Published in final edited form as:

West J Nurs Res. 2018 August ; 40(8): 1110–1130. doi:10.1177/0193945917712693.

Motivations and Features of Co-Parenting an Infant With Complex Congenital Heart Disease

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Abstract

This study described co-parenting motivations and quality of co-parenting features for parents of infants with complex congenital heart disease (CCHD), including differences over time by illness severity. Existing transcripts of parenting experience at infant age 1 and 12 months for 23 parent couples were analyzed using directed content analysis. Data were quantized for additional description. Six co-parenting motivations and five co-parenting features were identified. Two co-parenting motivations had not been previously described: *Developing the Co-Parenting Relationship* and *Maintaining the Couple Relationship*. Variability in quality of co-parenting features was evident. However, the majority of parents showed high ratings. Motivations and quality of co-parenting features changed over time and were related to illness severity. Our findings increase the understanding of what parents are working on as a couple to parent an infant with CCHD and the quality of this co-parenting. Several questions for further study are presented.

Keywords

congenital heart disease; chronic illness; parenting; co-parenting; caregivers

Infants with complex congenital heart disease (CCHD), that is, requiring surgical intervention soon after birth to sustain life, are at high risk for mortality, morbidity, and impaired growth and neurodevelopment (Costello, Gellatly, Daniel, Justo, & Weir, 2015; Marino et al., 2012; Razzaghi, Oster, & Reefhuis, 2015). CCHD is distinguished in infancy by the need for parents' careful attention to feeding, technical mastery of complex care procedures, vigilant monitoring, and adjustment of lifestyles, plans, and parent–partner relationships (Meakins, Ray, Hegadoren, Rogers, & Rempel, 2015; Pridham et al., 2010; Rempel & Harrison, 2007; Woodgate, Edwards, Ripat, Borton, & Rempel, 2015). A chronic

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Declaration of Conflicting Interests

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

Supplemental Material

The online supplements are available at <http://wjn.sagepub.com/supplemental>.

health problem, CCHD alters parenting by increasing its intensity, multiplying its functions, and, of necessity, drawing both parents into caregiving. In this article, we begin to describe how joint caregiving occurs for mothers and fathers, that is, co-parenting, for an infant with CCHD through the infant's first year using existing interview accounts from a larger study (Pridham et al., 2010).

Co-Parenting and CCHD

Co-parenting has been defined as “the ways that parents work together in their roles as parents” (Feinberg, Brown, & Kan, 2012, p. 173). Parents engage in co-parenting through responsibilities and tasks carried out more or less collaboratively with the other parent (Doherty & Beaton, 2004; Feinberg, 2003; McHale & Lindahl, 2011). Co-parenting does not necessarily imply equality in parenting roles. Rather, co-parenting refers to the way in which parents negotiate completion of the multiple tasks and responsibilities involved in parenting. Co-parenting healthy infants is associated with infant and parent outcomes, including child behavior and social-emotional development (Doherty & Beaton, 2004; Feinberg, Jones, Kan, & Goslin, 2010; Feinberg, Kan, & Goslin, 2009), infant growth and health (Feinberg et al., 2016; Majdandžić, de Vente, Feinberg, Aktar, & Bogels, 2012), attachment security (Feinberg et al., 2016; Frosch, Mangelsdorf, & McHale, 2000), parent–child interaction (Halford & Petch, 2010; Petch, Halford, Creedy, & Gamble, 2012), parent mental health and quality of life (Feinberg et al., 2016; Halford et al., 2010; Majdandžić et al., 2012), and parent sense of competence (Floyd & Zmich, 1991).

Co-parenting is especially important when an infant has a complex chronic condition requiring intensive home care (Feinberg, 2002; Jackson, Frydenberg, Liang, Higgins, & Murphy, 2015; Woodgate et al., 2015). An infant's CCHD increases the challenges and work of parenting (Connor, Kline, Mott, Harris, & Jenkins, 2010; Jackson et al., 2015; Rempel, Rogers, Ravindran, & Magill-Evans, 2012). Parents of infants with CCHD report extensive and often overwhelming caregiving needs (Pridham et al., 2010; Rempel et al., 2012), which may include tube feedings, administering oxygen and other medications, multiple appointments for health and rehabilitative services, and intense caregiving during acute illness and medically urgent events. Parents report working to manage fears about physical and developmental outcomes and concerns about their own and others' relationship with the infant, including integrating the infant into their existing family life (Pridham et al., 2010). The severity of the infant's neonatal disease and the infant's age may make a difference in co-parenting (McKechnie, Pridham, & Tluczek, 2016).

Many contemporary cultures support parental sharing of caregiving tasks (Hofferth, Fisher, & Glorieux, 2015; McHale, 2015; Pruett, 2000). However, the sharing is often not equivalent, particularly with the increasingly prevalent pattern of full-time employment for fathers and part-time employment for mothers (Wilcox & Dew, 2013). Even in cultures where mothers are traditionally the primary caregiver, cultural practices may be overridden by external demands, such as the birth of an infant with a serious health condition (Garcia Coll & Pachter, 2008). When parents have an infant with CCHD, there is likely more sharing of responsibilities than generally observed in parents of a child without special medical needs (Kline & Stafford, 2013; Rempel & Harrison, 2007; Rempel et al., 2012).

The relatively few research reports describing fathers' participation in caring for infants with health problems have primarily focused on perception of support and specific functions of each parent (Lee, Miles, & Holditch-Davis, 2006; Mooney-Doyle, Deatrick, & Horowitz, 2015; Rehm, 2013). One study explored the efforts mothers and fathers took to preserve the survival of their child with CCHD, themselves, and their couple relationship, describing strategies such as selectively sharing information, maintaining a common perspective, and avoiding conflict (Rempel & Harrison, 2007). How mothers and fathers of chronically ill infants communicate about parenting support and their satisfaction with it is unknown.

The current study was based on existing transcripts from interviews collected for a larger study focused on parents' experiences caring for an infant with CCHD over the first year. Consistent with the original study, the current study used a concept in Bowlby's (1969/1982, 1988) attachment theory as the guiding framework: the internal working model (IWM) of caregiving. An IWM is a metaphor for the thoughts, emotions, and actions which comprise the dynamic operation of a behavioral system, such as caregiving. An IWM structure of caregiving includes *motivations* for caregiving, that is, goals that drive parents' actions; *expectations* of self, others, and caregiving tasks; and *intentions* to act in relation to caregiving goals (Bowlby, 1969/1982, 1988; Bretherton & Munholland, 2008; Mayseless, 2006).

The interviews for the original study focused on an individual perspective, yet demonstrated parents referencing each other or actively working together on issues, suggesting the operation of motivations for co-parenting. These motivations for co-parenting were reflected in parents' work to maintain infant well-being through nurturing (feeding, supporting sleep, promoting development) and protecting (guarding against illness and identifying changes in physical status), to develop a relationship with the infant (providing a secure base of attachment through consistent care), and to maintain or strengthen the family life they desire (spending time together as a family; Pridham et al., 2010). The interviews also revealed aspects of parenting desired in their couple relationship, that is, co-parenting features. These features, also found in the co-parenting literature, include the *sharing of information* about day-to-day tasks as well as feelings, concerns, or goals; *agreement* about approaches to the required tasks as well as philosophical approaches to caregiving; *satisfaction* with how well parents are working together; how much each partner feels *supported* emotionally and functionally; and how much each partner feels parenting *responsibilities are shared* (Doherty & Beaton, 2004; Feinberg, 2002, 2003). These co-parenting features could be evaluated on their quality, that is, the extent to which these features facilitated or impeded goals for co-parenting and the parents' couple relationship (Doherty & Beaton, 2004; Fincham, 2004).

Infant severity of illness and age may make a difference in co-parenting motivations and the quality of co-parenting features (Bornstein, 2013; Woodgate et al., 2015). Severity of cardiac disease has not been examined in relation to parents' thinking, behavior, or practices related to co-parenting. Co-parenting motivations may be reoriented, and the quality of co-parenting features may evolve as the infant grows and the parents accrue caregiving experience.

Figure 1 depicts our conceptualization of relationships among IWM concepts, co-parenting, and outcomes. Each parent's IWM of caregiving configures each individual's approach to

co-parenting. Co-parenting motivations refer to motivation oriented to caregiving of a child, such as nurturing and protecting the child, relating to the child, and having the desired family life. The quality of co-parenting may be observed, through the parent couple's communication, in co-parenting features, such as the sharing of information, agreement, support, satisfaction, and the sharing of parental responsibility and caregiving tasks. The quality of co-parenting features is the extent to which these features facilitate or impede goals for co-parenting and the parents' couple relationship. Infant age and illness severity may make a difference for parents in co-parenting motivations and the quality of co-parenting features. We theorize that co-parenting affects outcomes, including infant neurodevelopment, parental well-being, and family functioning. Better understanding of co-parenting an infant with CCHD could facilitate identification of risk and design of tailored interventions.

Purpose

The research questions were as follows:

Research Question 1:

What co-parenting motivations and quality of co-parenting features were revealed in interviews at 1 and 12 months?

Research Question 2:

Did infant age affect motivations and quality of co-parenting features, given severity of neonatal illness?

Method

Design

We applied a qualitative descriptive approach (Willis, Sullivan-Bolyai, Knafl, & Cohen, 2016) for this longitudinal study using existing 1- and 12-month interview data for a larger study of IWM of caregiving through the infant's first year (Pridham et al., 2010). These time points demarcate early caregiving and the end of the first year when infant development alters parenting practices. Although these data were collected over a decade ago (2004–2006), parents' uncertainty about the trajectory of the disease and overall prognosis likely continue to affect co-parenting in spite of changes that may have occurred in surgical techniques and clinical caregiving. We incorporated quantizing to enhance description (Sandelowski, Voils, & Knafl, 2009). Approval from the Institution's Human Subjects Review Board and written informed consent were obtained for the original study.

Participants

The original sample consisted of 23 parent couples recruited from a cardiovascular service of a midwestern regional children's hospital. Eligibility included married or partnered parents at least 18 years old, English-speaking, and whose infant was diagnosed with CCHD requiring surgical intervention within the first month of life. Sample demographic information is presented in Table 1.

Data Collection and Measures

The original semistructured interviews were completed in-home or in-hospital by one of the coinvestigators and lasted approximately 90 min. The focus was on parenting and caregiving experience over the first year using six topics: (a) what the infant is like, (b) individual parent's caregiving experience, (c) parenting experience/caregiving as a couple, (d) parenting and the family, (e) being parents and a couple, and (f) quality of life. All 1- and 12-month interviews were used for the current analysis.

The interviewee was the couple-designated primary caregiving parent. The other parent was invited to participate. Because the parent relationship is co-constructed (Coyle-Shepherd & Newland, 2013), each parent is expected to have the other parent in mind as a component of their IWM of parenting. This component is expected to be operative in a parent's description of caregiving experience. Given this perspective, we accepted the reporting parent's view of the other parent's motivations. When both parents were present, the interviewer directed questions to the primary caregiver, then asked the parents to respond to each other. Interviews were transcribed professionally and proofread by the principal investigator with the original study.

Severity of neonatal illness was based on ratings by a pediatric cardiologist on an 11-point scale using cardiac anatomy and clinical data. Categories were modified with 0.5 or 1.0 point qualifiers that increased the severity, for example, chromosomal abnormalities, extra-cardiac anomalies, premature birth, and additional cardiovascular anomalies (Fedderly, 2009). In the sample, all infants had scores of ≥ 4 . Infants scored 4.0 to 4.9 were defined as having lower severity complex disease and likely had two-ventricle, moderate-risk repairs. Infants scored ≥ 5 were defined as having higher severity complex disease due to an uncorrectable defect, for example, single ventricle physiology.

Data Preparation and Analysis

Co-parenting motivations were identified in the transcriptions using directed content analysis (Hsieh & Shannon, 2005), structured by categories of caregiving motivations identified in earlier studies from the perspective of parents as individuals (Pridham et al., 2012) with openness to emergence of additional categories. Categories of co-parenting features were drawn from the literature (Doherty & Beaton, 2004; Feinberg, 2002; McHale & Lindahl, 2011; Pridham et al., 2010).

A manual to guide identification and naming of co-parenting motivations and quality of co-parenting features was structured prior to data analysis and developed as analysis progressed. Motivation for co-parenting was defined as an expression of intention, desire, or activity directed toward parenting the infant in relation to the other parent, for example, a mother commenting that she wanted to make her and the father's feeding styles more consistent. After a motivation was identified and named, an ordered value of its presence was assigned: 2 = both parents held the motivation, 1 = only the primary caregiving parent held the motivation, and 0 = neither parent held the motivation.

Categories of co-parenting features were similarly identified and named. Well-functioning (high quality) co-parenting features with no tension between parents were coded 5. Well-

functioning co-parenting features with some tension or issue that the couple recognized and was working on were coded 4. A code of 3 indicated some recognition of need for significant work on the feature with the parents making some effort to improve. A code of 2 indicated substantial and acknowledged difficulty in relation to the feature and little work on it. A code of 1 indicated substantial difficulty with the feature, but parents did not acknowledge or indicate intention to work on it. An example of criteria of quality codes for the feature *Sharing Information* is presented in Table 1.

Maxwell's (1992) concepts of descriptive validity were used for evaluating categories of co-parenting motivation and features of co-parenting and their ordinal quality ratings. Two or three trained investigators independently coded at least one third of the transcripts. Discussion of coding decisions followed, with discrepancies clarified and consensus reached, new instances of co-parenting motivations and features determined, and coding manual revisions made.

For Research Question 1, motivations are presented in tabular form using excerpts from the transcripts because motivations could generally be discerned in a statement or two. Quality of co-parenting features are presented in text using representative quotes because the ordinal rating of quality was determined considering the entire interview of what parents were working on, how they were approaching it, partner response, joint activity, and how the work was going. For Research Question 2, we used the Cliff's delta statistic, a nonparametric effect size measure for ordinal data to describe differences made by severity of infant illness on change in motivations and quality of co-parenting features between 1 and 12 months. Effect sizes, comparable with Cohen's *d*, are small = .147, medium = .330, and large = .474 (Cliff, 1993).

Results

Research Question 1: Co-Parenting Motivations and Co-Parenting Features

Co-parenting motivations.—Six co-parenting motivations were identified: (a) *Caregiving: Nurturing*, (b) *Caregiving: Protecting*, (c) *Living the Desired Life*, (d) *Relating to the Infant*, (e) *Developing the Co-Parenting Relationship*, and (f) *Maintaining the Couple Relationship*. Evidence for these motivations at 1- and 12-months is available electronically as Online Resource Table 1. Co-parenting motivations described by Mother R to illustrate consistency or change over time are available as Online Resource Table 2.

The percentage of couples coded as having a specific motivation is shown in Online Resource Figure 1. At 1 month, the co-parenting motivations *Caregiving: Nurturing*, *Caregiving: Protecting*, *Living the Desired Life*, and *Relating to the Baby* were observed in at least 50% of the transcripts. The motivation *Living the Desired Life* was described by the reporting parent alone for 34.8% of the couples. The lowest percentages of both parents holding a motivation were for *Developing the Co-Parenting Relationship* (34.8%) and *Maintaining the Couple Relationship* (43.5%). No evidence of these two motivations was found in 34.8% and 39.1%, respectively.

At 12 months, almost 80% of both parents held the motivation *Living the Desired Life*. Motivations *Caregiving: Nurturing*, *Caregiving: Protecting*, and *Developing the Co-Parenting Relationship* were described in over half the transcripts. The motivation *Relating to the Infant* was described more often for one parent (39.1%) than for both parents (34.8%). No evidence of work was found on *Relating to the Infant* in 26.1%, *Developing the Co-Parenting Relationship* in 30.4%, or *Maintaining the Couple Relationship* in 43.5%.

Quality of co-parenting features.—The quality of the five identified co-parenting features is illustrated with quotations from representative transcripts.

Sharing information.—Couple O was interviewed together. Their first infant had open-heart surgery for tetralogy of Fallot soon after birth. They described differences in their approach to sharing information. The father reported, “I have the feeling that I should read up on things. I want to know where science is at for her kind of disease. So I’m putting quite a bit of effort in that.” In contrast, this mother describes her response to hearing information she is not ready for:

I’m different because I get very depressed if I read negative information; so I decided to just go by what (baby) tells me and I worry about whatever might happen in the future when it happens because I started to worry too much. And I couldn’t really enjoy her anymore because I was so worried that we might lose her or she might be unhappy or something might go terribly wrong ...

This couple shared information about their feelings articulately and without reservation. Yet, because they differed in how much information should be gathered and discussed concerning their infant’s future and they reported ongoing discussions, *Sharing Information* was coded 4. By 12 months, they had developed their processes for sharing information and their rating was 5.

Agreement.—At 1 month, Mother B described differences in thinking about accepting the infant’s condition or dwelling on the wish for a healthy infant. “Of course ... I would want to make him better, but at the same time, this is the way it’s supposed to be. I wouldn’t change it.” Similar lack of agreement in how each parent viewed the infant’s condition was described at 12 months. The conflict in perspectives surfaced when a trip to urgent care prompted a medical decision to hospitalize. The mother quoted her partner saying, “We’re going home. We don’t need to be here. There are sick kids here.” The mother’s view was

... the physicians would not admit anyone who doesn’t need to be there ... So the two of us had to sit down and talk right then and there ... “If you can’t handle it here, go home. I’ll deal with the hospital stuff and then I’ll come home.”

This couple was rated “3” on *Agreement* at both 1 and 12 months. The parents acknowledged differences. This mother expressed understanding of her partner’s perspective, but insisted that he accept her point of view when the two differed.

Satisfaction.—Mother N’s second infant was born with a single ventricle. At 1 month, this mother described the father as having more difficulty with handling the infant than she did:

... for the most part I can get (baby) to calm down. He has a tendency to get frustrated more quickly. Then he ends up yelling at the baby, telling it to stop, which doesn't work when you're trying to get the baby to calm down ... For the most part if (husband) is taking care of the baby I'm here, so if he's starting to yell at the baby, I go in and take over. Then he goes and takes (older son). We flip flop. He has taken care of the baby a few times while I've been gone and as far as I know it's gone well, but I wasn't there.

Quality of *Satisfaction* was rated 2. Although the mother was uncertain about the father's ability to manage the infant alone, she depended on him to stay with the infant at times. She viewed her husband's parenting practices as not only different from her own but potentially unsafe. At 12 months, this mother expressed empathy for her partner's continued discomfort in being with his infant. "It's not his fault. He was never around kids when he was little ... But we do have different parenting skills. We work on it. You always have to communicate." The mother's increased satisfaction and the indication that both parents recognized the issue and were working on it resulted in a rating of 3.

Support.—Mother U's infant was hospitalized beyond 1 month following the first of two surgeries. Her two preschool children were left in the care of her husband and mother so she could stay with her hospitalized infant. She was beginning to manage the infant's gastrostomy tubes at the 1-month interview. When asked how she and her husband worked on problems, she responded, "We yell. My husband walks away" and that problems "just kind of get blown over. We don't really talk about it." And "he likes to make smart remarks about everything. That's his way of dealing with stuff ... I just have to yell what I say and I think. I guess that's my way of dealing with it." *Support* was rated 2 rather than 1, because the mother conveyed understanding that walking away was her partner's way of dealing with things. Because the mother did not indicate the couple was working on supporting each other, even at the level of talking about it, *Support* was not rated 3. At 12 months, the infant continued to be tube fed but had not been hospitalized for the previous 6 months. The mother described the infant as more content and attributed this to the environment:

My husband doesn't have patience. He says you do it or else, and I yell. I have tried to catch myself from doing that, and instead saying, "Let's sit down and talk." I'm trying to calm the house down so there's not a lot of bickering and just trying to make it better for all of us.

The work this mother was doing on *Support* at 12 months resulted in a rating of 3 because of her consistent attempts to support her partner in interacting and her reported arrangements for what she described as "parenting guidance" for them.

Sharing responsibilities.—Couple K tag-teamed caregiving. The mother worked during the day. The father worked evenings and cared for their gastrostomy-fed infant during the day, when clinic visits and in-home therapies were scheduled. At 1 month, this father worked on increasing infant's oral intake and ensuring time on the abdomen to support neck development. The father reported, "Mom did not want to do these tasks because she did not like to see (baby) cry." Evidence of tensions in sharing caregiving included the father's expression of being burdened by caregiving and the need to work together to make

caregiving manageable for each other and consistently done. These tensions resulted in a rating of 3. At 12 months, the father remained the primary caregiver with continued gastrostomy feedings and therapies. However, he saw caregiving becoming easier because the infant was growing, played with his school-aged siblings, and had no imminent surgeries. The father described sharing caregiving responsibilities:

We have our separate schedules with trying to make everything work out the best, and it does get stressful. I have it a little bit easier, during the day with just him. With Mom, there are parts of the week that she has (baby) with the other two (older siblings); she has to take care of three.

This father said they did a lot of talking and planning:

We try to work through most things together, make the decisions together for him. But there are times when I just have to make a decision and go with it. My wife made the comment, "Why ask me anyway; you'll just do what you want."

The developing sense of partnership, concern about fairness in responsibilities, and emphasis on communication were evidence of higher quality. However, the implied deficit in sharing responsibilities revealed in the father's unilateral decision making about care resulted in a rating of 4 rather than 5.

The quality of five co-parenting features is graphically displayed in Online Resource Figure 2. At both time points, most parent couples received codes of 4 or 5, connoting high quality for all co-parenting features. However, the percentages of couples with these high scores decreased over time. At 12-months, at least 30% of the couples were coded 3 on each of the five features.

Research Question 2: Co-Parenting Motivations, Quality of Features, and Illness Severity

Change in motivations and quality of co-parenting features from 1 to 12 months is shown in Online Resource Figure 3, grouped by severity of neonatal illness. Cliff's delta demonstrated small positive changes, that is, the motivation was held by more parents at 12 months than at 1 month, for infants with either lower or higher illness severity for *Caregiving: Protecting* (lower severity: 0.22; higher severity: 0.14) and *Developing the Co-Parenting Relationship* (lower severity: 0.22; higher severity: 0.19). For infants with lower illness severity, a moderate positive change was observed for *Living the Desired Life* (0.43). In addition, there was a small negative change for *Maintaining the Couple Relationship* (−0.18), that is, fewer reports at 12 months than at 1 month. For couples of infants with higher illness severity, the change was large and negative for *Relating to the Infant* (−0.51), that is, fewer parents held this motivation at 12 months than at 1 month.

Small changes were seen in qualities of co-parenting features for parents of infants with lower illness severity. Parents exhibited more *Agreement* (0.20) but less *Satisfaction* (−0.20) and less *Sharing Responsibilities* (−0.18) at 12 months than at 1 month. For parents of infants with higher illness severity, a small increase in *Support* (0.24) was seen with little change in the quality of the remaining features.

Discussion

These findings extend our knowledge about the parenting mothers and fathers do together for infants with CCHD. Existing interview transcriptions were a rich source for describing parent participation in co-parenting motivations and quality of co-parenting features. Four of the identified co-parenting caregiving motivations logically concerned activities expected of parents—nurturing, protecting, supporting the desired family life, and relating to the infant (Bretherton & Munholland, 2008; George & Solomon, 2008)—and were consistent with parents' individual perspectives in earlier studies (Pridham et al., 2012). Two of the motivations are newly identified and specific to co-parenting, that is, *Developing the Co-Parenting Relationship* and *Maintaining the Couple Relationship*. The features of co-parenting identified are consistent with the literature ((Doherty & Beaton, 2004; Feinberg et al., 2012; McHale & Irace, 2011) and our previous work (McKechnie et al., 2016; Pridham et al., 2010). The quality of the features described levels of communication, support, participation, and satisfaction with co-parenting, and are a new contribution to the co-parenting literature. These categories of co-parenting motivations and quality of co-parenting features may direct language and instruments for co-parenting description and clinical and research assessment. Infant age and severity of neonatal illness had an effect on motivations and the quality of co-parenting features, suggesting hypotheses and questions for further study.

One newly identified motivation, *Developing the Co-Parenting Relationship*, engaged greater numbers of parents between 1 and 12 months for both higher and lower levels of illness severity. This may reflect parents' learning through caregiving experiences that work on co-parenting was needed and could be accomplished together. Study of how this learning occurred could support clinical intervention to facilitate this work.

The other newly identified motivation, *Maintaining the Couple Relationship*, was mentioned less at 12 months than at 1 month for parents of infants with lower illness severity. These parents might have resolved couple relationship issues by 12 months, had given up working on them, or had accepted the existing relationship. The specific meaning of this category for a couple needs to be examined to identify its possible effect on other co-parenting motivations. Perhaps the more tangible parenting motivations that pertain directly to caregiving activities took precedence over the couple relationship.

The positive effect of infant age for the motivations *Caregiving: Protecting*, *Living the Desired Life*, and *Developing Co-Parenting* suggests contributions of developmental changes experienced in the 12-month-old child. The lack of effect of infant age on *Caregiving: Nurturing* suggests this motivation is relatively timeless for parents of a young child.

Unexpectedly, we found a moderate negative effect of infant age on the motivation for *Relating to the Infant* in parents of infants with higher illness severity compared with no effect for infants with lower illness severity. This finding is not easily hypothesized as a function of infant developmental change. Perhaps parents at 12 months felt confident of their relationship with their child with CCHD and no longer had the relationship in the forefront

of their IWM. However, the way in which serious heart disease affects a parent's expectations, intentions, and goals at any one age and over time has not yet been studied. The prospect of morbidity and mortality as well as the parents' experience of the infant's multiple surgeries and intense oversight by clinicians and therapists may contribute to expectations of vulnerability that impact co-parenting motivations, including the parent–infant relationship. Further study of co-parenting motivation directed to the relationship with the infant needs to include interview questions specific to this relationship and its evolution through the first year.

Variability among parents in the quality of co-parenting features was evident despite the majority of the parents showing high ratings. At 12 months, 43.5% of couples had ratings indicating they had issues with *Agreement*. These findings direct attention to future exploration of reported behaviors or interactions leading to the ratings and what interpersonal mechanisms are used by parents in working together, such as negotiating and compromising. In addition, more than half the couples were rated highly on *Satisfaction* at 12 months compared with less than a third at 1 month, raising questions about what changed to result in this improvement. Study of conditions that contribute to changes in the quality of co-parenting features is needed. In addition, independent measures of the couple relationship and style of coping over time would provide meaningful context for interpreting these co-parenting features.

The quality ratings of co-parenting features also demonstrated the effects of illness severity. *Agreement* showed a small positive effect of age for infants with lower severity that was not seen for infants with higher severity. Furthermore, positive effects seen in *Support* for higher severity infants were not seen for parents of infants with lower severity. For parents of infants with lower severity, *Satisfaction* and *Sharing Responsibilities* showed a greater negative change. These changes with infant age associated with lower illness severity may indicate changes in parents' IWM expectations because the infant was less likely to need another surgery, required less care, and commanded less concern from parents and clinicians. However, these findings were based on neonatal severity ratings. The effects of the infant's physical status across the first year, including additional operations, acute illnesses, and hospitalizations, on the quality of co-parenting features, as well as on co-parenting motivations, warrant study.

Because our report of co-parenting motivations and quality of co-parenting features was based on a secondary analysis of existing transcripts, there are several limitations. Our findings are a preliminary description and only suggestive of the variability among parents. By using existing transcripts, we did not have reports from each partner's perspective. Measures of the parental relationship were not collected because that was not the focus of the original study. Such measures, as well as measures of social support, would be useful in future studies. The study sample was fairly homogeneous, including only married or partnered heterosexual parents. Replication is needed with a larger, more inclusive sample of caregiving partners (e.g., grandparent–biological parent pair) in a longitudinal study that includes the prenatal time period. Another research direction is to examine the effects of the parents' motivations and quality of their co-parenting features on infant outcomes, including

feeding competence, development, physiological and behavioral regulation, and quality of life.

Although directed content analysis (Hsieh & Shannon, 2005) permitted identification of new categories within the IWM concept of motivation (Bowlby, 1969/1982), description of co-parenting could be extended with parental self-report on existing instruments designed for that purpose (Feinberg et al., 2012). Focusing on motivations as a starting place for assessment adds depth to analysis of the parents' experience and organizes the meaning of parenting. The ordered values for the quality of co-parenting features presented in this study could be an efficient, comprehensive approach to assessment for clinical or research purposes.

This descriptive study begins to fill a gap in understanding what parents are working on as a couple to parent an infant with CCHD and the quality of the co-parenting. Concepts of co-parenting motivations and the quality of co-parenting features demonstrate potential for use in future studies of co-parenting infants with CCHD and may provide support for assessment in clinical settings. A larger sample drawn from a population of parents who have an infant with any complex congenital disease is warranted to develop a platform for study of motivation and quality of co-parenting of infants with complex chronic health problems in general.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgment

We gratefully acknowledge the contributions of the parents who participated in this study; staff members of the Herma Heart Center of the Children's Hospital of Wisconsin; Margarete Sandelowski, PhD, RN, FAAN, for her input on the manuscript; and Mary Krolikowski, MSN, RN, and Kathleen Mussatto, PhD, RN, for their contributions to the project.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was supported with funds from the Herma Heart Center, the Children's Hospital of Wisconsin; The Children's Hospital of Wisconsin Foundation; The University of Wisconsin–Madison School of Nursing Florence Blake Fund and the Helen Denne Schulte Fund; the Clinical and Translational Science Award (CTSA) program, through the National Institutes of Health (NIH) National Center for Advancing Translational Sciences (NCATS), Grant UL1TR000427; and the National Institute of Nursing Research, Grant 5R03NR9272–2 to the University of Wisconsin–Madison School of Nursing.

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Figure 1.
Conceptualization of relationships related to co-parenting an infant with complex congenital heart disease.

Table 1.Attributes of Parents, Their Infants, and the Family (*N* = 23).

Characteristics	<i>n</i>	%
Interviewee ^a	1 month/12 months	
Mother only	16/17	69.6/73.9
Father only	1/2	4.3/8.7
Both mother and father	6/4	26.1/17.4
Race/ethnicity		
Mother		
White	16	69.6
Black/Asian/Middle Eastern	4	17.4
Latina	3	13.0
Father		
White	16	69.6
Black/Asian/Middle Eastern	5	21.7
Latino	2	8.7
Parity: Primiparous	7	30.4
Income category (annual household)		
Less than US\$50,000	6	26.1
US\$50,000-US\$90,000	7	30.4
US\$90,000 or more	8	34.8
Unknown	2	8.7
Infant male gender	15	65.2
Infant postmenstrual age		
31–36 weeks	4	17.4
37 weeks or more	19	82.6
Severity of illness		
Marked dysfunction	7	30.4
Severe medical illness ^b	16	69.6

^aData collected at home visits at infant ages 1 and 12 months. One infant was hospitalized until almost 8 months of age. Therefore, the 1-month data collection is missing for this family.

^bNine infants had hypoplastic left heart syndrome. Two infants had DiGeorge syndrome

Table 2.

Example of Coding Criteria for Quality of Co-Parenting Features: Sharing Information.

Code	Criteria
1	<ul style="list-style-type: none"> • Information sharing not valued, sought after, or necessary.
2	<ul style="list-style-type: none"> • Some information sharing to accomplish day-to-day tasks or responsibilities. • No mechanisms in place to assure information sharing. • Limited or no desire to have more sharing, but some parent-felt deficiency in information sharing may be apparent. • Information shared may be about disagreement. • Evidence of lapses in information sharing without indication of attempts to correct the lapse or develop processes to share information.
3	<ul style="list-style-type: none"> • Communication is inadequate, excessive, or intrusive. • Some information sharing along with desire to have more for accomplishment of day-to-day goals and/or sharing feelings, concerns, ideas, or plans. • Considering steps for more sharing of information. • Desiring less intrusive information sharing (e.g., less arguing).
4	<ul style="list-style-type: none"> • Much information sharing. • A desire or willingness to share information, to talk, or to stay on the same page for day-to-day life or long-range goals. • Evidence of an occasional lapse of information sharing with correction when the lapse is realized. • Serious problems with communication in the past currently resolved. Some residue of worry about resurgence of the problem exists, and attention is needed to prevent.
5	<ul style="list-style-type: none"> • Information sharing about a range of topics/issues (e.g., short or long term; simple, trivial, or highly significant and important). • Couple takes deliberate steps to share information. • Division of labor (sharing responsibility) so intermeshed that sharing of information about infant care and other tasks is imperative.