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African American and Latino bereaved parent health outcomes after receiving perinatal palliative care: A comparative mixed methods case study

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ABSTRACT

Background: Death of one's infant is devastating to parents, negatively impacting couple relationships and their own health. The impact of a prenatally diagnosed life-limiting fetal condition (LLFC) on parents of minority status is unclear.
Aim: This comparative mixed methods case study examined the person characteristics, quality of perinatal palliative care (PPC) received and parent health outcomes.
Methods: Bereaved couples, 11 mothers and 3 fathers of minority or mixed races (11 African American and Latino, 1 White Latino and 2 White parents) completed the survey; 7 were interviewed.
Results: Parents rated their general health close to *good*, physical health close to *normal* but mental health lower than the population norm. *Clinical caseness* (abnormal levels) of anxiety were reported in 50% of parents whereas depression scores were *normal*. The experience of fetal diagnosis and infant death had a negative impact on the health of 40% of participants however, parents could not identify what specifically caused their health problems. Most were *satisfied* with their PPC but some shared that original providers were not supportive of pregnancy continuation. After the baby's death, 71% reported *closer/stronger* couple relationships. Two contrasting cases are presented. Once parents found PPC, their baby was treated as a person, they spent time with their baby after birth, and found ways to make meaning through *continuing bonds*.
Conclusion: Despite high overall satisfaction with PPC, bereaved parents were deeply impacted by their infant's death. Mixed methods case study design illuminated the complicated journeys of parents continuing their pregnancy with a LLFC.

1. Introduction

Congenital anomalies account for 20% of the 30,000 fetal and neonatal deaths that occur annually in the US (Kirby, 2017). Many of the life-limiting fetal conditions (LLFC) are diagnosed prenatally, such as anencephaly and Trisomy 13 and 18 (ACOG Committee on Practice Bulletins, 2009). While mortality rates for babies born with LLFCs are higher in Hispanic and non-Hispanic black mothers (Wang et al., 2015) most of the research has been done in majority Caucasian patients. When parents learn that their baby has a LLFC, they experience shock and grief (Côté-Arsenault and Denney-Koelsch, 2016). Prior research shows that the trauma of a perinatal death can have a pervasive, long-lasting, negative effect on the parents' physical and mental health (Cacciatore, 2013; Christiansen, Olff, & Elklit, 2014; Gold, Boggs, Muzik, & Sen, 2014), but how these experiences differ and how to best help minority parents is unknown. The goal of perinatal palliative care (PPC) is to support families with LLFCs from diagnosis through bereavement through culturally-sensitive provision of psychosocial support, anticipatory guidance with medical decision-making and birth planning, and symptom management (Leuthner, 2004).

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1.1. Parents' experiences when their infant has a life-limiting fetal condition

Parents who learn that their unborn infant has a LLFC are faced with previously unthinkable choices. Rates of parents who terminate vary considerably from 36 to 90% (Hawkins, Stenzel, Taylor, Chock, & Hudgins, 2013; Tararbit et al., 2015), and increase with the severity of the abnormality (Schechtman, Gray, Baty, & Rothman, 2002). Unlike other forms of perinatal death (stillbirth, miscarriage) a death from a prenatally diagnosed LLFC is unique because the loss is anticipated throughout much of pregnancy. When continuing the pregnancy, parents must revise their developmental tasks of pregnancy (Côté-Arsenault & Denney-Koelsch, 2016) Amidst the anticipatory grief, parents still report some personal growth (Black & Sandelowski, 2010). Growth takes the form of “recasted hope”, which is a process of adaptation after fetal anomaly diagnosis (Lalor, Begley, & Galavan, 2009) and active parenting during pregnancy (Côté-Arsenault, Krowchuk, Hall, & Denney-Koelsch, 2015).

1.2. Parent outcomes after perinatal death

Poor parental outcomes after a perinatal loss are common, consisting of compromised physical and mental health (Christiansen et al., 2014; Gold et al., 2014), including, increased depression and anxiety (Blackmore et al., 2011; Cacciatore, 2013; Gold et al., 2014), traumatic stress responses Cacciatore, 2013; Côté-Arsenault & Denney-Koelsch, 2011; Gold, Leon, Boggs, & Sen, 2016) changes in the couple's relationship, an increased risk of marital dissolution (Shreffler, Hill, & Cacciatore, 2012) decreased work productivity (Fox, Cacciatore, & Lacasse, 2014) and even increased premature mortality (Calderon-Margalit et al., 2007; Harper, O'Connor, & O'Carroll, 2011). On the other hand, bereaved parents who try to make sense of their loss through meaning-making and seek something positive from their tragedy may experience positive personal growth (Black & Sandelowski, 2010) that leads to less maladaptive grief (Keesee, Currier, & Neimeyer, 2008; Lichtenthal, Currier, Neimeyer, & Keesee, 2010). Strong couple relationships and strong religious and spiritual beliefs have been found related to improved parent outcomes after perinatal loss (Avelin, Radestad, Saflund, Wredling, & Erlandsson, 2013; Côté-Arsenault & Denney-Koelsch, 2018).

The impact of race and ethnicity on responses to perinatal death is poorly understood. The limited research with perinatal loss in low-income African American parents has shown that these parents have many life stressors that compound their grief, including serious illness and premature death of close family members (Kavanaugh & Hershberger, 2005). They also perceived treatment disparities and racial discrimination (Kavanaugh & Hershberger, 2005). These parents coped by seeking diversions and support, relying on their spirituality and trying to make sense of the loss (Kavanaugh & Hershberger, 2005). The singular study of Latina women with early pregnancy loss indicated that negative interactions with health care providers contributed to women's distress. Women wanted providers who used carefully chosen words that did not minimize their experience, showed compassion, and continued to provide care into the weeks after their loss (Marek, 2013). These women's religious and cultural belief that life begins at conception and that they had lost a *baby* (and not just a pregnancy) influenced their loss experiences.

1.3. Perinatal palliative care: practices, parental satisfaction, and quality indicators

PPC programs have been proliferating, but many families still lack access and programs have little evidence on which to base practice (Allen & Friebert, 2009). A small but diverse sample of parents with a LLFC report their experiences with health care teams are variable and either reduce or add to their burden (Denney-Koelsch, Côté-Arsenault, & Hall, 2016). Parents want continuity of care from compassionate providers who provide information and expert guidance, maintain realistic hope, are caring and nonjudgmental, use an honest, straightforward manner; and are sensitive to the parents' developmental journey (Côté-Arsenault & Denney-Koelsch, 2016; Denney-Koelsch et al., 2016). Using the Parental Satisfaction and Quality Indicators of Perinatal Palliative Care Instrument with a largely Caucasian (89.8%) survey, Wool, Repke, and Woods (2016) showed that parental satisfaction with care is significantly higher when the PPC practices include compassion, continuity of care, emotional support, high quality medical care, and respect for the personhood of the infant. However, facilitating contact with a stillborn infant is the only practice which has been shown to enhance parent mental health (Kingdon, Givens, O'Donnell, & Turner, 2015).

Very little is known about the unique challenges of minority parents, their needs from health care, and ultimate health outcomes after loss of a baby from a LLFC. We conducted this study in preparation for a large national study of racially diverse bereaved parents using mixed methods sequential explanatory design. Our aims for this study were to recruit a sample of bereaved minority parents who experienced an anticipated perinatal death due to a prenatally diagnosed LLFC to (1) describe their person characteristics (obstetrical history, religiosity and spirituality), perinatal palliative care factors (quality of PPC received; satisfaction with care) and emotional and physical health outcomes (including couple relationship) and (2) gain detailed understanding of personal stories to allow case study comparisons.

2. Methods

A comparative mixed methods case study design with a sequential explanatory core (Creswell & Plano Clark, 2018) was used with quantitative data collection followed by qualitative interviews in a racially and ethnically diverse sample of bereaved parents. An on-line survey of multiple instruments was completed by parents, followed by telephone interviews of a sub-group of participants. Interviews were done to gain in-depth personal descriptions of the impact of fetal diagnosis, PPC experiences, health outcomes, and couple relationships beyond the ratings on the survey. This study was guided by an adaptation of the quality health outcomes model (Mitchell, Ferketich, & Jennings, 1998), using conceptual literature on palliative care (Stayer, 2012; Meghani, 2004), perinatal loss (Côté-Arsenault, 2003), and the outcomes model for bereaved parents. Key concepts include: *person characteristics* and *care factors* as they influence *parent outcomes* (see Fig. 1).

2.1. Sample and recruitment procedures

Mothers were sought with the following inclusion criteria: 1) English speaking, 2) minority status of either themselves or their

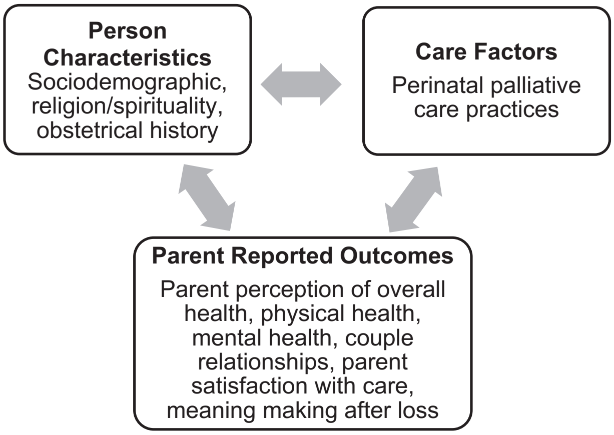

Fig. 1. Conceptual model.

partner, 3) have experienced a perinatal death (fetal or neonatal) due to a prenatally diagnosed LLFC 6 to 36 months prior, 4) were a recipient of PPC for that perinatal death, 5) were at least 21 years of age at time of loss. Mothers were asked to recruit the father of the baby. The inclusion of up to 3 years since the loss was based on our prior research in which bereaved parents were able to recall events vividly (Côté-Arsenault and Morrison-Beedy, 2001). Three years also allows for the time lag in appearance of symptoms such as depression in some parents (Cacciatore, 2013). The age criteria of 21 years or older avoids the unique developmental perspective of adolescent parents. Approval of this study was received from the Principal Investigator's (PI) university IRB. Each potential participant was contacted by phone or email (participant choice) to explain the purpose and process of the study, and that the consent document was embedded in the on-line survey.

Initial recruitment efforts through two PPC programs were time intensive and limited due to the need to manually review the records of a small pool of potential participants. Therefore, we posted our study with permission on a perinatal hospice listserv (extensively includes perinatal palliative care providers) and successfully recruited the sample.

2.2. Measures

The survey included demographics (Table 1). Obstetrical history was sought through a series of questions beginning with number of pregnancies and the outcome of each pregnancy. The date of loss and diagnosis for each pregnancy and infant loss were also requested. All measures have been used with samples of bereaved parents. Religiosity and spirituality were measured with the Intrinsic Spirituality Scale (ISS) (Hodge, 2003) plus two questions about religious affiliation and strength of religiosity. The ISS taps an individual's degree of spirituality “within and outside of a religious framework.” Internal consistency in Hodge (2003) was very high ($\alpha = 0.96$); construct and concurrent validity established with emotion variables and substance use. Couple relationship status was obtained with two questions: What is your current relationship with baby's other parent? and How has the experience of losing your baby affected your current relationship status?

Table 1
Survey sample demographics ($N = 15$).

Characteristic *n* (%) or *M* ± *SD* (min, max) *Med*	Overall ($N = 15$)	Mothers ($n = 11$; 73%)	Fathers ($n = 4$; 27%)
Age (years)	29.3 ± 6.2 (20, 41) 29.0	28.6 ± 5.2 (20, 37) 29.0	31.0 ± 9.0 (22, 41) 30.5
Past year combined family income (in $1000 s)	47.4 ± 49.2 (4, 200) 35.0	51.4 ± 55.8 (5, 200) 35.0	36.5 ± 27.0 (4, 70) 36.0
Race			
American Indian/Alaska Native	0	0	0
Asian	0	0	0
Black or African American	6 (40)	4 (36)	2 (50)
Native Hawaiian/Pacific Islander	0	0	0
White	3 (20)	3 (27)	0
Other (Hispanic, Mexican, Mixed)	6 (20)	4 (36)	2 (50)
Ethnicity			
Hispanic or Latino	7 (47)	5 (45)	2 (50)
Not Hispanic or Latino	8 (53)	6 (55)	2 (50)
Years of education completed			
Grade school (1 to 8)	0	0	0
High school (9 to 12)	9 (60)	5 (45)	4 (100)
College (13 to 16)	5 (33)	5 (45)	0
Graduate school (17 to 20)	0	0	0
Missing	1 (7)	1 (9)	0
How religious are you?			
0 (not at all)	0	0	0
1	0	0	0
2 (somewhat)	4 (27)	4 (36)	0
3	7 (47)	5 (45)	2 (50)
4 (very)	3 (20)	2 (18)	1 (25)
Missing	1 (7)	0	1 (25)
Religious affiliation			
Christian	9 (60)	7 (64)	2 (50)
Muslim	1 (7)	1 (9)	0
Other (Catholic)	3 (20)	2 (18)	1 (25)
Spiritual but not religious	2 (13)	1 (9)	1 (25)
Intrinsic spirituality scale score (range = 0 to 10)	6.8 ± 1.7 (4, 10) 6.6	6.8 ± 1.7 (4, 10) 6.7	6.7 ± 2.0 (5, 9) 6.2

PPC practices were captured with the Parental Satisfaction and Quality Indicators of Perinatal Palliative Care Instrument (Wool, 2015) that consists of 49 items scored in 8 domains (from the 2013 National Consensus Project for Quality Palliative Care; endorsed by the National Quality Forum) to be completed by bereaved parents for pre-, intra- and post-natal periods. The instrument addresses palliative care within the 8 domains of quality care at the end of life: structure and processes, care of the imminently dying patient, spiritual, religious, as well as physical, psychological and psychiatric, social, existential, cultural, and ethical and legal aspects of care. Satisfaction with care was self-report for 3 points in time. Content validity has been established as well as construct validity using factor analysis and reliability (all $\alpha > 0.90$).

Parent health outcomes were measured with four instruments. Perception of overall health was operationalized as 12-Item Short-Form Health Survey Version 2 (SF-12v2®) (Ware, 2002) (reliability 0.89 physical; 0.86 mental). Raw scores and normed T-scores ($M = 50$, $SD = 10$) based on 2009 population norms available for U.S. women ages 18–44 were used. Mental and physical health were measured with the Hospital Anxiety and Depression Scale (HADS); each dimension has 7 Likert-type questions (Zigmond & Snaith, 1983). The Impact of Event Scale- Revised (IES-R) tapped post-traumatic stress with 25 Likert-type items (Weiss & Marmar, 2004). These measures captured current health at the time of the survey. However, parents were also asked one standalone question regarding past history: “Have you received any health diagnoses since baby died?”

The concept of “meaning making” refers to how bereaved individuals understand and make sense of their life events. The Grief and Meaning Reconstruction Inventory (GMRI) operationalizes meaning making with Likert-type questions; 23 items from 4 subscales continuing bonds, personal growth, sense of peace and emptiness and meaninglessness were used (reliability α range = 0.76–0.85) (Neimeyer, 2000).

Semi-structured interviews were done to obtain a more in-depth understanding of personal characteristics, PPC experiences and parent outcomes. Each interview began with the person's “story” of the pregnancy and loss experience. Interviews began with broad question, “Is there anything you would like me to know about you and your baby?” Subsequent questions probed further to learn more about Obstetric history and care, PPC, impact of loss on couple relationship and on physical and emotional health.

2.3. Data collection

A web-based survey was used for data collection using Qualtrics (Qualtrics, Provo, UT). The survey was in English because the majority of these instruments were not available in Spanish. A link to the survey was sent via email to each potential participant. Offers were made to help two Spanish-speaking partners complete the survey but neither accepted this offer and did not complete it.

After survey completion, the PI contacted participants interested in and willing to be interviewed, as indicated at the end of the survey. Survey data were reviewed prior to each interview in order to be familiar with each participant's responses and circumstance, and to identify areas where clarification and expansion was desired or needed.

All interviews were done by the PI via telephone, although videoconference was also offered. All were audio-recorded, and professionally transcribed. Interviews were conducted until we reached an adequate amount of data with enough variation among participants on the impact on health that we needed to conduct the case study analysis. Transcriptions were verified, deidentified and uploaded on a secure university computer server.

2.4. Data analysis

2.4.1. Survey data

Quantitative analysis was performed using descriptive statistics for study measures, including for scale scores and PPC practices' ratings by time-frame (prenatal, intrapartal, and post-partal).

2.4.2. Interview data

Case study analysis (Yin, 2018) was done by first having three of the study investigators read all interviews to understand the breadth of experience while taking analytic notes in the process. Case summaries were created for each participant with integration of interview and quantitative survey data. Then the team met to discuss findings across participants that were deductively categorized within the theoretical framework as person characteristics, care factors, and parent reported outcomes. Aspects from each transcript were described and summarized. During this process, we performed cross-case synthesis (Yin, 2018) to note patterns within and between cases with particular attention to access to PPC, varying levels of depression, anxiety, couple relationship, and other parent health outcomes. Two cases were selected and summarized to illustrate contrasting experiences as they sought PPC and had different parent outcomes. Throughout, the quality of the data was maintained by digital recording, accurate transcription, and a multidisciplinary team analysis.

3. Results

3.1. Survey

While 20 parents agreed to be contacted about the study, the survey was started by 15 (75%) and completed by 14 (70%). Nine of these 14 participants agreed to be interviewed; 7 (5 mothers and 1 couple) were ultimately interviewed. Two of these nine were not interviewed because one was too emotional on the day of the interview; the interview from the other participant was not needed because had sufficient data to do the cross-case synthesis.

Fathers were slightly older on average relative to mothers (father's age *M* = 31.0 (*SD* = 9.0) vs. mother's age *M* = 28.6 (*SD* = 5.2)) (see Table 1 for demographics). Two of the mothers reported that they were non-Hispanic White (their partners were of minority status), 1 reported herself as White and Hispanic while the rest of the parents (*n* = 11; 78.5%) were African American, Hispanic, or mixed race. Some participants were part of a mixed-race couple. Half of the mothers (5 of 10) reported at least some college while all fathers reported high school education. Overall, all reported being somewhat to very religious. There was *medium-to-high* intrinsic spirituality (*M* = 6.8 on 0 to 10 scale for mothers and *M* = 6.7 for fathers). Sixty percent reported being Christian, one participant was Muslim and three reported being Catholic (separate from Christian). Seventy-one percent of the sample reported having closer or stronger couple relationship after baby's death (Table 2).

Obstetrical history was incomplete for several women, perhaps due to the survey design or their complicated stories. All women reported that they had been pregnant 2–7 times; three reported being currently pregnant. Fetal diagnoses reported by eight couples' included trisomy 13, osteogenesis imperfecta, kidney, lung, and heart anomalies, hydrops, and two with anencephaly. The infant losses from LLFC included: within the past year (1), one year ago (5), and four years earlier. Two participants did not specifically report timing of their losses on the survey, but their other responses indicated that they met the inclusion criteria.

Overall, mothers and fathers rated their general health close to *good* (*M* = 2.8 (*SD* = 1.2) on a 1 (*excellent*) to 5 (*poor*) rating scale) (see Table 2 for statistics for study survey measures). Physical health as measured by the SF-12v2 PCS was close to the population norm of 50 on average (*M* = 48.5, *SD* = 9.9) while mental health using the SF-12v2 MCS was lower (*M* = 39.8, *SD* = 13.3). Forty percent reported that the baby's death had *somewhat* or *a great deal* of negative impact on their own health. Almost half (*n* = 7; 47%) reported a HADS anxiety score level classified as *abnormal* (11 − 21), whereas HADS depression scores were in the *normal* range (*M* = 6.5, *SD* = 4.2). Multiple participants reported new physical and mental health diagnoses since their baby died.

Mean subscale scores on the Impact of Event Scale (IES-R) were very low, indicating no PTSD among study participants. The lowest GMRI meaning making score on average was among "sense of peace" (but had the most variation in scores) and the highest score on average was on "continuing bonds" (with the lowest variation). Fathers scored similarly on "continuing bonds" on average but lower on "sense of peace".

Most were satisfied with their intrapartal PPC care (*M* = 6.2 (*SD* = 1.8) on a 1 (Strongly Disagree) to 7 (Strongly Agree) rating scale), relative to prenatal (*M* = 5.6 (*SD* = 1.9)) and postnatal (*M* = 5.8 (*SD* = 2.0)). Table 2 also provides results for PSQI subscale scores for quality indicators of PPC care. Mothers generally rated quality indicators of care between 5 to high 6 on average on a 1 = Strongly Disagree to 7 = Strongly Agree rating scale while fathers rated between 4 to low 5 on average.

3.2. Interviews

Interviews painted a fuller picture of the challenges and positive experiences integral to parents' loss experience. Several parents shared that their original prenatal care providers were not supportive of continuation of pregnancy: three were offered termination and were pressured to choose that option. Two independently sought out more supportive care farther away, requiring one to move.

On the other hand, parents described positive experiences with PPC; their babies were treated as a person and not as a diagnosis, they spent time with their baby after birth and now have mementoes, and they have found ways to honor their babies. While parents reported quantitatively the degree to which their health was altered from their loss experiences, during the interview none were able to point to an individual aspect of care concerning enough to directly connect it to the cause of their health problem. Two mothers and one father acknowledged that they changed in a positive way because of their experience. However, their experiences were complex. One mother had severe pregnancy complications and her husband, who felt that he would never have a biological child, no longer wanted to socialize with others. Increased understanding of reported stronger couple relationships was gained during interviews.

A few parents were quite upset while recounting their experiences, more so than the experienced PI had encountered in prior studies. Strategies to deal with the emotional distress were enacted such as verifying that participant was not alone, had a care provider to call, and was calm before ending the phone call.

3.3. Case illustration

These cases, which are de-identified and given pseudonyms, illustrate the differences in the quality of the initial perinatal care received by the parents once their babies were diagnosed with a LLFC. Both parents eventually received PPC, which they described as very supportive. However, their journeys were very different. Sandra and her husband (1st case) were immediately referred to a PPC team once they made the decision to continue the pregnancy. Rosa (2nd case) independently sought out a PPC team after initially receiving very unsupportive care.

Table 2
Descriptive statistics of study survey measures.

Characteristic *n* (%) or *M* ± *SD* (*Med*)	Overall (*N* = 15)	Mothers (*n* = 11)	Fathers (*n* = 4)
Impact of baby's illness/death on relationship			
Relationship ended	1 (7)	1 (9)	0
Grew further apart	1 (7)	1 (9)	0
No impact	2 (13)	1 (9)	1 (25)
We are closer	1 (7)	1 (9)	0
Much stronger relationship	9 (60)	6 (55)	3 (75)
Missing	1 (7)	1 (9)	0
Health was negatively impacted by baby's death			
Not at all	3 (20)	2 (18)	1 (25)
A little bit	5 (33)	4 (36)	1 (25)
Somewhat	2 (13)	1 (9)	1 (25)
A great deal	4 (27)	3 (27)	1 (25)
Missing	1 (7)	1 (9)	0
New health diagnoses since baby died (check all that apply)			
Mental health	6 (40)	5 (45)	1 (25)
Physical health	5 (33)	4 (36)	1 (25)
Health (*n* = 12; 80%)			
General health[a]	2.8 ± 1.2 (3.0)	2.9 ± 1.4 (3.0)	2.7 ± 0.6 (3.0)
Physical health SF-12v2 (T-score)	48.5 ± 9.9 (50.9)	47.1 ± 10.3 (50.1)	52.7 ± 8.8 (57.7)
Mental health SF-12v2 (T-score)	39.8 ± 13.3 (41.6)	38.9 ± 14.6 (42.9)	42.7 ± 10.2 (40.3)
Anxiety (HADS)	10.6 ± 4.1 (11.0)	11.3 ± 2.8 (11.0)	8.3 ± 7.0 (9.0)
Normal (0–7)	1 (7)	0	1 (25)
Borderline abnormal (8–10)	4 (29)	3 (27)	1 (25)
Abnormal (11–21)	7 (50)	6 (55)	1 (25)
Depression (HADS)	6.5 ± 4.2 (5.5)	6.7 ± 4.8 (5.0)	6.0 ± 2.0 (6.0)
Normal (0–7)	8 (53)	6 (55)	2 (50)
Borderline abnormal (8–10)	2 (13)	1 (9)	1 (25)
Abnormal (11–21)	2 (13)	2 (18)	0
PTSD (IES-R) (*n* = 12; 80%)			
IESR – avoidance (mean of 7)	1.4 ± 1.0 (1.1)	1.2 ± 1.1 (0.9)	1.9 ± 1.0 (1.4)
IESR – intrusions (mean of 8)	1.7 ± 0.9 (1.6)	1.8 ± 1.0 (1.5)	1.6 ± 0.4 (1.8)
IESR – hyperarousal (mean of 6)	1.4 ± 1.1 (1.2)	1.4 ± 1.2 (1.0)	1.4 ± 1.2 (1.5)
GMRI meaning making (*n* = 12; 80%)			
Continuing bonds (mean of 6)	4.7 ± 0.4 (4.8)	4.7 ± 0.4 (4.8)	4.8 ± 0.4 (5.0)
Personal growth (mean of 7)	3.6 ± 0.6 (3.6)	3.6 ± 0.7 (3.6)	3.8 ± 0.6 (3.9)
Sense of peace (mean of 4)	3.0 ± 1.0 (2.8)	3.3 ± 1.0 (3.4)	2.3 ± 0.3 (2.3)
Emptiness & meaninglessness (mean of 5)	3.5 ± 0.6 (3.4)	3.4 ± 0.6 (3.4)	3.9 ± 0.7 (3.9)
Satisfaction with care (1 = strongly disagree to 7 = strongly agree)			
Prenatal	5.6 ± 1.9 (7.0)	6.1 ± 1.5 (7.0)	4.5 ± 2.5 (5.0)
Intrapartal	6.2 ± 1.8 (7.0)	6.8 ± 0.7 (7.0)	5.0 ± 2.8 (6.0)
Post-partal	5.8 ± 2.0 (7.0)	6.3 ± 1.5 (7.0)	5.0 ± 2.8 (6.0)
PSQI subscale: prenatal			
Compassion	5.0 ± 1.7 (4.8)	5.3 ± 1.4 (5.0)	4.2 ± 2.5 (4.5)
Support	5.2 ± 1.9 (5.7)	5.8 ± 1.5 (6.3)	4.1 ± 2.5 (4.3)
Process	5.1 ± 1.9 (5.7)	5.2 ± 1.9 (5.8)	4.9 ± 2.3 (5.4)
PSQI subscale: intrapartal			
Sensitive care	5.5 ± 1.9 (6.1)	5.9 ± 1.5 (6.9)	4.5 ± 2.5 (5.1)
Process of care	5.4 ± 1.8 (5.7)	5.7 ± 1.6 (6.4)	4.8 ± 2.3 (5.3)
Spiritual and cultural care	5.5 ± 1.9 (6.2)	6.1 ± 1.3 (7.0)	4.2 ± 2.5 (4.3)
Resources	5.3 ± 2.3 (6.5)	5.9 ± 2.1 (7.0)	4.3 ± 2.5 (4.5)
PSQI subscale: post-partal			
Compassion	5.9 ± 1.7 (6.9)	6.3 ± 0.8 (6.9)	5.0 ± 2.8 (6.1)
Process of care	5.6 ± 1.8 (6.2)	5.8 ± 1.4 (6.2)	5.1 ± 2.6 (5.9)
Infant treatment	5.3 ± 1.8 (6.4)	5.4 ± 1.8 (6.4)	5.3 ± 2.3 (6.0)
Bereavement	6.1 ± 1.8 (7.0)	6.7 ± 0.7 (7.0)	5.0 ± 2.8 (6.0)
Spiritual and cultural care	5.6 ± 1.7 (6.2)	6.0 ± 0.9 (6.2)	4.8 ± 2.8 (5.7)
End-of-life	5.5 ± 1.8 (6.0)	6.1 ± 1.3 (7.0)	4.4 ± 2.5 (4.9)

[a] *Note*. On a 1 = Excellent to 5 = Poor rating scale. All PSQI subscales are anchored by 1 = Strongly Disagree to 7 = Strongly Agree.

3.3.1. Sandra

Sandra is a 31 year old African American woman, married with two surviving children, who experienced the death of her daughter, Angel, 7 months prior to the interview. Sandra and her husband first learned at 16 weeks that Angel had serious renal and lung disorders. They declined the offer of termination. They then met with a PPC team whom Sandra described as very caring, who gave her options, made her feel like she and Angel mattered, and wanted to give them the best possible care. Angel was born at 34 weeks and lived for 5 h during which time Sandra held her and had pictures taken. Sandra kept Angel in her room after she died and then arranged for Angel's baptism and funeral.

Her husband accepted Angel's death but struggled because she was "his little girl." They grieved differently causing some strain during the early intense grieving period, but that has resolved. Sandra's scores for depression were 8 (*borderline case*), and an 11 for anxiety (*clinical caseness*). She described good days and bad days. Sandra reported a moderate level of intrinsic spirituality, no impact of baby's death on their couple relationship, moderate personal growth but a low level of emptiness and meaninglessness. Satisfaction with care was high at all 3 time points.

3.3.2. Rosa

Rosa is a 36 year old Latina woman whose son, Michael, died in utero five months ago at 32 weeks gestation. Rosa and her husband of nearly 20 years have 4 other children. She learned of Michael's diagnosis of hydrops at 18 weeks. She was initially told to terminate her pregnancy by a maternal fetal medicine physician. When she was unwilling, her primary obstetrical care provider refused to continue providing care. Rosa was very upset as she shared this history in the interview and was angry when saying that she later found out that this provider knew of her baby's condition at 10 weeks but did not tell her. Rosa was very dissatisfied with this care and sought out better care on her own. She pushed for a referral (initially denied) to a specialized children's hospital. She explained that the clinicians there had more skills, treated her like her baby mattered, commenting that they would never use the words “incompatible with life.” Rosa had complications which required intrauterine treatments. Rosa kept Michael in her room for an entire weekend after he was born still and received many mementoes including 3D molds. Michael was cremated, and his ashes are kept in an urn in their home. Rosa had kept her pregnancy complications private except to her own children and siblings, who had the opportunity to meet Michael. Rosa's extended family, and her husbands' family knew nothing about Michael's condition.

Rosa describes her husband as quiet and attends bereavement class but does not participate unless there is a craft project being done. She reported no impact on their couple relationship but did state that her husband is now an “emotional person.” Rosa had complications after the birth, including testing for cervical cancer. She was in a deep depression, only getting up from bed to care for her other children. She stopped taking antidepressants because of planning for another pregnancy. Rosa's depression and anxiety scores at the time of the survey completion were 13 and 14 respectively (both in the *clinical caseness* range) and her general and mental health were 25 and 23 respectively, which is well below the mean of 50 for each. The family has a shrine in their house and refer to Michael as an “angel baby.” Rosa believes that Michael is in a good place and will be reunited with her in the future. Rosa reported top scores of 7 for all of her care, but her story clearly points out her dissatisfaction with her initial care.

4. Discussion

This research is the first known study looking at the experiences of PPC in bereaved African American and Latino parents and contributes to the limited body of research on this population. In this sample of 15 bereaved parents the majority reported new diagnoses since their baby's death, most of which were within the area of mental health. The participants had high religion and spirituality scores and indicated a stronger couple relationship after the death of their baby. Several mothers were very dissatisfied with the care they received initially after the prenatal diagnosis was made and sought different care providers. Overall, most parents were satisfied with the quality of PPC they ultimately received.

Although the overall health of the parents in the study was close to population norms, the majority of parents reported worsening or new health problems. Three mothers reported that they were currently pregnant but healthy. Most of the mother's health issues were immediately post-birth and were learned of during interviews. The reported new health problems were not surprising and is similar to prior research on bereaved parents. Detrimental health reported elsewhere includes an increased use of drugs and alcohol, weight gain, newly diagnosed cancer and chronic health conditions, worsened immune response, fatigue, and increased mortality rate (Calderon-Margalit et al., 2007; Harper et al., 2011; Youngblut, Brooten, Cantwell, del Moral, & Totapally, 2013).

The parents in our research scored lower on mental health than the population norm on average, with almost half of the sample rated in *abnormal* range for anxiety, thus considered a case. Prior research has shown that bereaved parents experience a range of intense mental health problems in the first year post loss, as well as long-term responses, such as anxiety, depression, obsessive compulsive disorder, and post-traumatic stress response (Cacciatore, 2013; Christiansen et al., 2014;Gold et al., 2014 ; Youngblut et al., 2013). The 3 women who were pregnant at the time of data collection had high anxiety scores. This finding is consistent with established research on pregnancy after perinatal loss where mothers reported increased anxiety due to a fear of another loss (Côté-Arsenault, 2003). Like prior research on bereaved parents after an infant death (Gold et al., 2014; Youngblut et al., 2013), a lower percent of fathers than mothers in our study had high anxiety and depression scores. Furthermore, the prevalence of health problems and anxiety in this population is similar to literature demonstrating higher rates of anxiety, substance abuse, and excessive eating and weight gain and sleep disturbances in African American parents after perinatal loss than the non-Black population (Boyden, Kavanaugh, Issel, Eldeirawi, & Meert, 2014) and higher rates of moderate/severe depression in Hispanic and Black mothers than white mothers 6 months after infant/child death (Youngblut et al., 2013). Although the parents in our study did not report PTSD, symptoms of post-traumatic stress have been reported in both parents (Youngblut et al., 2013) up to 18 years after a perinatal loss (Christiansen et al., 2014).

In the research reported here, all parents reported that they were *somewhat* to *very* religious. This finding is supported by other research on African American (Kavanaugh & Hershberger, 2005) and Latino bereaved parents. These groups of parents often find religion as a source of support, by providing a way to cope or make sense of the loss. Religious and cultural practices within the Latino culture, such as having a shrine Clements et al., 2003), were also seen in our study, as illustrated in the case of Rosa. This practice is an example of meaning making through continuing bonds, which is a prevalent way that bereaved parents make sense of the loss (Neimeyer, 2000). Other types of meaning-making include personal growth and identity reconstruction (Gillies & Neimeyer, 2006; Meert et al., 2015).

Among the ways that parents make meaning, continuing bonds received the highest score in this study. The parents also described many examples of continuing bonds, mainly through memory making. PPC teams can facilitate memory making for parents through getting photographs of the baby and having opportunities to hold the baby. These are associated with improved coping and less incapacitating responses (Kingdon et al., 2015). Bereaved parents attempt to find meaning after experiencing a loss to restore a sense of purpose in their lives and reduce suffering (Gillies & Neimeyer, 2006). Bereaved parents who are unable to make meaning of their loss experience have more maladaptive responses (Neimeyer, 2000). Our finding is similar to other research on low income African American parents who also coped by creating memories and cherishing time with and keepsakes of their babies (Kavanaugh & Hershberger, 2005). In this study, the majority of parents reported that their couple relationship was stronger. The majority were married, likely increasing their unity through a crisis. This finding is similar to the authors' prior work where those with a strong couple relationship had improved coping during bereavement than those with weak relationships (Côté-Arsenault and Denney-Koelsch, 2018). Prior research on bereaved parents has shown a higher rate of divorce and separation than parents who are not bereaved (Gold, Sen, & Hayward, 2010) with the exception of those who are Black or Hispanic (Shreffler et al., 2012). This latter finding is supported by research reported here.

Overall, parents were satisfied with the quality of the PPC they received and rated quality indicators high across pre-, intra- and postnatal periods. For some mothers, that meant seeking out quality care on their own even if it meant travelling a great distance. The number of PPC programs has grown exponentially in the past decade (Wool et al., 2016). Yet, as shown in our study, parents do not always receive the benefit of received care in an established PPC program. Mothers were more satisfied than fathers and overall, parents were more satisfied during intrapartum care. It is not surprising that satisfaction with care was highest during the intrapartum period as most care practices in PPC occur during this time period. Findings here indicate a deficit in evidence-based care beginning in the prenatal period for those with life-limiting fetal diagnoses. For example, care models should be developed which are guided by the revised developmental tasks of pregnancy (Côté-Arsenault & Denney-Koelsch, 2016) in which care is provided in a patient and family-centered, developmentally appropriate way.

5. Strengths and limitations

We were able to demonstrate that African American and Latino parents can be recruited via PPC programs and listservs for this type of sensitive research and are willing to complete data collection in English via the Internet and participate in telephone interviews. However, a limitation of this study included the small sample size that precluded drawing statistical conclusions and comparisons between African American and Latino parents. Recruitment yield would likely be higher if a Spanish version of the survey was available, as well as an available Spanish-speaking interviewer. Future studies will need to include a multi-site recruitment approach to achieve the sample size needed for meaningful statistical analyses and generalizations. Also, a lack of variability in Satisfaction with Care mirrored that of Wool, Repke, and Woods (2016) but hindered the ability to see connection between satisfaction and health outcomes. Once parents found PPC, they were highly satisfied. Another challenge was collecting complex obstetrical history data in an on-line survey; an interview format may be more appropriate.

The Parent Satisfaction and Quality Indicators of Perinatal Palliative Care Instrument captures parent experiences cross-sectionally about a provider team or overall care but our study has revealed that prenatal providers might change at the time of fetal diagnosis. Additionally, the tool accommodates only assessment of a single team when there are likely several members of the obstetrical or neonatal teams. The instrument does not accommodate identification of individual providers who may have been exceptional or insensitive. Our mixed methods approach enabled us to collect these complex data and provide more insight into their experiences than survey alone would have.

6. Conclusion

The provision of perinatal palliative care and corresponding research are relatively young. Parents who continue pregnancy knowing that their unborn baby is not going to survive are in need of the best care possible. Minority parents have higher rates of these diagnoses as well as higher stressors than their non-minority counterparts. This study provides a beginning understanding of the impact of infant loss and PPC on minority parents' health outcomes. They found PPC to be accepting, helpful, and to have greatly improved their experience. Future research must include interventions that welcome minorities, begin during pregnancy, and support families through their intense and lengthy bereavement.

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