

**Exploring bereaved children's experiences of the death of a close relative and the ways they wish to be supported: an emancipatory repeated focus group study**

Maya Abraham-Steele

A thesis submitted for the degree of Professional Doctorate in Child, Community and Educational Psychology

Tavistock and Portman NHS Trust

University of Essex

May 2024

### **Abstract**

There is a lack of research considering childhood bereavement and education in the United Kingdom (UK), despite it being estimated that one in 29 children will be bereaved of a parent or sibling before their 16<sup>th</sup> birthday. The aim of this study was to explore the experiences of young people who were bereaved of a close relative during childhood, specifically a parent or grandparent. The study aimed to gain an understanding of bereaved children's perspectives, in a UK specific context, considering the cultural context and attitudes towards death. It hoped to give voice to the ideas and opinions expressed by the participants about what is supportive to them in the aftermath of bereavement, particularly within a school context.

The study consisted of two focus groups of young people (aged 13-21) who were bereaved as children; they were interviewed three to four times about their experiences within the context of school, home-life and socially. These areas were identified by the participants in a participatory, mind-mapping session before the project commenced. Data was analysed using Reflective Thematic Analysis (RTA). Analysis revealed one umbrella theme of 'battles and conflict' and nine major themes relating to bereaved children's experiences, including: 'impact at school'; 'experiences of support'; 'desire to be normal'; 'social challenges'; 'grieving'; 'complexity of grief'; 'impact on home life'; 'post-traumatic growth' and 'hopes for future support'. The research showed that young people had varied experiences of returning to school and receiving support in the aftermath of bereavement. The young people felt adults misunderstood: the longevity of grief; the intersectional nature of the ways grief impacts all areas of their life; and the long-term nature of the support

they require as their grief grows with them. The findings allow consideration to be made on how to best provide bereavement support for young people.

## Table of Contents

ABSTRACT	2
TABLE OF CONTENTS	4
TABLES AND FIGURES	9
ABBREVIATIONS	10
ACKNOWLEDGMENTS	11
CHAPTER ONE: INTRODUCTION	12
1.1 RESEARCH CONTEXT	12
1.1.1 <i>Prevalence of Childhood Bereavement in UK</i>	12
1.1.2 <i>Defining bereavement</i>	13
1.1.3 <i>Grandparents as close relatives</i>	13
1.1.4 <i>Death in British Culture</i>	14
1.1.4.1 Cultural attitudes towards the child's voice	15
1.1.4.2 Multicultural Britain	16
1.1.4.3 A case for grief education	17
1.1.5 <i>A socially biased-issue</i>	18
1.1.6 <i>Policy</i>	18
1.1.6.1 UK Commission on Bereavement	18
1.1.6.2 National Bereavement Policies	19
1.1.7 <i>Bereavement support</i>	20
1.1.7.1 Schools as a Support System	20
1.1.7.2 Bereavement Support Groups	21
1.2 THE CONSEQUENCES OF CHILDHOOD BEREAVEMENT	22
1.2.1 <i>Psychological consequences of bereavement</i>	22
1.2.2 <i>Educational Outcomes</i>	24
1.3 THE AUTHOR AND HER JOURNEY	25
1.4 THIS STUDY	27
CHAPTER TWO: LITERATURE REVIEW	28
2.1 INTRODUCTION AND PURPOSE	28
2.1.1 <i>Synopsis of narrative review</i>	29
2.1.1.1 Barriers to support	29
2.1.1.2 Facilitators of support	30
2.1.1.3 Identified gaps in literature	30
2.1.2 <i>Literature review question</i>	31
2.2 METHOD FOR REVIEW	31
2.2.1 <i>Search strategy</i>	31
2.2.1.1 Primary search	31
2.2.1.2 Inclusion/exclusion criteria	33
2.2.1.3 Snowballing	34
2.3 CRITICAL APPRAISAL	35
2.4 SYNTHESIS OF THE LITERATURE	37
2.5 THEMES WITHIN THE LITERATURE	38
2.5.1 <i>Support available</i>	39
2.5.2 <i>Barriers to support</i>	40



2.5.2.1 Lack of training	40
2.5.2.2 Pressure on teachers	41
2.5.2.3 Teacher-pupil relationships	42
2.5.2.4 Lack of bereavement policy	43
2.5.2.5 Emotional impact on staff and triggering of own grief	43
2.5.2.6 Adults feel uncomfortable talking about death	44
2.5.3 <i>Facilitators of support</i>	45
2.5.3.1 Training	46
2.5.3.2 Supporting systemically	46
2.5.3.3 Positive teacher-pupil relationships	47
2.5.3.4 Access to bereavement policy	47
2.5.3.5 Experience/personal qualities	48
2.5.3.6 Support for staff	49
2.5.4 <i>Summary of findings</i>	50
2.5.5 <i>Gaps within the literature</i>	52
<b>CHAPTER THREE: METHODOLOGY</b>	<b>53</b>
3.1 RESEARCH AIMS	53
3.2 PURPOSE OF RESEARCH	53
3.2.1 <i>Emancipatory</i>	53
3.2.2 <i>Exploratory</i>	53
3.3 RESEARCH QUESTIONS	54
3.4 POSITIONING	54
3.4.1 <i>Ontology</i>	55
3.4.2 <i>Epistemology</i>	55
3.5 RESEARCH DESIGN	56
3.6 PARTICIPANTS	56
3.6.1 <i>Identifying a group</i>	56
3.6.1.1 Aspects of the Charity	58
3.6.2 <i>Recruitment</i>	58
3.6.3 <i>Inclusion criteria</i>	59
3.6.4 <i>About the Groups</i>	60
3.6.5 <i>Table 5: Table of participants</i>	62
3.6.6 <i>Pseudonyms</i>	62
3.7 DATA COLLECTION	62
3.7.1 <i>Research setting</i>	62
3.7.2 <i>Participatory Element</i>	63
3.7.3 <i>Focus Group Interviews</i>	65
3.7.4 <i>Frequency and timing of meetings</i>	67
3.7.5 <i>Attendance</i>	68
3.7.6 <i>Technology usage</i>	69
3.8 DATA ANALYSIS	70
3.8.1 <i>Reflexive Thematic Analysis</i>	70
3.8.2 <i>Reflective diary</i>	71
3.8.3 <i>Procedure for RTA</i>	72
3.8.3.1 Participant checking of findings	73
3.8.3.2 Endings	73
3.9 ETHICS	74
3.9.1 <i>Power dynamics</i>	75
3.9.2 <i>Potential need for further support</i>	75

3.9.3 Interviewing	75
3.9.4 Safeguarding	76
3.9.5 Consent	77
3.9.6 Withdrawing from the study	77
3.10 TRUSTWORTHINESS	78
3.10.1 Credibility	78
3.10.2 Transferability	79
3.10.3 Dependability	80
3.10.4 Confirmability	81
CHAPTER FOUR: FINDINGS	82
4.1 FINDINGS	82
4.1.1 'Battle and conflict': an umbrella theme	82
4.2 TABLE 11: TABLE OF THEMES	85
4.2.1 Impact at school	86
4.2.1.1 Return to School	86
4.2.1.2 Impact of transitions	87
4.2.1.3 Being triggered in school	88
4.2.1.4 Impact on academics	89
4.2.2 Experiences of support	90
4.2.2.1 Support at school at the time of bereavement	90
4.2.2.2 Support at school in the longer term	91
4.2.2.3 Desire to be included in support plans	93
4.2.2.4 Social support	94
4.2.3 Desire to be normal	95
4.2.4 Social Challenges	96
4.2.4.1 Peers reactions	96
4.2.4.2 Being picked on	97
4.2.4.3 Humour as a coping mechanism	99
4.2.4.4 Comparative suffering	100
4.2.5 Grief	101
4.2.5.1 Being triggered	101
4.2.5.2 Dreams	102
4.2.6 Complexity of grief	103
4.2.6.1 Understanding has developed over time	103
4.2.6.2 Being told information (or not)	106
4.2.6.3 Loss of innocence	108
4.2.6.4 Letting go (or not)	109
4.2.7 Impact on homelife	110
4.2.7.1 Impact on family members	110
4.2.7.2 Financial impact	111
4.2.7 Post-traumatic growth (PTG)	111
4.2.8.1 My experience shaped me and my aspirations	111
4.2.8.2 Desire to work in bereavement	111
4.2.9 Hopes for future support	113
4.2.9.1 Training for schools	113
4.2.9.2 Grief education as part of the national curriculum	114
CHAPTER FIVE: DISCUSSION	115
5.1 OVERVIEW AND RESEARCH QUESTIONS	115

5.2 EXPLORING YOUNG PEOPLE’S EXPERIENCES AND DESIRES	115
5.2.1 <i>Experiences of bereavement across contexts</i>	115
5.2.1.1 Experiences of bereavement at school	115
5.2.1.2 Experiences of bereavement at home	118
5.2.1.3 Experiences of bereavement socially	120
5.2.1.4 Inter-relational impact of bereavement across contexts	124
5.2.2 <i>Desired support</i>	125
5.2.2.1 Desire to be included in support plans	125
5.2.2.2 Grief education	126
5.2.2.3 Training	127
5.2.3 <i>Return to school and support received</i>	127
5.2.3.1 Return to school	127
5.2.3.2 Key adults	128
5.2.3.3 Pastoral support	129
5.2.4 <i>The battle</i>	130
5.3 FEEDBACK TO STAKEHOLDERS	132
5.3.1 <i>Feedback meeting to the charity staff</i>	132
5.3.2 <i>Feedback meetings with participants</i>	133
5.4 DISSEMINATION	133
5.4.1 <i>Eastern Region Conference</i>	133
5.4.2 <i>Peer-reviewed journals</i>	134
5.4.3 <i>Book</i>	134
5.4.4 <i>Training and policy</i>	134
5.5 IMPLICATIONS	135
5.5.1 <i>Implications for research area</i>	135
5.5.2 <i>Implications for EP practice</i>	136
5.5.3 <i>Implications for the education profession more generally</i>	137
5.6 REFLECTIONS OF A LIVED EXPERIENCE RESEARCHER	139
5.6.1 <i>Sharing my experience of the project with the young people</i>	139
5.6.2 <i>Participatory approach</i>	140
5.6.3 <i>Ethical reflections</i>	141
5.6.4 <i>Reflection throughout the process</i>	142
5.7 LIMITATIONS	143
5.7.1 <i>Sampling</i>	143
5.7.2 <i>Culture</i>	144
5.7.3 <i>Group dynamics</i>	144
5.8 FURTHER RESEARCH	146
5.9 CONCLUDING STATEMENT	147
REFERENCES	149
APPENDICES	167
APPENDIX 2A: PAPERS FOUND AND MARKED AGAINST INCLUSION/EXCLUSION	
CRITERIA FOR LITERATURE REVIEW	167
APPENDIX 2B: CASP CHECKLIST, QUALITATIVE (2018)	177
APPENDIX 2C: SUMMARY OF PAPERS AND CASP	183
APPENDIX 3A: CONSENT/ASSENT FORMS	219
APPENDIX 3B: EXCERPTS OF MINDMAPS	227
APPENDIX 3C: INTERVIEW SCHEDULES	231
APPENDIX 3D: EXCERPTS OF CODED TRANSCRIPTS	234

APPENDIX 3E: STAGE ONE THEMATIC ANALYSIS _____	288
APPENDIX 3F: STAGE TWO THEMATIC ANALYSIS _____	307
APPENDIX 3G: STAGE THREE THEMATIC ANALYSIS _____	309
APPENDIX 3H: TREC FORM _____	310
APPENDIX 3I: ETHICAL APPROVAL _____	331
APPENDIX 3J: EXCERPT OF RESEARCH DIARY _____	332
APPENDIX 3K: A 15-POINT CHECKLIST OF CRITERIA FOR GOOD THEMATIC ANALYSIS PROCESS (BRAUN AND CLARKE, 2006) _____	333
APPENDIX 4A: FULL TABLE OF QUOTES CORRESPONDING TO THEMES _____	335
APPENDIX 5A: MENTIMETER RESULTS FROM THE EASTERN REGION CONFERENCE	387

## Tables and Figures

### Tables

Table 1: Search Limiters  
 Table 2: Inclusion/Exclusion Criteria for literature review  
 Table 3: Papers selected for review  
 Table 4: Subthemes within the literature  
 Table 5: Table of Participants  
 Table 6: Mind-mapping groups  
 Table 7: Themes for Focus Groups  
 Table 8: Attendance, group one  
 Table 9: Attendance, group two  
 Table 10: Audit Trail  
 Table 11: Table of themes  
 Table 2A.1: Primary Search Results  
 Table 2A.2: Secondary Search  
 Table 2A.3: Snowballing  
 Table 2A.4: Expanded search selected for abstract/full text review  
 Table 2C.1: Summary of paper one  
 Table 2C.2: CASP for paper one Table  
 2C.3: Summary of paper two Table  
 2C.4: CASP for paper two Table 2C.5:  
 Summary of paper three Table 2C.6:  
 CASP for paper three Table 2C.7:  
 Summary of paper four Table 2C.8:  
 CASP for paper four Table 2C.9:  
 Summary of paper five Table 2C.10:  
 CASP for paper five Table 2C.11:  
 Summary of paper six Table 2C.12:  
 CASP for paper six Table 2C.13:  
 Summary of paper seven Table 2C.14:  
 CASP for paper seven  
 Table 4A: Table of quotes to support themes

### Figures

Figure 1: Flowchart of literature searches, adapted from PRISMA  
 Figure 2B: Screenshot of search results for expanded search, April 2024  
 Figure 3B.1 Mindmap excerpt one for group one  
 Figure 3B.2 Mindmap excerpt two for group one  
 Figure 3B.3 Mindmap excerpt one for group two  
 Figure 3B.4 Mindmap excerpt two for group two

## Abbreviations

Artificial Intelligence	AI
Association of Educational Psychologists	AEP
Bereavement support group(s)	BSG(s)
British Psychological Society	BPS
Bronfenbrenner’s Theory of Human Development	BTHD
Child Adolescent Mental Health Services	CAMHs
Children and Young People	CYP
Continued professional development	CPD
Department for Education	DfE
Educational Psychologist(s)	EP(s)
Educational Psychology Service	EPS
Emotional Literacy Support Assistant(s)	ELSA
Lesbian, gay, bisexual and trans+	LGBT+
Local authority	LA
Model of Loss Navigation in Adolescence	MLNA
Office for National Statistics	OfNS
Post-traumatic stress	PTS
Post-traumatic growth	PTG
Personal, social, health and economic	PSHE
Reflective Thematic Analysis	RTA
Relationships and Sex Education	RSE
Social Emotional Mental Health	SEMH
Special Educational Needs and Disabilities	SEND
Teaching Assistant(s)	TA(s)
Trainee Educational Psychologist	TEP
United Kingdom	UK
UK Commission on Bereavement	UKCB
United States	US

## Acknowledgments

Foremost, I am grateful to my participants who shared with me their experiences and the deep wisdom they hold. It was a great privilege and responsibility to be trusted with your stories. It was a pleasure getting to know each of you throughout the study and I cannot emphasise enough how much I learnt from you. Your passion for bereavement support and trust in me was a great motivator to continue during the most challenging times of this study. I hope I have done it justice.

Secondly, acknowledgements go to the staff at the charity who supported the project and worked alongside me in the focus group interviews. Thank you for trusting in the project and giving your time and knowledge to ensure a safe environment was created for the young people to share with me.

Thank you to my supervisor, Dr Richard Lewis, for believing in the study since its conception, for challenging and supporting me in equal measure and encouraging my development as a researcher and psychologist. Your supervision style has been truly inspirational to me. I'd also like to thank Dr Martin Lytje, for his time, advice, and support in the early stages of the project; it was a privilege to learn from you and your experience as a researcher.

Lastly, I am forever grateful to my family, friends and colleagues for their unwavering support and encouragement throughout this journey. Thank you.

## Chapter One: Introduction

### 1.1 Research Context

#### 1.1.1 Prevalence of Childhood Bereavement in UK

It is estimated that each year, 46,300 children born in the UK are bereaved of a parent before the age of 18 (Childhood Bereavement Network, 2024). Fauth et al. (2009) found that in 2004, 3.5% of all 5-to-16-year-old children in the UK had experienced the loss of a parent or sibling; this was the last large scale review of the data and equates to one in 29 children are bereaved of a parent or sibling before their 16th birthday (McLaughlin et al., 2019), amounting to one in every classroom. It is estimated that an additional 16,000 children became orphaned due to the death of one or both primary care-givers as a result on the Covid-19 pandemic (Hillis et al., 2021), meaning that not only are there more bereaved young people, but young people whom also potentially had their grieving process impacted by pandemic restrictions, meaning they were less able to say goodbye or attend funerals and consequently may experience more complex grief (Winston's Wish, 2023).

The exact prevalence of childhood bereavement in the UK is unknown, as national annual data is uncollected. The above statistics are largely estimated based on mortality data combined with the number of adults currently living with dependent children (Winston's Wish, 2023). This is surprising, given that until recently, data was collected for the number of children who experience parental divorce (Childhood Bereavement Network, 2024), and that bereavement of a close relative is generally accepted as one of the most traumatic events a child can experience in international literature (Kaplow et al., 2010; Cerel et al., 2006; Melhem et al., 2007). Charities like Winston's Wish are advocating for details of dependents to be captured when a death is registered. It has been recognised that a significant



barrier to accessing bereavement support is ‘lack of data on support needed and service provision, locally and nationally’ (UK Commission on Bereavement (UKCB), 2022, p.27) and the UKCB recommend improvements in ‘research, data collection and revaluation’ to ensure good and appropriate support involvements can be made (UKCB, 2022, p.28).

The absence of prevalence data is perhaps reflective of the lack of prioritisation of childhood bereavement on a national level in the UK, most evident in the lack of a national bereavement policy and the rarity of planned and managed bereavement response policies in British schools (McLaughlin et al., 2019) despite significant evidence that bereaved children are a vulnerable group who require bespoke support.

#### 1.1.2 Defining bereavement

This study defines bereavement as ‘the objective situation of having lost someone significant through death’ (Stroebe et al., 2008, p. 5) as used previously by Abraham-Steele and Edmonds (2021). It is acknowledged that there are many definitions of bereavement which use the concept of ‘loss’ but do not specify ‘by death’ (Worden, 2009); however, this study focuses on a narrower definition of the concept of bereavement, specifying loss by death. Grief is defined as “a natural reaction to bereavement—a ‘primarily emotional (affective) reaction to the loss of a loved one through death. It incorporates diverse psychological (cognitive, social, behavioural) and physical (psychological-somatic) manifestations’ (Stroebe & Stroebe, p. 5)” (Abraham-Steele & Edmonds, 2021, p.3).

#### 1.1.3 Grandparents as close relatives

Current literature on childhood bereavement generally defines ‘close relative’ as a parent or sibling (McLaughlin et al., 2019), with the research base often only

considering experiences of children who have lost a parent. This study extends the definition of close relative to include grandparents. Research published by Age UK (2017) found that 40% of the UK's grandparents (over the age of 50) have provided regular childcare for their grandchildren. As such, grandparents play a significant care giving role for many young people in modern British society and are likely considered to be close relatives by many young people, so it is felt that the impact of losing a grandparent shouldn't be disregarded. Statham (2011) found that grandparents play a prominent role in providing child-care and supporting maternal employment, especially for low-income families, which is particularly significant given that childhood bereavement is more prevalent in lower income families (Paul & Vaswani, 2020). While data on prevalence of loss in the UK (and England) does not exist, Paul & Vaswani's longitudinal cohort study found that in Scotland, 50.8% of all children are bereaved of a parent, sibling, grandparent or other close family member by age eight and this rises to 62% by age ten. The most common death experienced was that of a grandparent or other close relative (Paul & Vaswani, 2020). People experiencing a bereavement may have varying closeness of relationship to the relative who died and the impact on them of the loss they have experienced can vary. As such, it is important that this group are included in the research and will be explored in this study.

#### 1.1.4 Death in British Culture

In British culture, death and dying are viewed as taboo subjects, which are generally left unspoken about (Walter, 1991). Although this was written over 30 years ago, it has been suggested that this continues as a cultural response and may be due to our own unconscious fears of mortality, causing us to avoid speaking and thinking about death and dying (Solomon et al., 2015). The UKCB state that these

‘ongoing taboos around grief and uncertainties around knowing how to help... inhibit support throughout our communities, in our schools, colleges, and workplaces, and even among those whose job puts them in contact with bereaved people every day’ (2022, p.3). Furthermore, beliefs about the appropriacy of exposing children to death mean that children are often excluded from mourning rituals and not always provided with information about their own and other family members' critical illness (McLaughlin et al., 2019). This sociocultural reluctance to talk to children, and particularly bereaved children, about death is perhaps due to the group’s status as vulnerable and born from a desire to protect children from the pain associated with loss and mortality. However, this can render the vulnerable group ‘forgotten’ and mean their voices are unheard in their own bereavement support plans, with a key feature in young people’s experience of bereavement being powerlessness (Ribbens McCarthy, 2007).

#### 1.1.4.1 Cultural attitudes towards the child’s voice

The main research base within the UK has considered teacher’s, parent’s and adult’s bereaved as children’s perspectives on supporting bereaved children, but failed to capture the voices of the young people themselves. An editorial by *The Lancet* (2013) recognised this gap in knowledge of childhood bereavement and called for more research to examine the long-term well-being of children who have experienced traumatic events. It seems paradoxical that children’s voices have not been captured, given the prevalence of ‘student voice’ in contemporary schools (Flutter, 2007) and policy (SEND Code of Practice, 2015). There is currently emphasis on co-production and a philosophy promoted within Educational Psychology of doing with, not doing to our clients (BPS Power Threat Meaning Framework, 2018). Further to this, Coleman (2013) claims that few British projects

aimed at changing school policies have been truly successful without including the opinions of students. As such, this research prioritised amplifying the voices of bereaved children, recognising their indigenous knowledge and viewing them as well placed to recognise and evaluate bereavement support, as its main recipients.

#### 1.1.4.2 Multicultural Britain

When thinking about death in British culture, it is important to remember that Britain is a multi-cultural society. The UK is a culturally diverse country with 81% of residents in England and Wales identifying from white ethnic groups, 74.4% of which identified as 'English, Welsh, Scottish, Northern Irish or British.' 9.3% identify from Asian ethnic groups, 2.5% from black ethnic groups and 1.6% other (Office for National Statistics (OfNS), 2021). It is important then, to consider cultural differences which may occur in terms of attitudes towards death and grieving within the population. It is also important to consider the religious diversity of the UK; while 46.5% identify as having no religion; 43.6% are Christian; 2.2% are Muslim; 0.4% are Hindu; 0.3% are Buddhist; 0.1% are Sikh; 0.1% are Jewish and 0.5% are other religions (OfNS, 2021).

Oyebode and Owens (2013) proposed that while death itself is universal, the ways in which people grieve are personal and specific. Multiple studies (e.g., Granek & Peleg-Sagy, 2017; Rosenblatt, 2013) have reported that grief, mourning and death rituals are culturally specific, and are often highly influenced by religious practices and doctrines. Moreover, religion provides a context for people to understand death and has profound effects on the way in which people respond to death (Deshpande et al., 2005). Lopez (2011) highlights that although culture is acknowledged to be an important factor in dealing with grief, there is little understanding of how it impacts the experience of grief within adolescents and McLaughlin et al. (2019) note that this

seems to be true for children as well, although there is little research exploring the ways in which this effects children's experiences of grief and loss. Douglas et al., (2021) studied whether systems of oppression linked to race, culture and socioeconomic status can be associated with higher odds of developing post-traumatic stress (PTS) and maladaptive grief. The study found that young black people were significantly elevated for PTS and maladaptive grief through polyvictimisation and violent death exposure relative to young white people. While this is an international study, and therefore should be applied cautiously to a British context, it is important to consider systems of oppression on race and how these may be impacting the way racially diverse children and young people experience bereavement and bereavement support in the UK.

#### 1.1.4.3 A case for grief education

A recent review has made the case for mandatory grief education in UK schools (Dawson et al., 2023). There is currently no requirement for schools to cover grief, death and loss as part of the national curriculum. The authors posit that grief education needs to be embedded into the national curriculum, based on a narrative review of the research in grief education in schools (Dawson et al., 2023). Evidence suggests that children and young people want to learn about death and grief in school. Most of the 99 bereaved young people who reported to the UK Commission on Bereavement (2022) and many of the 31,000 others who took part in the accompanying VotesforSchools (2022) survey supported the idea of grief education in schools. When a 2012 Ofsted survey asked 11–18-year-olds in England which Personal Social Health Economic (PSHE) education topics they would like to learn about in school but currently did not, coping with bereavement was the most popular response, suggested by 37% of young people. Furthermore, children and young

people who take part in dedicated grief education programmes are more able to understand, manage and communicate their feelings about death, bereavement and grief (Lee et al., 2009; Stylianou & Zembylas, 2018a), often exhibiting less death anxiety (Glass, 1990). The authors acknowledge that it is natural to want to shield children from death, but the evidence suggests that even very young children have a concept of death and benefit from talking about it (Paul, 2019; Martinčėková et al, 2020; Menendez et al., 2020; Dawson et al., 2023).

#### 1.1.5 A socially biased-issue

Within the UK, Childhood bereavement is a socioeconomically biased issue, with those from lower-income backgrounds more likely to be bereaved (Fauth et al., 2009; Parsons, 2011; Paul & Vaswani, 2021), and less likely to received high quality support (Abraham-Steele & Edmonds, 2021). Strong social networks are essential for alleviating the effects of loss and there are some concerns that these are less likely in households that face more increased social challenges (Prix & Erola, 2017). Lack of legislation or standardisation in bereavement policy and support contributes towards this issue and means those from less socioeconomically advantaged backgrounds are the most likely to be bereaved and least likely to receive high quality support (Abraham-Steele & Edmonds, 2021).

#### 1.1.6 Policy

##### 1.1.6.1 UK Commission on Bereavement

Historically, there has not been a national policy on bereavement for children (in education) or adults (in employment) in the UK. This is perhaps surprising given that the Department for Education (DfE) deploy national level policy in other key areas, such as safeguarding, bullying and special educational needs. Following the Covid-19 pandemic, it was recognised that death is a universal experience and our

current cultural practises towards grief are largely unacknowledged. As such, the UK Commission on Bereavement (UKCB) was founded in 2021. The Commission brought together a coalition of 16 commissioners, and an advisory group made up of 14 people directly affected by lived experience of bereavement, as well as academics from the Universities of Cardiff, Warwick and Bristol, and a steering group of six voluntary organisations. The commission has conducted a large-scale consultation with over 1000 bereaved people and professionals working with them, to produce advice on how to best move forward and improve bereavement support in the UK.

#### 1.1.6.2 National Bereavement Policies

One of the recommendations of the UKCB report (2021) was new legislation must require that ‘all employers have a bereavement policy and all education establishments (early years, schools and further and higher education) must be required to have a bereavement policy including staff training, and a process for supporting a bereaved child or young person and their family’ (p.15). These recommendations are supported by researchers who found teachers desired policy to feel more confident in providing bereavement support (Abraham-Steele & Edmonds, 2021; Demuth et al., 2020). A national policy in the UK would propose an opportunity for standardisation of bereavement support, which could encourage more equity in bereavement provision and address the social bias associated with childhood bereavement and available support at present.

Currently only Denmark and Australia have school bereavement response systems that are implemented on a national scale (McLaughlin et al., 2019). The Danish plan is well-implemented and mostly successful but fails to include the views of the students it was designed to help (Lytje, 2016a); yet Lytje found that 81% of Danish teachers felt a sense of security when responding to a bereavement, because

they knew they had a resource available if necessary (2017). These international findings further support the potential benefits of implementing bereavement policy nationally in the UK.

### 1.1.7 Bereavement support

#### 1.1.7.1 Schools as a Support System

There is evidence that schools are well placed to support children following a bereavement (Balk, 2001; Dyregrov, 2008; Abraham-Steele & Edmonds, 2021) when the family's ability to provide support to one another may be reduced due to collective grief (McLaughlin et al., 2019; Balk et al., 2011; Dimery & Templeton, 2021). Schools can be a significant protective factor as staff have pre-existing relationships with the children and can provide routine, consistency and a secure base to its students. The child psychotherapy profession have initiatives suggesting that those more difficult to reach children and young people (CYP), who may not attend Child Adolescent Mental Health Services (CAMHS) services, can be reached in schools (Argent, 2021). This is further supported by recent government policy. DfE consider school staff as, 'well placed to observe children day-to-day and identify those whose behaviour suggests that they may be experiencing a mental health problem or be at risk of developing one' (2023, P.13). Further, the 2017 green paper: 'transforming children and young people's mental health provision' recommended a designated senior mental health lead in every school and the development of mental health in schools teams, supporting the initiative that Social Emotional Mental Health (SEMH) support can be delivered in schools.

Several studies (e.g. Dyregrov et al., 2015; Holland & McLennan, 2015; Costelloe et al., 2020; Abraham-Steele & Edmonds, 2021) have shown that teachers



find the role of supporting grieving students highly challenging. Abraham-Steele & Edmonds (2021) found that bereavement support is inconsistent in the UK; that teaching staff generally felt under qualified to talk about death; and that systemic limitations such as funding and timing prevented them from employing qualified staff. Costelloe et al., found that providing emotional support to a bereaved child has a negative impact on the emotional well-being of staff and discussed how Educational Psychologists (EPs) are well placed to provide whole school and targeted bereavement support to children and school staff (2020). Further to these findings, the UKBC found just under half of CYP felt not at all or only a little supported by their school or college, which was especially the case amongst those aged 13-18 (2021). Therefore, while schools are in theory well placed to support children, the evidence suggests that in reality, many children do not feel well-supported by the schools and a lot of teachers do not feel equipped to provide adequate support.

#### 1.1.7.2 Bereavement Support Groups

Childhood bereavement services offer support through intervention to bereaved children and their families on a universal basis, or according to the objective circumstances of the death (Currier et al., 2008). This often takes the form of bereavement support groups (BSGs); the theory behind these groups is based on evidence that bereaved young people tend to feel socially isolated from their peers. BSGs can act as a protective factor against this isolation. Many of the young people that attend the groups explicitly comment on their surprise that there are so many other people who are bereaved and who are 'like them' (Siddaway et al., 2014). However, there is little empirical evidence of the effectiveness of these groups. Siddaway et al. (2014) found that those who participated in the CHUMS group program experienced a statistically-significant, medium-size decrease in symptoms

over time when rated by parents and children, and a statistically significant, small-size decrease in symptoms over time when rated by teachers. The amount of improvement was equivalent irrespective of the child's age or gender. However, this was measured using a single, generic, symptom-based measure to assess change over time, which may have missed important facets of young people's bereavement adaptation. Equally, the study did not include a control group, which limits internal validity as change in outcome cannot be attributed with certainty to the intervention. A 2022 study, by Linder et al., in the United States (US), found that a school-based grief group had higher retention rates than clinic-based grief work and the results demonstrated a significant reduction in grief symptomology pre-to-post-intervention, further providing evidence in favour of school-based bereavement support.

## 1.2 The Consequences of Childhood Bereavement

### 1.2.1 Psychological consequences of bereavement

The majority of bereaved children will experience grief (Stikkelbroek et al., 2016) and associated increased psychological distress, symptoms of which may include: fear, helplessness, anxiety, anger, regression in development, increased helplessness, insomnia, intrusive thoughts, apathy, psychosomatic symptoms and lower self-esteem (McLaughlin et al., 2019). This may be linked to reduced emotional capacity in the child's remaining relatives, such as parent(s), due to their own grief, which may impact upon their parenting style (Abraham-Steele & Edmonds, 2021); this has links to attachment theory, with attachment style being disrupted by loss. This has links to attachment theory, with attachment style being disrupted by loss. There is contradictory evidence for whether bereaved children are at an increased lifetime risk for psychological problems, with some studies finding that the majority of children overcome the loss of a parent during childhood without experiencing increased mental

health problems (Cerel et al., 2006; Dowdney, 2000; 2005; Luecken & Roubinov, 2012; Stikkelbroek et al., 2012; Worden et al., 1999) while others, such as Fauth et al. (2009), found bereaved children are one and a half times more likely to be diagnosed with a mental health condition. Stikkelbroek et al. (2016) found risk of potential mental health issues increases for the first two years following a bereavement (parental or sibling), but symptoms decline with time. A recent Chinese study reviewed the impact of bereavement on long-term outcomes for young adults bereaved as children in China, finding that the odds of experiencing emotional, physical, and sexual abuse as well as household substance abuse, parental mental illness, and parental incarceration ranged from 2.0–5.2 times higher for bereaved individuals (Woodward et al., 2023).

It is important to note that the quality of the research on the longer-term consequences of bereavement has been questioned, due to sample size and quality (McLaughlin et al., 2019). Moreover, studies have failed to distinguish between the many variables associated with bereavement. These include: age at bereavement, people who have experienced multiple bereavements and bereavements in different contexts to each other, and causes of bereavement. Equally, many of these studies are limited in that they consider the death out of context of the factors leading up to death (Abraham-Steele & Edmonds, 2021). Kapolow et al., (2021) made an attempt to address some of these contextual factors and found that youth bereaved by multiple deaths had higher posttraumatic stress scores than youth bereaved by a single death; youth bereaved by suicide were more likely to report experiencing suicidal thoughts or behaviours and alcohol use than youth bereaved by natural causes. Youth bereaved by homicide were at greater risk for substance use than youth bereaved by natural death and parentally bereaved youth were more likely to experience depression compared to those who experienced the death of an adult relative or unrelated adult. It

is promising that research is improving and responding to the criticisms and gaps highlighted by other researchers. While the quality of the existing research may account for the discrepancies in findings between studies, what is apparent is that the research agrees that bereavement and associated grief have the potential to cause negative psychological outcomes.

### 1.2.2 Educational Outcomes

Dyregrov et al., (2022) conducted a narrative review, describing the educational consequences, risks, and protective factors associated with parental loss; they found that research confirms that parental bereavement negatively impacts educational attainment and completion. They identified that early studies suffered from methodological weaknesses and small sample sizes, which led to divergent findings. Most studies (e.g. Abdelnoor & Hollins, 2004; Holland, 2003; Servaty-Seib & Hamilton, 2006) found a decrease in school performance. Dowdney (2000) and Silverman & Worden (1993) found that some bereaved children perform better in the time following the loss, potentially due to the desire to make their bereaved parent proud, or using schoolwork as a coping mechanism to distract from their pain. Furthermore, in a retrospective study, many adults bereaved in childhood recognised post-traumatic growth (PTG) in themselves (Chater et al., 2022). Holland (2008) suggested that reactions vary from child to child depending on age, experience, personality, and type of loss. In a survey of Norwegian teachers by Dyregrov et al., 2015, more than 80% of the participants answered that, to some degree, it is true that students' school performance declines following a death. Similarly, in a Swedish study, the proportion of school failure among children who had experienced parental loss was 6.5% versus 3.5% in the group of children who had not (Berg et al., 2014). Berg et al., (2014) also conclude that 'some of the association between parental

bereavement and school performance could be explained by childhood socioeconomic position' (p. 687). As reflected in this conclusion, it is difficult to establish a direct causality between bereavement and reduced educational outcomes, due to the difficulty controlling for other potential contributing factors and potential protective factors.

Prix and Erola (2017) established a protective factor in their study of children born between 1982 and 1987 who had lost a father; participants did not abandon high school if their mothers had robust socioeconomic resources. However, participants were less likely to start a university course compared with students who had not been bereaved. Moreover, this study compared bereaved children to their age-mates rather than comparing pre and post bereavement baselines, a flawed approach that fails to account for how individual difference could impact discrepancy in outcomes. It is evident, then, that bereavement impacts educational outcomes, most often negatively, but evidence must be interpreted with caution due to limitations of design. Grief and intrusive thoughts may lead to a decline in grades and bereaved children not attaining the same level of education as their classmates (Dyregrov et al., 2022). Low socioeconomic resources seem to increase the risk of children experiencing challenges with their education (Dyregrov et al., 2022), while strong support from the remaining parent and teachers appear to act as protective factors which help a child following the bereavement.

### 1.3 The Author and Her Journey

My name is Maya Abraham-Steele, and I am a 28-year-old Trainee Educational Psychologist (TEP). I grew up in a village in southeast England alongside my older brother. My father died when I was ten years old and as such, I am familiar with the

experience of grief in childhood. At the age of 18, I moved to London to study English; I had found a love of literature in childhood when I first read Harry Potter. At the heart of the magic was a boy bereaved of both parents, and reflected in his loss, I saw some of my own feelings about the death of my dad. During my undergraduate studies, I became fascinated by the psychological experiences of fiction writers and the notion of projecting one's inner world onto the page, which can be cathartic to author and reader alike.

After graduating I found myself in a temp position in business support for a local authority (LA) Educational Psychology Service (EPS). In the resources cupboard I came across a copy of Holland's (1997) book on bereaved children, composed following 'project iceberg' a retrospective study with adults who were bereaved as children. I learnt that there were many negative outcomes for bereaved children and became fascinated by what support bereaved children were receiving in the UK in present day. Around the same time, the Principal Educational Psychologist (EP) asked me if I was interested in pursuing a career in Educational Psychology and encouraged me to enrol into a master's programme. I worked for the EPS, and in a primary school as a one-to-one, whilst studying an MSc in Psychology online; I found great meaning and learning in working with young people.

I realised there were many gaps in the research base on childhood bereavement and completed my master's thesis on teacher's perspectives on supporting bereaved children in British primary schools (Abraham-Steele & Edmonds, 2021). The project answered some of my questions about the support children were receiving and how adults working with them perceived them but left many more unanswered. While retrospective studies like 'project iceberg' tell us how adults (in hindsight) feel about being bereaved, we know very little about how British

children experience bereavement from the child's perspective. Studies working directly with bereaved children have been conducted in Scandinavia but applying this research to the British context is limited, due to cultural and socio-political differences that may render the experiences of the children different. In this country, bereaved children's voices remain unheard, and it is my hope that this study will be emancipatory, providing a platform for bereaved children's voices and experiences to be recognised.

Being bereaved of my father has undeniably had a significant impact on me as a person and influenced my life path in many ways. I mention it here because it is only ethical to acknowledge that I bring that experience with me as a researcher. Whilst I must acknowledge my experience as an adult bereaved as a child, my true zeal lies in illuminating the voices and experiences of today's children who have been bereaved; they hold great wisdom and are experts in their own needs and experiences.

#### 1.4 This Study

Based on the literature this study set out to explore how 13–21-year-old students experience the bereavement of a closed relative, what they found supportive in the aftermath of their loss and give a voice to these children/young people about how the adults in their lives should undertake bereavement responses. A bereavement support charity, known hereby as 'Forget-me-nots', was approached and a group of young ambassadors for the charity were put forward to form two focus groups to explore their thoughts and ideas.

## **Chapter Two: Literature Review**

### 2.1 Introduction and purpose

This chapter aims to establish what research exists concerning the factors that facilitate or block schools' engagement in the support of bereaved children in Western countries at present. McLaughlin et al. (2019), conducted a narrative review between February and December 2018 on behalf of Winston's Wish. The review focused on research between the years 2000 and 2017, and included research within the fields of psychology, educational psychology, and psychiatry, although reference is made to other disciplines. The review aimed to explore the immediate and long-term consequences of bereavement for children in Western countries as well as the support being provided to bereaved children in UK schools; a synopsis of this comprehensive review is made in section 2.1.1.

The subsequent systematic literature review aims to provide an up-to-date exploration of the research on childhood bereavement and the support provided by schools conducted between 2018 and 2024, guided by the pre-existing narrative literature review by McLaughlin et al. (2019) but using a systematic, rather than narrative approach. A systematic review has been chosen over a narrative review for its transparency and replicability (Siddaway et al, 2019) and its aim is to provide an unbiased assessment of available literature (Jahan et al., 2016). While narrative reviews have been criticised for overemphasising highly quoted articles (Murlow & Cook, 1998), others posit that the narrative review is not a poor cousin of the systematic review but an alternative and often complementary form of scholarship (Greenhalgh et al., 2018; McLaughlin et al., 2019). As such, this review aims to be



complementary to the pre-existing narrative review, while adopting a systematic methodology to aid replicability and transparency of method.

### 2.1.1 Synopsis of narrative review

McLaughlin et al. (2019) produced a comprehensive review, exploring the long and short-term consequences of childhood bereavement; the current state of bereavement support in the UK and the factors that facilitate and block school engagement in bereavement support. The long and short-term consequences of childhood bereavement and types of support available have been explored in the introductory chapter of this study (see 1.1.7; 1.2.1; 1.2.2). As such, this synopsis will focus on the evidence they reported on the same research question underpinning the current literature review: the factors that facilitate and block school engagement in bereavement support. Key findings of the report are formatted in bold for ease of navigating.

#### 2.1.1.1 Barriers to support

The review found several studies (e.g. Holland, 2003; Lowton & Higginson, 2003) that revealed many teachers do not feel adequately qualified to deal with bereaved children; staff reported finding themselves ill-prepared to deal with loss, feeling worried about causing further distress to bereaved children, despite desiring to help them (Lowton and Higginson, 2003; Holland, 2001). Moreover, staff often feel burdened by the mental health needs of students (Davidson, 2008; Spall & Jordan, 1999). Studies have also noted that school staff generally request more training on childhood bereavement (Devlin-Friend, 2006; Holland & Wilkinson, 2015). Holland (2001) posits that these issues might explain why bereaved students reported on many occasions that they had received little or no help at all when returning to school. Further, evidence suggests that in British schools, children's grief is often forgotten

after the first few months (Holland, 2001). Spratt (2016) warns that lack of clarity around schools roles in supporting bereavement in mental health policy can lead to both confusion and disagreement on the forms of support schools should offer and to what extent. Further, Spratt et al., (2006) found teachers feel isolated when facing issues related to emotional wellbeing and unable to provide the precise support required.

#### 2.1.1.2 Facilitators of support

The review found that teachers had a strong desire to support bereaved children despite their fears (Dyregrov et al., 2015; Holland & McLennan, 2015; Lytje, 2017). Planned holistic responses appear to encourage teachers to begin to support and continue supporting bereaved children, while also allowing teachers to feel greater confidence in doing this (Lytje, 2017; Rowling & Holland, 2000). The Danish bereavement response provides information on how to talk about loss, and structures to ensure the child's loss is not forgotten after the first few months. The increasing interest in adolescent mental health in UK education (DfE and Department of Health (DoH), 2017) was cited as a factor that can facilitate school engagement in bereavement support. Evidence also suggests students show a high level of trust in staff who are engaged in extracurricular clubs of support staff e.g. playground assistants, TAs, and that these often were the most likely adults they would approach with sensitive topics (Spratt et al., 2006).

#### 2.1.1.3 Identified gaps in literature

A number of gaps in research were identified by this review, including: sibling bereavements; the role of parents in supporting bereaved students; the role of cultural and socioeconomic factors in bereavement; UK specific research; the challenges British teachers face when encountering childhood bereavement and the

views of bereaved young people. The current literature review aims to assess whether any of these research gaps have been fulfilled within the last seven years, specifically within the context of childhood bereavement in schools.

### 2.1.2 Literature review question

This review aims to answer the following question: *what is the evidence on the factors that facilitate and block school engagement in the support of bereaved children?*

While McLaughlin et al.'s review (2019) considers a wider range of research questions, including what the short and long-term consequences of childhood bereavement are, these questions have been explored in the introductory chapter of this study (see 1.2.1; 1.2.2). This review will consider specifically the part schools can play in providing support for bereaved children and the factors which facilitate and block them from providing this support.

Moreover, McLaughlin et al. (2019) only consider research on sibling and parent (mother or father) bereavements before the age of 18. This review expands its search to include literature on children bereaved of a close relative; as per section 1.1.4, this study and review consider grandparents as close relatives, due to their increased caring responsibilities in modern western society and as such, research relating to those experiencing grandparent bereavements will be considered in this review.

## 2.2 Method for review

### 2.2.1 Search strategy

#### 2.2.1.1 Primary search

On 28<sup>th</sup> February 2024, the EBSCO host database was used to search all available databases; all data bases were searched due to the researcher's knowledge that

childhood bereavement and education are under-researched topics and limiting the databases (for example, to only education and psychology) may over-reduce results from other relevant fields. The Boolean/phrase: ‘childhood bereavement’ AND ‘school’ AND ‘support\*’ were searched. The search was refined using the following limiters:

Limiters	Justifications
Published between 2018-2024	Review of literature prior to this already in existence Most up-to-date research
Written in English language	To yield results relevant to English speaking world Accessible to researcher (English speaking)
Academic journal and peer reviewed	For quality assurance; the high level of evaluation and rigour given to peer-reviewed research. Thesis were not included because due to their size they would need to be approached in a different way.

17 initial results were found; which was reduced to 15 when duplicates were manually screened for. The search was then expanded using the following:

- Also search within the full text of the articles
- Apply equivalent subjects

This search was limited to the database ‘education source’, with the hope of limiting results to those relevant to education while expanding the search so broadly.

The expanded search yielded 44 results, reduced to 28 results when duplicates within previous search were removed.

The search terms were then expanded to include synonyms. The Boolean/phrase was changed to: ‘childhood bereavement’ AND ‘school’ OR ‘education’ AND ‘support\*’ OR ‘help’ OR ‘facilitate’ OR ‘block’ OR ‘barrier’ were searched. The same limiters as defined above were applied. 253 results were yielded. 43 duplicates were removed, leaving 210 results.

#### 2.2.1.2 Inclusion/exclusion criteria

The initial 43 papers were subjected to a screening process, to check their relevance to the research question against several criteria. The titles and abstracts of all papers were screened against the inclusion/exclusion criteria in table 2 below.

Table 2: Inclusion/Exclusion Criteria for literature review

Inclusion/exclusion criteria	Justification
Study completed in: Northern and Western Europe; North America; Australia; New Zealand	Not enough studies exist within the UK to limit this search to British context. These countries have been selected due to being in the Western World and having a similar cultural context to the UK.  International studies are applied to a British context with caution due to the cultural differences which exist within countries in the western world.
Relates to school-aged children (5-18); day-care studies excluded	Due to relevance to research question; distinction made between ‘care’ and ‘education’ settings
Studies relating to children bereaved by death of close relatives, including siblings, parents and grandparents; excludes ambiguous/other loss	The researcher positioning acknowledges grandparents and siblings as significant relationships in children’s lives
Makes specific reference to school support; studies relating only to support outside of school e.g. grief camps excluded Relates specifically to teaching/support staff in school; excludes specialised support e.g. school counsellors; school nurses; hospices	Relevance to research question  School counsellors/nurses may not be available in all schools/roles may differ cross-culturally.
Answers research question	Specific to barriers and facilitators of school engagement in support

Reviews included as well as primary literature

Due to the limited evidence base on this research area, review papers have been included where they answer the literature review question

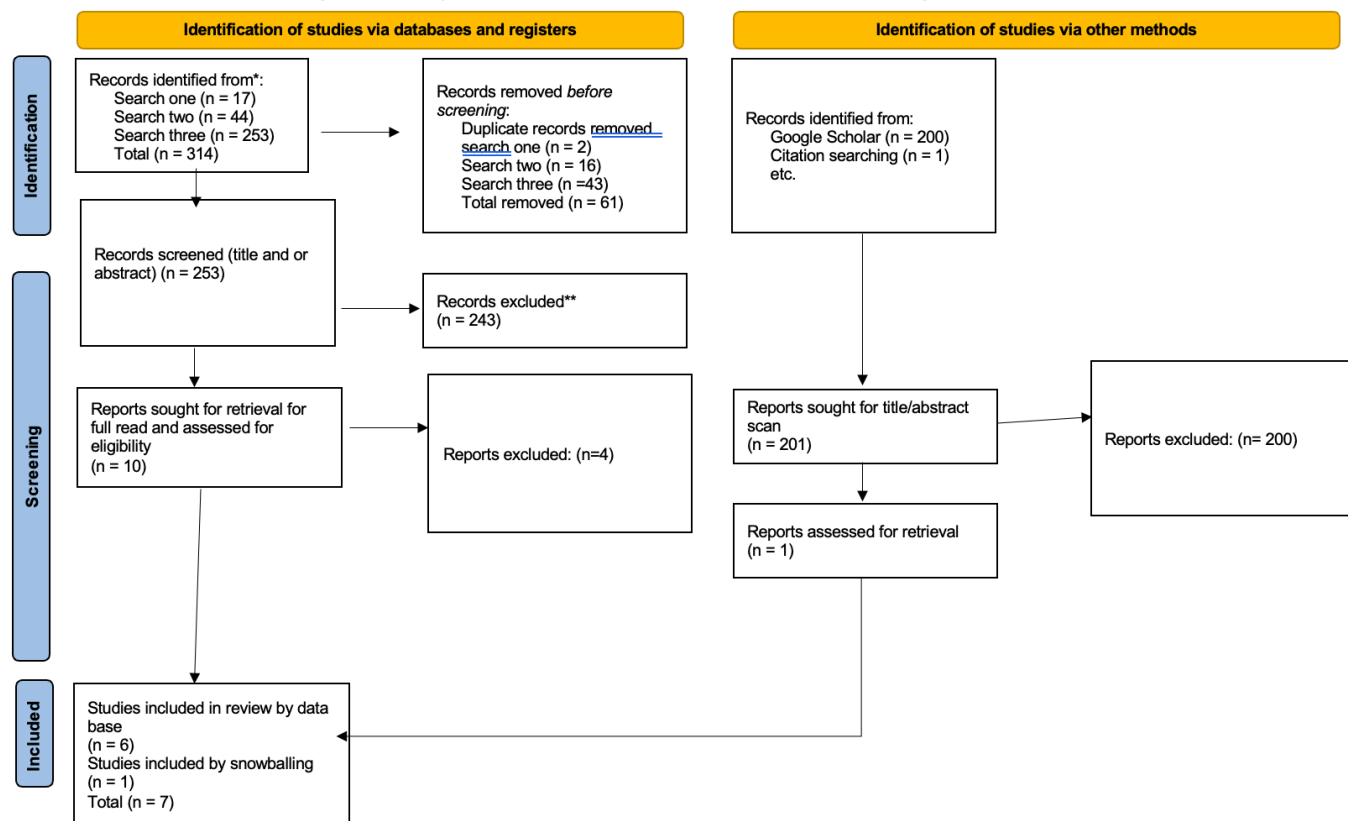
Six papers met all criteria for review. Of the expanded search: 210 results were screened by title only for relevance to research question. Following screening, five additional papers were retrieved and abstracts were read and screened against criteria. Four papers were read in full but did not answer the research question when evaluated. Please see table 2A.3 for screening of these additional papers. Zero additional texts were added for review from the expanded search. Tables illustrating all results and this review process can be found in Appendix 2A.

#### 2.2.1.3 Snowballing

An additional paper that met all criteria was known to the researcher from previous searches conducted throughout the project using Google Scholar and snowballing techniques so was included in the review. Snowballing was used by scanning reference lists of included papers to check for other relevant papers to this review but no further results were yielded from this technique. A further search was made on google scholar using the terms: ‘childhood bereavement’ and ‘school’; 37000 results were yielded. The first 200 titles and abstracts were scanned for relevance to criteria; however, no additional results were yielded. A total of seven studies were selected for this review. A flowchart illustrating the number of papers (adapted from PRISMA) can be found in figure 1 below.

Figure 1: flowchart illustrating the number of papers (adapted from PRISMA)

ADAPTED FROM: PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources



### 2.3 Critical appraisal

The final seven papers were critically appraised to inform how studies are interpreted and determine what judgements can be made on appropriateness of the evidence to contribute towards the body of knowledge (Aveyard, 2018). The studies were critically analysed using the ‘Critical Appraisal Skill Programme Checklist’ (CASP, 2018; see Appendix 2B). Critical appraisal for each paper was conducted; this, along with the aims, methods, and key findings, can be found in Appendix 2C. All papers met an appropriate level of quality and relevance as measured against their respective tools.

One of the main limitations of the research body is that the majority of studies are localised, qualitative studies on small populations, which renders the generalisability and transferability of findings limited. For example, Dimery & Templeton (2021) interviewed a sample of just three teachers in that section of their study; while their methodology (grounded theory) lends itself to an in-depth understanding, rather than generalising the findings to populations, there are limitations to working with small-sample sizes, in terms of the applicability of these findings to the wider population of teachers. Moreover, Abraham-Steele & Edmonds (2021) acknowledge the limitation of their study, regarding sampling. The study used an opportunity sample, meaning respondents are likely to be people with a particular interest or passion for the topic of bereavement and thus the results may give an exaggerated view of the level of support that is available in schools. This criticism can be applied to other studies in the review that used the same sampling technique (McManus & Paul, 2018; McAdams & Templeton, 2019). It is acknowledged by researchers in the field that larger scale studies, with bigger samples and across larger areas rather than single LAs are required, in order to gain a wider and more accurate perspective on practice and views of school staff (Abraham-Steele & Edmonds, 2021).



## 2.4 Synthesis of the literature

The following papers were selected for review (table 3).

Table 3: Papers selected for review

Authors	Title	Year
Abraham-Steele, M., & Edmonds, C.	A Thematic Analysis of Teacher’s Perspectives on Supporting Victims of Childhood Bereavement in British Primary Schools	2021
Lytje, M.	The Danish bereavement response in 2015 – Historic development and evaluation of success	2018a
McManus, E., & Paul, S.	Addressing the bereavement needs of children in school: an evaluation of bereavement training for school communities	2019
Costelloe, A., Mintz, J., & Lee, F.	Bereavement support provision in primary schools: an exploratory study	2020
Lytje, M.	Voices We Forget—Danish Students Experience of Returning to school Following Parental Bereavement.	2018b
McAdams D. E., & Stough, L.	Teacher Perspectives on Grief Among Children with Intellectual Disabilities.	2018
Dimery, E. & Templeton, S.	Death, bereavement and grief: the role of the teacher in supporting a child experiencing the death of a parent	2021

Research has been selected from the Western world, including four papers from the UK; two papers from Denmark; and one paper from the US. The papers include: a qualitative study on British primary school teachers’ experiences with bereaved children (Abraham-Steele & Edmonds, 2021); a systematic review of the Danish bereavement response (Lytje, 2018a); the qualitative phase of a mixed methods study, evaluating school staff (who had supported a child bereaved of a parent, sibling or peer in the last 5 years) insight into bereavement support in British primary schools (Costelloe et al., 2020); a mixed-methods study evaluating the impact of bereavement

training in schools in Scotland (McManus & Paul, 2019); a qualitative study on Danish parentally bereaved students experiences of returning to school (Lytje, 2018b); a qualitative study on special school elementary teacher's experiences of supporting parentally/caregiver bereaved children with learning disabilities in the US (McAdams & Stough, 2018) and a qualitative study of the teacher's role in supporting parentally bereaved children in the UK (Dimery & Templeton, 2021). Three papers in this review refer specifically to primary school populations (Abraham-Steele & Edmonds, 2021; Costelloe et al., 2020; McAdams & Stough, 2018). Four papers make reference to the school experience more generally, involving secondary school teachers (McManus & Paul, 2018); adults bereaved as children reflecting back on school experiences (Dimery & Templeton, 2021); bereaved children reflecting on school experiences (Lytje, 2018b) and an evaluation of bereavement support plans across primary and secondary schools (Lytje, 2018a). Three of the studies in this review (Abraham-Steele & Edmonds (2021); McManus & Paul (2019) and Lytje (2018a) involved teacher participants, for these three studies, who the children the staff supported were bereaved off is unknown.

## 2.5 Themes within the literature

The seven papers are presented thematically to answer the research question; they have been separated into three umbrella themes: support available (2.5.1); barriers to support (2.5.2) and facilitators of support (2.5.3). There are several subthemes within each theme, tracked in table 4. These umbrella themes are informed by the literature review question identified by McLaughlin et al (2019) and answered in this review. This review identifies several subthemes within 'barriers to support' and 'facilitators of support', tracked in table 4.

The subthemes are different to those identified by McLaughlin et al. (2019); while there are some similarities (e.g. need for policy; training; impact of student mental health upon staff well-being), this review identifies some additional factors that facilitate and block bereavement

support in schools, reflective of the additions to the research base since McLaughlin et al.'s (2019) review. The analysis was conducted by making note of the factors that facilitate support and block support for each study. A cross-comparison was then made between studies and evidence was themed based on similarities in the evidence. Papers were re-read multiple times for rigour, to ensure theme points were accurate and the findings from the papers were not only selected to fit within the themes. All points from the findings of the papers were able to be included within the themes identified. Taking a thematic approach meant it was possible to identify a pattern across the literature where each barrier has a parallel facilitator, for example, while lack of training was identified as a barrier to schools providing access to training was identified as a facilitator.

Table 4: Subthemes within the literature

Barrier	Facilitator
2.5.2.1 Lack of training	2.5.3.1 Access to training
2.5.2.2 Pressures on teachers	2.5.3.2 Supporting as a system
2.5.2.3 Teacher-pupil relationships	2.5.3.3 Positive teacher-pupil relationship
2.5.2.4 Lack of bereavement policy	2.5.3.4 Bereavement policy
2.5.2.5 Emotional impact on staff and triggering of own grief	2.5.3.5 Experience/personal qualities
2.5.2.6 Discomfort speaking about death	2.5.3.5 Support for staff

#### 2.5.1 Support available

Several studies revealed that there are currently inconsistencies in the way CYP are supported in school (Abraham-Steele & Edmonds, 2021; Dimery & Templeton, 2021). The literature suggests that grief is individual and presents

differently between CYP and consequently, the support required is also unique to individuals (Abraham-Steele & Edmonds, 2021; Lytje, 2018a; Costelloe et al., 2020; Dimery & Templeton, 2021). While Denmark has a national bereavement policy and Danish schools have bereavement plans in place, British schools seem to take a more ad-hoc approach to bereavement support (Lytje, 2018a; Abraham-Steele & Edmonds, 2021). There is evidence that bereavement support could be improved. Dimery & Templeton (2021) interviewed adults bereaved as children in their study and found that half of the participants were negative about schools' ability to support them with the majority stating that their teachers/school could have done more. It is important to be cautious with retrospective studies, as adults' current schemas may impact their perspectives and fill in any gaps in memory as stress and trauma can impair or strengthen memory (Howe, 2013), which Dimery & Templeton acknowledge as a potential limitation of the study. Abraham-Steele & Edmonds (2021) also found areas for improvement in the study with primary school teachers, including: lack of confidence; teachers demonstrating negative or low opinions of bereaved children; schools not considering child's wants/needs; not being culturally responsive in bereavement support. Despite their bereavement policy, Danish young people reported that their teachers sometimes tried too hard or did too much to support them, which made them feel uncomfortable (Lytje, 2018b), which was identified by the researcher as an area for improvement in bereavement support, alongside including bereaved children's voices in the support plans.

## 2.5.2 Barriers to support

### 2.5.2.1 Lack of training

All seven studies identified lack of bereavement training for teaching staff as a barrier to providing bereavement support in schools; teacher confidence in supporting

bereaved pupils was often low and linked to feeling underqualified (Dimery & Templeton, 2021). McAdams and Stough (2018) reported that teachers were frustrated with their lack of training and lack of professional acknowledgement of the need for bereavement training among special school teachers. While this is a US study, specific to a special school teaching population, this finding was common amongst teachers in mainstream British primary schools (Abraham-Steele & Edmonds, 2021; Costelloe et al., 2020; Dimery & Templeton, 2021; McManus & Paul, 2019) and in the Danish context (Lytje, 2018a; 2018b). None of the teachers in Abraham-Steele & Edmonds' or McAdams & Stough's studies received bereavement training in their initial teacher training, suggesting a deficit internationally (UK and US). The literature suggests that poor teacher confidence in supporting bereaved children is likely linked to lack of training and subsequent lack of knowledge and understanding of the needs of bereaved children (Lytje, 2018b; Abraham-Steele & Edmonds, 2021).

#### 2.5.2.2 Pressure on teachers

Lytje (2018a) and Abraham-Steele & Edmonds (2021) both identify the pressures faced by teaching staff as barriers to providing bereavement support. Abraham-Steele & Edmonds refer to this as the theme 'systematic limitations' and found that teachers did not feel there is enough funding in place to provide effective bereavement support; this was particularly because they felt they needed to hire specifically trained/experienced people to deliver it. Furthermore, class-teachers in this study felt they were stretched, and did not have the time to provide the level of support children need. It was found that teachers felt pressure towards focusing on pupils' academic attainment, and that the accountability systems prevented them from spending their time on pastoral support. Lytje (2018a) acknowledges that one of the

criticisms of the current Danish bereavement support system, is that the plans fail to provide long-term bereavement support; only 61% of Danish teachers felt the bereavement plan was effective in the following year after a bereavement, compared to 85% in the initial weeks, suggesting that providing long-term bereavement support is more challenging for teachers. Lytje links this failing to evidence that the number of tasks that teachers are asked to perform during school hours, as well as a strong focus on academic achievement, which can make it difficult for teachers to find the necessary time to support bereaved students.

### 2.5.2.3 Teacher-pupil relationships

Abraham-Steele & Edmonds (2021) found that the power-dynamics that may be innate in the adult-child relationship between a teacher and pupil were seen as a barrier to providing support by staff. A head teacher shared that pupils appear to fear her due to her role and as such she may not be best placed to provide support. Furthermore, participants commented that the class teacher is not always best placed to support a bereaved child, due to the pressure they are under, and that a member of support staff or TA was often viewed as better suited. Costelloe et al., (2020) acknowledge the potential role of Emotional Literacy Support Assistants (ELSAs) who have additional bereavement training in supporting bereaved children and interviewed three ELSAs in their study. Bereavement is a whole school responsibility (McManus & Paul, 2019) and there is emphasis on thinking about who is best placed to support individual bereaved children, based on their unique context. Lytje (2018b) found that many students interviewed about their experiences of returning to school felt alone, and that they had no one to talk to. This may be linked to the nature of child-adult relationships and the difficulty children may have initiating conversations in a power dynamic where they are in the less advantaged position.

#### 2.5.2.4 Lack of bereavement policy

Research within the UK reveals that generally, grief and bereavement policy and procedure is lacking in British schools (Abraham-Steele & Edmonds, 2021; Dimery & Templeton, 2021). All participants in Abraham-Steele & Edmonds' study felt they would benefit from government guidance, either on a national or LA level. It was felt that the absence of this policy and guidance was a barrier to delivering consistent, impactful support. Costelloe et al. (2020) found that there was no clear pathway for identifying bereaved children in primary schools. Participants were made aware of a bereavement through relatives, other staff, the media or the child themselves. A number of participants expressed concerns around the negative consequences of an unidentified bereavement, such as misunderstanding of the function of bereaved children's behaviour. Policy allows for clear pathways of support to be identified and for these kinds of barriers to support to be mediated (Lytje, 2018a). That said, Lytje found some limitations to bereavement policies in his evaluation of their implementation; one of which, was the idea that they prevent support from being individualised towards young people's needs (2018a).

#### 2.5.2.5 Emotional impact on staff and triggering of own grief

The literature revealed that providing bereavement support has a considerable emotional impact upon school staff (McAdams & Stough, 2019; Dimery & Templeton, 2021; Lytje, 2018a; Costelloe et al., 2020; McManus & Paul, 2019). McAdams & Stough (2018) found that teachers were moved by their experience of supporting bereaved children and expressed a range of emotions, including: sadness, frustration, shock, sympathy and vulnerability; participants related the experience to their own lives, including feeling their own grief triggered. Yet, teachers felt it necessary to put their emotions aside to support students. While, Costelloe et al.

(2020) found that providing bereavement support has a negative impact on staff wellbeing; teachers felt stressed and emotionally exhausted acting as a container for young people's emotions. Teaching staff reported wanting to cry, but not being able to due to not wanting to upset the pupil and reported crying and hiding this from the class. A number of emotions emerged in participants when supporting bereaved children, including worry, guilt, sadness, and stress. Akin to McAdams and Stough, staff found the experience to be a trigger for their own experiences of grief and loss. Likewise, the relevance of bereavement to personal lives of staff prevented them from accessing bereavement training, with participants less likely to attend a bereavement training had they recently experienced a bereavement (McManus & Paul, 2019). McManus & Paul highlight the personal resonance that bereavement holds for everyone and how this may be a barrier to engaging and responding to the needs of children (2019)

#### 2.5.2.6 Adults feel uncomfortable talking about death

Researchers acknowledge that many adults feel discomfort talking to children about death and make links between this feeling and death being a taboo subject in Britain (Dimery & Templeton, 2021; Abraham-Steele & Edmonds, 2021; McManus & Paul, 2018). McManus and Paul found participants explicitly named the taboo and reported feelings of reluctance to attend bereavement training as they felt it would be miserable. Equally, they reported this reluctance to talk about it was a barrier to them delivering bereavement support as they did not have the words to talk to children about it. Participants who did attend training reported feeling more able to talk about death and felt it had given them the permission and vocabulary to do so. Similarly, teacher respondents in Dimery & Templeton's (2021) study expressed feelings of discomfort in supporting bereaved children due to the unspoken nature of the topic. Abraham-Steele and Edmonds (2021) found that while the majority of



participants felt comfortable talking about death, they made reflections about lower levels of comfort in other school colleagues. Moreover, they found that participants had fears about upsetting bereaved children with their actions or other children upsetting the bereaved child, which led them to police the way children speak to each other about death. The authors reflect on the function of discouraging children from speaking factually about death, possibly projecting their own fear and discomfort around the topic onto children.

### 2.5.3 Facilitators of support

#### 2.5.3.1 Training

While lack of training was identified as a barrier to schools engaging in bereavement support, McManus & Paul (2019) identified that training was a facilitator to bereavement support for school populations. Their study evaluated a short and targeted bereavement training programme that aimed to develop school staff confidence in engaging and supporting bereaved children and promote a culture within school where needs of bereaved children are acknowledged and embraced. The training was aimed at all staff (teaching and support). 195 pre-training questionnaires and 218 post-workshop questionnaires were compared. About 65 percent of participants (141) said they felt more confident to communicate with the child and parents when someone had died after the training. Furthermore, six participants attended two focus groups six-18 months post training, and data was analysed thematically. Participants shared that the training gave them permission to talk about death, which they described as a taboo subject and they felt the workshop gave them the language to speak to children about death, which in turn developed their confidence to do so. Recruitment issues rendered evaluating the long-term impact of the training more challenging and researchers acknowledge that aiming to

change school culture in one, 2.5 hour training, is an unreasonable challenge.

However, the study shows potential for specific bereavement training to increase staff confidence in providing bereavement support.

#### 2.5.2.2 Supporting systemically

The research base suggests that providing school support systemically is a facilitator to schools engaging in bereavement support (Dimery & Templeton, 2021; Costelloe et al., 2020; McAdams & Stough, 2018). Costelloe et al. used Bronfenbrenner's Theory of Human Development (BTHD) framework as a theoretical framework for their study. They identified a number of proximal processes that influenced the support which was provided in primary schools, including cultural and systemic factors. Teachers appreciated guidance and regular contact from senior management, while senior managers discussed the importance of communication. Participants also valued external agency support, such as through charities or EPs. Some participants felt unsupported when carrying out bereavement support, suggesting that the adequate systematic supports e.g. from external agencies (like EPs) were not in place, meaning the pressure was on the members of the school system to provide support. But a small number of participants felt supported due to factors like access to external agencies; for example, ELSAs receive half-termly supervision from an EP. Evidence suggests that receiving appropriate support, such as supervision, supports staff to provide support for bereaved children (Costelloe et al., 2020). Dimery & Templeton (2021) found that the wider school community including parents were also highlighted as a potential protective factor in support; participants commented on the impact of bereavement upon the whole school community and the benefits of coming together as a team to deal with it. McAdams & Stough (2018) found that others in the school system facilitated bereavement support, including: school

counsellors, teaching assistances, and pupils. McManus and Paul (2019) aimed to produce and evaluate a whole school training for teaching and support staff, with the hope that training the entire school would have impacts upon school culture and attitudes towards bereavement support, allowing for the whole system to become supportive to bereaved children.

#### 2.5.3.3 Positive teacher-pupil relationships

Positive teacher-pupil relationships were highlighted throughout the research base as a facilitator of bereavement support (Costelloe et al., 2020; McAdams & Stough, 2019). McAdams & Stough (2018) found that interactions between school employees and grieving students often evolved into influential relationships; for example, a student formed a positive relationship with a TA whom became a very important person to him in the aftermath of bereavement. This study with specific to special schools (elementary) and as such, it is important to apply it to an international and mainstream context with caution. Special schools have higher numbers of staff to pupil ratios which may make the development of these relationships easier than in a mainstream context. Costelloe et al. (2020) comment on the positive influences of attuned relationships on facilitating bereavement support, for example, teachers agreeing secret signals to let children know they are thinking of them, without drawing attention to them. Attuned, trusting relationships and being led by the child were viewed as influential to interactions in bereavement support.

#### 2.5.3.4 Access to bereavement policy

Evidence suggests that bereavement policy is rare outside of Denmark and Australia, where national policies exist (Lytje, 2018a); in Denmark, 98% of schools have voluntarily implement bereavement plans. Lytje's evaluation of the implementation of Danish bereavement policies found that they were a facilitating

factor to providing effective bereavement support. The survey found high levels of teacher confidence in supporting bereaved children, linked to the existence of bereavement plans. 81% of respondents reported that the existence of a bereavement plan provided a feeling of security in their daily lives. Of those who dealt with bereavement, 78% reported the same feeling of security during incidents of bereavement. The article also found that students, in general, do receive some form of support from their teachers, even if the quality of the support varies, and bereavement plans are considered as the main tool being used by teachers in supporting bereavement in Danish schools (Lytje, 2018a). The study found that the system is designed to deal with the needs of individual schools and the creation of the plans by each school (based on a guide) helps teachers feel a sense of ownership; teachers reportedly find this system valuable as a means to providing support. One limitation of the study is that its evidence is primarily based on teacher's views and it is difficult to assess whether the system is supporting bereaved children as much as it is supporting the teachers; Lytje argues that for bereavement plans to truly succeed, they need a stronger emphasis on student voices (2018a).

#### 2.5.3.5 Experience/personal qualities

The literature found that in place of formal training, teacher confidence largely came from experience (Dimery & Templeton, 2021; Costelloe et al., 2020; Abraham-Steele & Edmonds, 2021). Dimery & Templeton, (2021) report that the support teachers provide is influenced by their own experiences, which develops their understanding and perception of death; one participant reported that their personal experience of familial death developed their own efficacy at providing support. Likewise, Costelloe et al. (2020) found that school staff felt that several life experiences (e.g., being a parent or being bereaved) and personal characteristics (e.g.,

being a good communicator) contributed to attuned relationships with bereaved young people. Abraham-Steele & Edmonds (2021) found that teachers' with more teaching experience felt more confident in supporting bereaved children, and also cited their experience as the main source of their knowledge over formal training. Similarly, a participant reported that her character and being direct makes it easier for her to provide bereavement support. Comparatively, two trainee teachers were interviewed in this study, who both reported low confidence levels and 'not knowing' what to say. Researchers suggest that initial teaching training and continued professional development training (CPD) on bereavement and how to provide support would help to support all school staff, regardless of experience levels, to develop confidence in bereavement support and reduce the dependence on experience for knowledge and confidence (Abraham-Steele & Edmonds, 2021; McManus & Paul, 2018).

#### 2.5.3.6 Support for staff

The evidence suggests that support for school staff is important in supporting the efficacy of the support (Dimery & Templeton, 2021; Costelloe et al., 2020; McAdams & Stough, 2018). Dimery & Templeton (2021) found that proactive approaches from the school such as training, external support, weekly meetings and pastoral support were key for their efficacy in offering support. External support may come from other professionals, such as EPs (Costelloe et al., 2020) or school counsellors (McAdams & Stough, 2018). Costelloe et al. found that some participants valued and appreciated external agency support such as from EPs and charities, but others felt this support was limited. This may speak to the ways in which access to support varies between schools, and can be a socially biased issue, with private schools able to afford more support (such as in house counsellors) due to more robust funding (Abraham-Steele & Edmonds, 2021). Similarly, teachers reported that help

from school counsellors was mixed, with some participants reporting support and others feeling frustrated with the lack of counsellor support received (McAdams & Stough, 2018). Costelloe et al. (2020) explore how EPs can act as a support system to schools when providing bereavement support. They suggest that school staff are often containers for children's emotions and suggest a containing the container model, whereby supervision is provided to those providing bereavement support, in order to support them with the emotional-stress experienced when providing bereavement support. It is suggested EPs could be extending their role to be supervisory towards those providing bereavement support, akin to the support they provide to ELSAs; or work discussion groups could be set up to support schools. They recognise that the school is a containing environment and that the macrosystem of the education system needs to be contained also (Costelloe et al., 2020).

#### 2.5.4 Summary of findings

The previous narrative review by McLaughlin et al. (2019) found five main barriers to schools providing bereavement support: teachers did not feel adequately qualified; teachers desired more training; staff often feel burdened by children's mental health; children's grief was often forgotten in the long-term; lack of clarity around bereavement support in policy; and teachers feel isolated providing SEMH support. The review found four main facilitators to providing bereavement support: a strong desire to support; and a planned, holistic bereavement response; increased interest in mental health in British education policy; pupils show high levels of trust in support staff.

The present review expands these findings, reviewing the developing research base over the last seven years. Six barriers to bereavement support and six facilitators to providing support were identified; interestingly, all barriers had a parallel

facilitating factor, for example: lack of training was a barrier to providing bereavement support, but receiving training was found to facilitate schools' confidence in and ability to support bereaved children. The evidence base therefore naturally reveals ways in which the factors that block schools engaging in bereavement support can be mediated.

The research base suggests that lack of bereavement policies is a barrier to providing bereavement support in schools and bereavement policies are a facilitator, and that while power dynamics in teacher-student relationships can impact the quality of support, positive, attuned relationships (especially from support staff) can facilitate feeling supported. While having personal experiences was a barrier to providing support for some staff due to the emotional impact, some school staff felt this was a facilitator, as they could use their personal experience and qualities as knowledge to provide better support. The evidence suggests that pressures on teachers, such as academic pressures and lack of time and funding may be remedied by bereavement support being embedded and supported by the whole school and education system coming together. This could also help to reduce the emotional impact that providing bereavement support has upon staff, and the ways it triggers their own grief, and makes them feel uncomfortable, as could support for staff from external agencies, such as EPs and charities. EPs may have a specialised role in providing containment for staff who are supporting bereaved children through supervision or working groups. This review reveals that the factors that block and facilitate schools engaging in bereavement support are often two sides of the same coin and viewing them as such may help us to better mediate the blocks to support and to better facilitate bereavement support in the future.

### 2.5.5 Gaps within the literature

This review focuses on a small body of evidence and reveals several gaps within the research base at present. Currently, there are no studies that focus specifically on bereavement support in secondary schools and the majority of the evidence in this review was specific to primary schools or spanned the entire school career. As such, the findings should be applied to secondary schools with caution and future research on a secondary school teaching and student population would be advantageous. One study in this review focused upon special schools but was localised to the US; it would be beneficial for similar studies to be undertaken of bereavement support in specialist provisions in the UK, to better understand how support is specialised in specialised contexts and to better understand the needs of bereaved children with additional needs. As acknowledged in section 2.3, the majority of the studies in this review are small, qualitative studies which are localised and there is a need for larger scale, national studies to explore the national picture of bereavement support in schools. Only one paper in this review considered bereaved children's own voices and perspectives on being bereaved and support. Applying this Danish research to a British context must be done with caution, due to the sociocultural differences between the two societies and education systems. It is important going forward, that young people with lived experience of bereavement are included in the western, and UK, research bases and that their knowledge can inform our practice. Lastly, within the UK, there is a gap in the literature in terms of young people's experiences of being bereaved and perspectives on bereavement support, which the present study hopes to address.



## **Chapter Three: Methodology**

### 3.1 Research Aims

The research here aims to explore the experiences of young people who were bereaved of a close relative during childhood, specifically a parent or grandparent. The study aims to gain a better understanding of bereaved children's perspectives, in a UK specific context, considering the cultural context and attitudes towards death. It hopes to give voice to the ideas and opinions expressed by the children about what is supportive to them in the aftermath of bereavement, particularly within a school context. This will build a better understanding of bereaved children's needs and views, which has the potential to inform bereavement support practice in the UK both in and out of the school context.

### 3.2 Purpose of Research

#### 3.2.1 Emancipatory

The research is both emancipatory and exploratory in nature, in that it hopes to give voice to bereaved children through exploration of their experiences. It is felt adults have previously avoided talking to children about their grief, often in attempts to protect them, but a consequence of such is that their voices are becoming lost. It is hoped that by opening up the conversation with bereaved children, there will be an element of empowerment for this group and that their voices will be amplified.

#### 3.2.2 Exploratory

The research hopes to develop an understanding of what bereaved children experience and find helpful, from their own perspectives. It aims to develop an understanding of how bereavement groups co-construct their ideas about loss and what they perceive to be supportive. This knowledge can set the foundations to understanding best practice and developing bereavement support further in the UK,

with the potential to develop the practice of specific bereavement groups (and provide advice to the wider bereavement support community) based on the findings. The research can also benefit the wider community, with the potential to inform wider death education for those who are not yet bereaved. Moreover, professionals, such as teachers, EPs and grief counsellors can benefit from the research to better understand the children they are working with and the support they require. The proposed research, which aims to gather children's experiences of loss and their views on what would help them, will be relevant to EPs, who may support bereaved children on an individual or systemic level by supporting their teachers/staff with training or critical incident support.

### 3.3 Research questions

The research aims to consider the following questions, these were informed by the participatory mind-mapping sessions (see section 3.7.2 for details):

1. What are 13-21-year-olds, bereaved as children, experiences of the death a close relative, within the contexts of family-life, relationships and school?
2. What do 13-21-year-olds, bereaved as children, perceive to be supportive following the death of a close relative?
3. How do 13-21-year-old young people experience their return to school and the support received following bereavement of a close relative?

### 3.4 Positioning

Ontology refers to assumptions about the nature of reality and existence, and what can be known, while epistemology refers to how such knowledge can come to be known (Pascale, 2011). These stances influence the data collection and analysis techniques employed across the methodology (Walsh et al., 2015). This research is underpinned by a social constructionist epistemology and ontology, with an aim to

understand how a pre-established group of young people bereaved as children have co-constructed their understanding of bereavement, through interaction and the mutual sharing of their individual experiences.

#### 3.4.1 Ontology

By adopting a social constructionist ontology, the assumption is that a universal psychology does not exist (Burr, 2015); rather, what is perceived to be real is the product of the cultural frame of social, linguistic, discursive and symbolic practices (Galbin, 2014). That is, the social constructionist framework allows the focus to be drawn to how individuals come to construct and understand the world as they do, within a group. Given the participants have been part of a bereavement group for some years, a social constructionist ontology allows for thinking about how groups come to collectively understand their experiences of loss.

#### 3.4.2 Epistemology

Knowledge is constructed through interactions between people and the world. Thus, an individual's 'truth' is a product of social processes and the interactions that an individual is engaging in rather than objective observation (Burr, 2015). It is assumed that attempting to elicit objective views of something as personal and individual as bereavement would fail to capture 'the multiplicity and complexity of the life world of individuals' (Scott & Usher, 2011, p.27). And as such, a social constructionist approach allows such complexity to be examined. Within this study, knowledge was co-constructed between individuals, through shared exploration and discussion of their subjective realities of the shared experience of having lost a close relative through death. A social constructionist lens allows for both the sharing of individual experience and knowledge, while acknowledging that that knowledge is a product of social processes and interactions that an individual experiences, rather than

objective observation.

### 3.5 Research Design

The research design consists of focus group interviews which were analysed using Reflexive Thematic Analysis (RTA), as per Braun and Clarke (2019; 2022). Focus group interviews were chosen as the most appropriate method of data-collection for both ethical and ideological reasons. Ideologically, a social constructionist lens lends itself best to focus group interviews as a methodology, as interviewing within group contexts produces data that can be analysed through a constructionist framework. From an ethical standpoint, conducting the interviews in a group rather than individually was decided to reduce the risk of causing distress to participants and to increase feelings of safety. Peers can be a significant protective factor for children following bereavement (Dopp & Cain, 2012). Group interviews also allow young people to avoid questions they do not feel able to answer and allow other members of the group who are more comfortable to speak for them. This was particularly important when interviewing around a sensitive topic and asking young people to discuss painful, personal experiences and is explored further in section 3.9. The pre-existing bereavement group allowed for some level of protection, as the participants were supported by peers they have pre-existing relationships with. This is explored further in section 3.7.

### 3.6 Participants

#### 3.6.1 Identifying a group

I identified several childhood bereavement charities/organisations in the Autumn of 2022, before the project had been formally proposed. Upon advice from my supervisor, I contacted three charities and one government commissioned bereavement service and tentatively proposed the idea of the research project to the

charities. I made it clear that the project had not yet received ethical approval and would only go ahead if this was granted. While several charities were interested in the project but could not participate due to having paused their groups during the Covid-19 pandemic or did not meet the criteria due to only running groups for a short period of time. It became apparent to me that I needed to find a long-term bereavement group and that this might be challenging in the UK context.

The charity involved with this project, Forget-me-nots, expressed an interest in the project and shared that they have a group of 12 ‘young ambassadors’ aged 11- 21, who have all completed a seven-week long bereavement support group programme with the charity. These young people have then been retained by the charity in an ‘ambassador’ role and are involved in ongoing projects, such as fundraising and raising awareness, by speaking about their experiences at conferences and events. All the young ambassadors were bereaved at least two years ago and had continued to meet with both the group and bereavement professionals regularly since joining the charity. It was felt that due to their age, the time since bereavement and longevity of involvement with a bereavement support service, this group was appropriate for the project and harm was less likely to be caused compared to working with more recently bereaved children. All of these factors increase the chances of the participants having already processed their grief/loss and reduce the risk of psychological harm being caused by the study. It also means they have pre-existing, supportive relationships with their peers/co-participants and the staff at Forget-me-nots, which also decreases risk, as children can feel safer and more willing to express their opinions when group members are familiar to them (Fielden et al., 2011; Hoppe et al., 1995; McGarry, 2015).

Forget-me-nots formally expressed support for the project and an interest in

involvement in December 2022 and wrote a letter to support the ethics application. Due to the longevity of the group, the enthusiasm of the clinical leads and the support available to the young ambassadors at the charity, it was felt Forget-me-nots was a good fit for this project and it was agreed that the young people would be introduced to the project and invited to participate once ethical approval was granted.

#### 3.6.1.1 Aspects of the Charity

Forget-me-nots is a charity in the south east of England, which provides bereavement support to children bereaved of a close relative. The charity is focused on providing support and information for bereaved families. The support package offered by the charity was co-designed by a group of young people, who were asked what they would have found helpful in the aftermath of their loss. The offer at present is mainly a bereavement group programme run over seven weeks by trained volunteers. Each week of the BSG is themed and aims to provide a safe space to share experiences and emotions with others who have had similar experiences.

The offer includes a telephone helpline, an informative website with resources publicly available and a schools service, including training for schools and supporting schools when a pupil has been bereaved. This includes establishing a key adult in school as a pastoral support; this can be any member of staff from the caretaker to head teacher and is selected by the young person. This person can link with the young person throughout the school day and support them where a deceased family member's absence might be particularly noticeable, for example, by coming to watch them in a school play.

#### 3.6.2 Recruitment

Once ethical approval was received, I offered two meetings to the young ambassadors and their families to introduce the project, one in person at the charity

headquarters and one on Zoom for people who could not attend the initial meeting. The meeting was intended to give the young people an opportunity to meet me and gain an understanding of the project, prior to deciding whether to participate. In the first instance, I introduced my position as an adult bereaved as a child and the aims of the project. How this was shared was carefully thought about to avoid a modelling risk; I shared that my dad died when I was ten years old and that my experience was in a different education system that was middle school so spans year five to eight (to enable separation from their experience as well as connection). Additionally, I shared that I was not in a formal bereavement group, but created a group with my best friends who were also bereaved children, to aid the CYP's understanding of my interest in their situation. Therefore, the aim here was to share my personal journey as someone who has an interest in this from their personal experience and wants to find out what others experiences have been when they have had support of a group within a charity. The schedule for the project was explained and there was an opportunity for them to ask questions. Information sheets and consent forms were re-distributed (they had already been shared digitally) with a three-week deadline to return. The three-week deadline was implemented to allow participants to take the time to consider whether they would like to take part in the project and to remove any pressure to decide.

### 3.6.3 Inclusion criteria

It was important that all of the participants were aged between 11-21, this inclusion criteria was chosen due to evidence suggesting that a mature understanding of death develops by the age of ten, and there being decreased risk talking to children who understand the permanency of death, than younger children, who have a less developed understanding. All the proposed participants were bereaved when they were under the age of 18, legally rendering them children at time of bereavement.

The decision was made to extend the age-range of the study to 21. Despite the legal definition being that adulthood begins at 18, research has proposed an extension of adolescence to ten-24 years due to understandings of continued development (Sawyer et al., 2018). This is reflected in the Special Educational Needs and Disability (SEND) code of practice, which is statutory guidance for young people (with SEND) aged 0-25 and as such, it is felt that these young adults can add valuable perspectives on what it is like to be a bereaved child and young person. The young people also had to be a young ambassador at the charity. This meant that a significant period of time had passed since their bereavement, and they had the support system of the charity and group of young ambassadors as a protective factor throughout the project.

#### 3.6.4 About the Groups

The current research involved eight participants aged 13-21; nine participants initially consented but one participant withdrew from the project before it commenced for reasons unknown to me as a researcher. I did not follow up with the withdrawing participant to avoid perceived pressure to participate. The participants included four young adults, aged 18-21 and four teenagers, aged 13-14. The participants were divided into two groups, based primarily on age, with the proposed groups being: with group one ranging from 15-21 and group two ranging from 11-14. Due to the actual ages of participants, the actual age groups were group one: 18-21 and group two: 13-14. The decision to group based on age was made with a hope to reduce the power-dynamics that can play out in mixed-age groups, and reduce the potential for older voices to dominate the group spaces. Grouping children according to age can be essential to group dynamics and discussion, due to differences in developmental stage impacting the quality of discussion (Fielden, et al., 2011; Hoppe et al., 1995; McGarry, 2015). Group two were all in early adolescence and were all



bereaved when they were in primary school, but have moved to a secondary school since their bereavement, giving them an increased level of shared experience.

As well as age, gender can influence the compatibility of children in a group; gender differences may arise in groups of older children (Fielden et al., 2011; Heary & Hennessy, 2002; Kennedy et al., 2001; Adler et al., 2019). For teenagers, interest in the opposite sex and differing interests, desires, and attitudes can negatively affect group dynamics in mixed-gender teenager groups (Heary & Hennessy, 2002; Adler et al., 2019) and as such, it is recommended to hold single-gender focus groups with teens who are not familiar with one another and whose ages differ by less than two years (Daley, 2013). In both groups, the participants knew each other, and as such it was not necessary to hold single-gendered groups. However, it is important to consider both how gender may have impacted group dynamics and how experiences of bereavement may differ between genders, which is explored in 5.7.3.

One criticism of focus groups is the notion of the halo effect, whereby high-status individuals may have an overbearing influence on the discussion, resulting in those with less privileged positions being reluctant to challenge those with a higher social status (Nyumba et al., 2015). The halo effect was a valid concern within the group of young ambassadors, as there is an established hierarchy whereby the oldest two ambassadors of each gender are ‘head’ young ambassadors, and in a leadership role. Furthermore, two members of the group now volunteer at the charity, supporting bereavement groups and leading on certain young ambassador projects. I was conscious of the power held by these individuals and the impact they may have on discussions. I particularly noted that the eldest member of the group was often looked to by the others to speak first. To ensure the other voices were heard and valued, I asked in-depth questions about alternative opinions to prompt discussion and allow

for differing opinions to be shared.

### 3.6.5 Table 5: Table of participants

Pseudonym	Age	Relative bereaved of	Age at time of bereavement	Gender	Time as young ambassador
Leo	21	Dad; Uncle	12; 14	M	6 years
Maddie	20	Dad	14	F	6 years
Ashley	19	Grandparent	12	Not shared	Not shared
Jared	18	Grandparent	6	M	6 years
Juan	14	Dad	9	M	4 years
Gretchen	14	Dad	8	F	8 months
Tord	13	Mum	9	M	3 years
Jason	13	Grandad	6	M	4 years

### 3.6.6 Psuedonyms

All participants were asked to choose a pseudonym to be known as in the write up of the project. I explained that this was a way of anonymising the data. Juan referred to himself as his pseudonym in the third person when describing details of his experiences, despite being reminded that I would anonymise the data and he did not need to do this, which was perhaps an attempt to distance himself from the painful experiences he describes. He would also refer to other participants as their pseudonym throughout the focus groups, which the group found humorous and enjoyed. This will be explored further in the discussion section 5.2.4. Members of group one also chose the pseudonym for the charity during their feedback session.

## 3.7 Data Collection

### 3.7.1 Research setting

The data collection took place at Forget-me-nots' head office, where the

young people typically access their bereavement support. The groups were held in a medium sized room that was familiar to the young people, with a large table in the middle. The young people were allowed to select their own seat each time. A member of staff from the charity was always present in the room during data collection, but sat away from the group, working quietly on their personal projects while listening to the discussion, rendering them an observer rather than group member.

The charity always provided snacks (such as snack sized chocolate bars; biscuits) and drinks for the young people, which they consumed. On reflection, this small gesture by the charity acted as a containing factor for the young people. It is my understanding that refreshments would typically be available to the young people in their regular meetings with the charity and as such, I feel their presence provided a level of consistency and familiarity, which helped to make the young people feel more relaxed in the groups. Furthermore, the snacks acted as a rapport building point, as I was able to snack alongside the young people and start light-hearted discussions around the best/worst chocolate bars. These conversations helped me to position myself alongside the young people and breakdown some of the power dynamics that may have been at play between an adult researcher and children/younger participants.

### 3.7.2 Participatory Element

The study also involved a participatory element, in which the young people co-constructed the themes to be explored in the focus group interviews. I met with each group separately, to generate themes to be explored in subsequent focus groups. The young people were not asked to share any personal experiences in the first meeting, rather, it was designed to facilitate rapport-building and function as a contracting session for the future work. A participatory element was introduced with a hope of both reducing harm and supporting the emancipatory element of the study -

that is - it was hoped that by giving young people autonomy over what they were willing to share, they would feel empowered and supported to share. It was important in ensuring the research was done with, rather than to, the young people.

Together, the group created a mind-map of themes that they wished to discuss from the perspective of what they think researchers and other professionals will find useful to know. The group talked and notes were transcribed with different coloured pens to represent each of their voices (excerpts in Appendix 3B). I had proposed three focus groups, so hoped to merge and group these into three over-arching/umbrella themes, which were agreed with participants, to be created as the prompts for the following focus group meetings. The aim was to ensure all participants have contributed to the creation of each theme area to be talked about across the subsequent sessions. Unfortunately, only three group members could attend each mind-mapping session. Attendees of each group are listed in the table below:

Table 6: Mind-mapping groups

---

Group one (18-21)	Group two (13-14)
Leo	Gretchen
Maddie	Tord
Ashley	Jason

---

I was mindful of the fact that Jared and Juan were not in the initial sessions, and explained the context of the mind-mapping session to them when they attended their first group. I held in mind that their ideas had not been considered in the initial themes, and tried to ensure there were opportunities for them to share, particularly by asking the group if there was anything else they would like to add or they felt was missed at the end of each session.

The two groups generated themes during the mind-mapping sessions and decided the order they would like to discuss them in. The young people shared some of their personal experiences despite not being required/asked to do so. The themes

generated by each group are listed in the table below. The data from the mind-mapping session has also been analysed in the results section.

Table 7: Themes for focus groups

Group one (18-21)	Group two (13-14)
1. School	1. School
2. Impact on family	2. Peer relations
3. Friends and relationships	3. Family
4. Past, present and future	

It is of note that both groups generated three of the same themes/topics in school; peer/friend relationships and family. The older group generated one extra theme, entitled 'past, present and future'. This theme was a reflection on how grief has changed over time and the ways in which it has impacted them, presently impacts them and will impact them in the future and the group did not feel it was possible to fit this content into any other themes. It is of note that this was a unique reflection by those who have technically reached adulthood and may reflect something of the way one's understanding of grief changes with cognitive development and maturity. As such, I felt it was important to honour an additional focus group session for the older group, and this request was approved by the ethical body after application.

I then wrote the interview schedules around these themes (Appendix 3C). Generating the themes meant that the young people could be prompted about what would be discussed prior to each focus group, which could then help them to prepare for the focus group ahead and, with hope, reduce the risk of unnecessary emotional harm.

### 3.7.3 Focus Group Interviews

Data was collected through a series of focus group interviews. Focus group interviews were as a general rule limited to 60 minutes to attend to the shorter

attention spans of children (Clark, 2010). The following procedure was followed:

1. Explanation of method

At the beginning of each focus group, the focus group methodology was introduced and explained. I explained that I would be noting down timestamps of who spoke when to aid the transcription process; the young people were reminded that the questions were based on the content from the mind mapping session and told that they did not have to answer any questions they did not feel comfortable answering. I then explained that if the discussion was not flowing, I would ask whether anyone else had something to add, but that it was okay to say no to this question and they would move onto the next area.

2. Commencement of interview

During the first interview, the participants were asked to introduce themselves to check whether the audio recorder was receiving their voice. Then, the first question was presented for the group to discuss. When a topic had been discussed sufficiently or participants no longer had additional contributions, the next question was presented. Follow up questions were asked at times to elicit additional information. The content of this step changed during the different sessions.

3. Closing remarks

When all questions on the interview schedule had been asked, or when the interview had reached approximately an hour, the participants were asked for any final remarks and whether they felt like anything had been left out.

4. Debrief

After the initial interview closed, the interviewer provided a brief emotional check in with the young people and reminded them of the theme for the following session. After the second interview, the debrief was extended to 30 minutes by the

charity. This was optional and the young people could leave whenever they wanted, but had the option to stay and talk if they wished. This change was made based on feedback from the young people. The charity were responsive to the young people's needs and adapted their support offer to manage the young people's requests. Some comments from the debrief were significant and written down by the interviewer, with the young people's permission. The young people were told they had the right to request that anything said in the debrief was not included in the data analysis, and any comments were removed as requested.

#### 3.7.4 Frequency and timing of meetings

I met group two (13-14) four times, evenly spread, once every three weeks, in May, June and July 2023. Group one (18-21) met five times within the same time period, and as such, their meetings were more frequent - with one to two week intervals between each group. The young people and staff at the charity were consulted on the frequency of the meetings and felt these timings were appropriate and manageable for the young people.

The focus groups took place on weekday evenings, as this was the time the charity could facilitate. It is noted that guidance suggests best practice is to run focus groups on Saturday afternoons, to avoid fatigue from the school/working day impacting young people (Adler et al., 2019); unfortunately, this was not possible due to a clash with the bereavement group run by the charity and the best-fit compromise was chosen. Group two (13-14) meeting at 16.15 and group one (18-21) meeting at either 16.15 or 18.00 depending on their availability each week. It is possible that some fatigue was present but the young people engaged well and were enthusiastic at the end of each session, often expressing desire to come back to the next session. Timings were carefully thought about, to coincide with the regular ambassador

meetings (monthly) that the young people receive.

It was hoped that by pre-agreeing themes with the young people in advance, some containment and certainty would be provided, allowing them to prepare in advance for what we will discuss and reducing the chances of something unexpected (and painful) arising. Initially, I ended each session by reminding the CYP of the theme of the next session. However, feedback from the CYP to the charity suggested that it would be helpful to be reminded of the theme again closer to the session commencing, so that they felt more prepared for the session, and as such, the charity facilitated this after the second focus group, meaning they were reminded at the end of each session by me and again the day before the session by the charity.

### 3.7.5 Attendance

Due to a range of other commitments, including work and sports, some participants could not attend all of the focus groups. It was not compulsory to be able to attend every focus group to participate in the study, and some level of attrition was expected from the onset. The tables below indicate who was present at each focus group.

Table 8: Group one, attendance

Focus Group	Attendees	Absent
1. School	Leo, Maddie, Ashley and Jared	Nil
2. Impact on family	Leo, Maddie, Ashley and Jared	Nil
3. Friends and relationships	Maddie and Leo	Ashley and Jared
4. Past, present and future	Leo, Maddie and Jared	Ashley



Table 9: Group two, attendance

Focus group	Attendees	Absent
1. School		Gretchen, Jason and Tord Juan
2. Peer relations		Jason, Tord and Juan Gretchen
3. Family		Gretchen, Jason, Tord and Juan Nil

It is important to reflect on how different participants may have impacted on group dynamics; due to the findings being socially constructed, different views may be elicited by different group members being present in different sessions, group sizes, and gender make-up of the groups. For example, in group two, Gretchen was always the only girl present. This was particularly noticeable on the day Gretchen was not present, and the tone of the group was more humorous, with the boys taking a less emotional tone, suggesting that Gretchen's presence and contributions may have made it easier for the boys to speak to their feelings. The impact of changing group membership and group dynamics will be explored further in the discussion section 5.7.3.

### 3.7.6 Technology usage

The focus groups were audio recorded on my MacBook Air, which is password and finger-print protected and can only be accessed by me. The audio was recorded using Mac's 'Voice Memos' application and the laptop was placed in the centre of the room. The audio recordings were safely stored on the secure laptop and transferred securely to the artificial intelligence (AI) programme for transcription, called Otter.ai. The produced transcripts were imperfect and were corrected, by me personally, by listening to the audio and tracking the transcript. This process allowed me to begin familiarising myself with the data as per the advice of Braun and Clarke

(2021).

Once the transcripts were completed, I exported them as raw text files and imported them as a data set to Microsoft Excel. This allowed the transcript to become a data set, which could then be coded in a table format (see excerpts in Appendix 3D). This decision was made so I could code the transcript digitally on a piece of software I was familiar with and knew how to navigate, without learning a new programme. It meant that codes could easily be searched for within the document, which made the process of transforming codes to themes easier, but reduced the chances of AI impacting upon the analysis process. Moreover, coding digitally enabled me to lift quotes easily between documents. I used Microsoft Word and several tables to transform codes to themes (see Appendices 3E; 3F and 3G). Initially, I tabulated themes separately for both data sets (group one and group two) before undertaking an adjustment phase, where themes were both refined and combined for both groups. There was some movement between codes and themes during this stage of analysis and evidence of this phase can be found in the audit trail (table 7).

### 3.8 Data Analysis

#### 3.8.1 Reflexive Thematic Analysis

The following section explores the tools used for data analysis. RTA (Braun & Clarke, 2019), developed from TA suggested by Braun and Clarke (2006) was chosen, as it recognises that assumptions and positioning are always part of qualitative research and reflexive practice is vital to understand and unpack these (Braun and Clarke, 2019). This approach feels particularly significant for me as a researcher who has personal, lived experience of bereavement in childhood and a consciousness of the way this impacts my positioning as a researcher. RTA was chosen as it acknowledges the knowledge and experience of the researcher and the value of this in the interpretation of data. I was conscious to ensure that own lived

experience did not override the experiences of the participants and aimed to stay true to the data without over-projecting my own experience into the analysis, while acknowledging the value and impact of my positioning as a lived experience researcher on the results. Continuous reflexivity and conversation about my own emotional experiences throughout the research process (through supervision and a reflective diary) were helpful throughout the RTA process.

Furthermore, RTA is well suited to focus group interviews and a social constructionist positioning, as it allows for interpreting, and creating, not discovering and finding the ‘truth’ that is within the data (Braun & Clarke, 2019). Identifying common themes within the focus group data can help us to understand the commonalities of experience for this group of bereaved children and the shared meaning they make from those experiences, as it excels in identifying common thematic elements across participants and the events they report. Several authors (e.g. Saldana, 2012; Wertz et al., 2011) suggest the method is appropriate for studies which examine the psychological world and TA is useful for research that seeks to answer questions about group conceptualisations of a phenomenon (Joffe, 2011).

### 3.8.2 Reflective diary

I kept a reflective diary throughout the research process. This became particularly significant throughout analysis. An entry was made after each transcript was completed, both noting my feelings that had arisen for me during the process and any initial reflections on the content of the transcript. I had research supervision regularly throughout the transcription, coding and analysis period (between weekly and bi-weekly) to ensure the feelings that were arising were appropriately processed and managed and did not impact upon the research project. The reflective diary allowed us to consider how my experiences may have been impacting the content the

young people brought to focus groups, which is explored further in the discussion section. Reflections on the emotional impact of undertaking this project and the positive and containing impacts of keeping a research diary alongside research supervision are discussed in 5.6.

### 3.8.3 Procedure for RTA

As per Braun and Clarke (2006; 2019), the six-step procedure of TA was followed. Each group's data set was analysed separately in the first instance. Common themes were identified across participants, through coding. These codes were used to generate themes, which were reviewed, defined and named. An inductive approach was utilised to ensure the themes are strongly led by the data, as opposed to having pre-existing codes and themes (Braun & Clarke, 2006). However, to ensure the analysis addressed the research questions (outlined in section 3.3) themes were grouped into four categories: school; social; experience and family. Initially, themes were generated for group one and for group two separately. These themes were then reviewed, with some combined and some discarded, resulting in eight final themes for group one and seven final themes for group two. Supervision regarding the analysis was sought to reflect on my assumptions, to inform better practice, particularly given that I was bereaved as a child and am aware of the risks of over-projecting my experiences of grief/bereavement into the data (Braun & Clarke, 2019).

Initially, I had planned to report the data sets separately, writing up themes for group one, themes for group two and a comparison section. As such, I wrote up group two's themes first. During this process, I noticed the high levels of commonality between the groups and decided to combine the data. Therefore, data for group two was written up first and group one's data merged. I was conscious of how this may

have impacted upon the write up (e.g. over representation of group twos data) and reflected on this in supervision, making my supervisor aware of the process so he could support my reflexivity. Themes and subthemes were then compared between the two focus groups and cross-checked, to decipher whether the themes are group-specific, or whether the data is consistent between the two groups. The data was then combined and compared and the identified similarities and differences between data sets for each group are discussed in both Findings (4) and Discussion (5) chapters.

#### 3.8.3.1 Participant checking of findings

A meeting occurred between myself and the employed staff at the charity in November 2023, to present preliminary findings and discuss next steps for the project. A final meeting with each group of participants occurred in November 2023 and January 2024, to present, discuss and cross-check the preliminary findings with the participants, to act as an ending for the project and to ensure that they agree to how their answers have been interpreted. The purpose of this meeting was multifactorial, aiming to provide a containing ending to the project for the young people; to maintain their role as co-participants in the study and ensure the project continues to involve them throughout and to aid reflexivity. By checking findings with participants, I was able to ensure that the interpretation was relevant to them and not overly influenced by my positioning, both as a TEP and adult bereaved as a child.

#### 3.8.3.2 Endings

The meeting also allowed for a containing ending for the participants and me as a researcher alike after the project. Throughout the process, the participants were told that it was important that my experiences were not shared with them, so as not to influence the project. Throughout the project, the older participants expressed a desire for friendships, for example, asking me to join their Whatsapp group and suggesting

we celebrate the end of the project socially together. I wonder if this ongoing desire for connection with me was linked to our shared experiences of being bereaved and it was important to carefully manage the boundaries around the project, which was perhaps amplified by the personal topic and connective nature of the research. However, I had agreed to answer any questions they had about my experiences once the project was completed. An hour and a half was contracted with each group, to allow for an hour of feedback and reflection on the project and half an hour to answer any questions/share my personal experiences. The feedback meetings (and endings) are reflected on in 5.6.1.

### 3.9 Ethics

A study on a topic as sensitive as childhood bereavement undoubtedly poses a number of ethical challenges, which required careful consideration and thought. Ethical approval was obtained from the Tavistock and Portman Trust Research and Ethics Committee (TREC); please see Appendix 3H for full TREC application and 3I for approval letter. This is particular true given the project involved interviewing children, who may be less resilient than adults when discussing a sensitive topic (e.g. Clark, 2010; Prince-Embury & Saklofske, 2012). Both the BPS Code of Ethics and Conduct (2018) and the BPS Code of Human Research Ethics (2021) were adhered to in this study and the research was undertaken with the “aim of avoiding potential risks to psychological well-being, mental health, personal values, or dignity” (BPS, 2018, p19). That said, the study needed to ensure that interviews do not become unnecessarily distressing. Unnecessarily is used here as it is likely participants will experience some distress when having to discuss painful memories. It is important that the study creates a setting where participants giving such accounts can feel safe and supported. Here I will outline the steps taken to ensure unnecessary harm was not

caused.

### 3.9.1 Power dynamics

One significant issue is the discrepancy in power between the child and the adult researcher with lived experience of childhood bereavement (Clark, 2010). I implemented the participatory element of the study to reduce the power discrepancies; by allowing the young people to decide the topics they feel are important to share, the researcher is no longer doing the research to, but instead with, the participants. Power discrepancies are here reduced through the creation of a respectful relationship between researcher and participants, emphasising that the voice of the young people is at the heart of the project.

### 3.9.2 Potential need for further support

As previously mentioned, there is a risk that discussing painful memories might cause distressing thoughts to be triggered by being part of a focus group. Furthermore, there is a risk in focus group interviews that the discussion may cause a young person to reprocess or re-evaluate their experiences and grief. To manage the risk that participants have distressing thoughts triggered by being a part of the focus group, further support, such as counselling or a follow-up session, after the focus groups was made available through the charity. The decision to recruit participants from the young ambassadors group allowed me to take advantage of their existing support network of bereavement professionals. A bereavement counsellor was present during the focus group interviews, providing both an element of familiarity and protection for the young people, as well as support if necessary. Recruiting from bereavement groups further ensures participants have previous experiences with talking about their loss and reduces the risk of distress compared to participants who may be talking about their loss for the first time.

### 3.9.3 Interviewing

Punch (2002) presents a range of issues that can arise specifically when interviewing children and warns that researchers risk invalidating their projects if they do not carefully consider how this changes the research process. She highlights that it is important that the interviewer has adequate training in interviewing children. I have previous experience conducting one-to-one interviews with adults in a research context, on the topic of bereavement. As a TEP, I also have experience of working with and talking to CYP, about their emotions, experiences, and difficult topics: such as gathering pupil views as part of the assessment process.

Furthermore, I sought advice and guidance from Dr Martin Lytje, who has conducted extensive studies with bereaved children, about how to conduct focus group interviews most ethically with this vulnerable group. He advised that from his own studies, he has learnt not to ask children to share their experiences too early and to spend time building rapport first. He also recommended I share that I was bereaved as a child with the group, to model talking about loss and build trust. I am experienced in talking to/on bereavement and have delivered training to teaching assistants (TAs)/teachers on bereavement. I have also undertaken a clinical placement in CAMHs as part of my training as an EP and as such am experienced in supporting SEMH, which meant I was able to mindfully watch the group for signs of distress alongside the colleagues from Forget-me-nots.

### 3.9.4 Safeguarding

Plans were in place in the case of safeguarding concerns arising to ensure they were being reported. The charity has established procedures in the case that such disclosures arose; and the staff were present during the focus groups and thus would have been able to support with this.



### 3.9.5 Consent

Written, signed consent to participate was gained from both the young person's remaining parent or carer(s) and the young person them self. If the young person is above the age of 16, they could self-consent without the consent of their parent based on principles of Gillick Competence. That said, I was mindful that a relationship with the remaining parent is a significant protective factor for bereaved children and it was deemed important that this process did not create unnecessary tensions within family networks for any young people; the seeking of dual consent for the younger participants was an attempt to mitigate this possibility. See Appendix 3A for consent/assent forms. Consent was attained from the young people to share demographic details, including gender identity, age, age at time of bereavement, which relative has died, time since bereavement and time as a young ambassador. The young people were given a 'prefer not to say' option on this form, and information sharing was voluntary.

### 3.9.6 Withdrawing from the study

The participants right to withdraw from the study was made clear to them at the beginning of the research process. The consent form (Appendix 3A) states that the young people are not obliged to take part in this study and are free to withdraw at any time during the data collection. The form makes clear that should they choose to withdraw from the programme they may do so without disadvantage to themselves and without any obligation to give a reason, and withdrawing or declining the invitation to participate will not impact their position in the ambassadors programme. It was explained that a young person's information cannot be taken out of the focus group sessions once the session has ended, as the data will be anonymised. However, as above, it was not compulsorily to attend all focus group sessions and a young

person could withdraw from future focus group sessions if they wished to.

### 3.10 Trustworthiness

As per Guba and Lincoln (1981), there are a set of constructs through which qualitative research can be established as being trustworthy, known as: credibility, dependability, confirmability and transferability. These are described as:

1. Credibility - confidence in the 'truth' of the findings
2. Transferability – showing that the findings have applicability in other contexts
3. Dependability – showing that the findings are consistent and could be repeated
4. Confirmability – a degree of neutrality or the extent to which the findings of a study are shaped by the responders and not researcher bias, motivation, or interest.

#### 3.10.1 Credibility

Credibility refers to whether data gathered and interpreted reflects the actual research findings (Nowel et al., 2017). Credibility can be supported by the effective use of peer/colleague debriefing (Anney, 2014; Shenton, 2004) to ensure the conclusions reflect the data; supervision was utilised throughout the research process to ensure reflexivity was in place and findings were accurate. As per Yardley (2007), it is also important to ensure that conclusions are congruent with and reflective of the participants accounts; I presented and cross-checked the preliminary findings with participants, to ensure they felt represented by the results of the study. Overall, the participants concluded that there was a high level of alignment between what the participants conveyed and my interpretation. Credibility was also achieved by presenting thick descriptions to show rather than tell the reader about the data, enabling the reader to interpret, check meaning and decipher the legitimacy of the claims (Nowell et al., 2017).

### 3.10.2 Transferability

This research did not aim to unearth definitive, generalisable answers to questions, but instead sought to explore perspectives of CYP within one bereavement group. Therefore, this study's findings do not claim to be broadly generalisable. This stance is in line with the social constructivist ontology epistemology, which appreciates that knowledge is constructed and thus relative to the situations from which and people from whom it derives.

It is acknowledged that the sample size of this study is small, with eight participants from one bereavement group and charity, divided into two subgroups of four. Conducting the focus groups and data analysis in two separate groups, findings can be crosschecked to see if they are context specific or common across two groups of young people, which will reveal some information about the transferability of results. The research also includes a detailed description of the focus groups (and bereavement group context) and also of the research process, which will allow others to evaluate this and to assess its transferability to other contexts, as it may be transferable to similar settings (Robson & McCartan, 2016). The rich contextual description of the charity and group enables readers to identify a comparable participant group and charity setting. However, it should be noted that long-term bereavement groups are relatively uncommon in the UK and thus the transferability is likely to have some limitations. That said, there is huge value to be gained from the experiences of those bereaved children we can reach and we can draw on those experiences to better inform future support plans. By providing thick descriptions of participants accounts, readers are supported to ascertain whether insights from this research can help others to understand bereaved children in similar and different contexts.

### 3.10.3 Dependability

Dependability refers to confidence in the research process; it is the assurance that it is logical, traceable and clearly documented (Tobin & Begley, 2004). It is hoped that the use of an audit trail increased the study's dependability by promoting transparency regarding how the data were selected, collected and analysed (Denzin & Lincoln, 2017; Joffe, 2011; Robson & McCartan, 2016). Table 10 shows the evidence of an audit trail and where the data are located within the thesis.

Table 10: Audit trail

Evidence	Location
Photographs of hand-written mind maps from initial meeting with participants (checked by supervisor to ensure interview schedules not biased by researcher's personal experience/positioning). Excerpts only to protect anonymity (some data was identifying).	Appendix 3B
Interview schedules based on mindmapping data	Appendix 3C
Excerpts of coded transcripts	Appendix 3D
Initial tables of codes and themes for groups one and two (stage one) – demonstrating how codes were transformed to themes	Appendix 3E
Secondary tables of themes and subthemes for groups one and two (stage two) – demonstrating movement between themes as data was sat with and worked with.	Appendix 3F

Initial table of combined themes for both groups (stage three)	Appendix 3G
Final iteration of table of themes	Table 11; Section 4.2
Example excerpt from research diary to demonstrate reflexivity in process	Appendix 3J
Evidence of researcher reflexivity	Chapter 5.6
Completed 15-point checklist for good thematic analysis	Appendix 3K

---

#### 3.10.4 Confirmability

Confirmability is achieved when the researcher evidences how their interpretations and conclusions are derived from the participants' data, as opposed to the researcher's own motivations or interests (Guba & Lincoln, 1994; Nowell et al., 2017). This can be achieved through a clear description of the research process, but also through the use of reflexivity: both functional (Braun & Clarke, 2013) and personal (Willig, 2013). Throughout this research, I kept a research diary, detailing my thoughts and changing beliefs throughout the process of the analysis of the data. This was a means of maintaining my awareness of my positioning, with a hope to draw to awareness their capacity to consciously and/or unconsciously pollute the analytic process and delimit this capacity in the process (see Appendix 3H). Reflections on the research process are made in section 5.6.

## **Chapter Four: Findings**

### 4.1 Findings

One umbrella theme was developed across the data set. Nine themes were generated for group one and seven themes were generated for group two, with several subthemes crafted within each theme. Seven themes were common between both groups (4.2.1 through to 4.2.7) and two themes were unique to group one (4.2.8 and 4.2.9). However, some subthemes were unique to each group. As such, unique subthemes have been colour coded in the table below. Themes and subthemes that only apply to group one are coded in blue and themes and subthemes that only apply to group two are coded in green. All other themes are applied to both groups. Please see table of themes and subthemes (table 11, p.83).

#### 4.1.1 'Battle and conflict': an umbrella theme

An overarching theme developed within many of the main themes and subthemes, described as 'battle and conflict'. Throughout the focus groups, tensions were central and participants acknowledged contradictory experiences of grief over time. The participants felt that there was a societal misconception that time heals and grief lessens with the passage of time (4.2.5.1E; 4.2.5.1A). However, they explained that in their experience, as they have aged (and developed cognitively) their understanding of their grief and understanding of the significance and permanence of death has grown with them. It was acknowledged that 'it has gotten easier, but then like I said, it has also gotten harder... it's developed into a different sort of grief' (Leo, 21).

The young people felt that on one hand things are easier, perhaps due to the reduced temporal proximity to the event allowing them to have processed the initial grief emotions. Yet, as they have developed cognitively, they feel they are more able

to process and understand the extent and long-term impact of what has happened (4.2.5.1A; 4.2.5.1D). As some of the young people began to observe their friends developing adult relationships with their parents, they began to realise they were never going to have that and that they would miss out on experiences because of their loss (4.2.5.1D; 4.2.5.1G). Leo said:

‘I think it's been more of like a realization... an understanding that obviously they are really like, gone. It's... cemented in sort of thinking you're never going to be able to ... go for a drink with them. You're never going to be able to, you know, they would teach you how to fix a car or do all these sort of things. And I think as I've slowly gotten older I think it's actually harder for me to always like, process it because I can understand it more.’

These young people shared that they had experienced teachers expecting them to ‘get over it’ within a certain timeframe (4.2.1.2E; 4.2.1.2L) and that their grief presentations were less tolerated over time. Some of the new processing that happens for young people may be triggered in schools, for example, the realisation that a young person may not have a beer with their father may be triggered by a science lesson on alcohol and may present as disruptive behaviour. In the young people’s experience, grief presentation was often misunderstood as disruptive behaviour in school, reflecting another battle/tension whereby their SEMH needs are misunderstood. Young people continue to process their grief parallel with their development, as they grow, their understanding of their grief grows with them, making the passage of time and their experience of grief in tension or conflict with one another. For bereaved children, time corresponds with cognitive and emotional development which allows their understanding of their experience to deepen, which can cause further grief and pain rather than healing.

There were many times when individuals would contradict themselves within the same session. This was particularly prominent around the topics of talking about

their bereavements and receiving support. For example, when asked whether they would like people to ask them more questions about the deceased person, such as what they were like, Leo initially said ‘I would and I wouldn’t’. Yet later in the session, when asked how they would like people to approach talking about their experiences, he said:

‘be casual about it, don't be all tense and act as if you know, it's all “I can't say anything!” I'd be very casual about it, ask them a few questions. If you know, of the person, know anything about them, ask a little something about it; ask what they liked, their interests, you know, any good experiences, they have of the person.’

Likewise, when asked the same question in group two, Jason said ‘Don't do it’; but, just two minutes prior, he had said: ‘yeah, if they're not rude and they're not going around being annoying about it. Yeah. You can ask.’ These contradictions were confusing for me as a researcher and I was curious about what might be happening for these young people; it seemed like there was an internal battle for them where their desires were at odds with each other. When speaking about asking for support, Maddie said:

‘Sometimes it's hard to approach a member of staff and especially kind of say “I'm not okay”, so sometimes you do, it's hard, isn't it? Because some days you want to be asked, “are you okay?” so you can say no. And other days? You don't want to be asked that question because you want to be okay.’

Her reflection demonstrates the internal battle of wanting to be okay, so not wanting to be asked but not actually being okay, so needing to be asked. I wonder how much this tension, of wanting to be okay, or as other participants described ‘normal’ may explain some of the contradictions expressed by participants, whereby their desire (to be okay or ‘normal’) is at odds with the reality in which they are bereaved and grieving.

Throughout the focus groups it was apparent that these inner battles are emotionally distressing for the young people and likewise, impact their ability to accept support.

These tensions can be observed throughout the findings section and is highlighted here



to draw light to the inner conflicts experienced by bereaved children.

#### 4.2 Table 11: Table of Themes

Code: black – both groups; green – group two only; blue – group one only

Theme	Subthemes
4.2.1 Impact at school	4.2.1.1 Return to School 4.2.1.2 Impact of transitions 4.2.1.3 Being triggered in school 4.2.1.4 Impact on academics
4.2.2 Experiences of support	4.2.2.1 Support at school at the time of bereavement 4.2.2.2 Support at school in the longer-term 4.2.2.3 Desire to be included in support plans 4.2.2.4 Social Support
4.2.3 Desire to be normal	4.2.3.1 Desire to be normal
4.2.4 Social challenges	4.2.4.1 Peers reactions 4.2.4.2 Being picked on 4.2.4.3 Humour as a coping mechanism 4.2.4.4 Comparative suffering
4.2.5 Grieving	4.2.5.1 Being triggered 4.2.5.2 Dreams
4.2.6 Complexity of grief	4.2.6.1 Understanding has developed over time 4.2.6.2 Being told/not told and ‘figuring it out’ 4.2.6.3 Loss of innocence 4.2.6.4 Letting go or not
4.2.7 Impact on homelife	4.2.7.1 Impact on family members 4.2.7.2 Financial impact
4.2.8 Post-traumatic growth	4.2.8.1 My experience shaped me and my aspirations 4.2.8.2 Desire to work in bereavement
4.2.9 Hopes for future support	4.2.9.1 Training for schools 4.2.9.2 Grief education as part of the national curriculum

In Appendix 4A are the full quotes from which either words or phrases have been shown in quotations, or the essence synthesised in the description, with the code system relating to their thesis chapter position. I have taken a discursive approach to the findings, in line with latest guidance from Braun and Clarke (2021) which suggests findings should be discursive rather than purely descriptive in nature.

#### 4.2.1 Impact at school

##### 4.2.1.1 Return to School

The experience of returning to school was experienced differently between both groups. All participants in group two shared that they found returning to school soon after the bereavement helpful, particularly due to being ‘surrounded by people’ rather than isolated (4.2.1.1A; 4.2.1.1B; 4.2.1.1C). All participants returned to school within days and reported a desire to return to normal. School was clearly seen as a part of normality for the young people:

‘I would prefer to just try and get back to normal instead of talking about it 24/7...’ – Jason, 13

For the young people, school provided some normality away from the bereavement which was present in their lives at home. Maddie similarly acknowledged the benefits of gaining structure and normality from her return to school, but balances this with the challenges that came with it:

‘going back was challenging... it happened during half-term. So it was nice to kind of have that time to not be at school but then to kind of get back into having that structure and some form of normality. I remember it being quite daunting, and not kind of knowing who knew or what to expect, how it was gonna feel...’ – Maddie, 20

Maddie acknowledges the duality of both benefits of schools’ structure but the uncertainty of not knowing what it would be like for her. Likewise, Ashley and Leo both described having a challenging return to school but associate this with being

bereaved during the transition to a new school in year seven (4.2.1.1D; 4.2.1.1E). They felt the transition to secondary school was amplified by their experiences of grief. Group one generally described their return to school as more challenging than group two, who appreciated the return to normality. For those bereaved during a transition to a new school, they were returning to something new rather than normality, and thus did not feel the benefit/comfort of returning to something known, but rather, as described by Ashley, the experience was ‘scary.’

#### 4.2.1.2 Impact of transitions

All participants in group two were bereaved in primary school and have since transitioned to secondary school. All participants acknowledged a difference in the level of support they received in their new school compared to in primary school, one described as a ‘huge difference’ (4.2.1.2A) and one of the main impacts of this transition being that none of the participants were asked whether they wanted their teachers and peers to be told when they transitioned from primary to secondary school. The group acknowledged that the emphasis was on them to disclose this information and consequently, not all their teachers know, partly because they would feel ‘awkward’ disclosing this information (4.2.1.2B). Likewise, group one reflected the yearly change of teachers was difficult because of lack of information sharing among school staff and challenges of having to repeat their stories to new teachers (4.2.1.2C; 4.2.1.2D). The emphasis on young people to share (and repeat) this information themselves was difficult for them emotionally.

Tord shared that the end of the summer holidays was particularly challenging for him, and he would stay up at night thinking about his mum when he was about to transition into a new year group:

‘I'd stay up, it was like insomnia, but I don't have insomnia. I'd just think about like oh my god that's insane... I was like staying up and I was thinking

about how I had literally no information about her except for what everyone else says. I didn't know anything about her. I didn't really have a relationship with her, because I was just little. And I would stay up thinking about that.' – Tord, 13

Transition points were potentially particularly triggering for Tord due to the loss associated with starting a new class and leaving familiar adults (class teacher) behind. Tord's experience demonstrates how grief can cause psychosomatic symptoms, disrupting his sleep and subsequently impacting upon his experience of new beginnings.

#### 4.2.1.3 Being triggered in school

The participants shared experiences of being triggered in school, be that by lesson content, such as being shown films where someone dies (4.2.1.3A); advertising on cancer research when their parent had died of cancer (4.2.1.3B); being asked to make a Mother's Day card for their grandmother after their mother died (4.2.1.3C). The participants shared that anniversaries, birthdays and events like Father's/Mother's Day can be particularly difficult for them, but this has not always been handled sensitively at school:

'Teachers basically shouting out to the whole class. I didn't want it to happen. Because like, on his anniversary one year... in form time I just wanted to be left alone. So my form tutor decided to go: "guys, don't worry, Jason, it's the Grandad's anniversary, the anniversary of his death, if you lot could be nicer to him", and then just kinda ended it there.' – Jason, 13

While this was likely well-intentioned, Jason shared that this experience was upsetting and not something he wanted to happen; Tord shared a similar sentiment of not wanting something to happen when his class were making Mother's day cards: 'I didn't want to be moved away' (4.2.1.3C).

Participants also shared difficult experiences with teachers who do not know they are bereaved:

'This teacher, she was all like, "ooh what if I tell your mummy that you've

been chatting in class” or something stupid like that. And then my mate was just like “oohh you shouldn't have done that” ... I burst out laughing and then left the room.’ – Tord, 13

Tord’s experience highlights the complications that can arise when information is not shared with teaching staff when a young person transitions between schools. This experience was evidently upsetting to Tord and understandably disrupted his ability to attend to the lesson, demonstrating the ways that being triggered in school can impact on ability to attend, as well as emotional wellbeing.

#### 4.2.1.4 Impact on academics

Participants acknowledge that their grief has an ongoing impact on their abilities to attend to and focus on schoolwork, their behaviour in school and subsequently their academic performance (4.2.1.4A; 4.2.1.4B; 4.2.1.4C; 4.2.1.4D).

They also described feeling pressured by the schools to focus on their academics:

‘the pastoral support there is not very good. ... he's having a rough time, they told him he needs to concentrate because he's soon doing his GCSEs and he was having a difficult moment and he got told that he should get on with his life and start practising and working for his GCSEs.’ - Juan, 14

Juan highlights the academic pressures of an assessment-based education system, and the difficulty of existing within these pressures whilst experiencing grief. Juan went onto reflect that the pressure he feels from the school to stay in lessons is impacting his mental health; this poignant reflection demonstrates the longevity of grief and its potential long-term impacts upon a young person’s schooling career. This reflection was shared by Leo:

‘I mean, I think schools are so, so fixated on education and learn, learn, learn, and I think they forget that people are like, almost human. Like, there's no, you know, school is not the be all end all.’

Both groups communicated that it can be difficult to prioritise your education when you are grieving as a young person; it was not felt that schools were particularly understanding of this but rather, placing pressure on them to attend lessons and

perform academically. Both Leo and Jason had a difficult time in school in the aftermath of their bereavements and both spoke about experiences of fixed term exclusions and threats of permanent exclusion for their behaviour, which they feel were linked to grief (4.2.1.4E; 4.2.1.4F).

#### 4.2.2 Experiences of support

##### 4.2.2.1 Support at school at the time of bereavement

Participants' experiences of support in the immediate aftermath of the bereavement were varied between them, which is to be expected given the number of variables that surround death. Most participants reported that their teachers 'avoided' talking about the topic (4.2.2.1A; 4.2.2.1B; 4.2.2.1C). Group two, who were all bereaved when in primary school, feel they were better supported in primary school than they are at present and that their teachers were more understanding and cared more (4.2.2.1D).

Group one, except for Jared, shared that they were offered to use the pastoral support room in the aftermath of the bereavement (4.2.2.1E; 4.2.2.1F; 4.2.2.1G). The group found this support difficult to take up for various reasons, including feeling 'rushed back into class' by staff members (Leo) and feeling 'more worried about missing important information' (Maddie). The group felt like their teachers thought they were using their bereavement as an excuse to get out of class and felt pressured to return to lessons due to the academic pressures of secondary school (4.2.2.1.H). The groups reflections demonstrated that it can be difficult for young people to take up support in the immediate aftermath of the bereavement, due to both the perceived academic pressures of the school system and the ways in which adults respond to their need for support.

By contrast, Tord reported that his school was 'pretty good' at supporting him prior to and immediately after the bereavement; Tord's mother was terminally ill and

his school were aware of this, and provided support to the family prior to the bereavement, such as letting Tord and his brother have time off during term time to spend quality time with his mum:

‘Yeah we were allowed off for like, maybe like a week or so, just so we could spend more time with her... I think my primary school was pretty good because they let us spend time off instead of just sending us back in like soldiers.’ – Tord, 13

An experience unique to Tord, was where careful thought was given to the support in place for the family before the bereavement occurred. Tord reported that the school listened to his family’s wishes and highlighted the importance of this to him. Tord’s likening of bereaved children returning to school to ‘soldiers’ is a powerful image and perhaps highlights the battle-like nature of a bereavement for young people and the perceived pressure to be strong in the aftermath of loss, akin to how a soldier must maintain resilience in war.

#### 4.2.2.2 Support at school in the longer term

Group two acknowledged their continued need for support in school into the present day and group one reflected on the longevity of grief and historic need for continued support. All participants in group two had been offered a time out card that could be used to exit a lesson and go to pastoral support if they became upset (4.2.2.2A). Participants described having negative experiences in the pastoral support room, where they often felt ignored and upset by attempts of support:

‘They gave me a colouring book that had already been coloured in and threw some pencils at me and then just left me there for the hour. Then [they] said “alright, you need to go to maths.” That was it. I just thought oh my God.’ - Gretchen, 14

Gretchen describes an experience of seeking pastoral support but being left ‘in tears’ for an hour while the teachers worked on their computers (4.2.2.2B). This resonated with the other participants who described similar experiences of not having

opportunities to talk when they need to and being given coping strategies (such as colouring) which felt unhelpful, or they had not been consulted on. Participants also describe being told to ‘get over’ their upset and ‘concentrate’ on their education (4.2.2.2C; 4.2.2.2D) and these experiences had made participants reluctant to return to the pastoral room or request support going forward (4.2.2.2E).

Group one reflected on the ways in which the support they received changed throughout their school career. Leo shared:

‘I think there's a common misconception obviously, that you're going to get over it as it's getting longer... So it went from being relatively supportive. And then sort of not and I just felt like a burden to an extent...’

The reflection that Leo’s need for support made him feel like a burden to his teachers is poignant and he attributes this to the adults’ misunderstanding of the longevity of the impact of grief on young people. This resonated with other participants, who felt their teachers assumed or expected them to be over it as time passed. However, for many participants, in both groups, they felt their need for support was increasing with age as their understanding of death and grief developed (4.2.2.2F; 4.2.2.2G).

The most helpful form of support described by participants in both groups was having a key adult in school; it should be noted that the charity run a school support programme which is based around establishing a key adult of the young person’s choice. The young people would often rather talk to the teaching staff than pastoral (4.2.2.2H).

‘I can talk to my PE teacher, because he's always there, willing to listen to me... He was also talking about his problems and how I wasn't alone, that everyone had problems, and then we went back and forth... for our entire PE lesson.’ - Jason, 13

Jason described the strength of his relationship with his PE teacher, who normalised Jason’s emotions for him by sharing his own experiences. This is a powerful example of when school support is successful and young people can feel emotionally contained



in school. Group two reflected on the discomfort associated with having to repeat your story to adults and the contrasting comfort of having an adult who remembers (4.2.1.2D; 4.2.2.2I). The positive impacts of a trusted relationship with an adult who could hold them in mind were apparent within both focus groups, highlighting the potential benefits of a relational-based approach for bereavement support in schools.

#### 4.2.2.3 Desire to be included in support plans

The participants in group two felt that they had limited options in terms of support and wanted to be asked what they wanted, rather than assumed (4.2.2.3A; 4.2.2.3B; 4.2.2.3C). They described the ways in which what they need changes daily but the feeling that the opportunity to talk is taken away when you have declined it once. Participants felt they did not want to talk when they first entered the room and were emotionally dysregulated but may want to talk ‘five minutes later’, but it was too difficult for them to ask for this support (4.2.1.3C). The participants also acknowledge that all children are different and want different things, but felt the most important thing was asking CYP what they want:

‘I think the most important part of teachers and staff trying to help a kid is ask them what they want. Make sure you sit down, have a conversation with them, ask them what would be helpful to them. Because every child is different, every child's grief will be different. So for them to have an opinion of what they would want, I think they just need to keep in mind that all children are different. They will grieve differently, so they should ask.’

- Jason, 13

Tord added that remaining family members should be asked when a child is too young to advocate for themselves. The young people felt strongly that everyone and every bereavement is unique and should be treated as such in terms of the support required. This was not a theme for group one; however, many members of group one remember being asked what they would like to happen, e.g. Maddie had a meeting with her head of year after her bereavement and Leo was asked who he wanted to be

told. This seemed less important to group one, with Leo reflecting that: ‘I was so young, I didn't really care to be honest. It was like the last thing on my mind.’ This was perhaps less important to group one, who are all young adults now, as they are no-longer living the experience of being supported in school and are speaking retrospectively of their experiences.

#### 4.2.2.4 Social support

Group two shared that they had experiences of some social support and felt able to talk about their bereavement with their ‘closest friends’ (4.2.2.4A; 4.2.2.4B) and that having friends around to ‘joke’ and laugh with helped them through the grieving process (4.2.2.4C). Most prominently, the group highlighted that it is much easier for them to talk to peers about their bereavements who have also been bereaved, that they have met through Forget-me-nots than it is for them to talk about it at school (4.2.2.4D; 4.2.2.4E).

‘I found it much easier to talk to people here. So I became friends with most people here. Because it's just easier because they've been through the same thing as us... So I guess it was just a lot easier making friends here and talking about it here than it was anywhere else.’

##### 4.2.2.4.1 Jason, 13

The young people acknowledged the power of shared experience in helping them connect with others and aid the building of relationships, which rendered it easier for them to talk about their experiences.

Likewise, group one shared positive experiences of peer support at Forget-me-nots. Maddie said:

‘...What I got most out of it was like, realising I wasn't the only one. Realising that, like, other people do know, kind of how I feel and what I'm going through.’

Group one found comfort in realising there were other young people like them and shared that their first experiences of meeting other bereaved children were at the

charity (4.2.2.4F). They shared that they experienced a loneliness or felt isolated in their experiences before joining the charity, which was remedied by peer support.

There is a description of shared experiences of feeling different to their non-bereaved peers and their experiences of social isolation/bullying due to being bereaved (4.2.3).

#### 4.2.3 Desire to be normal

Participants expressed a discomfort with feeling different and a desire to be 'normal' and treated the same as their peers. However, this desire then impacted upon their ability to ask for and receive support in school. For Jared, the fear of being judged as different prevented him from telling his school about his bereavements:

'I wasn't really offered anything seen as I didn't really tell anyone. Purely because well, I thought if the teachers knew I might get special attention or other things that would draw attention and then be, God forbid, judged by everyone else.'

Jared highlights the ways in which social pressures can prevent young people from taking up support. Participants across both groups shared Jared's dislike for receiving special treatment by teachers (4.2.3A) or peers (4.2.3B) because it made them feel different:

'they were like trying to give me one [a time out card] but I just didn't, I didn't really want one because it made me feel a bit different like... I don't want to be different, I wanna be the same.' – Tord, 13

Tord acknowledged that there are times when one needs to be treated differently (4.2.3C) but this did not seem easy for him or the rest of the group to accept. The desire to be treated the same as peers was a barrier to accessing support in school.

Similarly, the group did not want to be treated differently socially:

'I felt like people were treating me nicer because they felt bad. And it's like they weren't being like truthful. They were putting on a second face and being nice to me because of something that's happened. I wanna know people for what they actually are. So if you're just being pity nice to me, then I wouldn't want them to know.' – Jason, 13

Participants did not want to receive 'pity' or to be treated differently due to their

experiences and noticed people being nicer and gentler with them after the loss (4.2.3B). While this is evidently well-intended, the change felt uncomfortable to the young people, possibly because it reminded them of what they have been through. Leo also shared that he felt his friends were ‘beating around the bush’ after his bereavement and how he tried to show his friends that he is still ‘a normal person’:

‘Yeah, I remember trying to just get back to normal as much as possible with my friends. I remember, it was a girl I was talking to and I'd asked her out just before my dad died. And she obviously didn't give me an answer. And I asked her, “have you got your answer yet?” And she was so shocked like my dad had just died... but I was just like come on girl.”

Leo’s desire for normality impacted upon his relationships as a recently bereaved young person. The young people’s reluctance to accept different or ‘special’ treatment (support) is perhaps linked to their stages of grieving and respective abilities to accept their bereavements, as well as a strong desire to fit-in socially.

#### 4.2.4 Social Challenges

##### 4.2.4.1 Peers reactions

The participants felt that their peers ‘did not know’ how to act around them at first and it was ‘awkward’ (4.2.4.1A; 4.2.4.1B; 4.2.4.1C; 4.2.4.1D; 4.2.4.1E; 4.2.4.1 F). Group two reflected on the fact that their peers had been told by the school, with the hope that their peers would be more sensitive and they would not be asked about it all the time (4.2.4.1B). However, Gretchen reflected: ‘I was asked a lot anyway so it didn't really make a difference.’ For these participants, being asked is a part of their reality which they have had to accept, despite in some cases putting measures in place to try and avoid this happening. Group two agreed that they are all asked about the bereavement by their peers frequently, including questions such as ‘how does it feel to have them die?’ (4.2.4.1G). This experience was described as upsetting by the group and they shared that while they do not mind being asked, it is important to be asked respectfully and by people who know them, rather than

strangers (4.2.4.1H; 4.2.4.1L). However, they did not feel people were often respectful of their feelings when asking about their grief:

‘They're not protecting my feelings if they're asking about it.’ – Tord, 13

The reality of speaking to their peers about their bereavement seemed to be uncomfortable and at times hurtful for the participants, due to both the discomfort and awkwardness of their peers and their perceived lack of sensitivity in the way their peers broach the subject with them.

Group one reflected that it has become easier for them to talk about their bereavement with their peers as they have matured (4.2.4.1I; 4.2.4.1J). However, they feel their peers are reluctant to broach the subject in case they have an emotional response and they experienced the conversation being shut down quickly if they brought it up (4.2.4.1K). Maddie shared:

‘not asking questions or uncertainty about like talking about it, is they don't know what to say. Or yeah, they expect us to have like, a major breakdown and not know what to say or how to comfort you. So they're just like, I'll let someone else deal with that.’

For the younger group, it was common for their peers to ask them questions about their experiences whereas for the young adults, they experienced continued avoidance and felt it was because their peers' concerns about the emotions involved. It is possible that this increased sensitivity towards other people's emotions develops with age and as such, explains the differing experiences of the groups, with young adults becoming increasingly defended against difficult emotions as they mature. Group one felt more pressured to protect other people from the difficult feelings that arise talking about death which also perhaps develops with age and increased empathy for other people's emotions.

#### 4.2.4.2 Being picked on

The males in group two were particularly concerned about people ‘blabbing’

about their bereavement (4.2.4.2A) and telling other people about their experiences, which prevented them from seeking peer support. Among group two, the consensus was that violence, or having a go at someone, would be an appropriate response to someone 'blabbing their mouth' (4.2.4.2B). For Jared, the fear of being judged by others prevented him from telling anyone that he had been bereaved. He linked this to the social expectations of males:

'I was at an all-boys school. So it was kind of important, seen as in that type of environment it's kind of, an either, you're popular and you're always okay, and not made fun of or you're the complete opposite. And everyone makes fun of you and you're singled out. So in that environment is felt like you have to be okay, or you're going to be alone.'

Group one agreed that there is a pressure upon young males to 'be okay' which was observed in male siblings of female participants (4.2.4.2C) as well as through personal experience of the males in the group (4.2.4.2D). Leo shared that he has always found it easier to talk to girls about his experiences:

'I found it easier to talk to girls ...boys were very sort of like, be like macho and sort of, like, don't show emotion, blah, blah, blah. Where the girls seemed to be a bit more like, open to the facts.'

Group one reflect that societal expectations of maleness can lead to social isolation and bullying by male peers and that the pressure to appear emotionless negatively impacted upon their abilities to process their grief at times; the group perceive gender to have an impact upon how grief and the subsequent emotions are processed and how they were treated in the aftermath of their bereavements. The males in group two felt that their peers have their bereavement against them to provoke fights:

'Most of them have been because of my granddad. Yeah. So people who know that if they do want to start something can get under my skin. That's how you do it. So that's why most people who do want to fight me try that approach because that just sets me off.' – Jason, 14

This group of young people have had experiences of being bullied for their experiences of being bereaved and have had their grief used against them to provoke

an emotional response. Gretchen has experienced comments from friends after talking about her bereavement:

‘I can talk to my close friends about it. But I've had experiences with my closest mate saying that I like what do they say? They said I make my dad my entire personality and stuff. It's, I don't know...’

This feedback had clearly made it difficult for Gretchen to speak about her experiences with even her closest friends, and could be interpreted as a form of bullying, if it continues over a period. I will discuss how this may link to theme 4.2.3 – desire to be treated the same – and the ways in which being ‘different’ can lead to mistreatment in the discussion.

#### 4.2.4.3 Humour as a coping mechanism

The participants in group two all identified using humour as a coping mechanism to help them manage their feelings around their grief (4.2.4.3A; 4.2.4.3B; 4.2.4.3C). Juan shared: ‘I use it every day of the week. It sometimes makes you feel better to make a bit of a joke.’ The group agreed that joking about their experiences makes them feel better and helps them manage. However, they also acknowledged that joking can be awkward for their peers who have not been bereaved and they sometimes do not laugh or laugh uncomfortably (4.2.4.3D; 4.2.4.3E). They also discussed the possibility of their peers thinking it is acceptable to make jokes because they are joking about it:

‘Yeah I don't think it's ok for other people to make jokes because otherwise they don't really know where the boundary lies and where not to cross’ – Juan, 13

‘I feel like if I've been joking about it then like, it's okay if they make some like, light jokes about it...’ – Tord, 14

Individuals had different views on this, which demonstrates that while there are commonalities in experience, each young person is individual and has different boundaries around joking around their experience with others.

Leo shared that he uses humour all the time with his sibling and that this is typical in his family (4.2.4.3F). He explained that he also uses joking as a way of setting the tone in interactions about his bereavement:

‘So I think if I come out straightaway, and sort of laughing and do a bit of a joke about it, they're going to be ten times more relaxed to speak about it. They're going to think, okay, I can actually talk about it without, you know, thinking I'm going to break down in tears or something like that, or it's making me down.’

By joking, Leo is able to subtly communicate that he is not going to become upset in the interaction and is able to have a conversation about his experiences; humour has become a tool for him to navigate the interactions with more ease. While Maddie and Jared understood this, they shared that they were not comfortable with jokes themselves (4.2.4.3G; 4.2.4.3H). Maddie shared: ‘I don't like joke about it because I'm like, it's not funny.’ While for some young people, finding humour in their experiences provided comfort and rendered communicating about it easier, there was not a common consensus on this in group one, and individuals had different personal views on the appropriacy of making jokes about death.

#### 4.2.4.4 Comparative suffering

Comparative suffering is the idea that one makes sense of their pain through comparison to the pain of others; this was particularly apparent throughout group two, where young people would compare and contrast their experiences and comment on the similarities between their views (4.2.4.4A). The following exchange illustrates this:

Juan: ‘I think he died on a Wednesday, so I would've had Thursday, Friday and then I've had Saturday, Sunday. Then I went back in on the Monday.’

Gretchen: ‘Everyone got days off. I went straight back.’

Jason: ‘Innit! Everyone else is getting off...’

Gretchen: ‘My dad died on Friday. I went back on Monday!’



Tord: ‘Maybe you guys just had bad schools and our schools were normal?’

The group were trying to make sense of the differences between their experiences, and think about why they might have been different, potentially finding comfort in the similarity between each other, linking to the ideas they shared in subtheme 4.2.2.4, that it is easier to talk to people when you know they have experienced the same thing. The prominence of this theme in group two, and their desire to seek shared consensus on themes is likely linked to developmental age and stage, where sameness is more important to younger teens than their older peers. Tord also shared an example of comparative suffering outside of the group, at an extracurricular activity he attends:

‘If it ever comes up, like there's always one other person. Like, I'm not like dissing them, but like, they're always like well my sister died, like they're trying to top me out or something.’

Outside of the safety of the bereavement group, a sharing of common experience feels competitive to Tord, rather than comforting or something he and the person can bond over. This may speak to the primary task of the bereavement group, to think about grief, being a protective factor that allows discussion and connection to form safely, but this is not some contained in a group intended for extracurricular activity such as scouts.

#### 4.2.5 Grief

##### 4.2.5.1 Being triggered

Group one shared how they can still become triggered now, despite many years having passed since their initial bereavement. They shared that triggers are unpredictable (4.2.5.1A) and their mood can change very quickly; TikTok was highlighted as a medium that triggers them at times and can cause a ‘domino effect’, changing their emotional state for the entire evening (4.2.5.1B). Another trigger for

Leo and Maddie was when their remaining parent began dating, and these changes to their family life impacted them emotionally significantly (4.2.5.1C; 4.2.5.5D). Leo shared an experience where he was triggered at a music festival:

‘triggers are a massive thing, I went to a festival a couple of weeks ago, me and my dad's favourite song came on, I was bawling my eyes out like a child.’

Leo’s use of the simile ‘like a child’ is poignant, as it demonstrates how being triggered can regress a person back to the place when the initial event happened. Moreover, for the young people, music was highlighted as a particular trigger for them; this is likely music-evoked autobiographical memory, which is involuntary. However, it means young people may possibly be triggered in situations which are intended to be fun, positive experiences, such festivals (like Leo) and parties. Group one also spoke about the variability of how triggered they become by the anniversary, describing this as ‘like a rollercoaster’, with some years it impacting them significantly and others, not at all.

#### 4.2.5.2 Dreams

Group one shared that they sometimes have dreams about their relative who has died. Maddie shared:

‘... I was told he was alive and that really shook me up because I was like, really happy in my dream... but then waking up being like, oh he's not. I don't have loads about him. But when I do, I do not like it.’

For Maddie, dreaming about her dad was distressing, particularly waking up and remembering the reality that he had died; understandably, she does not like the experience of dreaming about him. Likewise, Leo reflected that he used to dream about the death around the time that it happened. However, with age, he has started to have more hyper-realistic dreams where his dad is alive:

‘I quite like them to be fair, because it's quite, I don't know, it's a weird sensation. ...everything about him is like to perfection. in my dream. It's like I'm living it, you know, like, smell, the way he looks, the way he talks. I can't remember how he smelt. You know, I can't remember how he talks or

anything like that, his voice...’

Leo reflects on how things that he cannot consciously remember, he is able to remember perfectly in his dreams about his dad and that he quite likes this. He went onto add:

‘What I wish so badly could happen in real life was happening in the dream. So [I] almost got to, like, live that sort of moment. But it's also a bit of a shitter when you wake up, and you realise it's not real.’

Akin to Maddie, Leo acknowledges the disappointment associated with waking up from dreams about a deceased relative; but he welcomes the dreams as he sees it as an opportunity to experience what he wishes he could experience – having an adult relationship with his dad. This raw and honest reflection from Leo demonstrates the ways grief continues to evolve into adulthood for bereaved children, showing up both consciously and unconsciously, at times impacting both their waking and sleeping hours.

#### 4.2.6 Complexity of grief

##### 4.2.6.1 Understanding has developed over time

Participants in group two described a developing understanding of death over time, feeling less impacted by the bereavement when they were younger due to less understanding:

‘I was only young. . I didn't really understand what happened. So I feel like it affects me more now. Because now I understand, like the concept of death and stuff. To be asked now probably upsets me more than it did at the time.’ – Gretchen, 14

Gretchen illustrates the ways in which grief can become more challenging for young people as they develop cognitively and their understanding of death evolves, dispelling the misconception that grief follows a linear model and becomes easier with time passed. Tord shared some of the processing he has experienced over time:

‘... it's kind of like just talking about a stranger that you don't really know that well... a couple weeks ago, dad just dropped this bombshell: she was doing a

PhD. I had no clue about that.'

Gretchen added:

'And that's the same for me, actually, my family when we talk about him, say the most random stuff like start telling his whole life story. And then you kind of put two and two together and then that upsets you.'

For these young people, their developing understanding and increased access to information from their relatives about the person they have been bereaved of, has left them feeling like they did not truly know the person who has died, which is upsetting and painful. There is a complexity to this grief, as they not only mourn the loss of their relative but the limitations of that relationship, due to their developmental stage and age at the time their relative was alive.

Group one also reflected that their understanding of their bereavement and the extent of what they have lost has developed over time. While the passing of time allows them to deal with the grief better, it was felt that the developing understanding of death made it harder for them at the same time:

'it gets longer so you sort of learn to deal with it better. But then you also you're growing up and you're actually understanding the actual reality of death. And you know, the absence of that figure in your life. So I guess it's, it's sort of, they go hand in hand and they kind of mess with each other a bit.'  
– Leo, 21

Leo also shared that he has realised he is never going to have an adult relationship with his father:

'I think it's been more of like a realisation... an understanding that obviously they are really gone... you're never going to be able to go for a drink with them... As I've slowly gotten older, I think it's actually harder for me to process it because I can understand it more... I get jealous because obviously, you see other people and you think God... I should be doing that sort of thing. I wish I could have that...'

Leo highlights the complexity of grief as an adult bereaved as a child, grieving for the relationship with his father that he cannot and will not have in the present and future.

Leo observes relationships others have with their parents and shares the emotions

associated with this increased understanding, including jealousy towards others who do have relationships with their parents. This increased understanding of what they will 'miss' because of their bereavement and acceptance of things that are not going to happen was common among the group (4.2.6.1A); they shared that it is particularly difficult for them around anniversaries and milestone birthdays, when the absence of their relative is particularly noticed. They have also considered how this will continue to evolve for them in the future:

'The things you wish the person or people would have seen, like, marriages, or kids, or literally anything else... Like some people, for example, at their wedding, they save chairs and put photos of the people they've lost on the chairs.' – Jared, 18

The reflections from group one illustrate the longevity and evolving nature of grief for children who are bereaved. Their understanding of death and loss develop with their cognitive development and their realisations and framing of what has happened changes and grows with them into young adulthood. They are aware of the ways their grief will be with them into the future and give thought and consideration to situations where their loss will be prevalent to them (such as birthdays, weddings), which is a continuation of the type of understanding group two appear to be developing in the present.

For some young people in group one, who have been bereaved of a parent, their understanding of that parent and their relationship has also developed over time. This was challenging for both Maddie and Leo because they both had difficult relationships with their fathers prior to the bereavements; they both described their evolving understanding of the negative parts of their dads as their 'biggest battle' and explored the tension they feel between protecting their image of their dad and accepting the reality of what happened (4.2.6.1B; 4.2.6.1C). Maddie shared:

'one of my biggest battles, to be honest... all those emotions that come with grief,

and that like, guilt, regret, like because I held a lot against my dad. And I think it prevented me from having a better relationship with him. But... you can't go back and change stuff. He's not here to kind of defend himself. And because he's not here anymore. You don't want to share that or hold onto that because you don't want other people having a negative or nasty image of that person.'

This highlights that for some young people, their grief is made complex by the complexities of their relationship with the person who died. For Maddie and Leo, this was made more challenging by the desire to 'protect his legacy' and not 'tarnish his memory' leading to what felt like a 'battle' within, which was both complex and painful for them.

#### 4.2.6.2 Being told information (or not)

All members of group two were bereaved of somebody who was unwell (and in hospital) before dying. The group shared their experiences of being told information about their relative's illness and subsequent death. Juan was told his dad was dying by his mother (4.2.6.2A) and felt this helped prepare him for the bereavement (4.2.6.2B). The others were not explicitly told their relative was dying. They all shared their experiences of 'figuring it out' (4.2.6.2A; 4.2.6.2C; 4.2.6.2D; 4.2.6.2E) from the information they did have, such as the physical condition of their relative and them being in hospital; however, this realisation happened after the bereavement.

Jason shared:

'You know the saying you'll get it when you're older? That's what I've got. Because I realised his condition was like slowly getting worse. Because you can see it from pictures if you put it in a timeline. He went from upright walking, talking normally, to slowly getting down into where he went into a wheelchair, to where he could barely talk. And then right at the end where he had, do you know, the respirators, helps you breathe? He had one on him, and I was sitting in the living room talking to him about that. And I realised about a few months after, they told me that the reason he was on that was because he was dying, but at the time I didn't know that. So I was happy, thinking he was gonna be here for however long, and then not much later he's gone.'

Jason describes his observations of the decline in bodily functions of his grandfather over time, and his ability to connect this with his grandad dying as he has matured.

Jason was six years old when his grandfather died and as such, was unlikely to have had a mature understanding of death and to have made links between breakdown in bodily function and dying. This experience, shared by most of the group, shows how this realisation comes later for children, once their developmental understanding matures to understand the links between death and bodily function. This lack of understanding impacted the young people's understanding at the time, enabling them to believe their relative was going to survive their illness.

The experience of having information withheld from them impacted some young people's opportunities to say goodbye to their relatives (4.2.6.2F). Gretchen shared:

'My mum didn't want me to see him in hospital. But she told me that we'd go and visit him and he died a week later. Afterwards, she was like, you probably didn't want to see him in hospital anyway. So I think she said that we were gonna go to make me feel better, but she knew he was gonna die. So she said that we're gonna go, but we weren't...'

Interviewer: 'Is that difficult to sit with?'

'Yeah, I would have wanted to see him. But we couldn't.'

This experience highlights the difficulty of balancing adults' desire to protect children from the realities of death and dying and consequently the decisions are made without consulting children, which may later feel painful or unfair to them. The group reflected on this, sharing that it protected them from being hurt at the time and understanding why their parent(s) made that decision (4.2.6.2G). Yet, as time has passed, they have begun to wish they had the opportunity to say goodbye (4.2.6.2G; 4.2.6.2B). The group concluded that there was no right way and the decision about how much information to share with children should be made on a case-by-case basis, reflecting that perhaps they would always wish for the opposite of what happened because neither option is 'right' (4.2.6.2H).

#### 4.2.6.3 Loss of innocence

Group one shared in the mind-mapping session that they feel they became adults when they experienced bereavement. For Leo and Maddie, who were the oldest child, they feel they became ‘the man of the house’ or another parent to their younger siblings (4.2.6.3A; 4.2.6.3B). Maddie shared: ‘when it happened, I had to grow up very quickly.’ For Maddie and Leo alike, this led to increased responsibility for their younger siblings (4.2.6.3C; 4.2.6.3E) and for Leo, some caring responsibilities for his mother who was struggling with her mental health (4.2.6.3D). The pair reflected on how this matured them and how quickly they grew up because of their bereavement.

Group two described a loss of innocence and change to reality after their bereavements.

‘You're just a little kid, you've got like, a mask over everything, everything just feels happy and like green you know? Oh not green. You know what I mean... But then it stopped being like that and things started to seem more real.’ – Tord  
13

For the group, this felt like a turning point in their lives where things became ‘more real’ and the ease of childhood appears to have been lost for them. Participants felt that their understanding of the grief, and ability to accept it, has developed over time as they have ‘grown up’ (4.2.6.3F).

‘It's like Gretchen said, when I first discovered, I didn't really think about, it was kind of like a dream. And I was like, actually growing up and realise that is true. But yeah, grief has definitely changed.’ - Juan, 14

The young people are increasingly able to accept their bereavement as a reality. But, they feel it is harder for them now, that they understand the permanency of death, to cope with the realities of their grief (4.2.6.3G). Group two could simultaneously see some benefits to their increased awareness through grief, they acknowledge that grief has made them who they are and increased their empathy for others (4.2.6.3.H; 4.2.6.3.I).



#### 4.2.6.4 Letting go (or not)

In our discussions about anniversaries, Jason shared that he releases a balloon on the anniversary of his grandfather's death. Juan commented that this happened at the end of his time with the bereavement group at Forget-me-nots, and shared:

'I kept my balloon because I felt very attached to it.'

This reflection from Juan highlights the tension between 'letting go', metaphorically and literally, or holding onto our grief and how difficult this can be for some young people. The balloon for Juan perhaps was symbolic of his grief, or his relationship with his dad, and he was not ready to let go of that yet. This led into a conversation about visiting graves and the significance of this. For Juan and Jason alike, they found visiting the grave 'weird':

'I just feel like he's not there. It's a bit weird. It's just a dead body. He's not there. Why are we going there?'" – Juan, 14

'Yeah, I don't like going. His body is there but that's not him. And that would never be him. So why do we do that?' – Jason, 13

For these two, the symbolism of the grave did not resonate with them and they found the idea of visiting the body strange and uncomfortable. Gretchen disagreed with this, sharing:

'I never thought about it like that. I go visit and pretend he is there with me. Because when he first died, we took Toblerone and a beer up there and we'd like poured the beer on the grave and then we sat and ate Toblerone. You just kind of have to use your imagination I guess.'

For Gretchen, the symbolism of taking her dad's favourite things to the grave seems to help her connect with his memory. Tord's mother was cremated, and he shared that they spread her ashes, but kept a small box which are kept on the mantel:

'Yeah, so she's there every morning when I get ready for school.'

For some young people, they feel like their person is 'with them' when they interact with their remains, and for others, this is a strange or uncomfortable experience. This

again illustrates how bereavement is individual, and grief changes and evolves overtime. The young people's reflections suggest grief becomes something that we can move in and out of, at times, stepping away from it and coming back closer, when we need to.

#### 4.2.7 Impact on homelife

##### 4.2.7.1 Impact on family members

Group two reported that they did not notice the impact on their families at the time of the bereavement but are becoming increasingly aware of it with age. This was for various reasons, including lack of proximity to extended family, family dynamics and developmental age and stage (4.2.7.1A; 4.2.7.1B; 4.2.7.1C; 4.2.7.1D). Tord shared that he is becoming increasingly aware of the impact on his extended family, and has recently realised the impact the bereavement had on his grandparents:

‘I think about it because my grandparents, they were my mum's mum and dad and it must've effected them a lot more. That's like their child. I saw a picture of them like them, with her, when she was my age, it just gave me clarity.’

As the young people come into adolescence, they are beginning to think about the feelings of other people and the ways in which the bereavement impacted on those around them (4.2.7.1E; 4.2.7.1F). Some of these realisations were happening during the focus groups for young people, where they were thinking about their experiences and processing the impact on their remaining parent first time, which was upsetting for some participants (4.2.7.1G). Again, this demonstrates the ways in which grief, and understanding, develop over time and the emotions that inevitably arise for young people as their processing of their bereavement develops.

Contrastingly, members group one noticed the impact on other family members at the time of their bereavement, for example, Jared described his parents as ‘struggling in front of their kids’ (4.2.7.1H) and Leo described ‘wanting to be a support worker’ to his family when his uncle died (4.2.7.1I). However, the group still

feel their understanding on how the bereavement impacted the rest of the family has improved over time (4.2.7.1J) and this is particularly true of extended family, such as grandparents, while impact on immediate family was more apparent to them from the onset (4.2.7.1K).

#### 4.2.7.2 Financial impact

Leo shared his experiences of the financial impacts of being bereaved of his father. He reported that the death of his father significantly impacted the family's financial situation to the point where they had to use foodbanks (4.2.7.2A) and reflected on the impact this situation had upon his mum's mental health: 'I'd say financially was probably worse because my mum was obviously sick trying to deal with it.' Leo explored how this also impacted his school-life:

'I've had my mum stressing, crying about bills, for example, and stuff like that, and really seeing that, and then having to go to school, wearing a pair of trainers that I bought myself. Black trainers, and they're my school shoes.

Teachers are saying "you need your mum to go buy another pair of shoes." I'd just come from my mum, literally upset about bills and finances.'

Leo highlights how bereavement can touch all elements of a young person's life and how they intersect with one another. For example, Leo was often in trouble at school for wearing incorrect uniform, but his family's financial situation limited his ability to rectify this, illustrating the ways in which stressors can accumulate for these young people. Although this reflection was unique to Leo within the groups, it is important to highlight given that childhood bereavement is more common amongst lower socioeconomic backgrounds.

#### 4.2.8 Post-traumatic growth (PTG)

##### 4.2.8.1 My experience shaped me and my aspirations

Group one reflected on the ways their grief has shaped them and their life paths (4.2.8.1A).

'As crazy as it sounds, I think him dying has shaped me into possibly a better

person than I would have been had he not died. Which sounds pretty crazy, but it's the truth, it has shaped me completely.' – Leo, 21

This is arguably PTG where a person sees positivity and opportunity for personal development in the aftermath of adversity. Group one recognises a level of resilience that they have developed through their experiences. Leo's reflection that it has completely shaped him demonstrates the significance of grief and bereavement in his life and the ways in which it can mould a young person's self-view. The young people felt the bereavement had motivated them to succeed and to 'honour the memory' of their relative (4.2.8.1B; 4.2.8.1C) and be the best person possible for the person who died. Leo also reflected upon the way the financial aspect of bereavement motivates him to succeed:

'Looking after my mum, for example, you know this, I've seen her struggle so much, and she's sacrificed a massive portion of her life for me and my brother. And I sort of think the cards have been dealt, but probably with my uncle not being there, and my dad not being there and the situation that has put us in, drives you to wanting to be more sort of like successful and a better person.'

Leo wants to be able to help his family and give them a better life. The young people had high hopes and aspirations for themselves, paired with a strong desire to support others and make-change, which perhaps reflects the perspective they have developed through experiencing death so early in their lifetimes.

#### 4.2.8.2 Desire to work in bereavement

The aspirations of group one have been shaped by their experiences, with the group all expressing a desire to work within bereavement support in some way. For Maddie, she shared that she works in a school at present and has a growing passion for supporting young people with their mental health and wellbeing (4.2.8.2A; 4.2.8.2B) while the others wish to continue their work for the charity alongside a primary career. Leo shared:

'You know, someone who has gone through is the best advocate for it, you

know, you've experienced it, you have first world, you know, real life knowledge of it. And I think there's no better person, or people to, you know, advocate.'

For these young people, part of their role as a young ambassador for Forget-me-nots is to raise awareness about childhood bereavement; they have experience of sharing their stories and talking about their experiences on video and at events. Leo described his experience of being a young ambassador as 'helping others while also helping yourself.' For these young people, there is a duality in being involved in bereavement support and they can acknowledge that there are benefits for others and for them, in being able to sit with their own grief throughout the process.

#### 4.9.2 Hopes for future support

##### 4.2.9.1 Training for schools

Group one shared their hopes for what they would like to see change in terms of the ways schools support young people who have been bereaved. Their biggest hope is for mandatory training for all teaching staff on childhood bereavement (4.2.9.1A; 4.2.9.1B; 4.2.9.1C). The group could not understand why this is not already in place and discussed how training is in place in schools for other vulnerable groups (such as lesbian, gay, bisexual and trans (LGBT+) (4.2.9.1D). This comparison, between bereaved young people and LGBT+ young people is interesting and perhaps suggests that bereaved children do not see the same representation for themselves within the curriculum as they have for other vulnerable groups but also see an element of diversity within themselves. The group reflected on how training could change things positively for bereaved children in schools. Maddie shared:

'For example, you're just a naughty kid. You're not, you've got so much going on. With that [training] in place, staff are gonna be more aware and hopefully work with you to work out what's going to help you and what doesn't, and, like, educate that so that they can work and continue to support you.'

It was felt that increased awareness of the longevity of grief, complexity of grief and

ways grief can present, would prevent teachers from viewing bereaved children as ‘naughty’ and punishing them (perhaps to the point of exclusion), instead increasing their understanding of and empathy toward bereaved children so that they can stay in school and achieve their potential.

#### 4.2.9.2 Grief education as part of the national curriculum

As well as training for teachers, group one felt grief education would be beneficial for all and should be part of the national curriculum. However, they felt this idea would be turned down by professionals on the basis that it would scare children:

‘It wouldn't hurt and it wouldn't, like take up too much time or resource to introduce part of the module in like, RSE [relationships and sex education]. But then people are like, “oh, we don't want to scare the children. We don't want to bring up hard things...” but actually it's their excuse for everything.’ – Maddie

Maddie reflects on the desire to protect children from ‘hard things’ but sees this as an excuse not to introduce grief education. Leo added:

‘it will prepare them I think much better... I didn't know anything about it. No one usually does. You don't even know what happens when someone dies, they get buried or cremated, what's a funeral? I think scaring them and things is stupid considering the stats on how many kids are bereaved.’

The group both felt that grief education would help bereaved children, and their non-bereaved peers, alike. The group explored the idea that bereavement is something all of us will inevitably experience (although not necessarily in childhood) and as such, they feel education around death, grief and bereavement would be beneficial in preparing people for this eventuality, as well as understanding others who have been bereaved.

## **Chapter Five: Discussion**

### 5.1 Overview and research questions

This chapter aims to discuss the findings of this thesis, in accordance to the research questions posed in chapter two. That is: 1) What are 13-21-year-olds, bereaved as children, experiences of the death of a close relative, within the contexts of family-life, relationships and school? 2) What do 13-21-year-old's, bereaved as children, perceive to be supportive following the death of a close relative? And 3) How do 13-21-year-old young people experience their return to school and the support received following bereavement of a close relative? The chapter will situate these findings within the context of existing literature and knowledge, evaluating how they relate to the research base.

### 5.2 Exploring young people's experiences and desires

#### 5.2.1 Experiences of bereavement across contexts

##### 5.2.1.1 Experiences of bereavement at school

Young people in this study found transitions, both between year groups within school and between primary and secondary schools, to be challenging for them. The young people recognised a 'huge difference' between the support they experienced in primary school compared to secondary school, which may be related to the differences in school systems; the primary school model revolves around one class teacher who can mindfully watch a CYP throughout the day and therefore hold them in mind while the secondary school model requires young people to interact with several, subject specific teachers who may not all be aware of or remember that a young person is bereaved. The young people reflected on how the emphasis was on them to share their story and the idea of disclosing their experience with adults feeling awkward. They felt the yearly change of teachers was difficult because of lack of information sharing among school staff and challenges of having to repeat their

stories to new teachers. This is in line with the findings of Keaney (2017, doctoral thesis) who found that bereaved children and young people are likely to be under identified in schools and when they are known to have experienced parental bereavement, school professionals struggle to understand and respond to their emotional needs. The young people and I reflected on whether a pupil passport or note on the register to make teachers aware of their experience could be a supportive mechanism to support their transition and teachers' understanding of them. Costelloe et al. (2020) proposed a bereavement passport as an intervention to support this need; however, it should be considered that bereaved CYP in this study expressed a desire to be treated the same as their peers and this may be a barrier to them accessing this type of support, which they may feel draws attention to their differences (a similar sentiment expressed regarding timeout cards).

All the young people had experiences of having their grief triggered at school, from being shown cancer research adverts when their parent died of cancer, to struggling on significant dates (e.g. anniversaries; birthdays; Mother's Day and Father's Day) and experiencing difficulties with teachers who did not know they were bereaved mentioning their deceased family member. These experiences were described as often disrupting the young people's abilities to attend to lessons as well as their emotional wellbeing. Likewise, Lytje (2016b, doctoral thesis) found that Danish young people had similar experiences, and grief reactions could also be triggered when the school taught topics related to death or when special occasions arose, such as school plays where parents' absence was particularly felt. Lytje also found that this was a trigger for reminding young people they were different, which influences the young people's behaviour and decision making, leading to conflicts and contradictory behaviour.



The CYP identified that bereavement had impacted on their academics, particularly their ability to focus and attend to learning. The research base on the impacts of bereavement on school performance shows inconsistent results, with some researchers finding bereaved children have an increased risk of underachieving in school compared to their non-bereaved peers (e.g. Abdelnoor & Hollins, 2004; Berg et al., 2014) and others have found that some bereaved children's academic ability increased (Dowdney, 2000; Silverman & Worden, 1993). In attempting to explain these findings, Dowdney (2000) highlights that many studies on the topic do not take factors such as previous academic skills, competence, and type of loss into account. PTG theory suggests some young people may focus on academic work to honour the memory of the deceased or distract from their grief (Worden, 1996). This study also found evidence that participants were impacted by PTG and motivated to honour the memory of their parent. However, in this study, the young people's own view is that their school performance was impacted. In particular, their ability to concentrate in the aftermath of their bereavement decreased. This is akin to Lytje's (2016b) findings, in which participants identified difficulties concentrating and with handing in homework. This self-perception of declined performance due to bereavement may indicate that young people's perception of self can change after being bereaved and may be indicative of a need for increased support with academic work in the aftermath of bereavement.

Two young men in this study described experiencing fixed-term exclusions and threats of permanent exclusion for their behaviour, which they feel were linked to grief. Keaney (2016) interviewed three young people who were parentally bereaved and had experienced exclusions, identifying that while this is a population who are at risk of exclusion, they are generally under-identified in schools which was reflected

in her difficulties with recruitment. When we link that teachers in secondary school may be unaware of young people's bereavements, it may mean that young people's behaviour, which is a communication of grief, is being misunderstood by schools due to a lack of knowledge. It is important then, for schools to be trauma-informed in their behavioural policies and adopt relational approaches to behavioural support.

#### 5.2.1.2 Experiences of bereavement at home

The younger participants (aged 13-14) noted that they were not aware of the impact of the bereavement on their other family members at the time of bereavement but are becoming increasingly aware with age, there are a number of reasons for this that include lack of proximity to extended family, family dynamics and developmental age and stage. Evidence suggests that the ability to apprehend the emotional states of others increases with age in terms of decoding confounded emotions, interpreting situational regulators of affect and understanding unexpressed affect (Decety, 2010) and as such, it is understandable that this group are gaining an increased understanding and empathy for other family members' experiences of grief. Contrastingly, the older group, who were generally older at the time of bereavement, felt they recognised the impact of the death on their other family members at the time; yet, still felt their understanding has grown alongside their cognitive and emotional development. Slaughter (2005) emphasised the link between cognitive and emotional development of CYP and their previous experiences of bereavement as being key to their understanding of death. Dimery and Templeton's (2021) teacher participants also highlighted the reciprocal relationship within this link, suggesting that a child's typical developmental trajectory may also have been impacted by their loss. Participants in this study who were older at time of bereavement, or had younger siblings, described taking on caring roles for their families and becoming 'the man of

the house' or a 'parent' to their younger siblings. This is akin to the findings of Dimery and Templeton (2021), who interviewed adults bereaved as children. They found that participants who were older at the time of loss made comments about taking on a supportive role for the remaining parent, demonstrating the ways in which developmental age and stage can affect the impact of bereavement upon a young persons' home life and the roles they take up at home and beyond.

The study also revealed that changes to a young persons' family system can trigger grief and grief can trigger changes to the family system. For example, the financial impact of bereavement was highlighted; as well as the impact of the remaining parents' mental health upon their ability to support the young person and the impact of blended families, such as gaining stepparents or parents beginning to date. In particular, young people found it difficult when remaining parents began dating and this emotionally impacted them. Likewise, Dimery and Templeton (2021) found adults bereaved as children experienced: financial stress, blended families and parental neglect as 'risk factors' for negative experiences in the aftermath of a death.

Moreover, the study revealed that grief impacts young people's home life in multiple different ways; group one shared that they dream about their deceased relatives. These dreams were distressing for some of the young people, such as dreaming their relative had not really died and coming round to the reality that they are still dead upon waking. To my knowledge, this theme has not been explored in previous research on bereavement. However, schools might consider how distressing or triggering this may be for a CYP to enter school after experiencing a dream of this kind. Equally, how difficult it might be for CYP to share this experience with an adult in school or to explain/articulate their distress. As such, it is important that we are mindful of the complexity of grief and how it may manifest for young people, in their

wakeful and sleeping hours, and how that may impact their presentation across all of their contexts.

### 5.2.1.3 Experiences of bereavement socially

The young people in this study faced social challenges; participants felt that their peers 'did not know' how to act around them at first and it was 'awkward'. The participants had difficult experiences of being asked about their bereavement by peers, either in insensitive ways or their peers avoiding the subject in case they have an emotional response. Participants expressed a discomfort with feeling different and a desire to be 'normal' and treated the same as their peers. When a young person is bereaved much of their reality changes beyond their control; perhaps we might understand their desire for 'normality' and 'sameness' socially and at school through this lens, as a desire for consistency in an otherwise changing life.

Within this study, bereavement impacted many of the young people socially, with group two experiencing being picked on and/or bullied for being bereaved. One participant did not feel able to share that he was bereaved with his peers, due to fear of being bullied for being different. The social stigma associated with being a bereaved child prevented these young people from accessing support for their bereavement in school on numerous occasions, as their 'desire to be normal' or 'the same' outweighed their desire to be supported in school, linking to the fear of being socially stigmatised; therefore, the social impacts of being bereaved were felt by the young people in school, as well as in their social lives. It is important then, to consider a systemic lens when supporting and understanding bereaved children and young people. This is in common with the evidence base, which has found that bereaved children/young people (CYP) can become a target of bullying (Rolls, 2009; Dimery & Templeton, 2021). Stuber (2001) suggests that peer-support needs to be

carefully managed by teachers and that they can help normalise the situation for the child's peers.

Participants in this study constructed that peers' responses to bereavement are gendered. The young men in this study linked being at all boys' schools to a pressure to be emotionally stoic to avoid being the victim of bullying. Likewise, they shared that they found it easier to talk to girls due to a male pressure to be macho and hide emotions; the girls in the group agreed with these observations. The groups perceived gender to have an impact upon how grief and the subsequent emotions are processed and how they were treated in the aftermath of their bereavements. This is akin to the findings of Silverman and Worden (1993) that boys were less likely to talk with peers about a parent's death and were less comfortable with sharing their feelings. Dopp and Cain (2009) note that these gender differences may be expected as there are higher rates of intimacy, self-disclosure, and caring among girls in peer relationships (Berndt, 2002) and that boys are less likely than girls to take advantage of peer-provided emotional support (Dopp & Cain, 2009).

Lytje (2016b) found bereaved Danish CYP did not like to feel, or be reminded that they were, different, akin to the young people in this study. Lytje conceptualises this desire for sameness within the Model of Loss Navigation in Adolescence (MLNA). Lytje identified three factors which seemed to be dominant concerns for young people navigating bereavement within the context of the school community: being in control, being different and being in grief. The model looks at the relationships and tensions between these factors. Lytje identifies the ways in which these factors can be in tension, for example, young people have a desire to control information about bereavement so that they are not perceived as different; this was a common finding with this study. For example, some young people did not want their

teachers or peers to know they were bereaved because they did not want to be perceived to be or feel different. Lytje also identifies being in grief, being in tension with being in control and being different. The MLNA provides a useful framework for understanding the tensions between factors of grief experienced by young people and their interrelatedness. An alternative way of understanding these tensions will be explored in 5.2.4.

Equally, the participants in this study also had some positive experiences of peers and peer support. This was largely within the charity, where they were part of bereavement support groups and felt shared experience supported them to talk about and process their grief. This is in line with evidence found by Siddaway et al., that young people who access BSGs often comment on their surprise that there are so many other people who are bereaved and who are like them (2011).

The participants in the current study are a particularly interesting cohort in the sense that they have remained ambassadors for the charity and received continued bereavement support over several years since their bereavement through the ambassador role. This is uncommon in the UK, where bereavement groups are often short term (between three-seven weeks). The groups have had long-term opportunities to build friendships with bereaved peers, while supported by trained professionals and shared that this opportunity has been supportive to them. Another finding of this study was that young people use comparative suffering to make sense of their own experiences and grief. This was particularly apparent in group two (aged 13-14) and may be due to their developmental age and stage. It also seemed there was a desire for sameness within the group, perhaps linked to the comfort of having peers like them, or perhaps linked to group dynamics and an unconscious desire to identify similarities, differences and hierarchies. While there is little empirical evidence on the impact of

BSGs, this finding perhaps reveals something about the importance of BSGs for young people, in order to better understand their grief and to support them to manage the difficult feeling of 'wanting to be normal'. BSGs can act as a space where being bereaved is the norm and therefore, this need to be normal can be mediated and grief can be observed and felt.

This study found that CYP use humour as a coping mechanism to help manage their feelings around grief. They explored how humour is a means for them to communicate to peers that they will not become upset by talking about their bereavement and to signal it is okay to talk about it. Although the young people in group one were not unanimous on this, they could acknowledge the intention of using humour to set the tone of a social interaction. Humour can be an unconscious defence (Winnicott, 1935); however, these young people seemed to be consciously choosing humour to manage social interactions around their grief. This finding may be culturally specific, as the British sense of humour is known to be dry and dark, with gallows humour known to be a feature of British comedy (Esser et al., 2023). The young people were able to acknowledge that dark humour can be uncomfortable for non-bereaved peers at times, but ultimately helped them to manage their grief and they enjoyed laughing with their friends about their experiences.

Use of humour was evident throughout the study. Participants in group two used their chosen pseudonyms when referring to each other during the study. This was despite being reminded that this was not necessary and I would anonymise the data several times. The pseudonyms became a point of entertainment for the young people, and they would laugh after making reference to each other by the name. Juan in particular would refer to himself as Juan in the third person and refer to the others by their pseudonym, which always made people laugh. I wonder if this type of

humour helps bereaved CYP to distance themselves from their grief and experiences, while maintaining the ability to discuss and therefore process it. Cramer (2006; 2008) suggests that individuals use humour to effectively distance themselves from threatening feelings without distorting reality. As such, while gallows humour can be uncomfortable for those on the receiving end of it, I would encourage those working with bereaved CYP to consider how it may be a tool used by CYP, to aid their processing of their grief, as well as a means to control the narrative around their grief among their peers.

#### 5.2.1.4 Inter-relational impact of bereavement across contexts

The young people identified family, friendships, and school to be the three areas that were most impacted by their bereavements and that they wanted to explore throughout the study. Reviewing the findings, the inter-relational nature of the way grief impacts these elements of their lives is evident. For example, Leo shared that the death of his father significantly impacted his family's financial situation, which put stressors upon the family emotionally. One consequence of the family's financial status meant that they could not afford the correct school uniform. Having the incorrect school uniform impacted Leo's relationship with the school and led to sanctions, further negatively impacting his experience of school; Leo did not feel his school were able to understand the stressors in his home life or the extent to which his family had been impacted by loss on a financial and emotional level. The relationship between home life and school life for Leo impacted the way he experienced his grief across both contexts. I also wonder how the change in Leo's approach to school, and lack of feelings of school-belong, may have impacted the social groupings he was drawn to and an increased need for belonging in his social life (e.g. seeking romantic relationships). Likewise, the desire to be normal impacted young people's abilities to



engage with support systems within the school context, demonstrating how social impacts interact with experiences of grief in school. It is important then for us to consider bereaved children systematically and consider how the levels of the system are interacting, when considering them and their experiences of grief.

## 5.2.2 Desired support

### 5.2.2.1 Desire to be included in support plans

Young people communicated a desire to be included in support plans in school; they acknowledged that all bereavements and all young people are unique and needs vary between individuals and as such, asking them, and if they wish, their family, what they need and want is fundamental. This was akin to Lytje's (2016b) findings, where young people felt positive about being included in how their return to school was handled and Costelloe et al., (2020) highlight the importance of hearing the child's voice and personalising support to meet need. With the focus on young person's voice in legislation (e.g. SEND Code of Practice, 2015) it is surprising that it is not common practice to seek bereaved young people's views regarding their support needs. But this perhaps links back to bereaved young children being an unidentified group (Keaney, 2016) and it being difficult for school staff to seek pupil views when they do not know this is necessary. This links back to the idea that no data is recorded nationally, or locally, on bereaved children (Childhood Bereavement Network, 2023; Keaney, 2016). A case might be made for keeping this data centrally, to better identify children who may require additional emotional support.

Furthermore, CYP exclusion from support plans may relate to adults' discomfort talking to CYP about death and their desire to protect CYP from difficult topics (Abraham-Steele & Edmonds, 2021; McLaughlin et al., 2019). Adults may feel they know what is best for young people, but as highlighted by Ribbens McCarthy (2007)

this can leave young people feeling powerless. The CYP in this study highlighted the importance of adults putting their own discomfort aside and empowering CYP to inform their own support plans.

#### 5.2.2.2 Grief education

This study revealed a desire for grief education as part of the national curriculum among group one (18-21 year olds). This is in line with evidence presented by Dawson et al. (2023) that young people desire grief education and they as researchers feel this would be beneficial to young people. The young people in this study felt that grief education would better prepare young people for grief and help their peers to better understand them and their experiences. Dimery & Templeton (2021) explored the idea that teachers may need to mediate peers' understanding of grief to help facilitate peer support, and likely this is the part of the bereavement professionals' role in a BSG. Grief education is one way that teachers could help mediate peers' understanding of grief, in an age and developmentally appropriate way and as part of a national curriculum. There is also potential for eventual cultural change in attitudes towards death, moving away from taboo and towards a more accepting culture through this type of education. The young people felt that adults would shut down this idea due to fear of upsetting or scaring young people and viewed this as a poor excuse, given the prevalence of childhood bereavement. Abraham-Steele & Edmonds (2021) suggest that adults' own defences against thinking about death and mortality can cause them to avoid conversations about death and grief, yet evidence suggests that young people desire them. Careful thought must be given as to how we can meet this communicated need of young people in a way that does not cause unnecessary harm but allows them to think about and explore bereavement and death in a containing and supportive environment, which is

developmentally appropriate and aware of the potential gender differences in speaking about emotions and grief.

#### 5.2.2.3 Training

The findings revealed young people's hope for mandatory bereavement training for all teaching staff. This desire was shared by teachers' when interviewed about their experiences of supporting bereaved children (e.g. Abraham-Steele & Edmonds, 2021; Dimery & Templeton, 2021). The shared acknowledgement of this need across both groups of stakeholders is promising and highlights the importance of this training to support those providing support. It would be beneficial to consider co-constructing bereavement training alongside young people who have been bereaved, so that their voices are heard and better understood by professionals.

There can be a desire sometimes from training events to seek a simple answer on the 'right' way to provide bereavement support. Yet there are complexities in each individual's experience that mean a one-size-fits-all approach is not possible for bereavement support. The participants highlighted that their needs may change day-by-day, even by the minute or hour. Bereavement training should reflect this reality and support professionals to develop an adaptive approach to providing bereavement support.

### 5.2.3 Return to school and support received

#### 5.2.3.1 Return to school

The participants in this study shared that they found returning to school soon after the bereavement helpful, due to returning to normal and being surrounded by people. This is in line with some participants in Lytje's study (2018b) who wanted their return to school to be a normal school day. In this study, participants who were bereaved in primary school shared that they felt well supported by their schools,

feeling primary school teachers were caring and understanding. Group one, who were mostly in secondary school at the time of their bereavements, felt more daunted and scared about their return to school. This difference in experience may be linked to developmental age and stage and the lower levels of consistency and routine in a secondary school setting. Some of these young people transitioned to secondary school after their bereavement, amplifying the feelings of uncertainty and unknown. Evidence suggests that school is a familiar safe space for young people and returning to school can feel like a return to normality where adults know them (Balk, 2001; Abraham-Steele & Edmonds, 2021). However, this study revealed that this is not always the case. If the young people are to transition to a new school at the same time as being bereaved, they will experience several changes and transitions at once. In this study, change of school setting amplified children's experiences of grief.

#### 5.2.3.2 Key adults

The findings of this study reveal that young people found having a key adult in school supportive. This finding was in line with Ashurst et al. (2009), advocating for teachers taking on key adult role offering care and support which may not be consistently available within the home context. Others have found that the teacher-pupil relationship is not always easy following the death of the parent (Christ, 2000). The young people in this study shared they would rather talk to the teaching staff than pastoral and that subject teachers were often felt best placed to provide support. It is important then that young people are allowed to choose their key adult rather than being assigned the person the school feel is best placed, in line with the findings of Abraham-Steele & Edmonds (2021) that the power dynamics of a teacher-pupil relationship can be a barrier to providing impactful support. The young people reflected on the discomfort associated with having to repeat your story to adults and

the contrasting comfort of having an adult who remembers. This finding is in line with the evidence base (Costelloe et al., 2020; McAdams & Stough, 2019) further highlighting the potential benefits of a relational-based approach for bereavement support in schools.

#### 5.2.3.3 Pastoral support

Participants reported that their teachers avoided talking about their bereavement; this is likely linked to low teacher confidence in supporting bereaved children and fears of saying the wrong thing (Abraham-Steele & Edmonds, 2021; Costelloe et al., 2020) as well as the emotional impact of providing bereavement support (McAdams & Stough, 2019; Dimery & Templeton, 2021; Lytje, 2018a; Costelloe et al., 2020; McManus & Paul, 2018). Having access to the pastoral support room was common in this study. Although this was offered to them, young people felt like their teachers thought they were using their bereavement as an excuse to get out of class and felt pressured to return to lessons due to the academic pressures of secondary school. This rendered it difficult for young people to access the SEMH support they needed.

One participant shared that the level of support he received decreased over time as his teachers expected him to be over his grief; he felt like a burden to his teachers for needing longer term support. All participants felt their support need was growing with their development and developing understanding of death but felt this was not understood by professionals due to the misconception that time heals. Sometimes the triggering of grief triggers a new realisation for CYP, e.g. a PSHE lesson about the dangers of alcohol may trigger the realisation that one may not ever have a pint with their dad; these significant realisation points may be incidentally triggered unintentionally during school hours, and may take more time for CYP to

regulate and process than typical. As professionals, it is important for us to reflect on what messages we give to young people, about themselves and their needs, when we respond to them emotionally. The ways we respond to young people can impact their self-construction, self-beliefs and self-esteem. It is common for young people to personalise other's behaviour towards them, due to egocentrism, which is a typical developmental stage of adolescence (Elkind, 1967). Throughout the findings of this study, young people voiced views that inferred the support they received was inadequate because teachers did not care or understand. The research suggests that teachers do care and wish to provide support for young people but there are barriers to providing this support which are not within child; it is important to note that this is, understandably, not understood by the young people and their negative experiences of support, and teachers' lack of understanding of their needs, felt personal to them. It is therefore important for practitioners to take a trauma-informed approach in their work with bereaved children.

#### 5.2.4 The battle

The battle is the over-arching theme throughout this study; it was apparent throughout the literature review, in which every facilitator of providing bereavement support in schools was paired with a parallel blocking factor and it was woven throughout the experiences of the young people in, and out of, their grief. It is evident in the contradictions in the answers of young people and it was explicitly described by the young people, in the ways they interact with their grief and the ways they are/are not able to receive support. For example, some young people described the difficulties they have with talking about their deceased relative because of the complexity of their relationship with that person and their difficulty managing the less-palatable parts of that person's behaviour when they were alive. Likewise, some

young people found it difficult to engage with bereavement support because of their battle with the need to be 'normal' and being supported being in tension with the idea of being normal. Some of the young people (group one) explained in the feedback session that 'normal' to them really meant their normality before being bereaved and their struggle was in part with accepting their new normal. It is posited then that, in part, the battle for young people is between accepting their new normal and accepting that their relative has died. There is a challenge for these young people: how do you remember your loved one fondly while simultaneously letting go of the pain of grieving? It brings us back to Juan's balloon, which he was supposed to let go of at the end of the initial grief programme but could not because he felt quite attached to it. If we are to consider this idea psychodynamically, the balloon may represent more than his relationship with his dad to Juan, but also his relationship with being with his grief. This battle is played out in literature and current fantasy films with characters describing how 'I lost my parents, that pain made me who I am' (The Flash, 2023, 1:27). As Batman talks to The Flash about the desire to change the past but how being able to accept that we cannot is an ongoing battle, in the midst of a world turned upside down by seeking to create a return to normality. The turmoil concepts of accepting loss but still struggling with it playing out in mass media.

Lytje (2016b) found similar tensions and contradictions in his study and posed the MLNA as a model of understanding adolescent grief. He posited that 'being different'; 'being in control'; and 'being in grief' were the three main themes of his study and were always in interaction and tension with each other for CYP. While this model is a useful way of understanding some of the challenges adolescents face when grieving, I suggest that it is not fully comprehensive of the emotionality of these tensions and battles. The young people throughout this study describe complex

emotional experiences and inner battles, which they themselves conceptualised to be beyond their years and to have forced them to grow up quickly. Grieving young people are wrestling with feelings of grief, shame, guilt and sadness; while considering huge philosophical ideas around death and mortality, supporting their remaining relatives and processing the realities of their experience, like realising their relatives were dying and they did not get to say goodbye or realising the impact of the bereavement on their other relatives for the first time. The desire to return to normal is in tension with the new reality, perhaps, because being with grief is inconceivably painful and difficult. It is my hope that this study has shone light on the complexity of emotion and the inner battles experienced by bereaved young people. They do not always know what they want or need and their needs can change on a daily basis; as professionals, it is our job to respond to this battle and their needs, as they change and develop with them, undertaking an understanding, adaptable and responsive approach, in hope of easing the battle for them.

### 5.3 Feedback to stakeholders

#### 5.3.1 Feedback meeting to the charity staff

In November 2023, the findings of the research were fed back to three members of paid staff at the charity, who had supported the research process. It was an opportunity to share the results with those working with the participants and further their understanding of the views shared by the young people. The meeting also served as a preliminary meeting prior to feeding back to the young people; so findings could be sense checked with staff, who were present in the focus groups in a supportive role, and any risk of harm of upsetting young people with the results could be considered and reduced. For example, we were able to discuss whether the young people would be okay with me describing their experiences as ‘bullying’ despite this



not being a word they used and think together about how to best have this conversation with the young people.

### 5.3.2 Feedback meetings with participants

Face-to-face feedback meetings were offered to both groups, separately, in November 2023. It was decided that it was imperative that both groups met separately so that the younger group were not exposed to group one specific themes, such as the realisation that they will not have an adult relationship with their loved one. It was felt that ethically, it would be potentially harmful to expose the young people to this realisation before they are ready. I met with group one in November 2023 and three participants attended (Ashley could not due to work). I shared the preliminary findings with them, in the form of the initial generated themes specific to their group (appendix H). The group agreed that the themes reflected their experiences and I then offered them the opportunity to ask me questions, which they took up. The group were particularly interested in how I took up the project and how it impacted me emotionally and I shared openly with them about my experiences (discussed in 5.6.1). I offered the same opportunity to group one but no participants attended the meeting; the charity then rearranged the meeting on Zoom in January 2024 and all four participants attended. Perhaps due to the meeting being online, the group were quiet and mainly reacted to comments by emoji or the chat function. All participants shared that the results felt representative of their views. The feedback meetings were also an opportunity for me to thank the participants and express my appreciation for their trust in me with their stories and acknowledge the power of what and gravity of them sharing their stories and what they have offered to the research base.

## 5.4 Dissemination

### 5.4.1 Eastern Region Conference

Preliminary findings were presented to an audience of 35 EPs at the Association of Educational Psychologists (AEP) Eastern Region Conference on 7<sup>th</sup> March 2024. The theme was trauma informed practice so the workshop included discussion about implications for practice. EPs asked for further dissemination, so that they can share findings with schools and support schools to think about their bereavement support plans. I would be keen to further present the study to disseminate the results more broadly and further the discussion around bereavement support among education professionals.

#### 5.4.2 Peer-reviewed journals

I intend to publish two papers in peer reviewed journal(s) as part of the dissemination strategy; a systematic literature review and a condensed empirical paper to showcase the findings. The hope is that it can be accepted by an international journal with a high impact factor such as *Omega: Journal of Death and Dying* or *Death Studies*, to maximise the readership and reach. It is also hoped that DfE will consider the potential policy influence and journals may peak the attention of funding agencies to support future research in this field (see 5.8).

#### 5.4.3 Book

Alongside the journals, it is my hope to write a book on childhood bereavement in the UK more generally, inspired by both my lived experience and this project. The book would encompass my experiences of being a lived experience researcher and reflections and learning on conducting this type of research (see 5.6), as well as trauma-informed, evidence based practice on childhood bereavement informed by the young people's voices in this study.

#### 5.4.4 Training and policy

I hope to support the development of bereavement policy and training in the

UK. Two key findings were that young people wish to be included in and asked about their desires for support plans and that training and grief education as part of the national curriculum were desired. Young people's voices must be at the centre of their design and implementation. My hope is that the voices amplified in this study may be the building blocks on which that work can begin to happen and I would be keen to support in the development of these support systems. Likewise, although not a finding of this study, the research base suggests that bereavement policy is a facilitator of schools providing impactful bereavement support (e.g. Lytje, 2016; Abraham-Steele & Edmonds, 2021). It would be my hope that, in line with the practice in Denmark, bereaved young people's voice would be considered in the development of any future bereavement policy in the UK.

## 5.5 Implications

EPs views on the implications were discussed at the dissemination conference and collected by Mentimeter, the results are appended in full (Appendix G). The thinking behind this section, in part, has been constructed through discussion with that group of 35 EPs.

### 5.5.1 Implications for research area

This study is one of the first of its kind to give a platform to the voices of bereaved young people and attempts to understand their needs for support, particularly in an educational environment. It is also the first study to include children bereaved of a grandparent, as such, shines light on what it is like to be bereaved of a close relative that has not been explored before. As such an in depth, rich perspective of the voices and stories of eight bereaved young people, their understanding of their experiences and their knowledge on what would be supportive to them is shared. There is great learning from these stories and our understanding of

how to support those who are bereaved in childhood is enriched by what has been shared. This is, to my knowledge, the first study in the UK to consider bereaved children's experiences of being bereaved and their ideals for support from an EP perspective. EPs have researched in this area, with a previous study by Keaney (2016) explored specifically the perspectives of bereaved children who've been excluded from school and Costelloe et al., exploring bereavement provision in British primary schools. However, this is the first study of its kind in the UK, to explore childhood bereavement more generally from the child's perspective, as an EP.

### 5.5.2 Implications for EP practice

EPs are mainly responsive to bereavement through critical incident when a bereavement happened in school (e.g. teacher or pupil in school). EPs role may extend to bereavement support more generally within the school community (e.g. relatives of pupils) and planning support for bereaved children. There is a valuable role in supporting schools to write bereavement policies, helping schools feel more comfortable and confident in providing bereavement support, and helping stay child-centred in the support they provide. Also supported by Costelloe et al. (2020) and Holland & Wilkinson (2015), that EPs are well placed to deliver bereavement training given their in-depth understanding of psychological theory applicable to separation, loss and trauma.

The literature review in this study revealed that the emotional impact of bereavement support is a barrier to schools providing support; likewise, it found that personal experiences of grief aided confidence in staff providing support. The need for supervision when providing bereavement support (or working with bereavement more general) is well documented throughout the research base. The young people in this study often felt their teachers were not prepared to support them. There is a role

for the EP in providing supervision to those who are providing bereavement support and containing the containers; likewise, this is highlighted by Costelloe et al. (2020), who recognise the salient need for support systems and emotional containment for school staff.

This research highlights the ways in which EPs can support schools to provide better bereavement support. While the implications are in line with Costelloe et al., (2020), they have been inferred from the perspectives of young people bereaved as children, rather than teachers' perspectives. Perhaps then, the most important implication for EPs, is the emphasis on them ensuring they, and schools, centre on student voice in bereavement support. EPs can support schools to do this, using person-centred approaches to gather young people's voice and ensure bereavement support plans are informed by young people's own wants and views.

### 5.5.3 Implications for the education profession more generally

The study equally has implications for the education profession more generally. Disseminating the findings of this study to schools will provide them with insight into what it is like to be bereaved and the types of bereavement support young people typically find helpful, with emphasis on the fact that this is unique and individualised.

The findings of the literature review support the idea that bereavement policy may be useful in helping schools to feel more confident in providing bereavement support. The young people in this study did not mention bereavement policies; however, they did not feel that their schools were always well-placed to support them with their grief. It is wondered whether a structured policy (national or localised) may help teachers feel more confident to provide bereavement support, in line with the findings of Lytje (2018a).

The young people in this study felt passionate that training for teachers on bereavement should be mandatory. The education profession may consider providing training on childhood bereavement, both in initial teacher training and as CPD. This is inline with the findings of other researchers (Abraham-Steele & Edmonds, 2021; Costelloe et al., 2020; McManus & Paul, 2019). The findings of this study suggest that young people's voice should be central to this training; it is imperative that alongside psychological theory, teaching staff are able to hear the voices of those with lived experience, so that they can understand the individual nature of bereavement and how one's grief grows, changes and evolves with them with time. Young people felt the longevity of grief was often felt to be misunderstood by teachers and it would be imperative to capture this in training, so that teachers are able to provide ongoing support throughout young people's education careers.

The young people were also passionate about grief education; this finding supports the view of Dawson et al. (2023) that grief education is desired by young people and should be a mandatory part of the personal, social, health and economic (PSHE) curriculum in the UK. The education profession should consider this request seriously. Current research by Adams et al. (2024) explored using creative pedagogies to explore death and loss in the classroom. While this study revealed that teachers found the use of interdisciplinary approaches useful, it will be important to extend this research to gather CYP's views on the intervention, particularly, given the context of the findings of this study that bereavement support should be individualised.

British cultural attitudes towards death render the topic a taboo, but it does not have to be this way. It is possible to make cultural shifts and create environments in which it is possible, and comfortable to talk about death; charities like Forget-me-nots

are evidence of that. A bereavement curriculum has the potential to help all of us to manage the difficult feelings we have about mortality, death, endings and loss in a more open, reflective way. I would welcome a conversation with the DfE about how to best approach this, in a trauma-informed, developmentally appropriate way, with a vision of revolutionising the British cultural approach towards talking about death and dying.

## 5.6 Reflections of a lived experience researcher

### 5.6.1 Sharing my experience of the project with the young people

All of the young adults in group one shared that they wish to work in bereavement throughout their adulthood and were motivated to make change and help other young people like them. It struck me how similar this was to my own experiences, which the young people were aware of, and how common it is for people to be motivated to work in areas that they have been personally impacted by. Ultimately, we are products of our environments and we chose the ways we continue to interact with our grief. Throughout the project, I reflected on the ways in which working so closely to my own experiences has impacted me, my processing of my own grief and my understanding of myself and role. At times, I have felt hugely pressured to make a difference for bereaved children, asking myself: if not me, who? Throughout the research process, I have been conscious of the ways the project impacts on me emotionally. I felt it was important to share this reflection with the young people, and for us to reflect together on the responsibilities we feel to help others. For many of us, this has been second-nature since childhood, as many of us felt caring responsibilities or the need to help our relatives grieve and stepped into an 'adult' role, before we chronologically reached adulthood. My training has enabled me to consider how my roles in my family system continue to play out

(unconsciously) in adulthood and what my valences are. At times, I wondered whether this was truly my choice to do this work or whether the path was paved for me. I reflected with the young people about the importance of supervision and permitting ourselves to step out of this role and away from our grief for periods of time, and acknowledging the emotional impact that helping others with their grief, or working in bereavement more generally can have on us. I reflected to the young people that the project has had an emotional impact on me and that being with my grief in this way has been challenging, eye-opening and painful, as well as beautiful, enlightening and inspiring. I am ever grateful to the supervisory space, for giving me room to explore these thoughts and consider where they left me: knowing that, like grief, bereavement work is something that it is okay to come in and out of.

#### 5.6.2 Participatory approach

A key element of this study was the participatory approach. Before commencing focus groups; this was introduced on the advice of Dr Martin Lytje based on reflections from his own research. My view is that the participatory element was important and effective in empowering the young people to share their stories with me. Through these discussions, I was able to physically demonstrate that I was hearing their voice (by writing their comments down in a coloured pen of their choice which represented them). It meant that the interview schedules were informed by the topics the young people wanted to share and their voices were interwoven into the study from its beginnings.

This approach also helped me to separate my voice from the young people's voices from the onset of the project. As a lived experience researcher, it was important that I was able to separate my experiences (which were often similar to those being shared) from the young people and not allow my lived experience to



interfere with their voices and stories. I was then able to share the mind-maps and interview schedules with my research supervisor, who cross-checked both the schedules and the mind maps to ensure participant voice was centralised and all voices were appropriately captured. Centralising the young people's voices from before the project began aided this process greatly and supported me to hear what they wanted me to hear, rather than investigate what I wanted to know. I would recommend this as an approach for future lived experience researchers, to centralise participant voice.

### 5.6.3 Ethical reflections

One of the main considerations of this study was ethics. The study came with ethical risks due to its nature, of asking young people to share and reflect on some of their most painful memories and experiences. It was essential that the study did not cause any unnecessary harm to participants. Careful thought and consideration was given to ethics in this study, and the processes followed were adapted following participant feedback. For example, during the data collection process the young people asked for a reminder of the upcoming theme ahead of the next focus group, so that they could emotionally prepare for what was to come. Moreover, the timings of debrief sessions were changed in the process to respond more closely to participant needs. The work of the staff at Forget-me-nots allowed this responsive support to happen. It is my hope that the young people did not feel harmed by the process of the research project; the feedback from the young people suggests that the process was empowering and the groups reflected that they were grateful to have the space to think and speak about their experiences, whilst also acknowledging that this is not something they often do now that time has passed since they were bereaved.

#### 5.6.4 Reflection throughout the process

Reflection has been an imperative part of this process as a lived experience researcher. Research supervision has been a truly inspirational process for me and I am honoured to have had a supervisor who was dedicated to holding space for me, containing me emotionally, understanding me as a person and practitioner and was so open to challenge. Together, we have been able to work through topics, thoughts and experiences which would have been too uncomfortable for many people, but demanded to be examined as part of this process. It was an absolute honour to look within in the ways I was empowered to, in order to ensure my experiences were not making their way into the findings of this study. My research journal became a good friend to me throughout this process. I would urge all researchers to keep a log of the way their research impacts them but particularly lived experience researchers, recording the feelings enabled me to notice what feelings are mine, what feelings are the participants and the places where they intersect.

Lived experience research has been hugely empowering for me. My personal experience has been one of post-traumatic growth and there has been something very special about having the opportunity to use my knowledge and experiences to attempt to make a small difference to the way those like me are understood. The young people often reflected to me that they would not have felt comfortable sharing their experiences with a researcher who did not have lived experience, and they trusted me because they knew I understood what they have been through. This feedback was truly inspiring and motivating. Though it should also be noted how lived-experience research can be painful, challenging and difficult. I have held the grief of other people in my hands throughout this process and been entrusted to do something meaningful with it; that is a huge responsibility for any researcher but involves an additional

complication when you are holding (or juggling) it alongside your own grief. At times, lived-experience research is triggering and it is imperative that your support network is strong and understanding. I am very fortunate to have been well-supported and this has been a great learning experience for me which has challenged me and developed me as a researcher and practitioner.

## 5.7 Limitations

### 5.7.1 Sampling

One of the limitations of this study is the sample; this study included eight young people who are from one locality and have received bereavement support from the same institution. These young people are some of the most supported young people, particularly given that they have received long-term bereavement support which is uncommon in the UK. As such, their views and the findings of this study are representative of their experiences, but evidence suggests that bereaved children are often an under-identified group and receiving support is less common. As such, there are limitations to the generalisability of these results, and the experiences of bereaved young children who have not been supported formally; have received support in other forms (e.g. one-to-one counselling or therapy) are likely to be different to those of the participants in this study.

Moreover, the young people in this study were speaking about the short-term impacts of their bereavement retrospectively. Of course, there are ethical complications with involving recently bereaved young people in research that would render gaining experiences of their bereavement at the time difficult. However, it is important to consider this element when looking at results. These teenagers/young adults have grown in cognition and understanding since they were bereaved and some of their retrospective views may differ to how they reviewed their experiences at the

time. This does not undermine the young people's voices or experiences but adds an extra consideration to the ways in which developmental age and stage impact grief and young people's experiences of it and may be a limitation in terms of the generalisability of the findings. It is my view that as research into bereaved children's voice grows, the generalisability of the findings will be more testable through comparison of results from other researchers and studies.

### 5.7.2 Culture

One of the limitations of this study is that it does not consider a multi-cultural perspective or the ways in which culture can impact different experiences of bereavement and grief. For example, in some cultures, burial practices happen very quickly and specific rituals must be followed; this may have an impact if a young person has relatives in a different country and requires time off school (Abraham-Steele & Edmonds, 2021). Perhaps due to sampling, different cultural experiences were not explicitly explored in this study and the young people did not explicitly reflect on the ways that British culture, or their personal culture, impact the ways they grieve. That said, the young people did speak extensively about other people's difficulty speaking about death, which may be linked to the taboo nature of death in British culture. Thus, while the findings may reveal the ways we as a British society construct death and bereavement, this is limited and does not perhaps truly reflect all the experiences of all cultures within British society.

### 5.7.3 Group dynamics

One limitation of this study is that the group make up changed between each session. For group two, there was only one focus group where all four participants were present and a different combination of participants were present each time. For example, in the second session (peer relations) Gretchen was absent. At the time, I

noticed that the dynamics in this session were very different to the previous session, where Juan was absent. Without Gretchen, and with Juan, the group was much more jovial, made more jokes and agreed with each other more. This observation struck me further in the final session, when Gretchen returned and all four participants were present. Gretchen was able to challenge the boys and disagree with them, whereas they were more inclined to agree with one another. The reduction in use of humour when Gretchen was present made me wonder if Gretchen's presence and contributions may have made it easier for the boys to speak to their feelings; this reflection was partially influenced by Leo's view that it was easier for him as a teen to talk to girls about his feelings than boys. This made me reflect on gender, its impact on our socialisation, the valences of people within the group and how these factors were impacting their co-construction of ideas. This finding is potentially relevant for bereavement support providers and would suggest that boys benefit from mixed-gender groups in order to facilitate speaking about their emotions.

For group one, session three (friendship and relationships) only included Maddie and Leo. This may well have impacted the data on friendships and relationships, as both young people were bereaved of a father. And as such, their views may have aligned and challenge from those with different experiences (bereaved of grandparents/mothers) may have been missed. While it would have been preferable for all participants to attend all sessions, these young people have lives outside of the project and had to attend exams, sports matches and jobs which meant full-attendance was not possible. Therefore, it is important to acknowledge the impact that different group make-up may have had upon the findings and that not all voices were able to be present each time, which may have had an impact on how the data was constructed by the group.

## 5.8 Further research

This study has explored young people who were bereaved as children's voices, experiences of being bereaved and perspectives on bereavement support in the UK. This is just the beginning of pupil-centred research in this area and was a small-sample of adolescents and young adults in a localised study specific to one charity in the east of England. Future research is needed to explore the experiences of bereaved children across the country, from a range of age groups (0-25), from different cultural backgrounds and with different experiences of support. It is my hope that researchers will be inspired and find here a model to utilise to ask more bereaved children their stories, so we can interweave their experiences into our understanding of the topic of childhood bereavement. Furthermore, specifically, there is very limited research on sibling and peer bereavement in the UK, perhaps due to its lower prevalence, but further research should look specifically at these types of loss.

Currently, there are no studies that focus specifically on bereavement support in secondary schools. As such, future research on a secondary school teaching and student population would be advantageous. To my knowledge, Cristie Hone (Year Three Trainee EP, University of East Anglia) is currently writing her thesis on secondary school teachers' perspectives on supporting peer-bereaved children, which will be a valuable contribution to the research base. Moreover, one study in the literature review of this study focused upon special schools but was localised to the US; it would be beneficial for similar studies to be undertaken of bereavement support in specialist provisions in the UK, to better understand how support is specialised in specialised contexts and to better understand the needs of bereaved children with additional needs.

As acknowledged in section 2.3, the majority of the studies in the field are

small, qualitative studies which are localised and there is a need for larger scale, national studies to explore the national picture of bereavement support in schools; it would be beneficial to gain a deeper understanding of the national context, so that bereavement policy and training can be better informed and responsive to need. Furthermore, this study revealed a potential difference in the way emotions in grief are processed due to gender; it would be advantageous for this to be explored further in future research.

### 5.9 Concluding statement

This study aimed to explore young people's (13-21) experiences of being bereaved of a close relative and their perspectives on what is supportive in the aftermath of loss by death. The key findings of this study highlight that grief and bereavement feel like an internal battle to young people and that there are many contradictions, trials and realisations that come with grief and loss. The findings revealed that bereavement impacts young people in all aspects of their life, including: family/home life; socially and at school. Young people also acknowledged the longevity and complexity of their grief, which grows with them as their understanding and knowledge of life and death develop. Young people feel that this is not always understood by the adults who support them and that their experiences of bereavement support are mixed; they have a desire to be normal or to return to normality (prior to being bereaved) and face many social challenges due to being bereaved, including bullying and challenging social interactions. Findings revealed that young people desire: support which is responsive to their needs and considers their voice; and grief education and training for teachers, so that they are better equipped to support them.

Findings showed that bereaved young people are complex, resilient,

empathetic and inspiring. All of the young people in this study were ambitious and passionate about helping other young people like them and raising awareness for the support children who are bereaved may need. They shared that it is imperative you ask them what they want when trying to support them; it is felt this should be the biggest take away from this study: the importance of considering pupil voice. Many researchers agree that being bereaved [of a parent] is one of the most traumatic things that can happen to a child (Kaplow et al., 2010; Cerel et al., 2006; Melhem et al., 2007). As such, it is important that professionals remember to take a trauma-informed approach when working with bereaved young people, coming alongside them to ensure they have opportunities to process their grief and fulfil their potential alike.



## References

- Abdelnoor, A. & Hollins, S. (2004). The effect of childhood bereavement on secondary school performance. *Educational Psychology in Practice*, 20(1), 43–54. <https://doi.org/10.1080/0266736042000180401>
- Abraham-Steele, M., & Edmonds, C. (2021). A thematic analysis of teachers' perspectives on supporting victims of childhood bereavement in British primary schools. *Review of Education*, 9, e3297. <https://doi.org/10.1002/rev3.3297>
- Adams, K. Sibylle, E., Ungerer, S. & Sossi, M. (2024). Supporting primary school teachers to address loss and death in the classroom: a case of an interdisciplinary, creative, pedagogical intervention using education, children's literature, architecture/design and the arts. *Pastoral Care in Education*. <https://doi.org/10.1080/02643944.2024.2327447>
- Adler, K., Salanterä, S., & Zumstein-Shaha, M. (2019). Focus Group Interviews in Child, Youth and Parent Research: An Integrative Literature Review. *International Journal of Qualitative Methods*. <https://doi.org/10.1177/1609406919887274>
- Age UK. (2017). *5 million grandparents take on childcare responsibilities*. Retrieved from: <https://www.ageuk.org.uk/latest-news/articles/2017/september/five-million-grandparents-take-on-childcare-responsibilities/> in February 2024
- Anney, V.N. (2014). Ensuring the Quality of the Findings of Qualitative Research: Looking at Trustworthiness Criteria. *Journal of Emerging Trend in*

*Educational Research and the Policy Studies (JETERAPS).*

Argent, K. (2021). *Child Psychoanalytic Psychotherapy in Primary Schools.*

*Tavistock Approaches.* Routledge.

Ashurst, K., Hans, J., and Smith, D. (2009). The resilience factor: what extension can learn from adolescents coping with parental cancer. *Extension Journal*, 47 (2), 1–13. Aveyard, H. (2018). *Doing a literature review in health and social care.* Open University Press.

Balk, D. E. (2001). College student bereavement, scholarship, and the university: A call for university engagement. *Death Studies*, 25(1), 67–84.  
<https://doi.org/10.1080/07481180126146>

Balk., D.E., Zaengle, D., & Corr., C.A. (2011). Strengthening grief support for adolescents coping with a peer's death. *School Psychology International*, 32(2). <https://doi.org/10.1177/0143034311400826>

Berg, L., Rostila, M., Saarela, J. & Hjern, A. (2014). Parental death during childhood and subsequent school performance. *Pediatrics*, 133(4), 682–689.  
<https://doi.org/10.1542/peds.2013-2771>

Berndt , T. J. ( 2002 ). Friendship quality and social development . *Current Directions in Psychological Science* , 11 , 7 – 10 .

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77– 101.

<https://doi.org/10.1191/1478088706qp063oa>

Braun, V., & Clarke, V. (2013). *Successful Qualitative Research: A Practical Guide for Beginners*.

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, 4.

Braun V., & Clarke, V. (2021). *Thematic Analysis: A Practical Guide*. Sage.

Braun, V., & Clarke, V. (2022). Conceptual and design thinking for thematic analysis. *Qualitative Psychology*, 9(1), 3

26. <https://doi.org/10.1037/qup0000196>

British Psychological Society (BPS). (2018). *Power Threat Meaning Framework*.

Retrieved from: <https://www.bps.org.uk/guideline/power-threat-meaning-framework-full-version>

The British Psychological Society: Code of Ethics and Conduct. (2018). The

British Psychological Society: Code of Human Research Ethics. (2021).

Burr, V., (2015). *Social Constructionism*.

Cerel, J., Fristad, M. A., Verducci, J., Weller, R. A. & Weller, E. B. (2006).

Childhood bereavement: Psychopathology in the 2 years postparental death.

*Journal of the American Academy of Child & Adolescent Psychiatry*, 45(6),

681–690. <https://doi.org/10.1097/01.chi.0000215327.58799.05>

Chater, A.M., Howlett, N., Shorter, G.W., Zakrzewski-Fruer J.K., & Williams, J.

(2022). *Int. J. Environ. Res. Public Health* 2022, 19(4),

2083; <https://doi.org/10.3390/ijerph19042083>

Christ, G., 2000. Healing children's grief: surviving a parent's death from cancer.

New York: Oxford University Press.

- Childhood Bereavement Network. (2024). *Key Statistics*. Retrieved from: <https://childhoodbereavementnetwork.org.uk/about-1/what-we-do/research-evidence/key-statistics> in Feb 2024
- Clark, C.D. (2010). *In a younger voice: doing child-centred qualitative research*.
- Coleman, J. (2013). Agency in adolescence: young people constructing their own adolescence. Presentation at the University of Cambridge. University of Cambridge.
- Costelloe, A., Mintz, J., & Lee, F. (2020). Bereavement support provision in primary schools: an exploratory study. *Educational Psychology in Practice*. 36(3). <https://doi.org/10.1080/02667363.2020.1767040>
- Cramer, P. (2006). *Protecting the self: Defense mechanisms in action*. Guilford Press.
- Cramer, P. (2008). Seven pillars of defense mechanism theory. *Social and Personality Psychology Compass*, 2(5), 1963–1981. 10.1111/j.1751-9004.2008.00135.x
- Currier, J. M., Neimeyer, R. A., & Berman, J. S. (2008). The effectiveness of psychotherapeutic interventions for bereaved persons: A comprehensive quantitative review. *Psychological Bulletin*, 134(5), 648–661. <http://doi.org/10.1037/0033-2909.134.5.648>
- Daley A. M. (2013). Adolescent-friendly remedies for the challenges of focus group research. *Western Journal of Nursing Research*, 35, 1043–1059. doi:10.1177/0193945913483881
- Dawson, L.D., Hare, R.E. Selman, L.E. Boseley, T & Penny, A. (2023). ‘The one thing guaranteed in life and yet they won’t teach you about it’: The case for mandatory grief education in schools. *Bereavement Journal*.
- Davidson, J. (2008). Children and young people in mind: the final report of the

National CAMHS Review. *London: Department of Health*

Decety, J. (2010). The Neurodevelopment of Empathy in Humans. *Developmental Neuroscience*. 32(4). 257-267. doi: [10.1159/000317771](https://doi.org/10.1159/000317771)

Demuth, M., Taggi-Pinto, A., Miller, E.G. & Alderfer, M.A. (2020). Bereavement Accommodations in the Classroom: Experiences and Opinions of School Staff. *Journal of School Health*. 90(3). doi: 10.1111/josh.12870.

Denizin, N.K. & Lincoln, Y.S. (Eds). (2017). *The SAGE Handbook of Qualitative Research. Fifth Edition*.

Department for Education. (2015). *SEND code of practice: 0 to 25 years*.

Department for Education. (2023). *Keeping children safe in education: statutory guidance for schools and colleges. Part one: information for all school and college staff*.

Department for Education and Department for Health and Social Care.

(2017). *Transforming children and young people's mental health provision: a green paper*. London: the Crown.

Deshpande, O., Reid, M. C. & Rao, A. S. (2005). Attitudes of Asian-Indian Hindus toward end of life care. *Journal of the American Geriatrics Society*, 53(1), 131–135. <https://doi.org/10.1111/j.1532-5415.2005.53025.x>

Devlin-Friend, N. (2006). Bereavement in primary education: A study of a group of schools. *Bereavement Care*, 25(2), 31–32.

Dimery, E., & Templeton, S. (2021). Death, bereavement and grief: the role of the teacher in supporting a child experiencing the death of a parent. *Contemporary Issues in Practitioner Education*. 3(2).

<https://doi.org/10.1080/25783858.2021.1882263>

Dopp, A. R. & Cain, A. C. (2012). The role of peer relationships in parental bereavement during childhood and adolescence. *Death Studies*, 36, 41–60.

<https://doi.org/10.1080/07481187.2011.573175>

Douglas, R.D., Alvis, L.M., Rooney, E.E., Busby, D.R., & Kaplow, J.B. (2021).

Racial, ethnic and neighborhood income disparities in posttraumatic stress and grief: Exploring indirect effects through trauma exposure and bereavement. *J Trauma Stress*. 34(5). DOI: [10.1002/jts.22732](https://doi.org/10.1002/jts.22732)

Dowdney, L. (2000). Annotation: Childhood bereavement following parental death.

*The Journal of Child Psychology and Psychiatry and Allied Disciplines*, 41(07), 819–830. <https://doi.org/10.1111/1469-7610.00670>

Dowdney, L. (2005). Children bereaved by parent or sibling death. *Psychiatry*, 4, 118–122. <https://doi.org/10.1383/psyt.2005.4.9.118>

Dyregrov, A. (2008). *Grief in children: A handbook for adults* (2nd Rev ed.). Jessica Kingsley Publishers Ltd.

Dyregrov, A., Dyregrov, K., Endsjø, M., & Idsoe, T. (2015). Teachers' perception of bereaved children's academic performance. *Advances in School Mental Health Promotion*, 0(0), 1–12.

<http://doi.org/10.1080/1754730X.2015.1051888>

Dyregrov, A., Lytje, M., & Christensen, S.R. (2022). The price of loss: how childhood bereavement impacts education. *Bereavement: Journal of Grief and Responses to Death*. DOI: <https://doi.org/10.54210/bj.2022.14>

Elkind, D. (1967). Egocentrism in adolescence. *Child Development*, 38(4), 1025–1034. <https://doi.org/10.2307/1127100>

Esser, A., Hilborn, M., & Steemers, J. (2023). *Screen encounters with Britain – interim report Denmark: what do young Europeans make of Britain and its digital screen culture?* <https://doi.org/10.18742/pub01-118>

Fauth, B., Thompson, M. & Penny, A. (2009). *Associations between childhood*

*bereavement and children's back- ground, experiences and outcomes.*

London: National Children's Bureau.

Fielden A. L., Sillence E., Little L. (2011). Children's understandings' of obesity, a

thematic analysis. *International Journal of Qualitative Studies on Health and Well-Being*, 6. doi:10.3402/qhw.v6i3.7170

Flutter J. (2007) Teacher development and pupil voice. *Curriculum Journal* 18(3):

343–354.

Galbin, A. (2014). An introduction to social constructionism. *Social Research*

*Reports*. 26.

Glass, J.C. (1990). Changing death anxiety through death education in public schools.

*Death Studies*. 14(1). 31-52. <https://doi.org/10.1080/07481189008252344>

Granek, L. & Peleg-Sagy, T. (2017). The use of pathological grief outcomes in

bereavement studies on African Americans. *Transcultural Psychiatry*, 54(3), 384–399. <https://doi.org/10.1177/1363461517708121>

Greenhalgh, T., Thorne, S., & Malterud, K. (2018). Time to challenge the spurious

hierarchy of systemic over narrative reviews? *European Journal of Clinical Investigation*. 48(6). doi: 10.1111/eci.12931

Guba, E. G., & Lincoln, Y. S. (1981). Effective evaluation: Improving the usefulness of evaluation results through responsive and naturalistic approaches. Jossey-

Bass.

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research.

- In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105–117). Sage Publications, Inc.
- Heary C. M., & Hennessy E. (2002). The use of focus group interviews in pediatric health care research. *Journal of Pediatric Psychology, 27*, 47–57.
- Hillis, S.D., Unwin, H.J.T., Chen, Y., Cluver., L., Sherr, L., Goldman, P.S...  
 Flaxman, S. (2021). Global estimates of children affected by Covid-19-associated orphanhood and deaths of caregivers: a modelling study. *Lancet, 31*(398). Pp.391-402. doi: 10.1016/S0140-6736(21)01253-8.
- Holland, J. (1997). *Understanding Children's Experiences of Parental Bereavement*.
- Holland, J. (2001). *Understanding Children's Experiences of Parental Bereavement*.
- Holland, J. (2003). Supporting schools with loss: 'Lost for Words' in Hull. *British Journal of Special Education, 30*(2), 76–78. <https://doi.org/10.1111/1467-8527.00287>
- Holland, J. (2008). How schools can support children who experience loss and death. *British Journal of Guidance & Counselling, 36*(4), 411–424. <https://doi.org/10.1080/03069880802364569>
- Holland, J., & McLennan, D. (2015). North Yorkshire schools' responses to student bereavement. *Pastoral Care in Education, 33*(2), 116–128. <http://doi.org/10.1080/02643944.2015.1047400>
- Holland, J., & Wilkinson, S. (2015). A comparative study of the child bereavement response and needs of schools in North Suffolk and Hull, Yorkshire. *Bereavement Care, 34*(2), 52–58.
- Hoppe M. J., Wells E. A., Morrison D. M., Gillmore M. R., Wilsdon A. (1995). Using focus groups to discuss sensitive topics with children. *Evaluation Review, 19*, 102–114.
- Jahan, N., Naveed, S., Zeshan, M., & Tahir, M.A. (2016). How to conduct a systemic



- review: a narrative literature review. *Cureus* .8(11). doi: [10.7759/cureus.864](https://doi.org/10.7759/cureus.864)
- Joffe, H. (2011). Thematic Analysis. *Qualitative Research Methods in Health and Psychotherapy: A Guide for Students and Practitioners*. Pp.209-223.
- Kaplow, J. B., Saunders, J., Angold, A. & Costello, E. J. (2010). Psychiatric symptoms in bereaved versus non- bereaved youth and young adults: A longitudinal epidemiological study. *Journal of the American Academy of Child & Adolescent Psychiatry*, 49(11), 1145–1154.  
<https://doi.org/10.1097/00004583-201011000-00008>
- Kaplow, J.B., Wamser-Nanney, R., Layne, C.M., Burnside, A., King, C., Liang, L... Pynood, R. (2021). Identifying Bereavement-Related Markers of Mental and Behavioral Health Problems Among Clinic-Referred Adolescents. *Psychiatry Clin Pract*. 3(2). doi: [10.1176/appi.prcp.20190021](https://doi.org/10.1176/appi.prcp.20190021)
- Keaney. C. (2016). A psychosocial exploration of bereaved children’s experiences of exclusion from school: what understanding can be gained from a psychoanalytic perspective? [Doctoral thesis, Tavistock and Portman NHS Trust; University of Essex].  
<https://repository.tavistockandportman.ac.uk/1561/1/Keaney%20-%20Psychosocial.pdf>
- Kennedy C., Kools S., & Krueger R. (2001). Methodological considerations in children’s focus groups. *Nursing Research*, 50, 184–187.
- Lee, J.O., Lee, J. & Moon, S.S. (2009). Exploring children’s understanding of death concepts. *Asia Pacific Journal of Education*. 29(2). 251-264.  
<https://doi.org/10.1080/02188790902859020>

- Linder, L., Lunardini, M. & Zimmerman, H. Supporting childhood bereavement through school-based grief group. *Omega – journal of death and dying*.  
<https://doi.org/10.1177/00302228221082756>
- Lopez, S. A. (2011). Culture as an influencing factor in adolescent grief and bereavement. *Prevention Researcher*, 18(3), 10–13.
- Lowton, K., & Higginson, I. J. (2003). Managing bereavement in the classroom: A conspiracy of silence? *Death Studies*, 27(8), 717–741.
- Luecken, L. J. & Roubinov, D. S. (2012). Pathways to lifespan health following childhood parental death. *Social and Personality Psychology Compass*, 6(3), 243–257. <https://doi.org/10.1111/j.1751-9004.2011.00422.x>
- Lytje, M. (2016). Voices we forget—Danish students experience of returning to school following parental bereavement. *OMEGA—Journal of Death and Dying*, 78(1), 24–42. <https://doi.org/10.1177/0030222816679660>.
- Lytje, M. (2016b). Unheard Voices: parentally bereaved Danish students’ experiences and perceptions of the support received following the return to school. [Doctoral thesis, University of Cambridge].
- Lytje, M. (2017). The success of a planned bereavement response – A survey on teacher use of bereavement response plans when supporting grieving children in Danish schools. *Pastoral Care in Education*, 35(1), 28– 38.  
<https://doi.org/10.1080/02643944.2016.1256420>
- Lytje, M. (2018a). The Danish bereavement response in 2015 – Historic development and evaluation of success. *Scandinavian journal of educational research*. 62(1) <https://doi.org/10.1080/00313831.2016.1212258>
- Lytje, M. (2018b). Voices We Forget—Danish Students Experience of Returning to school Following Parental Bereavement. *Journal of death and dying*. 78(1).

<https://doi.org/10.1177/0030222816679660>

- Martinčeková, L., Jiang, M.J., Adams, J.D., Menedez, D., Hernandez, I.G., Barber, G... Rosengren, K.S. (2020). Do you remember being told what happened to grandma? The role of early socialisation on later coping with death. *Death Studies*. 44(2). 78-88. <https://doi.org/10.1080/07481187.2018.1522386>
- McAdams, D.E. & Stough, L. (2018). Teacher Perspectives on Grief Among Children with Intellectual Disabilities. *Journal of Loss and Trauma*. 23(2). <https://doi.org/10.1080/15325024.2018.1434859>
- McGarry O. (2015). Repositioning the research encounter: Exploring power dynamics and positionality in youth research. *International Journal of Social Research Methodology*, 19, 339–354.
- McLaughlin, C., Lytje, M. & Holliday, C. (2019). *Consequences of childhood bereavement in the context of the British school system*. The Faculty of Education, University of Cambridge for Winston's Wish.
- McManus, E., & Paul, S. (2019). Addressing the bereavement needs of children in school: an evaluation of bereavement training for school communities. *Improving Schools*. 22(1). <https://doi.org/10.1177/1365480219825540>
- Menedez, D., Henandez, I.G. & Rosengren, K.S. (2020). Children's emerging understanding of death. *Child development perspectives*. 14(1). 55-60. <https://doi.org/10.1111/cdep.12357>
- Melhem, N.M., Moritz, G., Walker, M., Shear, K.M., & Brent, D. (2007). Phenomenology and correlates of complicated grief in children and adolescents. *J Am Acad Child Adolesc Psychiatry*. 46(4). Pp. 493-499. doi: 10.1097/chi.0b013e31803062a9.

Mulrow, C. D., & Cook, D. (1998). *Systematic Reviews: Synthesis of Best Evidence for Health Care Decisions*. Philadelphia: American College of Physicians.

Muschetti, A. (Director). (2023). *The Flash* [Film]. Warner Bros. Pictures.

Nowell, L.S., Norris, J.M. & Moules, N.J. (2017). Thematic Analysis: Striving to Meet the Trustworthiness Criteria. *International Journal of Qualitative Methods*. <https://doi.org/10.1177/1609406917733847>

Nyumba, T.O., Wilson, K., Derrick, C., & Murkherjee, N. (2017). The use of focus group discussion methodology: Insights from two decades of application in conservation. *Qualitative methods for eliciting judgements for decision making*. DOI: 10.1111/2041-210X.12860

Office for National Statistics. (2021). Census.

Ofsted. (2013). *Not yet good enough: personal, social, health and economic education in schools*. Available at: [https://assets.publishing.service.gov.uk/media/5a7f1a5f40f0b6230268d749/Not\\_yet\\_good\\_enough\\_personal\\_social\\_health\\_and\\_economic\\_education\\_in\\_schools\\_-\\_report\\_summary.pdf](https://assets.publishing.service.gov.uk/media/5a7f1a5f40f0b6230268d749/Not_yet_good_enough_personal_social_health_and_economic_education_in_schools_-_report_summary.pdf) (accessed April 2024).

Oyebode, J. R. & Owens, R. G. (2013). Bereavement and the role of religious and cultural factors. *Bereavement Care*, 32(2), 60–64. <https://doi.org/10.1080/02682621.2013.812828>

Parsons, S. (2011). *Long-term impact of childhood bereavement: Preliminary analysis of the 1970 British Cohort Study (BCS70)*. Childhood Wellbeing Research Centre. CWRC Working Paper.

- Pascale, C.M. (2011). Epistemology and the Politics of Knowledge. *Sociological Review*. 58(2). DOI:[10.1111/j.1467-954X.2011.01967.x](https://doi.org/10.1111/j.1467-954X.2011.01967.x)
- Paul, S. (2019). Is death a taboo subject for children? Developing death ambivalence as a theoretical framework to understand children's relationship with death, dying and bereavement. *Children and society*. 33(6). 556-571.  
<https://doi.org/10.1111/chso.12352>
- Paul, S. & Vaswani, N. (2020). The prevalence of childhood bereavement in Scotland and its relationship with disadvantage: the significance of a public health approach to death, dying and bereavement. *Palliative Care and Social Practice*. <https://doi.org/10.1177/2632352420975043>
- Prince-Embury, S., & Saklofske, D. H. (Eds.). (2013). Resilience in children, adolescents, and adults: Translating research into practice. Springer Science + Business Media. <https://doi.org/10.1007/978-1-4614-4939-3>
- Prix, I. & Erola, J. (2017). Does death really make us equal? Educational attainment and resource compensation after paternal death in Finland. *Social Science Research*, 64, 171–183. <https://doi.org/10.1016/j.ssresearch.2016.10.012>
- Punch, S. (2002). Research with children: The same or different from research with adults? *Childhood*, 9(3), 321–341.  
<http://doi.org/10.1177/0907568202009003005>
- Ribbens McCarthy, J. (2007). 'They all look as if they're coping, but I'm not': The Relational Power/lessness of 'Youth' in Responding to Experiences of Bereavement. *Journal of Youth Studies*. 10(3).  
<https://doi.org/10.1080/13676260701262574>

- Robson, C., & McCartan, K. (2016). *Real World Research* (4th ed.). Wiley.
- Rolls, L. (2009). The ritual work of UK childhood bereavement services. In: *S. Earle, C. Komaromy, and C. Bartholomew, eds. Death and dying: a reader*. California: Sage Publications, 175–183.
- Rosenblatt, P. C. (2013). Family grief in cross-cultural perspective. *Family Science*, 4(1), 12–19. <https://doi.org/10.1080/19424620.2013.819226>
- Rowling, L. & Holland, J. (2000). Grief and school communities: the impact of social context, a comparison between Australia and England. *Death studies*. 24(1). doi: 10.1080/074811800200685.
- Saldana, J. (2012). *The Coding Manual for Qualitative Researchers*.
- Scott, D., & Usher, R. (2011). *Researching education: data, methods and theory in educational enquiry*. (2nd ed.). London: Continuum International Publishing Group.
- Servarty Seib, H.L., & Hamilton, L.A. (2006). Educational performance and persistence of bereaved college students. *Journal of college student development*.
- Shenton, A. K. (2004). Strategies for Ensuring Trustworthiness in Qualitative Research Projects. *Education for Information*, 22, 63-75. <https://doi.org/10.3233/EFI-2004-22201>
- Siddaway, A., Wood, A.M., Schulz, J., & Trickey, D. (2014). Evaluation of the CHUMS Child Bereavement Group: A Pilot Study Examining Statistical and Clinical Change. *Death Studies*. 39(1-5). DOI: [10.1080/07481187.2014.913085](https://doi.org/10.1080/07481187.2014.913085)
- Siddaway, A.P., Wood, A.M., & Hedges, L.V. (2019). *How to Do a Systematic*

Review: A Best Practice Guide for Conducting and Reporting Narrative Reviews, Meta-Analyses, and Meta-Syntheses. *Annual Review of Psychology*. DOI: [10.1146/annurev-psych-010418-102803](https://doi.org/10.1146/annurev-psych-010418-102803)

Silverman, P. R., & Worden, J. W. (1993). Children's reactions to the death of a parent. In M. Stroebe, W. Stroebe, & R. O. Hanson (Eds.), *Handbook of bereavement theory, research, and interventions* (pp. 300–316). Cambridge University Press.

Slaughter, V. (2005). Young children's understanding of death. *Australian psychologist*, 40 (3), 179–186. doi:10.1080/00050060500243426

Solomon, S., Greenberg, J & Pyszczynski, T (2015). *The Worm at the Core: On the Role of Death in Life*.

Spall, B., & Jordan, G. (1999). Teachers' perspectives on working with children experiencing loss. *Pastoral Care in Education*, 17(3), 3–7.

Spratt, J. (2016). Childhood wellbeing: what role for education? *British Educational Research Journal*, 42(2), 223–239.

Spratt, J., Shucksmith, J., Philip, K., & Watson, K. (2006). 'Part of who we are as a school should include responsibility for well-being': Links between the school Environment, mental health and behaviour. *Pastoral Care in Education*, 24(3), 14–21.

Statham, J., (2011). *Grandparents providing childcare: briefing paper*. Childhood wellbeing research centre. Retrieved from: <https://assets.publishing.service.gov.uk/media/5a7adb7a40f0b66a2fc0348a/CWRC-00083-2011.pdf>

- Stikkelbroek, Y., Bodden, D. H. M., Reitz, E., Vollebergh, W. A. M. & van Baar, A. L. (2016). Mental health of adolescents before and after the death of a parent or sibling. *European Journal of Child Adolescent Psychiatry*, 25, 49–59. <https://doi.org/10.1007/s00787-015-0695-3>
- Stikkelbroek, Y., Prinzie, P., De Graaf, R., Ten Have, M. & Cuijpers, P. (2012). Parental death during childhood and psychopathology in adulthood. *Psychiatry Research*, 198(3), 516–520. <https://doi.org/10.1016/j.psychres.2011.10.024>
- Stroebe, M. S., Schut, H. & Stroebe, W. (2008). *Handbook of bereavement research and practice: Advances in theory and intervention*.
- Stuber, M. (2001). What do we tell Children? *Western journal of medicine*. 174(3).
- Stylianou, P. & Zembylas, M. (2018). Dealing with the concepts of ‘grief’ and ‘grieving’ in the classroom: Children’s perceptions, emotions and behavior. *OMEGA – journal of death and dying*. 77(3). 240-266.
- The Lancet. (2013). How and when to help children cope with trauma? *The Lancet* 381(9867): 600.
- The UK Commission on Bereavement. (2022). *2022 Summary Report: Bereavement is everyone’s business*.
- Tobin, G.A. and Begley, C.M. (2004) Methodological Rigour within a Qualitative Framework. *Journal of Advanced Nursing*, 48, 388-396. <http://dx.doi.org/10.1111/j.1365-2648.2004.03207.x>



VotesforSchools. (2022). Should learning about coping with loss & bereavement be included on the curriculum? (KS1: 'Is loss too hard to talk about?') 14-21 January 2022.

Walsh, I., Holton, J., Bailyn, L., & Fernandez, W. (2015). What grounded theory is... a critically reflective conversation among scholars. *Organizational Research Methods*. 18(4). DOI:[10.1177/1094428114565028](https://doi.org/10.1177/1094428114565028)

Walter, T. (1991). Modern death: Taboo or not taboo?, *Sociology*, 25(2), 293–310

Wertz, M.S., Nosek, M., McNiesh, S., & Marlow, E. (2011). The composite first person narrative: texture, structure and meaning in writing phenomenological descriptions. *International journal of qualitative studies health and wellbeing*. 12(6). DOI: [10.3402/qhw.v6i2.5882](https://doi.org/10.3402/qhw.v6i2.5882)

Willig, C. (2013). *Introducing Qualitative Research in Psychology*. McGraw-Hill Education.

Winnicott, D.W. (1935). *The Manic Defence. Through Paediatrics to Psychoanalysis*. Routledge.

Winston's Wish. (2023). *Q. How many bereaved young people are there in the UK right now? A. Nobody knows!* Retrieved from: <https://www.winstonswish.org/nobody-knows-how-many-bereaved-young-people-uk/> in April 2024

Winston's Wish. (2024). *Deferred grieving. How the Covid-19 pandemic has*

*impacted grieving children*. Retrieved from:

<https://www.winstonswish.org/pandemic-grief/> in Feb 2024

Woodward, K.P., Yu, Z., Chen, W., Chen, T., Jackson, D.B., Powell, T.W., & Wang,

L. (2023). Childhood Bereavement, Adverse and Positive Childhood

Experiences, and Flourishing among Chinese Young Adults. *Int J Environ*

*Res Public Health*. 20(5). doi: [10.3390/ijerph20054631](https://doi.org/10.3390/ijerph20054631)

Worden, J. W. (1996). *Children and grief: When a parent dies*. Guildford Pres.

Worden, J. W., Davies, B. & McCown, D. (1999). Comparing parent loss with sibling

loss. *Death Studies*, 23(1), 1–15. <https://doi.org/10.1080/074811899201163>

Worden, J. W. (2009). *Grief counseling and grief therapy: A handbook for the mental*

*health practitioner*. Springer Pub Co.

Yardley, L. (2007) Demonstrating validity in qualitative psychology. In, Smith,

Jonathan A. (ed.) *Qualitative Psychology: A Practical Guide to Research*

*Methods*. SAGE Publications, pp. 235-251.

## Appendices

### Appendix 2A: Papers found and marked against inclusion/exclusion criteria for literature review

Table 2A.1: Primary Search Results

NB: Yellow denotes included in final review

Article title	Journal title	Date	Geog	Age	Death	Sch	RQ	Inclusion
A Thematic Analysis of Teacher's Perspectives on Supporting Victims of Childhood Bereavement in British Primary Schools	Review of Education	2021	Y	Y	Y	Y	Y	Y
Supporting Childhood Bereavement Through School-Based Grief Group	Omega	2022	Y	Y	Y	Y	N	N
The Danish bereavement response in 2015 – Historic development and evaluation of success	Scandinavian Journal of Educational Research	2018	Y	Y	Y	Y	Y	Y
Ambiguous Loss in Schools: Guidelines for Practitioners	School Social Work Journal	2018	Y	Y	N	Y	N	N
Addressing the bereavement needs of children in school: an evaluation of bereavement training for school communities	Improving Schools	2019	Y	Y	Y	Y	Y	Y
Supporting the bereaved in the COVID-19 Era: A scoping review of interventions	Omega	2023	Y	N	N	N	N	N

Support needs and barriers to accessing support: baseline results of a mixed-methods national	Palliative medicine	2021	Y	N	N	N	Y	N
survey of people bereaved during the COVID-19 pandemic								
Covid-19 pandemic's disproportionate impact on childhood bereavement for youth of color: reflections and recommendations	Frontiers in paediatrics	2023	Y	Y	Y	N	N	N
The impact of Covid-19 on bereavement care in Ireland: a national survey of bereavement care providers	Journal of grief and responses to death	2023	Y	N	Y	N	N	N
'The one thing guaranteed in life and yet they won't teach you about it': The case for mandatory grief education in UK schools.	Bereavement: Journal of Grief & Responses to Death	2023	Y	Y	Y	N	N	N
Parental perspectives on the grief and support needs of children and young people bereaved during the COVID-19 pandemic: qualitative findings from a national survey.	BMC Palliative Care	2022	Y	Y	Y	N	N	N

What bereaved children want to know about death and grief	Journal of child and family studies	2024	Y	Y	Y	N	N	N
Childhood Bereavement: An Introduction to the Section	The Psychoanalytic Study of the Child	2023	Y	Y	Y	N	N	N
Parental death: a systematic review of support experiences and needs of children and parent survivors.	BMJ supportive & palliative care	2022	Y	Y	Y	N	N	N
Prolonged grief during and beyond the pandemic: factors associated with levels of grief in a four time-point longitudinal survey of people bereaved in the first year of the COVID-19 pandemic.	Frontiers in public health	2023	Y	N	N	N	N	N

Table 2A.2: Secondary Search

Article title	Journal title	Date	Geo g	Ag e	Deat h	Sc h	R Q	In c
When young children grieve: supporting bereaved children from the perspective of daycare staff.	Scandinavian journal of educational research	2022	Y	N	Y	N	N	N
Parental death during adolescence: a review of the literature	Omega	2023	Y	Y	Y	N	N	N
Parental engagement in Grief Programming is Related to Children's Outcomes	OMEGA – Journal of Death and Dying	2023	Y	Y	Y	N	N	N

“I don’t know what to say’: Teachers’ perspectives on supporting bereaved students after the death of a parent	Omega	2023	N	Y	Y	Y	N	N
The impact of parental bereavement on young people: a thematic analysis of using online web forums as a method of coping	Omega	2023	Y	Y	Y	N	N	N
Bereavement support provision in primary schools: an exploratory study	Educational Psychology in Practice	2020	Y	Y	Y	Y	Y	Y
Three Sibling Survivors' Perspectives of their Father's Suicide: Implications for Postvention Support.	Journal of child and family studies	2022	Y	N	Y	N	N	N
When young children grieve: Supporting daycare children following bereavement —A parent's perspective.	Omega	2023	Y	N	Y	N	N	N
Inventory of Youth Adaptation to Loss (IYAL): Psychometric Testing of a New Instrument for Bereaved Youth to Assess Social Support and Coping.	Omega	2022	Y	Y	Y	N	N	N
What to Say to Young Children Experiencing Loss: A Framework for Helping Children Move Through the Process of Grief.	Dimensions of early childhood	2023	Y	N	Y	N	N	N

Something Lost, Something Gained: Experiences of Psychological Therapists Bereaved of a Parent in Childhood.	Omega	2024	Y	N	N	N	N	N
What bereaved children want to know about death and grief	Journal of death and family studies	2023	Y	Y	Y	N	N	N
BeSAD . . . “it was truly an awful experience”: an exploration of pre-	Pastoral care in education	2020	Y	Y	N	Y	Y	N
service teachers’ experiences and training needs to support pupils experiencing issues of bereavement, separation and divorce								
Family Communication and Psychological Health in Children and Adolescents Following a Parent's Death From Cancer.	Omega	2021	Y	Y	Y	N	N	N
Voices We Forget— Danish Students Experience of Returning to School Following Parental Bereavement.	Omega	2018	Y	Y	Y	Y	Y	Y
Healing after traumatic events: Aligning interventions with cultural background and religious and spiritual beliefs.	Psychology in schools	2020	Y	N	N	N	N	N

The Meaning of Bonds: The Relationships Among Grief Rituals, Support From Relatives and Friends, and the Mental Health of Shiduers.	Omega	2022	Y	N	N	N	N	N
Understanding grief reactions, thwarted belongingness, and suicide ideation in bereaved adolescents: Toward a unifying theory.	Journal of clinical psychology	2019	Y	Y	Y	N	N	N
Teacher Perspectives on Grief Among Children with Intellectual Disabilities.	Journal of loss and trauma	2018	Y	Y	Y	Y		Y
Finding hope at camp: an investigation of the influence of grief camp on youth depression, anxiety and self-concept indicators	Journal of loss and trauma	2022	Y	Y	Y	N	N	N
Life came to a full stop: the experiences of widowed fathers	Omega	2021	Y	N	N	N	N	N
A research literature review to determine how bereavement programmes are evaluated	Journal of death and dying	2021	Y	N	N	N	N	N
Trauma-Informed Care and Posttraumatic Growth Among Bereaved Youth: A Pilot Study.	Omega	2020	Y	Y	Y	N	N	N
Interventions for Young Bereaved Children: A Systematic Review and Implications for School Mental Health Providers	Child Youth Care Forum	2018	Y	N	Y	N	N	N



Factors Underlying the Relationship Between Parent and Child Grief	Omega	2019	Y	N	Y	N	N	N
Grief, Tragic Death, and Multiple Loss in the Lives of Irish Traveller Community Health Workers	Omega	2020	Y	N	N	N	N	N
Exploring Characteristics of Children Presenting to Counseling for Grief and Loss	Journal of child and family studies	2018	Y	Y	Y	N	N	N
Children and Young People Living Through a Serious Family Illness: Structural, Interpersonal and Personal Perspectives	Children and society	2020	Y	N	N	N	N	N
Parental relationships following the loss of a child	Journal of loss and trauma	2020	Y	N	N	N	N	N
The resilience song writing programme for adolescent bereavement: a mixed method exploratory study	Journal of music therapy	2019	Y	Y	Y	N	N	N
The associations of complicated grief, depression, posttraumatic growth and hope among bereaved youth	Journal of death and dying	2019	Y	Y	Y	N	N	N
Multidimensional Grief Therapy: Pilot Open Trial of a Novel Intervention for Bereaved Children and Adolescents.	Journal of child and family studies	2019	Y	Y	Y	N	N	N
Dealing With the Concepts of "Grief" and "Grieving" in the Classroom: Children's Perceptions, Emotions, and Behavior.	Omega	2018	N	Y	Y	Y	N	N

Surviving Siblings' Illnesses, Treatments/Health Services over 13 Months after a Sibling's Death.	Journal of child and family studies	2018	N	Y	Y	N	N	N
Death is not the end: a register-based study of the effect of parental death on adult children's childbearing behavior in Sweden	Journal of death and dying	2020	Y	N	N	N	N	N
Embracing Death: Mexican parent and child perspectives on death	Child development	2020	N	Y	Y	N	N	N
Predictors of continuing bonds among bereaved adolescents	Omega	2018	Y	Y	Y	N	N	N
Prevalence of parental bereavement among female sex workers (FSW) in Kibra, Kenya	Journal of loss and trauma	2019	N	Y	Y	N	N	N
College granddaughters' memories and emotions related to their relationships with their deceased grandfathers	Omega	2018	Y	N	N	N	N	N
Spirituality for wellbeing of bereaved children in residential care: insights for spiritually sensitive child-centres social work across country contexts.	Child and adolescent social work journal	2018	Y	Y	Y	N	N	N

Table 2A.3: Snowballing

NB: Yellow denotes included in final review

Article title	Journal title	Date	Geo	Age	Death	Sch	RQ	Inc
Death, bereavement and grief: the role of the teacher in supporting a child experiencing the death of a parent	Contemporary issues in practitioner education	2021	Y	Y	Y	Y	Y	Y

Figure 2A.1: Screenshot of expanded search results on 10.04.2024

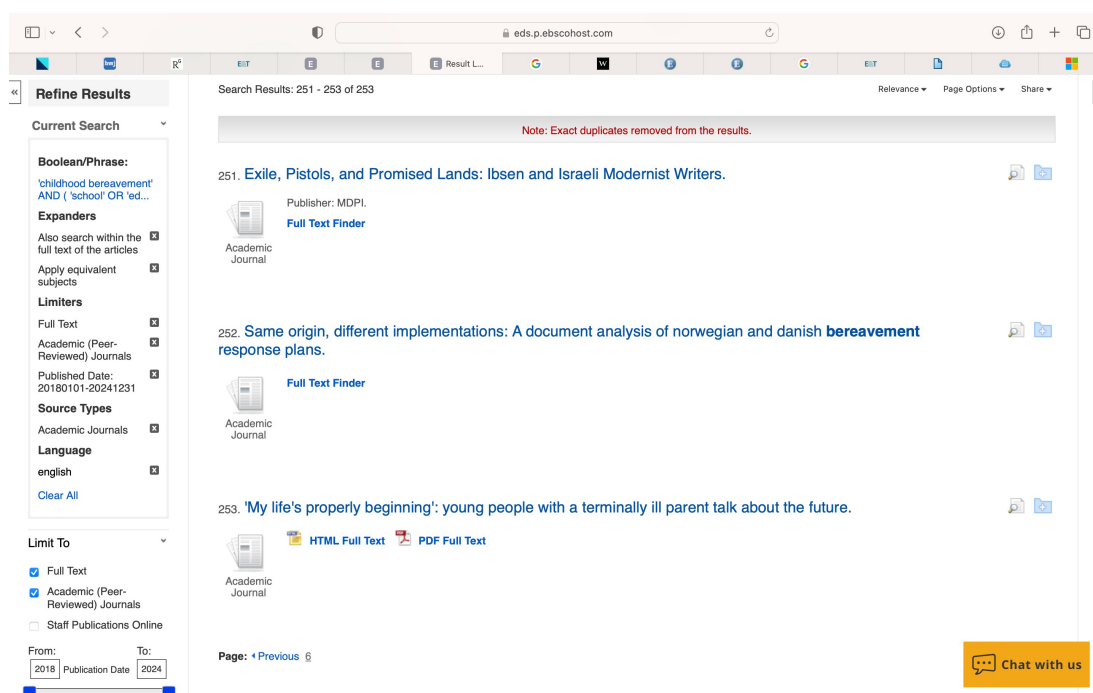


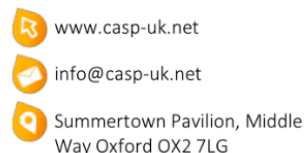
Table 2A.4: Expanded search results selected for abstract/full text review

NB: Yellow denotes included in final review

Article title	Journal title	Date	Geo	Age	Death	Sch	RQ	Incl.
---------------	---------------	------	-----	-----	-------	-----	----	-------

Who should support grieving children in school? Applying Winnicott's viewpoint to conceptualize the dyadic roles of teachers and school mental health professionals in the context of pediatric grief	Frontiers in psychiatry	2023	Y	Y	Y	Y	N	N
Kids are all in the same storm but not in the same boat	American journal of orthopsychiatry	2024	Y	Y	N	N	N	N
'Finding a safe space': a qualitative study of what makes help helpful for adolescents bereaved by suicide	Death studies	2022	Y	Y	Y	N	N	N
Survivors' perception of support following a parent's suicide	Death studies	2022	Y	Y	Y	Y	N	N
Bereavement accommodations in the classroom: experience and opinions of school staff	Journal of school health	2020	Y	Y	Y	Y	N	N

## Appendix 2B: CASP checklist, qualitative (2018)



**CASP Checklist:** 10 questions to help you make sense of a **Qualitative** research

**How to use this appraisal tool:** Three broad issues need to be considered when appraising a qualitative study:

- ▶ Are the results of the study valid? (Section A)
- ▶ What are the results? (Section B)
- ▶ Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

**About:** These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA ‘Users’ guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing:** we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

©CASP this work is licensed under the Creative Commons Attribution – Non-Commercial-Share A like. To view a copy of this license, visit <http://creativecommons.org/licenses/by-nc-sa/3.0/> [www.casp-uk.net](http://www.casp-uk.net)

Paper for appraisal and reference: .....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- what was the goal of the research
  - why it was thought important
  - its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
  - Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the researcher has explained how the participants were selected
  - If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
    - If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the setting for the data collection was justified
  - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
  - If the researcher has justified the methods chosen
    - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
      - If methods were modified during the study. If so, has the researcher explained how and why
    - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
      - If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
  - How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
  - If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
  - If approval has been sought from the ethics committee

Comments:



8. Was the data analysis sufficiently rigorous?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider
- If there is an in-depth description of the analysis process
  - If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
  - Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
  - If sufficient data are presented to support the findings
    - To what extent contradictory data are taken into account
  - Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes	<input type="checkbox"/>
Can't Tell	<input type="checkbox"/>
No	<input type="checkbox"/>

- HINT: Consider whether
- If the findings are explicit
  - If there is adequate discussion of the evidence both for and against the researcher's arguments
  - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
  - If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

## Appendix 2C: Summary of papers and

**CASP Table 2C.1:** Summary of paper one

Title: Abraham, Steele, M. & Edmonds, C. (2021). A Thematic Analysis of Teacher's Perspectives on Supporting Victims of Childhood Bereavement in British Primary Schools.		
Aim/purpose	Methodology	Key findings
<p>Aims to explore childhood bereavement and the support offered within primary schools in the UK. Specifically, the perspectives of teaching staff, including teaching assistants (TAs), teachers and senior leadership teams (SLTs), on supporting victims of childhood bereavement.</p>	<p>Individual interviews with school staff; thematic analysis.</p>	<p>Analysis revealed four major themes relating to bereavement support: 'support available is inconsistent', 'systemic limitations', 'lack of policy and guidance' and 'speaking to children about death'.</p> <p>Support inconsistent: Examples of good practice areas for improvement; a socioeconomic issue</p> <p>Systemic limitations: funding; time; teacher-child relationships (power dynamics) as barrier to sharing.</p> <p>Lack of training and guidance: Importance of experience for confidence in supporting bereaved children; desire for more government guidance; desire for further training</p> <p>Speaking to children about death: Bereaved children are individuals and are impacted differently/have different needs for support; some adults feel uncomfortable talking about death; policing the way children speak about death with each other.</p> <p>This study indicates that government policy or</p>

guidance with regards to childhood bereavement would be advantageous, for staff and children alike.

Table 2C.2: CASP for paper one

Title: Abraham, Steele, M. & Edmonds, C. (2021). A Thematic Analysis of Teacher's Perspectives on Supporting Victims of Childhood Bereavement in British Primary Schools.		
Qualitative CASP criteria	Examples within the data	Yes; can't tell; no
<p>Aims</p> <p>Was there a clear statement of the aims of the research?</p> <p>What was the goal of the research?</p> <p>Why was it thought important?</p> <p>Its relevance</p>	<p>Clear statement of aims; contextualised within British context; clear rationale of importance</p>	<p>Yes</p>
<p>Methodology and design</p> <p>Is the methodology appropriate?</p> <p>If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</p> <p>Is qualitative methodology the right methodology for addressing the research goal?</p>	<p>Appropriate design for qualitative study</p>	<p>Yes</p>
<p>Design match aims</p> <p>Was the research design appropriate to address the aims of the research?</p> <p>If the researcher has justified the research designs (e.g. have they discussed how they decided which method to use)</p> <p>Was the sampling procedure made explicit and was it appropriate?</p> <p>Has the researcher explained the recruitment strategy?</p>	<p>Yes design matches aims</p> <p>Research designs not explicitly justified throughout; some examples e.g. interview method justified (online due to Covid-19).</p> <p>Sampling method explicit and appropriate: examined (convenience sample; acknowledges not to generalise findings beyond sample and the limitations of the sample: likely to be people with specific interest.</p>	<p>Yes/can't tell</p>

<p>Was the recruitment strategy appropriate to the aims of the research?</p> <p>If the researcher has explained how the participants were selected</p> <p>If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</p> <p>If there are any discussions around recruitment (e.g. why some people chose not to take part)</p>	<p>See above – no there were not discussions about why some people chose not to take part; although limitations of sample and recruitment technique acknowledged</p> <p>Explained over-representation of white females appropriate relative to teaching population/UK demographics.</p> <p>Participants: school staff - teaching assistants (2), trainee teachers (2), class teachers (1) Special Educational Needs Co-ordinators (SENDCos) (3) and assistant head teachers (1) and head teachers (2) with a range of experience from 1 year to 37 years. Who the children they work with had been bereaved of not reported.</p>	<p>Yes</p>
--	--	------------

<p>Appropriate methods to collect data</p> <p>Was the data collected in a way that addressed the research issue?</p> <p>If the setting for the data collection was justified</p> <p>If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)</p> <p>If the researcher has justified the methods chosen</p> <p>If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) If methods were modified during the study. If so, has the researcher explained how and why</p> <p>If the form of data is clear (e.g. tape recordings, video material, notes etc.)</p> <p>If the researcher has discussed saturation of data</p>	<p>Clear how data collected and justified</p> <p>Methods not fully justified</p> <p>Way data collected addresses research issue</p>	<p>Yes</p>
<p>Role of the researcher/ interviewer</p> <p>Has the relationship between researcher and participants been adequately considered?</p>	<p>Not discussed</p>	<p>Can't tell</p>
<p>If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location</p> <p>How the researcher responded to events during the study and whether they considered the implications of any changes in the research design</p>		

<p>Ethics</p> <p>Have ethical issues been taken into consideration?</p> <p>If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</p> <p>If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</p> <p>If approval has been sought from the ethics committee</p>	<p>Yes</p> <p>Consent forms and participant info sheets discussed; death as a sensitive topic acknowledged</p> <p>Approval from ethics committee discussed</p>	<p>Yes</p>
<p>Analysis</p> <p>Was the data analysis sufficiently rigorous?</p> <p>If there is an in-depth description of the analysis process</p> <p>If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data</p> <p>Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</p> <p>If sufficient data are</p>	<p>Yes</p> <p>Clear quotes to illustrate themes</p> <p>Potential bias and influence not acknowledged</p>	<p>Yes/can't tell</p>
<p>presented to support the findings</p> <p>To what extent contradictory data are taken into account</p> <p>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?</p>		

<p>Discussion</p> <p>Is there a clear statement of findings?</p> <p>If the findings are explicit</p> <p>If there is adequate discussion of the evidence both for and against the researcher's arguments</p> <p>If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</p> <p>If the findings are discussed in relation to the original research question</p>	<p>Yes</p> <p>Findings explicit</p> <p>Adequate discussion for and some against researcher's arguments</p> <p>Credibility not discussed</p> <p>Findings discussed in relation to original research question</p>	<p>Yes/can't tell</p>
<p>Conclusion: Contribution to the field</p> <p>How valuable is the research?</p> <p>If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature</p> <p>If they identify new areas where research is necessary</p> <p>If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used</p>	<p>Valuable contribution to field</p> <p>Discussed by researcher</p> <p>Identifies new areas where research necessary</p> <p>Suggested not to transfer to other populations</p>	<p>Yes</p>

Table 2C.3: Summary of paper two

Title: Lytje, M. (2018). The Danish bereavement response in 2015 – Historic development and evaluation of success.		
Aim/purpose	Methodology	Key findings
<p>The purpose of this article is, based on current evidence, to evaluate the state of the Danish school</p>	<p>For this purpose, a literature review related to school support following parental bereavement has been</p>	<p>This article concludes that b-plans have succeeded in becoming the primary tool used by teachers, a feat that systems in other countries</p>



<p>bereavement response and to highlight its strengths and weaknesses.</p>	<p>conducted. Of the studies available, this article relies significantly on research conducted by Lytje (2014) who surveyed 967 Danish teachers about their feelings towards the current bereavement response structures. The review also utilises data from the focus group study by Lytje (2016), who interviewed 39 children that had experienced parental bereavement and conducted a document analysis of 60 b-plans with the aim of exploring their nature.</p>	<p>often fail to achieve. However, the system seldom includes the perspectives of the students it was designed to help. This is the challenge that the next generation of b-plans must remedy. Inconsistency in plans – varying lengths; don't address long term support/teachers less confident in long term support the multitude of tasks that teachers are asked to perform during school hours, as well as a strong focus on academic achievement, can make it difficult for teachers to find the necessary time to provide proper care for bereaved students. B plans lose sight of loss being individual; ambiguity around this B plans support teacher confidence in supporting bereavement Emotional impact of bereavement support: added strain on teachers</p>
--	--	---

Table 2C.4: Casp for paper two

Title: Lytje, M. (2018). The Danish bereavement response in 2015 – Historic development and evaluation of success.		
Qualitative CASP criteria	Examples within the data	Yes; can't tell; no
<p>Aims Was there a clear statement of the aims of the research? What was the goal of the research? Why was it thought important? Its relevance</p>	<p>Yes – clear aim</p>	<p>Yes</p>

<p>Methodology and design Is the methodology appropriate? If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants Is qualitative methodology the right methodology for addressing the research goal?</p>	<p>Yes appropriate method of review Thorough; clear</p>	<p>Yes</p>
<p>Design match aims Was the research design appropriate to address the aims of the research? If the researcher has justified the research designs (e.g. have they discussed how they decided which method to use) Was the sampling procedure made explicit and was it appropriate? Has the researcher explained the recruitment strategy?</p>	<p>Yes – not primary data so limited on some of these q</p>	<p>Yes/no</p>
<p>Was the recruitment strategy appropriate to the aims of the research? If the researcher has explained how the participants were selected If they explained why the participants they selected were the most appropriate to provide access to the type of</p>	<p>Not primary data but relies heavily on: Lytje (2014) and Lytje (2016): survey of Danish teachers (967) and interview with 39 children that had experienced a parental bereavement. Who the children that the teachers supported had been bereaved of is unknown.</p>	
<p>knowledge sought by the study If there are any discussions around recruitment (e.g. why some people chose not to take part)</p>		

<p>Appropriate methods to collect data</p> <p>Was the data collected in a way that addressed the research issue?</p> <p>If the setting for the data collection was justified</p> <p>If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)</p> <p>If the researcher has justified the methods chosen</p> <p>If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) If methods were modified during the study. If so, has the researcher explained how and why</p> <p>If the form of data is clear (e.g. tape recordings, video material, notes etc.)</p> <p>If the researcher has discussed saturation of data</p>	Not primary data	N/A
<p>Role of the researcher/ interviewer</p> <p>Has the relationship between researcher and participants been adequately considered?</p> <p>If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location</p> <p>How the researcher responded to events during the study and whether they considered the implications of any changes in the research design</p>	No	No

<p>Ethics</p> <p>Have ethical issues been taken into consideration?</p> <p>If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</p> <p>If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</p> <p>If approval has been sought from the ethics committee</p>	N/a	N/a
<p>Analysis</p> <p>Was the data analysis sufficiently rigorous?</p> <p>If there is an in-depth description of the analysis process</p> <p>If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data</p> <p>Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</p> <p>If sufficient data are presented to support the findings</p> <p>To what extent contradictory data are taken into account</p> <p>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?</p>	Yes appropriate	Yes

<p>Discussion</p> <p>Is there a clear statement of findings?</p> <p>If the findings are explicit</p> <p>If there is adequate discussion of the evidence both for and against the researcher's arguments</p> <p>If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</p> <p>If the findings are discussed in relation to the original research question</p>	<p>Yes; future research identified</p>	<p>Yes</p>
<p>Conclusion: Contribution to the field</p> <p>How valuable is the research?</p> <p>If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature)</p> <p>If they identify new areas where research is necessary</p> <p>If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used</p>	<p>Yes</p>	<p>Yes</p>

Table 2C5: Summary of paper three

Title: McManus, E., Paul, S. (2019). Addressing the bereavement needs of children in school: an evaluation of bereavement training for school communities.

Aim/purpose	Methodology	Key findings
<p>Evaluation of bereavement training that was offered to eight schools in Scotland and aimed to assist school communities to develop knowledge and</p>	<p>Pre and post questionnaires were used to measure the confidence, beliefs and values of 282 school staff that attended the training. Two focus groups were held for 6–18</p>	<p>Findings suggest that participants viewed bereavement support as part of their role and that a short and targeted bereavement-training programme can contribute</p>

confidence in engaging and supporting bereaved children.	months following the training to gain an understanding of the longer-term impact.	to raising the awareness and confidence of school staff to respond to the needs of bereaved children.  Barriers pre-training: not having the words to talk about it Barriers in training: taboo subject, its going to be doom and gloom Promimity to personal experience  Training = confidence building
--	---	---

Table 2C.6: Casp for paper three

Title: McManus, E., Paul, S. (2019). Addressing the bereavement needs of children in school: an evaluation of bereavement training for school communities.		
Qualitative CASP criteria	Examples within the data	Yes; can't tell; no
Aims Was there a clear statement of the aims of the research? What was the goal of the research? Why was it thought important? Its relevance	Yes clear – evaluate training	Yes
Methodology and design Is the methodology appropriate? If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants Is qualitative methodology the right methodology for addressing the research goal?	Methodology appropriate Yes qual – mixed methods study actually and appropriate	Yes
Design match aims Was the research design appropriate to address the aims of the research? If the researcher has justified	Yes addresses aims.	Yes

<p>the research designs (e.g. have they discussed how they decided which method to use)          Was the sampling procedure made explicit and was it appropriate?          Has the researcher explained the recruitment strategy?</p>		
<p>Was the recruitment strategy appropriate to the aims of the research?          If the researcher has explained how the participants were selected          If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study          If there are any discussions around recruitment (e.g. why some people chose not to take part)</p>	<p>Limitations to recruitment study but acknowledged by authors – e.g. recruiting for focus groups limited due to demands of school life</p> <p>Participants were:- 282 school staff that attended the training (questionnaires) and 6 staff in 2x focus groups. Who the children they work with had been bereaved of was not recorded.</p>	Yes
<p>Appropriate methods to collect data          Was the data collected in a way that addressed the research issue?          If the setting for the data collection was justified          If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)          If the researcher has justified the methods chosen          If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) If methods were modified during the study. If so, has the researcher explained how and why          If the form of data is clear (e.g. tape recordings, video</p>	Not fully justified in method	Can't tell

material, notes etc.) If the researcher has discussed saturation of data		
Role of the researcher/ interviewer Has the relationship between researcher and participants been adequately considered? If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes in the research design	No	Can't tell
Ethics Have ethical issues been taken into consideration? If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) If approval has been sought from the ethics committee	Not reported	Can't tell



<p>Analysis</p> <p>Was the data analysis sufficiently rigorous?</p> <p>If there is an in-depth description of the analysis process</p> <p>If thematic analysis is used.</p> <p>If so, is it clear how the categories/themes were</p>	<p>Own role not critically evaluated</p>	<p>Yes</p>
<p>derived from the data</p> <p>Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</p> <p>If sufficient data are presented to support the findings</p> <p>To what extent contradictory data are taken into account</p> <p>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?</p>		
<p>Discussion</p> <p>Is there a clear statement of findings?</p> <p>If the findings are explicit</p> <p>If there is adequate discussion of the evidence both for and against the researcher's arguments</p> <p>If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</p> <p>If the findings are discussed in relation to the original research question</p>	<p>Yes – limitations</p>	<p>Yes</p>

<p>Conclusion: Contribution to the field</p> <p>How valuable is the research?</p> <p>If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature</p> <p>If they identify new areas where research is necessary</p> <p>If the researchers have</p>	<p>Yes – areas for development</p>	<p>Yes</p>
<p>discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used</p>		

Table 2C.7: Summary of paper four

Title: Dimery, E. & Templeton, S. (2021). Death, bereavement and grief: the role of the parent in supporting a child experiencing the death of a parent		
Aim/purpose	Methodology	Key findings
<p>This research explores the nature of the teacher's role in supporting a child bereaved of a parent, investigates the views of teachers who have supported a bereaved child and individuals that have experienced the bereavement of a parent whilst they were of statutory school age.</p>	<p>Interviews with three teachers</p> <p>Questionnaire based on themes of interviews to 16 adults bereaved as children</p> <p>Thematic analysis</p>	<p>Overall, the study suggests that teachers have a significant role in the child's management of their grief. Despite a lack of initial teacher training in the area of loss, often their small, dynamic forms of support, such as listening and taking a genuine interest in the child, along with supportive proactive school approaches, are what makes a difference to the child effectively managing their grief.</p>

Child's context: adults bereaved as CYP felt robbed of childhood/took on caring responsibilities. Some additional stressors e.g. blended families; risk of bullying.

Role of teacher: Lack of training; teacher's knowledge comes from own experience. Teachers felt discomfort in supporting bereaved children due to taboo nature of topic; impact of grief on teachers with personal experience of grief. Potential protective

factor of close teacher-child relationship.

Role of school: teacher interview data identified proactive approaches from the school such as training, external support, weekly meetings and pastoral support as being key for their efficacy in offering support in turn

Table 2C.8: Casp for paper four

Title: Dimery, E. & Templeton, S. (2021). Death, bereavement and grief: the role of the parent in supporting a child experiencing the death of a parent		
Qualitative CASP criteria	Examples within the data	Yes; can't tell; no
<p>Aims</p> <p>Was there a clear statement of the aims of the research?</p> <p>What was the goal of the research?</p> <p>Why was it thought important?</p> <p>Its relevance</p>	Yes – clear aims	Yes
<p>Methodology and design</p> <p>Is the methodology appropriate?</p> <p>If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</p> <p>Is qualitative methodology the right methodology for addressing the research goal?</p>	Yes appropriate	Yes
<p>Design match aims</p> <p>Was the research design appropriate to address the aims of the research?</p> <p>If the researcher has justified the research designs (e.g. have they discussed how they decided</p>	<p>Some attempts to justify</p> <p>Issues relating to adult reconstruction of adult events</p>	Yes/can't tell
<p>which method to use)</p> <p>Was the sampling procedure made explicit and was it appropriate?</p> <p>Has the researcher explained the recruitment strategy?</p>		

<p>Was the recruitment strategy appropriate to the aims of the research? If the researcher has explained how the participants were selected If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study If there are any discussions around recruitment (e.g. why some people chose not to take part)</p>	<p>Recruitment strategy unclear Some justifications present e.g. adults bereaved as children for ethical reasons</p> <p>Participants were:- 16 parentally bereaved adults bereaved as children. 3 teachers who have supported bereaved children; who the children they were supported were bereaved of unknown.</p>	<p>Can't tell</p>
<p>Appropriate methods to collect data Was the data collected in a way that addressed the research issue? If the setting for the data collection was justified If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) If the researcher has justified the methods chosen If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) If methods were modified during the study. If so, has the researcher explained how and why If the form of data is clear (e.g. tape recordings, video material, notes etc.)</p>	<p>Some evidence of justifying methods e.g. face to face interviews</p>	<p>Yes/can't tell</p>
<p>If the researcher has discussed saturation of data</p>		

<p>Role of the researcher/ interviewer Has the relationship between researcher and participants been adequately considered? If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location How the researcher responded to events during the study and whether they considered the implications of any changes in the research design</p>	<p>Yes – bracketing interviews</p>	<p>Yes</p>
<p>Ethics Have ethical issues been taken into consideration? If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) If approval has been sought from the ethics committee</p>	<p>Yes Some ethical issues – intrusiveness - mitigated</p>	<p>Yes/no</p>
<p>Analysis Was the data analysis sufficiently rigorous? If there is an in-depth description of the analysis process If thematic analysis is used. If so, is it clear how the categories/themes were</p>	<p>Yes to triangulation Some issues with TA highlighted</p>	<p>Yes</p>

<p>derived from the data Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process If sufficient data are presented to support the findings To what extent contradictory data are taken into account Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?</p>		
<p>Discussion Is there a clear statement of findings? If the findings are explicit If there is adequate discussion of the evidence both for and against the researcher's arguments If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) If the findings are discussed in relation to the original research question</p>	<p>Ish – findings presented a bit woolly with the quotes Limitations of presenting both sets of data together – confusing Discussion good – e.g. contextualises within wider research base</p>	<p>Yes/no</p>
<p>Conclusion: Contribution to the field How valuable is the research? If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature If they identify new areas</p>	<p>Valuable in illuminating voices of adults bereaved as CYP Not generalisable No recommendations for further research</p>	<p>Yes</p>

where research is necessary If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used		
--	--	--

Table 2C.9: Summary of paper five

Title: Costelloe, A., Mintz, J., & Lee, F. (2020). Bereavement support provision in primary schools: an exploratory study		
Aim/purpose	Methodology	Key findings
The current paper reports on the qualitative phase of a mixed-methods study aimed to gain insight into bereavement support provision (BSP) in primary schools across one English Local Authority (LA) from the perspective of primary school staff who have been involved with supporting bereaved children. This exploration will provide insight into how EPs may be able to aid and empower schools to support bereaved children in their care.	Brofenbrenner as theoretical framework. This paper presents the qualitative phase of a mixed-methods study which aimed to gain insight into BSP in primary schools in one UK Local Authority. After completing an online questionnaire, 16 school staff took part in semi-structured interviews.	The findings of this study highlighted that BSP is characterised by emotional support and other indirect responses. A key finding is that providing emotional support to a bereaved child has a negative impact on the emotional well-being of staff.  Understanding Children's Grief; Bereavement Support Provision; Factors Influencing Proximal Processes in BSP; and Emotional Impact of BSP on School Staff.

Table 2C.10: Casp for paper five

Title: Costelloe, A., Mintz, J., & Lee, F. (2020). Bereavement support provision in primary schools: an exploratory study		
Qualitative CASP criteria	Examples within the data	Yes; can't tell; no



<p>Aims Was there a clear statement of the aims of the research? What was the goal of the research? Why was it thought important? Its relevance</p>	<p>Yes clear aims – including EP specific</p>	<p>Yes</p>
<p>Methodology and design Is the methodology appropriate? If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants Is qualitative methodology the right methodology for addressing the research goal?</p>	<p>Yes appropriate but only one phase of a mixed methods study</p>	<p>Yes</p>
<p>Design match aims Was the research design appropriate to address the aims of the research? If the researcher has justified the research designs (e.g. have they discussed how they decided which method to use) Was the sampling procedure made explicit and was it appropriate? Has the researcher explained the recruitment strategy?</p>	<p>No Sampling explicit yes – not clear why the 16 were purposefully chosen</p>	<p>Can't tell</p>

<p>School and Participant section</p> <p>Was the recruitment strategy appropriate to the aims of the research?</p> <p>If the researcher has explained how the participants were selected</p> <p>If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</p> <p>If there are any discussions around recruitment (e.g. why some people chose not to take part)</p>	<p>Can't tell – 16 purposefully selected but not explained why</p> <p>Participants were:- eight teachers, three ELSAs, two special educational needs co-ordinators (SENCOs), two assistant headteachers, and a pastoral lead, across 10 different primary schools within one LA. All participants had experience of supporting a child bereaved of a parent, sibling or peer in the past five years.</p>	<p>Can't tell</p>
<p>Appropriate methods to collect data</p> <p>Was the data collected in a way that addressed the</p>	<p>Yes clear – semistructured interviews; no not justified</p>	<p>Yes</p>
<p>research issue?</p> <p>If the setting for the data collection was justified</p> <p>If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)</p> <p>If the researcher has justified the methods chosen</p> <p>If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) If methods were modified during the study. If so, has the researcher explained how and why</p> <p>If the form of data is clear (e.g. tape recordings, video material, notes etc.)</p> <p>If the researcher has discussed saturation of data</p>		

<p>Role of the researcher/ interviewer</p> <p>Has the relationship between researcher and participants been adequately considered? If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location</p> <p>How the researcher responded to events during the study and whether they considered the implications of any changes in the research design</p>	No	Can't tell
<p>Ethics</p> <p>Have ethical issues been taken into consideration? If there are sufficient details of how the research was explained to participants for the reader to assess whether</p>	<p>Yes ref to debriefs, participant info sheet, consent form</p> <p>No ref to ethics boards</p>	Yes
<p>ethical standards were maintained</p> <p>If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</p> <p>If approval has been sought from the ethics committee</p>		

<p>Analysis</p> <p>Was the data analysis sufficiently rigorous?</p> <p>If there is an in-depth description of the analysis process</p> <p>If thematic analysis is used.</p> <p>If so, is it clear how the categories/themes were derived from the data</p> <p>Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</p> <p>If sufficient data are presented to support the findings</p> <p>To what extent contradictory data are taken into account</p> <p>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?</p>	<p>Some description of thematic analysis</p>	<p>Yes</p>
<p>Discussion</p> <p>Is there a clear statement of findings?</p> <p>If the findings are explicit</p> <p>If there is adequate discussion of the evidence both for and against the researcher's arguments</p> <p>If the researcher has discussed the credibility of their findings (e.g.</p> <p>triangulation, respondent validation, more than one analyst)</p> <p>If the findings are discussed in relation to the original research question</p>	<p>Yes clear findings</p>	<p>Yes</p>

<p>Conclusion: Contribution to the field</p> <p>How valuable is the research?</p> <p>If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature</p> <p>If they identify new areas where research is necessary</p> <p>If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used</p>	<p>Clear contribution</p> <p>Limitations and implications for EP practice</p>	<p>Yes</p>
--	---	------------

Table 2C.11: Summary of paper six

Title: Lytje, M. (2018b). Voices We Forget—Danish Students Experience of Returning to school Following Parental Bereavement.		
Aim/purpose	Methodology	Key findings
<p>This study explores how Danish students experience returning to school following parental bereavement.</p>	<p>Eighteen focus group interviews with 39 participants aged 9 to 17 years were conducted. All participants had experienced the loss of a primary caregiver. Data collection was divided into two phases. In Phase I, 22 participants from four grief groups were interviewed 4 times over the course of a year. During Phase II, confirmatory focus</p>	<p>This article explores findings related to the four themes of initial school response, long-term support, challenges within the class, and academic challenges. The study found that (a) students struggle to reconnect with classmates following the return to school and often feel alone, (b) schools fail to have guidelines in place for what they are allowed to do if becoming sad the class, and</p>
	<p>groups were undertaken with the 17 participants.</p>	<p>(c) schools seem to forget their loss as time passes. The issues of teachers doing too much or making the children uncomfortable seem to be linked to a lack of training</p>

and understanding regarding the needs of a bereaved child. The issue of long-term grief being forgotten by teachers

has been confirmed in this study.

Table 2C.12: Casp for paper six

Title: Lytje, M. (2018b). Voices We Forget—Danish Students Experience of Returning to school Following Parental Bereavement.		
Qualitative CASP criteria	Examples within the data	Yes; can't tell; no
<p>Aims</p> <p>Was there a clear statement of the aims of the research?</p> <p>What was the goal of the research?</p> <p>Why was it thought important?</p> <p>Its relevance</p>	<p>Yes clear – illuminate children's voices</p>	<p>Yes</p>
<p>Methodology and design</p> <p>Is the methodology appropriate?</p> <p>If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</p> <p>Is qualitative methodology the right methodology for addressing the research goal?</p>	<p>Yes - a pragmatic, multimethod design framework.</p> <p>TA/ focus group interviews: appropriate</p>	<p>Yes</p>
<p>Design match aims</p> <p>Was the research design appropriate to address the aims of the research?</p> <p>If the researcher has justified the research designs (e.g. have they discussed how they decided which method to</p>	<p>Yes -</p>	<p>Yes</p>
<p>use)</p> <p>Was the sampling procedure made explicit and was it appropriate?</p> <p>Has the researcher explained the recruitment strategy?</p>		

<p>School and Participant section</p> <p>Was the recruitment strategy appropriate to the aims of the research?</p> <p>If the researcher has explained how the participants were selected</p> <p>If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</p> <p>If there are any discussions around recruitment (e.g. why some people chose not to take part)</p>	<p>Yes – existing grief groups to reduce vulnerability</p> <p>Participants were:- 39 bereaved children aged 9 to 17 years. All participants had experienced the loss of a primary caregiver. Unclear if children who had a different relative as primary caregiver included (e.g. living with aunt/grandparent).</p>	<p>Yes</p>
<p>Appropriate methods to collect data</p> <p>Was the data collected in a way that addressed the research issue?</p> <p>If the setting for the data collection was justified</p> <p>If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)</p> <p>If the researcher has justified the methods chosen</p> <p>If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) If methods were modified during the study. If so, has the researcher explained how and why</p> <p>If the form of data is clear (e.g. tape recordings, video material, notes etc.)</p>		
<p>If the researcher has discussed saturation of data</p>		

<p>Role of the researcher/ interviewer</p> <p>Has the relationship between researcher and participants been adequately considered?</p> <p>If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location</p> <p>How the researcher responded to events during the study and whether they considered the implications of any changes in the research design</p>	No	Can't tell
<p>Ethics</p> <p>Have ethical issues been taken into consideration?</p> <p>If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</p> <p>If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</p> <p>If approval has been sought from the ethics committee</p>	Yes – adequate description	Yes
<p>Analysis</p> <p>Was the data analysis sufficiently rigorous?</p> <p>If there is an in-depth description of the analysis process</p> <p>If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data</p>	Yes – TA (2006) described	Yes



<p>Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</p> <p>If sufficient data are presented to support the findings</p> <p>To what extent contradictory data are taken into account</p> <p>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?</p>		
<p>Discussion</p> <p>Is there a clear statement of findings?</p> <p>If the findings are explicit</p> <p>If there is adequate discussion of the evidence both for and against the researcher's arguments</p> <p>If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</p> <p>If the findings are discussed in relation to the original research question</p>	Yes very clear	Yes
<p>Conclusion: Contribution to the field</p> <p>How valuable is the research?</p> <p>If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature)</p> <p>If they identify new areas where research is necessary</p> <p>If the researchers have discussed whether or how the</p>	Yes – within Danish context	Yes

findings can be transferred to other populations or considered other ways the research may be used

Table 2C.13: Summary of paper seven

Title: McAdams Ducey, E., & Stough, L. (2018). Teacher Perspectives on Grief Among Children with Intellectual Disabilities.		
Aim/purpose	Methodology	Key findings
Unclear. From abstract: little is known about how children with intellectual disabilities demonstrate grief or how teachers respond to student grief.	Constructivist grounded theory methods were used to analyse data collected from five special education teachers of elementary students with intellectual disabilities.	Teachers reported a range of grieving behaviors displayed by children with intellectual disabilities in the classroom and used various strategies to provide support. Grief in surviving caregivers and assistance from other school personnel were also described. The need for additional training of teachers and counselors about grief in children with intellectual disabilities is highlighted. (a) children with intellectual disability experiencing loss, (b) special education teachers assisting grieving students, (c) others within the school providing supports, (d) surviving caregivers coping after death, and (e) teachers experiencing emotion.

Table 2D.14: CASP for paper seven

Title: McAdams Ducey, E., & Stough, L. (2018). Teacher Perspectives on Grief Among Children with Intellectual Disabilities.		
Qualitative CASP criteria	Examples within the data	Yes; can't tell; no
<p>Aims</p> <p>Was there a clear statement of the aims of the research?</p> <p>What was the goal of the research?</p> <p>Why was it thought important?</p> <p>Its relevance</p>	<p>No statement of aims</p> <p>From abstract: little is known about how children with intellectual disabilities demonstrate grief or how teachers respond to student grief.</p>	No
<p>Methodology and design</p> <p>Is the methodology appropriate?</p> <p>If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</p> <p>Is qualitative methodology the right methodology for addressing the research goal?</p>	Yes fine	Yes
<p>Design match aims</p> <p>Was the research design appropriate to address the aims of the research?</p> <p>If the researcher has justified the research designs (e.g. have they discussed how they decided which method to use)</p> <p>Was the sampling procedure made explicit and was it appropriate?</p> <p>Has the researcher explained the recruitment strategy?</p>	Aims unclear	Can't tell
<p>Was the recruitment strategy appropriate to the aims of the research?</p> <p>If the researcher has explained how the participants were selected</p> <p>If they explained why the participants they selected were the most appropriate to</p>	<p>Purposive sampling was employed to ensure that participants had experienced the same phenomena of interest and met the same criteria (Creswell, 2007) – well justified e.g. elementary age due to close relationship to one teacher</p> <p>Participants were:- five special</p>	

	<p>education teachers of elementary students with intellectual disabilities. Had all taught had taught an elementary-aged student with intellectual disability who had a parent or caregiver die, and each teacher held special education certification</p>	
<p>provide access to the type of knowledge sought by the study If there are any discussions around recruitment (e.g. why some people chose not to take part)</p>		
<p>Appropriate methods to collect data Was the data collected in a way that addressed the research issue? If the setting for the data collection was justified If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) If the researcher has justified the methods chosen If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) If methods were modified during the study. If so, has the researcher explained how and why If the form of data is clear (e.g. tape recordings, video material, notes etc.) If the researcher has discussed saturation of data</p>	<p>Yes teacher interviews Yes saturation</p>	<p>Yes</p>

<p>Role of the researcher/ interviewer</p> <p>Has the relationship between researcher and participants been adequately considered? If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location</p> <p>How the researcher responded to events during</p>	<p>Our research positionality includes our own experiences as former teachers of students with intellectual disability, some of whom had lost parents to death.</p> <p>Research diary; reflexivity good</p>	<p>Yes</p>
<p>the study and whether they considered the implications of any changes in the research design</p>		
<p>Ethics</p> <p>Have ethical issues been taken into consideration? If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained</p> <p>If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)</p> <p>If approval has been sought from the ethics committee</p>	<p>Approved by ethics board</p>	<p>Yes</p>

<p>Analysis</p> <p>Was the data analysis sufficiently rigorous?</p> <p>If there is an in-depth description of the analysis process</p> <p>If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data</p> <p>Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</p> <p>If sufficient data are presented to support the findings</p> <p>To what extent contradictory data are taken into account</p> <p>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation?</p>	<p>Clearly described constructivist grounded theory</p>	<p>Yes</p>
<p>Discussion</p> <p>Is there a clear statement of findings?</p> <p>If the findings are explicit</p> <p>If there is adequate discussion of the evidence both for and against the researcher's arguments</p> <p>If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</p> <p>If the findings are discussed in relation to the original research question</p>	<p>Yes – findings explicit</p> <p>No research Q</p>	<p>Yes</p>

<p>Conclusion: Contribution to the field</p> <p>How valuable is the research?</p> <p>If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research based literature</p> <p>If they identify new areas where research is necessary</p> <p>If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used</p>	<p>Yes implications for practice; limitations</p>	<p>Yes</p>
--	---	------------

## Appendix 3A: Consent/Assent Forms

## Information Sheet

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:

Paru Jeram, Trust Quality Assurance Officer [pjeram@tavi-port.nhs.uk](mailto:pjeram@tavi-port.nhs.uk)  
Tavistock and Portman Trust Research Ethics Committee

## The Researchers

Maya Abraham-Steele, Primary  
Researcher Dr Richard Lewis,  
Research Supervisor [mabraham-steele@tavi-port.nhs.uk](mailto:mabraham-steele@tavi-port.nhs.uk) [rlewis@tavi-port.nhs.uk](mailto:rlewis@tavi-port.nhs.uk)

Telephone - 0300 300 5023

## Consent to Participate in a Research Study

This information sheet is intended to give additional detail so decisions can be made as to whether to give consent for either yourself or your young person to take part in the study

## Project Title

Exploring bereaved children's experiences of loss and the ways they wish to be supported: an emancipatory study

## Project Description

This research project hopes to explore 11-21 year-old bereaved children's experiences of loss and grief and the factors they found supportive in the aftermath of their bereavement.

The project aims to give voice to bereaved children, so we can gain a better understanding of what it is like to be bereaved as a child from a first-hand perspective. We will then hopefully be able to use the findings to inform how we help other young people who have experienced a bereavement.

The research is being conducted as part of the lead researcher's degree: professional doctorate in child, community and educational psychology.

## Participant Contribution

The study will consist of being part of a focus group and taking part in focus group interviews. The focus group is a group of people who come together to talk about a theme and this focus group will be made up of members of the Young Ambassadors



programme. The group will meet five times in total with Maya, the lead researcher, and a member of staff from Forget-me-nots.

The first meeting will be primarily for planning rather than talking about the young people's personal experiences. As a group we will think about what themes and topics would be helpful to explore. Maya will then plan each subsequent session around one of these themes.

There will be three focus group interviews – this is where Maya will interview the group. Each interview will be focused around a theme or topic linked to your experiences of bereavement and the support received, that we have agreed in our first session, so the young people will have an idea of what to expect to come up before coming to the session. The questions will be around their experiences of being bereaved of a loved one and what they found supportive. Each session will be audio recorded, so Maya can analyse the data at a later date.

There will be a final meeting in the autumn, where Maya will present her findings from the focus group interviews. The young people will have the opportunity to sense check the data and say whether it represents their experience. We will also reflect together on our experiences of being part of the research project.

#### Risks

We are going to be talking and thinking together about what it was like to experience the death of a close relative. We know Young Ambassadors have lots of experience talking about this area, but we also know that speaking about loss can be upsetting.

We hope that we can make things as comfortable as possible during the focus groups and hope it will be a positive experience, where we will connect with each other and the young people will have the opportunity to have their voices heard and potentially learn some new skills. They will never be expected to share anything they don't want to. The staff at Forget-me-nots know them well and will be there throughout the project. Forget-me-nots will be able to provide support for everyone during and after the study if they need it.

The young people will be invited to Young Ambassadors meetings in between the focus groups to make sure they have spaces where they can reflect on their experiences.

If the project is bringing up any difficult emotions, they can talk to the adults and we will be able to help you.

#### Benefits

Taking part in the project will allow the young people to learn a bit about how a research project works and they will gain some new skills: including sense-checking the results and helping to design the structure of the focus groups.

We hope the project will help us to better understand what it is like to be a

bereaved child and what support is helpful for children who have lost a close relative by death. The young people's experiences could help us to better support other children who experience the same thing in the future.

### Confidentiality of the Data

The focus group interviews will be auto recorded and later transcribed. The audio recordings and transcripts will be stored securely on a password protected laptop and only Maya and the research team will have access to the raw data. During transcription, a pseudonym (pretend name) will be allocated to each participant, so their data will be anonymised and not directly linked to them.

The data will only be kept for as long as is necessary for the completion of the project. All data will be deleted once the project is finalised.

Maya will write a paper based on the research, but will only use the pseudonyms, so any quotes will not be directly linked to individuals. However, the young ambassadors will be able to identify the things themselves and those in your focus group.

What is said within the focus group is confidential, unless we think there is a risk of harm to the person or others and we will follow the safeguarding policies at Forget-me-nots.

### Location

The project will take place at Forget-me-nots charity base.

### Disclaimer

The young people are not obliged to take part in this study, and are free to withdraw at any time during the data collection. Should they choose to withdraw from the programme they may do so without disadvantage to themselves and without any obligation to give a reason. Withdrawing or declining the invitation to participate will not impact their position in the Young Ambassadors programme.

A young person's information cannot be taken out of the focus group sessions once the session has ended, as the data will be anonymised. However, it is not compulsorily to attend all focus group sessions and a young person can withdraw from future focus group sessions.

### Consent to Participate in a Research Study Involving the Use of Human Participants (Young person - 16 years and over)

Exploring bereaved children's experiences of loss and the ways they wish to be supported: an emancipatory study

I have read the information sheets regarding this research in which I have been asked to participate and have been given a copy to keep. The nature and purposes

of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to the data. It has been explained to me what will happen once the research programme has been completed.

I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without being obliged to give any reason.

Participant's Name (BLOCK CAPITALS):

Participant's Signature:

Date:

Consent to share: demographic information

It would be helpful if you are happy to share the following information, but it is okay if you would prefer not to say!

Current age...../ Prefer not to say

Gender identity:...../ Prefer not to say

Age when bereaved:...../ Prefer not to say

Relationship to relative who died:...../ Prefer not to say

How long have you been a young ambassador? ...../ Prefer not to say

The Tavistock and Portman   
NHS Foundation Trust

Young Person Information Sheet

Exploring bereaved children's experiences of loss and the ways they wish to be supported: an emancipatory study

What is a research study?

A research study is what you do when you want to learn about something or find out something new.

Why is the study being done?

We are doing this study because we want to learn more about what it is like for young people who have experienced the death of a close relative. We want to make sure your voices are heard and learn about what you found helpful after the death – so that we can think about how to help other young people who might have similar experiences in the future.

### Who is doing the study?

My name is Maya and I am interested in researching this area, as I want to think more about how to help young people who have experienced death of a close relative. I experienced the death of a parent when I was a child. I want to come to one of your Young Ambassadors meetings, where I can explain a little more about the project so you can decide if you want to be a part of it.

### What will happen to me if I take part?

1. You will be asked to sign a consent form to say you understand the study and want to take part. Your parents will be asked to sign the form too.
2. If you agree to take part, you will meet Maya again with some of your friends from the young ambassadors programme; as well as with a familiar adult from Forget-me-nots . Together, we will come up with a list of topics and themes that as a group are thought to be important about childhood bereavement that can be talked about at a later meeting
3. We then meet again as a small group of those who are Young Ambassadors to share your thoughts about the topic/theme areas. This is called a focus group. Maya will pose questions and prompts while an adult from Forget-me-nots will be in attendance as an observer. This time, it will be audio-recorded, so Maya can remember what was said and think about it later. Each meeting will be about a topic we have agreed together, so you will know the type of things to expect before we meet.
4. Maya will look at what you have shared and analyse for themes.
5. You will meet with Maya, an adult from Forget-me-nots and your group a final time in the autumn. Maya will share the findings with you and ask you  
  
what you think. We will also use this as an opportunity to reflect together about what it was like to be a part of the study.

### Can I stop doing the study once I've started?

Yes – you can stop doing the study at any point during the focus groups. However, anything you have already said in a previous focus group cannot be taken away from the study because we will make the data anonymous – meaning we can't tell who said what. However, you do not have to attend all focus groups and if you want to stop coming, that's ok.

### Do I have to say yes?

No – not at all. It's up to you! Just say if you don't want to join in. Nobody will mind. If you change your mind, that's ok as well. It will not change anything for you as a Young Ambassador if you do not wish to take part.

### Who can I ask about this?

Your mum or dad or carer have been given lots of information, and so have the adults at Forget-me-nots. If you have any questions or would like to speak to Maya about this study then please email [mabraham-steele@tavi-port.nhs.uk](mailto:mabraham-steele@tavi-port.nhs.uk).

### Will the study upset me?

We are going to be talking and thinking together about what it was like to experience the death of your close relative. We know you have lots of experience talking about this as a Young Ambassador, but we also know that speaking about your loss can be upsetting.

We hope that we can make things as comfortable as possible during the focus group and hope it will be a positive experience. You will never have to talk about anything you don't want to. The adults at Forget-me-nots know you very well and will be there to keep an eye out for any signs that you might be upset. They will be able to provide support for everyone during and after the study if you need it. You will be invited to Young Ambassadors meetings in between the focus groups.

If the project is making you feel upset you can talk to the adults and we will be able to help you.

Will the study help me and others?

Taking part in the project will allow you to learn a bit about how a research project works and you will gain some new skills: including helping to design the structure of the focus groups and sense-checking the results.

We hope the project will help us to better understand what it is like to be a bereaved child and what support is helpful for children who have lost a close relative by death. Your experiences could help us to better support other children who experience the same thing in the future.

Who will be able to find out what I said in the focus groups?

The focus groups will be audio recorded. These audio files will be kept securely and only Maya and her research team will have access to them. When the recordings are looked at by Maya, she will type up what was said (transcribe) and make them into 'transcripts.' Everybody in the study will be given a pretend name (pseudonym) so that nobody will be able to figure out who said what. Maya will write a big paper based on the research and will only use the pretend names, so that means what is said will not be connected to you personally. However, you and the other young ambassadors will be able to identify the things said by yourself and those in your focus group. We will only keep the data (recordings and transcripts) for as long as we need to for the study, and then we will delete it.

Where will the study happen?

The whole study will take place at Forget-me-nots, where you usually meet.

Assent Form for Young People (11 – 15 years)

*To be completed by the young person and their parent/guardian*

Please circle all you agree with: (Young Person)

Has somebody explained this study to you? Yes / No

Do you understand what the study is about? Yes / No

Have you asked all the questions you want? Yes /

No Have you had your questions answered in a way you understand? Yes /

No Do you understand it's OK to stop taking part at any time? Yes /

No Are you happy to take part? Yes

/ No

If any answers are 'no' or you don't want to take part, don't sign your

name! If you do want to take part, please write your name and today's

date

Your Name:

Today's Date:

Your parent or guardian must write their name here too if they are happy for you to do the study

Parent/Guardian Full Name (BLOCK CAPITALS):

Parent/Guardian Signature:

Today's Date:

Consent to share: demographic information

It would be helpful if you are happy to share the following information, but it is okay if you would prefer not to say!

Current age...../ Prefer not to say

Gender identity:...../ Prefer not to say

Age when bereaved:...../ Prefer not to say

Relationship to relative who died:...../ Prefer not to say

How long have you been a young ambassador? ...../ Prefer not to say

## Appendix 3B: Excerpts of mindmaps

Figure 3B.1 Mindmap excerpt one for group one

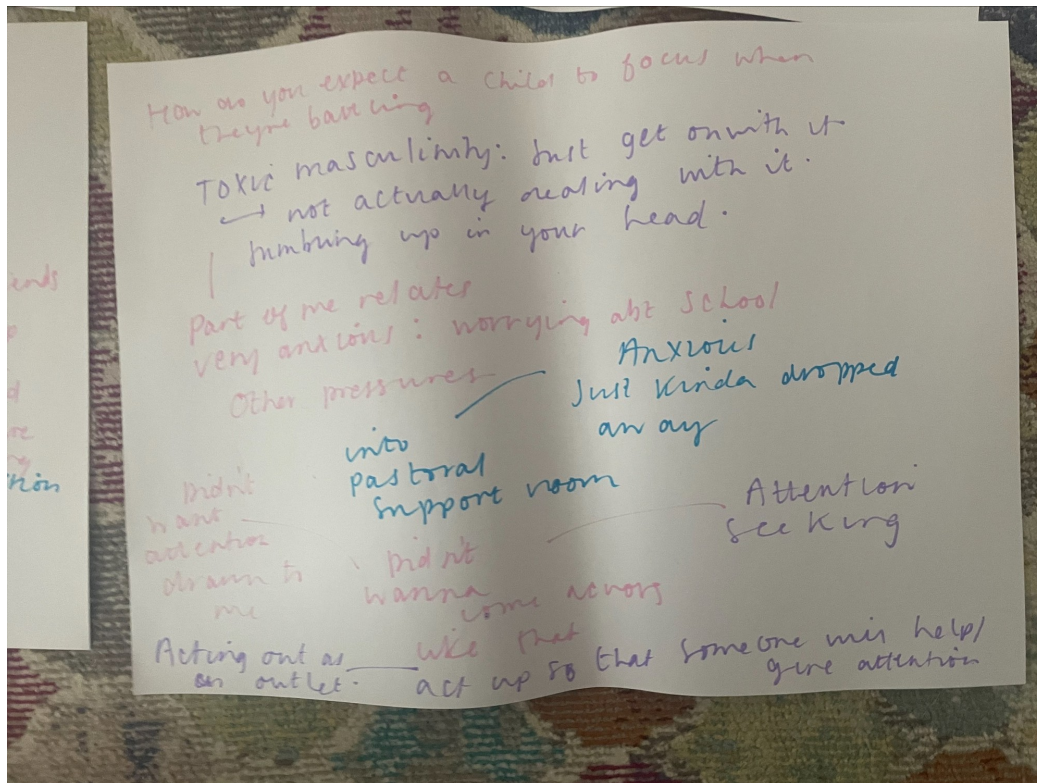




Figure 3B.2 Mindmap excerpt two for group one

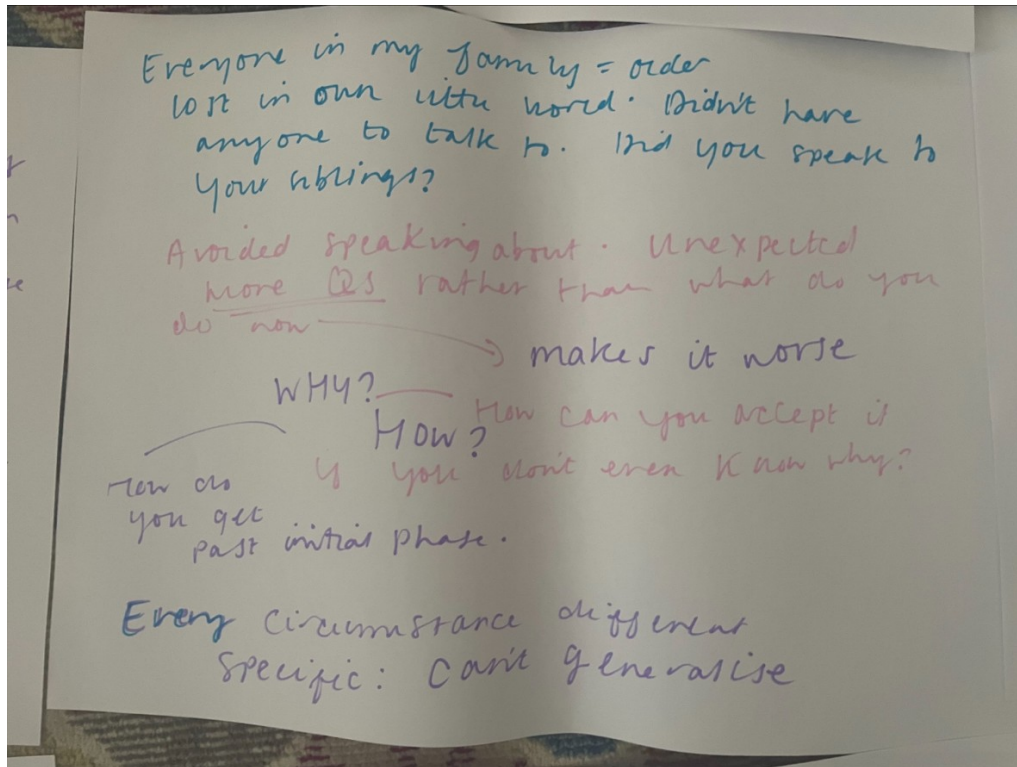


Figure 3B.3 Mindmap except one for group two

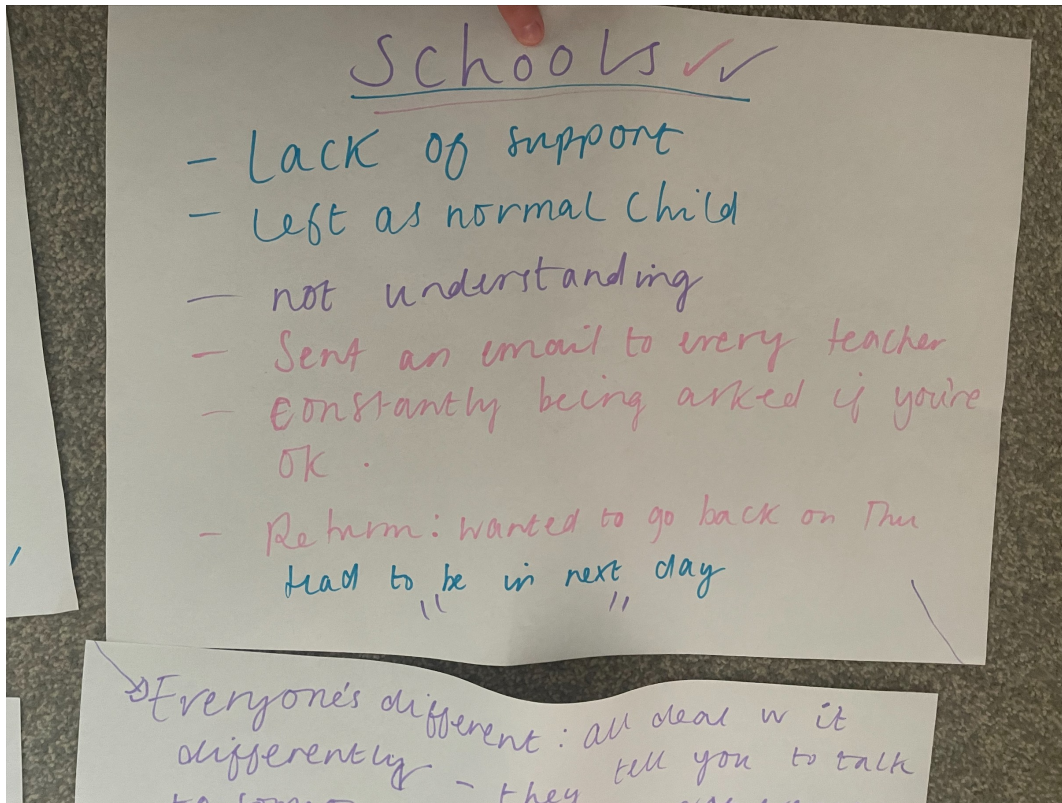
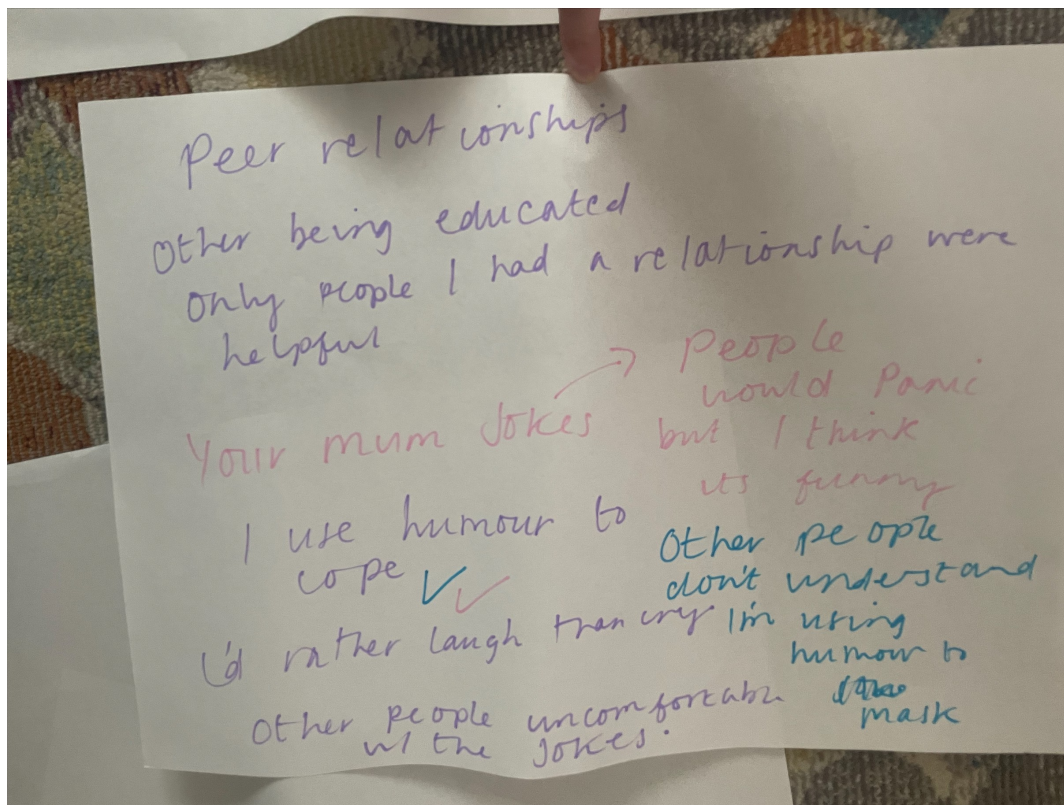


Figure 3B.4 Mindmap excerpt two for group two



## Appendix 3C: Interview Schedules

### Interview schedule 18-21

#### School

1. Were the adults in school supportive?
2. What did you find supportive/helpful?
3. What did you not find supportive/helpful?
4. Did your peers in school talk about it with you?
5. Do you think it is ok for people at school to ask you about your experience, or do you think grief is private?
6. Did any of your relationships change after the bereavement?
7. How did your experience at school change over time?
8. What was it like returning to school? Did you find going back to school helpful or unhelpful?
9. Anything you want to add?

#### Family

1. How did the bereavement impact your home life?
2. Do you feel the impact of your home life impacted school life? Social life?
3. Did you notice the impact on the rest of your family at the time?
4. Has your awareness of the impact on the rest of your family changed over time?
1. Acknowledge different experience for those who have siblings vs. Only children. Offer opportunity for both experiences to be shared.
5. I know one of the things you mentioned in the mind mapping session was the idea of 'becoming an adult' when you were bereaved: would anybody be happy to speak more to this experience?
6. Do your family celebrate anniversaries/birthdays of your loved ones? How do you experience this?

#### Friends/relationships

1. How were your relationships impacted by the bereavement?
2. How did you find being in a support group at Forget-me-nots?
3. Was it helpful to know there are other people who have experienced the same things as you?
4. Do you have a support network of friends?
5. Do you feel able to speak about your experiences of bereavement with your friends now?
6. What is that like?
7. Did you when you were younger? What was that like?
8. I know you said that it can be uncomfortable when other people don't know what to say. What would make it feel less awkward/easier to talk about?

#### Past, present and future

1. How would you say your grief affects you in the present?
2. Has your grief changed over time - was it different in the past?
3. Do you celebrate anniversaries; birthdays etc? Has the ways you celebrate them changed?
4. Would you say your reaction to anniversaries; birthdays etc has changed over time?
5. In the mind-mapping you mentioned it gets harder when you get older bc you realise the experiences you're missing. E.g. not being able to go for a beer with your dad. Can you speak more to that?
6. Another thing you mentioned is the way your childhood experiences have motivated you/shaped your world view. Can you talk more to that?
7. What helped you to get where you are today?

#### Interview schedule 11-14

##### School

1. Were the adults in school supportive?
2. What was it like returning to school? Did you find going back to school helpful or unhelpful?
3. What did you find supportive/helpful?
4. What did you not find supportive/helpful?
5. Did your peers in school talk about it with you?
6. Do you think it is ok for people at school to ask you about your experience, or do you think grief is private?
7. Did any of your relationships change after the bereavement?
8. How did your experience at school change over time?
9. How did the school manage special occasions e.g. anniversaries, fathers day?
10. If an adult in school asked you how to help a peer of yours going through the same thing, what would you say?
11. Anything you want to add?

#### Friendship

##### Jokes/humour

1. Do you use humour as a coping mechanism?
2. How do your friends react to that?
3. Do you like it when your friends make jokes?

##### Friendship

4. How have your friends reacted/have you felt supported?
5. Friends at standby?
6. Friends at school?
7. Do you feel able to talk to your friends about it?

8. Has that changed over time?

### Family

1. How did the bereavement impact your home life?
2. Did you notice the impact on your other relatives?
3. Did it effect you similarly or differently?
4. Do you talk about it as a family?
5. Do you feel the impact of your home life impacted school life? Social life?
6. Did you notice the impact on the rest of your family at the time?
7. Has your awareness of the impact on the rest of your family changed over time?
8. I know one of the things you mentioned in the mind mapping session was the idea of 'becoming an adult' when you were bereaved: would anybody be happy to speak more to this experience?
9. Do your family celebrate anniversaries/birthdays of your loved ones? How do you experience this?

Acknowledge different experience for those who have siblings vs. Only children.  
Offer opportunity for both experiences to be shared.

Appendix 3D: Excerpts of coded transcripts Excerpt one: group one; session one; school

Transcript 1	Codes						
Maya Abraham-Steele 0:01							
So, I would like to know both about what it was like to return to school and what your journey at school thereafter was like, but I think we should start with the return to school. So what was it like returning to school after the bereavement? And did you find going back to school helpful or unhelpful?							
Leo 0:20							

<p>It was sort of a bit of both really, for me... the bereavement happened on Friday and I went back to school on Tuesday; I lasted about an hour and a half. And it was all a bit patchy, like I'd go in for a day or so and then come out or go home early or I just wouldn't go in at all for pretty much all of year seven, so that was obviously an awkward bit, because a bereavement had happened, so you, you don't really want to go to school. But because I just joined year seven, a whole new school environment, you wanted to like make friends and not like, you know, and I ended up not having as many friends as you probably would, just because no one knew who I was probably for the first like, year or so. That was like, yeah, it was quite an awkward time to sort of miss</p>	<p>Time off school</p>	<p>Inability to stay in school</p>	<p>Impact on making friends</p>	<p>Return to school challenging</p>			
---	------------------------	------------------------------------	---------------------------------	-------------------------------------	--	--	--

<p>school because I didn't really find school, at that point, very helpful. You should kind of say, because I was quite young as well.</p>							
<p>Maya Abraham-Steele 1:21</p>							
<p>Does anyone else want to share their experience?</p>							



Maddie 1:26							
For me, going back for was, challenging, but we had like a week off because it happened during halfterm. So it was nice to kind of have that time to not be at school. But then to kind of get back into having that structure and some form of normality. I remember it being quite daunting, and not kind of knowing who knew or what to expect, how it was gonna feel. But I guess it was hard, but because I was lucky enough to have a really supportive tutor. That really helped and she kind of helped me keep going. So	Time off school	Return to school challenging	Difficult to return to structure	Having time off naturally : school holidays			
Maya Abraham-Steele 2:20							
Did anybody ask you what you wanted to happen in terms of who knew?							
Maddie 2:27							
I don't really remember. But I remember having a meeting beforehand, before I went into tutor, and into school with a member of pastoral, and in that I think we discussed it, and then she sent out an email so	Meeting before going back - being asked what want to happen						

Maya Abraham-Steele 2:44							
Okay, so you did, you think?							
Maddie 2:47							
Yeah.							
Ashley 2:51							
Mine was before year seven. So I had like, that time before I started school anyway	Having time off naturally : school holidays						
Maya Abraham-Steele 2:58							
Like summer holidays?							
Ashley 2:59							
Yeah. But it was quite scary because I was like, going into like, a new place sort of thing. So it was like a new environment as well. Yeah, it was a bit it was struggling because obviously, none of the teachers knew at all unless my mum came in for like a meeting and told them but apart from that it was okay.	Transition to new school: intimidating	Mum went in for meeting					
Jared 3:24							

Mine was, again, before year seven. But I don't really remember it, it was like 12/11 years. So, if I'm not wrong, I must have been at school the whole time. But I think it was. It was might have been around Halloween. So it's about half-term as well.	Don't really remember	No time off school						
Maya Abraham-Steele 3:53								
Okay, so I'm hearing like a mix of experiences. Did								

you? Do you remember like being asked what you wanted to happen? Do you know who was told, who wasn't told, those kinds of things?								
Leo 4:16								

<p>I think yeah. They asked me who I wanted to know, in terms of teachers I think. I was so young, I didn't really care to be honest. It was like the last thing on my mind. But I say it was quite different in terms of just I had two bereavements in school. The second one was more like I came back and obviously I was an older, I was in year nine, 14, so I was a bit sort of like maturer. And I remember I was in like the pastoral isolation for like, probably just under a week. Because homelife was just all over the place. So trying to sort of reintegrate myself slowly but one thing I found about schools is they were trying to sort of like rush me into it, thinking I was just using it as an excuse just to like bunk class, when, you know, it wasn't the case, I just sort of was using it as a, you know, like almost integration sort of session really, for like a week or two. But yeah, I just feel from the school's behalf they were just trying to rush into telling me how you know, you can't just spend all your time in here. I know how I feel, for example, so you</p>	<p>First bereavement, I was so young</p>	<p>Asked who I wanted to know - didn't care</p>	<p>Spent time in pastoral</p>	<p>Homelife was just all over the place</p>	<p>School rushed me</p>	<p>Thought it was an excuse to bunk class</p>	<p>Subsequent bereavements</p>
---	--	---	-------------------------------	---	-------------------------	---	--------------------------------

know, there's no timescale when I feel ready to go back into class, but yeah, this is probably the difference between the main two							
--	--	--	--	--	--	--	--

Excerpt two: group one; session two; family

Transcript 2	Codes				
Maya Abraham-Steele 5:55					
<p>Yeah, that makes sense. Did it feel... this is a question for everyone. But do you feel like you were included in conversations between adults? I'm aware that it also might be a different conversation for everyone.</p> <p>Do you feel like you were included in like family conversations about what was happening? And what was going on? Or do you feel like you were kind of kept out of that and protected from it?</p>					
Leo 6:23					
<p>I'd say I was, especially with my uncle, being a bit older I was definitely a lot more involved. With things like the funeral arrangements as well, and stuff like that. And obviously, due to him having quite a set of circumstances around his death, but not sort of normal. So was there was a lot of sort of parts to that which also kept up to date with which was nice to me, because it gives you closure on certain things without having to... in the same spot as my mum and grandparents about exactly what is going on. My dad was a bit different</p>	More involved when older	Nice to be kept up to date - closure	Wasn't involved in dad's funeral	Don't have greatest relationship with dad's family	Age thing - more likely to be told info when older

because I don't have the greatest relationship with his side of the family. Things like the funerals, we weren't really involved in as well. So yeah, it's an age thing					

Maddie 7:24					
I think in my situation, mum kind of, like, let us know, things that we needed to know. And like in terms of funerals, and kind of how we wanted things to be dealt or like who we wanted to be told in regards to like school and things. Mum was really good at kind of helping us decide rather than deciding for us. But I think because of yeah, the age that you're at, and the kind of nature of a parent wanting to protect a child. I think also, things were kind of told and said once they'd been decided or found out	Mum let us know what we needed to know	Who we wanted to be told, school things	Helping us decide, not deciding for us	Parent wanting to protect child	Told after things were decided

Jared 8:07					
As I was quite young, for three out of four, four now. I was I was completely left out. Like you said, I was just told stuff about a funeral. When, where, what wear. And I've obviously made it clear in my own way, I helped in my own way, for my most recent one last week. I'm kind of told things now because I'm old enough to understand everything. So	Left out	Told after things were decided	Because of my age		
Ashley 9:11					
I sort of kept out of it. Because I guess they didn't want to like hurt me in a way from like talking about it and stuff like that. But I was like told about like the simple things like the funeral and stuff like that. But I wasn't told like the main big things until like, the last minute sort of thing, I guess. Yeah, I think that's just because of my age. Well, was my age.	Kept out of it	Adults protecting children	Because of my age		
Maya Abraham-Steele 9:38					
Yeah. Do you guys think that children should be involved in discussions around like,					

Idk funerals for example? Do you think children should be evolved?					
Leo 10:03					



<p>I wish I was more involved in my dad's funeral because I don't think his was reflective of who he was as a person. So I feel like I would have things like input things I would have liked to put in there. Now when I get older or whatever, I don't look back on it and think it's a nice send off. And I feel like if I had little small things, like music was a big thing. You know, sort of like arrangements or what was said and things like that. But then, when I look back that are now as I am older, I wouldn't be so sour towards everyone almost. I felt like you should always have a part in it as well. Just because you're 12/13/14. And I feel like you should always have a part in it, because that is your loved one. So</p>	<p>Wish I was more involved in the funeral</p>	<p>I should have had a part in it</p>			
Maddie 10:53					

<p>I think like, a child or anyone involved, should always have the, the option. I find it really hard to hear when like people are like, I didn't give them the option. Like they're not going, they're too young. Obviously, I think it is down to like, the child, the relationship and the circumstance. But like, once you have the funeral, like that is a huge step. And that is like, your kind of chance to, I don't know how to put it but like say goodbye to... I don't know, it's a very kind of crucial part. And, you know, if someone doesn't want to go, that's fine, you should respect that. But also, if they do want to go, I</p>	<p>Should always be given the option to be involved or not, however old</p>	<p>Funeral as a stepping stone</p>	<p>Funeral as part of grief journey</p>		
--	---	------------------------------------	---	--	--

<p>think they should go and like I mean, it might it might not be relevant, and I'm going to talk about a soap. But like I think how like people portray it, like for example on EastEnders. Someone, like a mum has recently died. And the young girl like decided that she wanted to speak at her funeral. And her dad was like, You're not doing that and got really angry. And I think it is out of love and you see it in like day to day life and how it's portrayed. But I think yeah, the children should get a choice and a chance to kind of have and play a</p>					
--	--	--	--	--	--

part in that because they were part of that person's life so yeah, sorry I've talked a lot but					
Maya Abraham-Steele 12:45					
don't apologise it's good					
Jared 12:50					
I mean I mean I think certain extent Yes. Like they can't be involved in the conversations that like things like things like what's going to happen on the day in the funeral and how life will change and things like that what Yes, but things such as I don't know, I just think they should they should have a choice to want to know or not because otherwise if you just keep it from them, then years later they figure out like well I wanted to know that it just could be just could damage their relationship with other members of the family	Keeping things from young people can damage relationships with other family members				

Ashley 13:51					
I think what they should have their like own sort of like little input sort of thing, like to see what maybe they could add that's like special maybe?	Funeral as a stepping stone	Funeral as part of grief journey	Funeral helpful	Helpful to have a special part in the funeral	

That might help them like like support them maybe or like it's like not closure as such but it's like it's like stepping past the funeral sort of thing like it's it's it's helpful going to it sort of thing. Well, I found that was quite helpful going into it					
Maya Abraham-Steele 14:34					
thank you, everyone. Do you think did you feel the impact? Do you feel it? Hang on? I don't know how to word that. Did you feel that the impact of your home life affected your school life?					
Leo 14:47					

<p>Yes, more so. So like my dad kind of, it sort of did. But home life was a bit more structured. Uncle?</p> <p>Completely, because of the state of my mom and my grandparents. That's like our family, me, my brother, my mom, and my nan and granddad, that sort of like really, sort of family. So seeing, obviously, I had to grow up to sort of be like, man of the house after, sort of my dad died. So then when that happens, and seeing my mom and my granddad, all sort of like, kind of like, like they weren't present in those days, sort of like, they just weren't there, they were there, but they weren't there. So I was in, I'd go into school. And that was sort of my respite, you can say, but then, obviously, I'm having problems at school, because I'm doing, I'm trying to go home and do my homework but I look ... my main focus was looking after my mom, because of how bad she was, I was worried for her own health and stuff like that. So it got quite severe. So as they're coming</p>	<p>Man of the house after dad died</p>	<p>Impact of death on rest of family impacted home and school life</p>	<p>Fuse was shorter because home life was so stressful</p>	<p>Priority looking after mum</p>	<p>School as respite from home but problems at school</p>
--	--	--	--	-----------------------------------	---

to school, and I'm having all that jumbled up stuff going on at home, then school, I've got Mr. Bla bla shouting at me because my shirt is untucked. So it just made me made my trigger point a lot easier, made my fuse a lot shorter...					
Maya Abraham-Steele 16:39					
So perhaps not fully understanding, like the longevity of the impact of bereavement. And like the size of the impact of the bereavement, similar to what we're talking about before about, you know, them expecting you to have processed it within a certain timeframe and those kinds of things.					
Leo 16:59					

<p>It's an ongoing thing. My mum was constantly like that, you know, she's better now. But I think about as recently as COVID, you know, which was sort of like four or five years after that happened, she was still sort of in that same mindset. And that was way past I'd left school for like three years at that point. So there's you know, they didn't really understand that just for you is a two week thing and then you sort of come back and I think it made it worse that they knew about my dad and then obviously that you try to deal with me for three years about my dad's death and then another one comes which it all just comes out and it's like 2 in 1.</p>	<p>Longevity of impact of grief</p>				
--	-------------------------------------	--	--	--	--

Excerpt three: group one; session three; friendships

Transcript 3	Codes				
Maya Abraham-Steele 26:22					

<p>I know you said in like the what's it called mind mapping session, but also a bit today, that it can be uncomfortable when you talk to somebody and they don't know what to say? And I was thinking do you guys have any ideas about what would make it feel less awkward or anything that would make it easier to talk about?</p>					
<p>Leo 26:47</p>					
<p>It's just like, I don't even know if it's a word, like casual about it. There's no like, you don't have to be so tense about it, just ask a random question. You know, ask how you are or ask something about them. You know, when we went and did a lunch a couple of weeks ago, a guy asked me the same thing. How do I approach someone? I said be casual about it, don't be all tense and act as if you know, it's all I can't say anything! I'd be very casual about it, ask them a few questions. If you know, of the person know anything about them ask a little something about it; ask what they liked, their interests, you</p>	<p>Be casual about it</p>	<p>Ask questions - note he said yes and no to this earlier</p>	<p>Battle</p>		



<p>know, any good experiences, they have of the person. Just try and make it as casual</p>					
--	--	--	--	--	--

<p>as possible. Because when you get talking, you're fine. But it's an initial oh my dads dead or loved ones dead and then beating around the bush almost.</p>					
<p>Maddie 27:42</p>					

<p>I'd say like, I don't necessarily know how but like, it's definitely a conversation and a subject that I get. I was gonna say normalise, but a lot of our life experiences and situations aren't normal. So it makes it so hard. Like, it isn't what you think of, you know, you'll watch your parents grow old and they lived a nice, long life. Like, they're not normal scenarios. But I think the idea of talking about grief and bereavement Yeah, needs to like, not be so like, sugar coated, but not so serious and like scary, where people end up not talking about it, because that's the biggest issue really avoiding it.</p>	Normalise	Our experiences aren't normal	Battle	Balance between not sugar coating but not making it unapproachable	
<p>Maya Abraham-Steele 28:39</p>					
<p>Why do you think people do avoid it? Why do you think it is so? Uncomfortable? And scary?</p>					
<p>Leo 28:45</p>					
<p>I think they're scared of the reaction of the person.</p>	Scared of reaction of bereaved so avoid				

Maddie 28:47					
Yeah.					
Leo 28:47					
They don't know if it's going to trigger them. They don't know how they don't know the circumstances around it. They don't know, if it was a quite a bad death. If it was a sudden death, it was a, you know, long term death if sort of, they were close to them or not what their relationship was, because I see, some people lose a parent where they, they had no real connection with them. So obviously, they're going to be a lot more sort of, like, sort of it is what it is, as opposed to someone obviously had a really good connection with their parents. And so it's fear. Yeah.	Unknown how they will react	Don't know circumstances			
Maddie 29:19					

<p>I guess in some situations, in some situations, like, I mean, now, I, you know, feel like I could take kind of take the lead and open up that conversation. But sometimes you don't want to like sometimes you do want someone to kind of approach you about it and ask how you are or how things are going.</p> <p>And remember, like, you know, is coming up to that time, or is it like his birthday? Like, you don't always want to be the one that shows that people care if they remember and kind of</p>	<p>approach more casually</p>	<p>don't always wanna be the one bringing it up</p>			
--	-------------------------------	---	--	--	--

<p>asking you first but yeah, how will you do that? And I guess is just approaching it more casually, loosening up that really tense awkward situation well, doesn't need to be but tends to be.</p>					
<p>Maya Abraham-Steele 30:12</p>					
<p>Yeah. And I suppose one of the things it's making me think about is, like bereavement education more generally. Like, do you think that we</p>					

<p> speak enough about death? As a society like to children? In our culture? </p>					
Maddie 30:31					
No, not at all.					
Leo 30:32					
<p> It does surprise me as well, because I think there's such a push for like mental health now. One of the biggest factors for young people's mental health is bereavement, there's a direct link between it. So I think, why don't we talk about it as much if we could talk about mental health? Why don't we go back to the cause of that. You can deal with mental health. But when it's a bereavement. It's a completely different sort of mental health as well, in my opinion. </p>	<p> Don't talk about it enough societally </p>	<p> Why isn't it part of MH conversation? </p>			
Maddie 30:58					

<p>One of the things that on the one hand, I'd greatly appreciate rather than like ugh enough with that excuse is like, I was gonna say, like, it wouldn't hurt and it wouldn't, like take up too much time or resource to introduce part of the module in like, RSE. But then people are like, Oh, we don't want to scare the children. We don't want to bring up hard things.. but actually it's their excuse for everything. We just cant talk or teach them anything like</p>	<p>Want us to teach it in RPS in schools</p>	<p>Excuse: don't want to scare the children</p>			
<p>Leo 31:36</p>					
<p>this is the thing that is like you should be preparing kids for the reality of life, it can happen to every single one. Crazy and harsh as it sounds. I think it will,</p>	<p>Should be preparing kids for death</p>	<p>Everyone will experience</p>			
<p>Maya Abraham-Steele 31:45</p>					
<p>well, it will happen to every single one of us, right?</p>					
<p>Leo 31:48</p>					

<p>Well as like a child for example, it will prepare them I think much better. You know, I didn't know anything about it. No one usually does. You don't even know what happens when someone dies, they get buried or cremated, what's a funeral? You know, like, I think there's a new thing for everyone. I think scaring them and things are stupid considering the stats on</p>	<p>Prepare them</p>	<p>I didn't know anything about it - normal</p>	<p>You don't even know what happens when someone dies</p>	<p>Burials; cremations; funerals; all new to me</p>	<p>Worrying about scaring them is stupid</p>
---	---------------------	---	---	---	--

<p>how many kids are bereaved</p>					
<p>Maddie 31:48</p>					
<p>Yeah I agree</p>					
<p>Leo 32:00</p>					
<p>it's not like you're going to have so many schools where there's going to be not a single bereaved, there's bound to be at least one bereaved child in that primary school, for example, on average,</p>					
<p>Maya Abraham-Steele 32:25</p>					

Well, one in every 29					
Leo 32:26					
That's like one in every class or so. So it's like, why are... you're scaring the kids but it's happened where they're so the kid could just look at that. Oh, my God, you know, Milly lost their mom, what's gonna happen to Milly now? But that's inevitable? You know, so I don't see why they can't sort of teach it. And you know, like you said, in like RE or RNE or whatever its called now?	Its happened in every class	Why don't they teach you about it?	Should		
Maddie 32:52					

No, I think it is definitely, definitely with like, teachers stuff. And adults. I just think there should definitely be some training	Teacher training should be mandatory				
---	--------------------------------------	--	--	--	--



Excerpt four: group one; session four; past, present and future

Transcript 4	Codes				
Leo 44:23					
<p>Me and my brother say some foul things man. It's like, the person who my dad was, he would be exactly the same, but his dad died and he used to make some foul jokes. So like, but I do it when when I speak to someone and like today was a prime example. There was a girl that I worked with and she was talking about family and she was like, talking about like parents and stuff and she was like 'are your parents still together? Is your dad still with your mom?' I just lent in and went, 'the thing is he is actually dead.' And like made a joke about it, and it made it so much more like light hearted, like she laughed a bit, she was like, 'oh my god, I'm so sorry.' And I was like, 'no, like, it's fine.' I mean, but I feel like if I was sort of like 'my dad passed...' it will just make the conversation so much more awkward. You know, so I thought, you know, I can openly sort of joke about it. Five years ago, I couldn't. I would have been a bit more, like maybe with my brother but with other people. Maybe not so much. But now like, I just sort of think, what harm is it sort of going to do like, you know,</p>	<p>me and my brother joke about it</p>	<p>My dad would also have joked about it</p>	<p>I do it to make the conversation less awkward: signals I'm ok</p>	<p>Change d over time - couldn't joke 5 years ago</p>	

he would laugh about the way I was sort of talking					
--	--	--	--	--	--

<p>about it. I don't sort of joke about him personally. But a bit like you said, like, you know, someone's like, oh, yeah, like, you know, daddy's money. I'd be like 'yeah that must be nice.' Yeah, something like that. But me and my brother like, we do it to wind up my mum as well. I won't repeat stuff. It's just the way that we choose to sort of deal with it to an extent because you can't change anything, a joke is a joke, you know. My dad would laugh his head off probably. And, you know, say the joke to us, and cuss us out or something like that, you know, but that was sort of the relationship we kind of had. So I think it's more acceptable. But I understand where like other people probably wouldn't for their own sort of like, grief. Like I said, five years ago, I probably wouldn't. But now like, I just find, especially with someone who doesn't know, just makes that initial sort of like icebreaker, just so much more easier to deal with.</p>					
Maya Abraham-Steele					
because it sort of communicates to them like that it's not upsetting you?					

Leo					
Yeah, because like, yeah, that's the thing, like when you speak to someone that, obviously is quite, sort of like, obviously, they don't know much about bereavement, I think their fear is not knowing the circumstances around the death, how that person is going to react to speaking about it. So I think if I come out straightaway, and sort of laughing and do a bit of a	Relaxes other people if I'm laughing /joking				

joke about it, they're going to be 10 times more relaxed to speak about it, they're going to think, okay, I can actually talk about it without, you know, thinking I'm going to break down in tears or something like that, or it's making me down. And then it sort of the conversation just flourishes a lot more easily than if I sort of, I guess got down or visibly upset or down about it. And so, that's just the way I					
Jared 47:43					
Its kind of like the way the bereaved person reacts is how everyone else sets himself up too	How the bereaved person acts sets the tone				

	for intract i on				
Leo 47:51					
Yeah absolutely. So yeah, because when you think when you speak to a person whos is bereaved, you don't know their relationship with the dead person, you don't know how soon it was, you know, that you don't know, sort of, if it's really affected them like that, you know, some people are not, oh, yeah, like, my dad died, but I never saw him. It's like my granddad, like my granddad's dead, but I never met him. So I don't have no like emotional connection to it. So, you know, obviously, that is the case of some people will have like parents and siblings and grandparents and stuff like that. Whereas some people will see the complete other end of the spectrum, they're really close to them. And, you know, even like, the topic of them may just be a	Fear of the unknon w				

<p>trigger point for them. So I think that's the fear of someone who obviously hasn't gone through it when you're speaking to someone that's bereaved, is this that unknown of not knowing how they're going to react. So the way I sort of react, I think, you know, sort of just sets the tone. You know, kind of like, bumps up the mood a little bit maybe relieves the awkwardness of the situation.</p>					
<p>Maya Abraham-Steele 48:56</p>					
<p>Did you have any experience of like making jokes or other people making jokes when you were younger? Like still in school and stuff? And how do you feel about like friends or other people using humour around it?</p>					
<p>Leo 49:15</p>					

<p>that's my tactic for myself, so I'm a bit more... it depends, if they knew my dad, then yeah, my best friend for example, has been my best mate for 18 years, our parents are friends and stuff. He knew my dad so yeah, you know, I would. But say if someone was just bantering about the fact that I don't have a dad, depends who it is and depends on the context. It is a bit sort of like hard. You get the kids in school that would be like they'll use it as an insult to try and annoy you or something, you know, sort of like screw your mom and screw your dad. I remember being in the park and there was an instance where someone said that to me and I just like, switched completely. That's quite rare because I think it was quite well known about my dad. And they knew my reaction</p>	<p>Kids using it as an insult/ to annoy you</p>	<p>To provoke a fight</p>	<p>Violence</p>		
---	---	---------------------------	-----------------	--	--

<p>would be like, if they wanted to have a fight with me, then they'd say that because I would just go for them because I you just sort of see red back then. But I guess now, it's a little more chilled out, and I'm not just gonna attack anyone that says something.</p>					
<p>Maddie 50:19</p>					

<p>No one I don't think no one ever used jokes around me with this. I mean, when I was at school at that time. Maybe people could tell that I wouldn't be able to take it. Jokes were never like, appropriate or a things around me? I think in my experience, people didn't know what to say. Yeah, there wasn't anything really</p>	<p>No one ever made jokes</p>	<p>Peopl e didn't know what to say</p>			
<p>Jared 51:06</p>					
<p>people never really use jokes around me either. I mean? And I don't wanna say I use my height and stuff to intimidate people. But I mean, if that's what I have to do to stop people making jokes or even telling other people about it and things like that. Again, like Maddie said, I wouldn't. I just wouldn't have it.</p>	<p>Would n' t have ir</p>	<p>Intimidate people</p>			
<p>Maya Abraham-Steele 51:37</p>					
<p>The other thing that we kind of touched on, but you can veto if you, you can say whether you want to talk about this or not, because I'm aware it could be heavy. Dreams?</p>					
<p>Leo 51:50</p>					
<p>Yeah.</p>					
<p>Maya Abraham-Steele 51:53</p>					

I haven't formulated a question. I guess the question would be something along the lines of like, yeah, do you? Just do your dreams affect you? Do you dream about it? Have your dreams... changed over time?					
Jared 52:12					
It's not a dream. I just as I said earlier, I just replay the moment in my head, which, I guess some people say they get stuck in their own head, which a lot of people I assume do. But yeah, it's not a dream. I just think about it a lot. And I just don't want to but it's just how the mind works sometimes.	Replayi n g momen t s in mind when awake	Get stuck in head			
Maya Abraham-Steele 52:32					
So it's when you're awake. It's replaying not like asleep dream.					
Jared 52:36					
Yeah, no it's not a dreams. It's just an occurring for that I just hate. My brain just latches on to something and then it just doesn't let go sometimes.					
Maddie 52:53					



<p>Well like, when it initially happened, I remember having a few. And like one being that I was told like that he was alive and that really like, shook me up because I was like, really happy in my dream because he was alive, but then waking up being like, oh he's not. I don't have like, loads about him. But like, when I do, I do not like it. I had one my nice one.</p> <p>And it was like it was like a bit of a, like, religious? I saw him again when I died, and I was like, awww, like I am</p>	<p>Dreams when initially bereaved</p>	<p>Told he was alive</p>	<p>Shook me</p>	<p>Felt really happy and then woke up</p>	<p>Hate dreaming</p>
--	---------------------------------------	--------------------------	-----------------	---	----------------------

<p>gonna be with him again. But I hate dreaming. Like, I don't I don't enjoy it. Like when I do. It's not like often including or about him. But when I do yeah I don't like it.</p>					
<p>Leo 53:53</p>					

<p>I have loads of hyper realistic dreams about my dad. And I quite like them to be fair, because it's quite, I don't know, it's a weird sensation. Because like, even though I haven't obviously seen him for 10 years. Like, everything about him is like to perfection. Like in my dream. Like it's so hyper realistic.</p> <p>It's like I'm living it, you know, like, smell, the way he looks, the way he talks. I can't remember how he smelt. You know, I can't remember how he talks or anything like that, his voice. It's yeah, essentially is something like that. And I think I had one a couple of weeks ago where he has sort of just come back just just appeared out of nowhere, you know, just decided to rise from the dead I guess.</p> <p>And it was like really sort of like quiet nice because I always think like, you just wish, he could see me now. And everything can be I always, like, go visit his best friend, for example, like three times a week. And, you know, and sort of he, you know, a decade back and then we met him, I was in his van. And, you know, we were like talking and I was telling him everything that had been happening, and I was driving the van now. And, you know, it was sort of like, it was quite nice,</p>	<p>Hyperr e alistic dreams</p>	<p>I like it</p>	<p>Shitter when you wake up</p>		
---	--	------------------	---	--	--

<p>because it was something that I wish so badly could happen in real life was happening, in the dream. So almost got to, like, live that</p>					
---	--	--	--	--	--

<p>sort of moment. But it's also a bit of a shitter when you wake up, and you realise it's not real. And you know, but then I sort of think that was really sort of like nice and comforting to, you know, be able to sort of like actually kind of spend time with him, as me now with my past experiences as an adult.</p> <p>Obviously, in a dream setting, and really just being so realistic, there was no fantasy stuff. No, yeah, it wasn't floating around or anything like that, like, everything was just so real. And I'd quite, you know, I found it quite nice, because it's just something that I wish could happen in real life. And I've had like a little taster, I guess. So I'd welcome those dreams a lot more obviously.</p> <p>Obviously, when you wake up, it is a bit of a kick in the gut, I guess. Back to reality.</p>					
<p>Maya Abraham-Steele 56:34</p>					
<p>Did you have any dreams about it when you were younger? You might not remember but nearer the time to when it happened.</p>					
<p>Leo 56:42</p>					

I dreamt about death but not about the hyper realistic ones. They only sort of came as I got older, which is kind of weird, because obviously you'd think well, my memory would be starting to fade of him. It was sort of doing the reverse almost. Yeah.	Dreamt about death when younger	Hyper realistic dreams more recently			
Maya Abraham-Steele 56:59					
Anyone else wanna add anything? Okay, that's the end of my questions. So does anyone else want to add anything on this theme or any other theme or					

anything that sits outside our themes? Open floor					
Jared 57:24					
Well, I guess it hasn't for me. Because as I said I didn't really know them well. So I kind of had to just make my own aspirations and stuff. And just heard about what my grandparents did in their lives, how they worked and stuff because all parents tell us all parents and grandparents tell a stories. Like, back in my day, I used to do all these jobs...	Wont be at my wedding	Some people save chairs	Planning for future		

Excerpt five: group two; session one; school

Transcript 5	Codes				
Jason 8:02					

I think only about two teachers know because I've told them personally	Only teachers I have told know			
Maya Abraham-Steele 8:06				
So you've told them personally?				
Jason 8:07				
Cuz they're like, they're teachers but they're friends as well as you know how to teach you to really go to it. Yeah, I've got them two teachers				
Maya Abraham-Steele 8:20				
Would you? Is it your preference that the teachers don't know? Or would you prefer them to know? You might all have different answers obviously there's not a right or wrong answer either.				
Tord 8:32				
It depends really, if I just really don't like this teacher then I mean, not really I don't really want to share that personal thing with somebody I just	Only teachers I have told know	Only want teachers I like to know		

hate. There are some teachers I would tell				
Jason 8:53				
I personally don't like teachers knowing because it kind of feels like a pity thought. To where they're only nice to you and they give you that special treatment. I don't want that; I want to be a normal kid. I want the school experience, I don't want to be treated differently. So I'd	Don't want teacher's pity	Don't want special treatment	I want to be a normal kid	I don't want to be treated differently

personally not want them to know				
Maya Abraham-Steele 9:14				
because you want to be treated the same as everybody else				
Jason 9:17				
Yeah				
Gretchen 9:20				
I'm not bothered; either I tell them or another teacher tells them so it doesn't make any difference	Someon e will tell them: me or another teacher			
Maya Abraham-Steele 9:26				
What if somebody else was told them for you like somebody from Forget- me-nots or... your other parent				
Gretchen 9:36	What would they do if I was upset?			
I don't think it would make any difference? Because, if I was upset, what would they do?				
Jason 9:42				
Yeah, that is true, they are kind of useless.	They are useless			
Tord 9:45				

Yesssss.	They are useless			
Maya Abraham-Steele 9:50				
Okay. Do you agree with that Tord? You just said yes				
Tord 9:57				
Like I feel like right now. Maybe it would have made a difference in primary school, like all the teachers knowing, but I feel like right now just be a little bit awkward like, going in like, hey, my son's mothers died and then they just walked back out again. I feel like it'd be a bit awkward	It would be awkward telling all the teachers			
Maya Abraham-Steele 10:12				
for them?				
Tord 10:13				
For me	Awkward for me			
Maya Abraham-Steele 10:13				
For you. Yeah, it'd be awkward for you. Okay.				
Gretchen 10:16				
Yeah, I mean, what would the teachers do? Like? Yeah, once they know what do they do with it after that? Wait for us to be upset?	What can they do? Wait for us to be upset?			
Tord 10:26				
Maybe a couple of weeks after the fact if they don't know then tell them				
Maya Abraham-Steele 10:30				



Well, is there anything that you think they could do? That would be helpful? If they knew? If you if you were asked to give a teacher that was helping somebody else whose parent or grandparent had just died, would you have any advice for them?				
Jason 10:53				

Oh, I'd say give them some type of card or like tell the teachers that they can have time out of class if they want to. So even if it's like not all lesson, if it's 5-10 minutes just to like re calm yourself and make yourself focused again to the point you're not upset	Timeo ut card			
Tord 11:16				
yeah, my school has literally they've got like these green laminated piece of paper that say refocus card, they call it a refocus card, you can step out for five minutes or you can go to the people support room for like 15 minutes or so. Because like it would take five minutes to walk there and back	Timeo ut card			
Maya Abraham-Steele 11:43				
Yeah,				
Jason 11:44				
My little cards were called calm cards, I was given one for anger issues not for the bereavement				
Tord 11:52				

when I was in year 7, they were like trying to give me one but I just didn't I didn't really want one because it made me feel a bit different like... I don't want to be different, I wanna be the same	Made me feel different	Don't want to be different	I want to be the same	
Maya Abraham-Steele 12:03				
I'm hearing this big, big theme isn't it, not wanting to be different to the others				
Tord 12:08				
I want to be treated the same.	I want to be treated the same			
Maya Abraham-Steele 12:10				
Yeah. Okay.				
Tord 12:11				

Well then there are also times where you should be treated different	There are times you should be treated different	Note conflict		
--	---	---------------	--	--

Excerpt six: group two; session two; friends

Transcript 6	Codes			
Maya Abraham-Steele 4:22				
Okay, and the second question was, do you feel you can talk to your friends? Well, would you want to talk about it with your friends now? And do you feel you can?				

Jason 4:38				
I feel like I could. But it would have to be my closest friends. It would have to be my best mate that I'll talk to you about and if I really wanted to, I would. But usually I just don't really feel like it	Usually don't feel like talking about it to friends	If I do, best friend	Can talk to closest friends	
Tord 4:55				
Sometimes I just talk about. Honestly, I'm pretty open about it	Pretty open about it	Talk about it sometimes		
Maya Abraham-Steele 5:03				
Do you think your friends are pretty open about it too?				
Tord 5:08				
What do you mean?				
Maya Abraham-Steele 5:09				
Do you think that they feel as kind of comfortable talking about it as you do?				

Tord 5:13				
Yeah. Again, it depends on the person. Some people will talk about it, because cuz, they just will, other people like, oh, yeah. Okay. Before like just talking about stuff like	Depends on person if they are comfortable discussing or not			

that.				
Maya Abraham-Steele 5:29				
So sometimes it's awkward. Sometimes it's not...				
Juan 5:33				
Same as Jason very much.	Comparative suffering			
Maya Abraham-Steele 5:36				
You could but you don't tend to. And what about peers and friendships outside of school? So I know one of the things that you guys mentioned in the mind mapping was relationships here at Forget-me-nots what have your experiences of those been?				
Tord 6:00				
At Forget-me-nots It's way easier. Because other people have gone through the same thing. And I do scouting, and if ever comes up, like there's always one other person. Like, I'm not like dissing them, but like, they're always like well my sister	way easier to talk about it at Forget-me-nots	People done the same thing	Outside of Forget-me-nots - scouting - felt like someone try to compete	comparative suffering

died, like they're trying to top me out or something.				

Maya Abraham-Steele 6:22				
I see.				
Tord 6:23				
Just like, why? It's not like a flex or anything.	Comparative suffering			
Maya Abraham-Steele 6:28				
So it feels like a bit of a competition with that person?				
Tord 6:32				
It feels like they're trying to start competition.	Comparative suffering			
Maya Abraham-Steele 6:35				
And how is that uncomfortable?				
Tord 6:37				
Yeah.				
Maya Abraham-Steele 6:40				
But you didn't have that experience here.				
Tord 6:43				

Nah. It was at like scouts a couple weeks ago				
Maya Abraham-Steele 6:46				
oh, it's more recent that that happened. Okay, are they somebody get on with like is somebody you know, well, or is it?				
Tord 6:55				
Ugh no I just know them from scouts.				
Maya Abraham-Steele 6:59				

Okay. What about you guys?				
Jason 7:03				
At Forget-me-nots It's way easier. Because other people have gone through the same thing. And I do scouting, and if ever comes up, like there's always one other person. Like, I'm not like dissing them, but like, they're always like well my sister died, like they're trying to top me out or something.	Make friends	Been through same thing	Comparative suffering	Easier to talk to people here

Transcript seven; group two; family

Transcript 7	Codes					
Maya Abraham-Steele 5:38						

Did you notice the impact of the bereavement on your other family members at the time?						
Juan 5:43						
No, because all my family on my dad's side live in a different country.	did not realise impact at time	Dads side live in diff country				
Gretchen 5:49						
My parents weren't like my mom and dad went together. I didn't really notice it in my brother either. Because even like at the funeral, he didn't, I think he didn't even cry then so. I didn't notice it really? He doesn't really talk about it as much as me	Brother didn't cry at funeral	didn't notice impact on him	doesn't talk about it as much as me			
Tord 6:05						

In 2018 I was just a stupid little kid and I only cared about myself, because I was a little kid. But know, I think about it because my grandparents, they were my mum's mum and dad and it must've effected them a lot more. That's like their child. I saw a picture of them like them, with her, when she was my age, it just gave me clarity. You know? I don't	Only cared about myself	Stupid little kid	Now, I can see impact on grandparents			
---	-------------------------	-------------------	---------------------------------------	--	--	--

know what the word is						
Maya Abraham-Steele 6:46						
Yeah, I know what you mean, like a realise, realisation, almost. And when Tord do you think you started to think about the way it impacted? Like, for example, your grandparents?						
Tord 7:00						
Like, I mean, I didn't really think about my grandparents all that much about how it effected them. Because I always just saw them as these impenetrable figures of cool. I just thought they were really cool. I recall. I started thinking about it like a couple weeks ago actually	Couple of weeweeks ago: realisati o n	adults as impenetrable figures of cool				
Maya Abraham-Steele 7:17						
So really recently						
Tord 7:18						
Yeah.						



Maya Abraham-Steele 7:23						
Does anyone else have anything else they wanna add?						

Jason 7:26						
Mine was kinda like Tord's.						
Maya Abraham-Steele 7:30						
Yeah...						
Jason 7:30						
I was a kid so I only really thought about myself? But after he died, seeing how badly it hurt my mum. Because she was always a strong person who I could always go for for help. And she was nothing ever could break. But seeing her proper break down and cry, kind of woke me up. Because I started thinking about, I started trying to help her, before helping me, because I realise how much that hurt her.	Only cared about myself	Seeing mum break down: strong person	Tried to help mum before myself	Change of perception of parents		
Gretchen 8:07						

<p>I was gonna say I think I realised like it affects the other people. When when my dad was dying at my nan's house, like his mum's house, their dog was like, obsessed with him all over him. And I remember going around my nan's. I've never seen a dog look so sad. It was so weird. And then my nan came down with, like, Oo, look at this, and it was a pillowcase with his blood on it. And I thought that is so weird. That is just weird. You don't that is honestly weird. It had been like a year at this point, and she still had a pillow case with blood on it. And I was thinking, poor woman, you know, like, I didn't really think of it</p>	<p>Nan's dog looked sad</p>	<p>Nan had kept pillowcase with his blood on it and showed me</p>	<p>I found it weird</p>	<p>Poor woman</p>	<p>It wasn't just me grieving</p>	<p>even the dog</p>
--	-----------------------------	---	-------------------------	-------------------	-----------------------------------	---------------------

<p>affecting other people until I saw that. It wasn't just me who was grieving. Even a dog.</p>						
<p>Maya Abraham-Steele 8:49</p>						
<p>Absolutely. And that's really typical, you know, for children to be focused on their own grief. There's not anything wrong with that. It's interesting to hear you guys talk about, you know, when that changed for you,</p>						

you know, the difference? Do you talk about your bereavement in your families?						
Gretchen 9:18						
When I go to my dad's side? Yes, because they don't shut up about him. So I don't really like go to thiers a lot because it can get too much because when I go to my Nana's house on that side, the whole family comes, and then it's all like focused around my dad and my uncle because they're both on my dad's side and it's kind of weird seeing like, My other uncle who looks like almost spitting image of my dad. It kind of is hard, but we don't talk about like him dying. We just share their memories with him which can be nice, but then they're like, oh, you really remind me of your dad and you think oh God. You go home not in the best mood. You know what I mean?	Dad's side don't shut up about him	Can get too much	Hard seeing my uncle, looks like my dad	We don't talk about him dying	Share memories	Hard hearing that I remind them of my dad
Mhmm						

Juan 10:00						
What was the question again?						
Tord 10:01						
Yeah						
Maya Abraham-Steele 10:04						
Do you talk about your bereavement in your families?						
Juan 10:07						
I've talked about it with my mum but that is about it	Talk about it with mum					
Tord 10:12						
We talk about it on all the important days like the day she died, the day mom and dad got married and the date that something else happened... birthday! and then sometimes we talk about on Christmas and stuff. Like just like the important days you know but other than that we don't really talk about it.	Talk about it on important days	Date it happened, birthday				

## Appendix 3E: Stage one thematic analysis

Umbrella theme	Explanation
Gender	Males made a distinction between their experiences compared to females. E.g. male pressure to be ok; worry about being bullied for grief; talk of violence/beating people up for 'blabbing'
Age/developmental stage	Distinct difference in processing between both groups. Older group can acknowledge the differences in their understanding now compared to when younger. Grieving for the future you wont have, not just the present.
The battle	Wanting to be normal; not wanting to be singled out; wanting to be okay but not being okay; needing help; knowing experiences aren't 'the norm'.
Comparative suffering	Between each other, making sense of their experiences through comparison – constructing own grief within comparative context.

## Thematic analysis

*Umbrella themes illustrate the common experiences between both groups. The age/developmental stage theme illustrates how the processing of grief develops with brain development and how prominent this feels for the both groups, who are able to name and recognise the developments in their processing as their brains have developed. E.g.: younger group recognise their increasing abilities to consider how grief impacted the rest of their families (realisations happening around 13/14 y/o); both groups acknowledge an acceptance of the permanence of the loss. The older group acknowledge something beyond this, a consideration for how the loss will impact their future (weddings; loss of adult relationship).*

## Group 1 – School themes

Theme	Subthemes/codes	Linked umbrella(s)
-------	-----------------	--------------------

Return to school challenging	<p>Time off and ability to return to school</p> <ul style="list-style-type: none"> <li>- Varied experiences re time off or not</li> <li>- Return can be challenging if around transition (e.g. year 7 for one participant)</li> </ul> <p>Asked what they want</p> <ul style="list-style-type: none"> <li>- Varied</li> </ul>	Age
	<ul style="list-style-type: none"> <li>- Varied how much they felt able to engage with this at the time of loss</li> </ul>	
Don't want to be singled out/want to be normal	<p>Don't want to be different or singled out</p> <ul style="list-style-type: none"> <li>- Some participants didn't tell school as they didn't want to be singled out</li> <li>- Some participants didn't want special treatment</li> </ul> <p>Asking for help</p> <ul style="list-style-type: none"> <li>- This was hard for participants because it conflicted with their desire to be ok/normal</li> </ul> <p>School performance worsened</p>	The battle

School support is inconsistent	<p>Experiences of support varied between participants</p> <ul style="list-style-type: none"> <li>- Some found support consistent</li> <li>- Some found it inconsistent</li> <li>- Inconsistent between different staff members</li> <li>- Staff don't know what to say</li> <li>- Examples of staff saying 'wrong thing'</li> </ul> <p>Support worsened over time</p> <ul style="list-style-type: none"> <li>- Participants feel teachers don't understand longevity of grief</li> </ul> <p>Going to pastoral</p> <ul style="list-style-type: none"> <li>- Students felt like a burden</li> <li>- Felt teachers thought they were using it as an excuse to get out of lesson/for attention</li> </ul> <p>Contact</p> <ul style="list-style-type: none"> <li>- One key adult in school</li> <li>- Service implemented by Forget-me-nots</li> <li>- All had this; all celebrated this</li> </ul>	The battle
Things we wish were in place/schools knew	<p>More teacher training (mandator)</p> <ul style="list-style-type: none"> <li>- Understanding of longevity of grief</li> <li>- Need for longer term support/check ins</li> <li>- Someone to remember you on anniversary – to know how these can impact us</li> </ul> <ul style="list-style-type: none"> <li>- Impact on home life; understanding why I don't have right shoes on for example</li> <li>- Less pressure on attendance/learning</li> <li>- Respect</li> <li>- That you grow up fast</li> <li>- Should be in RPS curriculum: grief education</li> </ul>	The battle

School as a safe space	2 participants shared school was their safe space <ul style="list-style-type: none"> <li>- I didn't feel understood at home as I was the only child</li> <li>- I didn't feel there was anyone to look after me at home as I had to look after everyone else</li> <li>- School as respite from home but problems at school</li> <li>-</li> </ul>	Comparative suffering
Impact on school	<ul style="list-style-type: none"> <li>- Risk of exclusion</li> <li>- Risk to grades, performance dropping</li> <li>- Pressure on attendance, performance, unable to focus</li> </ul>	

## Group 1 – Social themes

Theme	Subthemes/codes	Linked umbrella(s) Gender; age; the
Don't want to be singled out/want to be normal	<p>To be popular you have to always be ok</p> <ul style="list-style-type: none"> <li>- Boys make fun of you for having emotions</li> <li>- Boys will use your grief to rile you up</li> <li>- Male pressure to be ok: perspective shared by girls; girls trying to normalise emotions for boys</li> </ul> <p>Wanting to show you're a normal person</p> <ul style="list-style-type: none"> <li>- By being ok</li> <li>- By asking people out/doing normal things</li> </ul> <p>Loneliness of the experience</p> <ul style="list-style-type: none"> <li>- Only one</li> </ul> <p>Forget-me-nots</p> <ul style="list-style-type: none"> <li>- Not the only one</li> <li>- Didn't like group at first (one)</li> </ul>	battle



Awkwardness	Awkward at first <ul style="list-style-type: none"> <li>- Didn't know who did/didn't know</li> <li>- Retelling story</li> <li>- Having to address it</li> <li>- People nicer at first</li> </ul> People are scared of your reaction so they avoid it <ul style="list-style-type: none"> <li>- Normalise</li> <li>- Grief education</li> </ul>	Age; the battle
Social support	A few friends they could talk to <ul style="list-style-type: none"> <li>- Awkward when other people uncomfortable</li> </ul> Become easier to talk to friends as time has passed <ul style="list-style-type: none"> <li>- People less scared to bring it up</li> <li>- Less raw</li> </ul> So sorry for your loss <ul style="list-style-type: none"> <li>- Don't know what we want them to say; no right thing</li> <li>- People shut down the conversation; prefer them to be interested</li> </ul> Forget-me-nots <ul style="list-style-type: none"> <li>- Others feel like me/have experienced same thing</li> <li>- Place where its easy to talk about</li> <li>- Special connection; know they relate</li> </ul>	The battle
Peers expectations	People expect you to react badly: <ul style="list-style-type: none"> <li>- Expect you to burst out crying</li> </ul> Coping through humour <ul style="list-style-type: none"> <li>- To manage the tone of interactions</li> <li>- To make it less awkward for others</li> <li>- To bond with siblings too</li> </ul> Desire for people to approach more casually	Age; the battle
Desire to protect others	From your difficult emotions	

## Group 1- Experience themes

Compl ex grief	Desire to protect parents reputation <ul style="list-style-type: none"> <li>- Conflict over who they were; the things they did</li> <li>- Not being able to reconcile with them due to loss</li> </ul> Angry at them but love them <ul style="list-style-type: none"> <li>- Described as a battle</li> </ul>	The battle
-------------------	--	------------

	<ul style="list-style-type: none"> <li>- Guilt; regret</li> <li>- Trying to protect other people's feelings</li> </ul> <p>Recurrent bereavements</p> <ul style="list-style-type: none"> <li>- Being retriggered</li> </ul>	
Formal support	<p>Long term support &gt; groups</p> <ul style="list-style-type: none"> <li>- YA programme most effective</li> <li>- Learnt most</li> <li>- Continuation of speaking about it</li> <li>- Too anxious and upset to participate in group</li> </ul> <p>Full circle</p> <ul style="list-style-type: none"> <li>- Opportunities to help other</li> <li>- Amazing opportunities like awards; public speaking; social mobility</li> </ul> <p>Community support</p> <ul style="list-style-type: none"> <li>- Short term; people made us meals etc for about 2 weeks then stopped</li> </ul>	
Grief made me who I am	<p>Changed me – growing up fast</p> <ul style="list-style-type: none"> <li>- Responsibilities increase e.g. caring</li> <li>- Made me a better person</li> </ul> <p>Influenced my life path</p> <ul style="list-style-type: none"> <li>- Made me want to work in bereavement</li> <li>- Made me want to make money</li> <li>- Made me want to be successful in their honour</li> </ul> <p>Post traumatic growth</p> <ul style="list-style-type: none"> <li>- Motivated to be a better person</li> <li>- Social mobility: desire for money due to our own poverty</li> <li>- Remind myself of how far I've come/can go</li> </ul>	
Grief changes over time	<p>Think about it less in the present</p> <p>Think about it differently</p> <ul style="list-style-type: none"> <li>- Less upset/crying, more able to think deeply</li> <li>- Realisations happen over time</li> <li>- Growing up with your grief</li> <li>- More able to througholough process</li> </ul> <p>Realising what you have lost</p> <ul style="list-style-type: none"> <li>- Relationship (adult)</li> </ul> <p>Triggered out of no where</p> <ul style="list-style-type: none"> <li>- Music; smells</li> </ul>	

<ul style="list-style-type: none"> <li>- Tiktok as a trigger – domino effect</li> </ul> <p>Dreams</p> <ul style="list-style-type: none"> <li>- More vivid as time passes</li> <li>- Dreaming everything normal/they are alive – gut wrenching when you wake up</li> </ul>
---

## Group 1 – Family themes

Theme	Subthemes/codes	Linked umbrella(s)
Impact of grief on rest of family	Financial aspect <ul style="list-style-type: none"> <li>- Stress on rest of relatives (mum)</li> <li>- Mental health of remaining parents</li> </ul> Pressure to parent younger siblings/parent <ul style="list-style-type: none"> <li>- No one to look after me</li> </ul> Parents struggling in front of their kids See impact on wider family (extended) more recently Grieving at different paces When remaining parent starts dating <ul style="list-style-type: none"> <li>- Set me back</li> <li>- Felt abandoned, I had been their support and suddenly I had no one and they had someone</li> <li>- Overtime come to understand importance of the remaining parents happiness</li> <li>-</li> </ul>	Age Battle
Being included/excluded from conversations	Only children feel isolated from adults grieving conversations <ul style="list-style-type: none"> <li>- I felt like I was different</li> </ul> Left out of conversations <ul style="list-style-type: none"> <li>- Didn't have a part in funeral; wish I did</li> <li>- Left out due to age</li> <li>- Parents want to protect children</li> <li>- Told after things were decided</li> <li>- Can damage relationships by keeping things</li> </ul>	Age Battle

Pressure to support relatives	Forget-me-nots helped me support the rest of family to talk	Battle
	Try not to cry in front of family; don't want to upset them	
Grieving rituals	<p>Funeral</p> <ul style="list-style-type: none"> <li>- Helpful</li> <li>- Stepping stones</li> <li>- Wish we had bigger parts/were asked more</li> </ul> <p>Importance of marking (or not) anniversaries/birthdays</p> <ul style="list-style-type: none"> <li>- Graves</li> <li>- Dinners</li> <li>- Acknowledging casually in conversation</li> <li>- Guilt when you forget</li> <li>- Proximity to own birthdays makes it challenging</li> </ul>	Battle

## Group 1 – THEMES PROPOSED (8 themes; 23 sub-themes)

THEME	SUBTHEMES	THEMES WHICH HAVE BEEN COMBINED
Experiences of support	<ol style="list-style-type: none"> <li>1. Support in school</li> <li>2. Social support</li> <li>3. Forget-me-nots</li> </ol>	<ol style="list-style-type: none"> <li>1. Support is inconsistent; things we wish schools knew; school as a safe space; return to school challenging</li> <li>2. Social support; desire to protect others</li> <li>3. Support; social support</li> </ol>
Desire to be normal	<ol style="list-style-type: none"> <li>1. At school</li> <li>2. Socially</li> <li>3. In family</li> </ol>	<ol style="list-style-type: none"> <li>1. Want to be normal at school</li> <li>2. Want to be normally socially</li> </ol>
Hopes for future support/changes	<ol style="list-style-type: none"> <li>1. Training for schools</li> <li>2. Understanding of the complexity and longevity of grief</li> <li>3. Grief education for all</li> </ol>	<ol style="list-style-type: none"> <li>1. Things we wish schools knew</li> </ol>

Social challenges	<ol style="list-style-type: none"> <li>1. Desire to protect others</li> <li>2. Unpredictability of others responses</li> <li>3. Return to school challenging</li> </ol>	<ol style="list-style-type: none"> <li>1. Socially awkward</li> <li>2. Peers expectations</li> <li>3. Desire to protect friends</li> </ol>
	<ol style="list-style-type: none"> <li>4. Humour to cope/set tone</li> </ol>	
Complexity of grief	<ol style="list-style-type: none"> <li>1. Grief changes over time</li> <li>2. Complex grief</li> <li>3. Grieving rituals</li> </ol>	<ol style="list-style-type: none"> <li>1. Grief changes over time</li> <li>2. Complex grief</li> </ol>
Post traumatic growth	<ol style="list-style-type: none"> <li>1. Grief made me who I am</li> <li>2. Grief motivates me to succeed</li> <li>3. Grief made me a better person</li> </ol>	<ol style="list-style-type: none"> <li>1. Grief made me who I am</li> </ol>
Impact on family	<ol style="list-style-type: none"> <li>1. Being included/excluded from conversation</li> <li>2. Impact on family members – seeing their grief</li> <li>3. Financial impact</li> <li>4. Pressure to support relatives</li> </ol>	<ol style="list-style-type: none"> <li>1. Impact of grief on family</li> <li>2. Being included/excluded in conversation</li> <li>3. Pressure to support family</li> </ol>
Impact on school	<ol style="list-style-type: none"> <li>1. Risk of exclusion</li> <li>2. Grades dropping</li> <li>3. Pressures of needing to be in lesson</li> </ol>	

## Group 2 – School themes

Theme	Subthemes/codes	Umbrella(s)
Varied experiences of returning to school	<p>Some participants had time off</p> <ul style="list-style-type: none"> <li>- Before bereavement</li> <li>- After bereavement</li> </ul> <p>Others returned immediately</p> <ul style="list-style-type: none"> <li>- Most favoured quick return</li> <li>- Benefits of being around others</li> <li>- But conflict of also wanting to be alone</li> <li>- ‘get back to normal’</li> </ul>	The battle

<p>School support</p>	<p>Teachers avoid it/are unhelpful</p> <ul style="list-style-type: none"> <li>- Lack of choice; didn't have opportunity to talk about it: wanted to be asked what I wanted</li> <li>- They are useless; what could they do if I was upset?</li> </ul> <p>Feeling ignored/dismissed in pastoral</p> <ul style="list-style-type: none"> <li>- Feel as if they think we are using it as an excuse</li> <li>- Time out cards</li> </ul>	
	<ul style="list-style-type: none"> <li>- Exp. Of teachers not following through on promises</li> <li>- Given colouring book already used and felt ignored</li> </ul> <p>The support I need changes day to day</p> <ul style="list-style-type: none"> <li>- Teacher assume its always same</li> <li>- What I need can change min to min but feels hard to ask to talk once you've turned down the offer</li> </ul> <p>Key adult</p> <ul style="list-style-type: none"> <li>- Impact when they leave (mat leave)</li> <li>- Unavailable (sickness; time limitations of school day)</li> </ul> <p>Prefer to talk to teachers than pastoral teachers</p> <p>Time off when parent was sick</p> <ul style="list-style-type: none"> <li>- Seats at front of school play</li> </ul>	

Impact of transition	<p>Teachers in secondary don't know about bereavement that happened in primary</p> <ul style="list-style-type: none"> <li>- Slip ups: what if I tell your mum?</li> <li>- Showing adverts that are triggering e.g. cancer; lessons on drugs/alcohol</li> <li>- Wasnt asked if wanted secondary teachers to be told</li> <li>- Onus on CYP to tell their teachers – awkward</li> <li>- More support in primary sch</li> <li>- Behaviour dropping/less engaged in learning]</li> </ul> <p>Friends also don't know</p> <ul style="list-style-type: none"> <li>- Different friends in primary to secondary (one participant)]</li> </ul> <p>Triggered before start of knew school year</p> <ul style="list-style-type: none"> <li>- What if new teachers don't know?</li> <li>- Staying up worrying</li> <li>- Effected sleep</li> </ul>	
Desire to be normal	<p>Don't want special treatment or pity</p> <ul style="list-style-type: none"> <li>- Want to be a normal kid</li> <li>- The ways this desire to be normal denies access to support (which would signify being different)</li> </ul>	
Impact on learning	<p>Inability to focus; only thinking about bereavement</p> <ul style="list-style-type: none"> <li>- Grades dropped overtime</li> <li>- Behaviour worsened</li> </ul> <p>Stressing about how school would manage it</p> <ul style="list-style-type: none"> <li>- Mothers day card making</li> <li>- Worrying they didn't know</li> <li>- Didn't want teacher shouting it out to whole class either</li> </ul>	
All children are different so ask us	<p>Desire to be asked what they want Ask remaining parent where too young to self-advocate</p>	

## Group 2 – Social themes

Theme	Subthemes/codes	Umbrella(s)
Being asked about it by peers	<p>I am asked about it all the time</p> <ul style="list-style-type: none"> <li>- Upsetting when don't know people and they ask</li> <li>- Don't be annoying or rude about it</li> <li>- I get asked every day</li> </ul> <p>NB participants contradicted themselves on this; within same focus group session said don't ask/it is ok to ask</p> <p>Friends awkward at first</p> <ul style="list-style-type: none"> <li>- Didn't know what to say</li> <li>- Some people still awkward; doesn't come up as often</li> </ul>	
Talk to closest friends	<p>Don't know if I want to talk about with peers really</p> <ul style="list-style-type: none"> <li>- Some exp.</li> <li>- Can upset me; helpful if I am already upset</li> </ul> <p>My friends helped me through the grieving process</p> <ul style="list-style-type: none"> <li>- Eventually started making jokes</li> </ul> <p>One participant never told friends; only closest friends</p> <ul style="list-style-type: none"> <li>- Worried people will blab about itl</li> </ul>	
Peers told to be nice to me	<p>Change in how peers treated me</p> <ul style="list-style-type: none"> <li>- Less roughhousing</li> <li>- Nicer to me – didn't like having pity</li> </ul>	



Experiencing bullying around it	<p>Girls</p> <ul style="list-style-type: none"> <li>- They say I make it my entire personality</li> <li>- People say I cry just to get out of class; makes me question if I am</li> </ul> <p>Boys</p> <ul style="list-style-type: none"> <li>- People using it to wind you up</li> <li>- Fighting – punched someone because they teased me about it</li> <li>- Blabbing: big worry</li> <li>- Threat of violence towards people who blab mouths</li> </ul> <p>Cheated on because I was too sad all the time</p> <ul style="list-style-type: none"> <li>-</li> </ul>	
Humour as a coping mechanism	<p>Makes you feel better to make a bit of a joke</p> <ul style="list-style-type: none"> <li>- Laugh through the pain</li> <li>- Looked up joking about your trauma</li> </ul> <p>Other people making unacceptable jokes</p> <ul style="list-style-type: none"> <li>- Other people don't know where the boundary is</li> <li>- Light jokes ok</li> <li>- Taking jokes too far</li> </ul> <p>Masking sadness with joking</p>	
Comparative suffering	<p>People sharing their bereavement e.g. well my sibling died</p> <ul style="list-style-type: none"> <li>- Interpreted as competition</li> </ul> <p>Forget me nots</p> <ul style="list-style-type: none"> <li>- Helpful that other people have been through same thing</li> <li>- Way easier to talk about it</li> </ul>	
Do not feel the need to protect other people's feelings	<p>They are not protecting my feelings; why would I protect theirs</p> <ul style="list-style-type: none"> <li>- Respect as mutual</li> <li>- If someone asks they have to deal with the answer</li> <li>- Its meant to feel awkward</li> <li>- Death isnt a fun, happy topic</li> </ul>	

## Group 2 – Experience themes

Theme	Subthemes/codes	Umbrella(s)
Didn't understand at the time	Didn't mind being asked at time due to lack of understanding but upsets me more now	Battle

	<ul style="list-style-type: none"> <li>- I understand the concept of death now</li> <li>- In shock at time; wasn't processing at all</li> <li>- Don't really remember being sad about it at first; more sad now</li> <li>- Didn't believe it had happened</li> </ul> <p>Its like a dream at the time; realise its true</p> <ul style="list-style-type: none"> <li>- Believe it more now (acceptance)</li> </ul>	
Being told/not told	<p>dad deliberately doesn't tell me it's the anniversary</p> <ul style="list-style-type: none"> <li>- annoyed me</li> </ul>	Battle
Changes in home	<p>Atmosphere in house</p> <ul style="list-style-type: none"> <li>- quiet</li> <li>- lots of people there</li> <li>- awkward</li> </ul> <p>Nothing changed for me as parents separated</p> <ul style="list-style-type: none"> <li>- the ways this impacted ability to grieve</li> </ul>	
Loss of innocence	<p>Life suddenly became real</p> <ul style="list-style-type: none"> <li>- lost its joy</li> </ul> <p>Realising you're not going to see them again is the hardest bit</p>	Age
If everything gets too much, my mind goes to my bereavement	<p>Everything leads back to him</p> <p>Everything reminds me</p> <p>Home = hard</p> <ul style="list-style-type: none"> <li>- School = hard; cant help relatives at home</li> </ul> <p>Distracted, worrying about mum</p>	Battle
I was so little, I didn't have a relationship with her	<p>Keeps me up at night</p> <ul style="list-style-type: none"> <li>- I didn't know anything about her</li> </ul> <p>Family tell me stories and I don't know them</p> <p>Feels like we are talking about a stranger sometimes</p>	Battle
Anniversary celebrations	<p>Go for meal</p> <p>Go to grave</p> <ul style="list-style-type: none"> <li>- Discussion on whether this is liked or not; mostly no; 'weird'; 'not there'; 'dead body'</li> </ul> <p>Let off balloons</p> <p>Celebrate by talking</p>	
Being told/not told	<p>Putting pieces together yourself</p>	Battle

	<ul style="list-style-type: none"> <li>- When family told me stories about my dad I put 2+2 together and realised he wanted to die</li> </ul> <p>You'll get it when you're older</p> <ul style="list-style-type: none"> <li>- Realised my gdad was sick and dying; didn't know at time</li> </ul> <p>Thought he/she was going to be fine Knew mum parent was going to hospital; didn't know why</p> <ul style="list-style-type: none"> <li>- 'I figured it out'</li> </ul> <p>Only 1 participant knew his relative was dying/was told</p> <ul style="list-style-type: none"> <li>- Believes this was the right thing</li> </ul> <p>Internal battle – one voice tells you theyre dying and you don't want to believe it; internal conflict</p> <p>Case by case whether you should tell children</p>	
Not being allowed to say goodbye	Sadness about this Recognising it was in protection of them Adults making decisions for you; powerlessness	Battle
Grief made me who I am	Made me more undersanding/accepting/empathetic	

## Group 2 – Family themes

Theme	Subthemes/codes	Umbrella(s)
Did not realise impact of rest of family at time	<p>Only cared about myself</p> <ul style="list-style-type: none"> <li>- being harsh on self about this; stupid little kid</li> </ul> <p>Only impacted me/sibling as parent was remarried</p> <ul style="list-style-type: none"> <li>- wasn't processing at home</li> </ul> <p>Brother didn't cry at funeral</p> <ul style="list-style-type: none"> <li>- Read as not being impacted</li> </ul> <p>My family live in a different country</p>	Age Battle

Can see impact on family now	Grandparents <ul style="list-style-type: none"> <li>- Realised they lost a daughter; realised they aren't impenetrable</li> <li>- My nan had a pillow case with dad's blood on; poor woman; not just me grieving even the dog</li> </ul>	Age Battle
	One parent had a realisation of the impact on their remaining parent during this session Change of perception of parents <ul style="list-style-type: none"> <li>- Seeing her break down; thought she was so strong</li> </ul>	
Being around extended family can be triggering	Uncle looks like dad; sharing memories; being told I remind them of my dad	Battle
Varying experiences of talking about it with family	Talk with mum only Only talk on important days My mum is too busy <ul style="list-style-type: none"> <li>- Awkward to talk about with step-dad</li> </ul>	

## Group 2 – THEMES PROPOSED

THEME	SUBTHEMES	THEMES WHICH HAVE BEEN COMBINED
Talking about grief	<ol style="list-style-type: none"> <li>1. With friends</li> <li>2. With remaining family</li> <li>3. Grieving rituals</li> <li>4. At school</li> <li>5. At forget-me-nots</li> </ol>	<ol style="list-style-type: none"> <li>1. Ask us, all different</li> <li>2. Being asked about it by peers</li> <li>3. Talking to closest friends</li> <li>4. Peers told to be nice to me</li> <li>5. Being around extended family is triggering</li> <li>6. Varying experience of talking about it w/family</li> </ol>

Impact on family	<ol style="list-style-type: none"> <li>1. Did not realise impact on family at time</li> <li>2. Increasingly realising as get older</li> <li>3. Changes in home: atmosphere, emotions etc</li> </ol>	<ol style="list-style-type: none"> <li>1. Can now see impact on fam</li> <li>2. Didn't realise impact on fam at time</li> <li>3. Changes at home</li> </ol>
Social challenges	<ol style="list-style-type: none"> <li>1. Being bullied</li> <li>2. People being awkward</li> <li>3. Being asked excessively</li> <li>4. Humour as coping mechanism</li> <li>5. People asked to be nice to me</li> <li>6. Do not feel the need to protect others feelings</li> <li>7. Comparative suffering</li> </ol>	<ol style="list-style-type: none"> <li>8. Being bullied</li> <li>9. People being awkward</li> <li>10. Being asked excessively</li> <li>11. Humour as coping mechanism</li> <li>12. Do not feel the need to protect others feelings</li> </ol>
Impact at school	<ol style="list-style-type: none"> <li>1. Varied experience of returning to school</li> <li>2. Impact of transition</li> <li>3. Inability to focus</li> <li>4. Being triggered in school</li> <li>5. Mind goes to bereavement when things get too much</li> </ol>	<ol style="list-style-type: none"> <li>6. Varied experience of returning to school</li> <li>7. Impact of transitions</li> <li>8. Inability to focus</li> <li>9. Impact on learning</li> <li>10. Mind goes to bereavement when things get too much</li> </ol>
Support	<ol style="list-style-type: none"> <li>1. At school</li> <li>2. Social support</li> <li>3. Not being asked what you want; desire for this</li> </ol>	<ol style="list-style-type: none"> <li>1. School support</li> <li>2. Ask us what we want</li> <li>3. Talk to friends</li> </ol>

Complexity of grief	<ol style="list-style-type: none"> <li>1. Didn't understand at time; has changed over time and now I understand more</li> <li>2. Being told/not told and figuring stuff out</li> <li>3. Loss of innocence</li> <li>4. Realising you didn't know the person</li> <li>5. Didn't get chance to say goodbye</li> <li>6. Grief made me a better person</li> </ol>	<ol style="list-style-type: none"> <li>1. Didn't understand at time</li> <li>2. Loss of innocence</li> <li>3. Being told/not told</li> <li>4. Realising you didn't know the person</li> </ol>
Desire to be normal	<ol style="list-style-type: none"> <li>1. Don't want special treatment or pity <ul style="list-style-type: none"> <li>- The ways this desire to be normal denies access to support (which would signify being different)</li> </ul> </li> </ol>	<ol style="list-style-type: none"> <li>1. Desire to be normal</li> </ol>
	<ol style="list-style-type: none"> <li>2. Don't want to be different, want to be the same</li> </ol>	

### Shared themes

Experiences of
support
Impact on
family
Complexity
of grief
Desire to be
normal
Social
challenges
Impact
at school

### Unique themes

Group	Does this exist in data for Why isn't a theme? other group?	
Talking about	Y	Captured in other
Group 1	Does this exist in the data for other group?	Why isn't it a theme?
Post traumatic growth	Y	Not as much as for older group, subtheme only?
Hopes for future support/changes	N	N

Appendix 3F: Stage two thematic analysis  
Themes as presented to group one

Theme	Subthemes
Experiences of support	<ol style="list-style-type: none"> <li>1. Support in school</li> <li>2. Social support</li> <li>3. Forget-me-nots</li> </ol>
Desire to be normal	<ol style="list-style-type: none"> <li>1. At school</li> <li>2. Socially</li> <li>3. In family</li> </ol>
Hopes for future support/changes	<ol style="list-style-type: none"> <li>1. Training for schools</li> <li>2. Understanding of the complexity and longevity of grief</li> <li>3. Grief education for all</li> </ol>
Social challenges	<ol style="list-style-type: none"> <li>1. Desire to protect others</li> <li>2. Unpredictability of others responses</li> <li>3. Return to school challenging</li> <li>4. Humour to cope/set tone</li> </ol>
Complexity of grief	<ol style="list-style-type: none"> <li>1. Grief changes over time</li> <li>2. Complex grief</li> <li>3. Grieving rituals</li> </ol>
Post traumatic growth	<ol style="list-style-type: none"> <li>1. Grief made me who I am</li> <li>2. My experience motivates me to succeed</li> <li>3. Grief made me a better person</li> </ol>
Impact on family	<ol style="list-style-type: none"> <li>1. Being included/excluded from conversation</li> <li>2. Impact on family members – seeing their grief</li> <li>3. Financial impact</li> <li>4. Pressure to support relatives</li> </ol>
Impact on school	<ol style="list-style-type: none"> <li>1. Risk of exclusion</li> <li>2. Grades dropping</li> <li>3. Pressures of needing to be in lesson</li> </ol>

Themes as presented to group two

Talking about grief	<ol style="list-style-type: none"> <li>1. With friends</li> <li>2. With remaining family</li> <li>3. Grieving rituals</li> <li>4. At school</li> <li>5. At Forget-me-nots</li> </ol>
Impact on family	<ol style="list-style-type: none"> <li>1. Did not realise impact on family at time</li> <li>2. Increasingly realising as get older</li> <li>3. Changes in home: atmosphere, emotions etc</li> </ol>



Social challenges	<ol style="list-style-type: none"> <li>1. Being bullied</li> <li>2. People being awkward</li> <li>3. Being asked excessively</li> <li>4. Humour as coping mechanism</li> <li>5. Comparative suffering</li> </ol>
Impact at school	<ol style="list-style-type: none"> <li>1. Varied experience of returning to school</li> <li>2. Impact of transition</li> <li>3. Inability to focus</li> <li>4. Being triggered in school</li> </ol>
Support	<ol style="list-style-type: none"> <li>1. At school</li> <li>2. Social support</li> <li>3. Not being asked what you want; desire for this</li> </ol>
Complexity of grief	<ol style="list-style-type: none"> <li>1. Didn't understand at time; has changed over time and now I understand more</li> <li>2. Being told/not told and figuring stuff out</li> <li>3. Loss of innocence</li> <li>4. Letting go or not</li> <li>5. Grief made me a better person</li> </ol>
Desire to be normal	<ol style="list-style-type: none"> <li>1. Don't want special treatment or pity</li> <li>2. The ways this desire to be normal denies access to support (which would signify being different)</li> </ol>

## Appendix 3G: Stage three thematic analysis

Table X: Table of Themes

+	
4.2.1 Experiences of support	4.2.1.1 Support at school at the time of bereavement X 4.2.1.2 Support at school in the longer-term X 4.2.1.3 <u>Desire to be included in support plans</u> X 4.2.1.4 Social Support X
4.2.2 Impact at school	4.2.2.1 Return to School X 4.2.2.2 <u>Impact of transitions</u> X 4.2.2.3 Being triggered in school X 4.2.2.4 Impact on academics X 4.2.2.5 <u>Risk of exclusion</u>
4.2.3 Desire to be normal	4.2.3.1 Desire to be normal X
4.2.4 Social challenges	4.2.4.1 Peers reactions X 4.2.4.2 Being picked on X 4.2.4.3 Humour as a coping mechanism X 4.2.4.4 <u>Comparative suffering</u> 4.2.4.5 <u>Desire to protect others</u>

42

4.2.5 Complexity of grief	4.2.5.1 Understanding has developed over <u>time</u> 4.2.5.2 <u>Being told/not told and 'figuring it out'</u> 4.2.5.3 Loss of innocence 4.2.5.4 <u>Letting go or not</u> 4.2.5.5 <u>Complex grief</u>
4.2.6 Impact on family	4.2.6.1 <u>Developing an understanding of impact on family members</u> 4.2.6.2 Impact on family members at the time 4.2.6.3 Financial impact 4.2.6.4 <u>Pressure to support relatives</u>
4.2.7 <u>Post-traumatic</u> growth	4.2.7.1 Grief made me who I <u>am</u> 4.2.7.2 My experience motivates me to <u>succeed</u> 4.2.7.3 Desire to work in bereavement
4.2.8 Hopes for future support	4.2.8.1 Training for schools 4.2.8.2 Increased understanding of the longevity of grief 4.2.8.3 <u>Grief education as part of the national curriculum</u>

## Appendix 3H: TREC form

**Tavistock and Portman Trust Research Ethics Committee (TREC)**  
**APPLICATION FOR ETHICAL REVIEW OF STUDENT RESEARCH PROJECTS**

This application should be submitted alongside copies of any supporting documentation which will be handed to participants, including a participant information sheet, consent form, self-completion survey or questionnaire.

Where a form is submitted and sections are incomplete, the form will not be considered by TREC and will be returned to the applicant for completion.

For further guidance please contact [Paul Jeran](mailto:Paul.Jeran@tavi-port.nhs.uk) ([academicquality@tavi-port.nhs.uk](mailto:academicquality@tavi-port.nhs.uk))

**FOR ALL APPLICANTS**

**If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters. You need only complete sections of the TREC form which are NOT covered in your existing approval**

Is your project considered as 'research' according to the HRA tool? ( <a href="http://www.hra-decisiontools.org.uk/research/index.html">http://www.hra-decisiontools.org.uk/research/index.html</a> )	Yes
Will your project involve participants who are under 18 or who are classed as vulnerable? (see section 7)	Yes
Will your project include data collection outside of the UK?	No

**SECTION A: PROJECT DETAILS**

<b>Project title</b>	Exploring bereaved children's experiences of loss and the ways they wish to be supported: an emancipatory <a href="#">study</a>		
<b>Proposed project start date</b>	January 2023	<b>Anticipated project end date</b>	July 2024
<b>Principle Investigator (normally your Research Supervisor):</b> Dr Richard Lewis			
Please note: TREC approval will only be given for the length of the project as stated above up to a maximum of 6 years. Projects exceeding these timeframes will need additional ethical approval			
<b>Has NHS or other approval been sought for this research including through submission via Research Application System (IRAS) or to the Health Research Authority (HRA)?</b>	YES (NRES approval) YES (HRA approval) Other NO		
<b>If you already have ethical approval from another body (including HRA/IRAS) please submit the application form and outcome letters.</b>			

**SECTION B: APPLICANT DETAILS**

<b>Name of Researcher</b>	Maya Abraham-Steele
<b>Programme of Study and Target Award</b>	M4 – Professional Doctorate in Child, Educational and Community Psychology
<b>Email address</b>	Mabraham-steele@tavi-port.nhs.uk
<b>Contact telephone number</b>	07707780166


**SECTION C: CONFLICTS OF INTEREST**

<p><b>Will any of the researchers or their institutions receive any other benefits or incentives for taking part in this research over and above their normal salary package or the costs of undertaking the research?</b></p> <p><b>YES NO</b> If <b>YES</b>, please detail below:</p>
<p><b>Is there any further possibility for conflict of interest? YES NO</b></p>
<p><b>Are you proposing to conduct this work in a location where you work or have a placement?</b></p> <p><b>YES NO</b> If <b>YES</b>, please detail below outline how you will avoid issues arising around colleagues being involved in this project:</p>

<p><b>Is your project being commissioned by and/or carried out on behalf of a body external to the Trust? (for example; commissioned by a local authority, school, care home, other NHS Trust or other organisation).</b></p> <p><small>*Please note that 'external' is defined as an organisation which is external to the Tavistock and Portman NHS Foundation Trust (Trust)</small></p>	<b>YES NO</b>
If <b>YES</b> , please add details here:	
<p><b>Will you be required to get further ethical approval after receiving TREC approval?</b></p> <p>If <b>YES</b>, please supply details of the ethical approval bodies below AND include any letters of approval from the ethical approval bodies (letters received after receiving TREC approval should be submitted to complete your record):</p>	<b>YES NO</b>

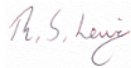
If your project is being undertaken with one or more clinical services or organisations external to the Trust, please provide details of these:	
For example – Children's Bereavement Support	
If you still need to agree these arrangements or if you can only approach organisations after you have ethical approval, please identify the types of organisations (e.g. schools or clinical services) you wish to approach:	
I have approached the organisations that are in support of the project (please see letters attached). Arrangements cannot be confirmed until after ethical approval.	
Do you have approval from the organisations detailed above? (this includes R&D approval where relevant)	<b>YES</b> NO NA
Please attach approval letters to this application. Any approval letters received after TREC approval has been granted MUST be submitted to be appended to your record	


**SECTION D: SIGNATURES AND DECLARATIONS**

<b>APPLICANT DECLARATION</b>	
I confirm that:	
<ul style="list-style-type: none"> <li>• The information contained in this application is, to the best of my knowledge, correct and up to date.</li> <li>• I have attempted to identify all risks related to the research.</li> <li>• I acknowledge my obligations and commitment to upholding ethical principles and to keep my supervisor updated with the progress of my <u>research</u>.</li> <li>• I am aware that for cases of proven misconduct, it may result in formal disciplinary proceedings and/or the cancellation of the proposed research.</li> <li>• I understand that if my project design, methodology or method of data collection changes I must seek an amendment to my ethical approvals as failure to do so, may result in a report of academic and/or research misconduct.</li> </ul>	
Applicant (print name)	Maya Abraham-Steele
Signed	
Date	02.12.22

**FOR RESEARCH DEGREE STUDENT APPLICANTS ONLY**

Name of Supervisor/Principal Investigator	Dr Richard Lewis
---	------------------

<b>Supervisor –</b> <ul style="list-style-type: none"> <li>• Does the student have the necessary skills to carry out the research?  <b>YES NO</b></li> <li>▪ Is the participant information sheet, consent form and any other documentation appropriate?  <b>YES NO</b></li> <li>▪ Are the procedures for recruitment of participants and obtaining informed consent suitable and sufficient?  <b>YES NO</b></li> <li>▪ Where required, does the researcher have current Disclosure and Barring Service (DBS) clearance?  <b>YES NO</b></li> </ul>	
<b>Signed</b>	
<b>Date</b>	26.01.23

<b>COURSE LEAD/RESEARCH LEAD</b> Does the proposed research as detailed herein have your support to proceed? YES NO	
<b>Signed</b>	
<b>Date</b>	27.01.2023

**SECTION E: DETAILS OF THE PROPOSED RESEARCH**

<p>1. Provide a brief description of the proposed research, including the requirements of participants. This must be in lay terms and free from technical or discipline specific terminology or jargon. If such terms are required, please ensure they are adequately explained (Do not exceed 500 words)</p>
---

The proposed research is an emancipatory study, which hopes to explore 11-21-year-old bereaved children's experiences of loss and grief and the factors they found supportive in the aftermath of their bereavement in the UK context. The young people will all have been bereaved of a parent, sibling or significant close relative. They will be accessed through a childhood bereavement charity, from which they have previously accessed a seven-week long bereavement support group, at least two years ago. There has been over two years since they attended the bereavement support group for their own bereavement and are now part of a longer-term group of 'young ambassadors' who receive on-going support from the charity and meet as a group on an on-going basis. The study will also be emancipatory, in that it will give voice to bereaved children. It is felt from research conducted previously that in attempts to protect them, adults have previously avoided talking to children about their grief, which has led to their voices becoming lost. It is hoped that by opening up the conversation with bereaved children, there will be an element of empowerment for this group.

The study will consist of focus group interviews of two focus groups of up to six young people, divided on the basis of age (group 1: 11-14; group 2: 15-21), with a hope to reduce the power-dynamics that can play out in mixed-age groups. The lead researcher will meet with the groups initially to build rapport and contract the project with them. There will be a participatory element of the study, in that the young people will be asked to suggest themes they would like to explore in the focus group interviews. The lead researcher will then use this data to inform the focus group interviews, with each focus group interview being centred on a theme suggested by the group (the types of bereavements it is anticipated may be on moments such as, return to school; funerals and grieving protocols). This approach will allow the young people to be prepared in advance for the topics that come up, with a hope to reduce potential harm through speaking about difficult topics.

There will be three focus group interviews for the younger group and four for the older group, each lasting approximately one hour, over a two-month period (proposed for Jun/July 2023). The lead researcher will analyse the data using thematic analysis, looking at how the bereavement group co-construct their experiences of grief, and the commonalities and differences between individual experiences within the group. The researcher will meet with the group again later in 2023, to present the research findings and have them sense checked by participants, to ensure the research is emancipatory with participatory elements.

**2. Provide a statement on the aims and significance of the proposed research, including potential impact to knowledge and understanding in the field (where appropriate, indicate the associated hypothesis which will be tested). This should be a clear justification of the proposed research, why it should proceed and a statement on any anticipated benefits to the community. (Do not exceed 700 words)**



While the exact prevalence of childhood bereavement in the UK is unknown, it is estimated that in 2015, approximately 41,000 children born in the UK lost a parent before the age of 18 (Childhood Bereavement Network, 2016) and other research suggests one in 29 children are bereaved of a parent or sibling before their 16th birthday (McLaughlin et al., 2019), amounting to one in every classroom (Abraham-Steele & Edmonds, 2021). Childhood bereavement is a socioeconomically biased issue, with those from lower-income backgrounds more likely to be bereaved (Fauth et al., 2009; Parsons, 2011; Paul & Vaswani, 2021), and less likely to receive high quality support (Abraham-Steele & Edmonds, 2021).

Despite the prevalence of childhood bereavement, there is limited research on childhood bereavement in the UK, with under-100 pieces being conducted between 2002 and 2019 (McLaughlin et al., 2019). While a growing body of research in Scandinavia exists, applying foreign studies to a British context is limiting due to cultural differences. In Britain, death and dying are viewed as taboo subjects (Walter, 1991), meaning they are often not spoken about. Equally, cultural beliefs about the appropriacy of exposing children to death mean that children are at times excluded from mourning rituals and are not always provided with information about family members' critical illness (McLaughlin et al., 2019). This sociocultural reluctance to talk to children, and particularly bereaved children, about death is perhaps due to the group's status as vulnerable. However, this can render the vulnerable group 'forgotten'.

Previous research by the primary researcher has explored teacher's perspectives on providing bereavement support; however, an important gap in the literature has been identified, namely bereaved children's perspectives on their loss and the support they receive (Abraham-Steele & Edmonds, 2021). The research here aims to explore, using an emancipatory approach, bereaved children's experiences of bereavement - specifically their views and experiences of close relative death - and their perspectives on what would be effective bereavement support. The research aims to gain a better understanding of bereaved children's perspectives, in a UK specific context, giving consideration to the cultural context and attitudes towards death. It hopes to give voice to the ideas and opinions expressed by the children about what is supportive to them in the aftermath of bereavement, particularly within a school context. This will build a better understanding of bereaved children's needs and views, which has the potential to inform bereavement support practice in the UK - both in and out of the school context.

The research has potential benefits to the community on multiple levels, including: developing an understanding of what bereaved children experience and find helpful, from their own perspectives. Developing an understanding of how bereavement groups co-construct their ideas about loss and support. Exploring these can set the foundations to understanding best practice and developing bereavement support further in the UK, with the potential to develop the practice of specific bereavement groups (and provide advice to the wider bereavement support community) based on the findings. The research can also benefit the wider community, with the potential to inform wider death education for those who are not yet bereaved. Moreover, professionals, such as teachers, EPs and grief counselors can benefit from the research to better understand the children they are working with and the support they require. The proposed research, which aims to gather children's experiences of loss and their views on what would help them, will be relevant to EPs, who may support bereaved children on an individual or systemic level by supporting their teachers/staff with critical incident support or training.

The research is aiming to consider the following questions (subject to adjustment if the participants focus does not cover all of the elements described):

1. What are 11-21 year-old bereaved children's experiences of loss of a close relative?
2. What do 11-21 year old bereaved children perceive to be supportive following their loss of a close relative?
3. How do 11-21 children experience their return to school and the support received following bereavement of a close relative?

**3. Provide an outline of the methodology for the proposed research, including proposed method of data collection, tasks assigned to participants of the research and the proposed method and duration of data analysis. If the proposed research makes use of pre-established and generally accepted techniques, please make this clear. (Do not exceed 500 words)**



#### Data Collection

The main data collection will be from the Focus Group Interviews, which will be transcribed using either an app which is compliant with GDPR, or a transcription service experienced in psychological research [transcription](#); for efficiency of time. The steps to get this data need to be followed sequentially in the following way:

#### Orientation

The current proposed research is underpinned by social constructionist epistemology and ontology, with an aim to understand how a bereavement group have co-constructed their understanding of bereavement, through the mutual sharing of individual experiences. The project will be a qualitative design. In the first instance, the researcher will meet with the focus groups to introduce herself and the project, including her position as an adult bereaved as a child and the aims of the project. How this is shared is to be carefully thought about to avoid a modeling risk; [so](#) sharing that her Dad died when she was 10 years old and that her experience was in a different education system that was middle school so spans year 5 to 8 (to enable separation from their experience as well as connection). [Additionally](#) that she wasn't in a formal bereavement group, but created a group with her best friends who were also bereaved children, aids the understanding of the interest in their situation. Therefore, the aim here is to share the researcher's personal journey as someone who has an interest in this from their personal experience and now want to find out what [others](#) experiences have been when they have had support of a group like Forget-me-nots.

#### Participatory Element

The children will not be asked to share any personal experiences in the first meeting; rather, it will be a rapport-building and contracting session for the future work. Together, the group will create a mind-map of themes that they would like to discuss from the perspective of what they think researchers / others will find useful to know. The group will [talk](#) and notes will be transcribed with different [colours](#) pens to represent each of their voices. [So](#) each are asked to say their name and pick a [colour](#) and their thoughts / words and ideas for themes will be noted. The researcher will attempt to merge and group these into three over-arching/umbrella themes. These are created as the prompts for the following three focus group meetings. The aim will be to ensure all participants have contributed to the creation of each theme area to be talked about across the three sessions. If a theme is offered, it will be considered/included, to ensure that all of children's voices are heard and to avoid making any children feel their voice or ideas will not be valued. [The older group have generated four distinct themes and as such, four focus groups will be run for that group.](#)

#### Focus Group Interviews

The researcher will meet with each group a further three [to four](#) times, with each session focusing on a different theme. It is thought, as an example from previous research, that 'returning to school' might be a theme and so this has been mock worked up as an example of the types of questions used in the focus group (see appendix A). By pre-agreeing themes with the children in advance, it is hoped that this will provide some containment and certainty, allowing them to prepare in advance for what we will discuss and reducing the chances of something unexpected (and painful) arising. The researcher will end each session by reminding the children of the theme of the next session.

There are communication aids that the researcher is familiar with such as a drawing activity, dilemma sheets and games that have been used with bereaved children in other [studies](#); which are hoped to not be needed, but are available if the young people struggle to communicate as a part of the focus group (see appendix A for details of the approach).

#### Data Analysis

Qualitative data from the Focus Group Interviews will be [analysed](#), using reflexive Thematic Analysis (TA) (Braun & Clarke, 2019), developed from TA suggested by Braun and Clarke (2006). Common themes will be identified across participants, through coding. These themes will be reviewed, [defined](#) and named following the phases of TA outlined by Braun and Clarke in 2006. An inductive approach will be [utilised](#) to ensure the themes are strongly led by the data, as opposed to having pre-existing codes and themes (Braun & Clarke, 2006). Supervision regarding the analysis will be sought to reflect on the [researchers](#) assumptions to inform better practice, particularly given that the researcher was herself a bereaved child and aware of the risks of her biasing the data with her own experiences (Braun & Clarke, 2019). Themes will then be compared between the two focus groups and cross-checked, to decipher whether these are group-specific themes or whether the data is consistent between the two groups.

#### Participant checking of findings

The findings (analysis) will be discussed with the participants to ensure that they agree to how their answers have been interpreted. This will provide a containing ending for the participants.

**SECTION F: PARTICIPANT DETAILS**

**4. Provide an explanation detailing how you will identify, approach and recruit the participants for the proposed research, including clarification on sample size and location. Please provide justification for the exclusion/inclusion criteria for this study (i.e. who will be allowed to / not allowed to participate) and explain briefly, in lay terms, why these criteria are in place. (Do not exceed 500 words)**

The participants will be recruited through a bereavement support charity, where they have attended a bereavement support group and are now part of a group of young ambassadors for the charity. Contact has already been made with the charity and a letter of support is attached. After ethical approval is granted, a meeting will be arranged between the lead researcher and the group of young ambassadors to introduce the project and begin recruitment. The group consists of 12, 11-21-year-old members who have all been bereaved of a close relative, parent, sibling, uncle or grandparent. Some participants have had multiple bereavements. Specific (e.g. only for parentally bereaved), long-term bereavement groups are rare in the UK and thus it is most representative of the type of support available.

**Age**

All of the participants will be aged between 11-21, this inclusion criteria has been chosen due to evidence suggesting that a mature understanding of death develops by the age of 10, and there being decreased risk talking to children who understand the permanency of death, than younger children, who have a less developed understanding. All of the proposed participants were bereaved when they were under the age of 18 (children).

**Time in group/since loss**

All of the participants have attended a 7-week bereavement support programme through the charity prior to joining the young ambassador group. All of the participants have been part of the young ambassadors group for at least 2 years, with 11/12 attending for at least 3 years. As such, it has been at least 2-years since the children were bereaved. All of these factors increase the chances of the participants having already processed their grief/loss and reduce the risk of psychological harm being caused by the study. It also means they have pre-existing, supportive relationships with their peers/co-participants and the staff at the charity, which also decreases risk.

**Two Groups**

In an ideal situation, all 12 members will wish to participate. In this case, the 12 will be split into two groups based on age (group 1: 11-14; group 2: 15-21), with a hope to reduce the power-dynamics that can play out in mixed-age groups.

**Minimum participants**

The minimum amount of participants the study could be conducted with is three. If less than three participants consented, we would seek an alternative bereavement group to carry out the study with.

**5. Please state the location(s) of the proposed research including the location of any interviews. Please provide a Risk Assessment if required. Consideration should be given to lone working, visiting private residences, conducting research outside working hours or any other non-standard arrangements.**

**If any data collection is to be done online, please identify the platforms to be used.**

The data collection will take place at the charity's head office, where the young people typically access their bereavement support. It will be conducted in a medium size room that are familiar with and there will be a member of the charity present at all times.

There will be no lone working or visiting of private residences and research will be conducted within working hours.

**6. Will the participants be from any of the following groups? (Tick as appropriate)**

- Students or Staff of the Trust or Partner delivering your ~~programme~~.
- Adults (over the age of 18 years with mental capacity to give consent to participate in the research).
- Children or legal minors (anyone under the age of 16 years)<sup>1</sup>
- Adults who are unconscious, severely ill or have a terminal illness.
- Adults who may lose mental capacity to consent during the course of the research.
- Adults in emergency situations.
- Adults<sup>2</sup> with mental illness - particularly those detained under the Mental Health Act (1983 & 2007).
- Participants who may lack capacity to consent to participate in the research under the requirements of the Mental Capacity Act (2005).
- Prisoners, where ethical approval may be required from the National Offender Management Service (NOMS).
- Young Offenders, where ethical approval may be required from the National Offender Management Service (NOMS).
- Healthy volunteers (in high-risk intervention studies).
- Participants who may be considered to have a pre-existing and potentially dependent<sup>3</sup> relationship with the investigator (e.g. those in care homes, students, colleagues, service-users, patients).
- Other vulnerable groups (see Question 6).
- Adults who are in custody, custodial care, or for whom a court has assumed responsibility.
- Participants who are members of the Armed Forces.

<sup>1</sup>If the proposed research involves children or adults who meet the Police Act (1997) definition of vulnerability<sup>a</sup>, any researchers who will have contact with participants must have current Disclosure and Barring Service (DBS) clearance.

<sup>2</sup> 'Adults with a learning or physical disability, a physical or mental illness, or a reduction in physical or mental capacity, and living in a care home or home for people with learning difficulties or receiving care in their own home or receiving hospital or social care services.' (Police Act, 1997)

<sup>3</sup> Proposed research involving participants with whom the investigator or researcher(s) shares a dependent or unequal relationships (e.g. teacher/student, clinical therapist/service-user) may compromise the ability to give informed consent which is free from any form of pressure (real or implied) arising from this relationship. TREC recommends that, wherever practicable, investigators choose participants with whom they have no dependent relationship. Following due scrutiny, if the investigator is confident that the research involving participants in dependent relationships is vital and defensible, TREC will require additional information setting out the case and detailing how risks inherent in the dependent relationship will be managed. TREC will also need to be reassured that refusal to participate will not result in any discrimination or penalty.

**7. Will the study involve participants who are vulnerable? YES NO**

For the purposes of research, 'vulnerable' participants may be adults whose ability to protect their own interests are impaired or reduced in comparison to that of the broader population. Vulnerability may arise from:

- the participant's personal characteristics (e.g. mental or physical impairment)
- their social environment, context and/or disadvantage (e.g. socio-economic mobility, educational attainment, resources, substance dependence, displacement or homelessness).
- where prospective participants are at high risk of consenting under duress, or as a result of manipulation or coercion, they must also be considered as vulnerable.
- children are automatically presumed to be vulnerable.

#### 7.1. If YES, what special arrangements are in place to protect vulnerable participants' interests?

Both the BPS Code of Ethics and Conduct (2018) and the BPS Code of Human Research Ethics (2021) will be adhered to in this study and the research will be undertaken with the "aim of avoiding potential risks to psychological well-being, mental health, personal values, or dignity" (BPS, 2018, p19). That said, there are ethical challenges involved when interviewing children who may be less resilient than adults when discussing a sensitive topic (e.g. Clark, 2010; Prince-Embury & Saklofske, 2012).

##### Power dynamics

One significant issue is the discrepancy in power between the child and the adult researcher with lived experience of childhood bereavement (Clark, 2010). The study needs to ensure that interviews do not become unnecessarily distressing, although it is likely participants will experience some distress when having to discuss painful memories. It is important that the study creates a setting where participants giving such accounts can feel safe and supported. Conducting the interviews in a group rather than individually has been decided as a means to reduce the risk of distress and pressure to speak to a topic area; helping also to increase feelings of safety alongside peers who are sharing and are a support network. Peers can be a significant protective factor for children following bereavement (Dunn & Cain, 2012). It allows children to avoid questions they do not feel able to answer, and allow other members of the group who are more comfortable to speak for them. The pre-existing bereavement group will allow for some level of protection, as the participants will be supported by peers they have pre-existing relationships with. However, it will be important to consider the group dynamics and power dynamics in these groups. It will be important for the lead researcher to ensure older voices do not over-dominate the space, and that everyone has a chance to be heard. The group (of 12) will be split into two groups based on their age (group 1: 11-14, group 2: 15-21), in an attempt to mitigate some of this.

##### Further support

To manage the risk that participants had distressing thoughts triggered by being a part of the focus group; further support, such as counselling or a follow-up session, after the focus groups will be made available through the charity. The decision to recruit participants from the young ambassadors group allows the researcher to take advantage of their existing support network, of bereavement professionals. The bereavement counsellor will be present during the focus group interviews. Recruiting from bereavement groups further ensures participants have previous experiences with talking about their loss, and reduce the risk of distress compared to participants who may be talking about their loss for the first time.

##### Timings to reduce harm

The timing of the focus group interviews will also be significant in reducing harm. It is assumed groups will meet at least monthly for their own support, and it will be preferable to time the focus group interviews within the week before their counselling session, so any issues that arise from the project can be supported in group. The clinical lead of Forget-me-nots has confirmed that additional sessions will be arranged for the group, to ensure they are fully supported throughout the project. Beginnings and endings will be a significant part of rendering the data-collection process safe and containing for the participants. In the final session, the researcher will present the key themes from her analysis to the group for proof checking, to continue their participation in the project and ensure that they feel represented by the data.

##### Interviewing

Punch (2002) presents a range of issues that can arise specifically when interviewing children and warns that researchers risk invalidating their projects if they do not carefully consider how this changes the research process. She highlights that it is important that the interviewer has adequate training in interviewing children. The lead researcher has previous experience conducting 1-to-1 interviews with adults in a research context. As a Trainee Educational Psychologist, she has experience of working with and talking to children/young people, about their emotions, experiences and difficult topics: such as gathering pupil views as part of the assessment process. She has also sought advice and guidance from Dr Martin Little, who has conducted extensive studies with bereaved children, about how to most ethically conduct focus group interviews with this vulnerable group. He advised that from his own studies, he has learnt not to ask children to share their experiences too early and to spend time building rapport first. He also recommended the researcher share that she was bereaved as a child with the group, to model talking about loss and build trust. As such, the researcher plans to meet the group at least twice (to introduce the project and for a rapport building/participatory planning session) before commencing any focus group interviews, in order to provide maximum containment and an environment where the young people feel most able to share.

##### Safe guarding

Plans need to be in place in case of safeguarding concerns are being reported. Grief groups have established procedure if such disclosures arise; the grief counsellor will also be present during the focus groups and thus be able to support with this. It is important to consider how to avoid potential forms of harm. Some distress during interviews

might be unavoidable, but these emotions must be met respectfully, as must the participants desire to share their experiences. Participants need to be met with an approach that is appropriate to their age.

**Consent**

The study needs to ensure methods used are specifically designed to be applicable with children. Disparity in power needs to be considered. To counter this disparity in power this study ~~utilises~~ <sup>utilises</sup> a co-participatory element. Power discrepancies are here reduced through the creation of a respectful relationship between the researcher and participants and supporting the participants to have a voice in the study. Parent involvement can complicate participant autonomy. Parents will be asked whether they will allow their child to decide if he/she/they ~~wants~~ <sup>wants</sup> to participate. Participants are hereafter allowed to make the decision of participation themselves but dual consent is essential for participants under the age of 16. See Appendix B for consent/assent forms.

Consent will also be attained from the young people to share demographic details, including: gender identity, age, age at time of bereavement, which relative has died, time since bereavement and time as a young ambassador. The young people will be given a 'prefer not to say' option.



<p><b>If YES</b>, a Disclosure and Barring Service (DBS) check <b>within the last three years</b> is required. Please provide details of the "clear disclosure":</p> <p>Date of disclosure: 23.07.2021</p> <p>Type of disclosure: Child and Adult Workforce</p> <p>Organisation that requested disclosure: Javistock and Portman NHS Foundation Trust</p> <p>DBS certificate number: 001743904600</p> <p><i>(NOTE: information concerning activities which require DBS checks can be found via <a href="https://www.gov.uk/government/publications/dbs-check-eligible-positions-guidance">https://www.gov.uk/government/publications/dbs-check-eligible-positions-guidance</a>). Please <b>do not</b> include a copy of your DBS certificate with your application</i></p>
<p><b>8. Do you propose to make any form of payment or incentive available to participants of the research? YES NO</b></p> <p>If <b>YES</b>, please provide details taking into account that any payment or incentive should be representative of reasonable remuneration for participation and may not be of a value that could be coercive or exerting undue influence on potential participants' decision to take part in the research. Wherever possible, remuneration in a monetary form should be avoided and substituted with vouchers, coupons or equivalent. Any payment made to research participants may have benefit or HMRC implications and participants should be alerted to this in the participant information sheet as they may wish to choose to decline payment.</p>
<p><b>9. What special arrangements are in place for eliciting informed consent from participants who may not adequately understand verbal explanations or written information provided in English; where participants have special communication needs; where participants have limited literacy; or where children are involved in the research? (Do not exceed 200 words)</b></p> <p>The lead researcher will meet the group of young ambassadors and their parents to present and propose the project to them. This will be done verbally, with some visual aids. It will be pitched at a level they can understand. The children will be given a participant information sheet to take away and consent forms to sign. Informed consent will be sought from both the parent and child where the child is under 16.</p>

**SECTION F: RISK ASSESSMENT AND RISK MANAGEMENT**

**10. Does the proposed research involve any of the following? (Tick as appropriate)**

use of a questionnaire, self-completion survey or data-collection instrument (attach copy)  
 use of emails or the internet as a means of data collection  
 use of written or ~~computerised~~ tests  
 interviews (attach interview questions)  
~~diaries~~ (attach diary record form)  
 participant observation  
 participant observation (in a non-public place) without their knowledge / covert research  
 audio-recording interviewees or events  
 video-recording interviewees or events  
 access to personal and/or sensitive data (i.e. student, patient, client or service-user data) without the participant's informed consent for use of these data for research purposes  
 administration of any questions, tasks, investigations, procedures or stimuli which may be experienced by participants as physically or mentally painful, stressful or unpleasant during or after the research process  
 performance of any acts which might diminish the self-esteem of participants or cause them to experience discomfort, regret or any other adverse emotional or psychological reaction  
 Themes around extremism or ~~radicalisation~~  
 investigation of participants involved in illegal or illicit activities (e.g. use of illegal drugs)  
 procedures that involve the deception of participants  
 administration of any substance or agent  
 use of non-treatment of placebo control conditions  
 participation in a clinical trial  
 research undertaken at an off-campus location (risk assessment attached)  
 research overseas (please ensure Section G is complete)

**11. Does the proposed research involve any specific or anticipated risks (e.g. physical, psychological, social, legal or economic) to participants that are greater than those encountered in everyday life?**

YES NO

If YES, please describe below including details of precautionary measures.

Speaking to bereaved children about their experiences of loss poses a psychological risk of harm greater than those encountered in everyday life. There is potential that the conversations in the focus groups could be upsetting to participants, or that something that is said (by the researcher or another participant) may reframe someone's loss/make them process something in a different way. I sought advice on this from Dr Martin Lyle, a highly experienced childhood bereavement researcher who has conducted many studies with bereaved children in Denmark/Norway.

Dr Lyle provided information on precautionary measures that he has put in place over the years following experience of conducting research in this area. Therefore the following measures are in place in order to reduce the risk of harm:

1. Introductory sessions; so that the researcher can develop rapport and allow children to feel emotionally safe to share information at a later date. The introductory session as well as the first theme generation session reduces risk as there is no seeking of information from them about their loss in the first few meetings.
2. Building relationships is a significant protective factor to reduce harm and so this is aimed to be achieved with the researcher as well as utilising the current relationships in their support group and with the staff member.
3. Contracting prior to focus group, so as to make sure the participants know where to go for help. This is why the design has an initial meeting to introduce the project prior to gaining consent so containment is considered in in the contracting of the roles.
4. Conducting research in a group rather than individual interviews provides a protective factor, where participants are not put on the spot/can avoid answering questions they do not feel comfortable answering, thus reducing the risk of harm. Thus, focus group interviews have been selected as the method.
5. The presence of professional support; hence the bereavement counsellor who usually works with the group will be present in the focus group. This provides protection as they know the children and can look out for signs of distress/changes in the child that they are familiar with. This also helps with containment.
6. To arrange for additional psychological support to be available to the participants if necessary. Thus, the charity have agreed to provide additional psychological support to these young people if/when necessary following the research and have the capacities to do so.
7. A feedback session; become a final session where findings are presented to young people will offer an opportunity for reflection for the young people and endeavour to provide a containing ending.

In addition there will be additional sign posting and Section 7.1 contains other elements intended to reduce potential harm, such as; the selection of this group of young people linked to the charity as they are experienced in talking about grief as a part of their young ambassadors roles, there has been careful consideration of the timings of the focus group to coincide with support as well as the group formation to manage potential power dynamics as well as researcher positioning.

**12. Where the procedures involve potential hazards and/or discomfort or distress for participants, please state what previous experience the investigator or researcher(s) have had in conducting this type of research.**

The researcher has conducted a study on teacher's experiences of supporting bereaved children; although this research was with adults, it was on the topic of bereavement/death and as such the researcher has experience in interviewing on a sensitive topic, which may well impact participants personally.

As a Trainee Educational Psychologist, she has experience of working with and talking to children/young people, about their emotions, experiences and difficult topics: such as gathering pupil views as part of the assessment process. The researcher is also experienced in talking to/on bereavement, and has delivered training to teaching assistants/teachers on bereavement.

The researcher has also undertaken a clinical placement in CAMHs as part of her training as an Educational Psychologist and as such is experienced in supporting SEMH, and would be mindfully watching the group for signs of distress alongside the colleagues from Forget-me-nots.



<p><b>13. Provide an explanation of any potential benefits to participants. Please ensure this is framed within the overall contribution of the proposed research to knowledge or practice. (Do not exceed 400 words)</b>  <b>NOTE:</b> Where the proposed research involves students, they should be assured that accepting the offer to participate or choosing to decline will have no impact on their assessments or learning experience. Similarly, it should be made clear to participants who are patients, service-users and/or receiving any form of treatment or medication that they are not invited to participate in the belief that participation in the research will result in some relief or improvement in their condition.</p>
<p>It is felt that the research could be beneficial to the participants in an emancipatory sense, by giving them a voice to speak about their lived realities. It is felt that voices of bereaved children are missing in the UK <a href="#">literature</a>, and the study will give the participants an opportunity to have their voices heard and amplified. The participants are passionate about childhood bereavement and act as ambassadors for the charity, with the aim of raising the profile of bereaved children. Many of them have spoken at fundraising events about their experiences. The charity hopes that the <del>programme</del> will help the ambassadors build life skills, and participating in the project would provide the children with an opportunity to be part of an empirical study and to learn about research to.</p>
<p><b>14. Provide an outline of any measures you have in place in the event of adverse or unexpected outcomes and the potential impact this may have on participants involved in the proposed research. (Do not exceed 300 words)</b></p>
<p>The bereavement counsellor who usually works with the group will be present in the focus groups at all times, which provides protection in that, they know the children and can look out for signs of distress/changes in the child. They would be able to remove the child from the group if distress arose. I would be mindfully watching the group for signs of distress alongside my colleague.</p> <p>The charity <del>have</del> offered to provide additional psychological support to these young people if/when necessary following the research and have the capacities to do so. There will be agreed group sessions interweaved between the focus groups, so the young people have the chance to reflect together. Individual support can be offered by the charity in the event of an adverse/unexpected impact on an individual.</p>
<p><b>15. Provide an outline of your debriefing, support and feedback protocol for participants involved in the proposed research. This should include, for example, where participants may feel the need to discuss thoughts or feelings brought about following their participation in the research. This may involve referral to an external support or counseling service, where participation in the research has caused specific issues for participants.</b></p>
<p>The final focus group will involve a debrief and a debriefing information sheet will be provided to participants, thanking them for their participation, sign posting them to within charity support protocols and inviting them to the feedback session in the autumn term. The charity will provide space for the ambassadors to discuss thoughts or feelings brought about following their participation in the research, if they feel it is necessary, between the final focus group and the feedback session.</p> <p>In the feedback session, the researcher will present the findings to the group, give them an opportunity to reflect on the findings and offer them an opportunity to reflect on their experiences.</p> <p>It is felt that referral to an external support or counseling service, where participation in the research has caused specific issues for participants would be unlikely to be necessary, as there are support services available within the charity. However, support would be offered to do so if the charity did not feel it could meet needs and there will be information provided for where else participants can seek support if they feel unable to approach the charity.</p>
<p><b>16. Please provide the names and nature of any external support or counselling <del>organisations</del> that will be suggested to participants if participation in the research has potential to raise specific issues for participants.</b></p>

<p>Forget-me-nots - childhood bereavement support – location  <b>Cruse Bereavement support helpline and online chat</b>  <b>NHS local mental health services</b>  <b>Winston's wish</b>  <b>Childline</b></p>
<p><b>17. Where medical aftercare may be necessary, this should include details of the treatment available to participants. Debriefing may involve the disclosure of further information on the aims of the research, the participant's performance and/or the results of the research. (Do not exceed 500 words)</b></p>
<p>N/A</p>

**FOR RESEARCH UNDERTAKEN OUTSIDE THE UK**

<p><b>18. Does the proposed research involve travel outside of the UK?</b> <span style="float: right;"><u>YES_NO</u></span></p> <p><b>If YES, please confirm:</b></p> <p>I have consulted the Foreign and Commonwealth Office website for guidance/travel advice?  <a href="http://www.fco.gov.uk/en/travel-and-living-abroad/">http://www.fco.gov.uk/en/travel-and-living-abroad/</a></p> <p>I have completed a RISK Assessment covering all aspects of the project including consideration of the location of the data collection and risks to participants.</p> <p>All overseas project data collection will need approval from the Deputy Director of Education and Training or their nominee. Normally this will be done based on the information provided in this form. All projects approved through the TREC process will be indemnified by the Trust against claims made by third parties.</p> <p>If you have any queries regarding research outside the UK, please contact <a href="mailto:academicquality@tavi-port.nhs.uk">academicquality@tavi-port.nhs.uk</a>:</p>
<p>Students are required to arrange their own travel and medical insurance to cover project work outside of the UK. Please indicate what insurance cover you have or will have in place.</p>
<p><b>19. Please evidence how compliance with all local research ethics and research governance requirements have been assessed for the country(ies) in which the research is taking place. Please also clarify how the requirements will be met:</b></p>
<p> </p>

**SECTION G: PARTICIPANT CONSENT AND WITHDRAWAL**

<p>20. Have you attached a copy of your participant information sheet (this should be in <i>plain English</i>)? Where the research involves non-English speaking participants, please include translated materials.</p> <p>YES NO</p> <p>If NO, please indicate what alternative arrangements are in place below:</p>
<p>21. Have you attached a copy of your participant consent form (this should be in <i>plain English</i>)? Where the research involves non-English speaking participants, please include translated materials.</p> <p>YES NO</p> <p>If NO, please indicate what alternative arrangements are in place below:</p>
<p>22. The following is a <b>participant information sheet</b> checklist covering the various points that should be included in this document.</p> <p>Clear identification of the Trust as the sponsor for the research, the project title, the Researcher and Principal Investigator (your Research Supervisor) and other researchers along with relevant contact details.  Details of what involvement in the proposed research will require (e.g., participation in interviews, completion of questionnaire, audio/<a href="#">video-recording</a> of events), estimated time commitment and any risks involved.  A statement confirming that the research has received formal approval from TREC or other ethics body.  If the sample size is small, advice to participants that this may have implications for confidentiality / anonymity.  A clear statement that where participants are in a dependent relationship with any of the researchers that participation in the research will have no impact on assessment / treatment / service-use or support.  Assurance that involvement in the project is voluntary and that participants are free to withdraw consent at any time, and to withdraw any unprocessed data previously supplied.  Advice as to arrangements to be made to protect confidentiality of data, including that confidentiality of information provided is subject to legal limitations.  A statement that the data generated in the course of the research will be retained in accordance with the <a href="#">Trusts's Data Protection and handling Policies</a>: <a href="https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/">https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/</a>  Advice that if participants have any concerns about the conduct of the investigator, researcher(s) or any other aspect of this research project, they should contact Simon Carrington, Head of Academic Governance and Quality Assurance (<a href="mailto:academicquality@tavi-port.nhs.uk">academicquality@tavi-port.nhs.uk</a>)  Confirmation on any limitations in confidentiality where disclosure of imminent harm to <a href="#">self and/or</a> others may occur.</p>

**23. The following is a consent form checklist covering the various points that should be included in this document.**

Trust letterhead or logo.  
 Title of the project (with research degree projects this need not necessarily be the title of the thesis) and names of investigators.  
 Confirmation that the research project is part of a degree.  
 Confirmation that involvement in the project is voluntary and that participants are free to withdraw at any time, or to withdraw any unprocessed data previously supplied.  
 Confirmation of particular requirements of participants, including for example whether interviews are to be audio-/video-recorded, whether anonymised quotes will be used in publications advice of legal limitations to data confidentiality.  
 If the sample size is small, confirmation that this may have implications for anonymity any other relevant information.  
 The proposed method of publication or dissemination of the research findings.  
 Details of any external contractors or partner institutions involved in the research.  
 Details of any funding bodies or research councils supporting the research.  
 Confirmation on any limitations in confidentiality where disclosure of imminent harm to self and/or others may occur.

#### **SECTION H: CONFIDENTIALITY AND ANONYMITY**

**24. Below is a checklist covering key points relating to the confidentiality and anonymity of participants. Please indicate where relevant to the proposed research.**

Participants will be completely anonymised and their identity will not be known by the investigator or researcher(s) (i.e. the participants are part of an anonymous randomised sample and return responses with no form of personal identification)?  
 The responses are anonymised or are an anonymised sample (i.e. a permanent process of coding has been carried out whereby direct and indirect identifiers have been removed from data and replaced by a code, with no record retained of how the code relates to the identifiers).  
 The samples and data are de-identified (i.e. direct and indirect identifiers have been removed and replaced by a code. The investigator or researchers are able to link the code to the original identifiers and isolate the participant to whom the sample or data relates).  
 Participants have the option of being identified in a publication that will arise from the research.  
 Participants will be pseudo-anonymised in a publication that will arise from the research. (i.e. the researcher will endeavour to remove or alter details that would identify the participant.)  
 The proposed research will make use of personal sensitive data.  
 Participants consent to be identified in the study and subsequent dissemination of research findings and/or publication.

**25. Participants must be made aware that the confidentiality of the information they provide is subject to legal limitations in data confidentiality (i.e. the data may be subject to a subpoena, a freedom of information request or mandated reporting by some professions). This only applies to named or de-identified data. If your participants are named or de-identified, please confirm that you will specifically state these limitations.**

YES NO

If NO, please indicate why this is the case below:

**NOTE: WHERE THE PROPOSED RESEARCH INVOLVES A SMALL SAMPLE OR FOCUS GROUP, PARTICIPANTS SHOULD BE ADVISED THAT THERE WILL BE DISTINCT LIMITATIONS IN THE LEVEL OF ANONYMITY THEY CAN BE AFFORDED.**

**SECTION I: DATA ACCESS, SECURITY AND MANAGEMENT**

26. Will the Researcher/Principal Investigator be responsible for the security of all data collected in connection with the proposed research? YES NO

If NO, please indicate what alternative arrangements are in place below:

27. In line with the 5<sup>th</sup> principle of the Data Protection Act (1998), which states that personal data shall not be kept for longer than is necessary for that purpose or those purposes for which it was collected; please state how long data will be retained for.

1-2 years 3-5 years 6-10 years 10> years

**NOTE:** In line with Research Councils UK (RCUK) guidance, doctoral project data should normally be stored for 10 years and Masters level data for up to 2 years

<p><b>28. Below is a checklist which relates to the management, storage and secure destruction of data for the purposes of the proposed research. Please indicate where relevant to your proposed arrangements.</b></p> <p>Research data, codes and all identifying information to be kept in separate locked filing cabinets.  Research data will only be stored in the University of Essex OneDrive system and no other cloud storage location.  Access to computer files to be available to research team by password only.  Access to computer files to be available to individuals outside the research team by password only (See 23.1).  Research data will be encrypted and transferred electronically within the UK.  Research data will be encrypted and transferred electronically outside of the UK.</p> <p><b>NOTE:</b> Transfer of research data via third party commercial file sharing services, such as Google Docs and YouSendIt, are not necessarily secure or permanent. These systems may also be located overseas and not covered by UK law. If the system is located outside the European Economic Area (EEA) or territories deemed to have sufficient standards of data protection, transfer may also breach the Data Protection Act (1998).</p> <p>Essex students also have access the 'Box' service for file transfer. <a href="https://www.essex.ac.uk/student/it-services/box">https://www.essex.ac.uk/student/it-services/box</a></p> <p>Use of personal addresses, postcodes, faxes, e-mails or telephone numbers.  Collection and storage of personal sensitive data (e.g. racial or ethnic origin, political or religious beliefs or physical or mental health or condition).  Use of personal data in the form of audio or video recordings.  Primary data gathered on encrypted mobile devices (i.e. laptops).</p> <p><b>NOTE:</b> This should be transferred to secure University of Essex OneDrive at the first opportunity.</p> <p>All electronic data will undergo <u>secure disposal</u>.</p> <p><b>NOTE:</b> For hard drives and magnetic storage devices (HDD or SSD), deleting files does not permanently erase the data on most systems, but only deletes the reference to the file. Files can be restored when deleted in this way. Research files must be <u>overwritten</u> to ensure they are completely irretrievable. Software is available for the secure erasing of files from hard drives which meet recognised standards to securely scramble sensitive data. Examples of this software are BC Wipe, Wipe File, DeleteOnClick and Eraser for Windows platforms. Mac users can use the standard 'secure empty trash' option; an alternative is Permanent eraser software.</p> <p>All hardcopy data will undergo <u>secure disposal</u>.</p> <p><b>NOTE:</b> For shredding research data stored in hardcopy (i.e. paper), adopting DIN 3 ensures files are cut into 2mm strips or confetti like cross-cut particles of 4x40mm. The UK government requires a minimum standard of DIN 4 for its material, which ensures <u>cross cut</u> particles of at least 2x15mm.</p>
<p><b>29. Please provide details of individuals outside the research team who will be given password protected access to encrypted data for the proposed research.</b></p>
<p><b>30. Please provide details on the regions and territories where research data will be electronically transferred that are external to the UK:</b></p>

## **SECTION J: PUBLICATION AND DISSEMINATION OF RESEARCH FINDINGS**

**30. How will the results of the research be reported and disseminated? (Select all that apply)**

Peer reviewed journal  
 Non-peer reviewed journal  
 Peer reviewed books  
 Publication in media, social [media](#) or website (including Podcasts and online videos)  
 Conference presentation  
 Internal report  
 Promotional report and materials  
 Reports compiled for or on behalf of external [organisations](#)  
 Dissertation/Thesis  
 Other publication  
 Written feedback to research participants  
 Presentation to participants or relevant community groups  
 Other (Please specify below)

**SECTION K: OTHER ETHICAL ISSUES****31. Are there any other ethical issues that have not been addressed which you would wish to bring to the attention of [Tavistock Research Ethics Committee \(TREC\)](#)?**

--

**SECTION L: CHECKLIST FOR ATTACHED DOCUMENTS****32. Please check that the following documents are attached to your application.**

Letters of approval from any external ethical approval bodies (where relevant)  
 Recruitment advertisement  
 Participant information sheets (including [easy-read](#) where relevant)  
 Consent forms (including [easy-read](#) where relevant)  
 Assent form for children (where relevant)  
 Letters of approval from locations for data collection  
 Questionnaire  
 Interview Schedule or topic [guide](#)  
 Risk Assessment (where applicable)  
 Overseas travel approval (where applicable)

**1. Where it is not possible to attach the above materials, please provide an explanation below.**

--



## Appendix 3I: Ethical approval

The Tavistock and Portman 

NHS Foundation Trust

Quality Assurance & Enhancement  
Directorate of Education & Training  
Tavistock Centre  
120 Belsize Lane  
London  
NW3 5BA

Tel: 020 8938 2699

<https://tavistockandportman.nhs.uk/>

Maya Abraham-Steel

**By Email**

30 March 2023

Dear Maya,

**Re: Trust Research Ethics Application**

**Title:** 'Exploring bereaved children's experiences of loss and the ways they wish to be supported: an emancipatory study'

Thank you for submitting your updated Research Ethics documentation. I am pleased to inform you that subject to formal ratification by the Trust Research Ethics Committee your application has been approved. This means you can proceed with your research.

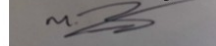
**Please be advised that any changes to the project design including changes to methodology/data collection etc, must be referred to TREC as failure to do so, may result in a report of academic and/or research misconduct.**

If you have any further questions or require any clarification do not hesitate to contact me.

I am copying this communication to your supervisor.

May I take this opportunity of wishing you every success with your research.

Yours sincerely,

**Michael Franklyn**

Academic Governance and Quality Officer

T: 020 938 2699

E: [academicquality@tavi-port.nhs.uk](mailto:academicquality@tavi-port.nhs.uk)

cc. Course Lead, Supervisor, Research Lead



## Appendix 3J: Excerpt of research diary

Written Dec 2023 – during data analysis

*I am experiencing strong resistance towards group one's data (older group) likely due to the proximity to my own experiences. Not helped by the fact I wrote all of group two's data first and have convinced myself I could write 10000 words on that alone. When the kids talk about grieving for all the things you cannot have (adult relationship with parent) I feel extremely sad. I am finding it incredibly hard to sit with and have thought a lot about why and interrogating my own feelings.*

*I have this thought that is: I never wanted to do an adults bereaved as children study anyway, even though I know 18-21 year olds are not 'adults', not properly, they are still young people. I also know this is an immature thought and can't stop think about the ways this process puts me in a position of 'bereaved child.' I have felt like I wish I didn't have this data set; I feel guilty about that thought. I have considered the ethics of abandoning this data set (I know I can't). I know it's not really about that; it's about how hard it is to look at some of this stuff. But I feel almost angry towards that data set, like rejecting of it, like I didn't even want it in the first place – which is probably symptomatic of how I actually feel about being bereaved (didn't even want it in the first place).*

*At the same time, I feel this huge responsibility, like these young people have trusted me with their most painful memories, on the promise that I would do something useful with them and now I am protesting to the task of even looking at them, which feels childish and irresponsible and unfair. I feel ashamed of myself, of the feelings I have, of the resistance I feel. Like it illuminates all the badness in me... like I'm not doing the right thing.*

*I've been working hard to try and make sure I am not over biasing group two's data because of this and that things are balanced; will discuss in supervision so that I can ensure Richard reads the results with this lens.*

Appendix 3K: A 15-Point Checklist of Criteria for Good Thematic Analysis Process  
(Braun and Clarke, 2006)

(Braun and Clark, 2006, p37)

Transcription	1.	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.	Y
Coding	2.	Each data item has been given equal attention in the coding process.	Y
	3.	Themes have not been generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive and comprehensive.	Y
	4.	All relevant extracts for all each theme have been collated.	Y
	5.	Themes have been checked against each other and back to the original data set.	Y
	6.	Themes are internally coherent, consistent, and distinctive.	Y
Analysis	7.	Data have been analysed rather than just paraphrased or described.	Y
	8.	Analysis and data match each other – the extracts illustrate the analytic claims.	Y
	9.	Analysis tells a convincing and well-organised story about the data and topic.	Y
	10.	A good balance between analytic narrative and illustrative extracts is provided.	Y
Overall	11.	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.	Y
Written report	12.	The assumptions about ThA are clearly explicated.	Y
	13.	There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.	Y

	14.	The language and concepts used in the report are consistent with the	Y
		epistemological position of the analysis.	
	15.	The researcher is positioned as <i>active</i> in the research process; themes do not just 'emerge'.	Y

## Appendix 4A: Full table of quotes corresponding to themes

Table 4A: Table of quotes to support themes

Theme	Quotes	Quotes	Quotes
4.2.1.1: Support at school at the time of bereavement	4.2.1.1D: I don't think much was helpful. Because most of the teachers know about it but tried to like avoid the subject. So I didn't really get any help from school at all. - Jason	4.2.1.1E Well, a bit of both. It would have been able to get help to talk about when I wanted to talk about it. But they didn't really give me a choice. They just didn't talk about it at all. - Jason	4.2.1.1F I mean, I think like why I was able to just like go back in when I wanted to. My parents they were like, they talk to the school a lot, they school, they let us, they're... my primary school was pretty good that they let us just spend some time off to spend time with mom because she was like, dying. So they'd let us to spend some time off. - Tord
	4.2.1.1G They were understanding more and in the school I'm in now, I've had a girl say that I've cried just to get out of class, which makes me guess, like, am I crying to get out of class? - Gretchen	4.2.1.1H I agree, there was, there was a huge difference between primary and secondary. In primary, I've got all the support I needed, I was quite, quite well with support, because if I needed it, I could go to anyone and ask, and they were quite understanding. But then secondary, is just they don't care at all.	

<p>4.2.1.1: Support at school at the time of bereavement</p>	<p>4.2.1.1I - And I remember I was in like the pastoral isolation for like, probably just under a week. Because homelife was just all over the place. So trying to sort of reintegrate myself slowly but one thing I found about schools is they were trying to sort of like rush me into it, thinking I was just using it as an excuse just to like bunk class, when, you know, it wasn't the case, I just sort of was using it as a, you know, like almost integration sort of session really, for like a week or two. But yeah, I just feel from the school's behalf they were just trying to rush into telling me how you know, you can't just spend all your time in here. I know how I feel, for example, so you know, there's no timescale when I feel ready to go back into class, but yeah, this is probably the difference between the main two</p> <p>- Leo</p>	<p>- Gretchen</p> <p>4.2.1.1J I was offered like a take five where I could go to pastoral but like I had a lot of anxiety in school anyway, and was more worried about missing like important information, not meeting deadlines, not doing homework and just missing. So actually kind of looking back I wish I took the take five and went to pastoral when I needed it. I was more worried about missing this or I'll draw attention to myself so just kind of sat there struggling; but I was offered it</p> <p>- Maddie</p>	<p>4.2.1.1K I was offered to like just go into like the pastoral room, so there was like a separate room to go in. They were pretty good with me. The head of year emailed round like the teachers to just like give them a heads up sort of thing but not let them know. Like everything that went on Yeah, that's it really?</p> <p>- Ashley</p>
	<p>4.2.1.2L Some, not all... Like, there were the odd few that were really supportive. And like</p>	<p>4.2.1.2M For me the teachers that I expected to be supportive, surprised me in the fact that</p>	<p>4.2.1.2N I mean, I think, for me, there was there were there were two teachers that I</p>

<p>that one teacher was always sort of had your back. But then there was some that I don't know, maybe a bit more, you know, the stereotypically strict sort of teachers had a 'get on with it; get over it' sort of mindset. So obviously, when you're year seven/year eight, it is the last thing you need. So yeah, I mean, I can't say that they were all terrible. But there was some probably that wasn't as supportive as I think they should have been, in my opinion.</p> <p>- Leo</p>	<p>they weren't. I don't know if that's maybe because my tutor was so good and so helpful. I feel like she was kind of the only one, I think the rest of my teachers either like, shied away from it, or yet didn't know what to say. So not saying something was easier. But yeah, because I was lucky enough to have my tutor, I didn't really use pastoral. Yeah.</p> <p>- Maddie</p>	<p>didn't really expect to be there. Like my two language teachers, one of them I mean, yeah, she was the safeguarding person, but she wasn't the typical, I'll always be there if you want to talk person, she was the kind of the opposite to that, she was a bit stricter, Come on, to keep working, keep going through it. And then my other language teacher was kind of giving me a bit more attention in class. And it was, was kind of easier to talk to knowing that as languages were probably my best subject back then. It was easy to talk to them as I was. I was always volunteering in class. So after class if I needed to talk it was probably easier than</p> <p>- Jared</p>
<p>4.2.1.2O um, I had like three main ones so like two of the pastoral ones and then my head year. The other ones they just it felt like they didn't really like understand what you</p>	<p>4.2.1.2P In pastoral, in they just like think that you're trying to get like out of like class and lessons and all of that. But like I have like a few more bereavements</p>	<p>4.2.1.2Q I think for me, there was like, a few factors because at the start, I think teachers kind of recognise and are aware, it's still raw, you know,</p>

was going through  
 as such, like they  
 didn't know how to  
 go around it and like  
 how to support you.  
 Whereas like these  
 three ones, like I  
 didn't have to like  
 keep repeating  
 myself at the same  
 things and like they  
 just understood and  
 took their time with  
 me and like allowed  
 me to have time if I  
 needed it sort of  
 thing  
 - Ashley

through there. And  
 then they just like  
 started to pick it up.  
 And then like after  
 like a six week  
 holiday is like just  
 started to drop,  
 again, sort of thing.  
 But apart from like,  
 seven, eight and nine  
 was quite a good  
 time, because they  
 did support me quite  
 a bit. So  
 - Ashley

like, if you need  
 anything, we're  
 here, or I think  
 they put a few  
 things in place.  
 And then I think  
 out of like, what  
 they think they  
 think they're doing  
 it right by kind of  
 saying, like, we  
 won't mention it,  
 because we don't  
 want to upset you  
 or embarrass you  
 in case it's in front  
 of anyone, so you  
 have to come to  
 us, which I  
 understand and  
 some people that's  
 how they want to  
 deal with it. But  
 sometimes it's  
 hard to approach a  
 member of staff  
 and especially  
 kind of say I'm not  
 okay, so  
 sometimes you do,  
 it's hard, isn't it?  
 Because some  
 days you want to  
 be asked, Are you  
 okay, so you can  
 say no. And other  
 days? You don't  
 want to ask that  
 question because  
 you want to be  
 okay. So there's  
 that and then I  
 think also when  
 you change years  
 or like rotations,  
 you change  
 teachers so then  
 they might not  
 know it was only  
 your current

			<p>teachers who found out so I think it was hard in terms of like, you'd kind of have to repeat your story if you do get upset or if it was like a anniversary or you know things cropped up on you. But I think like in my situation, I was just I was lucky because If I had someone who cared and remembered those things,</p> <p>- Maddie</p>
	<p>4.2.1.2R But then, since this, I mean, in my experience, the teachers a certain teacher, the one who safeguards, again, she's been one for countless years and could recognise, even though I acted the way I did, and normally and all okay, she could always tell that. Something, however small was always like bothering me, whether it was not volunteering as much or just losing interest in things that I used to say, enjoy.</p> <p>- Jared</p>	<p>4.2.1.2S Yeah. I didn't. Yeah, They didn't know what to say. Or like, they'd just panic. So worried they'd say the wrong thing.</p>	
4.2.1.2: Support at school at present	<p>4.2.1.2A: Like I feel like right now. Maybe it would have made a difference in primary school, like</p>	<p>4.2.1.2B Yeah, I mean, what would the teachers do? Like? Yeah, once they know what do they do with it after</p>	<p>4.2.1.2C Oh, I'd say give them some type of card or like tell the teachers that they can have time out</p>



<p>all the teachers knowing, but I feel like right now just be a little bit awkward like, going in like, hey, my son's mothers died and then they just walked back out again. I feel like it'd be a bit awkward</p> <p>- Tord</p>	<p>that? Wait for us to be upset?</p> <p>- Gretchen</p>	<p>of class if they want to. So even if it's like not all lesson, if it's 5-10 minutes just to like re calm yourself and make yourself focused again to the point you're not upset</p> <p>- Tord</p>
<p>4.2.1.2D The teachers were there on their computers? I just sat there in tears for the hour</p> <p>- Gretchen</p>	<p>4.2.1.2E One of my teachers told me to get over it and then I was sitting there proper, like proper upset, and he was like, come on, it's been five minutes get over it. And</p> <p>- Jason</p>	<p>4.2.1.2F Because he's having a rough time they told him he needs to concentrate because he's soon doing his GCSEs and I'm having, he was having a difficult moment and he got told that he should get on with his life and start practising and waiting for his GCSEs - start prepping for his GCSEs and stop coming out of lessons to pastoral</p> <p>- Juan</p>
<p>4.2.1.2G</p> <p>I mean, yeah, it got to the point that if I would, I'd ask if I could go outside and then sit on the floor. And if my teacher came out, she'd say do you wanna go to pastoral? and I would refuse. I don't want to go in there anymore. And again, I almost feel like there's a couple of teachers in there that</p>	<p>4.2.1.2H</p> <p>That's my PE teacher. Like that's my favourite subject and me and him just used to sit there talking. If I needed to talk to someone, he's also part of the pastoral team. So if I needed to talk to someone, I need to talk to him. And if they wouldn't let me talk to him, I wouldn't talk to</p>	<p>4.2.1.2 I</p> <p>Yeah, but she left. Well, she went on maternity leave. She comes back next year. Okay, that's that's the maths class I used to walk out of and she didn't notice I was gone. She was the best teacher ever. We like best friends, I used to go sit with her at lunch.</p>

	<p>like if I end up with them, I honestly cry more. I hate some of them, they're just horrible. That was like one of the things about why they walk me down there or you can go by yourself. If I refuse to go there because of her, because she didn't know and I'm not going in there</p> <p>- Gretchen</p>	<p>anyone. Because he was like the one teacher I could talk to</p> <p>- Jason</p>	<p>- Gretchen</p>
	<p>4.2.1.2J And I'd rather talk to my teaching teachers than the people who are supposed to be there to help me.</p> <p>- Gretchen</p>		
4.2.1.3: Desire to be included in support plans	<p>4.2.3.1A Like they'd say, like, do you want to join him and talk to someone? But if I knew if I said, If I said no, I get colouring book or be sat in a room by myself or have to go back to lesson so I just feel like, fine I'll go talk to someone, but I didn't want to</p> <p>- Gretchen</p>	<p>4.2.3.1B Yeah, cuz one day, I might want to talk to someone and then the next day, I might want to just be left alone with me and my thoughts. But then if one day I say I want to talk to someone then they automatically assume that every day I'm upset, I want to talk to someone, so they don't give you the choice after the first few times they just immediately put me...</p> <p>- Jason</p>	<p>4.2.3.1C For me, it's not day to day differences. It's like, maybe like, I'll go in the room. I don't want to talk I just want to be in my thoughts. Like maybe like five minutes later, I do want to talk to someone. There's no like good way to like get someone's attention without like drawing attention to yourself. It's like, there's like five or six other people in there most of the time.</p> <p>- Tord</p>
4.2.1.4: Social support	<p>4.2.1.4A I feel like I could. But it would have to be my closest friends. It</p>	<p>4.2.1.4B At Forget me nots It's way easier. Because other</p>	<p>4.2.1.4C I found it much easier to talk to people here. So I</p>

	<p>would have to be my best mate that I'll talk to you about and if I really wanted to, I would. But usually I just don't really feel like it</p> <p>- Jason</p>	<p>people have gone through the same thing.</p> <p>- Tord</p>	<p>became friends with most people here. Because it's just easier because they've been through the same thing as us. So it's like, with my friends at the time, I really felt like I wanted to talk to them. The people here I know could because they had been through the same thing. So I guess it was just a lot easier making friends here and talking about it here than it was anywhere else.</p> <p>- Jason</p>
	<p>4.2.1.4D</p> <p>I have a mate who I play cricked with and I'm seeing him tonight. I talked, I talked to him because I trust him and I know he won't like go share anything. But trust that like, my other best mate I go to school with. I do trust as well. But they're the only two people I would trust to not like blab about it.</p> <p>- Juan</p>	<p>4.2.1.4E</p> <p>People who have been through similar experiences</p> <p>- Juan</p>	<p>4.2.1.4F</p> <p>It's a lot harder to talk about it school.</p> <p>- Juan</p>
	<p>4.2.1.4G</p> <p>I agree with you to be fair. The loneliness sort of things, because I didn't know anyone who lost their</p>		

	<p>parents, or anyone like that. So when you come to something like that, can be good but I hated the first session to be fair. So it just wasn't for me, like group sessions just weren't for me... I just didn't like the group setting, I don't think I was ready for that. And then I went back to obviously, one-to-one counselling. And it wasn't until my uncle died. And I was a bit older, that's when I came back to like an older teen group.</p> <p>- Leo</p>		
	<p>4.2.1.4G After that stage of when I got to acceptance, and I accepted that he's gone it was sad, but knowing I had them there, I could, I could have been able to joke with them. Like it was something I could, I didn't know I wouldn't have been able to joke with them. But having them there helped me through the whole process of being sad, depressed, whatever, then I was able to</p> <p>- Jason</p>		
4.2.1.1: Return to School	4.2.1.1A: I think going back helped. Because of being	4.2.1.1B: I think it's better to be like around people, like	4.2.1.1C: I went back the next day, it happened at like

	<p>surrounded by people. - Gretchen</p>	<p>with my mates, so instead of just isolating myself. So then when I went back, it would be a bit like, wait, we haven't seen you for like years, where have you been!? I mean, I think it was better to go back quicker. But I mean, it might be different for some people. Tord</p>	<p>10 o'clock at night. And then I went back in the next morning. I think it kind of helped. But there was some parts of it where I would prefer to be alone. Because it was, I like to deal with stuff on my own. And being surrounded by a bunch of people. When I wasn't that kind of outdoors, I wasn't allowed to be by myself, I kind of felt trapped, as well as helped by people. So it was a mix - Jason</p>
	<p>4.2.1.1D It was sort of a bit of both really, for me... the bereavement happened on Friday and I went back to school on Tuesday; I lasted about an hour and a half. And it was all a bit patchy, like I'd go in for a day or so and then come out or go home early or I just wouldn't go in at all for pretty much all of year seven, so that was obviously an awkward bit, because a bereavement had happened, so you, you don't really want to go to school. But because I just joined</p>		<p>4.2.1.1E Mine was before year seven. So I had like, that time before I started school anyway.  Like summer holidays?  Yeah. But it was quite scary because I was like, going into like, a new place sort of thing. So it was like a new environment as well. Yeah, it was a bit it was struggling because obviously, none of the teachers knew at all unless my mum came in for</p>

<p>year seven, a whole new school environment, you wanted to like make friends and not like, you know, and I ended up not having as many friends as you probably would, just because no one knew who I was probably for the first like, year or so. That was like, yeah, it was quite an awkward time to sort of miss school because I didn't really find school, at that point, very helpful. You should kind of say, because I was quite young as well.</p> <p>Leo</p>		<p>like a meeting and told them but apart from that it was was okay.</p> <p>Ashley</p>
<p>4.2.1.1G Mine was, again, before year seven. But I don't really remember it, it was like 12/11 years. So, if I'm not wrong, I must have been at school the whole time. But I think it was. It was might have been around Halloween. So it's about half-term as well.</p> <p>- Jared</p>		
<p>Yeah. I didn't. Yeah, I didn't know what to say. Or like, they'd just panic. So worried they'd say the wrong thing.</p> <p>Yeah. Like, like an example was, we're watching a film and in that film, the</p>		

	<p>mom, the mom or the daughter died, and I think it did upset me because it was so raw. And my teacher kind of pulled me across and kind of said, I know it must have been hard. But how was your mom and dad? How's my dad? He's the one that's died!. But he would just like panic, say and stumble. Then he felt awkward. No, I just, I'm fine. I'm fine. I went to my next lesson. But it's like, I still remember thinking like, you know, I kind of understand it's hard for other people. But if I wasn't so strong, that would have made someone else like flip their lid. Yeah, so yeah, it's hard. People don't know what to say. But no one know how I was alright, because I had that one teacher, but if it wasn't for her, it would have been very different.</p> <p>- Maddie</p>		
..3 Impact on academics	<p>4.2.2.3A Probably doesn't even have anything to do with. But remember, in primary school, I was so good at everything. I was putting my hand up a lot of stuff. Yeah.</p>	<p>4.2.2.3B I think that it kind of got in my head a little bit. If you know what I mean? Where his death was kind of the only thing I could think about for weeks and months, but so that</p>	<p>4.2.23C I mean, I think schools are so, so fixated on education and learn, learn, learn, and I think they forget that people are like, almost human. Like,</p>

	<p>But now I just still tend to drift through class drift through class. Like I don't put my hand up as much and stuff. But I don't go like detentions every day. - Tord</p>	<p>kind of affected the fact that I wasn't listening in class. I was drifting off all the time. I couldn't focus a lot. But I've gotten I've gone from good when it happened, to like, really bad, and then quite good again. - Jason</p>	<p>there's no, you know, school is not the be all end all. Like, if you're going through like quite severe bereavement, you know, the last thing you're thinking about is going through each lesson, for example, but they put such pressure on attendance that, you know, you have to, you know, you have to do you have to do education, because like, if I take that extended leave to sort myself out, I'm going to come back and be ready to learn. - Leo</p>
	<p>4.2.2.3D For me personally, if you looked at my records at the start of each key stage, it was, it was always, it always stays high, and like dropped off. So I started well, then it would, I'd have a bereavement and then just go downhill... - Jared</p>	<p>4.2.2.3E And they said that if I get in one more fight, no matter the reason they're permanently excluding me. - Jason</p>	<p>4.2.2.3F school was a massive thing, because when I was coming to the group, I was going through the phase when I was about to get kicked out of school. So I was coming. I was like, yeah, I got excluded today, you know, and that was just sort of the way it kind of you know, went those sort of groups but that helps me because I needed an outlet to express myself because if I didn't,</p>



			I'd have to come out of school, and then you'll know where that sort of ends. - Leo
4.2.3 Desire to be normal	4.2.3.1A when I was in year 7, they were like trying to give me one but I just didn't I didn't really want one because it made me feel a bit different like... I don't want to be different, I wanna be the same - Tord	4.2.3.1B Well then there are also times where you should be treated different - Tord	-
	Being one of the sort of like taller kids, you know, wanting to sort of, you know, that sort of plays football and I don't wanna sound big headed but being on the popular side of things. You have that sort of reputation that you will uphold. So you sort of pushes to the side with sort of people you don't really sort of like, express it to. You're sort of a bit young, part of you sort of 'doesn't even bother me' , sort of thing, which then then just builds up and crashes at some point, for sure. It happened with me, when my uncle died, when I was younger, being a boy sort thought I'll be alright, you know,	I do think there is a difference because of the stigma. And I definitely kind of saw that with my brothers but. And I think that sort of encouraged me to be more honest about my feelings, and to kind of look out for my brothers because I was aware of that. But for me, like, personally, I had that conflict or trying to be okay, and wanting to be okay, but then also, and some people won't understand it, but because I was the oldest and kind of had other responsibilities, and maybe I had support at home, but maybe not so much, or, compared to the younger ones were when I was at	

	<p>and then obviously that happens it will just sort of explodes and I think sort of just progressively happens throughout your life, especially if you don't sort of deal with it. But there is that common sort of expectation upon, I'd definitely say males as sort of get on with it</p> <p>- Leo</p>	<p>school. That was my time to kind of to certain teachers to open up and not be okay. Or want that attention. Because I wasn't necessarily maybe getting that where getting what I wanted.</p> <p>- Maddie</p>	
4.2.3 – Rejecting pity	<p>4. .2.3C personally don't like teachers knowing because it kind of feels like a pity thought. To where they're only nice to you and they give you that special treatment. I don't want that; I want to be a normal kid. I want the school experience, I don't want to be treated differently. So I'd personally not want them to know</p> <p>- Jason</p>	<p>4.2.3D</p> <p>Some, some of them did. I felt like people were treating me nicer because they felt bad. And it's like they weren't being like truthful. They were putting on a second face and being nice to me because of something that's happened. I wanna know people for what they actually are. So if you're just being pity nice to me, then I wouldn't want them to know. I did have a few teachers that turned from all strict to all nice overnight. It was great.</p> <p>- Jason</p>	<p>4.2.3E</p> <p>Me and my mates we used to do like a bit of roughhousing, play fight, dog piling and stuff like that in primary school. Not so much in secondary school. But like after it happened, kind of turned it down a bit if you get me</p> <p>- Tord</p>
4.2.4.1 – People being awkward	<p>4.2.4.1A My friends, were kind of awkward at first. Yeah. So like, they didn't really know what to do. So, after a while, we kind of just left it alone. Like, we kind of just</p>	<p>4.2.4.1B I think my friends like, I wouldn't I don't really know how they react to that first because I think the day it happened, I think my parents contacted the school</p>	<p>4.2.4.1C Yeah because people didn't know how to act around me and it was awkward.</p> <p>- Juan</p>

	<p>let it be, let it pass over. - Jason</p>	<p>so then the school told everyone and made sure they're a bit more sensitive about it. But I weren't really there when that was happening, I took like a week off. So I don't know how they reacted at first, but when I got back then we're like, same as Jason, kind of awkward because they didn't know how to help. - Tord</p>	
	<p>4.2.4.1D It's hard to remember to be honest, because I remember finding school quite hard and awkward initially, just because I didn't know like, who knew and then plucking up the courage to tell people they'd be like, 'oh, yeah, I already knew'. Like 'oh'. I don't think it like impacted kind of positively or negatively. I think it kind of genuinely stayed the same. Maybe for a while, people were nicer. But then, like everybody else, they're like, oh, there you go, a week later, you're fine, But yeah, I don't remember it being like a huge impact</p>	<p>4.2.4.1E Yeah, I think so. That first time walking in. I think there was definitely like eyes and like oh look she's here. And then you obviously get like people who don't know what to say. So I guess that was more awkward, because you're like, it'll be normal. But then like, you kind of have to address it. Again, guess it was maybe like a slight change in the way I was treated, but not so much that I can kind of remember having a huge impact. - Maddie</p>	<p>4.2.4.1F I'd say it was an age thing really. Like, I mean, one of the things when my dad passed in year seven, it was a lot more like awkward everyone was sort of like 'oh god',, because I was one of the only people that had like, lost a parent. And in my estate, he was quite well known. So everyone sort of knew about it. So it's just a bit more of like awkwardness. Everyone was sort of like 'it's Leo, it's Leo!. He's the one who lost his dad...' it was being like, almost as if they'd try and distance themselves from me a little bit, it was quite weird.</p>

on friends and things.

- Maddie

But when my uncle died in year nine, everyone was a bit more supportive. almost understanding, they were a bit more mature, I guess, because they were a bit older. And they can kind of converse with you a bit better. But I'd say a big impact was me missing school in year seven, a lot.

Because obviously I'd just started year seven, when it happened, I found it hard to make friends.

Cause a lot of friends that I made in the first two weeks, were obviously still in the school making friends. And I was just home. So I wasn't in the mind space to, you know, be friendly, or try and make friends as I was sort of just in my own little sort of world. So I guess that made it harder throughout year seven.

- Leo

I'm the same I only told like a couple of people around me like my close friends. I didn't really want people

<p>knowing as such because it was like, we were quite young. So I didn't know how they were going to react or what they were gonna say. I didn't really know how to tell them sort of thing either. It's a bit of a weird subject. As such when you're like that age because you're just not sure how to handle it around other people like the same age as you.</p> <p>- Ashley</p>			
<p>4.2.4.1F I don't know if like, it's really strange, like what you remember so vividly. And then like it was a little bit of a blur. But like I had a few friends who like I could speak to about things, like one or two. And who like I really trusted I was happy to speak to about it. But like my friendships at school like it wasn't a set group. It wasn't like your traditional yeah like friends. But I think it's only like more recently, that other people are happier, or feel more comfortable to talk about things, which obviously makes it easier because I don't mind talking about my situation.</p>	<p>4.2.4.1G I think no one even asked like, carrying on the conversation, if I mentioned my dad, a lot of people try and shut down. Very few people actually prolong the conversation. They carry on... so sorry about that. Anyway, I'm gonna switch off it straightaway. I'm like I'm okay. You know, it makes me feel less awkward if you're actually showing a slight interest in it or just actually proactively asking the question, because I feel like I've scared them off the topic. Because I've gone, my dad's dead, and they go okay, well, anyway.</p> <p>- Leo</p>	<p>4.2.4.1H Now, I speak to anyone yeah. Yeah, I think I'm at the age now where, you know, we're adults. So I think there's still that bit of awkwardness for some people. It's not going to be everyone. But the majority of people. I think I talk about he was such sort of like, I don't know, calmness, I guess. I don't see myself getting worked up when I'm talking about stuff like that. So I think that they identify that and think like, okay, yeah, he's not gonna like burst out crying. As soon as he</p>	

	<p>But you can like read the room. And if they don't feel comfortable or don't look like they're gonna be willing to listen, and you end up looking a bit like a mug sometimes. So only to like now I think it's become more apparent of like that support network.</p> <p>- Maddie</p>		<p>mentioned his dad or something, you know, I can easily have a conversation about it.</p>
4.2.4. Being asked about it	<p>4.2.4.3A So I wasn't asked about it all the time, which they did. But I was asked a lot anyway so it didn't really make a difference</p> <p>- Gretchen</p>	<p>4.2.4.3B I asked them to tell my class so I wouldn't get asked so much but I still got asked so much. But I had do many people come up to me and say 'did your dad actually die!?' no, I'm just spreading it for no reason.</p> <p>- Gretchen</p>	<p>4.2.4.3C I get asked so many times. I get asked like twice a day</p> <p>- Juan</p>
4.2.4.3 being asked about it	<p>4.2.4.3D Or the how does it feel to have them die?</p> <p>- Jason</p> <p>Do people ask you that? The way it feels?</p> <p>- Maya</p> <p>Yep. People are always asking</p> <p>- Jason</p>	<p>4.2.4.3E</p> <p>I think anyone can ask as long as they're respectful</p> <p>- Juan</p>	<p>4.2.4.3F</p> <p>If they're respectful of it, and you know, I'll respect their feelings, but if they're being a knob, I'll be a knob.</p> <p>- Jason</p>
	<p>4.2.4.3G</p> <p>No! They're not protecting my feelings if they're asking about it.</p> <p>- Tord</p>	<p>4.2.4.1H Idk there's just so many people's feelings to protect when someone dies.</p> <p>- Maddie</p>	
4.2.4.2 Being picked on	<p>4.2.4.2A I can talk to my close friends about it. But I've had experiences with my closest mate saying</p>	<p>4.2.4.2B Yeah it was Primary School. They sent me home three days, because some kid when he</p>	<p>4.2.4.2C One other kid. This was always a bit insensitive. He was just rude</p>

	<p>that I like what do they say? They said I make my dad my entire personality and stuff. It's idk...</p> <p>- Gretchen</p>	<p>was like, haha, your grandad's dead. and I just fully swung on him. I had like three different teachers holding me back.</p> <p>- Jason</p>	<p>honestly. He was like, why are you doing a card to your grandmother you idiot? Um, I don't even know if he knew that he was in the class when the entire class got told. So I feel like, he might've known, I feel like he knew...</p> <p>- Tord</p>
<p>4.2.4.2 Being picked on</p>	<p>4.2.4.2D But they're the only two people I would trust to not like blab about it.</p> <p>- Juan</p>	<p>4.2.4.2E Most of them have been because of my granddad. Yeah. So people who know that if they do want to start something can get under my skin. That's how you do it. So that's why most people who do want to fight me try that approach because that just sets me off.</p> <p>- Jason</p>	<p>4.2.4.2F Someone was blabbing their mouth. I didn't punch them but they were blabbing their mouth to the whole entire year so I had a go at them.</p> <p>- Juan</p>
	<p>4.2.4.2G</p> <p>I was at an all boys school. So it was kind of important, seen as in that type of environment. It's kind of a, an either, you're popular and you're always okay, and not made fun of or you're the complete opposite. And everyone makes fun of you and you're singled out.</p> <p>So in that environment is felt like you have to be okay, or you're going to be alone.</p>	<p>4.2.4.2H</p> <p>Being one of the sort of like taller kids, you know, wanting to sort of, you know, that sort of plays football and I don't wanna sound big headed but being on the popular side of things. You have that sort of reputation that you will uphold.</p> <p>So you sort of pushes to the side with sort of people you don't really sort of like, express it to. You're sort of a bit young, part of you</p>	<p>4.2.4.2I</p> <p>I do think there is a difference because of the stigma. And I definitely kind of saw that with my brothers but. And I think that sort of encouraged me to be more honest about my feelings, and to kind of look out for my brothers because I was aware of that. But for me, like, personally, I had that conflict or trying to be okay,</p>

	<p>Jared</p>	<p>sort of 'doesn't even bother me' , sort of thing, which then then just builds up and crashes at some point, for sure. It happened with me, when my uncle died, when I was younger, being a boy sort thought I'll be alright, you know, and then obviously that happens it will just sort of explodes and I think sort of just progressively happens throughout your life, especially if you don't sort of deal with it. But there is that common sort of expectation upon, I'd definitely say males as sort of get on with it</p> <p>- Leo</p>	<p>and wanting to be okay, but then also, and some people won't understand it, but because I was the oldest and kind of had other responsibilities, and maybe I had support at home, but maybe not so much, or, compared to the younger ones were when I was at school. That was my time to kind of to certain teachers to open up and not be okay. Or want that attention. Because I wasn't necessarily maybe getting that where what I wanted.</p> <p>- Maddie</p>
	<p>4.2.4.2J</p> <p>Yeah, well, I had like the school was like, my safe.. Yeah, like my safe kind of space with like there were three teachers there. Because then at home, I didn't have like, I felt like they weren't like understanding me because they were like all adults, because I was the only child anyway, so I felt like it was hard to be like, understood what I like, what I was feeling type of thing. Apart from that, I think it also depends</p>	<p>4.2.4.2K</p>	



	<p>on like, what environment you're in as well. Maybe, if you're like at school, and there is a lot of pressures because you you want to have like friends and stuff like that, then you don't want to seem like you're sad and upset all the time sort of thing.</p> <p>- Ashley</p>		
4.2.4.3 Humour as a coping mechanism	<p>4.2.4.3A And then eventually, it got to a point where we started making jokes about it. But they were just kind of to cope.</p> <p>- Jason</p>	<p>4.2.4.3B You just have to laugh through the pain because then it don't hurt as much</p> <p>- Jason</p>	
4.2.4.3 Humour as a coping mechanism	<p>4.2.4.3D I looked up, joking about your trauma. Talking about trauma like makes it seem less like a problem or like a funny haha</p> <p>- Tord</p>	<p>4.2.4.3E I feel like if I've been joking about it then like, it's okay if they make some like, light jokes about it. Not like, show me a picture of a skeleton level</p> <p>- Tord</p>	<p>4.2.4.3F Yeah I don't think it's ok for other people to make jokes because otherwise they don't really know where the boundary lies and where not to cross</p> <p>- Juan</p>
4.2.4.3 Humour as a coping mechanism	<p>4.2.4.3G Yeah, sometimes. It is an awkward laugh? They don't know whether to laugh or not</p> <p>- Juan</p>	<p>4.2.4.3H If it's a really, really bad joke, like if it's a funny one yeah, we'll all laugh if I've made like a proper bad one. They would find it very awkward</p> <p>- Jason</p>	<p>4.2.4.3I I, like, I know that a lot of people like my sister definitely uses humour as a way to like, deal with it because she doesn't talk about her grief and stuff. But I can never like, appreciate those jokes. And I don't. I don't like joke about it because I'm like, it's not funny. Like, okay, like,</p>

			<p>okay, the limit I would go to would be like, oh are they using daddy's money, couldn't be me. But like, that is literally it., I don't. Yeah, but I know that, that's people's way of dealing with it. So but yeah, it's not me.</p> <p>- Maddie</p>
	<p>4.2.4.4J There was a girl that I worked with and she was talking about family and she was like, talking about like parents and stuff and she was like 'are your parents still together? Is your dad still with your mom?' I just lent in and went, 'the thing is he is actually dead.' And like made a joke about it, and it made it so much more like light hearted, like she laughed a bit, she was like, 'oh my god, I'm so sorry.' And I was like, 'no, like, it's fine.' I mean, but I feel like if I was sort of like 'my dad passed...' it will just make the conversation so much more awkward. You know, so I thought, you know, I can openly sort of joke about it.</p>	<p>4.2.4.4K Yeah, because like, yeah, that's the thing, like when you speak to someone that, obviously is quite, sort of like, obviously, they don't know much about bereavement, I think their fear is not knowing the circumstances around the death, how that person is going to react to speaking about it. So I think if I come out straightaway, and sort of laughing and do a bit of a joke about it, they're going to be 10 times more relaxed to speak about it, they're going to think, okay, I can actually talk about it without, you know, thinking I'm going to break down in tears or something like that, or it's making me down. And then it sort of the</p>	<p>4.2.4.4.L I understand that other people's other people's way. I'd much rather talk about it, but some people can't and that's how they do it so I respect that</p> <p>- Maddie</p>

		<p>conversation just flourishes a lot more easily than if I sort of, I guess got down or visibly upset or down about it. And so, that's just the way</p> <p>- Leo</p>	
	<p>4.2.4.4M</p> <p>But me and my brother like, we do it to wind up my mum as well. I won't repeat stuff. It's just the way that we choose to sort of deal with it to an extent because you can't change anything, a joke is a joke, you know. My dad would laugh his head off probably. And, you know, say the joke to us, and cuss us out or something like that, you know, but that was sort of the relationship we kind of had. So I think it's more acceptable. But I understand where like other people probably wouldn't for their own sort of like, grief.</p> <p>- Leo</p>	<p>4.2.4.4N</p> <p>people never really use jokes around me either. I mean? And I don't wanna say I use my height and stuff to intimidate people. But I mean, if that's what I have to do to stop people making jokes or even telling other people about it and things like that. Again, like Maddie said, I wouldn't. I just wouldn't have it.</p> <p>- Jared</p>	
4.2.4.5 Comparative suffering	<p>4.2.4.5A And I do scouting, and if it ever comes up, like there's always one other person. Like, I'm not like dissing them, but like, they're always like well my sister died, like they're trying to</p>	<p>4.2.4.5B Same as Jason very much</p> <p>- Juan</p>	<p>4.2.4.5C Everyone got days off. I went straight back.</p> <p>- Gretchen</p> <p>Maybe you guys just have bad schools and our schools were normal?</p> <p>- Tord</p>

	<p>top me out or something.</p> <p>- Tord</p>		
<p>4.2.5.1 Understanding has developed over time</p>	<p>4.2.5.1A I mean, I was only young. So to me, it didn't really. I didn't really understand what happened. So I feel like it affects me more now. Because now I understand, like the concept of death and stuff. To be asked now probably upsets me more than it did at the time.</p> <p>- Gretchen</p>	<p>4.2.5.1B Yeah, sometimes. It just feels a bit odd. Because like, it's gonna sound very rude. But like, it's kind of like just talking about a stranger that you really know that well. That's just what it feels like sometimes because I didn't know her. I was like a little kid. You don't go asking about people when you're a little kid. But a couple weeks ago, we we're off for a day trip somewhere and dad just dropped this bombshell. But she was doing a PhD. I had no clue about that</p> <p>- Tord</p>	<p>4.2.5.1C I was thinking about how I had literally no information about her except for what everyone else says. I didn't know anything about her. I didn't really have a relationship with her, because I was just little. And I would stay up thinking about that</p> <p>-Tord</p>
	<p>4.2.5.1D</p> <p>I'd say it's more like, as I've gotten older, I've realised that you kind of like I don't know, I guess as you get older, your mind gets more complex, and you're able to actually like, thoroughly process situations and things. And I think you kind of think, the way I see is, you have like one, obviously, like, one shot at life and you sort of think like,</p>	<p>4.2.5.1E</p> <p>Yeah, if they're sort of stripped, you're almost losing out on that person's input on your up bringing. You know, and obviously, when you're a kid, you're like a sponge aren't you. You're just soaking up everything around you. You don't have that person, you're missing out on whatever they have to give, and stuff like that. But I'd say</p>	<p>4.2.5.1F I just think it was a big thing. I think I understand him more. I think that's a bit more. It's tough. Obviously, I would have known him more as a person being able to speak to him properly, I think at this age now. And I think and I always just, I wish I could have. Because I was only 12. So we had pretty deep</p>

God, you kind of realise there's a lot of things that are very normal, in terms of like, you know, you have both sets of parents, you grow up. as a boy, maybe, you know, you start to socialise more with your dad, and you start to sort of almost have that sort of more deeper bond because you're both like the two sort of males in the family. And I think as I've gotten older, you sort of start to realise you're never going to get that. I think it's been more of like a realisation and a sort of like, an understanding that obviously they are really like, gone.

And his I don't know, it's like a proper sort of, like cemented in sort of thinking you're never going to be able to sort of go for a drink with them. You're never going to be able to, you know, they would teach you how to fix a car or do all these sort of things. And I think as I've slowly gotten older I think it's actually one harder for me to always like, process it because I can understand it more. And I think, I get

yeah, I mean, I hate to say that time heals. Because I think it gives the perception that it just gets better over time. In my case, I would say it has, it has gotten easier but then like I said, it's also gotten harder. So it's you know, I don't cry for example, I don't sit down and cry, but then I sit down is really like deeply think about it. And then obviously, that affects just like, the overall mood and stuff like I don't you know, sit and cry in a corner or on my bed at all and weep all the time but it affects your moods, it affects your sort of like temperament with other people and your patience and stuff like that.

It's like small, minute sort of things in your life that it affects as opposed to when I was younger, I was more like, just angry and sad. And it's not like that anymore. It's sort of developed into a different kind of grief. I'd probably say. I hate the saying time heals, because obviously people get a perception that, like I said, say it's been 10/20 years,

conversations, but obviously only sort of certain complexity due to my age and maturity. Well, I always think, I wish, you know, that's what I've grown up and I wish I could meet him now. And I'd be able to actually like, because there's a whole different side of him. You know, that obviously I would have never known because he was just like my dad when I was 12. And you know, as a kid. I think when you get older you learn a lot more about a person obviously because you're able to have those sort of conversations with them and sort of bond on a sort of different level, it'd be more like, a friendship as opposed to, like, you know, a father and son relationship. I think that's been like probably the toughest is have sort of almost like missed out on like, a proper deep friendship, you know, which is hard, because

<p>jealous because obviously, you see other people and you think God, like, I should be doing that sort of thing. I wish I could have that. But the way, you know, the cards have been dealt in my life in particular, I won't be able to experience that. So obviously, there is a bit of like jealousy and envy there. You know, you sort of like for God's sake, like, out of everything, why did that have to happen? You know, you start sort of like, you know, second guessing things, but yeah, I'd say it's just like, it's a more thorough understanding of the situation and the future that probably helps to be fair.</p> <p>- Leo</p>	<p>'oh, you're alright now. It's been time' Time should heal. I don't fully agree on a that.</p> <p>- Leo</p>	<p>there's not many males in our family as well, same with my uncle, you know, he was like, the big brother. And I was 14, again, I didn't, I wasn't able to relate to him on that sort of level. So I think that's been quite tough. As I've gotten into sort of my older years, and I've matured a lot and realise that, you know, you're never actually going to be able to sort of like bond on that kind of like, adult level, you can kind of say, and losing out on a friendship</p> <p>- Leo</p>
<p>4.2.5.1G I think it is that kind of growing up and reflecting, kind of reassessing, like where you are in your life? And those things that you kind of wished for, and realising that they're not going to happen. You're not going to get them. Because yeah, I think initially, like, well, for me when I was younger, and it first happened, I was sad, I was confused, I</p>		

	<p>was angry. But, like, being older, having responsibilities and seeing, like, your friends and their, like, relationship with their parents, or the things that they get, because of their parents and stuff, and, and yeah, realising, like, what you're gonna miss and how different your life is, because of it.</p> <p>- Maddie</p>		
<p>4.2.5.2 Being told information vs not being told</p>	<p>4.2.5.2A My mum didn't want me to see him in hospital. But she told me that we'd go and visit him and he died a week later. Afterwards, like she was like, you probably didn't want to see him in hospital anyway. So I think she said that we were gonna go to make me feel better, but she knew he was gonna die. So she said that we're gonna go, but we weren't?</p> <p>Is that difficult to sit with?</p> <p>Yeah, I would I would have wanted to see him. But we couldn't.</p>	<p>4.2.5.2B They will say they'd like they want to protect us from it but, for the last few days, that he was alive. They said I wasn't allowed to go round there when I wasn't to. I kept asking why, why? Why can't I go round there and they told me he was busy. And I've been told after it's just because they didn't want me seeing him because he was dying. But I probably would have preferred to know when he was dying, sort of could have said my goodbye to him. You now how when people die, they say I didn't even get to say goodbye. I would have liked to see him at least one more time. I was just kind of restricted and told no.</p>	<p>4.2.5.2C I knew my dad was dying.</p> <p>- Juan</p> <p>I guessed when they're wouldn't tell me</p> <p>- Gretchen</p> <p>I knew. My mum told me</p> <p>- Juan</p>

<p>4.2.5.2 Being told information vs not being told</p>	<p>4.2.5.2D You know the saying you'll get it when you're older. That's that's what I've got. Because I realised his condition was like slowly getting worse. Because I you can see it from pictures if you put it in a timeline. He went from upright walking, talking normally to slowly getting down into where he went into a wheelchair, to where he could barely talk. And then right at the end where he had, do you know, the respirators helps you breathe. But he had on him and I was sitting in the living room talking to him about that. And I realised about a few months after they told me that the reason he was on that was because he was dying, but at the time I didn't know that. So I was happy thinking he was gonna be here for however long and then not much later he's gone. - Jason</p>	<p>4.2.5.2E Yeah, that's similar to me. Right, my dad, I'd always go around on his shoulders, and then he couldn't pick me up anymore because he had bad knees and stuff. I thought he was going to be fine. And then he got a concussion from it. I just knew that that was the end. - Gretchen</p>	<p>4.2.5.2F Well, I I kind of guessed. Yeah. But I didn't want that to be the case. Because the fact that no one was telling me anything. And I had this little voice in the back of my head telling me he's dying. But then the rest of my head telling me no, he's not. Don't think about that. He's fine. He's gonna be fine. So I tried to believe he'd be okay, but deep down I knew we wouldn't be. It wasn't really confusing. And after a while I understood that it happens sometimes. Yeah. - Jason</p>
	<p>4.2.5.2G I feel like it depends on the situation too. Because like, the age, of course, you wouldn't want to if you've got a younger</p>	<p>4.2.5.2H I think it is important to prepare your child for someone's death? like without my mum telling me, I also kind of knew,</p>	<p>4.2.5.2I there's a thing, no matter what happens, if you tell your child, eventually they're probably going to think oh,</p>



child, you wouldn't want to tell them that they're dying, because they wouldn't necessarily understand that you'd have to tell them, I'm not going to see him again.

And I think that would hurt more. Because with death comes realising that you're not going to see him again. But I think that's one of the hardest bits. But I feel like yeah, it depends on the situation, because with like my dad, he was in hospital for three months, I didn't see him three months. So I kind of just, I knew, but I wasn't told much. So I feel like that kind of protected me from knowing what was really going on. And it didn't hurt me. But I would have liked to have known that. I would have liked to have seen him and known that I can go and say goodbye. If you know I mean?

- Gretchen

because my dad, he was in hospital for 50 days at least out of the year. Yeah, he was was a frequent visitor? He had a, what do you call it, the card that you stamp?

- Juan

I wish I wasn't told. If you don't get told, people are gonna think oh, I wish I was told

- Jason

4.2.5.2J I just sort of figured it out. But when she was in the hospital and they were doing the tests on her every single year when they're doing the test, I thought she was just

4.2.5.2K I was gonna say I think I realised like it affects the other people. When when my dad was dying at my nan's house, like his mom's house, their dog was like,

	<p>I don't know what I thought about it. I just I knew she was in the hospital. I just didn't know why. Because as far as I knew she was very healthy. She was not needing to go away for weeks of tests.'</p> <p>- Tord</p>	<p>obsessed with him all over him. And I remember going around my nan's. I've never seen a dog look so sad. It was so weird. And then my nan came down with, like, Oo, look at this, and it was a pillowcase with his blood on it. And I thought that is so weird. That is just weird. You don't that is honestly weird. It had been like a year at this point, and she still had a pillow case with blood on it. And I was thinking, poor woman, you know, like, I didn't really think of it affecting other people until I saw that. It wasn't just me who was grieving. Even a dog.</p> <p>- Gretchen</p>	
<p>4.2.5.3 Loss of innocence</p>	<p>4.2.5.3A Like when you're like a little kid you're not self aware? Yeah. Yeah, it's kind of that stops being that and started being normal. Does that make sense?</p> <p>Do you think you've become self aware?</p> <p>You're just a little kid, you've got like, a mask over everything, everything just feels happy and like green</p>	<p>4.2.5.3B Yeah, because I've mentioned this a few times. Like, at first I didn't understand. And I think honestly, it's hit me harder now that I actually understand. So at first anniversaries and birthdays and Christmas, and that were sad but not half as sad as they are now. Because I know like I actually understand death. So it's harder.</p>	<p>4.2.5.3C You know, it's it. Yeah. Cuz when I first was like... it's like Gretchen said, when I first discovered, I didn't really think about, it was kind of like a dream. And I was like, actually growing up and realise that is true. But yeah, grief has definitely changed.</p> <p>- Juan</p>

<p>you know? Oh not green. You know what I mean.</p> <p>I know what you mean. I know exactly what you mean.</p> <p>But then it stopped being like that and things started to seem more real.</p> <p>- Tord</p>	<p>Yeah, because I've mentioned this a few times. Like, at first I didn't understand. And I think honestly, it's hit me harder now that I actually understand. So at first anniversaries and birthdays and Christmas, and that were sad but not half as sad as they are now. Because I know like I actually understand death. So it's harder.</p> <p>- Gretchen</p>		
<p>4.2.5.3D</p> <p>you guys said something really interesting to me in the brainstorming session, which was that, and correct me if I'm wrong, but I'm paraphrasing it. But it was that you felt like you became an adult? When you after you've been bereaved that you grew up very quickly.</p> <p>- Maya</p> <p>Yeah for sure, 100%</p> <p>- Leo</p>	<p>4.2.5.3E</p> <p>I'd say to an extent. I mean, like, in my case, obviously, I became the man of the house.</p> <p>- Leo</p>		<p>4.2.53F</p> <p>I have to probably say, not, you know, man at the house, but that, you know, when it happened, I had to grow up very quickly. And I think I've always, like thought that, but I don't think I've ever given it much thought because I'm like, how does that happen? I feel like it just happens naturally. Like, there wasn't that, like, I wasn't forced to do anything. But yeah, so just grew up very quickly, and felt that I had a lot more responsibility. You kind of say, anyway, when you're the oldest, like, I everyone</p>

			<p>looks up to you, like, you have to set that example and blah, blah, blah. But when it's like, heightened to them, like not having a dad anymore, anything. And I think because, you know, have that love for my siblings, and, you know, feel for them for not having their dad especially like my brothers. I find it quite hard and, like sad that they've lost their dad and that male figure. Yeah, so it's really hard to put into words, but just grew up very quickly and felt that I had a lot more responsibility. And then, yeah, I think as well with like, parent, that word parent, parenting... - Maddie</p>
4.2.5.4 Letting go (or not)	4.2.5.4A I got a balloon. I kept my balloon because I felt very attached to it. - Juan	4.2.5.4B For the anniversary we go up to his grave, like everybody who lives in the house? Not my stepdad obviously but my mom and my brother and me go. But we didn't go this year because I was too lazy. And then for birthdays, we like go	4.2.5.4C I don't like going up to my dad's grave, I think it's weird...  Do you want to speak more to that? You don't have to.  I just feel like he's not there. It's a bit weird. It's just a

	<p>meet up with the dad's side of the family, well we did that last year we haven't really done that every year. But like we're gonna meet up with them and go celebrate Yeah. - Gretchen</p>	<p>dead body. He's not there. Why are we going there?</p> <p>Yeah I've only gone up to it once or twice.. Because yeah, I don't like going</p> <p>his body is there but that's not him. And that would never be him. So why do we do that?</p> <p>I never thought about it like that. I go visit and pretend he is there with me. Because when he first died, we took Toblerone and a beer up there and we'd like poured the beer on the grave and then we sat and ate Toblerone. You just kind of have to use your imagination I guess - Gretchen</p>
<p>4.2.5.4D</p> <p>I think it would depend on who it is like hold back how much I say or what I'd say, because my similar to you my relationship, I loved him. But there was a lot that happened that I didn't agree with at the time. But now</p>	<p>4.2.5.4E</p> <p>They say never talk bad of the dead. I did a counselling session. This woman, I can't remember her name now, Trish I think her name was, when she said that maybe she was like, you know, it's alright to be like, annoyed at him. and I was like,</p>	<p>4.2.5.4F</p> <p>That is probably, one of my biggest like, was one of my biggest battles, to be honest, especially when you think about like, all those emotions that come with grief, and that like, guilt, regret, like because I held a</p>

<p>looking back, you're like, I should have let them off a bit. And but it's just complicated. It's hard.</p> <p>- Maddie</p>	<p>no it's not. You can't be but then that person's dead and you start thinking. And there's a lot of things that he did, that a parent probably shouldn't do. For example, yes, not actually acceptable. And then you're in a battle with yourself, because you love him to bits and that's your dad, but then you've also got this other side of him, which you like, hate you you know, so it's quite a battle with yourself. And you obviously try and promote the best for him, because it's their memory. And, you know, you don't want to disrespect them. But in yourself, you know, that a lot of it is falsified, I'd probably say</p> <p>- Leo</p>	<p>lot of against my dad. And I think it prevented me from having a better relationship with him. But like, you say, you can't go back and change stuff. He's not here to kind of defend himself. And because he's not here anymore. You don't want to share that or hold on to that because you don't want other people having a negative or nasty image of that person. It's like, it's hard because you try and like please everyone and make it all look not happy and jolly because when someone dies, it is not happy and jolly. Idk there's just so many people's feelings to protect when someone dies.</p> <p>- Maddie</p>
<p>4.2.5.4G</p> <p>Yeah, like I wouldn't start blabbering on about stuff my dad did to some of my friends, because then they've gotta try and deal with that as well. I mean, it's a bit I don't know, I'm very sort of like, what they don't need to know. They don't</p>		

need to know. I mean, when I think of my dad, I think 80% Good, 20% bad. That's the way I sort of look at it you know, in my relationship with him anyway. But that 20% slowly seems to be getting bigger as you're growing older. It's creeping up like 25, 30. Because obviously when he died zero, it's like no he was perfect, he was amazing. But then obviously, as you grow up, people start asking more questions. You start realising sort of things, that he used to kind of, you know you think that's not right stuff like that, and then you try and obviously put that to the back your mind and you're trying to almost protect his legacy to a certain extent, because obviously, he's a well known guy, he had a lot of friends and all that, you know, all my childhood friends knew him, because he was the kind of guy to take you to the park or something or, you know, look over your kid while he's at the parks. So, you know, everyone sort

	<p>of likes him. So you don't want to sort of tarnish that? You know, deep down. They don't know the full picture, you could say, and that's where you have a bit of a battle with yourself, I'd probably say.</p> <p>- Leo</p>		
4.2.5.5 Being triggered	<p>4.2.5.5Aa</p> <p>I know, it's just a very like, unpredictable thing. Like, even like now, before I came, I was not worried and I wasn't sad. I guess it's like, I dunno, having that space to like, think and talk about it. And then also like different triggers. I can be fine like one minute and then I dunno a smell or song like, yeah, like it's got it's got easier but like Leo said, I think for me, like as I've gotten older, there are things that made it harder</p> <p>- Maddie</p>	<p>4.2.5.5Bb</p> <p>triggers are a massive thing, I went to a festival a couple of weeks ago, me and my dad's favourite song came on, I was bawling my eyes out like a child</p> <p>- Leo</p>	<p>4.2.5.5C</p> <p>You know, one evening I'll be fine. I'll watch a tiktok of something and it will make you think of this and think about and it's like a domino effect. And all of a sudden you're a bit like damn, you know, your mood is sort of like ruined for the evening. So it is so unpredictable.</p> <p>- Leo</p>
	<p>4.2.5.5D</p> <p>I was obviously a little intoxicated but I was bawling my eyes out. I hear it on the radio all the time, but because it's live, I was like weeping. My mom's looking at me like? I don't ever cry, I don't</p>	<p>4.2.5.5E</p> <p>I have and think it links this week. So I think like bereavement affects family relationships and situations. Like regardless, because everyone is so like, unpredictable when you don't know how</p>	<p>4.2.5.5F</p> <p>My mum was divorced. But just before my dad died, she started talking and seeing this new guy. So it was quite hard sort of getting used to some random guy in the house, being</p>



cry at all. And I was like, I can't believe this is happening to me. There's a small trigger of a song. You know, like, that song is like 12 years old. You know, but it just happens, do you know what I mean? Like, I never, I was extremely happy and then all of a sudden that happened. Out it flows and everything. That's like, that's the reality of it. You know, you never know when sort of just gonna hit. It is so unpredictable.

- Leo

people are feeling one day to the next, but for me, like, gradually was finding my feet. And then my mom, like started dating. And then I was back to square one. And our family dynamic changed, and relationships changed. All of us were very, like, angry and upset. So I think it, you know, we've kind of said it before, grief is no straight line. Like we were doing really well. Mom's getting to a point where she was happy, then that was again, like, the saddest point of my life again. And it was kind of like, where she was relying on me. And like, my mom was my best friend. She, you know, had someone to talk to. And I felt I had no one. So it was like, yeah, that changed our family again. So that was something to kind of touch on that. You might be alright, but as soon as yeah, people start dating again, yeah, things shift.

- Maddie

like a male figure. And dads just died. And I was very against that. And I was sort of like, trying to push him away. You know, who do you think you are coming in, you know, trying to tell me what to do. You know. You ain't my dad. As I've gotten older, I'm like an advocate for my mum. I'm like go out and cause I realise, you know, it's, it's her happiness as well. To an extent. you know, I can't just think about myself, and because obviously, growing up, you see parents together, and so does come a time where you can't think like that, I guess. And I think now I've got to a point where I'm an advocate for my mom, that she's not sometimes. But it's it's weird at first. I did, I was a bit sort of, like, very lucky when my mom, the way she sort of was implied where he wasn't too involved. Yeah. I think because of how soon it was

			<p>after, it was pretty much instantaneous that he sort of, that they were together. But he wasn't sort of staying around all the time or here, like, constantly. Because if he was, I think they just would have made our relationship like 10 times harder because...</p> <p>- Leo</p>
4.2.5.5 Grief made me a better person	<p>4.2.5.5A It has changed. I kinda went the opposite. I first started worrying about the other people and then myself. And after a while, you just kind of realise that they're not going to come back. It's almost as if waiting for the front door to open again, but realising it's not going to. Yes, that's the hardest bit. But if I didn't, if I didn't have that grief, I wouldn't be the same person I am today.</p> <p>- Jason</p>	<p>4.2.5.5B I feel like I've become a more understanding person because of it, a more like accepting person I feel like if I if I didn't deal with grief I wouldn't put myself in other shoes like other people's shoes as much</p> <p>- Gretchen</p>	
4.2.6.1 Impact on other family members	<p>4.2.6.1A I was a kid so I only really thought about myself? But after he died, seeing how badly it hurt my mum. Because she was always a strong person who I could always go for for help. And she was nothing ever could</p>	<p>4.2.6.1B In 2018 I was just a stupid little kid and I only cared about myself, because I was a little kid. But know, I think about it because my grandparents, they were my mum's mum and dad and it must've effected</p>	<p>4.2.6.1C My parents weren't like my mom and dad went together. I didn't really notice it in my brother either. Because even like at the funeral, he didn't, I think he didn't even cry then so. I didn't</p>

<p>break. But seeing her proper break down and cry, kind of woke me up. Because I started thinking about, I started trying to help her, before helping me, because I realise how much that hurt her.</p> <p>- Jason</p>	<p>them a lot more. That's like their child. I saw a picture of them like them, with her, when she was my age, it just gave me clarity. You know? I don't know what the word is</p> <p>- Tord</p>	<p>notice it really? He doesn't really talk about it as much as me</p> <p>- Gretchen</p>
<p>4.2.6.1D No, because all my family on my dad's side live in a different country.</p> <p>- Juan</p>	<p>4.2.6.1E</p> <p>I was gonna say I think I realised like it affects the other people. When when my dad was dying at my nan's house, like his mom's house, their dog was like, obsessed with him all over him. And I remember going around my nan's. I've never seen a dog look so sad. It was so weird. And then my nan came down with, like, Oo, look at this, and it was a pillowcase with his blood on it. And I thought that is so weird. That is just weird. You don't that is honestly weird. It had been like a year at this point, and she still had a pillow case with blood on it. And I was thinking, poor woman, you know, like, I didn't really think of it affecting other people until I saw that. It wasn't just me who was</p>	<p>4.2.6.1F</p> <p>So every little thing remind me of something. And that would remind me of him. So everywhere I looked and everything I heard would be, would remind me of it. So school was hard, but I think home was harder. Because at the time, just seeing my mum cry every day, like before school, but we're getting ready to go to school, and she'd be sitting on the sofa, bawling her eyes out. And I'd go to school not knowing what I could do to help her</p> <p>- Jason</p>

		<p style="text-align: center;">grieving. Even a dog. - Gretchen</p>	
	<p>Yeah, I mean, I could speak about it, while I wanted to tell them I just wanted to be like, their support worker to an extent. Because I was sort of like, I think my mom just lost her brother, and I know, there's no competition or anything. But this is the reality of it is, he was my uncle, my big brother, but he lived the way so we didn't see him much. This is my mum's brother and my grandparents, just lost a child. So if you put that into retrospect, they are the people that I felt needed supporting over my sort of grief. You know, I slowly sort of grieved over time, but I felt like I needed to step up. And whoever is the right thing to do or not, that's what I believed was the right thing at that point in time, was to sort of look after them, and I was trying to do my own stuff. Because, you know, they've been looking after me since my dad died.</p> <p style="text-align: center;">- Leo</p>	<p>For me, I think I could see the impact that it had on my, like, immediate family, like my mum and my siblings at the time, because it was very obvious, like, you know, our life is never going to be the same. We need to, like, learn how to live now. Like, without our dad. But in terms of like, it's only until like, recently, like, even in like the last year or two that I've seen and been able to kind of understand the impact that it had on like, my aunties like cousins, grandparents. Because, like, we've got to a point where we can talk about it. Because yeah, I think, like family relationships with my dad, like, they weren't, they weren't brilliant, because of his issues. Like, everyone loved him and whatever, but it like it was hard. And so I think sometimes you kind of maybe thought, you know, they're, like, no one knows how we're feeling or like, they might not understand the</p>	<p>I'd say as I got older, I like understood it more... and as I got older, I understood what they were sort of were feeling as well. So like yeah, yeah.</p> <p style="text-align: center;">- Ashley</p>

		<p>amount of like, love that we had for him because he was, yeah,. But like it did impact them. It did affect them. So yeah, I see the impact it had directly at the time but wider family later on.</p> <p>- Maddie</p>	
	<p>4.2.6.1G</p> <p>He just told her us she died. I've never thought about how sad he must've been then but he was holding it back just so we wouldn't be as sad</p> <p>- Tord</p>		
	<p>4.2.6.1H It was like a weird, I don't know, because I am also an only child as well, so I was quite like young as well. Whereas, obviously, the parents on like, my nan was like, older. So like, I felt like they had like a separate group like to talk to people around. But then I was like, stuck in a way. I don't know how to explain it really, because I was like an only child. So I felt like I was I didn't have an experience, like, different. I felt like I was, like different in a way. I don't.</p> <p>- Ashley</p>	<p>4.2.6.1I I mean, there's obviously a massive like, kick in the guts because someone's just died. I guess parents just be parents and they're like, just struggling in front of their kids</p> <p>- Jared</p>	<p>4.2.6.1K</p> <p>Yeah, I mean, I could speak about it, while I wanted to tell them I just wanted to be like, their support worker to an extent. Because I was sort of like, I think my mom just lost her brother, and I know, there's no competition or anything. But this is the reality of it is, he was my uncle, my big brother, but he lived the way so we didn't see him much. This is my mum's brother and my grandparents, just lost a child. So if you put that into retrospect, they are the people</p>

			<p>that I felt needed supporting over my sort of grief.</p> <p>You know, I slowly sort of grieved over time, but I felt like I needed to step up. And whoever is the right thing to do or not, that's what I believed was the right thing at that point in time, was to sort of look after them, and I was trying to do my own stuff.</p> <p>Because, you know, they've been looking after me since my dad died.</p> <p>- Leo</p>
	<p>4.2.6.1L</p> <p>For me, I think I could see the impact that it had on my, like, immediate family, like my mum and my siblings at the time, because it was very obvious, like, you know, our life is never going to be the same. We need to, like, learn how to live now. Like, without our dad. But in terms of like, it's only until like, recently, like, even in like the last year or two that I've seen and been able to kind of understand the impact that it had on like, my aunties like cousins,</p>	<p>4.2.6.1M</p> <p>I'd say as I got older, I like understood it more... and as I got older, I understood what they were sort of were feeling as well. So like yeah, yeah.</p> <p>- Ashley</p>	

	<p>grandparents. Because, like, we've got to a point where we can talk about it. Because yeah, I think, like family relationships with my dad, like, they weren't, they weren't brilliant, because of his issues. Like, everyone loved him and whatever, but it like it was hard. And so I think sometimes you kind of maybe thought, you know, they're, like, no one knows how we're feeling or like, they might not understand the amount of like, love that we had for him because he was, yeah,. But like it did impact them. It did affect them. So yeah, I see the impact it had directly at the time but wider family later on. - Maddie</p>		
4.2.6.2 Financial impact	<p>4.2.6.2A My parents had been divorced before, but obviously, he sent the house money for us and like child support and stuff like that. And obviously, my mom wasn't working. So she was a small sort of, like, part time job due to her mental health. So then, consider my dad died. We lost like, pretty much two</p>	<p>4.2.6.2B Because, like I said, previously, you know, I've had my mum stressing, crying about bills, for example, and stuff like that, and really seeing that, and then having to go to school, wearing a pair of trainers that I bought myself. Say the black trainers, and they're my school shoes, you need your</p>	<p>4.2.6.2C she had to go to food banks and things like that. Just telling us don't tell anyone at school, because it's bad, stuff does have eventually have an effect on you when you're older because we view money differently and you know, you go to school and it's</p>

	<p>thirds of our income. So financially, it flipped. I mean, we were never sort of, we were always very, you know, working class, but it just made us even lower to the point where it was sort of like a food bank situation, sort of. So I'd say financially was probably worse because my mom was obviously sick trying to deal with it. But she could deal with it a bit better because obviously, they've been divorced. And it was a kind of strange thing for her.</p> <p>- Leo</p>	<p>mom's go buy another pair of shoes on my world. I just come from my mom, literally upset about bills and finances and stuff in school, and I'm saying well, that's not right, who's gonna buy this or that? I'm sort of like, it just and that's how these things in schools happen, it is like a domino effect.</p> <p>- Leo</p>	<p>just so hard to explain that.</p> <p>- Leo</p>
4.2.6.4 Pressure to support relatives	<p>4.2.6.4A Yeah, it's hard. It's hard to explain because home like wasn't always easy. My dad had lots of mental health issues. Anyway. So I think I was already I still kind of had that role of protecting my mum and feeling. Yeah, feeling very protective of her and the kids and kind of having a lot of anger towards my dad, which then when he died, resulted in a lot of regret and guilt because I didn't understand until like, I was diagnosed myself with, like, anxiety and</p>	<p>4.2.6.4B I think for me, like being the oldest of five, and us all like living together and it being like, my mom was with my dad since she was 14. It was then I then, I don't know how I think it just naturally happened that I then had to kind of like, step up, and rather me feel like a child also like grieving for their dad. It was then like, right, how can I help my mum? And my siblings who are grieving? Yeah.</p> <p>- Maddie</p>	<p>4.2.6.4C I'm trying to go home and do my homework but I look ... my main focus was looking after my mom, because of how bad she was, I was worried for her own health and stuff like that. So it got quite severe. So as they're coming to school, and I'm having all that jumbled up stuff going on at home, then school, I've got Mr. Bla bla shouting at me because my shirt is untucked. So it just made me made my trigger</p>



<p>depression. How, like, how he must have been feeling with his level of mental health. But because of that, like things happened, and yeah, it just resulted in me being very protective. But because of that kind of bridge of mum now looking after the kids need, me looking after both, I then kind of felt like, there was no one to look after me. So that's when kind of like, school was a huge part for me, and especially that a member of staff who, like took me under her wing and looked after me.</p>		<p>point a lot easier, made my fuse a lot shorter... - Leo</p>
<p>4.2.6.4D I found out that my dad was always like the head figure. Sort of, the person you can always go to or, you know, someone to support you. When he died, I had to sort of start doing the things that he kind of did, and especially about my little brother, mt dad used to take us to football and training us and stuff like that. So I started having to train my brother, and you know, just things like that. And given like, let's say, male advice. It definitely makes</p>	<p>4.2.6.4E Yeah, I mean, like, I've always like, my mum has always said like, pretty much, have been, have been my brother's brother longer than he had a dad. So I've sort of been a father figure for him longer than he actually had his his proper dad. So when you put it into that context, perspective, you really realise that you have a responsibility, especially when you have younger siblings. - Leo</p>	

	<p>you, it matures you massively. - Leo</p>		
4.2.7.1 Grief made me who I am	<p>4.2.7.1A think, you know, as crazy as it sounds, I think him dying has shaped me into possibly a better person than I would have been had he not died. Which sounds pretty crazy, but it's the truth, it has shaped me completely. You know, it matured me, like I always say, you know, you turn into an adult when you're when you go through a bereavement as a child. And I think, you know, going through that sort of all those experiences and having to grow up quicker, led me to ultimately becoming a better version of myself, I think, even though it was a bit rocky - Leo</p>		
4.2.7.2 My experience motivates me to succeed	<p>4.2.7.2A Like, that person, or people made me or, and everyone else who has been bereaved, who they are today. And I guess, as a way to, like, thank them, is just honour their memory and just succeed. And then, and then you can, like, yeah, you're just, yeah, it's just</p>	<p>4.2.7.2B Yeah, all like positives and negatives really. Sort of, you know, like my dad, implemented in raising me, I think it's only right to honour their memory and actually do something productive with my life and actually be a good person as</p>	<p>4.2.7.2C that was. financially for me is always such a big factor. You know, looking after my mom, for example, you know, this, I've seen her struggle so much, and she's sacrificed a massive portion of her life. You know, for me and</p>

	<p>helped you, knowing that you're doing something good to yourself in their memory.</p> <p>- Jared</p>	<p>opposed to just, you know, sort of not you know, amount to anything and stuff like that. I want his friends to see, you know, that I'm doing well, my younger brother doing well, as opposed to just you know, ended up in prison or doing something stupid which a lot of kids from my sort of areas seem to do, you know. When things like that happen, you know, I think it is like, an honour thing for sure. And, you know, you're carrying the surname it's, you know, you sort of think you kind of look at it as if they're sort of watching over you. I'm not sort of religious or anything, but I still look at it and kind of like see as if they were watching you. You want to be the best person I think possible. You know, that's how that's probably my take on it.</p> <p>- Leo</p>	<p>my brother. And I sort of, you know, think the cards have been dealt, but then obviously, that probably with my uncle not being there, and my dad not being there and the situation that has put us in, drives you to wanting to be more sort of like successful and a better person and, obviously, you know, you want to give your mom a better life and, you know, your younger brother and sort of, you know, just be a better person overall</p> <p>- Leo</p>
<p>4.2.7.3 Desire to work in bereavement</p>	<p>4.2.7.3A Like, it's funny how it kind of, shaped, and influenced, like, my direction. I don't definitely know, like, what I want to do or have a set</p>	<p>4.2.7.3B You know, someone who has gone through is the best advocate for it, you know, you've experienced it, you have first world, you</p>	<p>4..2.7.3C going through it, is like my biggest passion. And I think I would, like continue to try and help support people but also,</p>

	<p>career plan. But when I was little, I just thought I'd never experienced bereavement until my dad. And it made me realise and then coming to the group that there are other people like me, and seeing like, the influence of having like that support. And then like that one teacher school, like it just showed me like, the power and impact on like, having someone who kind of knows and is aware of you. And like, I don't know how I'm going to do it, but I want to be able to like be there and help support young people who have been bereaved, but it might not necessarily just be bereavement. And there might be other things. Just try and like help them get through it and feel that hope that I was given. So for me like it has impacted and shaped where I want to go - Maddie</p>	<p>know, real life knowledge of it. And I think there's no better person, or people to, you know, advocate - Leo</p>	<p>hopefully, like, find a way to educate and work on mental health with adults and teachers and the students themselves. - Maddie</p>
4.2.8.1 Training for schools	4.2.8.1A Yeah, I think I'll do it for the rest of my life. Like, it's something you know, I think, I was saying, what did I want when I was a	4.2.8.1B No, I think it is definitely, definitely with like, teachers stuff. And adults. I just think there should definitely be some training	4.2.8.1C it's not like, it's not a quick fix. But once you like, start and like, put that in place, like it will start fixing, and you'll see the

kid? And I think, you know, there's so many things and factors that are still yet to be implemented to help kids that have gone through what we've gone through. You know, someone who has gone through is the best advocate for it, you know, you've experienced it, you have first world, you know, real life knowledge of it. And I think there's no better person, or people to, you know, advocate and go to these people that are, you know, implement policies and training and, you know, ministers and whatnot to sort of, you know, make a change, because, you know, it's all about supporting, but I think there's things that, you know, I think it's a prevention thing, as well, to an extent, especially like, within schools, I'd say, you know, that training, things like that could prevent a lot of things from happening in schools for children that really, which ultimately end up with them getting excluded or them going down a bad path, and you know,

- Maddie

effect of like, so much that affects, like, for example, you're just a naughty kid. You're not, you've got so much going on with. With that in place, staff are gonna be more aware and hopefully work with you to work out what's going to help you and what doesn't, and, like, educate that so that they can work and continue to support you. That's gonna then help other staff because they're too busy. We've got too much to do. Well, now you'll be less busy because your pastoral will not be full of all your children who are refusing to go to lesson because you're going to work with them and know how to respond like

- Maddie

	<p>sort of almost borderline ruining their life. And I think that's definitely something I want to focus on. It's like the sort of school system and change.</p> <p>- Leo</p>		
	<p>4.2.8.1D</p> <p>They get trained about literally everything. Yeah. I mean, now the big thing was like the LGBT community, and how to sort of converse with people like that. You know, I just think, why can't you do that for how to deal with a bereaved child as well, you know, it's not that hard. You know, have a session or so, Forget-me-nots, do it, you know, we do like the school thing. But, again, if a school wants to participate,</p>		
4.2.8.3 Grief education	<p>4.2.8.3A</p> <p>That's like one in every class or so. So it's like, why are... you're scaring the kids but it's happened where they're so the kid could just look at that. Oh, my God, you know, Milly lost their mom, what's gonna happen to Milly now? But that's inevitable? You know, so I don't see why they can't</p>	<p>4.2.8.3B</p> <p>Well as like a child for example, it will prepare them I think much better. You know, I didn't know anything about it. No one usually does. You don't even know what happens when someone dies, they get buried or cremated, what's a funeral? You know, like, I think there's a new thing for everyone. I think</p>	<p>4.2.8.3C</p> <p>One of the things that on the one hand, I'd greatly appreciate rather than like ugh enough with that excuse is like, I was gonna say, like, it wouldn't hurt and it wouldn't, like take up too much time or resource to introduce part of the module in like, RPS. But then</p>

sort of teach it. And you know, like you said, in like RE or RNE or whatever its called now?

- Leo

scaring them and things are stupid considering the stats on how many kids are bereaved

- Leo

people are like, Oh, we don't want to scare the children. We don't want to bring up hard things.. but actually it's their excuse for everything. We just cant talk or teach them anything like

- Maddie

## Appendix 5A: Mentimeter results from the Eastern Region Conference

Mentimeter

### What do you think are the potential implications of the findings for the EP profession?

Contributions to critical incident support in schools	Informing training/supervision for staff. Extending practice of bereavement support beyond critical incidents	Involvement in support planning	How to support YP and schools. Understanding of wider context that schools may be seeing in behaviour but not understanding what it is communicating.
To ensure of being child centred in this type of work. To help schools to understand bereavement.	Supporting schools to feel more comfortable with addressing grief and providing some resources to do so	Role for EPs in training school staff/supporting their understanding of grief	The development of policies to support schools to manage bereavement and develop a shared language. Supporting schools to gather pupil voice.

1 23

### What do you think are the potential implications of the findings for the EP profession?

Working with schools to consider their bereavement support	- Offer more training to schools - Highlight resources that can be incorporated into the curriculum - Include CYP (and possibly families) in support plans	Improving critical incident support and considering training	Research which can be drawn upon to discuss bereavement within schools to support and progress the normalisation of how we cope and manage bereavement in a healthy way.
Supporting adults in schools. Critical incidents in schools	Critical incident work - I wonder if there's an opportunity for a framework to be developed to work with schools to develop a response that is meaningful to young people	To disseminate findings like this to schools To use this information to inform conversations with bereaved children	developing change towards approach for bereavement e.g bereavement policy

### What do you think are the potential implications of the findings for the EP profession?

Critical incident support How we advise staff to work with bereaved children	Provides a research base upon which to start a conversation with schools when they are supporting a bereaved child.	Working on whole class level for supporting pupils to support bereaved peers	Helping schools with understanding how to support bereaved children in their settings. Providing general psychoeducation about bereavement.
Increased awareness of gaps in support and where training opportunities are	can you publish this so EPs are more resourced to support schools? its great work!	Young person's voice in the support they would like	Support for schools in support the need of CYP who have experienced loss.



## What do you think are the potential implications of the findings for the EP profession?

Bereavement training

Supporting schools to plan with young people and support their peers to support them too

Would like more details to form a strong opinion. But my perception is that death and bereavement is something uncomfortable to face or deal with by the society in the UK

Importance of capturing child's voice and experience in advice

Mentimeter

## What are the potential implications for the education profession more generally?

Listening to CYP

Considering death and loss within the RS or PHSE curriculum

Understanding whats behind behaviour. How to talk about it. How to support. Tailor to individuals not one size fits all.

Developing the curriculum, to include social and emotional focus in equal measure to academic.

- Consider incorporating grief education into the curriculum and school environment

Staff training would raise awareness and increase confidence

More trauma informed practices and more emphasis on therapeutic approaches in schools

To be better informed

23

## What are the potential implications for the education profession more generally?

Importance of listening to the voice of the child/young person and including them in decisions

Training is key Understand children and their needs will be different and this needs to be considered

Policies around how grief and bereavement is managed in education

Ensuring children have a key adult to talk to (chosen themselves)

Include children in their support plans

Behaviour policies - not one size fits all or zero tolerance.

Removing the stigma around death and bereavement, encouraging more conversations, being child-led

To make it safe to speak about death more naturally within society and school systems

## What are the potential implications for the education profession more generally?

Possibly including grief/loss within teacher training

Being more aware of grief and the lasting impact is really important. Teachers will have also experienced grief and their way of dealing with it may well impact their thoughts/actions towards a child

Trauma informed relational approaches

Grief education. Need a broad discussion about how it should be approached

## What are the potential implications for the education profession more generally?

Better equipping school staff with supporting children

Grief ed. should be part of the national curriculum

More research in the area to raise awareness and improve practice.

Gives permission to start discussions

Developing the curriculum and making it meaningful not box ticking

Whole school training involving individual pupil for bespoke support plans

Trauma informed relational approaches

Education for young people / children about grief  
Education for staff in how they might support  
Flexibility of approach needed depending on individual needs  
Working with rather than to