University of Alberta

Parenting a Child with HLHS Whose Treatment Includes the Norwood Surgical Approach

by

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I have seen something else under the sun:

The race is not to the swift
or the battle to the strong,
not does food come to the wise
or wealth to the brilliant
or favor to the learned;
but time and chance happen to them all.

Ecclesiastes 9:11

Dedication

I dedicate this dissertation to several people: to my mother, Evelyn Rempel, who unswervingly encouraged and supported me throughout my doctoral studies, a time in my life filled with gains and losses; to my husband, John Kleinschroth, whose quiet and steady support has buoyed my confidence and kept me focused on the Author and Finisher of my faith; and to my father, Henry J. Rempel (1929-2003), whose faithful prayers and practical help with moving, gardening and staying healthy I miss. Dad challenged me to follow the desires of my hearts for which I am grateful. To God be the glory.

ABSTRACT

Hypoplastic left heart syndrome (HLHS), the most lethal congenital heart defect, remains difficult and controversial to treat despite constantly advancing technology in pediatric cardiac sciences. A series of surgeries starting with the Norwood operation soon after the infant's birth present risk to the child's life, but compassionate care and heart transplantation pose equally difficult options. The purpose of this study was to describe what it is like to parent children with HLHS who undergo the Norwood surgical approach. Constructivist grounded theory informed the data collection and analysis in this study. Data were collected through multiple unstructured interactive interviews with nine mothers and seven fathers of children at varying stages of their treatment for HLHS. Parents were interviewed separately either in person or by telephone. Data were analyzed using open and selective coding.

A parenting process of safeguarding precarious survival in a context of certainty and uncertainty was found in this study. Parents became certain that the Norwood surgical approach was the best option for their child through a process of deliberating the options, discussing the numbers and discovering the best place of surgery. Parents remained certain of their choice by seeking assurance from the surgeon, reassurance from other physicians and buffering each other from the severity. Conversely, parents became uncertain about their choice for the Norwood surgical approach when they considered and experienced complications over the course of their child's treatment.

Extraordinary parenting was evident in this study as parents simultaneously safeguarded their child's and their own survival. Parents safeguarded the precarious survival of their child by taking charge, struggling for balance and involving others in the

care of their child. Parents safeguarded their own survival in two ways. They safeguarded themselves against worry by directing their minds, normalizing and trusting. They safeguarded themselves against regret by determining not to regret, reframing and delighting in their child.

As technologically advanced treatment for HLHS contributes to the survival of children with HLHS, clinicians and researchers must consider how parenting strategies in a context of ongoing uncertainty, affect the family, the parents, other family members, as well as the child with HLHS.

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CHAPTER ONE

INTRODUCTION AND RESEARCH PROBLEM

Health care and scientific communities alike applaud the advances of medical technology that are enhancing the longevity and quality of human life (Bergum, 1996). More broadly, Canadian society, through the media and its own inquiries, increasingly is interested in learning about technological developments with the potential to improve health (Ogle, 2004; Ruttan, 2004). The inherent message in the celebratory accomplishments and pronouncements is that technological advances uniformly translate into improved health for all concerned. While society, and scientific and health care communities praise the survival rates that the current technology affords, the influence of technological intervention on the lives of its recipients and their family members remains largely unquestioned.

In pediatric cardiology, we marvel at the improved survival rates for infants born with congenital heart disease (CHD), the most commonly occurring congenital anomaly (Weaver, 1999). One in 100 babies born in North America has CHD (Botto, Correa, & Erickson, 2001). Technological advances in preoperative, intraoperative and postoperative care have resulted in babies surviving beyond the newborn period despite complex and life-threatening heart disease (Ohye & Bove, 2001; Pearl, Nelson, Schwartz, & Manning, 2002). While health care professionals and society celebrate these accomplishments, few people wonder about the experience of parenting children who face uncertain futures.

Hypoplastic left heart syndrome (HLHS), is the most complex congenital heart defect. Because the systemic or left ventricle and left-sided mitral and aortic valves are

not adequately developed, HLHS is uniformly lethal without immediate diagnosis and intervention following birth. Although pediatric cardiologists, pediatric cardiac surgeons, basic scientists and other health care professionals and investigators have jointly contributed to progress in the successful treatment of most other heart lesions, treatment of HLHS is progressing slowly (Hennein & Bove, 2002). The treatment options remain controversial with regard to outcomes for the child and the child's family (Cohen & Allen, 1997; Goldberg & Gomez, 2003; Osiovich, Phillipos, Byrne, & Robertson, 2000).

Background to the Problem

Despite significant advances in pediatric cardiology, HLHS continues to represent immense challenges for medical and surgical management (Daebritz, et al., 2000). HLHS is the fourth most commonly occurring congenital heart defect with an incidence of 1:6000 births (Taeusch & Ballard, 1998). Although babies and children with HLHS have benefited from recent technogical advancements in pediatric cardiology (Andrews & Tulloh, 2002), HLHS remains the leading cause of death in babies with CHD during the first month of life (Dhillon & Redington, 2002).

Until the 1980s, babies with HLHS died unexpectedly with an undiagnosed heart problem or they received compassionate care after diagnosis. In the 1980s, American pediatric cardiac surgeon Dr. William Norwood pioneered a three-stage surgical approach to establish systemic blood flow using the right ventricle as the pump instead of the hypoplastic, non-functional left ventricle (see Appendix A). The first operation, still often referred to as a "palliative surgical approach," in contrast to a "corrective surgery," is the Norwood procedure and occurs within the first few days of the baby's life (Norwood, 1989; Norwood, Kirklin, & Sanders, 1980; Norwood, Lang, Casteneda, &

Campbell, 1981). With this surgical option, babies with HLHS may survive the newborn period and also live through childhood and even adolescence if they survive two additional surgeries during the first few years of their lives (Bove, 1998) (see Appendix B). The Norwood surgical approach is resulting in new survivors of HLHS (Chang, Chen, & Klitzner, 2002; Gutgesell & Gibson, 2002). One centre reports that from 1996 to 2001, 93% of babies with HLHS survived their newborn surgery, in contrast to only 53% of babies surviving in the time period from 1992 to 1996 (Tweddell et al., 2002).

The oldest children who have survived surgically treated HLHS are in their teen years, but uncertainty about long-term mortality and morbidity remains. Some studies suggest that these children have less optimal neurological outcomes than their playmates and classmates who do not have health problems (Kern, Hinton, Nereo, Hayes, & Gersony, 1998). These outcomes have been used to justify the decision of some health centres not to offer the surgical approach as a treatment option for HLHS.

Concerns that the Norwood approach is only a bridge to heart transplantation later in life (Hutchinson, 1999) have led other health professionals to view surgical treatment for HLHS negatively. Some argue that neonatal heart transplant is preferable. Growing evidence exists that the neonate's immature immune system is the ideal antidote for the long-battled immunosuppression complications with transplantation (Bailey, 2001). Additionally, ABO incompatible heart transplants have been conducted at The Hospital for Sick Children in Toronto, with impressive survival rates especially related to the decreased mortality while waiting for heart transplantation. Mortality on the waiting list went from 58% before ABO incompatible heart transplants to 7% since introduction of ABO incompatible neonatal heart transplants in 1996 (West et al., 2001). For the

increasing number of parents who learn antenatally that their baby has HLHS, the option of termination of the pregnancy may be considered along with the post-birth options for surgical repair, heart transplantation, or compassionate care (Allan, Apfel, & Printz, 1998).

Given all these choices and decisions, what is it like to parent children with HLHS who undergo the Norwood surgical approach? My review of the literature indicates that researchers have not examined the perspective of these parents and that information available to guide our nursing practice with parents of children with HLHS is limited.

Purpose of the Study

The purpose of this study was to describe the process of parenting a child with HLHS whose care and treatment included a series of high-risk surgeries starting with the Norwood surgical procedure soon after birth. Information about the process of parenting these children will provide direction for nurses who work with children with HLHS, their parents and families.

In this first chapter, I describe some background information regarding HLHS and the treatment of children with this lethal congenital heart defect. I also describe the lack of information about parental perspectives on parenting a child with HLHS who undergoes the Norwood surgical approach. In Chapter 2, I outline what is known about parenting children with HLHS, parenting children with CHD and parenting "imperfect children." I also summarize the literature on mothers' and fathers' parenting expectations and the relationship of expectations to grief from the loss of the imagined "perfect" child. This review provides the context for my research. In Chapter 3, I describe my research methodology and the constructivist grounded theory method employed in this study.

Chapters 4, 5, and 6 contain the key findings of the study. Chapter 4 focuses on the context of precarious survival, distinguishing the certainty of survival from the uncertainty of survival as viewed by parents. Chapter 5 focuses on how parents safeguarded their child's precarious survival through a process of taking charge, struggling for balance, and involving others. Their own emotional survival as parents was threatened in the course of caring for their child with HLHS. Chapter 6 focuses on how parents safeguarded their own survival through a process that included strategies of directing their minds, normalizing their child's difficulties, trusting, determining not to regret their decisions, reframing and delighting in how well their child was doing.

Chapter 7 includes the conclusions from the study. I discuss the key findings related to safeguarding precarious survival by reflecting on my role in data construction and interpretation and relating the major findings to other pertinent literature. I also discuss implications for clinical practice and future research.

CHAPTER TWO

LITERATURE REVIEW

While the diagnosis of HLHS challenges health care professionals (Jenkins et al., 2004), children with HLHS and their parents are those most affected (Emery, 1989; Hinoki, 1998; Jaworski, 2002). This literature review will demonstrate the need for research related to parenting a child with a life-threatening condition such as HLHS. The review encompasses parenting children with HLHS and parenting children with CHD as well as broader topics of parenting expectations, grieving the loss of the expected "perfect" child, and parenting "imperfect" children. I obtained the literature through CINAHL and Medline searches for the years 1982 to 2004 by using the search terms of "hypoplastic left heart syndrome," "congenital heart disease, "congenital anomalies," "parenting expectations," "unmet expectations," "expectations," "parenthood," and "parenting." I acquired further literature through the references cited in articles obtained through my electronic searches. I begin the chapter with a review of the limited literature on parenting children with HLHS followed by a more extensive discussion of the literature on parenting children with CHD.

Parenting Children with HLHS

In my review, I located only one research study on parenting and HLHS, an unpublished master's thesis by Ross Keizer (1993) who sought parents' perceptions of quality of life related to their children with HLHS who had undergone the Norwood surgical approach. Ross Keizer interviewed five mothers to gain their perspective and met with them a second time to verify the findings. The children with HLHS ranged in age from infancy to three years of age and had had their Norwood surgery at the Hospital

for Sick Children in Toronto. In this descriptive qualitative study, Ross Keizer invited the mothers to tell their story of being a parent with a child with HLHS, starting from the time of birth to the present. Ross Keizer started with a general open-ended question and used more specifically worded questions about quality of life, depending on how the interview progressed. She was interested in the mothers' decision-making process that led to their child having the Norwood operation and found that no one regretted having decided for "the chance for life" (p. 44). In this context, Ross Keizer then described her findings in terms of an iterative process of the maternal experience of anxiety, learning and normalization that occurred and reoccurred through many experiences with their children with HLHS. Learning was a means to alleviate anxiety and "pave the way for the mothers' experience of normalization" (p. 59). The strength of this study is the vivid descriptions of the life-threatening aspect of HLHS – "this mother said it was easy to fall back to anxiety because 'the death issue is always there.'... She said when he is sick 'he is lost in his illness'" (p. 67). Limitations of this study include the small sample size, the inclusion of mothers only, assumptions about the relevance of the concept of quality of life and the lack of information on antenatal diagnosis.

The remaining abundant literature on HLHS addresses concerns from a nursing and medical perspective, not from the perspective of parents. Nursing practice articles describe treatment options for babies with HLHS (Callow, 1992; Claxon-McKinney, 2001; Hutchinson, 1999; Johnson & Davis, 1991; Smith & Vernon-Levett, 1989, 1993; Swanson, 1995; Wright, 2002) as well as ethical issues related to the treatment of HLHS (Cooper, Caplan, Garcia-Prats, & Brody, 1996; Pager, 2000; Zeigler, 2003). Published medical research pertains to treatment recommendations (e.g., Bove, 1998; Reis, Punch,

Bove, & van de Ven, 1998), outcomes for babies who are antenatally diagnosed with HLHS (e.g., Munn, Brumfield, Lau, & Colvin, 1999; Tworetzky et al., 2001), surgical outcomes (e.g., Gaynor et al., 2002; Kern, Hayes, Michler, Gersony, & Quaegebeur, 1997), and transplantation issues (e.g., Ikle, Hale, Fashaw, Boucek, & Rosenberg, 2003; Johnston et al., 1997). As well, there is research about the neurological outcomes for children who have survived HLHS (Goldberg et al., 2000; Kern, et al., 1998; Mahle, Clancy, McGaurn, Goin, & Clark, 2001; Mahle et al., 2000). Most recent publications regarding HLHS reflect ongoing concern about the Norwood procedure and discussion of a new surgical option for the first stage of repair, the Sano procedure (Sano et al., 2004; Sano et al., 2003). The perspective of parents of children with HLHS remains unstudied.

In the past, other heart defects were as life threatening as HLHS until surgical procedures were pioneered to ameliorate their devastating effects. I reviewed the body of literature on parenting children with congenital heart defects, other than HLHS, that reflects the life-threatening nature of CHD that has always existed.

Parenting Children with CHD

The research on parenting a child with CHD draws attention to the unique aspects of parenting a child with a life-threatening condition. First I will review the research on parenting children with CHD that describes parental fear (Clark & Miles, 1999; Cohn, 1996; Glaser, Harrison, & Lynn, 1964; Gudermuth, 1975; Miles 2000) and stress (Carey, Nicholson, & Fox, 2002; Goldberg, Morris, Simmons, Fowler, & Levison, 1990; Lawoko & Soares, 2003; Morelius, Lundh, & Nelson, 2002; Uzark & Jones, 2003). I will then review a body of research literature that highlights the interrelationships or mutual influences between children with CHD and their parents (DeMaso et al., 1991; Goldberg,

Simmons, Newman, Campbell & Fowler, 1991; Linde, Rasof, Dunn, & Rabb, 1966; Lobo, 1992; Pinelli, 1981; Stinson & McKeever, 1995; Svavarsdottir & McCubbin, 1996).

CHD and Parental Fear

As treatment of congenital heart defects has evolved since the late 1950s, parents not only have feared for their child's life, but they also have feared the advancing technology. "Cardiovascular surgery has ... produced in a number of parents ... both hope ... and fear of being made victims of experimentation and imperfect techniques" (Glaser, Harrison, & Lynn, 1964). This pioneering research provided a basis for later research on parenting children with CHD. A multidisciplinary team of researchers (i.e., a pediatrician, medical social worker, and psychologist), Glaser, Harrison and Lynn conducted qualitative interviews with the mothers of 25 children with CHD. The children ranged in age from 5-11 years. Twelve children had had cardiac surgery, and the rest anticipated surgery. Analysis of the tape-recorded and transcribed interviews yielded a rich description of the problems that mothers faced as parents of children who survived their CHD. They identified themes of apprehension about the baby before diagnosis, uncertainty about diagnosis, anxiety about the child's symptoms, fears of death, guilt, disappointment and irritation with their burden, overprotective attitudes, attempts to provide child with a normal life, difficulties with discipline, fear of and preparation for hospitalization, cardiac catheterization and heart surgery. The strength of this qualitative research is the large sample size and the insightful discussion of the findings that remains relevant to the present. Glaser and colleagues highlighted the mothers' understanding of the vital nature of the heart that "led many parents ... to maintain expectations for their

child at a most elementary and primitive level ... goals for many of these children did not extend beyond those of survival and were directed simply toward day-to-day protection and nurturing" (p. 377). The children in this early study were new survivors of CHD, as children with HLHS are today's new survivors.

Over the years, research has continued to reveal the theme of parental fear. In a small qualitative study that focused on feeding behaviours and activity patterns of babies with CHD in relation to the mother-baby relationship, Gudermuth (1975) concluded that all eight mothers in her study had difficulty establishing mutuality with their infants. The small sample size and lack of a comparison group hold this conclusion up for further study, but the mothers' quotations throughout the research report reflected their fear: "'You don't know long she will live'" (p. 160), "'you might lose him'" (p. 161). Gudermuth does not comment on these expressions of fear. Nor did she specify the children's heart defects except that two of the children had undergone surgical intervention.

More recent studies (Clark & Miles, 1999; Cohn, 1996; Miles, 2000) also document the fear faced by parents of children with CHD. These studies address some of the limitations of previous research in that the studies include both mothers and fathers and have comparison groups.

In one study (Cohn, 1996), mothers and father of infants with CHD (n = 48) were significantly more fearful than mothers and fathers of "normal" infants (n = 154) at six weeks of age. Cohn had pediatricians and pediatric cardiologists administer a questionnaire she developed to measure the two groups of parents on sadness, fear, happiness, guilt, and anger. The strength of this study is in its inclusion of fathers as well

as mothers and in the comparative analysis between parents of children with CHD and those with "normal" children. The limitation of this study is in its use of a newly developed tool.

Miles (2000) reported that fear was one of the cognitive-emotional responses of 13 women to the birth of their baby with severe CHD. Miles' longitudinal study of parenting the medically fragile infant is unique in that it includes mothers whose infant was diagnosed with CHD antenatally. As well as fear, the maternal responses included anxiety, denial, shock and disbelief, sadness, anger, envy, and guilt, which Miles related to a four-stage process of appraisal and reappraisal. Mothers described their experiences and feelings of having a baby with severe CHD as it related to their baby's diagnosis, changing health status, and outcome. Mothers who found out about their baby's CHD antenatally started out in the Anticipation Stage as they waited for their baby with CHD to be born. The Provocation Stage occurred when the professionals diagnosed the baby with CHD or confirmed the antenatal diagnosis. The Unfolding Stage involved the mothers' appraisals and reappraisals of threat in response to the baby's changing condition in the intensive care unit. During the final Outcome Stage, the baby's condition became more stable or the baby died, and thus, the mothers' appraisals of threat were reduced or realized. I await the published report of this study to learn more of Miles' conceptualization of the four stages and whether the maternal experience differed if the baby's CHD was diagnosed antenatally or postnatally.

The simultaneous fear of losing their baby and a sense of a growing attachment to their baby was one of the conflicting responses of eight fathers of infants with severe CHD (not including HLHS) whom Clark and Miles (1999) interviewed as part of their

larger longitudinal study of parenting medically fragile infants. Although not specified in the article, fear may have also contributed to the other conflicting or paradoxical responses described in this qualitative study. Fathers felt the need to maintain control in the face of their infants' serious illnesses by continuing to work and keeping up with normal day-to-day activities. Simultaneously, the fathers felt no sense of control over their infants' illnesses and had to entrust their sick infants' life to the nurses and doctors. These fathers felt a compelling responsibility to remain strong for others, particularly the mothers, and to hide their emotional distress and needs: "'I need to be the focal point, I need to be the ... the steady... one of the group'" (p. 11). The strength of this study is its inclusion of fathers and the longitudinal data collection (i.e., the data for this analysis was from interviews while the baby was in the hospital and when the baby was 12 months old). The specific diagnoses of the eight infants of these fathers did not include HLHS, and Clark and Miles do not address the fathers' experience of antenatal diagnosis as Miles did in reporting the experiences of the mothers in this same study.

In the reviewed literature, the researchers have documented, both qualitatively and quantitatively, some of the common or shared emotional responses in parents of children with CHD. The more recent inclusion of fathers in the research is significant, and acknowledgement of the antenatal diagnosis of CHD is encouraging. None of the studies, however, included children with HLHS.

CHD and Parenting Stress

I reviewed five published studies that involved quantification of the stress experienced by parents of children with CHD. Goldberg, Morris, Simmons, Fowler, and Levison (1990) used the Parenting Stress Index (PSI) to compare parenting stress scores

of three groups of parents of children less than one year of age. One group of parents had children with cystic fibrosis (n = 15). Another group had children with CHD (n= 26) and the third group consisted of parents with "healthy" infants (n = 30). Both parents of all the children completed the PSI and there were no differences detected between the scores of the mothers and fathers. The parents of children with CHD reported the highest level of stress among the three groups of parents, and Goldberg et al. related this finding to the threat to life and uncertainties about outcomes that are associated with the diagnosis of CHD. Although cystic fibrosis is life threatening later in life, the researchers suggested that the lack of immediate threat to life and a hope for better treatment or a cure in the future contributed to the lower stress scores for parents of children with cystic fibrosis. The researchers did not analyze the statistically significant difference in parenting stress scores among the three groups to specify which groups differ. Review of the mean scores indicates that there may be significant differences between the CF group and the control group (225.7 vs. 204.0), and between the CHD group and the control group (228.5 vs. 204.0). There probably is not, however, a significant difference between the CF and CHD group (225.7 vs. 228.5). Thus, the conclusions about why parents with CHD have higher stress scores than parents with CF are not warranted. More appropriate would be statements about stress related to fear of death for both the CHD and CF group in comparison to the control group.

Morelius, Lundh and Nelson (2002) compared parents (i.e., 20 fathers, 25 mothers) of children with serious CHD (i.e., child has had a conduit replacement) with parents (i.e., 25 fathers, 31 mothers) of children with less serious CHD (i.e., child has a ventricular septal defect) using a Swedish version of Abidin's PSI, the Swedish Parenthood Stress

Questionnaire (SPSQ). Children in the study ranged from 0-9 years of age. There were no significant differences in the parenting stress scores between the two investigated groups. There also was no difference between the fathers' and mothers' parenting stress scores. These researchers concluded that parents should be offered the same amount of nursing time and intervention irrespective of the severity of the child's CHD. The strength of this study was that both mothers and fathers were included in the research and the mother and father data were analyzed separately. The researchers indicate that the SPSQ has been used to measure parenting stress in parents of "small children," but they do not use those results or any norms to situate the parenting stress scores of parents of children with CHD.

Nurse researchers Uzark and Jones (2003) administered Abidin's PSI to parents (70 mothers and 10 fathers) of children aged 2-12 years of age with CHD (41 simple CHD; 39 complex CHD). The parents in this study, irrespective of grouping, reported excessive parenting stress when compared to normative data. As Morelius et al. (2002) found, parenting stress was not related to the severity of the child's CHD. Additionally, stress was not related to the time elapsed since the most recent surgery or the family's socioeconomic status. Parents of older children reported higher stress that those of younger children. The strength of this research is the discussion of the findings related to clinical concerns of parenting when one fears for the child's life. The weaknesses of the study include the low number of fathers, which precluded the comparison of mother and father data.

Carey, Nicholson and Fox (2002) also employed the PSI in their comparison study of mothers of children with moderate to severe CHD and mothers of healthy children (30

mothers in each group). The findings were similar to Morelius et al. and Uzark and Jones; there were no differences in parenting stress levels related to child rearing between the two groups of mothers. The qualitative interview data in this study, however, did show differences between the two groups of mothers. The main themes identified for mothers of children with CHD included the unexpected, vigilance, uncertainty, positive outlook, normalization and stress. The main themes for mothers of healthy children included temperament, strains, rewards, expectations, discipline, and comparisons. The different findings between the quantitative and qualitative facets of this study raise further questions: Is there enough known about parents of children with CHD to determine that the PSI is the measure of choice? Does the PSI tap into the right dimension of parenting? What is the role of qualitative research in further investigation of parenting children with CHD?

Lawoko and Soares (2003) used a quality of life measure rather than a specific stress measure. They found a difference between fathers and mothers of children with CHD in their comparative study of parents of children with CHD (667 mothers and 424 fathers), parents of children with other diseases (n = 112 mainly with asthma and allergy) and parents of healthy children (n = 293). Parents of children with CHD reported lower quality of life than parents of healthy children. Mothers reported lower quality of life than fathers did, with the lowest levels among mothers of children with CHD. The large sample size, multiple measures (i.e., The Goteborg Quality of Life Scale; The Schedule for Social Interaction: The Symptom Check List-Revised; The Hopelessness Scale) and comparison groups allowed multivariate analysis that revealed distress, hopelessness and

financial situation as being more important in explaining reduced quality of life than gender of parent or presence and severity of the child's CHD.

In summary, these studies suggest that parents of children with CHD have high levels of stress and report a lower quality of life than parents of healthy children but the level of stress is not related to degree of severity of CHD. These studies also indicate that mothers may be more severely affected than fathers.

CHD, Parents and Parenting

As researchers have explored the relationship between the diagnosis of CHD and parental responses of fear and stress, they have also investigated the influence of CHD on parents and parenting. More specifically, research has focused on the interrelationships between mothers' perceptions of their children's CHD and their children's adjustment (Linde, Rasof, Dunn, & Rabb, 1966; DeMaso et al., 1991; Goldberg, Simmons, Newman, Campbell & Fowler, 1991; Lobo, 1992), as well as research relating to parenting demands created by CHD (Pinelli, 1981; Stinson & McKeever, 1995; Svavarsdottir & McCubbin, 1996).

In an early study with a large sample size and comparison groups, Linde, Rasof, Dunn, and Rabb (1966) found that maternal attitude had more impact on child adjustment than the severity of the child's CHD. Variables describing child adjustment and maternal attitude were devised and measured across four groups of children as part of a five-year developmental analysis of children with cyanotic CHD. The study group consisted of 98 children with severe CHD, as specified by "marked cyanosis and physical handicap" (p. 92). A second cardiac group consisted of children with CHD who had some deficits but no cyanosis. A group of 121 well children represented 81 normal siblings of the children

with CHD and 40 children referred from a well-baby clinic. Using simple correlational analysis as well as canonical analysis, Linde et al. concluded that limited coping of the child with CHD was related to maternal anxiety, more pampering and more protective behaviours of the mother towards the child. Additionally, maternal anxiety was the best predictor of maternal protectiveness, and maternal and child anxiety were related. "Maternal anxiety seemed related to the presence rather than severity of the heart condition" (p.101). The limitation of this study is the use of a seven-point rating scales for which Linde et al. provided no reliability or validity information. DeMaso et al. (1991) subsequently addressed this limitation in their research.

In DeMaso et al.'s (1991) replication study, the researchers hypothesized that mothers' perceptions of their children's illness would be a more significant predictor of their children's emotional adjustment than medical severity. Mothers of 99 children with CHD (ranging in age from 4-10 years) completed the Child Behaviour Checklist (CBCL), PSI, Parental Locus of Control Scale, and a measure of perception of the medical severity of their child's CHD. Using multiple regression techniques, DeMaso et al. found that maternal perceptions were more potent predictors of a child's emotional adjustment (as measured by the CBCL) than medical severity. Maternal perceptions accounted for 33% of the variability in child adjustment while medical severity accounted for only 3% of the child adjustment variability. Despite their utilization of tested tools with a large sample of mothers, the authors made no recommendations for supportive interventions for parents or mothers.

In contrast, Goldberg et al. (1991) made clinical and research recommendations when they found that significantly fewer infants (12 to 18 months of age) with CHD, in

comparison with a matched sample of healthy infants, were considered to have secure relationships with their mothers. Goldberg et al. recommended early attention to social development and to parent-infant relationships as well as "further exploration of parental conceptions and feelings about CHD to expand understanding about how an infant's CHD affects the family" (p. 665). Goldberg et al. based their study conclusions and recommendations on their observations of 42 infants with CHD and 46 healthy infants in a standardized laboratory setting with their mothers, as well as on results of the PSI and Rutter Health Questionnaire that the mothers completed.

Another study that authors frequently cite regarding the demands of parenting children with CHD is Lobo's (1992) descriptive comparative study of mother-infant interaction during the feeding of infants with CHD and healthy infants. Ten mother-infant dyads were observed in a laboratory setting as the mother fed her infant, and the investigator evaluated the parent-infant interaction using the Nursing Child Assessment Feeding Scale, a reliable and valid instrument consisting of four mother subscales and two infant subscales. Infants with CHD scored significantly lower than controls on the infant scales of Responsiveness to Caregiver and Clarity of Cues, a finding which meant that the infants with CHD were less responsive with their mothers than the healthy infants and provided their mothers with less distinct cues than did the healthy infants. Mothers of infants with CHD scored significantly lower on the Social Emotional Growth Fostering scale, which meant that they engaged in less play or affectionately engaging social interaction with their infant during feeding. Based on these findings, Lobo recommended teaching parents of babies with CHD to interpret the infants' cues and to identify the parental behaviours that encourage the baby to continue feeding. Lobo also

acknowledged the weakness of this study in that it measured one point in time for these mothers and babies, and recommended investigation of the development of parent-infant interactions over time in both feeding and non-feeding situations. Feeding is but one thread in a complex web of parenting challenges that have not been fully acknowledged in families with a child with CHD and have been hardly acknowledged in families living with a child with HLHS.

Svavarsdottir and McCubbin (1996) provided a more comprehensive view of parenting and CHD in their examination of the relationship between caregiving demands, family system demands, and parental coping behavior in 71 families who had an infant one year of age or younger with CHD. In this well-designed, well-sampled and effectively presented study, family demands were measured by the Family Inventory of Life Events, caregiving demands by The Care of My Child, a modification of the Caregiving Burden Scale, and parental coping by the Coping Health Inventory for Parents. The fathers in this study reported that their most time-consuming and difficult caregiving task was providing emotional support for their spouse or partner. The mothers in this same study reported that their most time-consuming task was providing for the physical needs of the baby (i.e., those of feeding, diapering, and bathing/dressing). Their most difficult task, however, was providing emotional support for their spouse or partner, followed closely by managing their child's crying, irritability or moodiness and feeding their child. No children with HLHS were included in the sample. As well, the sample is more reflective of the first few months of life rather than the first year of life, with the mean age of the infants being 4 months and 3 weeks. Although the Caregiving Demands scale included "observing/reporting symptoms, progress of the child" the information

needs of parents documented in other studies (Pinelli, 1981; Stinson & McKeever, 1995) did not emerge in this study.

Parental information needs regarding their child's CHD was the main finding in two Canadian nursing studies (Pinelli, 1981; Stinson & McKeever, 1995). Pinelli (1981) interviewed 10 mothers of hospitalized newborns with CHD before and after assuming their care at home to determine mothers' concerns regarding their care-taking tasks. The main concern of these mothers, as expressed in the semi-structured interviews, was learning how to anticipate and recognize the needs of their babies. Pinelli concluded that the mothers lacked confidence because of their inability to differentiate between the normal needs of their newborns and the needs associated with their baby's CHD. The aspects of care-taking that the mothers were most concerned about included symptomatic behaviour of the heart disease; feeding, nutrition and weight gain; surgery; normal infant care; medication; crying; and understanding their baby's CHD. Of note is that the mothers expressed more concerns one month after discharge than before discharge from hospital.

In contrast to this study outcome is Stinson and McKeever's (1995) finding that mothers' understanding scores and caregiving comfort levels were significantly higher post-discharge as these mothers settled into their role of vigilant observer and caregiver after their baby had heart surgery. The investigators in this study administered the Mothers' Information Needs Instrument (MINI) and the Comfort/Readiness Scale shortly before and after discharge to 30 mothers. The mothers' increased understanding post-discharge may be attributed to an unplanned intervention that was employed when the mothers' pre-discharge ratings of their understanding of crucial items were low. Nurses

provided these mothers with additional teaching to ready them for discharge. There is no indication that any of the mothers had antenatal knowledge of their baby's CHD or need for surgery, nor do the authors describe the severity of the babies' heart problems.

In summary, we need to enrich the conceptualizations and theories about the parenting children with complex heart disease. Studies that involve qualitative analysis of interview data are needed in addition to the studies already done that employ pre-determined conceptual frameworks and structured data collection tools. We also need to include parents who found out about their baby's CHD antenatally to determine whether the antenatal time influences parents' experience of parenting their baby with CHD. Additionally, in light of the research that demonstrated differences between mothers and fathers as they parented their children with life-threatening congenital anomalies including CHD (Clark & Miles, 1999; Miles, 2000; Svavarsdottir & McCubbin, 1996), we need to consistently gather data from both fathers and mothers. We also need accounts of fathers and mothers' parenting experiences beyond the first year of their child's life to gain a sense of the ongoing nature of parenting children with life-threatening conditions.

I will now broaden this literature review to research on parenting children with congenital anomalies such as spina bifida, Down syndrome, and cerebral palsy. This body of literature has the theoretical depth that is lacking in the literature about parenting children with CHD. Although this research also focuses largely on the mothers' experience of parenting there are cohesive themes related to parenting expectations that are not met when a child is born with a congenital anomaly. I will discuss parenting

expectations and grieving the loss of the "perfect newborn" before highlighting the research on parenting children with congenital anomalies.

Parenting Expectations

Most individuals planning to be parents have images and expectations of their anticipated children. Child development psychologist Galinsky (1987) described parenting as an experience that either does or does not fulfill these expectations and images. Galinsky's child development background and personal experience of parenting motivated her to examine parenting from a developmental perspective. Galinsky interviewed a diverse sample of 228 American fathers and mothers with 396 children (10 to 40 children of each age group, from in-utero to 18 years old). These parents had varied marital status and parenting experiences (i.e., they were married, divorced, or widowed, and step, foster, adoptive or guardian mothers and fathers), were from different age groups (i.e., they ranged from teen parents to older parents), and were expecting their first child or already had children. They came from different economic, ethnic, racial, geographical and religious backgrounds. Galinsky sought to form a theory on growth in parenthood in relation to the growing child. Based on analysis of her interview data and extensive review and discussion of child and human development literature, she described six stages of parenting.

Galinsky's first two stages of parenting (Image-Making and Nurturing stages) are especially relevant to parenting children with congenital anomalies and, more specifically, life-threatening heart disease. The tasks in these stages relate to forming images and expectations before birth, and then reconciling these with the actual baby. Galinsky concluded that during pregnancy, parental images of the anticipated baby and of

delivery are a rehearsal. Parents base these images on memories of their childhood, as well as their particular circumstances and culture. Several men and women in Galinsky's study spoke of images reflecting their fear of giving birth to a child with a congenital anomaly: "'I dreamed that the baby was born and didn't have any legs'" (p. 28). According to Galinsky, these images, both positive and negative, help parents to accept the separateness of the baby, prepare for their changing roles, form feelings for the baby, prepare for the birth, and thus prepare themselves for parenthood.

To illustrate the Nurturing Stage of parenting, Galinsky included narrative data from fathers and mothers that showed that parental attachment to the baby occurred as parents reconciled the actual birth with the imagined birth and the actual or "reality" baby with the imagined, hoped-for, and dreamed-about baby. Galinsky related the experiences of a mother of a baby with a cleft palate and a mother of a baby born with a malformed stomach to illustrate the challenge that parents have to face in order to resolve the discrepancy between the imagined and actual baby.

Galinsky's theory of parenthood sensitizes us to the potential problems that can occur when a baby is born with anomalies that do not fit the parents' images and expectations of a "perfect" baby. The main strength of this study is that Galinsky interviewed a large and diverse sample of fathers and mothers at all stages of their children's lives and discussed her findings and theory of parenthood in relation to an extensive body of literature, both theoretical and research. However, the broad scope of this study prevented an in-depth description of the experience of parents whose child had a specific health concern.

Researchers have not further developed Galinsky's work on parenting expectations. Readjustment of expectations regarding the baby, however, is central to the literature pertaining to parental grieving when a baby is born with a congenital anomaly. In this case, the received or "reality" baby does not measure up to the imagined and expected baby. Many scholars conceptualize the reconciliation of images of perfection with the received "imperfect" baby as grieving.

Grieving of the Loss of the Imagined "Perfect" Child

Theoretical concepts and constructs of grieving and attachment permeate the literature on parents who experience the loss of a "perfect" child. When a baby is born with congenital anomalies, the unfulfilled images and unmet expectations can be a source of anger for parents (Solnit & Stark, 1961). In an early study using a psychoanalytic perspective, Solnit and Stark described the experience of mothers when they learned that their baby had Down Syndrome as the "sudden loss of the baby that was expected; and the sudden birth of a feared, threatening, and anger-evoking child" (p. 525). Solnit and Stark likened the experience of having a baby with a congenital anomaly to that of experiencing the death of a child. Unlike the child who dies, however, the "defective" child whom the parent grieves is alive and requires investment. "There is no time for working through the loss of the desired child before there is the demand to invest the new and handicapped child as a love object" (p. 526). The methods employed in this study to reach this conclusion are unclear. The researchers did not appear to interview the mothers themselves; rather, the study was based on material collected from pediatric, psychiatric, and casework contacts with mothers and their "defective children" (p. 524). Other limitations include a sample limited to mothers and a single population of children (i.e.,

those with Down syndrome). This influential study, however, alerted family clinicians to parental grieving and the need for parents to reconcile the discrepancy between their "dreamed-for perfect child" and their "less-than-perfect child."

Authors have repeatedly referred to Solnit and Stark's psychoanalytic work in review articles and in literature for practitioners that address chronic sorrow, parental grief, bonding, disappointment and the concept of "defect" (Coughlin, 1989; Fajardo, 1987; Freitag-Koontz, 1988; Horan, 1982; Jenkins, 1996; Romney, 1984; Wolcott Choi, 1978; Young, 1977). This body of literature predominantly reflects the clinical experiences and theoretical perspectives of nurses working with parents of babies who have congenital anomalies (Coughlin, 1989; Horan, 1982; Jenkins, 1996; Romney, 1984; Wolcott Choi, 1978; Young, 1977) or severe neurological impairment because of birth injury (Fajardo, 1987; Freitag-Koontz, 1988; Jenkins, 1996). Although non-research based, this practice-based literature, which hypothesizes that parents simultaneously grieve and bond with their "imperfect" newborn, does provide researchers with a theoretical construct to examine.

Some researchers (D'Arcy, 1968; Drotar, Baskiewicz, Irvin, Kennell, & Klaus, 1975; Mercer, 1974a, 1974b) have endeavoured to describe grieving and attachment from the perspective of parents. Research social worker D'Arcy (1968) interviewed 694 mothers about their experience of finding out about their baby's congenital anomaly. Congenital heart disease and spina bifida accounted for the majority of the defects (i.e., 199 babies with CHD and 194 babies with spina bifida), and most mothers learned of the diagnosis within the first few days or weeks of their baby's life. The mothers described four areas of common concerns: the need for a sympathetic and understanding approach by the

medical and nursing staff, particularly at the time the baby is born; the importance of using simple language in explanations of the baby's problems; the mother's need to ask questions; and the desire for truth "avoiding unjustifiable pessimism and unrealistic optimism" (p. 798). The main strength of this study is the extraordinarily large and diverse sample. As well, this study reflects an attempt to gain the mothers' perspective and contains many direct quotations from the mothers to validate the author's conclusions. D'Arcy questions the reliability of the mothers' recollections of what they were told at the time of their baby's diagnosis, but emphasizes the clinical importance of mothers understanding the medical information conveyed to them.

From a pediatric medicine perspective, Drotar, Baskiewicz, Irvin, Kennel, and Klaus (1975) interviewed 20 mothers and 5 fathers of 20 children with congenital anomalies including "mongolism," CHD, and cleft palate to determine parental reactions to the birth of their "imperfect child" as well as the process of parental attachment. The strength of this study is that it included both fathers and mothers. The major weakness is that the authors' assumptions regarding adaptation, grieving and attachment are so evident in the interview questions that the authors appear to be attempting to test these constructs, and yet, the sample size is small and more suited for unstructured interviews. The findings consist of a series of stages parents pass through after the birth of a "defective" child. This result is not surprising, as one of the interview questions was "Could you tell me again what stages you remember going through since the baby was born?" (p. 712).

Mercer's (1974a, 1974b) study of the responses of five mothers and two fathers to their infants with visible congenital defects (i.e., Apert's syndrome, a third naris, "mongolism," absence of fingers and cleft lip) represented pioneering nursing research.

Mercer employed nondirective interviewing and direct observation in thirteen contacts with each mother and baby over the first three months of the baby's life. In the course of the study, Mercer also observed the responses of two fathers. Mercer found that mothers of infants with congenital defects demonstrated more attachment behaviours than aversion behaviours during the first week of their baby's life (79.4 per cent as compared to 20.6 per cent) and that these proportions changed very little over the three-month observation period (1974a).

One of the two fathers in Mercer's study (1974b) also demonstrated behaviours of attachment. For example, one father considered similarities in appearance between his baby with Down syndrome and his healthy older daughter. Although Mercer acknowledged the grief reaction of parents to their children with defects, none of her findings from the mothers related to grief. The main discussion of her observations of the fathers, however, did relate to grieving. One father seemed able to express feelings of grief while the other father did not seem able to do so and did not support his wife in her grieving responses. Mercer concluded that the baby's anomaly was a threat to this father's masculine identity. Mercer's work contributed to further understanding of parents' responses to their babies with defects by providing insight into the nature of attachment or investing in the child and, thus, disproved the hypothesis that parents would demonstrate more aversion behaviours than attachment behaviours. The limitation of this study is that apart from a brief discussion of the father's grief reaction, Mercer does not describe or discuss the mothers' grieving in terms of its absence, even though according to Solnit and Stark (1961), simultaneous grieving and attachment is the unique aspect of the parental experience of their baby's congenital anomalies.

Diachuk's qualitative nursing study (1994) does reflect the simultaneous or paradoxical work of grief and attachment that is demanded of parents when they learn of their baby's congenital anomaly after their baby is born. Diachuk's analysis of multiple interviews with four mothers whose babies had Down syndrome, along with transcripts from a fifth mother (from another study), enabled Diachuk to propose a process of maternal role formation. Diachuk related the mothers' descriptions of their antenatally formed expectations for a healthy baby, and the role that expectations in combination with the mothers' prior experience with Down syndrome and mothering played in their initial reactions. These reactions included shock, denial, grief, fear, disappointment, and shame. Although Diachuk did not discuss these responses under the larger construct of grief, she provided data that showed how the mothers came to terms with these intense feelings as they became more involved in caring for their babies and therefore more attached. In contrast to Solnit and Stark's (1961) conceptualization of the mothers' need to simultaneously grieve and attach through caregiving involvement as the core challenge faced by these mothers, Diachuk conceptualized the need to get involved with the reality baby as a way of coming to terms with the loss of the expected baby. Although grief is inevitable, the presence of the baby necessitated increasing maternal involvement and attachment, which in turn helped the mother accept the baby's diagnosis, according to the mothers in Diachuk's study. The strength of this comparison lies in the fact that both Solnit and Stark's (1961) and Diachuk's (1994) studies are of mothers of children with Down syndrome. Limitations of both studies are that fathers were not included in the studies and both studies reflect particular historical periods that render the results less relevant today. Solnit and Stark's study included parents of children born in the 1960s,

when the stigma of Down syndrome was such that professionals encouraged parents to institutionalize children with handicaps such as Down syndrome. Diachuck's article reflects a time when few congenital anomalies were diagnosed during pregnancy, in contrast to the 940 congenital anomalies that are currently detectable during pregnancy (Weaver, 1999). Parental grieving and attachment may differ if the diagnosis of congenital anomalies is made antenatally and this needs to be examined.

Grieving, Attachment and Antenatal Diagnosis of Congenital Anomalies

Technology to detect fetal abnormalities became increasingly available in the 1980s. Although few viable treatments or interventions exist for the fetus, specialists have long argued the benefits for the fetus in terms of planning the timing, mode and location of delivery so that tertiary care is immediately available for the baby (Goldberg & Gomez, 2003; Lin & Garver, 1988; Simpson, 1998). However, the literature shows that benefits for prospective parents who find out about their baby's congenital anomaly remain mixed. Many studies express concern for the mothers' emotional well-being, particularly their grief responses. Griffiths and Gough (1985), neonatal surgeons, presented six case reports of fetal diagnoses. The mothers' "enormous feelings of fear, guilt, and inadequacy" (p. 624) despite the professional's reassurance that "the eventual outcome could be satisfactory" caused Griffiths and Gough much concern. Hence they concluded that the news of the fetal abnormality benefited the mother only if this information resulted in termination of the pregnancy. Griffiths and Gough did not discuss the mothers' emotional responses in terms of a grief response as occurring regardless of when the diagnosis occurs, antenatally or postnatally. Another weakness of this study is that Griffiths and Gough did not interview the mothers. Rather, the case reports were

descriptions of medical events from the time of antenatal diagnosis until the specialists confirmed the antenatal diagnosis after birth and commenced treatment for the child's health problem.

Nurse researcher Matthews (1990) did interview mothers in her study of women's antenatal experience of congenital anomalies. Using a phenomenological approach, Matthews interviewed 20 women who knew about their baby's congenital malformation antenatally; five were still pregnant, and 15 women had already delivered their baby. Matthews described an Expectancy of Loss Model based on her interview data and concluded that the information that the women received during pregnancy regarding their baby's congenital anomaly influenced them positively. The antenatal information provided a basis for decision-making, allowed for the initiation of anticipatory grief reactions, and helped to decrease the mothers' guilt and self-blame. As well, these mothers were reassured regarding the care the baby would receive at birth because the physicians were informed of and prepared for the baby's problem before the baby was born. The strength of this study is that interview data from a relatively large sample enabled a rich description of the women's experience of antenatal diagnosis (e.g., the phases of uncertainty, verification, preparation, reconfirmation, reparation, and resilience). The limitations of the study are that it was restricted to mothers, and the infants' congenital anomalies were all of a severe nature, most babies dying shortly after birth. The mothers had little time to invest in or develop an attachment to their babies after birth. We, therefore, did not gain further knowledge about the simultaneous grieving and attaching parents must engage in, especially when antenatal knowledge of congenital

anomalies influences this process. Fathers' perspectives of their experience of antenatal diagnosis of congenital anomalies of varying severity are also needed.

In a qualitative study designed to discover and describe how prospective fathers and mothers managed their experience of learning of their baby's CHD during pregnancy we found that parents approached their antenatal decisions as their first parenting decisions (Rempel, Cender, Lynam, Sandor, & Farquharson, 2004). Mothers and fathers of 19 babies with antenatally diagnosed CHD (one baby was diagnosed with HLHS) participated in interviews during pregnancy and after the birth of their baby. These parents made their decisions with differing degrees of apparent ease or deliberation, and some parents more readily sought the opinion of professionals. The offered opinions offended some parents, even though the professionals may have intended the information as descriptive of options, not suggestive of a particular decision. Despite the life-threatening nature of some of the babies' diagnoses in this study, parents were determined to continue their pregnancies if only to have some time with the baby before she or he died (i.e., one baby had a lethal chromosomal anomaly in addition to CHD). The baby with HLHS died after her newborn surgery.

Many questions on the experience of parents over time, however, remain. The influence of antenatal diagnosis and other increasingly available high technology care on parenting expectations and experiences of grief and attachment during infancy and later years is unknown. According to Galinsky (1987), parents' initial reactions to their baby's CHD, whether in the antenatal or postnatal period perhaps, is a phase of parenting. Diachuk (1994), however, intimates that these initial reactions of shock, denial, shame, fear and disappointment keep parents from embracing their parenting role --"initial

reactions dampened [the mothers'] desire to take on the maternal role and influenced their attachment to their infants" (p. 240). Research addressing these questions for families with infants with heart defects is not yet available. Parenting research related to other congenital conditions (although not inclusive of the antenatal experience) however, is instructive and thus merits review at this point.

Parenting Children with Congenital Anomalies and Disabilities

I chose to review literature pertaining to parenting children born with congenital anomalies that lead to disability, rather than other bodies of literature, for two reasons. First, health care professionals offer termination of pregnancy as one choice to parents of children diagnosed antenatally with congenital anomalies such as Down syndrome and spina bifida as well as with the lethal cardiac defect of HLHS. Second, the notion of paradox permeates the literature on congenital anomalies that result in disability, similar to the paradox parents of newborns with congenital anomalies experience as they embrace their "imperfect" baby while simultaneously grieving the loss of their expected healthy baby. "Parental straddling" (Johnson, 2000), "staying in the struggle" (Monsen, 1999), "reluctantly taking charge" (Burke, Kauffmann, Costello, & Dillon, 1991), "normalization through accommodations" (Deatrick, Knafl, & Walsh, 1988), "the embrace of paradox" (Larson, 1998), "construing reality loops" and "transformed parenting" (Young Seideman & Kleine, 1995) all depict constructive and proactive parenting of "imperfect" children for whom their parents simultaneously grieve and hope. I will review these studies for their contribution to our knowledge on parenting "imperfect" children and identify the strengths and weaknesses in this body of literature.

The paradoxical nature of parenting "imperfect" children was described as "parental straddling" in Johnson's (2000) grounded theory analysis of telephone interview data from 10 mothers of disabled preschool to elementary age children. These children had a wide range of conditions (including spina bifida) that resulted in mild to moderate physical disabilities without mental retardation, and mainstream involvement in "normal" school activities. Mothers "straddled" living in the past (i.e., being preoccupied with the child's birth, diagnosis, and developmental milestones) and living day-to-day (i.e., facing the challenges associated with parenting a child with a disability). Mothers needed to address feelings and issues experienced by both themselves and their child. In addition, mothers were challenged by the paradoxical goal to treat their child normally despite all that was not normal in the child's life. Although Johnson used a small sample size for grounded theory analysis, especially considering that each child had a different diagnosis, her research contributes to our knowledge of the concurrent challenges presented by disability and parenting towards normalcy that require "parental straddling." Theoretical sampling to include fathers, children from a broader age span, and parents who found out about their child's disability antenatally would strengthen this study.

Mothers of children with spina bifida in Monsen's (1999) study similarly faced the paradox of trying to treat their child like other children while struggling not to lose hope for a meaningful future for their child. Hermeneutic analysis of interviews with 13 mothers of children (12 to 18 years of age) with spina bifida depicted parenting as "living worried." Constant day-to-day worry regarding their children's future led these mothers to advocate for their children's inclusion in school and peer circles and to constantly resolve within themselves not to give up their struggle for their children's self-

sufficiency. Monsen's research alerts us to the possible debilitating consequences of living with constant worry during the struggle to normalize children with spina bifida, including the potential for exhaustion, hopelessness, defeat, and resignation. Monsen's research does not address the perspective of fathers or the influence on parenting choices of present-day availability of antenatal diagnosis for spina bifida. Additionally, the influence of more acute and episodic conditions as pertains to parenting children with CHD was not addressed in this research with parents of children with spina bifida.

Unpredictable fractures and hospitalizations are common for children and adolescents with osteogenesis imperfecta, the focus of Deatrick, Knafl, and Walsh's 1988 study. Parenting in this population was characterized by the constant tension parents experienced between trying to accomplish things with or for one's child in the presence of barriers such as parental time constraints, acute and episodic exacerbations and set backs. Deatrick et al. further developed their theory of normalization (Knafl & Deatrick, 1986) by analyzing semi-structured interview data from 12 mothers and 6 fathers of 15 disabled children (age ranging from 4-21 years). The goal of normalization is to integrate the child into the family rather than making him or her a "special nucleus." The inclusion of fathers in this study and the age range of the children are strengths of this study. Parents in this study identified recurring illness exacerbations (i.e., fractures, hospitalization for surgery) as a threat to their preferred management style of normalization. The unique nature of osteogenesis imperfecta suggests that investigators should conduct further research to verify the behavioural strategies used by parents in Deatrick et al.'s study to normalize the life of a child with chronic, disabling conditions other than those typically studied.

Periods of hospitalization are common for disabled children and the research of Burke and her nursing colleagues (Burke et al., 1991) illuminated the threat that occurs during illness. In their grounded theory research study, mothers of disabled and chronically ill children described having to constantly monitor the hospital staff to protect their children from hazards or "hazardous secrets" inherent to the hospital setting. According to the mothers, the hazards included not receiving complete information about their child's diagnosis, medications and treatments, disturbing gaps or inconsistencies in their child's care without adequate explanation, and inexperienced health care professionals. The mothers in this study straddled, to use Johnson's (2000) term, advocating for their child and fearing the alienating label of "trouble maker." These mothers constantly evaluated the health care professionals, the care situations, and how their child was responding in each care situation, and made judgements and decisions about leaving the professionals in charge or "reluctantly taking charge" themselves. Burke et al.'s extensive theoretical sampling over a four-year period (1985-1989) is a strength of this research. They tested their emerging grounded theory prospectively through interviews and participant observation with nine mothers from two to three weeks before their child's planned hospitalization to two weeks after the hospitalization. Repeated hospitalizations are now less common for disabled and ill children than was the case during the time of Burke et al.'s research. Additional study of both the mother's and father's perspective of the health care provided in community, school and home settings for these children would further our understanding of parenting "imperfect" children.

Two studies have identified positive aspects of parenting children with disabilities (Larson, 1998; Young Seideman & Kleine, 1995). In their grounded theory study, nurse

researcher Young Seideman, and educational psychologist Kleine, (1995) sought a comprehensive understanding of the total experience of parenting in order to complement previous research on specific components (i.e., those of stress, coping, chronic sorrow, and adaptation) of parenting a child with developmental delay/mental retardation (DD/MR). They proposed a Transformed Parenting Model based on interviews with 29 mothers and 13 fathers of 31 children, 10 months to 69 years of age, who had mild to profound mental retardation. The strength of this study is in its large sample size and the range of parental experience across the life span of the children with DD/MR. The resulting model theorizes (1) an Entrance or initiating process when the parents receive the child's diagnosis, followed by their response to it and (2) the ongoing Performance process, characterized by reality-construing processes that influence and are influenced by contextual and operating processes. This model contributes to a positive perception of parenting, that is, "transformed parenting." The word "transformed" refers to the changes in the parenting role that extend beyond the parents' "original or envisioned role expectations to a new form of parenting" (p. 39).

Larson's research (1998) also portrays a positive reframing of parenting an "imperfect" child. Larson used the phrase "the embrace of paradox" to depict the parenting experience of six Mexican mothers parenting "high burden" children with disabilities (i.e., cerebral palsy-spastic quadraparesis, spastic quadraparesis, blindness and global developmental delay, and autism). Larson's theoretical construct, "embrace of paradox," not only described the mothers' paradoxical experience of parenting their disabled children, but also portrayed the motivating force or internal striving to maintain hope. The very tension between loving and accepting the child as he or she was and

wanting to "erase the disability," dealing with the incurability of the condition while pursuing solutions, or remaining hopeful in the presence of negative fear-producing information supported the mothers' optimism and the drive needed to parent their "imperfect" children. Although in-depth analysis of what appears to be rich data from her six case studies provides a meaningful theoretical construct for consideration, Larson does not discuss the unique contribution of the women's common cultural and, perhaps, religious or spiritual background to the findings.

The strength of the body of qualitative research reviewed, which describes parenting "imperfect" children, is the depth of conceptual analysis and similarity of the concepts or themes identified (i.e., straddling, struggling and paradox; normalcy and normalization). I do not find this same conceptual cohesiveness in the body of literature about parenting children with CHD, except for the theme of fear for the child's life.

Summary

In summary, the body of literature reviewed in this chapter represented a variety of well-designed qualitative and quantitative studies. Although there is a growing body of literature about parenting children with severe health issues, including some studies on what it is like to parent children with CHD, there is a lack of research on parenting children with HLHS. Qualitative research with indepth interviews of parents of children with HLHS will provide us with a fuller description of parenting experiences because the perspective of the parent is sought without the overlay of previous concepts and theories. Parents who found out about their baby's HLHS antenatally as well as parents who learn about their infant's condition at birth should be included to see if the extra time that parents have antenatally influences their experience of parenting. To address some of the

other limitations in the literature there is a need to include more fathers in studies and to include parents of children from infancy to school age to see if there are differences in the parenting over time.

Research Question

The research question, therefore, guiding this study is: What is the process of parenting a child with HLHS whose care and treatment includes the Norwood surgical approach?

CHAPTER THREE

RESEARCH METHODOLOGY AND METHOD

Increasingly complex health conditions and health care contexts require a sophisticated and comprehensive body of nursing knowledge to inform and transform our practice and research. Knowledge for nursing practice derived from the natural science paradigm of positivism/post-positivism alone is insufficient to address complex health and illness concerns and contexts in nursing (Schultz, 1987; Silva, 1977, 1999). A shift from a single paradigm to the acceptance and utilization of multiple perspectives for knowledge development in nursing has expanded the possibilities for inquiry. Each paradigm's distinct philosophical underpinnings uniquely shape inquiry and result in diverse knowledge as well as practical and moral imperatives for practice (Allen, Benner & Diekelmann, 1986; Anderson, 1999; Baker, Norton, Young, & Ward, 1998).

Theorists and philosophers from within nursing and other disciplines conceptualize the various paradigms somewhat differently. Mitchell and Cody (1992) refer to a human science paradigm as distinct from the natural science paradigm and counter Gortner and Schultz's (1988) position that human science constitutes the fields of biology, psychology, anthropology, and sociology. Mitchell and Cody argue for a narrower definition pertaining to the study of human life as lived experience with interwoven patterns of meanings and values. They intimate that a more unified nursing perspective such as the human science paradigm has the potential to further nursing science. Allen et al. (1986), on the other hand, advocate for a pluralistic perspective of research methodology. They describe three paradigms, those of the empirical-analytic paradigm, the interpretive paradigm, and the critical social theory paradigm. Similarly expressed is

Coyne, Immelt, Stashinko, and Campbell's (1999) delineation of three methodological paradigms, those of prediction, comprehension and emancipation. Social scientists, Guba and Lincoln (Guba & Lincoln, 1994; Lincoln & Guba, 2000), describe four paradigms, those of positivism, post-positivism, "critical theory et al.," and constructivism.

I will conduct my inquiry related to parenting children with hypoplastic heart syndrome (HLHS) from the comprehension or constructivism paradigm, using constructivist grounded theory. I will apply the distinction that philosophers have made between methodology and method (Harding, 1995) to discuss the philosophical and practical aspects of my proposed research. In this chapter I will discuss constructivist grounded theory from the perspective of method and methodology. I will then describe its application in the conduct of my research project.

Method and Methodology

"Method" is "a technique for gathering evidence" (Harding, 1995, p. 111), while "methodology" is "a theory and analysis of how research does and should proceed" (Harding, 1987, p. 3). From a feminist perspective, Harding provides examples of influential feminist researchers' utilization of methods of interviewing, observing or reviewing of records, pointing out that these feminist researchers have actually been using traditional research methods. Nursing scholars have transformed traditional research methods, such as grounded theory, into new research processes that feminist methodology informs (e.g., Keddy, Sims, & Stern, 1996; Wuest, 1995). The philosophical underpinnings, therefore, of one's particular inquiry do not reside in the method. Rather, the influence of one's chosen perspective or methodology on method is the notable factor. Using social constructivist methodology, Charmaz (1983, 1990,

1995a, 1995b, 2000) has transformed the traditional research method of grounded theory developed by Glaser and Strauss (1967) from a positivist/post-positivist mode of inquiry to a more interpretive, postmodern approach to research.

As methodology transforms method, ontology and epistemology inform methodology. Particular philosophical assumptions about the nature of reality and what can be known and who can be a knower provide the methodological underpinnings fundamental to constructivism and a constructivist grounded theory.

Methodological Underpinnings of Constructivism

In contrast to the positivist perspective of a reality that exists in and of itself, a constructivist conception of reality "assumes the relativism of multiple social realities" (Charmaz, 2000, p. 510). There is no single, "true," objective, or external reality that is awaiting discovery. Rather, realities are created and therefore "dependent for their form and content on the individual persons or groups holding the constructions" (Guba & Lincoln, 1994, p. 110-111). "Constructions," "co-constructions," or '"research findings" therefore are alterable and reflect the ongoing changes of their associated "realities" as well as ongoing change in "the viewed" and "viewer" (Charmaz, 2000). What one can know, therefore, cannot be viewed apart from the knower or viewer because knowledge is mutually created or constructed between the viewed and the viewer (i.e., the researcher and the participant) and becomes "an image of *a* reality, not *the* reality" (Charmaz, 2000, p. 523). Images therefore, may also change as their "constructors become more informed and sophisticated" (Guba &Lincoln, 1994, p. 111) or more intuitive and open to further impressions (Charmaz, 2000).

Guba and Lincoln (1994) précis the aim of constructivist inquiry as "understanding and reconstruction" (p. 112) and the nature of knowledge within this paradigm as "individual reconstruction coalescing around consensus" (p. 112). Knowledge accumulation occurs through ongoing formation and juxtapositioning of new and various constructions. This dialectical process in itself has evaluative, "quality control" features (Guba & Lincoln, 1989, p. 244), but Guba and Lincoln (1994) acknowledge the issue of determining appropriate criteria for judging the quality of constructivist inquiry. They suggest that "trustworthiness" criteria that parallel positivist concepts of reliability, validity and objectivity are inadequate. Instead, they espouse "authenticity criteria of fairness, ontological authenticity (enlarges personal constructions), educative authenticity (leads to improved understanding of constructions of others), catalytic authenticity (stimulates to action), and tactical authenticity (empowers actions) (Guba & Lincoln, 1989)" (p. 114). Guba and Lincoln (1994) acknowledge that the latter two criteria of catalytic and tactical authenticity overlap with criteria for the critical theory paradigm, again making the point that this area needs further critique and refinement.

In comparing constructivism with other paradigms, Guba and Lincoln's (1994) discussion of the inquirer's voice is helpful. Within positivism/post positivism, they describe the inquirer's voice as that of the "disinterested scientist" (p. 115). The inquirer's voice in critical theory is that of "transformative intellectual" (p. 115) and in constructivism, that of "passionate participant" who is "actively engaged in facilitating the 'multivoice' reconstruction of his or her own construction as well as those of all other participants" (p. 115).

As much as some scholars (e.g., Guba & Lincoln, 1994) distinguish positivism as realist in comparison to constructivism as relativist, Charmaz (2000) argues that constructivist grounded theory remains realist "because it addresses human *realities* and assumes the existence of real worlds," albeit real worlds that are not unidimensional, nor impervious to our influence and perspective. Constructivist grounded theory, according to Charmaz (2000), "celebrates firsthand knowledge of empirical worlds, takes a middle ground between postmodernism and positivism, and offers accessible methods for taking qualitative research into the 21st century" (p. 510).

Constructivist Grounded Theory

The appeal of grounded theory lies in its tools for effective facilitation of research aimed at understanding empirical worlds (Artinian, 1998; Beck, 1996; Charmaz, 1999; Olshansky, 1996). Critiques of grounded theory abound, however, especially in relationship to its positivist underpinnings. Smith (1993) situates grounded theory within the post-empiricism paradigm for reasons Addison (1989) describes: "grounded theory seems to hold the naïve realist assumption of inductively discovering some 'basic social process' that 'emerges' to accurately describe, at a theoretical level, something that corresponds with 'reality'" (p. 42). Addison describes the research method he used to investigate physician socialization as "grounded interpretive research." Although he found grounded theory lacked the "co-constitutive" process, which is inherent in the dialogical approach of hermeneutics, he was attracted to several features of grounded theory. He valued grounded theory's purpose of generating a theory or account and "its emphasis on systematically developed, processual, contextual accounts of social behavior" (p. 42). In addition to the promise of theory generation, Addison appreciated

the methodical, yet creative activity of constant comparative analysis (Glaser & Strauss, 1967) that directs grounded theorists to constantly ask questions of comparison or fit (Glaser, 1978). Addison contends that constant comparative analysis is a central feature and strength of both grounded theory and hermeneutics and claims to have modified the shortcomings of grounded theory. In reporting his research, he emphasized his data collection methods of immersion in the everyday practices of physician residents that he followed with interviews, as well as the changes that occurred within him and within the participants because of doing his research.

From another perspective, Melia (1996) laments the way that grounded theory has become "rather programmatic and overformulaic" (p. 370). She contends that Glaser and Strauss' original (1967) and Glaser's subsequent (1978, 1992) renderings of a discovery and emergent-oriented grounded theory are different from Strauss and Corbin's (1990) more procedure and rules-oriented rendition of grounded theory. Melia feels Strauss and Corbin's procedures may be getting in the way and wonders if "the technical tail is beginning to way the theoretical dog" (p. 376).

Charmaz has addressed perceived limitations of what she refers to as "objectivist grounded theory" by developing constructivist grounded theory (Charmaz, 1983, 1990, 1995a, 1995b, 2000). She believes that constructivist methodology provides a way of reclaiming grounded theory tools from "their positivist underpinnings to form a revised, more open-ended practice of grounded theory that stresses its emergent, constructivist elements" (Charmaz, 2000, p. 510). Flexible, heuristic strategies instead of formulaic procedures enable researchers to seek meaning instead of truth. Charmaz suggests that during such a search, our conception of the empirical world we wish to study changes

"from a real world to be discovered, tracked, and categorized to a world made *real* in the minds and through the words and actions of its members" (p. 523).

Charmaz (1995a) agrees with Van Maanen's comment (1988) contending that "grounded theorists typically provide dispassionate, objectivist accounts of their data and assume that by being objective observers they will discover processes in an external world of their research participants that remains separate from themselves" (p. 31). Charmaz addresses these critiques of grounded theory as she applies and further develops key elements of traditional grounded theory, simultaneous data collection and analysis, coding, and memoing. These key elements were foundational as I used grounded theory as described by Glaser and Strauss (1967) and Glaser (1978, 1992), and transformed by Charmaz (1983, 1995a, 1995b, 2000) to guide this research project.

Based on symbolic interactionism, a grounded theory approach to research enabled me to elicit parents' descriptions of the dynamic process of parenting a child with HLHS that essentially consisted of their social interactions over time. Parents' stories of parenting their children with HLHS yielded data appropriate to grounded theory, as stories are process-oriented (Morse, 1999; Morse & Field, 1995). I invited parents to recount their parenting stories from the time of the diagnosis of their child's HLHS, which for some was antenatally, to their present day reality and activities with their child. I was able to examine changes in the parents and their parenting over time through these accounts of their parenting and through multiple interviews with the parents over time.

A constructivist grounded theory assumes parents create and maintain meaningful worlds in their efforts to make sense of their experiences and act or live within these ever-changing realizations. Data about parents' meaningful worlds provided the basis for

my analysis and theory constructions. I will now discuss the practical aspects of simultaneously collecting and analyzing data from fathers and mothers in this constructivist grounded theory study.

Data Collection

Data collection and data analysis occur simultaneously when conducting grounded theory research. Following a brief description of the setting for this study I will describe my sample and sampling procedures. I will then describe my data collection and analysis procedures in a way that further illustrates the distinctive characteristics of constructivist grounded theory.

Setting

The Cardiac Sciences programme of a 133-bed pediatric tertiary referral centre was the setting for this study and provided a ready sample from which to recruit mothers and fathers who parent children with complex congenital heart disease. In 2001, 525 cardiac surgeries were performed in this growing programme, up from 400 the previous year. The centre serves several western Canadian provinces and provided cardiology and cardiac surgery services for 150 out-of-province children in 2001, compared with 60 children in 2000.

Until November 1996, health care professionals, at the tertiary referral centre referred to in this study, offered parents of babies with HLHS compassionate care. The pediatric cardiologist involved in making the diagnosis, whether antenatally or postnatally, informed parents about the heart surgery and transplantation options available in other centres. Between 1986 and 1996, several babies with HLHS survived neonatal heart

transplantation in Loma Linda, California, and one baby went to Ann Arbor, Michigan to have the Norwood operation (L. Hawkins, personal communication, August 8, 2001).

In the fall of 1996, the appointment of a new pediatric cardiac surgeon brought a new level of cardiac surgery expertise to this tertiary referral centre. Although neonatal transplantation, pregnancy termination and compassionate care remained options in other centres, the surgical approach has predominated. From November 1996 until August 2001, 53 first-stage surgeries (i.e., the Norwood procedure) had been performed. Three-quarters of these babies were living one month after their Norwood operation (74% survival rate). Seven babies had subsequently died. Twenty-four babies were from outside the province. Since November 1996, two babies diagnosed with HLHS in the programme received palliative care, and one baby underwent a neonatal heart transplant and subsequently died (L. Hawkins, personal communication, June 7, 2000; March 20, 2001; August 8, 2001). In December 2002 key members of this Cardiac Sciences program presented at Grand Rounds their views that compassionate care should no longer be offered for HLHS.

Sample and Sampling

The medical and nursing staff of this western Canada Cardiac Sciences centre welcomed me and supported my research within their programme. I conducted multiple interviews with seven fathers and nine mothers of nine children over a 13-month period (i.e., November 2001 to December 2002) for a total of 30 interviews. I obtained my sample with recruitment assistance from the pediatric cardiology clinical nurse specialist and utilized specific protocols to ensure the protection of all parent participants.

Criteria for inclusion.

Fathers and mothers parenting a child with HLHS who had the Norwood surgical approach were asked to participate in my study. An ability to tell their story with reflection on their experience of parenting was the primary criterion for participation (Morse, 1999). The study was limited to parents whose child was living and parents fluent in English. Although I preferred both parents to participate, I did not limit my sample to couples. I wanted at least one third of participants to be fathers.

Recruitment.

The clinical nurse specialist in the Cardiac Sciences programme contacted parents of children with HLHS who had the Norwood procedure and invited them to participate in the study. She briefly explained the research (see Appendix C) and obtained permission from the parents to forward their contact information to me. I then contacted the parents by telephone. In some cases, I talked initially with the father and in other cases I talked first with the mother. I described the purpose of the research, the nature, timing and location of the interviews and invited both parents to participate. Only one couple who gave permission to be contacted decided not to participate. They gave no explanation why they were not able or willing to participate.

In most families, both the mother and father chose to participate in the study. One woman, whose marriage ended after her child with HLHS was born, agreed to participate in the study as long as I did not invite her ex-husband to participate. The husband of another woman in the study did not participate. This woman insisted that her husband did not want to participate in a research interview about parenting his child with HLHS and I was unable to speak with him directly.

I mailed a package of information to the parents once they had agreed to participate. The package included the information letter, consent form, demographic data collection form and trigger questions. This was especially important for the parents with whom I was doing the interview by telephone as it gave them an opportunity to review the materials before the interview.

Ethical considerations.

The Health Research Ethics Board of the University of Alberta/Capital Health Region approved the research protocol of this study. I ensured free and voluntary participation of the parents by having the clinical nurse specialist make initial contact. She assured parents that my study was an opportunity for them to tell their story but that in no way should they feel obligated to participate. In my initial telephone contact with the parents, I emphasized the voluntary nature of the study. I informed the parents that the two interviews would be one to two hours in length.

At the first interview, parents reviewed the written Information Letter and Consent Form (see Appendix D & E) and had an additional opportunity to ask questions. I obtained signed consent in person-to-person interviews. In telephone interviews, I reviewed the Information Letter and Consent Form previously sent to the parents and obtained their verbal consent. I tape-recorded and transcribed the verbal consent. I kept transcribed consents and signed consents in a locked file cabinet separate from the completed Demographic Data forms and interview transcripts.

In one case, the parents did not receive the printed materials before their telephone interview. I took extra time to explain the study in detail and read the consent form line-by-line, as they did not have the documentation in front of them. This yielded a

satisfactory consent process that was tape recorded and transcribed. The parents subsequently received their written consent form and information letter.

In every consent conversation, I reassured participants that I would remove identifying information from the interview for the sake of anonymity. I informed them that their actual words might appear in write-ups and presentations of the data analysis but that I would not link identifying information with the quotes. I offered the participants a summary of the findings. With future research in mind, I obtained consent for secondary data analysis subject to further ethics approval.

Sampling.

In grounded theory, the researcher simultaneously collects and analyzes data while seeking a diverse sample. It is as important to find evidence of differences or variation in the data as it is to find similarity and agreement. I used maximum variation sampling to ensure a diverse sample and an in-depth understanding of the phenomenon being studied (Patton, 1990). Parents whose child was at different stages of their surgical treatment were recruited. As parents who found out about their baby's HLHS antenatally may have a different experience than those parents who learn about their baby's health problem after birth, I sampled parents from both groups. I included parents who lived in proximity to the tertiary referral centre as well as parents from rural communities or other provinces, as their experiences may differ. I ceased interviewing at the point of having 30 interviews with 16 parents as the data were rich in detail and covered diverse situations. "The number of participants depends on the quality of the interviews, the broadness of the topic, and the complexity of the setting" (Morse & Field, 1995, p. 44). I also interviewed parents over time to increase the depth of my understanding. For example,

the first parent recruited for the study was the mother of a two-month old baby who remained in the tertiary referral centre after the Norwood operation. The interview with this mother was rich in content about antenatal diagnosis and the experience of being from a rural community in another province. The data however, were thin in relation to parenting as this mother felt that she and her husband had not yet had the opportunity to parent their hospitalized baby with HLHS. A subsequent interview with the father, once the child had been home for two months, provided rich data on parenting a child with HLHS. A second interview with the mother a year after the child survived her Norwood operation provided rich data on parenting a child with life-threatening heart disease.

Description of the sample.

Seven fathers and nine mothers of nine children with HLHS who had undergone the Norwood surgical approach participated in this study. For ease of identification during data collection and data analysis I chose pseudonyms alphabetically for couples as they entered the study. For example, I named the first mother Annie and named her husband Allan. I named the second mother Bonnie; she was not partnered. The other participants were named Cam and Catherine, Dania and David, Ellen, Fiona and Fred, Gabriele and Gavin, Heather and Hunter, and Iris and Ivan. I will use these names throughout the remainder of this dissertation. Connecting names with the parenting stories described in the study serves to reflect the personal nature of this research and the ongoing relationship I developed with each parent and couple.

There were differences amongst parents regarding age, income, and geographical location. The average age of the mothers was 34.4 years, with a range from 22 to 48 years. The age of the fathers ranged from 30 to 50 years with an average age of 36.1

years. Over half of the parents in the sample (4 fathers and 5 mothers) were university/college graduates and annual family incomes were diverse. The single mother's annual income was less than $25,000, whereas, four of the couples had annual incomes of $36,000 to $85,000 and the four remaining couples had annual family incomes of greater than $85,000. Almost half of the parents (4 fathers and 5 mothers) lived in the province where their child had heart surgery. The rest of the parents lived in neighbouring provinces. There was less diversity in marital status and ethnocultural background as all of the parents in this study were married except for one mother who was divorced. At the time of her second interview, she had remarried. Most parents were Caucasian and one mother was Metis.

Diversity of the sample was also evident in the child's age and birth order. The nine children (3 boys and 6 girls) with HLHS whose parents participated in this study were 2 months to 5 years of age at the time of the first interview with the parent. For most of the parents, this child was their second. In one family, the child with HLHS was a twin and the parents had two older children. In the remaining three families, two children were first-born sons and the other the sixth child.

There also was considerable diversity among the participants in the time of the child's diagnosis of HLHS, the stage of surgical repair at the time of the first interview and the child's health status. The child's diagnosis of HLHS was made antenatally in four families and during the postnatal period for five. One parent was interviewed when her baby was still in hospital after the Norwood procedure. Four of the children had had their second surgery, the Glenn operation, at the time of the first interview, and four of the children had completed the Fontan operation, their third surgery. Two of the babies were

being tube fed at the time of their parent's first interview and all of the children were on medications except one girl who was awaiting her Fontan; one child was only on one medication while another child was on seven medications.

As the interviews in this study took place over an 18-month period changes occurred in the lives of most families. These changes included further surgery for the child (2 families), one woman's remarriage, changes in employment and housing, and in two families a new or expected baby.

Data Collection Procedures

The main method of data collection for this study was unstructured interactive interviews conducted in person or by telephone. The parents were interviewed separately. Of the 30 interviews I conducted, I did 18 face-to-face interviews and 12 telephone interviews.

Location.

The parents and I jointly determined whether face-to-face interviews in the parent's home was the preferred option. This was the choice for parents within a reasonable driving distance from my home. I interviewed three parents in the local area and drove 3-6 hours to interview an additional seven parents in their homes. One face-to-face interview was held in a meeting room at the hospital. I conducted telephone interviews with the remaining six parents who lived outside of the province. All telephone interviews were with parents in their homes except one father who was interviewed in his office at work. After the first couple of telephone interviews I realized that I needed to give more introduction to the nature of a phone interview. I talked to the parents about their being free to deal with interruptions, to take a break to get something to drink or

stretch. Not surprisingly, the more comfortable I became with the telephone interviews, the more comfortable the participants seemed to be to cry, to be silent, to deal with child interruptions, and even to excuse themselves to go to the bathroom. Time-wise, interviews ranged from one to two hours in length and there was no difference between the length of telephone interviews and the face-to-face interviews.

Interviewing parents separately.

I chose to interview the parents separately. Separate interviews afforded me the opportunity to hear each parent's story told in their own way and at their own pace and enabled me to look for differences and similarities in the data. Youngblut (1998), in a review of literature pertaining to parents' and families' responses to their children's acute illness, concluded that there is a positive shift to including fathers in research but many researchers "lumped mothers and fathers together into one group called 'parents'... This practice ignores the differences in roles and perspectives frequently found between men and women" (p. 124). Separate data from fathers and mothers is a unique outcome of this study. On a practical level, separate interviews allowed one parent to attend to their child/children while I interviewed the other parent. Whether doing in-person or telephone interviews, the parents seemed to understand the need for uninterrupted time during the interview and helped each other to that end.

First interviews.

After I obtained consent, I invited the father or mother to talk about their life with their child with HLHS. I started with an open-ended question such as "So what has it been like?" A general and yet inviting question was all most parents needed to begin telling their story. If a parent seemed unsure about where to begin his or her story, I used

one or more trigger questions to initiate and facilitate our conversation (see Appendix F). For example, I asked the parents to think back to when they first realized that there might be something wrong with their baby and to tell me what this time was like for them. I employed trigger questions that were open-ended rather than specific and related to concepts arising from the literature review for example, to intentionally elicit the parents' stories from *their* perspective.

Attentiveness without verbal interruptions was essential for participants to move into a less self-conscious story-telling mode. Recounting painful life experiences such as finding out about their child's life-threatening CHD initiated emotional expressions but also indicated that parents were perhaps moving beyond the "public version of the story" (Charmaz, 2000, p. 525). Warm attentiveness was more effective than interceptive verbal comments to show receptiveness to parents' private thoughts and feelings. Researcher-initiated interruptions are costly in that the person "is taken out" of his or her "story space" (J. Morse, personal communication, May 2000). When I summarized or reflected the parent's words and stories rather than welcoming a pause in the conversation, the participants tended to agree with my summary and say no more about the subject. I therefore was careful to consistently use phrases such as "tell me more," "I want to hear your whole story," and " I have lots of time" to encourage the parents to tell their story in their words and at their own pace (Morse & Field, 1995).

In telephone interviews, the absence of non-verbal cues made it especially difficult to encourage parents to talk without using verbal interjections. More often in telephone interviews than in face-to-face interviews, parents asked for reassurance with questions

such as, "Am I on the right track here?" and "Is this what I am supposed to be talking about?" Fathers asked these questions more often than the mothers did.

During the first interview, I also completed the Demographic Data form (see Appendix G). Demographic data in a study such as this are important only if they "force themselves" into the analysis (Glaser, 1978). I endeavoured to anticipate information that would facilitate my understanding of the parents' experience. Family member demographic data were especially helpful in constructing genograms and ecomaps that depicted the parents' network of support from immediate and extended family (see Appendix H & I). Demographic information about the child's course of treatment was helpful in constructing a time line for the children as to their hospitalizations, surgeries and procedures (see Appendix I). I sent all parents a thank you card after the first interview. At that time, I confirmed their interest in a second interview.

Second interviews.

I conducted second interviews with all of the mothers and five of the fathers 6 to 11 months after the first interview. Two fathers said that their busy work and family schedules precluded a second contact. In the second interview, I updated the demographic information to reflect changes in family structure and the course of the child's treatment. I had specific questions based on my analysis of our previous conversation that usually began with "Can you tell me more about ..." I then shared with the parents ideas and concepts that were emerging in my data analysis and invited them to reflect on these. For example, I indicated that regret could occur and I inquired about their experience.

Transcriptions.

I had each audiotaped interview professionally transcribed with all identifying information about individuals removed. I proof-read each transcription by listening to the taped interview and checking the spoken expressions against the written transcript for accuracy of transcription, anonymity of the transcript and complete recording of non-verbal data, such as silence, laughing, crying or marked voice changes. The vital nature of this process was evident. For example, when asked what life was like after the baby came home from hospital following the Norwood, the transcriptionist recorded the mother's response as "Dull." In fact, the response was "Hell" and this was picked up in my proofing process. Another example was the transcriber mistaking the word "x-rayed" for "extubated."

Reflective notes.

Throughout the data collection, I kept reflective notes about my contacts with the parents. Following telephone interviews, I went directly to my computer to document my reflections. While driving back from face-to-face interviews, I dictated my thoughts, feelings and observations related to the interview onto the same tape as the interview and had them transcribed with the interview. As well as serving to further contextualize the interview, this reflective process kept me aware of my role in data construction.

The reflective notes made me aware of the tension between my previous clinical work in pediatric cardiology and my current role as a researcher. There were times in the interviews when I responded as a clinician rather than as a researcher. The usual result was that the parent did not elaborate further on the topic. For example, one mother told me about a pediatric cardiologist she met when her baby was diagnosed antenatally with

HLHS. Rather than being curious about her interactions with this professional, I acknowledged that I had worked with this physician and that she was a good clinician. I lost the opportunity to hear the mother's perspective when she agreed with my comment about the doctor. Through my reflective writing I became increasingly aware of my clinician-oriented responses and this enabled me to stay in my researcher role.

Data Analysis

In grounded theory, data collection and data analysis occur simultaneously. Data analysis follows data collection and at the same time stimulates further data collection. I analyzed demographic and interview data in this study. I used genograms and ecomaps to summarize family demographic and support systems mentioned in interviews. I used grounded theory methods of coding (open and selective) to analyze the interviews.

Genograms and Ecomaps

I created genograms to depict the composition of each family in a diagram. I created ecomaps to depict the networks of support for each parent. While listening to and checking each interview tape against the transcript, I completed the genogram and ecomap that I had started immediately following the first interview. The genograms facilitated my recall of each family's composition (i.e., age, gender, and relationship of each family member as well as pertinent details depicting family members in a memorable ways). The ecomap allowed me to summarize the parents' perceptions of their support networks. After my first interviews with both parents of one child, I realized that one genogram sufficed to represent both parents but I needed to construct two ecomaps as the support network of each parent differed.

Coding

The process of coding is constantly stimulating ideas (Glaser, 1978). In analyzing my interview data I used two levels of coding, open and selective. Open or initial coding is an inductive process, where the researcher moves from the data to theory (Charmaz, 1983). Glaser's (1978) "theoretical sensitivity" is crucial to this process, and the researcher achieves it, in part, by continually asking questions of the data. The question "What is this data a study of?" allows the data to "declare itself" (Glaser, 1978, p. 57). In my study, I asked this question as I coded each interview sentence by sentence and thus remained open to the data being about something other than parenting a child with life-threatening heart disease. Another question that keeps the research theoretically sensitive while coding is "What category or property of a category of what part of the emerging theory, does this incident indicate?" (p. 57). I created code categories as similarities in data emerged. As the analysis proceeded to a more abstract level, I generated code categories related to other codes. By constantly asking this question of fit, the researcher enables code categories to "earn" their way into the theory (p. 57). A final question foundational to theoretical sensitivity and grounded theory analysis is "What is actually happening in the data?" (p. 57). What were the common problems faced by the fathers and mothers? What were the most satisfying aspects of parenting a child with HLHS? How did parents manage the day-to-day care of their child with HLHS? I sought to identify a core category or concept that accounted for the processes. Once I identified the core category or concept, further coding was selective or focussed for the core concept instead of aiming for additional code categories or concepts (Charmaz, 1983). I

eventually delimited coding to only those variables that related to the core variable in sufficiently significant ways for use in a parsimonious theory (Glaser, 1978).

I used theoretical sampling to add interview data from particular parent experiences to "check and fill out emerging ideas" (Charmaz, 1983, p. 110). For example, the sixth father that I interviewed talked about regretting the decision that he and his wife made for their child with HLHS to undergo the Norwood surgical approach. Although some parents described occasions early on in their child's life when they had second thoughts about their decisions, previous parents whose child was at the same stage in the surgical treatment (post-Fontan) had not alluded to regret. I intentionally recruited another father whose child had had her Fontan and I specifically asked him if he had any regrets about the decision he made for his child. He answered no and described some of the hardest experiences he had with his daughter and how he had learned to cope with the challenges of parenting a child with life-threatening heart disease. I decided to explore this concept further in second interviews with all parents rather than recruit additional parents as the aim was to "refine *ideas*, not to increase the size of the original sample" (Charmaz, 2000, p. 519). As code categories emerged from the data about how parents dealt with their babies' serious complications during the post-operative course, I approached other parents whose babies had complicated recoveries to see if their experiences were similar or different. When I started to hear similar stories from the parents, I considered the data saturated and ceased sampling. "Theoretical sampling on any category ceases when it is saturated, elaborated and integrated into the emerging theory" (Glaser, 1992, p. 102).

Theoretical Memoing

The conscientious practice of writing memos about the ideas I had regarding the codes and their relationships with each other was as important as the practice of constantly asking questions of the data. Theoretical memos enhance the process of conceptualization and modification of the emerging theory (Morse & Field, 1995). Theoretical memoing also reflects Charmaz's constructivist perspective that data do not exist in and of themselves. I played a role in creating the data because "what a viewer sees shapes what he or she will define, measure, and analyze" (Charmaz, 2000, p. 524). My reflective notes on how my perceptions of the parents and their stories were influenced by my interactions with the parents, and my previous clinical work with parents of children with CHD and HLHS kept me aware of my part in constructing the data. I wrote memos on how categories of data fit with other categories and to describe how emergent concepts fit with other concepts from the data or from existing theory. I also wrote memos on my thoughts about what I was discovering in the data and what I had experienced in my clinical practice and in my previous research. As concepts emerged from the data I wrote memos about connections I saw with the literature I was reading. I used QSR N-Vivo 1.3 qualitative computer software to assist me with data management because it is more conducive to theoretical memoing than Non-numerical Unstructured Data Indexing Searching & Theorizing (N6).

Constant Comparative Analysis

Grounded theory data analysis is an exercise of constant comparisons. With a sample of both mothers and fathers, I constantly compared the data from the father with the data from the mother of the same child. This comparative analysis enabled me to ask

questions like: "Did the parents of the same child describe the day of the Norwood operation similarly or differently from each other?" and "How did these differences and/or similarities affect their parenting or their relationship as a couple?" I also compared the data from the parents of one child with the data from the parents of another child. I asked questions like, "Did parents of children who had all three surgeries completed relate different thoughts about the future from parents whose children had not had the third surgery." Additionally, I compared the data from all the fathers with the data from all the mothers and thus asked questions such as, "Do fathers and mothers similarly or differently describe their challenges related to parenting their child with HLHS?" These questions of comparison facilitated an in depth understanding of key code categories that in turn illuminated and/or clarified the relationship between various code categories in the emerging theory.

Through the coding process I also compared incident to incident "with the purpose of establishing the underlying uniformity and its varying conditions" (Glaser, 1978, p. 49). For example, I learned that all parents struggled to remain positive about their child's future. Despite this uniformity, parents described different conditions or ways of managing their thoughts about their child's future. Some parents rarely talked about their worry while others "put it all out on the table." Both the uniformity and the conditions become categories or concepts as well as hunches for further analytic verification and data collection. Another activity of comparison occurred as I compared the identified categories or concepts to more incidents from within the same interview or from subsequent interviews. These comparisons were "for the purpose of theoretical

elaboration, saturation, and verification of the concepts, densification of the concepts by developing their properties, and the generation of further concepts" (p. 50).

In grounded theory, we are concerned about phases or stages of the phenomena, and concepts may fit within one or more of the emerging phases or stages. For example, parents recounted the choices they had and decisions they made when their baby was born. They also talked about further coming to terms with their choices and decisions as their child faced more surgery and ongoing care for his/her heart problem. Constant comparative analysis of the category of choices and decisions allowed me to further distinguish what characterized one phase of the parents' experience from other aspects or phases of their experience. Another grouping or fitting together of concepts or categories related to parents responding similarly or differently to circumstances related to their child with HLHS. As I analyzed more and more interview data, certain categories became "so full" that all the data in that category warranted further analysis. It became evident that I needed to characterize or split a category or concept into two distinct categories. For example, I divided the category pertaining to thoughts about the future into thoughts about the child's future and thoughts about their family's future that included thoughts about having another child.

In grounded theory, one looks for an idea or concept that occurs in all the interviews and accounts for the phases and stages of the experience. Pursuing this unifying concept "fosters the identification of connections between events" (Charmaz, 2000, p. 522). As it reflects a social world that is always in process and the lives of the research participants that are ever in flux with change from within and without, the core concept or basic social process is subject to ongoing questions of fit. I continually asked if the core concept and

emerging theory fit with existing theories. How was the theory I was constructing different, for example, from the theory on "embracing the paradox" in the literature on parenting disabled children (Larson, 1998)?

Considering the Quality of this Research

Rigorous grounded theory research yields substantive theories that have "grab"; theories that people remember and use (Glaser, 1978) and with a constructivist foundation remain at a more intuitive, impressionistic meaning-oriented level rather than a truth-oriented objectivist level (Charmaz, 2000). To facilitate such an outcome, Glaser (1978, 1992) identified four criteria (i.e., fit, work, relevance, and modifiability) to consider throughout the research theory generation process. These criteria are further elaborated in constructivist grounded theory (Charmaz, 2000). My emerging grounded theory about parenting children with life-threatening heart disease must fit with the data from which it emerged. It must work in that it facilitates understanding and interpretation of what it is to parent a child with life-threatening heart disease. The theory must be relevant for parents and researchers beyond this study. Finally, for my theory to be remembered and used in clinical practice and have value for further research and theory development, it must be readily modifiable (Glaser, 1978, 1992; Charmaz, 2000).

Fit

Grounded theory is generated systematically from research data. Code categories and emerging theoretical concepts fit the collected data because they have been developed through a rigorous data analysis process. My continual questions of fit and comparison, the crucial practice of constant comparative analysis, ensured that the concepts earned their way into the analysis (Glaser, 1978; Charmaz, 2000). Grounded theory is not about

fitting or forcing the data around pre-existing concepts to verify or enhance their conceptual existence. "Grounded theorists cannot shop their disciplinary stores for preconceived concepts and dress their data in them" (Charmaz, 2000, p. 511). Rather, concepts that explain the experience of the participants emerge in the data analysis process (Glaser, 1992).

In this study for example, the concept of normalization had potential to fit with the data from this study as it is discussed in the literature in relation to parenting children with health challenges. Although I am familiar with the concept of normalization, I did not attempt to verify the existence of this concept by forcing it into my code categories. It was not until I was analyzing second interviews that normalization became a code category. Parents told stories of their child's growth development and repeatedly described their children as being on "their own growth curves." The data seemed to indicate that parents interpreted their children's delayed weight gain and growth in height as normal for them rather than comparing their child's size to other similarly aged children. Only at this point in my analysis did normalization became a code category and only because it fit the data.

Work

Closely related to fit is the criterion of work. A grounded theory that emerges through my data analysis must work. Beyond conceptual intrigue, the theory "must provide a useful conceptual rendering and ordering of the data that explains the studied phenomena" (Charmaz, 2000, p. 511). For Glaser (1978), a theory about parenting children with life-threatening heart disease works when it explains what happened for parents in this study. As well, the theory works when it has the potential to predict what

might happen for other parents of children with HLHS who have undergone the Norwood surgical approach. In constructivist grounded theory, causality is "suggestive, incomplete and indeterminate" (Charmaz, 2000, p. 524). A constructivist grounded theory works when it portrays how the parents constructed their reality of parenting a child with a life-threatening health problem, how they gave meaning to the key aspects of their experience and how the various aspects played out in their lives.

The emergence of the concept of regret in this study illustrates the criterion of the theory working from a constructivist perspective. When I discussed the concept of regret with parents in second interviews, they readily understood the idea whether they had experienced it or not. They expressed understanding of why a parent might have regret and described how it was that they did not regret their decisions for their child but may have at times second-guessed their decisions. The theoretical notion of regret did not help them explain their experience or predict their future experience. Rather it raised questions for them about the conditions under which one might have regret.

Charmaz presents constructivist grounded theory as having the potential to offer "a set of hypotheses or concepts that other researchers can transport to similar research problems and to other substantive fields" (Charmaz, 2000, p. 524). My theory will work if clinicians and researchers concerned with parents whose children have undergone fetal surgery, for example, are led to an understanding of how parents manage their thoughts about their child's uncertain future. The criterion of work will also be met if it leads others to question, for example, the similarities and differences between fathers' and mothers' experience of parenting a child who has benefited from advances in medical technology and have "beaten the odds, thus far."

Relevance

Related to fit and work is the criterion of relevance. Do the theoretical perspectives I offer as an outcome of this research serve as analytic explanations of actual problems and basic processes encountered by parents of children with life-threatening conditions who are recipients of high-technology care and intervention? Does my theory have potential relevance beyond the parents in this study to other parents of children with life-threatening heart disease? Has the theory emerged such that it has relevance for understanding and/or interpreting the parenting process for fathers and mothers of children with non-cardiac life-threatening conditions?

Sufficient time for the emergent nature of theory development is crucial in achieving relevance. An intentionally sought diverse sample rendered through theoretical sampling results in a grounded theory that is "durable because it accounts for variation" (p. 511). The sample is this study was diverse as it included both fathers and mothers of children who had been diagnosed both antenatally and postnatally with HLHS. The parents were from diverse geographical locations and the children with HLHS were of different ages and at different stages of their surgical treatment for HLHS.

A relevant theory also emerges when sufficient time is taken to allow for the emergence of code categories, core problems and processes, and unifying concepts. Again, the issue of forcing code categories and concepts to fit the data threatens the quality of the sought-after, emergent theory. Relevance is achieved through a time-intensive, in depth relationship between the researcher and the data.

One of the key ways I allowed for the emergence of the core problems and processes of parenting a child with HLHS was through repeated and varied renderings of the data

and emerging concepts. I diagrammed and re-diagrammed the interrelationships of code categories in as many different ways as possible and using parents' actual words. I regularly discussed these various conceptualizations of parenting children with life-threatening heart disease with my committee supervisor.

I also used the parents' actual words to explore other words with similar meaning that might depict the nuances of their parenting in a more abstract but relevant way. I used the dictionary and thesaurus to more fully understand the words parents used such as regret, doubt, survive, blessing, curse, and chance. Charmaz highlights the "rendering through writing" that characterizes constructivist grounded theory. "Constructivist grounded theory spawns an image of a writer at a desk who tries to balance theoretical interpretation with an evocative aesthetic" (p. 526). Similar to the diagramming and re-diagramming, through writing and re-writing the theory emerges further and is further refined.

Modifiability

As I gather further data through my clinical experience and continued research and as I encounter other theoretical perspectives, I need to address when and how the theoretical perspectives that emerged from my data should be modified. As a constructivist grounded theorist, I offer a theory on parenting children with life-threatening heart disease that I intend to be flexible, responsive, and propagative of new perspectives and understandings of parenting children who are new survivors in an ever-advancing, technology-driven health care environment. I will further advance and refine this grounded theory in the context of my ongoing clinical, academic and research work. The durability and development of this theory over time will reveal its quality and contribution to

progressive clinical practice, integrated programmes of research, and meaningful theory development in family and pediatric nursing.

In this chapter on research methodology and method, I differentiated methodology from method to convey the distinctive nature of constructivist grounded theory as compared with more traditional grounded theory approaches. I described my process of data collection and data analysis and discussed the criteria by which I have and will continue to evaluate the quality of this research. I will now present the emergent theory in the following three chapters, starting with a discussion of the coexistence of certainty and uncertainty as the context for the parenting process of safeguarding precarious survival.

CHAPTER FOUR

PRECARIOUS SURVIVAL

"We don't know how long she's going to live."

Parenting a child with hypoplastic left heart syndrome (HLHS) involved contending with precarious survival as parents felt both certainty and uncertainty that their child would survive his or her life-threatening heart problem. Parenting under such extraordinary conditions began with parents taking a chance.

Chance in Latin is *cadere,* which means to fall and also may be akin to the Sanskrit word *sad*, to fall off (Merriam-Webster OnLine, 2004). Chance is the possibility of a particular outcome in an uncertain situation; the fortuitous or incalculable element in existence (Merriam-Webster OnLine, 2003). When parents chose surgery for their baby's HLHS, they knew that HLHS was life threatening. No one can accurately predict whether a child with HLHS will survive the Norwood surgery and subsequent procedures. Parents, however, gradually realized that their child might live if they took a chance on the Norwood surgical approach.

Although parents felt certain that the Norwood surgery represented the technologically advanced treatment that a child with HLHS needed to survive, they were also uncertain that the surgery would be successful for their child. The parents were convinced about the progress that pediatric cardiology specialists had made in the treatment of HLHS. Through their conversations with health care professionals and their own personal research, parents learned of the improved survival rates for children undergoing the Norwood surgical approach. Parents also learned about other potential outcomes; not all children survived the Norwood operation or subsequent surgeries.

Although parents concluded that the Norwood approach was the best choice for their child, they realized that they were taking a chance. Despite the precarious or potentially dangerous nature of falling or taking a chance, one mother described the decision that she and her husband made to choose the Norwood surgery as their desire to:

> Give him [her son] a chance. (Ellen)

Parents willingly chose a potentially life-threatening option for their child because there was a chance for survival. They chose new technology in the Norwood approach and they were overwhelmed with delight in their child's survival, as one mother said:

> I remember feeling ... that Christmas was the best Christmas in the world ... We had our little girl. (Fiona)

At the same time, parents faced their child's uncertain future as illustrated by other mothers' statements:

> We don't know how long we will have her with us. (Gabrielle)

> We're thankful for each day that we have no matter how long it is. (Annie)

In this chapter, I present the choices parents made and the specific things they did in the process of making their decision in favour of the Norwood surgical approach. This discussion is central to understanding how fathers and mothers parented their child whose survival was precarious as it is the context for their parenting of certainty and uncertainty. Although parents were certain that the Norwood surgical approach was the best option for their child, this decision exposed their child to a course of life-threatening surgeries (i.e., the Norwood, Glenn and Fontan operations) and potential complications. Parents therefore also experienced profound uncertainty when their child's life was in immediate danger as well as when they considered their child's uncertain future. Consequently, parenting for these fathers and mothers involved safeguarding their child's survival.

Parents also safeguarded their own survival in part by revisiting their decision to choose the Norwood surgical approach. I discuss the coexistence of the certainty and the uncertainty of precarious survival in this chapter, thus providing the context for Chapters 5 and 6. In Chapter 5, I discuss how parents safeguarded their child's survival and in Chapter 6 how they safeguarded their own survival (See Figure 1).

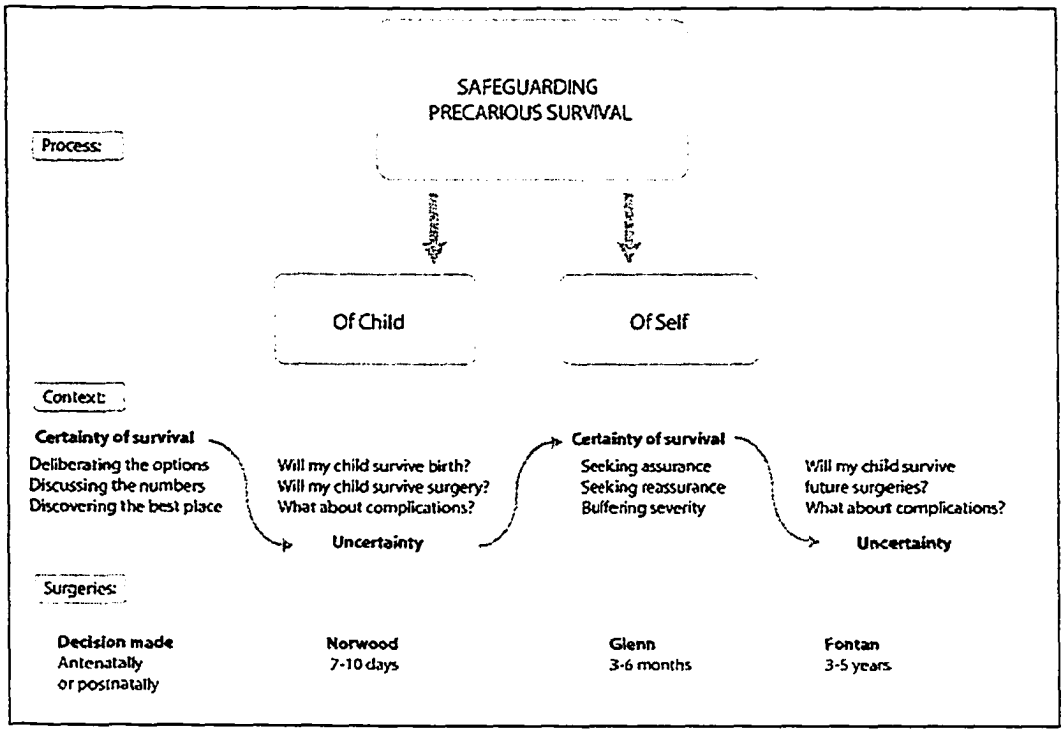

Figure 1. Safeguarding precarious survival of child and self

The Certainty of Survival: "We'll fix your son."

Parents in this study were willing to give their baby a chance for survival through the Norwood surgical approach because they were certain it was a viable option in the hands of a reputable surgeon. They described a process of deciding that the Norwood surgical approach was "the best option" for their baby with HLHS. Parents deliberated the options for their baby with HLHS and discussed with health care professionals mortality and survival statistics for the Norwood operation and subsequent surgeries. They also

described how they discovered that the Western Canadian centre to which they were referred was the best centre for the Norwood approach because of the particular surgeon associated with the programme. [I will refer to this centre as the tertiary referral centre for the remainder of the dissertation.] Especially important in the parents' process of decision making was the assurance and reassurance they sought through their relationships with the pediatric cardiac surgeon and other health care professionals as well as through the information they received and shared between each other as a couple (See Figure 2).

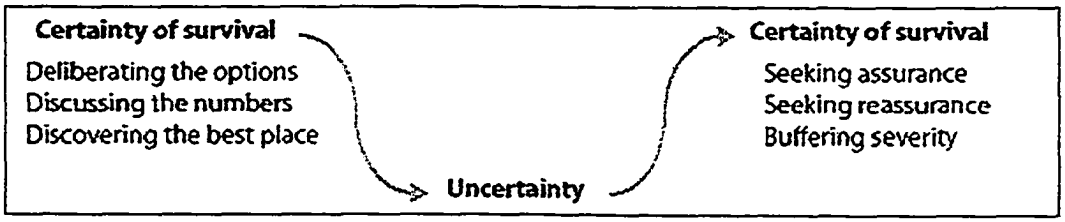

Figure 2. Parents' actions that contributed to their certainty of survival

Deliberating the Options: "We weren't leaving everything totally to chance."

The parents in this study came to their decisions regarding the Norwood surgical approach through varying amounts of deliberation depending on when their baby's HLHS was diagnosed, their beliefs and values, and the recommendations of health care professionals. Five families learned antenatally that their baby had HLHS and four families learned of this postnatally. Postnatal diagnosis resulted in less time for deliberation especially for the parents of two babies where the health care professionals immediately recommended the Norwood surgical approach. Bonnie's baby was not diagnosed until she was 4.5 months old at which time the baby was in heart failure and immediately hospitalized at the tertiary referral centre. Her Norwood operation was done two days later and Bonnie did not relate any discussion of other options. Helen and

Hunter's son was diagnosed with HLHS on his second day of life after he required emergency resuscitation and critical care stabilization at another centre. The health care professionals in this centre were confident in the success of the Norwood surgical approach and immediately arranged for the baby to be transferred to the tertiary referral centre. Hunter recalled:

> It was just like, "Okay, we're gonna send him to [tertiary referral centre]. They've got a great surgeon and there's possibly something he can do with it." ... He wasn't giving us any false hopes. ... "He has a very serious heart condition. ... This is what you have to do and we just did it. I honestly can't remember any options. (Hunter)

Helen also noted that she and Hunter did not have the opportunity to deliberate options.

> He'd [pediatric cardiologist in Calgary] come in a couple times. He was great – "[This is] what we're doing and we'll let you know what's going on" and then from that point we really didn't have an option. Like you know you're in the middle of it. You don't really have time to make choices and so he just said, "We're sending him out to [city of tertiary referral centre] for surgery." (Helen)

Health care professionals recommended compassionate care to two other families whose babies were diagnosed postnatally. Compassionate care was suggested to Dania and David because their baby had experienced other complications associated with a difficult birth. The cardiologist who diagnosed the heart problem for Ellen's son had a negative opinion of the Norwood surgical approach. Ellen described having to fight to get her baby transferred to the tertiary referral centre for the Norwood surgery:

> He [cardiologist] told us that he thought we should just take him [their baby] home and it was cruel to put babies through all that many surgeries ... As soon as he [cardiologist] told us the options we knew it was the surgeries. He sent us home and said, "You know, you have to think about it overnight" and we kept on trying to tell him that we were going to **give him a chance. ...** He kept on sending us away and, "You'd better think about it. This is what you want to put him through." We even told him Wednesday morning when he was first discussing, that we were going to go with the surgery and we just phoned him later that afternoon when we got home and we just told him, "We were doing the surgeries." I mean, he couldn't deny us that. So we just said, "Start making the arrangements." (Ellen)

Ellen did not want to deliberate the options and the cardiologist transferred her baby to the tertiary referral centre.

Five couples (Annie and Allan, Cam and Catherine, Fiona and Fred, Gabrielle and Gavin, Iris and Ivan) found out about their baby's HLHS antenatally. The only difference between these parents and those who found out about their baby's HLHS after birth that emerged from the data was the extra time that they had to deliberate in their decision making. During the remainder of the pregnancy, through their conversations with health care professionals and their own research on the Internet or through family, friends and/or work colleagues they deliberated three options: compassionate care, neonatal heart transplant and the three-staged surgical approach including the Norwood surgery. Three of the five couples were also offered the option of terminating the pregnancy.

Seven of the parents who considered options other than the Norwood surgery, viewed pregnancy termination and compassionate care (i.e., "letting nature take its course") as almost unthinkable. Annie and Allan were expecting twins and Annie recalled their response to the offer of termination or compassionate care for the twin with HLHS.

> I talked with my husband and neither of us could even come to terms with the idea of selective reduction or just simply letting her pass away after birth because I think we thought that would be just so much harder for us. (Annie)

In discussing her consideration of the options of pregnancy termination and compassionate care, Fiona said,

> I'd never terminate a pregnancy. That was in God's hands, not mine, if something were to happen. Fred didn't even have to ask me that ... to know how I felt. Compassionate care that would have been really hard. (Fiona)

These parents minimally deliberated the options of compassionate care or termination but did have time antenatally to choose between transplantation and the Norwood approach.

Three other parents described their uneasy deliberation over the option of compassionate care. Dania was upset that she had momentarily considered compassionate care after her baby was born. Both she and her husband, David, described Dania's worry that surgical treatment would cause too much suffering for their baby. Dania however, insisted that she never seriously considered the option of compassionate care, an option that did not fit with her religious convictions about the sanctity of life.

> When you do decide to do what you've done and you've lived with this child and you've grown to love her and you can't imagine your life without her ... [Compassionate care] doesn't seem like an option that I would even consider. But at the time, with my age and what I had just gone through and what she had just gone through and really the news that we were getting from the doctors wasn't all that great. ...So at that moment, at that time, I think for me, I probably thought it was an option and **maybe for me it was an easy way out.** (Dania)

Her decision against compassionate care was consistent with her earlier decision not to have a pregnancy termination when she learned she was pregnant at 44 years of age even though she had a tubal ligation eight years earlier. Dania was adamant that pregnancy termination did not fit with her and David's religious and family values.

> I grew up in a fairly religious family. So did David. Like I said before, abortion was never an option when I found out I was pregnant. ... Who knows what you're in for? You never know with any of them what's going to happen. (Dania)

Gavin also described his uneasiness about considering compassionate care for his daughter with HLHS. He spoke of religious convictions that opposed pregnancy termination but did not directly link his religious or spiritual beliefs with his decision about compassionate care. Like Dania, he recalled feeling afraid that he would come to see compassionate care as an easy way out of difficulties.

Cam and Catherine were the only couple who considered termination of the pregnancy if their child had a chromosomal abnormality in addition to HLHS.

> If the baby only had HLHS then we were prepared to go for it [the Norwood surgical approach]. (Cam)

When Cam and Catherine found out that the chromosomes were normal and their baby therefore "only" had a heart problem, they decided in favour of the Norwood surgical approach over compassion care. Cam's uneasiness about compassionate care related to the highly publicized Canadian case where the father of a child with severe cerebral palsy ended the child's life to alleviate her suffering.

> I don't know if you recall, all through that year there was a lot of the Robert Latimer stuff going on ... there's a lot of issue around here about that. So I had some feelings about that and then when they said, "You can have the baby and opt to do nothing; let nature take its course" I kind of had a bit of a dilemma with that, and I'm thinking in the back of my mind, "How would this be any different?" My lack of action would cause the baby's death where Latimer's, well he took an action and caused the baby's death. Either way the end result's the same. So I'm thinking, "How would I be any different if we decided to do nothing?" (Cam)

Parents based their opinions about pregnancy termination and compassionate care on their personal values and convictions but they formed their opinions about transplantation based on information from the health care professionals.

Most health professionals portrayed infant heart transplant in negative terms, describing the likelihood of the baby dying before an organ became available. Parents came to associate heart transplantation with enormous risk, taking a gamble rather than taking a chance.

> Odds of getting an infant heart are like winning the 649 ... you could opt for a heart transplant ... cross your fingers and hope that a heart becomes available and they kinda said, "You know, that's not very likely to happen and it's very uncommon." (Cam)

The words "they kinda said" in Cam's preceding quotation illustrated the fact that every parent who related discussions about transplant had been convinced through their conversations with the health professionals that their baby would die waiting for a donor

heart. Allan was considering the option of heart transplantation until he discussed treatment options with the doctors at the tertiary referral centre.

> I was probably looking towards a heart transplant as well, knowing that she wouldn't have a healthy heart. But after ... they told us the actual possibility of finding a heart for her age and her match ... she'd probably die waiting for it. (Allan)

All parents, except one father, came to the conclusion that they wanted to give their child a chance for survival and were confident that the Norwood approach afforded their child that chance. The Norwood surgical approach, therefore, was viewed as the best option among other options that meant certain death. To have a "game plan" was also a relief for parents especially as they compared the Norwood surgery with waiting for a heart transplant.

> With the Norwood, I mean you knew we were going ahead with something. Off the bat there was a game plan. We weren't leaving everything totally to chance. I mean you're pretty well flipping a coin at any time then anyways. (Fred)

In comparison, Ivan did not feel comfortable with the Norwood surgical option initially and could not identify why he was so uneasy. Over time, he identified his regret that his child had undergone so many surgeries and complications. Although Ivan regretted choosing the Norwood surgical option, he had no regrets about the choice of surgeon or the location for his daughter's surgeries.

Both the choice of surgeon and choice of location for surgery were crucial considerations for parents in their decision making concerning the Norwood surgical approach. Statistics or "the numbers" told the story of success of the surgeon at the tertiary referral centre where the children in this study received care. These numbers also depicted the risk to the child and helped the parents make their decisions about their choice of treatment for their child with HLHS.

Discussing the Numbers: "Sometimes it doesn't work and sometimes it does."

The seriousness of HLHS was most obvious to parents during their discussions with health care professionals about "the numbers." Parents recalled even the most basic use of numbers by health professionals. For example, this mother reported learning about her baby's HLHS antenatally through the physician's use of a scale of 1 to 10.

> She [ultrasound technologist] said, "A cardiologist will be with you in a little while." So she took half an hour, twenty minutes to half an hour to do the echo [fetal echocardiogram] and then [pediatric cardiologist] came in and he said, "On a scale from 1-10, 10 being the worst, your baby's heart has a problem and it's about 9 ½." Those were his words. (Fiona)

Parents knew that the numbers represented the chance of death and the chance for life. A mortality rate of 20 % had two meanings. One proportion (20/100) represented death or mortality and the complementary number (80/100) meant life or survival. Although these statistics vividly portrayed the risk of surgery, parents appreciated the forthrightness of the physicians, especially the cardiac surgeon, in providing statistics that gave them concrete information for their decision making.

> After talking with him [cardiac surgeon], having him explain it, I mean he doesn't fool around. He just lays the numbers out, tells you what it's like. ... He said, "Sometimes it doesn't work and sometimes it does." (Fred)

Both Annie and Allan recalled the conversations they had with physicians before and after their baby was born. Antenatally, Annie recalled the professionals constantly preparing her and Allan for the probability that their twin baby with HLHS would not survive. The professionals quoted a 30-40% mortality risk. Allan and Annie chose to focus on the 60-70% survival that the quoted mortality risk also indicated.

> Throughout my pregnancy ... we had been told not to prepare for twins. ... I think we really didn't pay attention to that. When we bought things, we always bought double and I think that was important to us because we couldn't ignore the fact

> that there was two of them and even if she did pass away ... it would be hard to act like she never existed. (Annie)

Postnatally the physicians portrayed a grimmer prognosis for Annie and Allan's baby than they had received antenatally. Allan recalled that the original survival statistics of 60-70% were "downgraded" to 40-50%. Hearing this news was the "lowest point" emotionally for Allan and Annie during the week between their baby's birth and her Norwood surgery. Annie told the story.

> They were telling us that things were a lot more complicated than they had first hoped. ... Because of the size of her aorta ... they were telling Allan that you know it may be, may be a 20% risk, 30 at the very most and once they were able to get a good scan of her heart and have a really good look at her and run lots of tests, they ... told us that it was more of a 60% risk for her and if we wanted to have her baptized before surgery we should do so. (Annie)

In other situations, parents had to reconcile different numbers from different health professionals in relation to the same outcome. For example, a cardiologist in a referring centre who lacked confidence in the Norwood surgical approach gave parents different numbers than the surgeon at the tertiary referral centre gave them.

> [Pediatric cardiac surgeon] made it sound a lot better than [cardiologist] did. Like he [cardiologist] had said our chances of survival were more like 25% and I think [pediatric cardiac surgeon] was 50. ... The way he [pediatric cardiac surgeon] explained everything to us was **way better** than [cardiologist] ever put. So we had a little bit more hope ... once we got there [the tertiary referral centre]. (Ellen)

Although the numbers alerted parents to the life-threatening nature of HLHS, the numbers also gave parents reason to hope. Fiona explained how the numbers given by the surgeon increased the confidence she and her husband had regarding the Norwood surgical approach. They moved from feeling that HLHS meant certain death for their baby to feeling confident that their baby might survive.

> He [cardiac surgeon] said he'll give her a 75 percent chance to live till she's 30 or 35. He actually gave some stats and so at the time, we didn't have a healthy baby,

> so all of that sounded very positive to us and we didn't dwell ... what if, what if. We were just like a couple days ago we thought we weren't going to have a baby. Now it looks like we're going to. She has a chance. (Fiona)

For Gabrielle, the numbers were not part of an abstract discussion of odds or chance; any chance of her baby not surviving was devastating. As good as some may have said the numbers were they did not offer her much comfort.

> [Pediatric cardiac surgeon] had told us that there was a 25 percent chance that she wouldn't survive and it was interesting that some people would say, ... "That's pretty good odds." But when you're talking about [your child's life] it's not [Tearful]. (Gabrielle)

The parents also soon realized that the success rate numbers for the Norwood operation and subsequent surgeries depended on the skill of the surgeon. Thus, it was the specific surgeon that made the tertiary referral centre the preferred place for the child to undergo the three-stage surgical approach for HLHS.

Discovering the Best Place: "We got awful lucky."

Parents determined that the tertiary referral centre was the best place for surgery because of its particular pediatric cardiac surgeon. Discovering that the Norwood surgery was only recently available at the tertiary referral centre because of the arrival of a new surgeon and favourable outcomes increased the parents' certainty that the Norwood approach was the best option for their child. They viewed the availability of the Norwood operation for their child at a local institution as fortuitous.

> We got awful lucky in a lot of areas. One of the ... foremost surgeons in this type of thing just happened to be moving ... to [tertiary referral centre] around that time. It allowed us to stay around home. (Fred)

Even the ways that parents discovered information about the surgeon and his record of success supported their view that the Norwood option was "meant-to-be" or providential. Gavin and Gabrielle had several weeks between learning about their baby's

HLHS and the baby's birth. Gabrielle was surprised that the surgeon's name "quickly came up" from two different sources and used the word happenstance, which is defined as "a circumstance especially that is due to chance" (Merriam-Webster OnLine, 2003).

> Just through **happenstance** discussions. ... My father spoke to someone who worked at Children's Hospital in [eastern Canadian city] and she mentioned [pediatric cardiac surgeon in tertiary referral centre] and then one of Gavin's co-workers, his sister worked in [another Canadian city] ... in the pediatric field and [pediatric cardiac surgeon]'s name came up again. (Gabrielle)

Similarly Gavin described the events that led him to believe that the Norwood operation done by the surgeon at the tertiary referral centre was the best decision.

> When we started looking into things ... this [pediatric cardiac surgeon] came up time and time again. ... I have friends who are in medicine. ... So the name came up. ... This happened a couple more times to the point where we weren't even sure that it was coincidence but even if it was, it was like there's a theme here and so we investigated this a bit more even before [daughter with HLHS] was born and when she was born ... we asked ... to see him. (Gavin)

Cam, whose baby was also diagnosed antenatally, investigated the options and concluded that the Norwood surgical approach at the tertiary referral centre would give his baby the best chance.

> My Internet research focussed more on hypoplastic left heart and the procedures, what our options were, heart transplant or ... the three-stage procedure, finding out where the best doctor was. We were considering going to [large centre in Eastern Canada] because Catherine has a sister who lives in [nearby city] and we thought ... we could stay with her. It would be a long course. Then we found out that [heart surgeon at tertiary referral centre]'s numbers seemed to be better, seemed to be having more success than people at [large centre in Eastern Canada] were having; slightly better. (Cam)

Not only did Cam independently discover through his Internet research, the surgical statistics for the Norwood procedure in Canada, but he also learned of a physician who was one of the foremost Norwood surgery specialists in the United States. Cam compared statistics between the American surgeon and the surgeon at the centre to which his baby was referred and was satisfied with the success rate at the Canadian tertiary referral

centre. Another father of a child with HLHS who had already had the Norwood surgery also reassured Cam regarding his conclusions.

> He had nothing but good to say about [heart surgeon in tertiary referral centre] and the people out there. ... He said, "You know, you're in good hands out there. Don't worry about anything." So that was kind of reassuring. (Cam)

The way in which health professionals referred the baby with HLHS to the pediatric cardiac surgeon also included an element of chance or good timing for some of the parents. Dania and David's baby's HLHS was not diagnosed antenatally despite a prenatal diagnosis of situs inversus and a subsequent fetal echocardiogram. Although his daughter suffered meconium aspiration and was critically ill soon after her birth, David was certain that an antenatal diagnosis of HLHS might have decreased his daughter's chance for survival. David believed that if the health professionals had diagnosed his daughter's HLHS antenatally, they would have referred her to the pediatric cardiac surgeon within their own province whose outcome statistics for the Norwood operation were inferior to the surgeon at the tertiary referral centre. David was aware of provincial policies that governed when one could seek out-of-province health care services and he was glad that his daughter's HLHS was diagnosed postnatally when the local surgeon was not available.

> Thinking back, had they known that she was hypoplastic before she was born, she would have been born in [home province]. She may have not experienced the trauma she did when she was born. We may have had [cardiac surgeon in home province] though for a doctor and not made it. (David)

Another out-of-province couple similarly described fortunate timing that allowed them to request that their baby be referred to the tertiary referral centre. Gabrielle and Gavin did not want to offend the professionals involved in the diagnosis and initial treatment of their child with HLHS but were determined to have their baby transferred to

the tertiary referral centre. When they found out that the local surgeon was not available for three days, they insisted on being transferred to the tertiary referral centre. They recalled feeling that they had to justify their request for the transfer of their child beyond identifying better survival rates at the tertiary referral centre.

> We didn't want to offend anybody there [referring centre] and so what we'd said is we're planning to move there anyway. Our family's there. There were lots of reasons to go to [tertiary referral centre] but [cardiac surgeon] was the main one and they [professionals at referring centre] didn't give us any trouble. (Gavin)

Although all the parents were certain that their child with HLHS was in the best tertiary referral centre and had the best surgeon, potential life-threatening complications and prolonged hospitalizations contributed to parents feeling uncertain about their child's survival. Their relationship with the surgeon therefore, went beyond his role in attaining good surgical results. He provided initial and ongoing assurance that played a key role in sustaining the parents' certainty about their child's survival.

Seeking Assurance from the Surgeon: "He was just so confident."

Although parents based their choice of surgeon for their child on his record of success with the Norwood surgery and his associated reputation, their personal relationship with the surgeon was key to feeling assured that their child would survive. The surgeon was certain that the baby had a chance for survival and did not hesitate to share that opinion with parents. The surgeon's straightforward approach to informing parents in the context of an ongoing relationship was a constant source of assurance for the parents.

The initial meeting with the surgeon was especially important for the couples whose babies were diagnosed antenatally and who had time to deliberate their options. Fiona contrasted the "very concrete," "very factual," and "very hard" approach of the pediatric

cardiologist that left her and Fred feeling pessimistic regarding their baby's chance for life, with the optimistic, hope-instilling approach of the cardiac surgeon.

> He seemed so secure of his abilities and that [daughter with HLHS] could live and do well. (Fiona)

The surgeon also provided Fiona and Fred with the opportunity to see two children who had surgery for HLHS and this immediately bolstered Fiona's confidence that their baby would survive.

> We saw a little boy who was I think five or six weeks old, post-Norwood and who was having feeding troubles but he was alive and doing well and pink. We saw a two year-old running around who was going in for the Fontan. So that's pretty much all we needed to see to know that we had hope, bang. (Fiona)

After meeting with the surgeon Fred also felt more confident in the decision he and Fiona were making in favour of the Norwood surgical approach.

> I mean he [pediatric cardiac surgeon] doesn't fool around. He just lays the numbers out, tells you what it's like and that's that. We liked what we heard. ... He answered a lot of questions. ... He **gave us the confidence** that we had made our right decision. (Fred)

Iris and Ivan, whose baby was also diagnosed antenatally, were unsure in their decision making and were considering compassionate care until they met with the pediatric cardiac surgeon at the tertiary referral centre. Following their meeting, Iris remembered feeling certain that the Norwood surgical approach was the best option and that she and Ivan did not even have to discuss the decision further.

> I was sitting there crying and Ivan's talking to him [pediatric cardiac surgeon] and then we weren't even in there fifteen minutes and I knew what my decision was. That we were gonna go for the surgery cause we were talking statistics and quality of life and how many had he done. ... **He was just so confident**. ... He knew his information and so right away ... we walked out and we just looked at each other and I knew right there that this [the Norwood operation] is what we were gonna do. (Iris)

Ivan did not feel the assurance that Iris and other parents felt after meeting with the surgeon. But, because Iris was so certain about the surgery option, and because she was carrying the baby, Ivan felt that he could not voice his hesitations regarding the Norwood surgical option.

> He [pediatric cardiac surgeon] was very, very, just dead serious and very to the point and almost regimented and that even scared me worse. I don't know what Iris went through cause obviously it's totally different. .... I think he instilled more confidence in Iris than he did in me. (Ivan)

Unlike parents who had an opportunity antenatally to establish a relationship with the surgeon, parents whose babies were diagnosed with HLHS postnatally had limited time to benefit from the surgeon's confidence that their baby would survive. Their baby was critically ill and needed immediate medical attention. Some parents appreciated the surgeon's straightforward, confidence-building manner. Hunter remembered the surgeon's promise of "We'll fix your son." Helen recalled the surgeon's ongoing assurance in the days leading up to her baby's Norwood operation.

> He comes by in rounds and checks things out and says, "Your son's doing okay. We're going to do everything to take care of your son, save your boy." (Helen)

The other parents who fought for their child to be given an opportunity for the Norwood operation, were less influenced by assurances from the surgeon or other health care professionals. David described his first meeting with the surgeon in matter-of-factly:

> I was quite satisfied with [pediatric cardiac surgeon] and he had an assistant that was really nice as well. They explained everything thoroughly, like all the procedures ... rate was for survival. It was clear at that point that the Norwood was where we were going. (David)

In order to have no regrets about their baby having the Norwood surgery, parents had to be certain that they had entrusted their baby to the best surgeon. Confidence and trust were fostered in their ongoing relationship with the surgeon and this was key to parents

entrusting their child to the surgeon. The fathers more than the mothers described this phenomenon. Although Ivan had ongoing regrets about choosing the Norwood approach for his daughter with HLHS, he had no regrets about the surgeon.

> I have lots of trust in him because if he can't do it and she doesn't make it, nobody could have done it. That's the best of the best ... I don't know of anybody that's any better. (Ivan)

Speaking fondly of the surgeon, parents also related how their relationship with the surgeon changed over time and was characterized by deepening trust and affection. After the second operation for his daughter, David felt more comfortable with the surgeon and surprised himself with a spontaneous show of affection.

> [Pediatric cardiac surgeon] was coming down the hall and I just gave him a big hug. [Laughs] He said everything went really good again and no complications. I don't know what over took me but I just had to hug him. (David)

Fiona also spoke of her fondness and appreciation for the cardiac surgeon. He made an impression on her by his regular visits to the hospital over Christmas.

> The first week was hard because you're not sure what to expect and [pediatric cardiac surgeon] would touch base with us and we learned how dedicated he was because it was over Christmas, over Christmas Eve, Christmas Day and eventually over New Year's Day and he was in every day. (Fiona)

Fiona also related the ways in which parents grew to understand the different sides of the surgeon's personality. She described the way in which the surgeon made specific efforts to assure the mothers.

> I can't remember her name [another mother] now but we bonded really quickly and she even said how [pediatric cardiac surgeon] came up to her and ruffled her hair at certain times and he did. [Pediatric cardiac surgeon] talks to the women. ... He hones in on the moms ... and perhaps gives them **assurance.** (Fiona)

The surgeon's confidence in the Norwood surgical approach and his ongoing assurance helped parents remain certain about their decision for surgery. At the same time, parents sought reassurance from other sources.

Seeking Reassurance from Other Physicians: "What would you do?"

Parents viewed the health professionals as trustworthy sources of "informed information" and valued a straightforward approach. Both fathers and mothers expressed disappointment that some health professionals, other than the pediatric cardiac surgeon, were not direct in providing them with opinions. Gabrielle and Gavin expressed the most dissatisfaction with health professionals who would not share their opinions with parents. Gavin was a health professional who wanted to know what health professionals who specialized in pediatric cardiology and HLHS would do if they were in his situation. He described his frustration.

> I was looking for a specialist in the field to say, "You know, if this were my child, I would do this." ... But they would never do that. They would say, "Well no, I can't answer. You're gonna have to decide this." I remember taking introductory psychology course and them saying, "Don't tell people how to solve their problems cause if it doesn't work, they'll hold you responsible." I kinda felt that's what was going on and I can understand it because the stakes are so high here. But I wasn't looking for them to say this is what you have to do. ... I was really looking for somebody to say, "**This is what I would do** but here's the pros and cons of each of these things." ... Maybe it's unreasonable to expect. (Gavin)

One professional in the programme where Gabrielle and Gavin found out about their baby's HLHS antenatally shared her opinion with Gabrielle about the tertiary referral centre. Gabrielle cried as she recalled the incident:

> She just sort of said, "Off the record you know I would do it [the Norwood] in [city of tertiary referral centre]." ... I understand that ... she has to be loyal to [referring centre] but you know when ... it's your child's life at stake you want to know [Crying]. (Gabrielle)

Health professionals were less likely to share their opinions in the antenatal period than postnatally. When professionals did not give their opinions, parents looked for cues in how the professional conveyed information about the options. Fred and Fiona learned about their baby's HLHS at 20 weeks gestation. As Fiona recalled the pediatric cardiologist's explanation of the Norwood surgical option, she imitated the change in cardiologist's voice intonation. She concluded from this voice change that the Norwood approach was the cardiologist's preferred option, and yet an option accompanied by risk to the baby's life.

> We could opt for a heart transplant or [said with lots of expression building up to the most hopeful option] he saved this for last. "Recently we've had some success in the hospital with a new surgeon and a series of operations" and he very briefly described the series of operations ... His tone was quite, quite calm. I think he wanted us to understand the seriousness of it. (Fiona)

During her first antenatal consultation, Iris formed her opinion about the best treatment option from the order that the health professional presented the three options.

> The very first option she said was not to do anything and so in my mind, I'm analyzing that. ... Right away I think, "Well number one option she's telling me is not to do anything." ... She says it would be a matter of days and the ductus will close and the baby will pass on. ... I'm like okay. And then the second option she said is a heart transplant and in the same breath she said but getting a heart for an infant is basically nil to none. So, to me that was almost like not an option anymore. And then the third option she said, "There's this surgeon that we now have in [city of tertiary referral centre] who specializes in this defect" and she just quickly said there's a three-stage surgery and you could, you could try for that. And that was basically it. (Iris)

Iris' analysis of subtle signs that might have revealed the doctor's opinion regarding the best option led her and Ivan to consider choosing the option of compassionate care until they met with the pediatric cardiac surgeon three weeks later.

Some parents, in particular parents of the older children in this study, were given the opinion that the Norwood was not the best option. Fred recalled how negative the

pediatric cardiologist was about the Norwood approach in 1997 at the time of the antenatal diagnosis of his daughter's HLHS.

> He [pediatric cardiologist] didn't have a whole lot of faith at the time. ... [Pediatric cardiac surgeon] had just got there and they hadn't worked with him a long time. I don't know what kind of things had happened for him [pediatric cardiologist], maybe watching kids like that beforehand. (Fred)

This cardiologist did refer Fiona and Fred to the cardiac surgeon despite his negative view of the Norwood surgical approach.

In contrast, three years later in 2000, Helen and Hunter encountered the pediatric cardiologist who was described by Fiona and Fred as negative about the success of surgery in 1997. At this time, he gave Helen and Hunter a positive opinion of the success of the Norwood surgery and the skill of the pediatric cardiac surgeon.

> He [pediatric cardiologist] sat with us for a while and just explained it and told us all about [pediatric cardiac surgeon] and how he's great; all his success with this surgery. ... So that made us feel a lot better. (Hunter)

The changing state of treatment for HLHS was reflected in the cardiologist's changing perspective.

The most direct opinion from a health professional described by the parents in this study occurred when Dania asked the pediatric cardiologist in the referring centre "What would you do?" as her newborn baby's condition deteriorated.

> I just asked him straight out. I said, "**What would you do if it was your baby?**" And he smiled at me and he said, "I would take her to [tertiary referral centre] and let [pediatric cardiac surgeon] do the surgery." As soon as he said that it was the first almost like glimmer that we had. ... He was optimistic and he was smiling ... That just made our decision. (Dania)

David described this same experience as follows:

> I'm glad we talked to him [pediatric cardiologist at referring centre]. He was really good cause he knows the operations. He explained them fully and he just, gung-ho, "This is what we've got to do." "**This is what I would do.**" (David)

David also described the reassurance he received that the Norwood operation had been the right choice when his baby was transferred back to the referring centre. A doctor who had been pessimistic about Dania and David's baby surviving the Norwood operation expressed his amazement that their baby was back to the referring centre.

> A young surgeon said, "Hey, there's that miracle baby from the west. I didn't think she was going to make it." He was just amazed to see how different she looked. It made me feel pretty good. ... You're not done with it yet but things are looking okay. You're optimistic and feeling like you did the right thing. (David)

Ongoing reassurance from health care professionals that they had made the right decision with the Norwood surgical approach helped parents remain confident in their certainty of survival despite the severity of their child's heart condition.

Buffering the Severity: "It came into focus, the seriousness of the situation."

Seeking assurance and reassurance about their child's survival from health care professionals, parents became more certain of their child's survival but at the same time they become more cognizant of the severity of HLHS through their information-seeking and patterns of information sharing with each other. It was rare that both parents simultaneously had the same knowledge and understanding of the severity of their child's HLHS. Usually the parent with more knowledge and understanding had access to medical information, the Internet, and/or the availability to attend medical appointments. The parent who had more knowledge about the severity of HLHS tried to buffer or protect the other parent from information that could erode his or her certainty that their infant would survive. These efforts helped the parents as individuals as well as indirectly influencing the couple and parent-child relationship.

The parent with access to the Internet took the lead in gathering information about HLHS and the related treatment options, and usually was the first to realize the severity

of the baby's heart condition. The lead parents often screened the information that they gave to their spouses to protect them from uncertainty. For example, Cam shared with Catherine information that showed that the tertiary referral centre to which they had been referred had equivalent or superior statistics for the Norwood operation when compared to other Canadian and American centres. He did not, however, tell her about a web site by parents whose children died following the Norwood operation.

> Catherine wasn't interested in looking at the Internet or anything. She just let me look after all that. She didn't want to read any of these stories [parent-posted stories about their child's Norwood surgery]. ... I mostly only told her the good things and stuff to give her some support. ... I was getting some of the wake-up calls of what could happen. So it felt like when it came down to making some of the decisions, it was more on my shoulders because she wasn't quite as informed. (Cam)

Catherine recognized the selective nature of the information she received from her husband's Internet research. She explained that she was content to focus on preparing to travel to the tertiary referral centre for the birth of their baby; "I did the arranging."

Fiona had access to the Internet at her work place and brought information home to Fred. Although Fred described being satisfied with this as it was occurring antenatally, in retrospect he realized that he did not fully appreciate the severity of his daughter's condition until after she was born. He expressed regret that he did not "get on board" sooner. Fiona had a biology background and so the heart "made sense" to her. She stated that this gave her an advantage over her husband in understanding the seriousness of their daughter's left-sided heart problem, especially when meeting with physicians.

> Being a teacher, we dissected cow hearts and you realize that the left side of the heart is that big muscle wall. ... I had a ton of questions for him [pediatric cardiac surgeon] and I had a chance to do a little bit of research and so we came with that and spent over an hour with [pediatric cardiac surgeon] ... Just him and Fred and I. And I did most of the talking. ... But Fred just kind of sat there and took it all in, poor guy. (Fiona)

Although Gavin had a medical background, Gabrielle and Gavin spoke of them both doing research. Gabrielle sought information by talking to other parents who had a child with HLHS undergo the Norwood surgical approach.

> One parent, who their [sic] son had had a heart transplant. Another parent who had gone through all three of the Norwood series of surgeries. ... I found that the most helpful ... to hear some real life experience. (Gabrielle)

Gavin did the Internet research and collected several academic articles on HLHS. Gavin also recalled learning about the high-risk nature of the Norwood surgical approach when he noticed and read research posters on the hospital walls when their baby's HLHS were being diagnosed antenatally.

> When we had to go back to the hospital there was a poster on the wall about congenital heart disease. ... I was reading these and the stats were really lousy. (Gavin)

Although Gavin did not describe keeping things from Gabrielle, she commented that he understood the life-threatening nature of their unborn baby's heart defect better than she did.

> Gavin from the beginning understood this was very serious, that she could die and I didn't appreciate that at first. (Gabrielle)

Helen and Hunter exchanged lead roles with each other over time. Helen had a healthcare background and described not disclosing to Hunter her uncertainty of their infant's survival based on her past education. She and Hunter soon learned that there were newer treatment options for HLHS, including the Norwood surgical approach. Although more hopeful, Helen worried about possible complications based on her professional knowledge and experience. She protected Hunter from these concerns by not sharing them with him. Hunter became the primary researcher while his son was recovering in hospital after the Norwood operation, doing his research in the hospital

library. He too was selective about the information that he shared with Helen. Like Cam, Hunter did not inform his wife about the web site that discouraged parents from choosing the Norwood surgical approach.

Geographical distance to the referring centre was the main influencing factor regarding information exchange between Annie and Allan. Annie was the key player in information gathering as they lived three hours travel time from the next largest centre and Allan could not always attend the antenatal appointments with Annie. Allan acknowledged that receiving the information through Annie was not sufficient for his understanding.

> I wish I would've been there to hear it from the doctor and it probably would have made more sense. (Allan)

He did not fully understand the extent of his daughter's HLHS until he and Annie met with the health care team at the tertiary referral centre while waiting for their baby to be born. Like Fred, Allan wished he had understood the severity of his daughter's HLHS sooner.

> We had pamphlets and books here and, when I read it. ... It didn't really make sense just reading on my own. ...I didn't understand it. But when [pediatric cardiac surgeon] told us everything there and then we had some more meetings with doctors and explaining everything and **it kind of came into focus, the seriousness of the situation**, of everything that's gonna happen. (Allan)

In summary, parents described an active parenting process of deliberation in decision making, assurance, reassurance, and information seeking to become and remain certain about their child's survival. Gaining reassurances from the surgeon and other health care professionals, as well as the information buffering that went on between parents served to sustain and at times bolster their certainty that the Norwood surgical approach was the best option for their child. As much as parents longed to remain certain that technology

was sufficiently advanced to afford survival for their child, they also were constantly faced with the life-threatening reality of HLHS. Their child's survival was indeed precarious and at times there was nothing they actively could do. They had to parent their child with life-threatening heart disease in a more passive way by waiting for their child's survival.

The Uncertainty of Precarious Survival: "I know what it is like to go to hell and back."

Although parents became certain that the Norwood surgical approach was the best option for their child with HLHS, they also experienced profound anxiety and uncertainty when their child's survival was threatened. At these times, their parenting role had to be passive as they waited for the threat to pass or for their child to survive the health crisis. This passive waiting was excruciating for parents as vividly portrayed by Iris who described their wait for their daughter to survive surgery:

> It was awful. ... I know what it's like to go to hell and back. (Iris)

Waiting for Their Child's Survival: "Will she make it?"

Parenting a child with life-threatening heart disease often meant waiting for survival. For example, parents waited antenatally to see if the baby would survive the pregnancy and birth. After birth, parents waited to see if their baby would survive until the Norwood operation and then they waited to see if their child survived this first surgery and subsequent surgeries. When their child was not in immediate danger of dying, parents waited for time to pass, particularly the time between birth and the Norwood surgery. Parents were not, however, just waiting for time to pass. They were waiting for their child to survive birth, to survive surgery and to survive complications. Although most parents felt that their previous discussion of worst-case scenarios with the health professionals

had helped prepare them for these difficult waiting times, their uncertainty was greater than their certainty during these times (See Figure 3).

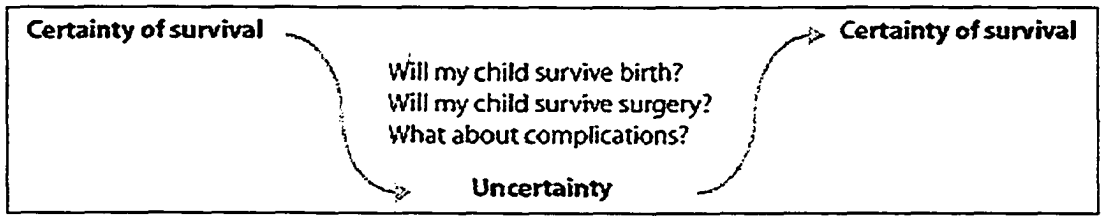

Figure 3. Parents' questions that contributed to their uncertainty

Will my child survive birth and surgery?: "It's awful, that waiting."

For parents who found out about their baby's HLHS during pregnancy, the first hurdle was survival through to the baby's birth.

> How is everything going to play out? It was one of my biggest concerns ... **will she make it**? Will she survive the actual birth? (Allan)

Health professionals had prepared Allan and Annie at the time of their antenatal diagnosis for the possibility that their baby with HLHS would not survive the pregnancy. Annie, pregnant with twins, was repeatedly told to prepare for the birth of one live baby. The health professionals constantly reiterated the threat to the one twin's life each time Annie attended a follow-up ultrasound and assessment appointment. The perinatologist would announce that there were "no signs of heart failure **yet**" and the word "yet" hung in Annie's mind. Both twins were born alive but waiting for the birth of the twin with HLHS was also about waiting for that baby's survival.

Parenting in the newborn period involved waiting for the baby to survive until the Norwood operation, hoping that worst-case scenarios would not materialize. Worst-case scenarios included critical illness, a small aorta, infection and brain abnormalities. Allan remembered his growing uncertainty that his daughter would survive when her surgery was postponed due to an infection.

> She came down with an infection. So her surgery was postponed. They would keep putting it off. They would tell us one day and then it would get postponed. So we're **like how long can she last before something happens**? (Allan)

Because of the precarious nature of their baby's survival, most parents described how immediate and extended family members gathered around the baby and parents for support rather than for celebration.

> When we actually found out what it was and how serious and our options, it was pretty scary. They said that he wouldn't make it so we had him baptized. We had him baptized because at that point we still didn't know if he was going to live or not. We had him baptized with the whole family. (Ellen)

The wait for survival of their baby was excruciating and the nurses attempted to comfort them. Dania had never held her baby and was shocked when, the night before the Norwood surgery, the nurse offered to have her hold her daughter.

> [Crying] So she [the nurse] got about 3 people to help her and they got her [daughter], all her tubes and everything, out so that I could hold her. I mean I couldn't hold her like tight or anything. They put a great big pillow on me. ...[Shaky voice] So that was pretty nice of her [nurse] I thought because I didn't even think it could happen. I mean she was too hooked up with so much stuff; ventilators and everything. (Dania)

Holding their baby, taking pictures and having other family members present helped parents cope while waiting for the surgery. Fiona described her uncertainty and the things she and Fred did with their daughter before surgery.

> We said our goodbyes. I'm sure Fred did. I'm not sure if we ever discussed that that closely but I did. ... So we kind of spent some special time that night, took some pictures, did some special things and then came in the morning [of surgery]. (Fiona)

On the day of the Norwood operation and subsequent operations, waiting had a precarious edge. Parents not only waited for their child's surgery to be done; they waited to see if their child survived. Annie tried to remain positive.

> It was a really hard day. You always have to try to have that positive outlook but in the back of your mind you're always, you're always thinking that it could, it could possibly just turn, not turn out the way you wanted. (Annie)

As Dania and David waited on the day of their daughter's Norwood operation, both described the plans they discussed in case their baby died during surgery. David described their conversation as follows:

> So you're there sitting there in the middle of a rain storm bawling and then I started thinking about, "Well what if she doesn't make it?" ... I've got to think about everything because my mind won't stop and so I start discussing with my wife. She doesn't want to talk about it. Like I'm talking, "What if she dies? Do we donate her organs? Where is she going to get buried?" You don't want to even talk about it but ... I just feel like I have to be prepared in case, in the event that does happen. But at the same time by me thinking it I think I'm jinxing the whole thing kind of. **So we waited.** The rain quit, we went for a walk and a black cat came across our path. It was awful that waiting. (David)

Dania's recollection was similar.

> We went for coffee and then we went for a walk. ... You don't know what to do ... like you've got the pager and don't know if you want to be in the hospital all the time or whatever. But we did make decisions about what we would do. ... Like we would donate ... anything that was usable from her to somebody else. We'd made all those decisions ... before the surgery was over. (Dania)

Bonnie felt lost and empty as she waited for her daughter to survive surgery.

> It's hard to explain the feeling you feel. You sort of feel lost. You feel this emptiness. ... There's that type of uncertainty cause you don't know the outcome. ... Even when they bring her up [from the operating room], you don't know how long she's gonna live. You don't know. Everything could shut down. (Bonnie)

"It's just so much waiting" Ellen remembered and the wait became excruciating when the operation took longer than the predicted three to four hours. The mothers especially used vivid words to describe their response when the wait time was extended. When I asked Ellen how she and the family members were doing as they waited, she replied:

> Oh hysterical. Yeah. Pacing. Crying. Worrying. ... It was awful. (Ellen)

Fiona recalled her intense feelings as she waited.

> It was that much longer. And I almost climbed the walls. I almost go crazy. I go nuts and Fred paced. We were outside of PICU (Pediatric Intensive Care Unit). ... You kind of feel it's out of your hands. (Fiona)

What about complications?: "I've never cried the way I cried that day."

As much as parents waited and hoped for the best, they also prepared themselves for the worst. They learned of worst-case scenarios through the Internet and in their conversations with health professionals. Many parents experienced a worst-case scenario and they had an excruciating period of waiting to see if their child would survive.

Some babies had complications coming off the heart lung machine or difficulties with the shunt between the pulmonary artery and the newly constructed aorta. Often the cardiac surgeon came out of the operating room to explain to the parents which complication was causing the delay. Bonnie described her experience when her daughter had the Norwood surgery.

> "We need to talk." [pediatric cardiologist] That didn't sounded really good and I said, "Well?" and then she said, "Well, they've tried taking [daughter with HLHS] off this machine five times and ... she's not coming off." Then they said, "Well if the shunt doesn't work, ... they're gonna try the second shunt and if it doesn't work, you basically don't have a daughter." **I've never cried the way I cried that day**. I still remember sitting there. I, I was sitting in this, this chair. ... They [?nursing staff or family members] said they could hear me all the way down the hallway. (Bonnie)

Iris and Ivan's baby also experienced complications in the operating room because her aorta was very small. Iris recalled her long wait.

> She was in surgery for over twelve hours. ... **That was hell.** ... We waited and waited. He [pediatric cardiac surgeon] said, "Meet me here at 11:00" ... As soon as he wasn't there by 11:30, I knew and I was ... upset and crying, crying, crying and then it must have been about 5:00. He finally came out. Five o'clock! He comes walking down that dreaded hall and he looked stressed and I'm just sick. I just stand up. I cannot sit and wait for them. As soon as I see him, I'm up and I'm pacing and he came up and he said, "This is what's going on." (Iris)

The surgeon assured Iris and Ivan that he would not "give up" on their baby and eventually she was transferred to the PICU.

The relief parents experienced when they heard that their child was out of the operating room was often short lived as the professionals were quick to caution them that the next 12, 24, 48 and/or 72 hours were crucial to their baby's survival. Fiona remembered fixing her attention on the pediatric cardiac surgeon's words, "the next 12, 24 hours."

> Every time [pediatric cardiac surgeon] gave me a figure, it just kinda stuck in my brain ... like a time bomb going off. Okay when I get to that I'm okay, we're okay. So I remember counting that and so we stayed there till very, very, very late. (Fiona)

Even though the day of the Norwood operation felt very long, so did the next few days.

> It **was the longest day of our lives** until the next two [after the Norwood operation]. (Fiona)

Helen recalled the surgeon saying, "It'll be a wait-and-see." Helen vividly described the first 24 hours.

> It was like holding your breath the whole time, that's what it was, and then once the 24 hours was gone, it's still touch and go and they made it very clear that things can happen any time but you've gotta think positively. (Helen)

Annie also described how difficult the first few days were for her and Allan.

> They came up to us right away and said that things had gone as well as they possibly could but that we needed at least 72 hours of complete stability before we could start to relax a little bit and that the hardest part wasn't over yet. ... Before we had thought, if we could just make it through the surgery everything will be fine then and realizing that we still had a lot of time to put in before we knew whether or not she would come through. (Annie)

Catherine and Cam's baby had a life-threatening complication within a short time of arriving in the PICU from the operating room. Catherine outlined the surgical complication and the reaction of the staff:

> We proceeded to walk in and then his chest cavity was filling up with blood and the chest tray thing underneath was filling up. ... So they scurried us out and [pediatric cardiac surgeon] was called and he had to open him up right there and stitch him up. He blew a stitch. So we had to wait an hour and they locked, they have lock down, they kick out everybody at the PICU ... then Cam proceeded to go in and they kicked him out cause he was getting nervous. (Catherine)

Cam was positive that his son "was gone for sure."

> We were in there five minutes and one of the stitches blew in his heart and he was bleeding out ... The op-site over it ... that was bubbling up like a balloon almost. ... So again we had two hours there, sitting outside the PICU knowing something was drastically wrong. (Cam)

Iris and Ivan's baby also had a complication after the Norwood operation and they were called back to the hospital from where they were staying. Iris had been hesitant to leave the hospital that evening and never stayed far from the hospital again.

> We were just exhausted and I remember that nurse that night looking at me saying, "You need to go get some rest" and I didn't want to go and Ivan, he's saying, "Iris, you've got to go." ... I felt so pressured and I was very uptight ... I didn't want to go but I allowed these people in talking me to go and it really peeved me off to this day because we left and then we got the dreaded phone call. She had had two cardiac arrests and it was just like, "You need to come to the hospital now." (Iris)

Although the parents vividly described complications related to the Norwood operation, complications also occurred with the Glenn and Fontan operations. Annie and Allan's baby hemorrhaged immediately after her Glenn operation while Fiona and Fred's daughter had a collapsed lung and period of organ failure after her Fontan operation.

Most parents appreciated the professionals' efforts to inform them of what could happen because it helped prepare them.

> I guess if they would just go and tell us all the positive things, it could be misleading. ... I'd rather have the worst case scenario because then you're kind of prepared for what could happen. But like it might never happen so then you can deal with it. .... Then if it's gonna be a worst-case scenario, you're not shocked. So that's how I kind of feel about having the worst-case scenario and when they told us they said this could happen or this could happen. They never really said, "It will happen." (Allan)

One father however expressed anger that the physicians did not prepare him for the complications his daughter encountered, the prolonged hospitalizations and the toll that this took on his marriage and family. In contrast to the parents who described "worst-case scenario" conversations with physicians, Ivan described receiving a "rosy-assed story" from physicians.

> They don't tell you what you're really gonna go through anyways, so how can you prepare. ... Well they don't tell you anything. ... I'd rather hear of worst-case scenario than some **rosy-assed story** that's not true. (Ivan)

Iris agreed with Ivan that she was thinking more in terms of her child's survival and did not think about the complications that her child might face with the Norwood surgical approach.

Through their child's experiences of life-threatening surgeries and complications, parents were constantly aware of the chance they had taken with their choice of the Norwood surgical approach for their child with HLHS. Annie's words depicted the reality of precarious survival.

> I think for us it was just as long as she [baby with HLHS] held on, I think we would too and I remember saying at one point just how much more can she take, you know. She's been through so much and, and more than most people go through in a lifetime and she's only weeks old and knowing that she'll still have surgeries to go through yet. It's really, really hard. ...Now so much it's not a matter of *if* she's going home, it's *when.* (Annie)

Summary and Conclusion

Parents learned about the severity of their baby's HLHS through worst-case scenarios from professionals and other sources, such as the Internet; they also experienced the life-threatening nature of their baby's complex heart problem. Each parent's certainty that the Norwood surgical approach would mean survival for their child changed to uncertainty when their child went for surgery and experienced complications. This occurred whether

parents came to their certainty of survival over a longer period of deliberation in the case of the baby's antenatal diagnosis of HLHS, or in their brief time-pressured conversations with health care professionals after the baby was born and became critically ill. Regardless of the timing of the diagnosis, parents had to move from a more active process of parenting as they chose the option of the Norwood surgery to a less active process of parenting as they waited for their child to survive.

Parents however re-embarked on an active process of parenting once they realized their child had survived the Norwood operation and it was a matter of *when* not *if* their child went home. In this study fathers and mothers parented their children after the Norwood surgery by safeguarding their child's survival. Safeguarding their child's survival was an all-consuming process and parents also had to safeguard their own survival as parents. I discuss how the parents safeguarded their child's survival in Chapter 5, and how they safeguarded their own survival in Chapter 6.

CHAPTER FIVE

SAFEGUARDING THEIR CHILD'S PRECARIOUS SURVIVAL

"We were prepared to do anything for her."

Parents' decision in favour of the Norwood surgical approach gave their child with HLHS a chance for life while setting them on a course of precarious survival through multiple life-threatening surgeries and potential complications. All of the children in this study had "beat the odds, so far" (Iris) but not without parents experiencing their child's life being threatened, times when the survival of their child was out of the parents' hands. As the child's condition stabilized and improved following the Norwood operation, parents gradually took more responsibility for the care of their child. They, in fact, became the experts in regard to their child's specialized care and embarked on a process of parenting that involved safeguarding their child's precarious survival.

In this chapter I will describe how the fathers and mothers in this study parented children who underwent the Norwood surgical approach. Their child was a new survivor of pioneering medical care and their child's continued survival depended on parenting strategies that ensured that their child gained weight and was shielded from infection.

Parenting a New Survivor: "Holy smokes this is, this is way out there."

As survivors of new surgical technology, the children were a learning experience for many health care professionals and their parents therefore received minimal direction in how to provide care. There were few established guidelines for care in hospital and even fewer for parents as they provided specialized care for their babies at home. In addition, parents were reminded of the precarious nature of their child's new survival status as they learned of families in similar situations whose babies with HLHS had died.

Although the parents in this study did not describe their children as "survivors" or "new survivors," they described their children as having *survived* their complex heart condition and related surgical intervention. Parents also understood that their child's survival was novel. Ellen stated that her son was the first child in their province to survive the Norwood surgical approach for HLHS. Fiona learned early in her experience that the care of babies with HLHS undergoing the Norwood surgical approach was still being developed, even at the tertiary referral centre. Feeding recommendations for her daughter both before and after the Norwood surgery were not clear.

> It was hard to have such a large baby on glucose. She [daughter] was hungry and I remember him [neonatologist] saying, "This is still relatively new ... we have to come up with a protocol for feeding these children." So I knew ... they didn't quite know themselves what to do with them. (Fiona)

Health care professionals outside the tertiary care centre were even less familiar with the care requirements of children with HLHS who had undergone the Norwood surgical approach. The local pediatrician attending Allan and Annie's baby with HLHS constantly reinforced the unique status of their daughter. He told Allan and Annie that "any baby with the same condition he ever saw was compassionate care only." Despite or perhaps because of his lack of experience with these babies, he went to extraordinary lengths to be available to Allan and Annie and their baby.

> He [local pediatrician] was very supportive for us. Not only did he cancel his Christmas vacation, he would call us constantly ... just to check in. He lives out of town and he would come into town constantly. We were able to call him at home. ... We were just always in such close contact and he was always talking to our cardiologist in [next largest centre], always looking into something. (Annie)

For most of the parents, however, their babies were a daunting challenge to local health care professionals. The lack of experience and knowledge of local health care professionals influenced the parents' determination to take charge of their child's care.

Ivan described his realization of the uniqueness of his child's health condition and growing realization that the care and survival of a child was the parents' responsibility.

> These kids are so unique ... I've really got a grip on, "Man this is way different." ... Now I look back and I think, "**Holy smokes this is, this is way out there.**" ... Some doctors and nurses get a grasp on that right away ... Others, ... **it's almost like walking with an egg in a spoon.** They're just not comfortable with it because there's so many scenarios that can happen in a second's notice. (Ivan)

Parents dreaded going to the Emergency department with their child because the professionals would not address the immediate concern, a sore throat for example, without becoming alarmed by symptoms related to the child's HLHS.

> She had a throat infection ... and I took her to the Children's Emergency ...Well she's been wailing and we get to the hospital and she's cyanotic ... you can just see everybody ... even in the Children's department with the pediatric residents and pediatrician, they're wetting their pants that this kid's gonna die on their shift. They don't know. ... "We gotta do blood tests, we gotta do this, gotta get urine." And they're gonna hook her up to this. (Gavin)

In these situations, parents were concerned that their child would be given unnecessary procedures, adding to all that the child had already experienced in other hospitalizations.

It was evident to parents that the professionals were still learning how to care for children following the Norwood surgery. Dania and David received a phone call from their daughter's pediatric cardiologist reminding them of the importance of monitoring their baby's hydration. Another baby with HLHS in the physician's care had just died and he immediately shared this information with Dania and David. David described the influence this had on him and his wife.

> We monitored everything. She has that shunt in her and they were concerned about that collapsing because if they get dehydrated that can collapse and if that does then there's no circulation so she'll die. And one of the other babies here that had the first, the same operation, he did die. I guess he got dehydrated and **they weren't monitoring him close enough and he collapsed and he died.** (David)

Through contacts parents made with other mothers and fathers during their hospitalizations or through parent networks, they also learned of babies with HLHS who died. Fiona described parents that she met at the hospital. Despite all the efforts these parents made to leave nothing to chance, their baby died. Poignant accounts like this reminded parents in this study that their child's survival was precarious.

> They were a couple that were told don't take oxygen home ... and she's like, "Take oxygen home." She goes, "Don't listen to them [the professionals]" and she had taken **every single precaution.** ... every single step to ensure that they were going to be a help if something happened, ... They needed that for their peace of mind. ... But ... **he [the baby] passes away.** (Fiona)

It was in this context of uncertainty related to their child's new survivor status that parents safeguarded their child's precarious survival (See Figure 4).

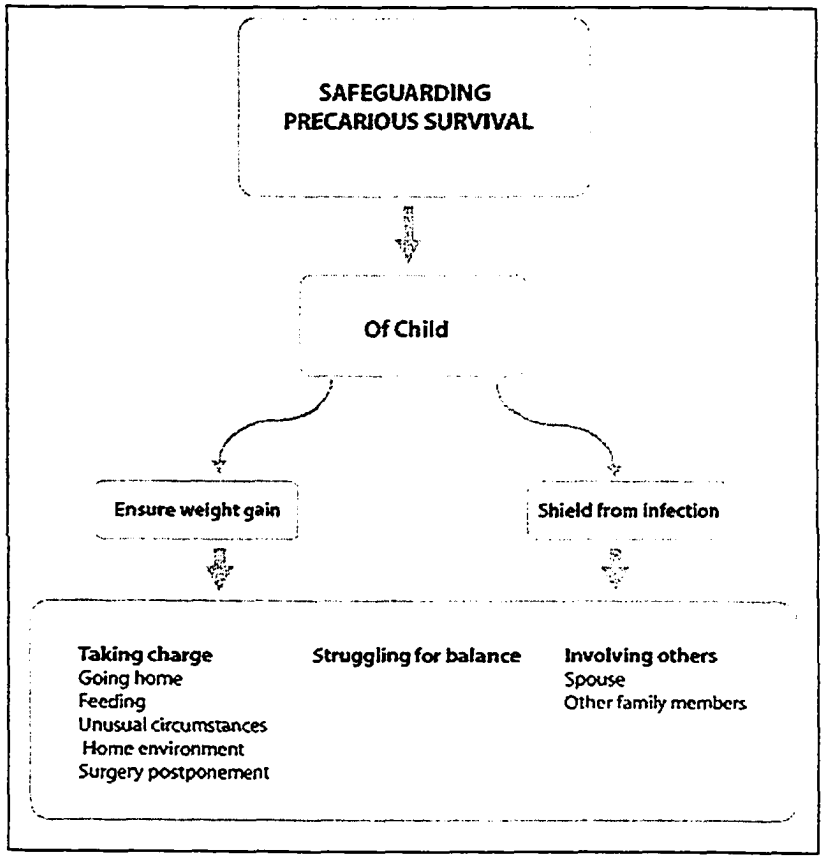

Figure 4. Safeguarding the precarious survival of their child

To meet the parenting challenges of ensuring weight gain and shielding their child from infection parents primarily used the strategies of taking charge, struggling for balance, and involving others).

Safeguarding by Taking Charge: "I just have to do what I have to do."

Parents took charge of their child's care and became experts regarding their child's condition and care, firstly so that they could take their baby home after the Norwood operation. Once home, parents took charge to ensure their infant's weight gain and to shield their baby from infection. In the absence of established guidelines for children with HLHS who were undergoing the Norwood surgical approach, parents devised their own methods of care. Parents described performing advanced nursing and medical assessments, judgements and skills in tandem with an all-consuming care regime that soon became a way of life. With few guidelines parents learned by trial and error. Annie described this well.

> Everything we've done is **trial and error** pretty much. We fiddled with concentrations [of formula]. We fiddled with volumes. We fiddled with gravity feeds and bolus feeds and, and pump feeds and this and that and, and we figured out how to run the pump in the car while we're driving to [next largest centre] and just every little thing ... I think we've done trial and error and when we couldn't figure it out, we'd find someone who could and just phone this person and that person in [next largest centre] and go on the Internet. ... And I think it also made a big difference cause [baby with HLHS] wasn't our first baby. (Annie)

Most of the fathers spoke of having to figure things out as they went along. Cam's comment was:

> Getting home, trying to **figure out** how to manage [baby with HLHS] on our own, all that kind of stuff. ... Trying to get used to having this baby, with special needs, trying to get him to eat cause he was NG tube fed at that time. (Cam)

Figuring out and taking charge of their baby's care meant parents could have their baby at home.

Taking Charge in Order to Go Home: "We were just so anxious to have her home."

Soon after the babies in this study were born, parents had to relinquish their care into the hands of health care professionals. While the baby was critically ill, there was little parents could do except be present at the baby's bedside. Some parents did not get to hold their babies until they were several weeks old. As babies began to show signs of improvement, especially in their feeding, parents were eager to have their babies at home. At the same time, they were nervous about all that their baby's specialized care involved. Parents had to be willing to take charge of their baby's care which involved complex feeding regimens, the administration of numerous medications, ongoing assessment of the baby's breathing, colour, energy for feeding, fluid balance, and temperature as well as sophisticated judgements about care. Some babies also went home on oxygen and one baby required wound care.

As daunting as their child's care was, parents were willing "to do anything" to have their baby at home. Few parents received formal teaching regarding the home care of their babies. The babies' prolonged hospitalizations following the Norwood operation did afford parents the opportunity to observe the nursing care their baby received. Parents assumed most aspects of their baby's care before discharge, although always with the support of nursing staff.

All babies in this study went home with a feeding tube, either a nasogastric (NG) tube or gastrostomy tube (G-tube). Demonstrating their ability to take charge of their baby's

tube feeding, especially insertion of the NG tube, was one of final criterion for discharge. Bonnie proudly described her success with her daughter's NG tube.

> I watched everything that happened and I watched how they would do everything and I guess I'm just a quick study. ... I don't think I ever screwed up once with the tube. It always went. ... It was real funny. The first time they came out to show me how to do that, I got it in the first, first thing and then the girl she says, "Gee, my nursing students don't even do that that well." (Bonnie)

Most of the fathers as well as all of the mothers learned how to insert their baby's NG tube before discharge. Even with his health care background Gavin described the pressure he felt to demonstrate his NG insertion ability.

> We hadn't had the lessons for the nasogastric stuff but I was trying to convince the cardiologist that ... I know the pathways. I know the anatomy. Just show me. I'm sure that I can do this. Well sure enough, it didn't work first time round. I kept getting stuck on something somewhere. ... This was a Friday. I was trying to get out on a Friday afternoon ... and basically no she's gotta stay till the Monday. (Gavin)

Gavin finally passed the "test" and described the happy homecoming.

> Then on the Monday finally I showed okay yes I can pass the test. I'm okay I can do it and go and, it was great 'cause [daughter with HLHS] was just in fine form that day and I'd love to show you the picture but she's just smiling and looking around, well this is great, and took pictures of the front door ... it was very, very happy we got out of there and we were just so sick of the hospital. (Gavin)

Having their baby out of the hospital and home with them was the parents' main motivation to overcome their nervousness of taking charge of their baby's care at home. The feeding challenges were numerous and parents responded by taking charge of their child's feeding regimen.

Taking Charge of Feeding: "She wasn't eating enough to stay alive."

Parents immediately took charge of their baby's feeding by adapting the hospital feeding routines and recommendations in response to their baby's needs. As weight gain was the primary criterion for discharge from hospital, babies had been pushed regarding

their feeding. Vomiting, reflux, and irritability showed that the baby was not tolerating feeds and the mothers took charge by changing the strength and timing of feeds, often to a weaker concentration and to more frequent feeds.

Dania described how difficult feeding was in the hospital; her baby was "screaming with gas pains ... throwing up ... puking ... projectile vomiting." Once home, Dania took charge of the feeds:

> When I got her home ... I put her on just regular strength formula. And within probably 2 days she wasn't getting Ovol. And it didn't click with me then but it was the high calorie formula that she couldn't tolerate ... I mean she wasn't throwing up, she didn't seem to be as upset like, you know, sort of colicky almost or crying all the time when with stomach problems. (Dania)

Although Dania's daughter's feeding tolerance improved with these changes, the professionals continued to be concerned about her slow weight gain and so referred Dania to a dietician. Dania implemented the dietician's recommendations but it was not long before Dania again took charge of her daughter's feeding:

> She's very small for her age and of course, the weight gain was a big concern with everybody and [pediatric cardiologist]. ... We went to see a dietitian first. "I want you to put her on a high calorie formula." ... So I did that and within ... the first day but probably the second day she just did nothing but cry, all day, all night. I brought the stroller in to try to keep her quiet and I wasn't sleeping, she wasn't sleeping. I was just about a nut case. I phoned [pediatric cardiologist] back and I said, "I can't, she can't tolerate this. I can't, she's crying off everything." I said, "You know, if she is given an extra calorie she's burning it off because she's crying." So then he said, "Well you just put a ml of oil in the bottle". So I did that but I only made up 2 bottles and after the second bottle she was screaming. So I said "She can't take that." So, she has been a slow gainer. I just have to do what I have to do, that's all. (Dania)

Dania was not the only parent who " gave up" on the dietitians and other professionals. One mother indicated that she held the phone away from her ear when a professional was giving her feeding advice over the phone. All of the mothers, except for Fiona, discussed how the professionals' feeding recommendations did not fit their baby.

For Fiona, the insistence of health professionals that Fiona tube feed her baby did not fit Fiona's desire to exclusively breastfeed her daughter.

In retrospect Helen wished there had been a "handbook for parents" to guide her in the feeding challenges she encountered with her son. She noted the lack of "common sense information" from health professionals that addressed the unique needs of babies with heart-related feeding problems.

> The health nurse's focus is completely different of course and the new thing is ... you wait nine months to maybe a year before you even try solids. Well these kids you can't do that. And so the nutritionist, we would see her in clinic and she was great when we saw her but then you come home and you're kinda left to your own devices. (Helen)

Feeding her four-month-old "Minigo [condensed yogurt] because he needs the calories" and adding butter to everything were some of the things Helen and other parents did to ensure their baby's weight gain. "Normal" worries about milk allergies, wheat issues or heart disease were of less concern than weight gain during that first year of life. There were as many different feeding regimens as there were babies in this study but all parents agreed that one had to be "very scheduled" and that the feeding regimen was time-consuming. Dania described setting the alarm for every two hours to feed her baby. Catherine also described living by the clock:

> Like if you sleep in, that mucks him up because he has to have his medication an hour before his feed. So no sleeping in at this house. [laugh] ... Cleaning his syringes and his tubing and making his formula every day. It's a little routine. ... Then you know his feeds are, [deep breath] they go over an hour for every three hours so you don't have a lot of leeway in between to do things right now. Like you have to run an errand, you have to do it within the hour and a half that he's off the machine so our time, free time is not that free. (Catherine)

Despite the parents' constant feeding efforts, slow weight gain characterized the baby's first year of life and was one of the most challenging aspects of parenting. Hunter showed some pictures of his son as he explained the feeding difficulties.

> See how skinny he is. ... Normally he's a really happy kid. You'd never know he had a problem for the most part. But he's really underweight, which is one of the hardest things, to have these kids gain weight. (Hunter)

Prior to the second surgery, the Glenn operation, all of the babies did not have enough energy to feed well. Parents knew that their child needed to gain in order to have the next surgery. Catherine spoke about "making sure he [baby] packed on the weight" between the Norwood and the Glenn operations. Fiona's awareness that her baby's feeding and weight gain were linked to the timing for her next surgery motivated her to give tube feedings despite her strong desire to breastfeed.

> But we [Fred and Fiona] were also concerned ... (because surgery was coming) that she [baby] was a little bulked up and so if she didn't eat properly, I usually topped her up [with tube feeds] and so **we kept right on top of her.** (Fiona)

Cam expressed concern that his son would not gain enough weight in preparation for the third operation, the Fontan surgery. At 15 months his baby weighed 20-21 pounds and Cam said that the surgeon wanted the children to be 30 pounds for surgery. Parents such as Cam worried that their child's chance for surviving surgery would be less if there was not enough weight gain.

> That's our worry, weight. To get him feeding to get him to the weight for the next surgery and then if he doesn't get the weight for the next surgery, then doing the next surgery underweight, there will be difficulties in that. (Cam)

Parents therefore persevered with tube feeding as long as possible even when the babies became more active and repeatedly pulled at the NG tube. Parents were aware of the risk of aspiration and monitored their baby closely for this potential complication. They used a variety of strategies to protect their infant. Most of the babies on tube feeding slept right next to their parents' bed so they would be quickly aware if the baby pulled the tube out or worse yet, part way out. Hunter vividly described the challenge.

> He wouldn't get it [the NG tube] all the way out so you're wondering if it was going to his lungs. All that stuff goes through your head. A couple times we woke up, we had him right at the foot of our bed, ... and he'd be [make a choking noise] you know choking, like he'd have it half way out. (Hunter)

Helen designed flannel "handcuffs" to keep her son from pulling his NG tube out at night when tight bundling no longer worked. But he would still manage to get at the tube. Parents constantly checked their child's breathing and had difficulty stopping this even after they stopped the tube feeding.

> **The tube feed was the scariest** not having to do it but the risk of aspiration. ... That was always going through my mind. I think I probably stopped three months ago, listening to him every night, watch his respirations, see how his lungs are. ... It was scary. (Helen)

Fear of aspiration and the constant monitoring eventually took a toll on the parents. They then switched their baby to oral feeding. This happened more often after the Glenn operation when most of the children showed improvement in their ability to feed orally. Helen and Hunter, however, switched to oral feedings before the Glenn operation, willing to feed frequently in exchange for less worry about aspiration.

> I think it was at six weeks, we talked to [pediatric cardiologist] and we said, "Can we bottle feed him every 20 minutes if we have to? Can we just stop the tube feeds during the day?" Cause he was pulling it out and I don't want to be inserting it into this kid six times a day. So they said sure, as long as he's gaining weight. So, they let us do that and so at first we bottle fed every half hour or twenty minutes and then he started to suck better and then got used to the bottle and ah, we were able to go to every hour after that and then every two hours and every three hours and then we knew there was a certain amount ... that if he drank during the day then we could stop, finally stop the tube feeds at night and we would bottle feed him every three hours throughout the night. (Helen)

Other parents took charge of changing from tube feeding to oral feeding when they felt that their baby's weight was adequate. If the baby had been on continuous feeds, parents decided when to switch them to bolus feeds in preparation for oral feeding. The child's improvement after the Glenn operation and their response to solid food

determined how gradually or suddenly their parents discontinued the tube feeds. Bonnie remembered talking to her 15 month-old daughter about stopping her tube feeds.

> "By Christmas you're going to eat solid food." ... I told the tube and I told (Child with HLHS). I said, "We're not putting this tube down anymore." So ... sometime in December I pulled the tube out for the last and said, "You're gonna eat food" and she started doing it. (Bonnie)

Some children remained on tube feeding until long after their Glenn operation. Ellen's son remained on G-tube feeds until he was six years old. Prolonged tube feeding presented parents with additional opportunities to employ the strategy of taking charge.

Taking Charge in Unusual Circumstances: "I ended up putting it in."

Parenting a child with HLHS meant frequent medical appointments and procedures between hospitalizations and surgeries. Taking charge in unusual circumstances meant fewer hospital visits. David and Dania took charge of re-inserting their daughter's G-tube when it was accidentally removed during the night. They did not want to wait in the Emergency department's "fricking mile line up." They knew that the physicians would be reluctant to "touch" their baby because of her serious heart problem "We had an extra one [tube]" David recalled. He recounted arguing with his wife, "Here, you put it in." "No you put it in."

> I ended up putting it in and that was quite the experience. Like I had never done it before and I ended up getting some of that Petroleum Jelly and she's screaming and I'm pushing and it won't go in. It won't go back in and then I just pushed a heck of a lot harder and it did go in and I got the saline solution in it and after about an hour or so everything settled down. It was okay. I can't believe these tubes would break open inside. Like the saline, I guess the stomach acids eat it away. So I experienced that and then the next time it happened again, more like 11:00 o'clock at night and so, "Let's go to the hospital." and it wasn't, we didn't get home until 3:30 in the morning. (David)

Cam and Catherine's son had a G-tube that he pulled out several times. Usually they went to the emergency department at their local hospital for re-insertion. As the baby

became more active and the tube came out more frequently, Cam found these repeated trips stressful. Catherine described one instance when she was not home and her husband "installed" his son's G-tube after it got "caught in his booster seat" and was dislodged.

Gavin and Gabrielle learned how to administer subcutaneous low molecular weight heparin via an indwelling catheter that they replaced when necessary. Although this enabled their baby to be home sooner after her Glenn operation, it was not an easy skill to master. Gavin described one particularly difficult evening.

> The Enoxaparin given through an Insuflon that had its challenges. To put on the EMLA cream and put in the Insuflon, which looks so long and seems so mean but works quite well. When [Daughter with HLHS] was struggling when I was trying to put it in through, you know, the needle into the Insuflon, I perfed the Insuflon, it bled into her leg. We had to take it out. It'd only been in there a couple days and I was really mad at myself for this because it was her bedtime and we'd had an hour to put this on. ... I finally just injected it [the medication] ... and she wailed and ... and I was really mad at myself. (Gavin)

Helen and Hunter were taught how to assess their son's breathing and lung congestion and took charge of administering diuretics as necessary to avoid extra trips to the hospital when their son had a cold.

> When he has a cold, we give him an extra dose of Aldactazide just because his lungs get wet. It's amazing how fast they can change, that's the scary thing. Couple hours and they're a different kid. ... I listen for him I think. You know the way he breathes or whatever. And then is it upper airway? ... Just sinuses or his, you know, actually in his lungs? Which is hard to tell sometimes. ... You know him better than anybody and they all admit that here too, that what all the doctors say, when we go in there, they know there's something wrong. (Hunter)

Fiona arranged for a standing bronchodilator order at the local emergency department so that her daughter could easily receive help when her breathing was laboured with her colds. As well as taking charge in these unusual circumstances, parents took charge in their home environment to keep their children as healthy as possible.

Taking Charge of Home Environment: "We didn't want her to catch anything."

Taking charge was the main strategy parents used to shield their child from infection. The fear of infection was greatest during the first year of the child's life when their feeding and weight gain was so precarious and parents felt pressure to have their baby healthy and "bulked up" for their second surgery, the Glenn operation. Professionals warned parents that babies with HLHS did not tolerate being sick with a cold or influenza. Parents worried about their child's heart.

> The doctors tell you and it's true, ... if they get a cold, if they get the flu or if they get anything it really affects them way harder; makes their heart work harder and just it affects them so we never really went anywhere. (Hunter)

Parents, therefore, took charge of their child's environment by keeping them home.

> We never took her anywhere for the first year of her life. ... We just didn't want her to be where there could be a lot of germs. (David)

> We didn't go out for a year. (Annie)

Despite parents' best efforts to shield their children from infection, they all experienced their children getting sick and described how sick they became. Fiona compared her daughter with HLHS to her healthy older brother.

> When she gets sick, it's not like [older child] getting sick. [Older child] getting sick is like whatever. Of course I care about him and I love him and I worry when he gets sick, but when [she] gets sick it's a whole different thing. (Fiona)

Once sick with a cold for example, these babies did not recover quickly, another motivating factor for parents to protect their child from infection.

> When she gets a cold ... sometimes it lasts months. It's awful. (Iris)

Parents protected their children from infection by keeping them home but they were also aware of preventing germs from being brought into the house. All of the couples except for Helen and Hunter had at least one older child in preschool or school. Parents

expressed fear that these older children and their friends would bring germs into the home. They managed this fear by enforcing frequent hand washing, and by restricting and screening visitors.

All parents described how they emphasized the importance of hand washing in their households. The fathers especially vividly portrayed the constant and practical aspects of hand washing in their efforts to keep their child with HLHS healthy.

> Well trying to keep them healthy is always an issue too. Especially with other kids around and with [other child] in school now. ...You hear friends from down the street are coming over and they come in the door, **"Go wash your hands."** You're telling adults to wash their hands ... That has to be done. (Cam)

David made physical changes in their bathroom to promote diligent hand washing and attributed his freedom from colds to hand washing.

> And in all that time, the first years, I never had a cold either. I've installed a paper towel dispenser in the bathroom with antibacterial soap and anybody that entered the house had to wash. And that includes all my kids, all these hands. Children's friends, company and everybody just kind of got used to it. Everybody should do that all the time. It helps. (David)

Although parents viewed hand washing as a key approach to protect their children with HLHS from infection, all parents also recalled screening visitors to their home. Most parents counted on their friends to inform them of colds, influenza or infections in their homes in the unlikely event that the parents of the child with HLHS were venturing outside of their home.

> They [friends] don't come over with anybody who has anything and ... they'll warn us before coming over. "Oh well maybe you better not bring [baby with HLHS]" or "You better not come over cause so-and-so's got a cold." (Cam)

Screening visitors meant periods of isolation from extended family members as well as from friends. Hunter and Helen's siblings all had young children and at least one child in each family usually had a cold.

> Like my little brother's kids, I'd didn't see them for four months, because you know one of them always had a cold ... same with Helen's sister. (Hunter)

After the Glenn operation most parents eased up on shielding their child from infection but when a date for the Fontan surgery was set, they were determined to keep their child from "getting bumped" due to infection so again took charge of their child's environment.

Taking Charge to Prevent Surgery Postponement: "The bubbled life."

Any sign of infection meant postponement of surgery and so parents took charge to keep their children healthy before their scheduled surgeries. Parents worried that surgery delays put their child more at risk for survival because plans for surgery were often initiated when the child's oxygenation had deteriorated. The wait for surgery was excruciating without delays; postponements were avoided at all costs.

Keeping their children free from infection was especially difficult to achieve when waiting for the Fontan operation because the child was involved in activities outside the home. Parents therefore kept their child home from school and all outside activities and curtailed the activities of their older children to avoid exposure to infection. Iris and Ivan could not take a chance that their daughter's surgery would be postponed. Their daughter's oxygen saturations had dropped significantly and she needed to have her Fontan operation as soon as possible to prevent hypoxemia-related complications. Iris' description was as follows:

> Her oxygen levels were so low that we really need to get this kid to surgery so we lived basically the bubbled life from the beginning of December. ... So she wasn't allowed to go back to school. ... She didn't play with any kids. I didn't take her to shopping malls. I didn't take her to stores. Her and I lived in this house or we went outside in the backyard and played or we were around family members that totally knew that they were well. (Iris)

Ivan's description was similar:

> [Iris and our daughter] were almost in **quarantine** from November till February. I mean we had to take her out of school. She couldn't go to swim lessons. She couldn't play with her friends. So that was awful. I mean I didn't see it all the time but lots of times she would just freak right out and be screaming and bawling and saying, "Why can't I go to school? Why can't I play with my friends? Why can't I?" I mean that's not fair but we wanted to get surgery out of the way. ... I think we'd had surgery cancelled one other time cause she got sick on us. So we just figured that if we could do our part then we could get in there and get it done. (Ivan)

When Iris and Ivan's daughter's surgery was postponed for a second time because of bed shortages in the hospital, Iris "lost it," becoming angry and despondent. She recalled dismissing all her efforts to shield her daughter from infection as "this kind of half-assed bubbled life" and threatened to stop isolating her daughter.

> I'm just freaking. I'm crying. ... So needless to say I got on the phone and I called [pediatric cardiologist] and I'm just like, "This is crazy. Like enough is enough. You know what?" I said, "My kid is going back to school. She's doing all these things. Our life is going back. We are not putting our lives on hold anymore, I've had it." ... And I'm just like, forget it. I have gone the mile. I've gone beyond keeping my kid healthy and they just call and cancel. (Iris)

Fortunately, Iris and Ivan's daughter's surgery was rebooked for two weeks later and Iris continued her quarantine efforts to keep her daughter healthy for surgery. A week before surgery Iris and Ivan's older daughter got a cold and the isolation of the family members escalated.

> [Older sister] did get a cold the week before. ... So [older sister] is ripped over to my mom's and then when [child with HLHS] was sleeping, we bring [older sister] home. It was awful. ... I just thought why does this have to be like this? ... I was just so PO'd. So off I go to the medical store and buy masks for everybody. So we draw faces but the kids hated wearing them. It's awful. (Iris)

Isolating their child before surgery was also about isolating their child during what might be the last days of his or her life. Iris alluded to the risk of surgery as she thought about her two daughters being apart in the days before surgery.

> It could be, I don't know what's gonna happen with [child with HLHS] and I thought, "These little girls. [This] could be their last time together and they couldn't even be together [due to the cold]. (Iris)

Although the pressure on parents to safeguard their children's survival was intense when their child's life was threatened, safeguarding their child also included finding a balance between protecting their child and facilitating normal life for their child. Most parents described their constant struggle to find the balance their child needed.

Safeguarding by Struggling for Balance: "Are we being overly paranoid?"

Parents frequently questioned the care they provided for their child. Were they doing enough? Were they going "overboard"? What was necessary and what was excessive? Dania wondered if she overemphasized staying home during her daughter's first year of life.

> When we got [her] home it was like we didn't take her anywhere because of germs ... probably to the extreme, I realize now. (Dania)

Fiona and Helen wondered if they had relied too much on the tube feeding at the expense of not breastfeeding their baby. Looking back, Iris wondered if she and Ivan had overdone the pre-operative quarantine before their daughter's Fontan operation. Dania acknowledged her worry that the isolation of the "bubbled life" was not good for her daughter's emotional health but her top priority had been to keep her daughter physically healthy until the Fontan operation. Other parents in the study shared similar concerns. Gabrielle worried about the influence of their isolated family life on her older daughter.

> How much do we disrupt life both for [older sister] and how much do we limit [daughter with HLHS]? So again it's finding that, that balance. (Gabrielle)

Parents wondered how to "take the precautions we need to" (Gabrielle) while at the same time helping their children to lead "normal" lives. Gabrielle's question was "How much do we protect her and how much do we just let her live life?" (Gabrielle)

Parents lacked direction from others as how to parent their child with a life-threatening condition. David wanted to treat his daughter like his other children and yet knew that she was different.

> I don't know. You just treat them like you did the rest? Or caution in a lot of things that you do with them. They can't do as many things physically as the other ones. Like it took her, I'm just trying to think how old she was before she actually walked. I'm thinking she was like 15 months old ... maybe longer than that. I can't remember. No. It was a long time. The [other] kids were, you know, walking by 10 months sort of thing. (David)

Gabrielle compared how she fed her healthy older child with how she was feeding her daughter with HLHS. She sought to strike a balance in how much she worried about her younger daughter's weight and yet made sure that she was eating.

> With my first daughter. ... I wouldn't force feed her ... just let her eat as much as she wanted. With [daughter with HLHS] it's such a concern ... always worrying about her getting sick. ... My other daughter ... she wouldn't eat much and it wouldn't panic me. If [daughter with HLHS] won't eat a meal, I'm just like, "I have to get food in you." ... With [older daughter] I would just look at her and say you know she's active, she's happy, she's doing okay. With [daughter with HLHS], I don't know if I can just rely on that or if I really do have to force-feed her. (Gabrielle)

Parents had mixed feelings as to whether they had been "overly paranoid" in their efforts to keep their children healthy. Professionals provided parents with few guidelines and so parents learned by trial and error and acknowledged that they may have erred on the side of excessive worrying and shielding. Dania recognized that her difficult experience of feeling "tied down" might have been something that she created for herself.

Despite feeling overwhelmed by all they needed to do for their babies, most of the parents expressed how relieved they were to have their baby at home.

> We were just so glad to have him home. (Helen)

> It was very, very busy, but it still was good to have her home. (Gabrielle)

Ivan, on the other hand, described this transition from hospital to home after the Norwood operation as "stepping out of one storm and into another."

> You know it's still not that happy time. ...We were trying to get her to eat first and oxygen and I don't know what the exact order of all that happened cause I know she was home when she wasn't eating right and I think she was reflux or something like that ... and we're having to learn to stick a tube down her head and I don't know. **It just seemed to be climbing the hill to hell** or something ... and of course then you got your other kid looking and saying "Oh, who's this kid?" and "Oh, that's my baby sister" and it's just a strange time. (Ivan)

Here Ivan described what many parents experienced as they tried to juggle multiple care needs of a sick child with the ongoing demands of their family's life. Most parents had little choice but to rely on each other and involve others in the care of their child. Family members, especially grandparents, more than friends or professionals filled the gap.

Safeguarding by Involving Others: "We just made it under the wire."

Parents could not single-handedly provide care for their child with HLHS. There was, however, a notable absence of day-to-day involvement of friends in the care of the child. Parents took comfort knowing that they had "good friends" in their life, but the friends were not involved in their daily lives. Parents valued their friends' understanding the threat of infection to their child with HLHS, for example, and their choice to stay away when anyone in their family was ill. Several families had friends from their faith community supporting them indirectly through prayer. Only Cam and Catherine who had

no family members living nearby described "two sets of friends that are very good" who helped them with day-to-day caregiving challenges.

> Well one's a teacher; one's a babysitter. One's a crown prosecutor and the wife is a library aide in the morning. She does not work in the afternoon so if, for example, I had to go to the doc with both boys on Monday and Cam was sick she came and helped me take them. Cause, if [baby with HLHS] was walking I could handle it but he's not walking. So she came and helped me out carry the kids in and helped with one while one was in the office and switched kids. (Catherine)

Parents also managed the day-to-day care of their children with minimal involvement from professionals. For some families, a community health nurse made a few visits to check on the baby's weight when the baby was first home from hospital after the Norwood operation. On one occasion, the visiting nurse helped Gabrielle reinsert her baby's NG tube. Annie worked tirelessly to secure some respite nursing care (69 hours per month) for her family and felt fortunate that there was a nurse willing to take on the assignment. Annie and Allan soon came to view this nurse as a member of their family.

> We don't wanna ever think of her leaving, she's just been a Godsend ... She just jumped in and ... she took over and she really, really made our lives so much easier, so much easier. ... We're to the point where [respite nurse] is just going to have to keep coming. ... [Baby with HLHS] goes crazy when she [respite nurse] walks through the door. ... [Respite nurse] was there for their [the twins] first birthday and she's to the point where she talks to our pediatricians and everyone in [next largest centre] and she's as close with everyone [the health care professionals] as we are. (Annie)

Cam and Catherine had funding through their health insurance to hire a nurse to provide home care for their baby when Catherine went back to work. Despite efforts to advertise for a nurse, Cam and Catherine were unable to find a willing nurse and so hired a practical nurse who had lost her license due to drug problems. Cam and Catherine carefully monitored this woman's involvement with their baby in their home and were pleased with the conscientious care she provided.

> She did everything by the book whereas we cheat. We didn't gas him all the time. We don't flush his line all the time with water, while [LPN who took care of child with HLHS] does everything to the book. His skin was very good. He has bad eczema and in fact when I came home in June [on maternity leave with next baby], his [child with HLHS] skin was kind of bad and so I had to phone her up and tell her to come back and show me how to take care of his skin. So she was really good, very conscientious ... she actually tried to feed him [orally]. Just the little exercises with him and stuff. She was very good. (Catherine)

Most families did not have this level of professional support. Rather, parents relied primarily on each other in the care of their child with HLHS and secondarily on their child's grandparents, and aunts and uncles for help with the all-consuming care demands of their child with HLHS.

Working Together with Spouse: "We were a team."

All of the fathers in this study played a key role in the day-to-day care of their babies with HLHS. The care their baby required placed demands on the involvement of both parents, and the concomitant need for extensive communication and negotiation between husband and wife. Cam described his most difficult parenting challenge as giving and receiving support from his spouse in the midst of all that needed to be done for the baby;

> Finding ways to support each other, like spouses, you know. You parent the child, ... that's not the challenging part. It's you know who's going to do what and when kind of thing. There's always something needs to be done for [baby with HLHS]. You know he gets meds at different times of the day, feeding that gastrostomy button at different times of the day. (Cam)

Allan described how important it was for him and Annie to set time aside for them as a couple to sort out their demanding parenting roles and to make sure that they were safeguarding time for themselves. Fred emphasized that as a couple they had to be "on the same page" regarding caring for the baby. For these fathers, the couple relationship influenced their ability to parent their child with HLHS.

Parents relied on each other in the care of their baby with HLHS and had little time together away from the baby. Parents had time away from their baby while the other parent provided care. For the fathers, work was the main source of relief from caregiving demands. Often their wives insisted that they not phone home during their time at work in order to have a complete break from the caregiving demands. David worked night shifts and often came home on his breaks to see how his wife was managing as their baby did not sleep well at night. Most parents described in detail the one or two times they went out by themselves. Concerned family members initiated this joint time away for parents by offering or even insisting that they would care for the baby in the parents' absence.

Involving Family Members: "We're extremely lucky to have great family."

Specialized care for a child with a life-threatening heart condition seemed to be a family affair, with much help coming from grandparents, aunts and uncles. Bonnie was parenting on her own and received help from her parents. Initially, Ellen's husband was not involved in their baby's care and Ellen's parents and brothers were her main source of help. For the other families, the couple worked as a team to accomplish all that needed doing for their baby with HLHS, and also received help from the child's grandparents, aunts and uncles. Parents provided detailed descriptions starting right from the time of diagnosis of specific things family members did to help.

Most of the first phone calls that parents made when they found out that their baby might have a heart problem were to the baby's grandparents. In all families, grandparents were either with the parents at the hospital after the baby was born and critically ill, or they were at home with the other child(ren). In most cases, two sets of grandparents were

involved. Next to their spouse, parents were most likely to trust grandparents with the care of their child and some also involved the child's aunts and uncles.

Entrusting their child with HLHS to another person for care was a monumental step for the parents, and family members were the ones they felt they could trust.

> David's sister was really good. Like when I was going through that thing with the formula where she was crying and crying. I phoned [sister-in-law] and I said, "I just need some help. You have to come over." She came and spent the night. I went to bed and she took the monitor and was up 3 or 4 times in the night with [daughter with HLHS] and I could sleep because I trusted [sister-in-law] with her. And she did come and get me once but that was fine. So [sister-in-law] was really good. ... **There was very few people that I trusted with her care** and I found out that there's no respite available to families unless your child is mentally handicapped. So, I mean, then **you have to depend on family** and I was lucky enough that we did have family. (Dania)

Ellen trusted her parents and younger brothers with her son's tube feeds and they took care of him while Ellen took some breaks from her child's constant care. Helen's mother was a teacher and spent her summer helping Helen and Hunter care for their baby when he came home from his first surgery. David and Dania had assistance from David's sister who insisted that she take care of the baby while David and Dania spent a night in a local hotel. David recalled their time away as a couple.

> **You're just completely exhausted** after all the things that happen. And even in their first year when we're at home with the feeding tube and stuff **you're pretty wiped**. Most of the time my sister and her husband actually, like my sister took a video of her of all the medications that she has to have for, in case something happened to us and what they have to do. So she came and said, "Here you guys. Take the weekend off." We went and got a hotel room here in [local community] and had a day and a half to ourselves ... which was nice. (David)

Dania also described her and David's night away.

> David and I did spend one night in a hotel. ... It was just, just great! [Sister-in-law] came and stayed here. The people from work sent some stuff to the hotel, some baskets and stuff. ... We went out for supper and it was just like I don't know. I guess **you just appreciate the little things** because to some people it

> wouldn't be like a big deal. Because we weren't far away. We were just in the same city but we were away from everything else. So it was nice. (Dania)

Gradually parents came out of their "cocoon" and tested the waters of survival. It took concerted effort to reclaim some of their former life and to incorporate their child with HLHS into their ongoing life. The baby's grandparents and aunts and uncles played a key role in providing parents with more freedom to pursue "normal" family activities.

Parents repeatedly expressed their appreciation of the invaluable support they received from their family members. Iris could not imagine how parents could survive without family support. Her parents moved from the next province to provide more help to Iris and Ivan. Fiona's parents also moved from another province and so were closer during the first few years of their grand daughter's life. Catherine's parents lived in another province but were available to help Catherine:

> If push comes to shove and things are getting crazy, they [her father and mother] will come out. (Catherine)

Other mothers also described the numerous trips they made to see their parents. Catherine arranged to have her third baby in another province to be in the same town as her parents lived so that they could take care of her child with HLHS while she was having her baby.

Gabrielle and Gavin had the active involvement of both sets of their parents. They described all the support they had and yet that they only barely "made it."

> We had it so good. We had ... support behind us like anything and what we have here, a lot of other people wouldn't have **and even with all that support, I feel like sometimes we just made it under the wire.** (Gavin)

Even with extensive grandparent involvement in the care of their child with HLHS, parents, more than anyone had the constant responsibility for their child's demanding care. And yet, they described their constant willingness to do everything they could to

safeguard their children to give them the best chance to thrive despite their heart condition. At times, parents even minimized the strain that excessive parenting placed on them and their family. As Dania said,

> It wasn't a big deal. (Dania)

Summary and Conclusion

Parenting children with HLHS involved safeguarding their children's survival through taking charge, struggling for balance, and involving others. Parents' intense caregiving began while their baby was in hospital following the Norwood surgery and was prerequisite to being able to take their baby home. Parents had to ensure that their baby fed well enough to gain weight and they described constant monitoring of their baby's feeding, weight gain and hydration, oxygenation, response to medications and signs of worsening health. The parents described the all-consuming nature of caring for their baby accompanied by constant worry about upcoming surgeries.

> You're just so busy with the meds and the feeds and stuff like that and you always know in the back of your mind that the next surgery is coming up. (Gabrielle)

In order to ensure the survival of their child with HLHS, parents also had to safeguard their own survival. The strategies that parents used to protect their own well-being are described in the next chapter.

CHAPTER SIX

SAFEGUARDING THEIR OWN SURVIVAL

"It's always on my mind"

For the fathers and mothers in this study, parenting their child with hypoplastic left heart syndrome (HLHS) was all-consuming as they safeguarded their child's precarious survival in a context of uncertainty. Parents described how their lives revolved around caring for their child with HLHS. As the physical care demands decreased over the first year of the baby's life, the emotional demands persisted; parents worried about their child's survival and they faced regrets. Worry threatened the parents' "sanity" and regret threatened their faith in the choice they made for their child to have the Norwood surgery. Maintaining a positive perspective was difficult and parents had to safeguard their own survival.

Parents employed several strategies to safeguard their own survival. They safeguarded themselves against worry by restraining or directing their minds to "not go there." To allay their worry, parents also normalized their child's feeding difficulties and developmental challenges. There also were times when parents chose to trust in someone or something beyond themselves in order to relinquish their worry. To avoid regret parents used determination, reframing and delight. Parents were determined not to second-guess or regret their decisions. They reframed the difficult experiences they had with their child with HLHS as positively changing their individual and family lives, and they delighted in their child's progress. In this chapter, I discuss these strategies parents used to safeguard their own survival while parenting their children whose survival was precarious (See Figure 5).

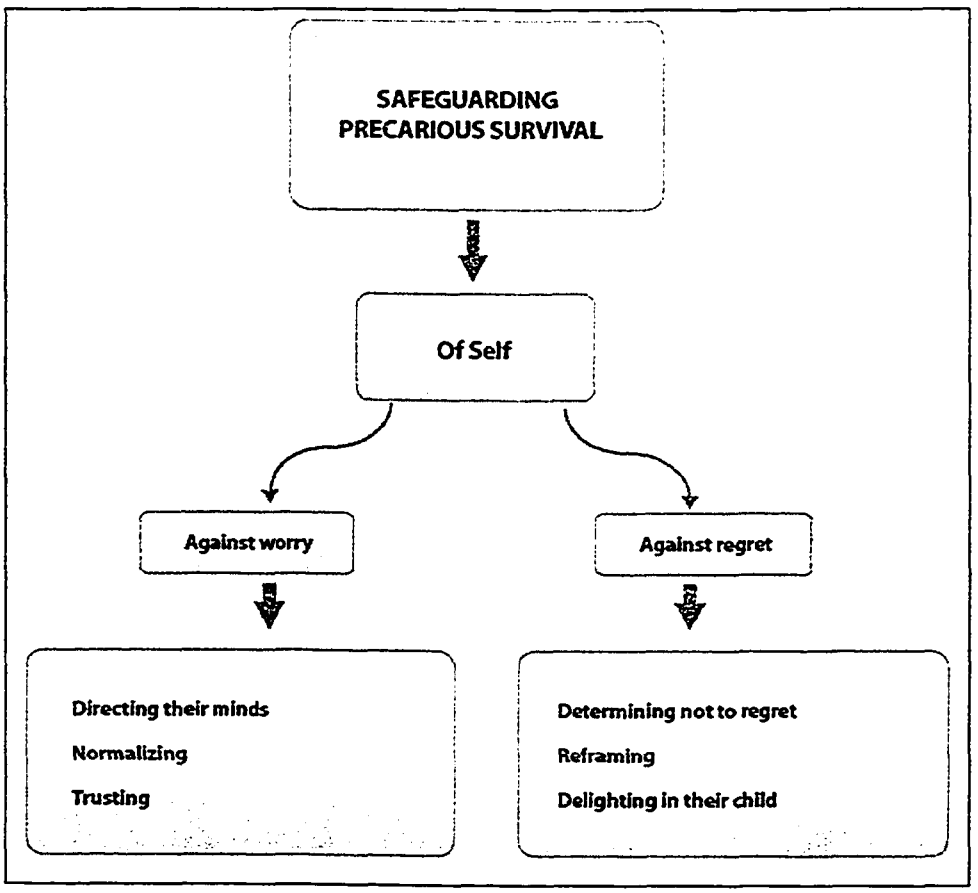

Figure 5: Safeguarding precarious survival of self

Safeguarding Against Worry: "You never know."

Persistent uncertainty, "not knowing the outcome," (Gavin) was the context in which parents safeguarded their own survival. They were grateful that their child had "beat the odds, thus far" (Iris) but could not help but worry about their child's day-to-day needs and future health and survival. Statements like "I don't know what the future holds," (Gabrielle) "I'm hoping [she'll] stay healthy, but you never know," (Bonnie) and "He could die" (Helen) reflected the parents' constant awareness of their child's precarious survival.

During the first year of their baby's life, the parents were constantly worried. Annie explained:

> The first few months at home ... we thought, "Is she going to make it till the second surgery? Is she going to make it through the second surgery?" There would be so many nights in between the first and second surgery when she'd be at home and we'd check to make sure she was breathing ten times a night. (Annie)

David described how constant worry about his daughter's health changed his life. It kept him from "being able to take anything in life for granted anymore; can't just carry on with life" (David). David worried about the effect of the care demands on the rest of his family. He described the challenge to "keep sanity at home" amidst his daughter's gastrostomy tube feeding and other care demands, "all the medications and the hours that you put in to look after her" (David).

Although the physical care demands lessened after the Glenn operation, parents continued to worry.

> It's always in the back of your mind. I have a son with a heart condition. (Hunter)

Between the Glenn and the Fontan operations, parents were concerned about how their children would cope with the third surgery because the child was older and aware of what hospitalization and surgery meant.

> He'll know that he's going to the hospital for something. (Helen)
>
> She'll be older and we're gonna have to explain things ahead of time. (Gabrielle)

Parents were concerned also that they would have more difficulty emotionally when their child was hospitalized.

> It'll be **harder the next time** I think cause ... he's an older kid. You gotta hand him over and do that worry again. (Hunter)
>
> First little while ... he was our baby but he was just another little person in the NICU. He's ... a real little person now. So this time when we have to go hand him off to go to surgery it'll be a hell of a lot tougher I think. (Cam)

Several dads (especially David and Ivan) worried about "preparing mentally for what you're going to be experiencing" (David). As they anticipated upcoming surgeries for their child, they did not want to worry about all the negative things that could happen, but at the same time, they felt that they had to prepare themselves and others for what might happen. Ivan worried about how to emotionally prepare himself, his daughter with HLHS and his older daughter for the life-threatening nature of the Fontan operation.

> You're constantly trying to prepare [daughter with HLHS] for what's gonna happen. ... You're reading the Franklin Goes to the Hospital books. ... I watch all those programs on TLC ... and of course she'll [daughter with HLHS] come in the room and I'm switching the channel off cause they're doing heart surgery. ... As soon as she sees that scenario, you can just tell it just takes the life out of her because she knows. So that's the worst part about the last one [the Fontan operation], is they know. How do you prepare them? You try but I mean you can just feel the tension in your house building up and even in [older daughter]. She knows that she's gonna be shipped off to Gramma's. It's just life is awful, right. ... I don't hold nothing back from her [older daughter]. I mean lots of times we'll go out and about and I'll tell her you know, there's many things can happen and I said, "We don't know if we're coming home or what." (Ivan)

David also worried about preparing his immediate and extended family for the possible death of his daughter during her upcoming surgery. He wanted to face all possible outcomes and knew that his wife was upset when he alluded to the life-threatening nature of the Fontan operation.

> Yeah, you *should* get together [family gathering at Christmas]. It might be the last time you see [daughter with HLHS]... My wife gets mad at me. (David)

At the same time, David described his struggle *not* to worry about potential complications related to his daughter's upcoming Fontan operation.

> I try to not to worry about the things that haven't happened ... even though I want to know what all could happen. ...You have to think positive. (David)

Parents also worried about their child's future beyond the Fontan operation. Four children had survived all three surgeries but their mothers worried about the child's entry

into school and their long-term future. These mothers described worries about their child's health when going to school and whether their child would be able to keep up and fit in with their peers. Mothers also worried about how their child would cope with being different and wondered how they themselves would be able to help their child cope.

> When we think ahead, it starts to get scary. ... anything that's different is always hard and especially in a smaller town. [Child with HLHS] covered from the neck down in scars. ... That could be really, really hard on a little girl ... We're not sure how to go about things as time goes on. (Annie)

> I don't know what grade it is, if it's 3 or 4, but we live right beside [a popular park]. They'll actually take the class and they'll go trekking and they'll go on nature walks way up in the hills. So I worry about that. How am I going to deal with that? ...She's gonna have to be left behind. ... It makes me sad cause ... she'll be sad ... I think about things ahead of time. (Iris)

The uncertainty of their child's future health and development created worry for the parents about the quality of their child's lives as they got older.

> I just worry about when he gets older. ... Will he take care of himself and eat well? ... Be a healthy, active individual? Have a long and fulfilling life? (Catherine)

> I worry that she has a really full life ... that if she ever got sick how I'd deal with that ... How much would I tell her? What would I do? ... I worry about her brother if anything happened to her because they're so very close ... We've chosen not to have any more children ... I worry that that's a good choice. Am I doing it for the right reasons? Those are a lot of things to worry about. (Fiona)

Parents employed several strategies to deal with their many worries. They directed their mind to "not go there," they normalized their child's difficulties and they chose to trust their child's precarious health to God and the doctors, and their child's future health to further technological developments.

Directing Their Minds: "Don't go there."

One of the ways that parents in this study managed their worries was by controlling their thoughts. They directed their minds to not think about certain things or to think less

often about them. When parents felt that their own survival was threatened, they used words like "losing my mind" (Iris) and "losing track of you" (Bonnie). They were motivated to manage their worry because it affected their ability to care for their child and family. For example, Dania acknowledged that her worry about her daughter's future surgeries threatened her ability to care for her daughter in the present.

> Thoughts of a second surgery or a third coming up ... You can't deal with that when you're trying to get through ... each day that you have to get through. (Dania)

Fiona described trying to manage her worry for the sake of her other child.

> It was hard to be up ... and I'm a very positive person. ... but you know I've got a son and he was here first and he's my responsibility and so [I tried to do] life as usual. (Fiona)

Several parents (David, Fiona, Gavin, Helen, and Iris) admitted that they tended to go to "the worst-case scenarios" and "what-ifs" and to worry. The main strategy used by parents to manage these and other worries was to direct their minds to "not go there" and to direct their worries to the "back of their minds." Fiona articulately described what all parents tried to do with their minds to keep them from dwelling on the "what ifs."

> Not spend[ing] much time thinking about the bad. ... I caution my brain, "Don't go there." (Fiona)

Parents described their strategy of "not going there" as an action over which they had control. Fiona recounted an experience of being called back to the hospital because her daughter suddenly had become critically ill. Fiona wondered if she and Fred would ever understand how sick their daughter had been that night. She then said that she did not "*let* her mind go there." Fiona said that she "*blocked* a lot of that out of her mind" referring to the times when she thought that her daughter would die. When parents successfully managed to "not go there" they described their worry as being in the "back of my mind"

or on the "back burner" rather than being "front and centre." They were able to ignore concerns that had preoccupied them and they tended not to speak about their worries to others.

Parents were less successful with their strategies to direct their mind in certain ways if those around them, especially their spouse, differed in the way they responded to their worries. Iris and Ivan were "totally different" from each other in managing their worries. Iris recalled waiting with Ivan for their daughter to return from an emergency surgical procedure after unexpected complications from the Fontan operation. Iris was worried her child would not survive the procedure. She shared her worry with Ivan and recounted his response.

> He looked over at me. He goes, "Iris, don't even think like that. You're gonna drive yourself insane." This is like after all we've been through in life and I said to him, "Have you never ever had that thought?" And he says, "I just don't think it." ... **He doesn't go there**. So it's amazing. So that's the first time verbally I came out and said those words to him ... just what I was going through at that moment. ... He had this look on his face like he was really shocked that I would say something like that. ... That's just the way I process it and that is the way I think. (Iris)

Ivan also acknowledged how different he was from Iris.

> **I don't go there**. ... When I leave that hospital, I shut off the switch ... Wrong or right, I don't know. It's just the way I am. That's the way I have to handle it. (Ivan)

In a couple, one parent often was more prone to worry than the other parent. Fiona described herself as being more worried than her husband. Fred was "more calm." Fiona therefore, felt that her experience of having a child with HLHS was harder for her than for Fred.

> I panic more than Fred. ... I tend to think the worst ... his mind doesn't go there. ... So I think that, in that respect it was harder on me because I always **thought** of the bad things and I wanted so bad not to go there but .... (Fiona)

Some parents expressed concern that their worries would upset their spouse and described their attempts to manage their worries without discussing them with their partner. Fred chose to do his thinking at work to "get [his] ducks back in a row,"

> Like I'll talk a little bit [about his worries with Fiona] but it's probably nice just thinking ... sometimes there's a lot to be said just for everything to be quiet [for thinking]. ... It's just time to have anything else on the perimeter. ... When you're at work sometimes you get that time. You know where you are. You're in a comfortable place. ... I think I did a lot of thinking [at work]. (Fred)

Helen often thought the worst, attributing this to her professional health care background. She described trying to "keep her theatrics to herself" so as not to "take anyone else [especially Hunter] down with her." When Helen and Hunter did share their worries with each other they would do this only to a certain point. At that point they chose to stop their minds from "going there." Helen described their response to their worry when they thought about their son's upcoming Fontan operation.

> There's still some times, we're sitting down and we're having a quiet time or conversation and we look at each other and think, "Oooohh, there's a third surgery coming up." There's always that little slim possibility that he might not make it through and then we, "Okay! That's enough," and then stop. (Helen)

In Dania and David's relationship, David was the one who verbalized worries about their daughter dying and he admitted that his wife was reluctant to think about this possibility. He justified his actions by his beliefs that his worries were "on everybody's mind" and "you're family and you're supposed to be open and discuss things." At the same time, David chose to keep some of his worries about his daughter's future in the back of his mind.

> Who knows what down the road holds for us. You don't know. Sort of put away in the **back of your mind** and it's one of those things you don't talk about. Well I guess, I haven't gone there yet. I don't see any point in going there until it really happens. (David)

Parents acknowledged that it was easier to keep their worries on the back burner when their child was doing well. This was most often between the Glenn and Fontan operations and after the Fontan operation. In her interview, Gabrielle stated her conviction that she was less worried about her daughter who was doing well between her Glenn and Fontan operations.

> As I say, it's all **really on the back burner** because she's doing so well. It's just not an issue right now but I think once we get closer to knowing that she's gonna have to go back in the hospital, it's gonna be harder. (Gabrielle)

Hunter's son was also between his Glenn and Fontan operations and Hunter contrasted the overwhelming worry he experienced during the first six months of his son's life with his present less-worried state.

> For the first six months [of his son's life] it [the worry] overwhelmed me and now it's just I don't even think about it, or I try not to think about it, let's put it that way. (Hunter)

Although parents described less worry after the final planned surgery, parents were never worry-free. Ellen's son was doing well after his Fontan operation two years previously. Although she was still uncertain about her son's future, Ellen directed her mind to how well he was doing.

> It's always in the back of your mind ... but ... he just had his check-up on Thursday and he's doing great. His [oxygen] sats are 94 and he's doing wonderful. (Ellen)

Iris was relieved to get life back to normal after her daughter's complicated recovery from her Fontan operation but at the same time acknowledged that she remained vigilant for signs and symptoms of deterioration in her daughter's health.

> Well it's just to be consciously aware, **to be always aware** [of deterioration in her daughter's health]. ... She kinda gets healthy and it's almost like you forget about that defect. You know life is so normal. She's going to school. We're all living our life. (Iris)

While parents directed their minds to think in certain ways to manage their worry, they also tried to view their lives as normal. One of their strategies was to reinterpret their child's feeding difficulties and development challenges as part of who their child was, not part of their child's heart problem.

Normalizing Life: "She's been like the normal kid."

Similar to the strategy of "not going there," parents, as much as was possible, directed their minds to think of their children as normal. This strategy enabled parents to worry less about their children with HLHS. Parents described feeling that it was better for their child to be treated "normally."

It was beneficial for the parents to view their children as normal because it was exceedingly difficult to constantly worry about their child's life-threatening heart problem. Hunter articulated the struggle to view his son as normal.

> It's always in the back of your mind. I have a son with a heart condition ... It's the hardest thing to just forget about the heart condition sometimes because you have to, cause you can't keep him in a box.. ... It's not so much the challenge that he gives you, it's the challenge you have to do within yourself to forget about the problem and just treat him like a normal child, which he is pretty much. (Hunter)

When their children got off tube feeding for example, parents were so relieved that their child was now feeding "normally." When parents realized that their children were going to crawl, walk and talk they were reassured that their child was going "to be okay."

Helen recalled an early conversation that she and Hunter had with a pediatric cardiologist at the tertiary referral centre about children with HLHS who were doing well. The physician had told them that it was the parents' responsibility to make sure that their children were not unnecessarily limited or held back.

> There's some kids [with HLHS who have undergone the Norwood surgical approach] who are 10 or 12 in the States and doing really well. They're living just

> a normal life and it's up to us what limitations we put on him. And so when he [pediatric cardiologist] said that it's up to us, the limitations, I kind of thought, "Oh, okay." A light bulb went on. (Helen)

Bonnie was motivated to parent her daughter with HLSH as she would other children without HLHS because her daughter with HLHS wanted to be "a normal kid... not this kid that has some kind of heart condition and can't do what all the other kids do" (Bonnie).

Viewing their children as "normal" was natural for parents in some ways and difficult in other ways. In their detailed descriptions of their child's unique needs and struggles, parents would conclude that their child was "pretty much a normal kid" (Allan). Allan described his daughter's sleeping difficulties and her eating challenges and then concluded:

> Other than that, we just treat her like a normal child and to us, she is pretty much a normal child. (Allan)

Fred described how he and Fiona had to administer "medicine a couple times a day" and monitor their daughter's colour and hydration in response to cold and hot weather. Despite these extraordinary parenting tasks, Fred concluded as follows:

> Her quality of life I'd say is, it's right on par with a normal kid. She was out skiing last winter, doing stuff like that. (Fred)

On the other hand, parents knew that their child's life was different from the lives of other children and would continue to be different from the lives of others in some way. Cam aptly expressed his desire for his son to have as normal a life as possible.

> My wife had a student at her school in kindergarten that was still getting fed that way [tube feeding]. I don't want that for my boy. He has enough; enough issues throughout his life. ... Some things he would want to do that he may not be able to do. I don't know, we'll have to wait and see. ... [Their town]'s a big hockey and soccer town. Is he just going to be with his dad out golfing all the time and bowling or low impact sports? ... He better like fishing that's all I can say. (Cam)

Feeding difficulties and developmental challenges were where parents used the strategy of normalizing.

Feeding Difficulties: "It's just his personality."

One of the most striking ways that parents in this study normalized life was in relation to their child's feeding difficulties. In all of the parents' detailed descriptions of feeding difficulties and slow weight gain, there were only two mothers who made brief comments that acknowledged that poor feeding was related to their child's HLHS.

> He was little. But I guess they say that's common in heart babies. (Ellen)
>
> He always eats more than [his cousin of similar age]. But you know his metabolism is so high. So our perspective is a little bit different here. (Helen)

Rather, parents viewed their child's small size and small appetite as related to their child's own personal growth curve, personality or food preferences rather than to the heart problem. Although parents tried to normalize their child's slow weight gain by comparing their child with HLHS to their other children who may also have been petite or "did not eat that much either", the differences were evident. Dania compared her daughter with HLHS to her other children who were apparently small for their age as well. She noted however that health care professionals responded differently to her daughter with HLHS lack of weight gain:

> My other daughter was ... really small for her age and [son] was small for his age. ... That's just the way my kids have been. But, for her, it's been a totally different I mean when [older daughter] was underweight, in the lower percentile ... the Public Health Nurse might mention it to you but it wasn't a real concern. But with [daughter with HLHS] everything is different. (Dania)

Several parents described their babies as being on their own personal growth curve even though it was below the normal growth curve, percentile-wise. This allayed their worry.

> Even though she's below the growth curve, she's following a normal growth curve and so I really stopped worrying about it so much. (Gabrielle)

Helen compared her son's slow weight gain with the growth pattern of her sisters' children. She was reassured by her son's progress and saw him as on a normal growth curve, even though he "was always a pound or two behind the other two kids."

> My sisters both have babies within a month of us, and so they were all the same kind of body type and shape. They all gained weight pretty much in proportion to each other. So that was reassuring ... **He's on his own growth curve** but he is putting weight on. (Helen)

Personality, activity level, and desire for food were other reasons given for their child's lack of weight gain and were viewed by parents as normal attributes. Although Helen mentioned that her son's higher nutritional needs were related to his heart problem, she described his inability to eat enough to achieve steady weight gain in this way:

> He doesn't like to eat ... **just his personality,** like **he couldn't care less about food.** (Helen)

David also viewed his daughter's small stature as due to personality traits rather than a physiological problem. He described the child's tendency to constant activity and limited appetite as the reasons for her lack of weight gain.

> She still only weighs 26 pounds, maybe 27 now. She is still tiny, but she never sits still. ...She's just, she's up when she's up. She's moving... all the time. She's not a big eater yet. She eats pretty much everything but just little bits. She doesn't sit down and eat a great big meal very often. (David)

Dania was comforted by her view that her daughter's short attention span contributed to her small appetite and that small stature was part of her daughter's identity, not related to her child's heart problem.

> She'll eat anything that you give her. But she just doesn't eat a lot. And then if the kids are done and they leave the table or whatever then she jumps down. So if I bring her back to the table and feed her then she'll sit there and eat. But if you let her go she'll just go and not eat anything. That's a bit of a challenge, the feeding

> thing. But at least ... I feel more comfortable with it now because I get to know her better and she's just a little thing. (Dania)

Several parents attributed their children's feeding difficulties to disinterest in food:

> Oh yes, the feeding issues. He just didn't **want to** eat. He still doesn't. (Ellen)

> Normally he's a really happy kid. You'd never know he had a problem for the most part. But he's really underweight, which is one of the hardest things, to have these kids gain weight, for us anyway. **He doesn't like to eat.** (Hunter)

Although they knew that "these kids" struggled to gain weight, most parents tended to separate feeding difficulties and slow weight gain from the heart problem. Allan and Annie had the ultimate comparison opportunity, as their baby with HLHS was a twin. Allan reported that their twin without a heart problem was twice as heavy as their twin with HLHS. It would seem difficult to normalize such a striking difference but Allan attributed his daughter's heart-related failure to thrive to the child's lack of desire to eat.

> [The twin without HLHS is] almost double [in size]. ... It's hard to look at but I guess she [twin with HLHS] just wants to stay small is how we look at it. I don't know. (Allan)

Developmental Challenges: "She's come so far."

Parents also worried about their child's development. Gavin recalled the health care professionals telling him that " a third of these kids have some sort of cognitive developmental problem." As parents normalized their child's feeding difficulties and slow weight gain, parents also chose to describe their child's development positively despite difficulties experienced by the child. Motor, behavioural and language concerns were common amongst the children in this study but parents expressed satisfaction as they described their child's physical, cognitive and social development. They used markers of their child's developmental progress to reassure themselves that they had made the right decision concerning the Norwood surgical approach even though they

were aware of the possibility of their child experiencing lags in their development. Gavin, for example, gave many positive examples of his daughter's language development and finished with this expression of reassurance:

> That is a tremendous encouragement to us so, I think she's doing well. (Gavin)

Most parents noted their child's slower motor development. Annie and Allan were anxious for their daughter to have her second operation because she was not progressing in many areas including her motor development. When she did have her Glenn operation at 9 months, Allan and Annie's daughter "couldn't even sit up to play" or " tolerate sitting in a bouncy chair to play" (Annie). At 13.5 months when I interviewed Annie for the second time, Annie was thrilled to report that her daughter was sitting but "not quite strong enough to crawl but she rolls everywhere." At 15 months when I interviewed Allan for the second time, he was pleased to announce that his daughter was "just starting to crawl a little bit." When other children in the study entered school some of their motor challenges became more evident. Bonnie's daughter needed help with her fine motor skills in kindergarten and David and Dania also described their daughter's difficulty using scissors and colouring when she started kindergarten.

Most of the children in this study did not feed normally, in addition to, or related to their feeding difficulties. They did not bottle or breast feed between the Norwood and Glenn operations and many continued with tube feeding after their Glenn operation because they did not easily learn to feed orally, whether that was bottle feeding earlier on and eating solid food later on. I interviewed Cam when his son was 21 months old. Cam described his son's oral feeding as follows:

> He'll gnaw a bit on a carrot, some mashed potatoes, some crackers. The odd potato chip, bad thing that dad gives him. For me, I'm at the point if he'll stick it

> in his mouth and eat it, I'll give it to him. Chocolate milk he doesn't seem to mind that. (Cam)

At 21 months, Cam and Catherine's son was managing to drink a few sips of chocolate milk and water, and Allan's and Annie's daughter had just eaten her first cracker at 14 months of age. Ellen's son was still receiving the majority of his nutrition by his G-tube when he was in kindergarten. In a letter from Ellen 10 months after my final interview with her, she reported that her son was finally feeding orally and that his G-tube had been discontinued. He was in Grade 1 at this time.

Most parents also described their worries about their child's language delay. Several children received some form of speech and language services. Hunter and Helen's son was slow to start expressing himself in words that they could understand. Bonnie described the extra help her daughter received from age 2.5 years till 5.5 years for her speech and language development. In Grade 1 she was continuing to receive early literacy assistance for half an hour daily. Iris had just received her daughter's first kindergarten report card and although her child had received speech therapy "right from the first words she ever said in her life" she remained difficult to understand. Iris worried about their child's future problems with speech

> Her report card said, "We have a hard time communicating [with her]," and so then I thought, ... "When they get to ... grade three when they stand up in a classroom and have to read their story to the class." I'm thinking, "How's she going to communicate?" That worries me. "What am I going to do?" [Pause]. (Iris)

Of all the children in the study, Annie and Allan's daughter was the most delayed in development and in the most fragile health. Regardless, Annie described her daughter's development as the most satisfying aspect about parenting her baby with HLHS.

> Just watching her grow and change. And she smiles. That's, that's big, the biggest thing. She smiles and she waves and she just, anything she does just melts your heart completely ... Just to see the change in her is, is just wonderful. I think to see how far she's come makes a big difference. (Annie)

Although Annie and Allan's twins were developmentally very different from each other, their parents never described the development of their twin with HLHS negatively. In fact they attributed the healthy twin's greater developmental progress as helping her twin sister with HLHS:

> [Baby with HLHS] sees [healthy twin] crawling or walking, or having [twin] on the other side of the room and has this toy and [baby with HLHS] motivated to go and get it I think that's made a big difference for her. She [healthy twin] really pushes her [twin with HLHS]. So we've been really lucky that way. I think it's almost nice in some ways, having them at different stages. (Annie)

Although his daughter continued to be markedly behind her twin, Allan positively framed her slower development, saying that the daughter with HLHS was "not really mobile enough to get into any trouble." Parents allayed their worries about their child's slow progress in development by providing plausible explanations for the delay, questioning the meaningfulness of early developmental testing and celebrating their child's developmental progress. In the same way that parents described their child being on "their own growth curve," parents happily reported that their children were developing at their own pace.

> [Child with HLHS] does things at her own stage and she gets ready to do things on her own so I said I just let her do them when I feel she's ready to do them. I don't push her into anything. I mean the only thing I've been pushed on her is the discipline but as far as everything else in her life, she does it at her own stage. (Bonnie)

When Catherine compared her son's development with his older sister's development she knew that her son was slower in his development but she reassured herself that he was "gonna get there but on his own speed." Catherine was also positive about her son's

developmental progress because she could understand reasons for his delay and this allayed her worry as well.

> I don't think his brain's slow. He's definitely on the ball that way. ... His speech is a little bit behind but he's been so in and out [of hospital] and on his back but I think he's just a couple months behind that way. Then his mobility; he probably should be walking by now but you know that's coming. That's just around the corner and then look out. As [Sister of Baby with HLHS] says, I'm gonna catch him with my butterfly net. (Catherine)

Like Catherine, other parents explained their child's slow development as related to the their child's hospitalizations; they were not surprised by the delays as they saw the prolonged time in hospital as impeding psychomotor development, for example.

> I think the times that they've spent recovering from operations, they missed those kind of skills getting developed and like okay they had her in the hospital for say two weeks and then there was like a three and a half, four month, even six month recovery process after the fact when they're healing and they can't move around and do all those kind of things. So I can see them getting delayed by a year in development on that kind of thing. (David)

Parents did not acknowledge that their child's low oxygen levels, intraoperative circulatory arrest and possible brain injury during postoperative complications as possible explanations for their child's slow development. Parents however provided additional explanations for their child's delays that were not related to their child's heart problem or the surgical treatment that they had received. David's daughter for example was in kindergarten and not colouring inside the lines. He wondered if this was because she had not been given enough opportunity to practice with real crayons. Rather she had coloured with specially designed paper and pens that showed colour in all the right places despite the child's colouring ability.

> So she thinks she's pretty good [colouring with the specially designed paper and pencils] but then that's never developing the thing that you have to stay inside here. Good one way and hurts in the other way. That's the way I look at it anyway. (David)

Helen believed that her son's speech delay was related to parenting rather than brain injury. Being their first child, she and Hunter had anticipated their son's every need so that he had not needed to talk.

> He's speaking better. They were a little bit concerned because I guess on the CT scan originally, the area where there was a little bit of swelling was the area that affects speech so they've always kept an eye on that. But in retrospect, I think it was more us than anything else because we were always trying to, for having the, well the first child, trying to get help him communicate. I think we overdid it and so he didn't need to speak. (Helen)

Most of the parents referred to their children's appointments for developmental testing but did not express concern with the results. Gabrielle described the physical delay that was detected in her daughter.

> She was also part of the follow-up study. ... She's only had one follow-up appointment, ... and they did check some developmental things ... They thought physically she was a bit delayed cause, what was it? Oh, I know. She didn't like to, I didn't put her on her stomach very much so she ... wouldn't really push herself up ... That was the main thing and that's just cause she didn't like being on her stomach so I didn't put her on her stomach very much and I hadn't with [my older daughter] either really. I would say at this point there, I wouldn't say that she's behind at all. (Gabrielle)

Gabrielle also described some developmental testing that her pediatrician had done at her daughter's 12-month checkup. Again, Gabrielle was not concerned about her daughter's development.

> One thing [pediatrician] tested was if she could pile little blocks and she wasn't really doing that very well so she said that was one thing that she said she might not be on track. But I would say overall if she's not right on track, she's very close. (Gabrielle)

Helen questioned whether the developmental testing her son had undergone thus far could reveal anything meaningful.

> They test him developmentally but what you can do with a two-year-old? It's really hard to assess right now ... he's not going to speak to strangers that much anyway ... he really wasn't speaking much to anybody except us at home. (Helen)

When the speech therapist saw Helen's son, she reinforced Helen's questions about working with children at such a young age.

> So then they referred us to speech and the speech therapist that we saw was excellent. She said, "Well you know, what are you going to do with a two-year-old? Let's just see how many words he knows and what he picks up in a month." She said she really doesn't have any concerns. ... "Let's track him for a couple months and then he'll probably just go on his way." So no big deal ... especially because of the way he started out because he did have a couple of anoxic episodes and they just didn't know where that would go. (Helen)

A final way that parents allayed their worry about their child's slow development was to celebrate their child's developmental achievements regardless of the timing.

> I think every little thing that [baby with HLHS] has done or is doing right now is just a huge, huge deal to us. The first time she ever sat up, we called 20 people and with every little action she does, when she waves ... it is a huge ordeal to us. She took a bite of her first cracker the other day and I think it took me 20 minutes to finish calling everyone to tell them about it. It was just from where she is to where she started out ... it makes every little thing a huge celebration. (Annie)

> He's a great kid. He's a lot of fun and like I said he's a normal kid too. Like he's talking tons. He's running, walking and things like that. Actually they did do a follow up on him for his speech cause he wasn't talking a lot, you know, at I guess 18, 20 months there when he should have been talking more. He was still fairly, fairly quiet. He had some words but now he's, you know, they gave us a chart and he does all the words on the chart pretty much. (Cam)

Parents were also confident that their children would do well because of their exceptional social development. All parents described their children's social personalities that were especially evident when the children entered school.

> She certainly is probably above average in those skills [social skills]. So hopefully the other stuff will kind of pick up. ... The teacher knows about her and I told her ... "There isn't one thing in [Child with HLHS]'s pre-school life that could compare to the other kids in your class. It hasn't been even close to normal compared to what they've had." (Dania)

> The whole school knows (Child with HLHS). They all love him. They all fight to play with him. So it's worked out unbelievable. (Ellen)

> She's such a social butterfly. ... Her kindergarten teacher, she can't believe it. She says everybody in the whole school just loves her. I mean she's always going up and hugging and they say she is so concerned about everybody if they fall down and get hurt. ... It is kind of comical when you go pick her up. The janitor walks by, "Hi Arnie" and he "Oh hi [Child with HLHS]." He knows her too. (David)

Unlike the many things that parents did to help their child feed and gain weight, parents did not describe specific things that they were doing to help their child's motor and language development. Some of the babies received infant development services and some of the children received speech and language assistance but parents did not describe a role in assisting their child developmentally. Bonnie was the only parent to acknowledge the potential for parents to "block out" things they did not feel able to deal with. She shared her experience of another mother:

> I know with [mother of boy who has had a heart transplant] there's been times where she said, "I can't do this anymore" or "I don't want to do this anymore" and she's blocked out different things and in some ways, it's not good. Like I told her you can't do that. Like for me anyway, I couldn't do it. I have to know everything that's going on and I'm not gonna limit her development or her medical part of it because I don't want to do something at that point. (Bonnie)

Normalizing their child's feeding and developmental delays helped allay some of the parents' worry. There were times however when the only way that parents could deal with their worry about their child was to trust someone or something beyond themselves.

Trusting God, Doctors and Technology: "It's out of my hands."

Another way that parents dealt with their worry was to concede that some of their worries concerned things that were " out of their hands." When parents feared for their child's immediate survival, they described having to trust the medical staff and/or God. When parents feared for their child's future survival, they described having to place their trust in further technological advancements.

Fred and Allan both articulated the trust that parents had to have in doctors. Fred spoke highly of the cardiac surgeon who performed his daughter's surgeries and almost apologized for having so much appreciation for him when the surgeon was straightforward about what was going to happen.

> I don't want to make him sound like I think he's God or anything cause I've seen him in there when he's lost a child too and you just know he's human, that's all there is to it. But that's what you want. (Fred)

In describing the things that he and Fiona did to safeguard their own survival, including "talking about stuff" together, Fred conceded, "the rest is in the doctor's hands." Parents talked about their children being in "good hands," while in the hospital. As much as parents tried to spend time with their child in hospital, there were times when they felt comfortable leaving their child in the "capable hands" of the hospital staff. Parents had no choice but to give up control of their child to the operating room staff when their children went to surgery and there was momentary relief in that action.

> We went for something to eat and the first little while. ... Someone else is in control now. I felt a little bit of release that, "Okay it's out of my hands. (Fiona)

Parents came to trust the "hands" of those in the tertiary referral centre and therefore found it difficult when their child was discharged from the hospital.

> You've put her in their hands and they've looked after her and they're the ones that are the experts on her condition and there's nobody here [local community] that is. So it's scary leaving that, you know, leaving that place [tertiary referral centre]. (Dania)

Allan interchanged "God" and "the doctors" in the same sentence as he articulated his trust in the physicians and in God as he anticipated the birth of this baby with HLHS.

> It was difficult. ... Every day you're thinking about it and it's not gonna go away. ... All we can do when she's born is **put her in the doctor's hands** and they'll take care of it or at least they'll try to and this is the way we looked at it after is that really we couldn't do much about it. We'll just **let God, put it in His hands**

> and stuff and **let the good doctors take care of it**. That's about all we can do. (Allan)

Fiona felt the survival of her baby was in God's hands and this influenced her decision making during pregnancy.

> I'd never terminate a pregnancy. That was in God's hands, not mine, if something were to happen and Fred didn't even have to ask me that. (Fiona)

Parents worried about their child's future and described their choice to trust technology. Dania recalled a moment of realization about her daughter's precarious survival.

> **We still don't know what the future holds for her.** We went to a cardiology appointment ... and everything went okay but I asked and I had never asked that before, I said, "What is the prognosis for babies with this?" And he said, "Ooh, it's not that good." He said, "You are in for a lifetime of health problems ... ." And it was just like getting kicked in the guts. ... I don't even know why I asked it because I wasn't ready to hear that I guess. (Dania)

Realizing that their child's future survival was uncertain, parents chose to believe that technological advancements would keep stride with their child's need for complex care to survive. Parents were grateful for the technological advancements available for their children with HLHS.

> We're thankful to have her [daughter with HLHS] and that technology was at the point it was. Her timing when we had her was appropriate. [Pediatric cardiac surgeon] moving from Toronto and the stars lined up. We feel fortunate to live near [city of tertiary referral centre], to be around people who are so knowledgeable and skilled and so those are all really good things. (Fiona)

> Now that things have worked out in retrospect, there are no regrets. We'll go through this Fontan, hopefully this keeps her going till her 20's and then hopefully we've got some other option, maybe even something other than a heart transplant. Like just a ventricular replacement or something like that, since we expect it'll be the ventricle that's going to be the first having problems. So when I look at, kind of base my hopes on that ... there are no regrets that way. (Gavin)

The desire of parents to be free from regret is reflected in Gavin's words. As well as safeguarding themselves against worry, parents safeguarded themselves against regret.

Safeguarding Against Regret: "It's all worth it."

Despite the challenges inherent in safeguarding survival, their child's and their own, most parents had no regrets. Like Gavin, they described the difficulty of parenting a child with HLHS, but did not regret their decision to pursue surgical treatment for their child.

> It's not smooth sailing but also I still think I would consciously or subconsciously put a positive spin on it that it's all, **it's all worth it.** (Gavin)

Parents however did have to actively safeguard themselves against regret. They described occasions when they second-guessed their decision to pursue the Norwood surgical approach on behalf of their child and contemplated regret. These were moments of despair that parents wanted to avoid revisiting. Gavin recounted his experience of despair during his baby's recovery from her Norwood operation when he wondered if he and Gabrielle had made the right decision regarding the Norwood surgical approach.

> After being in the hospital for my stint I went back to Gabrielle's folks and I was in the shower and I remember just breaking down there. I just felt like I couldn't even stand up in the shower, trying to hold myself up and then I'm crying and I'm sad and I'm angry and I'm thinking she was gonna die. [Lots of emotion] I wish, let's just, let's just get it over with and let's not keep going through all this and then have her die and I remember that one particular time and fortunately this was one of the times when Gabrielle was strong when I was going to pieces. (Gavin)

Ellen also recalled second-guessing her decision for the Norwood surgical approach early on in her son's life.

> I've second-guessed myself for a long time cause he was so sick for that first year. ... I thought, "Am I doing him good by putting him through all this?" I mean it all goes through your mind. (Ellen)

Another crucial time for second-guessing or the contemplation of regret was during the recovery from the Fontan operation. Both Iris and Fiona remembered their experiences of despair.

> She was on heparin getting two shots of that twice daily for three weeks straight and then they [Insuflons] weren't working and then it was three of those put in, taken out and putting in her arm and in less than a three day period and **I was losing my mind**. ... I had to raise hell because it's like why are we doing this? ... I said, "Is it life threatening that she have this heparin shot tonight? ... She [pediatric cardiologist] said to me, "Yes." They held this kid down and they injected or put it in her leg and she fought three nurses and the one nurse holding her legs. Her leg got away and the needles scratched her leg and it was bleeding and she went over the edge. She stood on her bed and the look in her eyes and she grabbed her tubes off that IV pole and I was the first one to get in her way. She'd punched anybody who was coming at her. When I saw that, I thought "She's toast. How will she ever recover from this experience?" Like everything she's gone through. (Iris)

> You could tell the pain was changing her personality and I worried from that point on. ... **"Was this all worth it?"** because now you see a kid in total pain whose personality's changing. ... I'm like "**Have I done permanent damage**?" "In my decision making to follow through with this all, have I just put her through hell?" (Fiona)

These experiences of despair-filled second-guessing were excruciating for parents because regret was contrary to what parenting meant for them. As some parents articulated, a parent would never choose not to parent their child, whatever the health concern. They had no choice but to embrace their parenting role with their child with HLHS and therefore had to safeguard themselves against regret.

> I have a lot of people say, "Well, I couldn't go through what you're going through." And you know what? You could. If you had to, you could cause **you have no choice**. I just have a lot of people saying that comment like, "Oh I could never go through that." You know what? I probably said that at one point too before I had him. I could never deal with a sick child but you do cause you have no choice. You make the best of it. (Ellen)

Dania also referred to not having a choice to parent her baby with HLHS.

> If you're gonna have a healthy baby, whatever you just sort of, you have to take what you get I guess. That's just the way I feel about it. For some reason, somebody figures that you're the one to do it. I don't know. That might sound stupid. (Dania)

Gavin expressed his perceived lack of choice in this way:

> We played our cards and this is where we're at and there was nothing else to do. (Gavin)

Helen referred to the innate quality in parents to care for their children and regretting their child's life was incompatible with that quality.

> Well you have to be [resilient] and I think it's probably an innate quality in most parents, just that caring takes over and you have to do what you have to do. Put yourself aside for a little bit. Take care of your child. (Helen)

One couple lived with regret, Ivan more than Iris. The closest that Iris got to regret was to admit that she regretted the heart problem that her daughter had.

> She's in our lives and she is who she is and we are who we are now because of her and probably the only thing is that I would ask God if she could just have a different heart defect, that's all. [Sounds deflated and quiet.] Could we just have something at the other end of the scale? I'll live this life okay, but just give us something else. (Iris)

Ivan, on the other hand, regretted the decision he and Iris had made to pursue the Norwood surgical approach on behalf of his daughter.

> And lots of times I think back and it's kind of not right but I think, "Geez what if we had of just let her go and moved on, did something different?" Well of course Iris' view is, "Well how can you say that when you got your kid here?" I'm saying, "No, think, think back before that. What, how would life be now? Would it be better? Would it be worse?" I don't know. Maybe that would haunt you forever that you let your kid go but I don't know. I don't know the answer to that. (Ivan)

Although his daughter had survived her three operations, she had experienced numerous complications and Ivan could not help wondering if they had chosen the right "road."

> Still of course she's here running around, then you think, "Well geez, how did I even think like that, right?" But I don't know. I drive tons and tons of miles by myself cause I'm in sales and stuff so you have all this time to think and I don't know. Sometimes you'll just start reviewing everything. Where would that road have taken us? (Ivan)

Unlike Ivan, most parents were determined not to regret their decision and it was through a combination of determination, reframing, and delight that they accomplished

this. Parents were determined to believe that they had made the right decision, and they positively reframed their difficult experiences while taking delight in their child with HLHS.

Determined Not to Regret: "There's no second guessing."

Parents were determined not to regret and therefore chose to believe certain things. Believing that they had made the right decision for the Norwood surgical approach and believing that their life was better for having made that choice were the main strategies parents used to safeguard themselves against regret.

The fathers in particular described having to believe that they were on the right track or route, using travel analogies of being on a plane or train.

> We went through the Norwood and now she's got a perforated bowel and whatever else from the medication and she's wasting away. It wasn't at the point say, "Okay now let's just do compassionate care." You don't do compassionate care over a bowel perforation. ... There was no issue. There was nothing else to do at that point than **to go on the track that we were on.** (Gavin)

Gavin attributed his doubts at that point to being "worn out" and "frustrated."

> It's always one thing after another. Like the minute something goes good, then it almost seems one step forward, two back rather than the other way ... It was just sort of in my down moments that I wondered if we'd made a mistake; when I saw what she was going through and not getting any better ... But by the time I had doubts, we were already committed to the track we followed ... **There was no getting off the train at that point.** (Gavin)

Fred also spoke about having to "believe in what you're doing." He said it this way:

> If you decided this is what you want to do, you have to stick with the belief that it's gonna be right no matter what. ... **There's no second-guessing.** If you're on your plane to go wherever, you gotta be happy with what you're doing, your decision to start with. ... You can't be thinking should I have done this six months after you've started either. I mean you got three operations to go through so it's not always gonna be pretty. (Fred)

The mothers were less adamant about having to believe they had made the right decision. In Helen's mind it was more a matter of regret not making sense to her.

> You can spend your whole life looking back and saying, "Well I wish I had done this" or "I wish I had" but you know the fact is, you didn't and so **you just go the course** that you're taking. (Helen)

Mothers described moments of second-guessing their decision for the Norwood surgical approach but their thoughts about other options (i.e., compassionate care or heart transplantation) were short-lived because they were so happy to *have* their child. Gabrielle's words were as follows:

> There's different times I look at her and think I'm so glad we did it [pursued the Norwood surgical approach]. Like I can't imagine her not being with us and even if it's for a short time ...she's so good-natured, so sweet. I just can't imagine her not being with us. (Gabrielle)

Several mothers described a turning point when they "could see the blessing in this whole situation" of having a child with a life-threatening heart problem. This turning point occurred a few months after the baby's second surgery when the feeding and monitoring demands had eased up somewhat and the mothers felt more confident that their child would survive. Dania recalled her turning point experience after a reassuring appointment with the pediatric cardiologist.

> One day my sister called and just to see how I was doing and whatever. I said this is **the first day that I feel blessed instead of cursed.** And it was sort of a, kind of a turning point I guess. (Dania)

The different ways that the parents in this study arrived at their no-regret approach to parenting, the fathers through travel metaphors and the mothers through focussing on the survival of their child was the only difference between the fathers and mothers that emerged from the data.

Positive Reframing: "Some people just have a baby."

Not only did parents demonstrate their determination not to regret their decision to pursue the Norwood surgical approach for their child with HLHS, they also demonstrated their extraordinary ability to reframe their difficult experiences. Most parents reframed their parenting challenges positively and were grateful that they had an opportunity to face such difficulty and be changed by it. Hunter thoughtfully stated, "Some people just have a baby." He went on:

> It's such a beautiful experience, the whole having a baby thing. I mean it [having a baby with HLHS] actually just makes it more rewarding to me and I think it makes you appreciate what you have even more and as much hard work as it is, you don't think about it. You know it has to be done. It's a job but it's a really rewarding one. (Hunter)

Parents described appreciating their children more, having more compassion for others, and living their lives in more satisfying ways having gained a different perspective on their life. In acknowledging these positive changes they did not however, downplay the difficulties they had experienced. Allan's comments reflected this:

> It just puts a whole perspective, different outlook on things. ... A whole new outlook on life in general. It's been quite an ordeal but just seeing her grow every day and just do her own thing here ... sometimes it makes your day. (Allan)

Gabrielle also described the contrasts in her experience of parenting a child with HLHS.

> We've gone through a very incredibly challenging time but I think it has had a lot of benefits ... It's been a very good and helpful life lesson that I wouldn't have chosen but it's been positive in a lot of ways. (Gabrielle)

Most parents described the positive effect their new perspective on life had on their appreciation for their children. Gabrielle described this as follows:

> I really appreciate my kids more and [it] **put life in perspective**. It really does. It's not getting caught up in the things that aren't meaningful, hopefully **focussing on the things that are more, that are meaningful.** [Pause]. (Gabrielle)

David described appreciating his children more and challenged his children who ranged in age from 5 to 22 years of age to appreciate their health more.

> Appreciation for life and appreciate the children you do have and the health you do have and try to make your children aware that you should thank God once in a while for being as healthy as you are. ... Don't take any of those things for granted and treat your body right and look after it. (David)

Gabrielle also came to view her child's serious heart condition as having a higher purpose and this kept her from contemplating regret.

> I mean there certainly have been times where you know sort of questioned why, why, especially when she had been in so much pain and discomfort, like why, why does she have to go through this ... She hasn't done anything wrong yet. ... Early on a friend reminded me of a portion of the Bible where Jesus healed the man who was born blind and the disciples asked, "Who sinned, this man or his parents?" cause he was born blind. And Jesus said, "Neither but this happens so that God can be glorified." I sort of cling to that with her. I **think she's a special little girl**. [Crying] [Pause]. (Gabrielle)

Annie described a shift in priorities in her family because of her daughter's heart condition. Annie's previous priorities of always keeping the house clean and making sure that she made three balanced meals a day for her family changed as she had to spend more of her time taking care of her daughter with HLHS. She jokingly admitted that her family now ate "macaroni and cheese" on occasion, a change that reflected Annie's shifted priorities. Annie also described the shift of priority in their family concerning their other children's activities outside the home. Annie and Allan chose one activity for their older daughter, not five – "we're not running to ballet, tap dancing, swimming lessons, and six different things five days a week" (Annie).

> I think just simplifying our lives in certain ways. We just made choices of we're not going to let this drive us nuts. You know I think if we were to keep doing things the way we were before the twins were born, I think we would just go absolutely insane. (Annie)

The shift in priorities afforded Annie and Allan more time with their daughter with HLHS and reflected the changed view of life resulting from their daughter being so close to not having survived her HLHS.

> You just expect to have a healthy child and you kind of plow through things normally. Whereas with this, it just changes your life so incredibly much. ... I think of all the things that we feel like we've missed out with her, that we are unable to do with her makes everything that we're doing now so much more important. We didn't hold her when she was born. There are so many pictures of things we don't have. ... [Baby with HLHS] and [twin] were baptized the day after they were born and it was just in such haste, everything. You know, we felt like everything was in case of. We need to do this in case of or because and everything now is just making up for it almost. (Annie)

Most parents also described satisfaction in living their lives on a more day-by-day basis. In some ways the parents had no choice but to live day-to-day because of the unpredictable aspects of their child's health and care needs. Parents, however, positively framed this necessary shift as a better way to live. They valued their child's life more and were thankful for the time they had with their child who was thus far surviving their life-threatening heart disease.

> I'm gonna live for each day and count all my blessings. (Helen)

> We live day-to-day and we enjoy the days we have with him. You know we're very grateful. I think it's better that we knew him for five years or whatever than to not at all. (Ellen)

> You learn to live one day at a time with a sick child. You don't plan three weeks ahead. You just do your day-to-day routine and if everything goes through well, good, but tomorrow's another day. So you don't know what tomorrow brings so you just have to deal with whatever happens tomorrow. That's my philosophy in life. One day at a time and you take it as it's given to you. (Bonnie)

Parents also described the ways in which they had personally changed for the better. Several parents described becoming more compassionate for other parents in similar situations. Bonnie described learning "not to judge people cause you don't know where

they're coming from." Bonnie reported the most dramatic change in her personal life over the first few years of her child's life and attributed this positive change to her daughter.

> She's taught me amazing things about my own life. ... It's taught me to evaluate where I was to where I am now. ... I needed to get out from the hole I was in you know, climb out of the hole and, and get on with life and she did that for me. ... The last six years have been a real learning experience for me. (Bonnie)

Parents also concluded that they had no reason to regret because parents never had guarantees that their child would remain healthy.

> I recognize I don't know what the future holds but then I also look around and say no one really knows what the future holds for the children. I know that there's an issue of heart, but as I say, this family that just last week lost a 14 year old boy in a car accident on Friday. No one knows and **there's no guarantees** that any child is going to have a long life. (Gabrielle)

> I mean nobody has any guarantee of how long they're gonna be in this world or whatever but ah, you just have to take one day at a time and I've learned that more with [Child with HLHS] than with anybody I think. (Dania)

Parents agreed that it was easier not to second-guess or have regret when their child was doing well and when they focussed on how well their child was doing.

> We have so many friends now that we've got to know who have hypoplastic kids; you know what I think we all feel the same way. We all second-guess ourselves but you know what? When you see the outcome, the finished product, I mean it's just, he's doing so well! Other than his tube, he's fine. The heart has never ever been an issue for us in a long time. So it's hard to think that he's not going to have a bright, happy future. Like it's hard not to think that way. (Ellen)

Taking Delight in Their Child: "She's just such a joy."

Taking delight in their child was an effective strategy for parents as they safeguarded themselves against regret. All of the parents in this study delighted in their children, although several mothers also admitted to having to come to a place of acceptance of their parenting role with their child with HLHS before they could take delight in their children. Dania described the day that she came to the place of seeing her daughter with

HLHS as "a blessing not a curse." Gabrielle also recalled when she began to see her daughter as a blessing. Helen described a similar turning point at about nine months when she felt that things were going to be "okay." If she had second-guessed taking the Norwood surgical approach, she stopped second-guessing at that point.

> About nine months ... it started to get easier and easier and easier ... I thought it's all going to be okay. (Helen)

Parents marveled at their child's progress and were adamant that there was something special about their child's personality.

> **She's just such a joy** that no there's no regrets at all. (Gabrielle)
>
> [Child with HLHS] just brings a funniness. I mean **she's a clown**. She's the life of the party and she brings a real funness to wherever she's at ... I'll have a day where I cry or whatever, she'll just come and say, she'll give me a hug and she'll say something really funny and that's just her. She loves to be the brightness I guess in everybody's life. (Bonnie)
>
> I'm happy we have him. **He's such a great kid** so he's very congenial. Everybody likes him he's got such a big winning smile. He's very good and I'm very happy. (Catherine)
>
> Most satisfying thing is knowing that **she's with us.** She's doing well and kicking and smiling on her good days, so we know we've got her and she's doing quite fine. So that's gotta, waking up every morning knowing she's, she's here. That's pretty much the most satisfying thing we could ask for. (Allan)
>
> She's a people person ... She was just little baby and going down for heart cath and all the way down she's running into people and "Hi, hi, hi." She's always being friendly to people ... They wished all their cases were as cheerful and happy as [Child with HLHS] was. ... **She loves life.** (Dania)
>
> **He's got personality**. He's a ham. He's got his buddies. ... He's happy, I can tell you that much. He's a happy little lark. (Cam)

The context for the paradox of determination and delight was the child's new survivor status. Parents were determined not to regret their decision because their child had indeed survived. Parents took delight in how well their child was doing considering the life-

threatening nature of their child's heart condition. Several parents described health care professionals telling them that their child was the "best Norwood" they had known. Gavin wondered how genuine this was. "Maybe they say that to everyone." Parents were willing to be seen as "out there" with their children who had survived HLHS but they did not appreciate being seen as guinea pigs. In their decision to go with the Norwood surgical approach they were clear that it was:

> A viable option and **it's not just an experiment. ...** We were prepared to do anything for her ... if it means you know she needs special care throughout her life but we didn't want to put her through any experimental surgery. (Gabrielle)

Summary and Conclusion

As described in Chapter 4, parents made the best decision they could on behalf of their child, certain that there was a chance for their child to survive through the Norwood surgical approach. Although parents remained uncertain about their child's future they were certain of their parenting role. They safeguarded their child's and their own survival and they parented without regret. Fathers spoke of being on a "track" of their own choosing and mothers focussed on the blessing of their child's survival. They would continue to safeguard their child's survival as well as their own "for as long as we have her." Parents safeguarded their emotional survival by employing strategies to lessen their worry and decrease their contemplation of regret. Parents even safeguarded themselves against future regret by framing their child's difficult course of three life-saving surgeries as helping other children with HLHS in the future. David and Fred both expressed this:

> Whatever happens to her now and in the future, it's gonna benefit other kids that come along in the future. (Fred)

> Some people think we're guinea pigs and experimenting and maybe they are to some degree but down the road it's going to help somebody somewhere and I wouldn't, I wouldn't change anything in that way. (David)

Parents knew that their child's survival was precarious but their resolve to parent their child with HLHS who had undergone the Norwood surgical approach was unshakeable. Although efforts to protect the couple relationship and family unit were evident in the data, most parenting strategies were directed towards to protecting the child and the individual parents. This process of safeguarding their child's and their own survival enabled the fathers and mothers in this study to delight in their child and anticipate a bright future for their child who had "beat the odds, so far."

CHAPTER 7

DISCUSSION OF FINDINGS AND IMPLICATIONS

Mothers and fathers embarked on a parenting process of safeguarding precarious survival as they considered their decision to pursue technologically advanced surgical treatment for their baby's lethal heart defect. They desired to give their baby with HLHS "a chance." Over time, parents required assurance and reassurance that they had made the right decision as they safeguarded their child's and their own survival in a fluctuating context of certainty and uncertainty. Parents employed numerous strategies to meet the extraordinary parenting needs of their child with HLHS and to ward off the worry and regret that threatened their own survival. Despite the difficulties that parents encountered with their child with HLHS and the anticipated challenges regarding their child's future health, the parents in this study were delighted with their child, as depicted in this summary diagram of parenting from decision to delight (Figure 6).

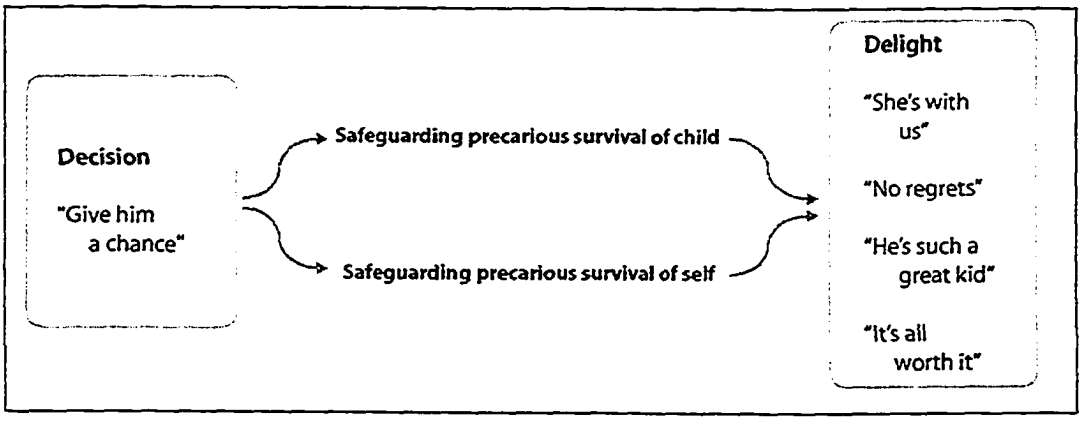

Figure 6. Safeguarding precarious survival – Decision to delight

This study addressed limitations identified in the literature by focussing on mothers *and* fathers of children with HLHS. The sample included parents of children whose condition was diagnosed antenatally or postnatally. Qualitative methodology and the

qualitative research methods from a constructivist perspective afforded rich descriptions of parenting children with life-threatening heart disease. Repeated interviews with the majority of participants and the age range of children from infancy to 5 years of age provided descriptions of a full range of parenting experiences over time including all three surgeries for HLHS. Multiple interviews over time combined with the "intimacy of intensive interviewing" (Charmaz, 2004, p. 979) also contributed to a "deeper view" (p. 979) of the parents' lives than single structured interviews could have afforded.

In this final chapter I will draw attention to some major findings of this study both from my perspective and in relation to literature on children with chronic and life-threatening illness. The method used in this study was constructivist grounded theory. Consequently, my assumptions and understandings about parenting as well as my clinical experience with children with CHD and their families influenced my observations, data construction and interpretation, and the findings of this study. The finding regarding "unusual" or "extraordinary" parenting illustrates my role in data construction and I will begin by discussing this finding. The other three findings that I will discuss in this final chapter also reflect my reflexive role in this research and build on the theories of normalization, regret, and father involvement. In this final chapter, I will highlight implications for clinical practice related to each key finding as well as future research questions that might further our understanding of parenting children with complex health conditions who receive technologically advanced treatment.

Extraordinary Parenting: A Constructivist Perspective

The finding regarding "extraordinary" parenting best illustrates the influence of constructivist methodology in this study. My role in data construction and interpretation

was influenced by my assumptions and understandings about parenting that in turn was shaped by my clinical experience in pediatric cardiology as a staff nurse and advanced practice nurse. Interplay between my assumptions and understandings, my clinical background, and parents' descriptions sensitized me to what I came to refer to as "unusual" or "extraordinary" parenting. My perceptions of the unique parenting that was undertaken by the parents in this study stood in contrast to my beliefs about usual or familiar parenting.

One of my assumptions about usual or familiar parenting was that irrespective of child-, family-, and/or society-related circumstances that may at times stymie parenting efforts, most parents endeavour to love, nurture, and protect their children, employing their resources, however plentiful or meager, as best they can. The responsibility that parents have for their children overwhelms some prospective parents (Nystrom & Ohrling, 2004) but most mothers and fathers undertake their parenting roles with anticipation that they will love and nurture a human being despite inevitable challenges. Based on these assumptions, I view parents as potentially resilient. Extraordinary parenting therefore did not consist of dealing with the challenge per se of having a sick child.

What constituted "unusual" or "extraordinary" parenting was the complex nursing care that fathers and mothers provided for their seriously-ill child. According to Charmaz (2004), "researchers' different sensitivities alert them to different facts" (p. 986). I was alerted to the high-level nursing skills of assessment, decision making, and problem solving as parents performed physical nursing skills such as medication administration, tube feeding, oxygen therapy and wound care. I have worked with parents of children

with CHD who have embraced their child's needs for ongoing monitoring and treatment with courage and competence. Parents of children with CHD cope with periodic acute episodes when their child becomes symptomatic and/or requires heart surgery. Parents monitor their child for worsening cyanosis or worsening congestive heart failure and administer medications when their child is symptomatic or recovering from surgery. My previous experience with parents of children with CHD sensitized me to the *additional* care and responsibility that the parents of children with HLHS in this study shouldered. Their parenting was also extraordinary, as it occurred in a context of ongoing uncertainty regarding the survival of the child and the use of new technology.

After each contact with the families in this study, I wrote or dictated my thoughts, feelings and observations about the interaction. These reflective notes not only served to keep me aware of my role in data construction but they also influenced my findings by sensitizing me to the tremendous responsibility these parents had in caring for their children with HLHS. As a nurse who had worked with cardiac babies and children for many years, I was sensitized to the severity of the child's CHD through my observations of the child's appearance and behaviour. In my post interview reflections I wrote:

> He does look like a blue heart baby and I am struck with the image I have of him and my images of the little girl from yesterday; just how fragile these heart babies are with their pale bluish complexions. He has a bit of clubbing of his fingers and he's just a little guy making his way and having a ways to go with his walking and all of that but he is a bright little boy with lots of toys around. He was sitting looking at a book at one point and this was very impressive because his small size and delayed walking gives you the impression that he would not have the attention span to sit on his own and look through a book.

This same child was suffering with a cold on one of the days I visited and I could not help but worry about him. After the interview I wrote:

> I was a bit worried when I first got there because the little guy looked and sounded quite sick. I guess I am not as used to seeing these desaturated children in a non-hospital setting. And they look worse with a cold on board. I think I would be worried if I had a child with such a serious heart problem. He was coughing and crying and looking quite miserable. Mom talked about how they [her and her husband] are still trying to learn how to make decisions about how sick he is; how wet his lungs are. There is a lot going on for these babies and these parents as they are constantly monitoring their child's illness and trying to distinguish the normal baby stuff from the heart stuff.

Another child with HLHS was very sick with the chicken pox when I came to interview her parents. The father called me the morning of the interview and I offered to postpone the interview. He insisted that it was fine for me to visit. My post-interview reflections captured my worry:

> I worried about [child with HLHS] as I did the snowy drive home. I know that chicken pox can be devastating for children with compromised health and wondered if [child with HLHS] was getting sicker and would need medical attention. I had a sinking feeling as I drove back to the city realizing how far this family was from the [tertiary referral centre]. I had a keen awareness of how it must feel for families caring for their medically fragile children when living away from major centers.

These descriptions of my worry not only illustrate my role in data construction but also reflect Charmaz's (2004) concept of "entering the phenomenon" which means "being fully present during the interview and deep inside the content afterwards" (p. 981). Experiencing the worry that parents described was disturbing for me and helped me recognize the fundamental need of parents to employ strategies to allay their worry.

Another aspect of extraordinary parenting that was reinforced through my direct contact with these families was the contrast between their familiar lives of busyness and the periods of isolation they recounted as they cared for their child with HLHS. When I interviewed parents in one high-energy, high-activity household I learned that the father was involved in coaching his older child's soccer team. The family had just been given a

trampoline and the child with HLHS was excited to go on it but needed her father's help and supervision. Unlike her husband, the mother was anxious about the trampoline and was unsure about having a trampoline considering their child with HLHS. The weekend for this family was especially busy however, not because of soccer or the new trampoline, but because the family was also involved in the construction of an adventure playground in their neighbourhood. It was evident that the father was taking a leadership role in this community project. My involvement with this family as I spoke with each parent over the course of their busy weekend, gave me a deeper sense of the activities and interests that the parents said they relinquished during the "to hell and back" experiences with their daughter with HLHS at the time of her surgeries.

Another striking aspect of extraordinary parenting was the parents' non-questioning attitude as they took on complex nursing care for their child. In constructivist grounded theory, the researcher pays attention to what is said by the participants but also pays attention to what is not said. Although parents expressed gratitude that technologically advanced care was available for their child, they did not speak at length about the technology that they experienced in the hospital nor the influence of technology on the care their children received at home. This context of technology seemed to occupy a taken-for-granted place in their lives. In contrast, the parents in this study described how thrilled they were to have their babies at home with them. Although they described how difficult it was to parent their babies with such demanding care needs, the parents did not question the technologically-oriented nursing tasks that they were expected to perform. The closest that any of the parents came to acknowledging the unusual nature of their parenting was Iris' comment:

> I became a nurse ... that's what my job was. (Iris)

Although there was a sense of pride in Iris' voice as she described how well she took care of her daughter she also explained that she felt she had no choice.

> I had no choice. So this is how I feel and I don't know if Ivan and I have ever, ever talked about this but I truly believe this is what I saw. (Iris)

Her uncertainty about whether she had expressed her feeling that she had no choice to her husband suggested that parents may not have felt comfortable expressing ambivalence about their expanded parenting role to each other, to others, or to me in a research interview. The "issue of silence" (Charmaz, 2004, p. 979) in qualitative research, alerted me to matters that parents may not have discussed and caused me to consider reasons why certain topics may not have been addressed in the interviews. Parents reported that professionals were amazed with the survival of their child. This response may have imposed limits on the types of feelings parents could share. The parents had a "good outcome" in that their child had survived because of new technology. They may have lacked the freedom to express concerns about the strain of extraordinary parenting and been reluctant to share these concerns, even in the context of in-depth interviews.

Extraordinary parenting as described in this study shares some common attributes with Ray's (2002) "parenting plus" and Miles and Holditch-Davis' (1995) "compensatory parenting." Parenting plus was largely invisible work that addressed familiar aspects of parenting that were made more difficult because of the child's special needs related to their developmental delays and disabilities. Parenting plus included "closing or filling the gap" (p. 427) and "paving the way" (p. 427) and involved a "level of anticipation well beyond that of typical parenting" (p. 428) in a context of uncertainty. Compensatory parenting was similar in that mothers altered the protection, stimulation, attention and

limit setting aspects of parenting by providing their prematurely born children with special experiences and avoiding other experiences to compensate for their children's neonatal experiences. Although the children with HLHS and the children in these two studies varied in age, health condition, and degree of delay and/or disability, they were parented similarly in the extra effort put forth by their parents in a context of uncertain outcomes. The parents in Ray's study felt they had no alternative but to do everything they could for their child, while Miles and Holditch-Davis credited the mothers' overriding perception of their child as normal but special as contributing to their compensatory parenting. The concept of normalization warrants discussion in relation to this study's finding of extraordinary parenting, as the parents of children with HLHS appeared to normalize their children's growth and development delays.

Another Look at Normalization

The children in this study were part of another research study in which they were followed for developmental outcomes (Robertson et al., 2004). Although some of the parents mentioned these testing sessions, they did not consistently describe things that they as parents or others as professionals did to assess and promote their child's development. It is not that the parents did not recognize their child's delayed growth and development but they preferred alternative explanations for the delays that did not focus on the child's severe heart problem. Additionally, parents described their child's developmental progress, however delayed, with delight because progress showed how well their child was doing despite their severe heart problem. These positive perspectives of the parents surprised me. I struggled to accept the parents' apparent lack of concern about their child's slow development and had to acknowledge that in this regard I viewed

the children from a medical model in contrast to the parents' view of their children from a social model (Landsman, 2003). Parents of the older children in the study did discuss developmental intervention that was initiated once the child was in school or pre-school. Several of these children had diagnosed speech and learning problems.

Developmental delay in children with HLHS is documented in the literature (e.g., Mahle et al., 2000; Rogers et al., 1995). Most of this research is retrospective and examines small samples of children from specific centres. In this growing body of research related to the neurodevelopment of children with complex heart disease, researchers raise their concern that parents tend to over look their child's delays or be overly optimistic about their child's development and quality of life (Hagemo, Rasmussen, Bryhn, & Vandvik, 1997; Mahle et al., 2000). Mahle et al. (2000) tested 28 school-age children who had undergone the surgical approach for their HLHS and found that although the majority of school-aged children with HLHS had IQ scores within the normal range, the average IQ was lower than that in the general population. Mahle et al. noted that most of the parents described their child's school performance as average or about average even though many of the children were receiving some form of special education. As well, the children consistently scored lower than expected for the normal population in standardized tests of cognitive outcome (i.e., IQ, achievement, language and motor function tests). Mahle et al. acknowledged that for the school-aged children that they studied "survival was considered an extraordinary achievement at the time of palliative surgery and long term outcome uncertain" (p. 1086). Similar findings were documented in a Norwegian study of children with HLHS who underwent the Norwood surgical approach. Only 3 of the 10 children were found to have normal

neuropsychological functioning, while the mothers scored their children's quality of life and functioning above that of normal children (Hagemo et al., 1997).

A prospective study in Canada addressed the developmental concerns of children who had undergone open-heart surgery for complex heart disease during infancy, not including children with HLHS. Limperopoulos et al. (2002) found that 45% of the children who had surgery as newborns (first month of life) and 37% of children who had surgery as infants (first 2 years of life) had abnormal neurologic findings, including muscle tone abnormalities, abnormal behavioural findings, cranial nerve abnormalities and /or microcephaly. Forty-two percent of all the children in the study (n = 98) had gross and fine motor impairments at 12-18 months as measured by the Peabody Developmental Motor Scales. Many of the children tested also demonstrated some functional limitations (Limperopoulos et al., 2001). According to the WeeFIM (Functional Independence Measure), 37% of children had moderate disability and 6% had severe disability. Four to five years post cardiac surgery, neurological deficits persisted with 26% of the children (A. Majnemer, personal communication, January 17, 2003). Functional limitations also persisted and 24% of the parents reported a high level of stress. Limperopoulos et al. (2002; 2001) concluded that severe disabilities are rare in children with complex heart disease who had surgery as infants but moderate delays exist which would be responsive to early intervention. They recommend perioperative interdisciplinary assessments of infants and counselling of families to encourage them to pursue early intervention for their children. To date this research program has not included children with HLHS.

In my study, parents of children with HLHS normalized their child's lags in development and slow weight gain. The question raised is whether parents were less

motivated to seek early intervention for their child because they wanted to focus on their child's development as a sign of how well their child was doing, not on development as a source for concern and intervention.

Normalization has been conceptualized as both a cognitive process and a behavioural parenting strategy (Deatrick, Knafl, & Murphy-Moore, 1999). As a cognitive process parents define their family life as normal despite their children's chronic condition that alters family life (Robinson, 1993). Parents also do things to integrate their children with disabling conditions into family and community life so that the child does not feel different from siblings and peers (Deatrick, Knafl, & Walsh, 1988; Krulik, 1980). The parents in this study used normalization to characterize their child's delayed growth and development positively. Parents recognized the differences in their children but did not see their child's delayed developmental milestones as setting their child apart from other children or as indicative of future problems. In fact, the parents considered their children's achievement of delayed milestones with delight and reassurance regarding their child's future health and progress. This finding illustrates Robinson's (1993) conclusion that "the story of normalization" in the lives of those managing their child's or their own chronic illness supports hope.

My perspective that parents may have missed opportunities to enhance their child's development through their normalization is perhaps shaped by my view of life with a serious health concern as "problem saturated" (Robinson, 1993, p. 20). Robinson asserts that health care professionals tend to reflect society's view of illness as problematic and this can result in negative judgements of normalizing for example, as evidence of denial. Health care professionals may also provide anticipatory guidance that disrupts or

diminishes parenting practices that reflect the parents' positive perspective of their child's health problems (Landsman, 2003).

Although the positive effects of normalization strategies at the family and child level are evident (Deatrick, Knafl, & Walsh, 1988; Krulik, 1980; Robinson, 1993) normalization is not always possible. Deatrick, Knafl, and Murphy-Moore (1999) in their concept analysis of normalization based on 19 articles concluded that there might be some situations where the illness is so serious that normalization is not possible. Managing the stress and uncertainty that accompanies, for example, the early stages of childhood cancer or diabetes during infancy, becomes the focus for parents, not normalization of the child's or family's life. Deatrick and her colleagues also concluded that chronic uncertainty is a threat to successful normalization, intimating that normalization may still be a reasonable goal for these families. In a subsequent report of study findings, Knafl and Deatrick (2002) presented three illness scenarios of families who did not experience normalization in their lives with their chronically ill child (i.e., diabetes and rheumatoid arthritis). The seriousness of the child's illness was not the major reason that parents did not experience normalization. Rather, the parents' perceptions of the illness, its management and the influence on their family were barriers to normalization. For the parents in this study, the seriousness of HLHS, the accompanying uncertainty, and the parents' perceptions did not seem to deter them from normalizing their child's delayed growth and development. Normalization remained possible, but the question remains as to whether the use of normalization by the parents was helpful for the child.

Many of the studies of normalization (Deatrick et al., 1988; Knafl & Deatrick, 2002; Krulik, 1980) involve parents whose children are older than the children with HLHS in this study and whose chronic illnesses are stable as parents carry out established regimens of illness care and management. Normalization may be a goal that is more appropriate for children whose condition has been stabilized and where there are established care and monitoring guidelines for parents (e.g., asthma, diabetes, or juvenile rheumatoid arthritis). In contrast, there were few established care guidelines for the children with HLHS in this study. Both health professionals and parents were learning how to care for survivors of a new technology and there were no established indicators of future developmental or health concerns. In this situation, it is unclear whether the parents' use of normalization was an asset or a disadvantage.

There may be other explanations as to why the parents in this study did not emphasize their child's developmental needs or perceive them as requiring their attention. Sullivan-Bolyai et al. (2003) described the mothers of young children with diabetes in her study as not having time to focus on their child's developmental needs. Their study is similar to my study because it included children of the same age; the average age of both cohorts of children was 2.9 years. Sullivan-Bolyai and her colleagues raised the concern that mothers may become so burdened with concerns related to the day-to-day illness management that they lose sight of normal development. The influence of all-consuming care on the parents' ability to attend to the developmental needs of children with life-threatening conditions is verified in O'Brien's (2001) research with families caring for a child who is technology-dependent (e.g., mechanical ventilation). She found that many

parents did not have the time to concentrate on development because of the physical demands in caring for their child.

In summary, children with HLHS who undergo the Norwood surgical approach are at risk for developmental delay. Parents' apparent lack of concern regarding these delays in early childhood raises concern that parents and health professionals may miss opportunities to facilitate the child's development. Although more research is needed to determine the long-term development of children with HLHS who have had the Norwood surgery, it seems worthwhile to support parents in enhancing their child's development in early childhood. At the same time it is important to support parents' hopeful outlook and optimistic view of their child's activities. Awareness of and a balance between the medical and social models of illness and disability is especially important for health care professionals in their work with these families.

The pervasive view of childhood disability as tragic is also reflected in the perceptions of healthcare professionals that parents of children with HLHS must have regrets because they as professionals would make different choices than the parents who chose treatment (Kon, Ackerson, & Lo, 2003; 2004), thus the ensuing discussion of another major finding in this study, that of no-regret parenting.

No-Regret Parenting

Because most parents perceived they had a choice regarding their child's treatment, they subsequently sought assurance and reassurance that they had made the right choice or decision. The all-consuming care demands and episodes of acute illness and life-threatening complications led most parents at some point to question or doubt their decision that the Norwood surgical approach was the best choice. Second-guessing

whether the Norwood surgical approach was the best option for their child was distressing for the parents. Many of them were tearful as they described their momentary experiences of regret. All of the parents also recounted their process of decision making. The one difference between fathers and mothers that emerged from the data was the fathers' use of travel metaphors to indicate that there was no turning back regarding the decision they had made on behalf of their child for the Norwood surgical approach. Most of the fathers but none of the mothers described their decision as putting them on a path or course that they could not change. It was not helpful, therefore, for the fathers to think about the options they did not choose. The mothers also described moments of wondering if they had made the right decision but unlike the fathers, who focussed on the decision itself, the mothers focussed on the blessing of *having* their child. When their child experienced a severe setback or complication, the parents' hope and confidence that their child would survive was threatened. These intense experiences of threat and uncertainty led parents to entertain thoughts of regret and subsequent feelings of guilt about their regret.

Despite periods of occasional regret, all parents, except one, claimed they did not regret their choice for the Norwood surgical approach. The one parent in the study who continued to regret the decision that he and his partner had made in favour of the Norwood surgical approach, found out about his baby's HLHS antenatally. This finding raised the question whether parents who had more time to consider their decision had more episodes of second-guessing or regret. The data however, revealed that parents in both the antenatal and postnatally diagnosed group recounted experiences of doubt, second-guessing and /or regret.

Closer examination of regret in the social psychology literature (Baron, 2000; Landman, 1993) helps us understand the parents' intense desire to avoid regret and the possibility that parents did not feel free to express their regret. It also points to the positive role regret can play when individuals must make difficult choices among uncertain outcomes such as the decisions parents in this study made on behalf of their children with HLHS. Regret theory (Landman, 1993) is a branch of decision theory (Baron, 2000; Janis & Mann, 1977; Kahneman, Slovic, & Tversky, 1982) that includes research in which individuals are presented with scenarios or vignettes that depict decisions involving risk (e.g., to buy a lottery ticket, to wear a seat belt). Landman's (1987a; Landman & Manis, 1992) research focussed specifically on regret. She presented undergraduate students with vignettes of decision-making situations that involved action or inaction. As well she surveyed or interviewed undergraduate students and adult women about their life choices, using questions such as "If you could start over again, what would you do differently, if anything in each of the following life domains..." (e.g., education, work, and relationships, and having children) (Landman & Manis, p. 474).

Landman (1993) argues against the commonly held view of regret as being negative, even destructive, and therefore something to avoid. She suggests that regret is "a dynamic, mobilizing, and rational experience" (p. xviii) that can be positive. Regret illustrates the interdependence of reason and emotion in human thought and action (Landman, 1987a) as well as the potentially negative or positive outcomes of our human responses depending on what we do with our thoughts and feelings (Landman, 1993). As illustrated by the parents in this study, regret can be a positive coping strategy (Baron, 2000; Landman, 1993) through a process identified in the decision-making and regret

literature as counterfactual thinking; the process by which one imagines how things might have been had a different choice been made.

The parents in this study experienced the instructive nature of retrospective regret (Seelau, Seelau, Wells & Windschitl, 1995) as well as the inevitability of regret as they parented their child with life-threatening CHD. Regret, "the sense of sorrow, disappointment, or distress over something done or not done" (Landman, 1987b, p. 524), stimulated thoughts and feelings that actually helped the parents. Through consideration of other possible outcomes, parents came to terms with the ongoing losses they experienced as they parented a child whose new survivor status was precarious. Counterfactual thinking enabled them to come to a place of genuine delight in their child.

Regret theory (Seelau et al., 1995; Landman, 1987a) states that events that are perceived to be exceptional rather than normal, and events that involve actions rather than "inactions" represent situations that have easily imaginable alternatives. These types of events more frequently precipitate counterfactual thought. The diagnosis of HLHS, the ensuing decision-making process and subsequent decision to pursue the Norwood surgical approach constituted an exceptional life event. Parents described the role they played in deciding to pursue the Norwood surgical approach and therefore revisited their actions through counterfactual thinking. By considering other alternatives, such as compassionate care, parents were able to compare the consequences, such as their child's certain death and view their present demanding parenting role of safeguarding their child's survival more positively. Counterfactual thinking did not change the reality of parenting a child whose survival was precarious but it helped parents to positively reinterpret their reality.

The experience of ongoing regret described by one parent supports the argument in regret theory that assigning blame through the process of counterfactual thinking (Seelau et al., 1995) can enable one to perceive some control over the outcome. The parent who continued to have regret about the choice of treatment for his child with HLHS expressed anger with the health care professionals. He felt that he and his wife had made their decision based on inaccurate information and he claimed that they had been given a "rosy-assed" view of the Norwood surgical approach. He blamed the health care professionals for the choice that he and his partner made not to pursue compassionate care. It was his opinion that it was not their fault as parents that his daughter and family had suffered so much in the course of multiple surgeries and innumerable complications. This perspective enabled him to continue to express regret. The question remains as to whether he was the only parent in this study who could break the conversational sanction prescribed by society and medicine's "wonder and wonderment" with technology (Cassell, 1993). Most of the parents in the study did describe their experiences of second-guessing or short-lived regret but it was clear that these thoughts and feelings were private in nature. One father talked about his worst moments of regret taking place when he was alone in the shower. He stated that he did not share these thoughts with his wife. As Seelau et al. put it, "public expression of alternatives that violate the consolation purpose tends to yield socially inappropriate statements" (p. 74). Did parents keep their thoughts and feelings of regret private to avoid hurting others or were they free of regret?

Another possible explanation of the no-regret parenting that was evident in this study was the parents' perceptions that they did have some control over the outcomes for their child. Despite ongoing uncertainty about how their child would do in the future, their

parenting strategies to safeguard their child's survival reflected their beliefs that they did have some control over their child's health. Parents described the control they exercised in their decision to pursue the Norwood surgical approach and their vigilant care and monitoring reflected the control they were taking over their child's survival. If they considered regret appropriate only for matters where they lacked control, ongoing regret was not an option for them.

In summary, parents in this study described their thoughts and feelings of second-guessing or regret but they concluded that they did not regret their choice. If in fact parents were not harbouring regret that they could not express, this application of regret theory illustrates the potentially positive role that regret can play through counterfactual thinking. The life-threatening aspect of HLHS contributed to inevitable expressions of regret but also contributed to parents rejoicing or delighting in their child because the imagined alternative of death of their child had not been experienced. The parents perceived that they did have some control over the outcomes for their child, thus their no-regret parenting process of safeguarding their child's survival supports one of the theoretical propositions of Landman's regret theory. A final major finding for discussion is the involvement of fathers in the care of their children with HLHS.

Parenting a Child with HLHS is a Family Affair

The research to date about parenting children with CHD and other congenital anomalies has predominantly focussed on the role of the mother. The findings in this study, however, demonstrated considerable involvement of other family members in the care of children with HLHS. The fathers in this study were extensively involved in the care of their child with HLHS, as were grandparents. This was not unusual as I

considered my advanced practice nursing role in which I engaged mothers *and* fathers in every aspect of their children's illness and care. It was unusual, however, considering the literature where mothers are predominantly studied and their care-taking role surpasses that of fathers. Although the mother was the primary care provider during the first few years of the child's life, all of the fathers in this study played key roles in their baby's repeated hospitalizations and ongoing care at home. Even though most of the fathers in this study were the primary earners in their family, they were knowledgeable and skilled regarding their child's complex care. The next most involved family care providers were the grandparents of the child with HLHS.

The extensive father involvement in this study is both different from and similar to other studies where comparable round-the-clock parenting is required for a child's life-threatening condition (O'Brien, 2001; Sullivan-Bolyai, Deatrick, Gruppuso, Tamborlane, & Grey, 2003). Sullivan-Bolyai and her colleagues reported a similar parenting process of "constant vigilance" in their research with mothers of young children with type 1 diabetes but their research revealed limited involvement by fathers. Although most of the mothers identified their spouse as an important source of emotional support, the fathers provided only occasional relief from daily child care. Constant vigilance was also a key strategy for mothers and fathers who were caring for their ventilator-dependent child at home (O'Brien, 2001). The involvement of fathers as distinct from the mothers was not delineated in O'Brien's research report even though both mothers (n = 15) and fathers (n = 4) were interviewed. If the involved care attributed to the "parents" in this study reflects the actions of both fathers and mothers, then the fathers in O'Brien's study were as involved in their child's care as the fathers of the children with HLHS. Employment

outside the home was not an explanation for the different findings as most fathers in all three studies, Sullivan-Bolyai et al., O'Brien and the current study, worked outside the home.

A possible explanation for the similarity between the level of father involvement in O'Brien's study and this study is the life-threatening aspect of both health conditions, ventilator dependence and HLHS. The threat of death for the technology-dependent children is largely mechanical as compared to physiological for children with HLHS. However in both groups, the care the parents provide directly influences their child's survival. Fathers may be motivated to provide care as they see this as essential for the child's survival.

The fathers of children with diabetes (Sullivan-Bolyai et al., 2003) were less involved in their child's care than the fathers in this study. Children with HLHS experience prolonged hospitalization starting right after their child's birth and many fathers had to take time off work to accompany their child with HLHS and spouse to another city and or province for their baby's surgery. The fathers' employers may have gained an understanding of the need for fathers to be with their family during hospitalization and to attend to needs at home. Ivan's employer was remarkably understanding as demonstrated by his offer to pay for Ivan's daughter to have surgery in the United States when her surgery was postponed due to unavailability of a hospital bed. Although most fathers of children with HLHS returned to their jobs while their baby was still in hospital, the drama of life-and-death treatment may have afforded the fathers in this study some added empathy from their employer and leeway regarding work responsibilities that allowed them to be more involved with their baby's care. Children with type 1 diabetes may

experience hospitalizations but these are of short duration and episodic. Consequently fathers and their employers may be less likely to adjust work responsibilities.

Other possible explanations for the different level of father involvement are potential differences in work responsibilities and motivation between fathers in this and Sullivan-Bolyai et al.'s study as well as the specific circumstances of fathers in each study. Two of the fathers of children with HLHS had extended medical leaves from work during the first year of their baby's life that may have contributed to their extensive involvement in their child's care. Allan sustained a knee injury at work and was off work and able to be more involved with his baby's care. Cam had an exacerbation of a pre-existing chronic health condition and thus had extended time at home. Two other fathers experienced job changes during the first year of their baby's life. Hunter had time off between positions and Gavin chose a shorter workweek in his new professional setting to have more time with his family. Whether these changes occurred as a result of having a child survive against the odds or would have happened anyway was not explored with these fathers. David and Fred worked shift work and so had extended times when they could care for their child with HLHS. The uniqueness of the fathers who agreed to participate in the study may also have accounted for their high level of involvement. Most of the fathers of children with HLHS were highly motivated to provide care. Of the families represented in the study, the one father who declined study participation was, according to his wife's reports, minimally involved in the care of the child with HLHS, especially during the first few years of the child's life.

In the literature on father involvement, fathers become more involved in the parenting process as their children get older (Belsky, Rovine, & Fish, 1989). This explanation

supports the dominant role of mothers in Sullivan-Bolyai et al.'s (2003) study where children were on average 1.25 years old and the higher level of involvement of both parents in O'Brien's (2001) study where children were on average 5.84 years old. This argument however does not hold true for the parents in the HLHS study where fathers were extensively involved from the time the child was born.

Another possible explanation of the difference in father involvement between this and other studies may be that this study focussed on parenting and efforts were made to include fathers and mothers of each child in the sample. Mothers and fathers were interviewed separately, and the father data were analyzed separately from the mother data. Many studies include mothers only (e.g., Sullivan-Bolyai et al., 2003; Tomlinson, Kirschbaum, Harbaugh, & Anderson, 1996) and when fathers are included they are usually fewer in number than the mothers (O'Brien, 2001; Ray, 2002). Additionally, father and mother data are not always analyzed separately for comparisons. O'Brien included 4 fathers in her study of "15 families." No comments, however, were made about the roles that the fathers played that were the same or different from the mothers. Often the term "parent" was used in reference to particular findings or quotations, not distinguishing between father and mother data. Exclusion of fathers from studies and the grouping together of father and mother data may obscure the parenting role of fathers.

Extensive involvement of grandparents in the complex care of children with HLHS was also evident in this study. One of the first telephone calls that parents made after they found out about their baby's HLHS, whether antenatally or postnatally, was to their parents. In most cases, this contact initiated immediate responses that ranged from caring for other children while parents of the child with HLHS traveled to the referral center to

accompanying the child's parents to the referral centre for further consultation and/or the birth and treatment of the baby.

The findings on grandparent involvement in this study differed from other studies (Sullivan Bolyai et al., 2003; O'Brien, 2001). Lack of grandparent involvement was attributed to grandparents' fear, especially in the grandparents of very young children with diabetes (Sullivan-Bolyai et al., 2003). Few grandparents were involved in the care of their technology-dependent children (O'Brien, 2001) and the researchers suggested that this was related to the grandparents' anxiety in providing care. Parents in O'Brien's study were also concerned about caring for their aging parents. O'Brien's study included an older sample of children (ranged from 2-12 years of age) and therefore it was more likely that the grandparents were older and had health concerns that limited the amount of assistance they could provide in caring for a child on a ventilator.

The high level of involvement of grandparents in this study may be related the life-and-death nature of HLHS at birth. Grandparents were called into action right from the time these babies were born. Parents who found out about their baby's HLHS antenatally informed grandparents of the diagnosis and elicited their emotional support. Their instrumental help was also enlisted as parents planned for the birth of their baby with HLHS. All the families, except one, had other children that needed care. Grandparents in this study also had opportunity to gain experience caring for the babies while they were still in hospital. This experience may have helped them overcome the fear that Sullivan-Bolyai and colleagues (2003) identified. This hypothesis is supported by findings from a study of grandparents (7 grandmothers and 7 grandfathers) of 4 babies with life-threatening illnesses who required intensive care (Hall, 2004a, 2004b). "Double concern"

characterized the experience of these grandparents as they responded out of their concern for their children and their grandchildren. Their value of "family first" motivated the grandparents in Hall's study to immediately assist their adult children whose babies were in the midst of a health crisis. Perhaps the suddenness of an intensive care hospitalization in Hall's and my study mobilized grandparents in a situation where they felt that they had no choice or no time to consider their involvement. This suggestion requires further investigation based on data collected from the grandparents of children with HLHS.

The parents in this study, whether they found out about their baby's HLHS before or after their baby's birth rapidly mobilized personal and family resources, a contributing factor to family resiliency when illness stressors are present (McCubbin, Thompson, & McCubbin, 1996). A key resiliency factor identified by McCubbin and colleagues (McCubbin, Balling, Possin, Frierdich, & Bryne, 2002) for parents of children with cancer was the rapid mobilization and reorganization in response to the family crisis of having a child diagnosed with cancer. The urgency for treatment was similar for both children with cancer and children with HLHS. The parents in McCubbin et al.'s study (2002) were not allowed to go home and pack; they were asked to drive immediately to the hospital where their child would commence treatment. In both situations, cancer and HLHS, the mothers and fathers quickly established new patterns of family functioning that involved help from other family members.

Unlike most of the parents of children with cancer, the parents of children with HLHS were already facing a life transition that mobilizes family resources, that is, the birth of their baby. For parents of a baby critically ill with HLHS, the accompanying life transition of childbirth may have contributed to grandparents being poised to help. Recent

research on the role of grandmothers, especially maternal grandmothers on providing support during birth and related to breastfeeding (Ekstrom, Widstrom, & Nissen, 2003; Polomeno, 2000; Winterburn, Jiwa, & Thompson, 2003) highlights the willingness and availability of grandparents, a resource that contributes to family resilience. Parents in this study were repeatedly grateful for all that their parents did for them and their children. These expressions of gratitude are evident in other studies (O'Brien, 2001; McCubbin et al., 2002; Tomlinson & Mitchell, 1992) and again speak to the apparently easy flow of help between parents and grandparents when a child's life is in danger.

Parenting a child with HLHS was indeed a family affair, and it is important to note that there was evidence in this study that family members were able to work together with minimal strain or conflict. The mothers and fathers described how they cooperated with their spouse to meet the care demands of their child with HLHS. This is not always the case. Knafl and Deatrick (2002) reported that fathers and mothers of children with chronic illnesses such as diabetes and rheumatoid arthritis who did not agree on how much effort should be directed towards their child's care experienced their child's illness as a source of conflict. Knafl and Deatrick also described the tension that arose between spouses when husbands perceived their wife's extensive involvement in their child's illness management as negatively impacting the family. The parents in O'Brien's (2001) study confirmed the importance of spousal relationship in the midst of demanding caregiving for their technology-dependent children. All parents in this study felt that their relationship with their spouse had been significantly affected by having a child with special needs. The impact was often negative and O'Brien provided parent data that

illustrated the tension and conflict between spouses as they cared for their technology-dependent child.

My finding of lack of conflict between parents is supported by the lack of role strain found by Tomlinson and Mitchell (1992) in couples who were together during their critically ill child's intensive care hospitalization. The child's life-threatening illness fostered cohesion between some of the husband-wife dyads and the parents attributed this to the stressful, uncertain nature of the hospitalization that removed them from the usual routines and environment. Other couples in Tomlinson and Mitchell's study experienced isolation and role strain related to excessive demands, separation from spouse and difficulty understanding and supporting each other during their critically ill child's hospitalization for intensive care. All of the parents in my study had extended time together away from home, as they cared for their child in the hospital setting. This shared experience may have contributed to mutual understandings and decreased the possibility of conflict.

The agreement between parents about their child's care also may be a factor that explains the lack of conflict between the parents in this study. In a mixed method study with parents of school aged children with chronic illness that required daily monitoring and management (e.g., asthma, diabetes, juvenile rheumatoid arthritis), Knafl and Zoeller, (2000) found that parents in the same family are likely to have a shared view of their child's illness situation and management, whether positive or negative. Knafl and Zoeller concluded that mutuality, a shared positive perception of their child's illness management, plays a part in parents approaching their child's care in ways that contribute to family resiliency. Being on the same "wavelength" (p. 292) echoed the statements that

parents of children with HLHS in this study made about needing to be on "the same page" regarding their child's care. Perhaps the daily nature of care necessitated the mutuality that characterized parenting of children with chronic illness (Knafl & Zoeller, 2000) and children with HLHS in this study.

The major findings in this study related to normalization, no-regret parenting and father involvement reflect the characteristics of normalcy, an accommodative parenting philosophy and couple mutuality that contribute to thriving and accommodating family management styles (Knafl, Breitmeyer, Gallo, & Zoeller, 1996). The extraordinary parenting that the fathers and mothers in this study undertook as they safeguarded their child's and their own survival not only resulted in delight in their child but undoubtedly contributed a thriving family environment that contributed to the health and well-being of all members including the child with life-threatening heart disease.

Limitations

As with all research endeavours, alternative or additional ways of approaching the research questions become evident as the research progresses. One consideration that was discussed earlier in this chapter is the possible uniqueness of the sample. The parents in this study demonstrated resiliency while parenting under constant threats to their child's well-being. The clinical nurse specialist contacted parents to see if they were interested in participating in the study. Nothing is known about those who chose not to participate or about those who were not contacted. Did the parents who participated in the study have characteristics that predisposed them to more positive experiences of parenting their child with HLHS? Other parents of children with HLHS chose pregnancy termination or compassionate care for their infant. It is unknown how these couples might have differed

in their ability to be resilient. Most of the parents in the study were partnered and from middle to upper middle class Caucasian families. The study findings might differ if the participants were more heterogeneous in ethnicity and social economic status.

Another reality of research is that a study is always time bound. The children of the parents in this study had their first surgery for HLHS between January 1997 and September 2001. Surgical procedures have continued to change during this time, the major change being the recent introduction of a different first stage repair, the Sano procedure, at the tertiary referral centre. Health care professionals associated with the tertiary referral centre believe there are fewer family concerns now because there have been a smaller number of health complications in the children who had the Sano procedure (Lea Legge, personal communication, October 26, 2004). Other centres are less optimistic about this new technology. A multi-centre randomized controlled trial is being conducted in the US to compare outcomes of the Sano procedure to outcomes of the conventional Norwood procedure (Jaquiss, 2004). Although some of the experiences parents described in this study related to the complications faced by their child, other aspects of their parenting experience described the intense demands of daily care for an ill child. It is possible that changes in surgical techniques will not decrease the demands on mothers and fathers for extraordinary parenting.

Clinical Implications

The findings from this study have the potential to influence the clinical practice of health care professionals who work with parents whose children face uncertain futures related to the lack of knowledge regarding the outcomes of the new treatments. The parents' descriptions of their experience illuminate the hurdles and rewards of parenting a

child who survives pioneering surgical approaches. Clinicians must acknowledge the distinctive status of these children and provide support and intervention for the parents related to their extraordinary parenting efforts to safeguard the child's survival. Health care professionals have the opportunity to work collaboratively with these pioneering parents and must ensure that the resources provided to support parents in their unique parenting role match the exceptional technological resources that the child has received. Ongoing support and counseling from a consistent program-based advanced practice nurse in a clinical nurse specialist role is a key resource for parents, starting at the time of their child's diagnosis of HLHS, whether that be antenatally or postnatally. The influence of optimistic physicians at surgical centres has been shown to be a factor in parents choosing surgery for their children with HLHS (Corrow et al., 2001). The involvement of an advanced practice nurse with parents during their decision making is vital to ensure that they are fully informed of the day-to-day challenges that their decision may incur. Adequate staffing both in the hospital, community and home settings consisting of nurses and other health care professionals who are knowledgeable and experienced with children with complex heart disease and their families is essential to continuity of care during and between hospitalizations. Increasing involvement of nurse practitioners in hospital care has the potential to contribute to improved continuity during the child's numerous hospitalizations. In-home respite care must become increasingly available for parents especially when they are providing round-the-clock feeding and monitoring for their child with HLHS.

In response to the extensive father and grandparent involvement documented in this study, clinicians must ensure that they assess and address the needs of mothers, fathers

and grandparents in their care of families of children who have survived life-threatening conditions related to new treatments. Information resources, program development, and clinical interventions need to respond to the involvement of all family members. Those mothers who do not have support from their child's father or grandparents may need additional emotional and instrumental support from health care professionals while the child is in hospital and when the child goes home with nursing care requirements. We must pay attention to the needs of all family members such as parents who may not have support from their aging parents. Aging grandparents may also be at risk for lack of support as their children may be overwhelmed by care of their child with HLHS and not be able to help their parents.

Clinicians in pediatric cardiology have the opportunity in partnership with other members of the health care team including mental health practitioners to help parents reframe regret as a beneficial coping strategy rather than evocative of guilt. Clinicians can invite parents, both on their own and together as a couple, to revisit their decision-making process regarding technologically advanced treatment for their child. A question such as, "If you could do things over since you found out about your child's HLHS, what would you do differently?" would give parents the opportunity to express thoughts and feelings of regret that they may not have had the freedom to share with their spouse or other family members. This review, with the support of professionals, could initiate counterfactual thinking that could lead parents to feel free to express their regret and in fact benefit from such expressions.

Health care professionals also have the opportunity to identify clinical approaches and interventions that are unique to the care of parents whose child's survival can be

attributed to recently available technology. Regarding the prevalence of developmental delay in children with complex heart disease, including those with HLHS, professionals need to establish intervention guidelines based on the research findings. We can affirm parents for the beneficial effects of normalization but also alert them to the reality of many unknowns regarding their child with HLHS. Professionals need to inform parents of potential risks to their child's development so those parents have the opportunity to help their child and thus avoid negative outcomes. Perhaps if professionals framed early intervention as a prevention strategy rather than one of remediation, parents would be more apt to pursue assistance for their children from developmental specialists.

Future Research

Future research needs to include replication of this study with a larger and more diverse sample of parents, a parallel study with grandparents, and similar qualitative investigations of parenting children who have a different yet similar life-threatening condition. These three directions for further research collectively have the potential to enrich our conceptualizations of parenting children with life-threatening conditions who benefit from new technology and yet whose future health is uncertain.

Replicating this study with a larger and more diverse sample is key to determining if the current sample was exceptional in some way. Inviting all parents whose children undergo surgical treatment for their HLHS to participate in the study would potentially yield a more diverse sample of mothers and fathers from different ethnic, education and employment backgrounds. Replication of this study at the tertiary referral centre from which the current study participants were recruited would also capture the recent change in surgical approach from the Norwood surgery to the Sano procedure in the newborn

period. Although potential concerns regarding heart function are emerging with this new approach (Tanoue, Kado, Shiokawa, Fusazaki, & Ishikawa, 2004), professionals anecdotally report fewer feeding problems during the first months of the baby's life. These differences, as well as the decision-making process that led to the Sano procedure, need to be explored from the parents' perspective. The continued inclusion of fathers in equal numbers to mothers participating in the replication study is vital to further examining father involvement when the care of a child with a life-threatening health condition is at stake. Replication of this study with parents who chose compassionate care or whose children died would deepen our understanding of parental decision making and regret.

Conducting a parallel study with grandparents of children with life-threatening heart disease would also add to our understanding of how families care for children with unstable health conditions where few guidelines for care exist. The role of grandparents in contributing to family resiliency warrants further research as well as the apparent ease with which their caregiving is incorporated despite the ongoing pressures on the family of multiple surgeries and prolonged hospitalizations for the child with HLHS.

Programs of research that follow children and their families over many years are needed to capture the influence of long-term uncertainty for the parents and families of children who have survived their lethal health condition through the application of new technology. Interviews with parents and grandparents at key times in the child's life such as school entry, adolescence, further surgical intervention, and transition to adult care (Higgins & Tong, 2003) would build on the findings of this study. Data collected at these key times may provide insights into changes in parenting and grand parenting roles,

especially considering the context of advancing technology and the concepts of regret, normalization, protectiveness, parenting stress and fear.

Research with parents of children with life-threatening conditions other than HLHS who are survivors of new technology would enrich our conceptualizations of parenting in uncertain contexts. Parents of children with congenital diaphragmatic hernia face crucial treatment decisions that involve new technology (Aite et al., 2004; Stege, Fenton, & Jaffray, 2003). Replication of this study with the parents of children with congenital diaphragmatic hernia at different stages of their diagnosis and treatment would provide valuable comparisons to further our understanding of parenting children who receive technologically advanced life-saving intervention.

Conclusion

Our society experiences and values a health care culture of rapidly developing technology that is used to address complex and life-threatening conditions. The findings of this study, however, raise questions regarding the impact on parents of the care of children who are survivors of new technology.

The parents in this study demonstrated resilience in their extraordinary parenting and they were delighted in their child with HLHS who had survived having undergone the Norwood surgical approach. Many cardiac specialists claim that the treatment of HLHS has already been conquered and that the new frontier is fetal surgery (Park & Park, 2001). Similar progress and aspirations in other pediatric specialties exist (Choi, 2001). Nursing research and practice must reflect an in-depth understanding of the needs of these parents so that benefits of technological advances are fully realized for the child, parents and family.

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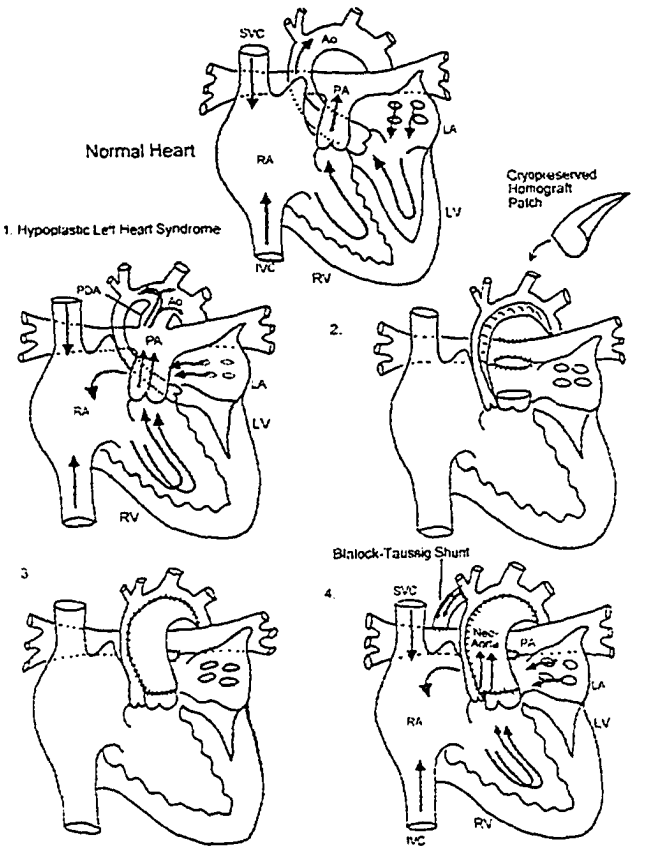
APPENDIX A

HLHS Anatomy and Norwood Procedure



Source: Eliot May, L. (1999). *Pediatric heart surgery: A ready reference for professionals*. Milwaukee, WI: Maxishare.

1. *Hypoplastic Left Heart Syndrome*: Systemic or left ventricle (LV) and left-sided aortic and mitral valves are not adequately developed. Oxygenated blood from the lungs that would normally flow from the left atrium (LA) to the left ventricle (LV) to be pumped out to the body is re-routed to the right atrium (RA) through a fetal opening between the right and left atria. The oxygenated blood mixes with the deoxygenated blood from the body in the RA and then the right ventricle (RV) pumps this blood out to the lungs. As well, the RV pumps this mixed blood to the body through another fetal opening between the pulmonary artery (PA) and the aorta (Ao).

During the neonatal period, creating a new or "neo-aorta" between the RV and the Ao constitutes *the Norwood procedure.*

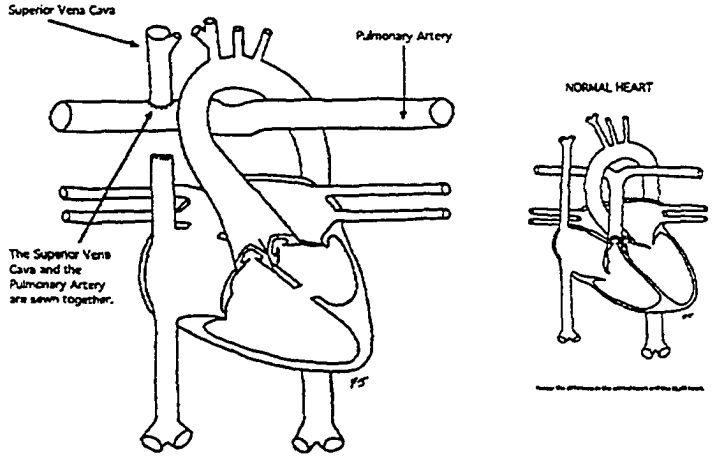
2. Surgeons remove the main PA from the pulmonary artery branches and uses patch material to construct a new aorta.
3. The "neo-aorta" carries oxygenated and deoxygenated blood out to the body.
4. Surgeons also create connection between the neo-aorta and pulmonary artery (Blalock Taussig shunt) so that blood also reaches the lung for re-oxygenation.

APPENDIX B

Subsequent Surgeries for HLHS

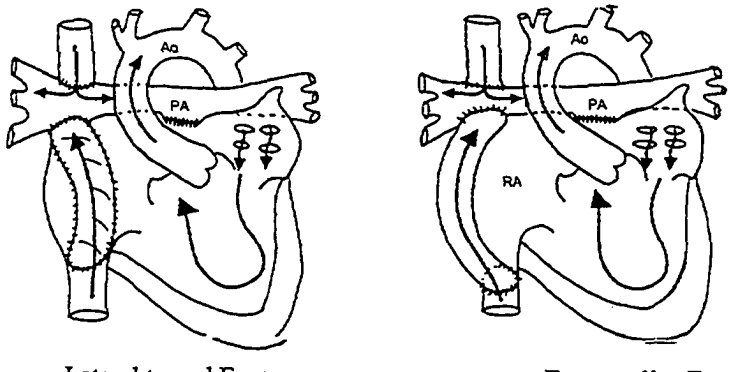
Following the Norwood procedure, the pulmonary (deoxygenated) and systemic (oxygenated) blood is mixed. The goal of the two surgeries that follow the Norwood is to separate the pulmonary and systemic blood.

Bi-directional Glenn: When the child is 6 to 9 months of age, surgeons remove the superior vena cava (SVC), (the blood vessel that brings deoxygenated blood from the upper part of the body to the right atrium → right ventricle → lungs), from the RA and attaches is to the pulmonary artery so that this pulmonary blood go directly to the lungs and does not mix with the oxygenated or systemic blood that comes to the right side of the heart for pumping through the new aorta. Surgeons remove the BT shunt at this time.



Source: Jaworski, A. M. (1995). *Hypoplastic left heart syndrome: A handbook for parents*. Panama City Beach, Florida: Baby Hearts Press.

Fontan: At 18 months to 4 years of age, surgeons redirect the deoxygenated blood from the lower part of the body directly to the lungs, through a tunnel in the RA (Lateral tunnel Fontan) or a tube on the outside of the heart (Extracardiac Fontan) from the inferior vena cava to the pulmonary artery.



Lateral tunnel Fontan Extracardiac Fontan

Source: Eliot May, L. (1999). *Pediatric heart surgery: A ready reference for professionals*. Milwaukee, WI: Maxishare.

APPENDIX C

Recruitment Information

PROJECT TITLE: Parenting a Child with Hypoplastic Left Heart Syndrome

INVESTIGATOR: Ms. Gwen R. Rempel Doctoral Candidate (780) 492-3032
SUPERVISOR: Dr. Margaret J. Harrison Faculty of Nursing (780) 492-5931
Faculty of Nursing University of Alberta, Edmonton, AB

Thank you for agreeing to contact potential parent participants for my dissertation research. All mothers and fathers whose child with HLHS will have or has had surgery at Stollery Children's Hospital are eligible for study participation. Please include parents who have found out about their baby's HLHS antenatally and are still pregnant and anticipating surgery after the baby is born. As well, please approach parents whose child who had surgery for HLHS has died.

When talking to parents please feel free to refer to the following "script" that highlights the purpose of the study and how parents could be involved.

"Gwen Rempel, a clinical nurse specialist, is doing her PhD in nursing at the University of Alberta. She is interested in what it is like to parent a child with hypoplastic left heart syndrome (HLHS) whose care and treatment includes [or will include] the Norwood surgical approach. She wants to talk to as many parents as possible about life with their child with HLHS. If you join her in her research, she would meet with you twice for an interview in a place you choose. For the first interview, she would like to meet with each parent separately. For the second interview, she will interview you together or separately, depending on your preference. She wants to talk with both mothers and fathers about their experiences, but if only one parent is able to participate that is also fine.

If you are interested in hearing more about Gwen's study you can call her at 492-3032 or I can give her your name and number so she can contact you. You can also contact her by e-mail at grrempel@ualberta.ca."

APPENDIX D

Information Letter

PROJECT TITLE: Parenting a Child with Hypoplastic Left Heart Syndrome

INVESTIGATOR: Ms. Gwen R. Rempel Doctoral Candidate (780) 492-3032
SUPERVISOR: Dr. Margaret J. Harrison Faculty of Nursing (780) 492-5931
Faculty of Nursing University of Alberta, Edmonton, AB

The purpose of this project is to help nurses understand what it is like to parent a child with hypoplastic left heart syndrome (HLHS). Improved survival statistics for children like yours are only one measure of our success. Learning about your day-to-day experience as a parent of a child with HLHS is also important. I want to talk to as many parents as possible whose children with HLHS had surgery.

I will meet with you two or three times. I will tape-record our conversation, which will be 1 to 2 hours long. The first interview is usually the longest. I want to hear what it was like for you when you found out about your baby's heart problem and when your child received care. I keep the tapes and typed-out interviews in a locked file drawer. Doctors and nurses involved in your child's care do not have access to the interview tapes. I remove your name and any identifying information from the typed-out interviews. I will discuss the interviews with my research committee only. The final report may contain your actual words but nothing will identify you. There is opportunity for what you tell me to be used in future studies if you consent to this.

There are probably no direct benefits for you or your child of being in this study. You will have the opportunity to tell your story. I hope that other parents of children with HLHS will benefit from what we learn from you. The only risk to you is being uncomfortable about what you tell me. You can stop the interview, however, at any time. If there is anything that you would like erased from the tape, I will be glad to do that. You are also free at any time to withdraw from the study. I welcome your voluntary participation. I would be happy to give you a report of the findings when I am finished the study. *[Flesch-Kincaid Grade Level 7.0]*

If you have any concerns about any aspect of this study, you may contact the Patient Concerns Office of the Capital Health Authority at 492-9790. This office has no affiliation with study investigators.

APPENDIX E

Consent Form

PROJECT TITLE: Parenting a Child with Hypoplastic Left Heart Syndrome

INVESTIGATOR: Ms. Gwen R. Rempel Doctoral Candidate (780) 492-3032
SUPERVISOR: Dr. Margaret J. Harrison Faculty of Nursing (780) 492-5931
Faculty of Nursing University of Alberta, Edmonton, AB

Do you understand that you have been asked to be in a research study? Yes No

Have you read and received a copy of the attached Information Letter? Yes No

Do you understand the benefits and risks involved in taking part in this research study? Yes No

Have you had an opportunity to ask questions and discuss this study? Yes No

Do you understand that you are free to refuse to participate or withdraw from the study at any time? You do not have to give a reason and it will not affect you or your child's care. Yes No

Has the issue of anonymity and confidentiality been explained to you? Yes No

Do you understand that the interview data you provide for this study may be analyzed in future studies? Yes No

Would you like a report of the research findings sent to when the study is done? Yes No

This study was explained to me by: _____

I agree to take part in this study and for the data I provide to be used in future studies.

_____	_____	_____
Signature of Research Participant	Date	Witness
_____		_____
Printed Name		Printed Name

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

_____	_____
Signature of Investigator or Designee	Date

APPENDIX F

Trigger Questions

Trigger questions were used to initiate and facilitate our conversation about parenting a child with HLHS who underwent the Norwood surgical approach. These trigger questions were intended to elicit the parents' perspective and thus were general in nature rather being specific questions based on the literature review (e.g., questions about fear or parenting stress).

1. Can you start by thinking back to when you first found that that [baby/child's name] might have something wrong with his or her heart? Tell me what that was time like for you.
2. What was it like for you as a parent when you found out that your baby had hypoplastic left heart syndrome?
3. Thinking back to when you first heard about the Norwood procedure, tell me what that was like for you.
4. As you think about the surgery (ies) your child has had, tell me what you have experienced as a parent.
5. How are things now for you?
6. What has been the most challenging thing about parenting your child with hypoplastic left heart syndrome?
7. What has been the most rewarding/satisfying thing about parenting your child with hypoplastic left heart syndrome?
8. Anything else about your experience parenting [baby/child's name] you would like to tell me.

APPENDIX G

Demographic Data

Code No: _____

Information about your child with HLHS: **Interview Date:** _____

Age of child: _____ Child's Birthday: _____

Gender of Child: Female _____ Male _____ Birth Location: _____

Diagnosis of HLHS was made:

- ☐ Antenatally
- ☐ Postnatally?

If child's HLHS diagnosed antenatally:

Date of diagnosis: _____ Weeks Gestation: _____

Antenatal Diagnosis - Cardiac: _____

_____

Other/Associated: _____

Plans for delivery: _____

Were these plans realized? _____

Post-natal diagnosis

Cardiac: _____

_____

Other/Associated: _____

If child's HLHS diagnosed postnatally:

Date of diagnosis: _____ Baby's age: _____

Cardiac: _____

_____

Other/Associated: _____

Information About Child's Treatment for HLHS:

Heart surgeries:

- ☐ Norwood Date: _____ Length of hospitalization: _____
- ☐ Bi-directional Glenn Date: _____ Length of hospitalization: _____
- ☐ Fontan Date: _____ Length of hospitalization: _____

Other surgeries: _____

Hospitalizations at times other than surgery:

Date: _____ Length of hospitalization: _____

Date: _____ Length of hospitalization: _____

Medications that your child has been on when at home: _____

_____

.../2

Information about family members living together in your home:

SIBLINGS	Age	Gender	Health status
	_____	Female __ Male __	_____
	_____	Female __ Male __	_____
	_____	Female __ Male __	_____
OTHERS:			Relationship to child w/ CHD
	_____	Female __ Male __	_____
	_____	Female __ Male __	_____
	_____	Female __ Male __	_____

PARENTS:	Mother	Father
Age	___	___
Ethno-Cultural background	_____	_____
Education:		
University or college graduate	_____	_____
Some university or college	_____	_____
High school graduate	_____	_____
Some high school education	_____	_____
Less than high school education	_____	_____
Employment:		
Working full time	_____	_____
Working part time	_____	_____
Full time student	_____	_____
Full time homemaker	_____	_____
Laid off	_____	_____
Unemployed	_____	_____
Maternity leave)	_____	_____
Other	_____	_____
Occupation:	_____	_____

Yearly Family Income

Less than $25, 000 _____
$26,000 to 35,000 _____
$36,000 to 45,000 _____
$46,000 to 65,000 _____
$66,000 to 85,000 _____
Greater than $85,000 _____

Years parents have been together: _____

Baby's primary caregiver: _____

You and your family live in:

___ BC ___ AB ___ SK ___ MB

.../3

-3-

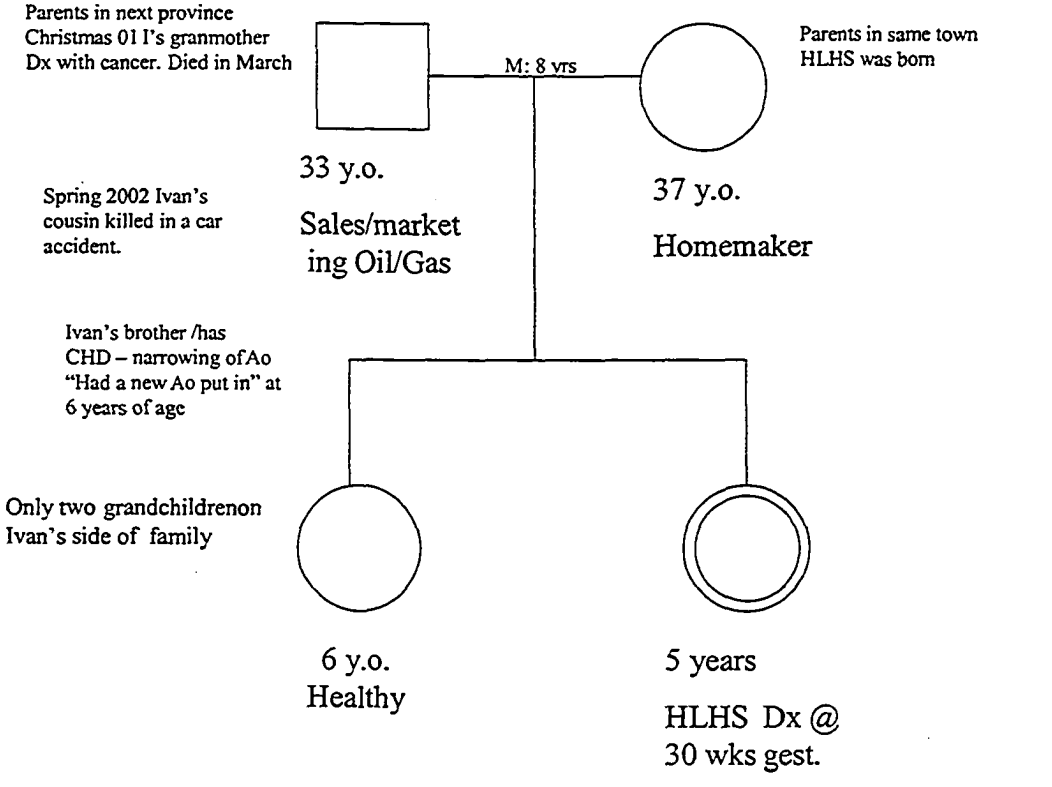
GENOGRAM

ECOMAP

APPENDIX H

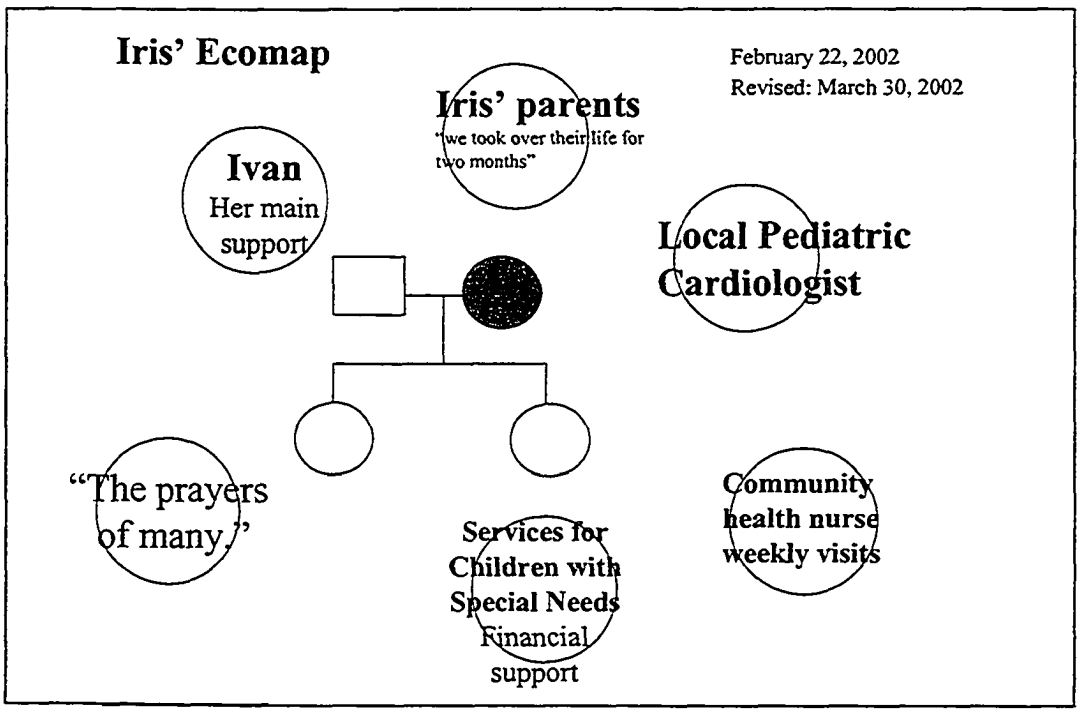
Example of Genogram

Code Name: **Iris and Ivan** May 16, 2002



APPENDIX I

Example of Ecomap and Timeline



Timeline

Antenatal dx at 30 wks locally
BD: **May 29/97** in Edmonton
Day 3 → Norwood in OR 12 hrs
First night cardiac arrest
PICU 2.5 weeks → NICU →
Local Children's Hospital → Home at end of July
Sept /97 Heart cath locally – balloon dislodged in groin vessel – abdominal. Surgery to remove balloon. 1 wk in hosp
Chicken pox
Nov 2/97 Glenn – 1 week
Jan 2000 Heart cath locally – IVC Blocked → Edmonton for venogram
June 00 Fontan cancelled d/t cold
Sept 00 Fontan cancelled by team
Feb 02 Fontan done 2 wks at Stoll
Mar 02 Calgary 3 wks for chylothorax
Middle of April "we got out."