

Pain without reward: A phenomenological exploration of stillbirth for couples and their hospital encounter

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ABSTRACT

Stillbirth constitutes a unique form of grief related to the death of an unborn child. This study explores the experiences of eight couples who lost a child to stillbirth, from the time they suspected something was wrong to their release from the hospital and beyond. Couples were interviewed conjointly and data were analyzed qualitatively using a phenomenological approach. Analysis revealed themes of positive and negative encounters with hospital staff, grief and loss, relationships with spouse and family, and long-term impacts. Implications for clinicians are discussed, including gender differences in the grief process for fathers and mothers.

Introduction

In the United States, pregnancy loss after 20 weeks of gestation constitutes a stillbirth (Center for Disease Control, 2017). The Center for Disease Control estimates around 24,000 stillbirths in the United States (Center for Disease Control, 2017), which constitutes 1% of all pregnancies. Stillbirth is a devastating and life-changing event for parents (Burden et al., 2016; Cacciatore, 2013). In many cases, the causes of stillbirth cannot be determined, and it can occur regardless of the level of risk to the pregnancy (Silver, 2007). Parents experience psychological, physical, social, and spiritual consequences (Burden et al., 2016; Campbell-Jackson & Horsch, 2014). As a couple, parents are at an increased risk for marital dissolution (Cacciatore, 2013).

In a sample of hundreds of obstetricians, virtually all had provided care for women who experienced a stillbirth (Farrow, Goldenberg, Fretts, & Schulkin, 2013). When interacting with parents after a stillbirth, physicians felt uncomfortable taking on the role of “grief counselor” and expressed discomfort about how to approach conversations about parents’ loss (Kelley & Trinidad, 2012; Silver, 2007). Parents reported stillbirth became more difficult when the hospital process was confusing (Kelley & Trinidad, 2012), or when they were unsure of their involvement in medical decisions or options in the hospital (Burden et al., 2016). As researchers, we know more about the

stillbirth experience for mothers than we do for fathers. The purpose of this qualitative study was to understand the hospital experience of stillbirth for parents in intact relationships, particularly the fathers, as well as to understand how they experienced the loss together.

The multidimensional effects of stillbirth on parents

Many couples do not realize that, following a stillbirth, the birthing process, whether vaginal or cesarean section, must still take place (Kelley & Trinidad, 2012). Depending on the age of the fetus and the risk to the mother, birth may involve evacuation of the uterus or labor induction (Silver, 2007). As with live births, the experience of labor varies for each woman, and some experience a relatively short delivery while others take multiple days (Turton, Hughes, Evans, & Fainman, 2001). In addition to the physical recovery from labor and delivery, many mothers report chronic pain and fatigue, hormonal changes, and milk production following the stillbirth (Burden et al., 2016).

For both mothers and fathers, many psychological issues occur. Depression and PTSD symptoms are often present, as well as feelings of shame and guilt (Badenhorst, Riches, Turton, & Hughes, 2006; 2016), and an increased likelihood of complicated grief (McSpedden, Mullan, Sharpe, Breen, & Lobb, 2017).

In one study, 28% of mothers reported seriously considering suicide following the stillbirth (Human et al., 2014). Mothers of stillborn babies also reported more anxiety than the mothers of live babies (2013). The physical reminders of their loss (e.g. hormonal changes, milk production) are also potentially psychologically painful (2016). Despite these considerable negative psychological impacts, some parents resolved not to take life for granted and to be more compassionate (2016).

Stillbirth also typically affects parents' relationships with family and friends. Parents felt disconnected from their social environment and recognized these relationships as irrevocably changed (2016). Women may often feel social pressure to prove their reproductive capabilities and soon attempt to have another child (2016). Parents also voluntarily isolate themselves from activities where they could be reminded of their loss and when parents engage in social interactions, they perceive others as uncomfortable talking about the stillbirth (Kelley & Trinidad, 2012). Parents often experience this same avoidance from hospital staff during the hospital encounter (2013), and turn to online support groups to connect with those that empathized and spoke openly about the experience (Bakker & Paris, 2013; 2016).

For many parents, spirituality plays an important role in coping with stillbirth and precipitated an increased faith in God (Bakker & Paris, 2013). After a stillbirth, many parents reevaluate their religious beliefs (Bakker & Paris, 2013) and religious or spiritual activities can help to reduce pain and allow parents to be more accepting of the tragedy (2016). For some, the experience of stillbirth weakens their faith in God or a higher power (Cacciatore, DeFrain, & Jones, 2008) and some parents express anger that God allowed the death of their child (2016; DeFrain, 1986) or feel the stillbirth is punishment for sins committed (Bakker & Paris, 2013; Cacciatore, DeFrain, & Jones, 2008).

A couple's relationship has "both risk and great opportunity" (Cacciatore, DeFrain, Jones, & Jones, 2008, p. 363) following a stillbirth. The period following a stillbirth is often characterized as a struggle to find a new normal (Cacciatore et al., 2008). In some studies, parents reported difficulties in their relationships following a stillbirth, which were deepened by the stresses of hospital bills and funeral expenses following a stillbirth (2016; Cacciatore, DeFrain, Jones, et al., 2008). In addition, some parents lack interest in sexual activity – particularly women who associate the trauma of stillbirth with sexual contact (2016).

Couples also differ in their grieving styles (Cacciatore et al., 2008), which created problems in their relationships (2016). For many couples, the experience of stillbirth brought them closer together and created a new special bond, which was often the result of respect for grieving style, an emotional connection, and tolerance for their partner through the grief (2016; Cacciatore et al., 2008).

Grieving a stillbirth is painful for both parents, often in different ways. Women tend to react more intensely to pregnancy loss (Stinson, Lasker, Lohmann, & Toedter, 1992). Many mothers report dealing with grief privately and alone (2016); fathers report feeling their grief was unacknowledged (Bonnette & Broom, 2012; 2016), and reported anger towards those who did not understand (Kelley & Trinidad, 2012). Some fathers suppress their grief in order to focus on providing emotional support to their wives (2016; Kelley & Trinidad, 2012). Parents of a stillborn child tend to report that their grief is not legitimate to surrounding family, social circles, medical professionals, or society; that people made hurtful comments that implied the child was "replaceable" or not a real person; and that mourning the stillbirth was not acceptable (2016).

Many parents describe benefit from taking part in research projects, providing support and mentorship to others who experience stillbirth, and working with hospitals to improve stillbirth services (Burden et al., 2016; Kelley & Trinidad, 2012). Opportunities to make memories with their baby, along with a postmortem evaluation can bring a sense of finality, which may help parents heal and decreased their negative symptoms; however, social taboos, stigma, and overall silence were significant sources of distress (Burden et al., 2016). The purpose of this study was to allow parents an opportunity to share their individual experiences as individuals and couples with stillbirth, particularly with the experiences that occurred at the hospital. While we have some idea of the multidimensional effects of stillbirth, we do not understand much about how healthcare providers factor into those effects.

Methods

We chose a phenomenological approach to describe the experiences of stillbirth (Creswell & Poth, 2017). In phenomenology, the sacred, mundane, ordinary, and extraordinary are equally intriguing (Boss, Dahl, & Kaplan, 1996). The focus of this approach is to describe the essence of participants' commonalities in that experience (Creswell & Poth, 2017) of stillbirth.

To do this, we interviewed couples who had experienced a stillbirth. In phenomenology, it is important for researchers to recognize that they are not separate from the phenomena they study and that their beliefs and worldview will influence their work (Boss et al., 1996). The primary researcher never experienced a pregnancy loss personally; however, as a child, he had a brother who was stillborn and he witnessed the impact of this on his parents. While this experience informed the interview questions, we focused on the experience of participants and bracketed the researcher's experience with the phenomenon. Bracketing is a process by which the researcher attempts to suspend his/her own experiences with the phenomenon in order to let themes emerge from the study data (Tufford & Newman, 2012).

Recruitment and sample

Couples were recruited through social media, and local and national support groups. Inclusion criteria for this study were intact couples, 18 years or older at the time of stillbirth, married for at least 6 months at the time of stillbirth, biological parents of the stillborn, English-speaking, within 10 years of the stillbirth, and able to take part in the interview together. After examining various support groups for stillbirth, a 10-year window was chosen to accommodate as many willing participants as possible. Interviews continued until the research team reached saturation (when no new themes emerged during coding), which typically occurs in phenomenology with between 5 and 25 participants (Creswell & Poth, 2017). The final sample included 16 individuals (eight couples).

The mean age of participants was 30.75 (females: $M = 29.88$, $SD = 6.06$; males: $M = 31.63$, $SD = 6.65$). All participants were White/Caucasian. Fifteen were US natives and one participant was Bolivian. The mean length of the relationship was nine years. Most participants ($n = 13$) were in the \$35,000 or more income range. The amount of time spent in the hospital following the birth ranged from 15 to 96 hr ($M = 37.75$, $SD = 24.33$). Hours spent in labor ranged from 2 to 24 hr ($M = 9.43$, $SD = 7.09$). The number of total pregnancies before the stillbirth ranged from 0 to 4 ($M = 1.38$, $SD = 1.65$). Among the stillborn babies, six were female and two were male. Seven couples delivered their stillborn vaginally, and one couple had a Cesarean section. Gestational age of the babies ranged from 20 to 38.5 weeks ($M = 30.10$ weeks, $SD = 9.06$). The years since the stillbirth occurred ranged from 3–6.5 years ($M = 5.00$, $SD = 1.58$).

Materials and procedures

We interviewed couples at a university family therapy clinic, in their homes, and through video conferencing software. Prior to each interview, participants completed individual and couple assessments. The interviewer used a semi-structured interview approach and started by asking the couple to describe their overall experience with stillbirth in as much or as little detail as they wanted. The interviewer used follow-up and clarifying questions about their interactions with medical staff, and the differences and similarities in their grieving process, the impact of the hospital encounter on their relationship, recommendations for medical professionals, and advice to parents who experience stillbirth. We relied on participants' responses to understand their reality. Following the interview, the interviewer answered any additional questions, offered referrals to therapy, and gave \$30 compensation. Couples were also invited to complete a post-interview survey about their experience with the interviews. Fourteen participants reported the experience was "very positive" and two participants reported the experience was "somewhat positive".

Coding and interpretation

Interviews were transcribed verbatim, and four coders coded the transcripts. Researchers first reviewed their experiences with the phenomenon and then set those experiences aside to focus on what was said by the participants (Creswell & Poth, 2017). Coders read the transcripts first without making any markings or notes. They then re-read interviews and created a list of significant statements. During the third review of the transcript, coders marked significant statements and grouped them into larger themes or "meaning units". Coders used constant comparison to reach determine whether or not they had reached saturation with the data. Coders then described participants' experiences, referred to as the textural description, and provided verbatim examples. Coders sought to provide a representation of the context of the experienced phenomenon, referred to as the structural description. The coders wrote a composite description of the phenomenon incorporating both textural and structural descriptions (Moustakas, 1994).

When conducting a qualitative study, it is important to establish trustworthiness, or evidence researchers' interpretations truly represent the data. In addition to having all four coders code each interview, coders held meetings to discuss in pairs, and then as a group to finalize codes and themes. Additionally, we

gave participants an opportunity to review the themes, referred to as a member check (Creswell & Poth, 2017). Four of the eight couples participated in member checks. Each received a list of the themes the coders developed. They were encouraged to provide any corrections or additions to the list. Most felt the list represented their experiences well, and one participant added thoughts to the results.

Results

The following codes were isolated as the major themes: the hospital encounter, grief and loss, relationship with spouse and family, and long-term impacts. Each section includes quotes that illustrate participants' experiences of the themes.

The hospital encounter

Couples reported that the hospital staff, policies, and accommodations played a large role in shaping the hospital encounter experience. They reported a variety of positive and negative experiences associated with the hospital encounter. The experiences were often described in chronological order, so that is how we will present it here. The hospital encounter started with the existing relationships couples had with their unborn babies and ended with hospital discharge.

Anticipation and excitement for baby

Each couple expressed anticipation or excitement for the arrival of their baby. Couples shared their pregnancy with family and friends, which added to the excitement. One father noted:

Lots of our friends have had their babies. My best friend, they got pregnant right away when they started trying. Another ... really close friend, they got pregnant at the same time as us essentially. And my brother did as well ... And my best cousin. So we had a group of babies that were all going to be born at the same time. So, we were very excited.

Some couples reported complications and setbacks attempting to become pregnant, making the pregnancy especially meaningful. One couple mentioned they had been trying for two years to get pregnant. Other couples described preparations that were already underway (e.g. purchasing cribs, decorating the nursery). One couple described how they purchased a fetal Doppler so that they could hear the baby's heartbeat on a nightly basis:

(Father) ... early on, we had decided it would be cool to listen to the baby's heartbeat every night. (Mother)

I remember we started doing that, probably at like nine weeks. And looking back on it, we're so thankful for that, because we felt bonded to her.

Other participants reported pregnancy being a time of anticipation and excitement for the arrival of the baby. One couple described the pregnancy as a "happy accident".

Notification of loss

Many parents reported the news that their baby had died was completely unexpected. Two couples knew that their pregnancy was at risk, but hoped or assumed their baby would be okay. One parent described this hope: "We're going to be in the percentage that our baby (is) small, but she makes it." Some mothers felt that something was wrong when their baby decreased or stopped moving. With all participants, an ultrasound confirmed the death, and the technician immediately went to confirm with a doctor. When they received news that their baby had passed, parents reported being in a state of shock or disbelief. One mother reported what took place during the ultrasound:

I could see the picture, but I couldn't hear anything. [The doctor] actually checked the volume. I remember he kind of stepped back and said, "Well, as you can see your baby's heart is not beating. So, it's dead". At that point, I was in disbelief. I just remember covering my face with my hands and I started to cry. I was like, "I was just here two days ago, and she was alive". At that point, I just kind of melted on the table. I just remember sitting there again, in shock. It wasn't sinking in.

Another father described the experience of being informed by saying:

The lady was doing the ultrasound pauses, and she's like, "who's your doctor?" We told her, and she just runs out, she didn't say where. And then the doctor came, and he's like, "so if you look here and here you can see swelling". Then he explained that he had somehow passed away, so from that point it was really, really tough ... when you're expecting something to come, and then, next thing you know, it's not coming.

Some mothers received this news alone, attending what they thought was a routine appointment. One father was an hour away when he received news that their baby was stillborn.

Some mothers were caught off-guard or unprepared for the physical exams and the delivery that followed the news of the stillbirth. One mother reported:

I hadn't showered that morning because I didn't think anything was wrong. I was going to come home

and clean up, so I was just like humiliated that this person, this emotional rag who shows up and I felt unhygienic and dirty because I hadn't prepared for any examination. I remember being so embarrassed in so many ways.

Just as parents described difficulty not being prepared physically, other parents described the difficulty of not being prepared emotionally. One mother, who went directly for a Cesarean section, described the rush of thoughts and difficult decisions that needed to be made:

And the anesthesiologist kept reminding me you need to breathe. Because, I was just so nervous the whole time, I kept thinking. Ok, so, do we still name her? Is she still (baby name)? Do I want to hold her? What is she going to look like? All that was running through my head.

Couples reported it being especially difficult to inform family members. One mother described informing her mother:

I came in, and I think she already knew. Cause I walked in and I was like, "ugh, she's gone." And my mom made me cry more, because it's hard to see somebody else feeling pain for you. That's was the hard part. But then she started crying, she patted my belly and said, oh, (baby name). Cause we'd named her already. She was like, "oh, (baby name)." She was just so sad, and I was like kind of crying too, but trying to have a stiff upper lip.

Mothers and fathers reported many similar emotions and initial reactions to the loss. For fathers, the initial reactions of shock largely mirrored what was happening for the mother, except that it was common for the father to be absent when the news of the death was shared with the mother.

Labor and delivery

Despite the grief from losing the baby, some discussed feelings of peace or a sense of joy at getting to meet their baby. One mother described this experience by saying:

I felt her moving down the canal, I was like "oh she's coming!" It was like this surge of, "I can't wait to meet her". Even though I knew she was dead, I couldn't wait to meet her, see her for the first time. But, having been through that experience, there was still so much joy when she finally arrived. Even though she was dead, she was perfect.

Describing this period, couples discussed their appreciation for clarity and directness from medical staff on what procedures were going to be taking place. One mother said:

They asked us what we wanted to do. [We wanted] to be able to see and hold her, and they said, "Well, just to prepare you, we don't know how she will look and

we don't know how her body will be. We need you to be prepared for that. We can wrap [her], and you guys can hold her ... And so, delivery was fantastic.

Many couples had the option to induce labor immediately or return to the hospital later after spending some time at home. While some appreciated having the time to return home for an evening to process what was happening, others wanted to start the process right away. After the birth, parents described their babies' physical appearance on a spectrum. One mother reported:

The baby didn't look very attractive because she had been dead for so long, her skin had started to slip off. So, I think that was that other part of the hush. Because she kind of looked like an alien. Most newborns do anyway. But she looked different. She didn't look like this cute baby, that's when it became real.

On the other end of this spectrum, one father reported:

They pulled her out, and I could see her immediately before they held her up. But, she was absolutely perfect, and I was shocked that she was that perfect. I mean, she looked absolutely fine. Totally healthy. She was gorgeous.

Time with their baby

Each couple reported having time with their baby. Parents reported a variety of emotions taking place during this time. Parents used this time to choose a name, take pictures, bond with their baby, and introduce the baby to family members. One father recalled, "You don't want to rush it. Especially where it's so little time. You don't want to miss anything." Parents cherished the time they had to examine their baby, take photos, give them baths, dress them, and create hand and foot molds. Many couples wanted to have a few minutes alone with their child before they said goodbye. One mother described:

We just asked everybody to leave. After everybody left, it was probably 11:40 at night, almost midnight. Everybody went home, they were gone, it was just us. And, we said our goodbye, then the nurses came and took her.

Some parents wished for more time with their baby. At the same time, some parents felt guilty for doing so because of how fragile the baby was. Some parents worried that they might "damage" the baby.

Accommodations and hospital care

Many parents discussed the accommodations the hospital made. For many, the parents had a room in a separate area away from the cries of other babies or

the conversations of those after live birth. One mother noted that staff had put “a sticker on the door...to let the staff know that she was stillborn.” Parents reported feeling that this helped medical professionals that would visit the room be more sympathetic. One couple noted how they wanted to perform a religious ceremony for their child:

They rearranged a conference room...so that we could have that gathering and it didn't have to be just in a hospital room. It was really thoughtful of them to think of those little details to make sure that we didn't feel like just another patient; I feel that they took really good care of us.

Parents appreciated the connections hospitals had with external support groups. While in the hospital, and afterwards, these support groups provided a number of helpful services. Parents connected with individuals from these groups who had experienced a similar loss. These groups provided meaningful mementos, including pictures and molds of the baby's hands and feet, or things for the baby like stuffed animals and jewelry. In addition, these groups shared knowledge and direction on what to expect moving forward, without rushing to other patients.

Many parents felt overwhelmingly positive about how medical staff treated them during this difficult time. Other parents noted negative interactions they wish they could have avoided. Parents appreciated any time that medical staff kept them informed of what was happening, what was going to happen, and what the options were. When one couple found out they had lost their baby, their doctor said, “you don't need to make a decision right now, just go home and think about all these options you have and then you can tell us what you'd like to do”.

Parents appreciated when hospitals were flexible with rules meant to help keep the baby safe, which no longer applied because the baby was already dead. One mother expressed:

One other thing the hospital allowed us to do the night that we had to stay, they helped to make my hospital bed bigger to allow (husband), and then we were able to have our son with us, instead of just in the bassinet across the room. I think that helped us a lot. Just throwing rules out the window.

Parents were grateful for the expression of kindness, sympathy, and empathy that they received from the hospital staff. Many parents reported that staff would consistently offer help and ask if anything was needed. Some mothers worried that the staff forgot or did not care for fathers the way they did mothers

during this process. One mother said:

I do think there's some amazing support for moms. I had people reach out to me that was amazing, and I don't feel like there's that same support for dads, so in a way, I do think a lot of times, he did get forgotten.

Parents also appreciated when staff treated their stillborn like a live baby. Examples included when staff would point out and make comments about the baby's features, take measurements, and hold the baby like a live baby. One mother said:

I loved it when the nurses would come in, and say, “Oh, what's her name?”, “Oh, how big was she?” They would ask how much she weighed. They would ask who she looked like, whose nose does she have? They would ask those detailed questions. Or they would comment about her long skinny fingers, or [make] comments about her just like she were a living baby. I really appreciated it.

In addition, some parents appreciated when medical staff experienced a difficult time with them. Some appreciated physical gestures (hand on hand, hand on the shoulder, etc.) when medical staff gave comfort, while others were averse to these gestures.

On the negative side, while many parents appreciated the skill the medical professionals had but sensed that they were just another task on their long 'to-do lists. One father reported:

At least in my experience, if you don't speak up, medical professionals...it's so routine for them to just go through and do their thing, and the next thing. And they're great, and they're very skilled, but it's almost like they think everyone else thinks this is routine, too.

One mother described a very negative interaction:

There was one [nurse that was] really abrupt, and it was on the last day. [She] had been rounding all night, and she was tired and wanted to go home. And she came in, and I just had been on the phone with my family, so I was crying. She needed to take my blood pressure, and it came up really really high, and it hadn't been high any other time, and she said, I'm just gonna go and wait for you to calm down and then I'll come back and wait to check it. I was kind of taken aback, because she seemed really abrupt. I [said] sorry, I was just talking to my family, we lost his sister. She [said] “I know, I saw the thing on the door, I just didn't have time to talk to you about it.” I was ready to go home. I started getting out of bed and was ready to leave.

Grief and loss

Grief was a common response. Couples described this grief as both short- and long-term. Parents described feelings of shock, disbelief, devastation, sadness, and

anger, associated with the loss. Parents experienced anticipation and excitement for their baby.

Differing grieving styles between partners

Parents consistently reported that their grief differed from their partners'. Their responses highlighted long-term experiences with grief. The mother said:

I think we definitely grieve differently. I got really depressed, I kind of clammed up to myself a lot. I probably just laid in bed for like three months after. And then (my husband)'s like, "OK, you gotta get up. You gotta go do something." ...

The father added:

Yeah, I have to keep my mind going, because if you focus on it, it drives you down. So, the more focused you are, the further on you can go.

Another mother said:

I was really open, I cried about it, I wanted to go to [support groups], I talk to anybody who will share my grief, anybody at all, but not in a way that would force it on anybody... If somebody's interested, I'd be happy to talk about it, so. And [he] hasn't as much. He is 100% OK to do it his way. We give each other a lot of slack. A lot of people have different ways to grieve.

When asked what advice they would give to a couple experiencing stillbirth, a mother reported:

You're going to grieve differently. The wife needs to see the husband cry. The husband doesn't need to be tough. He may think, I'm the man, I don't need to cry. He needs to grieve too. And he has to go through his own process. Because it is a process, and you have to go through all the stages. There's nothing wrong with that. Especially for the males. I mean if they're supposed to be the big tough, nothing affects them.

One father noted how he and his wife remember details of events differently:

It was more of a blur, for me. She has a lot more memory of the little details, those kind of things... When she mentions those things that comes back to me, but if you were to ask me what details I remember, I just remember generalities... Some of it may be that it was probably just a shock for me. My mind kind of blocked out all the detail. But, for me, it was a bonding experience, I think, just to be there. Be with [her]. That was one of the main things that I took out of it.

Some fathers reported they were less emotional, at least outwardly, about the experience. Fathers reported feeling that their role in the experience was to be a support to their wife.

Mothers noted a feature specific to their grief was physical reminders that the baby was gone. One mother described:

...my milk came in, and that was a horrible experience, because it felt like it was a reminder of, I don't have a baby to feed. On top of it, it was painful, because I couldn't do anything. They made me bind my breasts. Couldn't take a warm shower for a week, because they were trying to get my milk to go away.

Paradoxes associated with stillbirth

Couples reported a number of activities they did not expect that was in direct opposition to what they thought they would be doing. One couple recalled: "Instead of looking for cribs, we were shopping for coffins. And instead of looking for best educational stuff, and baby monitors, and stuff, we were looking for headstones." Some parents were overwhelmed by the arrangements that needed to be made for a funeral when a live birth would have allowed time to go home and recover. One mother expressed that:

We had a funeral to plan. We had arrangements to make. We needed a florist. We needed to go to a mortician. I didn't get even just to sit at home for a few days, like if I had had my baby and to recover. I had to be back, and getting stuff done.

Relationship with spouse, family, and friends

Parents reported relationships were crucial to their experience. Whether it be their spouse, family, or friends, parents reported a variety of different acts of kindness and support.

Impact of stillbirth on the relationship

Most couples discussed how the stillbirth could bring a couple closer together or push them apart. One mother noted:

I absolutely perceive it being one or the other. For us, I definitely think it brought us closer together. There's still no one [else] that felt the same pain. My mom had a hard time because it was her first grandchild, and his mom had a hard time. But no one else was going through the loss of their child. And so for me, when I wanted to cry about it, no when else got it. It didn't matter how good of a friend they were, how much they loved me. No one understood that like [he] did.

The vast majority of couples felt the experience brought them closer together. One father described the situation as what "glued us together as a family". One couple differed in their opinions about whether the experience brought them closer or pushed them apart. The father reported, "I think if anything, it

brought us closer together. Because after that, I was with [her] non-stop". The mother reported, "I think at the beginning it kind of did, but now that time is going on, I just feel like it's kind of slowed down. Growing apart a little bit". When asked if she felt that the stillbirth was the cause of them growing apart, the mother responded, "I don't think so. It just is, as time passes, things change. I guess that's a big part of what it is".

One mother's encouragement to couples was that they "Just cut each other some slack. Let each other grieve... Just because you don't see another person's grief, or it doesn't look like yours, that doesn't mean that they don't have grief. They're just experiencing it differently".

Friends and extended family

Many parents reported friends and family being a tremendous help through the experience. Many friends and family members made an effort to be there at the hospital to be with the family and meet the baby. Offers of help came to help plan services, let other people know about the loss, purchase a burial plot, or to simply be there with the couple. One mother reported: "I just [said], 'Mom, you tell everybody else please.' So she was my voice. I told her and asked her to contact everybody else. Then, I just went home." She later added that her mother planned everything.

While some couples stressed the need for time alone, overall, participants were happy and eager to have family members meet their baby. Some couples reported that family members' efforts to help did not align with how they wanted to grieve. One more reported:

My mom kind of was hard for me, because in her day, you didn't, you certainly didn't look at the baby. You didn't cry about it. You moved on and tried to talk yourself out of that it ever really happened. That's what she wanted me to do. At (support group), everyone else's mom tried the same thing... I had to realize that that doesn't work for me. It's OK, I'm all good. She doesn't have to tell me what to do. I'm grown up.

Long-term impacts

Many couples reported on the long-term impacts of their loss. Couples discussed the importance of helping others in their journey with grief. Couples felt constant reminders of their loss, including due dates, anniversaries, birthdays, and running into hospital staff. Couples reported the flood of emotions often appeared without warning. One couple had a code

word to use when they were having a hard time. Many parents described allowing the grief to happen. One mother expressed a particular reminder of the day she lost her baby:

But I don't resist it, I like it to come back to me. And if I cry, I cry if I want to. If somebody sees me, who cares? I don't try to hide my grief. I embrace it. It's a memory and its part of me.

While the emotions were difficult, parents wanted to remember the baby and keep them as part of their family. Many celebrated birthdays for the baby and spoke openly about the child with their other children. Parents wanted to be sure their child was not forgotten.

Guilt

Parents felt guilty when they began to smile again or have joy. One father reported this guilt extended into fulfilling basic needs saying, "We shouldn't be laughing together, or having joy... that soon after. It felt like it would be disrespecting of our loss or something. So we often had to remind each other to eat."

Mental health and suicidality

Couples reported the stillbirth affected their mental health. For some, the depression was manageable and faded with time. For others, depression led to suicidal thoughts. One mother described this:

There were times when I didn't get out of bed. I was struggling. There is even a point where I wrote a suicide note, I just wrote it out, and then I shredded it, and it seemed like that was the turning point. I just rolled up thinking, I cannot handle this anymore. I seriously contemplated it. But I wrote that suicide note and shredded it, and it felt like a burden had been lifted. That was my turning point.

Some parents reported feelings of emptiness and of missing a part of themselves. One mother described returning from the hospital:

I felt very empty. Because, I had just given birth. I think that most women at this point, they get to learn how to be a mom. They're learning how to breast-feed, and they have their baby, but I was just there. Instead of being a person and a half, I was just a person, and I didn't have the half.

Many mothers reported the experience became more difficult when others, particularly their husbands, would return to normal activities like work. One mother said when her husband returned to his normal activities that, "it was just me, alone. By myself. Without a baby, without a husband. Without anything. That was probably my lowest point."

Support groups

Some participants continued to use support groups long after they left the hospital. One mother discussed how meeting with a support group helped to normalize her grief. Parents spoke about the mementos that these groups help create or provide and how much they appreciated having them. One participant described these mementos saying, “Looking back now, I didn’t know I wanted them then. But now, that’s literally the only tangible thing we have”.

Lasting grief

Many discussed that the pain does not ever completely leave. One expressed, “you have to stop loving for it to stop hurting.” One participant encouraged those that grieve to remain strong in the grieving process:

Go forward, and just be strong. But, at the same time, I have told people this, it’s ok to cry. It’s ok to just have days where you’re just furious at the situation. It’s ok to have days where you’re sad about the situation, and it’s ok to be upset. Because people handle things differently.

Discussion

While the study of stillbirth is not new, the new knowledge this research produces is threefold: (1) the impact of stillbirth on fathers, (2) the impact of stillbirth on a couple’s relationship, and (3) the experience of healthcare providers on the stillbirth experience. The overarching concept identified in the interviews was pain without reward. Mothers endured and had to recover from the same labor and delivery process as any other mother. Mothers and fathers had to continue on with life without their imagined child.

As reported in previous studies, the participants described difficulties processing the magnitude of the situation (Lindgren, Malm, & Rådestad, 2014). Most parents agreed the stillbirth could either strengthen or weaken their relationship (Cacciatore et al., 2008) and most felt that the experience had brought them closer together. Others considered the event as a special bond between them and their partner. This supports previous findings stillbirth provides a meaningful connection between partners (2016; Cacciatore et al., 2008). Some participants took time to evaluate their spiritual beliefs and practices (Bakker & Paris, 2013), and some parents described how ceremonies and rituals were helpful to the entire family (Kelley & Trinidad, 2012). Among the most important social relationships for couples at this time were supportive

friends and family that could help with physical, logistical, and emotional needs. Support groups were also listed among the strongest resources for healthy grieving because they were a safe place where they could have their grief normalized and be able to voice their frustrations (Cacciatore, 2007). Mental health was a major concern for many participants (Badenhorst et al., 2006; Campbell-Jackson & Horsch, 2014). Importantly, because mental health concerns and suicidality appeared after the hospital encounter, it was key for participants to receive follow-up and encouragement to seek help. This could be in a combination of the follow-up from the hospital as well as from their families and social networks. Finally, participants referenced the Kübler-Ross (1969) stages of grief. Given its criticisms (e.g. Corr, 1993), it would be pertinent to provide them with information about grief and other models such as the dual-process model of coping with bereavement (Stroebe & Schut, 2010), as well as ambiguous loss (Boss, 2004).

Strengths and limitations

Participants expressed an overall appreciation for having the opportunity to share their experience. Researchers may fear that grieving individuals will not want to revisit painful experiences. However, parents often appreciated the opportunity to participate in projects to benefit those who experience stillbirth (2016; Kelley & Trinidad, 2012). During the interviews, participants made comments that the experience was helpful or good for them, and this finding was echoed in the post-interview survey.

The findings may not generalize to all couples who experience stillbirth. One limitation is the lack of diversity in our sample. A more racially diverse sample would have allowed for a better understanding of these experiences from the perspectives of different cultures. While a homogenous sample allowed us to focus on the phenomenon, it also ended up being a limitation, as it excluded the experiences of single parents, divorced parents, nonbiological parents, and same-sex parents. With these populations, there is a risk of greater levels of disenfranchisement. Another potential limitation was interviewing both partners together. Words spoken by mothers outweighed those spoken by fathers. While all questions were posed to both partners, it is possible that the husband felt that he should defer to the wife’s experience or that the complexities and contextual factors unknown to the interviewer kept them from being as open about the experience (e.g. Hooghe, Neimeyer, & Rober, 2011).

Researchers should be encouraged by the willingness and desire of parents to participate in these types of studies. As a major motivator of this project was examining stillbirth experiences within dyads; future studies should also seek to understand this experience further into the family system including siblings and others in the extended family. In addition, future studies should include diverse populations and those that have a smaller or no support network. From this study, it was clear that medical staff had a significant impact on the couples' hospital experience, and future studies should examine what, if any, impact additional training for medical professionals could have on couples' hospital experiences and their grief.

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