Published in final edited form as:

Qual Health Res. 2012 December ; 22(12): 1694–1706. doi:10.1177/1049732312458371.

Preparing Heart and Mind Following Prenatal Diagnosis of Complex Congenital Heart Defect

Anne Chevalier McKechnie¹ and Karen Pridham¹

¹University of Wisconsin–Madison, Madison, Wisconsin, USA

Abstract

Drawing on attachment and caregiving theory and the concept of motivation, the purpose of this descriptive study was to examine parents' retrospective accounts of their prenatal experiences after receiving the diagnosis of a fetal heart defect. These parents constituted a subgroup of participants in a larger longitudinal study of parenting an infant with a complex congenital heart defect. Data were derived from 14 semistructured interviews with 13 mothers and 3 fathers in the home or hospital setting. A directed content analysis yielded a central category of preparing heart and mind for infant caregiving. Preparing heart and mind is a preliminary caregiving goal within the caregiving system that generates intentions and expectations indicative of specific caregiving motivations to relate to the baby, handle circumstances practically, and manage infant medical care. A theoretical model illustrates the prenatal process these parents engaged in to provide care to their infants with life-threatening medical conditions.

Keywords

families; caregiving; hope; infants; high-risk; motivation; parenting; pregnancy

A complex congenital heart defect (CCHD) is defined as a structural abnormality of the heart or its major blood vessels requiring corrective or palliative surgery within the first year of life. Infants are born with a CCHD in approximately 2.3 per 1,000 births (Lloyd-Jones et al., 2009). Technological and surgical advancements in the past decade have resulted in more infants prenatally diagnosed and surviving with a CCHD. Consequently, increasing numbers of parents are providing care for these infants at home at an early age (Ghanayem et al., 2003; Rosamond et al., 2008; Tweddell et al., 2002).

The quality of caregiving by parents is an important factor for study and intervention, and as reported in a recent study, caregiving motivations differ within and among parents across the infant's first year (Pridham et al., 2010). In the context of expecting an infant with significant caregiving needs, the preparations related to becoming a parent and the caregiving motivations that form before birth could have significant implications for parent psychological and infant psychophysiological outcomes. Knowledge of expectant parent preparation and motivations for caregiving give health care professionals (HCPs) a starting point for assessment and intervention.

Corresponding Author: Anne McKechnie, University of Wisconsin–Madison School of Nursing, 600 Highland Ave., Madison, WI 53792-2455, USA, amckechnie@wisc.edu.

Portions of this article were presented at the *33rd Midwest Nursing Research Society Annual Conference*, March 27, 2009, in Minneapolis, Minnesota, and the *36th Midwest Nursing Research Society Annual Conference*, April 14, 2012, in Dearborn, Michigan.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Background

Prenatal Diagnosis

A prenatal diagnosis is most often determined from routine ultrasound screenings during 18 to 22 weeks of pregnancy. Some expectant parents who receive such news have described initiating parenting by deciding to continue the pregnancy and undertake caregiving through medical management and surveillance of fetal health (Rempel, Cender, Lynam, Sandor, & Farquharson, 2004). Over the past several decades, scholars have contributed to our theoretical understanding of the goals and actions of parents, primarily mothers, during the transition to parenthood (Draper, 2003; Mercer, 2004; Rubin, 1976, 1984). However, little is known about this process in the context of a prenatal fetal diagnosis. In this article, we describe parents' emotions, thoughts in terms of predominant mental activities, and states of being as reflected on a continuum of social-emotional status. Preparing heart and mind subsumes these emotions, thoughts, and states of being and leads to prenatal caregiving motivations for the infant expected to be born with substantial medical needs. The findings reported here appear to be the first to theoretically relate prenatal experiences to the caregiving system and the concept of motivation drawn from attachment theory (Bowlby, 1982, 1988; George & Solomon, 1999, 2008; Heard & Lake, 1997).

Theory

We chose a broad framework based on recent expansions of attachment and caregiving theory to guide our exploration of parent perceptions of caregiving. George and Solomon (1999, 2008) extended Bowlby's (1982, 1988) concept of caregiving as a behavioral system reciprocal to attachment (i.e., care seeking). We examined other models that described caregiving in general and caregiving for infants and children with developmental or congenital disabilities in the literature (Raina et al., 2004). However, these models focused on parent and child characteristics, functional factors such as stress and coping, and physical and psychological outcome measures that support testing hypotheses concerning processes and outcomes that were identified a priori to the study. Using the caregiving system framework was a good match for our inquiry because our intent was to explore parents' experiences and the dynamics of what they expected and intended to do for caregiving.

The caregiving system is viewed as a distinct motivational system with behaviors aimed at meeting adaptive goals and ensuring reproductive fitness that develops extensively during the transition to parenthood. More specifically, caregiving includes a large subset of parenting behaviors such as parents' efforts to protect, nurture, and comfort their offspring (Bowlby, 1988; George and Solomon, 1999, 2008). These behaviors organized within the caregiving system are influenced by an individual's cognitive, emotional, and social processes. Heard and Lake (1997) elaborated on the concept of motivation for caregiving originating from Bowlby's (1982, 1988) views of motivation within the attachment and caregiving systems. Motivation functions to orient and maintain momentum to achieve a goal. Caregiving motivations are directed toward achieving goals of caregiving for the infant (Bowlby, 1988). A caregiving motivation can be discerned in a parent's descriptions of intentions and expectations for caregiving and in caregiving behavior (Bowlby, 1982).

Applying these theoretical perspectives, we found that parents experienced emotions, thoughts, and states of being, and developed specific motivations related to caregiving before as well as after birth. For example, in anticipation of birth, immediate surgical interventions, and potential threats to infant health, parents in this sample initially set limits on interactions with others to shelter themselves as they were confronted with an unexpected process of caregiving. Many parents bolstered their hopefulness while they struggled to understand, prepare for, and put into context the medical problems their infant would face

after birth. Some parents made plans within the family to go beyond the usual care that would be needed for the infant, yet others appeared weighed down by fear of the unknown. All parents formed intentions and expectations concerning their abilities to care for the expected infant that characterized specific caregiving motivations before birth. The purpose of this theoretically guided qualitative inquiry was to examine parents' experiences in terms of prebirth caregiving motivations following a prenatal fetal CCHD diagnosis reported retrospectively 1 to 3 months following birth.

Methods

The longitudinal study (Pridham et al., 2010), of which the study reported here is a component, examined caregiving motivations of parents who had an infant with a CCHD at three time points during the first year postpartum. The aims of the larger study included an examination of the variation and evolution of parents' motivations, theoretically based on attachment and caregiving theory. Although these aims did not include the prenatal time frame, the interview protocol we developed included this time frame because it was clear that some parents experienced aspects of parenting as a consequence of prenatal diagnosis before the infant's birth. With this recognition, an impetus for this study was to explore parents' motivations relevant to parenting and caregiving prior to the infant's birth. Thus far, only postnatal motivations based on these data have been reported in the literature (Pridham et al., 2010). In Figure 1, we illustrate how this study was used to give a prenatal continuity to the larger study.

From January 2004 through January 2007, parents of 27 families were recruited from a children's medical center in a Midwestern United States city shortly after the birth of the infant. Eligible parents included mothers and fathers who were 18 years of age or older, English-speaking, and self-identified as primary caregiving parents of infants diagnosed with a CCHD. Clinical members of our research team included nurses and physicians who assisted with recruitment, data collection, and severity-of-illness ratings. While the infants were hospitalized, a hospital nurse sought parental consent to be contacted by research nurses to explain more about the study. The research nurses described the study and invited these parents to become participants in the study.

Although the research nurses conducted three semistructured interviews with each family during the first year postpartum, only data analysis of the first interview is reported in this article. This first interview took place 1 to 3 months after birth, in the home or hospital setting, following the infant's first heart surgery. This first interview was the only one of the three time points during which the research nurses explicitly explored parents' prenatal experiences with respect to parenting and caregiving. The interview guide comprised both open-ended and probe questions. Examples of open-ended questions used for the first interview include: Thinking back to the time when you first knew that you were pregnant and going to have your baby, tell me about that time. What was the pregnancy like for you? When you found out about the heart defect, how was the experience for you? When you first heard about the baby's heart defect, what did you expect it was going to be like having her at home? And how is the reality the same or different from what you expected? How did you handle your feelings? Tell me about your experience with your baby's health care providers. What is your understanding of her heart defect?

Furthermore, only during the first interview did the research nurses use probe questions to elicit parents' specific descriptions of the prenatal experience, the diagnostic process, early caregiving, and the infant before and in the first weeks after birth. The interviews were audio-recorded for verbatim transcription.

Our clinical research team derived data from infant medical charts needed to complete the Severity of Medical Illness (SMI) index (Fedderly, 2008). Using the initial postbirth echocardiogram and data from neonatal assessments, a pediatric cardiologist completed the index by quantifying the medical significance of infant CCHD and associated pathophysiology based on the anatomical cardiac defect(s). Five categories describe the overall severity of the CCHD: (a) no or insignificant disorder (disorder has no impact on the infant's health); (b) mild disorder (lesion requires no operative intervention, only long-term follow up); (c) moderate disorder (infant is asymptomatic, but has or will require low-risk surgery or cardiac catheterization); (d) marked disorder (high likelihood of corrective, two-ventricle repair; infant is quite symptomatic and has had or will require a major, high-risk repair); and (e) severe disorder (uncorrectable as a two-ventricular repair and requires complex palliation or transplant). Within each category, the pediatric cardiologist added points to account for associated medical and birth conditions (e.g., extracardiac and chromosomal anomalies, birth weight, and prematurity), thereby increasing the index score. The final severity score for an infant was, maximally, an 11-point scale.

Sampling Method

We selected interview data for analysis of caregiving motivations using theory-based sampling. Theory-based sampling, a more specific form of criterion sampling, allowed us to focus on conceptual phenomena. This approach to sampling includes sampling of events, incidents, time frames, or people on the basis that there is potential for theoretical concepts to be uniquely represented by them (Patton, 1990, 2002). The sample of parents included those who had a prenatal diagnosis which, theoretically, could be related to caregiving. We identified and characterized these parents' caregiving motivations after a prenatal diagnosis and examined how these experiences related to or expanded theory pertaining to caregiving.

Participants

Participants in this study included 13 mothers and 3 fathers who self-identified as primary caregivers to 14 infants, representing 14 families who received a prenatal diagnosis between 17 and 22 weeks of pregnancy. Research nurses interviewed 12 families in their homes shortly after discharge from the hospital and two families in the hospital setting. Data included individual interviews with 12 parents, including 11 mothers and 1 father, and two interviews with both the mother and father interviewed together. Parents ranged in age from 21 to 39 years. Most parents (80%) were college educated, and completed education ranged from eleventh grade to a graduate or professional degree. Parents reported their annual household incomes in categories that ranged from \$30,000 to \$90,000 or more. Eleven couples were married (78.6%), two were partnered (14.3%), and one parent was single (7.1%). This sample was comprised of parents who self-identified as White (14, 87.5%), Black (1, 6.3%), and Asian (1, 6.3%); two of these parents also indicated Hispanic ethnicity (12.5%).

We were unable to collect demographic data from all families who received a prenatal diagnosis of a complex CCHD in the state during the recruitment period; however, we did compare this sample of parents to publically available state data from the United States Census Bureau (USCB, 2010) and the United States Census Bureau, Housing and Household Economic Statistics Division (USCB, HHESD, 2010). In this state, children were reported to live with married parents (65.7%), unmarried parents (3.6%), one parent (26.6%), and neither parent (4.1%). A higher percentage of parents in this sample were married or partnered and a lower percentage of parents were single compared to these state data (USCB, HHESD, 2010). The racial/ethnic distribution of this study sample was consistent with recent U.S. Census Bureau data (USCB, 2010) showing most state residents to be White and non-Hispanic (89.4%). Although this sample was more highly educated

compared to 22.4 % of state residents with college degrees, the income range of our sample was comparable to median statewide household income of \$52,103 (USCB, 2010).

We anticipated the severity of the CCHDs of infants in this sample, as shown in Table 1, and the severity was indexed after birth as marked or severe, requiring hospitalization for an average of 6 weeks. All 14 infants had multiple diagnoses, including hypoplastic left heart syndrome, tetralogy of Fallot, and other serious aortic and valve defects requiring a minimum of one surgical intervention shortly after birth. Approximately half of the families enrolled in the larger study received prenatal diagnoses. The number of families and medical severity represented in the pre- and postnatally diagnosed groups were similar. Ethical approval for this study was obtained through the University of Wisconsin and participating hospitals. All participants provided written informed consent to enroll in this study.

Data Analysis

Working independently and collaboratively, we conducted a three-stage analysis of interview data collected 1 to 3 months postbirth. In our first stage of data analysis, we used Hsieh and Shannon's (2005) methods for directed content analysis. This method did not limit us to predefined categories or require us to tally the frequency of observations of a category. Rather, we used this theoretically directed content analysis to focus on parent retrospective descriptions of their experiences and caregiving motivations. We began by reading the transcripts thoroughly to gain a sense of the whole, and large sections were reread frequently for purposes of immersion in the data. Then we examined the data word by word, highlighting exact words from the text that related to theoretical concepts. In the margins of the transcripts, we wrote codes that included several aspects of a concept. Codes included content on parent recollections of emotions and thoughts related to the diagnosis, the parent him- or herself, and the expected infant before birth.

We searched the interview data for parents' accounts of caregiving kept on course by parent-set goals of protecting, nurturing, and comforting the offspring; energy invested in the caregiving; and a direction undertaken related to the caregiving. Our coding of caregiving motivations included intentions and expectations expressive of these forms of caregiving. We developed and organized categories based on how codes were related (Hsieh & Shannon, 2005). Categories and codes, as well as parents' statements concerning their experiences and caregiving motivations, were documented in an abstract of each interview transcription.

To examine descriptive and interpretive validity (Maxwell, 1992, 2002), we reviewed all identified emotions, thoughts, states of being, and caregiving motivations for accuracy and completeness. When codes differed, we determined final codes by consensus. Throughout the analysis, we checked our agreement on the relationship of the data to the theoretical framework, the terms used to characterize the phenomena, and the evidence that existed for determining the categories. A higher order of categorization included parents' emotions, thoughts, states of being, and caregiving motivations. We created a coding manual with comprehensive definitions of the categories and corresponding evidence from the abstracts and notes relating parents' statements to the larger context of the interview.

We used the results of the first stage of analysis to look for patterns in the data, verify that theoretical saturation had been reached, and focus our analysis. In the second stage of analysis, we organized categories for data display in a matrix format which allowed us to visually examine categorical patterns and density (Miles & Huberman, 1994). Finally, in the third stage of analysis, we used theory on caregiving and caregiving motivation to narrow the analytic focus. We refined the categories by identifying how parents' experiences and

caregiving motivations were related and oriented toward achieving the primary goal of caregiving set within the caregiving system.

Findings

The prenatal diagnosis impacted all aspects of the caregiving system. The motivation to become a caregiver appeared to activate the caregiving system as a whole, to reach the primary goal of protecting, nurturing, and comforting the offspring (Bowlby, 1988). Beginning before birth and continuing throughout the first year of life, parents sought to protect, nurture, and comfort their offspring in various ways. However, after receiving a prenatal diagnosis of a CCHD, parents in this sample vividly recalled directing significant energy toward preparing heart and mind, which involved their varied emotions, thoughts, and states of being. For these parents, preparing heart and mind was needed to achieve the primary goal of caregiving for their infants who were expected to be born with a life-threatening medical condition. Parents described preparing heart and mind as they formed intentions and expectations indicative of specific motivations.

Specific motivations in service of caregiving for the expected infant were sorted into the following three categories: motivations to relate to the baby, handle the circumstances practically, and manage the medical care. As shown in Figure 2, the theoretical model includes preparing heart and mind as the central category and preliminary goal within the caregiving system. The dashed line identifies interrelated processes within the category of preparing heart and mind; solid lines represent associated processes and arrows indicate influential conditions. Although a general progression toward achieving the primary goal of caregiving for the infant is expected, it should be understood that the process within the caregiving system does not appear linear, but rather iterative in nature.

Preparing Heart and Mind

The interrelated nature of emotions, thoughts, and states of being were most apparent when parents emphasized the strain resulting from learning of the diagnosis combined with needing to prepare with the knowledge of uncertain infant health status. Parents described the initial shock and devastation of the diagnosis. Reflecting this common experience among these parents, one mother said, “It was like the whole world just came down on me.” A wide range of emotions, thoughts, and states of being then began to surface. States of being related to regulating emotions and developing a workable understanding of the diagnosis, treatment, prognosis, and the consequences for their infant and family. Waiting for the infant’s birth and the reality of the defect while receiving complicated medical information and determining the meaning of this information was described as the “difficult stuff.” For many parents, “not knowing” was accompanied by descriptions of “getting into” or “getting through a difficult time.”

Many parents recounted consciously allowing themselves to be open to and experience emotions alone and with others. The initial need for self-protection and privacy fostered an integration of the diagnostic news on an individual level and in the context of being a couple. This required a period of isolation, often including staying home from work and keeping a distance from family, friends, and coworkers. Parents described their efforts to sort out their emotions by first talking with their significant other and then expanding the talking to family members, other close contacts, and support groups.

Parents’ responses varied in time spent experiencing specific emotions and the level of energy and awareness put into managing them. One mother explained that time was an important factor for her and told how she needed the time spanning pregnancy through the early weeks postpartum to experience her emotions surrounding her “unnatural experience.”

She eventually recognized these emotions as she experienced them, and began to talk with others about them despite the fear of giving voice to these emotions. This process of experiencing her emotions led to reaching an acceptant state of being regarding her medically complicated pregnancy, birth, and infant, but not until after the infant's birth:

I accept it. I would have to say I didn't, until she was born really. It was just the unnatural experience, you know, in comparison to having your regular baby. I had the Cesarean section which made it even more unnatural for me. And so, I think it was when I could hold her and now that we're home, I totally accept that she has these issues. This is the way it's going to be, you know, this is the way it's going to be for her. And that's fine, and I do accept it now. But yeah, it definitely was a slow process.

The process of experiencing emotions, however, was not a universal one. Some parents described cordoning off negative emotions, narrowly focusing on when and with whom sensitive emotions were allowed to surface rather than focusing on the need to sort out these emotions. One mother kept the diagnosis and her feelings related to it private during her pregnancy, and described expressing her strong emotions only in the presence of her own mother. When emotions rose to the surface in other contexts, this mother diverted her thoughts to squelch and avoid the emotional content.

As parents processed their emotions in different ways over the perinatal time, they reinterpreted reality to prevent themselves from sinking into negativity and instead to move toward hope. Regulating the intensity of despair was most evident in parents' investments in strengthening hope. For many parents, cultivating hope became a vital antidote to their anger, sorrow, and anxiety. Hope was also useful in minimizing the negative scenarios that inhabited parents' minds. One father maintained his hope by reframing the uncertainty as a positive possibility:

Hope! Yeah, that's all we had, really. I think that throughout the whole thing, the only hope that we ever had was basically that they [diagnosing physicians] were wrong. You can only be so precise when you're looking through mom, through baby, into a heart. What we heard from the beginning, though, was, "Know we can be wrong." This is the one case I do not mind doctors being wrong at all. So that was the basis of hope right there.

For this parent and others, striving for a hopeful state of being allowed them to think about the positive and not only the negative possibilities.

Parents searched for answers to their questions and an understanding of the heart condition. However, such basic questions as "Why did this happen? What caused it? What did I do to cause this?" could not adequately be answered. Searching for answers and other information on the Internet was often unsatisfying because of the difficulty in finding specific, current, or hopeful information. One mother said, "We just couldn't find some of the answers we were looking for, and maybe, they weren't there anyway." Struggles also emerged as parents attempted to understand the diagnosis, presenting a steep learning curve for some on the anatomy and physiology of the heart. As one couple discussed their struggles, the mother remembered that they were "totally overwhelmed with the thing. ... Looking at the diagram of the heart would not do, would not mean anything to either of us." Lack of understanding over time sometimes led parents to stop struggling for an understanding. One mother described her experience:

So many people have explained it to me. And somebody will ask me what the problem is and I, I don't know. He has a heart disease, that's about it. Like, I understand, kind of. But then it seems, as soon as I get an understanding, I forget it.

So, I don't know. There are lots of papers that show me and tell me, and I don't really [understand].

Giving up the struggle to understand and a simplification of the condition were often validated with the reasoning that it was a "fixable" problem, or that not until the baby was born could "the extent of the damage" be known. These parents tended to rely a great deal on their partners or HCPs to understand and assess the condition.

Searching for information varied greatly among the study participants. Some parents "had to know" as much as possible about the diagnosis and its consequences, and after reaching a saturation point, "couldn't look anymore." It seemed that through reaching this saturation point, some parents also managed the intensity of their emotions: "The more I read about it, the more I understood it.... If I don't understand what is going on, then it does terrify me." Conversely, one mother explained that the information she found on the Internet was more than she needed to know, saying it was "very scary." As birth approached, parents had imagined numerous outcomes and recalled evaluating the level of uncertainty of their circumstances and whether they felt prepared.

Caregiving Motivation: To Relate to the Baby

The caregiving motivation to relate to the baby involved sorting out emotions, thoughts, and beliefs and searching for meaning in the unexpected circumstances. This category was characterized by parents' intentions and expectations to love, bond with, or distance themselves from the infant before and after birth. One mother remembered her emotional commitment to her infant, which shaped the relationship to her infant:

This was the way he came and there are so many children who have much worse things. How can I be, he's perfect. This is the only thing wrong with him. Everything else with him is perfect. How can I be upset with that? It's my baby and I love him immensely. I loved him before he was born and I loved him when he was born.

Special knowledge about the physical attributes of the fetus sometimes raised disbelief of the diagnosis. A mother told about her trouble in aligning the embodied experience of a moving, reacting fetus with a future infant with a serious disability:

Before he was born, he moved so much in utero. This little boy was moving all the time, and he was so strong. Anyone could put their hand right here and they'd get kicked hard enough to move their hand. He was just phenomenally strong, and it was just hard to believe that he was missing half a heart.

Some parents recalled thinking about special ways to "bond" with the infant. Intentions and expectations regarding bonding through breastfeeding were discussed:

I prayed even before she was born that we'll be able to have a long breastfeeding experience. Especially with the surgery, and knowing that it's going to be open-heart. "How can we bond?" We'll figure out some way so that we can still breastfeed.

In contrast, other parents expected a distance between themselves and their infants: "When I was pregnant, it was all about the diagnosis, and you nearly forget that there's a baby there at all." Another mother expected to relate to her infant after birth with a sense of trepidation: "I didn't think I'd be able to do anything, that I'd have to walk on egg shells, and that I wouldn't enjoy him."

Parents also described preparing to relate to the baby with the expectations that their newborn would be transferred into a highly technical medical environment for assessment

and treatment just minutes following the birth. On being admitted to the hospital in labor, one mother's response was triggered by an HCP's anticipatory guidance:

I already know I can only have him for five minutes and then I have to give him up to you. I already know that once he goes into surgery, I wouldn't be allowed to hold him for a week. We knew those things ahead of time, but it didn't affect me in the moment. It affected me months before, when I was told.

Separation of the newborn from the mother and father was expected. One couple described preparing to give up their prerogative as parents after hearing a well-intentioned HCP's statement, recounted by the mother: "He's not your baby because you are not going to have any say, you are not going to have any choices." Both the mother and father later validated this prediction with their individual experiences of when the infant "became" their baby. There was much variation among parents in preparing to relate to the baby, with some parents intending to foster close connections to the infant, whereas other parents were focusing on the prenatal diagnosis and the consequences of the expected severity of the condition. Parents also reported preparing themselves before birth for obstacles, such as the expected limited access to the infant and their lack of voice in the care of their infant, which could prevent them from relating to the baby.

Caregiving Motivation: To Handle Circumstances Practically

This caregiving motivation was characterized by parents' reflections on putting energy into thinking about and working on handling the possible circumstances they faced. Although parents described tasks related to medical insurance and covering financial needs through hospital and needs-based paperwork, the burden of medical cost was not raised. Most parents described their intentions and expectations to plan and organize around having a medically complex infant in a psychosocial way, while wondering and waiting to find out what their family's unique experience would be. Parents communicated extensively with everyone who would be involved with the infant, formed flexible plans to match the expected infant's medical condition after birth, and sought out other parents who had a child with a heart problem to access their experiential knowledge. One mother recounted seeking out a friend who had a child with a heart defect before the birth of her infant:

"What's going to happen? How bad is this?" Especially coming home with the more severe diagnosis, too. With multiple surgeries and, life, you know. The "what ifs" were the big thing. But once I talked to [friend] and learned and listened to her calmness and her organization of things—how to prepare, how to function at home—just listening to what she had to go through, prepared me. So, just asking all the questions and the "what ifs" just calmed me and helped me deal with it.

Tapping into the experiential knowledge of other families helped some parents to determine what the diagnosis would mean for their own family. However, intentions to seek out this kind of personalized information were frequently not realized, because doing so was a low priority or was incongruent with the parent's emotional response. For example, one mother described her response to reading a special interest story about a family with an infant with a CCHD, which was reported in the newspaper as traumatic. Parents in this sample also shared their preferences for learning about other families' experiences either anonymously through the Internet or not at all.

Caregiving Motivation: To Manage Infant Medical Care

This caregiving motivation included parents' intentions and expectations regarding medical care for their infants with uncertain and complicated medical needs in the hospital and at home. One father prepared to manage his infant's medical care before the birth by orienting himself to the system that would be providing the medical care for his infant. He explained

that the prenatal diagnosis allowed him time: “Time, to look up our doctors, doctors that would follow his condition.... And how the [hospital] operates, to prepare for it. So that really helped.” Although this process was useful to this parent, other parents worried a great deal about the sensitivity of the care provided. One mother emphasized that it was not only the medical care but the care for her child as a person that mattered to her. She stated her intentions: “Making sure that [her daughter would be] well taken care of, well nurtured, and just providing her with support most of all.”

Preparing to manage medical care for the hospitalized infant was just as important for some parents as preparing to provide direct care for the infant at home. The level of competency needed to manage infant medical care outside of the hospital setting was of significant concern for some parents in this sample. One mother recalled questioning, “Am I going to do this right? Am I going to have to poke her with medicines? I’m not a medical person, you know?” Despite these doubts, she was able to bolster her intention to be there for her baby and do what was necessary: “You do what you’ve got to do, because it’s your child, you know? Because you love your child, you’ve got to be there. That’s what’s needed.”

Preparing to manage infant medical care also included issues related to infant feeding because difficulties with feeding were anticipated, and good medical outcomes depended on adequate feeding and weight gain for the infant. Parents remembered thinking about what might be needed for reaching medically set feeding goals as well as what would be most manageable for themselves as the parents. The thought of needing a feeding tube for the infant was described by one mother as “frightening.” She wondered what daily life would be like if feeding was a medical problem: “How normal is life going to be with him attached to a feeding pump all the time?” In addition, this mother worried that using a breast pump to maintain her milk supply, initiating breastfeeding and ensuring that her infant was able to take in enough, would be an overwhelming prospect and would not hold up over time. Overall, the caregiving motivation to manage infant medical care involved parents familiarizing themselves with the medical environment and determining what would be important for infant care. Parents also considered their own respective role in and capacity for managing infant care.

Discussion and Clinical Implications

We learned from these parents’ retrospective descriptions of experiences following a prenatal diagnosis that the caregiving system was activated before birth. The proposed theoretical model illustrates activation of the caregiving system and includes an additional process of preparing heart and mind. The length of the process and the level of intensity required to regulate emotions and reconfigure thoughts following a prenatal diagnosis varied. The states of being related to preparing heart and mind were described as changing in focus or emphasis through the remainder of the pregnancy and following the infant’s birth. Preparing heart and mind was associated with forming specific caregiving motivations before birth that were directed at achieving the primary goals of the caregiving system.

Parents described their emotions and thoughts as conscious and reflective or emergent under specific conditions, and that their states of being influenced how preparing heart and mind was undertaken. Addressing emotional needs often involved conscious and intentional expression of and reflection on emotions unfolding over time. Parents reported that this approach allowed them to reduce and regulate their emotional intensity, and to engage in the work of making sense of their new circumstances. This finding is in contrast to parent responses that came about automatically and with little cognitive attention afforded to the emotional content. Among these parents, significant energy was required to squelch giving voice to their emotions and thoughts within themselves or to carefully limit expression.

Constricting emotions and thoughts could delay or impair reaching an acceptant state of being, indicative of progression through the grieving process or utilizing hope as a counter to despair. Limited reflective capacities could put these parents, already at risk for depression and anxiety, into an even higher risk category for mental health problems.

Parents' experiences of conscious reflections on intense or full-fledged emotions as compared to reactive emotions that induced the need for control were similar to what Baumeister, Vohs, DeWall, and Zhang (2007) described as a dual processing of emotions. Dual processing of emotions suggests that, regardless of their manifestations, all emotions function as part of an indirect feedback system that triggers appraisal of actions. This differs from the view that emotions serve as a direct cause for behavior. Rather, conscious emotional states of being can facilitate taking in new information and change expectations for future behavior. Behavior can also be chosen to pursue or avoid anticipated outcomes related to emotions, thoughts, or other behaviors. This indirect influence of emotions supports the findings that reflective capacity of the parents influenced their outlook and ability to engage in understanding the unexpected infant health status. Variation in parents' reflective capacity was observed in this sample; however, the extent to which reflective capacity alters the formation of specific caregiving motivations is unclear and remains a topic for future inquiry.

Preparing heart and mind was facilitated in a number of ways. Hope appeared to serve as a protective factor and buffer for all parents in this sample. Managing negativity, gaining a new perspective, and building fortitude hinged on the level of hope that parents were able to develop and maintain. This finding was consistent with the functions of hope specific to parents of medically high-risk infants described in a recent concept analysis of hope with implications for nursing care (Amendolia, 2010). Hope as a state of being might be key to achieving the goal of preparing heart and mind, and thus allows parents to form intentions and expectations that shape their caregiving motivations. For some parents, hope was easier to ascertain and fear was minimized when medical information was well understood; for others, hope was developed independently of medical knowledge. It might be that hope is gained in differing ways to prepare heart and mind and remains a question for additional study.

Recognizing how parents are reacting emotionally to news of the diagnosis, thinking about their circumstances, and forming caregiving motivations requires HCPs' time and sensitivity. Being open and present with parents at many points during the perinatal time puts HCPs in position to assess whether a need exists for parents to express or contain emotions and thoughts or to secure privacy. The HCP can then provide necessary and requested information in an individualized manner that does not overwhelm or confuse parents. HCPs can also assess parents for their level of hope frequently before birth, because it seems to represent an essential means for parents to endure the fear and uncertainty that is an undercurrent for the pregnancy following the prenatal diagnosis. This approach is supported by Feudtner's (2009) discussion of the benefits of hope in clinical practice. Understanding each parent's complex and numerous hopes can illuminate how they engage in relationships, adapt during adverse times, and make difficult decisions.

These parents' intentions and expectations served as a window into specific caregiving motivations, formed before birth, that included motivations to relate to the baby, handle circumstances practically, and manage infant medical care. For some mothers, the caregiving motivation to relate to the baby was reflected in a desire for closeness. This closeness was described as an embodied experience of a fetus who was "strong," as well as the poignantly anticipated closeness that could be experienced through breastfeeding the expected infant. HCPs can support the expectant parent in preparing to relate to the baby by

acknowledging any descriptions or unique knowledge of the fetus and their developing relationship. Additionally, HCPs can support breastfeeding as an important personal decision and a means of bolstering the motivations regarding preparing to relate to the baby. This support includes providing specialized resources to help parents prepare for feeding challenges. The absence or low intensity of this caregiving motivation might be demonstrated by parents who maintain a guarded, tentative distance from the fetus and focus on diagnostic outcomes and unknown infant capacity or survival. A guarded response to preparing to relate to the baby could be exacerbated as a cautious process of relating following birth. Thus, the approach to preparing to relate to the baby could have significant consequences for the parent–infant relationship, and is a question for future study.

Preparing heart and mind allowed parents to determine how to best handle their circumstances practically. Some parents placed a priority on planning and organizing their lives to manage the pregnancy, plan for birth, and anticipate providing complex infant care. Yet other parents described avoidant states of being, perhaps for reasons of self-protection during pregnancy. The parents experiencing avoidant states of being reported difficulty adjusting to and taking on the role of caregiver for their infant. Assessing how and to what extent parents are preparing to handle the circumstances practically can provide the HCP with insights into parents' decisions to take or not take action regarding caregiving, and possibly serve as an alert for intervention.

Preparing to manage infant medical care included the need for parents to make medical decisions and ensure that the infant would be treated like a person. Many parents oriented to an experience of pregnancy in the medical context and began to take on an advocate role for the infant before birth. Other parents described their position as outside the medical world and shared their fears regarding inability to do what would be needed for their infant. An assessment of parent knowledge and interpretations of the diagnosis will allow for individualizing care and providing anticipatory guidance that can prevent inaccuracies in parent expectations and additional disruption of the perinatal experience. In the context of a highly managed pregnancy following a serious prenatal diagnosis, HCPs have a particularly important role in identifying parent caregiving readiness. Assessing parents' caregiving motivations to manage infant medical care before birth might provide a basis for determining the level of guidance and teaching parents will require before the infant's discharge to home following surgery.

The caregiving motivations to relate to the baby, handle circumstances practically, and manage infant medical care can be considered as foundational aspects of the primary caregiving goals of protecting, nurturing, and comforting the infant. HCPs can learn about parents' progress in reaching preliminary and primary goals by asking parents about what they are putting time and energy into, and what is most important to them concerning the pregnancy, the fetus, the expected infant, life circumstances, and medical care. Responses to these types of clinical inquiries can indicate parents' intentions and expectations, indicative of the presence and prioritization of caregiving motivations.

Assessing how parents are directing their caregiving early on could also alert HCPs to the need for referral to supportive mental health services. The open and present approach taken by the HCP suggested here to accurately assess and treat their patients is supported by recently published qualitative findings. Henshaw et al. (2011) described how women at risk for mental health problems during the perinatal time perceived HCPs as a resource for information and help. Represented in the basic question, "Can this person help me?," women determined whether they felt heard, and could place trust in a given HCP who was perceived as competent and able to provide a feasible treatment plan. The HCP's interaction with expectant parents experiencing distress following a prenatal diagnosis could set a tone

for the duration of perinatal care and determine whether or not these individuals or couples receive necessary information or referral to mental health services. Additional study is needed to identify specifically what HCPs can do to support parents in preparing heart and mind as a goal preliminary to the primary goals of caregiving during medically complicated pregnancies.

Theoretically, prenatally expressed caregiving motivations influence the early formation of the parent–child relationship and the health and development of medically at-risk infants. Future prospective studies beginning in pregnancy are needed to understand how and when caregiving motivations are constructed and reconstructed, and how these influence what parents do. This type of inquiry would benefit from inclusion of a comparison group comprised of parents who received a postnatal diagnosis after experiencing a healthy pregnancy. The intensity of emotions and thoughts experienced prior to birth could differ between pre- and postnatal diagnostic groups and lead to differences in caregiving goals and motivations.

Limitations

The qualitative approach used in this study was not intended to produce generalizable results but rather a starting point for discovering representative findings and hypotheses for future examination with other parents within the population of parents who received a prenatal diagnosis of CCHD. This study included a small and homogenous sample of parents. Although the racial and ethnic composition and income level of this sample was reflective of the state population, caution should be exercised regarding the representativeness of these findings. Most participants were women who met eligibility criteria that included self-identification as primary caregiver. Although mothers and fathers were fully engaged in the interview process, the larger number of mothers in this sample led to a higher prevalence of their responses in the reported findings.

The retrospective nature of this study risked issues of decline in memory of the experience and sharpness of recall. However, interviews were conducted within 3 months after birth and could have allowed parents time to reflect on their prenatal experiences. It is not known if this self-selecting sample included parents who were experiencing maladaptive psychosocial responses because formal psychological evaluations were not part of this study. It is possible that unresolved emotions such as intense fear and despair could impair parents psychologically and effect the activation and functioning of the caregiving system. It appeared that the caregiving system was activated for all parents in this sample. Whether and to what extent the caregiving system is activated is assumed to vary among expectant parents and perhaps to vary by gender. These questions warrant additional study.

Conclusion

The theoretical framework of caregiving and attachment that guided this study led to the exploration of how parents' experiences following a prenatal diagnosis of a CCHD could be understood in terms of the caregiving system and specific caregiving motivations organized within this system. Findings included the central category of preparing heart and mind that appeared to serve as a preliminary goal to protecting, nurturing, and comforting the offspring, which are the primary goals of the caregiving system. Attention to achieving this preliminary goal led to forming specific caregiving motivations identified by parental intentions and expectations, expressive of a psychological or behavioral activity kept on course by a parent-set goal, energy invested in the activity, and a direction undertaken related to the activity.

The specific caregiving motivations described by this sample of parents were sorted into three categories that included motivations to relate to the baby, to handle the circumstances practically, and to manage infant medical care. Knowledge of caregiving motivations that are operating for a parent at a particular time puts clinicians in a better position to make well-attuned assessments of the need for support and to be identified as a helpful resource for parents before and after birth. The theoretical model of the caregiving system that includes the goal of preparing heart and mind as preliminary to caregiving goals of providing care and protection describes the findings of this study and suggests questions and hypotheses for future studies.

Acknowledgments

We extend our appreciation to the families who generously shared their experiences with us. We also acknowledge Lioness Ayres, Mary Elizabeth Bathum, Stuart Berger, Inge Bretherton, Cheryl Brosig, Raymond Fedderly, Michelle Frommelt, Tondi Harrison, Mary Krolkowski, Kathleen Mussatto, Margarete Sandalowski, and Kathleen Sawin for their valuable contributions to the study.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Anne Chevalier McKechnie received support from the following sources: the National Institute of Nursing Research Traineeship (T32NR007102), the University of Wisconsin–Madison Gwendolyn H. Shapiro–Wisconsin Distinguished Graduate Fellowship, and a National Research Service Award (F31NR011563). Karen Pridham received support from the following sources: Herma Heart Center, the Children’s Hospital of Wisconsin, the Children’s Hospital of Wisconsin Foundation, and the National Institutes of Nursing Research (R03NR009272). This work was also supported by grant 1UL1RR025011 from the Clinical and Translational Science Award (CTSA) program of the National Center for Research Resources, National Institutes of Health.

References

- Amendolia B. Hope and parents of the critically ill newborn: A concept analysis. *Advances in Neonatal Care*. 2010; 10(3):140–144. [PubMed: 20505424]
- Baumeister RF, Vohs KD, DeWall CN, Zhang L. How emotion shapes behavior: Feedback, anticipation, and reflection, rather than direct causation. *Personality and Social Psychology Review*. 2007; 11(2):167–203. [PubMed: 18453461]
- Bowlby, J. Attachment and loss: Vol. 1. Attachment. New York: Basic Books; 1982.
- Bowlby, J. A secure base: Parent-child attachment and healthy human development. New York: Basic Books; 1988.
- Draper J. Men’s passage to fatherhood: An analysis of the contemporary relevance of transition theory. *Nursing Inquiry*. 2003; 10(1):66–77. [PubMed: 12622806]
- Fedderly, R. Severity of medical illness associated with a cardiac defect through the first year. Milwaukee, WI: Unpublished instrument. Herma Heart Center, Children’s Hospital of Wisconsin and the Medical College of Wisconsin; 2008.
- Feudtner C. The breadth of hopes. *New England Journal of Medicine*. 2009; 361(24):2306–2307. [PubMed: 20007559]
- George C, Solomon J. The development of caregiving: A comparison of attachment theory and psychoanalytic approaches to mothering. *Psychoanalytic Inquiry*. 1999; 19(4):618–646.
- George, C.; Solomon, J. The caregiving system: The behavioral systems approach to parenting. In: Cassidy, J.; Shaver, P., editors. *Handbook of attachment*. 2nd ed.. New York: Guilford Press; 2008. p. 833-856.
- Ghanayem NS, Hoffman GM, Mussatto KA, Cava JR, Frommelt PC, Rudd NA, Tweddell JS. Home surveillance program prevents interstage mortality after the Norwood procedure. *Journal of Thoracic and Cardiovascular Surgery*. 2003; 126(5):1367–1377. [PubMed: 14666008]
- Heard, D.; Lake, B. The challenge of attachment for caregiving. New York: Routledge; 1997.

- Henshaw EJ, Flynn HA, Himle JA, O'Mahen HA, Forman J, Fedock G. Patient preferences for clinician interactional style in treatment of perinatal depression. *Qualitative Health Research*. 2011; 21:936–951. [PubMed: 21429945]
- Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qualitative Health Research*. 2005; 15:1277–1288. [PubMed: 16204405]
- Lloyd-Jones D, Adams R, Carnethon M, De Simone G, Ferguson TB, Flegal K, Greenlund K. Heart disease and stroke statistics—2009 update: A report from the American Heart Association statistics committee and stroke statistics subcommittee. *Circulation*. 2009; 119(3):e21. [PubMed: 19075105]
- Maxwell JA. Understanding and validity in qualitative research. *Harvard Educational Review*. 1992; 62(3):279–300. Retrieved from <http://www.metapress.com.ezproxy.library.wisc.edu/content/8323320856251826/fulltext.pdf>.
- Maxwell, JA. Understanding and validity in qualitative research. In: Huberman, AM.; Miles, MB., editors. *The qualitative researcher's companion*. Thousand Oaks, CA: Sage; 2002. p. 37-64.
- Mercer RT. Becoming a mother versus maternal role attainment. *Journal of Nursing Scholarship*. 2004; 36(3):226–232. [PubMed: 15495491]
- Miles, MB.; Huberman, AM. *Qualitative data analysis: An expanded sourcebook*. Thousand Oaks, CA: Sage; 1994.
- Patton, MQ. *Qualitative evaluation and research methods*. 2nd ed.. Newbury Park, CA: Sage; 1990.
- Patton, MQ. *Qualitative research and evaluation methods*. Thousand Oaks, CA: Sage; 2002.
- Pridham K, Harrison T, Krolikowski M, Bathum ME, Ayres L, Winters J. Internal working models of parenting motivations of parents of infants with a congenital heart defect. *Advances in Nursing Science*. 2010; 33(4):E1–E16. [PubMed: 21068545]
- Raina P, O'Donnell M, Schwellnus H, Rosenbaum P, King G, Brehaut J, Wood E. Caregiving process and caregiver burden: Conceptual models to guide research and practice. *BMC Pediatrics*. 2004; 4(1) Retrieved from <http://www.biomedcentral.com/1471-2431/4/1>.
- Rempel GR, Cender LM, Lynam MJ, Sandor GG, Farquharson D. Parents' perspectives on decision making after antenatal diagnosis of congenital heart disease. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*. 2004; 33(1):64–70.
- Rosamond W, Flegal K, Furie K, Go A, Greenlund K, Haase N, Kissela B. Heart disease and stroke statistics—2008 update: A report from the American Heart Association statistics committee and stroke statistics subcommittee. *Circulation*. 2008; 117(4):e25. [PubMed: 18086926]
- Rubin R. Maternal tasks in pregnancy. *Journal of Advanced Nursing*. 1976; 1(5):367–376. [PubMed: 1050350]
- Rubin, R. *Maternal identity and the maternal experience*. New York: Springer; 1984.
- Tweddell JS, Hoffman GM, Mussatto KA, Fedderly RT, Berger S, Jaquiss RD, Litwin SB. Improved survival of patients undergoing palliation of hypoplastic left heart syndrome: Lessons learned from 115 consecutive patients. *Circulation*. 2002; 106(12 Suppl. 1):I82–I89. [PubMed: 12354714]
- United States Census Bureau. State and county quick facts. 2010. Retrieved from <http://quickfacts.census.gov/qfd/states/55000.html>
- United States Census Bureau, Housing and Household Economic Statistics Division, Fertility & Family Statistics Branch. America's families and living arrangements, Table C9: Children by presence and type of parent(s), race, and Hispanic origin: 2010. 2010. Retrieved from <http://www.census.gov/population/www/socdemo/hh-fam/cps2010.html>

Biographies

Anne Chevalier McKechnie, MS, RN, IBCLC, is a doctoral student at the University of Wisconsin–Madison School of Nursing in Madison, Wisconsin, USA.

Karen Pridham, PhD, RN, FAAN, is the Helen Denne Schulte Professor Emerita at the University of Wisconsin–Madison School of Nursing in Madison, Wisconsin, USA.

Figure 1.
Preparing heart and mind in relation to the larger, longitudinal study

Figure 2.
Theoretical model of preparing heart and mind within the caregiving system

Table I**Infant Medical Severity**

Infant	Primary Diagnosis^a	Severity Rating^b	Weeks Hospitalized^c
1	Interrupted aortic arch	5.0	4
2	Coarctation of the aorta	5.0	5
3	Hypoplastic left heart syndrome	6.5	12
4	Hypoplastic left heart syndrome	6.5	3
5	Hypoplastic left heart syndrome	6.5	5
6	Hypoplastic left heart syndrome	6.5	7
7	Hypoplastic left heart syndrome	6.5	3
8	Hypoplastic left heart syndrome	6.5	4
9	Hypoplastic left heart syndrome	6.5	13
10	Double outlet right ventricle	5.0	6
11	Hypoplastic left heart syndrome	6.5	8
12	Hypoplastic left heart syndrome	6.5	4
13	Tetralogy of Fallot with aortopulmonary collateral	4.5	1
14	Ventricular septal defect with hypoplastic aortic arch	4.5	12

^aInfants with a primary diagnosis of hypoplastic left heart syndrome underwent a minimum of two surgical interventions.

^bSeverity of medical illness rating 4 indicates marked disorder and a rating 5 indicates severe disorder on an rating scale that ranges from 1 to 11 (Fedderly, 2008).

^cDuration in days of infant hospitalization was rounded to the nearest number of weeks.