

Research Article

Cole JCM, et al. Arch Palliat Care Med 3: 1012.

DOI: 10.29011/APCM-1012.001012

Leading up to Loss: Understanding the Perinatal Grief Experience for Expectant Fathers when a Life-Limiting Fetal Diagnosis is Confirmed

Joanna CM Cole^{1*}, Joy N Macdonald¹, Huma Qamar²

¹Center for Fetal Diagnosis and Treatment at Children's Hospital of Philadelphia, Philadelphia, USA

²Clinical Research Business Manager in the Perelman School of Medicine, University of Pennsylvania, Philadelphia, USA

***Corresponding Author:** Joanna CM Cole, Center for Fetal Diagnosis and Treatment at Children's Hospital of Philadelphia, Philadelphia, USA. Tel: +2155903718; Fax: 2155903751; Email: Colej3@email.chop.edu

Citation: Cole JCM, Macdonald JN, Qamar H (2019) Leading up to Loss: Understanding the Perinatal Grief Experience for Expectant Fathers when a Life-Limiting Fetal Diagnosis is Confirmed. Arch Palliat Care Med 3: 1012. DOI: 10.29011/APCM-1012.001012

Received Date: 26 August, 2019; **Accepted Date:** 23 September, 2019; **Published Date:** 30 September, 2019

Abstract

The study aims to understand how men cope with the anticipated loss of their child when a life-limiting fetal diagnosis is confirmed in pregnancy. Twenty-five fathers responded to an online qualitative survey exploring their perinatal loss experiences. Data provide the reader with a glimpse of fathers' thoughts and feelings between the time of the confirmed fetal diagnosis and the baby's birth. Study participants chose to either engage with their pregnant partners through showing protection, emotional strength or by being productive in the areas in which they felt they could control; while others chose to avoid by not expressing their feelings with their partners, socially isolating, and turning to their work as a source of refuge. Therapeutic birth planning was shown to be a beneficial method to prepare fathers for their pending loss, involve fathers and their partners in the prenatal decision making and allow fathers to express their feelings throughout the process leading up to the loss. Study results hope to enhance the dearth of research on men's bereavement experiences in the context of perinatal palliative care and encourage providers to acknowledge fathers' grief in anticipation of a perinatal loss.

Keywords: Coping Mechanisms; Expectant Fathers; Grieving Fathers; Life-limiting Fetal Diagnosis; Perinatal Loss; Perinatal Palliative Care

Precis: When a life-limiting fetal diagnosis is confirmed, little is known about how fathers grieve during the perinatal period in anticipation of their baby's death prior to, or shortly after, birth. It is becoming widely accepted that paternal attachment begins before birth [1], as fetal ultrasound scans play a significant role in initiating the bonding process for expectant fathers [2,3]. Due to the medical advances of ultrasonography and genetic studies, congenital anomalies, which account for approximately 20% of all neonatal deaths [4], are often diagnosed early in pregnancy. The experience of confirmatory fetal imaging via routine ultrasound scan is a factor related to increased levels of grief and stress among expectant fathers [5]. O'Leary found that fathers who saw their babies on ultrasound, expressed a greater sense of loss at the time of the neonatal death, than those who had not [6].

When parents decide to continue a pregnancy with the knowledge that their baby will likely die prior to, or shortly after, birth, perinatal palliative care is a model that supports these expectant parents. This model of care offers a gentler "good-bye" for parents and families by engaging a multidisciplinary team approach to include preliminary medical decision making and therapeutic birth planning before the child is born [7-10], as well as supportive care at the time of birth and into the postmortem period [3,11,12]. When a life-limiting diagnosis is confirmed in pregnancy, often the attention is directed towards the expectant mother and the grief among the expectant father is often overlooked. Fathers-to-be have shattered parental expectations as well, yet they have been described in the literature as the "forgotten mourners [13]". Men can experience marginalization and neglect of their unrecognized emotional needs [1,3]. Men are not just bystanders in their partners' pregnancy experiences. They may have been present for the excitement and worry of each prenatal appointment, viewed the ultrasound images during their partners' scans, listened to the

sound of their child's heartbeat, were present at the determination of the fetal sex, and embraced the fetal movement through a gentle touch of their partners' abdomen. Expectant fathers often envision their "would be lives" with their babies as they make preparations at home and by talking, reading, and singing to their children in utero.

Fathers' feelings of grief can be disregarded, as close relatives and friends often expect men to "be strong" and finish their grief processes quickly in order to care for the needs of their partners [14,15]. When faced with challenges in pregnancy, expectant fathers are often asked, "How is she doing?" This question not only ignores the grief that men may be experiencing, but also leads to an assumption that his priority must be "to protect" his partner and unborn child. In other words, if she is not doing well, then somehow this is his fault or it is his job "to fix it" in order to remain accountable to those individuals posing the question. Even though fathers may be well aware that they have no control over the neonatal outcome, attempts to maintain control in other areas of life can remain a focus for day-to-day coping [16]. The way that healthcare providers assist grieving parents, particularly those who anticipate the death of their child shortly after birth, has an important impact on how both women and men experience the pregnancy and remember their loss, and may have a significant effect on their healing process [17].

Goals of the Study

The paternal experience of perinatal loss is not well understood and is often overlooked in clinical practice and within the research literature [1,18-20]. Little is known about how men grieve during the perinatal period in anticipation of their baby's death prior to, or shortly after, birth; thus the impetus for the current study. This paper shares qualitative survey responses from fathers whose partners gave birth with perinatal palliative care for a baby with a life-limiting fetal diagnosis confirmed in pregnancy. Results explore the accounts of twenty-five fathers who anticipated the death of their child, in order to better understand paternal experiences leading up to their perinatal loss.

Method

Study Location

The Center for Fetal Diagnosis and Treatment (CFDT) located in the Children's Hospital of Philadelphia (CHOP) is a high risk fetal and diagnostic center dedicated to healthy mothers carrying high risk fetuses with anatomic birth defects and/or complex medical and genetic conditions. Close to 1,800 pregnant women are referred for a comprehensive diagnostic evaluation to the CFDT annually. Approximately 8% of the patients seen for an initial evaluation in the CFDT will choose to pursue perinatal palliative care at the time of birth based on a life-limiting fetal

diagnosis. The model of the CFDT's Perinatal Palliative Care and Bereavement Program is described elsewhere [7].

Study Design

The project utilized a qualitative survey methods design to ask fathers about their perinatal loss experiences at the Children's Hospital of Philadelphia (CHOP) to better understand how men cope with the anticipated loss of their child. Due to the sensitive nature of the study, face to face interviews were a preferred method of data collection; however, since more than 70% of all CFDT patients travel farther than 100 miles to CHOP, in-person interviews were not possible for this retrospective study. Due to the dearth of research in the field of paternal perinatal loss in the context of palliative care, the research team was interested in the feasibility of capturing fathers' experiences via a detailed REDCap online survey. The questionnaire consisted of demographic variables as well as 28 open ended questions, exploring fathers' experiences leading up to the anticipated loss of their child.

The participants consisted of a retrospective cohort of male partners of former CFDT patients seen within a five year period. These previously expectant parents received a life-limiting fetal diagnosis within the CFDT and chose to continue their pregnancies. They were referred to the CFDT's Perinatal Palliative Care and Bereavement Program for grief support and birth planning, and mothers gave birth at the Children's Hospital of Philadelphia on The Garbose Family Special Delivery Unit (SDU) with perinatal palliative care support. Additional information about the SDU is described elsewhere [21].

After securing approval from CHOP's Institutional Review Board, a recruitment email containing the study consent form and questionnaire was sent to all eligible patients (N = 57). Since email contact information was not readily available for fathers, former CFDT patients (mothers) were asked to forward the questionnaire link to their partners for completion. Participants were provided with specific instructions on how to access the link in order to complete the REDCap questionnaire. In the recruitment email, the purpose, methodology, study aims, and procedures were described, and the contact information of the primary investigator was provided. Fathers were assured of anonymity in reporting the results, confidentiality, and their right to decline or withdraw from the study at any time. When the questionnaire was not completed within one week, a reminder email was sent. If the participant did not respond within two weeks' time, a member of the research team (JM) contacted the former CFDT patient by phone for follow-up. If a CFDT patient or potential study participant indicated that they did not wish to participate in the study, this information was added to the database and they were excluded from further contact. This occurred on two occasions. An inductive analysis approach was used to review and code data in order to capture patterns and main themes found among participants.

Participants

During the five-year study period, 121 families received a perinatal palliative care consultation and, of these, 106 mothers gave birth on The Garbose Family Special Delivery Unit (SDU). Of the total consultations, 64 fathers were excluded as they did not meet the study criteria. The exclusion criteria and survey completion data are described in Table 1. Overall, 57 eligible fathers were invited to participate in the current study. In total, twenty-five fathers (43.8% response rate) were included in the current data analyses. See Table 2 for the description of the study participants.

Category	N
Pregnant patients who received perinatal palliative care consultation at CHOP	121
Eligible Fathers	57
Excluded fathers	64
<18years old	2
Non-English Speaking	10
Father not involved	3
Birth not on the SDU	15
Child lived 21days+post-birth	34
Complete Response after First Outreach	
Completed REDCap survey after first email	15
Completed REDCap survey after first email	15
Incomplete Response after First Outreach	
Did not complete REDCap survey after first email	42
Inactive emails	3
Patients and/or participants opted out of the study	2
Complete Response after Second Outreach	
Completed REDCap survey after additional outreach	10
Total Completed REDCap surveys	25

Table 1: Determination of Study Inclusion and Exclusion Criteria.

Characteristic	N = 25
Age	26-44 years (M= 35.6)
Race/Ethnicity	
Caucasian	23
African American	1
Hispanic	1

Marital Status	
Married	25
Other	0
Highest Education Level	
High School Graduate	3
Some College	7
College Graduate	15
Employment	
Employed	25
Unemployed	0
Partner’s Reproductive History	
Primigravida	2
Multigravida	23
Number of Living Children	(0-4 range)
0	5
1	13
2	5
3+	2
Partner’s Reproductive Loss History	(0-4 range)
0	15
1	6
2+	4
Gestational Age at Time of Diagnosis	(9-27 weeks range)
<15	1
15-20	18
21-25	5
26-30	1
Gestational Age at Time of Birth	29.3-40.5 weeks
Current Pregnancy	
Singleton	23
Twins	2
Fetal Sex	
Male	13
Female	12
Length of Time of Neonatal Survival	
Stillbirth	4
0-4 hours	15
5-10 hours	3
11+ hours	3
Time since Child’s Death	
1-3 months	3
4-6 months	0

7-12 months	2
1-1 ½ years	7
Over 1 ½ years	13

Table 2: Sociodemographic Description of Study Participants.

Results

The direct quotes presented in this manuscript are from the study participants' responses to the online survey, which asked fathers about their experiences from the time of the fetal diagnosis, through their partners' pregnancies, and into the first moments following their child's birth.

Response to the Fetal Diagnosis

"We had a connection with our baby. We watched him move around, kick and spoke to him. We were pretty far along in the pregnancy when we found out something was wrong. In my opinion, it was too late to end the pregnancy". Upon receiving the fetal diagnosis, 17 out of 25 fathers described feeling "sad," "devastated," or "depressed". Six bereaved fathers expressed feelings of "anger" and a sense of "unfairness" and "injustice". Five fathers reported feeling "hopeless" and "out of control" in response to the confirmed fetal diagnosis. "[I was] Angry (straight up pissed off and ready to punch something. I was ready to fight someone). Self-doubting (Did I make the right choices?). Useless (I felt like I was no good at providing comfort to my wife). Not suicidal, but I surely did not care if I woke up in the morning". "I felt hopeless and useless. My wife was carrying the baby and although i did the driving and set up the hotel stays and used all of my medical contacts and prayed, it could not guarantee our baby would thrive. Many late night hours while I was alone. It broke me to tears". Thirteen fathers reported struggling with untreated emotional issues and/or psychosomatic reactions in response to their stress. "Nightmares. High blood pressure, light headed, inability to concentrate. The sadness of life was hard to shake off. I fell into an 'I don't care about myself attitude' and I put on a lot of weight". "I had extreme anxiety issues that resulted in loss of sleep, headaches and panic attacks. I took anxiety medication during her pregnancy".

The Choice for Perinatal Palliative Care

"Once I learned of the options involved with perinatal palliative care support, I felt that it gave me, my wife and our son the best opportunity to be able to meet and spend quality time with our child if she made it to delivery and beyond." Fathers were asked to describe the reasons why they and their partners chose to continue their pregnancy and pursue perinatal palliative care after a life-limiting fetal diagnosis was confirmed. Twenty-two fathers identified their longstanding connection with their child in utero and their desire to embrace quality time with their baby, regardless of the quantity of time spent. "Palliative care was the

gentlest way of dealing with this pain. It was an option to allow us to have a fulfilling connection to our baby despite the prognosis". "Termination was not an option for us, we wanted to meet our daughter regardless of the amount of time we would have with her. We wanted her to know love and her family for the brief time she was alive."

Father's Primary Coping Strategies: To Engage or to Avoid

"It is a stigma that men just have to be strong and push through". Traditionally, men often act, solve problems, and refrain from expressing sadness and grief [22-24]. There are societal pressures for men either to not grieve or to recover quickly in order to "stay strong" for their partner by silencing their anxiety, stress and grief [2,16]. "Men are expected to be the workers and providers while keeping their emotions in check. In our society, men aren't supposed to be emotionally expressive and needy". Fathers often find themselves caught between believing the societal expectation that they should comfort their partners, while following the advice that they need to express their feelings in order to best cope with their own grief. This often leads many men to experience complex tension between grief expression and supportive caretaking [2,15]. Lang and colleagues claim that men exert more control over their emotional expressiveness and tend to intellectualize their grief, when compared to women [25]. Data analysis revealed that fathers demonstrated two main strategies to cope with their pending perinatal loss. Fathers chose to either engage with their pregnant partners through showing protection, emotional strength or by being productive in the areas in which they felt they could control; while others chose to avoid their grief by not expressing their feelings with their partners, socially isolating, and turning to their work as a source of refuge.

Fathers Chose to Engage

The majority of the study participants chose to engage with their pregnant partners by demonstrating protection, emotional strength or productivity, and actively embraced the role of primary caretaker during this time of distress. "My primary interest during the planning period was high quality, coordinated support for my wife and unborn son. Knowing that they were being taken care of with minimal drama was the most important thing to me". Cacciatore and colleagues found that fathers report feeling pressure as the protector and often neglect their own grief experiences in order to care for the needs of their partners and families [18]. "We need to be tough 24/7. We are supposed to protect, provide for, and take care of our family". Findings found four participants that felt an increased sense of protectiveness toward their partners and regretted not being able to fully safeguard their partners from the physical and emotional pain of the anticipated loss [23,26]. Two fathers in the current study alluded to their "paternal instinct" that motivated them to protect their loved ones and care for their families. One father described his inability to protect his baby as "a sense of

failure for the most basic responsibility of fatherhood”. Fathers are frequently expected to remain strong and deal with the practical details of everyday functioning when a perinatal loss is expected [15,27]. Cholette stated that fathers often feel overwhelming responsibility and need to portray “unwavering strength and stoicism,” which can prevent men from addressing their grief [19]. Cacciatore and colleagues stated that grieving fathers experience a “double bind” social pressure to remain “strong” as caregivers for their partners, while also being more emotionally expressive [28]. “As a society, we have this image that men are supposed to be tough, and while that is true to a certain degree - we are talking about losing a child. No amount of toughness can ever compensate for that kind of loss”.

Three participants admitted to refraining from openly expressing feelings with their partners and felt the unspoken pressure to “be the man” and “keep it together”. In addition, eight participants internalized the stereotypical gender-role messages that their job was to “be strong” for their partners and to “not break down and cry”. A common strategy among study participants was the use of compartmentalization and refusing to look back upon something that they were unable to change. Common themes such as “Just keep moving” and “Don’t slow down” helped support the grief process for nine fathers. The focus often shifted towards goal attainment and the ability to manage day to day challenges effectively (e.g., daily working, paying bills on time, addressing the needs of the other children, etc.). “I was handling most of the stuff around the house along with caring for our other daughter. As the pregnancy progressed, my wife was put on bed rest which only added to my list of responsibilities”. One father reported that caring for his wife became his “primary project,” which alludes to a false belief that men may be able to “fix” their partner’s pain if they just worked hard enough. As one father stated: “It was important to me to be good at taking care of my wife”.

Fathers Chose to Avoid

Five study participants chose a strategy of avoidance throughout the perinatal period as a way to cope with the anticipated loss. An avoidant coping style was characterized by suppressing and underestimating individual feelings. “I was somewhat distant. I coped by not thinking about it, which made her feel alone”. These fathers in the study demonstrated avoidance tendencies, blocked their negative thoughts, and primarily focused on task centered coping and solitary grieving [28]. These fathers denied the existence of their own grief and tended to grieve alone [29]. Similar to findings by Wing and colleagues, study participants reported that they chose not to express their grief openly, because they feared their partners would respond by crying, which they felt would create additional emotional pain [30]. Two fathers stated that they wished to “spare her the pain” of expressing their own struggles, which at times led to increased tension within the

relationship. Four men chose to consciously isolate themselves and not ask people for help during the pregnancy.

Preoccupation with “Life must go on” and “You just can’t stop” were other ways that participants attempted to manage their emotional distress. The anticipated grief also caused men to actively disengage by falling into the throes of work and other activities as a temporary distraction (e.g., work, alcohol use, hobbies, video games, DIY house projects, physical fitness, etc. 32). “I dove right back into work, trying to keep my mind occupied off of the fact that I was going to lose my little girl. I was so focused on work that I stuffed my emotions”. “Tried to keep busy and probably suppressed my emotions. Turned to alcohol for a few weeks but quickly snapped out of it”.

Clinical Implications

Therapeutic Birth Planning: Supporting Both Engaged and Avoidant Fathers

Men can experience a depth of loss that is largely unrecognized [1], as fathers are often caught between attending to their own needs and the needs of their partners [8]. A study by Lang and colleagues found that the more the women showed their grief, the more the men tended to withhold showing their grief, which led to men withholding and suffering internally or silently in order to protect their partners [23]. Recognizing that gender roles exist and greatly influence the relationship dynamic in anticipation of a perinatal loss, therapeutic birth planning [7] is one way to support both engaged and avoidant coping styles among fathers. “Give fathers the freedom and forum to realize their feelings. Even if they don’t understand what their feelings are”. By initiating a therapeutic relationship with both men and women within the couple, the skilled clinician can help expectant parents understand, anticipate, and cope with their individual reactions, as well as those of their partners, in order to facilitate the grieving process prior to and following the death of their child [3,30]. One father describes his birth planning process: “Knowing that there was not going to be any surprises gave us a sense of readiness and control when we had none. It was the sense of being completely taken care of and knowing what to expect”.

Lang and colleagues stated that “by attending to a couple’s intimate relationship as well as their individual emotional reactions, the skilled clinician may help decrease the vulnerability and distress experienced by bereaved parents” (p. 54) and this can also help create a safe space for emotional healing within the couple [25]. One father described the process of perinatal palliative care birth planning: “We transitioned to a palliative mindset which was incredibly hard, but also tremendously freeing. When you are confronted with the news that your little one is not going to survive, it shakes you to your core. In the birth planning process, we were taken step by step in a methodical and deliberate

manner. Despite having no control over the ultimate outcome, we had a small sense of control in developing the ‘life plan’ for our daughter”. As the clinician partners with fathers in their individual and dyadic processes, therapeutic birth planning increases their sense of control and competence over their emotional experiences and helps guide them through the prenatal, intrapartum and postpartum course. Mental health clinicians can assist grieving fathers to identify and challenge unrealistic beliefs, to reduce blame and guilt-inducing behaviors, to minimize avoidant tendencies and to develop effective anger management skills [30]. “Both my wife and I would fight verbally. I think this was a way we released pain, but it was unhealthy to our relationship”.

Since men often defer to their partners’ wishes during pregnancy, birth planning empowers both men and women in the discussion. By asking fathers “How are you doing?” in front of their partners helps open up communication that may have otherwise been closed [6,31]. Asking questions and relating to them both as parents, begins a conversation likely to guide intervention and dyadic cohesion. Working through anticipatory grief is associated with less complex grief following the death of a child [31]. Therapeutic birth planning allows both mothers and fathers to outline their wishes for the time of birth and to work through any doubts or fears, so that traumatic stress is minimized [7]. Clinicians who provide empathy, a strong therapeutic alliance and a sense of safety, create ideal conditions for expectant parents to begin to work toward joining with one another [30]. “Fathers, like myself, approach this with strength, but the true strength is in feeling and experiencing these feelings together, which I went through in this experience”. Twenty-four out of 25 fathers in the study actively participated in therapeutic birth planning, which consisted of therapy sessions (M=3) with the CFDT’s clinical psychologist (JC). In one case, the palliative care consultation occurred on the same day as the precipitous birth; not allowing time for the couple to develop a formalized birth plan. “Developing a birth plan allowed us to think through the process ahead of time and answer some very difficult questions without feeling rushed or overwhelmed with emotion”. “There are certain things we would not have been aware of and it was good to not have to decide these things on the day of delivery. It gave us a strong sense of comfort knowing what was going to be done regarding our baby and what we could expect during and after delivery”.

The Birth: Men in the Role as Fathers

The delivery room creates an environment that allows for privacy and a sacred atmosphere to acknowledge a newborn’s existence surrounded in a family’s love. Whenever possible, fathers should be encouraged to be present at the time of birth and to make connections with their babies even following their child’s death. One father recalls his presence at the time of the birth and death of his daughter: “I took you to hold you and feed you and

[your mother] was waking up from a nap. I didn’t know that you were closing your eyes for the last time. So I was the first face you saw and the last face you saw because you passed away in Daddy’s arms”. It is often a father’s “job” to cut the umbilical cord at the time of birth, yet cutting of the cord can signal the beginning of the dying process. This decision is discussed during the birth planning process as it is important to explore fathers’ thoughts and feelings about this traditional act. The support that healthcare providers offer around the time of a newborn’s birth and death is important for families, and can have an effect on parents that lasts forever [32]. One father remembers the day of his daughter’s birth: “Despite the tragedy we had experienced, I look back on that day and remember everyone smiling and taking pictures and celebrating her life”.

When a baby dies, the anguish of the mother is visible to the world because she has the physical experience of pregnancy and giving birth [16]. This does not happen for fathers. It remains clear from the feedback from seven participants that men also want to be recognized and cared for at the time of birth. One father made a recommendation for the obstetric staff: “My wife knew I was in pain. I guess my only suggestion [for the care team] is to focus on the mother and child, but watch for any signs with the father. Body language speaks volumes. If the father looks tired, confused, ill, emotional...a simple ‘how are you doing?’ may not be enough”.

Ensuring that fathers are involved in the decision making and are able to express their needs also helps support their grief process [30,33]. Healthcare providers must recognize and anticipate the physical, spiritual and emotional needs of mothers, fathers and their families at the time of death. If they wish, both parents should be given the opportunity to be actively involved in the memory making process with the labor and delivery nurse and/or child life specialist, which helps to authenticate and actualize the true existence of their child. Interventions offered (e.g., bathing, holding, making hand prints on canvas, etc.) should focus on making meaning of the child’s life and death [3,34,35] and provide a supportive environment for the family [12]. Although the study participants were unable to control the neonatal outcome, the various rituals, such as talking to, bathing, dressing, and taking pictures with their baby were significant in allowing fathers to reconcile the birth experience with their fatherhood identity and claim their child as their own (4.40). When asked what stood out the most at the time of birth, fathers reported: “Being involved in the birth, skin to skin contact with her, and being a part of the baptism”. “My daughter looking into her Mommy’s eyes while she grasped onto my finger”. “The silence in the room when we first got to hold our daughter”.

Discussion

Although the literature is mixed, many assert that a father’s grief is not less, rather qualitatively different, than a mother’s grief

[30,36]. The primary aim of this study was to enhance the narrative of men's bereavement experiences when an anticipated perinatal loss was expected. Similar to other studies, the bereaved fathers reported appreciation for participating in the study and twenty-five fathers welcomed the opportunity to answer questions about their experiences [24,29,37]. This study adds to the small but growing body of literature on grieving fathers when the death of a baby is expected. Findings also highlight important considerations for healthcare providers for ways in which bereaved parents, both mothers and fathers, can be emotionally prepared as a couple prior to, as well as at, the time of birth [28]. There is also the opportunity to validate both the engaged and avoidant coping styles by providing men with a space to not have "to do," while allowing them "to be" with their own unique experiences [38]. Attending to the needs within a couple's relationship is key when a perinatal loss is anticipated. Through the therapeutic process of birth planning [7], both men and women can be lead through an in-depth discussion about many possible outcomes prior to and following their child's birth, in order to help them prepare and minimize the risk for a traumatic birth experience. As providers, it is important to give men permission to not be "okay" and to challenge men to identify their own emotional experiences. The majority of study participants who engaged in birth planning found it to be a helpful process and agreed that it gave them a safe space to process their thoughts and feelings with their partner.

A major strength of this study was the participation rate, for fathers, especially bereaved men, are often difficult to recruit for research [24]. It is important to note that the results from this group were due to a self-selection process of participating in the study. The sample was relatively homogenous and represents a convenience sample of predominantly Caucasian, college-educated, married and employed male partners of former patients cared for in the CFDT. The sample is not representative of all men who have experienced an anticipated perinatal loss; rather the purpose was to obtain a sample to begin to explore this lived experience from men's perspectives [2]. Study results demonstrate the feasibility of capturing data on perinatal loss among men via an online survey, as almost half of the participants eligible responded to the online survey within a three week period. Fathers were also willing to respond to the questionnaire as early as one month and even after 1 ½ years post-loss. The focus for future study will be to find an effective method of interviewing fathers in-person, prior to, and following, the birth and death of their child in order to gather in-time experiences and recommendations for care management. Additional objective measures may also be used to track fathers' emotional coping, and/or physical and relational changes over time.

Conclusion

"About an hour after our son had passed away on the SDU,

I got in the shower. I later came out of the bathroom and saw [my husband] sitting in a chair holding him. He looked at me and said "Just watching Sports Center with my son". This was such a raw moment for me and it really hit home at that point that a grieving father also needs to grieve all the things that he will never get to do with his only son. This is not just the job of a grieving mother".

After a life-limiting fetal diagnosis is confirmed, hospital staff and the wider community must learn to recognize the profound impact on the expectant father's emotional, relational and physical well-being, as well as acknowledge his unique grief experience in anticipation of the perinatal loss [1,39]. Similar to other studies [9,10,40], findings highlight that for fathers who receive a life-limiting fetal diagnosis, the time between diagnosis and birth is a valuable time where they can be helped to process their anticipated loss and find meaning with the support of a multidisciplinary team. Therapeutic birth planning may be an effective intervention used to address the needs among engaged and avoidant fathers prior to birth; while helping men to attend to their own self-care needs and remaining connected to their partners when the loss of their child is expected.

References

1. McCreight BS (2004) A grief ignored: Narratives of pregnancy loss from a male perspective. *Social Health Illn* 26: 326-350.
2. Bonnette S, Broom A (2011) On grief, fathering and the male role in men's accounts of stillbirth. *Journal of Sociology* 48: 248-265.
3. Koopmans L, Wilson T, Cacciatore J, Flenady V (2013) Support for mothers, fathers, and families after perinatal death. *Cochrane Database Syst Rev* CD000452.
4. Levick J, Fannon J, Bodemann J, Munch S (2017) NICU bereavement care and follow-up support for families and staff. *Adv Neonatal Care* 17: 451-460.
5. Johnson MP, Puddifoot JE (1998) Miscarriage: is vividness of visual imagery a factor in the grief reaction of the partner?. *British Journal of Health Psychology* 3: 137-146.
6. O'Leary J (2005) The trauma of ultrasound during a pregnancy following perinatal loss. *Journal of Loss and Trauma* 10: 183-204.
7. Cole JC, Moldenhauer JS, Jones TR, Shaughnessy EA, Zarrin HE, et al. (2017) A proposed model for perinatal palliative care. *J Obstet Gynecol Neonatal Nurs* 46: 904-911.
8. Munson D, Leuthner S (2007) Palliative care for the family carrying a fetus with a life-limiting diagnosis. *Pediatr Clin North Am* 54: 787-798.
9. O'Connell O, Meaney S, O'Donoghue K (2016) Caring for parents at the time of stillbirth: How can we do better?. *Women Birth*, 29: 345-349.
10. O'Connell O, Nuzum D, Meaney S, O'Donoghue K (2014) Incompatible with life but not with love: The value of prenatal palliative care in cases of lethal abnormalities diagnosed in the prenatal period. *Journal of Palliative Care* 30: 219
11. Calhoun BC, Napolitano P, Terry M, Busse C, Hoeldtke NJ (2003) Perinatal hospice. Comprehensive care for the family of the fetus with a lethal condition. *J Reprod Med* 48: 343-348.

12. Capitulo KL (2005) Evidence for healing interventions with perinatal bereavement. *MCN Am J Matern Child Nurs* 30: 389-396.
13. Samuelsson M, Radestad I, Segesten K (2001) A waste of life: Fathers' experience of losing a child before birth. *Birth* 28: 124-130.
14. Aho AL, Tarkka M, Astedt-Kurki P, Kaunonen M (2009) Fathers' experience of social support after the death of a child. *American Journal of Men's Health* 3: 93-103.
15. Campbell-Jackson L, Bezance J, Horsch Q (2014) "A renewed sense of purpose": Mothers' and fathers' experience of having a child following a recent stillbirth. *BMC Pregnancy and Childbirth* 14: 423.
16. O'Leary J, Thorwick C (2006) Fathers' perspectives during pregnancy, postperinatal loss. *J Obstet Gynecol Neonatal Nurs* 35: 78-86.
17. Gold K (2007) Navigating the care after a baby dies: The systematic review of parent experiences with health providers. *J Perinatol* 27: 230-237.
18. Cacciatore J, DeFrain J, Jones KL, Jones H (2008) Stillbirth and the couple: A gender-based exploration. *Journal of Family Social Work* 11: 351-372.
19. Cholette ME (2012) Through the eyes of a father: A perinatal loss. *International Journal of Childbirth Education* 27: 33-38.
20. Kersting A, Wagner B (2012) Complicated grief after perinatal loss. *Dialogues Clin Neurosci* 14: 187-194.
21. Howell LJ (2013) The Garbose Family Special Delivery Unit: A new paradigm for maternal-fetal and neonatal care. *Seminars in Pediatric Surgery* 22: 3-9.
22. Lang A, Fleischer AR, Duhamel F, Sword W, Gilbert KR, et al. (2011) Perinatal loss and parental grief: The challenge of ambiguity and disenfranchised grief. *Omega (Westport)* 63: 183-196.
23. Hunt S, Greeff AP (2011) Parental bereavement: A panoramic view. *Omega (Westport)* 64: 41-63.
24. Lang A, Gottlieb LN, Amsel R (1996) Predictors of husbands' and wives' grief reactions following infant death: The role of marital intimacy. *Death Stud* 20: 33-57.
25. Proulx M, Martinez A, Carnevale F, Legault A (2015) Fathers' experience after the death of their child (aged 1-17 years). *OMEGA- Journal of Death and Dying* 73: 308-325.
26. Black B, Sandelowski M (2010) Personal growth after severe fetal diagnosis. *West J Nurs Res* 32: 1011-1030.
27. Murray JA, Terry DJ, Vance JC, Battistutta D, Connolly Y (2000) Effects of a program of intervention on parental distress following infant death. *Death Studies* 24: 275-305.
28. Cacciatore J, Erlandsson K, Radestad I (2013) Fatherhood and suffering: A qualitative exploration of Swedish men's experiences of care after the death of a baby. *Int J Nurs Stud* 50: 664-670.
29. Aho AL, Tarkka M, Astedt-Kurki P, Kaunonen M (2006) Fathers' grief after the death of a child. *Issues Ment Health Nurs* 27: 647-663.
30. Wing D, Burge-Callaway K, Clance PR, Armistead L (2001) Understanding gender differences in bereavement following the death of an infant: Implications for treatment. *Psychotherapy* 38: 60-73.
31. Donovan LA, Wakefield CE, Russell V, Cohn RJ (2015) Hospital-based bereavement services following the death of a child: A mixed study review. *Palliat Med* 29: 193-210.
32. Brooten D, Youngblut JM, Seagrave L, Caicedo C, Hawthorne D, et al. (2012) Parent's perceptions of health care providers' actions around child ICU death: What helped, what did not. *Am J Hosp Palliat Care* 30: 40-49.
33. Flenday V, Boyle F, Koopmans L, Wilson T, Stones W, et al. (2014) Meeting the needs of parents after a stillbirth or neonatal death. *BJOG* 4: 137-140.
34. Swanson PB, Pearsall-Jones JG, Hay DA (2002) How mothers cope with the death of a twin or higher multiple. *Twin research* 5: 156-164.
35. Uren TH (2002) Attachment and meaning-making in perinatal bereavement. *Death Stud* 26: 279-308.
36. Stinson KM, Lasker JN, Lohmann J, Toedter LT (1992) Parents' grief following pregnancy loss: A comparison of mothers and fathers. *National Council on Family Relations* 41: 218-223.
37. Wood J, Milo E (2001) Fathers' grief when a disabled child dies. *Death Stud* 25: 635-661.
38. Milstein J (2005) A paradigm of integrative care: healing with curing throughout life, "being with" and "doing to". *J Perinatol* 25: 563-568.
39. Erlandsson K, Saflund K, Wrediling R, Radestad I (2010) Support after stillbirth and its effect on paternal grief over time. *Journal of Social Work in End-of-Life & Palliative Care* 7: 139-152.
40. Nuzum D, Meaney S, O'Donoghue K (2018) The impact of stillbirth on bereaved parents: A qualitative study. *PLoS One* 13: e0191635.