

"My Baby Is a Person": Parents' Experiences with Life-Threatening Fetal Diagnosis

Denise Côté-Arsenault, Ph.D., R.N.C., FNAP and Erin Denney-Koelsch, M.D.

Abstract

Diagnosis of a lethal fetal diagnosis (LFD) early in pregnancy is devastating for parents. Those who choose to continue with the pregnancy report intense emotional reactions and inconsistent, often insensitive treatment by health care providers. This qualitative descriptive study sought to clarify the experiences and needs of families in order to design responsive perinatal palliative care services, and to establish the feasibility and acceptability of conducting intensive interviews of pregnant women and their partners during their pregnancy with a LFD.

We interviewed 2 women and 3 couples during pregnancy or just after birth, using open ended questions. Audiotaped responses were analyzed by two investigators. Two dimensions and six themes emerged. In the dimension of Personal Pregnancy Experience, "Grieving Multiple Losses" elucidates that parents grieve the loss of their normal pregnancy, healthy baby and future parenting. "Arrested Parenting" describes their sudden interruption in the normal process of becoming a parent. The theme "My Baby is a Person" reflects parents' unanimous desire to honor and legitimize the humanity of their unborn baby. In the dimension of Interactions of Others, three themes were found. "Fragmented Health Care" describes parent's disjointed and distant encounters with multiple providers. "Disconnected Family and Friends" describes the lack of understanding of what the families were experiencing. "Utterly Alone," which crosses both dimensions, expresses how the parents' sense of social isolation adds to their personal sense of loss and loneliness. Recommendations are made for palliative care's role in respecting and validating the experience of parents living through a doomed pregnancy.

Introduction

SCREENING PRENATAL ULTRASOUND is the standard of care starting between 12 and 20 weeks gestation. Seeing one's developing baby on the sonogram screen can be a joyous experience, but for some families the images bring the worst of news. Potentially lethal abnormalities such as trisomy 13, 18, or renal agenesis are detected in an estimated 2% of all pregnancies.¹ Learning that one's unborn baby has a condition that is incompatible with extrauterine life is traumatic, requiring difficult decision making about the pregnancy.²⁻⁴ For those who choose not to terminate, a substantial period of time is left to anticipate a potentially dire outcome.

Some women continue the pregnancy because they lack the legal option to terminate; others (estimates range from 20% to 85%) choose to let the pregnancy take its natural course. Couples have reported that they chose not to intervene with the course of the pregnancy for a variety of reasons including religious beliefs, viewing the baby by sonogram, experience with people with disabilities, and prognostic uncertainty.⁵

Those women who choose to continue are not always supported in their decision by care providers. Some have been pressured to terminate or have been refused ongoing perinatal care.^{6,7} Parents are asked to make critical decisions about mode of delivery, degree of neonatal resuscitative efforts, and options for comfort measures and bonding time, decisions that could potentially be guided by palliative care (PC) consultation.⁸ Perinatal PC is not commonly available, however, and has not been adequately studied. Previous research has largely been retrospective, and has not gone in depth into parents' experiences and needs.

Emotional distress, grief, and even post-traumatic stress disorder (PTSD) are known reactions to perinatal loss (miscarriage, stillbirth, neonatal death)⁹⁻¹¹ and pregnancy after a previous perinatal loss.¹¹⁻¹⁵ In retrospective U.S. and European studies, couples have reported experiencing significant emotional and physical distress after ultrasound diagnosis, including anger, sadness, and sleep and eating disturbances.^{3,4,16,17} Parents have expressed frustrations over poor communication, feeling abandoned, and needing

more time to make decisions.^{2-4,17-19} Parents coped using denial, optimism or pessimism, privacy and control, and attachment to or detachment from the baby. They reported that it was not helpful when providers encouraged pregnancy termination or focused only on maternal health.

The only US prospective study of parents who chose to either terminate or continue with pregnancy with a lethal fetal diagnosis (LFD) found that many parents experience personal growth out of this traumatic experience.²⁰ Other studies focused on a single diagnosis²¹⁻²³ or used survey data based on recall rather than conducting in-depth interviews with parents during the pregnancy. Therefore, we conducted a qualitative descriptive study, using semi-structured, open-ended interviews of parents in the perinatal period to allow in-depth, personal storytelling. Our goal was to explore the parents' experience of pregnancy with a LFD in order to gain insight into their needs. We also sought to demonstrate the feasibility and acceptability of research participation of couples during this stressful period, so that more information, gathered by future studies in larger samples, can guide the formation of improved care programs in perinatal palliative care.

Methods

Qualitative descriptive design^{24,25} was used for this study, with convenience sampling. Following receipt of institutional review board approval, pregnant women and their partners were recruited after a referral was made for PC consultation through regional perinatal centers in two upstate New York cities. A phone call was made to confirm the woman's (and her partner's) willingness to be interviewed. An appointment for an interview was made at a time and place convenient for the family, either during pregnancy or after birth.

Sample

Inclusion criteria were 1) the mother was pregnant with a baby with a postbirth life expectancy of 2 months or less (i.e., diagnoses such as trisomy 13 or 18, renal agenesis, or anencephaly), and 2) she planned to continue the pregnancy. Seven families were identified as meeting inclusion criteria; all agreed to be contacted by the research team. Five families were interviewed: two women and two couples were interviewed during pregnancy, and one couple was interviewed postbirth, for a total of eight parents. The remaining two couples initially agreed to be contacted, but subsequently they refused participation because their ill newborns required their attention. All families in the study had received PC consultation, although this was not a requirement. Informants were 19 to 38 years of age. Seven were Caucasian, and one woman

was of mixed Asian background. All had a minimum of high school education; half had graduate education. Household incomes ranged from \$0.00 to more than \$120,000. The index pregnancy was either the first or the third for the woman. Two women had a history of one prior loss, and one woman had had one elective abortion. One couple had one live child. See Table 1 for pseudonyms, prenatal diagnoses, and pregnancy outcomes.

Interview guides

Interviews during pregnancy focused on the chronological events and the mother and/or father's responses to those events by asking them to tell their pregnancy story. Prompts, such as "Could you tell me more about that?" and "How was that for you?" were interjected when more detail or direction was needed (see Table 2 for interview questions). A postbirth interview included both events in the pregnancy and parents' recent experience with PC services.

Procedures

Recruitment was done through the obstetrician or PC physician who briefly explained the study to the mother at the end of their consultation, and who obtained permission to send her contact information to the investigators. One investigator then contacted the mother to further explain the study, invite the father to also participate, and schedule a time and place for an interview. Interviews took place wherever the mother chose, that is, in the couples' home, in the hospital, at a prenatal care site, or at a coffee shop. After informed consent was given, a single, audiotaped interview of 45 to 75 minutes was conducted with each family by one of the researchers. Couples were interviewed together.

Data analysis

Thematic analysis followed principles outlined by Morse and Field,²⁵ and began at the time of data collection. Field notes were written during or immediately following the interview. Tapes or transcripts were reviewed repeatedly by two investigators across the analysis process.

The authors reviewed the interview data independently prior to each team meeting; memos were written as analysis proceeded. Initially, each shared emerging themes, as well as relationships between themes. Subsequent analyses and meetings led to deeper understanding, thus moving from comprehending, to synthesizing, and to theorizing.²⁵ Consensus was reached on a final list of themes with illustrative descriptors and quotes. Further analysis led to the recognition

TABLE 1. PARTICIPANT PSEUDONYMS, FETAL DIAGNOSES AND OUTCOMES, AND GESTATIONAL PERIOD AT TIME OF INTERVIEW

<i>Mother</i>	<i>Father</i>	<i>Time of interview</i>	<i>Fetal diagnosis</i>	<i>Pregnancy outcome</i>
Amy	(did not participate)	Third trimester	Trisomy 18	Death during labor
Barbara	(did not participate)	Second trimester	Hypoplastic left heart	Death shortly after birth
Carrie C.	Christopher C.	Third trimester	Trisomy 18	Fetal death
Darria D.	David D.	Third trimester	Renal agenesis; Potter's sequence	Death shortly after birth
Elena E.	Eric E.	1 month postbirth	Multiple GU malformation	Live birth, infant's condition better than expected

TABLE 2. SAMPLE INTERVIEW QUESTIONS

1. "Please tell me about this pregnancy from the beginning?"
2. "How have other people reacted to the baby's diagnosis?"
3. "What could the doctors and nurses provide you right now that would be helpful?"
4. "What has it been like to talk with the palliative care team?"
5. "Has the palliative care team made a difference? If so, how?"

that the themes fell into two dimensions: Personal Pregnancy Experiences and Reactions of Others. (See Fig. 1.)

Strategies used to insure the trustworthiness of the process and findings of this study included the interdisciplinary team of investigators, audiotaping of interviews, writing of field notes and memos throughout data collection and analysis phases, and independent and joint analysis meetings that led to agreement on the findings. Member checks were not done because we wanted to ensure that parents' observations were contemporaneous to their experiences during pregnancy.

Results

Our overall impression was that the parents, in spite of their grief, demonstrated love for their baby and determination to find meaning in and honor their baby's life. The dimensions and themes are depicted in Fig. 1, showing the disconnect between the parents' personal experiences and that of others, experienced through their interactions with others, leading to an intense sense of isolation that heightened the parents' experience of loss. Table 3 provides quotations from the interviews that support each dimension and theme.

Personal pregnancy experience

The dimension Personal Pregnancy Experience includes the powerful and deeply personal responses of parents, singly and as a couple, who learned of an LFD during pregnancy.

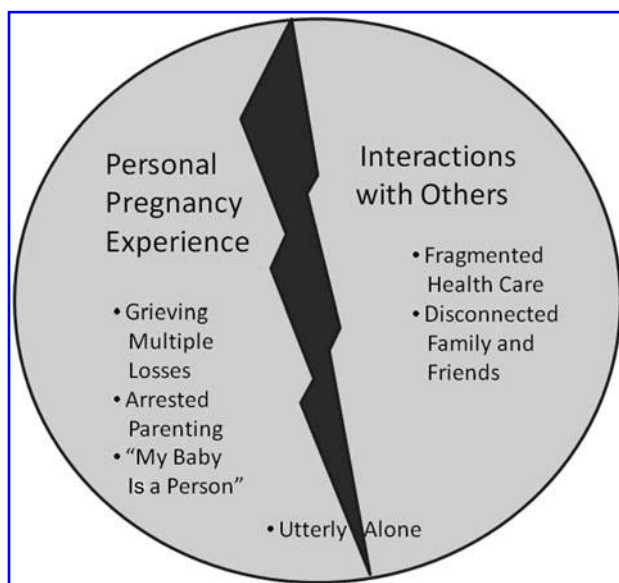


FIG. 1. Study dimensions and themes.

Interview data from parents revealed three themes within this dimension: Grieving Multiple Losses, Arrested Parenting, and "My Baby Is a Person."

Grieving multiple losses. Parents described experiencing a number of losses: loss of their healthy baby, of the normal pregnancy experience, and of the future parenting of their child. Their realization of these losses changed over time as their shock subsided and the pregnancy progressed. Their immediate sense of loss eventually extended into their social pregnancy experience and loss of the future. This theme describes the multiple ways that the parents experienced their grief, including disbelief, the sense of it being surreal, loss, guilt, and anger. (See examples in Table 3.)

Several parents expressed an initial hope that the bad news would not really be true. Christopher said, "We were really hopeful that there was a mistake, or at least I was... We were like, maybe it'll go away by next time... I was really confident that there wasn't really going to be any problems." Darria shared that, "I kept thinking they put me on bedrest and now I'm out of [work] and everything was going to be fine."

Several people said that their experiences were surreal. Amy said, "It's just, it's weird because it's almost like right now I'm just taking it so well, that I almost think that I feel like it's not happening to me. But, I think that when I see him, and when I deliver him, it's going to be totally different. Then I will have that, I-I-I will just—I know it's my baby, and I do love the baby, but I don't feel connected to the baby." Her boyfriend told her that she should be mourning now. She told him, "You can't mourn something you haven't lost yet."

Parents reported "mourning" or being "depressed," grieving the loss of their "perfect" baby, but they also spoke of losing the normal, happy pregnancy experiences that most couples enjoy. Parents yearned for the rituals inherent in pregnancy, such as setting up a nursery, gathering clothes and supplies, and planning birth announcements. The timing of when they learned the dire diagnosis was critical for Darria, who compared herself with other women who had spontaneously lost pregnancies. "This is different; they got to be happy up to that point." Darria stated that she had little time to enjoy a normal pregnancy before recognition of complications (see Table 3).

Some parents felt guilty. They questioned why this had happened to them, and if their actions had played a role in this outcome. Amy repeated several times that, "This isn't my fault. As long as I hold on to that, well, because I don't want to lose my sanity." She also felt a sense of unfairness that she has an infant who is going to die, when some people mistreat their children, when she would never do that. Barbara described regret that her boyfriend was stuck "going through all of my emotional ups and downs. I got the bad news and then I kind of took it out on him." She described "flare ups" when people try to be understanding or tell her to be relaxed (see Table 3).

Arrested parenting. This theme describes how the eight parents' normal pregnancy excitement and anticipation came to a sudden halt with the first news of possible abnormal development of the unborn baby. Amy and the baby's father had been decorating the nursery early in the pregnancy. "Really, really pretty. But then, when we found out, we just stopped. So the room is like, the paneling's done around like boom-boom, and then just...stopped. We just stopped. It just stopped. And we don't go in the room."

TABLE 3. DIMENSIONS, THEMES WITH DEFINITIONS, AND EXAMPLE QUOTES

<i>Dimension</i>	<i>Theme</i>	<i>Definition</i>	<i>Quotes</i>
Personal Pregnancy Experience	Grieving Multiple Losses	The complex emotional responses to the grief of losing the normal pregnancy experience, their baby's life, and their role as a parent.	<p>"As soon as I heard the diagnosis, I started mourning." "I guess I've been getting depressed lately just thinking about it." "We're going to have to spend over half of our pregnancy knowing that this baby isn't going to live." "Elena kept asking, 'Am I doing something wrong? Is this my fault? This has got to be because of something that I did.'" "I didn't do anything wrong; this isn't my fault." "Angry that I'm 38 years old. I can support this baby. I can insure this baby. I'm a good person." "Emotional ups and downs." "It's like we're giving this baby up for adoption, except the person who is adopting him is God."</p>
	Arrested Parenting	Recognition that their normal parental role is halted by the news of a lethal diagnosis	<p>"Everything that a mom gets to do, I can't do. I get to plan a funeral. It's all I can give him. He exists." "I'm going to be a mom; then I have to do what's best for my child and me." "We've given him everything we could as parents."</p>
	"My Baby Is a Person"	The essential need to acknowledge the personhood of their baby and his/her role within the family.	<p>"Treat us normally. This is our baby and we want to enjoy the pregnancy and our time with her. Don't act as if she isn't there." "I really do want a memory of my baby. Regardless if he's alive, or you know..., he's still my baby." "It's a person; [its] important to have a name. He's part of our family" "Legitimize his life." "I want him here as long as possible; a little longer so that I can bond with him. I felt I was bonding with him when I found that I was pregnant."</p>
Interactions with Others	Fragmented Health Care	Parents' disjointed and distant meetings with many specialists.	<p>"The person who did the ultrasound didn't talk very much. And I was a little confused, [the] lady before us came out with pictures. And then we went in and she said the ultrasound machine was broken for pictures and so I thought something was wrong then. And then she didn't really say much. She just took some measurements." "I don't think some doctors know how to communicate with patients." "I was a wreck. I was bawling my eyes out and I couldn't sit still for the procedure." "I need to have hope. I know what the reality is, but I still need the little bit of hope." "Plan for the worst; hope for it being better."</p>
	Disconnected Family and Friends	The awkwardness and lack of understanding from family and friends	<p>"It's almost like I'm trying to make everyone else feel better about my circumstances because they can't wrap their brain around it." "At a certain point, I don't want to hear everybody's sob story because I just want to deal with my own." "I'll just randomly get mad because of the situation. I know people mean well when they say to relax and stay/be [sic] calm. I just get mad at them 'cause I don't see how you can be relaxed and be calm in this situation." "She was like, maybe there will be a miracle. And I'm thinking, this isn't [a] Charlie Brown special!" "She's trying too hard to be [helpful], which is making her not helpful at all." "We were the white elephant in the room...It was the first time I realized how differently we were going to be treated."</p>
	Utterly Alone	The sense of being alone and marginalized, which comes as a result of accumulated separations	<p>"We were in limbo." "We were stuck on an island, not really knowing." "We felt deserted." "So isolated." "The hard part is that we are so [geographically] isolated [from our families]."</p>

Irreversible diagnoses may have changed the parent's role, but in all cases, these parents still wanted to be parents. Barbara expressed her desire to be a real mother by venting her frustration with her own mother. "I feel like she's [my mother's] been trying to make my decisions for me...I'm going to be a mom, then I have to do what's best for my child and me." Even in grief, they felt that being a parent was important. After feeling that she had completed the funeral plans, Darria had some sense of satisfaction that they had given their baby everything they could.

"My Baby Is a Person." This theme quickly reached saturation (see Table 3 for examples). It describes parents' unanimous and strong need to acknowledge the personhood of their baby, and his/her role within the family. They wanted people to legitimize the baby's life and not to pretend the infant does not exist. Carrie stated very clearly that they wanted to be treated normally and enjoy the time they had. Barbara was bargaining for more bonding time. Amy, who admitted that she would likely have terminated her pregnancy if it had been possible, still felt connected and wanted memories of her baby. All the parents had named their babies, and proudly shared the names. Darria felt tremendous frustration that the sonographers could not guarantee the sex of the baby due to the low amniotic fluid levels, because naming the baby was so important to her. All parents wanted to continue hearing their baby's heartbeat and to see the baby on ultrasound. They stated that these were opportunities to "get to know" their baby.

Interactions with others

The dimension Interactions with Others describes how the families perceived their treatment by other people in their lives. When they were coping with their personal pregnancy experience, they reached out to friends, family, and medical providers for support, but didn't always find the understanding and support for which they were looking. Three themes emerged in this dimension: Fragmented Health Care, Disconnected Family and Friends, and Utterly Alone.

Fragmented health care. Parents heard bad news over time, in disconnected, uncomfortable interactions from different providers. Diagnoses often took many weeks, leaving the mother and father anxious and worried, but still hoping for the best. For example, parents described having ultrasounds during which they sensed that something was wrong, but the sonographer was very quiet and disclosed very little. Similarly, when prenatal test results indicated an abnormality without a clear diagnosis, parents knew something was not right. However, they were told that they would have to wait several weeks to do repeat ultrasounds and often amniocentesis, usually at different offices, before a definitive diagnosis could be established. As one mother described, the day they saw the cardiologist for a prenatal echocardiogram, the provider wanted to do the amniocentesis on the same day, but she couldn't do the procedure due to her ongoing crying (Table 3). These interactions left parents without any answers and without support, which lead to distress and being "in limbo." Care providers did not seem to consult with each other, thus, care lacked continuity and coordination. Elena and Eric described frustrations with communication. "It's hard for doctors. Their focus is on what needs to be done, what's wrong and how do we fix it."

Attempts to be reassuring were not always helpful. Barbara did not understand how the nurses could say that her baby's heartbeat was "perfect" when half of his heart was not there. "How is that possible?" she asked.

Although parents needed clarity about the baby's condition, they also felt that they needed to maintain hope. Amy said, "I wouldn't be as depressed...if they saw a little bit of hope, or showed it, not even believing it." Several parents expressed similar sentiments (Table 3).

Parents appreciated learning about their options from knowledgeable staff. One family was incorrectly told that comfort care could not be provided if the baby was kept with them, but fortunately they got reliable information from another provider. All the parents interviewed were eventually referred to PC services by their third trimester, but several commented that they wished it had occurred sooner. Carrie and Christopher found the consultation "very helpful with things we can do" such as choosing care options and preparing, even planning photos. Families said that they would never have known about Now I Lay Me Down to Sleep™²⁶ a program in which professional photographers donate their time to take photographs of families with ill infants.²⁶ Elena and Eric found that PC support provided a "different focus" while "being there for us on the emotional side." "They made me feel like they would take care of her like I would take care of her as a parent, not as they would take care of her as a doctor [crying], that was the most important part to me."

Disconnected family and friends. This theme describes the awkward and painful feelings the parents experienced in social situations. All of the interviewed parents felt a lack of understanding by many of their family members and friends. They picked up on the discomfort and uncertainty of others. Amy describes having to be the one to comfort other people (Table 3). Darria described a coworker who had lost a baby during pregnancy, but even she was not very helpful because, "She's more bitter than I am" (Table 3).

Amy described interactions with strangers, "I feel like how can I, you know, be so pregnant and everyone thinks you're so pregnant and everyone thinks it's happy." Those without family nearby felt especially alone, but extended family members, despite good intentions, often offered little comfort. Some acted as if the baby did not exist; others were too overbearing (Table 3). Although the parents hoped for the best, they did not appreciate their family's unrealistic expectations.

The parents also described the social stigma they felt; they felt they were avoided by others and judged with disapproval. One couple described going to a gathering where everyone knew their baby had a serious condition, but no one said anything at all to them about the pregnancy. Yet when another pregnant woman arrived at the party, they showered her with love and compliments. The couple said they felt like "the white elephant in the room."

So few people in their lives could truly understand how it was for the parents. Barbara: "Some people say I know how you feel or I know what you're going through, but you really don't. I understand if you've lost a child, but maybe not a baby when he's born."

Utterly alone. This theme, that crosses both dimensions, describes how parents' sense of social isolation led to loneliness. Feeling that no one really understands what they were going

through left them feeling "stuck on an island." These feelings contrast poignantly with a normal pregnancy experience, where social acknowledgement of the expected baby, even from strangers, adds to the joy of the pregnancy. The deep divide between the parents' personal experience and the social experience was a source of pain beyond their feelings of grief and loss.

Discussion

This study was unique in allowing parents living with a lethal fetal diagnosis to tell their own stories. Although the sample size was small, parents' descriptions of their feelings and responses to their experience were very powerful, and a number of consistent themes emerged. We were impressed by the parents' resiliency and ability to find something positive to offer, even in the presence of their grief. This finding is consistent with the results of Black and Sandelowski²⁰ who showed that parents often undergo a positive personal change during the experience of a pregnancy with a LFD. Most of the parents were willing to be interviewed during pregnancy and stated that they wanted to help other families in similar circumstances. Hence the study succeeded in demonstrating that interviews of these families in the perinatal period were both feasible to conduct and acceptable to parents. The exception to this were the two couples who had initially agreed to be contacted but then declined to be interviewed due to the live birth of their baby and their understandable need to focus on their fragile baby. Several parents expressed gratitude for the caring attention of the interviewer.

The interviews painted a picture of the deep divide between the personal experience and the social experience of parents who were traversing a pregnancy knowing that their baby would die. In normal pregnancies these two contexts are fairly congruent (positive and supportive),²⁷ however, the parents in this study experienced incongruity between these dimensions. Parents experienced deep heart-wrenching grief, with all of its typical manifestations, while maintaining some hope of a good outcome. The complex feelings of grief we observed are consistent with previous studies showing that learning of abnormal prenatal echocardiography led to significant changes in parents' sense of self and relationships with others, including feelings of guilt and self-blame, fear and anxiety, anger, sadness, or hopelessness.^{21,22} All parents were clear that they wanted their baby to be considered a real person, and they needed to feel like real parents for the short time that they could do so. They also wanted to be understood, hopefully by friends, certainly by family.

Parents were often perplexed that their health providers were not able to understand their needs. This finding is consistent with previous work showing that some physicians question the parents' decision to continue the pregnancy.^{6,7} As reported in other studies, parents found that planning for the birth allowed time to enjoy being with the baby, celebrate the birth, and grieve appropriately.⁷ They indicated that they needed information, with minimal delay, provided with directness and compassion, rather than vagueness and avoidance.

This study yielded powerful data about parents' experiences, but it was limited in several ways. The study included only a small number of families from one geographic region; however, the themes and dimensions reached saturation with a small number. All parents had at some point in the pregnancy received PC services, and thus were not typical of

many parents in similar circumstances. Because mothers and fathers were interviewed together, clear differentiation of gender roles was not possible. Moreover, the study was cross-sectional: although we interviewed families during or soon after their pregnancy experience, we were not able to track the evolution of their feelings over time. Future studies would provide additional understanding of parent needs with the use of observation and provider interviews.

Conclusions and Implications

The study reveals a number of issues to be considered in the development of perinatal PC programs. The compelling stories of these parents suggest that health care providers need to recognize their need to be treated as real parents, with acknowledgement of their baby as a person with a name and a life, however short its prospect. These parents ask for supportive counseling to help them understand medical conditions, make informed decisions, and communicate with multiple providers. They want counseling that is provided with attention to continuity of care, a hopeful approach that acknowledges prognostic uncertainty, and advice that is nonjudgmental.

PC approaches in other settings use empathic counseling, sometimes over several visits, to reframe a family's expectations for hope for the loved one's long-term survival to hope for a meaningful life and peaceful death with dignity. Parents also need support as they make difficult decisions regarding advance care planning; advice that is too directive or judgmental makes their decisions more difficult. Strategies are also needed to address the families' sense of isolation; caring support is clearly important, but offering web-based connections with parents in like circumstances might also be helpful.

We recommend that future studies begin soon after parents receive a LFD and continue longitudinally in order to capture the evolution of their thoughts and feelings. In addition, individual interviews with men and women are needed to clarify the unique perspectives and roles of each gender. Interviewing families with and without PC support will help to clarify what parts of their experience are influenced by this service, and how services can be improved. Perinatal PC is a relatively new addition to the health care system, and much needs to be learned to optimize its potential to help families through a painful passage from life to death with their unborn baby.

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Address correspondence to:

Denise Côté-Arsenault, Ph.D., R.N.C., FNAP
4607 Dartmouth Circle
Manlius, NY 13104

E-mail: Denise_Cote-Arsenault@urmc.rochester.edu