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# Mind Yourself So You Can Mind Me; The Role of Parental Behaviour in Perinatal Death on the Surviving Sibling's Grief

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**Abstract**

Children's grief, in perinatal loss, can be misunderstood and overlooked. Parental behaviour while mourning infant loss and parental ability to respond to their own grief has a crucial role in the child's grief. This study aimed to explore parental behaviour as a determining factor in siblings' grief following perinatal death. Six mothers and two fathers experiencing perinatal loss were interviewed about their perception of the child's experience of perinatal death. Thematic analysis allowed for identifying of relevant themes. The main themes related to parents' expression of grief, insight and understanding of their children's grief and communicating the death/anticipated death with their surviving children. Findings showed that children seek out information on their deceased sibling and need supportive parents to guide them through their grief. Our study highlights that supporting parents in their grief is a key factor for a healthy grieving process in children and must be considered when supporting families in perinatal death.

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## Introduction

The loss of a pregnancy or a baby through stillbirth or neonatal death can be a devastating time for families. Nuzum et al. (2018) reflect on the immense impact and burden of stillbirth on bereaved parents and how it has an enduring impact on lives and relationships.

Studies have reported that the death of a child elicits a more intense and complicated grief reaction than other types of bereavement and that few experiences in contemporary society are more traumatic than the loss of a baby or child (Currie et al., 2019; Nuzum et al., 2018). We also know that men and women use different coping mechanisms during the grieving process. Meaney et al. has referred to differences observed in the aspirations of men and women post perinatal loss in relation to future pregnancies (Meaney et al., 2017).There is also much research on masculine and feminine responses to grief (Currie et al., 2019; Stroebe & Schut., 1999). This research has helped professionals understand grief responses and therefore how both grieving parents can be supported after a perinatal death.

Within the context of perinatal death, the associated grief is often considered a disenfranchised grief. Doka, 2002, first defined disenfranchised grief as "grief that is experienced when a loss cannot be openly acknowledged, socially sanctioned, or publicly mourned" (Doka, 2002). In short, while a person has experienced a loss, the person does not have a "right" to grieve that loss since no one else recognizes a legitimate cause of grief. Meaney et al. reported how parents described unhelpful societal responses such as "they were young and that there would be plenty of opportunities to have more children" (Meaney et al., 2017).

For a child their grief is often even more disenfranchised. Often the sibling's grief is not acknowledged or supported in the belief that they are not grieving. Fernandez – Sola et al. (2020) referred to the lack of support and attention siblings of pregnancy loss receive in their grief, "in general they do not receive any kind of support and suffer the consequences of the grief that their parents are going through".

However, research on pregnancy loss and perinatal death shows evidence of sibling grief in perinatal death. Jonas-Smith et al., 2015, referred to the "short length of time a child knew their infant sibling, even if only in – utero, did not diminish the significant impression of sibling death" (Jonas-Simpson et al., 2015). Children's grief may not present itself in the same way as adults, but their grief is apparent in changed behaviours, regression, emotional outbursts and separation anxiety. Often this challenging behaviour is misunderstood by families as being naughty or seeking attention from emotionally exhausted parents (Machajewski & Kronk. 2013).This misunderstood behaviour often results in reprimands, which only intensifies children's grief-related guilt.

The aim of this study is to retrospectively explore parental behaviour subsequent to a perinatal death as a determining factor in sibling's grief. The intended outcome is to gain an understanding of the role parents play in sibling's grief response and to inform healthcare professionals working in the area of perinatal death.

## Methods

### Study Design

A qualitative approach was chosen for this study as the qualitative approach will allow for a richness in data collection (Barrett D & Tycross A, 2018). Parents of bereaved children were interviewed to explore their perception of the child's experience of perinatal death. Semi structured interviews with opened ended questions were used as they provide most appropriate method of collecting the data, allowing for in-depth discussion of this complex issue.

### Sample

The sample consisted of six mothers and two fathers. One of the families had experienced a neonatal death and five had experienced a stillbirth. The details of the participants are included in Table 1. Two out of the six families had received an antenatal diagnosis of a fatal foetal anomaly or life-limiting condition.

Inclusion criteria included families who experienced a perinatal death between January 2016 and December 2020, families who had surviving siblings aged 4–16 years' both female and male children were to be included.

Exclusion criteria included families where the perinatal death occurred within the past three months. This was to allow time for families to grieve their loss and begin to process their grief. A second exclusion criterion was families who were engaged in a complaint procedure with their maternity unit. These families were not included due to the complexity of this process and ensuring the wellbeing of participants would not be affected by the research.

### Recruitment

Suitable participants were identified by Pregnancy Loss team and Lead Clinician (KOD) in a tertiary maternity unit. Contact details for participants who agreed to be contacted were then provided to the researcher and consent sought from them to participate in this research. In consultation with the pregnancy loss team, families were contacted by letter by OJ (BSS, Bachelor in Social Studies; Social Work) and invited to participate in the research.

The interviewer, OJ, was an experienced social worker (female) who is a member of the pregnancy loss research team and had a keen interest in the field of pregnancy loss and bereavement care.

**Table 1.** Overview of Participants Characteristics.

| Participant | Parent | Surviving sibling | Age at time of death | Baby | Perinatal loss type | Gestation |
|---|---|---|---|---|---|---|
| Parent A | Father | Child AB1 | 13 yr | B1 | Stillbirth- | Very |
| | | Child AB2 | 7 yrs | | Intrapartum | preterm <24 weeks) |
| Parent B | Mother | Child AB3 | 6 yrs | | | |
| Parent C | Mother | Child C1 | 4 yrs | B2 | Neonatal death | Very Preterm (<24 weeks) |
| Parent D | Father | Child DE1 | 6 yrs | B3 | Stillbirth- | Very Preterm |
| Parent E | Mother | Child DE2 | 4 yrs | | Intrapartum | (<24 weeks) |
| Parent F | Mother | Child F1 | 12 yrs | B4 | Stillbirth- antepartum | Preterm |
| Parent G | Mother | Child G1 | 16 yrs | B5 | Stillbirth- Intrapartum | Term |
| Parent H | Mother | Child H1 | 3 yrs | B6 | Stillbirth- Intrapartum | Term |

Detailed consent forms and information sheets were provided to families by OJ and initial communication took place with parents to obtain verbal consent prior to qualitative research commencing. Written consent was subsequently obtained on the day of the interviews.

Parental interviews consisted of both parents or only one depending on the wishes of the parents. Parents were given the option to be interviewed separately or together, and again this was dependent on their wishes.

## *Data Collection*

Subsequent to recruitment, participating parents took part in semi structured interviews. All interviews were undertaken by OJ. One interview was undertaken in a room onsite in the hospital, two were undertaken in the family home and three were undertaken by telephone due to restrictions imposed by the COVID-19 pandemic. Two interviews were undertaken with both mother and father and the four subsequent interviews were undertaken with the mother alone.

The interviews were based on an open ended 7 question approach, covering specific themes, of parental experience, communication with surviving children, surviving children's involvement, surviving children's understanding of the death and sibling behavioural changes. These were identified as key issues through literature review undertaken by (OJ) and in discussion with the pregnancy loss team and Lead Clinician (KOD) in a tertiary maternity unit. Each interview lasted approximately 1 hour.

Interviews were initially recorded then transcribed manually and anonymised for confidentiality purposes.

### Ethical Approval

This study conforms to internationally accepted ethical guidelines and also conforms with the national Social Workers Registration Board's Standards of Proficiency. Ethical approval was obtained from the Social Research Ethics Committee in University College Cork (study code Ref 2018-198). All participants gave verbal and written consent to participate in this study.

### Data Analysis

In this research an inductive thematic analysis approach was used when collating data (Braun & Clarke, 2006). Using thematic analysis as a research method allowed identifying, analysing and reporting themes within a complex data corpus.

Data analysis was undertaken in several steps. The first involved reviewing transcripts and identifying initial codes. The next step was creating and reviewing themes This was done with the assistance of an experienced researcher (SL). Through this refining and structuring of the data the main and most relevant themes were identified. Themes were then reviewed with another peer researcher (SL) which led to refining and structuring the main and most relevant themes to report from the data.

## Results

### The Participants

Twenty families who had experienced perinatal death were invited to participate. Eight families did not respond and six declined to participate after initial contact due to personal reasons, including a familial bereavement, a new pregnancy and inability to commit to interviews. Subsequently six mothers and two fathers agreed to engage in the study; six mothers and two fathers were interviewed. In total, there were nine surviving children in these six families. At the time of the interviews the perinatal death had occurred within the previous 24 months. Table 1 outlines some of the characteristics of the participants and their family.

### Themes Identified

Analysis of data identified four subordinate themes related to the overarching theme of the impact of parental response to perinatal death on the grief of bereaved sibling children: Parent's expression of own grief; Parental insight into the children's grief processes; Communication of the death/anticipated death to surviving children and Parental ability to facilitate enduring bonds.

These themes are explored and expanded on further in the sections below.

*The Parents' Expression of Own Grief.* All of the parents involved in the study referred to their own overwhelming grief at the loss or anticipated loss of their baby. This grief was expressed in different ways depending on the type of perinatal death and whether this was anticipated or sudden. Although the parental experiences were different, all identified intense sadness at the loss of their baby,

> "And it was just awful. I just couldn't listen to it because I just knew they were going to say that he was dead. So I just remember begging them to get me out of there that I couldn't be in the room." (Parent H)

> "I just cried and cried that week" (Parent F)

For many parents there was evidence of anticipatory grief wherein parents described the fear and anxiety of hearing bad news but were still hoping for good news. For those where anticipatory grief was present there was an acceptance that their baby may die but there was still hope that there had been a mistake and their baby might survive. Parents identified looking for opportunities for hope and reassurances regarding their baby's viability.

> "I'd say I was having a scan every week and then just one day I said I just couldn't keep coming back because… I suppose I kept going back and hoping that something was going to change." *Cries* (Parent E)

> "You kind of hold on to this hope all day that there was something wrong with the machine that they were wrong. You know you kind of… until she was born and I could see for myself I don't think I actually thought it was real." (Parent G)

One recurring aspect of parental grief was contact with their baby. Five out of the six parents in this study roomed in overnight with their babies after they had passed away. In the case of the neonatal death parents spent time alone with their baby in the family room after their baby passed away. Parents reflected on this time alone with the baby, with all of them valuing the time they had with their babies after they had passed away.

> "We had planned not to see her. Yeah. We kind of decided not to see her. I didn't know what way she would be. We didn't realise she'd be so perfect." (Parents A & Parent B)

Some parents referred to a sense of comfort from the time spent with their baby. This contact with their baby allowed them to parent and love them even if only for the briefest of time.

> "I think having him there was such a comfort to be able to hold him. I think it was just the knowing I wouldn't be able to hold him again. So I couldn't. I just couldn't think about it" (Parent F)

One set of parents referred to wanting to hold the baby but expressed being nervous holding him 'properly' as they described him as bring very fragile.

> "And did you get to hold him soon afterwards?
>
> Yeah. Yeah…..But not properly like. Ah we did I suppose as best we could….we were warned that he was very fragile." (Parent D)

A sense of experiential trauma relating to the death of their baby was identified in many statements throughout the study. Both mothers and fathers referred to traumatic birthing experiences when delivering their baby. Many parents expressed very emotive memories and had difficulty recalling the challenging experiences they had when delivering their babies.

One mother describes waiting on her own in the delivery suite during labour. She recalled the sense of being on her own and feeling afraid.

> "I was left in the room on my own for a good while and I felt like it was scary…. And I was like please help me and nobody seemed to come in like. And I couldn't get to the button or anything. ***Cries*** And then eventually a nurse came." (Parent B)
>
> "It was just this scene going on but I wasn't really involved and I didn't really know what was happening. It was very strange. It's really hard to describe." (Parent H)

*Parental Insight and Understanding of Their Children's Grief.* Some parents were able to display insight and understanding of the grief and sadness that their children had experienced on the death of their baby brother/sister. Some parents placed significance and importance on their children's grief. They displayed a sense of understanding that telling their children about the death of their baby brother/sister was going to be difficult and upsetting for their surviving children. This was an instinctual response for some parents in responding to the grief of their surviving children.

> "We had to go tell him and that was hard. He cried where we were able to compose ourselves to try and stay strong for him. But yeah he was really really hurt and sad." (Parent F)
>
> "So my initial thought was about her as opposed to even us. It was just the first thing I just thought how will I tell her because that was how involved in it she was" (Parent H)
>
> "The kids are actually well able for it…They wanna be part of the situation and be acknowledged about the sadness of what's happening you know." (Parent C)

For other parents, it was more difficult to appreciate the impact of the death of their baby would have on surviving children. Parents reported that they did not think that the loss of the sibling had an impact on their surviving children or they found it difficult to identify occasions or times when their surviving children displayed typical grief

responses. They reported that this was due to what they perceived as a lack of understanding of the death of their baby brother/sister or a lack of a relationship with their deceased baby brother/sister.

> "But they didn't show a lot of attachment but I suppose they never really had the attachment did they? I don't think they ever felt the loss because they never had a brother. They had an experience but they never had a brother as such like. I just don't… That's my take on it anyway." (Parent D)

> "She [Child AB2] said 'oh that's because I missed B1 but it wasn't like."

> "Yeah sometimes I don't know is she just saying it just to get away with stuff or what." (Parent B and A)

For some the need to minimise the death and facilitate return to 'normality' was perceived as important for their surviving children's emotional well-being

> "I suppose that was it. Now look as I say we made a huge effort then to try and make life kind of seem normal we'll say for G1 after." (Parent G)

Some parents were aware of sibling's grief and their interest in their deceased brother/sister. These parents were able to report occasions where children asked about their baby brother or sister. Parents expressed that they felt happy to engage in these conversations and facilitated a permissiveness for these conversations to happen.

Some parents expressed comfort in talking about their babies with their surviving children and acknowledged that being able to talk about their baby brother or sister was important for their grief.

> "Because he is talking about B2 any time he wants to. He is talking about him freely. Like he's not afraid to bring him up again any time he wants to. You know so I think for his own grieving and the process that he's going through its very important you know." (Parent C)

> "We want her to talk about him and we want her to remember him. And I think especially because she was an only child you know she was so excited that she was going to be a big sister. And I think you know we wanted to keep that." (Parent H)

Another parent was also able to identify the need to involve her surviving child in age-appropriate decisions, acknowledging his grief as important.

> "'It was very important to keep him involved in everything and let him be a part of the decisions because it's his grief as much as it is our grief you know so you need to let him ride it out the way he needs too as well like." (Parent F)

Some parents displayed a mis-attunement to their child's distress and seemed often confused as to the cause of the children's distress despite their children's efforts to communicate this to their parents.

One couple spoke of their child's angry outburst prior to a visit to her baby sister's grave. Child AB2 had refused to go to the sisters grave and, when leaving the house to visit the cemetery, the child became very angry and distressed. In their account, the parents stated that the child clearly said that she was missing her baby sister. Nevertheless, the parents did not seem to understand Child AB2's behaviour nor relate it to her grief and interpreted it, otherwise, as insubordinate behavior or just "acting-out".

"- Like, she didn't know what was wrong with her or something.

- I don't think it was the grave either.

- No it wasn't because of going to visit the grave.

- But in the end she went up into your arms and just chatted a lot about that she missed B1 and wanted her to be here." (Parents A &B)

*Communicating the Death/Anticipated Death With Their Surviving Children.* All of the parents involved in the study told their children of the death of their baby brother or sister. In circumstances of a parental diagnosis of a fatal fetal anomaly parents had the opportunity to communicate the anticipated death of their baby brother or sister to the other children. For parents who had this opportunity they were able to choose, when, where and how their child (ren) would be told. Some also chose to involve their child (ren) in their antenatal journey.

"I had prepared AB1 for it… I think we were after doing the farming and I took her for a walk and I explained that… I didn't say there was a chance that she wouldn't make it, I said it was more than likely it would be just me and your mum coming home." (Parent A)

"So we had to sit him down properly that night and explain it thoroughly to him you know that there was no baby going to be coming home. The baby was going to die either shortly or in a few days, a few weeks or a few months but the baby was going to die." (Parent F)

Some parents identified their own emotional distress about communicating with their surviving children about the death of their baby brother and they understood that this news was going to upset their surviving child (ren). This emotional distress was related to parents' anxiety in knowingly causing upset or distress in their surviving children. Parents displayed an understanding of the significance of the conversation and language they would use when speaking to their child.

"It was literally my first thought in the room when the neonatologist was telling us and all of the doctors were kind of standing around. They were all just saying that they didn't

know what had happened and that he had died. I kept saying so how am I going to go home and tell my daughter this, how can I tell her, she's only three, how can I tell her." (Parent H)

"The part that was upsetting me was that we had to go tell him, he was over at my mam's. That was the part that was killing us." (Parent F)

Other parents placed less emphasis on telling their surviving children. This seemed to happen for a couple of reasons; one being that the death was sudden and parents did not have time to prepare their children. Other reasons related to families placing less emphasis on the sibling relationship and therein the impact of the loss on the children.

"And I was like well its time DE1 knows because she's going to go into school and everyone is going to say oh your mam is having a baby. And at this stage I was 28 weeks and I wasn't holding back. We told them that we were having a baby but he wasn't strong and he wasn't going to live. Yeah and we explained exactly what it was and what we'd been told and that we were really sad about it and that was why I was sad. And that was kind of it. We went to [wildlife park]." (Parent E)

Some parents could not recall how they told their surviving children and others did not know what their children were told as their partners had told the children of the death of their baby brother/sister.

"I suppose we had them well primed at that stage. I can't really remember now. But there wasn't any real show of emotion I don't remember." (Parent D)

"No I don't remember nothing sorry…..Yeah. I think I told AB2 that B1 had gotten a bug or something. Not a bug. I told her she got sick inside mammy's tummy the way we can all get sick. So because she was so young that it was really hard for her to fight it off. Something along those lines. I can't remember." (Parent A)

"To be honest I remember my husband, basically he decided to talk to him and that was the first thing when he got back from hospital. When he got back from hospital he had a proper chat with him and he explained what's happened and that the baby got (I'm guessing because I wasn't part of that conversation at that time) the baby got sick and unfortunately he passed away." (Parent C)

In one situation, one participant narrates how she was not involved in the process of sharing this news with her son and how she did now know how he was informed of the death of his sibling:

"(…) and I think my brother was to do the talking but I think half way through he fell apart so I think it was my mother that kind of had to finish telling him [the son]. You know I never asked her (…what she told him)." (Parent G)

One significant element of communication was understanding the causality and whether parents were able to communicate causality when breaking the news of the siblings' death. Causality refers to what processes, cause or lead to death (Machajewski & Kronk, 2013). The cause of their baby brother or sister's death was something mentioned by all parents in their conversations with their surviving children.

> "- I don't know if we went into detail with them of what happened with B1.
>
> - I did tell AB1 yeah. I don't think AB2 understands why." (Parents A & B)

> "And after we told him that the baby was really really small and it was sick and we don't know if the baby is going to survive or not. (…) we explained that he had bacteria in his body like a virus and because he was so young and small and you know he couldn't fight it." (Parent C)

> "He asked me that night in the hospital did we know what happened to her and I said no that they didn't know what happened to her but that they'd be doing the postmortem and that hopefully we'd find out in a few months' time." (Parent G)

Parents were able to acknowledge the importance of appropriate language when communicating with their children.

One parent recalled how she had told their surviving child that his baby brother had died as a result of a bacteria in his tummy and that he was too small to fight it. The following year she had a baby girl and, in the weeks following her birth she noticed her son was scrubbing his hands. He had told her he was removing all bacteria from them so she would not die like his baby brother.

> "One day I could see he was scrubbing his hands so bad you know. And I'm like, what are you doing? And he was keeping washing them all the time. And that was when [names his new baby sister] was born. And I was like are you okay. And he's like mum remember you told me I have to wash my hands because I have bacteria on my hands. And she is so small so I'm afraid she's gonna die too." (Parent C)

Parents also tried to use language that their children would understand the finality of death. One parent attributed concepts of non -functionality such as play and cry to help her daughter understand the finality of death.

> "We said that he had died and that he wouldn't be able to play, he wouldn't be able to cry and she wouldn't be able to play with him" (Parent H)

*Parents Ability to Facilitate Enduring Bonds.* All parents in the study referred to situations where siblings remembered their baby brother/sister. However only some parents placed significance on these memories and allowed for siblings to engage in moments of remembering and nurturing of this sibling bond through various ways.

Throughout the interviews with parents there were many examples where parents were able to reflect on these moments and displayed insight into the importance of this enduring bond. Parents were able to recall conversations initiated by their surviving children about their deceased brother or sister and an awareness that their surviving siblings do talk about their deceased brother and sister with other people. All of the parents encouraged and engaged in these conversations with their surviving children.

> "He talks about her quite a bit. He'd bring her up in conversation. Yeah, he still talks about him. And he would say things like if he was born properly and I know he means like in January and in health, if he was born properly what do you think we'd be doing now." (Parent A)

> "When she was telling some of her cousins that I was pregnant her aunt said oh that's great you're going to be a big sister and she said I'm already a big sister don't I have B6. She still has the memories of that you know and she still talks about meeting him and she can give you specifics of that day of what she remembers and everything." (Parent H)

> "And we had a few situations I will say that happened before but someone approached me and was like oh so those two kids are yours, those two kids you have and I go yeah yeah a boy and a girl and hey is getting upset giving out to me that mammy actually you forgot about [names baby brother]" (Parent C)

Parents were also able to identify facilitation of the enduring bond through the use of mementos. During the interview parents spoke of the of significance of items belonging to their deceased baby. All families had items belonging to their deceased baby. Only one family chose not to share items with their surviving children. For those parents whose children had mementos, they acknowledged how important these were in facilitating and nurturing their surviving children's relationship with their deceased brother/sister. Parents also identified that having these mementos in the home allow opportunities for remembering their deceased baby brother/sister.

> "And he has his favourite little teddy bear and he calls him {baby brother's name] and when he has a bad day he will cuddle him and go to sleep with him you know. So small things like that make me feel like they really still, he feels like he's part of the family." (Parent C)

> "And when we were leaving he was looking at them (Hand and Foot moulds) and he was on about the size of her feet. She'd fair big feet. He said I'd say she was going to be taller than [names a younger sibling]. And we were talking about that." (Parent G)

> "If we ever seen anything with love you to the moon and back on it he has to buy it because he just associates that with [names baby brother]. So we look at the moon and the stars and we say that he is like a twinkling star up in the sky." (Parent F)

One parent did question their surviving children's relationship to their deceased brother identifying that they did not have an attachment to their baby brother.

> "They didn't show a lot of attachment but I suppose they never really had the attachment did they? I don't think they ever felt the loss because they never had a brother. They had an experience but they never had a brother as such like. I just don't… That's my take on it anyway." (Parent D)

These parents chose not to put photos up on view in the home and instead stored them at home.

> "We don't have pictures up anywhere. We don't put them up but we have pictures." (Parent D)

## Discussion

A child's grief is inextricably linked to parental grief and how a child grieves is modelled through parental behaviours at home and within the family unit. Blaustein and Kinniburgh (2010) referred to the most "salient component of a child's emotional climate is the affect of his or her caregivers. All children take cues from caregivers' expressions and learn to interpret the world in part through these emotional cues." Jonas-Simpson et al. (2015) used the term inter-relational when describing the connection between parental and children's grief. Therefore, understanding how the parents in this study grieved was vital to understanding their children's grief. Some parents in this study reported intense grief in the days and weeks around their baby's anticipated death and at the time of their baby's death. They reported periods of intense crying and overwhelming distress. Some parents chose to hide this grief from their children for fear of causing their children any distress.

However, research would indicate what appears to be an important aspect of children's grief is the parental ability to share their grief within the family unit (Bugge et al., 2014; Jonas-Simpson et al., 2015; O'leary & Gaziano, 2011). Data from this study supports this with parents reporting times of crying together and sharing moments of expression of grief with their surviving children. Bugge et al. (2014) in their study on young children's grief also reported on the close connectedness of parental grief with their child's grief. In our study, findings show that some parents allowed their children to bear witness to their grief and thus allowed their children to know that it was normal to be sad, to cry and to miss their baby brother or sister. What we can understand from this, is that this parental expression of grief gives permission to their children to also grieve and, further, confirms that this emotional expression is both valid and important.

Interestingly some parents in this study were unable to recall how they told surviving children that their baby brother/sister had died and had little memory of how their surviving children responded to being informed of their baby brother or sister's death. Research undertaken by Fernandez- Sola et al. (2020) echo the findings of this study

with regard to parental communication with surviving siblings. "In most cases, parents failed to inform their children of what happened. They omitted information and avoided facing the difficult moment of telling their children what really happened." (Fernández-Sola et al., 2020)

Some parents in the study referred to being concerned about the language that they should use with their children as it might frightening or overwhelming. Barnardos Children's Bereavement Service (2023) outline the need to be honest and open with children about death. These include being careful about the words parents use when explaining death. "Use the words dead and died. Children can become confused with the less factual words or concepts" (Barnardos Children's Bereavement Service, 2023)

The importance of healthcare professionals providing comprehensive pyscho-education on children's grief responses must remain a priority in the care and support given to all parents experiencing a perinatal death where there are surviving siblings. Findings in this study reflect those of other research on the importance of supportive healthcare professionals, who can provide sensitive and timely support to parents in their grief. (Neelam & Zoe, 2022) Fanos et al. (2009)also reported that clinicians should allow siblings to be active participants in the infant's brief life and death. Given the outcomes of this study, it is important that staff in maternity units working with families experiencing perinatal death are provided with adequate training not only on parental grief, but also on the need to involve siblings and how to support and guide parents around this. This research emphasises the need for sensitive and skilled practitioners who not only support parents in their grief but also guide parents in the sensitive and appropriate involvement of siblings in their baby brother's/sister's short life and death. Healthcare professional training on perinatal loss must also encompass the needs of surviving siblings to ensure a holistic and family approach to perinatal loss. O'Connell et al. (2016)in their study on caring for parents at the time of stillbirth, cited that, parents stated that the "highest satisfaction was reported on the dedicated postnatal bereavement ward where midwives are trained and experienced in perinatal medicine". This exemplifies the importance of having trained and skilled practitioners in maternity units who can provide holistic support to families experiencing perinatal death.

A significant aspect of surviving children's grief that is also presented in this study was that of the surviving siblings' experience of disenfranchised grief. Researchers have previously identified the prevalence of disenfranchised grief in sibling's experiences of perinatal loss (Avelin et al., 2014; Jonas-Simpson et al., 2015; Robinson & Mahon. 1997). This theme is also reflected in a study by Wallace Chi Ho Chan (2022) who found that bereaved parents were often unaware of the grief of the bereaved sibling. Aspects of disenfranchised grief were also seen in the data collected in this study in that children's loss was not perceived as being a valid loss as the children were not seen to have a relationship with their deceased baby brother or sister. Many were not given the opportunity to grieve. Some parents in this study believed that this perinatal death did not represent a "real" loss for the surviving sibling as they did not know their baby brother/sister. Some parents also endeavoured to instil normality in the home by

not talking about the death of the baby in an effort to protect their child from the pain of their grief. Bugge et al. (2014) echoed this in their research stating that some parents believed that their child was too young to remember and as they were not asking questions, they were unaware or not thinking about their baby brother/sister.

Changed behaviours is another response that is noted in the literature on children's grief. Only one parent in the study clearly reported changes in behaviour of their surviving children after the death of their baby brother/sister. Nevertheless, it is important to consider that changed behaviours can also be unnoticed by bereaved parents as they themselves may be coping with intense emotional dysregulation. Research highlights the need to support parents to attune to their child's behaviours and understand the underlying causes for this behaviour. This attunement happens when "parents respond to the emotion underlying children's behaviour, rather than simply reacting to the most notable or distressing symptoms" (Blaustein & Kinniburgh. 2010). Again, this can only be achieved through providing parents with support from suitably trained professionals so that they are emotionally more available to their children and have appropriate psychoeducation on children's grief. The findings in this study revealed situations where parents were uncertain of what a child's behaviour signified and a subsequent mis-attunement in parental responses occurred. Wallace Chi Ho et al. (2022) also outlined the "importance and relevance of supporting the bereaved parents, to enhance their own capacity to support the bereaved siblings".

There is much research ascribing to the concepts of enduring bonds, connectedness and evolving bonds in grief (Cameron Meyer & Carlton-Ford. 2017; Kempson & Murdock. 2010; O'leary & Gaziano, 2011; Packman et al., 2006). This however creates a challenge for many families in the context of a perinatal loss, where the surviving sibling has not known their deceased baby brother/sister. Parents in our study encouraged their children in the use of mementos to nurture this enduring bond and facilitate an evolving imagined bond through objects such as teddies, clothing and photos. O'leary and Gaziano (2011) described these tangible objects as providing opportunities for surviving children to "attune to their baby brother/sister's spirit and allowed for a uniquely crafted emergent relationship that evolves over the years". In our research, this is seen in parents who encouraged and facilitated their surviving children to engage in memory making and new traditions which remembered their baby brother/sister. This ongoing lived connection provides families with important opportunities for shared grief and to talk about shared feelings of sadness and loss.

## Strengths and Limitations

There is a paucity of research on the impact of perinatal death on children. This study has highlighted the needs of these often-forgotten grievers of perinatal death. It has provided the opportunity to consider the impact on surviving siblings when the much-anticipated baby does not come home. The use of thematic analysis in gathering qualitative data through open ended questions allowed for a richness and depth in understanding the experience of surviving siblings of perinatal loss. A larger sample

would provide for an even richer and more in-depth understanding of the impact of perinatal death on children. This study also recruited from one geographical demographic and all families had attended the same maternity unit. Similarly, all participants were of white-Irish ethnicity (except for one individual), over 25 years of age and from a household of two parents (co-parents) where at least one was employed. A wider cross section of families attending different maternity units, from different ethnic and socio-demographic background and perhaps representative of different family structures would create more expansive and representative data on children experiences. The current study is, however, the first exploratory view on this issue in Ireland.

Additionally, it is important to consider that the ages of the children included in the study ranged from 3 to 16 years. Children at different developmental ages have diverse grief responses (Favazza & Munson, 2010) and so, this study may capture a wide range of reactions to sibling loss, representative of the variety of ages included. Hence, further research delving deeper into the siblings' reaction to loss within specific age groups would be relevant.

Future studies in this area should also consider including the voice of the children. Having involvement of children and details of their personal experience would add to the data and provide a deeper understanding of children's experiences.

## Implications for Practice

The role parents play in their children's grief must be considered when supporting families in perinatal death. Parents serve as primary educators and role models in all aspects of their children's lives. In the same way that children learn about cultural and family values through their parents and significant adults in their lives, children will also learn how to grieve through their parents and significant adults in their lives. How parents grieve, value rituals of death and nurture enduring bonds, will have an effect on their children's ability to grieve the loss of their baby brother/sister.

Healthcare professionals can have an impact on this by helping parents understand their own grief and the significant role they play in their children's grief. The importance of empathic healthcare professionals supporting families experiencing perinatal death cannot be emphasised enough.

The findings of the study indicate that there is a need to involve the surviving siblings and keep them in mind when supporting bereaved parents in perinatal death. The need to provide accurate, developmentally appropriate information on children's grief should be a key element of care when working with families who experience perinatal death. Remembering a dead sibling and the circumstances of that sibling's death is a way of somehow keeping the person alive. As Rowe said so beautifully, "If no one remembers us we have well and truly disappeared". Rowe in (Kempson & Murdock. 2010)

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