

AS NORMAL A LIFE AS POSSIBLE:  
MOTHERS AND THEIR DAUGHTERS  
WITH CONGENITAL HEART DISEASE

by

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As normal a life as possible: Mothers and their daughters with congenital heart disease.

Thesis directed by Associate Professor Denise Webster.

This study utilized qualitative descriptive methodology to examine the impact of the chronic illness, specifically congenital or acquired childhood heart disease, on the mother-daughter relationship. Many studies have examined the effects of the child's illness on the mother-child relationship when the child is very young, but few have looked at the ongoing problems that chronic illness may cause. The investigator observed in her own clinical practice that the mother-daughter relationship when the daughter was chronically ill frequently appeared more antagonistic and ambivalent. Fourteen mothers, eleven daughters, and three sons were interviewed. Daughters and sons ranged in age from nine to fifty-six. Three variables arose from the data. The core variable, which the author called "normalizing our relationship," included themes related to how mothers and their chronically ill daughters and sons try to maintain as normal a life as possible. The second variable, called "relating as mother and daughter," included those themes concerning how mothers and daughters cope with the daughter's chronic illness and how their relationship is impacted. The third variable, "relating to health care providers," spoke to how practitioners can help mothers and their chronically ill sons or daughters to

manage their health problems. The core variable was related to the other two variables in that: (1) mothers and chronically ill daughters saw their relationships as very normal and unaffected by illness, and (2) all participants felt that the role of health care providers should be one of helping to maintain a normal lifestyle despite chronic illness. This study adds to existing nursing literature by reinforcing previous studies which describe attempts at and strategies for normalization by families of chronically ill children. It builds on this literature by examining the mother-child relationship when the child is chronically ill over the course of the lifespan.

The form and content of this abstract are approved. I recommend its publication.

Signed

  
Faculty member in charge of thesis

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## CHAPTER I

### INTRODUCTION

The rapid advancement of medical technology over the last several decades has markedly improved the survival capabilities of persons with certain chronic illnesses. Nowhere is this more evident than in neonatal, pediatric, and adolescent medicine. Within the last five years, the gene responsible for cystic fibrosis (CF) has been identified and isolated, making patients, families, and health care professionals hopeful that genetic engineering can change the course of what has been an eventually fatal disease. Similarly, scientists have located the gene which causes muscular dystrophy (MD) and gene therapy treatment has begun on babies afflicted with severe combined immunodeficiency syndrome (SCIDS) (Thompson, 1993).

Unfortunately, however, comparable progress is not being made in diseases with assumed multicausal etiology. For example, because congenital heart disease (CHD) is believed to be the result of interplay between environmental, maternal, and genetic factors, single therapies may not prove as useful in prevention of this disease.

Because many chronic illnesses can now be successfully managed medically, children with these diseases now reach adulthood and even middle age. The path of these individuals is often complicated by episodic physical illness and sometimes severe mental and emotional distress related to medical

monitoring, invasive procedures, and surgeries. However, for the most part, these clients make the daily adjustments which allow them to successfully cope with their potentially life-threatening diseases over a lifetime. Because they are frequently undergoing treatment or follow-up for their diseases, adolescents and young adults with chronic conditions may tend to downplay all but the most significant illnesses (Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980; Zeltzer, Kellerman, Ellenberg, Dash, & Rigler, 1980), preferring to manage more "minor" illnesses at home. In truth, these illnesses may not be so minor; nonetheless, the chronically ill person and the family have learned to manage all but the most serious or catastrophic of these. Researchers in various fields have demonstrated that social support, specifically family support, often makes the largest difference between adjustment or maladjustment for these persons (Barnes, Kenny, Call, & Reinhart, 1972; Gottesfeld, 1979). It is the family that bridges the gap between the long-term needs of the chronically ill person and what the health care system, which is designed for treatment of acute, short-term problems, is able to supply.

The family, however, may or may not be able to cope successfully with the strains of providing care to the chronically ill child. Goldberg, Morris, Simmons, Fowler, and Levison (1990) found that parents of infants with CF and CHD experienced more problems with depression and a decreased sense of competence than parents of children without health problems. Fathers were found to have more difficulty than mothers adjusting to the child's illness.

Mothers, on the other hand, reported greater trouble with marital strain, role restrictions, and personal health. Parents of children with CHD reported more stress than parents of children with CF, though both groups reported more stress than parents of healthy children. This implies that the parent-child relationship may be "at risk" when the child is chronically ill.

### **The Intrigue**

The author's interest in the area of women and chronic illness arises from her past work with adolescents and young women with CHD and their mothers. My initial interest was in issues surrounding sexual decision-making, birth control practices, and reproductive choices of adolescents and young women with CHD. My previous research (Gantt, 1992) examined some of these issues. In addition, however, I found that the participants frequently discussed their mothers and the influence they had on various aspects of their daughters' lives. I suppose that this should not have been so surprising to me; Mercer, Nichols, & Doyle (1989), however, were equally surprised when participants in their study of transitions in women's lives spoke as often of the importance of being a daughter as they did of being a mother.

Much literature and research addresses the effects of chronic illness on the family. There has been no such emphasis on the mother-daughter relationship, though it has been the author's experience that it is the mothers who are constantly at the bedsides of their children with CHD when they are hospitalized. The mothers are also often the ones who take responsibility for

the day-to-day care of these children, giving medications, attending to routine doctors' appointments, and managing more emergent problems. However important health care professionals may believe themselves to be, the mothers are the true experts at caring for children with chronic illnesses. The chronically ill adolescent and young adult learns as much, if not more, about coping with illness from the mother as from health care providers. This is not to say that fathers or other family members are absent or negligent, but theirs is a different type of vigilance toward the child with a chronic illness. For example, several researchers (Kazak & Martin, 1984; Steele, 1983) have noted that fathers and mothers play different roles in caring for the child with a chronic illness; fathers play a larger role in financial support, while mothers assume the majority of caretaking activities. While these traditional roles may be characteristic of most families, they are more pronounced in the families with handicapped children.

Because of the relatively consistent prevalence of CHD in the general population, the lack of definitive treatments for certain types of CHD, as well as the potentially lethal long-term consequences of many forms of CHD, my particular interest in chronic illness is primarily confined to patients with CHD. While the types of problems these persons have may change as technology progresses, the fact remains that they experience ongoing illness-related difficulties. Though advances in cardiology and cardiothoracic surgery during the last several decades have been phenomenal, the overall picture for many

of these patients has changed very little. It is with these patients that family support, as well as nursing support, can be expected to have the greatest impact.

### **Why Study Just Mothers and Daughters?**

The author's interest in researching the mother-daughter relationship when the daughter is chronically ill stems not only from her own work with these women, but also from previous research demonstrating considerable bias against mothers of children with CHD.

Beginning with the first pediatric heart surgeries in the late 1950's, a new genre of scientific literature emerged on the psychological impact of CHD and its treatment (Chazan, Harris, O'Neill, & Campbell, 1951; Cooper, 1959; D'Antonio, 1976; Linde, Rasof, Dunn, & Rabb, 1966). At the time, the prevailing view of childrearing held that mothers had the largest responsibility for the psychological well-being of their children (Bowlby, 1951, 1966; Ehrenreich & English, 1978; Levy, 1951, 1966). The mother of the "cardiac child," as children with CHD were labelled at the time (D'Antonio, 1976), was held no less accountable for the psychological adaptation of her child despite the problems associated with raising a child with physiologic limitations. Research conducted at this time failed to take into consideration the impact that CHD, or the health care system, might have on the mother, the child, or their relationship. The assumption that mothers were somehow liable for the adjustment of their children set the stage for further conjectures about the

nature of the mother-child relationship. The premise that mothers are still the greatest contributors to the psychological orientation of the child remains in recent literature (Kong, Tay, Yip, & Chay, 1986), having never been proven or disproven, despite societal changes that involve fathers, day care workers, and others in the day-to-day concerns of child care.

To some extent, the author's decision to study only the mother-daughter relationship in chronic illness is merely an attempt to remove potentially confounding issues from this research. Differences between mother-daughter and mother-son relationships have received extensive documentation (Chodorow, 1978; Dinnerstein, 1976; Jordan, Kaplan, Miller, Stiver, & Surrey, 1991), though these differences have not been discussed within the context of chronic illness. Therefore, the author has elected to confine this research to the mother-daughter relationship in CHD.

### **Relevance of the Study for Education, Practice and Research**

By doing this research, the author's greatest hope is to affect clinical practice by challenging the stereotypes of the "overprotective mother" and "the cardiac child." Historically, research has failed to acknowledge the consequences of medical monitoring and manipulation on the mother-child relationship. Instead, health care professionals have often found it easier to blame the mother in most cases, and in others, the child as well. Mothers of chronically ill children need to be validated as the real experts in the care of

their children. As this proposal discusses, it is families, and mothers in particular, that allow children, adolescents, and young adults to grow and function outside of our very expensive health care system.

Our society has long harbored the view that people with chronic illnesses are "a problem" and "different" (Kleinman, 1988; Turner-Henson, Holaday, Corser, Ogletree, & Swan, 1994). "Different," in and of itself, is not a problem, so long as it is not equated with "bad" or "unequal." The author also hopes to impact clinical practice by encouraging the view that persons with chronic illness and their families are simply going through life in a different way and, as Newman (1986) has said, that it is possible to have a chronic illness and be healthy at the same time.

As health care professionals, we need to encourage normal family relationships while we find ways to be supportive of those who need our services. The mother-child relationship is universally accepted as very important. This research could contribute a needed perspective on how clinicians could better approach women with chronic illnesses and their mothers. By changing our own biases, we can begin to change the status quo and model a better perspective for our nursing students.

Finally, nursing research into problems surrounding chronic illness often involves the entire family as a unit, without looking at the individual family members' responses to the illness or the ill family member. Fortunately, this is beginning to change as research addresses siblings, mothers, fathers, and

grandparents of chronically ill persons. This is not to say that the response of the family as a whole is not important. However, Woods and colleagues (1993) found that certain types of responsibility in caring for the person with chronic illness were assumed differently by the individual with the illness, his or her partner, and the family. This means that dyads within the family may be affected differently from the family as a whole and that different family members' relationships may be more "at risk" than others.

### **Purpose**

The purpose of this research was to study the effect of CHD, a potentially life-threatening chronic illness, on the mother-daughter relationship. The researcher anticipated being able to address the following broad questions: (1) How is the mother-daughter relationship affected by the daughter's illness? (2) What helps or hinders the relationship? Other specific aims of the study are discussed at the end of Chapter II within the context of specific bodies of literature.

## CHAPTER II

### MOTHER-DAUGHTER RELATIONSHIPS IN CHRONIC ILLNESS: LITERATURE AND RESEARCH

While literature addressing the effect of a child's chronic illness on the family is common within the fields of nursing, psychology, and sociology (Daniels, Moos, Billings, & Miller, 1987; Deatruck & Knafl, 1990; Hauser, et al., 1985; Knafl & Deatruck, 1986), very little literature addresses the mother-daughter relationship when the daughter has any form of chronic illness. What does exist is a fair amount of popular, nursing, feminist, and psychological literature and research on mother-daughter relationships in which the daughter is without ongoing health problems. Those areas which might be relevant to mother-daughter relationships in chronic illness include: (1) mothers and daughters as they are presented in popular culture and clinical literature; (2) mother-daughter identification, including issues of separation and individuation; (3) developmental stages of or transitions in women lives, which often include stage-related data on the mother-daughter relationship; and (4) mothers and daughters in lay literature. A great deal of overlap exists between these areas; one cannot always separate these topics into distinct categories.

Many other bodies of literature, such as those concerning vulnerable child syndrome, child temperament, and maternal-child bonding could also be

considered applicable. However, because adolescents and women are the subject of this study, the discussion will be limited to the areas listed above.

### **Mothers and Daughters in Popular Culture and Clinical Literature**

Authors (Boyd, 1989; Walters, 1992) have posited that interest in mother-daughter relationships has become something of an obsession for some persons in our culture. Certainly one does not have to look far to find evidence of this. Women's magazines frequently tell stories of adopted daughters searching for their biologic mothers; mothers and daughters are depicted in television advertisements for everything from feminine hygiene to household cleaning products. Though these examples emphasize a positive bond between mothers and daughters, it is frequently the case that this relationship is portrayed in the media as one of antagonism and painful ambivalence.

In her book, Lives Together, Worlds Apart, Suzanna Walters (1992) discusses her in-depth study of women and mother-daughter relationships as seen in magazines, movies, and on television. In the opening chapter, entitled "Separation and Affiliation," Walters reviews the societally created dichotomy with which women and mother-daughter relationships have struggled since World War II. For example, mothers have been expected to understand, often simultaneously, the importance of bonding with their daughters while allowing them plenty of room for adequate individuation (Walters, 1992). For some

mothers, a daughter's differentiation of identity within a close mother-daughter relationship may be easily accomplished. For other mothers, the concepts of separation and affiliation may seem more like polar opposites; achievement of a satisfactory mother-daughter relationship integrating both of these concepts may seem impossible.

Meanwhile, daughters have grappled, as their mothers did, with whether to try to "have it all" in terms of marriage, children, and career, or to go with the more potentially limiting cultural messages of the day (Walters, 1992). Unfortunately, these messages have seemed ever-changing. On some days, the cultural theme for women has been to forsake motherhood, to get out and make the most of themselves in the workplace. On other days, the message has instead been that motherhood, nurturing, and childrearing are more important than career success.

But whatever other messages the culture has given, the clearest one has been that, regardless of circumstances, whatever happens to the daughter or the mother-daughter bond is the mother's and not the daughter's responsibility. Walters discusses this phenomenon:

In a film called 'night, Mother, a mother is trying to prevent her thirtyish daughter from shooting herself. During the climactic scene, the mother clutching her breast and trying to comprehend her daughter's decision, screams in anguish, "I don't know what I did but I know i did it!" In an otherwise forgettable film, these few words stand out as poignant and resonate with what we take to be the truth about mothers and daughters. Whatever else occurs between these two women..., we know - like the mother - that somehow, ... she was responsible (Walters, 1992).

Interestingly, Walters' explication of popular culture parallels what occurred in clinical literature beginning in the 1950's. Mothers were frequently seen as the focus of blame for their children's behavior and often readily took on that guilt (Ehrenreich & English, 1978). Not until nearly the 1980's did literature for health care professionals begin to address the role of the *parents*, rather than mothers, and in more than name do so. For example, the title of the article, "Parenting attitudes: The role of personality style and childhood long-term illness" (Boll, Dimino, & Mattsson, 1978), purports to address the personalities of parents. However, on further examination of the article, it becomes apparent that only the mothers were studied.

If, indeed, movies, books, and other forms of media continue to lend credence to the belief that mothers are always responsible, perhaps we cannot expect major changes in our characterizations of life in the "real world." For example, Caplan and Hall-McCorquodale (1985) postulated that the women's movement might have altered the commonly held view that mothers are always to blame for their children's shortcomings. They then studied the incidence of mother-blaming in major clinical journals for the years 1970, 1976, and 1985. Not only were the investigators disappointed to find no significant decrease in mother-bashing, but they also found that women authors tended to mother-blame nearly as often as did men. Further, the tendency toward mother-blaming was pervasive all types of journal surveyed.

What is missing in clinical literature is a balanced view of the possible influences on mothers' and daughters' psychological well-being and their relationship when the daughter has a chronic illness. A study by Gantt (1992) examined the painful experiences of young women growing up with congenital heart disease. Though their mothers were not included in the study, participants made frequent reference to the importance of their mothers in their lives. Though the young women acknowledged the sacrifices their mothers had often made in raising them, their mothers had also forced them to eat so that they would be healthier, dragged them to doctors when they had even the smallest physical complaints, and kept them from engaging in many activities that their peers had enjoyed. This caused them to feel ambivalent towards their mothers, grateful in some regards and resentful in others. "Adjustment" to heart disease appears to be difficult process for both mother and daughter. Gantt (1992) concluded her study with several recommendations for further research, including the need for a study that would address the perspectives of mothers in relation to having a child with chronic illness.

From the 1950's through the 1980's, studies of mother-child relations in the presence of the child's chronic illness typically have used a variety of instruments and quasi-experimental designs to study the influence of mothers on the psychological development of the child, often without any clear theoretical justification for doing so (Cooper, 1959; D'Antonio, 1976; Linde, 1982; Linde et al., 1966; Kong et al., 1986). For example, articles in major

journals by Linde (1982) and Cooper (1959) fail to discuss research findings by the authors or others, but instead merely blame "overprotective" mothers for the potential problems of their children with heart problems. Though these articles do not report any research writings, they may have done much to reinforce the belief that mothers of children with cardiac disease were overprotective, pampering, and anxious (Linde et al., 1966). These writings by Linde and Cooper were probably meant to build on the work of Levy entitled Maternal Overprotection, originally published in 1943. Levy conducted case study research on twenty children, five of whom had various types of illnesses and three of whom had developmental delays, all of which were thought to perhaps cause their mothers to be to feel that they must be overprotective of them. The remainder of the children came from families in which the mothers had various obstetrical problems or other children with health problems, thereby supposedly putting the mothers at risk for being overprotective. Levy (1951, 1966) identified what he describes as three groups of maternal overprotective behavior: (a) excessive contact with the child; (b) infantilization; and (c) prevention of independent behavior by the child. Levy's definition and description of maternal overprotection appears to have continued in the literature concerning children with heart problems. For example, Kong and colleagues (1986) used a descriptive comparative design to examine the emotional and social consequences of congenital heart disease. However, rather than really researching whether heart disease causes emotional

problems, the authors seem to have made the assumption that maternal maladjustment, guilt, and pampering are really the causes of problems in these children. Various unpiloted measures were administered to the mothers, though the study fails to discuss any theoretical background for including them in the study.

However, studies using qualitative methods to examine the mother-daughter relationship, such as that by Gantt (1992), are rare. D'Antonio (1976) used extensive interviews to examine the responses of mothers to the behavior of their "cardiac children" in child-rearing situations. This very lengthy study, involving twenty mothers of pre-school children is one of the few early qualitative studies examining how mothers cope with the experience of having a chronically ill child. Though this research was published in 1976, some years after articles began to appear regularly on the subject of the psychological well-being of children with heart problems, it unfortunately perpetrates the label "cardiac child" as previously mentioned in works by Linde and colleagues (1966) and others (Green & Levitt, 1962).

Additional focused qualitative research would be valuable since it could validate or refute earlier studies on mother-daughter relationships, adding to existing knowledge and providing a less biased view by examining mothers' and daughters' own perceptions of their relationships.

## **Mother-Daughter Identification:**

### **Issues of Separation, Individuation, and Relation**

Even within nursing, interest in mother-daughter relationships has grown to the extent that one nurse researcher has begun concept analysis and testing of models of mother-daughter identity. No other nursing theories or conceptual frameworks specifically address the mother-daughter relationship in any context. Building on psychoanalytic and social learning perspectives, Boyd (1985, 1989, 1990) cites the interdisciplinary nature of interest in the mother-daughter relationship and the need for nurses interested in women's health to have an understanding of "normal" mother-daughter relationships. However, Boyd acknowledges the lack of consensus regarding just what constitutes "normal" mother-daughter identification.

In her model building and testing, Boyd (1990) utilizes previously applied classic concepts such as attachment and conflict to postulate an intercorrelation (Boyd, 1990, p. 452) between the daughter's attachment to her mother, mother and daughter conflict, and a new concept, which Boyd calls dyadic identity. Previously, mother-daughter identification has been viewed as a process relative only to the intrapsychic development of the daughter (Freud, 1933). However, in Boyd's work, dyadic identity can be defined as a shared identity between mothers and daughters which is the result of the intensity and mutuality of identification and a merging of self-concepts (Boyd, 1990, p. 449). Boyd bases some of her premise concerning dyadic identity on the work of

Martha Rogers and human-environmental field integrality; both the mother's and the daughter's identities are affected by the identification process.

Boyd discusses the "integrality" of mothers' and daughters' identities. Though Boyd never specifically defines mother-daughter identification, in her view, the identification process is observed when mothers and daughters "show evidence of mutual influence and shared identities" (Boyd, 1990, p. 451). Interestingly, however, Boyd further speculates that it is the very close nature of the mother-daughter relationship that contributes to conflict over "intradyadic differentiation" (Boyd, 1990, p. 452). While Boyd acknowledges the daughter's need for separation, her work raises questions concerning whether or not the daughter can possess a separate identity in the context of dyadic identity and whether or not mother-daughter identification can occur if the two do not share an identity. In addition, Boyd operationally defines some components of her theoretical model, but does not define others as she has used them throughout her work, making it difficult to understand her intentions.

Boyd's efforts at defining normative mother-daughter relationships through model building are to be admired, especially as she tries to study both individual and dyadic contributions to mother-daughter identity. However, her model suffers from conceptual and methodologic problems. For example, Boyd's model specifies only one hypothesis. Boyd hypothesized that, within her model, daughter's attachment to mother, mother and daughter conflict, and

the identity of the dyad will be intercorrelated. Hypotheses relating components of the model are not stated.

Boyd seems to be saying in her hypothesis that dyadic identity is positively correlated with mother-daughter conflict, specifically the daughter's conflict, though the mother's conflict was never measured in this study. While several studies have documented the normative nature of conflict within the mother-daughter relationship (Bromberg, 1983; Fischer, 1986), particularly during adolescence (Apter, 1990) and the possibility of a shared identity between mothers and daughters (Rollins & White, 1982), there is no theoretical evidence within the literature for Boyd's contention that conflict between mothers and daughters would increase dyadic identity. In her commentary on Boyd's model, Eggert (1990), also a nurse, points out that mother-daughter conflict should have a negative impact on mother-daughter dyadic identity, based on perspectives of symbolic interaction and developmental communication theory. Perhaps Boyd means to say that a daughter's conflict about the mother-daughter relationship is increased when they identify more closely with one another, but this is not clear from her article.

Additional problems with the model, however, stem from the instruments used. Daughters' attachment to their mothers was measured using a 9-item instrument which had received previous testing; internal reliability for this instrument was reported to range from .86 to .91 (Chronbach's alpha). Mothers' attachment was not measured. The Mother-Daughter Conflict Scale,

an 8-item scale designed specifically for this study, was previously unpiloted. Finally, mother-daughter dyadic identity was derived using separate, but summed scores for mothers and daughters on the Tennessee Self-Concept Scale. It is unclear how these individual measures of self-concept reflect dyadic identity, which theoretically should also have an interactional component.

Boyd's work stands in sharp contrast to other studies reflecting current thinking about mother-daughter relationships within the field of psychology. Since the landmark work of Gilligan (1982), feminist writing and research has sought to discount previous theories which presented separation and individuation as necessary in normal male and female adolescent and adult development. The classic works of Erikson (1950) and Freud (1933) established the tasks of separation from parents and development of the individuated self as necessary for normal adult development. However, in recent years, researchers such as Carol Gilligan (1982) and others at the Stone Center for Developmental Studies (Jordan et. al, 1991; Stiver, 1986) have questioned whether these models truly reflect what occurs in female, or even male, development. Recently, authors and researchers have begun to document the relational nature of women and their relationships (Brown & Gilligan, 1992; Gilligan, Lyons, & Hanmer, 1989; Jordan et al., 1991). However, none of these authors or studies have proposed that daughters' identities must be one and the same as that of their mothers.

Jordan and colleagues (1991) have proposed that women's identity is a complex process of differentiation within relation to others. Perhaps this is Boyd's intended meaning. However, in her work, Boyd is unclear as to whether the daughter's identity differentiation occurs as the result of the relationship between mother and daughter or as a result of the daughter's separation.

One other author, Kaschak (1988), provides a different viewpoint on the concept of the relational nature of women. Kaschak, a psychologist, proposes that women have been forced into relation with one another because they have not been allowed to have separate identities in a world dominated by men. Instead they have been compelled to develop relationships with other women and their own families because they were not permitted to establish separate identities in the workplace. Kaschak discounts the current view of women's relationships and needs as completely affiliative, stating that by compelling women to adopt this stance, we are denying a place for women who do have high needs for individuation. Kaschak's work raises the possibility that a fairly flexible model of women's development will be needed. In the future, avoiding a model which places some women outside the its boundaries, such that they are seen as "deviant," (Jack, 1991) will be both necessary and desirable.

In summary, our present knowledge about mother-daughter identity is that it is a process that definitely occurs, but we remain uncertain about exactly how it occurs. In the current social climate, it may very well be that by the

time we have discovered how personality development in women unfolds, and what the mother's role is in that process, the process itself will have changed just as women's roles are changing.

In addition, what small amount of research is conducted on mother-daughter identification discusses only certain cultures. The preoccupation with the mother-daughter relationship within American culture is not shared by Navajo culture, for example, in which mother-child relations, whether the child be a son or daughter, are considered more important than relationships between any other family members (Witherspoon, 1975). How this process evolves within different cultures is largely unknown. Further, we have no idea whether the illness of a daughter, especially when that illness is potentially life-threatening, may affect mother-daughter identification.

### **Changes in the Mother-Daughter Relationship as a Reflection of Stages in Women's Development**

Within the last several decades, researchers and writers have come to realize that the developmental stage models of Erikson and Piaget evolved out of research conducted predominantly on men. This has resulted in research directed towards providing separate accounts of female personality or identity development. These studies of identity development provide much relevant data on how the mother-daughter relationship may evolve over the course of a woman's lifetime.

Josselson (1987) identified four paths to identity development in women interviewed during their final years of college and again about ten years later: (1) the Foreclosures, those women likely to continue with the beliefs and practices of their childhoods, without rethinking choices or experiencing a crisis; (2) the Identity Achievements, those women who forged new identities on their own terms, having examined and reworked the identities assigned to them during childhood; (3) the Moratoriums, those women who were aware of their many choices, but were paralyzed due to indecision; and (4) the Identity Diffusions, those women who were adrift and lost, without crisis or commitment. Josselson did find that, with the exception of women who were unable to develop a stable identity, identity diffusion group, most women had fairly positive relationships with their mothers.

In a longitudinal, retrospective study, Fischer (1986) studied approximately 40 mother-daughter pairs. She found that mothers and daughters experienced positive changes in their relationship when the daughter married and became a mother herself. Because the daughter was more able to comprehend her mother's previous roles as wife and mother, the daughter became more understanding of the mother. In addition, the mother and daughter shared a common bond and the mother was more valued by the daughter for her ability to offer advice and support. Fischer identified four types of mother-daughter relationships in the daughter's adulthood:

(1) responsible mothers, dependent daughters; (2) responsible daughters, dependent mothers; (3) peerlike; and (4) mutual mothering. The work of Fischer (1986) provides a useful model of how adult mother-daughter relationships go through developmental stages just as mother and daughter do individually.

In their study of pivotal transitions in women's lives, Mercer, Nichols, and Doyle (1989) conducted life history interviews with women. The researchers had particular interest in how the decision to become or not to become mothers might have influenced the lives of these women. During the course of study, the focus changed somewhat as the researchers discovered that women were also affected by the decision to marry or not marry and by their own experience of being mothered. In fact, one chapter in their book is entitled, "The Awesome Mother." Findings by Mercer, Nichols, and Doyle (1989) support the work of Fischer (1986): the daughter's motherhood may provide a time for daughters to potentially reestablish a mutually satisfactory relationship with their own mothers. The mother-daughter relationship was also found to be a factor affecting daughter's decisions concerning careers and motherhood for themselves; daughters tended to do as their mothers did in these matters. The work of these investigators moves towards a new stage theory of adult female development beginning with the launching period at ages sixteen through twenty-five and ending with the period of creativity or destructiveness between ages seventy-six and eighty. Though this last stage

sounds much like Erickson's (1959) final two developmental stages of generativity versus self-absorption and integrity versus despair, other stages as named by Mercer and colleagues bear little resemblance to Erickson's work.

In summary, though all of these studies on identity and personality are quite useful in the establishment of a knowledge base about women's development, they also raise additional questions. In short, while each contributes significantly to our understanding of mother-daughter relationships, they are like bits of a puzzle with many more missing pieces. Researchers have approached this relationship from a many viewpoints using a variety of methods. As pointed out by Mercer, Nichols, & Doyle (1989), we actually know very little about adult mother-daughter relationships.

### **Mothers and Daughters in Lay Literature**

What little lay literature is available on mothers and their chronically ill daughters lends credence to the concept of changes in the mother-daughter relationship as each matures. Deborah Samuelson (1986) writes to and about her daughter Heidi, whose multiple congenital anomalies necessitated several surgeries over the course of her life. Though Samuelson never states the age of her daughter at the time the article was written, one gets the impression that she is probably school-age. Samuelson writes of how alienated she and her daughter have become and the anger each feels for one another, society, and the health care system.

On the other hand, Jacquie Gordon (1988) chronicles the life of her daughter who died of cystic fibrosis at the age of twenty-one. Though Gordon speaks of stress points in her relationship with her daughter, one has the sense that theirs was a relationship characterized by support and friendship, or what Fischer (1986) calls "mutual mothering." It is important to note that Gordon's book was written at a later time in her life and after her daughter's death, as compared to the work of Samuelson. This may have some bearing on the more positive view that Gordon takes of her relationship with her daughter.

Roberta Cepko (1987), born with club feet as well as other anomalies, wrote a brief story about her relationship with her mother. This piece, also written during the author's adulthood, describes a very positive relationship with her mother, who fostered her daughter's positive self-image by kissing her feet and pronouncing them beautiful despite multiple childhood surgeries. Perhaps it is easier for women with chronic illness to relate to their mothers once they have become adults. This may be because the battles of adolescence are over and the life-threatening surgeries and procedures are usually behind them causing they may feel less dependent on their mothers.

In summary, popular culture and lay literature provide an inconsistent picture of mother-daughter relationships as antagonistic and ambivalent at times and mutually supportive at others. The body of scientific literature on

mother-daughter relationships is growing, but also presents no consistent picture.

In the meantime, the role of women, including mothers and daughters, continues to evolve. Further research into the nature of this relationship is needed, particularly as it relates to other cultures, the influence of illness or other life-challenging events, and evolving societal influences.

This study began with the following questions:

1. How does the daughter's heart problem affect the relationship between mother and daughter?
  - a. What is the role of the mother, if any, in the "adjustment" of the daughter to her chronic illness?
  - b. Are there developmental stages in the mother-daughter relationship when the daughter has a chronic illness ?
  - c. How do daughters with heart problems and their mothers perceive the labels "cardiac child" and "overprotective mother?"
2. How do daughters who have a chronic illness and their mothers perceive health care professionals? What do they feel that health care providers can do to help them with the daughter's illness?

## CHAPTER III

### METHOD

This study utilized a qualitative descriptive design, minimally structured interviews, and maximum variation sampling. According to Miles and Huberman (1994), the main task of all types of qualitative research is to explicate ways people in particular settings come to understand, account for, take action, and otherwise manage their day-to-day situations. Marshall and Rossman (1989) state that one purpose of qualitative methods is to discover important questions, processes, and relationships.

The particular aim of this study was to illuminate the meaning of chronic illness to women and their mothers as constructed within their relationships and with other persons, including health care professionals. Although theories about the nature of the mother-daughter relationship exist in traditional psychiatric, popular, and feminist literature, little research has examined the possible differences in this relationship when the daughter has been chronically ill since birth. In this study, the mother-daughter relationship was seen as affecting and being affected by the daughter's illness. The illness was assumed to have an ongoing, dynamic impact over time. In other words, the particular implications or problems for the mother-daughter relationship when the daughter has a heart problem were expected to change over the course of the lives of each.

### **Human Subjects Review**

The study was approved by the Colorado Multiple Institutional Review Board. This human subjects review board, which oversees research conducted by students and faculty at the School of Nursing at University of Colorado Health Sciences Center, also evaluates proposals for several health care institutions.

### **Sample**

Initially, convenience sampling was employed for this study. The investigator was able to establish contact with some potential participants in her current nursing practice. The investigator then contacted pediatricians well known to her and requested permission to contact appropriate clients from their practices. After an initial contact by the physician of record to obtain permission, the investigator then contacted the mother or daughter. Any English-speaking adolescent or young woman with congenital or childhood heart disease and her mother, regardless of the daughter's diagnosis, treatment, racial or socioeconomic background were included. Only one mother-daughter dyad in this study was known to the investigator from her previous research. The sample included Anglo, Navajo, and Hispanic adolescent and adult women and their mothers. More detail on the sample for this study is provided in Chapter IV. Demographic, diagnostic, and severity of illness data on study participants, including mothers and daughters or sons with heart problems, are included on the following pages in Tables 1 and 2.

| <b>Table 1: Demographic Information on Daughters and Sons</b> |            |                  |                      |                            |                |                      |
|---|------------|------------------|----------------------|----------------------------|----------------|----------------------|
| <b>Name</b>   | <b>Age</b> | <b>Ethnicity</b> | <b>Diagnosis</b>     | <b>Severity of Illness</b> | <b>Repair?</b> | <b>Other Disease</b> |
| <b>DAUGHTERS</b>  |            |                  |                      |                            |                |                      |
| Stacy   | 9          | Anglo            | TOF                  | 2                          | Yes            | No                   |
| Jean  | 10         | Hispanic         | TOF                  | 2                          | Yes            | No                   |
| Megan   | 14         | Anglo            | DORV, VSD            | 3                          | Yes            | No                   |
| Laura   | 16         | Anglo            | Heart Murmur (?PS)   | 1                          | No             | ?Learning disab.     |
| Erin  | 16         | Anglo            | VSD                  | 2                          | No             | No                   |
| Veronica  | 17         | Anglo            | TOF                  | 3                          | Yes            | ?Growth Disorder     |
| Norma   | 19         | Anglo            | TA                   | 4                          | Yes            | No                   |
| Teri  | 34         | Anglo            | VSD                  | 4                          | Yes            | CVA, seizures        |
| Lainna  | 35         | Anglo/Iraqi      | Truncus Arteriosus   | 3                          | Yes            | CVA                  |
| Nell  | 42         | Anglo            | RF, AI, MVR          | 4                          | Yes            | No                   |
| Lucy  | 56         | Anglo            | ASD                  | 1                          | Yes            | Asthma               |
| <b>SONS</b>   |            |                  |                      |                            |                |                      |
| Mark  | 12         | Hispanic         | TAPVR                | 2                          | Yes            | No                   |
| Brad  | 15         | Hispanic/Anglo   | WPW                  | 1                          | Yes            | No                   |
| Matt  | 18         | Hisp/Native Am   | Coarctation, VSD, PS | 3                          | Yes            | No                   |

KEY: AI = Aortic Insufficiency      Coarctation = Coarctation of the Aorta      PS = Pulmonic Stenosis  
 RF = Rheumatic Fever      MVR = Mitral Valve Replacement      VSD = Ventricular Septal Defect  
 TA = Tricuspid Atresia      TAPVR = Total Anomalous Pulm. Venous Return      WPW = Wolfe-Parkinson-White  
 ASD = Atrial Septal Defect

| <b>Name</b> | <b>Age</b> | <b>Age @ Child's Dx</b> | <b>Child's Dx</b>                       | <b>Severity of Child's Disease</b> | <b>Culture</b> | <b>Child's name/age</b>   |
|-------------|------------|-------------------------|---|------------------------------------|----------------|---------------------------|
| Lynnette    | 45         | 24                      | Tetralogy of Fallot, repaired           | 3                                  | Anglo          | Veronica - 17             |
| Mary        | 35         | 25                      | Tetralogy of Fallot, repaired           | 2                                  | Hispanic       | Jean - 10                 |
| Marion      | 40         | 33                      | Pulmonary atresia, repaired             | 4                                  | Anglo          | Linda - 6                 |
| Shauna      | 45         | 29                      | Heart murmur only                       | 1                                  | Anglo          | Laura - 16                |
| Roberta     | 40         | 25                      | Atrioventricular Canal, Down's Syndrome | 3                                  | Hispanic       | Margaret - 15             |
| Jane        | 55         | 20                      | Truncus arteriosus, repaired            | 3                                  | Anglo          | Lainna - 35               |
| Lucinda     | 30         | 28                      | Ventricular Septal Defect, unrepaired   | 2                                  | Navajo         | Keely - 2                 |
| Jaimee      | 35         | 26                      | Tetralogy of Fallot, repaired           | 2                                  | Anglo          | Stacy - 9                 |
| Karen       | 40         | 26                      | Double outlet right ventricle, repaired | 3                                  | Anglo          | Megan - 14                |
| Martha      | 35         | 25                      | Pulmonary atresia, palliated            | 4                                  | Anglo          | Chris (deceased at age 9) |
| Dawn        | 40         | 25                      | Ventricular Septal Defect, unrepaired   | 1                                  | Anglo          | Erin - 16                 |
| Joan        | 40         | 22                      | Aortic Coarctation, Vent. Sept. Defect  | 3                                  | Hispanic       | Matt - 18                 |
| Lori        | 30         | 18                      | Total Anomalous Pulm. Venous Return     | 1                                  | Hispanic       | Mark - 12                 |
| Beth        | 36         | 21                      | Wolfe-Parkinson-White Syndrome          | 1                                  | Hispanic       | Brad - 15                 |

Over the course of the research, the sampling became more purposeful. The aim of purposeful sampling is to illuminate the specific questions under study (Patton, 1994). Patton (1994) recommends certain strategies for selecting such "information-rich" cases in a qualitative study, several of which were utilized in this research. For example, Patton advocates sampling of extreme or deviant cases. In this study, one daughter with a repaired ventricular septal defect and multiple other health problems, including a stroke and seizures, discussed having been told by her physician that her heart disease was the likely result of her mother's having tried to have a miscarriage while carrying her. This woman had "divorced" her mother and represented the ultimate in the worst possible mother-daughter relationship.

Patton (1994) also recommends intensity sampling in qualitative studies, which involves sampling cases which manifest the phenomenon of interest very richly or intensely. After months of consideration by the investigator, the decision was made to contact and later interview a woman who had lost her daughter to a severe form of congenital heart disease. The intensity of this woman's attachment to her daughter was evident, despite her daughter's death eighteen months prior to the interview.

Maximum variation sampling, also advocated by Patton (1994) in qualitative studies, was employed in the decision to interview a variety of types of participants. For example, mothers of varying ages, educational backgrounds, and employment were interviewed. Daughters who had varying

types of heart disease in terms of severity and type of treatment were also interviewed. The study included mother-daughter dyads who were obviously very attached to one another as well as those who were not close and even estranged. In addition, several young men and their mothers were included interviewed. These participants were included in order to differentiate between those issues which were unique to mothers and daughters and those which were common to mothers and their children with heart problems in general.

### **Setting**

Interviews took place at locations mutually agreed upon by the researcher and participants. Most interviews took place at the homes of the participants. Two interviews were conducted at the home of the researcher. One woman chose to be interviewed at an office, as did one mother-daughter dyad. One mother-daughter dyad and one additional daughter elected to meet the researcher at restaurants.

The majority of interviews took place in the vicinity of Farmington, New Mexico, a community of approximately 40,000 persons. However, two individual and one dyadic interview took place in North Carolina, where the researcher practiced before moving to New Mexico, and one dyadic interview took place in the Seattle area.

### **Instruments**

The principal method of data collection was the unstructured formal interview (Chenitz & Swanson, 1986). The open-ended interview is a data

collection tool frequently employed in qualitative studies. The investigator introduces themes with brief open-ended questions or statements related to the topic of interest; participants are encouraged to elaborate on these themes or others which they feel are more relevant to them.

Appendix A includes questions typically asked of daughters in this study; Appendix B includes examples of questions asked of the mothers. These lists of questions are not all inclusive, but do reflect the evolution of questions over the course of the study as participants suggested themes and as appropriate literature was reviewed. Interview questions were designed to progress from general to more specific to allow participants to suggest themes as much as possible. In the event that the participant did not suggest an emergent theme, then a specific question related to the theme was asked. Probes were used to gain more information about or explanation of particular themes introduced by the subjects, but only after a period of silence designed to allow the participant to provide as much or as little information as he or she wished.

### **Data Generation and Collection**

Data collection took place over a fifteen month period between May 1994 and August 1995.

### **Informed Consent**

Participants were contacted by phone or mail and asked to take part in the study. Mothers were asked to provide signed consent for themselves and their daughters if the daughter was under eighteen years of age. Daughters

under eighteen were also asked to sign forms of assent. Daughters over eighteen provided signed consent for themselves. Only two sons were interviewed, both with their mothers. One additional mother was interviewed without her son for logistical reasons. Copies of all consent forms are included in Appendices C-F. The consent form in Appendix E was modified slightly for use in interviews of mothers of sons with congenital heart disease.

The original plan was to interview mothers and daughters first together and then separately to allow observation and documentation of dyadic interaction as well as exploration of individual responses. Chenitz and Swanson (1986) discuss the advantages and disadvantages of interviewing the "natural unit" in qualitative studies, in this case the mother-daughter dyad, stating that both individual and dyadic interviews have their place in providing rich data which helps to provide range and variation to categories. The investigator's past experience had demonstrated that adolescent women, in particular, were often unwilling to explore certain themes with their mothers present. However, the investigator wanted the opportunity to observe mothers and daughters together as well. Unfortunately, circumstances frequently prevented both dyadic and individual interviews. For example, some adolescents were reluctant to be interviewed alone because of lack of familiarity with the investigator. Mothers often seemed more willing to explore certain themes, such as their daughter's health status, when the daughter was not present. In other cases, mothers and daughters lived in geographically

distant cities and could not be interviewed together. As a result, some mothers and daughters were interviewed only together and others were interviewed only separately. It was not possible in any case to conduct interviews with the dyad together and then apart. Five mother-daughter dyads were interviewed together, while two additional dyads were interviewed separately. Four daughters and four mothers were interviewed separately; these participants were in no way related. Three mothers of sons with heart disease were interviewed, two dyads together and one mother separately.

Participants were interviewed only once, except in the case of one daughter and one mother-daughter dyads who were interviewed a second time for purposes of validation. Interviews were tape recorded unless the participant requested that they not be audiotaped. In these instances, which included one daughter and one mother-daughter dyad, extensive field notes were taken.

### **Data Analysis**

Miles and Huberman (1994, p. 9) have proposed that the following analytic practices, which the investigator employed in this study, are used across most qualitative methods:

1. Affixing codes to a set of field notes drawn from observations or interviews.
2. Noting reflections or other remarks in the margins.
3. Sorting and sifting through these materials to identify similar phrases, relationships between variables, patterns, themes, distinct differences between subgroups, and common sequences.

4. Isolating these patterns and processes, commonalities and differences, and taking them out into the field in the next wave of data collection.
5. Gradually elaborating a small set of generalizations that cover the consistencies discerned in the data base.
6. Confronting those generalizations with a formalized body of knowledge in the form of constructs or theories.

Content analysis was used to analyze data in this study in order to identify patterns, themes, and generalities. Content analysis is a technique that allows examination of data to determine whether or not the data supports a research objective using a coding system developed by the researcher (Marshall & Rossman, 1989). According to Morgan (1993, p. 120),

qualitative content analysis facilitates making comparisons because the counts it produces form explicit answers to questions about what differences are present in the data (pattern detection), as well as further explanations about why these patterns occur (interpretation).

First, audiotapes of interviews were transcribed verbatim and pseudonyms were assigned to each mother and daughter for purposes of anonymity. The interview data were then subjected to successive stages of reduction. Each transcript was first read for overall content, then for development of substantive codes. Substantive or first level codes are those concepts or terms which summarize the processes or thoughts of the participants and which reflect, as much as possible, their language and descriptions.

Substantive codes included such broad categories as "initial effects on the mother-daughter relationship" in which mothers talked about those things that happened to them in the beginning as a result of the realization that the

daughter had heart problems. Another code, "adjustment" summarized those behaviors and experiences of mothers and daughters adjusting to the daughter's heart disease. Seven substantive codes were discovered in the data. Data which the researcher felt was relevant, but was not classified according to a specific code, was kept in a "miscellaneous" code.

No interpretation of data occurred during substantive coding, though the investigator began to make process memos concerning ideas about the data. For example, some of the researcher's early process memos discussed how severity of illness affected the mother-daughter relationship and the issues considered important by the participants. Eventually the researcher developed a severity of illness scale, which is discussed later in this chapter. Other memos addressed whether or not increased closeness in the mother-daughter relationship, which might be expected as a result of the daughter's illness and subsequent increased dependence, might lead to increased tension within the relationship. However, eventually the researcher determined that the participants viewed their relationships as "normal," and that the distribution of types of relationships within the sample was probably not markedly different from perceptions of mother-daughter relationships within the general "healthy" population. Other process notes concerned the researcher's observations about the participants and their relationships. These observations are presented in summary form at the end of Chapter IV.

Interpretive coding followed substantive coding in the second stage as relationships between substantive codes were developed to contain and explain the data. For example, the variable, "it's no big deal" was developed to explain how mothers and their chronically ill daughters view their lives and relationships as essentially normal and like others who are healthy. "It's no big deal" included substantive codes such as "adjustment" to the disease by the participants and their view of heart problems not as disease, but as a way of life.

In addition, a conceptually clustered matrix (Miles & Huberman, 1994) was designed during the course of data collection to allow visualization of data for each participant and groups of participants, including mothers, daughters, and sons, according to substantive code. This helped the investigator to account for missing data and to see trends in the data. Appendices G through I contain these matrices.

#### Severity of Illness Scale

During the course of analysis, each daughter or son with a heart problem was assigned to a category which reflected their severity of illness. The researcher had not originally anticipated that severity of illness would turn out to be a major contributor to a sense of well-being, or lack of it, in the lives of daughters with heart problems and their mothers. Because the severity of the daughter or son's illness or disability was an obvious concern and a major component of how easy or difficult it was to cope with the heart problem, the

author designed her own severity-of-illness scale during the course of the study. The development of this scale was an analytic decision, while the scale itself was meant to aid with analysis.

Unlike classification schemes such as that of the New York Heart Association, which is almost based entirely on physiologic factors and functional status related to those factors, the author's scale took into consideration the adolescent or young adult's, and in some cases the mother's, psychological reaction to or attitude toward the disease. This meant that in some cases, a participant with heart disease could be classified as more severely ill despite the fact that the type of heart disease might have been viewed by health care practitioners as only somewhat minimally limiting physiologically. The author operated under the premise that if the participant or family viewed the person with heart disease as severely ill or limited, then this perspective could have affected how well or ill the person might be. In other words, the researcher felt, based on study findings, that severity of disease and severity of illness were not necessarily equivalent. While severity of disease is strongly correlated with physiologic factors, severity of illness entails both physiologic factors and the person or family's response to them.

Mothers and their sons or daughters with health problems contributed to these premises by the researcher. For example, to have seen Stacy, a nine year old with corrected Tetralogy of Fallot, one could not help but conclude that she was very healthy. She was of normal size for a child her age, her

color was good, and she interacted with her parents much as one would have expected. Nevertheless, her parents remain very fearful about her health. It seemed impossible that they would not sometimes communicate this to Stacy as they spoke openly in front of her about her past health problems and their future concerns.

However, there were other participants in the study with potentially life-threatening heart problems whose mothers viewed them as quite healthy. This could have resulted in that participant being categorized as less severely ill. In some cases, potential illness, such as planned future surgeries or deterioration expected with growth and development, biased the view of the person with heart disease and his or her parents about the severity of the problem.

The author did not base her scale on any other currently in use. Initially the author rated the participant with the heart problem on a scale of 1-10 with 10 being the most severe disease. Eventually the scale was collapsed into four categories.

Category 1 included those participants with very minor heart disease. Daughters and sons in this category might have had heart murmurs which required occasional monitoring by doctors or heart problems, such as atrial septal defects or mild pulmonic stenosis, which had been repaired in the distant past and which probably would not need additional surgery. Mothers of participants in this category, as well as the participants themselves, viewed

their heart problems as minor, thought about them very little, and considered their lives virtually normal.

Category 2 included daughters and sons with mild heart problems such as ventricular septal defects and repaired Tetralogy of Fallot. For these participants and their mothers, the heart problem was slightly more in the forefront. More frequent medical monitoring was necessary and issues such as future pregnancies were of concern. However, both the person with the heart problem and his or her mother considered the disease to have a minimal impact on their lives and found it relatively easy to live a normal life.

Category 3 included those participants with moderate to severe heart disease such as truncus arteriosus or severe Tetralogy of Fallot which might require multiple surgeries and moderate monitoring. Pregnancy might or might not ever be possible for these daughters. Nevertheless, these participants and their mothers maintained a very positive outlook on life and their ability to cope with the disease. Achievement of a normal life was possible for these participants, though it was sometimes more difficult with interruptions such as surgeries and exacerbation of illness.

Category 4 participants sometimes had additional health problems such as asthma, other congenital defects, or cerebrovascular accidents which might or might not have been the result of the heart problem or surgery. Types of heart problems common to these participants included pulmonary or tricuspid atresia which could only be palliated or probably not completely repaired.

These mothers and their children with heart disease struggled to keep life as normal as possible in the face of frequent surgeries and potential or actual deterioration in health status.

### Verification of Data

Authors and researchers (Chenitz & Swanson, 1986) have proposed that methods commonly used to insure the reliability and validity of quantitative studies are not appropriate for qualitative studies. Authors writing about validity have mentioned a variety of considerations in judging qualitative studies. For example, Maxwell (1992) refers to the descriptive validity of the qualitative study and states that all other types of validity depend upon this. Descriptive validity is achieved by providing as accurate an account as possible of what happened in situations specific to the study, as well as the findings of the study. Throughout the study, the investigator kept process memos to document ideas and decisions concerning the data and direction of the study, as well as to help provide an audit trail. Data matrices are displayed in the appendix also to help provide an audit trail. While Strauss and Corbin (1990) note that no qualitative study is reproducible, another researcher should be able to obtain comparable results given an understanding of the original researcher's theoretical perspective and decisions about the data as documented in the audit trail.

Numerous authors (Chenitz & Swanson, 1986; Rodgers & Cowles, 1993) have also discussed the importance of the audit trail in establishing the

credibility of a qualitative study. From an investigator's account of a study, the credibility and trustworthiness of the study are judged (Lincoln & Guba, 1985). Credibility refers to the confidence that experiences as they are lived or perceived by the participants have been discovered in the course of the research and that the findings of the study do not seem contrived or unplausible. Credibility and truth value constitute the equivalent of internal validity for quantitative studies (Miles & Huberman, 1994). Descriptive validity, credibility, and the audit trail are dependent upon and related to one another.

Maxwell (1992) also recommends that researchers consider the interpretive validity of the qualitative study. In interpreting data, the researcher seeks to understand the phenomena from the perspective of the participants and present that data and interpretation. According to Maxwell (1992), interpretive validity is inherently a matter of inference from the words and actions of the participants in the situations studied. As the study progressed, the investigator conducted several validation interviews to confirm with the participants the interpretation of the data. Findings were also confirmed by triangulation of data sources and by theory, as discussed by Miles and Huberman (1994). In other words, mothers and sons were interviewed to confirm or disprove findings from mothers and daughters. In addition, the concept of normalization, which was identified as applicable in this study to mothers and their sons or daughters with chronic illness, has been previously

identified in the literature; normalization will be discussed more thoroughly in Chapters IV and V.

## **CHAPTER IV**

### **RESULTS**

#### **Description of Sample/Participants**

A total of twenty eight persons were interviewed, including eleven daughters and three sons with heart problems, and fourteen mothers. The sample included three mother-son dyads, seven mother-daughter dyads, four mothers, and four daughters. Table 1, as discussed previously in Chapter III, includes a list of the daughters' and sons' ages, ethnic backgrounds, diagnoses, additional health problems, and mothers' names. Demographic information on mothers is contained in the Table 2, which is also part of Chapter III. A listing of mothers, sons, and daughters names is contained in Table 3 on the following page, to allow pairings of mothers and their children.

#### **Daughters**

Eleven school age, adolescent, or young adult women with heart disease participated in the study. One woman had childhood rheumatic fever, one adolescent woman had a heart murmur only, and the others had congenital heart diseases. The daughters' types of congenital heart defects included pulmonary atresia, double outlet right ventricle, atrial or ventricular septal defects, transposition of the great vessels, or coarctation of the aorta. Almost all of the daughters had surgical repair or palliation of their heart problems; in two cases, the type of heart problem did not warrant surgery.

| <b>Table 3: Mother-daughter, Mother-son Pairs, Type of Interview, Degree of Conflict &amp; Normalization</b> |              |                             |                      |                          |                              |                      |
|--|--------------|-----------------------------|----------------------|--------------------------|------------------------------|----------------------|
| <b>Name</b>  | <b>Age</b>   | <b>Yrs. since dx./surg.</b> | <b>Mother's Name</b> | <b>Dyadic Interview?</b> | <b>Mother-child conflict</b> | <b>Normalization</b> |
| <b>DAUGHTERS</b>   |              |                             |                      |                          |                              |                      |
| <b>Keely</b>   | 2            | 2                           | Lucinda              | No (mother only)         | Low                          | Moderate             |
| <b>Linda</b>   | 7            | 2                           | Marion               | No (mother only)         | Low                          | Low                  |
| <b>Chris</b>   | 9 (deceased) | 1                           | Martha               | No (mother only)         | Moderate                     | Moderate             |
| <b>Stacy</b>   | 9            | 5                           | Jaimee               | Yes                      | Low                          | Moderate             |
| <b>Jean</b>  | 10           | 7                           | Mary                 | Yes                      | Low                          | High                 |
| <b>Megan</b>   | 14           | 13                          | Karen                | Yes                      | Low                          | Moderate             |
| <b>Margaret</b>  | 15           | 5                           | Roberta              | No (mother only)         | Low                          | Moderate             |
| <b>Laura</b>   | 16           | 13                          | Shauna               | Yes                      | High                         | High                 |
| <b>Erin</b>  | 16           | 15                          | Dawn                 | Yes                      | Low                          | High                 |
| <b>Veronica</b>  | 17           | 10                          | Lynnette             | Yes                      | Low                          | Moderate             |
| <b>Norma</b>   | 19           | 6                           | Barbara (GM)         | No                       | Moderate                     | Moderate             |
| <b>Teri</b>  | 34           | 5                           | (unknown)            | No                       | High                         | Low                  |
| <b>Lainna</b>  | 35           | 5                           | Jane                 | No                       | Moderate                     | Moderate             |
| <b>Nell</b>  | 42           | 20                          | Donna                | No                       | Moderate                     | Low                  |
| <b>Lucy</b>  | 56           | 36                          | (unknown)            | No                       | Low                          | High                 |
| <b>SONS</b>  |              |                             |                      |                          |                              |                      |
| <b>Mark</b>  | 12           | 10                          | Lori                 | Yes                      | Low                          | High                 |
| <b>Brad</b>  | 15           | 5                           | Beth                 | Yes                      | Low                          | High                 |
| <b>Matt</b>  | 18           | 2                           | Joan                 | Yes                      | Low                          | Moderate             |

Several of the daughters were noted to have health problems in addition to heart disease, which sometimes caused more of a difficulty than the heart disease itself. Two young women had suffered cerebrovascular accidents (CVA) in the course of heart surgery; in one of these cases, the CVA had also resulted in a seizure disorder. Another daughter had experienced some difficulty with a possible learning disability that was unrelated to her heart problem or any other known physical problem. One woman had experienced episodes of severe asthma that she had felt were much more debilitating than her heart problem; the asthma and the heart problem were unrelated. One adolescent girl had Down's syndrome, which is frequently associated with congenital heart disease. One daughter had been on growth hormones for varying periods of time; she and her mother were unsure whether her extremely small stature was related to her heart disease or some other problem.

The youngest daughter included in the study was nine years old and the oldest was fifty-six years old. Age groupings of daughters were as follows: (a) two participants were under the age of twelve; (b) five participants were ages 14-19; (c) three participants were ages 34-42; (d) one participant was 56. Efforts were made to sample participants in their twenties; however, the investigator was unable to locate eligible participants in the 20-30 year old age range.

Of the daughters, nine were Anglo, one was Hispanic and one was Anglo-Iraqi. Of the daughters over the age of eighteen, one was a student, three were employed, and one was disabled to the point of being unemployed. All of the daughters under eighteen were enrolled in school.

Of the daughters interviewed, two were classified as category 1, three as category 2, three as category 3, and three as category 4. Based on their mothers' reports and the investigator's knowledge of the disease process involved, the four mothers interviewed without their daughters resulted in the classification of those four daughters as one in category 2, one in category 3, and two in category 4.

### **Sons**

The three sons with heart problems ranged in age from 12 to 18. These problems included one son who had multiple heart defects including ventricular septal defect and coarctation of the aorta, one son who had total anomalous pulmonary venous return, and one son who had Wolfe-Parkinson-White syndrome. All three of the young men in the study had surgical or interventional procedures and all were students. Of the sons interviewed, two were classified as category 1 and one as category 3. One of the sons was Hispanic-Native American, and two were Hispanic.

### **Mothers**

A total of thirteen mothers were interviewed. The mothers ranged in age from their thirties to their fifties. Seven mothers were in their thirties, five

were in their forties, and one was in her fifties. All of the sons' mothers and seven of the daughters' mothers were interviewed. In addition, four mothers were interviewed without their daughters ever being interviewed for reasons of the daughter's health status or age, and in one case, because the daughter had died during the previous year. Of the total group of mothers, two were students, five were unemployed, and seven were employed. Of the mothers who were not employed, only one stated that she was unemployed because of her daughter's health problems.

When asked about the influence of heart disease on their lives and relationships, mothers, daughters, and sons most frequently replied with regards to how normal their lives were or were not. Normalization in the face of chronic illness was the overriding theme of the study. Two sub-themes related to normalization arose from the data. "It's no big deal" was found to best describe how most mothers and their daughters or sons with heart disease view their lives and relate to one another, others, and the world. Most mothers, daughters and sons described trying to keep their lives as normal as possible. One other sub-theme, which the author called "Sometimes it is a very big deal" described the lives and relationships of those mothers and daughters or sons who could not, for reasons of health problems, maintain normalcy. "Caught in the middle" described those mothers and daughters or sons who strived for normalcy, but who because of the fear of future deteriorations in health could never really feel normal. "Caught in the middle"

was not a theme explicitly expressed by participants, but one developed by the researcher to describe a pattern noted in the data. The ability to normalize, as demonstrated in this study, can be viewed as a continuum with "It's no big deal" at one end and "Sometimes it's a very big deal at the other." "Caught in the middle" is the middle ground between the two ends of the continuum. Relationships with family and health care professionals as well as age, severity of illness, and developmental stage, were seen as mediators of normalcy in the lives of the participants. The results of this study are organized around the results of the study as they presented themselves, rather than around the original research questions.

### **"It's No Big Deal": Mothers and Their Sons or Daughters with Heart Problems**

#### **Normalizing: A Strategy for Living with Heart Problems**

The most common theme discussed by the participants when asked about their experiences with heart problems, including their interactions as mother and daughter or mother and son, was that it was "really no big deal." Mothers, daughters, and sons really did not seem to understand the investigator's questions concerning "adjustment" to their health problems, and frequently replied with references to normalizing their lives as much as possible. This attitude was expressed by about 75% of all participants, mothers and children alike. There were no perceptible differences between mothers and daughters and mothers and sons in terms of their attitude toward

their heart problems or the desire to live as normal a life as possible. Mothers frequently said that they and their families had tried to forget that the daughter or son had a heart problem. For example, Mary, a mother whose ten year old daughter Jean had Tetralogy of Fallot repaired as a toddler said, "We've just tried to get on with our lives. I just get on with it and I want others to get on with it, too, forget about it and go on."

Part of this process of getting on with their lives was an unwillingness to accept heart problems as "disease." Mother, daughters, and sons described congenital heart disease as "just something you're born with," or "a birth defect that you live with." Disease, to most of the participants, meant something severe and incapacitating, which was not what they felt they were living with.

Karen, mother of fourteen year old Megan, said,

I take exception to the use of the word 'disease' throughout all of these questions. When you're living with a chronic condition such as a congenital heart defect it becomes a way of life and when you look at it as a disease, it inhibits any type of movement or growth in the family. I look at Megan's heart as the way she was born and we are all born with different things. I have treated her as normally as possible....

Though a certain amount of denial seemed to be involved in maintaining a normal life, this is not to say that all mothers or their sons or daughters were in a state of denial concerning their heart problems or the potential problems associated with them. Several participants spoke openly of the types of precautions that they were aware they must take in light of their heart problems, such as antibiotic prophylaxis against subacute bacterial endocarditis before dental procedures. Sixteen year old Erin, who had an

unrepaired ventricular septal defect, spoke of her concerns about future pregnancies. A seemingly very normal, gregarious teen-ager, Erin was told by her doctors that her heart problem could complicate her health in the event that she should choose to try to have a child. Similarly, Megan, whose mother Karen is quoted above, mentioned the potential risks of using illegal or even legal drugs with her type of heart problem, though she clearly does not see her heart problem as limiting:

It really doesn't make me any different from other kids, just because I was in the hospital for four months. I do everything everyone else does and more. I have to be extra careful about any drugs or alcohol I get into, but I'm not planning on doing that. But besides that, it hasn't affected me. It isn't a problem. I am just a regular everyday person who happened to have been in the hospital. I have met quite a few kids who have this also, so it makes me feel no different.

What is evident in Megan's account is how perspective influences the ability to perceive that life is normal. Certainly Karen did not feel that anything about her life was normal at the time that Megan spent four months of her infancy in the hospital. However, Karen's attempts to maintain normalcy in her daughter's life have obviously been a positive influence on Megan's ability to view her own life as normal.

### Relationship Issues

When asked whether heart disease had affected their relationship as mother and daughter or mother and son, the majority of participants said no. A few dyads reported increased closeness and one dyad noted increased conflict, while most dyads reported that they were no closer than other mother-

daughter or mother-son dyads within or outside of their families. There were five "only children" among the participants, four daughters and one son. In these cases, mothers and daughters or sons compared their relationships to those of good friends.

Table 3, shown earlier, shows levels of conflict as described by either mother, son, daughter, or dyads in the course of the interviews. Those mothers and daughters or sons interviewed together tended to discuss less conflict in describing their relationships than mothers and children interviewed separately. For example, Teri with hostility of her mother, who was not interviewed. Lainna and Norma expressed moderate amounts of conflict with their mothers. Lainna's mother was interviewed separately, while neither Norma's mother or grandmother was interviewed. Laura and her mother Shauna were the only dyad to admit high levels of conflict within their relationship in front of one another.

Also evident in Table 3 is the tendency for conflict to increase as the age of the daughter increases. For pre-pubescent daughters, conflict with their mothers was not readily apparent. The one exception to this was Chris, whose mother described a moderate amount of conflict with her daughter throughout her short life, primarily over activity restrictions due to her severe heart disease.

Most mother-daughter dyads viewed their relationship similarly, with two exceptions. Megan, age fourteen, said that her heart problem might have

made her and her mother closer, but thought that they probably would have been close anyway. Karen, Megan's mother, however, said that Megan's illness in infancy had caused her to re-examine her life and to re-evaluate her priorities, both of which had caused her to always feel closer to her daughter. Karen also acknowledged in her interview that at times she had to work not to be distant from her daughter out of a fear of possibly losing her to her heart problems in the future.

Jane, mother of thirty-five year old Lainna felt that she and Lainna had always been closer than she was with Lainna's sister, but Jane felt that this was more a matter of personalities than of heart disease. Lainna, on the other hand, frequently resisted her mother's attempts at closeness, feeling that her mother was somewhat smothering or overprotective. Lainna and her mother were well known to the investigator from her previous clinical practice. Though they were interviewed separately, the investigator had seen them many times together. When together, Lainna often reminded her mother that she was an adult and could care for herself. Interestingly, Jane never seemed particularly put off by Lainna's efforts to distance her, perhaps because Jane had witnessed first-hand Lainna's multiple life-threatening surgeries and had, in fact, nearly lost her on several occasions. While Jane recognized in her interview that she had always been protective of Lainna, she seemed to accept her own efforts as something she had to do, acknowledging that on some level her daughter had needed her and might very well need her again.

As discussed earlier, Jaimee noted that nine-year-old Stacy's heart disease had increased closeness within her entire family, though there was no specific mention of increased mother-daughter closeness. Sixteen-year-old Laura and her mother Shauna, the dyad experiencing increased conflict, admitted that recently they could rarely seem to agree on anything; however, Laura acknowledged that she felt that she probably got along no better or worse than her peers did with their parents.

Not only did mothers try to keep the parent-child relationship as normal as possible, attempts were also made to normalize family relationships by not showing favoritism toward the child with the heart problem. In this regard, mothers and daughters sometimes differed in their perceptions. For example, Lainna made reference to wishing that she had not always been "so scared" concerning what might happen to her during her childhood and discussed how her mother had contributed to that fear by not allowing her to participate in the same activities that her sister did. However, several mothers made note of trying to treat the son or daughter with the cardiac problem just as they did their other children. Roberta, mother of fifteen year old Margaret, said,

She's always been thin all of her little life, but the doctor said that she can participate in PE, but no competitive sports. We take her and do everything just like our others. You know, helping around with chores and stuff like that. She gets in trouble too if she's out of hand, just like our other two. They are all treated the same.

### Maternal Overprotection and "The Cardiac Child"

Mothers were specifically asked if they had ever been told that they were overprotective of their daughters or sons or that they might turn them into "cardiac cripples" by not allowing them to do what they could for themselves.

Overall, however, there was little evidence that maternal overprotection, a characteristic frequently associated with mothers of children with heart disease, was a particular problem for the mother-daughter or mother-son dyads.

Though two mothers did make reference to feeling that they might have been overprotective at times, these incidences occurred, understandably, around the times of surgeries or severe illnesses. In both of these cases, the mothers themselves noted that they felt overprotective. They had not gotten the impression from health care personnel that they were overprotective. In fact, mothers stated that they had received few instructions from doctors or nurses about how to care for their children in the context of heart disease, except about specific treatment regimens or restrictions. Most stated that they were told to treat the child as if he or she was normal, and that they had made every effort to do so. In fact, none of the mothers acknowledged that treating their children with heart problems as if they were like normal children was even a problem. Martha, whose nine year old daughter had died the previous year said:

They never told us, "Take this baby home, coddle her, and never let her do anything." That was not how her doctor thought this worked. Let her do what she wants to, let her live a life. If it's two months that she lives,

fine; if it's two years that she lives, fine. Let her live that life and that's the way we felt, too.

Only one mother was familiar with the term "cardiac cripple;" she was the only health care professional and mother in the study.

Only one daughter mentioned ever feeling that her mother was particularly overprotective of her, though several daughters discussed the nurturance their mothers had provided for them during times of acute illness. Lainna mentioned how important having had her mother "be there for me" was to her recovery from multiple surgeries. Norma said the same thing about her grandmother, who had raised her since she was small.

The presence of a strong mother-child tie did seem to have a positive effect on the daughter's resilience in the face of recurrent health problems. For example, Lainna, who is discussed above, was unable to have any surgery until age twelve, simply because none was available for congenital heart defects until that time. However oppressive she sometimes felt that her relationship with her mother was, she endured multiple cardiac catheterizations and at least three open heart surgeries, completed college, and nearly finished law school before she had a CVA during surgery. The strength she gathered from her relationship with her mother enabled her to fully recover from her CVA and she now works for a company which reviews contracts.

On the contrary, not having their mothers available had been deleterious for several participants. Teri, whose parents had repeatedly abused her as a child, was the only participant who was disabled, unable to work or attend

school, at the time of her interview. Nell, whose mother had always been busy caring for her brother with cerebral palsy, noted that she thought her mother might have felt guilty about missing the rheumatic fever that she had undoubtedly had while growing up. Listening to Nell, one can not help but wonder if she too blames her mother for her current heart problems: "My impression is the fact that had my parents paid attention to me, it may or may not have made any difference."

### **"Sometimes It's A Very Big Deal":**

#### **The Impact of Severity of Illness**

For those mothers and children who did not feel that they could live normal lives, severity of illness was perhaps the largest contributor to a sense of "not-normalness." For example, Martha, mother of nine year old Chris, described the impact of her daughter's severe illness on the entire family:

I think our other daughter has had a lot of problems through all this, because once Chris came along, it took so much of our time and so much of my energy, and so much of my worrying went into Chris. They said they didn't expect her to live and get out of the hospital. Then they said we don't expect her to live a year. All of the expectations up until she was 7 1/2, the dreaded waiting for respiratory failure to set in.

Like Chris, ten of the eighteen daughters or sons who were interviewed or whose mothers were interviewed concerning them were classified as either category 3 or 4 in severity of illness by the investigator. In all but one of these cases, the mothers and/or daughters nevertheless made reference to trying to live their lives as normally as possible, despite frequent doctors visits,

surgeries, or a sense that a deterioration in health status could be just around the corner.

For Teri, a thirty-four year old with a repaired ventricular septal defect, a history of CVA and seizures, there seemed to be little about life that was normal. Teri was disabled and unable to work, partly due to complications from her heart disease and partly because she was severely abused as a child, which had resulted in emotional and psychological problems. Abused by her mother, father, and stepfather, Teri had terminated all relations with any members of her family of origin, including brothers and sisters who had also been abused. She had established an entirely new identity for herself, partly out of a fear for her life, because she knew too much about her parents' illegal activities. In looking at the mother-daughter relationship in chronic illness and at the mother-daughter relationship as a concept, Teri constituted what could be called a negative or contrary case (Walker & Avant, 1988). Teri simply had *no* relationship with her mother. Her health had suffered because of her relationship with her mother when she was growing up. Having no relationship with her mother had allowed Teri to achieve some sense of normalcy in her own life.

Table 3 also shows the relationship between severity of illness as ranked by the investigator and the ability to normalize as expressed by mothers, daughters, or sons in the course of the interviews. For those participants ranked as category 3 or 4, high levels of normalization were much

more difficult to achieve. The table also shows the relationship between years since diagnosis or a major procedure, such as surgery, and the ability of the participant to normalize, as expressed by the mother, daughter or son.

Unfortunately, the table fails to capture what the researcher felt was the trend in the data: In general, the length of time since diagnosis or the latest major procedure was something of a predictor of normalizing ability. For example, for Matt, an eighteen year old, the last surgery he had two years ago is still a recent memory and reminder that he has a significant health problem. Had his surgery been less recent and discussed less in the course of the interview, the researcher might have classified him as high rather than moderate in normalization.

While some participants described their present lives as normal, they easily recalled those times, usually around times of surgeries or procedures, when their lives were anything but normal. Beth, mother of fifteen year old Brad, describes the time around Brad's catheter ablation for Wolfe-Parkinson-White syndrome:

He told Brad all the nice things he could hear, then he ushered him out of the room. Then he told us that, without the correction, he would die and no one had ever told us that. I had always suspected it, because at one point in time his heart rate did accelerate to 258 beats per minute and I could never get anyone to plain out tell me that. He hasn't gone for a check-up recently, I need to take him. It's something that we have tried to just forget about, you know, now that he's well.

## **"Caught in the Middle":**

### **Sometimes Normal and Sometimes Not**

For the most part, participants painted a fairly clear picture of feeling like their lives were either fairly normal or not normal. For some participants, however, the distinction between feeling that heart problems were "a big deal" and "not a big deal" was not a very clear one. The investigator felt that this was perhaps one other underlying theme in the data. While few of the participants would not describe themselves as such, much of what the mothers, sons, and daughters sometimes said made them appear "caught in the middle" between normal and not-so-normal lives. Exacerbations of illness symptoms, surgeries, and hospitalizations caused some participants to live back and forth between the extremes of ill and not ill and the researcher frequently had difficulty placing these participants in any one category based on their interviews.

For example, mothers like Marion, whose seven year old daughter had pulmonary atresia, a very severe form of congenital heart disease, spoke of still trying to maintain some degree of normalcy about their own lives and the lives of their daughters. Marion cried during many parts of her interview saying, "I just don't know what it will like if she starts to go," while smiling and talking about her daughter's positive self-concept in other parts of the interview. Like many participants, Marion appeared to be trying to maintain a sense of hope about her daughter's future, while also expressing the frustration

associated with having those hopes destroyed by the reality of living with a chronic condition:

I'm not sure if after the first surgery, if we understood I don't know what. But they kind of led us to believe, or maybe we wanted to believe, maybe they didn't tell us. We had the impression that kids could do pretty well without a pulmonary valve. If things were fixed, she would do o.k.

For some participants, the process of normalization of life within the family came only after extreme changes necessitated by the daughter's or son's heart problem. Hence, while some participants wanted very much to place their heart problems in the background, they were sometimes unable to do so very effectively. Forgetting about their heart problem, as Mary described in the quotation above, was very hard to do. Lainna, a thirty five year old with truncus arteriosus, a type of heart problem which is difficult to repair, said she always felt guilty that her mother and father had been obligated to live apart because of her heart problem. Her father, who was from Iraq, and her mother, who was American, decided when she was very young that she and her mother must live in the United States to allow her to benefit from better medical care. Her father tried for years to immigrate to the U.S., but was never allowed to because of strained relations between the two governments, and died last year in Iraq. As a result of the sacrifices that she felt that her family had made for her, she was unable to simply forget about those sacrifices. Having her family spread around the globe served as a reminder of her heart problem.

Karen, mother of fourteen year old Megan, spoke of her strategy for dealing with health problems as they arose:

I have to be on constant guard not to spoil her, or make her afraid, because I do have a lot of fears around her heart, and I have to be real careful that I don't convey those to her, so when she gets breathless or has leg pains, or whatever, I am very careful to be nonchalant about it and ask her if she wants to be checked out and stuff. So far, we've been doing fine that way.

But what Karen really communicates in this quotation is her inability to completely forget about Megan's heart problem, though she tries "to be nonchalant about it."

As discussed previously, the perspective of the participant had a large affect on whether life was viewed as "no big deal," "a very big deal" or somewhere in between. While the daughter or son's perspective might be one of the relative normalcy of life with heart disease, the mother's perspective might be one of realizing the accommodations necessitated by the disease. Roberta, for example, had been the one to sacrifice in order that her daughter's life might feel normal:

I was employed as a caseworker for the welfare dept. and my mother took care of her for awhile. Then it got to the point that I was very nervous about letting her grandmother take care of her when she got colds constantly. So I quit work to take care of her. And I loved my job. Well, she started to get somewhat better, so I decided maybe I could go back. I went back and then we were told she needed her second surgery.

On the other hand, the daughter or son's perspective of living with the disease was often very different than the mother's perspective of seeing and experiencing the disease from the outside. While the mother might work hard

to act normal within the context of chronic illness, the daughter or son knew more about whether they were able to feel normal with the heart problem. Hence feeling and acting normal were seen as different in this study. How participants acted and desired to be perceived by others might be different from how they actually felt.

**Mediators of Normalcy: Personal Strength, Family,  
Health Care Providers, and Developmental Stage**

Mothers, sons, and daughters freely mentioned those things which made it easy or hard to live their lives normally, or without constant reminders of the sons' or daughters' heart problem. Certain factors such as age, developmental stage, or family involvement, or personal characteristics, such as resilience, made it possible or impossible for participants to lead normal lives. The researcher came to see these factors and characteristics, along with the influence of health care providers, as mediators of whether the participants saw themselves as normal, not-so-normal, or somewhere in between. As mentioned previously, being able to carry on with their lives without too much emphasis on the heart problem was very important to the participants. As Karen said,

I think the most helpful thing health care people can do is have children live as normally as possible and not have the family revolve around the heart condition as their whole lives, otherwise the children become cardiac cripples and their own lives revolve around the disease. I don't think that is healthy at all.

What Karen exemplified, as did many of the mothers, daughters, and sons who were interviewed, was a certain strength of character that allowed them to get through the rough times. For participants like Karen, getting on with their lives, despite the influence of heart disease, involved nothing short of sheer determination. For others, specifically one daughter and two mothers, faith in God played a large role in that strength. For Martha, whose nine year old daughter Chris died of a lethal arrhythmia, the support that she and her family had received from the Mormon faith made living with Chris' heart problem and her death somewhat bearable. Nell, who realized that she had probably had childhood rheumatic fever only after she became pregnant with her first child, felt that her Christian faith had played a large role in her ability to cope with the twenty years of declining health she had suffered.

Other participants mentioned the importance of family in getting through the tough times with heart problems. Jaimee, mother of nine year old Stacy, said that her family had grown closer because of their concern for Stacy's health. That closeness had, in turn, made living with Stacy's heart problem easier. Norma, a nineteen year old newly-wed, had been more or less "adopted" by her maternal grandmother as a baby when her own mother, who was only a teen-ager herself at the time, could not manage her daughter's rather complicated medical regime. Though Norma maintained a very positive relationship with her mother, her grandmother was the one who had always

been there for her, frequently accompanying her to the hospital for surgeries or to doctors' visits.

Families, discussed previously as a source of strength for many participants, were sometimes a hindrance to the process of normalization for those same participants or others. Two mothers, both of them Hispanic, discussed how their extended families, had made the process of just living life more difficult. Roberta, mother of fifteen year old Margaret, spoke of how her own brothers' and sisters' families had wanted to include them in family outings when Margaret was younger, but still insisted upon cigarette smoking around the baby. Margaret, who had an atrioventricular canal as well as Down's syndrome and failure to thrive spent most of her first eight years very ill and frequently had upper respiratory infections, which her parents had been told were exacerbated by smoking. Roberta obviously found maintaining family relationships very important, but her extended family's habits had the effect of isolating them from one another. Mary, mother of Jean, spoke of how her parents, Jean's grandparents, refused to let go of Jean's heart problem, always wanting to ask about it and belabor it. Mary felt that their unwillingness to "forget" about it, as her immediate family had tried to do, had caused unnecessary strain within her family.

Mothers and their daughters and sons with heart problems also discussed the effects of ongoing, long-term medical monitoring on their ability to forget about heart problems. With the exception of one mother-daughter

pair, all participants lived three to four hours from their pediatric cardiologists. This meant that going to see the cardiologist was something of an ordeal and the participants saw it as such. For most of the participants, the time around seeing the cardiologist was one of getting blood tests, x-rays, echocardiograms, and electrocardiograms. Surrounding this period of test-taking was the fear that, as Lucinda said, "they would find something" that might mean a new activity restriction or having to undergo surgery. Hence, the weeks immediately prior to regular check-ups were frequently anxiety-provoking, making it impossible for the participants to feel that their lives were normal. In fact, just the mere necessity of having to go to the pediatric cardiologist was in and of itself enough to make participants feel not-normal. Participants found that traveling long periods of time and distances for check-ups, however routine, heightened their anxiety by reminding them that the outcome was uncertain. Recent efforts made by pediatric cardiologists to hold clinics at locations closer to the participants' homes made them feel like follow-up would be less of an ordeal.

In general, participants were fairly complimentary toward their health care providers. Those that they liked the most were those who helped them keep their lives as normal as possible. For example, Roberta spoke of how she liked the fact that her daughter Margaret's cardiologist had gotten into the habit of addressing Margaret, rather than her parents, about her health even

though she had Down's syndrome, especially since Roberta had become a teenager.

Mothers also felt that their daughters' or sons' health care practitioner should be prepared to meet them on a personal level, without a sense of professional distance, especially since it was their understanding that the practitioner was someone with whom they would share a long-term relationship. Karen, mother of Megan and also a nurse, wanted the opportunity to meet and talk with her daughter's new doctor before the office visit, before all of the tests. Karen said:

I'm still shopping for a cardiologist who is a little more aware of the chronicity of this condition and some of the ways that parents and families get through with less pain. This is not the way this cardiologist seems to be approaching this. [He seems to feel that] it is strictly a medical condition and there is no reason to talk to a family without all the records in hand. I basically wanted to get to know his philosophy.

Karen was the only participant with medical background and in that sense was atypical of the mothers as a whole. However, the sentiments she expressed were not unlike other mothers who participated in the study. She is quoted frequently because she was often able to articulate what others had more difficulty saying.

During the course of data collection, the investigator classified mother-daughter dyads into one of the four types of relationships as delineated by Fischer (1986). Fischer's classification is discussed more thoroughly in the literature review. The purpose of the author using this classification scheme was to ascertain if there were perhaps greater numbers of certain types of

relationships among mothers and their daughters with heart disease. For example, the investigator hypothesized that there be more dependent daughters with responsible mothers, regardless of the daughter's age, due to chronic illness. The case was, however, that most mother-daughter pairs, by reason of the daughter's age alone, were classified as "responsible mothers, dependent daughters." Six of eleven of the daughters who participated were under eighteen years of age. Hence, this classification did not seem to be meaningful for purposes of this study. In this study, for daughters over the age of eighteen, who like healthy women would be expected to be working toward greater independence, there was only one case of increased dependence, as perceived by the investigator, as a result of heart problems. This was the case of Teri, who, as discussed previously, was permanently disabled and dependent on social security disability for financial assistance, as well as increased help from her son and friends. Teri summoned her son on multiple occasions during her interview to help with miscellaneous tasks and it was during a visit to the emergency room, when Teri was brought in by friends, that the investigator met her.

There was no clear evidence within the data of developmental stages in the mother-daughter or mother-son relationship as a result of the daughter or son's chronic illness, though the investigator hesitates to state any definitive conclusions concerning mothers and sons based on only the three mother-son dyads who were interviewed. Prior to data collection, the investigator

hypothesized that mother-daughter relationships might undergo certain types of development based solely on the daughter's chronic illness. For example, the investigator wondered what additional developmental changes might be necessary within the mother-daughter relationship if the daughter were undergoing an acute period in her chronic illness, such as deterioration in health status or recovery from significant surgery. It stands to reason that the mother-daughter relationship might have to accommodate the daughter's illness in particular ways, unrelated to normal age-related developmental patterns experienced by mother and daughter. Perhaps it is the case that the ability to look at the mother-daughter relationship and life in general as "normal" within the context of chronic illness requires certain developmental changes in perspective over the course of the lifespan.

The lack of a significant number of dyads in any one age group may have affected the investigator's ability to note clear developmental stages. However, certain trends in the data were apparent as a result of interviewing mothers and daughters across the lifespan. For example, mothers whose daughters or were younger or closer to the life-challenging events of birth and subsequent diagnosis or surgery appeared less able to look at their lives or their daughters' as normal or potentially normal. Two mothers and one son described the experiences of surgery within the two years immediately prior to their interviews. These interviews were filled with stories of recent illness and how the participants were affected. Though many types of heart disease

require intervention and surgery over the course of the patient's life, mothers with younger children seemed more affected, as if some period of years were required to come to terms with the daughter or son's heart problem and the possibility of on-going therapy. For example, Matt, an eighteen-year-old, clearly felt that congenital heart disease had a huge, continuing impact on his life. Matt had his second surgery at age sixteen. However, both he and his mother Joan, felt that he was a "pretty normal teenager." Neither of them seemed overcome with his fairly significant heart disease. On the other hand, Marion, whose seven year old daughter had two surgeries, the most recent of which was about a year prior to the interview, still seemed overwhelmed by all that had happened around her daughter's birth, diagnosis, and treatment. When asked how her daughter's heart problem had affected her and her family, Marion said:

Traumatic. I don't even know how to describe it. Traumatic. You know, I'm not sure if after the first surgery we understood, but they kind of led us to believe, or maybe we wanted to believe, maybe they didn't tell us ... we had the impression that kids could do pretty well without a pulmonary valve. If things were fixed, she would be okay.

What Marion alludes to here is how little prepared she and her husband were to be told that their daughter would require at least one, and perhaps several, more surgeries.

### **Observations**

When observing the mother-son and mother-daughter dyads together during interviews, the investigator made note of only a few differences.

Mothers and daughters frequently interacted more with each other during the course of the interview than did mothers and sons. This is not to say that the investigator was ignored, but mothers and daughters interacted with one another while also interacting with the investigator. Mothers and daughters tended to sit side by side on a couch or in chairs, whereas sons and mothers sat opposite one another on chairs or across a table. Daughters frequently elaborated on something their mothers might have said or vice versa. In addition, mothers and daughters did not openly argue with one another, but frequently disagreed with one another's opinions or memory of an event. Most of these types of discrepancies occurred when mothers and daughters were interviewed separately, as was the case with Lainna and her mother Jane.

Lainna recalls that her childhood was difficult, in part, because her mother and father lived apart, in separate countries, because of her illness. Jane, on the other hand felt that this was no particular sacrifice. Other such differences in accounts occurred over mothers' and daughters' feelings about their level of closeness, as noted previously.

The importance of family to participants in the study was underscored by the way in which family members who were not scheduled to be interviewed often took a more than casual interest in the interview process. Because the investigator was interviewing mothers and daughters and mothers and sons, it was anticipated that siblings of those participants with heart disease might have some curiosity about the interviews. Indeed this was the case. In five

interviews, younger siblings of the participant with heart disease often put themselves in the middle of the interview. However, the investigator was not prepared for the two grandmothers or the two fathers who could not be dissuaded from participating in the interview process. In these cases, however, these other family members often had useful input for the study or as a source of support for those persons that the investigator interviewed. In one case, the mother looked to the grandmother to validate and confirm her responses to questions. In another case, a father often elaborated on what a mother said about her son.

Mothers and sons, on the other hand, listened more carefully to one another and seemed to find it easier to hear each other out without disagreeing or interrupting. However, mothers and sons were always interviewed together, which may have decreased those instances in which mothers and sons would have provided different accounts of similar events. It should also be noted that the investigator interviewed twice as many mother-daughter dyads as mother-son dyads. These her observations may or may not be indicative of any clear difference in mother-daughter versus mother-son patterns of interaction.

## **CHAPTER V**

### **DISCUSSION**

#### **Effects of Disease on Relationships and the Need for Normalcy**

This study demonstrated that mothers and their daughters or sons with heart disease report that they are affected much less by chronic illness in terms of their lives and their relationship than might be expected from findings of some studies (Doucet, 1981; Miles et al., 1993; Travis, 1976). With few exceptions, most mothers and daughters related stories of attempting to, and succeeding at, living lives which were as normal as possible. Those who were less likely to find normalcy in their lives were those mothers and daughters who perceived a greater severity of illness or those who had most recently experienced life-threatening surgeries or procedures. These findings are in keeping with those of Clements, Copeland, and Loftus (1990) and Deatrick, Knafel, and Walsh (1988), who found that certain critical times, such as diagnosis, exacerbation of symptoms, and developmental changes, posed particular problems for families with a chronically ill child. In this study, however, even those mothers and daughters experiencing particular crises said they were striving for normalcy in their lives.

Findings from this study, as they concern a desire for normalcy by those affected by chronic illnesses, are generally supported in nursing literature.

Since the early 1980's, various authors have described the normalizing

strategies of families with chronically children (Anderson, 1981; Bossert, Holaday, Harkins & Turner-Henson, 1990; Deatruck & Knafl, 1988; Knafl & Deatruck, 1986; Krulick, 1980). Knafl and Deatruck (1986) further developed the concept of normalization through concept analysis, stating that the management style of normalization was recognizable by criteria which include (1) acknowledgment of the impairment, (2) normal definition of family life, (3) assignment of minimal social significance to the impairment, and (4) the management behaviors used to demonstrate normality. While the author had reason to believe from her own clinical observations that the relationships between mother and daughter when the daughter had congenital heart disease were often fraught with conflict and frustration, the participants did not view their relationships this way. This is not to say that the mother-daughter relationship is always without problems when the daughter is chronically ill. However, in this study, these struggles seemed to have more to do with normal developmental stages and changes as noted by such researchers as Bromberg (1983), Fischer (1986), and others (Clements, Copeland, & Loftus, 1990; McCubbin & McCubbin, 1993; Mercer, Nichols, & Doyle, 1989) than with chronic illness.

**"Adjustment," the "Overprotective Mother," and "the Cardiac Child":****Labeling by and Relationships with Health Care Providers**

Because normalcy was the goal of mothers and their daughters with heart problems, "adjustment" to the disease was not an issue that most participants discussed. In fact, some participants seemed not to know what "adjustment" to their heart problems meant, since life for them was just what it was, not something to be adjusted to. "Adjustment" or "maladjustment" seems to be a word that some health care providers have chosen, perhaps inappropriately, to describe the ability of those with chronic illnesses to achieve a normal life (Chazan, Harris, O'Neill, & Campbell, 1951; Cooper, 1959; Kong, Tay, Yip, & Chay, 1986; Linde, Rasof, Rabb, & Dunn, 1966). One mother in this study said, "Our family has adjusted just fine. It seems to be others that haven't been able to accept our daughter's problem." Statements like this one speak to how families with a chronically ill child do, indeed, assign minimal significance to their child's impairment and define their family life as being as normal as possible (Deatrick & Knafl, 1986). In fact, it may be the case that they may wish to assign so little significance to it that they do not wish to discuss it with researchers at all.

Though Karen was something of an "outlier" participant as a Ph.D. prepared nurse and the only person in the study with knowledge of Margaret Newman's work on health as expanding consciousness, other participants mirrored her concerns that congenital heart disease has always been

considered a disease, as opposed to just another way of being or going about life. In other words, living with a chronic illness is not a matter of adjustment at all. Karen said:

I made a big shift out of disease orientation years ago with Margaret Newman's Health as Expanded consciousness and any disease or manifestation as underlying pattern. I don't treat it as disease, I treat it as Megan, as she is, she is embodied with a heart that is different from other people's hearts and she needs care for it.

Part of being normal for the participants in this study was the sense that disease, illness and health could peacefully coexist and that one could be basically healthy while living with even a potentially life-threatening disease.

As Roberta said of her fifteen year old daughter, who had both heart problems and Down's syndrome:

As far as her heart problem is concerned, since she has done so good, I guess I really haven't concentrated too much on the heart problems, other than take that one step at a time, and if anything comes up, I guess we would just deal with it at that time.

These ideas support Newman's theory that each person is seen as having an underlying pattern which may or may not include disease, and health is seen as the synthesis of disease and non-disease (Marchione, 1993; Newman, 1986). Newman's theory parallels many of the participants' responses in this study. Just as health encompasses disease, a normal life can include the not-so-normal aspects of living with chronic illness.

Participants for the most part felt that health care providers had generally been supportive of them, rarely communicating that they, as persons with heart problems, were in any way "strange," "different," "cardiac cripples,"

or "maladjusted." As a nurse herself, Karen had experienced perhaps the most difficulty in dealing with health care providers concerning having a daughter with heart disease. She felt that her colleagues in the medical profession had not known how to interact with her personally or professionally when her daughter was born with a congenital heart defect. In addition, even though as a nurse she was a knowledgeable medical insider, as a mother, she was frequently treated as an ignorant outsider, as she discusses here:

It started from the day she was born and I was a nurse in intensive care nursery. In labor and delivery, they did not know what to do with me. First of all, there was this big gulf, because God, it had happened to one of us. Then she was seriously, seriously ill and people didn't know what to say. And then I made everyone nervous, just my presence, knowing a little bit about medicine and a lot about nursing. There is probably something written in my charts, something like, "Mother has doctorate, be careful."

Karen's expectations of health providers, like those of other mothers in this study, are very much in line with perceptions of parents as discussed in the nursing literature. The work of KnafI, Breitmayer, and Gallo (1992) and Dunst, Trivette, and Deal (1988) emphasize the role of the health care provider in strengthening the family's ability to deal effectively with the ongoing problems and demands of raising a child with a health problem. KnafI and her colleagues (1992) found that parents advised health care providers to establish a relationship and interactional style of communication to facilitate information exchange with the family and chronically ill child and to foster parental competence whenever possible.

### **Alternative Explanations: Normalization and Private versus Public Accounts**

The overall findings of this study stand in sharp contrast to the findings of the investigator's earlier study, as well as that of other investigators (Doucet, 1981), in which participants described the experiences of growing up "heartsick" throughout their lives as a result of congenital heart disease. This is not to say that participants were not deeply affected by their heart problems or that there were not some participants who were experiencing serious difficulties living with the disease. However, the women and men in this study with heart problems and their mothers, were overall, extremely upbeat. This may be due to the continuously improving therapies, including reparative surgeries, medications, and interventional cardiac catheterizations, which have become available over just the last several decades. Data collection for the investigator's previous research was completed in approximately 1985, a full ten years before data collection for this research and just as such procedures such as balloon angioplasty became alternatives to open heart surgery for some types of congenital heart disease.

Subjects from the investigator's earlier study ranged in age from approximately thirteen to thirty. The wider range of ages in this study provided a view of chronic illness over the lifespan that may have temporized the negative effects seen when only a smaller age range was researched. For example, while this study demonstrated that younger participants and their

families were sometimes those most affected by chronic illness, it was also these subjects who benefitted most from newer therapies and treatment approaches. As a result, future research may demonstrate that younger subjects are affected less by chronic illness than their older counterparts. On the other hand, the older participants in this study provided a view of how individual and familial coping with chronic illness may improve as one matures.

However, the possibility does exist that the picture of normalness presented by most participants to the investigator was inaccurate, though not intentionally so. With the exception of two mother-daughter dyads, the investigator did not know any of the participants in the study extremely well. The investigator had previous contact with some of the other participants in her nursing practice. In some cases, interaction with participants as well as observations in the clinical setting help to establish rapport and to validate interview findings. A lack of ongoing relationship could have influenced some participants' willingness to share the negative aspects of chronic illness with the researcher.

This phenomenon, the tendency of participants to provide "public" versus "private" accounts of the same situation, is discussed at length by West (1990). West studied families of children disabled by epilepsy by a variety of methods, including a series of interviews with each family, as well as direct observations in the clinic setting. West then compared his findings to that of another researcher who had also studied families of disabled children with

single interviews only. West felt that his research had benefitted from the ongoing relationship he had with the families and that his research was more accurate as a result of the more "private" accounts he had received from families as opposed to the more "public" accounts obtained from the other researcher.

The investigator also wondered how much participants might have been influenced by their physicians' instructions to "be normal" or "treat your child as if he or she is normal." West (1990) made note of this same phenomenon, the tendency of physicians he observed to emphasize the normalcy of the epileptic child, regardless of the degree of disability. Perhaps it was the case that participants had worked so long to be normal that they felt they could present no other image. Certainly in some cases, it was apparent that the mother had worked hard to enable the normalization of the child, as was the case for Roberta, who had quit her own important work to care for her daughter. In the following quotation, it is evident that Karen has also done her best to normalize her daughter's life:

I have treated her as normally as possible; really tried to make light of anything, her scars, that sort of thing from her surgeries, just it is such a miracle that she is alive, that those sort of things are really kind of incidental, and that's how she accepts them.

In addition, as discussed in the previous chapter, acting and feeling normal are not necessarily synonymous. In some cases, the investigator felt that mothers were more able to maintain normalcy because they were not experiencing or feeling the disease themselves. In others she felt that the daughters and sons

were more able to maintain normalcy because their mothers encouraged, enabled, and acted it. While participants may have wanted to present a picture of normalcy to the researcher, longer-term relationships with the researcher might have revealed a different, less consistent picture.

The investigator also considered how the personality type of the son, daughter, or mother interviewed affected the type of account provided, "public" or "glowing," "private" or "gloomy." In some instances, the investigator felt that she received fairly dire "public" accounts, and fairly cheerful "private" ones. The tendency may have been for some participants to be more open than others, regardless of how well or little they felt that really knew the investigator.

This study did not examine the relationship between hope and the outlook of the mother, son, or daughter affected by a chronic illness. Nevertheless, the investigator often felt that the "glowing" accounts provided by some participants, or even those accounts which vacillated between happy and unhappy, were a way of maintaining hope and minimizing the importance of the illness.

### **The Mother-Daughter Relationship, Chronic Illness, and Developmental Stages**

As noted in the previous chapter, this study failed to find any clear developmental stages in the mother-daughter relationship when the daughter is chronically ill. However, this may have been due to faulty conceptualization on the part of the researcher concerning how developmental stage theory might fit

into the study. What the researcher failed to take into consideration when she began this study was what became obvious over the course of it: When conducting research into relationships, one must consider the developmental stage of both parties in the relationship, as well as the relationship itself. For example, in this study, the researcher did not consider the developmental stage of the daughter or son, the mother, and mother-child relationship. In addition, as discussed previously, this study did not include any participants in their twenties. Other age groupings were also underrepresented, making any clear trends concerning developmental stages in the mother-daughter relationship impossible to ascertain.

What can be said from the data is that the mother-daughter relationship, and probably the mother-son relationship as well, when the child has heart problems may be subject to certain "critical periods," some of which are undoubtedly affected by the child's and mother's developmental stage. Most children are diagnosed with congenital heart disease between birth and one year of age, while those who have rheumatic fever or Wolfe-Parkinson-White syndrome are usually diagnosed in adolescence. Therefore, the years between birth and early school-age can be particularly trying for the mother-child relationship when the child has congenital heart disease, as can adolescence for young women or men and their mothers when the adolescent has either congenital or acquired heart disease. In this study, those mothers with the younger children and those with adolescents seemed the most

affected by their child's disease process and the potential problems associated with it. In the cases of the adolescent men or women, mothers were often as disturbed by the normative changes that their daughter or son was experiencing as a result of being a teenager as by the heart problem that he or she had. Several adolescents in the study discussed the possible use of drugs and alcohol, as would other healthy adolescents. It could be the case that risk-taking behaviors are part of normalization for adolescents and young adults with heart problems.

Researchers have examined the impact of a diagnosis of chronic illness on the mother-child relationship within the first several years of life (Goldberg, Washington, Morris, Fischer-Fay, & Simmons, 1990; Goldberg, Morris, Simmons, Fowler, & Levison, 1990) and have found that this relationship is potentially at risk as a result of increased parenting stress and possible changes in attachment between mother and child. They have also shown that the quality of the mother-daughter relationship has implications for the health of each member of the dyad. Patsdaughter (1989) examined predictors of general health perceptions of mid-life daughters and their aging mothers. She found that, for both mothers and daughters, the best predictor of general health perceptions was the perceived health of the other member of the dyad. In addition, the daughter's perception of the quality of the mother-daughter relationship was the next second greatest predictor of her perceptions of her general health. However, researchers have not studied the ongoing effects of

chronic illness on the mother-child, mother-adolescent, or mother-adult child relationship. This study was an attempt to add to the existing knowledge in this area.

### **Mother-Daughter and Mother-Son Relationships:**

#### **Is There a Difference?**

Although not an identified focus of the study, the investigator expected to find more differences between mothers and daughters and mothers and sons than was actually found in the data. Perhaps this was because of overall sample size, including a lack of participation by daughters in the twenty year old age group, and because so few mothers and sons were interviewed. As noted previously, mothers and daughters interacted more during the interviews than did mothers and sons. This may or may not be evidence of the more relational personalities of women, as discussed by Gilligan (1982), Gilligan, Lyons, and Hanmer (1989), Kaschak (1988), and Stiver (1986). This tendency was not necessarily captured in the dialogue of the transcribed interviews, but was observed during the interviews.

For example, when I interviewed seventeen year old Veronica and her mother Lynnette, one of the issues they both discussed was Veronica's not being selected for the cheerleading squad at her school. While the selection committee would not come right out and say so, Veronica apparently was not selected because of the death of nine year old Chris, whose mother I interviewed, at school during physical education class the previous year.

During the interview, much of the discussion of this terrible event took place between mother and daughter. Both mother and daughter seemed to be processing what had happened, almost as if the researcher was not there.

Similarly, Laura and her mother spoke openly of the conflict between them over activities that Laura felt she should be allowed to do, but that her parents frequently vetoed. During their interview, they sometimes seemed to interact more with one another than the researcher as they described the problems in their relationship. The role of culture, as all mother-son dyads were Hispanic, may also have been a factor in the observed relationships.

#### **Research on Chronic Illness:**

##### **Intra-family Dyads or the Family As a Unit?**

While the investigator continues to be of the opinion, like Woods, Haberman, and Packard (1993), that intra-family dyadic interviews have their place in research on the impact of chronic illness, the participants in this study clearly seemed to believe that the family as a whole was the unit that should be studied. Participants, particularly mothers, frequently referred to the effects of chronic illness on their families, rather than on themselves or on specific dyads. Daughters and sons understandably discussed the chronic illness more in terms of themselves and their individual feelings, since they were the ones experiencing illness first-hand. In addition, as noted earlier, participants' families often invited themselves to the interviews, seemingly out of a sense that they should be included or had something to contribute. Much research

addresses how the family both impacts and is impacted by stressors such as chronic illness (McCubbin & McCubbin, 1993; Patterson, McCubbin, & Warwick, 1990). How well the family is able to cope with the changes brought about by having a chronically ill family member has much to do with that same family member's health (Patterson, McCubbin, & Warwick, 1990).

This study did find evidence that Hispanic families tend to receive more input and support from extended family members than Anglo families and that Hispanic families tend to consider this a mixed blessing. Zayas and Solari (1994) and Hanline and Daley (1992) note that Hispanic cultures tend to expect and reinforce a cultural and family solidarity as well as a sense of obligation toward the family. The Hispanic families in this study obviously felt a need or obligation to remain connected to their immediate and extended families, despite the fact that extended family members frequently failed to understand the needs of the family with the chronically ill child to maintain as much normalcy as possible. At the same time Hispanic parents were actively normalizing their child's health problems, they had to be aware of and protect the child's special needs. Hanline and Daley (1992) found that seeking social support from extended family was predictive of accord in families of Hispanic children with disabilities. However, their study also found that use of internal coping strategies within the family was more important in maintaining family strength than use of external social support, including formal support by health care providers, in all ethnic groups. Internal coping strategies included

reframing events to make them more manageable and minimizing reactivity to problematic situations. These internal coping strategies sound very much like Knafli and Deatrick's (1986) normalization strategies discussed earlier.

### **Implications for Theory, Research, and Practice**

The results of this study help to answer some questions, but raise many others. Early literature on children with heart problems and the impact of chronic illness on the child, mother-child relationship, and family may not offer a realistic portrayal of these effects since so much has changed in the treatment of these problems over the last thirty years. This study found no consistent pattern in how mothers, daughters, and sons viewed their lives and relationships as a result of chronic illness. Instead, this research demonstrated that how those affected by illness perceive their situations is the result of a complicated interplay of factors including severity of illness, age, family and professional support, and other mediators. For example, the researcher occasionally found evidence of divergence of response to illness, in which participants with high severity of illness still managed to achieve moderate amounts of normalcy in their lives, perhaps due to their age, family support, or other unknown factors. Advances in surgery and medicine make ongoing research into the effects of illness and treatment, as well as perceptions of families concerning health care providers, a must.

The study clearly showed that a severity of illness scale would be useful for conducting research on persons who have chronic illnesses. The

investigator put together her own severity of illness scale for use during this study, but a more standardized, well-tested scale would have been desirable. Inaccuracies in the development and application of the scale, which was actually a ranking system, could have influenced study results. For example, inconsistencies in the use of the author's scale might account for the divergence of illness response seen in the cases of some participants. Scales currently in use, of which there are very few, rely on physiologic measures to determine a patient's severity of disease and frequently equate illness with disease. These scales do not take into account the individual or family response to the illness, how well or poorly the illness is managed, or other confounding variables, such as multiple diseases or psychological difficulties.

This study showed that access to care and support services for families with a chronically ill family member remains an issue and deserves the continuing attention and efforts of health care providers. Participants in this study appreciated efforts by practitioners to provide comprehensive care on the local level and found that such care reinforced their ability to lead normal lives. Participants also mentioned the importance of an ongoing, close relationship with their health care providers. This may have implications for those providers who frequently rotate services to families among several practitioners. Participants clearly preferred seeing the same doctor or nurse each time they were put in the position of having to see their providers. They also resented being made to feel as though they were stupid or difficult if they

asked questions or requested certain things which were unusual, but necessary, to their ability to cope with illness. For example, Karen's attempts to see her daughter's prospective new doctor in advance of her daughter's visit was unusual, though certainly not unreasonable, and probably could have been easily accommodated. Several mothers also mentioned having benefitted from support groups in learning to cope with chronic illness, and at least one mother mentioned how much she would like to have access to such a group. Families experiencing the chronic illness of a child need a wide variety of potential supports from which to choose whatever works for them. While some persons might find support groups helpful, others might find them to be a hindrance to normalization since those who tend to utilize support groups may be those who are the sickest or have the sickest family member.

Participants in this study clearly saw the family as it is affected by chronic illness in the infant, child, adolescent, and young adult the unit that should continue to be studied. This does not necessarily minimize the importance of documenting the effects of chronic illness on dyads within the family. Studies have documented the differential impact of illness on various family dyads (Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Goldberg, Washington, Morris, Fischer-Fay, Simmons, 1990; Woods, Haberman, & Packard, 1993), but have failed to show how these influences may change across the lifespan. For example, the mother-child relationship has been shown to be at risk when the child has a chronic illness beginning at birth;

however, little research addresses how the "at risk" relationship changes or does not change as both mother and child age and confront new developmental tasks.

As noted previously, this study suggested that mothers and sons may be different from mothers and daughters, though differences in these relationships is clearly documented in the literature (Chodorow, 1978; Maccoby & Jacklin, 1974). This may be due to this study's small sample size or due to evolving societal changes which minimize differences between girls and boys. In addition, the groups of sons interviewed in this study were all Hispanic adolescents. The author asked several mothers in the study whether they felt that rearing girls was different from rearing boys. This question resulted in a wide variety of responses, particularly as it related to culture. For example, one Hispanic mother who was asked this question spoke to how mothers in Hispanic culture have traditionally held their male children in higher esteem than their female children. It may be the case that some cultures minimize differences between boys and girls and mother-daughter or mother-son relationships, whereas cultural influences make this impossible in other cultures. Research which emphasizes the differences between girls, boys, and mother-daughter, mother-son relationships is, at this point, very dated and more current research is much needed. Perhaps it is the case that there is no clear answer to the question of whether mother-son and mother-daughter relationships are different.

Despite the small group of Hispanic and Native American participants, this study showed that culture may be an important factor in how chronic illness affects families. The ongoing inability of researchers to document the nature of the mother-daughter relationship in Native American culture is problematic in and of itself. It had been the hope of the investigator to contribute to this body of knowledge, while also looking at the effects of chronic illness on the mother-daughter relationship. While many research efforts are thwarted by government red tape designed to protect this culture, the investigator also found that potential Native American participants simply failed to respond to attempts at contact. This may be due to cultural taboos in which discussing illness is considered bad luck. For example, in Navajo culture, death is not discussed because talking about it is thought to cause it. As documented by McCubbin and colleagues (1993), Native American culture stresses the wholeness and harmony of life, of which illness is a part, and focuses on the abilities, rather than the disabilities, of children within the family and larger community. Perhaps potential Native American research participants simply see no purpose in discussing the effects of chronic illness. Researchers will need to continue attempts at studying these cultures while finding less intrusive and less threatening research methods in order to do so.

Finally, the researcher wishes to emphasize the importance of an ongoing relationship with participants which allows multiple interviews and contacts. The researcher felt that her truest perceptions of the mother-

daughter relationship in the context of the daughter's chronic illness were the result of a longer, more in-depth relationship with several participants, which allowed her to observe them over a period of time in a variety of settings. This type of relationship with participants prevents maximalization or minimalization of the effects of illness and helps the researcher determine if her account of a phenomenon is valid and plausible.

### **Limitations of Study**

The most significant limitations of this study were those imposed by the problems encountered in conducting the research itself. The investigator encountered multiple problems in gaining access to clients, particularly age-appropriate and racially diverse participants. For example, finding mothers of younger children who were interested in participating in the study was much less of a problem than finding daughters or sons in other age ranges. This is probably because diagnosis and repair of heart defects most frequently occurs in infancy and by early school-age; hence, these younger children are the ones most often seen in doctors' offices and other health care facilities. By the time that the child with a heart problem reaches adolescence and young adulthood, the need for frequent follow-up is much less common. As has been noted, this study included no young adults in their twenties. The timing of the study may have had some influence on this. Potential participants in their early twenties frequently declined to participate because of school commitments either in or out of town; the investigator felt that had she pursued this age group more

aggressively, participants in their twenties could have been recruited for the study.

In addition, a wide variety of participants of different ethnic groups were contacted, but many, particularly Navajo mothers and daughters, declined to participate. Over the last several decades, the tendency for Native American populations to avoid sharing many facets of their culture, for fearing of losing control of those aspects which they value the most, has posed particular problems for those researchers conducting even the most uninvasive of studies. At this time, the Navajo Nation, which now has its own Institutional Review Board, refuses to allow research without extremely clear relevance to and potential for improving the health status of the Navajo people. This means that studies designed to describe special features of the culture, such as the unique nature of the mother-daughter relationship, may or may not receive approval. Currently, the federal government still has some input into what should or should not be studied on the Navajo Indian reservation. However, over the next several years, jurisdiction over their Institutional Review Board will be turned over entirely to the Navajo Nation. It is not known at this time whether this will improve or diminish the chances for approval of purely cultural studies, though some persons in positions of authority feel that the "red tape" will only get worse (Personal Communication, Michael Everett, Chairperson, Navajo Area Indian Health Services Research & Publications Committee, September 1994).

Both of these problems, the reluctance of Navajo mothers and daughters to participate, as well as the more difficult access to mothers and their adolescent or young adult daughters, introduces the possibility of "elite bias" into the study. "Elite bias" is a potential problem in qualitative studies caused by the possibility that the subjects who act as participants may be the most articulate, accessible or high-status members of their groups (Miles & Huberman, 1984).

In addition, the quality of the data may have been affected by several factors, including the variability of interviewing conditions. In other words, in some cases mothers and daughters were interviewed together but not separately while in others, they were interviewed separately but never together. It is the hope of the investigator that future studies will be built on these preliminary findings and suggestions.

## REFERENCES

- Anderson, J. (1981). The construction of the illness experience: Families with a chronically ill child. Journal of Advanced Nursing, 6, 427-434.
- Apter, T. (1990). Altered loves: Mothers and daughters during adolescence. New York: Fawcett Columbine.
- Barnes, C., Kenny, F., Call, T., & Reinhart, J. (1972). Measurement in management of anxiety in children for open heart surgery. Pediatrics, 49(2), 250-259.
- Belenky, M., Clinchy, B., Goldberger, N., & Tarule, J. (1986). Women's ways of knowing. New York: Harper Collins/Basic Books.
- Boll, T., Dimino, E., & Mattsson, A. (1978). Parenting attitudes: The role of personality style in childhood long-term illness. Journal of Psychosomatic Research, 22, 209-213.
- Bossert, E., Holaday, B., Harkins, A., & Turner-Henson, A. (1990). Strategies of normalization used by parents of chronically ill school age children. Journal of Child & Adolescent Psychiatric & Mental Health Nursing, 3(2), 57-61.
- Bowlby, J. (1951, 1966). Maternal care and mental health. New York: Schocken Books.
- Boyd, C. (1985). Toward an understanding of mother-daughter identification using concept analysis. Advances in Nursing Science, 7(3), 78-86.
- Boyd, C. (1989). Mothers and daughters: A discussion of theory and research. Journal of Marriage and the Family, 51, 291-301.
- Boyd, C. (1990). Testing a model of mother-daughter identification. Western Journal of Nursing Research, 12(4), 448-468.
- Bromberg, E. (1983). Mother-daughter relationships in later life: The effect of quality of relationship on mutual aid. The Journal of Gerontological Social Work, 6(1), 75-92.
- Brown, L., & Gilligan, C. (1992). Meeting at the crossroads: Women's psychology and girls' development. Cambridge: Harvard University Press.

- Caplan, P., & Hall-McCorquodale, I. (1985). Mother-blaming in major clinical journals. American Journal of Orthopsychiatry, 55(3), 345-353.
- Cepko, R. (187). On oxfords and plaster casts. In M. Saxton & F. Howe (Eds.), With Wings: An anthology of literature by and about women with disabilities. New York: The Feminist Press.
- Chazan, M., Harris, T., O'Neill, D., & Campbell, M. (1951). The intellectual and emotional development of children with congenital heart disease. Guy Hospital Reports, 100, 331-341.
- Chenitz, W.C., & Swanson, J.M. (1986). From practice to grounded theory: Qualitative research in nursing. California: Addison-Wesley.
- Chess, S. (1982). The "blame the mother" ideology. International Journal of Mental Health, 11(1-2), 95-107.
- Chodorow, N. (1978). The reproduction of mothering. Berkeley: The University of California Press.
- Clements, D., Copeland, L., & Loftus, M. (1990). Critical times for families with a chronically ill child. Pediatric Nursing, 16(2), 157-161.
- Cooper, H. (1959). Psychological aspects of congenital heart disease. South African Medical Journal 33(17), 349-352.
- Daniels, D., Moos, R., Billings, A., & Miller, J. (1987). Psychosocial risks and resistance factors among children with chronic illness, healthy siblings, and healthy controls. Journal of Abnormal Child Psychology, 15, 295-308.
- D'Antonio, I. (1976). Mothers' responses to the functioning and behavior of their cardiac children in child-rearing situations. Maternal-Child Nursing Journal, 5(4), 225-257.
- Deatrick, J. & Knafelz, K. (1990). Management behaviors: Day-to-day adjustments to childhood chronic conditions. Journal of Pediatric Nursing, 5(1), 15-22.
- Deatrick, J., Knafelz, K., & Walsh, M. (1988). The process of parenting a child with a disability: Normalization through accommodations. Journal of Advanced Nursing, 13, 15-21.

- Dinnerstein, D. (1976). The mermaid and the minotaur. New York: Harper & Row.
- Doucet, S. (1981). The young adults' perception of the impact of congenital heart disease on his lifestyle. Nursing Papers, 12-13, 3-16.
- Dunst, C., Trivette, C., & Deal, A. (1988). Enabling and empowering families: Principles and guidelines for practice. Cambridge: Brookline.
- Eggert, L. (1990). Commentary to "Testing a model of mother-daughter identification." Western Journal of Nursing Research, 12(4), 462-465.
- Ehrenreich, B., & English, D. (1978). For her own good: 150 years of experts' advice to women. New York: Anchor Press/Doubleday.
- Erikson, E. (1950). Childhood and society. New York: W.W. Norton.
- Erickson, E. (1959). Identity and the life cycle: A review. New York: W.W. Norton.
- Fischer, L. (1986). Linked lives: Adult daughters and their mothers. New York: Harper & Row.
- Freud, S. (1933). New introductory lectures on psychoanalysis. New York: W.W. Norton.
- Gadow, S. (1988). Covenant without cure: Letting go and holding on in chronic illness. In J. Watson & M. Ray (Eds.). The ethics of care and the ethics of cure: Synthesis in Chronicity. New York: National League for Nursing.
- Gantt, L. (1992). Growing up heartsick: The experiences of young women with congenital heart disease. Health Care for Women International, 13(3), 241-248.
- Gilligan, C. (1982). In a different voice: Psychological theory and women's development. Cambridge: Harvard University Press.
- Gilligan, C., Lyons, N., & Hanmer, T. (Eds.). (1989). Making connections: The relational worlds of adolescent girls at Emma Willard School. Troy, New York: Emma Willard School.

- Goldberg, S., Morris, P., Simmons, R., Fowler, R., & Levison, H. (1990). Chronic illness and parenting stress: A comparison of three groups of parents. Journal of Pediatric Psychology, 15(3), 347-358.
- Goldberg, S., Washington, J., Morris, P., Fischer-Fay, A., & Simmons, R. (1990). Early diagnosed chronic illness and mother-child relationships in the first two years. Canadian Journal of Psychiatry, 35(9), 726-733.
- Gordon, J. (1988). Give me one wish. New York: W.W. Norton & Co.
- Gottesfeld, I. (1979). The family of the child with congenital heart disease. MCN, (March/April), 101-104.
- Green, M., & Levitt, E. (1962). Constriction of body image in children with congenital heart disease. Pediatrics, (March), 438-441.
- Hanline, M., & Daley, S. (1992). Family coping strategies and strengths in Hispanic, African-American, and Caucasian children families of young children. Topics in Early Childhood Education, 12(3), 351-366.
- Hauser, S., Jacobsen, A., Wertlieb, D., Brink, S. & Wentworth, S. (1985). The contribution of family environment to perceived competence, and illness adjustment in diabetic and acutely ill adolescents. Family Relations, 34, 99-108.
- Jack, D. (1991). Silencing the self: Women and depression. Cambridge: Harvard University Press.
- Jordan, J., Kaplan, A., Miller, J., Stiver, I., & Surrey, J. (1991). Women's Growth in Connection. New York: Guilford Press.
- Josselson, R. (1987). Finding herself: Pathways to identity development in women. San Francisco: Jossey-Bass.
- Kaschak, E. (1988). Limits and boundaries: Toward a complex psychology for women. Women & Therapy, 7 (4), 109-123.
- Kazak, A. & Martin, R. (1984). Differences, difficulties, and adaptation: Stress and social networks in families with a handicapped child. Family relations, 33, 67-77.
- Kellerman, J., Zeltzer, L., Ellenberg, L., Dash, J., & Rigler, D. (1980). Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. The Journal of Pediatrics, 97(1), 126-131.

- Kleinman, A. (1988). The illness narratives: Suffering, healing, and the human condition. New York: Harper-Collins Basic Books.
- Knafl, K., Breitmayer, B., & Gallo, A. (1992). Parents' views of health care providers: An exploration of the components of a positive working relationship. Children's Health Care, 21(2), 90-95.
- Knafl, K. & Deatrick, J. (1986). How families manage chronic conditions: An analysis of the concept of normalization. Research in Nursing and Health, 9, 215-222.
- Kong, S., Tay, J., Yip, W., & Chay, S. (1986). Emotional and social effects of congenital heart disease in Singapore. Australian Pediatrics, 22, 101-106.
- Krulick, T. (1980). Successful "normalizing" tactics of parents of chronically ill children. Journal of Advanced Nursing, 5, 573-578.
- Levy, D. (1951, 1966). Maternal overprotection. New York: W.W. Norton.
- Lincoln, Y.S., & Guba, E.G. (1985). Naturalistic inquiry. California: Sage Publications.
- Linde, L. (1982). Psychiatric aspects of congenital heart disease. Psychiatric Clinics of North America, 5(3), 399-406.
- Linde, L., Rasof, B., Dunn, O., & Rabb, E. (1966). Attitudinal factors in congenital heart disease. Pediatrics, 38(1), 92-101.
- Maccoby, E., & Jacklin, C. (1974). The psychology of sex differences. Stanford: Stanford University Press.
- Marchione, J. (1993). Margaret Newman: Health as expanding consciousness. Newbury Park: Sage Publications.
- Marshall, C. & Rossman, G. (1989). Designing qualitative research. Newbury Park: Sage Publications.
- Maxwell, J.A. (1992). Understanding and validity in qualitative research. Harvard Educational Review, 63(3), 279-299.
- McCubbin, H., Thompson, E., Thompson, A., McCubbin, M., & Kaston, A. (1993). Culture, ethnicity, and the family: Critical factors in childhood chronic illness and disabilities. Pediatrics, 91(5), 1063-1069.

- McCubbin, M., & McCubbin, H. (1993). Families coping with illness: The resiliency model of family stress, adjustment, and adaptation. In Danielson, C., Hamell-Bissell, B. & Winstead-Fry, P. (Eds.). Families, health, & illness: Perspectives on coping and intervention. St. Louis: Mosby.
- Mercer, R., Nichols, E., & Doyle, G. (1989). Transitions in a woman's life: Major life events in a developmental context. New York: Springer.
- Miles, M., & Huberman, A. (1984). Qualitative data analysis: A sourcebook of new methods. Beverly Hills: Sage.
- Miles, M., & Huberman, A. (1994). Qualitative data analysis: An expanded sourcebook. (2nd ed.). Thousand Oaks: Sage.
- Miles, M.S., D'Auria, J., Hart, E., Sedlack, D., & Watral, M. (1993). Parental role alterations experienced by mothers of children with a life-threatening illness. In: Funk, S., Tornquist, E., Champagne, M., & Wiese, R. (Eds.). Key aspects of caring for the chronically ill. New York: Springer.
- Morgan, D.L. (1993). Qualitative content analysis: A guide to paths not taken. Qualitative Health Research, 3(1), 112-121.
- Newman, M.A. (1979). Theory development in nursing. Philadelphia: F.A. Davis.
- Newman, M.A. (1986). Health as expanding consciousness. St. Louis: Mosby.
- Newman, M.A. (1990). Newman's theory of health as praxis. Nursing Science Quarterly, 3(3), 37-41.
- Patsdaughter, C. (1989). The mother-daughter relationship in menopause and the aging process. Seattle: University of Washington. Dissertation.
- Patterson, J., McCubbin, H., & Warwick, W. (1990). The impact of family functioning on health changes in children with cystic fibrosis. Social Science and Medicine, 31(2), 159-164.
- Patton, M. (1994). Qualitative Evaluation and Research Methods. Newbury Park: Sage.
- Piaget, J. (1932). The moral judgement of the child. New York: The Free Press.

- Rodgers, B. & Cowles, K. (1993). The qualitative research audit trail: A complex collection of documentation. Research in Nursing and Health, 16, 219-226.
- Rollins, J. & White, P. (1982). The relationship between mothers' and daughters' sex-role attitudes and self-concepts in three types of family environments. Sex Roles, 8, 1141-1155.
- Samuelson, D. (1986). A letter to my daughter/myself on facing the collective fear of being different. Feminist Studies, 12(1), 155-167.
- Steele, S. (1983). Health promotion of a child with a long-term illness. Norwalk, CT: Appleton-Century Crofts.
- Stiver, I. (1986). Beyond the Oedipus Complex: Mothers and Daughters. Wellesley, Mass.: The Stone Center for Developmental Studies.
- Thompson, L. (1993, June 7). The first kids with new genes. TIME, 141 (3), 50-53.
- Travis, G. (1976). Chronic illness in children: Its impact on child and family. California: Stanford University Press.
- Turner-Henson, A., Holaday, B., Corser, N., Ogletree, G., & Swan, J. (1994). The experiences of discrimination: Challenges for chronically ill children. Pediatric Nursing, 20(6), 571-577.
- Walker, L., & Avant, K. (1988). Strategies for theory construction in nursing. (2nd ed.). Norwalk: Appleton & Lange.
- Walters, S. (1992). Lives together, Worlds apart: Mothers and daughters in popular culture. Berkeley: University of California Press.
- West, P. (1990). The status and validity of accounts obtained at interview: A contrast between two studies of families with a disabled child. Social Science and Medicine, 30(11), 1229-1239.
- Witherspoon, G. (1975). Navajo kinship and marriage. Chicago: The University of Chicago Press.
- Woods, N., Yates, B., & Primomo, J. (1989). Supporting families during chronic illness. Image, 21(1), 46-50.

- Woods, N., Haberman, M., & Packard, N. (1993). Demands of illness and individual, dyadic, and family adaptation in chronic illness. Western Journal of Nursing Research, 15(1), 10-30.
- Zayas, L., & Solari, F. (1994). Early childhood socialization in Hispanic families: Context, culture, and practice implications. Professional Psychology, 25(3), 200-206.
- Zeltzer, L., Kellerman, J., Ellenberg, L., Dash, J., & Rigler, D. (1980). Psychologic effects of illness in adolescence. II. Impact of illness in adolescents - crucial issues and coping styles. The Journal of Pediatrics, 97(1), 132-138.

## Appendix A

### Questions Asked of Daughters

"How has having heart disease affected you and your family?"

"How has having heart disease affected your relationship with your mother?"

"Did anyone ever treat you as if you were different from other children or other people because of your heart disease?"

"Did your doctors or nurses ever discuss what it meant to 'be adjusted' to having heart disease? If so, what sorts of things did they discuss with you concerning this."

"What sorts of things do you think your mother should tell you about your heart disease as you get older?"

"What does the term 'cardiac cripple' mean to you?"

## Appendix B

### Questions Asked of Mothers

"How has having a child with heart disease affected you and your family?"

"How has this disease impacted your relationship with your daughter?"

"Do you feel any differently towards your daughter because of her heart disease?"

"Do you feel that raising male and female children is the same?"

"Have health care professionals ever treated you or your daughter or your relationship as if you were different or strange?"

"What does the term 'cardiac cripple' mean to you? Were you ever told by health care professionals that you should do certain things to help your child 'adjust to her disease?'"

## Appendix C

### Consent for Research (for daughters under eighteen)

#### A Research Study Concerning the Effects of Chronic Illness on Family Relationships Investigator: Laura T. Gantt

Purpose: To explore the impact of chronic illness, specifically congenital heart disease, on relationships within the family.

By signing this form, I am agreeing to participate in the research project named above. I am aware that my mother has already signed a consent form for my participation in the study. However, I have been informed that I may still refuse to participate.

During the course of the study, I understand that I will be interviewed at least once and possibly a second time. In addition, I will also be interviewed with my mother. These interviews will be audiotaped in private settings convenient to me.

I have been informed that I may refuse to participate in this study and that my refusal will in no way interfere with my medical care. I also understand that I may refuse to answer any questions that I do not wish to answer.

I understand that my participation in this study will not cost me anything nor will I be paid anything for my participation.

I understand that any information collected about me will be used exclusively for research purposes which may involve publication and/or presentation at conferences. I also understand the investigator will ensure that any information collected is not presented in such a way that I could be identified nor will it be shared with other family members.

**Appendix C (cont.)**

I have been assured that I will be exposed to no physical risks. I may be exposed to psychological risk involved in sharing personal details of my life with another person. Yet I may find that, by being in this study, that I may be helped by having the opportunity to discuss my feelings about having congenital heart disease and how that has affected my relationships with my family.

I know that I will obtain a copy of this consent form. I may receive a copy of the completed study upon request from the investigator named above. If I have any questions about the study or my participation in it, I may contact Laura Gantt at (██████████). If I have any questions about my rights as a research subject, I may also call Desiree Fernandez, secretary of the Colorado Multiple Institutional Review Board at 3 ██████████. I understand that I may withdraw from the study at any time.

Participant \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Investigator \_\_\_\_\_ Date \_\_\_\_\_

## Appendix D

### Consent for Research (for daughters over eighteen)

#### A Research Study Concerning the Effects of Chronic Illness on Family Relationships Investigator: Laura T. Gantt

Purpose: To explore the impact of chronic illness, specifically congenital heart disease, on relationships within the family.

By signing this form, I am agreeing to participate in the research project named above. During the course of the study, I understand that I will be interviewed at least

once by myself and possibly a second time. In addition, I will be interviewed with my mother. These interviews will be audiotaped in private settings convenient to me. I understand that after completion of the study that the investigator will keep the tapes, but that information on the tapes will be kept confidential.

I have been informed that I may refuse to participate in this study and that my refusal will in no way interfere with my medical care. I also understand that I may refuse to answer any questions that I do not wish to answer.

I understand that my participation in this study will not cost me anything nor will I be paid anything for my participation.

I understand that any information collected about me will be used exclusively for research purposes which may involve publication and/or presentation at conferences. I also understand the investigator will make ensure that any information collected is not presented in such a way that I could be identified nor will it be shared with other family members.

**Appendix D (cont.)**

I have been assured that I will be exposed to no physical risks. I may be exposed to psychological risk involved in sharing personal details of my life with another person. Yet I may find that, by being in this study, that I may be helped by having the opportunity to discuss my feelings about having congenital heart disease and how that has affected my relationships with my family.

I know that I will obtain a copy of this consent form. I may receive a copy of the completed study upon request from the investigator named above. If I have any questions about the study or my participation in it, I may contact Laura Gantt at [REDACTED]. If I have any questions about my rights as a research subject, I may also call Desiree Fernandez, secretary of the Colorado Multiple Institutional Review Board at [REDACTED]. I understand that I may withdraw from the study at any time.

Participant \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Investigator \_\_\_\_\_ Date \_\_\_\_\_

## Appendix E

### Consent for Research (for mothers only)

#### A Research Study Concerning the Effects of Chronic Illness on Family Relationships Investigator: Laura T. Gantt

Purpose: To explore the impact of chronic illness, specifically congenital heart disease, on relationships within the family.

By signing this form, I am agreeing to participate in the research project named above. During the course of the study, I understand that I will be interviewed at least once and possibly a second time. In addition, I will also be interviewed with my daughter. I may also be asked to participate in focus group sessions with other mothers of daughters with congenital disease. These interviews and focus group sessions will be audiotaped in private settings convenient to me. I understand that after the completion of the study that the investigator will keep these tapes but that the information on the tapes will be kept confidential.

I understand that my daughter will also be asked to participate in this study. If she is under the age of eighteen, I will be asked to sign a separate consent form for her. If she is over the age of eighteen, she will be asked to sign her own consent form.

I have been informed that I may refuse to participate in any part of this study and that my refusal will in no way interfere with my daughter's medical treatment, nor will it affect how I am treated by the medical staff involved in my daughter's care. I also understand that I may refuse to answer any questions that I do not wish to answer.

I understand that my participation in this study will not cost me anything nor will I be paid anything for my participation.

**Appendix E (cont.)**

I understand that any information collected about me will be used exclusively for research purposes which may involve publication and/or presentation at conferences. I also understand the investigator will ensure that any information collected is not presented in such a way that I could be nor will it be shared with other family members.

I have been assured that I will be exposed to no physical risks. I may be exposed to psychological risk involved in sharing personal details of my life with another person. Yet I may find that, by being in this study, that I may be helped by having the opportunity to discuss my feelings about and experiences of having a daughter with congenital heart disease. If I decide to participate in the focus group sessions, I may also be helped by having the opportunity to meet other mothers who have daughters with congenital heart disease.

I know that I will obtain a copy of this consent form. I may receive a copy of the completed study upon request from the investigator named above. If I have any questions about the study or my participation in it, I may contact Laura Gantt at (██████████). If I have any questions regarding my rights as a research subject, I may also call Desiree Fernandez, secretary of the Colorado Multiple Institutional Review Board at ██████████. I understand that I may withdraw from the study at any time.

Participant \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Investigator \_\_\_\_\_ Date \_\_\_\_\_

## Appendix F

Consent for Research  
(for mothers for their underage daughter)

A Research Study Concerning the Effects of  
Chronic Illness on Family Relationships  
Investigator: Laura T. Gantt

Purpose: To explore the impact of chronic illness, specifically congenital heart disease, on relationships within the family.

By signing this form, I am agreeing for my daughter, who is under the age of eighteen, to participate in the study described above. During the course of the study, I understand that my daughter will be interviewed at least once and possibly a second time and that she will also be interviewed with me. These interviews sessions will be audiotaped in private settings convenient to me and my daughter. After completion of the study, I understand that the investigator will keep these audiotapes, but that information on the tapes will remain confidential.

I have been informed that I may refuse to allow my daughter to participate in any part of this study and that my refusal will in no way interfere with my daughter's medical treatment, nor will it affect how I am treated by the medical staff involved in my daughter's care. In addition, I understand that my daughter may refuse to participate in the study or to answer any questions she does not wish to answer and that she will not be forced to participate without her assent.

I understand that my daughter's participation in this study will not cost me anything nor will I be paid anything for her participation.

**Appendix F (cont.)**

I understand that any information collected about my daughter during her interview will be used exclusively for research purposes which may involve publication and/or presentation at conferences. I also understand that the investigator will ensure that any information collected is not presented in such a way that my daughter could be identified, nor will it be shared with me or other family members.

I have been assured that my daughter will be exposed to no physical risks. She may be exposed to psychological risk involved in sharing personal details of her life with another person. Yet she may find that, by being in this study, that she may be helped by having the opportunity to discuss her feelings about and experiences of congenital heart disease.

I know that I will obtain a copy of this consent form. I may receive a copy of the completed study upon request from the investigator named above. If I have any questions about the study or my participation in it, I may contact Laura Gantt at [REDACTED]. I may also contact Desiree Fernandez, secretary of the Colorado Multiple Institutional Review Board at [REDACTED]. I understand that I may withdraw from the study at any time.

Participant \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Investigator \_\_\_\_\_ Date \_\_\_\_\_

**Appendix G**

| <b>Table 4: Data Matrix for Mothers of Daughters</b> |            |                         |                                    |                |   | <b>1</b> |
|--|------------|-------------------------|------------------------------------|----------------|---|----------|
| <b>Name</b>  | <b>Age</b> | <b>Age @ Child's Dx</b> | <b>Severity of Child's Disease</b> | <b>Culture</b> | <b>Critical Incidents</b>                       |          |
| <b>Lynnette</b>                                      | 45         | 24                      | 3                                  | Anglo          | Infancy, surgery; cites lack of insurance early |          |
| <b>Mary</b>  | 35         | 25                      | 2                                  | Hispanic       | Times around dx, surgery, illnesses             |          |
| <b>Marion</b>  | 40         | 33                      | 4                                  | Anglo          | Infancy/dx.; especially surgery                 |          |
| <b>Shauna</b>  | 45         | 29                      | 1                                  | Anglo          | Time of discovery of heart murmur               |          |
| <b>Roberta</b>                                       | 40         | 25                      | 3                                  | Hispanic       | Dx., surgeries                                  |          |
| <b>Jane</b>  | 55         | 20                      | 3                                  | Anglo          | Dx., surgeries, periods of worsening health     |          |
| <b>Lucinda</b>                                       | 30         | 28                      | 2                                  | Navajo         | Dx., yearly doc visits                          |          |
| <b>Jaimee</b>  | 35         | 26                      | 2                                  | Anglo          | Infancy, dx.                                    |          |
| <b>Karen</b>   | 40         | 26                      | 3                                  | Anglo          | Infancy, 1st four months of life, doc visits    |          |
| <b>Martha</b>  | 35         | 25                      | 4                                  | Anglo          | Infancy   |          |
| <b>Dawn</b>  | 40         | 25                      | 1                                  | Anglo          | Dx., doc visits                                 |          |

Appendix G (cont.)

| <b>Table 4: Data Matrix for Mothers of Daughters</b> |   |   | <b>2</b> |
|--|---|---|----------|
| <b>Name</b>  | <b>Closeness</b>                              | <b>Is CHD a "disease?"</b>                            |          |
| <b>Lynnette</b>                                      | Mother and daughter appear very close         |   |          |
| <b>Mary</b>  | Mother and daughter appear close              | No - "you just have to get on with life"              |          |
| <b>Marion</b>  | Mother and daughter not observed together     | Seems unable to forget CHD, recent surg.              |          |
| <b>Shauna</b>  | Mother states that daughter does not like her | "We don't think much about it."                       |          |
| <b>Roberta</b>                                       | No closer to daughter than other children     | "I haven't concentrated too much on it."              |          |
| <b>Jane</b>  | Very close, but mother thinks not due to HD   | Family seem to have difficulty escaping CHD           |          |
| <b>Lucinda</b>                                       | Mother states no closer than other kids       | Daughter's level of disability not severe             |          |
| <b>Jaimee</b>  | Mother, father seem equally close to child    | Family very affected by child's CHD                   |          |
| <b>Karen</b>   | Mother states no closer than to son           | No - child just born with different type of ht.       |          |
| <b>Martha</b>  | Mother states child was closer to father      | Very much affected by daughter's HD, death            |          |
| <b>Dawn</b>  | Mother and daughter appear close              | No, just something you live with (hasn't had surgery) |          |

**Appendix G (cont.)**

| <b>Table 4: Data Matrix for Mothers of Daughters</b> |  |   | <b>3</b> |
|--|--|---|----------|
| <b>Name</b>  | <b>Family resilience/Maternal resilience</b>     | <b>Adjustment/Normalizing</b>                   |          |
| <b>Lynnette</b>                                      | Family seems accepting of all members            | Difficult due to growth problems and CHD        |          |
| <b>Mary</b>  | Mother & daughter interact well, easily          | Have tried to get beyond Julie's illness        |          |
| <b>Marion</b>  | Family obviously shaken by daughter's problems   | Difficult due to recent surg.? (1 yr. before)   |          |
| <b>Shauna</b>  | ? learning disability of child more of a problem | None necessary due to ht. murmur only           |          |
| <b>Roberta</b>                                       | Mother gave up SW profession due to child        | Normalize as much as possible                   |          |
| <b>Jane</b>  | Parents separated geographically due to HD       | Normalized as much as possible                  |          |
| <b>Lucinda</b>                                       |  | Child never particularly ill to date            |          |
| <b>Jaimee</b>  | Resilience increased by family closeness         | Mother feels child is well adjusted             |          |
| <b>Karen</b>   | Family struggling for a whole lot of reasons     | Mother feels like child adjusted well           |          |
| <b>Martha</b>  | Resilient due to family, religion                | Child very unimpaired except for times of surg. |          |
| <b>Dawn</b>  | Mother and daughter appear upbeat                | Little adjustment needed since VSD minor        |          |

**Appendix G (cont.)**

| <b>Table 4: Data Matrix for Mothers of Daughters</b> |  | <b>4</b> |
|--|--|----------|
| <b>Name</b>  | <b>Miscellaneous/Notes</b>   |          |
| <b>Lynnette</b>                                      | This mom seems to have worked hard to support her children financially                     |          |
| <b>Mary</b>  | This mom notes the stress of having in-laws and other family dwell on heart problem        |          |
| <b>Marion</b>  | Child's health very much in the forefront of this mom's mind; concerned RE: child's future |          |
| <b>Shauna</b>  | This daughter was two months premature; heart murmur discovered at age 8                   |          |
| <b>Roberta</b>                                       | Adolescent also with Down's Syndrome. Extended family has hindered adjustment              |          |
| <b>Jane</b>  | Mother returned to the US, left husband in Iran due to child's illness                     |          |
| <b>Lucinda</b>                                       | Mother currently pregnant with 4th child; blames self for 3rd child's health problems      |          |
| <b>Jaimee</b>  | Mother feels that daughter's illness has increased her compassion toward others            |          |
| <b>Karen</b>   | Child very ill for first four months of life   |          |
| <b>Martha</b>  | Mother/child separated at birth due to illness of both                                     |          |
| <b>Dawn</b>  |  |          |

**Appendix G (cont.)**

| <b>Table 4: Data Matrix for Mothers of Daughters</b> |  |  | <b>5</b> |
|--|--|--|----------|
| <b>Name</b>  | <b>Child's Dx</b>                              | <b>Treatment by HCP's</b>                          |          |
| <b>Lynnette</b>                                      | Tetralogy of Fallot, repaired; growth disorder | Fine except for certain incidents around surg.     |          |
| <b>Mary</b>  | Tetralogy of Fallot, repaired                  | Good   |          |
| <b>Marion</b>  | Pulmonary atresia, repaired                    | Parents' anxiety strains relationships             |          |
| <b>Shauna</b>  | Heart murmur only                              | Good   |          |
| <b>Roberta</b>                                       | Atrioventricular Canal, Down's Syndrome        | Appreciates way MD deals with dau. directly        |          |
| <b>Jane</b>  | Truncus arteriosus, repaired                   | Mother sometimes at odds with HCPs                 |          |
| <b>Lucinda</b>                                       | Ventricular Septal Defect, unrepaired as yet   | O.K.   |          |
| <b>Jaimee</b>  | Tetralogy of Fallot, repaired                  | Good relationship with HCPs                        |          |
| <b>Karen</b>   | Double outlet right ventricle, repaired        | Hates med system, good relationship with some HCPs |          |
| <b>Martha</b>  | Pulmonary atresia, palliated                   | Got along well with HCPs                           |          |
| <b>Dawn</b>  | Ventricular Septal Defect, unrepaired          | Good   |          |

Appendix G (cont.)

| <b>Table 4: Data Matrix for Mothers of Daughters</b> |   |                            | <b>6</b> |
|--|---|----------------------------|----------|
| <b>Name</b>  | <b>Fischer Classification</b>                       | <b>Daughter's name/age</b> |          |
| <b>Lynnette</b>                                      | ? peerlike  | Veronica - 17              |          |
| <b>Mary</b>  | dependent daughter (due to age)                     | Jean - 10                  |          |
| <b>Marion</b>  | dependent daughter (due to age)                     | Linda - 6                  |          |
| <b>Shauna</b>  | dependent daughter (due to age)                     | Laura - 16                 |          |
| <b>Roberta</b>                                       | dependent daughter (due to age and Down's Syndrome) | Margaret - 15              |          |
| <b>Jane</b>  | mutual mothering                                    | Lainna - 35                |          |
| <b>Lucinda</b>                                       | dependent daughter (due to age)                     | Keely - 2                  |          |
| <b>Jaimee</b>  | dependent daughter (due to age)                     | Stacy - 9                  |          |
| <b>Karen</b>   | dependent daughter (due to age)                     | Megan - 14                 |          |
| <b>Martha</b>  | dependent daughter (due to age)                     | Chris (deceased at age 9)  |          |
| <b>Dawn</b>  | dependent daughter (due to age)                     | Erin - 16                  |          |

Appendix H

| <b>Table 5: Data Matrix for Daughters</b> |            |                                    |                            |                |   | <b>1</b> |
|---|------------|------------------------------------|----------------------------|----------------|---|----------|
| <b>Name</b>                               | <b>Age</b> | <b>Diagnosis</b>                   | <b>Severity of Disease</b> | <b>Culture</b> | <b>Critical Incidents</b>                           |          |
| <b>Stacy</b>                              | 9          | Tetralogy of Fallot                | 2                          | Anglo          | Dx., surgery.                                       |          |
| <b>Jean</b>                               | 10         | Tetralogy of Fallot                | 2                          | Hispanic       | School incidents                                    |          |
| <b>Megan</b>                              | 14         | Vent. Septal Defect, DORV          | 3                          | Anglo          | Infancy, in hospital X 4 months, MD visits          |          |
| <b>Erin</b>                               | 16         | Vent. Septal Defect, unrep.        | 1                          | Anglo          | Dx., Doc visits                                     |          |
| <b>Laura</b>                              | 16         | Heart murmur only                  | 1                          | Anglo          | Adolescence; loss of one year in school             |          |
| <b>Veronica</b>                           | 17         | Tetralogy of Fallot                | 3                          | Anglo          | Infancy, surgery                                    |          |
| <b>Norma</b>                              | 19         | Tricuspid Atresia, S/p Fontan pro. | 4                          | Anglo          | Very ill until age 8 when surgery done              |          |
| <b>Teri</b>                               | 34         | Vent. Septal Defect, seizures      | 4                          | Anglo          | Abused by parents and stepfather from birth         |          |
| <b>Lainna</b>                             | 35         | Truncus Arteriosus                 | 3                          | Anglo/Iraqi    | No surgery available till age 5, very ill childhood |          |
| <b>Nell</b>                               | 42         | Rheum. Fever, Mitral Valve Rep.    | 4                          | Anglo          | Pregnancy accompanied by dx., surgeries, illness    |          |
| <b>Lucy</b>                               | 56         | Atrial Septal Defect, asthma       | 1                          | Anglo          | Surgery @ 19, frequent problems with asthma         |          |

**Appendix H (cont.)**

| <b>Table 5: Data Matrix for Daughters</b> |   |  | <b>2</b> |
|---|---|--|----------|
| <b>Name</b>                               | <b>Closeness</b>                            | <b>Is CHD a "disease?"</b>                 |          |
| <b>Stacy</b>                              | Close family overall                        | Family very affected by daughter's illness |          |
| <b>Jean</b>                               | Mom very supportive of daughter's view      | Mother reports family tries to minimize    |          |
| <b>Megan</b>                              | Very close to mom, ? due to HD              | No big deal now                            |          |
| <b>Erin</b>                               | Mother and daughter interact easily         | No   |          |
| <b>Laura</b>                              | Mother and daughter report current friction | Remembers little of when ht. murmur dx.    |          |
| <b>Veronica</b>                           | Mom and daughter appear very close          | Probably not                               |          |
| <b>Norma</b>                              | Mother gave child to grandma as newborn     | Yes  |          |
| <b>Teri</b>                               | Now "divorced" from entire family           | Yes  |          |
| <b>Lainna</b>                             | Layla always resistant to closeness to mom  | Yes  |          |
| <b>Nell</b>                               | Ambivalent regarding relationship with mom  | NA   |          |
| <b>Lucy</b>                               |   | Feels had more problems with asthma        |          |

**Appendix H (cont.)**

| <b>Table 5: Data Matrix for Daughters</b> |  |   | <b>3</b> |
|---|--|---|----------|
| <b>Name</b>                               | <b>Family resilience/Maternal resilience</b>       | <b>Adjustment/Normalizing</b>                 |          |
| <b>Stacy</b>                              | Family resilience increased by religious faith     | Sara feels restricted; ? due to HD            |          |
| <b>Jean</b>                               |  | Daughter currently having peer problems       |          |
| <b>Megan</b>                              | Family seems to be struggling, not due to HD       | Aware of own limitations                      |          |
| <b>Erin</b>                               |  |   |          |
| <b>Laura</b>                              | Mother defers to discipline of father for daughter | None necessary due to ht. dz                  |          |
| <b>Veronica</b>                           | Family appears very accepting of its member        | More limited by size than CHD                 |          |
| <b>Norma</b>                              | Grandma and Nicole resilient together              | Adjustment through manipulation of med system |          |
| <b>Teri</b>                               | This woman has survived it all!                    | Very poor quality of life                     |          |
| <b>Lainna</b>                             | Father always live apart; very resilient           | CHD has never slowed her down                 |          |
| <b>Nell</b>                               | Appears to have lots of inner resources            | Still working FT, just re-married             |          |
| <b>Lucy</b>                               | Parents were reluctant to allow surgery            | Feels no adjustment to CHD was necessary      |          |

Appendix H (cont.)

| <b>Table 5: Data Matrix for Daughters</b> |  | <b>4</b> |
|---|--|----------|
| <b>Name</b>                               | <b>Miscellaneous/Notes</b>   |          |
| <b>Stacy</b>                              |  |          |
| <b>Jean</b>                               |  |          |
| <b>Megan</b>                              |  |          |
| <b>Erin</b>                               |  |          |
| <b>Laura</b>                              |  |          |
| <b>Veronica</b>                           |  |          |
| <b>Norma</b>                              | Mother/father separated. Mom 19 at Nicole's birth.                         |          |
| <b>Teri</b>                               | Has had seizures, CVAs, cervical cancer                                    |          |
| <b>Lainna</b>                             |  |          |
| <b>Nell</b>                               |  |          |
| <b>Lucy</b>                               | Murmur at birth. Lived 19 years with disease before surgery was available. |          |

Appendix i

| <b>Table 6: Data Matrix of Mothers and Sons</b> |                  |                      |                     |                                  |                                    |                | <b>1</b> |
|---|------------------|----------------------|---------------------|----------------------------------|------------------------------------|----------------|----------|
| <b>Son's Name</b>                               | <b>Son's Age</b> | <b>Mother's Name</b> | <b>Mother's Age</b> | <b>Mother's Age @ Child's Dx</b> | <b>Severity of Child's Disease</b> | <b>Culture</b> |          |
| <b>Mark</b>                                     | 12               | Lori                 | 30                  | 18                               | 1                                  | Hispanic       |          |
| <b>Brad</b>                                     | 15               | Beth                 | 36                  | 21                               | 1                                  | Hisp./Anglo    |          |
| <b>Matt</b>                                     | 18               | Joan                 | 38                  | 20                               | 3                                  | Hispanic/NA    |          |

| <b>Table 6: Data Matrix of Mothers and Sons</b> |   |  |                            | <b>2</b> |
|---|---|--|----------------------------|----------|
| <b>Son's Name</b>                               | <b>Critical incidents</b>                         | <b>Closeness</b>                       | <b>Is CHD a "disease?"</b> |          |
| <b>Mark</b>                                     | Times around dx, surgery, illnesses               | No closer to son than to daughters     | No-just born with it       |          |
| <b>Brad</b>                                     | Time around beginning of sx., time of pr          | Appears close to all of sons (4)       | No-"we've tried to forget" |          |
| <b>Matt</b>                                     | Times around dx, surgery, illnesses & adolescence | Mother says relationship is very close | No-it's a birth defect     |          |

Appendix I (cont.)

| <b>Table 6: Data Matrix of Mothers and Sons</b> |  |  | <b>3</b> |
|---|--|--|----------|
| <b>Son's Name</b>                               | <b>Family resilience/Maternal resilience</b> | <b>Adjustment/Normalizing</b>                |          |
| <b>Mark</b>                                     | Mother appears to rely on own parents        | No problem except for interface with HCPs    |          |
| <b>Brad</b>                                     | Illness was fairly short-term                | "We've tried to forget." "Brandon is cured." |          |
| <b>Matt</b>                                     | Mother was single parent X 6 years; divorced | CHD "no big deal" - "you just go on"         |          |

| <b>Table 6: Data Matrix of Mothers and Sons</b> |  |  | <b>4</b> |
|---|--|--|----------|
| <b>Son's Name</b>                               | <b>Child's Dx</b>                            | <b>Treatment by HCPs</b>                     |          |
| <b>Mark</b>                                     | Total anomalous pulm. venous return, seizure | Family complained about travel for f/u       |          |
| <b>Brad</b>                                     | Wolf-Parkinson-White Syndrome                | Child initially told problem was in his head |          |
| <b>Matt</b>                                     | Coarct., vent. sept. def., pulm. stenosis    | Fine; Marino notes privileges of peds. pts.  |          |