FACTORS INFLUENCING THE ADAPTATION OF PARENTS WITH CHILDREN HAVING ACUTE LYMPHOBLASTIC LEUKEMIA

by

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Introduction

Statement of the Problem

Parents who have children with a chronic condition have additional stresses that parents with healthy children do not experience. "A child's chronic illness engraves a family's life with worry" (Hobbs, Perrin, and Ireys, 1985, p.62). In spite of this, many parents and their children appear to be functioning at normal levels. What enables some families to adapt effectively while others do not is a question that has direct implications for nursing. Nurses who work with these families need to understand what factors are associated with families who adapt so they can encourage the development of these helpful factors for others who have more difficulty.

This study describes the ways by which families adapt when their children have acute lymphoblastic leukemia. It also partially replicated a study by Venters (1981) of parents with children who had cystic fibrosis. Venters' interviews revealed some important factors related to adaptation. Although there are some essential differences between these two chronic conditions, there is reason to believe that the adaptation process for parents may have many similarities. Yoos (1987) stated "... critical psychological concerns cut across diagnostic categories and are common to most children and families coping with a chronic physical disease" (p. 25). This study explores the assertion of common coping coping strategies through comparison of families who have children with cancer with previous research findings.

Review of the Literature

The following review incorporates an historical research perspective to provide information on past and future research needs in the area of family adaptation to children with chronic conditions. It also includes a discussion of the variables identified in the literature which have been found to be related to parental coping. Venters' (1980) investigation which relates social and cognitive coping strategies to a dependent measure of outcome is presented. A study which illustrates that the severity of the illness affected the severity of the stress experienced by the parents is presented (Holroyd & Guthrie, 1986). A study which demonstrates the influence of parental coping on hopelessness in children (a dependent variable and a measure of outcome) is included (Gurwitch, Smith, Blotcky, & Racfznsk, 1985). Another study which associates family functioning instead of chronic illness with behavior problems in children is discussed (Lewis & Khaw, 1982). The final section includes a discussion of the studies which relate specifically to the stress, coping and adaptation experienced by parents whose children have cancer.

Historical Perspective

The development of the research on the psychological effects of illness on children and their families has been tangential at times due to social forces. Hobbs, Perrin and Ireys (1985) traced the development of this area of investigation. The authors stated that the first investigations in the area of psychological effects of illness on the childrearing family were concerned only with the impact of separation on children due to hospitalization. Studies which were concerned with the effects of specific diseases on children began in the 1950's and were usually case studies that were analyzed from a psychoanalytical perspective. The first diseases explored by these studies were asthma and diabetes. The effects of cancer on children was the next area of inquiry. Since these early days, the effects of kidney disease, cystic fibrosis and hemophilia on children have been explored. Few studies have concerned themselves with coping with acute lymphoblastic leukemia after the initial diagnosis. In addition few studies have examined the long term effects of a chronic condition in childhood on the family. Most have focused on the child's adjustment or the parents reactions soon after diagnosis. It was not until the 1960's that studies concerned themselves with the effects of the illness on both the child and the parents. Many of these studies focused on the negative effects of these diseases on the children and their families. Recently studies have investigated the positive effects as well. In addition, objective measures of family functioning have been developed in an effort to determine the impact of illness on the functioning of the family as a unit.

Mrazek (1985) summarized the conceptual basis of the research literature which concerns the adaptation of families with children to cystic fibrosis. The historical progression of the research in this area mirrors the stages described by Hobbs, Perrin and Ireys (1985). The author divided the research looking at the adjustment to cystic fibrosis into three categories. The author termed the first stage of this particular line of inquiry, the clinical descriptive phase. These early studies were credited with highlighting the emotional difficulties associated with this disease. A limitation of this phase was that it did not acknowledge the fact that many families do successfully adjust despite the presence of many stresses. The second phase described was the corrective empirical phase. This phase revealed that family responses to this illness were heterogeneous, or in other words responses varied with the individuals involved. This was an important observation although many of the measures used in this phase of development had questionable reliability and validity (Mrazek, 1985). The final phase which Mrazek identified as the current one was identified as the system sensitive phase. This phase was credited with documenting the variables that influence the final outcome, adapting to the experience. The next section will discuss research findings associated with the system sensitive phase.

Variables Influencing Parent Child Adaptation

Research in this system sensitive phase, has identified several variables as antecedents to adaptation. Demographic, cognitive and social variables have been found to be related significantly to parental coping. Other factors such as severity of the illness, the stress experienced by the parents, and the degree to which the family functions adequately have also been shown to effect various measures of adaptation. The following review of the the literature will discuss studies which have contributed to our understanding of adaptation to the experience of having children with a chronic condition.

Demographic Variables Related to the Use of Parental Coping Mechanisms.

McCubbin (1984) studied 100 families who had children with cystic fibrosis to find out which coping patterns were used by mothers and fathers. This study was conducted using the Coping Health Inventory for Parents (CHIP). The CHIP measures the use of three coping patterns: (1) maintaining family integrations, cooperation and an optimistic view, (2) understanding the health care situation through communication with other parents and consultation with the health care team, and (3) maintaining social support, self-esteem and psychological stability.

The researcher found that parents used all three coping patterns. Both fathers and mothers used the first pattern of maintaining family integration most often. Mothers used the second coping pattern of understanding the health care situation more than fathers. Fathers used the third pattern of maintaining social support more than mothers. However differences between mother's and father's predominant coping patterns were not significant. Two independent variables, age of the child and income of the family, were found to be significantly related with the mother's and father's coping patterns. A mother's effort to maintain social support decreased as the child's age increased. Since cystic fibrosis is progressive in it's manifestations, this result gives credence to the empirical notion that coping with cystic fibrosis can become more difficult as the child's condition worsens. The father's effort to maintain family integration did increase with greater income. There was also an increase in the father's use of the second coping mechanism (understanding the health care situation through communication with other parents and consultation with the health care team) in those families who had higher income and older children. In summary, this study identified two independent variables, income and age of the child, that related significantly to coping behaviors used by parents who had children with cystic fibrosis.

Social and Cognitive Coping Strategies Related to Family Functioning. Venters (1981) identified two coping strategies which were associated with long term adequacy of family functioning in 100 families with cystic fibrosis. Families who demonstrated high or medium level of family functioning, as measured by the Adequacy of Family Functioning Scale, were found to use two coping strategies. The scale measured three dimensions: cohesion, communication, and satisfaction. Hill's ABCX Model (1958) of family adjustment to crisis was used as the theoretical basis for the study.

Venters' (1981) findings revealed that the strategies used by parents were endowing the illness with meaning and sharing the burden of the illness. The former strategy was demonstrated by parents' ability to explain their children's illness situation utilizing a preexisting religious and/or medical-scientific philosophy of life. Those that were able to find meaning in their situation were more likely to adopt an optimistic philosophy. Parents shared the burden of the illness through talking with and through the physical assistance of, both family members and others outside their family. Families who demonstrated high or medium functioning were more likely to share the burden of the illness with others within the family and those outside. These factors are extremely important when one considers that families may need these strategies in order to achieve the "maintenance of motivation and morale" which has been identified by Duvall (1971) as a developmental task of the family.

Illness severity and stress. The severity of the illness has been thought to be positively related to the stress experienced by families with children with chronic conditions. The following results identify severity as a variable in the amounts of stress experienced by families. Holroyd and Guthrie (1986) studied 47 families of children who had renal disease, cystic fibrosis, or progressive muscular dystrophy and compared their scores with 47 normal controls who were matched based on age with the ill group. Their intent was to show the different ways each disease impacted the family as measured by the Questionnaire on Resources and Stress (QRS). QRS is a widely validated family evaluation questionnaire specifically developed for assessing the impact of chronic illness and handicapping conditions on the family. There are 15 scales to the original measure and 11 scales with a shorter form. Some of the QRS scales measure personal problems of the respondent, some measure family problems and some measure problems of the ill or handicapped member. The questionnaires have been tested numerous times for reliability and validity but the results were not provided.

Holroyd and Guthrie (1986) expected each clinical group of chronically ill children and their families to score higher than the control group on several scales and that the pattern on elevated scores would reflect the nature of stress experienced within the family system. As predicted, the group with neuromuscular disease showed the highest elevations in the greatest number of areas of any group. The cystic fibrosis group did not have as many scales elevated as the researchers predicted, but had more elevated scales than the renal group. The results showed that there was more stress and different patterns of stress in parents who were caring for children with different kinds of chronic illness than there were with families who had healthy children.

Parent coping and children. In another study the effects of parental coping on their children's development of hopelessness was measured. Gurwitch, Smith, Blotcky, and Racfznsk (1985) studied 32 families whose children were diagnosed with cancer for three months or more. These researchers measured parental distress and coping and their relationship to child hopelessness. The authors concluded that parents coping influenced the child's early response to the experience of having cancer. This finding points to the importance of parents, as a major part of the social environment of the child, in the child's ability to cope with a major illness. This finding also gives credence to the measurement of parental coping as a litmus test for other family members.

Family functioning and children's adjustment. The effects of family functioning on the development of behavior problems in children with chronic illness was demonstrated. Lewis and Khaw (1982) studies families with children who had cystic fibrosis or asthma and compared them to healthy children. There were a total of 84 families studied with approximately equal distribution in each group. The purpose of the research was to identify mediating variables that were important to the coping process in these families and which differentiated healthy from unhealthy adjustment. They did not find a significant difference in family functioning as assessed by mother's scores on the Family Adaptability and Cohesion Evaluation Scales. The authors concluded, "Either families of chronically ill children are not experiencing stress associated with the illness or they are successfully coping with any stress" (p. 639). Their results also showed that chronically ill children had significantly more behavior problems than healthy controls. However, contrary to expectation, these children did not differ from healthy controls in self-concept. The results indicated that the relationship between family functioning and behavior problems in the children was more significant than the relationship between chronic illness and behavior problems.

The Experience of Cancer in Children and Their Families

The outcome of cancer in children has changed from one of a terminal illness to a chronic life-threatening illness. This change in outcomes has increased the survivor rates but the "... psychosocial problems faced by the children and their families have multiplied" (Spinetta, 1982, p. 1939). Spinetta (1982) describes this change as it has been reflected in the research literature, "A comparison of newer volumes, with the classic volumes and papers of a decade ago, points to the change in emphasis from one of preparing for death to one of preparing for life" (p. 1939). Today the emphasis in the research literature is on coping and adapting to the experience of cancer.

Stress Experienced and Coping Mechanisms Used by Parents. Chesler and Barbarin (1987) studied children with cancer and their families using intensive interviews and questionnaires. The study sample included 95 parents in 55 families and 26 children with cancer and 23 siblings. Volunteers were obtained through the Candlelighters Childhood Cancer Foundation. Participants represented a variety medical diagnostic categories of childhood cancer. A "stress-coping-support paradigm" was used as a conceptual basis for the study (p. 12). In the words of the authors the concepts were used as "orienting points" and the study "... proceeded from a phenomenological and inductive basis to understand families' experience as they themselves reported them" (p. 14).

These interviews included questions concerning many aspects of the process of adaptation to the cancer experience for parents and children. The type of stress experienced by the parents were the following: intellectual, instrumental, interpersonal, emotional, and existential. These categories of stress were correlated with coping strategies. The interviews revealed the following coping strategies used by parents: denial, optimism, acceptance, maintenance of emotional balance, reliance on religion, search for information, problem solving, and search for help from others. The last three strategies, search for information, problem solving, and search for help from others were thought to be externally directed strategies. The remaining strategies were termed internally directed strategies. The coping mechanism of acceptance was used most by parents and search for help from others was used the least. Coping with existential stress was accomplished in three ways: reliance on religion, acceptance (the most often used coping strategy) and search for information. These are both internally and externally directed strategies. Intellectual stress was coped with using the strategies of search for information and search for help (the least used coping strategy). The authors concluded, "The passive or emotion-focused coping strategies (denial, optimism, acceptance, religion, and emotional balance) appear most useful in responding to the emotional stresses of childhood cancer" (p. 104).

Coping strategies for the entire family were also assessed by the study. The following strategies were used by families: managing internal emotional relations, adapting flexibly to new tasks, and managing external relationships.

The parents use of the same (symmetrical) or different (complementary) coping strategies were also examined. The data revealed that couples used symmetrical coping strategies more than asymmetrical strategies. The authors observed that few studies have looked at this phenomena and there may be benefits to either strategy at different times depending on the strategy. In summary, when parents were questioned about the over-all effect of these experiences on their families, 50% reported that their family had improved as a consequence of the illness, 42% reported that the quality of family life is the same, and 7% reported that family life is worse. This is interesting considering it has been assumed that these families would see their situation as worse. These results also illustrate that normalization of the experience is a factor in coping.

Parents adjustment to illness and helpful support. Many have speculated as to the type and quantity of support from others parents need most in this situation. Morrow, Carpenter and Hoagland (1984) studied 107 parents of children with various cancers to examine their degree of adjustment relative to the type and amount of support they perceived as helpful. The sample was composed of 68% of a volunteer population attending a convention of a national mutual-help organization. In this population 34.6% had children who died from cancer, 44.9% had children that still received some form of treatment, and 20.5% had children who were no longer in active treatment. The parents ages ranged from 23 to 58 years with a mean age of 37 years. The parents responded to two measures: The Psychosocial Adjustment to Illness Scale (PAIS) and a Likert-type scale rating 11 sources of potential support as well as their helpfulness to the parent. The reliability and validity of the PAIS were not noted by the authors. The results of the study showed younger parents (i.e., less than 30 years) had significantly greater psychosocial adjustment difficulties in their domestic environment, sexual relations, extended family relationships, personal psychological distress as well as total psychosocial adjustment. Parents whose child had died demonstrated significantly poorer adjustment in their extended family relationship, domestic environment, as well as in their overall psychosocial adjustment. Parents whose children were in treatment found several sources of support helpful. Parents whose children were out of treatment found support from relatives most helpful. Parents whose children had died did not find any support helpful. This study shows the importance of social support to the adjustment of parents whose children have cancer especially those who are younger and may not have a social network to assist them. It also shows the difficulties in adjustment faced by families whose children have died who may tend to isolate themselves from others instead of being receptive to support that could be helpful. Limitations of these findings were that the sample was derived from a self selected group who used support.

Summary: Review of the Literature

In summary, the nursing research concerning families' and children's adaptation to chronic conditions has just begun. The present focus has a multidimensional theoretical base and research support. There is still not an overall trend of how families and children adapt and what characteristics of adaptation are common to or different from other chronic conditions.

This review has provided the reader with a summary of the historical evolution of research in the area of coping and adaptation to a childhood chronic conditions. Current literature reviewed reflected several independent variables which influence parental adaptation; one study showed the effects that parents have on children's coping while the interaction between severity of the illness and stress was shown through another study. The importance of family functioning on children's development of behavioral problems was also evident. And finally, studies were reviewed which specifically addressed the coping and adjustment of families whose children have cancer.

As evidenced by the literature review there have been many studies which associate independent variables with various measures of parental adaptation. This study by providing information on the processes of family adaptation will attempt to determine whether adaptation has occurred, measured only by parents perception of their experience. Few studies have explored this process within a singular illness category. This study contributes to the knowledge of how parents adapt to the experience of acute lymphoblastic leukemia as a category of cancer, in their children. This study also contributed to the knowledge of family adaptation for these study families through the exploration of the applicability of the Double ABCX Model (McCubbin & Patterson, 1981). This approach generated many unanswered questions, and results in several suggestions for further inquiry.

Conceptual Framework

McCubbin and Patterson's (1981) Double ABCX Model of family adaptation to stress forms the conceptual basis of this study (see Figure 1). This model was derived from Hill's (1958) ABCX Model. Hill (1958) theorized that this model could predict "crisis-proneness" in families (p.145). In this model there are three variables considered to influence the crisis, factor x. The first variable, factor a, is the stressor; the second factor b, is the family's crisis meeting resources before the crisis; and the third variable, factor c, is the family's definition of the event. McCubbin and Patterson (1981) theorized that Hill's model only looked at pre-crisis variables so they expanded the model by adding post-crisis variables. That is, they duplicated the same three variables described by Hill as influencing the pre-crisis in the post-crisis period as well.

The post-crisis period takes into account the regenerative power of the family. In the post-crisis period there are also three variables plus coping behaviors of the family which leads to the final outcome, adaptation, factor xX. The first variable, aA is defined as the additional life stressors and changes which may make family adaptation more difficult to achieve. The second variable, bB is the critical psychological and social factors in which families engage to achieve satisfactory resolution. Factor cC, the third variable is the family's perception in the post-crisis period. In the post-crisis phase the family's perception of the crisis is oriented to redefining their initial views. Factor xX, adaptation, is the outcome of these family efforts.

McCubbin and Patterson (1981) defined crisis as, "... a continuous variable denoting the amount of disruptiveness, disorganization, or incapacitatedness in the family social system" (p.8). The outcome of this crisis in the post-crisis period is adaptation. McCubbin and Patterson (1981) stated, "The concept of family adaptation is used to describe a continuum of outcomes which reflect family efforts to achieve a balance in functioning at the member-to-family and family-to-community levels" (p. 11). Adaptation is considered to be on a continuum with bonadaptation on one end, and maladaptation on the other. Bonadaptation is characterized by, "... (a) the maintenance or strengthening of family integrity; (b) the continued promotion of both member development and family unit development; and (c) the maintenance of family independence and its sense of control over environmental influence" at both levels of family functioning (McCubbin and Patterson, 1981, p. 11). On the other hand, maladaptation, "... is an outcome characterized by a <u>continued imbalance</u> at either level (member-to-family or family-to-community) of family functioning or the <u>achievement of a balance</u> at both levels <u>but at a price</u> in terms of (a) deterioration in family integrity; (b) a curtailment or deterioration in the personal development of a member or the family unit's development; or (c) a loss or decline in family independence and autonomy" (p. 11).

Walker (1985), who critiqued several research models of families under stress, stated that the resources of the family are the most important aspects of the ABCX model and the one most often tested in empirical research. The author also concluded that the perception of the event is the least studied aspect of this model. Both factors b, and bB (i.e., the resources) and c and cC (i.e., the family's perception of the illness and the experience) form the basis of this inquiry of parents who have children with acute lymphoblastic leukemia.

Double ABCX Model's Application To This Study

This theoretical model is applicable to parents in this study because several conditions exist. Parents of children with acute lymphoblastic leukemia experience stress from the time that symptoms first appear. This stress continues to accumulate through both diagnosis and treatment. Activities of everyday family life are interrupted by hospitalizations, treatment regimes and uncertainties of the diagnosis. Structural changes in the family such as changes in family roles may occur. All these stresses are incorporated in factor aA in the post-crisis period.

Applying factor bB of this model to this study population takes into consideration the coping resources of the family. Resources such as emotional and physical support from family and friends are included in factor bB. Parents ability to think through everyday problems and find workable solutions is another dimension of this factor. Communication among family members and the families' sense of cohesiveness are also included.

Parents' perception of their children's condition is incorporated into factor cC. Many facts and fantasies will influence parents' perception. Their view of the illness may change as diagnosis and treatment becomes clear to them. Their view may also change with improvement or worsening of their children's condition. Parents previous experience or knowledge of the condition or similar condition will influence their perceptions. Parents' perception of how others view their children will also be of influence. Finally parents' perception may change as a result of their degree of adaptation, factor xX. Evidence of perceptions would include statements such as, "This experience has ruined our life together" or "This experience has brought us closer together". In summary, the Double ABCX Model expresses many aspects of the experience of chronic illness in families.

Conceptual and Operational Definition of Terms

Stressor Event; Factor a: "A stressor ... is a situation for which the family has had little or no prior preparation and must therefore be viewed as problematic" (Hill, 1958, p. 140). The presenting symptoms, the uncertainty and the final confirmation of the diagnosis of acute lymphoblastic leukemia in a child are included as stressors. Question I and II of the questionnaire (see Appendix C) will collect data relevant to the nature of the stressor event.

Family's crisis-meeting resources; Factor b: "... a set of resources in family organization which, by their presence or absence, kept the family from crisis or urged it into crisis," (Hill, 1958, p.144). This includes the ways in which the family has met previous crises. Resources also includes the ways families make decisions, the ways they communicate, and the values and goals that effect the way they deal with a crisis. This factor is measured by question IV of the questionnaire (see Appendix C).

Definition of the event by the family; Factor c: "A family's definition of the event reflects partly the value system held by the family, partly its previous experience in meeting crisis, and partly the mechanisms employed in previous definitions of events" (Hill, 1958, p.145). Statements made by parents that display the meaning of the event to them and to their family are included in this factor. This factor is represented by question V in the questionnaire (see Appendix C).

Crisis; Factor x: A varied amount of disruptiveness, disorganization, or incapacitatedness in the family caused by the stressor event (McCubbin & Patterson, 1981). This factor is represented by question I (see Appendix C).

Additional life stressors; Factor aA: These include other stressors that are normative or transitional which may make adaptation more difficult (McCubbin & Patterson, 1981). This may include additional financial burdens, pressures at work, siblings causing problems, psychological or physical absence of one of the parents, role changes in the family, changes in family activities, repeated hospitalization and exacerbations of illness. This factor is addressed by question III in the questionnaire (see Appendix C).

<u>New family resources; Factor bB</u>: New psychological and social factors families develop in response to the new or additional demands emerging out of a crisis to achieve satisfactory resolution of the crisis (McCubbin & Patterson, 1981). These may include developing clearer communication within the family. It may also include developing ways of eliciting help from others inside and outside the family without losing autonomy. The family may also develop a new sense of cohesiveness or flexibility which helps them through the crisis. This factor is represented by questions IV in the questionnaire (see Appendix C).

<u>New family perception; Factor cC</u>: The family's orientation is toward redefining their situation in a way that is understandable to them (McCubbin & Patterson, 1981). This includes parental statements concerning what they learned about the strengths in the family through the experience, or

how they defined what has happened to them. This factor also includes how the preceptions are different from initial perceptions. This factor is illustrated by question V, VI, and X in the questionnaire (see Appendix C).

Adaptation; Factor xX: The outcome of the family's efforts to achieve new levels of balance in family functioning (McCubbin & Patterson, 1981).

Coping: This includes, "The behavior responses of family members and the collective family unit to eliminate stressors, and manage the hardships of the situation, resolve the intrafamily conflicts and tensions, as well as acquire and develop social, psychological and material resources needed to facilitate family adaptation" (McCubbin & Patterson, 1981, p. 14).

Bonadaptation: This reflects the family's effort to maintain the family integrity, sense of autonomy, and promote individual and family development (McCubbin and Patterson, 1981). Families who become active in organizations that serve other victims of this disease are examples of bonadaptation. Bonadaptation must be achieved at two levels (ie. the individual-family and the family-community) by all families.

Maladaptation: This occurs when only one of the following exists: 1) deterioration in family integrity; or 2) a curtailment or deterioration in personal development of a member or the family unit's development; or 3) a loss or decline in family independence and autonomy (McCubbin & Patterson, 1981). Maladaptation is also "... characterized by a continued imbalance at either level (member-to-family or family-to-community) of family functioning ..." (McCubbin & Patterson, 1981, p. 11). Families in which one spouse has psychologically withdrawn from the family as a result of their inability to cope with the condition would be an example of this.

Purpose of Study

This study described the experience of parents and therefore part of the process by which they adapt to their children having acute lymphoblastic leukemia. Through the application of a semi-structured interview, this study explored five areas believed to be essential to the process of adaptation in families: (1) what changes in family activities and structure are a result of the condition; (2) what coping mechanisms and resources were utilized by parents; (3) how have parents perceptions of the experience changed from the onset of the condition to the present; (4) how do demographic factors, such as age of the child, age of the parents and the length of time since diagnosis relate to parental coping, perceptions and changes in family activities and structure, and (5) what trends and themes in the lives of these families are related to adaptation and in what areas do they occur?

These five areas of inquiry were directly related to the Double ABCX Model (McCubbin & Patterson, 1981). The first area, changes in family activity and structure, elicited information about factor A and factor aA, the nature of the stress and the pile up of stressors. Factor B and factor bB, the family's resources, was obtained through the questions that inquire about the coping mechanisms used by the family and the support experienced from within and outside the family. Responses about the parents' past and present perceptions of the illness describes the parents perception of the meaning of the illness, factor C and factor cC. These questions will attempt to describe the process of adaptation of families who have children with acute lymphoblastic leukemia.

This investigation is based on two assumptions concerning the nature of the human spirit. The first of which is that families do many things to help themselves cope and the second is that people generally adapt to difficult situations. By describing and attempting to understand how parents do successfully adapt, nurses can develop interventions that can assist others. Drotar, Crawford and Bush (1984) stated the following which supports the need for this type of research, "The families of the chronically ill have much to teach us about human resilience in the face of severe and chronic stress" (p.125).

Chapter II

Methods

Design

This non-experimental investigation analyzed retrospective descriptive data. This research replicated, in part, the study conducted by Venters (1980) which illustrated how parents adapt to their children with cystic fibrosis. This design was replicated since Venters' interviews revealed many important results concerning the nature of the adaptation process that requires verification in other populations of families with children who have chronic conditions.

The descriptive retrospective approach utilized in this investigation provided detailed information about the process of adaptation. Retrospective data collection was the most suitable strategy for this kind of data because people often view their previous experiences differently with the benefit of time for reflection. When people are involved in a crisis situation, they often do not have perspective on the all the circumstances. This idea is vital since this investigation was focused on what parents have learned through their experience. This study was also concerned with the changes these parents have experienced. Because the participants described their experience in their own words, the data collected has a greater possibility of containing valid perceptions and revealing process rather than one perception at one point in time. However, memory distortion in ex post facto studies can be a threat to internal validity (Polit & Hungler, 1983). People may for instance only remember the best or worst parts of their experience while forgetting less stressful experiences. Another threat to internal validity lies in the fact that the sample of parents with children with leukemia comprise a convenient sample. Since the parents also volunteered to participate there is some inherent self-selection bias present.

There were also threats to the external validity which reduces the generalizability of the findings (Polit & Hungler). Volunteer parents will be aware that their remarks are under scrutiny, and they may phrase their answers to create an impression that they have adapted better than they actually did. The investigator tried to minimize this by two methods. First the parents were assured that there are no right or wrong answers. The process they experienced was the sole interest of the investigator. In addition, the interviews were conducted in family homes. It is hoped that this environment would provide a comfortable setting and help parents maintain the a sense of control over the interview process.

Rational for design

This investigation is an example of one of two categories of research established by Knafl and Deatrick

(1987): Namely, "Subjective active process approach" (p. 302). The authors stated, "Research consistent with this orientation focuses on understanding process rather than measuring outcomes" (p. 302). This category of study emphasizes discovery and understanding. It also defines, according to the authors, the family's subjective definition of the illness experience. These kinds of studies are concerned with how the families are managing the illness situation. They lay the ground work for future research strategies that combines an objective measurement of adaptation with this approach. This approach also lays the ground work for understanding adaptation to life events that are beyond human control.

According to Knafl and Deatrick (1987) the approach used in studies evaluating the experience of chronic illness in families is an objective passive outcome approach. Studies in these categories "... tend to ignore or discount family subjective definition of the situation and conceptualize the family as responding passively to member's chronic illness or disability" (p. 300). According to the authors these studies see the family as passive victims. Their intent is to find evidence of coping mechanisms or underlying pathology. These studies looked at what the illness does rather than how families manage the illness. The emphasis is on precise measurement to associate outcomes with intervention. They wish to identify groups at risk for negative outcomes and to identify needs and services. In the future, investigations should combine both approaches to obtain realistic richness in the data and to promote generalizability of the results.

Subjects

The study sample consisted of 22 parents of 12 children who had acute lymphoblastic leukemia. The data was gathered by interviews that were conducted at the home of the parents using an interview guide (see Appendix C). Two pilot interviews were completed and modifications in the interview guide were made as shown in Appendix C. Information obtained during these pilot interviews were not included in the results. All interviews were fully audio recorded. Detailed transcriptions of the interview data were made to facilitate the analysis.

Volunteers for the study were originally solicited through Oregon Candlelighters Childhood Cancer Foundation's newsletter (a support group for parents whose children have cancer). However, only one family volunteered as a result of this advertisement. Therefore other resources were utilized. Names of families were given to the investigator by other parents, a pediatric oncology clinic at a university medical center, and through a private pediatrician's office in the area. Those families were then contacted by the investigator, informed about the study and asked to participate. In some specific cases the pediatric oncologist preferred to call his patients to ask their permission for the investigator to call. Two families who initially were interested in participating later declined. Criteria for inclusion are as follows:

(1) parents of children who have been off protocol for treatment of acute lymphoblastic leukemia for at least six months;

(2) parents of children who have no other problems in addition to leukemia, such as neurological deficits prior to the illness;

(3) the children must be between the ages of 6 through 12 years.

This information was supplied by the parents and recorded on the Family Information Form (see Appendix B). Adolescents were not included in this study because of the biological and psychosocial changes that occur in this age group. Since the investigator spoke English, only English speaking parents were asked to participate. Father and mother pairs were interviewed together.

Protection of human subjects

Participation in this study was voluntary and without financial remuneration. Approval of the Oregon Health Sciences University Human Subjects Research Committee for this study was obtained. Verbal consent for the interviews was obtained by the investigator during the initial phone contact made by the parent. Informed consent was obtained in writing from each parent willing to participate prior to the start of the interview. A copy of the signed consent form was given to the parents at that time. Parents were assured of confidentiality. Each parental couple received an identification number which was recorded on the Family Information Form, the Adapted Interview form and on each audio tape. In addition a master list of the subjects names and their corresponding assigned identification number was kept by the investigator in a locked cabinet in the investigator's home. The information on the tapes was erased after the analysis procedure was completed.

There were no physiological risks to the participants in this study. Interviewing was the only method of data collection and therefore there were some psychological risks. These psychological risks stem from the nature of the material being discussed. Painful memories or feelings of being overwhelmed by present life situation may surface. These risks were discussed with the parents and they were informed in the introductory letter that they could withdraw from the study at any time prior to or during the interview. The participants were asked if they had any questions or concerns that may have emerged as a result of the interview at completion of the interview. These final moments as well as a follow up phone call by the investigator in 24 hours were offered as a means of debriefing.

Instrumentation

The primary data gathering instrument was a semi-structured interview guide adapted from Venters' interview guide (1980). The Adapted Interview Form (see Appendix C) was changed only slightly so that it would apply to families with children with leukemia rather than cystic fibrosis and produce a smooth flow in the interviewing process. It was divided into 12 questions. The amount and kinds of probing questions used are included in the interview guide. Demographic data was recorded by the parents on the the Family Information Form (see Appendix B).

The questions in the questionnaire pertain to three areas: (1) changes in family activities and structure that result from the experience of having children with leukemia, (2) coping mechanisms and resources utilized by the parents in the process of adaptation, and (3) the parents perceptions of the experience from the time of the diagnosis of leukemia to the present. These areas relate directly to the Double ABCX Model of family adaptation.

Interviews

Volunteers for this study were elicited primarily from local physicians who supplied names of potential participants who met the study criteria. Only one family volunteered in response to an advertisement and their child was too young to meet study criteria. When parents were phoned either by their physicians or the researcher they readily agreed to participate. Mothers were the usual initial phone contact. Many said they willingly participated in research because they felt their children's successful treatment was the result of research efforts of the past. They were simply very willing to talk about their experience. All but one father was present for the interview. Most participated a little less eagerly than the mothers. Except in one family, mothers were the primary spokes-persons.

Some parents talked without a break after only a few introductory remarks from the investigator. Others required the interviewer to probe more carefully. For the very talkative there seemed to be an element of tension and also one of relief in their outflow of experiences. They may have also been to afraid to let the interviewer guide the interview with the questions. Perhaps sending parents the questions beforehand would have averted these problems.

After the families were recruited, the interview process was piloted. Important questions to ask are: How do the researchers themselves feel about the subject they are discussing? Are there certain trigger words that you may hesitant to say in the interview? Certain subjects may be suddenly found untouchable, such as how did the parents get along during the ordeal. The pilot interviews were helpful to point out those soft spots to the interviewer. For example, in this study, words such as cancer, leukemia, and die were found difficult to say to the parents.

Research Procedures

A pilot of this study, which included two audio recorded interviews, was carried out prior to the start of the data collection. The pilot interviews provided the investigator with a formal rehearsal of the interview and the analysis procedure. The investigator took notes, and summarized the major themes immediately after the interview. One pilot interview was completely transcribed. The method of summarizing major themes was compared with direct transcription of the interview for clarity and completeness in terms of the analysis procedure. From this comparison the decision was made to transcribe only important remarks from the tape recordings and not the entire conversation for analysis purposes. The tape recording, the summarization notes, and the transcription was reviewed by the Master's Research Project (M.R.P.) advisor who provided feedback on the interviewing technique and the analysis procedure. Following the pilot, the actual interviews were conducted. These were all audio recorded.

The research procedure proceeded as follows:

1. Approval of the M.R.P. committee members was obtained.
2. Approval of the Human Subject's Review Committee at O.H.S.U. was obtained.
3. Pilot interview was audio recorded and transcribed.
4. Volunteers were sought through a notice in the newsletter published by Candlelighters Childhood Cancer

Foundation.

5. Volunteers were notified by the investigator by phone.
6. The purpose of the investigation and the requirements of the participants and the risks involved were explained in this phone contact.
7. Verbal consent was obtained in the initial phone call and convenient time for the interview was established.
8. The interview was conducted in the parent's home with both parents present.
9. The purpose of the investigation, the requirements of the participants and the risked involved was reiterated by the investigator. The consent form was given to each parent for their review. A signed copy of the consent form was given to them at this time.
10. The parents filled out the Family Information Form.
11. The interview were audio recorded.
12. The investigator allowed time for questions and concerns emerging as a result of the interview.
13. The investigator summarized major themes of the interview immediately after leaving the interview site.
14. The data were analyzed through descriptive analysis.
15. Each family was contacted by phone 24 hours after the interview to answer questions and voice concerns emerging from the interview process.
16. Each family was notified of the anonymous results of the study when data analysis was completed.

Analysis

The data were analyzed through descriptive analysis. The information obtained in the interviews was divided into five areas of inquiry: (1) what changes in family structure and activities are a result of the condition, (2) what coping behaviors and resources were utilized by parents, (3) how have the parents perceptions of the experience from the onset of the condition to the present, (4) how do demographic factors, such as the age of the child, age of the parents, and the length of time since diagnosis relate to parent coping, perceptions, and changes in family activities and structure of the experience, and (5) what trends and themes in the lives of these families are related to adaptation and in what areas do they occur? The data were also analyzed for evidence of the eight factors and coping that are represented by the Double ABCX Model (McCubbin & Patterson, 1981). The applicability of this model to the experience of these families and their perception of their adaptation was evaluated. Themes not representative of the model were also noted.

Interrator reliability was established by comparing the number of similar themes obtained by the investigator with the number of themes independently obtained by another nurse who has experience with caring for children who are chronically ill (Brink & Wood, 1983). Two interviews were reviewed in this way. With one interview the researcher found 47 themes and the assistant found only 40, which was calculated to have a 85% reliability. In the other interview the researcher found 35 themes compared to the 28 themes the assistant found, which calculated at 80% reliability. These are acceptable levels of interrator reliability according to Polit & Hungler (1983). These levels ensures that the majority of the interview material was considered by the investigator. The investigator always found more themes than the assistant, this may have been the result of the investigator familiarity with the conceptual components of the adaptation process.

Chapter III

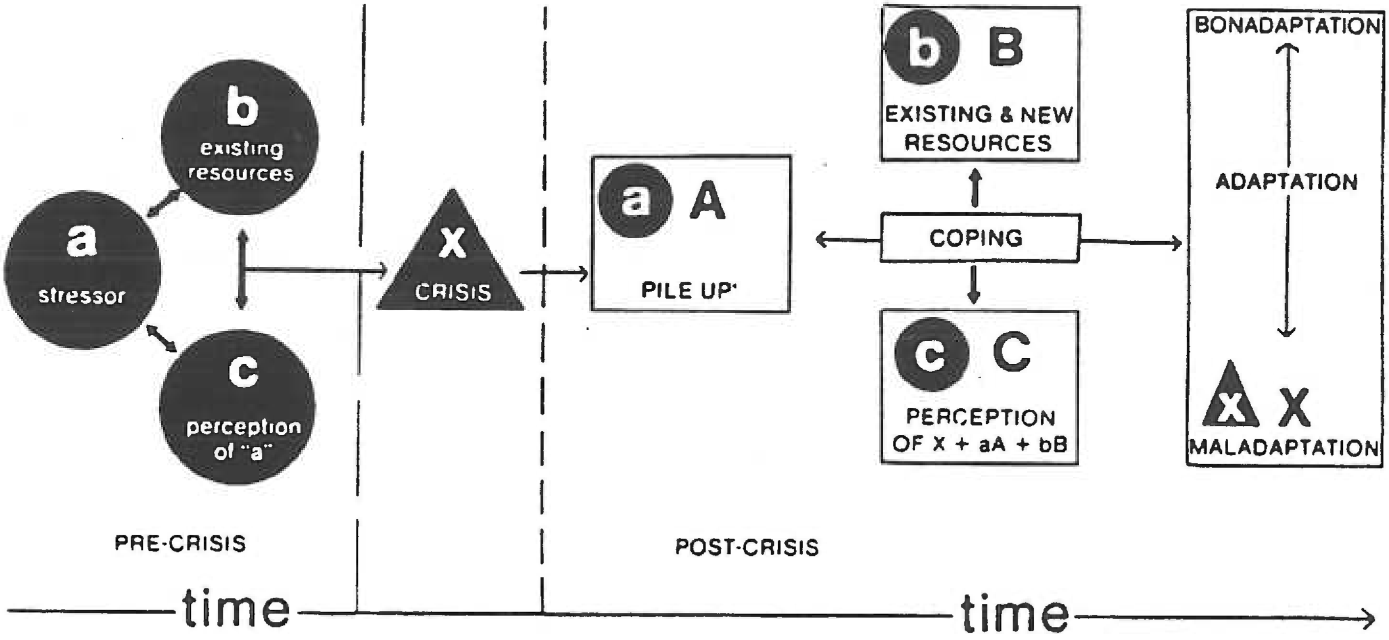
Results and Analysis

The purpose of this study was to describe the experience of parents and therefore the process by which they adapt to their children having acute lymphoblastic leukemia. Through the use of a semi-structured interview, the study explored five areas believed to be essential to the process of adaptation in families: (1) changes in family activities and structure which result from the condition; (2) coping behaviors and resources utilized by parents; (3) parents perceptions of the experience from the onset of the condition to the present; (4) demographic factors, such as age of the child, age of the parents and the length of time since diagnosis related to parent coping, perceptions and changes in family activities and structure, and (5) trends and themes in the lives of these families which exhibit adaptation. All five areas directly relate to the Double ABCX Model (McCubbin & Patterson, 1981).

The results of the study were analyzed primarily in relation to the conceptual framework of the Double ABCX Model (McCubbin & Patterson, 1981) and the research findings of Venters (1981), and Chesler and Barbarin (1987). The data were examined for the presence of the eight factors and coping in the Double ABCX Model (see Figure 1). These factors are: 1) factor a, stressor; 2) factor b, existing resources; 3) factor c, perception of event; 4) factor x,

Figure Captions

Figure 1. Double ABCX Model, Family Adaptation Model



(McCubbin & Patterson, 1981)

crisis; 5) factor aA, pile up; 6) factor bB, existing andnew resources; 7) factor cC, perception of crisis, pile up, and existing and new resources; 8) factor xX, adaptation; and 9) coping. Although all eight factors and coping were reviewed, four factors and coping were of primary concern. The factors of primary concern were, factor aA, additional life stressors; factor bB, new family resources; factor cC, new family perception; factor xX, adaptation; and coping that occur in the post crisis period. They are a primary concern of this analysis because these factors are believed, based on the review of the literature, to be related to the final outcome of adaptation. Venters' (1981) research was selected as a basis of comparison and analysis because that researcher also applied the Double ABCX Model (McCubbin & Patterson, 1981) to parental experience with a chronic childhood illness. The concepts of support and perception were major foci of Venters' (1981) interviews and were used as a basis to view families adaptation to chronic illness. The study by Chesler and Barbarin (1987) was also selected as a basis of comparison and analysis because the researchers' findings related to parent roles and coping styles.

Descriptive characteristics of families and profile of their illness provide the initial basis for the analysis of their responses to the five areas of inquiry. Following the descriptive data, the actual interview findings and preliminary interpretations are discussed. The interview data is presented according to the eight factors and coping of the Double ABCX Model (McCubbin & Patterson, 1981) which correspond to the five areas of inquiry. The data will be presented in the following sequence. First, factor a, stressors, and factor aA, pile up, are discussed in relation to specific interview questions and to the first area of inquiry, changes in family activities and structure which result from the condition. Next, factor b, existing resources, and factor bB, existing and new resources and coping, are discussed in relation to the second area of inquiry, coping behaviors and resources utilized by parents and specific interview questions. And finally factor c, perception of the stressor, and factor cC, perception of the crisis, pile up, and existing and new resources are discussed in relation to the third area of inquiry, parents perceptions of the experience from the onset to the present and specific interview questions. This chapter includes a discussion of the findings in comparison to the fourth area of inquiry, demographic factors that relate to family coping, perceptions and changes in activities and structure. This chapter also includes a discussion of the fifth area of inquiry which is the trends and themes in the lives of families which exhibit adaptation. The discussion, Chapter IV, follows and includes an analysis of factor xX, adaptation in relationship to the findings and the applicability of the Double ABCX Model. Chapter V concludes this study with a summary, implications for nursing, limitations of the study and recommendations for further research.

Characteristics of the Sample Subjects

The sample consisted of 22 volunteer parents of 12 children who had had acute lymphoblastic leukemia. Parents in the sample were a heterogeneous group. Selected characteristics of this sample were gathered through the Family Information Form (see Appendix B). Table 1, Parent Characteristics and Table 2, Child Characteristics, summarizes this data. This section will discuss the overall characteristics of this sample.

Two of the 11 two-parent couples were not married. These couples are indicated in Table I by "000 months" in the column with the heading of "period between marriage and diagnosis". One of these couples had cohabitated for six months before the onset of the condition in the mother's daughter. The other unmarried couple met a year after the mother's daughter's diagnosis. Both of these unmarried mothers had been married to the children's biological father who did not participate in the care of the ill children. These two unmarried step-fathers were actively involved in the care of the ill children. The nine married couples had been married between 22 months and 18 years before the diagnosis was made in their children. The mothers ages

Table 1

Parent Characteristics

Parental couple subject no.	Age in years of Mother	Age in years of Father	Hollingshead Social status score couple	Hollingshead Education factor score Mother	Hollingshead Education factor score Father	Religious preference[a] Mother	Religious preference[a] Father	Period between marriage and diagnosis
01	38	42	57	6	7	P	P	096 mos
02	37	42	61	6	6	P	P	132 mos
03	36	40	42	5	6	P	C	120 mos
04	39	40	48	4	6	P	P	000 mos
05	33	41	41	4	5	E	E	006 mos
06	42	44	45	5	5	C	C	084 mos
07	27	36	20	4	5	P	P	022 mos
08	32	34	27	4	4	O	O	048 mos
09	52	47	61	5	7	P	P	216 mos
10	42	42	66	5	7	C	C	180 mos
11	36	42	56	7	7	C	A	084 mos
Mean	39.5	41	47.2	5	5.9			89.8 mos

[a] P = Protestant, C = Catholic, E = Epicopal, O = Other, A = Agnostic

Table 2

Child Characteristics

Parental couple subject no.	Age of child Present	/ at diagnosis	Months off protocol	Period since diagnosis	No. of children	Birth order of affected child
01	08 yrs	42 mos	21 mos	048 mos	3	first
02	09 yrs	72 mos	11 mos	036 mos	3	first
03	08 yrs	46 mos	24 mos	048 mos	2	second
04	11 yrs	18 mos	81 mos	108 mos	4	third
05	08 yrs	36 mos	36 mos	060 mos	2	second
06	12 yrs	36 mos	60 mos	105 mos	2	first
07	08 yrs	13 mos	51 mos	084 mos	4	first
08	10 yrs	72 mos	21 mos	047 mos	3	second
09	11 yrs	21 mos	77 mos	108 mos	4	fourth
10	12 yrs	96 mos	20 mos	048 mos	3	second
11	8 yrs	48 mos	06 mos	046 mos	2	first

ranged from 27 years to 52 years. The fathers ages ranged from 34 years to 47 years. The mean age was 39.5 years for mothers and 41 years for fathers. One father was late for the interview and had limited participation in the interview.

The 12 children whose parents were interviewed consisted of one set of identical twins. (The twins were diagnosed within 10 days of each other.) Ten of the children were girls, only one was a boy. All the children met the study criteria which was that they had been diagnosed with acute lymphoblastic leukemia and were off protocol for at least six months. (Off protocol meant that they were no longer receiving any chemotherapy for leukemia). Their ages at diagnosis ranged from 13 months to 8 years. Their ages at the time of the interview were between eight and twelve years. The time they had been off protocol ranged from six months to six years.

All families were Caucasian with the exception of the step-father of one of the unmarried couples who was Asian. All parental couples spoke English as their primary language. Of the eleven couples interviewed the religious preferences were as follows: eleven Protestant, six Catholic, two Episcopalian, one agnostic and two listed their religious preference as other.

The Four Factor Index of Social Status (Hollingshead) was used to determine each families' social status. The scores for each family ranged from 20 to 66. The mean score was 47. Two families said financial concerns were a major source of stress. The mean educational score was 5 for mothers and 5.9 for fathers, indicating that the fathers had somewhat more formal education than mothers. All parents were high school graduates. Some college education or additional training after high-school was attained by seven parents. Five of the parents had received graduate degrees. Occupations of the parents were varied; the largest single group being five homemakers in the group who consisted of five of the mothers. Four were teachers and one parent was a college professor. There was one parent in each of the following professions: social worker, registered nurse, and counselor. Two fathers were engineers. Other occupations represented were sales persons, claims supervisor, facilities technician, custodian, and truck driver.

The numbers of children in each family ranged from two to four. Four families had two children, four families had three children and three families had four children. Six of the affected children were first born including the family with the twins. Three of the affected children were the youngest in their families.

Profile of the Illness

Even though each child in the study was diagnosed as having the same condition, many differences in initial onset, illness course and residual effects were experienced by each family. This section will describe the stressful events experienced by parents in these three phases of the illness. In the initial phase four out of 11 parental couples said their child's diagnosis was missed by the first medical contact. In one instance this occurred due to unusual presenting symptoms. Three other children presented with mild lethargy related to developing anemia, which was subsequently diagnosed as leukemia. One child became critically ill with infection several months before the diagnosis of acute lymphoblastic leukemia. One father delayed seeking medical care because of his religious beliefs. The child was extremely weakened when the diagnosis was finally made. This initial phase was perceived by most parents as stressful because the diagnosis was missed, treatment was delayed, sudden emergence of symptoms and development of life-threatening infections.

Many of the families experienced additional stress after the diagnosis was established due to factors such as complications during the illness course or stressful experiences not related to the illness. Some of these additional stresses were that six children experienced life-threatening complications during the course of treatment. One child developed severe infections in the form of abscesses, another developed severe respiratory impairment due to infection, another developed pneumonia, one child needed emergency surgery for a perforated ulcer, and another child had a life-threatening seizure. One child had an uncontrollable nosebleed requiring emergency treatment. Only one child suffered a relapse after remission was achieved. Two families had to move either during treatment or just before the diagnosis was made. New babies were born in three families during treatment. In two of these families, the mothers also needed surgery during treatment. Two fathers became unemployed during treatment. Two mothers' husbands gave them no emotional support during treatment. The lack of insurance coverage and the need for mothers' to work to maintain coverage, and the large volumes of paper work involved in keeping track of medical payments were also stressful for families. In only one family were there no complications, and in which the parents experienced very little stress in other areas of their lives during treatment.

Parents described the residual effects of treatment that persisted after completion of treatment protocol in seven out of 12 children. Three girls have developed what may be termed phobic reactions to taking solid medication. They still are unable to swallow any medication in pill form without promptly throwing up. One child had been off protocol six years and the other two for 21 and 20 months. One child who was diagnosed at 18 months and who subsequently suffered a relapse because leukemic cells were found in the spinal fluid, has been diagnosed with having cerebral palsy. This severe complication has added to the parents' difficulties. One of the identical twins has more difficulty in school than her twin. She suffered a severe anoxic seizure in the early stages of treatment. Another child who was diagnosed at 21 months was so critically ill for so many months that she became delayed in language and motor skills, which are now marginal for her current age of 11 years. This child also suffered from bowel incontinence, which is associated with a severe rectal infection during treatment. Another child suffered a severe attack of epiglottitis, which permanently altered her voice to a low pitched one.

Interview Findings

The following section will include actual interview findings and preliminary interpretations. Each factor in the Double ABCX Model (McCubbin & Patterson, 1981) and its corresponding area of inquiry will be discussed in terms of the interview questions and subsequent data obtained.

Stressor: Characteristics of the Event; Factor a

Initial reactions. Parents were asked several questions that were designed to give a profile of each families experience during the course of the illness. These questions were related to factor a, the stressor, defined as characteristics of the event. This is the first pre-crisis variable of the Double ABCX Model (McCubbin and Patterson, 1981). Families were asked the following questions: What events led up to the diagnosis of leukemia and how was your family affected by the diagnosis? Sometimes parents have said that right after the diagnosis they felt things fell apart for awhile. In other words, the family routine did not seem to go as smoothly as before. Did you find this happened to your family? What happened? How did you handle it? or were you able to do anything? Parents usually experience many painful feelings when first hearing that their child had leukemia. Was this true for you and your family? Was it long before things seemed to be a little better? Had you expected the diagnosis, or was it a shock? Parents have also told us that accepting the diagnosis was often difficult and took time. Was this true for you and your family? How long did it take? (Refer to Appendix C, questions I, and II).

When asked these questions, many families related the events surrounding the initial diagnosis as described in the preceeding section on profile of the illness. The initial phase was dominated by several themes. Sudden awareness of symptoms followed by a period of uncertainty of varied length before the diagnosis was confirmed was a predominant theme. Initial feelings experienced by parents were those of shock, numbness, devastating feelings, denial, anger, and dazed. Some parents also described their struggle to maintain control of their emotions during this period.

Parents perception of when the crisis was over and things began to run more smoothly varied greatly. For some it took only a few days. For others the timing of remission was a turning point for them, for still others normalcy returned only when their child was off all treatment. For a few normalcy has never returned, their lives continued to be effected by side effects of this devastating experience.

Most parents said that accepting the diagnosis came almost immediately. One parent said that after the the acceptance came the questions such as "Why me?", and "Why us?". One mother said she accepted the diagnosis, but she felt that denial played a part in her lack of acknowledgment of the effects this situation had on the whole family. Such immediate acceptance of the diagnosis probably occurred because of the unequivocal nature of the diagnosis of acute lymphoblastic leukemia.

Pile up: Additional Life Stressors and Changes; Factor aA

This section will continue to address the first area of inquiry; that of changes in family activity and structure which result from the condition. These changes are presumed to have resulted from the pile up of stressors parents experienced. This section therefore encompasses factor aA, additional life stresses, of the Double ABCX Model (McCubbin & Patterson, 1981). This information was attained by asking the following: Many families have told us that after their child began treatment for acute lymphoblastic leukemia the family routine changed. In what ways, if any, has your family's daily activities been influenced by X's illness? For instance who cares for X when he/she is ill? Who usually accompanies X to the clinic? Has anyone taken on new or different household chores? Which ones? Sometimes families find that the treatment routine is so busy at home that they have to cut back on some of their outside activities. To what extent, if any, have your family members had to give up some things outside the family that were previously experienced as sources of satisfaction? If yes, what and why? Have you now resumed these activities? On the other hand, some families find that the diagnosis stimulates involvement in new activities outside the home that were taken on as a result of X's illness. Which ones? (possible probe, new interest in health consumer groups, or parents' groups such as Candlelighters Children's Cancer Foundation, church, etc.) (Refer to question III, IIIA, & IIIB in Appendix C). The data revealed the following categories of pile up of stressors: a) influence on daily routine, b) parents participation in treatment, c) activities as a result of the condition and d) employment of parents during treatment.

a) <u>Influence on daily routine</u>. All families in the study had their routine changed by the fact that at least daily clinic visits were required for treatment. For some this imposed no inconvenience, for others the numbers of visits were problematic. Many of the children were hospitalized for a few days. For some, the days turned into weeks because of fulminating infections or their resistance to remission.

One mother found the visits to the clinic emotionally exhausting and her concentration on return to work diminished.

> [This mother found it] hard to work after coming from the hospital. People would say you look exhausted. It was very exhaustive to sit up there in the waiting room. Waiting through the spinal tap and the bone marrow it was very difficult for me to be strong for her because I knew it hurt so bad. It was very mentally draining on me and it would take me a couple hours after getting back into the work to really concentrate on what I was doing. (mother)

Several parents stated they strived to maintain normalcy for their family. One mother stated, "The first thought was to drop everything, a few days later rational thought came, life goes on, our goal became to maintain the same routine we had always maintained and not to let the disease rule us". For example, the older sibling started soccer that year and they took the ill child to every game even when it rained. This mother also continued to work full time. This family, however was fortunate because their child had no serious setbacks and they were able to maintain the same reliable child care they had in the past. Another mother said, "You try to keep things as normal as possible. All they want to be is normal. They [the ill child] don't want to be any different, so you try to keep things as normal as possible".

b) <u>Parents' participation in treatment</u>. Many of the parents went to the clinic together and some siblings participated in the various treatments by holding their ill siblings hand throughout. All mothers went to clinic visits, only one did not participate in treatments because it was too emotionally devastating for her. Several fathers took their children to the clinic when the mothers were unable to attend because of illness, childbirth, or if the fathers were not working or were laid off work while the mothers were working.

When mother's participation was prohibited by circumstance, a close bond between father and child developed. For example the father said, "I wanted to be with her and to help her to face what was going to happen and just let her know I was there". Even now this daughter insists on her father's presence for spinal taps. In another family where father's participation in treatments did not occur until several months after treatment was started because of his fear of needles, he describes his awakening to involvement in the following dialogue.

First three months [after the diagnosis] we [saw]

> each other passing. Like I was saying, I was in a daze. I didn't know what was going on because she was there and saw everything and I missed all that. I don't know about the gruesome and gory things that were happening. I was just hearing about it. When I'd go up there at night she was sick and didn't look right but I didn't see all those things. She was smiling because she was glad to see me. I didn't really hit me until I took her up there. Until I really started getting into ... For a long time I just sat there, didn't even know what was going on and didn't ask any questions, I'm sitting there watching her get these needles, and I have a fear, I have a fear, I'm sitting there watching. I'm sitting there and every time she's getting a bone marrow I pass out. Oh, yeh. (father)

Only the maritally-separated mothers complained about their husbands lack of participation in the experience. One mother said this about her former husband, [I] "became busier, more to do, but I accepted that. Went through a couple of operations all by myself. He had to work. He never came up [to the hospital] until after the divorce." Not surprisingly both unmarried mothers' strong bonds with their boyfriends revolved around their participation and strong concerns for the children who had leukemia. One of these step-fathers went into the treatment room for all procedures and stayed overnight when the child was hospitalized because the mother could not bear to do either.

c) Activities as a result of illness. Most of the families said there was very little change in the activities in which they and their families engaged during treatment. At least two parents said they still went out alone without the children but it was just less frequently and the reduction was hardly noticeable to them. One couple said that when they did go out all they thought about was their child with leukemia so there was no point in going out. Five couples said they did not get involved with any new outside activities, but one of these were able to keep up their previous ones such as bowling on a weekly basis.

Many parents said they changed or reduced activities for fear of exposing the ill child to illness. One parent stated that the biggest change for them was that they couldn't plan ahead because they never knew if their child would be feeling well enough. Several families spent holidays by themselves to avoid exposing their children to infection. One mother explained her adaptation to this problem.

> Most of it is when you have a kid whose immunosuppressed you have a sixth sense about where you can go or where you can't go. So the things... because I was with X more during those

> times like take him to the library time or whatever the kinds of things, we changed what we were doing. ... we would go ... [earlier than] other kids. If he was going to a birthday party I would let the mother know to ... ask the kids before if they had chicken pox .... These were activities that weren't associated with school. Most people were real good. ... We always sent out letters. This is the first year we haven't had to, ... I think that's the main thing. Now we can go wherever we want and not think about it. (mother)

Three couples said they could not have become involved with outside activities because their lives were consumed with physical and emotional duties related to their child's condition. One couple described the emotional drain their increased busy schedule had on them.

> The thing that was the hardest was that emotionally we had a hard time accepting the thing they had to go to. It was more an emotional thing rather than a physical one. I just couldn't face having one more thing. It was just one more thing. (father)

> I was just overwhelmed for a number of months with a brand new baby and a sick little girl. I was not caring for the baby or caring for X or driving

> to the doctor or from the doctor or to the hospital or from the hospital I did not want to be bothered to go to a baby shower, or a wedding reception or even a party. I wanted to stay home and read the paper or take a bubble bath. I just needed some time for myself. I didn't take on anything new. I cut back on church activities and taking part in social activities just because I preferred to sit and regroup. (mother)

The three families whose daughters would not take their oral medications found their evenings and even whole days occupied with this process. One mother describes this experience,

> From the beginning she never moved or anything during spinal or bone marrows. She was really excellent. The pills were ... really hard. Now what do I do? She just threw them up all those pills I gave her. Now it wasn't that they had been down there very long. Her gag reflex was just .... She'd stand in the living room and they all came up and I'd say to [the ill child] run for the bathroom and she'd never make it. She couldn't run for the bathroom. It was terrible. And her father, he doesn't get mad at much. He's pretty even keel but he'd get mad at her. She wasn't taking them and she just dragged it on.

> And he just wanted her to get them down so we knew she would be all right. Especially after we knew later on, after 8 months into the treatment, after we knew she'd been hiding them.

After their children's diagnosis, some families became involved in new activities as a coping behavior. One mother joined a spa just to get away. Another couple made a rare trip out of town because they needed to get away.

> That was strange because we only did that one other time in our married life. It's very hard to leave a child who is ill because you always worried. I asked the doctor one time, when does this stuff start feeling normal, because that takes a long time. It was hard to do that but I felt that we both needed it. Especially me in a way because I dealt with it on a daily basis, but my husband in another way ... you're at work and you supposed to function, I don't think I could have done that.

Another outside activity was becoming involved with Candlelighters Childhood Cancer group. Of the couples that participated in the group one said that they became involved in activities because there was less chance of exposure to infectious diseases. Three other couples became involved after their children were off treatment. One couple now wished they had been involved all along because of the children, their children are meeting and the kinds of activities the Candlelighters Childhood Cancer Foundation sponsors. Another one of these later involved families felt there was too big of a difference between themselves and the rest of the group, calling the differences, those that exist between country and city people. Two couples found the meetings too depressing.

d) Employment of parents during illness. In some families major changes in employment of one the parents took place during treatment for the condition. Two fathers were laid-off for several months during treatment, but this had nothing to do with this illness. Two other fathers had very supportive employers who allowed them time off work for appointments and other illness related circumstances. Two mothers took leave of absences from their jobs. One mother took a leave of 3 years from work and decided to have a new baby during treatment. The other mother had a new baby just one month after diagnosis and took a year leave from work. Another mother eventually quit her job because she was unable to concentrate on her work like she had in the past. Three mothers continued to work because they needed to maintain insurance benefits and financial needs.

Summary of Stressors and Pile Up

This section described the initial stressors (factor a) and the pile up of stressors (factor aA) families experienced which occurred during the course of the treatment for each family. Initially parents were shocked by the diagnosis even though some had suspected something very serious. Parents varied in their statements regarding the time it took for family routine to run more smoothly. This probably varied because each family's circumstance was different. Some children had more complications, some families had more support, and for other parents their perception of what routine family life should be may have been finer tuned. Finally most parents accepted the diagnosis immediately or within days. However, one parent admitted that total acceptance of the impact of the condition on the whole family did not come until much later.

All the mothers in this group of parents were the primary caregivers of their children when they were ill. A minority of the mothers continued to work largely because of financial and insurance reasons. Nearly all fathers participated by going to the hospital, clinic and being supportive during painful procedures. The only fathers who did not participate subsequently became divorced. Mothers who lacked supportive husbands became involved with boyfriends who participated in the ill children's care. On the other hand, in instances where the mother could not participate, a special bond between father and the child developed. Evidence of this special bond may have implications for increasing parental participation. Families on the whole did not get involved in new activities, with the exception of the Candlelighter's support group for parents. Most families strived to maintain their normal pattern of activities for the benefit of all. Many families limited their activity in some way to reduce the chance of exposure to infection in their children. Most families felt an emotional overload that kept them from being involved in any extra activities.

Family Resources Existing and New; Factors b and bB

The second area of inquiry for this study was that of resources (both existing and new) used by families. This information corresponds to factors b and bB, existing and new resources which are present according to the model in the pre-crisis and post-crisis period. New and existing resources include those which minimize the impact of stressors; those in the initial phase and those that pile up over time. Parents were asked the following questions about resources: What seemed to help most in providing you and your family with strength, support and encouragement? During these early months after the diagnosis? maybe friends, relatives, neighbors, religious leader, doctor, or other health personnel. Who was strongest in your immediate family? or, what about religious philosophy and teaching, hard work and keeping busy, reading and talking with others who have had trouble, learning more, about illness, or other ideas? (Refer to questions IV, IVA and IVB in Appendix C.)

From these questions many types of support emerged which served to reduce the impact of the stressors. This section therefore includes the types of support parents received from people, either physical or emotional support. It also includes information of a psychological, spiritual or medical nature that were supportive to parents. The following types of support were described by parents: a) family support, b) support from outside the family, c) negative support, d) health care personnel support, e) supportive information, f) spiritual support, and g) psychological support. In addition, this section includes a discussion of the present findings in comparison to those described by Venters (1981) concerning support.

a) Family support. Of the eleven families interviewed six said that physical and emotional support from the mother's family was helpful to them. Five families obtained support from the fathers' parents. Some grandparents provided physical assistance in the form of baby-sitting the other siblings during hospitalization or during outbreaks of chicken pox in one of the siblings. Other grandparents were able to give only emotional support because they lived at too great a distance. Only one grandparent took care of the ill child and also went to clinic visits with the parents. One mother whose husband was not supportive said this of her parents,

> A lot of support came from my family, my mom, my dad, X was really close, she is my younger sister,

> she is very close to [the ill child]. My mom, there wasn't a day go by that she didn't make a call or wasn't over there, they are only 3 miles away, we always take [the ill child] there to go swimming. Being around my parents at the beginning knowing that they were always there helped me a lot. They were up at the hospital. I think that was a lot of that helped me, was knowing there was someone to cry with, some one to be there. (mother)

Four families said that their support came from within their nuclear family. And one family said they that their emotional support came from within themselves.

> Both my husband and myself are very much individualists, self-sufficient, we both, neither one of us has ever had a large group of friends neither one of us live near our families we don't have any relatives close by. We are both independent. Strength that comes from being an independent personality helped us deal with it. We didn't feel the need to go outside ourselves to get help and reassurance. I relied more on the people that I work with just to keep my mind on other things. Emotional support came from within, we pretty much dealt with it that way, independently. There wasn't much interaction

> between us. We dealt with it ourselves. (mother)

b) Support from outside the family. Various people who were not relatives were also helpful to some of the families. Two families mentioned that church friends were helpful. In one family these friends cooked meals for two weeks and another person took care of the family's ironing for months. Another family said that their neighbors provided them with support in the form of making meals in the first few weeks and offering to baby-sit during the course of treatment so they could go out alone. Two mothers said that talking with others was very helpful in understanding what they had gone through. Another church friend was a emotional support just by her presence which was constant in the initial phase of treatment, "Didn't say alot, we didn't talk alot, it was just her presence. We just knew she cared so deeply to give up all that time". Of these friends, this mother noted a common feature among them,

> What is interesting is that these people, if you knew their background are ones that have really gone through a lot of hard times themselves, had lost children for one reason or another. There is something about your kids that is really emotionally hard to deal with .... You can be sick yourself, your sister, parents, spouse that is one thing but, when its your kids it just tugs at your

> heart. They all knew what that felt like. They had felt a lot of devastation and shock that comes with a major crisis like this. They knew the questions to ask, how are you feeling? How did yesterday go? What do you have to do today that I can help you with?

After talking with other families it became apparent that this family had an unusual amount of caring support. Another family said that a neighbor who was a physician was available for consultation when they needed him and that was a secure feeling. This support was particularly helpful since the ill child had two sudden life-threatening complications that added to the mother's sense of vulnerability.

A mother and a father talked about their work environments as being supportive. One father said this about his work setting,

> [I was] able to verbalize to somebody. Some of the fellows I work with I was able to relate what was happening. They were interested, you know, and allowed me to verbalize, get it off my chest .... It may be the difference between men and women. You have to break beyond that barrier that says you don't share personal feeling and you don't own up to the idea that I am feeling rotten about the situation. It is hard to break out of

that barrier that restrains you.

c) Negative support. Three parents talked about people giving negative support, or showing insincere concern. One parent said their inquiries took the form of blame. She said they would say,

> Didn't you have any idea before she got sick that she had something wrong with her. What kind of a parent are you that you are ignoring your child all this time and she is so sick, you must have noticed something. They didn't say it outright, it was just the implication that you must have known something and you're already going through that. You are already saying, gosh when she had that fever I should have suspected something. (mother)

This mother's child presented with unusual symptoms that were misdiagnosed at first. With this kind of response from people it is no wonder that this mother relied solely on her own inner strength. Another family explained the lack of sincere interest on the part of some people was due to the following,

> People are threatened if you say anything but I'm fine. People don't really want to know, only close friends really want to know. They wanted to know how [the ill child] was but they really didn't want to know how I was or my wife was.

(father)

In another family the step-father explained what negative support was like, "We quit answering the phone, everybody wanted to know the same thing. How's ________ [the ill child]?"

Parents gave conflicting reports about the effect on them of other peoples outward display of grief. Two parents felt that this type of support was not helpful to them and another talked about the fact that it showed that people sincerely cared. One mother said this about other people who showed their grief.

> The hardest thing to do was deal with other people's grief and sympathy. I was almost physically ill thinking about going back to work and having to face all those people who knew, ... To try to deal with peoples inability to deal with it themselves, people don't cope with grief very well. I myself don't deal well with sympathy. It is difficult for me to accept sympathy and to understand it. The most difficult thing is to try to reassure people that I was OK. I was coping fine, please leave me alone. I can work all day long if you don't keep bringing it up and rehashing it to me.

Another mother said this in the same vein,

> Don't come up [to the hospital] to cry, don't come

> up and show us your crying and upset, ... Come up and visit, have happy faces, if your gonna cry, cry on your way home in the car, because I don't want to know you're upset.

One father talked about the fact that he learned that some people have limited ability to cope. "There were people who never came to the hospital to visit. We found out later that it wasn't that they didn't care, but visiting the hospital especially a sick child was too much for them". His wife added that outward evidence of grieving showed that people sincerely cared, "There is a false feeling that you shouldn't cry,but when actually it shows people that you care".

d) Health care personnel support. Health care personnel were found to be very supportive for five families. In four other families the physicians in particular were very important supports for the families. For many families support from health care personnel, especially physicians, were their primary and sometimes sole source. One mother said,

> I just put my faith in God and the doctors. There was nothing I could do for her and they could, more than I. I cannot say enough about those doctors up there. I love those doctors. Several nurses were super too. They would fuss over the kids. They always made a fuss over her younger

> brother. (mother)

Another father spoke to their physician's characteristics that were supportive,

> I think our experiences at the hospital were very positive. I think Dr. X was very effective. He was a good physician for me to deal with in the sense of how he approaches patients met my needs more effectively than some styles of other physicians would have, so I felt very comfortable with the medical staff up there. It's a great hospital. Partly if I ever had a question, ... he always answered accurately and fully. He had a tendency not to beat around the bush. If he didn't know the answer, ... he would explain that and say this is the information available and its gonna be somewhere between here and here. He's an incredibly effective communicator. It's probably his greatest strength.

Another father said this about his child's physician and the care they received,

> That guy can not say a word and say a whole bunch. He's a neat guy. The place, you go up there sometimes and the place is like a day care center, the environment around there, I mean they are almost like kids themselves. You go in there and those kids can't help but like it. Every little

> kid in there is always holding Dr. X's hand or they're hugging each other. ... that is where it has to start right there mentally.

e) Supportive information. Eight parents stated that learning about the illness through their own reading or from information given by health professions helped them to cope. All families were given a book called, "Leukemia and Me" which was designed for school age children, but was found helpful to many parents that needed an introduction to the pathophysiology of leukemia. All parents said they became very knowledgeable about leukemia. Some felt their extra reading and inquisitiveness helped them learn more than most parents whose children have the disease. One mother explained her reason for wanting to know as much as she could,

> Knowledge is ammunition, the more I know the more confident I am with dealing with it. I'm a sort of person who is comfortable with it. I can categorize it. We made an effort to learn about leukemia as much as we could, to learn about the treatment, to learn about the drugs just so we could have the knowledge. So we could deal with all the questions. Knowledge is confidence building. The more you know about something the less frightening it is.

f) Spiritual support. Four families said their support came from their religious philosophy, directly from God or from the Bible. One mother's encounter with God was described in this way,

> I had an encounter with the Lord and it gave me strength, it was when I was furthest down. It was after she relapsed, right afterward, when the marriage was falling apart, he didn't want to have anything to do with the kids or me and I just went outside and prayed and He answered me. Ever since then I have taken one day at a time and been more relaxed. I gave her to the Lord and that lifted everything off of me. It made me more patient, I was able to take on more if need be because I know I would make it. He said to me, the Lord will provide and after that I was more at peace.

g) Psychological support. Only one family sought therapy. This was reportedly to help sort out developmental problems from problems in behavior that could have been related to the long treatment regime this child required.

Summary of family resources existing and new/ and other research findings. Parents received support from a variety of sources. The most frequently mentioned ones were medical information, support from health care personnel especially physicians, and physical and emotional support from their own parents. Emotional support that showed concern for how they were doing was deemed most helpful. Physical assistance for the parents as in taking care of routine chores were also deemed helpful but infrequently offered. One parent felt that people who knew how to be supportive were those that had experienced personal tragedy. Support that was not helpful included insincere comments or comments that contained allusions to blame toward parents. Parents gave conflicting reports on how they were effected by others showing their grief in their presence. Support from God and the Bible was particularly helpful to families that had a preexisting religious philosophy. And finally, families gave evidence that many relied on support within and outside the family, but for those who had little of this it did not seem to be detrimental to their adaptation to the experience.

Support in the form of what Venters (1981) called "sharing the burden of the illness" was found by the researcher to be significantly related to high and medium family functioning as measured by the Adequacy of Family Functioning Scale. This included talking with and physical assistance of both family members and others outside the family. The findings of the present study suggested that this was an important factor but not a critical one for adaptation to occur. For example, in one family the mother was only minimally supported by her extended family that lived many miles away. This mother also did not discuss her worries or feelings about the disease with her husband or her co-workers, yet the family in the mother's view was very close, did things as a family quite frequently. She also felt they had gotten through the experience without any residual problems. However, most families did obtain some physical and emotional support from others, but parents did not usually attribute this to be a major part of their adaptation.

Coping Behaviors

This section will discuss a variety of coping behaviors that were used by families. The concept of coping relates to the second area of inquiry of this study, as it is a resource utilized by parents.Coping behaviors are included after the section on resources because the concept of coping is closely related to resources. For example, coping behaviors may be seen as personal resources. However, there are no specific interview questions that asked parents how they coped, but the information was obtained from their description of the experience and sources of support. Coping is defined as, "The behavioral responses of family members and the collective family unit to eliminate stressors, manage the hardships of the situation, resolve the intrafamily conflicts and tensions, as well as acquire and develop social, psychological and material resources needed to facilitate family adaptation" (McCubbin & Patterson, 1981, p. 14). The concept of coping also bridges all three factors (ie., factor aA, additional life stressors; factor bB, existing and new resources; and factors cC, families perception of the experience) in the post-crisis period of factors cC, families' perception of the experience in the post -crisis period of the Double ABCX Model (McCubbin and Patterson, 1981) (see Figure 1).

Table 3 lists the ways parents coped, and the number of parents that used that particular coping behavior. Each coping behavior is divided into either a passive or active category as defined by the Chesler and Barbarin (1987). The following section defines these two categories of coping and applies these concepts to the findings of this study.

Categories of coping. Passive or emotion focused coping, and active or external focused coping is a useful catgorization of coping strategies (see Table 3). Emotion focused strategies were defined as, "Internally directed strategies, aimed primarily at managing and controlling one's emotional reactions ..." (Chesler & Barbarin, 1987, p. 102). Active focused strategies on the other hand were defined as, "Externally directed strategies, aimed primarily at managing and manipulating events and resources in the social environment outside the person, ..." (Chesler & Barbarin, 1987, p. 103). Findings of the present study suggest that parents used both strategies frequently. Chesler and Barbarin (1987) found that emotion focused strategies appeared most useful in responding to the emotional stress of childhood cancer. Thus, this

TABLE 3

Coping Behaviors

Frequency	Active	Passive
4		Parent immersed self in employment
3	Family life kept as normal as possible	Used humor in coping with hair loss, and chemotherapy
2	Mother found supportive Father substitute	Talked to fellow workers to relieve stress associated with illness
2	Supports healing with nutrition	Prepared self for negative outcomes by thinking about them
2	Diary kept of treatments and tests	Maintained positive attitude
1	Built in rewards after treatments for children	Gave up ill child to the Lord
1	Developed assertiveness with medical personnel	Did not tell child about treatments ahead of time
1	Family activities	Hair loss was compared to baby cousins
1	Bought pink shoes for daughter when hair fell out	Trusted God and the doctors
1	Joined spa	Truck radio to reassure Father about home situation
1	Refused to visit hospital	Parents find things to be grateful to God for
1	Controlled who would take care of child in hospital	Parents urged daughter to talk about condition
1	Child controlled injection rates	Focuses on crisis, not prognosis
1	Parents went on walks together	Applied philosphy of persistance in the face of crisis
1	Parents socializing with family and friends	

environment outside the person, ..." (Chesler & Barbarin, 1987, p. 103). Findings of the present study suggest that parents used both strategies frequently. Chesler and Barbarin (1987) found that emotion focused strategies appeared most useful in responding to the emotional stress of childhood cancer. Thus, this classification is useful when looking at various strategies parents adopt throughout the experience and both types are needed for successful adaptation.

The same researchers enumerated several conceptual categories of these internal and externally focused coping strategies (Chesler & Barbarin, 1987). Internally directed strategies included denial, acceptance, maintenance of emotional balance, optimism, and reliance on religion (Chesler & Barbarin, 1987). They included only three externally directed strategies, search for information, problem solving and search for help. This grouping seemed a bit too narrow especially in the realm of external strategies. As noted in Table III there are many active strategies such as joining a spa or parents going on walks together which required external action that would not fall into any of the active categories listed above. Thus, the conceptual coping strategies noted by Chesler and Barbarin (1987) are too narrow to be applied to the findings of the present study.

Most parents in Chesler and Barbarin's (1987) study adopted symmetrical or similar coping styles. Five couples in the present study commented on their different or asymmetrical coping styles. Most of this difference stemmed from the fact that one parent, the mothers usually, freely expressed her emotions. The fathers were supportive but less expressive. One couple explained how their different coping strategies worked for them,

> I don't think this even bothers you. It made me angry that I didn't see a lot of emotion. This is our daughter why aren't you upset. My way of dealing with it was to cry about it; to get angry and holler. (mother)
>
> I was concerned about getting it all over with and getting back to a more normal route. They wouldn't let [the mother] do anything, at the hospital she was just supposed to sit. So I had to do all the running around the hospital, running all the errands. I was right in the middle of it. Maybe I didn't have time to think about it all. I could see things were being done. They were proceeding with course of treatment. [The mother] was sitting in the room and wondering what would happen next." (father)

This complementary coping style, or as Chesler and Barbarin (1987) termed it, asymmetrical coping style, may be attributed to cultural conditioning of men and women. It may also have a functional purpose in that each member takes on a distinct role and there is no adaptive motivation for the couple to duplicate the other's role.

Another form of this complementary coping occurred around the theme of information seeking. This situation was not specific to sex role identity. For example, one parent would frequently read all the medical literature while the other relied on the reader parent to verbally inform them of the information.

Summary of coping and preliminary interpretations. The findings of the present study suggest that parents used both passive and active coping mechanisms in their adaptation to this experience. Whether one strategy is more useful to parents than the other can not be determined from the data. The conceptual categories for coping mechanisms used by parents need to be broadened to define and include more action oriented strategies. The interview comments and data reflect that parents more frequently engaged in complementary coping strategies than symmetrical ones, which may have some adaptive value. And finally, families gave evidence that many relied on support within and outside the family, but for those who had little of this it did not seem detrimental to their adaptation to the experience.

Perception of Stressors and Experience, Factors c and cC

Parents perceptions of the stressors, factor c, and perceptions of the experience, factor cC, from the onset to the present is the third area of inquiry of this study. These factors are present in the pre-crisis and the post-crisis period of the Double ABCX Model (McCubbin & Patterson, 1981). These areas were explored in the interviews by means of the following questions: At the time of the diagnosis what were your impressions about what this would mean for X? the whole family? Have you changed your mind in any way about these first impressions? (Parents were given a choice as to which probes they could respond too.) How about your attitudes or values toward life, have they changed at all? About what's important in life? About God and religion? About scientific medical knowledge? About the order and meaning of life in general? If someone were to ask you to explain the reason for X's condition what would be your explanation? A deliberate act of God? A random event for which God's guidance is necessary to survive? A condition which afflicts a family which has multiple causes which are not clear to us today. or maybe no explanation? Have you ever thought that X's illness had changed, or might change your overall plans for your family? How, why? Today? What about the future of the family? What about X's future? any vocational plans? Some parents have found they have grown away from their child as time passes and life becomes busy with other things. On the other hand, parents have found family members have become closer over time. What has been your experience with you family as far as relating to X? In general would you say that leukemia tends to draw your family closer together, make things more difficult, or no change? (Refer to questions V, VI, and X in Appendix C). The following section will discuss parents' initial knowledge of the condition and the following areas of parents' perception of the experience: a) changes in values, b) the order and meaning of life, c) ideas about God and religion, d) beliefs about scientific medical knowledge, e) causes of acute lymphoblastic leukemia, f) future plans for family, and g) family closeness. Intermediate summaries with preliminary interpretations are presented as subsections throughout the data in this section on perception of the experience. This will allow detailed data to be identified for each of these important areas.

Initial knowledge. Most of the 22 parents had some familiarity with the term leukemia at the time of diagnosis of their children. Most knew it was a "dread disease" which was believed to be commonly fatal. Two mothers had encountered leukemia in their employment. One mother had worked in pediatric nursing during the days when most children died of leukemia. One mother, for example, who worked with adult hospice patients had also been very familiar with the fatal aspects of adult forms. One mother was alerted to the seriousness of the disease by the fact that she was referred to a specialty hospital after a work-up at another hospital failed to confirm the diagnosis. This mother said, "If they didn't know what to do with you they sent you to the [specialty hospital], that scared me".

Parents knowledge about leukemia quickly changed because all physicians of the children in this study gave parents frank accounts of the treatment and the possibilities for a more favorable prognosis with this condition.

a) Changes in values. When parents were asked how their values had changed, the responses were varied. Only one parent said that there were no changes in values. Five parents said that people in their lives became more important to them. Two other parents said that relationships with other people became more important as well as their children after this experience,

> I always knew in my head that the most important things were people. There is nothing more important than the relationship with the people we are close to, whether its our spouse, our kids.

One father very movingly told how he began to recognize his own self-centeredness and become more cognizant of others in his family through this experience.

> I was raised in a macho man society, I guess. I had three brothers, my dad was in the military 25 years. And you don't have sympathy. If you fell down and broke your arm it was your own damn fault. I don't feel sorry for you. See I had to

> deal with that because I just don't sympathize. Like things were going bad for her sister, I just couldn't sympathize with her, because if there was a way out she could find it and work for it. When this happened with [my daughter] I had to deal with that. I think part of it was that we were not overly sympathetic to her that helped her. [On the other hand, you had to realize that [your daughter] couldn't really help her situation and to a certain extent you did have to be sympathetic toward her?] (investigator) I did. Here I was 29-30 years old, you see I didn't grow up until about five years ago and it took a long time. I was ignorant or naive about a lot of things emotionally. I was too busy doing other things. I was number one and these guys were just pawns. [The experience with your daughter changed all that?] (investigator) Oh, yes, it did, I hurt for her. ... like I said it's just been in the last few years I began thinking about these things.

One father specifically said that his family became more important than advancing his career as he had planned. Two mothers said they became closer to their children. This mother said,

> It probably helped me take a little more time with

> him, and really value my kids, the time with them. And personally to be closer and to hug more. I tend to be that way anyway with my kids, but I probably am more so.

Another parent said that life became more precious for them, along with appreciating her children more and living day to day.

> Life became more precious. Just happy to be here everyday. Just happy to have her. When she was so sick it was just a ... we are grateful she is here, if we lose her now we will have had her three years. You've had them for that length of time be grateful for what you've had. It's the only way you can deal with it. (mother)

Another theme mentioned by five parents was that of living day to day. They said they worried less about the future and the past but tried to live for today. Another parental couple said living day to day is the only way one can function in a crisis.

Four parents talked about their increased awareness of other people especially children who are ill or have cancer. With this awareness also came a sense of vulnerability. One mother said,

> Then I started looking around at the children ... [in the hospital] ... connected to all these tubes, parents riding them around the halls.

> There are no lights at the end of the tunnel for lots of those kids. ... I always believed from the minute they told me that it would be all right, I try to be optimistic. Then when I see those kids, I would think that God we have a lot to be grateful for. It hits me mostly when I see a movie or I'm out and see a kid in a wheel chair or at a baseball game and I think god, or when you go to church or whatever.

Another mother said similarly,

> I probably appreciate more in a broader sense anyone that's in this situation with any kind of illness. And probably in my work too its probably really helped me because I deal with people who, ... I think its given me a better understanding of what people go through when they're effected by an illness. The social problems, the emotional issues and the kind of anxieties they have. I think probably I am more effective at my job, but also just in a personal sense. When someone tells me their child had surgery or something I think I have a better understanding since he's been sick.

b) The order and meaning of life. Families were also asked if this experience had changed their thoughts on the order or meaning of life in any way. Few parents responded to this probe, probably because it is intrinsically ambiguous. Two fathers said they didn't perceive any changes. Another father said that he now appreciated more the small things in life.

> You appreciate the smaller things in life, you appreciate what you have, that what she doesn't have, you also appreciate how she adapts to what she does have, what I mean that, the meaning of life is being now and to make the best of the moments, I think that is what it comes down to, you face challenges, you see oh that is interesting.

Summary of initial knowledge, changes in values, and the order and meaning of life. Most parents had some familiarity with the term leukemia and its life-threatening nature. Almost immediately after the diagnosis parents became informed by physicians of the probable favorable prognosis for their children. Many families' values were enhanced and they were forced to reexamine priorities because of the experience. Parents reported that they valued their relationships with other people and their children more. Parents said relationships with others became more important than advancement at work or having a clean house. Many parents focused on living day to day. Another father talked about learning to appreciate the small things in life because of the experience. These two areas, values and meaning, are closely related areas of perception.

c) Ideas about God and religion. Families were also asked how their ideas about God or religion had changed as a result of the situation. Four parents said there was no change in their ideas. One couple said they did not espouse to a religion then or now. Three other parents described themselves as having a religious faith but there was no change in it as a result of the experience.

Five parental couples said that their faith in God was enhanced in some way. One father said, "When you look at how it all worked out it really enhanced what we already knew and believed. Somethings became more personal". This father also applied the living for today philosophy to God, "When it comes to having a relationship with God there is no tomorrow because if you keep putting off tomorrow you may miss it". One mother said this about her faith,

> My faith has grown in that I always felt the presence of God, I always felt that inner strength but there were times when I was so physically tired and emotionally drained that I am sure that the strength of God was the only thing that got me through. I'm not sure I will ever need that again unless I go through another difficult situation like this but I firmly believe that my prayers and prayers of my husband, my family, and my church were one of the things that really got us through our day and I never questioned or doubted why this

> has happened to me, I don't ever remember thinking that.

One mother described the following experience which caused her to feel closer to God,

> ... there was more opportunity to be close, not that you just pray in bad times, you pray in good times too, but there was more petitions, plus there were a lot more answers ... [One of the ill twins] used to come down the stairs and say mommy Jesus is going to come help us and make me all better, make my sister and brother all better. I said how do you know this, did somebody tell you this? She says I just know and she would say it so matter-of-factly that it was like somebody told her that and this was during the time when they were coming up for randomization. And I was struggling with how do I explain to this child, yeah, he could make her better, sometimes he chooses not too. I struggled for two weeks, that was really difficult. ... It wasn't two weeks later when [this same twin] came down the stairs and says mommy Jesus is coming to our house to make our blood all better and the other [twin] said, maybe not! That was the end of it. It was like, I sat down and cried. ... It was like I wanted to sit in their room at night and see who

they were talking to or who was talking to them. Another parent was beginning to return to regular church attendance when her child became ill with leukemia. Just about the time of the diagnosis when the mother went to church one day the reverend gave a sermon that said, "If you've come to church just to ask God to cure an illness or repair a broken marriage or whatever ... that's not what you come to church for". This mother quit going to church for some time after that. Thus, this mother who was beginning to be drawn closer to her former religion found that religion offered her no solace in a time of need.

Summary of ideas about God and religion. Families didn't change their beliefs about God and religion because of this experience. Some of those who had previously believed in God or a religion said their faith was strengthened by the experience. None of the parents who did not previously consider their religious views fundamental to their identity, did so as a result of this experience. Only one mother described a situation that kept her from attending church and perhaps asking help from God.

d) Beliefs about scientific medical knowledge. Parents were also asked about how there their feeling about scientific medical knowledge changed after this experience. Five parents were surprised at the progress medical science had made, especially with leukemia, in such a short span of time. One father said, "I came away, I was never antimedicine or science, but I came away with tremendous appreciation for it". He also added, "I was very scornful of others that we met who were disdainful of medical treatment and who sought alternative treatment". One parent said that she was disappointed at where medical science was at,

> I was really disappointed as far as the research has come with cancer, that here, gee being the 1980's, I thought it would be more than it actually is. I found that out by the group A, group B. You got to be kidding me, you mean you people don't know in the 1980's that a kid who has a 95% chance of recovery, low risk, you don't know what protocol to put them in? I was surprised by that. (mother)

Several parents felt that their children's cure came from the family or the children's positive attitude or fighting spirit. One father said,

> But I really firmly believe its got a lot to do with attitude. If you don't have a good attitude that medicine they give you is not going to do you any good. If you want to die, your gonna die. I just think attitude is 95% of the healing process. (father)

Summary of beliefs about scientific medical knowledge. Most families were surprised by the advances medical science had made in such a short time in the area of acute lymphoblastic leukemia. Parents believed that their family had influence however, over the course of the disease by their positive thoughts, prayers, and creating a positive family environment, etc.. Many parents also felt their children's positive attitude and fighting spirit effected their continued survival. Perhaps this is because to think otherwise would be in effect saying we have no control over this; we are vulnerable.

e) Cause of acute lymphoblastic leukemia. Parents were asked what they felt was the cause of their children's condition. The answers to this varied greatly although six parents said there is a cause we just don't know what it is today. One parental couple explained what they saw as the cause. "Many are susceptible genetically and something triggers leukemia that is unknown". (father) The mother added, "There are a lot of things that bring it out but it doesn't mean that gave it to them. The way we understood it is that 80% of the world's population has the cells in them and their is a trigger mechanism". This family was very aware of the genetic propensity since their identical twin daughters became ill with leukemia ten days from each other. Another speculated that the stress she endured through the pregnancy with the ill child might have caused leukemia.

> How [the ill daughter] got it out of everybody else, no cancer in the family, just the way the

> cards were dealt. No definite answers about the cause. With [the ill daughter] I was extremely stressed because I knew my marriage was going down the tubes, knowing also that my marriage wasn't going to last very long and knowing I had another child on the way I would have to take care of on my own. I was very stressed so I thought maybe being stressed out could have been part of it.

Another family whose daughter became ill with another serious condition just before the diagnosis of leukemia felt that perhaps taking their daughter abroad had caused it.

> Yes, one of the questions I had was had we in some way inadvertently caused this by exposing her to something or having her in the wrong place. There is some leukemia that is environmentally caused ..., but [the doctor] assured us that so far as ... But even if it had been, there is nothing we could do about it.

As in many other aspects of parenting these parents had some guilt about the causation of the disease.

One parental couple said they did speculate, but did not let it come to the forefront of their minds.

> I have absolutely no idea, if I did I'd be rich.
>
> I have a tendency to very lightly speculate then quickly put it out of mind, because if I wanted to come up with all the risks and possibilities, by

> the time .... Because everything you come up with has equal weight so you could .... Speculation about nothing is a waste of your time and energy. If you take your speculations too seriously it'll just upset the apple cart. Maybe you could speculate that the cause of leukemia was eating the right stuff.

Another family was confronted by people at their church who wanted to know what they had done wrong. This couple explains their version of God's will.

> We didn't think God brought this into our lives to punish us or to teach us a lesson. (mother)
>
> We don't believe God does this. Things happen to human beings because we live in a world where there is disease, sickness and death and that is just part of being in the world. We just felt so fortunate that we knew a loving God that could give us the strength and help to get us through hard times. (father)

<u>Summary of the cause of acute lymphoblastic leukemia</u>. The parents interviewed had all wondered about the cause of leukemia. Many had speculated on the cause and had come to the conclusion that there was a cause or multiple factors, but that it remained unknown to us. This unknown factor led many parents to speculate as to the cause. Guilt caused by parents' own fears or the comments of others was an issue

parents had to struggle with. Blame from others led one couple to articulate their beliefs about God's role in human affairs.

f) Future plans for family. Parents were asked how this experience changed their plans for the future of their family or their children with leukemia. Two parental couples felt the future was not changed for their children or their families. One child's side effects from therapy were so severe that the parents wondered if she would ever be able to live an independent life away from them. Another family said they don't make plans for the future.

> No, we don't make plans. (father) No we've had so many financial and emotional wipe outs in the last year. We can't plan anything. We just go by day by day. If we go through a week without having any bad news I just go woopie. (mother)
>
> Yes, maybe inside we do. We just hang out at home a lot. We encourage the kids to take part in school activities. (father)

For another family the financial stress was very high because they were ineligible for insurance coverage under their policy for the leukemia for the first six months of treatment. During this time both of their daughters were critically ill needing intensive care. The mother explained that it was difficult because, "We couldn't get anything or have anything for fear it would get taken away". This uncertainty about their financial future kept them in a survival mode of living day to day. This family is just now beginning to recover from the financial devastation.

Another mother talked about the effect the condition had on her daughter;

> If its done anything for [the ill daughter], she's always been spunky, its made her more spunky. It's made her fight harder. It's made her want things more. It made her know that I'm sure if its not a pediatric oncologist it will be something in medicine. It made her realize she can do anything she sets her mind out to do. For now she has conquered cancer, whether or not that's the case as he said on our last day of treatment. It can come back so you always live with that, but she knows she can fight .... When you deal with cancer you deal with the worst.

<u>Summary of future plans for family</u>. Parents on the whole did not see any change in their future as a result of the experience. With some families the future seemed uncertain because of residual effects on the ill children. For others there was hesitation about looking to the future because of an increased sense of vulnerability to calamity they felt. For one child a sense of purpose and possibility was kindled by the experience.

g) <u>Family closeness</u>. Parents were asked how the experience had effected family closeness. Only three parents said that family closeness of any of the members was not effected by the experience. Three families cited negative effects in terms of family closeness because of the experience. The negative effects of the illness noted, had to do with causing stress in the family, causing neglect of healthy siblings and causing the divorce of one parental couple. In spite of these negative effects many of these same families identified increased closeness between parents, parent-child and grandparents.

Summary of family closeness. This current study suggests that most families are drawn closer together because of this experience. Chesler and Barbarin (1987) found that 50% of families in their study said family life had improved, 42% reported quality of family life was the same and 7% said that family life was worse. This concept is not exactly the same as family closeness but in this study most families saw some benefits of the experience to the family while the other study did not. One explanation for this lack of effect seen may be that the words quality of family life may not elicit the same kinds of feelings as does the words family closeness.

Summary and preliminary interpretations of perception of stressors and the experience. Most parents had some familiarity with the term leukemia at the time of the diagnosis. It was commonly believed to be either a very serious disease or a fatal one. Physicians informed all parents in the study of the possibilities for a more favorable prognosis soon after diagnosis.

Many areas of perception of the experience were explored during the interviews. Most parents experienced a greater appreciation for their children and other people as opposed to personal ambition or the appearance of their homes, and so forth. Many parents became focused on living day to day. This was probably due to two factors reported by parents. One parent said that the crisis situation kept her family in a survival mode which does not allow for looking beyond the present circumstance. Several parents indicated that this occurred because one becomes more appreciative of the present moment due to the increased sense of vulnerability that develops. On the whole parents did not change their ideas about God or religion because of this experience. However several parents who had a preexisting religious philosophy felt their faith was strengthened by the experience. Most parents were surprised by the progress medical science had made in the treatment of acute lymphoblastic leukemia. One parent was disappointed with the progress in the treatment. This may be due to a belief that science has answers to all problems. This belief may also have a certain protective function. In spite of parents praise of medical science in this area, parents reported that their children's positive attitude and a fighting spirit or their own prayers had actually influenced the success of the treatment. Perhaps this is because to think otherwise would be in effect saying we have no control over this; we are vulnerable. Most parents perception about the causes of leukemia were linked to unknown factors. Some parents worried about various things they could have prevented as possible causes. Blame from others caused one couple to articulate what they believed God's role in the experience entailed. Most parents did not think the experience had effected their future. Some parents, because of an increased sense of vulnerability, had not yet begun to consider the future. For one child many positive possibilities for the future were kindled. Most parents felt the experience brought two or more of the family members closer together. Parents perception of the stressors and the experience was a major factor in their outlook. The results of this study are in agreement with Venters' (1981) study which found that parents used a preexisting scientific or religious philosophy of life to interpret and define the illness situation.

Endowing the illness with meaning was a phenomenon found by Venters (1981) to be associated with high and medium family functioning. The author defines this as, "... the parents ability to give specific illness related hardships more of a positive than negative interpretation and define the illness situation within a previously existing religious and/ or medical scientific philosophy of life" (Venters, 1981, p. 292). A prexisting scientific or religious philosophy of life was used by parents to obtain this meaning. The present interview comments reflect similar results. Most parents' explanation of the illness was a scientific or religious one. No family gave evidence that they had made changes in their previous belief pattern because of their child's illness. One parent had a major change in thinking about others. This experience did not make any parents become religious, when they had previously not been or vice versa. Some of the the families who previously had based their beliefs on a religious philosophy said their faith in God had been enhanced.

Demographic Factors' Relationship to Adaptation

The fourth area of inquiry examined in this study concerns demographic factors (e. g., age of the children, the age of the parents and the length of time since diagnosis) as they relate to the interview findings. These demographic factors are discussed here in relation to the families' general adaptation.

First, the age of the children played a significant role in how they reacted to the experience of having leukemia. Children's reactions and their impact on parents' adaptation is important because the young children's reactions were often perceived as difficulties for parents in this study. For example, the child that was the oldest, eight years when the diagnosis was made, had the most difficulty accepting the diagnosis. A theme discussed by this child's parents was that she wouldn't talk about her illness to anyone and she didn't want anyone to know. This child also refused to take her medication and vomited immediately after ingesting any. This was a constant sources of stress for her parents. This behavior can be explained developmentally in part by Erickson's (1963) concepts of "industry versus inferiority", which is the developmental task for the school-age children. Erickson (1963) states the following about the dangers present for the school-age child. "If he despairs of his tools and skill or of his status among his tool partners, he may be discouraged from identification with them and with a section of the tool world" (p. 260). Thus, the refusal to take medication was possibly due to her growing awareness that the medication was now a symbol of her differences from her peers. Another child who was six years old when diagnosed also refused to take her medication, vomited immediately after ingesting medication. She also sought control of injections by telling the nurses when to stop and start injecting in the middle of the procedure. All of these actions may be attempts to maintain control and thus accomplish industry versus inferiority. Waechter, Philips and Holaday (1985) state that the school-aged children "... are also very concerned about mastering the experience and maintaining self-control" (p.1275). This growing awareness of their differences and their still limited view of the future compound the problem of administering medication to this age group.

Another developmental factor for school-age children is their limited ability to focus on future goals. According to Waechter, Phillips and Holaday (1985) children in concrete operations still are unable to project into the future and therefore will not see the necessity to take medication to cure their illness (p. 65). This behavior however, caused parents to become very anxious; for they perceived that these treatments could save their children's lives.

The children who were youngest at the time of diagnosis were reportedly very compliant with their treatments; laying still and not crying through the most painful ones. This behavior can be explained developmentally in part by Erickson's (1963) developmental tasks of autonomy versus shame and doubt, which is the developmental task of the toddler age group. Erickson explains shame in the following way, "He who is ashamed would like to force the world not to look at him, not to notice his exposure. He would like to destroy the eyes of the world. Instead he must wish for his own invisibility" (p. 253). Thus, their compliance may have been due to their shame which caused them to want to reamin unnoticed.

In conclusion regarding age of the child, children respond to illness according to their developmental level and an understanding of this will lead the nurse appropriate intervention. In addition it is important to always in keep mind that children, just as adults, may regress to an earlier developmental stage which is more familiar to them during a time of stress (Waechter, Phillips & Holaday, 1985).

The demographic factor which seemed to have some significance for families was the length of time since diagnosis to the time of the interview. For the majority of families the length of time since diagnosis did not seem to vary their responses. However, one family whose child had only been off treatment for six months (which was the shortest amount of time for anyone in the study) did seem to note less changes in their lives as a result of the condition and emphasized the amount of stress involved in the experience more than other families. It is difficult to say whether this is directly a function of an all-too-fresh experience or something particular to this family's orientation. Two families had been off treatment for as much as six years. One father had published an account of the struggles and the things he had learned through the experience. This parent showed no hesitation to the interview questions probably because he had already formulated many of same questions in his own mind. His responsiveness may be attributed to two phenomena: writing as therapy and a matter of time. These data suggest that time may help in two ways. First of all, time may help a person forget the day to day stressors that make such an experience very tiring. It also may give one the space to synthesize the experience (especially when reflecting about the experience through writing) and come to some resolution from within.

Another demographic factor which was proposed as possibly making a difference in parents' responses was the age of the parents. This did not seem significant except that the younger couples seemed to have more difficulty financially because of lack of insurance coverage and unemployment of one or both parents. However, more subtle differences may have been evident if the research tools had been more sensitive.

Past experience with a crisis, rather than age of the parents, may have had an effect on the parents' adjustment to the experience. Some parents said that past hardships or the experience with leukemia had taught them that they could get through anything. Nearly half the families had no previous experience with a crisis of this proportion. One mother talked of how being forced into the all too familiar survivor mode effected her,

> I would get angry most of the time when I was alone. With growing up with what I grew up up

> with, abuse with my parents, it was never directed at me. Everybody in the family said I was tough, she's a survivor, she'll buck-up and go on no matter what and I remember getting very angry, going outside and getting angry. I don't want to go on, I don't want to buck-up. I want to sit and bawl and have a fit and I want everybody else to take care of me and it just wouldn't happen. I remember getting really frustrated with that. I had to do it, I had to go on, I went outside had my fit and would come in the house and would be over with it and go on.

This data is by no means conclusive. It is, however, interesting to speculate whether people who adapt more easily do so because of past experience, or whether the phenomenon has something to do with their personality traits or developmental level. It is probably a combination of these.

Summary of demographic factors in relationship to adaptation. In summary, age of the child seemed to effect the responses to treatment both in the immediate situation and over an extended period of time. This has implications for clinicians as well as researchers. Length of time since diagnosis did not seem to effect most families' adaptation. However, in two families the time since diagnosis from the interview seemed to have had some effect on their adaptation. One father whose child had been off treatment a very long time seemed to have adapted very well to the situation, even though his daughter had experienced residual effects from the treatment. Age of the parents also did not seem to effect their adaptation to the experience. It is proposed that past experience with crisis may have more to do with adaptation than age of the parents.

Trends and Themes Related to Adaptation

The fifth and final area explored by this study was trends and themes in the lives of these families that were related to adaptation. These themes emerged from and were identified after each interview. They were the themes that emerged from the parents' statements that were noted by the investigator and seemed to directly contribute to adaptation. However, they were probably not the only ones that may have contributed to adaptation. (See Table 4 for a listing of other themes discussed by parents that were not related to the research questions). These themes related to adaptation are divided into five categories for clarity, and are: parental interaction, personality factors, religious or personal philosophy, changed attitude due to crisis, and support from others outside the family.

Parental interaction. Parental interaction between parents seemed to foster adaptation. Parents who could openly discuss issues and disagree seemed to have adapted more successfully. Where this behavior was evident it seemed to foster problem solving behavior on the part of the parents. Secondly, in several families, mothers were able to express their feelings openly to the fathers. This behavior seemed to help families know how the other person was doing. In these same families the fathers did not seem to express their emotions as readily. However, the fact that the fathers were supportive of the mother seemed to be a helpful factor in the couples adjustment. This interaction could also be termed complementary roles as presented previously along with data concerning coping. Complementary roles occurs where one parent actions are in effect condoned or supported by the other. This was displayed in one couple where the father was apparently did not worry through most of the ordeal while the mother seemed to carry the emotion for both. In several families the differences between parents' coping styles was evident and openly discussed by them. In families where the the parents were aware and accepting of each other's personal coping behavior, this acceptance seemed to have fostered adaptation.

Personality factors. Specific personality factors that seemed to be conducive to families adapting were: (1) mothers' ability to be assertive; (2) mothers' learned ability to survive hard times; (3) fathers' ability to escape from current problems, yet not denying their existence; (4) mothers' ability to withstand difficult times; (5) mother's strong belief in their inner ability to cope; and (6) mother's ability to immerse self in work and be successful. These personality factors could also be seen as coping behaviors, but they are listed here because they seemed to be innate qualities of the parents that played a significant role in their adaptation.

Religious or personal philosophy. In several families adaptation could be explained by a personal or religious philosophy. A personal philosophy of not giving in to an affliction seemed to be what helped one step-father to be patient and encouraging to a child who had many residual effects to overcome. A strong religious faith seemed to be the guiding factor in several families.

Changed attitude due to crisis. A change in attitude seemed to help two parents adapt. One father became more concerned about others and another mother reaffirmed her belief that she could handle anything that came her way.

Support from others outside the family. In only two families did external sources appear to play a significant role in their adaptation. In these two families these external sources were help from others, such as relatives or friends.

Summary of trends and themes. Parental interaction that was open, complementary, and supportive presented as the most prevalent factor in these families' adaptation. Personal factors such as ability to express feelings, learned survivor ability, assertiveness, and ability to not let thoughts about the crisis predominate their lives, seemed to be the overriding themes that families reported helped them adapt. A strong belief that God would help them endure was also an overwhelming theme.

In Table 4 themes are listed that were discussed by parents but which were not directly related to either the research questions or the conceptual framework. They are in themselves interesting but their analysis is beyond the scope of this study.

Table 4

<u>Other Themes Related to Parents' Experience</u>

1. Cure is worse than the disease
2. Answering hard questions posed by siblings
3. Having to deal with other peoples emotions
4. Grandparent has faith crisis
5. Re-experiencing feelings when confronted with other people with cancer
6. Younger siblings look forward to doctor visits
7. Questioning ability to cope if prognosis hadn't been as good
8. Trying not to cry in front of ill child
9. Looking at ill child is painful
10. Alcohol as an escape
11. Realizing severity of illness by environmental cues
12. Grandparents wishes to change places with child
13. Realizing ill child's developmental needs
14. Experiencing God's healing
15. Implications of suffering

Chapter IV

Discussion

This section will discuss the concept of adaptation as defined by the Double ABCX Model (McCubbin & Patterson, 1981) and how that relates to participant families' descriptions of their experiences with their children having acute lymphoblastic leukemia. Also discussed here is the applicability of the model to the crisis of parents having children with acute lymphoblastic leukemia. In addition, this section will include a discussion of the similarities and differences between the adaptation of families who have children with acute lymphoblastic leukemia in this study and those that have cystic fibrosis according to Venters' (1981) findings. This section will conclude by considering how this investigation is congruent with current research issues concerning adaptation to childhood chronic conditions.

Adaptation

Adaptation is the central concept of the Double ABCX Model (McCubbin & Patterson, 1981) and the culmination of the eight factors and coping previously addressed in this text. The concept represents a continuum of behaviors that range from the ideal state, called bonadaptation to a less than an ideal state called maladaptation. According to the authors, adaptation also includes a "... family's efforts to achieve a new level of balance at both the individual-family and family-community levels" (McCubbin & Patterson, 1981, p.

11).

The definition of bonadaptation (McCubbin & Patterson, 1981) includes a balance between both individual-family and family-community levels which results in the attainment of three criteria. Bonadaptation includes: 1) maintenance and strengthening of family integrity, 2) continued promotion of both member development and family unit development, 3) maintenance of family independence and its sense of control over environmental influences. According to the authors, all three criteria must be met in the analysis of family functioning.

Maladaptation at the other end of the continuum of adaptation occurs when only one of the following exists: 1) deterioration in family integrity; or 2) a curtailment or deterioration in personal development of a member or the family unit's development; or 3) a loss or decline in family independence and autonomy (McCubbin & Patterson, 1981). Maladaptation is also "... characterized by a continued imbalance at either level (member-to-family or family-to-community) of family functioning ... " (McCubbin & Patterson, 1981, p.11). The theorists also add that "... family adaptation is but a descriptive criterion of family post-crisis outcome rather than a clearly defined and operationalized set of measures" (McCubbin & Patterson, 1981, p.11). Thus, for this reason the labeling of families at either end of the adaptation continuum is beyond the scope of this study.

As stated above, the criteria for adaptation is at the descriptive level, but the subsequent analysis will attempt to illustrate the criteria in terms of the information given by families in this study. All families interviewed felt that they had "made it" through the experience. Families were not asked specifically if they had met the criteria for bonadaptation, but rather it was inferred by the investigator from their statements about their experience.

Several families had met the criteria described for bonadaptation which is the maintenance and strengthening of family integrity. As mentioned previously, the family's perception of closeness was increased in some way in all but three families. In the remainder three families, the parents maintained that they were equally close before the experience. If one can say closeness is a component of family integrity, then it was strengthened.

A deterioration of family integrity was experienced in two families who divorced during the treatment phase. Of these two families, only one, in the mother's opinion, was directly related to the child developing leukemia. In the other family the deterioration of the marriage occurred some four years before the leukemia when the mother was pregnant with the same child.

Although the interview questions did not specifically refer to member or family unit development, one criterion on the adaptation continuum, a few families did indicate that there was a decrease in outside activities. Frequently mothers and sometimes fathers put their own personal or social growth on hold even after the crisis had past. Several couples did not really become involved in any activities outside their family. However, they encouraged their children to get involved in school activities. Family unit development on the family-to-community level appeared to be inhibited.

Some families also appeared to experience difficulty meeting the third criterion for bonadaptation, maintenance of both family independence and its sense of control over environmental influences. This may be attributed to a common theme reported by parents, that being an increased sense of vulnerability to illness and to calamity in general. Some of these couples had been under a huge financial strain due to illness related expenses or had experienced other devastating calamities during the course of the illness and treatment.

The process of adaptation was examined in view of the factors of the model. There were no specific interview questions which asked parents to explain this process. The process of their adaptation was inferred from their experiences. As a result of this fact and of analysis, no clear pattern of this process emerged from this data. It was, however, evident that all families experienced changes in factors of the model (stressors, resources, coping and perception) which culminated in adaptation. Therefore the process of adaptation seems to include the factors of the model.

Applicability of the Model

The Double ABCX Model (McCubbin & Patterson, 1981) has formed the conceptual framework for this study and has successfully outlined the basic factors of adaptation inherent in a crisis. Many of the themes discussed by parents were representative of the eight factors and coping presented in the model. The current findings suggest that perception of the experience may be the most important factor in determining adaptation. Each couple interviewed said that they had successfully coped with the experience of having a child with leukemia, even though each had experienced various levels of support and used different coping strategies. In addition, many parents attributed their child's recovery to their own or their child's positive attitude, or their child's fighting spirit. Clearly this shows the value parents held for their perception of the experience. Also, families felt that they had made it through the experience even though it was evident by their remarks that many were still suffering from the effects of the crisis. What they thought about the experience clearly played a larger role than the support they received. Because of the importance of perception, it should be emphasized by depicting it larger than other factors in the diagram of the model and tying it in more directly to adaptation.

Another source of concern regarding applicability of the Double ABCX Model (McCubbin & Patterson, 1981) was that the criteria for adaptation adequately reflect reality. Since each couple interviewed perceived that they had successfully adapted to the experience, this perception needs to be weighed against the previous contrasting analysis by this researcher. The determination of the analysis was that at least some of the families may not have met the criteria for bonadaptation. The question must be asked; "Is it realistic to expect that families who have been through such a crisis can meet all the criteria for bonadaptation when many families who have not had a similar experience could not have met them either?" On the other hand, maybe some degree of maladaptation is to be expected, at least in some families, considering the nature of the experience. Or, do families call what they have achieved adaptation, or consider themselves to have "made it" because the thought of disintegration is too overwhelming?

Another aspect of model applicability under scrutiny was how well the factors of the model represented the three criteria used to determine adaptation as outlined above. All three concepts of bonadaptation, (integrity, development, and independence) were difficult to associate with the concepts of the essential factors (stressors, resources, coping and perception). Thus in a broad sense, the model outlines the factors of adaptation but the concept of adaptation is not clearly defined in terms of the factors.

It is interesting to note the changes in the model that have been advanced by the theorists in recent years (McCubbin & Thompson, 1987). The name of the new model is the T-Double ABCX Model of Family Adjustment and Adaptation. This model, although it looks schematically very different, is fundamentally the same as the old one except for two basic differences. The first difference is that the pre-crisis period is now the adjustment phase and the post-crisis period is the adaptation phase. This apparent rewording seems to eliminate some of the confusion about what exactly these previous phases represented. The second difference in the the new model is that the "T" factor represents family typology. This consideration has developed another area of theory which specifies four family types. These family types are then included in evaluation of the final outcome. This new dimension of the model should help to add predictability to the model in terms of determining which families adapt better than others. Whether these four typologies includes all possible family types should be considered by future research.

It is important to note that time is an essential element of the Double ABCX Model (McCubbin & Patterson,

1981) (see Figure 1) which is not addressed specifically by the theorist, but is inferred as being essential by the existence of the crisis and the post-crisis period. This span of time forms the basis of the model which acknowledges that time is essential to adaptation. As noted previously, for most families in the study, time from the initial diagnosis to the interview did not seem to play a significant role in their adaptation. However, in two families time may have had a hindering or an enhancing effect on their perceptions of the their adaptation at the time of the interview. This information leads to the question of whether time by itself or the quality of time influences this process. A person may spend time exploring their experience or they may totally avoid exploring it in any depth. Thus, time may be an important part of adaptation which should be defined as a factor of the model by the theorists.

In summary, the factors of the model seemed to reflect the experience of the families, but the model was too broad to be predictive of which families would adapt well. In addition, the factors of the model do not clearly reflect the criteria for adaptation. Also, the criteria for adaptation did not seem realistic under the circumstances these people faced which forced them to decrease their outside activities, caused them to feel more vulnerable to calamity and disrupted their family relationships. And finally the new version of the mode, T-Double ABCX Model includes some needed changes. However, further research is needed to test the applicability of the four family types added to the model.

Comparison of Acute Lymphoblastic Leukemia and Cystic Fibrosis

There are some important similarities and differences between the cystic fibrosis the diagnosis which was employed in the study by Venters (1981) and leukemia and parental response that most likely affected the parents responses. First of all, very few families in Venters' (1981) study had heard of cystic fibrosis (CF). For many of these families, there was an additional source of early frustration due to the fact that the diagnosis of CF was often missed for some time. This early experience, however difficult, was not found by Venters to be related to long term family functioning. Although there were parental reports of problems with the diagnosis of leukemia being missed, the time frame was probably shorter because of the severe symptoms children with leukemia eventually experienced. Once finally diagnosed correctly, families whose children had acute lymphoblastic leukemia were given encouraging statistics about the probability of a favorable prognosis and detailed information on the treatment. This was very different for families of children with cystic fibrosis whose treatment was based on symptoms and thus the prognosis was very tentative. Venters (1981) found that parental anticipation of the severity of the diagnosis was significantly associated with a long term level of family functioning. In other words, if parents were informed of what to expect in relation to terms of the disease process, they could anticipate and adapt to the situation more effectively. According to parents' reports in this study, the frank information about the favorable prognosis and the prescribed treatment plan assured families of a more favorable outcome. Undoubtedly, the favorable prognosis helped families adjust. However, repeatedly they remarked that the frank and informative information they received early in the treatment let them know what to expect and served to diminish their fears.

Another difference between lymphoblastic leukemia and cystic fibrosis comes from the nature of the disease and popular thinking about them which relieves parents guilt or bestows it upon them. On the whole, leukemia is a disease that most people do not consider themselves to have any control over. This disease is not in the category that is commonly thought of genetic or caused by life-style. Even though some parents experienced blame, most did not. For these reasons leukemia may be easier to deal with than cystic fibrosis, which has genetic origins and implies a parental link of responsibility.

Congruence with Historical Perspective

Considering the historical perspective this study was congruent with the current focus as identified by Hobbs, Perrin and Ireys (1985), Mrazek (1985), and Knafl and Deatrick (1987). As previously discussed Hobbs, Perrin and Ireys (1985) viewed the current trend to be one in which the positive as well as the negative effects of illness on the child, the parents and the family are examined. All these aspects were considered in this study of adaptation to acute lymphoblastic leukemia (ALL). Thus, this study added additional information to this current trend. Mrazek (1985) called the current research stage in the area of cystic fibrosis the "system sensitive phase". That researcher identifies this stage as documenting the variables that influence adaptation to cystic fibrosis. This current study identifies several variables which influence adaptation to ALL. The variables identified included the effects of fathers' participation on feelings of closeness to their children, the effects of the illness experience on children which were dependent on their developmental age, and the effects of parent coping styles on adaptation. These variables identify the similarities between the current research phase in the area of cystic fibrosis and this current study of ALL. Knafl and Deatrick (1987) identified two research focuses. The present study of adaptation to ALL was similar to the research focus that was identified as the "Subjective active process approach". This research concerning adaptation to ALL focused on the families' subjective definition, looked at how families manage the illness, and focused on understanding the process rather than measuring outcomes which were all identified as major components of this phase.

Chapter V

Implications, Limitations, and Recommendations

This study described the experience of parents who have children with acute lymphoblastic leukemia. Nurses who work with these families need to understand what factors are associated with families who adapt so they can encourage the development of these helpful factors for others who have more difficulty. Considering the historical perspective of research in the area of adaptation to childhood chronic conditions this study is congruent with the current trend of focusing on positive aspects of the illness on the whole family rather than the negative ones (Hobbs, Perrin, and Ireys 1985) and by the "system sensitive phase" identified by Mrazek (1985). This study also reflects the criteria for the "subjective active process approach" identified by Knafl and Deatrick (1987) as being essential to the future establishment of well defined objective measurements of outcome. McCubbin and Patterson's (1981) Double ABCX Model of Family Adaptation formed the conceptual basis for data collection and analysis. The data was collected through intensive, semi-structured interviews that were audio recorded; then analyzed for common and different themes according to the factors of the Double ABCX Model (McCubbin & Patterson, 1981). The factors of the model seemed to reflect the experiences of the families, but the model was too broad to be predictive of which families would adapt well. The criteria for adaptation used in the model did not seem realistic under the circumstances these families faced. Also, factors of the model (stressors, resources, coping and perception) did not clearly reflect the criteria required for adaptation (integrity, development and independence). However, both adaptation criteria and factors of adaptation were found to be useful starting points in understanding the process of adaptation, which was exemplified by the factors of the model. All families perceived that they had "made it" through the experience although they experienced different levels of difficulty. This is in contrast to the analysis by this researcher that explained how a few families in this study did not meet the criteria for bonadaptation. Therefore, perception, factor cC of the model, was shown to be the most significant aspect of this model. The factor of time as inferred by the model may have had some effect on two families in the study but the exact source of the differences seen in these two families is unknown.

The findings of the study suggest several trends. School-aged children seemed to have more difficulty complying with treatment. Toddlers may be in danger of being too compliant. Parents used both active and passive coping strategies frequently and their coping behaviors were often complementary with each other. Parental couples in which one partner chose not to participate experienced divorce. Fathers who participated when mothers were unable formed strong bonds with their children. Families usually were brought closer together by the experience of having a child with ALL.

This study also adds to the findings of Venters (1981) in that parents found obtaining information on prognosis and treatment regimen soon after the diagnosis helped them cope. This data also seem to support Venters' (1981) findings that parents used a preexisting scientific or religious philosophy to define the illness situation.

Implications for Nursing

This study has contributed to nursing research, theory, clinical practice and education. Implications for these four areas are as follows.

Nursing Research

Nursing research should include further testing of models such as the T-Double ABCX Model with families who have a member with a chronic condition. A model which could predict those who will have more difficulty adapting successfully has applicability in terms of prevention. In addition, researchers need to explore the changes that may occur in family development when a member has a chronic condition.

This study has contributed to the knowledge base of the process by which families adapt to a chronic illness, and further studies can be built upon this base. Research employing in-depth analyses of several data sets, such as this study, may be very valuable for exploring the applicability of models for guiding practice and for understanding families' experiences more fully. Contextual in-depth analysis provides a quality of data more useful in determination of factors in real life because it is more reflective of the complex realities of life. In the future, studies combining this "subjective active process approach" with an "objective outcome approach" as defined by Knafl and Deatrick (1987) are needed. The current investigation has posed many questions. For example, what are other conceptual categories for active coping strategies, and which coping strategies, passive or active, seem more effective in dealing with acute lymphoblastic leukemia and other illnesses of this nature?

Future research should explore the role of personal factors and previous experience with a crisis in family adaptation. Further exploration is needed to compare father's participation in married and unmarried couples. Also interesting would be a study of mothers who divorced during treatment, and a comparison of the adaptation of mothers who remained single to those who found a father substitute. And finally, since age-at-diagnosis seemed to make a difference in the children's responses to treatment, it would be important to compare the responses to treatment with larger sample of children from various age groups.

Nursing Clinicians and Educators

Nurse clinicians and educators can consider the important interventions for working with parents that have been revealed by the interviews and interview analysis in this study. This study has implications for practice that include parents' need to have frank open discussions with physicians, on whom they rely heavily for support, about treatment and prognosis. Since families rely heavily on the support of other health care workers this has implications for also nurses in their practice.

There are many implications for practice that relate to family interaction that have emerged from this investigation. Clinicians who view parents who use complementary coping styles should begin to view this behavior as very prevalent and also possibly conducive to adaptation. Clinicians should be cognizant of the important role fathers can play in children's care as their participation is seen as vital. In the same vein, fathers who don't participate during this kind of a crisis may eventually leave or be left by the family. The knowledge that family closeness is frequently strengthened by a crisis of this nature has implications for practice. Finally, clinicians should be cognizant of the fact that a family's perception of the experience is an important indicator of their eventual adaptation.

The findings of this study reiterate the need for clinicians who care for all children to be aware of their developmental stage, in particular children who must succumb to a variety of treatment modalities. Also, since nurses frequently administer and teach parents about giving oral medication, they should be mindful of possible complications school-age children might encounter with emesis. Since this behavior has its origins in the child's need to control, other ways to increase their participation and sense of industry should be explored. Young children may develop subtle adjustment problems that can be as disturbing as those occuring in the school-age child. Overcompliance to treatment by a toddler, at a normally very autonomy-seeking age, should be a warning to clinicians. Clinicians should offer these children ways of acting out their experiences through play. These interventions need to employed with the understanding that regression to an earlier developmental stage is common under stress. These suggestions are important for those working with parents in clinical settings as well as those preparing future clinicians.

Nursing Science

This study has contributed to the science of nursing and its further development through the evaluation of the applicability of the Double ABCX Model (McCubbin & Patterson, 1981). Perception, factor cC of the model, was shown to be the most significant aspect of adaptation. The model seemed too broad to be predictive of which families would adapt well. The criteria for adaptation did not seem realistic under the circumstances these families faced. For example, one criteria for bonadaptation is that the family meet all criteria on both the individual-family level and a family-community level. In times of crisis of this nature, out if necessity, families typically draw inward and become less involved in outside activities. Also, factors of the model did not seem to reflect the criteria needed for adaptation. For example, no factor of the model specifically addressed the development level of family members, although meeting developmental needs of the family and the individual family members are criteria for bonadaptation. Nonetheless, the model was found to be a useful starting point in understanding the process of adaptation. The predictive value of this model's presentation of factors related to or contributing to adaptation need further testing.

Limitations

The generalizability of the results of this study are limited by several factors. As previously mentioned, the length of time the children had been off protocol may have affected parents' responses to questions. Memory distortion may increase over time and can be a threat to internal validity. How important the possible memory loss was cannot be determined because of the small sample size. External validity could have also been affected by the openness of parents responses. Some parents' may have tailored their responses to the investigator. This, however, was probably minimal because most parents were very eager to discuss their experience. Minimal participation by two fathers may have been their indirect way of selectively participating. Even though families were assured that their comments about health care professionals would be strictly confidential, the association of the investigator to physicians who referred them to the study may have affected their responses.

Internal validity was most probably affected by the selection of subjects. Subjects were often asked by their physicians whether they would be willing to have the investigator telephone them. This may have exerted a subtle form of coercion on the parents. They may not have felt in a position to refuse a physician or anyone connected with the facility that saved their children's life.

Further limitations have involved the interview process and the applicability of the questions to the theoretical model. Families in general were very eager to relate the circumstances involved with the illness, but had more difficulty responding to direct questions, especially those that related to perception. The semi-structured questionnaire, as a mode of data gathering, limits the kinds of information that may be obtained. In addition the questionnaire adapted from Venters (1980) did not always specifically coincide with the factors of the Double ABCX Model (McCubbin & Patterson, 1981) and the criteria for adaptation which were used as a basis of analysis.

Another limitation is that this investigator has views that may have affected the synthesis of this data. Peshkin (1988) purports the importance of acknowledging the researcher's own subjectivity in the research process. The author states, "When their subjectivity remains unconscious, they insinuate rather than knowingly clarify their personal stakes" (p. 17). With this in mind the following thoughts will be discussed.

In the present study, the author's subjectivity took the following forms. For instance, open communication between married partners was thought to be healthier than some other form. This notion may have affected how this author viewed married couples in this study. Another aspect of possible bias is religious beliefs. The investigator may have played down or diminished the apparent effect religion had on people because of lack of allegiance to an organized religion and a particular skepticism toward certain religious beliefs.

Another form of subjectivity that may have effected the data are based on the assumptions of the study. Earlier it was stated that the assumptions included: (1) families do many things to help themselves cope and (2) people generally adapt to difficult situations. Whether this attitude came across to the parents and encouraged them to look at positive aspects and minimize the negative ones it can not be determined, but should be considered.

Recommendations for Further Research

The recommendations for further research that were derived from this study are related to the significant findings, the limitations of this study and the conceptual framework. Hopefully these efforts will lead to a better understanding of how families adapt to the experience of having children with a chronic life-threatening condition. Recommendations for further study are suggested.

1. Information is needed about the effectiveness and prevalence of complementary coping strategies between parents.

2. Studies are needed to examine the influence of parental participation on family adaptation when their children have a chronic illness.

3. The factors of the Double ABCX Model, especially as they apply to the criteria for adaptation, need refinement.

4. The Double ABCX Model needs to be tested as to its predictive ability concerning which characteristics or perceptions correlate with family adaptation.

5. The responses of different age groups of children in response to specific treatments and interventions need to be explored to prevent long term adverse behavioral responses.

6. The time factor needs to be explored in relation to the Double ABCX Model.

7. The data needs further analysis in relation to the T-Double ABCX Model.

8. Family development in families faced with a chronic condition in a family member needs to be explored.

9. The role of personal factors and previous experience with a crisis in facilitating adaptation needs to be explored.

10. Investigators of future studies of this nature should consider sending interview guides to families before the actual interview.

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Appendix A

Interview Form

Appendix A

Interview Form

Patient's Name________________________

Sex: Male_____

Female_____

Birth order of this child is:

________out of _______children

Birth date:___________

Approximate age at diagnosis___________

Interview respondent is:

mother________

father________

both mother and father_________

Date of marriage________) Period of time between date of marriage

Date of Diagnosis_______) and ________diagnosis.

Approximate period of time since diagnosis_________

I. First of all let's discuss ways in which X's illness might have changed the family routine. (Or if diagnosed at birth and is first child, how is the routine different than you imagined it would be before X was born?)

A. Many families have told us that after their child began home treatment for cystic fibrosis the family routine changed. In what ways, if any, has your family's daily activities been influenced by X's illness?

1. For instance-

    a) Who helps with treatment?

        1. mother____

        2. father____

        3. other_____

    b) Who usually accompanies X to the clinic?

        1. mother____

        2. father____

        3. other_____

2. Has anyone taken on new or different household chores? Which ones?

    a) mother_____

    b) father_____

    c) other______

B. Sometimes families find that the treatment routine is too busy at home that they have to cut back on some of their outside activities, To what extent, if any, have your family members had to give up some things outside the family that were previously experienced as sources of satisfaction? If yes, what and why? Have you now resumed these activities?

a) mother_____

b) father_____

c) other______

C. On the other hand, some families find that the diagnosis stimulates involvement in new outside activities.

To what extent, if any, did family members become involved in new activities outside the home that were taken on as a result of X's illness? Which ones? (possible probes, new interest in health consumer groups, or CF parents' group, church, etc.)

1. mother_____
2. father______
3. other______

D. Sometimes parents have told us that right after the diagnosis when home treatments begin they feel things fall apart for awhile. In other words, the family routine does not seem to go as smoothly as before. Did you find this happened to your family?

1. What happened?
2. How did you handle it? or were you able to do anything?
3. How long did it take for things to run more smoothly?

II. Parents usually experience many painful feelings when first hearing that their child has CF. Was this true for you and your family? (possible probes-denial, anger, confusion, etc.)

A. Was it long before things seemed to be a little better?

B. Had you expected the diagnosis, or was it a shock?

C. Parents have also told us that accepting the diagnosis is often diffucult and takes time. Was this true for you and your family? How long did it take?

III. What seemed to help most in providing you and your family with strength, support, and encouragement?

A. During these early months after diagnosis?

B. What about later when things were the roughest?

(probes) maybe-

1. friends, relatives, neighbors, or who?
2. religious leader
3. doctors, other health personnel
4. who is strongest in your immediate family or

what about-

1. religious philosophy and teachings
2. hard work and keeping busy
3. reading and talking with others who have had trouble
4. learning more about illness
5. or other ideas?

IV. At the time of the diagnosis what were your impressions about what this would mean-

A. for X?

B. the whole family?

C. have you changed your mind in any way about these first impressions?

D. how about your attitudes or values toward life, have they changed at all? (possible probes)

1. About what's important in life?
2. About God and religion?
3. About scientific medical knowledge?
4. About the order and meaning of life in general?

E. If someone were to ask you to explain the reason for X's condition what would be your explanation? (possible probes)

1. A deliberate act of God?
2. A random event for which God's guidance is necessary to survive?
3. A condition which afflicts a family which can be traced to genetic history?
4. Or maybe there is no explanation?

V. Have you ever thought that X's illness has changed, or might change your overall plans for your family? How, why?

A. Today?

B. What about the future of the family?

C. What about X's future? Any vocational plans?

VI. How informed do you think orders are about cystic fibrosis? Does this present problems or help?

A. People in general.

B. The medical profession-

1. What about the period before diagnosis when you knew something was wrong, but didn't know what?
2. How about when you need emergency care in your own community?

3. What have been your experiences with hospitalization?

VII. How informed do you think your family is compared to other similar families?

A. Today?

B. In the past?

C. Have you found that you know enough about cystic fibrosis to realistically access the problems that arise and discover good soutions?

1. If yes, what has been your best source of information?

a. U of Minn. clinic?

b. Reading health literature?

c. Parent's groups?

d. A close friend of relative that is a health professional?

e. Local medical community?

f. Other source?

2. If no, what kinds of information would have helped you now or in the past to better cope with some of the problems that seem to accompany managing a child with cystic fibrosis?

VIII. In the past has your has your family ever been involved in a difficult situation where one person had some problem which needed a lot of help from the other family members? (possible probes-illness, death of member, etc.).

If yes-

A. How did that come out?

B. Did that experience help in any way in solving the problems resulting from X's illness? Why or why not?

IX. Some parents have found they have grown away from their child as time passses and life becomes busy with other things.

On the other hand other parents, have found family members have become closer over time.

A. What has been your experience with your family as far as relating to X ?

B. In general would you say that cystic fibrosis tends to draw your family closer together, make things more difficult, or no change? (probes)

1. For example to what extent does X's illness-

a) create strain on the marriage relationships, or does it provide an opportunity for sharing?

b) create problems with other children? such as?

c) caused a lot of worry for everyone, making everyone feel helpless? Or has it more likely served as a source of strength?

d) create more affection or cause more arguments? How is it between?

X and the other children? you and X, your spouse and X ?

2. Parents sometimes say that chilren with a chronic illness act sicker than they realy are and try to manipulate the rest of the family just to get more sympathy, or maybe their own way. How is it with X ?

a) how do you handle this?

b) Is it just at certain times?

X. As you reflect back on your experience with X's illness what has been the biggest hardship for you and your family resulting from X's diagnosis aand illness?

A. How did you manage this situation?

B. What happened, how did it come out?

XI. Have there been other kinds of problems that were difficult to deal with that we haven't already discussed? (possible probes)

1. Having less time together?

2. Having less time for personal daily activities outside the home?

3. Less time for vacations?

4. Too busy to think about anything but CF?

5. Not enough money?

6. Not enough emotional support?

a) I feel alone.

b) We feel alone.

c) Our family feels alone.

XII. Interviewer Impressions:

A. Physical appearance of X

1. Size
    a) very small for age _____
    b) small for age ______
    c) average for age _____
2. Sickliness
    a) very sickly______
    b) slightly sickly _____
    c) average _______

B. Apparent personal attitudes that might influence ability to function and cope.

C. Apparent observable behavior and family interaction during interview that might influence ability to function and cope.

Appendix B

Family Information Form

Appendix B

I.D. Number:

Factors Influencing the Adaptation of Parents with Children having Acute Lymphoblastic Leukemia

Family Information Form

To enable the investigator to compare the results of this study with people from different groups and situations, she would like the following information. Please complete the following items.

1. Sex of Parents' Child: 1. Male_____
   2. Female_____
2. Birth order of this child is: __________
   ________out of _______children
   Birth date:___________
3. Approximate age at diagnosis___________
   Number of months off protocol _________
4. Marital status of the parents
   1. single never married _________
   2. married __________
   3. divorced or separated _________
   4. widowed _________
5. If married, date of marriage________) Period of time between date of marriage and ________diagnosis.
6. Date of Diagnosis_______)
   Approximate period of time since diagnosis_________
7. Education level of Mother

What is the highest grade of regular school that you completed? (circle one)

Grade School	High School	College	Graduate School
1 2 3 4 5 6 7 8	9 10 11 12	13 14 15 16	17 18 19 20 21

8. Education level of Father

What is the highest grade of regular school that you completed? (circle one)

Grade School	High School	College	Graduate School
1 2 3 4 5 6 7 8	9 10 11 12	13 14 15 16	17 18 19 20

9. Ethnic Background
    1. Asian ________
    2. Black ________
    3. Caucasian ________
    4. Hispanic ________
    5. Other, (specify) __________

10. Religious Affiliation
    1. Protestant ________
    2. Catholic __________
    3. Jewish ___________
    4. Other ___________
    5. None ___________

11. Birth Date of mother ________

12. Birth Date of father ________

13. Occupation of Mother ____________________________

14. Occupation of Father ____________________________

15. Distance traveled to treatment site ________________

16. Please list sources of support services each family member receives.

Family Member ____________

Care Provider or support services __________________

Care Provider or support services __________________

Family Member ____________

Medical care provider ______________________________

Support services ___________________________________

Family Member ____________

Medical care provider _____________________________

Support services __________________________________

Appendix C

Adapted Interview Form

Appendix C

I.D. Number:

Factors Influencing the Adaptation of Parents with Children having Acute Lymphoblastic Leukemia

Adapted Interview Form

I. What events led up to the diagnosis of leukemia and how as your family affected by the diagnosis?

A. Sometimes parents have said that right after the diagnosis they felt things fell apart for awhile. In other words, the family routine does not seem to go as smoothly as before. Did you find this happened to your family?

1. What happened?

2. How did you handle it? or were you able to do anything?

3. How long did it take for things to run more smoothly?

II. Parents usually experience many painful feelings when first hearing that their child has leukemia. Was this true for you and your family? (possible probes-denial, anger, confusion, etc.)

A. Was it long before things seemed to be a little better?

B. Had you expected the diagnosis, or was it a shock?

C. Parents have also told us that accepting the diagnosis is often difficult and takes time. Was this true for you and your family? How long did it take?

III. Many families have told us that after their child began treatment for acute lymphoblastic leukemia the family routine changed. In what ways, if any, has your family's daily activities been influenced by X's illness?

1. For instance-
    a) Who cares for X when he /she is ill? *
        1. mother____
        2. father____
        3. other_____
    b) Who usually accompanies X to the clinic?
        1. mother____
        2. father____
        3. other_____
2. Has anyone taken on new or different household chores? Which ones?
    a) mother_____
    b) father_____
    c) other______

A. Sometimes families find that the treatment routine is so busy at home that they have to cut back on some of their outside activities. To what extent, if any, have your family members had to give up some things outside the family that were previously experienced as sources of satisfaction? If yes, what and why? Have you now resumed these activities?

a) mother_____

b) father_____

c) other______

B. On the other hand, some families find that the diagnosis stimulates involvement in new outside activities. To what extent, if any, did family members become involved in new activities outside the home that were taken on as a result of X's illness? Which ones? (possible probes, new interest in health consumer groups, or parents' groups such as the Candlelighters Children's Cancer Foundation, church, etc.) *

1. mother_______
2. father______
3. other______

IV. What seemed to help most in providing you and your family with strength, support, and encouragement?

A. During these early months after diagnosis?

1. friends, relatives, neighbors, or who?
2. religious leader
3. doctors, other health personnel
4. who was strongest in your immediate family or

what about-

1. religious philosophy and teachings
2. hard work and keeping busy
3. reading and talking with others who have had

trouble

4. learning more about illness

5. or other ideas?

V. At the time of the diagnosis what were your impressions about what this would mean-

A. for X?

B. the whole family?

C. have you changed your mind in any way about these first impressions?

D. how about your attitudes or values toward life, have they changed at all? (possible probes)

1. About what's important in life?
2. About God and religion?
3. About scientific medical knowledge?
4. About the order and meaning of life in general?

E. If someone were to ask you to explain the reason for X's condition what would be your explanation? (possible probes)

1. A deliberate act of God?
2. A random event for which God's guidance is necessary to survive?
3. A condition which afflicts a family which has multiple causes which are not clear to us today. *
4. Or maybe there is no explanation?

VI. Have you ever thought that X's illness has changed, or might change your overall plans for your family? How, why?

A. Today?

B. What about the future of the family?

C. What about X's future? Any vocational plans?

VII. How informed do you think orders are about leukemia? Does this present problems or help?

A. People in general.

B. The medical profession-

1. What about the period before diagnosis when you knew something was wrong, but didn't know what?

2. How about when you need emergency care in your own community?

3. What has been your experiences with hospitalization?

VIII. How informed do you think your family is compared to other similar families?

A. Today?

B. In the past?

1. If yes, what has been your best source of information?

a. Your child's physician?

b. Reading health literature?

c. Parent's groups?

d. A close friend of relative that is a health professional?

e. health professionals in the community?

f. Other source?

2. If no, what kinds of information would have helped you now or in the past to better cope with some of the

problems that seem to accompany managing a child with leukemia?

IX. In the past has your has your family ever been involved in a difficult situation where one person had some problem which needed a lot of help from the other family members? (possible probes-illness, death of member, etc.). If yes-

A. How did that come out?

B. Did that experience help in any way in solving the problems resulting from X's illness? Why or why not?

X. Some parents have found they have grown away from their child as time passes and life becomes busy with other things. On the other hand other parents, have found family members have become closer over time.

A. What has been your experience with your family as far as relating to X ?

B. In general would you say that leukemia tends to draw your family closer together, make things more difficult, or no change? (probes)

1. For example to what extent does X's illness-

a) create strain on the marriage relationships, or does it provide an opportunity for sharing?

b) create problems with other children? such as?

c) caused a lot of worry for everyone, making everyone feel helpless? Or has it more likely served as a source of strength?

d) create more affection or cause more arguments?

How is it between?

X and the other children?

you and X, your spouse and X ?

2. Parents sometimes say that children with a chronic illness act sicker than they really are and try to manipulate the rest of the family just to get more sympathy, or maybe their own way. How is it with X ?

a) how do you handle this?

b) Is it just at certain times?

XI. As you reflect back on your experience with X's illness what has been the biggest hardship for you and your family resulting from X's diagnosis and illness?

A. How did you manage this situation?

B. What happened, how did it come out?

XII. Have there been other kinds of problems that were difficult to deal with that we haven't already discussed?

(possible probes)

1. Having less time together?

2. Having less time for personal daily activities outside the home?

3. Less time for vacations?

4. Too busy to think about anything but leukemia?

5. Not enough money?

6. Not enough emotional support?

a) I feel alone.

b) We feel alone.

c) Our family feels alone.

XIII. Interviewer Impressions:

A. Physical appearance of X

1. Size

a) very small for age _____

b) small for age ______

c) average for age _____

2. Sickliness

a) very sickly______

b) slightly sickly _____

c) average _______

3. Residual effects experienced by child.

B. Apparent personal attitudes that might influence ability to function and cope.

C. Apparent observable behavior and family interaction during interview that might influence ability to function and cope.

D. Areas of Family Adaptation: Areas of strength determined from the family's questions, answers, and the researchers observation.

Appendix D

Consent Form

Appendix D

Oregon Health Sciences University

Consent Form

Patient's Name: ______________________________

Date: ________________

1. I understand that this is an experimental study of how parents adapt to the experience of having children with acute lymphoblastic leukemia. I consent to having a researcher interview me at my home at my convenience.

2. I understand that participation in this study will cause neither risk or discomfort. I understand that while I am encouraged to answer all interview questions, I am under no obligation to do so.

3. I understand that this study may benefit myself and my family by encouraging me to assess our family's strengths. I also understand that this study will assist other nurses in understanding the experience of parents as they adapt to the experience of having children with leukemia.

4. I understand that my responses will be kept confidential at all times. I consent to have my interview audiotaped and understand that the tape will be destroyed as soon as the data has been collected. Neither my name nor my identity will be used for publication or publicity purposes.

5. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If you suffer any injury from the research project, compensation

would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions please call DR. Michael Baird, M.D. at (503) 279-8014.

6. I understand that <u>Marsha</u> <u>Stover</u> will answer any questions that I may have.

7. I understand that I may refuse to participate or withdraw from this study at any time without affecting my relationship with or treatment at the Oregon Health Sciences University.

8. I understand that I have the right to information as to the results of the study in which I am participating.

9. I understand that in the event of physical injury resulting from this research there is no compensation and /or payment for medical treatment from Oregon Health Sciences University for such injury except as may be required of the University by law. The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Fund. If I suffer any injury from the research project, compensation would be available to me only if I establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, please call Dr. Michael Baird at (503) 225-8014.

I acknowledge that <u>Marsha</u> <u>Stover</u> (investigator) has explained to me the risks involved and the need for the research; has informed me that I may withdraw from participation at any time and has offered to answer any inquiries which I may make concerning the procedures to be followed. I freely and voluntarily consent to may participation in this project.

I understand that I may keep a copy of this consent form for my own information.

I have read the foregoing and agree to participate in this study.

____

volunteer (parent) (sign & date)

____

volunteer (parent) (sign & date)

____

investigator (sign & date)

Abstract

Title: Factors Influencing the Adaptation of Parents with Children having Acute Lymphoblastic Leukemia

Author: Marsha Marre Stover

Approved: ______________________________

Advisor

This retrospective descriptive study describes the experience of parents who have children with acute lymphoblastic leukemia and partially replicates a study by Venters (1981). Nurses need to understand what factors are associated with families who adapt so they can encourage the development of these helpful factors. The study sample consisted of 11 parental couples whose children were off treatment. The data collected through intensive interviews were audio recorded in each home and analyzed based on the Double ABCX Model (McCubbin & Patterson, 1981).

The findings suggest several implications for practice. Nurses should anticipate that children will respond to treatment based on their developmental age. Parents used both active and passive complementary coping strategies which were conducive to their adaptation. Fathers' participation strengthens their bond with their children. This study agrees with Venters' (1981) findings that parents used a preexisting scientific or religious philosophy when attributing meaning to the illness. Factors limiting generalizability of these findings include the small sample

size, self-selection bias, memory distortion, and participants selectivity in what they reveal.