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UCC
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Coláiste na hOllscoile Corcaigh

Hidden Grievers: Supporting siblings through perinatal loss- a parent's perspective

Lucy Mulvihill

CARL Research Project
in collaboration with
Féileacáin

CARL
COMMUNITY - ACADEMIC
RESEARCH LINKS
University College Cork, Ireland

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Date completed:	April 22nd, 2020

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- provide their services on an affordable basis;
- promote and support public access to and influence on science and technology;
- create equitable and supportive partnerships with civil society organisations;
- enhance understanding among policymakers and education and research institutions of the research and education needs of civil society, and
- enhance the transferrable skills and knowledge of students, community representatives and researchers (www.livingknowledge.org).

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Declaration of Originality

I hereby state that this research project titled 'Hidden Grievers: Supporting siblings through perinatal loss - parents perspective' submitted to the School of Applied Social Studies, University College Cork, in partial fulfilment of the requirements for the award of 'Masters in Social Work' is my own work.

Throughout this research project, work that is not my own, has been acknowledged and referenced appropriately. This dissertation has been submitted through TurnItIn and any changes necessitated by the originality report generated, have been addressed.

Name: _____ Date: _____

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Firstly, I want to thank all the participants of this research. Thank you for trusting me to carry your experiences throughout this project. Thank you for voicing your own experiences and those of your children. Please know that it is through your bravery and honesty of sharing the stories of your loved ones and families that this research can work towards furthering services such as Féileacáin in supporting siblings into the future.

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This is dedicated to you.

This research project is dedicated to:

Baby Ross Paul Mulvihill

26/6/01 – 3/7/01



Abstract

This research aims to gain a better understanding of the experiences parents have when supporting their other children through a perinatal death in their family. It looks to establish awareness of the possible impact perinatal death has on other children within the family. It examines the difficulties that arise for parents and siblings at the time of perinatal death in the family. It explores the support provided by Féileacáin to families in relation to children within the family. The research conforms to social constructivism, an interpretivist approach and a community-based research process. This research was undertaken in collaboration with Féileacáin and completed as part of a CARL initiative in UCC. The research was completed through an online questionnaire which elicited responses from 20 participants. These responses were thematically analysed into four themes. The findings illustrate the importance of communication, sibling involvement, professional support structures and long-term support when supporting siblings through perinatal loss. A number of recommendations were suggested in the final chapter. It is hoped that this research and recommendations will assist in generating much needed data that will inform and identity future service requirements for siblings experiencing perinatal loss.

Glossary of Terms and Acronyms

Perinatal Death: A stillbirth or death of a baby within the first 2 weeks of life (WHO, 2018).

CARL: *Community Academic Research Links*

UCC: *University College Cork*

WHO: *World Health Organisation*

HSE: *Health Service Executive*

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Chapter One: Introduction

1.1 Introduction:

This chapter introduces the chosen research project '*Hidden Grievers: Supporting siblings through perinatal loss - a parents perspective'* which was completed in collaboration with Féileacáin, through the CARL initiative.

1.2 Background to the research:

This research project is completed in collaboration with Féileacáin as part of University College Cork's (UCC) Community Academic Research Link (CARL) initiative. This involved a community-based research process that offered the opportunity to work collaboratively with a community organisation, such as Féileacáin, while carrying out a piece of research. By completing this research with Féileacáin, I will be giving back to the community. I will be helping an organisation complete beneficial research for their service users. As a future social work practitioner, I recognised this opportunity would utilise the completion of my research project to benefit those in the community, an opportunity I could not ignore.

Féileacáin is a national organisation that supports families who have experienced a death of a baby before or shortly after pregnancy. Féileacáin works with 19 maternity units and two children's hospitals in Ireland. The organisation offers a range of supports to parents, siblings and broader social networks of bereaved parents.

There is some albeit little research surrounding the supports provided to siblings through perinatal loss. Research completed discussed "the importance of helping parents with their children, not just around perinatal loss, but death and dying, in general" (O'Leary & Gaziano, 2011). This involves letting the sibling be involved in the process of grief. "Involving siblings after stillbirth has been stressed as important to enable them to understand what has happened" (Avelin, Erlandsson , Hildingsson, & Rådestad , 2011).

The research project, in collaboration with Féileacáin explores how siblings were supported at the time of perinatal loss in their families. Given the sensitive nature of the topic, for ethical reasons interviewing siblings was not possible. Therefore, given this limitation the community organisation and the researcher decided to generate data on the topic by gathering the parents' perspectives of supporting siblings through perinatal loss.

1.3 Research Rationale:

It is important to acknowledge the personal connection the researcher has to the chosen research project. The researcher personally recognises the importance of organisations supporting families through a loss of a baby, not only for parents but other family members such as siblings. The researcher was determined to avail of the opportunity to collaborate with Féileacáin. The researcher had previously completed her own personal research into perinatal death of siblings. The researcher recognised the need for current research around supports provided to siblings. Research had been completed on the effects of perinatal loss on siblings, however little was completed on how to support them. Through discussions with Féileacáin and the research supervisor the proposed research project was agreed. Supports for families experiencing perinatal loss are reported to be slowly improving however, Féileacáin recognised that siblings were often missed or forgotten and therefore can become 'Hidden Grievers'. Féileacáin wanted to understand the level of awareness from parents and external systems in relation to the effects of perinatal loss as well as the level of supports siblings receive. This research rationale is to provide much needed data for Féileacáin to identity future service requirements for siblings experiencing perinatal loss.

1.4 Research Aims and Objectives:

The aim of this research project is to generate much needed data that will inform and identity future service requirements for siblings, by gaining a better understanding of the experiences parents have when supporting their other children through a perinatal death in their family.

The core objectives of the research project are as follows:

1. To establish the awareness of the possible impact perinatal death has on other children within the family.
2. To explore the difficulties that arise for parents and siblings at the time of perinatal death in the family.
3. To explore the support provided by Féileacáin to families in relation to other children within the family.

1.5 Research Questions:

The research questions deriving from the research objectives are as follows:

1. Were parents aware of the potential impact of the loss on their children at the time of the perinatal death?

2. Were other organisations e.g. hospitals, schools and extended family members aware of the impact of the loss on the other children of the family?

3. How were parents supported by Féileacáin in relation to other siblings within the family?

4. What were the challenges that parents faced at the time of the perinatal death in relation to their other children?

1.6 Research Project Outline:

Chapter 1: *Introduction* - This chapter introduces the research project. It provides an outline of the background and rationale for completing the research . It outlines the aim, the objectives and the research questions underpinning the study.

Chapter 2: *Literature Review*- This chapter provides relevant literature in relation to the research topic, specifically in relation to X.

Chapter 3: *Methodology*- This chapter discusses the methodological approach taken within this research piece. It outlines the researchers theoretical and epistemological perspective in relation to the research topic and the methods used throughout the project. It includes the ethical considerations and the process taken for completion of this research.

Chapter 4: *Findings and Analysis* - Chapter four presents the analysed data that was collected through the online questionnaire. The data will be analysed through thematic analysis. This analysed data will then be discussed in relation to the research shared within the Literature Review.

Chapter 5: *Conclusion and Recommendations*- This chapter draws on the literature and online questionnaire results, to conclude the research project. This chapter includes proposed recommendations in relation to practice and further research of the overall topic. This chapter finishes with a reflective piece on the researchers experience of completing the project.

1.7 Conclusion:

This chapter gave an overview of the chosen research project. It provided a deeper understanding of the project by discussing the background and rationale for completing the research. It outlined the aim, the objectives and the research questions underpinning the study and concluded with a chapter outline.

Chapter Two: Literature Review

2.1 Introduction:

This chapter will give the reader an in-depth understanding of the literature surrounding supports provided to children experiencing perinatal loss. It will discuss theory surrounding children's grief and ways in which their parents can best support them through this. It will also explore the literature surrounding external supports for children such as hospitals, schools and Féileacáin.

2.2 Children's grief:

This research project explores the supports provided to siblings through perinatal loss. Supporting children through perinatal loss means supporting them through their grief. It is important to note that children do grieve. Each child will grieve in their own unique way and this will be influenced by numerous different factors (Heath, et al., 2008).

Grieving by Age: Children grieve differently depending on their age (Capitulo, 2005). Like adults, children grieve, and this can be a confusing experience for them. Young children need time to understand fully what has happened, therefore they may continue to ask difficult questions and need a lot of reassurance (Pettle & Britten, 1995).

Research has shown that young children are usually hyper aware of those around them and end up displaying their grief through sadness, anger or withdrawal (Capitulo, 2005). They may not have a full understanding of the reality of death, however, they do grieve and recognise the change in both themselves and their environment.

Middle aged children "gradually absorb the irreversible, universal elements of death" (Pettle & Britten, 1995, p. 397). They slowly gain an understanding of what is happening around them. This developing understanding can be expressed through anxiety, confusion or sadness (Capitulo, 2005). They begin to understand that the person is not coming back. This understanding can be supported by concrete explanations from those around them (Capitulo, 2005).

Into adolescence, teenagers begin to have a full understanding of death, however, in doing so they are also "realizing their own mortality and that of those dear to them" (Pettle & Britten, 1995, p. 398). They can express this understanding through denial or numbness before entering a phase of sadness or depression (Capitulo, 2005). Older adolescents have their own thoughts and understandings of death

also. They will also be very aware of the explanations and support given to them by those in their surroundings. These can be either conflicting or comforting (Pettle & Britten, 1995). Older adolescents generally express clearer feelings of anger, depression and bitterness (Capitulo, 2005).

Individual Grief: While research provides understandings of grief in accordance with age, it also highlights that "each child needs to be respected as an individual" (Pettle & Britten, 1995, p. 398). Equal attention should be given to other factors such as social environment and behaviours displayed when trying to understand and support a child through their grief. (Heath, et al., 2008) discuss how children's cultures and gender can have an effect on their grief responses. For example, some males may be taught to be strong for those within the family and show their emotions less than females. Other cultures or families may encourage emotion and openness (Heath, et al., 2008). It is important to mention, there is no right way of grieving and each individual will grieve different and in their own way. What is important is for those around them to understand and support their grief.

Long-term Grief: Research shows that sibling loss can affect people into the future as well as at the time of loss. A study completed by (Fanos, Little & Edwards, 2009) stated that siblings expressed themes of anxiety after losing a sibling in neonatal units. Themes included, their mothers health, their own health and future pregnancies also (Fanos, Little & Edwards, 2009). Similarly "Callister (2006) found that siblings in grief after a perinatal loss experience disappointment and sadness that might entail a feeling of helplessness over a long period of time" (O'Leary & Gaziano, 2011, p. 174). This recognises the long-term effect of sibling loss and highlights the importance of continued long term supports.

Associated Loss: Siblings often have to deal with their own grief and the grief of people close to them. Children are more in tune to their surroundings and especially adult figures in their life. (Bennett, Litz, Maguen & Ehrenreich, 2008, p. 487) mentioned that "siblings of an infant who dies are also affected by their own sadness and/or the grief and sadness they witness around them (Balk, 1991)". This can be due to their awareness of other people's emotions and social responses. Other research stated that "the grief process in children is often complicated by feelings of loss, guilt as well insecurity about their parental wellbeing" (Hendeson, Minchella, & Vasudevan, 2017). As mentioned above siblings are often not only experiencing the loss of a brother/sister but sometimes a form of parental loss. Given the stress and shock of the loss, "parents may have difficulty supporting their children during this difficult time" (Bennett, Litz, Maguen & Ehrenreich, 2008, p. 487).

2.3 Parents supporting children through grief:

Communication: (Avelin, et al., 2012) completed a study which involved parents advice in relation to supporting their children through perinatal loss. The study suggested that, "When it comes to facilitating the grieving process for a child, communication between parents and the child is very important" (Avelin, et al., 2012, p. 90). Other research shows that communication is important for children to understand their grief. The main route of communication for most children are adults or primary care givers. "Even though adults want to be supportive, they often feel uncomfortable, discussing death and may not know how to answer children's questions" (Heath, et al., 2008, p. 263). Research gives advice for adults communicating to children about grief and death.

It is important to remember that " a child's grief and pain are caused by the death- not by talking about it" (Schonfeld, 2019, p. 75). Research suggests that parents should be open and honest with their children as early as possible (Avelin, et al., 2012). This will allow the child to understand changes in surroundings, feelings and behaviours of themselves and those around them. When doing this, adults should take time and give correct and honest information to the child. It is important to use clear language that they'll understand (Avelin, et al., 2012). While it can be the natural instinct to tell children abstract explanations such as 'they are gone for a long sleep' this must be avoided. This can be confusing for children. (Avelin, et al., 2012, p. 94) states that " Abstract explanation should be avoided, and the word death should be used". While the initial conversation may be difficult for parents, it's important that they continue to check in with their child and be open to further questions (Avelin, et al., 2012).

Children's involvement: In the study completed by (Avelin, et al., 2012, p. 93) " The parents advice was to involve the siblings and let them join in, for them to understand what is happening". Participation can be involvement in the funeral, preparations for the funeral, a family gathering or even a mass. This may be uncomfortable for most parents. However, research suggests it can be helpful to " encourage the siblings to participate on their own terms" (Avelin, et al., 2012, p.94). It is important to respect the child's option to participate by gathering their understanding and wishes surrounding their grief. This engagement can make the death real for the sibling.

Research suggests that preserving memories can help "the siblings retain the dead little sister or brother in their memory as they grow older" (Avelin, et al., 2012, p.94). This helps the sibling cope with their grief and give them ownership of their connection. They not only have lost their sibling but the role they took on of becoming an older sibling through their mothers pregnancy. "It is important for them to

be given the opportunity to tell others that they have become a big brother or sister" (Avelin, et al, 2012, p. 94). Memory preservation can be completed by celebrating birthdays and acknowledging anniversaries (Bugge, Darbyshire, Rokholt, Haugstvedt, & Helseth, 2014). Other " mementos may include hand and footprints, a lock of hair or hospital bracelet" (Hendson & Davies, 2018, p. 550).

"The presence of a trusted adult whose primary concern is the child and not their own grief is essential for their support" (Pettle & Britten, 1995, p. 399). This may not always be possible for parents, especially in the early days of the death of their child. This is where the support of health care professionals, organisations such as Féileacáin and other external supports is vital for siblings.

2.4 Support from Health Care Professionals:

The research completed in relation to the role of health care professionals in supporting siblings through perinatal loss is limited. The broad advice relates to communication, awareness and professional responsibility.

Open discussions: It is important for health care professionals to have open discussion with families surrounding their bereavement. They will be the first point of contact the family have following their loss. "Professionals dealing with sudden or unexpected deaths could also take the opportunity to enquire about children" (Pettle & Britten, 1995, p. 401). Professionals should practice asking parents if the children will be involved and how they want to approach this. Professionals should have an awareness of conversations already undertaken surrounding the children (Cole, 2016). Professionals should become aware of how the family wants to involve the child in the management of the death It is essential to acknowledge the cultural beliefs of the family also. "There are important cultural differences in how death, and particularly the death of a baby, is managed" (Hendson & Davies, 2018, p. 550).This is essential knowledge when supporting a family through their loss.

Acknowledge the siblings: When professionals are dealing with families of perinatal death it is important, if the families wishes, to give time to the children. "The impact of infant bereavement on siblings also warrants attention" (Hendson & Davies, 2018, p. 551). As mentioned above children may need to have repeated conversations to come to terms with their loss. Once the professional has checked in with the parents, they too can help support children within the family. Speaking to a working professional can make the understanding more real for children This can also " help parents understand how other children may be interpreting the death" (Hendson & Davies, 2018, p. 551).

External Supports: Another important aspect of a professionals role is providing information on external supports. These can include, "family friends, co-workers, health care providers and support groups" (Hutti, 2006, p. 633). Parents have to deal with their own grief and their child's grief. This is a heavy task to take on alone. Research has shown grief is an ongoing process therefore supports are needed beyond the hospital. "Health care providers should encourage couples to ask for and accept help from a variety of sources" (Hutti, 2006, p. 633). This is important to allow all family members to come to terms with their grief.

Standards of Care for siblings: Standards for bereavement care were established and published in 2016 by the HSE. This document is known as the National Standards for Bereavement Care Following Pregnancy Loss and Perinatal Death. Within this document there are four standards in relation to bereavement care, the hospital, the baby, the parents and the staff ((Health Service Executive, 2016). Siblings are mentioned briefly within the Bereavement Care Standard. Under Bereavement Care, Time of Diagnosis, it states that "Parents are offered access to the BST for support and guidance in relaying the loss to siblings. Involvement of the siblings is considered in accordance with the parents' wishes." (Health Service Executive, 2016, p. 18). Under Bereavement Care, Treatment Options it states, "When parents have chosen to continue their pregnancy, and as part of palliative care approach, they will meet with a member of the Bereavement Specialist Team (BST) for anticipatory care inclusive of; … sibling involvement in accordance with parents' wishes and consent" (Health Service Executive, 2016, p. 21). Also under Bereavement Care it mentions that all parents, siblings as well as extended family are offered support and provided with information via leaflets and verbal communication. This completed to ensure that the supports available in the hospital and community are made known to the family (Health Service Executive, 2016). The researcher recognised that despite siblings being acknowledged in the document, it did not incorporate specific guidelines for health care staff dealing directly with siblings experiencing perinatal loss.

2.5 Support from schools:

Importance of schools: A study completed by (Dyregrov, Endsjo, Idsøe, & Dyregrov, 2015, p. 290) stated that "it is generally considered desirable that bereaved children resume schooling soon after a death in the family, and so the need for support from the school is essential". There is a lack of literature in relation to school support for children experiencing perinatal loss. However, there is available literature on support of general grief of children within schools.

Current literature would suggest that teachers acknowledge the importance of supporting children through grief, however there is a lack of protocol and knowledge surrounding it. (Dyregrov, Dyregrov, & Idsoe, 2013) completed a study on teachers perceptions of their role supporting children in grief. The participants acknowledged the importance of the school environment for children who are grieving. They acknowledged that the school is a place where children spend a great deal of time. It can be a " reality away from the sad circumstances in the home of a bereaved family" (Dyregrov, Dyregrov, & Idsoe, 2013, p. 130). The strong support of trusted adults (teachers) and their peers can be vital for a child to feel supported through their grief when away from their family and getting back to their normal routine (Dyregrov, Dyregrov, & Idsoe, 2013).

Information and Training: While the literature highlights the awareness surrounding the importance of school for children grieving, it also recognised the expressed need for clear outlined procedures for teachers supporting these children. Teachers have expressed a lack of knowledge and awareness around the approach/ steps to take when dealing with children experiencing loss. Throughout the literature there was an echoed need for " a template or a formula of how to respond to a bereaved student" (Dyregrov, Endsjo, Idsøe, & Dyregrov, 2015, p. 292). The demand for training and information for teachers was clear. In fact, most respondents to the study "claimed that the topic of grief in schools should be given a higher priority then was currently the case" (Dyregrov, Endsjo, Idsøe, & Dyregrov, 2015).

The information required relates to the effects of grief on children, the behaviours expressed, and effective supports individuals can offer in such circumstances. A folder was suggested by one participant to have within the school containing advice, information, policies and procedures for children experiencing grief within the classroom (Dyregrov, Endsjo, Idsøe, & Dyregrov, 2015). It is clear from the literature that if information and training was readily available to teachers then they would feel more confident in approaching the grief with the child, therefore increasing their chances of effective supports within school. It was suggested that contact to " support groups for grieving children would ease the pressure for the school to act upon bereaved students" (Dyregrov, Endsjo, Idsøe, & Dyregrov, 2015, p.

297). This would enable teachers to get support and information as well as have a direct link to refer students if needed.

2.6 Support from Féileacáin:

Acknowledging the other children: "The impact of the loss of their little brother or sister on older siblings is immense, and they are often forgotten about during the trauma of infant loss" (Féileacáin, 2018). Féileacáin recognises the impact perinatal loss has on siblings within family. It has numerous supports in place for siblings. (Pettle & Britten, 1995) discuss the positive impact bereavement groups can have for young children by reducing their sense of isolation. Féileacáin offer opportunities for siblings to meet other children who have had similar experience of perinatal loss. Féileacáin also offers play therapy to children. This allows for an " exploration of a child's feelings and beliefs and fantasies" surrounding the death of their sibling while in a safe supported environment.

Continuing Bonds: Féileacáin does not only support the child's grief. They state that they work to acknowledge the child's role of being a big brother/sister. According to (Avelin, et al., 2012, p.94) "Elder siblings must be allowed to feel proud". Féileacáin facilitates this by providing sibling teddy bears to hospitals for siblings experiencing a loss (Féileacáin, 2018). This shows respect and marks the child's connection to their sibling. Féileacáin supports this connection further through memory making for families through Gifts of Remembrance. These include, memory boxes, cuddle cots, clay imprints of the child's hands and feet, remembrance candles and photographs (Féileacáin, 2018). This is "acknowledging the stillborn baby by letting siblings create, collect, and preserve memories" (Avelin, et al., 2012, p.94). This process of remembrance is continued through remembrance services held by Féileacáin, where families come together to remember their loved ones. Féileacáin offers indirect support in relation to siblings through their parents. They provide a support leaflet in relation to supporting other children and a telephone service which is available for support and questions (Féileacáin, 2018). According to (Dyregrov, Dyregrov, & Idsoe, 2013, p. 129) "people in crisis are not supposed to be abandoned and let alone in their crisis". Féileacáin acknowledges this both for the siblings and their wider family.

2.7 Conclusion:

This chapter introduced the reader to the context from which this research project stems. The above literature has been considered in developing the online questionnaire which explores parents experience of supporting their children through perinatal loss. The methodology of this research will be presented in the following chapter.

Chapter Three: Methodology

3.1 Introduction

This chapter outlines the methodology and the methods employed in the research process.

3.2 Epistemological and Theoretical Perspectives:

This research chose an epistemological approach of social constructivism leading to interpretivism.

Epistemological approach: Epistemological approaches look at how we gather knowledge about the social world (Ritchie, Lewis, Nicholls, & Ormston, 2014). This research aimed to explore the experiences of parents supporting their children through perinatal loss within their family. The decision to examine the parent's perspective in this study was chosen for ethical reasons which will be discussed later in the chapter. In doing this, the researcher acknowledged that the experiences of participants, while similar, can have multiple representations and therefore decided to adopt a social constructivism paradigm in the research. Social constructivism is an approach to knowledge that seeks to inquire into how people make sense of their own experiences (Carey, 2009). In the study there are different levels of diversity throughout the data received. The experiences of participants taking part in the research differ. For example, individuals may grieve differently therefore they will make sense of and experience the loss of their loved one differently. There is also a difference in the level of supports utilised and received by participants. Given the different experiences of participants, the data obtained through the primary research can be described as socially constructed. Therefore the chosen epistemological approach to this research is social constructivism.

Theoretical Approach: The theoretical approach to this research is interpretivism. According to (Carey, 2009, p. 53) "Interpretivism attempts to uncover the meaning and 'reality'(or interpretation) of people's experiences in the social world". The researcher endeavours to understand the opinions, emotional responses and attitudes articulated by the participants. As the research was interested in participants experiences , the researcher took an interpretivist lens in the study, this means gathering and interpreting peoples experiences and how they felt in relation to these experiences.

The research questions emerged in consultation with the CARL partner. The data collected was from the parent's perspective which was then interpreted in the final findings and recommendations. This was all completed so that the experiences of the participants and their children can be acknowledged and highlighted throughout the research.

3.3 Methodology:

"Methodology influenced by interpretivism will emphasize the importance of meaning, identity and personal experience to research participants" (Carey, 2009, p. 90). Therefore, as this research took an interpretivist approach, the researcher chose to complete primary research through the CARL Project initiative. Primary research was chosen as the researcher recognized the need within research literature to voice the experience of siblings who have lost a sibling through perinatal loss. The researcher initially wanted to interview siblings, however, for ethical reasons this was not appropriate or possible given the sensitive nature of the topic, this will be discussed under limitations of the study bellow.

3.4 Methods:

Given the limitation mentioned above, the researcher and the community organisation decided to generate data on the topic by gathering the parents' perspectives on the topic This involved gathering direct experiences of participants through a chosen qualitative method. The chosen qualitative method for this research was an online questionnaire, produced through Microsoft Forms (See Appendix 1).The researcher wanted to ensure that the chosen method would gather personal experiences of participants in detail while respecting the sensitivity of the topic. The questionnaire was selected as the most appropriate data collection instrument to give the participants the space and time to answer the questions in private, given the sensitive nature of the topic. Undertaking personal interviews was discussed but rejected by the community partner and researcher , given the sensitivity of the topic.

3.5 Sampling:

Féileacáin identified the participants for the study from its closed data base. All participants were recruited through an online closed Féileacáin website. The organisation gave permission for this recruitment and nominated a liaison person from within the organisation for the study. All participants who took part in the research were supported by Féileacáin in the past. Each of the participants experienced their loss between the years 2012-2016. The rationale for this inclusion/exclusion criteria was to acknowledge that parents needed time to process their grief and loss before being asked to participate in the research. Therefore, all participants in the study were bereaved for over a period of 3 years. The participants in the study are parents who have experienced a perinatal loss and have other children. Both male (fathers) and female (mothers) participants were recruited. All participants are over the age of 18. Anonymity of all participants was maintained at all times throughout this project.

3.6 Data Collection and Analysis:

Data collection: The data collection method for this study was an online questionnaire. This online Microsoft Forms questionnaire was developed within the UCC-Office 365 suite. The questionnaire was reviewed by the UCC supervisor and Féileacáin before being shared with participants. As previously mentioned, all participants were selected by the community partner from their closed website. All questionnaires were completed anonymously through the Microsoft Forums link posted by the community partner within the Féileacáin closed database. Once a participant completed the online questionnaire, the researcher received notice within their UCC email that a response was complete. A total of 20 responses were collected through this process.

The Forms Questionnaire was set by the researcher to NOT log Names or email addresses. Therefore, the responses were recorded anonymously through the researchers UCC online Microsoft forms account, which is secured, and password protected. It is important to note also that the Questionnaire included the Participant Information Sheet, which informed participants that their names and email addresses would not be logged and a Consent Question for their participation within the study.

The collected data was only accessed by the researcher and the supervisor of the project. On completion of the research project, the researcher provided the data to a designated UCC staff for secure data storage within a protected UCC server, which will be destroyed after a minimum of 10 years to meet the UCC Code of Research Conduct requirement and CARL Project procedures. Once the data was provided to the UCC designated staff on completion of the project the Microsoft Forums Link was deleted. It has been agreed that a copy of the completed and published thesis will be shared with the organisation (Féileacáin). The raw data will not be available to the community partner and is the property of UCC.

Data analysis: The data collected was analysed using a mix of methods. The data gathered from the closed ended questions were analysed using the Microsoft Forms software. This data is presented using graphs in Chapter 4. The open-ended questions from the questionnaire were analysed using thematic analysis. “This approach attempts to look for specific identified themes within data…that can be used to generate debate and draw conclusions from” (Carey, 2009, p. 29). For this project it involved going through the participants responses and looking to identify continuing patterns. Once this step was completed, the researcher divided the patterns into possible themes. These themes were reviewed and broken down further. The four final themes will be identified and then analysed using the existing literature to inform the overall findings. The results will be presented in Chapter 4.

3.7 Ethical Considerations:

To complete this research project I had to receive ethical approval. I first began this process by applying to the School of Applied Social Studies Ethics Committee. The committee reviewed my application and advised me to apply to the Social Research and Ethics Committee (SREC). I completed the SREC application form as required. The committee responded with questions for clarification before granting approval. The first question was in relation to ensuring the collected data would not remain on the web server and how this was to be achieved. The second was a request to ensure participants have access to Féileacáin supports at any time during the project, before during or after. There queries were explicitly addressed and made clear in the amended information sheet. Firstly, the researcher made changes to the Information Sheet, making it clear that support was available throughout the entire process of the research for participants. Secondly, I explained in detail, the process of the online questionnaire through Microsoft Forms and how the questionnaire was set by the researcher to NOT log names or email addresses. Therefore, the responses were recorded anonymously through the researchers UCC online Microsoft forums account. SREC granted ethical approval for this project on the 18/2/20. Given the nature of the research topic, there were various ethical questions considered in the ethical approval process and during the completion of the project itself.

They were as follows:

- *Voluntary Participation:* All participants must do so on a voluntary basis. This was made known to participants by Féileacáin through the recruitment process. It was also achieved through the information sheet/ consent question which was to be read and completed by participants prior to completing the questionnaire.

- *Informed Consent:* It was my responsibility, as the researcher, to give each participant the time to understand what was involved before giving their consent to take part in the questionnaire. To ensure informed consent was given, several discussions were held between Féileacáin, the researcher and research supervisor. In the discussion, it was decided that participants needed a significant amount time to have elapsed since their loss to ensure they were able to give an informed consent. A clear description of what the study involved, and details of the requirements needed to take part were devised, participants must be bereaved for at least 3 years and be over the age of 18, they were identified through the Féileacáin's closed website and participants has to read the

information sheet. All participants had to complete a consent question before completing the online questionnaire.

- *Confidentiality:* All names and identifying information is excluded within the research. Names and all identifying information were changed for the purpose of preserving the confidentiality of participants.
- *Language:* Given the sensitivity of the topic, appropriate language was used at all times. This meant no use of discriminatory or insensitive language throughout the questionnaire and research project itself. This was completed through the support of Féileacáin.
- *References:* All works from other authors/researchers used throughout the research were acknowledged and referenced appropriately using APA.
- *Support of Féileacáin for the participants:* Given the sensitivity of the topic all participants had access to the support of the professionals in Féileacáin should they've needed it at any stage of their participation in the research project. The same support was available to the researcher.
- *Objectivity of the researcher:* To achieve this I kept a reflective research journal to examine my own position in the research throughout the research process. I also consulted with my UCC supervisor as part of the research process.

3.8 Reflexivity as the researcher:

"Reflexivity in a research context refers to the process of critically reflecting on the knowledge we produce, and our role in producing that knowledge" (Braun & Clarke, 2013, p. 37). This means looking at how we the researcher may influence the research being completed. For this research project the researcher had to be personally reflexive. "Personal reflexivity in research is about bringing the researcher into the research, making us visible as part of the research process" (Braun & Clarke, 2013, p. 37). Given the researchers personal experience of losing a sibling to perinatal death, the topic was extremely personal. However, as the researcher, she also had to acknowledge her own position in the research and reflect on how this influenced the research.

Personal reflexivity can be very positive for a research project if " used as part of a meaningful and engaged process that helps the author better understand and contextualise findings" (Carey, 2009, p. 163). The researcher completed personal reflexivity through a research journal where she recorded her thoughts, feelings and assumptions throughout the research process. This allowed the researcher to be in tune with any personal feelings in relation to the research process and the findings that were being

produced through the online questionnaire. The researchers personal reflexivity was also reflected on throughout conversations with both the research supervisor and organisation representative. These steps taken, allowed the researcher to acknowledge how her experience helped better understand the participants involved. However, adopting a reflexive stance, allowed the researcher to be aware of any personal bias throughout the research and helped her to manage her subjectivities when analysing the research findings.

3.9 Challenges and Limitations:

There are a few limitations/ challenges to the study that the researcher acknowledges. They are as follows:

- *Access to siblings:* The research project was interested in exploring how siblings were supported at the time of perinatal loss in their families. The researcher initially wanted to interview siblings but for ethical reasons this was not appropriate or possible given the sensitive nature of the topic. Given this limitation the researcher and the community organisation decided to generate data on the topic by gathering the parents' perspectives on the topic. Although this research is still of great value to Féileacáin, the researcher believes there is still a great need for direct research with siblings who have experienced perinatal loss. This will be discussed further in the recommendations in Chapter 5.
- *Research Method:* The online questionnaire was chosen to give the participants completing it the space and time to answer the questions in private, given the sensitive topic. This method was overall successful in keeping anonymity of the participants also. Overall, the researcher was happy with the level of data received. However, when reading the responses, the researcher found it hard not being able to probe certain responses further, given the responses were not given face to face. The response the participant submitted to the online questionnaire was final. Some responses were more in depth than others. This made the researcher question were people giving their full experience through the online method or would they have discussed more if in person.
- *Covid 19 Pandemic:* The researcher completed the thesis during the Covid 19 world pandemic. The Covid 19 restrictions limited the researchers access to various resources. There was no access to the UCC library, therefore, she had to rely on online articles via the UCC online Library or literature she had retrieved prior to the pandemic. The pandemic also limited the researchers access to face to face meetings with both her research supervisor and community partner of Féileacáin. These meetings were held online via Microsoft Teams or via email as a result. The

restrictions also limited the researcher in terms of her environment. The researcher was confined to her home throughout the research process which proved difficult at times for space and concentration.

3.10 Conclusion

This chapter set out the main elements of the research process which included description of the data analysis methods which research findings and conclusions have been drawn and will be presented in the final two chapters. A more in-depth discussion of the researchers experience of the research process will be discussed under the research reflection in Chapter 5.

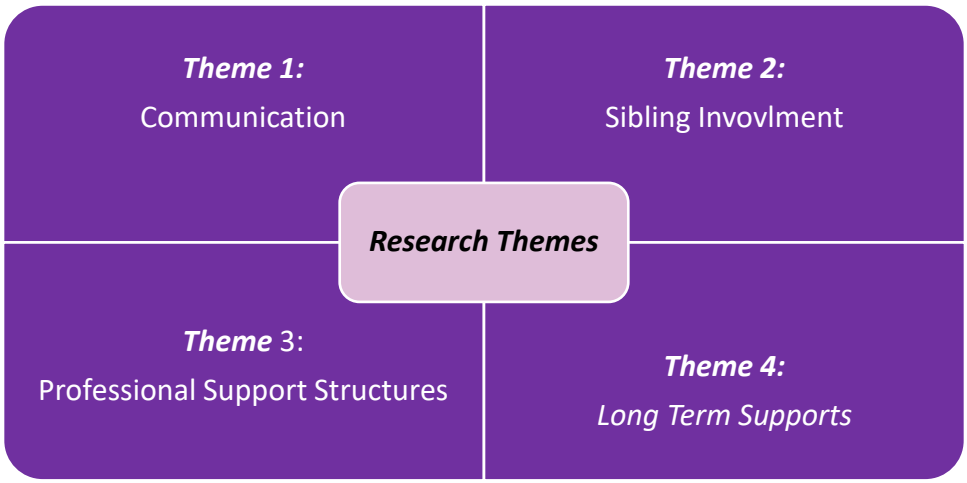
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Chapter Four: Research Findings

4.1 Introduction:

This chapter presents and discusses the research findings gathered from the online questionnaire. The findings are grouped thematically into four key themes based on sibling support through perinatal loss. For the purpose of confidentiality pseudonyms have been given to babies whose names have been mentioned in questionnaire responses.

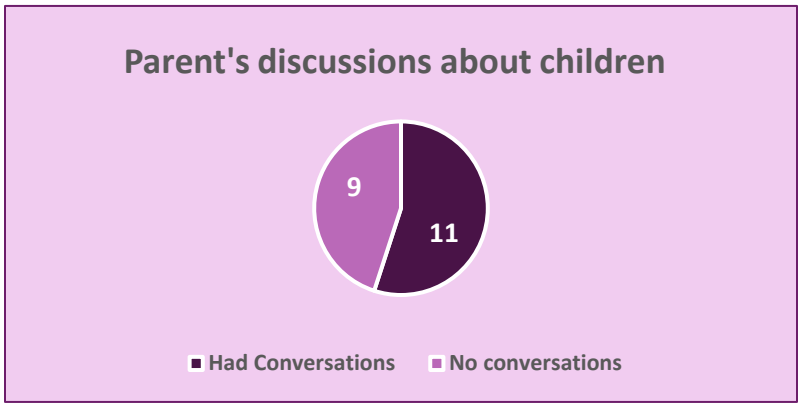
Figure 1: Research Themes



4.2 Theme One – Communication

Communication was a significant theme throughout this research. Participants were asked if they had conversations about supporting children within the family at the time of their baby's death. 11/20 participants questioned had such conversations, however of those stating yes, all had done so through support e.g. Féileacáin or the Bereavement Team within the hospital. Participants mentioned the importance of communicating with their children but highlighted the difficulty they had in doing so.

Figure 2: Parent's discussions about children



4.2.1 The Challenge of Communication for parents

Participants expressed the challenge they had in having conversations with their children surrounding the death of their child. For most participants they mentioned that they didn't know how to start the conversation as they were still in shock and coming to terms themselves. One participant stated:

> *"I was so shocked myself I don't know if I took it in that they would be badly affected. I didn't know what to do"* (P3).

Similarly another participant explained:

> *" I didn't know where to start. We were so shocked ourselves"* (P17).

The challenge of knowing what to say and not to say was faced by many participants:

> *" I was worried about how much information to give her"* (P8).

> *"We had 3 older children who were very excited at the thought of a baby. We struggled with how to tell them the baby would more than likely die before birth. How can you explain that?"* (P18).

There was a shared feeling of uncertainty around communicating with other children about the death of their family member. Parents expressed the need for support around knowing what steps to take. One participant expressed how a conversation with a member of Féileacáin helped her in relation to communicating with their other children:

> "*They gave me examples of how to tell the kids and how to comfort them"* (P18).

Another participant suggested a leaflet about approaching the conversation with other children.

> "*Even a leaflet to describe what to say, or don't say gone asleep or in the sky to help confusion*" (P6).

4.2.2 The Importance of Communication for siblings grief

Participants acknowledged the importance of communication for their other children at the time of their child's death. Participants described how their children had repeated questions and struggled to get a full understanding of what had happened:

" *Why Anna died, why she couldn't come back, how come the doctor couldn't help. Also it was very unexpected she was due to come home within days."* (P6).

"*My son could not understand why the baby was not coming home*" (P9)

"*Because she had survived the birth the kids thought that the doctors were wrong and that she'd survive"* (P18).

Participants reported children expressing a need for conversations around feelings and emotions surrounding their grieving process. Another participant mentioned the children's need for conversation surrounding the grief of those close them also:

"He wanted to know why mommy and daddy were so upset" (P10)

There was a collected belief that children speaking to other children through siblings groups was of huge benefit to children in their grief.

"*They love being part of the groups too where they can talk about the baby in an accepted and natural way"* (P19).

4.2.3 Discussion:

The findings highlight the importance of communication in supporting siblings through perinatal loss. Participants showed that children had questions surrounding the death of their sibling and processes that followed. The findings showed how important communication was to allow the sibling a chance to gain answers to these presenting questions. These findings can be supported by (Pettle & Britten, 1995) who states young children need time to understand fully what has happened, therefore they may continue to ask difficult questions and need a lot of reassurance (Pettle & Britten, 1995).

Participants explained how children had repeated questions after the death of their sibling. This

suggests that siblings need to have numerous discussions surrounding these aspects to fully understand the long-term outcome of what has occurred. This highlights the need for clear and honest communication with the children. Those supporting them should be clear on what they are explaining to the children to help them gain an overall understanding of the death. The need to avoid abstract explanations was also acknowledged by participants in communication with siblings about perinatal death. These findings are supported in the literature by (Avelin, et al., 2012) who explains the importance of clear and open communication and avoidance of abstract explanations.

Findings show that communication is essential for children to deal with their grief and feelings, as well as that of those close to them at the time of the death and after. In the literature, it states that children are hyper aware of the feelings of those surrounding them (Bennett, Litz , Shira, & Ehrenreich, 2008). Open communication can help siblings to understand these emotions and move on through the process of grieving.

Communicating to children about death is extremely difficult. Parents experience extreme challenges when speaking to their other children about their loss (Heath, et al., 2008). This was supported by the participants responses. Findings show the importance of supporting parents through this process to ensure support for other children within the family.

4.3 Theme Two – Sibling Involvement

The theme of sibling involvement can be seen throughout the findings of this research. In describing their experience of supporting their other children participants acknowledged the benefits of their children being involved in proceedings. This involved funerals and masses and continuing bonds.

4.3.1 Participation

Participants mentioned how they believed that participation in proceedings can be of benefit to the other children. Most participants suggested that they would involve their children more in the process if they had a chance to. They believed it would help them with their grieving and understanding of their siblings death. One participant gave this example:

> "*We did not bring Ruby to Molly's burial. The day after we visited Molly's grave Ruby was confused about whether Molly was in the ground or up in the sky in heaven. I think it would have been easier for her to have come to the burial to understand what was actually happening"* (P8).

4.3.2 Continuing Bonds

The research findings showed the significance of continuing bonds for siblings. This included the siblings participation in support groups and remembrance services:

"They find the Féileacáin meetings for their age validating" (P1).

"Jane loved being a part of the remembrance services where she could talk about her brother and say his name" (P17).

"They know that each event/ service or workshop is in memory of their sibling and this brings them closeness which is lovely" (P10).

Participants .acknowledged the importance of memory making for their other children. This was completed for most participants and their families through the supports of Féileacáin. This helped the children feel like they have a continued connection with their loved one and something to hold onto going forward:

"We have both our sons handprints and lovely pictures of them together taken by Féileacáin and this helped down the road" (P9).

It also respected their role as a big brother/sister which parents stated their children valued significantly:

"They received the big sister teddy bears which they adore" (P5).

4.3.3 Discussion:

Research findings show the importance encouraging sibling involvement when supporting siblings through perinatal loss. Participants mentioned that getting the children involved can help them gain an understanding of what has happened to their sibling. Similarly in the literature, (Avelin, et al., 2012) suggests that getting siblings involved can make the death real for the child. This can be scary for parents, but findings show parents now have a gained understanding of the possible benefits of this for their children in their grief. The literature also stated that it can be helpful to " encourage the siblings to participate on their own terms" (Avelin, et al., 2012, p.94). Parents know their own children and should have discussions to decide the best possible ways of involving them in grieving processes. Each family

will involve their own children differently to suit them.

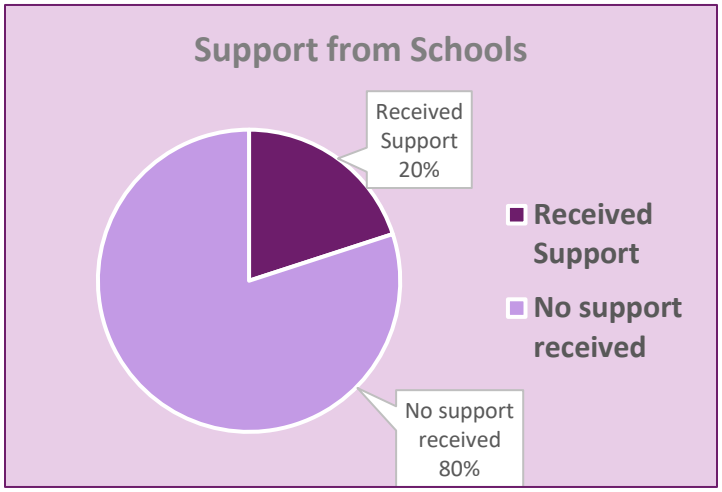
The research findings show that continued bonds allow a continued connection between the sibling and the baby who has died. The literature mentioned that this helps the sibling cope with their grief and give them ownership of their connection. They not only have lost their sibling but the role they took on of becoming an older sibling through their mothers pregnancy (Avelin, et al., 2012). Participants gave examples of this being practiced within their families through Féileacáin's sibling teddy bears. Literature states that this can be achieved through other mementos such as "hand and footprints, a lock of hair or hospital bracelet" (Hendson & Davies, 2018, p. 550). Some of which were mentioned by participants as beneficial to their families within the findings also.

4.4 Theme Three – Professional Support Structures

4.4.1 Schools

Research findings show that 80% of participants did not receive support from their children's school in relation to their children and the death of their sibling.

Figure 3: Support received from schools



Research findings revealed that those who received support from schools had to request the support for their children:

"*I insisted that they be included in a Rainbows programme, but I had to fight to get them in!"*(P13).

"At my request for them to be able to talk about their feelings I asked that they attend Rainbows"(P5).

Research findings show that participants who received positive support from professionals within the school noticed the people who provided the support had similar personal experiences. This would suggest that the professionals personal experience increased their awareness of the child's needs at that time:

*"We had linked in with the principle prior to Kate's death and he was very understanding, sadly he lost a baby a number of years ago. The girls teachers were informed, and we were reassured if there was any change in their behaviour or any issues they would contact us straight away"(*P11)

"*One of the boys teachers was good- I think she would have had some experience of loss herself. But the other boys had a really hard time."* (P12)

"The teacher of our second child was a bereaved parent herself and was very understanding and supportive" (P18)

Participants who did not receive support from their school highlighted the need for professionals within schools to have a greater awareness of the impact perinatal loss can have on children. Many had experienced lack of awareness from teachers towards their children within schools:

"We had to phone the secondary school as the teenagers were getting grief over their schoolwork. No account was taken of the fact that their brother had died, one teacher said to my daughter that miscarriage is common, and we must move on!" (P3)

"*A lot of the teachers hadn't a clue- how would they??? I didn't have a clue myself until it happened to me."* (P20).

Participants also addressed the demand for training to be provided to teachers and staff around perinatal loss and the long-term effects it can have for children they work with:

"*Schools haven't a clue how strong an impact there is on bereaved siblings, all the anxieties and worry that lasts so long. Teachers should be trained in this"* (P1)

"Awareness, education and training is the first step" (P20).

4.4.2 Health Care Professionals

Research findings show there is an imbalance of care being provided to families across hospitals. Research findings show there is an imbalance of care being provided to families across hospitals. Participants explained both positive and negative experiences of support provided to their children within hospitals prior to their baby's death. The findings would suggest that there is no set standards being implemented nationally in relation to providing care to siblings who are experiencing perinatal loss within their family.

The findings show that majority of participants received no support in relation to their other children at the time of their loss within the hospital. Various participants mentioned that their other children were not mentioned throughout their time in the hospital.

"*The emphasis was on me, and to a lesser extent my husband…The other kids got left behind again"* (P1).

"*Great Support for my husband and myself- kids weren't mentioned. Didn't come into it."* (P3).

Majority of participants also mentioned that they were not referred onto external supports by health care professionals in relation to their other children and had to find support themselves once leaving the hospital for their family.

" *Supporting our children wasn't addressed at all by the hospital it was a case of trial and error and hoping for the best*" (P10)

"*Nothing. We googled our baby's condition and found Féileacáin*" (P19)

"*So many professionals DO NOT GET THIS! Loss of a baby is not seen as significant enough for referral to supports available"* (P12)

Participants who explained more positive experiences, spoke of bereavements teams whose care and knowledge made a huge impact on their family and other children at the time of their loss:

"*We had access to a bereavement team from the time we got our diagnosis. Our bereavement midwife was lovely. We also had our own 'key' midwife at the time of the birth. Both of these knew their job and were able to discuss the issues with us*" (P15).

"During his naming service on the day he was cremated the Chaplain and bereavement midwife made a fuss over them and told them they were amazing big sisters" (P5).

Research findings indicate the requirement for training and development of awareness of the impact of perinatal loss on siblings within a family.

"Losing your baby at birth is a terrible lonely and frightening time, and there needs to be more awareness of this. The other kids get left out…They need to be acknowledged and supported" (P3).

"All professionals who come in contact with bereaved families should also receive mandatory training" (P8).

"*They should know about it for a start! And get training in how to help support whole families"* (P14).

4.4.3 Discussion:

Research findings show the impact professionals can have on siblings dealing with perinatal loss. The findings show the importance of recognising the siblings and acknowledging their grief. Research findings show the need for this at the time of death within hospitals and following the bereavement by schools. This was also acknowledged within the literature by (Hendson & Davies, 2018), who mentioned that professionals need to acknowledge the siblings at the time of death. (Hendson & Davies, 2018) also stated that professionals can have an impact on how the child understands their grief and what has happened.

Research findings show how families remember and recognise when support was provided to their children. Participants expressed the benefits of professionals having the knowledge and understanding and how it helped with both the parents and child's grief. This was highlighted as extremely important for the children as parents were too shocked or upset themselves to take on supporting roles at the time. Likewise, participants recognise the effect of a lack of awareness had on their children in dealing with the loss of their sibling.

The research findings show a clear imbalance of care which identifies the need for training and a set of guidelines for both schools and hospitals in supporting children through perinatal loss. This was expressed throughout the literature by (Dyregrov, Endsjo, Idsøe, & Dyregrov, 2015), whose study acknowledged the demand for essential training of teachers/professionals dealing with children after experiencing a significant loss.

4.5 Theme Four – Long Term supports

Research findings identified the importance of long-term support for siblings experiencing perinatal loss. Children are affected by the death of a sibling by perinatal loss well after the death occurs. Long term supports such as extended family and external supports proved to contribute positively siblings experiencing perinatal loss.

4.5.1 Long term expression of grief

Research findings showed the long-term effect perinatal loss can have on siblings. Participants expressed siblings experiencing pain months after the death of their sibling:

> *"One day I took him to the grave and he cried all night complaining of a pain in his body, but he couldn't tell us where it was"* (P9).

Other participants explained how that later on their children's behaviours changed and associated this with the grief they were experiencing from their loss.

> *"We have seen issues with worry fear and anxiety due to our loss"* (P10).

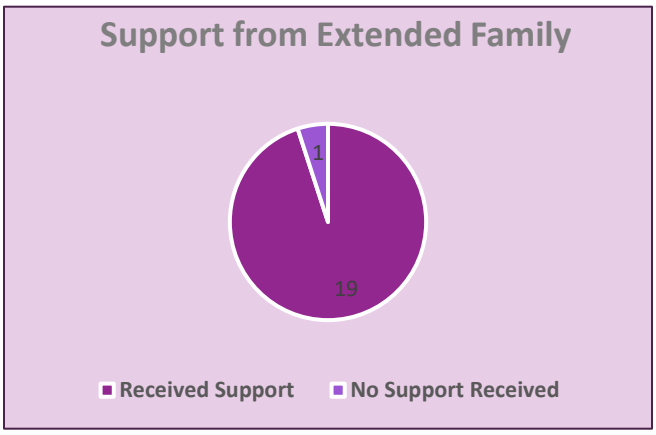
> *"I think everyone forgot when my son acted up around Christmas time there was no real understanding of what was going on for him"* (P9)

> *"Our girls has huge anxiety issues in the years after our baby's death that stems from this experience and how it was managed"* (P19).

4.5.2 Extended Family Supports

19 out of 20 participants questioned received supports from extended family in relation to their other children at the time of their loss.

Figure 4: Support from Extended Family



Majority of participants mentioned the benefits of family members supporting siblings when they felt they couldn't. One participant said:

> *"Family rallied around and looked after the girls when I was in hospital. They comforted them and offered to have them for sleepovers so we could come to terms with what had happened"* (P5).

> *"Friends and family helped make life a little more normal as they were able to be more normal for him"* (P10).

Participants expressed the need for external families to receive support and guidance around the effect the loss can have on children. They found this would help in the long-term support of their children through the loss. Some participants explained that family members were good at the time of the loss but as time went on forgot how the children could continue to be impacted.

> "*Maybe advice for extended family members on how to help children…The parents need the time to deal with stuff in those first few weeks and the other children need to feel as normal as they can"* (P2)

> *"They were very supportive but didn't really know what to do"* (P20).

4.5.3 External supports

Participants expressed the importance of external supports such as Féileacáin for their other children. Participants explained how this gave their children a sense of normality and acknowledgment for what they had experienced.

> *"Féileacáin validated, included, acknowledged and showed Kate's sisters that THEY MATTER"* (P11).

Participants expressed their need for ongoing support for other children and how external supports such as Féileacáin had a broader knowledge and understanding of this.

> *"I never thought 4 years later I would still need support around issues like the other kids. You don't know at the time how EVERYTHING in your life had changed forever…My daughter has anxiety now that came from what happened and the only ones who really get it are the Féileacáin Support Team"* (P1).

Research findings show how external long term supports such a Féileacáin help families including their children to recognise their loss as a whole family. It allows them to continue on the memory of their loved one, as well as support future family who experience the same.

> *"We are going through this as a family- not individually. Féileacáin helped us see that"* (P15)

> "*We are a family again and not just 5 people who are separately mourning. We would not be where we are without Féileacáin"(*P12)

4.5.4 Discussion

Research findings demonstrate the long-term effects of perinatal loss on siblings. Participants reported their children experiencing depression, anxiety and general fear and upset from loosing their sibling. This confirms the need for supports for siblings not only at the time of the loss but afterwards also. This was supported within the literature in a study completed by (Fanos, Little & Edwards, 2009). This study stated that siblings experienced long term anxieties that could be in relation to their mothers health, their own health and future pregnancies also (Fanos, Little & Edwards, 2009). Within the literature we also saw (O'Leary & Gaziano, 2011) speak of study by Callister (2006) which looked at the long-term effect perinatal loss has on siblings. The research findings and previous literature suggest a long-term effect of siblings loss by perinatal death and highlights the importance of continued long term supports.

The research findings sought to understand the ways in which parents were supported in relation to their other children after the death of their sibling. The importance of cooperation from extended family members was evident throughout the research findings. Participants spoke of the ways in which extended family helped support other children at the time of the loss. Participants also expressed the need for supports of extended family to fully support siblings at a time where parents often found themselves

unable due to grief. This highlights the importance of support beyond the hospital which was also mentioned by (Hutti, 2006) in Chapter 2.

Research findings revealed how important external services such as Féileacáin are for siblings. They acknowledge the effect the death of their sibling can have on them. Participants expressed how the Féileacáin's services helped their other children feel normal and become a family again. The Féileacáin services helped families come together and support one another through their grief as a family unit. This was evident from various testimonies of participants.

4.6 Conclusion:

This chapter has presented the research findings that have been gathered from responses to the online questionnaire. Four themes derived from the collected responses. These themes were then correlated with the literature presented in Chapter 2. The overall findings of this research project show the importance of communication, sibling involvement, professional support structures, and long term supports when supporting siblings experiencing perinatal loss. The conclusions and recommendations drawn from these findings will be presented with the concluding chapter.

Chapter Five: Conclusions and Recommendations

5.1 Introduction:

This chapter sets out to draw conclusions arising from the research findings outlined in the previous Chapter. These conclusions drawn from the research have informed the recommendations that follow. Recommendations will be representative of the opinions of research participants and the researcher. This final chapter will conclude with a reflection piece on the researchers participation in the primary research project.

5.2 Conclusions:

The overall aim of this research was to gain a better understanding of the experiences parents have when supporting their children through a perinatal death in their family. This primary research was completed through an online questionnaire which elicited responses from 20 participants. The following conclusions were drawn from the analysis of these responses.

The death of sibling by perinatal death impacts on other children within the family. This impact is evident through behaviours and emotions expressed by children following the death of their sibling. Majority of parents realised this impact well after the death of their child due to changes in behaviour of their children. However, parents who received support at the time of the death become more aware of this impact as it was explained to them early and they could prepare for it. Despite acknowledgement of this impact, parents can find it hard to give the needed support to children given their own grief at the time of the loss.

Communication was the biggest challenge facing parents in relation to supporting their other children through their loss. All parents expressed the need for guidance from external supports and professionals in relation to communicating with their children following the death of their sibling. Open and honest discussions from parents and professionals helped children grasp what had happened and continue the process of their grief. Guidance and support around this is essential for parents supporting their children.

Research findings suggest there is a lack of consistent procedures established to deal with siblings following perinatal loss within hospitals. At the time of loss, health care professionals are the first in contact with parents, therefore it is essential that they can support parents in any way necessary to cope with their other children. Responses show that siblings are not always considered when it comes to

perinatal loss. Parents have stated they are less likely to think of their children immediately after the loss. Health care professionals should take more responsibility in addressing this with parents to prepare them to best support their other children.

There is a requirement for schools to be more aware of the effects of perinatal loss on children. Children spend most their time in school therefore supports within this environment are essential. Participants explained how their children found this time extremely confusing, if they sense those around them disregarding how they are feeling or behaving, this can add to the confusion. There is a need for development of awareness within schools in relation to behaviours following perinatal loss so that children can be supported at all times possible.

Participants expressed the importance of Féileacáin for their families at the time of their loss and years later. Féileacáin's knowledge provides parents with guidance and reassurance that is fundamental in the care of their children. Féileacáin provide essential supports to siblings following perinatal loss. Féileacáin's acknowledgement of siblings is cherished by families. The work completed by Féileacáin also allows families to continue the memory of their loved one together, which is meaningful for families in their grief. The need for long term support following perinatal loss is crucial. Féileacáin implement long term support through the provision of services for both parents and siblings.

5.3 Recommendations:

The following recommendations are reflective of the data gathered and analysed in this research project:

- This research acknowledges an imbalance of care within hospitals for siblings experiencing perinatal loss. It is recommended that Féileacáin use this research to encourage and support hospitals to proceduralize defined professional support for siblings which can be delivered with a consistent approach following a perinatal death within a family. This should be encouraged along with training for all staff involved with families experiencing perinatal death.

- Children spend a great amount of time at school following the loss of their sibling, therefore the importance of staff awareness and ability to support children is vital in their grieving process. It is recommended that Féileacáin, following this research, acknowledge the need for awareness and training for schools in relation to perinatal death. It should be encouraged that schools gather an understanding of how the family is supporting their other children through the loss so that it can be continued as much as possible within school hours.

- It is recommended that Féileacáin continue to provide support to extended family members in supporting parents and other children through their loss. The findings show the importance of support from extended family for both parents and children. Extended families need guidance and reassurance when providing this care so that it is completed confidently and respectfully for all involved.

- It is recommended that that social work within the hospital are more involved with families and in particular siblings following a perinatal death. The systems approach that social workers have would help families utilize the surrounding supports available to them, therefore supporting their entire family through their loss.

5.4 Research Reflection:

I have a personal connection to the research topic being completed and know the benefits and importance it has for people within the organisation. This provided the drive and ambition to complete this research. I believe this personal determination helped me to stay focused along the research journey. I met with my tutor, Féileacáin co-ordinator and the director of CARL during the summer. We discussed the proposed research structure including necessary changes such as providing the online questionnaire to parents instead of siblings for ethical reasons. This was initially disappointing, however through further discussion, I understood the research outcome would remain the same, while also being ethically compliant. From this meeting, I began to put together my application for the MSW Research Ethical Committee. I felt organised and motivated.

At the end of September I was on my second-year placement for the masters. It was a busy and stressful time. I was managing portfolio work, research and practice. I couldn't help feeling a little run down and very jealous of those not doing a CARL project. I held onto my personal drive for the project and the comforting advice of past students, who ensured me that all the work would be worth it towards the final stretch.

Mid- placement the MSW Research Ethical Committee advised that I needed to apply to SREC (School Research Ethical Committee) and began the application as soon as possible. The application for SREC was stressful. I found that I was already managing so many aspects of placement and college that I was being stretched even further. The application was thorough and involved many communications between myself and my tutor as well as the Féileacáin co-ordinator. There was also concern that this process could be lengthy and ethical approval was not guaranteed.

There came a time when I really did not know if my ethical approval would be received on time to complete the intended research project. I reluctantly began to think of alternative options as advised. This was difficult, not only due to the work I had completed but also due to the personal connection I had to the research. I recognised that this research meant more to me thana thesis. I recognised the importance of this research for families such as mine and felt a huge disappointment at the possibility of not succeeding in completing it. This was something I had to reflect on and be mindful of. I made sure to look after myself and did so through reflection and discussions with family and friends.

Regaining my focus, I began working on other aspects of the thesis that could be completed while awaiting ethical approval. I spoke to people within college for advice and wrote down possible ways of altering the project if necessary. I felt more focused and prepared. I thankfully received ethical approval from SREC in February and continued with my research project. Again this was a busy time completing both final assignments and research. I completed my assignments ahead of due dates to ensure more time to begin the remaining chapters of my thesis. I could now see how all the hard work I had completed was paying off.

Myself and my peers are faced with completing the thesis in unprecedented times. Covid- 19 has affected our access to resources. We have had to familiarise with new technology to communicate with our tutors. There is added worries of our health and that of our families and those close to us. Organisation and self-care skills have never been more useful than at a time like this. I am extremely grateful for these skills that I have learned to utilise throughout this research project and given the current circumstances of isolation I continue to rely on them. I am proud personally and academically of the research completed. I am very grateful that I had the opportunity to complete research that will hopefully have potential to improve the lives of future families supported by Féileacáin.

5.5 Conclusion:

The analysed data demonstrates that participants are satisfied with the work completed by Féileacáin in supporting their children, however there is further need for awareness and training of others supporting families and siblings experiencing perinatal loss. Recommendations have been made towards the improvements of the supports provided to parents supporting their children through perinatal loss and it is hoped that the data will aid Féileacáin to identity future service requirements for siblings experiencing perinatal loss.

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Appendices

Appendix 1: *Online Questionnaire Design (including Information Sheet and Consent Question)*



Information Sheet

Information Sheet
Thank you for considering participating in this research project. The purpose of section of the questionaire is to explain to you what the work is about and what your participation would involve, so as to enable you to make an informed choice.

The purpose of this study is to gather the views of parents who had a perinatal loss and have had experience of supporting other children in dealing with the loss. I will be completing this research with the support of Féileacáin. Should you choose to participate, you will be asked complete a questionnaire, which will include items on the following;

- What awareness parents had themselves of the possible impact of the loss on their other children at the time of the perinatal loss.
- The awareness of others surrounding the impact of loss on other children such as schools, hospitals and extended family members.
- The supports parents received from Féileacáin in relation to their other children.
- The difficulties that arise for parents in relation to supporting other siblings at the time of perinatal death in the family.

Participation in this study is completely voluntary. There is no obligation to participate, and should you choose to do so you can refuse to answer specific questions or decide to withdraw from the study. All information you provide will be confidential and your anonymity will be protected throughout the study. IP addresses will not be collected at any point, meaning the data you provide cannot be traced back to you.

You maintain the right to withdraw from the study at any stage up to the point of data submission. At this point your data will be collated with that of other participants and can no longer be retracted.

The anonymous data will be stored on the University College Cork OneDrive system and subsequently on the UCC server. On completion of the project, the data you provide will be securely retained for minimum of a further ten years and then destroyed in compliance with UCC Data Storage policy. The information you provide may be contributed to my research thesis which is part of the requirements to obtain my Master's in Social Work at UCC. The working title of the study is 'Supporting Hidden Grievers: Parents' experiences of supporting their children through perinatal loss.' This data also may contribute to research publications and/or conference presentations.

We do not anticipate any negative outcomes from participating in this study. It must be stated that Given the sensitivity of the topic it is important to be aware of the available supports offered by Féileacáin when you complete the questionnaire. In the event of you feeling distressed about any aspect of the questionnaire you may contact Marie Cregan. By contacting Marie, we will pass you on to any necessary support needed through Féileacáin. This can be used at any stage, before, during and prior to your participation in the study.
CONTACT- Marie Cregan (Féileacáin) : 086-2738371

This study has obtained ethical approval from the UCC Social Research Ethics Committee.

If you have any queries about this research, you can contact:

Researcher Name: Lucy Mulvihill
Email: 118224632@umail.ucc.ie.

Supervisor Name: Mary Hurley
Email: m.hurley@ucc.ie

If you agree to take part in this study, please complete the consent section bellow.

1. Consent Form: Having read the above information sheet- Do you consent to take part in this study?

- ◯ YES
- ◯ NO

2. At the time of the loss of your child, were there any conversations had around supporting your children in the family or how this may be approached? If answering yes, please explain and state who with.

Enter your answer

3. Were you worried about anything in particular for your other children at the time of the loss? If yes, please explain.

Enter your answer

4. Were there any specific areas that your children found hard to understand at the time of the loss? If answering yes, please explain.

Enter your answer

5. Was there any support provided to you in relation to your children or the children themselves from their school?

- ◯ YES
- ◯ NO

6. If answering yes to the above Q5, please explain how.

Enter your answer

7. Did you receive support from your extended family/ friends in relation to your other children at the time of the loss?

- ◯ YES
- ◯ NO

8. If answering yes to the above Q7, please explain how.

Enter your answer

9. What support was provided by professionals within the hospital for you in relation to your children at the time of your loss? Please explain

Enter your answer

10. Were there any other organisations that provided support (other than Féileacáin) at the time of your loss for your children. If answering yes, please explain how.

Enter your answer

11. Based on your experience were there any challenges you faced in receiving support (from professionals or extended family) in relation to your other children at the time of loss? Please explain how.

Enter your answer

12. Have you any observations or recommendations in relation to how practitioners can support families with other children at the time of the loss?

Enter your answer

13.
Did you receive support from Féileacáin in relation to your other children within the family?

- ◯ YES
- ◯ NO

14. If you answered yes to above Q13, what aspects of the support were most helpful for your other children? Please explain why.

Enter your answer

15. If you answered yes to the above Q13, what aspects of the support were most helpful for you as a parent to support the children within your family? Please explain why.

Enter your answer

16. What aspects of the support from Féileacáin was least helpful to you in supporting your children through your families loss? Please explain why.

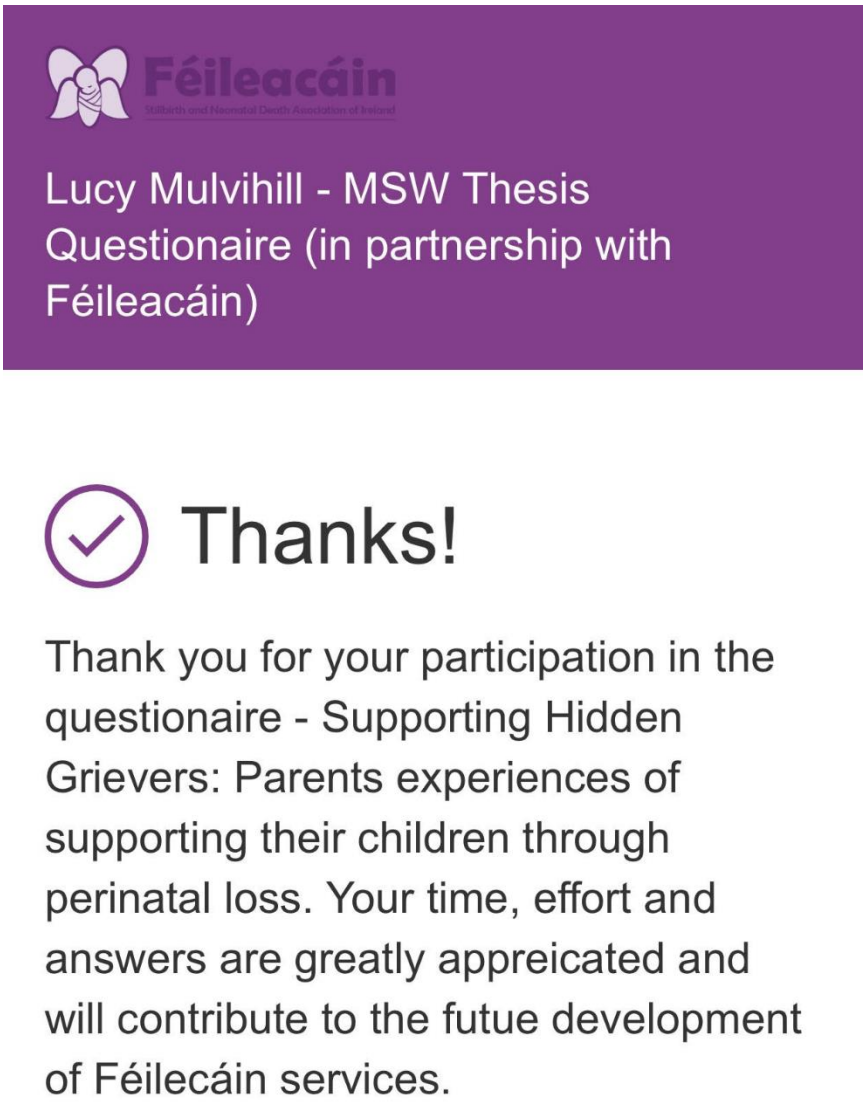
Enter your answer

17. What is the significance of the support you received for your family from Féileacáin currently (if any) ? Please explain how.

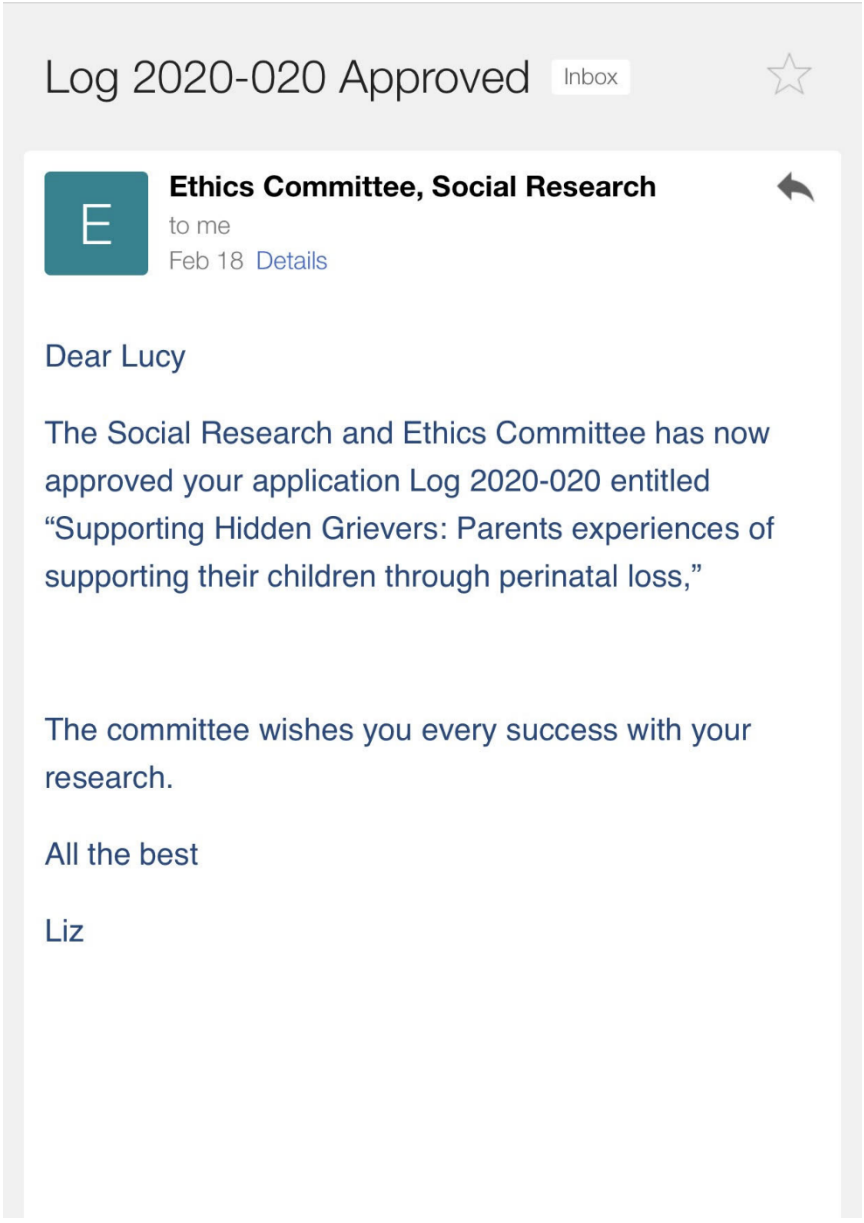
Enter your answer

Submit

Appendix 2: *Thank you message for participants on completion of Online Questionnaire.*



Appendix 3: *Ethical Approval*



Log 2020-020 Approved Inbox

E **Ethics Committee, Social Research**
to me
Feb 18 Details

Dear Lucy

The Social Research and Ethics Committee has now approved your application Log 2020-020 entitled "Supporting Hidden Grievers: Parents experiences of supporting their children through perinatal loss,"

The committee wishes you every success with your research.

All the best

Liz