

# Safeguarding Precarious Survival: Parenting Children Who Have Life-Threatening Heart Disease

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## Abstract

The purpose of this study is to describe the process of parenting a child with life-threatening heart disease. Despite advances in pediatric cardiac sciences, hypoplastic left heart syndrome remains difficult and controversial to treat. The Norwood surgical approach is a developing technology, and little is known about how mothers and fathers experience parenting a child who survives this treatment. Constructivist grounded theory informed this Canadian study that involved multiple interactive interviews with 9 mothers and 7 fathers of children with hypoplastic left heart syndrome who were at various stages of treatment. Extraordinary parenting in a context of uncertainty was evident as parents simultaneously safeguarded their child's precarious survival as well as their own survival. As technologically advanced treatment contributes to the survival of children with complex health conditions, health care professionals must consider how to promote and support parenting strategies that benefit the new survivors of technology as well as their families.

## Key words

parenting; grounded theory; congenital heart disease; hypoplastic left heart syndrome; technology

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## **Safeguarding Precarious Survival: Parenting Children Who Have Life-Threatening Heart Disease**

Despite significant advances in pediatric cardiology, hypoplastic left heart syndrome (HLHS), the fourth most commonly occurring congenital heart defect (CHD) with an incidence of 1:6,000 births (Taeusch & Ballard, 1998), continues to represent immense challenges for medical and surgical management (Daebritz et al., 2000). HLHS remains the leading cause of death in babies with CHD during the first month of life (Dhillon & Redington, 2002).

The Norwood surgical approach (NSA) has resulted in new survivors of HLHS (Chang, Chen, & Klitzner, 2002; Gutgesell & Gibson, 2002). One center has reported that from 1996 to 2001, 93% of babies with HLHS survived their newborn surgery, in contrast to only 53% of babies surviving in the period from 1992 to 1996 (Tweddell et al., 2002). The NSA involves the Norwood surgery within the first week of the baby's life followed by two further surgeries, the Glenn operation at 3 to 6 months of age and the Fontan operation at 3 to 5 years. The oldest children who have survived surgically treated HLHS are now in their teens, but uncertainty about long-term mortality and morbidity remains. Some studies have suggested that these children have less-than-optimal neurological outcomes than their playmates and classmates who do not have health problems (Kern, Hinton, Nereo, Hayes, & Gersony, 1998).

Health care and scientific communities alike have applauded the advances in medical technology that are enhancing the longevity and quality of human life (Bergum, 1996). The inherent message in celebratory pronouncements of medical breakthroughs is that technological advances uniformly translate into improved health for all concerned. Although both 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 new survivors and their family members remains largely unquestioned.

There is literature on HLHS that has addressed concerns from a nursing and medical perspective, not from the perspective of parents. Nursing practice authors have described treatment options for babies with HLHS (e.g., Claxon-McKinney, 2001; Soetenga & Mussatto, 2004; Wright, 2002) as well as ethical issues related to the treatment of HLHS (e.g., Pager, 2000; Zeigler, 2003). Published medical research pertains to treatment options and recommendations (e.g., Bove, 1998; Kon, 2005; Reis, Punch, Bove, & van de Ven, 1998), outcomes for babies who are diagnosed antenatally 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, Clancey, Moss, et al., 2000). Most recent publications regarding HLHS have reflected 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). There has been, however, limited research on the experiences of parents whose child with HLHS was treated with the NSA. Information on parenting issues and the strategies that parents used is needed to guide our professional practice with parents of children with HLHS who have survived advancing technologies for the treatment of HLHS (Rempel, 2004).

Ross Keizer (1993) has described mothers' experiences and perceptions of the quality of life of their children with HLHS after the Norwood operation. Ross Keizer interviewed 5 mothers and found that no one regretted choosing "the chance for life" (p. 44) for their child. Her study highlighted the life-threatening aspect of HLHS, exemplified in the quote "The death issue is always there" (p. 67). One of the limitations of Ross Keizer's study is the exclusion of fathers. Fathers in North America are increasingly involved in parenting young children (Gaunt, 2005; McBride

et al., 2005) and may take an active role in caring for their child with HLHS. Another limitation of Ross Keiser's study was her self-described a priori assumption that children with HLHS had poor quality of life: "Most of these children died in the ICU and those that survived lived a life of frailty and suffering" (p. 33). The purpose of her study and the interview questions reflected her view that quality-of-life and decision-making issues were key aspects of parenting children with HLHS. Ross Keiser reported that one mother in her study asked if the purpose of the study was to determine whether physicians should discontinue offering the Norwood operation. A broader perspective on this little researched topic is needed.

The research question guiding the present study, therefore, was For mothers and fathers, what is the process of parenting a child with HLHS whose care and treatment includes the Norwood surgical approach?

## **The study**

### **Aim**

The aim of this study was to describe the parenting experience of mothers and fathers whose child with HLHS underwent treatment that included a series of high-risk surgeries starting with the Norwood surgical procedure soon after birth.

### **Design**

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 from the time of the diagnosis to their present reality and activities with their child (Glaser, 1978, 1992). I used constructivist grounded theory (Charmaz, 1983, 2000) to construct a theory within the context of the relationship of medical technology to survival from life-threatening diseases. A constructivist grounded theory assumes that parents create and maintain meaningful worlds in their effort to make sense of and live within their ever-changing experiences and that the researcher to some degree enters and is affected by the parents' worlds (Charmaz, 2000). The researcher offers an interpretation of the studied worlds, not an exact representation, and accounts for her reflexive role in data construction and theory development.

### **Participants**

The cardiac sciences program of a Canadian tertiary referral center was the setting for this study and provided a population from which 16 parents of 9 children participated. Maximum variation sampling was used to ensure a diverse sample and an in-depth understanding of the phenomenon being studied (Patton, 1990).

There were differences among parents regarding age, income, and geographical location. The average age of the mothers was 34 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 years. More than half of the parents in the sample (4 fathers and 5 mothers) were university or college graduates, and annual family incomes were diverse. One single mother's income was less than Cdn\$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. More than half of the parents (4 fathers and 5 mothers) lived in the Canadian province where their child had heart surgery. The rest of the parents lived in neighboring 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 White; one mother was Métis.

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 child. 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 and the stage of surgical repair at the time of the first interview. The child's diagnosis of HLHS was made antenatally in four families and during the postnatal period for five families. 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.

## **Data collection and analysis**

The main source of data for this study was the verbatim transcriptions of audiotaped unstructured, interactive interviews conducted separately with participating parents. I conducted 30 interviews over a 13-month period (November 2001 to December 2002), 18 face-to-face interviews and 12 telephone interviews.

Data collection and data analysis occurred simultaneously. I employed theoretical sampling until theoretical saturation was reached, at which time no further data were collected. Through theoretical sampling, I sought to add interview data from particular parent experiences, such as those whose babies' HLHS was diagnosed antenatally, to "check and fill out emerging ideas" (Charmaz, 1983, p. 110). Theoretical sampling necessitates multiple interviews with participants (Charmaz, 2003) so that the researcher can gain more insight as to when, how, and to what extent emerging themes are relevant. For example, in second interviews with most parents in this study, I further explored the ways in which they chose to think about certain things and not think about other things. As I shared with parents my interpretation of their stories of "not going there" as an intentional cognitive strategy to ward off worry, I acknowledged my role in data and theory construction and invited their further involvement in our mutual construction.

In analyzing the interview data, I used open and selective coding. Open coding is an inductive process whereby the researcher moves from the data to theory (Charmaz, 1983). Theoretical sensitivity (Glaser, 1978) is crucial to this process and is achieved by continually asking questions of the data. As I coded each sentence in an interview, I asked, "What is this data a study of?" (Glaser, 1978, p. 57), and thus remained open to the data being about something other than parenting a child with life-threatening heart disease. I created code categories as similarities in the data emerged. As the analysis proceeded to a more abstract level, I generated code categories related to other codes. By constantly asking questions of fit, I enabled code categories to "earn" their way into the theory (p. 57). A further question was "What is actually happening in the data?" (p. 57). Through this question, 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 focused for the core concept (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).

## **Considering the quality of this research**

Rigorous grounded theory research yields substantive 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, I considered four trustworthiness

criteria: fit, work, relevance, and modifiability (Glaser, 1978, 1992; Charmaz, 2000) throughout the theory generation process. My emerging grounded theory about parenting children with life-threatening heart disease had to fit with the data from which they emerged. It had to work, in that it facilitated understanding and interpretation of what it is to parent a child with HLHS. In addition, the theory had to have relevance for parents and researchers beyond this study. Finally, for my theory to be used in clinical practice and to have value for further research and theory development, it has to be readily modifiable (Glaser, 1978, 1992; Charmaz, 2000). Evaluation of the latter two criteria is ongoing.

## **Ethical considerations**

The health research ethics board members of the local university and urban 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. Before conducting the interviews with parents, I obtained informed consent from each of them. Identifying information was removed from each interview transcript for the sake of anonymity.

## **Findings**

The mothers and fathers in this study exemplified extraordinary parenting. Their children with HLHS were survivors of advancing surgical technology and a learning experience for many health care professionals, who therefore were not in a position to provide parents with direction for care. In the absence of established guidelines for children with HLHS who were undergoing the NSA, parents devised their own methods of performing advanced nursing and medical assessments, judgments and skills in tandem with an all-consuming care regime that soon became a way of life. Parents learned by trial and error. One mother 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 pump feeds and this and that and we figured out how to run the pump in the car while we're driving ... and when we couldn't figure it out, we'd find someone who could and just phone ... and go on the Internet.

Extraordinary parenting within the context of certainty and uncertainty over the course of multiple surgeries occurred through a process of simultaneously safeguarding the survival of the child, of self (i.e., the parent) and of the couple relationship.

Although parents felt certain that the NSA 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. Through their conversations with health care professionals and their own personal research, parents learned of the improved survival rates for children undergoing the NSA. Parents also learned that not all children survived the Norwood operation or subsequent surgeries. In choosing the NSA for their child, parents realized that they were 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 [their son] a chance."

Parents willingly chose a potentially life-threatening option for their child because there was a chance for survival and they were overwhelmed with delight in their child's survival as expressed in this mother's statement:

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

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

We don't know how long we will have her with us.

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

One father expressed his uncertainty about his child's survival as he anticipated her upcoming Fontan operation:

I don't know what would happen if she died now. I don't know. I don't want to think about it or...

[Pause] I can't think about it.

Extraordinary parenting included the need to simultaneously safeguard their child, themselves and their couple relationship. Parents were keenly aware of the uncertain outcomes faced by their child. As they cared for their child, they also had to keep their own worries under control and nurture their spousal relationship. Their relationship as a couple had the potential to fortify or weaken their safeguarding efforts (See [Figures 1 and 2](#)).

### **Safeguarding their child's precarious survival**

Regardless of the context of uncertainty, parents were eager to care for their babies and children at home and to meet the parenting challenges of ensuring weight gain and shielding their child from infection. To safeguard their child's precarious survival, parents used the strategies of taking charge, struggling for balance, and involving others.

#### ***Taking charge: "I just have to do what I have to do"***

Parents safeguarded the precarious survival of their child first by taking charge of "going home" after the initial surgery. Most of the babies experienced prolonged hospitalization due to complications. Once the parents were convinced that it was a matter of when their baby was coming home, not if their baby was coming home, they made every effort to learn how to monitor, feed, medicate, and care for their child. All babies went home on tube feeding and parents had to demonstrate their ability to feed their child by nasogastric (NG) or gastric tube before discharge. Most of the fathers as well as all of the mothers learned how to do this. Even with a health care background, one father described the pressure he felt to demonstrate his NG insertion ability before his child went home.

We hadn't had the lessons for the nasogastric stuff but I was trying to convince the cardiologist:...

"I know the pathways. I know the anatomy. ...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."

At home, the inadvertent removal of the gastric tube meant a prolonged visit to the emergency department. To avoid this, 2 of the fathers took charge and replaced the tube themselves. One father explained the procedure as follows:

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.

At home, parents also took charge of their baby's feeding patterns. Jointly, the mothers and fathers in this study made decisions about changing amount, strength, and timing of feeds to ensure that their baby gained weight. "She wasn't eating enough to stay alive" was one father's recollection. In retrospect, one mother wished that

there had been a “handbook for parents” to guide her in the feeding challenges she encountered with her son. She noted the lack of appropriate and readily available information from health professionals that addressed the unique needs of babies with heart-related feeding problems.

The [community] 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 was great when we saw her but then you come home and you’re kinda left to your own devices.

As well as taking charge of their child’s feeding, parents took charge in their home environment to keep their children as healthy as possible. They took care to protect their baby from infection. Fathers were especially vigilant about making sure that everyone, including all visitors, washed their hands. Parents limited visitors to the home to prevent postponement of their child’s surgery due to illness. The family experienced periods of isolation. One mother described the “bubbled life” when she kept her older preschool child home from school prior to her younger daughter’s surgery to avoid contact with communicable disease, including colds and influenza. Any postponement of surgery put their child with HLHS at more risk for survival because plans for surgery often were initiated when the oxygen saturation levels of their child’s blood had deteriorated. The wait for surgery was excruciating without delays; postponements were avoided at all costs. One father described it as follows:

[My wife and daughter with HLHS] were in quarantine from November till February. We had to take her out of school. She couldn’t go to swim lessons. She couldn’t play with her friends. That was awful. 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?” I mean that’s not fair but we wanted to get surgery out of the way.

### ***Struggling for balance: “Are we being overly paranoid?”***

Although parents unquestioningly extended themselves to safeguard of their child’s precarious survival, struggling for balance was a constant concern. Were they doing enough? Were they going “overboard”? What was necessary and what was excessive? One mother 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.

Another mother asked herself, “How much do we protect her and how much do we just let her live life?”

Parents lacked direction from others as how to parent their child with a life-threatening condition. One father expressed his struggle to balance his treatment of his daughter with HLHS with how he treated his other children.

Do 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. ... 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. It was a long time. The [other] kids were, you know, walking by 10 months sort of thing.

One mother 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 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 rely on that or if I really do have to force-feed her.

Related to struggling for balance was the parenting strategy of involving others.

***Involving others: "We're extremely lucky to have great family"***

Parents had to involve others, as they could not single-handedly provide care for their child with HLHS. Parents relied primarily on each other in the care of their child with HLHS and secondarily on other family members, mostly their child's grandparents. There was an absence of day-to-day involvement of friends in the care of the child and parents managed the daily care of their children with minimal involvement from professionals.

The fathers and mothers relied on each other in caring for their baby with HLHS. "We're a team" was one father's comment. One couple 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. The father described one particularly difficult evening.

She was struggling when I was trying to put 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 a couple days and I was really mad at myself because it was her bedtime. ... I finally just injected it [the medication] ... she wailed ... I was really mad at myself.

Specialized care for a child with a life-threatening heart condition was a family affair, with considerable help coming from grandparents. 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 and they were essential for the family to function.

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. As one mother put it,

There were 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 then you have to depend on family and I was lucky that we did have family.

The parents in this study could not imagine how other parents could survive without family support. The parents of two mothers in this study moved from the next province to provide more help. Another mother said this about her parents who lived in another province: "If push comes to shove and things are getting crazy, they will come out." Mothers described the numerous trips they made to see their parents. One couple arranged to have their third baby in another province where the maternal grandparents lived so that they could take care of their grandchild with HLHS while their daughter was having her baby. Another couple who had the active involvement of both sets of their parents described all the support they had and yet that they only barely "made it." In the father's words,

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.

## **Safeguarding survival of self and couple**

In addition to safeguarding their child's precarious survival, parents safeguarded their own survival as well as their survival as a couple through a number of strategies that warded off worry and relational strain. Although the physical care demands decreased over the first year of the baby's life, the emotional demands of parenting persisted and parents described three ways in which they safeguarded themselves against worry as they parented their child with HLHS. They directed their minds to avoid certain thoughts, they used normalization and they used trust.

### ***Directing their minds: "Don't go there."***

One way that parents managed their worries was to direct their minds to not think about certain topics or to think less often about them. Parents described this strategy as an action over which they had control. One mother recounted an experience of being called back to the hospital because her daughter suddenly had become critically ill. She wondered if she and her husband would ever understand how close to death their daughter had been that night. She then said that she did not "let her mind go there" and she "blocked a lot of that out of her mind." When parents successfully managed to "not go there" they described their worry about their child's survival as being in the "back of my mind" or on the "back burner" rather than being "front and centre."

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

Parents, as much as was possible directed their minds to think of their children as normal to alleviate their worries about their child's present and future health. 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, both mothers and fathers would conclude that their child was nevertheless "normal." One father articulated the effort to view his son as normal and to thus lessen his worry.

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 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.

One of the mothers in the study also was motivated to parent her daughter with HLHS as she would other children 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." Seeing her child's desire to be "normal" helped this mother to worry less about the fact that her daughter could "get sick at any point."

One father described how worried he was about bringing his baby home after the Norwood operation, especially regarding her need for tube feeding and careful handling because of her chest incision. He quickly normalized these unusual parenting considerations with the comment: "That was relatively minor compared to some stuff we could have been going through." As he recounted his daughter's sleeping difficulties and her eating challenges, he also concluded,

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

Although viewing their child's life as normal helped parents to ward off worry about their child, 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. One father aptly expressed his desire for his son to have as normal a life as possible focusing on the things he hoped his child would be able to do rather than worrying about his child not being able to participate in contact sports.

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 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. ... Our 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.

### ***Trusting: "It's out of my hands"***

A third way in which parents lessened their worry was to concede that some things 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 future technological advancements. One father interchanged "God" and "the doctors" in the same sentence as he articulated his use of trust as he anticipated the birth of his baby with HLHS.

It was difficult. ... Every day you're thinking about it and it's not gonna go away. ... We couldn't do much about it. We'll just let God, put it in His hands and let the good doctors take care of it. That's about all we can do.

Parents chose to believe that technological advancements would keep stride with their child's need for complex care and expressed gratitude for the technological advancements available. One mother imagined that more technology beyond heart surgery or transplantation would be available in the future: "Who knows what other technology will be available in twenty years." Her husband expressed his trust in technology in this way:

This Fontan hopefully keeps her going till her 20s and then hopefully we've got some other option, maybe even something other than a heart transplant. Like a ventricular replacement or something like that, since we expect it'll be the ventricle that's going to be the first problem. I kind of base my hopes on that.

The mothers and fathers in this study also described ways that they safeguarded their couple relationship. Despite both physical and emotional parenting demands, the mothers and fathers reported minimal relational strain or conflict within their couple relationship. They effectively used strategies of buffering severity and staying on the same page.

### ***Buffering severity: "I mostly only told her the good things"***

The parents who had more knowledge about the severity of HLHS chose to buffer their partners from information that might fuel their uncertainty rather than emphasizing the difference in their knowledge that could lead to strain in the relationship. 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 the Internet or had a medical background. Around the time of diagnosis, 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, one participant shared with his wife 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 centers. He did not, however, tell her about a Web site by parents whose children died following the Norwood operation.

[Mother of child with HLHS] 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.

This mother recognized the selective nature of the information she received from her husband. 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."

One couple buffered each other from the knowledge of the severity of their child's HLHS at different times. The mother had a health care background and described not disclosing to her husband her immediate uncertainty concerning their infant's survival based on her past education. She worried about possible complications based on her professional knowledge and experience but protected her husband from these concerns by not sharing them with him. Her husband became the primary researcher while his son was recovering in hospital after the Norwood operation, doing his research in the hospital library. It was then his turn to be selective about the information that he shared with his wife. Like other fathers in the study, this father did not inform his wife about the Web site that discouraged parents from choosing the NSA.

Buffering severity involved parents' withholding information about possible complications to support their partner's belief that they had made the right decision regarding their child's treatment. This supportive strategy helped to decrease their worry about the infant's survival and positively influenced the couple relationship.

### ***Staying on the same page: "Who's going to do what and when?"***

The extensive care required by the babies of the parents in this study placed demands on the involvement of both parents and coordination of their efforts to "stay on the same page." Although the mothers were the primary caregivers for their babies with HLHS, most of the fathers in this study played a key role in the day-to-day care of their babies. Several of the fathers took extended leave from work, and even when they were at work, they kept in touch with what was happening at home. One father 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. Some of the wives encouraged their husbands not to phone home from work to give the father a break from caregiving.

The beneficial involvement of both parents required extensive communication and negotiation between husband and wife. One father described his most difficult parenting challenge as giving and receiving support from his spouse.

Finding ways to support each other as spouses. You parent the child ... that's not the challenging part. It's who's going to do what and when kind of thing. There's always something needs to be done. He gets meds at different times of the day; feeding that gastrostomy button at different times of the day.

Another father described how important it was for him and his wife to set time aside for them as a couple to sort out their demanding parenting roles and to make sure that they were protecting time for themselves as a couple.

Another father 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 and most of the couples in this study were successful in safeguarding their relationship. They reported minimal strain or conflict in their relationship, another characteristic of their extraordinary parenting.

When a couple was not on the same page, relational strain added to the challenges of parenting a child with life-threatening heart disease. One couple in this study described times of disagreement regarding how much to express to each other regarding their fears for their child’s life. The mom described one such incident as she and her husband waited for their child to return from a lengthy procedure:

We were sitting in that room ...just waiting ... and I’m like, “Who would be the one to come and talk to us [if our child died during the procedure] and he looked over at me. He goes, “Don’t even think like that. You’re gonna drive yourself insane” ... He had this look on his face like he was really shocked that I would say something like that but he knows I have come right out and asked ... [the surgeon] “Is my child going to die?” I have to know. That’s just how I am. He [husband] gets angry. He’s like, “Don’t even ask that question” and I’m like “I have to ask that question.”

When one articulated what the other one considered to be unspeakable there was tension between them and expressions of disbelief that the other could even think such thoughts, much less express them. Examples of parents not being on the same page were rare in the data. Rather parents affirmed the support they received from each other. One mother described her husband as her main support. Another mother said about her husband, “He asks such good question,” in reference to their meetings with health care professionals. One father described his wife as “a rock ... she seems to hold together pretty good.”

## Discussion

Mothers and fathers in this study demonstrated extraordinary parenting through a multifaceted process of safeguarding precarious survival as they pursued technologically advanced surgical treatment for their baby’s lethal heart defect. Extraordinary parenting was characterized by unusual parenting activities that occurred in a taken-for-granted context of technology and family involvement.

In constructivist grounded theory, the researcher pays attention to what is said by the participants but also pays attention to what is not said (Charmaz, 2004). 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. Similarly, parents acknowledged with much gratitude the involvement of their parents in the care of their children with HLHS, but were not as awestruck as I was, for example, about the extent to which grandparents were involved. The extent of father involvement was also striking although not described as out of the ordinary by the parents.

A constructivist approach involves the researcher’s recognizing that the categories, concepts, and theoretical depth of an analysis emerge from the researcher’s interactions with the participants and questions about the data (Charmaz, 2000; 2004). My understanding about parenting has been shaped by my clinical experience as an advanced practice nurse in pediatric cardiology. This background sensitized me to the unique tasks mothers, fathers, and grandparents in this study performed on behalf of their child and grandchild and thus contributed to my role in data construction and interpretation of their parenting as extraordinary.

## **Extraordinary Parenting**

What constituted unusual or extraordinary parenting in this research with parents of children with HLHS was the extensive assessment and problem-solving knowledge that parents applied as they took charge of complex nursing skills, such as tube feeding, medication administration, oxygen therapy, and wound care. Their parenting activities were extraordinary, as were their unquestioning attitudes as they took on all-consuming nursing care to safeguard their child's survival.

Extraordinary parenting as described in this study shares some common attributes with Ray's (2002) "parenting plus" in a study of parents of children with chronic health conditions. Parenting plus, a component of special needs parenting, 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. Even though the children in the two studies varied in age, health condition, and degree of delay and/or disability, parents of children with HLHS and parents of children with developmental delays and disabilities both described the extra effort they put into parenting in a context of uncertain outcomes. The extra effort, however, in parenting plus as described by Ray, was directed toward the development of the child's relationships with others, such as playmates and school peers. In contrast, extraordinary parenting in the present study related to the unique efforts that parents directed toward their child's survival as they ensured their child's weight gain and shielded them from infection.

Another commonality between this study and Ray's (2002) research is the recognition of the importance of safeguarding self and the couple relationship, particularly in Ray's depiction of minimizing consequences by keeping yourself [parent] going and maintaining relationships. The self-care strategy of staying healthy in Ray's study, however, was rarely mentioned in the present study. The older age of children in Ray's study (i.e., 15 months to 16 years in comparison to 2 months to 5 years for the children with HLHS) might partially explain this difference in parental orientation. The parents in Ray's study were further along in their parenting experience and thus more aware of the potentially negative health effects of extraordinary parenting.

Parents in the present study and in Ray's study also used similar cognitive strategies to safeguard themselves or keep themselves going, that is, normalization of their child's behavior and growth as well as constructing explanations for their child's differences. Parents in both studies focused on their child's progress even when progress was minimal and delayed in meeting developmental milestones. The result of normalization differed in the two studies. Ray attributes the parent success in receiving help to their positive perspective on their child's progress, while the consequence for parents of children with HLHS was decreased worry about their child.

### **Extraordinary Parenting: A Family Affair**

The research to date about parenting children with CHD and other congenital anomalies has predominantly focused on the caregiving 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.

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, Deatrck, Gruppuso, Tamborlane, & Grey, 2003). Sullivan-Bolyai and her colleagues reported a parenting process of "constant vigilance" in their research with mothers of young children with type 1 diabetes, but their

research revealed limited involvement of 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.

A possible explanation for the potential similarity between the level of father involvement in O'Brien's (2001) 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 provided directly influenced their child's survival. Fathers might be motivated to provide care as they see this as essential for the child's survival.

Another possible explanation of the difference in father involvement between this and other studies might be that this study focused on parenting, and efforts were made to include both fathers and mothers 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). In addition, father and mother data are not always analyzed separately for comparisons (O'Brien, 2001). Exclusion of fathers from studies and the grouping together of father and mother data might obscure the parenting role of fathers.

Extensive involvement of grandparents in the complex care of children with HLHS was evident in this study and differed from other studies. Lack of grandparent involvement in the studies of very young children with diabetes (Sullivan-Bolyai et al., 2003) or technology-dependent children (O'Brien, 2001) was attributed to the grandparents' anxiety in providing care. It is unclear why grandparents were more involved in the care of children with HLHS, as the demand for skilled care and decision making seems to be potentially as anxiety provoking. O'Brien's study included an older sample of children (ranged from 2 to 12 years). Possibly the grandparents in that study 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 might be related to the life-and-death nature of HLHS at birth. This hypothesis is supported by findings from a study of grandparents 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 "family first" value motivated the grandparents in Hall's study to immediately assist their adult children whose babies were in a health crisis. Perhaps the suddenness of an intensive care hospitalization of the infant mobilized grandparents in the present study and Hall's study. The grandparents might have felt that they had no choice or no time to consider their involvement.

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 toward their

child's care experienced their child's illness as a source of conflict. Knafelz 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 affecting the family negatively.

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, which 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 tertiary hospital setting. This shared experience might have contributed to mutual understandings and decreased the possibility of relational strain or conflict.

## **Implications**

Despite the extraordinary parenting evident in this study, health care professionals must recognize the distinctive status of parents of children who are survivors of new technology and provide support and intervention related to their parenting efforts to safeguard their child's survival and their own individual and couple survival. Health professionals have the opportunity to work collaboratively with these pioneering parents and must ensure that the resources provided to support mothers and fathers match the exceptional technological resources that the child has received. Comprehensive needs assessment, ongoing support, and counseling from a consistent, program-based social worker or advanced practice nurse in a clinical nurse specialist role, for example, are key resources for parents and grandparents, starting at the time of their child's diagnosis of HLHS. Not only can clinical nurse specialists directly intervene with parents through education, support, advocacy, and coordination of care, they play a key role in program development and development of clinical guidelines (Canam, 2005), of vital importance when advancing technology is resulting in new survivors. Those mothers who do not have support from their child's father or grandparents might 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.

Clear guidelines for home surveillance of infants with HLHS who have undergone the NSA have been shown to decrease mortality between the Norwood and Glenn operations (Ghanayem et al., 2003). Professional support must be available for these parents who are responsible for strict measures of daily weights and oxygen saturation monitoring to support their knowledge base and decision making capacity. In-home respite nursing care is another community resource that could assist parents, especially when they are providing continuous care and monitoring for their child with HLHS.

## **Future Research**

There are several areas for future research. Research to elicit the perspectives of parents whose children did not survive the NSA or who elected compassionate care on behalf of their children with HLHS, as well as non-English-speaking parents, would address some of the limitations of this current study. Research with parents and grandparents of children with HLHS who are now undergoing the Sano surgical approach or children with other life-threatening conditions other than HLHS who are survivors of new technology would enrich our conceptualizations of parenting in uncertain contexts. Replication of this study with the parents of children with congenital diaphragmatic hernia at different stages of their diagnosis and treatment (Stege, Fenton, & Jaffray,

2003; Aite et al., 2004), for example, would provide valuable comparisons to further our understanding of parenting children who receive technologically advanced life-saving intervention.

## Conclusion

The parents in this study demonstrated extraordinary parenting as they safeguarded the precarious survival of their children with HLHS and themselves as care-providing parents. Many cardiac specialists have claimed 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). 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.

## References

- Aite, L., Trucchi, A., Nahom, A., Casaccia, G., Zaccara, A., Giorlandino, C., et al. (2004). Antenatal diagnosis of diaphragmatic hernia: Parents' emotional and cognitive reactions. *Journal of Pediatric Surgery, 39*(2), 174-178.
- Bergum, V. (1996). *The house that technology built*. Unpublished manuscript, University of Alberta, Edmonton, Canada.
- Bove, E. L. (1998). Current status of staged reconstruction for hypoplastic left heart syndrome. *Pediatric Cardiology, 19*(4), 308-315.
- Canam, C. (2005). Illuminating the clinical nurse specialist role of advanced practice nursing: A qualitative study. *Nursing Leadership, 18*(4), 70-89.
- Chang, R. R., Chen, A. Y., & Klitzner, T. S. (2002). Clinical management of infants with HLHS in the United States, 1988-1997. *Pediatrics, 110*(2), 292-298.
- Charmaz, K. (1983). The grounded theory method: An explication and interpretation. In R. M. Emerson (Ed.), *Contemporary field research: A collection of readings* (pp. 109-126). Prospect Heights, IL: Waveland.
- Charmaz, K. (2000). Grounded theory: Objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 509-535). Thousand Oaks, CA: Sage.
- Charmaz, K. (2003). Qualitative interviewing and grounded theory. In J. A. Hostein & J. F. Gubrium (Eds.), *Inside interviewing: New lenses, new concerns* (pp. 311-330). Thousand Oaks, CA: Sage.
- Charmaz, K. (2004). Premises, principles, and practices in qualitative research: Revisiting the foundations. *Qualitative Health Research, 14*(7), 976-993.
- Choi, S. H. (2001). The role of fetal surgery in life threatening anomalies. *Yonsei Medical Journal, 42*(6), 681-685.
- Claxon-McKinney, B. (2001). Hypoplastic left heart syndrome. *Pediatric Nursing, 27*(3), 245-252.
- Daebritz, S. H., Nollert, G. D., Zurakowski, D., Khalil, P. N., Lang, P., del Nido, P. J., et al. (2000). Results of Norwood stage I operation: Comparison of hypoplastic left heart syndrome with other malformations. *Journal of Thoracic & Cardiovascular Surgery, 119*(2), 358-367.

- Dhillon, R., & Redington, A. N. (2002). Hypoplastic left heart syndrome. In R. H. Anderson, E. J. Baker, F. J. Macartney, M. L. Rigby, E. A. Shinebourne, & M. J. Tynan (Eds.), *Paediatric cardiology* (pp. 1191-1211). Toronto, Canada: Churchill Livingstone.
- Gaunt, R. (2005). The role of value priorities in paternal and maternal involvement in child care. *Journal of Marriage and Family, 67*(3), 643-655.
- Gaynor, J. W., Mahle, W. T., Cohen, M. I., Ittenbach, R. F., DeCampi, W. M., Steven J. M., Nicolson, S. C., & Spray, T. L. (2002). Risk factors for mortality after the Norwood procedure. *European Journal of Cardio-Thoracic Surgery, 22*(1), 82-89.
- Ghanayem, N. S., Hoffman, G. M., Mussatto, K. A., Cava, J. R., Frommelt, P. C., Rudd, N. A., et al. (2003). Home surveillance program prevents interstage mortality after the Norwood procedure. *Journal of Thoracic and Cardiovascular Surgery, 126*(5), 1367-1377.
- Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociological Press.
- Glaser, B. G. (1992). *Basics of grounded theory analysis: Emergence vs. forcing*. Mill Valley, CA: Sociology Press.
- Gutgesell, H. P., & Gibson, J. (2002). Management of hypoplastic left heart syndrome in the 1990s. *American Journal of Cardiology, 89*(7), 842-846.
- Goldberg, C. S., Schwartz, E. M., Brunberg, J. A., Mosca, R. S., Bove, E. L., Schork, M. A., et al. (2000). Neurodevelopmental outcome of patients after the Fontan operation: A comparison between children with hypoplastic left heart syndrome and other functional single ventricle lesions. *Journal of Pediatrics, 137*(5), 646-652.
- Hall, E. O. (2004a). A double concern: Grandmothers' experiences when a small grandchild is critically ill. *Journal of Pediatric Nursing, 19*(1), 61-69.
- Hall, E. O. (2004b). A double concern: Danish grandfathers' experiences when a small grandchild is critically ill. *Intensive & Critical Care Nursing, 20*(1), 14-21.
- Ikle, L., Hale, K., Fashaw, L., Boucek, M., & Rosenberg, A. A. (2003). Developmental outcome of patients with hypoplastic left heart syndrome treated with heart transplantation. *Journal of Pediatrics, 142*(1), 20-25.
- Johnston, J. K., Chinnock, R. E., Zuppan, C. W., Razzouk, A. J., Gundry, S. R., & Bailey, L. L. (1997). Limitations to survival for infants with hypoplastic left heart syndrome before and after transplant: the Loma Linda experience. *Journal of Transplant Coordination, 7*(4), 180-186.
- Kern, J. H., Hinton, V. J., Nereo, N. E., Hayes, C. J., & Gersony, W. M. (1998). Early developmental outcome after the Norwood procedure for hypoplastic left heart syndrome. *Pediatrics, 102*(5), 1148-1152.
- Kern, J. H., Hayes, C. J., Michler, R. E., Gersony, W. M., & Quaegebeur, J. M. (1997). Survival and risk factor analysis for the Norwood procedure for hypoplastic left heart syndrome. *American Journal of Cardiology, 80*(2), 170-174.

- Knafelz, K. A., & Deatrick, J. A. (2002). The challenge of normalization for families of children with chronic conditions. *Pediatric Nursing, 28*(1), 49-53.
- Kon, A. A. (2005). Discussing nonsurgical care with parents of newborns with hypoplastic left heart syndrome. *Newborn and Infant Nursing Reviews, 5*(2), 60-68.
- Mahle, W. T., Clancy, R. R., McGaurn, S. P., Goin, J. E., & Clark, B. J. (2001). Impact of prenatal diagnosis on survival and early neurologic morbidity in neonates with the hypoplastic heart syndrome. *Pediatrics, 107*(6), 1277-1282.
- Mahle, W. T., Clancy, R. R., Moss, E. M., Gerdes, M., Jobes, D. R., & Wernosvsky, G. (2000). Neurodevelopmental outcome and lifestyle assessment in school-aged and adolescent children with hypoplastic left heart syndrome. *Pediatrics, 105*(5), 1089-1089.
- McBride, B. A., Brown, G. L., Bost, K. K., Shin, N., Vaughn, B., & Korth, B. (2005). Paternal identity, maternal gatekeeping, and father involvement. *Family Relations, 54*(3), 360-372.
- Munn, M. B., Brumfield, C. G., Lau, Y., & Colvin, E. V. (1999). Prenatally diagnosed hypoplastic left heart syndrome: Outcomes after postnatal surgery. *Journal of Maternal-Fetal Medicine, 8*(4), 147-50.
- O'Brien, M. E. (2001). Living in a house of cards: Family experiences with long-term childhood technology dependence. *Journal of Pediatric Nursing, 16*(1), 13-22.
- Pager, C. K. (2000). Dying of a broken heart: Ethics and law in a case of hypoplastic left heart syndrome. *Journal of Perinatology, 20*, 535-539.
- Park, H. K., & Park, Y. H. (2001). Fetal surgery for congenital heart disease. *Yonsei Medical Journal, 42*(6), 686-694.
- Patton, M. Q. (1990). *Qualitative evaluation and research methods*. London: Sage.
- Ray, L. D. (2002). Parenting and childhood chronicity: Making visible the invisible work. *Journal of Pediatric Nursing, 17*(6), 424-438.
- Reis, P. M., Punch, M. R., Bove, E. L., & van de Ven, C. J. (1998). Obstetric management of 219 infants with hypoplastic left heart syndrome. *American Journal of Obstetrics & Gynecology, 179*(5), 1150-1154.
- Rempel, G. R. (2004). Technological advances in pediatrics: Challenges for parents and nurses. *Journal of Pediatric Nursing, 19*(1), 13-24.
- Ross Keizer, J. (1993). *Parent perceptions of quality of life of children with HLHS who have undergone the Norwood surgical procedure*. Unpublished master's thesis, McMaster University, London, Ontario, Canada.
- Sano, S., Ishino, K., Kado, H., Shiokawa, Y., Sakamoto, K., Yokota, M., et al. (2004). Outcome of right ventricle-to-pulmonary artery shunt in first-stage palliation of hypoplastic left heart syndrome: A multi-institutional study. *Annals of Thoracic Surgery, 78*(6), 1951-1958.
- Soetenga, D., & Mussatto, K. A. (2004). Management of infants with hypoplastic left heart syndrome: Integrating research into nursing practice. *Critical Care Nurse, 24*(6), 46-48, 50, 52.

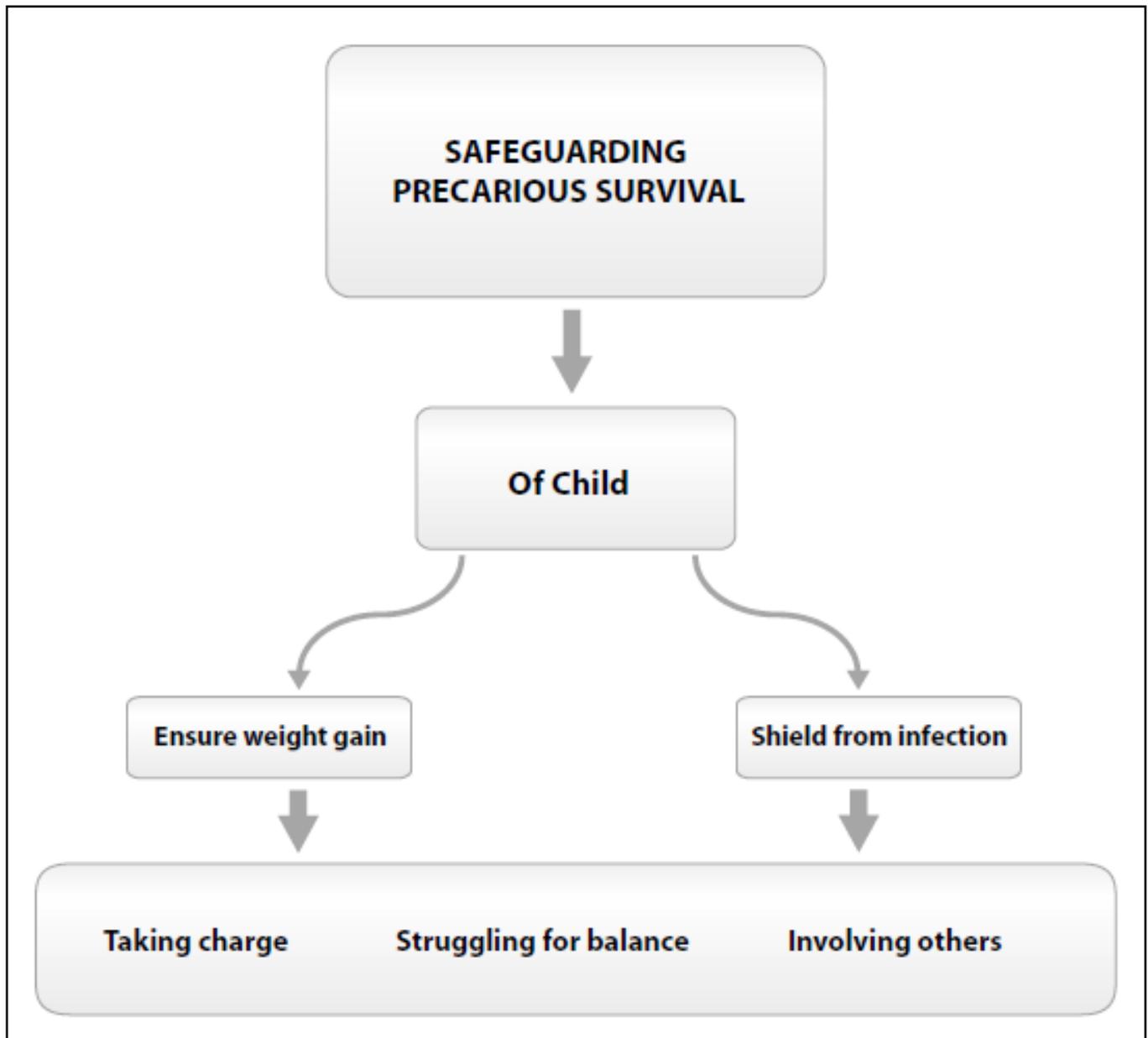
- Stege, G., Fenton, A., & Jaffray, B. (2003). Nihilism in the 1990s: The true mortality of congenital diaphragmatic hernia. *Pediatrics*, *112*(3 Pt 1), 532-535.
- Sullivan-Bolyai, S., Deatrck, J., Gruppuso, P., Tamborlane, W., & Grey, M. (2003). Constant vigilance: Mothers' work parenting young children with type 1 diabetes. *Journal of Pediatric Nursing*, *18*(1), 21-29.
- Taeusch, H., & Ballard, R. (1998). *Avery's diseases of the newborn*. Sydney, Australia: Saunders.
- Tomlinson, P. S., Kirschbaum, M., Harbaugh, B., & Anderson, K. H. (1996). The influence of illness severity and family resources on maternal uncertainty during critical pediatric hospitalization. *American Journal of Critical Care*, *5*(2), 140-146.
- Tomlinson, P. S., & Mitchell, K. E. (1992). On the nature of social support for families of critically ill children. *Journal of Pediatric Nursing*, *7*(6), 386-394.
- Tweddell, J. S., Hoffman, G. M., Mussatto, K. A., Fedderly, R. T., Berger, S., Jaquiss, R., et al. (2002). Improved survival of patients undergoing palliation of HLHS: Lessons learned from 115 consecutive patients. *Circulation*, *106*(Suppl. 1), I82-I89.
- Tworetzky, W., McElhinney, D. B., Reddy, V. M., Brook, M. M., Hanley, R., & Silverman, N. H. (2001). Improved surgical outcome after fetal diagnosis of hypoplastic heart syndrome. *Circulation*, *103*(9), 1269-1273.
- Wright, C. (2002). Cardiac surgery 2002: Staged repair of hypoplastic left heart syndrome. *Critical Care Nursing Quarterly*, *25*(3), 72-78.
- Zeigler, V. L. (2003). Ethical principles and parental choice: Treatment options for neonates with hypoplastic left heart syndrome. *Pediatric Nursing*, *29*(1), 65-69.

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**Figure 1**



**Figure 2**

