On Track or Off the Rails? A Phenomenological Study of Children’s Experiences of Dealing with Parental Bereavement Through Substance Misuse

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ABSTRACT

Parental bereavement has widely been considered, in the context of child development and well-being, to be one of the most traumatic events that can occur in childhood. Parental bereavement through substance misuse is a previously unresearched aspect of bereavement research, and a previously unresearched aspect of ‘hidden harm.’ This qualitative research looks at the lived experiences of four girls who have been parentally bereaved through substance misuse, using interpretative phenomenological analysis (IPA). IPA serves the dual purposes of ‘giving voice’ to these previously unheard voices, and interpreting their experience of dealing with bereavements, through the lens of psychological theory and the wider canon of bereavement research.

The information for the analysis was collected in individual meetings with each of the girls, gathered through semi-structured interviews which took place over one to four meetings. Life for all the girls was difficult and complicated as a consequence of their parents’ troubled lives, and for all the girls their lives were marked by multiple losses and adverse childhood events both before and after their mother’s or father’s death. The analysis tries to capture the children’s narratives about their lives as a journey in which one girl is managing to stay ‘on track’, whilst the others have gone ‘off the rails.’ None of the girls had made a deliberate choice to be ‘off the rails’, yet the environment in which they live meant their life journey is a stormy one, with no safe haven, and their lives have not offered them the ‘lifelines’ they needed in order to stay ‘on track’, and navigate their way through this traumatic event. They feel shame for their disruptive manifestations of grief, for the ways in which they ‘cope ugly.’ They now have ‘spoiled identities’, and are struggling to achieve a sense of self that will help them to make the transition to adulthood. The experience of the fourth girl demonstrates the ways in which she works to achieve her personal identity, preserve her ‘reputation’, and the secure attachment she needed, in order to police her potentially disruptive manifestations of grief. In the context of this research ‘on track’ or ‘off the rails’ are positioned as more helpful constructs than ‘normal’ and ‘complicated’ grief.

The findings of this small scale research demonstrate the risks and inaccuracies in accepting the conclusion of large scale research studies which seem to indicate parental bereavement is not a risk factor for child wellbeing when family variables are taken into account. Instead it demonstrates the ways in which dealing with parental bereavement, especially when compounded by other complex life events and insecure attachments, can result in children being positioned as ‘bad’ rather than ‘sad’ as villains rather than victims, children for whom their troubled lives and loss offer ‘no excuse’ for their troubled grieving. More research is needed to understand more about the lives and experiences of this vulnerable sub group of parentally bereaved children.
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PREFACE

Graduate and post-graduate qualifications
1986  MA (Hons) Psychology  University of Edinburgh
1989  PGCE (Primary)  University of Glasgow
1994  MEd Social Justice and Education  University of Glasgow
1997  MSc Educational Psychology  Institute of Education, University of London

Summaries of previous assignments submitted in part fulfillment for this degree of Doctor of Educational Psychology:

Assignment 1: Understanding and Addressing Self Harm in Secondary Schools

Child and Adolescent Self Harm in Europe is a continent wide self report study which looks at the incidence of self harming behaviour in children aged 12-16 years. (CASE 2005). CASE report that 10.5% of 12-16 year olds have self harmed at least once, with 6-7% reporting self harming behaviour on several or more occasions. Self harming behaviour is defined by a certain set of behaviours with a deliberate intention of causing harm through cutting, burning, ingesting substances or hitting. It does not include substance misuse nor extreme risk taking behaviour. It is usually associated with stress, and is seen by those who self harm as a coping technique, albeit a maladaptive one. Although deliberate self harm is distinct from suicidal behaviour, often seen by self harmers as a way to keep on living, those who self harm are more vulnerable to suicide than those with no history of self harm.

This study compared the likely number of pupils who had self harmed in one secondary school, with a school wide survey of the number of pupils known by staff to have self harmed in the past, or to be currently self harming. Using CASE data one would predict approximately 40 of the pupils in this school to have self harmed. Teachers knew of only four pupils who had self harmed, leaving the possibility that that around 36 pupils may be experiencing significant emotional distress, and maladaptively responding through self harming behaviour. It asks whether school staff are likely to have an accurate picture of those pupils who self harm, and uses focus group discussion to explore perceptions and stereotypes about self harm in secondary school teachers, and to consider the most effective ways of responding to the needs of those pupils who are self harming, whether or not they are known to staff. The research was used as the starting point for an authority wide initiative to address mental health in secondary schools.

This research evaluates a popular intervention, ‘Let’s Learn how to Learn.’ It asks: What impact, if any, does this intervention have upon a group of struggling Year 5 learners?’ The intervention was delivered over ten weeks, with eight one hour sessions, by the researcher and a teaching assistant.

A mixed method flexible design was used to evaluate the impact upon participants. Pre intervention questionnaires to assess learner beliefs about fixed vs. incremental intelligence, performance vs. mastery motivation, optimism vs. pessimism in learning and self efficacy were compared with post intervention scores.

Results from the intervention specific questionnaire yielded a statistically significant shift (p=0.012) with children reporting more optimistic beliefs and more efficacious learning behaviour. Qualitative data, gathered from post session discussions and analysed using a theory driven framework, supported these findings and indicted that children reported stronger self efficacy and more successful learning behaviour as a consequence.

The paper proposes a cognitive behavioural framework for understanding and promoting successful learning. This addresses thoughts, feelings about learning and learning behaviour, engages learners in exploring how these impact upon learning, and how they can develop more enabling learning beliefs and behaviour. It suggests that using such a framework makes “Let’s Learn How to Learn’ a positive intervention, but that the theory underpinning this and other such interventions needs to be made much more explicit if we are to achieve a successful translation of research findings into practice, as a foundation for promoting more effective learning for young people.

Assignment 3: Can What We Know About Self Efficacy Help Educational Psychologists to Help Schools Help Children Learn Effectively? A Review of the Literature into Self Efficacy

This literature review explores the relevance and use of self of self efficacy as a psychological construct in educational settings. Self efficacy describes the beliefs which people hold about themselves which are critical to the exercise of self control and personal agency. Self efficacy has a long, venerable research tradition, demonstrating the benefits of high perceived self efficacy across all areas of human functioning, including education.
The research has demonstrated the ways in which self efficacy can be promoted in classroom settings, but in this review it appears that much of this research has been conducted by researchers rather than by education practitioners. It therefore has reduced educational validity. The review indicates that there is still a substantial way to go in translating robust psychological theory into applied psychological and educational practice. That this has not yet been done is not because self efficacy is an irrelevant construct in the psychology of effective learning. It is too widely used across the range of human endeavours to be dismissed so easily. The literature searcher here suggests that within education self regulated learning is used as an applied psychological construct, which draws upon self efficacy as it’s over arching meta theory. The review concludes with a suggestion that applied psychologists use a deliberate theoretical framework if they are ‘to give psychology away.’ (Miller 1969) and that a cognitive behavioural framework, underpinned by an understanding of the processes and effects of self efficacy, could offer this theoretical framework.
Chapter One: The Research In Context

1:1. The Rationale for the Research: Integrating Theory, Research and Interventions in Educational Psychology Practice

This research started with the story of a boy I worked with whom I shall call Luke. It is Luke’s story that has made me, as an educational psychologist (EP), believe that understanding and responding to the needs of children and young people who are parentally bereaved through substance misuse is an important but as yet unexplored area for research.

EPs work with individual children, within the context in which each child lives and learns. As an EP I strive to identify, demystify, represent and to address the interconnected factors which shape a child’s sense of self, the lives they live and the challenges they face. As well as seeking to address issues affecting individual children EPs also work within the context, at a systemic level, to try to address and influence these factors. It could therefore be argued that Educational Psychologists (EPs) undertake micro research with each case, whether it focuses upon an individual child, or a wider systemic issue. In addition to this ‘micro research’ within each case EPs may take on an advocacy role where the voice of the child may not have been heard, or is misrepresented, and seek to bring about therapeutic change by recruiting others who work with and for the child, as well as the child themselves, to understand and address these factors.

Sean Cameron has described the ‘distinctive contribution’ and purpose of applied psychologists as providing an integrated and coherent perspective of:
1. complex environments
2. the complex problems and situations that occur in these environments
3. the complex needs of people which arise from such problems or situation. (Cameron 2006:292).

In some cases this may mean bringing to the surface factors or issues which have not previously been acknowledged. For example, the death of Luke's father, as a consequence of his drug use, was a factor which had not been acknowledged in the challenges which Luke had to deal with, in understanding his needs, nor in the solutions
which other people had sought to impose on Luke. I wondered how many other children
might have experienced parental bereavement through substance misuse, what their
circumstances were, how they experienced the bereavement and the kinds of things that
might help or hinder their abilities to deal with this potentially traumatic experience.

The psychological perspective, ‘the distinctive contribution,’ which I hope I make as an
EP, draws upon five distinct elements, again summarised by Cameron, and demonstrates
the close links between qualitative research methodologies and professional practice. I
have slightly adapted Cameron’s formulation in my presentation of these key factors.
These are: adopting a psychological perspective of the nature of human experiences and
problems; drawing upon psychological theory to uncover mediating variables, which may
explain how certain events or experiences are connected, provide a ‘simple but useful map
of the interaction between people and their environments’, draw upon theory, evidence
based practice and practice based evidence to recommend strategies for change. (adapted
from Cameron 206: 293 and Fox 2011). It is these elements which mean EP practice
might be described as ‘micro research.’

I attempted to incorporate elements of these five factors into my work with Luke, in trying
to understand Luke’s experiences, and to help Luke make sense of these, and how these
might have come to influence the life he led and the challenges he was currently facing. I
work within a phenomenological framework which strives to recognise and value the lived
reality of the individual, and to understand this lived reality, both within the context in
which it occurs, including the immediate realities of the individual within their family,
school and community, as well as recognizing some of the institutional and cultural
discourses by which individuals and groups come to be stigmatized and marginalized and
disempowered. In a sense, as an applied psychologist, I am undertaking qualitative
research with each client, working with their participant generated meanings, exploring
their construction of the world and exploring ways of changing it for the better (Willig
2008:19).

Within the broad sweep of qualitative research methodologies my professional practice, as
an EP, shares the philosophical foundations and aspirations of interpretative
phenomenological analysis (IPA). These have been summarised, by Larkin, Watts and
Clifton, as:

‘The phenomenological requirement to understand and give voice to the concerns of
participants; and the interpretative requirement to contextualise and ‘make sense of’
It is my hope and intention, in this research, to identify and understand some of the needs of a group of children and young people who have experienced parental bereavement through substance misuse, to ‘give voice’ to a potentially very vulnerable sub group of children who as yet appear to be unidentified in either bereavement research, or in sub groups of vulnerable children, and to ‘make sense’ of their experiences within a psychological framework which helps to identify ways of addressing the needs of children who have been parentally bereaved through substance misuse.

1.2. The Genesis of the Research

This thesis starts with Luke’s story. Through my representation of Luke’s story I attempt to make explicit:

a) Luke’s complex environment: the interweaving of adverse childhood experiences (ACEs) which Luke has experienced, which can be understood within a framework of disruptive transitions, which amplify risk and reduce resilience factors

b) the complex emotional, social and educational problems he has, as a consequence of his life experiences

c) the ways in which Luke’s needs are exacerbated as he attempts to cope with his difficulties, and the ways in which his maladaptive ‘coping ugly’ strategies compound a ‘spoiled identity’ and legitimize his stigmatization.

Telling Luke’s story demonstrates the interpretative phenomenological framework through which I have attempted to give him a voice, and to make sense of his experiences within a psychological framework, as a starting point for enabling Luke, and those around him, to develop different perspectives i.e. more compassionate and less stigmatizing, so that Luke is able to explore and develop different aspects of his identity.

At this point I had only a rudimentary knowledge of bereavement research and theory. My knowledge of the impact of parental substance misuse was based upon my knowledge of risk and resilience factors in influencing psychosocial outcomes for children. The psychological knowledge I used in attempting to weave together different strands of Luke’s story was based upon social constructivist psychology, which holds that the our sense of self, our ‘agentic self’, is developed from the interactions we have with the world.
around us and those within it. Attachment theory, self efficacy and agency, and cognitive
behavioural approaches are all rooted within this social constructivist paradigm. Social
constructivism is epistemologically consistent with post structural philosophies which are
underpinned by a belief that people are recruited into the subjugation of their own lives by
power practices and social discourses. Goffman’s construct of ‘spoiled identity,’
developed from his work into the social construction of identity and stigma (Goffman
1963), fits into the social constructivist paradigm. All of these have shaped my
interpretation of Luke’s experiences, and all of them are coherent with a commitment to
an interpretative phenomenological framework for EP research and practice.

1.3. Luke’s Story

Luke lives with his paternal grandmother, Karen, whom he calls ‘mum.’ His father died
from septicaemia when Luke was four, following years of injecting drugs. His birth
mother has been in and out of prison for drug related offences, and unable to care for him.

Luke had done well at primary school; he was academically able although underachieving
slightly, had a secure group of friends, engaged in a range of extra curricular activities and
was well liked by peers and staff. He was not identified as a child who would need
additional support on transition to secondary school. He had never been on the special
educational needs register for any reason, including social, emotional and behavioural
difficulties.

Luke’s gran/mum had been treated for cancer when he was nine, and he had been fearful
that there might no one to look after him. His gran/ mum told me that he was loving and
attentive to her throughout her treatment. She has now recovered. Luke’s mum/ gran had
never talked to Luke about his father, and Luke did not know the circumstances
surrounding his father’s death.

Over the Summer between primary and secondary school Luke’s mum/ gran separated
from her partner, with whom Luke had had a good relationship, and with whom he spent a
great deal of time. He had enjoyed making intricate models with him, and helping him
with DIY. Karen and Luke moved house, several miles away from their previous home
and from Luke’s primary school. Luke started at secondary shortly after the move. He
had therefore experienced three disruptive transitions with three months: the relationship
break up of his carers/parents, a house move, and a move from primary to secondary school.

Luke was in conflict with teachers from his second week. Over the first term he developed a reputation for aggression and violent behaviour. His reputation and his behaviour deteriorated. He was put on a part time table and allowed to attend school for two lessons a day. He spent some time in the Pupil Referral Unit. The school staff came to see him as a child with severe behaviour difficulties.

Over the year Luke’s mother’s boyfriend, who Luke knew, died of a drug overdose. His gran/mum went to the funeral. Luke chose not to go. School staff knew about this bereavement, staff noted a further deterioration in his behaviour, and his punishments escalated as a consequence.

School submitted a request for a statutory assessment\(^1\) of Luke’s special educational needs on the basis of his challenging behaviour, stating that in their view Luke’s needs could not be met in a mainstream school, as he was a danger to himself and to others.

I met Luke to carry out the psychological assessment of Luke’s needs in response to the request for statutory assessment. I noted that Luke had not had any support to deal with the complicated losses he had experienced. Luke seemed to be being blamed for choosing to behave in these maladaptive ways, and blamed for choosing not to comply with the behavioural management strategies which school attempted to put in place. Luke frequently alleged that other children taunted him about his father’s death, and about how his father died, but school staff had never been able to verify any of this. I was not in any case interested in the ‘veracity’ of Luke’s claim. If this was what he felt, or needed to tell me, and others was happening, then I felt this represented a matter of concern to Luke. This was one of the issues which I explored in my work with Luke, as I wondered if this was Luke’s ways of expressing his need to talk about his father, and to know more about the circumstances surrounding his death. Luke found this a useful ‘working theory’ and was able to ask his mum/gran for the information he needed. We were therefore able to focus on a phenomenological aspect of Luke’s experience of dealing with his father’s death, rather than debating the truth or otherwise of claims made about taunts from peers.

\(^1\) Schools or parents submit a request for statutory assessment of a child’s educational needs, to the local education authority, when they believe that they child has significant and long term special educational needs requiring additional special educational provision to the provision normally made within mainstream schools. (Education Act 1996)
He now talks more openly about his father with his gran/mum.

Sociology and psychology both explore theories of personal resistance to emotional and social pressures, to social exclusion and to traumatic life events. The phrase ‘coping ugly’ has been coined by George Bonnano, to explain the process of socially unattractive but psychologically effective processes of dealing with traumatic life events, including bereavement (Bonnano and Mancini 2008).

At a time of multiple disruptive transitions, compounded by earlier loss and trauma, it seemed that perhaps that Luke was ‘coping ugly’, to help him through a time of crisis. The ‘coping ugly, however, may have triggered a set of social responses which compounded his trauma, and removed him even further from help and understanding.

Coping ugly removed Luke’s entitlement to sympathy and understanding, and legitimated a chain of socially excluding responses, which in turn create a stigmatized identity. The stigma, or spoiled identity arising from the ‘coping ugly’ response, might therefore hold the potential to do more long term damage to the traumatized individual who is ‘coping ugly.’ As Hinshaw warns,

“Stigma transcends these processes [stereotyping, prejudice and discrimination] by including the strong likelihood that the castigated individual will internalize the degradation.” (Hinshaw 2005)

The significant transitions and risk factors that Luke had experienced were buried within the story of his day to day crimes within school. The institutional processes by which Luke’s behaviour was labeled as pathological, and which ‘spoiled his identity’ did not allow Luke to be positioned as a child needing, let alone entitled to help. Luke was internalizing his degradation, he was starting to be verbally abusive to his gran, to cease to care for his appearance and hygiene, and to become more different from the other children in school. Luke’s gran/mum had to choose between colluding with the school version of reality, as a ‘co-operative parent’ by confirming Luke’s deviance, or resisting this process and being labeled a ‘problem parent.’ She chose the latter.

For Luke the emphasis had been on his behaviour, not upon the emotional needs and life experiences which underpinned those needs. This very emphasis on his bad behaviour exacerbated his emotional needs and contributed to his shame, anger and isolation. The therapeutic work which I undertook with Luke, his gran/mum and school staff
focused upon a developing an alternative version of reality, a ‘story of resistance’ to build on Luke’s many resilience factors, to develop his strengths and to help him and others to see his strengths as an achievement in the context of the challenges he had faced. As I wrote the first draft of this thesis Luke was in school full time and life seemed to be becoming easier. He was subsequently excluded from school for persistent low level disruption, and now attends a Pupil Referral Unit where he is happier, has developed relationships with staff and pupils and is able to engage in some purposeful activities. However, his formal education is suffering and he has lost what he hoped to hold to, being in a ‘normal’ school and being a ‘normal’ kid.

Luke’s story has inspired this research. As an EP my role is to identify and address barriers to personal development, to link theory with practice in order to develop ‘simple but useful maps’ to represent the lived experiences of my clients, and to apply psychological theories and evidence based practice and practice based evidence to try to chart a way out of ‘complex problem situations.’

Developing knowledge and understanding of the needs of children who are parentally bereaved through substance misuse, how they deal with this experience, the kinds of support they receive and the kinds of support they need seemed to be a useful and important piece of research.

1.4. Researching How Children and Young People Deal With Parental Bereavement through Substance Misuse: Aspirations, Aims and Research Questions

The aim of this research is to understand the experience of dealing with parental bereavement through substance misuse, through attempting to represent and interpret the accounts of young people who are living through experience. The research has been carefully framed to focus on children’s experiences of dealing with parental bereavement, and the lived identities of these parentally bereaved children.

The research uses interpretative phenomenological analysis (IPA), which aims to explore the lived experience within the context in which it occurs. I hope that IPA will enable me to weave in the social context in which the bereavement occurs, and the sociological processes of inclusion, exclusion, stigma and shame, if indeed, these are part of the lived experiences of the young people contributing to this research.
The aspiration is that this research will contribute to a process of ‘giving voice, to a group of young people who have experienced a complicated parental bereavement, and who may not have the opportunity, either collectively or individually, to represent their views, nor to have them represented by other people on their behalf.

The main research question asks:

• How do children and young people deal with parental bereavement, when the bereavement is caused by substance misuse?

Some of the issues I anticipate arising in my research meetings are:

• How do children and young people say they deal with parental bereavement?
• Are children and young people able to identify factors which make it more or less difficult for them to deal with their parent’s death?
• What might professionals and / or carers do to help children and young people deal with parental bereavement through substance misuse?
• Do current bereavement theories and a risk and resilience framework allow us to predict and plan ways of amplifying resilience factors and counteracting risk factors?

1.5. An overview of this thesis.

Chapter 1 has described the real world context for this phenomenological research, in terms of the lived experience of my professional involvement in Luke’s story. This chapter gives a brief overview of the themes which I think are interwoven into Luke’s experiences, some of which may be shared by other children and young people who have also experienced parental bereavement through substance misuse.

Chapter 2 presents a review of the research literature addressing bereavement and in particular research into parental bereavement in childhood. It explores a psychological framework for understanding the psychosocial experience of bereavement through an attachment perspective, and common themes in research into parental bereavement, the possible long term consequences of this, and interventions to support children who have experienced parental bereavement.

Chapter 3 describes the scoping exercise and feasibility study undertaken to explore the scale of this phenomenon, by looking at facts and figures about drug related deaths, and
provides a brief literature review about the experiences and outcomes of living with and
dealing with parental substance misuse in childhood.

Chapters 4 describes the methodology, the ethical challenges and the procedure of
undertaking this research. This chapter also explores IPA as a research philosophy as well
as an analytic procedure through which I, as researcher, make sense of the stories of my
contributors as lived experiences, with individual and metathemes emerging from the
research data.

Chapter 5 presents the results and analysis of the research interviews, analysed using the
IPA framework, as individual stories with particular themes, and as a overarching
framework for understanding the experiences of my research contributors, as a series of
master themes.

Chapter 6 attempts to weave these into a theoretical framework which gives a voice to
these children who share this experience and which may indicate ways of addressing their
needs. In particular it considers the implications of this research for applied educational
psychology.
Chapter Two: Parental Bereavement in Childhood

2.1. Chapter Overview

In this chapter I summarise some of the key aspects of bereavement research over the last half century, before focusing in more specifically on research literature about bereaved children. My literature review is broad based, to try to explore and capture the different aspects of bereavement research which seem most likely to offer me a theoretical framework from which I will be able to interpret the experiences of the children who are contributing to this research, as this is an important aspect of interpretative phenomenological research. Within the context of presenting a conventional literature review it is important to acknowledge that human endeavours to understand, explore and mitigate grief predate contemporary research by millennia. Shakespeare captured a dominant theme in bereavement research over five hundred years ago, when he wrote: ‘Give sorrow words. The grief that does not speak whispers o’er the fraught heart and bids it break.’ (Macbeth: Act IV Scene III)

2.2. Bereavement Research: An overview

In the last fifty years bereavement has emerged as a unique field of psychological and psychiatric research, with the emphasis upon understanding the experience of grief, and those factors which aid or exacerbate the experience and/or pain of grief.

Within Western Society this area of research has developed alongside an epidemiological change in mortality, as early mortality and the experience of death in early or mid life has become the exception rather than the norm. Stroebe, Hansson, Schut and Stroebe have edited three seminal ‘Handbooks of Bereavement Research’ (1993, 2001, 2008), demonstrating the depth and breadth of bereavement research, with different chapters focusing on the different aspects of bereavement research, from trajectories of grief, physiological sequelae, psychometric measurement of grief, post traumatic growth, to the efficacy of online bereavement support, as well as a range of chapters dealing with different aspects of the sociopsychological experiences of grief including the existence or otherwise or ‘normal’ and ‘complicated’ grief. The complexity of grief as a psychological construct, and the ways it in which individual trajectories of grief unfold, underpins all of
the research documented in these handbooks.

I am seeking to establish a theoretical framework for something that is and always will be a core aspect of human experience, which reaches further and deeper into the heart of human experience than can be truly or completely captured in any research study.

Within the language of bereavement research ‘bereavement’ is the fact of losing someone significant in an individual’s life, ‘grief’ is the behavioural, cognitive, affective and somatic expression of bereavement for each individual. ‘Mourning’ describes the cultural context, concepts and rites which shape social and personal responses to bereavement. There is some overlap between ‘mourning’ and ‘grief’.

Through the second half of the last century there have been two dominant major foci within bereavement research:

- one which explores models of grief and proposes ways of understanding the trajectory of grief for individuals and groups,
- one which explores the notion of ‘normal’ grief, and the ways in which experiences of grief may be ‘abnormal,’ ‘complicated’, ‘disenfranchised’ or ‘pathological.’

Much of this research is drawn from large scale epidemiological studies which seek to measure the experience of grief, to map out how grief is experienced differently by different individuals and groups, and to measure the outcomes or sequelae of grief, compared to people who have not experienced significant bereavement. A theme that is consistently demonstrated in the various chapters over Stroebe, Hansson, Schut and Strobe’s three handbooks (1993,2001, 2008)is that there is no single model or theory to account for the bereavement experience, because there is no unitary ‘bereavement experience.’ Indeed, these books reveal the challenges of research into this intensely private aspect of personal experience, and legitimates qualitative research as an essential precursor to explore previously unresearched aspects of bereavement experiences.

Quantitative studies, by their nature, cannot capture the individual experience of grief and bereavement, the way it shapes life experience and identity, how it fits into the lived experience of each individual’s life story. The role and contribution of qualitative research, and practice based evidence is crucial in developing the field of bereavement research. Neimeyer, Hogan and Laurie, whose main focus of research is within meaning making in bereavement, makes the case:
Qualitative research is especially important in generating theory where little good theory exists; in revealing how particular people make meaning of events and in moving towards a deeper understanding of a particular phenomenon, rather than a nomothetic set of causal influences. (Neimeyer, Hogan and Laurie 2008: 154)

My research focuses not upon establishing the incidence of parental bereavement through substance misuse, nor the outcomes for children whose parents have died through substance misuse. It is concerned with attempting to capture the ‘lived experience’ of such a loss, how children express and communicate their grief and their loss, the kinds of things which make dealing with the bereavement easier, or more difficult, the ways in which they remember the parent who has died and the ways in which these memories shape their current lives, to achieve a ‘deeper understanding of a particular phenomenon’ of parental bereavement through substance misuse.

In representing and interpreting these lived experiences I anticipate that I will draw upon a psychological framework of bereavement research which I discuss below. The themes emerging from bereavement research may inform the interpretation I make of the stories my research contributors share with me. I hope to be able to use existing theory to start to build a theoretical framework for representing and interpreting the bereavement experiences of this group of children.

2.2.1. Theoretical Models of Grief

Contemporary research into the psychological experience of bereavement demonstrates that each experience of bereavement depends upon the interweaving of personal, intrapersonal and social and factors, within a cultural context. For many people normal grief means an emotional distress so intense that it prevents the person, for some time, from continuing with activities and relationships of everyday life. (Lindemann 1944, Engels 1961, Weiss 2008). Researchers who have categorized the sequelae of normal grief into behavioural, cognitive, affective and somatic categories demonstrate the abnormality of many of these aspects of individual functioning in normal life, and their normality within the context of a bereavement. (eg. Lindemann 1944, Parkes 1996, 2002, Klass Silverman and Nickman 1996, Worden 2009). In sum therefore, bereavement may be a time of intense abnormality, with the individual experiencing and/or displaying a range of thoughts, feelings, behaviours and somatic symptoms that might be considered abnormal.
or pathological in other contexts. In the context of grief, however, these are construed as ‘normal’.

The psychoanalytic view of grief as work which needed to be undertaken in order to relinquish bonds with the deceased, and release energy for new relationships with the living (Freud 1917, Lindemann 1944) which prevailed until the early 1970s in research, and longer in everyday relationships, has lost it’s hold in bereavement research. The bereavement work of recent years has developed a new direction. Within this there is a constellation of differently named but conceptually similar theories which explore the ways in which the bereaved seek to reconstruct a new relationship with the deceased person, as they come to terms with the loss of their physical presence and come to redefine themselves, their relationships and the world around them, following the bereavement.

The most influential of these models are Klass and Silverman’s continuing bonds theory (Klass, Silverman and Nickman 1996), Worden’s task model of grief (1996, 2009) Stroebe, Hansson, Schut and Stroebe’s dual process model (2001, 2008), Niemeyer’s ‘meaning reconstruction’ (Neimeyer 2001). All of these identify the following as aspects of grief: to accept the reality of the loss; to process the pain of grief; to adapt to a world without the deceased; and to find an enduring connection with the deceased in the midst of embarking on a new life.

Another crucial element of current bereavement research is the move away from a conceptualization of grief as a linear process, marked by different stages, to a conceptualization of grief as a cyclical process, in which grief is experienced in different ways at different times, influenced by age, developed stages and external life events. Crucially these theories maintain the relationship between the dead person and the bereaved that endures a lifetime. This is vividly brought to life in personal accounts of children and spouses who have been parentally bereaved. (Abrams 1991, Holland 2001, Didion 2005)

Reorientation theories have paved the way for the recognition of post traumatic growth as an aspect of bereavement research, with many studies demonstrating the way in which the bereaved seek to incorporate aspects of the deceased into their own identity, as a way of remembering and honouring them, and of maintaining bonds and finding meaning the death. (Schulz 2007, Davis 2008, Brewer and Sparkes 2011).
All of these have, as an essential element, meaning making, as the bereaved person strives to reconstruct their cognitive and emotional schemas, or their personal narratives, their sense of who they are in a world without the deceased person, their experience of what it is to be bereaved. It is this complex, cyclical, multi layered experience that can only being fleetingly captured in quantitative research.

The stories people tell about their personal journeys through grief are the starting point for quantitative research and theoretical models. The relatively new area of bereavement research started with practice based evidence, with case work, by psychiatrists, psychologists and counselors with individuals. The personal stories of individual children are the starting point for this research.

2.2.2. The Role of Attachment in Bereavement Theories

Post traumatic growth theorists explore the ways in which bereaved individuals make meaning in order to recreate or recalibrate an ‘assumptive world’ which has been threatened by the bereavement (Janoff Bulmen1992). The construct of the assumptive world is drawn from Bowlby’s attachment theory. Attachment theory explains the ways in which different attachment experiences with the primary caregiver/s lead to different assumptive worlds. The assumptive world is the view we have of ourselves, our relationships with others and the world in which we live and which underpins our development and functioning. Our assumptive world, it is argued, shapes the way in which bereavement is experienced.

An attachment perspective on bereavement suggests that:

‘psychologically successful mourners can integrate elements of their identity that were related to the lost relationship into a new identity, maintain a symbolic bond to the deceased even while adjusting to real circumstances and restore or even enhance their sense of security and wellbeing on the basis of both the continuing attachment bond with the deceased and new attachment bonds with living companions.’

(Mikulincer and Shaver 2008: 94)

All current bereavement research recognizes the role of attachment in the experience, expression and readjustment to an altered world. The relationship which the bereaved person had with the deceased, and the relationship which the person has/ had with her his primary caregiver/s are both important in understanding bereavement. Different aspects of
this research show that those with ambivalent or insecure attachments to a primary
caregiver in childhood, and / or to the deceased are likely to experience more difficulties
following a bereavement. (Parkes 2002, Mikulincer and Shaver 2008, Field and Sundin,
2001, Wayment and Vierhaler 2002). In Mikulincer and Shaver’s terminology, they are
more likely to be ‘psychologically unsuccessful mourners.’ (Parkes 2002)

The fundamental tenets of Bowlby’s attachment theory underpin much of my work as an
EP, often guiding the interpretation I make about a child’s needs, and the strategies I
develop in order to address these needs. I often cite Bowlby’s expression, ‘that all of us
are at our best when our lives are organized as series of excursions from a secure base.’
(Bowlby 1980). When I started this research I did not know that attachment theory was
also a core construct in bereavement research. This is theoretically consistent with the
phenomenological framework which underpins my practice, and is likely to provide a
model for predicting how different children might deal with bereavement in different ways,
depending upon their attachment experiences. It is theoretically plausible to suggest that
children with insecure attachments are less likely to have a secure sense of self, and are
therefore more likely to have their assumptive world and their sense of self undermined by
a bereavement. With no secure base they are probably less well equipped to navigate an
excursion through grief, and more likely to be thrown off course by the hazards that this
presents. They may be more likely to be ‘psychologically unsuccessful mourners.’ I will
explore research evidence about the risk and resilience factors which influence the
experience and impact of parental bereavement in subsequent sections.

2.2.3. Complicated Grief: Definitions, Risk and Resilience Factors

Mikulincer and Shaver posit ‘psychologically successful’ and ‘psychologically
unsuccessful mourners’ as a construct to explain and describe the outcomes of
bereavement upon the lives of individuals. This continuum is also represented as
‘traumatic’ versus ‘non traumatic grief’, ‘prolonged grief disorder’ (Prigerson,
Vanderwerker and Maciejewski 2008) or ‘normal’ versus ‘abnormal,’ ‘pathological’, or
‘complicated grief’ (Rubin, Malkinson and Witzum 2008). Whilst the terminology varies,
what these terms strive to represent is the experience of grief where the individual is not
able to return normal functioning within a culturally expected timescale, or whether the
grief is more intrusive, more intense or results in more disruptive manifestations than is
culturally expected. It is believed that 15-20% of bereaved individuals have difficulties in
The role of attachment is, as we have seen, a crucial risk factor for complicated grief, and all of the different constructs identify the relationship of the bereaved and the deceased as a determining factor. Rubin and co-authors caution that without nuanced assessment of the relationship between the bereaved and the deceased, there is a risk that an overemphasis on biopsychosocial functioning may lead to interventions which could actually suppress healthy ways of adapting to the bereavement, by suppressing or altering the relationship with the bereaved. They assert the importance of striving to:

‘identify fundamental aspects of the cognitive emotional map of the bereaved and the relationship[of the bereaved] to him or her.’ (Rubin et al 2008: 189).

Those experiencing traumatic grief are at risk of longer term adverse outcomes, may be more likely to have ongoing mental health difficulties and to require professional support to help to find a way forward from grief. Diagnosing complicated grief is important in identifying potentially vulnerable individuals who otherwise may be at risk of poor long term outcomes, or even suicide (Parkes 1996). Accurate identification also helps to ensure that those who experience normal grief do not have unnecessary treatment thrust upon them. This risks undermining those support factors which occur naturally within the individual’s life.

Despite the disagreements over nomenclature bereavement researchers have almost perfect agreement on the risk factors which indicate vulnerability to complicated grief. These include, as previously stated, attachment experiences, but there are other important risk factors. Parkes is the foremost researcher within the field of bereavement in the UK and I borrow his presentation of risk factors for complicated grief (Parkes 2002). These risk factors fall into one of three categories: mode of loss; personal vulnerability and lack of social support. Within mode of loss Parkes has also included Doka’s construct of disenfranchised grief (Doka 1989) which arises in situations where grief is discouraged or where it must be concealed or where the death is shrouded in secrecy and / or shame.

Examples of stigmatized deaths identified by Doka include suicide, the death of a clandestine lover, homicide. Doka does not include death through substance misuse as an example of disenfranchised grief but it seems plausible to suggest that many of the issues around disenfranchised grief, such as lack of entitlement to sympathy or support, shame, guilt and rage are likely to be experienced by some of those who are bereaved through substance misuse. There are likely to be additional cultural constructs about death through substance misuse, with the possibility that those who die through substance misuse have
brought it on themselves, and perhaps that their families and society are better off without them. Children whose parents have died through substance misuse may also be less likely have to a secure attachment figure, if their primary carer is the substance misuser, and perhaps to come from a family and where there are relatively low levels of social and familial support. These propositions will be explored in more detail in the next chapter.

These risk factors identified by Parkes reflect the personal context which shapes the ways in which each bereavement is experienced. Whilst these risk factors are specific to vulnerability to complicated grief, they map onto risk and resilience factors which are used more widely in mental health promotion and demographic studies to identify those at risk of mental health difficulties.

The previous section indicated the link between attachment and grief experiences, with those with more unstable or insecure attachments to primary caregivers more vulnerable to complicated grief, and more likely to become psychologically unsuccessful mourners. Parkes’ risk factors add lack of social support or isolation, and mode of loss to this as other significant risk factors. As an EP I often use risk and resilience factors in my whole school training for mental health awareness, as well as in individual work to explore risk factors which can be mitigated as well as resilience factors which might be developed. Again, the broad field of bereavement research fits within my theoretical framework for my professional practice.

**Table 1: Risk Factors in Bereavement**

<table>
<thead>
<tr>
<th>Mode of loss</th>
<th>Sudden or unexpected loss for which people are unprepared</th>
<th>Violent or horrific losses</th>
<th>Multiple losses</th>
<th>Losses for which the person feels responsible</th>
<th>Losses for which others are seen as responsible</th>
<th>Disenfranchised losses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personal vulnerability</td>
<td>Dependent on deceased person</td>
<td>Ambivalence to deceased person</td>
<td>Person lacking in self esteem and / or trust in others</td>
<td>Persons with previous history of psychological vulnerability</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of social support</td>
<td>Family absent or seen as unsupportive</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Parkes 2002)
2.3.4. Mode of Death as a Risk Factor for Complicated Grief: Bereavement following Death through Substance Misuse

This is an active area of research enquiry, and there is a substantial body of bereavement research which explores the sequelae of different modes of death, and the correlation between mode of death and vulnerability to complicated grief. The research usually classifies death through accident, suicide and murder as traumatic death.

Much of the data from quantitative research in this area runs counter to clinical evidence, in suggesting that mode of death does not predict complicated grief. It is likely that this is in part consequence of the nomothetic measures used in quantitative research studies. Many of these studies have been conducted on student populations, (e.g. Gillies and Neimeyer 2006) and therefore may not be representative of the wider population, let alone those who are most likely to experience violent and sudden loss. In large scale quantitative studies it is possible that effect sizes for relatively small sub groups are not detected in broader research, and that general conclusions which are drawn do not reflect the experiences and vulnerabilities of specific sub groups.

I was surprised to discover that death from substance misuse is not classified as ‘traumatic death’ in research studies which explore bereavement outcomes by mode of death. A subject search through key reference books, including Stroebe, Schut and Strobe’s three handbooks and a recent four volume anthology of seminal bereavement research texts by leading researchers in the field from the US and Europe in the last twenty years (Doka 2006) did not yield any citations.

I was not able to find any relevant literature in key word search of the major bereavement journals; Mortality, Bereavement Care and Death Studies. A key word search using different combinations of key words including bereavement, death, dying, grief, substance misuse, drugs and alcohol to search through PsychINFO brought up only two relevant citations, exploring a parent or grandparent’s experiences following the death of a child through substance misuse (Guy 2004).

Guy’s work explores the challenges of accepting the death, living with guilt and a feeling of responsibility and most poignantly, a sense of shame and stigma, and a feeling of being judged rather than sympathized with by others. All these are features of ‘disenfranchised grief.’ (Doka, 1989, 2006) It appears that those who are bereaved through substance
misuse are forgotten and disenfranchised by bereavement research. Given the likelihood that those bereaved through substance misuse will experience some if not all of the risk factors identified by Parkes this seems a surprising omission in the field of bereavement research.

Although there does not appear to be any research in this area as yet, the theoretical framework which I am building, to help me understand and interpret the experience of parental bereavement through substance misuse, suggests that these children may be more vulnerable to complicated grief because their assumptive worlds will be more unstable, they are more likely to have insecure or disrupted attachments, may be more personally vulnerable, may feel the shame and secrecy of disenfranchised mourners, and may have more difficulty making sense of the death and in recalibrating a relationship with the person who has died. I review research into the experience and impact of living with parental substance misuse in the next chapter, as this may indicate the extent to which this tentative theoretically framework is consistent with research evidence.

This theoretical framework is broadly consistent with the theoretical framework which I use in my practice, and with the phenomenological framework of this research. This is a theoretical framework that has been woven largely from bereavement research with adults. The emphasis upon the pivotal place of attachment, the relationship with the deceased, and the importance of sense making as people navigate their way through different phases and aspects of grief validates the emphasis upon a research methodology which seeks to understand the inter and intra personal processes through which people experience bereavement and they ways in which they deal with this experience as they continue with their lives.

In this research ‘bereavement’ often refers to the death of any significant other, and so covers a range of relationships, from friends, colleagues, parents, children and partners. This broad field needs to be narrowed in order to develop a more nuanced understanding of the experience of parental bereavement in childhood.

2.3. Parental Bereavement in Childhood

Julie Stokes, chair of Winston’s Wish, a UK organization working with and for bereaved children states:
Every 22 minutes a child in Britain is bereaved of a parent, which equates to 224,000 children each year learning to live with a powerful range of conflicting and confusing emotions. Bottled up, these emotions can have a devastating impact upon the individual child and upon society (Stokes 2009)

Almost all research into parental bereavement in childhood starts with the assertion that this is one of the most traumatic events that can occur in childhood (e.g. Worden 1996, Dowdney 1999, Haine et al 2008). There is a substantial body of research which explores the consequences of this traumatic childhood experience, and in particular whether parental bereavement in childhood should be construed as a risk factor for long term mental health difficulties. There is much less research to explore which sub groups of children are most vulnerable to experiencing this traumatic event and whether the effects are different for these different sub groups.

In this section I will attempt to chart some key aspects of research into parental bereavement in childhood. I look at research evidence about how children grieve and what is known about the different ways in which they express and experience grief. I then move on to exploring the incidence of parental bereavement in childhood.

The final parts of this chapter consider whether some children are vulnerable to complicated grief, what this means in terms of childhood development and wellbeing, and introduces a ‘contextual resilience model’ which helps to predict which children are most vulnerable to complicated grief and the kinds of factors which may be developed in order to help them and their families build resilience and reduce risks.

2.3.1. Facts and Figures: Children’s Experiences of Parental Bereavement

As clinical evidence and bereavement charities frequently assert the potentially devastating impact of parental bereavement I was surprised that until last year, there had been no national studies to identify the prevalence of parental bereavement, as distinct from other kinds of bereavement. Outcomes of child bereavement had tended to conflate sibling and parental bereavement, or even any bereavement construed as significant by the child, including the death of a pet. (e.g Ribbens McCarthy 2006, Harrison and Harrington 2001). The incidence of parental bereavement, cited above, had been extrapolated from small scale local studies (Holland 1995, 2001)
In 2011 the Childhood Wellbeing Research Centre (CWRC) used the cohort data from the 1970 British Cohort Study (BCS70) to look at the statistical prevalence and long term impact of childhood bereavement (Parsons 2011).

Parsons research for the CWRC addresses two of the flaws of previous epidemiological research into childhood bereavement, allowing for causality in relation to later life outcomes to be explored, rather than simply identifying correlation:

1. it separates parental bereavement from other bereavement experiences
2. it controls for other forms of disadvantage and other markers of social exclusion.

This study demonstrated that for a cohort of 11,500 people born in 1970 4.5% had experienced the death of one or both parents by the age of 16 years. Statistically then, children who have been parentally bereaved before the age of 16 represent a significant sub set of all children. If this is mapped onto a school population this would suggest that by secondary school, in a school with 1000 pupils there may be as many as 45 pupils who have experienced the death of a parent by the time they reach the age of 16. Such figures would suggest that parental bereavement could be presented as a ‘normal’ childhood experience.

This research concludes that:

*Much of the initial statistical association between growing up in a bereaved family and having poorer outcomes at age thirty than children from intact families was found to be related to pre existing differences in characteristics of their families of origin. Children experiencing other forms of family disruption may suffer more extensive influences on their ability to negotiate a successful transition to adult life.*'  
(Parsons 2011:2)

This research does seem to demand a much more critical consideration of the assumption that parental bereavement is linked to damaging consequences. It suggests that whilst growing up in a bereaved family was significantly associated with a wide range of poorer and disadvantaged outcomes the majority of these outcomes could be explained by pre-existing family characteristics from around the time of the child’s birth.
It appears therefore, to suggest that whilst parental bereavement may be construed, as clinicians assert, as one the most traumatic events which happens in childhood, it is appears to be a trauma from which most children recover. This analysis challenges the received wisdom that parental bereavement places children at risk of poorer long term wellbeing outcomes. It is cited in a rapid literature review mapping out research into childhood bereavement, undertaken at the request of the Department for Education and also carried out by the CWRC, in which the authors conclude:

*This BCS70 analysis showed that childhood bereavement does have some long term impact, but that the effect is limited after family background is taken into account (Akerman and Staham 2011:8) (my emphasis)*

Any such conclusion should be challenged. This study measured long term impact against indicators such as drug and alcohol use, mental and physical wellbeing, employment and education. These are important indicators of social inclusion, and are linked to well being. They do not of themselves prove that there is ‘limited long term impact’ of bereavement. Perhaps the impact, ‘the consequence of learning to live with a powerful range of conflicting and confusing emotions’ (Stokes 2009) is simply not reflected in these broad markers.

As a practitioner I am concerned that to take the conclusions of the BCS70 analysis at face value risks ignoring the impact of a potentially traumatic childhood event upon a significant number of children. Furthermore, to treat all parentally bereaved children as a homogenous group does not adequately address the uneven distribution of parental bereavement in childhood.

**2.3.2. Parental Bereavement is disproportionately experienced by the most vulnerable children in society**

This is powerfully demonstrated in a secondary analysis of Office of National Statistics data on the mental health of children and young people in Great Britain (ONS 2005) undertaken by the National Children’s Bureau. This examined the differences and similarities in life experience and personal outcomes between children who had experienced parental or sibling bereavement, or the death of a friend, or no significant bereavement.
This analysis indicated across the sample of 7,977 children, aged 5-16 that 9.5% had experienced the death or a parent, friend or sibling, and 3.5% the death of a parent or sibling. Their evidence shows:

*Children who had experienced the death of a parent/sibling tended to come from the most disadvantaged backgrounds relative to other groups in terms of living in lone parent households, economically inactive households, low earning households and households where educational attainments were low.*

*(Fauth, Thompson and Penny 2009: 5)*

In addition this study demonstrated that the following are correlated with parental or sibling bereavement in childhood:

- more stressful life events, including one parent having a major financial crisis, parental mental and physical illness, serious illness of the child
- more likely to have been referred to support agencies for concerns about learning, behaviour or attention difficulties
- six times more likely to have been looked after the local authority at some point
- more likely to have been excluded from school and more likely to have experienced multiple school moves
- less likely to participate in extra curricular activities

All of these are identified as risk factors associated with poor wellbeing outcomes in later life (e.g. Rutter 1999, NICE 2008). It is useful to chart the demographic variables associated with experience of childhood bereavement. It demonstrates that whilst parental bereavement is not as uncommon as might be assumed from our rising mortality figures, the most disadvantaged and therefore the most vulnerable children within our society disproportionately experience it.

Many children do appear to learn to live with the powerful and painful feelings that follow parental bereavement. They appear to weather, as Parson’s analysis indicates (Parsons 2011) the effects of parental bereavement without this making a demonstrable impact upon statistical measures of childhood wellbeing. This does not mean that parental bereavement should not be considered a risk factor in childhood. As Dowdney asserts, *It is important to note that whilst most children do not develop severe mental health problems following parental death, children who experience parental death are at*
elevated risk for the development of a wide range of problems (Dowdney, 2000).

The ONS study (2005) showed parental bereavement is most likely to be experienced by children who have disrupted family lives because parental bereavement is linked to poverty and social exclusion. (Fauth et. al 2009, Meltzer 2000, ONS 2005). Those children who are most likely to experience parental bereavement are those who are likely to have experienced other ACEs and to come from families with lower levels of social and cultural resources. They are therefore least likely to have the protective social or personal factors identified in childhood resilience research (Matsen 2001) which may help to deal with this traumatic event, and the conflicting and confusing emotions arising from this.

It is for this reason that I am concerned that the main effects model used in the BCS70 analysis does not adequately explore the possible interaction of risk and resilience factors which may place children ‘at elevated risk for the development of a wide range of problems.’ (Dowdney 2000). To suggest that childhood bereavement has a ‘limited effect’ upon childhood development and well-being is to ignore the cumulative detrimental impact of risk factors upon children’s wellbeing. It runs counter to the theoretical framework which I started to weave in the last section, drawing upon research into adult bereavement, which suggests those with fewest social and personal resources are most vulnerable to adverse outcomes. If these children have experienced some combination of the adverse childhood events (ACES) described by Fauth, Thompson and Penny (2009), then they are likely to have reduced social networks, fewer personal resources, and more complicated relationships.

This is especially important in considering the impact of parental bereavement through substance misuse because children whose parents misuse drugs or alcohol may be more likely to experience other ACEs, to be more vulnerable to complicated grief and perhaps to experience this ‘devastating impact’ of parental death on their journey through childhood into adult life of which Stokes (2009) warns.

2.3.3. How Do Children Grieve?

The experiences and expressions of grief in childhood, as in adulthood, tend to be categorised into cognitive, emotional, somatic and behavioural (Worden 1996, Parkes 2002, Luecken 2008). The large body of research into the effects of early parental death on children’s development indicate that in the short term children experience this as ‘an
acute and profound crisis.’ (Luecken 2008:399). In children as in adults it is ‘a departure from a state of health and wellbeing.’ (Engel 1961). In the short term parentally bereaved children are at risk of a wide range of mental health problems, including depression and anxiety, conduct problems, social withdrawal, fear of abandonment and a low sense of internal control (Worden 1996, Dowdney 1999, Holland 2001, Mannarino and Cohen 2006).

Childhood grief is an ongoing, changing process that is shaped by a host of factors present in the ecological system of the child, and heavily influenced by the surviving parent. Unlike bereavement in adults, which is typically characterised by a discrete period of mourning which abates over time (Oltjenbruns 2001), the loss of a parent at an early age informs and becomes incorporated in a bereaved child’s personality, identity and world view (Holland 2001, Schultz 2007, Brewer and Sparkes 2011). The general bereavement literature suggests that grief does not end for children and might more aptly be described as ‘regrief’ (Abrams, 1999, Oltjenbruns 2001). The intermittent nature of children’s grief responses is characteristic of children’s affective states in general, which are often more changeable and reactive than those of adults (Cohen and Mannarino 2010).

It is important for researchers, policy makers and practitioners to understand the ways in which children move through a grieving process from this ‘acute and profound crisis’ following bereavement; the ways in which some children recover from this, and perhaps ways in which some children remain ‘stuck’ in this state of crisis; the things which might trigger ‘regrief’ or how this is experienced; and the kind of things which might help or hinder children in the different ways in which they deal with grief; and the ways in which children make meaning of their parent’s death, and may move to a sense of post bereavement growth.

Most research into parental bereavement in childhood seems to chart the correlates of parental bereavement in terms of the behaviour which can be observed by others, as much of the research into outcomes following bereavement is based upon teacher and parent questionnaires. Of necessity this tends to capture externalising behaviour, i.e. that which can observed by others, although some studies attempt to capture inferred internalizing behaviour. In US studies this is often construed as ‘psychopathology.’ The work that Luecken and her colleagues are undertaking on the physiological consequences of parental bereavement in childhood is charting the long term impact of an overworked stress regulation system on physical wellbeing (Luecken 2008).
This research helps to identify the psychopathological indicators of those children who are ‘psychologically unsuccessful mourners, and to map out the relative prevalence of psychologically unsuccessful and successful mourners. Luecken’s work may help us to understand long term impacts which are not identified in current impact measures. This nomothetic research only offers part of the picture of what happens to children when a parent dies.

It does not help us understand what it feels like to lose a parent, and how bereaved children think this shapes their ‘cognitive emotional maps’, and their ‘assumptive worlds’. It does not help us understand how nor why children learn to deal to with the powerful range of conflicting and confusing emotions described by Julie Stokes. Furthermore it is possible that the measures of outcomes are simply too limited, that they miss important features of childhood grief which are not captured in measures of childhood ‘psychopathology’ but which nonetheless derail children as they attempt to journey through life.

Brewer and Sparkes’ exploration of post traumatic growth following bereavement is a rare example of qualitative research of parental bereavement in childhood. (Brewer and Sparkes 2011). Their research demonstrates the ways in which this process of meaning making helps to heal, and to restore some level of wellbeing. The other notable exception is John Holland’s Iceberg project (Holland 2001) in which the researcher interviewed almost a hundred adults who had been parentally bereaved in childhood. Holland’s study has the methodological disadvantage that it is retrospective and draws upon adults’ recollections of parental bereavement in childhood. However, this is also an advantage because it allows Holland to trace the changing experiences of childhood grief as the individual journeys through childhood and adolescence and into adulthood.

Holland does not measure psychopathology, he does not diagnose complicated grief nor map out and categorise normal grief. He does explore the psychological and social consequences of parental bereavement, from the perspective of the adults who were bereaved in childhood. He depicts an emotional landscape in which adult attempts to shield children meant that children developed fears and fantasies which they felt unable to express, they felt responsible for protecting their surviving parent which often prevented them from talking about their feelings and their grief, many of them felt their school work and life opportunities had been affected by the death of their parent.
2.3.4. Adult Recollections of Childhood Experiences of Grief following Parental Bereavement

The hundred participants in John Holland’s research remembered initial feelings of guilt, numbness, embarrassment, anger and fear, with some also recollecting that they had felt fragile and / or stupid. All of the participants felt marked out as different by their loss. Over 50% recalled a feeling of ‘not understanding’ and not being able to take in the news but also that they felt ‘shut out’ from the adult world. An eighth of the participants report feeling relief following the death. Although only one seventh of the participants reported ongoing depression two years after the death over two thirds did not feel that any sense of ‘normality’ had returned, and reported an increase in anger as sadness waned.

Most striking of all participants reported feeling very isolated or isolated, ‘that the adult world was of little help at the time of their parent’s death’. Holland goes on to report: ‘Few children confided…the majority of Iceberg volunteers did not talk to anybody about at all about their feelings, and this seemed to reinforce the general impression of being isolated at school and at home. (Holland 2001: 124)

On a 0-10 rating scale, where 0 represented intense isolation and 10 represented feeling connected with others, 47% of Holland’s participants rated their feelings of isolation at 0, with 64% rating this between 0-2. The adult participants said that what they yearned for as children was someone to listen, to feel ‘a basic human connection.’ Holland reports that: ‘Those few teachers who did have the courage to talk with their pupils were very well received (Holland 2001: 127)

Despite feelings of isolation and depression the effect of the bereavement was not indicated in declining academic performance, one of the key variables used as a marker of long term adverse outcomes for children. Only one in ten of these adults reported a decline in academic performance, with one in twenty five reporting an increase in academic performance.

Holland recounts the experiences of one his participants, Keith, who explained that he was teased about his father’s death, so he retaliated by fighting back, he was then blamed for the fights and, becoming enmeshed in a cycle of blame and punishment, his ‘world had collapsed.’ This represents clear evidence about the insidious processes of stigmatization and social exclusion which can be unleashed as children
struggle to cope with the fall out of a parent’s death. This is corroborated by Stokes, who notes:

*Often there is a short window when grief arising from a family death will be acknowledged; afterwards a boy’s disruptive behaviour is the most likely thing to be noticed.* (Stokes 2009:3)

It is this which I observed in my own work with Luke, whose story opens this research. The death of Luke’s father was real and present for Luke, but was a historical fact for school staff attempting to manage Luke’s behaviour in school. Luke’s aggressive behaviour was treated as a deliberate choice which Luke was making, rather than a maladaptive way of communicating a need to make sense of his father’s death, and as a ‘coping ugly’ mechanism to help him find a way through multiple challenges at a time of transition when his world seemed especially threatened. The focus on his disruptive behaviour increased his isolation and vulnerability, and cut him off from possible avenues of support.

Rebecca Abrams’ autobiographical account, ‘When Parents Die’, weaves in bereavement theories with personal accounts from those who have experienced parental bereavement as children, and from her own experiences. (Abrams 1999). She traces the way in which this experience is etched upon the lives and personal identities of those to whom this happened and suggests,

‘*Asking when grief is finished is like asking how high is up? There is no ready answer.*’ (Abrams 1999: 64)

Her accounts demonstrate the ways in which children experience old grief in new guises throughout their childhood, particularly at times of transition, and also how, for some periods children may need to put grief ‘on hold’ until they have the space and emotional resources to deal with it.

The fears and features of parental bereavement in childhood show the struggle these adults recalled in their attempts to find their lonely passage through grief. Most of these adults did seem to chart a way through grief, but their stories demonstrate that their journeys have been long and hard, and the struggle to build a stable sense of self within the world is hard won, if it is achieved at all.
This evidence provides a stark challenge to Akerman and Statham’s assertion (Akerman and Statham 2011) that the effects of parent bereavement in childhood are ‘limited.’ Parental bereavement in childhood appears to have a long term impact upon the course of these adults lives, though the impact may not be measured by the long term indicators used to measure the effects of the bereavement. In particular children who ‘cope ugly’ risk punishment rather than care, resulting in isolation rather than support. Through removing possible social support this then exacerbates their vulnerability to complicated grief.

2.3.5. Complicated Grief following Parental Bereavement in Childhood

Constructs of complicated grief and childhood psychopathology are more prevalent in the US where access to support via insurance claims, requires a medical diagnosis. The construct of psychopathology is derived from the heavy reliance upon quantitative research, with its focus upon external markers of psychological distress. Within the UK practitioners and researchers should be free to focus less upon diagnosing grief reactions, and more upon understanding the ways in which children experience grief in order to alleviate psychological distress, and to reduce the risk of adverse outcomes. Rather than elaborate the classification of childhood traumatic grief (CTG) (Cohen and Mannarino 2010) or psychopathology (Cerel, Fristad, Weller and Weller, 1999; Cerel, Fristad, Verducci, Weller and Weller 2006) and who to include or exclude from these categories, we can focus on understanding why some children ‘bottle up’ their emotions following bereavement, and the ways in which this has a ‘devastating impact’ upon themselves and upon society. (Stokes 2009)

In terms of my professional practice, I focus on identifying the ways in which bereaved children might be helped to manage their painful emotions, and the ways in which those around can support them in this. Part of this process involves helping the child herself and those around her to understand the ways in which grief might be manifested. For this reason it is important to know the broad range of thoughts feelings and behaviours which might be a part of each child’ experiences, whilst acknowledging that for each child the experience and expression of grief will be unique.

The reactions which adults have to those manifestations, and they ways in which they are able to help the child make sense of her thoughts feelings and behaviours can either build a more reliant and effective way of dealing with grief, or can isolate the child from sources of support, and compound a sense of isolation and entrench that ‘devastating impact.’
This of course fits within a mental health perspective which holds that the network of balancing supports which helps each of us to navigate difficult times can either ameliorate our difficulties and help us to manage mental distress, or can entrench our difficulties and lead to spiraling mental health difficulties.

Within the last decade researchers into childhood bereavement have used a risk and resilience framework for understanding the ways in which children navigate through childhood trauma, with some children seeming to adapt to the loss, whilst others may have their lives derailed by parental bereavement. (Brown, Sandler, Tein, Liu and Haine 2007, Sandler, Wolchik, Ayers, Tein, Coxe and Chow 2008; Luecken 2008, Stokes 2008). This offers more theoretical and practical utility than attempting to define and diagnose complicated grief in children. The next section explores a carefully researched risk and resilience model which identifies those factors which help a child to adapt, and those factors which place a child’s development and well being at risk following parental bereavement.

2.3.6. A Contextual Framework on Adaptation Following Bereavement

Clinical researchers into parental bereavement in childhood at Arizona State University have proposed a theoretical model which they have called ‘a contextual framework on adaptation following bereavement’ (Sandler et. al 2008). The authors draw upon Balk’s definition of ‘recovery’ as ‘redefining and reintegrating the self into life’ (Balk 2004 cited in Sandler et al. :524) but suggest that ‘adaptation’ is a more useful concept than ‘recovery’, because it does not imply a return to a pre bereavement state. The model identifies a range of fixed and potentially modifiable risk and protective factors which mediate, moderate or compensate for the disruption following parental death and divorce.

This contextual framework uses broader measures of childhood wellbeing, construed as risk and protective factors, rather than focusing solely on grief related outcomes to identify and promote resilience in bereaved children. Risks are construed in terms of children’s ability to adapt to the disruptions and restructuring of their environments following the death. These disruptions affect children’s ability to satisfy basic needs, including needs for esteem, social connectedness and control, and their success in age salient development tasks. The disruptions are thus to children’s self systems, or assumptive worlds, as well as to their family and social circumstances. These disruptions have the potential to influence multiple levels of functioning including problematic outcomes (poor mental health,
problematic levels of grief) and positive outcomes (positive sense of self, post traumatic growth).

The cumulative effects model mean that positive and negative outcomes are best predicted not from any single factor, but from the accumulation of multiple risk and protective factors that may proceed or follow the parent’s death. Sandler and his colleagues explain: *We refer to our model as a contextual resilience framework, to emphasise the central role that person – environment transactions play, versus the heavy emphasis on intrapersonal processes in some approaches to resilience. (Sandler et a; 2008: 60)*

Within this model they identify fixed markers of risk, i.e. those risk factors which cannot be changed by an intervention e.g. age, gender, mode of death, and potentially modifiable risk and protective factors. Those factors which may be changed by an intervention, and which can affect the outcomes targeted through interventions are considered causal risk factors. Of these are there are three marked risk factors, which are consistently cited in research studies both into adaptation following bereavement, and in general studies of risk and resilience. These are:

1. Stressful events that follow the death
2. Positive parenting, including warmth and discipline
3. Mental heath problems of the surviving caregiver

The social constructivist underpinnings of the contextual model acknowledge the role of person – environment transactions in shaping the child’s world, the way they come to think about themselves, and their assumptive worlds. All of these risk factors influence the attachment that child has with primary caregivers, and impact upon the lives that children live, prior and following the bereavement. They play an important role in shaping the intrapersonal constructs which form the child’s assumptive world.

This contextual model suggests that higher levels of coping efficacy, self esteem, mastery, and adaptive control beliefs are associated with lower mental health problems in bereaved children. Conversely perceived level of threat, low coping efficacy and fear of abandonment are associated with poorer mental health outcomes.

This contextual framework for understanding adaptation following bereavement moves from identifying causal environmental risk factors, such as those described here and in Parkes classification of risk factors for complicated grief (Parkes 2002) to identifying
some of the ways in which this might impact upon a child’s own intrapersonal processes, on sense of self, the hopes and fears children may have, the beliefs they may hold about the world and about their beliefs in their own abilities to exercise some agency within the world. All of these move beyond a focus on outcomes or a correlation with adverse impact measures, and to try to reach deeper into the understanding what it might be like to experience parental bereavement.

2.3.7. Mode of Death: Bereavement through Parental Substance Misuse

Sometimes people kill themselves systematically over a period of time, as is the case for people who die from drug or alcohol abuse. If your parent died in this way the feelings you may have about the death may be very much akin to those experienced by people who have been bereaved by a more conventional suicide. (Abrams 2001:49)

As with the wider literature on impact, and vulnerability to complicated grief the statistical evidence does not match practice based evidence when considering the associations between mode of death and outcomes for the bereaved child. In particular parental suicide does not seem to be a risk factor for poor outcomes, despite the long history of researchers documenting the case evidence to indicate the contrary (Shepherd and Barraclough1976). This is not borne out in quantitative research studies. In a study which compared outcomes for children bereaved through suicide compared with other causes of parental bereavement, Brown and her co authors found no difference in mental health problems, grief reactions, beliefs about the world and about themselves, coping strategies and expressions of feelings. They concluded that:

the same risk and protective factors are associated with problem outcomes for children who experience parental death from suicide and other violent causes as for children whose parents die from illness….Individual differences in themes of grief e.g. shame, guilt and stigma that can be associated with different causes of death will need to be addressed in interventions. (Brown, Sandler, Tein, Liu and Haine 2007:330)

Hung and Rabin (2009) point to the risks of assuming that childhood grief is adequately captured in quantitative measures, suggesting that many of the differences between suicide survivors and those bereaved through other causes are,
Internally contained and may not appear on behaviourally orientated batteries of psychopathology. Even if most young survivors do not experience severe behavioural or emotional symptoms as a result of a parent’s suicide they may still experience qualitative differences in their grief. (Hung and Rabin 2009: 807)

It is these qualitative differences in experience that remain so elusive, the ways in which children who have been parentally bereaved through suicide understand and express their thoughts and feelings, about themselves their parents and the world around them.

There is no research to explore or explain or represent the experiences of children who have been parentally bereaved through substance misuse, or if there is I was not able to find it. Key word searches of Medline or PsychINFO, journal searches and index searches of key references did not yield any results. The Childhood Bereavement Network, Winston’s Wish and Cruse do not publish information on bereavement through substance misuse. For this reason it is only possible to conjecture, as Abrams does, on the basis of the theoretical framework drawn from wider literature on bereavement research, practice and intervention, about what are likely to be essential aspects of the experience of dealing with parental bereavement, when the bereavement is caused through substance misuse.

Abrams suggests that:

‘perhaps part of the process of grieving is recognizing that the parent had been lost before they died…….. the two losses have to be separate before they can fit together again in a way that makes sense. (Abrams 1999:51)

The key themes are, I think, the relationship which the bereaved child had with her/ his deceased parent, and the relationship which s/he has with a key attachment figure, who may or may not have been the deceased parent. It is likely also that the child’s assumptive world, her his view of the world as safe or threatening will also be influenced by these factors, and by the number of adverse childhood experiences to which s/he has been exposed.

All of these are likely to shape the way in which the child experiences the bereavement, whether they are able to think about and make sense of the bereavement, ‘cope ugly’ or perhaps try to avoid grieving altogether in an attempt to avoid the pain of the loss.
2.4. Drawing Conclusions from this Overview of Bereavement Research

The purpose of this literature review was to provide a theoretical framework which might help me to interpret the bereavement experiences of my research participants. It was intended to support the psychological interpretations I make of the bereavement experiences which I aim to represent.

The broad threads of the bereavement literature weave neatly into my own epistemological framework for EP practice, and are consistent with a social constructivist experience. This is not surprising. Bereavement is a personal experience, which is shaped by personal, social and cultural beliefs and practices. It is de facto in part a socially constructed experience, with these social constructs influencing personal experience.

The research threads corroborate what I would have predicted from my own professional practice, and the broad parameters of risk and resilience theories in understanding how to predict and address vulnerability in children. The modifiable intrapersonal processes made explicit in Sandler’s contextual resilience model are core underpinnings of cognitive behavioural therapy and used in preventative approaches to building emotional resilience.

The role of attachment, so central to understanding adult’s experiences of grief, and central in predicting vulnerability to what is called complicated grief are implicit within the narrower field of research into childhood bereavement. Dimensions of attachment are inferred through variables such as self efficacy and fear of abandonment. These are helpful in identifying aspects of children’s cognitive schemata which are open to influence. They are less helpful in building up a coherent psychological representation of what it feels like to lose a parent in childhood or adolescence and how it feels trying to deal with that powerful range of conflicting and confusing emotions described by Stokes.

Quantitative research, into childhood bereavement in general and those who have experienced traumatic loss specifically (Cerel et. al. 2006, Cohen and Mannarino 2010) indicates that most children do move through childhood and adolescence into adulthood without significant adverse outcomes. This runs counter to the oft cited
assertion that parental bereavement is one of the most traumatic childhood experiences. Although most children do seem to adapt following this trauma we know very little, from children’s perspectives, about the ways in which this may have shaped childhood and the child’s sense of self.

To show that children adapt to life following parental bereavement is not the same as asserting that parental bereavement has only a limited impact upon children’s lives. I am concerned that the statistical evidence to demonstrate this through proxy indicators of psychological adjustment may conceal the emotional scars and the struggle which children go through in this process of adaptation, and argued that we need more qualitative research to represent and to try to understand children’s experiences of parental bereavement.

The evidence from Fauth, Thompson and Penny’s research (2009) corroborates national epidemiological mortality figures and demonstrates that parental bereavement is most likely to be experienced by those who are most socially vulnerable. Bereaved children are least likely to have protective factors to help them to weather parental bereavement, because they are most likely to come from families which also experience other known risks for childhood wellbeing and least likely to provide a network of balancing supports. I am concerned that the research evidence, demonstrating a limited effect upon children’s lives when other family variables are taken into account, means that researchers and practitioners may underestimate the impact of parental bereavement on children’s lives, when those lives may already be chaotic and disordered because of other family events.

The focus of this research is the experiences of children and young people who are dealing with parental bereavement through substance misuse. There is no specific research on the needs of children whose parent’s have died through substance misuse within bereavement research yet because of the correlation between parental substance misuse and other ACEs they are likely to come from a highly vulnerable sub group of children, with a high level of risk factors and a relative low number of resilience factors.

In the next chapter I explore this assertion in more depth, and in particular I will consider the extent to which these children may experience those factors which disrupt psychologically successful mourning, including insecure attachments, limited
social support and the extent to which death through substance misuse is construed as a traumatic death.
Chapter Three: Drug Related Deaths, Living with Parental Substance Misuse and Parental Bereavement through Substance Misuse

3.1. Chapter Overview

The previous chapter has demonstrated that parental bereavement through substance misuse is not addressed through bereavement research. Death through substance misuse is not categorised as a traumatic death, along with death from suicide, homicide and accidents. Although traumatic death is a risk factor for complicated grief the specific experiences of those who are bereaved through substance misuse are not addressed within this construct. This is the case for both adults and children.

I also suggested that children who are bereaved through parental substance misuse may be more likely to have insecure attachments to primary caregivers, and to experience a relatively high number of ACEs, whilst possibly having fewer of the resilience factors which can help children to navigate their way through childhood adversity. For other children who have had secure attachments to primary caregivers, whether or not this is the person who dies, it is possible that the primary caregivers will be adversely affected by the death, thereby undermining the secure attachment between them and the parentally bereaved child. I will explore the plausibility of these assertions, by mapping them against what is known, from research, about the needs of children whose parents are substance misusers.

It is possible however, that the experiences and the needs of children who are parentally bereaved through substance misuse are addressed in policy and research into parental substance misuse. This is a relatively new area for research, and I have borrowed the term ‘Hidden Harm,’ given to a government initiative in this area between 2003 and 2007, to represent the impact of parental substance misuse upon children. (Advisory Council for the Misuse of Drugs ACMD 2003, 2007)

An overview of bereavement research in general, and of parental bereavement in childhood in particular demonstrated the importance of protective factors in helping children to adapt following parental bereavement. I suggested that children who were
parentally bereaved through substance misuse were less likely than other children to have these protective factors, or to have access to a network of balancing supports.

I wondered whether qualitative research into the experiences of living with parental substance misuse might contribute to my understanding of the context and concerns of these children, how the lived experience of dealing with parental substance might shape the lived experience of dealing with the death of a parent through substance misuse. In particular I was interested in identifying the links between parental substance misuse and other adverse childhood experiences, as these are likely in turn to influence intrapersonal processes which are shaped by the dynamics of parent – child attachment.

This chapter looks at evidence about how many children are affected by parental substance misuse, before drawing some key conclusions from hidden harm research which I think are relevant to my research and which I think demonstrate the importance of undertaking research into this apparently hitherto unresearched area. It demonstrates, I hope, why it is appropriate to undertake qualitative research which seeks to try to identify and to understand the different dimensions of experiences which are likely to shape the experience and effectiveness of dealing with parental bereavement through substance misuse, dimensions which may be missed in a researcher focused nomothetic study. It is especially important to strive to identify similarities and differences in parental bereavement through substance misuse, with parental bereavement through other causes.

3.2 The Scale of the Problem: How Many Children are Parentally Bereaved through Substance Misuse?

As part of a scoping exercise to explore the feasibility of this research, and how useful it was likely to be, I trawled local and national databases to try to find out how many children are parentally bereaved through substance misuse each year. For 2009 the number of drug related deaths recorded by the National Programme on Substance Abuse Deaths (Ghodse, Corkery, Oyefeso, Schifano, Ahmed and Naidoo 2009) was 2182. The National Treatment Agency recorded 2878 deaths for the same period (http://www.nta.nhs.uk/preventing-drug-related-death.aspx) and the European Monitoring Centre for Drugs and Drug Addiction recorded deaths 2092 for 2009. (http://www.emcdda.europa.eu/stats11/drd). Because these organizations all use slightly different definitions of drug related deaths they have all produced different figures. None of these organizations collect information about whether those who have died have
children. It is not possible, therefore, to answer the question, how many children are parenally bereaved by substance misuse each year?

Employment statistics are recorded in the data collected by the np-SAD. Within the employment categories 1.5% of those who died are recorded as having 'childcare' or 'houseperson' as their employment (23 people). The np-SAD also collect information on living arrangements, and record whether the person was living alone or with others. At the time of death 42% of were living with others, 40% living alone, and for 10% this information was not available. However, this information does not yield information on whether the person who died had children, whether or not they were living with them or had parental responsibility for them. I cite this data because it indicates the extent to which statistics on drug related death are not concerned with the possible impact on others, especially the hidden harm (sic) that may be done to children. Information on employment status is seen as important in mapping the causes and consequences of drug related deaths, as opposed to parenthood. It is impossible to identify how many of those people who die each year because of illegal drug misuse have children.

Alcohol related deaths and drug related deaths are collected separately by separate organisations. Drugscope UK suggests that figures for alcohol related deaths in the UK in 2006 ranged from 20,000 to 200,000 although statistics for 2010 recorded 8,790 (http://www.drugscope.org.uk/resources/goodpractice/statisticsandavailability/statistics-mortality). Again, information about whether these people are parents, and the ages and care and living arrangements for these children is not collected.

Identifying the number of children who are parenally bereaved through substance misuse is not possible with current ways of recording drug or alcohol related deaths. New nationally and / or locally agreed protocols would be required to make this information available.

In terms of a rationale for the research this scoping exercise revealed two issues which I consider to be important for this research

i) it is not possible to ascertain the scale of the problem because data on children and young people who are parenally bereaved through substance misuse is not collected nor recorded

ii) It is likely that there are a significant number of young people in the UK who have this experience, but local and national agencies do not know who they are, or
where they are, and as a consequence it is not possible to monitor or address their needs.

3.3. Hidden Harm: Parental Substance Abuse – How many children are affected?

As it was not possible to establish how many children are affected by parental bereavement through substance misuse I wondered if broader statistics on children living with drug and alcohol misusing parents might yield useful information. As the bereavement literature demonstrates, the ways in which risk and resilience factors interact influence the trajectory of a child’s grief. It is relevant therefore to try to uncover more about the kinds of risk and resilience factors to which children with substance misusing parents may be exposed, as this is likely to have an impact upon the child or young person’s experience of dealing with parental bereavement.

Just as it is difficult to find out how many children have been affected by parental bereavement, it is difficult to find out how many children live with parents who have problematic substance misuse. It is known, for example, that 62% of clients entering drug treatment programmes have children, and that 55% of these have their children living with them, whilst 45% of these children live with others, usually the other parent, or relatives, grandparents or in care (Cairns 2007).

In the UK between 250,00 to 350,000 children are believed to be living with a parent who is classified as a problem drug user (NTA 2000). This represents about 2-3% of all children under the age of 16 (4-6% in Scotland) and represents one child per problem drug user in treatment. Figures from the Advisory Council for the Misuse of Drugs indicate that 37% of fathers and 67% of mothers were still living with their children (ACMD 2003). Most children who were not living with a parent were living with relatives, about 5% of the children of drug misusing parents were in care. Around 780,000 to 1.3 million children are believed to be living with parents who are similarly classified as ‘problem drinkers.’ (Alcohol Concern 2000). In both cases the classification ‘problem’ is given when the substance misuse impairs the individual’s ability to carry out daily task, including parenting.

The above figures are frequently cited, (Mariathasan and Hutchinson 2010, Bancroft, Wilson, Cunningham Burley, Backett- Milburn and Masters 2004)) and just as frequently
they are presented with the caveat that these are likely to be an underestimate of the true number of children living with parental substance abuse.

This clearly remains a difficult area in which to establish reliable data. As research into the impact of parental substance misuse upon children comes more sharply into focus, so there is a growing recognition that better estimates of the number of affected families and children needs to be gathered. A meta analysis conducted by the National Addiction Centre in 2008 goes further:

*In contrast to considerable policy investment in addressing the needs of children living with substance misusers and in identifying good practice, the underlying epidemiological evidence has fallen short. For policy and commissioning responses to adapt to the scale of the problem we first need to understand the nature and the scale of the problem. Without knowing the number of potentially at risk families we are unable to assist them until they come to the attention of agencies at crisis point.*

(Manning, Best, Faulkner and Titherington 2009 Biomed Central 3)

As the authors report, gathering information on substance misuse, especially by parents, is fraught with unreliability because of the stigma and shame surrounding substance misuse, and the difficulty of reaching marginalized groups. They estimate that over eight million people and over two million children are living in families affected by substance misuse. This research has moved away from collecting separate data on ‘hidden harm’ from drugs and alcohol, to looking at the total figure, to give an overall picture of the number of children affected by problematic parental substance abuse.

Those challenges around statistical evidence about the scale of the problem of hidden harm are likely to be amplified for children who do not live with their parents and for children whose parents have died from substance misuse and who therefore are no longer monitored by hidden harm initiatives. If it is not possible to identify how many children live with parental substance misuse and it is not possible to establish how many children have been parentally bereaved through substance misuse then I think these figures are helpful in establishing a context for my research. Parental substance misuse is widespread, and it is plausible to suggest that a significant number of those who die from drugs or alcohol will have children, whether or not these children live with them. If parental bereavement is one of the most devastating traumas that can occur in childhood we are, it seems, missing out on identifying a significant sub group of children who have lost parents in this way.
3.4. Hidden Harm: The Impact of Parental Substance on Children

An overview of conclusions and issues identified in research into parental substance misuse and the impact upon children

The publication of Hidden Harm, by the Advisory Council on the Misuse of Drugs (ACMD 2003) was the first government sponsored research document, which explored the consequences for children of living with parental drug misuse. Hidden Harm mapped out some of the challenges in meeting the needs of these children, whilst mapping out some of the consequences for children of living with parental drug misuse.

In the previous chapter I started to develop a theoretical framework for understanding the needs of children who have been parentally bereaved through substance misuse. This framework, drawing upon Sandler’s contextual model for adaptation following parental bereavement, tentatively suggests that these children are likely to experience a high number of risk factors and perhaps a lower number of protective factors compared to the general child population. In addition the framework suggests that these children are likely to have insecure attachments to their parent, and ambivalent relationships with them, which are known risk factors for complicated grief. It is clear therefore that children’s life before bereavement influences the impact which bereavement has upon their lives, because it has shaped their personal protective resources, and reflects the network of balancing supports available to the child. I turn now to research evidence compiled as part of the Hidden Harm initiative, and from the grey literature, produced by child facing agencies such as Childline, to examine what is known about the lives of children who live with parental substance misuse.

The unequivocal conclusion of Hidden Harm was that:

The complexity of the situation means that it is not possible to determine the precise effects on any individual child. However, a large proportion of the children of problem drug users are clearly being disadvantaged and damaged in many ways, and few will escape entirely unharmed. (ACMD 2003:11) (my emphasis)

The research demonstrates the challenges of gathering reliable data, whilst pointing to the importance of this challenge if, as a society, we are to act effectively to meet the needs of this group of children. There are some clear messages which do come from this complex
area of research. As these messages are important in justifying some of the assumptions I make in my theoretical framework, and because they identify the vulnerability of ‘hidden harm children’ I include these messages in this chapter. I think these messages also point to the necessity of undertaking research into the impact of parental bereavement through substance misuse.

3.4.1. Adverse impact of parental substance misuse up on children and young people

Parental substance misuse exacts a heavy toll on children’s wellbeing. ACMD’s follow up report cites a qualitative Glasgow study, which corroborates the above conclusion. It records:

*Parental drug use was not a neutral experience for these children and young people. [children and young people who participated in this study]* It had deep reaching ramifications for them, which tended to be played out in their subsequent behaviours.

It is notable that the children and young people interviewed in the Glasgow study seldom referred to situations where they had been at risk of harm. Their focus was not risk, nor particularly their experiences of material deprivation, rather it tended to be the social and emotional effects of living with parents who too often put their drug-related needs first. Primarily these children and young people described feelings of hurt, rejection, shame, sadness and anger over their parents’ drug problems, and it was with difficulty that they lived with these feelings. They often expressed a deeply emotional sense of absence and isolation which was conveyed in the often-used phrase that their parents were not ‘there for them’ (ACMD: 2007 Hidden Harm Three Years On my emphasis)

This quote underpins some of the key aspects into the impact of parental substance misuse on children. All the qualitative research in this area consistently represents the heartache, shame, fear and emotional scars of living with parental addictions. It is rare for children not to be affected, and the impact is felt more deeply upon emotional well being, upon feelings of being loved and cared about, rather than in physical deprivation or neglect. It is the experience of parents who may be physically present but emotionally absent, of not having a secure base that defines childhood and shapes children’s emotional schemata or assumptive worlds.
In addition children whose parents were dependent upon drugs or alcohol frequently took on a caring role, for their parent and perhaps for siblings, and attempted to protect their parent both from the drugs and from the stigma of their dependency. Sometimes children felt responsible for their parent’s drug use, and sometimes their parents blamed their child for their dependency. Parents who are substance dependent are less likely to protect their child from unsafe events, and their children also worry about the risks to which the parent may expose themselves, e.g. through theft, debt or prostitution.

The evidence from Hidden Harm supports the assertion that children who live with parental substance misuse are more likely to have ambivalent and complicated relationships with their parent, and less likely to have the secure attachment which is the foundation of emotional resilience. In addition these children are vulnerable to physical emotional and sexual abuse.

Qualitative and quantitative studies explore different aspects of this. (Barnard 2007, Templeton, Zohadi, Galvani and Velleman 2006, Templeton, Velleman, Hardy and Boon 2009). The statistics from serious case reviews (Brandon, Belderson, Warren, Howe, Gardiner, Dodsworth and Black 2008) and analysis of child protection registers demonstrate that parental substance misuse figure in a significant number of these cases (Forrester and Harwin 2006). In Northern Ireland the Hidden Harm Action Plan records that 70% of looked after children are in care because of parental drug and alcohol misuse. (DHSSPSNI 2008).

Qualitative research, especially that undertaken by children’s services, supports the conclusion drawn by Kroll and Taylor, that:

*For most children living with chronic substance misusing parents life can be very painful, difficult, frightening or dangerous’* (Kroll and Taylor 2003)

and it is:

*‘only under conditions of stringent and controlled drug use that children are not negatively affected.* (Barnard 2007) (my emphasis)

Research commissioned by services in the voluntary sector provide compelling and disturbing evidence of this, with none of the children who were quoted reporting any positive or neutral effects from their parents’ or carer’s substance use. (Childline Casenotes, 2009, EMCDDA 2010, Alcohol Concern 2006).
This is in stark contrast to the previous prevailing belief that:

*For far too long services and policy have entertained the notion that children can remain in the care of their drug addicted parents and remain unharmed. Parental drug addiction is incompatible with providing a safe and nurturing environment for young people.*  (Neil McKeganey in Children and Young People Now 27/08/09)

In addition children who live with parental substance misuse also experience a higher number of adverse childhood experiences (ACEs) such as living with domestic violence, poverty, bereavement sexual and physical abuse. (Manning et al 2009, Childline 2010, Bancroft et al 2004) than other children. As the previous chapter demonstrated parental bereavement is also correlated with higher numbers of ACEs.

Other research voices suggest that social stigmatization of drug using parents (My mum loves drugs more than me headlines) is part of a hegemonic process of social exclusion which ignores the structural determinants of drug use (Furedi 2008, 2006). The issue of structural determinants and the demonisation of substance misusing parents appears to be a separate issue, and certainly one in which there is a tension between the critical realist perspective of policy organizations, and epistemological integrity of academic research. However, in order to draw parents and communities into working to safeguard their children, the issues arising from demonisation and social exclusion need to be addressed. In this study I am interested in whether the blame or demonisation ascribed to such parents affects the ways in which their children grieve for them.

In ‘Looking Beyond Risk’ the researchers suggest that the emphasis within ‘Hidden Harm’ research is moving towards promoting resilience factors. This is a feature of more recent work with and for the children of substance misusing parents, (e.g. Rhodes, Bernays and Houmoller 2010), focusing upon interventions to build up resilience within individual children and to work within families and communities to develop shared responsibility and to mitigate risk through promoting resilience factors. (e.g. Templeton et. al 2006; Copello, Velleman and Templeton 2006). These resilience-building initiatives include strengthening parent child interaction, exploring ways of protecting children from other ACES, and finding and developing support networks within the local community. In this the initiatives are conceptually similar to the Family Bereavement Programme which has been developed to amplify protective factors following bereavement.

This is important for my research because it suggests that children who live with parental
substance misuse are more likely to have had inadequate parenting and therefore less likely to have formed a secure attachment to their parent. They are less likely therefore to be emotionally equipped to deal with the trauma of losing a parent, and to struggle, in consequence, to achieve the normal developmental tasks of childhood and adolescence. In addition issues such as stigmatization, and the demonisation of substance misusing parents in the media may contribute disenfranchisement around grief.

3.4.2. Statistics produce an uncertain picture, and are likely to be an underestimate of the scale of the problem

The research cited above, including the most recent research by Manning et al (2009) demonstrates this. There are particular groups of children who are not identified at all within research, including children who no longer live with their parent/s and children who have been parentally bereaved through substance misuse.

The shared conclusion is that studies to date do not yet provide an adequate basis for effective harm reduction strategies for the children of substance misusing parents. ‘Hidden Harm’ is no longer on the political agenda; with the focus of harm reduction policies now being on reducing drug related crime, rather than reducing harm to the children of substance misusing parents. The momentum for changes in statistical monitoring will therefore need to be driven by researchers and practitioners involved in identifying and addressing barriers to children’s wellbeing. It is possible that this research will help to identify whether this is important for children whose parents have died through substance misuse.

3.4.3. Research on parental substance misuse should include both drug and alcohol figures

Information on drug and alcohol misuse should be collected together, since the effects for children are broadly similar. It is notable that the emphasis of research tends to reflect the scope or remit of the commissioning organization, which has, historically, given rise to a distinction between alcohol and drug misuse that appears not to be justified in terms of understanding and addressing ‘hidden harm.’

Research does demonstrate that there are some differences in the consequences of drug or alcohol misuse, and in different types of drug misuse. However, as ‘Looking Beyond
Risk’ notes,

Nevertheless it would be wrong to overemphasize these differences in type of drug and pattern of misuse. The core dimensions (physical, psychological, interpersonal, social, academic, behavioural) of the experience of living with a parent with substance misuse are believed to be very similar. It is the behavioural impact of the substance misuse (family disharmony and disruption) rather than the substance misuse itself that causes the greater problems. (Templeton et. al 2006).

The theoretical framework for this research proposes that it is interpersonal and intra personal protective and risk factors influence the experience, and perhaps the expression of grief. It is because the core dimensions of the psychological experience of parental substance misuse seem to be similar that I have chosen to research on bereavement through substance misuse, rather than focusing on either drugs or alcohol.

3.4.4. Qualitative research is required, especially research into children’s views, and research focused on the needs of specific groups.

The EMCDDA draw upon Article 12 of the United Nations Convention on the rights of the Child (UNRC 1990), states that ‘children must be able to express their views in dialogues and decisions affecting their lives, and that they should have the right to freedom of expression.’ EMCDDA assert that:

Qualitative research among children provides a channel for that expression and can help to reveal and interpret what lies behind child and adolescent statistics. Research that focuses in the meanings and perceptions of drug and alcohol use from the perspectives of children whose lives are in some ways exposed to these substances offers a way to understand their needs and to plan appropriate interventions. (EMCDDA 2010:3)

This conclusion is shared by every research study, and scoping exercise, which explores the impact of parental substance misuse upon children and young people. The qualitative research that does exist (Bancroft et al 2004, Mariathasan and Hutchinson 2010, Childline 2010, EMCDDA 2010) corroborates, in stark and harrowing detail, the pain and harm caused by parental substance abuse, demonstrating the ways in which ‘parental substance misuse was at the centre of a web of problems that often included violence and neglect. (JRF 2004:1)
Researchers and policy makers call for more qualitative research especially research which addresses the needs and concerns of children from their perspective and research which focuses upon specific groups, including those who experience domestic violence, from gay and lesbian households, from ethnic minority groups and children whose parents in prison because of substance misuse, or who have been bereaved through parental substance misuse. (my italics)

However, as the Hidden Harm follow up report notes, ‘There appears to be less investment in qualitative research involving direct contact with children and young people themselves….key gaps include research focusing on the needs of particular groups of children. (ACMD 2007:6)

This research involves direct contact with children and young people, with the aim, ‘of understanding their needs and perhaps planning appropriate interventions’ as advised by the EMCDDA. It focuses upon a particular sub group of children. It therefore attempts to contribute to filling in some of the gaps identified in Hidden Harm research.

3.4.5. Children who no longer live with their parent/s disappear into the long grass

Of all the children for whom harm is hidden it may be that it is children who do not live with their parent who are the most hidden, and about whom the least is known. We know that 37% of father and 64% of mothers presenting for drug addiction treatment do not live with their children, but at present data monitoring does not enable us to track where these children live. Furthermore, it may be that parents themselves do not know where their children are living or who cares for them. Hidden Harm notes: ‘very little is known about the circumstances of many of the children who no longer live with their natural parents.’ (ACMD 2003:11)

Furthermore they report that they ‘could not establish the number of children who are in care as a result of parental problem drug or alcohol misuse (ACMD 2003:17). In Northern Ireland, as a result of the Regional Hidden Harm Action Plan, these figures are now collected and demonstrate, as previously stated, that 70% of children in care in Northern Ireland are looked after because of parental substance misuse. (DHSSPSNI: 2008)
The challenges of tracing and monitoring children who no longer live with substance misusing parents is explored within a local context, in Xxxxxxx, by Cairns (2007). Based on figures supplied by third sector, voluntary and statutory services within Xxxxxxx she reported that 55% of people who said they were parents and presented for drug treatment services had at least one child living with them. However she also states that of the 2271 children of problem drug users in Xxxxxxx, residency status is known for only 83 of these children. For 2188 children their residency was not known (my emphasis). It is not clear from the data whether the 2271 children identified were birth children, step children, relatives or from other household arrangements.

What Cairns was able to establish from her research was that, in the majority of cases ‘grandparents who take on the care of their grandchildren do so informally….it may…mean that the children themselves are inadvertently taken off the radar. The needs of those children may or may not be met by the new circumstances.’ (Cairns 2007:10)

I think this is important because it indicates there may be significant numbers of potentially vulnerable children and young people who have been or continue to be exposed to ACEs and to the emotionally impoverished parenting associated with parental substance misuse. However, because these children are not seen as a discrete group of vulnerable young people, their needs may not be properly conceptualized nor effectively addressed. Whilst this may not be directly relevant in this qualitative research it is important in terms of mapping out the life experiences of children who are parentally bereaved through substance misuse, and in exploring the extent to which they might be construed as a distinctly vulnerable sub group of children.

3.4.6. The research literature does not focus on children who have been parentally bereaved through substance misuse

Children who have been parentally bereaved through substance misuse are identified as a specific group when considering specific gaps in research into the effects of parental substance misuse. There are no other references to this group of children. What is known, as stated above, is that there is little knowledge or information about children of substance misusing parents who no longer live with their parents. We know that 5% are in care, but have no other knowledge about the other children do not live with their parents.

These children appear to be invisible in research into parental substance misuse as they are
in bereavement literature. Surveying this area generally demonstrates the challenges into researching with and about the children of substance misusers. It does not mean that they are no such children, but it does demonstrate that these children may be hard to find.

For the purposes of this research I did not conclude there was no need for this research, and that none or few children were affected.

3.5. Dealing with Parental Bereavement Through Substance Misuse: Lessons from Hidden Harm Research

The original aim of this scoping exercise was to find out nationally and locally how many children had experienced parental bereavement through substance misuse. I was astonished that despite careful monitoring of drug related deaths, with information about patterns of drug use, employment status and living arrangements being collected, information about whether those dying through drugs were parents, and the living and care arrangements for those children is not collected. This seems to me to be a significant omission in the way in which statistics are used to inform harm reduction strategies. It is however, consistent with the overall emphasis of statistical monitoring of substance misuse, which focuses on the needs of the user, rather than the consequences for their family.

To those involved in childhood wellbeing initiatives this is worrying, because the evidence consistently demonstrates that children are harmed by parental substance misuse, whether or not they live with their parent. The quality of the relationship which children have with their substance misusing parent, especially the experience of the parent ‘not being there for them’, and ‘not being cared about’ or ‘cared for’ seemed to be of potential importance in researching the lived experience of dealing with parental bereavement through substance misuse. These children are more likely to have ambivalent relationships with their parents, and to feel the shame and stigma of their parent’s substance misuse, they may also feel responsible for it. All of these are likely to shape the ways in which the child grieves when their parent dies as a consequence of the substance misuse. The research also shows that children with substance misusing parents have a higher likelihood of other adverse life experiences, and fewer opportunities to develop or experience resilience factors.

All children of substance misusing parents are emotionally vulnerable, because their
parent may not be able to meet the child’s emotional and developmental needs, and to provide a secure attachment figure. This impacts upon the child’s ability to navigate the challenges of life effectively, especially when those challenges are traumatic, likely to trigger life changes and to evoke powerful and painful emotions. It is for these reasons that I think children whose parent’s die through substance misuse are a potentially vulnerable, albeit previously unidentified, sub group of children, both within the fields of bereavement research and in hidden harm research. It is for this reason that I have focused my research on this area.

3.6. Understanding the Experience of Parental Bereavement Through Substance Misuse: A Summary of Key Themes from Bereavement Research and Hidden Harm Research

These two chapters form a literature review which maps out areas which I consider relevant for this phenomenological research about children’s experiences of dealing with parental bereavement through substance misuse.

Research into bereavement in general, and into parental bereavement in childhood indicates that some people experience complicated or traumatic grief, which means that they struggle to adjust to their loss, and that the effects of grief last longer and or have a more derailing effect than that experienced by the majority of people who are bereaved. Of those factors which influence vulnerability to complicated grief it is the nature of the relationship between the bereaved and the deceased, and the quality of the relationship between the bereaved person and their primary caregiver that are the most influential factors in shaping how each individual adjusts to bereavement.

Sandler’s contextual model identifies those risk and protective factors which influence the ways in which children adapt following the death of a parent. These factors are psychologically consistent with attachment theory of child development and well being, and with general theories of risk and resilience. In sum, where the caregiver is able to provide a stable supportive relationship, build self efficacy and safeguard the child’s environment to maximize stability and minimise disruption and trauma the child is likely to have the emotional tools and environmental support to navigate their way through parental bereavement. This is the case for the majority of children who, 24 months after their parent’s death, no longer show elevated levels of distress or difficulty. (Cohen and

The minority of children who do continue to have difficulties tend to be children whose environment does not provide contextual support to build resilience, and whose caregivers are less likely to be seek support to help the child. These are the children who are vulnerable to complicated grief. It is for these reason that population studies must be interpreted cautiously, and why clinical evidence seems to contradict epidemiological research.

My literature review demonstrates the risk factors for children who experience parental bereavement through substance misuse. It shows that while parental bereavement in childhood is not necessarily a risk factor for child wellbeing and development, it can nevertheless have a devastating impact. The research into Hidden Harm provides compelling evidence that children of parental substance misusers are harmed by their parent’s substance misuse, because their parents do not respond effectively to their children’s emotional needs, that children feel unloved, that they often live in unstable and unsupportive environments in which they provide support for others, rather than being supported themselves. They are at risk of neglect, and emotional, physical and sexual abuse. For all these reasons I think the research supports my assertion that children who are parentally bereaved through substance misuse form a distinct, and distinctly vulnerable sub group of bereaved children.

I hope that this research will make two distinctive contributions to bereavement research:

1. It identifies children who are parentally bereaved through substance misuse as a distinct and potentially vulnerable sub group of bereaved children.
2. I do not use proxy measurements of grief. Instead I undertake qualitative research to map out and try to understand the lived experiences of dealing with parental bereavement through substance misuse, and to try to draw a multi layered representation of these experiences.
Chapter Four: Researching Lived Experience: Matching the Methodology to the Research Question

4.1. Chapter Introduction and Overview

The research question asks:

- How do children and young people deal with parental bereavement, when the bereavement is caused by substance abuse?

The wider theoretical framework outlined in the literature review may be helpful in analysing the interviews but it is important that this is secondary to the process of eliciting and mapping out what seem to be the essential aspects of children’s experiences. That is, those constructs which seem to emerge as relevant from the literature should not direct or predetermine the representation or analysis of children’s experiences. The aim of this research is to try to develop knowledge and understanding of children’s experiences of dealing with parental bereavement, when the bereavement is through substance misuse. As the literature review has shown this seems to be a new dimension of research. It is important therefore that the research process is sensitive enough to try to capture something of the lived experiences of children who are dealing with this.

Interpretative Phenomenological Analysis (IPA) offers a research methodology which seems well suited to this task. IPA has a dual focus; towards the phenomenology of the participant, and their lived experience, and towards the interpretation of this lived experience through the lens of the researcher and her/ his research or theoretical or context. Larkin identifies:

*two complementary commitments of IPA: the phenomenological requirement to understand and ‘give voice’ to the concerns of participants and ‘make sense’ of these claim and concerns from a psychological perspective. (Larkin, Watts and Clifton 2006: 102)*

IPA addresses some key concerns within qualitative methodologies, about the power of language to represent experience, about the role of the researcher in altering experience by
exploring experience with the participant, and about the ways in which personal, social
cultural and academic contexts shape both the experience and the interpretation. IPA
adopts a critical realist position, that is, it does not seek to establish the nature of ‘reality’,
nor veracity of participants’ stories, but rather to map out ‘reality’ as it seems and feels to
be for each person’s experience of the phenomenon which is being researched.

In the introductory chapter I tried to demonstrate how IPA matched my professional
practice. This chapter is presented in two parts. In the first section I will explore different
dimensions of IPA as a research methodology, to demonstrate how its two complementary
commitments help to address the research question and achieve the aims of the research.
The second part describes the research process, from recruiting participants to
representing and interpreting their stories.

4.2. Aims and Aspirations for this Research

In their third ‘Handbook of Bereavement Research Theory and Practice’ the authors assert
that;

_Research should ultimately not only lead to deeper scientific understanding but also
be practically useful._

_(Stroebe, Hansson, Schut and Stroebe 2008:12)_

I hope that this research will be practically useful, to those living and working with
children who have been parentally bereaved through substance misuse and most of all
useful for these children themselves. The needs of these children, though perhaps small in
number, are likely to be significant and there appears to be a high risk that these needs
have hitherto been unacknowledged.

I hope that this research will ‘give voice’ to children whose experiences seem
unrepresented, and that the psychological framework through which these experiences are
interpreted will generate some practical strategies to try to ensure that the needs of
children who have been parentally bereaved through substance misuse are addressed.
4.3. Ethical Issues

4.3.1. Professional Obligations
As a practitioner and researcher psychologist I am professionally bound by the British Psychological Society (BPS) Code of Ethics (BPS 2009) and the Code of Human Research Ethics (BPS 2010). The BPS sets out four clear principles to guide researchers in conducting ethical research:

1. To respect participants,
2. To ensure research is of scientific value,
3. To ensure that the research practices are socially responsible
4. To maximize benefit and minimise harm. (BPS 2009)

Ethical considerations weave into the research in different ways and at different levels. The ethical considerations are especially important in this research because I am working with participants who are vulnerable because they are all aged sixteen or younger, and they are also potentially vulnerable because I will be asking them to tell me about experiences which may be painful and which may evoke difficult memories and difficult feelings.

At the most obvious level is the duty to comply with BPS Code of Ethics and the duty to minimise risk by taking clear and careful steps to safeguard participants before during and after the research meetings. This was a crucial part of my research planning and the practical steps I took to try to secure this are outlined in the next section.

As a professional psychologist I am used to talking with children and young people about difficult aspects of their life and abide by the same code of ethics to minimise the risk of psychological harm. I use psychology to help people explore issues of concern to them, and to support in them in developing their capacity to address these. The skills I use in my professional practice are similar to the skills I used in the research interviews, and are underpinned by the same Rogerian principles of active listening, empathy and unconditional positive regard, (Rogers 1961). In both roles I am intruding, in a sense, into personal territory, and in both roles I am professionally bound to minimise harm and to safeguard the wellbeing of my client or participant.

I was mindful that I was, ‘as a researcher. ...potentially an intruder into the world of the bereaved.’ Stroebe, Stroebe and Schut 2003: 239. The risks of ‘intruding’ therefore
need to be weighed against the risks of avoiding research into potentially difficult areas, and risking gaps in professional knowledge which may leave potentially vulnerable groups of people with their needs neither recognised nor addressed.

In practice many bereavement researchers report positive benefits from participating in research. In a follow up study to investigate the experience of taking part in bereavement research Dyregov reported that all participants rated the experience of taking part as ‘positive’ or ‘very positive’ even though they also reported the experience as ‘a little painful’ or very painful.’ (Dyregov 2004).

Flood, researching the experiences of families bereaved by suicide, reported one parent telling her ‘I think about him every minute of every day,’ suggesting that the research did not reopen old wounds, those wounds were still very much present (Flood 2009:29) I think this is important. Bereaved people may weigh up the costs and benefits of participating in research, and may decide to allow the researcher to intrude into their world. If informed consent is given, and if the researchers safeguards the wellbeing of the participant then the research should be ethically defensible.

In this research I took careful steps to safeguard the wellbeing of my participants. I explained the nature of the research, how my work with Luke had been the starting point for the research, and how I hoped the research might raise awareness for children whose parents have died from substance misuse. The steps I took to safeguard the wellbeing of participants are outlined in Appendix A, in the request for ethical clearances submitted to the University of Manchester University Research Ethics Committee (UREC). The consent letter from UREC is also in this appendix.

4.3.2. The Role of the Researcher in Qualitative Research Methodologies: Giving Voice or Voicing Over?

The steps taken to safeguard the wellbeing of participants, to demonstrate this to ethical review committees and to address the principles of the BPS codes are relatively straightforward. There are deeper ethical issues which should come into focus in qualitative research methodologies. One is underpinned by an epistemological concern with the nature of knowledge and the ownership or appropriation of participant’s stories.

Kathleen Gilbert, who uses narrative approaches in grief research, explains how she has
I once described myself as essentially a conduit for the stories of participants in my research. I have since abandoned that view, since I no longer believe it to be accurate. I clearly must make choices about what I will report, which part of a transcript I will use in my reports and how I interpret the statements made by participants. Rather than see myself as a conduit, perhaps the more appropriate analogue would be that of transformer. It is essential that researcher’s recognise their role in the transformation of stories, first in the listening to them being told, and then as they write their own narrative, the research report. In sum, the investigators role is to listen, report, interpret, and to recognise their own participation in the process. (Gilbert 2002: 229)

This is an ethical issue as well as an epistemological one, because the researcher must take care to identify their own role in shaping the knowledge or understanding emerging from the research. The researcher also needs to be alert to risk of altering the participants meaning, to the risk that instead of giving voice they may be putting words in the mouths of participants which may alter their meaning. In any research interview in which there is a discrepancy between the linguistic and social capital of the researcher and the participant this must be an important consideration. The researcher runs the risk of disempowering participants.

It is especially important for researchers to be mindful of this in research with vulnerable groups to be clear in the steps they have taken to try to guard against this, or to demonstrate the rationale and context for the interpretations they make. One of the reasons for choosing IPA as a research methodology is the rigour with which it directs the research focus onto the experience of participant, and the clarity with which it should make the role of the researcher in interpreting the representation explicit.

I have tried to do this in two parts. Firstly by producing an account of each participant’s experience which is grounded in the conversations we have had, and could be said to represent a story each girl has told me, and secondly by weaving these into an interpretative framework which draws upon the my professional knowledge and bereavement research and through which I try to answer the research question.
4.3.3. The Researcher Participant Relationship

The professional skills which I use to try to safeguard the wellbeing and dignity of my participants are, as I have explained, the same skills and principles which underpin my client focused work as an EP. This is also one of the risks for this research, as the two interactions have different aims. In my professional role my focus and my duty is to help my client, the therapeutic relationship is an important part of this. In my research role my focus is to gather rich and meaningful information for my research study. Gilbert suggests that therapists, talk show hosts and research interviewers all need to be able to ‘elicit in-depth narratives’ (Gilbert 2002). Polkinghorne clarifies the skills needed by researchers and psychologists as:

*an ability to form an accepting relationship, skill in active listening and to focus on the other’s experiential world. It is important for counselors doing a research interview to make clear to themselves and the participants the goal that is being pursued.*’ (Polkinghorne 2005: 142)

I needed to make clear to my participants that they were helping me, rather than me helping them, and that I did not create the hope or expectation of a therapeutic relationship or ongoing involvement.

The ethical issues within my research cannot be solved or smoothed out during the planning process. Rather, as Brinkmann and Kvale caution they will surface throughout the research process, and require me to be ethically attuned throughout the research process (Brinkman and Kvale 2008).

4.4. We live in Stories not Statistics: Choosing Qualitative Research Methodology

Bereavement and grief research have been growing fields of academic endeavour for the last fifty years. Whilst the aspiration of the research is to try to alleviate suffering through understanding there is a risk of superimposing academic ‘Knowledge’ on human understanding and undermining non medical support. This is especially true for quantitative research methodologies, which try to measure and represent the complex and contradictory experiences and expressions of grief through discrete and measurable variables. For example some bereavement researchers claim:

*Bereavement needs to be understood from a sound base of theoretically oriented and...*
empirically derived knowledge...we strive wherever possible to report methodologically stringent research and to suggest ways in which claims made in clinical or theoretical contexts can be put to rigorous test. (Stroebe, Hansson, Schut and Stroebe 2008: 12)

Of course there is a case for mapping out the experiences of bereaved people, of striving to understand and to address these, to try to make sure that help is offered to those in need, and conversely, that it is not offered where is not needed, and where it may disrupt the naturally occurring healing processes. Empirical knowledge and statistical analysis of different dimensions of grief may help with this. However, it will only ever capture a part of what it is to experience bereavement and to grieve. There is a danger of in asserting the value of empirical knowledge, as Stroebe and her co-authors do above, that it is seen to represent the truth and the whole truth and nothing but the truth. Some research methods may achieve rigour at the expense of sensitivity, and so significantly reduce the validity of their research.

Parkes sounds a warning note for the profession of bereavement researchers when he warns,  

*I must express my sympathy for Els Footman whose own experience of bereavement causes her to see all theories of bereavement as, like the work of a loss adjuster, an attempt to adjust downwards a claim for a loss which she experienced as devaluing the loss. All theories about people are a poor approximation to the real thing, an attempt to make sense of another by means of a reductive analysis, by simplifying the complex. Yet this is the way the mind works, we can never take in the whole of anything.*

(Parkes 2002: 1)

Qualitative research methodologies make clear their limitations. They do not assert the right to stake out empirical knowledge but to represent ways of seeing and understanding. They do not claim to represent the whole picture but to explore some aspects of it. Most importantly qualitative researchers do not work with variables that are defined by the researcher before beginning the research. This is because the researcher is interested in identifying and understanding those aspects of experience, which are important to the participant. Using predetermined variables would lead to the imposition of the researcher’s own meanings and might obscure the identification of critical aspects of the participant’s experience. Qualitative research methodologies which strive to elicit and
analyse participants’ accounts are messier but richer, requiring creativity as well as method, sensitivity as well as rigour, artistry as well as science.

Carla Willig, experimenting with phenomenological research, showed how she experienced the limitations of her research, and how she attempted to address this:

...Colliazi’s [phenomenological] method had helped me to condense and integrate participants accounts, but by doing that I had lost their emotional tone. I decided to look for a way in which I could reintroduce participant’s voices into the research and turned to Ohlen’s (2003) work on poetic condensation of oral narratives as a way of evoking and intensifying embedded meanings. (Willig 2007: 217)

The poem Willig weaves from her participant accounts does indeed capture the essence and the tone of the lived experience of participating in extreme sports more powerfully and more persuasively than her ‘final statement.’ Her poem also demonstrates the subjectivity and the artistry involved in the process of qualitative analysis, in the process of weaving together the different threads of experience into meaningful representation.

I hope that the care and reflexivity demonstrated in Willig’s analytic process demonstrates the rigour with which her knowledge is constructed, and the sound theoretical context within which it is embedded. Willig, would not, I think, claim that this is ‘empirical’ knowledge, but she does make a persuasive case for this as a legitimate way of understanding and representing experience.

Stroebe, Schut and Stroebe do recognise the role of qualitative research in bereavement studies:

Qualitative research provides an alternative paradigm for bereavement research, one that has the potential to add depth to the assessment of the grieving process. Qualitative approaches explore socially and personally constructed realities, with the goal to discover unique and common perspectives of the person being studied, rather than to generate incontestable ‘facts.’ .....Such approaches are suited to revealing the unique meanings that underlie the reactions of bereaved individuals or cultural groups. It is easy to see that these methods have the potential to broaden and deepen the study of bereavement. There is a lot to be said for quantitative evaluation to be preceded by qualitative in depth assessment.’ (Stroebe, Schut and Stroebe 2003: 238)
As researching parental bereavement through substance misuse seems to be a new area within bereavement research I hope that the qualitative research methodology I have chosen will broaden and deepen bereavement research by exploring the social and personal realities of children with this experience. I hope to demonstrate the ‘methodological stringency’ (sic) of IPA, and that its descriptive orientation does not ‘limit the potential for causal explanations of grief phenomena’ (Stroebe, Schut and Stroebe 2003: 238)

4.5. Choosing IPA

IPA sits within a social constructivist epistemology, and within the broader sweep of qualitative research methodologies, which holds that human experience is mediated by the personal, social, cultural and linguistic contexts in which it occurs. Rather than seeking to build up a cannon of empirical knowledge, social constructivist methodologies explore dimensions of knowledge, whilst attempting to demonstrate the ways in which these ‘knowledges’ are shaped by the context in which they occur.

Within the continuum of social constructivist epistemologies is the critical realist position, which combines ‘the realist ambition to understand what is ‘really’ going on in the world with the acknowledgement that the data which the researcher gathers may not provide direct access to this reality. (Willig 2007) Critical realism is the philosophical position that there are real external objects and events, but that our interpretations and impressions are necessarily partial and imperfect, meaning that science is necessarily imprecise and interpretative. (Bhaskar 1990). Another in between position holds that whilst experience is always the product of interpretation and is therefore both constructed and flexible, it is real to the person who is having the experience. Taking a critical realist position in this study means that I have made the assumption that these are not just stories which I am hearing, but that they are ‘real windows onto real events, real people real lives and real emotions’. I believe at all times that my participants are ‘reliable witnesses.’ (Robinson and Smith 2010: 174)

This is the phenomenological perspective which underpins IPA, and which I hope addresses the ethical concerns and commitments of the research. Larkin, Watts and Clifton try to capture the essence of IPA:
At the heart of this perspective at the core of any piece of IPA research lies a clearly declared phenomenological emphasis on the experiential claims and concerns of the persons taking part in the study. (Larkin, Watts and Clifton 2006:104)

They go on to grapple with some of the epistemological tensions within qualitative accounts, and how these are addressed through IPA. IPA aims to try to understand the participant’s world, and to try to describe ‘what it is like’, to represent it in a way which remains true to the participant whilst accessible and meaningful to others. But IPA has the phenomenological essence of experience at its very core. Access to experience is always partial and always complex, perhaps for the person who has the experience and certainly for the other trying to understand this experience. Phenomenon is not the same as reality and so the analytic process cannot ever achieve a genuinely first person account – the account is always constructed by the researcher and the participant’s experience of the phenomenon may be changed by the experience of reflecting on that phenomenon. This is the phenomenological aspect of IPA.

Not withstanding this concern the central goal of phenomenology is to reveal any subject matter in it’s own terms, to strive to capture the essence of the phenomenon without the imposition of preconceived assumptions.

IPA makes explicit the role of the researcher as an integral part of the world they are describing and the ways in which participant’s emergent meanings are shaped by the dynamic interaction between the participant, researcher and the phenomenon or ‘lived experience’ which is being explored. IPA addresses the concern of the qualitative researcher in presenting participant’s meanings, by explicitly recognizing the role of the researcher in attempting to interpret and analyse those meanings. This is the interpretative aspect of IPA which:

affords the researcher an opportunity to deal with the data in a more speculative fashion, to think about ‘what it means’ for the participants to have made those claims and to have expressed these feelings and concerns in this particular situation. Aspects of this interpretative work may also be informed direct engagement with existing theoretical constructs. (Larkin Clifton And Watts 2006:104)

In order to justify my choice of IPA as a research methodology I will explore the dual philosophical underpinnings of IPA research, phenomenology and hermeneutics or
interpretation, in more detail.

### 4.5.1. Phenomenology: Exploring The Essence of Experience

Phenomenology is a philosophical approach to the study of experience. It strives to define the nature of experience, the relation between the self and experience, and how this is shaped and experienced by the relationship of the individual within their world. It is fundamentally concerned with the ‘essence’ and the aim of phenomenological enquiry is to transcend the contemplator’s current preconceptions to consider the ‘thing’ for itself.

Phenomenological philosophers are concerned with how people come to know their own experiences, and in capturing the essential qualities of that experience. Psychologists and researchers are interested in how people experience different phenomena and how they come to understand and represent these experiences. Within both perspectives the dynamic interplay between living the experience and knowing about the experience alter both the nature of the experience and the ways in which individuals think about the experience.

Smith’s description of the process of phenomenological enquiry demonstrates how phenomenologists try to capture what is at the core of a subjective experience, what is the essence or ‘eidos’ or ‘idea’ at the heart of any phenomenon, whether it is attempting to capture the essence of the idea of phenomena as diverse as ‘house’ (Husserl’s example) or ‘love’ or, in the case of this research, a parent dying through substance misuse.

The method which Husserl describes proceeds through a series of reductions. Each reduction offers a different lens or prism, a different way of thinking and reasoning about the phenomenon at hand. Together, the sequence of reductions is intended to lead the inquirer away from the distraction and misdirection of their own assumptions and preconceptions and back towards the essence of the experience of the given phenomenon. (Smith et. al. 2009: 14)

As phenomenological enquiry evolved so it has moved from an essentially descriptive focus, to a more complex relationship between the nature of experience and the context in which the experience occurs. The essence of phenomenological enquiry is underpinned by

The complex understanding of experience [which] invokes a lived process, an
unfurling of perspectives and meanings, which are unique to the person’s embodied and situated relationship to the world. (Smith et al 2009: 21)

Whilst philosophers reflect on the nature of experience and consciousness the focus of phenomenological psychologists is more concrete and more pragmatic. They are concerned with attempting to understand particular experiences as experienced by particular individuals or particular groups of people. The processes by which we do this are interpretative, as we seek to weave together the different elements and the meanings that our clients or participants have of the phenomenon we are exploring with them. This is central concern of my research. At all times the data collection and analysis in IPA is underpinned by the belief that the data are not ‘just stories’ but are windows onto real events, real emotions and real lives.

The paradox within phenomenology lies in the recognition that our understanding of the ‘thing’ is shaped by our relationship to the ‘thing itself’ and can never therefore be purely objective. Larkin and his co authors attempt to capture the essence of IPA and the paradox within for psychologist researchers. They explain:

*In this Heideggerian sense, the central goal of phenomenology is to approach and deal with any object of our attention in just such a way that it allows itself maximal opportunity to show itself ‘as itself.’ Another way of putting this is that the phenomenologist aims to reveal any subject matter on its own terms (i.e. not according to any preconceived set of assumptions and expectations.) It is nonetheless inevitable that we will fall short of this target, for being a ‘person – in – context (and hence an observer indelibly situated within the world we observe) we can never fully escape the preconceptions that our world brings with it. But this should not discourage us from making the attempt. If the empathetic treatment of our subject- matter is central to our approach, and we are prepared to adjust our ideas and assumptions in response to the promptings of that subject matter then we are on the way to developing a Heideggerian phenomenology.* (Larkin, Clifton and Watts 2006:105)

4.5.2. Interpretation: The Paradox of Hermeneutics

Hermeneutics, in brief, is the discipline of interpretation, with its origins in the interpretation of sacred texts. In contemporary research the interpretative hermeneutic approach underpins qualitative methodologies which identify a role for the researcher in
shaping the outcome of the research, including narrative research methods, discourse analysis and IPA.

All of these make explicit the ways in which the researcher is ‘indelibly situated’ within her/his interpretive world, and cannot engage with the participant nor perceive the phenomenon entirely free from her his preconceptions. This is described, by Willig (2007, 2008) and Gilbert (2002), as a process of co-construction rather than discovery. That is, the researcher is more architect than archaeologist, playing an essential and explicit role in creating the research outcome, rather than simply discovering or describing something which exists. This means that the personal reality created in the interview is not a product of objective reality, the interview becomes a part of the lived experience which shapes the reality which the interview explores.

Hermeneutics or interpretation is thus a dynamic and interpersonal and intrapersonal process, requiring epistemological and personal reflexiveness. It is also a dynamic process as the researcher moves between the different aspects or elements of the thing, and the thing itself, in a process of progressive elaboration or representation. We can only build up an understanding of the whole by understanding the different parts of the whole. Initially our understanding is made of the expectations we bring to our encounter with the thing, our ‘forestructure.’ Paradoxically it is these that make understanding possible, but at the same time may impede our ability to true perception or understanding. The hermeneutic circle is the process by which we delve deeper into understanding the experience because each encounter with a part of the whole, or the whole, may lead to new perceptions or understandings, gradually deepening our understanding as we come closer to the true essence.

Thinking hermeneutically encourages us to be aware of the understandings we bring to our research, to read our data carefully and deeply, and to engage with it in a progressive cycle of immersion and analysis, which lead from description, through classification to analysis.

4.5.3. Interpretative Analysis – The researcher’s theoretical context

It is the interpretative analysis that distinguishes IPA from other phenomenological research methods. The interpretation which the researcher makes of the participant’s experience is grounded both in the account of experience and the theoretical framework used to analyse and make sense of this experience. It is dual facing. Smith calls this the
‘double hermeneutic’ which weaves between the ‘hermeneutic of empathy’, as the account is elicited and represented, and the ‘hermeneutics of questioning’, in which the researcher strives to makes sense of the participant’s account from a psychological perspective.

It is this explicit focus upon the psychological perspective of the researcher which means that IPA is able to satisfy its twin commitments, to ‘give voice’ and to ‘make sense.’ It is this also, I think, that lifts IPA from a purely descriptive process which arguably, could be achieved by a journalist, or as Polklinghorne suggests a skilled talk show host, and into ‘methodologically stringent research’ (Stroebe et al 2003) upon from which it may be possible to build or develop a useful framework of psychological theory. Smith suggests that herein lies the ‘added value’ of IPA:

In the context of IPA research some of this added value is likely to be a product of systematic and detailed analysis of the text itself; some of it will have come which emerge through having oversight of a larger dataset, and some of it may come from dialogue with psychological theory. (Smith, Flowers and Larkin 2009:23)

4.6. Using language as data: Capturing experience

In common with many qualitative research methodologies IPA tends to use semi structured interviews as a source of ‘languaged data’ (Polkinghorne 2005). There are opportunities and challenges in using language as a source of information which are central to the philosophical underpinnings of qualitative research methodologies in general, and to IPA in particular.

At the heart of these is the extent to which participants have access to understanding and representing their own experiences. Crudely, this means ‘is what participants tell us really ‘true’?.’ It leads to the questions, do participants really know and understand their own experiences? Are participants expert enough to provide the information researchers, clinicians and professionals need to build up a scientific knowledge and understanding of these experiences?

This question is especially important when the researcher is working with disempowered groups, or individuals, and is a core concern for post modern researchers who hold that the language shapes experience and linguistic capital is a cultural resource which is used to maintain unequal power relations.
In a sense some qualitative research methodologies, especially those that use languaged data could be said to be an attempt to liberate untold stories from people whose voices have not hitherto been heard. Indeed the attempt to liberate people from the stories that oppress them, and to understand the ways in which these dominant stories may have oppressed them is the essence of narrative therapy.

For me as a researcher the question is really can children who have experienced trauma, and who may or may not be used to talking about their lives, hopes and concerns use language in one to one interviews to capture and share the essence of their lived experiences? Will the data which I generate in my research interviews enable me to answer the research question? Are my participants able to discern aspects of their own experience and effectively communicate these through the symbols of language? Will my participants fit Polkinghorne’s guidance for purposive selection, as ‘participants who can adequately reflect on their experience and verbally describe it? (Polkinghorne 2005: 140)

It is this that makes clear the interrelationship between participant, researcher and data. The data for this study will depend not just upon my participants’ experiences, nor upon my participants’ willingness and ability to talk about their experiences but upon my ability, as a skilled interviewer, to create a context in which participants are enabled to tell their stories.

Children’s own experiences are an unresearched area, for bereaved children and for children living with parental substance misuse. There are limitations to the use of languaged data in all research and for all participants, and this includes children. Perhaps one of the reasons why there is so little rich qualitative research with bereaved children lies in the belief that children are not able to use language to report on their experiences and emotions.

As I explained in my introduction, one of the underpinnings of my professional practice as an EP is that I try to make explicit some of the ways in which dominant discourses shape experiences and perspectives, and try to help people to weave together from the same threads a story which is less judgmental, more enabling, more hopeful. One of the challenges for me as a researcher was to resist this process, and allow the story each child told me to heard with as little shaping as possible from me.
This interview process yielded a rich set of information, located within authentic accounts, not fragmented responses to questions. The children’s stories did cover all of the aspects which I had hoped to address, but yielded also a much wider perspective of on their lives, experiences the ways in which they made sense of the world around them.

4.7. Method

4.7.1. An Overview of Data Collection: The Interview Process

4.7.1.1. Sampling and Participant Selection
The essential inclusion criteria for all participants was that they had been parentally bereaved through substance misuse. For the purposes of this research all participants needed to be over fourteen, to be able to give consent to participate in the research, to be referred by a professional who was willing and able to offer emotional support and debriefing following the research meetings. As the research focused on the experience of dealing with the bereavement the bereavement needed to have occurred over 12 months prior to the research interviews.

All educational psychology colleagues asked SENCOs in schools about the numbers of children who had been parentally bereaved, and of these how many had been bereaved through substance misuse. In total 236 local authority Schools reported 36 children as having been parentally bereaved, with seven of these bereavements thought to be have been through parental substance misuse. Using national statistics as a guideline this is likely to be a gross under representation of the numbers of parentally bereaved children in Local Authority schools, however, it does suggest that perhaps 20% of these deaths had been caused by substance misuse. This is a potentially fruitful area for further research.

I also contacted colleagues in community care homes, social care and fostering and adoption teams, Young Carer’s, Drug and Alcohol Support Teams, CAMHS and the Youth Offending Team. I sent out a covering letter with information about ethical review procedures and leaflets for young people and also for parents and carers. These leaflets are in Appendix B. I asked professionals to discuss this research with young people who they felt might be willing and interested in participating in this research, if they knew that the young person had been parentally bereaved through substance misuse.
From the young people who initially expressed interest when the research was discussed with them by a referring professional. Four participants took part in the research.

IPA is an intense idiographic research, with the purpose of illuminating individual experiences of a particular phenomenon, and sharing Warnock’s aspiration that ‘delving deeper into the particular may bring us closer to the universal’ (Smith 2004 citing Warnock 1975.) For these reasons four participants was judged to be an appropriate number for the research.

4.7.1.2. Participants

All of the participants were girls, aged 14-16 years. Emma, Katie and Charlotte were white British, and Alana was mixed race, as her mother had been, as her grandfather was African Caribbean. Although some boys had expressed interest they subsequently lost contact with their referring professionals and so I was not able to contact them. It is possible therefore that I will need to reframe the research as girl’s experiences of parental bereavement through substance misuse.

I came into contact with Katie through a worker at Young Carer’s. Katie’s mother had died from alcohol misuse just over two years previously. Katie lives with her maternal grandmother and attends mainstream school. She was fourteen and I met her at school.

I came into contact with Emma through her Youth Offending Officer. Emma was fifteen when I met her, and her mother died when she was nine years old. Emma’s mother used drugs and alcohol, and died from drugs, although Emma told me that her mother also had cancer. Emma was living with her aunt but shortly after I met her was asked to leave, and went to live with her grandmother. Emma attended a referral unit within her mainstream school. She was fifteen when I met her, at her aunt’s home, with her youth offending officer.

I came into contact with Charlotte through discussion with the manager at the community care home where Charlotte lived. Three of the seven residents had parents who had died through substance misuse, of whom only Charlotte chose to meet with me. Charlotte was sixteen and her father had died when she was ten. Charlotte attends mainstream school.

I came into contact with Alana through a learning mentor at her school. Alana was sixteen
and her mother died when she was eleven, through taking drugs. Alana lived with her nan, with whom she had lived all her life. Alana was attending mainstream school, although her attendance was very low.

4.7.1.3. Safeguarding Procedures

All of the participants were referred by professionals who felt that they would be able to manage the emotional demands of talking about their parent’s death. Indeed all of the professionals felt that it would be helpful to the young people. One of the inclusion criteria was that the referring professionals would undertake to check on the young person’s well being, inviting them to talk about the interview and offering support if requested. Each referring professional was given information about a childhood bereavement service which had agreed to offer counselling to participants who requested this.

At the end of each interview I asked each girl about her experience of the meeting, and asked whether they would like some follow up support.

The wellbeing of my participants was my primary responsibility, ahead of my research responsibilities. The research was classed as ‘high risk’ because it involves children under the age of 16, The steps I took to safeguard the well being of participants are outlined in Appendix A within the research application to the University Review of Ethics Committee (UREC). The consent from the UREC committee is also included.

All participants were asked to sign a consent to be contacted form (Appendix B) which also asked where they would prefer to meet me.

The interviews were held at home or at school, with location chosen by the participants.

At the start of each interview I summarised the purpose of the research, that it was about the experiences of children and young people whose parents had died through substance misuse, and that I hoped the research would be helpful in addressing the needs of these young people. All participants were asked if they had seen the information leaflet about the research. I explained that I would need to record the interview and then type it up afterwards. I emphasized that they could choose to stop at any time.
All the young people chose to go ahead, and then signed a consent form to say they consented to participate in the research.

4.7.2. Conducting The Interviews

When consent had been obtained I asked each young person, in the initial interview,

‘Tell me the story about what it’s been like for you, dealing with your mum/dad dying’

I had originally prepared a set of prompts based on my research question and the issues and aspects of experience which I hoped to explore in the interview. I prepared a ‘virtual map’ for the interview. (Smith 2009:59). However, I was mindful that my questions might interfere with the participants ability to tell their own stories in their own, with the themes which mattered most to them. I did not want to be so beholden to an interview framework that I my participants’ stories were broken up with questions and probes which fragment.’ (Gilbert 2002: 232)

I decided to focus instead upon responding to the story I was being told, rather than attempting to shape the interview. This process allowed me to ensure that I was able to ‘permit participants to tell me their own stories in their own words.’ Smith et al 2009: 57). I did however ensure that I asked all the participants whether they felt that dealing with a parent dying from drugs or alcohol was different from dealing with a parent dying through illness or an accident. These approach allowed the girls to tell me their stories, and allowed me to listen

In subsequent interviews I started by asking participants how they had felt about the previous interview, and whether there was more they wanted to tell me. I explained I had listened to and transcribed their previous interview, and wanted to ask some questions about it. These subsequent interviews allow me to prepare questions based on the initial story, and on the themes which seemed to emerge from it. In these subsequent interviews with Katie and Charlotte my focus remained on their stories, and I continued to try to immerse myself in their narratives rather than in my own interview agenda.

I had one interview with Alana and Emma, two with Katie and four with Charlotte. For the purposes of this research two interviews felt adequate to talk, listen, think, reflect and
clarify. The additional interviews with Charlotte were more because she asked for them, and did not add greatly to the research. Alana had been keen to meet again, but I was not able to contact her again, as she stopped going to school. Emma had a great deal of upheaval and decided she did not want to meet me again. I gave Charlotte and Katie copies of their transcripts.

4.7.3. Debriefing

I contacted each participant at the end of the academic year, to ask them about their experience of taking part in the interview, and whether they would like some follow up counseling from the childhood bereavement service. None of the girls have requested this additional support.

4.8. Analytic Procedure

4.8.1. Step 1: Translating the audio recording to written transcript.

Prior to conducting the research interviews I had considered either using a voice to text software, or even commissioning someone to transcribe the interviews for me. However, I realised whilst doing the interviews, that the intimate process of transcribing is the first step in the analytic process.

Listening to the transcript allowed me to relive the interview, with all the non verbal and expressive elements of the interview captured through the pauses and cadences of each child’s voice. Whilst I transcribed I paused the tape to record my initial impressions in a separate word document. Some of the impressions cued me in to questions which I wanted to ask in subsequent interviews, some were themes which I wanted to capture in the analysis. Sometimes I wanted to record my concern that I had not listened carefully, or had asked leading questions, or had imposed my interpretation and my language in a way which was unhelpful. Sometimes listening to the transcripts brought me to tears.

I included the full dialogue of each interview, including most of my ‘fillers, i.e. the ‘umms’ and ‘ers’ which I used whilst listening to the children talk. This rarely interrupted the flow of what the children were saying, and so although some of the conversation looks fragmented these fillers do not represent broken speech. I have recorded hesitancy using a
sequence of dots.

The transcript was produced in table form, with a column to record emergent themes, and the column on the right to capture initial thoughts.

Each child was given a transcript of their interview, if they requested this.

In total I transcribed eleven and a half hours of interviews. Part of Katie’s transcript is shown in Appendix C1

4.8.2. Step 2: First engagement with the written transcript.

Having produced a written transcript I listened to the recording again, all the way through whilst reading the transcript. I then recorded the initial thoughts and impressions in the column to the right of the transcript. Many of these were my subjective experience of how it felt to be listening to these often harrowing stories. This was important because it represented my personal difficulties in conducting the interview and allowed me to reflect on ways in which I might be shaping the interview.

4.8.3. Step 3: Descriptive, Linguistic and Conceptual Coding:

As I progressed through my analytic cycles I started to use Smith’s proposed descriptive, linguistic and conceptual comments to help separate out my interpretative themes from the child’s life experiences (Smith et al 2009: 83-84). I added these to the initial comments on the right hand column of the transcript.

Descriptive codes are those which use the child’s own language, such a ‘lifeline’, or ‘all quiet.’ In the descriptive coding I attempted to identify key events in each child’s life, to identify the context of their concerns within their lived world.

I also wanted to identify some linguistic themes. In particular I was interested in fluency-hesitancy continuum, which subjectively I construed as the ease or difficulty with which each child was able to talk about their lives. I thought this might help me to consider the extent to which each child was able to access their experiences, and to make sense of
them. This was important as I was not sure that language based interviews could be sensitive enough to capture children’s lived experiences.

Smith suggests that the conceptual coding involves personal reflection, and is the start of the process in which the researcher draws upon professional knowledge and experience, to help with the coding process. Smith calls this:

* A Gadamerian dialogue between your own pre-understandings and your newly emerging understandings of the participant’s world. (Smith et al 2009: 89)

I tried to stay close to each child’s own language, but also to identify what appeared to be key elements, e.g. ‘ambivalence to mother’, ‘intrusive questions’, or ‘thinking of the future’. I used high lighter pens and a key code to start to try to build up a picture of how different elements of the transcript seemed to fit into these different codes. There was no limit on the number of codes.

A sample transcript with initial coding, is shown as an example, in Appendix C2.

4.8.4. **Step 4: Towards Identifying and labeling emergent themes**

The process of conceptual coding led to exploring emergent themes. In the initial stages of developing emergent themes I tried to stay close to the themes represented in each child’s experiences, and to use each child’s words. I wanted at this stage to try to make sure that the emergent themes were ones which would be recognizable to the child.

Having read and re read my notes and coding for each child several times I then attempted to label these. As I labeled I kept up a parallel document to record what I thought I was capturing in each emergent theme, and some of these themes changed labels, split into two or merged into one, as I went through the text.

Having identified these emergent themes I then went through the transcript line by line to match transcript and comments to the themes. These were copied into a table in which each theme was supported by relevant parts of the transcript.

I then checked each theme against the definition I had recorded, to try to ensure that my coding and clustering was consistent, and that the different elements did fit into the key themes. Sometimes this resulted in quite substantial realignment or redefinition of key
themes, which meant checking the transcript against the themes again.

These tabulated themes tables are shown in Appendix C3.

4.8.5. **Step 5: Giving Voice: Weaving Children’s Stories**

At this point I started to write up a summary of each child’s story, capturing what I felt to be the essential elements of the child’s experiences, as they told their stories to me. As I did so I moved between the annotated transcript and my tabulated themes and the prose which I was starting to write. I hoped that this would help me to present a coherent account of each child’s experiences, and that this account would adequately represent the experiences of each child, in dealing with the death of a parent through substance misuse.

This felt more art than science. It perhaps represented the ethical tensions between my role as researcher, to capture the essence of the phenomenon as it is experienced across participants and my ethical commitment as a psychologist to my individual clients. I did not want to lose the voice of each child by moving from analysis to superordinate themes without a more intense focus upon the personal experience of each child.

Writing these stories felt an important testament to the experience of child and an important step in the research process. It was an intense and intensely personal experience. Each story undoubtedly represents the shared experience of the interview, as well as offering, I hope, a window onto the complex, multifaceted experiences of each child dealing with the death of a parent through substance abuse. They show how and why the themes I have chosen have emerged from each story, and start to reveal the similarities and differences across each child’s experiences. These stories form the second part of the results chapter.

4.8.6. **Step 6: Identifying Theme clusters and super-ordinate themes**

It felt to me that the analytic process so far has been idiographic, focused upon creating sensitive and honest accounts of each child’s experiences, to represent their individual experiences of dealing with the death of a parent.

The next challenge was to interpret these within a psychological framework and to start to
move beyond the idiographic and to look for commonalities and differences between the different accounts. At this point I moved away from the transcript – the raw data, and on to the themes which I had identified. At this stage it is interpretation of the phenomenon rather than the phenomenon itself that is under investigation. This is very much the researcher driven element of the process, and I have started to try to capture feelings and expressions about how the children think and feel their experiences have shaped their lives and themselves, rather than simply describing their experiences.

I have summarised these in a table to try to give an overview of similarities and differences in different aspects of the experience of dealing with bereavement through substance misuse. This forms the first part of the results chapter.

4.8.7. Step 7: Elaborating key themes

Qualitative research often presents results and discussion together (Smith 2009, Willig 2008). I have chosen to do this here, as integrating research findings results into an existing psychological or theoretical framework, which may be informed by the researcher’s own experiences, their knowledge of the subject, their motivation for undertaking the research and their background reading and literature review prior to undertaking the research are an integral part of the research process.

All of these factors have influenced this research, and therefore influenced my interpretation of these stories. It is for this reason that the discussion is woven into the results chapter, with an elaboration of each of the key themes undertaken in part four of the next chapter.
Chapter Five: Representing and Interpreting the Lived Experiences of Four Girls whose Mother or Father have Died through Substance Misuse

5.1 Chapter Overview
The purpose and challenge of IPA is to capture the essence of lived experience, and in so doing to try to make sense of it, within the context in which it has been experienced, and also within the world in which it is interpreted and represented.

Each researcher will chose their own way of presenting their IPA results, or perhaps their data will dictate this to them. My results, and this chapter are presented thus:

Section 1
An overview of my analysis: a table showing the master themes and constituent themes for all the girls, with the superordinate themes which capture elements of shared experiences for all the children. The themes reflect my subjective interpretations of each girl’s experiences, although I hope that reading each interpretative account the reader will understand how I have come to these themes. Appendix C shows the tabulated tables for each child, with excerpts to illustrate each constituent theme.

Section 2
An interpretative account of each girl’s individual experience, in which I try to represent their ‘voice’, and distill the experiences they have had, and the intrapersonal, interpersonal and social contexts in which they live these experiences. I try to use the words each girl uses throughout the text, to weave together something that is coherent and meaningful beyond the context of our meetings.

This is sometimes seen as the soft end of IPA, not real science, because it is descriptive not analytical, not rigorous. It was not until I embarked upon the process of creating these accounts, of striving to create something which was true to and for each child, that I appreciated the depth, rigour, reflection and integrity required to create coherence from the different threads and textures of being and experiencing, to strive to build an accurate representation of the essence of these girls’ experiences of bereavement. It became a personal and political endeavour, as well as an academic one.
The process of weaving the disparate and sometimes contradictory elements of complex and troubled experiences, emotions and thoughts into a coherent whole is hard. Making sense of life events is a challenging and integral part of human experience. Arguably those who are least able to tell their own stories, perhaps because they lack the resources in order to do so, or because their stories are too hard and too fragmented to tell, or because for others these stories are too hard to listen to, are those who most need to be able to make sense of their complex lives so that they can chart a way through their lives, to find some direction.

This process of creating and living in a coherent story is likely to be hardest for those who are least likely to be able to access social and cultural resources and to be able to participate in society, to belong. Barham and Hayward have suggested, for example, that the social exclusion of schizophrenics is the outcome of their inability to present their lives as socially intelligible projects (Barham and Hayward 1991). Salmon (2008) explains it thus:

*Being accountable to others- to story our actions and our experience in socially and culturally comprehensible ways is crucial to our standing as persons, as recognised members of human society.* (Salmon and Reissman 2008: 78)

Our stories, and the stories others tell about us, define our sense of who we are and how we act within the world, engage with it, or perhaps rage against it. It is for these reasons that it seemed important to me to offer each girl’s story as a distinct and coherent whole, to strive to capture some essence of each girl and her story, as well as to strive to explore elements which may be common across all of these girls’ experiences. Most of all these unique stories are important because, for each girl sharing their experience, in the hope that this might help others and also help themselves, was their motivation for participating in the research interviews.

Section 3
An interpretative examination of the similarities and differences in key themes which emerged from the data. located within a theoretical framework informed by bereavement research, and by psychological meta theories of risk and resilience and attachment.

In this interpretative overview my main aim is to answer the question: how do children deal with parental bereavement, when the bereavement is through substance misuse? The question is addressed in this section through considering the stories and the common
themes through the lens of bereavement research and psychological theory.
### 5.1.1. Thematic table

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5.2. Representing: Individual Stories

5.2.1. Representing and Interpreting Emma’s Lived Experience

My meeting with Emma took place in her aunt’s house, where she was living, with Mike, her youth offending officer, present. Emma greeted me politely, and started to tell me her story, even before I had sat down, and before I had a chance to thank her, to explain a little about the interview, and before I obtained her consent. I had a feeling that Emma was almost inhabiting a role, that she was ‘telling me about Emma’, rather than ‘being Emma’. With the other girls the rapport we established meant that I felt as though I was giving as well as getting, they were intense interpersonal experiences, and I felt tied to them and found maintaining my researcher role as distinct from my helping psychologist role a difficult tension to manage. I didn’t feel this with Emma. She was giving something to me without any apparent expectation of getting anything in return.

Against this backdrop, in a matter of fact voice, Emma told me the harrowing tale of her life and her losses. I was struck by the dissonance between the weight of the story she was telling me and the pragmatism with which she spoke, between the intimacy of the story she was telling and the distance between us.

Linguistic threads

As I listened and analysed her transcript it was the linguistic elements of my meeting with Emma which struck me first. I asked questions but hardly used any of the conversation fillers that appeared to break up my meetings with the other children, but which in fact sustain a dyadic rhythm. The linguistic threads form part of Emma’s story, that shape it and are important to the overall experience of attempting to immerse myself in her world, of being with, and attempting to capture the quintessence of her experience.

Two phrases she used over and over, which I think capture her experience of powerlessness in her chaotic world, are ‘not knowing’ and ‘at the end of the day.’ She also uses passive verbs which I think capture a sense of being ‘more sinned against than sinning,’ of having things done to her over which she had no choice. ‘They put me in counselling,’ she told me, ‘they put me in anger management’, ‘I was getting told.’ Emma
moves between pronouns, shifting from ‘me’ to ‘you’ which I think represents some of the
dissonance between the world as it is for Emma, how it is for ‘me’; and the world as it
should be, how it is for ‘you’ some impersonal or unnamed ‘other.’ ‘It’s family what you
need,’ she told me This is particularly striking in the way in which she talks about her
mother ‘my mother is the best mother I could have had………..Your mum is your best
friend, I think.’

These linguistic threads are woven through the themes I have chosen, to try to capture
Emma’s experiences of dealing with her mother’s death. It is difficult to know how much
to read into these linguistic themes, and whether I am capturing the essence of her
experiences, or whether I am moving away from her experience, from ‘the thing itself’,
and into my own realm of interpretation and pattern matching. I have struggled to settle on
distinct and stable themes, and I think in part, this is a consequence of the inchoate
experiences of Emma’s life and her feelings, and the struggle she has had with sense
making. I am attempting to impose order upon chaos in the context of Emma’s ‘not
knowing.’

**Powerlessness in an uncertain world**

Emma’s life is one of multiple losses, multiple rejections and confused relationships. Prior
to her mother’s death she had been ‘passed around the family like a parcel. It felt like I
weren’t wanted anywhere.’ And then ‘I ended up going back living wi me mum and she
got with this complete arse. Beat her up. Beat me up. And everything.’ Her sister, aged
four, had died when Emma was one. Her grandfather died ‘seven week and two days after
me mum.’ ‘It’s kinda complicated’, she told me, ‘because the guy I thought were my dad
died a few year ago……a few months ago, so it gets harder.’

Within this context Emma is trying to work out what she should be doing:

‘My mum were doing drugs. She were drinking. She ended up with cancer. I didn’t
know how the hell I could help so in the end I thought it were my fault cos I was
getting told it was my fault at the same time. I didn’t know what to do.’

Over and over again Emma comes back to the experience of ‘not knowing.’ ‘I didn’t know
how I felt,’ ‘I didn’t know what to do.’ ‘Not knowing,’ not being able to make sense of an
uncertain world represents, I think, Emma adrift in a world of chaotic events, of multiple
rejections and uncertainty. No wonder, I reflected, she needed to take charge of our meeting as she attempted to impose some coherence upon her life story, her experiences.

Emma doesn’t know how she feels about her mother’s death, about how to react or what to do, or about how to make sense of her relationship with her mother. ‘Not knowing’ captures her sense of confusion, of being overwhelmed by events which happen to her, and the difficulties she has in making sense of her world:

‘I didn’t know where my mind were or owt...cos it’s like...how can I put it? ...it’s like you don’t have any control over what’s going on in your life.’

About her relationship with her mother she explains, overwhelmed by trying to make sense of her relationship with her mother, She ruined that part of my life. I don’t really know how to put it.’ Not knowing features powerfully in Emma’s experiences of ‘being helped’ to cope with her mother’s death:

‘You had to put a picture of the person what died at the front [of a memory book] and how you felt and everything. And I didn’t know. And I didn’t know and I felt a bit after each one and yeah it were but ummmm’

‘I didn’t know how it felt and they were telling me just put this down and this down and half the time I felt like smacking one of the teachers cos you get this anger inside you like you want to kill someone cos your mum or dad’s gone.’

This theme of powerlessness in an uncertain world is captured in Emma’s use of the phrase ‘at the end of the day’, as though her life is a chain of events over which she has no agency:

‘I ended up going back living with me my mum....I ended up standing by my mum because at the end of the day she’s still my mum...my mum being as she were...it were like um...at the end of the day....I ended up hurting other people in the same process as hurting myself.’

**Adrift: No safe haven**

The title of the theme is informed by attachment theory, by Bowlby’s tenet that ‘all of us are happiest when our lives are organized as a series of excursions from a secure base.’ (Bowlby 1980). Emma has no secure base to anchor her as she navigates her life journey.
Emma’s complicated relationship with her mother, her conflicting feelings and her yearning, is the major constituent to the ‘being adrift’ theme. Her mother is both: ‘a proper xxxx. I hated her but at the same time I loved her,’ and ‘the best person I could have had in my life.’ Within the context of her feelings and experiences of rejection Emma tries to make sense of her mother’s relationship with her:

‘She didn’t really play a part. She ruined that part of my life. I don’t really know how to put it. She didn’t have anything to do except eat, drink but I know my mum loved me or she wouldn’t have kept me. If she didn’t love me she’d a put me into care or poured me off to someone else. You wouldn’t have a kid and then let it go would you?’

That seems to be exactly what Emma’s mother did. Several times she tells me, ‘I always got told my mum didn’t want me.’ The certainty with which Emma feels rejected is in stark contrast to her experiences of ‘not knowing’. And after her mother’s death she explains: ‘I were sleeping I think it were the front room cos I didn’t know where I were and it felt like I weren’t wanted anywhere.’ The feeling of not being wanted and the feeling of anger are the only feelings that she names. ‘My mum didn’t want me…….She’d get rid of me to my auntie or uncle’s and it felt like I weren’t wanted there…

Emma’s relationships with her family are unstable, and started to break down after her mother’s death, ‘I didn’t get along with my brother after my mum died and my brother were the person I looked up to so that were hard.’ … and ‘after my grandad died I stopped getting along with my nan.’ When I ask about things that help she tells me, ‘it’s family what you need’ ....and says, ambivalently, ‘at the end of the day I had my family around me. Mostly.’

Emma’s experiences of her mother’s funeral are tainted by the tensions in her family relationships:

‘At the funeral I proper broke down in tears and I were screaming and I were like I can’t say goodbye and my grandma were like (adopts an angry hissing tone) Stop making a scene! Stop it! And my biological dad or the guy I thought were my biological dad were sat at the back of the room and he stood up and said Right Emma if you don’t want to say goodbye don’t say goodbye. and I’ve never said goodbye so I’ve got in my head still she isn’t dead.’
There are some shoots of connectedness. She told me that she and her brother were thinking of doing something to remember her mum, ‘like dunno put flowers on her grave or summat.’ Although the idea is abstract rather than concrete, she talks of ‘we were’ rather than ‘we are’ Emma uses ‘we’ for the only time in her story suggesting some togetherness against the loneliness of the ‘I’ against ‘they’ in the rest of her story. She talks too of her cousin, ‘me and my cousin were talking….If he hadn’t been there I’d a done summat I’d regret.’

Emma experiences rejection at school as well as within her family. She felt shouted out, humiliated, not understood: ‘headmaster….everyone coming at me….why you sat there……..my mum’s dead…well that’s no excuse get back in yer bloody lesson.’ The children as well as staff rejected her, ‘I started y’know, getting grief at school from y’know kids had parents and I didn’t and they were like oh you don’t have a mum you don’t have a mum, and I’d proper flip out.’

Emma talked twice in our interview about these experiences, and about being told that her mum and grandad dying was ‘no excuse.’ This clearly represents an important experience, which to her was a traumatic event, compounding the trauma of the bereavements.

It seems that here Emma is describing a sense of being judged and rejected because of the emotional consequences of her mother’s death. School does not give her permission to ‘act out.’ She is punished for it, shamed for it, and her experience seems to be that the responses of adults and children in school were harmful not helpful, and increased her ‘flipping out.’ Is this I wonder, an indication of the process by which children are punished for ‘acting out,’ for behavioural responses to feelings and fears which are too overwhelming and too complex to express in other, safer and more socially acceptable ways? Is it the case that Emma’s anti social behavioural responses compound her difficulties by legitimating her exclusion from the school community and her entitlement to sympathy and support?

The experiences of being helped were also traumatic events, compounding her sense of rejection and her powerlessness: ‘They put me in counseling’…. ‘I punched the counsellor’s nose’... ‘they put me in anger management’.... ‘I got kicked out for being angry.’
Emma’s experiences seem to be of help that was offered being intrusive, because it triggers memories and feelings she doesn’t want to have. She explained, ‘I didn’t want to go back to relive those memories. So questions aren’t always that good.’

She would rather have ice cream and chocolate, and I wondered if in some sense this represents her need to be nurtured, and perhaps the risks of accepting that nurture. She told me about ‘one person who stuck by me,’ a teaching assistant from her primary school, who sat with her, and let her cry and gave her chocolate and ice cream. Even this had a sting in the tail: ‘...then you put weight on a bit and then you get a bit like about being fat...y’know everything just goes down t’pan when someone dies.’

Emma’s experiences of being helped exacerbate her difficulties and contribute to a spoiled identity, for, as she explains she fought back, resisting having these forms of unhelpful helping thrust upon her.

**Fighting Back**

In the context of not knowing how she feels or what to do it is the angry reactions that define Emma. It is caused by the treatment she experiences by others, from the assaults upon her self. She does not choose to be angry, it her reaction rather than her action. She ends up ‘battering shit out of people’ ‘feeling like smacking one of the teachers.’ Within the story of hitting and hurting others is the sense that she has lost something of herself as well:

*I never wanted to hurt no-one but....when I were younger I were the cutest thing, I wouldn’t hurt a fly but as I got older I started getting nasty so I ended up hurting other people in the same process as hurting myself.*

The essence of Emma’s experiences is chaos, rejection and powerlessness. It is not surprising, within the context of her life, that she struggles to make sense of who she is, of her relationship with her mother and her feelings about the bereavement. The things she suggests for children who have been bereaved are the things that help to form a sense of agentic self, the core elements of a secure attachment; being there, listening, letting her cry, and containing her feelings and sharing her pain.
Dying through Drugs and Alcohol

Emma falters when I ask whether she thinks it feels different when your mother dies from drugs or alcohol, rather than from an illness. She focuses upon irrevocability, explaining that whilst you can’t stop cancer if it’s gone too far, it’s the same with drinking and drugs. ‘You can’t stop it without locking someone in a padded cell. And my grandma’s always saying if I’d a known about it I’d a got her into rehab. But it wouldn’t have worked cos it were her choice.’

I think for Emma it is not the experience of dealing with her mother’s death through drugs and alcohol, but the experience of living with a mother who chooses drugs and alcohol over her, which has shaped how she has dealt with the bereavement. It is not the nature of her mother’s dying but her chaotic and unloved life that shaped her responses, her interactions and wounded sense of self.

Reflecting on Emma’s needs and experiences through an attachment lens it is not surprising that she is chaotic and disordered, her basic needs for security and belonging have not been met. The emerging neuroscience of attachment (Schore, 2002, 2008) demonstrates the impact of early neglect upon self regulation. With no safe base from which to venture into the psychic world of sense making and the social world of intrapersonal relationships, it is not surprising that Emma’s experiences are shaped by a sense of ‘not knowing,’ that she experiences the world as confusing, a world in which she is positioned as a reactor rather than an agent, as an object rather than a subject. Emma is not yet able to tell her own story, instead it seems she is telling a story of her self and her life that is authored by the world around her.

It hasn’t been possible to check out my interpretation of her story with Emma. I am not sure how much she would recognise and I fear that reading this interpretation might be painful for her. It might make explicit things she is struggling to make sense of outwith the context of a therapeutic relationship to support her sense making, as she constructs her own narrative about her experiences.

I only met Emma once. Although she had said she would like to meet again, and was enthusiastic about the possibility of helping other children with her experiences I did not manage to see her again. She was thrown out of her auntie’s, where she had been living, to
her cousins, and then back to her grandma’s house. At the same time Mike was on compassionate leave. When he returned Emma told him she did not think she needed to see me again.

5.2.2. Representing and Interpreting Katie’s Experience of Dealing with Her Mother’s Death Through Alcoholism

Katie is an articulate speaker. She seems confident and at ease with herself. I feel as though we quickly established a sense of rapport, a sense of shared purpose. She talks fluently and I listen carefully, asking few questions and interjecting conversation fillers, ‘umms’ and ‘rights’ to maintain our dyadic flow. She tells a clear coherent story, and for her, telling her story seems closely intertwined with thinking about her life. As I listened and transcribed I was struck by how often she said, ‘I think’. She was surprised, at our second meeting, when I commented that this had struck me, but she agreed: ‘I think a lot. I think things through a lot. I actually realize that I think things through more than other people my age….I’ll think, ‘Should I do this? What will the repercussions be? I do. I process things in my head a lot more.’

Thinking and sense making are woven into the story she tells, and she uses thinking to inform the choices she makes, about how to behave, about her hopes for future, how to grieve and how to construe her relationship with her mother and her life past and present. Katie has a clear story, and a clear sense of who she is. She asserts ownership over her life and acts purposefully to maintain and enrich her sense of self.

I’m Powerful!

Katie’s sense of self is closely tied to her ‘reputation.’ Her reputation is not just what others think of her but how she thinks about her self, how she processes the affirmations she receives and incorporates them into her sense of self:

‘I know if they think highly of me it’ll make me do higher. And if they think ‘Oh Katie wouldn’t do that,’ it’ll make me stop doing stuff that I think other people would do.’

It is important to Katie how others perceive her and she values the affirmations she receives from them,
'Everyone always says, Katie, you've been amazing. And I am proud of myself. How I've coped.'

Katie’s sense of self, as someone self controlled, someone coping is something hard fought for and hard won, ‘the reputation that I’d built, I didn’t want to destroy it.’ She needs to safeguard her reputation, this sense of someone strong and self controlled, in order to get through each day. She holds onto it protectively and the positioning of herself as someone different, who would not swear, or chuck chairs or ‘be horrible’, is something she guarded fiercely, controlling when and how she let her emotions out. She contrasts how she has dealt with the experience with how other children might deal with it, and clearly and consciously positions herself as someone different:

‘Many children, after their parents have died they go off the rails and become y’know badly behaved and there’s times I wanted to do that…go to school and just scream but I know that people think um… I don’t want to do that for my reputation because I like the fact that people think ...y’know I don’t care what people think of me but..’

She prevents her identity from being spoiled by the experiences that she’s had, and regulates where and when she lets her emotions out, at home, in her bedroom, by throwing something soft, crying into her pillow millions of times crying over it…but not crying herself to sleep cos she’s ‘not that kind of person.’ It’s not so much what people think of her, but her carefully constructed self, her sense of knowing who she is through the interactions she has with others, that is important to her.

‘I realized what more I could do. And I wasn’t just clever and polite to please my mum.....I just did it because it’s me. And I discovered that what I thought I did for my mum I was doing it for me. And I just discovered that I was a strong person without doing it for my mum.’

She uses the success she has in maintaining her daily life, her success in keeping her emotions under control, in safeguarding her reputation, to make positive attributions about herself. There is a real sense of personal growth and self discovery in Katie’s story, she expected less of herself, but succeeding, she knows she ‘can turn negative into positive.’

‘I am proud of my self that I didn’t go off the rails……I’m powerful(laughs)

Katie uses a metaphor of a plate of mash to represent how she feels about the challenges that life that has thrown at her, and which threaten to engulf her.
'What I describe as my plate of mash was building up. As in like um I had my mum and then I had my grandma, then I had all that stuff that I now could realize all the stuff in the past that had gone on that I hadn’t done, cos like when you’re a child you don’t realize that your mum’s been hit, you don’t realize that’s domestic abuse, so that’s like another scoop, and then like school and homework, another scoop. Then looking after my grandma another scoop – scoop. I was like grandma, this mash on my plate. It’s too much........

I’ve got all this mash. I don’t know how to deal with it. I thought, ‘I can’t deal with it.’ So just forget about it all over again. And then that made it worse.

The tension between needing to suppress in order to continue with daily life, and the sense that somehow that makes things worse, because the pain and the challenges are still there, is implicit in Katie’s story. Some of the language that Katie uses, ‘clinging’ and ‘lifelines,’ to express how she strives to stay on top of the mash, to stop herself from being engulfed indicate the intensity of this challenge. Her carefully protected identity helps her to see a way forward:

‘I think without the fact I wanna make something of my life I think it’d be worse for me cos I’d sink under. Cos I really cling to the fact I wanna do something with my life..........And then I saw education as a way out. You know. Getting a future so that’s like a life line. I sort of clung to that. That sort of directed me out of the mash.

**Katie’s Lifelines**

Katie uses the key metaphor of ‘lifelines’ several times, as these unlock her future, ‘the way out of the mash.’ She is clearly able to identify the things that have helped her. In all of these her grandma is the ‘backbone,’

‘She’s like the key piece, as I say, the backbone. I know she’ll always be there and I know that it in my head. And I think that’s how I survived....if she wasn’t there I would’ve gone down.’

Education and her hopes for her future are also key pieces, but school and education are important not just because it holds the key to her future but because, like her grandma’s house, it provides somewhere safe,

‘I could go there, forget about my troubles, you know, learn, have fun with my friends.’
Friends are important too for Katie. Katie’s friends are there for her, they listen while she talks, they keep listening even when they are shocked by things she tells them, and they help her to think through her grieving. In the early days she also really valued expressions of sympathy and acknowledgement of her loss from other pupils, school staff and people in the community.

Katie’s experiences of professional help are more equivocal. Counselling ‘helped but it didn’t’, she saw a clear role for emotional support from teachers who could acknowledge, show they care and give her the chance to have a ‘connection’, without making a fuss. She told about a teacher who offered Katie a listening ear, who said, ‘I’m here if you ever want to talk. That meant so so much to me.’ She definitely did not want too much fuss, or to feel stigmatized by being sent to a special room for people with problems to be helped. She has positioned herself as not one of those children who rampage and chuck chairs, and wants to preserve her coping identity, to maintain her position as different from ‘those kids with problems.’

Friends, school, dance and drama her own hopes and dreams and of course her gran are all lifelines that Katie is able to use. Young Carers is Katie’s biggest help. She goes to have fun, talk, to experience being with people who understand, who are friends. Glowingy she tell me, ‘it was great…it was amazing…and it was great cos I could just tell them my experiences’

**That Gap of a Hug: Loving and Longing**

With a strong sense of self, a safe refuge with her grandma and with school, and the lifelines she clings to, Katie works hard to make sense of her life with her mother, the relationship she has with her mother now and the ties she still has with her. Just as she is careful to protect her own identity she seems to be careful in selecting the memories she has of her mother and with her mother. Katie expresses a strong sense of loving and being loved, even whilst she is able to acknowledge the chaos of life with her mother, and is able to say that ‘it has worked out for the better.’

‘You know when my mum was alive she had all these like different boyfriends. And not having dinner all the time. And I just think it made me a better person. Through not having her there. I don’t want to sound horrible. But yeah.’
She cherishes the memories she does have, works hard to turn the negative into the positive, and has succeeded, I think, in establishing ways of celebrating the positive, without denying the negative. Her yearning for her mother and her sense of loss is powerfully and painfully expressed in her sense of physical loss, that seems to be the most tangible expression and experience of her grief:

*Just one night I was laid in bed and my mum’s arm wasn’t around me and I squeezed myself and there’s millions of times I’ve cried over it……Cos I’ve thought where’s her arm? Why isn’t her arm there? That tore me apart sometimes.*

She yearns for hugs still, especially as her grandma *isn’t a very huggy person* ‘and now ‘hugs the death out of people’ ‘who hug her. Other people can and do hug but still, ‘it wouldn’t fill that gap of a hug.’

Katie and her grandma talk about her mother and the memories they have they, look at photographs together, have finally been able to acknowledge that nothing they could have done would have changed the ways things were, would have kept her mother alive. Katie, defines this as a ‘massive milestone’ in her experience of grief, ‘I told my grandma recently when we were upset about her. ‘Grandma, there’s nothing we could have done.’

**‘Proper Grieving’: Katie’s Experiences and Expressions of Grief**

For Katie the process of knowing her mother was dead, and accepting it, experiencing it as real was a slow process. A friend triggered another pivotal moment in her experience of grief:

‘I started crying and hearing what she said, ‘“Oh Katie, you haven’t grieved properly.” And that sort of obsessed my mind thinking I haven’t grieved at all…….I don’t know about it? (questioning tone)

Just as thinking is a thread that runs through Katie’s story so is her questioning the nature of grief. What is grief?? How do you know when it starts and when it ends? What is real grief and what is proper grieving? She talks of expecting it to feel like a switch – that she would somehow recognise when she stopped blocking and started grieving, and when the switch would end her grief.

‘And I just thought it’s gonna be one day where I’m gonna wake up and I’m going to be in tears and I’m just going to think about it all. And there’s going to be a week of tears and everything’ll remind me of her and I’m just going to cry and cry and cry
and talk about her and cry more and it'll be just one day I'm gonna wake and up and think, 'I've accepted it.' That never happened. And I thought why isn't it happening? And I thought, 'well is it me thinking too much about grieving and alright I should try and put my mind on other things. But I always thought it would just happen. I thought myself would do it. I didn't think I had to think about it really. I just thought it would happen.

As Katie tells her story, expressing the uncertainty and doubts she has about the nature of her grieving, how it is more insubstantial, more contradictory, and less tangible than she expected, I can clearly trace Worden’s tasks of grief, described in chapter 2, as distinct elements. She clearly articulates her retrospective awareness that she needed to block the pain of her loss in the early stages, of being ‘in denial’:

*I completely blanked it and I realize instead of trying to process the thought ‘my mum’s dead’ I just stuck it away and didn’t even attempt to think ‘my mum's dead I need to do this that and the other.’*

She allows herself to think about the nature of grieving, what it means to her and how she expresses it, just as she thinks about and controls her emotions. She manages her expressions of grief, the second of Worden’s identified grief tasks carefully, as I have described, to persevere with her coping identity, whilst mindful that she does need to let herself experience the pain of grief to prevent ‘it’ from becoming worse.

The third of Worden’s tasks, adjusting to life without the deceased is a bittersweet journey for Katie. She is able to acknowledge without ambiguity that her life is better now that it was whilst living with her mother whilst treasuring the time she had with her mum, ‘the fun what we had’, the closeness. She can value thinking back over her memories whilst realizing ‘That's it. These are the (Katie’s emphasis) memories. There won’t be anymore.’

Katie is as purposeful in constructing her connection with her mother now she is gone as she has been about constructing her own identity. She values what her mother has given her, being brought up to be polite, learning how to behave and how to speak to people, and she safeguards an idea of what her mother would want to be. ‘I still want to make my mum proud, even though she isn’t here any more.’ She also has a clear sense of wanting to avoid the choices her mother has made, the life she led, ‘I think I’ve turned it into a positive ’cos I know what not to do.’
Katie’s ongoing connection with her mother is clear and unambiguous, now that she has made the journey from ‘knowing’ to ‘Knowing’ that her mum is dead she can clearly explain, ‘my mum’s never been past for me.’

**Dying through Drinking**

Katie makes a clear distinction between dying through illness or an accident, and dying through drink or drugs which is preventable and a matter of personal choice, ‘With alcohol. My mum’s just done that to herself. Nobody killed her. She killed herself. You know. It’s not committing suicide, but in a sense it is. Yeah……..It wasn’t just a thing like you know happy and healthy and then in a tragic accident. You saw her degrading every day. Getting worse.’

Accepting that her mother died through alcohol means that grieving is harder, because Katie has to make sense of the fact that her mother chose this, ‘she’d chosen the drink over me.’ Katie needs to reconcile her strong sense of her agency, and the determination she has to exercise in achieving personal agency, with her mother’s agency being consumed by her addiction.

Although this wasn’t a conscious part of Katie’s grieving, during our meeting she wonders now if ‘it could be one of the reasons she didn’t grieve straight away.’ She talks about the way alcohol changes people and I wonder if I am being too far fetched when I wonder if perhaps among the positive benefits of her mother’s dying is also the sense that she can preserve the memories and the mother she chooses and whom she needs, rather than the mother who has become ‘degraded’ by alcohol.

**5.2.3. Representing and Interpreting Charlotte’s Lived Experience of Bereavement after her Father’s Death**

In the meetings I had with Charlotte I was conscious of the role I played in co-constructing her story, in helping her to shape her story through the questions I asked and the interpretations I suggested to her. With Charlotte I found the difference between my role as helper and my role as researcher difficult to maintain. As she herself explained, ‘some people can express it easier and some people can’t talk about freehand’. Charlotte couldn’t talk about her story by herself, she needed it to be drawn out of her, to be shaped.
Charlotte’s fragility, in the context of the losses she has experienced, is the overwhelming impression I have from listening to and reading the transcripts of her meeting. She herself is overwhelmed by the losses she has faced, and which face her in the future and she struggles to even process the thoughts. The linguistic thread which runs through Charlotte’s story is a sense of ‘weirdness’, as she struggles to deal with her losses whilst dealing with intrusive memories. The emotional thread is one of a wounded child, desperate to be healed.

‘You just feel like you’re nothing’

Charlotte has lost her father, her elder sister Donna who died of a drug overdose, her grandfather whom she ‘didn’t know about, he never cared about us’. She lived with the fear of losing her mother who has ‘mental issues’, and who talks of killing herself. Her mother had post natal depression when Charlotte was born so in a sense she lost her mother for that time. She has lost her whole family because ‘it was my dad who held the family together. Then everything just drifted.’ She has lost her home now, as her mother was unable to cope and she ‘went to school with a massive black eye and straight away I got put in care. Within that first day. Within about five hours.’

With the loss of so much, the trauma of her life, her losses and being taken into care it is no wonder that Charlotte has lost her sense of who she is and feels like she’s ‘nothing.’

Charlotte has lost her hopes of future too. She dreamt of her mother and father arriving at school with her to collect her exam results. She captures her sense of her spoiled future, her ongoing longing for her dad and the distance she places between her life now, at, Willow Hall (the community care home) and the life she longs for…. ‘it’s gonna be someone from Willow Hall. That’s gonna be there. And that’s not family to me. I’d rather my dad be there.’

She formed relationships with staff at school who were ‘like a mum and dad. It was like they got to know me inside out.’ But now she has to move onto other people, she experiences another disruptive transition, ‘That was like the hardest bit...like this year I had to let go of the two people who meant the most and start again with two other people for this year.’ She has been displaced because her old teachers ‘have got their own children to deal with now.’
School seems a refuge for Charlotte, emblematic of something stable and normal in her life. She is desperate to finish school without being excluded and is conscious that she is the only child at Willow Hall in mainstream education. She is mindful however that her behaviour, ‘being awful’ means that she is onto her ‘last lifeline’ after ‘so many chances’ and at risk of being thrown out of school. Whilst desperate to cling to school, and jeopardizing her chances through swearing and ‘being awful’ she is fearful of leaving:

And now look where I am....I’m in school at the end of year 11 and I’m scared now. Cos I thought schools gonna take ages. And it’s not. It's like what’s life going so fast for? Cos sometimes I wish I could pause, rewind, fast forward sometimes. I can’t but I wish I could.

As well as losing people and the fear of losing school as well as her home Charlotte has also lost the girl she might have become. ‘If my dad was still here’, she told me, ‘it’d be like a different thing. A different story.’ Despite being told she’s clever she ‘struggle[s] to concentrate, gets distracted easily…I’ve just failed altogether in the stuff that I’ve done. Instead, she has become someone she has not chosen to be:

Because if my mum. Well. If my dad was here I wouldn’t have done half the stuff I’ve done in year nine and year ten and um it’s like awful what I’ve done and I know that if I did that my dad would be proper disappointed in me like but....he’d be disappointed but I can’t see it on his face that he is so....(she trails off)

If my dad just showed me a sign.....

Charlotte yearns to have her dad back, to help her to make sense of things, to restore her life to how she would like it to be, ‘Like you really really want him to be there and I want to talk to him about stuff that I’ve done. It was my fault the stuff I’ve done. I don’t know how to explain it to you.’ A little later she tells me:

‘I try to sometimes [talk to her dad]. But I don’t get no reply.....Like if I go along to his grave I try to talk to him in my head but I don’t get no answer. But I don’t know why. Like I want to sometimes but I don’t know. Like if I’m upset sometimes then I don’t know. It’s just like I don’t know because I don’t want to get scared of him. Like scare him away.’

The yearning and the fear are closely linked for Charlotte:

It’s like I want to think about him. And sometimes I’m scared he’ll just appear. Sometimes I feel like he’s gonna come out and say everything’s alright. And then at
other times I’m scared….and I don’t wanna be scared of my dad. And then at other times I’ll cry. And if I cry for my dad it’s the same. I’m scared he’ll appear.’

Struggling to manage the contradiction of the fear and the yearning keep Charlotte locked in magical thinking, not able to accept the reality of her father’s death. She is so desperate to have him at school when she receives her GCSE results, at that symbolic transition point, that she seems to really believes he’ll be there:

*My dad promised. Well he didn’t promise but he like……well my mum says as well….she says he is gonna be there but I just want……I just want him to be there and if I want summat so much from my dad then he’d give it to me.’*

Charlotte can imagine her dad being disappointed in her, but she can’t imagine him saying well done to her, and she can’t imagine or remember having been hugged by him. Charlotte yearns to see her father because she can’t imagine him. She has not yet developed a way of keeping him in her life, and that feeds a state of unreality, of her not able to accept her father’s death. She is still struggling with the tasks of grief, to accept the reality of the death, to learn to tolerate the pain of grief and to maintain a connection with her father.

**More bad memories come than good**

Charlotte struggles to remember him too. Her memories are locked away, good memories blocked by the bad.  *’It’s like more the bad stuff takes over from the good stuff cos it’s only the bad stuff that goes on and it gets too much and overtakes it.’*

The experiences and memories that Charlotte tells me about are traumatic ones, of her parents fighting, being stuck in the moment of being told that her father had died, her mum cutting her arms and holding a knife to heart, of the funeral when  ‘*my mum tried jumping in the grave because…..I think that were the hardest bit. Watching him go down….and they weren’t even careful with it…..they were like dropping it and everyone went schizo.’*

Another traumatic memory for Charlotte is the experience of seeing and feeling her father’s presence,  ‘*just like he was hiding in my box’*; a few months after he died. Now she’s scared that it may be the devil coming to get her, explaining:  ‘*I think weirdly compared to other people. It’s like I’m more scared than I think I am. I get scared really easily and I don’t like it. I don’t like it.’*
Charlotte’s memories seem dominated by memories of the fighting and violence she witnessed at home. She tells me about remembering that her dad gave her and her sister bikes one Christmas, although they were stolen soon after and ‘my dad weren’t impressed about that.’ She recalls her father’s strong feelings about which secondary school she should go to, but this too is associated with memories of conflict with her mother. By our third interview Charlotte talks about her and her dad’s shared sense of humour, laughing at things no-one else laughed at, and the TV programmes they watched together. Throughout the interview it is Charlotte ‘s memories of everything being quiet, of her mother and of school, and her traumatic memories of her father which seem more substantial than her memories of her father whilst he was alive.

**Me and Them: Other people grieve**

The theme of difference appears again when Charlotte talks about how hard she found it to manage life since her father’s death:

*Like some people can use it to do grief. But some people who don’t know how to deal with it and can’t get used to it. And some just like cope. Completely different to my life. Some people deal with it easily. Like the people what have been grieving more.*

She seems to make a distinction between adaptive and maladaptive coping, ‘I think it’s better to understand than to go through what other people go through like grieve and harming themselves and wishing theirselves dead.’

People with different lives are able to grieve more and cope better. Charlotte ‘swears so much it’s unbelievable’, has ‘done awful things’, has developed ‘a bad reputation’ and puts herself at risk. She told me her teachers worry about what will happen to her over the weekends and holidays, and ‘putting on the radio and hearing about young girl called Charlotte’s been found dead. …… The sense of her lost self, of being someone other than the girl who she might have been is a clearly articulated consequence of her loss: ‘If my dad was still here I wouldn’t have done half the things I’ve done.’

Charlotte’s sense of being different from other people is a sub theme of her story. She construes her life as different, because ‘children normally have parents’ and being different, living in a children’s home, feeling like ‘you’re nothing’ has made it harder for her to cope, harder to grieve. At the same time she does not explain her maladaptive
coping as a consequence of her troubled life, but as a sign that ‘there was like something really badly wrong with me.’

I feel like I’m helping you

Charlotte contrasts herself with people who ‘take everything for granted.’ She has a dream of going to do voluntary work in Africa. There, she thinks, ‘people who are less fortunate enjoy what they’ve got….I don’t know how they do it. So that’s what I want to find out….so happy and everything, even though they don’t have nothing they’ve got their family but hardly no food nor water but make the most of it.’

At the moment Charlotte defines herself in negative terms, blaming herself for how she’s coped, the ‘awful’ things she’s done, her mother’s mental health. Feeling like she’s ‘nothing’ Charlotte seems to be searching for meaning and purpose, for a sense of herself. She identifies with people in Africa who ‘have nothing’ and it seems as though she thinks there she might find the key to coming to terms with her life in which she has nothing, feels she ‘is nothing’.

Ever since the age of six, she explains, she has wanted to do voluntary work. It’s important to her to feel that she is helping me and helping other children in her position so that their lives and experiences might be different from hers, ‘like I just really want to help other people deal with it’. Being in the position of helping others opens up the possibility of receiving positive affirmations that might help to shape a different sense of who she is. She articulates the importance of other people’s responses in shaping how she deals with life:

_If someone is disappointed in you then obviously you don’t believe in yourself. But if someone smiles at you or praises you, says “Oh you’ve done great”, or something then it makes you have a little bit more confidence.’_

I think the sessions we have had have given brief opportunities for Charlotte to experience a sense of herself through feeling she can explore her life story, let herself be pushed and given her the sense of a future in which she does not have to be trapped by her past and the person she has become. Instead she talks of wanting to move away where no-one knows her, doesn’t know about any of the things she’s done and where she is free to make ‘a new fresh start.’ ‘It’s like a different feeling I’ve got now. And I think it’s cos you want to help
people I think that's why and it's like you understand. "Those sessions, agreed and delivered in accordance with ethical guidelines, are finished now and I am in the process of negotiating other ways of continuing to support Charlotte, including organizing for her do some voluntary work at the local primary school.

**Dying through Drugs and Alcohol**

Charlotte’s account of her father’s death is confused and confusing. I am not establishing the veracity of what she tells me rather than trying to capture the essence of her experience. She told me her father died in hospital from cancer. This gave me an ethical dilemma. My research information, for referrers and child clearly states that the research is about children whose parents have died through substance misuse, and I explained this at the outset of the interview. It is the focus of my research and my prime inclusion criteria. I decided, because of information from professionals, and because of some of the things Charlotte told me, and also because cause of death in people who misuse drugs and / or alcohol can be difficult to establish and may not be recorded on the death certificate, to include Charlotte’s account. And there were contradictions here which indicate that this was, and is an issue which perhaps Charlotte has not yet faced:

'It’s like with my mum and dad they’re not choosing to die. They just don’t know the outcomes of what’s going on and that’s like the hardest thing to establish….I wouldn’t have wanted him to die of drugs or alcohol cos I know what he would’ve got into and I know it was painful for him to get out of.....’

**5.2.4. Representing and Interpreting Alana’s Lived Experience of Bereavement after her Mother’s Death**

Alana’s story flowed easily from her. Alana’s fluency led me to think initially that Alana, like Katie was able to position herself as an agent in her own story, playing an active role in constructing that story. Right at the end of my analysis I reflect that Alana’s story seems fluent because she is able to give a clear a time line of events, but this fluency lies in accurate chronology, identifying all the elements of her traumatic life experiences, rather than a fluency which captures a coherent narrative. The processes of recalling factual events, and making sense of interpreting these events are not the same thing.
I was struck by how much of Alana’s story was about her making sense of her mother’s life and death, and how different this was this to all of the others. I wondered if the energy that Katie invested into thinking and sense making about her own life journey and her grief, was for Alana channeled onto protecting her mother.

Alana was keen to meet again and although we did set up several further meetings I did not manage to see Alana again. Her attendance, always a challenge for her, dropped and she stopped attending school and neither her year tutor nor I were able to contact her.

**Dying through Drugs**

I have started Alana’s story with the theme of dying through drugs because it is central to one of the most dominant themes in Alana’s story, the way in which she positions herself as protector of her mother’s reputation, reclaiming her from the dominant narrative that drug addicts have chosen their path, with a different narrative that celebrates her mother for her goodness and recalls the struggles she had to try to ‘come clean.’

Alana is emphatic that dealing with bereavement through drugs is different from dealing with bereavement from natural causes. ‘I know some people would say if she had cancer it weren’t her fault. But I know people would say oh well she were a drug addict and no-one told her to do that so it were her fault that she died. So I find it harder to cope with. Cos it makes me think what other people would think. More than what I think……

It is only in specific contexts, with trusted and experienced people who know about complex bereavement that she ‘can speak about it without being ashamed.’ She doesn’t use the word stigma but it is what she describes. Yet in Alana’s community her mother’s story is not unusual, ‘cos all my mum’s friends have died. Most of em.’

**My mother’s story**

Alana is an agent in the construction of her mother’s story, she has constructed a coherent identity for her mother in which she makes sense of her mother’s life and death, positioning her mother as victim rather than villain, as ‘the same as’ many other people in her community rather than ‘different’.
Obviously no-one makes you do anything but he [Alana’s dad] got her into it, them things. And she were only young. A lot of people do mad things when they’re young, don’t they?....And when you’re on that bad stuff you’re hooked. A lot of people mainly for life and probably die from it. Cos all my mum’s friends have died. Most of em.

She explains her mother’s story and her battles against addiction, a battle which she lost when one of her sons, Alana’s little brother, was taken into care at birth and then adopted. But she were doing ‘Recharge.’ It’s like rehab. And she did all the course and she did very well but then Luke, my little brother, he got adopted. And um she went back to how she were. And ‘cos she didn’t have enough money and everything she became a prostitute.’

Alana tells me her memories of hearing others talk disparagingly of her mother, and how powerless she felt then to defend her mother. ‘I were too young. I didn’t have a say in anything. I couldn’t say owt. She called her a smackhead. Called her all sorts.

She tries instead to reclaim her mother, a mother who she can remember and mourn for, so perhaps her defence of her mother’s reputation is as much for Alana as it is for her mother: ‘she were a respected woman just as much as the bad things she’d done and a lot of people knew her from younger, when she was good. That’s when she were... I need to remember the good things so I don’t know.... I hate to think of people bad mouthing her.’

Alana sees Luke’s adoption as the trigger for her mother giving up hope, having beaten her addiction and been ‘clean’ she gave up hope and ‘went back to how she were.’ Her mother’s brief success against addiction is important to Alana: ‘All I can say is I don’t care what happened to her. I don’t care what she did. Or all them bad things. I know she tried to get her life back on track because I’ve got the evidence. In black and white. On paper. From when she went to rehab to sort herself out.

Alana seeks to understand how her mother’s life turned out as it did:

I think, why did you do it? But I don’t blame her as in I hate her. For what’s done. I just think why did you have to go and do that. .... Obviously no-one makes you do anything but he [Alana’s dad] got her into it, them things. And she were only young. A lot of people do mad things when they’re young, don’t they?....And when you’re on
that bad stuff you’re hooked. A lot of people mainly for life and probably die from it. Cos all my mum’s friends have died. Most of em.

**Alana the daughter**

Alana’s story is rich with detail about how Alana defends her mother, protects her reputation and resurrects her as someone loving and good.

*I want to make her proud. Make her and my Nan proud. And try to be more like my mum. But the good points of my mum and not the bad ones. And think what she would’ve done with her life. Instead of going the bad way.*

Yet the last contact which Alana and her mother had together perhaps indicates how hard Alana has had to work to achieve this focus, and the tensions and ambivalences with in this.

*The way it happened as well. That’s what I can’t let go. So that’s what makes me angry. Cos the week before my mum died I hadn’t seen her for six months. Bearing in mind she asked me to go and stay with her after I hadn’t seen her for six months. I thought about it after she died. God told me something. Probably your last chance now. Anyway we ended up having a big argument the next morning and I said to her I don’t want to see you ever again. I hope you die. And that’s what makes me think it was my fault. Even though I was so young and everyone says things to their parents. But I shouldn’t have said that. And that’s why I can’t let go of thinking it were my fault that my mum died.*

When I ask her for memories about her mother there is less detail. Alana lived with her Nan as her mother ‘couldn’t look after me that well, ’but she cherishes memories of times when they went to the park together and ‘it would just seem like that’s how it were meant to be from the start.’ She talks of being allowed to say and do things she wasn’t allowed to say and do at her Nan’s, about her mum not having the same boundaries and expectations as her Nan.

When I asked Alana to tell me about a happy memory she told me about a time when she visited her mum in hospital and she begged her mother for a food shake.

*I said ‘Mum mum I want one of them milkshakes can you get me one?’ And it were somebody else’s but she got me it anyway. And give it to me. And I drank it in t’ room so no-one could see. I remember.......*
She tells me as well about a time when her mother ate three trays of Indian sweets, one after the other. These are the only concrete memories she shares with me. Alana’s loyal defence of her mother, her compassion and her understanding seem much more developed than the memories of her mother when she was alive, as though she is somehow more real to Alana in her memory than in life.

Alana identifies the capacity to eat a whole pack of biscuits with a cup of tea as a similarity between her and her mother. There are no others. Had I met Alana again I would have asked about similarities in her mother’s battle to try to beat her drug addiction and ‘try to get back on track’, and Alana’s own struggle to try to ‘get back on track.’

**What else is gonna come? Loss upon loss**

Alana has lost her mother to drugs. In a sense she lost her mother before she died, as her mother was not able to care for her, she lived with her Nan who was able to keep her safe. Nonetheless she had a sense that things were not as they were meant to be, as it was when she was with her mother that ‘it just felt that this was how life was meant to be.’

She has lost her little brother who was taken into care, whom she is not allowed to see. Her father died last year. Her two uncles, her mother’s brothers, are also heroin addicts and Alana fears their deaths are imminent.

‘And that’s what makes me hurt even more. Cos I don’t want to be able to face again. And watch my Nan and granddad do it. Cos that killed me more than anything…….I think that would just be my grandad’s time and give up. Losing my mum killed him and if he lost any of them it’d probably kill him even more.’

Last year Alana’s best friend also died. His memorial was just a few weeks before our meeting, and Alana showed me a photograph of his grave. No wonder she told me ‘And what makes me worry as well is that all this has happened in such a short time. What else is gonna come? Cos I’ve got a long life to live yet. And I know this isn’t the end of the badness cos they’ve got to have some bad things in, some more. I’m only sixteen.’
Alana, the protector

Within this life of loss and the injustices piled upon her Alana carves out a role for herself as protector. She protects her mum’s reputation, she protects Luke’s role within her family, and she strives to protect her Nan and her granddad. She also strives to protect others. She hates bullying and steps into to defend others when she perceives they are being bullied, even though she also thinks ‘that’s probably what makes my head go a bit more mad. Cos I take other people’s problems in as my own.’

Other people tell Alana that she is strong, and perhaps she feels strong when she is standing up for other people, and this makes her feel ‘wanted and respected.’

Coping Ugly?

Alana can exonerate her mother but she cannot exonerate herself. When Alana is talking about herself there is a sense of bewilderment that she is not who she wants to be, not making an active or purposeful choice to behave the way she does. Alana as agent invests her energy in protecting her mother, and perhaps her own role as protector casts her as aggressive agent not vulnerable victim. She tries to be strong to protect others but it’s harder perhaps to be strong without being aggressive, and there seems to be a tension between Alana needing to be angry and aggressive, even though this is not what she wants, not an active choice. I just carry on. The same. I don’t know why. I really don’t have a clue why. That’s why. That’s one thing I really don’t understand. Why I still am the way I am.……. Aggressive.

Of all the girls it is Alana who most clearly articulates her need to ‘cope ugly’ with the hope that one day “I won’t need to be like it anymore.”

Alana the survivor: Off the rails and back on track

Alana is conscious of the ways in which her mother’s death has affected her, and conscious that it feels like a watershed moment in her life, the time before her mother’s death when her Nan was able to keep her safe so she didn’t need to worry about anything, and the time following her mother’s death when she got into ‘loads of bad stuff’. This what she told me when I asked what it had been like, dealing with her mum dying:
Um. Um. Well. I don’t really like show it. As in. That’s the thing that makes me angry and upset all the time. Constantly. I use other excuses. But.....I don’t know. Sometimes I wish I could go back to then and find out what happened and try to stop it. And it’s too hard. I can’t really deal with it. In some aspects. But in other ways I can. I’m strong. That’s what people say. But deep down it has really affected me. In school. Even outside of school, on the streets, with my friends, family. And now I’m just trying to get back on track again.

Like her memories of her mother, the concept of getting ‘on track’ seems more real than the detail. When I ask Alana how she is getting her life back on track she talked about getting her head down, and saw her current school as having ‘saved her’ despite having ‘some bad times in here cos my emotions haven’t really helped.’ She talks of how hard it is to ‘use motivation’. I don’t really want to put any effort in cos I’ve got this thought in my head that everything will go wrong anyway.......and if someone praises me for summat I won’t accept it.’

Alana battles to believe that she can have a good life, and that she is entitled to this. She can talk about this rationally but her thoughts can’t stop her feelings and her fears that ‘my life’s just gonna be like this for ever.’ She knows she is entitled to be happy, to experience good things. She says:

I know I’ve got the ability to go to college. And go to university? And my behaviour and attitude sometimes take over......And that’s not a good thing to have. But I know that if I keep trying, and carrying on then I won’t need to be like it anymore.

Knowing and believing are different things for Alana. She has lost the life she could and should have had, her childhood, her sense of security. She has lost her sense of entitlement to be happy, and the ability to feel happy. She tells me:

When I’m really happy I get this thought in my head. Not me doing it. It just happens. That I’m not being normal cos that’s not usually me. Being happy. I’m usually depressed and upset. So then I just. And I see it. In my head. My head tells me that I’m being selfish? Sometimes. For being happy. Because of the things that’ve happened. That I shouldn’t be happy. That I should be sad. And then I just go back to normal again.
I ask Alana if she thinks if she had had different kinds of help or support whether she thinks things might have turned out differently, whether she might have been able to cope without going off the rails. Even as I asked this I was conscious of the inappropriateness of the question. There has been so much trauma and loss in Alana’s life that it is difficult to see how she would be able to conceptualise support which might alter this. Alana’s traumas are embedded in the life she leads, in her family dynamics and the community in which she lives. She sought refuge in the support which available, the girl gang which felt like a family. It made me feel I don’t know safe and that nothing would happen to me as such. ’ Yet that ‘turned bad’ and Alana ended up in hospital with a fractured eye socket.

Asking for help and receiving help are complicated for Alana. She sometimes makes excuses when really she has a sense that its emotions connected to loss which have triggered a situation. At other times Alana wonders whether she uses her mother’s death as an excuse, when things aren’t really that bad. She told me that some school staff also say that she uses her mother’s death as an excuse, and that this means she cannot talk to people in school about this, ‘I don’t like to tell anyone in case they think I’m using it for attention. Do you get what I mean?’

The different story is the one she hopes to write for her self in the future…..I know if I keep trying and keep carrying on then I won’t need to be like it anymore……..

When I met Alana I thought she was, despite her harrowing story, a survivor. Despite the blow upon blow which she faces Alana uses the language of agency, she strives to position her self as agent in her own story, to assert control and ownership. She hunted out the evidence to prove her mother’s success in beating her addiction, she is determined to make it to prom although others tell she won’t, she stands up for those who are weaker than her, she hates bullying, she wants to ‘get her head down’ ‘keep on trying.’

As I read this in hindsight, I am fearful that with more bad things to come, as she predicts, that each blow will send her life further off the course she hopes for, further off the rails, and that with each blow it will be harder for her to succeed in using her motivation and clambering back onto the rails.
5.3. **Interpretation: Weaving Together Individual Stories to Address the Research Question**

The research question asked ‘how do children and young people deal with parental bereavement, when the bereavement is caused through substance misuse?’

An authentic response to this question needs to be able to tolerate the ‘messiness’ of making sense of aspects of authorship and agency, and the ways in which these shape and have been shaped by interwoven dimensions of self and experience. An authentic response needs to be able to capture something of the essence of contradictions, ambiguities and struggles involved in the process of living a life shaped by the death of a parent.

In this section I do this through exploring aspects of experience and the ways in which the stories the girls tell, the lives they live, and similarities or differences across their different aspects of these experiences. Some of the dimensions of experience that emerge from this research are those which are familiar and meaningful in the context of bereavement research. Others emerge from the research methodology, from striving to capture and represent the essentials of experience, before reducing or pigeonholing these into discrete variables which are measured in quantitative bereavement research.

In interpreting these experiences through a lens of psychological theory I explore constructs of identity and meaning making, drawing on Bruner’s cognitive psychology of meaning making and canonical narratives emerged from the data, and I have drawn upon Bruner’s cognitive psychology of meaning making and narrative construction( Bruner 1991) as well as Bowlby’s attachment theory, reviewed in chapter 2, in interpreting the experiences of Alana, Katie, Emma and Charlotte.

In the literature review I considered how and why attachment experience shapes responses to bereavement, and how it influences vulnerability to complicated bereavement. In the literature review I also proposed that it is possible that children who have a parent who is a substance misuser may be more likely to have insecure attachments to their parent, and to live in more unstable worlds where emotional support, and physical and emotional security are more difficult to achieve. As a consequence they may be more vulnerable to complicated grief. My data analysis shows how these propositions are supported by the research data.
The thematic table in 5.1.1 demonstrates the individual themes for each child. The last column of this table proposes superordinate themes which identify the similarities and differences between the girls, in what have emerged as crucial dimensions of bereavement experience. The following sections elaborate on these common dimensions of bereavement experience, and refer back to the literature review in chapters two and three.

This interpretative section is divided into three sections, matched to the superordinate themes that emerged from analysing the interviews. These are:

1. Hopes Dreams and Belonging which identify the contextual factors against which the children experience bereavement, the combination of adverse childhood experiences, and the relationships and opportunities they have which help them to stay connected to the world, and to continue to engage successfully with the world.

2. How bereavement shapes the agentic self: phenomenological aspects of the girl’s experiences which influence the ways in which they think about themselves and how this influences and is influenced by the ways in which they act and react within the world.

3. Bereavement Experiences: Experiences and expressions of grief and grieving. This section maps the girls’ narratives onto influential themes within bereavement literature, including Worden’s four tasks of grief, personal growth, and constructs of normal and complicated grief which I reconstrue as being ‘on track’ or ‘off the rails.’

5.3.1. Hopes, Dreams and Belonging: Contextual Risk and Resilience Factors

5.3.1.1. What else bad is gonna happen? Cumulative Adverse Childhood Events

The literature in chapter 2 demonstrated that adverse childhood events are all identified as risk factors for complicated grief (Cohen and Mannarino 2010, Cerel 2006, Sandler et al 2008) and for mental health problems, including complicated grief. (ONS 2005, NICE 2008). Katie, Alana, Emma and Charlotte all have four or more of these adverse childhood experiences (ACEs) in their lives:

- Alana has experienced the deaths of her mother and father, she has experienced the death of her best friend, she truants from school, her grandmother has had cancer, and is now
gravely ill, her little brother has been taken into care, there is a history of substance misuse in her family, not just in her mother, and further death seems imminent.

- Emma has experienced physical and emotional abuse and neglect. She did not have a stable home or a stable caregiver. Her mother, sister, and father (or the man she thinks as her father) have died. She is in trouble with police. She has been excluded from school.

- Katie witnessed domestic violence, she experienced neglect, she is a young carer for her gran, her mother has died and she does not know her dad.

- Charlotte’s father and sister have died, her mother has severe mental health difficulties, she witnessed domestic violence, she experienced emotional and physical abuse, and she is a child in care.

These are important in understanding the worlds the girls live in and the context in which they are able to make sense of the death of their parent and find a way of adapting to life after this loss. The number of ACEs, and the severity of these ACEs demonstrate the extent to which none of these girls had parents who were able to manage the world or the lived environment to make it safe for their child, thereby complicating their ‘secure base’. In the context of this unsafe world the opportunity to receive and to benefit from social support, one of the key factors in influencing vulnerability to complicated grief, is compromised, or not available.

5.3.1.2. A secure base? I was just passed around like a parcel. I didn’t know where the hell I were……..

All of the literature into adaptation following bereavement identifies a secure base, both emotional and physical, as the single most important contextual resilience factor. (Sandler et al 2008 qv 2.3.5). For all four girls having a parent who lived with and died from substance misuse raises complex challenges and meant that ‘home’ was not a secure place. The words of the sub title are Emma’s, capturing her sense of rejection, of not belonging, that is tangible throughout her story and she talks about the different places she lived whilst her mother was drinking.

Charlotte, Alana and Katie all had a physical home base. Katie’s home wasn’t safe because of all the boyfriends, some of whom were violent and physically abusive, and she
often went without tea. But throughout her childhood she always had her grandma’s house down the round, where she could go and ‘feel safe.’ Alana lived with her Nan who ‘protected [me] from everything bad’ till [my] mum died.’

Charlotte had a physical home base, but it is full of traumatic experiences and memories; of her parents arguing, of her parents seeing her watching, shocked, as they pushed each other down the stairs but not stopping for her, of her mother cutting herself and the ‘table covered with blood’, of the house ‘being quiet’ with her mother locked in her room, and Charlotte left alone to go ‘on secret walks.’ Both she and her sister were taken into care because of their mother’s physical abuse, and Charlotte now lives in a community care home.

Katie’s Nan emerges as a secure base for Katie, ‘the backbone’, which gives Katie the strength and stability she needs to manage the challenges life has thrown at her. Alana’s Nan was able to do this for when she was a child, but lost that power when mother died. Charlotte sees her dad as the one who ‘held the family together,’ and when he died ‘it all just drifted.’

In addition to the high number of ACES experienced by these girls only Katie has a secure attachment figure who figures as a protector or as security in her life. For the others they have the vulnerability associated with a high number of ACES without the protection afforded by that key resilience factor, a secure and stable attachment to a primary caregiver.

The stories that these children tell demonstrate the risks of taking population studies about the impact of parental bereavement at face value. I think they justify the cautions that I made in my literature review, in which I argued that large scale population studies cannot capture the complex interweaving of risk factors in some children’s lives. These are potentially harmful in understanding the needs of children who have experienced parental bereavement because if adjustment to parental bereavement is represented as the norm, than those children who don’t adjust are positioned as ‘not normal’ as ‘different.’ If this conclusion is drawn then some of our most vulnerable children are at risk of censure rather than support, from a society that has not helped them to deal with the pain of their parent’s death.

I will return to these important issues in the conclusion of this section.  

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5.3.2. Phenomenological Themes Emerging from the Research Process

5.3.2.1. Participating in the Research: Being Heard and Feeling Understood

I had not anticipated this as a theme in my research, and yet it emerged as an element for all the girls, closely tied to the theme of making meaning, or sense making. They wanted to help with the research so other people didn’t have to go through what they’ve been through, so other people could learn, so others could understand what it is like. I think the sense that all girls had, of wanting something good to come out of their bad experiences, of helping others, so they ‘don’t have to go through what I’ve gone through’ (Emma), was an important part of the research.

It is linked I think, to a sense of agency, as an attempt to create something positive from negative, to be heard, to share their story and to co-author a story which has meaning because it may be helpful to others, as well as being helpful to each girl herself. For it was important to tell her story without ‘feeling ashamed.’

When I asked the girls at the end of our meetings all of them said that it had been positive, although Emma later said she didn’t ‘need’ to see me again. For Alana and Charlotte in particular the feeling that I understood was important. Alana and Charlotte wanted to be helped by taking part in the research, and both said they found it positive – for Alana it was important that this was reciprocal. When I asked how it had felt she told me:

‘It has really helped. I think I’ve helped you too.’

For Charlotte I think this was the first time that she had been able to talk about her father’s death, and to bring out into the open some of the feelings and fears she had suppressed. She told me;

*If you weren’t here asking these questions then I think I’d be in the same place I was would be a few weeks or a few months ago even. And I think I just used to be sad all the time……..You understand. It’s a different feeling I’ve got now.*
Katie was the most explicit about how and why taking part in the interviews was helpful to her:

*It’s like the more you ask then the more you reveal and then the more you accept. And you accept it a bit more. And you get used to it. Cos the more you say the more used you are to knowing it’s real. I found it really helpful.*

Katie was conscious that talking and thinking are part of a continuously evolving process. Emma, Alana and Charlotte are still constructing their stories about their mother’s death. Reconstructing meaning following bereavement is an aspect of grief work which is perceived as a significant aspect of shaping personal experiences of grief. It is an aspect of grief explored by Neimeyer who the factors and processes involved in reconstructing meaning after bereavement. (Neimeyer et al 2008). The importance of story telling and narrative is explored Gilbert (2001) and by Riches and Dawson (2002), who consider the factors which can help or hinder making sense of bereavement, and in constructing narratives of loss. Because story telling is an interactive process it demonstrates the importance of creating a relationship in which personal stories can unfold, to find words to shape complex and contradictory experiences. It is why it is so important to identify people who can build a connection with bereaved young people, to counter the sense of isolation identified by Holland (2001) and Abrams (1999). It is why it is so important that support following bereavement responds to children’s experiences, rather than seeking to shape them.

5.3.2.2. Making Sense of My Story: Constructing a Coherent Narrative

The fluency with which the girls told me their stories, and the linguistic emblems in their stories demonstrate the extent to which each girl is an active agent in creating and making sense of her own story, or by contrast, seems to be positioned within it as object rather than subject. I could not represent and interpret content of the stories the girls told me without weaving the ways in which they told their stories.

Katie thinks constantly, making sense, reworking her relationships and her constructs. She has been able to construct a coherent account which is a close match to her experiences, and which allows her to position herself as an active agent in her own story, as proactive in managing her own world and creating her own stability. Narrative is, Bruner shows,

‘transmitted culturally and constrained by each individual’s level of mastery and by his [sic] conglomerate of prosthetic devices, colleagues and mentors. (Bruner 1991:4)’

Katie
has achieved a high level of narrative mastery, perhaps supported by her ‘prosthetic devices and mentors’ and it is no accident that her story is the most fluent, and holds no unresolved conflicts or ambiguities.

By contrast the linguistic emblems in Charlotte and Emma’s stories are ones which demonstrate how hard it has been for them to make sense of their experiences. Perhaps the difficulties they have in making sense reflect the difficulties they have had in positioning themselves as author of their own stories, as proactive agents who exert influence over their world. Charlotte repeatedly talks of ‘weirdness’ while Emma talks over and over again about ‘not knowing.’

Alana is extremely proactive in creating a coherent story about her mother’s life and death. She has constructed an alternative narrative to challenge the canonical narrative about people who die from drugs. She has been able to save her mother from this but has not yet been able to construct a narrative for herself in which she can ‘understand why she is the way she is.’

‘Narrative,’ Bruner proposes, ‘operates as an instrument of the mind in the construction of reality. It not only represents but constitutes reality.’ (Bruner 1991:5) In the telling, and in the living of these stories the story becomes the person. Only Katie has managed to tell, and to live an account which matches the person she wants to be and the life she wants to live, a story which she can be proud of. Emma, Charlotte and Alana live more troubled and troubling stories, in which they see themselves as people they don’t want to be, living lives they have not chosen.

5.3.2.3. ‘I used to be the cutest thing:’ How Grieving Shapes a Sense of Self

Charlotte thinks there’s ‘something badly wrong with me.’ She’s ashamed of who she is and what she’s done, she feels like she’s ‘nothing’. Alana too feels like she’s ‘nothing’, like she’s ‘been put on this earth just to be treated badly.’ Emma thinks back to when she ‘used to be the cutest thing... wouldn’t hurt a fly.’ Alana talks about how aggressive she is, how she can’t understand why she still is aggressive after all the counseling she’s had, although she hopes she has a sense that she needs to be like this to survive. Charlotte is ‘sad all the time’; Emma cries every day and Alana does not believe she is entitled to be happy, and feels guilty and selfish if she does feel happy, then it ‘just goes back to normal
again. ’ Katie is conscious that she has to guard against public expressions of grief, again becoming the stereotype of the ‘horrible child’ who chucks chairs. If she did this, she told me, then she’d ‘have nothing.’

In contrast to Katie’s personal growth, Alana, Charlotte and Emma all have spoiled identities as a consequence of their reactions to their bereavement. Although stigma and spoiled identity was a focus of my telling of Luke’s story in the introductory chapter it is not an aspect of bereavement research, even in Doka’s work on disenfranchised grief (Doka 2006 q.v. 2.2.3). However this has emerged from the qualitative phenomenological data and is the single most important theme to emerge from this research. The following sub sections explore in more detail some of the different psychological processes through which disruptive manifestations of grief, which I addressed in chapter 2, shape the sense of self and can lead to a sense of shame and a spoiled identity, to what Hinshaw calls ‘internalized degradation’ (q.v. 1.3: Hinshaw 2005)

It was this which Holland’s contributor, Keith, alluded to when he talked about the downward spiral of rejection and exclusion arising from his grief reactions to his father’s death. (Holland 2001 q.v. 2.3.5). It was this that Stokes referred to when she suggests that it is only in the immediate aftermath of parental bereavement that children’s disruptive manifestations are understood as grief reactions, subsequently children are castigated for disruptive behaviour which is attributed to some other cause, or to children’s deliberate choices. (Stokes 2008 q.v.2.3.5)

5.3.2.4. Agency And Attribution: Internal and External Loci of Control

Charlotte and Katie talk about lifelines which are helpful to them, and Alana and Emma talk about getting ‘back on track,’ and the kinds of things that will help with that.

Alana identifies intrapersonal processes, ‘getting my head down’ ‘using some motivation’ as the way in which she will get ‘back on track.’ She tries to use her own within person factors to mitigate the impact of person environment transaction. Her focus on her own within person variables means that she feels she has failed when she does not change, still continues to be angry and aggressive, still feels that her life is just gonna be like this for ever. The help she has had, the counseling, contributes to this because it focuses on intrapersonal variables rather than attempts to build stability within her environment. It
leaves her feeling she has somehow failed: ‘I’ve had loads of counseling. That’s what I don’t understand. Why I still am the way I am. (Alana.)

Alana tries to exert agency over how she helps herself, and attributes her difficulties in getting back on track to her own shortcomings. She makes internal attributions of failure in this, compounded by the reactions of others who have told her bereavement is ‘no excuse.’

Emma wants to get her life back on track but when I ask her how she tells me about her auntie’s plans for her future, ‘my auntie wants me to make something of myself.’ Emma doesn’t really believe in them. She seems to make external attributions, because she is reactive rather than proactive, perhaps because she has learned to be helpless, because she can’t really imagine life being different.

Charlotte makes internal attributions for her behaviour, ‘it’s my fault the things I’ve done.’ She doesn’t attribute these to her environment or to the things that have happened to her, but she wants to leave her environment behind, to go somewhere different where no one knows her. She wants to find a different environment in which values and judgments are different, to find out how people who have nothing can be happy.

Katie makes positive internal attributions for the ‘amazing way’ in which she’s coped. She is able to identify how proactive she had to be, but also how crucial her grandma has been in providing the stability she needed in order to be able to do this. She sees herself as powerful and yet she knows she needs to protect her public persona, her reputation, in order to be able to maintain her positive self attributions.

Constructs of self attribution and internal and external loci of control are pivotal constructs in cognitive behavioural theories of depression and cognitive behavioural therapy. (Beck, Rush, Shaw and Emory 1979, Seligman 1999). They could be potentially useful constructs in helping these girls, and other children who have been parentally bereaved through substance misuse to make accurate attributions about those areas of their life in which they can and cannot exert agency, and in helping less to make less shaming self attributions about their disruptive manifestations of grief.
5.3.2.5. Grief is ‘no excuse’

Charlotte does not make excuses for herself and blames herself for the things she’s done. Although she knows if her dad was still alive she ‘wouldn’t have done half the things she’s done’, she does not make an association between these awful things, and her grief. She takes ownership of her negative behaviour but wants to create a whole new identity, to change, ‘not how I behave, but who I am.’

Emma, and Alana don’t explicitly link their actions or reactions to their mothers’ deaths, but there’s an implicit sense of injustice when teachers imply that they are using their mothers’ deaths as ‘an excuse.’ Whilst they don’t explicitly link their mother’s death with their behaviour they feel that this is unfair when it is not acknowledged. Even this is not straightforward, both Katie and Alana are aware of how easy it is to slip into using their mother’s death as an ‘excuse.’ Katie deliberately chooses not to behave in ways, which need excusing. Alana, like Charlotte, thinks there must be something wrong with her, neither of them are deliberately choosing to do awful things, just as Emma has not made a conscious choice to be violent. ‘I don’t make decent choices. I just end up doing summat really wrong.’

Emma, Alana and Charlotte have internalized their negative behaviour, blaming themselves for what they do and who they are. They themselves do not use their grief as an excuse and unable to make sense of behaviour, which they have not chosen and don’t control, they have spoiled identities, and come to believe they deserve the social censure they receive. For all of them their maladaptive behaviour, or ‘coping ugly’ is an aspect of grief for which they take responsibility, to differing degrees, but which they do not feel they have the personal power to change.

The cyclical nature of censure and social exclusion is implicit; it’s too complex to be easily articulated. Ironically, it is Katie, who polices her grief, and who does not do awful things, does not ‘act out’ who identifies just how risky this can be. She told me: ‘you felt happy that you didn’t have to be shouted at for what you’d gone through and how you’d reacted.’

5.3.2.6. ‘What’s life going on so fast for?’ On track or off the rails

Sometimes bereavement is represented as a journey, with the bereaved passing through different stages of grief towards some end point. In all the girls’ narratives there is a sense
of grief as a process. Katie can trace hers with milestones, and identify different phases as she charts her journey. Charlotte wants a different track altogether. ‘What’s life going on so fast for?’ she asked me, explaining she’s about to come to the end of school and she’s scared. She wants a different track, a different journey with different reference points. She would like to go to Africa to find out how people who have nothing manage to live their lives. She is looking not to change her behaviour but to ‘change who am.’

Alana marks her life out in terms of having been ‘off the rails’ after her mother died, but now struggling to get back ‘on track’. The difficulty is that the track she sees ahead of her is fraught with obstacles, with more trauma and adversity looming. It’s hard for her to believe she can manage to clamber back ‘on track’ when life throws her off course. Emma’s auntie was talking of future plans for her, but Emma herself does not seem to believe that she can ‘get back on track.’

5.3.4. Themes which Match Bereavement Literature: Dimensions of Grief or Grieving

In bereavement literature ‘grief’ is construed as the behavioural, cognitive, affective and somatic expression of bereavement for each individual. In chapter 2 I summarised the wide range of experiences associated with grief, which can be seen as a period of abnormal functioning, after a bereavement. For those who grieve it is important that they and others around them are able to understand this period of abnormal functioning in this way. Different cultures have different mourning practices to support bereaved individuals and families in this. In this way the bereaved individual and those around them are able to ‘make sense’ of this period of abnormal functioning, to accept it without censure or shame. In the context of their bereavement their abnormal behaviour is normal, understandable and excusable. Their abnormal behaviour does not result in their exclusion from society. They do not think there is ‘something badly wrong with them’ because of the way they grieve. (Parkes 2002, Kastenbaum, 2008)

Grief marks a period of adjustment whilst bereaved people recalibrate their life. Most people are able to get back on track after bereavement, even if the path they take is now an altered one. They will probably always have grief with them but it becomes less present in their lives, less of a challenge to deal with on a day to day basis. In time grief may come to feature less in people’s lives as other dimensions of life are resumed or developed. It is not
so much that grief is a journey, distinct from life as journey, but that grief dominates the journey through life to differing degrees and in different ways.

5.3.4.1. Like some people do grief: Conscious awareness of grief as a process

In this research only Katie talks explicitly about grieving. Only Katie sees grieving as something she needs to do, to think about. Katie is conscious that for a time she needed to block out her grieving, it was too overwhelming for her to deal with, and that there came a time when she couldn’t block it out, she needed to deal with it to stop 'it' from engulfing her in her ‘bowl of mash.’

Katie can trace different stages of grief; denial and unreality processing the pain of grief and making adjustments whilst she settles in to her new life she is able to treasure her memories of her mother whilst acknowledging, awful though it may sound to other people, the reality that her life is better now than it had been when her mother was alive. She also talks of her realisation that grief was something she had to do consciously, to move from knowing that her mother had died to ‘really knowing.’ I explored this idea further with Katie as we talked about the importance of ‘thinking.’ it is in a sense moving from Heidegger’s knowing to ‘Knowing’ as conscious and deliberate realisation, an active construction of Knowledge with the Knower as agent rather than a passive experience with the knower as object.

Charlotte’s experience is different. For her grieving is ‘weird,’ the cognitive and somatic experiences associated with grief, physical sensations, imagining her dad are ‘weird’, she is ashamed of her behaviour and, six years on, she feels ‘sad all the time.’

She talks about grief as something which other people do:

Like some people do grief. But some people who don’t know how to deal with it and can’t get used to it. And some just like cope. Completely different to my life. Some people deal with it easily. Like people what’ve been grieving more.

Alana and Emma do not talk about grief. They talk about feeling sad all the time, feelings of hopelessness and difficulties in carrying on. Emma grieves for the person she might have been ‘I used to be the cutest thing’ and about her ambivalent feelings for her mother.
Yet the girls do not, it seems see these as aspects of grieving. Indeed they are told the grief is ‘no excuse’ for their behaviour.

None of the girls have been able to identify their behaviour as a normal and anticipated grief reaction, which fits with the broad constellations of grief responses identified within the spectrum of normal grief. Katie sees her suppression as abnormal, as not grieving’ although it is, as numerous researcher practitioners assert a normal, and often functional dimension of grief (Bonnano et al 2004, 2008, Parkes 2002, Worden 2009)

5.3.4.2. Worden’s Tasks of Grief

In chapter 2 I looked at the body of research which has aimed to make sense of grieving. Much of this research has developed models of grief which capture some of the essential aspects of grieving experiences. As with any model of human experience there must be caveats about over simplification. People who have difficulties with one or more of these aspects of grief may be at risk of complicated grief. The four tasks of grief, conceptualised by Worden (1996, 2009) and used to shape bereavement interventions in this country (Monro 2007, NCB 2007) are: accepting the reality of the death, experiencing the pain or emotional aspects of the loss, adjusting to an environment in which the deceased is missing, to relocate the dead person within one’s life and to memorialize the dead person.

These are helpful in understanding each individual’s experience of dealing with the death of her mother or father, and I will address each of the four tasks separately.

Task 1: Accepting the reality of the death

Alana hunted for evidence, she needed to put all the pieces together to make sense of her mother’s death. She has accepted the reality of her mother’s death and made sense of it as a painful but inevitable consequence of a drug addiction. In this sense she is, like Katie, an agent in constructing her own representation of her mother’s death. Katie’s journey from knowing to Knowing is tangible. She can now fully accept her mother’s death whilst still saying ‘my mum will never be past for me.’

Charlotte has not yet accepted the reality of her father’s death. She clings to the belief that if she wishes hard enough that he will appear on the day she goes to collect her GCSE results. As well as wishing and believing that if she wants it enough her father will appear
Charlotte is also scared that her dad might appear. She clings to the hope that her dad will appear and yet is scared of grieving or crying for her dad in case that makes him appear, as that would terrify her and she fears he might hurt her. She perceives the world and her own reactions as ‘weird,’ and this prevents her from taking an active role in making sense of her father’s death.

Emma fully accepts that her mother is dead, and yet struggles with the reality that ‘because I never said goodbye she’s not ‘fully dead’ to me.’

**Task 2: Tolerating the pain of grief**

Katie chooses when and how she lets herself give way to the pain of grief. In public arena she polices this carefully so that it does not harm her carefully guarded ‘reputation.’ She is able to tolerate the pain of grief in order to get on with the challenges and opportunities of living. She told me of a time when all of this overwhelmed her, she ‘just had the biggest meltdown,’ but she was able to tolerate and the pain, and to accept help to help her with this.

In Katie’s narrative her power over the pain of grief is striking:

*I thought, if I let this get on top of me what will I make for myself? There’ll be nothing. If I let all these problems get on top of me what will I become?* (325 Katie)

For Emma, Charlotte and Alana it is the pain itself that it most striking, and their sense of personal failure and shame associated with their struggles to deal with the pain. These three girls all behave in ways which make them feel ashamed. Emma and Alana link this to the anger and pain of grief:

*You get so mad and you don’t know what to do and you think summat. It feels so bad you just hurt yourself or hurt somebody else* (Emma 140)

Emma and Alana talk about suicidal feelings. *Sometimes I do actually just want to give up. It gets that bad. But it only comes now and again now. It used to be all the time* (Alana 15). Emma cries all the time. Alana feels she has no right to be happy, that if she does ever feel happy she ‘feels selfish and then it all goes back to normal again.’ She told me ‘I can’t throw the pain away – it takes over from the good.’ (Alana). Alana and Charlotte both feel like they’re ‘nothing.’
Charlotte wants to be a different person, to escape from herself and escape from all the things she’s done, ‘like change who I am.’ Charlotte and Emma have both self harmed, although both have stopped now. Emma told me:

*When I were younger the only release I had were self harming cos like you gotta release how you feel and when I were self harming I didn’t know what to do cos my mum had died and I had to be strong inside cos of my gran and that so I just used to go and slice and dice my arms up.* (Emma 72)

Emma, Alana and Charlotte all told me they could not imagine anything helping them to cope differently, anything that would have helped them to avoid sublimating the pain of grief into maladaptive aggressive behaviour but all of them talked about the importance of having someone to talk to, someone who understood and listened, someone who would be there to respond when they felt ready and able to talk. I will explore this further in a section on Bereavement Interventions: Helpful and Unhelpful Helping.

‘it’s not as bad as I make out sometimes. But it is to me. Cos it seems to me my life’s just gonna be like this forever.

**Task 3: Adjusting to an environment in which the deceased is missing**

This is an area of significant difference between the girls. Only Alana has stayed in the same home, but she has had to adjust to an environment in which she has learned that as well as being a drug addict, there were other complicated and upsetting elements in her mother’s life. No wonder she no longer believes that her Nan can ‘protect her from everything bad.’

Emma did not have a stable home before her mum died, she felt passed around like a parcel. This continued after her mother’s death. ‘I didn’t know where I were. I think I were sleeping in my nana’s front room.’ She has to make sense of the death of her father, or the man she thought was her father. She continues to move from one family member to another. She is rejected at school as she is at home. No wonder adjusting to her environment is difficult task to accomplish. Of course it was difficult for Emma before her mother died, but after her mother dies the task becomes even harder.

Charlotte’s life too is more unsafe after her dad dies. Her home is quiet – there’s no welcome or support when she comes in from school. She lives with the fear of her mother
killing herself and the reality of her mother’s violence to her. Then she is taken into care, is marked out as different because she doesn’t have a family, and ‘feels like [I’m] nothing.’

The reality is that for Alana, and Charlotte life is much more unsafe after their mother or father has died, Emma’s life was unsafe before her mother died, and continues to be so after her mother’s death. These girls have not been able to accomplish the task of adjusting to their environment after their mother or father’s death, because their environments do not provide the security they need in order to do this.

By contrast Katie’s life is safer and more settled now. She has ‘settled into a new life’ and can accept that her life is better now. She is free now to live with her good memories of her mother, whilst being able to acknowledge:

*You know when my mum was alive she like….all these different boyfriends…. And not having dinner all the time. And I just think it made me a better person. Through not having her there. I don’t want to sound horrible, but yeah.* (Katie 298)

Task 4: Relocating the dead person within one’s life and memorialising the dead person.

Alana and Katie both have a strong sense of their mother within their lives. Alana has worked hard to relocate her mother with her life, perhaps more substantially now she is dead than when she was alive. Alana has photos of her mother, her mother’s clothes, she has written songs about her mother and she talks of her often with her Nan. Katie too is able to talk about her mum, to look at photos with her Nan, and to accept ‘This is it. These are the memories. There won’t be any more.’ She can let the good memories take over from the bad ones, whereas in life ‘it was the bad more took over the good.’ Katie also has the letter which her mother wrote to her, for her to read after her death, encouraging her to keep on with life, and keep on loving life.

Alana’s memories are those which capture the essence of her mother, of the mother she wants to remember. ‘I just want to remember her for the goodness.’ Her specific memories seem thin on the ground but she creates a sense of her mother which can she can cherish – of how hard her mother fought to keep Luke and to beat her addiction, of how it felt ‘just how it were meant to be’ when she and her mother spent time together. Charlotte and Emma do not have a positive sense of their dead parent and the clumsy attempts by others, using text book not child focused interventions, have made this harder, because
they have not been able to acknowledge the ambiguity of the child’s relationship with their dead parent, and the emotional toll this has placed on the bereaved child.

Katie, Alana and Emma all have, in differing ways, a symbolic relationship with their dead mothers. All of them believe that their mother’s are ‘looking down on them’ want the best for them, and in some way are a positive force, helping them to keep on with their lives.

Both Emma and Alana are trying to relocate their mother within their lives, and perhaps it is helpful to suggest that after death they can have more control over how they relocate their mother within their lives than they did when their mothers were alive. Both girls struggle with this, although Alana has been able to do this less painfully. She can rationalise the last thing she said to her mother, ‘I hate you. I wish you were dead’ as the ‘kind of things kids say.’ (Alana) Emma has to rationalise the fact that her mother said those things to her, but ‘they do that when they’re all drugged up and that.’ (Emma)

Emma has strong memories of rejection and hurt, and of course she still has strong emotions associated with this. She has to reconcile her memories of her mum as a ‘pisshead,’ ‘a right slag’ and a ‘cunt,’ with the canonical narrative that mothers love their children and want what’s best for them.

The notion of canonical narratives, and means dominant beliefs or discourses about ‘how life is meant to be.’ In our society there are powerful canonical narratives about parental love; parents put their child’s needs above their own, parents love their children, parents keep their children safe.

Alana has managed to create a narrative about her mother which is congruent with this canonical narrative. Her mother strove to be a good mother, to fight her addiction but ultimately was not powerful enough to do so. In so doing she is able to relocate her mother within her life, and to want to do the best for her mother, to make her proud, and to be strong, not a victim, so she does not fall into the life her mother led.

For Emma the dissonance between these canonical narratives of parent child love, and the story of her own relationship and rejection by her mother makes the challenge of relocating her mother within her life immensely difficult. Emma has to grieve for the loss of mothering which never had, the love she never had, of a mother figure, ‘the best friend you could have’, ‘the best person who could be in your life’, with the reality of a life in
which she never had this, in which she has to deal with the inherent contradiction of the fact that ‘She weren’t like a mum to me at first she were a proper cunt I hated her but at the same time I loved her to bits.’ (Emma)

Charlotte can’t relocate her father within her life because she has not yet accepted that he has died. She still hopes that if she wants him badly enough that he will come, that he will do that for her. Because she has not yet accepted the reality of her father’s death she cannot have a symbolic relationship with him and she can’t memorialize him. She fears him appearing before her, fears that the devil may appear as her father, fears that if she cries for him she may somehow make him appear, that would scare her and ‘I don’t wanna be scared of my dad.’ Because she fears this she can’t let herself remember her dad, and shuts down when other people talk about him. Charlotte can’t let herself remember her dad because memories trigger painful recollections, and ‘that’s not how I wanna remember my dad.’

Struggling with this aspect, or task of grief means that Charlotte and Emma have not been able to experience, or even to see the possibility of the kinds of post traumatic growth, the reworking of a negative experience into a positive dimension of self which, when this is achieved, can help to heal and can help the young person to recalibrate their lives and their sense of self, now that a key attachment figure has been lost. The ways in which relocating the dead person within one’s life, and of memorializing the dead person with false idolatry, as an important dimension of post bereavement adjustment has been addressed in by Brewer and Sparkes (2011), Davis (2008) and Schultz (2007). The life stories told by these girls demonstrate the complexities involved in achieving this relocation.

5.3.4.3. Normal versus Complicated Grief

Katie bears all the hallmarks of a ‘psychologically successful mourner.’ Psychologically successful mourners are able to:

Integrate elements of their identity that were related to the lost relationship into a new identity, maintain a symbolic bond to the deceased even while adjusting to real circumstances and restore or even enhance their sense of security and wellbeing on the basis of both the continuing attachment with the deceased and new attachment bonds with living companions. (Mikulincer and Shaver 2008: 94)
Alana, Emma and Charlotte are all less safe than before their parent died. They all fit the broad spectrum of complicated grief because for all of them their grief is more intrusive, (though they don’t call it grief) more intense, more prolonged and results in more disruptive manifestations than is culturally expected. (Mikulincer and Shaver2008, Rubin et al 2008, Prigerson et al 2008)

Katie’s narrative documents how hard she has to work to be able to return to normal functioning, and to exercise power of the manifestations of her grief so that it does not emerge in ‘disruptive manifestations’(sic). Katie has learned to live with the ‘powerful range of conflicting and confusing emotions (Stokes 2009 q.v.2.3.5) which she experiences as a consequence of her bereavement, including being able to reconcile herself to the acknowledgement that her life is better now, with her mum gone.

There was, for a while, a trend to conceptualise grief as ‘work.’ This conceptualization fell out of favour, but it seems to match the experiences of grief which Katie describes, in which she was able to engage, proactively with the tasks of grief, and positioning herself as agent in the sense making process, in order to accomplish the tasks of grief.

This conceptualization also enables us to ask why Charlotte, Alana and Emma have not been able to do this. Is it because they have ‘chosen’ not to engage in this work? Is it because they are ‘work-shy?’ These are not psychologically viable explanations. They do demonstrate the extent to which it is harmful and wrong to see Emma, Alana and Charlotte as ‘choosing’ to be psychologically unsuccessful mourners who have ‘chosen’ the path of ‘complicated’ as opposed to ‘normal grief’.

Charlotte, Alana and Emma are still struggling to live with their emotions, to make sense of their parent’s death and to recalibrate their assumptive worlds. Whilst Katie presents as a psychologically successful mourner they are psychologically unsuccessful in mourning. Like the notion of grief as work the conceptualisation of mourner as something at which you succeed or fail serves to support the notion that lack of success is down to lack of effort or personal choice. Perhaps this too is a canonical narrative which needs to be exposed so that it can be challenged.

Alana and Emma are told their maladaptive or disruptive manifestations of grief are ‘no excuse,’ and teachers imply that Alana is ‘using’ her mother’s death to excuse her behaviour. All of the girls come to believe that this is true, they are responsible for their
behaviour and that there is something wrong with them. They define themselves and are defined by others by their problem behaviour, their ‘disruptive manifestations.’ Their identities are spoiled ‘because of what you’ve gone through and how you reacted’ (Katie) and the canonical narrative or dominant discourses, of grief as something that you should recover from, means that they see themselves as having failed at grief.

Normal grief and complicated grief are research imposed constructs which don’t help children and young people themselves to make sense of their own experiences of grief. Furthermore there is always the risk that medical diagnosis leads to within person attributions which detracts from the impact of the child’s context in shaping their experiences of grief, of the impact of the ‘conglomerate of prosthetic devices, colleagues and mentors which help the individual to achieve mastery in authoring their own stories. For this reason I think it is more helpful to borrow the language which the girls themselves use, of being ‘on track,’ or ‘off the rails,’ of the ‘lifelines’ which help them to stay ‘on track,’ and the life experiences which can sweep them, again and again, ‘off the rails.’ Normal’ and ‘complicated grief’ are irrelevant constructs in helping children and young people to make sense of their own grief.

5.4. Drawing Conclusions from the Research

5.4.1. Understanding Risk: Should Parental Bereavement through Substance Misuse be Construed as A Traumatic Bereavement?

Until the turn of this century mode of death was conceptualised as a risk factor for complicated grief, with suicide, homicide and some accidents categorised as traumatic deaths. Death through substance misuse has not been included in these categorizations of death, though there does not seem to be any logical reason for this omission, other than perhaps, those affected may be more likely to conceal the death and / or to be hardest to reach by researchers, and least likely to access support services. It is reasonable to include it and to suggest that those who are bereaved through substance misuse may therefore be more vulnerable to complicated grief, because of the traumatic death. However, because they may constitute a hard to reach group their needs may not perhaps be identified, and because their needs are not identified they are not addressed in planning and provision of support services.
However more recent research (Hung and Rabin 2009, Brown et al 2007) suggests that mode of death is not a significant predictor of complicated grief, it may increase the likelihood of complicated grief for those who are prone to complicated grief, but it does not of itself predict complicated grieving.

In short the answer to the question should probably be ‘yes’ bereavement through substance misuse should be construed as a traumatic bereavement, and included in research into the sequelae of traumatic bereavements. The caveat to this response is that this is perhaps a spurious question as, limited though the categorisations have been, traumatic bereavement does not appear to be a significant marker of complicated grief. As I show in this research, the complex interweaving of risk factors means that mode of death may exacerbate vulnerability when other risk factors are present. Furthermore, this research has suggested that children who experience this kind of traumatic bereavement are vulnerable to long term adverse consequences because of the cumulation of risk factors and the relative absence of possible protective factors.

5.4.2. Are Children who are Parentally Bereaved Through Substance Misuse Vulnerable to Complicated Grief?

We know, from the testimony of children who live with parental substance misuse that drug and alcohol misuse are associated with shame, social disapproval and concealment. We know that children who live with parental substance misuse, even if they don’t live with their parent/s, are more likely to have unstable lives, and to have insecure attachments with their parent/s. They are more likely than other children to experience neglect, physical, emotional and sexual abuse (Kroll and Taylor 2003, Barnard 2007, Templeton et al 2006). Because, by it’s very nature addiction takes over the addict’s life, children take second place. As a consequence they live lives in which the social representation of parental love and care is at odds with the reality of their lives. The own lives are not congruent with canonical narratives of parenting. They feel are likely to feel shame, guilt and blame, and to have ambivalent relationships with their parent.

It is for these reasons that children who are parentally bereaved through substance misuse are a highly vulnerable sub group of parentally bereaved children. They are vulnerable to complicated grief and, because of disruptive manifestations of grief, they risk being pushed further to the margins of society, where support networks are fragile or non existent and
there is a high risk of further loss and instability undermining attempts to be ‘psychologically successful’ at mourning.

The Arizona State University Contextual Framework for Adaptation Following Bereavement identifies those risk and protective factors which render a child more or less vulnerable to complicated grief. They explain:

*We refer to our model as a contextual resilience framework to emphasise the central role that person-environment transactions play, versus the heavy emphasis on intrapersonal processes in some approaches to resilience.* (Sandler et al. 2008: 60)

My research bears witness to the hypothesis presented in chapters 2 and 3, that children who are parentally bereaved through substance misuse are distinctly vulnerable, and that this vulnerability is a consequence of the unstable lives they live, as a consequence of their parents substance misuse. They are less likely to have either a symbolic secure base, in a stable and reliable attachment figure, and also less likely to have a physical secure base in which they can be confident that their basic needs for food, shelter and love will be met. Their person environment transactions are therefore more likely to place them at risk of complicated grief, and less likely to be able to adapt to their parent’s death.

This is crucially important both because it provides the rationale for challenging discourses which blame and shame bereaved children for their grief reactions, these can be better understood in terms of environment person transactions, rather than intra personal or within child processes. It is important too because it provides some guidance for the kinds of interventions which are most likely to he helpful to children, following parental bereavement through substance misuse.

### 5.4.3. Bereavement Interventions: Helpful and Unhelpful Helping

All the girls express negative or ambivalent experiences of formal bereavement interventions and / or professional helping. For Emma and Charlotte the experience of being ‘helped’ through creating a memory book in school, was traumatic. Neither girl wanted to face her memories, to deal with the fact that their memories were intrusive and upsetting, Charlotte simply didn’t have any good memories.

Emma is unequivocal the professional help did not help her. She did not need adult led grief work imposed on her, indeed it harmed her for, in not tolerating the help she was
further positioned as a problem child, deserving of punishment not nurture. What she needed was nurture, and she recalls one person who was ‘there for her through it all,’ although the nurture was in the slightly poisoned chalice of chocolate and ice cream which led to comfort eating, weight gain and more censure.

Katie is ambivalent about counselling. ‘It helped but it didn’t’ she told me. What was really helpful to her was to be able to maintain her lifelines of school, friends, dance and drama, and to go to Young Carers where she could share her experiences with people who understood.

Alana has a clear sense that talking should be helpful to help ‘get it off my head,’ and yet at the same time she feels this should have helped her to ‘move on.’ ‘I’ve had loads of counselling so that’s one thing I can’t understand, why I still am the way I am?’ (Alana)

Although the girls are ambivalent about counselling all of them wanted to talk. Although talking should be helpful it is fraught with danger. Alana doesn’t want to talk to her Nan and granddad for fear of upsetting them. She doesn’t want to talk in school for fear people will think she is using her mother’s death as an ‘excuse’ and she does not want to feel ‘ashamed’. Charlotte yearns to talk to her mother but this risks triggering her mother’s self harming behaviour.

Talking and timing was important for all the girls. They wanted to be able to talk when it felt right for them to talk, not in response to opportunities offered by others. Charlotte explained:

*When I wanted to talk about it with someone they weren’t there but they when wanted to talk about it I didn’t want to because um they didn’t want to talk about it at the same time as I did. Just like so…so…* (Charlotte)

This was true for Katie too who recalled:

*At the time I wanted to talk but people you know didn’t want to talk cos they you know they didn’t want to upset me or anything.* (Katie)

This does not mean that opportunities to talk, to feel secure and not judged, to experience perhaps the Rogerian conditions of empathy, acceptance and unconditional positive regard are not valued. (Rogers 1961). When I asked about the kinds of things which might help at school Katie suggested: *If somebody said at the time I know your situation, would you like*
Charlotte, who has experienced this from her teachers, explained how they let her go through phases of swearing, and then crying as a prelude to talking, and about how ‘talking to them made me feel one step closer to my mum and dad. I don’t know how they did it.’ These girls confirm the verdict from Holland’s research participants, that those teachers who did acknowledge their pupil’s bereavement, and who did talk to their pupils about grief were well received Holland 2002 q.v. 2.3.5)

5.4.4. Helpful and Unhelpful Helping: A Focus on Person Environment Transactions

It is possible that experiences of formal ‘helping’ are unhelpful because they focus upon intra personal processes which place the onus upon the child to do the coping, to do the managing of their adjustment to their parent’s death. Yet the risk and protective factors, which are most significant, within Sandler’s contextual framework of resilience, and within Parkes’ risk factors for complicated bereavement, are contextual or environmental factors.

It is possible that the emphasis on delivering ‘help’ through individual person centered interventions actually exacerbates vulnerability, because it leads the children to feel as though they have failed when things don’t change. They make internal attributions for things which are outwith their control, and then feel shame and blame because they haven’t had the power to change their behavioural responses nor their feelings.

Katie’s story clearly identifies her person environment transactions as the lifelines that have helped her through. She has her grandma, of course, who is the most critical factor, and with her grandma securely anchoring her Katie is able to move forward, to continue with her life journey and to access and enjoy the opportunities and challenges of her life. I am surprised at how clearly Katie has articulated her ‘reputation’ as pivotal in this, her strong sense that without this ‘there’s nothing.’

In a sense Charlotte’s wish to sever ties with her environment to go to a different place where people have different values and where no-one knows her or what she’s done also demonstrates the importance of person environment transactions in helping or harming the
ways in which children find their way through life, succeeding or struggling in getting back ‘on track.’

I come back to Bruner’s concepts in his exploration of the role of narrative in meaning making and in self making, to consider how person environment transactions and dominant narratives operate to blame and marginalize Charlotte, Alana and Emma’s for their disruptive manifestations of grief. These girls need ‘consoling plots…..not the comfort of a happy ending but the comprehension of a plight that by being made interpretable becomes bearable.’ Bruner 1991: 16)


This research focused upon representing and understanding the lived experiences of children who have been parentally bereaved through substance misuse.

The dominant themes which emerge are of children striving to make sense of what has happened, make sense of the relationship they had with their dead parent, and make sense of who they are. Sense of self or ‘Identity’ has emerged as perhaps the most important element or aspect of this phenomenological research, with the children struggling to find a way both to make sense of themselves within their pasts, and to find a way forward into the future.

For these children it is not so much that grief is a journey, but that grief, or bereavement, is a formative experience in their journeys through life. The ways in which they deal with this experience becomes part of a cyclical process of identity formation. The children’s sense of who they are, and how they see themselves and are positioned by others, as their try to manage their complicated feelings associated with their complicated relationships with their dead parent, and their lives which have been affected by parental substance misuse.

For Katie this has led to personal growth, but for Alana, Emma, and Charlotte it has thrown them off the track they want to follow, with few lifelines to help them to climb back on. Their ‘disruptive manifestations’ of grief threaten to derail them, sending them spiraling further away from the very lifelines that may help them through. Their
‘disruptive manifestations’ have spoiled their identities and positioned them as children who are ‘shouted at because of what [you’ve been through and how [you’ve] reacted (Katie)’). Bereavement is ‘no excuse’ and they come to be positioned, and to position themselves as ‘bad’, or ‘mad’, rather than ‘sad.’ Their identities have become spoiled because of the ways they have dealt with their parents’ deaths.

The research demonstrates that dealing with parental bereavement through substance misuse is a complicated and traumatic experience. As well as losing a parent these children are in danger of losing the lives they could have had, and the people they may become. Of course this could be measured in outcomes and variables which serve as proxy indicators of wellbeing or ‘coping’, but these mask the complicated narratives of these children’s lives. Most of all, in measuring discrete variables, they risk grief and help as being seen as something which is experienced, and can be resolved, in discrete packages, with no regard for the messy interweaving of different fragments of identity and experience which can contribute to personal growth, or to personal decline following bereavement.

It is not possible to say that other children who are parentally bereaved deal with bereavement differently from children who are parentally bereaved through substance misuse. However, it is possible, and important, to conclude that children who are parentally bereaved through substance misuse are a highly vulnerable sub group of parentally bereaved children. It is important, because to date there has been no acknowledgement that these children exist, no understanding of their needs and no consistent way of identifying these vulnerable children, of knowing just how many children are dealing with this, with all the risks that it entails, or of considering ways of attempting to create or strengthen networks of balancing supports to help them navigate their way through the experience.
CHAPTER SIX: CONCLUDING COMMENTS: THEORY INTO PRACTICE

6.1. Making a distinct and unique contribution to research

This qualitative research study tries to capture lived experiences, to represent the voices and lives of children who have been dealing with a traumatic but uncharted experience. Children who have been parentally bereaved through substance misuse have not previously been identified as a sub group of parentally bereaved children, in marked contrast to children whose parents have died through murder or suicide, or through chronic illness.

This research is unique because it identifies parental bereavement through substance misuse as a potential category for identifying children who may be at risk of poor outcomes and for whom the sequelae of bereavement ‘can have a devastating impact, upon the child and upon society.’ (Stokes 2009: 20)

I think another important contribution that this research makes is in providing evidence to contest the conclusion drawn from population studies, that parental bereavement is not a risk factor for child wellbeing. This research does demonstrate is that children are vulnerable to complicated grief when this network of balancing supports is not available and therefore and it is highly risky, if not harmful, to use conclusions from population studies to conclude that parental bereavement is not a risk factor for child wellbeing and development. These children are vulnerable to going off the rails, and the kinds of support and interventions which will help them to get ‘back on track’ are not individually focused interventions, aimed at developing within child coping strategies, but child environment transactions which seek to identify and implement appropriate ‘life lines’ for each child.

There are few qualitative research studies of parental bereavement, and few qualitative research studies about the experiences of living with ‘hidden harm’, the impact of parental substance misuse. This research has used a rigorous qualitative research methodology to try to capture something of the essence of these children’s experiences, to ‘give voice’ to hitherto unheard members of our society, to try to interpret their experiences within a coherent framework of psychological theory, but a framework which also stays true to the contributors’ experiences, and which locates the interpretation within the social and
cultural context in which these experiences are lived. It demonstrates, I hope, the importance of establishing the voice of the child so that their stories can be heard, rather than their experiences distilled out of contexts and into statistics that run the risk of reductive and potentially distorted interpretations. I hope my research will also make a distinct contribution in paving the way for these children’s voices to be represented so that their needs can be sensitively and effectively addressed, without this resulting in shame, blame and spoiled identities.

6.2. Limitations of this research

These children’s stories offer the researcher and practitioner far more useful data for making sense of bereavement than scores on an inventory of grief. These stories do not categorise grief, nor offer statistical measures of disruptive manifestations of grief. Instead they map out the different dimensions of grief and how these shape all aspects of each child’s life, life chances and identity. The two sections of chapter five, and Appendix C, demonstrate the richness of the data yielded through this research; and the personal accounts of each of my participants show the relevance and richness of the girls’ stories in addressing the research question. Identifying superordinate themes and rooting the interpretation of personal experiences within wider psychological theories about self-identity and agency and linking these to relevant aspects of bereavement research, establishes the theoretical validity of this research within wider theoretical fields.

This was a small scale qualitative research study. It does not provide evidence about how many children live with parental bereavement through substance misuse. In this study three of the four participants would meet the diagnostic criteria for complicated grief. Of course these results are not statistically generalisable, this was not the intention. It captures the experiences of four girls, of similar age, in one city. It is not representative of the wider population of parentally bereaved children, nor of children who are parentally bereaved through substance misuse.

However, I think it is plausible to assert that this study does have theoretical generalisability, because it is theoretically consistent with the conclusions of research into risk and resilience factors for parental bereavement, and with narrative psychology and it’s focus on identity and the formation of a sense of self. These may help to frame some
effective ways of conceptualizing the needs of children who are dealing with parental bereavement through substance misuse.

The research captures my interpretation of these children’s lived experience, through my particular lens, as an applied educational psychologist. It is a detailed picture, but does not capture every aspect or dimension of these experiences, nor does it focus as closely on each girl’s individual experience as it might have done. Other people from other backgrounds, with other perspectives and with other skills may weave different interpretations, or focus on other aspects of these experiences. What I hope this research does achieve, despite these limitations, is that it starts to mark out some distinctive features of an experience, a traumatic experience, which has hitherto been unresearched.

I hope that this will be the start of further work into the experiences of children who live with parental bereavement through substance misuse, and that this in turn will lead to researching ways of supporting these vulnerable children through this experience.

6.3. Future Directions for Research

This research considers the experiences of four girls, all aged fourteen to sixteen years. Further research should explore the similarities and differences between experiences of this phenomenon, across different ages and between boys and girls.

Identity formation, and the risks to an enabling identity have emerged as important factors in this research. I think it would be helpful to develop this aspect of the research through further phenomenological and narrative research, and perhaps to explore the ways in which developing different narratives, about children’s relationships with their dead parent, about the cause of their parent’s death, about the parenting they have had and the lives they lived before their parents died, and the ways in which they construe their own responses to the bereavement. This might help to consider ways of supporting the girls to develop more enabling identities, to perhaps experience personal growth, grow stronger.

However, this suggestion is with the caveat that we develop our sense of who we are from the ways in which engage with and are positioned within the society in which we live. The focus of research onto effective interventions should be on person environment transactions which can help to create a balancing network of support for the individual.
Crucially I think this network needs to make explicit the ways in which children can positioned as problematic following parental bereavement, because of their disruptive manifestations, and perhaps because the help that is offered to them is harmful. Making explicit the ways in which these processes occur will be an important aspect of future research.

Of course it will also be important to establish how limited, or conversely how widespread, the phenomenon of parental bereavement through substance misuse actually is. At present there is no way of establishing this information, and all we know is that for children whose parents die from drugs or alcohol, like children who live with ‘hidden harm’ often disappear ‘off the radar’ (Cairns 2007).

6.4. Applying Research Findings in Educational Psychology Practice

This research started with Luke’s story, a story which emerged from the individual casework which I undertook with Luke, ostensibly to provide psychological advice about Luke’s special educational needs to the local education authority, but actually to ratify Luke’s position as a problem child with special educational needs who could not be accommodated within mainstream school or life.

I hope that my involvement actually helped to unearth a different story, one which made more sense to Luke and his grandmother, and which was less shaming. Instead of blaming Luke for his disruptive behaviour, it explored the way in which Luke had been positioned, through disciplinary processes in school, and the ways in which he sought to resist the position that was being thrust upon him.

I think this research demonstrates the ways in which the processes of exclusion and positioning can operate to drive vulnerable children into a spiral of social exclusion and despair, because it represents them as choosing to behave maladaptively, with ‘disruptive manifestations’, and blames them for their failure to police their behaviour, as Katie did, to become ‘psychologically successful mourners.’ It demonstrates the ways in which some parentally bereaved are treated, which betrays the canonical narrative that parentally bereaved children need sympathy and understanding, and that society looks after its most vulnerable members.
Making sense of the lived experience of parental bereavement through substance misuse will, I hope, help other educational psychologists to help vulnerable children, their families and those around them, especially in school, to make sense of their experiences and their presenting behaviour, as they strive to find ways of dealing with the experience, without losing a foothold in society.

As educational psychologists we work with individuals but also strive to apply knowledge and understanding from individual casework to address wider issues. We can help, perhaps, to help these children, and others with similarly cruel stories and similarly fragile support networks and serves to be able to ‘story their own actions, to make sense of their experiences in ‘social and culturally comprehensible ways [as this is] crucial to our standing as persons, as recognized members of society. (Salmon and Reissman 2008) I hope it will help individual children in identifying how to make sense of their presenting behaviour and to start to make sense of feelings of despair, how to create more enabling, less shaming narratives about themselves and their experiences and how those around them might strive to build safe networks of balancing supports, so that their person environment transactions can strengthen these more enabling narratives.

I hope it will help these children as a group through identifying these children as a vulnerable sub group of bereaved children about whom we know relatively little, in terms of their needs and where and who they are, and helping to create a discourse around their entitlement to understanding and support, a discourse which is strong enough to expose and contest the social and cultural practices which further entrench the hurt and harm experienced by some children who are parentally bereaved through substance misuse.

6.5. Closing Comments

‘But the hearts of small children are delicate organs. A cruel beginning in this world can twist them into curious shapes.’ (Carson McCullers)

The death of any parent, but especially perhaps the death of a parent through substance misuse, could be construed as a cruel beginning. These bereaved children need love, support, understanding and most of all emotional and environmental security to help them find their way past this cruel start to their lives. Professionals and psychologists need to
explore and develop ways of embedding these into children’s lives, rather than superimposing bereavement interventions that are not congruent with their lives or experiences upon them. Each time we fail to do this for each individual we risk devastating consequences, both for each individual child, and for our society as a whole.
References


Robinson, O and Smith, J. (2010) Investigating the Form and Dynamics of Crisis Episodes in Early Adulthood: The application of a composite qualitative method. *Qualitative Research in Psychology*. 7:2 170-191


Appendices

Appendix A: Ethical consent

University Review of Ethics Committee (UREC) : Request for ethical clearance review form
Consent letter from University of Manchester UREC

Appendix B: Research literature

Research information leaflet for children and young people
Research information leaflet for parents and carers
Consent form: Consent to be contacted about this research
Consent form: Consent to participate in this research
Consent form: Consent for research to be undertaken on school premises

Appendix C: Data analysis

Complete sample transcript: Emma
Sample transcript with initial responses: Emma
Table of themes and illustrative excerpts for each contributor

Katie’s tabulated themes with illustrative excerpts
Emma’s tabulated themes with illustrated excerpts
Charlotte’s tabulated themes with illustrated excerpts
Alana’s tabulated themes with illustrated excerpts
Appendix A1: University Research Ethics Committee Form

UNIVERSITY OF MANCHESTER
COMMITTEE ON THE ETHICS OF RESEARCH ON HUMAN BEINGS

Application form for approval of a research project

This form should be completed by the Chief Investigator(s), after reading the guidance notes.

1. Title of the research

Understanding and Responding to the Needs of Young People Who are Parentally Bereaved Through Substance Misuse: A Phenomenological Study.

2. a. Chief Investigator (student)

Title: Ms
Forename/Initials: Philippa
Surname: Grace
Post: Student Doctorate in Educational Psychology
Qualifications: MA (Hons) MEd, MSc, PGCE (Primary) CPsychol
School/Unit: School of Continuing Education, University of Manchester
Email: philippa.grace@btinternet.com
Telephone: 01422843220 - 07786031163

b. Investigator (Supervisor)

Dr Garry Squires
Co Director of the Professional Doctorate in Educational Psychology

Qualifications:
BEd (Hons), BSc (Hons), Dip Psychol., MSc, DEdPsy, CSci, EuroPsy, CPsychol, AFBPsS

School/Unit: Education
Email: garry.squires@manchester.ac.uk
Telephone: 0161 275 3546

3. Details of Project
3.1 Proposed study dates and duration

Start date: as soon as UREC permission is granted
End date: April 2012

3.2 Is this a student project?
Yes
If so, what degree is it for?
Doctorate in Educational Psychology

3.3. What is the principal research question/objective?
(Must be in language comprehensible to a layperson.)
The research question asks: “How do children and young people deal with parental bereavement, when the bereavement is caused by substance abuse?”

3.4. What is the scientific justification for the research? What is the background?
Why is this an area of importance / has any similar research been done?
(Must be in language comprehensible to a lay person.)

Research into bereavement aims to understand trajectories of grief within a personal and social context, to explore ways of helping people to deal with bereavement and grief. Within bereavement research much work has been undertaken to identify those factors which put individuals at risk of complicated or traumatic grief. Complicated or traumatic grief are two of the diverse terms used to describe grief has severe long term consequences for the individual’s well being and which puts them at risk of long term mental health difficulties. Those factors which put individuals, especially children and young people, at risk of complicated grief are often related to other factors known to put people at risk of mental health difficulties. They are often related to disrupted family lives before and after the bereavement, ambivalence in the relationship and a history of attachment difficulties with primary relationships. Other factors which put people at risk of mental health difficulties are related to poverty. Early death and parental bereavement is more likely to occur in poor families. This interrelation of the personal and social risk factors put children who are parentally bereaved at an increased risk of traumatic grief. It seems reasonable to suggest that many of the children and young people who’s parents have died through substance misuse are likely to experience some combination of these risk factors which puts them at a high risk for traumatic grief.

Bereavement through substance misuse is not categorized as a traumatic death in research studies. The literature review to date has not yielded any research into parental bereavement through substance misuse, either as a sub category of traumatic death, or through research into the consequences of living with parental substance misuse. Children who are parentally bereaved through substance misuse appear to be an invisible group within current childhood bereavement research. As they appear to be invisible it is possible that their bereavement experiences are unacknowledged, and not understood. This is likely to mean that the needs of these children and young people may not be effectively addressed, making them vulnerable to traumatic grief and unable to access appropriate support within their families and community, and from professionals.

This is a potentially important area to address because the needs of these children, though perhaps small in number, are likely to be significant and there appears to be a high risk that these needs have hitherto been unacknowledged.

This research aims to understand children and young people’s experiences of dealing with bereavement through substance misuse, and the experiences of carers and professionals who live and work with children and young people who are dealing with such bereavement. I hope that through generating an understanding of the lived experiences of dealing with such bereavement, and interpreting the experiences within the context in which it occurs, that I will be able to generate a framework for addressing the needs of these young people.

As a chartered educational psychologist an important aspect of my role is to identify potential or actual barriers to children and young people’s development and wellbeing, and to work with others
to overcome these barriers in ways which develops the skills and confidence of the child or young person to manage the challenges and opportunities life presents them.

This research has a professional justification in that I do, in the course of my work, come across young people who have been parentally bereaved through substance misuse, and often this bereavement is not acknowledged as a life event which may have an adverse impact upon them. Indeed the bereavement is often buried within a network of other complicating risk factors which may lead to the marginalisation, and perhaps stigmatisation, of the child or young person.

In undertaking this research I hope to be able to develop a framework which educational psychologists and other professionals can use to ensure that children and young people receive appropriate support to help them to deal with their parental bereavement, and that they needs do not go unacknowledged nor unaddressed.

3.5. How has the scientific quality of the research been assessed? (Tick as appropriate)

☐ Independent external review
☐ Review within a company
☐ Review within a multi centre research group
☒ Internal review (e.g. involving colleagues, academic supervisor)
☐ None external to the investigator
☐ Other, e.g. methodological guidelines (give details below)

If relevant, describe the review process and outcome.

If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

University of Manchester School of Education: Thesis proposal panel 07/04/11

Educational Psychology Team Education Xxxxxxx: Peer review senior management team 30/03/11

3.6. Give a full summary of the purpose, design and methodology of the planned research, including a brief explanation of the theoretical framework that informs it. It should be clear exactly what will happen to the research participant, how many times and in what order. Describe any involvement of research participants, patient groups or communities in the design of the research. (This section must be completed in language comprehensible to the lay person.)

This research uses Interpretative Phenomenological Analysis (IPA) to address the research questions. IPA has been chosen because it has dual aims: a) to give voice to respondents whose voices previously may not have been heard, nor understood, and b) to interpret or make sense of these voices, and to interpret them within a social and cultural context. The interpretive dimension also allows the IPA researcher to draw upon existing theoretical frameworks. (Larkin et. al 2007)

The preliminary and crucial part of the research process is identifying potential participants who interested in contributing to this research and who, in the professional judgement of the researcher, and the referring professional, will be likely to be able to contribute without being harmed by the experience of taking about their bereavement. There is some research evidence to suggest that participants report that contributing to research on bereavement is a positive experience (Dyregov 2004, Holland 2001)

More information about the recruitment procedure, and the professional and ethical responsibilities which the researcher has for the participants will be dealt within subsequent sections.

The research procedure is a six stage approach involving:
1. eliciting accounts about dealing with parental bereavement through semi structured interviews with participants over 1-3 sessions
transcribing and reading these accounts  
representing these accounts  
interpreting these accounts, identifying themes within and across transcripts  
developing a theoretical framework which professionals can use in understanding and responding to the needs of these children and young people and those who care for them  
seeking respondents’ responses to my interpretation for these accounts and the proposed framework, and making amendments or progressive interpretation as appropriate.

The semi-structured interviews with each participant are the data gathering element of the research. It is this part of the research process, along with participant validation in stage 6, in which the participants are involved.

The research question and the probe questions during the interview have been carefully constructed to focus upon dealing with bereavement – rather than bereavement itself, or the relationship of the bereaved person with the person who has died. The research is thus orientated both to serve a pragmatic purpose – to find what might support young people and children to deal with bereavement – and to ask for information about what helped them and they think might help other young people rather than intruding into the private area of how the child or young person thinks of their dead parent, and the relationship they have with them.

One of the central foci of this research is to ‘give voice’ to experiences from and about young people and children who have been little heard to date. In order to enable participants, especially young people, to develop their thoughts research interviews will take place over 1-3 sessions. It is anticipated that the research interviews with professionals take place over one session.

A follow up session with each participant will be arranged, to discuss the transcript of the interview, and the interpretation which I have made.

3.6.1. Has the protocol submitted with this application been the subject of review by a statistician independent of the research team? (Select one of the following)

○ Yes – copy of review enclosed  
○ Yes details of review available from the following individual or organisation  
(give contact details below)  
○ No – justify below

This is a qualitative study and no statistical analysis is involved.

3.6.2. If relevant, specify the specific statistical experimental design, and why it was chosen?

N/A

3.6.3. How many participants will be recruited?
If there is more than one group, state how many participants will be recruited in each group.

Professionals : 4-5 ;  Young people over 14: 4-5; Parents/ carers : 4-5

3.6.4. How was the number of participants decided upon?
The decision was based upon the number of participants needed to give a rich context into the experience of dealing with parental bereavement through substance misuse and the intensive process of IPA. 12-15 participants is a relatively high number for an IPA study. It allows for some attrition during the interview cycle. It also means that I could proceed with a viable study if it is not possible for me to identify young people who, in my professional assessment, and in the opinion of the referring professional, may be harmed by participating in the study.

3.6.5. Describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Data will be transcripts of the semi structured interviews undertaken with young people, carers and professionals. Cumulative coding, within each transcript, and integrative coding across transcripts, should generate a thematic account about the experience of dealing with parental bereavement through substance misuse. Existing theoretical concepts may help in identifying and developing these themes.

Transcribing each interview
Reading the transcript and recording initial impressions
Identifying themes
Labelling themes and then master themes
Producing a summary table of master themes and sub themes, with verbatim quotes to illustrate each theme for each interview
Participant validation
Further interpretation following participant validation if appropriate
Cumulative coding across transcripts within each participant group, to explore common themes, and significant exceptions or variation
Cumulative coding across transcripts and across groups of participants to explore common themes and significant exceptions or variation
Theoretical analysis, to explore how the themes emerging from this phenomenological research map onto the existing themes and theoretical frameworks within bereavement research and into risk and resilience.

3.7. Where will the research take place?

Xxxxxx

I anticipate that most of the interviews will take place on the premises of the referring profession i.e Barnado’s offices, CAMHS, community care homes and schools.

I will inform the head of each establishment where research interviews will take place, and obtain their written consent to conduct research interviews on the premises of their establishment prior to conducting any research interviews. (Establishment consent forma attached)

3.8. Names of other staff involved.

None

3.9. What do you consider to be the main ethical issues which may arise with the proposed study and what steps will be taken to address these?
1. Identifying, approaching and recruiting young people who are able to give informed consent to participate in the research interviews
2. Conducting the research interviews in a way which does not put participants at risk of psychological or emotional harm
3. Maintaining a research orientation whilst using my professional skills as a psychologist, without creating the hope or expectation in participants that the interview is part of a therapeutic relationship, or that I will enter into a professional relationship with them.

A) All the young people will be recruited via professionals with whom they have a supportive relationship. The referring professional will undertake to be meet with the young person to debrief them after the interview, if appropriate.

The referring professional will explain the nature of the research and give them the information leaflet. If the young person is interested in contributing they will sign a consent form.

The referring professional will seek the written consent of the parent/ carer for any potential participant under the age of 16, with the consent of the young person themselves.

I will contact the young person by text or email to make initial contact and arrange a time to talk over the telephone.

I will arrange to meet with the young person by telephone, and will again check that they wish to participate.

At the initial interview and any subsequent interviews I will discuss consent and willingness to take part, reminding the participant that they can stop the interview or their involvement at any time.

B) I am professional educational psychologist, chartered by the British Psychological Society, and registered with the Health Professionals Council. I have the same professional responsibilities to my research participants as I do to my clients, and am bound by the codes of conduct of these two organisations to protect my clients from harm, to treat them with honesty, respect and integrity, and within the bounds of my professional competence.

My professional role is a therapeutic one, helping clients to explore painful and difficult topics in a way which enables them to find ways of dealing with or overcoming these issues, through developing their understanding

In my professional opinion these skills will enable me to conduct my research interviews safely, without placing the participants at risk of harm. I have agreed two supervision sessions with senior colleagues, a family therapist and the principal educational psychologist, to explore the process of conducting these interviews whilst protecting participants from harm.

Research cited above (Dyregov 2004 and Holland 2001) actually suggests that participating in bereavement research is often a positive and rewarding experience for participants, although none of this research has been undertaken with children)

C) I will make clear the boundaries of the research interviews and ensure that young people / carers know that the referring professional has agreed to meet with them, to debrief them if they request this. I will also provide information about other agencies which offer support locally and by telephone, and will give information leaflets about the local bereavement support service. I will also offer this information to parents and carers. I will not conduct research with young people who are known to me through casework as I wish to ensure that the boundaries between a research relationship and professional relationship do not become blurred.

3.9.1. Will any intervention or procedure, which would normally be considered a part of routine care, be withheld from the research participants?

No
4. Details of Subjects.

4.1. Total Number
4-5 young people aged 14-19 and parents/ carers and professionals

4.2 Sex and Age Range
14 years up – either sex

4.3 Type
Young people who have been parentally bereaved through substance misuse

4.4. What are the principal inclusion criteria? (Please justify)
Experience of parental bereavement through substance misuse more than 12months previous to research interviews
Able to give informed consent, according to the guidance within the Fraser Competence ruling

4.5. What are the principal exclusion criteria? (Please justify)
Young people under the age of fourteen
Young people who are assessed as not emotionally robust enough to attend interview by referring professional or by researcher at first meeting, or at any stage in the interview cycle.
Young people and parents / carers where the bereavement has occurred in the last 12 months
Young people whom I already know through my work as an educational psychologist
Parents/ carers who are assessed as not emotionally robust enough to attend the interview by the referring professional or by the researcher at first meeting or at any stage in the interview cycle
Young people whom the researcher does not assess as Fraser competent at the preliminary meeting
Young people who do not, at initial contact, have support from a link professional to address any issues which might arise from the interview, and where the researcher assesses that the contributor may benefit from further support.
Participants who are not fluent in English

4.6. Will the participants be from any of the following groups? (Tick as appropriate)
Children under 16 may be included

Justify their inclusion

The aim of the research is to understand how children and young people deal with parental bereavement through substance abuse through a phenomenological study which aims to give voice and make sense of the experiences of the children and young people who have experienced this, and through hearing the experiences of those who care for and work with these young people.

It is considered the research will be richer, and will be give voice to a previously under researched group of children and young people who are especially vulnerable.

Although this is a high risk study, the risk of continuing to ignore and therefore not to respond to the potential needs of these children and young people is, in my professional judgement, a greater ethical risk.

4.7. Will any research participants be recruited who are involved in existing research or have recently been involved in any research prior to recruitment?

☐ No

4.8 How will potential participants in the study be (i) identified, (ii) approached and (iii) recruited?
Where research participants will be recruited via advertisement, please append a copy to this application

Young people: via referring professional from health, social care or education
Parents/carer: via referring professional from third sector support agencies or directly by attending a support group run by a third sector agency, describing the research and inviting appropriate participants to volunteer.
Professionals: via meetings with local agencies, email contact and local networks

4.9 Will individual research participants receive reimbursement of expenses or any other incentives or benefits for taking part in this research?
I have considered this issue carefully and have decided not to offer payment or other inducements.

5 Details of risks

5.1 Drugs and other substances to be administered
Indicate status, eg full product licence, CTC, CTX. Attach: evidence of status of any unlicensed product; and Martindale’s Phamacopoeia details for licensed products

<table>
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<tr>
<th>DRUG</th>
<th>STATUS</th>
<th>DOSAGE/FREQUENCY/ROUTE</th>
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<tr>
<td>Not Applicable</td>
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5.2 Procedures to be undertaken
Details of any invasive procedures, and any samples or measurements to be taken. Include any questionnaires, psychological tests etc. What is the experience of those administering the procedures?

5.3 Or Activities to be undertaken
Please list the activities to be undertaken by participants and the likely duration of each

3 semi structured interviews 30-90 minutes duration

5.4 What are the potential adverse effects, risks or hazards for research participants, including potential for pain, discomfort, distress, inconvenience or changes to lifestyle for research participants?

Emotional distress of talking about painful issues, and of possibly reactivating painful memories

5.5 Will individual or group interviews/questionnaires discuss any topics or issues that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could take place during the study (e.g. during interviews/group discussions, or use of screening tests for drugs)?
Yes.
If yes, give details of procedures in place to deal with these issues:
This research addresses sensitive issues, and may well be upsetting in parts for the participants. However, my professional skills as a practising chartered psychologist will enable me to conduct the interviews safely and with dignity. My professional skills and duty means that I will be monitoring the interview and if, in my professional opinion, there is a risk of harm to the research participant I will stop the interview, and arrange for the participant to meet with his/her referring professional for support. I will also liaise with our local bereavement service to offer ongoing support if this is required.
At the start of each interview I will explain that contributors can stop the interview at any time, and can choose to withdraw. At the end of each interview I will ask contributors to rate the experience of the interview, and to say whether they are willing to meet again.

Studies investigating the experience of contributing to bereavement research indicate that many contributors find this helpful and evaluate the research experience positively, even though it explores a painful issue. (Holland 2001, Dyregov 2004)

I am bound by the professional and legal regulations of confidentiality, and will maintain confidentiality unless there are child protection concerns. In this case I will follow child protection procedures as a 'named person' with a duty to report the Xxxxxxx Safeguarding Children Board.

5.6 What is the expected total duration of participation in the study for each participant?

Up to 4 hours over 3 interviews and follow up participant validation

5.7 What is the potential benefit to research participants?

Research cited above indicates that participating in research is perceived positively by participants, and that they report therapeutic benefits

I hope that participants feel that contributing knowledge about their own experiences will help others with similar experiences, and that this is also a positive experience for them

5.8 What is the potential for adverse effects, risks or hazards, pain, discomfort, distress, or inconvenience to the researchers themselves? (If any)

It is possible that I, as researcher, will experience what is known as vicarious trauma, the consequences of hearing about and responding to stories of traumatic events experienced by others. However, this is something which I encounter routinely within my professional role, and which is addressed through professional supervision around case management. This professional supervision is available to me in my professional role, and I have a professional duty to use supervision

It is possible that I might be at risk of harm if conducting research interviews on unfamiliar premises, especially participant’s homes. My service has a strict home visiting policy. This means that I must not visit any client’s home by myself, unless I have previously visited and in my professional judgement am safe to visit and work there. In practice this means I would not visit any home unless I had already met the client, already undertaken a joint home visit with a colleague, or been informed by another professional employed by Xxxxxxx Council or by the Health Authority that it was safe and appropriate to conduct a home visit.

My service protocol for home visiting requires that I leave a full address of an home which I visit, with start and end times. If the visit takes place at the beginning or the end of the working day then I will telephone the office to let them know that the visit has been completed.

I anticipate that most of my interviews will not be conducted in participant homes but I will adhere to this protocol if I do conduct interviews within participant’s homes.

6. Safeguards

6.1 What precautions have been taken to minimise or mitigate the risks identified above?
Pre interview / recruitment precautions: The participant inclusion criteria means that only young people who are judged by the referring professional to be able to deal with the research interviews, and who are able to give informed consent, will be invited to contribute through the research interviews.
The interview probes have been carefully constructed to answer the research question, without straying into questions which might put the contributor at risk of emotional harm.

Only young people who have the support of the referring professional will be invited to contribute, as this is a principal inclusion criteria.

Interview precautions: Contributors will be reminded that consent is voluntary, and that they may withdraw at any time. My professional skills and duty means that I will be monitoring the interview and if, in my professional opinion, there is a risk of harm to the research participant I will stop the interview, and, if appropriate, arrange for the participant to meet with his/her referring professional for support. I will also liaise with our local bereavement service to offer ongoing support if this is required.

Follow up monitoring of participant well-being: All contributors will have a date to meet with their referring professional. I will give all contributors an information leaflet from the local bereavement support service and explain that this service will offer a priority referral to research contributors. I will ask if they would like me to make a referral and will do if requested.

I will contact all contributors after 6 months, to ask about their well-being, and if they have experienced any positive or adverse consequences to participating in the research. I will also ask if they would like my help in identifying a source of ongoing emotional support, and will refer to the bereavement support service if requested.

6.2 Will informed consent be obtained from the research participants?
Yes

If yes, give details of who will take consent and how it will be done. Give details of the experience in taking consent and of any particular steps to provide information (in addition to a written information sheet) e.g. videos, interactive material.

If participants are to be recruited from any of the potentially vulnerable groups listed in Question 4.6, give details of extra steps taken to assure their protection. Describe any arrangements to be made for obtaining consent from a legal representative.

If consent is not to be obtained, please explain why not.
Where relevant the committee must have a copy of the information sheet and consent form.

Recruiting professionals will give potential participants a research leaflet and will ask if they feel they would be willing to meet with me. (leaflet appended) Professionals will only suggest this to young people whom they feel would be able to participate in research interviews, and where they are able to offer ongoing support to the young person through their professional role.

If young people express an interest the professional will obtain a signed consent form from them, and from their legal guardian if they are under 16 years. The consent form includes contact details. (consent form appended).

I will contact the young person, and their legal guardian if appropriate by text, phone or email to arrange to meet, and remind young people that consent is voluntary.

All participants will give written and verbal consent to participate and this will be reviewed at each meeting. I will make it clear to participants that they can withdraw at any time.

I am used to working with vulnerable young people, and exploring potentially painful issues with them and in ensuring that young people consent to this, and are not there simply because they have been instructed to meet with me. As part of my professional role and responsibility I always explore consent issues with young people and only work with children and young people who say they consent to work with me. I use similar expectations for sessions with individual clients that I expect to use in the research interviews.

6.3 Will a signed record of consent be obtained?
Yes
6.4 How long will the participant have to decide whether to take part in the research?

Flexible, at least one week it is more likely to be a month from initial identification, through first contact with the researcher to the first interview.

6.5 What arrangements have been made for participants who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? (e.g. translation, use of interpreters etc.)

None – only English speaking participants will be involved.

6.6 What arrangements are in place to ensure participants receive any information that becomes available during the course of the research that may be relevant to their continued participation?

I will have up to date contact details and will share any relevant information within one week.

I do not anticipate this being relevant to this research.

6.7 Will the research participants’ General Practitioner be informed that they are taking part in the study?

No

If No, explain why not
Only if requested by participant. Unlikely to be relevant.

6.8 Will permission be sought from the research participants to inform their GP before this is done?

☐ No Not relevant unless requested by participant

6.9 What arrangements have been made to provide indemnity and/or compensation in the event of a claim by, or on behalf of, participants for (a) negligent harm and (b) non-negligent harm?

I am seeking cover under the University’s insurance policy for student research, as this is research for an educational qualification.

7. Data Protection and Confidentiality

7.1 Will the research involve any of the following activities at any stage (including identification of potential research participants)? (Tick as appropriate)

☐ Home or other personal computers encrypted data held on home computer
☐ Laptop computers encrypted data may be held on lap top computer

7.2 What measures have been put in place to ensure confidentiality of personal data? Give details of whether any encryption or other anonymisation procedures have been used and at what stage?

I will be using a private computer. All data will be encrypted. Information and data will be held, encrypted, for five years after completion of the research and then deleted. No-one else will have access to this data which will be on my private home computer.
7.3 Where will the analysis of the data from the study take place and by whom will it be undertaken?

Analysis will be undertaken in the my home, by me, the researcher.

7.4 Who will have control of and act as the custodian for the data generated by the study?

Dr Garry Squires, my supervisor, will act as custodian of the data.

7.5 Who will have access to the data generated by the study?

Myself, as researcher, and the University of Manchester.

7.6 For how long will data from the study be stored?

2 Years 0 Months

Give details of where they will be stored, who will have access and the custodial arrangements for the data:

Voice recordings will be stored until the Viva is completed as encrypted MP3 files

Encrypted data held on researcher’s computer for two years

8 Reporting Arrangements

8.1 Please confirm that any adverse event will be reported to the Committee

Yes

8.2 How is it intended the results of the study will be reported and disseminated? (Tick as appropriate)

Peer reviewed scientific journals yes

Internal report yes

Conference presentation yes

Thesis/dissertation yes

Written feedback to research participants yes

Presentation to participants or relevant community groups yes

University Library yes

8.3 How will the results of research be made available to research participants and communities from which they are drawn?

Each participant will receive a written copy of their interview transcript, a copy of the theme summary table and my written interpretation of the interview. This may be amended during the process of participant validation.

I plan to write up recommendations as a proposed framework for understanding and action, and I will present this to the three separate groups of contributors at a focus group meeting, for those who wish to attend.
8.4 Has this or a similar application been previously considered by a Research Ethics Committee in the UK, the European Union or the European Economic Area?

No

If yes give details of each application considered, including:
Name of Research Ethics Committee or regulatory authority:
Decision and date taken:
Research ethics committee reference number:

N/A

8.5 What arrangements are in place for monitoring and auditing the conduct of the research?
Ongoing supervision from my academic supervisor and professional colleagues

Will a data monitoring committee be convened?
○ Yes
○ No

What are the criteria for electively stopping the trial or other research prematurely?
It would only be stopped if something unforeseen has arisen and cannot be remedied

9 Funding and Sponsorship
9.1 Has external funding for the research been secured?
No

9.2 Has the external funder of the research agreed to act as sponsor as set out in the Research Governance Framework?
No

9.3 Has the employer of the Chief Investigator agreed to act as sponsor of the research?
No

9.4 Sponsor (must be completed in all cases where the sponsor is not the University)
Name of organisation which will act as sponsor for the research:
University of Manchester

10 Conflict of interest
10.1 Will individual researchers receive any personal payment over and above normal salary and reimbursement of expenses for undertaking this research?
No

10.2 Will the host organisation or the researcher’s department(s) or institution(s) receive any payment of benefits in excess of the costs of undertaking the research?
No

10.3 Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share-holding, personal relationship etc.) in the organisation sponsoring or funding the research that may give rise to a possible conflict of interest?
No

11 Signatures of applicant(s)

Philippa Grace..............................................……………… 08/06/11............
Signed Date
12 Signature by or on behalf of the Head of School

The Committee expects each School to have a pre-screening process for all applications for an ethical opinion on research projects. The purpose of this pre-screening is to ensure that projects are scientifically sound, have been assessed to see if they need ethics approval and, if so, go to the relevant ethics committee. It is not to undertake ethical review itself, which must be undertaken by a formal research ethics committee.

The form must therefore be counter-signed by or on behalf of the Head of School to signify that this pre-screening process has been undertaken.

I approve the submission of this application

Signed by or on behalf of the Head of School

Date
Appendix A2: Letter granting consent from University Research Ethics Committee

Secretary to Research Ethics Committees  
Room 2.004 John Owens Building Compliance and Risk Office  
University of Manchester  
Tel: 0161 275 2206/2046 Oxford Road  
onFax: 0161 275 5697 Manchester, M13 9PL  
Email: timothy.stibbs@manchester.ac.uk

Ref: ethics/11134

Dr Garry Squires  
School of Education,  
A6.6 Ellen Wilkinson Building.

30th August 2011

Dear Ms Grace and Dr Squires,

Research Ethics Committee 4  
[Grace, Squires: Understanding and Responding to the Needs of Young People Who are Parentally Bereaved Through Substance Misuse: A Phenomenological Study (ref. 11134)]

I write to thank you for coming to meet the Committee on 27th July 2011 and to confirm that it gave the above research project, after the submission of amendments / clarifications, a favourable ethical opinion.

This approval is effective for a period of five years and if the project continues beyond that period it must be submitted for review. It is the Committee’s practice to warn investigators that they should not depart from the agreed protocol without seeking the approval of the Committee, as any significant deviation could invalidate the insurance arrangements and constitute research misconduct. We also ask that any information sheet should carry a University logo or other indication of where it came from, and that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a university computer or kept as a hard copy in a location which is accessible only to those involved with the research.

Finally, I would be grateful if you could complete and return the attached form at the end of the project or by the end of June 2012.

We hope the research goes well.

Yours sincerely,

Dr Deborah Bentley  
Secretary to University Research Ethics Committee 4

UNIVERSITY OF MANCHESTER

COMMITTEE ON THE ETHICS OF RESEARCH ON HUMAN BEINGS
Appendix B: Research Literature for Participants and Referrers

Appendix B1: Information leaflet for children and young people
Appendix B2: Information leaflet for parents and carers
Appendix B3: Consent to be contacted about the research form
Appendix B4: Consent to participate in the research form
Appendix B5: Establishment consent form
Appendix B1: Information leaflet for children and young people

Request to Take Part in Research

Educational Psychology Team
Education XXXXXX
What is this research for?

This research is to try to understand how children and young people deal with life when their parents die because of drug or alcohol abuse, and to try to plan some ways of giving support which will be helpful to young people.

Why am I doing this?

There are different ways of offering support for people, but if the support is to be helpful we need to understand more about young people’s experiences, and to hear from them about the kinds of things which have happened to them, and what they think might be helpful.

We are also asking parents and carers, and professionals to help us with this research.

Who am I?

My name is Philippa Grace. I work as an educational psychologist with Education XXXXXXX, so I work with young people aged 3-19 years, mostly when things are tough for them in school. My job involves trying to help young people and those around them to make sense of what is going in their lives, and to find ways of helping them cope when times are tough.

What would I have to do?

Step 1: Decide if you want to meet to talk about this - only people who choose to take part will be involved. Sign the consent form if you would feel OK about me contacting you. If you are under 16 I will also ask your carer to sign this consent form.

Step 2: I will contact you to arrange to meet with you. I will meet with you where you feel comfortable, and where it is convenient for you. You can ask me any questions you wish – and you can pull out if you want to.

Step 3: Meet with me, and talk about how things have been for you since your parent’s death, and things that have helped or not helped. You can change your mind, or stop taking part at any time. I will check that you feel safe about doing this. I need to tape record our meeting, so it is important that you feel OK about me doing this. This meeting will probably take about 45 minutes long. We will meet somewhere which is easy for you and hopefully where you feel comfortable.

Step 4: I will think about what you and other young people have said, and start to put some ideas together. I would like you to meet with me again, to see if you agree with what I am suggesting, and to correct any mistakes I have made.

Why do I have do it?

You don't!!!! Nobody should feel they have to do this. It is your choice. I hope some of you feel you can help as I really want to hear from young people themselves. Sometimes professionals and carers think they know what will help without checking it out properly with young people.

What happens if I feel upset afterwards?

If I think our meeting is upsetting you I will stop, and arrange for someone you know and trust to meet you. In any case I will make sure that either the person who gave you this leaflet, or an adult you trust or your parent or carer meets you after our session. I will also arrange more support for you if you ask me to.
However, people often find it quite helpful to have the chance to talk about personal issues.

**What will I get from doing this?**
If you take part in this research you will, I hope, be helping other young people to receive help and understanding to deal with their parent’s death. **You will be contributing to professionals’ understanding** of what it feels like to lose a parent because of drugs or alcohol, and how to cope with this.

I will be asking you if you feel you have gained anything from taking part in this project.

**Who is checking to make sure you are doing this professionally?**
I am a chartered educational psychologist and am registered with the Health Professionals Council and the British Psychological Society. I have to follow the codes of conduct of these organizations. This means I must not put you at risk of any harm.

I am doing this as part of a course at the University of Manchester. The university have to check that I am doing this study properly, and am not putting you at risk of harm. If you are interested in taking part in this research please fill in the form attached to this leaflet.

If you would like more information before agreeing to meet with me please email me philippa.grace@educationXXXXXX.com, or text/phone me on 07718025057.
Appendix B2: Information leaflet for parents and carers

REQUEST TO TAKE PART IN RESEARCH

EDUCATIONAL PSYCHOLOGY TEAM
XXXXXXX COUNCIL
What is this research for?
This research is to try to understand how children and young people deal with life when their parents die because of drug or alcohol misuse, and to try to plan some ways of giving support which will be helpful to young people.

Why am I doing this?
At present there is very little research into the needs of children and young people whose parents die through substance misuse, or the needs and concerns of those who care for these children, and their families.
This research is aimed at trying to fill this gap, to help other children and young people who may be bereaved in this way.

Who am I?
My name is Philippa Grace. I work as an educational psychologist with Education Xxxxxxx, so I work with young people aged 3-19 years, mostly when things are tough for them in school, and with their parents/carers and teachers. My job involves trying to help young people and those around them to make sense of what is going in their lives, and to find ways of helping them cope when times are tough.

I am doing this research as part of my professional role, because educational psychologists work to overcome obstacles to young people’s development. It is part of a professional doctorate in educational psychology with the university of Manchester.

Why are you asking parents and carers?
People have different views on the same experience. In order to build a helpful way of working it is important to try to build in the perspectives of people who help young people and children to deal with life, and the bereavement. I am asking young people over the age of 14, professionals who work with young people who are bereaved through substance abuse and families and carers to help with this research.

What would I have to do?
If you decide to contribute to this research I will arrange to meet with you, and will ask you about your experiences of dealing with this bereavement, and your opinions about things that are helpful and unhelpful. We would meet between 1-3 times.

Step 1: Decide if you want to meet to talk about this - only people who choose to take part will be involved. Sign the consent form if you would feel OK about me contacting you.
Step 2: I will contact you to arrange to meet with you. I will meet with you where you feel comfortable, and where it is convenient for you. You can ask me any questions you wish – and you can pull out if you want to.
Step 3: Meet with me, and talk about how things have been for your child since their mother or father died, and things that have helped or not helped. You can change your mind, or stop taking part at any time. I will check that you feel safe about doing this. I need to tape record our meeting, so it is important that you feel OK about me doing this. This meeting will probably take about 45 minutes long. We will meet somewhere, which is easy for you and hopefully where you feel comfortable.
Step 4: I will transcribe our interview make notes about what we have discussed. I would then like to meet with you again to make sure that you are happy that these notes do reflect what you think and what we discussed. I will make changes to the written accounts after we have met.

Everything we discuss is confidential and I will make sure all information is anonymous. That means no-one will you know you have
been part of this research and what you said, unless you tell them yourself.

Why do I have to do it?
You don't!!!! Nobody should feel they have to do this. It is your choice. I hope some of you feel you can help, as I really want to hear from parents and carers.

What will I get from doing this?
If you take part in this research you will, I hope, be helping children and young people to receive help and understanding to deal with their parent’s death. You will be contributing to professionals' understanding of what it feels like to lose a parent because of drugs or alcohol, and how to cope with this. I will be asking you if you feel you have gained anything from taking part in this project. People often find it quite helpful to take part in research interviews.

Who is checking to make sure you are doing this professionally?
I am a chartered educational psychologist and am registered with the Health Professionals Council and the British Psychological Society. I have to follow the codes of conduct of these organizations. This means I must not put you at risk of any harm.

I am doing this as part of a course at the University of Manchester. The university has to check that I am doing this study properly, and am not putting you at risk of harm. The University of Manchester Research Ethics Committee has scrutinized my research. If you are interested in taking part in this research please fill in the form attached to this leaflet.

If you would like more information before agreeing to meet with me please email me philippa.grace@xxxxxxx.gov.uk or text/phone me on 07807 591786
Appendix B3: Consent to be contacted about the research form
Understanding how children and young people deal with parental bereavement, when the bereavement is from substance misuse

Consent to be contacted about research project

Thank you for reading the attached leaflet, and for thinking about taking part in this research.

Filling in this form does not commit you to taking part in the research, but it means that you give your permission for me to contact you.

I agree that you may contact me about this research.

<table>
<thead>
<tr>
<th>Yes / No</th>
<th>Initials:</th>
</tr>
</thead>
</table>

Your name:____________________________________________________
Your address (so I can write to you - I will not visit you at home unless you request this)____________________________________________________________________
Your phone / mobile number:____________________________________
Your email address:____________________________________________

I understand this does not mean I have to agree to taking part in the research.

<table>
<thead>
<tr>
<th>Yes / No</th>
<th>Initials:</th>
</tr>
</thead>
</table>

I have seen the information leaflet: Request to take part in research project:

<table>
<thead>
<tr>
<th>Yes / No</th>
<th>Initials:</th>
</tr>
</thead>
</table>

I would prefer you to contact me by:

phone      mobile      email      letter
(please circle the best way of contacting you)

Where would you prefer to meet with me? (e.g. at your home/ my office/ somewhere else?)____________________________________

How did you find out about this research?

____________________________________
Appendix B4: Consent to participate in the research form
Understanding how children and young people deal with parental bereavement, when the bereavement is from substance misuse

Consent to participate in research project

Thank you for meeting me, to talk about the research project.

This form is to show that we have talked about the research project, and that, having met me, you are willing to talk to me and to contribute to this research. **You are free to change your mind at any time.**

Please circle yes or no in answer to the following, and write your initials in the box.

I have read the leaflet “Request to Take part in Research”

<table>
<thead>
<tr>
<th>Yes / No</th>
<th>Initials:</th>
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I am willing to be interviewed by Philippa Grace, about how children and young people cope with parental bereavement, when the bereavement is from substance misuse

<table>
<thead>
<tr>
<th>Yes / No</th>
<th>Initials:</th>
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I understand that the interview will be taped and I give my consent for this

<table>
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<tr>
<th>Yes / No</th>
<th>Initials:</th>
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I know that I can change my mind at any time, and stop the interview

<table>
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<tr>
<th>Yes / No</th>
<th>Initials:</th>
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</table>

I know that all information in the written report will be anonymous, and my words may be quoted directly

<table>
<thead>
<tr>
<th>Yes / No</th>
<th>Initials:</th>
</tr>
</thead>
</table>
Your signature:

---------------------------------------------------

Signature of your parent or carer if you are under 16:

---------------------------------------------------

Signature of researcher:

---------------------------------------------------

Thank you.

Philippa Grace: Doctorate in Educational Psychology, University of Manchester.
Specialist Senior Educational Psychologist, Educational Psychology Team, Xxxxxxxx
Telephone: 07807 591786 or 01274 385772
Email: philippa.grace@educationXxxxxxx.com

Registered Health Professional as a Practitioner Psychologist
Chartered Educational Psychologist British Psychological Society
Appendix B5: Establishment consent form
Understanding how children and young people deal with parental bereavement, when the bereavement is from substance misuse

Consent for research to take part on the premises of your establishment

I am undertaking some research about the needs of young people who have been parentally bereaved through substance misuse. This research has been scrutinized and approved by the University of Manchester Ethical Review Board and there are safeguards in place to protect the wellbeing of participants.

This form indicates that you, as head of establishment, give consent for me to interview participants on the premises of your establishment. Each interview will take 45-90 minutes.

I give consent for Philippa Grace, Specialist Senior Educational Psychologist, to conduct research interviews on the premises of this establishment, as part of the above research project.

Your name:____________________________________________________
Name of establishment:__________________________________________

Your signature:_________________________________________________
Signature of researcher :__________________________________________

Date: ________________________________________________________

Thank you.

Philippa Grace: Doctorate in Educational Psychology, University of Manchester.
Specialist Senior Educational Psychologist, Educational Psychology Team, Xxxxxxx
Telephone : 07807 591786 or 01274 385772
Email: philippa.grace@educationXxxxxxxx.com
## Appendix C:1 Sample of interview transcript prior to analysis

Katie’s Story: 20/09/11

<table>
<thead>
<tr>
<th>Emergent themes</th>
<th>Transcript</th>
<th>Initial thoughts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>PG:</strong> And so Katie, I know nothing about you or your story- ok- um except that Amanda from Young Carers told me that you’d lost your mum –is it your mum​</td>
<td></td>
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<tr>
<td></td>
<td><strong>KT:</strong> Yes my mum yeah</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>PG:</strong> Through substance misuse</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>KT:</strong> Yeah Alcohol yeah</td>
<td></td>
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<tr>
<td></td>
<td><strong>PG:</strong> How old were you when that happened</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>KT:</strong> Oh (deep sigh)– it was - I think – I were – eleven? (questioning voice) I think just eleven? Eleven bordering twelve? I think I were twelve actually. Yeah</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>PG:</strong> Right right right…so can you tell me what it’s been like for you dealing with your mum dying</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>KT:</strong> (I hardly finish before Katie starts her story….. it’s been really hard because after me mum we’d lived together so basically had to clear all the house and stuff em I wasn’t up to it and um I didn’t realize at the time but now ah reflecting on it I can see that I was in denial from bout 7 months and I didn’t ever really realize it because um its like it even… and….it really upset me this actually that because even in her funeral I wasn’t fully aware that she’d died (questioning, emphatic voice) and I was there thinking I was laughing because it d’you know to me it was like I didn’t have a handle on it I felt I could just look up she’d be there and um</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>PG:</strong> Right</td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>KT:</strong> everyone else you know cos they were grieving for her and I was upset but I wasn’t crying through the whole funeral I was just um a bit upset that I’d realized</td>
<td></td>
</tr>
</tbody>
</table>
sort of oh this is the funeral day – but I’d laughed more and and I think that I had my friend afterwards the meeting afterwards you know the meeting afterwards and everyone else was crying and I was just laughing with her and it was like times afterwards like in citizenship lessons at school when they did like y’know sex and alcohol there were sometimes that I though ok right try your best and I didn’t want to tell anybody and I just sat there and broke into tears and then I went sir can I go outside and he went yeah and it was in about three citizenship lessons cos we do about it a lot and I just had to move

PG: yeah

KT: out of class cos I was so upset and um I got upset a lot because I missed my mum and that I couldn’t hug her anymore

PG: Right

KT: and then me and my grandma she did counseling for it as well and we both got really upset cos we thought what could we have done? could we have taken her to hospital?

PG: Right

KT: and I felt worse because I that day, the last day I saw her we had an argument because, because she because she was going into hospital to see what was wrong with her because she had a ballooned belly and um she said right get me up early with you and she can have a bath and get stuff ready for there but because she was tired I thought I’d let her sleep and um I went and got myself ready and stuff and I woke her up and we had an argument and she went “Katie come to shops with me” cos she was um she didn’t like being outside and um I said “no I’ve got to go” cos my friend picks me up and I was waiting for fifteen (emphasizes 15) minutes at the bus stop and anyway I went to my mum “no I’ve got to go” and we had an argument and the last thing I shouted through the door which I pray to god she heard was “I love you” and I left and I knew that she’d
be going to hospital that day and that I
were staying at my grandmas house and
then um I was in the hospital with my
grandma and we sorta of called each other
and sorry I’m going on about it now but
we went into the hospital to see her but I
didn’t actually see her because my uncle
went in and said you don’t want to see her
cos you know she were jerking cos you
know they’d taken it out and em that was
in about 3 o’clock in the morning and um I
were there till um we went home and the
Saturday morning I didn’t have er….well I
was ….I was asleep and my grandma went
in and she went I’ve had a call from your
Uncle Ross and your Mum’s dead and
from that point I….I didn’t cry I just
looked at the door thinking she’d walk
through the door and then we went
through the process of like moving the
house and I couldn’t sort through any of
the stuff um cos I cried all the time and I
went to through the things and
whenever….. anyone…. and moments that
I thought my mum would have loved I
went into tears and I haven’t grieved and
my grandma …..the hospital told us about
counseling we got onto that and that sort
of helped but it didn’t ….it did….. cos I
got to talk about it( questioning tone) and
it was that I think that sort of helped me
accept that she has gone

PG: Right

KT: and grieve more….and ..it … it just it
shocked me so much to the system
and…..and people went Katie you’ve
coped so well with it (voice rises as
though imitating their voices) (chokes)

PG: Right:

KT: and I used to say thank you it but it
was the time that everyone thought we
need to stay away from her she’ll be upset,
but I wasn’t ……and the times that I was
people – at that time I wanted to talk about
it but people you know they didn’t cos
they you know they didn’t want to upset
me or anything and then afterwards when I
suppose I had …I had started grieving and
I was upset people had just…. had got
over that……. they thought I’d have
grieved by now and it was just the fact that it took me so long to start to grieve about her it’s been a long process since…… really

PG: Yeah

KT: That – slightly bemused gentle laughter

PG: And is it still going on?

KT: Yeah…but I think,…..I don’t really know because I don’t know you’re never fully over it

PG: Yeah

KT: But it’s it’s a lot easier now cos I’ve got used to my life with my grandma and I’ve been to Young Carers which has helped massively to sort of talk through it all and just get so relaxed over it

PG: Right. So having somewhere safe to go and some stability?

KT: Yeah. I think I sort of realize now that my grandma has always been the backbone of us. She’s always been there if I needed anything. She’d take me to school because she …. my grandma was always there. My mum needed money She didn’t want to give her it. My grandma’s a stubborn lady. But my mum. She’d be there. My grandma would be there She’d be there my grandma. She’d be there to give me tea and stuff cos there’s times with my mum when I didn’t go with tea I had to steal money to get food from my own mum to give her it when she was y’know wanting a drink or whatever. And I think with all this it’s made me realize that if my grandma wasn’t there right now and if she’d….because she’s elderly, if she died now and I was with my mum I would’ve been in a worse mess

PG: Right

KT: and I used to think…… I think it has worked out for the better…… and knowing that I had my grandma there and
school helped. It doesn’t help…cos like some people don’t wanna go to school because they have people talking about it but I had friends who were here to support me and stuff and to me as soon as I went to school I forgot about my mum

PG: Right

KT: it was a complete – for me – it was different it was just I could go there, forget about my troubles, y’ know learn, have fun with my friends then go home and I suppose now I feel bad that my grandma’s…that…….I have to live with my grandma cos she’s so old and she has to take so much from me as a teenager (jokingly) and like me being stroppy all the time and she shouldn’t have to cope with that. But if I didn’t have my gran there and my uncles I don’t know what I would have done

PG: Right

KT: Because I just think it would have been worse and d’you I think may…many children after their parents have died they go off the rails and y’know become badly behaved and there’s times that I just wanted to do that……

PG: Yeah

KT: just go to school and just scream but I know that people think that um I don’t want to do that for my reputation because I like the fact that people think…. y’know….. I don’t care what people think of me but it’s the fact that people thought I’d grieved over I didn’t want to you know start being all upset all about it so I think that you know it was nice to come home and have time to myself and with my grandma but the thing is that my grandma isn’t an open huggy person she doesn’t…. she never liked talking to my mum about it

PG: Right

KT: I mean to me about my mum

PG: Right
Long pause

PG: So there’s loads of things I want to ask you

KT: Oh go for it! (laughs)
PG: So um I’m going to start by … it sounds like you were saying at first like you were so numbed by what had happened that you didn’t…… it’s like you were going through the motions of life in a way

KT: Yeah

PG: Like going through the funeral without really thinking about it.

KT: Oh yeah. It was like I was there (emphatic) but in my head I wasn’t. At the time I felt I was but I suppose… you go to a funeral and you think like this is the time I’m finally going to say to goodbye but

PG: Right

KT: It wasn’t to me. I didn’t. She wasn’t alive. She wasn’t dead. She wasn’t anything. She just she was my mum I knew that. And at times I’d talk to her like she was still present

PG: Right

KT: Yeah I suppose it was a numbing thing because I thought right I would like accept. If anyone asked about my mum I’d say yeah she’s died but I wouldn’t say y’know she’s at home home eating dinner whatever. She just. She wasn’t. She wasn’t in my head at all. And it’s like that Saturday that I got told I went to the library with my friend (pause)

PG: Right

KT: and.. I had to…. I was happy as Larry with her and everything and I had to go and break the news to my friend’s family and they were all crying and I was crying but yet it wasn’t hard for me to tell them it
was because I knew them and I didn’t want to make them upset but it wasn’t hard for me to say my mum’s died at all……because it just…hadn’t clicked.

PG: Right: So it was kind of like you were being very matter of fact about it?

KT: What does that mean?

PG: Kind of matter of fact. Like suppose not being emotional about it in a way you just said it like um you’re teas out my mum’s died

KT: Sort of yeah. Yeah. I broke it…..well I didn’t just want to say my mum’s dead.

PG: Yeah

KT: I said it quite – I’ve got some bad news and I could… I could feel myself welling up about it

PG: yeah yeah

KT: but I don’t know if this makes sense……not as much as a person who’d accepted it would

Right

KT: Because if a person was saying they knew what I thought was that they’d really clog up in their throat but I could just feel a little bit getting upset I said so “I’m sorry to say but um my mum passed away this morning” and then um they just broke down in tears and it got me upset but just saying it doesn’t get me upset because I was just admitting it

PG: Yeah. I suppose……was that kind of like you’re trying to make sense of it now and I suppose what you’re saying is it was too hard to make sense of it so you just put it somewhere for a bit

KT: I…I thought it was….I never thought about that until just now. I think I really realized that I’m um I was not accepting it

PG: Right……right
KT: Because then I thought it was normal. No I don’t mean normal, it’s just …..yeah. I completely blanked it and I realize I think I was too shocked to even accept it so instead of trying to process the thought ‘my mum’s dead’ I just stuck it away and didn’t even attempt to think my mum’s dead I need to do this that and the other.

KT: I think I just completely shut it off. I didn’t want to face it and telling people and help my grandma and people when someone dies people don’t go up to them and ask them all stuff and I think that makes it sort of worse cos people say oh Katie we’ll give her a break we won’t go up to her we don’t want to upset her anymore (emphasises more) and that didn’t help me because if somebody had said it….if they’d of talked to me about it when it happened I’d ve accepted it because nobody talked abut it….and people doing their own thing to do the planning……I didn’t

PG: Right

KT: I just shut it off and thought well I don’t need to look at it like that

PG: You mean like people planning the funeral and stuff

KT: Yeah I think…… I mean I went to do the flowers and stuff and and it was just talking abut my mum’s favourite things and the florist was lovely I sort of said ‘Oh look at them, grandma. They’re my mum’s favourite’ and I didn’t say they were mum’s favourite, I said they are mum’s favourite and she was like ‘would you like one?’ and I had them and I was like ‘wow.’ I thought she’d love these. Picking out …..going for the funeral and I knew it was a funeral but to me it wasn’t my mum’s funeral.

KT: I couldn’t accept that the person I’d loved had gone.

PG: Yeah

KT: Cos you knew that we’d done so
much together. It’d just been me and her.

PG: Right

KT: And she wasn’t there.

PG: Yeah?

KT: I remember at the time contemplating……thinking that. I just sort of thought……I didn’t plan ahead. I didn’t think anything. If someone said ‘we’ve got a funeral to go to’ I’d go to the funeral and I got my clothes ready and I didn’t yeah I went very numb in thought….I didn’t think much about anything at all.

PG: And then over time you did start to think about it and you say you did start to grieve?

KT: Yeah. It was a good few months until one day I was at a friends um we went we were at the pub cos we were about to go to her house cos we were meeting up and I can’t remember the situation but I was crying I started crying and hearing what she said “Oh Katie, you haven’t grieved properly.’ And that sort of obsessed my mind thinking I haven’t grieved at all I don’t know about it?(questioning tone) and then…… I suppose I didn’t know how?…. I tried but I didn’t oh d’you know I you know….. how……. I just thought……oh ok she’s dead…and ..and I sat there and I said ‘my mum’s dead my mum’s dead”. I can say it now…

PG: ummm

KT: but I didn’t understand how I feel. I think it….. I can never feel that actual click.. where I realized? (questioning tone)

PG: Umm

KT: And I still don’t think I’ve fully realized? (questioning tone)

KT: I just think I’ve accepted it more and I’ve always realized you know that she’s completely dead but I’ve got the full
knowledge that I know what happened to her……….and you know I’ve got better at the understanding of the whole thing of the whole stuff………. I suppose I sort of have realized more. I’ve realized that now. Like……. (resolutely) If someone asked me now where I live I’d say ‘with my grandma.’ ‘Why do yo live your grandma? ‘Cos my mum’s dead.’ I can say it knowing that she is this time (rushed and breathless as though demonstrating how matter of factly she can relay this information)

PG: Yeah

KT: This time. Before I could say but just not have any meaning to it.

PG: So is there – or was there a difference in your mind between like knowing the facts of your mum having died and the cause of her death and its somehow different from knowing or feeling that your mum’s gone….she’s not there any more?

KT: I think. (long pause) Yeah. When I was there I was with there you know well I lived with my grandma. We’d always just planned that I’d stay while my mum was in hospital I was just going to stay with grandma and that was normal. And then. I don’t. Because it wasn’t the usual thing for me to go to my grandmas. I wasn’t like you say like with the week some families would stay at my mum’s for a week then stay at my grandma’s. That didn’t happen. So I didn’t expect. I thought that by Sunday, or Monday I’d see my mum so if it was set then I suppose I’d realize because um I’d be thinking oh my mum should be coming to pick me up now but she’s not because um well because that wasn’t the norm and um I suppose I didn’t I didn’t feel that she was gone. I didn’t feel anything until it was afterwards that. And I started my counseling and a bit before that I realized late at night that um it yeah it was like three months afterwards that it was just one night I was laid in bed and my mum’s arm wasn’t around me and I squeezed myself and there’s millions of times that I’ve cried
I haven’t cried my self to sleep cos I’m not that type of person. But I’ve cried. ‘Cos I’ve thought where’s her arm, why isn’t her arm there and sort of. That tore me apart sometimes. And

KT: But the thing is my grandma…… wasn’t……… a huggy person….she could hug me but it wouldn’t fill that gap of a hug. So I don’t think I felt missing her…… um…… for a few months as well as the denial, till I actually realised because I was used to getting hugs off her and stuff until I actually realized that I hadn’t got her any more. And I felt. And when somebody else hugged me – like a massive (emphasises massive) hug I felt…. I felt strange….. it was like” I haven’t been hugged in ages” and if anyone hugs me now I hug them like the death out of them because like I don’t get hugs off my mum anymore and my gran doesn’t give me them. So I…..I definitely think that at the time I didn’t feel anything umm I didn’t but the fact was ‘my mum’s dead.’. I didn’t think about little details like feeling she was gone till months afterwards really.

PG: And now that absence of physical affection it’s becomes like a…..

KT: Yeah. It’s had an effect on me because you know this’ll sound a bit weird but when kids d’you know kiss their mum I’m like ‘that’s a bit weird isn’t it?’ because and I remember like going there and I can feel……in my head I can know how it’ll feel to hug her (questioning tone?) and cos you know I know how her body feels and stuff and I’d just grab her and give her a hug and I can feel the way her arm would be at night……But it’s not there. (slowly)

And I suppose that is that is the worst part of it…..because I realize… and that’s at times I can remember running to my gran and giving her hug and she’s like ‘are you alright?’ and I’d sort of explain … and she says ‘is it your mum?’ And I go ‘yeah’ because she knows I’m missing her and I just want to hug her. It’s times like it’s just realizing. It’s worse – the hugs
(questioning and empathic) talking about it it’s realizing I don’t get hugs off my mum anymore that’s made me sort of realize it more. Cos she wasn’t there. And that. That really hurt. At times. It wasn’t. I can’t. I don’t get so upset I can’t recover from it. It’s just. She isn’t hugging me and then I’d break down in tears. I’d be totally emotionally upset I’d get you know I’d recover over it with my grandma and I really felt ‘she’s gone now.’ (very emphatic) That’s when I most felt the impact. Really.

PG: Yeah. Cos that’s very powerful sense of loss…..

KT: Yeah

PG: Like the loss of that physical affirmation of your relationship

KT: Yeah

PG: When you talked about grieving you talked about….how did you know when you were grieving?

KT: I think

PG: What is that?

Its when you think of…to me… I think it’s when I’m just thinking about the times we’d had and then knowing she was gone and having a good cry about it and looking through photos and then it was so upsetting this time as well, but talk…… and thinking through the memories, the good and the bad, talking through them with my grandma occasionally.. it ......helped but it didn’t?  Because she she sort of…..she didn’t disown her as a daughter but she you know she’d done alot and she wouldn’t… you know I think she more gave up on her side of life and the end. My mum’s life.. And I think if she have just. If she’d. And we’ve had arguments about this. If she’d have just….if she’d have paid more attention it’ve been better for my mum. She’d try and done a little bit more but she was so used to taking all this crap of my mum that she didn’t want to?
KT: So I talked through with my grandma about it and it was just understanding that these memories would be the (emphasises) memories. There wouldn’t be any more. And. And the fact that my day to day life wouldn’t involve her. And stuff we’d do wouldn’t happen anymore. And that. It was…. I was grieving I suppose as I was settling into the new life. I was. I think that more kicked it off as. Cos I was used y’know staying with my grandma but it being a prolonged thing I suppose. I don’t think I had a starting point from when I grieved. I I can’t think of one.

PG: Sure. Yeah…..

KT: Or when I’ve ended. It’s been a slow steady process and I think I started it without fully realizing and I think it’s just been where I’ve been settling in, working in school and it’s just those times when I’ve been thinking about mum and looking through the photos and talking to people about it really that I’ve felt it more, that she’s gone, and grieved. But. I’d say I’d finished grieving but I don’t think I have done. I don’t think I every will.

PG: Tell me about that

KT: I think. I just think. I don’t know cos everyone says grieving’s accepting it? And I understand that I didn’t accept but now I just feel yeah…. She’s gone but it’s I don’t know. I was just used to living with gran and I think it’ll be more the future that…cos she’s not there….made me… as I’ve been planning towards my future I’ve accepted more of it

PG: Yeah

KT: because I…..I used to mark every 13th, every 13th of every month, cos she died on 13th, for the first year( voice tremulous) and then I used to tell my grandma oh it’s the thirteenth today and I used to get upset pretty much every day of that month and then I suppose each half a year milestone was meet I’d notice and
then helped grieve as well cos I talked to my counselor about it right how you doing at six months? So the second year I sort of did it six months but with a few months in between and I think, I think by my fourteenth birthday I’ve accepted it more. I think I’ve grieved more. By sort of letting go well I realized at Christmas – that gets me upset and the actual you know September the 13th and stuff and the six month mark for me getting from every month to just doing six months I felt I’ve accepted it. That felt a bit of – it I’ve accepted. And then as now I’m fully-well occasionally I’ll know it's the thirteenth but I’m on to six and twelve and I think, the fourteenth birthday to me, I felt I’d accepted a big chunk. I felt I’d fully accepted she had gone.

PG: Right. Can I ask you? When you say you’d accepted she’s gone what do you mean by that?

KT: um I think in my head I realised in that instead of blocking it out, if somebody asked me who you know didn’t know about it ‘how’s your mum? I could realize and instead blocking going um I could say she’s gone and realize she has passed away and she isn’t there no more. And I could have meaning behind that. And I could fully realize

PG: Right. Right.

KT: Is that um does that explain it for you?

PG: I think it does it’s kind like you’re saying at first you just block it out and just say things quick

KT: Yeah without really realizing that I did it

PG: but now its like more genuineness…….genuine’s the wrong word ‘cos it’s not like you were being phoney before

KT: Yeah but no but yeah like I understand what you mean by that because to me I feel that I know what I’m saying
instead of just somebody telling me she’s gone and you live here now and me just going ‘ok.’ And I think I do (emphatic) live here now and this is the daily basis thing.

PG: So it’s kind of like now you own it and it’s part of you?

KT: umm

PG: And you own the acceptance that your mum’s dead.

KT: Yeah. Cos Im more used to my life and when I compare it to what it used to be like I really realize……instead of….. oh this is my new house. I think…That is the past.

KT: But. My mum’s never been past. But to me this is my new section. My mum has you know gone now. And I think it was really when I became a teenager when I hit thirteen I was I’m a teenager now and that sort of kicked of the process of me accepting it more, and then fourteen I really realized. I’ve gone a year. Another year. And I thought of what it would’ve been like with my mum. And I thought. That was. That is the past. She is you know. It wasn’t as if I instead of saying she likes it…oh she would have liked it ………because I have more acceptance in what I’m saying instead of…………. I’m probably repeating myself loads of times but I know that she is never going to come back. And I know that I am never going to have that hug.

PG: Yeah.

KT: And of course it still upsets me but it I definitely know for a fact the ……….. that she isn’t coming back.

PG: Right. Yeah.

KT: Otherwise. Whereas before I thought of all the possibilities that she could. And I was still thinking about. ‘Cos at the time when they told me she probably would die -my brain just went into overdrive. I thought of everything way to save her. I
thought- blood transfusions- I'll give her a kidney! I’ll give her my liver! You know. I’ll come in every week with her! I’ll be her carer! I don’t care. She can live in bed I’ll give her food. D’you know what I mean? I thought of every way to keep my mum alive. And then….. After she died……..There were certain areas when I could accept it. Well not accept it but think about it. Whereas I thought how I could’ve saved her. What’d happened to her? As in she’d died but I thought, “Could she have been saved by this? Could we have done that?” …Could we’ve gone to hospital? … ……whereas daily life didn’t hit me at all it was just me thinking over and over again “Could we have saved her?” And stuff like that that hurt. That I was thinking about more than the daily life about it and I just …. I think that now I can think of all areas of it and I understand more.

I always thought that when you finished grieving you’d feel something inside you like an actual switch

PG: Right

KT: That I suppose I’m always thinking ‘is it going to happen? Or has it happened already?’ I suppose I was thinking I could hear it and I was thinking right I can fully just accept it. Right. Get over it. But whereas there, d’you know when you sort of d’you know when you’re in between a switch and you press it I felt like that and I felt d’you is it going to be a switch? Is it going to happen?. I thought………I suppose really I thought grieving was going to happen automatically. Cos sometimes I just expected right I’ve gotta I’m just gonna break down in school I’m gonna run down the corridors screaming my head of. I’m gonna break down….I’m gonna be a horrible girl and I’m scream at teenagers, I’m gonna swear. I’m gonna. I thought I’d really go for the rampage. I expected to less of me than myself. I suppose. I thought right she’s you know I’m gonna go mental. I’m just gonna hit the roof….do what everyone says because I didn’t want to accept it. I just thought I didn’t feel like I um I was
going to get through it.

PG: Is that what you thought grieving was?


PG: Yeah.

KT: And I just thought it’s gonna be one day where I’m gonna wake up and I’m gonna be in tears and I’m just going to think about it all. And there’s just gonna be like a week of tears and everything’ll remind me of her and I’m just gonna cry and cry and cry and talk about her and cry more and it’ll just be one day I’m gonna wake up and think I’ve accepted it.

That never happened. And I thought why isn’t it happening? And I thought well is it me thinking too much about grieving and alright should I stop and try put my mind on other things. But I always thought it’d just happen. I thought myself would do it. I didn’t think I had to think about it really. Just thought it would happen.

PG: So you had this idea that there’s normal grieving and you had this idea that it would happen to you, rather than being something that you did in your own way.

KT: I suppose yeah. I thought that when you do I suppose it’s going back to the acceptance cos you say oh someone’s died and you can both think that and know it and then you grieve I suppose? But I suppose because I never accepted it, that’s why I didn’t grieve. But I suppose I was always waiting, expecting to just burst into tears about it. And when I never did it sort of came to a shock about it and umm

PG: So for you that numbness wasn’t part of your grief

KT: Yeah – No - Ooh - I dunno - I suppose I just think that – I think it might have been actually – I never realized – cos you get told your mum’s died and I didn’t accept it I just shut it away and I … when
I started to talk about it I realized that I had shut it away. Anyway I sort of explored those feelings you know about what I’d done and then I really I thought back to the funeral I can’t remember it. I couldn’t. There’s hardly things that I can remember. I can hardly remember going to see her. All I can remember is like going down the corridor and seeing her and not collapsing but just seeing her face and I didn’t go in……. I just turned around and crying and er just having no control I just went you know when it all goes and I just remember there’s like er beds she was there and I just remember walking there falling into the side of the wall and the nurse coming to pick me up and I was just there in absolute tears and everyone was staring at me that’s all I remember and then we were walking back and we were given this leaflet and the doctor came to talk to us, and I was looking out of the window that wasn’t even a proper one and I just staring out of the window. I was just breathing it all in. I wasn’t listening. I wasn’t taking notice and then we were driven out in the car and we were talking about I suppose grieving and funerals and stuff and I wasn’t there. I thought. I couldn’t. I felt as if I wasn’t there (very final)
I felt as if it was happening to me but my mind wasn’t thinking it was. It gets back to that. I just think yeah. I shut off. I didn’t think about being upset. I saw my mum and it just that was the one point. That was the short time that I thought ‘yeah, she’s dead.’. That face. I can imagine it now. Her face. It it hit me. That’s why I fell over on the floor. Because I was so shocked. And then everything after that point didn’t sink in. So I think I realized it was shock. And I couldn’t think about it. And then I didn’t want to think about it until,„ I suppose I realized that I hadn’t grieved at all. I hadn’t sort of been upset because I’d just been getting on with life. I hadn’t I hadn’t been thinking oh right I need to grieve oh right I’ve got school, I’ve got a funeral and stuff.

PG: And sometimes…..it’s really interesting you say that cos I think it sums
up….um one of the things that young people do say is um they do get on with life and it’s too much um they need to get to a safer place before then can do that.

KT: The really weird thing was that all my life I’d been……me and my mum……my mum had friends at the pub and I wanted to be there and um I’d walk past the pub and I wanted to go past and people say “Hey Katie” and had have that connection….again…… and I er it was me. I didn’t say this to anyone but I wanted everyone to come to me to talk about it. I was……..I wasn’t upset but everyone was just quiet. They wouldn’t they would shut off because they didn’t want to upset me and that annoyed me the most. Cos I just wanted to talk about it and think oh she’s dead why should I be upset? I wanted to talk about her all the time and it was worse because I wanted people from the old life to come to me and talk to me about it but they didn’t and and it was horrible because I’d walk past the pub and it was just like I wasn’t there and and I sort of realized not the beginning but now that they don’t they didn’t know me as me, they knew me as Fiona’s daughter that ur …..they knew me as Katie, Fiona’s daughter, but not as a self I was always with my mum and I was going why should they talk to me and it was like I saw someone from the past ages ago, and I hugged him? It was amazing because I thought it was just that connection again. And he went I’m sorry about your mum” and I went, “It’s fine.” And I just went absolutely with a beaming smile on my face and

it’s even when I saw Nick , which was my mum’s ex boyfriend and um he was abusive towards her and stuff and I hated him. I hated him with all my soul. And I saw him…..right outside….I gave him the most biggest hug of my life and I never wanted to let go because I thought you’re the closest thing to my mum and I wanted to carry on hugging him for ages. And then he sort of went, and I went back and I just had school.

I suppose when I thought we need to leave
her was the worst part.

And thinking there’s a lot to do. I just thought “Right. Get on with life!” And I thought I was. I can’t. I sort of. And.

I felt I needed to be there for my grandma and that I knew I needed to do stuff to be happy for her. And that people weren’t there to talk to me like with the past. That I couldn’t accept it so. Well. I could accept it but I mean people weren’t there……… so I couldn’t have that connection to really think about her. So I just went home for school and forgot about feelings that and just……

PG: Like you were plodding on and plodding on?

KT: And there was one day I just had a massive breakdown and it freaked my grandma to death because um I was just crying it was like two hours and and I was shaking and I was saying of everything we’d ever done all the bad stuff and good stuff and that my grandma had never heard of before and what I describe as my plate of mash…was building up… as in like um I had my mum, then I had my grandma, then I had school and all the stuff that I now could realize all the stuff in the past that had gone on that I hadn’t done, cos like when you’re a child you don’t realize that your mum’s been hit, you don’t realize that’s domestic abuse, or realize that you’ve been talking about, so that’s like another scoop, and then like school and homework another scoop. Then looking after my gran another scoop – scoop. I was like grandma, this mash on this plate. It’s too much.

And she was like sat there? Like crying. Like seeing me upset. And she said I need to get you a psychotherapist – psychiatrist – cos she didn’t know what was wrong with me. And I just think all that’s built up. And I needed the most biggest cry of my life. To get it all out. I say to get it all out. But it wasn’t. Cos it was still there. But sort of to say it all. Just like blurt it all out. It was……
PG: Like make it real? Instead of keeping on trying to deal with it by denying it?

KT: Yeah put it in my head

PG: (we talk in synchrony)

KT: Yeah. Just tell her what was in my mind.

PG: Yeah

KT: And that’s really hard to sort of say. In words. What’s going on in your head. So that’s why I use like the plate of mash like all this stuff is going on and it’s too (emph) much…to handle…

PG: Umm

KT: And it’s too much. I want to deal with it. But I can’t. But where do I begin? And I was just saying where do I begin? What do I do? I can’t go from the top and then. This is getting confusing here but from me saying I’ve got all this mash. I don’t know how to deal with it I thought “I can’t deal with it. So just forget about it all over again.” And then that made it worse.

PG: Right.

KT: Because um I’d accept that I had all these problems but yet I wouldn’t start to accept and try and deal them out. And so I sort of. We went to counseling and I sort of did. And. And….it sort of helped just getting that first bit off. And it calmed me down more. And I realized I could sort of do it?

PG: Right.

KT: It was just having the confidence to just talk through it. And knowing that somebody was going to listen. Cos I’m an open person so I’ll blurt it out to anybody and I just wanted someone just to talk to me about it. And um talk to me what I was going through and that sort of helped me deal with it. A bit. Well. To start dealing with it. So I could sort of deal with the mash. And the plate really
PG: And say sort of this is a massive plate in front of you.

KT: So massive

PG: How are you doing it? Yeah. And it is alot to deal with. So what’s helped you to deal with it?

KT: I think. Having school’s helped. Because to me school is a place I can go away and you know be upset about it and get away from the problems. Go to school. Learn stuff and…..when I’m at school I don’t think about it. It’s not on my mind and sort of I suppose it’s a bit worse at home because I knew I had to go back and deal with it all. And I had to you know. Cope. And do stuff at home. And then me thinking right well I can’t deal with it. And at school it turned into an excuse which was worse because I thought right I have to um…

KT: Um I had a history essay and the teacher was like why aren’t you……. And I can’t remember if I had done it or not and I thought well yeah – if she’s got summat to say it’s cos I’ve got to look after my grandma. It’s not my fault. *(Voice rises indignantly)* You know. I’ve been through all this rubbish and all and you know. Because. It was ages after my mum had died and I suppose people get. People should’ve. People expected me to of grieved. And I just wanted to say “Yeah well.” It says in my file I live – well I look after my grandma and I just wanted people to think well yeah I live with my grandma and I have all this stuff. My mum’s just died and I just…..and in in. That turned into an excuse for school

PG: Right.

KT: And in the end I’m not doing homework and getting upset about my mum and stuff and it it was a bit like a cycle I suppose. But what helped was was talking to my grandma a bit. But that…that sort of got it worse cos she kept saying…. herself….talking to a counselor….. talking to friends and telling
them about it and not having someone who… like my grandma was …I’d talk to her but she’d talk back….

PG: Yeah

KT: And um so did the counsellor talk back. It was just my friends who’d sit and listen and I’d just say it all. And I’d say stuff that shocked them and stuff that they knew and stuff that they didn’t know and they were shocked but they’d just listen *(appreciatively? wonderingly?)*

KT: And that was great. And when. Another big step was thinking which has been recently was from Dee ‘cos – she put me onto Young Carers which and that was the most biggest help I’d had.

PG: Right

KT : It was era amazing just to. We did a group called Hidden Harm. About drug and alcohol abuse. And I was the only one with a deceased parent?

PG: Um. Yeah?

KT: And that was great cos I could tell them my experiences?

PG: Yeah.

KT: And they’d go through the same but a completely different thing. It was nothing like I expected. It was…..I thought it’d be y’know all proper and… you’d talk about everything but it was so relaxed. It was just. I don’t know…..I just felt these people are my friends. I can talk to them about anything and.

Another big massive milestone that I’ve just had is that my gran and I always used to talk. Why couldn’t we….. What could we have done to save my mum. Could’ve changed her drug use….taken her to …. you know gone to whereever. And I told my grandma recently when we were upset about her, “Grandma, there’s nothing we could have done.’

PG: Right.
KT: We could have taken her to hospital. Yeas. We could have taken to hospital. She’d have discharged herself. It was really realizing that I really couldn’t have done anything. There’s nothing. Because we knew that if she didn’t do it. She didn’t do it for my granddad. She wouldn’t do it for my grandma. She wouldn’t do for me.

PG: Yeah…um..

KT: She…………

Knock at door – times up You’re welcome to stay but I’ve got to get off.

Chat about this..........warning we might get locked in!!!!!

PG: Well we’ve been talking for nearly an hour now Katie

KT: Have we (astonished tone) Time Flies! Sorry for jabbering on!

PG: Don’t be sorry. It’s been really interesting. Have you has it been alright for you?

KT: Yes. I love it. It’s fine.

PG: Will it…. Can I meet you again?

KT: Yes. Fine……You’ve only had half the story!!!!!!!

PG: And there’s loads I want to ask you.

KT: Yeah. Fine.

PG: And what I’d like to do as well is just kind of write down what you’ve said and what you’ve talked about. And have a really good think and then come back and talk about it and check out

KT: Yeah

PG: Cos there’s all sorts of ….some of the choices you’ve made…… (Another door interruption!)
KT: Yeah there’s loads of things I’d really like to kind of ask you and think about. Especially like you making a choice not to act out…like you know you were saying kids – when they grieve- they go off the rails but you didn’t….

KT: I suppose um I sort of expected a bit that I would do yeah…because I suppose it’s fairly stereotypical that you see it on TV…. You see kids just go beserk and you know throw chairs around and I think I did something slightly immature in school. And a teacher said, ‘Katie. I’m shocked. Y’know. I wouldn’t expect you to do that.’ And I was like I was what can I do to the teacher to say sorry when I was….I you know ‘I didn’t mean to’ and I suppose I wanted …. The reputation that I’d build. I didn’t want to destroy it. But yet there was times. There’s times now when I just want to be so immature and just……be a kid again. Because half of my life I haven’t been.

PG: Yeah. And that plate of mash is so massive.

KT: (voice rising) somebody understands the plate of mash. Yeaaaahhh. But my grandma was like whoa. She was scared about it.

PG: I kind of like the mash thing as well cos it's kind of like all fuzzy round the edges and it could collapse

KT: yeah… it gets into everything it goes everywhere

PG: Like it collapses into itself, and you can’t tell one bit from another…

KT: It’s messy as well

PG: …It’s a very powerful metaphor.

KT: laughs

PG: It’s been great meeting you. Thank you so much I’m glad it’s been a good experience for you.

KT: I hope it helps your study.
PG: D'you know. I think it's really going to. But I it would be great to come back.

KT: I don’t want to meet you in school time and take you out of your lessons.

PG: Oh OK. I can, if you would rather.

KT: No after is best.

PG: Sounds like you’re pretty motivated.

KT: It’d be better out of school. My Education’s a big thing for me. That holds my future.

PG: So……..we fix a date……..and a place (5/10/11 at 2.30pm)
Appendix C2:

Samples of initial transcripts with annotations

C 2:1Alana pp 8-12
Tell me you'd lost your dad as well?

Yeah. He died last year.

He died last year?

Yeah.

So um. A lot of very complicated events to go... I won't say make sense of it in a way you can't make sense of them. And so...

Can I ask you... I'm gonna ask you a really general question. Tell me the story of what it's been like dealing with your mom dying?

Um. Um. Well, I don't really like to talk about it. It's one of the things that makes me angry and upset all the time. Sometimes I use other excuses. But... I don't know. Sometimes I wish that I could go back to then and find out what happened and try and stop it. And it's too hard. I can't really deal with it. In some aspects. But in other ways I can. I mean, that's what people say. But deep down it's really affected me. In school. Even outside of school on the streets, with my friends and family. And now I'm just trying to get back on track again.

How are you doing that?

Putting my head down. Getting on with my work. Using some motivation.

Right. And um. You said you didn't put it down to your mom...
dying. When you are angry, or whatever?

Yeah.

But it sounds like you know that's what's happening. So other people might see you being madly. And think Alisha's off on one.

Yeah. That's what they do.

And you kind of think well I've got all of this. That's going in my heart.

And I don't know where to put all this stuff.

Yeah. I do think that. And it's not even that you don't want to think about it cos I mean....I don't wanna forget about my mam.

But it's even harder when I'm the spitting image of her. And it's even harder when everyone who knows me or knows my mam says constantly isn't she like Lynette? Or... I was in town the other day and this woman came running up to me shouting 'Lynette, Lynette, Lynette.' And I turned round and I just looked at her kind of funny. And she said 'Oh sorry, I'm so sorry. I thought you was my friend Lynette. But you can't be cos she's died now.' And then said, 'well that's me mam.' And everybody says I look like her. And people sometimes think I am her. So it's even harder to try and let it go.

Just...that kind of idea about letting go, Alisha. You said on the one hand you don't want to let go and forget, but on the other...
I just want to remember her for the goodness. And forget about everything bad that’s happened.

Sure.

When I watch the news stuff and read about things that happen to women and stuff getting raped, it just brings it all back. And it just makes me think about all the time.

Sure.

And I don’t wanna remember that.

Sure. But those complicated memories are interfering with your ability to remember the good times? The mom who cared for you?

So now, see... So it sounds like there’s a tension there. On the one hand you’re blocking. On the other hand, there’s this sense that if you block it’s gonna spill out in getting angry, or being nasty or un... and that’s ultimately that’s destructive for you.

Ultimately it interferes with your ability to remember your mom and grow as a person. Am I right what I’ve said?

Yeah. Definitely.

And then I’ve worked with a few kids who’ve been stuck in that place. It’s too painful to remember. But they haven’t been able to make sense of it really. But it sounds as though you have. Is that a fairly recent thing do you think? Or have you always had that?
Yeah, I've always had that.

So is it like you've got to make a choice and you've got to try and fight if you like the traumatic memories. So you like have to know they are there so you can deal with them and um

Sometimes it's that bad that I get ill.

Right?

I always get depressed really badly. I don't wanna come to school. I don't wanna do anything. It's not as bad as sometimes when I make it out. But it is to me. Cos it happens to me constantly. Then it seems to me that my life's just gonna be like this for ever.

Right. The emotional battle of trying to keep strong when things are so hard?

Yeah. And every time summat had gone wrong as well I automatically think well ever since my mum's died everything's going wrong so I may as well just give up cos that's... it's just an automatic thought that comes into my head?

So once you've had one blow it decreases your resilience if you like?

Yeah. Yeah.

To cope with the next blow.

Yeah... And confidence and everything. As well. I don't really want
So put in any effort cos I've just got this thought in my head that everything will go wrong anyway.

So in a way it's easier not to try?

Yeah.

Got then you don't have to deal with it. Not working out how you want?

Yeah.

And if somebody praises me for sommat that I do I won't accept it.

Tell me about that!

Like if I'm praised for my work at school I won't like be happy about them telling me that they're happy with my work or my behaviour. I just carry on. The same. I don't why I really don't have a clue why. That's why. That's one thing I really can't understand. Why I still am the way that I am.

What do you mean the way you are?

Aggressive.

So one the one hand you say you don't know why you are the way you are. Aggressive.

Yeah.
C2:2 Emma pp 1-3
Elizabeth's Story: 15/09/11

2) I introduce myself, engage in a bit of small talk and then thank Elizabeth for agreeing to take part in the research, and explain why I am doing it to try to understand more about what it's like dealing with your mum or dad from drugs or alcohol, and hopefully use this understanding to help other kids in who this has happened to

5) Elizabeth agrees, explaining that she had help so did the other kids to have help like her it helped.....

4) She starts to tell me about the help she had at primary school, before I had gained consent and got her agreement to record her, about school not knowing how to help, and they got her a book and helped to make a volcano and create a memory box.

5) I switched on the recorder while she was in mid flow.....

6) EC: Um a diary, and a volcano thing and I did read all I felt a bit better after each one and you had to put a picture of person who died at the front and then a picture of you and then a picture of person who died then a picture of something they liked and a picture of something you liked and how you felt and everything and I didn't know and I didn't know and I didn't know and I didn't know I felt bit better each one and yeah it were fun

7) Then I started getting y'know great at school from y'know kids had parents and I didn't and they were like you don't have a mum you don't have a mum and I'd proper flip out

8) um were um headmaster and everything were coming um and then he was like why you sat there and I'd get proper mad at him because I'd throw chairs and everything

17) as Elizabeth says, "I didn't know"
9) PG: Um, umm

10) EC: And, and it was just like really hard and I just needed someone to talk to but I don't really have that many people to talk to back then, so they put me into counseling, I got kicked out of counseling coz I went broke the counselors room and they put me in anger management, I got kicked out of anger management for being angry, one day I had my family sound me nearby

11) PG: Right

12) EC: I had my family it's just family what you need people to talk to...

13) PG: And did talking help?

14) (sharp intake of breath) Not at first cuz you don't want to relive the memories like when my momma, my mom died in kitchen and it was me and my brother what found her and my counselor was like you found her does that make you feel a bit worse? And she was getting me mad and everything and that's why I ended up punching my counselor

15) PG: Right cause she was asking you questions that made you focus on

16) EC: Yeah that made me like go back to it

17) PG: Right

18) EC: I didn't want to go back to relive those moments......so questions aren't always that good.

19) PG: Right
20) EC: But ice cream is good. Yeah ice cream. If you got a kid, that's mum's died just give em a bucket of it. (wryly)

21) PG: There's something in that isn't there. Making sure kids have got some nice things — there's some balance

22) EC: Indulging in ice cream and indulging in chocolate, it did help cos I did it when my mum died. It was comforting with me

23) EC: When I'm upset I just gotta get a bucket of chocolate and then you put weight on a bit and then you get like a bit about being fat, y'know everything just goes down. I pan when someone dies. (Heavy sighs)

24) PG: I'm gonna ask you to tell me more about that, in a bit. You know I'm recording everything don't you?

25) EC: I kinda guessed

26) PG: Because you started talking straight away and telling me things that were really important, I wanted to kinda capture them and not forget them but you

27) You just need to put your initials here to say that you know I'm recording this and you're ok with that

28) Yeah

29) PG: And you know you can change your mind at any time...send me away
C2.3 Katie 4-7
there till we went home and the Saturday morning I didn't have a call, well I was. I was asleep and my grandma went in and she went. I've had a call from your Uncle Ross and your Mum's dead and from that point, I... I didn't say I just looked at the door thinking 'she'd walk through the door and then we went through the process of moving the house and I couldn't sort through any of the stuff and cos I cried all the time and I went through the things and whenever... anyone... and it was that I thought my mum would have had. I went into the hall and I haven't got used to that yet... the hospital told us about counselling we got used to that and that sort of helped but it didn't... it did... cos I got to talk about it, questioning when and it was then I think that sort of helped me accept that she has gone.

PG: Right.

KJ: and grieve more, and... it just it shocked me so much to the system and... and people went 'are you're expected so well within' (voice rises as though mimicking their voices) 'choked.'

PG: Right.

KJ: and I used to say thank you for but it was the time that everyone thought we need to stay away from her she'll be upset, but I wasn't... and the times that I was people... at that time I wanted to talk about it but people you know they didn't... cos they know they didn't want to upset me or anything and then afterwards when I suppose I felt... I had...
started grieving and I was upset people had just... had got over that... they thought I'd have grieved by now and it was just the fact that it took me so long to start grieving about her it's been a long process since... really.

PG: Yeah

KT: I had... slightly bemused gentle laughter

PG: And is it still going on?

KT: Yeah... but I think... I don't really know because I don't know you're never fully over it

PG: Yeah

KT: But it's sort of easier now and I've got used to my life with my grandma and I've been to grief and Young Carers which has helped massively to sort of work through it all and just get used to living with it.

PG: Right. So having somewhere safe to go and some stability?

KT: Yeah. I think I sort of realize now that my grandma has always been the backbone of us. She's always been there if I needed anything. She'd take me to school because she... my grandmother was always there. My mum needed money. She didn't want to give it. My grandma's a stubborn lady. But my mum, she'd be there. My grandma would be there. She'd...
PG: Right

KT: it was a complete — for me — it was different it was just I couldn't go there, forget about my troubles, you know, learn a lot — and my friends then go home and I suppose now I feel bad that my grandma's... that... I have to live with my grandma cos she's so old and she has to take so much from me as a teenager (rolling eyes) and like me being snappy all the time and she shouldn't have to cope with that. But if I didn't have my own there, my uncles I don't know what I would have done.

PG: Right
KT: Because I just think it would have been worse and if you think any many children after their parents have died they go off the rails and you know become badly behaved and there's times that I just wanted to do that......

PG: Right

KT: Just go to school and just scream but I know that people think that can I don't want to do that for my reputation because I like the fact that people think you know I don't care what people think of me but it's the fact that people thought I'd grieved over I didn't want to you know start being all upset all about it so I think that you know it was nice to come home and have time to myself and with my grandma but the thing is that my grandma she can never forget or never does she never likes talking to my mum about it

PG: Right

KT: I mean to me about my mum

PG: Right

KT: Long pause

PG: So there's loads of things I want to ask you

KT: Oh go for it! (laughs)

Kira says she cops it upon e wrong there & her

They helped around her so she didn't go off the road so she had parental dealing with they didn't like coming to school

Kira has the power to choose for she before regard to good

Color me telling I didn't matter

Wish he the power to choose from she before regard to good

This explanation is important is it about what other thinks of her or is it more about the kind of person she used to be I have this really hard of her to mention so it's good to have me & him clinch she doesn't have to cry so kind.
C2.4 Charlotte pp 31-33
and I know that it was painful for him to get out of and or am that's what I saw in my sister. She couldn't get out of it and you could see it in her eyes and everything she... no matter how hard she tried she couldn't.

201. So you and your mum and your brother and your little sister have got all those lessons to deal with...

202. Yeah

203. And do you all try and be strong and not talk about it in front of each other.

204. Um. Me and my sister do talk like once every... once every few months or something and she might get happy and say do you remember this do you remember this because I can't really remember too like it puts a smile on her face but I can't... any one always used to be... here for the good memories because I was like young and my sister was like young as well so but I'd rather be like this age and I don't know like just to be... if he'd dealt with those it would've been easier to understand.

205. Umm

206. And yeah but I think because, I was like not young but like yeah young like it's harder.
It's harder. I think losing someone at a younger age is harder to deal with while if you lose someone at an older age, even though it's like the same thing that I think, people when they're younger don't know how to overcome like emotions and like mixed and it's a similar thing but older people they don't know what to do even like I've seen that in my mom like she couldn't cope with it either like sleeping on one side of the bed by herself and sometimes just waiting like her dad was there cos she's still got his dressing gown on the side of the bed.

207. PG: Umm is that hard for you when you see it?

208. ST: Yeah. It's like um I've got um something that my dad bought me that he didn't buy my little sister or anything like um it's up a teddy that says like 'darling's little girl' and I didn't want to lose it.

209. PG: And these things that you've got, when you look at them how does it make you feel?

210. ST: Happy cause it's like my dad bought one for me and like he didn't buy one for anyone else and like yeah obviously I was proper daddy's girl. And like I don't think my brother or my sister were... like cos they would sell my Mum stuff but I...
211. PG: Right. So that grief is different for you?

212. SL: Yeah.

213. PG: And is it well like you said it's harder if you lose your mum or the younger ones like it's harder to understand.

214. SL: Yeah um you think um you don't knew whether to be happy or sad and um if it is its like with my sister she was just five or six and she were just happy I didn't understand why. But I think it's cos she didn't understand that well um. It even helped like... No matter how hard people tried to explain to her like he's not coming back she just thought he's just gonna walk through the door and he's just going to be there and

215. PG: Yeah

216. SL: Now she understands

217. PG: Yeah. And when you're little like that you don't have those memories for that long so like you might think about it and feel sad but like five minutes later you'll be playing and you'll be
Appendix C3: Table of themes and illustrative excerpts for each contributor

C3:1 Alana’s tabulated themes  
C3:2 Katie’s tabulated themes  
C3:3 Emma’s tabulated themes  
C3:4 Charlotte’s tabulated themes
Appendix C3:1 Alana’s Tabulated Themes

Alana’s Tabulated Themes

Alana as a protector, protecting herself from people who don’t understand, protecting herself from fear and uncertainty of what life might bring. Most of all protecting her mother from what others say and think about her

Links to managing memories  Alana works hard to create affirmative memories of her mother, of the mother she was before she got into drugs ‘when she used to be good’, and also of her intentions which were thwarted by her drug addiction. Focuses on her mother’s battle to get clean for Billy and how well she was doing. Talks positively about all the memorials they have to her mother in the house, the photos, the rose tree and her brothers tattoo on his back. Her memories seem much thinner- some are about not having the boundaries that her grandmother put in. When I ask her about her mum keeping in touch there’s a vague response. Alana hadn’t seen or been in contact for six months before her mum died, until the day before her mother’s death when she told her, “I hate you. I hope you die.’

Alana talks about the pervasive depression and wonders why she is still that way she is. It feels as though this is to with the almost impossible talks of being able to make sense of the life she leads

Also link to the life she should have had ‘ how things were meant to be’

How life should be is another theme and links to Alana’s struggle to assert her ownership of her own life, to take control, to get on track after being off the rails

Grieving includes the four tasks of grief, the pain of grief and how it is expressed (depression and aggression are linked) and denying the reality of the death.

Linguistic themes are about things being ‘hard, and also some contradictions. It’s difficult to capture in the transcripts but in Alana’s voice is a sense of indignation and injustice, especially when she talks about her little brother being adopted, and the way some of the teachers have implied she uses her life story and her mother’s death to ‘get attention’ and so much so that she herself thinks may be she is hiding behind this as an ‘excuse’ for not getting her life on track.

As I listened to Alana’s story I was shocked by how much has happened to her, by the awfulness of her story. This matches with her linguistic theme of how hard life has been how unfair it is that these things have happened  she only uses the word unfair once, when talks about Billy, but the theme of blow upon blow weaves through her story.

No wonder she has to fight to keep safe, even though she doesn’t understand why she still aggressive she can’t imagine dealing with it any other way, and can’t imagine any choice to responding like this. For the others making sense of the death and making sense of the lost relationship is important, building other relationships or feeling the lack of them. Alana’s struggle seems to be more with making sense of the world around her, the hard life which throws bad things at her with no prospect of stopping. She values some of her relationships, with her nan and her granddad, with her friends even though she doesn’t like to do things with them and
<table>
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<tr>
<th>Alana’s themes</th>
<th>Transcript reference</th>
<th>Illustrative excerpts</th>
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<tbody>
<tr>
<td>Talking</td>
<td>1</td>
<td>1: I know that talking about to somebody helps get it off my head&lt;br&gt;1: …To somebody who I will get to know but not know personally like in my family cos I don’t really speak about to them cos I don’t like to upset them.&lt;br&gt;16: Sometimes I don’t like to tell anyone in case they think I’m using it to get attention. Do you get what I mean?&lt;br&gt;16: But there’s a couple of teachers in school who er I wont be able to talk to ‘em. I have done. And then every time something’s happened they’ll say stuff like oh it’s just sometimes using it for attention. Oh your mum and that.&lt;br&gt;24: The only teachers I can speak to and trust are the ones who are like professionals like a job – like people like you, and people who have actually experienced it&lt;br&gt;24: [when I am with a person I trust, a professional.] It just comes out cos I can speak about it without being ashamed. It just comes out. I believe people should know about it. Should know about what happens to other people and that and it should make em wiser and think well I need to keep to myself and then I don’t know it’s kind of hard to explain in other ways. 25: Some people can be really like say stuff….You understand what I mean? So I don’t really tell people what happened. And I find it hard to communicate with some people as well.</td>
</tr>
<tr>
<td>Things that’ve helped</td>
<td>32, 52,</td>
<td>19: This school’s changed my life cos when I used to go to this x school that was bad. I was awful there.&lt;br&gt;32: Nothing could have changed things or helped and there was no alternative to the aggression that Alana showed&lt;br&gt;52: The music really helps Helping people makes her feel wanted and respected.</td>
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<tr>
<td>Helping others</td>
<td>44</td>
<td>44: I think I’ve helped you too.&lt;br&gt;47: I actually do one to one sessions in my house. I just say you can come to my house and I’ll help you.</td>
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<td>Feeling safe</td>
<td>5</td>
<td>5: Most of my life I’ve lived with my Nan. Cos. Like through the week cos my Nan could take care of me better.&lt;br&gt;19: Like when I was a child I didn’t have to worry about anything. Before my mum died. I didn’t have any responsibility. I didn’t need to do anything. I didn’t need to get my self upset because my Nan would protect me from everything bad. Now everything’s out in the open I have to face bad things.</td>
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<tr>
<td><strong>Protector or protected</strong></td>
<td>1,6,20, 21</td>
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<tr>
<td>1:</td>
<td>cos I don’t really speak about to them cos I don’t like to upset them.</td>
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<td>6:</td>
<td>I asked my mum to see the coroner’s report. She wouldn’t show it cos they were protecting me.</td>
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<td>20:</td>
<td>I like to help other people…I take other people’s problems as my own.</td>
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<td>21:</td>
<td>Cos um like some of my friends. I don’t want em to be how I am. Upset about things. So I help them.</td>
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<td>26:</td>
<td>Like my grandad’s mum used to bad mouth my mum all the time. And I were too young. I didn’t have a say in anything.</td>
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<thead>
<tr>
<th><strong>What do others think of me</strong></th>
<th>8, 9, 14, 16, 18, 20, 21</th>
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<tbody>
<tr>
<td>8:</td>
<td>I’m strong. That’s what people say.</td>
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<td>9:</td>
<td>People think I’m being mardy. Think I’m off on one</td>
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<td>14:</td>
<td>I want my mum to be proud of me</td>
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<td>16:</td>
<td>Teachers and stuff tell me I’ll fail. But they don’t know what’s going on. And sometimes I don’t like to tell anyone in case they think I’m using it to get attention. Do you get what I mean?</td>
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<td>18:</td>
<td>And people say I’m too mature for my age.</td>
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<td>20:</td>
<td>With my age group I’ve got a lot of respect from people. Some people find me intimidating. And others see me as like their protection. Like my close friends.</td>
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<td>21:</td>
<td>It [helping] makes me feel wanted and respected by people.</td>
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<td>22:</td>
<td>That’s one thing they told me, ‘you’ll never make it to Prom.’ And I know I will.</td>
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<td>22:</td>
<td>And I wanna make everybody proud of me. That’s the only thing. I don’t care what else happens. I just want to make my family and the teachers who told me that I would do it. Proud.</td>
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<tr>
<th><strong>What do others think of my mum</strong></th>
<th>15:</th>
<th>Obviously my Nan can’t judge her [mum] now because she’s dead</th>
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<tr>
<td>15:</td>
<td>I know she didn’t make my Nan proud</td>
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<td>25:</td>
<td>I know some people would say if she had cancer it weren’t her fault. But I know people would say oh well she was a drug addict and she were a prostitute and no-one told her to do that so it were her own fault that she died. <strong>So I find it harder to cope with. Cos it makes me think what other people would think. More than what I think.</strong></td>
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<tr>
<td>Empathy for mum</td>
<td>2</td>
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<tr>
<td>25: I know some people what’ve like said it……..</td>
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<td>26: so sometimes I do just wish if my mum was going to die then it should’ve been in a different way</td>
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<td>26: Like most of the estate knew my mum very well. Cos she were a respected woman just as much as the bad things that she’d one. A lot of people knew her from when she was younger, when she was good. …….I hate to think of people bad mouthing her and saying ‘Oooh that Leanne and this that the other.’</td>
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<td>26: SO I sometimes wish people not to be able to know that….didn’t know about…that she were a drug addict…..but obviously it’s hard. You can tell when somebody’s on drugs. Her body was really swollen as well. You could just tell in the end.</td>
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<td>26: Other people. It makes me think….well I know they badmouthed her before they died anyway.</td>
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<td>27: I do know that if people can say that about my mum then other people can say it too.</td>
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<td>37: My mum’s funeral…..It were successful…..Definitely. There were so many people there that half of em didn’t get seats.</td>
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<th>My mother as a victim</th>
<th>2</th>
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<tr>
<td>2: She were doing Ripple. It’s like rehab. And she did all the course and she did very well but then Billy my little brother got adopted. And um she went back to how she were.</td>
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<td>27: I do in some ways [blame my mum]. For some things she has done. I think why did you do it? But I don’t blame her as in I hate her. For what she’s done. I just think ‘why did you have to go and do that?’</td>
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<tr>
<th>Family relationships</th>
<th>28</th>
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<tr>
<td>28: Probably my dad brought it around the estate. From the first time.</td>
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<tr>
<td>28: My dad……not being boastful…was a gangster.</td>
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<tr>
<td>28: And it hurts my Nan even more because they</td>
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used to come my Nan’s house and was my mum and their friends.
28: And the worst thing as well is that my uncles Dave and Wayne are heroin addicts.
28: my Uncle Chris has just come out of prison
40: Two more brothers as well…Prison and…… one just don’t get involved

| Injustice       | 5: I’m not allowed to see him [Billy] till he’s eighteen… Ten years.  
|                 | 6: It’s not my fault. So anyway. He got adopted. And then I just. She [adoptive mother] were awful to me. And she says I’m not seeing him. How could they let me see him for a good six months till he were adopted and then cut me off and say I can’t see him  
|                 | 16: I don’t feel like a human being. I feel like I’m nothing. Like I’ve been put on this earth just to be treat badly.  
|                 | 20: I hate bullying or anything like that. Anything that’s bad I see it as wrong cos obviously what I’ve experienced.  
|                 | 26: I know they bad mouthed her before they died anyway. Like my grandad’s mum used to bad mouth my mum all the time. And I were too young. I didn’t have a say in anything.  

| Remembering vs. forgetting | 9: I don’t want to think about it cos I mean… I don’t want to forget about my mum. But it’s even harder when I’m the spitting image of her. Everybody says I look like her. And sometimes people think I am her. So it’s even harder to try and let it go.  
|                            | 10: I just want to remember her for the goodness. And forget about everything bad that’s happened.  
|                            | 10: When I watch the news and stuff it brings it all back. And it just makes me think of it all the time.  
|                            | 10: And I don’t wanna remember that  
|                            | 26: A lot of people knew her from when she was younger, when she was good. That’s when she were… I need to remember the good things so I don’t know…  
|                            | 33: The way it happened as well. That’s what I can’t let go. So that’s what makes me angry. Alana said to her mother I hate you I hope you die the day before she died – she can’t rid herself of this memory.  
|                            | 34: And I remember once I’d said (in a hospital visiting room) ‘Mum, mum I want one of them milkshakes, can you get me one? And it were someone else’s but she got me it anyway. And give it to me. And I drank it in t’ room so no-one could see. I remember……  
|                            | 34: And I remember as well she used to buy these Asian sweets….she ate like 36 cakes altogether.  

| Life is hard           | 6: Worst thing is though. Cos I was so young then |
I didn’t really….I know she were a drug addict. And I knew about the heroin. But I didn’t know anything about the prostitution.

11: Cos it happens to me constantly. Then it seems to me that my life’s just gonna be like this for ever. 11: I think well ever since my mum’s died everything’s going wrong so I may as well just give up cos that’s….it’s just an automatic thought that comes into my head.

11: I don’t want to put any effort in cos I’ve just got this thought in my head that everything will go wrong anyway.

14: I’ve got so used to the fact of everything happening that it just seems normal. So I have to get on with it. With what I’m doing. I don’t have a choice any more to think I’m not getting up. And I’m not going. And I have to do it because if I don’t my mum won’t be proud of me. And I won’t have done the right choice

16: I don’t feel like a human being. I feel like I’m nothing. Like I’ve been put on this earth just to be treat badly.

18: Cos everything that’s happened I feel like an adult. So sometimes I think I have to act like an adult. So my friends. I don’t really hang around em as such, cos they do things that I see as childish. Even though I’m a child I don’t wanna do them things because um so many things have happened. And people say I’m too mature for my age.

19: I have to face bad things….the only bad thing is I have to face……everybody has to do that but I can’t cope with it as much as some people can

19: And what makes me worry as well is that all this has happened in short time. What else is gonna come? Cos I’ve got a long life to live yet. And I know this isn’t the end of the badness cos they’ve got to have some more bad things in, some more. I’m only sixteen.

22: And then I got into loads of bad stuff. I ended up getting really badly beat up. I was in hospital. I had a fractured eye socket and a haemorrhage.

28: And it hurts my Nan even more because they used to come my Nan’s house and was my mum and their friends.

28: And the worst thing as well is that my uncles Dave and Wayne are heroin addicts.

31: And that’s what hurts me even more cos I don’t want to have to face it again. And watch my nanna and granddad do it. Cos that killed me more than anything. And knowing that my granddad had to identify my mum’s body as well. I don’t want the same thing to happen.

31: I think that would just be my grandad’s time and give up. Losing my mum killed him and if he
lost any of them it’d just kill him even more.

Grief | 8, 11, 31, 33, 8: Um. Um. Well. I don’t really like show it. As in. That’s the thing that makes angry and upset all the time. Constantly. I use other excuses. But. I don’t know. Sometimes I wish I could go back to then and find out what happened and try to stop it. And it’s too hard. I can’t really deal with it. In some aspects. But in other ways I can. I’m strong. That’s what people say. But deep down it has really affected me. In school. Even outside of school, on the streets, with my friends and family. And now I’m just trying to get back on track again.

11: Sometimes it’s that bad that I get ill
11: Like depressed really badly. I don’t wanna come to school. I don’t wanna do anything. It’s not as bad as I sometimes make out. But it is to me. Cos it happens to me constantly. Then it seems to me that my life’s just gonna be like this for ever.

11: And every time summat bad goes wrong as well I automatically think well ever since my mum’s died everything’s going wrong so I may as well just give up cos that’s ….it’s just an automatic thought that comes into my head.

11: Confidence and everything. As well. I don’t want to put any effort in cos I’ve just got this thought in my head that everything will go wrong anyway.

Yeah. I’ve had some bad times here cos my emotions haven’t really helped.

18: I’m usually depressed and upset. So then I just. And I see it. In my head. My head tells me I’m being selfish. Sometimes. For being happy. Because of all the things that’ve happened. Then I shouldn’t be happy. I should be sad. And then I just go back to being normal again.

19: I can’t have a good time. And I can’t throw the pain away.

19: Well all this has happened in such a short time. What else is gonna come? I know this isn’t the end of the badness cos they’ve got to have some bad things in, some more.

31: He don’t. He don’t…. he’s [granddad] more of a football maniac and how do I ..I don’t get upset and stuff. One of them ones. He don’t really let any emotion out at all. The only thing he does is get really really angry sometimes….Like he don’t hit anyone or physically assault anyone but he does get very angry verbally….sometimes scares me as well. But I know it’s not his fault why he’s doing that.

33: The way it happened as well. That’s what I can’t let go. So that’s what makes me angry. Cos the week before my mum died I hadn’t seen her for
six months. Bearing in mind she asked me to go and stay with her after I hadn’t seen her for six months. I thought about it after she died. Probably your last chance now. Anyway we ended up having a big argument the next morning and I said to her ‘I don’t ever want to see you again. I hope you die.’ And that’s what makes me think it was my fault. Even though I was so young and everyone says things to their parents. But I shouldn’t have said that. And that’s why I can’t let go of thinking that it was my fault that my mum died.

36: My mum’s coffin was in the front and all the cars had stopped. And just looking. It were awful. It were awful.

37: And yeah it were hard. It were really hard. 37: I left before it ended so I didn’t get a chance to say goodbye. And everyone were going up to the coffin and touching her. But like I didn’t believe it, it felt like a fantasy and it weren’t actually happening.

37: So it were really hard. I were looking at everyone. And I just wanted to tell everyone to shut up and stop crying. Cos she weren’t there. 37: Then you’re completely gone. It were awful.

39: Then when my dad died that got to me even more. Cos even though I didn’t see him …I always used to think well ‘I’ve got a dad out there.’ And my mum dying coulda brought us closer together.

43: Sometimes I don’t sleep

Pain and depression

11: Sometimes it’s that bad that I get ill
11: Like depressed really badly. I don’t wanna come to school. I don’t wanna do anything. It’s not as bad as I sometimes make out. But it is to me. Cos it happens to me constantly. Then it seems to me that my life’s just gonna be like this for ever.

11: And every time summat bad goes wrong as well I automatically think well ever since my mum’s died everything’s going wrong so I may as well just give up cos that’s …it’s just an automatic thought that comes into my head.

12: If somebody praises me for summat I wont accept it.

13: I’ve had all sorts [counselling] it don’t change. …Oh it’s still there. That anger and that pain. Oh it’s still there. Definitely still there. Because I aren’t one of those people that who has to build my anger up. If something happens that I don’t like. Or my body won’t react. I just blow up straight away. And afterwards I calm down. And I think I shouldn’t have done that. Sometimes I do actually just wanna give up. It gets that bad. But it only comes now and again now. It used to be all the time. But when something goes really bad I get really depressed. Go like into my
own world. Before. Last year, it was so bad I were
telling my Nan I were going to kill myself if I don’t
get help.
17: And sometimes as well. When I ’m really
happy I get this thought in my head. Not me doing
it. It just happens. That I’m not being normal cos
that’s not usually me. Being happy. I’m usually
depressed and upset. So then I just. And I see it.
In my head My head tells me that I’m being selfish.
Sometimes. For being happy. Because of all the
things what’ve happened. That I shouldn’t be
happy. I should be sad. And then I just go back to
normal again……being depressed.
18: It’s bad……The fact that…..I can’t have a
good time. And I can’t throw the pain away. They
take over more that the positive.
20: That’s probably what makes my head go a bit
more mad. Cos I take other people’s problems in as
my own.
45: The way I get my emotions out. I’m a rapper.
48: His funeral [Alana’s best friend, Dean, 20]
were really successful. That’s definitely one of the
things that made me rearally depressed last year.
Even….when I found out Dean had died it hurt me
even more than when I found out my own dad had
died.

My relationship
with my mum

14: I want my mum to be proud of me
27: I do in some ways [blame my mum]. For some
things she has done. I think why did you do it? But
I don’t blame her as in I hate her. For what she’s
done. I just think ‘why did you have to go and do
that?’
33: And my mum wouldn’t want me to think it
were all my fault.
34: There were certain things I could do with my
mum that I couldn’t do at my Nan’s house. I don’t
know like. Saying words that I’m not meant to say
at home. Eat stuff that I’m not meant to eat at
home. Do really crazy things with my mum..
Things that kids would enjoy. I’m not saying I had
a bad life at home but things that would make me
happy. Like she used to take me places and go to
park with her and it would just seem that’s how it
were meant to be from the start. And just some
crazy stuff. (Alana describes a time when her
mother, in hospital being treated for anorexia, stole
another patient’s treatment milkshake for Alana.
41: All I can say is I don’t care what happened to
her. I don’t care what she did. Or all of them bad
things. I know she tried to get her life back on track
because I’ve got the evidence.
41: Everyone knows the real reason why my mum
gave up was cos Billy got adopted

Being

9: People think I’m being mardy. Think I’m off on
aggressive

12: I just carry on. The same. I don’t know why. That’s one thing I really can’t understand. Why I still am the way that I am. Aggressive.
19: When I used to go to X school that was bad. I was awful in there. Really naughty. I didn’t have any grades. I didn’t even know a question what you’d ask me. I was so disrespectful and rude.
20: My behaviour and attitude sometimes takes over. And that’s not a good thing to have. But I know that if I keep trying, and keep carrying on then I won’t need to be like it anymore.
20: I know that if I keep trying and keep carrying on then I won’t need to be like it anymore. [i.e. aggressive]
20: [without the aggression] I wouldn’t be where I am now. And...sometimes it’s a kind of a good thing...and it’s kind of a bad thing.
22: Before I came here I was into gangs and stuff. I was in a girl gang and it wasn’t kind of good. And um some of em used to come to this school. But it felt like a family. So it made me feel I don’t know safe and that nothing would happen to me as such. And then I got into loads of bad stuff. I ended up getting really badly beat up. I was in hospital. I had a fractured eye socket and a haemorrhage.
31: He don’t. He don’t. He’s [granddad] more of a football maniac and how do I...I don’t get upset and stuff. One of them ones. He don’t really let any emotion out at all. The only thing he does is get really really angry sometimes...Like he don’t hit anyone or physically assault anyone but he does get very angry verbally...sometimes scares me as well. But I know it’s not his fault why he’s doing that.
PG: So is that like you then?
Yeah. Yeah. exactly.

On track – plans for life

18: I wanna have a life again.
19: I wanna go to college. I wanna make sure I finish through this school...I’ve only been at this school two years and this school’s changed my life.
20: And when I came here. Yeah. I’ve had some bad times here cos my emotions haven’t really been...haven’t really helped. But when it’s good it’s really good. Cos I know that I’ve got the ability to go to college. And go to university? And my behaviour and attitude sometimes takes over.
20: I know that if I keep trying and keep carrying on then I won’t need to be like it anymore. [i.e. aggressive]
22: I need to crack down a little bit. I want to get all my grades. Definitely I want to make it to prom. Cos that’s one they told me. “You’ll never make it to prom. And I know I will. If I carry on being....
And then I wanna go to college. And I wanna make everybody proud of me. That’s the only thing. I don’t care what else happens. I just want to make my family and the teachers who told me that I would do it. Proud.

23: When I got moved from X school the group just split up …**I was able to get on with my life again. And school helped.**

34: I’m not saying I had a bad life at home but things that would make me happy. Like she used to take me places and go to park with her and it would just seem that’s how it were meant to be from the start.

<table>
<thead>
<tr>
<th>Alana as agent</th>
<th>6, 8, 11, 12, 13, 14,</th>
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<tbody>
<tr>
<td>6: After that I knew that there was….there must have been some evidencing my house to prove that um to prove it cos I asked my mum to see the coroner’s report. She wouldn’t show it cos they were protecting me. So they went out and I searched the house for all this stuff and in the end I found it.</td>
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<td>8: And now I’m just trying to get back on track again.</td>
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<td>8: It’s too hard. I can’t really deal with it Watching the news brings back memories that can’t be controlled</td>
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<td>8: Putting my head down. Getting on with my work. Using some motivation.</td>
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<tr>
<td>11: And every time summat bad goes wrong as well I automatically think well ever since my mum’s died everything’s going wrong so I may as well just give up cos that’s ….it’s just an automatic thought that comes into my head.</td>
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<td>12: I just carry on. The same. I don’t know why. That’s one thing I really can’t understand. Why I still am the way that I am. [aggressive]</td>
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<tr>
<td>13: Because I aren’t one of those people that who has to build my anger up. If something happens that I don’t like. Or my body won’t react. I just blow up straight away. And afterwards I calm down. And I think I shouldn’t have done that.</td>
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<td>14: So I have to get on with it. With what I’m doing. I don’t have a choice any more to think I’m not getting up. And I’m not going. And I have to do it because if I don’t my mum wont be proud of me. And I won’t have done the right choice.</td>
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| 15: If I’m in a positive mood and I know I’m gonna do something right then it’s easy [to try to do something to make grand and mum proud]. Even when I have one of them odd days where I can’t cope with other things then no. It’s hard. Sometimes I do actually just wanna give up. It gets that bad. But it only comes now and again now. It used to be all the time. But when something goes really bad I get really depressed. Go like into my
own world. Before. Last year, it was so bad I were
telling my Nan I were going to kill myself if I don’t
get help.
16: I don’t feel like a human being. I feel like I’m
nothing. Like I’ve been put on this earth just to be
treat badly.
17: When I ‘m really happy I get this thought in my
head. Not me doing it. It just happens.
18: When I’m with them I feel more like a leader
than anything.
19: I have to face bad things….everybody has to do
that but I can’t cope with it as much as some people
can
19: What else is gonna come? Cos I’ve got a long
life to live yet. And I know this isn’t the end of
the badness cos they’ve got to have some more bad
things in, some more. I’m only sixteen.
20: And my behaviour and attitude sometimes
takes over.
22: That’s one thing they told me, ‘you’ll never
make it to Prom.” And I know I will.
45: I think I’ve helped you too.
45: I’m trying to point across that everyone should
have an opportunity to do summat they wanna do.
46: I’m gonna put my point across on this
documentary. And hopefully somebody will see it
and understand what I’m saying.

| Off the rails-      | 6 |
| things are hard    |   |

6: It only hit me after about two years. Then I
started growing up. And I went off the rails?
19: When I used to go to X school that was bad. I
was awful in there. Really naughty. I didn’t have
any grades. I didn’t even know a question what
you’d ask me. I was so disrespectful and rude.

| What’s wrong with me? Why I aren’t I better? I am overwhelmed | 8, 12, 13, |

8: And it’s too hard. I can’t really deal with it. In
some aspects. But in other ways I can. I’m strong.
That’s what people say. But deep down it has
really affected me. In school. Even outside of
school, on the streets, with my friends and family.
12: I just carry on. The same. I don’t know why.
That’s one thing I really can’t understand. Why I
still am the way that I am. [aggressive]
13: And I’ve had help as well. I’ve had all sorts. It
don’t do anything. It don’t change. I have got
better
18: It’s bad……The fact that…..I can’t have a
good time. And I can’t throw the pain away. They
take over more that the positive.
19: I have to face bad things….everybody has to do
that but I can’t cope with it as much as some people
can

| Critical life events |   |

15: I want to make her proud. Make my mum and
my Nan proud. And try to be more like my mum.
<p>| Positive from negative | But the good points of my mum and not the bad ones. And think what she would’ve done with her life. Instead of going the bad way. 18: It’s bad……The fact that….I can’t have a good time. And I can’t throw the pain away. They take over more than the positive. 24: I believe people should know about it. Should know about what happens to other people and that and it should make em wiser and think well I need to keep to myself and then I don’t know it’s kind of hard to explain in other ways. 35: And what my mum used to do as well and I can do it as well everyone knows I can eat a full pack of biscuits with a cup of tea. 39: One good thing came out of it though. I have actually got another brother 45: The way I get my emotions out. I’m a rapper. |
| Critical life events | Harrowing story of what happened to Alana’s mother, and why she needed police protection and a new identity  Loss of little brother who was adopted  Loss of mum’s reputation when A finds out, two years after the death, that her mother was a prostitute 7: It [death certificate] says died of er drug overdose….crack cocaine and something pure heroin. That’s what it says. He [dad] died last year. 22: And then I got into loads of bad stuff. I ended up getting really badly beat up. I was in hospital. I had a fractured eye socket and a haemorrhage. Uncles’ drug dependency 36-38: Her mother’s funeral 39: Dad dying – finding out she has a brother |
| Memorial activities | 35: We got her ashes. Some of those are scattered in t’garden cos we’ve got a rose tree for her. All her pictures. Loads of ‘em. Some of my mum’s clothes as well. 36: Describing the funeral 42: A shows me photos of her mother 43: A describes her brother’s tattoo of her mum. 48: A talks about a rap she’s written to remember her mother and the other people who have died. |
| Community support | 27: Cos all my mum’s friends have died from it. Most of em. 28: And everybody who, even my mums age and a lot of people who were close to my mum and her brother’s a lot of em are dead 28: A lot of my Nan’s friends who were their mum’s as well that’s their kids so it’s hard 48: A couple of people have asked me to put their |</p>
<table>
<thead>
<tr>
<th>Contradictions</th>
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<tbody>
<tr>
<td>People say I’m strong but I can’t deal with it</td>
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<tr>
<td>I want to talk but I can’t talk in school</td>
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<tr>
<td>I want to let go of some of the memories but I don’t want to forget.</td>
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<td>I’m still the way I am still aggressive but I have changed, have got better.</td>
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<tr>
<td>CAMHS didn’t help</td>
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<tr>
<td>Things are still hard but they have got better – I’m scared of the future but looking forward to it.</td>
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<td>I deserve good things but I can’t accept them</td>
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<tr>
<td>I make out it’s worse than it really is – but actually I don’t it’s just that other people think I am doing that- think I am using it as an excuse. Am I? Can I make sense of how am I coping with my grief?</td>
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<tr>
<td>Mum not really in touch with Alana – but she represents how life was meant to be. Calls mum ‘mum’ and Nan ‘mum.’</td>
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parent’s names in my song. Cos I know them. Their families really well.
## Appendix C3:2 Katie’s tabulated themes

<table>
<thead>
<tr>
<th>Superordinate theme</th>
<th>Constituent themes</th>
<th>Excerpt reference</th>
<th>Illustrative excerpts</th>
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<tbody>
<tr>
<td>‘I’m powerful’</td>
<td>My reputation: I am who I chose to be</td>
<td>36</td>
<td>36: know that people think that um I don’t want to do that for my reputation because I like the fact that people think…. 128: I expected less of me than myself 195: The reputation that I’d built. I didn’t want to destroy it.</td>
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<td></td>
<td>The thinker: I make sense of my life</td>
<td>8,10, 16, 24, 28, 30, 34, 64, 66, 67, 71, 78, 82, 85, 89, 90, 102, 104, 106, 108, 110, 116, 120, 121, 128, 130, 132, 133, 136, 138, 64: I think I really realized that I’m um I was not accepting it</td>
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<td></td>
<td>I can control my feelings choosing adaptive over maladaptive coping</td>
<td>10, 34, 36, 89, 93, 128, 133, 143, 146, 155, 163, 194</td>
<td>10: I just thought Ok right. Try your best. And I didn’t want to tell anybody and I just sat there and broke into tears and I went sir can I go outside? 34: I think may…many children after their parents have died they go off the rails and y’know become badly behaved and there’s times that I just wanted to do that…… 36: I didn’t want to start being all upset over it so I think that you know it was nice to come home and have time to myself and with my grandma 89: there’s millions of times I’ve cried over it. I haven’t cried myself to sleep cos I’m not that type of person. But I’ve cried. 93: I don’t get so upset I can’t recover from it. 128: Sometimes I just expected I’m gonna break down in school….I’m gonna be a horrible girl …I thought I’d really go for the rampage.</td>
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<tr>
<td>Affirmations from others</td>
<td>18, 36, 194, 18: people went Katie you’ve coped so well with it (voice rises as though imitating their voices) (chokes) 194: A teacher went Katie, I’m shocked. Y’know I wouldn’t expect you to do that. And I was like. I was what can I do to the teacher to say I’m sorry. 195:</td>
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<tr>
<td>My future</td>
<td>106, 210</td>
<td>106: As I’ve been planning towards my future I’ve accepted more of it</td>
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<tr>
<td>‘Proper grieving’</td>
<td>‘Knowing’ and knowing: coming to terms with the reality of the death</td>
<td>8, 10, 46, 48, 50, 52, 56, 66, 67, 72, 85, 90, 104, 106, 108, 110, 116, 123, 8: It’s been hard. I didn’t realize at the time but basically I wasn’t up to it and um I didn’t realize at the time but now ah reflecting on it I can see that I was in denial from about 7 months and it really upset this because even in her funeral I wasn’t fully aware that she’d died (questioning emphatic tone) 48: She wasn’t alive. She wasn’t dead. She wasn’t anything. She was just my mum. I knew that. And at times I’d talk to her like she was still present. 50: She wasn’t in my head at all 66: I completely blanked it and I realize I think that I was too shocked to even accept it so instead of trying to process the thought ‘my mum’s dead’ I just stuck it away and didn’t even attempt to think my mum’s dead I need to do this that and the other. 72: I couldn’t accept that the person I’d loved had gone 85: I just think I’ve accepted it more and I’ve always realized you know that she’s completely dead but I’ve got the full knowledge of what happened to her 87: I can say it. My mum’s dead. Before I could say it but not have any meaning to it</td>
<td>80: 80: I started crying and hearing what she said, ‘Oh Katie, you haven’t grieved properly.’ And that sort of obsessed my mind thinking I haven’t grieved at all.. I don’t know about it (questioning tone)</td>
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</table>
I don’t think I had a starting point from when I grieved. I can’t think of one. I think it’s just been where I’ve been settling in, working in school, and it’s just those times when I’ve been thinking about mum and looking through photos and talking to people about it that I’ve really felt it more, that she’s gone, and grieved. Everyone says grieving is accepting it.

I always thought that when you finished grieving you’d feel something inside you like an actual switch. I suppose I really thought grieving would just happen automatically.

And I just thought it’s gonna be one day where I’m gonna wake up and I’m gonna be in tears and I’m just going to think about it all. And there’s just gonna be like a week of tears and everything’ll remind me of her and I’m just gonna cry and cry and cry and talk about her and cry more and it’ll just be one day I’m gonna wake up and think I’ve accepted it.

That never happened. And I thought why isn’t it happening? And I thought well is it me thinking too much about grieving and alright should I stop and try put my mind on other things. But I always thought it’d just happen. I thought myself would do it. I didn’t think I had to think about it really. Just thought it would happen.

I suppose grieving and funerals and stuff. I wasn’t there. I thought. I couldn’t. I felt as if I wasn’t there. (very final)
Experiencing the pain of grief

8, 10, 12, 14, 52, 80, 82, 89, 90, 138, 142, 146, 147, 153, 155, 157, 163

10: I got so upset cos I missed my mum and I couldn’t hug her anymore.
18: it just shocked me so much to the system.
62: But I could just feel a little bit upset {instead of the strong feelings she expected}.
93: I’d be totally emotionally upset I’d get oh you know I’d recover over it with my grandma and I really felt, ‘she’s gone now.’ That’s when I most felt the impact.
123: I just thought I didn’t feel like I was gonna get through it.
146: KT: And there was one day I just had a massive breakdown and it freaked my grandma to death because um I was just crying it was like two hours and and I was shaking and I was saying of everything we’d ever done all the bad stuff and good stuff and that my grandma had never heard of before and what I describe as my plate of mash… was building up… as in like um I had my mum, then I had my grandma, then I had school and all the stuff that I now could realize all the stuff in the past that had gone on that I hadn’t done, cos like when you’re a child you don’t realize that your mum’s been hit, you don’t realize that’s domestic abuse, or realize that you’ve been talking about, so that’s like another scoop, and then like school and homework another scoop. Then looking after my gran another scoop – scoop. I was like grandma, this mash on this plate. It’s too much.
147: And she was like sat there? Like crying. Like
seeing me upset. And she said I need to get you a psychotherapist – psychiatrist – cos she didn’t know what was wrong with me. And I just think all that’s built up. And I needed the most biggest cry of my life. To get it all out. I say to get it all out. But it wasn’t. Cos it was still there. But sort of to say it all. Just like blurt it all out. It was………

| Adjusting to life after death | 26, 104, 106, 121, 120, 143 |
| I want that connection: Finding a place for my mum in my life | 121, 140, 141, |
| Life changes | 8, 16, 102, 120, 121 |
| Changing experiences of grief | 16, 20, 24, 66, 78, 80, 82, 90, 100, 102, 103, 104, 106, 110, 125, 177 |
| 26: but it’s a lot easier now that I’ve got used to my life with my grandma 138: I hadn’t sort of been upset cos I’d just been getting on with life 143: I just thought ritht get on with life! And I thought I was. I can’t. I sort of. And. I felt needed to be there for my grandma and that I knew I needed to do stuff to be happy for her. |
| 121: But my mum’s never been past for me 140: I saw someone from the past. Ages ago, and I hugged him? It was amazing because I thought it was just that connection again. And he went “I’m sorry about your mum.’ And I went it’s fine. And I just went with an absolutely beaming smile on my face. |
| 16: I couldn’t sort through any of the stuff cos I cried all the time and moments I thought my mum would have loved I went into tears and I haven’t grieved 102: I was grieving I suppose as I settled into the new life |
| 16: I couldn’t sort through any of the stuff cos I cried all the time and moments I thought my mum would have loved I went into tears and I |
haven’t grieved
20: people thought I’d have
grieved by now and it was
just the fact that it took me
so long to start to grieve
about her…it’s been a long
process since really
So I…..I definitely think that
at the time I didn’t feel
anything umm I didn’t but
the fact was ‘my mum’s
dead.’. I didn’t think about
little details like feeling she
was gone till months
afterwards really
177: Another big massive
milestone …I told my
grandma recently when we
were upset about her,
“Grandma, there’s nothing
we could have done.’

| Guilt and         | 14, 100, 124, 178 | 178: It was really realizing
| blame            |                  | that I couldn’t have done
|                  |                  | anything

| Mourning and      | 67, 71, 100, 102 | 67: People doing their own
| mourning         |                  | thing to do the planning
| rituals          |                  |

| She’s mother     | 28, 30, 74, 120, 121, | 28: I had to steal from y
| mother – that     |                  | own mum to get food…It
| says it all      |                  | made me realize if my I was
|                  |                  | with my mum I would have
|                  |                  | been in a worse mess
|                  |                  | 30: I used to think……I
|                  |                  | think it has worked out for
|                  |                  | the better
|                  |                  | 74: Cos you knew that we’d
done so much together. It
|                  |                  | had just been me and her.
|                  |                  | 120: Cos I’m more used to
|                  |                  | my life. And when I
|                  |                  | compare it to what it used to
|                  |                  | be like I really
|                  |                  | realize…instead of……this
|                  |                  | is my my new house…..I
|                  |                  | think. That is the past.
|                  |                  | 121: And I thought of what it
|                  |                  | would have been like with
|                  |                  | my mum

| ‘The gap of a     | 10, 89, 90, 92,93 | 89: just one night I was laid
| hug’             |                  | in bed and my mum’s arm
| Physical         |                  | wasn’t round me and I
| yearning         |                  | squeezed myself and there’s
|                  |                  | millions of times I’ve cried

Physical
yearning
over it. I haven’t cried myself to sleep cos I’m not that type of person. But I’ve cried. Cos I’ve thought where’s her arm? Why isn’t her arm there and sort of….? That tore me apart sometimes.

90: [my grandma] could hug me but it wouldn’t fill that gap of a hug. And when somebody else hugged me – like a massive (emphasises massive) hug I felt…. I felt strange….. it was like” I haven’t been hugged in ages” and if anyone hugs me now I hug them like the death out of them because like I don’t get hugs off my mum anymore and my gran doesn’t give me them.

92: in my head I can know how it’ll feel to hug her(questioning tone) …I can feel the way her arm would be at night…But it’s not there(slowly)

Memories

16, 102

The last thing I shouted through the door and I pray to God she heard was ‘I love you’

102: it was just understanding that these memories would be the memories. There wouldn’t be any more.

Lifelines

My grandma my backbone

28, 30, 32, 36, 90.93

28: I think I sort of realize now my grandma has been the backbone of us. She’s always been there if I needed anything.

32: But if I didn’t have my gran here and my uncles I don’t know what I would have done

School

30, 32, 163

32: I could there, forget about my troubles, you know, learn have fun with my friends

Friends

10,30,32, 80, 167, 169

10: I had my friend and [at the funeral] and afterwards at the meeting everyone else
was crying and I was just laughing with her.

30: I had friends who were her to support me and stuff.

16: that sort of helped [counseling] but it didn’t

20: I wanted to talk about it but you know people you know they didn’t cos they didn’t want to upset me or anything and then afterwards when I suppose I had… I had started grieving then people thought I’d have grieved by now and it was just the fact that it took me so long to start to grieve about her…it’s been a long process since really.

67: when someone dies people don’t go up to them and ask them stuff and I think that makes it sort of worse….if they’d of talked to me about it when it happened I’d ‘ve accepted it more because nobody talked about it…..people doing their own thing to do the planning.

144: I felt I needed to be there for my grandma and that I knew I needed to do stuff to be happy for her.

And that people weren’t there to talk to me like with the past. That I couldn’t accept it so. Well. I could accept it but I mean people weren’t there……so I couldn’t have that connection to really think about her. So I just went home for school and forgot about feelings that and just……

159: I just wanted someone to talk to me about it. And um to talk to me about what I was going through and that sort of helped me deal with it. A bit. Well to start dealing with it.

26: I’ve been to Young Carers which has just helped.
massively to sort of talk through it all and just get so relaxed over it
170: And that was great….it was amazing….and that was great cos I could tell them my experiences 176: I just felt, ‘these people are my friends. I can tell them anything.’

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<thead>
<tr>
<th>Facts</th>
<th>Critical life events</th>
<th>16,138, 146,</th>
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</thead>
<tbody>
<tr>
<td>The facts of the death</td>
<td>6,8, 16, 138,</td>
<td>6: Oh (deep sigh)– it was - I think – I were – eleven? (questioning voice) I think just eleven? Eleven bordering twelve? I think I were twelve actually. Yeah</td>
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</table>
### C3:3 Emma’s tabulated themes

<table>
<thead>
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<th>Superordinate theme</th>
<th>Constituent themes</th>
<th>Transcript reference</th>
<th>Key phrases</th>
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<tr>
<td><strong>Emma’s World: life is unpredictable, I have to accept things the way there are and there’s no way of making sense of things</strong></td>
<td>Critical life events</td>
<td>14,37,43, 45,47,78, 8082107, 117</td>
<td>37:7 weeks and 2 days after my mum died my granddad died. So I was sleeping in I think it were the front room. I didn’t know where I were. I ended up going back living wi me mum. She got with this complete arse beat me up, beat me up and everything 76: when my granddad died 7 week and 2 days later I think I was back in school for a few weeks when I was back in school 80: I were only little at the time so I didn’t really know about it [her sister’s death] But I’ve been told what happened and at the time my mum were married to my sister’s dad but she were shagging his brother so it’s kinda complicated because the guy I thought were my dad died a few year ago a few months ago…so it gets harder again</td>
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<tr>
<td><strong>Loss</strong></td>
<td>14,23, 37,45,47, 80,82,105, 125,</td>
<td>23: y’know everything just goes down the pan when someone dies 37: 7 weeks and 2 days after my mum died my granddad died 80: the guy I thought were my dad died a few year ago a few months ago… 105: my sister died when I just turned one</td>
<td></td>
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<tr>
<td><strong>Life is unpredictable and out of control</strong></td>
<td>7,10,23,3 6,37,39,4 1,4347,49 76,97</td>
<td>7: headmaster……everything were coming 39 I didn’t know where my mind was or owt cos it’s like……. how can I put it…..it’s like you don’t have any control over what’s going on in your life 49 I ended up standing by my mum because at the end of the day she’s still me mum 97 my mum were doing drugs, she were drinking she ended up w cancer I didn’t know how the hell could I cope so in the end I thought it were my fault cos I was getting told it was my fault at the same time. I didn’t know what to do</td>
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<tr>
<td><strong>Not knowing</strong></td>
<td>6,39,43,4 4,52,54,8 0,8,101,1 25,134,14 0</td>
<td>43: I were getting told it were my fault at the same time. I didn’t know what to do 134: It’s like when my mum died I didn’t know what to do</td>
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<tr>
<td><strong>Adrift – no port in the storm</strong></td>
<td>Relationship with mother</td>
<td>47,49,50, 51,62,64, 70,80,87, 88,89,97, 99,103,10 5,110,112 1 121</td>
<td>49 I won’t forgive for half the shit she’s done but she’s still my mum so….. 50: when she’s there it’s like you’ve got your best friend cos your mum is your best friend. Or your dad. It depends who you’re closest to, I think. 62: I’ve always been told that my mum’s looking down on me so if my mum were there she’d know the stuff that I were doing and everything so at the end of the day if you think you mum or dad’s watching you it’s sort of easier 97 you know those bloomin’ bungee things you use</td>
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</tbody>
</table>
for bikes well she’d get one of those and she’d lock me
in my room and she’d tie one to the banister and one to
my bedroom door and whenever she could she’d get
rid of me – get me to my aunties or my uncles and it
felt like I weren’t wanted there
99 to me at first she were a proper cunt I hated her but
at the same time I loved her to bits
103 She weren’t like a mum to my brother either cos
when she had my brother she was with her first
husband and again there were problems there cos she
was shagging around oh my mum was like a right slag
121 I were like I can’t do it. I can’t do it. I can’t do it.
I need my mum. I need my mum. I need my mum. I
just didn’t know what to do.

| Relationships within the family | 36,37,47, 49,78,82, 84,89,97, 103,113,17, | 37: I had my granddad but after my granddad died I
stopped getting along with my gran
At the end of the day I had my family around me. It’s
family what you need.
47: I were getting passed around the family like a
parcel cos my mum didn’t want me
82: When my dad died it were alright for me because I
didn’t see him. I only seen a coupla times my entire
life. But it was like oh it’s alright, he’s dead.
89 he [cousin]were like you alright and I were like no I
need a cuddle. |

| Rejection | 7, 37, 47, 80, 97 | 7: I started getting grief from the kids at school…they
were like you don’t have a mum
8: headmaster were like why you sat there and I’d get
proper mad and throw chairs
47: I was getting passed around the family like a parcel
cos my mum didn’t want me
97: whenever she [mum] could she’d get rid of me to
my auntie’s uncle’s or my grandma and it felt like I
weren’t wanted there |

| Help that has been given | 6,10,12,1 4,16,18,2 0,21, 36,52, 9 | 10: they put me in anger management and I got kicked
out of anger management for being angry14: I didn’t
want to go back to relive the memories. So questions
aren’t always that good.
52 When I got given this book it were right weird
because I didn’t know how it felt and they were telling
me just put this down and put this down and half the
time I felt like smacking one of the teachers cos you
get this anger inside you |

| What bereaved children need | 12, 20, 12: It’s just family what you need. People to talk to.
Just give time basically if they have time….. |

| Who has been there for Emma? | 12, 23: when I’m upset I just gotta get a bucket of
chocolate, and then you put weight on and then you get
grief about being fat
70: there’ll be days and days when I don’t stop
thinking about my mum and I just want to cry so I’ll
cry and cry |
<table>
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<tr>
<th>Externalising behaviour</th>
<th>140: I never wanted to hurt no-one but…when I were younger I were the cutest thing I wouldn’t hurt a fly, but as I got older I started getting nasty so I ended up hurting other people in the same process as hurting myself. You get so mad and you don’t know what to do and you think summat…it feels so bad you just hurt yourself or hurt somebody else</th>
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<tbody>
<tr>
<td>Fighting back</td>
<td>76: I’d just get proper mad. I’d end up battering shit out of people cos they’d get to me.</td>
</tr>
<tr>
<td>Feelings</td>
<td>41, 43, 80,</td>
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<tr>
<td>The desired world – how life should be</td>
<td>Linguistic categories – use of pronouns and tenses</td>
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<tr>
<td>A sense of the future</td>
<td>123: Usually I wouldn’t make decent choices I’d end doing summat really wrong and I’d get kicked outta school or like….but now it’s like I’m sticking by it. I’m trying to get sorted…like my auntie’s talking about going to this course….and she’s wanting me to do well in life</td>
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<tr>
<td>Tangled words – challenges to sense making</td>
<td>Mourning rites and rituals Saying goodbye Stages of grief – accepting the reality of the death</td>
</tr>
<tr>
<td>Sense making – thoughts about her mother’s death and death in general</td>
<td>43, 140</td>
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### Appendix C 3:4 Charlotte’s tabulated themes

<table>
<thead>
<tr>
<th>Charlotte’s Themes</th>
<th>Overview</th>
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<tbody>
<tr>
<td>1. Sense of loss</td>
<td>Mostly I want to ask Charlotte:</td>
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<tr>
<td>2. Coping / not coping</td>
<td>Does she have a sense that she had to cope with her dad’s death by doing awful stuff – could anything have helped her to cope better?</td>
</tr>
<tr>
<td>3. School as a lifeline</td>
<td>Does Charlotte feel she has grieved for her dad, or does she feel she has tried to block grieving?</td>
</tr>
<tr>
<td>4. Sense of weirdness</td>
<td>P 42 Like some people use it to do grief but some people who like don’t know how to deal with it and can’t get used to it. <strong>And some just like cope. Completely different to my life. Some people deal with it easily.</strong> Like the people what’ve been grieving more</td>
</tr>
<tr>
<td>5. Is my Dad really there? Thoughts about Dad coming back</td>
<td>There are four tasks of grief – to accept the reality of the loss to process the pain of grief to adapt to a world without the deceased to find an enduring connection with the deceased in the midst of embarking on a new life Can I talk about this with Charlotte? I want to ask if these make sense to her, and if it would help if she was able to do these things.</td>
</tr>
<tr>
<td>6. How life is now</td>
<td>Charlotte talks a lot about things being weird – things that are weird are scary – life being out of control is scary – how are these things all tied up for Charlotte?</td>
</tr>
<tr>
<td>7. Memories</td>
<td>Does she try to make sense of it in her head, or does she try to block it out?</td>
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<tr>
<td>8. Stages of life</td>
<td>School has been a lifeline for her – what should schools do to help children who have been bereaved like this?</td>
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<tr>
<td>9. Talking about the loss/ dealing with the loss</td>
<td>What would she like to happen as a result of doing this research, and what does she think I should do?</td>
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<tr>
<td>10. Knowing/ not knowing</td>
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<tr>
<td>11. Signs and symptoms of grief</td>
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<tr>
<td>12. Sense of self/ sense of agency</td>
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<tr>
<td>13. Sense making/ working things out</td>
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<tr>
<td>14. Relationships</td>
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<table>
<thead>
<tr>
<th>General themes for all research contributors</th>
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<tbody>
<tr>
<td>Why have you volunteered to take part in this research?</td>
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<tr>
<td>How did you find out about your parent’s death?</td>
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<tr>
<td>Is there a difference for children if their parents have died from drugs or alcohol, rather than from an illness or an accident?</td>
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<tr>
<td>What kind of support do you think should</td>
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be there for children when their parents have died through substance misuse? Do you think this is different from support that should be there for kids whose parents have died from other causes?

<table>
<thead>
<tr>
<th>Theme</th>
<th>Transcript Thread</th>
<th>My comments</th>
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<tbody>
<tr>
<td>Relationships</td>
<td><strong>Sense of loss</strong></td>
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<tr>
<td></td>
<td>p1 I said I thought I was going to see my dad and I didn’t cos my mum said it was the last time I’d ever see him. And I said ‘why’ and she went he’s died.</td>
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<td>p2 everyone was just quiet…..cos like my dad was really well known my mum was like oh couldn’t live without him I wished I would’ve known more and then I could’ve seen him but I didn’t</td>
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<td>p5 my mum used to hurt herself and she was…she didn’t sleep for weeks or months and we just didn’t………It was even worser and my mum started to get ill and the family started to fall apart cos my dad was the one that held it together</td>
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<td>p5 it was like quiet it’s like you just come home from school and it’s just you went up to your room</td>
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<td>p6 my mum tried jumping in the grave because….I think that was the hardest bit…watching him go down…and they weren’t even careful with it…..they were like dropping it and everything, and everyone went schizo.</td>
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<td>p7 Here you’ve got loads and loads of people looking after you. And I’d rather just like have my mum and dad.</td>
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<td>p8 my mum’s like got mental issues and she couldn’t cope and she used to hit me and everything. And I went to school with a massive black eye and I straight away got put into care. Within that first day. Within about five hours.</td>
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<td>p9 if you’re in town and you see all these little girls with their mums and dads and everything, or older girls with their dads in town its like they’re saying oh dad I don’t want you to come to town with me. But I’d love that.</td>
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<td></td>
<td>p9 I don’t think people properly understand the problem till they’re gone.</td>
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<td></td>
<td>p9 When I’m in my room at night or something everything just comes back cos it’s all quiet and I think about it then.</td>
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<td>p13 That was the hardest bit…like this year I had to let go of the two people who meant the most and start again with two other people for this year. It’s like you’re only with them for a few weeks, I mean months and then that’s it. End of it.</td>
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<td></td>
<td>p14 It’s like they got to know me inside out its like really weird they just knew stuff about what I</td>
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wanted and liked and everything……I think it’s gonna be harder cos I was so close to them.
p14 Now I have to move on to other people….
p20 children normally have parents
p20 Losing a parent is worse. Your mum and dad were there when you were born and have been growing up through every stage of your life.
p21 it’s like coming to the end of the year and finishing high school and that’s the worst thing cos others like I’m proper proud of you and you can do whatever you like and ….I’m not saying my mum’s bad or anything but I’d rather have my mum and my dad be there through the whole of the school year.
p23 If he was here it would be a different story
p24 being in this place…just makes everything harder. You just feel like you’re nothing. I just don’t like it here.
p25 my mum’s mentally poorly herself and she said if it weren’t for me and Morgan and my brother she wouldn’t even be here.
p26 it’s like you’re going to a different teacher that doesn’t know you. Then if you come to school and you’re not feeling too good what’s the point of coming to school? It’s like people who’ve had a good life. Not a good life but where they haven’t actually lost someone. I think losing someone is the hardest thing you can cope with especially when you’re so close to them.
p27 it’s like erm the grief bit is not understandable to other people…you just think it’s happened to me….I hate it when people say I wish I was dead….my mum says it….once you’re gone you don’t come back.
p29 I didn’t know what my mum were going to do when my dad died….I thought she might kill herself or something
p30 when you lose that person it’s just like a massive chunk of your heart that’s gone and it’s there…no-one else is gonna fill that place and it’s always going to be there, that hole.
p42 Like some people use it to do grief but some people who like don’t know how to deal with it and can’t get used to it. And some just like cope. Completely different to my life.
Some people deal with it easily. Like the people what’ve been grieving more
A8 I swear so much it’s unbelievable, and if I was with my mum I wouldn’t like If I were with my mum I wouldn’t ( swear at everyone)
p52 It all just drifted (family life)
p54 She wasn’t there for me as much as she is now, last year even….she just used to keep herself to
herself she just used to do the jobs and then go back to bed. She just used to sleep all day.
p55 Hid herself in her room. Locked herself in her room.
p55 [I was] alone just watching TV. Just me and my little sister. I used to go for secret walks.
p56 ‘Cos you’ve watched your mum do all that and I watched her stop eating for months and I didn’t like that.
p61 It’s like someone ripping a big chunk out of you and it’s gone and you don’t have nothing left
p70 I’ve got more pressure on me cos I’ve got to get my GCSEs and everything….and it’s going to be so hard because I pictured my mum and my dad both being there, both of them…for my exam results….and it’s gonna be someone from Skyview. That’s gonna be there. And that’s not family to me. I’d rather my dad be there. So at least I can see how proud I’ve done and I can’t. Can’t see him.
B28 And now look where I m…I’m in school at the end of year 11 and I’m scared now. Cos I thought school’s gonna take ages. And it’s not. It’s like what’s life going so fast for? Cos sometimes I wish I could pause, rewind and fast forward sometimes. I can’t but I wish I could.
B29 I wish I’d told my dad stuff.
B33 It’s gonna be like the most important day of my life cos it’s like a step to another place.. At the end of my school year I just wish he were there smiling at me. But that’s the day…my emotions are gonna be mixed, and I just want him and my sister there to comfort me and say ‘oh it’s alright.’

Coping/ not coping

p1 it’s been proper hard.
p2 I understood and it was hard to go to school and everything through it. But we still did.
p3 everyone was um like you alright and I was like I’d rather not talk about it ’y’know and when um someone dies like when you go and visit his grave it’s like you think it’s a different person. It’s not him.
p41 It was my fault the stuff I’ve done
Coming to this place…that’s made it harder
p9 When I’m in my room at night and everything’s quiet it all comes back to me. I think about it then.
p11 I used to do this cutting
p14 With Ms H and Ms H I proper rebelled against them at first
p14 it’s gonna be weeks of rebelling against them (She’s all alone – she has to try to find a way to cope all by herself because her mother can’t be there for her and her family has fallen apart

Charlotte and I talked about ‘coping ugly’
We also talked about soldiers in WWI and recovering from
the new head of year)

p16 I got myself into loads of trouble……..they( HOY) said the most worrying thing is getting told that a young girl called Charlotte got found dead. p16 it makes me feel one step closer to my mum and dad properly it helps me through it. [talking to head of year]. And it’s really weird how they did it. They used to talk to me and they just knew how if I was upset or you know, just…..

p21 If my dad was here I wouldn’t have done half the stuff I’ve done…it’s like awful what I’ve done and my dad would’ve been proper disappointed in me

p23 I haven’t done well, I haven’t tried my best in school….I don’t concentrate and get distracted easily….I’ve just failed altogether in the stuff that I’ve done

p24 My mum didn’t cope and she’s not 6 years down the line she’s just starting to cope with it. p56 Just be there for them….show em that you’re always going to be there…whenever they need to talk you’ll always be there for there….Like it’s a better way for you and the kid to deal with it together. Instead of dealing with it on your own. Cos ur sort of when you’re on your own it turns into something like….you start hurting yourself and um do other stuff and it’s not nice

p24 It’s hard to do[coping]

p25 being in this place…just makes everything harder. You just feel like you’re nothing. I just don’t like it here.

A1 It’s been hard.
A1 I’m on my last warning and if I swear at a teacher, walk out of class then I get kicked out of school….You get so many chances and if you don’t like do as your told it’s no good.
P 77 I ask Charlotte what will help her to deal with this……Talking about it. Like to my mum. And you know that could take a long time. But yeah…..I’ll keep trying. Cos sometimes she listens. It depends what mood she’s in. I don’t want to make her upset.
P85 Lost their mum and dad and keep it to theirselves and then if they get into trouble or fights it’s like your mum this or your dad that. Like bad. And they get so worked up and start hurting themselves and hurting other people. And it’s better to get it out than hurt yourself. Cos I tried that and it’s no good at all. It’s left me with scars on my body. And other people. So I just think you need to be calm with other people.

wounds – if you stay in the firing line your body doesn’t have a chance to heal. If you stay in an emotional firing line your soul or your mind or your heart doesn’t have the chance to recover. Charlotte talks about the scars on her body and the scars she has maybe inflicted on other people.

Does Charlotte make a link between the losing her dad and doing the things she’s done? Could anything have helped her not do these things? What could people have done to try to protect her from this? Here there’s a sense that Charlotte knows that she needs to talk in order to heal – she needs to get better through making sense of what has happened and also through making connections with people – that helps too, as it has with her heads of year.
They were like another mum and dad to me at school. And they took. Well the day school’s out they took me out. They let me go places. They gave me chance after chance. And um because I didn’t well I still don’t behave in school really. In year 10 I was on the edge of being kicked out to a different school but they just kept giving me chance after chance….They were there for me when I got taken into care.....that was the hardest bit like this year I had to let go of the two people who meant the most, and start again with two other people…it’s like you’re only with them for a few months and then that’s it. End of it…… Now I have to move on to other people.

Now I have to move on to other people

p13 now I have to move on to other people and they need to know a little bit your story and everything, it’s like because they only get told certain bits and you have to tell them the rest

p14 like they’ve said I can go and talk to them if I want but it’s like they’ve got their own kids to deal with now. It’s like they’ve said I’ve got to get used to Ms H and Ms L but it’s going to take time cos it took weeks to get used to them.

p14 it’s gonna be weeks of rebelling against them every year I proper rebelled against them the first few weeks…. its like they got to know me inside out its like really weird they just knew stuff about what I wanted and liked and everything……I think it’s gonna be harder cos I was so close to them.

p15 you had those people to talk to they were always there if you were upset or summat they’d come and give you a hug and everything and sit you down and talk to you and I used to be like with them nearly every single day….well every day for a few hours

P16 This year I had to let go of the two people who meant the most, and start again with two other people…it’s like you’re only with them for a few months and then that’s it. End of it…… Now I have to move on to other people

p25 Ms H and Ms H knew when something was wrong…it’s like having people that notice you

A1 You get so many chances and if you don’t like do as you’re told it’s no good.

A2 I’m onto my last lifeline

A2 I’ve only got five months left and then that’s it.

p57 my school have sorted it out now cos like I’ve got a counselor in school as well as a nurse….she’s gonna be in every Wednesday now so that’ll be alright.
<table>
<thead>
<tr>
<th>B2</th>
<th>I want to take advantage of it [school] while I have it. I’ve been in full time mainstream and I haven’t been kicked out yet, and I don’t want to be.</th>
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<tbody>
<tr>
<td>B28</td>
<td>And now look where I m…I’m in school at the end of year 11 and I’m scared now. Cos I thought school’s gonna take ages. And it’s not. It’s like what’s life going so fast for? Cos sometimes I wish I could pause, rewind and fast forward sometimes. I can’t but I wish I could.</td>
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<td>I want to go into sixth form. That’s my main thing. If I don’t get in then what’s the point? That’s what I want to do. I want to do A levels.</td>
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<tr>
<td>B46</td>
<td>I feel excited going to school at the moment.</td>
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| Sense of weirdness | p3 when you go to visit the grave it’s like you think it’s a different person. It’s not him
p35 I’ve only told a few people this….I felt something really weird….I saw my dad’s face and I absolutely popped it. If he could’ve died then he couldn’t talk to me. I felt stupid…..I had this feeling that it was my dad…..I couldn’t sleep cos I were that scared….sometimes it’s like you wish you could talk to that person but in a way it’s scary so I wouldn’t want to.
p36 I would’ve been proper scared of that of my dad’s face staring at me in the mirror. It shows something bad is gonna happen or do summat and it’s really weird.
p36 Some people say its comforting to see your family after they’ve died, but I wouldn’t, I’d be scared. I wouldn’t like to see him that way. You think it’s the fact he’s died. I couldn’t picture him as anything else.
p37 my heart started racing. I wasn’t thinking ‘oh my god!....I was more shocked. (about seeing her dad) I know if I’d stayed on the same spot I would’ve died or summat. It’s just like he was hiding in my box
p39 I can’t really understand why he was stood behind me. Why was he sat in my box? I don’t know what he were doing. He was stood behind me just looking. I could see his face at my shoulder. I don’t know.
p42 its weird cos sometimes I get goosebumps down my back just when I’m looking at a picture |

| world. School is a more neutral and normal context |

| In the third interview Charlotte seems much more optimistic about school and has started to have a sense of what she might want or strive for – a sense of moving forward instead of looking back. She’s excited about this and even after I have turned off the tape she carries on talking about her plans |

| I don’t really know how to define this category – Charlotte’s word is ‘weirdness’ and it makes her scared of her memories of her dad, and scared of letting her feelings out. So she tries to block it? |

| I get the sense that if she had some one to talk to – someone to help make sense of things and to understand how normal it is to have weird feelings and a sense of unreality in grief, then she would have been able to accept this as a part of her grieving, instead of blocking or denying it. |
or summat….I get this weird feeling in my stomach and that’s what I’m getting now….It’s really weird, and there’s nothing there, but it’s like there’s something in my ear or summat. It’s weird.
p47 I think it was my crying chair or mad chair or summat cos I could always swear, and then I started crying after then I’d just go to the other chair and that was like my talking chair. It was weird!
p73 She’s epileptic and she like she can see dead people…it’s a bit weird…and she scared me sometimes….And she explained everything about my dad, and everyone thought it were really weird. How she could see my dad.
p74 It was really freaky. I don’t know how she could see my dad…..I think about it a lot. How strange it is
B30 My mum saw my sister (Donna, who died of an overdose) my sister looked straight at her and smiled. And my mum liked it. I would’ve been scared.
B30 I know they’re not there to hurt you. And I know they’re only here to like show you a sign that they’re here looking after you. But I’m scared. If they just like…showed me a sign…only something that my dad or sister knew…..I’d believe it and I wouldn’t be scared. If I saw him I’d be scared. **But I know the devil’s nothing to do with it but he likes to play tricks on you…and that’s what I’m most scared of…like something’s coming to hurt me.**
B32 I’ve got my head so much in films and that….I think weirdly compared to other people. It’s like I’m more scared than I think I am. **I get scared really easily and I don’t like it. I don’t like it.**

PG I wonder if that’s cos you haven’t been safe?

Probably. If my dad just showed me a sign that only me and him knew about then I’d be more comforted by that. And then I wouldn’t be as spooked as I would be if I saw him.

Is this what Charlotte thinks she’s done? Does she have a sense of trying to block, and yet at the same time reach out into the world of the paranormal?

The weirdness relates to memories and fears of her dad reappearing – but she also thinks her own feelings are weird. The goosebumps, the crying…. To me it seems as if the two are linked

For many people the ‘magical thinking’ and the fantasies is a phase which lasts a short time – it is prolonged for Charlotte, suggesting in Worden’s terms that she is stuck in being able to accept the reality of her father’s death

Is my Dad really there?  
Thoughts about Dad coming back

P2 and when um someone dies like when you go and visit his grave it’s like you think it’s a different person. It’s not him.
p3 It’s like sometimes it feels as if he just died yesterday and sometimes it feels like if I’m at my mum’s like he’s just going to walk through sometimes it just feels as if he’s going to walk through the door. But it’s like cos he used to go working away sometimes it just feels like that and everything. Like he’s just gonna walk through that
door anytime. But he doesn’t.
p7. But it doesn’t matter how hard you wish that
person isn’t gonna come back.
p19 it’s like he’s in the[the grave] but in a way
he’s not
p21 people say he’s with you but obviously I can’t
see him so I don’t believe it.
p21 my dad would’ve been proper disappointed in
me but I can’t see it on his face….
p23 I’ve just failed altogether in the stuff that I’ve
done and he’d be disappointed
p23 (I ask Charlotte if her Dad would understand
her behaviour) He didn’t. I don’t know. If he was
here then it would be like a different thing…a
different story. But I don’t know what my dad
thinks. I can’t see what he thinks.
p33 No matter how hard people tried to explain
…he’s not coming back she just thought he’s
gonna walk through the door…..now she
understands
p36 it’s the fact he’s died. I couldn’t picture him
as anything else.
p37 It’s just like he was hiding in my box….
p40 (re going to a spiritualist meeting) I do want
to do it but I’ll be scared if he doesn’t come
through. If he talks or if he doesn’t come
p41 Like you really want him to be there and that
I want to talk to him about the stuff I’ve done. It
was my fault the stuff I’ve done……But I don’t
know how to explain to you….
p 41 I would like to talk to him but not in the
mirror, if we were in one of those churches with
my brother or sister I’d feel safe but if he were
here now I wouldn’t be able to move…
p 70 And that’s not family to me. I’d rather my
dad be there. So at least I can see how proud I’ve
done and I can’t. Can’t see him.
P71 I try to sometimes[talk to her dad] but I don’t
get no reply. Like if I go along to his grave I try to
talk to him in my head sometimes and then I don’t
get no answer but I don’t know why. Like I want
to sometimes but I don’t know. Like if I’m upset
sometimes then I don’t know. It’s just like I don’t
know because I don’t want to get scared of him.
Like scare him away
P71 Like if my dad replied to me….just started
talking to me then I’d think it was him
B4 Sometimes it’s like ….you think……I don’t
know…..’What would my dad say?’ Like I said to
my mum, ‘What would my dad say if he was here
right now? She went, ‘ I don’t know. Probably
he’d be proud of you’, and I went ‘Ooooooh.’
B17 It’s like I want to think about him. And
sometimes I’m scared he’ll just appear.
Sometimes I feel like he’s gonna come out and say everything’s gonna be alright.’ And then other times I’m scared….and I don’t wanna be scared of my dad. And then other times it’s like I’ll cry. And if I cry for my dad it’s the same. I’m scared he’ll appear. But then I just want…it’s not like a sign or a thing…..it’s like yeah more of a sign. It’s just like I want to know he’s alright/ I don’t know….I do block him out sometimes cos if everyone talks about my dad and everything and it’s just like I put my head down and go on my phone or summat.

B29  I wish I’d told my dad stuff.
  B33 I’m hoping it’ll happen at the end of this year. 
  {she’ll see her dad]  I’m hoping that I’ll see him even though I’m gonna be spooked. I hope I’m gonna see him on the day I get my GCSEs. Cos I’ve always wished he’ll be there. That I’ll see my dad and my sister together. I’ll probably see them smiling.
  B33 My dad promised. Well he didn’t promise but he like….well my mum says as well…..she says he is gonna be there but I just want….I just want him to be there and if I want summat so much from my dad then he’d give it to me. It’s gonna be like the most important day of my life cos it’s like a step to another place.. At the end of my school year I just wish he were there smiling at me. But that’s the day….my emotions are gonna be mixed, and I just want him and my sister there to comfort me and say ‘oh it’s alright.’
  B34 I imagine he’d come up to me and give me a hug. And I awlys see his false teeth and everything. I imagine them falling out when he’s smiling….I just can’t imagine him saying ‘Oh you’re doing well and everything. I wish I could but I can’t.

PG: Can you remember him giving you a hug?
No, like I imagine him giving me one I think it seems so long ago.

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<thead>
<tr>
<th>How life is now</th>
<th>p 48 In the past week or two I’ve been proper kicking off and arguing, everything…..I’m in more trouble for lying then I just kick off</th>
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<td></td>
<td>p 78 I’m doing a hair and beauty course and I quite like it but last year I hated it….I want to like do a gap year like in Africa or some place where they don’t have as many things as we do in our houses. .....</td>
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<td>p79 I’m trying to get into my primary school to do voluntary work after school and stuff, helping out. But I need to start behaving first, cos if I go in swearing my mouth off that’s no good in front of the little ones and everything. I can’t go in and just start swearing in my job, when I get one. I ‘ll</td>
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Charlotte is speaking with some optimism – in contrast to the life before
just get sacked or something.
P80 I’ve done stuff at school. Just helping out
But I’d rather work with younger kids than kids
my age. But I’d work with people my own age
that I don’t know. Just say in other countries.

B4 I’ve got loads[ o course work] So I can do
that. I’m finishing off my history exam…..
B5 I’d rather do more [GCSEs]
B6 I want to do more. I want to do like 14 or
summat. That’s why I need to try harder, cos if I
do all my work then I can do it. ….I want more,
cos the more I can do the more I want. And then
the more jobs I can get offered.
B7 My teacher says I’ve got a brain in there but
sometimes it can be like just echoey and there’s
nowt in there. When I tap my head or summat it
just echoes, there’s nothing in it. And that’s when
I misbehave and everything.
B7 They say how come I’m behaving. I don’t tell
them the reason. I just do. Yeah.
B7 I thought it was gonna be really hard. Like,
‘oh I can’t do that.’ But when you set your mind
on summat and you really really want it then you
can achieve it.
B15 Like 2 week ago I were getting pulled into
the office for all bad stuff. And now I’m getting
pulled in for like, ‘Well done you.’
B15 ( re dealing with feelings ) The crying bit
is[still happening] the swearing isn’t.
B29 It’s been good[these interviews] I go out and
like I’m going to my mum’s soon and I’ve told her
about what you’re doing and everything and she’s
like, that’s good because you do need someone to
talk to that’ll understand…she’s really happy
about me doing it.
B46 I feel excited going to school at the moment.

Memories

p6 My mum tried jumping in the grave because…I
think that was the hardest bit. Watching him go
down….and they weren’t even careful with
it….they were like dropping it and everyone went
schizo

p17 ( I ask Charlotte to tell me a memory of her
dad)
When he was away for like days or weeks or
summat he used to come back he used used to get
that little summat extra cos like he always used to
to bring…..and everything….yeah…. 

p18 it’s like more the bad stuff [memories]
takes over from the good stuff cos it’s only the
bad stuff that goes on and um it just gets too
much and overtakes it.

p31 Me and my sister do talk….she might get
happy and say do you remember but I can’t really remember cos like it puts a smile on her face but I can’t…..my dad always used to be……
p33 I was a proper daddy’s girl…my brother and sister would tell my mum stuff but I wouldn’t I’d tell my dad
p51 I wrote half a page cos it was er like write all your good memories down and everything and it’s like er I didn’t have any
p52 My mum and dad were fighting all the time. Just screaming and smash stuff…it was regular
p59 At night I used to go downstairs and she’d be there with a blade in her hand like- just cutting her arm and everything
p60 I just used to sneak downstairs. I’d see all the blood all over the table and then……I didn’t talk about it then.
B18 She’s [Morgan] like do you remember this do you remember that? And like sometimes I do sometimes I don’t cos all I remember is being told that he died. And that’s like the last thing I heard about him. ….( I ask…..So has that stopped you having any good memories of your dad? ) Yes (very softly)
B19 It’s like more bad memories come back than good. If you know what I mean….like my mum and dad arguing…hitting each other…pushing each other down the stairs….
B20 I’d rather think of all the good memories of my dad but I can’t cos they’re blocked by all the bad memories….it’s like they’ve overtaken him but I wish they wouldn’t…..they knew I was awake cos they looked in and my eyes were open and then they just went downstairs and started fighting there.

Insert B23-B28 Charlotte talks about some of her memories of her dad. She pulls them up and they seem to become more fluent as she tells the story.
B34 I can remember his voice now.[after telling me some memories] He talked very clearly( laughs)

Stages of life

P7 my mum couldn’t cope. She’s got mental issues and she used to hit me and everything
p8 I went to school with a massive black eye and straight away I got put in care. Within that first day. Within about five hours.
p31 if he died at this age it’d be easier to understand
p32 I think it’s harder losing someone at a younger age. It’s harder to deal with
p19 I don’t think I’ve come to that stage yet[grief making you ‘stronger’]
p20 Your mum and dad were there when you were
born and have been growing up through every stage of your life.
p21 It’s like coming to the end of the year and finishing high school and that’s the worst thing cos the others are like I’m proper proud of you[other parents of other children]
p34 I would rather lose him at an older age but not now during school cos I don’t think I would’ve coped before.
P78 I want to do a gap year to Africa or some place
p79 I’m trying to get into my primary school to do voluntary work after school and stuff, helping out.
But I need to start behaving first, cos if I go in swearing my mouth off that’s no good in front of the little ones and everything. I can’t go in and just start swearing in my job, when I get one. I’ll just get sacked or something.
P80 I’ve done stuff at school. Just helping out.
But I’d rather work with younger kids than kids my age. But I’d work with people my own age that I don’t know. Just say in other countries.
B2 And these[other children in the home] they’re not even going to get any GCSEs cos they have to go to college, and I don’t even think they’re going to get in there.
B28 And now look where I m…I’m in school at the end of year 11 and I’m scared now. Cos I thought school’s gonna take ages. And it’s not. It’s like what’s life going so fast for? Cos sometimes I wish I could pause, rewind and fast foward sometimes. I can’t but I wish I could.
B36 I want to go into sixth form. That’s my main thing. If I don’t get in then what’s the point?
That’s what I want to do. I want to do A levels.
B39 I done a lot of bad stuff last year. And the year before. And I had a bad reputation.

| Talking about the loss/ dealing with the loss | p3 everyone was um like you alright and I was like I’d rather not talk about it p5 I didn’t want to ask my mum questions cos my mum used to hurt herself p10 People deal with it in different ways…some people can express it easier and some people can’t talk about it like freehand and everything and others dpn’t want to talk about it. p10 I could talk to my mum but it makes her upset so I don’t like talking to her some people here[have given me the chance to talk] but I don’t like talking about it with them and I don’t like talking about it. p11 ( I ask about ways of releasing feelings) Well, there’s talking to people but I don’t want to Is this blocking? No there’s a clear message that I want to talk to someone – but it has to be the right person at the right time |
talk to all these lot….I’d rather talk to someone who had experience of it. It’d be easier. Like
talking to these it doesn’t feel the same and I don’t like…it’s not easy to talk about.
p13 now I have to move on to other people and they need to know a little bit your story and
everything, it’s like because they only get told certain bits and you have to tell them the rest
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few weeks…. its like they got to know me inside out its like really weird they just knew stuff about
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p16 it makes me feel one step closer to my mum and dad properly it helps me through it. And it’s
really weird how they did it. They used to talk to me and they just knew how if I was upset or you
know, just…..
p43 Sometimes I find it easier to talk about and then it just comes back to me. The whole thing
and I think that’s how my mum feels cos she can talk about it and then she can’t. Not good.
p29 I don’t like writing about it…it’ll always be there…..I’ll always have that memory…if I keep it
I’ll get even more upset. Talking like it just….yeah….
p49 It depends what mood I’m in. Sometimes I can talk about it but like for ages there were times
when like people can’t be bothered then it’s like I wanna talk about it. But when people can be
bothered then maybe I don’t. And then they’re really tired and they don’t want to talk about it and
they when they want to talk about it I don’t want to. Like my mum.

p58 I’d rather talk to somebody outside……outside the world that I’m in ……
p58 I get really nervous when I talk to my mum
and it’s like ‘oh my god.’…..it’s easier to talk to you than it is to my mum
<table>
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<tr>
<td>p59</td>
<td>If I talk to my mum she just starts crying and everything and it's like oh my god look what I just did.</td>
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<td>I didn’t like talking to my mum cos I didn’t like seeing her upset…..I just didn’t want to talk to them cos I didn’t want to see them upset and make them do anything they’ll regret. Or I’ll regret.</td>
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<td>p77</td>
<td>ask what will help Charlotte deal with her grief?) Talking about it. Like to my mum. And you know, that could take a long time( laughs) but yeah, I’ll keep trying……Sometimes she listens. It depends what mood she’s in. I don’t want to make her upset.</td>
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<tr>
<td>P1</td>
<td>we don’t know……me and my sister didn’t get told</td>
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<td>P1</td>
<td>I didn’t really click right</td>
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<td>P1</td>
<td>My mum didn’t say anything and I said I thought I was going to see my dad</td>
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<td>P2</td>
<td>everyone was just quiet</td>
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<td>P2</td>
<td>My mum didn’t say anything</td>
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<td>P2</td>
<td>But I understood and it was hard to go to school and everything through it. But we still did</td>
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<td>P3</td>
<td>my mum just told me he were very poorly</td>
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<td>P4</td>
<td>I don’t know. I don’t know like. I wished that I could’ve known more and then I could’ve seen him, but I didn’t</td>
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<td>P6</td>
<td>Nobody told me or Morgan. I was telling everyone I’m gonna see my dad today. And everyone just looked at each other and went out the house</td>
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<td>P7</td>
<td>Obviously I knew why he died and I didn’t want to ask my mum questions</td>
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<td>P17</td>
<td>I think that’s what he died of</td>
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<td>P3</td>
<td>You don’t know whether to be happy or sad</td>
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<td>P3</td>
<td>It’s like sometimes it feels as if he just died yesterday and sometimes it feels like if I’m at my mum’s like he’s just going to walk through</td>
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<td>P6</td>
<td>my mum tried jumping in the grave because….I think that was the hardest bit…watching him go down…and they weren’t even careful with it…..they were like dropping it and everything, and everyone went schizo.</td>
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<td>P7</td>
<td>coming to this place….that’s made it harder</td>
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<td>P7</td>
<td>But it doesn’t matter how hard you wish that person isn’t gonna come back</td>
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<td>P9</td>
<td>I don’t think people actually understand the problem until they’re gone.</td>
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<td>P10</td>
<td>When I’m in my room at night or something everything comes back to me cos it’s all quiet and I think about it then</td>
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<tr>
<td>P10</td>
<td>Like some people deal with it in different</td>
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<td>All of these are in the first few moments of meeting – it’s the surprise and unreality that seems to have hit Charlotte – her story isn’t coherent and it’s hard to piece together – is this what is is like for Charlotte?</td>
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<td>This is a difficult category because Charlotte hardly talks about grief at all. She uses the word grief or grieve twice over our three interviews.</td>
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<tr>
<td>I am interpreting things as signs or symptoms of grief and have included references to feeling and to behaviour which I think is ‘blocking’</td>
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ways. Like some people can express it easier, and
some people can’t talk about it like freehand and
everything. It’s like others don’t want to talk
about it. When people bring it up it’s like more
emotional over it…..like yeah…..

p11 a few weeks ago or a few months ago I used
to do this cutting[when I ask if she’s dealt with
grief in ways that have hurt her]
p16 it makes me feel one step closer to my mum
and dad properly it helps me through it. And it’s
really weird how they did it. They used to talk to
me and they just knew how if I was upset or you
know, just…..
p19 (I ask about holding onto good memories)
When I’m with my mum it’s a bit hard it’s like
will you take me down to my dad’s grave it’s like
he’s there in a way but he’s not.
P21 people say he’s there with you but obviously I
can’t see him so I don’t believe it

p34 When you’re little you don’t understand….I
would’ve coped easier if…when you’re older you
know how to cope with it better.
p34 It’s weird for other people watching cos how
can you be like that when your dad’s just died?
p42 Like some people use it to do grief but some
people who like don’t know how to deal with it
and can’t get used to it. And some just like cope.

Completely different to my life. Some people
deal with it easily. Like the people what’ve been
grieving more

p44 I think it’s better to understand than go
through what other people have to go through and
like grieve and harm theirselves and wish
theirselves dead and everything. It’s not right.

A8 I swear so much it’s unbelievable, and if I was
with my mum I wouldn’t like If I
were with my mum I wouldn’t (swear at
everyone)
p47 I think it was my crying chair or mad chair or
summat cos like I could always swear, and then I
started crying after then I’d just go to the other
chair and that was like my talking chair. It was
weird!
P53 (talking about her grandfather’s death) I
didn’t have no feelings in my body to make like
tears
p56 Just be there for them…show em that you’re
always going to be there…whenever they need to
talk you’ll always be there for there….Like it’s a
better way for you and the kid to deal with it
together. Instead of dealing with it on your own.
Cos ur sort of when you’re on your own it turns
into something like….you start hurting yourself
and um do other stuff and it’s not nice

or which she
acknowledges as
blocking

This is really
important. This is
Charlotte saying
that it’s her grief
that has shaped
how she has
reacted to her life’
the things she’s
done which she
says are awful.

If Charlotte could
see her behaviour
as her grief, and
understand as the
reaction she had to
have, given how
her life was, how
would that make
her feel when she
looks back?

Charlotte couldn’t
cope because she
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<tr>
<td>p58</td>
<td>(things adults shouldn’t do…) In a few years time you just sort of get better…sometimes it does….sometimes it doesn’t. It depends what kind of memories you have with that person.</td>
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<tr>
<td>p61</td>
<td>It’s like someone ripping a big chunk out of you and it’s gone and you don’t have nothing left</td>
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<td>p68</td>
<td>I sort of felt done in[the day she heard her father died] Like really weird.</td>
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<td>B15</td>
<td>When I think about my dad or my sister then yeah, I cry all the time. Uh when I see my mum crying which she nearly every day.</td>
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<td>B17</td>
<td>It’s like I want to think about him. And sometimes I’m scared he’ll just appear. Sometimes I feel like he’s gonna come out and say everything’s gonna be alright.’ And then other times I’m scared….and I don’t wanna be scared of my dad. And then other times it’s like I’ll cry. And if I cry for my dad it’s the same. I’m scared he’ll appear. But then I just want…it’s not like a sign or a thing….it’s like yeah more of a sign. It’s just like I want to know he’s alright/ I don’t know….I do block him out sometimes cos if everyone talks about my dad and everything and it’s just like I put my head down and go on my phone or summat.</td>
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<td>Sense of self/ sense of agency</td>
<td>p60</td>
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<td>Sense of self/ sense of agency</td>
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<td>Sense of self/ sense of agency</td>
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<td>Sense of self/ sense of agency</td>
<td>B11</td>
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<td>Sense of self/ sense of agency</td>
<td>B13</td>
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<td>Sense of self/ sense of agency</td>
<td>B13</td>
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<td>Sense making –</td>
<td>p74</td>
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working things out could see my dad.....I think about it a lot. How strange it is

P80 People here.....take everything for granted...But people who are less fortunate enjoy what they’ve got....I don’t know how they do it. So that’s how I want to find out.....so happy and everything, even though they don’t have nothing they’ve got their family and hardly no food nor water but make the most of it.

P82 When you’re in that situation you think ‘Oh it’s just happened to me.’ But I went to the graveyard and I realized it’s not just me. Loads of people have lost a parent, brother or sister mum or dad.

B42 re art project about family You make yourself really upset doing it. And then in the end it comes out a really good piece and you’re happy. And it’s like I said, mixed emotions.....like your emotions are everywhere, like spiders.

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General analysis for all contributors

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| Taking part in the research | p43-44I get like this feeling that you do understand, and you do want to help other people and like I’m ok to talk to you. I’m just trying to help you. Like I just really want to help other people deal with it.......It’s like a different feeling I’ve got now and I think its like cos you want to help other people I think that’s why and it’s like you understand  
B36 I feel more comfortable with talking to you than talking to the staff. I talk to you for an hour, maybe more.  
B36 If you weren’t here I think I’d be in the same place I was a few weeks ago or a few months even. And I think I used to be just sad all the time.  
A5 it felt better (after talking in the interview)  
B45 I don’t mind being pushed cos it helps. |
| The kinds of help or support you have received | Everyone was there( at the time Charlotte found out about the death) and I wasn’t um I’d rather not talk about it...... ..  
p5 I stayed in my room. I didn’t talk to anyone. I didn’t want to ask my mum questions cos my mum used to hurt herself.  
p13 Now I have to move onto other people and it’s like they need to know a little bit of your story and everything and its like because they only get told certain bits and you have to tell them the rest.  
p28 I had my book to write in in year 5 |
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<td>284</td>
<td>I don’t like writing about it…it’ll always be there….I’ll always have that memory…if I keep it I’ll get even more upset. Talking like it just….yeah…. B44 When people don’t push other people in schools they just fail. Sink and everything.</td>
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<td>56</td>
<td>Just be there for them…show em that you’re always going to be there…whenever they need to talk you’ll always be there for there….Like it’s a better way for you and the kid to deal with it together. Instead of dealing with it on your own. Cos ur sort of when you’re on your own it turns into something like….you start hurting yourself and um do other stuff stuff and it’s not nice B44 Everyone thinks oh it’s just happened to me. Cos that’s what I thought. Why hasn’t it happened to any other person? B44 Everyone needs someone to talk to. To share. I was talking to X cos I didn’t know her dad had passed away. How many similarities we had. I was blown away. Gobsmacked. …Nobody’s by themselves, ther’s always someone out there.</td>
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<td>1-2</td>
<td>Charlotte describes how she found out. Um Like my mum knew but me and my sister didn’t get told……I didn’t click…..my mum didn’t say anything……my mum said it was the last time I was ever going to see my dad and I went why? And she said he’s died……everyone was quiet…my mum just told he were very poorly. ….I wish I would’ve known more. I wish I would ‘ve seen him…nobody told me or Morgan…..p5 I was telling everyone I’m going to see my dad and everyone just looked at each other and went out of the house………..p5 I didn’t want to ask my mum questions cos my mum used to hurt herself….. p6 My mum tried jumping in the grave because…I think that was the hardest bit. Watching him go down…..and they weren’t even careful with it….they were like dropping it and everyone went schizo P7 My mum couldn’t cope….she’s got mental issues and she used to like hit me P16 I think that’s what he died of P30 Description of her sister dying It’s like with my mum and dad they’re not choosing to die they just don’t know the outcomes of what’s going on and that’s like the hardest thing to establish I wouldn’t have wanted him to die of drugs or alcohol cos I know what he would’ve got into and I know it was painful for him to get out of p67 I know how he died and why he died. Why he died is um not nice. I know how he died. Charlotte gives me a clear chronological account of events the day her father died.</td>
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