt to control, manage or live with a stressful situation. (Folkman, 1984)  

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 person turns to cognitive processes such as distancing, wishful thinking or self-blame. (Folkman, 1984). Coping efforts include several behavioral and cognitive strategies. These fall into 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.  

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.
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 into 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 things such as medication, chemotherapy, blood transfusion which help to improve their child’s health and assist in holding back the progression of the disease.

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. 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.
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.  

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 thalassemia.
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\textsuperscript{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 (2003) 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\textsuperscript{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)\textsuperscript{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 efforts to deny or
minimize the situation\textsuperscript{64}.
Annika Lindahl Norberg (2005) conducted a study examining 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.

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 into 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 into 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).

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%.

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.  

Simon et al. (2006) conducted a study to determine the effectiveness of relaxation technique on parents of children with Thalassemia. 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.  

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.\textsuperscript{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.\textsuperscript{76}

Fatemeh Hashemi, Maryam Sedghi Nursing and Midwifery College, Shiraz University of Medical Sciences, Shiraz, Iran.\textsuperscript{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.

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.\textsuperscript{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.\textsuperscript{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.\textsuperscript{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\textsuperscript{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.\textsuperscript{82}

Lalrinhlu, 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.  

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.  

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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 necessitates 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 this 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, sick 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.  

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 listen, offering support and reassurance, recognizing and focusing on feelings and appreciating the uniqueness of each individual and family.  

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.\textsuperscript{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).\textsuperscript{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.\textsuperscript{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, Thallasemia)

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.