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PERINATAL PALLIATIVE CARE AND PARENTS' GRIEF EXPERIENCE: AN INTEGRATIVE REVIEW

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Perinatal Palliative Care and Parents' Grief Experience: An Integrative Review

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Abstract

Introduction: Perinatal loss due to fetal congenital anomalies places parents at high risk for complex grief. Perinatal palliative care is a holistic option that may decrease complex grief yet is under-utilized in midwifery practice in the United States.

Purpose: To examine: (a) the impact of perinatal palliative care (PPC) on parental grief, and (b) how PPC can be integrated into holistic midwifery practice.

Methods: A keyword search of the literature from 2011–2023 was conducted in Covidence, software that pulled entries from the following databases: CINAHL, SCOPUS, ScienceDirect, PubMed, and Google Scholar. The search yielded 22 original studies that met the exclusion and inclusion criteria defined by the authors of this paper. Study findings and demographics were extracted from the literature and classified according to Worden's theory of the four tasks of grieving.

Results: Lived experiences of 1,277 parents demonstrate complex grief occurring at the time of diagnosis due to the emotional attachment already formed to the baby. Throughout pregnancy and birth, parents valued consistent, empathetic health care providers and particularly valued care from midwives. Findings revealed parents' benefits from PPC include: (a) affirming their identity as parents and the baby's "personhood," (b) birth planning, (c) quality time with baby after birth, (d) memory making, and (e) opportunities to hold and care for the baby. Some findings revealed that memorials and the option of organ and/or breast milk donation were also meaningful.

Discussion: This review demonstrated that perinatal palliative care is a valuable resource when presented as an option for families with a lethal fetal diagnosis. It fits well within the midwifery model of shared decision making and can be part of midwifery care even where a formal program does not exist. Opportunities for research include: (a) PPC in low-resource settings and (b) integration into midwifery education.

Keywords: perinatal palliative care, perinatal hospice, grief, bereavement, mourning, midwifery, holistic care, parent experiences

Perinatal Palliative Care and Parents' Grief Experience: An Integrative Review

Background

Perinatal loss is a heartbreaking topic, but a circumstance every midwife will likely encounter in their career. In the United States, 20,927 infant deaths were reported in 2019. At 21%, congenital malformations were the leading cause of all deaths, indicating 4,395 babies and their families are potential candidates for perinatal hospice each year. Grief is often described as a person's emotional response and reaction to a loss; families are devastated when they receive a *lethal fetal diagnosis* (LFD), defined as a fetal condition in which survival is anticipated to be only the first hours to weeks of life. Receiving an LFD often causes a complex grief (CG) reaction in parents—evidence of their attachment to the unborn child—and this grief may increase if the parents choose termination (Côté-Arsenault & Denney-Koelsch, 2016; Kersting & Wagner, 2012). Parents who experience perinatal loss have increased rates of post-traumatic stress disorder (PTSD), CG, and divorce. The loss of an infant, regardless of the reason, is a traumatic life event (Kersting & Wagner, 2012). The purpose of this review is to examine: (a) the impact of perinatal palliative care (PPC) on parental grief and (b) how it can be integrated into holistic midwifery practice.

What is perinatal palliative care? Martín-Ancel et al. (2022) describe it as a holistic, multidisciplinary approach to the physical, emotional, spiritual, and social aspects of the neonate and family, from the time of diagnosis to the bereavement period. According to the American Congress of Obstetricians and Gynecologists (ACOG, 2019), it is a coordinated maternal and newborn care strategy whose focus is on maximizing comfort and quality of life for newborns with LFDs. A palliative care program is built on a model of shared decision making between the birthing person, her partner, and the palliative care team, and includes a specific birth plan. This aligns with fundamental midwifery values of promoting woman- and family-centered care, empowerment of women in their healthcare, and advocacy for informed choice (ACOG, 2019; American College of Nurse Midwives [ACNM], 2012). The palliative care team usually includes the providers of maternal and pediatric care, a social worker, a bereavement counselor, a chaplain (if the family wishes), and nursing staff (either in-hospital or infant home-hospice, if appropriate). ACOG's Committee Opinion on PPC (2019), endorsed by the American Academy of Pediatrics, states:

> "Perinatal palliative comfort care is one of several options along a spectrum of care, which includes pregnancy termination (abortion) and full neonatal resuscitation and treatment, that should be presented to pregnant patients faced with pregnancies complicated by life-limiting fetal conditions."

The International Confederation of Midwives recommends that PPC be incorporated into basic midwifery education (ICM, 2013). Van Hoover & Holt (2016) propose that as holistic health care providers, midwives are qualified for and well suited to give palliative care. There are currently 272 perinatal hospice programs in 45 of 50 states in the US (perinatal hospice.org, 2021). Only 10 programs list an advanced practice registered nurse (APRN) or certified nurse-midwife (CNM) as the primary contact person, though many other PPC programs likely intersect with midwifery practice. If PPC is beneficial for parents, then midwives have a duty to promote increased access to these services.

Theoretical Framework

The theory on grief outlined by Worden (2018) will provide the structure for our review, since it explores the ongoing work of mourning and integration of loss. Worden identifies four key tasks of grieving, namely to: (1) accept the reality of the loss, (2) process the pain of grief, (3) adjust to a world without the deceased (including both internal, external, and spiritual adjustments), and (4) find an enduring connection with the deceased in the midst of embarking on a new life (Worden, 2018). This review views the literature through the lens of these four tasks and identifies how PPC has assisted parents in working through them.

Methods

Design

This literature review utilizes the methodology proposed by Whittemore and Knafl (2005) for qualitative, original research aimed toward decreasing errors and biases; this provides an appropriate, rigorous framework to address the grief experiences of parents who chose PPC in the face of life-limiting fetal condition (LLFC) diagnosis. Following their updated guidance on literature review methodology, the area of interest was identified, an extensive search of literature across multiple databases was conducted, data was strategically evaluated and analyzed, and finally the results were presented within the framework of grief. This methodology is the ideal foundation for a literature review because it provides a systematic, rigorous, and reproducible strategy for presenting comprehensive findings; it involves a holistic approach to diverse data sources, and its results could play a significant role in establishing new practice guidelines and addressing complex concerns within the health care community.

Search Strategy

Following consultation with the Bethel University reference librarian and their advisor, the authors of this review created a systematic search strategy to effectively target relevant data in extant literature. On January 17, 2023, a complete search across five databases was conducted—including CINAHL, Scopus, ScienceDirect, PubMed, and Google Scholar—utilizing Boolean operators with key terms: *perinatal palliative care*, OR *perinatal hospice*, AND *grief*, OR *bereavement*. To be included within this review, studies had to meet the following criteria: original research studies published between 2011 and 2023, in English, and available in full text.

Upon completion of the search in Covidence (a systematic review software), the resulting abstracts and full-text articles were screened for inclusion and exclusion criterion. A Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) was constructed to exhibit the search strategy and is presented in Figure 1 (Page et al., 2022). The initial search revealed 739 articles with 286 removed as duplicates. Of the remaining 453 articles, 267 were excluded through abstract-screening, with the balance (*n* = 186) independently evaluated in full-text. Discussion on inclusion and exclusion criterion resulted in 21 articles eligible for review. One additional article was included through citation searching.

Criteria for inclusion were: (a) a fetal age of 20 weeks' gestation through 28 days of life, (b) diagnosis with a life-limiting fetal condition during pregnancy, (c) parents' perspectives on care, and (d) utilization of perinatal palliative care. Because PPC is not always provided through a structured program, if a study included counseling and care throughout the pregnancy within the lens of palliative and hospice care, it was included. Studies from countries outside the US were incorporated to maximize the scope of perinatal palliative care across cultures and environments. Exclusion indicators were: (a) stillbirth without previous life-limiting condition diagnosis, (b) care of patients choosing termination of pregnancy, and (c) perspectives of healthcare professionals only.

Analyzing Findings

Summarizing findings for each article, a literature matrix was created that includes the characteristics: author, date, purpose, design, methodology, sample, results, recommendations, strengths, limitations, level, and quality. Appraisal for each article was completed utilizing the Johns Hopkins Nursing Evidence-Based Practice appraisal tool to assign a grade of quality—with A(High), B(Good), or C(Low)—based on the attributes, design, rigor, and transparency of each article (Dearholt & Dang, 2018). Only high- and good-quality articles are included. The matrix is provided in Table 1.

Results

Sample Characteristics

The 22 research articles examined represent the voices of 1,277 mothers and fathers who have received perinatal palliative care. The studies were conducted between 2011 and 2022. All were qualitative; seven were retrospective; and four were individual case studies. Several methodologies were used: three longitudinal phenomenological, two cross-sectional descriptive surveys, one comparative mixed methods case study, and one grounded theory. Geographically, most studies (*n* = 13) were from the US. The remaining nine came from Australia, Canada, Germany, France, Ireland, Italy, New Zealand, Poland and Uruguay. Though representing parents from a variety of countries, these articles revealed consistent experiences across international borders.

The studies examined PPC from multiple perspectives. The largest studies had 405 and 379 participants, respectively. Thirteen of the other studies had small samples of 4 to 30 parents, while the three remaining mid-range ones had 52 to 85. Four case studies each gave deep insight into an individual family's experience with PPC (Bennett et al., 2011; Chapman, 2013; Korzeniewska-Eksterowicz et al., 2021; Kuchemba-Hunter, 2019). Data were collected through retrospective chart reviews (*n* = 2), validated questionnaires/surveys (*n* = 8), or face-to-face interviews (*n* = 8). Three studies used large-scale surveys for Phase1 and individual interviews of a targeted smaller sample for Phase 2. One study examined the impact of PPC from only the father's perspective (Cole, et al., 2019); another sought the perspective of African American and Latino parents (Côté-Arsenault et al., 2019).

Racial and ethnic backgrounds were mainly European American, European, and South American. Only 5% of the samples were Latino and 2% were Black. Parents were aged 18 to 45 at the time of loss. English was the primary language spoken; participants also spoke French, German, Italian, Polish, Portuguese, and Spanish. Most of the participants had a college level of education or higher. The majority identified as Christian, but non-practicing participants, and those with other religious affiliations or atheistic backgrounds were also represented.

Examining Data Using Worden's Grief Theory

Data was examined through the lens of Worden's grief theory involving four tasks of grief: accepting the reality of the loss, processing the pain of grief, adjusting to a world without the deceased, and finding an enduring connection with the deceased in the midst of embarking on a new life. Results for these and other findings are summarized in Table 2.

Accepting the Reality of the Loss

Parents from all 22 studies identified perinatal palliative care as significant to the process of accepting the reality of their loss. One study compared grief scores between parents who chose to continue their pregnancy and those who chose termination of pregnancy for lethal fetal anomaly (TOPFA). While initial grief scores were similar between the two groups, the parents who chose TOPFA expressed more feelings of guilt and were more likely to suffer from PTSD after the loss (Depoers-Béal, 2019). The initial communication with parents about their child's diagnosis, and the conversations with the healthcare team that followed, had a significant impact on parents' acceptance of their child's terminal diagnosis. Prenatal attachment to one's unborn baby is well-documented for both mothers and fathers; therefore, the grief process begins at diagnosis for parents of a child with an LFD. Mothers' attachment to the fetus may begin early in pregnancy; fathers' attachment often grows once they "see" their baby during an ultrasound. It is undeniably devastating when this first "meeting" is accompanied by the news that the baby has a major anomaly and likely will not survive (Cole et al., 2019; Korzeniewska-Eksterowicz et al., 2021; Limbo & Lathrop, 2014).

For most parents, the initial reactions to the diagnosis are shock and intense feelings of grief, followed by a fog of confusion and anxiety. Some parents temporarily dissociate from the pregnancy, then return with a stronger attachment to the baby once the initial shock dissipates (O'Connell et al., 2019). The PPC model of care enters this crisis and brings empathy, calm, and coordination of care that meets parents where they are in the process and lifts their burden of information-seeking and decision-making. Parents then commonly report that the pregnancy "slows down" while they research the diagnosis, come to accept it, and treasure each day with their baby before birth and death (Bennett et al., 2011; Côté-Arsenault & Denney-Koelsch, 2016; Denney-Koelsch et al., 2018; Korzeniewska-Eksterowicz et al, 2021).

Processing the Pain of Grief

Perinatal palliative care provides multiple ways to help parents work through the inescapable pain that accompanies infant loss. Both health care providers that offer consistent, empathetic care throughout pregnancy and a sensitive, multidisciplinary birth team have essential roles in facilitating this process. Hein et al. (2022) described the "trusted midwife" as the most effective member of the entire PPC team. Families often change providers after the initial diagnosis to one who will honor their wishes to continue the pregnancy; midwives are the usual choice due to their holistic model of care (Chapman, 2013; Côté-Arsenault et al., 2019). Parents identified the following PPC interventions as most comforting: validation of their role as parents, frequent ultrasounds, birth planning, and opportunities for caregiving after the birth.

To validate parenthood, Thornton et al. (2021) utilized grounded theory to conceptualize "affirmed parenthood," involving guidance from caregivers, cultivating the sense of "being a parent," and creating evidence of their baby's short life (p. 52). Parents have a deep need for validation of their identity as mothers and fathers of a real baby, and the baby's LFD can threaten this identity. Effective caregivers affirm parental identity and refer to the baby by name, thereby affirming the baby's personhood. Ultrasounds provide opportunities for both parents to experience a sense of "being a parent" and to bond with the baby while still alive in utero. Mothers may even experience increased bonding with their unborn child beyond that of a "normal" pregnancy, since every movement is precious (Côté-Arsenault et al., 2019; Crawford et al., 2021; Kuchemba-Hunter, 2019; Lathrop & VandeVusse, 2011; O'Connell et al., 2019).

Birth planning was a tool that parents found to be comforting, helping them anticipate rather than dread the baby's birth. When parents can define their wishes and formulate birth plans, a measure of autonomy is regained in a situation that is beyond their control. This hallmark of PPC results in higher patient satisfaction with their birth compared to care based on typical hospital routines. Many mothers described the birth as a joyful event, contrary to what providers may expect (Côté-Arsenault & Denney-Koelsch, 2016; Depoers-Béal et al., 2019; Lathrop & VandeVusse, 2011). One author describes her birth this way: "I had already made my birth plan…to hold him, swaddle him, take pictures and footprints. My wishes were not only respected but were respected honestly, compassionately, and sincerely" (Kuchemba-Hunter, 2019, p.1). Her story further highlights the importance of caregiving for those in the midst of the acute pain of grief.

Mothers valued the often-fleeting chance to hold their babies, breastfeed, dress them, swaddle them, and bathe them (Chapman, 2013). Fathers also found that being able to simply sit and hold their child while watching TV, or talk and sing to them, was irreplaceable (Cole et al., 2019). Family pictures and footprints and handprints are treasured mementoes. A theme throughout the literature is the importance of time with the baby and the need to "have no regrets" about parenting their child during their short life (Côté-Arsenault & Denney-Koelsch, 2016). A Polish mother states: "I thank God that he let us see him, to baptize Mieszko, and say goodbye to him. This one day, when he was with us, became the most wonderful day in all my life." (Korzeniewska-Eksterowicz et al., 2021, p. 907).

Adjusting to a World without the Deceased

Grief throughout a pregnancy may feel and look different to those experiencing it. Parents who were expected to celebrate a new life are now mourning the loss of their baby while remaining in an "in-between" time when their hopes to parent a healthy baby have been dashed (Côté-Arsenault & Denney-Koelsch, 2016). While this time can be incredibly difficult to navigate, parents who choose PPC are able to create attachment and a relationship with their baby during the time they have. Specifically following diagnosis, parents can "mindfully enjoy" time with their baby. This experience allows parents the ability to create these memories and process the grief throughout pregnancy instead of coming to terms with the loss over a short period of time. Some parents chose to make funeral preparations prior to birth, allowing them the ability to value, honor, and anticipate their last days with their baby. Memorials such as gardens, shelves within the home, or statues were chosen by parents to adjust to their lives without their babies. Because many mothers experienced breast milk coming in, having the ability to donate milk became a healing experience for them.

A large part of coping after loss is finding support through others who have experienced the same type of situation. With PPC, parents were able to connect with others who had faced similar struggles and decisions. These connections promoted growth and healthy relationships that modeled how to incorporate their loss experience into their daily lives (Crawford et al., 2021). Another way to adjust to life following the loss was to allow parents the opportunity to spend time with their live infant or even to care for their dead infant (Thornton et al., 2021). This quality time reinforced parenthood and bonding, prevented regrets, and facilitated recovery and bereavement. For parents who don't experience these connections, grief may remain unresolved. Furthermore, when the parent can interact with their baby following death, they are better able to understand, accept, and adjust to the permanence of death (Hein et al., 2022).

Finding an Enduring Connection with the Deceased while Embarking on a New Life

Time with their baby, parents revealed throughout the literature, provided a strong connection they felt months and years later. Parents treasured time spent integrating their baby into their family, whether born alive or stillborn; rocking, bathing, and singing to their baby, making meaningful connections with a little one whose life was brief (Cole et al., 2019). In contrast, the loss of time with the baby, through separation after a C-section or the baby being in the neonatal intensive care unit (NICU), was a deep regret for many parents (Korzeniewska-Eksterowicz et al., 2022) Making the most of the time with the baby was universally important, and most parents were able to remember joy at meeting their baby, amid sorrow (Côté-Arsenault & Denney-Koelsch, 2016).

Making memories both during and after the pregnancy helped parents to connect with their baby and move forward after the loss. Ultrasounds were particularly meaningful since they can capture live movement and allow parents to "see" their baby. Fathers, who (unlike their partners) were not feeling fetal movements, reported increased bonding with their baby following an ultrasound (Cole et al., 2019). Keepsakes helped parents remain connected to the baby they lost and move forward in life. Accepting death as part of pregnancy was an important, albeit excruciating task for parents (Crawford et al., 2021). Most studies stressed the importance of providers' empathic care throughout the process. (Denney-Koelsch et al., 2018).

Affirmation of the baby's unique identity or personhood was another important element. Parents like Jennifer (Kuchemba-Hunter, 2019) valued when caregivers treated their baby with dignity and respect, used their name, and were sensitive to their physical needs, such as pain, hunger, or dyspnea. After death, it is important to parents to talk to others about their baby, using their name and validating their humanity. Having individual and family pictures of the baby on display is often deeply meaningful (Chapman, 2013). Some parents will pursue organ donation to give life to another child, or mothers will donate breast milk to a milk bank (Côté-Arsenault & Denney-Koelsch, 2016). All these elements validate that the baby's life was unique and precious, not an unfortunate mistake. Further, they aid parents in forming a healthy and enduring connection to their child.

Dahò,(2020) describes metaphors parents may use, such as seeing the baby as a *gift* and the time spent with them as a *path,* becoming positive affirmations for a painful experience. These metaphors are closely tied to the parents' spiritual beliefs, which have been linked to a more complete grieving process and less complex grief in the time following a perinatal loss. Spiritual care is an essential component of hospice care, even for those parents who declare themselves atheists; humans all acknowledge a spiritual dimension that must be honored in times of deep conflict and loss(Korzeniewska-Eksterowicz et al., 2021).

Care from the parent's whole community—including the PPC team, extended family, friends, support groups and whoever else can comfort the grieving parents—gives meaning to the baby's life and helps parents integrate their grief into their life going forward (Chapman, 2013). They will never "get over" the loss of their baby, but they can grow and move forward as stronger, more compassionate people from the experience of perinatal bereavement. Midwives who integrate PPC as part of their care have a pivotal role in this process.

Discussion

Methods and Theory Integration

A literature review was performed using Whittemore & Knafl's (2005) methodology, searching across multiple databases and collating results acording to common themes. This methodology was used to increase rigor and provide reproducibility in the results. Themes were chosen based on Worden's Grief Theory which identifies four key tasks of mourning, highly relevant to parents experiencing perinatal loss. Commonalities were identified across these four key tasks: (1) accepting the reality of the loss, (2) processing the pain of grief, (3) adjusting to a world without the deceased, and (4) finding an enduring connection with the deceased in the midst of embarking on a new life (Worden, 2018).

Clinical Implications

Perinatal palliative care is a care strategy that focuses on maximizing quality of life and comfort while honoring patient values and decreasing suffering in the obstetric and newborn population (ACOG, 2019). This literature review demonstrates that PPC is a key component of options-counseling for parents facing a pregnancy with a lethal fetal defect. Perinatal palliative care is more than a program: it is a philosophy of care applicable to any birth setting. Common themes identified throughout the literature were the support and comfort perceived by parents who chose PPC and the dignity it conveyed upon their baby's life and death. Fathers found PPC particulary beneficial, and this theme was consistent across the larger body of literature. Inconsistencies included whether birth planning and funeral planning were helpful or unwanted during pregnancy, and whether those in areas where abortion care is not accessible, such as Ireland, would have ultimately chosen PPC if TOPFA (termination of pregnancy for fetal anomaly) were an option.

The authors recommend PPC integration as a standard of practice into midwifery and obstetric care, alongside options-counseling about TOPFA. Depoers-Béal et al. (2019) noted that 18% of parents in their study chose PPC, with the remaining 82% opting for TOPFA; perinatal grief is unavoidable with either option, though there was an increased incidence of pathological grief observed with termination.

Perinatal palliative care can decrease complicated grief while supporting parents who wish to maximize time with their child (Kersting & Wagner, 2012). Within most obstetric settings, PPC is limited to parents who seek it out, though some are fortunate enough to have providers who refer to this resource (Wool et al., 2016). While these programs are extremely beneficial, PPC can and should be provided outside of a formal construct. As patient- and family-centered providers, midwives can bridge this gap and offer this resource to their patients or support them through TOPFA if that is their choice. Shared decision making is the guiding principle of care for families faced with decisions regarding lethal fetal anomalies.

Application to Midwifery Practice

Midwives are unique providers who approach medical care from a holistic model. As a profession, midwifery is guided by principles of caring for the entire individual including the therapeutic value of human presence, empowerment of women as partners in their care, and support for individualized shared decision making (ACNM, 2020). Applying the hallmarks of midwifery to practice aligns with the principles that guide PPC, namely: compassionate communication, a fostered environment of partnership, and culturally competent care.

Significant barriers to integration of PPC exist within standard practice. One of these barriers is a lack of incorporation of PPC principles within perinatal providers' education. LoGiudice & O'Shea (2018) suggest that midwifery programs weave PPC throughout their curriculum to better prepare new graduates to enmesh PPC into their practice. Their model includes lectures and readings on PPC and ethical issues as well as simulated scenarios with rehearsed conversations and debriefing to equip students for difficult real-life conversations.

The model also provides tools for each stage of pregnancy, birth, and postpartum/postmortem. Students who can apply these principles in a safe space, during the support of parents with LLFCs, will foster a network of resources and support into their future model and philosophy of care. Midwives educated with knowledge and skills in PPC are prepared to empower women to create memories of a meaningful birth even in their darkest hours (LoGiudice & O'Shea, 2018).

Future Research

Recognition of and research about PPC have increased over the last two decades. However, this research remains focused on high-income countries and higher income families (Wang et al., 2022). A lack of access to PPC is the norm globally in low-resource communities. Global analysis reveals five main focal areas of PPC research: eligible candidates for PPC, models of service, components of PPC framework, satisfaction/perspectives of parents receiving PPC, and the challenges faced by healthcare professionals (Wang et al., 2022).

This review focuses on the experiences of parents whose high levels of satisfaction with their perinatal palliative care demonstrates the necessity of PPC as a standard of care. Still, further research is needed to understand the impact of PPC when fully integrated into perinatal care, rather than an outside community resource. Holistic healthcare providers, including midwives, are natural candidates for incorporating PPC into their repertoire of skills and knowledge.

Research into PPC is in its early stages (begun in the last 20 years), and this model of care remains a developing framework. One area marked by rapid growth is the effort to understand the impact of PPC. While this field will continue to grow as a discipline and in different geographical regions, research must also address collaboration on a national and international level (Wang et al., 2022). By cooperating and sharing information and resources on a global scale, growth and development in the academic field will benefit all families in need of PPC. Another barrier to developing more robust PPC support is a lack of understanding of what PPC entails. Generally, the discipline is not well understood by the public, professionals, or policymakers across the globe (Stenekes et al., 2019). As a result, funding and support is insufficient for rigorous research efforts at its current level (Wang et al., 2022). This literature review serves as an additional effort to contribute to further research and availability of PPC for every family who needs it.

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Figure 1

PRISMA Flow Chart

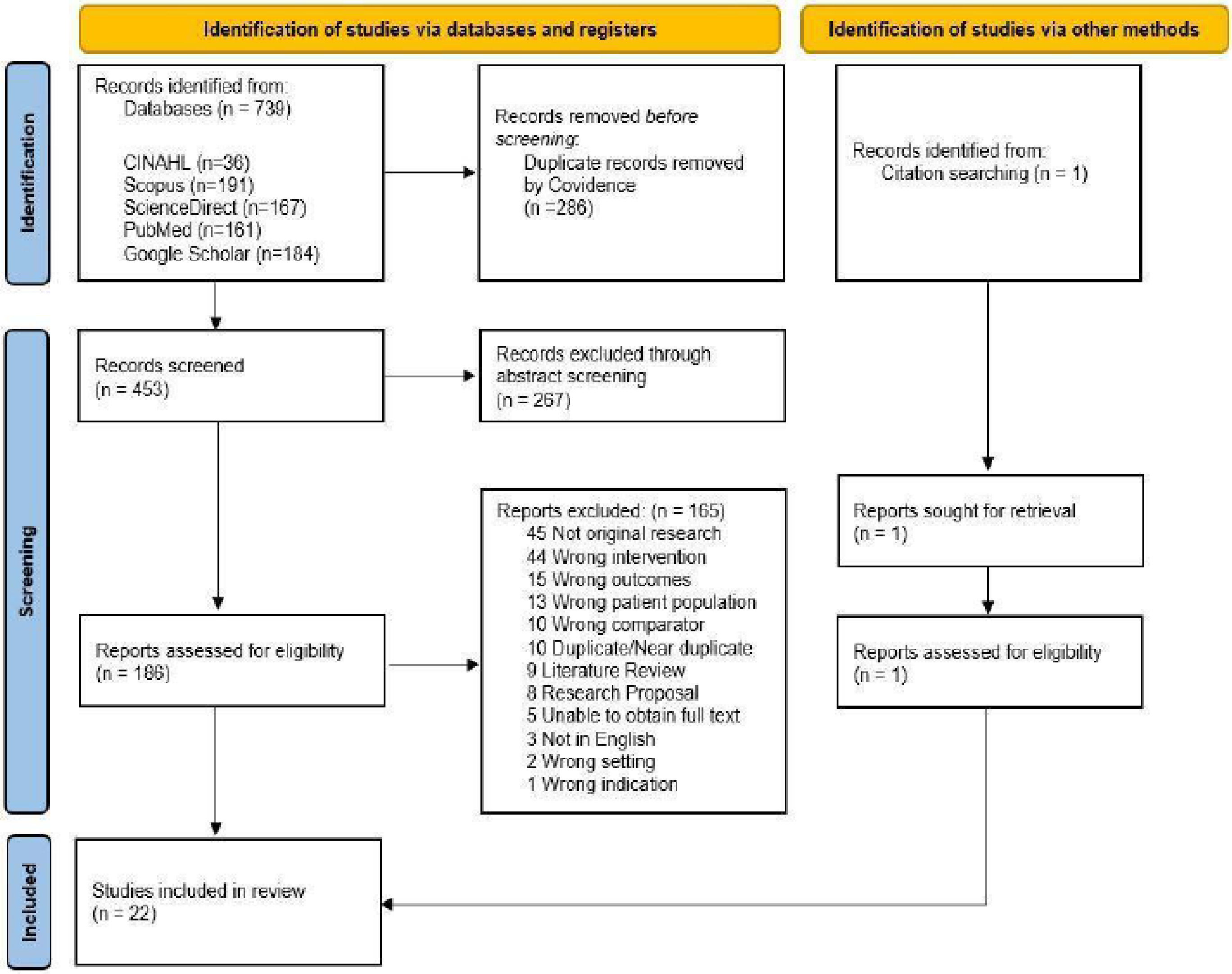

Table 1

Literature Review Matrix

Table 1

Literature Review Matrix

#	Characteristics	Findings
1	Author (Date)	Dahò, M. (2020)
	Purpose	To understand, through use of metaphor, parents' perspectives on the experience of perinatal hospice care for their infants who are affected by life-limiting or terminal conditions and are treated with personalized comfort measures.
	Design/Methodology	Qualitative exploratory study questionnaires asking parents to describe their perinatal hospice experience through a symbol, metaphor, or image. Open-ended questions
	Sample	52 questionnaires filled-out by parents who elected a perinatal hospice option
	Results	35 questionnaires returned of which 29 used metaphors to represent their personal experience with perinatal hospice. Data include 5 themes: Family Time, Protection, Spirituality, Gift, and Path
	Recommendations	Note the power of metaphorical statements and encourage their use to create a therapeutic setting for grieving families. Acknowledge the individual lives of babies with life-limiting conditions, to foster within their families a sense of support.
	Strengths (+) Limitations (−)	− Parents were not asked to explain the metaphor used to describe their perinatal hospice experience − Findings were gathered in survey form instead of deeper feedback from interviews or focus groups − Short-term results only available
	Level, Quality	III, B(Good)

#	Characteristics	Findings
2		
	Author (Date)	Patil, P. S., Brar, B., & Balderrama, A. (2019)
	Purpose	To describe the outcomes of pregnancies for birthing persons enrolled in a perinatal hospice program after prenatal diagnosis of a life-limiting fetal condition.
	Design/Methodology	Retrospective analysis to evaluate for psychological benefits that positively impact grief in a perinatal hospice program
	Sample	83 patients with life-limiting fetal conditions Surveys 6 years after experience
	Results	55 patients who received PPC support participated in the survey. 100% of parents stated that perinatal hospice helped them cope with their experience. 100% recommended perinatal hospice to others.
	Recommendations	Encourage perinatal hospice as a viable option in lieu of pregnancy termination, an option which has the potential for tangible psychological benefits to parents.
	Strengths (+)	− 12 participants did not follow up
	Limitations (−)	− Some data were not available for all participants
	Level, Quality	III, B(Good)

#	Characteristics	Findings
3		
	Author (Date)	Rufo, R., Boccarato, A., & Lujambio, M. (2017)
	Purpose	To establish a model training questionnaire to evaluate the needs and coping mechanisms of those who could benefit from PPC.
	Design/Methodology	Qualitative, retrospective, observational, and descriptive study Interviews to establish families' needs and coping resources were conducted
	Sample	379 families who received perinatal palliative care in a state maternity of Montevideo, Uruguay, in a period of five years (2010–2015) who had no less than three interviews during hospitalization
	Results	Established parents' needs (physical, emotional, behavioral, spiritual, and social) through interviews. Developed coping resources and a questionnaire based on these needs.
	Recommendations	Implement weekly meetings with parents and relatives in intensive care and meetings with the medical staff to improve inclusion and care for the family.
	Strengths (+) Limitations (−)	+ All subjects were asked the same or similar questions to identify families' needs. − Barriers included communication problems and differences in cultural beliefs about end-of-life care
	Level, Quality	III, B(Good)

#	Characteristics	Findings
4		
	Author (Date)	Côté-Arsenault, D., & Denney-Koelsch, E. M. (2016)
	Purpose	To understand the experiences of those who choose to continue pregnancy despite a lethal diagnosis.
	Design/Methodology	Longitudinal phenomenological study Interviews conducted with mothers and fathers from mid pregnancy until 2–3 months post birth
	Sample	15 mothers who were all English-speaking,18 years of age or older, with or without partner representation, and 15 spouses from 4 states, receiving care at different institutions. 45 prenatal interviews and 45 postnatal interviews in total
	Results	Identified these developmental tasks: navigating relationships, comprehending implication(s) of the condition, revising goals of pregnancy, making the most of time with baby, preparing for birth and inevitable death, advocating for baby with integrity, and adjusting to life in absence of baby.
	Recommendations	Provide patient-centered care that is matched to the different stages of developmental tasks, to potentially improve care and patient satisfaction.
	Strengths (+) Limitations (−)	+ Interviews were conducted with the same questions for each participant. + While small, the subject group was varied in age, race, education, income, occupation, and religion
	Level, Quality	III, B(Good)

#	Characteristics	Findings
5		
	Author (Date)	Doherty, M. E., Power, L., Williams, R., Stoppels, N., & Grandmaison Dumond, L. (2021)
	Purpose	To understand the characteristics of infants and families referred for PPC and the referral characteristics, interventions, and outcomes.
	Design/Methodology	A retrospective chart review
	Sample	84 referrals for PPC during a 10-year period
	Results	84 patients who chose to continue the service were diagnosed on average at 23 weeks, with a mean time to referral (after diagnosis) of 7 weeks. 99% of referred parents (*n* = 84) chose to continue care.
	Recommendations	Proactive referral to PPC programs since the findings validate the need/demand for PPC and earlier referral. Recommend that future research evaluates effectiveness of referral to PPC and collaboration between providers. Focus on comfort, reducing suffering, and improving quality of life for infants prenatally diagnosed with a lethal fetal anomaly.
	Strengths (+) Limitations (−)	− This study was unable to identify those individuals who would have been eligible for PPC who weren't referred or chose to terminate pregnancies upon receiving a LLFC diagnosis − Data collection was retrospective from record review and not directly from patients/families − This study was not able to assess the short- and long-term impacts of palliative care
	Level, Quality	III, B(Good)

#	Characteristics	Findings
6		
	Author (Date)	Berry, S. (2020)
	Purpose	"To describe the experiences of 3 families whose neonates with anencephaly were discharged home, identify parents' primary care concerns, and discuss end-of-life care interventions that health care professionals may offer in the home setting."
	Design/Methodology	Secondary analysis of 3 experiences in which parents were discharged home with a live neonate diagnosed with anencephaly. A qualitative descriptive summary of each participant's experience is presented. Experiences are viewed through the lens of an ontological death to identify elements that are important to patients' care during their perinatal loss.
	Sample	24 participants who enrolled voluntarily from an advertisement on anencephaly support group websites. 3 parents' experiences were analyzed more deeply
	Results	Seven primary topics of concern were identified: transportation, feeding, wound dressing, life length, end of life, grieving, and uncertainty. Patients with greater perinatal palliative support had lower Perinatal Grief Intensity Scores (PGIS).
	Recommendations	Promote shared decision making and memory making and begin bereavement support upon diagnosis. Give parents control over their care, including education on end-of-life symptom management. Normalize grief to reduce stigma and prepare parents for interactions with friends and family. Routinely screen both partners for complex grief as part of routine follow-up protocols after perinatal loss.
	Strengths (+) Limitations (−)	+ In-depth secondary analysis of parents' grief experiences at 10 years after the loss, compared to one year after the loss. − Small sample size and the length of time since the initial analysis, with possible changes in practice in that time
	Level, Quality	III, A/B(High/Good)

#	Characteristics	Findings
7		
	Author (Date)	Bennett, J., Dutcher, J., & Snyders, M. (2011)
	Purpose	"To use a case study to demonstrate the use of a palliative care interdisciplinary approach to intervene at these vulnerable moments, thus meeting the multifaceted bereavement needs of a family who was expecting to deliver a baby whose outcome would be poor."
	Design/Methodology	Individual case study of a family receiving PPC
	Sample	Single case study
	Results	Open communication through use of a birth plan created a feeling of safety for parents and clear guidelines for providers. Grief was acknowledged from diagnosis to after discharge, facilitating bereavement care.
	Recommendations	Recommended the family develop a written birth plan with assistance from the PPC team. Provide relationship-based care that focuses on grief support for families throughout pregnancy.
	Strengths (+)	+ Detailed account of a PPC service in action in a specific family's case study
	Limitations (−)	− Single case study
	Level, Quality	III, B(Good)

#	Characteristics	Findings
8		
	Author (Date)	Wool, C., Black, B. P., & Woods, A. B. (2016)
	Purpose	"To describe Quality Indicators (QIs) associated with satisfaction of parents who have continued a pregnancy with a LLFC."
	Design/Methodology	Cross-sectional descriptive survey design
	Sample	405 complete surveys
	Results	Parents who reported that the health care team (HCT) treated their baby as a person and that the HCT took care of their medical needs had nearly 3 times greater chance of reporting satisfaction with their intrapartum care.
	Recommendations	Recognize the infant as a valued child. Support parents in holding, bathing, and spending time with their child. Make keepsakes, photos, and mementoes. Provide compassionate words, which are likely to be remembered by parents in bereavement. Cultivate excellent communication.
	Strengths (+) Limitations (−)	+ Examination of four intrapartum subscales + Data compiled by logistical regression + Work is congruent with previous research − Homogeneous sample − Overrepresentation of trisomy 18 diagnosis − Ambiguity in the neutral category on the Likert scale
	Level, Quality	II, A/B(High/Good)

#	Characteristics	Findings
9		
	Author (Date)	Chapman, B. (2013)
	Purpose	To describe the journey for a family who decided to continue a pregnancy with anencephaly and how the PPC model was integrated into their care.
	Design/Methodology	Descriptive, case study
	Sample	Single case study
	Results	Breaking the news of a lethal fetal diagnosis requires spiritual and emotional support for the parents. Family-centered decision making is best accomplished through multi-agency assessment of the family's needs and care plan. End-of-life planning and bereavement support are standard of care.
	Recommendations	Provide one central care coordinator (can be the primary midwife) within a multidisciplinary support network. Use community support as well as health care providers and keep the family at the center of all PPC efforts.
	Strengths (+) Limitations (−)	+ Detailed description of use of a PPC model in a community where no official PPC service exists + Parents' reflections of the value of their baby as a person and time with their baby are consistent with other research. − Single case study − No formal tools used to assess parents' grief
	Level, Quality	III, A/B(High/Good)

#	Characteristics	Findings
10		
	Author (Date)	Cole, J., Macdonald, J. N., & Qamar, H. (2019)
	Purpose	"[T]o understand how men cope with the anticipated loss of their child when a life-limiting fetal diagnosis is confirmed in pregnancy."
	Design/Methodology	Qualitative survey method
	Sample	A retrospective cohort of 25 fathers of infants with lethal fetal diagnoses from the previous 5 years, recruited through an email survey
	Results	Fathers all expressed strong emotional reactions to the diagnosis, from depression to anger. Most cited a connection with their baby as the reason for choosing PPC. Fathers coped either through engaging or avoiding in equal numbers. Therapeutic birth planning helped fathers to participate in the process of caring for their wife and child.
	Recommendations	Recommend steps to address the health of a couple's relationship when a perinatal loss is anticipated. Encourage therapeutic birth planning, which helps both men and women prepare for and thereby decrease the risk of a traumatic birth experience. Allow men to not be "okay" and to encourage them to connect with their own emotional experiences.
	Strengths (+) Limitations (−)	+ High participation rate of bereaved fathers (a sample set that has not been often studied) − Homogenous sample − Lack of in-person interviews
	Level, Quality	III, A/B(High/Good)

#	Characteristics	Findings
11		
	Author (Date)	Denney-Koelsch, E. M., Côté-Arsenault, D., & Jenkins Hall, W. (2018)
	Purpose	"To describe parents' experiences of continuing pregnancy with a known LLFC and to examine the parents' needs and responses to health-care provider interactions" across the pregnancy, birth, and postpartum periods.
	Design/Methodology	Longitudinal phenomenological study
	Sample	30 parents who chose to continue pregnancy with lethal conditions. Completed 1–5 interviews each during antepartum, intrapartum, and postpartum period
	Results	Parents perceived two themes: "feeling cared for" and "experiencing added burden." Parents' needs include: a caring manner, straightforward information, nonjudgmental care, maintaining hope, sensitivity, continuity of care, accurate information, expert guidance, and minimal waiting times.
	Recommendations	Be intentionally consistent, trustworthy, caring, straightforward, and sensitive —traits parents desire in their care providers. When providing PPC, focus on parents' needs across diverse groups.
	Strengths (+) Limitations (−)	+ The parents who participated were offered termination and chose to continue the pregnancy. − Parents who chose termination were not included, nor were their experiences with their healthcare team − Study performed on a small group of 70% White English-speaking participants
	Level, Quality	III, B(Good)

#	Characteristics	Findings
12		
	Author (Date)	Côté-Arsenault, D., Denney-Koelsch, E. M., McCoy, T. P., & Kavanaugh, K. (2019)
	Purpose	To examine "the person characteristics, quality of perinatal palliative care (PPC) received and parent health outcomes."(for parents who received PPC).
	Design/Methodology	Comparative mixed methods case study design with a sequential explanatory core Retrospective parental interviews
	Sample	14 parent surveys and 9 interviews of minority parents (African American and Latinx) who received PPC
	Results	Most parents reported "strongly agree" when asked if they were satisfied with PPC. Parents reported negative experiences with their original providers of prenatal care but reported that PPC was "very supportive".
	Recommendations	Encourage the development of care models that incorporate the revised developmental tasks of pregnancy and are implemented prenatally.
	Strengths (+) Limitations (−)	+ Mixed methods approach allows for collection of complex data and provides more insight into experiences. − Small sample size − Spanish interpretation not available for Latin@ population which might have limited the sample size
	Level, Quality	III, B(Good)

#	Characteristics	Findings
13		
	Author (Date)	Crawford, A., Hopkin, A., Rindler, M., Johnson, E., Clark, L., & Rothwell, E. (2021)
	Purpose	"To explore the experiences of women who received life-limiting fetal diagnoses during pregnancy and support from a perinatal palliative care program."
	Design/Methodology	Descriptive qualitative study
	Sample	Convenience sample of 12 women receiving PPC following LLFC diagnosis who were mailed invitations to complete semi structured interviews with content analysis about their experience with PPC
	Results	Four themes were identified during interviews: importance of memorabilia to cope with the health and documentation of the pregnancy, acceptance of death as part of the pregnancy experience, continued life without a child, and importance of empathy throughout the process. Parents reported empathy and sense of direction from the PPC team were the most important aspects from the program.
	Recommendations	Encourage or conduct additional research about women's and men's experiences of life-limiting fetal diagnoses to potentially improve the responsiveness and sensitivity of health care providers and the development of PPC programs. Note how these findings demonstrate the necessity and importance of PPC programs.
	Strengths (+) Limitations (−)	− Only women (not their partners) were interviewed − Small sample size − Responses received were only from participants willing to share about their experience with PPC, which might have included only participants who were satisfied with their use of the PPC program
	Level, Quality	III, B(Good)

#	Characteristics	Findings
14		
	Author (Date)	Limbo, R., & Lathrop, A. (2014)
	Purpose	"[T]o define and extend caregiving theory in the context of perinatal bereavement, specifically perinatal hospice mothers."
	Design/Methodology	Qualitative secondary analysis of data from exploratory investigation with applied caregiving theory
	Sample	Audio-recorded face-to-face interviews with 15 women, 90–180 minutes in length, in settings chosen by the participants
	Results	Mothers' caregiving evoked the following major themes: protecting, nurturing, socializing, and (finally) accepting the reality of death. One prevailing theme was validation from the PPC team that the baby existed and holds significant meaning.
	Recommendations	When providing care to a family whose baby dies, use caregiving theory as a framework and guide. As a clinician, cultivate an open-minded response by understanding that a mother is in a relationship with her child—and her goals for this relationship exist no matter the baby's condition.
	Strengths (+) Limitations (−)	+ Sample included a variety of fetal diagnosis. − Fathers were not included in the study − 13 of the 15 women were White and all identified as Christian
	Level, Quality	III, B(Good)

#	Characteristics	Findings
15		
	Author (Date)	Korzeniewska-Eksterowicz, A., Kozinska, J., Kozinski, K., & Dryja, U. (2022)
	Purpose	To examine the parent's and doctor's perspectives of the first perinatal hospice patient.
	Design/Methodology	Single case study
	Sample	A perinatal hospice (PH) provider and the first mother and father supported by PH provided personal reflection on perspectives on PH in a hospital without a PPC program or support
	Results	The mother reported enjoying her pregnancy, getting to say goodbye, and being grateful that her son met family. Father reported feeling cheated and disappointed at diagnosis. Both parents reported feeling that through perinatal hospice, they achieved everything that was important to them.
	Recommendations	Be resolved (as health care providers) to fight and change the standards of care in the "medical world" to include PPC.
	Strengths (+) Limitations (−)	− Limited case study with only perspectives from one situation in an environment with a new perinatal hospice platform, but no PPC program − Study in Poland, which might not reflect care provided in the US
	Level, Quality	III, B(Good)

#	Characteristics	Findings
16		
	Author (Date)	O'Connell, O., Meaney, S., & O'Donoghue, K. (2019)
	Purpose	To examine the maternal experience of continuing pregnancy with a prenatal diagnosis of anencephaly.
	Design/Methodology	Qualitative study using interpretive phenomenological analysis
	Sample	Four mothers who participated in semi structured interviews on their experience of pregnancy and delivery
	Results	Five themes emerged from the mothers' experiences: emotional impact, decision making, evolving relationship with the baby, experiences that hurt and helped, and lasting impact.
	Recommendations	Realize that for some mothers prenatally diagnosed with lethal fetal condition, PPC is a positive life experience. Consider recommending a comprehensive multidisciplinary team approach for PPC and know the patients' relationship with their healthcare professionals is vital to the PPC process.
	Strengths (+) Limitations (−)	− Only studied mothers of babies with anencephaly − Small sample size (only 4 mothers interviewed) − Population from Ireland where termination is not easily accessible, so these mothers may not have had the choice to choose PPC
	Level, Quality	III, B(Good)

#	Characteristics	Findings
17		
	Author (Date)	Thornton, R., Nicholson, P., & Harms, L. (2021)
	Purpose	To explore the significance of memory-making for bereaved parents and the impact of memory-making on parents' experience of neonatal end-of-life care.
	Design/Methodology	Qualitative research utilizing grounded theory
	Sample	Extended interviews with 18 parents who had experienced neonatal loss and received PPC
	Results	Parents identified contact with their baby as central to their experience of memory-making. Time to say goodbye was important. Contact, Engaging and Caregiving were overarching themes.
	Recommendations	Encourage parents to have unrestricted contact with their baby, to engage with them, and to provide infant care throughout the baby's brief life as well as after death. Using your unique position as a health care provider, support and encourage patients to engage in memory-making and affirming parenthood.
	Strengths (+) Limitations (−)	− Relative homogeneity of the sample − Sample was recruited through bereavement support groups and might not be representative of the broader population − All participants were English-speaking
	Level, Quality	III, B(Good)

#	Characteristics	Findings
18		
	Author (Date)	Hein, K., Flaig, F., Schramm, A., Borasio, G. D., & Führer, M. (2022)
	Purpose	To enhance our knowledge about care experiences and needs of parents who decide to continue pregnancy despite the life-limiting condition of their unborn child and to reconstruct their pathway through existing healthcare structures.
	Design/Methodology	Qualitative methodological study
	Sample	11 families who received PPC participated in semi structured, narrative-oriented interviews at least 1 year following the death of their child
	Results	Caring for their dead infant reinforces bonding, prevents regrets, supports bereavement, and facilitates recovery. Parents appreciated the ability to spend time with their child, participate in farewell rituals, and to grieve their loss. None regretted their choice to continue pregnancy.
	Recommendations	Note that a PPC program requires early and comprehensive information, sensitivity, and a non-directive approach. Provide a multiprofessional team to inform patients of diagnosis. While PPC was provided, it was not done in a formal fashion, the study authors endorse a need for a structured PPC program.
	Strengths (+) Limitations (−)	+ Study performed in Germany where PPC is well established and includes end-of-life care, follow-up after hospital discharge, and bereavement support. + Services are much more robust than in the US. − Services are often uncoordinated. − Patients must seek services without guidance
	Level, Quality	III, B(Good)

#	Characteristics	Findings
19		
	Author (Date)	Kuchemba-Hunter, J. (2019)
	Purpose	To discuss the necessity of community to and the nature of compassion in PPC and how providers can integrate these into their provisions of care.
	Design/Methodology	Case study/patient perspective narrative
	Sample	One patient recalling her experience receiving PPC
	Results	Author/patient states that parents who have used PPC believe in its value and understand the importance of care that embodies compassion and a sense of community.
	Recommendations	Provide social support, including resources for community programs, counseling, or services-to assist with all stages of pregnancy and birth. These resources may include bereavement doulas, spiritual care, advisors, online groups, and donations.
	Strengths (+)	− Limited case study
	Limitations (−)	− Only perspective is from one, well-educated patient
	Level, Quality	III, B(Good)

#	Characteristics	Findings
20		
	Author (Date)	Depoers-Béal, C., Le Baccon, F. A., Le Bouar, G., Proisy, M., Arnaud, A., Legendre, G., Dayan, J., Bétrémieux, P., & Le Lous, M. (2019)
	Purpose	To assess the perinatal grief experienced after continuing pregnancy and comfort care in women diagnosed with LLFC compared to TOPFA.
	Design/Methodology	Single-center, observational, retrospective cohort study utilizing Perinatal Grief Scale and questionnaire
	Sample	Comparing grief scores between 28 patients who chose to continue pregnancy and receive PPC matched to 56 patients who underwent TOPFA for the same type of anomaly
	Results	Parents who chose TOPFA expressed more guilt. Women in the continuing pregnancy and comfort care group were "very satisfied" with the support provided by the medical team. There was no difference in pathological grief between the two groups. Continuing pregnancy and comfort care was more likely to be associated with a better experience by the women.
	Recommendations	Establishment of comfort care support requires a trained and experienced team. After the event, reinforce psychological support in all cases of fetal loss. Perinatal grief process should continue to be studied for several years following loss.
	Strengths (+) Limitations (−)	− Because the group of patients who continued pregnancy was smaller, it might not represent pathological grief as well as the larger/TOPFA group − Since data was gathered up to 10 years later, pathological grief might have existed prior to the study − Women choosing to participate might have come to terms with the event whereas those who chose not to participate might not have which could represent the population differently
	Level, Quality	III, A(High)

#	Characteristics	Findings
21		
	Author (Date)	Kamrath, H., O'Conner-Von, S., Needle, J., Osterholm, E., George, T., & Stover-Haney, R. (2017)
	Purpose	To gain a deeper understanding of the maternal experience among mothers who contemplated PPC during pregnancy.
	Design/Methodology	Phase 1: Retrospective Review of Medical Records Phase 2: Qualitative Focus Group Interview
	Sample	Retrospective chart review of 18 mothers with diagnosed LLFC who chose to utilize PPC. Interviews with 7 of the mothers were conducted to gain a deeper understanding of the maternal experience
	Results	None of the participants who completed Complicated Grief Questionnaires met the criteria for such a diagnosis. Three main themes emerged: Care, Choice, & Legacy.
	Recommendations	Note that empathic interprofessional care can serve to promote women feeling cared for and cared about, as well as promote opportunities for hope.
	Strengths (+) Limitations (−)	− Single-center study with retrospective demographic data that are limited due to inconsistency in documentation of ethnicity, religion, and education
	Level, Quality	III, B(Good)

#	Characteristics	Findings
22		
	Author (Date)	Lathrop, A., & VandeVusse, L. (2011)
	Purpose	To explore the experiences of women who chose to continue pregnancies affected by LLFCs and to develop knowledge useful to nurses and other healthcare professionals who provide perinatal hospice (PH) care.
	Design/Methodology	Qualitative descriptive study using narrative analysis
	Sample	15 women who learned of LLFC during pregnancy and chose to continue pregnancy with PPC from 3 different perinatal bereavement agencies were interviewed face-to-face and common themes identified
	Results	Mothers reported feelings of love and connection with their babies, drawing personal meaning and life lessons from their experiences. Themes included: continuity of connection to their baby, transient phases of difficulty and strength, and evolving changes with decreases of intensity of grief.
	Recommendations	Provide care focused on the evolving nature of grief and encourage mothers to connect through support groups, since this approach is valuable to participants of PPC. As a health care professional, facilitate mothers' self-discovery of personal meaning in the face of loss (rather than offer your own interpretations).
	Strengths (+) Limitations (−)	− Homogeneity of the sample with relatively privileged socioeconomic backgrounds − Fathers and siblings were excluded − While longitudinal studies typically span long-term intervals, this study was limited to 1-to-2-year intervals
	Level, Quality	III, B(Good)

Note: PPC = Perinatal palliative care; LLFC = Life-limiting fetal condition; TOPFA = Termination of pregnancy for fetal anomaly.

Note: Studies are listed by chronological order in which they were reviewed.

Table 2

Applying Worden's Grief Theory to Perinatal Palliative Care

Worden's Tasks of Grief	Parents' Experiences with PPC
Accepting the Reality of the Loss	Acceptance of an LLFC begins at different times for each parent. Fathers are more likely to choose to avoid accepting the loss and with PPC they can attend to their own self-care and remain engaged with their partners. PPC respects parents' wishes to continue pregnancy which allows time to accept the reality of the fetal condition.
Processing the Pain of Grief	PPC assists both parents to process pain and grief during pregnancy and leading up to birth. Parents who have access to mementos such as photographs, infant keepsakes, and rituals or traditions during their loss are better able to process their grief.
Adjusting to a World without the Deceased	Parents who choose PPC felt significantly less guilty than parents who chose termination. Parents receiving PPC are more equipped to adjust to life following fetal or infant loss. Families are provided with assistance through PPC on how to navigate the world without their baby and how to break the news of a LLFC to others.
Finding an Enduring Connection with the Deceased in the Midst of Embarking on a New Life	Ultrasounds, hand/footprints, recordings of heartbeats, hair, lockets, and many other physical reminders are used to help parents remain connected to their babies while also supporting them to move forward when they are ready. PPC allows parents to consider organ donation as an option to contribute to saving other babies' lives. PPC recognizes the importance of identifying the fetus as a patient and the parent as such even when the life of their fetus or infant is limited.

Note: PPC = Perinatal palliative care; LLFC = Life-limiting fetal condition.