

Charlotte Wool, Rana Limbo, and Erin M. Denney-Koelsch, "I Would Do It All Over Again": Cherishing Time and the Absence of Regret in Continuing a Pregnancy after a Life-Limiting Diagnosis," *The Journal of Clinical Ethics* 29, no. 3 (Fall 2018): 227-36.

"I Would Do It All Over Again": Cherishing Time and the Absence of Regret in Continuing a Pregnancy after a Life-Limiting Diagnosis

Charlotte Wool, Rana Limbo, and Erin M. Denney-Koelsch

ABSTRACT

Parents, after learning of a life-limiting fetal condition (LLFC), experience emotional distress and must consider options that impact the remainder of the pregnancy, their future lives, and family members. For those who continue, little is known about their long-term presence or absence of regret about their choice, the reasons for this feeling, or its impact on their life. The aim of this research was to examine the concept of *decision regret* in parents who opted to continue a pregnancy affected by an LLFC. The contextual factors, conditions, and consequences surrounding the presence or absence of regret were analyzed.

Data were retrieved from a cross-sectional study using the Quality of Perinatal Palliative Care and Parental Satisfaction Instrument. Participants were parents ($N = 405$) who experienced a life-limiting prenatal diagnosis and opted to continue their pregnancy. Secondary data analysis examined qualitative responses (121/402) to an item addressing regret. Dimensional analysis was

used to examine data, identifying context, conditions, and consequences associated with the presence or absence of regret.

Absence of regret was articulated in 97.5 percent of participants. Parents valued the baby as a part of their family and had opportunities to love, hold, meet, and cherish their child. Participants treasured the time together before and after the birth. Although emotionally difficult, parents articulated an empowering, transformative experience that lingers over time.

INTRODUCTION

Advances in prenatal screening and diagnostics enable providers to identify life-limiting fetal conditions (LLFC) and make recommendations for care. Data indicate that the leading cause of infant death in the United States is congenital malformations that can be lethal or severely shorten infant life-span.¹ Despite technological advancements, prognostic uncertainty is a reality, and in some cases infants live longer than expected.² Until recently women were offered a limited number of options, typically termination of pregnancy or infant admission for intensive care; however, expectant obstetric management and the growth of perinatal palliative care (PPC)—the option to continue the pregnancy and receive interdisciplinary support during pregnancy, birth, and postnatally—have been formally recognized, and these options are now included when careproviders offer counseling to parents.³

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Perinatal loss is an especially sensitive and sorrowful topic. According to a meta-analysis of studies about perinatal palliative care and perinatal hospice published from 1995 to July 2012, between 37 percent and 85 percent of parents opt to continue a pregnancy affected by an LLFC.⁴ As parents anticipate the shortened life-span of their infant, careproviders need to ensure that their encounters with parents do not increase the parents' distress and suffering. Parents who continue a pregnancy report the desire to "have no regrets" and wish to be supported by careproviders.⁵ Research confirms that parents are more satisfied when quality metrics, such as compassion, consistent care, and emotional support, are rendered.⁶ Understanding the absence or presence of regret in parents who continue a pregnancy with an LLFC will provide additional and important data that careproviders can use when counseling parents.

LITERATURE REVIEW

Making a decision about continuing a pregnancy through the lens of an LLFC is a heart-wrenching decision. Decisions are complex and multifactorial, and clinicians and researchers acknowledge that perinatal loss is a traumatic event that can result in emotional devastation.⁷ Still, the concept of post-traumatic growth has received some attention in the perinatal literature and is worthy of examination as parents must live on after making such complicated, nuanced decisions.⁸ To make the decisions that are best for them, patients need nonjudgmental counseling about options, with the opportunity to voice concerns and ask questions, which may lead to more realistic expectations of outcomes, present an opportunity to examine personal values, and reduce uncertainty or decisional conflict.⁹ If, in retrospect, a parent views a decision with regret, there may be adverse psychological implications. The idea that a decision may result in a protracted period of regret is concerning and, therefore, deserves careful study. Self-blame, a concept often associated with regret, has a negative impact on adaptation following the death of a baby during or soon after the birth.¹⁰

Decision regret has been presented in the literature from different perspectives. Defined as the measurement of distress or remorse after making a healthcare decision, decision regret is considered an undesirable outcome and best avoided when possible.¹¹ Several theorists have attempted to bring clarity to the concept of decision regret. One theory of decision regret includes two core components, the first is associated with self-recrimination or self-

blame about having made a poor decision; another identifies that individuals may experience regret when they have knowledge that a different choice may have resulted in a better outcome.¹²

From an alternative perspective, the wish to avoid regret may play a part in individual choices. In fact, one decision-making theory suggests that decisions may be cognitively processed so as to reduce feelings of regret after the decision and its consequences are complete, especially if the outcome is expected to be less than ideal.¹³ In other words, individuals can anticipate regret, and this fact may influence how a decision is processed and eventually reached. This is especially profound in the context of anticipated perinatal loss, when making a decision—or series of decisions—is an emotionally intense experience with far-reaching, potentially life-long impact. We postulated that parental-fetal attachment and a desire for parental caregiving, that is, nurturing, protecting, and socializing,¹⁴ may contribute to a choice to continue the pregnancy and a wish to avoid regret.¹⁵ Some—or perhaps many—people assume that ending a pregnancy shortly after a diagnosis of an LLFC would subsequently relieve regret and lessen the grief parents anticipate from carrying a baby with severe problems. Data from this study and others suggest that more profound regret comes from failure to spend as much time with their child as they would like, even during pregnancy.¹⁶ Nurturing, protecting, and socializing are not reserved for infants who live only outside their mother's uterus. Instead, parents who choose to continue the pregnancy find joy and gratitude in time spent with their child. Researchers in the perinatal hospice field identify one aspect of caregiving as a thoughtful process of saying good-bye to a much-loved offspring, described as "final acts of caregiving."¹⁷

GAP IN KNOWLEDGE AND STUDY PURPOSE

As the evidence base for PPC grows, it is important for careproviders to understand whether parents who continue a pregnancy that is affected by an LLFC experience feel regret, and in what context. New knowledge about the presence or absence of regret will allow obstetric and neonatal careproviders to align counseling information with data and take a more pro-active role in providing decisional support.

Participants in the study responded to the following question: "Do you have any regrets about your decision to continue the pregnancy?" with a "yes" or "no" answer, and were invited to provide

comments. The purpose of this study is to fill a gap in our understanding of parental experiences after they have had time to live with their decision to continue a pregnancy affected by an LLFC and have had an opportunity to reflect on it.

METHODS

Data were retrieved from a cross-sectional study using the Quality of Perinatal Palliative Care and Parental Satisfaction Instrument.¹⁸ A secondary data analysis of qualitative data from the *decision regret* item was undertaken using the lead author's original database to answer a new research question. The original study was conducted in February 2015 over four weeks. Participants were parents ($N = 405$) who experienced a life-limiting prenatal diagnosis and opted to continue their pregnancy. Infants' diagnoses included Trisomy 18 (53 percent), anencephaly (30 percent), and other conditions (17.2 percent). Participants were mostly White (90 percent) and were from Australia, Canada, the United Kingdom, and the United States. Parents reflected retrospectively on their experiences. At the time of the survey, death of the infant had occurred within five years (61.5 percent), from six to 10 years (25 percent), or after 10 years (13 percent).¹⁹ An online web-based platform was used, and data about quality indicators, parental satisfaction, parents' demographics, infants' characteristics, and additional open-ended questions were posed. The item targeting the concept of *decision regret* was the final item on the survey and invited participants to reflect on their decision to continue the pregnancy. Of the 405 participants, 402 (99 percent) responded quantitatively to the item, and 121 (30 percent) responded qualitatively to the item using an open-ended text box. The study was approved by the York College of Pennsylvania Institutional Review Board.

Authors used the method *dimensional analysis* (DA) to identify context, conditions, and consequences of the absence or presence of decision regret. Dimensional analysis is a method of analyzing qualitative data that grew out of Leonard Schatzman's work with the grounded theorist, Anselm Strauss, and through his work with graduate students who needed an explicit explanation for analysis when using grounded theory methodology.²⁰ One of the unique features of DA is its effectiveness in describing common, everyday experiences, which Schatzman calls "natural analysis."²¹ His point refers to the usefulness of DA for both research analysis and reflection on everyday, usual events, decisions, or happenings. In the case of the

data on which this article is based, the "everyday experience" is reflection on a past decision, albeit during a most stressful and difficult time in the life of a parent. DA provides the framework for answering the question "What all is involved here?" or "What is the big picture?" In our case, Schatzman's model for DA includes analysis of the central unifying concept embedded in the question "Do you have any regrets about continuing the pregnancy?"

DA has been used by numerous researchers as a way of bringing together natural analysis and theory development.²² First identified as a method for developing grounded theory, DA is also a robust method for coding existing data, an appealing choice for a study such as this one, in which participants had already written a brief narrative about regret.²³ DA met the "good fit" criteria for data in which participants identified their relationships as a central issue.

We identified an overarching central issue of regret from analysis of the data. From there, we moved to the next level to bring clarity and understanding to participants' responses regarding the absence or presence of regret. We examined three dimensions that stemmed from the central issue, including:

1. How does the context apply to the central issue,
2. What are the conditions upon which the central issue is understood, and
3. What are the consequences that result from the central issue.²⁴

Initially, our data set was read independently by the authors. Guided by DA, the three authors together organized the data into three dimensions of context, conditions, and consequences (see figure 1). DA is designed to be a close approximation of the participants' experience (their reality) and is ideal when one is looking for the saturation of a specific category or variable. Identifying context, conditions, and consequences moves away from thematic analysis and focuses on interrelationships among the three dimensions. The report of our findings supports the interrelationship detailed in figure 1.

RESULTS

This section will explore the central issue (regret) embedded within the research question, "Do you have any regrets about continuing the pregnancy?" The primary finding was "the absence of regret." More than 400 ($n = 402$) participants answered the quantitative item "Do you have any regrets about your decision to continue the pregnancy?" by checking a "yes" or "no" box. Of those

402 responses, 97.5 percent ($n = 392$) said they did not have regrets; 2.5 percent ($n = 10$) said they did. Participants clearly represented “absence of regret” as the central issue (see figure 1).

Of the 402 participants, 12 (30 percent) provided qualitative feedback on this item, three of whom made statements about their regret (compared with 118 who wrote about the absence of regret). The following were contained within the statements of the three participants who wrote about regret:

1. One participant regretted not being strong enough to “fight for my daughter’s life,”
2. Another hoped that her baby did not suffer, and
3. The third regretted that she had not said goodbye to her daughter “on my own terms.” This mother further elaborated by clarifying that she felt forced to follow state guidelines rather than her own “medical decisions.”

Because so few commented on having regret, DA was not possible for those comments. The rest of the analysis reports on the 97.5 percent of participants who did not experience regret for continuing the pregnancy.

Contextual Factors

Context is an important element of DA to make sense of qualitative data.²⁵ In the data from this study, participants identified the context for “absence of regret” by describing *relationship* as central (see figure 1). Participants acknowledged themselves as parents to their baby and took on the various roles of parenthood.

Acknowledging themselves as parents. Four select examples from our data demonstrated how participants recognized themselves as parents. Participants talked about the fetus, newborn, or infant in relational terms, such as “son” or “daughter.” Frequently they referred to their baby by name and themselves as parent: “I am her mother” or “I was just being the momma I knew to be.” Some parents also spoke in even broader terms of “family” and acknowledging the baby “as much a part of our family as our other children.”

Parental roles. Roles included advocacy, responsibility, and decision maker. Participants explained *advocacy* using simple statements such as “I wish I could have kept my daughter safe inside me forever” and “I did everything I could to give him a chance.” *Responsibility*, on the other hand, was to “ensure comfort,” using words such as “She was in my arms when she left this world and she was safe and comfortable. That was all I could ask; for her to not suffer.” Another parent wrote that she wished to “avoid

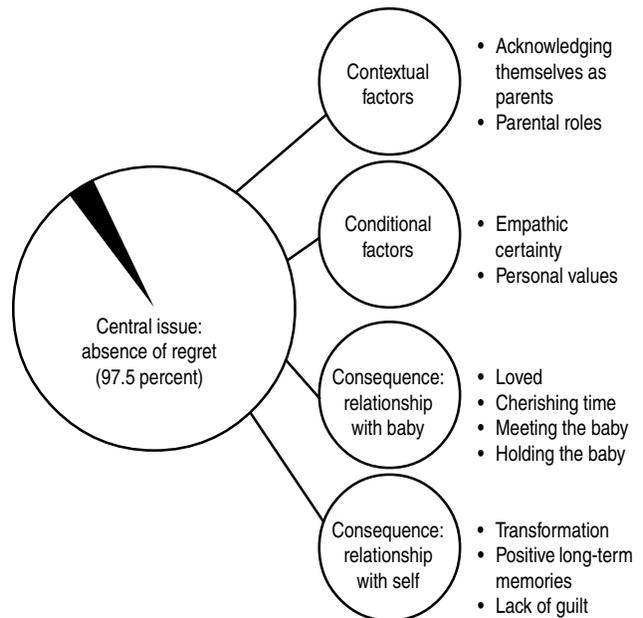
infant pain and suffering,” and yet another noted that protecting the twin sibling was a critical part of her parental role. In relation to a *making a decision* to continue or terminate the pregnancy, one participant stated, this “was the hardest decision I’ve ever made.”

Conditional Factors

A second dimension of analyzing the participants’ data includes conditional factors or conditions. Participants identified two primary conditions in stating that they had no regrets, which include emphatic certainty and personal values (see figure 1).

Emphatic certainty. The authors were impressed with the show of strong feelings and emotions in the category of *emphatic certainty*, made possible through the handwritten comments made as an answer or response to a question. The participants’ written words illustrate how powerful their responses were. Some participants used uppercase letters to emphasize the absence of regret, for example, “NO REGRETS” and “If I had to relive this situation I would NOT do a single thing differently!!” In addition to emphasizing the negative with using both “none” and “no,” this parent used 30 exclamation points to separate the two words. Many parents used the single word “never” in response to the ques-

FIGURE 1. Parental absence of regret in continuing pregnancy with a life-limiting fetal condition: factors from dimensional analysis



tion about regret, emphasizing their strong sense of certainty.

Personal values. Parents referred to their *personal values*, including the sanctity of life, a higher power, and an emotion linking parent and child. Statements such as “Every life is precious,” “It was God’s plan and purpose,” and “I love my girl” reflected parents’ spiritual and moral perspectives on the meaning of the experience.

Consequences

Schatzman defined conditions as being linked through accompanying *actions* or *processes* with consequences.²⁶ Both the context and the conditional factors ultimately lead to an outcome. Our participants expressed several consequences related to the concept of *regret*. Two clear pathways emerged that stemmed from the context of relationships. Choosing to continue the pregnancy resulted in opportunities to be in relationship with the baby and a personal reflection of emotional feelings related to self (see figure 1).

Relationship with the baby. Mothers identified their relationship with their baby as having four major dimensions:

1. *Love:* “All my son knew was love.” “We are rich in love because of her.”
2. *Cherishing time:* “We would not trade those six hours for anything in the world.” “I will always cherish the time I had with her” [during pregnancy and after].
3. *Meeting:* “My family was able to be present when she was born and everyone got to meet her and hold her while she was alive.”
4. *Holding:* “I got to hold my baby for an hour . . . no regrets.” “I got the chance to see her, hold her, and honor her sweet life.”

Relationship with self. Growth and transformation have been suggested as potential consequences of perinatal loss.²⁷ Mothers in this study described growth and transformation as consequences that involved relationship with self. They reported that having no regret for their pregnancy decision affected them in three ways; that their experience was:

1. Transformative,
2. Their long-term reflections on the experience were positive, and
3. Their decision contributed to the healing process and prevented feelings of guilt.

Growth and transformation. Examples of how parents framed transformation as a consequence of not having regret included:

1. Acknowledgment of personal learning and growth, a process that shaped and changed them, the opportunity to heal, and
2. Profound effects on their family’s faith and relationships.

These outcomes lasted over time. Some examples of transformation include the following. “The experience has helped form who I am today, who my husband is today. We learned and grew from the experience.” Another parent expressed it this way: “This became perhaps the most profoundly positive experience our family has ever had. I think nothing else has ever strengthened our faith or drawn us closer together.” Mothers also reported that “He changed me forever” and “Never [did she have regrets]! It was so healing to have met her.”

Positive long-term memories. Some participants in our study experienced loss within a year of taking the survey while others reflected on an experience that occurred more than 10 years earlier. The idea of “long-term,” noted also in the explanation of transformation, is evident as parents discussed their memories. “I have memories that has [sic] carried me through,” “I will love her until the day I die,” and “Thankful every day that we decided to continue,” all exemplify how strength, love, and gratitude can come from one of life’s greatest tragedies: the death of one’s child.

Lack of guilt. The consequence of “lack of guilt” was expressed in numerous ways by participants. One said, “I think it made the grieving period ‘better,’ I mean it is easier to say good-bye to someone you know and have seen.” Another affirmed that the experience “Left me with no questions of ‘What if.’ ” One parent was so pleased not to have missed out on “15 beautiful days with our baby.” Concerns about termination were occasionally but infrequently mentioned for why parents chose to continue the pregnancy: “I cannot imagine the guilt and grief I would still carry had I aborted the pregnancy.” Finally, this quotation summarizes the main finding of the absence of regret: “If I had to relive this situation I would NOT do a single thing differently!!”

DISCUSSION

Most strikingly, our data indicate an overwhelming, emphatic, and almost unanimous response indicating an absence of regret in parents who continued a pregnancy with an LLFC. The participants described the absence of regret with remarkable, emphatic certainty. Parents in our study nearly all felt that they had made the right choice for themselves

and their family, based on their personal values, and showed an absence of post-decisional regret, guilt, or self-blame. Those inexperienced with families who experience an LLFC may find it unusual that continuing a pregnancy likely to result in the death of the baby can produce positive consequences for parents and families, but this has been found in other works also.²⁸ The positive experiences our participants describe affirm theoretical underpinnings that link decision making and outcomes with a lack of self-recrimination or regret. Parents expressed that despite the distressing life event, the best possible outcome was achieved. Parents had an opportunity to meet and love their baby and, in many cases, participants described positive transformative experiences consistent with Beth P. Black and Patricia Moyle Wright.²⁹

Posttraumatic growth (PTG) is a process that occurs in response to suffering.³⁰ The authors noted that the concept has its roots in theories of change, specifically in response to traumatic events that change one's attitudes, meanings, and assumptions of what life is and offers. Significant to PTG in those who experience the death of a baby is that the growth may be private and not noticeable by others, or it may be demonstrated on a continuum to obvious growth, change, and transformation that occur when the growth has social consequences (for example, the design and organization of a remembrance walk named in honor of the baby who died). The authors also noted an important paradox in understanding the interlocking aspects of trauma and growth: The distress from the first is a companion to the positive change experienced and/or noticed with the second. To better understand the structure of PTG, researchers developed a Posttraumatic Growth Inventory (PTGI), which includes five dimensions gleaned from a study of 926 participants.³¹ The dimensions included relating to others, new possibilities, personal strength, spiritual change, and appreciation of life.

As noted by Beck and Watson, "only a handful of studies have been conducted on perinatal post-traumatic growth."³² Their study of 15 women who self-identified as having had a traumatic birth identified four factors of growth, each of which could be linked to one of the five dimensions identified by the PTGI. The women opened themselves up to a new present (new possibilities), were more open and transparent about themselves with others (relating to others, appreciation of life), increased spiritual understandings related to self (spiritual change), and forging new paths personally and professionally (personal strength).

A study of 15 women and 11 of their male partners whose baby had an LLFC used the PTGI to demonstrate that the earliest and most enduring change occurred in relating to others.³³ Participants described positive changes in varying ways. One father/husband said, "We cried the whole way home [after the diagnosis]. But a part of me was sad to see [my wife] so distraught . . . [it] just broke my heart."³⁴ Another participant, a mother, spoke of becoming more compassionate toward strangers: ". . . that felt really good to be an encourager to someone else: to have something positive come out of these feelings and this experience."³⁵

This study confirms prior research that parents' overall goal in a pregnancy with an LLFC is to have "no regrets."³⁶ Parental relationship with the fetus/baby and their desire to be good parents may explain the overwhelming driving force for their decision making. Parents who choose to continue their pregnancies after LLFC displayed "prenatal parenting"³⁷ and wanted their baby to be thought of and treated as a person.³⁸ While anticipatory grief is a reality for all parents continuing an affected pregnancy, palliative careproviders are well positioned to support parents throughout their journey in an effort to minimize potential harm and maximize positive memories and experiences.³⁹

A large body of literature suggests that denial and avoidance of death and grief can have harmful effects. Denial is a defense mechanism described by Freud to unconsciously protect a person from the anxiety aroused by unacceptable thoughts or feelings.⁴⁰ While it is possible that some of the parents who confirmed feeling no regrets were "in denial," the emphatic certainty with which they affirmed their lack of regret and their nearly uniform responses contradict this idea. The lack of regret and prolific expressions of positive feelings after an extended period of time also fits with the authors' clinical experience that parents who choose to continue a pregnancy with an LLFC are not in denial or avoiding death. The parents are living out their dreams of being caregivers for their child in the best way possible, given the circumstances.

Parents' words reflect positive changes that endured over time through relationships, memories, and emotions. For example, the memory of holding their baby, an experience that ended in a relatively short time, was something the parents carried with them, remaining important enough to share with the research team many years after it happened.

Their ability to have time to be a parent to their child and spend time with their baby was meaningful. The concepts of advocacy, responsibility to en-

sure comfort, and making the best decisions are all part of caregiving, consistent with John Bowlby's theoretical framework,⁴¹ in which caregiving is reciprocal to attachment, and parents have goals in relating to their child.⁴² Caregiving goals include nurturing, protecting, and socializing the baby, highlighting the parents' relationship with the baby and the baby's relationship with others (for example, showing an ultrasound photo with pride). Nurturing their child is a common parental caregiving goal.⁴³ Parents in this study described looking forward to meeting, holding, and cherishing time together, suggesting that caregiving goals could affect the decision to continue the pregnancy without regret.

Presence of Regret

While 10 parents indicated the presence of regret, only three of them provided qualitative responses, making it impossible to say in a transferable way why those who had regret felt that way. One participant raised the concern of infants' suffering. Parents in other studies have also voiced this concern.⁴⁴ A cornerstone of PPC includes anticipating and addressing this concern with parents at various points in the pregnancy journey, and especially during the decision-making process. To date, there is no evidence to suggest that LLFCs cause suffering for the fetus during pregnancy, and parents should be given this information as a part of counseling services. Further, to avoid any potential suffering after the birth, parents should be invited to co-create a treatment plan for their infant that recognizes the importance of careful assessment and treatments.⁴⁵ Treatment plans should also address comfort strategies that assess infants' pain and suffering and address them. Evidence-based interventions include both pharmacological pain and symptom management, as well as nonpharmacological approaches, including bonding, holding, skin-to-skin care, suckling, massaging, cuddling, and rocking.⁴⁶ Further, treatment plans should support, as appropriate, comfort measures for infants that address relieving hunger or thirst and maintaining body temperature.⁴⁷ When parents desire life-sustaining treatments that carry a potential for pain or distress post-birth, excellent palliative care can help minimize any pain and suffering that might accompany those treatments.

CLINICAL IMPLICATIONS

This work informs all interdisciplinary health-care team members who work with parents facing

LLFCs—including nurses and physicians in obstetrics, neonatology, and perinatal palliative care—by demonstrating with data a profound lack of regret for the vast majority of parents who continue their pregnancy. Decision regret may be modified through collaborative decision making between careproviders and parents as the best available scientific data are presented and coupled with parents' preferences and values.⁴⁸ Counseling, which traditionally includes information about termination, should also include apprising women of a palliative care option that includes data about the emotional and psychological aftermath of those respective decisions.

Women are compelled to weigh and decide on a course of action that remains in their personal history forever. Caroline Lafarge and colleagues found that women who terminate a pregnancy and indicate that they are unsure they would make the same decision again have difficulty coping and report increased despair and grief.⁴⁹ In the same study, self-blame was one variable involved in positively predicting active grief, difficulty coping, despair, and general grief. When women opt for termination for fetal anomalies (TFAs), the nature of such a choice is voluntary. Suddenly, a happily anticipated life event (birth of a child) is coupled with a life-limiting diagnosis, which creates an existential crisis both for and against something both wanted and not wanted.⁵⁰ Judith L.M. McCoyd's research addresses the intense and unbearable stress felt during the decision-making process by women who opt for TFA.⁵¹ McCoyd posits, "The responsibility for decision-making complicates and seems to intensify [this] grief."⁵² Perhaps the voluntary nature of TFA accounts for some of its psychological aftermath. In addition, McCoyd identifies a confluence of other factors that may contribute to psychological outcomes, such as the stigma of termination, a society unwilling or unable to offer support and advocacy, fear of judgment from others, the difficulties inherent in the delivery and birth of an infant with a life-limiting condition, and a lack of accessible, streamlined healthcare services from careproviders and health insurance organizations.⁵³

After TFA, women have reported negative emotions such as grief, posttraumatic stress, depressive symptoms, anxiety, sadness, and distress.⁵⁴ Over time, the negative effects of TFA subside, although Marijke J. Korenromp and colleagues noted grief reactions that persist years later.⁵⁵ Our study did not examine those who chose to terminate a pregnancy, and we cannot comment on those families' presence or absence of regret. At the same time, we were struck that the adverse psychological outcomes found in

the literature are in contrast with the positive emotions and consequences parents almost unanimously reported in our research.

Clinicians have a responsibility to translate evidence into practice and provide comprehensive information to parents so that they can make informed decisions. Maria-Margarita Becerra-Pérez and colleagues examined participants' satisfaction with the information they received; low satisfaction with provided information is associated with decision regret.⁵⁶ Many institutions do not have PPC, and even those that do have a low number of PPC referrals,⁵⁷ which represents a formidable barrier for parents who may benefit from hearing about the option to continue a pregnancy and receive supportive services offered by PPC teams. Leaders in PPC programs in the U.S. stand ready to provide exceptional family-centered, individualized care and support to parents.⁵⁸ Clinical pathways and position papers are available to inform practice, and the Perinatal Hospice and Palliative Care internet site provides a convenient avenue to find and contact available PPC programs (*PerinatalHospice.org*).⁵⁹

LIMITATIONS

Our study begins to lay a foundation for understanding decision regret in the context of an LLFC. This is a first step in such inquiry through a single, open-ended question. The population was largely White and English speaking, limiting the transferability to minority and other cultural groups. There is no literature to suggest that LLFC in other cultural settings is a profoundly different experience, making this less likely of a concern. The possibility of parental recall bias is inherent in the study design, although research suggests that women have enduring and accurate memories of their birth experiences.⁶⁰ So few parents indicated having regret that their qualitative responses were quite limited, and we cannot draw any conclusions from them.

Social desirability bias is another possible limitation, if parents felt it was not socially appropriate to express regret about birthing a child. We concluded that social desirability was a minor concern, given the findings of "emphatic certainty" with which they answered the qualitative portion on their lack of regret.

Our study did not include a valid measurement tool specifically targeting regret, although such a tool exists and has been used with a variety of populations.⁶¹ Use of the Decision Regret Scale may have led to a deeper understanding of the concept of regret and provided a more in depth examination.

Qualitative research with focus groups or interviews would also have expanded upon parental perspectives and experiences.

The strengths of the study include the use of DA and a research team that included two nurse scientists with perinatal loss expertise and a palliative care physician. From these data, perinatal clinicians will be able to counsel patients that continuing a pregnancy with an LLFC is usually not viewed with regret by a vast majority of parents who opt to continue. This study confirms that an overwhelming percentage of parents had no regrets about continuing a pregnancy when the baby has an LLFC, and in many cases had a meaningful, loving, precious time with their baby. These meaningful moments can inform the counseling practices of all clinicians who care for these families and the experience of the families themselves. As one participant said, "[I was] able to hold and kiss her and sing to her. I will always cherish those moments." Those tender words lead the reader to conclude that she "would do it all over again."

ACKNOWLEDGMENTS

The authors wish to thank the families who took the time to respond to the survey and share a part of their personal story. Although not all families provided the name of their child within the survey, many did. We honor you and your children and recognize your children who were not named and children who were named: Abigail, Abby, Alyvia, Carrsyn Faith, Clara, Elias, Landon, Lilly, Matthew, and Noelle. We also acknowledge Cathy Mikkelson Fischer, MA, ELS, for editing the manuscript.

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