

PARENTS' PERCEPTIONS OF THEIR FAMILY'S EXPERIENCE
WHEN THEY HAVE A CHILD
AWAITING CORRECTIVE HEART SURGERY

By

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Abstract

Parents' Perceptions of Their Family's Experience When They
Have a Child Awaiting Corrective Heart Surgery

The purpose of this phenomenological study was to determine the meaning parents give to their family's experience when they have a child awaiting corrective heart surgery. A secondary purpose was to identify appropriate interventions for nurses who deal with families during the transition period, from initial diagnosis of congenital heart disease until admission to hospital for corrective heart surgery.

A convenience sample of six couples were interviewed at various times during the identified transition period, for a total of 11 interviews. An interview guide of open-ended questions provided some loose structure for the initial interviews. Analysis of the verbatim transcriptions began concurrently with data collection and continued during the formal analytic phase with meaning units emerging from the data.

The parents described four facets of the experience: diagnosis of congenital heart disease, adjusting to caring for child once home, living with a child with a chronic condition, and waiting for corrective heart surgery. Not only did parents talk about how they felt during the four facets but they also described the range of coping strategies they employed through their experience. In

discussing these findings within the context of other chronic illness experiences it became evident that parents draw from a common pool of coping strategies whether the child is in a chronic or more acute phase of an illness.

Most of the parents in discussing their overall impressions of the experience had not found their child's illness to be as disruptive to family life as they had first anticipated. Those families with the most symptomatic infants seemed to have a particular need for an alliance with one health care professional to support them through the transition period. Generally, parents did not spend a lot of time dwelling on the corrective surgery until close to the anticipated date for that event; instead they employed various coping strategies which allowed them to normalize their lives.

Implications for nursing practice which arise from these conclusions are multiple. Overall, nurses must assess the meaning that individual families give to their experience, assist families to employ suitable coping strategies, and offer support as necessary. General implications for nursing research are in the realm of studies which will further nurses' understanding of the waiting period for corrective heart surgery both from the parents' and the siblings' perspective.

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CHAPTER 1

Introduction

This study is an exploration of parents' perceptions of their family's experience when they have a child awaiting corrective heart surgery. The specific time period that is explored is the transition period from initial diagnosis of congenital heart disease (CHD) until admission to hospital for corrective surgery.

The impetus for this study grew out of the investigator's clinical experience. In working with families of children with CHD in both intensive care unit (ICU) and ward settings, the investigator gained a certain understanding of the family's hospital experience. However, a broader understanding of their overall experience was derived from involvement over a three year period with a parent support group. In this group parents talked more about issues related to caring for the child at home. When the date for corrective surgery was known, this then became the focus of discussion. Through this involvement, it became evident that the experience of having a child awaiting corrective surgery is multi-faceted and complex. Therefore, the investigator decided to explore further how parents make meaning of these various aspects of their family's experience including having the child at home, making contact with the health care system,

and acknowledging that their child with CHD requires corrective heart surgery.

The background to the problem will now be explored in a chronological manner following the sequence of the identified transition period.

Background to the Problem

The incidence of CHD is approximately eight cases per 1000 live births (Stapleton, 1983). "As the heart has long been recognized as an organ vital to life, it is not surprising that a high degree of apprehension is aroused when its function is threatened" (Glaser, Harrison & Lynn, 1964, p. 377).

A diagnosis of CHD is likely to be made within the first few days of life if the infant has one of a number of defects that most often cause early symptoms, for example, transposition of the great vessels, coarctation of the aorta, and pulmonary atresia/stenosis (Moller & Neal, 1981). In one study in the U.S., 43% of cases of CHD were diagnosed within the first week of life (Feldt, Avasthey, Yoshimasu, Kurkland, & Titus, 1971). This percentage will vary depending on the diagnostic skill of the physicians involved. When a problem is suspected shortly after birth, the infant will often have to be transported to a tertiary care centre for definitive diagnosis and treatment. This may mean separation of the mother from her baby and also separation of the parents if the father follows the infant to the tertiary care centre. Some infants may have to

undergo cardiac catheterization and/or palliative surgery during this initial hospitalization. "Cardiac catheterization and surgery represent the ultimate strain for infants' parents. To submit their helpless, miniscule being to these bodily invasions unnerves them" (Neill, 1970, p. 42).

The birth of any baby, healthy or not, creates changes in a family and all family members must make adjustments for the new member to be incorporated (Friedman, 1981). Transitional stress is identified by Minuchin (1974) as that which occurs when there is an addition or loss of family members. If a baby is born with a congenital defect, the transitional stress and process of incorporation take on new dimensions. Before the infant is fully accepted into the family, the parents are faced with certain tasks such as acknowledging the defect and searching for information about manifestation and cause (Waechter, 1977).

Certain cardiac defects, such as ventricular septal defects, often do not cause problems until the infant is close to two months of age (Moller & Neal, 1981). As a result, the parents may initially think that they have a normal healthy infant, only to find out after having the infant home for several weeks that this is not the case. At that time, they are still adjusting to having a new family member and perhaps taking on the role of parent for

the first time only to be faced with the news that their infant has a potentially life-threatening heart defect.

Many infants with complex heart disease now survive because of improved diagnostic testing and surgical techniques (Clare, 1985). Some of these infants have corrective surgery in the early neonatal period. However, there are a large number who are managed medically or have a palliative surgical procedure to sustain them until they are considered better surgical risks. As a result, these children spend a period of time at home during which mild to severe symptoms of CHD are evident.

Corrective cardiac surgery of increasing complexity is now being performed on very young children. The waiting period for corrective heart surgery has become shorter as surgical techniques and post-operative monitoring have improved. However, the family is often left with the uncertainty of not knowing exactly when the corrective surgery will be done. The timing of this event depends on how the child manages with whatever other interventions can be offered in the meantime.

Some of the concerns of parents having a child with CHD have been documented (Apley, Barbour, & Westmacott, 1967; D'Antonio, 1976; Dunning, 1984; Garson, Benson, Ivler & Patton, 1978; Glaser et al., 1964; Gudermuth, 1975; Linde, Rasof, Dunn, & Rabb, 1966; Maxwell & Gane, 1962; Pinelli, 1981). However, there are limitations to this research. For example, the time period prior to corrective

surgery was not well identified or described and most studies only asked for mothers' perceptions of the experience. In our present decade of increased mixing of traditional roles, it has become important to elicit the opinions of both fathers and mothers. There are also few studies which concentrated on families having young children. Considering the early age at which most heart surgery is now being performed, it is the experiences of families with young children which are important for nurses to understand, now and in the future. These limitations serve to limit the utility of the findings for current nursing practice.

Nurses are involved with families having children with CHD at many different stages during the waiting period for corrective surgery. The nurse working in a maternity setting may have first contact when CHD is suspected. The nurse working in a pediatric tertiary care centre may have contact with these families on a number of occasions including admissions for: initial diagnosis, medical management, cardiac catheterization, and surgery, both palliative and corrective. The nurse working on a pediatric ward in a community hospital may also have contact if the child is admitted there with pneumonia or congestive heart failure. The community health nurse may see these families during home visits and in baby clinics. Hence, families are potentially in contact with many

different nurses with varying levels of knowledge and skill during the course of their child's illness.

Thus, the present study was designed to explore the experience of families having a child with CHD, awaiting corrective heart surgery. The information gained will hopefully be utilized by nurses and other health care professionals to assist them in providing quality family-centered care to families having children with CHD.

Theoretical Framework

The UBC Model for Nursing: The Family provided the theoretical framework for this study. In this Model, the family as client is "conceptualized as a social system with three subsystems, each representing one family need. The family attempts to meet these needs by using a range of transactional patterns. If these needs are met, the family is in social system balance" (UBC Model, May/1986, introduction). Nursing's function is identified as nurturing families during transition periods to assist them "to attain their goals, achieve stability and reach optimal health" (UBC Model, May/1986, p. 1). The broad definition of nurture, to "foster; protect; sustain; and teach" (UBC Model, May/1986, p. 6) provides a framework onto which knowledge of specific transition periods, such as the one under study here, must be built.

It is fitting that The Family Model be used when considering the young child awaiting corrective heart surgery.

A child who is at risk creates many difficulties for the other family members, including crises, grief, and other reactions. Regardless of its timing--at birth or in early or late childhood--any child-related risk situation results in a family at risk. (Hall Johnson, 1986, p. 109)

In The UBC Model for Nursing: The Family, transition period is defined as "a time during which an expected or an unexpected event occurs requiring the family to mobilize and/or develop its transactional patterns to meet family needs" (UBC Model, May/1986, p. 6). In this study, the unexpected event is the diagnosis of CHD and the transition period is the period from initial diagnosis of CHD until admission to hospital for corrective surgery.

The nurse, in attempting to nurture families during the identified transition period, must understand the meaning of the child's illness to that family.

Phenomenology is the research method which allowed the researcher to explore the experience of families having a child awaiting corrective heart surgery. The meaning of the illness to these families could then be identified from the data. By understanding their experience, including any accounts of nursing's involvement, we can take the first step toward identifying how best to nurture these families.

Introduction to Methodology

The phenomenological approach of qualitative research was used to answer the study's research question.

Qualitative research is the method in which the characteristics, attributes and meanings of the phenomena

under study are identified, documented and interpreted (Leininger, 1985). Hence, this broad methodological category is useful when studying unexplored phenomena. The literature review for this study revealed some attempts at understanding aspects of the experience of families having a child with CHD. However, the identified transition period was not well identified or explored and the perspective of both parents was seldom elicited.

Phenomenology is an inductive, descriptive research method which has the goal of describing lived experience from the subjective perspective of the person(s) who lived it (Omery, 1983). "The task is always one of learning how those involved interpreted and gave meaning to the situation" (Rist, 1979, p. 20). Therefore, phenomenology was an appropriate method for this study in which the researcher wanted to capture the meaning of the experience of having a child with CHD, awaiting corrective heart surgery.

Purpose of the Study

This study was an exploration of the family's experience during the transition period from initial diagnosis of CHD until admission to hospital for corrective surgery. The major purpose of the study was to gain insight, from the parents' perspective, into the experience of families during the transition period including any interactions with health care professionals, positive and/or negative. A further purpose was to identify

appropriate interventions for nurses in their role of nurturer during the identified transition period.

Definition of Terms

Child: male or female who is under three years of age and has CHD requiring corrective heart surgery.

Parents: biological parents of the child with CHD who live together with that child.

Family: the child with CHD, his parents, his siblings and any other relatives who live in the same dwelling.

Corrective heart surgery: heart surgery (open or closed) done to correct the underlying defect(s) as opposed to a palliative procedure.

Transition period: for the purposes of this study, this period was the period from initial diagnosis of CHD until admission to hospital for corrective heart surgery.

Assumptions

1. When an infant with CHD is born into a family some degree of adjustment is required by the family unit.
2. The experience of having a child awaiting corrective heart surgery has meaning for the parents of that child.
3. Parents are able to accurately recall and describe their experience and that of their family during this transition period.

Limitations

1. As this is an MSN thesis, the sample size was restricted to 12 participants (six couples), therefore limiting the generalizability of the results.

2. Only parents were interviewed therefore limiting the perceptions of the families' experiences to these two family members.

Summary

This introductory chapter has provided the background to the problem, a description of the theoretical framework, methodological theory, purpose, definition of terms, assumptions and limitations. Chapter 2 will cover a review of selected literature based on the theoretical framework.

CHAPTER 2

Review of Selected Literature

Introduction

The theoretical framework provided the concepts which will be explored in this chapter. These concepts are: the unexpected event of the diagnosis of CHD, the transition period from initial diagnosis of CHD until admission to hospital for corrective surgery, and the expected event of corrective heart surgery.

This selected review of the literature will include both experientially and research-based publications. Both types of literature were reviewed in an attempt to understand the concepts underlying the study. Because there was a dearth of recent research literature specific to the identified transition period, literature of a more general nature was also reviewed. Thus, reference will be made to the general literature on the diagnosis of any congenital anomaly, the impact of any chronic illness on the family and waiting for any type of surgery.

Diagnosis of a Congenital Anomaly

This section will combine references to what is generally known about parents' reactions to the diagnosis of various congenital anomalies with what is known about their reactions to the diagnosis of cardiac anomalies. It will also include a brief review of the stressors inherent

in the transition to parenthood because when CHD is diagnosed within the first two months of life parents are concurrently having to deal with the role transitions of this period.

Research has shown that negative feelings which are often identified by parents as accompanying the diagnosis of a congenital defect include guilt, inadequacy, irritation, disappointment (Glaser et al, 1964), as well as sadness, anger, and anxiety (Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975). If the diagnosis follows shortly after the birth, the parents have to cope with the loss of the expected healthy baby. Therefore, they usually need to grieve their loss before trying to incorporate the new member into the family (Waechter, 1977). Anger, a natural reaction to loss, is often displaced onto the nurse (Drotar et al., 1975; Mercer, 1977; Waechter, 1977). In some cases of CHD the diagnosis may not be made until several weeks after the birth. At this point the infant is already considered a member of the family but parents still experience many of the same emotions as they would have if the diagnosis had been made shortly after birth (Clare, 1985; Glaser et al., 1964).

It is generally acknowledged that parents' reactions of shock and disbelief at hearing the diagnosis of any congenital defect block the amount of information they can absorb initially (Burton, 1975; Clare, 1985; Drotar et al., 1975; Garson et al., 1978; Gottesfeld, 1979). Denial

or distortion of information are coping behaviours sometimes used by parents and may be suitable in the initial period after diagnosis of a defect (Drotar et al., 1975; Gidding & Rosenthal, 1984; Holaday, 1984; Kupst, Blatterbauer, Westman, Schulman, & Paul, 1977). A congenital heart defect is an invisible defect which may make it easier for parents to use such coping behaviours especially if the child is asymptomatic and little medical intervention is required initially (Garson et al., 1978; Kupst et al., 1977).

The etiology of CHD is unknown in over 90% of cases (Nadas, 1984). If the cause of an anomaly is not readily known most parents will search out a cause (Horan, 1982; Sahin, 1978; Waechter, 1977). This gives parents a feeling of control because they hope to be able to prevent the anomaly in future pregnancies (Horan, 1982). However, if no cause can be confirmed parents sometimes attribute the defect to something having no scientific basis (Horan, 1982).

In the case of CHD there may be some uncertainty about the definitive diagnosis at first and thus parents may react with uneasiness or anger (Kupst et al., 1977). Once the specific diagnosis is confirmed, infants with heart conditions will often require some type of medical treatment and/or surgery early on.

The decision regarding operation for congenital cardiac defects is always an individual decision with multiple factors to be considered, including complexity of the primary lesion, consideration of

associated or secondary defects, patient's age and size, other medical or surgical problems, and psychosocial considerations, which include both patient and family factors. On a theoretical basis, surgery would be most appropriate for psychosocial reasons in the early neonatal period. (Graham, 1984, p. 1275)

Sometimes information regarding the treatment plan accompanies the confirmation of the diagnosis, or it may come later after a period of observation of the infant. In Dunning's study (1984) many parents expressed difficulty with not knowing exactly when surgery would be done.

When CHD is diagnosed within the first two months of life the parents have to cope with this unexpected event in addition to having to deal with the transition to parenthood. Many theorists view the role transitions normally required at this time as stressful (Duvall, 1971; Friedman, 1981; Minuchin, 1974). The transition to parenthood takes place over time and involves numerous coping strategies (Miller & Sollie, 1980).

Parenting is one of the most difficult roles anyone undertakes. No other task is so complex, so difficult or so risky. Parenting is a role subject to recurrent stress: therefore crises occur with regularity and certainty. No population is at greater risk for dysfunction, and no population deserves the consideration of health care givers more than parents and children. (Murray, 1978, p. 4)

First-time parents have the added stress of not having had experience with a normal infant before having to cope with an infant with CHD. Several studies have shown that infant behaviour or temperament can affect the ease of this transition to parenthood (Roberts, 1983; Russell, 1974; Ventura, 1982). This may have implications then when

considering the sometimes irritable behaviour of the infant with CHD.

Thus, diagnosis of a congenital defect evokes a variety of emotions in parents who had expected to have or thought they already had a healthy infant. Because cardiac defects are invisible parents may find it hard to believe the diagnosis. Parents of infants with CHD find factors such as the often unknown etiology and uncertainty about treatment plan difficult to deal with. The already stressful transition to parenthood is further compounded when a diagnosis of CHD is made within the first few months of life.

A child with the diagnosis of CHD can be termed a chronically-ill child until after corrective surgery is successfully completed. Therefore, a review of the literature on the family having a chronically-ill child will add to our understanding of the experience.

Impact of Chronic Illness on the Family

Although each type of chronic illness may have some specific ramifications for the families involved, there are also general sorts of implications for families having children with any type of chronic illness. "Illness in childhood has physical, psychosocial and social implications for the child and the family" (Sargent, 1983, p. 982). This section, then, will deal with how families make meaning of a child's chronic illness, what hardships they must face and what strategies they use to cope with

those illnesses. Although the impact of a child's chronic illness on the family unit is widely described in the literature, many accounts are experientially based.

The meaning of a chronic illness to the family is influenced by many factors such as characteristics of the event, perceived threat to family relationships, status and goals, resources available to the family and past experience with the same or similar events (MacVicar & Archbold, 1976). Research has shown that the meaning of the illness to the family may be quite different from the perceptions of the health care professionals involved with that family (Anderson, 1981).

Patterson and McCubbin (1983) summarized the following hardships experienced by families having a chronically-ill child: strained family relationships, modifications in family activities and goals, the burden of increased tasks and time commitments, increased financial burden, need for housing adaptation, social isolation, medical concerns, and grieving a variety of losses or anticipated losses. Experience has shown that if one parent has full responsibility for coordinating a chronically-ill child's care there is a danger that an excessively close relationship will develop with that parent (Travis, 1976). Research has supported this idea (Sargent, 1983).

Consistent with a social system model of the family, when one member is ill then all members are affected, including siblings. When parents were asked about the

impact of the chronic illness on well siblings they cited a variety of positive and negative reactions (Lavigne & Ryan, 1979; Menke, 1987; Taylor, 1980). According to Taylor (1980), the negative effects include feelings of isolation, deprivation, egocentricity and inferiority while the positive effects are manifested by empathy, cooperation, rewards, increased self-esteem and cognitive mastery.

Parents of chronically-ill children are required to accomplish three major tasks.

They must be able:

1. To understand and manage their child's illness
2. To assist their child in understanding and coping with his/her illness
3. To meet the needs of all family members as well as those of the ill child

For parents to master these tasks successfully, their basic needs for information, trust, guidance and support, and resources must be met. (Hymovich, 1976, p. 13)

In striving to meet the needs of the sick child both parents may have to expand their roles in several directions (MacVicar & Archibald, 1976).

In order to accomplish the first two tasks cited above, parents of chronically-ill children seek information from health care professionals, family members, other parents, friends and literature (Holaday, 1984). By learning all they can about the illness, parents can conceptualize what their child's future might be like and thus lessen the anxiety caused by uncertainty (Mattsson, 1972).

Seeking support from within and outside of the family is another coping strategy used by parents. The parents'

ability to support each other has been identified as integral to long-term acceptance of the chronically-ill child (Drotar et al., 1975; Holaday, 1984). Parents may learn for the first time how their partners cope with grave disappointment and loss, and if the coping styles do not complement one another there may be problems (Sabbeth, 1984). Families generally have some kind of informal social support network of relatives and friends. However, when the family is coping with a chronically-ill child and requiring long-term or continuous support this network may become exhausted (Norbeck, 1981). A parent support group can augment this network by helping parents to understand their child's disease and cope with it more effectively (Johnson, 1982).

Chronic illness, by virtue of its long duration, is characterized by prolonged stress and although the anxiety associated with it may be minimized during daily life it never totally disappears (Gottesfeld, 1979). There is a small body of somewhat outdated literature dealing with the family having a child with CHD. This literature will now be addressed.

Impact of Congenital Heart Disease on the Family

CHD may be similar to other chronic illnesses in some respects but there seems to be an extra element of concern when a vital organ such as the heart is involved (Glaser et al., 1964). Both the range of parental concerns associated with the illness throughout the transition period and

reports of the impact of the illness on family life will be reviewed in this section.

At the time of discharge from hospital, research has shown some of the concerns of parents to be: apprehension about the behaviour of the infant, uncertainty about the diagnosis, anxiety about symptoms and fears of death (Glaser et al., 1964). In her small sample of 10, Pinelli (1981) compared mothers' concerns regarding the care-taking tasks of newborns with CHD before and after assuming their care. There was a substantial increase in concern about a number of categories of care when the infant had been home for one month.

One ongoing concern of mothers has proven to be the infants' feeding difficulties (D'Antonio, 1976; Gudermuth, 1975; Pinelli, 1981). As well as feeding difficulties, behaviours such as increased crying and irritability have been shown to strain the infant-mother relationship (D'Antonio, 1976; Glaser et al., 1964; Gudermuth, 1975). The impact of these infant behaviours on parents is often discussed in experientially-based literature as well (Bindler, 1979; Clare, 1985; Cloutier & Measel, 1982; Condon, 1973; Higgins & Kashani, 1984; Loeffel, 1985; Perrin & Gerrity, 1984). In addition, conflict between parents may result over the best way to handle the infant (Neill, 1970).

A few of the care-taking tasks in relation to the infant have already been described. The toddler with CHD

presents another set of concerns. Parents may overprotect their child by unnecessarily limiting activity and avoiding discipline (Loeffel, 1985; Maxwell & Gane, 1962).

Experience suggests that the toddler who is restricted in this stage of developing autonomy may feel defeated and become passive, apathetic, and clinging (Perrin & Gerrity, 1984). A lack of appropriate discipline can result in poor impulse control (Perrin & Gerrity, 1984).

Two major changes in family life attributable to the diagnosis of CHD have been identified by researchers as economic strain and limitation of social engagements (Apley et al., 1967; Maxwell & Gane, 1962). Other changes that have been identified are impaired parental health (Bindler, 1979; Gottesfeld, 1979; Maxwell & Gane, 1962) and the necessity for relocation closer to a tertiary care hospital (Apley et al., 1967; Gottesfeld, 1979).

There are also changes in family life which affect the siblings. If the illness is diagnosed in early infancy young siblings have to cope not only with the intrusion of this new person into their lives but also with the fact that their parents have to spend extra time with the intruder because of the illness (Clare, 1985). During hospitalizations of the ill child, siblings face separation from family members. Feelings of helplessness and aloneness may surface for the sibling at such times (Bowen, 1985).

An element of parental concern seems inevitable when a vital organ such as the heart is affected and a child diagnosed with CHD also invariably necessitates certain changes within the family. However, the child's chronic illness may not disrupt the stability of the family unit. Two fairly recent studies found that divorce was not more frequent in families having a child with CHD as compared to control groups (Finley, Putherbough, Cook, Netley & Rowe, 1979; Silbert, Newburger & Fyler, 1982). In fact, Finley et al. (1979) showed that the stability of the families in which the marriage was intact prior to the diagnosis was at a high level.

Corrective surgery is the event that parents wait for to restore their child's health. Because there is little specifically written with regard to waiting for heart surgery, a general look at the literature on waiting for any kind of surgery is included. This will encompass both children and adults awaiting surgery.

Waiting for Surgery

Most studies involving families with children awaiting surgery focus on preparation of the child of over two years for minor surgery, in the immediate preoperative period (Meng, 1980; Vardaro, 1978; Visintainer & Wolfer, 1975). Meng (1980) found that many parents, especially mothers, perceived their own anxiety as being much greater than their child's.

In contemplating the population under study, it was difficult to think of other populations with characteristics similar enough to consider their experiences as adding significantly to our understanding. The population which probably comes closest are children born with chronic renal failure who are awaiting renal transplant. However, no research was found which exclusively addressed such a waiting period. One study which did address the patient of over 16 years awaiting renal transplant, noted the "absence of nursing studies related to a prolonged waiting period prior to surgery, as is true with the patient awaiting a cadaveric renal transplant" (Weems, Taylor, & Davidson, 1983, p. 23).

A few studies have been done with adults awaiting coronary artery bypass graft surgery (Pieper, Lepeczyk, & Caldwell, 1985; Rakoczy, 1977). In the Pieper et al. (1985) study the subjects had been waiting from 7-76 days for surgery at the time of the interview. The major findings were that the perceived effect of waiting on the relationship with the spouse/partner and on life in general, diminished the longer the patients had to wait, and increased as their concerns about the surgery increased. The waiting period in the Rakoczy study (1977) was limited to "the three day time span (or 72 hours) between the first interview and cardiac surgery" (p. 282). That investigator identified four phases that represented the thoughts and feelings of those patients in the waiting

period: confrontation, self-reflection, resolution, and countdown (Rakoczy, 1977). It is conceivable that the experience of those patients might have some similarities to the experience of parents whose child is awaiting corrective heart surgery.

Waiting for Corrective Heart Surgery

CHD, unlike many other chronic illnesses usually has an end point represented by corrective surgery, beyond which life for the involved child can be virtually normal. This section will highlight the findings of the few studies which have dealt with the family's experience of waiting for corrective heart surgery. Most studies were of a retrospective nature done after the child had already had the surgery or else only the immediate preoperative period was considered.

Several of those studies included mixed groups of pre and post-operative patients (Apley et al., 1967; Garson et al., 1978; Glaser et al., 1964; Gudermuth, 1975; Maxwell & Gane, 1962). The age range of the children in these studies was broad. Some of the findings of the studies done in the early 1960's have little relevance today as there are many new surgical procedures available now, and the mortality rates for those procedures done in the early 60's have dropped. Also, families of the 80's tend to be smaller, more nuclear, and when there are two parents they often both work. These changes may have ramifications for the impact of "waiting" on the family.

Two authors contributed case studies of children undergoing heart surgery in the late 1960's (Barnes, 1969; Moore & Rose, 1967). In both instances there were four children and their ages ranged from 2 1/2 to 12 years. Their older ages at the time of surgery may partially reflect the stage of diagnostic and surgical knowledge and technology at that time. Barnes (1969) found that "the parents needed as much help from the nurse clinical specialist as the children did in overcoming their fears" (p. 12). Moore & Rose (1967) visited three of the four families at home a few days prior to admission, in an attempt to reduce the anxiety which they had observed to increase in many other families over the few weeks just prior to admission.

Parents sometimes have mixed feelings about the waiting period for heart surgery (Glaser et al., 1964) and their feelings have been shown to vary according to whether or not the child is symptomatic (Garson et al., 1978; Glaser et al., 1964). Some parents may view surgery as a solution to their current situation (Rogers, Forehand, Furey, Baskin, Finch & Jordan, 1984).

Two studies were found which exclusively addressed parents' concerns in this transition period (Dunning, 1984; Pinelli, 1981). Although "waiting for surgery" was not the focus of questioning, the topic did come up. Pinelli (1981) found that mothers' concerns about impending surgery increased in the one month post-discharge visit. Dunning

(1984) reported that parents' concerns varied according to the child's age and developmental level.

Summary

From the literature, it appears that the diagnosis of a congenital anomaly results in a variety of parental reactions including disbelief which may be heightened if the anomaly is not readily visible, and anger about the lost perfect child. When a diagnosis of CHD is confirmed in the first few months of life, the parents are also coping concurrently with the stressors of the transition to parenthood.

CHD, by virtue of its chronic nature, requires families to cope with ongoing concerns and make numerous adjustments in their lives. However, unlike most other chronic illnesses, the chronicity is usually time limited. Corrective heart surgery represents the end point of the illness for most children with CHD. Unfortunately though, the exact timing of this surgery is often uncertain which may be a concern for parents.

Little has been written about the experience of families having a young child awaiting corrective heart surgery. It is evident that in order for health care professionals to provide quality care to these families, an understanding of the meaning of the illness is crucial. This study was designed to add to that understanding.

CHAPTER 3

Methodology

Introduction

The term methodology, in its broad sense, refers to the principles, process and procedures which are used to address problems and seek answers (Bogdan & Taylor, 1975). The method which guided this study was a qualitative one.

The label qualitative methods...is at best an umbrella term covering an array of interpretive techniques which seek to describe, decode, translate, and otherwise come to terms with the meaning, not the frequency, of certain more or less naturally occurring phenomena in the social world. (VanMaanen, 1983, p. 9)

Phenomenology was the specific approach used to answer the study's question. In applying this approach, the investigator tries to see things from the participant's point of view and thus understand the meaning he or she attaches to the experience (Bogdan & Taylor, 1975; Giorgi, 1985; Omery, 1983; Rist, 1979) This chapter will describe how the phenomenological approach guided the study including: selection of participants, ethical considerations, data collection and data analysis.

Selection of Participants

Purposive or purposeful are the terms used to describe the sampling technique used in this study (Diers, 1979; Polit & Hungler, 1983). In this method, the participants are selected because they have certain characteristics or

knowledge which are deemed important in answering the research question. The parents selected for this study all had children with CHD who were waiting for corrective surgery, therefore making them knowledgeable about the experience of a family having such a child in the transition period between diagnosis and corrective surgery.

Criteria for Selection

The sample consisted of six families who all met the following selection criteria, with one exception which will be subsequently explained.

1. The heart disease was diagnosed within the first two months of life and it was anticipated that the child would require corrective heart surgery before the age of three years.
2. The child had not had corrective heart surgery but may have had a palliative procedure done. The often complex combinations of defects sometimes requires initial palliation to allow the infant time to gain weight prior to corrective surgery. Although it was recognized that palliative surgery might alter the meaning attached to the overall experience, it was important to determine what influence this surgery did have on the overall experience.
3. The child with CHD had no other life-threatening congenital defects and was not mentally handicapped.
4. The parents were able to converse fluently in English.
5. Both parents were willing to be interviewed.
6. The family lived in the Lower Mainland of Vancouver.

The third criteria was not met for one family in the study. A lack of information concerning the child's other problems led to the investigator's contacting the family under the assumption that they met the criteria. This particular infant had Down's syndrome and Hirschsprung's disease as well as an AV canal cardiac defect. However, because of their enthusiasm to discuss their experience and a difficulty in obtaining other participants, the investigator elected to include them in the study.

Selection Procedure

All ethical considerations were adhered to as will be subsequently discussed in the section entitled, "Ethical Considerations." Two pediatric cardiologists agreed to supply the investigator with names of families who met the criteria. A letter of explanation (see Appendix A) was sent to these families by the investigator. As stated in the letter, this was followed by a phone call from the investigator approximately 10 days later to ask if they were willing to participate in the study. At that time further explanation was given about the study. The first family to be interviewed actually phoned the investigator to indicate their interest in participating before the 10 days had passed.

Prior to starting the first interview, a written consent was obtained from both parents (see Appendix B) after asking if they had any further questions about the study. A copy of the consent form, which also explained

the study, was left with them. Demographic data was collected (see Appendix C) at the end of the first interview. The investigator made it clear that the parents had the option of not answering any questions with which they felt uncomfortable. One father did not state his type of employment, which may have been an oversight, but was not pursued by the investigator. Otherwise, all the questions were answered.

Two families declined to be interviewed. In both instances the investigator spoke only to the mothers on the phone. Although the mothers were willing to participate, the fathers were not. In the first case, the infant was booked for corrective surgery in two weeks time and the father was too upset to talk about the experience that close to the anticipated date for surgery. In the second instance, the message relayed by the mother was that the father did not think he would have anything to say on the subject.

Characteristics of Participant Families

Six married couples having a child with CHD participated in the study. All were Caucasian and five couples were Canadian born and English-speaking; one couple had emigrated from Norway and were bilingual (see Table I for more detailed demographic data about these families).

Table I
Demographic Data

	Parent's Age		Education	Employment Before Birth/Now	Family Income	Siblings No./Age
1.	M	27	grade 12	F.T./none	\$40-49,999	none
	F	29	grade 12	F.T.		
2.	M	32	college	F.T./E.L.	\$40-49,999	1/3 yrs.
	F	33	college	F.T.		
3.	M	29	grade 12	F.T./P.T.	\$40-49,999	1/3 yrs.
	F	29	college	F.T.		
4.	M	33	grade 12	F.T./P.T.	>\$50,000	none
	F	31	grade 12	F.T.		
5.	M	28	college	none	>\$50,000	1/5 yrs.
	F	32	college	F.T.		
6.	M	26	grade 12	none	\$10-19,999	1/5 yrs.
	F	29	grade 12	F.T.		

Note. M = mother F = father
F.T. = full-time P.T. = part-time E.L. = extended leave

The children with CHD all had their conditions diagnosed within the first week of life. They had complex cardiac lesions requiring various types of medical and surgical interventions. (see Appendix E for more detailed information).

Ethical Considerations

The approval of the University of British Columbia's Behavioural Sciences Screening Committee and the In-Hospital Research Review Committee were obtained prior

to data collection. The rights of the participants were safeguarded by:

1. The investigator explained the study prior to obtaining written consent.
2. The written consent clearly stated that the parents were under no obligation to participate, they could withdraw at any time, they could refuse to answer questions and they could request erasure of the tape or any portion of the tape (see Appendix B).
3. The parents were given a copy of the consent to keep.
4. The investigator maintained confidentiality by using a code to identify the transcripts of the recorded material only to her.
5. The tapes were erased once the study was complete.
6. The potential benefits of the study were outlined in the participant information letter (see Appendix A).

Data Collection

The processes of data collection and data analysis will be described separately in this text to enhance clarity for the reader. However, it is important to note that "there is no clear-cut line between data collection and analysis" (Glaser & Strauss, 1966, p. 57) in qualitative research. Instead, the two processes were intertwined for the period of data collection.

Intensive interviews were carried out in the homes of the participants. For the first-round interviews an interview guide of open-ended questions (see Appendix D)

provided some loose structure. The UBC Model for Nursing: The Family provided the framework for this guide while the content of the questions arose from both the available literature reviewed in chapter 2 of this thesis and the investigator's prior experience with families during the stated transition period.

The first-round interviews were initiated with the broad overall question, "what has your family's experience been having a child with CHD, awaiting corrective heart surgery?" Other questions were asked to either clarify what the parents had said or to further the investigator's understanding of a particular aspect of the experience being discussed. Reflective statements ensured that the accounts were validated as the story unfolded. The questions in the interview guide were asked if those particular aspects of the experience were not discussed as a natural part of the conversation. Generally, these aspects of the experience were discussed by the parents without initiation by the investigator.

A total of 11 interviews were conducted with the six couples. The interviews lasted from 25-75 minutes for a total of 7 hours, 37 minutes of taped interview. The intent was to interview all families multiple times but the investigator elected to do a single interview with one of the couples who had very little to say. Two interviews were conducted with each of the other five couples.

The interviews occurred at a variety of points during the transition period, depending upon when the names were obtained from the cardiologists. All first interviews were done at least six weeks after the initial diagnosis. The investigator had hoped to do all the first-round interviews before initiating the second-round in order to look for themes across all the accounts. However, this became impossible because of the anticipated dates of corrective surgery and the difficulty in obtaining participants. As a result, the interview schedule was as follows: 1A, 2A, 2B, 3A, 1B, 4A, 5A, 6A, 5B, 4B, and 6B (A = interview 1, B = interview 2).

All of the interviews were tape-recorded. Field & Morse (1985) suggest placing the tape recorder out of sight to enable the participants to forget about it and thus interact normally. Therefore when possible, the tape recorder was placed on the floor under a table so that only the microphone was visible on the table. However, none of the parents commented on the presence of the tape recorder as having any effect on the discussion. There were no requests to either stop tape recording or to erase a portion of the conversation. In fact, one mother recalled something about the experience once the tape had been turned off and her husband suggested that the investigator might want to turn the tape back on. This was done with the mother's permission.

The parents were told that the investigator wanted to hear about their experience, anything that was important to them, and would not ask a lot of specific questions. With the exception of the family who were interviewed only once, the parents seemed quite eager to talk about their experience. In fact, several of them spent some time between the interviews trying to think of other aspects of the experience that they wanted to share with the investigator. If the parents asked questions about a child's upcoming hospitalization, these were deferred to the end of the two interviews and appropriate information given then or they were referred to another source.

All the interviews but one were conducted in the evening to give the parents an opportunity to settle their children in bed for the night before the investigator's arrival. However, on occasion, the elder siblings made an appearance. All of the children with heart disease were present for part of at least one interview and the parents took turns entertaining them. The tape recorder was at times turned off to afford the parents the opportunity to leave the room to tend to their child(ren)'s needs. There was never any problem continuing the interviews once the child(ren) had been looked after.

At the end of the first interview, the rationale was given for doing another one. The investigator explained that the first interview would be transcribed and read to determine what further validation was required. Thus, the

second interview would incorporate a summary of the themes from the first to seek validation, a request for any other aspects of the experience that the parents forgot to bring up the first time, as well as an introduction of themes from other participants' accounts that had not come up. Given this explanation, the five couples asked, agreed to a second interview.

One family had friends visiting when the investigator arrived for the second interview. The parents had decided that one of them would continue visiting with the friends in the livingroom while the other parent talked to the investigator in the kitchen. As a result, the parents were interviewed separately, the mother first and then the father. The parents seemed a little distracted by their friends' presence but the interview was an informative one, that lasted 40 minutes.

Some parents seemed unsure about their contributions to the study, as indicated in these statements.

F: So that's the long and short of it--kind of hard to put that in a report.

F: It probably would have been a better idea to talk to us after his operation.

According to Spradley (1979), most participants question whether in fact they know enough to be of help to the investigator. The parents were reassured about their contributions to the study and the importance of their individual family's experience.

Data Analysis

As previously stated, data analysis started at the same time as data collection. The two processes ran concurrently until the data collection was complete. Then the final stage of analysis became "a period for bringing final order to previously developed ideas" (Lofland & Lofland, 1984, p. 131).

The investigator's professional background made it imperative for her to use a technique called bracketing. This involves setting aside what the individual thinks she or he knows about the experience (Oiler, 1982; Ray, 1985) and is necessary to achieve reduction, which is basic to the phenomenological method. Reduction "is a reflective turn back toward experience with a conscious effort to bracket what is known, and a creative process of intuiting and analyzing human experience" (Munhall & Oiler, 1986, p. 82).

Giorgi's steps for the phenomenological method provided a broad framework for data analysis (Giorgi, 1985). These steps are as follows:

1. The entire transcription of the interview is read by the investigator to get a sense of the whole.
2. The investigator once again reads through the interview to identify meaning units, focusing on the phenomenon being researched.
3. Redundancies in the units are eliminated.

4. The investigator reflects on the constituents and transforms the meaning into the concepts of the science.
5. This analysis is integrated and synthesized into a descriptive structure.

Each interview was transcribed verbatim. Because the investigator transcribed all but one interview herself, she soon became very familiar with the data. In the course of transcribing, the process of data analysis began, with notes being jotted down as meaning units became apparent. Meaning units "are the linguistic categories that make up the participant's view of reality and with which they define their own and others' actions" (Lofland & Lofland, 1984, p. 71). Once the entire interview was transcribed, it was again read and further meaning units noted. As suggested by Field & Morse (1985), the initial categories were broad to keep the data manageable and then sub-categories were later derived from these major categories when more data was in. These broad meaning units were validated when the second-round interviews were conducted.

Once data collection was complete, a more formal system of coding took place. Numerous categories were identified in the margins of the transcripts using a coloured letter to identify each. Then each of these minor categories was also sorted under five chronological type categories which seemed to describe the experience. These five major categories were listed, with a column for each

of the participant couples under each category. Then as the transcripts were read again, the coloured letter codes for the minor categories were listed in each column with a few words to exemplify the participant's thoughts. By including these descriptors the investigator was able to ensure representability.

At this point in the process, these major and minor categories were discussed with two faculty advisors. The labels of the major categories were changed somewhat and again the transcripts were read through. Higher level concept labels were used to encompass a number of lower level concepts. "Often the first tentative set of categories is just a list of all the possible labels for the data the investigator can imagine. Some of them will turn out to be too trivial or too general, or will not fit the data" (Diers, 1979, p. 117). The investigator was very conscious of ensuring that as much data as possible was accounted for and that the concept labels were indeed true to the data. It was important to keep in mind that meaning units are "context-laden" (Giorgi, 1985, p. 14) and therefore must not be considered in isolation. As Field & Morse (1985) suggest, evidence disconfirming tentative constructs was sought to enhance representability.

The meaning units were once again discussed with the faculty advisors, giving examples of participants' statements to illustrate how these units were derived. A little more shuffling of concept labels occurred before the

investigator had her final outline and was able to start writing. However, further changes were made in the course of writing chapter 4.

It seems, in fact, that you do not truly begin to think until you attempt to lay out your ideas and information into successive sentences.... For better or worse, when you actually start writing, you begin to get new ideas, to see new connections, to remember material you had forgotten.... The process of thinking while actually writing means that your outline is not likely to be identical to the completed text.
(Lofland & Lofland, 1984, pp. 142-143)

In essence, the process of data analysis continued as the investigator interwove her analysis with verbatim quotes from the participants' accounts.

Summary

The qualitative methodology used to study the experience of families having a child with CHD, awaiting corrective heart surgery was described in this chapter. A brief introduction to the phenomenological approach was followed by a section on selection of participants. This section described the criteria for selection, selection procedure and characteristics of the participant families. Ethical considerations were discussed next. Finally, the concurrent processes of data collection and data analysis were considered in some detail.

CHAPTER 4

Parents' Perceptions of Their Family's Experience

Introduction

The accounts given by parents of their family's experience when they have a child awaiting corrective heart surgery will be presented in this chapter. Each family's experience during the transition period was a unique one. However, there were common themes across all the accounts. This chapter will be organized around these themes.

A diagnosis of CHD marked the beginning of the transition period and this is where most parents began their accounts. It became obvious to the investigator that the experience was closely linked to a series of events. The four facets of the experience which incorporate these events are: diagnosis of CHD, adjusting to caring for child once home, living with a child with a chronic condition and waiting for corrective heart surgery. Feeling states were identified as accompanying these facets. Uncertainty was the predominant feeling state which persisted to one degree or another through the whole experience. This uncertainty, or lack of definite knowledge, was created by a number of events and circumstances through the course of the transition period. The characteristics of this uncertainty will be discussed as each facet of the experience is described. Feeling states then led to the testing out of various coping

strategies by these families. The following table depicts the identified themes.

Table II

Facets, Feeling States and Coping Strategies

Facets: Major Feeling States	Coping Strategies
<u>Diagnosis of Congenital Heart Disease:</u>	
Shock	
Uncertainty	
Fear	Trusting Health Care Professionals
<u>Adjusting to Caring for Child Once Home:</u>	Seeking Support
Uncertainty	Being Vigilant
Fear/Frustration	Normalizing
<u>Living with a Child with a Chronic Condition:</u>	Focusing on the Present
Uncertainty	Anticipating the Future
Frustration	Being Hopeful
<u>Waiting for Corrective Heart Surgery:</u>	
Uncertainty	
Fear	

"Trusting health care professionals," "seeking support," "being vigilant," "normalizing," "focusing on the present," "anticipating the future," and "being hopeful" were the major coping strategies employed by all parents. Only some strategies were used in every facet of the experience, for example "being hopeful," while others were used more selectively, for example "being vigilant."

Facets of the Experience

Each of the four facets of the experience will now be described with particular emphasis on the emotional reactions of parents including, how their feelings changed between facets. The predominant emotional state of uncertainty will be followed through the facets and discussed in relation to its characteristics at any given time. Demands for explanations about the child's condition were made of parents throughout the experience. Their reactions to these demands will also be described as each facet is explored.

Diagnosis of Congenital Heart Disease

The parents in this study were all informed of the diagnosis of CHD within the first few days of their children's lives and a problem had been suspected in most cases at birth or shortly after. Therefore, the expected event of the birth of a baby was accompanied by the unexpected event of the diagnosis of CHD for these families. Learning of and trying to assimilate the implications of the diagnosis was a facet described in detail by the parents. Not only was a diagnosis of CHD totally unexpected, but most of the families had no experience with anyone having this problem and thus had no concept of the possible implications of the diagnosis.

Initial reactions.

The most pervasive reaction to the diagnosis of CHD was one of shock.

* M: I think it was a bit of a shock. I mean, of course we didn't expect anything like that when he was born.

F: It wasn't somethin' we even expected 'cause there's no heart problems on either side of our families.

M: And my pregnancy, like I didn't even have morning sickness. It was just--it was almost too perfect a pregnancy, I guess.

F: It would be a shock for anybody, I guess. There was no reason to expect it. There was never a problem, you know, with anything so you wouldn't..

These parents assumed that there would have either been a family history of problems or some indication during the pregnancy that something was wrong. Sadness was also obvious at this time.

M: ...but I think, we had our cry...

Disbelief was another reaction.

M: You're not really listening to what's being said. You hear it but you don't want to believe it.

A feeling of helplessness was described by some parents.

F: I feel, I just feel sorry for him, you know, I felt, when they told me about him the first time I was holding him and I--there was nothing you can do. He's too little.

I: You feel helpless.

F: Yeah, you're helpless and this poor little baby hasn't got, hasn't had the chance, a good chance, a good start. I've never really been related with --nobody close to me has ever been--had any major problems so I--all of a sudden.

* Note. I = Investigator
M = Mother
F = Father

When names and initials are cited in the accounts, they are fictitious.

I: It's a new experience.

F: One of my little--my kids. I grew up with a family--I'm from a family of eight kids and there were never any defects or problems so I--all of a sudden it hit me--my children ...

Once the parents got over the initial shock they became angry and started questioning why such a thing had happened to them.

M: Well, I guess when he was first born--just wondering why it was us. You know, why did it happen in the first place? And I guess the hardest question is that nobody knows why, you know, why--nothing that you did or you know, caused it or that, but you're still wondering why, you know, did it happen.

I: You feel like you need an answer.

M: Ya! So as, you know, the next time, you know...

One of the major motivators behind searching for a cause was concern about the results of future pregnancies. Most couples found some solace in the fact that the heart defect was not hereditary and the chance of recurrence was slim.

M: Mind you it doesn't scare me to think that something, you know, something different (another type of heart defect) will happen the next time. You know, it doesn't--you know, to me it's--this is just ah, well a fluke of nature and for it to happen again--'cause it's not genetic, you know. It's not hereditary or that, you know, so ...

M: Then she explained that the most causes of defects is just some kind of virus and I know I did have a cold so that could have been it and I know it was in the first three months of the pregnancy so that you know, if there's any explanation that's probably what it is. And I think that made Mark and I feel better because we knew it wasn't something in our genes or just something abnormal, like every baby we might have will have this problem.

F: It would be different if it was something hereditary--you kind of expected, well is the baby going to have something wrong with him or not, but it's not.

M: And then they explained to us that it's very rare that a couple that has a baby with a heart defect will have another baby with a heart defect.

In searching for a cause, most parents initially either blamed themselves or something or someone else. This blaming was sometimes intensified by the reactions of relatives.

M: I think the first part was--it was why us, what did we do wrong? Um, they asked like 'cause I do smoke but I didn't smoke that much. I didn't drink or you know, so they asked us everything but of course you blame yourself. You think that you did something wrong. I thought at work maybe I did--lifted something I shouldn't have lifted and you know, all that. I think a lot of people can't accept, like family members and that, can't accept the fact that your baby has something wrong with it my mother um, she almost wanted to say like, "what did the doctor do wrong when he was born to cause him to do this?" And I said "it it wouldn't happen like that, like it grew like that." But I think, the pediatrician--we were talking one day and she just said that some people have to find someone to blame--you know, whoever that could be.

Coming to terms with the child's condition was sometimes made more difficult by grandparents who were struggling with the same thing. The need to accept the child's diagnosis was mentioned by several parents.

F: There isn't much sense in worrying to death all by yourself or fighting or blaming or anything.

M: Yeah, you accept. The sooner you accept.

F: Hope for the little guy and make it as pleasant as possible for him, you know.

Uncertainty.

From the time of the first suggestion of a problem a large measure of uncertainty surrounded the experience as described by these parents. First of all, there was uncertainty about the specific diagnosis, especially before the infant was transported to the tertiary care centre.

With this uncertainty came discomfort and fear.

M: He was born at four in the morning, so it was like the next morning that we found out that something was wrong. We didn't know what exactly They did whatever tests they could do out here and our doctor thought it was actually a worse heart defect than what he does have, so I'm sure that that was better. And then as soon as he went down there, then we found out what was wrong with him and talked to the different doctors down at [the tertiary hospital], so we had a better idea. But it, it was scary!

One couple were overwhelmed with grief because of the information given to them at the community hospital.

M: The nurses, the first night, they noticed that her colour was a bit off so they put her in the oxygen tent there for the night and then Dr. L., the childrens' doctor, he came and checked her out on the Friday and there was a murmur there and he wanted to send her down to Dr. B ... But also they did some x-rays of her down there at [community hospital] and that's when they said that--see her heart flips over the opposite way so when they saw the x-rays they just assumed that the heart was in the right place but the stomach and liver were on the opposite side--so that was another thing. We were checking out and then he came up and said, "well, I've got something else for you."

F: They'd looked at the x-rays backwards.

M: They'd looked at them backwards so he told us that this was wrong too and well, as soon as we heard that, I thought 'oh my god, what else!' So, this was what we found out when we left the hospital so we were just totally devastated by this time.

F: On the way to [tertiary hospital] we thought there

was all kinds of things wrong with her.

M: And then, when down there, they took more x-rays and they said, "they must have read them wrong at [community hospital]" so we were quite relieved about that at least.

The misinformation given to these parents at the community hospital was extremely anxiety provoking. For these two couples then, the news at the tertiary care centre was better than anticipated.

There often remained some degree of uncertainty regarding diagnosis, prognosis and treatment even once the baby had been seen at the tertiary hospital.

F: After the Friday night we came home and we still had--we were still quite confused as to what was going on. And it was a weekend too, and so, Dr. B., that was looking after her wasn't there all weekend. I guess nobody else was really wanting to say one way or the other what's happening. It was more or less his decision. But once we saw him on the Monday, he filled us in and drew pictures and gave us a book. He said he'd let us take her home.

Uncertainty could arise, therefore, when the parents were both ill-prepared to accept the information given to them and the information was not given in a form that was easily understandable.

Sometimes the doctors themselves could not predict the severity of the child's condition, especially if a heart catheterization was not done until later.

M: And of course at that stage they couldn't tell us how serious it would be so that was a little bit --we just had to wait and see type of thing, when he got a little bit older.

I: I see, so it was hard not knowing exactly how he was going to be.

M: Yeah, how he was going to be. Yet though, I knew in the worst cases how bad it could be and in the best cases how okay it could be.

General knowledge of the spectrum of possible implications of the diagnosis was usually felt to be better than no knowledge at all.

Many parents were afraid that their infants might die in this early period. One couple had their baby sent back to the tertiary hospital after being discharged to the community hospital, which served to heighten their uncertainty and fear regarding their baby's prognosis.

M: So, so okay two days he was back at [community hospital] and we'd just kinda got used to, you know, five minutes away for us, and they said that he was getting congested and they kept on talking about--I don't know what it's called, but it's the small opening when a baby's born when they go from the mother's circulatory system to their own, and they kept talking about "well, if that hole closes then we're in real trouble!" So when we got a call from the hospital saying, "we're sending him back down to [tertiary hospital]," we thought, 'oh my god!' It was just--we finally kinda felt, okay, he's not going to die, type of thing.... And when [tertiary hospital] got him back, I think it was Dr. J. that was on call, and he said--he phoned us like when he got him back--and said, "I don't know why they sent him back because..."

F: "He's just the same as when we sent him there in the first place."

These parents had little confidence in the health care professionals at the community hospital as a result of this incident.

An incident during a cardiac catheterization intensified one couple's anxiety about their child's prognosis.

F: Well, he had a really serious episode of bradycardia when he was just about six hours old. Luckily, he was in the ICU at the [tertiary hospital]. They were trying to do a balloon septostomy and it stimulated the vagus nerve. So, he was eight minutes with a heart rate of 60-80. They actually did do CPR on him--well, cardiac compressions. You know, so that, that's what, you know, we were really scared of, yep.... Especially when it comes to something like that, where you know, you hear all the horror stories of ah, you know, cerebral palsy and mental retardation and things like that, caused by severe anoxia, you know. It really does stick with you.

These parents were living with the extra uncertainty of not knowing if their child was going to be normal mentally. Because the father was an allied health care professional and had a better understanding than a lay person about the possible implications of an episode such as this, he was perhaps more worried.

Thus, it is apparent that uncertainty in this early period revolved around the specific diagnosis and prognosis of the infant. When the physicians themselves did not have all the answers then the parents were also unsure. At other times parents lacked definite knowledge because of an initial state of shock and disbelief which limited what they could take in, misreading environmental cues, or an unsuitable manner of information delivery.

Explaining to others.

For most of the parents, having to explain their baby's problem to relatives and friends was an extra burden. It was particularly difficult at the beginning when they were still in shock and feeling uncertain about their baby's diagnosis and prognosis themselves.

M: It was--it was hard, and we--you know, the day we found out--it was a very hard day for us. Um, you know, as well as Mark's parents in Toronto phoning --you know, having to phone people and keep saying the same thing over and over and over again So you're explaining to them--you're trying to make them feel better and you're thinking, 'well, they should be making me feel better.' But you do --like when Mark phoned his parents in Toronto...

F: Yeah, it was hard on them.

M: His dad said, uh you know, kind of like, "like, will he grow out of it?" and Mark was trying to explain to him "well no it's, it's quite serious." I think his dad found it hard to accept that his grandson had..

F: Yeah, he didn't want to accept it.

These parents and others, reported that when relatives lived at a distance, explaining became even more difficult.

M: The only reason why I had a little bit of difficulty telling them is I just didn't want to worry them--type of thing.

F: Yeah, from that distance so much goes on--they don't really see. You know all they think is he's got a heart problem, poor little... If they'd seen him, they'd see, well he's fine, but just to tell them.

A few families described health care professionals' actions which lessened the burden of having to explain their child's problem to relatives and friends. A cardiologist explained the problem to one set of grandparents when they were visiting the hospital. The explanations were made easier for another couple by having a copy of a booklet about congenital heart defects.

I: Where did you get that?

M: From the social worker at the hospital. She found a copy and brought it to me. She said it's got all those answers for those questions that relatives ask and you know how to answer them.

And I really did because we ended up photocopying and sending them home because my mother then went home and his mother then went home and tried to explain to other relatives and she said, you know, "send us out a book."

Just as diagrams enhanced the parents' comprehension of the diagnosis, they were also necessary to other peoples' understanding.

Those parents who had a child prior to the birth of the baby with CHD also had to contend with explaining the situation to a young child. The siblings were all between three to five years of age.

M: Ahh, but it's been hard on her especially when he was born, 'cause she knew all along that there was a baby, you know, coming right from the very beginning. When I found out she was more or less told and ah, the day that I went into the hospital she, you know, knew that I was going to have the baby and that, and ah--then coming, not me, not coming home and him not coming home at night or being away for such a long period of the day and then I came home with no baby. That really threw her off. I mean "like wait a minute, you know. Did you lie to me?"

These young children found it very hard to understand the situation and thus the parents often had to deal with their anger as well.

Preparing to take the infant home.

Prior to the infant's discharge from hospital most of the parents felt somewhat assured regarding their knowledge of the child's condition and how to care for the child once home. Reassuring information included the signs and symptoms that would indicate a deterioration in their child's condition.

F: Well, they said that her appetite might not be

that great and when it got onto the point where they might think she needs an operation--things like that--her appetite..

M: She wouldn't sleep--they said that she probably wouldn't sleep very much, she wouldn't eat and he said we'd really notice a change. It wouldn't be like a sudden thing and that we'd have to take her in right away. It would be gradual over a week or two. He said that we'd notice her sort of deteriorating a bit.

M: The nurses down at [tertiary hospital] were excellent and they told us a lot about what to look for in Brent, like when we were taking him home....remember when they explained about what to look for when he got congested.

F: They were really good.

M: About the fingernail beds and that. So we found that was really helpful because everyday we'd check his fingernails.

F: His lips--the colour of his lips.

M: Inside the mouth--they said inside the mouth really shows, you know, if he's going blue, that's where it is, um.

The parents appreciated this information. Perhaps it gave them some sense of control in a situation which often made them feel quite helpless.

When health care professionals made an effort to teach parents about caring for their newborn, their anxiety was reduced. Participating in the infant's care while in hospital was particularly important to the two sets of first-time parents. They were already unsure of their skills as new parents. This insecurity was then aggravated by having to learn to care for an infant with a serious congenital heart defect.

M: They were just really patient because I mean when he was at [tertiary hospital]--I never even, I mean, I didn't really have that much to do with babies before he was born and they wouldn't even let me really touch him when he was out here (at community hospital). So, I'd never even changed him and that, so, I was like--but they were really patient and you know, (nervous giggle) kind of showing me what to do and that 'cause I didn't --you know, most mothers at least get a few days just to practice that kind of thing and I didn't. That was nice. I like the atmosphere down there that they don't mind that you change their diapers and do whatever you can do with your baby instead of just leaving it up to the nurses. So I really find that makes it not so much like being in a hospital.... It kind of showed me in the hospital that even though they're delicate they're not as fragile as you first think they are. Like when you watch the nurses that have to handle the babies--I don't know how many babies everyday--that you realize that you don't have to treat them like they're a piece of glass or something.

Thus for some families, the hospitalization was long enough for them to gain a measure of comfort in caring for their child but for others this initial hospitalization was a matter of only a few days. As a result, they had very little time to deal with their shock and uncertainty. This then had implications for how they felt once they had the infant home.

Adjusting to Caring for Child Once Home

Again, uncertainty was a significant aspect of this facet of the experience and arose when the parents found themselves "on their own" with the infant. Not having health care professionals immediately available led to anxiety. Although those parents who had another child did feel some degree of competence in caring for a normal baby, they felt uncertainty and fear about caring for the ill

infant. For the two sets of first-time parents the degree of uncertainty was even more pronounced. The parents all had contact with both physicians and community health nurses during this facet. Reactions to their interactions with these health care professionals will also be described.

Uncertainty.

Most of the parents had been advised by the doctors to treat the baby like any normal child.

M: Then he said, "first of all treat your child like you done the first one and it's good that you have another one because then you know what it's all about." He said, " don't treat him differently. Let him cry if that's what you do with your children. Don't pick him up right away. Let him cry for a little while. Just check that, you know, he's not fainting on you. If it's just suddenly stopping and it's quiet in there, then you better check."

This advice was not always easy to follow because with it often came precautionary words about symptoms to watch for, possibly indicating a deterioration in the child's condition.

M: The things that the doctor told you like, "be prepared, if she's blue too long go to the hospital with her. Watch out for colds" and all this. And you sort of think, 'when do I take her to the doctor?' You're watching--is she blue or is it just..

M: Um, at first, like I said, at first I was scared. I mean I just--like every minute, you know, make sure he's still breathing and that, 'cause I, I didn't--I just had no idea what to expect. And ah, and then they talked about um (pause)--what's that when they get congestion--what do they call it?

I: Congestive heart failure?

M: Ya! That word--the word sounds so ominous--like ohh, you know, if he has that--and you know, you just think that it's gonna happen like, within an hour, he's gonna have it. And you know, that was more or less explained to us that it--it doesn't happen that fast, like it's over, you know, at least a few days that it builds up.

Parents were confused about how exactly to treat their children when the instructions given by physicians were often paradoxical. They were told on the one hand to treat their children "as normal" but at the same time to watch out for specific symptoms indicating that they were not normal. This confusion was further compounded by instructions given by nurses on what untoward symptoms to look for. Although most parents seemed to feel somewhat assured that they could detect such symptoms, which facilitated bringing the baby home, they were uncertain about their ability to judge the relative seriousness of these symptoms and thus act appropriately.

Sometimes parents also got conflicting messages from the type of care received by the child in the hospital. One infant spent three days in the ICU and was sent directly home from there. Therefore, it was difficult for the parents to treat the infant "as normal" when this was not how she was treated in the hospital.

M: We sort of were leary about taking her home because we didn't know what to do with her--because when she was in the hospital she was all monitored. She had leads on her chest and she had the nurses watching her all the time and I thought 'well, are we going to be able to just bring her home and let her be' and he said, "oh yeah, just treat her like a normal child."

This couple were forced to deal with caring for their infant when they were barely over the shock of learning about the diagnosis. Also, the fact that they had very little time to get used to the infant's behaviour before taking her home exacerbated their uncertainty. This is how the father described their feelings once they had the infant home.

F: Well at first, you think that she's going to-- you're so conscious of every noise in the bedroom when you're sleeping at night. If you haven't heard from her for an hour or two you're scared that she's maybe died on us or something. That was our biggest worry was whether she had to be continually watched and really pampered, or--but as we got her home and as each day went by and she was acting like a normal baby we realized that she didn't have to be pampered quite so much as we were expecting. The things that they said might happen weren't happening. Like she was gaining weight and everything was going along smoothly and every time we took her back for a checkup the doctors kept saying she was doing great.

Thus, some parents were able to gradually feel more comfortable with their children once they had observed their "normal" behaviour and been reassured by the physicians about their progress.

Fear for the infant's safety accompanied the predominant emotion of uncertainty during this facet of the experience. Parents dealt with this by "being vigilant." In the meantime, however, parents did not forget the health care professionals' advice to treat their children "as normal," therefore parents usually tried to normalize the situation as soon as they felt more comfortable with the infant. These two opposing strategies of "being vigilant"

and "normalizing" will be discussed in detail in the coping strategies section.

Interactions with health care professionals.

During this facet of "adjusting to caring for child once home," parents were often in contact with several physicians and a community health nurse. The physicians seemed to be the primary providers of health care and parents looked to them for information and support.

Visits by the community health nurse were not usually described by parents unless the subject was brought up by the investigator, although all the families had had visits shortly after the infant was brought home. These visits were not particularly helpful to most mothers. Generally, fathers were not at home at the time of the visits so they had nothing to add on the subject.

M: She was good (no enthusiasm in voice). It's just that she seemed more concerned about other things like making sure he got immunized and making sure he got this and that and I thought, you know--I know it's important but right now I don't want to really concern myself with that.

I: Things other than the heart problem, you mean?

M: Uh huh.

The child's heart condition was foremost in this mother's mind but her concerns were not properly addressed by the nurse. Another mother commented about the nurse's apparent lack of knowledge regarding her child's heart problem.

I: What did she do?

M: Nothing really. She weighed her and she just asked if I had any questions about feeding and that was about it. She really wasn't a lot of

help but I guess she was just there in case I did have any questions. See we were going to the doctor regularly so she really didn't need to come over. We were seeing some kind of a doctor once every couple of weeks. She was getting weighed regularly at the doctors.

I: So you were getting your questions answered there were you?

M: Yeah. And plus the nurse that came--she didn't know a lot about, you know, what was happening with her.

I: In terms of her heart problem?

M: Yeah, she's just your basic health nurse so she didn't get into anything.

The overlap of services which is alluded to by this mother was mentioned by several others.

"Trusting health care professionals" was an important coping strategy for the parents, as will be discussed in more depth later. When the nurses had their own agendas and did not address the mothers' concerns, it was difficult to establish a trusting relationship. Also, perhaps some parents felt more comfortable with a physician they already knew who was meeting their needs for information and support.

Living with a Child with a Chronic Condition

The period of time from initial diagnosis to corrective surgery ranged from four months to approximately three years for the children in this study. As a result of this somewhat lengthy duration, the term chronic can be used to describe their conditions. Once the families got over the initial period when most of their energy was focused on caring for the infant, they had to work out some

pattern of family living which could incorporate the needs of the ill child while at the same time meeting the needs of the other family members. Parents talked about the "ups and downs" of their experience. This section will show how the parents felt during this part of the transition period and what constituted highs and lows for them.

Major alterations in lifestyle.

All families had to make some alterations in their lives as a result of the child's condition. When the infants showed obvious symptoms, the alterations were of a greater magnitude. Half of the parents had fallen into the habit of picking their infants up almost immediately if they started to cry. The infants got used to this parental response and the parents found it hard to break, if they wanted to, after the initial period of adjustment. This was tiring and frustrating for them as illustrated by this account.

M: Like I said, he's still--he's spoiled. Like other babies, you just lay 'em down and they go to sleep, but he likes to be rocked to sleep and you have to walk around until he falls asleep most of the time.

I: How do you feel about that?

M: Sometimes I get mad. I think, 'why can't you just go to sleep like any other baby?' You know, I understand that he was--he got that extra attention for so long that we just can't cut it off. We just do it. We take turns.

F: Ya, we have to take turns!

One mother, in particular, had a difficult time juggling the demands of her children, husband and home.

M: You know, you put him down and he'll sleep for twenty minutes whereas she'd sleep for your regular two hours--two hours in the morning and two hours in the afternoon--whereas he wouldn't do that. That's when I really started getting disorganized and I felt things were really falling apart around me--you know, housewise--stuff like that--time with her and that. I'd set aside an afternoon to do arts and crafts with her, you know --really couldn't because he was so unpredictable. But ah, like the strain comes out when you start snapping, "well, why didn't you--I asked you to do this today?" "Well, I didn't have time." Then you don't realize that the other partner didn't have time because they're walking around the house all day, trying to calm him down and that, you know, like I'm tired tonight...

The infant's unpredictable behaviour led this mother to feel disorganized and unable to meet her daughter's needs and keep up with household demands. She seemed to have the most difficult time of all the parents because her infant was more irritable than the others.

The two mothers who had planned to go back to work full-time after their maternity leaves changed their plans.

M: I couldn't see myself going back to work wondering, if you know, what was going on and find somebody who wouldn't sorta get scared or be phoning me--you know, at work--saying, you know, "he's crying or he's turning, you know, blue" and that.

M: I was planning on going back to work, and it's just--he seems to take so much time--like he needs that extra attention and, and he's doing well with his motor skills and that. But like the pediatrician says, it's probably just because we spend the time with him and not just lay him down somewhere and expect him to occupy himself, type of thing. So in that way, I think, well, maybe it's just better to stay at home with him and then again I think that if I get a job then when he has another operation he might be in for a longer time and I want to be there. So you know, in that way it's changed.

It seemed that these mothers had worked to maintain a certain income and the jobs themselves were not described as particularly fulfilling. By staying home with their infants these mothers could reassure themselves that the infants were getting the needed attention. This was the preferred alternative to constantly worrying about the child while at work.

A few of the families did not have to alter their lives very much to accommodate the ill children because these children had few obvious symptoms of the disease. However, for all of the parents reminders of their child's condition came in the form of feeding problems, frequent visits to the doctor, questions from relatives and friends, and hospitalizations for cardiac catheterization.

Feeding difficulties.

All but one family commented on how time-consuming infant feeding was. In several instances, this subject was not brought up by the parents but was introduced by the interviewer because other parents' accounts had pointed to its importance as part of the experience.

M: I think that if he was, you know, completely normal he ah, would probably take in his full quota at night and would sleep through the night by now. Whereas, he only-probably takes about maybe three-quarters of what he would--what he can take. So, he wakes up at 12 o'clock, takes a little bit more then nods off because he's tired and then he'll wake up again maybe at 3 o'clock for a little bit more...

Some mothers were almost defensive and seemed to need to minimize their infant's problems with feeding.

F: One of us will sit there for half an hour or more and give him the bottle as he wants it. Eventually he'll drink the bottle. Sometimes it doesn't happen--sometimes he does it in five minutes and sometimes it takes him an hour to drink it...

I: So, it is time-consuming.

F: Sometimes, sometimes he'll down it--other times..

M: Well, look at nursing babies. You know, nursing babies--you have your baby on your breast all day long.

One mother indicated during the first interview that there were no problems with feeding.

M: Yeah, she eats really well. As you can tell, she's not starving.

In actual fact this baby looked quite small for her age.

This mother contradicted herself in a subsequent interview, done after the palliative surgery.

M: We noticed before she would ah--she wouldn't drink a whole bottle. She'd get kind of tired and she'd push it away but now she can eat quite a bit. She still doesn't drink much more than four ounces but ah, she's eating now--solids now...

For another mother, feeding and weight gain were major concerns and these issues were brought up numerous times through the course of the two interviews.

M: Well, he was kind of a hard baby because he wasn't eating all that well, and they, you know, they--I said, "well, should I breast-feed him or bottle feed him?" And they said, "well the breast milk is the best, but it's harder for him--like he's gotta work harder to get it." So it was, always one way or another and with breast-feeding, I didn't know how much he was getting, and he wasn't feeding well. So, I found--I was just--really getting, really--because he was so small and I wanted him to eat...

From this data, it seems that satisfactory infant feeding and weight gain are important to a mother's feelings of adequacy about her ability to parent. This is perhaps why several of these mothers felt a need to minimize their infant's difficulties.

Dwelling on "it".

Several parents found themselves dwelling on "it," meaning their child's condition. One mother made several references to feeling depressed when thinking about her child's future.

M: You still always think about it. Like sometimes I just sit there and get all depressed because you think that--knowing what's going to have to happen. This operation, he says is fairly routine. It's the next one that's the biggy but we just have to take each one as they come. You have to--you have no choice.

Thinking about "it" sometimes interfered with work.

F: It comes out mostly in my work. I find that I make a lot of mistakes... I just find that I seem to think a lot more, you know. I have a lot more trouble concentrating on doing really specific tasks and ah.

I: Do you find your mind wandering too?

F: Mind wandering! Yes, that's what I mean! Ya, it just goes off and I start thinking about him or, you know, start thinking about the surgery...

The parents were often reminded of their child's cardiac-related characteristics and behaviour patterns by family, friends, health professionals and even strangers.

I: So that's something you notice now or is that something you've always noticed?

M: Well, I think people made me aware of it because that's the only time I've heard people react, you know, telling me "have you heard how he's

breathing when he's eating?"

I: These are friends?

M: Yeah, these are friends. You know, when we're together for lunch or something. Until they made me aware of it, I didn't really know but then of course you think about it...

These reminders sometimes made parents angry, especially when they were trying hard not to think about their child's condition.

M: But you find yourself explaining a lot, like even, when I go out--"he seems so small"--you're put on the defensive right away. You know, even strangers, you don't want to tell them, "oh, my baby has a heart defect" but you want to somehow say something, so I was a little bit mad. I used to get angry at everyone that said anything.

Dwelling on "it" was something that parents tried to avoid because they did not want thoughts about "it" to depress them or interfere with their daily activities.

Explaining to others.

Demands for explanations about the child's diagnosis, prognosis and treatment plan were something that all parents dealt with. This was not limited to the diagnosis facet but occurred throughout the course of their experience. While friends and family were at times reassuring and helped the parents to maintain an optimistic attitude, there were other instances when the parents had to do the reassuring.

M: ... but in some ways it's hard too because everything has to be explained and my mum tends to worry a bit more about Brent. With us going to the doctors and it's explained directly to us and we kind of understand it better. She says, like "oh my, he's got to go in for another heart cath." When you explain to her what it is, it just sounds

so horrible and "oh, is it going to hurt him?" I find like I have to reassure her where I'm just trying to reassure myself.

F: Well, there's stuff that gets lost in the translation, eh. You get panic phone calls. Like one minute we tell one grandmother he's got a little bit of a cold or something..

M: Ya right! And the next day, the other grandmother's phoning and..

F: What's wrong?

Those families who had other children also had to explain to them what was wrong with their sibling and why they were sometimes treated differently.

M: She's had a problem with, that he goes to the doctor so often and she never does because she's never sick... And she gets terribly upset because he gets to go to the doctor all the time and she thinks this is lots of fun. "Why isn't this her turn--why isn't she going?"

M: We just keep telling her that he's, you know, that he's not feeling all that well and that he has a 'boo-boo' heart. "Well, where did he get his 'boo-boo' heart?" "He was born with it." But, it's, it's hard to explain to a child that young...

It was very important to the parents that people understand the relative seriousness of their child's heart condition. They did not want people to overemphasize the impact of the heart problem on their daily lives.

M: Just explaining to relatives exactly what the problem is, you know, and letting everybody know that he's not as fragile as they think he is. You know, he's just your regular baby, you know, really... It's as though they think he'll be, well he shouldn't be developing as fast as he normally would if he didn't have the heart problem.

At the same time they did not want people to minimize the seriousness of the upcoming cardiac surgery.

M: A couple of the guys Mark works with, they see pictures of Brent that Mark puts on his desk and that--and now it's the thing, "oh well, it's not that serious then, is it?" It really is serious and some of them are his bosses so they really should know that if you ask for time off when he goes in for surgery or something that it is serious.

I: So, you want them to understand. You don't want them to overemphasize..

M: It either seems to be one way or the other. It's either that they take it really hard that Brent's really sick and poor Mark and Susan or else it's the opposite, like maybe it's just a slight heart murmur which it isn't either, so.

Uncertainty.

Uncertainty during this facet was probably not as overwhelming an emotion as it was during the other three. However, it was present and became more obvious at specific times. One type of uncertainty, already mentioned, resulted from the infants' often unpredictable behaviour. This behaviour was even more evident right after palliative surgery. As a result of this behaviour, it was sometimes very difficult for parents to plan family activities. Uncertainty also revolved around not knowing how the child would develop in comparison to other children and whether predictions about developmental delays would come true. This will be discussed in the "anticipating the future" coping strategy section. At the time of diagnosis, the number and timing of required surgeries was usually not known for sure. Knowledge gained through subsequent heart

catheterizations could potentially decrease the amount of uncertainty about these events.

Cardiac catheterization.

Five of the children had had at least one cardiac catheterization prior to data collection. When a heart catheterization was done, the parents were often given more definitive information about the severity of their child's heart condition. Sometimes a catheterization was not done in the neonatal period so parents had to wait for this information. Cardiac catheterizations were often done to monitor a child's progress and determine the appropriate timing for future surgery, both palliative and corrective.

F: That was what our concern was this time when Dr. B. was talking about doing the heart cath. was whether the surgery is going to be right away or whether it's just to see how things are progressing. We found out it's just to see how things are progressing.

I: How do you feel about that?

F: Good, good. I'm glad to see they're monitoring it. It's not just, "oh well, we'll wait and see when they bring him in" type of thing.

Parents had confidence in the health care professionals when they demonstrated concern about the child's progress in this manner.

No matter what the reason was for the heart catheterization, most parents looked forward to this procedure because it could help eliminate some of the uncertainty they were living with.

M: The catheter, that's a big one, that's a first step. Once that's over with, you know, then a good part of it is over with--you know, because

we're hearing the news of what's going to be happening, his future.

Palliative surgery.

Three of the six children underwent palliative surgery, one in the neonatal period and the other two later. For the two couples who had been told that their children would require palliative surgery later, there was a period before the surgery when they could see their children's conditions deteriorating to some degree. This was very stressful for them.

M: They explained to us about the banding and you know, because of what was wrong--why, you know, because of the pressure on his lungs and that... we could even see, like he'd be sleeping and he just--his little chest would just be--you know, we couldn't even--we'd try to count it ourselves and we couldn't 'cause he'd take that kind of like a deep shuddery breath... And I was scared. Like what bothered me is I thought that, that like, his lungs would be damaged or something.

These two families had quite different experiences in the waiting period just prior to the surgery.

M: We took him in and he had the catheterization, ... and then they said, "we've got an opening on Tuesday in surgery"... so they did it right away. So that was really good, I thought, because it didn't give us a chance to really think about the surgery coming up--it was just going to happen the next day.

I: Did you anticipate at all when he went in for the heart catheterization?

M: Yes, we had talked about it. We felt just from what we had seen of his condition that, that he was going to have it done. So, it was really not much of a surprise. You know, the doctors have been very good explaining to us, um what his--you know, what his heart rate is, and, and his respiration--so we knew it was climbing up. So it was getting to the point that he was breathing really fast and even we could see it and not being

trained--but we could see it a lot.

M: Well, they told us that she had to be just totally healthy before she went in. She had a rash under her arm--her right arm and that's the side they were going to operate on. So we took her to the pediatrician and he thought the rash was actually worse than it was--like, I don't think it was really that bad but he didn't want to take any chances so he phoned and said it was postponed and he gave her some antibiotics and it cleared pretty well right away. So we were kind of disappointed, in a way, because we wanted to get it over with. It was another week of worrying about it but um, it wasn't too bad in the long run.

These accounts illustrate how important it was to the parents that they not have to wait once surgery was anticipated. For the first family, surgery was anticipated because of the understanding these parents had about the implications of their child's symptoms. The second family had been given a date for surgery, which then had to be postponed. This then, led to feelings of disappointment and prolonged worry.

All of the children who underwent palliative surgery were required to spend some time in the ICU. The parents described their vivid recollections of that time.

F: It um, the first day she had all these tubes and things sticking out..

M: It was terrible.

F: So it was, you know, kind of depressing the first day. But she progressed so fast that I think at the end of the first day she had some of the things off her.

M: Yeah well, you worked that night. We went to see her in the afternoon after surgery and she had a tube in her nose and in her side and she was under oxygen... I picked her up that night, yeah. She

had the thing out of her nose but she still had the tube in her side. It was pretty sad. I went home--I drove home that night by myself and I just--I just broke down on the way home. It was terrible and the next day I went in and all the tubes were out. Was that when they moved her out--they moved her out of Intensive Care the next day.

F: The very next day.

M: They wheeled her upstairs and she was smiling and I felt a lot better that day and then it got better. But the first day--I wouldn't want to go through that again.

I: Yeah. Were the tubes what you expected or was it just the fact that they were on her?

M: Yeah, she was kind of bloody. She still had the blood all over her side and you know, the tube in her nose, that wasn't too bad. They really didn't wash her up too much but I gave her a bath. That night I washed her down. But it just wasn't very pleasant to see this little baby. And you know when she cried you could tell she was in a bit of pain...

For this family, the tubes, the bloody incision and the child's pain were the main concerns. Pain management was an issue for most of the parents.

M: Most of the days I was okay but I remember one day we went in there and they said that he wasn't taking very well to the sedatives or whatever they were giving him. And um, they said that he was trying to fight it and he still had the respirator in and it was the first time since the operation that he'd opened his eyes but his eyes were completely glazed over and he couldn't make any sounds because of the respirator. And he just kind of looked up and I just started crying and I had to leave. It was just like, it was such a helpless look, like what are they doing to me--please help me.

Two couples expressed their surprise at the size of the thoracotomy incision.

M: ... we were surprised on how big it was, but we thought it was gonna be.. Well, when the doctors

or anyone was talking about it, they say, "oh, we're just gonna go in here" and they just kinda show it here. And when we went in the day he was operated on, and you know, it was this big cut on such a little body and we both kinda just looked and "oh my God!"

M: It doesn't look great. I mean it goes from underneath her arm to partway around her back. It's a little bigger than what we thought it was going to be. Yeah, he said it was only going to be a couple of inches.

F: Yeah, we expected this (showed length with hands) from talking to him. It turned out to be about three times that size.

Viewing their children in the ICU then was one of the lowest points of the whole experience for these parents. They felt sad and helpless seeing their children in such a state.

Following surgery, the parents watched the children to determine what changes may have resulted from the surgery.

F: Her colour's a lot better now.

M: We didn't notice it for the first couple of days. We were expecting it.

F: It took awhile. We expected, you know, the very first day to walk in and see a change but it was slow, over a couple of weeks...

M: She doesn't have the bluey tone to her when she cries a lot. So I think it's improved quite a bit but it wasn't something that we would just notice overnight.

The child's behaviour when first home post-operatively could be upsetting to parents.

M: But when we got him home, like the incision-- like, I mean he was crying so hard, and I thought, like, 'oh my God, he's going to rip the incision open.' 'Cause he would just cry, like, for three hours solid. And it wasn't so much the crying

that bothered me--I just thought he was gonna hurt himself, and I'd get all upset and you know, it was kind of a hard time.

Palliative surgery was significant for a number of reasons. The child's condition improved post-operatively although not as immediately or as dramatically as parents had hoped. There seemed to be a period of adjusting to caring for the child once again, as there was in the neonatal period. It was also apparent that experiencing this hospitalization had an impact on how parents viewed the subsequent hospitalization of the child for corrective surgery.

In summary, the experience of living with a child with a chronic condition, although unique for each family, also had common elements. Lifestyle changes were required by all families and those who had more symptomatic infants had a more difficult time. There were frustrations associated with feeding the infant and having to answer questions from relatives, friends and strangers. Although every hospitalization evoked a certain amount of anxiety, heart catheterizations were generally viewed in a positive way because they represented the possibility of diminished uncertainty.

Because of the length of the transition period, most families had to utilize strategies which helped them maintain a somewhat optimistic outlook about their child's future. To constantly dwell on their child's heart condition would have severely compromised their ability to

satisfy their family's needs. Coping strategies such as, "normalizing," "focusing on the present," "being hopeful," "trusting health care professionals" and "seeking support" helped them to maintain an optimistic outlook. These strategies will be discussed in detail in the last major section of this chapter.

Waiting for Corrective Heart Surgery

The families knew from the time of their child's birth that corrective heart surgery would be required. Thus it was an expected event, the event which would end the transition period under study here. The corrective surgery was something that all of the families thought about intermittently throughout the transition period. However, the amount of energy expended in thinking about this event and preparing for it depended partly on the child's condition and primarily on how soon the surgery was anticipated.

Uncertainty.

The families were given some idea about the timing of the corrective surgery when the children were born. These were merely educated guesses, subject to change and dependent on the condition of the infant and further information obtained on heart catheterization.

M: You know, they said two years when he was first born, then they said a year, so it could be anytime. Like, we just don't know.

M: Well, he's hoping she won't have to have it done until school-age but he said it could be when she's two or three. It's all going to depend on

how she goes. I don't even know--what does it determine--like, what does it depend on?

F: Well, I guess she's going to outgrow the shunt that's put in.

This uncertainty about the timing of the surgery made it difficult for families to do much planning for the future. Most of the families were ambivalent about the timing of the corrective heart surgery.

M: I still think in some ways you'd like to say, "just do it and get it over with" but in some ways you'd just rather, just wait and put it off and put it off. But, you know, they said, "as long as he's doing well then they'll just leave him" which I can understand.

F: I'm hoping for the surgery as quickly as possible. Like I said, it's gonna be hard to finally take him in for it.

M: I know it's going to get harder to see him in the hospital again because we've had him home now. And now he's getting stronger and stronger and it's going to be more difficult when he does go through the heart surgery. I'd just like to see the thing over with.

These families all wanted to get the surgery "over with" so they could stop worrying about it, but at the same time they were afraid to take their children in. Several families talked about hoping the surgery would be done before the child was old enough to really understand or remember the event.

F: I always just hope that they'll do it before he gets to the stage where you have to explain it to him, what he's going to go through. I mean you can just put him in and they do it and you don't have to tell him anything....

I: Can you tell me a bit more about that.

F: The older he gets, the more he understands, the more you have to prepare him for it. "We're going to this place and they're going to do so and so with you and when you wake up." That, I don't really want to do that. It's more, I guess easy on me, I guess--the whole linguistic thing probably--but I don't really want to do that... The thing is with small kids like that, if you have to explain things it's so easy to say things wrong.

I: So you're afraid you might make it worse for him.

F: Yes, yup. It's difficult for us to think the way their mind is. I guess that's what I'm trying to say.

M: You have to simplify it but it's dangerous when you do because you might get it all wrong, really --it's too simple.

F: It's, it's a little ways off but we're kind of glad that the surgery will be done or from what we understand anyway, done before he gets into school-age and starts into that...

M: I think when they're older too, they probably remember and I'd rather him not. I mean he's going to have the scar and we can explain that to him when he's older but I'd rather have him not remember the surgery.

Not only was the timing of the surgery uncertain, but for two of the families there was uncertainty about where the surgery would be done.

F: I think the only thing we're sittin' around here now waiting for is his next operation. And there is of course the talk that he may go to Toronto for the next operation or he may have it out here.... One thing we've got that's lucky for us is that my parents live in Toronto. So, as far as staying somewhere and uh, you know, that sort of thing--that end of things is good for us. Um, if that's where he has to go and that's where the people are going to do the best job for him, fine. That doesn't bother me at all.

M: He still said that she may have to go to Toronto for hers.

I: How do you feel about that?

M: He said he would look at it and if he felt that it was in her best interest to go to Toronto then that's where she'd go. But if he felt comfortable with the people here doing the operation then she'd have it done here....

F: It wouldn't make any difference--just a slight inconvenience.

This particular facet of uncertainty, about where the surgery would be done, did not seem to be a major concern for these families. Uncertainty about the timing was more of a concern.

Impact of previous experience.

In thinking about the corrective heart surgery, parents who had experienced the ICU environment when their child had palliative surgery reflected on what that was like for them. This was one tactic for preparing themselves for what lay ahead.

F: You know we saw a young guy come out of open heart surgery while he was in there so we kind of know what to expect.

M: All the tubes again.

F: You know if you didn't--those guys would probably be wise to tell somebody what's actually going to happen--show them pictures because it could be a major shock.

M: ... We've seen him with tubes coming out of every part of his body. We sort of know what to expect. For somebody who doesn't know and you walk in there when they're allowed after the surgery to see all that. It's bad enough seeing the incision, never mind all the tubes and seeing the child just lying there, like--well, just lying

there. Because the little fellow next to him-- they gave him curare and I didn't realize, but I guess they have to give them something to keep them from moving. That's another thing, too-- that, you know, seeing that and overhearing them talking--you know that he's going to be more or less--I guess they paralyze them so that they don't toss and turn so much.... That ICU's a real scary place with all those beepers going off and everybody and you don't know if it's yours, you know, that's beeping--if it's the I.V. that's occluded or somebody else's or if it's what!... That place, it really is scary and of course you can't help but notice what's going on around you and there are so many other cases and, you know, I mean it's a life and death situation down there.

From this account, it appears that the incision, the tubes, the immobility of the child and the strain of other families were the major sources of stress in the ICU. The ICU experience will be discussed further under the coping strategy of "anticipating the future."

The outlook of those families whose children had not had palliative surgery was different. They seemed to be more optimistic. This optimism perhaps arose out of ignorance and a resulting ability to minimize the situation.

F: I'm not really worried about it. Um, any surgery is serious but from what they've told me and from what I've heard it's--it's not something that's really, really new. They know what they have to do. Um, I don't anticipate a problem. I'm not going to let it bother me, put it that way.

At the conclusion of this interview these parents asked the investigator how long their infant would be in the hospital post-operatively. They had been told about five days, by their family practitioner. Their surprise was obvious when they were told it would probably be at least ten days to

two weeks. They were not aware that she would be in the ICU, have multiple tubes and probably ventilator assistance initially. Another couple were initially extremely optimistic about the cardiac surgery.

M: Awaiting the surgery isn't very intense.

F: Waiting for it--whether it just hasn't hit us yet or reality. I mean it's not an uncommon thing. They do do it successfully.

M: We're not worried about losing him on the table.

F: There's a 10% risk. They told us there is a risk but the odds are in our favor, so--if they said it was 50/50, or..

I: It would be different.

M: Yeah.

F: The risks are that high with any operation.

At the time of the second interview, two months later, they were obviously more concerned about the surgery. A heart catheterization was to be done four days after that interview. At that time a decision would be made about the timing of the surgery. This fact, coupled with an enhanced understanding of the possible implications of surgery had heightened their anxiety.

M: It's scary right now, I tell you.

I: Do you feel different than maybe the last time I talked to you, do you think?

M: Probably, I know a little more now and like you know, I can find myself doing the dishes and the next, I break into tears. You know, it's scary. ... It's a touchy situation for anybody, you know, it's hard not to get really emotional.

Contemplating risks.

Most of the families talked about the risks involved in heart surgery. Although they found it difficult to discuss, they did voice their fears about the ultimate risk --death.

M: There's always that thought--like I know when he was young, our family doctor said that there was a chance that--I mean there's always a chance with any surgery and especially with heart surgery--so, the thought of that too. Of course that's going to bother you--what happens if he didn't make it and especially after--it's bad enough if something happened right when they're born but after you've lived with them for a year or two years and then something was to happen. It's really hard but it's something you've got to try not to think about. There's no point in worrying yourself.

F: Yeah.

I: It's certainly something that creeps into your thoughts, I'm sure.

F: You know, it's not the fault of the doctor to mention it. It's certainly a reality and it's something that you have to know.

When the child had few overt symptoms of the disease, parents sometimes found it hard to come to terms with the necessity of surgery.

M: You always think about 'what if the surgery doesn't work out and in the worst case if he doesn't survive it'. You know, if you will blame yourself after, that you went through with the surgery at all. But then of course we've both got to the conclusion that of course we'll go through with the surgery because when he gets up to the age where it's really going to bother him and he dies at thirty, you're really going to blame yourself because you didn't let him take the surgery.

I: Right. Do you think because he hasn't had a lot of problems that that makes it even more difficult?

M: Yes, I think so. Because it's not that obvious that he needs the surgery.

Besides the normal risks with any heart surgery, one family had an extra concern.

F: So, apparently he'll be the youngest that they're gonna do it on yet, you know.

I: At [tertiary hospital]?

F: Ya.

I: How do you feel about that?

F: Um well, they're getting better and better results the younger and younger they do them so I feel pretty good about that but I sorta wished he was --he hadn't been the youngest...

Anticipating surgery.

The corrective surgery became more of a reality for families as the date drew nearer and they therefore spent more time thinking about it.

M: Oh, I worry about it. As it gets closer, I worry a little more.

Some parents also had physical symptoms of the uncertainty and fear they were experiencing.

F: Well, I think now that we've gotten an O.R. date..

I: You do have one--when is that?

F: 27th--I've sort of not been sleeping that well, you know, and things like that.

I: You're thinking more about it now, are you?

F: Oh yeah! Rather than being optimistic about what's going to happen I'm just sort of holding back saying, "well, I'm not going to be too optimistic because what if something does, goes wrong and ah, he's not corrected 100% and he's gotta go back or you know, something else has gotta be done." I find that creeping into my thoughts.

- I: Because you have a definite date, you think it's made a difference.
- F: Yeah, now it's sort of ah, no longer--it's not in the future, the indefinite future. It's coming up.
- I: It's more of a reality.
- F: You know, it's going to be in 20 days or 21 days. It's ah, I find I've been having a lot of trouble sleeping...
- I: How are you feeling now that you know--now that you have a date? Is it any different for you? (to mother)
- M: A little bit scarier now that I know that he will be going in. I haven't been sleeping all that good. I've been having a lot of dreams--not so much about him but just about other people in my family and that--in unpleasant situations and stuff like that.

The coping strategy of "being hopeful" usually helped parents maintain an optimistic outlook. However, in this situation being too hopeful would not have allowed the parents to prepare themselves in case something went wrong.

Explaining to others.

Once again, explaining to siblings and other relatives was something which the parents had to deal with. One three year old greeted the investigator at the door with the question, "are you here to fix my baby?" When asked, "fix her how?" she replied, "cut her open and fix her heart." This question was repeated several more times through the course of the interview. One could assume that this child also questioned her parents about the upcoming event on more than one occasion. This is what one parent had to say about a young sibling.

M: In a way, I think it's going to be worse to deal with his sister--how are we going to tell her--because she certainly understands so much now.

I: How old is she now?

M: Almost five.... It's when you have to go into details and then they really start to ask a lot, that's when I think it's going to be hard. And that's what I think she's probably going to do.

Some of the grandparents questioned the necessity of surgery.

F: My mother is asking, "is it really necessary for him to have the surgery because he looks so good?"

I: What do you say?

F: I try to explain, once again, what's really wrong with him, you know, and why he needs it. You know, that he won't continue to look this good once he starts to really grow...

When relatives questioned the necessity of surgery, parents were forced to put on a confident front when they were feeling less than certain themselves about the necessity for and/or outcome of surgery.

In attempting to decrease the amount of uncertainty surrounding the surgical experience, the parents used the coping strategy of "anticipating the future" which included the tactics of reflecting on previous experience and seeking information. At the same time, they tried to maintain a somewhat positive outlook by "trusting health care professionals," "seeking support," and "being hopeful." All of these strategies will be explored in the next section of this chapter.

Coping Strategies

Implicit in the parents' accounts were a set of goals related to the identified transition period. These were: ensuring that the ill child was properly cared for, keeping family life as normal as possible, reducing uncertainty, maintaining an optimistic outlook, and preparing for the future.

The plans the parents employed to deal with their difficulties and strive for these goals have been termed coping strategies. While the strategy is the overall plan, the word tactic implies a more precise, specific device for accomplishing that plan. Seven coping strategies were identified which all of the parents used during their experience. The specific tactics utilized will be discussed as each strategy is described. This delineation will also include information about when the strategies were employed, when they worked and when they did not.

Trusting Health Care Professionals

To trust someone generally means having confidence in that person. Trusting those responsible for their childrens' health was a very important coping strategy for these parents. It enabled them to feel reassured that their ill child was being properly cared for by the health care professionals. They were then able to maintain a somewhat optimistic outlook.

Most of the parents had little previous personal experience with health care professionals. None of them

related any stories of negative encounters which would have affected their ability to trust. The parents had an intense need to trust the health care professionals and most of them had no reason not to, at least when the infant was first born.

Half of the parents related at least one negative incident which had occurred at the community hospitals where the infants were born. However, they seemed to be able to put these experiences behind them when their infants were transferred to the tertiary care hospital. In fact, they expressed relief at having their children at the tertiary care centre because they had confidence in the health care professionals working there. This evaluation may have been based on a contrast with the sometimes negative experiences at the community hospitals and/or a need to trust in those ultimately responsible for their child's welfare.

M: ... like everyone was so confident, like at [tertiary hospital], it was just--as soon as he was down there it was like he was going to be all right because they knew what they were doin'. And whether it was nurses, doctors, whoever or you know, even the doctors like the interns or whatever--they were just really confident about what they were doing, 'cause I guess they had seen it a lot more and it was like "we understand your baby's sick but there's a lot--he could be worse --he's doing really well." So I think that, that really helped.

Confidence on the part of the health care professionals was an important quality which enabled the parents to feel they were worthy of trust.

Being well-informed was important to all of the parents. Most of them felt that their child's physicians did a good job of explaining what was happening, whether it was the cardiologist, pediatrician or family practitioner.

F: But I think what's made it most comfortable for us is the explanations that we've been given from the doctors along the way. It's really helped. I think it's made us feel a lot more comfortable rather than worrying about it constantly....

M: The pediatrician that we deal with talks to Dr. B. quite often and she phoned me at home after an appointment with her ... and Dr. B.'s phoned us at home so it's really been nice. It's not like with some doctors--it's kind of cold and you just find out basic things and you go home. Where you know --everyone really worries about what we go home and think about.

The parents were able to trust those who made an effort to keep them informed.

Trusting the health care professionals was particularly important when the child was hospitalized and the parents had to relinquish most of their control.

M: ... I've just grown up that you put trust in your doctors and your nurses and that's just the way I feel, so I'm not going to question different things. You know, if one of the nurses maybe asked me, "well, what does he like to do, this or that," fine, okay, I'm with him all the time. But you know, I'm not going to tell her how she should take his temperature and that, so that made it a lot easier because I just really relaxed and really felt that they knew what they were doing and that was it...

By trusting the health care professionals this mother was able to relax when her child was in their care.

When the families were contemplating surgery they needed to trust the physicians.

F: Uh, I've got a lot of confidence in the doctors

that he has and uh, I don't know, we're not really worried about it. I'm not worried that we're going to lose him because I don't think for a minute that we are.

Other parents remarked that they had no choice but to trust the surgeons at the tertiary care hospital.

M: We just hope that they all know what they're doing --they're the experts. We don't know a lot about it... We sort of leave it in their hands and we kind of--maybe we just have so much trust, because we don't know enough to question what they're saying, what they're doing. Everyone always says, "get a second opinion" but with this type of thing there aren't a lot of experts around so you can't. But um, our pediatrician was talking about the surgeons. Actually, another friend of ours, a doctor, he's checked into it too. They're all finding out about it.

Seeking information about the health care professionals was one tactic used by parents to help them decide if a professional was worthy of trust.

For one couple, trust was mixed with a little doubt.

M: Even now, like sometimes I hope that they do the next surgery when he's a year just to get it over with. Well, they say that they would never leave it that long but you always hear--there was a show from the States on T.V. that says that this doctor does it when they're four months so their other organs don't get damaged. So right away you think, 'well, why are they leaving Brent until he's a year?' But you know, we trust their judgment and I'm sure that they would never--I mean, Dr. B. said he's the right weight that they could do it now so I'm sure that they would if anything needed to be done.

Having information that contradicted the treatment plan mapped out by the child's physicians resulted in some doubt. It is obvious though that this mother has an intense need to trust and she seems to feel powerless to question their judgement.

Several families described one health care professional with whom they had a particularly close relationship. This was the person whom they seemed to trust and turn to the most. The common qualities that these individuals seemed to possess included: demonstrating genuine concern by spending a lot of time with the families, being honest in answering questions, and preparing the families for upcoming events by sharing relevant information. It is interesting to note that the three families who described a "special" health care professional were also the ones who had the most symptomatic infants. Perhaps they had a greater need than the others for a particularly close, trusting relationship with one health care professional to help them through the experience.

One such trusted individual was a community health nurse.

M: She's becoming more like a friend now. She's just --without her, gosh I don't know. Like you know, Roy goes for his heart catheter on the fourth of May and she's going to be here on the fifth to explain every little detail. Like I'll be there when the catheter's over and Dr. B. will be explaining this and I'll have these words, probably this long, asking him "well, how do you spell this one and that one?" She'll be here the next day to tell me what they mean and things like that. But she's become a really, really good friend and she--right now she's ah--Tom and I are very confident about this operation--about anything that's going to be happening with Roy. I mean it's scary right now but she's more or less getting us prepared for the worst and for the best.

This community health nurse provided emotional and informational support to the family. She was obviously a trusted professional whom this mother would rather ask some questions of than the cardiologist.

Another couple described their interactions with the clinical nurse specialist as being very positive.

F: Um, there was a bit of a delay when he first went in because the nurse specialist, nurse practitioner or nurse specialist..

I: Clinical nurse specialist, maybe?

F: Yeah, she was off sick so she never came to talk to us the first time.

M: And I ended up going to the social worker.

F: Yeah. She (clinical nurse specialist) was really good--maybe there should have been a back-up--another one that comes from another ward or whatever they've got. Because she was--you know, that would have been nice to talk to her the first time we were in there because she did have a lot of little tidbits and information and uh, was a good person to talk to--spent a lot of time.

M: When we went in for the heart cath. we finally met her.

One infant was hospitalized in the community hospital with congestive heart failure. This family described their previous experience with this hospital in a very negative way. However, this time, actions on the part of certain health care professionals left a more positive impression.

M: Um, but when he went in the second time, it was different because the pediatrician put him in there. She came with me to the hospital, checked him in.... she showed me, you know, where you could see the fluids in the lungs and that.... Um, she was there everyday. Um, they would phone her about anything. You know, "oh, should we change this or change that?" So, and he was not in the nursery. He was in the pediatric ward and

the care I found was a lot different. And they were, more confident it seemed, with what they were doing.

Having a physician, whom she obviously trusted, monitoring her child's progress was a major contributing factor to her change in attitude.

To summarize then, the ability to trust the health care professionals arose from an intense need to do so, as well as the presence of certain qualities in that professional. The most important characteristics were a confident manner and genuine concern demonstrated by spending quality time with the families.

Seeking Support

As was mentioned in discussing the previous coping strategy of "trusting health care professionals," there was sometimes one particular person who seemed to be most trusted and sought out for support. Although some families had a close supportive relationship with one particular health care professional, this did not appear to be a generalized phenomenon. Therefore, this section will encompass only the social support network that families relied on for assistance during this experience.

The support of relatives was important to most of the families. Being able to talk to sympathetic grandparents was identified as helpful.

M: Like we, we you know--I talk to my parents more about it now. I think they can really sort of sympathize with us.

Extended family sometimes provided needed reassurance about the parents' caretaking abilities.

M: It's really helped having my mum here because when I've been worried that he wasn't eating enough, you just kind of had someone to talk to and fall back on--like friends are fine but sometimes you want someone like your own mother or mother-in-law--I mean that's someone that you figure they've raised us, so they must know what's going on.

For a few families, having no relatives nearby was identified as making the situation more difficult.

M: Ya, no family here at all.

I: Do you find that hard?

M: It's very hard! Not--like when he's working days or even, you know, when he's out of town or that, there's nobody for me to go even to visit. I'm in the house with the two of them, you know, so it's hard--or even to leave him with somebody, like with my mother or his mother or that--but at least it'd be some freedom away for awhile...

F: ... we figured we were really independent and strong and could get along, you know, really well on our own. This has sort of proved that things come up and we really need other people around, especially your family... Like when you've got, you know, people related--closely related to you right there--you can really lean on them, saying anything you want, behave the way you want.

Most families agreed that the support that relatives gave was of a more meaningful quality than that offered by friends. At the same time however, relatives often demanded more in the way of explanations and reassurance than did friends so their support had a negative edge to it.

Sometimes support was sought from friends or relatives who were also health care professionals.

F: One of my cousins here is a doctor so if we have a problem we can ask him. It's a comfort too.

Not only was emotional support important but specific practical actions also helped.

F: Our friends were really good. They were excellent. People from around here right now. They were lots of help. The neighbours were bringing food over.

M: Holy heavens! That was incredible!

F: They were always here, wanting to drive Mary here or there if I had to work or whatever.

The social support network was particularly important at the time of palliative surgery. Having relatives spend time with the child in the hospital gave the parents a needed break.

I: And how have your families been when she had this surgery?

M: Great--they were there almost everyday, down at the hospital--sort of relieving us every now and then. They were really good.

Sometimes the best support was found in the spouse. For one mother, her husband's support was integral to coping with the ICU environment.

M: Well ah, we were always there together but just--this is a very scary place for me and I find in situations like that I tend not to ask questions, you know, and people--they're telling me something, I understand it but I don't understand it, you know. So that way, with him there, I let him do all the talking and all the asking and then when I get home I ask him, you know...

One family had thought about contacting a parent support group at the time of their baby's palliative surgery but never did. They did however, find it helpful to talk to other parents they met in the hospital.

M: ... I enjoyed talking to them and I think they felt the same way.

I: Able to share some of the same feelings.

M: Yup, 'cause nobody can really understand it unless it happens to you.

These parents valued the unique kind of support that parents who have experienced a similar situation can offer. Another family intended to contact a parent support group at the time of the corrective surgery.

In summary then, a supportive network of relatives, friends and other parents was important to all of the families. This network offered assistance in the form of, emotional, practical, and informational support thus helping families to attain the goals for this transition period. The support was particularly important at certain more stressful times, for example when the child was hospitalized for palliative surgery.

Being Vigilant

A period of vigilance or alert watchfulness was described by all the parents. This occurred once they had the infant home from the hospital and was necessary to dispel their fears that the child's condition might deteriorate. The length of time that this strategy was used, varied depending on a number of circumstances.

For half of the couples, use of this strategy was short lived, from two weeks to two months, because of the good condition of the infant.

F: That was something, in the beginning at least, we ran very quickly if he was crying. I don't know

why. And also we checked him very often when we went to bed.

I: So that was a bit different than..

F: Yup, I at least, woke up and checked his breathing. I never did that with Mary.

I: How long did you find that sort of went on?

F: A couple of months.

M: Yeah, when you saw that nothing was wrong.

I: Do you think that having another child first, made a difference?

M: Definitely. I think it would be terrible having the first one. Oh!

I: In what way?

M: Oh, I would be so--first of all getting a child then taking care of it--just that part you are really uneasy about that. Then knowing that he has a heart problem on top--that would be just--oh, I think that would be hard.

I: Did you find yourself comparing him to her?

M: Oh yeah, just to make sure.

All of the couples who had other children talked about comparing the new baby to the older child to determine any deviation from the "norm." Thus they were able to decide whether there was any need for continued vigilance.

I: Do you think having had another baby before, that it was maybe easier too?

F: Oh, yes.

M: It would have been twice as hard if it was the first.

F: We wouldn't have known reactions or what to do. With the first one obviously, I mean there was experience there. You know, that one was normal so it was easy to compare. Well, the first one could do this and so on. Oh yeah, I think it made it a lot easier to have one beforehand. It might

have been--at this stage we probably would have been the same where we are right now, but those first few months probably would have been a lot worse.

The remaining three couples were not able to relax as much after the initial period of vigilance. Their infants showed more obvious symptoms of the underlying heart problem and they therefore maintained a certain degree of watchfulness. They described the symptoms and their responses to the infants this way.

M: ...even though we could probably let him cry for awhile he tends to go blue.... So in that way sometimes I think 'oh, other mothers can just let the baby, if they're just being, to the point where they just know that they want to get up--there's nothing wrong with them and just letting them cry and go back to sleep' and I just didn't feel right doing that with him and I think--feeling all sorry for myself.

Although a positive coping strategy in decreasing anxiety, vigilance was also associated with frustration.

F: Some nights, maybe you'd even let a baby who's really being a pest, you know, just let him cry for awhile.... with him, you just drop whatever you're doing and go after him and pick him up and try and calm him down, 'cause..

M: 'Cause I mean he just really gets, you know, well upset.

F: He really gets himself worked up and that's not that great for him and really not circulating all that well, so..

I: Does his colour change at all?

M: Oh ya! Ya, and he gets very clammy.

I: Does he?

M: Ya! His breathing patterns just, you know, thrown right off what it was. Ya, you try to let him, you know, cry a bit, but like I say, you don't let him cry too long.

Several parents would not leave their infants with a babysitter because they were afraid of what might happen in their absence, therefore, they maintained a personal watch over their children. As a result, they could not get out as a couple and felt "tied down."

M: And I really don't want to leave him with a sitter yet, for the simple fact that he does go into crying fits, and ah, I can calm him down. He (husband) can calm him down sometimes, but for a sitter they may get panicky and ah, you know, "why's he crying, why's he crying?" and all this here...

M: I mean my mother usually babysits for us now, but I could tell without her coming out and saying it that she was just scared to babysit for the first three months, because she just didn't, didn't know what to do with him--or you know, if something would happen to him. So for the first three months we basically didn't go anywhere...

F: Until he gets over this heart thing, there's no real--I feel safe for us to be here anyway. Just to be sure. If something does happen, I'd feel awfully guilty if I was out somewhere. Both of us, especially if it was the both of us.

This third family had in fact left their baby with a sitter when the investigator interviewed them two months later.

M: ... But it was good for us to get out together. We need that--we definitely need that. If you want to stay sane, you know. So it was good and it was fine.

Here, they were utilizing the opposite strategy of normalizing which will be described in the next part of this section.

To summarize then, parents were most vigilant when the infant was first home from the hospital. Being vigilant

enabled them to ensure that their infant received proper care and it also decreased their uncertainty about the child's condition. Those families whose children were quite symptomatic maintained a certain degree of watchfulness throughout the transition period. Use of this strategy over the long term resulted in the parents feeling "tied down" and frustrated.

Normalizing

Normalizing is an overall coping strategy that describes the tactics parents used to make their child's life and family life "as normal as possible." Of course, each family's definition of normal varied. Because the transition period included not only the unexpected event of the diagnosis of CHD but also the incorporation of a new child into the family, the parents did not expect their lives to be exactly as they were before the birth. Some of the parents based their expectations on previous experience with incorporating a newborn into the family. For the two couples who were first-time parents, expectations were based on knowledge of their relatives' and friends' experiences at such a time.

Attempting to normalize the situation became an important coping strategy for most parents during the facet of "adjusting to caring for child once home." It followed the strategy of vigilance and was contradictory to vigilance. Normalizing was important for several reasons. First of all, it was part of the advice given by most

physicians and the parents themselves were afraid that their child would become spoiled as a result of being treated "as different." Some parents also admitted, although rather sheepishly, to their initial frustration with having to respond to the child's cries immediately. They wished to change this pattern if it was safe for the infant. Normalizing was attempted by allowing the child to cry for ever-increasing periods of time while the parents watched for any adverse effects.

M: They told you not to let her cry too long so you were getting to the point where you'd just hear her and you'd go and pick her up. And then we decided that--to treat her just like a normal child and it made me feel more at ease because I mean it didn't hurt her, crying a little longer than what she normally would. She got used to it. Otherwise, she'd get spoiled which you can't have.

I: So, when did you sort of change your way of doing things?

M: About a month.

F: I'd say about a month, you know. That was--you know, you can't go on doing it that way If she started crying a bit, let her cry a bit longer and, you know, we could see it wasn't affecting her.

For some couples, the first trip with the infant reinforced their ability to achieve a high level of normalcy.

I: Can you give me a sense of when you felt you were able to relax a bit more with her in the beginning? Do you remember?

M: Well, in September we went away. We took her camping. That was the first week of September so she was only about three weeks old or four weeks old. We felt pretty comfortable there.

F: After, yeah after a couple of trips to the pediatrician, Dr. M., and he kept on saying that everything's perfect and just fine and you can

take her anywhere, so about then we went away with her for five or six days, camping.

M: We were way out in the boonies, too. Well, we were outside Kamploops.

F: She was good in the car and everything else, so it was pretty good. After that we were pretty well, pretty well used to..

M: That was about--within a month after.... So, we're trying to make things as normal as possible.

Having family life "as normal as possible" was a goal that all the parents cherished. However, they had to come to terms with various aspects of living with a child with CHD which could not be the way they had originally planned. Therefore, some families had to alter their expectations and redefine normal in order to decrease the frustration accompanying unsuccessful attempts to make family life more normal.

A good example of this tactic of altering expectations was in changing the mode of feeding. Two of the mothers who had initially intended to breast-feed had to supplement with formula.

M: But when it came to breast-feeding versus bottle feeding, um, it was kind of a catch-22 situation because one was easier to digest but one was easier to nurse out of so we just did whatever was best for him and that.

M: And that was another thing too--when I did bring him home, not breast-feeding him for three weeks, I just never got up to 'full load' I guess you'd say. He completely depleted my reserve of breast-milk in the freezer the first weekend we were home. And so, it was like, boiling water until I got out to the store to get him some formula. So I just decided at that point that he was just going to have formula and breast-milk.

One mother had to totally give up the idea of breast-feeding her infant because he was in the hospital for three months.

M: He had my breast milk for a month and a half. I got tired of pumping and gave it up and that was it.

I: Was that a disappointment for you?

M: I don't know. In a way, yeah. In a way, no. It was a little disappointing at first but--I never knew what bottle-feeding was like. But it isn't that bad.

All of these mothers talked about changing the mode of feeding in a very matter-of-fact sort of way. They just did what had to be done and did not seem to dwell on it. Perhaps because bottle-feeding is still within the realm of normal, it was fairly easy to adjust to this alternate mode. Also, of greater concern was whether or not the infant was consuming enough.

Most parents continued to employ this strategy of normalizing to one degree or another throughout the transition period. One tactic was to spend extra time with the child and encourage physical development. However, when normalizing the child's life meant spending extra time, this was not consistent with normalizing family life.

I: Mrs. W., you said that the doctor suggested that you treat him like any other child and that you really kept that in mind.

M: Ya, ya. That was really the best advice we ever got I think--that, you know, just treat him like a regular child with no problems... I think I have more in my mind, especially with physical activities, that I do try actually to push him to see where his limits are and so far I haven't really--could have pushed him far enough because

he's really active and he seems to enjoy it.

Sometimes there was an emotional penalty to pay for making the child's life "as normal as possible," such as when one mother decided not to tell the child's babysitters about his heart condition.

M: Well, sometimes I feel guilty that I don't in case something should happen yet I know in my mind that, you know, there is 99.9% chance of nothing happening with him while they look after him. And I don't think he should get special treatment and I'm afraid if I do tell people--at least that's what I've seen, the first reaction you get is "oh, oh that's terrible, what can we do?" and they get really nervous about it and uneasy about it and they don't really know and then you start to look for signs that aren't really there so I think that the best thing is for them not knowing....

I: So, it's important to you that people treat him normally and if they know about it they might not.

M: Especially since the doctor said too, it made me more aware. I thought, you're right really because when he's operated on he's fine and then he'll drag on with all this special treatments that he got earlier and I think it will be upsetting for the child too, suddenly finding out that I'm like everybody else and I don't get this special treatment anymore.

Since the parents could anticipate a time when their children would be able to lead normal lives, it was particularly important that they be treated "as normal as possible" from the start.

All of the parents pointed out numerous times, through the course of the interviews, those qualities in their children that were normal. By focusing on these normal aspects they were able to minimize the underlying heart condition. Of utmost importance was the child's disposition.

F: He's certainly a lot of fun though. You know, you come home from a bad day at work and he's sittin' there smiling at you and all happy and--so that way it's good.

F: But he's a pretty happy little guy.

M: He sure is.

F: He's pretty easy to take care of. Just give him his bottle or give him his suckey. He likes to be held--he loves to be held--just a typical normal little baby.

If the child was happy then the parents could feel some degree of optimism. Another important characteristic was the child's mental development.

M: A lot of our friends just had babies, you know, a month before or a month after, across the street and you know, you can really see the difference.

F: With his size mainly--his alertness, he's really, you know, he doesn't miss much.

F: That's one thing, I'm not worried about his mental development at all. 'Cause as far as I can see, he's right up for what he should be doing.

Although the children were generally smaller than normal, several parents talked about the fact that this did not necessarily slow their activity.

M: Then he is the type of child that seems to get in trouble all the time too. He cut the tip off his finger. He broke his arm....

F: In a way that's a good thing. It shows, at least, that he's active and normal.

F: We kid ourselves jokingly about how he's going to be the terror of the neighbourhood 'cause he never sits still. As soon as he's awake he's goin'. You know, Donna takes care of the baby across the

road on Wednesdays--and Brent, he's bigger than Brent--same age, they were born the same day--but Brent is very aggressive towards him.

Other "normal" children provided a yardstick against which to measure the child with the heart condition.

M: She's only been sick--she's had one cold since she's been born which is, you know, good. My sister-in-law--all their kids--they've had colds you know, three or four colds in their first five months.

The importance of making life "as normal as possible" became obvious in the parents' reactions to certain comments. Those parents who perceived their lives as quite normal got angry when people insinuated otherwise.

M: They seem to feel sorry for you. They don't even know what he's like really but they just, "Oh, I don't know how you do it".... and we said, "there's nothing to do really--really right now, he's just like a normal baby."

Comparing their lives to those of friends with healthy children sometimes helped reinforce that they were not that different.

M: We really haven't changed our lives that much. All of our friends had babies--had them last year as well--and we do a lot of things with them. So, like the kids are always there.

I: You feel what you're doing is about the same as what your friends are doing.

M: Yeah.

F: Yeah, staying home more often.

Because these infants took extra time, the families had to adjust their lifestyles and curtail some of their normal activities. The paradoxical part of normalization is illustrated here. Family life could often not be normal

if the child's life was to be "as normal as possible." It became very important for the fathers to help with child care when they were home. This allowed mothers to engage in some of their normal activities.

M: Mark's really active in sports and he's had to slow down a bit. I just find with Brent because he takes a lot of time--he's just not happy to sit there by himself because he's just used to the --a lot of attention. So when Mark gets home it's "you look after him for an hour and I'm going away to do something else" so you know, in that way..

F: I put a lot of things on hold--a lot of things we wanted to do.

I: Like what?

F: Oh well, I wanted to go to school, you know, at night. I've sorta had trouble doing anything, like other than work and ah, justifying that to myself, you know. 'Cause I wanna spend time at home and ah, I like to go out and work out, things like that. And I haven't been doing that for quite awhile since he was born because I just find I, you know, just can't say, "well, I'll go out two or three nights a week" and be away, you know, even for an hour or two at night... You've still got your meetings once a month, eh!

M: Ya!

F: Your big night out!

M: Ya, big night out! I'm on the council for the strata. So my one night out a month I leave him if he's crying or not. I just walk out the door.

Although sharing child care responsibilities enabled the mothers to pursue some of their normal activities, this sometimes posed a problem because the babies had gotten used to the primary caregivers.

M: It seems as though he doesn't take to Jeff too well. (laughs)

F: No, he don't like me that much.

M: You know, he'll be as happy as anything and let him stay downstairs with Jeff, and two minutes later he's just crying blue murder. And of course I'm downstairs getting him--I pick him up and you know, sometimes he'll slow down right away and other times he'll take awhile.

M: I went to an aerobics class last night and half an hour later--Tom said, he never stopped crying until I got home. He was crying his head off and then I picked him up and gave him a few kisses and he stopped.

In an attempt to normalize the home routine one particularly harassed mother made herself a schedule.

M: Made myself a schedule on what to do, you know, this day I do the washing and ironing, vacuum on Tuesday. I had to put on schedule for myself 'cause I wasn't getting anything done. It's worked out pretty good.

Although none of the other mothers talked about a schedule, several did mention the importance of the father's help with child care to allow them to tend to household chores.

In employing the two-pronged coping strategy of normalizing, parents were attempting to attain the two goals of keeping family life "as normal as possible" while promoting as normal a life as possible for the child with CHD. It became a balancing act trying to achieve both goals. Some of the tactics used were: decreasing the amount of time spent checking on the baby, gradually attempting normal activities, altering expectations, spending extra time encouraging the child's development, focusing on the child's normal aspects and working together as a couple. The other goal parents were trying to attain

through use of this strategy was to maintain an optimistic outlook.

Focusing on the Present

One strategy that parents employed to help them feel less overwhelmed and out of control was to focus on the present. This was particularly important because there was so much uncertainty surrounding the whole experience. The parents talked about taking each day, one at a time, which enabled them to maintain a certain degree of optimism and keep family life "as normal as possible."

M: I don't know, a lot of people say, "you're so strong, you're so strong." But it's not a matter of being strong--it's just, you do what you have to do and you can't sit back and cry because your baby was born with something wrong. You just take it day-by-day and you do what you have to do.

M: I don't know, you just live day-by-day. Just get this darn heart operation over with and that's the worst but you have to definitely take it day-by-day.

When the subject of the corrective surgery came up, most parents indicated that until they got closer to the anticipated date for this event they tried not to think about it.

M: I, I just try not to think about the whole thing, you know. You know, until reality'll really set in--you know, when it gets closer to the middle of November. I just try not to think about it.

M: I do think about it. I push it away. I'd rather

concentrate on what's happening now. I don't want to worry too much about it until it comes up. We've talked about it, of course.

I: What about for you, Mr. Jones?

F: You don't really want to think about it--it worries you, of course, yeah...

M: ... we just have so much faith in him and the surgery coming up doesn't even bother me. You know, maybe it will be a different story once the time hits but right now, you know.

I: Right now you don't really think about it.

M: No, no, I don't even think about it. It's a few months away.

This strategy of focusing on the present sometimes enabled parents to maintain a certain degree of optimism and keep family life "as normal as possible." There were times however, when it did not work and this will be explained under the next coping strategy of "anticipating the future."

Anticipating the Future

The parents sometimes found it necessary to use the opposite coping strategy of anticipating the future. Generally, this strategy was employed at some very specific points in the experience. These included: when the diagnosis was first made, when hospitalization of the child was anticipated and when the child was actually in hospital. By anticipating their child's future, the parents could prepare themselves for what lay ahead. Through anticipating and preparing, they could feel some sense of control over their lives and be reassured about

their ability to meet their family's needs in the face of their child's illness. Two specific tactics for anticipating the future were a primary one of seeking information and secondarily, reflecting on past experiences.

Throughout the experience most of the parents wanted to be kept informed about their child's condition and any plans for treatment. This was one tactic for accurately anticipating the future. Not only was it important that the health care professionals impart this knowledge to the parents as soon as it was available but that it be given in an easily understood form.

Several parents talked about the difficulty in trying to understand the medical terms often used to explain the diagnosis. Their understanding was enhanced by concrete drawings and pictures.

I: Did you find it hard to explain to other people what was wrong with her?

F: For a couple of days, but after a few days of going down to [tertiary hospital] and talking to --we were able to explain it pretty well after that.

M: Yeah, he gave us a little booklet.

F: Drew pictures of her heart.

M: Yeah, 'cause they were explaining it to us and it was really complicated. All we wanted was for them to draw it actually in black and white and show us what it was all about. All these technical terms really meant nothing to us.

Parents sometimes sought out specific health care professionals to answer their questions. For example, one

mother went to the social worker, in the clinical nurse specialist's absence.

M: When they said, you know, he had transposition and they sorta said, you know, the greater vessels are switched and that--it's very, very hard to understand until I actually saw a picture. You know, the American Heart Association, their little booklet there for parents with--congenital heart defects. And I saw that and said, "now I understand what's really the problem!"

I: Names don't mean a lot to the lay person.

M: No! And to say they're switched. Well, what's switched? You know, why can't they just sorta, you know, put them where they're supposed to be.

The health care professionals at the tertiary care hospital were described as being approachable. Hence, the parents seemed to have no qualms about asking questions.

F: They were very good in that respect, all of them, especially the doctor. You'd ask him anything and he'd, you know, tell you--the specialist.

M: All the doctors we've dealt with are really good and they'll explain really anything that we want.

F: It puts us more at ease to know exactly what's going on and what's going to be done.

Although the health care professionals were generally approachable, some families felt that certain information should be more readily available to aid them in accurately anticipating the future. One such family were in another country when their child was born and the mother had some suggestions to make, based on her experience at the hospital in her native country.

M: And that was one thing I reacted to when we came here. I don't know, maybe they took it for granted that we knew about what was going on, but

that's one thing I feel here, when we came to [tertiary hospital] there was no information whatsoever on--if there existed, groups like parents groups like that--and you know, what's out there. And no pamphlets, no nothing. I mean in [native country], when I came to the hospital they were just lined up there and even the doctors handed that out... I felt like I got more information from both the nurses and the doctor, of--especially where can I go for help, for ideas, for books even to read about it... I don't know really, what I would have done if I didn't have have all the stuff to read. I think I would be much more uncertain--what is this really--what is going on here?

Thus, seeking information was a primary tactic used by parents to anticipate the future and reduce uncertainty. Sometimes parents picked up information just by listening to explanations being given to other parents.

M: I'd overheard one of the other--one of the nurses at [tertiary hospital] talking with another parent that had a baby with the same kinda condition, saying that these babies don't gain weight that fast. So I knew, and I'd mentioned it to the doctor and she said, "oh well, I didn't want to put too much on your shoulders. I didn't think you knew." But I'd rather know. To me it was--I mean once you find out--I felt once you find out that they have a heart problem then the things that go along with it, you might as well know--'cause it's not going to change the fact.

Before the baby was discharged from the hospital most parents had developed a set of expectations about the potential impact of their baby's illness on family life. This vision of the future was based primarily on their interpretation of information from health care professionals and other sources, as well as their initial experience with the infant. By anticipating the future, parents could prepare themselves for what lay ahead.

F: I think initially, when we first found out and

weren't really aware of what was going to be taking place, we thought there'd be a big change. But since he had his first..

I: What had you sort of expected at that point in terms of change?

F: Um, a lot more time in hospitals. It seemed initially we were spending a lot of time in the hospital and I thought we were going to run into that all the time. But since his first operation and we've had him home, he's no different than anybody else.

M: But you know when he was born, a few people had made comments, you know, some of the nurses and that had said, "ohhh, you're gonna be spending a lot of time in here," or--so we thought, oh, these kids are in and out all the time... I think we both expected when he was first born that we were just going to have this really pale, like kind of laxidasical kind of child that just lay there, didn't have the energy or you know, the strength to do anything, because we'd never known anyone with--really a heart problem.

F: It's definitely been different than what I thought the first couple of days.

I: What did you think?

F: I thought it was going to change our lives.

I: What kinds of things did you think were going to happen?

F: Um, I guess what went through my mind was that you hear about a lot of sicknesses where it almost takes the whole time for the parents. You have to look after--it takes much of their time.

From these accounts, it is apparent that most families envisioned that their child's illness would have more of an impact on family life than it eventually did. It was important for them to anticipate the future so they could muster all their resources to cope with what lay ahead.

When it turned out better than expected, they were thankful.

The parents knew to expect developmental delays which helped them accept their child's sometimes slower than normal progress.

M: My doctor has had--this is his third case.

I: Your pediatrician.

M: My G.P., and he said that she would be slow and probably after the surgery she'd probably have a spurt of growth. But they tire easily, so he says it takes a lot of energy to roll over.

M: ... but like the pediatrician said he could tend to be a little slow but he wouldn't necessarily be. But he wasn't doing a lot of things--he wasn't crawling--he still won't crawl... but at least we were prepared that if he was slow to walk and that, that we knew that okay there's a reason for it.

Preparatory information allowed parents to anticipate their child's progress and thus diminished their anxiety.

A parent support group was considered a good source of information and support for one family.

M: They had this booklet that they sent out once a month and you knew what was going on and they told you what possibilities he had... They had parents write about their child with so and so heart problem and they told a little bit about family life. And it definitely seemed to change many people's lives.

I: So in some ways it was uh, made you more concerned because you thought these types of things might happen for you too.

M: Yes, yeah, but I wanted to be prepared for the worst. I wanted to because I didn't want to go and live and think that it will never be so bad for us... I wanted to be prepared for the worst so I could be happy if it didn't happen.

Again, the importance of being prepared for the possibly negative implications of CHD is emphasized here.

When the child had palliative surgery it was imperative that the parents be prepared for the ICU environment.

M: But they were really good, you know, explaining to us like he's gonna have all these tubes and you're gonna have to, you know, get used to it.

I: Who explained that to you?

M: The nurses, because it--like I said, it was so sudden that we were in there--but they were trying to take us down to intensive care to just have a look around but they were just too busy to have anyone go through. So, we really didn't have a chance, but they just kinda kept on saying over and over, like, all the tubes are necessary--just keep on saying that to yourself when you see him. So, that wasn't bad. I'm really squeamish and I did okay so I figured that was all right.

F: We knew what to ask. If there was anything that wasn't--that someone didn't answer um, to our satisfaction, we could ask sort of the right questions. You know, I think communications is the real key--keeping parents really informed of what's happening.

I: You think it might have been different if you hadn't known the right questions to ask.

F: Oh yeah. You know that ICU is a real frightening place. Maybe the first time somebody goes in there, they should be taken in there and told by someone special that's got a background, told what's going on.

I: That didn't happen for you?

F: Well, no. I knew what a lot of the stuff was but you know, they said, "well, if you've got any questions on the machines, just start asking."

It appears from these accounts that the parents were not consistently prepared for the ICU environment. An attempt

was made to prepare the first family but not the second, perhaps because the father was an allied health care professional.

Reflecting on past experiences was a useful tactic for anticipating the future. One example of this was thinking about their previous experiences in the ICU while trying to anticipate the future surgical experience.

M: We saw the little boy across from her. She was in one little station at [tertiary hospital] and there was this little boy--he was about eighteen months old--across from her. He just was lying on his back and he had tubes through him and we thought, 'oh God, what's the matter with him!' and apparently he had just had corrective surgery, so that's what we have to go through.... They had him strapped to the bed because he wanted to move around and that, and he couldn't and the mother was there trying to comfort him, and it was pretty sad actually.

M: It's just that I don't want him to hurt at all. I think that it just really bothers me because even though he couldn't say anything it's just all the things that they had to do. I try to imagine, like people doing them to me and it's just something--it's not something I think about all the time or everyday. It's just like sometimes if I'm falling asleep, all of a sudden I think about it and you know, sometimes I'll get really upset. 'Cause I just think, you know, they're going to have to make such a big incision and that must be painful and all the tubes again. It's just hard to see him like this and you think why couldn't he stay like this and just leave him alone. And then I think, 'well no, they have to do it,' so, it's hard.

For several fathers, concerns revolved more around their child's activity potential once the surgery was done and not so much around the immediate post-operative phase as was the focus of most mothers.

I: So, what's it like for you to know that he has to have some more surgery?

M: I find I think about it.

I: Do you?

F: Yeah, quite a bit.

M: Do you? I didn't know you did (nervous laugh).

I: What aspect of it do you think about?

F: I know or have a good idea of what's going to be done. But I think it's just wondering afterwards --what he's going to be like afterwards... Well, the concern I had was if he wanted to be involved in something, say sports, because I'm involved in sports and I just, you know. If he did want to be involved in that--would he be able to do it or would he have to stand on the sidelines.... Dr. B. said, sure he could do it. He might not be the star of the team or the standout or be a professional athlete but at least he can get in there and do what he wants to do, so that's nice to hear.

Once more, the importance of the tactic of seeking information in an attempt to accurately visualize the child's future came through in this account.

When the surgery became a reality parents sought information from a variety of sources. The investigator was asked surgery-focused questions by several families. These questions were either deferred until the end of the interviews or referred to another source.

Planning a meeting with the surgeons ahead of time was one way to ensure that they got the information they needed in order to anticipate and prepare themselves for this event.

F: Hopefully we'll be able to get the surgeons to sit down in a little bit of a meeting before the surgery, maybe next week or the week after.

M: Before--instead of, you know, either the day before when we're so uptight and ah, everybody'll be more or less ah--we'll have the time to sit down and ah, a little bit more relaxed. Instead of having the pressure of, you know--how they come around the day before and ask you all those questions. You know, they've asked them to you about a month before. They go through it all over again and ah, this way--you don't ask what you really want to ask because you're pressured for time, you know. And it's not in the most private of places either...

F: Because, you know, I want--I want some fairly good answers. I wanna know where and how and what exactly they're gonna do and things like this.

To summarize, the overall coping strategy of "anticipating the future" included the tactics of, seeking information and reflecting on past experiences. Goals implicit in the accounts and related to this coping strategy were, reducing uncertainty and preparing for the future.

Being Hopeful

Hope, as a coping strategy, was employed by all of the parents to one degree or another. In some conversations it was spoken of explicitly while in others it was more implicit. By way of definition, "being hopeful" means to long for with the expectation of fulfillment. Sometimes the parents hoped for very specific things while at other times the hope was more general, relating for example, to a happy future for the whole family. "Being hopeful" was an important strategy in attainment of the goal of maintaining a positive outlook.

The parents were able to sustain hope as long as they believed they had grounds for hope. They found grounds for

hope in: reassurance from relatives, friends and health care professionals; first hand experience with other children; child's progress to date being better than expected; comparisons to others who are worse off; thinking about improvements in child's condition after surgery; and postulating a philosophical overall meaning for the experience. Although all of the parents employed the coping strategy of "being hopeful," they used various combinations of the above listed grounds for hope.

Relatives and friends were often instrumental in reassuring the parents about their child's future. As a result, the parents were able to be hopeful and thus maintain a somewhat optimistic outlook in the face of their child's chronic illness.

F: Like I'd never really heard too much about it until this little guy came along. Then all of a sudden everyone was saying, "oh, I've got a brother or a cousin or somebody who had a hole in the heart. That's no big problem--you don't have to worry about that--he'll be okay."

M: Once they heard about Susan almost everyone has heard and knows some other people who have a baby with similar kinds of problems and how good the care is at [tertiary hospital]. So everyone's always telling you that there's going to be no problems and everything's going to be okay.

I: Do you find that encouraging?

M: Yeah, like you don't know if maybe they're just saying it to make you feel better but you know it's nice to hear it anyways.

Friends and relatives continued to provide reassurance to the families as the surgery became more of a reality.

F: I've got a friend of mine, plays on the same ball team as I do. His mum's a head nurse at [community hospital] so she knows about the problem and she was telling him and he told me-- they know some people personally that have the same problem and the kid is rambunctious as any other kid, so..

I: This child had his surgery?

F: Yeah, it's already--yeah, I think the child is about three or four now. He had it way back when, as well. You know, they said it's serious but once it's done and it's done correctly, it's over, finished. There's no more worries--just go about it and watch 'em grow.

The parents were also encouraged by optimistic reports from the physicians.

F: The doctors think he's doing great. Dr. D. thinks he's doing fantastic.

M: She's so pleased, yeah.

M: She's growing really well. The doctors are happy with her growth.

All of the parents had some exposure to the hospital prior to their child's corrective heart surgery. Sometimes first hand experience with other children helped them to feel hopeful.

M: Well also, there was a lot of kids who'd had open heart surgery so we kind of saw what it's going to be like for us the next time. And uh, you know, we see all these little kids that just had open heart surgery a week before and they're up running around so that made us feel better in a way because we know we have to go through that again.

An important reason to hope was based in the child's progress to date being better than expected.

M: We've been really lucky because he has been really healthy otherwise and he's doing well. You know, he's going longer without the surgery than they

thought so everything's going well and it looks good for him.

M: When he was born--a few days later he had an operation. He survived it just incredibly. You know it was a rough start and he's doing good now. You know, and we just have so much faith in him and the surgery coming up doesn't even bother me.

It was originally predicted that one child would need a shunt at three months of age. When that time had passed, the parents felt they had grounds to hope that perhaps her condition would remain stable enough to not require a shunt at all.

M: Last time we went to see the doctor and he said, "well, we're going to bring her in." It was just before Christmas we saw him. He said it will probably be within the next few weeks then. When he said that, I kind of--you're hoping that maybe he's going to say, "well, I don't think she's going to need it, everything's fine" but...

In this case the grounds for hope was not very realistic which led to disappointment when the parents found out that their child would in fact need surgery.

Most parents compared their situation to others whom they considered to be worse off and in this way minimized the seriousness of their situation. This tactic of minimizing enabled them to have more hope for their own child. Having their children in the hospital often made parents more aware of the plight of other families.

I: So was she in ICU the whole time?

M: Just for three days. They just were watching her basically. Yeah, we saw--opens your eyes to some of the kids down there. You always think that you've got problems and there's always people that are a lot worse off.

F: I guess all and all we're--we've been pretty lucky. He could've had other problems--a lot of other problems.

M: ... going by the ah, ICN, premature babies scare me so much, you know. And I said, you know, for something to happen like that to a premature baby --I mean, I mean, there's nothing there to start off with, you know. So, it was--it made me feel better that he was such a good weight, and that he had that weight behind him.

From this type of comparison, they were able to feel hopeful about their family's experience. Even the father whose child had Down's syndrome and Hirschsprung's disease on top of the heart defect, was able to find a situation which he thought would be worse.

F: It could be worse. He has some problems, sure --but you know, I seen a little boy in the North Shore News, on the cover of the North Shore News --with his mum--who was three or four years old, who was blind. I think that is a little--I would rather see the problems he has than a little baby who is blind. At least he'll see and he knows what he wants--it's a lot less. You can imagine a little blind--you can imagine always having the baby in your hand--always having the baby by the hand. It's a lot of work.

I: So you've thought about how things could be worse.

M: Oh yeah, definitely could be worse.

F: Could be worse--could be a lot worse. You know, he has his hands and his feet and he can see and hear.

Parents hoped that their child's life and consequently their family's life would improve after surgery. Thinking about this positive future sometimes helped them cope with the trials of the present.

M: Keep saying that when he's--it's all done and over with, things'll get back to normal and you

know, he'll probably start sleeping through the night because he'll be feeding properly.

The surgery therefore represented a grounds for hope.

M: Well we're hoping--he said we'll notice quite a change in her colour and that especially so we just have to think about that.

A philosophical overall meaning for the experience was articulated by two families. By postulating that the experience would have some overall positive repercussions for their families, they were able to remain hopeful about their families' futures.

One family had an infant who was quite symptomatic and also the youngest, at four months of age, to have a Mustard procedure at the tertiary hospital. This is how they viewed it.

F: ...I think that once we come out of the other end of it we'll be a lot, you know, a lot stronger for it, you know...

I: Can you tell me a little bit more about what you were thinking of there?

F: Well, just that, ah, how is anything ever going to worry us again. You know, I mean what could be worse than losing one of your children or you know, having that threat hanging over your head, with the exception of losing each other or your own life or whatever. Um, I used to think that money matters, things that, like a lot of people think are really important. God, if you lose your job, what are you going to do?! Well you know, after you go through something like this, big deal. Everybody's here--we're all fine. You know, what more could worry you, and that's essentially what I meant was the kind of strength you gain from coping with something like this--no matter how it affects you at the time, I think is immeasurable. You really come out of it with a whole different--I know I look at a lot of things differently.

I: So, it's sort of changed your view of life in a

way.

F: Yup, yup. I think ah--not changed a lot--the way I think of a lot of things. I still think things are important, like paying bills and stuff like this but I don't attach the same priorities to them as I did, you know, before this happened.

I: What about for you (to mother)--do you feel similarly?

M: Yeah. I think we'll probably be closer as a family too because we've had to pull together for the last four months and you know, even through the three or you know, how many weeks he is in the hospital. I think we'll be ah--I mean we were close and we were always close to our family back home but I think we'll just be even that much closer.

I: Yeah, because you've gone through a hard time together.

F: Yeah, I guess that's a good way of putting it.

The second couple made a similar comment about the child's illness bringing them closer as a family. They had a baby with Down's syndrome, Hirschsprung's disease and an AV canal heart defect, who spent the first three months of his life in the hospital.

M: It put us closer together. It brought the best out of the both of us.

I: Is that right.

M: Definitely.

I: Strengthened you as a family?

M: It sure did. It sure did. You have your downs for awhile but it's amazing how you do come together in a crisis like that.

This mother also found meaning in her family having an infant with Down's syndrome.

M: ...And um, I used to wonder why Down's syndrome children, people, were born. The more everyday

goes by, I think gosh, they're given to you for a reason, definitely for a reason. He's just one heck of a happy little boy--he's just incredible, just incredible.

These were the two families whose lives were probably the most disrupted by the infants' illnesses. Perhaps they had a greater need than the others to look for some positive meaning in an otherwise trying experience. When a few other families were asked if they thought the experience had brought them closer together or changed their outlook on life in any way, it was obvious that they had not given the matter any thought.

The major goal of being hopeful was to maintain a certain degree of optimism through the experience. All the parents found grounds for hope, although some of the grounds seemed a bit shaky and unrealistic. Minimizing was one tactic that parents used to help them perceive that they had grounds to hope.

To summarize then, the seven coping strategies which have been described enabled parents to attain, at least in part, the goals related to the transition period under study here. Although all of the parents used all of the strategies, some used certain ones more than others. For example, a couple of the families talked about the importance of "being hopeful," "focusing on the present," "normalizing," "trusting health care professionals," and "seeking support" so as to maintain an optimistic outlook. Several of the others were more interested in "anticipating the future," in order to reduce uncertainty and prepare for

the future. Also, the importance of certain strategies became clear during specific facets of the experience.

The final section of this chapter will be a brief look at the parents' overall impressions of the experience. This overview will help to clarify the meaning that parents gave to the experience as a whole as compared to the meaning given to the separate facets.

Overall Impression of Experience

All of the families made statements about their overall impressions of the experience. These statements were often made in opening or closing the discussion. It is interesting to consider these statements in light of the specifics of the experience as described by the parents.

M: I don't know what other babies are like that have this condition but I just think that we've been really lucky, compared to what we thought things were going to be like, they're wonderful like we couldn't ask for anything better.... You know the thought of having other kids and that, it hasn't changed for us. Like, we wouldn't be scared to have another baby... He's doing well, you know. He's going longer without the surgery than they thought, so everything's going well and it looks good for him.

Although this is a very positive statement, this couple had many examples of stressful aspects of their experience. Perhaps because they expected worse, they could view the experience in a positive light. Also, at the time of this interview, their baby had not been hospitalized for eight months and was doing well. As a result, their current situation may have also affected their overall impression.

Another couple viewed their experience in a more negative manner. The father summed it up this way.

F: It's been an all around trying experience really and I guess now that things are coming to a head again, that we're starting to show stress and strain again, more than we were three weeks ago.

His wife showed her agreement when she stated:

M: It's very trying, you know, it's very stressful... The father is referring to their knowledge that the corrective surgery would be in three weeks time, when he says, "things are coming to a head again." This fact, coupled with a symptomatic infant requiring a lot of time and energy, may have influenced this family's impression.

The parents of one child seemed to differ in their overall impressions of the experience.

F: It's been way better than I thought it would be. I was expecting her to be a lot worse but she's been great.

M: A lot of people have asked us if we'd want to have anymore children and I--it sort of scares you, in a way, to think this could happen again. I mean the chances--they've already told us it would probably be very very slim that it could happen again but it's always in the back of your mind too. It is actually--I wouldn't want to go through this again.

Perhaps the mother's more negative view could be attributed to the fact that she is the primary caregiver and would have to physically invest more in a future pregnancy than the father. In trying to clarify, at the second interview, whether in fact the father had similar feelings about another pregnancy, it was discovered that the mother was pregnant. This is what they had to say.

M: It was quite a shock actually... at first I didn't know whether I was happy or not. If I had to go through that again it would be terrible.

F: It took a long time for Donna to get pregnant the first time so..

M: We thought it will take a long time again. Surprise!

F: Just in case something.

M: We're feeling a lot better about it now. I talked to a couple of doctors and they said that they've only ever heard of it happening, you know for the second time--once, I think. And um, that it was probably a freak thing and I'm just not going to let it, you know--worry about it full time...

Again, the father had very little comment to make but the mother did refer to "we" as though her husband felt the same way she did. It is difficult to know whether in fact their overall impressions were contradictory. However, the father generally spoke about the experience in a more positive manner than his wife. She referred several times to feeling depressed about the whole experience.

Two mothers were particularly positive about their experience.

M: I feel really fortunate, to be honest, I do. I think--we have a child with a heart problem--I don't feel it as a problem. I feel as if he would have problems with colour--like colour blind, you know.

I: It hasn't been a big deal.

M: No, not at all.

This mother had a two and one-half year old who had one heart catheterization at five months of age and no surgery to date. He had few symptoms and had been very active. Because this mother had sought information about her

child's condition, she was quite aware of the worst scenarios, which may have also influenced her overall impression. Another mother had this to say.

M: What it's been like--it's like he doesn't have a heart condition.... That's what it feels like. Like, he takes his medicine--two different types of medicines, twice a day, in the morning and at night--and that's basically the only thing that you're dealing with. Other than you notice he gets tuckered out much more than a normal child his age would. And other than that you wouldn't even notice that the heart condition was there.

In this case, the baby had only been home two weeks after having spent three months in the hospital. The parents were very glad to have him home and were feeling optimistic at the time of the interview. The baby also had Down's syndrome and the mother's major concern at this point was his poor muscle tone, not his heart condition.

From these examples, it becomes apparent that there are a multitude of factors which may influence a parent's overall impression of the experience. Although many parents had a positive overall impression, this did not mean that there were no difficult times encountered. In fact, they all recounted stressful aspects of the experience. There seemed to be a multitude of situational factors which influenced a parent's overall impression of the experience at any given time. Some of these were: initial expectations, timing of the interview in respect to child's current condition and hospitalizations, knowledge of future events, general philosophy of life, other concerns and experience to date. Also, it was apparent

that the overall impression was negative when family life was perceived to have been severely disrupted over the long term. It is also important to note that a mother/father dyad may not totally agree on the impact of the experience on family life. The situation is complex and the overall impression does not necessarily reflect impressions of the individual facets of this transition period.

Summary

Although the families in this study were interviewed at various points during the transition period, they were able to recall and relate their experiences from the time of initial diagnosis. Their recollection of the events, their feelings and coping strategies was excellent.

The experiences of these families were closely linked to a series of events which provided the basis for the four facets outlined. These events evoked feeling states, the primary one being uncertainty. Because of the discomfort and fear accompanying this state, families tried to reduce this uncertainty. Having to repeatedly explain their child's condition to others was a demand which frustrated the parents and sometimes increased their anxiety.

Parents used a range of coping strategies to attempt to attain the goals implicit for this transition period. For some families, the wait for corrective heart surgery was three years. As a result, three of the chief strategies employed were "normalizing," "being hopeful," and "focusing on the present" in an attempt to maintain an

optimistic outlook at least until close to the anticipated time of the surgery. The three families who were interviewed within one month of this event, discussed their increasing anxiety, evoked by the reality of the surgery. At this time they spent more time "anticipating the future," "trusting health care professionals," and "seeking support." One family, who declined to be interviewed stated that the father was too upset about the upcoming surgery to talk to anyone.

Two-thirds of the parents, in discussing their overall impressions of the experience, had not found their child's illness to be as disruptive to family life as they had anticipated. The two families who were most affected by the child's illness felt that they would be stronger and closer as a result of the experience.

CHAPTER 5

Discussion of Findings

Introduction

The purpose of this chapter is to discuss the findings of the study in relation to other research studies. Some of this empirical data was mentioned in chapter 2 where a selection of both experientially and research-based publications were reviewed. In this chapter, only empirical data which either supports or refutes the specific findings of this study will be discussed.

A number of studies were found which focused on the concerns of parents having children with CHD. However, the limitations of these studies are multiple when considered collectively. These limitations will be described as data is cited from each. It is difficult to generalize the findings of many of these studies because of problems in study design, reporting and out-dated results. Several of these studies were conducted in the 60's and most of the others in the early 70's. Advances in the diagnosis and surgical treatment of CHD since then has affected the experience of these families. At least half of the studies included only mothers' perceptions which narrows the view of the family's experience to this one parent. Because of the broad range of diagnoses, ages and operative experiences of the children in many of the studies and lack of separation into smaller more homogeneous groups, it was

difficult to compare the data to the findings of the current study.

Because of the limitations of the published research on families having children diagnosed with CHD, this chapter will also include a look at more general family literature. Publications describing the experience of families after learning the diagnosis of a variety of defects and diseases and while coping with these illnesses over the long term will help to explain the findings of this study.

This discussion will follow the same basic outline as chapter 4. However, the themes of "uncertainty" and "explaining to others" which recurred throughout the four facets will be described separately at the end of the facet section to minimize repetition.

Facets of the Experience

Diagnosis of Congenital Heart Disease

A diagnosis of CHD meant the loss of the normal child the parents in the current study had envisioned. While parents were reacting to this loss they were also having to deal with their feelings about an ill infant whom they also thought they might lose.

Initial reactions.

Shock was one reaction to the diagnosis which all of the parents in the current study described. They talked about having no reason to suspect a problem and most had never heard of cardiac defects which perhaps increased

their feelings of shock. Johns (1971) reported that those parents in her study who had never heard of their child's specific defect(s) felt more intense shock than those who had heard that such an abnormality could occur. The 12 families interviewed in that study had children born with various combinations of congenital abnormalities. Other studies reviewed also described this reaction of shock (Drotar et al., 1975; Waechter, 1977¹).

Other reactions to the diagnosis in this study included disbelief, sadness, anxiety, helplessness, anger and guilt. These emotions were not described by all parents, however, those parents who spent a lot of time talking about this facet did describe most of these reactions. There was no clear progression from one feeling to another, instead it was like a flood of mixed emotions. This is contrary to the findings of Drotar et al. (1975) who reported that families go through emotional stages following the birth. In that study, 25 parents of 20 children with a variety of defects, including cardiac, were interviewed using a structured interview guide. The timing of the interviews ranged from 7 days to 60 months after the birth. Five stages of parental reaction to the birth were identified. These were: shock; denial; sadness, anger and anxiety; adaptation; and reorganization. The questions asked of parents, although open-ended, were quite directive. One of the latter questions specifically asked parents, "could you tell me again what stages you remember

going through since the baby was born" (p. 712). This implies that a stage model was conceived prior to data collection. Even in reporting the stages, a clear demarcation was often clouded by comments such as, "accompanying and following the stage of disbelief were intense feelings of sadness and anger" (p. 712). Therefore, this investigator has considered that stage model with some reservation. The reactions of parents in the current study did not fit a stage model because they were described as being concurrent or overlapping.

Several researchers have reported that when defects are invisible, as are cardiac defects, disbelief may be intensified (Drotar et al., 1975; Garson et al., 1978;² Kupst et al., 1977;³ Waechter, 1977). In the current study, disbelief was only mentioned by a few parents and seemed to be short-lived. This could perhaps be related to the necessity for immediate medical intervention in the form of balloon atrial septostomy in two cases, coarctation repair in one case and ICU monitoring in four cases.

Sadness, anxiety and helplessness were three interrelated emotions for some parents in the current study. Parents were sad, first because their child was not normal and, second, because of the severity of the defect. The diagnosis of any congenital defect is anxiety provoking for parents but doubly so when it is perceived to be life threatening. Not only have parents lost the expected normal infant but they are threatened with losing the ill

infant as well. Words such as "scared" and "worried" described the anxiety they felt as a definitive diagnosis was being made and also after it was confirmed if the child's life seemed to be in danger. Helplessness was described by a couple of parents in relation to their lack of control over the ill child's future. Sadness or grief are almost always described as reactions to the diagnosis of any congenital anomaly (Drotar et al., 1975; Garson et al., 1978; Johns, 1971; Waechter, 1977). However, anxiety and helplessness are less often reported. Perhaps these emotions are related to the severity of the anomaly and are therefore more often reported if the anomaly is potentially life threatening, as are cardiac defects. Drotar et al. (1975) stated that fear of death caused reluctance on the part of some parents to become attached to their infants. This was never brought up by the parents in the current study. It could be that such reluctance had more to do with the visibility of the anomalies in those children and not so much with the threat of death.

In the current study, most parents talked about initially searching for a cause for the defect and in the process sometimes blaming themselves or something or someone else. The need to find a cause was linked to concern about the results of future pregnancies. Waechter (1977) related this search for a cause to the need for a "satisfactory, security-producing answer" (p. 304) which would absolve the parents of any blame. The mothers

interviewed in John's study (1971) had multiple theories of causation but the salient point was that this was something which concerned them all. Drotar et al. (1975) did not mention this searching behaviour but perhaps the directive nature of their questioning did not allow parents to describe this aspect of their experience.

Garson et al. (1978) remark that in the case of CHD parents often blame themselves for the defect because the etiology is usually not known. In that study a large number of parents decided against having more children because of a fear of worse defects. Of the three couples in the current study who talked about having more children, only one mother seemed really fearful about a recurrence of cardiac defects. The others were reassured that the cause was not genetic and the chance of recurrence was slim. In a recent study, Dunning⁴ (1984) reported that the second largest category of concerns were about etiology, including what caused the defect and what the hereditary properties were.

Adjusting to Caring for Child Once Home

In the current study, fear that the child might die suddenly was not isolated to the initial facet surrounding diagnosis but extended to the period of adjustment once the child was brought home from the hospital. This was a finding common to other studies, both those considering a variety of defects (Waechter, 1977) and those specific to

cardiac defects (D'Antonio, 1976;⁵ Dunning, 1984; Glaser et al., 1964;⁶ Maxwell & Gane, 1962⁷).

"Sudden death is an unusual mode of exitus, except perhaps in the case of tricuspid atresia" (Maxwell & Gane, 1962, p. 453). It is curious that parents today often fear sudden death, given the advances in the medical and surgical management of children with CHD and hence the more optimistic prognostic outlook given by physicians. Perhaps more understandable were the fears of sudden death in the early 60's when there were fewer surgical interventions available and the long-term and sometimes even short-term outlook for the children was bleak. Why then this recurring theme over more than two decades? Waechter (1977) links this fear to the invisible nature of congenital defects involving vital organs and says that even reassurance by a medical team will not necessarily dispel such fears.

In the current study, parents were told of untoward symptoms to watch for which might indicate a deterioration in the child's condition. Although parents appreciated this information, it also made them think that sudden deterioration and death was a possibility. Also, parents were uncertain about their ability to judge the relative seriousness of symptoms and act appropriately. This feeling of uncertainty was supported by Dunning's data (1984) when parents asked questions about symptoms and what to do should they develop.

Pinelli (1981)⁸ found that mothers' foremost concerns were about the symptoms of heart disease. Some worried that symptoms such as heart failure, tachycardia, heart attack or blue spells would occur suddenly. As in the present study, a major concern of parents was that they either would not recognize dangerous symptoms or if they did recognize them that they would not react appropriately. This was reflected in their concerns that related to an "inability to differentiate between normal crying episodes and those signalling problems caused by the heart disease" (p. 266).

Dunning (1984) found that a few parents in her sample had known another child with CHD who died unexpectedly hence their fear for their own children. Both Dunning (1984) and Garson et al. (1978) reported that some parents were afraid that their children might have heart attacks. This was not brought up by the parents in the current study which could mean that either they were not concerned about this or felt uneasy mentioning it.

D'Antonio (1976) reported that mothers thought that their child's cardiac functioning might change suddenly and unexpectedly. The fear of sudden death was not alleviated even when reassured by physicians about the child's future and thus this fear was still prevalent during the preschool years.

To summarize then, a fear of sudden death in the current study was linked to the knowledge that cyanosis

and/or congestive heart failure were expected. Parents worried that they might not detect symptoms indicating a deterioration in the infant's condition or if they did detect them they would not act appropriately. Reassurance by physicians often did not dispel fears of sudden deterioration and death, as was supported by other research. Parents need to live with the child for awhile and see for themselves how the child is before they can feel reassured about his/her condition.

Interactions with health care professionals.

Interactions with health care professionals during this facet of adjustment were described by parents in the current study. Visits by the community health nurse were not helpful to most of the parents interviewed. One might conclude that this is solely because of the nurses' lack of expertise in dealing with infants with CHD. However, Harrison (1983) had similar findings in her study of the sources of help utilized by 158 women with normal newborns. Nurses ranked last after others, including husband, physician, and relatives or friends. She offers several explanations, including: the use of other resources prior to the community health nurse's first postnatal visit, nurses not available when concerns do arise, and a lack of understanding of the role of the community health nurse. In the current study, the family physicians and pediatricians were already viewed as major sources of information and support prior to the nurse's visit. This

was also true in Pinelli's study (1981). However, the mothers in that study requested more detailed information related to CHD at the time of the second interview, one month post-discharge. Pinelli (1981) interpreted this to mean that their informational needs were not being met. Several of the parents in Dunning's study (1984) wished they had access to the teaching program she offered when their children were infants. It is difficult to evaluate whether in fact the informational needs of the parents in the current study were actually met during this facet but several parents did allude to unanswered questions during that time.

Living with a Child with a Chronic Condition

In the current study each couple told a unique story of their family's experience of living with a child with a chronic condition. There were, however, a number of common alterations that they all had to make. The families who had the most symptomatic, demanding infants had to make major shifts in lifestyle while for others the alterations were less dramatic.

Reports of irritable, demanding and unpredictable infant behaviour were given by several mothers in the current study. Other investigators had similar findings. Glaser et al. (1964) reported that one-third of the mothers interviewed recalled behaviours such as increased crying and irritability during infancy which made them feel frustrated and angry. The mothers that D'Antonio (1976)

interviewed "described the child from early infancy through the preschool period, as more irritable, distant, resistant and demanding than as affectionate or compliant" (p. 253).

Major alterations in lifestyle.

These alterations in lifestyle were a direct result of the amount of time and energy parents had to invest in caring for the ill infant. There was less time to spend with other family members, to tend to household chores, and to engage in outside activities. Two of the early quantitative studies (Apley et al., 1967;⁹ Maxwell & Gane, 1962) noted a modified social life as one impact of the illness on families. Several parents in the current study attributed this modification to the child's illness while others felt that the degree of change would have been the same had the child been normal. Studies of the transition to parenthood when the child is normal do reveal "being tied down" as a concern for mothers (Dyer, 1963; Harrison, 1983). Dunning (1984) asked parents "to rate how much they felt the needs of the family tend to revolve around the needs of the child" (p. 76). Fifty-seven per cent answered "somewhat" to "most of the time." However, some of the parents qualified their answers by saying that all families lives revolve around their children.

A couple of mothers in the present study decided not to return to work until after the child's corrective heart surgery was done. None of the other studies reported a direct impact of the illness on the mother's intent to

work. This may be partially explained by considering the fact that most of the studies which asked questions about impact on family life were conducted in the 60's when it was much less common for mothers to work.

Feeding difficulties.

Most of the parents in the current study reported difficulties associated with infant feeding. Generally, they commented on how quickly the infants would tire and thus feeding became a very time-consuming proposition. This finding is supported by a number of other studies. Gillon (1973) observed and participated in the care of 82 hospitalized infants with CHD, ranging in age from 24 hours to 8 weeks. When discussing the feeding behaviour of these infants she said that 63% had some difficulty. These problems included: difficulty coordinating sucking, swallowing and breathing; the need for frequent rest periods; anorexia; and emesis. In Pinelli's study (1981), feeding, nutrition and weight gain were identified as major concerns for mothers one month after the infant's discharge from hospital.

Most of the mothers in D'Antonio's study (1976) reported feeding difficulties. Eighteen had propped bottles when they were "fed up" (p. 235) with the length of time feedings took (one to two hours). Some mothers actually forced the infants to eat solids "because they had been told that the child had to gain weight before corrective surgery could be performed" (p. 237). These

inappropriate and unsafe practices illustrate the degree of frustration felt by mothers whose infants with CHD are difficult to feed.

Maxwell & Gane (1962) reported only 20% of families having problems related to feeding. This is a fairly low percentage compared to both Gillon's (1973) and D'Antonio's (1976) findings and those of the current study.

Unfortunately, there was no information given about specific diagnoses so it is impossible to tell whether fewer feeding difficulties could be attributed to less severe defects. A finding common to both the current study and Gudermuth's qualitative study (1975) was the reluctance on the part of many mothers to report difficulties with feeding. This may have also partially accounted for the low numbers in the strictly quantitative Maxwell & Gane (1962) study. Gudermuth (1975) asked eight mothers what concerned them the most about their child's health in general and then offered examples of possible problems including feeding difficulties and infant size. None of the mothers identified those as problems. On further probing about feeding patterns, however, three mothers qualified their responses about their children being good eaters. One stated that her child "eats better now than before surgery" (p. 158). This was similar to an account given by one of the mothers in the current study. By way of explanation Gudermuth (1975) suggests, "to admit that her child is not thriving would seriously threaten the

already vulnerable mother and further limit her ability to provide maternal care" (p. 159). The current study supports this conclusion. This threat became obvious when a few mothers reacted with anger to people's comments about the small size of their infants.

Hospitalizations.

Very little was reported on parents' reactions to either cardiac catheterization or palliative surgery in the studies reviewed. Also, most of the studies did not clearly delineate pre and post-operative groups and few gave statistics about how many children had undergone palliative surgery. One exception was Dunning (1984) who reported that the concerns of parents of four children who had recently had palliative surgery and of three children who had recently had cardiac catheterizations revolved around these procedures. However, "no relationship was found between the amount of parental anxiety and whether the child had previous surgery or invasive testing" (p. 69).

The post-operative appearance of the child, including tubes and incision and any evidence of pain were the major concerns of parents in the current study whose children underwent palliative surgery. However, other concerns which were cited were: alarms going off, feeling helpless and the stress of other families. The results of a recent quantitative study (Eberly, Miles, Carter, Hennessey & Riddle, 1985) of sources of parental stress for 510 parents

of 357 children who were admitted to pediatric intensive care units, lend some support to the findings of the current study. In the expected admission group, the items with the highest mean stress scores were on the following items from highest to lowest: "being unable to protect my child from pain, not knowing how best to help my child during this crisis, and seeing my child act or look as if in pain" (p. 61). Seeing "tubes in my child" and "bruises, cuts or incisions on my child" (p. 62) were 11th and 12th of the items ranked in the 1985 study. Not all of the patients in this group had had surgery, therefore one could presume that not all had incisions and the number of tubes would have also varied, therefore possibly lowering the rank of these items.

Worrying that their child was in pain was a major stressor for parents whose children underwent palliative surgery and this is congruent with the findings of the Eberly et al. study (1985). The thoracotomy incision was described by several parents as being longer than expected. Often their shock at the appearance of the incision was directly related to how painful they imagined it must be for the child.

In summarizing the experience of families living with a child with a chronic condition, when there were parental reports of major shifts in lifestyle the infants had obvious symptoms of CHD and were irritable. The feeding problems identified, albeit somewhat reluctantly by the

parents in this study, have been reported by other investigators. Parents' reactions to heart catheterizations and palliative surgery are almost never reported in the research literature. A general study on sources of parental stress in a pediatric ICU did however offer some support to the sources of parental stress identified by parents in this study who had experienced the ICU after palliative surgery.

Waiting for Corrective Heart Surgery

The six families in the current study each had a child awaiting corrective heart surgery. Waiting for surgery is an experience common to families having children with a variety of chronic illnesses, however there is a dearth of research on the subject. Most of the studies specific to families having children with CHD also had little to report on this specific facet. This was even true of Dunning's (1984) sample which was comprised solely of families having a child awaiting surgery. The quantitative portion of her data collection focused on other aspects of the experience and hence she had little to say about the "waiting" facet. From the qualitative part of her study she identified 12 categories of parental concern. The "procedures" category included 20% of the concerns of parents. Subsumed under this title were concerns about surgery or cardiac catheterization. A major concern was not knowing exactly when these procedures would be done. This was also a major

concern of parents in the current study and will be further addressed under the "uncertainty" section of this chapter.

In the present study, parents generally fluctuated between wanting the surgery "over with" as soon as possible and wanting to delay it as long as possible. On the one hand, they felt a need to extinguish the anxiety they were feeling as quickly as possible while on the other hand they were afraid of the outcome of surgery. This ambivalence about the wait for surgery was alluded to by Glaser et al. (1964). They reported that most mothers were glad of this interval because it meant the possibility of improved surgical techniques by the time their children needed surgery. This, of course, was more of a concern over two decades ago than it is now. Some mothers also regarded this interval as a chance for the child to grow and hence be better able to withstand the operation. On the other hand, a few mothers were afraid that the child's condition might worsen during this interval. It was impossible to determine if in fact the same parents fluctuated between wanting the surgery "over with" and wanting to delay it, or if it was different parents wanting each alternative. Similar to the Glaser et al. (1964) findings, in the current study one couple were afraid that lung damage might occur if the wait was prolonged while most felt that their child would probably stand a better chance if he/she was bigger. Eighty-three per cent of parents in the Maxwell & Gane study (1962) said that "surgery and short-term risk

were more tolerable than prolonged anxiety" (p. 453). Generally, this also seemed to be the overall feeling amongst parents in the current study--that is wanting to get the surgery "over with" was a stronger feeling than wanting to delay it.

While some parents in the present study wanted to delay the surgery somewhat, they usually wanted it completed before the child was old enough to understand or remember the event. They also worried about having to prepare an older child. In Dunning's (1984) study, six mothers questioned how best to prepare themselves and their children to cope with the procedures. Parents often do not feel competent to prepare their children for such a procedure perhaps because they are unsure about many aspects themselves. They may also worry that they lack the specific knowledge necessary to teach to a child's developmental level as several parents in the current study stated.

Contemplating risks.

It was quite apparent to most of the parents in the current study that their children needed surgery because they had obvious symptoms of the cardiac condition and several had already required either balloon atrial septostomy and/or palliative surgery. However, one toddler appeared essentially normal and his parents had to weigh the risk of surgery against the risk of disallowing surgery and encountering complications later. In three other

studies (Dunning, 1984; Garson et al., 1978; Glaser et al., 1964) parents whose children were virtually asymptomatic also questioned the necessity of surgery and had difficulty deciding to allow it. Although parents are generally told about the cardiac and lung damage which will occur over time they apparently still have some doubts. The crux of the matter seems to be that this is their child and therefore ultimately they have to live with the consequences of their decision.

The majority of the parents in the present study expressed a fear that their child might die during surgery. In some cases this risk had been mentioned by physicians while in others it seemed to stem from what they had seen of other children in the hospital or heard or read about. Only 5 of 56 parents in Dunning's study (1984) expressed the fear that their child would die during surgery. Dunning (1984) did not report how soon the surgery was anticipated for the children in her study. Perhaps there was a longer anticipated interval to corrective surgery therefore decreasing the likelihood of parents either thinking about or reporting such fears. The parents in the current study tried not to think about the surgery until quite close to the date and had obvious difficulty voicing their fears about this ultimate risk. It could be that actually expressing such fears makes death seem more real or possible. Lewandowski (1980) observed and interviewed 59 parents of children who had undergone open-heart

surgery. She reported that almost all of the parents either expressed openly or hinted that they had been afraid that their children might die during surgery. This data was collected post-operatively when perhaps parents can more easily express such fears.

Impact of previous experience.

Those parents in the current study whose children had had palliative surgery seemed more concerned about the upcoming corrective surgery than those whose children had not. Partial evidence of this concern was the fact that all of those parents whose children had previous surgery expressed a fear that their child might die during the corrective surgery. If indeed there is such a relationship, then the fact that only 11% of the children in Dunning's study (1984) had palliative surgery may partly account for the fact that only 9% of the parents in that study expressed this fear. Palliative surgery brings parents close to what they envision the corrective surgical experience to be and it also increases their exposure to other children who have undergone corrective surgery. As a result, their anxiety may be intensified through the palliative surgical experience.

Anticipating surgery.

The finding of the current study that time spent thinking about the surgery and apprehension about the event increased when a date was actually known could not be corroborated with any other research studies. Information

about the anticipated time interval between data collection and surgery was not given in any of the other reports.

To summarize the facet of "waiting for corrective heart surgery," although parents generally felt ambivalent about the time interval to corrective surgery most also felt that a short wait was preferable to a long wait. In contemplating the risks, the majority felt that death was a possibility but they had difficulty discussing this fear. Two findings could not be corroborated. These were that previous experience with palliative surgery seemed to heighten concerns about the anticipated corrective surgery and when an actual date had been set for the corrective surgery the apprehension of parents increased.

Common Themes of the Facets of the Experience

Uncertainty.

Uncertainty was the major feeling state which persisted through the entire transition period for the families in the current study. The characteristics of this uncertainty varied during the four facets of the experience and from one family to the next but it did persist.

The concept of uncertainty has been studied and several instruments developed by M.H. Mishel. Reference to one of her studies will help explain the findings of the current study. According to Mishel (1983), "... the characteristics of uncertainty may reside in the nature of the stimulus, in the characteristics of the perceiver, or in an interaction between stimulus and perceiver in

relation to four general classes of illness-treatment events" (p. 325). In one study (1983) she measured parents' perceptions of uncertainty concerning their hospitalized child by looking at the four characteristics of ambiguity, lack of clarity, lack of information and unpredictability. She compared the perceptions of 272 parents of three groups of children hospitalized for a variety of reasons. Mishel (1983) found that the absence of predictability was not associated with a strong negative evaluation of the seriousness of illness and thought that this might mean that unpredictability was preferable to a negative predictability. The current study does not support her conclusion that parents prefer unpredictability to a negative predictability. In fact, just the opposite, most parents wanted to know the worst possible scenarios so they could be prepared. By using the coping strategy of "being hopeful" in conjunction with "anticipating the future" parents were able to diffuse their anxiety while at the same time preparing for negative events. Another finding in Mishel's study (1983) was that a negative correlation existed between lack of information and judged seriousness of illness, implying that lack of information may moderate the evaluation of the gravity of the situation. This certainly seemed to be true in the current study. For example, those parents whose children had not experienced palliative surgery were obviously more optimistic about the corrective surgery and their child's

post-operative course than those who had experienced this surgery.

Uncertainty about diagnosis was a concern for parents in the current study before the infants were transferred to the tertiary care centre but once there, this uncertainty was quickly dispelled. Older studies sometimes mention a prolonged delay in pinpointing the diagnosis which was most troublesome for parents (Apley et al., 1967; Maxwell & Gane, 1962). This is not a frequent occurrence today, especially once the child is referred to a cardiologist, because of the accuracy of current diagnostic tests such as the echocardiogram.

Some of the most troublesome types of uncertainty in the current study revolved around not knowing the timing of surgery, both palliative and corrective, and also not knowing the outcome of those operations. Similarly, Kupst et al. (1976) reported that parents were obviously uncomfortable with uncertainty and wanted definite answers to questions about prognosis and the necessity and timing of future surgery. The purpose of that quantitative study was to evaluate communication between parents and physicians in a cardiac outpatient department. In Dunning's study (1984), of the 11 categories of concern identified, the "future" category included the most concerns (23%) of both mothers and fathers. The major type of concern in that category was the uncertainty of not

knowing whether the child would require cardiac catheterization and/or surgery.

When parents first find out about the diagnosis of CHD, they want to know what the future holds in terms of prognosis and treatment. Although a definitive timetable cannot usually be offered, most parents want to know the range of possible scenarios for their child. This need to know what the diagnosis will mean is a common finding no matter what the specific defect or illness is. Those families in John's study (1971) whose children required later surgery or other treatments were constantly trying to clarify time schedules and prognoses. The 10 fathers of chronically-ill children interviewed by McKeever (1981) felt the most troublesome issue for them was the uncertainty associated with the relatively unpredictable nature of the diseases.

Comaroff & Maguire (1981) conducted a study in England with the families of 60 children with leukemia. The report of the methodology is unclear, therefore the reader should view the findings with some reservation. The unpredictability of the course and outcome for a child with leukemia was of major concern to the parents. This is a common feature of most chronic illnesses. The virtual absence of "bench-marks" during a period of remission can be likened to such an absence during the course of CHD once the child has been stabilized with medical or surgical intervention. Parents in that study (Comaroff & Maguire,

1981) looked to bone marrow aspirations with anticipation, hoping that they would give more information about the child's progress and eventual outcome of the illness. Similarly, in the current study, heart catheterizations represented the possibility of information which would decrease the uncertainty felt by parents about their child's future.

Explaining to others.

Demands for explanations about the child's condition from relatives, friends and even strangers was something which parents had to contend with throughout the transition period. It was of such concern to one mother that this was the topic she started her account with.

Limited corroboration was found for the concerns that parents expressed about having to repeatedly explain their child's status. The fact that the majority of the other studies focusing on families having children with CHD used a quantitative methodology may partially account for this difference. There was one isolated piece of data found which supports this concern. Gudermuth (1975) did report that one mother identified the most difficult parental task confronting her as a result of the heart defect was answering peoples' questions about her child.

The difficulty of explaining to siblings, identified in the current study, was well supported by Taylor's study (1980). The purpose of that study was to elicit

descriptions directly from well children about the effects of their sibling's chronic illness (CHD, asthma or cystic fibrosis) on their life. Twenty-five siblings between the ages of 7-12 years who were older than the ill child took part in the study. When the parents were asked what they told the well children about the illnesses, they reported having difficulty explaining at an appropriate level. Several parents in the current study also mentioned this as a concern. Some parents in Taylor's study (1980) had difficulty remaining patient when a lot of repetitive questions were asked and most parents said that they did not discuss the topic of the child's illness very often. The statements from the well siblings indicated that indeed they did not have adequate knowledge about the ill children's conditions and they all indicated an interest in knowing more.

Coping Strategies

Like other chronic illnesses, CHD is associated with some acute phases either caused by the disease itself or its treatment. Therefore, it seems appropriate in introducing this section, to focus on a quantitative study entitled, "coping strategies used by parents during their child's hospitalization in an ICU" (Miles & Carter, 1985). A review of their findings show that many of the coping strategies which are used by parents in an acute phase of an illness are also used during more chronic phases as described by the parents in the current study. The

subjects, 21 mothers and 15 fathers of 27 children, were interviewed within five days of their child's discharge from a pediatric ICU. Reasons for admission varied, but 65% were expected or planned. The coping strategies perceived by parents as the most helpful included:

1) "being near my child as much as possible" 2) "making sure my child is getting proper care" 3) "believing my child is getting the best care possible" 4) "praying" 5) "asking questions of the staff" 6) "seeking as much information as possible" 7) "having hope" 8) "talking with other parents" 9) "seeking help or comfort from others" (Miles & Carter, 1985, p. 17). All of these strategies can be subsumed under five of the strategies used by the parents in the current study; "being vigilant" (1,2), "trusting health care professionals" (3), "being hopeful" (4,7), "anticipating the future" using information seeking tactic (5,6), and "seeking support" (8,9). The findings of that study therefore lend support to the premise that parents of children with CHD use similar coping strategies to other parents of ill children, in acute as well as chronic phases of illness.

Most of the studies of families having children with CHD focused on the feelings of parents and not so much on the coping strategies used by those parents. Therefore, fewer references will be made to those studies in this section. Studies that are not specific to CHD will be primarily cited here in an attempt to discern which

strategies are generally used by parents having children with a variety of chronic illnesses.

Trusting Health Care Professionals

An important coping strategy for the parents interviewed was to trust the health care professionals involved in their child's care. Through trusting, the parents were able to feel reassured when the child was in professional care and maintain a somewhat optimistic outlook about the child's future.

A phenomenon noticed in the current study was that parents did not let negative experiences with health care professionals at community hospitals interfere with the building of trusting relationships at the tertiary care hospital. Kirkpatrick, Hoffman & Futterman (1974) noted the same phenomenon in their qualitative study of 24 families having children with leukemia. They explained it this way, "the efficiency, competency and certainty demonstrated by the hospital at this time reduced parental uncertainty and reassured parents that they were in the hands of trustworthy medical care givers" (p. 170).

This phenomenon maybe further explained by Thorne & Robinson's (in press) model of health care relationships. Such relationships are conceptualized as a process, including the phases of: naive trusting, disenchantment, and guarded alliance. At the time of transfer to the tertiary care centre the parents seemed to still be in the phase of naive trusting. In this phase, people assume that

their perspective is a commonly held perspective with the health care professionals who care for their ill member and thus, they expect "to be consulted and informed regarding professional management of care" (p. 14). However, Thorne & Robinson (in press) go on to say, "when family members experienced unmet expectations over time, their trust faltered and they moved into the phase of disenchantment" (p. 15). Perhaps if the infants had spent more time at the community hospitals prior to transfer, the parents' assumptions would have been irreparably shattered and all remnants of their naive trust lost. As it was, any feelings of dissatisfaction with health care professionals were put aside when they got to the tertiary centre. Also, parents who were dissatisfied with community health nurses still seemed able to trust the nurses at the tertiary care hospital. This demonstrates how very important it is for parents to try to hold onto their naive trust. They must be truly dissatisfied before they actually move into the phase of disenchantment.

Generally, parents in the current study were pleased with the efforts made by the physicians to keep them informed. Dunning (1984) asked parents to indicate who they discussed their concerns with and whether or not these people were helpful. The cardiologists were consulted most frequently and were found to be helpful 81% of the time. When parents did not find them to be helpful it was usually because they either were too upset to assimilate the

information or did not understand what was being said. Apley (1967) also found that anxiety impaired a parent's ability to understand what was being said and this was one reason for parental dissatisfaction with a consultation. One mother in the current study relied on her community health nurse to clarify what the cardiologist said that she did not understand. She was the only mother who identified the community health nurse as a helpful, trusted health care professional. Thus, in this particular situation, the nurses had the ability to answer questions specific to the cardiac condition and this provided a basis for a trusting relationship.

Dunning (1984) found that nurses were ranked fifth as a source of support and rated as helpful only 55% of the time. Only hospital nurses, not community health nurses, were mentioned in her discussion. Nurses were rated as not helpful when they did not know the answers to questions or gave conflicting information. The fact that there was no designated ward for cardiac patients at that particular children's hospital and heart surgery was done at another agency probably limited the nurses' expertise with this particular patient population. Some parents did not consult nurses because they assumed that the nurses would not be able to answer their questions. In the current study, the nurses at the tertiary care hospital were described as being helpful but those at the community hospitals and from the community health unit often were

not, usually because of their lack of expertise with children with CHD.

A confident manner and honest, caring communication were important qualities looked for by parents in the current study. Thorne & Robinson (in press) found that family members evaluated competence almost solely on the basis of "human qualities such as the degree to which the health care professional expressed interest in their care" (p. 19). Kupst et al. (1976) reported that parents were pleased when staff showed that they were genuinely interested in them and cared about what they understood. Similarly, Hayes & Knox (1984) found that parents of children hospitalized with long-term disabilities were able to trust those health care professionals who were competent and caring.

In the current study, some parents had a particularly close relationship with one health care professional who provided information and support over the long term. The need for such an alliance may be greatest when the child is obviously symptomatic and requiring a lot of time and energy, as was the case for those parents describing such a relationship in the present study. Other studies reviewed did not describe such long-term alliances. However, most of those studies that did ask parents about sources of support were quantitative, thus not allowing for the description of such relationships.

To summarize, the qualities which parents in this study looked for in health care professionals were a confident manner; honest, informative communication; and genuine interest in their child and family as a whole. The importance of these qualities was supported by the literature. A special alliance with one health care professional was particularly important to those parents whose children were obviously symptomatic and demanding over the long term but corroboration for this was not found in the studies reviewed. Naive trust was not easily shattered which illustrates how crucial the coping strategy of "trusting health care professionals" is to parents.

Seeking Support

A social support network comprised of relatives, friends and other parents of ill children was identified as helpful by all of the parents in the current study. The extent of help offered by each of the three groups varied depending on the family's needs and availability of those people. For most of the parents, when relatives were available, they offered a more meaningful quality of support than that offered by friends. Those families whose relatives lived at a distance really missed their support. However, the families also identified that relatives demanded more in the way of explanations and reassurance than did friends.

Three of the eight mothers in Gudermuth's study (1975) identified the childrens' grandmothers as sources of help

in the early care of those children. Friends were not mentioned. Dunning (1984) identified friends as the third and family members as the fourth most frequently used sources of support, after cardiologists and pediatricians. The friends were also found to be helpful more often than the family members because friends were "not so involved" whereas family members tended to be "just as upset" as the parents (Dunning, 1984, p. 71). This corroborates the findings of the current study.

Now, turning to research focusing on families having children with other chronic illnesses, similar needs for social support and similar limitations can be found. Burton (1975) reported that parents of children with cystic fibrosis were often cut off from the emotional support of friends and relatives because they were too threatened by the disease to be able to discuss the child's condition realistically and often continued to deny its existence. This lack of acceptance was something several parents in the current study talked about and it was even more of a problem when the child had few symptoms and/or relatives lived at a distance so seldom saw the child.

Parents of children with cancer who rated sources of support, identified relatives as the most often sought out along with physicians but the relatives ranked only sixth in terms of perceived helpfulness (Morrow, Hoagland, & Morse, 1982). Friends, who were less often contacted, were perceived as being slightly more helpful. "Other parents"

were the sixth most frequently contacted group and they ranked third in terms of perceived helpfulness, behind only the spouses and physicians. The fact that all of the parents belonged to mutual help groups very likely skewed this finding. Parent support groups were identified as sources of support by only two mothers in the current study--one had actually sought out a group and the other planned to. A couple of fathers found talking to other parents in the hospital helpful but none showed any interest in parent support groups. In McKeever's study (1981) fathers were generally hesitant to associate with parent support groups. Some stated that their child "was not that sick" while others preferred "to socialize with normal people" (p. 127).

The two mothers in the current study who sought out other parents did so at the time of diagnosis and surgery. Similarly, Comaroff & Maguire (1981) reported that other parents of children with leukemia were sought out at points of crisis such as initial diagnosis and relapse. They explained that parents did not seek out other sufferers when their lives were relatively stable because they wanted to avoid the possibility of disorienting information.

Spousal support was not explicitly addressed by most of the parents in the current study. Perhaps this was a reflection of the fact that the parents were interviewed together. Much of the time however, they did use the term "we" as though it was a joint experience and in most

instances what each had to say during the interview did not come as a shock to the partner so previous discussion had obviously taken place. The fact that most couples worked together to care for the ill child was also evidence of spousal support. Other researchers have addressed spousal support. Drotar et al. (1975) concluded that a positive long-term acceptance of a child with a congenital malformation "involved the parents' mutual support of one another through the time after the birth" (p. 713). The fathers interviewed by McKeever (1981) did not seek outside sources of emotional support but instead relied on their wives.

To summarize, various groups of people were identified as helpful during this transition period. Relatives were important in providing emotional as well as practical support but sometimes their own need for reassurance took a toll as supported by other research. Parent support groups were seldom sought out but when they were it was mothers who used them, especially at more critical times such as hospitalizations for surgery.

Being Vigilant

Parents in this study were vigilant for at least several weeks after the infant first came home from the hospital. When the children showed obvious symptoms of the disease a certain degree of watchfulness was maintained throughout the transition period. Use of this strategy by parents of children with CHD has been recognized in a few

other studies. However, it is usually not explicitly identified as a coping strategy.

D'Antonio (1976) identified "watchful" as one category of maternal response to cardiac children. This watchful response was the one most often identified when the children were either engaging in motor activities or sleeping. Those children often had weak cries as infants so the mothers felt they had to watch them more closely during activity because if they injured themselves the mothers might not hear them. Similarly, Holaday (1981) found that mothers kept their chronically-ill infants within visual range most of the time so that they could more easily interpret their often weak cries and also respond to them quickly.

Parents in the present study were particularly watchful at night. Some of the infants slept in the parents' rooms and they all talked about frequently checking on their babies. D'Antonio (1976) reported that when the children were infants they had all slept right next to the parents' beds. Mothers in that study stated that they had to listen for the infants' breathing and therefore got little sleep at night.

This vigilance at night was also reported by Maxwell & Gane (1962). Most of the children in that study were not infants but 14% of children shared the parental bed and 64% of parents checked on their children at night. Dunning (1984) reported that 9% of parents always had their

children sleep with them while another 33% had their children sleep with them sometimes or frequently. This investigator questioned whether in fact these watchful behaviours were that different from those found in families with healthy children. The parents in the current study who had another child did state that they had not checked on that child as much as they had the ill child. Dunning (1984) supported this finding when she said, "mothers of the children in the study who were not first born did comment that they were much more attentive to the ill infant than their normal infant, 'until we got used to him/her'" (p. 68).

The anxiety of parents and use of vigilance in the current study was also evident in their reluctance to leave the children with babysitters other than family members. A couple of other studies corroborate this finding. Forty-five per cent of Dunning's (1984) sample seldom left their children in the care of another person. Only 16% of the Maxwell & Gane (1962) sample shared the care of their children with other than "intimate" family.

To summarize, all parents were vigilant when the infant was first home and some continued to use this strategy over the long term because their infants had obvious symptoms of the disease. By being vigilant parents could reduce their anxiety but frustration resulted when they continued this vigilance for a long period of time.

Normalizing

Having life "as normal as possible" for the child with CHD and having life "as normal as possible" for the family as a whole was important to those parents in the current study. Their success in attaining this two-pronged goal was mainly dependent on the condition and temperament of the child. Definitions of normal varied from one family to the next but those who already had another child used that child as a yardstick against which to measure the ill child's progress.

A few other studies of families having children with CHD mentioned the importance of this strategy. Glaser et al. (1964) reported that approximately 16 of 25 mothers expressed a hope that their children would lead "normal" lives. However, all but one of these mothers treated the ill child differently than siblings especially with respect to discipline. Dunning's (1984) overall results are unclear with regard to normalizing. She does say though that 10 of 14 children diagnosed with a ventricular septal defect were reportedly treated "as normal" by their parents. Those children's cardiologists had suggested that they be treated "as normal" and since they looked and acted normally the parents were able to follow through with this advice.

Comaroff & Maguire (1981) described the dilemma parents face when they are told by the physician to treat the child "as normal" but they know that the child may not

live to adulthood and in that case, what will it matter that his/her socialization was less than normal. The children with leukemia in that study often did not behave "as normal" due to either the disease and/or its treatment and this added another dimension to the dilemma. Similarly, infants with cardiac defects often do not behave "as normal" but instead are irritable or lethargic making it difficult for parents to treat them "as normal." To further complicate the issue, parents in the current study were told of symptoms to watch for, also indicating that their child was not normal. The parents generally felt that it was important to try to normalize the child's life especially when they realized that he/she would be virtually healthy after the corrective surgery. Parents worked around this dilemma by watching their children closely when first home and then eventually treating them "as normal as possible" given their conditions and temperaments. If necessary, parents redefined normal to decrease the frustration they felt in not coming close to their previous definitions of normal.

Anderson (1981) did an ethnographic study of four families, each having a chronically-ill child between the ages of 3-12 years. All of these children were treated "as normal" according to the parents, however, in observing family interactions Anderson (1981) found inconsistencies. Perhaps these families in fact redefined normal as some of the families in the current study seemed to do. As a

result of this redefinition, they were able to feel that they were following the health care professionals' advice to treat the children "as normal" when in fact they were actually treating the children "as normal as possible" in deference to the illnesses.

Krulik (1980) defined normalization the same way as the investigator of the current study has defined it, that is meaning "as normal as possible" versus "as normal" as some others have defined it. In her study, Krulik (1980) interviewed 20 mothers using a structured interview schedule. The children had chronic life-threatening illnesses and ranged in age from 8-10 years. The normalizing tactics used by these mothers were directed at two targets; the first was altering the environment to compensate and accept the child, and the second was strengthening the resources and coping abilities of the child. The parents in the current study who were intent on encouraging their child's physical development were using this second tactic. Because the children were so much younger, the first tactic was not really appropriate for parents in this study to use.

Altering their expectations of themselves and their ill children was one tactic used by parents in the present study to carry out this strategy of normalizing. Burton (1975) also reported use of this tactic. Many mothers of children with cystic fibrosis lowered their expectations of themselves in terms of housework so that they could

properly care for the child. A number of mothers in the current study had to alter the mode of feeding their ill infants. By considering bottle feeding within the realm of normal they were able to keep this change in perspective.

Another tactic used by parents in this study was to focus on the more normal qualities in their children. Drotar et al. (1975) also found that mothers of children with a variety of congenital anomalies emphasized the normal aspects of their infants' development in an effort to positively adapt to the situation.

In summary then, parents tried to balance their efforts to normalize the ill child's life while at the same time keeping family life "as normal as possible." Generally, the child's needs came first and the more symptomatic and demanding the child, the less successful parents were in employing either prong of this strategy. Definitions of normalizing vary in the literature but when parents say that they are treating their chronically-ill child "as normal" they are in fact usually treating the child "as normal as possible" considering the ramifications of the disease.

Focusing on the Present

This strategy was utilized by parents to help decrease the frustration associated with the uncertainty experienced throughout the transition period. By focusing on the present and not letting thoughts of the future overwhelm them the parents were able to feel some sense of stability

in their daily lives. Other studies of parents coping with a chronically-ill child report use of this strategy. It was not discussed in any of the studies specific to CHD but then most of them did not focus on parental coping.

Burton (1975) reported that in her study, 80% of mothers and 76% of fathers of children with cystic fibrosis "found the best way of living with the illness was to take each day as it came" (p. 229) and not plan or think about the future. She explained that this strategy "prevents the growth of unrealistic expectations which both contribute to ultimate disappointment and preclude the enjoyment of lesser things" (p. 228). The same approach was described in another study of families having children with cystic fibrosis (Venters, 1981). Parents in that study stated that this approach to life allowed them to relax more and not worry so much about the future. Comaroff & Maguire (1981) found that oncologists actually suggested that parents use this strategy to diffuse their focus on the medical uncertainties inherent in the treatment of leukemia.

In the current study, one couple identified that they had always approached life this way but some of the others seemed to have adopted this strategy to deal with this specific transition period. The knowledge that their children had to eventually undergo corrective heart surgery was of paramount concern. However, they could not let their anxiety about that event take over their lives so

they tried not to think about it until close to the anticipated date.

Anticipating the Future

At times, "focusing on the present" was not helpful and parents needed to anticipate the future in order to reduce uncertainty and prepare for anticipated events. Two tactics, important to anticipating the future, were seeking information from a variety of sources and reflecting on past experiences.

In this study, a parent's understanding of the diagnosis was enhanced when concrete drawings and pictures were used as an adjunct to the verbal explanations. This was a common finding in a study by Kupst et al. (1976). Parents who were asked what would improve communication, suggested a written summary of the child's heart condition as well as a diagram of the heart. Parents of children with cystic fibrosis suggested it would have been helpful to have follow-up visits with the specialist to ask the questions that parents thought of in the interim (Burton, 1975). In a latter study, Kupst et al. (1977), found that parents who were given psychological support by a social worker after seeing the cardiologist, "raised significantly more questions about diagnosis and prognosis" (p. 271) on follow-up than those who were not given this type of support. This active search for information was viewed as a positive tactic in the parents' attempts to cope with the situation. In the current study, one mother who was

offered access to a psychologist, a parent support group, and books and pamphlets, actively used all of these resources. Generally, parents used the resources offered to them and many also looked to the media and their social support network for information. Easy access to accurate sources of information is very important because otherwise parents may seek information from inaccurate sources and/or remain uncertain about the implications of the diagnosis.

A desire for a complete and honest discussion of the implications of the diagnosis which the parents in the current study expressed was echoed by parents having children with cystic fibrosis in Burton's study (1975). Those parents explained that knowing the truth helped them start to accept the diagnosis of cystic fibrosis right away and saved extra unnecessary worry which resulted from uncertainty. Dunning's study (1984) included an intervention of teaching and support. This intervention was rated as helpful by 50 of 56 parents and many cited that it gave them a clearer understanding of the condition and its effects. Thirteen of those parents suggested that such a program would have been more helpful at the time of diagnosis or when the child was an infant. When mothers in Pinelli's study (1981) were asked to "identify the ways in which hospital staff could have helped them adjust to the baby's heart condition" (p. 267), nine responses indicated that staff should explain everything and answer mothers' questions. Thus, parents generally want to know the truth

about their child's condition right from the start so they can anticipate occurrences such as slow growth, developmental delays, and specific symptoms of the disease and therefore prepare themselves for these eventualities.

Parents in this study whose children underwent palliative surgery were not consistently prepared for the ICU environment, including the appearance of their child post-operatively. Miles & Carter (1985) reported that the most frequently neglected nursing intervention in their study was an orientation to the ICU environment. However, this intervention was only viewed as very or extremely helpful by 61% of parents. Therefore, the question arises as to what type of orientation is actually helpful to parents. In the current study, the parents did want to be oriented to the ICU environment and prepared for the appearance of their child by a knowledgeable health care professional.

Fathers in the current study were particularly concerned with being able to anticipate their child's future after the corrective surgery. Two other studies mentioned this as a concern of fathers. Dunning (1984) reported that 4 of 28 fathers were worried about the results of surgery. McKeever (1981) who interviewed only fathers found that the majority were concerned about the ability of their children to survive as independent adults. This future orientation may be associated with the father's usual role as primary wage-earner of the family. Also, the

fathers in the current study seemed not to identify as much with how it might be for the child in the immediate post-operative phase perhaps because they were not the primary caregivers or because men sometimes have more difficulty expressing emotion.

Reflecting on previous experiences was a second tactic used by parents in the current study to accurately anticipate the future. Although this is alluded to in many of the qualitative studies reviewed, it is not explicitly stated as a tactic.

To summarize, when a diagnosis of CHD was first made parents tried to anticipate the future by seeking information from a variety of sources about the course of the illness. The research literature supported the finding that parents generally want to know the implications of the diagnosis, not only of CHD but also of other chronic illnesses. When a child was hospitalized for palliative surgery the parents needed information which would help them to anticipate the appearance of their child post-operatively and the ICU environment. Fathers were particularly interested in anticipating their child's future after corrective surgery.

Being Hopeful

Very little reference to this coping strategy of "being hopeful" was found in the research specific to families having children with CHD, however, it was referred to frequently in the general chronic illness studies.

Again, this probably reflects the fact that most of the specific studies did not focus on parental coping.

One study which provides substantial corroboration for the use of this strategy by families having chronically-ill children was conducted by Wright and Shontz (1968). They taped interviews with parents, teachers and therapists of 14 crippled children. Reality surveillance was the term they used to describe the search for a realistic base for "being hopeful." They emphasized it is most important for the person to believe "he has grounds on which to rest his hopes" and "not the issue of whether the person is actually being realistic" (p. 326). From the data they identified methods for achieving reality grounding. Only those methods which were also substantiated in the current study will be discussed here. What the investigator of this study has called "reassurance from friends, relatives and health care professionals," Wright & Shontz (1968) have termed "consensual validation." The "first-hand experience" cited in the current study would be included under their category of "environmental conditions" (Wright & Shontz, 1968). A grounds for hope entitled "child's progress to date better than expected" would be subsumed under the Wright & Shontz (1968) category of "assets of the child." A child's continuing progress was also cited as a source of hope for parents of children with cystic fibrosis (Burton, 1975).

Common reliance on a grounds for hope called "comparisons to those who are worse off" was supported by several studies. Wright and Shontz (1968) entitle this "group comparison." Burton (1975) states that such comparisons helped the parents "develop a sense of perspective" (p. 225). In another study of parents of children with cystic fibrosis, Venters (1981) reported that such comparisons were often made when the children were hospitalized and the parents could readily find others who were worse off. This was also true in the current study.

A fifth grounds for hope identified in the current study was "thinking about improvements in child's condition after surgery." This was quite specific to CHD and therefore no reference was found in the general chronic illness literature. Garson et al. (1978) did however concur that parents of children who show obvious symptoms of CHD have all their hopes invested in surgery and look forward to "a change in the present condition" (p. 90).

The final grounds for hope was found in postulating that the experience would have some overall positive repercussions for their families. Again, the two studies of families having children with cystic fibrosis supported this as a grounds for hope. Burton (1975) stated, "the parents' adaptation to the illness was greatly eased where they were able to see some positive reason for its occurrence" (p. 227). One example of a positive reason was the fact that 64% of mothers and 53% of fathers felt that

the experience had drawn them closer together. This positive reason was also cited by a couple of parents in the current study. Venters (1981) found that when parents endowed the illness with a more positive than negative meaning, this was associated with a higher level of family functioning. Also, she explains, "those study parents who demonstrated optimism found a reason for confidence in the present and hope for the future" (p. 294). In the current study maintaining an optimistic outlook was usually possible when parents found grounds for hope.

To summarize, "being hopeful" was a strategy employed by all parents and they found various grounds for hope which enabled them to believe that their hope was based in reality. Use of this strategy by parents of children with a variety of chronic illnesses was supported by empirical data. When a child is chronically ill the parents must find some reason to hope otherwise they would have difficulty maintaining a degree of optimism and functioning on a daily basis.

Overall Impression of Experience

In recalling their overall experience of having a child awaiting corrective heart surgery, the majority of parents were more positive than negative. Some combination of the following factors contributed to the optimism displayed by each of these parents: experience not as bad as initially expected; child progressing well at time of interview; surgery either not anticipated soon or if

anticipated, parents not aware of or concerned about risks; parents have generally positive outlook on life; and parents use coping strategies which help to maintain an optimistic outlook such as "normalizing," "being hopeful," and "trusting health care professionals." A positive overall impression did not signify that the whole experience was without its trials. In fact, all parents recounted that the two facets of "diagnosis of CHD" and "adjusting to caring for child once home" were at least somewhat stressful.

This positive overall impression of the experience was not corroborated with any other empirical data. In fact, a few investigators have concluded, from data about specific aspects, that the overall experience is a very negative one. D'Antonio (1976), for example, had this to say:

Family life appeared to revolve around the cardiac child. The needs of other family members were secondary to the needs or wants of the cardiac child. Stresses resulted because the family, and in particular the mother was trapped with a child with a congenital cardiac anomaly and the cardiac child was trapped within his own defective body. The high incidence of divorce and separation between spouses may be a reflection of the stresses experienced by these families. (p. 254)

No references were cited to support her statement about the high incidence of divorce and separation. Two fairly recent research studies do in fact contradict this statement (Finley, Putherbough, Cook, Netley, & Rowe, 1979; Silbert, Newberger, & Fyler, 1982).

Because other studies focused on specific parental concerns and did not generally ask parents for their

overall impression, it could be that the conclusions reached by the investigators are similar to the conclusions that many health care professionals would reach in thinking of the overall experience as a sum of all the stressful aspects recounted by parents.

Summary

Many of the findings of this study have been corroborated with empirical data from a variety of research reports. In the facets section of the experience, the findings were supported with literature primarily dealing with families having children with CHD. Although some support was found amongst these specific studies, several of them had major limitations which must be considered. The recent comprehensive study by Dunning (1984) probably lends the most support to the findings of this study.

General literature relating to families having children with a variety of chronic illnesses lent the most support to the coping strategies section of this discussion. The studies specific to CHD had less to contribute, probably because few of them actually focused on parental coping.

Several specific findings arose from the current study for which limited or no support was found in the research reports reviewed. One of these findings was that having to repeatedly explain their child's condition to relatives, friends and even strangers was often quite stressful for parents. A second finding was that those parents who had

the most symptomatic and irritable children had a close alliance with one particular health care professional. A third finding was that heart catheterizations were generally viewed positively because the information gained from these tests could decrease the uncertainty about prognosis and guide physicians in deciding about surgery. A fourth finding was that parents whose children had undergone palliative surgery demonstrated more concern about the upcoming corrective surgery than those whose children had not. The final finding which was not supported was that once parents were given a date for their child's corrective surgery their apprehension increased and they spent more time thinking about that event.

Footnotes

1. Waechter (1977) conducted semi-structured interviews with 50 parents of children with a variety of anomalies, including cardiac. There were no details given about either the method of recording or analyzing data. It was also unclear whether any fathers were interviewed, however, all specific quotes cited were from mothers' accounts.

2. Data from the Garson et al. (1978) report should be considered with some reservation as the methodology is of concern. A retrospective analysis was done of the records of weekly interdisciplinary, unstructured meetings with a group of parents attending a cardiology clinic. After each session which usually included about 10 families, the team met to "discuss specific families and to conceptualize the observed behavior" (p. 87). A total of 260 families attended the sessions but the records included only those families exemplifying certain behaviours.

3. In this experimental study (Kupst et al., 1977), 83 mothers and 45 fathers of 84 children visiting the cardiac outpatient service for the first time were put in one of four groups. Each group offered a different intervention strategy to help parents cope with the implications of the diagnosis of CHD: medical information intervention, psychological intervention, medical/psychological intervention and a control group. The effectiveness of the strategies was evaluated immediately after and then one month after.

4. Dunning (1984) examined the effects of an individualized teaching and support program on the anxiety of parents having children with CHD. Two semi-structured interviews were done, one before and one after the program. A modified pretest-posttest two group design was used with 14 couples in each group. The data was tape-recorded during three interviews with the parents in their homes.

5. D'Antonio interviewed the mothers of 20 preschoolers with CHD, asking open-ended questions about the child in the child-rearing situations of eating, eliminating, sleeping and motor activity. The single interviews were not audiotaped, instead notes were taken, which may have affected the representability of the data.

6. In the Glaser et al. study (1964), 25 mothers of children from 5-11 years of age were interviewed to elicit family reactions to the child's illness. The specific nature of the questioning was not reported.

7. The earliest study reviewed, on families having children with CHD, was conducted in the early 60's (Maxwell & Gane, 1962). In that study, a social worker administered a questionnaire to 150 families (? one or both parents) either at the time of the first clinic visit or in a subsequent visit to find out about the impact of CHD upon the family.

8. Pinelli (1981) collected data about mothers' concerns regarding the care-taking tasks of newborns with CHD through two semi-structured interviews, one prior to the infant's discharge and the second, one month post-discharge. The limitations of this study are several and are well documented in the published report. Most important are the small sample size of 10, and the questionable reliability and validity of the instruments which were developed by the researcher.

9. In that study 88 mothers and 54 fathers of 88 children were interviewed multiple times in their homes. "Standard question sheets were used and assessments were made on predetermined criteria, using point-scales when possible" (Apley et al., 1967, p. 103).

CHAPTER 6

Summary, Conclusions, and Implications for Nursing

Summary

The family's experience of having a child awaiting corrective heart surgery was elicited from the perspective of both parents in this study. A summary of the process followed in, eliciting, analyzing, and reporting these accounts will now be presented.

The UBC Model for Nursing: The Family (UBC Model, May/1986) provided the theoretical framework for this research project. In this model, the family is conceptualized as a social system with three subsystems. "Nurturing" is the term used to describe nursings' function with families and is defined simply as to "foster; protect; sustain; and teach" (UBC Model, May/86, p. 6). The nurse nurtures families during transition periods when expected or unexpected events occur.

Concepts derived from the theoretical framework directed the literature review. These included the unexpected event of the diagnosis of CHD, the transition period from initial diagnosis until admission to hospital for corrective surgery and waiting for the expected event of surgery. Both experientially and research-based publications were used to place this study in the context of what is generally known about families having children with CHD and also children with other chronic illnesses.

Because the investigator wanted to explore the experience of families in the identified transition period this led her to choose the phenomenological method of qualitative research to guide her study. Through this method, the investigator was able to learn how the parents interpreted and gave meaning to their family's experience of having a child awaiting corrective heart surgery.

Data collection and data analysis occurred concurrently until the interviews were completed and then the final analysis was done. Verbatim transcripts of the taped interviews were analyzed as the data collection proceeded. Themes from the first-round interviews were verified with the parents at subsequent interviews and themes from other parents' accounts were also introduced at that time for discussion. Parents were encouraged to explain as fully as possible how they interpreted and gave meaning to facets of the experience. Once the interviews were completed, further sorting and categorizing of data took place. Throughout this process the investigator frequently returned to the original accounts to ensure that meaning units were "context laden" as suggested by Giorgi (1985, p. 14).

Major themes which came from the accounts were organized into two sections to enhance clarity for the reader. The first section included the four facets of the experience. Two concepts apparent through all four facets were uncertainty and explaining. The second section

subsumed the seven coping strategies employed by all of the parents in their attempts to attain the goals specific to this transition period.

For discussion purposes, the findings of this study were compared to the findings of a variety of other studies, not only those specific to families having children with CHD, but also those focusing on families having children with other chronic illnesses. Most of the findings were supported.

Conclusions and Implications for Nursing Practice

Some specific conclusions about the findings of this study will be presented here. After each conclusion is discussed, the implications for nursing practice which evolve from these conclusions will be described. These conclusions have not been prioritized in any way as they are all considered important.

The first conclusion is that parents who expect corrective heart surgery to occur months and sometimes years from the time of the diagnosis do not spend a lot of time anticipating that event. Instead, they utilize coping strategies such as "focusing on the present," "normalizing," and "being hopeful" to allow them to maintain a somewhat optimistic outlook and get on with their daily lives. Only when a date is set for the surgery do parents really view it as a reality. At that time, their apprehension increases and coping strategies such as

"anticipating the future," "seeking support," and "trusting health care professionals" become more important.

The implications for nursing practice are several. Nurses who deal with families throughout the identified transition period should not dwell on the corrective surgery or try to inform parents about the event until they show that they are ready for this information. However, once a date has been identified for the surgery it is appropriate to prepare parents for the event so that they can accurately "anticipate the future," "trust health care professionals" who make an effort to keep them informed, and "seek the support" that they need to cope with this event. This preparation should be multi-faceted. Information relevant to the parents' learning needs could be offered by a knowledgeable nurse in conjunction with the medical team. In assessing their learning needs the nurse should find out whether or not the parents previously experienced the ICU environment and if so what their impressions were of it. Their previous experience will affect their present learning needs. A nursing assessment of the family's social support network, if not already done would be useful at this point in time. Anything nurses can do to enhance the strength of this network would be helpful for parents, for example, explaining the necessity of surgery to relatives and reassuring them so they can in turn support the parents.

A second conclusion has to do with the uncertainty which the parents felt throughout the experience. Uncertainty was generally a very uncomfortable feeling and most parents did whatever they could to decrease it, including using whatever resources were made available to them and seeking out other resources if they still lacked knowledge and understanding. The major nursing implication is to help ensure that the parents have easy access to the resources they require, including written statements about their child's diagnosis, prognosis and treatment plan. Parents must be given multiple opportunities to clarify anything they do not understand because many forces may interfere with their understanding, including: their initial disbelief about the diagnosis, their anxiety about the child's condition, and the use of medical terms by those doing the explaining. Another nursing implication is to encourage families to get on with their normal daily activities and not dwell on the uncertainties of the future. A further implication is for nurses to assist parents to view a cardiac catheterization as a positive diagnostic test which has the potential to answer some of their questions and decrease the uncertainty they are experiencing.

The third conclusion is in relation to having to explain their child's condition to others. Parents find it hard to have to repeatedly explain their child's condition to the people around them. They get frustrated with this

demand for several reasons. First, they may be having difficulty understanding the problem themselves, especially at the time of diagnosis, and therefore have a lot of trouble articulating exactly what it is. Secondly, it is a reminder that their child is not normal, when all they want to do is concentrate on his/her normal features. Also, after an explanation is given the receiver of this information often expects reassurance from parents who may be feeling very uncertain themselves about their child's future. The difficulties are compounded when relatives live at a distance or siblings constantly demand explanations.

Nurses can help parents deal with this demand for explanations in several ways. First of all, at the time of diagnosis, offering to assist parents in explaining the problem to relatives and friends who visit the hospital would be helpful to them and also a good way of evaluating the parents' own understanding. Nurses also have a potential role with any siblings. Parents identify explaining at an appropriate developmental level as a concern. Therefore, the nurse can either role model an explanation getting the parent to play the child, or actually help the parents explain directly to the child.

A fourth conclusion is that parents' overall impressions of the experience do not reflect their feelings about every specific facet of that experience. Instead, these impressions are based in a number of situational

factors. The basic nursing implication from this is that statements of overall impression should not be taken at face value, neither should statements about specific facets be assumed to reflect the overall impression. Nurses who have these families as clients need to explore such statements further to gain a better understanding of the parents' perspective and then care planning will not be based on false assumptions.

The fifth conclusion is that families who have children with obvious symptoms of CHD, requiring major alterations in lifestyle, are most in need of long-term alliances with one health care professional. Implications for nursing therefore, are to assess the impact of the child's illness on the family and determine if a need for such an alliance is being met. If not, the parents should be assisted to find a person who can meet their needs. This might just mean an occasional phone call from someone such as a clinical nurse specialist, to indicate to the parents that their ongoing needs are recognized.

Another conclusion is that parents go through a period of initial adjustment when the child first comes home from the hospital. At this time they have to resolve how to handle the double-message given to them by health care professionals--treat your child "as normal" but watch for symptoms of deterioration. They generally deal with this issue by first being vigilant and then gradually attempting

to normalize the situation to whatever degree is most comfortable for them.

A number of implications for nursing practice arise from this conclusion. Parents should be told by health care professionals at the hospital that it will take a little while for them to get used to their baby and what is and is not normal behaviour for him/her. Once they feel more comfortable with the infant, then they should attempt to normalize. Nurses should give clear guidelines about what they mean when they say to treat the baby "as normal as possible." During the period of initial adjustment parents will often have questions about symptoms--when to get worried and what to do about them. Parents need to be able to turn to a knowledgeable health care professional with their questions. Although a family physician or pediatrician may supply some of the answers, the parents may need someone else to rely on when the physicians are not available. The community health nurse often does not have enough experience with these infants to feel comfortable in that role. In that case, perhaps a clinical nurse specialist could either support the community health nurse or give direct telephone support to the parents themselves.

A final conclusion is that "trusting health care professionals" is an important coping strategy for parents, and it takes a lot of unmet expectations before their trust is shattered. This is particularly true when a child with

CHD is awaiting corrective heart surgery and the parents know that they must rely on the health care professionals to get their child through that event.

The major implication is for nurses to be aware of the expectations parents have of health care professionals and to work together with others to meet the parents' expectations. Parents look for confidence as a measure of competence, genuine interest in their child and family, and honest, informative communication. A team approach with clear communication between health care professionals will go a long way in meeting the parents' expectations and nurses should be major players on this team. Socialization of nurses about the importance of their role on the health care team must start at the student nurse level in order for this attitude to become pervasive. Student nurses also must be taught the communication skills which will enable them to be active participants on this team.

From the above listed conclusions comes one major general implication for nursing practice. There is potentially a large role for nurses to play with these families in nurturing them during the identified transition period. Nurses need to work together to assist families to use suitable coping strategies to attain their goals when they have a child awaiting corrective heart surgery. Because of the varying levels of knowledge and skill of nurses working with these families it is imperative that nurses consult the appropriate resources if they do not

feel equipped to help. It is also important for those with the expertise to make themselves available to others; for example, a clinical nurse specialist could act as a consultant to nurses in community hospitals and community health units.

Implications for Nursing Education

Some very general implications for nursing education which arise from the findings of this study will be mentioned here. It was very clear that when a child with CHD was awaiting corrective heart surgery the whole family unit was affected and the individual members had to work together to use suitable coping strategies to attain the goals of that family. One major implication is to incorporate a family focus as well as an individual client focus into nursing curriculums. In discussing the findings of this study in relation to other chronic illness experiences cited in the research literature, it became apparent that parents often draw from a common pool of coping strategies no matter what the child's chronic illness is. Offering general theory about family coping with chronic illness and then giving students the opportunity to apply this theory in the clinical setting will help them to see what the common concerns and coping strategies are. At the same time it is imperative to always emphasize the importance of eliciting the individual family's perspective before planning care. Although certain concerns and coping strategies were common to all

the families in this study, the way in which the concerns were manifest and when and how the coping strategies were used varied. There was also some degree of variance between spouses so it is equally important for students to be taught to elicit the perspective of each individual family member.

Implications for Nursing Research

During the research process, the investigator became aware of a number of questions which evolved from her study that had not been well addressed in the currently reported empirical data. These questions will now be addressed.

In the current study the investigator got at the meaning of waiting for surgery for these particular parents. This is only the "tip of the iceberg," though, considering the dearth of research in this area. Therefore, suggestions for further research in this area are appropriate. One question would be, what are parents' perceptions of their needs during the waiting period for corrective heart surgery? Data collection at three points in time, for example, six weeks after diagnosis, right after the date for surgery is announced, and a few days before admission to the hospital, would help to clarify the changing needs.

Another question arises from the different degrees of concern expressed by parents whose children had palliative surgery versus those whose children had not. Do the concerns of parents about corrective heart surgery change

when a palliative procedure has been done? This could be addressed in one of two ways; either by comparing the concerns of two groups of parents, or by comparing the concerns of one group of parents, before and after a palliative procedure. The results of such research could potentially guide nurses in effectively addressing the emotional and learning needs of these two groups of parents.

The sample for this study was totally comprised of parents having children diagnosed with CHD within the first few days of life. It would be interesting to find out about the experience of families whose child's illness was not diagnosed immediately but instead one to two months after birth, as is common with certain types of cardiac defects. One could hypothesize that their reactions to the diagnosis might differ and also their use of certain coping strategies, vigilance for example.

Two of the children with CHD were first-borns and four were second-borns in this study. Although the first-time parents seemed a little more anxious when first adjusting to caring for the child once home, it was difficult to retrospectively compare degrees of anxiety and coping strategies. It might be useful therefore, to compare degrees of anxiety and use of the coping strategy of "being vigilant" amongst three groups of parents; first-time parents of healthy infants, first-time parents of children

with CHD, and second-time parents whose first child was healthy and whose second child has CHD.

Parents gave their perceptions of the impact of the child's illness on well preschool aged siblings. A few studies which have compared parents' perceptions to well siblings' perceptions have shown some significant differences. Most studies which ask siblings directly for their perceptions use a sample of school-age siblings. Therefore, it might be helpful to find out about the perceptions of preschoolers who have a sibling with a chronic illness to enhance our ability to help parents meet their needs.

To conclude, the experience of families when they have a child awaiting corrective heart surgery is multi-faceted, the "waiting for surgery" facet being only one aspect of the total experience. Only by asking parents directly can we learn about the meaning they give to their family's experience. By listening to their accounts nurses can start to understand how to "nurture" families during the transition period which was studied here.

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APPENDICES

Appendix C

Demographic Data

This information will enhance the researcher's understanding of your family's experience. If you do not wish to answer any of these questions you are free to refuse.

Information About Child

Age of Child	Male	Female
Diagnosis		
Age of Child at Diagnosis		
Any Cardiac Surgery to Date (palliative)		
Medications Child is Presently on		
Any Other Health Problems Child Has		
Treatment to Date for Other Problems		

Information About Other Child(ren)

Age	Male	Female
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Information About Parents

Age of Mother	Cultural Background
Age of Father	Cultural Background

What is the highest educational level you attained?

Mother Father

1. University or college
2. Some university or college education
3. High school graduate
4. Some high school education
5. Less than high school education

What category does your yearly family income fall into?

1. Less than 10,000
2. 10,000 - 19,999
3. 20,000 - 29,999
4. 30,000 - 39,999
5. 40,000 - 49,999
6. greater than 50,000

Mother

Are you employed now? yes - no -

If yes, what do you do?

Do you work 1) full time?

 2) part time?

If no, did you give up work to stay home to care for your child?

Father

Are you employed now? yes - no -

If yes, what do you do?

Do you work 1) full time?

 2) part time?

If no, did you give up work to stay home to care for your child?

Thank you very much for taking part in this study.

Appendix D

Sample Interview Guide

Overall Question: What has it been like for your family to have a child awaiting corrective heart surgery?

Probing Questions (to be asked if overall question does not elicit certain aspects of experience):

1. What has it been like to look after a child with a heart problem?

- was it any different than looking after your other child(ren)?

2. Has the fact that your child has heart disease had any effect on your family's lifestyle?

3. What effect has your child's heart disease had on you as a couple?

4. Has the fact that _____ has a heart problem affected your other child(ren)?

5. What do you think it's like for _____ to have a heart problem?

6. What has it been like for you to know that your child will have to have heart surgery at some point?

7. What has helped you since you found out that your child has heart disease?

8. Are there any people who have been important to you through this experience?

9. Did the nurses in the hospital adequately prepare you to look after your child at home?

10. Has a community health nurse visited?
- what was that like for you?

11. Is there anything that nurses could have done to help your family through this experience?

Appendix E

Information About Children with CHD

	Initial Diagnosis	Heart Cath. @ Age	Palliative Surgery/Age	Age @ 1st Interview	Age @ 2nd Interview
1.	TGA VSD	2 mos. ? 11 mos.	Banding of PA/2 mos.	8 mos.	10 mos.
2.	TGA Coarct.	birth/ BAS	Coarct. Repair/birth	3 mos.	4 mos.
3.	TGA	birth/ BAS 5 mos.	None	6 mos.	not done
4.	TGA, VSD PA stenosis	?	Blalock Shunt/6 mos.	5 mos.	8 mos.
5.	TOF	5 mos.	None	30 mos.	32 mos.
6.	AV canal	5 mos.	? 7 mos.	3 mos.	5 mos.

Note.

TGA = transposition of the great arteries

VSD = ventricular septal defect

PA = pulmonary artery

BAS = balloon atrial septostomy

Coarct. = coarctation of the aorta

TOF = tetralogy of Fallot

AV canal = atrioventricular canal

? = uncertain of age of child when procedure was done