



**Exploring the experiences of support with parentally
bereaved children and their surviving parents using
constructivist grounded theory**

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PhD by Thesis

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April 2023

Abstract

Background: In the UK, 46,300 children are bereaved of a parent each year. We understand bereaved people need a supportive response from those around them. However, there is limited evidence to inform our understanding of this.

Aim: To explore how children and families best support each other after a parent's death and to understand how those within their existing networks can provide a supportive response.

Methods: Following a systematic review to identify and synthesise the experiences of support for children and surviving parents following parental death, a qualitative study was undertaken. Using a constructivist grounded theory approach, in-depth interviews were conducted with children and their surviving parents after the death of a parent to explore their experiences and perspectives of support needs. Data were analysed using constant comparison, following Charmaz's open, focused, and theoretical coding stages.

Findings: Systematic review findings highlighted the limited studies, including children and parents, that explored bereavement support. Seventeen parents and eleven of their children participated in on-line interviews. Theoretical coding of key categories from both interview data sets culminated in developing a substantive theory, 'masking your grief - because you feel you have to', articulating the behaviour patterns amongst children, surviving parents and those around them following their bereavement. Families gave examples of the supportive response they received from each other and those within their networks. However, the response was not sustained. 'Masking your grief - because you feel you have to' is something children and parents do to protect each other and the people around them. It often happens because the immediate bereavement support dwindles as the people around them do not understand what they continue to go through.

Conclusion: This study highlights gaps in bereavement support and how existing networks can provide a supportive response. It is essential that children and surviving parents' grief is considered within the context of their social networks, which will impact how they grieve. A public health approach to bereavement is required, with everyone recognising their role in supporting bereaved families.

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Abbreviations

ACE Adverse Childhood Experiences

Covid COVID-19 pandemic

GP General Practitioner

HCP Health Care Professionals

ICU Intensive Care Unit

NHS National Health Service

PPI Patient and Public Involvement

UK United Kingdom

USA United States of America

Acknowledgements

There are a number of people I would like to thank for their contribution to this thesis. First and foremost, I would like to sincerely thank all the participants who willingly gave me their trust, time and commitment, sharing their experiences so we could make a difference.

Thank you to the families who helped me with Patient and Public Involvement in the study, who gave me reassurance and confidence and helped me from the initial planning to reviewing the study findings – it would have been impossible without them.

Thank you also to the staff working in services supporting bereaved children and their families. Your interest in and support of the study has been crucial.

My sincerest gratitude goes to my supervisors, Dr Jason Boland, Prof Fliss Murtagh, Dr Clare Whitfield, Dr Julie Seymour and Prof Barry Wright, for their mentoring, expertise, guidance and constant encouragement throughout my PhD journey. I extend my thanks to Yorkshire Cancer Research for funding my PhD as part of the TRANSFORM programme.

My Thesis Advisory Panel, Dr Mark Pearson and Prof Joanne Reeve, for their wisdom and direction, as I navigated the PhD. Mark's comment, 'Keep up your enthusiasm and passion – you are flying now,' gave me a much-needed boost that I could carry through this journey.

My virtual office friends who helped keep me sane and motivated whilst we all worked from home, 'Other' Alex, Sophie, Ben, and Matthew. Jenna, my CGT pal, who, although we have never met in person, yet, dragged each other along the last stretch of writing. I feel lucky to have met some amazing friends who have constantly encouraged me along this journey.

To my neglected friends and family who believed in me and have been my constant cheerleaders offering words of encouragement and support all the way.

And last but not least, thank you to Tom. Who had complete confidence in me, picked up the slack, and gave me unwavering support from embarking on the PhD. Now onto our next chapter.

Author Declaration

"I confirm that this work is original and that if any passage(s) or diagram(s) have been copied from academic papers, books, the internet or any other sources these are clearly identified by the use of quotation marks and the reference(s) is fully cited. I certify that, other than where indicated, this is my own work and does not breach the regulations of HYMS (Hull York Medical School), the University of Hull, or the University of York, regarding plagiarism or academic conduct in examinations. I have read the HYMS Code of Practice on Academic Misconduct and state that this piece of work is my own and does not contain any unacknowledged work from any other sources. I confirm that any patient information obtained to produce this piece of work has been appropriately anonymised".

Publications, presentations, and prizes

Publications

Wray, A., Pickwell-Smith, B., Greenley, S., Pask, S., Bamidele, O., Wright, B., Murtagh, F. & Boland J, W. Parental death: a systematic review of support experiences and needs of children and parent survivors. *BMJ Supportive & Palliative Care* Published Online First: 16 November 2022. <https://doi.org/10.1136/spcare-2022-003793>

Wray, A., Seymour, J., Greenley, S. & Boland, J, W. Parental terminal cancer and dependent children: a systematic review. *BMJ Supportive & Palliative Care* Published Online First: 28 January 2022. <https://doi.org/10.1136/bmjspcare-2021-003094>

Wray, A. (2021) Alex's blog: a nurse's honest experience of navigating a PhD. *British Journal of Child Health*. 2(4). <https://doi.org/10.12968/chhe.2021.2.4.201>

Prizes

Innovate UK funded PreCURE Programme completed at the University of Warwick March 2022. The programme introduced the Innovation to Commercialisation of University Research Programme. Awarded prize for video presentation which summarised final value proposition and findings.

Invited speaker presentations

Invited by Alison Penny and Gail precious to share findings with The Childhood Bereavement Network through their monthly bereavement sector webinar, open to all bereavement organisations within the UK. Date to be confirmed.

Invited by Dr Julian Abel to share findings with the Compassionate Communities UK during an online members meeting. Date to be confirmed.

Invited by the Hull Child Bereavement Advisory Group to present findings to the members representing bereavement services in the area. Planned for June 2023.

Invited by the 0-19 Research Network (CRN Yorkshire & Humber) to present findings to their summer face-to-face meeting.

Conference presentations

Wray A, Whitfield C, Murtagh F & Boland JW. "How can children and families best support each other following the death of a parent and how can those within their existing networks provide a supportive response? A study protocol". Poster presentation on 24th November 2022 at NHS Education for Scotland, Bereavement Education Annual Conference 2022 - Exploring Bereavement from a New Perspective [Online].

Wray A, Bamidele O, Pask S, Pickwell-Smith B, Greenley S, Murtagh FEM, Wright B, and Boland JW, "Parental death, support experiences and needs for children and surviving parents: a systematic review". Poster presentation on 14th July 2022 at Hull York Medical School Postgraduate Research Conference, University of Hull.

Wray A, Wright B, Murtagh, FEM, Boland JW. "Supporting children and their surviving parent following the death of a parent. A study protocol". Poster presentation on 28th June 2022 at Wolfson Palliative Care Research Centre & University of Technology Sydney's Creating Connections Palliative Care Conference, Changing Policy and Practice, University of Hull.

Wray A, Bamidele O, Pask S, Pickwell-Smith B, Greenley S, Murtagh FEM, Wright B, and Boland JW. "How are children and their surviving parents supported following the death of a parent? A systematic review". Presented on 8th July 2021 at the University of Hull, Hull York Medical School, Postgraduate Research Conference [Online].

Accepted presentations yet to be presented:

Wray A, Whitfield C, Murtagh FEM & Boland JW. "Interviews with Children - The Seldom Heard Voices of Parentally Bereaved Children". Poster presentation planned for 15th to 17th June 2023 at the 18th World Congress of the European Association for Palliative Care in Rotterdam, the Netherlands.

Wray A, Whitfield C, Murtagh FEM & Boland JW. "Care of Families through Loss: A Grounded Theory Interview Study of Parents' Experiences Supporting their Children Following Parental Death". Poster presentation planned for 15th to 17th June 2023 at the 18th World Congress of the European Association for Palliative Care, in Rotterdam, the Netherlands.

Wray A, Whitfield C, Murtagh FEM & Boland JW. 'I didn't realise what our community meant until I needed to pull on it' - bereaved families support experiences following the death of a parent. Oral presentation planned for 10th and 11th July 2023 at the Compassionate Communities UK conference, Compassionate Cities: Igniting Community, in Birmingham, UK.

Wray A, Whitfield C, Murtagh FEM & Boland JW. 'Everything is down to me' – bereaved parents' experiences of support following co-parent death' Oral presentation planned for 20th and 21st July 2023 at the International Conference on Policies and Parental Support at York St John University.

1 Introduction

1.1 An overview to the thesis

Death is inevitable, and most people at some stage in their life will experience bereavement and grief¹. Despite this, death remains taboo in many societies¹⁻³. As a nation, we find it difficult to talk about death, dying and bereavement and struggle to help bereaved people; we fear causing harm or saying the wrong thing, which may stop people from offering support^{2,3}.

Death can be seen as a social issue present in all human societies that will all experience dying, death and bereavement, taking place within the social and cultural worlds⁴. Nevertheless, despite this being a universal issue, social and cultural diversity means that death is dealt with differently⁴. Consequently, there are many complexities and experiences within different societies⁴.

The experience of grief is unique and can be affected by several factors, including circumstances of the death, characteristics of the bereaved person, relationship with the deceased, availability and provision of support and other sociocultural factors⁵.

Within the United Kingdom (UK), 127 children are bereaved of a parent each day⁶. A parental death causes a radical change in a child⁷. The consequences within the family and home will be the most fundamental loss they will experience, altering the core of their existence^{7,8}. Children who experience the loss of a parent describe the sense of loss as a heavy cross to bear; daily life acts as a constant reminder of the loss of their parent⁹.

Following a parental death, how children react and cope is closely related to how their surviving parent is acting and coping⁷. Children require support, nurturance and continuity, which can be difficult for a grieving parent to provide⁷, and often affects the child-parent roles⁹. Parents are not always sure how to support their children and if their actions are right⁹. Children are also unsure of how to behave and often avoid talking about their problems and suppress their emotions to protect their surviving parent^{10,11}. Although parents and children put effort into protecting each other⁹, such protection may result in them being unable to provide each other with the support they require¹¹.

Recent empirical studies have focused on supporting children when a parent is terminally ill. Some have involved the children of a terminally ill parent¹²⁻¹⁴, others have focused on both the ill and healthy parents¹⁵, and others have included professionals in the research^{14,16-18}.

A UK study with children living with parental life-limiting illness found that children have agency and want to be actively engaged and be enabled to have a role supporting their family¹². Systematic reviews have also explored the qualitative evidence and experiences of children, ill parents, surviving parents and health and social care professionals when a parent is terminally ill and dying^{11,19,20}. Many of these studies have focused on the roles of health and social care professionals in supporting families when a parent has a terminal illness and has died. However, few have focused on how those within children and surviving parent's networks can support such families following parental death.

Following a death, social support, which is helpful and timely, is a strong indicator of positive psychosocial outcomes²¹. However, many bereaved people do not receive the quality or quantity of social support they would like²². A review exploring factors which could help or hinder the provision of such support found many determinants in its provision and identified the complexity of processes that motivate people to recognise and respond to distress²³. Findings suggest further research to understand grief norms and supportive practices, including the perspectives of the support giver and receiver, is required to enhance the community's capacity to provide bereavement support²³.

1.2 Personal motivation

I wanted to undertake a PhD exploring bereavement support for children and parents because of my clinical experiences as a nurse supporting families through the end-of-life care. Although I saw firsthand the lack of bereavement services, I often felt like I had let families down with a lack of support and felt there was much more we, as health care professionals (HCPs), could do to help. Then, less than a year into my studies, the world changed for us all with the Covid-19 pandemic (Covid).

Death was brought to the forefront of society in 2020 when Covid resulted in mass bereavement on a scale that has rarely been seen in recent history, with millions of deaths worldwide²⁴. The death of a parent became a reality to many²⁵. Covid highlighted the limited knowledge and understanding surrounding the impact of bereavement and

bereavement care, prompting new and urgent questions to be answered about the nature of bereavement^{3,26}. The result of the pandemic is a greater focus on the need for bereavement research.

During Covid, I took a leave of absence from the PhD to return to clinical practice and work in the Intensive Care Unit. I was tasked to develop and manage a family support service to keep families updated on their next of kins' condition whilst they could not visit. Although the six months I spent working in the service brought home to me the importance of my research and the need to improve the care for bereaved families better, it also highlighted how difficult it was for professionals to support children and families. Below (Figure 1) is an excerpt from my diary reflections on my experience. The rest of the reflection can be found in Appendix 1.

October 2020

Another family who will always remain with me was a young mum who died leaving behind her two children. A close friend of mine who was also the sister on the intensive care unit (ICU) had called me over and asked if I could bring a memory box and any information to help the children.

I took a memory box and book for the children about when someone dies. On arrival to the unit I was ushered into a side room to be met with grandma, two children and a social worker. I did not realise I would be meeting the family, I was completely out of my depth, I had no time to prepare and felt ill equipped to try and support them.

However, I was absolutely the best person to try and support the family, I probably had the most experience in the full hospital of supporting bereaved children, despite having no formal training. The ICU staff had no time and also, like me, felt ill equipped, or probably even less equipped than I was. What can you say to children about to lose their mum? There was no dad, so grandma, was trying to cope with losing her own child and would now have to take on the care of her grandchildren. It was horrific.

Grandma wanted to spend some time with her daughter so I and the social worker sat with the children, we asked if they understood what was going on and answered any questions. I remember showing them the memory box which they really appreciated and we spoke about what they could put into the box, they both then wrote letters to their mum and said their goodbyes. My ICU colleagues were so grateful for the time I gave to this family, in reality I did very little but be with them and listen.

The next day the social worker came to meet me to collect the memory box, he was so upset. I will never forget how grateful he was for the support I gave him with the children, I honestly did not feel like I had done much at all. His manager had been very supportive and

gave him the afternoon off and a pack of beers, acknowledging what a difficult situation he had faced.

I was grateful he had good support but it made me sad for my nursing colleagues. I know that as soon as 'mum' died, another patient would fill her bed. The nurses may be lucky to get a break before the bed was filled again. My two colleagues had the task of reading the children's goodbye letters to their mum, they have since told me how this still haunts them.

This once again made me realise how difficult it is for the majority of professionals supporting bereaved families, especially when children are involved. It also made me wonder that if professionals and adults do not push themselves out of their comfort zones and speak to children, this will leave them extremely isolated and scared. Yet, there is little if any support for professionals supporting families, it is just seen as 'your job'.

My experience working clinically during the pandemic reaffirmed the importance of my research and gave me even more desire to be able to make a difference to these families.

Figure 1 Diary reflection of clinical practice during Covid

1.3 Thesis structure

An overview of the thesis structure is provided in Table 1.

Table 1 Structure of thesis

Chapter	Chapter content
Chapter 1: Introduction	This chapter provides an overview of the study, its context, and a rationale. There is a brief overview of the thesis structure at the end of the chapter.
Chapter 2: Background	This chapter provides a brief overview of the background literature of the thesis and identifies the gaps in evidence.
Chapter 3: Aims and objectives	This chapter provides the aims and objectives of the thesis.
Chapter 4: Systematic review background chapter	This chapter presents the findings from the published systematic literature review exploring support experiences for children and surviving parents following parental death.

Chapter 5: Methodology	This chapter outlines the researcher's philosophical assumptions and provides a comprehensive description of the researcher's methodology.
Chapter 6: Methods	This chapter outlines how the study was conducted, including research design, sampling, participant and researcher considerations, data collection and analysis, ethical considerations and patient and public involvement (PPI).
Chapter 7: Child findings	This chapter reports study findings from the child participants in the study.
Chapter 8: Parent findings	This chapter reports the findings from the parent participants in the study.
Chapter 9: Integration of findings and the substantive theory	This chapter integrates findings from child and parent perspectives and explains how the theory was then developed. Then the theory and model are presented.
Chapter 10: Discussion and conclusion	This chapter discusses the research findings. Then the implications for practice, policy, education and research are presented. The research reflections are provided including strengths and weaknesses. The study's contributions to knowledge and directions for future research are identified. The chapter ends with the study's conclusion.

2 Background

2.1 Introduction

This chapter provides an overview of the background literature on which the studies in this thesis are based. The chapter begins by exploring the prevalence of childhood bereavement. Next, the literature on the impact of parental death and children's needs is discussed, followed by the literature on bereavement research with children and the need for bereavement to be seen as a public health issue. Informal and formal bereavement support networks are then explored. Finally, the chapter overviews some grief models and theories relevant to parentally bereaved families.

2.2 Prevalence of child bereavement

Parental bereavement is described as prevalent yet hidden²⁷, as seen in the absence of official data surrounding the number of children bereaved of a parent each year^{6,28}. However, limited evidence within the UK highlights the prevalence of childhood bereavement. A study published more than ten years ago found that 78% of 11 to 16-year-olds were bereaved of a close relative or friend²⁹. Another study found that 1 in 20 young people will experience the death of one or both parents by age 16³⁰. A 2020 Scottish study found that by the age of ten years, 62% of children were bereaved of a parent, sibling, grandparent or another close family member²⁸.

Looking specifically at parental bereavement, within the UK, it is estimated that there are 46,300 dependent children bereaved of a parent each year⁶. With this in mind, child bereavement services are campaigning for the urgent need to collect information on childhood bereavement, plan service development and better understand the impact bereavement has on children's lives³¹.

Globally there are 147 million orphans (aged 0-17 years)³². Following on from Covid, a modelling study found that worldwide, 5.2 million children experienced the loss of a parent or caregiver due to Covid^{33,34}. Covid has raised the profile of parental bereavement and orphanhood, providing a global stage to create a strategy for change to support children and families³⁵.

Although it may not be possible to know the full extent of the Covid pandemic, within the UK, there were three million people bereaved in the first two years of the pandemic, which is around 750,00 additional bereavements³. In addition, the Lancet Public Health Editorial has recently recognised the prevalence of child bereavement, which the pandemic has amplified²⁷.

Parental bereavement is argued to be a public health challenge that needs attention and urgent management²⁷. Described as 'one of the last taboos in public health', parental death causes acute and chronic pain for children and surviving parents, which society often struggles to acknowledge, understand or address²⁷. Described as 'its own public health emergency of international concern', the editorial highlights the need to enable young people to converse about grief and the offering of multidisciplinary support services to families²⁷.

Health inequalities within the UK have grown with socioeconomic deprivation increasing the risk of preventable deaths³⁶. For example, the most common causes of death are cancer in women and cardiovascular disease in men³⁶. In addition, life expectancy is affected by social class, geography and locality, and people's health is impacted by the conditions in which they live, work and their age, meaning that it is more likely that children living in deprived areas will experience bereavement^{28,37}.

Despite the lack of official data on childhood parental bereavement, the evidence presented highlights the prevalence of childhood bereavement and an urgent need to prioritise and respond to the needs of parentally bereaved children³⁴.

2.3 Impact of death on children

Grief is a normal reaction to bereavement³⁸. Although the intensity and duration of grief reactions vary, immediate common reactions can include shock, disbelief, numbness, and other strong emotions⁹. Bereaved children can have similar psychosocial difficulties to bereaved adults³⁸. However, their experiences will differ according to their maturity, development level and relationship with the deceased⁹.

Following the death of someone close, children often lack energy, have trouble sleeping, experience vivid memories, and become preoccupied with the death; they may have problems with appetite, have increased physical and emotional restlessness, may feel guilty,

withdraw socially and have difficulties with concentration and school^{9,29}. In addition, some children will have anger, frustration, depressive symptoms, and anxiety and may experience suicidal thoughts; children have also described experiencing reduced self-image and a crisis of identity⁹.

The psychological, physical and social consequences following parental death are well evidenced³⁹. Children bereaved of a parent have a greater risk of experiencing adverse reactions, including increased feelings of aggression, despair, anxiety, depression, social isolation and post-traumatic stress disorder, compared to the general population^{7,20}. Children can avoid discussing their problems or showing emotions to protect their surviving parents and those around them^{7,10,11}. However, this can be misunderstood, and the child can be seen as not being affected by their bereavement^{7,10}.

Analysis from two large-scale longitudinal survey data sets with families suggests that parental death in childhood can have a continuous and cumulative effect on young people's emotional and social wellbeing long after their loss⁴⁰. In addition, smaller qualitative studies have found that children bereaved of a parent can have their grief reactivated over their lives, which could happen at significant life events or triggered by a memory^{41,42}. A large Swedish cohort study undertaken with children and young people identified that those who had experienced parental death had a greater risk of substance abuse and suicide-related behaviours related to the anniversary of parental death⁴³.

Several studies have explored the long-term impacts of parental bereavement on health and social wellbeing^{4,24-27}. Many found that children bereaved of a parent are more likely to engage in risk-taking behaviours, including smoking, drinking alcohol, substance abuse and underage sex, which could lead to further problems and a greater risk of convictions for violent criminal offences^{29,44-47}. A recent systematic review highlighted how the death of someone close to a young person affects their educational outcome in many ways, including creating a barrier to educational achievement, compromising academic performance and affecting their educational engagement and attainment⁴⁸.

A large (n=189,094) cohort study undertaken in Nordic countries found that children who experienced parental death before 18 years had a 50% increased all-cause mortality risk compared to those who were not bereaved of a parent in childhood⁴⁹. Similarly, a large

(n=55,818) population-based cohort study, also undertaken in Nordic countries, found that a sibling death in childhood was associated with a 71% increased all-cause mortality risk⁵⁰. In addition, genetic risk of disease can increase individuals' risk of dying from some diseases^{51,52}. Although the cohort study found this to account for a small part of the association between childhood parental death and increased mortality⁴⁹, the findings suggest that the long-term impact of parental death on children's health and social wellbeing, the social and economic disadvantages caused by the parental death and lifestyle changes following parental death which led to more risk-taking behaviours, increased the mortality risk⁴⁹.

The evidence presented has shown the potential negative impact of parental death on children. However, despite this, many bereaved children manage life and can function and do well during their childhood and adult life³⁹. A systematic review identified that children living with a dying parent develop strategies to cope and want to be involved despite a desire from their parents to protect and shield them¹⁹. Another systematic review and other studies have found that many children experienced post-traumatic growth following parental death, which can have a positive effect on their mental health^{41,53,54}

2.4 Needs of bereaved children

Results from a longitudinal study undertaken with parentally bereaved children (n=125) identified several needs of grieving children, which mental health professionals could help the surviving parents to interpret those needs⁷. The bereavement needs are presented in Table 2. Furthermore, children's needs must be met in a stable and supportive family, with their usual networks, such as school and community groups helping⁷. If children's support needs are unmet, they can become vulnerable to poorer outcomes³⁷.

The Child Bereavement Network outlines the support children require following a death³¹. Children's grief and experience of loss should be acknowledged; services should respond to their needs, views and opinions, respecting their family and social situation, including culture, language, beliefs and religious background, and should promote self-esteem, self-confidence, and help develop communication, decision making and other life skills³¹.

Table 2 Bereavement needs of grieving children, from Worden, pp 140-147⁷

Bereavement needs of grieving children

- Adequate information
- Fears and anxieties
- Reassurance that they are not to blame
- Careful listening
- Validation of individual's feelings
- Help with overwhelming feelings
- Involvement and inclusion
- Continued routine activities
- Modelled grief behaviours
- Opportunities to remember

Studies have found that not all parentally bereaved children will need or benefit from professional support^{7,29}. For example, a UK cross-sectional study was undertaken with 1746 school children aged 11 to 16, which found that 77.6% of participants had experienced the death of a close relative or friend⁴. Within the bereaved group, 87% admitted they had never or rarely spoken about the deaths; furthermore, 88.5% stated they never or rarely required professional support for how they felt after the death⁴. Similarly, a prospective longitudinal USA study interviewed 70 families and 125 children aged 6 to 17 years who had been bereaved of a parent found that only a third of child participants required professional support¹⁷. However, in contrast, following a parents' death, a systematic review found that relatively brief interventions can prevent children from developing more severe problems, including traumatic grief and mental health problems¹⁰. The interventions also positively affect the remaining caregiver's health¹⁰.

Public health models of bereavement support successfully describe the types required, whom this is provided by, and the level needed by the bereaved population^{31,55-58}.

Furthermore, they all agree that bereaved children and adults will receive the most support from their families, friends, and existing networks^{31,55-58}. However, despite acknowledging that all bereaved children need a supportive response from their existing networks, the models focus on how services can help children. As a result, the models fail to explain what

a supportive response is between bereaved children and their families and how existing networks can provide a helpful, supportive response.

It is argued that the high prevalence of childhood bereavement means that the needs of children cannot be met by professional services alone²⁸. Furthermore, there is a need to explore beyond individual experiences to understand the social conditions in which children are bereaved, identifying the resources and deficits in their communities which help or hinder their experiences²⁸. Although, historically, studies in this field often used parents or teachers as participants¹⁷, more recently, the limited studies within this field often include children and parents exploring their experiences as individuals or as a family unit. No studies have been identified that explore the experiences of children and surviving parents in the context of them within their communities.

Following parental death, evidence has shown the importance of the relationship between the child and surviving parent^{7,59,60}. Worden argues that the most powerful predictor of a child's adjustment to parental death is the functioning level of the surviving parent⁷. Surviving parents struggling to function will have children who show more sleep and health-related issues and greater levels of anxiety and depression⁷. Poor family relationships between children and surviving parents are linked to health-damaging psychosocial problems and lower social support in adulthood⁵⁹. The qualities of family relationships which were identified to help protect against depression were the supportiveness of family members, open expressions of feelings and low levels of conflict and anger⁵⁹.

2.5 Bereavement research with children

A recent scoping review explored the ethical issues identified when conducting bereavement research with children⁶¹. The review included peer-reviewed studies and dissertations from the year 2000⁶¹. Studies were excluded if they only mentioned the general ethical procedures and concerns⁶¹. Worldwide, 68 studies (n=40 peer-reviewed articles and n=25) were identified; only five were from the UK, highlighting the lack of bereavement research undertaken with children⁶¹. Furthermore, the review found that fifteen of the included studies categorise participants aged over 18 as children⁶¹. The United Nations Convention on the Rights of the Child characterises children as under 18⁶².

Therefore, it could be argued that the studies including children aged over 18 are providing the experiences of adults bereaved as children. Many studies exploring experiences of parental death have included adult participants who were bereaved as children^{41,63-69}. Nevertheless, it could be seen that the views they provide are through an adult's lens, not a child's.

Rather than undertake research with children, often research is done on or about children, with parents or teachers providing their perspective of a child's experience^{29,70-72}. For example, an integrative review exploring bereavement experiences of children following sibling death identified 25 studies; only 14 were qualitative, and 8 included parent-proxy report⁷¹. The review also highlighted discrepancies between child self-report and parent-proxy reports emphasising the importance of undertaking research with children⁷¹. Research when a parent is dying or following their death often focuses on the experiences of children^{55,56}, their terminally ill and surviving parents^{15,73}, or health and social care professionals^{16,17,73}. The limited research with parent-child dyads often focuses on parental terminal illness⁷⁴⁻⁷⁶. Or, as identified in a systematic review, the relationship quality in the parent-child dyad, bonding, communication, adjustment and impact of parental death⁷⁷. No studies (to the best of my knowledge) focus on support experiences within parent-child dyads following parental death.

Despite the growing recognition of children's abilities to participate in research, they are often seen as a challenging group to reach^{19,78,79}. In addition, children can be perceived as vulnerable, with research around parental death deemed especially sensitive⁷⁹. Studies undertaken in the UK and USA with children living with a parent at the end-of-life reported difficulties accessing child participants^{78,79}. Researchers embarking on research with children must navigate complex ethical issues and requirements and contend with gatekeeping from parents and professionals^{78,79}. A UK study raised an important question; if the routes 'in' to accessing young people are difficult, do children have routes 'out' which allow them to access the support they need⁷⁹.

When research is undertaken with children experiencing parental illness and death, thematic analysis is often used to explore experiences^{12,14,75,80,81}. Some studies adopt a phenomenological approach⁸²⁻⁸⁴, and others have used a grounded theory approach but have not developed a grounded theory^{74,76,85}. Constructivist grounded theory, a

methodology developed by Charmaz has recently been highlighted as an appropriate methodology to use with children^{86,87}. Despite the lack of published evidence of constructivist grounded theory as a child-sensitive methodology, Sudarsan et al⁸⁶ make the case for this methodology which recognises children's agency, is tailored to the rights of a child and allows children to make an authentic and meaningful contribution to research⁸⁶.

Within childhood parental illness and bereavement, studies often represent the voices of white adolescent children in Western countries affected by parental cancer, who are mainly recruited from support services suggesting they are functioning well^{11,19,20}.

2.6 Bereavement as a public health issue

Bereavement has previously been viewed as a problem to be dealt with by health services⁸⁶. However, it is argued that this approach is neither correct nor sustainable. Furthermore, it is argued that bereavement support should be addressed with a Compassionate Communities approach⁸⁶. As a result, we have begun to see a movement away from the medical approach to palliative care towards the inclusion of public health approaches, recognising that death, dying, and bereavement are inevitable in life, they are not just medical events, and the community should be prepared to help⁸⁷.

Services increasingly recognise the importance of viewing bereavement as a public health issue, supporting community development approaches to unleash the potential of communities to provide help and support⁸⁸. However, evidence suggests that communities want a compassionate response to bereavement but do not feel empowered to help and support those dying or bereaved⁸⁹.

The National Palliative and End-of-Life Care Partnership recognised the need to improve support for bereaved families⁸⁷. It developed an ambition to apply a public health approach to end-of-life care⁸⁷. It sought to enhance supportive networks in the community to build compassionate and resilient communities, raising public awareness around bereavement, and practical support to enable families, neighbours and community organisations to help and volunteers who were trained to help support the bereaved, their families and community⁸⁷. More recently, spurred on by the bereavements seen during the pandemic, it is argued that a public health approach to grief is required, with a need for bereaved people's support networks to be equipped to offer support to those who need it^{3,90}.

Death can cause distress and life changes and require adjustments for the bereaved, which for the majority is managed by drawing upon their inner resources alongside support from their family and existing networks⁹¹. The three-component model and public health approach to bereavement support developed by the National Institute for Health and Care Excellence (NICE) recognise the importance of those networks⁵⁸.

The three-component model of bereavement support in palliative care following a cancer death was based on a systematic review of the available evidence and recognised that not all bereaved people need specialist support⁵⁸. The model has since been adapted and complemented using a public health approach to bereavement, with an emphasis on how social networks and communities respond to the bereaved^{56-58,92}. Bereavement care is situated as a responsibility that communities and health services must share, which allows us to understand what support bereaved individuals require (Table 3 and Table 4)^{56-58,92}.

The three-component model proposes three levels of bereavement support that should be made available depending on the individual need^{58,92,93}.

Table 3 Levels of need, adapted from the three-component model^{58,92,93}

<p>Level one - All bereaved people will have some level of need, with much of their support being provided by friends, family and existing networks. The information they require about bereavement and sources of support will be provided by HCPs involved in their care</p> <p>Level two - Some bereaved people will seek support and may be at risk of developing complex needs. They may require specific bereavement support with groups promoting mutual help or trained bereavement workers providing structured support</p> <p>Level three - A minority of bereaved people will have complex needs or prolonged or complicated grief requiring specialist bereavement, mental health or psychological support</p>

Table 4 The three-component model and public health approach to bereavement support, adapted from the National Bereavement Alliance⁵⁶

Level of support	Types of support	Target population and level of support seeded	Support provided by
1 Universal	Information about bereavement and sources of support	All bereaved people Low level of need	Verbal, written, and online information is provided by professionals involved in end-of-life care, registrars and others providing day-to-day care to families
2 Selective or targeted	Non-specialist support	Some bereaved people. Those seeking support or at risk of developing complex needs	Social support: self-help groups, faith groups, befriending and community groups
			Trained bereavement support workers
3 Indicated	Specialist interventions	A minority of bereaved people Those with complex needs or prolonged/complicated grief. High level of need	Specialist bereavement counsellors/practitioners
			Specialist mental health support for those with mental health problems which pre-date or are triggered by their bereavement

The model has since been adapted to outline what bereavement provisions should be like for children and their parents³¹. The bereavement triangle, presented in Figure 2, suggests that all bereaved children require a supportive response from their existing networks. In addition, families need information about how children grieve, what can help, when to seek more support and what services there are³¹. Some children will need one-to-one, family, peer or group support, and a few will need specialist support³¹. Children's needs must be met in a stable and supportive family, with their usual networks, such as school and community groups helping⁷. If children's support needs are not met, they can become vulnerable to poorer outcomes³⁷.

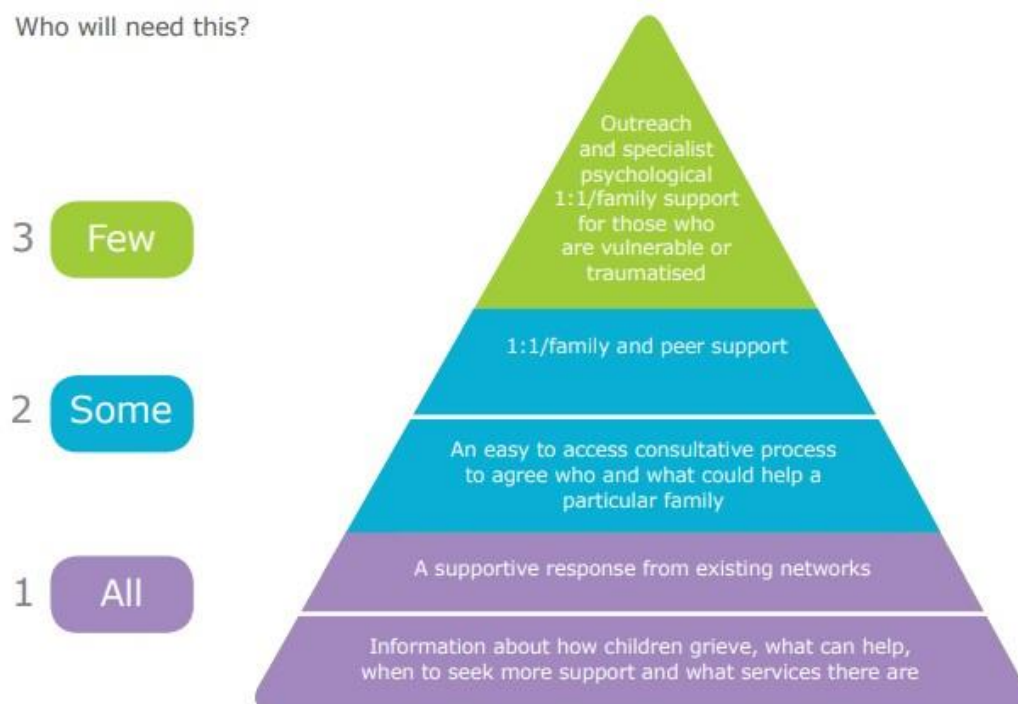


Figure 2 What good provision for bereaved children and young people and their parents and carers looks like. From *Childhood Bereavement Network*³¹

Public health models of bereavement support successfully describe the types of bereavement support that may be required, whom this is provided by, and the level of support needed by the bereaved population. Furthermore, they all agree that most of the support bereaved children and adults receive will be from their family, friends, and existing networks^{31,55-58}. However, despite acknowledging that all bereaved children need a supportive response from their existing networks, the models focus on how services can support children. As a result, the models fail to explain what a supportive response is between bereaved children and their families and how existing networks can provide such a response.

A small pilot study seeking to test the theoretical public health model for bereavement support with adults found that a lack of support from existing networks could contribute to persistent, prolonged grief or complex reactions to a loss⁹⁴. Availability of support for the bereaved has also been described as a risk factor that can influence grief and increase the vulnerability of the bereaved⁹⁵. Therefore, it is of utmost importance that all bereaved individuals receive an effective supportive response. It is argued that bereavement support

in palliative care requires a public health approach, with a partnership between palliative and primary care services, which draw and build upon community resources⁹².

A large amount of bereavement support is currently provided by the community by those involved in the lives of the bereaved, and these 'everyday assets' require support, recognition and appreciation⁹³. As the public health model argues, most bereaved people cope with bereavement with support from their existing networks⁹⁶. Adopting a Compassionate Communities approach would build the communities' capacity to provide social and practical bereavement support without overreaching professional support⁹⁶.

Professionals must be careful not to disrupt this support with unnecessary professional involvement, resulting in the family and friends of the bereaved withdrawing their support⁹⁷. Although previous bereavement research and practice developments have focussed on acute care models and therapeutic interventions, it is now proposed that a population approach to grief is required⁹⁸. Acknowledging the compassionate community's approach, which up until now has focused on end-of-life care for those who are dying, there is a need for this to be developed in the context of grief and bereavement⁹⁸.

A recent article investigating the prevalence of childhood bereavement in Scotland alerts us to the lack of discourse surrounding bereaved children and argues that childhood bereavement is a universal issue requiring public health approaches to death and dying²⁸.

A Scottish study identified the prevalence of childhood bereavement and found that children born into lower-income families are at greater risk of experiencing the death of a parent or sibling²⁸. Bereavement must be understood as a universal issue requiring a public health approach²⁸. Despite bereavement being an individual experience, which may require specialist support, it is affected by the social conditions in which a child is bereaved²⁸.

2.7 Support networks

Death, dying, and bereavement do not occur in a social vacuum^{99,100}. We are beginning to understand that the people within a bereaved person's network can influence how they deal with their loss^{5,101}. Bereavement support can be broadly divided into formal support from professionals and informal sources of support, often from within a person's existing network.

2.7.1 Informal support

In 1979 a seminal study by Berkman and Syme¹⁰² linked a lack of social relationships and community connection to an increased mortality risk. Since then, a growing body of evidence has highlighted the relationship between greater social support and improved physical and mental health¹⁰³⁻¹⁰⁷. When faced with life's challenges, evidence suggests that being alone promotes a sense of isolation and feelings of despair¹⁰⁶

The people within a bereaved person's network are well-placed to provide social support following their bereavement. According to the seminal work of House¹⁰⁸, four types of supportive behaviours make up social support; *emotional support* refers to empathy, love, trust, listening and care; *instrumental support* describes the provision of tangible support, *informational support* refers to advice, suggestions and information that can be used to address problems and finally *appraisal support* provides affirmation, allowing social comparison and self-evaluation¹⁰⁸.

A recent UK report on bereaved people found that informal sources of support came from family, friends, pets, faith communities, colleagues, employers and teachers³. Formal sources of support came from counsellors, bereavement charities, funeral directors, GPs (General Practitioners) and community healthcare professionals, hospitals, and healthcare professionals³. It is argued that a bereaved person's inner resources, along with the support from their existing network, are usually enough to help them following a bereavement⁹⁵. Furthermore, most people seeking help are unlikely to require professional help; instead, they need reassurance that their reactions are 'normal'⁹⁵.

A small Irish study of partners bereaved by cancer found that informal networks of family, friends and neighbours provided valuable support during the first year of bereavement¹⁰⁹. The quality of this support affected their adjustment to their loss; however, it appeared to be time-limited¹⁰⁹. A small pilot study seeking to test the theoretical public health model for bereavement support found that a lack of support from existing networks could contribute to persistent, prolonged grief or complex reactions to a loss⁹⁴. Availability of support for the bereaved has also been described as a risk factor that can influence grief and increase vulnerability⁹⁵. A risk factor for poor psychological outcomes following bereavement is a lack

of social support¹¹⁰. Therefore, all bereaved children and adults must receive an effective supportive response.

For adults bereaved of a parent as a child, their overwhelming need to feel loved and social support during the grieving process was essential⁴¹. Following sudden or violent bereavement in adults, a systematic review found that better social support following sudden and violent bereavement leads to better psychosocial wellbeing¹¹¹. Another quantitative study with older adults found that social support was a protective factor against depressive grief reactions. Good social support was described when the bereaved connected with the supporter and received emotional support and acts of emotional care¹¹². However, a study with bereaved adults found that despite the increased need for support to buffer their high risk of poor emotional and physical outcomes, many were dissatisfied with the social support they received¹¹².

Limited evidence exists on the experiences of those providing support, resulting in a limited conceptual understanding of the factors that encourage or hinder someone from supporting a bereaved person^{23,113}. A systematic review exploring this issue highlighted the need to improve the community's understanding of the uniqueness of grief and how timely social support can positively help a bereaved person²³. There is evidence developed from survey responses telling us who and what is most supportive to bereaved children and adults¹¹⁴^{98,110}. However, little is known about how the existing network can successfully support children and families and why families seek additional support. The majority of studies exploring social support following bereavement focus on bereaved adults^{111,115,116}.

As the evidence has shown, the majority of studies exploring social support following bereavement have focused on bereaved adults. However, a large Chinese study (n=2804), using self-report measures, surveyed children and adolescents to explore relationships between depression and life events and the variables of social support and cognitive styles¹¹⁷. Although the study was not specific to bereavement, it can provide insight into the experiences of social support for children in general. The findings showed that social support was a protective factor against depression for children¹¹⁷. Furthermore, the study found that the more life events children experienced, the less social support they received, which increased their risk of experiencing depressive symptoms¹¹⁷.

It has been argued that social support is a strong determinant of bereavement outcomes, yet little is known about what specific behaviours are helpful, especially for children, how bereaved people interpret and define social support and how the community supports the bereaved^{112,118}. Furthermore, there has been little exploration of who may be the most effective provider of social support¹¹⁹. When considering bereavement support within families, it is vital to take a sociological perspective to understand and respond to families' challenges with a holistic view⁹⁹. However, the sociological perspectives are often omitted⁹⁹.

2.7.2 Formal support

Grief needs to be seen as a normal reaction to loss which may increase vulnerability, rather than viewing it as a mental health problem, which could encourage families to seek help from services rather than their family and friends⁵⁶. Evidence suggests that routine referral for bereavement counselling is not effective, and most people will adapt well to their loss without intervention¹²⁰⁻¹²²

The provision of bereavement support is varied, mainly found within voluntary services and can range from information, befriending and self-help groups to more formalised support groups and psychological interventions such as counselling; there is limited research to tell us what types of support are most effective^{2,3,58}. Further research is required to assess what type of support bereaved people find most helpful and to recognise how professionals and the general public can help^{2,26}.

A recent UK survey (n=1,119) with adult participants found that 28% of respondents received no bereavement support from family, and 46% received no support from friends³. Findings from a previous UK survey (n=2,000) with adult participants found that aside from the support of family and friends, only 9% had received any other support². In addition, 31% of participants believed formal support would have helped, and 38% did not know how to get support or felt uncomfortable asking for it². The current UK survey supports these findings, and four years on found 33% of participants wanted to access bereavement services, but none were available, and 37% did not know how to access support³. A further national survey in the UK (n=8,555) found that support was not always available when needed, and 70% of respondents could not access the support they wanted following their

bereavement⁹⁰. Those respondents cited counselling, financial support and written information on managing grief as the support they wanted but did not receive⁹⁰.

A systematic review exploring children's experiences when a parent had terminal cancer highlighted the role of HCPs in encouraging parents to include their children in what is happening with the ill parent, engaging with open and honest communication¹¹. The review also identified the need for further research to understand the support needs of families experiencing parental illness and death¹¹. Despite HCPs having a role in supporting bereaved families¹²³, many bereaved people do not feel comfortable asking HCPs, hospice staff, priests or social workers for bereavement support². However, acknowledging that not all bereaved people will need professional support, HCPs still have a role and should encourage them to mobilise their existing networks¹²⁴.

The public health approach model of bereavement support highlights the need for formal support for some individuals^{58,92,93}; although, currently, it is unclear how many children or surviving parents access formal support²⁶. Furthermore, it is unknown why some children access support and others do not and the potential barriers faced^{26,31}. A cross-sectional study undertaken in the USA with parents who had lost a child to cancer identified that parents need, want and struggle to access bereavement mental health services; however, common barriers to not accessing support were identified as difficulties finding help and it is too painful to talk about their loss¹²⁵.

Despite a good understanding of how professionals engage with bereavement, less is known about the everyday life experience of bereavement⁵⁷. Evidence suggests that professional support will not be effective for all bereaved people⁵⁷. Early interventions from professionals could disrupt the natural grieving process, cause social networks to withdraw their support and stop bereaved people from seeking their own solutions or recognising the support available to them from within their networks⁵⁷. In contrast, a systematic review identified that brief interventions with children following parental could prevent children from developing traumatic grief or mental health problems¹⁰. Research suggests that when caregivers supporting bereaved children are supported, they have an enhanced capacity to support them^{10,126,127}. Healthcare professionals are well placed to enhance parents' capacity to provide support¹²⁷.

2.8 Grief models and theories

The following section briefly outlines some models and theories relevant to bereaved children and parents. Many attempts have been made to identify and describe the stages and types of grief; however, the reality is that grief is not straightforward, and everyone grieves in their unique way.

Historically, the study of loss and grief was situated within psychology and psychiatry, which led to the understanding that grief could be normal or pathological and is a universal experience⁴. There have been several grief theories, stage and task models of grief that have dominated our understanding of grief. Many were based on the concept of 'grief work' and influenced by attachment theory; they provided processes of grief that the bereaved should follow that would result in a detachment from the deceased allowing them to move on and start new relationships^{4,128-132}.

More recent understanding accepts that grieving is unique, and everyone requires their own way and time to grieve. Although the different phases of grief have provided us with the notion of grief being a process that the bereaved must work their way through, it is argued that there has been a misuse of the stages of grief, and they have not always been helpful¹³³. Further criticism of stage theories of grief is that despite the appeal of making sense of a complex process using a conceptual order to work through to find 'recovery' and 'closure', they fail to recognise the grieving experience as complex, diverse, and idiosyncratic¹³⁴. Furthermore, the stage models fail to recognise other needs that bereaved people and their families may experience, such as physical, psychological, social and spiritual needs¹³⁴.

2.8.1 Continuing bonds

The term continuing bonds was devised to offer an alternative model to grieving¹³⁵.

Continuing bonds shows that successful grieving did not mean severing bonds with the deceased, thus refuting previous stage models which alleged the need to sever bonds with the deceased^{131,136}. Continuing bonds suggests not 'letting go' of the deceased; bereaved people need to negotiate and renegotiate the meaning of their loss over time¹³⁶.

Bereavement is not a state from which one 'recovers'; continuing bonds allow the bereaved

to adapt and change following their loss by constructing and reconstructing new connections and relationships with the deceased¹³⁶.

Following a parental death, continuing bonds facilitate children's coping¹³⁶. A narrative review exploring how children continue bonds with deceased family members found that developing a connection with the deceased family member was a crucial element of their grief¹³⁷. Children had different ways they connected with the deceased, which were categorised into unintended connections, which occur spontaneously and unintentionally¹³⁷. The next were intended connections, which were when children sought to remember and reconnect with the deceased; and finally, internalised connections which developed and evolved as the young person grows up¹³⁷.

2.8.2 Tasks of mourning

The tasks of mourning recognise that grieving is an active process which engages with four tasks which are a process to adapt to loss⁴². Grief does not fit neatly into boxes, and bereaved people will move back and forth through the different tasks, which include: 1) accepting the reality of the loss, 2) processing the pain of the grief, 3) adjusting to a world without the person who died, and 4) finding an enduring connection with the person who died whilst starting a new life⁴². The tasks of mourning are relevant to children, but they must be understood in terms of children's cognitive, emotional and social development⁷.

2.8.3 Growing Around Grief Model

Tonkin, a grief counsellor developed a theory of grief following her work with a mother who had lost her child (Figure 3)¹³⁵. She found that when working with bereaved people, their grief did not end as she had expected it would¹³⁵. Instead, she found that grief stays the same, but life grows around it¹³⁵. At times the intensity of grief is the same as when bereaved people are newly bereaved, but there are times when they can live a life outside of their grief¹³⁵. Counsellors providing bereavement support have found Tonkin's model helpful for clients to normalise their grief¹³⁸.

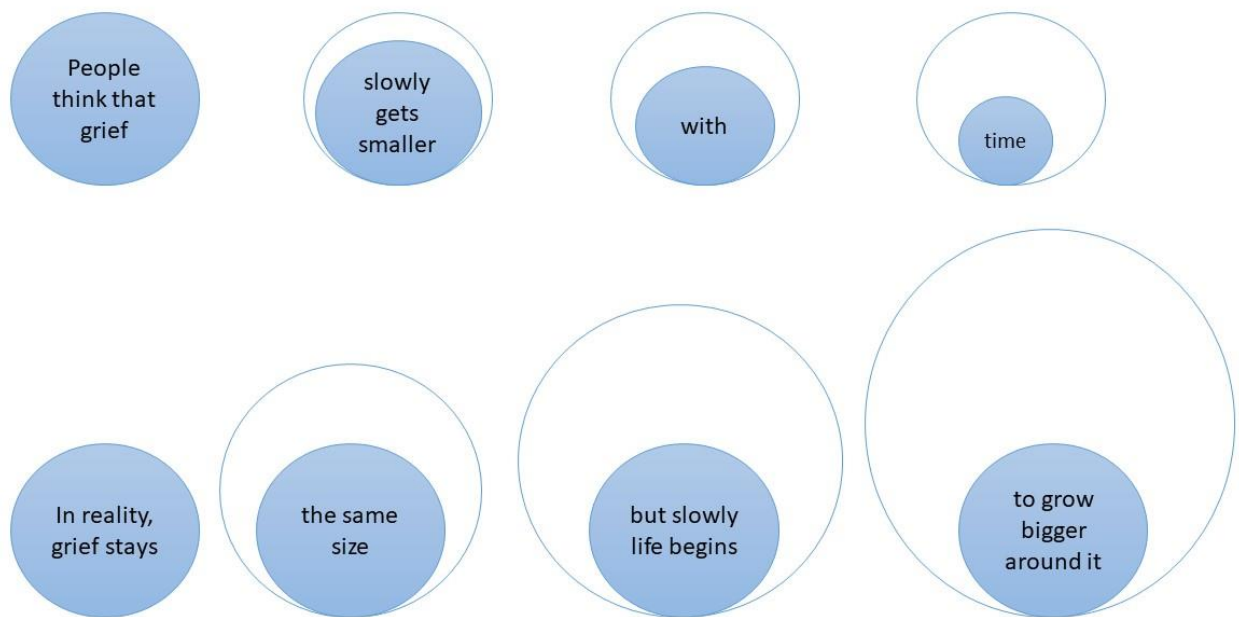


Figure 3 Growing Around Grief Model developed by Tonkin, image adapted from *whatsyourgrief.com*^{135,139}

2.8.4 Death within a family

Many grief theories, like those previously described, focus on the impact of grief on the individual, leaving a gap in evidence of family approaches¹⁴⁰. Over 25 years ago, Gilbert claimed that to understand grief in families, there was a need to recognise individual and relational factors happening simultaneously¹⁴¹. Within the family, individuals affect and are affected by others as they grieve within their family's social and relational contexts¹⁴¹. However, despite her claim, little was done to integrate individual and family perspectives¹⁴⁰.

The integration of perspectives is vital to deepen the evidential understanding, identify the influential factors in the family domain, and help identify those most vulnerable¹⁴⁰. Within the context of parental bereavement, it is increasingly recognised that it is necessary to move beyond the focus of bereavement at the individual level and take a family approach¹⁴⁰.

There can often be assumptions about grief in a family context. For example, it can be assumed that each family member's grief will be the same because they are grieving the same person¹⁴¹. However, depending on the individual's relationship with the person who

died, their loss may be deemed more significant because of their relationship with the person who died¹⁴¹. Alternatively, they may feel their loss was insignificant and feel uncomfortable when expected to express their loss in front of other family members¹⁴¹.

2.8.5 Family adaption to loss

A family systems perspective describes the transactional process of death in which there is a shared life cycle that involves the deceased and those who are left behind¹⁴². This process acknowledges the finality of death and the continuity of life, which will be the most challenging life process a family must confront¹⁴². This approach concentrates on the social context of death and how the family adapts to that loss¹⁴³.

Following a parental death, children and their surviving parents must come to terms with the loss on them as individuals and the effects the loss has on the family as a whole, often whilst attempting to support each other in their grief¹⁴¹. A death in the family creates multiple losses for the family members, including those unique relationships with the deceased, functional roles, them as an intact family unit and their future hopes and dreams¹⁴³.

Four family tasks are proposed, similar to those of Worden, which emphasise the relational aspects of mourning, recognise individual grief responses, facilitate adaption for the individual family members, and strengthen the family as a unit¹⁴⁴. The tasks include; 1) a shared acknowledgement of the death and loss, 2) a shared experience of the loss, 3) the reorganisation of the family system and 4) reinvestment in other relationships and life pursuits¹⁴⁴.

The model encourages open communication, sharing grief, involving the family in rituals, and expressing feelings¹⁴². The goal of bereavement is to adapt to the loss by allowing the individual experiences of grief and strengthening the family as a functional unit¹⁴². The model emphasises the vital role of extended family and social and economic resources in supporting bereaved families to adapt to the loss however is not forthcoming with explaining how extended family and social networks can best support families¹⁴².

2.8.6 A dual process model of coping with bereavement

The Dual Process Model of Coping with Bereavement builds on the phase and task models of grieving¹⁴⁵. Developed from a cognitive stress perspective, the model describes grief as a

process of oscillation between two different aspects of responses to loss: loss-orientated and restoration-orientated¹⁴⁶. The model normalises grief and identifies what constitutes a healthy grieving process¹⁴⁶. The grieving person focuses on the restoration plans or activities when focusing on the loss becomes too much to bear. Both orientations are sources of stress; they are burdensome and associated with distress and anxiety¹⁴⁶. They suggest the coping task may not be to return to the level of functioning before the bereavement but to negotiate a meaningful life without the deceased¹⁴⁶.

The model was extended (Figure 4) to incorporate the individual and family level, recognising that people do not grieve alone; they grieve with their families who have also experienced the loss¹⁴⁰. In addition, the extended model integrates Worden's four tasks⁴², allowing an understanding that family dynamics can impact the adjustment of an individual in positive or negative ways. For example, families may experience reduced finances, legal processes and changes within their relationships¹⁴⁰.

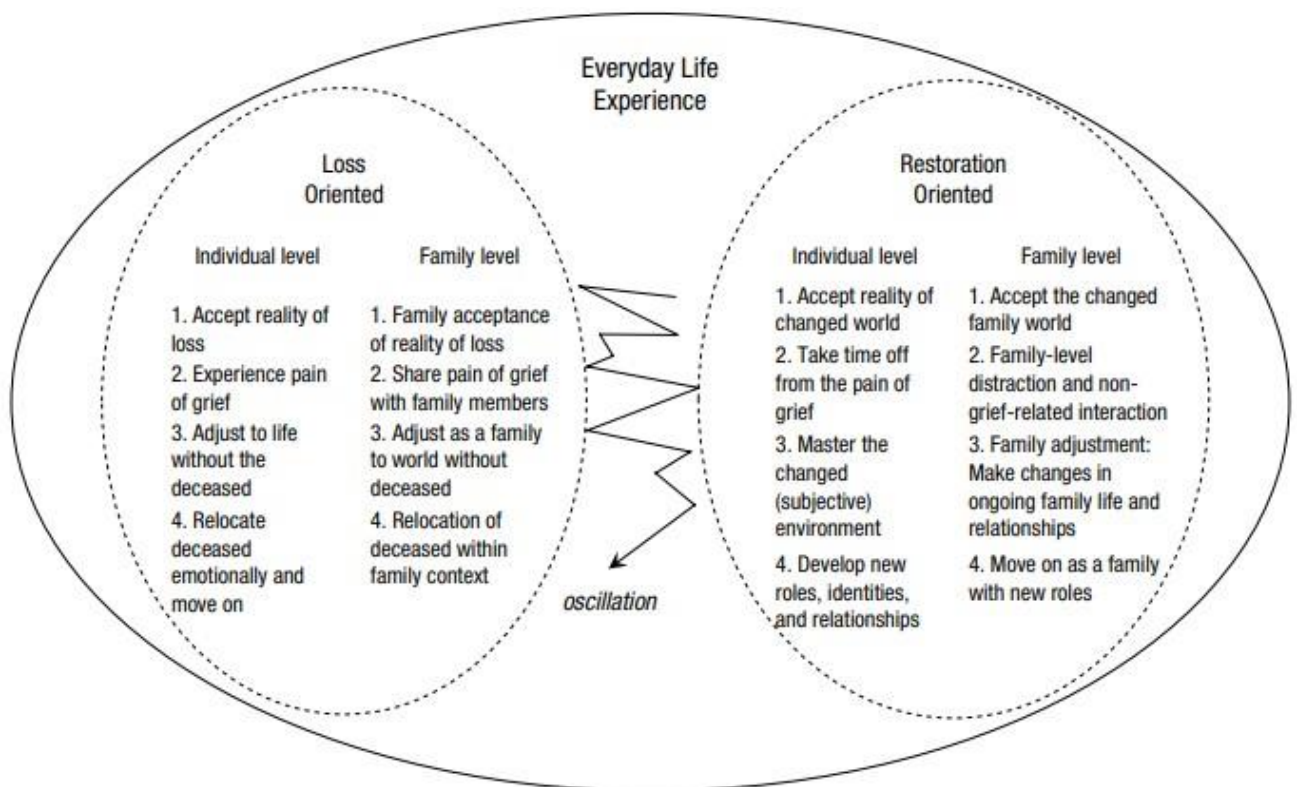


Figure 4 The Dual Process Model-Revised: Individual and Family Level Coping, from Stroebe and Schut¹⁴⁰

The Dual Process Model has been evidenced to represent the experiences of bereavement and how individuals cope accurately; moreover, interventions adopting the Dual Process

Model could effectively treat grief, stress and coping¹⁴⁷. The Dual Process Model – Revised has made good progress in integrating the loss and restoration-orientated tasks at the individual and family levels¹⁴⁰. However, the researchers also acknowledged the limitations; different family roles and relationships were not addressed, and other sources of support in the absence of family¹⁴⁰.

2.9 Summary

This chapter has highlighted the prevalence of childhood bereavement and explored the impact and needs of bereaved children. In addition, the chapter has argued that childhood bereavement is a public health issue and highlights the importance of support networks. The lack of research undertaken with children has also been highlighted. Finally, the chapter gave an overview of some of the recognised grief models and theories to help understand grief and set it within the family context.

3 Aims and objectives

3.1 Overall study aim

The study aims to explore how children and families best support each other after a parent's death, and to understand how those within their existing networks can provide a supportive response.

3.2 Objectives

To achieve these aims the following objectives were set:

1. To identify and synthesise previously published evidence of experiences of support for children and surviving parents' following the death of a parent.
2. To explore children's experiences and perspectives of support needs.
3. To explore surviving parents' experiences and perspectives of support needs.
4. To consider how existing support networks can provide a supportive response and why it is helpful.
5. To synthesise the information from objectives 1-4 and develop and/or refine existing bereavement theories and models in the context of bereavement support for children and surviving parents following parental death, in order to improve understanding of how to provide a supportive response.

Objective 1 is achieved through a systematic review presented in Chapter 4.

Objectives 2, 3 and 4 are achieved through the qualitative study. The qualitative findings of the study are presented in Chapters 7, 8 and 9. Objective 5 is achieved through the developed substantive theory presented in Chapter 9.

3.3 Qualitative study design

The qualitative study will be situated in the social constructivist paradigm, adopting a relativist ontology and interpretivist epistemology. Following a constructivist grounded theory approach to explore children's and parents' support experiences. The study design is discussed in further detail in Chapters 5 and 6. An overview of the qualitative study design is provided in Table 5.

Table 5 Overview of the qualitative study design

Research paradigm	Social constructivism
Ontology	Relativism
Epistemology	Interpretivism
Methodology	Constructivist grounded theory
Method(s)	In-depth interviews

4 Systematic literature review

4.1 Introduction

This chapter presents the first component of this thesis: a systematic review. It presents the methods used, the findings from child and parent perspectives, followed by discussion.

The background chapter highlighted the importance of a supportive response from a bereaved person's existing network. Despite this, there is a lack of understanding of what a supportive response is for children and surviving parents following parental death.

Furthermore, there is limited child-centred research and little evidence of what support is helpful and when for bereaved children^{26,28}.

4.2 Aim

To identify and synthesise previously published literature exploring support experiences of parentally bereaved children and their surviving parents.

4.3 Methods

A qualitative systematic review and thematic synthesis were conducted. The review followed an *a priori* protocol and was reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocols (PRISMA) 2009 guidelines¹⁴⁸. Before the search was completed, the review protocol was registered on PROSPERO (registration no. CRD42020166179).

4.3.1 Search Strategy

A detailed search strategy was developed in Ovid MEDLINE with assistance from a university information search specialist (Table 6). The search was then adapted and used in the other databases. The search strategy was designed to include all potentially relevant qualitative studies (or studies with a qualitative component), using both Medical Subject Heading (MeSH) terms and text word searches to increase inclusivity.

Table 6 Medline search strategy

1. exp child/ or exp child, preschool/	22. Attitude to Death/
2. exp infant/ or exp infant, newborn/	23. Needs Assessment/
3. exp INFANT/	24. unmet needs.ti,ab,kf.
4. Adolescent/	25. psychosocial needs.ti,ab,kf.
5. Young Adult/	26. exp social support/ or exp psychosocial support systems/
6. (child* or adolescen* or teen*).ti,ab,kf.	27. help-seeking behavior/
7. or/1-6 [child concept]	28. "Health Services Needs and Demand"/
8. exp bereavement/ or exp grief/	29. ((bereav* or grief or griev*) adj2 (support or service* or counsel* or group* or program*)).ti.
9. (bereave* or grief or grieving or death* or dying).ti,ab,kf.	30. (need\$ adj2 assessment\$).ti,ab,kf.
10. 8 or 9 [broad death/bereavement concept]	31. (coping or coped or copes).ti,ab,kf.
11. exp parents/ or exp fathers/ or exp mothers/ or exp single parent/ or exp surrogate mothers/	32. ((child* or adolescen* or teen* or parent* or mother* or father*) adj2 (experience* or feeling* or emotion* or view* or perception* or describ* or description*)).ti,ab,kf.
12. (parent* or mother* or father*).ti,ab,kf.	33. exp Family Relations/ or *Psychology, Adolescent/
13. 11 or 12 [parents]	34. *Family/px [Psychology]
14. 10 and 13 [broad death concept AND parents]	35. or/21-34 [child/family experience,needs - broad third concept]
15. exp parental death/ or exp maternal death/ or Widowhood/	36. 20 and 35 [child AND parental death AND family experience/needs]
16. ((parent* or mother* or father*) adj2 (death* or bereave* or grief or grieving or widow*)).ti,ab,kf.	37. limit 36 to (case reports or comment or editorial)
17. (surviv* adj2 parent*).ti,ab,kf.	38. 36 not 37 [remove case reports, editorials, comments]
18. 15 or 16 or 17 [specific parental death concepts]	39. exp *fetal death/ or exp *infant death/
19. 14 or 18 [death AND parents or parental death specifically]	40. exp parental death/
20. 7 and 19 [child concept AND parental death]	41. 39 not 40
21. exp Adaptation, Psychological/	42. 38 not 40

The SPIDER (Sample, Phenomena of Interest, Design, Evaluation, Research Type) tool was used to develop the search strategy chosen as it has been refined for qualitative research that intends to include the most relevant qualitative research studies (Table 7)¹⁴⁹. The search terms were developed to incorporate three concepts to explore the support experiences for children and surviving parents following parental death:

- Concept one identified the population using terms for children, adolescents, young adults, parent, widow, and surviving parent
- Concept two identified the phenomenon of bereavement and death
- Concept three identified the population's support experiences and needs

The search was then modified to exclude studies related to child death and case studies. Electronic searches were undertaken in September 2021 using the databases of Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily (1946 to September 9, 2021), Ovid Embase 1974 to 2021 September 9, OVID PsycINFO 1967 to September Week 2 2021, CINAHL Complete via Ebsco and the British Nursing database via Proquest. In addition, grey literature searches were conducted using Google Scholar and OpenGrey to identify research not indexed in the electronic databases and unpublished data. Forward and backward citation searching of relevant studies was used to supplement the search.

Table 7 SPIDER tool

Sample	Parentally bereaved children and surviving parents
Phenomena of interest	Support following parental death
Design	Qualitative methods including interviews and surveys
Evaluation	Qualitative themes include but are not restricted to the samples experience following a parental death, including support and coping
Research Type	Any study that has a qualitative element that describes the experience of children, surviving parents or caregivers of the initial post-death family environment following the death of a parent

4.3.2 Data Parameters

Searches had no date parameters set.

4.3.3 Inclusion and Exclusion Criteria

A set of inclusion and exclusion criteria (Table 8) was developed to ensure that only studies relevant to the review aim were included. Studies were excluded if participants were aged over 18 years or adults who were bereaved as children (to avoid the known issues with recall bias in this group). There were no minimum age criteria, purposefully to develop an understanding of all research undertaken with bereaved children and what different age groups have participated.

4.3.4 Screening

A PRISMA diagram of the study illustrates the process of selecting studies relevant for inclusion (Figure 5). Search results were imported into an Endnote database and Covidence systematic review software for screening. Duplicates were removed. Within Covidence, titles and abstracts were firstly screened in duplicate by two reviewers against the inclusion/exclusion criteria. Next, full-text papers were retrieved via the University Libraries, the British Library, and contacting authors directly. Once retrieved, full-text articles were screened in duplicate and independently considered against the inclusion criteria. Finally, studies not meeting the inclusion criteria were recorded with the reason(s) for exclusion. Any disagreements were flagged at all stages within Covidence and consensus was achieved through discussion or by consulting a third reviewer.



PRISMA 2009 Flow Diagram

Database	Number of records
MEDLINE	4368
Embase	5029
PsychINFO	3170
CINAHL	3241
Pro Quest	320
Total	16,128

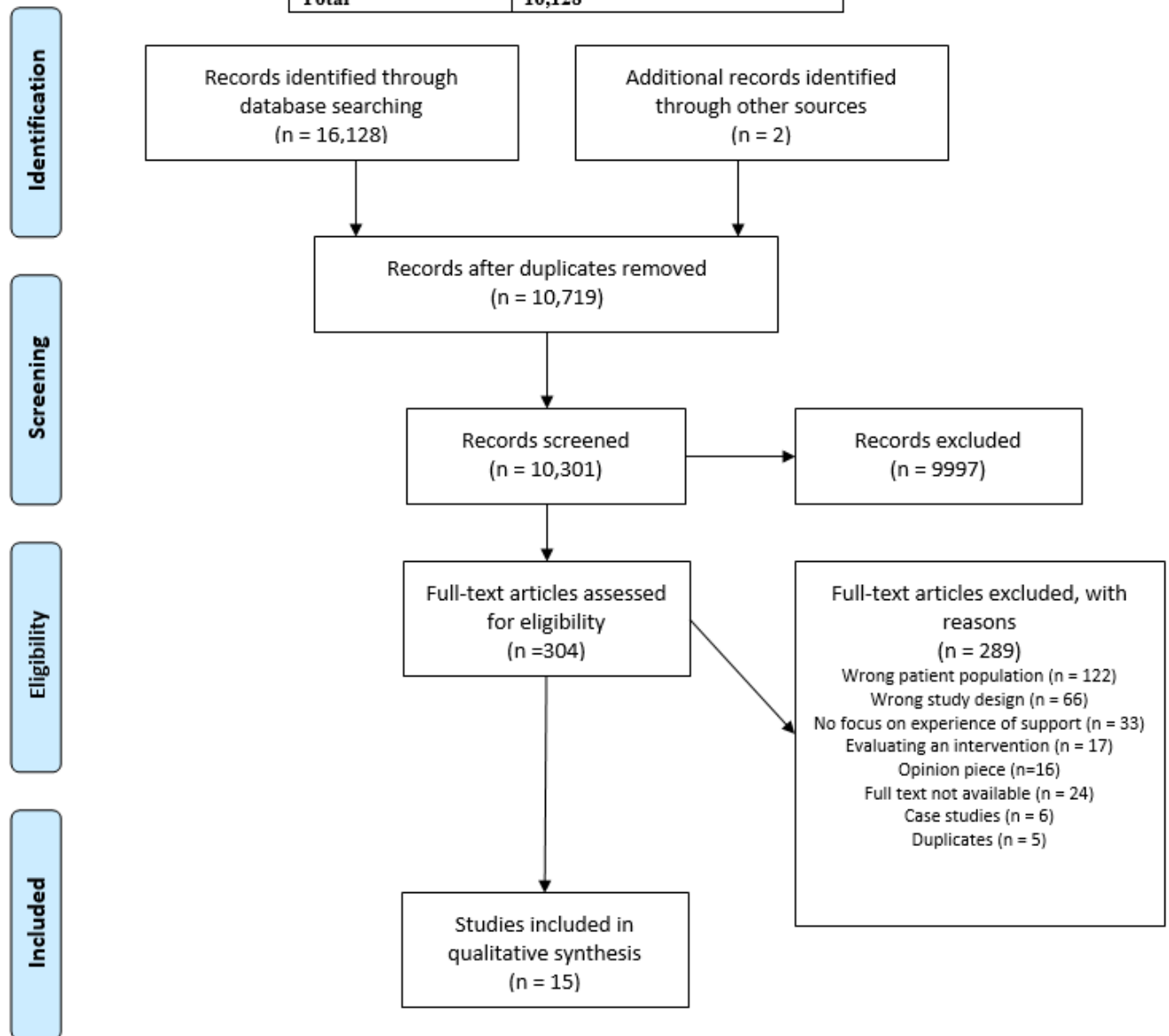


Figure 5 PRISMA flow diagram

Table 8 Inclusion and exclusion criteria

	Inclusion	Exclusion
Participants	Children or adults who were < 18 when their parents died . Surviving parents of children < 18 when the other parent died.	Children who have died. Parents whose children have died. Children whose siblings have died.
Study design	Qualitative studies, questionnaires, and surveys if they were qualitative in design, interviews, narrative research studies that describe in the words of children and surviving parents, their experience of support following the death of a parent. Mixed method studies which include a qualitative aspect that describe in the words of children and surviving parents their experience of support following the death of a parent.	Quantitative studies that do not give the children's or surviving parents experience. Surveys or questionnaires that do not describe the children's or surviving parents' experience. Case studies, case series, reflection/opinion pieces.
Interventions	Studies that describe children's or surviving parents' experience of support immediately following a parental death.	Studies that focus on the long-term experience or impact following a parental death. Studies that do not describe experiences in the immediate post-death family environment. Studies that evaluate support interventions.
Language	English Language papers.	Non-English language papers.
Setting		There will be no restrictions by setting or country.
Date		There will be no restrictions by date.

4.3.5 Quality Appraisal

While critical appraisal is essential to ensure robust judgements on trustworthiness, value, and relevance¹⁵⁰, no single critical appraisal checklist is all-encompassing^{151,152}. Therefore, a checklist offering good ground rules, but some flexibility was sought, rather than a strictly protocol-driven tool. The Critical Appraisal Skills Programme (CASP) checklist¹⁵³ was therefore chosen to appraise the quality of the included studies. A widely accepted critical appraisal tool, it allowed systematic consideration of issues related to the quality and

trustworthiness of the selected studies and was devised for use with health-related research^{153,154}. It also offers structure and a systematic process to review studies and recommended for novice researchers^{152,155}. Studies were assessed for quality using the CASP checklist and 25% of included papers were independently verified by a second reviewer. Studies were not excluded based on the quality assessment recognising that those included studies with lower methodological quality could provide similar findings and credible and transferable data in this under-researched field^{26,155}.

4.3.6 Data Extraction

Data were managed using an extraction table created in Covidence. The first author extracted data which included authors, year and country of study, study aims, participant demographics, recruitment, research design, key findings, theoretical frameworks, and methodological criticisms. A second reviewer independently verified data extracted from 25% of the included papers. The study characteristics are presented in Table 10. Full-text papers were uploaded to NVivo software¹⁵⁶. Results sections of the included studies, participant quotes, and any text describing findings were included as data for synthesis.

4.3.7 Qualitative Thematic Synthesis

As eligible studies were qualitative, a thematic synthesis was conducted based on the approach by Thomas and Harden¹⁵⁷. This involved three steps: (1) coding of text, (2) developing descriptive themes, and (3) generating analytical themes that will produce a new interpretation that will go beyond the original studies. Child and parent perspectives were analysed separately. The reviewer became immersed in the studies by reading and re-reading the included studies to allow themes to develop while maintaining connections between concepts and context¹⁵⁸. Findings were coded line by line using NVivo software¹⁵⁶, allowing findings to remain close to participants' experiences; helpful with child participants whose experiences can be marginalised¹⁵⁹. The synthesis process was iterative; descriptive themes were developed by mapping the participants' perspectives and experiences against the review aim. Discussions between the research team facilitated mutual agreement on the descriptive themes developed from the included studies. These findings were compared and interpreted across the studies to generate new analytical constructs¹⁵⁷. Thematic synthesis has previously been used to explore experiences and perspectives and thought to suit this review's aim of exploring different experiences of bereavement support¹⁵⁷.

4.4 Results

4.4.1 Study selection

Database searching identified 10,301 unique studies following deduplication. Of these, 9,997 studies did not meet the inclusion criteria and were excluded. Full-text articles were reviewed for the 304 remaining studies, of which 289 were excluded leaving 15 studies eligible for this review (Table 10). The identification, screening, eligibility, and inclusion process for the included studies are summarised according to PRISMA guidelines in Figure 5.

4.4.2 Study characteristics

All 15 studies^{54,75,100,160-171} used different qualitative methodologies. They were described as phenomenology^{54,168,169,171}, grounded theory^{100,160}, ethnography^{162,163}, fundamental qualitative description¹⁶¹, qualitative approach with a descriptive and interpretive design¹⁶⁷, qualitative descriptive research design and methodology¹⁶⁵ exploratory study⁷⁵, and pragmatic multi-method design¹⁶⁴. In addition, two studies used qualitative methods but did not describe the methodology used^{166,170}. Nevertheless, all qualitative approaches were appropriate to address the research goals and allow researchers to collect rich and detailed data about bereavement experiences from small numbers of participants¹⁷².

Two studies used focus groups^{164,171}, which can be beneficial and empower some children to share their experiences. However, the dynamics within focus groups can affect contribution, and for some children, it may not be easy to talk about a sensitive topic within a group¹⁷³.

The remaining studies used face-to-face, in-depth, or semi-structured interviews. Interviews allow flexibility and adaptability, using open-ended questions to explore ideas and probe deeper¹⁷². All the studies adopted purposeful sampling strategies, which are crucial to identify and recruit participants with experience of parental bereavement^{152,174}. Most participants were recruited from support services, meaning many participants could have received formal bereavement support, although this was not represented in the data. The sample size ranged from 4 to 39 participants per study. There were 210 child participants aged 6 to 18 years old. There were over 54 parent participants. Not all studies reported the number of parent participants^{75,166}. Participants were from eight countries, including Canada (2), Denmark (2), Iran (1), South Africa (1), Sweden (1), Taiwan (1), Uganda (1), UK (2), and the USA (4). Studies were published between 1975 and 2021. Only one study

justified the ages of child participants (10-12 years), which was thought to be a particularly vulnerable and under-researched group¹⁶⁵. Seven studies collected data directly from children^{54,160-165}, three collected data from children and parents^{75,166,167}, and the five remaining studies collected data from parents^{100,168-171}. Although data collection and analysis were rigorous in most studies, some did not clearly describe data analysis^{160,168,170}. Children and parents were interviewed at different times following their loss ranging from 2 months to 13 years. Some studies interviewed children alone^{161,163,164}. One had parents present during the interviews¹⁶⁷. For the remaining studies, it was not clear if children were interviewed alone or in the presence of their parent.

It is acknowledged that the included papers derive from different countries and contexts. Culture can influence how bereavement and grief are dealt with in relation to help-seeking and coping, and cultural traditions surrounding death, bereavement and mourning¹⁷⁵. Furthermore, social and welfare systems and policies vary drastically between countries, affecting how children are supported. For example, Danish schools have bereavement response plans which guide how to respond to grief and what needs to be done to support a child following a bereavement¹⁷⁶. In contrast, children bereaved in Uganda have little resources available to them due to the country's limited domestic funds and health infrastructure¹⁶².

4.4.3 Quality appraisal

The design of the studies was considered in the previous section. The findings from the quality appraisal using the CASP tool are displayed in Table 9. The CASP tool considers three broad issues related to the quality and validity of studies. These include whether the studies are valid, the results and whether they will help locally¹⁵³. Those issues are considered using ten questions with three responses, 'yes', 'can't tell' or 'no'¹⁵³. As highlighted in previous research, there is a need for greater nuance in those response options¹⁵⁴. Often responses are more complicated and require further description than is permitted¹⁵⁴. Therefore as demonstrated by other researchers using this tool, a fourth response was added 'relatively', meaning partly or to some extent, which would account for studies that had made a reasonable attempt to fulfil that particular domain¹⁵⁴. The difficulty of assessing quality in qualitative research has identified that sometimes it may be unclear if a quality issue is a result of the study's methodology or the reporting of the study, which is often limited by

publishers requirements¹⁵⁴ - applying the tool to the included studies deemed all studies to be moderate to good quality.

Only half reported the ethical considerations well. All used appropriate data collection tools, including interviews, open-ended questionnaires, or focus groups that addressed the study's aims. Only a third of the studies reported the researcher's positionality. This is important; the need to understand a researcher's own personal characteristics, experiences, beliefs and biases and how this affects the research process^{177,178}. All studies used participant quotes, which supported study findings. All papers provided valuable findings and insight into this under-researched area.

Table 9 Results of critical appraisal using CASP tool

First author Year	Key to CASP Questions: Answers (questions 1-9): Yes Can't tell/relatively No 									
	1. Clear statement of aims?	2. Qualitative methodology appropriate?	3. Research design appropriate to address aims?	4. Recruitment strategy appropriate to address aims?	5. Data collected addressing research issue?	6. Researcher/participant relationship adequately considered?	7. Have ethical issues been considered?	8. Data analysis sufficiently rigorous?	9. Clear statement of findings	10 How valuable is the research? Answer (question 10): Very valuable Average value Poor value
Asgari 2020	Yes	Yes	Yes	Relatively	Yes	Can't tell	Can't tell	Yes	Yes	Highlights post-traumatic growth following traumatic and sudden loss.
Berman 1988	Yes	Yes	Relatively	Yes	Yes	No	Can't tell	Yes	Yes	Highlights challenges and support needs at diagnosis.
Cranwell 2007	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Highlights importance of open and honest communication.
Harms 2010	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Identifies needs of adolescents and if needs have been met.
Holmgren 2019	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Describes the challenges faced by widowed fathers.
Hsu 2002	Yes	Yes	Yes	Relatively	Yes	Can't tell	Can't tell	Yes	Yes	Describes the experience of adolescents when a parent has advanced cancer.
La Freniere 2015	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Explores teenagers reasoning following recent parental death to cancer.
Lowe 2010	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Can't tell	Yes	Provides perspectives, strategies and interventions to work with widows.

First author Year	Key to CASP Questions: Answers (questions 1-9): Yes Can't tell/relatively No 									
	1. Clear statement of aims?	2. Qualitative methodology appropriate?	3. Research design appropriate to address aims?	4. Recruitment strategy appropriate to address aims?	5. Data collected addressing research issue?	6. Researcher/participant relationship adequately considered?	7. Have ethical issues been considered?	8. Data analysis sufficiently rigorous?	9. Clear statement of findings	10 How valuable is the research? Answer (question 10): Very valuable Average value Poor value
Lytje 2018	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Provides in teenager's words the experience of losing a parent to cancer.
MacPherson 2007	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Describes children's needs when a parent has died.
McClatchey 2018	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes		Describes widowed fathers' experiences with their dependent children.
Parsons 2021	Yes	Yes	Yes	Can't tell	Yes	Can't tell	Yes	Yes	Yes	Provides recommendations to develop resilience and coping strategies.
Silverman 1975	Yes	Yes	Relatively	Yes	Relatively	Can't tell	Can't tell	Can't tell	Relatively	Highlights widows' perspectives on how they and their children cope.
Taylor 2016	Yes	Yes	Yes	Relatively	Yes	Can't tell	Can't tell	Yes	Yes	Describes the challenges of young widowhood.
Weber 2019	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Identifies family's ability to adjust is affected by their ability to communicate.

Table 10 Study characteristics of included studies

Author Year Country	Aims/objectives	Participant demographics Time since death Cause of death	Recruitment	Research design Methodology Methods Analysis method Creative methods Interview details	Relevant findings Key findings/themes	Methodological criticisms
Studies with child participants only						
Asgari et al. 2020 Iran	To explore the experience of post-traumatic growth (PTG) among 14 Iranian adolescents who have experienced a sudden loss of their fathers.	Bereaved Children (n=14, F-9, and M-5) aged 14 to 17, all Iranian. Interviewed 4-9 years after the death of father Cause of death heart attack (7), stroke (1), fire (1), suicide (1), accident (4)	Purposive sampling, no further details.	Phenomenology. In-depth, semi-structured interviews. Descriptive phenomenology using the 7 step Colaizzi method. None. Unclear if parents present for children's interviews.	One of the most important findings in this research was the role of time in experiencing PTG. All participants needed some time to feel positive changes in their life, and they experienced growth through having a positive vision of life, social support and networks, school activities, psychological wellbeing, and to find meaning for their existence.	No discussion on ethical considerations, consent, or recruitment process. Small homogenous sample. Possibility of interviewer's bias acknowledged. Good use of participant transcripts to support findings. No justification of age chosen for participants.
Cranwell 2007 UK	To explore how decisions and assumptions by adults have a direct bearing on the progress of a child through grief before and following death.	Bereaved children (n=30, F-17, M-13) 6-12 years old, unknown ethnicity. Unclear of time since parental death, for some it was 2 or 3 years. Unclear causes of death, 10 were very sudden,	Recruited from local education authorities, church schools and counselling organisations.	Grounded theory Semi-structured interviews. Unknown data analysis. None. Unclear if parents present for interviews; some interviewed in school.	Adults' interventions can affect child's progress through grief. Children need truthful information about impending death, knowing the cause, reassurance the child is not to blame, and that everything possible had been done. Children should have the option to be involved in rites of passage. Recommend need for loss, death, and bereavement education in school and for parents and professionals.	Fairly large sample with younger children which is not normally seen in these studies, other than age no further demographics of children given. No information included about participant ethnicity. Included children who had and had not accessed formal support. Ethical considerations well described, including post-interview support. No

		bereavement by suicide, murder or human or natural disasters not included.				information to describe data analysis process. Limited use of children's narratives.
Harms et al. 2010 Uganda	To describe the experiences of entering orphan hood from the perspectives of Ugandan youth orphaned by HIV (Human Immunodeficiency Virus) or AIDS (Acquired Immunodeficiency Syndrome).	Bereaved children (n=13, F-8, and M-5), aged 12-18, all Ugandan. 7 lost both parents, 5 lost father and one mother interviewed between 2 months and 13 years after death of parent. Cause of death HIV/AIDS.	Recruited from 2 non-government organisations.	Fundamental qualitative description. In depth, semi-structured interviews. Qualitative content analysis. Family genogram to illustrate family relationships, organisation, and structure. Children interviewed alone.	Becoming an orphan is a dynamic process, marked by several difficulties and challenges. Orphan hood begins with parental illness, not death. The implications of parental death to HIV/AIDS starts the onset of several struggles including poverty, lost educational opportunities, living with extended family systems marked by difficulty, potential exploitation within their homes and culturally specific forms of stigma relating to their HIV/AIDS orphan status.	Small homogenous sample size. Narratives could have been influenced by non-governmental organisations (NGO) staff responses and monetary support received. Clear methods and methodology. Good ethical considerations including post-interview support. Data specific to Ugandan youths orphaned by HIV/AIDS.
Hsu et al. 2002 Taiwan	To explore the lives of fatherless children in Taiwan.	Bereaved children (n=30, F-18, and M-12) aged 9-18, ethnicity not documented. Unknown time since death. Cause of death, cancer (9), accident (6), non-cancerous disease (4) and suicide (1).	Unknown	Narrative. Open-ended questions in the form of narratives. Interpretive ethnographic techniques. None. Unclear who present for interviews.	The responses of adolescents and mothers to the deaths of their fathers and husbands are interwoven with Taiwanese cultural ideology, including concepts of one man in a lifetime, continuity wholeness, a harmonious household and taboos associated with death. The death of a father gives children a sense of incompleteness. They worry about their mother, they hold their feelings tightly inside to protect the family; this can create distance between the children and peers, siblings, and other relatives. This can affect their normal development. Children maintained a connection with their father.	Study aims not clearly stated. Small sample, limited data on participants. Unclear how participants recruited. No acknowledgement of ethical consideration or bias. Good use of children's narratives to support discussion.

<p>La Freniere et al.</p> <p>2015</p> <p>USA</p>	<p>To investigate peer interaction and peer support for parental bereaved children and adolescents.</p>	<p>Bereaved children (n=35, F-20, M-15) aged 6-15. Caucasian (33), Native American/Mexican American (1), Asian American (1).</p> <p>Interviewed 8 to 36 months after death of parent.</p> <p>Cause of death anticipated (20), sudden (15).</p>	<p>Recruited from funeral homes, a hospice organisation, and a newspaper story about the project.</p>	<p>Ethnography.</p> <p>Semi-structured interviews.</p> <p>Grounded theory constant comparative method.</p> <p>None.</p> <p>Parents present in home but not interview area.</p>	<p>The study goes further than recognising types of social support and the distinction between received and perceived support and the framing of the transactional nature of support. It recognises support ambivalence, avoidance, and even active rejection of support, the bereaved child's need for different types of support at different times or under different conditions and the importance of who is giving the support. It also shows negative support in the form of taunting and how peer support can hinder rather than help a complex situation.</p>	<p>A relatively homogenous study in terms of social-economic status and race. Self-selection bias. Only one child per family included in final sample to assure the statistical independence of each participant. No clear statement of aims of study. Discussion is presented with the corresponding theme rather than an overall discussion at the end of the study. No acknowledgement of ethical considerations or bias.</p>
<p>Lytje et al.</p> <p>2018</p> <p>Denmark</p>	<p>To explore how children, experienced their return to school and the support received following bereavement.</p>	<p>Bereaved children (n=39, males, and females) aged 9-17. Unsure of ethnicity.</p> <p>Participated 3 months to 6 years following death of parent.</p> <p>Unknown cause of parental death.</p>	<p>Recruited from 5 different grief groups across Denmark.</p>	<p>Pragmatic multi method design framework.</p> <p>Thematic analysis, supported by document analysis.</p> <p>Focus groups.</p> <p>Video for recruitment.</p> <p>Focus groups with just children.</p>	<p>Bereaved children often struggle to return to school following loss, classmates uncertain how to welcome them back. Made them feel different, so they would pretend nothing had happened or try to overcome the new situation. Choosing the second sometimes they were avoided so left feeling isolated and in rare cases taunted. Teachers tried to actively support for most children, this could be overwhelming. In the initial period of return children need structure returning to school. As the months passed schools neglected to attend to the loss, everyone had forgotten making it to be difficult to be in school.</p>	<p>Recruited from 5 different grief groups, so all had accessed support, recruited as they had experience of talking in a group about bereavement and had existing support mechanisms in place. Very good ethical considerations, including consent process. Good use of children narratives. No acknowledgement of bias. Failed to provide any participant demographics in paper, including gender.</p>
<p>Parsons</p> <p>South Africa</p>	<p>To describe how children experience losing a mother during</p>	<p>Bereaved children (n=22) aged 10-12. Gender not documented. Sample</p>	<p>Convenience sampling to locate 10 schools, then</p>	<p>A qualitative descriptive research design and methodology</p>	<p>Children's experiences of losing a mother during middle childhood, their concept of death and various responses to losing their mother, and the coping strategies they</p>	<p>Although the participants were from the same school district, they were fairly heterogenous in terms of</p>

2021	middle childhood. The second aim is to identify coping strategies to help them come to terms with this traumatic loss.	was heterogenous in terms of race, culture, gender, religion, and language. All lost their mothers aged 6-12 but not within previous 12 months Unknown cause of death.	purposive sampling.	Semi-structured interview following interview schedule. Qualitative content analysis. None. Unclear who was present for interview.	employed to cope with the loss of a mother.	race, culture, gender, religion, and language.
Author Year Country	Aims/objectives	Participant demographics Time since death Cause of death	Recruitment	Research design Methodology Methods Analysis method Creative methods Interview details	Relevant findings Key findings/themes	Methodological criticisms
Studies with child and parent participants						
Berman et al. 1988 Canada	To describe the experience of adolescents whose parents have died of cancer.	Bereaved Children (n=10, F-5 M-5) aged 11-17, 9- white, 1 black West Indian, adopted by white family. Unknown number of parent participants.	Recruited from a cancer clinic or palliative care unit in one city.	Unknown. Semi-structured questionnaire used for interviews. No specific named data analysis method. None.	Communication after the death of a parent changed. Some adolescents felt isolated in their experience, wanting to protect surviving parent who was preoccupied with their illness or grieving. Peers who have experienced the death of a parent and siblings are the most helpful source of support. Nurses have a role to support these families, helping them identify and	Small sample size, recruited from 2 sites in one city. Sample not ethnically diverse. Appears that more than one child per family could have been interviewed. Limited information about recruitment. Limited data from parent's interviews, unclear how many parents

		<p>Interviewed 6 months to 2 years after death of parent.</p> <p>Cause of death cancer.</p>			<p>mobilise their existing support and identify any families who would benefit from support groups.</p> <p>Parents and adolescents had different perceptions within the themes, specific to changes in routines and responsibilities the support teenagers received.</p>	<p>participated. Limited examples of children's narratives. Bias and ethics not addressed. Good explanation about implications for health care professionals. Good use of table to demonstrate what support was useful as identified differently by children and parents.</p>
<p>MacPherson et al.</p> <p>2007</p> <p>UK</p>	<p>To identify the psychosocial needs of children facing the death and subsequent bereavement of a parent from cancer.</p>	<p>Bereaved children (n=13, unknown gender but boys and fathers were underrepresented), aged 6-14, unknown ethnicity.</p> <p>Unknown number of parent participants.</p> <p>Interviewed 6 months to 3 years after parental death.</p> <p>Cause of death cancer.</p>	<p>Recruited from a bereavement service.</p>	<p>Exploratory study.</p> <p>Semi-structured interviews.</p> <p>Thematic analysis.</p> <p>None.</p> <p>Unclear if parents present for children's interviews.</p>	<p>Before a parental death there is a need for the activation of a network of support before it is required. Children had a desire to take back control. Children and families need practical and emotional support during the terminal phase and afterwards need help to find a new normality which helps children make renewed and continuing sense of their experience, maintain memories, and feel held, heard, and understood.</p>	<p>Literature review, rational and methods presented in a separate paper. Good ethical considerations. No gender/ethnicity demographics or cause of parental death provided. Good use of children's narratives. Some parents spoken to but no data for number of parental participants or demographics. Did not include families who had not accessed support.</p>
<p>Weber et al.</p> <p>2019</p> <p>Sweden</p>	<p>To explore communication in parentally bereaved families from the perspective of the children and surviving parent.</p>	<p>Bereaved children (n=4, F-3, M-1) aged 6-18.</p> <p>Bereaved parents (n=4, F-3, and M-1).</p> <p>Interviewed 4 to 14 months after parental death.</p>	<p>Convenience sampling, participants identified using deceased medical records in 2</p>	<p>Qualitative approach with a descriptive and interpretive design.</p> <p>Open interviews based on interview guide.</p> <p>Inductive content analysis.</p>	<p>The relationship between family adjustment and communication may be circular whereby the family's ability to adjust to their new circumstances is affected by how the family communicates. Similarly, family communication may be affected by the family's coping strategies and ability to adjust to their new circumstances. Parents needed to reach</p>	<p>Very small sample size, no information given about family ethnicity. Parents present during children's interviews, unsure of how open children were, parents prompted the child if they were reluctant to share. Follow up interviews gave a</p>

		Cause of death cancer.	palliative care units.	None. Parent present for interviews.	out to the social network for help with day-to-day tasks to prevent them feeling overwhelmed. They sometimes felt guilt and shame which hindered their adjustment to a new identity of single parent. If older children saw parents struggling, they would help.	deeper understanding of family experiences. Focus on early stages of bereavement. All families had received palliative care. Findings not transferable to other settings, cultural background. Gender and child age could have affected results. Study could have been biased to participants who were better able to cope with the bereavement.
Author Year Country	Aims/objectives	Participant demographics	Recruitment	Research design Methodology Methods Analysis method Creative methods Interview details	Relevant findings Key findings/themes	Methodological criticisms
Studies with parent participants only						
Holmgren 2019 Denmark	To explore the experiences of men who are faced with raising their dependant-age children on their own following the death of their partner.	Bereaved fathers (n=4). Interviewed 1 to 2 years after death of parent. Unknown cause of death, 3 had illness before death.	Recruited from a closed, online mutual support network for bereaved spouses, author part of the group and a widow with dependent children.	Elements of constructive grounded theory. Open ended interviews. Thematic analysis. None.	Men found it particularly challenging dealing with their own grief and at the same time supporting their grieving children. Those with younger children appeared to be coping with the various ramifications of death at the expense of coping with their own grief. There was a lack of adequate offers of help to bereaved families.	Good use of participants' narratives. Limited information on participants' demographics and no details of ethnicity. No documented cause of parental deaths. Small sample size. No acknowledgment of ethical considerations. Considered own risk of bias and measures taken to prevent this.
Lowe et al.	To understand the lived experience	Bereaved mothers (n=5). All Caucasian	Initially snowball	Phenomenological approach, heuristic inquiry.	Young widows need to give themselves permission to grieve their hopes and	Small homogenous sample, consisting of Caucasian

<p>2010</p> <p>Canada</p>	<p>of spousal bereavement from the perspective of young Canadian widows.</p>	<p>Interviewed 15 months to 7 years after death.</p> <p>Cause of death, cancer (3), respiratory (1), heart attack (1).</p>	<p>recruiting, approached bereaved known to researcher within faith community.</p>	<p>In depth interviews.</p> <p>Moustakas approach.</p> <p>None.</p>	<p>dreams if they desire to move on in their new lives. Women felt the need to continue bonds with the deceased. The support received was of significant benefit in learning to cope with their grief. Health care providers have a role in supporting and understanding rather than offering advice. and require education to do so.</p>	<p>middle-class women in an urban area, Researcher had first-hand experience of phenomenon and could have bias, not discussed. Limited discussion on ethical considerations.</p>
<p>McClatchey</p> <p>2018</p> <p>USA</p>	<p>To present the experiences of widowed fathers, as they coped with their new parenting roles after the death of their wives.</p>	<p>Bereaved fathers (n=10), aged 30's to 50's, ethnicity, black (4), white (5).</p> <p>Interviewed 1 to 2 years after parental death.</p> <p>Cause of death expected/non-sudden (3), unexpected/sudden (7).</p>	<p>Recruited from a bereavement camp.</p>	<p>Unknown.</p> <p>Open ended questions.</p> <p>Phenomenological approach, inductive analysis.</p>	<p>The men relied heavily on support from various sources to manage the care of the children. Fathers felt it was difficult, frightening, and lonely to make decisions. Fathers put their children's needs before their own even when caring became overwhelming. Fathers are concerned and worried about their own mortality. Fathers felt a newfound respect for their deceased wives, taking on the mother's tasks they realised the magnitude of childcare.</p>	<p>Relatively diverse background of participants regarding ethnicity, income, and age. Recruited from one specific area, children were receiving support, fathers had brought them to, so they had a child-focused attitude. Researcher was the founder of the grief camp so fathers may have wanted to please. Good use of father's narratives to support findings. Risk of bias and ethical considerations described well.</p>
<p>Silverman et al.</p> <p>1975</p> <p>USA</p>	<p>To report the widow's view of her child's reaction to the death of their father, problems she had with children as a result; how she coped and what help was available and what help she</p>	<p>Bereaved mothers (n=19), aged 23-50, ethnicity, white.</p> <p>Interviewed 3 years after parental death.</p> <p>Cause of death for most was sudden and some following extended illness.</p>	<p>Recruited from a widow's support programme.</p>	<p>Unknown.</p> <p>Interviews.</p> <p>Unknown.</p> <p>Unclear.</p>	<p>Widows did not see their child's behaviour as a response to loss, this could be accounted for in several ways, cultures evasion and confusion, the widows cannot focus on the child's needs due to their own grief and the relationship with the child before the death. Widows used avoidance and denial to protect themselves and their children.</p>	<p>No systematic data analysis process. Participants recruited from a support programme. All participants were mothers. No acknowledgement of ethical considerations or bias. Unclear qualitative approach and methods. Limited discussion of findings.</p>

	did use in solving any problems she had with the children.					
Taylor et al. 2016 USA	To understand the challenges faced by young widows and widowers.	Bereaved parents (n=12), F-9, M-3. All Caucasian Interviewed 1 to 8 years after parental death. Causes of death, cardiac problems (2), diabetes (1), unknown (2), cerebral haemorrhage (1), drug overdose (1), drowning (1), breast cancer (1), car accident (3)	Convenience sampling via a widower conference.	Phenomenology. Semi-structured focus group. Immersion/ crystallisation technique. None.	Young widowers share similar experiences in the phenomenon of young widowhood. It is important to find meaning. The widowers expressed difficulty in accepting support and they did not discuss loss of social identity or lack of long-term support compared to the widows. New findings included humour as an important coping strategy and telling the children and other family was the most difficult experience for all.	No acknowledgement of ethical considerations or bias. All participants Caucasian, middle class. Focus group could limit the amount of data collected. Participants were able to provide feedback on themes.

4.5 Synthesis of findings

Thematic synthesis produced nineteen descriptive themes. These were developed across the reviewed papers relating to children’s perspectives of support (child perspective themes) and further categorised into four broader analytical themes: 1) Openness of communication with children about death and dying, 2) Children’s challenges of managing change, 3) Navigating emotions, and 4) Children’s acceptability, access, and engagement with support. Seventeen descriptive themes were developed from the parent perspective (parent perspective themes), further categorised into three broad analytical themes: 1) Adjusting as a parent, 2) Supporting their children, and 3) Parents’ acceptability, access, and engagement with support. Themes for both perspectives can be found in Table 11, findings are presented separately for each perspective.

Table 11 Child and parent perspective themes

Child perspective themes		Parent perspective themes	
<i>Analytical themes</i>	<i>Descriptive themes</i>	<i>Analytical themes</i>	<i>Descriptive themes</i>
1) Openness of communication with children about death and dying	Preparing children for the death of their parent	1) Adjusting as a parent	Redefining normal
	Anxiety of adults		Change in identity
	Involving children following the death		Accepting and feeling alone in their situation
	Bereaved children and their peers lack of knowledge and experience of death and grief		Uncertainty for the future
	Others acknowledging the loss		Changing your parenting style
A shared experience of loss			

2) Children's challenges of managing change	Change in identity	2) Parents acceptability, access, and engagement with support	It can be difficult accepting support
	Redefining normal		Finding appropriate support
	A different relationship with their surviving parent		Dwindling support
3) Navigating emotions	Avoiding bereavement interactions with peers for fear of sharing emotions		The role of religion and faith
	Suppressing emotions for reciprocal protection		A shared experience of loss
	Worry for surviving parent		Having people around who care
	How losing a parent makes you feel		Flexibility within the network
4) Children's acceptability, access, and engagement with support	Timeline to grief	3) Supporting their children	Understanding children's grief and needs
	Understanding the sources of support		Children are the motivation
	Support from those who knew them before their loss		Open and honest communication
	Distraction from their loss		Continuing a relationship with the decease
	Continued relationship with the deceased		Suppressing emotions for reciprocal protection
	The role of religion and faith		

4.6 Child perspective themes

The following section presents findings from the child perspectives.

4.6.1 Openness of communication with children about death and dying

4.6.1.1 Preparing children for the death of their parent

The amount of preparation children received varied. Some had open communication and knew their parent was dying, allowing them to spend time together^{75,162,166} and see the reality of what was to come⁷⁵. Others valued extra time with their parent despite being unaware they were dying⁷⁵. This time also allowed some parents to say goodbye to their children, which was challenging but important⁷⁵. For many children, the death of a parent was a shock^{54,160,162,166}. Some children had received some preparation or were forewarned of the death; for many, this helped them adjust to the situation, but the death still was a shock^{160,162,166}. A lack of preparation left children feeling isolated in their experience^{160,162,166}. Even those witnessing the death described feeling isolated and dissociated from the death event, which contributed to the death being experienced as a sudden event^{54,162}.

4.6.1.2 Anxiety of adults

Communication within families varied; some found their communication with each other improved, they encouraged each other to talk about feelings, and that validated their experience, and acknowledged their grief^{54,165}. Others reported a lack of or decreased communication^{162,166}. Some recognised the importance and wanted to talk to someone about their loss^{75,164}. Others spoke of the importance of expressing and understanding feelings, offering comfort and support, and appreciating each other with verbal and non-verbal communication¹⁶⁷. There was enormous variation in how and when the news of the death was delivered to children and the information they received¹⁶⁰. Some were already together or told soon after¹⁶⁶. Some were not told the cause of death¹⁶⁰, and others were not told of the death for several days, at the funeral or beyond^{160,162}. Children were often considered too young to understand¹⁶². Despite their parents dying from cancer and other long-term illnesses^{54,162}, it appeared many were protected from the death event. Adults used unhelpful euphemisms when talking to children, 'dying was just like going to sleep', 'he's gone, he's up there'^{160,166}. Families who avoided conversations left children with

unanswered questions about death and dying, with some blaming themselves for the death¹⁶⁵.

4.6.1.3 Involving children following the death

Regardless of their cultural backgrounds, children appreciated having information and choice^{160,164,166} when feeling helpless and worried¹⁶⁵. Being involved in what was going on around them, including the opportunity to view their parents' bodies, help plan or participate in the funeral, and plan their return to school, was helpful^{75,160,164-166}. Viewing the body helped accept the finality of the death; it could be a relief, seeing their parent free from pain, helped them remember, stop feeling scared, and gave a chance to say goodbye^{160,165,166}. Unfortunately, not all children were given information, choice, or an opportunity to be involved; some would have wanted to see the body¹⁶⁰. Not being given choice or information about the funeral left them fearing what would happen¹⁶⁰. Not all children spoke of the funeral or viewing the body, but it is important to note that the way children are involved in communication and death rituals varies by culture. Children appreciated others, such as friends and teachers, attending the funeral, and they were comforted to see the number of people who attended¹⁶⁰. Many children enjoyed being welcomed back when returning to school, but some found it overwhelming, and others had no acknowledgement from the school regarding their loss¹⁶⁴. Issues with how children were included in their return to school seemed to stem from poor communication between the teacher and child and a lack of preparation by the school¹⁶⁴.

4.6.1.4 Bereaved children and their peers lack of knowledge and experience of death and grief

A parental death can affect a peer group, and for some, another child's bereavement was their first encounter of death^{54,163}. Children's lack of knowledge and experience about death and grief was mentioned in several studies^{54,75,160,163,164}, and added to children's feelings of isolation⁵⁴. Children need to be supported to understand that their needs and grief are legitimate and how to communicate those to others⁷⁵. Children sensed the taboo around death, making people fearful, uncomfortable, and anxious¹⁶⁴. Some found others unprepared to deal with their grief; they did not know what to say, how to react, what to do, or how to be, adding to their isolation^{163,164}. Children withdrew from their social circles, which impacted their relationships¹⁶⁵. Most peer responses were well-intentioned but highlighted their lack of knowledge about what it means to lose a parent⁷⁵. At times, peers

were sadder than the bereaved¹⁶³. Children's parental loss was unique and could not be compared; they were insulted when peers tried to show they understood by comparing their losses¹⁶⁴.

4.6.1.5 Others acknowledging the loss

Children appreciated friends acknowledging their loss and showing they cared^{75,163,164}. Being received openly by classmates and teachers who were aware of their loss and showed understanding of their experience made returning to school easier^{75,164}. Some found teachers unprepared to deal with their loss, while others had a greater understanding, and children could talk about their loss^{75,164}. Some appreciated empathy from others; however, they disliked excessive discussion about their loss¹⁶⁴. Empathy from peers opened avenues to support, helping children feel less isolated and different¹⁶³. It was important that peers were authentic and approached their loss naturally and genuinely¹⁶³. Peers understanding and acting upon their needs and friends simply caring for them was valued support^{163,165}. Some children felt overwhelmed by peers and wished they would stop asking how they were¹⁶⁴. Children recognised that talking to peers about their deceased parent could be difficult, but it helped knowing someone really cared about them¹⁶³. However, not all children experienced acknowledgement of their loss or felt cared for. Some found their loss was spoken about on their first day back to school and never again, while others had no peer response; peers acted like nothing had happened¹⁶³. Half the children in the Ugandan study were no longer attending school, some had to take on caring roles within the family and others had no money for school fees meaning they did not have access to school as a form of support¹⁶¹.

4.6.1.6 A shared experience of loss

Children found it easier to speak to other bereaved individuals who understood, could empathise, and relate to their loss, which also helped them cope by normalising their own experience^{54,75,163-166}. Siblings were an important source of support, sharing similar emotions¹⁶⁶. Adults and peers who had lost a parent were helpful, allowing children to see they had survived their loss⁷⁵. Children also mentioned peers who had experienced parental divorce as they could empathise and understand to some degree the internal and social experience of losing a parent¹⁶³. One child was able to relate to a book about a child who had experienced a parental death as she recognised her own emotions in the book; for

others, it could be a connection with a pet or fictional character^{75,165}. Some children found solace when caring for and playing with pets¹⁶⁵. Children recognised that others who had not experienced a catastrophic loss could not understand the impact of what they were going through and how they were feeling, which made it more difficult to talk to them about their loss^{75,163,164,166}. However, some children admitted they disliked bereaved peers and would avoid them¹⁶³.

4.6.2 Children's challenges of managing change

4.6.2.1 Change in identity

After their loss, many children returned to school while their families remained in disarray, experiencing drastic change, uncertainty, and instability^{163,164}. Children needed normality, consistency, predictability, stability, and life to carry on as normal^{75,163}. Some were anxious about returning to school; others looked forward to a place of normality^{160,163,164}. Returning to school, they felt the change; their loss made them feel different from peers and how they perceived them; they were 'fatherless' or 'motherless'^{160,162-164}. Increasing feelings of isolation made children feel incomplete, experiencing discomfort and unease, feeling less than others, and some were embarrassed¹⁶²⁻¹⁶⁴. Some hid the death, so they were not different and did not have to talk about their loss^{54,162,163,165}. Children were treated differently, avoided, excluded from play, ignored, or not spoken to because they were different^{163,164}. Others were treated as normal as if it had not happened, which helped^{163,164}. Some children experienced anger when peers spoke about their parents; having one parent was undeserved and unfair^{162,163,165}.

4.6.2.2 Redefining normal

Losing a parent was devastating. Life would never be the same again. Children had to discover and adapt to their new normal. Children faced disruption at school and home. While most teachers were supportive, children felt they should receive extra support¹⁶⁴. Children experienced further losses, some moved home¹⁶⁰⁻¹⁶², relationships with others and roles changed, some were teased or taunted by peers^{160,163,164}. Children yearned for what they had lost in their deceased parent^{162,165,167}. Others found peers guarded against too much attention and defended them from bullies^{75,163}. Those orphaned faced increased responsibilities, lacking stability, lost childhood, education, future hopes, and worry about who would care for them¹⁶¹. They lived with different relatives, and often they were not

wanted, which was shown in how they were treated^{160,161}: some experienced family conflict, social stigmatisation, physical and mental abuse^{161,162}. Social stigmatisation or being treated differently because of their bereavement was not found to be related to the cause of death or country.

Children found death made them re-evaluate life, values, and goals⁵⁴. After a time, children found they experienced post-traumatic growth (PTG). PTG is a theory that explains transformation following trauma¹⁷⁹. Positive growth can be experienced as a result of one's struggles following trauma¹⁷⁹. Children's PTG was shown in several ways - caring for others more, possessing strength, resilience, self-confidence, hope, optimism, and self-awareness^{54,160,166}.

4.6.2.3 A different relationship with surviving parent

Children's relationship with their parents changed, the family restructured itself, and their individual and family needs could not be met in the same ways^{162,167}. A consistent relationship with their parent was crucial⁷⁵. Some felt fortunate to have a parent or other family members to care for them¹⁶⁵. Not all children had the availability of a parent⁵⁴, but other adults or extended family provided a consistent relationship^{54,75}. As a result, children did more to help their surviving parent¹⁶⁵⁻¹⁶⁷. They saw their parent differently; some realised the challenges they faced and noticed how they had to adapt, change, and take on roles previously undertaken by the deceased^{160,167}. Children recognised the gap left behind by their deceased parent, yearning for the bonds they missed^{160,162,165,167}. Relationships with parents could be strained¹⁶². Children worried about how their parents would cope¹⁶² and had a strong need for their attention¹⁶⁷. Some children faced difficulties with detachment from extended families or witnessed grandparents mistreating their parent¹⁶². Some children were orphaned, and many were cared for by extended family and experienced complicated relationships^{160,161}.

4.6.3 Navigating emotions

4.6.3.1 Avoiding bereavement interactions with peers for fear of sharing emotions

Many children avoided peer bereavement interactions, fearing rejection or showing emotions, not only their emotions but also their peers^{54,75,162,163}. Children also believed peers avoided talking about their loss to protect them from becoming upset, for which they were grateful^{163,164}. Some children coped by pretending everything was fine when at

school¹⁶². Distancing oneself from others was seen as a form of protection⁵⁴. Some described the most supportive response from peers was saying nothing at all¹⁶³. Children also reported not wanting to evoke adverse emotional reactions in their peers, described in one study as 'empathic avoidance'¹⁶³. Empathic avoidance was seen between bereaved participants and peers, and it described a mutual concern they had for each other's comfort, which led them to use avoidance of the bereavement rather than promote support¹⁶³. Children also realised that peers might show them sympathy and feel sorry for them, which not all children could accept^{75,162,163}.

4.6.3.2 Suppressing emotions for reciprocal protection

Many children suppressed their emotions^{160,162,163,166,167}, grieving alone, pretending, and hiding, leaving them feeling isolated^{162,166}. Their reluctance to share feelings with their parent was often a fear of causing upset and a desire to protect^{160,162,166}. Some were able to speak to peers about how they felt and felt well supported^{75,160,164,166}. Others refused to discuss the death with anyone^{162,163}. Children did not want peers to feel sorry for or pity them^{54,75,162,163}. Some believed that if peers did not talk to them about their loss, it was an act of kindness; they protected them from becoming upset¹⁶³. Even when peers were trying to be supportive, some children preferred they were not asked about their feelings; some felt they should keep the death 'out of peoples faces'¹⁶³. Other children found they expressed emotions more and were more thoughtful of the needs of others, especially their immediate family, which brought them closer together^{54,167}. Children had increased sympathy for others and became more sensitive to the feelings of others⁵⁴.

4.6.3.3 Worry for surviving parent

Following a parental death, the family dynamics change, resulting in insecurity for children^{160,162}. Children worried for their parent and how they would cope taking on the roles of the deceased^{160,162}. Children also worried about how roles and relationships would affect their parent and worried about finances¹⁶⁰. Some children saw their parents struggling to cope, some heard them secretly crying, failing in their new roles, and some witnessed psychological breakdown, including attempts of suicide and clinical depression¹⁶². One child felt anxious and insecure, having told her mother to stop crying; on reflection, she realised her mother was trying her best, and she should not have spoken to her in that way¹⁶². Some children described how they modified their behaviour and were good to

prevent their parent from becoming upset¹⁶⁰. Other children recognised how well their parent adapted to their new roles and coping¹⁶⁰.

4.6.3.4 How losing a parent makes you feel

Children's approach to grief was individual, including physical, behavioural, emotional, and spiritual reactions⁵⁴. Initial reactions to loss started with shock, denial, disbelief, and distress⁵⁴. Next, children felt sad, afraid, upset, anxious, lonely, hateful, bored, angry, stressed, and some refused to show any emotion^{54,75,165,166}. Some children experienced abnormal behaviours following their loss including, aggression, noncompliance at school, hiding their loss and avoiding communicating^{54,165}. Some children recognised that their responses and needs following their loss could be different to those of their siblings, which was difficult to understand, while others recognised grief is unique to each individual⁷⁵. Some children believed that managing their emotions, clarifying values and goals, accepting what had happened, and coping strategies contributed to their psychological wellbeing⁵⁴. Following their loss, some children found they expressed their own emotions more and were more thoughtful of the needs of others, with increased sympathy and sensitivity towards others' feelings, especially their immediate family^{54,167}. They expressed more emotions and love within the family, bringing them closer together^{54,167}.

4.6.4 Children's acceptability, access, and engagement with support

4.6.4.1 Timeline to grief

Children realised that grief did not disappear, it was constant, taking time to recover, and they will always miss their parents^{54,164}. Birthdays and celebrations reminded them of their loss¹⁶⁵. Some found their grief became worse as time went on¹⁶⁴. Children found support did not match their grief timeline and quickly dwindled. Support was available immediately, with peers and teachers asking how they were doing, approaching them and talking to them about their loss regularly¹⁶⁴. However, many found their loss was soon forgotten at school; others moved on faster than they did, not understanding that grief does not vanish¹⁶⁴. Children missed being asked how they were doing and needed to know that people cared even a long time after¹⁶⁴. Children felt teachers could be more considerate. Teachers lack of awareness resulted in insensitive, unintentional and hurtful comments or situations^{75,162,164}. Such situations caught children off guard, evoking emotions they would not want peers to

witness^{75,164}. This was not the experience for all; some, for instance, described teachers who understood grief, remembered birthdays and anniversaries, which was supportive and reassuring for children to feel ongoing support^{75,164}.

4.6.4.2 Understanding the sources of support

Children did not always understand the sources of support. What some found most beneficial, others found most hurtful¹⁶³. Children's perceptions of who should support them varied, including parents^{75,163}, themselves or friends¹⁶³. Professional support, although mentioned infrequently, was described as helpful. Children described professional support from counsellors, psychologists and the healthcare professionals (HCPs) caring for their parent^{54,75,166}. Professionals were seen as helpful when they were being honest with them, checking on their wellbeing, helping them develop coping strategies, being open and flexible to their needs, and being available quickly^{54,75,166}. Although children wanted professionals to converse with them, it was important that they were not forced to talk. Most children appeared unaware of professionals as a source of support¹⁶⁶. The school could be a good source of support, a safe place, providing a sense of belonging, routine and escape, with extracurricular activities^{54,75,160,164}. However, some children could not relax in school, and they felt they had to hide or put a 'pretend' face on so that others thought they were fine¹⁶². Children recognised they received more attention from peers and teachers, which could feel great, with everyone looking out for them and being friendlier¹⁶³.

Nevertheless, support needed to be genuine and not peers acting like friends when they were not¹⁶³. Sympathy could make children feel looked down on and devalued^{162,163}. For some, the worst response was too much attention; they appreciated others empathy, but unwanted physical contact made them uncomfortable, and it was difficult having excess questioning or being forced to talk about their loss^{163,164}.

4.6.4.3 Support from those who knew them before their loss

Children in several studies spoke of the most helpful types of support coming from people who were well known to them before their loss^{54,75,160,162-164,166}. Children welcomed speaking to those who knew their deceased parent; friends, in particular, could give special conversational support, as it was easier to talk to them and share memories¹⁶³. Children also felt more secure speaking with close friends; they could talk more freely with less worry of being teased or hurt¹⁶³.

4.6.4.4 Distraction from their loss

Many children found that having fun and doing normal things with friends helped them cope^{75,163,165}. Sports and physical activity provided escape with a physical and emotional release for some children^{75,165}. Normality was a form of escape and provided security and stability, explaining why many children wanted to return to school soon after their loss^{75,160,165}. Friends could offer a good distraction and a temporary escape that allowed children to take their mind off what was happening at home, and some normal play and closeness without talking about their loss¹⁶³. One child found it easier to be with friends than at home alone or with family, who sometimes made them more upset¹⁶³.

Following their loss, some children re-evaluated what was important to them; their life values and goals for the future were important^{54,162,165}. Re-evaluating goals could make children feel empowered, happier and content⁵⁴, and some did so to try to feel complete again; however, this came at a cost and often created more stress for them¹⁶².

4.6.4.5 Continuing a relationship with the deceased

Continuing a relationship with their deceased parent helped children cope^{54,75,160,162,165-167}. Children used many ways to maintain this relationship, such as using mementoes to keep their parent's legacy and memory alive^{75,165}, speaking to the deceased in the present, letting them know what was happening in their lives, how they were feeling, and their struggles and asking for advice or protection^{160,162,165,167}. The presence of the deceased parent in this way comforted some children^{160,162,165,167}. Speaking to the deceased also gave them stability, unity, and a sense of belonging¹⁶². Some children kept these conversations secret, as they did not want to cause others upset and were from a culture where talking about death was discouraged¹⁶². They put effort into remembering happy and positive memories, avoiding talking about sad or scary times that made them feel sad or distressed¹⁶⁷. Having an image of the deceased helped some feel more whole, for instance, filling the void their father left¹⁶².

4.6.4.6 The role of religion and faith

Some children were comforted and supported by their faith^{54,160,165,166}. Children's faith could become stronger with a sense of God's presence, helping them overcome their problems⁵⁴. Some children were comforted in the belief in the afterlife¹⁶⁰. In families where religion was important, children identified the clergy as supportive following their loss¹⁶⁶. In contrast,

other children began to lose faith, feeling angry and blaming God for their loss and how their life had changed^{54,161,165}. Some of the children who initially lost faith found later that their faith did help them overcome the trauma, and they subsequently felt a stronger relationship with God⁵⁴.

4.7 Parent perspective themes

The following section presents findings from the parent perspectives.

4.7.1 Adjusting as a parent

4.7.1.1 Redefining normal

Parents in most studies described their lives as changing, with challenges, losing 'normal' life, changing family dynamics, and making significant adjustments to their lives. They were forced into a new way of life as one parent^{100,167-171}. Some coped by setting new priorities, committing and using help from those around them¹⁶⁹. Parents felt heavy demands on their time and mental resources, struggling to share their time with their children, which often led to arguments and misunderstandings^{100,167}. Some parents found they had too much spare time, leaving them feeling alone, frustrated, and craving companionship^{100,169,170}. Parents changed their lifestyles to care for their children. Fathers' jobs were often incompatible with caring for children, meaning some changed working hours, jobs, or stopped work altogether^{100,169}. Some parents found previous social networks vanished, and others were treated differently by friends^{168,169,171}. They lost couple friendships, often because friends felt uncomfortable, and they realised they did not have an affinity with each other as they had prior to their loss^{100,168,171}. These reactions were often unexpected and hurtful, leaving parents feeling abandoned and let down by the people they depended on^{168,171}. Not all parents had this experience; some had continued and sustained support from friends^{168,171}.

4.7.1.2 Change in identity

Parents often face a loss of identity. Many had a new status of being a 'single' parent but still felt they were married and often found themselves struggling, stuck between the two identities with a feeling of not belonging anywhere^{100,168,171}. Some parents struggled to accept their new identity, which revolved around going to work and caring for the children¹⁰⁰. Parents lost sense of the person they were and found it very lonely^{100,170}. Work

was part of their identity, so it was a considerable change to give up work and become the children's primary caregiver¹⁰⁰.

4.7.1.3 Accepting and feeling alone in their situation

Whilst adjusting to new parental roles and family life, parents were grieving themselves. It was challenging and took time to accept their loss and address their new realities^{100,168,170}. The permanence of their loss and the situation they faced hit them hard, and this caused some to embrace their new reality, finding meaning or purpose, which helped some parents cope¹⁷¹. However, other parents felt stuck and unable to face their new reality¹⁶⁸. Parents in one study adjusted with support from family reaching out and recognised that humour helped¹⁷¹. Parents had sole responsibility for their children, which was often daunting and scary; parents felt alone, helpless, and vulnerable, with considerable pressure having to make decisions without their partner^{100,168-171}. Parents worried about their children and what was best for them. Some found they questioned everything they did and feared they might get it wrong; to help this, parents sometimes spoke to extended family or others for advice^{169,170}.

4.7.1.4 Uncertainty for the future

The death made parents consider their mortality and re-evaluate how they lived their lives, frequently prioritising their children^{100,169}. Parents often feared future relationships. They knew it would be difficult to enter into new relationships with their responsibilities, and some lacked the mental energy to do so. They worried how their children would react, could a new partner accept the role of the deceased within the family. Parents also feared losing someone again and questioned if they could re-marry^{100,168}. Despite this, parents spoke of missing the companionship of a partner. They wanted to feel whole again as a family, so many were open to entering a new relationship in the future^{100,168,169}. In many instances, the thought of entering a new relationship came with more questions than answers¹⁶⁸. Parents also reflected on the futures they had lost, including a loss of hopes and dreams, growing old together, the loss of being a traditional family, and they felt sad for the children having to lose a parent¹⁶⁸.

4.7.1.5 Changing your parenting style

Parenting alone was stressful¹⁶⁹. Parents took on roles and responsibilities previously filled by the deceased, and some struggled to become the primary caregiver, disciplinarian, and

provide emotional support^{100,167-170}. Mothers in one study noticed their sons assuming the father role; relatives had told one this was expected, some put a stop to this as it was inappropriate to their age and role in the family, and others had not realised and actively encouraged their sons to be like their father¹⁷⁰. Fathers in one study spoke of newfound respect for their partners and mothers in general, having taken on the care of their children and household chores previously done by the deceased, so they had great respect and felt regret they had not appreciated their partners' work more before¹⁶⁹. Parents in several studies found their children took on more responsibilities, helping around the house and caring for siblings^{167,170}.

4.7.2 Parents acceptability, availability, and engagement with support

4.7.2.1 It can be difficult to accept support

It was common for parents to struggle to recognise their inability to manage everything alone and accept support, even when needed and beneficial^{100,167,169-171}. Feeling they should be independent and capable, asking for help was seen as a weakness and made some feel ashamed¹⁶⁷. Some parents felt a strong desire to show others they could cope alone¹⁶⁸. Fathers in one study appeared to be more accepting of support, acknowledging they could not manage without the help of others¹⁶⁹. However, some fathers found they had more help than needed with family members trying to take over¹⁶⁹. Others reluctantly realised they did need help and acknowledged that was okay^{167,171}. They had to learn to communicate their need for help to their family and social network, and having them to rely on helped them manage their new responsibilities and maintain effective communication with the children¹⁶⁷.

4.7.2.2 Finding appropriate support

It was difficult for some parents to find professional support, and they often reported experiencing a mismatch between needs and help provided, with some professionals not equipped to deal with their needs or situation^{100,171}. Parents desired more professional help both pre and post bereavement^{100,166}. Some found that counselling helped them cope¹⁶⁸. In particular parents wanted professionals to be honest, but deliver information that the family could handle, and show concern for the family's individual needs¹⁶⁶. Some fathers needed reassurance and would have liked a professional to check in on their family to ensure they were coping adaptively and provide information about their options, practical

help and guidance¹⁰⁰. The same fathers also preferred to cope and work out personal problems alone, believing they had to help themselves, but at the same time, they had all actively sought help for themselves and their children and joined a bereavement support group¹⁰⁰. Some parents found others expected and encouraged them to seek professional support, and if they chose not to, this was questioned¹⁰⁰. Parents had mixed experiences with school support, with some receiving tremendous support and appreciated teachers providing extra support to their children^{75,169,170}. Others found a lack of communication and understanding at school⁷⁵. School support was not mentioned by a study with widowed fathers in Denmark¹⁰⁰, despite those schools having bereavement response plans¹⁷⁶.

4.7.2.3 Dwindling support

Following their loss, parents found immediate support often came from family, friends, community, and sometimes the church who rallied around, offering help and practical support^{168,170,171}. Although appreciated, this support could be overwhelming¹⁷¹. Despite feeling well supported by those around them in the immediate aftermath of their loss, many found support quickly dwindled. This happened after the funeral, while others had little sustained support in the first year of bereavement^{170,171}. Professional support could also dwindle with a lack of follow up or interest in how they were coping over time¹⁰⁰. Some parents were frustrated that those around them moved on quickly, whilst others understood and accepted that people moved on and believed they should. Their loss was theirs to cope with¹⁷¹. Many parents needed and would have appreciated continued and sustained support from those within their networks and the professionals around them^{75,100,170,171}. Nevertheless, this was not all parents' experience; some had enduring and continued support from 'angels' in their networks¹⁷¹, while others felt their grief was a burden to friends and relatives who expected them to have got on with their lives as usual^{170,171}.

4.7.2.4 The role of religion and faith

Faith helped many parents, knowing they could rely on church friends, call without hesitation, and know the positive response they would receive¹⁶⁸. Fathers in one study described the church support they received to be invaluable, both practically and financially¹⁶⁹. Vicars and priests were described as supportive, sympathetic and provided sound advice^{100,170}. Some parents found praying helped their grief by bringing them closer

to God¹⁶⁸. Those with a deep belief in the afterlife experienced premonitions and spiritual experiences that gave them purpose and hope¹⁷¹. Not all parents found their faith helpful; however, some felt anger towards God or questioned if there was a God or felt let down because of their situation¹⁶⁸. Two parents in one study spoke of their children's faith, reporting that one child prayed to her father every night, while the other gave up religion but attended monthly formal worship on the day his father had died¹⁷⁰.

4.7.2.5 A shared experience of loss

Parents in several of the studies found those with a shared experience of loss to be most supportive, as they understood and could relate, sharing similar struggles and feelings, normalising their own experiences, and helping them adapt to their new lives and the challenges they faced^{75,100,168-171}. Some parents actively sought out others who understood what they were going through, as they recognised they could learn from those who had been through a similar experience^{100,168,170,171}. Reading about or meeting others and sharing experiences helped parents realise they were not alone, normalising their feelings and allowing them to adapt to the challenges they faced^{100,168}. They were given hope for the future and realised that grief was time-limited^{100,170}. Others described relief of sharing their problems with someone who understood¹⁷⁰. They did not have to be strong, they could honestly confide their feelings, including hopelessness and despair, and they did not feel like a burden because they were understood¹⁷⁰. Parents also saw their children find support from others who had been bereaved⁷⁵.

4.7.2.6 Having people around who care

Families needed to have people around them who cared and people within their social network whom they could rely on to help them manage day to day¹⁶⁷. Parents across many studies spoke of instantaneous rallying support from those around them, and for some, this support provided them with encouragement and strength¹⁶⁸. After the death, some parents just needed to be with their families¹⁷¹. Parents in one study described creative support, which made them feel loved and cared for¹⁷¹. Examples of this included people putting up hearts in the community, practical help, writing memories of the deceased, honking the horn when driving past when they had requested no visitors¹⁷¹. However, other parents found their friends could be unable or unwilling to provide the support they anticipated¹⁶⁸.

Some struggled when others reacted like they were ‘weird’ because of their loss¹⁶⁸. Other people did not always know how to support them, causing offence rather than comfort¹⁷¹.

4.7.2.7 Flexibility within the network

Parents in several studies found flexibility and understanding from their workplace and within their networks to be helpful^{75,100,167,169,170}. Parents were often faced with increased financial responsibilities, so they would have pressure to hold down their jobs whilst managing family life^{75,100,169}. Some parents experienced employers who were not supportive, which forced them to change roles¹⁶⁹, but the majority found employers and workplace supportive and understanding of their situation^{75,100,167,169,170}; which allowed parents to be available for their children whilst still financially supporting their families⁷⁵. Work could also help keep them busy and occupied¹⁷⁰. In order to carry on working, some parents reduced their hours, changed jobs, or had to rely on their neighbours to help collect and look after children when they had finished school¹⁶⁹.

4.7.3 Supporting the children

4.7.3.1 Understanding children’s grief and needs

Parents needed to understand how death affects children and what they should expect⁷⁵. Some families coped by maintaining normal routines¹⁷¹. Parents seldom asked children about their needs and used their judgments to handle situations more often. Parents in some studies were less aware of the support their children received from other sources, including teachers and siblings^{166,170}. Some parents misunderstood their child’s reactions and believed denial, disbelief and shock to be signs that the child had not understood what had happened and meant they were not in mourning¹⁷⁰. The same study found that some mothers failed to connect changes in their child’s behaviour to their loss and needed someone else to point out this connection¹⁷⁰. Even when parents saw changes, they often felt ill-equipped to deal with these and support their children¹⁷⁰.

4.7.3.2 Children are the motivation

Parents in half of the studies described how their children brought meaning to their lives, giving them motivation^{100,169-171}. They were committed and devoted to putting their children first^{100,169-171}. Their loss experience made them appreciate how precious life was and commit to helping their children cope with their newfound lives^{100,169}. Such commitment to their children came at a cost for many parents, leaving them with no time for themselves¹⁶⁹.

At times they struggled and wanted to give up, but the children gave them focus and a reason to carry on, focusing on the needs of the children¹⁶⁹⁻¹⁷¹. For some, it was a struggle to meet the needs of the children without contemplating their own needs¹⁷¹.

4.7.3.3 Open and honest communication

Many parents described difficulties breaking news of the death^{170,171}. Some felt guilty that their children did not know their parent was going to die, which on reflection, they could see would have helped⁷⁵. Some admitted they were in denial; others felt the children's lives would be affected soon enough, so why do that before they had to⁷⁵. Following the death, some families acknowledged their difficulties in maintaining open and honest communication¹⁶⁷. Even when parents lacked energy, they talked to the children, gave comfort and support, and were open with their own emotions. They found that these efforts led to less conflict in the family¹⁶⁷. However, not all families could have open and honest communication, and some parents did not speak to their children or put effort into hiding their emotions¹⁷⁰. Sharing emotions was burdensome, and they avoided talking about anything that may upset each other¹⁷⁰. One parent who had avoided talking about the deceased was shocked when told by a teacher that their children had misunderstood their silence to mean they did not miss or care for the deceased and wanted to forget¹⁷⁰. Some parents were unaware their children spoke to others outside of the home about their deceased fathers¹⁷⁰.

4.7.3.4 Continuing a relationship with the deceased

It was seen as important to carry on a relationship with the deceased to ensure children remembered the deceased parent. Some promised this to the dying parent, while others could not have such conversations¹⁶⁸. Parents created memory boxes, shared memories, and stories of the deceased, bringing them into everyday life, telling the children what the deceased would have liked, and highlighting similarities between the deceased parent and the child^{167,168,170}. Parents noticed that they chose to remember the good memories¹⁶⁷. However, not all parents were sure how or if they should continue a relationship with the deceased¹⁶⁸. When talking about the deceased, many waited for the children to initiate conversations and then seized the opportunity to ask how they were feeling¹⁶⁷. Mothers in one study found it painful when children asked questions about the death, and so avoided conversations¹⁷⁰. Some parents also noticed that their children stopped talking about or

asking questions about the deceased when they saw it upset them¹⁷⁰. Others believed children avoided the conversations as it made them sad¹⁶⁷. Others forced themselves to talk and show emotions, so their children knew it was okay to remember¹⁷⁰.

4.7.3.5 Suppressing emotions for reciprocal protection

Parents in many studies suppressed their emotions and avoided their grief to protect their children^{100,170,171}. Some found this made them feel more lonely¹⁷⁰. Focusing on the needs of their children meant they did not have to think about themselves, which helped some cope¹⁷¹. Some fathers felt under strain, lacking the time or mental resources to deal with their grief as well as their children's¹⁰⁰. If parents were advised to be open with their children's emotions, they saw the benefits for the family and how doing so could bring the family closer¹⁷⁰. Parents also noticed their children modified their behaviours and took on more responsibilities to protect them, and some relied on support from their children^{167,170}. Parents in one study noticed their children worried for them, and in some instances, a role reversal could be seen between child and parent¹⁷⁰. Children were terrified of losing the surviving parent, which sometimes led to 'clingy' behaviour, and anxiety, worry and distress when they left them¹⁷⁰.

4.8 Discussion

This review is the first that has looked at parentally bereaved children's and surviving parents' experiences of informal support. The review demonstrated that little research had been undertaken exploring support experiences. However, the synthesis of this review has provided good insight into support experiences from the perspectives of children and surviving parents following the death of a parent, including both sudden and expected deaths. The findings show that experience can vary according to cultural and country context. The review highlighted the necessity for families to have open and honest communication with one another, no matter how difficult that may be. Adults need to recognise that children have agency and must be informed and involved in what is happening to them and their families, which in turn will help them adjust and cope. The review indicated that a societal taboo surrounding death contributes to a lack of support. Bereavement support within a family must be tailored to the individual; understanding what can be supportive for one individual can have opposite results for another. The review has also demonstrated universal findings for both parents and children, including a lack of

support from others and support dwindling over time. Both identified someone who could relate to their loss as a good form of support, yet they did not appear to see that they could get this from each other.

Findings from the review support the National Institute for Clinical Excellence, three-component model of bereavement support⁵⁸, which the Childhood Bereavement Network adapted to show what good provisions for bereaved children should look like³¹. All children and parents had the most support from those within their existing networks, with support from professionals seldom mentioned by participants.

4.8.1 Children's perspective

Open and honest communication and information surrounding the death of a parent, alongside opportunities to be involved, such as spending quality time with a parent and having a choice in involvement after the death, are reported as crucial in enabling children to process and cope with the death of a parent¹¹⁻¹³. However, this often did not happen, despite its benefits, including helping to facilitate better adjustment in their grief²⁰. A parental death came as a shock to most children, even when death was expected^{54,160,162,166}. This lack of communication may be an effort by parents to protect their children, or they do not know how to talk about death, with parents needing clear guidance from HCPs or others about how to communicate and support their children^{18,20}.

Some children were not told of the death for many days after, and some were not until the funeral^{160,162}; reasons included protecting the child or fearing the child would not understand. However, parent anxieties or fear of what to say were also reasons for this lack of communication. Avoidance techniques and beliefs that children were too young to understand death have led to limited, complex, and variable exposure of children to death¹⁸⁰. However, other work poses that younger children (aged 5-7) do not view death as an unfamiliar topic, with most understanding death as a biological process, which was underestimated by their caregivers¹⁸¹. An awareness and understanding of death can reduce fear or confusion around death and improve communication for children⁶⁰. For example, many children recognised the importance of talking about their loss with someone^{54,75,164,167}, but did not know how to talk about this or felt they required permission to discuss death^{75,167}.

Further communication difficulties are seen when children want to communicate with a parent at the end-of-life but fear causing upset¹⁸². This difficulty navigating their own, and their parents' emotions is commonly seen. This is compounded by parental avoidance of talking about death and affects how children cope, leading to difficulty regulating their emotions and a lack of skills to cope with death effectively¹⁸³. In addition, a failure of open and honest communication led to misunderstandings and some children blaming themselves for the death¹⁶⁵. This lack of communication affects children into adulthood, affecting trust, relationships, self-esteem, the ability to express emotions and feelings of self-worth, loneliness and isolation⁶⁷. Combatting this, children want open and honest communication and information to support them and create an environment where they feel safe to ask questions about death and show their emotions¹⁸³. This allows children and parents to experience their suffering and survival together⁶⁰, suggesting a requirement (for some) for specific support from health and social care professionals and those around them to create an environment fostering open communication. Previous research with children and parents who have a life-limiting illness found that children needed open, transparent and age-appropriate discussions with their parents and HCPs to help them make sense of what was happening¹⁴. Despite parents looking to HCPs for support, this often did not happen because of HCPs lack of confidence and a professional fear of making the situation worse¹⁴.

Allowing children to be involved in death rituals provides an essential opportunity for children to acknowledge and accept the reality of the death, honour their deceased parent, and receive support and comfort from others¹⁸². The evidence shows that children are not simply reactive but have agency as family members¹⁸⁴. Children's agency must be respected. Children need to be given informed choices and an opportunity to be involved in these matters that affect them. Children's desire for agency has also been seen when a parent has a terminal illness; however, parents often do not recognise this need and children's capability and fail to give children agency over matters affecting them^{11,19}.

Some of the children in this review identified they experienced a taboo surrounding death¹⁶⁴. The taboo was often further enforced by those around them, parents, teachers, and peers, who sometimes failed or refused to have open discussions with them¹⁶⁵. In western societies, death can cause social awkwardness, creating uncomfortable social

reactions, or ambivalence which can prevent individuals from supporting a bereaved person for fear of causing harm or being unprepared^{2,185-187}. This lack of understanding and awareness surrounding death meant children did not always get a supportive response to their loss. However, children do not perceive death as a taboo. It is something many have experienced or are aware of¹⁸⁸, yet both personally and socially, children cannot access information about death, with avoidance of death seen in both their family and school lives¹⁸⁸. Adults are often gatekeepers to information¹⁸⁸. Although well-intentioned, a desire to protect children from death resulted in unhelpful language, euphemisms, or delays in informing children of parental deaths. This lack of emotional support from avoidance¹⁸⁸ can create further problems for children. This highlights the benefits of socialising children about death¹⁸⁸. Children desired information and opportunities to discuss death, including advice on how to grieve adaptively and receive timely communication about the death¹⁸³.

In contrast, some children described receiving a supportive response but failed to realise that the changes they experienced in relationships and how they were treated were well-meaning and supportive gestures. Instead, they felt people showing attention, sympathy or being nice merely emphasised that they were different^{162,163}. Many children were unsure who should be supporting them, naming parents, teachers, or friends, with some believing they should support themselves alone. Some hid the death to avoid being perceived as different or to avoid the attention^{54,162,163,165}. This highlights children's lack of awareness and understanding of death, grief, and the effects and reactions of others.

Many children found support from those who knew them before their loss especially helpful. This allowed them to share memories of the deceased, with some finding it easier to reach out and ask for help from those they knew could cope or those they felt they would receive more appropriate responses from. Despite this, children found that peers often struggled to understand unless they had similar experiences. Some did not know how to behave or react, leaving children feeling isolated. The stigma surrounding parental death exists⁷ with social comparison, teasing, or taunting by peers, which shows a lack of awareness about their behaviour towards a bereaved child¹⁸⁹. This stigma may cause children to hide themselves and how they are feeling. Some are unable to talk to anyone about what they are going through. Some withdraw from their social circles as an avoidance method or as a distraction or coping strategy¹⁶⁵. Some children also felt that it might be too

much for their peers to handle, isolating them further. Parents add to this isolation by avoiding talking or waiting for the children to initiate conversations. Lower bereavement morbidity is seen when emotions are addressed and acknowledged within a family¹⁹⁰. Avoidance can be an adaptive response to loss and is a common reaction associated with anxiety and fear¹⁹¹. However, reliance on avoidance as a coping strategy can contribute to complicated grief and poor long-term adjustment^{191,192}.

Hiding and suppressing emotions and avoiding peer bereavement interactions are forms of coping and reciprocal protection. Children showed ambivalence, avoidance, and even active rejection of support offered to them for these reasons¹⁶³. Children refrain from speaking about their loss with peers for many reasons; some include fear of crying in front of them, the subject not arising, and friends being awkward⁷. Children and parents hiding their loss, emotions and avoiding bereavement interactions could be accounted for with Goffman's theory of dramaturgy which likens social interaction to a theatrical performance¹⁹³. How people present themselves and their activities to others is a performance used to create an impression that will provoke the desired response - consisting of the front stage, visible for the audience and backstage, which is not visible, allowing a safe place for people to vent feelings¹⁹³. Participants in this review often displayed front and backstage performances. Children avoided bereavement interactions and suppressed their emotions to prevent themselves or others from becoming upset. This was a way of protecting themselves and others, and by avoiding interactions they would not be perceived as different. Worryingly for some children, their parents and peers only saw their front stage performance, meaning backstage performances were enacted entirely alone. This supports previous research, in which bereaved children had not spoken to anyone about their feelings, both immediately following their loss and in the longer term^{37,194}, with children fearing the reaction of family members, finding it too difficult to talk or not knowing where to go for help^{37,194}. Society also influences grief reactions by implying that intense sadness should not be seen in public¹⁹⁵. For many children, this was their first experience of death, and they would look to their parent to learn how to mourn. Where parents hid their grief or suppressed emotions, their children could learn this is how they should mourn¹⁹⁶. This review supports recent recommendations to tackle the taboos surrounding death and dying and a greater need for a public health approach that encourages conversations surrounding dying, death and

bereavement¹⁹⁷; coupled with a better understanding and response to the needs of the bereaved from their social networks and communities²⁸.

4.8.2 Parent perspective

Parents coped through commitment and dedication to their children, who motivated them, putting their children's needs first^{100,169-171}. Child-centred parenting has been shown to help children adapt better to their loss¹⁹⁸. Furthermore, having a purpose when bereaved has been shown to improve life satisfaction, provide a solid reason to live, increase social support, and lessen the impact of loss¹⁹⁹. Parents struggled to balance time between children and described how this often led to arguments and misunderstandings. This was supported by some of the children who spoke of competing for attention from their parent, perceiving a lack of attention to mean they were not important. It seems vital that parents dedicate one-on-one time to their children. Parents found themselves in a challenging situation and often lacked advice or support to cope. Some families were lucky that onlookers to their bereavement intervened and offered helpful advice about communicating with and sharing emotions with their children. Fathers in these studies would have liked reassurance from professionals that they and their children were managing all right. Becoming a single parent through bereavement and taking on the other parent's role can make parents question their parenting abilities, especially parenting a grieving child²⁰⁰.

Parents, too, described difficulties accepting support, realising their inabilities to manage and a reluctance to rely on others^{167,169-171}, which could be perceived as a failure to cope. Those who sought support sometimes experienced difficulties finding available support appropriate to their family needs^{100,166,170,171}. HCPs are well placed to signpost families to appropriate support; however, they are often unaware of available and appropriate support. There was sometimes an expectation from others that families should seek professional support even though they felt they did not need it¹⁰⁰. There is a belief by some that professional support is required following bereavement. However, not all bereaved people need professional support; evidence suggests most are well supported by their existing networks⁵⁷. If the natural course of grief is interrupted by early interventions, this could cause the withdrawal of support from the bereaved person's network⁹⁷. This review

supports the evidence that most families are initially well supported by their networks, but highlights a need for ongoing and sustained support.

4.8.3 Shared perspective

Children and parents usually experienced immediate support from their social networks^{164,168,170,171}. This quickly dwindled with an imposed timeline to their grief from those around them^{164,168,170,171}. Others move on quickly, with an expectation that the bereaved should too; highlighting a lack of understanding about how grief affects individuals. Both children and parents appreciated sustained support from those around them, but few experienced this^{75,100,170,171}; supporting previous research findings that bereaved children wanted more sustained support¹⁹⁴. Some parents found those they expected would have given them good support did not^{168,171}, which could be due to fear of not knowing what to say. Insecurity and fear have been described as factors that prevent social networks from providing support²⁰¹. Findings show that such networks may need advice and guidance on how to provide support.

Having someone or something to relate to their loss appeared to be an effective support for both children^{54,75,163-166} and parents^{75,100,168-171}. Someone who had experienced a similar loss allowed them to normalise their feelings and see how others had coped. Parents found it easier to talk to others who had been bereaved as they understood, could relate, and did not feel a burden¹⁷⁰. A lack of someone to relate to could leave them holding their grief inside with a desire not to burden others with what they are going through. As a result, some parents actively sought others with a shared experience.

Continuing a relationship with the deceased provided comfort and helped many children cope^{54,75,160,162,165-167}, and some parents^{167,168,171}. Other parents believed it important to continue a relationship to ensure children did not forget the deceased^{167,168,170}. Both children and parents emphasised talking about the good memories¹⁶⁷. Some parents thought their children actively avoided talking about the deceased because it was difficult or sad. Instead, they waited for children to initiate conversations¹⁶⁷. Children verified they avoided these conversations, as they did not know how to initiate or upset their parents^{160,162,166}. Some children hid relationships with the deceased to protect their parents¹⁶². This could be seen as reciprocal protection and was seen throughout the review,

with children and parents acting in ways to protect each other. Differences were seen in how children continued relationships with the deceased, many talked about them and shared memories they had with their surviving parent^{54,75,160,162,165-167}. However, children from Taiwan hid their continued relationships with their deceased parent to protect their surviving parent¹⁶². This culture prohibits talk around death, with death at a younger age seen as a taboo, and symbolically mothers may be regarded as failures²⁰². Despite parents being well placed to help their children maintain healthy connections to the deceased²⁰³, they may not appreciate the value²⁰⁴. Families can struggle to reminisce and understand that doing so is crucial to help them in their bereavement²⁰⁴. Furthermore, parents need an awareness that their children's lack of communication about their loss or the deceased is their way of protecting their parents.

Both children and parents experienced similar challenges and changes following their loss, and there is a gap in the family that needs filling by changing roles and relationships¹⁴². In line with Family Systems Theory, how families behave and function are interdependent, meaning a change in one family member's functioning will lead to changes in others²⁰⁵.

Children and parents showed examples of the Dual Process Model of coping with their bereavement¹⁴⁶. They adapted coping strategies and processes in their everyday lives, which oscillated between loss-orientated activities and restoration-orientated¹⁴⁶. However, despite the similarities in experience, there was little evidence to suggest children and parents were aware of or spoke of each other's shared challenges. Instead, they managed their experiences alone, contributing to feelings of isolation and, at times, suffering in silence. Sharing their experiences could open an avenue of support from each other in which they can both relate and feel less isolated in their experience.

4.8.4 Strengths and limitations

This review has several strengths; it is the first review to focus on children's and surviving parents' experiences of informal support following parental death. It includes the experiences of 210 children (female=80, male=56, gender not stated=74) and more than 57 parents across multiple countries, highlighting their experiences of support, in different contexts, following a range of expected and unexpected parental deaths. Children were under 18 years old when data were collected, which meant they provided a child's

perspective. Previous research undertaken with adults bereaved as children highlighted the limitations and potential for inaccuracy in their memories and reflections of the past and highlights that data collected this way is not seen through the eyes of children^{64,67,183}. A strength of the review is the synthesis of fathers' perspectives, which adds to the limited literature surrounding widowed men.

Findings were drawn from these different perspectives to explore and bring together the common themes from these unique experiences of children and their surviving parents. Parent participants were reflective of two-parent families with a mix of mothers (n=39) and fathers (n=18). Thematic synthesis allowed for rigorous analysis and inclusion of studies from various methodologies, settings and causes of parental death.

The review is limited to qualitative studies, which was necessary to gain in-depth insights into how families were supported. These findings are subject to researchers' interpretations in the original studies and during the synthesis. To increase rigour within the review, multiple team members independently screened and assessed the quality of studies. Discussions were held during data extraction and synthesis. The findings are limited by a lack of cultural diversity among the included participants.

4.8.4.1 Limitations of included studies

Researchers must be mindful of potential bias and power dynamics in which children anticipate the 'correct' answer or want to please the researcher or parent¹⁷³. Parents present during interviews can both help and prevent children's voices from being heard^{173,206,207}. Most of the studies did not discuss the potential for power imbalance or provide the location of interviews, which is important as location can amplify unequal power relations between children and researchers²⁰⁸. Most of the studies recruited via bereavement support groups and services; therefore, it is likely that participants had received formal support. Consequently, these findings may represent families who have good support around them. Previous research has shown that females are more likely to participate in support groups²⁰⁹, although this was not represented in this review with participating fathers being recruited from support groups^{100,169,171}.

The included studies had a lack of diversity in included participants. Findings are limited to two-parent families that will not consider blended families' experiences. The children

included in the review were predominantly adolescents; therefore, these findings are not necessarily transferable to all children who have experienced a parental death. Not all studies reported on the gender of participants^{75,164,165}. And further demographics, including social class, sexualities and disabilities were not provided by most studies.

4.8.5 Recommendations for research

This review highlights the importance of involving children and parents in this field of research and offers insight into their differing perspectives of support. The lack of studies shows that this topic remains an under-researched area. Further research needs to explore families' differing relationships and perspectives of support. How children and parents may or may not support each other and what they can do to help each other in their grief. Future research should explore what support is helpful and when from those around the bereaved family and examine the benefits of sustained support. Social networks that provide bereavement support to families need to understand how they can provide a supportive response. Research with children and parents to understand what a supportive response entails is crucial to improving social network support. This review has highlighted a lack of support from peers for both children and parents, which requires further exploration. Research needs to examine the experiences of blended and lone families. Research with families who have not accessed formal support is crucial to discover how they cope and why they have not received formal support.

Ethical considerations must be considered and clearly reported when undertaking research with this population. Researchers must also consider their positionality and understand how their position may impact the research. This includes gaining access to the field, the relationship between researcher and participant and how the researcher's worldview may shape findings and conclusions¹⁷⁷. All of which are important when undertaking sensitive research. It is also essential to understand how researchers can overcome adult-child power dynamics.

4.8.6 Recommendations for practice

Recommendations for practice are presented in Table 12.

Table 12 Recommendations for practice

Recommendations for professionals working with bereaved families in health, social care and educational settings
Encourage parents to have open and honest communication and information sharing with their children. Help them understand it may be difficult but essential to help children accept, adapt and cope with parental death.
Help parents understand that children may have limited knowledge and understanding of death but a desire to know more. A better understanding will help them cope.
Parents can help their children understand what is happening by involving them and giving them a choice, empowering them to make their own decisions. Examples of this could be attending the funeral and viewing the deceased parent's body.
If a family declines support at one time, that does not mean they will not need professional support in the future. Children's grief is ongoing throughout their lives.
Families may experience a taboo from some of the people around them. As professionals, we should not be adding to this and ensure we have open conversations with children and surviving parents about their experiences.

4.8.7 Conclusion

This review explored support experiences for children and parents following the death of a parent. Open and honest communication and involving children is central to how families cope and adapt to life following parental death. A lack of support resulted from a death taboo, meaning some of those around a bereaved family did not understand or know how to respond to their needs. Both children and parents suppressed emotions and avoided conversations to protect each other and those around them. Parents were anxious to engage with open communication; however, death is not a taboo for children, and if parents were supported to realise the benefits of sharing their grief and engaging with open communication with their children, this would lead them to offer each other better support. Furthermore, this adds to the discourse that childhood bereavement is a public health issue,

with a need for professionals and communities to better understand and respond to the needs of the bereaved. The review has demonstrated the necessity to include children within research as the only way to understand their unique experiences.

4.9 Summary

The main findings from this chapter include:

- There are limited studies including children and their surviving parents that focus on the support they received.
- Children hide their grief to protect themselves, their surviving parents and the other people they have around them.
- A taboo remains around death and often people struggle to know how to support bereaved families.
- Support from social networks quickly dwindles.

The outlined recommendations for research highlight the research gaps and identify a need for further research with children and surviving parents to explore their support needs. The qualitative study follows from the findings of this systematic review. It aims to expand on these findings and address the research gaps that have been identified. The next chapter presents the methodological considerations of the qualitative study. The study development and conduct are informed by the systematic review and described in Chapters 5 and 6.

5 Methodology

5.1 Introduction

This chapter explains the methodological underpinnings of the thesis, beginning with the philosophical assumptions that informed the research design and chosen approach. The first section explores personal and professional perspectives. A discussion of the philosophical assumptions that informed the research design follows. Next, an overview of grounded theory research is provided, with a justification for using a constructivist grounded theory approach to examine the support experiences for children and parents following parental death. Then, the core grounded theory processes are briefly described. Finally, methodological rigour is considered.

5.2 Personal and professional perspectives

As a researcher, I must consider my starting point, beliefs, judgments and practices throughout the research process, acknowledging and reflecting on how they influence the research process²¹⁰. Considering my background and motivations for this research, I identify as a white female, a registered nurse who has experienced loss and bereavement, and from a middle-class background. Although I have not experienced parental bereavement, I have experienced parental loss as a child through divorce. As a result, I saw my father intermittently throughout my life and experienced a breakdown in relationships with my father's family. My best friend's mother had cancer when we were younger and died shortly after we left school. I wonder now what sort of friend I was to her back then. A close friend experienced her mother's death over 25 years ago, and I only now see the ongoing impact on her.

I have many years of experience in informally supporting bereaved families and individuals professionally and within my social network, I understand that every grief is unique.

However, as a nurse, I have often felt helpless and inadequate when supporting bereaved families. Early in my career, I realised there was nothing I could say or do to make it better when someone died. This realisation allowed me to feel comfortable supporting families in end-of-life care, and unlike some interactions I witnessed, I did not feel the need to shy away from difficult discussions or encounters with families.

In my most recent clinical role, I supported families at the end-of-life, facilitating discussions and exploring the possibility of organ donation. Within this role, I frequently faced the prospect of supporting children or offering parents advice to support their children. Caring for end-of-life patients and their families has been a constant theme throughout my career as a nurse in the NHS. I am often seen as the expert in supporting bereaved families, yet I had never had any training to assist me. From my own experience and that of others, there is a sense we 'fumble' through, and I have witnessed varying degrees of support and information provided to bereaved families. Literature has reported that when parents of dependent children are dying, healthcare professionals can struggle to communicate with them, identifying their fears, self-confidence, time and a lack of training as barriers^{18,211,212}.

Despite many years of supporting bereaved families in the initial period following the death, I do not know how best to support them, which has motivated me to undertake this study. My motivation for this research was to make a difference in childhood bereavement by better understanding how children and their surviving parents want to be supported following a death. It is understood that bereaved people need a supportive response following a death; however, there is little evidence describing what is needed for children and families.

5.3 Philosophical perspectives

The choice of research approach requires consideration of one's philosophical assumptions, which will underpin the research design and inform the approach needed to address the aims and objectives of the study²¹³. Ensuring these are aligned contributes to the rigour and credibility of research findings²¹⁴. The choice of research approach is influenced by the researcher's assumptions on ontology, which is their beliefs about reality; epistemology, which is the relationship between the researcher and what can be known; axiology, which is the role of value; and methodology, which is how to carry out the research relative to the question and context²¹⁵. Ontology, epistemology, axiology and methodology make a research paradigm²¹⁵. A research paradigm describes a researcher's worldview, which informs their interpretation of research data and impact decisions made within the research process²¹⁶.

The ontological position for this study is identified within relativism, with a view that multiple realities exist, which are subjective and can be influenced by context and interpretation²¹⁴. The epistemological position is interpretivism, which assumes that reality should be discovered inductively²¹⁴. Interpretivism acknowledges that we cannot understand the world from an individual perspective; realities are multiple and socially constructed; with the interaction between the researcher and participants, context is vital for knowledge and knowing²¹⁷.

Within interpretivism, the social constructivist paradigm underpins this study. Social constructivism sees that knowledge is subjective and is socially constructed through interaction with others²¹⁵. Individuals are at the centre of meaning-making, formed through interactions within a particular social context²¹⁸. Within social constructivism, researchers know their position in the research and how their background influences interpretation²¹⁹.

As a theoretical approach, constructivism is often used interchangeably with constructionism^{213,220}. Constructivism focuses on individuals constructing knowledge of their social and psychological worlds through their cognitive engagement in the world²²¹. In contrast, constructionism considers knowledge of social and psychological worlds historically and culturally constructed through social processes and actions²²¹. The researcher's perspective concurs with Charmaz²²², that knowledge and understanding are derived from personal interpretation and social interaction, thus drawing together elements from constructivism and constructionism. To give consistency and clarity within the thesis, the term constructivist is used to describe this perspective.

The social constructivist paradigm is suited to the study aim and aligns with the researcher's professional perspectives. It will allow exploration of the multiple, subjective meanings of an individual's experiences of bereavement support and understanding of how these experiences have developed through social interaction²¹⁵. This study understands that people's bereavement support experiences will vary. Individuals' views about their need for bereavement support may be similar; however, what constitutes good bereavement support may differ and may be related to or constructed based on their experience of receiving it. This view that there are different subjective realities of bereavement support fits with the philosophical underpinnings of the interpretive paradigm, particularly the social constructivist worldview.

5.4 Qualitative Research

Qualitative methods were chosen to address the study's aim of seeking a detailed understanding of an under-researched area by collecting in-depth, authentic, robust and contextualised data from the target population, in their own words and natural settings²¹⁴.

Qualitative methods recognise the importance of exploring individual perspectives and experiences of both children and their surviving parents. Furthermore, qualitative research is deemed an appropriate method in the field of bereavement to hear bereaved people's experiences and how they make meaning of this within their networks of relationships²²³.

In order to address the aims and objectives, the study takes a subjectivist inductive approach to the research, which begins with a desire to understand and explain the phenomenon using a range of different perspectives to develop a theory from the data²²⁴.

The interpretive paradigm situated within qualitative research methods has been chosen to guide the study's design, with an inductive approach to develop a theory by exploring how the social world is interpreted by individuals²¹⁴. As a research strategy, qualitative research focuses on gaining a deeper understanding of a phenomenon and focuses on words instead of quantifying data collection and analysis²²⁵. These methods allow an in-depth subjective exploration, allowing the researcher to interpret and understand the meaning and complexity of different views²¹⁴. The ability to produce descriptions and explanations of a phenomenon also gives a voice to those who are marginalised²¹⁰, as children often are in research¹⁷³. Therefore, a qualitative approach was deemed appropriate to address the study's aims to explore the different experiences and psychosocial needs of parentally bereaved children and surviving parents. Furthermore, the study does not aim to test existing theories but to generate a substantive theory from participants' experiences that could provide a conceptual understanding to explain how children and parents can best be supported.

5.5 Grounded theory

5.5.1 History of grounded theory

The grounded theory method is a qualitative research method widely used across many disciplines and subject areas¹⁷⁵. The term 'grounded theory' is confusingly used to refer to the methodology, research design, procedural methods, and the end produce of the

research process; as a grounded theory^{175,226}. Since its inception, grounded theory has evolved into different versions, influenced by differing opinions, philosophical perspectives, styles, approaches, and methods²²⁷. The method and some of the publications from the developers of grounded theory are often criticised, misunderstood and ill-judged²²⁸. The literature recognises the challenges for novice researchers undertaking a grounded theory study due to its complexity, differing versions and approaches²²⁹⁻²³². A brief history of grounded theory follows to describe some of the differences between the main versions of grounded theory, including Classical, Straussian and Constructivist.

5.5.2 Classical Grounded Theory

Grounded theory was first developed by sociologists Barney Glaser and Anselm Strauss in 1967 and derived from medical sociology and health research²³³. Glaser's background was in quantitative methods and middle-range theories, as opposed to Strauss's in symbolic interaction and pragmatist philosophy²³⁴. Grounded theory was developed when the research was dominated by a positivist approach²³⁵. Glaser and Strauss challenged the criticism that qualitative research was not scientific and lacked rigour²³⁵. They aimed to offer a clear platform for systematic qualitative research to show the significance and outcomes that could match quantitative outputs²³⁴.

In contrast to deductive methods, which generate data to provide evidence for a priori assumptions, the grounded theory uses inductive reasoning to discover theory from the data²³⁶. Their ground-breaking approach was first used to study the experience of terminally ill patients in hospitals, who had differing knowledge about their prognosis. Next, the study examined how they dealt with the knowledge that they were dying and the reactions of the HCPs caring for them. Their research resulted in a theory of dying, 'Awareness of Dying' (1965). The constant comparison method was developed during this study to organise and analyse the data²³². Following the study, they wrote their seminal work, *The Discovery of Grounded Theory: Strategies for Qualitative Research*²³³ explaining how theory could be derived from data inductively.

5.5.3 Straussian Grounded Theory

Following the emergence of classical grounded theory, researchers took up the methodology with different interpretations and applications of its use²¹⁰. Although Glaser

and Strauss disagreed over the nature of the original method and its practice²¹⁰, they diverged, taking grounded theory in different directions²³⁵. Variations of grounded theory evolved, which were influenced by different philosophical perspectives. Strauss's approach evolved with interactionism and pragmatism²³⁷, asserting the importance of using symbolic interactionism to interpret a phenomenon's personal and social impact²³⁷. They provided a detailed outline of data analysis and emphasised ongoing validation, both inductive and deductive^{229,237}. The focus was to follow their step-by-step formula to produce a good grounded theory study²³⁷. This version is underpinned by an objectivist view that there is an objective, external reality that the researcher can discover and report on. This version of grounded theory advocates a literature review and provides a more systematic and analytic process²³⁵. Corbin has developed this version further to include the role of researcher reflexivity²³⁷.

5.5.4 Constructivist Grounded Theory

Constructivist grounded theory was developed by Kathy Charmaz, a student of Glaser and Strauss²³⁸. Charmaz evolved a grounded theory underpinned by a constructivist philosophical approach wherein the researcher and participants co-construct meaning during data collection and analysis²²². There is a clear role for the researcher in generating data and theory, and participants are active in the construction process²²². Adopting a constructivist perspective view, there are multiple perspectives of reality influenced by the subjectivity of individuals' views and the researcher engages passionately with its interpretation²³⁵. The constructivist grounded theory explores how and why individuals construct meanings and actions in certain situations²³⁵, making it useful when the researcher is aware of changing contexts or competing perspectives of reality. The researcher's knowledge and experience are recognised as aiding knowing²³⁹. There is an emphasis on researcher reflexivity with the research process and outcomes, and it is essential for the researcher to reflect on their assumptions and interpretations and how these may have influenced their analysis²³⁵.

5.5.5 Rationale for using grounded theory

Grounded theory was thought to be the most appropriate approach for this study, following consideration of other methods. Thematic analysis is a theoretically flexible approach concerned with description over in-depth analysis and has limited interpretive power; it will

not provide continuity or contradictions between individual participants' responses and can lose their individual 'voices'²¹³. Therefore, thematic analysis was thought unsuitable to meet the study's aims to explore the unique experiences of bereavement support.

Phenomenology was also considered as it would allow in-depth insight into the experience using an iterative and inductive approach; however, the role of the wider socio-cultural context can be unclear²¹³. Understanding the socio-cultural context is vital for understanding how bereaved families are supported by each other and their social networks. In addition, a lack of guidance for interpretive analysis means it can be limited to describing participants' concerns²¹³. Therefore, this study sought to go beyond describing experiences of bereavement support to generate a theory to explain how best to provide bereavement support based on a range of different participants' experiences²⁴⁰.

Grounded theory is an appropriate methodology when little is known about a phenomenon to generate a theory, with explanatory power grounded in the data from the perspective and in the context of those who have experienced the phenomenon²⁴¹. Grounded theory is suited to exploratory studies as it is flexible and allows the pursuit of unanticipated directions the research could take, which is useful in an under-explored topic²⁴¹. Grounded theory is helpful for researchers interested in a phenomenon's social and psychological processes instead of focusing on individual experiences²¹³. This allows exploration of the multiple dimensions of the social processes of bereavement support²⁴⁰. Grounded theory offers a pragmatic and systematic approach to research to construct a theory grounded in data²³⁷. It offers explanations and emphasises the process of how people interact in response to context and the consequences of those interactions²³⁷ - aligning well with the study's aim to understand how children and families are supported following the death of a parent. The planned study did not seek to test a hypothesis; instead, it sought to inductively build an understanding of the realities and needs of the participants. The focus of the study is to construct a grounded theory to fill a gap in knowledge about how children and their families are supported following the death of a parent. Grounded theory requires the researcher to remain open to the data, trusting the process will ensure the theory is generated from the main concern of participants and the emergence of how they process or resolve this²⁴². The literature points to the need for a supportive response from existing networks following a death³¹. The study intends to develop an in-depth understanding of

how children and their surviving parents are supported following the death of a parent. Grounded theory has explanatory power to highlight the common issues for bereaved children and families so they can relate the theory to their own lives²⁴³. Grounded theory studies aspire to be theory-building. However, it is acknowledged that due to practical considerations of time and funds, it is common for grounded theory studies to create greater conceptual clarity or a conceptual framework²³⁰.

5.5.6 Rationale for choosing constructivist grounded theory

Although the history of grounded theory and the evolved versions show differences, they use similar procedures. When selecting a version of grounded theory, it was essential to critically reflect on the different versions, considering the philosophical underpinnings of each alongside the approach that best fits the research field, topic and researcher's position. Glaser and Strauss adopted a post-positivist stance, with Corbin and Strauss using a symbolic interaction and pragmatist, whilst Charmaz used a constructivist approach²²⁷. This approach preserves the complexities of social lives whilst asking the why questions about a phenomenon²⁴⁴. Constructivist grounded theory appealed to the researcher's philosophical beliefs and how the study should be undertaken. With its approach, research is a co-construction between researcher and participant, acknowledging the researcher's subjectivity and knowledge, which adds value²²². The constructivist grounded theory approach recognises the subjective nature of the researcher and participant relationship and considers the positionality of both^{222,244}.

The theory does not emerge from the data; instead, researchers construct categories from the data²⁴⁴. Participants' views and voices are central to analysing data and how they are presented²⁴⁴. Charmaz's²²² approach allows an exploratory, interactive, interpretive and co-constructive approach, which would allow understanding of the main issue and breadth and depth of bereavement support in this context. Unlike classical grounded theory, which insists on finding a core category, constructivist grounded theory aims to understand and theorise the complexities of different worldviews and actions²³⁵.

Constructivist grounded theory was selected as it was appropriate to answer the research question. It resonated with the philosophical values for knowledge development personally with the researcher and their personal beliefs, values, and goals within the field. The

researcher identified a gap in knowledge related to the phenomenon of interest that lacked theory development. Regarding bereavement support, this is underpinned by social interactions and processes. Having limited knowledge of how to best offer bereavement support and a passion for improving it through hearing the voices of and understanding the experiences and needs of the bereaved. For these reasons, Glaser's and Strauss, and Corbin's grounded theory approaches were not appropriate as they both emphasise a distance from the phenomenon, which seemed unachievable.

In contrast, Charmaz's approach is to understand people's experiences and interpretations and produce a co-constructed theory⁸⁷. Sudarsan et al⁸⁶ promotes constructivist grounded theory as a useful methodology to promote the voice of the child in research as discussed previously (Chapter 2). Furthermore, the methodology has proved successful exploring participants experiences of negotiating new social environments⁸⁶. This methodology is suitable to explore the interactions between people and their social settings and allows for investigation of the complex social processes involved⁸⁶, therefore, it is deemed a suitable methodology to explore children and surviving parent's experiences of bereavement support.

5.5.7 Reviewing the literature prior to conducting a grounded theory study

A PhD commonly undertakes a literature review to provide a clear rationale and justification of the thesis's contribution by identifying gaps in the literature²⁴¹. The literature review in grounded theory is a disputed and contentious debate over how and when to engage with literature²⁴⁵. The construction of grounded theory is a process informed by interactions between researcher, participant, environment and the literature²⁴⁵. In classical grounded theory, the researcher must avoid subjectivity, which they can achieve through avoiding engagement with a literature review prior to undertaking the research, producing a theory that has been obtained objectively. Although classical grounded theorists warned against engagement with the literature prior to data collection, it is now recognised that there is a need to engage with the literature in order to identify the area of focus and to be able to justify the research questions. Furthermore, it is acknowledged that a literature review is required at the start of a research project to fulfil requirements of ethics, scholarship and funding applications. Rather than a hindrance, it is seen as valuable, providing the researcher tries to remain open to what the data provides. Constructivist grounded theory

believes data are co-constructed between researcher and participants, delivering an emergent theory whilst acknowledging the influence of their social, historical and cultural backgrounds, academic training and worldviews^{222,235,246}. Charmaz believes that researchers should adopt a conscious, deliberate and informed approach to the literature review, recognising the importance and benefits of engaging early with the literature whilst being aware of the drawbacks^{235,245}. The research process should generate the research question²⁴¹. For a problem to be relevant, it must come from those it is of significance²⁴². An initial research question should be broad and reflect the problem-centred perspective of those experiencing the phenomenon, allowing the flexible and dynamic principles of the research methods²⁴¹. With this in mind, grounded theory researchers should be reflexive and acknowledge their preconceptions and assumptions throughout data gathering and analysis²²². Charmaz advocates the benefits of performing a thorough and focused literature review, giving credibility and strength to your arguments²²².

The previous chapter outlined the systematic review undertaken to explore the experiences of support for children and surviving parents following a parental death by any cause. Undertaking the review allowed me to broaden my knowledge of the literature and increase 'theoretical sensitivity' to otherwise oblivious issues²⁴². Furthermore, it was not feasible to delay engaging with the literature as I would not have been able to identify the gaps that existed or had a reasonable understanding of existing literature, which is a requirement of the ethics committee and the thesis advisory panel examination process²⁴⁷. The systematic review, alongside public involvement, helped generate the initial research question and the development of topic guides. The systematic review also guided the methodological approach and methods used for this study and highlighted potential ethical issues.

5.5.8 The grounded theory processes

A grounded theory study must be open to new and unanticipated findings, and researchers must keep their knowledge of the literature and field in the background to prevent putting data into a priori categories²³⁰. This can be achieved using unstructured or lightly structured interview guides open questions, and which remain flexible throughout data collection²³⁰. All grounded theory approaches share a pragmatist influence, asking questions relating to process and interaction and striving to approach the inquiry as open to new findings²⁴⁸.

Glaser²⁴⁹ highlighted that many studies presenting grounded theory only provide a qualitative descriptive analysis. Birks and Mills²⁴¹ suggest that when undertaking a grounded theory study, the researcher must follow essential processes:

- Initial coding and categorising of data
- Concurrent data generation or collection and analysis
- Writing memos
- Theoretical sampling
- Constant comparative analysis
- Theoretical sensitivity
- Intermediate coding
- Identifying a core category
- Advanced coding and theoretical integration

These processes are followed throughout the study and discussed in further detail in the following chapter.

5.5.9 Becoming a grounded theory researcher

When deciding to use grounded theory, I initially spoke to colleagues within the University who had used the methodology. From these discussions, it seemed the methodology would fit well with the project and my philosophical assumptions.

I widely read grounded theory literature to learn about grounded theory. I found a general grounded theory book written by Birks and Mills²⁴¹ (*Grounded Theory, A Practical Guide*), provided an accessible way of understanding the different types of grounded theory and the grounded theory processes. This book, along with broader reading, helped me decide which of the strains of grounded theory was best suited to the project and my philosophical understanding.

When I decided on constructivist grounded theory and developed a basic understanding of the processes involved, I attended a training session facilitated by the Social Research Association. This training gave an insight into undertaking the grounded theory processes.

I found out about Grounded Theory online, which is a virtual network of researchers led by Fellows of the Grounded Theory Institute. I attended 'coffee and connect' virtual seminars, which gave me opportunities to speak with experienced grounded theorists. I also attended a grounded theory trouble shooting seminar. In this seminar, I was able to discuss my study plans, and I met other PhD researchers who were using constructivist grounded theory.

Attending the coffee and connect was initially helpful in learning more about the grounded theory processes and having a space to discuss concerns or ask questions. However, as my study developed, I realised that in this forum, the more experienced researchers remained bound to the strain of grounded theory they used. At times, this was unhelpful as coming from a constructivist grounded theory perspective, if I asked a question, the reply may be from a classical grounded theory perspective, which was confusing and not helpful.

Realising a need for support to use the constructivist grounded theory processes and methods, I developed my own network with PhD students I had met using the constructivist strain. We would meet monthly and discuss how our projects were progressing and how we are managing the different grounded theory processes. We all faced similar struggles, such as knowing when to move to the next stage of coding. Talking through this together provided a safe space to explore and learn together.

Prior to beginning data collection, my supervisory team highlighted their lack of knowledge and understanding of the methodology, and a supervisor joined the team who is an experienced grounded theory researcher.

5.6 Methodological rigour

There is debate surrounding what makes for rigorous qualitative research, which can be shaped by your epistemological standpoint and the particular qualitative tradition²⁵⁰. In their seminal text, *Naturalistic Enquiry*, Lincoln and Guba²¹⁷ suggested that methodological rigour in qualitative research comes from establishing trustworthiness based upon credibility, dependability, confirmability and transferability as outlined in Table 13²¹⁷. The research outcomes' credibility depends on the quality of the research process and on demonstrating rigour in the research conduct²⁴¹. The quality of research can be enhanced by conditions relating mainly to individual attitudes²³⁷. These include methodological consistency, clarity of purpose, self-awareness, being trained to conduct qualitative

research, sensitivity to participants and data, willingness to work hard, the ability to connect with your creative self, a methodological awareness and a strong desire to do research²³⁷.

Table 13 Establishing trustworthiness, from Lincoln and Guba²¹⁷

Credibility	Confidence in the truth of the findings. Findings are trusted and believable as coming from the participants
Dependability	A consistent research design that is transparent, auditable and can be repeated
Confirmability	The integrity of findings which the researcher does not bias
Transferability	The degree to which findings can be used in other contexts and settings

Quality is an important component in any research study. Charmaz proposes four main criteria to ensure quality in a constructivist grounded theory; credibility, originality, resonance and usefulness²²².

Other factors that are said to influence quality when conducting grounded theory research include, researcher expertise, methodological congruence and procedural precisions²⁴¹.

In the final discussion chapter (Chapter 10), the quality of the study is assessed, using these markers to evaluate the quality of the grounded theory study.

5.6.1 Reflexivity and positionality

Reflexivity in qualitative research is essential, requiring critical reflection of self and researcher²¹⁹ and recognising your role in constructing meaning throughout the research process²¹⁰. Reflexivity in grounded theory research allows the researcher to reflect on their biases and assumptions and show how decisions were made²³⁵. Reflexivity can be described as personal and epistemological²¹⁰. Personal reflexivity requires reflection on how your values, experiences, interests, beliefs, life aims, and social identities shape your research and how the research has affected or changed you as a person and researcher²¹⁰.

Epistemological reflexivity requires consideration of how knowledge has been generated in the study, including considering the research question, which may define or limit findings and how the research design and analysis methods have constructed the findings²¹⁰. It was essential to acknowledge that my personal and professional background could sensitise me to specific participant experiences and block my view of others. From the start of my PhD, I

engaged with reflexivity using a reflexive diary. Acknowledging my philosophical assumptions and preconceptions, derived from professional experience and informed by the literature prior to data collection, along with ongoing memo writing, helped ensure the analysis was informed by theoretical sensitivity rather than bias from preconceptions²³⁸.

Positionality refers to the researcher's position within the research and includes their attributes and social position²¹⁵. A researcher's positionality affects the entirety of the research process, from the study construction to the dissemination of findings¹⁷⁸. It also acknowledges the multiple roles of the researcher and participants within the research process²¹⁵. Reflecting on my positionality has provided a realisation of the multiple roles and positions that the participants and I may take in the research process and the need for critical self-reflection to understand how my identity could influence the research²⁵¹.

It has been necessary to reflect on my different identities as a researcher, nurse, and bereavement support facilitator and the influence these roles can have on the research. Although the difficulties of positionality when researchers have different roles and identities have been recognised within research on a sensitive topic, some researchers set clear boundaries of their role whilst others blur the boundaries and see the research role as a more counselling relationship²⁵¹.

It is acknowledged that nurses undertaking research with vulnerable populations may need to alternate between their roles²⁵². For example, participants may have questions related to bereavement support, and although this may shift the relationship from researcher-participant to nurse-client, an awareness of this means such interactions would not contaminate the research data²⁵².

A researcher's positionality can impact access to the field; knowing a phenomenon, information and resources can be helpful¹⁷⁷. Being sympathetic to participants' situations may help them feel more open to sharing their experiences, and the relationship between researcher and participant affects the information shared¹⁷⁷. Moser argues that positionality focuses on addressing categories and issues important to academic analysis, including race, religion, and class, and fails to acknowledge how personality can help or hinder a study. A researcher's personality, behaviour and interaction with participants, social abilities, and emotional intelligence can affect the research process and outcome²⁵³. I can recognise that

my background and experiences will be beneficial to me whilst undertaking fieldwork. This was cemented with public involvement sessions when families told me I was approachable, calm and had a friendly manner that allowed them to open up and made them feel comfortable for me to speak with their children. Although I have worked in end-of-life care for many years, I do not know how to best support bereaved children and families. As a researcher in this position the participant becomes the expert, which can be empowering and is important when studying marginalised groups¹⁷⁷.

5.7 Summary

This chapter described why the constructivist grounded theory was chosen as the appropriate methodology for the study. The methodology was informed by the research objectives, the researcher's social constructivist world view, and a lack of substantive theory to understand a supportive response needed for bereaved families. Next, the importance of child-centred research was addressed, acknowledging that children possess agency and can be active research participants and have a right to have their voices heard. Finally, the processes required to develop a grounded theory were outlined, followed by an explanation of how methodological rigour is upheld. The following chapter describes the methods of the study, including how the study was developed, planned and undertaken.

6 Methods

6.1 Introduction

The previous chapter outlined the methodological underpinnings of the thesis and justified why a qualitative design was most appropriate. This chapter describes the grounded theory methods and processes undertaken to generate and analyse the data. The chapter begins with an overview of the study's overall design and how this was shaped by public involvement with those with lived experience. Next, the ethical considerations are discussed, followed by the justification and reasoning behind the chosen data collection methods. Next, the study sample described in terms of eligibility and recruitment methods, followed by an outline of the data collection and analysis processes that led to theory development.

6.2 Overall Design

This qualitative study addresses the thesis objectives using in-depth qualitative interviews with children and their surviving parents to explore support experiences following parental death (Objective 2, 3 and 4).

6.3 Consideration of the population

6.3.1 Child-centred research

From initially embarking on this study, it was clear that to research children's experiences of bereavement, children needed to have their voice in the research. Children are the only experts in their own lives, yet adult-child power dynamics can cause a barrier to children's voices being heard²⁵⁴. Adults cannot explore children's lived experiences without including them²⁵⁴. Historically research was done on children, but never with them²⁵⁵. Following the new sociology of childhood, research involving children was embraced²⁵⁵. Recognising that children are capable social actors possessing agency²⁵⁵, they need to have their say and share their own experiences. If we deny children their right to have a say, there is an essential body of evidence that remains unknown, and children are not allowed to input into matters that affect them¹⁷³.

Furthermore, there are risks and harms of silencing and excluding children from research about their views and experiences²⁵⁶. The study balances the opportunity for children to

have their experiences, realities and views investigated whilst avoiding or minimising any harm the research may cause¹⁷³. It has been acknowledged that researchers, parents/guardians and those working with children can have assumptions about children's ability, insight, maturity and understanding¹⁷³. There are sometimes presumptions that a child cannot make a valuable contribution to research or that a desire to protect them can override their right to participate¹⁷³.

Data collection with children can be daunting and unpredictable, requiring the researcher to be observant and adaptable to the situation²⁵⁵. It is crucial that children actively engage with the study to allow the researcher to listen to them and understand their experiences of support following their parent's death. Research with children differs from research with adults and must be considered when planning any study²⁵⁷. The main differences are verbal competence, which includes understanding and maintaining attention, the unequal power balance between adults and children, and the fact that children are more vulnerable and can be persuaded or manipulated²⁵⁷. To enable children to engage, the researcher must be open and flexible in using methods that meet the needs of children, considering their understanding, knowledge, interests and location in the social world²⁵⁷.

Within this study, children are viewed as unique, with different and individual abilities and competencies from each other and their parents. Therefore, children have agency and will be active participants in the research. A key aspect of researching with these groups was flexibility and adaptability to the children's and parents' individual needs.

6.3.2 Identifying risk and minimising harm

Bereavement research with children has found that participants' distress is not always experienced as harmful; instead, they may see it as cathartic or beneficial to help them make sense of their experience⁷⁹. Bereavement research recognises that the researcher can have a role as interviewer and therapist, participants' may benefit from describing their loss and its impact, so the interview itself can have a therapeutic effect²⁵⁸. The researcher was aware of the potential therapeutic benefit for the bereaved by talking about their experiences and was clear of the researcher's role as the interviewer, supporting the participant throughout their interview and signposting participants to formal support

services if needed. The researcher is not a trained counsellor or therapist and worked within their professional scope, signposting to appropriate services.

Adopting an opt-in approach meant that participants had complete control over their participation choice. Bereaved people may choose not to participate for fear of becoming upset in an interview or feeling it could worsen their grief; others may feel they are over their loss and do not want to look back²⁵⁸. Bereaved research participants may take part to share or come to terms with their loss or help researchers further understand bereavement to help other bereaved people²⁵⁸. The main reason participants in this study took part was to help other bereaved families.

Acknowledging that bereavement is an emotive subject, participants could become upset when sharing their experiences. A distress protocol was devised (Appendix 2), and grounding techniques were practised with children before interviews should they be needed. All participants received a signposting leaflet detailing different support services following their first contact with the researcher. All families were offered a follow-up call and signposted to support services as required.

The most common risks to children and young people participating in research are 1) time lost, disruption and impact on opportunities to do other things, 2) psychological or emotional distress, 3) safeguarding and child protection, 4) breach of confidentiality, anonymity or privacy and 5) negative impact from the research findings¹⁷³. The researcher respected participants' time, schedules, and commitments to minimise these risks.

Participants had the opportunity to discuss and negotiate their preferred timings, who was present with them and where they were. Using a virtual platform meant less time was required to participate in the research as the participants did not need to travel. Interviews with children were often shorter, acknowledging the tiring nature of virtual communication. Participants were thanked for their time, both verbally and in writing.

Considering the nature of the topic, asking children about their experiences following the death of a parent had the potential to be distressing and could be re-traumatising to some children and young people. For some participants, this may be the first time they have shared their experience or feelings with anyone; some children do not know it is an option to talk to someone or who best to talk to or get support. Face-to-face interviews are

deemed the best data collection method for sensitive issues, as they allow the researcher to monitor and respond to any negative impact caused by the research¹⁷³. As this is anticipated, it can be planned for.

Before taking part in the interviews, participants met the researcher, virtually, face to face in a 'get to know me' session, which allowed the development of rapport, and gave respect to participants, allowing the researcher to enter their world²³⁵. In the session the researcher used self-disclosure by sharing some personal information about themselves, their family, the motivation to do the research and the hope it would make a difference to other families. Evidence has shown researcher disclosure can give participants a sense of comfort, put them at ease and greater promote trust to allow them share their stories²⁵⁹. Researcher self-disclosure can also reduce researcher and participant power balances and allow the research interview to be more like a conversation, with the researcher taking on the role of co-participant²⁵⁹.

The 'get to know me' session allowed the researcher to discuss with the families that they may or may not get upset, which is entirely normal, and there is a plan to follow if they are upset (grounding technique/distress protocol), which is sent out to them before the interview. Children knew they were able to stop the interview at any time using the stop/go cards (Appendix 3) or by telling the researcher. The researcher watched for signs that the child was upset and may need a break, move on to another topic, or stop the interview altogether. The study allowed establishing a route to accessing help and support in the family or individuals they may not have considered. All participants were provided with a support sheet that gave them organisations to seek other sources of support (Appendix 4). Participants had the opportunity to speak with the researcher after the interview, providing an opportunity to signpost them to relevant sources of support if required. It has been acknowledged that research data can be misreported in the media, which could be upsetting. Children will have the opportunity to be involved with the presentation of findings, thus making them child friendly.

Whilst everything was done to minimise harm, the researcher was keen to benefit the participants. The participants knew their experiences would help other bereaved families and those who encounter bereaved families by increasing our knowledge and improving

policy and services. Participants were sent a personal thank you card following involvement, and they were allowed to help make findings child-friendly at the end of the project.

Recognising the power imbalances in research relationships, the researcher was alert that potential participants could feel obliged or required to participate. To ensure participation was voluntary, it was unnecessary for the parent and child from each family to participate. If a parent or child from the same family did not want to participate in the research, the other could (children can participate without their parent as long as parental consent has been provided). Furthermore, every participant had to give their own consent, which will be discussed further.

6.4 Sampling

Driven by the research objectives, there were two sample groups involved in the study:

- 1) Children aged 10 to 18 years who had experienced the death of a parent
- 2) Surviving parents of parentally bereaved, dependent aged children.

6.4.1 Eligibility criteria

The eligibility criteria for the study can be found in Table 14. Children were eligible for the study if they were bereaved between ages six and eighteen at the time of their parent's death. This age was decided as developmental psychology suggests that children under six may have cognitive difficulty understanding death²⁶⁰. From this age, children become more curious about death and the surrounding rituals and are aware of others' responses²⁶¹.

Children must be ten years or above to participate in the research; this age was agreed upon by members of the young person's advisory group (YPAG), bereaved family's group and from speaking to professionals offering virtual bereavement support. Research suggests that most children fully understand that death is final and inevitable by age ten⁷⁵. It was agreed that most children aged ten or above would have the concentration to participate in a virtual interview. Some children under ten may not fully understand the research's aim, benefits, or risks²⁶². However, it is argued that informed consent is a fundamental right of every child irrespective of age or ability. The researcher's obligation was to help children understand what the research is about and what they agree to by using child-friendly language, explanations and information; meaning young children can give consent providing

they have the appropriate information, and they are supported in the process²⁵⁴. The principles of the Gillick Competency Framework will be used to assess whether a child has the maturity to make their own decisions and to understand the implications of those decisions^{263,264}. The National Society for the Prevention of Cruelty to Children (NSPCC) advises professionals to consider several things when assessing a child's capacity to consent - the child's age, maturity and mental capacity, their understanding of the project and what it involves including advantages, disadvantages and potential long-term impact, their understanding of the risks, implications and consequences that may arise from their decision, how well they understand any advice or information they have been given and their ability to explain the rationale around their reasoning and decision making²⁶³.

Potential parent participants were initially approached and offered the opportunity for themselves and their child/children to participate when they had been bereaved for at least 12 weeks. There was no upper time limit to how long since the bereavement they could participate, providing they met the eligibility criteria. Limited research shows the best time to offer support; however, guidelines suggest the first meeting should be between 8 and 12 weeks²⁶⁵. Murray Parkes, an expert in grief and bereavement, suggests that in the initial period following a death, the bereaved have support from those who rally around them. However, this support typically lasts one to two months, and then the bereaved person often finds themselves alone²⁶⁶. Public involvement consultation suggested that families will only choose to be involved with a study when they are ready to speak about it, which will differ for each family. Although bereaved members of the public involvement group had been bereaved between 11 months and 10 years, they agreed that if they had been given information about this project soon after bereavement, it would have not added to their upset or distress. If they had been interested, they felt they would have asked for more information or they would have discarded the information.

Table 14 Study eligibility criteria

Eligibility criteria for parents/guardians	Eligibility criteria for children
Parents or guardians of dependent children aged 18 years or under who have experienced the death of the other parent by any cause	Children must have experienced parental death by any cause when they were aged 6 to 18 or and be aged 10-18 years at the time of recruitment
Parents or guardians must be resident in the UK at the time of the interview	Children must be residents of the UK
Parents or guardians must have been bereaved at least 12 weeks prior to approach or participation in the study	Children must have been bereaved at least 12 weeks prior to approach or participation in the study
Parents or guardians may participate without their child's participation	Children's parent/guardian does not have to participate to enable the child to participate; however, children under 16 years must have parent/guardian consent to participate
Parents or guardians must be able to read, understand and speak English	Children must be able to read, understand and speak English

6.4.2 Sampling and recruitment

Sampling describes the process of selecting research participants for the study. The study aims to explore an under-researched phenomenon in greater depth through the eyes of children and their surviving parents. They are viewed as a 'hard to reach' population, which is evident in the limited research with their involvement¹⁹. Grounded theory studies do not have a specified number of participants; instead, sampling is driven by the developing theory²⁶⁷. Recruitment was an ongoing process. This is an essential feature of grounded theory research involving a continuous cycle of data collection and analysis, facilitated through ongoing recruitment, which would stop when the constructed theoretical categories were saturated with data²²². Figure 6 provides an overview of the recruitment process.

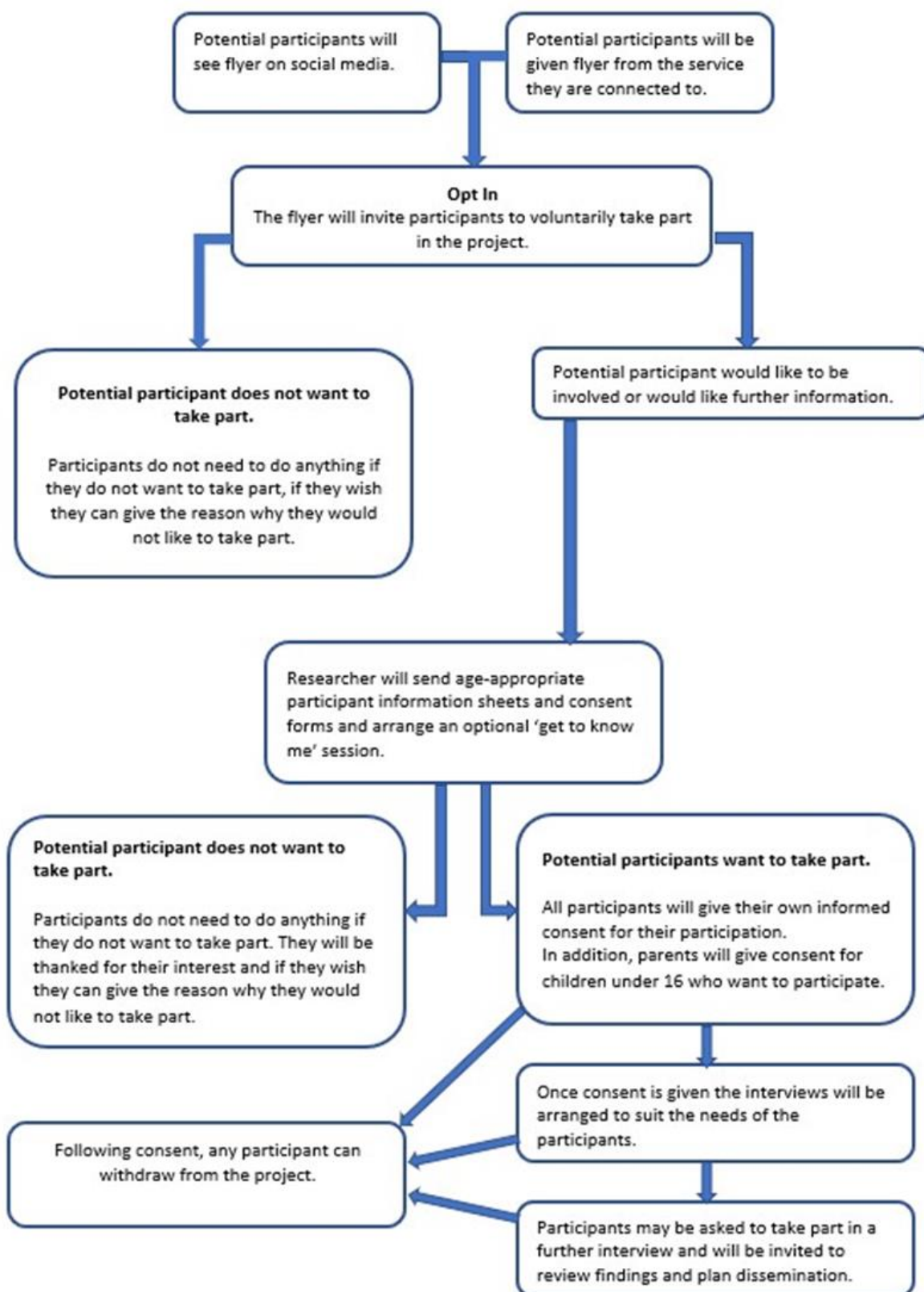


Figure 6 Recruitment flow chart

The decision to recruit through social media was primarily made because of Covid. However, it soon became apparent that this recruitment method had the scope to reach thousands of people quickly, which proved beneficial when the time was limited and allowed the inclusion of geographically dispersed participants. The initial search strategy was to firstly approach and invite third-sector bereavement organisations to share the recruitment flyer using their social media platforms, including Facebook and Twitter.

Purposive sampling was used to recruit the first sample of families aiming for maximum diversity. Participants were recruited between September 2021 and April 2022. In the first wave of recruitment, four families were represented, two mothers, two fathers, and five children aged eleven to seventeen who experienced expected and sudden deaths. There was a pause during December 2021 as the researcher found that families involved at that stage had asked to participate after the Christmas period. Whilst recruitment was on pause, the ethics committee approved an amendment to the study protocol to allow hospices to share the recruitment flyer. In January 2022, several hospices agreed to share the flyer, and the researcher used their social media platforms to re-share the flyer resulting in another recruitment wave.

Sharing the recruitment flyer (Figure 7) in January 2022 proved successful, with ten families seeing the flyer on Twitter and contacting the researcher. It was expected that NHS Ethics approval would be needed to recruit via other settings. However, successful recruitment using social media meant this was not required. Snowball sampling procedures were also undertaken with participants, but the consent forms were not returned despite the study information being requested by two other families.

Overall, one family was recruited through the researcher's professional network, five families were recruited from bereavement services, including hospices, and the remaining eleven families had seen the recruitment flyer on social media (Twitter n=10, Facebook n=1).

Are you bereaved?

What helped you?

This project wants to speak to bereaved children and parents to ask how you supported each other and what helped you.

Why: Your experience is extremely valuable and will help us to improve the support we give to children and families following the death of a parent.

Who: We would like to speak to parents whose partner has died and their children aged between 10 and 18. Families must live in the UK.

Hello, my name is Alex Wray. I'm a nurse and researcher at Hull York Medical School. I want to learn how we can best support children and families following the death of a parent and I need your help.

If you think you can help or you would like to find out more, please contact me: alexandra.wray@hyms.ac.uk or phone 07423508088. You can also visit the HYMS website for further information www.hyms.ac.uk

Share your story

What: We would like to invite each of you to take part in an interview to hear about how you were supported during this time. It will take around one hour.

When and where: Online using Zoom or the telephone and at a time that is convenient for you.

Bereaved children, young people and families can often feel alone in their experience. Help make a difference by sharing your experience and improve how we can support bereaved families.

Share your story

Hull York Medical School

Yorkshire Cancer

Figure 7 Recruitment flyer

6.4.3 Theoretical sampling

Following interviews with the first family, theoretical sampling began and continued until theoretical saturation was achieved. In their early writings, Glaser and Strauss²³³ defined theoretical sensitivity as the ability of the researcher to "conceptualise and formulate a theory as it emerges from the data", which is developed through practice and application²³³ (p. 46). Glaser²⁶⁸ described how researchers embarking on theoretical sampling do not know what to sample for and where that will lead them; as codes are discovered, they are saturated by looking for groups to compare them with. As previously discussed, sampling began with a small purposive sample that strived to ensure maximum variation and a manageable quantity of data²³⁸. As data were analysed, theoretical sampling focused on the constant comparative analysis to show which categories required further development allowing the researcher to follow leads in the data²⁴¹. Strategic decisions were made about what or whom to gather further data from²⁴¹. Memos aided theoretical sampling by allowing the researcher to consider sources to aid theoretical sampling and create an audit trail of the decisions made²⁴¹. As the theory developed, theoretical sampling was used to

check the emerging conceptual framework²⁶⁸ and continued until the researcher no longer identified new codes in the data²⁶⁷.

6.4.4 Screening for eligibility

Prior to sending participant information packs, potential participants interested in the research were screened for eligibility to ensure that only the participants who met the inclusion criteria were recruited into the study. As this was opt-in, potential participants contacted the researcher directly in the first instance. Once confirmed to be eligible for the study, a participant information pack was sent, and they were offered a 'get to know me' session. Parents made the first contact and then spoke to their child(ren) to ask if they would like to be involved. Participant information packs included information for parents, and age-appropriate information for their children, was sent to 22 families. Each pack consisted of: a participation letter (Appendix 5) to thank participants for their interest in the study and provide information on the next steps; a participant information sheet (PIS) for parents (Appendix 6) and a different age-specific child PIS (Appendix 7 for children aged 14-18 years and Appendix 8 for children aged 10 to 13 years) explaining the purpose of the study, what taking part would involve; a parent (Appendix 9) and separate child consent form (Appendix 10 for children aged 14-18 years and Appendix 11 for children aged 10-13 years), a parent and child-focused support signposting leaflet; and a pre-stamped envelope to return their signed consent form to the researcher. Once a signed consent form was received, the researcher contacted the participant again to plan the 'get to know me session' if this had not already taken place and then agreed on interview arrangements. If a consent form had not been received within ten working days, the researcher contacted the participant to follow up. Unfortunately, there was often a delay in receiving consent forms. Parents gave reassurance that they were keen to be involved; however, they were often busy and had forgotten to return the consent form. Of the 22 participant information packs sent out, consent forms were returned by 17 families. The four families who did not return consent forms did not respond to the researcher's follow-up; therefore, it is unclear why they subsequently chose not to participate.

6.5 Gatekeeping

Evidence suggests that well-intentioned gatekeepers wishing to 'protect' children can further marginalise vulnerable groups by not allowing them an opportunity to make an

informed decision or receive the benefits of research participation²⁶⁹. Bereaved individuals are a hard-to-reach group. Research has questioned if routes 'in' to accessing bereaved young people are challenging for us, then how do they navigate routes 'out' and access to support during challenging times⁷⁹. Therefore, this study and children's participation are paramount to help improve how we support bereaved children and their families. As discussed earlier, gatekeeping was experienced throughout the study, beginning with public involvement and initial meetings with professionals in the field.

Anticipating gatekeeping from professionals and parents, I identified myself as an experienced nurse facilitating bereavement support groups to gain access to the field. It was important for parents and professionals identifying participants to have confidence and trust in my abilities to research with bereaved children and families. The public involvement work helped me understand how to present myself to participants, and an understanding of my background helped them feel confident, comfortable, and safe to share their experiences with me. It is recognised that developing rapport and trust provides interactions that can deepen our understanding of the phenomenon under research²⁵². I needed an approachable personality for participants to open up and share their experiences. Personality and emotional intelligence are important and can shape the research process and product, yet they are often not considered within research²⁵³. Research has shown that participants can judge the researcher by their personality, social skills, and emotional responses, impacting accessing participants and the amount they open up to share their experiences²⁵³.

Recognising parents as gatekeepers, it was crucial to provide them with confidence in my expertise and skills and develop rapport to allow the parent to know and trust the researcher. Therefore, the parents initially spoke on the phone to the researcher and the family were allowed to take part in a 'get to know me' session to address any concerns and satisfy the parent that the needs and safety of the child will always take precedence over the research²⁶⁹.

6.6 Participants' autonomy and informed consent

The University of Hull Research Ethics Policy²⁷⁰ defines a child as any person under 18 years. According to the age when a young person turns 16, they are presumed to possess the

capacity to consent themselves; for those under 16, there is no deemed 'competent' age. Following the Research and Ethics Policy, any participants under the age of 16 required formal consent from their parent/legal guardian to potentially participate. However, age categorisation can be problematic as it does not recognise a child's intellectual ability, development speed, maturity or experience²⁷¹. Due to the sensitive nature of the research, parental consent was to be obtained for all participants under the age of 16, with children over the age of 16 providing their own informed consent. If parents were not participating in the project, children were asked to discuss their participation with their parents and seek their agreement to proceed (even though parental consent is not formally required). Parents must be aware of their children's involvement as they will support them and help make sense of the research²⁷².

For those over 16 years, once parental consent has been granted, children give their own informed consent, as parents cannot consent on behalf of their child. The child's right, under Article 12 – The United Nations Convention of the Rights of a Child⁶² stipulates that a child who is capable of forming their own views is to have the right to express those views freely in all matters which affect them⁶². Children are citizens with agency and lived experience and have a right to say in matters that may affect them¹⁷³. Empowering children to consent to participate in research freely, without coercion, threat, or persuasion, even if a gatekeeper has provided consent, acknowledges the child as an expert in their own life and promotes autonomy¹⁷³. The study adopted Lundy's Model of Participation, conceptualising Article 12 of the UN Convention of the Rights of the Child to ensure that children have the space to express their views, their voice is enabled, they have an audience for their views, and their views will have influence²⁷³.

For all participants, consent was checked throughout the study. Participants needed to be fully informed; participant information sheets were made understandable and accessible to participants of different ages. There are three participant information sheets: parent participant information sheets; children participant sheets for ages 14 and above; and children participant information sheets for ages 10-13. These ages were chosen as from age 14; children appear to have an abstract understanding that is similar to adults; between the ages of 10 and 14, children have a developing understanding of what is involved in research participation, so they will require information at a level they can understand²⁶².

Individual participants' right to voluntary involvement was respected at all times. Initially, ten parents participated without their children's involvement. The reasons for this were that the children were too young and did not meet the eligibility criteria (n=4), and parents did not want to ask their children if they would like to participate (n=4), although as the study progressed, one parent did ask their child who subsequently participated. They did not want to ask their children because they felt they were doing well, did not want to cause any setbacks, or felt they already had other things going on and did not want to put more on them. In addition, two children who had been bereaved less than six months were not approached to participate (n=2). One child was struggling with extreme physical symptoms and awaiting an urgent mental health review, and the other was receiving professional bereavement support but had not been able to speak with anyone about her mother since the death. This decision was discussed with the parents and professionals providing support and agreed upon with supervisors.

If a child would like to participate but their parent would not, any child under 16 would need parental consent. Had any participant agreed to be involved and subsequently changed their mind, they would be reassured that it was okay to change their mind at any time without providing a reason.

6.7 Supporting participants and distress protocol

Supporting families in the project has been the primary concern and plans to support families were developed following public involvement.

I am a registered nurse; working within the local hospital's bereavement support team. In addition, I chair the local child bereavement advisory group and am a certified Grief Recovery Method specialist. During a leave of absence in the pandemic, I developed and managed a family support team and incorporated bereavement support for families. Before this, I worked in different end-of-life settings within the hospital and am experienced in supporting families during end-of-life care. My background provided some expertise in supporting bereaved families within the study and was carefully managed through reflexivity to identify pre-existing knowledge and potential bias.

Efforts were made to minimise distress. Participants were offered an introductory session with the researcher prior to participation. This session allowed the development of rapport

and trust, allowing families to get to know the researcher and for participants to feel comfortable sharing their experiences. It also allowed participants to use Zoom if this was not a platform they had previously used. Before any interview with a child participant, the researcher contacted parents to gain their support in keeping the researcher informed of how the child was doing. The participants were sent a grounding technique to practice with the researcher. All participants were told in the participant information and at the beginning of each interview that: they did not have to answer any questions they did not want to; they could stop the interview at any time; the research is not a test with right and wrong answers; everyone is an individual; the researcher is interested in different experiences and views; and participants could tell the researcher if and when they need a break.

Interviews began with an icebreaker game that was accessible and age-appropriate. The researcher was acutely aware of the potentially different needs of participants and would ensure interviews were flexible and adaptable to those individual needs.

Photo elicitation had not been considered as an interview method. However, the researcher shared family pictures during the 'get to know me' session. During the first interview with a child, they were asked if they could show the researcher a picture of their parent. Using photos with children can help develop rapport at the beginning of the interview and provide an opportunity to identify anything that may be significant to the participant to explore further¹⁸⁴. Subsequently, during the 'get to know me' session, families were invited to share photos of the deceased parent should they wish.

Childhood traumatic grief is not a normal reaction for children to experience following the death of a loved one, even when the cause of death is traumatic²⁷⁴. However, the researcher recognises the potential for any participants to display trauma-related emotions. Children with childhood traumatic grief often avoid talking about the death or the person who has died; therefore, they would likely not want to participate in the study. The UK Trauma Council²⁷⁵ has recognised the need to identify and support children experiencing traumatic bereavement and developed resources that were added to the parent's and children's bereavement support leaflet.

Undertaking sensitive research with bereaved participants required their well-being to be of utmost importance. It required developing a process to ensure that should participants

become distressed, they would receive the professional support they may need²⁵⁸. At the start of the interview, the researcher confirmed the participant's best contact number and current address. For children, this was their parents' contact number and their own if they had one. If a participant became upset during the interview, I followed the distress protocol. A few parents and one child became upset during the interviews. They all wished to continue with the interview and were supported to do so. Reflecting on participants who became upset during the interviews when this first happened, it highlighted to me, the gravity of their involvement and what I was asking of participants. I believed it important to offer a chance to take a break or stop the interview. However, I was very keen to acknowledge that it was okay to be upset. In the case of the child who cried during the interview, had I stopped, it felt like this would be telling the child it was not okay to be upset. This was reflected in a memo presented later in this chapter (Figure 8). Participants were made aware that if they left the interview unexpectedly, the researcher would use the contact number to call and check their well-being. However, this did not happen. The grounding technique was sent to all child participants, and they had an opportunity to practice this with the researcher if it was not something they were familiar with (Appendix 12). Apart from practising the technique, it was never needed during an interview.

6.8 Confidentiality

Confidentiality and anonymity are essential considerations in research, especially when children are participants²⁷². Therefore, the confidentiality of all participants was protected throughout data collection and analysis. Initially, children were asked to think of a pseudonym used when the interviews were transcribed. However, following the first family interviews it became apparent that the names the children chose would be known to the rest of their family. Therefore, it was decided that the researcher would allocate names to each participant that were culturally appropriate and remove any identifiable data during transcription. Children were also made aware that confidentiality may have to be broken if they disclose any information regarding safeguarding issues. As a registered nurse, if I had been concerned that participants were at risk of harm, I have a duty of care to act on that. Depending on the disclosure, this may have required reporting to and discussion with the supervisory team and the University or possibly adherence to the hospital's safeguarding policies and processes that I am familiar with through my clinical work.

6.9 Data collection

All data collected was relevant, not excessive, and collected and stored following the Data Protection Act 2018 and General Data Protection Regulation (GDPR) according to the ethics approval. Raw data included consent forms, audio or video files, transcripts and memos. Hard copies of data such as consent forms were converted to digital files and stored on a password-protected file on the researcher's University account. Original copies of consent forms were destroyed once digital copies were made. All interviews were undertaken by the researcher, who also transcribed each interview.

6.9.1 Interviews with children and surviving parents

In-depth interviews with parentally bereaved children and their surviving parents were deemed most appropriate due to the sensitive nature of this research. Undertaking interviews with bereaved people who share their experiences of loss and its impact can have a therapeutic effect, with the researcher having a dual role as researcher and 'therapist'²⁵⁸. Focus groups were considered and may have the ability to empower some children to share their experiences, with safety in numbers and less pressure to answer questions^{173,255}. However, it could make others feel more exposed when sharing their own experiences and may restrict sharing¹⁷³. Previous research with bereaved children found that a group environment to share their experiences was intimidating for some, and not all children were ready to share their stories within a group²⁷⁶. In addition, self-completion questionnaires may raise difficult issues for children who could be left in a distressed state without support¹⁷³. Undertaking in-depth interviews allowed the researcher to give more thorough explanations to ensure children understood, to provide reassurance, and put participants at ease, allowing the flexibility to adapt timing, clarify and reframe questions as required. This type of interview is useful when discussing sensitive subjects allowing the researcher to sensitively broach the subject whilst judging any discomfort and adjusting the pace, wording, language, and style to meet the child's needs¹⁷³.

In-depth interviewing was used as it is conversational and allowed a deep exploration which would elicit each participant's interpretation of their experience²³⁵. Broad, open-ended questions allowed unanticipated experiences to emerge²³⁵. Individual interviews were the preferred method; however, the researcher remained flexible with the participants to control who would be present during the interview. For example, being aware of the change

in power dynamics if a parent was present could make gathering and interpreting the child participants' responses more difficult¹⁸⁴. Individual interviews meant the participants had the researcher's complete attention and were recommended to explore sensitive topics such as bereavement¹⁸⁴. It was clear that both children and parents appreciated having someone listen to their story; many thanked me for listening. The children especially liked taking control in the interviews, and the younger ones especially would use the stop and go cards, with one child asking if he could use a film clapboard to start and end the interview.

The researcher used their professional skills to help develop rapport and communicate effectively with participants, whilst mindful of the need for the interviews to be flexible to allow for the emergent nature of grounded theory²⁴¹. The interview guide was used iteratively and modified as concepts developed during the analysis²⁷⁷.

6.9.2 Online interviews

As the interviews would not be face-to-face, it was necessary to consider the ages of children who would be considered eligible to participate. Public involvement agreed that Zoom was an acceptable method of performing interviews in the current situation of the pandemic; children must be at least ten years old to participate, and any younger than they may not have the concentration to complete an interview. It would also be necessary to develop a rapport with the participants before the interviews as this was a sensitive topic.

A recent study investigating online technology in interviews with young people found Zoom to be a successful method to undertake interviews and recruit a diverse purposeful sample, including those deemed harder to reach²⁷⁸. It provided participants with a feeling of safety and anonymity, allowing greater participation and inclusion of those who may not have wanted an in-person interview, including those who are shy, introverted, and unlikely to engage in an in-person interview²⁷⁸. The study found that most participants preferred video chat, finding it easy to use and convenient and allowing them to feel comfortable talking about their personal lives²⁷⁸. The disadvantages of video interviewing included problems with electronic device, connectivity and challenges for participants in finding a private space for the interview²⁷⁸. With this in mind, interviews timing was flexible to suit the individual participant's needs. During the introduction session, time was allowed for connecting, and participants could try the online platform.

Zoom interviews were undertaken and recorded using the Zoom software via a University-managed account. One of the preferred platforms of the University was GDPR compliant and configured to force passwords and protect privacy. Interviews began without recording, and once consent to record was given the recording commenced, with Zoom automatically alerting participants that the interview was being recorded.

6.9.3 The topic guides

The topic guides (Appendix 13 for parents and Appendix 14 for children) consisted of open-ended questions to allow participants to direct the interview and allow the researcher to follow emerging leads whilst ensuring focus on the research question and objectives. The initial open-ended questions were broadly framed around the study's objectives that were informed by gaps in the systematic literature review and talking to families in the public involvement sessions. As the study progressed, there was a need to explore specific aspects of participants' experiences; topic guides were revised accordingly. Initially, the topic guide began with questions to build rapport with participants. After the first few interviews, it became apparent that rapport had already been established via the 'get to know me' session. This meant the start of the interview could be tailored more to the individual and what the researcher had learnt from previously meeting them. For example, one of the young people had recently started driving lessons; rather than ask questions from the topic guide, it was more personal to ask how the lessons were progressing. Having previously met the participants, it became easy to develop rapport within the interview setting and make it less formal.

6.9.4 Piloting topic guides

To validate the topic guides prior to the primary interviews with children and surviving parents, they were piloted by researchers in the field using role-play to allow the researcher to become familiar with the topic guide, develop self-confidence and an increased ability to create safe and stimulating interactions. Pilot interviews then progressed with members of the public involvement group, including one parent and three children who gave feedback on the acceptability of the questions and how the interview should be undertaken. Children trialled the activities, including the emotions blobs and grounding technique which they thought would be helpful in the interviews.

6.10 Data analysis

The next section describes the processes followed to analyse the data. Although they are described linearly, they were undertaken iteratively with movement backwards and forwards between the processes.

6.10.1 Concurrent data collection and constant comparative analysis

Grounded theory data analysis sees everything as a concept²⁴¹. Concurrent data collection and analysis are fundamental to grounded theory design²⁴¹. Meaning data were generated with an initial small purposive sample of participants with experience with the phenomenon under investigation. Data were transcribed, coded and analysed before further data were generated, and this analysis process was repeated^{222,241}. Constant comparative analysis is the process used when coding and developing categories²⁴¹; described as an analytic tool which promotes reflective thinking^{222,247}. The constant comparison involves identifying similarities and differences in the data, comparing codes, emergent categories and reflexive memos with further data until theoretical saturation has been achieved^{222,241}.

6.10.2 Transcribing

Interviews were recorded using the Zoom recording feature via a University managed account. The researcher transcribed the interviews verbatim into Microsoft Word as soon as possible and before subsequent interviews. Transcribing the interviews allowed the researcher to become fully immersed within the data. It also allowed analysis to begin immediately, including what and how participants spoke and considering any pauses, emphasis on words, tone and body language. In addition, using these complete interview transcriptions for coding allowed the researcher to develop ideas and understandings that could otherwise be missed²³⁵.

6.10.3 Computer-assisted qualitative data analysis

Computer-assisted qualitative data analysis software (CAQDAS) helps organise large amounts of data into manageable codes for more efficient analysis²⁷⁹. Once interviews were transcribed, they were uploaded into NVivo software for analysis. NVivo 12 was the chosen software that facilitated quicker coding and allowed the creation of large volumes of codes from the interview transcripts, which were more easily grouped into categories as appropriate. In addition, NVivo allowed coding to be tracked and data analysis to be easily

accessible, supporting the process of data gathering and analysis and the constant move back and forth between data and the ability to link memos to the data²³⁰. Using analytical elements such as linking transcripts, codes, excerpts, and memos would allow swift movement between the elements and aid in the comparison, interpretation, and coding of the data.

6.10.4 Memo writing

Memo writing is crucial to grounded theory; it begins during the planning of the study and continues until it is completed²⁴¹. Memos allow the researcher to record their analysis, thoughts, feelings, interpretations, and questions and direct further data collection^{222,241}. They allow the researcher to analyse the data and codes from the start of the research process, moving towards theoretical categories²²². Charmaz suggests memos take the form of raw and unedited writing, which allows for creative freedom whilst analysing the data²²². Whilst coding, memos help write about the codes and any questions on the data²⁴⁶. Memos document the research process, including accessing and working in the field and developing and defining categories from the data, which are then sorted and developed to form the theory²⁸⁰. Memos are crucial to ensure quality within a grounded theory study²⁴¹.

Memos began in an ongoing reflexive diary at the beginning of the researcher's doctoral studies. Once the project began, memos were written following encounters with participants, following interviews, when decisions were made relating to the study and whilst transcribing and analysing interview data. Memoing allowed the researcher to maintain a reflexive stance throughout the research process and provided opportunities to stop and focus on the codes, taking them apart, comparing them and identifying links between them²²². Maintaining reflexive and analytical memos supported theoretical sensitivity whilst concurrent data collecting and analysing gave the researcher validation of their interpretation of the emerging categories, ensuring these were grounded in participant data²²². In addition, memos provided a form of debriefing following interviews, reflecting on how the interview had gone and how the researcher felt. An example is provided in Figure 8.

22nd November 2021 post interview memo

From my initial memo post interview with Leo, my reflections were that it did not go very well and I did not get much depth. I spoke a lot more in this interview than I had in the previous two child interviews. During the interview, he was tearful at times, but I got the impression he wanted to talk to me despite him finding it difficult to talk. This seems like it will be a finding in itself, not knowing how to talk about it. I acknowledged his upset and asked what was making him upset. On further reflection I questioned if I should have been more explicit asking if he wanted to stop the interview when he was upset – I didn't do this. I think this is maybe the clinician in me that is comfortable with silences and people getting upset in difficult conversations. I feel like if I asked him if he wanted to stop that could be taken as me saying that it is not ok to be upset and reinforce any issues he may have about talking about it and getting upset, rather than seeing being upset talking about it as a normal reaction. Also, if this is an issue for children it is important to explore that. At the end of the interview he seemed happy and said he would like to take part in a follow-up interview. Fifteen minutes after his interview I interviewed his mum who reassured me he was fine. Maybe I am overthinking this too much? Very conscious of what I am asking from these families.

I will make sure that any interviews when parent and child interviewed at the same time, I allow a gap in between. Meeting my supervisors next week so will discuss with them when they have seen the transcript.

Figure 8 Post interview memo

The data analysis followed an iterative process of three key stages of coding as summarised in Figure 9. Each stage is now be discussed.

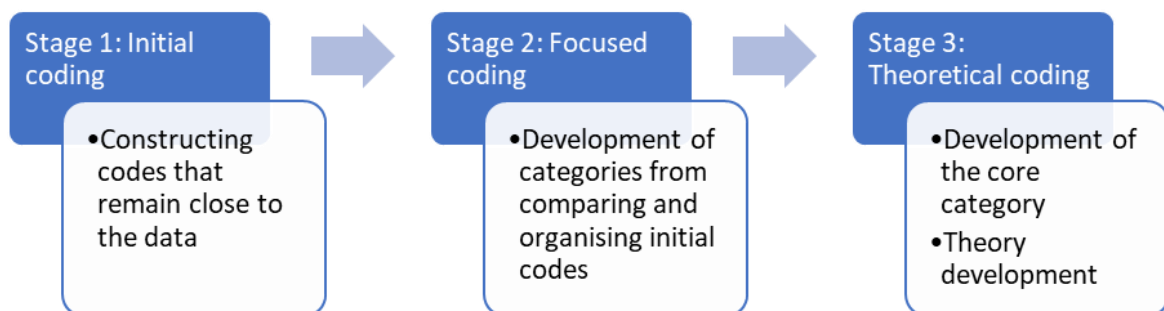


Figure 9 Stages of data analysis, adapted from Birks and Mills²⁴¹

6.10.5 Initial coding and categorising of data

Once transcribed, the completed interview transcripts were initially coded within a few days of the interview to maintain the grounded theory method's principle of simultaneous data collection and analysis²⁴¹. Initial coding is described as a process of fracturing the data, allowing a deep understanding of the phenomenon and generation of ideas which could have otherwise been missed^{235,241}. Careful initial coding fulfils the fit and relevance required to complete a grounded theory analysis²²². The study is set to fit in the empirical world when codes have been constructed and then developed into categories that make clear participants' experiences²²². For it to be relevant, there must be an analytic framework to interpret and explain the relationships between the processes and structures seen²²².

During initial coding, transcripts were read and each line allocated a code that provided a short summary of that data - highlighting similar words, phrases and patterns using gerunds (action words and processes). Initial coding was done quickly and spontaneously, as suggested by Charmaz, using participants' own words, where possible, to keep close to the data^{159,222}. By coding each line of data, the researcher developed a good oversight of what was happening in the data. Memos were used to capture thought processes and identify gaps in the data and relevant areas for further exploration in subsequent interviews²²². Initial coding yielded a considerable number of codes that were grouped to describe themes. For example, in parents' data, there were narratives around communication. These included the difficulties in telling the children, how they told them, what helped, and the importance of honesty. These were grouped as a theme, 'talking to the kids', which captured the narrative around communicating with their children. Other ideas relating to communication were also included in this theme. This process was adopted for all parent data and then separately for the child data.

6.10.6 Focused coding

Where initial coding fractured the data, focused coding is the process of bringing the data back together in a conceptually abstract form allowing the theory to emerge from the data²⁴¹. A more conceptual coding level required comparing initial codes and data to decide which had the greatest analytical power²²². These dominant codes become categories that could synthesise and explain other segments of the data²³⁵. Focused coding was used to fully develop the categories, their properties and dimensions²⁴¹; connecting categories to

sub-categories and linking categories²⁴¹. These categories were explored in greater detail in subsequent interviews (theoretical sampling)²⁴¹.

A small purposive sample of four families, including two mothers, two fathers and five children aged eleven to seventeen, provided maximum variation. All had experienced expected and unexpected parental deaths. One father was separated from the deceased prior to their death, so, along with his child, they provided a seldom-heard perspective. The place of death varied within these families, including hospice, hospital and home. Following these interviews, the diversity of experiences allowed the researcher to begin focused coding.

In order to raise codes to a category, it was necessary to compare data, incidents, contexts and categories²²². Charmaz²²² suggests writing memos to define the category, analyse its properties, outline the circumstances in which the category arises, is maintained and changes, describe the consequences of the category and finally show how it relates to other categories²²². The themes deemed important for further exploration were guided by the most prevalent themes in the data and following discussions with the researcher's supervisors whilst focusing on the research aims and objectives.

Theoretical sensitivity and reflexivity supported the decisions about which initial codes should be raised to focused codes that would incisively and completely categorise the data²²². These tentative categories were then used in the coding of subsequent interviews to determine their fit. Following further data collection, tentative category names were changed to ensure the data were completely encompassed. For example, parent codes of choosing to live for the children, focusing on the children, and neglecting your needs were combined and renamed 'putting everything into the children' to account for the different experiences fully. This code became a subcategory of a major category.

Using mind maps and diagramming whilst collecting data and analysing helped connect and map codes during the initial analysis and, as this progressed, aided a more conceptual understanding of the phenomena. Storylines were also helpful during analysis to encourage focus and integration by explicating the relationships between the concepts that would

eventually make up the theory, ensure evidence was grounded in the data and limit any gaps.

Further data collection, memoing and constant comparison allowed the continued refinement of the categories, and their subcategories and properties to understand which would stand alone and which would be subsumed by others.

6.10.7 Theoretical coding

Advanced coding is crucial to theoretical integration, and produces a theory that is grounded in data and has explanatory power²⁴¹. When beginning theoretical coding, the previously developed categories from the focused coding were abstract²³². Theoretical coding adds precision and clarity by going beyond creating relationships between categories to exploring and analysing the relationships by conceptualising how they are related²³⁵. Theoretical codes must earn their place in the developed theory²⁶⁸. The initial coding fractures the data, focused coding brings the data back together in conceptual groups that emerge, and theoretical coding weaves together the fractured story into an organised theory²⁶⁸.

The data were constantly interpreted for external validation through speaking with peers, supervisors, professional colleagues, other researchers, and professionals in the field, some of whom have personal experience of parental bereavement as a child. Doing so helped deal with the researcher's subjectivity and any potential bias in the analysis process.

Data analysis to this point resulted in a set of categories for children and separate categories for parents. Categories from child and parent perspectives were compared and explored with additional data to identify similarities and variations. The storyline analysis technique was used to integrate, construct, formulate and present the findings from the data²⁴¹, resulting in the identification of a theoretical concept encompassing parent and child support experiences.

Member checking was used to ensure the major categories were saturated and to enhance credibility and rigour, and to reduce researcher bias²⁸¹. Lincoln and Guba²¹⁷, and Charmaz²²² suggests that member checking be used as an opportunity to take ideas back to participants for verification and gather further data to expand developing categories²²². Member checking adopted a constructivist stance, as concepts emerged, these were explored in

subsequent interviews with children and parents, allowing participants to validate and expand on the researcher's interpretation of the data²⁸¹.

Once the analysis of findings from the initial interviews was complete, the researcher presented the synthesised and analysed data and the initial emerging theory to three members of the public involvement group and then in follow-up interviews with four participants (one daughter, one son, and two mothers). This allowed validation that the findings and proposed theory resonated with their experiences and remained grounded in the data²⁸¹. Following these follow-up interviews, it was deemed that theoretical saturation had occurred, categories were well saturated, and no further properties or dimensions were added to the presented categories.

6.10.8 Theory development

Grounded theories result in models or theories at different levels, either substantive or formal²⁴¹. A substantive theory is a theory that has developed from and is grounded in empirical work within a specific area²³⁶. In contrast, a formal theory addresses more conceptual and abstract areas of research that have broader applications than substantive theories specific to a particular context²³⁶. The scope of this study was to produce a substantive model reflecting a supportive response for children and parents following parental death. The researcher generated the theory by following the grounded theory processes as previously described²⁴¹. Birks and Mills²⁴¹ explain the grounded theory processes as three separate wheels consisting of essential processes, which the researcher can drive like a machine to generate a theory²⁴¹. Their original figure has been adapted to map the constructivist grounded theory generation processes, which have been followed in Figure 10.

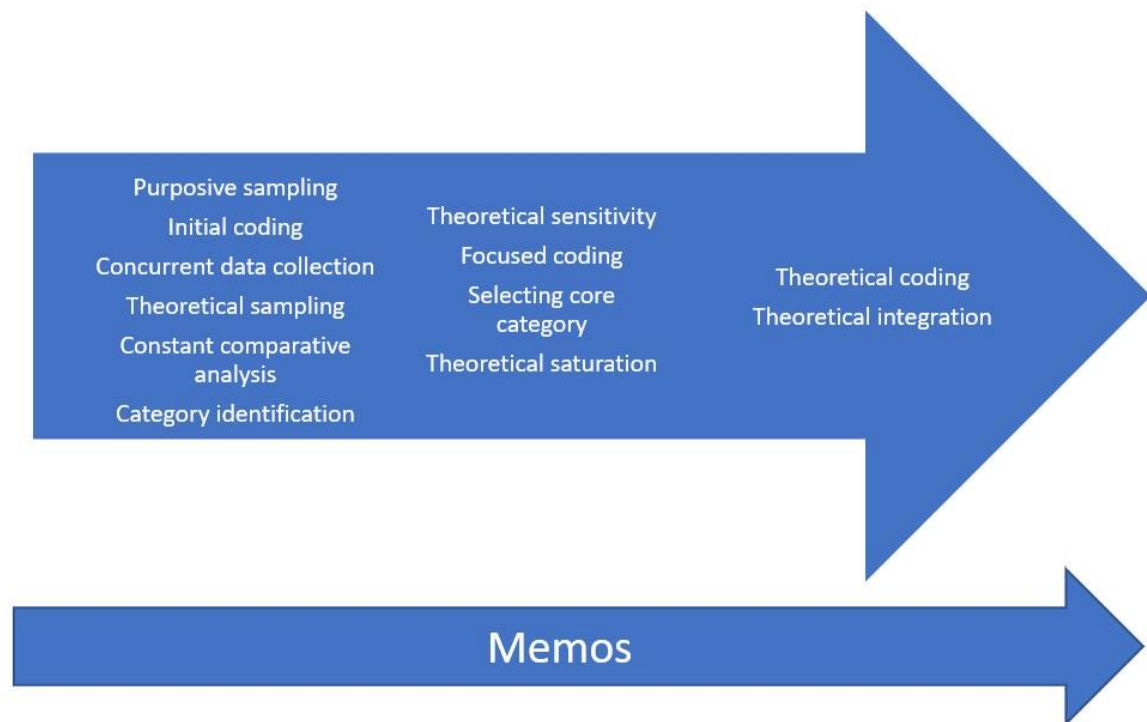


Figure 10 Grounded theory processes leading to theory development, adapted from Birks and Mills²⁴¹

6.10.9 Identifying a core category

Intermediate coding allows the development of categories formed around a core concept or category²³². Although not deemed essential by Charmaz²²², this core category becomes evident²⁴¹. It will be broad and abstract and relate to all the other categories, frequently appearing within the data and representing all participants²³⁷. Furthermore, the core category will be sufficiently abstract for research in other substantive areas²³⁷. Theoretical coding of the key categories from parent and child data sets culminated in the development of a substantive theory that explained the major social processes in play when children and parents are supported following parental death.

6.10.10 Theoretical sensitivity

Theoretical sensitivity is an important aspect in the process of theory development. According to Glaser²³³, it is related to the researcher's personal and temperamental inclinations alongside a theoretical insight into the field of study, with the ability to 'make something of' your insights²³³. Charmaz describes how theoretical sensitivity and coding influence each other, allowing researchers to bring analytical precision to their research²²². Theoretical sensitivity can be developed through theorising²³⁵. Whilst collecting data and

analysing, the researcher uses their personal and professional experiences and prior knowledge from the literature to build a conceptual framework for the phenomenon under study²⁴¹. The more immersed the researcher becomes in their data, the greater their theoretical sensitivity²⁴¹.

The substantive theory developed in this research required theoretical sensitivity adopting Charmaz's approach to theorising, which includes 'stopping, pondering and thinking afresh'²²² (p.244). When theorising, the phenomenon under study is taken apart, studied from multiple stances, comparisons are made, leads are followed, and ideas are built upon. Charmaz describes the acts required for theorising as seeing possibilities, establishing connections and asking questions²²².

6.11 Ethical considerations

6.11.1 Ethical approval

Ethical approval for this study was granted on 27th July 2021 through Hull York Medical School Ethics Committee (Reference 21 34, Appendix 15). The University of Hull sponsored the project. Before ethical approvals, the study protocol was peer-reviewed. All documentation relating to the study was reviewed and amended accordingly, following feedback from the public involvement groups. The study adopted an opt-in approach that relied on potential participants seeing the recruitment flyer. If potential participants were interested in the study or wanted further information, they would contact the researcher directly. The recruitment flyer was widely disseminated on social media platforms. Study information was shared with many bereavement charities offering bereavement support in the UK, who agreed to share the flyer on the charity's social media platforms and with families in their groups. The first wave of recruitment successfully identified five families through social media and bereavement charities who wished to participate. In addition, several hospices showed interest in participating in the study. It was decided to seek an amendment to the original ethical approval to allow hospices to share the recruitment flyer on their social media channels and in their newsletters and display the flyer within the hospice. This amendment was granted ethical approval from HYMS Ethics Committee on 15th December 2021.

6.11.2 Benefits to participation

There were benefits to children and young people being involved in research; it gave them an opportunity to have their say and share their experiences and views and a chance to help other bereaved families receive the support they could have been lacking. Many of the families who participated cited their motivation to help others in a similar situation. This is supported in previous studies, with children and parents feeling pleased to be involved in research regarding a parental death, welcoming the opportunity to speak about their experiences and to help others in a similar situation^{75,100,160}. Children were open and engaged with the interview process¹⁶⁷ and desired to be heard and for others to understand their experience⁷⁹.

A previous study interviewed parentally bereaved children about their experiences and invited them to comment on the interview. Children reported they were glad to be asked to participate as: they wanted to talk about what it felt like when their parent was dying; they wanted the researcher to know about their deceased parent and how they felt; it was nice to talk to someone who did not know their parent; and they felt they could talk about things more knowing the researcher would not cry when they talked about their parent¹⁶⁰. A systematic review investigating the benefits and burdens of paediatric palliative care and end-of-life research found patients and family members more heavily emphasised the benefits of being involved with such research than the researchers and clinicians who heavily emphasised the burdens²⁸². The benefits of research involvement described by families were largely intrapersonal. They found it helpful to talk about their situation and tell their story to a non-judgemental researcher. It was therapeutic, offering an outlet for their emotions and giving them hope that their participation could benefit other families in similar situations²⁸². The most significant burden was the timing of the research while their child was dying. Parents found the topic painful or sad yet consistently found the process of telling their story healing²⁸². Researchers found an inherent bias when clinicians only referred families they perceived to be doing well²⁸², which could be possible in this study.

Other benefits to children being involved in research are that like adults' children enjoy sharing their views about their unique lived experiences. It allows them to have a say in what matters to them, they receive respect from adults through having their views and opinions heard and can see how their voice can lead to positive change that may allow

children to feel more confident sharing their voice. Findings could inform future services, policies and decision-making. The participants and their peers could benefit from any improvements made to bereavement support following this project. Also, the project gives children the chance to gain new knowledge, experience and skills¹⁷³.

All participants were asked to provide anonymous feedback following their involvement that would add to the limited evidence about the impact of participation in bereavement research for bereaved families. This feedback form was piloted with the public involvement group following their pilot interviews about their involvement in the study. One child feedback form, which is shared with permission (Figure 11), gave the researcher confidence in their abilities to undertake the study and confirmed that the study would benefit participants and add to this under-researched area.



Supporting families when a parent has died

Interview feedback

Thank you for your help with the interview, what you have told me will help me learn how we can better support families when a parent has died.

If you have time, I would be very grateful if you could answer these questions about the interview and what it is like being in the project and doing research.

1. Can you remember what you first thought when you were asked to take part?

I felt quite nervous at first but after a bit it was good.

2. Why did you want to take part?

Because it sounds like a good thing your doing and I wanted to help

3. How was it talking to Alex?

It was really nice because she has a lovely voice and is really kind.

4. How did you feel after the interview?

I felt happy knowing that Alex is going to help other kids/teens like me.

5. Was there anything you enjoyed about taking part?

I enjoyed using the emotion blobs

6. Was there anything you didn't enjoy about taking part?

No, not really all of it was great.

7. Is there anything else you would like to tell me?

I don't think so just I hope your research goes well and im glad I took part.

Thank you very much for filling this in, please can you post it back to me in the envelope provided.



Figure 11 Feedback form following child participation during public involvement

6.12 Researcher considerations

Evidence suggests that researchers working with sensitive topics and marginalised groups often feel ill-prepared for the work's emotional impact and dealing with challenging situations²⁵¹. My previous experience of over 14 years work supporting families through end-of-life care and bereavement will be highly beneficial, meaning that I am prepared and experienced in this emotional work and dealing with difficult situations. I am compassionate and experienced in communicating in difficult situations, delivering distressing news and facilitating the end-of-life discussions with families. I am chair and facilitator of a hospital bereavement support group, and I chair the local Child Bereavement Advisory Group. I am registered with the Nursing and Midwifery Council and adhere to their code of conduct. Certain aspects of the code are very relevant to the study, including acting in the best interests of people at all times, recognise and working within the limits of your competence, acting with honesty and integrity at all times, and treating people in a way that does not take advantage of their vulnerability or cause them upset or distress, and raising concerns immediately if you believe a person is vulnerable or at risk and needs extra support and protection²⁸³.

Recognising bereavement research is emotionally charged with the potential to cause pain and discomfort to the researcher, and it was vital for me to protect myself whilst researching a distressing subject. I drew on my resilience and experiences of many years in clinical practice working in end-of-life care. In previous roles, I had been close to experiencing burn out. Therefore, I was acutely aware of the importance of looking after myself and what I had learned over the years that I needed to do in order to protect myself.

Reflexivity was crucial to this study; before and after all interviews, the researcher reflected on the interviews and the impact of the research on their emotional, practical and safety needs. An example of reflexivity is provided in Figure 12. Memos were helpful in checking in on myself. I would write a memo before the interview about what I was thinking, what I knew about this family, and how I thought the interview would go. Afterwards, I wrote a memo about how the interview had gone and whether there were any issues or anything I was worried about.

Soon after the interview, I completed the transcription and sent the interview transcript to my supervisor. My supervisor read the transcript before meeting me to discuss how the interview had gone. This happened soon after the interviews and allowed me a space to reflect on the interview, check in with how I felt, and also for them to acknowledge the difficult things that I had heard.

As a clinician, I have extensive experience in facilitating difficult conversations and have enhanced therapeutic communication skills, which have been developed over many years. I am emotionally intelligent and have good self-awareness, which means that I am confident in being able to show my own emotions to participants without being overcome by emotion.

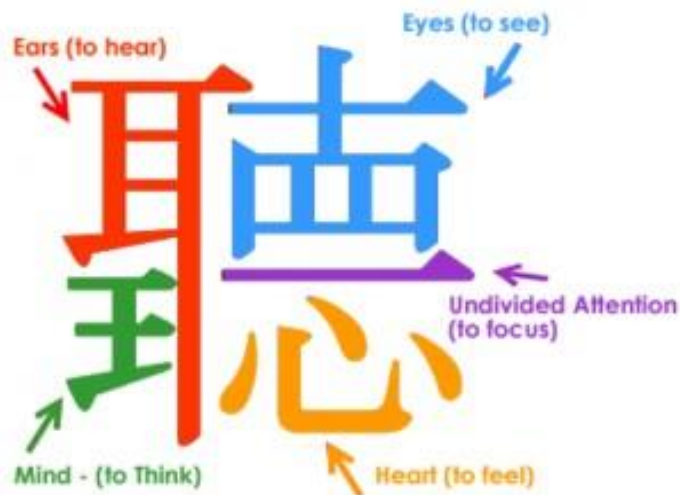
I took practical actions to mitigate against the risk of emotional exhaustion and would, where possible, limit interviews to one per day.

I had a good support system with informal and formal support mechanisms, which included three supervisors with planned monthly meetings and access available anytime between those meetings. Plus, professional colleagues, both in the field and within the wider research group who were available to provide support as required. The researcher has extensive experience working in emotionally and mentally draining environments and was aware of the importance of managing one's well-being and debriefing. Should I have required further debriefing, I had access to the hospital chaplaincy and psychological team as a staff member.

All interviews took place virtually. Should any have happened face to face, the researcher's safety would have been considered assessing risk in any interviews, and the researcher lone worker policy would have been followed. The research administration team would know any interviews with contact details, addresses and expected interview length, and the researcher would check in before and after the interview.

From embarking on the qualitative interviews, I worried about my ability to elicit rich data from the participants. I worried if I could do this with children. However, reflecting on the findings, I gathered rich data, which has given me confidence in my abilities and developed my skills to listen and hear participants' experiences in a non-judgmental way, as I describe in this reflexive memo.

Whilst writing my findings, I came across the Chinese character “TING” which captures the spirit of effective listening. The character sums up how I listened to the stories the participants shared. I listened with my ears to hear their stories, my eyes to see how they were coping during the interview, and understand what their story meant to them. I gave them my undivided attention, listened with my mind to think about what they were telling me, what cues they were giving me and finally, I listened with my heart to feel their stories.



Following the initial interviews, I realised how much I was asking participants to share their experiences and worried about this impact on them. However, I soon found that participants enjoyed sharing their stories. Participants were grateful for the opportunity to talk and be heard. Although not intended to be therapeutic, it became clear that participating in an interview was having a therapeutic benefit to participants. Both parents and children believed the research was needed and expressed thanks and gratitude for their opportunity to be involved. As demonstrated in the following quote from a parent.

"I think, just like this, now, has helped me massively, so I'm very grateful, thank you because it's, it's. Every time you do this, for me, it's like a weight gone, and it sustains you for a bit longer than, I'm hoping that eventually that that period of time will get longer. But yeah just talking to somebody about it so whether that's counselling, or just another person who's been through it, or a group of people. But there doesn't seem to be much about for people to access." Cathy (mother).

Figure 12 Reflexive memo

6.13 How public involvement from those with a lived experience influenced the Methods

Public involvement refers to the process in which research is conducted with or by patients, carers, or members of the public to improve the quality and relevance of research²⁸⁴. The public involvement essential to this study required children and families with the lived experiences of parental bereavement. Including those with lived experience has been of paramount importance in the design of this study, ensuring that research was carried out 'with' bereaved families rather than 'to', 'about' or 'for' them²⁸⁴. For the purpose of this thesis, the public involvement group refers to the involvement of bereaved children and families.

Research requires careful consideration to build and maintain relationships and to provide individuals with a safe environment to discuss emotionally sensitive research topics, using flexible approaches to involvement and finding those with relevant lived experience²⁸⁵.

Public involvement began during the development of the research protocol and included two separate groups who helped improve the quality of the research, ensuring the accessibility of language and content of information, that methods were appropriate and sensitive to the situations of potential participants and ensuring the outcomes of the research were important to the public²⁸⁴.

Public involvement sessions were virtual using the Zoom platform due to the ongoing restrictions imposed by Covid. No public involvement groups existed in the UK representing bereaved children and families. Initially, it was decided to approach a Young Persons Advisory Group (YPAG). Contact was made with existing groups, and Generation R Liverpool was keen to support the study and participated in one session. Part of a National network, they are one of several groups based across the UK and funded by the National Institute for Health Research (NIHR) with the primary remit of designing and delivering paediatric research in the UK. The YPAG members did not have experience of parental bereavement, but some had experienced bereavement within their families and communities. They were all interested in children's perspectives and involvement in research. Their demographics and background can be found in Table 15.

Table 15 Public Involvement demographics for Young Persons Advisory Group

Demographics	Background
<p>Seventeen children and young people aged 10 – 20 and 3 parents.</p> <p>There was an equal mix of gender and ethnicity between White, British and British with Asian heritage.</p>	<p>Members of the Young Persons Advisory Group had not experienced parental death. Some had experiences of bereavement within their family and community. However, all had experience and interest in research and children's perspectives and involvement.</p>

The YPAG were the first group to provide good insight into research with children. However, it was thought essential to involve those who have experienced parental death to ensure it was designed for the well-being of participants. Recruited nationally, this second group consisted of four mothers, one father, three daughters and two sons living within the UK. All families were White and British, except one parent from Czechoslovakia. Families were bereaved between eleven months and ten years before participation and bereaved by sudden (n=2) or expected deaths (n=4). Their demographics and background can be found in Table 16.

Families have had regular involvement in the project's design since January 2021, including Zoom sessions and written feedback on over 30 occasions. As this group consisted of children and parents with lived experiences of parental bereavement, it was unnecessary to involve the YPAG further. It was decided between the researcher and the University public involvement coordinator that due to the sensitive nature of the topic, the family's busy schedules and the sessions taking place remotely, they should be undertaken individually with families at a time that was convenient to them, rather than bring a group of bereaved families who had never met together virtually.

Furthermore, it would have been difficult for the researcher to offer adequate support to anyone who may be distressed in a group setting. Public involvement has been incorporated throughout the project. Professionals working within bereavement services and researchers in the field were consulted and contributed to the planning of the study, including reviewing protocols and information sheets and participating in pilot interviews.

Table 16 Public involvement demographics for bereaved families

Demographics	Background and relationship to the bereaved child
Mother & Daughter age 18	Recruited via the researcher who met this family professionally when they were initially bereaved. Father died suddenly three years ago.
Mother	Recruited from Involve Hull (A general Hull York Medical School Public involvement group) Father died from cancer eleven months ago. Their son, aged seven, was decided too young to input into the project after discussion.
Father	Recruited via Involve Hull member. Mother died of cancer ten years ago, leaving a son aged 20, who was too busy to participate.
Mother & Daughter aged 11	Recruited via social media posts. Father died of cancer three years ago.
Son aged 18	Recruited from social media. Father died of cancer three years ago.
Mother & children, Daughter age 9 Son age 12	Recruited through the Association of Palliative Care Social Workers. Father died in an accident eight years ago.

Those with lived experiences of parental bereavement have greatly helped the researcher plan the study to ensure participants' needs and well-being remained at the forefront of all decisions. Their input has been instrumental to the success of the study. They firstly confirmed the need for the study and provided an understanding of the acceptability of the research. They aided the study's design and gave valuable insight into how to undertake research with bereaved families, ensuring they were supported and gave ideas of how to recruit families and gave assurance they believed it acceptable, if not essential that bereaved families should be offered an opportunity to participate. The families gave insight into how the researcher should present themselves and build rapport with participants. As the study progressed they gave feedback on the study findings and offered their ideas of how to disseminate these findings. The key findings from the public involvement work are summarised in Table 17. Further details, including comments from the public involvement members, can be found in Appendix 16.

Table 17 How public involvement shaped the study

Public involvement key findings from bereaved children and families:	How public involvement shaped the study:
Confirmed the need for the research and the importance of speaking with those who have lived experience.	Interviews would be undertaken with both bereaved children and their parents. A distress protocol was devised to support participants, and a grounding technique was available to support distressed children.
Both children and parents must have the opportunity to be involved. Families thought participants would be pleased to be asked to be involved.	The study would be opt-in, so anyone who saw the recruitment flyer would be invited, and it would be up to the individual if they chose to participate. There would be no pressure to participate.
These families experienced a lack of support from those around them and were sometimes unaware of what support was available.	A bereavement support signposting leaflet was developed and given to each participant. The researcher checked in with each participant following the interview.
Virtual interviews were deemed acceptable for interviewing children and parents about their bereavement experiences. In addition, the actual public involvement work was virtual, giving the families an insight into how that would work.	Participants could choose a virtual, telephone or face-to-face interview.
Considering how soon families would want to be involved after their bereavement, the group believed this was unique and should be up to the individual family. For some, it may be ok weeks after. For others, it may be years later when they feel comfortable talking. However, families confirmed that receiving the recruitment flyer soon after their bereavement would not have caused them further distress.	The researcher would speak to any participant when they were ready but providing it had been at least 12 weeks since they became bereaved.
Families reviewed and gave feedback on all of the study information to ensure information was understandable, age-appropriate, and contained sufficient information about the study, including recruitment flyer, participant information sheets, consent forms, support signposting leaflet, and how to support someone becoming distressed and interview topic guides.	All documentation was reviewed, amended and approved by the families. Families also gave feedback on the 'get to know me session' and participated in pilot interviews.

<p>Undertaking public involvement work allowed the researcher insight into how difficult recruitment could be. There would likely be gatekeeping from parents and professionals who felt protective over the children. However, undertaking the public involvement work, the researcher found that when families and professionals met her, they were more comfortable and interested in the study.</p>	<p>The researcher met with services and parent participants who could find out her background, experience and plans for undertaking the research before they decided to participate.</p> <p>The protocol was devised to recruit bereaved children initially. Then, if unsuccessful, the study would recruit adults bereaved as children who may be easier to reach.</p>
<p>Families highlighted the importance of developing relationships and building trust and rapport with participants to help them feel safe and comfortable with the researcher.</p>	<p>A 'get to know me' session was devised and piloted with families. This session allowed participants to learn about the researcher's background, personally and professionally and why they were doing the research, and also allowed them to ask questions.</p> <p>Parents could meet the researcher and participate before deciding if they wanted to approach their children. The 'get to know me' session was offered to all child and parent participants. Child interviews also used an ice-breaker game before and after the interview.</p>
<p>The interview needs flexibility with timing, place and who was present. Some children want to be alone, and others may want their parent present.</p>	<p>Each individual would decide when and where to be interviewed and whom they wanted to be present, which could change as needed.</p>
<p>Research with children requires an evolving and dynamic interaction requiring the researcher to be flexible, adaptable, and responsive to the individual needs of the participants</p>	<p>For child interviews, they started with an ice-breaker game. Children were also sent stop and go cards so they could control the interview. The child could use several activities during the interview, including drawing, mapping, and vignettes. These activities will not add to the research findings but act as a distraction to make the interview less formal.</p>
<p>All public involvement members wanted to be told the findings from the study and consented to further involvement to comment on findings and dissemination.</p>	<p>Throughout the study families have received updates about the study progress.</p> <p>Families believed findings would need to be accessible, and short summaries would be helpful for bereaved families.</p> <p>Some of the families reviewed and offered feedback of the initial findings.</p>

6.14 Developing the substantive theory

The substantive grounded theory ‘Masking your grief - because you feel you have to’ was constructed by iteratively developing and comparing the similarities and differences between the categories that emerged from the two data sets (children and surviving parents) until theoretical saturation was achieved^{222,241}. This new theory explains the major social processes when children and surviving parents experience support following parental death. The substantive theory developed and presented in this thesis contributes to understanding how children and surviving parents support one another, the support they receive from their existing networks and, importantly, identifies areas where support is lacking.

The following section aims to provide insight with examples of the grounded theory processes to explain how the findings were constructed and developed to form the substantive theory. First, parent and child interviews were coded separately. Then, each interview was coded line-by-line. Once the initial coding was complete, there were 1031 initial codes from the child's perspective and 1225 from the parent's perspective. Table 18 provides an example of the initial line-by-line coding of excerpts from the initial parent interview transcripts.

Table 18 Examples of initial coding from parent interviews

Participant	Narrative from interview	Line-by-line code
Jenny (mum)	“Mmm, yeah it really, it really is, cause there's a there's a fear that you should be getting on with life, and you know, you've had your first year, so, which is what we've just passed, so you know, now, now it's time to kind of get on with it and (pause), don't burden yourself on other people, which is how I feel, but I know I can tell them in this group that it's not right.”	After a year you feel like you should get on with it and not be a burden

Sarah (mum)	“You know, I don't want to be a widowed and young. You know it's happened. It is **** but I don't really want to be labelled as as that and it won't define me as that”	Don't want to be labelled as widowed and young.
John (dad)	“The problem was I depleted my savings early on, which meant that, when she passed, there was almost a slight pressure to get back to work”.	Financial worries
Chris (dad)	“...the whole process of, trying to get your head around the fact that she was terminally ill, at 43 with young kids and then obviously then her actually dying and then adjusting into a new, new, new normal, I guess, as they as they put it.”	Adjusting to a new normal

Focused coding meant initial codes were grouped to form categories and subcategories, which began to identify and explain conceptual patterns identified in the data through the analysis²⁴¹, as shown in

Table 19.

Table 19 Examples of focused codes forming categories from parent interviews

Category	Subcategory	Initial codes
Alienating yourself	Hiding the death to protect others	<ul style="list-style-type: none"> • Delaying telling others to protect them • Starting a new job with no intention of telling them about it • Not wanting people to know your back story • Talking about it in normal social situations can be too heavy and the intensity is too much for some people • Talking about your child not having a mum anymore, brings people down and they don't want that, so they shut down conversations

As concurrent data collection and analysis progressed, theoretical sampling began. The data analysis focused on what or who to sample next by identifying and following clues which arose during the data analysis ²⁴¹. Figure 13 provides examples of methodological memos.

23rd November 2021

First interview was with Zack. Before the interview I was conscious this could be a tricky one as he was not very chatty in the get to know me session, mum didn't help my anxiety about this when she e-mailed an hour before the interview to confirm Zack had the link and said I hope he is chatty with a laughing face! Will be interesting to hear her perspectives of how he coped. Surprisingly he chatted more than I expected. It was a little more difficult him having camera off with pauses, usually I'm very comfortable with long pauses but I feel I maybe did not do this so well with not having visual cues. Minimal prompts did still work although I had to probe more than I did with previous family. He spoke a lot about not talking to anyone so that makes me feel even more honoured that he has spoken to me and seemed very honest with his experience. Looking forward to transcribing his interview and hearing back. It wasn't as bad as I expected and thing we spoke for at least 40 minutes, a few things were similar to what was said by the previous family.

4th February 2022

Just completed my sixth parent interview, definitely seeing themes coming through and feel that I'm much more focused in my interviewing. Although I have written about theoretical sampling, I wondered when I will know that I need to start and how. The penny has only just dropped that I am actually doing it and without realising! So, the interviews I have transcribed so far and coded, that analysis is leading me to what categories I explore further in subsequent interviews, so that is theoretical sampling!

15th March 2022

Had a quick chat with OB who raised a point, when something comes up in data are you exploring why that happens to some and not others, for example the differences between support in school, why is some good and some bad, I think this is something I have been doing sub consciously, have been exploring but maybe not given much thought to it so need to try and think a bit more about those different social processes and what makes them different, why are some people stepping up and others are not, I think that is a tough one to answer and parents may not even know although that is something I have been exploring a little so for people who step up, some have an insight into bereavement, some are just better than others. Whilst some people feel uncomfortable, don't like to see people suffering, too painful to be with, don't know what to say, something about the taboo surrounding death as well playing into it.

It feels like I'm on the right track with my analysis just need to spend a lot more time sorting my concepts and developing those into categories and sub categories and see how they relate to one another and question it all a bit more.

22nd March 2022

Something I want to keep a check on is how much I'm guiding the interview, am I leading answers? I think today as I had been looking at the focused codes I was getting an idea of what I wanted to be asking and obviously asked those questions accordingly. In a way it is also checking out some of those ideas I have had with focused coding. I think communication is going to be a big part of children's support.

Figure 13 Methodological memos

Throughout the study, memos have aided theory development and development as a researcher. Memos gave the space to reflect on findings and encourage the emerging theory to develop, as shown in the reflexive memos documented in Figure 14.

22nd February 2022

Just wanted to reflect on the families I have spoken to do date, some of them get to you a lot more than others. Cathy will stick with me, I felt so sad for her, I could really resonate with her background, she had given everything to her NHS career, even took unpaid leave because she felt bad, husband died, they had a shitty time then she got stage 3 cancer which was late diagnosis because of a hospital mess up, so now she has nothing, no job, no husband, she can't yet see a future, she has been so busy supporting and looking after everyone else that she has nothing for herself. How cruel to have given so much of you and your life to others and then when you need it the most you have nothing.

24th February 2022

Something that I hadn't expected but has come out quite strongly from the data is this feeling of being judged, or people questioning your decisions, and the feeling that you never know if you have made the right decision, you wonder what people will think about everything you do, being happy, posting a picture on Facebook, getting help around the house, parents question what others including their children think and also judge themselves. This seems to be a big worry for them and this is an extra thing on top of all the other stuff they have going on.

18th March 2022

Just finished interview with mum 17, after the interview when we were chatting, as I have seen with other parents, when I tell them others have said the same they have a sense of relief, it gives them reassurance that what they are feeling and experiencing is normal as they often have nothing to compare that with.

I guess this is showing the power of talking to someone.

They had a real lack of professional support. She just needed someone to go through everything with her, and a year later would have liked someone to check in with her and how they were doing.

13th May 2022

Parents get hit with this absolute minefield of stuff to deal with and there is no support in that, there should be stuff that just clicks in to help you, nothing comes to you there needs to be a wraparound service where they come to you and help with practical and emotional stuff and point you in the right direction. This dad went back to work after 3 weeks, which he reflected was a bit daft really, seems work served a purpose to keep him busy, but then over a year later it all got too much the juggling. He crashed and took some time off work a year later about that was questioned. His boss who had been really supportive in the

beginning could not understand that he needed time off now a year later. These poor parents face challenges all the time and it keeps coming back to lack of understanding.

5th July 2022

Core category could be something around masking your grief/balancing your grief, learning to hold your grief, when, how and who, guilt over not grieving so force the mask down, take yourself to a dark place, accept it's okay.

In the beginning your grief is okay, then people are bored, you are a burden, should be 'moving on'.

August 2022

I received a parent feedback form, it came out of the blue as I have not recently done interviews. One of the questions was about their experience talking to me, to which they said it was always tough to relive but I was sensitive and did not approach the discussion with any pre-conceived ideas or 'at least'. This was really helpful and made me think that I have been clear not to have pre-conceived ideas, because I have not experienced it I cannot even begin to imagine what family's experiences are. However, the interviews have provided me a unique opportunity, as someone without lived experience of parental death, entering the world of those who have experienced it which has allowed me to develop an understanding of the massive impact and enormity of parental death on families.

Figure 14 Reflexive memos

As data analysis progressed, categories emerged from the child and parent perspectives. In order to develop the integrated theory, it was important to use theoretical coding in the latter stages of analysis and theory development. Theoretical coding added precision and clarity by moving beyond the constructed categories. It ensured that only categories with 'earned relevance' were included in the theory²⁴¹.

During this stage of coding, the analysis focused on drawing mind maps. This provided a visual representation of the parent and child categories, providing a visual opportunity to see how they related and differed to each of the individual child and parent perspectives and how they may be incorporated in the new theory²⁴¹. An example is provided in Figure 15. This technique required the researcher to use their theoretical sensitivity. It allowed the researcher to take a step back from the data and, as guided by Charmaz, to stop, ponder and think afresh²²².

Storyline was another analysis technique used to develop and explain the theory²⁴¹. To produce a storyline that is grounded in the data, the guiding principles are that the theory

takes precedence, it allows for variation, it limits gaps, the evidence is grounded, and the style is appropriate. See Figure 16 for an example of a storyline.

Memos written during analysis helped the developed categories become more analytical. The researcher constantly revisited memos written throughout the data collection process, which aided the development of the theory. Memos captured the similarities and differences between the two data sets. The memos helped theoretical sampling and the development of each of the categories. Memos were reviewed and sorted in order to integrate the emerging theory. Sorting the memos allowed the comparison of categories at an abstract level and an opportunity to go back and forth in the data.

Categories from the child and parent data were compared and explored to identify similarities and variations. The relationships between those categories were analysed to look at how they related to one another and how they fit. The related categories were aggregated to develop the core category, 'masking your grief because you feel you have to'. The core category made sense of the data. It embodied the central idea in the data of the need to mask your grief and succinctly captured the main themes within the varied perspectives of children and parents.

The core category was constantly compared with subsequent data until it was fully refined and saturated. External validation was sought through discussions with the supervisory team and other professionals working in the field.

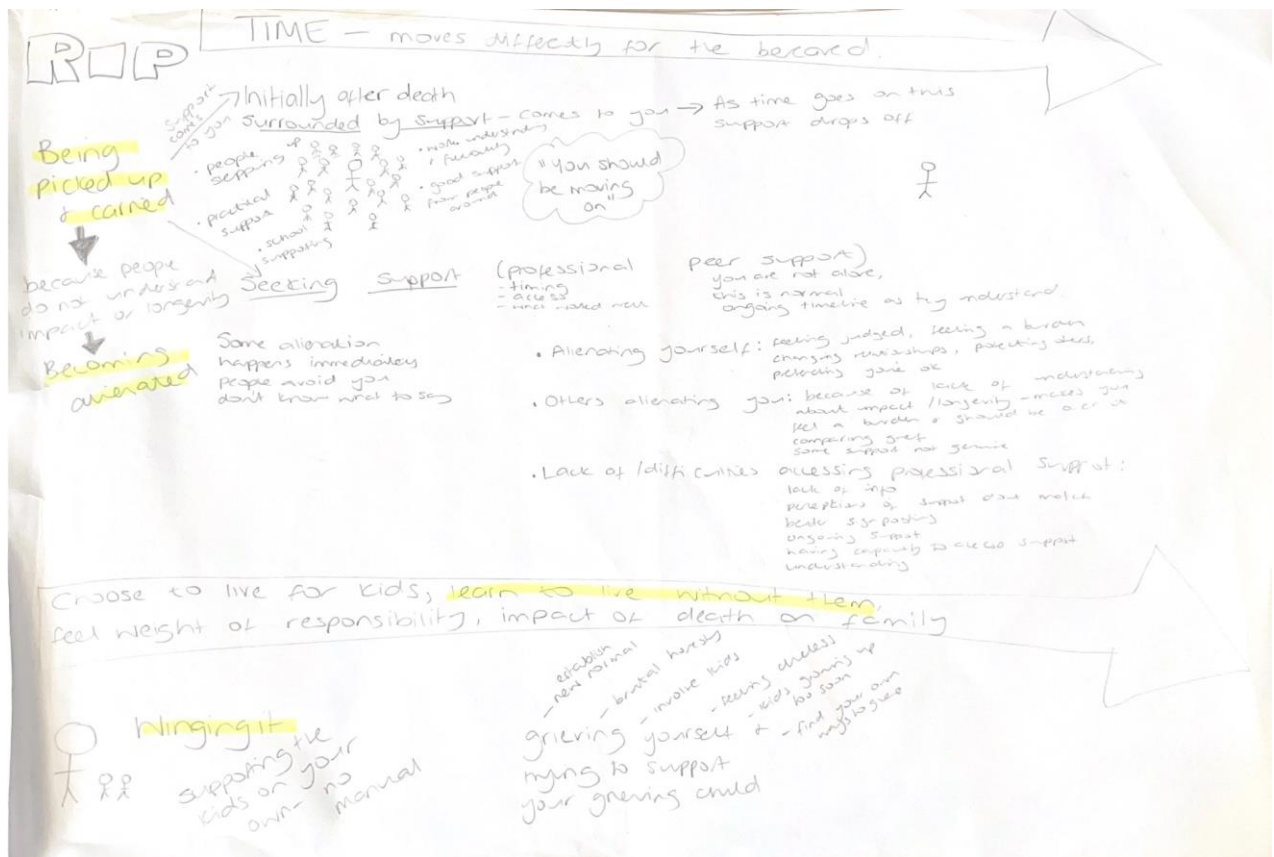


Figure 15 Diagramming example from parent categories

18th March 2022

Becoming alienated storyline- this is two parts so people alienate them because of how they behave and lack of understanding, judging, wanting to fix, avoiding you, their behaviours and perceptions in turn cause you to alienate yourself even more, choosing who you can and can't speak to, putting that mask on I'm okay, not putting your sad on others, people you see you carrying on and think you're over it when you are surviving. Sometimes it is easier to hide the death. Difficulties accessing services, feeling your kids aren't bad enough to get support, feeling you have let your kids down because there isn't support. Moving the mountain to the people, support reaching out to the bereaved.

7th July 2022 Storyline

When the death happens, it's acceptable to grieve, people rally around and try to help, communal coping, so they are trying to share the load with you. Then over time which is dictated by them, who have not been through it, they decide when that support stops, for some this is after the funeral, others it may be a year later, when others think you have done the firsts of everything, anniversaries etc. Lots of timelines are imposed by others, even professionals in the timing of when you can access support.

Parents are living for their children and getting through each day, to outsiders looking in they see they are functioning, they may even see them happy and laughing but they don't

see what goes on at home and the ongoing impact of the death across their entire lives which is ongoing.

That initial understanding, flexibility and allowances starts to tail off as well, this is seen in work place and schools, with an assumption the further away from the loss it won't affect you so much. Possibly others feel you grieve for so long and then move on, which is seen when parents are asked about dating again. Not everyone can move on and rather than having a period to grieve, grieving never goes away, you just learn to live with it.

September 6th 2022 Storyline

Charmaz asks you to consider what the main concern is for participants and how they resolve this concern (2008). In respect of the parents the children are their main concern. Most parents had researched and feared the impact parental death could have on their children. Parents needed support from professionals but most have to go out to look for it, they constantly doubt the decisions they make and how best to support their children. Their children worry about them and often feel helpless in supporting them during the initial grieving. They all naturally step up to help at home. In a sense they are all winging it supporting each other.

In terms of parents support from their network and the children to some extent, they are supported very well but as time goes on there is a lack of understanding about their grief which leads to them masking their grief and pretending they are okay. That results in supporters deeming they have 'moved on' and no longer require the same level of support. Their grief never goes away, they are always grieving they learn to live with it. Are they trapped in their social world of grief forever, wearing the mask to come out and live how they are expected to?!

Figure 16 Storyline memos

The early development of the substantive theory was member checked with three of the parents from the public involvement group firstly, followed by four participants (two mums, one son and one daughter), to verify that the findings and proposed theory resonated with their experiences and remained grounded in the data. Presenting findings to participants for feedback also provided an opportunity to ensure categories were saturated and identified any gaps²⁴¹. The data used for member checking can be found in Appendix 17 for parents and Appendix 18 for children. Finally, the storyline analysis technique was used to integrate, construct, formulate and present the findings from the research²⁴¹.

6.15 Summary

This chapter has provided a detailed description of the methods of the study, outlining the overall research design, which included an overview of the extensive public involvement work used to support the planning and design of the study. Then, the ethical considerations were outlined, the recruitment strategy and considerations, how data were collected, including writing, and concurrent data collection and analysis. Followed by the coding techniques used to analyse the data and develop the theory. The following chapter presents the findings from this study.

7 Findings from the child's perspective

7.1 Introduction

This chapter and the following two chapters (Chapters 8 and 9) draw on the analysis of the interviews and accounts of children and parents to present and conceptualise the study's main findings.

This chapter is presented in two sections. Section one provides an overview of the research findings, including participants' demographic details. The second section reports the data from one of the study's two sample groups, the children. Participant quotes are used to support and contextualise the findings.

7.2 Overview of findings

Seventeen parents (10 mothers and 7 fathers) and eleven of their children (6 daughters and 5 sons) participated in 32 in-depth interviews (including 28 initial interviews and then two parents and two children participated in follow up interviews reviewing findings). Six of the children were siblings from three participating families, two had no siblings, and the remaining three had siblings who did not participate. All the parents were married to the deceased except for one father, who had been separated for several years before the parent's death. Parent participants were parenting 30 children in total. Reasons the remaining 19 children did not participate included not being eligible due to age ($n=7$ outside of age criteria, aged under 10 years or 19 or over), parents did not want to ask the child ($n=7$), the child did not want to participate ($n=3$), or children were recently bereaved and unable to talk about their experience ($n=2$).

Children were aged ten to eighteen when recruited. Of the eleven interviews with children, all were given a choice to be interviewed alone or with their surviving parents. All chose to be interviewed alone. All children and most parents attended a virtual 'get to know me' session before the interview. Interviews took place using the virtual Zoom platform and lasted between 24 and 69 minutes (median 46 minutes) for children's interviews and between 44 and 105 minutes (median 75 minutes) for parents' interviews. The duration of the interviews varied with each child, dependent on their attention span, which was shorter for the younger children. Participants' demographic details are provided in Table 20.

Participants were bereaved between three months and seven years, following expected (n=15) and unexpected (n=13) parental deaths. Two of the children were bereaved of their mother, the remaining nine children were bereaved of their father.

Table 20 Participant demographics

		Children (n=11)	Parents (n=17)
Gender	Male	5	7
	Female	7	10
Ethnicity	White British	11	16
	White Welsh	-	1
Age	10	1	
	11	2	
	12	1	
	13	1	
	14	-	
	15	3	
	16	-	
	17	2	
	18	1	
Length of time since bereavement	0-1 year	1	3
	1-2 years	4	5
	2-3 years	1	4
	3-4 years	2	2
	4-5 years	-	1
	5-6 years	-	-
	6-7 years	2	1
	7-8 years	1	1
Cause of death	Cancer	5	10
	Cardiac event	2	2
	Brain haemorrhage	2	1
	Road traffic collision	-	1
	Suicide	1	2
	Covid-19	1	1
Recruited via flyer from	Twitter	-	11
	Facebook	-	1
	Bereavement charity	-	2
	Hospice	-	3
	Parents saw the flyer first	11	-

Interviews were analysed separately for child and parent perspectives to ensure the voice of children was heard. Using concurrent data collection and constant comparison whilst

undertaking interviews with both participant groups allowed consideration of how their different experiences were related and how support was experienced similarly or differently.

Findings from child and parent data are presented separately. To ensure participant confidentiality a decision was made not to provide a background of each family as individual participants would easily be able to identify themselves and their other family members taking part. Children aged 10 to 14 are referred to as younger children and those aged 15 to 18 are referred to as older children.

7.3 Children's findings

Eleven children participated in the interviews and were randomly assigned names. The younger children aged 10 to 14 are named Simon, Leo, Flo, Ava, Freya and James. The older children aged 15 to 18 are named Katy, Toby, Zack, Lizzie, and Charlotte. Analysis of the children's data yielded 26 themes which were theoretically coded into five broad categories: 1) what helps, 2) talking on my terms, 3) dealing with a tornado of emotions, 4) difficulties gaining support, and 5) stepping up to help at home, all describing their experiences of support following parental death.

7.3.1 Introducing the child categories

Each category is briefly introduced here, before a more detailed explanation follows.

Category one: What helps

Six themes contributed to this category which described the good support children received and what helped them with their grief. Children found it helpful being involved in what is going on in their families. They wanted to feel cared for, needed stability, normality and distraction. Children found that other people who had similar experiences of bereavement could understand what they were going through, which helped. Children also found it helpful to remember their parent.

Category two: Talking about it on your terms

Eight themes contributed to this category relating to communication. Children needed open and honest communication from those around them. They learnt who they felt comfortable speaking to. Many found the people around them became awkward because of their loss. Children felt uncomfortable talking about it although they found it easier to talk about when others already knew about their loss. Children accepted that people were trying to help them and it was okay if they did not always get it right. After some time, children realised that talking about the loss helped them.

Category three: Dealing with a tornado of emotions

Five themes contributed to this category which describes the challenges children face whilst dealing with their emotions. The death of a parent caused many emotions. Children found that within their family they may grieve differently from their parent or siblings. They realised that their grief differed because they all had different relationships with their parent. Children struggled to see their surviving parent cry and often held in their own emotions to protect the people around them. Children found things would trigger their grief and gave examples of when this happened and how they coped.

Category four: Difficulties gaining support

Six themes contributed to this category which described some of the challenge's children faced receiving support. Some children believed they should be supporting themselves and not relying on others. Many found a lack of understanding from others that led to a lack of support. Children learnt that support was individual and they had to work out what worked best for them. Some children experienced a lack of support because of Covid. As time passed children found people had forgotten about their loss and expected them to move on, which also led to a lack of support.

Category five: Stepping up to help at home

Two themes contributed to this category which explained how children were stepping up to help at home. Children felt that their loss forced them to grow up and gave examples of the responsibilities they had taken on. They felt guilty about the additional responsibilities the surviving parent now had and worried about them.

7.3.2 Category one: What helps

7.3.2.1 Being involved in what is going on

Many of the children were involved in death rituals and given opportunities to be involved in viewing their parent's bodies and attending the funeral. Children felt it was important to be given that choice, although suggested it may not be appropriate for younger siblings. Doing so allowed them a chance to say goodbye and get rid of the images they had of them dying. It meant they felt part of what was happening to them and their family. Their grief felt valid and allowed them to realise and accept the reality of death. When reflecting on that decision, the children who viewed the body or attended the funeral were pleased they had done so despite how hard that was.

"I saw my dad. Like his body in a coffin before, like a few days before the funeral, um, which I think was probably the right option or the right thing to do, of my mum, because, even though it was a bit scary, because it's like a dead body, I think it probably, being so young, like seeing that he wasn't in there anymore,

like he wasn't alive, like knowing that it was just an empty body, probably helped me sort of move on a bit more I would say, because I remember when I was sort of in the first week or two, like I will trying to send him letters, like I was writing him letters, and my mum was trying to explain he wasn't like here anymore, and I was like well send them to where he is then, but like seeing his body, sort of helped me understand" Flo (younger daughter).

Some children described how the death did not feel real; they expected their parents to walk through the door and it all to be a joke. Children described a need to be given detailed information about what had happened, to help to understand and begin to accept. A few children spoke of the need for reassurance that everything would be okay. For some, hearing this from their surviving parent was sufficient; others needed it to be someone outside of the home. For example, children named other family members and Charlotte found it helpful speaking to her relative who had a medical background.

7.3.2.2 Wanting to feel cared for

All the children spoke of the importance of feeling cared for, knowing that other people cared about you. Children appreciated it when their loss was acknowledged, and those around them were nice, offered support and comfort, and checked that they were okay. Friends could be good at making them feel cared for and listened to. Some children felt they could not have gotten through it without their friends. Supportive friends were described as good listeners, who they could trust and be vulnerable around, who did not judge them, and who were not uncomfortable around them. They looked out for them, gave them comfort, and just listened when needed.

"she would just like, listened, and she doesn't look uncomfortable or anything like when I'm talking about my dad she just like talks about it naturally which helps" Katy (older daughter).

7.3.2.3 Needing stability and normality

Children also spoke about their need for life to be back to normal. Home life had turned upside down and was out of their control. This was scary, leaving some children feeling insecure. School and friends could provide stability and normality and give children some control over their lives. Whilst some children returned to school within days of the death, others needed more time to be with their families or felt that they had too much on their

minds to face school. The time which children had off school varied between siblings. For instance, Katy took a few weeks off school after her loss, whereas her older brother never missed a day of school, because he preferred to be distracted. Returning to school could be difficult. Some children felt like an 'alien' and did not fit in with their friends when they returned. They felt different and found other kids could be mean to them because of their loss.

"when he first died, and just kids would sort of look at me differently, like, I feel like they just looked at me like, I was some kind of alien, so that was like quite hard" Flo (younger daughter).

Many children spoke of teachers making allowances for them, being more lenient and putting processes in place allowing them to leave a class should they become upset. Although many children did not want to be treated differently, they appreciated having these allowances made, especially when they were newly bereaved. For instance, Ava was bereaved during Covid and felt isolated in her grief. She was much happier when allowed to go back to school and be amongst friends.

'I was so much happier when we went back to school and like it was really helpful because I just needed to talk to my friends, I needed to see them I needed to just, I mean, I just needed my friends to talk to, and I just found it so helpful and I loved it.' Ava (younger child).

In another example, Simon lived with his dying mother. His parents were separated and he would see his father every other weekend. Living at home and witnessing his mother deteriorate became too much for him. So, it was decided he would move in with his father, creating a huge change and disruption within both of their lives.

"It was just too hard to stay in that house. Honestly, I couldn't bear to stay in there any longer, seeing her dying in the front room. So, what's the word, it was so fucking, sorry about the swearing, it was just so like, it's like someone was taking a huge gun and shoving into my heart, and just bang bang bang just like it was so bad, like but I could not... I could not bear to stay in that house any longer" Simon (younger child).

7.3.2.4 Needing distraction

Alongside normality, all the boys and some girls among the participants spoke of the need to keep busy and be distracted at times. Doing so meant they did not have to think about the loss. For some children, school provided a distraction. For others' hanging out' with friends, exercising, painting, listening to music or playing video games proved to be good forms of distraction.

"Video games, a good distraction, it kind of like helped me like, I get the pain is there, and I know the pains there but it also kind of like helped me because it's like instead of having like constant anger and sadness, I've got like a way of erm kind of like releasing it" Simon (younger child)

7.3.2.5 People who have been through it understand

All the children described support from others who had been through parental bereavement as a good source of support because they understood. They knew how to cope and what could help. Speaking with them also proved that they could get through this. Children did not have to worry about the reaction they would receive or need to explain it because they knew precisely, making it easier to talk to them openly. This could be a child's siblings, bereaved peers, or adults who had been bereaved as children. Having someone your age was especially helpful for most children because it allowed them to realise they were not the only one going through it.

"I didn't feel it was right to speak to an adult properly about everything that I was feeling 'cause even, even some adults weren't emotionally intelligent enough themselves to understand the complex emotions that I was going through at the time and I was, just remember being so, so desperate to have someone my age and I, you know I didn't even need to specifically talk about it to someone 'cause if anything, 'cause, we, you understand after a certain amount of time after you...I think specifically talking about grief isn't, and how you're feeling isn't exactly the necessary thing at that point, that just the thing that I craved more than ever was just to have someone there that understood my emotions and understood how I was feeling and why I was maybe acting in the ways that I was" Toby (older child).

In contrast, one participant, Ava had declined to meet bereaved peers as she did not want it to minimise her experience and be told she would get over it. In addition, she also felt there was an expectation that people who have lost a parent have a bond and are the same, which is not the case. Some children found that friends who had experienced an ill parent could also be supportive and understanding.

7.3.2.6 Remembering them

It was important to children that their parents remained part of their lives. However, some children found it too painful to remember them or look at pictures soon after their death. For example, Freya remembered that shortly after her father's death, all people asked her to do was remember him and tell stories which she felt was unfair. She reported that she could not remember the good times because she could no longer have them. However, as time passed, children learned how to enjoy their memories. In contrast, Charlotte spoke of her difficulties making new memories without her father, because it felt like she was moving on even though she felt she was not.

Children were comforted by remaining connected to their parent in many ways, including: making keepsakes and memory boxes; talking about their parent's favourite things; what made them happy; doing things they know their parents enjoyed doing; having a picture of them as your phone screensaver or looking at photos and videos, and sharing pictures on social media to show others what an amazing parent they were. For Simon, it was vital he remembered his mother how she was before her illness as opposed to the images he had when she was dying. A few children feared they would forget their parents.

Some of the children also found it helpful to remember their parents with friends who knew them because they could share their memories.

7.3.3 Category two: Talking about it on your terms

7.3.3.1 Needing open and honest communication

Open and honest communication was important from when parents became ill. For instance, Simon felt hurt by his mother who did not tell him straight away when she was terminally ill. He sensed something was being hidden from him and would listen through the wall when his mother was on the phone. He knew his mother was in denial and trying to protect him, but she lied to him, which hurt.

Most of the children spoke of their need for open and honest communication about what happened to their parent, with detailed explanations followed by an opportunity to continue conversations as they navigated their grief. Children believed they needed to understand what had happened to allow them to start grieving. Even when it hurt to hear, they found that hearing the truth was less stressful than being kept in the dark.

Some children were aware they had been kept in the dark in the beginning. Leo did not know what had happened to his father. Flo was aware her mother's friends were encouraging her mother not to tell the children the truth about their father's suicide as they believed it would be too damaging. She was pleased her mother told her the truth. Other participants described making up worse scenarios in their head when they were not told everything.

Some children found family life easier and less worrisome when they were able to talk openly about how they were feeling and if one of them were having a 'bad grief day' they could support each other. For example, in Zack's family they spoke about memories of his father, but never spoke about what happened to him, which suited Zack because he did not like to talk about his emotions.

Child participants advised that parents should check in with their children about how they felt. Children admitted to acting normal even when upset. However, it is a fine line, and child participants did not want to be forced to talk about it if they were not ready. Child participants also suggested that parents could also ask if children want someone else to talk to about it.

7.3.3.2 Learning who you can talk to

Children learnt whom they felt most comfortable talking to, which was very individual. It was important that the people they spoke to were confidential, did not judge them and did not feel uncomfortable when they were talking. Children learnt which friends they could or could not speak to in class.

"But there are like some girls who I really like, who are really good to talk with, because they won't, so there's like this thing, there is a girl in my year, not my class who really likes attention. So, she'll constantly tell like gossip and be just not a very good person to her friends. I wouldn't really tell her anything 'cause

she could spread it, but with more drama, so I'd tell, like someone who I know would keep it, not a secret but would not like tell everyone" Freya (younger child).

Toby and Charlotte, both older children reported that they could not talk to adults because they found that not all adults had the emotional intelligence to understand or had not experienced a parental death. Furthermore, Toby craved someone his age with a similar experience but did not find anyone, which made him feel lonely. He eventually spoke with a counsellor. Zack, another one of the older children, did not talk much about his father and found it easier speaking to strangers because he could be entirely truthful and honest. He had a good circle of friends but found no way to talk about his loss, and it did not come up in conversation.

Some of the child participants found it helpful talking to their teachers, whilst others did not. James, one of the younger children found it easier talking to his teacher and she had also experienced the death of a parent when she was younger. In contrast, Freya, another of the younger children, did not like to talk to teachers because she worried they may not keep what she said confidential and may tell her mother.

Some of the older children in secondary schools had multiple teachers, and were unsure if the teachers knew their parent had died. For instance, after her father died, one of Lizzie's teachers asked if he would be coming to parent's evening, she described this as a 'very awkward interaction'. Lizzie also gave an example of another teacher who knew about her loss and contacted her mother and asked if she should be nicer towards her. Lizzie's mother said she should treat her the same and Lizzie confirmed she wanted her teachers to treat her the same and not differently.

Lizzie had some teachers she could speak with because she knew they cared. Other children found that the teachers who did know would ask them how they were doing at what they perceived as inappropriate times, for instance whilst they were sat with their friends.

Most children spoke with their friends. This could be face-to-face or sometimes over messages. For example, one of the younger children spoke with friends over teachers because she believed her friends would keep what she said confidential. In contrast, another participant worried about friends gossiping about what she shared with them.

Some participants reported that having a counsellor could be helpful because it meant they had a dedicated time in which they would be talking about how they were feeling, which allowed some of the children to talk about their loss.

Two of the sisters were able to speak to each other, and they were able to understand what they were going through. However, some of the other children with siblings of the opposite sex or more significant age gaps found they could not talk to each other. The older siblings also tried to stay strong to protect their younger siblings.

7.3.3.3 People being awkward around you

Nearly all the child participants found that people, including friends, classmates and teachers, could be uncomfortable or awkward around them because of their loss. This often made the children uncomfortable and stopped them from talking about it. For example, James heard teachers and classmates whispering about his mum so they did not upset him, but their whispering upset him more.

Children believed people were uncomfortable because they were scared, the loss of a parent at a young age is a shock because it is unexpected. People do not always know what to say, they do not want to upset or trigger you. Some child participants found friends were tiptoeing around them which was fine initially but then they wanted them to stop and treat them normally.

Children did not want to be perceived as different. However, Charlotte, an older child found that people in general treated her differently even years later when they found out about her father's death. Some children found that people stopped talking to them when they knew or told them they were 'weird' because of their loss. The children did not want to make anyone else uncomfortable because of their loss.

Some children spoke of the taboo around death and reported that people 'just do not understand it'. They felt that death should not make people uncomfortable, but it does. Charlotte described how people learn about death from the movies, which are often gruesome; she might see people crying, but she never saw people grieving.

7.3.3.4 Wanting to talk to them on your terms

Sometimes children did not want to talk about their loss, other times they were open and wanted to talk about it. Most children found it took some time after the death until they

could talk about their parent or what happened. Many children enjoyed talking about their parent with others as it meant they were not forgotten, and it was a way of keeping them in their lives. If people asked questions about their parent, it showed children that they really cared and wanted to keep their legacy alive. One of the older children said this made her want to cry with happiness, giving her a warm feeling about bringing her father into her life now.

Katy, an older child had been seeing a therapist whilst her father was dying. A week after he died, she stopped seeing the therapist because the last thing she wanted to do was talk about her father. He was always on her mind as it was, so she did not want to think about him or his death whilst in therapy. Consequently, she did not speak with anyone or her therapist about her father for a few months.

7.3.3.5 Feeling uncomfortable talking about it

All the children felt uncomfortable and faced difficulties talking about their loss. Their loss made them feel vulnerable. For many, it was not knowing the words or how to bring it into a conversation. Nearly all the children were anxious and scared of the reaction they would receive from others, preventing them from talking about it. Other children feared talking about their loss because they thought they would be treated differently or may lose friends. For instance, Flo saw how her mother had lost friends because of her loss. Flo worried that she too may lose friends, which could account for why she pretended to everyone but her mother that she was fine.

Their parent's death could make them the centre of attention, which was difficult for some children to handle. Some children admitted many occasions when they had lied about their parent's death because that was easier than dealing with others' reactions. Although doing so meant they may feel guilty for lying, one of the older children reflected that lying about it meant people did not realise how common it is to lose a parent.

Some children found that people became uncomfortable talking about their parents who had died and would avoid them or shut down the conversations, hurting the children. For example, Freya believed her friends felt uncomfortable because they did not want to think that such a loss could happen to them. A few children struggled to speak about their parent's death to people who they felt could not understand their feelings or what they

were going through. Some of the child participants thought people did not speak to them through fear of them having an emotional breakdown.

"I would say for the whole school year like no one like talk to me like no one who wasn't in my immediate friends or who I wasn't already friends with like most people didn't like talk to me or like hardly like look at me (laugh) you know, cos like everyone, people like heard that my dad died and I guess people thought like I'd start crying if they talked to me so it's, that can be hard" Katy (older child).

Some children were uncomfortable when they were excessively questioned about their loss. In addition, Charlotte reported she had learnt that it is okay to shut down a conversation if she was uncomfortable.

Toby, one of the older children, struggled to talk to adults. When he was asked how he was doing he explained that he had a defense system that meant he could never honestly say how he was feeling. Most children did not want to make others uncomfortable or upset them by talking about their loss. For example, Zack did not want to talk about it, and he did not feel he could speak with anyone but also felt he did not need to; he believed he could cope with his loss alone. Within his friendship group, he felt that boys were less open to speaking about 'that stuff', and he even had friends who had also lost a father, and still, it was not something they ever spoke about.

Freya found that when her father died, everyone looked at her like an 'alien', so she learnt after a few weeks to 'fake being happy' to prove to people that she was the same person. She could not be open with anyone except her mother.

7.3.3.6 Others knowing about your loss makes it easier

Some of the children did not want people to know about the death of their parent at first. Nevertheless, most children found it easier and less awkward when the people around them, especially in school, knew about their loss. Some of the children appreciated it when school friends acknowledged their loss and allowed them to talk if needed. Whilst a few preferred it when their loss was not mentioned. It helped when people outside their close friend circle knew about their loss, so they had someone to talk to when their friends were not around. If people already knew, children did not have to initiate the awkward conversation of telling people, which was one less thing to deal with. When everyone knew

about it, children had other people they could speak to if they had questions, which some preferred to do rather than speak to their parents, who were already upset. Simon was given a book from his school class full of kind notes, which he was surprised and grateful for.

7.3.3.7 Accepting people are trying to help, and it's okay if they get it wrong

Some of the children realised that it was hard for people to support them because they did not understand what they were going through. Talking about it also helped some children process what they have been through. Although people wanted to support, help, and be there for them, they did not always get it right. Children forgave those who obviously cared about them but did not always say the right thing. The child participants realised they did not mean to cause upset and offered advice on what they should or should not say to a bereaved person. Simon tried not to be angry if someone said something upsetting, and would tell them directly that people might not appreciate them saying such things if their parent had died. Charlotte found a lot of people trying to give her advice, but she did not need advice, she just wanted support and love and the understanding that the other person was there for them.

7.3.3.8 Realising that talking helps

Many children realised that talking to someone helped, although it could be draining. Talking to friends initially about what had happened helped some children realise and accept that their parents had gone forever. A few spoke of feeling 'worn out' after counselling sessions, or sometimes it made them feel down and deflated afterwards, but it could also be a relief. For example, Toby felt that everything would build up, he would be okay for a while, and then he would break down and explode, but counselling gave him a release that sustained him in his everyday life. For him, it was important for the counselling to be ongoing. In contrast, Freya felt she had talked about it initially, which helped, but she was fine now and did not need to talk about it anymore.

Some of the children commented on the benefits of talking about their experiences in their interviews; many felt lighter afterwards like a weight had been lifted from them.

7.3.4 Category three: Dealing with a tornado of emotions

7.3.4.1 How it makes you feel

Children faced varying, and at times overwhelming, emotions following their parent's death. Initially, many experienced shock and disbelief. Simon, on the other hand, was relieved his

mother was no longer suffering and he also took comfort in remembering how she was before her illness. Some children described feeling like they were a different person after the loss. Some felt alone in the way they were feeling. Ava explained the importance of facing the fact your parent was dead, to not be afraid of what people are thinking or saying, or life will be harder.

Charlotte described how every type of emotion could be found in grief. Emotions frequently mentioned were anger, guilt, anxiety and depression. A few worried friends would cut them off because of these emotions. Some felt ashamed that they no longer had two parents. Flo realised her behaviour was difficult for her mum to deal with. Flo was 'fake' with everyone else, and completely hid her emotions because her mum was the only person she felt she could be open with. Consequently, her mum had to deal with all of her anger and sadness and Flo admitted she always started arguments with her mum as a way to 'get the anger out'. In another example, Charlotte felt incredible guilt about being happy. She also developed a sense of responsibility for her family and became more conscious of her health; for instance, she avoided drinking alcohol in case something happened to her.

Children spoke of how their outlook on life changed. For some, this could have negative consequences with some children lacking motivation, leading to their school grades falling. School often felt pointless after their loss. Other children had a positive outcome and found they became more motivated in school and their grades improved.

"I think I'm better now, better than I was, starting to care more and have more motivation. I still find it hard because before my dad died I had so much motivation and wanting to like do my GCSEs and study and like after it all went down to like minus (laughs), like minus that and erm it's like starting to come back but somethings in school it's just like feels so pointless and I don't know like they probably like be less of a good student than I used to be, not like I'm a bad student it's just like I don't know it's like with detentions and stuff it's kind of hard like to care cos if I get one it doesn't really matter" Katy (older child).

Charlotte spoke of the fear she felt because of her grief. She feared she might lose another person, which led her never to want to rely on anybody else.

Some of the children also spoke of the impact of their parent's death on their siblings and parents, which often made them feel helpless. Katy felt jealous of an older sibling who had known their parent for longer.

7.3.4.2 Everyone is grieving differently

Many of the children found within their families they grieved differently. Despite grieving for the same person, they all had very different relationships with that person and experienced different losses. It was essential to find their own way of grieving and accept this is okay and not disregard someone else's way of grieving because that does not work for themselves. They reported that it could be challenging for children when they are grieving differently from their siblings and parent, until they understand there is no one way of grieving. Toby questioned why he was not as expressive with his grief compared to his mother and sister and, at times, he felt pressured to respond and react in the same ways as they did. Siblings in one family found they grieved very differently, for example where one of them was helped in her grief by her religious views, the other became anti-religious and questioned if there was a God.

Some children saw that grief had the potential to break up relationships, so it was important to understand that other people were grieving and working together to try and understand one another. It was clearly painful for many of the children to witness their parent's and siblings' grief, which made a few feel helpless. Some children experience huge changes within their family dynamics following the loss. Ava experienced a breakdown in her relationship with her older step-brother who felt they were not a family anymore. Simon had lived with his mother full-time and now lived with his father full-time.

Children sometimes felt their parents might not understand how their grief was different, which caused arguments in some families. For example, Charlotte felt like her mother could get another husband, but she could not get another father. She also mentioned that her grief was not easier because she had known her father less than her mother. However, she learnt that she should not compete with her grief. On the other hand, Flo felt like her mother forced her to grieve together in the same ways that she did.

"I lost my dad, she lost her husband, it's not the same, like we weren't feeling the same because she would have been sort of feeling heartbreak and betrayal like

how could you leave me with our kids, and I was just sort of feeling sadness and like wanting him back, but she was quite angry at him, so it was just, it was very different, but a lot the time it felt like she wanted, she was sort of trying to force it to be the same, um, which really annoyed me, and it still kind of annoys me now, because she still does it a bit to me now" Flo (younger child).

Children also described having a 'tornado' of very different emotions, which could be different to those of their parents or siblings, and it was constantly changing and challenging for them to navigate and understand. For example, they could go from being really upset to really happy and then feel guilty for being happy.

7.3.4.3 Struggling seeing your parent cry

Many of the children spoke of seeing their parent cry, and how difficult that could be. They felt it was not normal to see a parent cry. Parents are supposed to comfort them. Children described feeling worried, scared, and helpless. Many children provided comfort to their crying parents.

Despite how difficult it was seeing a parent cry; it reassured some children that they did not have to stay strong and that crying is not a weakness. However, constantly seeing their parent upset was very difficult and stressful. Some children felt under tremendous pressure to look after their parents. For example, Lizzie remembered her mother crying at the funeral and after that did not see her mum cry, which she knew was her mother keeping strong for them. Katy would text her mother's friends and ask them to support her mum, because it was too much for Katy to handle on her own.

"I get she needs to cry and everything, but sometimes it's really hard because your mum is like your safety net and if your safety nets crying, it feels weird like it doesn't feel safe erm so it's like sometimes I text my mums' friends and ask them to call her because like sometimes I feel like it shouldn't just all be on my shoulders" Katy (older child).

7.3.4.4 Holding in your emotions

All the children had times or situations when they held in their emotions. This often was dependent on who they were with. Ava was more upset when told her dad might die than when he died. She believed this was because it had not sunk in. Freya found it 'weird' that

she could not cry when her dad died; her siblings and mother were crying, but she could not, she thought it might have been the shock. Following the death, Flo used the metaphor of 'opening the door a little bit', to speak to her mother about her emotions, but her mother tried to 'force the door open' and make her talk about it. This made her angry; she had chosen to share what she wanted and did not want to be forced to talk about her feelings. However, she understood that her mother was worried and wanted to help her, but she felt she could not be helped then. She just needed to be by herself.

Although most of the child participants admitted holding in their emotions at certain times, many admitted instances where they could be upset in front of people. Both younger and older children found school could be a place to be upset initially following the death. However, in contrast, a few children could not be upset in front of other people. Some noticed they were judged about how they grieved. People would expect them to cry, so when they did not, they would be surprised and praised for doing a good job and staying strong, which reinforced that they should not cry. Children did not want to hear this because they did not feel strong; they were trying to live their lives. After suppressing her feelings for a long time, Flo realised it was okay to have feelings and cry. Zack was encouraged by others that he should be feeling and reacting in a certain way, even though that was not what he felt.

Flo hated being different and perceived that if she acted the same at school, she would be treated the same, so she pretended to be okay. She went on to explain how different her home life was and that she needed to control her school life and keep it the same for her to cope.

In contrast, some of the children kept their emotions to themselves. Often this was because they knew if they were upset, that would upset their parent. The older siblings especially felt a responsibility and held in their emotions to protect and be strong for the rest of their family. Toby felt lonely, having feelings he wanted to express but not feeling in a position where he could let them out.

There were often occasions when children could feel themselves welling up but held in their grief when they were in class or with people they did not feel comfortable showing their emotions to. This often happened in class when whatever they were learning triggered this.

James struggled to manage his anger. He wanted to lash out but knew he would be in trouble, so he held it inside. His father arranged for him to take boxing lessons, which really helped. In contrast, Zack did not feel anything at first, and it was not until a year later that the realisation of what had happened hit him but at that point it felt like everyone else had forgotten.

Several children described holding their own emotions inside to protect their parents from becoming upset. Some of the older children felt that being the eldest, they had to hide their emotions in front of their siblings because they did not want to appear vulnerable. They wanted to show them they were strong and there for them, holding their family together.

"I remember just holding her in my arms that night, and that is the hardest thing above anything else, firstly seeing your mum, having to be the one to hold your mum while she was crying, and a lot of it, throughout this process has been, I didn't, I haven't wanted to fully express my emotions, because when I have done it's made her upset, and that's the hardest thing is, it's, you know, it's alright being upset yourself, but when it upsets her (emphasised her), it's the hardest bit, because the parent is the one that's supposed to look after you when you're feeling down, so when you're feeling down makes her feel down, that's not something that you want to put on her, or put on yourself, so for the first, you know, I could, I could only cry by myself for a long period, erm, you know, I would, I think I did cry the next day at school, they had a really good support system there for me, erm, but I could only really cry by myself, because I didn't want to put that on her, and I didn't that was just too hard in the first place"

Toby (older child).

7.3.4.5 Being triggered

Over half of the children spoke of times and situations when their grief was triggered; this could be anything, including remembering their parent, looking at pictures or listening to music. As time passed, one of the children believed it was important that they should not feel guilty if something was no longer a trigger. They felt that looking at pictures does not always have to be sad and depressing. Furthermore, things that triggered them one day may not affect them the next. Triggers could make them feel sad or sometimes they could

provide happy memories. Some of the children sensed that other people worried about saying something that could trigger them, leading them to avoid conversations.

7.3.5 Category four: Difficulties gaining support

7.3.5.1 Doing it on your own

Some of the children felt alone in their grief and believed that no one could understand what they were going through. Some did not have anyone they felt they could speak with. A few believed they should be helping themselves. They did not want to rely on someone or make their situation worse and felt a stigma around counselling. Charlotte an older child initially believed she was stronger than needing a counsellor, and if she did need one, she would not be able to hold herself together and support her mother and siblings. However, she learnt that she could only help herself to an extent and did end up accessing counselling. Zack, another older child believed he could support himself alone.

"you feel like you're alone in the world, like no one else knows what it feels like, just you" James (younger child).

A few children admitted finding it difficult to be around other families. It sometimes made them feel jealous, angry and upset because it reminded them of what they no longer had.

7.3.5.2 Lack of understanding from others

All the children found that a lack of understanding from the people around them affected the support they received. All children believed that someone could not fully understand their situations unless that person had been through it themselves.

"Like if someone hasn't been through it, they have no clue what's going on"
James.

Children also struggled when people who had not experienced a parental death advised on how they should feel, what they needed to do, and what support they needed. Other examples of lack of understanding included friends comparing the loss of their parent to a break-up with a boyfriend and adults comparing the loss of their parents at an older age, which children felt was not a fair comparison. Some children found it hard when friends would complain about or say they hated their mother or father. Some of the children realised their peers were not as emotionally mature as they were and could not offer the

support they needed. Friends could also make insensitive and hurtful comments about their parent's death that were upsetting. A couple of the girls commented on other fathers trying to be a father figure, which they hated as they could never be their father.

Most child participants found school life easier when teachers and friends were aware of their loss. However, schools were also found to sometimes lack understanding, which seemed to worsen as time passed. For example, Zack was made to try counselling through school, which he tried but did not want to continue. Following this, the school treated him like nothing had happened, and as if his grief had gone away because he had refused the support they offered, which made him not want to speak to anyone again. Some children felt that teachers stopped looking out for them and checking in with them. Charlotte missed out on special exam considerations because of the length of time since her father died, despite having to undertake one of her exams on her father's birthday. She was angry because she felt there should be no time limit on this. Several children found that school covered death-related topics without warning, and sometimes teachers made insensitive comments. The child participants would have appreciated being forewarned to try and prepare for what was to come. Furthermore, Lizzie believed that the school became less supportive because they did not see her upset. Therefore, she felt she was not a priority.

Charlotte was told by her mother's friends that she should be there for her mother, allow her the time she needed to herself, help her more, and help her with her siblings. This left her feeling confused. She felt that because she was the eldest, she went from being a child to being like a 'mother' herself. If she had time to herself, she reported feeling guilty and would do more to help, but this meant that she had no time to herself. She felt therefore that adults disregarded her grief. They gave advice because they believed they had more life experience, yet they did not understand the grief she was experiencing.

7.3.5.3 Finding what works for you

Some children were told or encouraged to attend support groups by their parents, schools or people around them. However, the participants felt that it was not helpful when children were told what they had to do because being supported was very individual, and even with their siblings, children realised that what worked for their siblings did not work for them. So, children had to figure out what worked best for them.

Some children found peer support groups helpful in meeting other bereaved children, whereas others did not want to meet other bereaved children. Some children found counselling beneficial. Others did not; it felt more like a chore. Like some parents, a couple of the children spoke of the importance of having the right counsellor who needed to be someone they could click with and who 'gets you': when that happened, children found they could talk freely and easily. Counselling helped because it was someone who was there just for them. They cared about them, their wellbeing, and their life, they would maintain confidentiality, and they could say whatever they wanted without being judged.

In contrast, a few of the children spoke about lying to their counsellor, feeling an expectation to have an emotional release and be cured, or trying to please the counsellor by saying what they thought they wanted to hear or pretending they were okay; this generally lasted until they trusted that person with their story. Charlotte found counselling most helpful when the support from friends and family dwindled. It was important for children to know that professional support was available to them again when needed.

7.3.5.4 Realising support is not always genuine

A few children realised that sometimes support was not genuine, for a variety of reasons. Sometimes, people were trying to be friends when they had previously not been, or people tried to make their grief about them. They felt that other children may want to be there for them because they want others to know they had supported them. Others would ask questions not because they cared but because they were nosey or wanted to gossip about it. Some people were only interested in how their parents had died.

"...a lot of the time you think that people are just asking you because they're nosey, a lot of the time when it's a death, people just want to know what happened, like how did they die. Oh my God. People are so nosey" Charlotte (older child).

7.3.5.5 Lack of support because of Covid

Two children mentioned the impact of Covid on how they were supported. Ava was bereaved during the pandemic and struggled with the lack of physical contact, inability to see friends and lack of comfort from others. Charlotte had been bereaved a few years when the pandemic came but struggled because the family had never been alone without support. She also found that prior to the pandemic, her life was normal, and people knew

about her father's death, but when Covid restrictions were lifted, she struggled to socialise with people who did not know her situation and worried about people asking her about her father. Freya became aware that many people were dealing with grief because of the pandemic, which made her reflect that she never knew who may be grieving.

7.3.5.6 People are forgetting and expecting you to move on, but this is something you are always carrying

Children, like their parents, found they had a lot of support from those around them soon after the death, but as time passed, this support dwindled. Freya felt she needed to try and forget and move on to have a normal childhood and be happy. However, some children experienced an expectation from others that they should have moved on because it had been a certain amount of time since the death. Zack felt angry that it seemed like people had forgotten. Despite this, nearly all the children realised this was not something they would ever get over. They would always miss their parent and would always be grieving, but they would learn to live with it and carry it with them forever. Some of the children spoke of accepting that they would always have 'bad grief days', no matter how long it has been since their parent had died.

"you'll realise that at the beginning, you think you've got all the support in the world and you've got everything. But then when life just goes back to normal you realise that people don't have that much time always, to be there for you and give you that much support" Charlotte (older child).

7.3.6 Category five: Stepping up to help at home

7.3.6.1 It forces you to grow up

Many of the children described how their loss forced them to grow up. Having both parents allowed them to be children, be looked after and not have any responsibilities or worries. However, when one parent died, they had to take on responsibility and not depend on their remaining parent as much. Consequently, some felt pressure to work harder and do better in school. All the children took on extra chores and roles at home. Even when they did not want to do things, they saw their parents doing more, so they felt obliged they should too. Some children described it as everyone 'moving up a place' within the family. The surviving parent had to take on the role of the parent who died, the eldest siblings took on more of a parental role, and the younger siblings stepped up to help. This 'stepping up' happened

naturally; children did not even think about it, so it was especially difficult when the people around them told them to help more.

Three older siblings described taking on more of a parental role. They felt a weight of responsibility being the eldest to hold their family together and stop it from breaking under the pressures of everything that needed to be done. They put their parent's and siblings' needs before their own. Before, they would have argued about doing chores. Now they just got on and did them. Toby felt he was a parental figure to his younger sibling, but that was not received well by his sibling, who would snap because he was the brother, not the father. This felt like a lot of responsibility.

"I think that's where it came from, is my desperation for us not to just crumble and fall down, and under the weight of everything that we had to do, and instead just get on with it, and, and get going, but it does feel like a lot of responsibility" Toby (older child).

7.3.6.2 Feeling guilty and worrying about your parent

Initially, a few of the children worried that their parent's grief would never get better and that they might be inconsolable forever. All the children were acutely aware that everything now fell solely on the surviving parent's shoulders. Some of the children worried about the stress their parent was under. A few children worried that their parent was also lonely. Some children worried about how the family would manage financially, knowing they did not have the same income coming into the house. Charlotte reported being very stressed about finances and that she was working hard now to make herself financially stable in the future, so she need not rely on someone else. Friends questioned why she was always working in the summer and not enjoying herself, but she felt the need to prepare for the worst thing that could happen.

Flo saw that her mother was not the same. She described her as being a ghost for a while and that she was depressed, angry, and sad. Flo reported that it felt fake if they were playing and she was smiling or laughing. Her mother also drank quite a lot. It took a toll on Flo, who wanted to help but knew there was no solution to how her mother was feeling. They had to work their way through it, leaving Flo feeling helpless.

Some children feared something would happen to their surviving parent or people close to them. For example, Freya was concerned about catching a cold, which meant her mother would have to look after her when she was already busy. She also worried about passing a cold to her mother and wondered how her mother would manage to do everything in the house if she became sick.

7.4 Summary

This chapter has presented the findings from the in-depth interviews with children. Child participants described what helped them following their loss. They needed to be able to talk about their loss and the parent who died, but this had to be on their terms. Children had to deal with a tornado of conflicting emotions. Children sometimes faced difficulties gaining support, and the majority stepped up to help their surviving parent at home. The next chapter presents the findings from the in-depth interviews with the surviving parents.

8 Findings from the parent's perspective

8.1 Introduction

This chapter presents the findings from the in-depth interviews with the parents who were the second of the study's two sample groups. Participant quotes are used to support and contextualise the findings.

8.2 Parent findings

Seventeen parents participated in the interviews and were randomly assigned pseudonyms. The ten mothers have been allocated the names Jenny, Sarah, Zoe, Ellie, Cara, Cathy, Laura, Natalie, Rachel and Mel. The seven fathers are named John, Chris, Dan, Tony, Dave, Mark and Steve. Analysis of the parent's data yielded nineteen themes that were theoretically coded into three broad categories; 1) Winging it, supporting the kids with no 'rule book'; 2) Being picked up and carried; and 3) Becoming alienated, describing their experiences of support following parental death.

8.2.1 Introducing the parent categories

Each category is briefly introduced here, before a more detailed explanation follows.

Category one: Winging it, supporting the kids alone with no 'rule book'

Ten themes contributed to this category. Parents felt they were 'winging it' and often alone in supporting their children. Following the death, they were putting everything into their children and doing the best they could for them. Parents took on many more roles and responsibilities as they became a single parent and they felt the weight of responsibility this brought. Parents worried for themselves and their children; about how their lives had changed and the impact of parental death on their children. Many parents felt that the death meant that their children were growing up too soon. Parents admitted having no idea how to support their grieving children. They expected professional support to be readily available but found they had to seek this themselves. All parents learnt that being open and honest goes against everything they want to do as a parent but it helped their children cope and stopped them from imagining worse situations. Parents also found it empowering and involving the children helped the children adjust. Parents found that they and their children

were finding their own ways of grieving, and although they were grieving the same person, their grief was unique.

Category two: Being picked up and carried

Five themes contributed to this category. These themes provide insight into the support that they automatically received from those within their existing networks. Parents gave many examples of how others were supporting them well. Parents found that immediately after the death, the people around them stepped up and rallied around them, offering good practical support. Parents found employers understanding the impact and giving flexibility helped them adjust to their new lives. With regard to school support, parents were reassured when schools gave good support, communicated well and looked out for their children. Some parents considered the best support was that from bereaved peers, describing it was like finding the door to Narnia – magical and hard to find. Bereaved peers understood what they were going through. Many parents described feeling lucky with the support they had received and wanted to help others.

Category three: Becoming alienated

Five themes contributed to this category. All parents experienced some sort of alienation attributed to their bereavement or grief. Parents found at times they were alienating themselves. There was also the alienation from the people around them. Peoples lack of understanding around grief and its impact and longevity meant people struggled to provide support in the way they wanted and after time, support also dwindled. Parents described difficulties accessing professional support and described what could be better from professionals and likewise what could be better from schools. Some of the families described how Covid impacted their experience, including positive and negative aspects.

8.2.2 Category one: Winging it, supporting the kids alone with no 'rule book'

8.2.2.1 Putting everything into the children

After the death, parents went onto autopilot, parental instincts kicked in, and they had no choice other than to function and care for their children whilst life around them carried on.

Over half of the parents spoke about this deliberate choice to carry on, their sense of responsibility, putting all their energy into the children, and 'getting through' each day. Some parents spoke of feeling angry at people around them who praised them for being strong when they felt they were not strong; they were surviving.

"... they'd lost one parent, they couldn't lose two, and on the days where I wanted to say in my head, I wanted to stay under the duvet, and I wanted to drown myself in a bottle. But the sense of responsibility weighed so heavily upon me. I got up every single day, and I sort of almost dogmatically, you know, fought against that" Zoe (mother).

Whilst putting everything into the children, many parents found they were so focused on the kids that they sometimes neglected their own needs. Some were unable to voice their own needs. Some parents desperately tried to carry on as they did before, which often led to them 'crashing and burning' before accepting everything had changed, and they could not carry on the same.

8.2.2.2 Feeling the weight of responsibility

Most parents described their immense responsibility; becoming a single parent was stressful and an enormous burden. They were often exhausted and overwhelmed, constantly firefighting, juggling, doing everything, and feeling trapped with no one to help them with the load.

"Everything is down to me. And that's really, really stressful because if you drop the ball, there's nobody else here to pick it up again and pass it back to you. At all, and that's quite scary" Rachel (mother).

Alongside having sole responsibility for the children, parents had responsibility for running the household and finances and taking on the previous roles of the deceased. A few parents found undertaking roles they had never previously done, enjoyable and empowering, but also guilty they could have done more to help the other parent when they were alive. Some

parents changed their parenting style; John realised he had become softer, whilst Zoe became stricter with the children. Some spoke of not being the parent they wanted to be.

"I am very strict. I'm very strict with it, when it comes to school. And, you know, bed times. And I think because I think it's just too easy, to say go to bed when you want, you know, I'm watching telly and I'm drinking, and whatever you do what you want, and you've lost your dad, you know, you do whatever you want, because you've been through enough but actually for me it is the other way around. They need it more than ever. It's just too easy an excuse. And I think, as I said, I'd like to think I'm doing right by them" Zoe (mother).

Many parents struggle with making decisions regarding their children alone. Previously parents did that together, bouncing ideas off of each other. Now the pressure was all on the surviving parent to make such decisions; many doubted their decisions and feared getting them wrong. Some parents found those around them gave advice and helped them make decisions despite having no experience of their situation.

8.2.2.3 Worrying for yourself and the children

Parents' main concern was the impact of the death on their children, both now and in the future. Although it was agonising seeing their children grieve, parents often felt helpless. Some parents became more overprotective of their children. Some worried about their health, finances and their abilities to manage. A few parents constantly feared something could happen to them and what that would mean for their children. As a result, some parents modified their behaviour and become aware of their physical and mental health. One mother received a cancer diagnosis shortly after her husband died. After that, she constantly feared her cancer could come back and leave the children orphaned.

Many parents were aware of the ongoing negative consequences of parental bereavement on their children, and a few mentioned adverse childhood experiences (ACEs). Many parents believed that parental death was something that would affect their children's mental health and would be something they would always need support with, others knew it could cause their child to 'go off the rails'. Some parents knew about this from their professional lives.

Others had described doing research themselves by reading books and searching the internet. Nevertheless, parents were desperate that their children would not be adversely affected by the death.

Alongside these worries, many parents had financial worries to contend with. Many parents went from having two to one income, and some had to seek government benefits. Some parents had to move house, leave or change their jobs to afford their lifestyles. A few parents were fortunate in receiving full pay with no pressure to return to work or receiving insurance money that allowed them to become financially secure. However, many parents felt pressured to return to work as soon as possible to ensure money kept coming into the house.

"I haven't got a choice I have bills to pay. You know I had to go out to work. Obviously, I did have some time off but I went back, if I don't work I don't pay the bills. I haven't got choice, again going to work it's not brave, going to work is a means to an end" Cara (mother).

8.2.2.4 Children are growing up too soon

The parents recognised that their children were growing up too soon, which seemed to be outside of the parents' control. Parents saw positive and negative aspects resulting from 'growing up' because of parental death. A few parents were surprised by how well their children coped following the death, which saddened some. Jenny remembers her child, who was usually very quiet and shy, taking the lead with the funeral planning meeting and speaking at the funeral. As time passed, a few parents found it unbelievable that their children were doing well. Despite this, they always worried this would not always be the case.

"...when people have been saying you know how are the boys doing? I'm generally like they're doing great...like how can they be, and I'm always waiting for it not to be great, but with all things considered, they've been great, yeah, which is quite unbelievable, to be honest with you" Sarah (mother).

Many parents found their children were stepping up to help them and taking on responsibilities, filling roles, including chores around the house and caring for siblings. However, some felt guilty about this, feeling their children's childhood was being snatched from them.

One mother, who was bereaved by suicide, later found out her husband had spoken to their eldest son in the months before his death, telling him he should look after her. This burdened the child with a responsibility that she felt was wrong. The same mother found the people around her were telling the children to look after her, which she resented because they were children and she felt it was not their responsibility.

Some parents found their children were looking after them - becoming overprotective, sending messages or ringing from school to check in on them, sitting with them on an evening, having a hug and telling them they loved them and consoling them when they were upset. Their children could also be their 'crutch'. Having them with her helped one mother attend social events. However, she was conscious there was a fine line, and wanted to remember that her children were children.

8.2.2.5 Having no idea to support a grieving child

Parents did not know how best to support their grieving children; many said they were not given a rule book or a manual. Parents expected a professional to provide support automatically. Instead, however, they found that often they were the main support for their children. Some parents struggled to be able to support their children whilst grieving themselves. Many parents were desperate for immediate professional support for their children following the death. For some, this happened; for others, this did not begin for months following the death. For example, Tony felt the support came too late, and he was unsure of the benefits a year after the death. Many parents would have benefited from guidance and reassurance in supporting their children.

Parents learned to follow their gut instincts about what was right for their family. Some acknowledged that they would not always get it right, but they were doing their best. A few parents drew on their past experiences and professional knowledge to know how to support

their children. However, parents also questioned their abilities to support their children, with a fear they could make it worse. Many parents would have appreciated professional reassurance, but often this was absent, making them feel they were in this alone, 'blagging' their way through.

"dealing with your child who's grieving, I have no idea whatsoever, it was really difficult. And then you are feeling bad about that, so it's grieving, grieving for her, and then feeling bad thinking am I doing a good job here, am I scarring her for life even more, and that was just really difficult, you know, I think if somebody could come along and say to you. Because you can't even think straight anyway, this is what you should be doing, this is what you need to do, someone to just come along and take charge" Natalie (mother).

Many parents found the people around would offer their advice and opinions despite having no experience of their situation. Some parents sourced literature on parenting or bereavement or spoke to charities, which many found helpful in supporting their children.

8.2.2.6 Seeking out and experiencing professional support

All parents spoke of seeking out professional help. Most researched online or were given leaflets. Some were encouraged by those around them to seek counselling. Most self-referred to services, including counselling and bereavement charities and a few were referred through employers. A few parents were grateful for their GP surgeries, or the hospital chaplain reaching out to them offering support, acknowledging the death and signposting, or hospices inviting them to attend support services.

A few parents tried to find pre-bereavement support, fearing how their children would cope. Chris realised there was a gap in pre-bereavement support for his children. However, a few parents were able to access counselling for themselves whilst the other parent was terminally ill.

Following the parent's death, all surviving parents sought professional support through fear of the impact the death could have on their children and an awareness that this would be

something they would 'carry' for the rest of their lives. Ellie and Zoe sought help because they felt that 'a grieving person could not give their all to another grieving person'. Meaning that they did not feel that whilst grieving themselves they could provide enough support to their children, and like the majority of parent participants, they admitted that they just did not know how to support the children. Steve was surprised to hear that the service to support his children required them to be bereaved for 12 months. He was mindful that he could not give the children all the support they needed, so he asked for his children to be added to a waiting list to access support as soon as they were able.

"I was very much there's a problem, find a solution - bereavement charity. They'll sort the problem" Zoe (mother).

Some parents described wanting any support for their children to give them the best opportunity to be able to deal with the death of their parent throughout their lives. Many parents believed peer support groups were important to show their children that there were others in this situation. Zoe believed professional support was important to provide her children with someone other than herself or a family member, someone to vent to who was independent and non-judgmental. Tony just needed reassurance from a professional that he was doing everything right for his child. Several parents found reassurance that they could access professional support in the future.

Some parents sought support for themselves. A few were worried about becoming depressed, so they sought support to prevent this. John attended a bereavement support group hoping to find someone who, like him, was resentful that his life as he knew it had gone. Whilst in the support group, he felt like a 'tourist'. None of the others could relate to his situation. Laura attended a group support session. She was the only bereaved widow trying to support her children, so she found the group was unhelpful as no one in the group could relate to the difficulties she was experiencing because of her bereavement. However, from that group, she was offered one-to-one support. She was surprised she could access this for free and without a waiting list. She found that support invaluable. Several parents accessed counselling; for instance, Sarah accessed counselling soon after the death and found the support amazing. She appreciated having that set time just for her, with someone

who would listen and give her coping strategies. Tony found it helpful to have his thinking challenged.

Natalie sought help via her GP when struggling a year after the death. She was prescribed sleeping tablets which she found she had to stop as she could not function the next day. She was grateful to her GP, who shared his experience of suddenly losing his father. She appreciated this and found it more helpful than speaking with a counsellor who could not understand her situation. Ellie began struggling around a year after the death and required targeted therapy for post-traumatic stress disorder therapy to stop her recurring nightmares.

The timing of professional support after the death varied and needed to be individual for each parent and child. Some parents accessed support within weeks of the death, while for others, it was several months later. The few mothers who wanted support soon after the death had to persuade services that it was not too soon. Rachel was offered counselling a few weeks after the death but she herself felt this was too soon. Tony and Dave spoke with bereavement charities within days of the deaths, and found them very helpful in signposting to other services.

"We needed somebody in my house, the next day, talking to us, and saying this is how we're going to help you two, we're going to help you two deal with this, mentally, we're going to help you. Nothing. But then, this resilient hub they said that they can help us as a family but that's just for NHS staff. So, all these people who don't work for the NHS what have they got?" Mel (mother).

Parents who accessed support appreciated talking with someone that listened and had time for them, who understood their situation and the impact of the death, and gave constructive advice. They reported that it was important to feel comfortable talking openly in a non-judgemental way. Some parents appreciated parenting advice. Many parents found that having support for themselves gave them strength and helped them to support their children. This was especially the case in families where the children were not ready to talk to anyone.

8.2.2.7 Being open and honest goes against everything you want to do as a parent

Half of the parents described how difficult it was to break the news of the death to their children. Natalie described it as the worst moment of her life. Most parents believed being open and honest with their children was essential. However, this could be very difficult to do when their instinct was to shield and protect their children. Many parents spoke of not wanting to lie to their children and that they did not want them to look back and think they had done a bad job. However, a few parents realised that they could not fool their children. They felt that they picked up on what was going on and sensed how their parent felt. Some parents worried that if they were not honest with their children, what they could make up in their heads could be worse than the truth. Ellie followed a rule if the children were asking the questions; they were ready for the answers. However, a few parents struggled and were unprepared for their children's questions about burial and cremation. A few parents failed to find any literature or guidance to help explain those concepts.

"she wanted to know where he was going to go, so I did explain what cremation was, which was awful, because to her, to be essentially burnt, and then she said well what's the other thing they do, and I said they bury you in the ground, both really traumatic things to try and explain to a child" Natalie (mother).

A few parents spoke of the importance of the language used with children surrounding death and gave examples of when language was misinterpreted or misunderstood by their children. For example, some participants had told their children that their parent was 'in a better place' or 'up there'. All of which they reported was confusing for children to understand. One younger son had asked his mother if he killed them all could they go and live with daddy.

A few parents spoke with charities for support on how to communicate with their children. Chris and his terminally ill wife, were brutally honest with their children, meaning they had some really tough conversations before she died. On reflection, he believed that his children were coping well after the death because of this. He felt they had a more challenging time during the illness. Dan struggled to be honest with his young daughter whilst her mother

was terminally ill. He was trying to protect her, although, on reflection, he did not know if this was the best way. Following the death, he became research-informed to support his child and learnt about having open conversations, which he reported could be difficult and required the parent to fight the urge to shut them down.

"the biggest support I've tried to do is to try and get as research informed as I can, to try and support in my own way around just talking about Hannah's death, talking about her life, memory boxes. Just all of those little things really, not to kind of closing it down, the subject that's inherently sad, but one that, I guess, we all need to work through really, I don't know, yeah, I don't know what I was expecting really, not that I was expecting certain people to ring up and say right, but they never really, no one ever tells you what kind of you need to do next, and what are the things are around" Dan (father).

Some parents found that when they were open and honest with their children, this was reciprocated. They also highlighted the importance of keeping the lines of communication completely open and providing safe spaces so their children would come and talk to them. Sarah admitted she did not speak much with their children about the loss; she said it was sad, but they were 'cracking on' with their lives. However, she also questioned if that was the best approach.

Although some parents found their children did not want to talk about the loss, this could differ between siblings, particularly when children were recently bereaved. They reported that some of their children did not talk about it because they did not want to upset their parents.

8.2.2.8 Empowering and involving the children

Many parents believed it was necessary to involve their children and give them informed choices over what was happening within the family. They felt that this could be a delicate balancing act between doing what they thought was right for their children and trying to protect them. Parents knew their children would pick up on what was happening, even when it was not spoken about.

Most children were involved in decisions about viewing their parents' bodies, planning, attending and taking part in the funeral, and some were given decisions over when to go back to school or if they wanted counselling. Many parents believed they might regret their decisions had they not involved the children. They worried their children might resent them or think they had mishandled the situation. However, many questioned if they made the right decisions. Many participants found that the people around them had strong opinions about children's involvement. Chris believed involving his children gave them empowerment in the process which helped them as time went on; things were done with them rather than to them; it also helped his children talk more openly to him. Other parents echoed this.

"She said she wanted to come (to the funeral) and yeah I just let her make that decision, I was so worried that she would grow up and be like, I never got to say goodbye, and I was left out from, where everybody else was going to say goodbye to my dad, and I was just left with my mum's mate down the road or whatever, you know, and I still don't know if it was right" Natalie (mother).

John allowed his child to see his mum's body. John described how horrible she looked, and his child told him he felt traumatised afterwards. He did not say if or how he had prepared the child to see their mum. John felt terrible that he had allowed it but still felt he had made the right decision. He felt that if he had not, his child would always resent them for that. Ellie also struggled to decide to let her children view the body, but they insisted on seeing him to prove he was dead. She felt that she needed to prepare the children and be matter-of-fact with them to help them decide if they wanted to see their dad. This involved giving explicit detail on how different he looked and smelled, which meant it was not so shocking for the children to see.

At the funeral, parents found it helpful to have a trusted friend or family member allocated to support each child. Some of the parents spoke of how they put great effort into the funeral being a positive day that the children would be able to remember, not just as a sad day. For example, asking people to wear bright clothes, taking photos and videos that they

would then watch together in the future. Children who spoke of viewing the body or attending the funeral did not speak of any regrets of involvement.

Dan's child did not attend the funeral after he sought advice from his family and they decided that attending could have caused more trauma. However, when reflecting during the interview, he said he had previously viewed funerals as sad events, but since then, having attended other funerals he realised they were a celebration of life which made him question if he had made the right decision.

8.2.2.9 Finding your own ways of grieving

The majority of parents realised that not all family members were grieving in the same way. Despite grieving for the same person, they each had a different relationship with that person; therefore, they recognised that each could not fully understand what the other was going through.

Many parents found that their children both grieved and showed their emotions in very different ways. For example, one child could be very emotional and upset, whereas their sibling may not even acknowledge or want to talk about the deceased parent. On the other hand, some parents found some of their children were grieving in similar ways to them, which made supporting them easier.

Parents sometimes had to reassure their children about how they were feeling. For example, Laura's child was worried because she did not cry when her dad died or at the funeral and believed something was wrong with her. Laura believed she felt an expectation from others of how she should be feeling but was able to reassure her that whatever she was feeling was okay.

Many parents believed it was important to show their emotions to their children. They thought this would help permit them to cry. Following the death, they would openly cry in front of the children and cry together, but as time went on, that became more difficult. Some parents found a role reversal where their children comforted them. Jenny's children, for instance, felt out of their depth with her grief and would text her friends for help.

After a time, many parents found their children could not bear to see them upset, or it made them uncomfortable or frightened them to see their parents out of control. As a result, the parents had to learn to control how and when they grieved. Their grief became private. Some parents spoke of trying to be strong for their children. During Covid lockdowns, this proved to be more difficult when families were always together, as they had no respite. Examples of how they grieved privately included crying in the car, in the shower, at night when the children were in bed or holding it together until after the school run. Parents then learned to balance their grief by showing their children an 'acceptable' amount of grief. Dan felt he could not 'totally' grieve because a 'little person' relied on him. Having to control his grief meant Dan felt he had 'elongated grief' rather than 'acute grief'.

"I needed to find a way of managing my grief, so that with my daughter, I would cry when she cried, so I would cry with her, whereas to begin with, you know my view initially, had been that I would show them that it's okay to cry, which I think yeah that was important, but when I saw that she really struggled with that, I then had to change that around, and manage my grief and when I cry...I found a way... it's a hard thing to describe, something just kicked in, enabled me to do that, and there would still be the odd time, you know if we went to the grave together...so if I would cry at the side of my wife's grave, because there's space there, she was able to say 'oh he is crying again', and she'd run off, so that was fine, because she was able to do what she did...I had to find a way, but it took time and I got there, and actually it was quite healthy I think, she still had the message it was okay to cry, but equally, it made it safe for her" Steve (father).

Some parents were aware that their children were holding their grief. Jenny knew her eldest child would cry late at night when she had gone to bed. Natalie found that her younger child was worried about crying in front of her because she did not want to make her cry. The same child wrote letters to her pleading with her to be happy, which made Natalie feel guilty.

8.2.2.10 Remembering them

While alive, a few parents with a terminal diagnosis had prepared memory boxes or books for their children. These included letters, books, jewellery, items of clothing, photos, stories and other mementoes. Rachel recalled how her husband had written letters to their children. One of the children had read these, which was emotional but cathartic; the other had not wanted to read it yet.

Many parents spoke about how they remembered the deceased parent. Most parents did this by talking about them and bringing them into everyday conversations and life. Some parents tried to do this as much as possible, others less so. However, many parents admitted they did not know if what they were doing was right or wrong.

Other parents looked at photos and videos together, which helped them remember and allowed talking about them. Parents were grateful that their children had memories of their parents.

Ellie felt guilty about forgetting them or forgetting specific memories or their voice. Rachel explained how her child had forgotten what their dad sounded like, and she could not find any audio of his voice. She believed it was her responsibility to ensure the children did not forget.

A few parents spoke of ways they remembered them together on subsequent birthdays and anniversaries, which they all enjoyed. However, for Natalie, whilst she wanted to create such memories, her child did not.

8.2.3 Category two: Being picked up and carried

8.2.3.1 How others are supporting them well

All parents received initial support from family, friends, and their communities. Some parents found their own families more supportive. For others, it was their in-laws who supported them the most. Parents generally found that people wanted to help and do whatever they could to support them. Dan spoke of the power in the collective grief he received within his family network who were grieving together. Jenny described her team of

supporters as her 'protective shield' who managed the support others within the network provided. When talking about support, many parents described good support as something that made them feel that they were not on their own, that others cared, and were doing what they could to try and make it better.

Support with childcare was invaluable when parents were trying to navigate all the practicalities that arise following a death. It was helpful to have someone who could care for the children whilst they attended appointments. Parent participants also appreciated offers to take the children out to play to give them a break and support with the school runs and offers of lifts, especially when they were getting back to work. Mark described his mother-in-law as a 'godsend' when she stepped into the primary childcare role to allow him to work full time.

It was also helpful to know people were there when needed, and parents particularly appreciated those who were non-judgmental. Parents found that people wanted to help them and do what they could. Parents advised that anyone in their situation should accept any help offered to them and not think they can 'do it all themselves'.

Some friends set up rotas of support or WhatsApp groups providing or coordinating support. For example, Laura's network developed a news tree with a nominated person she would update, who then disseminated it to others. This worked well, and it stopped her from getting lots of messages which was exhausting, responding to other people's needs when she could not fathom her own.

Some parents received what they described as 'hollow' offers of support, 'let me know what I can do', 'if there's anything I can do just shout', which was not helpful as parents lacked the capacity to tell them what to do. However, many parents struggled to ask for help, so they appreciated the people who would just get on and help them, taking away decisions.

"like take the decision away from me almost, yeah just go, I'm going to leave you a lasagne, it will be in your porch on Wednesday, if that doesn't work for you just let me know...and the people that did were just great, just thank you so much

because, because actually saying if there's anything I can do to help, it's actually just throwing another task on me, which I was just like, eugh I don't know what I want you to do" Chris (father).

A few parents were not afraid to ask for help. Dave described himself as proactive in seeking help; he had found that in his situation, whenever he asked he always got it. He had also spoken to peers who were resentful about a lack of support; when he questioned if they had asked for the support, he often found they had not.

All the parents mentioned practical help. Many spoke of the abundance of food cooked for them, which meant there was 'one less worry'. Some parents were given so much food that they were giving it away to neighbours or homeless shelters. Parents appreciated little acts of kindness, people being thoughtful and thinking about them, giving condolences and showing their love and support. Parents also found that good support did not always need to be face to face; text messages and telephone calls, checking in on how they were doing, were appreciated.

Parents appreciated those around them who did not shy away from them when they struggled. It was helpful when people talked openly about the parent who died. This was their life now, this had happened, and they did not want it to be a taboo subject. Nevertheless, parents found that not everyone was comfortable talking. Some people did not know what to say, which was fine, but acknowledging that with them and not overthinking it, rather than avoiding them, was supportive.

A few parents found great support from people within their networks who had also suffered a significant bereavement. Those people understood, could give good advice, and would not shy away from difficult conversations.

"in terms of practical stuff, you know, I mean, well, everything really I mean the cooking, cleaning, you know, I was actually joking that my house was the cleanest that it had ever been ever...I think that's what people do, you know, there's a feeling with others that not being able to do enough, I think, I got that

feeling at times that people are trying to sort of, they want to feel useful" Dave (father).

Chris realised it would be impossible for him to manage to work, look after the children and run a household, so he had taken on paid help from someone who would come and clean, do the washing and prepare some meals for the family each week, which he found to be a massive help. He was conscious not to have this help straight after the death as he did not want the children to think he was trying to replace their mother. However, he did still wonder what the children thought about it. Other friends had immediate family members or friends move in with them, which helped them through the first months, supporting with childcare, returning to work, and teaching one of the fathers how to cook and clean. Generally, this support was invaluable; however, one participant, Tony, found it hard work and added to his stress.

Some parents found it challenging but necessary to let others know when support was not working for them. For example, Laura was inundated with food; however, her children had sensory issues, which meant most food was wasted or given away. When she asked people not to bring food around, they took it upon themselves to create a 'daddy's pizza fund', which was fantastic and meant she could get food the children would eat and did not have to worry about cooking all of the time.

In terms of support, parents found it helpful to draw on what different people could offer, pulling on the strengths within their network. This could be wide-ranging; from someone who can entertain the children, someone they trusted to give sound advice, someone who can help them manage their finances, or someone who could make them laugh.

A Jewish family followed a set framework of mourning, which involved many visitors to the house, bringing food and sharing memories. The mother found that this support helped her get through the first week. Although this was immensely supportive, it was a blessing and a curse. It was overwhelming and intense at times, feeling like she had to look after everyone. At times, the family would borrow dogs to walk to escape. Another father, Dave, received much support within his community but described his house as 'Kings' Cross station', with

people coming and going. He also found he had to escape that environment sometimes as it could be too much.

A few parents were overwhelmed by the flowers and well wishes they received, sometimes from people they had not spoken to for years. However, Natalie struggled to receive flowers. She did not appreciate them at the time, and she did not want them because of the reason she was getting them; it was a reminder that her husband had died.

Some parents were surprised by the people who stepped up to help them. At times, they were people they would least expect and who they felt had no obligation to support them. Some parents found their relationships with those who supported them well were strengthened, leading them to reflect on other relationships and if they actually have time and energy to invest in them.

The families who integrated well into their communities found fantastic support from within them and a sense that the death affected everyone. Zoe reflected that she had not understood what a community was until she needed to pull on their support and realised what it meant to be part of something.

Several parents were grateful to have ongoing sustained support from those around them, including someone to talk to when they were having a bad time, support with childcare, and offers of playdates with the children. However, not all of them received sustained support, and Laura believed this was because it was a long journey to acceptance and new normality; 'some people are better at long journeys than others'.

8.2.3.2 Employer understanding the impact and giving flexibility

Many parents spoke positively about their experiences of support from employers. It was beneficial when employers gave them flexibility regarding their return to work and the hours and time they worked. However, despite many employers being understanding and supportive, none of the parents knew any processes or policies that the employers followed to support a bereaved employee.

Sarah had counselling arranged through work and during work time. Mark worked in the public sector; his organisation did not know how to handle the situation. He was not referred to occupational health or offered counselling. Chris was given all the school holidays off work, which was a huge help. Some parents who were bereaved during the pandemic appreciated the ability to work from home, and flexibility over working hours relieved the pressure of having to do the school run and arrange childcare.

Dave knew he had received exceptional support from his employer, who is family-friendly. His manager rang straight away to assure him he did not need to worry financially and that there was no expectation for him to go back to work in the months following his loss. In addition, his manager attended the funeral and has maintained weekly check-ins to see how he is doing. His company also reviewed their policies and developed a death-in-service package.

The few parents who were given extended periods off work often felt guilty for receiving full pay. Dave offered to have his pay reduced, whilst Cathy requested unpaid leave.

A couple of parents could no longer fulfil their jobs, sometimes due to lack of childcare or the nature of their roles. For instance, Mel could not manage financially with her income, so had to look for a better-paid job which meant working unsocial hours.

Not all parents had good experiences with employers. For example, Dan was the primary breadwinner, and he had previously been able to attend the early morning meetings whilst his wife did the school run. Now he had to do the school run; he could no longer make those meetings. Although his employer was supportive at first, after some time people often forgot and questioned where he was, and he felt an applied assumption that he should have moved on and sorted things to allow him to work as he had done previously.

Some parents described how the death had affected their career aspirations and abilities to provide for the family. A few parents felt trapped in their jobs because they were so flexible and understanding. They knew new employers may not be the same and were then in a quandary as to disclosing their situation or not.

"I did look for another job, gave them full disclosure, and was told 'actually that's not going to work for us', and then you think, well actually, right okay, maybe you don't tell people that you've gone through this, but then if you don't tell them that you can't expect them to kind of make some adjustments for you" Dan (father).

8.2.3.3 Being supported by school

School had the potential to play a huge role in offering support to families. Many parents received good support from their children's schools. However, few schools had policies or procedures to support bereaved children. School support was seen as very good when it was tailored to the child's needs rather than the situation. Furthermore, good support reassured parents. Ellie felt the support they received from school came from kindness and care.

Parents appreciated home visits from schools to identify children's needs and make plans to return and for staff to attend the funeral. It was helpful when the school made the school community aware of the death, meaning parents were not subjected to many questions on the school run. Some schools had an identified well-being officer who supported the child and ensured the teachers were aware of the situation.

Parents found comfort knowing that the teachers knew their children and were looking out for them. Examples they gave were teachers contacting them directly to ask how they should treat the child, asking what support they needed, or being sensitive to what may upset children, including mothers and fathers days or giving them a warning about topics they would be doing in class that could cause upset. Such warnings helped prepare the children for lessons and allowed them to sit out if they wished. It also meant parents were aware their child might need more support than usual. In addition, some teachers would regularly check in with the child to ask them how they were doing.

Rachel was impressed with her child's support when transitioning to college, taking a proactive approach, informing her about their on-site counsellor and providing a free bus

pass and lunch vouchers. Other parents found schools provided immediate professional support to their children, including pastoral support, play therapy, counselling, cognitive behavioural therapy, workshops with the other children, and teacher support. In addition, a few schools ensured teachers received bereavement training.

Parents appreciated good communication from the school about how their children were doing. Examples included updates on any worrying behaviour, if the child was having a bad day, or the school checking in on them and their children. One participant, Dan, had a background working in education; he told the school he did not expect them to sort the problems, but to be an empathic listener to the child and let him know what was happening so he could provide support. He then wondered if the good communication he received from the school came from him pushing this point.

"my primary concern was about the children actually, so that was my big worry. So, school were the big part of their lives, and the way school responded meant I didn't have those worries as such" Steve (father).

If children were moving schools, then parents chose schools with good pastoral support that they felt confident could support their children. However, many parents knew that school support was 'hit and miss'. Several had met bereaved peers who had a very different experience.

8.2.3.4 Finding the door to Narnia – with bereaved peer support

Most of the parents received great comfort and support through connecting with someone who understood. Nearly all participants named a charity offering peer-to-peer support as invaluable. Dave described this as finding 'the door to Narnia', a community he never knew existed, which opens up communities of people who create a safe place to be supported.

Connecting with someone who understood was powerful and allowed the bereaved parent to see that they were not alone in what they were going through and how they felt. This was especially helpful when the parent was newly bereaved. Many parents instantly felt that hearing about other people's experiences normalised what they were going through

and gave reassurance they were not going mad. Receiving advice from someone who had been through it proved that a bereaved parent could get through because other people had. It was also helpful to understand how others handled situations.

For example, Dave realised the benefits of speaking with bereaved peers. It provided social normality and a safe place to be honest with how he was doing, as opposed to normal social situations where he had to censor or hold back what he said because he did not want to make others uncomfortable.

Some parents struggled to find peer support despite wanting to speak with someone who understood. For example, Cathy had great support from peers she met on an online forum for people with children whose partners were terminally ill. When their partners died, they asked the charity if they could have a forum for them as bereaved parents but were told this was not possible. As a result, Cathy felt she had to set up her own peer support group on Facebook.

Bereaved peer support was not suitable for all parents. For instance, Tony found great benefit from that support but admitted it was depressing to hear other people's stories. A mother bereaved by suicide found peer support helpful when peers had been bereaved in similar circumstances. However, she also said that although this support could be a comfort, it made her feel more isolated and alienated in her experience. Natalie found that the charity peer support network was not for her. However, she met someone who was a similar age and had lost his wife, leaving him with young children. They went on to become good friends because they understood what they were going through and could be completely honest with each other about how they were feeling, which was not always possible with other friends.

8.2.3.5 Feeling lucky with the support received and wanting to help others

Over half of the parents felt lucky with the support they had received. However, speaking to bereaved peers often demonstrated that good support was not the standard. Regardless of their support, parents participated in the study because they wanted to make a difference and help other bereaved families by sharing their own experiences. Some spoke about not

wanting to be a statistic, and a few parents have taken on active roles within bereavement support charities, becoming ambassadors, writing blogs and books. One mother had developed bereavement support groups for children and separate groups for adults. All of these have not only been beneficial and cathartic to them but helped other bereaved families.

8.2.4 Category three: Becoming alienated

8.2.4.1 Alienating oneself

All the parents described ways in which they 'alienated themselves'. Many parents believed others judged how they were grieving, coming to terms with their loss, living their lives, and making decisions about their children. A few parents worried that because they were getting on with their lives, others may think they had 'moved on'. Some parents also judged themselves on how they were doing. Several parents worried about what people thought of them. For example, Cara and Cathy avoided posting anything on social media. In contrast, others consciously decided not to care about others' opinions. Tony used social media to share pictures to prove to others that they were getting on with their lives.

Two mothers who were bereaved suddenly, one by suicide, the other attributed to lifestyle choices, felt they were undeserving of grief because of how their husbands died. They felt shame and thought other people might think they were not entitled to grieve in the same way as people bereaved by other causes.

Some families struggled to be around 'complete' families because it reminded them that theirs was broken. Parents suggested ways they alienated themselves by avoiding or removing themselves from social events and social media because it was too difficult to see families enjoying themselves together. Certain times of the year were more difficult, especially the holidays when families were supposed to be together.

John went from seeing his son every other weekend to him living with him full-time. His life as he knew it was 'gone', making him resentful of his ex-partner. He missed his old life and the freedom he once had. He attended a support group hoping to find someone in a similar

situation who felt the same resentment but the other parents had been in a relationship with the other parent.

After a time, often after a year, many parents experienced expectations from others about 'moving on'. Sometimes this was said directly; other times, it 'bubbled under the surface', but the people around them often had their own timelines for grief. Their loss was no longer at the forefront of their minds. Despite their best intentions, they have not been through a loss like this and can be unsympathetic to their ongoing grief. Ellie joked that others got bored of her grief and were thinking, 'aren't you over it by now'.

Sometimes the people around the parents expected them to have 'moved on', and they could not see that they could not move on. Parents were still adapting to their new lives or sometimes just existing in that life whilst ensuring they attended to their children's needs. Some parents disliked the term 'moving on'. It was not helpful, and Zoe said she could never move on. In another instance, Dan explained how he might not be able to 'move on' at the pace expected because he was trying to adapt to his new life and look after the needs of those around him, which meant his time to himself was limited. Others' expectations to 'move on' made it harder for many parents to show their grief. Rachel felt guilty about lying to people saying she was not grieving when she knew she would always be grieving. However, she needed to function; the only way she could do that was by masking her grief.

Some parents alienated themselves from others because they did not want their grief to be a burden or believed people were bored of their grief. A few spoke of not wanting to make other people sad, uncomfortable, or helpless, so they kept their grief to themselves. A few worried they no longer had things in common with friends, so they avoided them. Some parents advised other parents in their situation to be honest with the people around them about how they were feeling or coping, despite them being unable to do this themselves.

"Every single day, I still four years on, go to text him, still, when I see something fun or we have run out of milk, you know just stupid things like that I think, I'll just text, no I can't do that. Every day, every minute, occurrence, but I can't let that rule my life, because, you couldn't do anything, so you have to become

functional, and the only way to become functional, is to mask that pain and say yeah, I'm fine, I kind of feel like I'm living a lie, a little bit. I'm not outwardly lying, because at the moment I probably am okay, yeah I'm not okay, if you know what I mean." Rachel (mother).

Many parents felt society did not help them with their grief because, generally, grief is not handled well. People looking in and think the bereaved person seems fine. People tell them they are strong and make comments like, 'they do not know how you do it', so because the person is outwardly functioning, they take that to mean that they have made everything work, so all is okay now. They do not see what goes on behind closed doors when the children are struggling and cannot sleep.

Their finances alienated some parents who had no choice but to go back to work to pay the bills, and others had to apply for government benefits. Families went from two to one income, many had to work less hours to be able to manage their child care affecting how some families lived. Some parents could not afford the social lives they previously had, which was not always noticed by the people around them, yet it affected their relationships with friends. Some parents had to look for different jobs to afford their lifestyles, and others had to move houses. Some parents had to make decisions about what they could afford. This meant the dynamics with friends could change; some may be aware that they could no longer afford to do the things they used to do and would try and offer other social events which cost less, whilst others were completely unaware of the financial impact.

"I'm definitely a lot skinter than all my couple friends now, they will be like 'oh, you know we're doing this or we're doing that' and I will kind of think well I'll go out that night, but I'm not doing that as well... so it's changed the dynamic... some friends are aware of it, I've got a friend who will say things like 'oh, let me come and help you, with your garden and we'll have an easy lunch in the garden'... so it's a way round the fact that I haven't got as much money as a lot of my friends. And that's, you know it's a big change. You know, particularly if you've gone from two incomes to one, but also, you're then responsible for child

care so um, you know you can generally work less and I don't think a lot of people will think about that" Ellie.

8.2.4.2 People's lack of understanding around grief

Parents recounted numerous occasions when they were 'socially avoided'. For example, Mark's friend of 20 years avoided him; when asked why he made excuses about being busy and life getting in the way. Other parents found their loss put them in the 'spotlight' for a long time. Some parents, especially those bereaved, suddenly experienced rumours, people staring and talking behind their backs.

Some parents experienced breakdowns in relationships with family and friends following their loss. Some parents had friends who completely abandoned them. Others had friends who tried to be there for them but could not hide their discomfort. Parents lacked the energy to maintain friendships with friends who could not handle their grief. Some parents found relationships with their in-laws deteriorated, with competition over who was grieving the most. One mother was blamed for her husband's death by suicide. In contrast, Mark and Chris found that their relationships with their in-laws became closer, providing more emotional support than they received from their own family.

Parents learnt whom they could trust and felt most comfortable speaking honestly as they continued to grieve, often with people who had experienced similar grief. As a result, many made their social circles smaller.

"That kind of drives the people I do, and I don't want to hang out with...I genuinely feel quite comfortable talking about it, I'd rather be talking about it openly rather than people think let's avoid that subject at all cost." Chris (father).

Some parents found that those around them and those closest to them could not bear to see their pain and grief because they loved them so much and could not fix them. For example, Chris stopped talking to his mother about his grief because she would become too

upset, believing his life was ruined. Laura found that her church family believed 'bad things did not happen to good people', so her husband's death challenged their faith.

Some parents described how people would compare grief, which was never helpful. An example would be someone who had lost a grandparent saying they understood what they were going through. Parents sympathised that losing a grandparent was terrible; however, losing your spouse, the parent to your child, changes everything about your and your child's life and could not be compared to other losses.

Parents found that their loss made some people uncomfortable and awkward. Sometimes people shut down conversations about the person who died because it was upsetting, or they just did not know how to talk about it, so it was easier to say nothing. Some parents found that even their family members struggled to know what to say to them. Dave found that some people avoided talking about his wife because they genuinely believed they were helping by not reminding him about her.

Parents often suppressed emotions or were not honest about how they were doing to protect the people around them and stop them from feeling uncomfortable and experiencing the pain the parents were going through. Some parents were clear that they did not want their grief to define them. Sarah withheld her bereavement from her new work colleagues because she did not want them to feel sorry for her.

Most of the parents found that the people around them did not understand the impact and longevity of their bereavement. Unless people had experienced the death of a partner, they could not understand what they were going through. Because dying young is not the norm, many parents found they did not have peers around them who had experienced it. As time passed, the initial shock of the death was accepted and was not at the forefront of people's minds, their lives continued, and they soon forgot or did not understand that grief continues, which meant that initial support stopped.

Parents found that even the people in their networks who were grieving the person who had died could not understand the impact the death had on their daily lives as the loss had

not caused the same daily impact on their lives. Some parents even commented that they could not understand what their children were going through as they had not experienced parental death at a young age. Ellie and some children mentioned that adults told the children to look after their parents, which infuriated Ellie who believed that children were children and should not be looking after their parent.

"I think that's the thing general across the board, with work, friends, family and just in society in general, that grief has a lifespan according to people, that aren't going through it really" Natalie (mother).

Parents believed people saw them functioning and thought they were 'over it' or doing well. They did not see what was happening behind closed doors and the ongoing grieving and struggles they faced in every aspect of their lives. A few parents found others expected their children to be 'used to' not having their parent after a few years. After the first year, many parents found that people expected they had completed 'the firsts' in terms of anniversaries, birthdays, and events without the deceased parent. However, as parents said, those 'firsts' will never stop and will continue throughout the child's life. Zoe wondered if it was beholden on the bereaved to educate others who had not been through it and were not as sympathetic in their understanding.

Some parents found that people became less willing to help as time passed. An example of this was childcare. Mark found his parents would initially always help with childcare at the drop of a hat, to give him needed alone time. However, now when he asks for that help, it felt like he is asking a massive favour of them. He felt they did not understand and that his life is just work or his children.

8.2.4.3 Difficulties accessing professional support

Parents spoke of their difficulties accessing professional support, a lack of available or accessible services. Sometimes not knowing what services were available could alienate them in their grief, and contribute to their perception that they were alone in supporting their children.

Parents' perceptions of what support would entail often did not match the reality. This was especially seen when most parents expected a professional would automatically contact them to offer support. This did not often happen. However, all parents wanted or believed a professional should be involved with their family after the death. For example, social services contacted one mother within 24 hours of telling the school that her husband was drinking, yet when he killed himself, no one contacted her, and she was left to deal with the bereavement alone. This experience was echoed by many of the parents. A few parents bereaved suddenly felt there was more support available to those who had been bereaved through expected deaths. However, Zoe who was bereaved unexpectedly received excellent support from a charity.

Some parents felt people might be wary of counselling as they did not understand what it entailed, or that people would have unrealistic expectations of what counselling could deliver. Some parents who accessed counselling believed it had not helped, whilst others found it invaluable. Several spoke of the importance of understanding that it might take a few goes with different counsellors to get the right fit for you.

Following the death, many parents felt they were just left to figure things out themselves. They received a lack of pre- and post-death information about things they may want to think about, the practicalities and processes they must follow after the death, and how to support their children. Only a few parents were signposted to support services, mainly with leaflets that they struggled to read and digest. A few parents suggested a tick list would have helped. Other parents had people around them who had experienced death and knew what was required so they could guide them.

Several parents struggled to decide if children should be involved in the funeral and found a lack of information or guidance about this. Some of the parents described how someone dying became a demanding full-time job regarding what needed to be done and dealt with. This was hard enough without trying to support your grieving child, grieving yourself, and finding support services. Dave suggested the way support is offered needs to change, 'move the mountain to the people'. Many parents found that support was available, but it was up

to them to go and find it, and whilst managing the household, parenting and grieving, they lacked capacity to look.

Several parents believed it would have helped after the death if a professional had sat and spoken with them and their children. Explaining about the next steps, what must be done, what their children were experiencing, how they could support them and what professional help was available. Parents were terrified that they were alone and responsible for their grieving children. Some were desperate for reassurance that, as a family, they would survive this and reassurance that they were doing the right things to support their children.

"My experience of bereavement is that nothing comes to you, like there's nothing, there's not like a some wraparound service where they come to you and say right, this is out there, that's out there, you're entitled to this, this person might be able to help you, this person might be able to help the kids in this group, you've got to go looking for it, and you know, sometimes, when you're in that state of mind, you've just lost some one, that's very close to you, you don't want to be picking up the phone and scrolling through the Internet, and all the rest of it" Mark (father).

Realising they were 'it', some parents tried to research what support services were available and found they faced multiple barriers. For example, Steve found that the services in his area seemed to be for older children. Others found the number of services and navigating what they offered was overwhelming. Dan believed a central directory of services would have massively helped.

While some parents had 'check-ins' from their GP, others had no contact, which surprised them. Parents were often unaware of what services were available. Laura found group support was not for her and was surprised when she was offered free counselling with no waiting list through the hospice. Another mother diagnosed with cancer soon after her husband's death was initially told she could not access hospice counselling because her husband had not been a patient. She found her cancer treatments caused a delay in her grieving and she needed to re-access counselling but felt guilty doing so as she had already

had counselling (she felt she was denying someone else the opportunity). Ellie suggested that a 'bereaved buddy system' would have helped, with a bereaved peer contacting her and guiding her through her options. Unfortunately, very few parents had any follow-up on how they and their families were coping.

Several parents experienced a lack of information about financial support. Some received financial support towards funeral costs. Many received government bereavement support payments. However, often they found out about these payments by chance. To receive the total amount, there was a requirement to claim within three months of the death, which was difficult when parents did not know it existed. Trying to navigate the bank accounts, insurances, and mortgages whilst registering the death, planning a funeral, supporting grieving children and grieving oneself was a real struggle for some parents. Dave believed the processes could be more streamlined, and rather than add to the stress of the bereaved person seeking financial support, it should be provided automatically.

Some parents faced long waiting lists to access support. A few parents felt let down by services that had performed quick assessments and deemed their children not a risk, therefore, not a priority for accessing mental health services. Hearing from services how bad other children were, had led to Laura not accessing support for her children, who were deemed to be 'doing all right' following a telephone assessment. Other difficulties accessing support included the timing, which was often during school time, and children did not want to be pulled out of school. Parents struggled to attend sessions themselves because of childcare issues or not wanting to leave the children. Parents faced a 'post-code lottery' of what support was available. Some could not find professional support or had to make long journeys to access it.

Some parents who did find services felt these services could not meet their needs. Due to Covid, some services offered virtual support, which was not always helpful. Mark remembered a few occasions he had joined virtual meetings to find no one else had joined. Some parents also found that if they had missed a session, they received no further contact.

Parents and children found that to get the most out of the support they received, they needed to connect well with the person offering that support. Quite often, this would not be the first person they saw. Ellie had bad experiences with professionals not understanding their situation, and it took her a long time and three professionals to find someone who was able to support her daughter. She was very conscious that had the last person not worked, her daughter would probably not have been willing to try again. Some parents had tried counselling but could not connect with their therapist, so they stopped. A few parents resorted to paying for suitable counselling. Ellie did so on the advice of her GP, who told her about the lack of available services and questioned their quality.

Support needs to be available when families need to access it. For example, Mel desperately sought support straight after the death but felt let down by services who said no because she was too newly bereaved or it was too traumatic, and so their service could not help. She and other parents just needed someone to reassure them that they would survive, what help was available, be advised on how they could support their child and have a number to ring if they needed to talk. Other parents were desperate to have professional support as soon as possible after the death. Parents often saw bereavement as something that needed to be 'fixed' by professionals.

Cathy described how her son had seen his father in the mortuary. Outwardly, he appeared fine, but several months later, he told his support worker how traumatic it had been. He was asked if he would like to write a letter to them about how they could improve it. He did this and as a result the mortuary implemented changes to make the environment less daunting for children.

Parents felt professionals sometimes did not understand the enormity of what they had been through, which impacted how they offered support or not. This was seen with some GP surgeries and bereavement services. This lack of understanding made some parents not re-access those services. For example, Mel thought she had good support from a mental health charity, but when she experienced a crisis and needed immediate support, it was unavailable, so she lost faith in them as they were not there when she needed them.

In another example, Ellie attended a bereavement charity event one December. At the end, the staff said they were taking Christmas off to be with their families and would be unavailable. She lost confidence in them at this point, realising they had no idea that Christmas would be the absolute worst time and when they would need to support the most. It made her think this showed a fundamental lack of understanding around what they were going through.

Parents found that funding often limited the number of support sessions offered to their children. Parents identified a need for ongoing and more permanent support to be available as needed as children went through each developmental stage. Natalie believed someone checking in with her after a year to see how she was coping would be beneficial because that is when she struggled the most and when she felt forgotten about.

"I think it's because there's a taboo around grief and, and this is just my personal opinion, and I don't think we talk about it and I don't think we talk about grief and I don't think we talked about bereavement because it's too hard and, everyone goes through it differently, and I think that's also part of the reason we don't talk about it is because what works for me might not work for you or somebody else, it is so incredibly personal, so the easiest thing is not to talk about it, um," Cara (mother).

Findings showed that professionals did not always understand families' pressures and demands. A few parents found that the professionals did not always attend planned sessions. This was especially difficult for one of the children with additional needs, who would get worked up and stressed before the session. Rachel accessed support from a charity, but they could not relate to her child's special educational needs and disabilities and could not communicate with him.

Another type of support that was only mentioned by two parents was the police. This support was felt to normally only be applicable to those bereaved in certain circumstances, but could be the first type of support a family receive. Dave felt well supported and received good information and signposting to available support, unlike Mel who was disappointed

with her experience. She found the police lacked understanding, compassion and empathy and only offered a referral to a mental health charity.

8.2.4.4 Lack of understanding from school

As previously discussed, many parents spoke of positive ways the schools supported them. However, not all parents had this experience. Several parents found school support depended on individual teachers as some had a better awareness of supporting bereaved children than others.

There could be a lack of forethought about what families were dealing with and ways the school could support them. For example, some teachers were not informed that a child was bereaved. Sarah received an attendance warning after her child was absent while attending the funeral. Although it was an auto-generated letter for which the school apologised, this was just one example of the school not taking a person-centred approach.

One school had arranged for a counsellor to see a bereaved teenage son. However, he was pulled out of lessons and would sit in silence, refusing to talk to the counsellor. Rather than speak to him, the school took the opinion they had tried to help but the child would not talk, so there was nothing else they could do. As the child's behaviour worsened, his mother felt like the school did not support her, her son was labelled a troubled child, and he was expelled from the school during his exams. She believed the school should have worked closely with her to understand him and his loss and be more forgiving of his situation.

Ellie believed that bereaved children of a parent should be entitled to pupil premium funding currently offered to 'disadvantaged children' to improve education outcomes. She believed doing so would allow schools to improve how they supported bereaved children.

8.2.4.5 How Covid impacted their experience

Over half of the parents mentioned the impact of Covid on the way they were supported. Some were bereaved during the pandemic while others had been before it and were grieving during the pandemic. For some parents, being forced together with no other

contact meant they became closer as a family unit, but at the same time could be difficult as they had no time to grieve alone.

Some parents found it easier to juggle work and childcare during a lockdown, and it helped some parents avoid social events or being around complete families. However, although helpful at the time, it was no easier being around complete families after lockdown.

Parents missed having physical contact when grieving. Many had difficulties with the restrictions around funerals but overcame these challenges by doing things differently. Jenny found that the entire journey to the crematorium was lined with people offering their condolences. Some parents recorded and transmitted the funeral on a live feed. This also provided a recording to look back at with the children, which was helpful.

Some parents found it difficult to access support as usual services were limited or unavailable. Virtual support was better than nothing. However, some felt that face-to-face support was much more helpful, making it easier talking to someone than over the phone. Laura reflected that there would be more bereaved children because of the pandemic but only the same services, so it could be even more challenging to access the limited available services.

8.3 Summary

This chapter has presented the findings from the in-depth interviews with parents. Parent participants felt they were 'winging it' and supporting the children alone, without a rule book. However, after their loss, there was a sense that the people around them picked them up and carried them through the initial bereavement period. Parent participants also found they became alienated because of their loss. The following chapter integrates findings from the child and parent perspectives. It presents the substantive theory, which helped move the data beyond description to analytical conceptualisation.

9 Integration of findings and theory development

9.1 Introduction

The chapter begins by integrating the key findings from the child and parent data. Next, there is an explanation of how the substantive theory was developed. Then the substantive grounded theory constructed from the study's results is presented. Finally, there is a discussion about reflexivity.

9.2 Integration of findings

This section combines and presents key findings from parent and child data sets. The findings were integrated using the grounded theory methods of concurrent data collection, constant comparison and memoing.

Throughout both data sets, it became clear that grief is a unique experience for everyone within a family. The findings showed similarities and differences between children and parents within the same families and also similarities and differences between the two data sets.

These findings are discussed under two headings. The first heading, 'supporting each other', explores parents' and children's experiences of trying to support each other. The second heading, 'support from those around', explores how those within their networks and professionals support them.

9.2.1 Supporting each other

This section is broken down into six sub-headings which explain children's and parents' experiences of supporting each other: (1) feeling responsible for each other, (2) worrying for one another, (3) not knowing how to support each other, (4) being open and honest and involving the children, (5) grieving differently and (6) expressing emotions.

9.2.1.1 Feeling responsible for each other

Findings showed that many child and parent participants felt immense responsibility towards the other. Parents carried a weight of responsibility as the sole caregiver to their children whilst managing everything else. Children, too, had a sense of responsibility and felt forced to grow up.

Parents and children were acutely aware of the impact of death on each other. All children spoke of ways they tried to help and do more at home, with some ensuring their actions outside the home positively impacted the family too. For example, children worked harder at school and were better behaved. Children also spoke of comforting their parents. Data from older children showed that they felt they had to take on more of a parental role at home, caring for siblings and doing things around the house.

Parents often recognised and felt guilty that their children were doing more at home, and looking after and consoling them. However, some parents realised they could not do everything independently and needed help from their children, which meant the children were growing up too soon.

9.2.1.2 Worrying for one another

Parents and children worried for each other. Parents worried about the impact of the death on their children and how that would affect them throughout their lives.

Many parents became more conscious of their own health and worried about what would happen to their children if something happened to them as the remaining parent. Some children shared this worry and feared something happening to their surviving parent or someone else close to them.

Many parents had financial worries, with most families going from two to one income. However, only a few children spoke of the financial impact on the family, worrying if they could manage on one income.

Children worried that their parent's grief would not get better, and many worried about how much responsibility they could see their parents now had.

9.2.1.3 Not knowing how to support each other

There was a sense from both parents and children that they were 'winging it', not entirely sure how they could best support the other but doing what they thought best to try and help them.

All parents admitted having no idea how to support their grieving children, and they constantly questioned if they were 'doing it right'. As a result, parents had a strong need for professional support and guidance. However, finding professional support could be difficult.

9.2.1.4 Being open and honest and involving the children

All children and parents advocated open and honest communication. However, parents acknowledged it could sometimes be difficult for them to be honest when their parental instinct was to protect their children.

Some parents were honest and open when the deceased parent was ill and felt this had helped the children cope better following the death. Other parents withheld information about the terminal illness to protect the children. Some parents were unaware that their children could sense when things were not right, or that they overheard conversations that often would only give them part of the story. One younger boy knew his family were not telling him what was really happening. He secretly listened to conversations until they eventually told him. He reflected that his mother knew her illness was incurable but she was in denial and believed she had beat the cancer and did not want to 'admit' she was dying. But then his dad and the doctor stepped in and said he needed to be told the truth. It hurt him that she lied about her terminal illness. Still, he understood she did it to protect him.

All children wanted to know what was happening. They knew conversations could be difficult to hear, but they believed that knowing the truth was less stressful and stopped them from making up worse scenarios themselves.

Children needed open, honest and detailed information during and after their parent's death. Some of the children, especially those bereaved suddenly, felt they could not begin grieving until they had understood what had happened.

Children bereaved following an expected death were grateful to be involved and informed about their parent's condition, which supports parents' decisions to be honest with children from the beginning.

Some parents and children found benefits in fostering ongoing open communication within the family, especially in how they cope individually. For example, communicating openly meant they could better support one another if they were having a bad day.

Some parents found their children did not or could not talk about it soon after the death, which echoed the child's data. Some children found it too painful to speak, not wanting to cause upset their parents or not knowing how to talk about it.

Children felt they should not be forced to talk if they were not ready. However, it would have helped some children if their parents continued to check in with how they were feeling, so they could talk when they were ready. Furthermore, when they start to speak, this should be done gently without parents forcing them to talk more than they were prepared.

9.2.1.5 Grieving differently

Both child and parent data revealed that children, siblings and parents often grieve differently within their families. Grieving differently could cause conflict in families when they do not understand how each other is feeling or coping. An example of this was between two sisters, one was comforted by the faith they shared, whilst the other found her faith made her angry.

Some participants realised that despite grieving the same person, grieving for a spouse compared to a child grieving for a parent was a completely different type of grief.

Some parents and children admitted they could not understand what the other was going through.

Within families, the child data showed there could be jealousy and sometimes what felt like a 'grief competition' between siblings, between children and their surviving parent, and among the extended family regarding how long they knew the deceased parent.

9.2.1.6 Expressing emotions

Showing and hiding emotions was something all participants described. Parents would consciously show emotions initially, often to permit their children to be upset. However, as time passed, many found that their children could not bear to see their emotions, so those parents had to find ways to manage and control their grief in front of their children.

Children found it difficult to see their parents upset, and many found a role reversal in which they were comforting their parents. As a result, many children suppressed their emotions to 'stay strong' and protect their parents or younger siblings from further upset.

Many children struggled to manage the tornado of emotions they experienced. When trying to suppress those emotions, children often feel alone. Some parents were aware of their children holding in their emotions to protect them but were unsure how best to help.

9.2.2 Support from those around

This section presents children's and parents' experiences of support from those within their existing networks. Findings are presented under four subheadings, by who was providing the support (1) family, friends and communities; (2) school; (3) bereaved peers; and (4) professional help.

9.2.2.1 Family, friends and communities

A theme emerging from the parent data related to a sense of being picked up and carried through their initial grief by their existing networks, as described by one father as the 'standard outpouring of support'. This support was invaluable and helped parents feel they were not going through this alone. Parents found that most people within their networks wanted to do what they could to help them and provided a lot of practical help, including cooking, cleaning, and childcare. Some parents had so much support that they were grateful for supporters who coordinated the support.

In comparison, children's initial supportive response came from their surviving parents. However, children did not perceive any of the support described by the parents as support for them (as children). Instead, some found those supporting their parents encouraged them to do more at home to help their parent and sibling, which added to children's feelings of responsibility and may have encouraged them to suppress their emotions. In addition, children believed that sometimes adults did not seem to recognise that although they were children, they too were grieving.

Parents and children found it helpful when they felt that other people cared about them. Participants also appreciated non-judgmental support from those around them.

Something which children – and also some parents - predominantly mentioned were their difficulties in being able to talk about their loss. Children often did not know how to bring it into a conversation and, like some parents, feared the reaction they would receive or did not want to upset others.

Children and parents also found that some people around them did not know how to support them or what to say. Death made some people awkward around them, some made inappropriate comments, and some found they were avoided. These reactions or the fear of the responses they may receive encouraged participants to suppress their emotions or, at times to hide the death, leaving them alone in their grief.

9.2.2.2 School support

Parent participants saw the school's potential in supporting them following a bereavement. However, for some children, school was their place to escape or provided a welcome distraction. They appreciated having school as a place where they did not have to think, talk or be reminded about their grief.

The data showed that schools offered no standard response or support; instead, it came down to each school or teacher. Many parents and some children experienced tremendous support from the school, but this was not the case for everyone. Parents highlighted a lack of training and understanding with some school staff around grief and bereavement, whilst other parents found that school staff were provided training to support them.

Both parents and children found that school support, like support from others, was not sustained, and their grief sometimes felt forgotten.

9.2.2.3 Bereaved peer support

All participants described the best support they received from peers with a lived experience of bereavement. For parents and children, this could be peers of a similar age who had experienced parental illness, death, or divorce. For children, this could also be adults who were bereaved of a parent when they were a child.

Meeting other bereaved people gave participants a sense that they were not alone and helped them normalise what they were feeling and experiencing. For many parents and children, seeking support from established peer groups proved beneficial. In addition, meeting people further along in their grief allowed for social comparison. It gave them hope to move forward from where they were currently, showing that grief is survivable.

Parents and children found it easier to speak with others with lived experience because they just understood, which meant they did not have to moderate what they were saying, worry about causing upset or fear the reaction they may receive.

9.2.2.4 Professional support

Regarding professional support, parents were shocked that no automatic professional support kicked in after such a significant event, which reinforced that they should be doing it alone; they need to try and find support alone. Despite being surrounded by support from their networks, parents still felt alone in supporting their children.

Parents were desperate for professional support for their children with a commonly-held belief that bereavement is an issue that requires professional help. However, to get the support, parents found that they must find it for themselves and parents and children face barriers to accessing support.

Both child and parent data showed that accessing formal support needed to be done when the individual wanted it, not at times set by services. Children often needed to feel ready to talk about their loss and their grief. For all participants to feel well supported, they needed someone they could connect with, someone who understood their situation and could support them in a non-judgmental way.

9.3 The substantive theory: 'Masking your grief – because you feel you have to' - the truth behind the mask

The conceptual model (Figure 17) was constructed to symbolise and explicate the new theory. The theory includes all the key players whom participants received support from, including support from each other, the people in their existing networks who consist of family, friends, communities, religious communities, schools and employers. This also includes professional support, which included counsellors, therapists, mental health charities and bereavement charities and services. A description of the theory is presented following the visual representation of the model.

From interviewing bereaved children and parents, it was apparent that they all had situations when they masked their grief. The reasons seemed tied to their interactions with each other and interactions with those around them in their existing networks, with a strong sense to protect others and not make them feel uncomfortable. A lack of understanding from the people around them about the impact on the longevity of grief also encouraged them to do this. As a result of masking their grief, often those around them do not see the truth behind their mask, which means support dwindles.

Before parental death children and surviving parents lived in the 'normal' world as depicted in Figure 17. Following their bereavement, they were thrust into a world they had not anticipated - a social world of grief. This was the start of their journey to realise and accept the enormity, experience the impact of their loss and learn to live new lives without the parent.

Whilst most of their existing networks joined them (as shown by the pink arrows in Figure 17), to some extent in their social world of grief, some were unable to enter this world, and remained in the 'normal' world'. Remaining in the 'normal' world possibly because of their fears about how they could or could not support the family, resulted in some people avoiding them.

When they were initially bereaved, it was acceptable for children and parents to show their grief outwardly. Some parents admitted they could not hold in their grief even if they had tried. Some children struggled to show their grief; some purposefully put a brave face on and pretended they were fine. For some, this would be the start of their learning to mask their grief.

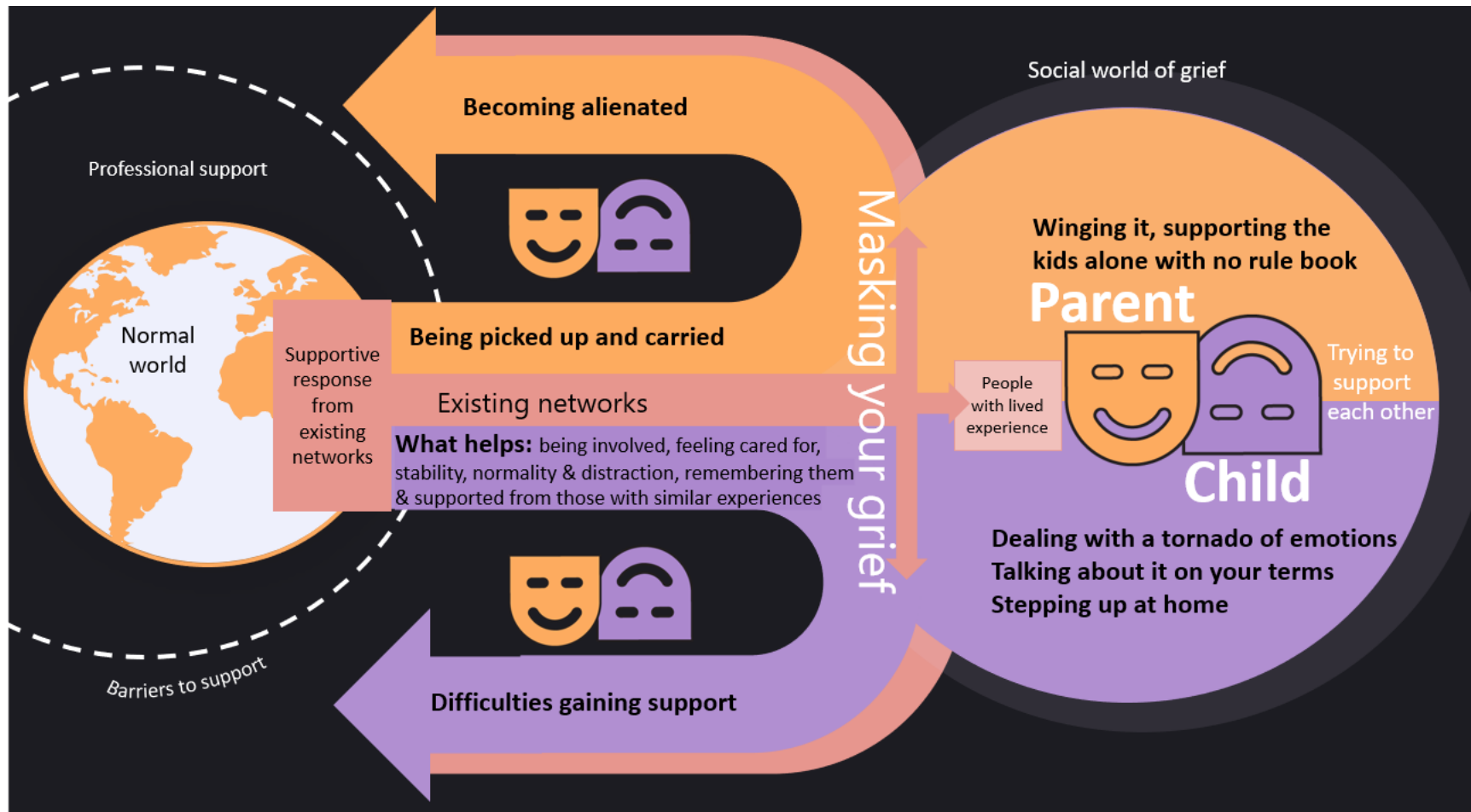


Figure 17 The substantive theory: Masking your grief - because you feel you have to

At first, their existing networks wanted to do everything they could to help them, which made parents feel they were not going through it alone. The orange arrow heading towards the social world of grief in Figure 17 shows how parents were 'being picked up and carried', which provided insight into how parents experienced good support from those around them. For parents, practical help seemed most valuable when they were newly bereaved, especially help with childcare, running the house and helping with school runs. Parents found those around them could not do enough to help. Flexibility from employers helped some parents continue to work and ease financial worries. Good school support and communication also helped parents by reassuring them that the school was there for the family and looking out for their children, again giving a sense that they were not alone.

Knowing that the people around cared about them helped both parents and children. However, children did not feel the sense of being picked up and carried as their parents did and did not mention the practical support provided to the family by their existing networks. A few children described many people being around for their parents, but they did not perceive that as support for themselves. Some children also found that some of those people encouraged them to do more for their grieving parents, making them think that those people did not understand that they were also grieving.

Instead, for children, 'what's helping', as depicted by the purple arrow entering the 'social world of grief' in Figure 17, was being involved in what was happening within their family, which included seeing their parents' body and planning and attending the funeral. Most parents involved their children; although, many questioned if they had made the right decisions. However, the children who spoke of their involvement confirmed this had been the right choice, as even when those events were hard, they were pleased to have been involved. It also helped them to have stability, normality and distraction. School and friends were also able to provide this.

Whilst in their social world of grief, children and parents had many issues to contend with, as they tried to support each other. The social world of grief as depicted in Figure 17, highlights some of the issue's parents faced in the orange section and the issues children faced in the purple section.

Child and parent participants spoke of the importance of ongoing open and honest communication. For children, it was essential that they could 'talk about it on their terms'. Children needed to be given lots of detail to understand what had happened. Parents realised that talking helped, as did children over time. Many of the children described how they struggled to talk initially because it was sometimes too upsetting even to mention their deceased parent. When they were ready to talk, they often faced challenges. They had to learn who would keep their confidence and be non-judgmental, which was also echoed by some of the parents.

All parents and children found that people around them were uncomfortable and awkward because of their loss. Moreover, both participant groups gave examples of hiding the death or refraining from speaking about it to protect themselves and others. They did not want to make other people uncomfortable; when people were awkward or uncomfortable, this made *them* feel uncomfortable. Children's main problem was knowing how to talk about it and bring it into conversation whilst fearing the reaction they would receive. Some parents also experienced this. Children found that people knowing about their loss made it much easier as they did not have the worries of having to tell them. The interactions with other people led participants to choose if they should mask their grief or not. Interestingly, many participants commented that they would not have known what to say or how to support a bereaved person before their bereavement.

For children and parents, connecting with others who had lived experience of bereavement proved supportive. Such people understood what they were going through and how they were feeling, and showed them that they could survive this. Participants also found supportive peers who had been through parental divorce or illness gave good support. People with a lived experience whom they could connect with could sit comfortably within their grief social world, and it was always easier for children and parents to talk to them.

"Winging it supporting the children" helps understand parents' feelings of being out of their depth supporting their grieving children. Their focus was on their children and worrying about the impact of parental death. Parents felt alone in supporting their grieving children. Parents often viewed bereavement as a problem that needed fixing and believed professionals were needed to fix this problem for their children. To receive professional help, parents had to seek this themselves whilst grieving, which could be a struggle. Figure

17 shows professional support behind the white dashed line, showing it is available, but it is out of reach for parents and there are barriers.

Those around them provided practical support to help parents with their children but could not provide them with solid advice or guidance on parenting a grieving child. Some found support through bereaved peers. Many parents found those around them gave advice or made judgements on a decision they made or how they should support their children. This was often unhelpful as they had not experienced parental death. Children also found that adults around them would advise how they should feel and act, encouraging them to support their parents and siblings more.

From the children's perspectives, they all found that parental death forced them to grow up; worrying about their surviving parents and finding ways of 'stepping up' to help at home. In addition, the older siblings within families often felt it was their role to look after the rest of the family and stay strong for them, which was often reinforced by those around them.

Interviewing children and surviving parents made it clear that the way they grieved and felt was often very different. Some child and parent participants realised that although they were grieving the same person, they each had a very different relationship with them. Therefore, their grief would be different. Some parents found it easier to support their children when they grieved the same way. However, both children and parents admitted occasions of feeling helpless when supporting the other.

As mentioned, 'masking their grief' was a process that both children and parents learnt about. When to wear the mask and in front of whom. In-depth probing with further interviews indicated how and why participants did this. Wearing a mask could involve pretending that they were okay, suppressing emotions, lying about or not disclosing the death to others. Mask wearing serves two main purposes: protecting yourself and others. Both parents and children did not want to make people uncomfortable, and they feared the reaction of others. They did not want to be a burden and felt others were judging them. Some parents found that those closest to them could not bear to see their grief, so they had to control it.

Parents and children often grieved openly in front of one another initially. However, after time many learnt to suppress their emotions in front of each other to protect from upsetting one another. Children had to learn to experience and 'deal with a tornado of emotions'. Often their emotions were something they managed themselves, friends did not have the experience to understand, and they did not want to upset their parents.

"there's putting the mask on, 100% everyone I think everyone who grieves does it, mum does it. My friends, always say to me, 'I don't know how you're so strong', I'm like, well I'm not, and then they are like 'you are' and I'm like well what do you want me to show you like, you know, I think people, I think other people sort of do judge you, that it's just, you know, you can't help when you get upset some times, personally, I don't get upset around other people, I like do it on my own, like just being by myself, and it took me a while, before I got upset around my friends and stuff" Charlotte (older child)

(talking about hiding parental death) *"Yes, because, like, it was someone in my class who I didn't really like, they were new...so cuz she had no clue what happened, she's like, 'should I come to your house, and I can meet your mum', I'm like you can't come to my house because I'm going out, I wasn't going out and I didn't feel comfortable at all with her coming around and my mum died"*.
James (younger child)

"you definitely feel you have to put the mask on" Ellie (mother)

Children and parents found that their grieving often had to fit in with what was socially acceptable between each other and those around them. Often the people around them and society had expectations of how long grief should last (although, having never experienced grief following parental death). This lack of understanding resulted in children and parents becoming 'alienated in their grief' and 'masking their grief', and sometimes not receiving the support they needed. As shown in the orange and purple arrows in Figure 17, which are moving back to the 'normal' world. To highlight that people most people around a bereaved

family go on part of that grief journey with them, but they decide for how long and when they should leave.

For parents when they first entered the grief world, many could not put a mask on and struggled to control their emotions. However, it was accepted by the people around them that it was acceptable to grieve. Parents made a conscious effort to show their children that it was okay to be upset. As time passed, parents realised their children could no longer bear to see their grief, so they learnt to mask it. As a result of masking their grief, the people around them perceive that they may have 'moved on' and are doing okay, so their support dwindles.

It is more acceptable to grieve openly when newly bereaved, so the mask does not need to be worn. However, as time passes, parents feel they are a burden and must wear the mask. As they continue and survive their new lives, people only see the mask; they do not see the truth behind it. Therefore, they assume they are 'over it' and no longer need their support.

On the other hand, some children struggled to show emotions and wore masks, but for the people looking in, they appeared fine and not affected by the death. One child actively pretended she was okay. Children appeared more sensitive to wearing the mask and whom they should wear it in front of.

Some children wore a mask in school and grieved at home. For others, it was the other way; they had a mask at home and grieved at school. A few older children seemingly wore their masks most of the time unless they were alone.

Moving the data beyond description towards analytical interpretation, 'Masking your grief – because you feel you have to' provides helpful insights into how children and parents manage their grief with each other and those around them. The study sought to explore families' experiences of support from each other and those in their existing networks, the participants highlighted a strong need for professional support; therefore, it was necessary to highlight those findings.

To conclude, it is socially acceptable to grieve when newly bereaved, and most people take a step with a bereaved person into the social world of grief. However, as time passes, other people's lives continue, and the bereavement is no longer at the forefront of their minds.

After some time has passed, there is often an expectation that they will be 'over it' or have moved on. The interactions with those around the bereaved make them learn to control their grief, what they can and cannot show to each other and the outside world and what must be kept inside. Masking grief is unique to everyone, and participants do this in front of different people at different times. Participants masked their grief to fit in and protect others, yet by masking their grief, they (inaccurately) showed others that they were okay, resulting in dwindling support.

9.4 Summary

This chapter provides a novel integration of findings from child and parent data sets exploring their experiences of support in the context of them alone, together and within their communities. The integration of findings allowed the development of a theory of how children and parents are supported following parental death. The theory, 'masking your grief - because you feel you have to', provides an innovative contribution which has allowed the construction of a model which describes the major social processes of support experiences for children and surviving parents following parental death.

The following chapter discusses the new theory in the context of existing research and theories.

10 Discussion

10.1 Introduction

The overall aim of this study was to explore how children and families best support each other after a parent's death and to understand how those within their existing networks can provide a supportive response. This final chapter concludes this PhD thesis by firstly discussing the key findings from the child and parent data. The next sections discuss the contributions of this thesis, including the substantive theory constructed in the study. The final sections evaluate this grounded theory study, highlighting its strengths and limitations, and the thesis conclusion ends this thesis.

10.2 Thesis summary

The study began with a systematic review, which identified, and synthesised the published evidence of support experiences for bereaved families (findings are presented in Chapter 4); this aided the qualitative study design.

The qualitative study used constructivist grounded theory to collect qualitative data by conducting virtual, in-depth interviews. 17 parents and 11 of their children participated in the study (Chapters 7, 8 and 9 present findings from their qualitative interviews).

Concurrent data collection and constant comparative analysis were used throughout the study. Data analysis followed the constructivist grounded theory process of initial, focused and theoretical coding, resulting in the construction of a substantive theory, 'masking your grief - because you feel you have to', which explains the social processes involved with support experiences for bereaved families.

10.3 Discussion of findings

A key finding from this study is that grief is often socially constructed and is affected by the social interactions children and parents have with each other and those around them.

Throughout this discussion, the term 'participants' refers to data representative of child and parent findings. The findings are discussed under two headings, bringing together the different aspects of *supporting each other* and *support from those around*. The construction of these headings is depicted in Table 21.

Table 21 Construction of the discussion headings

Supporting each other	Feeling responsible
	Being open and honest and involving the children
	Expressing emotions
Support from those around	Family, friends and community support
	School support
	Employers support
	Bereaved peer support
	Professional support
	The impact of Covid on support

10.3.1 Supporting each other

10.3.1.1 Feeling responsible

Although participant data highlighted the individuality of grief, it is essential to acknowledge and understand the impact of a death on the family, with participants responding differently to their loss. These individual responses affected their relationships and how they supported each other. For example, parents felt a responsibility to support their children. Likewise, children felt the responsibility to support their parents and siblings.

Family Systems Theory, as discussed in Chapter 2, recognises the critical role family plays in emotional and physical wellbeing²⁸⁶ and is helpful to understand my findings of how children and parents interact and support one another. This theory of human behaviour, developed by Bowen²⁸⁷, views the family as an emotional unit. Systems thinking describes the complex interactions within a family, which are emotionally connected and reactive to each other. A family's functioning is interdependent on the family members—a change in one family member's functioning results in reciprocal changes to the others²⁸⁷. The findings from my study showed how children and parents adapted to meet the needs of the other and how challenging this can be for them. Bowen found that death affected a family's functional equilibrium²⁸⁶. My findings support this and highlight the loss of equilibrium within families, with one child using the words 'in -equilibrium' to describe the changes he felt in his family.

My findings showed the imbalance and instability in families following their loss, leading to children having a sense of responsibility to take on extra roles within their families and parents taking on roles previously fulfilled by the other parent. A similar study by Afifi et al.²⁸⁸ found that in post-divorce families, children took on roles within the household to protect their parents from role burden. The systematic review (Chapter 4) highlighted the gap children were trying to fill in their families following their loss²⁸⁹. Similarly, a study of children living with parental illness found they felt a sense of obligation and responsibility to look after the family¹². Parental death requires families to adjust to more than the loss itself. Therefore, it is essential to recognise the roles and responsibilities that change within families. In my study, the older male and female children felt more responsibility for their parents and families, contradicting findings from a study by Jiao et al.⁷⁷, that suggests that the caregiving role is assumed more by surviving daughters due to social gender role expectations⁷⁷. Findings from my study suggested it was more related to them being the eldest sibling rather than a gender expectation.

For parent participants, their children gave a reason for them to continue, and they 'put everything' into their children. A similar study by Hanna et al.¹⁵ reported that parents need to 'get it right' for their children when a parent has a terminal illness. My findings resonate with this. They highlighted that putting everything into the children meant some parents neglected their own needs, and might also have misunderstood or misinterpreted the needs of their children. Hanna et al.¹⁵ recommended that professionals encourage parents to practice self-care and embrace rather than suppress their grief. This need is also illustrated in my findings.

Furthermore, parents should be encouraged to explore with their children what support they need, with the understanding that their children's needs may differ from their own. For example, my findings show that children worry about their surviving parents and want to be involved and support them. Therefore, parents must be honest with their children about how they are really coping and feeling, and suggest ways that their children can support them. Doing so will model to their children, help them learn more about grieving, feel more secure and in turn, ensure their parents are in the best position to support them.

10.3.1.2 Not knowing how

My findings contradict the public health model of bereavement support^{31,56,92,290}. As discussed in Chapter 2, the model takes a public health approach, recommending a tiered approach to different types of support in recognition of the differing needs of bereaved people^{31,56,92,290}. This model suggests that 60% of bereaved people deal with their grief without formal interventions, with only the support of family and friends^{22,58,92}, whilst 30% will have moderate needs requiring non-specialist structured support^{22,58,92}. The remaining 10% will require specialist mental health interventions, and this group is at risk of prolonged grief disorder^{22,58,92}. My findings from the parents' perspective disagree with this percentage as all parents had a need to seek professional support. However, research has shown that grieving for a spouse and 'out-of-time deaths' are known to increase the risk factors for developing more complex grief that may require specialist intervention²². This could explain why the parent participants needed a supportive response from the people around them, and in addition, they also needed professional support and guidance to enable them to support their grieving children. This contradiction has recently been reported by a study with adults bereaved in the pandemic; most felt they needed additional support, with only 29% (n=207) of their sample believing they had adequate support from their networks²⁹¹. Findings from my study also validate Aoun's²⁹² predicted increase in the needs of bereaved people post-pandemic, estimating only 30% of bereaved people will deal with their grief with only support from family and friends, the rest needing some form of formal support. Despite this claim, currently within the UK, most bereaved people neither automatically receive support, with such support also neither easily accessible or widely advertised, as my study and others have highlighted^{3,291}.

Previously little was known about why some parents accept help from services for their child whilst others decline²⁶. Most parents in my study viewed bereavement as a problem which required solving. It identified that parents felt it was essential they had professional help, if only to advise them on what support was available and give them reassurance and confidence in how best to support their children. Again, my findings highlight that the first tier of the public health model approach to bereavement support does not apply to parents supporting their parentally bereaved children.

My findings also shed light on why support is not accessed. First and foremost, parents often lack information about services or find nothing available in their area. In contrast, some parents felt overwhelmed with the different types of support available and did not know which was best. Other reasons for not accessing support were because the timing or location was unsuitable to the family's needs. Also, the perceptions some participants had about what professional support would be like.

Some parents faced long waiting lists to access support. Also, after speaking with professionals, they were made to feel other bereaved children were in a far worse situation than their own, leading some to decline support, thinking other children needed the limited resources more. Some participants started receiving support but quickly stopped if they did not connect with the person offering the support or felt they did not understand their situation. For some, this short encounter cemented that 'counselling' was not for them; they were not offered counselling by a different practitioner. However, a few participants thought it essential for bereaved people to be told if the counselling does not work the first time, they should try with someone different until they can get that connection, but services did not advertise this.

Seeking support was challenging whilst grieving, which supports a recent study by Selman et al.¹¹⁶. This highlights that nearly half of their bereaved sample was not provided with information about bereavement support services. The findings from mine and previous studies support the need for better ongoing signposting to support services. Crucially those services must reach out to bereaved families soon after the death and also follow up later in their grief^{3,116}.

10.3.1.3 Being open and honest and involving the children

Parents withholding information from their children about parental illness and death was highlighted in the systematic review²⁸⁹ and found in other studies. This was often caused by fear and anxiety from parents trying to protect the children^{13,19,77}. For example, a seminal study on coping behaviours described this as 'protective buffering'²⁹³(p. 134), which involves withholding information from others to protect them from distress²⁹³. Protective buffering is a widely used coping strategy among people who are chronically ill²⁹⁴ or bereaved^{13,19,289} and is often associated with increased psychological distress for the protector and the protected²⁹³.

Most of the child data alleviate the worries identified by parents. My findings support the consensus within the literature of encouraging parents and families to have open and honest communication with children before and after parental death^{11,18,19,289,295,296}. Child data echoes similar studies highlighting the importance of the quality and quantity of information; children knowing about pending parental death helped them understand and manage the situation^{11,14,19,297}. Previous research has identified that poor communication with the surviving parent is associated with increased anxiety and depression²⁹⁸ and poorer adjustment for bereaved children²⁹⁹. The surviving parents' emotional and physical availability can also affect the child's adjustment⁷, which may lead to inappropriately matched support, as was found in my study.

Child data also offers reassurance to parents that despite their worries and difficulties around being open and honest about parental illness and death, it is vital for the children's understanding and acceptance and aids their grieving. My findings support previous studies that found it can be more stressful for children not to know, and the truth they imagine can be worse than the reality^{14,73}. Children in my study also spoke of the importance of detail in the information they were given; for many, the more detail they received, the easier it was to accept and understand.

Both parent and child data supported the need to involve children and give them a choice in what was happening within the family—often starting with viewing the body and planning and attending the funeral. A study by Søvting et al.²⁹⁷ found that when children were included they felt they were a 'full' member of the family and their grief was legitimised. Evidence suggests that when a parent is dying, children should be empowered and given agency; they are not passive; they develop strategies to cope and want to be involved^{11,19,38}.

However, in my study, many parents found it challenging to make decisions about involving their children and found little advice or support about this. As a result, even many years later, they questioned if they had made the right decision to involve the children. However, child data in my study add to the limited evidence surrounding the importance of including children in funerals³⁰⁰. The children did not voice any regret about attending, which supports the findings from the systematic review²⁸⁹. Funerals allowed children to say goodbye and feel part of what was happening, and their grief was validated. It helped them accept their new reality. This echoes similar findings from children and adults bereaved as

children who felt attending their parent's funeral had been a positive and helpful event, allowing them to feel important and useful in the family, with no reports of negative consequences^{7,300}.

Holland's study³⁰⁰ found that children excluded from the funeral are more likely to feel regret, anger, hurt, isolated and frustrated. Children are usually excluded as decided by their parents, who act in their child's best interest but without consultation^{7,300}, as was the case for one family in my study. Parents within my study and others have shown the need for reassurance and guidance concerning children's involvement¹⁷. Studies have identified funeral directors as being well-placed to offer this support¹⁷. Only two parents in my study mentioned such support. In contrast, one parent felt that her funeral director was not supportive of her decision to allow her children to view the body, supporting findings from a recent study by Hanna et al.¹⁷. This involved funeral directors, with many not perceiving it within their role to offer support to families with dependent children. These funeral directors feared causing more distress, and despite many believing children should be involved with funeral plans, only some actively encouraged parents to involve them¹⁷. As with other types of support in my study, support from funeral directors is variable, with some more involved with supporting families than others¹⁷. My findings support other studies advocating for children's involvement with funeral plans, being given adequate preparation of what to expect, and highlighting the role funeral directors can have in supporting parents with this preparation^{16,300}.

10.3.1.4 Expressing emotions

Parents and children suppressing emotions or not talking about it to protect their children is not a new finding in my study. It was identified in the systematic review and has been reported previously^{11,15,70,289,295,301}. In addition, research suggests that it is helpful for parents to show emotions in front of their children^{11,15,295,302}.

However, my findings begin to show how the surviving parent's grieving process can affect their children, which has not been answered in the current literature. My findings suggest that parents initially try to show their emotions, doing what they think is correct for their children. However, as time passes, they find their children cannot bear to see their emotions, forcing parents to adapt how they grieve and suppress and control the amount of emotion they share. Such protection can be accounted for with empathic avoidance¹⁶³

(p.105). This is a term previously identified to describe bereaved children's concern for the emotions of their peers, which encouraged avoidance rather than support for their grief¹⁶³. A study by LaFreniere et al.¹⁶³ found children used empathic avoidance because they did not want to cause distress or make peers uncomfortable. Children in my study confirmed that empathic avoidance is a common occurrence and was evident through interactions with their peers.

In my study, many parents and children also showed empathic avoidance of each other, which can foster avoidance or an evasion of what is happening instead of supporting one another. A recent Australian study following a familial death from cancer found bereaved children and young people reported unmet psychosocial needs, which were associated with their levels of psychological distress³⁰³. The highest unmet needs were reported as 'support from other young people' and 'time out and recreation'³⁰³. Findings from my study provide evidence that children in the UK also want, but do not always get, support from other young people (although time out and recreation were not reported as unmet needs).

The older siblings in my study tried to stay strong to protect and comfort their surviving parents and siblings. Other research has found that children sometimes turn to siblings for support rather than burden their parents²⁹⁵. A previous study found mothers turning to their adolescent children for support with their grief³⁰⁴. This was seen with some of the mothers in my study. It is essential to be mindful of older siblings' responsibilities and pressures.

Protective buffering, the withholding of information from others to protect them from distress²⁹³, and staying strong were common occurrences observed between children and their parents, and children and their siblings. People in their networks can enforce this by telling or praising children and parents for being strong. This can shut down support by saying, 'you are doing really good, keep it up'. People do not seem to realise they are coping because they must and then faking it because that is what people want to hear; they want to hear that the bereaved individuals are fine. As a result, participants mask their grief.

A study undertaken more than 20 years ago by Harrison et al.²⁹ found that 87% of bereaved children had never or rarely talked about the deaths they had experienced. Findings from

my study have shown that children are still struggling to talk about death and can begin to explain why children do not speak about a death and mask their grief.

My participants masked their grief for many reasons: fear of others' reactions, not knowing how to bring it up in conversations, and the consequences of others knowing might be held against them. People would not want to be their friends. They saw it made others uncomfortable and did not want to do that. They saw that the people closest to them struggled to see their grief. If people did not understand, it was hard to be honest because they just did not get it. Participants knew they will always have bad grief days, and that can make them feel a burden. People said things that did not help, advising on situations they have not been in and comparing their different grief, which is just a reminder of how much they do not understand. Parents also worried it could affect their own career development or leave them trapped in their workplace, so some kept their loss and grief to themselves.

However, my participants found there are people they can be with and let down their grief mask. This may happen between children and parents, between siblings or close friends, or what was most mentioned was with other people who have been bereaved. They understand, so they did not have to worry about their reaction; because they 'get it'.

10.3.2 Support from those around

This section discusses the experiences and perspectives of the support needs for children and parents when their existing networks provided support. The support families received is considered in terms of who was providing it, including family, friends and communities, schools, employers, bereaved peers and professionals.

10.3.2.1 Family, friends and community support

When the death happened, parents found it acceptable to grieve. People rallied around and tried to help however they could, which was invaluable in helping surviving parents cope. However, some parents found the amount of support overwhelming. Within communities, connections are often strongest during illness, death and grief¹, as found in my study. Nevertheless, despite an immense amount of support from those around them, most parents felt alone in supporting their children. This reflects a study by Hanna et al.¹⁵, who found parents maximised social networks to help with the practical aspects of parenting but felt intense loneliness parenting alone.

As mentioned, most parents in my study believed they needed professional support for their children. Currently, professional and network support (friends, family, communities) work in isolation from the other¹. A recent report suggests professionals and existing networks should work as equals to create an explicit network around a bereaved person¹. Findings from my study would support this.

Coping with a stressful life event has been described as a social process³⁰⁵. Communal coping is used to describe the coming together of resources, families and communities to manage distressing events³⁰⁵. A death activates the communal coping process, attempting to make this 'our problem and responsibility' instead of something managed alone³⁰⁵. Examples are seen in my study when parents felt those around picked them up and carried them, providing practical help to try and share the load and make them feel they were not facing this alone. Parents also saw how the death affected others within their networks. Communal coping was also seen when social network members communicated with and arranged supporters.

Communal coping is said to enhance the wellbeing of relationships, and improve coping, psychological and physical health in stressful situations^{306,307}, as was seen with my participants. However, there can be a cost to communal coping, which could limit the bereaved individual's adaption. Furthermore, the distress of the bereaved can force the supporters into a sustained confrontation with the bereavement, which may mean supporters need to distance themselves and require respite³⁰⁵. My findings showed that some supporters could not bear to see their grief, which could be the effects of communal coping.

Evidence suggests women are more likely to engage with communal coping³⁰⁵. Conversely, men try to hide vulnerability and weakness, and will try and deal with the problem alone and not seek help from their network³⁰⁵. However, findings from my study contradict this understanding, as all the fathers in the study sought and accepted support from their networks and some sought professional help in the form of counselling.

As time passes, the people around the bereaved families who have not been through it, decide when that support stops. For some participants, this happened after the funeral. For others, it was around a year later when others believed they have done the 'firsts' of

everything, such as significant dates and anniversaries. The data show that many timelines were imposed by others, even professionals, regarding when they can access support and for how long. A recent study with bereaved adults found a decline in the initial support they received from social networks after some months²⁹¹.

It has been argued that society polices bereavement by instructing the bereaved in how they think, feel and behave³⁰⁸. There was a sense from my participants that they entered a 'social world of grief', which made some people uncomfortable. The way they experienced grief inside and presented it outwardly was often shaped by the social construction of grief, influenced mainly by the expectations and reactions of those around them. My findings support the argument that dying, death and bereavement do not occur in a social vacuum; they are influenced by the social and cultural contexts in which they occur^{99,101}. Together with my study's findings, we are beginning to understand that those within a bereaved person's network have a great influence over how the person deals with their loss and grieve^{5,101}

Sociological concepts are crucial to understanding participants' experiences. For example, anomie is a social concept used to describe a state of normlessness. This can describe situations that occur, such as bereavement, which leave people feeling lost; their normal patterns of behaviour are no longer acceptable, and they must find new ones^{99,309}.

Many participants described instances of alienation. Doka's concept of disenfranchised grief provides an example of alienation insofar as instances of disenfranchisement separate the griever from the usual sources of social support that people receive in normal circumstances^{310,311}. Doka coined the term disenfranchised grief, which refers to grief that does not fit with society's attitude about dealing with loss. It is a feeling of loss that the bereaved person does not feel entitled to, and is not understood^{310,311}. In my study, two mothers bereaved by suicide which they viewed as their husbands' actions, felt undeserving of support because of how their husbands died, a classic form of disenfranchised grief³¹¹.

Surprisingly, my findings suggest that most participants experienced a form of disenfranchised grief, or rather a feeling that their grief was not understood or fitting with society's attitudes of how grief should be. This led them to hide or suppress their grief, which in turn led to support dwindling.

My findings showed that grief was culturally contingent. Previous work identifies contingent factors influencing how individuals process grief, including historical, personal, social and cultural conditions³¹².

There is a suggestion that stage models of grief have shaped our understanding of an appropriate way to grieve and for how long⁹⁹. However, my findings highlight an expectation from others surrounding the timeline of grief. Similar findings have been reported^{15,291}. It is beyond the scope of this study to suggest whether stage models of grief have contributed to that understanding.

Parents are living for their children and getting through each day, but to outsiders looking in, they are seen as functioning. They may even see them happy and laughing and think they are 'over it' or 'moving on'. However, parents described how those people saw their mask, and they do not see what goes on at home and the impact of the death across their entire, ongoing lives. Children's grief is initially experienced by them as a child, but it will not end, it will continue to resurface throughout their adult lives. Surviving parents and those within their networks must continue to offer support and compassion over the years¹⁶⁵. Findings from my study highlight the absolute need for such ongoing support.

That initial understanding, flexibility and allowances start to tail off as well; this is seen in the workplace and in schools. There is an assumption that the further away from the loss, the affect is not so much. Possibly others feel they grieve for a certain period of time and then move on, which is seen when parents are asked about dating again. Not everyone can move on, and rather than a period to grieve, grief never goes away; they learn to live with it.

The misunderstandings people had about the impact and longevity of grief when they have no personal experience can be described with Tonkin's model of growing around your grief¹³⁵. Tonkin's model suggests grief does not go away, and it is something that a bereaved person learns to live with and grow around. However, there is a misconception that grief is something that grows smaller over time¹³⁵.

Findings from my study resonate with Tonkin's model, with my participants understanding that grief does not go away, it is something they learn to live with. My participants also found that the people around them believe that the grief becomes smaller as time passes. My findings can add to Tonkin's model. They show the misconception that grief gets smaller

over time is a reason why the support dwindles and why people have expectations of the bereaved to 'move on' or 'be over their grief' after a certain amount of time. Another explanation and something worthy of consideration is how long support is sustainable for other people. Supporters may feel an emotional cost to continuing, as some parents described how close family members were struggling to see their pain. Furthermore, there may be a perception that encouraging a person to grieve could encourage them to prolong their pain.

My findings also add to Tonkin's model about why those with lived experience can be so supportive of a bereaved person. Having experienced grief, they can understand and model that grief does not go away. They understand bereaved people grow around their grief¹³⁵. In addition, for bereaved people to meet others who are further along in their grief shows them that their grief is survivable.

Some children in my study found their grief was not recognised or acknowledged, sometimes by those within their networks. This supports a recent UK study in which some young people experienced a hierarchy of grief that did not help them and meant others did not recognise or validate their feelings and experiences³. A previous study with adolescents reported that their intense grief was underestimated by their parents, teachers and other adults³⁰⁴. Sjøfting et al.²⁹⁷ found that including children in the death rituals helped them be recognised as grievers like the adults around them.

A new finding to emerge from my study was children voicing their struggles of being able to talk about 'it'. Initially, the reason for many children was that they were too upset or it was too difficult to articulate. However, as time passed, there continued to be situations where children could not talk about it, meaning they often carried their grief alone. Other research has found that boys were less comfortable sharing their feelings and talking to peers about parental death³¹³. To contradict these findings, although one adolescent boy in my study did not want or receive peer support, another boy the same age was desperate to speak to a peer. Again, highlighting the individuality of support needs.

Children admitted they did not know how to bring 'it' into a conversation. They feared the reactions they would receive from others or worried about the emotional impact of their grief on others. As a result, they sometimes hide their loss and emotions to protect

themselves and others. Similar studies found children kept their sadness private due to the fear of the impact on others^{3,12}.

The UK Commission on Bereavement³ found a dominant theme for bereaved people around persistent emotional pain and its impact on mental health. For some adults, their pain worsened as time passed because they were expected to move on³. Children in the study found it unhelpful when support was reduced over time or there was an expectation they would 'get over it'. This was also found with some of my participants who, after a time, 'crashed and burned'. Furthermore, many child and parent participants experienced an expectation from others to have moved on. This was hard when they realised their grief would never go away and was something they would always have to live with.

The taboo around death was a constant theme throughout parent and child data. Many spoke of the taboo they had experienced, people avoiding them, being uncomfortable, lacking an understanding of the impact and longevity of grief and not knowing how to support them. All of these experiences created barriers to receiving support. Similar findings are echoed, including a lack of understanding and empathy from social networks following bereavement^{3,291}. Ongoing taboos surround dying, death and bereavement, a lack of understanding of grief and its longevity, not being aware of how to support a bereaved person, a stigma surrounding specific causes of death, and disparities regionally in community initiatives³.

10.3.2.2 School support

Children spend most of their time in a school setting. However, my findings suggest that teachers, like parents and health professionals, feel ill-equipped to speak to children about death, which can constrain children's emotions³¹⁴⁻³¹⁶. As parents in my study struggled to know how best to support their children, similar findings have been reported by teachers³¹⁴. Furthermore, a UK study with school staff highlighted the negative impact on their own emotional wellbeing when providing support to a bereaved child³¹⁷.

Many of my participants cited schools, teachers and peers as good sources of support. Research found that school-based sources of social support can reduce grief and promote growth for bereaved siblings³¹⁸. Peer support provides a vital role for children in the context

of parental bereavement. It could be invaluable when a child's family system is bereaved and may struggle to provide effective support³¹⁹.

The initial response from a school can also reduce the adverse effects of parental bereavement³²⁰, and teachers can provide timely and continued support to bereaved children²⁹⁹. Additionally, teachers, friends and peers providing support can lessen the impact of a lack of support from the surviving parents who are grieving themselves³¹⁸.

Some parents found that the schools their children attended ensured staff had bereavement training, for which they were grateful. However, this was often a 'knee-jerk' reaction to hearing the news of a terminally ill parent or following a sudden parental death. In addition, not all schools had bereavement policies in place. Similar findings have been reported despite the positive impact they can provide in supporting bereaved families^{316,321}. Training around bereavement, loss and emotions should be mandatory for anyone whose job role may bring them into contact with a bereaved child and family.

Parents felt reassured when they had good communication and updates from the school. They appreciated teachers 'checking-in' with how the child was coping. Similar findings have been reported¹⁵.

Those supporting a bereaved child and their parent must understand that they do not need to move on and get over their grief. Instead, they need to understand that their role is to support these families through an ongoing journey of processing their grief^{7,15,315}

It must also be recognised that teachers, like other professionals, experience an emotional burden when supporting bereaved children. Therefore, when encouraging teachers to provide support, support must be in place for the supporters. Previously teachers have expressed support from colleagues as a helpful factor when dealing with bereavement³¹⁴.

10.3.2.3 Employers support

Employers varied in the quality and amount of support they provided. Parents appreciated the flexibility. However, parent data highlight the need for greater awareness of bereavement within the workplace. My findings call for policies to be in place to better support families to manage their employment whilst grieving and experiencing such a life-changing event. Findings support a study highlighting problems in the work place for

bereaved people, including perceived insensitivity and a lack of compassion and understanding from others³²².

10.3.2.4 Bereaved peer support

Parents and children often voiced that it was difficult for others to understand if they had not experienced such a bereavement. A recent UK study found a widespread perception that people could not understand the loss of someone important without first-hand experience. It led to a barrier to empathy and increased feelings of loneliness³.

My findings highlight the benefits of bereaved peer support in reducing isolation, loneliness and feeling different. They demonstrate that people with lived experience of bereavement, illness or parental divorce could comfortably support families within their social world of grief. As opposed to many people around them who had no idea of the impact of the death on the family or could not cope with their grief. Similar research found that meeting others with a similar experience gave children and parents hope for the future, normalise their experiences and reduced loneliness and isolation^{15,303}.

10.3.2.5 Professional support

Parents expected a professional to reach out to offer support. However, they found they had to seek support themselves. A similar finding reported disappointment from bereaved people around not being offered support³. The perceived lack of professional support in my study left some parents in disbelief. Before and immediately following their children's birth, they had automatically received support from midwives and health visitors, offering a universal service centred around child health promotion and the wellbeing of the family³²³. After the death of a parent, children did not receive any automatic support, which 'made no sense' to parents in my study. A similar study reported a lack of coordination in support for parentally bereaved families¹¹⁰.

Several studies have identified the relationship and closeness to the deceased to be linked to higher levels of grief and support needs^{22,116,324,325}. For many people, the relationship between parent and child or parent and partner will be the most important and close of all their relationships. My findings recommend that the death of a parent should automatically identify the potential for that family to have higher levels of grief and support needs that should receive ongoing assessment from professionals.

Studies with adults bereaved during the pandemic found that those who received support from health care professionals immediately after the death had more positive bereavement outcomes^{116,326}. This highlights the importance of compassionate care, timely communication and support around the time of the death³²⁶. My findings suggest that parents would welcome and benefit from such support following the death

My findings also showed a lack of good quality, appropriate and available services forcing some parents to pay for professional support, as has been found in similar studies⁷⁰. My data were collected nationally and highlight considerable inequities in support provision throughout the UK.

My data from parents reported a lack of information, signposting to services, and no follow-up from professionals. This created a barrier to parents accessing support. Similar findings have recently been reported in literature with bereaved adults^{1,3,116,291}. Furthermore, bereavement services have recognised that some groups would benefit from their services yet do not know how to access them³²⁷. They acknowledge the need for a more proactive approach with better information and signposting, but that is a challenge for them³.

When a parent dies, bereaved families are in crisis. An understanding of crisis management processes could be used by services to better support bereaved families. Effective crisis responses require certain processes, including cognition, communication, coordination and control³²⁸. Adapting these processes to support parentally bereaved children would require parents to have the cognition to recognise the potential risks and potential consequences of their children's grief³²⁸. Communication is needed with parents, children, and bereavement services, including clear, concise, and timely information³²⁸. Following this, crisis coordination would involve the exchange of information surrounding a bereaved child and mobilising resources to support them³²⁸. Finally, control would be maintained by shared knowledge, the development of supporting skills and adjusting to meet the ongoing needs of the child³²⁸.

Many parents suggested that a professional supporting them from the start would have been beneficial. Most importantly, this would help parents best support their children and navigate the demanding tasks and processes they must follow. A systematic review reported how parents could influence their children's adjustment to loss through parenting,

communication, and coping strategies⁷⁷. A study in 2012 found parents were unaware of how to support their children and highlighted their own support to be able to support their children was a priority⁶⁰. Despite this, findings from my study suggest there have been no change in how parents are supported, and they still desperately need guidance in knowing how to support their children.

Both children and parents were reassured that formal support would always be available. It is likely that knowing that support was there reassured them that their grief was normal and to be expected.

Findings highlight that these parents feel alone in supporting their bereaved children, and they need professional support themselves to be able to support their children. Providing such support will likely be sufficient for their children. However, because of a lack of information and professional advice, many parents desperately seek professional support for their children.

Evidence has shown that when a parent with dependent children is coming to their end of life, professionals feel uncomfortable, some believe it is not their role to support children, they fear making the situation worse or not being able to manage an emotionally charged situation. All those factors impact the way families are supported and highlights a training need³²⁹. Another suggestion for why professional support is not automatically in place or why there can be a lack of support could be that parental death is not recognised as an adverse childhood experience (ACE).

ACE is a term originating from a ground-breaking study to describe potentially traumatic events that children experience, which can have long-lasting negative effects on health and well-being^{330,331}. In their original study (n=13,494), ACEs referred to adversity children faced in their home environments, including physical and emotional abuse, neglect and household dysfunction³³¹. The study found that ACEs are commonly experienced and can lead to an increased risk of poor outcomes in later life, such as the increased risk of heart disease, diabetes, obesity, depression, substance abuse, smoking, poor academic achievement, time off work and early death³³¹. The ACEs concept highlight the vulnerability of children affected by an ACE and provide an understanding of how childhood experiences can affect them in

later life³³². Furthermore, the ACEs framework allows for development of trauma-informed practice and responses that are recognised internationally³³²

Parental divorce is identified as an ACE, yet parental bereavement is not³³¹. A recent NIHR report also failed to identify childhood parental death as an ACE. Instead, the report described ACEs as highly stressful events experienced by children, which they outlined according to an overview provided by Public Health Scotland³³³ as depicted in Table 22.

Table 22 Overview of adverse childhood experiences, from Public Health Scotland³³³

Overview of adverse childhood experiences
<ul style="list-style-type: none">• Domestic violence• Parental abandonment through separation or divorce• A parent with a mental health condition• Being the victim of abuse (physical, sexual and/or emotional)• Being the victim of neglect (physical and emotional)• A member of the household being in prison• Growing up in a household in which there are adults experiencing alcohol and drug use problems

The Centers for Disease Control and Prevention (CDC) in America have recognised that ACEs can take many forms. They highlight that parental death is a childhood adversity which can cause a traumatic experience that can negatively impact health and wellbeing³³⁴. A more recent UK study defined household adversity where a parent or guardian had died to be an ACE³³⁵. Findings from the current study provide strong evidence that parental death should be recognised as an ACE, and several parent participants spoke of parental death as an ACE. The NIHR acknowledges the complexities of caring for children with ACEs³³⁶. Furthermore, children affected by ACEs require support from health and social care services that are helpful and acceptable to their needs³³⁶. Recognising parental death as an ACE could lead to a better understanding and support for bereaved children and the surviving parents.

10.3.3 The impact of Covid on support

For some families bereaved around the Covid-19 pandemic, additional challenges were identified in the way they were supported. When lockdowns were in place, many families were isolated and unable to receive the usual informal, face-to-face support from their existing networks. Similar findings have been reported in the literature^{116,291}. Mourning practices had to be adapted with limits on the number of people who could attend any gathering. Children could not attend school, felt isolated from their friends and found this disrupted their grieving. Disrupted grieving was reported with adults bereaved during the pandemic²⁹¹. Moreover, professional support became limited with greater demand, and a switch to virtual or telephone support did not always meet the needs of families. Supporting evidence that online support can be more accessible for some groups but also exclude others, especially young children or parents with childcare responsibilities³²⁷.

10.4 Evaluating this grounded theory research

Charmaz suggests that the strength of a grounded theory study can be assessed by the study's originality, significance, usefulness and relevance²²². A key strength of this study is attributed to using the grounded theory processes to maintain methodological rigour. The following section evaluates the grounded theory of this study, firstly using the criteria suggested by Charmaz, followed by Birks and Mills suggested criteria for evaluating quality in grounded theory studies.

10.4.1 Credibility

The theory's credibility derives from methodological rigour and the researcher's reflexivity. Charmaz describes credibility as beginning with having sufficient data, asking incisive questions, making systematic comparisons and developing a thorough analysis^{222,246}. Strong reflexivity throughout the process is crucial²⁴⁶ to gain 'methodological self-consciousness' by identifying ourselves in the research process and ensuring our beliefs do not enter the research in ways we would not usually realise³³⁷.

Throughout the thesis, rigour has been demonstrated. Several strategies were employed to achieve credibility, including ongoing reflexivity, awareness of positionality and member checking (as discussed in Chapters 5, and 6).

The in-depth interviews allowed the researcher to explore emerging concepts further in subsequent interviews using theoretical sampling. In addition, concurrent data collection and analysis allowed the checking of emerging categories against data collected from participants. This ensured the emerging theory was representative of the views and experiences of participants.

Credibility is said to be enhanced when participants guide the interview process³³⁸. The initial interviews stayed closely aligned with the topic guide until I developed confidence in interviewing participants. Following this, the topic guide served as a checklist to be used as needed during the interview. I told participants that although I had questions I would ask them, they would guide what we spoke about and what was important to them. Concepts introduced by participants were used to develop interviews³³⁸. Following each interview's initial coding, the topic guide was continuously reviewed and revised to incorporate new concepts to explore in subsequent interviews. When formulating the theory, credibility can be enhanced using participants' words³³⁸. I used participants' language throughout the coding processes to ensure participants' experiences and meanings were upheld^{237,338}.

An example is the category 'winging it', which came from participants and was also used as a concept to explore in the interviews. Follow-up interviews and member checking allowed verification and elaboration of the findings with PPI members and participants. These provided opportunities for the researcher to ask follow-up questions to assist in developing the emerging theory, and ensure the developed categories were saturated. Alongside member checking, findings have been discussed with professionals in the field who have indicated the study's relevance and theory.

10.4.2 Originality

Originality refers to creating fresh and new categories and insights which provide an original conceptual representation of the data²²². This study makes several original contributions to knowledge, offering new insights into bereavement support for children and surviving parents. This will be discussed in further detail in the following section.

The systematic review (Chapter 4) highlighted the lack of studies involving children and surviving parents to explore their support experiences following parental death. This study

is one of the first (to the best of the researcher’s knowledge) to explore child and parent dyad experiences following parental death with a focus on support.

The substantive theory developed in the study provides a new understanding of how children and parents are supported and where this is lacking or requires improvement. The study highlights that how individuals are supported by their existing networks affects how they grieve.

10.4.3 Usefulness

This study has proved its usefulness by adding to the limited child-centred research in the field of bereavement, incorporating parent-child dyads. The study contributes to our understanding of the impact of children participating in research and the challenges and benefits of children's participation in research. Furthermore, the substantive theory could inform the development of bereavement support and services for families living with parental death in the UK.

The multiple implications to practice, education, policy and research are discussed in section 10.6. However, the usefulness and resonance of the study were cemented during member checking interviews, sharing categories and the emergent theory with participants and PPI members. Examples are provided in Table 23.

Table 23 Participant feedback on categories and emerging theory

Participant details	Feedback from participants when presented with categories
Charlotte (older child)	<i>“I think you summed it up so well, definitely, so well, I think everyone needs to read it, everyone needs to see this”</i> <i>“I think those topics are so perfect, but I think they're such broad topics as well, they just pretty much capture everything, those are definitely the main things that I would say, have helped me”</i>
James (younger child)	<i>“Yep yep yep yep yep yep yep yep yep yep yep yep”</i> <i>“You've done an amazing job”</i>
Natalie (mother)	<i>“you have covered everything, literally”</i> <i>“it's surely a massive gap in research in this sort of area, I've never come across anything like this before”</i> <i>“yeah absolutely, yeah I can relate to that one definitely still ongoing”</i>

Ellie (mother)	<p><i>"I think it's good, yeah, I think the categories feel right"</i></p> <p><i>"That was exactly mirrors our experience"</i></p>
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10.4.4 Resonance

Resonance refers to the categories expressing the fullness of participant experience, revealing explicit and implicit meanings²²². The thesis provides in-depth detail of how the constructivist grounded theory processes were followed. The emerging theory was a co-construction between the researcher and participants (as presented in Chapters 5 and 6).

The findings offer anyone supporting a bereaved child or parent deeper insight into their main concerns following parental death. Through member-checking, the findings showed resonance with participant experience, as presented in Table 23. In addition, peer checking with other researchers in the field and professionals working within bereavement services further validated the usefulness and resonance of the findings.

Birks and Mills provide three criteria influencing the quality of grounded theory research. These are research expertise, methodological congruence and procedural precision²³⁸. The following section demonstrates how these criteria were met.

10.4.5 Researcher expertise

To produce a successful research project, the researcher requires knowledge, skills, and professional attributes relevant to the research they are undertaking²⁴¹. As a doctoral student, I engaged with the Researcher Development Framework³³⁹ to plan, promote and support my development within the domains of knowledge and intellectual abilities, personal effectiveness, research governance, organisation, engagement, influence and impact³³⁹.

I participated in educational activities with the University's postgraduate training scheme and the wider research community. I completed modules relevant to my identified needs and developed confidence and competence in the research process. In addition, I engaged with continual reading, accessing resources, and engaging with peer groups relating to constructivist grounded theory.

I am a clinical research fellow and a registered nurse working within the local hospital's bereavement support team. I chair the local child bereavement advisory group and am a

certified Grief Recovery Method specialist. During a leave of absence during the pandemic, I developed and managed a family support team and incorporated bereavement support for families. Before, I worked in different end-of-life settings within the hospital, and I am experienced in supporting families during end-of-life care. This background provided some expertise in supporting bereaved families within the study, and it was carefully managed through reflexivity to identify pre-existing knowledge and potential bias.

10.4.6 Methodological congruence

Methodological congruence provides the foundation of a credible qualitative study. It requires accordance between the researcher's philosophical position, the research aims, and the methodological approach undertaken to achieve these²⁴¹. As explained, the philosophical positioning of the researcher and the research methods are compatible with a constructivist grounded theory approach. The study's credibility was enhanced following constructivist grounded theory processes, including reflexivity, member checking, involving participants and peer review. Transferability is demonstrated by clearly explaining the study background and context, methodology, and methods using thick descriptions to present findings. Member checking and public involvement were essential to methodological congruence and discussed in detail in Chapter 6.

10.4.7 Procedural precision

To generate a theory that fits, works, is relevant and modifiable requires rigorous application of grounded theory procedures³⁴⁰. Procedural precision requires rigorously applying methods to allow the developed theory to be deemed a quality product²⁴¹. To demonstrate procedural precision, I maintained an audit trail, managed data and resources, and showed procedural logic²⁴¹. The grounded theory processes were rigorously carried out throughout the study and contributed to its dependability. Dependability is achieved by reporting the entire research process throughout this thesis and following the necessary governance and ethical requirements²⁴¹. Memo writing throughout the study alongside a reflexive diary provide an audit trail of the research to support confirmability. Excerpts of both have been presented throughout the thesis.

10.5 Strengths and limitations

10.5.1 Strengths

The previous sections demonstrate the strengths of the grounded theory study. This next section highlights other strengths.

The need for further research in the field of bereavement has been highlighted, including the need to understand the support needs of bereaved people and ensure the voice of bereaved people is central to the research³. This study has placed bereaved children and parents at the centre of the research. Using grounded theory allowed the findings to remain grounded in their individual experiences and offer a good understanding of children's and parents' support needs.

There are multiple strengths to the study. The most important is how the study used a child-centred approach providing children with the agency to participate. Children and parents were interviewed, contributing to the limited evidence from both perspectives. In addition, some of the families were interviewed as child-parent dyads providing greater insight into the relationships within families. Interviewing children and parents separately and child-parent dyads, the findings have contributed a rich insight into support experiences.

The involvement of bereaved families has remained central throughout this research and from the initial involvement of the young person's advisory group, followed by the establishment of a bereaved family PPI group early in the design process through to reviewing findings. The involvement of these groups has strengthened the study and contributed to its success in recruitment and helping participants feel supported. In addition, the 'get to know me' session with all participants before the interview helped develop rapport, which increased their willingness and openness to share their experiences.

Previous research with parentally bereaved children and their surviving parents is largely representative of mothers and often adolescent children^{20,289}. One of the strengths of this study have been the participants recruited. The study successfully recruited participants from various causes of death and differing lengths of time since bereavement. Just under half of the children were younger (10-13), and five sons and seven fathers represent 43% of the total participants.

Participants included non-married couples, one separated couple and blended families. Recruitment required the researcher to be patient, flexible and able to build relationships to create a safe place for children and parents to feel comfortable sharing their experiences.

It could be argued that including children and parents from within the same families provides a greater understanding of the experiences and dynamics within families when they are grieving—providing insight into their different perceptions.

The study aimed to recruit participants who had not accessed services to understand why some families access formal support and others do not. Despite most families being recruited via social media and not directly via support services, most had accessed formal support.

Recruiting with social media and the ability to offer virtual interviews allowed national recruitment, providing a good spread of participants across geographical areas. Virtual interviews were seen as acceptable by participants and the chosen interview method by all. Findings have shown that virtual interviews can successfully elicit rich data on sensitive topics³⁴¹. Online interviews with young people can create a feeling of safety and anonymity²⁷⁸. Findings from this study support the evidence that virtual interviews are beneficial in many ways; they are convenient, accessible, enhance personal interface to discuss sensitive topics, and are time-saving³⁴¹.

The successful recruitment of bereaved children and families to this study adds to the growing evidence of research which encourages the inclusion of bereaved participants, particularly children, and highlights the benefits of their participation.

10.5.2 Limitations

Qualitative research and constructivist grounded theory do not seek to generalise findings from a large representative sample²²². Instead, the study aimed to generate a theory providing a deeper understanding and greater insight^{222,241} into bereavement support for children and surviving parents.

Purposive sampling was used to recruit most participants. This self-selecting sample may be biased towards families who chose to participate and may be more inclined towards help-seeking and research participation. In addition, those coping or adapting well to their loss

may be more likely to participate. However, it was clear that one of the mothers recently bereaved was struggling to cope, which would support why many of the families had received some formal support.

There was only one parent participant who was separated from the deceased parent. The lack of separated parents in the study also suggests that findings may not be representative of the views of such families. Not all parents who participated had their children participating. Therefore, the experiences of their children were not explored. Of the child participants, only two were bereaved of their mothers. The rest were bereaved of their father. Unfortunately, the children of the three other father participants were either too young to participate or, in one case, their father did not want to ask them. A limitation of this study is the eligibility age criteria for child participants, as some parent participants felt their children under the age of ten would have had the capacity and desire to participate.

The study did not collect families' socioeconomic status; however, the interview data identified a significant variation in participants' social and economic status, with some families clearly in lower socioeconomic groups.

Most participants took part in the 'get to know me session' and one interview. This showed some insight into family dynamics but one interview limited participant observation. In addition, some dyad interviews were completed one after the other. Although this benefitted the families, there was no time for the researcher to analyse the interviews. Instead, multiple interviews within dyads would be needed to greater explore the dynamics within a family. For example, having completed a parent interview followed by a child interview or vice versa. Undertaking the parent interview first meant any findings from the child interview could not be followed up with the parent and vice versa.

A further limitation resulted from the busy lives led by participants, coupled with the timescale of the study period, which meant all participants could not participate in follow-up member-checking interviews. Therefore, the second interviews were only completed with two parent and two child participants.

The National Institute for Health Research (NIHR) identifies the importance of including underserved groups within research³⁴². Some of those underserved groups they identify

who were relevant to this study are children under 18, different ethnic minority groups, different sexual orientations, and socio-economically disadvantaged³⁴².

The study was open to all underserved groups, and it successfully recruited children and socio-economically disadvantaged groups. However, despite efforts to reach those other groups, using social media and offering online interviews, which has been found to increase the diversity of participants²⁷⁸, there was little cultural or ethnic diversity. The study failed to recruit parents from a same-sex partnership. All families were of a white, British background; therefore, the support experiences and needs of families from other ethnicities and those from same-sex partnerships are not accounted for in this study. The need for research with bereaved people from different ethnicities is highlighted as a priority, recognising these groups are less likely to access formal bereavement support^{3,343}, which could contribute to the lack of diversity within the sample. Sampling from within these groups could extend and densify the current findings.

Therefore, it is particularly important to recognise that the developed theory, as well as the research findings, are not applicable to all bereaved families. As previously mentioned, these findings do not represent the experiences of minoritised groups who are not represented in this research. The theory is grounded in the data generated by the participants in this study.

Although the findings present rich data, as the interviews were undertaken virtually, there were possible missed opportunities to pick up on non-verbal cues and body language (as the researcher and participant were not occupying the same space³⁴⁴). Furthermore, there is a chance of disruption due to poor internet connection³⁴¹, which happened on a few occasions. Also recruiting online meant there was less chance of reaching digitally marginalised groups.

The findings report how families are supported by their existing networks. However, no interviews were undertaken with members of the participants' existing networks. Doing so would have explored their perceptions of providing support that could have contributed to the constructed theory.

A final limitation of the study is that the researcher was a novice researcher in constructivist grounded theory. While undertaking the research, she learned about the processes and applied them to the study.

10.6 Contributions of this thesis

The substantive theory, 'masking your grief - because you feel you have to', provides a theoretical understanding with evidence to improve practice in how families are supported. Based on this, recommendations and implications are made to theory, practice, education, policy and research.

10.6.1 Contribution to theory

The following section discusses the new substantive theory with existing theories. 'Masking your grief - because you feel you have to' is the emerged theory that was inductively developed from participants' data. It offered an understanding of the patterns of behaviour of bereaved families and those within their existing networks. My theory suggests that masking their grief to protect themselves, each other, and those around them can lead to a lack of ongoing support. My new theory is now situated with some relevant existing theories.

Some grief theories and models were discussed in Chapter 2. The findings from my study have highlighted how these have failed to explore the influence of existing social networks on how children and surviving parents grieve. This is despite the argument that grief is not just an individual process, it is intricately social³⁰⁸.

Many of my participants viewed their grief as an ongoing learning journey. Murray Parkes and Prigerson¹³⁰ previously described grief as a learning process, resulting in the bereaved developing a new set of assumptions about the world. My participants often found that people did not know what to say to them. Several admitted that before they had been bereaved, they, too, would not know what to say to a bereaved person. Threshold concept theory is an educational theory³⁴⁵ that I do not believe has ever been considered with grief. However, it could be applied to grief to understand this interaction.

A threshold concept happens when a new portal opens to a new and previously inaccessible way of thinking about or understanding something³⁴⁵. Threshold concepts are described as

transformative, giving significant change in the perception of a phenomenon. This can involve a change in identity and how one sees themselves and views the world. These are irreversible, meaning they cannot be unlearned and provide a new worldview, they are integrative, meaning they expose you to something previously unknown, and they are troublesome and can feel alien³⁴⁵. When comparing these processes to my findings, these characteristics can also be seen to describe the bereavement experience. Many participants spoke of grief being a learning journey, and one even questioned if it was the role of the bereaved to teach others about grief. Applying this theory to the experience of becoming bereaved helps us understand why those with lived experience can provide another level of support. They too have been through the bereavement threshold, which has opened their understanding. It does not make them feel awkward or uncomfortable.

Death and dying are social issues we often try to solve with a medical lens^{1,186}. Using Goffman's dramaturgical metaphor as an alternative lens to understand the study's findings allows a good understanding of bereavement support experiences. The theory of dramaturgy likens social interactions to a theatrical performance, with the world as the stage and life as the performance¹⁹³. Both children and parents display front and backstage performances of grief. The masking of grief highlights the complex performances and the impact of interaction with others. This affects how a bereaved person can grieve if their grief is acceptable to be shown front stage or must be shown privately backstage.

Bereaved people choose what they show to the outside world. When masking their grief, this can result in the outside world interpreting their grief mask to mean they have finished grieving and 'moved on'. Similar findings have recently been reported²⁹¹. Several of my participants showed disdain and took offence when they heard the term 'moved on' as they had realised they never move on, they learn to live with their grief. This supports the theory of grief developed by Tonkin¹³⁵. Tonkin's theory, as described previously, suggests that grief remains the same as time passes, but people begin to grow around their grief. They have new experiences, meet new people and begin to find moments of enjoyment¹³⁵. As the participants in my study found, their grief will always be there, but they learn to live with it and it becomes part of who they are.

The dual process coping model which was introduced in Chapter 2, allows us to understand how bereaved people cope with grief, by oscillating between loss-orientated and

restoration-orientated work in their everyday lives¹⁴⁶. The findings from my study resonate and can expand on this model. They show people within a bereaved person's network can influence their ability to be loss or restoration orientated as dependent on the reactions and expectations from those supporting them; bereaved people must control and mask their grief at times. Denial and avoidance of grief are described as restoration orientated, and within the dual process of the coping model are healthy and adaptive ways of grieving¹⁴⁶. However, findings from my study highlight that bereaved people deny and avoid their grief as part of the restoration-orientated activities. Importantly, findings have highlighted that sometimes they deny or avoid their grief because they feel forced to do so because of the interactions or need to protect those around them, and not for their own benefit.

Part of loss orientation involves confronting and trying to accept the loss and reminiscing about the deceased person. Some participants in my study found that those around them could not bear to see their grief, or it made them uncomfortable talking about it, so they would suppress their emotions and not talk about it. Consequently, the loss orientated could be impacted by how open and accepting those around them are to hear about their loss. Previous work surrounding support from existing networks to the bereaved suggests that the bereaved need to have an openness of their personal needs and should educate their networks about how best they can support them⁹. Some participants in my study were able to be open with their network about their needs. However, when support was not sustained, this was accepted; some of the children, especially when thinking about support from the school, just accepted that it had been a while now. They did not expect all teachers to remember and remain sensitive to their situation.

Over ten years ago, Harris discussed the oppression of the bereaved in Western Society³⁴⁶. Identifying four social rules for grieving that are not explicitly stated but are widely known and rather than support, they can constrict grief. Those rules include; who has permission to be identified as bereaved and if their relationship to the deceased is valid; how long grief can last; how grief should be shown; and if the cause of death is 'acceptable' or has stigma attached³⁴⁶. These rules put profound social pressure on bereaved people to conform to societal norms that constrict rather than support grief experiences³⁴⁶. Findings from my study have proved that such 'rules' remain in operation. Moreover, the social and cultural

influences on how bereaved people *should* respond to their loss affect how they respond to their loss³⁴⁶.

Furthermore, Harris suggested that bereaved people want to be socially accepted and reduce the risk of being socially isolated or excluded because they are not conforming to expectations³⁴⁶. As a result, grieving people may 'mask' their grief, resulting in them internalising and oppressing their grief, which does not fit the social rules of grieving³⁴⁶. The theory developed within my study centres around bereaved people masking their grief and provides evidence of the oppression of the bereaved by society.

Hogan et al.³⁴⁷ developed a substantive theory of bereavement offering seven major sequential grieving processes that can overlap and re-emerge following a consistent overall pattern³⁴⁷. The process begins with 1) getting the news, 2) finding out, 3) facing realities, 4) becoming engulfed with suffering, 5) emerging from the suffering, 6) getting on with life, and 7) experiencing personal growth³⁴⁷. All seven processes were seen throughout my study. As with the previously discussed models and theories, this theory focuses on individuals moving through bereavement. It does not consider or situate the external support received. When applied to this theory, my findings add another dimension which are not illustrated by Hogan et al.³⁴⁷; for many bereaved people, the support they receive has often gone whilst they are still engulfed with suffering or trying to emerge from it. Due to the reactions and expectation of those around them, they are forced to mask their grief and suffering. Parents had to get on with life, to keep routine and normality for the children. However, as discussed, this can be misconceived by others that they are further along or 'over' their grief.

This section considered existing grief theories and models and has shown how my new substantive theory, presented here, complements and goes beyond the existing models. It provides insight into how the people within a bereaved person's network can and do impact how they grieve. My findings highlight the essential need for bereavement models and theories to look beyond grief in the individual or family context and understand the importance of viewing grief within the context of them as an individual, in their family and also in their networks. Doing so will ensure a supportive response is provided appropriate to a bereaved person's individual needs, allowing them to grieve how they wish and not feel a need to mask their grief.

10.6.2 Contribution to practice

My findings showed that most families receive good support from those around them to help them manage following the death of a parent. However, the data provided by parents highlight their perspective that bereaved children require professional support.

Understanding their fears draws attention to prime opportunities for bereavement service providers to pro-actively intervene soon after parental death. Doing so would reduce parental stress and worry, and build confidence and competence in surviving parents' abilities to respond to and support their bereaved children.

My findings highlight a great need for professionals to work with families to help them engage in open communication and to normalise, explore and understand their emotions and how they may manage those separately and together. Doing so will hopefully reduce their need to grieve alone, reduce the amount of empathic avoidance they feel they need to protect one another and allow them to understand that they do not need to mask their grief.

Services providing support to bereaved parents must harness the power of peer support. Findings highlighted the power of this for both parents and children. Although peer support is very variable, a few participants did not find it supportive. However, for most, it helped to meet someone who had some understanding, could relate to them and normalise their feelings. Being with bereaved peers made it easier for participants to open up. They felt they did not need to hide their feelings or censor what they were saying to protect the other person.

A local hospice developed an initiative in a local school with many bereaved pupils. The hospice provided some general school wide education around grief and invited children who are bereaved to meet with other children in their school for peer support. Although my study has highlighted that peer support would not appeal to all bereaved children, the early feedback from the hospice initiative has been positive. Many children had not known there were other bereaved children at their school and they were grateful to meet others who understood what it meant to be bereaved. Such initiatives could be easily rolled out into schools and maximise the peer support already there.

The findings have started to fill the knowledge gap and highlight why families may not access support and the difficulties faced whilst accessing support. However, further research focusing on access to support is needed. In addition, my findings can offer services good insight into how they can improve to better meet the individual needs of bereaved families. A starting point for bereavement services when developing a new service or reviewing one is to work with bereaved families to find out what works for them, ensure services are co-designed and meet the needs of bereaved families.

Professionals providing support in these situations need a better understanding of the impact of the bereavement on the family unit and the difficulties they face accessing support. Professionals need to work with bereaved families to identify their barriers and help them overcome them. For example, a common barrier was the provision of services that did not match the family's needs or the distance to travel or how the timing could fit around work and school. Another barrier was not knowing what services were available to a family, with many trying to search what was available. Services have a responsibility to ensure that information about their services is accessible to those who may need them. Furthermore, families should be able to access support at the time that they need it, not as dictated by procedures and policies that do not have any evidence base.

Findings from my study highlight the need for any support to be tailored to the need of the individual, with an awareness that within one family, parents and siblings may have differing needs.

Professionals must manage the expectations of bereavement support with individuals. They must highlight the possible need to work with other professionals providing different types of support to find what is most helpful. Connection, being non-judgmental and understanding their situation seem to be critical factors in receiving good support. If participants did not receive this, they were more likely to stop accessing that support. It is important that professionals acknowledge with those they are supporting that they may not develop that connection and that is normal. For example, if someone has a counsellor they do not connect with they may feel that counselling is not for them. However, if they were encouraged to try counselling with another practitioner, as some of my participants did, they may find that connection and understanding. The relationship with the person offering the support is vital to it being a success.

In the study, when categorising the cause of death into sudden and expected deaths, it became clear that what I thought was an expected death, for example, from cancer, was sometimes described as a sudden death by participants. Despite parents being ill for some time, some deteriorated quickly and died suddenly. Some were fit and well, received a cancer diagnosis and died within months. For many of these families, these deaths felt sudden, making me cautious about categorising a death as expected when it felt sudden for a family. Clinicians often categorise deaths as expected, unexpected or sudden in research and practice. It is important to understand that our categorisation may not fit with how that family experience a death and we need to be mindful of the language we use.

All health and social care professionals supporting parentally bereaved children require training to develop their knowledge, skills and confidence to offer sustained support. A recent report recommended that to provide competent care, it should be integral, substantial and mandatory for all health and social care professionals to receive education on end-of-life care and death and dying ¹. My findings would support this and recommends that all health and social care professionals be aware of the services available in their own area to accurately signpost families to support services.

In addition, my findings support the need for funeral directors to acknowledge their role in supporting bereaved families as recommended by Hanna's study¹⁷. Funeral directors are the one service most likely to interact with a bereaved family; they are looked to for advice and seen as experts in their field. They require discursive training to recognise their role and the impact they can have on supporting bereaved families and develop their knowledge and confidence to be able to provide this and also signpost to relevant services.

Reflecting on my own experiences supporting bereaved families over many years and from speaking with different professionals who may be in contact with bereaved families, professionals often think that supporting a bereaved family is the job of another professional. A prime example of this was when I spoke informally to a funeral director about how they support a bereaved family. I was told that they do not offer support as this is done by the doctor at the hospital. Having worked within end-of-life care for many years I know this does not happen. My findings show that it can be difficult for bereaved people to ask for help. Leading me to wonder if a reason why a family is not getting the support they

need is because the people around them believe someone else is already giving them the support they need.

In 2013, Kellehear⁸⁶ highlighted the need for a compassionate communities approach, with end-of-life care being the responsibility of everyone. Ten years on, the UK Commission on Bereavement³ report, 'Bereavement is everyone's business', shows how bereavement impacts everyone. All my findings fully support that each and every one of us needs to understand the effects of bereavement and how to best support bereaved people living within our communities.

10.6.3 Contribution to education

Bereavement and loss are something everyone will encounter. A systematic review highlighted how bereavement can negatively impact children's education. This is often more debilitating initially and then eases⁴⁸, but for some children they may develop prolonged grief disorder and the bereavement can affect their functioning for many years³⁴⁸. My findings highlight the need for greater awareness of loss and bereavement within schools. Firstly, school staff whose roles encounter children and families must receive support and training to support bereaved children. All schools should have a bereavement policy with guidance for staff, providing a clear role for them and a greater understanding of the longevity and changing nature of grief. School staff should be encouraged to maintain ongoing communication with children and families to identify their individual needs throughout the time spent at school. My findings suggest a need for schools to recognise that bereavement is an ongoing issue that may affect the child throughout their life. School staff must be aware of all bereaved children within their care and recognise the ongoing need to continue to be sensitive. For example, around family events, anniversaries and when teaching subjects that could be potentially distressing. Furthermore, my findings agree with the UK Commission on Bereavement, who identified that schools should ensure when children are moving, information about their bereavement is passed on to the next school³.

The accounts from my participants identify the school as an environment that can offer consistent and sustained support to bereaved children as they grow and continually process their grief. However, this must be individualised to the needs of each child. Currently, there

is variance around individualised support and lack of sustained support throughout the child's time at school.

Furthermore, the school curriculum needs to teach children about loss and grief and how to support one another, as previous studies have highlighted^{3,316,321}. Implementing grief education into schools would mean that the next generations of young people will have the skills and confidence to support the bereaved people around them. Children recently highlighted how learning about loss and bereavement would help them understand support for bereaved peers, better prepare them for the future, and normalise the experiences and feelings they may have³. Such grief education could have a considerable impact on bereaved children by empowering and equipping them with the skills and confidence to talk about their loss, and receive the support they need from peers and teachers. In turn that grief education will continue to help those who receive it to better respond to any bereaved person they come across.

Most children and some parents in my study spoke of their difficulties talking about 'it' and often received negative responses when they did. This suggests that bereaved people, children especially, need to be supported by those around them to know how they can talk about their loss and bring it into everyday conversations without fear of repercussions. If professionals facilitated such conversations with children within school settings, it would give children permission to be able to talk about their loss, should they wish. It would begin to reduce the taboo around death by normalising those conversations and modelling to children how to have a conversation and how to respond.

Families' primary sources of professional support could come from bereavement services or the school. My findings recommend there should be interprofessional working between services and schools to ensure every child and family receives the support they need. Not only when families are newly bereaved but as they navigate life carrying their grief. Schools are well placed to identify and signpost bereaved families and work with services to provide ongoing support. My findings support the UK Commission on Bereavement suggesting all schools have a bereavement policy which includes information about sources of support, signposting and making referrals³. Adopting a wrap-around approach could identify individual needs and provide the right support at the right time. Ensuring that bereaved

families' needs are identified and acted upon as they arise may reduce the need for individuals to access services in the future.

The power of school support has recently been highlighted from a UK nationwide programme seeking to improve children and young people's mental health through implementing mental health support teams into schools³⁴⁹. It provides early intervention and access to support, and promotes good mental health and wellbeing. Part of the training staff receive is on bereavement³⁴⁹. The early review of the service found that school staff felt more confident talking with children about their mental health³⁴⁹. Such initiatives have the potential to support children's mental and emotional health, help them develop coping skills and learn how to manage difficult experiences and feelings³⁴⁹. It is vital that this programme be evaluated in the context of providing bereavement support.

10.6.4 Contribution to policy

Findings have shown a great need for society to be more grief aware to help reduce the taboo around death and dying. As discussed, grief education within schools would be a great step towards raising grief awareness. The findings advocate for a Compassionate Community's approach to bereavement, with the belief that everyone plays a role in supporting a bereaved person. Recognising that the pandemic has added to grief, bereavement and mental health, Australia recognised the need for improved grief literacy to improve community understanding of grief³⁵⁰. Findings from this study suggest that the same improved grief literacy is required in the UK to improve how we understand grief and support those grieving.

Improving grief literacy will support a greater understanding of the impact and longevity of grief, and mean that children and parents do not have to mask their grief to fit in with society's expectations. Doing so would allow them to receive the support they need.

Findings showed a need for all employers to have bereavement policies in place to provide adequate support to fulfil their roles without placing extra pressure. For instances where this is not possible, the employers should work with the employees to offer alternative employment. Like the other people in a bereaved person's existing network, employers need to recognise the need for flexibility and ongoing and sustained support. For many bereaved parents, following the death, their priorities changed; even after time, they may

still not be able to work at the capacity they once did. Childcare will often be a concern for them, which can be alleviated with workplace flexibility.

Parents experienced far greater allowances and flexibility from employers during the pandemic. The ability to work from home and fit their hours around their family life allowed many to manage their competing life demands better. If employees can be supported in this way during a pandemic, the same support and allowances should be made available to them following parental death.

Recognising the financial implications of parental death on the family unit is essential. When people are nearing the end-of-life, families with dependent children are more likely to fall below the poverty line³⁵¹. That situation worsens for lone-parent families³⁵¹. Bereavement support payments offer a lifeline to many families. However, families often found out they were entitled to the payments by chance. Bereaved families must be provided with all the information they need about the support they are entitled to and how they can access it, as recently recommended¹. There is limited evidence to suggest what types of information bereaved children and surviving parents would find most helpful. My findings highlight the need for better information and signposting around the practicalities of a parent dying and the administration tasks, bereavement services, children viewing the body and attending the funeral and the financial support available. Similar findings have recently been reported by the UK Commission on Bereavement³ and Selman et al.¹¹⁶. Both studies found only a third of people received information about bereavement services and faced challenges around completing the practical tasks after death. Together this evidence recommends that local providers and commissioners review the information and modes of delivering it to bereaved people, recognising the needs of bereaved people are currently not being met. Further work is needed to understand the information bereaved people need, the timing and accessibility of information and how it is delivered.

As mentioned, recognition of parental bereavement as an ACE could lead to better understanding and support for bereaved families. Using an ACEs approach has already been identified as a helpful way to consider the impact of parental death on children³⁵².

Furthermore, ACEs are present in UK policy, with Scotland and Wales having established ACE 'hubs' that promote the shared learning of research and practice surrounding ACEs³⁵³.

Identifying parental death as an ACE would ensure supporting bereaved families is firmly on the agenda.

The availability of bereavement services requires significant review and greater system-level investment. Currently, most bereavement support is funded by third sector organisations, which means there is an inequity in availability in the UK. Parents described a 'post code lottery' to what was available to them locally. Some travelled long distances, others accepted there was no support. The way bereavement support is provided requires an overhaul to ensure every child and parent has the same access to services and opportunities in their grief.

My study has highlighted the lack of information sharing between health, education and social care professionals following a parental death; meaning it is often the responsibility of parents or children to share news of the death with professionals. Parents were disappointed that after such a life changing event there was no automatic support system in place. My findings suggest it would be highly beneficial to families if there were formal structural processes in education and healthcare settings that identify bereaved families and alert local support services who then have a responsibility to engage with bereaved families.

Findings from my study and others suggest the public health model approach to bereavement, which is the gold standard for bereavement services, may not accurately represent the different tiers of support needed by bereaved individuals. Currently the model suggests most people will be supported by friends and family alone. Many services adopt this model without an understanding of the limitations. This means services may misunderstand the needs of bereaved people, and in particular the needs of bereaved parents who may be at greater risk of developing complex grief²². Firstly, if services are supporting a group of bereaved parents, will they apply the model that only 10% of that group may require specialist intervention, and will they assume that because a parent has a good support network, they are receiving the support they need. As my findings show, along with recent studies undertaken with bereaved adults, not all bereaved people get adequate support from friends and family, some report unmet needs and many have a desire for professional support^{291,292}. Further research is needed to understand the types of support bereaved people may need, under what circumstances, and identify the factors that

contribute to needing more specialist support. With further understanding of the needs of bereaved people the public health model approach should be revised.

10.6.5 Contribution to research

The follow sections outline the multiple contributions this thesis has made in relation to research.

10.6.5.1 Research with parentally bereaved families

This is the first study (that I know of) which successfully recruited bereaved children and surviving parents online using an opt-in approach. Online recruitment has demonstrated the power of reaching many individuals and has taken away some of the gatekeeping often experienced when recruiting vulnerable populations. In addition, most participants were recruited by seeing the recruitment flyer online. This meant there was no requirement to gain ethical approvals to recruit through HCPs. This method could help other researchers who are struggling with recruitment.

As far as I know, this is the first study that uses virtual, online interviews to explore bereavement experiences with children and surviving parent dyads—providing a unique insight into how they support one another. The feedback from the PPI group and participants is that online interviews are an acceptable and favourable form of data collection. Furthermore, virtual interviews worked exceptionally well for bereaved families who are already navigating challenging and busy lifestyles but are keen to be involved with research—making involvement more accessible to this often hard-to-reach group.

The successful recruitment and in-depth interviews with 28 child and parent participants have shown that bereaved people want to be involved in research. Furthermore, children have agency and can contribute to research to provide valuable insight into their lived experience, which must be used to shape services. Doing so will value their voices and ensure research is person-orientated rather than service-orientated³⁵⁴. The findings have proved that bereaved children and parents are not hard to reach, and reducing barriers around gatekeeping and a need to protect children is achievable when participants are placed at the centre of the research.

This study has made contributions to knowledge through peer-reviewed publications in journals accessed by professionals who provide care and support to families at the end-of-life and through presentations at local and international conferences.

To date, research focusing on bereavement support from social networks is limited⁹⁸. Studies focusing on how children and parents support each other following parental death and how their social networks support them are even scarcer. This study contributes much-needed insight into parentally bereaved children and their surviving parent's experiences within a UK context and highlights the areas of support requiring improvement.

This study has provided a better understanding of the support experiences for parentally bereaved children and their surviving parents, through the lens of children, parents and a systematic literature review.

The study has contributed to bereavement research by identifying that bereaved children and families do want to have their voices heard. It can be upsetting and painful, but that is not always bad. Participants get something out of participating, not only knowing they will help other people but that they have a therapeutic benefit to being heard. This study is novel in that all interviews were undertaken virtually, which provided much more flexibility. It was easier to arrange to talk with these busy families causing as little disruption as possible. It is likely that virtual methods improved recruitment and meant that families could be recruited across the UK instead of being undertaken face-to-face when the geography would have imposed limitations.

The interviews provided rich data, part of which could be attributed to the rapport developed with participants using the 'get to know me' session. Disclosing information about myself and my family allowed participants to feel more comfortable talking and opening up to me about their experiences. Some children felt I could relate to their situation because I experienced parental divorce. This was not something I had expected to find. Future research with children should incorporate activities or pre-interview meetings to develop rapport and for participants to feel comfortable and safe with a researcher.

When setting out to undertake this study, I worried about my ability to speak with children about their bereavement. Undertaking the first few interviews, the gravity of what I was asking from these families dawned on me, giving me a tremendous sense of responsibility.

Luckily for me, I began receiving positive feedback soon into the study. Participants were grateful for their involvement; they thanked me for listening to their stories. For some, this had been the first time they had shared their experience. Other bereavement researchers have also found a willingness from participants to share the intimate and detailed personal experiences of bereavement and often feel positive having taken part³⁵⁵. This gave me great encouragement knowing that participants were getting something positive and supportive by sharing their stories in a safe, non-judgmental environment.

Reflecting on participants' gratitude to be heard reinforced the difficulties children and families face being able to talk about their loss and the taboo they felt, which often resulted in them not talking about it. I believe I am a good listener and non-judgemental, allowing participants to open up to me. If I can listen to their stories, I see no reason why those around them cannot do the same.

Participants were grateful for the opportunity to participate and thankful for someone listening to them in a non-judgmental way. Many told the researcher how beneficial it had been for them to participate. Participants were invited to provide feedback on their experience of participating in interviews. Anonymous feedback was returned by five children and eleven parents (61% of the total participants). Every participant provided a positive response about their involvement. These findings support the need to allow bereaved people, especially children, to be involved in research^{1,3}.

10.6.5.2 Research in a pandemic

The study was developed and designed during a pandemic which influenced how the study was undertaken. Initially, it was planned to perform interviews face to face. Covid meant the research had to be adapted to allow for government restrictions that could halt face-to-face interviews, resulting in a decision to undertake interviews virtually. The public involvement sessions took place virtually for the same reason, which worked well. The patient and public involvement groups (PPI) identified digital technologies as an acceptable data collection method to allow the research to be flexible and continue regardless of any restrictions imposed. Young people are generally engaged with the digital world, which can give voice to marginalised groups, enable a more representative sample, and provide greater privacy and anonymity when exploring a sensitive topic than a face-to-face interview³⁵⁶. Both children and parents from the PPI groups supported virtual interviews,

with much of society having experienced working or schooling from home using digital technologies during the pandemic. Virtual interviews had advantages; they were convenient, allowed participants to choose a comfortable setting, provided a greater sense of control and empowerment, and were accessible as not limited by a participant's location geographically, meaning they could be more accessible to some groups.

Furthermore, they could be more anonymous, with some hard-to-reach groups more likely to participate in a virtual interview rather than face to face. Potentially they can be ideal for sensitive topics, allowing some participants to feel more comfortable disclosing sensitive information virtually and there is less social pressure²¹³. Virtual interviews have been successful in previous studies to improve diversity and inclusion with young people²⁷⁸, allowing them to feel comfortable. They are non-intrusive and safe; engaging and convenient, and easy when exploring sensitive issues with vulnerable people³⁴⁴.

Disadvantages to virtual interviews include lesser acceptability for some groups²¹³. In addition, difficulties have been seen with virtual interviews relating to conversation flow, reading body language and also difficulties with set-up and Wi-Fi connections³⁴⁴. To prevent digital exclusion, the study protocol was flexible and allowed for telephone or face-to-face interviews should they be requested by participants, and it was safe and permitted.

During the pandemic, the researcher had first-hand experience of offering bereavement support virtually and over the telephone, which was an acceptable form of communication with those bereaved. Public involvement sessions also took place virtually, giving the researcher experience and confidence in using a virtual platform with bereaved families. To the best of the researcher's knowledge, no other study has used virtual interviews to explore children's experiences of parental bereavement.

Overall, the study has proved that research in a pandemic is not only possible but can have many benefits as highlighted in the strengths section.

10.6.5.3 Research with children

The rich data gathered from children highlight the agency they possess and the contributions they can make to research. Undertaking research with children requires flexibility and adaptability throughout the process. Planning the research with children and piloting topic guides and different methods proved useful to ensure the gathering of rich

data. Interestingly the vignettes worked very well with some of the younger children who at times struggled to answer a question, but when re-phrased as a vignette and the child was asked to give advice to someone in the same situation, they found it easy to answer.

To build trust and rapport with children and parents I found it helpful to meet with them when they showed an interest in the study. Using researcher self-disclosure allowed them to see I was a warm, friendly, open and 'normal' person which helped them when making decisions to participate and lessened any power imbalances²⁵⁹. The rapport and trust built prior to the interviews allowed the interview to feel less like an interview and more like a conversation guided by participants²⁵⁹. All children chose to be interviewed alone which is a strength of the study, ensuring children's voices are heard. It is possible that the rapport and trust building prior to interviews contributed to children's willingness to be interviewed alone.

A concern and identified gap in the literature is the underlying assumption that within the parent-child dyad, children play a passive role and parents an active one⁷⁷. Recent studies have begun to identify children's agency during parental illness and death^{12,289}. However, this study is among the first to highlight examples of children's agency within the parent-child dyad and contribute to the understanding that children should be viewed as active and equal agents^{77,357,358}. Children protect their parents by suppressing their emotions so as not to burden them, as reported in a similar study³⁰¹. However, children did not shy away from their parents' emotions, and many comforted them when upset. Another active action of protection is when children take on more roles and responsibilities within the household; as they see their parents struggling with increasing demands and workloads, trying to reduce the burden. Parents sometimes worry about their children's level of support. Nevertheless, many acknowledged they could not manage without it, providing a seldom reported insight into children's agency in supporting parents.

10.6.5.4 Directions for future research

This study has made an excellent start to exploring support experiences for children and families, highlighting some barriers they face. Further research with children and parents is required to explore the problems they face accessing services and how that can be tackled.

A primary concern for parents was a lack of information and professional support to help them to support their children. Therefore, research should explore exactly what parents need from those professionals and understand how having that support will benefit parents and their children. Furthermore, research must identify what information bereaved families need, who should provide the information and when.

Findings showed the significant need for education about grief and loss. Research with children is vital to understand what education is required to be delivered in school to raise the understanding and awareness of loss and grief.

Although these findings give a good insight from the perspectives of bereaved children and their surviving parents, it would be helpful to explore the perceptions of those providing support to bereaved families. In particular, with people in their existing networks to better understand the reasons behind support dwindling and the expectations to 'move on'. Such research could also explore why some people step up and do not shy away from death, and others avoid the bereaved person. Similarly, it would be useful to explore experiences for children supporting a friend whose parent has died.

Future research requires a longitudinal approach to follow families throughout their bereavement experiences to provide insight into the types of support needed most and when. Such research would raise awareness of the need for ongoing support throughout a child's life.

Regarding supporting bereaved children, research should map all the people who encounter a bereaved child to identify who is best placed to support the child's needs. In addition, further research is needed to explore how interprofessional working between bereavement services, HCPs, and school staff can work together to provide ongoing support.

Research could investigate why some schools and workplaces do not have bereavement policies or training to identify barriers or reasons.

Some families found that when they fostered open communication, which allowed them to better support one another. Research could further explore how to support parents in bringing open communication into their families. Furthermore, children often struggle to bring their loss into a conversation. Research could explore with children how their parents

and social networks best support them to feel comfortable to talk about their loss and show their emotions. Such research could allow the development of interventions to enable children to be able to talk about their loss and ensure they receive support.

Undertaking research with this population requires the utmost flexibility and patience. Families often needed multiple reminders, and although they may be extremely interested in participating, they lead such busy lives and are juggling so much that they will often forget. Parents often forget to return consent forms, attend scheduled interviews, and return feedback forms. The first parent interviewed in November 2021 completed and returned her participation feedback form 11 months after the interview. The form was received with a note which read, 'Alex – so sorry but I found this in a pile of paperwork, huge apologies'. The determination to be involved with the study and help other people was evident with all participants.

10.7 Conclusion

“I was only seven like even though my friends tried to help, they can only really understand so much, because not many children know about death, like how to deal with death at that age, so they sort of tried to help me as much as they could, I guess, but they couldn't really. And then, because I was so young, I sort of had to move on quite quickly like, to sort of try and keep up with like getting a normal ish childhood, I guess, I would say, like, I had to sort of try and forget about it and pretend to be happy” Flo (younger child)

Through the lens of parentally bereaved children and their surviving parents, this study has identified the many challenges following the death of a parent. The findings highlighted what a supportive response is following parental death. There were also many examples of children and parents not receiving a supportive response, making them feel they had to mask their grief.

My findings identified that children and their parents enter a new, unfamiliar, social world of grief. They are trying to navigate their bereavement and the internal work that involves. They experience changing dynamics within their families and networks. Parents and children try their best to support one another but often, they don't know how, and that can make them feel helpless. The interactions from those within their networks can initially support

the bereaved family. However, the network's lack of understanding around grief leads them to unintentionally oppress children and parents' grief. Leaving participants feeling they had to control their grief according to the influence and expectations of those around them, whom they found had often not experienced grief. The impact of bereaved people's networks is not often considered, as has been highlighted in existing grief models and theories.

My findings indicated that although families are well supported initially following parental death by their existing networks, this support quickly dwindles, and there appears to be a societal expectation to 'move on'. For bereavement support to be improved, society needs to recognise that, as coined by the UK Commission on Bereavement, 'Bereavement is everyone's business'³ (p. 1). We all need to acknowledge the role we must play in supporting bereaved people around us. My findings have shown the amazing response to bereavement in many communities. However, communities require support to understand grief and grieving, how they can provide that supportive response and how they can sustain the support they provide over time.

Recommendations have been made for all professionals involved with the health and social care of children and their parents to recognise the pivotal roles they can play in supporting bereaved families. Acknowledging that they require bereavement training to be able to offer ongoing and sustained support. Parents and children recognise that grieving is a process they learn to live with. Yet, those within their informal and formal networks often fail to realise that grief is ongoing.

The study shows the individuality and complexity of experience for children and surviving parents following parental death and the need for any support to be individually tailored. Furthermore, the lack of information, signposting and available support services is identified as an area requiring urgent attention.

My findings indicate the current public health approach to bereavement support may not accurately represent the needs of parentally bereaved children and their surviving parents. They call for action to review the model with collaboration from bereaved families; to improve the support offered or in some cases to offer support to bereaved families.

Importantly, this study has shown how those within a bereaved persons network can and do affect how they grieve, which is crucial to understand when providing support.

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Appendices

Appendix 1: Covid diary

Covid diary – Returning to the PhD and reflecting on my experience of working clinically during the pandemic

During the pandemic I returned to work clinically full time in the Critical Care Units at Hull University Teaching Hospitals NHS Trust, taking a leave of absence from my PhD for 6 months.

I was very grateful for the university supporting us to go back, having worked in the NHS for nearly 20 years and many of my closest friends still working in the NHS I know I would have struggled being sat at home at the computer whilst my colleagues were facing the toughest times in their careers.

I was scared about going back, I had been out of practice for a while and wondered what I would be able to remember, I don't think I was scared for my safety, at the beginning we were told it was just the vulnerable and older people who were affected, it wasn't until much later we saw the devastation of the disease.

I remember being worried most about my family, I had my sister and sister in law both pregnant and my mum and step dad falling in the over 60's bracket. I remember telling everyone that they wouldn't see anything of me whilst I was working, I couldn't risk passing on this horrible disease to any of my loved ones.

Initially I went to work in the Intensive Care Unit, somewhere I had not worked for over 12 years, I worked for two weeks supernumerary, I felt out of my depth, I had only worked for one year in neurosurgical ICU when I first qualified, I had never worked on a general ICU.

The staff were amazing and so grateful for those who had gone to help. My first week I was on the 'clean unit' it felt a bit like being a student again, after a few shifts I had my own level 2 patient to look after, he was a lovely man and he ended up doing ok and being transferred to the ward. It was during my second week I went to get changed ready for the shift to begin, our names were all written on a piece of paper stuck to the changing room door which told us which ICU and which bed space we would be working at. My name was down for the COVID ICU, my heart sank and I wondered if it had been a mistake. I hadn't been 'fit tested' as they had run out of masks. I made my way to the unit and one of the senior nurses did a 'fit check' for my mask, there were a few of us in this position – I wondered if a 'fit check' was good enough to protect me.

It took a while to get dressed ready to go onto the ICU, we wore scrubs and could not take anything onto the unit with us. Luckily, we had staff who usually worked in sterile services who had been redeployed to help us get the PPE on and check we were safe, I was so grateful for their help, I remember initially with the PPE shortages from day to day it would change slightly what you should wear, they always supported us to wear the full lot even though the guidance told us we could wear less.

First you would put on a pair of gloves, shoe covers, a hair net, climb into a boiler suit, hood up, a second pair of gloves on which would be taped to your boiler suit, an FFP3 mask and a visor, then we would have our name written on the boiler suit, we all looked the same. Then through the two sets of temporary double doors into the ICU. At the end of the shift I always had a shower, the shower room was gross, 1 shower for the full ICU, we had loads of toiletries donated which was lovely then we had the tiny hospital towels to get dry, there were hardly any so I only ever use one. As soon as I got home I took my shoes off and left them in a box at the door, my clothes went straight in the wash and I got showered again, hoping that I would not be bringing anything home.

It was so hot working in the full PPE, and that was in April, I did a bed bath and had to sit down for ten minutes afterwards because I was so hot. I wondered how everyone would cope in the height of Summer. Over the summer I went on the unit a few times, I saw staff had to change their scrubs whilst on break because they were saturated. It was horrific seeing the conditions my friends and colleagues were working in, they were often nursing outside of the numbers and death happened too often to imagine.

I felt so sorry for the patients who were awake, it must have been so frightening for them to see us all dressed like that, communicating was really difficult because of the masks.

I remember attending a bereavement webinar later in the year and something really hit home with me, those COVID patients at home, their loved one called an ambulance, they said goodbye to them and for some of those loved ones that was the last time they saw them. For the patients that were collected by an ambulance, the crew wore full PPE as did all the staff at the hospital, if they died that meant when they said goodbye to their loved ones before getting in the ambulance, that was probably the last face they will ever have seen. I still cannot get my head around how incredibly sad that was.

I remember in those first couple of weeks we had no visitors at all, even for end-of-life patients on the clean ICU, they died without a loved one. I remember there was an elderly gentleman who was dying, his family wanted to come and be with him but they were not allowed, I was grateful the nurse who was looking after him that day, she was really caring and she sat and held his hand until the end.

On the COVID ICU we had managed to get I pads and a communication system to allow video calls between patients and relatives, in those first weeks I remember there being an elderly patient who was not going to survive, she was able to video call her family to say goodbye. This was horrific for this patient and her family, but also the impact that had on the staff who facilitated and witnessed those conversations. Still now over a year on this doesn't seem real.

After those first few weeks the ICU matron asked me if I would set up a family support team, I had two weeks to develop and set up the team and then I would have to return back to ICU, fortunately for me I was able to stay and manage the family support team throughout my time back in ICU.

I was given a team of 12 ICU nurses; the majority were pregnant and unable to work clinically. I set up a model of what the service would look like having looked at what was happening in other trusts.

The week we rolled out the service I went on the ward round of each of the ICU's the patients who were awake I spoke to and told them about the service we were starting, I told them they would get a knitted heart and one would be sent to their loved one, we would ring their loved one every day and give them an update and we would pass on any pictures or letters their loved one sent.

Our first week was awful, every one of the Covid-ICU patients we spoke to deteriorated suddenly and ended up being ventilated, with the majority of them dying.

Our 'clean unit' did no better, the families we spoke to that first week, nearly all of their loved ones died, at that point I wondered how we would all cope, my team were fairly junior and not used to seeing this intensity of death and having to speak to bereaved families they had never met over the phone. They did me proud though, they all did such an amazing job, we debriefed with each other regularly and we became a close little family supporting each other. The team were also nominated for a golden hearts award which I thought they were very deserving of.

Another family who will always remain with me was a young mum who died leaving behind her two children. A close friend of mine who was also the sister on the unit had called me over and asked if I could bring a memory box and any information to help the children.

I took a memory box and book for the children about when someone dies. On arrival to the unit I was ushered into a side room to be met with grandma, two children and a social worker. I did not realise I would be meeting the family, I was completely out of my depth, I had no time to prepare and felt ill equipped to try and support them.

However, I was absolutely the best person to try and support the family, I probably had the most experience in the full hospital of supporting bereaved children, despite having no formal training. The ICU staff had no time and also, like me, felt ill equipped, or probably even less equipped than I was. What can you say to children about to lose their mum? There was no dad, so grandma, was trying to cope with losing her own child and would now have to take on the care of her grandchildren. It was horrific.

Grandma wanted to spend some time with her daughter so I and the social worker sat with the children, we asked if they understood what was going on and answered any questions. I remember showing them the memory box which they really appreciated and we spoke about what they could put into the box, they both then wrote letters to their mum and said their goodbyes. My ICU colleagues were so grateful for the time I gave to this family, in reality I did very little but be with them and listen.

The next day the social worker came to meet me to collect the memory box, he was so upset. I will never forget how grateful he was for the support I gave him with the children, I honestly did not feel like I had done much at all. His manager had been very supportive and

gave him the afternoon off and a pack of beers, acknowledging what a difficult situation he had faced.

I was grateful he had good support but it made me sad for my nursing colleagues. I know that as soon as mum died, another patient would fill her bed. The nurses may be lucky to get a break before the bed was filled again. My two colleagues had the task of reading the children's goodbye letters to their mum, they have since told me how this still haunts them.

This once again made me realise how difficult it is for the majority of professionals supporting bereaved families, especially when children are involved. It also made me wonder that if professionals and adults do not push themselves out of their comfort zones and speak to children, this will leave them extremely isolated and scared. Yet, there is little if any support for professionals supporting families, it is just seen as 'your job'.

My experience working clinically during the pandemic reaffirmed the importance of my research and gave me even more desire to be able to make a difference to these families.

My clinical time was very beneficial, it gave me the opportunity to develop a new service that provided telephone support to families who had a loved on the Intensive Care Unit. I was also able to introduce bereavement support to those families, something that is not provided in normal times.

I found that families were extremely grateful for that support including a sympathy card and follow up phone calls. I also observed how staff were reluctant to undertake these calls as many feared they would not know what to say. The experience has made me realise there is so much more that could be done in the hospital setting to support bereaved families, there is also an eagerness of staff to do this, but they just do not know how.

Returning to the PhD has been difficult, having 6 months away has definitely been detrimental and has set me back, it has knocked my confidence and I feel I have not been able to pick up where I had left off as swiftly as I would have wished. Some of this is probably due to the experience I have had and gaining some clarity on what I want to achieve from my PhD means the focus has changed slightly and again getting used to the difference of clinical practice to academic work. I feel guilty that I am not working on the front line knowing how difficult it is for my friends and colleagues. However, the sooner my research is done, the sooner I can begin to help more bereaved families.

A service evaluation is underway, in 19 weeks the service supported over 400 families, making over 4000 calls. Bereavement support was offered to around 80 families. I also had the opportunity to present a virtual poster at the British Association of Critical Care Nurses conference, I have been asked to present the service to the Hospital Executive Team and the service has also been shortlisted for a Golden Hearths Award at HUTH under the category 'making it better'.

Whilst working in the hospital I was able to work closely with a team developed to specifically support all families bereaved in the hospital setting during the pandemic. That service like the ICU service has found that families were very appreciative of the support

and signposting they received. In normal times this extra support is not provided so I have been able to see the benefits of implementing bereavement support to families.

As a result of my time at the hospital I have become a member of the DAWN hospital bereavement support group. This group was a face to face group bringing bereaved individuals together offering bereavement support and a social group. Due to the pandemic the group had to stop. I am currently involved with setting up the group virtually. Before leaving the hospital, I spoke with 12 bereaved families, many of whom were having the same struggles, mainly being unable to visit their loved one whilst in hospital. This made me realise the potential benefit of bringing these families together for peer support. I mentioned the DAWN support group to all families to see if this would be something they may be interested in, every family I spoke to want more information and were interested in getting this support. This really made me realise that there is so much more that needs to be done and can be done to support bereaved families.

We have now had the first virtual bereavement meeting with good feedback, I will be continuing working with this group which will also benefit me when I come to undertake the qualitative interviews, if they have to be performed virtually I will already have experience of speaking to bereaved individuals using this method.

Having worked in the dawn group I have been able to invite some of those families bereaved in ICU. There are similar themes with how they are coping, what is common is how difficult it is for them not being able to visit during the weeks their loved one was in ICU, not knowing what was happening and relying on a phone call to have an update. One ladies husband died of Covid, he had a chance to speak to her on a video call before he was intubated but declined, she is upset that he chose not to as this would have given her one more chance to speak to him. Obviously, he did not know that he was going to die at that point. This particular patient was one I spoke to whilst setting up the new service, I remember him having his phone and saying he had been texting his wife. It feels so strange that I spoke to him and she never got that chance, this was at the beginning of Covid and we didn't know exactly what we were up against, I would hope things had changed since then and patients encouraged to use the video calls more however I'm pretty sure the calls will not happen so much because the staff are all so busy and unfortunately probably do not realise the importance of those calls.

Overall my time at the hospital has been very beneficial on a personal and professional level, allowing me to network with crucial staff members who are now aware of my research and may be involved with my PhD and also to allow me to have a clear direction for the PhD.

Whilst developing the new service I was able to learn what other hospitals were doing to support bereaved families and it has also made me realise that as a hospital there is more support that can be offered, what is unclear is what bereaved families actually would want from hospital staff. Overall, I think the time has helped me see the first-hand experience of bereaved families and help me focus on the PhD and what I would like to achieve.

Returning to the PhD has been difficult, having 6 months away has definitely been detrimental and has set me back, it has knocked my confidence and I feel I have not been able to pick up where I had left off as swiftly as I would have wished. Some of this is

probably due to the experience I have had and gaining some clarity on what I want to achieve from my PhD means the focus has changed slightly and again getting used to the difference of clinical practice to academic work. I feel guilty that I am not working on the front line knowing how difficult it is for the staff.

Jason and Barry have been very supportive of my return and what would happen if there was a second surge. TRANSFORM have issued guidance that any return would need to be carefully planned and approved. My thoughts remain that I would not want to return to full time clinical practice however I do remain apprehensive about the situation knowing of the impact the second surge is having. Seeing how my friends and colleagues are struggling is hard.

Appendix 2: Distress protocol

Distress protocol

In the event of a participant becoming upset during the interview, the researcher will follow the following procedure to manage the distress.

The grounding technique will be available, and the family will have had chance to use this at the 'get to know me' session.

- Stop the interview/research activity and allow time for the participant to calm down and compose themselves
- Participants will not be rushed
- Take time to listen
- Use grounding method if the participant would like
- When the participant is composed give them the option of taking a break, continuing, rescheduling or stop completely
- Remind them participation is voluntary
- Should participants wish to stop completely consent will be requested by the participant to use data collected up to that point
- Participants will all have been provided with a leaflet signposting them to relevant support
- At the end of the interview the participant will have the opportunity to speak to the researcher who is able to support the participant and guide them where they can access further support if required
- The researcher will make a courtesy follow-up phone call to the participant one or two days later to check their well being and available support

- For the case of a distressed child or a child who unexpectedly leaves the interview the same process will be followed and in addition the researcher will contact the parent/guardian by telephone to ask them to check the child is ok

Appendix 3: Stop and go cards

Stop/go cards

Stop/go sign to be used by participants during interviews



Appendix 4: Support sheets



Thank you very much for your time helping with me with this project. As part of the debriefing process, you will be given the opportunity to talk about any difficult memories or feelings or anything else that came up in the interview. Sometimes, talking about difficult life experiences can bring up difficult memories or feelings later on, after the interview has ended you may feel that you need some support or would like to talk to someone. The below websites provide different levels of support, including peer support, one to one support, counselling and more.

Support for children:

Childline gives information and advice about lots of different things, online, on the phone, anytime 0800 1111 <https://www.childline.org.uk>

Child Bereavement UK has lots of information on their website to support young people and you can talk to someone: <https://www.childbereavementuk.org/Listing/Category/support-for-young-people>

Child Bereavement Network has useful information about how to cope and how others can help <http://www.childhoodbereavementnetwork.org.uk/help-around-a-death/what-you-can-do-for-young-people.aspx>

Grief encounter also has a helpline <https://www.griefencounter.org.uk/get-support/children-and-young-people/secondary/>

Hope Again is a youth website, it is a safe place for young people dealing with the loss of a loved one: <https://www.hopeagain.org.uk>

Winston's Wish supports children and young people after the death of a parent: <https://www.winstonswish.org> They have a website especially for young people which gives advice and shares other young people's stories <https://help2makesense.org/>

UK Trauma Council Traumatic bereavement. Information for when you are worried about your child's struggles following a bereavement <https://uktraumacouncil.org/resource/traumatic-bereavement-guide-for-parents-carers>

Support for parents Day/Evening Support Lines:

Sudden Bereavement Helpline 0800 2600 400 Mon-Fri-10am-4pm, immediate support <https://sudden.org>

National Bereavement Partnership Helpline 0800 448 0800 7am-10pm- for emotional support <https://www.nationalbereavementpartnership.org>



Cruse 0808 808 1677 Nationwide bereavement support
<https://www.cruse.org.uk>

GriefChat Mon-Fri, 9am-9pm, live instant chat with a qualified bereavement counsellor
<https://griefchat.co.uk>

Grief Talk 0808 802 0111 Mon-Fri, 9am-9pm Support for anyone, 1-2-1 chat with Grief Talk counsellor <https://www.griefencounter.org.uk>

Marie Curie Bereavement Support 0800 090 2309
<https://www.mariecurie.org.uk/help/support/bereavement>

Survivors of Bereavement by Suicide 0300 111 5065, Mon-Sun, 9am-9pm helpline
<https://uksobs.org>

Sudden 0800 2600 400 providing help for suddenly bereaved people
<https://sudden.org/about-our-help/>

The Good Grief Trust will help you find local and national support services
<https://www.thegoodgrieftrust.org>

WAY Widowed & Young support, understanding and friendship, offering peer to peer support network, online support and 24 hour telephone line
<https://www.widowedandyoung.org.uk>

Do you need to speak to someone now?

24 Hour Support Lines:

Samaritans 116 123 (UK) For anyone at any time for any reason
<https://www.samaritans.org>

Childline 0800 1111 Support for 18 years and under and their relatives
<https://www.childline.org.uk>

Thank you very much for helping me with this project. After the interview you will be able to talk about any difficult memories or feelings that came up in the interview. Sometimes talking about difficult things can bring memories or feelings later on. You might feel that you need some help or someone to talk to. Please find below some useful places where you can get information and support.

These websites can give you advice on how to cope and share stories from other children and young people.



Childline gives information and advice about lots of different things, online, on the phone, anytime 0800 1111 <https://www.childline.org.uk>

Child Bereavement UK has lots of information on their website to support young people and you can talk to someone:

<https://www.childbereavementuk.org/Listing/Category/support-for-young-people>

Child Bereavement Network has useful information about how to cope and how others can help <http://www.childhoodbereavementnetwork.org.uk/help-around-a-death/what-you-can-do/for-young-people.aspx>

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Hope Again is a youth website, it is a safe place for young people dealing with the loss of a loved one: <https://www.hopeagain.org.uk>

Winston's Wish supports children and young people after the death of a parent: <https://www.winstonswish.org> They have a website especially for young people which gives advice and shares other young people's stories <https://help2makesense.org/>



Appendix 5: Participation letter



UNIVERSITY
OF HULL

INSTITUTE FOR CLINICAL AND
APPLIED HEALTH RESEARCH

Date

Dear,

Re: Research participation to explore how we can best support children and families following the death of a parent.

Thank you for expressing an interest to participate in the above project to support families when a parent has died. As discussed, please see attached participant information sheets for you and your child/children containing detailed information regarding the purpose of the study and what participation would involve.

If you have not already, I would like to invite you to a virtual 'get to know me' session on zoom so you can find out a little about me, my background, why I'm doing this research and can ask any questions.

Please kindly read through the information sheets and if you are happy to proceed with your participation, please sign the attached consent form and post back in the attached pre-stamped addressed envelope within 2 weeks of receiving this pack, to myself at the address below.

Once I receive your signed consent form, I will contact you again to arrange a time that is convenient for you for the interview.

I look forward to hearing from you again soon. If there are any questions about any aspect of the study, please do not hesitate to contact me.

Yours sincerely,

Alex Wray

Alexandra.Wray@hyms.ac.uk

07423508088

Address to return consent form:

For attention of Alex Wray (ICAHR)
1st Floor, Allam Medical Building
The University of Hull
Cottingham Road
HULL
HU6 7RX



Appendix 6: Participants information sheet - parents



Participant Information Sheet: Parent/Guardian

Supporting families when a parent has died

My name is Alex Wray, I am an experienced nurse and support families with bereavement in the local hospital. I am also a researcher in the medical school (Hull York Medical School). I am doing a PhD research project supervised by Dr Boland, Professor Murtagh and Professor Wright. I want to meet families who have experienced bereavement to ask what their experiences are and what their opinions are of the best ways to support children and parents after the death of a parent. I am asking if you would like to take part in the project.

Before you make your decision, this leaflet gives you information about why the study is being done and what it will involve. Please read this carefully and feel free to ask any other questions. Talk to others about the study if you wish and take as much time as you like to decide.

What is the purpose of this project?

It may sound difficult to consider talking to me about your experience and I apologise in advance if the thought of this is distressing. I am undertaking this project to make improvements in how children and families are supported. I am very aware that this is a sensitive subject. However, it is also very important that we understand better. Very little research has been carried out with children and families following the death of a parent. Listening to the views and experiences of children and families, I hope we can improve how other bereaved families are supported.

I hope to speak to 30 parents and their children.

Why me and my child/children?

I am asking you to take part because of your experiences of the death of a partner and parent to your child.

Do I have to take part?

It is completely up to you and your child to decide if you would like to take part. I will invite you both to take part, but you can take part without your child or your child can take part without you, if you give them permission. If you decide to take part, you will both be asked to sign a form saying you are happy to take part. You are still free to stop at any time without giving reason.

What would I be asked to do if I took part?

If you decide to take part in this project, I will arrange a suitable time for you to meet me on Zoom or the telephone to answer any concerns or questions you may have. You will be asked to do two main things:

- Participate in a recorded interview with me lasting approximately one hour, this can be via Zoom or the telephone
- Consent to your child/children's involvement if they are happy to participate (but not if you or child do not want to do this).



For a small number of people very interested in helping us there are some other things that you could help with, but these are completely optional and include:

- Possibly participate in follow up interviews but only if you would like to
- Have the opportunity to help plan how findings will be shared

After the interviews I will check that you and your child are ok. I will also send you and your child an anonymous questionnaire to complete about what it was like being involved in a research project.

What would the interview be like?

The interview will take place using zoom or the telephone and it will be a little like a conversation. I will ask you to talk about your experiences following the death of your partner. I will ask questions about what you and your child needed at that time, how you and your child supported each other and how those around you gave support.

While people sometimes find it helpful to talk about their story to researchers this research is not the same thing as counselling. However, I will give everyone a list of useful contacts which can be used to get more help if you want.

What if I'm concerned about my child's involvement?

It is normal to be concerned and want to protect your child. You and your child/children will have the opportunity to get to know a little about me and the project before you decide to take part. This will allow you the opportunity to ask any questions or voice any concerns you may have.

It is ok for you to meet me first and have your interview before you decide if your child would like to take part.

If your child decides they would like to take part I will schedule a time and date that is convenient for you both. Your child can choose if they would like you present for all, some or none of the interview.

Similar research with bereaved children has found that they enjoyed being involved in the research, giving their opinions and having the opportunity to speak about their parent was helpful. They often wanted to take part in the research to help other children like them.

If your child does get upset, I will support your child, they will be given time to calm down and be given the choice to continue, reschedule the interview or stop. I will also let you know and check they are alright following the interview. Distress is not always experienced as harmful, it can be cathartic and beneficial to help someone make sense of their experience.

If you or your child requires further support following your interviews, I will be able to talk to you about this and signpost you to relevant support.

Will my participation be kept confidential?

Yes, anything you say during this research will be kept strictly confidential unless you reveal something which indicates the likelihood of harm to yourself or others. In that case, I may need to raise the matter with the relevant people or agencies.



The interview will be recorded and then transcribed word for word from the recording and stored securely on a password protected computer and only accessed by relevant research staff. Once this process is complete the recording will be erased. Your name and the name of your child will not appear on any electronic transcripts, reports or published papers. However, quotations about you or your child's experience may be used anonymously in the reports.

What are the possible benefits of taking part?

There may be no direct benefits to you as a participant taking part in this study. You will not be paid for your involvement, and the only cost to you, will be the cost of your time participating. However, the information you provide may prove beneficial for helping us understand how we can best support children and families who experience a similar set of circumstances to yourself.

I realise that taking part in this research may be upsetting. Should you be interested in participating in the project I will meet you before consenting to any involvement for a discussion about the study and as an opportunity for you to talk about any concerns you have either in relation to you or your child taking part and/or how you have been managing since your bereavement. During the interview if anything is upsetting for anyone, they will be given the choice to take a break or stop the interview.

Who has checked the project?

The project has been reviewed by Hull York Medical School Ethics committee, on 10/06/2021 (ref XXX)

What if there is a problem?

If you have a concern about any aspect of the project, you can speak to the Alex who will do the best to answer your questions. If you wish to place a complaint, please contact:

Maureen Twiddy - Institute for Clinical and Applied Health Research
University of Hull, Hull, HU6 7RX.
01482 463279 Maureen.Twiddy@hyms.ac.uk

Who can I contact for more information?

I hope this information sheet has told you what you need before deciding whether or not to take part. If you have any questions at all about the project or would like to chat to me before you make your decision, please e-mail or telephone me directly on this mobile number dedicated to the project:

Alex Wray **07423508088**

Alexandra.Wray@hyms.ac.uk

Allam Medical Building
The University of Hull
Cottingham Road
HULL
HU6 7RX

Thank you for reading this information sheet.

Appendix 7: Participants information sheet – children aged 14-18 years



Supporting families when a parent has died

Participant Information Sheet: Young people aged 14-18

My name is Alex Wray, I am a nurse and a researcher at Hull University. I am doing a university course to carry out a research project. We are asking you and your family to take part in helping us answer this question:

How can we best support children and families when a parent has died?



Before you decide if you want to join in, it is important that you understand what the project is about, why the project is being done and what it will mean to take part. Please read this leaflet carefully with your family. If something doesn't make sense or if you have any questions, you can ask your parent to give me a call and we can arrange a chat.





Why are we doing this research?

To see what children and parents need and how they want to be supported by each other and those around them when a parent has died. Sometimes when a parent dies you can feel alone. Other people do not always know what to say or how to act and may not know how they can best help you. We want to find out what families, friends and those around you can do to best support and help.



Why have I been asked to take part?

You have been chosen to take part in this research because you understand what it is like when a parent has died.

Do I have to take part?

No. It is your choice to take part in the study. If you decide to take part but then want to stop you can always change your mind. You can stop being involved in the project whenever you want, and you do not have to give a reason why. Just tell your parent or me.

What will happen to me if I take part?

- I will meet you and your parent so you can get to know me and decide if you want to join the project
- If you want to take part, you will sign a form and choose when you would like your interview using Zoom
- After the interview I will send you a questionnaire about what it was like being involved with the project

Will it help me?

Sometimes it can be upsetting talking about difficult things, but many young people say that it can help to talk to someone outside the family. I have spoken to lots of different people when someone they loved has died. I hope that what I learn from speaking to you and other young people will tell me how we can help other families when a parent has died.



What will the interview be like?

The interview is just like a conversation. I will ask you some questions. There are no right or wrong answers. I'm very interested to hear about what it was like for you and what you have to say. I will send you some activities that we can do while you are answering the questions, but you do not have to do them, it is up to you.

What will you ask me?

I will send you a list of the questions to see before the interview. The questions will be about you and your family, how you supported each other and who else supported and helped you. You do not have to answer any questions that you do not want to. I will send you a green and red card so you can stop if you would like a break or to move onto another question.

Who will be there?

You and me. If you would prefer your parent to join us that is ok. It is your choice.



How long will it take?

The interview will take about 30 minutes, but it can be longer if you have more things you want to tell me.

What if I don't understand?

If there is anything you don't understand or you have questions at any time you can ask me to stop and explain.





Who has reviewed the study?

Before any research is allowed to go ahead it has to be checked by a group of people called the Research Ethics Committee. This is to make sure that the research is fair and safe.

There is a lot of information here, hopefully this sheet has answered any questions you might have.

If you think you might be interested in taking part or have any questions before you decide, ask your parent to contact me to arrange a chat, ask me any questions you like.

Thank you for reading this form.

Alex's contact details:

E-mail Alexandra.Wray@hyms.ac.uk

Telephone number: 07423508088



Appendix 8: Participants information sheet – children aged 10-13 years



Supporting families when a parent has died

Participant Information Sheet: Children aged 10-13



My name is Alex Wray, I am a nurse and a researcher at Hull University. I am doing a university course to carry out a research project. We are asking you and your family to take part in helping us answer this question:
How can we best support children and families when a parent has died?

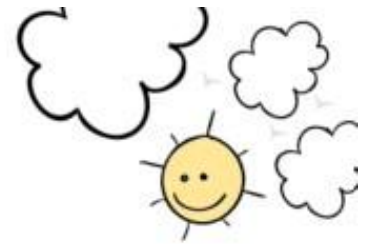


Before you decide if you want to join in, it is important that you understand what the project is about, why the project is being done and what it will mean to take part. Please read this leaflet carefully with your family.



Why are we trying to answer this question?

Sometimes when a parent dies you can feel alone. Other people do not always know what to say or how to act and they may not know how they can best help you. I want to find out what families, friends and those around you can do to best support and help you.



Do I have to take part?

No. You don't have to if you don't want to. It is up to you to decide. If you take part, you can always change your mind. You can stop taking part in the project whenever you want, and you do not have to give a reason why. Just tell your parent or me.

Why have I been asked to take part?

You have been chosen to take part in this research because you know what it is like when a parent has died.

Will it help me?

Sometimes it can be upsetting talking about difficult things, but many children say that it can help to talk to someone outside the family. I have spoken to lots of different people when someone they loved has died. I hope that what I learn from speaking to you and other children will tell me how we can help other families when a parent has died.

What will happen to me if I take part?

1. I will meet you and your parent and see if you want to join the project. You can get to know me and ask any questions first.
2. If you want to take part, you and your parent will sign a form.
3. I will ask you to choose a day and time when you would like to have your interview
4. After your interview I will send you some questions to answer about being in the project



The Interview

What will you ask me?

I will send you a list of questions, so you know what I'm going to ask. There will be some questions about you and your family and what it was like when your parent died, what you needed and who and what helped you.

You do not have to answer any questions you do not want to. You will have a green and red card so you can stop the interview if you would like a break or to move to another question.



What will the interview be like?

The interview is just like a conversation. I will ask you some questions. There are no right or wrong answers. I'm very interested in what you think and what you have to say. I will send you some activities that you can do while you are talking if you would like.

How long will it take?

It should take about 30 minutes, but you can talk for longer if you have more things you want to tell me.



Who will be there?

You and me, if you want your parent can be there, it is up to you.

What if I don't understand?

If you do not understand something or have any questions just tell me.



Will I get upset?

You might do or you might not. You might enjoy telling me about your parent and family. If you do get upset during the interview, that is ok. I have an activity to help. I will give you some time and you can decide if you want to move to another question, have a break, or stop. I might ask your parent to check that you are alright afterwards.

Will the information I give be shared with other people?

What you say to me is completely private – it is between you and me and I will not tell anyone else what you have said. The only time I would tell would be if I was worried about you or someone else. If that happened, I would talk to you and your parent.

I will record our conversation so that I can remember everything you tell me.

You will choose a made-up name. I may use some of the things you and other children have said in my report, but no one will know it was you who said it.

The information from what all of the children and families tell me might be written in journals or books and might be talked



What happens after the interview?

I will check that you are ok, and you will have my details if you would like to ask me any questions. After the interview I may ask if you want to check what I have written, take part in another interview or if you would like to help plan how to share what we have learnt. You can choose if you want to take part in those or not.

At the end of the project, I will ask if you would like to be sent a summary of what I have found.

There is a lot of information here, hopefully this sheet has answered any questions you might have.
If you think you might be interested in taking part or have any questions at all ask your parent to contact me to arrange a chat.



Appendix 9: Consent form - parents



Supporting bereaved families

Parent Consent Form

Name of lead researcher: Alex Wray

Please initial each box

- I confirm I have read and understood information sheet for the above project which explains what the research is about and what my involvement will be. I have had time to think about the information and the opportunity to ask questions.
- I understand that taking part in this project is voluntary and I know I can withdraw from the study at any time without giving any reason.
- I understand that my child, with my permission will choose if they want to take part in the project. If my child chooses to be involved, I understand they can withdraw from the project at any time without giving any reason.
- I give permission for our discussions to be recorded and understand after the recording the discussions will be written down and the recording erased.
- I understand that any information or quotes (exact words) used from this project will be completely anonymous and that we will not be able to be identified.
- I understand we can discuss the project with the researcher at any time.
- I agree to be contacted if needed for further information following our interview.
- I agree to take part in the project.

Name:

Signature:

Date:

Contact number:

Address:

I agree for my child to have the opportunity to take part in the research should they wish. Child's name:

Parent Signature:

Date:

Thank you for your help

Appendix 10: Consent form – children (aged 14-18 years)



Supporting families when a parent has died

Young Persons Consent Form

If you agree with the statement, please write your initials in the box

I have read the information about the research she would like to do. Alex has explained the project to me. I have had the chance to think about the information and ask questions and these have been answered.

I know that Alex will ask me to choose a day and time when I'm free to talk to her. I am happy to talk to Alex about who helped me when my parent died and what I needed. I understand I do not have to answer any questions I do not want to.

I agree that Alex can write about the things we talk about, and I understand my name will not be mentioned anywhere in the project.

I understand that if I do not want to be part of the research I do not need to be, and I can leave the project at any time, and I do not have to give a reason.

I understand there may be further opportunities for me to be involved with the research, further interviews and group sessions to talk about the findings and plan how those can be shared to help other children and families. I am happy for Alex to ask me about those and if I would like to take part.

I understand that I can discuss the project with Alex at any time.

I agree to take part in this research project.

Name:

Signature:

Date:

Thank you for your help



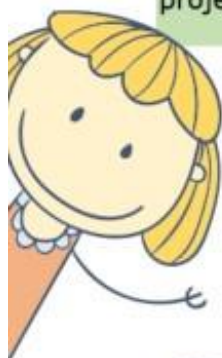
Appendix 11: Consent form – children (aged 10-13)



**Supporting families when a parent has died
Children's Consent Form**

Please draw a circle around Yes or No for each question

Have you read the information about the project?	Yes	No
Has somebody talked to you about the project?	Yes	No
Do you understand the project?	Yes	No
Do you want to ask any questions about the project?	Yes	No
Do you understand that you can stop taking part in the project at any time?	Yes	No
Do you understand that your name will not be anywhere in the project?	Yes	No
Do you understand there may be other times you can help with the project; you can choose if you want to take part in any of those or not?	Yes	No



Name:

Date:

If you would like to take part in the project, please write your name and today's date below:

Thank you for your help




Appendix 12: Grounding technique


Grounding technique

5 4 3 2 1

SLOW DOWN & CALM DOWN


FIRST- TAKE 3 SLOW BELLY BREATHS!

5 List 5 things you can SEE 

4 List 4 things you can FEEL 

3 List 3 things you can HEAR 

2 List 2 things you can SMELL 

1 List something you like to TASTE 

FINISHED? - TAKE ANOTHER 3 SLOW BELLY BREATHS

Appendix 13: Topic guide - parent

Topic Guide – Parents

Introduction

- Welcome participant and introduce self ('get to know me' session will have been completed prior to interview)
- Confirm participant has had a chance to read the participant information sheet and is aware of purpose of interview, the aim of the interview is to explore how families can best support each other and be supported by those around them when a parent has died.
- Explain format of interview, We will start by talking a little about you and your family, about what happened to your husband and what life was like for you all, I will ask about how you and the children supported each other and how those around you may have supported you. Although I will be asking you questions you will lead what we talk about and if there is anything you think is important, we do not cover please let me know.
- Explain consent procedure, the presence and purpose of recording the interview and double check consent form has been signed and received
- Address confidentiality
- Explain participation is voluntary and it is ok to stop at any time, if you need a break that is fine
- Any questions before we start

Rapport building: Background and introducing death of partner

To explore their family, home life situation and learn about their deceased partner. Also, to ask why they wanted to take part in the project.

To start off please can you tell me a little bit about yourself?

Who are the main people in your family? Are you close?

How important is family? Has this always been the case?

Do you have friends you would describe as family?

If I were to ask you to describe [name] what would you say? (eg: personality, likes and dislikes, favourite places/activities)

Where and when did you meet?

Proposed Interview Questions:

The following topic will be used to open up discussions in line with the study objectives. Participants will be allowed to lead the discussion whilst the researcher will use prompts where necessary.

Would it be ok now, if I ask you to tell me your story of what happened when [name] died? If the death was from a long-term illness, ask about the days just before their death, involvement with services, where they died etc

Objective 1: To investigate the experiences of support for children and surviving parents' following the death of a parent.

- And how have things been since [name] died?

Objective 2: To explore children's and surviving parents' perspectives of support needs and the needs of each other following a parental death.

- When (name) died what was life like for you?
- Could I ask what it was like to become a single parent? How did you feel/manage/what was most difficult?
- How did your role as a parent change?
- What did you need at that time?
- what did the children need at that time?

Objective 3: To understand how children and surviving parents support each other following the death of a parent.

I can't begin to imagine how difficult it must have been for you. I just wondered if and how you and the child(ren) were able to support each other.

- Did you feel confident in supporting the children?
- Were they able to support each other? How? What helped? What didn't help?
- How did parent support child?
- How did child support parent?
- Has your relationship with each other changed? *In what ways?*
- How did communication change between parent and child?
- Is there anything that could have helped you at this time?
- Looking back is there anything you wish you had done differently?

Objective 4: To explore how existing support networks can provide a supportive response and why it is helpful.

- And what about in terms of support from others? Who gave you support? Both formal and informal.
- And what was that support like? Experience and quality of support since the death
- Explore what support has been accessed, how and why and where from (friends, work, neighbours)
- How long did the support from those around you last?
- Was there anyone in their network who helped?
- How did they help and how were they supportive?
- What didn't they find helpful or supportive?
- What can support networks do to best help families?

Objective 5: To consider suggestions for how children, surviving parents and their existing networks can provide a supportive response.

- What is a supportive response?

- What advice would you give to other bereaved parents/children about supporting each other?
- What advice would you give to those around a bereaved family in terms of what can help?
- In an ideal world what support should be available to families?
- What do you wish you had known back then?

Closing

- Check if there is anything else not covered in the interview, they would like to discuss
- Ask if they have any questions or anything else they would like to discuss
- Check their wellbeing, ask if they would like a call in a couple of days to check how they are doing.
- Thank the participant for their time and re-emphasise confidentiality
- Check they are comfortable to be contacted for a further interview if necessary and to help design the findings to be family friendly
- Ask if they would like a summary of findings when available

There will be time at the end of the interview should the participant wish to ask the researcher about support services or reflect on the interview.

Appendix 14 – Topic guide (children)

Topic Guide – Children and young people

Prior to the interview all participants will have been involved in a rapport developing session with the researcher. The participant will have an activity pack which will include some of the broad questions for the interview, grounding exercise, emotion blobs, mapping activity, plasticine, start/stop cards.

Introduction

- Welcome participant and thank them for taking part today.
- Check the participant has read the participant information sheet and is aware of the purpose of the interview.
- Check they have activity pack and pens.
- Discuss purpose and length of interview. Today we are going to talk about you, your family and what it was like for you when your mum/dad died, if there is anything that you don't understand don't worry just let me know.
- Recording of interview- check it is okay to record and explain that it is beneficial for the purposes of accuracy. Reassure participant that no one else will see or hear the recording but me.
- Confidentiality – confirm that anything said will remain private unless you say something that makes me worried for you or someone else. All personal data will be kept safely by me.
- Anonymity- All data will be anonymised, ask child for their made-up name, if they don't have one a name can be allocated.
- Participant focus – the topic of conversation will be guided by the participant and what they want to talk about. Reassure participant we can take a break or move on if anything is too upsetting to talk about. We can return to the topic later if they want to.
- Ability to stop – confirm we can stop anytime; they just need to hold up their red card or say stop. We can stop for a break, until another time or they can stop their participation in the research entirely. I will also look out to see if you might need a break.

Questions

- Do you have any questions before we start?
- Is there anything you are not clear on?

Emotion game – researcher and participant each pick an emotion blob about how they are feeling before the interview.

Rapport building: Background and introduction of bereaved parent

- Can you tell me a bit about yourself? What do you like doing/not doing etc?
- What school do you attend?
- What do you like to do for fun?
- Who do you like to spend time with?

- What have you been doing in the holidays? I have only spoken to you and your mum, who else is in your family Who is in your family?
- Can you tell me about how your family has changed?
- I did not know your mum/dad, please can you tell me a little bit about her/him?
 - Prompt: photo
 - Prompt: what did you enjoy doing with them the most?
 - Prompt: was there anything special you did with them?
- Can I ask what happened to your mum/dad? And how have you been doing since they died?

Proposed interview questions

The following topics will be used to open discussions in line with study objectives. Participants will be allowed to lead the discussion whilst the researcher uses relevant prompts where necessary.

Objective 1: To investigate the experiences of support for children and surviving parents' following the death of a parent.

- What was it like when your mum/dad died?
- How was it at home? Probe: what was different/same
- Who looked after you?
- Was there anything or anyone that helped you?

Objective 2: To explore children's and surviving parents' perspectives of support needs and the needs of each other following a parental death and Objective 3: To understand how children and surviving parents support each other following the death of a parent.

- How were you feeling?
- Did you have any worries?
- Was there anything that helped you?
- Who did you talk to?
- Did you talk to your mum/dad?
- Did your mum/dad know how you were feeling? If not, why not? If yes, and what did they do?
- Is there anything else they could have done to help?
-
- What was it like for your mum/dad?
- Did she/he speak to you about what was happening, how they were feeling?
- Were they worried about anything?
- Was there anything you did to help your mum/dad? Probe: extra roles and responsibilities, modifying behaviour.

Objective 4: To explore how existing support networks can provide a supportive response and why it is helpful.

- What were other people like after your mum/dad died? Probe: what was different, what was said or not said
- Did anyone say or do anything to help you?
- Who helped you the most after mum/dad died?
- Who else helped you?
- What can other people do to help you?
- Have you ever met any other people whose mum or dad has died? How was that?

Objective 5: To consider suggestions for how children, surviving parents and their existing networks can provide a supportive response.

- When a child loses their mum or dad is there anything their family or those around them can do to help?
- What advice would you give to a child who has lost a parent?
- What advice would you give to their parent and those around them?
- What about formal support? Would it help so speak to someone outside the family? Who? Professional, someone who has had a similar experience.

Creative methods to be used as required

Mapping

Aim: To map relationships and support by writing or drawing those who helped and supported the child.

Draw/write self and those who supported you around.

Vignette task

Aim: To help elicit insights whilst minimising exposure, using fictional characters to allow a discourse to open. The researcher designs a starting point to match the participant and their experience and the participant can fill in the story, give advice and describe the best outcome. In this case this would be describing what others can do to help a bereaved child and family.

Example Vignette: Billy is 13 years old; he lives with his dad; his mum has died. He feels like he is alone and had no one he can talk to.

What advice can you give him?

What should we tell his dad and the people around him to do to help?

Plasticine

Aim: Used as a parallel activity while the discussion is going on. Both participant and researcher can make a model which the participant can choose, for example their favourite animal.

Conclusion

Has anything been missed?

We are coming to the end of our interview now, I wondered if there was something I have missed or something else you wanted to tell me?

Emotion game – researcher and participant pick an emotion blob about how they are feeling after the interview?

Next steps

- Thank you again for giving your time to take part in this research. Your answers and information are very important.
- During our meeting I know some of the things that we discussed were hard for you to think and talk about. Do you feel okay now? Would you like to talk to me or ask me anything?
- If you need to talk to someone about the research or what we did today, feel free to contact me. My contact details are on the information sheet.
- I will now go away and type up what we have said today. It will be added to the information I have gathered by speaking with other children and I will start writing the report. Would you like to help design how we present findings, and would you like a summary of the report once it is finished?

Appendix 15 Ethical approval letter from Hull York Medical School Ethics committee



Hull York Medical School

Hull
University of Hull
Hull, HU8 7RX, UK

York
University of York
York, YO10 5DD, UK

T 0870 1245600
info@hyms.ac.uk
www.hyms.ac.uk

27 July 2021

Ms Alexandra Wray
Clinical Research Fellow
Hull York Medical School

Dear Alexandra,

21 34 – How can children and families best support each other following the death of a parent and how can those within their existing networks provide a supportive response? (Supporting families when a parent has died)

Thank you for submitting your application to the HYMS Ethics Committee. The application has been reviewed on behalf of HYMS Ethics Committee with respect to the documents received on 16th July 2021.

I am pleased to inform you that I do not have any HYMS specific ethical concerns and am happy to confirm HYMS Ethics approval.

On behalf of the Ethics Committee, we wish you success with this study.

Kind regards

Yours sincerely

A handwritten signature in black ink, appearing to read "Sathyapalan", written over a horizontal line.

Professor Thozhukat Sathyapalan
Chair
HYMS Ethics Committee

Appendix 16: Key findings from Patient and Public Involvement (PPI)

Summary of public involvement

Acceptability of this study for bereaved families

The YPAG and public involvement group thought the research was essential and that bereaved children and parents would want to participate. The bereaved families confirmed that families do struggle to access support or know where to turn. For example, one family were in the process of setting up their own bereavement charity. A child shared how she had recently spoken to a school friend; he apologised that he could not understand how she felt when her dad died. His dad had just died; he had no one to talk to and did not know what to do. He was trying to be strong for his mum and sister, so he could not talk to them. She remembered feeling the same. Understanding these families' experiences resulted in the researcher developing signposting leaflets, which were sent to participants about what support was available.

The public involvement work demonstrated that it is essential to speak to bereaved children and families about their experiences; with all bereaved children and parents agreeing that everyone has a right to be involved and asked about taking part, it is up to them if they accept. Thus, the study suggested adopting an opt-in approach, so bereaved families will be given information about the project, and it will be up to them if they would like further information or to be involved. The families thought this was good as participants would not feel pressured to participate. One bereaved father said he would rather be asked to be involved than not considered. Bereaved people appreciate being listened to; he thought people would be pleased to be asked to be involved, a bereavement is a massive event for you, and if no one wants to know more about it, that would not feel right; people will appreciate being asked and sharing their experience. He recalled being invited to share his bereavement story with the hospital a few months after his wife's death, and he was pleased to have been asked and that someone was interested. A mother said if she wanted to participate, she would; if she did not, she would not; she would not be offended to be asked. Another mother said a year earlier she would not have been able to talk about it; now, three years later, she felt she could. Most parents could recount times when they had been avoided as they were bereaved, and people did not know what to say, so they would welcome an opportunity to share their experience and be able to help others going through a similar situation. A bereaved young person strongly believed in asking children about their experiences; he said you might be the only person who asks that child. People put their shields up when it comes to death as it is a difficult topic to discuss, but you cannot shy away from it. Children do need to be involved as they are the only ones who know what it is like; he described feeling alone in his experience at the time and suggested we need to break down the stigma of talking about death as everyone is going to experience it, talking about it helps people realise they are not alone. The experiences of these families highlighted the lack of support and the importance of involving children in this research to understand their needs and what support they require.

Design considerations

Both groups contributed to the acceptability of interviews and a consensus that using Zoom was acceptable for children and adults. They also agreed that the minimum age is 10 for virtual interviews, which was supported by professionals providing bereavement support virtually. In addition, both groups have inputted into the research design, including the information families would need before taking part, the importance of developing rapport, what families need to know about the researcher, ensuring participants have the broad interview questions prior to their

interview, how to make the interviews more appealing and child friendly, and how to support participants who could be distressed.

They advised how to recruit families and how soon after their bereavement, a family may want to participate. They were clear that being handed a project recruitment flyer immediately after their bereavement would not cause further distress. It would provide an opportunity to share their story if they wanted to. All families agreed that bereaved people would only participate in the project if they felt ready to do so, and you could not put a time frame on when this would be as it is so individual.

Both groups fully supported the study and provided advice and feedback on the study's design. All study information has been reviewed and amended accordingly to ensure information was understandable, age-appropriate, and contained sufficient information about the study, including recruitment flyer, participant information sheets, consent forms, support signposting leaflet, and how to support someone becoming distressed and interview topic guides.

Undertaking research with bereaved families

Undertaking public involvement with the target group for the study has suggested that recruitment will be difficult, and these children and their parents are extremely hard to reach. Professionals within services and parents may act as gatekeepers to granting access to children and families, highlighting the need for a broad sampling strategy.

Gatekeeping was experienced with a parent who wanted to participate in public involvement but not her child. However, once she met the researcher, she changed her mind and felt comfortable with her child participating. Another example was when the researcher met with a bereavement service to tell them about the research and gauge interest in recruiting families. At the end of the session, the professional said they came to the meeting reluctantly, feeling very protective, wanting to look after their families, and anxious to be involved with the research. Having met the researcher and found out about their background, experience, plans for undertaking the research, and how the findings could help bereaved families made them change their minds. They said they would feel comfortable telling their families about the research knowing they would be in safe hands. All groups felt it was important for participants to know the researcher's background and were surprised to learn about the researcher's previous experiences as an experienced nurse in end-of-life care. One parent said knowing the researcher's background made them feel safe and know the researcher could handle whatever they shared. Public involvement gave assurance that families found the researcher to be supportive, friendly, and approachable, and parents would not have any concerns for themselves or children participating in an interview with the researcher.

Public involvement highlighted the need to develop relationships and build trust and rapport with professionals and parents to help them feel safe and confident with the researcher and comfortable with participation. Children also needed to get to know the researcher before the interview.

The researcher has developed relationships with professionals working within the field through informal meetings to achieve this. Parents would initially speak to the researcher over the phone, and if interested in participating, they and their child(ren) would be invited to participate in an optional 'get to know me' session with the researcher. A 30-minute session via Zoom would allow participants to feel comfortable with the researcher, acknowledging that some may find a one-to-one interview intimidating and inhibiting, especially when talking to a stranger (Brady & Graham 2019). Families could learn about the researcher's personal and professional background through a PowerPoint presentation with photos. The presentation explained why the researcher was

undertaking the project and allowed participants to ask questions. Both groups saw this session necessary to build rapport and develop a trustworthy relationship with families (3). The session was piloted and received positive feedback. They found the session informative and friendly, with enough information about the researcher and project to decide to participate. They appreciated the researcher's honesty and how they opened up to them about their family situation, which included their parents divorcing as a child. One child gave feedback on this session, saying it was nice to know about my family and that I knew what it was like not to have a dad. When I reflected on this, I realised it had not crossed my mind that my experience of losing a parent through divorce as a child may have some resonance with the families I would encounter. Children also said they would feel comfortable talking to the researcher alone, and without worry, they would be asked something they did not want to answer as they felt ok to say I do not want to answer that question. One child said, 'If I lost my dad now, I'd be happy to speak to you. It is nice to have someone understand what we are going through. You are lively and energetic; you really want help people'.

Children and young people in the YPAG and some bereaved families were asked what would help them feel comfortable sharing their experiences. Children agreed they might speak more honestly if not with their parents. Older children said they would feel comfortable and prefer talking to the researcher alone. Younger children thought they might like their parents with them, at least at the start of the interview. Children also suggested the 'get to know me' session, and being sent some questions before the interview so they would know what to expect would help. They emphasised the need to be flexible and adaptable with what children wanted and suggested you could do some of the interviews with the parent, and then they could go away to make a cup of tea if the child was happy for them to do so.

Public involvement highlighted that research with children requires an evolving and dynamic interaction requiring the researcher to be flexible, adaptable, and responsive to the individual needs of participants. The child could use several activities during the interview, including drawing, mapping, and vignettes. These activities will not add to the research findings but act as a distraction to make the interview less formal.

Considering Dissemination

Both groups suggested they want to know what has come of their participation. They participated in these sessions to make a difference to bereaved families, and they felt this study had the potential to make a difference. One teenager said that no child would read a thesis; there needs to be a short, snappy, child-friendly summary of findings. Some families wished to continue their involvement and follow the project to the end. All those who participated will be updated on the study progress, and some will be invited to review the findings as they develop and offer suggestions on how findings can be disseminated.

Appendix 17: Parent findings used for member checking

Categories	Subcategories	Summary
Learning to live without them	Trying to accept and cope with the death	Being angry with deceased, being on your knees before they died, death is a shock, experiencing physical symptoms, doing the practical things, ways of coping
	Putting everything into the children	Making the decision to live for your children, they can't lose two parents, neglecting your own needs, life goes on around you
	The weight of responsibility	Feeling the burden of being in charge, everything flowing through you, difficulties making decisions on your own and question all the decisions you make, constantly juggling
	Worrying for yourself and the children	Worry for your own health, financial worries, worrying about the impact of the death on the children, losing the deceased as a role model (male/female figure), the impact of dying in the home
	Learning to live without them	Having no choice but to cope, learning new roles, miss sharing the happy times, constantly juggling, you change, you always have bad grief days, missing how things were before
	Thinking to the future	Realising what you have lost, fear for meeting someone new and experiencing this pain again, accepting you will be happy again, appreciate life, having your wings clipped
Being picked up and carried	Work understanding the impact and giving flexibility	It helped when work recognised your needs, you didn't have to worry about pay, had flexibility, some felt guilty not being at work but having full pay, some had to change jobs, lack of sustained support
	Seeking out and experiencing professional support	Timing of access, reasons for accessing- self or kids, and what worked well – including ongoing support with people you met pre-bereavement, services being together and having guidance, giving parents support to support their children, face to face support, tailoring needs to suit individuals, having someone listen to you who understands, services reaching out to you, reassuring knowing help is there.
	How others are supporting them well	Recognising individuality of support, the community rallying around and going out of their way to pick you up and carry you through this, giving practical support. At times could be overwhelming, people stepping up you wouldn't have expected, sustained support, pulling on supporter's strengths, when people just get on and do, feeling that people care and you are not alone, practical help, talking openly about the deceased, asking for and accepting help.
	Being supported by school	Importance of school support, reassuring when it is good, staff have bereavement training, awareness of impact of grief, support tailored to child, communication between school and parents, immediate professional support being available.

	Bereaved peer support – finding the door to Narnia	You feel on your own then find widowed peers and it's like going through the Narnia wardrobe, you are not alone, these people get it, what you are feeling is normal, connecting with someone who understands. Peer support isn't for everyone.
	Feeling lucky with support received and wanting to help others	Those parents who had received good support felt they were the lucky ones, realising not everyone has that experience. Parents want to share their story to help others who are going through this.
Winging it, supporting the kids with no rule book	Having no idea to support a grieving child	Parents do not know how to support their children, they want reassurance what they are doing is right or if they are damaging them further, worry you have done a bad job, lack of confidence in their abilities.
	Being open and honest goes against everything you want to do as a parent	Breaking the news of the death, giving reassurance, reluctance from children to talk, difficulties answering questions, being open and brutally honest, language you use.
	Empowering and involving the children	Involving them in decisions, giving them an informed choice, don't want them to look back and regret not doing something or not having a choice.
	Finding your own ways of grieving	Within the family each of them grieves differently, even the children have different ways of grieving which parents must learn, crying together, holding in grief, kids struggling to see parents cry.
	Children are growing up to soon	Children are protective and worrying for parent, they are stepping up at home, surprising how they cope, parents put themselves into child's shoes, try to establish a new normality.
	Remembering the deceased	Talking about the deceased in everyday life so it becomes normal and they are still a part of their lives, having keepsakes, having rituals for anniversaries or birthdays.
Becoming alienated	Alienating yourself	Seeing complete families reminds you yours is broken, avoid socialising, feeling judged, needing someone to trust to talk to honestly, hiding the death or not talking to protect others, feeling a burden, putting a mask on.
	Other people alienating	Offers of help that aren't genuine, being avoided, people don't handle grief well, do not know what to say or do, act awkward which makes the bereaved then feel awkward, people avoid you, people struggle to see your grief, talking about the deceased makes them uncomfortable, grief comparison doesn't help, lack of understanding about impact and longevity of grief, relationships with others change.
	What could be better from professionals	Needing to connect with supporter and they need to understand your situation, more information giving and support with finances and paperwork, parents had perceptions of what support would be and were disappointed/let down, better sign posting to services, services reaching out to families- move the mountain to the people, better pre-bereavement

		support, recognising the need for ongoing support, better access to support, difficulties accessing support.
	What could be better from school	Communication, understanding, tailoring support
	How covid impacted their experience	Negative - Restrictions around funerals, physical contact after the death, resulted in difficulties getting support, no time for self, no normality for some it was a positive effect, helped them avoid social situations and speaking to people, allowed them to be home.

Appendix 18: Child findings used for member checking

WHAT I HAVE LEARNT TALKING WITH YOUNG PEOPLE



WHATS HELPING

Being involved in what's going on

Wanting to feel cared for

Needing stability and normality

Needing distraction

People who have been through it understand



TALKING ON YOUR TERMS



Needing honest and open communication
Feeling uncomfortable talking about it
People around you are being awkward
Learning who you can talk to
Wanting to talk on your terms
Accepting people might get it wrong
Others knowing about it helps
Realising that talking helps



DEALING WITH EMOTIONS

Struggling when they were dying
How it makes you feel
Everyones grieving differently
Seeing your parent cry
Holding in emotions
Expressing emotions or not
Being triggered





DIFFICULTIES BEING SUPPORTED

- Doing it on your own
- Lack of understanding from others
- Finding what works for you
- Realising support isn't always genuine
- Lack of support because of covid
- People are forgetting and expecting you to move on

A LEARNING JOURNEY

- Living with an ill and dying parent
- Life is changing
- Seeing the impact on others
- Changes your perspective
- Grieving takes time
- Remembering them



STEPPING UP

- It forces you to grow up
- Stepping up to help at home
- Worrying about your parent
- Feeling guilty everything is on them
- Changing relationship with your parent
- Staying strong

THANK YOU

