We want what's best for our baby:
Prenatal Parenting of Babies with Lethal Conditions

Denise Côté-Arsenault, Heidi Krowchuk, Wendasha Jenkins Hall, and Erin Denney-Koelsch

Abstract: This article reports on qualitative research into the experience of couples who chose to continue their pregnancies after receiving a lethal fetal diagnosis, and to embrace the parenting of their baby in the shortened time they have. This analysis of interview data is part of a larger research project describing parents' experiences of continuing pregnancy with a known lethal fetal diagnosis (LFD).

Keywords: prenatal parenting, lethal fetal diagnosis, LFD

Pregnancy is a complex bio-physical and psychosocial process in which the goal for a mother is good health for her baby and herself (Côté-Arsenault, Brody & Dombeck, 2009; Rubin, 1984). The father, in relationship with the mother, is also experiencing psychological and social development as well as physical changes across pregnancy as he anticipates being a father with his partner (Conner & Denson, 1990; Valentine, 1982). It follows then, that when the couple learn that their unborn child has a life-limiting condition, the pregnancy experience is profoundly changed. The couples in this study chose to continue their pregnancies after receiving a lethal fetal diagnosis, and to embrace the parenting of their baby in the shortened time they have. This analysis of interview data is part of a larger research project describing parents' experiences of continuing pregnancy with a known lethal fetal diagnosis (LFD).

Review of the Literature

Given that prenatal diagnosis of lethal conditions is relatively new, little is known about the parents' experiences of continuing pregnancy with these diagnoses. Personal stories in the lay literature and social media are increasingly evident (Kuebelbeck, 2003; Kuebelbeck & Davis, 2011) but published research is primarily retrospective and focuses on the events surrounding the birth and death of the babies (Chitty, Barnes, & Berry, 1996; D'Almeida, Hume, Lathrop, Njoku & Calhoun, 2006). Two exceptions were identified. Lathrop and VandeVusse (2011) reported that in retrospective interviews of 15 women, all called themselves *mothers* and their child *baby* and they each assumed maternal roles. Côté-Arsenault and Denney-Koelsch (2011) reported their finding of *arrested parenting* when couple's reported halted parenting behaviors in their pregnancy with LFD as expressed in one-time interviews. What is lacking is an understanding of what it is like for both parents during their pregnancy and over time. This study aims to add these perspectives to our knowledge.

The experience of pregnancy has changed a great deal in the last quarter century (Feldhusen, 2000). Prenatal care within current traditional health care systems involves prenatal testing including maternal blood tests and ultrasound screenings of the growing fetus (Abramsky & Chapple, 2003). It is through this testing in the first 20 weeks of pregnancy that some parents learn that the *perfect* baby of their dreams has abnormalities that may be life threatening (Rubin, 1984). This news shatters dreams, transforms the pregnancy, and propels most into recognizing that their anticipated parenting experience will be cut short (Côté-Arsenault and Denney-Koelsch (2011).

Denise Côté-Arsenault PhD, RNC, FAAN, Principal investigator on this study, is currently the Eloise R. Lewis Excellence Professor and Chair of the Family and Community Nursing Department at the University of North Carolina Greensboro School of Nursing. Heidi V. Krowchuk, PhD, RN, FAAN is an Associate Professor and Associate Dean for Academic Programs at the University of North Carolina at Greensboro School of Nursing. Wendasha Jenkins Hall, MS is currently a PhD student at the University of North Carolina Greensboro in the Department of Public Health Education. Erin Denney-Koelsch, MD is an Assistant Professor at the University of Rochester Medical Center. Contact: d_cotear@uncg.edu

The parenting literature is by and large focused on the role of parenting after the child is born, when there is bi-directional interaction between parent and child (Deave, Johnson & Ingram, 2008; Virasi, Yunibhand & Chaiyawat, 2011). The assumption is that parenting is a long-term developmental process that continues and evolves throughout the life of the child. By contrast, most pregnancy scholars see pregnancy as the time for *preparing* to become parents (Ammaniti, Trentini, Menozzi & Tambelli, 2014; Deave, Johnson & Ingram, 2008) but there are a few who take the view of mother, and sometimes the father, as actively parenting during pregnancy (Bouchard, 2011; O'Leary & Warland, 2012; O'Leary & Thorwick, 2008). This is referred to as *prenatal parenting*. Prenatal parenting includes making emotional space for the new baby, attaching to that baby, and having on an intentional focus on the parent-child relationship. The prenatal parenting scholars contend that this early parenting lays the foundation for parenting after birth (Bouchard, 2011; O'Leary, Warland & Parker, 2011; O'Leary & Thorwick, 2008).

Parenting is defined here as the process of becoming a parent as an expectant mother or father in relationship with their unborn and newborn child. Characteristics of parenting include being attached, committed, caring, and nurturing towards a child. Prenatal parenting is seen as a developmental process that begins during pregnancy and evolves over time (Deave et al., 2008).

The concept of prenatal attachment first appeared in the literature in the 1970s. Characterized as the emotional bond parents develop for their unborn baby, it has been proposed as predictive of parenting behaviors after birth (Brandon, Pitts, Denton, Stringer & Evans, 2009). Rubin (1975), Cranley (1979), Condon (1985), and others recognized that mothers fantasized and thought about their unborn and their relationship to that child as mother. Prenatal attachment, also referred to as bonding or binding-in, is a concept frequently addressed within the context of pregnancy but not necessarily as part of parenting (Brandon, et al., 2009). It refers to the mother and father's awareness of the baby as separate from self, with its own personality, and an increasing commitment to love, protect, and be with that baby. Our conceptualization is that prenatal parenting is broader than and includes prenatal attachment and that both are demonstrated through parenting behaviors.

Parenting behaviors have been categorized and defined in various ways by researchers. For instance, Belsky (1984) theorized that parenting behaviors are determined by the psychological and personal characteristics of the parents as well as the context in which the parenting takes place (e.g., the relationship between the parents, quality of social support, and other life circumstances). There is some agreement that two domains encompass the majority of parenting behaviors: warmth and control (Skinner, Johnson, & Snyder, 2005). The positive affect that parents display towards their baby is conceptualized as warmth (Pomerantz & Thompson, 2008). Within the domain of warmth are behaviors such as nurturing, praising, smiling, and vocalizations of love and acceptance. The domain of control includes parenting behaviors of limit setting, autonomy, discipline, expectations and consequences (Pomerantz & Thompson, 2008). Parenting behaviors displayed during the prenatal period likely fall largely within the domain of warmth rather than control since control behaviors are pertinent only after the baby is born.

The parenting literature does not include prenatal parenting behaviors with a known lethal diagnosis, likely because this circumstance of knowing the diagnosis during pregnancy has only recently been on the rise. Therefore, the purpose of this paper is to describe our findings of parents' prenatal parenting when faced with a lethal fetal diagnosis.

Methods

Women were purposively recruited for this longitudinal, phenomenological study through high-risk maternal-fetal programs and networking in four states. Care providers identified and approached eligible women who were 18 years or older, English-speaking, pregnant with a singleton fetus with a prognosis of 2 months or less, and who were choosing to continue their pregnancy. Once referred to the study, the principal investigator (PI) asked interested women if they would be willing to include their partner; lack of a participating partner was not an exclusion criterion.

Approval from the Human Subjects Review Boards was obtained from the home institutions of the authors. Eligible participants were identified by healthcare providers in the Eastern and Midwestern regions of the United States. Providers gave potential participants a brief description of the study; if they demonstrated interest, they then gave permission to be contacted by the PI. Informed consent also was obtained from each study participant prior to beginning the study. Recruitment continued until redundancy of parent experiences was reached.

Data Collection

Participants were interviewed multiple times (range 1-5; mode of 4) beginning as soon as possible after the fetal diagnosis, through the birth, and postpartum. Interviews were conducted in-person, over the telephone, or via teleconference (Skype™), first with the couple together and then separately when possible. Interviews ranged from 25-120 minutes. Using the interpretive phenomenological approach (Lopez & Willis, 2004; Merleau-Ponty, 1945/1962), the aim of the interviews was to learn the couples' and individuals' lived pregnancy experiences. Each participant was given $20 per interview and was also given small gifts following their initial and last interviews.

The PI (DCA) conducted all interviews using an interview guide that included open-ended prompts that explored issues of priority for the parents during their pregnancies. Interviews allowed participants to freely discuss all aspects of their pregnancy experiences. All interviews were digitally recorded, professionally transcribed, and meticulously verified. Field notes were written following each interview to capture the nuances and tone of each interview and participant. Non-verbal behaviors exhibited by the participants during in-person and teleconference interviews were included in the final interview transcripts.

Data Analysis

Transcripts were de-identified and imported into Atlas.ti7® for data management. The research team consisted of two nurse researchers, a palliative care physician, and a graduate research assistant. The process of data analysis co-occurred with data collection and continued throughout transcript verification, coding cycles, theme verification, within- and cross-case analyses, (Miles, Huberman & Saldaña, 2014) and the writing of results. All data coded as "parenting," "parenting during pregnancy," or "parenting after birth" were queried and compiled in one document. Within this document major themes were identified and discussed among the research team. Memos were written during coding sessions whenever patterns in the data were identified. Case matrices were displayed as case-by-case chronology to aid in cross-case comparisons. Cross-case analysis occurred through constant comparison. During data analysis, the research team recognized the need to further clarify and define parenting and parenting behaviors. It was at this point that the team examined the parenting literature.

Trustworthiness

Numerous strategies were put in place to increase the study's trustworthiness (Lincoln & Guba, 1985). A detailed audit trail, including field notes, memos, and process notes were written and referred to throughout the data collection and analysis. Prolonged engagement with a single qualified and experienced interviewer and multiple interviews with participants over time were key elements of the study design. The multi-disciplinary research team, including both maternity and pediatric nurses, a palliative care physician, and a public health doctoral student worked independently and came together weekly during analysis and writing. Member checks were done at every interview through clarification of previously revealed details and perceptions.

Results

Sample

The final sample was comprised of 30 parents (16 mothers, 13 fathers, 1 partner) residing in four Midwestern and Eastern states. The mothers' ages ranged from 22 to 42 years (M= 32.9; SD= 5.5). The fathers' ages ranged from 21 to 49 years (M= 33.64; SD= 7.2). Participants were 70% Caucasian (N=21), 30% minority (N=9; African American, Hispanic, Pacific Islander). Range of family income was broad, from less than $10,000 to greater than $120,000 (modal bracket: ($60-80,000). Fetal diagnoses were varied including genetic abnormalities (N= 10), oligohydramnios and kidney disease (N=3), anencephaly, skeletal dysplasia, and ectopia cordis. The majority of participants had other children, and this was a first pregnancy for 6 mothers and 5 fathers. The majority of the participants were married (N=11), including one lesbian couple. Five of the mothers were not married to the father of the baby; two of these fathers participated in the study. Three couples had a history of infertility; and three had a history of prior pregnancy losses.

Parenting Behaviors

Discovery of parenting behaviors was not a goal of the larger study, rather these behaviors emerged from every parent's story throughout data analysis. The extent to which the individuals assumed their role as parent was unique and compelling, and could not be ignored. Although many participants had other children the behaviors described here were in relationship to the unborn baby.

Antecedents to parenting.

Prior to entry into our study each mother and partner had come to terms with being pregnant, and when learning about their baby's condition chose not to intervene with the continuing pregnancy. Each couple named their baby and referred to themselves as their baby's parents. These behaviors are indicative of a commitment to this baby as a person, to themselves as parents, and to the remainder of their pregnancy journey.

Within this context parents told their on-going story during interviews. All were shocked and devastated by their baby's diagnosis and likely prognosis. They shared their thoughts, feelings, and hopes about their baby. They created opportunities to be with and interact with their baby. Participants were trying to be the best parents they could be in the short time they had. In fact, it seemed that their parenting was deliberate, accelerated, and compressed knowing that their time with their baby was brief. As one first time father stated, "We both decided to take this attitude that we are going to cherish every day, every moment that we have with her." Parenting behaviors we identified fell into five categories: 1) Taking care; 2) Promoting baby's personhood; 3) Interacting with baby; 4) Being with baby; and 5) Loving baby. Data saturation was reached within each category. As with all parenting behaviors, a single behavior could be classified in more than one category but we used the participant's words and meanings as our priority guide for category designation. Pseudonyms are used to protect confidentiality of the mother, father, or baby.

Taking care.

The parenting category of *Taking Care* was the most prominent and prevalent within our data, and refers to decisions made and actions taken by the parents in the best interest of the baby. Four behavioral dimensions of *taking care* emerged from the data: the physical care of mother and fetus/baby during pregnancy and after birth, finding best health care for pregnancy management, birth and death planning, and protecting the baby.

All parents sought prenatal care to insure the physical health of mother and baby. When they heard that there was something seriously wrong with their baby they immediately desired to see Maternal-Fetal Medicine (MFM) specialists. Several couples were grateful that they were promptly referred to MFM so they could gain more knowledge. In fact, one couple was quite distressed when they had to wait several days before seeing a specialist. The mother was herself a

care provider, “Especially as a care provider, that was my first frustration, just feeling like—we were told something’s not normal, but just wait until your next appointment.” Following an official diagnosis, there was a drive to learn everything they could about their baby’s condition. Another mother in her first pregnancy described, “I went on the internet to kind of get a little bit more research on it. I did see some of the photos of the babies online that are diagnosed with trisomy 13.”

Mothers lamented that they had done “everything I was supposed to do” to insure the health of themselves and their baby and yet the diagnosis was there. They questioned how much impact they could have but were ready to do anything that might help. This included reducing their stress, drinking water, and getting rest so that the baby could grow as much as possible and have the best chance possible at birth. One mother explained what her focus was at 30 weeks gestation, “Right now, keeping myself healthy to keep her healthy, protecting her, doing my part and giving her the longest time.” Mothers wanted to keep baby in utero for as long as possible, to provide as much time as they could for lung and organ development as well as wanting time with baby while alive. As another mother explained why she was advocating for her daughter, “At least I’ll be able to look in her face and tell her I love her, hold her, and let her know that I did try all I could.”

Decisions were made about amniocentesis, timing and mode of delivery, and degree of intervention and comfort care, always keeping what was best for the baby a priority in decision-making. Making decisions was something that the parents could do, it was their tiny bit of control. For example, one mother explained that, “I could’ve had the amnio but the statistics of the mother going into labor early from it, I was like I’m not giving any…chances of her coming early. I want her to last as long as she can.” A father clarified why he and his wife wanted resuscitation efforts to be done immediately after the birth of his daughter, “We couldn’t just, NOT!..but we had to try—I mean [we] put up a hell of a battle for these last months. Why can’t we fight a little more for her now, that we have some control? I think we…did what was right for her.” With her baby in the neonatal intensive care on a ventilator a different mother explained her assumed role as parent, “Even though I can’t do much or whatever, I can read his stats, I could look and see what’s going on.”

Care providers were chosen to *take care* of mom and baby as best they could, often done by specifically transferring their care to a high risk pregnancy medical center and perinatal palliative care. Unsure of their baby’s diagnosis and subsequent prognosis, one couple traveled a distance to seek care. For one father it was essential that they try everything they could due to their son’s uncertain prognosis, “Knowing that we’re pulling out the stops, and leaving no stone unturned and leaving it all on the field, so to speak, gives me solace.”

The *taking care* was somewhat different for an unmarried couple with an unplanned pregnancy. They decided, prior to any pregnancy complications that they needed to give the baby up for adoption. The mother of seven other children explained, “Because I just can't handle another baby right now. Yeah, I didn't want to raise another fatherless baby, that's not fair… I just thought I'd find the perfect people, and I actually did. I found the perfect people.” The mother was unconvinced of the diagnosis so plans for adoption stayed in place despite the uncertain fetal prognosis.

Birth planning was another major area of focus as a way to *take care* of their baby. The process of planning for the labor and delivery occurred over time with input from care providers. Many wrote formal birth plans with several contingency plans for various scenarios, and others never put their desires on paper, their time cut short by preterm births. Going into premature labor meant that there was little time to plan, as a mother described, “Neither one of us felt ready. We were not ready to do this.” One couple had written that they wanted a cesarean birth if their baby was in distress during labor. Indeed, that is what happened, the mother had emergency surgery and said,

> . Then our pastor baptized him right away in that first minute. That right there was like our primary goal with Tyler once we found out, you know, what he was diagnosed with [trisomy 18], was just to have that live birth and have him baptized. Being able to see that was really nice.

Protecting the baby, even after death, was expressed by all parents. During pregnancy that same couple wanted to keep their life as normal and upbeat as possible for their other children and for their unborn as the father described, “We know Tyler can hear everything. We don’t want [our other children] to feel like it’s a negative environment. We want to be as happy as we can and keep things positive.”

A similar approach was displayed by a mother who told hospital visitors to cover up her deceased daughter as you would a normal baby, “I was like, just cover [her] up like, you know, like she’s fine… Yes. That meant a lot to me. I mean I didn’t think about it before, but I was like protective of her.” A father described being, “Protective about who would take his baby to the morgue. We actually asked someone that we felt close to [a nurse], to please take him and not leave him alone until they came because they were on their way and we weren’t able to do it.” His wife added “She took care of him for us when we couldn’t. We felt good about that.”

Protection was also conveyed through baptism. Several parents expressed concern about their baby’s afterlife and were adamant about their baptism. As conveyed in a previous quote, parents often invited clergy or close relatives to perform the rites immediately following the baby’s birth. Another expression of protection was seen with the desire to keep the baby warm even after death. “I kept asking her, ‘Do you have extra blankets to make him comfortable?’… because I didn’t want him to be cold in the morgue.” Other mothers dressed their baby with warm clothing and put more blankets in the coffin to keep baby warm.

Promoting Baby’s Personhood.

Various behaviors were undertaken to acknowledge the existence and value of their baby, as well as the uniqueness and purpose of their baby’s life. These parents placed high value on their baby as a person. All parents called their baby by name and referred to baby’s gender; they were a person. They asked others to call the baby by name, including health care providers. Elsa’s mother reported that “The doctor even asked us if we had a name picked out for the baby before he told us the results. That tiny gesture right there skyrocketed my respect for him.” Some parents went further with their sense of their baby as a person by referring to their baby’s personality with pride, describing baby as “feisty” or “a fighter.”

One mother donated her breast milk to insure that their son’s life had significance, “[My milk] came in and I kind of—I was kind of surprised, but then I made the decision that all this is happening for a reason. I was accepted as a donor at the… milk bank. So, I’ve been donating milk there.” One baby with trisomy 13 lived for over two months. His mother posted photos each day on a social media site not only to celebrate each day of his life but also to increase understanding of the disease that eventually ended her son’s life. They wanted his life to make a difference. The mother commented,

> Our goal was to let Blake know that we loved him more than life itself and we were so honored and proud of him. I felt so bad for crying when I found out about his disease that I wanted him to know how much I do/did love him. It was never me crying about him I was crying about what was happening to him.

After baby’s birth and death parents found several ways to hold their baby’s place in the family. This was done through hanging “his hand and footprints, and photos” up with other family photos, having a baby photo as one’s wallpaper on their cell phone, displaying items in their home such as “Her urn is in our bedroom and kind of just on display for the two of us.” Other families created a garden as a memorial or bought a special angel Christmas ornament that would be hung on the tree every year.

Interacting with Baby.

Interacting with baby was a common parenting behavior which includes the physical, visual, and audial contact with baby in utero or after birth where parents perceive or seek a reciprocal response from the baby. Likewise, parents offered reciprocal responses to perceived interactions initiated by the baby. Reciprocity is a clear criterion of interaction. Several parents established a bond with their babies through talking, touching, watching their babies during ultrasound, and making eye contact after birth. Couples often believed that their babies responded to their physical and audial contact through movement or facial expressions seen through ultrasound images. One mother discussed how the ultrasounds brought her family closer to her daughter by giving them the opportunity see and interact with her baby. The mother commented how her teen-aged son would direct his sister to “kick mommy” during the ultrasound. The brother’s gentle prodding was believed to have convinced the baby to actually kick the mother when directed. This interaction brought much pleasure to this family and reinforced their sense of mutuality with the baby.

Through their interactions, parents attributed characteristics and personalities to their babies and often adjusted their actions to suit the baby’s apparent mood or temperament. For example, one mother gave up sweet tea because her baby did not like sugar and would “ball up in a lump” when the mother consumed sweets. Another mother discussed how her baby had the personality of a troublemaker. She commented how her baby would “lick her tongue” and do “sneaky things” like kick her and smile about it during the ultrasound; this interaction led the mother to believe that her baby would be a “hell raiser” like her sibling. In fact several mothers believed their babies took direction and cues for action when prompted. These verbal-physical exchanges were often seen by mothers as the baby’s display of satisfaction or dissatisfaction with the parents’ decisions or external stimuli. For example, one mother in her first pregnancy commented,

> Well, me and Darnell talk to her all the time. We have family time every day, ask her if there’s something that she wants us to do, we’ll do it, you know, kick once for yes or kick twice for no. We read to her. We just laugh. We laugh!

Although mothers were more likely to comment on their interactions with the baby, fathers and partners also experienced interaction with the baby through touch and voice. Unlike mothers who could feel the baby within them, fathers and partners were not able to have constant contact and bonding time with the baby during the pregnancy. Family time with the baby was an essential part of the fathers’ experiences as they were able to feel the movement of their babies at the sound of their voices.

> I'm pretty sure that Elsa knew his voice. When we'd crash on the couch after the other kids were in bed, she would start moving around a little bit more when he started talking. When he and I ‘argued' over what to watch on TV, she kicked more when he talked about football.

Parents also experienced interaction with their babies after birth. The post-natal period was a time to bond with babies through interactions deemed impossible in utero such as touch and eye contact. These brief, yet important, moments allowed parents the opportunity to experience the joy, grief, and closure of their babies’ life and death. One mother often visited her baby in the NICU to participate in her care. During these moments, she would hold her baby for eight hours a day in attempts to comfort her ailing daughter.

> Then I’d put my head down on her chest and let her do my head like that with her little hands [she demonstrated the position]. I’d be like, “Calm down, Brianna. Stop it,” and she would just [whimper] and fall on off to sleep.

Being with Baby.

All of the parents expressed feelings about needing to be as close to their infant as possible. Being with baby has two aspects, seeking physical closeness and enjoying time with baby. This was much more pronounced in the mothers' comments prior to birth. However, both parents and partner comments reflected the idea that spending the time with their infant needed to be purposeful, given that their infant may not live more than a few hours after birth. Therefore, seeking physical closeness is a parenting behavior marked by any activity undertaken to achieve close physical proximity to the infant, both in utero and after birth.

Prenatally, mother's often commented on the reassurance they felt when their baby moved or kicked. One mother commented, "I'm paying close attention to her kicks and punches, so I know she is here." This same mother recounted the meaningfulness of the ultrasounds that helped her be closer to her baby,

> Watching her move and kick is amazing, given the circumstances. Seeing her suck her thumb made everything feel so *normal*. I can't wait to hold her. But I've heard her heart beating - many times now. I've seen her squirming. I've felt her kicking. I know she's very much alive.

Fathers also sought physical closeness to their baby, although they did not talk about their behaviors as frequently as mothers. One father commented, "We talk to her [the baby] all the time. We have family time every day, she hears what's going on, and she is with us." Another father voiced the desire to be physically close to his baby as part of the birth planning process, "The important part is to keep Aaron with us as much as possible because we don't want him to pass away from us basically so as much as they can do in regards to him being with us most of the time."

While most parents were expecting that some measures would be taken to promote an optimal outcome at the time of the birth, all made comments that they needed to have their babies close to them, no matter the outcome. One mother commented, "We all need to do what we can and just be her parents and let her know that we are here with her." Another mother expressed her desire for physical closeness as.

> I just would rather her have whatever time she has here and make it the best of all of us, you know, spend as much time with her as possible…Now, I do find myself, you know, putting my hand on my stomach and trying to find the movement to make sure she's still in there. I need to feel her there and I need to feel her move. I really want her to be born alive so I can hold her for just a few minutes.

After the birth, and at the time of the baby's death, parents expressed thankfulness that they were able to spend as much time with their baby as was possible. One couple talked about having the staff understand and accept their request to keep their baby close. One mother commented, "I wanted her [the baby] to still be close to me like she'd be laying there over on the table. I actually slept with her in my arms the whole night." Clearly, the physical closeness parents reported helped them engage and bond with their baby. In the post-partum interviews, all parents commented on the importance of the physical closeness, particularly during the time of their baby's death.

The enjoyment parents felt in being close to baby is evident in previous quotes but other statements illustrate more clearly that enjoying *time with baby* occurred during pregnancy and after birth and death. A mother shared that during the pregnancy they went camping as they often did, her other children recognized their unborn brother's presence, "That's been nice because [the other children] were like, 'Oh, this is Tyler's first time at Yogi Bear [camp grounds]!'" Another couple recognized that, "It's like when it's just me and her, like we're still trying to be happy and enjoy life and we're not dwelling on the fact that he's going to pass away and they are."

During pregnancy Melissa was not ready to plan his birth/death, she just wanted to enjoy the pregnancy and feeling Caleb alive inside. Even after birth of her stillborn son this mother enjoyed being with her baby,

> It was wonderful. We had him all wrapped in a special blanket and I held him. We had some family come in and our priest came in. I got to like show him off. I was kind of like introducing people to him and everybody has said to me that like they were kind of in shock. I promise you, I was gloriously happy.

Loving Baby.

Parents in the study expressed love for their baby, defined here as an affectional affinity, an unconditional emotional attachment to the baby. Their behaviors were found to be similar to prenatal attachment described elsewhere but with unique dimensions.

Words of emotional ties to their unborn baby were frequent and tender, once the baby was born some parents expressed unconditional love for baby and pride in their child just as they were, anomalies and all. The mother of a baby with trisomy 13 who lived for 2 months stated,

> He was my miracle, my joy, my greatest accomplishment. He was why I was here on the earth. I was supposed to bring him to life and introduce him to the world. I loved him the minute he was born and every day since.

Another mother, whose baby was in NICU with a skeletal dysplasia on CPAP, said this to the neonatologists,

> My baby was perfect. She [could] move her little arms, kick her little legs. There just wasn't much of it. She could get mad. It was just so funny. That's the part that I love the most when she would just get so upset…I just want you to do everything you can. I need her. I want her. I don't want to be selfish, but I want my baby.I want her.

After birth many of the parents described a joy at meeting their baby. After the still birth of her son a first time mother reported, "It wasn't anything I was prepared for because everybody kept telling me that, you know, it's your baby and when you see him, he's just perfect and all this stuff and that really was it. He was just <u>awesome</u>!"

A second mother shared those sentiments after giving birth to her stillborn son, her second child, "Yes, I wasn't sad for hours. Hours. I just basked in his angel glow…I wasn't sad. I wasn't sad until later when I realized I couldn't keep him."

Fathers often expressed their love for their child by carrying the body to the funeral director and carrying the casket at the funeral. A mother agreed with this interpretation,

> When we had to say goodbye to her in the hospital, John was the one who took her from my arms and placed her so gently in a basket. A nurse didn't do it. The funeral home man didn't do it. Elsa's daddy did. It took an immeasurable amount of love - for me and his Elsa - to do that…At the end of the service, I watched John walk over to Elsa's casket and pick it up. It was probably the moment he felt his weakest as a daddy. But he showed more strength and love and sacrifice in that moment than I have ever seen. As awful as it was, there was beauty in that moment.

While most parents described intense love for their babies, some expressed ambivalence. One mother described, "I'm so torn. I want so much to enjoy her now, but I'm so afraid of getting even more attached to her." Several fathers shared the same concern, "I think I'm scared, scared of getting too attached. Others recognized that their time with baby was limited so they focused on their relationship with the baby while they could."

Fathers also recognized that it was easier for them to stay detached because they were not carrying the baby the way the mother was,

> I explained to everybody [in the support group] that we don't know what the women are going through because we don't feel the baby; we don't have that bond like they do. If I looked like I'm not being emotional about it or if I don't care about it, it's not that…Even though it's our baby, you know, we care about it, we love it but we'll never know the feelings like they do…

The mothers and fathers in this study demonstrated many behaviors in the warmth domain of parenting. In spite of their grief they saw the personhood, value, and uniqueness of their babies. Each baby was held close to the parent's heart.

Discussion

As 30 parents shared their stories of continuing pregnancy with a known lethal fetal diagnosis, we were surprised and touched by the words and emotions used throughout our interviews, of love and commitment to their unborn children. Despite the lethal diagnoses, the participants viewed themselves as parents, and their babies as precious. Contrary to common societal reaction where the focus is on what is wrong with the baby, these parents focused on everything positive about their babies. Our overall impression is that these parents were very mindful in their parenting, consciously treasuring every moment with their babies (Duncan, Coatsworth & Greenberg, 2009). The idea of prenatal parenting is not new, and we are convinced that indeed, that is what the vast majority of our participants were doing. Through taking care, loving, interacting and being with, and promoting baby's personhood these parents displayed an extensive list of parenting behaviors, consistent with the Skinner et al. (2005) parenting domain of warmth.

Mothers wanted to keep their baby in utero for as long as possible, to provide as much time as they could for physical development. They also did everything possible to optimize the conditions of their baby's birth to maximize time with baby while alive. Through choosing to continue their pregnancy, parents are affirming the personage of their baby and the importance the baby has in their lives/family. The findings here are consistent with the parental view that "My Baby is a Person" despite his or her lethal condition (Côté-Arsenault & Denney-Koelsch, 2011). Despite the grief and distress of realizing their baby's diagnosis, the participants in this study embraced being parents to their child and all that that entailed. They made numerous medical decisions keeping their baby's well-being front and center. None of the mothers stated that they wanted their pregnancy to end, even in light of their own discomforts. They treasured each day with their baby because they knew that there would likely be little time together after birth.

It should be noted that there were some parenting behaviors common to normal pregnancy that were rarely reported in this study, such as such as setting up a nursery and having a baby shower. This was consistent with the unlikelihood of their baby going home after birth. One couple had set up a nursery in case they needed at-home hospice, and another couple had ordered furniture prior to their diagnosis but did not have it delivered until they knew that their baby was able to go home.

A few of the fathers who participated in the study (N=3), but were not married to the mother, were less engaged in the pregnancy and thus, were noticeably less engaged in the parenting role, particularly after the lethal diagnosis. This is consistent with the previously reported theme of *arrested parenting* (Côté-Arsenault & Denney-Koelsch, 2011) where parenting behaviors stopped after the lethal diagnosis. Most of the parents here, however, did not show arrested parenting. Our data suggests that their parenting was actually accelerated as described here. Parents in this study chose to focus their love and attention on what they could do at the present moment and on memory-making.

Strengths of the study

Our sample of mothers and fathers was quite diverse, geographically, socioeconomically. It also included a wide range of both commonly encountered and rare fetal diagnoses with largely expected outcomes. All of the characteristics of the sample increase the transferability of the findings. The longitudinal nature of the interviews allow significant depth of parent experiences to emerge.

The diverse research team brought multiple perspectives to bear during analysis which contributes to the dependability and confirmability of the findings. The researchers' rich descriptions of the participants' prenatal parenting experiences enhances the study's transferability. Recruitment was done from large medical centers and smaller community settings over multiple states, with wide variation in palliative care access. However, it is unclear how the nature of their medical care influenced their pregnancy experiences. This is an area that deserves attention in future research.

Limitations of study

Given the recruitment methods used to identify potential participants, self-selection may have resulted in a sample different from the overall population of those who choose to continue their pregnancies. All parents saw participation in research as a positive thing to come out of their difficult situation. Participants were also limited to those who were capable of sharing their experiences. Indeed, we were told by one mother that her baby's father did not participate because he was too emotional to tell his story. All participants had chosen to continue their pregnancy, so the perspectives of parents who chose to terminate are not represented here (Hawkins, Stenzel, Taylor, Chock & Hudgins, 2013; Sandelowski & Barroso, 2005). Lastly, while there was some ethnic diversity in the sample, all were English-speaking, and thus the results likely do not reflect the experiences of all.

Clinical Implications

A primary desire of the parents in our study was to feel like good parents. Providers should be aware of the role of prenatal parenting as they facilitate decision making, goal-setting, and providing support. Care providers can facilitate parenting by calling the baby by name, provide opportunities for parents to see the positive qualities of the baby through ultrasound and after birth, and explore the factors that influence their decision-making.

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