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ORIGINAL PAPER

The Spiritual and Theological Challenges of Stillbirth for Bereaved Parents

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Abstract Stillbirth is recognized as one of the most challenging experiences of bereavement raising significant spiritual and theological questions. Semi-structured qualitative interviews were conducted with bereaved parents cared for in a tertiary maternity hospital to explore the spiritual impact of stillbirth. Data were analysed using interpretative phenomenological analysis. Stillbirth was identified as an immensely challenging spiritual and personal experience with enduring impact for parents. The superordinate themes to emerge were searching for meaning, maintaining hope and questioning core beliefs. Most parents reported that their spiritual needs were not adequately addressed while in hospital. The faith of all parents was challenged with only one parent experiencing a stronger faith following stillbirth. This study reveals the depth of spiritual struggle for parents bereaved following stillbirth with a recommendation that spiritual care is provided as part of comprehensive perinatal bereavement care in the obstetric setting.

Keywords Spirituality · Stillbirth · Bereavement · Spiritual care · Chaplaincy

Introduction/Background

The death of a baby through stillbirth is recognized as one of life's most challenging bereavements with long-lasting consequences (Burden et al. 2016; Froen et al. 2011; Leon 1990; Leoni et al. 1998; Worden 2009). In pregnancy, parents begin a journey of

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expectancy and hope, with immense personal investment in a new future with their baby. New life is expected and experienced as pregnancy progresses, and for most couples, it is a time of great joy as bonds of attachment are formed with a new baby (Condon and Corkindale 1997; Lumley 1982; Tsartsara and Johnson 2006). At an early stage, this new baby takes his or her place within the story of their family. It is a sad reality, however, that not all babies will survive. The diagnosis that a baby has a life-limiting condition or has already died ruptures the experience of expectancy and hope for parents with the unwanted presence of death and grief. Stillbirth is defined as the death of a baby during pregnancy and varies internationally from the period from 20 to 24 weeks of gestation up to birth. In Ireland, where this study was conducted, stillbirth is defined in the Stillbirths Registration Act 1994 as 'a child born weighing 500 grammes or more or having a gestational age of 24 weeks or more who shows no sign of life' (Eireann 1994).

Birth and death are the two most significant life events in their own right: in stillbirth they fuse inseparably, with devastating impact not just for the baby who has died but also for parents, families, healthcare professionals, communities and wider society (Burden et al. 2016; Heazell et al. 2016; Newitt 2015; Nuzum et al. 2015a, b, 2016). The care that bereaved parents receive during this time can shape their whole grieving process and recovery (Kingdon et al. 2015; Leon 1990; Leoni et al. 1998). The psychosocial burden of stillbirth is well documented in the published literature and has had heightened awareness following a renewed global focus on stillbirth as a global public health challenge to be addressed (Cacciatore 2013; Flenady et al. 2014; Heazell et al. 2016). What is less studied is the spiritual impact of stillbirth whether anticipated following a diagnosis of a life-limiting condition or anomaly during pregnancy or the sudden unanticipated death of a baby during an otherwise healthy pregnancy. In stillbirth, the 'natural order' of birth, life and death is disrupted raising existential questions (Jones 2001).

Most published studies in the wider field of pregnancy loss have been quantitative and have identified that perinatal death is a source of spiritual distress and challenge for parents but are inconclusive concerning the place of religious support and practice in bereavement recovery (Cowchock et al. 2010, 2011). Qualitative studies by Kelly and Newitt have identified the relationship with pastoral care and ritual following perinatal death (Kelly 2007; Newitt 2015). For those of faith, stillbirth can rock belief structure to its core especially where there is negative religious coping and expressed religious distress (Cowchock et al. 2010, 2011). Conversely for others, the death of a baby can invite a deeper reliance on faith as a supportive anchor in the turbulence of grief (Cacciatore and Ong 2011).

This study explores qualitatively the spiritual and theological struggle of stillbirth for bereaved parents.

Methods

Qualitative methods are used to understand complex social processes, and capture essential dimensions of a phenomenon from the perspective of study participants, and were therefore seen as appropriate for this study (Biggerstaff and Thompson 2008; Smith et al. 2009). Phenomenology is concerned with the study of experience and how experiences are understood. Interpretative phenomenological analysis (IPA) focuses on the specific and particular nature of a phenomenon or experience at depth and what it means for each individual participant (Smith et al. 2009). The researcher is tasked with entering as far as

possible in an empathic way into the world of the participant (Biggerstaff and Thompson 2008). IPA as a methodology complements the approach of theological reflection as a hermeneutical tool to reveal new insight into spiritual care and practice in a healthcare environment (Ballard and Pritchard 2006; Green 2009; Nuzum et al. 2005b).

A semi-structured interview schedule was developed by the authors informed by the literature in the field and the professional experience of the research team who work in a specialist perinatal bereavement team as a healthcare chaplain (DN), consultant obstetrician (KOD) and a social researcher (SM).

Following Ethical Approval from the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No: ECM 4 (pp) 06/03/12), a purposive sample of bereaved parents of twelve babies who had died following stillbirth were invited to participate in the study. Inclusion criteria were that the participants had been cared for at the study hospital, were not currently pregnant, were over 18 years old and had not previously indicated that they did not wish to be contacted by the hospital for study purposes.

Initial contact to participate in the study was made to bereaved mothers by a bereavement and loss midwife specialist known to them. Following agreement, each bereaved mother then received a personal invitation from the researcher to participate in a semi-structured in-depth interview with the stated aim to explore the spiritual and pastoral needs of bereaved parents following stillbirth and what their experiences of care were. Each participating mother was invited to extend the invitation to her partner to participate in the study.

Sample

IPA as a research methodology focuses on the depth of data, and by their nature, IPA studies have small sample sizes to allow experience to be studied at depth (Smith et al. 2009).

Twelve mothers and five fathers participated in the study. Half of the babies ($n = 6$) in the sample had received a diagnosis *in utero of* a life-limiting condition (for example, anencephaly or skeletal dysplasia) and were unlikely to survive up to birth. The remaining babies died through an unanticipated stillbirth.

Data Collection

Each interview took place in a private environment without interruption at a location and time of the participants' choosing. Most participants ($n = 14$) were interviewed in their home environment, and the remaining ($n = 3$) chose to return to the study hospital for their interview. Interviews lasted between 31 and 104 min, were digitally recorded and subsequently transcribed verbatim. Transcripts were anonymized to protect the identity of the participants. Following transcription and before analysis, each transcript was checked for accuracy against the original recordings by the researcher. The researcher kept a reflective journal to capture the experiences of the interviews and to record additional data such as body language and non-verbal communication to aid in personal theological reflection.

Analysis

The data were analysed using IPA. Data analysis is thorough and undertaken using the established five steps of IPA: (1) familiarization of the transcripts, (2) preliminary themes

identified, (3) themes are grouped together as clusters, (4) the creation of a master table of superordinate and subordinate themes and (5) the integration of cases—this involves moving from one analysed transcript to the wider sample to compare and contrast themes and identify emerging overall patterns (Nuzum et al. 2014a, b; Smith et al. 2009).

The data were analysed by the research team, and consensus was formed on the emergence of superordinate and subordinate themes. Data were managed using NVIVO version 10 (QSR International).

Results

All participants were emotional as they recalled the experiences surrounding the diagnosis of a life-limiting condition or stillbirth and the care they received in hospital.

The superordinate themes arising from the data relating to faith were: searching for meaning, maintaining hope and questioning core beliefs (Fig. 1).

Theme 1: Searching for Meaning

Every parent expressed a deep sense of devastation and shock when they discovered that there was something wrong with their baby. This led to considerable personal reflection and questioning concerning the circumstances of the diagnosis and possible events leading up to diagnosis. The subordinate themes that made up the superordinate theme of searching for meaning were: being chosen, value of their baby's life and spiritual significance (see Fig. 1).

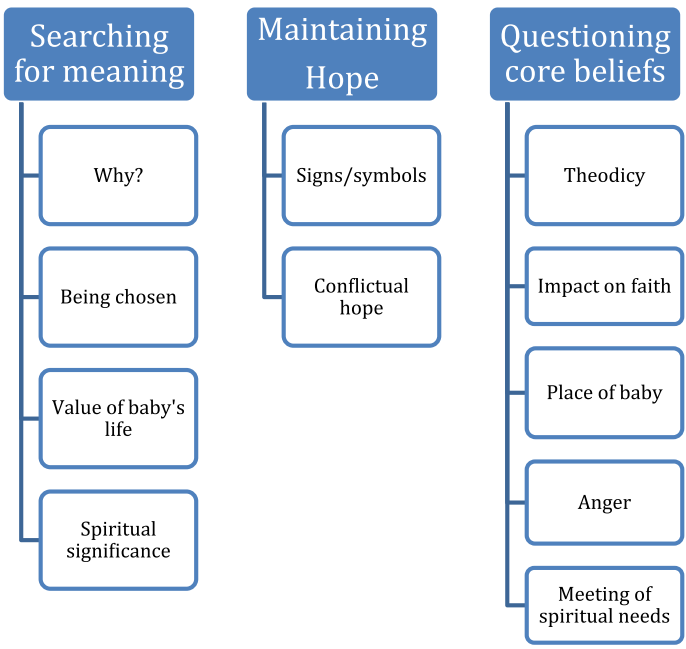

Fig. 1 Superordinate and subordinate themes

Parents demonstrated a strong desire to seek to understand why their baby had an anomaly or died unexpectedly, especially during an otherwise healthy pregnancy. This questioning was expressed most often by 'Why did this happen to our baby, or to us?'. In seeking to answer what are in many ways unanswerable and existential questions, parents revisited experiences and events that occurred during their pregnancy. Searching for meaning was an active pursuit. A core part of searching for meaning was honouring the life of a baby, that his or her life was not in vain.

> Like I definitely feel that everything is meant for a reason. I think that's what made us happy, that this was her life cycle. This is all she knew. This was all she was meant for.[2013P1]

> Very important to me was to know that it [baby's death] wasn't in vain.[2010U1]

Being Chosen

The sense of being chosen for this role only arose for mothers. The sense of being chosen was expressed in the data by mothers as an honour and a privilege and yet at the same time carried with it a certain conflict of wishing that they had not been chosen to be the mother of a baby who had died. Those who had time to prepare for the impending death of their baby were more expressive about being chosen for this 'special role' in the life of their baby. For some parents, being chosen was attributed to an intentional act on the part of their baby whom they believed had chosen them. This ascription to an independent identity of a baby also features in a further superordinate theme of personhood.

> She was a little angel and she needed to be born and she picked us to bring her into the world and that was our gift to her, was to bring her into the world. She knew from the outset that wasn't going to last longer than the pregnancy and she needed someone strong to be able to bring her into the world and she picked me and James.[2013P1]

Being chosen also conveyed an interpretation of inner strength on the part of mothers. They expressed a sense of pride that, as mothers, they were able to be parents of a stillborn baby with the inference that not all mothers would. Mothers who had experienced a sudden unexplained stillbirth expressed being chosen more as a posthumous hope as they reflected on their memories than as an experienced reality at the time.

> So when I was chosen there could be reasons he [baby] came into my life to help me on my journey, that maybe he was helping God. He knew my faith was strong enough to go on his way or maybe God called him, I don't know. I got a good sense without any help from anybody; I was sensing all this in hospital.[2010U1]

> I can remember [when people said] 'Oh God, he's chosen you' and I remember saying 'I wish he'd chosen me for something else.' But it was more, in some ways I kind of treasure the fact that we were chosen.[2008U1]

Value of Their Baby's Life

All parents placed a strong emphasis on the value of finding meaning in both the life and death of their baby. For parents who had received a diagnosis of a life-limiting condition, this subordinate theme was especially significant as they used the time between diagnosis and death/birth to create memories, to make the most of every day and experience.

> Getting the diagnosis early I think was a blessing because I was able to enjoy everything.[2013PI]

Even though this was not the life or outcome that parents would have chosen for their baby, they nonetheless sought to find value in the importance of the life of their baby in their own right as they searched for meaning.

> I don't think it would have mattered to me if he had two heads. He was lovely.[2008U1]

Parents who had an unexpected stillbirth recalled the experiences they had during pregnancy. This retrospective grieving and attribution of significance was an important part of honouring the life of their baby and establishing patterns of meaning that provided ongoing comfort.

> I see his life as being the nine months that he lived. He had his own kind of life. He didn't live any kind of life in my world, he lived his own life in another world, that was very real, very his own. He had his own experiences. He got to have all the adventures that I had. He got to go swimming; he got to go to San Francisco. He got to taste funny food. He got to taste bakery cakes. He got to go to the cinema. He got to have all those experiences in his own way. … He had his own life. We shared in it in a lot of ways and we didn't in other ways … he must have seemed to be another part of me also.[2013U2]

Spiritual Significance

All parents were from a Christian faith background although one mother did not now belong to any faith group. She described this as

> I wouldn't call myself religious; I wouldn't attach myself to any particular religion now. I think nature is one of the defining forces in the world, in the planet, in our lives. I would say there is an awful lot going on that we have no grasp, that I have no grasp on … I don't associate that with a god or something, but I see it as a huge part of us. It's an area I don't have a huge inclination to define … possibly partly because of a lack of interest in a religion.[2013U2]

Most parents had a ceremony of naming/blessing for their baby after their baby was born. Three couples had a baptism for their baby. Some mothers also engaged in spiritual practices during pregnancy such as a service of blessing for their baby in utero following a diagnosis of a life-limiting condition. This involved an intentional 'prayer of blessing and protection' by a priest friend and was conducted in the family home with the couple. All parents had a funeral/prayer service for their baby prior to burial or cremation. All parents expressed how these ceremonies helped them to attribute spiritual significance and value to their baby's life. Participation in a ceremony helped parents to express their grief and to confront the reality of physical separation by saying 'goodbye'. A ceremony was also something that parents were able to invest in for their baby as they planned an individualized ceremony. For many parents, it was important that their baby received the same honour as every other baby in terms of ritual and ceremony.

> We had him Christened, same as the rest of us (very upset).[2013U1]

> It was in some way, it was before the service that was the really difficult part, the service was part of the process, you know the really hard parts were before the

service because they had to be done before the service could happen. So it kind of pushed us into some things that we really needed to do. The writing of the service was as important as the having of the service. The finding of the painting and the working out the booklet and working out the words that I'd like to put in and things I wanted to say and what things I wanted to remember him by, what music I wanted.[2013U2]

Theme 2: Maintaining Hope

Al parents reported that hope was an important value that sustained them during their care. Hope was described as something that provoked a level of inner conflict for parents when their wishes for their baby were at odds with the medical evidence or diagnosis. This was particularly so if a baby was diagnosed with a life-limiting condition.

The subordinate themes to emerge in this area were: signs and symbols, and conflictual hope.

Signs and Symbols

Many parents spoke of how they had received various 'signs' which they interpreted as being from their baby or that pointed towards their baby. In addition, parents also mentioned that various symbols had taken on significance for them following the death of their baby. These signs and symbols were interpreted as being very closely connected with their baby's person and were of immense meaning and enduring comfort to parents. Signs and symbols were experienced as an ongoing connection with a deceased baby and were cherished by parents as embodying hope that their baby was still close to them. These signs of hope were described in liminal terms, as of threshold significance between this world and the next. Two signs in particular stood out for bereaved parents: white feathers and butterflies. Two mothers spoke about how butterflies were important symbols for them following the deaths of their babies.

I remember the week after he was born … there were all these little white feathers on the path ahead of us. There's a lot of places you go and you find these little white feathers. You know, in your head you're thinking, that's him.[2010P2]

You would go to bed and the next morning you would pull up the blind and there would be butterflies inside the house, it was just very weird. And right up until Christmas, Christmas Eve, there was a butterfly, so we all associate butterflies with the baby … I just always feel like it's baby saying 'hello'.[2010P1]

Other parents shared how they had other experiences that gave them closeness to their baby.

Sometimes at night-time it happens here, someone blowing into my ear or my head. It's always my head and I think maybe Samuel is present. I don't know. It's very strange. It has happened three times and it wasn't my husband as he wasn't there so I take comfort in that.[2010U1]

Conflictual Hope

Parents reported that they struggled with a sense of conflictual hope when they found it hard to accept the finality of a diagnosis that their baby was unlikely to survive until birth. This was heightened as mothers in particular continued to feel their baby move *in utero*. An inner conflict arose for mothers as they explored whether there was anything they could do to alter the prognosed outcome for their baby. One mother following a diagnosis that her baby had a cardiac anomaly where she was informed that her baby was unlikely to live longer than 2–4 weeks after the diagnosis, expressed this sense of hoping against hope as:

> I started going to a homeopath … I took every remedy and supplement, everything you could think of, everything under the sun to try and make him stronger, that his heart might get stronger. So I felt like I really had to keep going for him. I kept trying to think of ways to make him better. I was reading and everything trying to find out things that might help him but Dr Y said I couldn't do anything.[2013P2]

For parents who received a diagnosis of sudden unanticipated stillbirth, they expressed how they tried to cling on to hope from the moment they suspected that something might be wrong. This created inner conflict and turmoil.

> I think I knew, my gut feeling was like, that I had either lost the baby or whatever, and I just didn't want it to become real. Because I suppose there was a chance they could save him.[2008U2]

Theme 3: Questioning Core Beliefs

Parents expressed that they questioned their belief structure and practice following the death of their baby. For all parents, the death of their baby caused them to reflect existentially on their life values and belief systems. For all but one, this was based on their Christian understanding of God, and for one, it was based on a more humanistic approach. One mother who was a committed Catholic before her baby died expressed the impact on her faith as:

> My faith has changed. I used to go to mass all the time but I rarely go to mass now. … I was very much the traditional, go to mass, sit down and I suppose I always had that kind of spiritual side. The God I believe in is not the same as [formal church] … I went to mass on [last] Sunday, the first time in a long time and I nearly walked out … the priest is doing the Catholic church thing, he said that people who voted for the abortion thing were evil and they should never go to mass … and I'm there thinking 'will we try for another [baby]?'[2008U2]

Subordinate themes that were part of the superordinate theme of questioning core beliefs were theodicy, impact on faith, place of baby and anger.

Theodicy

Theodicy is one of the most challenging aspects of pain and suffering for people of faith. Cooper-White's definition is perhaps the most appropriate for the context of stillbirth. She defines theodicy as 'the tension between three mutually incompatible axioms: divine goodness, divine omnipotence/sovereignty and the existence of suffering …' (Cooper-White 2012).

The struggle of some parents with theodicy found expression in feelings of unfairness and injustice at why their baby died.

> I wondered why this happened to me. I had no baby, Why me? It's beyond my capability of understanding, so I asked questions about God.[2010U1]

> I was angry and I said why is this happening to me? What did I do to deserve this?[2013P2]

> I can always remember the day I found out, that, I had the scan. I went outside the front door and there was a couple of girls there. I know this is a completely horrible thing to say, but they were out smoking out the front and they were as big as busses now and I don't mean to, I was thinking 'they're fine now and here am I, haven't touched a drink. I don't smoke, didn't drink and this is happening to me and these ones out smoking, like, fit to have their babies. I felt it very unfair.[2008P1]

Parents who were practicing their faith found this area particularly hard as it jarred with their sense of devotion and religious commitment. It created an unsettling relationship with their faith and belief in a caring God. This is discussed further under the subordinate theme 'impact on faith'.

> Sure we always went to Mass and everything like, you're kind of saying 'why?' then like, wouldn't you? You'd be wondering what you did wrong, what you did to anybody that drew this down on your doorstep?[2013U1F]

Impact on Faith

All parents experienced the death of their baby as challenging to their faith and belief. This challenge for eight mothers and four fathers led them to question their faith and belief in a caring God with four mothers and three fathers expressing that their faith was weaker as a result. One mother felt that her experience of stillbirth led her to a deeper faith. Four parents expressed that their faith, although challenged, remained unchanged following stillbirth.

> I still believe in God and I still believe as I did before but I just (deep sigh) never expected this thing would be so hard. I never thought I would have to go through something like that (voice breaking and emotional) Life can be hard enough without going through something like that. It has made me worry about what's around the corner. It has made me fearful for my three kids that are here with me. I'd still say my prayers but sometimes I feel 'is there any point?' It didn't work with the baby anyway.[2013P2]

> When he died it was like, what? Why is he [God] doing this and 'why would you do this to anyone?'[2010U2]

> I used to go to mass and that sort of stuff; I haven't gone for five or six months. I found it was something I was doing rather then something I was partaking in, I just find religion confusing now. It's like I'd be questioning at times, is there anything after? I just don't know.[2010P2F]

The diagnosis of a life-limiting condition led some parents to express strong feelings of anger towards God yet at the same time feeling a sense of dependence on God to get them through the experience. This led to a confusing sense of dependent ambivalence.

> Oh I screamed at him [God], I gave him the big finger there. I did suffer a long time. I just couldn't leave it, praying went out the door. I found it very hard to pray, but I spoke. I didn't say prayers, I spoke and I screamed and I roared at him … maybe I was given the grace to help me along because I was struggling so much …'Why am I going through this? God, what are you doing?' And at the same time going 'please help me, I'm leaving it in your hands.'[2008P3]

Place of Baby?

Many parents reflected on the question about where their baby is now. This subordinate theme was expressed as parents shared their sense of ongoing connection and relationship with their baby. For some parents, it was closely linked with their sense of the after-life. Is my baby still a person? Where is my baby now? Parents wrestled with these questions as they shared how they still felt a close connection and relationship with their baby.

> I felt great frustration and confusion around where like, where would a spirit, where would that spirit go?[2010P2]

> I kept getting reassurances that he's in heaven, and that was great.[2010U1]

> One mother connected with her baby through a medium which was a source of comfort.

> She [medium] just said that the baby is very happy where he is and that he doesn't want us to be miserable, to be grieving over him, that he is just feeling loved. He just came to me to be loved, to feel loved and just wants us to be happy.[2013P2]

The experience of loneliness and grief was also part of this subordinate theme. Parents described this as the reality of the absence of their baby, as if they were missing something, yet at the same time feeling close to their baby.

> The first three or four times we got the ferry out to the island, it was just the oddest thing. I got off the ferry and we had our bags and I was going, 'I'm missing something'. I'm missing, I'm missing a bag, there's a bag missing, there's something missing. I'm supposed to be carrying something else off the boat and I went down to the boat again and the man said 'no, no, no all your bags are up'. And I'm missing something. And then we get everything into the car and went to the house and he's [partner] also saying 'I'm missing something, I'm missing a bag.' I said 'no, I thought the same thing' and then an hour later it's like, 'I know what it is, I'm missing a baby.'[2013U2]

Anger

Anger was a subordinate theme running through most interviews as parents expressed the pain associated with the death of their baby. As a subordinate theme, anger challenged the world view of parents where the natural order of birth and death is reversed and most especially where there were no identifiable reasons.

> With God you'd be saying 'why my baby? This is a baby that would have been loved', there's the bitter side to it.[2010P1]

> Sometimes you'd be quite angry how God can let something like this happen.[2010P2]

> When he died, it was like, what, why is he [God] doing this? I just stopped doing it [going to Mass] for a good while … I was very angry, angry, just devastated. Just why? Why us? Why anyone? James was almost full term; you know moving around and kicking. So, yeah, very angry,[2010U2]

Parents recalled expressing their anger to God during their pregnancy. Two parents found the experience of labour very difficult and were angry with God and with the healthcare team. One mother expressed:

> My husband was crying, I just went, I discarded God at that point and I shouted to Our Lady saying 'what's wrong with you, why have you left me?'[2008P1]

One father described his anger and sadness from a faith perspective because he and his partner were denied a funeral for their baby son in their church as he had not been baptized.

> I suppose because he hadn't been christened, we couldn't have a service in the church. … I remember the priest saying one day, 'you can't pick and choose what parts of being a Catholic you want to be' and I just thought to myself, then everyone in this room will have to get out[2010P2F]

Two parents expressed that stillbirth had transformed their relationship with God through the awareness of their anger. This transformative growth led to an integration and acceptance of anger as a justified response to the death of their babies.

> She has taught me that it's ok to be angry with God … He's very understanding and that he understands and if you got angry with him and said 'I'm cross' that he'd be ok with that … you can be cross with him and you can go away from him for a while and the door is always open and he's understanding.[2008U2]

Spiritual Needs

Parents expressed that they struggled with existential questions following the diagnosis of a life-limiting condition or stillbirth of their baby. All parents shared emotions such as fear, anxiety, sadness and doubt that indicated spiritual distress. Most parents availed of chaplaincy services during their time in hospital; however, these services were reported as being exclusively for ceremonial functions such as naming/blessing ceremony or a baptism. These ceremonies were described in functional terms. While this was valued by parents, most parents ($n = 13$) felt that their deeper spiritual needs were not adequately met while in hospital. The parents of three babies felt that their spiritual needs were met during their time in hospital.

> I met with [chaplain] she came up and had a chat with me and she was lovely … I suppose in a way nobody did address my faith or where I was there…I guess you need somebody to knock off the question to 'why is God so horrible?'[2008P2]

> He [chaplain] blessed the baby but I suppose we didn't really have any … I suppose we could have asked, but we didn't have anyone that sat down and kind of talked about the spiritual side of it.[2013P2]

No parent had received any follow-up pastoral care from the hospital. Of note, only three of the twelve babies had a ceremony/funeral in a church prior to burial/cremation. Most parents had a private ceremony in their home or at the hospital prior to discharge.

Participants were asked if they would have appreciated if their obstetrician had discussed their spiritual needs as part of their care. Only one parent said that they would have valued this. All other parents said that they felt this was not something they would expect from their obstetrician but would like the doctor to recognize that they needed support.

> I would be okay. I don't know whether [partner] would be though … you'd have to use your judgement.[2008U2]

> I would have been shocked if she [consultant] had asked me [if the baby's death was impacting on faith/belief] … I would assume that her job is to look after the mother and the baby … she'd be in there hours if she started asking questions like that.[2008P1]

> I didn't need to go into depth with faith [with consultant] to be perfectly honest with you. At the time I was more concentrating on the scans, my faith is always there. I didn't need [doctor] to ask me about my faith as such. It was more 'How are you doing overall?'[2008P2]

> I would rather they asked you than not say anything about it and just ignore it, because it did happen and you do want them [doctors] to acknowledge it.[2010U2]

Three parents said that they felt that their obstetrician and bereavement and loss midwives were very sensitive to their deeper needs and provided deep empathic care.

> Every time we went in [for appointments] it was a case of we sat down and we talked for about five minutes or so [about how I am in myself which this participant described as spiritual] before we went into the medical stuff. Not pregnancy related stuff, not up in your head. They were phenomenal … so caring all the way through.[2013P2]

Discussion

The spiritual reality of stillbirth on bereaved parents is immense and impacts significantly on the faith, practice and belief of parents. The findings from this study demonstrate the presence of spiritual distress and ongoing struggle following stillbirth for parents. Bereaved parents voiced strong emotions and spiritual distress towards God as part of the interview process. Parents expressed the tension between trying to believe in a compassionate and caring God on the one hand and yet on the other hand struggling with the reality of theodicy. The expressions of theodicy and lament, while often difficult for people of faith, are close to the strong expression of spiritual distress and existential pain recorded in many sacred writings—not least in the Hebrew psalms where voice is given to the emotions of pain, angst, anger, fear, loneliness and abandonment. The heart-rending lament finds echoes in the words of Psalm 44:20 and 25 '…you have crushed us … and covered us with the shadow of death. Why do you hide your face and forget our grief and oppression?' (*NRSV Anglicized Bible* 1998). These are strong emotions which deserve sensitive spiritual care and attention.

Considering the depth of spiritual distress expressed by parents, it is a concern that only four parents felt that their spiritual needs were met during their time in hospital as they experienced the acute phase of bereavement following stillbirth. The role of spiritual care and chaplaincy is recognized as being of value in perinatal bereavement (Kelly 2012, 2007; Newitt 2016; O'Connell et al. 2016; Pierce 2003). The experiences from bereaved parents

outlined above reveal the raw edge of lament and theodicy following the death of a baby. It is in this painful wilderness that healthcare chaplains are best placed to provide sensitive and meaningful spiritual care. Accompanying parents as they acknowledge and give voice to these deep spiritual and heartfelt feelings has positive therapeutic implications for healing and recovery and demands a high level of spiritual and pastoral competence and maturity coupled with the capacity to wrestle theologically with the depths of lament and theodicy (Nuzum et al. 2015b). When the data from this study are compared with a study of the provision of pastoral care in Ireland which identified that 40% of maternity healthcare chaplains are not board-certified, it raises a concern that spiritual need is not being adequately met following stillbirth in Ireland (Nuzum et al. 2016). The findings from bereaved parents concerning the importance of searching for meaning, maintaining hope and questioning core beliefs highlight areas of sensitivity and importance for parents which should be attended to as part of holistic perinatal bereavement care. These areas are best attended to by appropriately trained healthcare chaplains working as integrated members of multidisciplinary perinatal bereavement teams in the acute setting. These findings are also of importance to community clergy and spiritual advisors who provide ongoing care for bereaved parents.

The role of clinicians in the recognition of spiritual distress as part of clinical care is recognized in the published literature, most notably in the area of palliative care (Balboni et al. 2014; Puchalski and Ferrell 2010; Puchalski 2010). The findings from this study, however, identified that parents did not expect that obstetricians would have this responsibility as part of their care. In a related study at the same study site, most consultant obstetricians recognized that stillbirth does cause spiritual distress, but felt unable to address it or respond to it and saw this as something that the wider bereavement team should attend to (Nuzum et al. 2015b). These results further support the recommendation above for the provision of multidisciplinary perinatal bereavement teams in the overall provision of comprehensive bereavement care following stillbirth.

The strengths of this study are the depth of personal spiritual pain and wrestling that have been shared by bereaved parents to contribute to this field. This study explores and gives voice to often unarticulated spiritual distress as parents seek to understand the death of their baby and to find meaning in their loss.

The limitations of the study are that the participants were all from one study site and that the results pertain to one group of parents of whom nearly all are Christian.

The findings from this study suggest that further research be conducted to explore how spiritual distress is identified by the wider clinical team and following identification and referral how this distress is then attended to both by the wider specialist perinatal bereavement team in general and healthcare chaplains in particular.

Conclusion

The data from this study reveal the depth of spiritual struggle experienced by bereaved parents leading up to and following stillbirth. That this spiritual distress and struggle were not adequately responded to as part of the care experienced by the participating parents highlights the need for professional spiritual care as an important component of overall perinatal bereavement care in the obstetric setting.

Compliance with Ethical Standards

Conflict of interest Daniel Nuzum declares that he has no conflict of interest; Sarah Meaney declares that she has no conflict of interest; and Keelin O'Donoghue declares that she has no conflict of interest.

Ethical Approval Ethical approval for this study was received from the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No: ECM 4 (pp) 06/03/12).

Human and Animal Rights All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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