The experience of losing a sibling in adult life:
an interpretative phenomenological analysis.
This thesis is submitted in partial fulfilment of the requirements for the Degree of Doctor
of Existential Counselling Psychology and Psychotherapy at the New School of
Psychotherapy and Counselling and Middlesex University Psychology Department.
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#### **Abstract**

The aim of this study is to explore the experience of losing a sibling in adult life. The research investigates the participants' individual experience from an existential perspective, with the view of contributing to the field of bereavement in counselling psychology and psychotherapy; and adding to the very limited existing research about the death of a sibling in adulthood.. Ten participants took part in semi-structured interviews, and the data was analysed using Interpretative Phenomenological Analysis (Smith et al., 2009)

Key findings showed paradoxes on several levels; the experience provoked strong emotions when the relationship with the sibling was loving, difficult or abusive. Similarly, support was complex, as the participants were often not regarded by others to be in need of support to the same extent as the dead sibling's spouse, children and parents. At the same time the participants did not consider others to understand the loss without having had the same experience, which limited available support.

Further findings and the discussion of this research indicated the importance of counselling psychologists acknowledging the death of a sibling when working with adult clients, as the participants told of the great impact on psychological well-being, everyday life and relationships. The participants expressed wanting to be seen and heard by others, as well as wanting more literature, research and therapeutic groups for this kind of bereavement to be available. Future research would benefit from more specific criteria, such as whether the relationship was loving or abusive or if the death was sudden or followed a terminal illness, thus adding greater depth to the research. For clinical practice the research established the importance of therapists to be aware of clients' often complex and multi-layered emotions following the death of an adult sibling.

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## **Key words**

Bereavement, grief, adult sibling, qualitative research, interpretative phenomenological analysis, hermeneutic phenomenology, critical realism, love, abuse, sudden death, long-term illness.

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# **Abbreviations**

BPS	British Psychological Society
DSM	Diagnostic and Statistical Manual of Mental Disorders
APT	Improving Access to Psychological Therapies
PA	Interpretative Phenomenological Analysis
NHS	National Health Service
TCF	The Compassionate Friends

## **Foreword**

As a trainee counselling psychologist and a doctoral student on an existential course I have encountered the topic of bereavement throughout my training and many were the times when I became intrigued by the personal, social and cultural experiences following a death. Several members of my family and friends of my family have lost a sibling in adult life and as I witnessed the immediate grief and the long-term void I became interested in the psychological and social aspects of the experience. When I started working as a bereavement counsellor it soon transpired that several of my clients came to counselling after having lost an adult sibling. I heard similar accounts from clients of feeling unsupported and of their grief not being acknowledged by others. As an existential therapist I became increasingly intrigued with how clients felt that care and concern were not available from their existing relationships following their sibling's death. While seeing the clients mentioned above I was working on my research proposal for the doctorate and made the decision to research this topic since there seemed to be a particular significance to this type of loss.

Finding participants for the research proved to be difficult, which was primarily due to there being very few channels to such potential participants. Bereavement organisations offering counselling were opposed to advertise the research to their

clients, as counselling was often free of charge and the organisations were concerned that the clients could therefore feel obliged to take part in the research. Over the course of a year and after travelling to the west, southeast and north of the UK I had finally interviewed sufficient number of participants to commence the analysis.

# **Introduction**

The relationships between siblings can involve strong and at times contradictory emotions such as love, friendship, indifference, conflict and frustration (Coles, 2003). Being in a relationship characterised by a family tie means that contact is often continuous even through difficult situations and emotions, allowing for change as the siblings grow up (Martin et al., 2005). The relationship between siblings is often the longest relationship in a person's life (Wray, 2003; Robinson and Mahon, 1997; Walter and McCoyd, 2009; Cicirelli, 1995).

As pointed out by Wray (2003), bereaved adult siblings tend to be marginalised in society, as relatives' primary concerns are often focussed more upon the parents, spouse or children of the deceased. Based upon my review of the current literature the experience of adult siblings' bereavements has not attracted much attention from researchers, academics or health professionals either. However, much has been written about bereavement more widely and this will to a large extent form the focus of my review.

The aim of this study is to research the experience of bereaved adult siblings, using an interpretative phenomenological analysis, in order to investigate how society and counselling psychologists can better support this bereaved group. There was a focus on whether bereaved adult siblings felt the need for support and if so, what kind of support would be helpful from family, friends and potentially from counselling psychologists. The research question enquired about the experience of losing a sibling in adult life, without assumptions of what the participants' experiences may be. Additionally, I have aimed to develop an understanding of the cultural and historical aspects of my topic to provide greater depth to the participants' psychological experiences.

Throughout the analysis and the theoretical parts of the research I continued to be intrigued by the individual, social and historical aspects of sibling bereavement in adulthood. I grew up in Sweden and after spending some time in Spain I moved to the UK, where I have lived most of my adult life. In Swedish culture and in my own family, I was used to the deceased being part of everyday conversation, with photos and memorabilia on display at home. In Spain, deceased family members were often brought up in conversations, although some of the funeral and grief traditions were undeniably louder and of a more dramatic nature than their Swedish counterparts. When living in the UK, people told me of their recent bereavement, but without continuing to disclose who had died, how they had died or disclosing their personal emotions, initially this perplexed me. I found myself waiting for more information but when the other person did not voluntarily provide this I got a sense that I should

not ask any further questions and therefore the conversation came to a halt. The lack of further verbal details became clearer when I researched the history of grief in the UK, as the two world wars caused bereavement(s) in most families and verbal recognition of individual losses was scarce.

I will present suggestions of how counselling psychologists and psychotherapists can provide appropriate care and therapy for the possibly complex concerns and needs of bereaved adult siblings. These suggestions will include ideas about provision of individual and group therapy; how to reach bereaved adult siblings through the NHS and charities. As an existential-phenomenological practitioner I will reflect on the research topic throughout the thesis, aiming to understand the individual's unique life experience and perspective in relation to the historical, socio-cultural and relational context. By doing so, I intend to develop an understanding of how the participants' loss is reflected in their world and in their relationships. Therefore, the reviewed literature will include how grief was experienced in the past and today, various models of grief, the lived experience of grief, sibling relationships and bereaved siblings. This will include, but will not be restricted to, a comprehensive exploration of relevant existential and phenomenological literature to deepen the understanding of the loss of an adult sibling, in particular the relational aspects of this kind of bereavement. Thereafter, the method section will be presented, including my epistemology, the reasons for choosing Interpretative Phenomenological Analysis (IPA) as a method and a section about reflexivity.

Subsequently, the research findings will be presented through three super-ordinate themes, which were extracted from the analysis of the interviews including quotations from the transcripts to illustrate and support the findings. The Discussion of the findings will then follow, with additional literature where appropriate, including considerations on how the findings could be applied to therapeutic practice, reflections on the research process, followed by an appraisal of the limitations of the research and finally implications for future research and therapeutic practice.

## **Literature Review**

When reviewing the bereavement literature it became clear to me that bereavement and the death of a sibling needs to be reviewed within the context of how society, traditions, the family unit and medical settings have evolved and changed over time, as these influence the support the bereaved may or may not receive. Research in the field of bereavement has been carried out in numerous disciplines: psychology (e.g. Neimeyer, 2004), nursing (e.g. Agnew et al., 2010), medicine (e.g. Hansen et al., 2006) and sociology (e.g. Smith et al., 2011). Non-academics have written about their personal experiences (e.g. Wray, 2003; Sandmaier, 1994; Berman, 2009; De Vita-Raeburn, 2004). When searching for the literature about losing a sibling in adult life I used the books, journals and on-line facilities at the British Library, the on-line BPS members' website EBSCO, and I have also consulted autobiographies written by

bereaved siblings and websites developed for and used by this particular group. Search terms included bereavement, grief, deah, siblings, qualitative research, IPA.

### Introduction

The bereavement literature to date that has focused on specific kinds of bereavement has primarily explored the experiences and emotions of the deceased person's spouse, children and parents. Sibling loss in childhood and adolescence has also attracted some attention (Potts et al., 1999; Cicirelli, 1995), however there is a lack of literature about losing a sibling in adult life.

The historical overview of sibling bereavement in adulthood will be followed by a discussion of the different models of grief introduced by practitioners and theorists and a review of the literature on the culture and different traditions of grief to create an understanding of why contemporary Western society often do not recognise this kind of loss. Thereafter, the literature of sibling relationships will be examined, followed by literature concerning the emotions and issues of bereaved siblings. Finally, I will present existential understandings of bereavement, grief, care and relationships, as the existential approach provides holistic and in-depth views of relationships and loss. I have chosen to focus upon an existential understanding of my research topic in order to explore the bereaved person's experiences in their social and cultural worlds. Additionally, from an existential perspective the bereavement will reveal the participants' individual emotions and choices not only

towards the deceased but also how they relate to their own death and the world they now need to navigate.

## **Historical overview of bereavement**

Bereavement researchers and practitioners have used a variety of different words to describe how we as humans experience the death of someone close to us (Weiss, 2008; Worden, 2010). Rando (1984, p.15) defines the terms grief, mourning and bereavement as bereavement referring to having lost someone, grief to being 'the process of psychological, social and somatic reaction to the perception of loss', while the term mourning has also come to include how people respond to grief in accordance with their culture. Worden's (2010) definition is similar, as he presents mourning as being the process following the loss of a person, while grief is seen as the individual's experience of the loss. Thus, a person may feel expectations from their culture and family of how to grieve while processing the unique emotions connected to the loss. However, the above texts do not explore possible difficulties arising when an individual's emotions about the deceased do not meet traditional expectations of grief, as may be the case when a relationship has been abusive or neglectful. I will largely use the term bereavement for discussing the death and grief for the participants' emotions connected to the deceased.

The works of Walter (1999), who specialises in death studies from a sociological perspective, and Jalland (2010), who has also researched the social and cultural history of death, identify how grief experienced by a population and traditions surrounding grief are embedded in a society's history. The literature in this section explores how the social expectations of grief have changed from the Middle Ages to contemporary times in the UK, leading to subsequent sections about changes in grief traditions and sibling relationships in order to provide a contextualised in-depth background to understanding the experience of losing a sibling in adult life.

During medieval times death and religion was entwined through guidance and rites of Christianity (Houlbrooke, 1998). Belonging to a religious community can provide support, increased psychological well-being and can facilitate meaning-making following a bereavement (Hays and Hendrix, 2008). However, as the Medieval church dominated governance, law and social traditions, dissenters risked being physically punished or even killed (Bovey, 2015). As pointed out by Houlbrooke (1998), death in the Middle Ages was not the end of life for believers of the Christian religion, as heaven or hell would be waiting after death, a viewpoint still held by most Christians today (Granger and Price, 2007). In Medieval times, the Christian church in England held a strong influence on public understanding, with its promised hope of reunion in death while instilling fear of sinning in the living (Houlbrooke, 1998). Despite the fear of hell, the hope of being re-united with loved ones in an afterlife could be seen to also console the bereaved and decrease psychological stress (Hays and Hendrix, 2008). Although grief continued to be connected with the

church, the increased social acceptance of grief being displayed appears to provide more space for the individual.

The reviewed literature shows how cultural changes during the English Renaissance (Kelley and Sacks, 1997; Braddick and Smith, 2011) meant that literature and art flourished and grief came to be expressed verbally to a greater extent (Swiss and Kent, 2002; Pigman, 1985). Poetry of this era suggested that tears, wailing and speaking of one's sorrow could help the bereaved to overcome the grief (Spenser, 1591), hence showing social acceptance of emotional expressions. Poetry became part of the mourning process as poets were asked to write funeral elegies (Brady, 2006).

Such emotional and verbal expressions became more restrained during the Victorian era in the UK when death was a quiet family matter and the last communion was given at the bedside (Jalland, 2010). The majority of those dying were cared for in the home with the body remaining for a number of days following the death. Jalland (2010) specifically identifies closer contact with death as a result of poverty, high mortality rates, and grief therefore being more visible than today, as widows wore black mourning clothes and mourning jewellery. Similarly, Littlewood (2015) argues that although the rituals of grief in the Victorian era may have provided emotional support, the majority of people would lose one or several close family members due to limited medical care which therefore fostered a greater acceptance of death. Houlbrooke's (1998) examination of mourning found that a widow in the eighteenth

century would be excused from social commitments whilst wearing mourning clothes. However, he added that the very same garments could show that she may be considering the possibilities of re-marrying, thereby conveying two different messages to the surrounding society. Houlbrooke (1998) further argues that for widows in the Middles Ages and the Victorian era re-marrying would not only have been a sign of their grieving process ending, but would most likely also have been a financial necessity.

Despite the observations of grief traditions providing us with a greater understanding of the topic there are assumptions of a homogenous society where people grieve in specific manners regardless of their personal circumstances. Walter's (2015) research and publications in the last two decades advocate the study of death and society, including working with multi-disciplinary academic colleagues to understand death in modern society. Walter (1999, p.36) tells how 'immersion in grief is a luxury only to be afforded by those with the requisite time and space'. Strange (2005) points out that much of the literature about grief in the Victorian era relies partly on correspondence, which largely excludes the working classes, and partly on literature, mainly written by men and therefore not accounting for women's experiences. Adopting these reflections, conclusions about grief need therefore to be presented with the awareness that there may be no record of most stories of grief. The division in society did however start to change, albeit slowly, as women demanded more rights (Vicinus, 2013) and increasingly so during the First World War, as women were increasingly required to work (Walter, 1999).

Through reviewing the history of grief I found some explanations to why grief has changed from being visible and verbally expressed to being silent, less noticeable and therefore often leaving the bereaved without sufficient support. The social expectations of grief changed from explicitly showing one's sorrow to silent grief early in the twentieth century (Damousi, 2014). During and after the First and Second World Wars the large numbers of deaths among UK soldiers created silence around those who had died early and often horrific deaths (Jalland, 2010). Gregory (1994) carried out a study to further investigate this new expectation of silent grief. His research, which focused on the effects the First World War had on the British people, linked the silent grief to the bereaved being unable to access the circumstances of how their loved ones died, neither having been able to see the bodies of those who had been killed abroad nor having been able to identify the bodies killed in air raids at home. The study shows that grief was being shared through war memorials and wreaths being placed on these, albeit in silence. It appears that due to the vast numbers of deaths there was not space for individual grief, rather entire communities were grieving the dead and those missing in action. Fierke's (2004) article defines grief as a personal loss which may evoke compassion in others, while a death emotionally connected to a social disaster or betrayal by a person can result in trauma and isolation. This idea fits well with the silent grief in the UK following the two world wars. Jalland (2010) argues that the silence of those grieving after the two world wars could also be observed in the mainly absent material from historians and sociologists at this time. She emphasises how moving the dying from the home to hospitals enforced the silence for families and those who were dying. During the second world war Lindemann (1944) researched acute

grief, interviewing patients in hospitals and their relatives, the armed forces and those who survived the Cocoanut Grove Fire. Although the findings show how the reactions to acute grief can be very individual, the range of who the participants had lost and in what manner, appears at times too vast. Equally, there was limited psychological knowledge about traumatic stress experienced by the dying and their relatives in the decades following the Second World War (Heyse-Moore, 2016). Walter (1999) offers further explanations to the silence of the bereaved in the 20<sup>th</sup> century; not only had people across the world lost loved ones, they had also taken the lives of others and therefore caused grief. Additionally, the wars in the 20<sup>th</sup> century brought an additional aspect of silence, as the returning soldiers often refrained from verbalising their experiences of losing fellow soldiers or killing enemy soldiers (Walter, 1999). Similarly, the civilians who lived through one or both world wars often adopted a stoic silence (Jones, 2016). These texts do however focus on evidence of records of written material and do not take in to account personal verbal communication between soldiers during or after the wars.

The introduction of hospices after World War II transformed the care for both the dying and their families, as the terminally ill received medical treatment and those who would soon be bereaved were offered counselling (Partridge, 2005). In the late 1950s and during the 1960s Saunders, who initially trained as a nurse, actively worked to develop hospice care in the UK (Clark, 2006). Although the dying patients were not in their own homes the hospice movement developed to provide more personal care than hospitals could provide (Overy and Tansey, 2013). Saunders (1959) wanted the dying to receive care not only for their physical pain but also be

given care and support for their emotional needs. Due to the lack of facilities offering such support at the time Saunders opened St Christopher's Hospice in 1967, after years of overcoming practical and financial obstacles (Saunders, 2003). She emphasised the importance of the dying person having the time to talk through any issues with their family while receiving, at times silent, support and a listening ear from the hospice staff. Similarly to Saunders, in the 1960s Kübler-Ross' (1969) work in the US focused on greater communication between the dying, their relatives and the medical staff. However, she developed her work with terminally ill patients in hospitals, interviewing and working with the patients themselves. The medical advances since the 1940s have brought great relief to the patients with regard to pain management, although Saunders (2003) pointed out that the terminally ill patient's search for meaning has been a present feature throughout her hospice work. A more open manner of communication, together with reduced physical pain, may have enabled the terminally ill to use the, sometimes short, time they had left to find meaning in their lives and in the present time. Breitbart's (2004) work with cancer patients, individually and in groups, focused on how individual patients' can find meaning in their own narrative while accepting that their life may shortly come to an end. As he aims to provide therapeutic care which is person-centred and holistic, there is space for each person's own meaning making following reflection of their experiences. Despite valuable work by the authors above, there are assumptions that the dying and their relatives had a close relationship. As my research is a phenomenological inquiry I have aimed to understand what the bereaved has lost, i.e. emotional, practical and social aspects, including how the psychological support for each bereaved individual could be increased. Additionally,

looking in-depth at the relationship would make it possible to work with close and difficult relationships alike, allowing for a multitude of emotions to be expressed in a non-judgemental setting. Although counselling psychologists have only recently been employed in palliative care (Golujani-Moghaddam, 2014) the National Health Service (NHS) is increasingly working towards offering psychological support to patients approaching the end of life and to their families (NHS England, 2014). Thus, while contemporary bereavement support may not be offered by extended family and friends it is becoming more available from counselling psychologists. An understanding of the historical perspective has been vital for my research, as the sociological change of grief has moved from being visible and expressed openly in society to the bereaved grieving in silence. I will now review models of bereavement in order to provide additional social and psychological understanding of the emotions following a death that may be experienced when losing a sibling in adult life.

## Sibling loss in adulthood and models of bereavement

Models of bereavement have been developed with the aim of understanding the emotional process and social aspects following a death (Dutton and Zisook, 2005). Some of the principal models and theories will be outlined below to establish an understanding of how theories and the practice of working with the bereaved have changed since the models were first established in the 1950s.

Bowlby initially became interested in loss when he studied children's reactions following separation from their mothers, leading to the development of Attachment Theory and later to studies of bereavement in adults (Bowlby, 2005b [1988]). Bowlby (2005a, [1979]) introduces four phases of loss following bereavement:

1. Phase of numbness that usually lasts from a few hours to a week and may be interrupted by outbursts of extremely intense distress and/or anger. 2. Phase of yearning and searching for the lost figure, lasting some months and often for years. 3. Phase of disorganisation and despair. 4. Phase of greater or lesser degree of reorganisation. As the majority of his work concentrated on children and their development (Bowlby, 2005b [1988]), his bereavement model is inevitably influenced by his theories of the separated child's anxieties. Bowlby (2005a, [1979]) recognises the differences between each individual's grief; however, he considers there to be clear similarities between the child's anxiety and the bereaved person's grief. He presents the anxiety experienced through separation and loss to be the human response to the attachment formed (Bowlby, 2005a, [1979]). He explains that when the person to whom the attachment was formed is no longer there, the healthy response is panic and anxiety. The emotional parallels he draws between the separated child and the grieving adult do however appear somewhat oversimplified, as the bereaved adult will have a more comprehensive understanding of death than a young child would have of momentarily loss of its mother. Further, the time span in which a child looks for its mother in Bowlby's studies is considerably shorter than the time which adults spend yearning for the deceased loved one. In his research the child was reunited with its mother while the bereaved adult could not be certain of meeting the deceased person again, depending on their views regarding the possibility of an afterlife.

Kübler-Ross (2003 [1969]) proposed a different grief model, containing five stages of loss; denial, anger, bargaining, depression, acceptance. Despite presenting loss as being experienced in stages Kübler-Ross (2003 [1969]) carefully pointed out the model's limitations. She considered the stages to be tools, which the bereaved can experience in a different order or possibly only go through some stages but not others. However, difficulties of applying the model may arise partly due to its broadness, as it was developed with both the dying and the bereaved in mind, and partly due to the model often being applied without flexibility or concern for the individual (Worden, 2010). The stages proposed by Kübler-Ross were introduced in the late 1960s when family and friends tended to live nearer to each other and therefore possibly have more frequent contact, while contemporary Western society, with its greater geographical dispersal of family members, has moved from considering mourning as a duty to suppressing the grief experienced (Parkes and Weiss, 1983).

Considering the two models above, Bowlby's (2005a [1979]) terminology for the phases of mourning differs from Kübler-Ross' (2003 [1969]), although the essence of the phases and the stages are similar. Taken together, Kübler-Ross' and Bowlby's work summarise the long process of grief together with the strong and complex emotions experienced by the grieving person, which initiated support from others outside the immediate family. However, the validity of Attachment Theory for

researching grief has been questioned due to its origin being in the mother-andinfant relationship, rather than separation caused by death (Kastenbaum, 2008). Additionally, the value of Bowlby's grief work has been questioned due to the lack of empirical evidence and his focus on the pathology of grief (Archer, 2008). Parkes (1996), a UK-based psychiatrist whose work connected him with Bowlby, Kübler-Ross and Saunders, initially proposed four phases of grieving; numbness, pining, disorganisation and despair, and recovery. He argues that a bereaved person's emotions can oscillate between the different phases for months and even years, providing the example that a photo can re-initiate the pining. Since his initial presentation of grief Parkes, in collaboration with Prigerson, propose abandoning the phases and instead viewing grief as a process during which emotions and experiences connected to the deceased overlap (Parkes and Prigerson, 2010). The theories and models above appear to assume that bereaved people had experienced similar relationships with the deceased and would grieve in similar manners. Therefore the theories and models do not account for relationships that are either strained, indifferent or excessively dependant (Gamino et al., 1998). The expectation of relationships and grief leaves minimal space for the bereaved person to express their individual emotions, experiences and process. Indeed, the idea of stage models of grief has been questioned numerous times since they were first proposed and as society has changed, which will be further investigated below.

The clinical psychologist Bonanno (2009) challenges Kübler-Ross' and Bowlby's theories of stages, specifically focusing on how these theories of bereavement were not devised specifically for the bereaved. The stages therefore refer to numerous

people and a variety of situations, possibly simplifying the relationships and emotions of those involved. Furthermore, Bonnano (2009) highlights how Bowlby's work derived from his work with children who had been separated from their parents or caregivers, creating attachment difficulties, rather than how children or adults deal specifically with loss caused by death. Although Bonnano (2009) agrees that these theories contain some value he emphasises that grief is more complicated than presented by Kübler-Ross and Bowlby. When researching contemporary grief, Bonnano's (2009) main concern about stage model is the lack of space for the individual and the unique relationship between the bereaved and the deceased. He warns that the bereaved may possibly comply with the advice from a professional, rather than grieving in a manner that feels right for them. Deciphering between individuals' different experiences is also seen as crucial to the research presented in this text, as each sibling relationship is unique. Furthermore, should the stages be regarded as the norm both the bereaved person and those who try to offer support could feel that they are not coping or helping if they do not fit in to the proposed stages (Cohen Silver and Wortman, 2007).

In their longitudinal quantitative study Maciejewski et al. (2007) argue that, at the time of writing their article, the stages of bereavement proposed by Bowlby (2005, [1979]), Parkes (1996) and Kübler-Ross (2003 [1969]) were based on theories, without empirical evidence. Maciejewski et al.'s (2007) findings show that following a natural death the bereaved participants reported acceptance as the most experienced stage, and yearning was the strongest negative emotion over a 24 month period after the loss, with the participants expressing feelings of depression,

disbelief and anger although less prevalent. It appears that previous models of grief emerged from work with both the dying and the bereaved, with the intention of providing a framework for both these groups. Despite the lack of empirical evidence I believe the models were of value at the time, as they defined the different emotions during a time when death often took place at hospitals, away from the family and the home. Maciejewski et al.'s (2007) study puts the individual in the centre by investigating each participant's grief at different times, adapting the stages of grief to a modern society in which the personal experience forms the basis for the theory.

Similarly to Bonnano (2009), Parkes and Prigerson (2010) emphasise the importance of considering the circumstances of the bereaved individual to allow for the person's own experiences, in order to avoid viewing grief as prescriptive stages or phases. They argue that the relationship between the deceased and the bereaved needs to be investigated in order to understand what has been lost, providing the example of how the death of a husband can involve the loss of all the roles he played in the widow's daily life, such as sexual partner, accountant or gardener. In a similar manner, Rubin (1981) regards previous theories to have missed the relational aspect of grief. The lack of focus on the relationship between the bereaved and the deceased prompted Rubin to develop the Two-Track Model of Bereavement (TTMoB) (Rubin, 1981; Rubin et al., 2009), with Track 1 being concerned with general or biopsychosocial functioning and Track 2 with the ongoing relationship with the deceased.

Rubin aims to understand loss throughout life by adding the unique relationship between the bereaved and the deceased. In particular, by researching what the bereaved individual misses about the deceased person greater depth of their understanding of the experience may be achieved and subsequently appropriate support could be offered.

Stroebe and Schut (1999) have further followed up the idea of the individual being central, as they present the Dual Process Model of Coping with Bereavement as an alternative to earlier theories of grief. They argue for the importance of the bereaved oscillating between grieving and still maintaining a relationship with the deceased. The relationship aspect is particularly interesting for my research, firstly as the participants' siblings had not anticipated their siblings death until several decades later and secondly as the individual relationship between each sibling couple would strongly influence the experience.

Similar to Bonanno and Rubin, Stroebe and Schut (1999) argue for a strong focus on the individual, rather than on pre-established theories by proposing a greater focus on in-depth aspects of the loss and the adaptation after the loss. Following reviews of existing theories and research they developed the Dual Process Model in which the bereaved is understood to oscillate between a loss orientation and a restoration orientation, rather than moving from one stage to another. Loss orientation involves the bereaved concentrating on emotions and experiences connected to the deceased, meaning that the loss is confronted. The restoration orientation includes situations and times when the bereaved is adjusting to life without the person they

have lost. For example, taking over tasks that the deceased used to carry out or becoming used to having a different identity, such as being a widow instead of a wife. Stroebe and Schut (1999) do not regard denial of grief to be negative, rather they consider the restoration orientation to be beneficial to the bereaved person's health as some respite is provided by the movement between the two processes. However, their theory is not prescriptive, leaving sufficient space for the bereaved person to grieve in the way most appropriate for them. This model is particularly relevant to my research, as it allows space for the bereaved sibling's individual emotions and experiences while not restricting these to a specific order. The orientation of loss and restoration may vary depending on whether the siblings were close and how much attention is given to other bereaved family members. Although the restorative models proposed by Rubin et al. (2009) and Stroebe and Schut (1999) allow space for the individual's own grief, there appears to be an assumption that the relationship between the bereaved and the deceased was healthy and caring. Greater attention to abusive relationships could allow emotions and experiences to surface once the abused feel safe. Sofka's (1999) article about grief and sexual abuse in childhood brings up the importance of psychologists working with abused clients considering the possible or actual death of an abuser, in addition to the grief for lost innocence and disruptions in relationships with other family members if the abuse was revealed and hence stopped.

In line with Stroebe and Schut (1999), Dent and Stewart's (2004) research and clinical work in the field of palliative care and bereavement emphasise how Kübler-Ross' five stages are referring to the person who is dying rather than to the

bereaved. Although Dent and Stewart's (2004) article focuses on families who have lost a child suddenly, the combination of their clinical and theoretical experiences in combination with personal stories from those bereaved, provide in-depth understanding of many of the grief theories and models concerning any kind of grief. While Dent and Stewart agree with Stroebe and Schut's view of considering the individual they emphasise the importance of the family, the culture and the society in which the individual lives. Hence, counselling psychologists and psychotherapists working in multi-cultural communities need to acquire an understanding of the bereaved person's background, culture and present circumstances in order to provide the best possible care.

Worden regards the models of mourning presented by Bowlby (2005, [1979]), Parkes (1996) and Stroebe and Schut (1999) to lack an active approach from the bereaved (Worden, 2010). Instead of the bereaved person passing through different stages or phases, Worden (2010) argues for a number of tasks of mourning being of greater benefit for the bereaved individual, whereby Task 1 is to accept the reality of the loss, Task 2 is to process the pain of grief, Task 3 is to adjust to a world without the deceased and Task 4 to find an enduring connection with the deceased in the midst of embarking on a new life. Worden's main critique of other models is the lack of flexibility, which he considers is necessary for a grieving process to take place (Worden, 2010). Hence, the tasks he proposes can overlap or occur in any order until the grieving person has adjusted to life without the deceased person. Although Worden strives to introduce a model with greater flexibility he, and the authors of the other grief models presented above, are assuming that the bereaved will feel

pain and the wish for an ongoing connection with the deceased, which does however, not account for abusive or indifferent relationships. Further, presenting a grief model to a person who has been abused may be experienced as controlling, which could remind them of the abuse and therefore be counterproductive. In addition to the specific relationship between the bereaved and the deceased each model was written in a specific time, in a certain social setting, which will be further explored below.

It is suggested here that each model or theory needs to be considered in relation to the time and society in which it was developed. Bowlby and Kübler-Ross' models were presented at a time when society and the family unit were less individualistic than today (Vale-Taylor, 2009). Kastenbaum (2011) argues that by searching for the experiential core of the individual's grief we will no longer need to refer to general models which are not based on empirical evidence. Indeed, I have aimed for my research to take the unassuming stance of the relationship between each participant and their sibling to allow for emotions and experiences in contemporary society and in the individual family constellations. The more recent models presented above by Parkes (1996), Parkes and Prigerson (2010), Bonnano (2009), Rubin (1981) and Stroebe and Schut (1999) provide contemporary ways of working with the bereaved. Additionally, the models, phases and theories above show how there has been a gradual move away from the earlier medical settings and theoretical models towards an understanding of grief where there is space for the individual to experience the emotions unique to their loss.

Worden (2010) echoes this as he argues for an increased focus on a multitude of emotions and a deeper understanding of the relationship between the bereaved and the deceased in order to comprehend what has been lost. McCabe (2003) presents similar ideas about grief theories in her presentation of comprehending loss to be a circular process rather than a number of stages. She regards the stages in grief theories as overly rigid, leaving insufficient space for the multitude of emotions and experiences following bereavement. By moving away from models and medical language she suggests that there can be space for individual and relational aspects of grief, thus creating a more comprehensive understanding of the experience. This is similar to my own experience as a therapist in numerous settings, and specifically in a bereavement organisation, where I have experienced how clients' grief is fluid and tends to oscillate. Indeed, allowing for the loving as well as the difficult emotions and aspects of relationships is at the core of this research. However, grief models do not appear to take a holistic approach to death and loss as something that is a natural part of living.

Based on my literature review, I find that despite the authors of grief models' intention of understanding the emotions connected to bereavement, they have a need to create neatly presentable models, leaving little space for the strong, and at times contradictory, emotions following a death. Similarly, in his theoretical overview of death Fairfield (2015) critiques bereavement models of trying to create a neat order of an experience that is unique to each person. He regards a deep understanding only to be possible when one has the freedom to relate to the death.

Following the theories presented above, empirical studies have in recent decades explored more diverse aspects of bereavement (Neimeyer, 2004), including the role of continuing bonds and attachment for the bereaved person's adjustment to life (Klass, 2006). Continuing bonds were introduced to facilitate the bereavement process by recognising that some form of the relationship would still exist, although naturally changed (Klass et al., 1996). A useful example of this is Stroebe et al.'s (2012) research, which involved 60 bereaved spouses, who took part in semistructured interviews and filled out questionnaires on three occasions during the first two years after the death. The qualitative and quantitative methods measured continuing bonds with the deceased, grief and depression. They suggest that continuing bonds can be explored by creating a deeper understanding of the unique relationship with the deceased and the attachment experiences of the bereaved. The findings showed that continuing bonds, although comforting to some, were not beneficial to all the participants, nor linked to greater adjustment. In particular the participants who had strong continuing bonds and lost their spouse suddenly struggled most to adjust after the death. Root and Exline's (2014) review of the empirical literature of continuing bonds further emphasises the need for greater nuances of the unique relationship and longitudinal research of healthy and less healthy grief processes. The importance of being unassuming about the bereaved wishing to have continuing bonds with the deceased was indeed an important part of my research, which will be discussed later. Small (2009) suggests that Bowlby's phases of mourning derived from linear and sequential concepts of time, while those bereaved may benefit more from a less ordered approach to time. He regards constructs of bereavement to stand in the way of the bereaved experiencing their loss without constraints of time, possibly preventing them from grieving at a natural pace. In a similar manner, Kastenbaum (2011) argues that contemporary grief research and literature should cease simplifications and instead aim to understand what is at the centre of the bereaved person's experience; the unique relationship with the deceased, a shared world or memories of a specific time in history. By moving away from pathologising and sequential ways of approaching grief he proposes that greater fluidity between theory and the individual's experience can take place. The acknowledgement of the individual person allows for a multitude of experiences following a bereavement, which I will explore further in the following section.

### The experience of bereavement

The actual experience of bereavement is complex, and multiple factors can impact on it: the relationship with the bereaved (Gilbert, 1996), how the death occurred and the social response (Parkes and Prigerson, 2010; Worden, 2010), experiences of previous losses (Castro and Rocha, 2013) and general physical health (Stroebe, Schut and Stroebe, 2007). Park and Halifax (2011) argue in a theoretical text that the bereaved can be helped by religious and spiritual traditions. They do, however, emphasise that it is the social support and rituals that aid the grief process, rather than the religion or spirituality. Similarly, McLellan (2015) state that a religious community is often experienced to be supportive by providing those belonging to it with a sense of continuity and create an understanding of the past.

A further aspect to the experience of grief is the level of expression allowed and expected by the community and society in which the bereaved person is living. Walter (1999) argues that the white English population, in particular the male part of the population, adhere to silent grief while bereaved people in Ireland, the Mediterranean countries and Orthodox Jews express their grief more openly. He points out that there is less social pressure on the bereaved in the UK to grieve in specific ways, although greater freedom can leave the grievers insecure about whether their emotions are normal and appropriate.

Blanche and Parkes (1997) state that the traditions and close communities of the Roman Catholic, Eastern Orthodox and Jewish faiths can provide structured and regular support for those grieving, while bereaved individuals in less traditional parts of society will rely on others to actively provide support without prescribed guidelines (Blanche and Parkes, 1997). The population in England today includes a great number of cultures, nationalities and religions, hence it cannot be claimed that there is a single culturally sanctioned way of grieving. Generalisations about communities appear similar to models of grief, as the individual relationship is not attended to. Rack et al.'s (2008) quantitative study focused on what kind of support family and friends could provide for young bereaved adults, following loss in the last two years prior to taking part in the research. The research investigated the specific circumstances around the death and the relationship between the bereaved and the deceased. They found that person-centred support from family and friends in form of listening and showing willingness to discuss memories were regarded as most helpful, in particular by the female participants; while impersonal advice or suggestions of social activities were not experienced as helpful. They aim to use the results to inform the public in how to support others following bereavement.

The debate about the similarities and differences between grief and depression has been ongoing in the 20<sup>th</sup> century in academic as well as clinical settings (Boelen and Prigerson, 2007). Literature about bereavement was limited until Freud (2005 [1917]) published 'Mourning and melancholia'. Today, grief and depression have replaced Freud's initial terms. Freud (2005 [1917]) presented the bereaved person as viewing the world as empty, while the depressed person experiences a lack of sense of self. He regarded the similarities to be the low mood and a lack of interest in the world. Worden (2010) suggests that both depression and grief include problems with sleeping and appetite while only those with depression express a lack of self-esteem.

Not all writers and researchers see a need to separate grief and depression. In her theoretical article about grief Hughes (2011) agrees that some aspects of the two can be similar, although she warns about grief being pathologised. Her concern is that grief and depression cannot be clearly separated and any diagnosis will depend on the psychiatrist's opinion. Hughes (2011) warns of treating bereavement with medication only, as she regards there to be a danger of the grief being suppressed. In a similar way, Parkes and Prigerson (2010) see grief as less divided. Instead of viewing grief as complicated or uncomplicated they consider grief to exist on a wide spectrum.

The latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM5) (American Psychiatric Association, 2013) stipulates that adults have persistent complex bereavement disorder only if symptoms of distress and disruption to daily life continues beyond 12 months following the death, as the emotions experienced in the initial year are considered to be part of the normal grief process. This disorder can be diagnosed if the bereaved continues to struggle to accept the death or is behaving considerably different to cultural, religious or age norms (American Psychiatric Association, 2013). In differentiating between grief and a major depressive episode the American Psychiatric Association (2013) present the former to include emotions of emptiness and loss while the latter is seen to manifest itself through a constant depressed mood without being able to feel happiness or pleasure; however a person may have both disorders. Kinderman (2014) objects to the psychiatric diagnosis of bereavement, as he considers the emotions following the loss of a loved one to be natural and ought not to be pathologised or medicated. Additionally, he disagrees with setting a time limit for how long the bereaved should grieve for, stating that missing someone we love is not an illness which we can be cured from.

Indeed, I have aimed to research grief experienced by adult siblings holistically by looking at the social, personal and spiritual dimensions in order to explore the psychological impact of the bereaved in conjunction with knowledge of the finality of the death. Thus, the bereaved individual would benefit from greater social support and access to therapeutic care specifically tailored to their personal needs and experiences. As I discovered during my research, a void of acknowledgement is

common when there is stigma connected to the death or when some of the bereaved are regarded by society as having less of a right to grieve. In particular, the experience of bereaved adult siblings has not been researched empirically within the field of counselling psychology. However, in order to understand this experience I will firstly review the emotional, social and often complex aspects of relationships between living siblings.

## **Sibling relationships**

Emotions experienced between siblings can vary greatly, as supported by Stocker et al. (1997), who carried out a quantitative study with undergraduate students in order to investigate sibling relationships in young adults. Three main dimensions emerged in the research: warmth, conflict and rivalry, depending on the individual relationship. One dimension did not exclude one or both of the other dimensions and the participants reported fluidity in their relationship with their sibling(s). Although this study provides a useful starting point for researching adult sibling relationships, the pre-established scales used for psychometric testing limit the participants' freedom to express their individual experiences. For researching the personal emotions of sibling relationships qualitative methods would provide greater depth and allow for the social and cultural aspects of the research topic (McLeod, 2001).

Contemporary aspects of sibling relationships include the increasing geographical movement of populations and different levels of emotional closeness or distance

(Eckel, 2015). In his review of sibling literature Sanders (2004), a lecturer in social studies, puts forward the need for a reviewed understanding of sibling relationships based on empirical data following a century of theoretical work and observations in staged settings. By moving away from analytic models and measurable components, such as age, number of siblings, birth order etc, and instead considering social and relational aspects Sanders aims to provide an understanding of the complex layers forming sibling relationships and by including the whole family he strives to add depth to the topic. He concludes that each sibling relationship and each family needs to be considered individually to understand the various dynamics. Thus, contrary to earlier psychoanalytic work, which applied theories to real life, Sanders argues for an inductive approach to research.

Similarly, Bank and Kahn (1982) have researched the complexities of sibling relationships. During their research they conducted interviews with siblings, from young children to the elderly, and subsequently propose that each sibling needs to tolerate each other's personalities and values on a daily basis to have a healthy and supportive relationship. Should these needs not be met in childhood or adolescence Bank and Khan (1982) consider it to be unlikely that the siblings would be able to maintain a relationship in adulthood. However, they argue that most adult sibling relationships include both frustration and the provision of support to each other. Therefore, each sibling relationship is unique and will depend on the efforts put in by each sibling.

Cicirelli's (1995) writings on siblings share many of the topics presented by Bank and Khan (1982) above, although Cicirelli (1995) takes into account aspects outside of the nuclear family and therefore provides a more in-depth understanding. Cicirelli (1995) acknowledges a number of issues likely to influence sibling relationships, starting with the diversity of sibling relationships such as biological siblings, half siblings and step siblings. He points out how industrialised societies define siblings depending on biological or legal criteria, while non-industrialised societies have less rigid definitions of who is a sibling.

Therefore, research about losing a sibling needs to take into account the society in which the siblings have lived to understand the impact of the loss. Further, Cicirelli (1995) points out how different environments outside the immediate family will influence the siblings as individuals and how the culture in which the siblings grow up in have influenced the relationship. Thus, the relationship between siblings in childhood also involves parents, teachers, extended family members and other adults. The involvement of adults during childhood needs to be considered with divorces and separations in mind, as parents and step-parents will decide how much time the siblings spend together (Milevsky, 2004).

The social worker and psychodynamic psychotherapist Edward (2011) further investigates the cultural influences on sibling relationships by reviewing theories, research and clinical case studies. Her monograph aims to increase understanding of emotions such as envy, sibling rivalry and the developmental causes of healthy and unhealthy siblings relationships. She points out how siblings in the Western world

lead considerably more separate lives than siblings who are from other parts of the world. Social responsibilities between siblings, in childhood or in adulthood, are presented as minimal in the Western world, while the eldest in non-Western cultures often have considerable involvement in their younger siblings' upbringing. When families migrate to a Western society, such as the US or the UK, Edward (2011) describes how the oldest sibling's responsibility may be increased, should the younger siblings as well as the parents need practical and linguistic help. Therefore, an implication being that an understanding of the relationship between siblings will require detailed background knowledge about the family structure and the culture(s) involved, in order to gain a comprehensive assessment of emotions and social issues.

In some cases the relationship between siblings can be abusive, rather than caring (Desautels, 2008; Sanders, 2004). Notably, abuse within the family has only recently been recognised as a social matter, although of course it is not a new occurrence (Appignanesi, 2008). Wiehe (1997 [1990]) has researched sibling abuse, which like other relational abuse can be manifested in physical, sexual or emotional ways – or a combination of these. The research is presented in a book, which was published in order to make abused siblings, parents and professionals aware of the signs of sibling abuse. He explains how some behaviour is age appropriate, such as an interest in physical gender differences being natural in toddlers while a young teenage boy's interest in his three-year-old sister's body should be taken as a warning of an abusive relationship. Additionally, Wiehe (1997 [1990]) tells how children often convey abuse in subtle ways to their parents, and adults who were abused as children may present with problems to mental health professionals

without making links to the abuse. Hence, parents as well as health professionals working with siblings of all ages can improve care by recognising the signs of abuse in order to prevent abuse and provide suitable care for their children, clients or patients who have been abused. Having looked at these complex relationships, the following section will review literature about bereaved siblings and the social difficulties they can encounter in relation to their loss in order to further explain the rationale for the current research.

#### **Bereaved siblings**

The loss of a sibling is a specific kind of loss and is often not recognised nor researched in the way that the loss of a partner, parent or child is acknowledged (Osterweis et al., 1984). This is reflected in the work of De Vita-Raeburn (2004), Wray (2003), Sandmaier (1994) and Berman (2009), who have written about their personal experiences of losing a sibling including the lack of support and acknowledgement and the lack of available literature about sibling loss. Although these writers have not carried out academic research on the topic, their books expose the difficulties of losing a sibling. Wray combines her academic experience as an associate professor of religious studies with her personal experience of losing a sibling in adult life. De Vita-Raeburn (2004) and Sandmaier (1994) argue that the experience of losing a sibling is difficult to define, as there is minimal recognition of the psychological impact for this kind of loss. Similarly, Wray (2003) states that the recognition bereaved siblings often wish for tends to not be available, as the loss is not considered a major loss. This is reiterated by Berman (2009) who is a writer specialising in the emotional

aspects of family relationships. She combines her background in journalism with her experience of losing her sister to understand her own loss and to inform others on how to provide support to bereaved adult siblings. Hibbert (2013), a clinical psychologist by profession, published a book following her experiences of losing her sister suddenly.

Although her profession meant she had the necessary experience to write an academic text, she decided to write a memoir reflecting emotions and pressure to support others, similarly described by other authors presented. This choice speaks about the importance of presenting the unique psychological experience of losing her sister and the difficulty in coping with the emotions following the sudden loss of an adult sibling. The above authors describe struggling with the absence of care, as many people around them were unable to show care verbally or in other ways. They identified three main areas of concern: namely a lack of written texts about sibling loss, lack of contact with other bereaved siblings and lack of social recognition of their loss.

Authors such as De Vita-Raeburn, Wray, Sandmaier, Berman and adult bereaved siblings report similar difficulties. Finding written information and emotional support appears to depend on several factors. Firstly, the general sibling literature often refers only to living siblings, omitting literature about siblings who have died (Robinson and Mahon, 1997; Cicirelli, 1995), which could deter bereaved siblings from reading it. Secondly, support groups for bereaved siblings tend to be subgroups within either bereavement support organisations (The Compassionate Friends, 2012) or bereavement services offering counselling for many kinds of

person may have difficulties in concentrating (Howarth, 2011), making it more difficult to search for information and support. It is this lack of research that lends particular support for the aims of the current research.

This said, adult sibling loss has been researched in medical settings, where the participants have been recruited due to their siblings' actual or possible future physical health issues, or following a sibling's murder or suicide. Herberman Mash et al. (2013) have researched young adults' experiences following the loss of a sibling or friend. 107 participants aged 17-29 took part in the research; 66 had lost a close friend and seven had lost a sibling in the three years leading up to the research, with the remaining participants not having lost anyone significant. The data was analysed using Statistical Package for the Social Sciences (SPSS), with findings showing that the bereaved siblings experienced more complicated grief and depression compared to the participants who had lost a friend. Although this research is interesting in relation to my own research, the focus on a possible psychiatric diagnosis of complicated grief shows how the medical aspect of grief in the United States is strong, which together with the broad participant criteria, point to the strong link between a country's history and culture of grief.

Sobel and Cowan's (2003) study about ambiguous loss and disenfranchised grief, which investigated families who had been DNA tested for Huntingdon's disease, showed how the entire family struggled with potentially losing a sibling, child, spouse or parent, as the life cycle had been greatly challenged for the entire family.

The adult siblings in the study had greater concern for their parents' loss of a child than for their own loss of a sibling. The primary family, i.e. the spouse and children, of the person who died is often perceived as the chief or only mourners, leaving adult brothers and sisters without recognition and support (Riches and Dawson, 2000). The concern for others, and parents in particular, has been research by Pretorius et al. (2010), in their study of adults in South Africa whose siblings had been murdered, analysing the data using Van Manen's (1990) hermeneutic phenomenological method. Three female participants aged 21-39 who lost their brother were interviewed. The findings showed that the participants often felt the pressure to take on a caring role for their own parents, which meant that the family members did not grieve together, leaving the participants without recognition and support. The participants reported conflicting emotions towards their parents; wanting to support them and not burden them further, while at times feeling resentful for not being emotionally supported by them. Powell and Matthys' (2013) study of siblings of those who had committed suicide echoes these findings. 45 bereaved siblings aged 20 to 75 took part in semi-structured interviews and an interpretive method was used for analysing the data. The participants reported frequently being asked how their parents were coping and, due to not being used to having to support their parents, initially appreciating others' concern for their parents. However, similarly to the literature presented in the beginning of this section, they gradually felt that their parents and society in general did not acknowledge that they were also grieving for their sibling.

The difference between a death preceded by an illness and a sudden death needs to be noted here. An ill child would require the parents' time, restrict family outings and may affect the mental wellbeing of all members of the family (Havermans et al., 2011). Following the death of a brother or sister with a long-term illness the remaining sibling(s) may experience unresolved grief for several years without sufficient psychological support, as their well-being is often overlooked by professionals and family (Sveen et al., 2013).

The sudden death of a sibling will naturally be a shock for the entire family, making it difficult for parents to cope with both their own and their remaining children's grief. Parents provided with psychological guidance on how to support their remaining child or children can increase communication in the family and in this manner acknowledge their grief (Horsley and Patterson, 2006). Whether the death occurred following illness or suddenly, the most important issue appears to be what has been expressed by several authors, as described above (Osterweis et al., 1984; De Vita-Raeburn, 2004; Wray, 2003; Sandmaier, 1994; Berman, 2009), namely the recognition of the sibling's own loss and grief.

Switzer et al. (1998) carried out quantitative research about the psychosocial aspects of living organ donation following bone marrow transplants between siblings, in particular when the receiving sibling died. The research found that despite the ill sibling not always being saved by the donated bone marrow, the donors reported greater closeness to other family members, providing meaning and comfort at the immediate time before and after the donation. The findings suggest greater co-

operation between the physicians and psychological professionals in order to provide long-term psychological support for donors, as the research showed that emotionally difficult aspects emerged several months after the donation. In this manner, referrals from specialist medical institutions to counselling psychologists or psychotherapists could provide improved care for organ and tissue donors.

A longitudinal quantitative study carried out by Rostila et al. (2012) investigated sibling loss in adulthood with a focus on the increased mortality rates of the participants compared to siblings who had not been bereaved. The research investigated how the participants' health, and deterioration of health, was affected by their sibling's death. Their conclusion is partly in line with other bereavement texts (Kübler-Ross (2003 [1969]; Rubin, 1981; Rubin et al., 2009) in that terminally ill patients and their families need support during the illness as well as after the death, although with the specific recommendation that psychological support should actively work towards including adult siblings not only at the time of the illness and the death but should also follow up on physical and mental health in the long-term. By providing emotional and therapeutic support, and therefore recognition of the participants' loss, Rostila et al. (2012) argue that decreasing physical and psychological health can be prevented. Similar to Switzer et al. (1998) above, Rostila et al. (2012) identify the lack of collaboration between the medical profession and psychological support, which suggests that the medical professions are increasingly moving towards referring patients to therapeutic services.

When researching the present literature on my chosen topic the question inevitably arose of why bereaved adult siblings often seemed not to be considered by family, friends and society. Lamerton's (1980) book based on his experiences of working in palliative care and articles previously written refer to the family as an entity, rather than as individuals, which reflect the time of his initial work in the 1960s and 1970s. His concern for the dying includes concern for those who will soon be bereaved or who have already been bereaved. Due to contemporary Western society having evolved rapidly to be less focused on the family as a group, as presented by Lamerton (1980) above, and instead concentrate on the individual it appears adult siblings are no longer regarded as immediate family. Thus, care and support is not available for this group.

In their review of hospice care and support for those who lost a sibling to acquired immunodeficiency syndrome (AIDS) Robinson and Pickett (1996) point out the difficulties in researching the topic, as literature about siblings mainly focuses on experiences in childhood and literature about bereavement rarely take adult siblings into account, as previously stated. Their reviews of different theories and research concludes that support needs to be tailored to the individual depending on the relationship between the siblings, as well as how much, or little, energy the bereaved person has. Although the medically based settings presented above have limitations, as regards of considering the social and psychological needs of the individual or the relationship between the siblings, these settings could be useful for finding participants for future research about sibling loss in adulthood.

In his theoretical text of sibling relationships Cicirelli's (1995) presents the future in relation to the implications of long-term loss by focusing on how the absence of the sibling in adulthood and old age continues to be part of a person's life. He established that sibling relationships are not always necessarily close, however a relationship, whether supportive or not, has been eradicated by the early death. Hays et al.'s (1997) quantitative study focused on physical health, social support, mood and personal finances in later life. They found that older bereaved siblings had decreased function and cognition compared to those who had not lost a sibling. The participants regarded their health to be generally worse than the health of others in the same age group, showing that the loss of sibling in adult life can have a negative impact on many areas of a person's life. As presented above the relationship between the siblings in childhood, adolescence and adulthood will influence the experience of losing a sibling. Robinson and Mahon (1997) stress the importance of the shared history of the family in which the siblings grew up in, although the emphasis on their experiences of the family may vary, depending on whether the relationships were caring or abusive. Although medically based research commences with physical concerns as seen above, the awareness of the psychological aspects of loss increasingly takes a more holistic view of health and well-being. In order to increase the use of present and future research about bereaved adult siblings in the medical field closer work with counselling psychology could improve the clients' psychological well-being, should they be offered therapeutic support in for example Improving Access to Psychological Therapies (IAPT) services or through palliative care settings.

When the relationship between the siblings has been difficult on a temporary or permanent basis the emotions following a sibling's death can be further complicated due to the unresolved issues (Packman et al., 2006). In their theoretical article about sibling bereavement Packman et al. (2006) argue that children and adolescents should not be pressurised to have continuing bonds with their dead sibling if the sibling had been abusive. They present continuing bonds between siblings to often exist naturally, although in the absence of such bonds the bereaved sibling should not be made to create any bonds unless they express a wish to do so. Furthermore, the article points to how an abusive sibling relationship may be a manifestation of parental neglect and other unhealthy or abusive relationships within the family. This can be seen in Green's (1984) case studies about intergenerational abuse focusing on children who were abused by their parents and in turn abused their younger sibling. Hence, this shows that taking an unassuming stance about the relationship between siblings is vital to allow for exploration of abusive relationships. Similarly, in his writings about bereavement Weiss (2001) highlights how adult siblings can experience previously dormant emotions following the death of their sibling. When a relationship has been of a bitter and hurtful nature, he presents the loss to be distressing but not overwhelming. Thus, bereaved siblings need to be allowed to have the emotions appropriate to the relationship with the dead sibling, rather than the emotions possibly expected by relatives, friends and society.

Doka has published numerous books and articles based on his experiences of working within the medical and hospice professions. In a theoretical chapter he presents the idea that loss can be disenfranchised (Doka, 2007), which is similar in

meaning to the term 'the forgotten bereaved' (Wray, 2003, p.22). Grievers who are not socially recognised can become isolated, as others do not regard them as having the 'right' to mourn (Mallon, 2008). Doka (2007) points out that every society and culture has specific norms and rules for grieving, including who should grieve and in what manner. He claims that certain groups may therefore not be recognised as grieving, for example those who are not kin to the bereaved, although they were emotionally close, i.e. friends or colleagues. Further, he draws attention to the kinds of deaths which may carry stigma, such as suicide, deaths following a self-destructive life or deaths caused by AIDS. Thus, support needs to be fluid in order to include a true reflection of relationships and circumstances in society, including step-siblings and half-siblings.

In her study of support groups Pietilä (2002) interviewed people who had lost a child or a parent through suicide in adult life. She used membership categorisation device (MCD) to analyse the data with the aim to understand the participants' descriptions of their every day life and the social implications of their loss. The study showed that some of the interviewees regarded themselves to 'own' the grief and felt the right to deny others the space to grieve. The idea of grief being 'owned' may explain why many adult bereaved siblings feel there is no room for them to grieve, since the parents, spouse or children of the dead sibling consider themselves to 'own' the grief.

Pietilä (2002) observed the same difficulties of grief 'ownership' during group sessions as several group members felt that they had a greater right to grieve than

the other members of the group. Although the group members found the support groups helpful they voiced their frustration that their particular experiences were not recognised as more important than those of other group members. Pietilä's argument puts the terms 'forgotten mourners' and 'disenfranchised loss' mentioned earlier in a different light. She argues that social support is withheld actively, as one grieving person is unable to see how anyone else has the right to grieve the same person. The bereaved are thus each fighting for their individual right to be the main griever instead of finding support from each other. During my work as a bereavement therapist, this is something I have been aware of many times. Although it often puzzled me, I was also intrigued about how one person would regard their grief to be more painful than the grief of another person. What remains unclear from Pietilä's research is how the individualistic thinking of one person having a greater right to grieve has developed for the interviewees and in the society they live in.

Flomenhaft (2006) has further researched the psychological need for support after losing an adult sibling. He researched the experiences of thirteen siblings who lost their brothers after the bombings of the World Trade Centre. They named themselves 'the forgotten ones', similar to the terms mentioned previously. His research shows a division of care within the family and in society; the findings reveal how the bereaved siblings were expected to cope with both practical and emotional issues, in order to support their parents and the sibling's widow. In addition to lacking acknowledgement of their grief from their own families, society and media chose to portray the victims' parents, spouse and children as main grievers.

Flomenhaft's observation of the lack of support for siblings did however bring the positive outcome of a support group for siblings being set up.

The literature above emphasises the importance of taking into account the individual's circumstances for determining if and what kind of support may be available and required. Much of the literature and research suggests that changes in society, community and family, together with the unique relationship with the sibling are at the core in medical as well as therapeutic settings, although relevant research is scarce. In the following section I will review the literature from the vantage point of my work as a practitioner and researcher, in particular with regard to the existential literature which specifically explores the relational and social aspects of living.

# **Existential literature**

Existential philosophers will be able to throw light onto our existence, what it means to be alive and how we make sense of death, those of others and our own potential death. Their work will allow for exploration of my research topic without applying medical models, pre-existing theories or judgements of the experiences. Instead the subjective experience of the individual is central in existential therapy, as it is in counselling psychology; the therapist works with the client to actively improve the latter's psychological health. The previously presented literature is complemented here through examining the uncertainty of health, relationships, social change and

life expectancy from an existential perspective. By exploring how a person is in the world and how they relate to others (Heidegger, 1962 [1927]; van Deurzen, 2010; van Deurzen, 2009) existential therapists can create a comprehensive understanding of what each individual client has lost. Further, an existential view can facilitate an understanding of a person's lived experience by finding one's personal will and self while living with the despair this may cause (Kierkegaard, 2004 [1849]). Barnett (2009) suggests that existential therapy is beneficial for grief work, as it takes a holistic approach while at the same time allowing for the bereaved person's experiences to be central for the therapy. In particular, the combination of personal and social aspects in existential therapy allow for a phenomenological exploration of what the loss has meant for an individual, which may facilitate greater social interaction and re-establishment of relationships following bereavement (Madison, 2005). By researching bereavement holistically the person's relationship with their own spiritual beliefs may be understood, which together with their environment and relationships with others may provide greater insight in to the experience of bereavement. Further, an existential outlook highlights the importance of recognising the limitations of time and life in order to live life fully (Young, 2009).

I will present existential literature to explore the great variety of emotions and, at times, complex relationships following bereavement. Specifically, a person's way of beingin-theworld can be greatly challenged by losing a sibling, depending on the relationship and subsequent changes in the family and social structure. The sense of meaninglessness that may follow bereavement can become an enriching experience, if new opportunities are sought out when old ways of living and being can no longer

be continued. The following section will consider existential texts which focus on relationships and the perception of time and space.

#### **Existentialism and relationships**

As we are never isolated in the world, but always exist in relation to others (Buber, 2004 [1958], Sartre, 1969 [1943]) bereavement therefore needs to be understood in relation to others. Heidegger's (1962 [1927]) hyphenated words, Being-in-the-world, illustrate the connection between individuals and their environment; his concept presents relationships as existing together, without clear divisions. Being-in-theworld does not only concern the physical world but also the world where people relate to others, themselves, their work and interests. This concept, which can at first appear to simplify human existence, is instead multi-layered and complex. The physical, social and personal dimensions were first presented by Binswanger (1963), who was influenced by Heidegger's philosophy, to facilitate the individual's holistic understanding of their life, to which van Deurzen (2010) later added the spiritual dimension. Van Deurzen's (2009) idea of an Existential space demonstrates the complexity of how physical, social, personal and spiritual space overlap, particularly at times of crisis. The merging of the different spaces introduces an understanding of how different areas of a person's world can meet and overlap to an extent while still being separate. To provide an illustration using my research, the overlapping of the worlds would aid the exploration of how for example changes in the personal world will have a strong impact on the social world, which will be investigated further in the discussion. Heidegger's concept of Being-in-the-world provides an understanding

that people are not isolated but live in a relational world. However, as Macquarrie (1973) points out, humans and philosophy are situated in specific times in history. Thus, to use Heidegger's ideas of relationships for research we would need a comprehensive exploration of the society and time the participants live in.

Chessick (1986) argues that Heidegger's negative view of urbanisation and science in the 20<sup>th</sup> century mirrors the latter's reclusive living without appreciating improved social and economic improvement for the majority of the Western population. However, people often die in hospitals, rather than at home, making the death hidden and removed from the community (Young, 2009). In his client work with dying patients in the NHS Mandic (2008) highlights how a person may talk to a medical professional or their therapist, rather than a family member or a friend, about how to live the short period of time that they have left. Similarly, Lockett (2009) expresses her concern that counselling for cancer patients could have the result that important conversations with close friends and family would not take place. Although people who are dying may talk to family members and friends as well as professional staff, it appears that there is a void of enquiring what the dying person and their family would find helpful, for example therapeutic support to facilitate conversations of a difficult nature.

Heidegger's term Dasein, translated as being-there, is grounded in the idea that as human beings we are always in the world with others, meeting, caring and being together in a continuously changing world (Heidegger, 1962 [1927]; van Deurzen, 2010). We are always in relation to others and to our own experiences. People meet in a specific time and under specific circumstances, bringing with them their own

history and their intentionality. Each person will have their own intentionality of how they engage with others and the world, deriving from their experiences (Heidegger, 1988 [1975]). Therefore, the encounter between two people can never be existentially separated, as the past and present become entwined when meeting another person. Heidegger (1962 [1927]) presents hermeneutics as an important part of understanding human existence through the interpretation of both the speakers in a conversation. His ideas about being-with-Others are interesting in relation to the level of support provided or not provided by those around a bereaved person. Care, according to Heidegger (1962 [1927]), is not something which can be found in a specific incident or which can be explained in simple terms. Rather, he regarded it to be a part of Being-in-the-world, something which people show each other through their actions. However, those who have been bereaved often express feeling alone in their grief, yet being surrounded by others (Young, 2009). Heidegger (1962 [1927]) describes concern as always present between people but further explains that when concern is deficient things are not carried out in the fullest or most caring ways. Therefore, what is experienced is not the care offered between people, rather it is what has not been done or said. Although we know that we will die at some point thistends to only cause us anxiety when the impending death is our own or that of someone close to us. Thus, bereaved people may experience a strong sense of loneliness when being reminded of their own mortality, as others are in denial of their own death. In his phrase Being-towards-death Heidegger (1962 [1927]) argues that we can be authentically with death by accepting the limited time we have and living this to the full. Hence, this awareness could make us relish our daily experiences while at the same time possibly causing anxiety about the timelimitations of our lives. Yalom (2008) presents this oscillation to be a means of protecting ourselves, as the awareness of our own death would cause unmanageable levels of emotional distress if experienced on a constant basis. Bereaved adult siblings may well develop an increased sense of Being-towards-death, therefore living their lives more authentically then prior to the death. Ontological awakening following traumatic bereavement has been researched by Paidoussis-Mitchell (2012), resulting in five themes; the embodied experience, experiencing the loss of meaning, the ontological awakening, searching for meaning and the spiritual awakening. Unexpected, sudden loss is presented as particularly challenging to the bereaved person's being and meaning making, leading the researcher to conclude that existential-phenomenological therapy would be beneficial to those who have been traumatically bereaved. This resonates with my research and work in bereavement services, as many bereaved adult siblings lost their sibling without little or no warning, which often left them in great distress and without others' verbal recognition of their loss.

In his writings about language Heidegger's student and subsequent colleague Gadamer (1976) argues that speaking includes a "we", rather than simply an "I". At first sight this seems similar to Heidegger's being-with-Others, although looking closer Gadamer's focus on the language takes meetings and conversations to a different level by showing how a person can be excluded or included through verbal interaction. Gadamer (1975) acknowledges that people meet in the world, as Heidegger suggests, however, he insists that every person and the context of each meeting should to be understood as unique. For people to truly meet in a

conversation each person needs to acknowledge the other person's view, which allows for a hermeneutic conversation and a mutual language to develop (Gadamer, 1975). When the bereaved adult siblings' grief is not recognised by others the siblings become excluded from both a "we" and verbal meetings that could have supported them. Gadamer (1975) argues that in the process of experiences being conveyed in language, the hermeneutic experience is stretched to a new level. Although Gadamer's ideas are interesting, he is making the assumption that people would be able to develop a mutual language. As seen in the literature presented above bereaved adult siblings often experience a void of verbal recognition and support. Therefore, the experience of sibling bereavement remains untold and those involved will not have a conversation of a hermeneutic nature.

Heidegger saw the need to move beyond phenomenology and used hermeneutics in order to interpret what was being explored, which has come to be known as the hermeneutic turn (Langdridge, 2007). A hermeneutic experience could possibly be through art or music but the research proposed here is firstly concerned with how the experiences are expressed and interpreted through language, in spoken or written form. It should be noted that hermeneutic research can never leave out the person who is analysing the text, nor can there be any certainty that the interpretation will include an exact understanding of the very issue which is being investigated. Therefore, the interpretation of the text needs to pay very close attention to the many levels of the words spoken, so as not to make general assumptions or draw hasty conclusions. Hermeneutics applied to research is presented by the social scientist Giddens (1987) as the double hermeneutic, due to the interviewee having interpreted their own experiences, which in turn are

interpreted by the researcher. Single hermeneutic research is used in the natural sciences, where the researcher is required to understand for example the chemical reaction without further interpretation (Danermark et al., 2002). Although Giddens (1993) in his later work acknowledges that a double hermeneutic analysis of scientific discoveries is possible, as science is part of the social world we live in, he regards it to be limited due to the findings only being interpreted by the scientist. However, he suggests that sociological studies of science could use hermeneutic phenomenology to deepen research in scientific fields, as the social aspects of participants' lives would be analysed in combination with their illness or health. By adopting the double hermeneutic it is possible to reach new and deeper levels in the research, including areas which have not previously been researched, such as the perception of time and space which will be presented in the next section.

#### The perception of time and space

When searching for literature it became clear to me that the potentially changed understanding of time and the view of the future in relation to bereavement have often been overlooked. The French psychiatrist Minkowski (1970) writes that one's own mortality, but not necessarily one's death, becomes visible when another person dies. He regards the encounter with death to create the first understanding of the limits to one's own life. Those who lose a sibling, or another close relationship, in early adulthood or middle age may therefore come to this understanding earlier than those whose siblings live a longer life. The future could therefore have a new limit, in which the knowledge of one's own death is present (Minkowski, 1970).

Minkowski (1970) argues that life consists of activity or expectation, the former being a process of becoming, while the latter can hold a person in moments of pain or joy. Thus, activity is about moving towards the future and expectation is in the present. Adopting these ideas for understanding the experiences of bereaved adult siblings, their lives will be in constant movement as the activity of life cannot be changed or stopped. Neither can the emotions connected to becoming be avoided. For the bereaved time may therefore become a paradox through an increased awareness of the limits of life expectancy while grappling with comprehending the loss.

In contrast to Minkowski, Merleau-Ponty (2002 [1948]), another seminal existentialist, is less concerned with time and instead draws attention to the space human beings inhabit. He argues that people are embodied beings in space, constantly relating to other humans and objects. Specifically, he sees the body as central to a person's world, as the unified body and mind need to navigate life in the world. Applying this theory to my research could mean that the physical and emotional space of a person who had lost a sibling in adult life may change considerably, prompting them to review the relationships and the landscape that is their life.

A case study by Young (2009) illustrate the benefits of including both time and space to create a deeper understanding of the roots of a client's experience; a woman who came to counselling after having been in a minor accident. Young's client had a busy

life both privately and professionally. It was only when she was physically injured that she started to grieve for her mother, who had died more than twenty years earlier. It appears that having time off work and time to herself, allowed her to grieve (Young, 2009). Meanwhile, creating space for emotions and having physical space between herself and her otherwise intense life was vital for this bereavement work. Thus, by integrating Minkowski's work on the need for time and exploration of expectation and Merleau-Ponty's ideas of space in the therapeutic work could create a deeper understanding of bereaved clients' experiences.

Although much can be understood from the literature reviewed in terms of our way of being- in- the- world and human relationships there is equally something missing when it comes to specifically looking at adult bereaved siblings. My proposition is that it is a unique influential relationship, whether it is close or strained, so it is worthy of focussed attention, something that has been lacking to date. Greater exchanges between the experiential texts written by bereaved siblings themselves and the academic and professional areas of counselling psychology and psychotherapy could provide in-depth theoretical and therapeutic knowledge for clients who have lost an adult sibling. Additionally, counselling psychologists and psychotherapists may well have valuable experiences without having published anything on the topic. Therefore, this research could create greater awareness of this client group and lack of research, instigating greater enquiries about sibling loss in individual therapy and commencement of specific support groups.

## **Summary and research rationale:**

The aim of this study is to investigate the experience of bereaved adult siblings, using an interpretative phenomenological analysis, in order to investigate how society and counselling psychologists can better support this bereaved group. This kind of loss tends to be a significant life event, however, support needs to be unassuming of the relationship: whether it was loving, distant or abusive. There was a focus on whether the participants felt a need for support and if so, what kind of support would be helpful from family, friends and possibly from counselling psychologists. Additionally, I have aimed to include cultural and historical aspects to understand the participants' experiences.

Death and grief in UK society have gradually become less visible and verbal expression has also decreased. Bereavement models proposing a general way of how people grieve have given way to empirical studies, which have allowed space for the individual's emotions, including different religious and traditional aspects of grief. As seen in the literature above the relationship between siblings, which can be complex, needs to be explored without preconceived ideas to allow loving or distant relationships, as well as abusive experiences to be presented. Bereaved adult siblings are often forgotten by others and due to supporting their grieving parents, tend to not demand space and attention. Therefore, counselling psychologists need to be particularly aware of clients with this experience, in order to acknowledge this loss and the potential added pressure of caring for other family members.

Present research of my chosen topic is limited and often linked to medical settings. Collaborations between these settings and counselling psychology are however on the increase, as there is greater awareness of links between mental and physical health within the NHS. Bereavement theories and models of support and have generally held the assumption that a death will cause grief, however this does not take into account the unique relationship between the deceased and the bereaved which will affect the way in which the bereavement is experienced.

The limited social recognition and professional research of the topic provides a strong rationale for exploring the kind of support bereaved adult siblings feel would most benefit to them. In an increasingly urban society I anticipate that bereaved adult siblings will require psychological support from professionals, as families can be geographically distant and socially this type of grief is often not acknowledged.

Professional doctorates in Counselling Psychology have been developed relatively recently in the UK and this research will aim to contribute to the field. With today's criteria for becoming chartered all Counselling Psychology trainees are also researchers. In addition to theoretical and clinical work all Counselling Psychology trainees carry out their own research with the view to contribute to existing knowledge. By continuing to do research after completing their studies Counselling Psychologists can use their experience to enrich the discipline and share their knowledge with other professions. Although the BPS provides information about bereavement for the public and chartered psychologists of all divisions there is not a specific faculty for the topic. The positive aspect of this can be seen as bereavement

being included in many BPS chartered psychologists' work, for example disaster work or work with young children. However, my exploration of adult sibling bereavement has similarities to bereavement in the BPS in general and the division of counselling psychology specifically, in that there is not an easily accessible route for counselling psychologists to find research and information about different kinds of bereavement. Similarly, although there is bereavement counselling available through the voluntary sector, training for the volunteers may not be mandatory and therefore limiting the support for the bereaved. While the division of counselling psychology has a faculty for cancer and palliative care there is not to date a faculty for bereavement that has not been preceded by physical illness, something this research seeks to initiate. By creating a bereavement faculty within the BPS counselling psychology division extended experience of working with bereaved clients could be combined with new research to improve practice and develop the profession.

# **Research methodology**

This section begins with the rationale for the choice of method, the stance of critical realism as epistemological position, followed by a discussion of the philosophical background influencing the chosen method. Thereafter, a description of the method, the participants and the process of the analysis will be presented in order to provide

an overview of how the research was carried out. Lastly, a reflexivity section about myself as the researcher will be presented.

The aim of this study is to explore the participants' individual experiences of losing a sibling in adult life with a view of developing a deeper understanding of this, largely unacknowledged, form of bereavement. An in-depth understanding of the participants' losses involves gathering knowledge about their experiences and their process of meaning-making which can be achieved through qualitative research (Kvale, 1996). A qualitative approach was adopted in order to develop an understanding of how the participants' made sense of their lived experiences (Willig, 2012, Elliott et al., 1999). The focus on meaning and context in qualitative research allows for both the less neat and organised aspects of the participants' lives and the researcher's meaning making to be part of the research (Braun and Clarke, 2013). This view of qualitative research is further highlighted by Hunter et al. (2002), who argue that meaning making will be enriched by the researcher analysing multiple areas of the participants' lives; their personal experience of the topic researched, their socio-cultural situation and what the experience researched has meant to them. Despite appreciating and partly agreeing with Hunter et al.'s (2002) suggestions, the areas mentioned above appeared to be decided upon prior to the analysis, rather than deriving entirely from the findings. Following my experiences as a bereavement counsellor, a psychotherapist working within the NHS as well as privately and a counselling psychologist trainee I would consider qualitative research to be more true to the clients' experiences if the multiple areas mentioned were drawn from the findings during and after the analysis.

Researching the experience of adult sibling loss will inevitably include the participants' relationship with their sibling, their family structure and culture, amongst other aspects. Therefore, this research aims to develop an understanding of the participants' unique experiences without having preconceived ideas or hypotheses about their relationship with their sibling or their emotions following the bereavement, leaving the research and the analysis open to whatever findings arise. Further, the words used by the participants can play a greater part than simply conveying their story, as discussed by Polkinghorne (2005). He argues that by listening carefully to the specific phrases and expressions used by the participants a deeper meaning can be extracted. Therefore, a multitude of experiences will emerge from the analysis when using qualitative research. Additionally, there will be sufficient space for personal and in-depth findings that could not have been predicted prior to the research being conducted.

Parker (2005) argues that when qualitative research incorporates the researcher's interpretations with the data, new ideas are conveyed about the research area, which engage the reader's attention. In this way, he says qualitative research is more than a report on the results found, rather it becomes a creative text involving the participants, the researcher and the readers. Similarly, Smith (1995) emphasises the importance of the researcher's curiosity in qualitative research, as he considers this to be crucial for developing an understanding of the participants' experiences. Lincoln and Guba (1985) further stress the fluidity of the findings in qualitative research where there is a convergence of the participants' and the researcher's

ideas. By acknowledging the connection between the researcher and the participants, rather than dismissing it, both parties become integrated in the research and this integration brings new knowledge to the surface. While I agree with this idea I would advocate some caution regarding fluidity to ensure that the findings remain true to the participants' experiences, as well as the researcher being reflective about their previous research and therapeutic practice to provide clarity of the origin of the findings and the final presentation of the research.

Parker (2005) argues that qualitative research can open up and expand a topic in a way which scientific quantitative research, with its more formal and more mechanistic approach, will not do. Although I agree with these ideas as a general viewpoint about qualitative research, I would be cautious about stating what the researcher will find. To both decipher their understandings from, and connect the same, with those of the participants the researchers would need to be deeply reflective about their own backgrounds and experiences to expose how they arrived at their findings. In the next section I will present the epistemology of my research.

# **Epistemology**

In order to gather knowledge about a specific topic, it needs to be studied comprehensively and in depth. Willig (2008) stresses the importance of understanding the epistemology (what can be known and how) in order to understand what kind of knowledge can be found with a specific research question. Furthermore, Willig (2012) emphasises how a hermeneutic phenomenological

analysis will illuminate unique strands of the topic researched (i.e. participants expressing grief or relief after their sibling's death) as well as providing a more comprehensive view (i.e. reactions from family, friends and colleagues following the death). The aim of the present research is to include both the relational and the individual aspects of the loss, thus creating a deep and comprehensive understanding of the participants' unique experiences and the social and cultural contexts in which they live. This is in line with Zagzebski's (2013) view of epistemology being based on the individual's knowledge about a particular topic or person, including knowledge about others immediately or distantly involved and the surrounding society and community. Hence, the epistemology of this research will be formed not only by the participants' experiences of the topic researched, but also by their relationships, cultures and traditions which will be embedded in what can be known. In a similar vein of thought, Finlay and Evans (2009, p.19) regard epistemology to be based on numerous aspects of a person's life:

'Interpretivist epistemology states that people's perceptions and experiences are socially, culturally, historically and linguistically produced: in other words, that our situatedness determines our understanding.'

Their added focus on language links with how the data in this research is interpreted by the researcher and how the participants use, or struggle to use, language to express their experiences. Therefore, what can be known about the topic in question involves the researcher's experiences in addition to the participants' experiences. Although I have found the above views very useful I was conscious of that despite

the participants in my research sharing the experience researched, they were from a number of different countries, of different ages and had, at times, very different experiences of the sibling relationship and the death of their sibling. This made me acutely aware of creating an understanding of knowledge that could be cohesive in regards to the research topic while being aware of the participants' backgrounds. Aiming to maintain openness during the research as proposed by Finlay and Evans (2009) is intrinsic to this research, since what can be known about the participants' relationships and the emotions in relation to their sibling cannot be known prior to the interviews. By incorporating these different aspects of the participants' experiences, knowledge will emerge from multiple areas, and the researcher's interpretations will remain close to the original topic.

For this research, I have adopted a critical realist position, drawing on Bhaskar's work. Critical realism was initially strongly influenced by Harré, who was Bhaskar's tutor. Harré used philosophy to create an understanding of how people experience the world and how the world can be understood (Harré and Madden, 1975). Bhaskar (2011), on the other hand, has chosen to adapt critical realism to the social sciences, stressing that the social structures that influence people's lives must be considered in order to understand their experiences. He regards social structures to be multiple and the importance of different structures to depend on the topic researched.

Longhofer et al. (2013) clarify the 'real' in Bhaskar's critical realism:

'...the real is that which exists: physical (i.e., atomic, chemical, and biological structures), social (i.e., ideologies and social class), and psychological (i.e., mental structures, schemas, unconscious processes and memory, object relations).'

Longhofer et al. (2013) argue that critical realists take an open approach to the knowledge that can be established about a person's life due to the numerous aspects and experiences of a person's life, as described in the quote above. This openness and holistic view of human life may facilitate knowledge that mirrors the unique world of each participant.

As seen in the literature review presented earlier, grief can be influenced by numerous social aspects; family structure, the availability or lack of social support and whether grief is allowed to be expressed openly in the society in which the individual is living. In this way, a multi-dimensional view of reality arises through each person's perception of the reality they live in.

Reality as perceived by one individual is likely to differ from another person's sense of reality, as reality is based on a person's unique understanding of their experiences and the world they live in (Parker, 1992). Bhaskar (2011, p.191) states that:

'Critical realism embraces a coherent account of the nature of nature, society, science, human agency and philosophy (including itself)'.

This view of knowledge allows for a deep and rich exploration of the topic, as it entails numerous aspects of the lived experience of losing a sibling in adult life while simultaneously leaving space for the individual's unique understanding of their loss. However, critical realism regards knowledge to exist prior to it being researched or investigated (Danermark et al., 2002). Therefore, the knowledge gathered in this research will consist of the participants' and the researcher's observations and interpretations, as well as knowledge acquired prior to the research being conducted.

#### Phenomenology

For this research I have chosen to use a hermeneutic phenomenological approach to investigate the multitude of experiences involved in losing a sibling in adult life. The chosen research method, Interpretative Phenomenological Analysis (IPA), which will be discussed later in this section, is based partly on hermeneutics and partly on phenomenology. A brief history of phenomenology will be presented in order to provide the theoretical underpinnings and evolution of the approach. Although a strictly phenomenological approach was deemed limited for this research due to social, cultural and relational aspects being important the basis of phenomenology needs to be outlined in order to facilitate an understanding of how hermeneutic phenomenology developed.

Phenomenology as proposed by Husserl (2006 [1910/1911]) focuses on a person's experiences by leaving out pre-conceived ideas; leaving the mind open to what

presently is being said. In particular, he presents epoché, or bracketing, as an essential method of leaving out knowledge of a scientific or factual nature in order to create an understanding that is concerned only with the phenomena studied, with the aim of excluding previously acquired experiences (Husserl, 1907; Husserl, 1929; Moustakas, 1994). Hence, phenomenology can capture the participants' experiences at the time of the interview, without preconceived ideas about the emotions and reactions following the loss of a sibling in adult life. The phenomenological reduction of what is known at the outset prevents hasty conclusions and creates space for the unique phenomena investigated to emerge (Kvale, 1996). By using the phenomenological reduction Husserl (1999 [1931]) regards it to be possible to achieve pure, or transcendental, consciousness and gain in-depth knowledge about what is being investigated.

In his work on phenomenology, Husserl uses Brentano's interpretation of Aristotle's idea of intentionality, which will be explained below, as it illustrates how phenomenological thinking can elevate the analysis of an experience or emotion, although further interpretation by the researcher is needed for the analysis to be comprehensive. This research can benefit to some extent from the idea of intentionality, as the latter aims to draw out the essence of one specific experience. Additionally, intentionality focuses on the emotions directly connected to the experience, disregarding practical or logical aspects and facilitating drilling down to each participant's unique experience. Brentano (1874) presents intentionality as a mental phenomenon that is distinct from physical phenomena:

'Every mental phenomenon includes something as object within itself, although they do not all do so in the same way. In presentation something is presented, in judgement something is affirmed or denied, in love loved, in hate hated, in desire desired and so on.' (Brentano, 1874, p.88)

Applying intentionality to this research would mean thinking about death and loss in general, while sibling bereavement would mean thinking specifically about the experience of losing a sibling. Husserl (1970 [1900]) applies Brentano's intentionality to his own theory of phenomenology, aiming to grasp the essence of an experience. He is looking to draw out not a multitude of specific experiences, but the unique essence of one experience. According to this idea the essence of this research is the experience of losing a sibling in adult life; therefore it is the loss that will be the essence of this experience. However, what is lost will be individual to each participant, depending on the relationship with the sibling and the emotional experiences following the death.

Phenomenological research aim to learn about the participants' worlds by understanding how they create meaning in their lives (Smith, 1995) and provides them with a voice (McLeod, 2001; Dallos and Vetere, 2005). Furthermore, existing knowledge can benefit from taking a phenomenological stance, as the latter can add greater depth to new research (Caelli, 2000). Additionally, phenomenology allows for the individual experiences of the participants to emerge and for the researcher's insight into the psychological meaning making of the participants (Giorgi and Giorgi, 2003).

In his later writings Husserl started to consider what he called 'the life-world' (Husserl, 1970 [1938]; Giddens, 1976). However, following this attempt to include what initially may have been bracketed out Husserl returned to the phenomenological method, although it should be noted that he died prior to finishing his last piece of work (Carr, 1970). Husserlian phenomenology facilitates an analysis of the participants' unique experience and meaning making of losing a sibling, without imposing others' views or social or cultural pressures on the emotions following the sibling's death. As will be outlined below, the phenomenological approach will be complemented by interpretations of the participants' experiences in order to obtain a deeper understanding of the topic researched.

Although a purely phenomenological method can provide valuable knowledge, it was deemed unsuitable for this study given that the experience investigated may involve broader areas than just the participants' own experiences, i.e. their relationships with their sibling, family and friends, the society and culture they live in.

## **Hermeneutic Phenomenology**

Husserl's phenomenological approach has been embraced and challenged by several other authors, among them Gadamer, who argue that history and culture need to be included to a greater extent in order to understand a person's experience (Moran,

2012). The search for an integrated philosophy that includes, rather than excludes, all aspects of life followed the Husserlian phenomenology and continues today (Wilber, 2000). Heidegger expresses appreciation of phenomenology in relation to how knowledge is gained, although he regards it as insufficient for understanding human existence (Kearney, 1994; Heidegger, 2002 [1962]). For Heidegger (1962 [1927]) a person is always in the world with others, knowing the world only through being in it. He considers it impossible to exclude others, the world and one's own experiences in the way Husserl proposes (Cooper, 1996; Langdridge, 2007). Heidegger's wish to understand Being requires a fuller, rather than a reduced, account of a person's life and experiences (Heidegger, (1962 [1927]). He rejects the Cartesian mind-body split and Husserl's idea of bracketing, instead proposing the hermeneutic circle; understanding through inclusion of all aspects of a person's world (Koch, 1995). Heideggers's concerns include the need for human existence to be interpreted and he challenges in particular Husserl's view of a person being able to bracket off lived experiences (Langdridge, 2007). A purely phenomenological approach may result in findings being highly descriptive and thus impose limitations to the researcher's personal interpretations of the participants' experiences (Larkin et al., 2006).

Instead, Heidegger presents hermeneutic phenomenology, as he regards any interpretation to include the analyst's own experiences (Smith et al., 2009; Willig, 2012). Indeed, human life can be regarded as hermeneutic, as one constantly interprets and tries to understand what is being experienced (Eatough and Smith, 2008). According to hermeneutic phenomenology it is not possible for a person to

simply describe or understand something or someone, as there will always be a relationship between existing or developing (Willig, 2012). In line with hermeneutic theory a phenomenon exists on its own, although once knowledge about the phenomena has been established it will be influenced by the culture and society surrounding it (Liamputtong Rice, 1999; Liamputtong and Ezzy, 2005). Therefore, research adopting a hermeneutic phenomenological approach will include the cultural and social backgrounds as well as the voices of both the participants and the researcher, with the latter's interpretations of the data being clearly present in the findings. Dahlberg et al. (2001) present a particularly useful explanation of Heidegger's development of phenomenology and hermeneutics, stating that:

'[h]ermeneutics is the phenomenological tool with which we understand being; the hermeneutic process, the process of interpretation, reveals to us that what is hidden' (Dahlberg et al., 2001, p.79).

Hence, experiences and interpretations are interwoven and cannot be dissected, only understood cohesively. Additionally, a hermeneutic interpretation unfolds, rather than reduces, a multitude of meanings about the experience investigated (Cohn, 1997). Heidegger regards it as possible to achieve an authentic life through hermeneutic phenomenology, as the latter facilitates the examination and interpretation of one's life (Warnock, 1970). Therefore, hermeneutic phenomenological research can create a full and deep understanding of the chosen topic and the individual participants without pre-conceived ideas clouding the true findings.

What Heidegger describes as the 'turn' is illustrated by how his later writings concentrate more on the world being understood through language and his texts being more poetic than his earlier work (van Deurzen, 2010; Alvesson and Sköldberg, 2000). He argues that by turning away from metaphysics towards the artistic side of language it is possible to develop openness towards the world and history (Wurzer, 1999). Further, Heidegger (1971) emphasises the diversity of language; the everyday spoken language, poetic language, how language is spoken and how it is listened to. This multiple ways of viewing language illustrates Heidegger's wish to include, rather than reduce, what can be perceived. By taking account of the oscillation between various aspects of language, interview analyses based on Heidegger's approach can aid the investigation of the participants' experiences. Heidegger (2007 [1949]) regards the poetic aspect of language to be the entry to understanding being. Hence, it is not the specific words spoken that are significant, rather it is description of what is being experienced that is of importance. This approach to language may facilitate the research of sibling loss in adulthood by listening to what is being said, as well as what is concealed. The various layers of language are important, as culture, traditions, individual circumstances and relationships can surface through the spoken words.

When introducing the double hermeneutics Giddens (1987) argues that social science research cannot be detached from the environment in which it is being studied. By adopting this standpoint, the participants will interpret the environment

and the particular phenomena studied, with the researcher aiming to understand the participants' lived experience through their own interpretation.

Heidegger's ideas about the understanding of human existence are regarded by Gadamer to need further development in a number of areas (Gadamer, 1975). Primarily, Gadamer (1975) argues that hermeneutics need to include history and tradition to a greater extent than Heidegger allows for. Although Heidegger (2009 [1934]) discusses history he does so in general terms, while Gadamer (1975) argues for a more specific approach through which a person can only work hermeneutically once they understand their own unique history and prejudices. Therefore, Gadamer (1975) regards it as vital to have deep and personal insight into one's own history and tradition in order to develop a full understanding of the area researched. Hence, I was aware of constantly needing to keep my own background and understanding of society and relationships in mind when working with the data in order to maintain a professional stance to the participants' experiences. Additionally, Gadamer (1975) places a strong focus on how an understanding of the world emerges in conversation and language, which he did not find in earlier hermeneutic texts. He provides the example of translating a language, which needs the text to be translated correctly, although the translation is not complete without the poetic part of the language. Thus, what can be known about something, language or research, will always need interpretation. It will always fail to reveal everything, as it is not a first-hand account but an interpretation. Furthermore, Gadamer (1976) considers language to facilitate infinite ways of describing and interpreting experiences. He bases this partly on language being interlinked with the culture and setting in which it is being spoken

and partly on how language can act as a bridge when one culture is being interpreted by another culture.

Gadamer's (1970) view of the fluidity of language is useful for researching adult sibling loss, as the spoken words reveal a person's opinion and may additionally show how a person is living in the world and communicating with others, for example with family members. This hermeneutic aspect of language needs to be considered throughout the research in order to grasp how the participants verbalise, or struggle to verbalise, their experiences of losing their sibling and to what extent they are being heard by others.

A hermeneutic approach is regarded as suitable for this research, as it allows the tone of the participant's voice to be present while the researcher's knowledge can draw out the relevant themes. The interpretations of both parties are vital for the process of extracting important areas from the interviews. However, interpretations of the participants' life stories need to be done with caution, in order to be as true as possible to their experiences.

By analysing the interviews using hermeneutic phenomenology, the aim of the research is to investigate the unique experience of each participant, while maintaining an open mind in order to allow for the researcher's interpretation to be heard. However, I as the researcher recognise that the stories told will be influenced by the relationship between the researcher and the participants, as the participants may have told a different researcher other aspects of their experiences (Cohn, 1997).

Despite intending to stay as close as possible to the participants' experiences, I am aware that these have been interpreted.

## **Interpretative Phenomenological Analysis**

The aim of the research was to look at the experience of losing a sibling as an adult in a phenomenological way in order to find out each participant's experience of losing their sibling and what it has meant for them. I chose Interpretative Phenomenological Analysis (IPA) as presented by Smith et al. (2009) as the method of analysis for a number of reasons. The Husserlian phenomenology in IPA facilitated the extraction of each participant's experience. Specifically, as preconceived ideas were bracketed out it was possible for me as the researcher to have an open mind towards existing knowledge and to focus on the unique phenomena investigated (Langdridge, 2007).

Meanwhile, the interpretative part of IPA kept the analysis closely connected to both the researcher and the participants, capturing each participant's experience of losing their sibling through their stories and the subsequent interpretations. The hermeneutics of IPA allowed for a holistic understanding of the world the participants had found themselves in, their view of the temporality of life and relationships. By considering both the part and the whole of the participants' experiences I, as the researcher, could draw out aspects of their loss which may not have been clear previously.

In particular, IPA was considered appropriate for researching complex topics not previously investigated due to the explorative stance together with psychological as well as social aspects being considered, which could add considerable depth to the research (Smith and Osborn, 2003). When deciding to use IPA I regarded hermeneutic phenomenology useful for several of the aims of the research. Firstly, by moving between the participants' individual experiences of losing a sibling and society as a whole, there would be sufficient space for less apparent meanings to surface by exploring how culture and history shaped how they grieved and how others related to their grief. Secondly, the aim of understanding whether the participants felt the need for support and if so, what kind of support would be helpful, would be aided partly by looking at each participant's needs and the view of grief in their culture. This made IPA suitable for this study, as the aim was to search for the participants' lived experiences in relation to their bereavement.

Additionally, the relationship between the siblings should not have been assumed, as emotional closeness, or the lack of it, varied greatly between participants. The analysis of the data was based on the double hermeneutic; the researcher's interpretation of the participants' understanding of their experiences (Smith et al., 2009). Through being immersed in the data I worked on drawing out areas that stand out based on research rationale and research questions, although I have strived to keep the experiences as told by the participants in focus. Furthermore, the semi-structured aspect of IPA interviews ensures that the participants have sufficient space to expand on their individual experience of losing a sibling (Smith et al, 2009). This method allowed me to follow the participant, facilitating greater depth to the

interview by asking prompting or probing questions beyond the initial interview questions (Smith, 1995). Using a more structured interviewing technique would mean being rigid about which questions to ask participants and in which order these questions would be asked (Smith, 1995). The openness of semi-structured interviews allowed the research to concentrate on the lived experience, rather than simply on what is being said (Van Manen, 1990). Thus, the participants' individual emotions and meaning making could be drawn out from the transcript.

The idiographic aspect of IPA allows for in-depth analysis of a selected group of participants. The focus on the details of the experience provided sufficient space for the unique relationship each participant would have had with their sibling and the circumstances surrounding the death.

In the last decade published papers using IPA have increased considerably, which has prompted Smith (2010a) to be more explicit about how IPA is different from other qualitative methods. He states that someone using IPA for researching a topic is trying to draw out how the participants make sense of what they have experienced, rather than providing a linguistic account of the experience. Additionally, he has published an IPA quality evaluation guide with three categories; good, acceptable and unacceptable. However, he anticipates that the quality of IPA publication will increase as it is more widely used and qualitative research is being used to a greater extent. Smith (2010a) establishes four criteria of quality: 1) the study clearly subscribes to the theoretical principles of IPA, i.e. it is phenomenological, hermeneutic and idiographic, 2) it is sufficiently transparent so the reader can see

what was done, 3) it is a coherent, plausible and interesting analysis, 4) there is sufficient sampling from corpus to show density of evidence for each theme. Furthermore, he proposes for IPA to be used not only by psychologists but also by doctors, scientists and health psychologists to add greater depth to the researched areas. In recent years IPA has come under criticism from Giorgi (2010), who argues that the method is not sufficiently scientific and that the phenomenological reduction is not truly adhered to. His main concern is about what he regards as the lack of possible replications in IPA studies;

'The ability to check the results of a study or to replicate it is a scientific criterion, and phenomenologically grounded science accepts that criterion' (Giorgi, 2010).

Smith (2010b) challenges Giorgi's view of what the term scientific actually entails by highlighting that science in quantitative research indeed needs to be replicable, whilst this is not the case in qualitative research. As the double hermeneutic aspect of IPA involves the researcher, the findings will depend on the researcher's previous experiences. In the present case, my work as a bereavement counsellor most likely means that the themes I extracted during the analysis would be different from those of a nurse or a health psychologist who had analysed the same transcripts.

Two interpretative phenomenological methods, in addition to IPA, as presented by Langdridge (2007) were considered prior to IPA being the chosen method; hermeneutic phenomenology, as developed by van Manen (1990) and Template Analysis (TA). van Manen's hermeneutic phenomenology was potentially an

interesting method, as it is concerned with meaning and language. However, his focus on language in combination with a strong concern for history and culture (Langdridge, 2007) could divert the focus of the research from the participants' personal experiences towards more general areas of their lives and was therefore deemed unsuitable. As seen in the literature review, history and culture strongly influence how people grieve but only if the experiences can be drawn out from the participants' stories in the analysis process, rather than being the primary focus of the method. In particular, the participants' experiences of their loss may be contradictory to the expectations of the society and the culture they are living in. Additionally, one of the main reasons for using IPA was to retain the focus on the participants' experiences without imposing cultural norms of grief on them. Additionally, with the strong focus on language in the form of rewriting and themes there could have been a risk of leaving out some of the participants' experiences, which I did not share on a personal level. As pointed out by Langdridge (2007), van Manen's hermeneutic phenomenology is at times more concerned with the academic aspects of the research than the psychological understanding.

Template Analysis (TA), although being hermeneutic, would not have been suitable if codes had been selected prior to reading the transcripts. As mentioned previously, research on the topic of adult sibling bereavement is limited, making it problematic to find codes. There would also be a risk of missing aspects of the participants' experiences, which had not been previously been researched. Additionally, when TA research involves several participants a template based on a few transcripts tends to be used for the analysis of the remaining transcripts (Langdridge, 2007). However, as

I, as researcher, aimed to take an unassuming stance to understand each participant's experience in-depth it would not be appropriate to use a template created from the first few interviews or use another researcher's themes.

Method of data collection

The selection process of specific criteria for the participants and the interview process will be presented below together with ethical aspects of the research.

# **Participants**

The participants were given synonyms in order to protect their identities.

Participant	Gender of	Gender	Age at	Age when	Nationality	Sudden or		
	participant	of sibling	interview	sibling		prolonged		
				died		death		
Beatrice	F	М	34	32	Congolese	Sudden		
Georgina	F	F	32	30	British	Prolonged		
Francesca	F	М	45	43	British	Prolonged		
Nick	М	М	23	20	British	Sudden		
Nora	F	М	55	53	Dutch	Sudden		
Leon	М	F	55	47	British	Prolonged		
Caroline	F	М	32	31	Canadian	Prolonged		
Lucy	F	М	33	28	British	Sudden		
Sally	F	М	31	22	British	Sudden		
Rosie	F	М	35	33	British	Prolonged		

# Inclusion/exclusion criteria

To take part in the research participants needed to have lost a sibling when they were between the ages of 20 and 55 and still be within this age group at the time of the interview. The mean average age was 37.5 years and the ages of the participants ranged from 23 to 55. The upper age limit was set to ensure that participants were not of an age when their siblings may die of age related illnesses. It was not considered appropriate for participants to be younger than 20, as at least one year needed to have passed since the death and the participants needed to have been adults both at the time of the death and the interview. A minimum of one year and a maximum of ten years should have passed since the death; the minimum criteria of one year was set to ensure that the participants had had the possibility for some reflection after the death. The maximum of ten years was decided upon in order to include participants who had lost their sibling within a similar time frame and creating some homogeneity (Smith et al., 2009). Participants who had lost contact with their sibling for reasons other than death could not take part. Further, there is a substantial amount of research on children and adolescents losing a sibling and one of the reasons for carrying out the research was to investigate an area that has not previously been researched in depth.

Former clients from the bereavement service (where I had previously had a placement) could not be recruited for the research. It would have been unethical to approach these clients, as they had contacted the organisation for bereavement counselling, not to take part in research (McLeod, 2003). No research had been mentioned in their initial assessment and as the service was free of charge the clients may have felt obliged to give something back by taking part in the research.

#### Recruitment

When commencing the recruitment of participants I contacted a number of bereavement services in the UK. The recruitment was slow and I therefore broadened the initial ideas to include more specific organisations as well as more settings. Additionally, I posted research advertisements on relevant websites and hard copies at universities and research libraries.

Potential participants contacted the researcher using a dedicated mobile phone and email, both which were used solely for the purpose of the research. They received the Participant Information Sheet (PIS) (Appendix 3) and the Consent Form (Appendix 4) before deciding whether they wished to take part in the research. They were also able to ask any questions regarding confidentiality and the research before making a decision.

As recruitment was slower than anticipated the number of participants was altered from 10-12 to 4-10, to concur with the latest IPA publishing at the time of the interviews (Smith et al., 2009), aiming for at least six participants. The number of interviews was also changed from two to three interviews to one, possibly two. The change to the number of interviews was made due to the very large amount of data that would have been accumulated with a greater number of participants and interviews. Additionally, Smith et al. (2009) advise professional doctorate research to conduct between four and ten interviews, providing the option of interviewing fewer

participants twice or more participants once. Further, Smith et al. (2009) emphasise the importance of limiting the number of interviews when carrying out research for professional doctorates to ensure a higher quality of analysis, rather than a moderate quality of larger sets of data. The changes were discussed with the academic supervisor and submitted to the ethical board, which subsequently approved the changes.

#### Ethical awareness

The interviews were conducted according to the BPS Code of Ethics and Conduct in order to ensure the emotional and physical well-being of the participants (British Psychological Society, 2006). The participants were informed prior to the interviews about what would be involved and their right to withdraw at any time, should that be their wish. The participants were naturally talking about a loss that could have been traumatic in various ways, including unresolved issues, family dynamics and previous bereavements. These, and other, experiences may surface as a result of taking part in the research. When communicating with potential interviewees the researcher aimed to adhere to the BPS ethical guidelines by explaining the interview process in as much detail as possible prior to meeting for the interview and consent being given (Langdridge, 2007). There was the possibility of distress to the participants during and after the interview. Firstly, the information given to the participants could have stirred up old as well as new emotions. Secondly, during the interview there could have been risk of distress, should the participants have been at an early stage in their grief or have blocked off their grief. Thirdly, after the interview

there could have been risk of distress in both the short- and long-term. The participants were given information about support services (Appendix V), such as individual counselling, group therapy, online charities and telephone support services available 24 hours a day, should they feel the need for support. As it would not have been appropriate to have a counselling aspect throughout the interview the participants were asked towards the end of the interview if they wished to ask any questions about the research. Should an unexpected aspect of the research topic arise during an interview semi-structured interviews are sufficiently ethically flexible to allow for additional interview questions to be included (Kvale, 1996). The NSPC ethical committee approved the various locations of the interviews and other therapists were present in the building at the time of the interviews for the safety of the interviewees and the researcher.

#### Informed consent

Participants' informed consent was obtained by providing a Participant Information Sheet (PIS) (Appendix VI). This explained the relevant information about the research, the purpose of the study, benefits and risks of taking part and how the information from the interview would be accessed, stored and finally destroyed. Once participants had agreed to take part in an interview they were able to ask questions when we met, either before or after the interview.

Participants were assured that only the researcher and relevant academic staff would read the entire transcripts. In addition, they were informed about how the

personal details would be changed in order for them not be identified in the final write up of the thesis.

#### Procedure and interview schedule

Following the pilot interview some minor changes were made to the interview schedule; firstly at the beginning of the interview the researcher asked the participants to provide a brief background of how they had lost their sibling. This was done in an open manner, as to create space for the participants to speak about the most important aspects of their bereavement. Secondly, the order of the questions was changed to commencing with the question about relationships first. Although, these changes appeared small at first the remaining interviews benefited from a better flow.

The researcher had the questions below as guidelines:

Can you tell me how you have experienced your relationships with others

after your bereavement?

Prompt: Relationships with family, friends, colleagues etc?

How has your health been since the loss of your sibling?

• How have you found work and everyday tasks after losing your sibling?

• Can you describe where you feel you are now in relation to the first period

after losing your sibling?

Due to the open question at the start of the interview the participants at times spoke

about the areas of one or more of the interview questions without me asking the

questions. When this happened the natural flow of the interviews enabled the

participants to speak about their unique experience, which added depth to the

interview. In several of the interviews the answers to the interview questions

invariably overlapped as the participants spoke about the personal, emotional and

professional aspects of their lives. Additionally, by having openness in regards of the

questions the participants were able to return to topics they had spoken about

earlier in the interview. This added further depth to the research, as the researcher

could ask further questions and the participants saw their experiences in a different

light after having voiced them, sometimes for the first time.

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#### **Process of analysis**

Immediately after each interview I made notes of the most prominent aspects of the interview. These notes were at times based on specific experiences or emotions of what the participants had spoken about, at other times the notes referred to more abstract thoughts involving the intonation of the voice or the emotions I experienced in the room with the participant.

Following the completion of each interview I transferred the recordings to a secure hard drive on a password-protected computer. After listening to each interview I then transcribed each interview onto an Excel spread sheet, with each row being assigned as R for researcher or the anonymous letter for each participant, i.e. B for Beatrice etc. Each row was also numbered for easy referencing. Thereafter I listened repeatedly to each section, concentrating on every sentence and the individual words used, as this made it possible to pay attention to the tone of voice, repetitions, hesitant speech and the emotions in the voice.

After transcribing the interviews I analysed the data using IPA, allowing both the part and the whole to be present, according to the hermeneutic circle. I commenced with reading each interview three times according to Smith et al. (2009), creating three columns on the right hand side of the transcript for descriptive, linguistic and conceptual comments and one column on the left hand side for the emergent themes. I started with the descriptive section, staying with the phenomena as told by the participants by drawing out the essence of their experience; being words,

events or feelings. For the linguistic section, I analysed how the participants expressed themselves, their struggle at times to find words or keep their concentration to end the sentence they had started. I also included their tone of voice and when they quoted their own thoughts or speech, as well as conversations with others. In the conceptual section of the analysis I looked at the broader aspects of the participants' experiences; their relationships, the society they lived in and how their sibling's death had impacted on their lives. In this section I included my own questions as well as questions the participants had directly or indirectly spoken about. I then started to create the emergent themes by interpreting and reflecting on the entire interview material as well as smaller sections, being aware of the hermeneutic circle. First I put the emergent themes on the right hand side of the transcript, then started to create groups for similar themes or polarised themes. Following this I commenced the work of looking at patterns across the participants' experiences. As the research involved ten participants who at times appeared to present with very different experiences I used Smith et al.'s (2009) recommendation for re-occurrence to be present in at least a third of the interviews when developing a super-ordinate theme. The work on the super-ordinate themes continued throughout the write-up of the thesis and involved a careful balance between the unique experiences of participants and group as a whole.

During the process of transcribing and analysing the interviews my understanding of the participants' experiences deepened, at times leaving me perplexed and at other times fascinated as themes and ideas emerged. Although having commenced the research proposal with the idea that bereaved adult siblings may experience a change in their sense of time, once I started to interview participants I realised that the issues arising were more complex and diverse.

In my research journal I kept thoughts, ideas and questions, providing me with the freedom to immerse myself in the interviews without being concerned about theoretical texts. I discuss this further in my reflexivity section below.

## **Research validity**

In considering the quality of the research I have used Yardley's (2000) four essential qualities, which are especially developed for qualitative research. The criteria for quality included allowing space for the participants' experiences and emotions to ensure that the research was considered in relation to the society and time in which the participants live. In particular, I found Yardley's (2000) writings about transparency and coherence particularly useful during the analysis, as I was working through how to present paradoxical themes and draw them together in superordinate themes.

## Sensitivity to context

Approaching the topic with great sensitivity to the context, as Yardley (2000) suggests, was important throughout due to the experience often evoking strong emotions for the participants. I became greatly aware of the need to consider the wellbeing of the participants during the interviews when they spoke of feelings, thoughts and experiences that they had not mentioned to others. Due to some of these emotions being outside of what may be viewed as the social norm, such as anger and resentment towards the dead sibling, it was important for me as the researcher to maintain a non-judgemental approach to the experiences and emotions revealed. Additionally, increased urbanisation together with social and cultural differences between participants required a careful approach so as to not assume the nature of the sibling relationship or the feelings following the death. As mentioned previously, there is limited literature and research on the topic, which put more weight on sensitivity of the data and the participants' experiences. When participants talked about others not being able to understand their loss and emotions I was intensely aware of being in this group of 'others', which made me wonder how this would affect the interviews and the participants. However, the participants appeared to regard me, as a researcher of the topic and as a therapist, to be able to have some understanding of the context.

#### Commitment and rigour

As recruiting the participants, arranging and conducting the interviews took one year it certainly tested my commitment to the topic. However, overall it felt beneficial as I had time to immerse myself in each interview before carrying out the next one. The commitment to the topic was further tested as I was at times surprised by the participants' experiences and views, yet I managed to stay with their experiences and therefore be true to the topic researched. The extensive period of interviewing also provided me with space to contemplate the findings in depth, which was particularly useful when analysing the differences and the similarities between the participants. Further, by rigorously immersing myself in the data during the transcribing process I was hearing the sighs, hesitations, tones of voice etc, giving me a rich understanding of the experience of each participant. During the analysis and write-up I spent extensive time on drawing out the specifics of the data and previous literature and at the same time creating cohesive themes presenting the overall findings, as suggested by Yardley (2000).

## <u>Transparency</u> and coherence

In line with Yardley's (2000) criteria for transparency I set out to be open about what the findings of the research would be, although naturally I did not know what the data would reveal until after I had analysed all of the interviews. Indeed, I needed an open mind when working on the analysis in order to include the participants' strong and varied emotions following the sibling's death. In particular, I needed to be transparent about how some of the themes were paradoxical, with different subgroups emerging within the participant group depending on the emotions and

experiences surrounding the relationships and the deaths. By being open I could find coherence among the paradoxes, drawing out overarching context to create super-ordinate themes. Additionally, as mentioned previously, reflexivity was important (Yardley, 2000), as I had not had the same experience as the participants, although I had known people privately and as clients who had lost a sibling in adult life. I believe provided me with some, albeit secondary, understanding of the experience.

## Impact and importance

Yardley's (2000) final principle highlights how my research topic is important in an increasingly urbanised society, while at the same time being in the early stages with regard to research. Certainly as clients are being referred to psychological therapy for specific reasons to a greater extent it is important for bereavement therapists to have access to research investigating different kinds of bereavement. The value of the study weighs heavily on the lack of present research on the topic and the previously mentioned paradoxical findings, as each of these would be valuable for future research projects.

## Reflexivity

As a researcher, I aim to develop an understanding of the participant's world and not impose my own assumptions on the research, although my thoughts will be present through the analysis of the data. The participants were from a variety of countries and cultures, of different ages, had different professions and had individual experiences of their bereavements. I believe each of the participants' experiences to be unique and need to be considered holistically to understand the cultural and emotional circumstances of their grief. During the transcription and early analysis my assumptions were that the participants' experiences would depend on the relationship with the sibling. Although this did indeed emerge, relationships were more complex strands throughout the research than I first expected, as the participants expressed strong emotions towards family and friends. After the final analysis, I could see how I had underestimated the relief felt by some of the participants, despite trying to maintain an open mind.

Willig (2008) introduces two kinds of reflexivity: personal reflexivity and epistemological reflexivity. She proposed that personal reflexivity influences the research through experiences, beliefs, social identities and so on. Considering my personal reflexivity I am aware that aspects such as age, nationality, gender and ethnicity can limit my comprehension of the other's world. When differences between my own experiences and those of the participants emerged I took the opportunity to deepen my understanding of their backgrounds, lives and emotions. When listening to the interview recordings and reading the transcripts I became aware of the cultural, and possibly personal, differences between myself and the participants in regards to grief; when a relative or friend of my family has died they

have continued to be part of daily life by being brought up in conversations and by photos and other memorabilia being on display. While trying to keep cultural differences in mind, I had assumed that there would an openness to talk about the life of the deceased, which I have often found facilitating a balance between grief and personal anecdotes. However, this assumption did not resonate with the findings. The majority of the participants struggled to talk about their dead sibling or see items in their home that reminded them of the sibling. At times I found the interviews difficult, as eight of the ten participants; Georgina, Francesca, Caroline, Rosie, Lucy, Sally, Nick and Nora, repeatedly contradicted themselves by saying that no one could understand their loss, although expressing great disappointment of not feeling supported after the death of their sibling. I was strongly aware of needing to stay in the researcher role and not venturing into the therapist role, as the participants had only consented to taking part in the research and not in therapy sessions. During my work as a bereavement therapist I had seen many clients, including bereaved siblings, benefitting from sharing their grief with myself and others around them. However, as most of the participants did not express a wish to do so, I felt this had been my assumption based on my therapeutic experience which I could not apply to my research. Further, I was concerned that bringing this observation up during the interview could have upset the participants rather than been beneficial to them.

Epistemological reflexivity, according to Willig (2008), involves questioning how the design and the method influenced the data and the findings, the limitations imposed

by the research question and how researching the topic differently could have created an altered understanding.

Holding this kind of reflexivity in mind, I question whether semi-structured interviews restricted the participants sense of what they felt they could talk about and indeed the opposite; if this form of interviewing could have made the participants feel that the interview lacked structure for an experience that may have brought on turbulence in emotions, relationships, expectations of life and the future. Following this questioning and the analysis of the interviews, it is clear to me that the participants felt comfortable in telling me about their bereavement without feeling neither restricted or unsupported. This could be seen in how they spoke about their personal and very emotional experiences without needing much prompting. The research question could potentially not have been suitable due to the wording of 'loss', which could be perceived as participants needing to have had a loving relationship with the sibling who died and therefore deterring those who had had a difficult relationship with their sibling. Furthermore, throughout the research process I wondered to what extent it is possible to gather knowledge about an experience that may include aspects that can be difficult to verbalise, such as the individual sibling relationship coming to an early end due to the sibling's death and the participants' present and future lives no longer including the sibling. However, I believe the method and the research question were sufficiently open to facilitate space for the participants' individual experiences and emotions. As mentioned in the foreword, witnessing a number of relatives and family friends living with this kind of loss provided me with a useful platform for the research, although I am

strongly aware of needing to withhold assumptions about the participants' experiences. Similarly, my previous experiences of working as a bereavement counsellor has provided me with insights into the lives of those who have lost a sibling in adult life, although I will need to be careful to not let that experience colour my interpretation of participants' lives.

Langdridge (2007) presents Wilkinson's three areas of reflexivity: personal (which relates to the participant), functional (the researcher's influence) and lastly disciplinary reflexivity (involving theory and method). The first and second areas are similar to Willig's (2008) personal reflexivity while the third needs to be considered together with epistemological reflexivity to provide an objective view of the research and the researcher. I will consider these different aspects of reflexivity to better understand my own part in the interview material and process. In order to be fully aware of my impact on the research I have used Langdridge's (2007) work on reflexivity. In particular, throughout the research process I have returned to his list of questions in order to reflect on my part in the research and the greater aspects of the findings (Langdridge, 2007, p. 59).

The initial research idea was to investigate how the issue of time had changed, as it was a theme I had heard clients speak about repeatedly after losing a sibling. My assumptions about time derived from long-term therapy with clients who were grieving a loved sibling, which proved to be relevant to only some participants in my research. However, this was only the starting point and I was aware of the importance of not bringing in previous clients into the research.

The title of the thesis was changed a few times as the research progressed. For the initial proposal, the title was 'An existential phenomenological study of how the death of a sibling in adult life can change the experience and concept of time', which the viva proposal panel recommended to be changed to 'How the death of a sibling in adult life changes the experience and concept of time (an existential phenomenological study).' The initial idea derived from my therapeutic work with clients who had lost a sibling in adult life. However, both the above titles were assuming what the experience would be and that there would be some form of change in the experience of time. Although my bereavement work meant I was biased about time being a major aspect for clients, it became clear during the proposal process that I could not assume that research participants would have similar experiences. With hindsight, I wanted a more open title, enquiring about the participants' experiences. The changes were made to ensure that the participants felt able to speak about their personal experiences, without feeling constrained due to assumptions being made that time would necessarily be an important aspect. Some participants did indeed talk about time, although as will be seen in the findings this was not their main focus. Following numerous conversations with my supervisors we agreed on the present title, which was subsequently passed by the ethics board. The semi-structured interview style together with only a few broad questions did however leave space for the participants to venture into their unique experiences.

The research assumes that losing a sibling in adult life would have had an impact on the participant. Had the siblings not been in contact for a long time and been indifferent to each other the death may have played a minor part in the participant's life. Despite this being an assumption, I consider it a valid one that is part of the platform for carrying out the research. However, throughout the research process I have continuously worked towards keeping pre-established ideas about the participants' individual relationships and experiences at bay. At times, it was difficult to grasp the different, and at times complex, aspects of the sibling relationship during the interview. However, assumptions I had about the participants grieving for their sibling or being open to support from others was challenged during the transcription and from repeatedly going through the interviews during the analysis. This proved to be particularly important for allowing the participants to express their emotions and experiences, which were at times very strong and sometimes contradictory. In a few of the interviews I was first taken back by the anger expressed towards the dead sibling, although the reasons for the anger became clearer as the interview progressed.

I have aimed to keep a fluid awareness of the complexity of cultures, experiences and identity issues throughout the research. Despite this, I am aware that I have my own beliefs, assumptions and biases on individual, personal, social and cultural levels. Firstly, I was biased about siblings having a caring relationship, which came from my work with clients at a bereavement service. Secondly, my biased idea of participants possibly struggling to share their personal experiences with me, effectively a stranger, proved wrong as they spoke freely. Thirdly, my assumption on

a social level was of participants wishing to share their loss with others did not resonate, which again was something I could see came from my work at the bereavement service. A further assumption of mine was cultural; I initially had the view that there would be an openness about grief in the participants' extended family and social circle. It became clear to me early on in the research this assumption came from my own culture and my own family. In addition to academic supervision I have used the support of my peer group to ensure coherence of the themes. Early on in the analysis I found my peer group invaluable for deciphering between possible themes. Additionally, my fellow doctoral students were very helpful during my process of deciding on the wording to capture the essence of the participants' experiences, ensuring that these were not my preconceived ideas. Later on in the analysis, my academic supervisors aided the work of organising the different themes, including a number of re-arrangements of sub-themes and deciding on super-ordinate themes. This took some time of re-naming the themes and merging some themes to ensure that I stayed true to the content of the interviews in the findings, without diverting attention to my initial ideas of for example time. Finally, I have been writing a research journal to keep a record of ideas, questions and progress.

I will aim to draw together the literature and the results of the research to provide a rich contribution towards the fields of bereavement, Counselling Psychology and psychotherapy.

# **Research findings**

Through my analysis three super-ordinate themes emerged; 'The paradoxical emotions connected to loss', 'Living after loss' and 'The complexities of support'.

This section will commence with exploring the first super-ordinate theme; The paradoxical emotions connected to loss. The paradoxes of emotions can be seen in the individual participant's experiences and between different groups emerging through the analysis; five of the participants lost their sibling through terminal illness and the remaining five participants' sibling died suddenly. Further, six of the participants had a loving relationship with their sibling, while the other four participants had experienced various forms of abuse in relation to their sibling. The second super-ordinate theme will investigate how the participants' daily lives were affected by the death of the sibling. Finally, the third super-ordinate theme will present the complexities of support, as the latter can be withheld, rejected or not be offered due to lack of verbal and social expressions following a bereavement.

# Transcript keys

Suj	per-	ord	linat	te t	heme

<b>Theme</b>
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Sub—theme

[] information added by researcher
[] text omitted

... participant pausing or drifting off

Super-ordinate theme 1	Super-ordinate theme 2	Super-ordinate theme 3				
The paradoxical emotions connected to loss	Living after loss	The complexities of support				
The tensions of terminal illness - Being with limited time	Connecting with grief	Lack of support is hurtful				
Sudden death leaves issues unresolved - Unanswered questions - Meaninglessness	Continuing bonds with sibling - Loss and having children - (Re)-connecting with sibling's children	The uncertainty of available support				
Grieving a loved sibling - The impact on relationships and the future	Break from everyday life heals	Paradox of wanting support but rejecting it				
Death ending abuse and bringing relief - Newfound freedom	Bereavement affects sense of time					

# Themes table: participants

	T	1	1		1	1	1	1	1	
	Dootsies	Coorsins	Franceses	NI: al.	Nors	Loan	Congline	Luci	Caller	Doc's
<u>The</u>	Beatrice	Georgina	Francesca	Nick	Nora	Leon	Caroline	Lucy	Sally	Rosie
<u>paradoxical</u>										
emotions										
connected to	x	x	x	х	х	х	x	x	x	x
loss The tensions	^	^	^	^	^	^	^	^	^	^
of terminal										
		V	x			V	V			x
illness		Х	X			Х	Х			X
5										
Being with			.,							.,
limited time		Х	Х			Х	Х			Х
Sudden death										
leaves issues					,			,	,	
unresolved	Х			Х	Х			Х	Х	
Unanswered										
questions	Х			Х	Х			Х	Х	
Grieving a										
loved sibling		Х	Х				Х	Х	Х	Х
The impact on										
relationships										
and the future		Х	Х				Х	Х	Х	Х
Death ending										
abuse and										
bringing relief	X			Х	Х	Х				
					]					
Newfound										
freedom	Х			Х	Х	Х				
Living after					1					
loss	Х	Х	x	х	х	х	Х	х	х	х
Connecting					1					
with grief	Х	Х	x	х	х	х	Х	х	х	х
Continuing										
bonds with					1					
sibling		х	X	х	1		х	х	х	х
8	1	L	ı	l		l				l

I					1					1
Loss and										
having children		х					Х	х		х
(Re)-										
connecting										
with sibling's										
children	Х				х	х				
Break from										
everyday life										
heals	Х	Х	x	Х	Х	Х	X	Х	Х	Х
Bereavement										
affects sense										
of time		Х	Х	Х	Х		X	Х	Х	Х
<u>The</u>										
<u>complexities</u>										
of support		Х	Х	Х	Х		X	Х	Х	Х
Lack of										
support is										
hurtful		Х	Х	Х	Х		X	Х	Х	Х
The										
uncertainity of										
available										
support		Х	Х	Х	Х		X	Х	Х	Х
Paradox of										
wanting										
support but										
rejecting it		Х	Х				X	Х	Х	Х

# The paradoxical emotions connected to loss

This super-ordinate theme presents the participants' emotions and experiences of losing their sibling suddenly or after a long-term illness and provides brief backgrounds of the deaths. The themes and sub-themes under this super-ordinate theme are; 'The tensions of terminal illness' with the sub-theme 'Being with limited time', followed by 'Sudden death leaves issues unresolved' with sub-themes 'Unanswered questions' and 'Meaninglessness', 'Grieving a loved sibling' with the sub-theme 'The impact on

relationships and the future' and finally 'Death ending abuse and bringing relief' with the sub-theme 'Newfound freedom'.

# The tensions of terminal illness

Five of the participants (Georgina, Francesca, Leon, Rosie and Caroline) lost their sibling after a terminal illness, hence the death had not been a surprise. These participants spoke of their appreciation of having time with their sibling before the death, although they often found living with the impending death to be anxiety provoking and exhausting.

The sibling's illness was part of the participants' lives for months or even years and inevitably created strong and at times turbulent emotions. The participants' lives during this period was two-fold; they became aware of the possibility of losing their sibling in the near future while nursing hope of the medical professions finding a cure for the illness. Georgina in particular lived with the knowledge of her sister's illness for a number of years prior to her sister dying.

'Anna was ill for seven years before she died, so I think that process started before she died, whereas from the contact I've made with other siblings who lost their siblings instantly, it's almost like re-started the process of mourning and grieving and the things that quite often happen after a death, I think we started beforehand...' (Georgina: 4)

Although Georgina tells of the illness as lasting for seven years, the doctors declared her sister cured and well after the initial treatment. However, the hope instilled was crushed

when the illness returned, this time to be terminal. The process Georgina talks about in the quote above shows how her family went through the grief process while her sister was ill.

Francesca's brother had been living with non-life threatening health problems for a number of years. He then became ill suddenly and his health declined rapidly.

'...I got closer to my brother at the end, although it was extremely painful...not as close as I would have liked ....but.....certainly spent much more time with him, at the hospital, talking....' (Francesca: 6)

As can be seen in the excerpt above Francesca found the courage to speak openly to her brother when she understood that his illness could not be cured. For Caroline, her brother's health problems had been present during her whole life.

'...I think...something was wrong with his chromosomes from birth or something, something was really wrong because he was so vulnerable to so many things...' (Caroline: 4)

Although Caroline and her family were struggling emotionally towards the end of her brother's life, the shared experience also brought them closer.

'....we're really close emotionally, so that's been actually really positive and things were really clear.....with my brother, at the end, we were really clear with each other, like there's a lot of love....'(Caroline:, 28)

Despite her deep love for her brother Caroline found watching him suffer more unbearable than living without him.

'I guess it's different because he.....suffered so much before he died so it was like really...that was the thing that we were all obsessed with right after he died, like I wasn't even worried about him dying, I just wanted his suffering to end, we were like 'Whatever' about our grief...' (Caroline: 191)

Similarly to Caroline's brother, Rosie's brother had been living with a non-life threatening medical condition for many years when he was diagnosed with the illness that later ended his life.

'He....has had...he had had...ahh...his illness for quite a long time.' (Rosie: 2)

It was only towards the very end of her brother's life that Rosie found closure to difficulties in their childhood:

'... I just heard everything that he said in a different way, I kind of feel he liked me and I made peace.' 9 (Rosie: 79)

As can be seen above, terminal illnesses created strong emotions and ongoing tensions for the participants with hope for a cure being present at times, which had to be abandoned when the impending death could no longer be denied. Additionally, the participants expressed paradoxical emotions, as they wanted to continue having the sibling in their lives and simultaneously wanting the suffering to end although this could only happen through death.

#### Being with limited time

The illness provided the participants and the siblings with time to talk, ask questions, trying to resolve old conflicts, express love or simply be together. Georgina, Francesca, Rosie and Caroline found it helpful to tell their sibling about thoughts and feelings that may otherwise not have been said. Georgina describes the conversations with her dying sister to entail what they wanted to say, implying they did not hold back their emotions verbally during the limited time they had left together.

'...yeah, to talk...to say what we wanted to say.' (Georgina: 102)

In a paradoxical way the time limitation provided time and space for conversations that may not have been had otherwise. The knowledge that not only had time become limited, potential conversations in middle or old age had become eradicated by the impending early death. The majority of the participants felt particularly relieved by telling their sibling how much they loved them and cared for them. Francesca was emotionally close to her

brother prior to him becoming ill, although only after his illness had been confirmed was she able to express her appreciation of him verbally.

'I did manage to say how much he meant to me...... I got the courage to say it more then...umm...it wasn't easy to, but I did manage to do it...' (Francesca: 8)

Francesca mentions how she 'got the courage' and 'managed to' express her appreciation of her brother, which shows how the limited time reinforces the verbal expressions of existing thoughts and emotions. The time before the death was characterised by both positive and negative aspects for the participants. While they appreciated having time to prepare for their sibling's impending death they found it difficult to watch the suffering caused by the illness.

'And we had time with him, to say goodbye and to make sure that he knew how much I loved him and be a good sister to him, I know that's a gift, even though it was really painful to see him suffer that much, I'd say that's the worst part but if he died suddenly I might be thinking...' (Caroline: 602)

The dichotomy of the illness is illustrated in the quote above where Caroline refers to the time of her brother's illness to be positive and a gift, while at the same time being a very painful experience. The pain Caroline experienced appears to derive from her feelings of guilt for not having appreciated her brother for his personal qualities prior to his life-threatening illness. Caroline's strong need to verbalise her love was important to her in two ways; her brother was assured that he was loved and she did not feel that she had

held anything back before he died. The feelings of guilt gradually subsided after her brother's death and instead Caroline expressed feeling sad about not being able to share time and experiences with her brother any more.

However, there is an undercurrent theme for the majority of the participants feeling guilty for wanting more time with their sibling, as this meant the ill sibling would be ill and in pain for longer.

The participants spoke of feeling particularly comforted by having had the opportunity to talk openly with their sibling and at times to resolve old misunderstandings. Rosie connected with her brother in a way she was certain she would not have done if he had died suddenly;

'... I suppose I've got the approval...the approval from him that I didn't necessarily have, because we misunderstood each other for such a long time...' (Rosie: 93)

Despite Rosie stating that her brother finally approved of her as an individual her hesitant manner of speaking and verbal uncertainty manifest the difficulties of understanding each other and expressing emotions in the limited time left. The time they had together during his illness comes across as too limited to bridge the lifelong emotional and relational distance between them.

The illness created an extended grief process for months or years, as the participants were living with their sibling's impending death. There is a paradox of the illness providing time

for conversations, which need to take place urgently in case the sibling would die in the next day or the next hour.

'...and now, I would have liked to have said more, but...certainly spent much more time with him, at the hospital, talking...' (Francesca: 6)

Thus, thoughts and emotions were not held back as they often had been before the seriousness of the illness had been confirmed.

Leon's experience of his sister's illness was different from the experiences of the four participants above as he had not been in contact with his sister for a number of years prior to being told that she had a life-threatening illness. Her illness did however create a focus on the limited time the siblings and the family had left together, which was similar to the experiences of the other participants. The conflict originated between Leon's two sisters and consequently affected the whole family. The illness brought the siblings and the whole family together again for social occasions, albeit without mentioning nor resolving the previous conflicts.

"...we went and saw my mum and dad yet another time and they said 'Look, you've got to now get in touch with Beth, we've got to tell you this, she's got cancer and she wants to get in touch with you'...um...now...I was quite prepared to do this...' (Leon: 96)

Leon does not mention the reasons why he agreed to re-instigate contact with his sister.

However, there were several aspects in the quote above implying he did not feel it was up

to him whether he wanted to resume contact with her. He is quoting his parents, who are telling him to get in touch with his sister, rather than asking him what his wishes were. The repeated referral to 'get in touch' gives a removed feeling of the two siblings being old acquaintances, rather than having a shared past. He refrains from mentioning his own emotions but the word 'prepared' implies that he considered seeing his sister as a duty, rather than a choice. He knew that declining to see his sister would upset his elderly parents at a time when they were already emotionally fragile.

'...we all got together with mum and dad and we had the thing that mum and dad longed for, the whole family back together...'(Leon: 108)

Hence, family gatherings once more included all three siblings, their children and their parents, although Leon describes people to avoid confrontations by acting rather than behaving naturally.

'...we used to go and take all the kids together.....and it was as good as it could be and we were all perfectly nice to each other...' (Leon: 108)

Leon's description of family gatherings speaks of the siblings putting their arguments to one side as to make the most of the time his sister had left. Due to the disputes being unresolved there was an unspoken agreement to not mention previous conflicts, to be in the moment and concentrate on the elderly parents and the children having an enjoyable time.

This theme shows how these participants used the time of the illness to express emotions and thoughts, which would otherwise have been unsaid or undone and at times simply spent quiet time together, as they knew that there were limitations of being together. The participants above became closer to their siblings during the illness, although it should be noted that those who were already close became closer while for those who had not been close there were still barriers that were not overcome. The emotional distance between the siblings who were not close did however decrease.

## Sudden death leaves issues unresolved

When the sibling died suddenly there was no time for conversations or to prepare emotionally in the way described in the theme above. Despite some of the participants having very little contact with their sibling, there was an unspoken sense that there would be time for important conversations at a later time. One matter that needs to be clarified is that there is some overlap regarding abuse in this theme and the theme of death ending abuse.

# **Unanswered questions**

The five participants (Beatrice, Nick, Nora, Lucy and Sally) who lost their sibling suddenly expressed feeling left with questions about the circumstances of the death. Although there were no interview questions specifically about abuse three of the participants (Beatrice, Nora and Nick) who lost their sibling suddenly talked about their experiences of

abuse connected to the sibling. Beatrice associated her brother with physical violence and emotional abuse.

'...the power he had over me as the older sibling.....and he was very abusive when we....when I was young, he was young as well, so physically abusive and a lot of that stuff...' (Beatrice: 36)

Similarly, the abuse Nora's brother subjected her to was physical and emotional.

Additionally, she is quite certain that the abuse was also of a sexual nature, although her family's reluctance to acknowledge the sexual abuse makes Nora doubt her memory:

'...it's very diffic...well, there are things which are very obvious from, you know, he...trauma.....it was, one thing was very conscious that he found my hidden diary, which was locked and broke it open and then he... and read it and even then boasted about it. 'Til today, I wished he'd never told me, kind of thing, and then there was physical abuse and there was probably also sexual abuse...' (Nora: 85)

Nick's experience of abuse was different from the abuse Beatrice and Nora were subjected to, as the abuse he connected the abuse to his step-father's emotionally abusive behaviour towards the whole family.

'...he would make a really bad atmosphere in the house, so...umm...I didn't like the way he was with my mum...umm...yeah, it was just not a nice environment really.' (Nick: 26)

The sudden death prevented Beatrice, Nora and Nick from receiving explanations for the abuse they had endured. They expressed having to live with a lack of closure, which will be further explored later in this section. Medical staff, the police or friends and relatives visiting immediately after the death provided information of a practical nature, although personal and emotional aspects relating to the death remained largely unattended to.

Lucy in particular was left with many questions after her brother died abroad, where the laws and investigations were not of the same standard compared to those in the UK. Due to the suddenness of his death she was trying to find out the circumstances of her brother's death while being in a state of emotional shock. Lucy and her parents felt that the meaninglessness of his death was reinforced due to the lack of information about why and how he had died. This can be seen in the following excerpt:

'And they'd had a meal but they hadn't eaten anything out of the ordinary so there is a lot of unanswered questions that we will never...never find out about now...'(Lucy: 12)

Lucy's reference to unanswered questions is explicitly related to how and why her brother died. On a more implicit level her referral to unanswered questions could be linked to her questions regarding the life her brother could have lead and the relationship they could have had. Lucy's questions about the future emerged a few years after her brother's death, as seen in the quote below:

'...when I've met his friends and things now and I see that their lives have moved forward and they've got families and jobs and I find that....that's the most difficult thing to deal

with a the minute.....cause I....it's like wondering about the 'What ifs', what if it hadn't happened, what would be doing now?' (Lucy: 159)

The other participants received more detailed information about the death, yet questions of an emotional and spiritual nature persisted.

Sally found meaning by seeing her brother as saving her from a destructive life and therefore having an ongoing connection to him.

'...when it gets into spiritual beliefs and whatever else, you know, I toyed with the idea and now I really have to accept that there was some kind of pact between us and that was one of the things that really got me through it in the early days is, if we had an agreement and I get to chose my own life, so I chose this life, knowing that my brother would die...' (Sally: 222)

The lack of answers about the death often made the participants speculate about why the deaths had happened, although inevitably they had to return to the notion of having to live without knowing why the death happened. Nora voiced her question of whether her brother's accident had been a passive form of suicide. Her hesitation and searching for words in the quote below manifests the uncertainties surrounding her brother's death.

'...no one knows......and he was already drunk, but I mean, how the girl friend described it to me, how she found out, I mean, he was drinking vodka in bottles...ahmmm...put in bags,

you know, paper bags, driving....so, that's also a form of...it would take suicide into account, isn't it, if you do that...' (Nora: 75)

Although speculating about how he died Nora appears to want her brother's girlfriend and the researcher to confirm whether her ideas may be well grounded. This can be linked to the unknown circumstances of the death as well as her unclear memories of sexual abuse and her family's refusal to acknowledge the abuse. The obscurity surrounding her brother's death carries similarities to her memories of the sexual abuse:

'...there was physical abuse and there was probably also sexual abuse but I don't have, 'til now, still not a very conscious memory, was haunted by nightmares for years, waking up screaming and so on...' (Nora: 85)

Despite questions around the sudden deaths being very present in the interviews, most of the participants expressed little or no hope of gaining further understanding about the specific circumstances of their sibling's death. Their questions often focused on how the minutes and seconds prior to the death remained unknown. Sally's account tells of the uncertainty about the circumstances around her brother's death still being with her nine years later.

'...whatever happened, we're still not completely clear...' (Sally:2)

The impact of her brother's sudden death can be seen in the quote below:

'...there was a lot of fighting and what not......I would say that my whole family fell apart before the pieces came back together...' (Sally: 26)

Although Sally refers to the unclear circumstance around her brother's death she was the participant who was most at peace with the knowledge that she and her family would never find out exactly what had happened. This appears to be partly due to how she, eventually, turned his death into something positive by starting to lead a physically and emotionally healthier life and partly due to nine years having past since the death.

## **Meaninglessness**

The void of knowledge about the specific circumstances surrounding the death as seen above can be of a pragmatic nature, however, the psychological nature can manifest itself in a lack of meaning in the participant's life. Nick struggled with the meaninglessness of his brother's death and at the time of the interview he struggled to connect emotionally with his brother's death. The void of knowledge about the circumstances surrounding the death and the lack of emotional connection can be linked to the violent way the sibling died, as the shock following the death appeared to be lasting for months or even years. Nick knew how his brother had died but had little hope of understanding the extreme violence:

'I tried to understand that and...don't at all....r.' (Nick: 155)

There was a strong connection between his brother's sudden and dramatic death and Nick's depression, as both had strong connotations to meaninglessness. In the interview the depression manifested itself in Nick's quiet voice and struggle to verbally express his emotions. The quote below shows how he struggles to engage with life and other students at university:

'...it's kind of just general emotional detachment and ...umm...just not enjoying things, that kind of thing, not enjoying new people. '(Nick: 44)

When the sibling relationship had been strained the participants' focus was on themselves, with the death and the relationship with the sibling in the background. Beatrice and Nora felt left without the possibility of receiving the apologies and explanations they had wanted from their brothers. They had both refrained from seeing their brothers for a number of years before the deaths after having been abused in different ways by their brothers. Beatrice had rehearsed the conversation she wanted to have with her brother many times.

'...I want to talk to him about what happened and why he was so mean to me, you know, as a child, and all this stuff...' (Beatrice: 66)

The physical and psychological abuse he had subjected her to during childhood made her fear him to the extent that in adult life she was unable to talk to him even on the telephone.

'But for me, it is also a recognition of sometimes that person has so much power over you...you allow them or whatever, in a psychological way, that you're unable to have that conversation...' (Beatrice: 68)

In this quote the distance between the siblings and Beatrice's fear can be seen in how she changes from first person to a more removed generic you. Further, the quote shows how the physical and emotional abuse Beatrice had been subjected to by her brother meant she did not feel able to ask him in adulthood why he treated her badly. Her reference to 'recognition' can be linked to her understanding that her brother's behavior was abusive, which subsequently prompted her to leave her country to protect herself from him.

In a similar way to Beatrice, Nora found speaking to her brother too emotionally difficult and instead wrote him a letter, asking him to acknowledge the distress he had caused her in childhood as well as in adulthood.

'I wrote to him about it and I said 'At least, I need this reciprocity and I need that you apologise for it'....'(Nora: 47)

The theme of a sudden death leaving matters unresolved is further reflected in Nora's narrative of how much her brother's apology would have meant to her, although she did not receive anything back in writing, nor verbally. Nora felt that she had done all she could to facilitate contact with her brother and her nephews.

'Yeah, yeah, that one could never...yeah, and all I could do was...you know, sort of bring it in the open and say what I needed and if then that was not addressed...' (Nora: 276)

As can be seen in the quote above, Nora changes tenses when talking about her abusive brother. There is a sense of self-protection in this distant manner of talking, as to maintain a distance to the abusive sibling. Possibly, she may have had some anxiety of about being believed in the interview. This idea is grounded in her referral to not being able to prove the abuse with memories of specific incidents. Nora felt that her family had not cared for her and protected her in childhood.

'...only remember always screaming for our mother to protect us [from the brothers] and whatever, or leave us alone, that was the...there was a lot of cruelty, you know, and my parents were also very...very cruel, it was just handed down, so to speak.' (Nora: 85)

Despite finding the strength to protect herself, the care Nora wanted from her family remained absent and many conversations were avoided.

Whether the participants associated their sibling with love or abuse, the sudden death created a lack of closure and the participants were left without knowing about issues which were important to them.

### **Grieving a loved sibling**

For the participants who were grieving for their loved sibling, Georgina, Francesca, Caroline, Lucy, Sally, Rosie and Nick, there was a strong sense of their lives having become unpredictable. The grief tended to be for the future, rather than the past, as regular contact and family celebrations would no longer include the sibling. Grieving for the loss of a loved sibling showed a strong focus on relationships on a number of levels; between the participants and the siblings, between the siblings and the participants' existing or unborn children and between the participants' children and parents.

## The impact on relationships and the future

The sadness for the future expressed by the participants who had lost a loved sibling was strongly linked to the future having become unpredictable. The participants grieved for the time they would not have with their sibling on several levels; the immediate days and weeks, upcoming family gatherings and life in middle age and retirement. Further, there were changes to the roles within the family, with the participants shouldering increased responsibilities for their immediate family. The role that the participants had expected to have in their family in the future now needed to be re-defined.

As mentioned previously Georgina's sister had been seriously ill for a number of years and Georgina had cared for her during some of the time. In addition to losing her sister Georgina felt that she had to an extent lost the parents she knew and had expected to have in the future.

'...dealing with your parents grief, as well as your own grief and very much seeing your parents turn into...it's just...it's like part of them dies really, you...you know, you lose a huge...something of your parents...'(Georgina: 96)

The heaviness in the above quote is illustrated by Georgina using generic you, as if the multiple losses she describes would be too much to endure if spoken in a first, and therefore more personal, tense. The enormity of her sister's death is depicted in how she hesitates and struggles to find the words for what she has lost. Her grief becomes bottled up, which surfaces in crying and depression in her daily life. There is a sense of these participants having to live with loss on a daily basis, making the present and the future become heavy and grief-stricken. Further, there is an added burden on these participants, as the support for aging parents cannot be shared with the sibling anymore. Georgina's experience of supporting her mother, who lost her daughter and her father in less than two years, highlights the increased pressure.

'...she was really improving, she was climbing a kind of...you could see...uhm...differences in her and then when her father died...uhm...it knocked her right back...uhm...and that was June, so that was four months ago and recently, I've been saying to my partner, I've been saying that she is just in such bad place at the moment and it's...it's very, very hard, cause again, it's another loss for you, I think.' (Georgina:96)

After her sister's death there is a feeling that Georgina is uncertain of what may come next. It is as though she is fearful of the future, rather than expecting it to hold pleasant surprises for her.

For Lucy and Francesca the void of their brothers in the present and the future was acutely present. At the time of the interview Lucy is staying away from celebrations and family gatherings with the extended family, as her brother's absence becomes painfully obvious at these times.

'I used to sort of enjoy family things, now I would say that I would avoid it if...if I could, cause it always feel like there's...there's someone missing...(Lucy: 116)

The death of Lucy's brother means that not only has she lost him in her daily life, she has also lost him for all the future gatherings which would otherwise have been times of joy and celebrations. Additionally, she has to some extent lost her extended family, as she is keeping any contact with them to a bare minimum.

'it's just had a massive, massive impact on our lives and I often think back to how different things would have been, had it not have happened...(Lucy: 126)

Lucy's reference to thinking about a future that could have happened comes across as a way of escaping her grief and the reality of her brother's death in the present time.

Prior to her brother's death Francesca had imagined how she would spend time with her sister and her brother, when they were all older. The enjoyable times she had envisaged are not possible now and the security of her sibling group has been damaged, albeit not destroyed.

'...my brother loved walking and when I saw him, he'd take me walking and used to

sometimes think 'One day, you'll be [years of age] and I'll be [years of age] and we'll be

pooteling along'...umm...and in a way, how nice that would be...umm...and I feel the same

about my sister, that we'd sort of...something about the three of us, would survive and it

was a shock when it didn't (Francesca: 60)

There is a sense of the majority of the participants who grieved for their sibling feeling

robbed of the enjoyable aspects they had expected their lives to contain. Any mutual

support between the siblings has been taken away, leaving the participants to take care of

their parents' and their own emotional needs. The accounts of changed roles within the

family have undertones of the participants feeling abandoned by both their sibling and

their parents when they intensely need support themselves.

There is an underlying theme of tiredness and the need to preserve one's energy for the

participants who lost a loved sibling. It can be linked to the immediate future, such as the

upcoming days, weeks and the more distant future. Caroline struggles to find sufficient

energy to get through each day:

"...I'm pretty like, like living on that edge, it's more like a sort of survivor sort of mode..."

(Caroline: 333)

The 'survivor mode' implies that Caroline can only find sufficient energy and vision for

each day. Further, living on the 'edge' brings to mind an unsafe existence, in which grief

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has challenged the safe life and future she had envisaged. At times the participants' tiredness is verbalised, as manifested by Lucy:

'...it was a constant struggle for...two to three years, cause I had another daughter afterwards, there's not a great big gap between them and that was so very, very difficult when I was tired...ahm...just to...to handle things...' (Lucy:80)

At other times, it comes across through the tone of voice or difficulties in concentrating during the interview. It should be noted here that Nick had loved his brother, although the abusive behaviour from his brother's father had overshadowed the relationship. Hence, Nick felt both grief and relief. The unpredictable and violent death of Nick's brother had shaken the family profoundly. At the time of the interview Nick was still struggling to understand what had happened, which can be seen in how he searched for words for his written work and during the interview, filling out sentences with repeated phrases.

'Yeah, I don't really have a desire to express myself and...um..., so yeah, just...and you know...ahh...get really kind of...self-critical...um...you know, can't get a few words out without deciding it's just crap...' (Nick: 95)

Participants who were still early in their grief process at the time of the interviews wondered if they would be in a grieving, depressed mode for their remaining lives. The new and painful experience of knowing that life can be unpredictable made the participants re-consider how to spend their energy. When the grief made them exhausted they instinctively preserved their energy for only the necessary work and the people

closest to them. While some participants did not make a conscious decision about how to spend their time and energy, Rosie took a firm stance to those who would not reciprocate her efforts of sending cards or visiting.

'...the real thing that's happened since he died is that I've given up with my step-sisters, kind of just...it's not worth my time, they're not related to me, they're as old as me...I...I send birthday cards and Christmas cards and you know...kind of make an effort and get...nothing in return, just...I actually went "Ok, no matter how much pressure there is from my dad to do this, no, the answer is no, it's not worth my effort'. There's other things I'd rather be doing with my time.' (Rosie:36)

The notion of unpredictability for the future created an additional layer of tiredness combined with anxiety about any further issues the participants may need to deal with on a practical, relational and emotional level. Georgina's quote below shows the strong impact the death of a sibling can have on the daily life of the participants and their families.

'I think my parents are a little bit more protective of me and worrying more about me...uhm...and probably it's the same with me with them, I'm very... worry lots about them and anxiety I think becomes quite an issue ......a good example is for example I touch base with both my parents every day on the telephone even if it is just a five minutes, two minutes conversation 'Are you ok?', by the shortest you know....' (Georgina: 6)

Georgina's quote above provides an insight into the anxiety provoked by the death.

Although the contact within her family increased, it arose from anxiety of another family member becoming ill or dying. Hence, the loss of an adult sibling can change the experience of the both the immediate and distant future.

Sally's experience was different from the participants above in the sense that she expressed a feeling that her brother's death gave her the chance to start leading a healthier life and envisage a future for herself. However, her grief for the future involved an extremely intense urge to embrace both the present and the future that her brother was not able to experience.

'I had almost burnt myself out...so, where I am now...ahm...I am a lot more conscious of the fact that taking breaks and going out for walks is actually work, going and laying in the bath is actually work, because in order to be the best that you can and what you need to do, you need to manage stress and... the challenges...' Sally: 122

Being close to burning herself out highlighted the strong paradox in Sally's account; instead of filling her life with people, alcohol and drugs in the same manner her brother had done, she filled it with work. However, she eventually learnt to reduce her stress by looking after herself physically and emotionally. Sally came to this point a number of years after her brother died, while the other participants who grieved for their sibling had lost them more recently.

The emotions connected to the loss appears to arrive like waves without warning for the participants who were grieving their sibling, overwhelming them and taking over their lives. The uncertainty of when their feelings of joy would become replaced by sadness created feelings of anxiety and exhaustion.

### Death ending abuse and bringing relief

Four of the participants, Beatrice, Nick, Nora, Leon, had expressed feeling relief following their sibling's death, as they had experienced different kinds of abuse in relation to their sibling; physical, sexual, psychological, emotional. They strongly associated their siblings with conflict and feeling controlled in different ways and expressed a sense of relief and freedom after the death. However, the psychological issues in particular were a dichotomy as the abuse was removed without the possibility of receiving apologies or recognition of the pain caused by the abuse. The participants who had been physically abused, Beatrice, or sexually abused, Nora, by their sibling told of strong feelings of anger both before and after the death of their sibling. Prior to the death the anger had been focused on the sibling, however, after the death there was nowhere to channel it and the participants were left with their often hostile emotions.

#### Newfound freedom

For Beatrice and Nora issues around age, gender and social customs were closely linked to how they had been treated by their brothers. Beatrice's brother had been physically violent towards her and bullied her psychologically during their childhood and

adolescence. He was not stopped or challenged by their family nor by wider society, which left Beatrice feeling unsafe and lacking in confidence.

'...he'd beat the hell out of me. I just never understood it. I remember, sort of, my parents would come home and sometimes I'd cry until they came home just so they'd see I'm in pain. And nothing was ever done, really, my mother was like 'Oh, don't do that!'. You know, the sort of regular occurrence where I'm being brutalised and nobody seems to care.' (Beatrice:84)

Age and the male gender were especially connected to wisdom and authority in the culture and society in which Beatrice grew up. Hence, moving to the UK and becoming older than her brother had been at the time of his death created a sense of freedom.

'My brother was a year older than me, so today I'm officially older than him, so today has been an absolutely...it's been...and I knew this day was coming...Our history, you know, isn't particularly good, so it's almost as if from today onwards I almost get my freedom back....'(Beatrice: 34)

Only after his death did she feel sufficiently liberated to overtake her brother in work and academic studies.

'I could never achieve better than him, you know, because psychologically I was raised to believe that he was better so even when my potential could allow me to succeed I would never actually transcend that.' (Beatrice: 36)

Although her brother's death stopped any kind of abuse it took time before she could embrace her newfound freedom.

'... because I'm managing to achieve now, since he died I'm managing to push through certain barriers that I wasn't able to before......it was almost as if life became chaotic at the point of achieving higher or better than him...(Beatrice: 46)

Breaking the rules and challenging the norms of her family and her culture was a slow and difficult process. The chaos Beatrice refers to above was very present in the interview as she interwove her personal stories with her creative work. At times, the stories became very intense and the distinction between reality and fiction was less visible, which is similar to her brother's lack of respect for her personal boundaries. Additionally, by using creativity as examples of her own life there was a distance to her brother and the abuse, possibly a way of establishing a safe space for herself.

Similarly, Nora describes paradoxical feelings of anger and relief following her brother's death. She expresses anger about being abused by her brother who died, as well as by one brother who was still alive at the time of the interview.

'...but talking about, wanting to kill them [the brothers], there was an element of relief in the very first instance...(Nora: 89)

The relief derives from the freedom of living in a world that no longer includes the brother who abused her.

'...I currently don't want to kill them [the brothers], I mean, what is that anyway?

Ahmmm...no, that has clearly, that very strong feeling has subsided...(Nora: 233)

Nora's question to the researcher is an example of how her family's lack of recognition of her brother's behaviour has left her uncertain about her own memories and emotions connected to the abuse. The memories were manifested in nightmares and gut feelings of needing physical distance to her brother. Thus, she was unable to provide her family with proof of the abuse. She had wanted to receive an apology from her brother for the abuse he subjected her to, however, this became impossible due to his death. As can be seen in the quotes above she does however express feeling relieved and less angry after his death, as she no longer feels threatened by him. Beatrice also experienced the death of her brother as bringing feelings of lightness and relief after having felt controlled by him for her entire life.

'...it was a real, sort of, almost physical shift in my body when he died, almost relief, I mean, I've gone through the kind of mourning, the loss, looking at what I've actually lost but the biggest impact has been this sort of pressure on me, which has been lifted.'

(Beatrice: 148)

Beatrice is saying that she has looked at what she has lost, although it is not clear what she considers this loss to entail. There is a sense that Beatrice was expected by her family

and her culture to grieve, yet the emotion she is experiencing is relief. The pressure being lifted can be linked to her brother no longer being able to put her down emotionally or through physical violence. Additionally, the pressure being lifted has a strong connection to how after her brother's death she has moved from a position of feeling pressed down to a place where she can achieve higher goals than ever before.

For Nick the abuse was connected to his sibling through his step-dad, who was controlling on a social and psychological level.

'...just generally being unable to be comfortable in the house...um...and...amm...just having a lot of conflict really' (Nick: 119)

Living with conflict on a daily basis created fractures within the family and limited the contact Nick had with his immediate family. The issue of feeling controlled remained strong throughout the interviews for the three participants above.

As seen above abuse can be experienced on many levels. For Leon the abuse was on a social and psychological level, caused by his sister spreading rumors about the family for a number of years prior to her becoming ill and dying. The tension between his sisters had escalated several years before his sister became ill and he was asked to take sides.

'And I was kind of being cast in the role of referee [between the two sisters]...'(Leon: 34)

'....it was horrible..... as horrible as you can imagine and I'm afraid to say that things have
got worse.... (Leon: 42-44)

Although refusing to take up the role of referee he was unable to escape the family conflict, as his parents would update their children about any news within the family. Leon's quote above indicates that his sisters were playing games, which subsequently divided the family. The referral to games and acting continues as the family meets once the sister's illness has been confirmed, albeit without resolving or mentioning previous conflicts.

'Nobody thought anyone was acting out of a pure motive, but none the less, we went ahead and did it and for the last two years of her life I used to take [my son] to make sure he saw his auntie...'(Leon:102)

Leon describes his attempts of protecting his family and himself from the rumors but found it difficult due to the impossible situation of not knowing who had heard which rumors. His reference to the family acting without a pure motive reflects how the rumors have tarnished the relationships within the family. The rumors sound like acts within the play that is the life of Leon's family.

'So, for a good decade, up until now, I've been through a fair of sequence [with the family] but that's all gone through and passed through...'(Leon: 176)

The conflict continued until after the funeral, albeit under the surface for the last few years. The reconciliation of the family, although simmering with unresolved conflict, put a stop to the vicious circle of a long family history of people dying without having said

goodbye. Additionally, the youngest generation of the family was not restricted by conflicts created by the older generations and therefore had the freedom to develop relationships with everyone in the family.

Leon's concern for his family, rather than for himself, is reiterated in Nick's excerpt below.

Nick's family, and his mum in particular, was experiencing greater freedom following his brother's death, as it coincided with the death of his mum's controlling partner.

'That is kind of...that's is kind of a fresh start for her, she [mum] is...she is having a really good time at the moment. She is....um...travels quite a lot. She almost couldn't leave the house, unless it was to go to work, whilst she was with him, like she lost all her friends.'

(Nick: 221)

The sacrifice for living without being controlled was enormous for Nick's family, since they were not able to share this freedom with Nick's brother. The reference above to his mum having a good time initially sounds positive but is rife with paradox, as the price for her freedom was her son's life.

As seen in this super-ordinate theme, the death of a sibling in adult age can create many paradoxical emotions and situations. While a long-term illness provided time to express love or disregard conflicts, a sudden death often left the participants with unanswered questions about the relationship with the sibling and the death itself. The emotions were strongly connected to the relationship between the participant and the sibling.

# **Living after loss**

This super-ordinate theme involves the investigation of how the participants found living with their bereavement on a daily basis. There are four themes under this super-ordinate theme; 'Connecting with grief', 'Continuing bonds with sibling', which has the sub-themes of "Loss and having children' and 'Re-connecting with sibling's children', followed by the last two themes; 'Break from everyday life heals' and 'Bereavement affects sense of time'.

#### **Connecting with grief**

The participants approached their loss at individual paces and reported difficulties of coping with the loss in their daily lives. Some described putting their loss in a metaphorical "box" or placing memorable objects in an actual box for the majority of the time, while others blocked out or bottled up their emotions. The purpose seems to be a form of self-care, providing some control of when to face the emotions connected to their sibling and the bereavement. The "box", metaphorical or other, can be considered as blocking the

grief out, however, for most of the participants the box was saving them from the intense pain of grief at times when they felt unable to deal with it.

The metaphorical box refers mainly to the time soon after the death and periods when the participants felt unable to be immersed in the emotions connected to their loss. However, they implied having expectations of facing the bereavement at a later stage. The shock of a sudden death tended to leave the participants unable to remember details surrounding the death, including their own emotions and reactions at the time. Lucy is uncertain of whether she can connect with her initial feeling after her brother's death.

'It's hard to think back to the very early days because I feel that a lot of it I've blocked off...'
(Lucy: 169)

Despite the shock wearing off gradually, the strong emotions were often placed in a metaphorical box as described by Lucy.

'I sort of shut it [the grief] away in a box...' (Lucy: 171)

At the time of the interview Lucy shares her grief with her parents and her daughters, while still struggling to share it with those outside of her immediate family.

Sally found that she was eventually able to share her grief with others, instead of bottling it up.

'I'm a great believer in, once you've experienced it and understand it, you can then talk to other people and the odds are that it resonates with other people...' (Sally: 210)

This is an interesting example of how grief is kept in a 'box' and will only be communicated to others after the participant had managed to understand it, providing little or no support in the early stages of grief. It should be noted that the time since the death could play a role in the participants sharing their grief and experiences with others. Nine years had passed since Sally's brother died, which was the longest among the ten participants. She had also actively sought out literature and information about death and spirituality to help her understand her loss, which she felt had been very beneficial to her grief process.

Francesca knew her brother was dying, although witnessing his last breath was still traumatic. The self-care aspects of keeping grief in boxes described earlier can be seen in how Francesca treasures her metaphorical box of her brother's death but can only open it when she has prepared herself emotionally.

'It's interesting to sort of bring it out of the box again in a way, cause I think, it means a lot to me but I put it away and then I sort of occasionally, as you said, anniversaries or the mountains, get it out of the box....... the reason I think I put it in a box is that when he died, I really, I felt like the bottom dropped out of my world and there were some very experienced hospice nurses and one of them was physically holding me. I think she might have thought...I don't even remember, she must have thought that I was going to faint or something, I remember...umm...cause I think it is still quite vivid in my mind and

I...umm...if I really think about what I have lost I feel really upset and that's why I sort of put it in a box and get it out occasionally.' (Francesca: 148)

The participants' need to put the grief away in a box can be linked to their lack of energy and time after the bereavement. Georgina describes distracting herself when she only has limited free time.

'I'm very funny about going into certain places in the evening when I'm tired and before bed so I tend to then block things out, put on films...' (Georgina: 55)

The metaphorical box comes across as a form of life jacket that can stop the participants from drowning in their grief until they are able to open the box. Nick was still in the very early stage of his loss at the time of the interview due to having bottled his experiences up. Although uncertain, he is guessing that his brother's death is connected to his present depression.

'I think I've got depression at the moment, I've been diagnosed with it, so that's the best guess so far ...and.... I think, it obviously makes sense for it to have something to do with [the death]...umm...yeah, there isn't like a...it isn't like a reason in my mind why anything is wrong...um...'(Nick: 38)

The participants felt comforted in knowing that the emotions as well as memorable items could be put away but also brought out of actual or metaphorical boxes at a time when

they felt prepared for it. The participants described photos and other items connected to the sibling as passive but constant reminders of what they have lost.

'I had a box that I kept initially...ahm...of all his..some of his belongings and the cards from the funeral and some of the cards I got sent and I kept it all in a box and I had a note pad and I wrote down in the note pad all the things I could remember about him, things...the way that he spoke and the phrases that he used and I wrote it all down, but I can't...ahm...I can't physically open that box now...' (Lucy: 173)

Lucy and her parents have a book with personal notes from the funeral but are unable to read it.

'...we've got a book at my mum and dad's house that...that we had at the funeral where all his friends wrote in it, none of us can even open it, it just stays on the shelf...' (Lucy: 181).

It seems that Lucy and her parents initially wanted the book as a memory and a form of support. Instead it has become a strong visual and emotional presence that is too emotional to approach and it is left on the shelf. Although the family does not open the book its existence may be re-assuring when and if they feel ready to read the messages in it. The family's reluctance to open the book shows further links to how they have kept their grief within the immediate family, without sharing the grief by asking for support from others.

Caroline fluctuates between wanting to make her brother present but often finds her own attempts to do so more upsetting than comforting.

'I do try to keep him around me but then sometimes I... I like have a picture and I'll just cover it with something else cause I just can't...I can't deal...I can't yet...think about him and not feel sad.' (Caroline: 269)

Despite Caroline's intense grief she has hope that she will be able to make her brother present in her life and remember the positive aspects at some point. Covering the photo appears to be a form of putting the visual impact of the loss away until the grief had become less raw.

Connecting with the grief was immensely difficult for the majority of the participants and they often regulated their grief by putting emotions, memorabilia and photos in actual or metaphorical boxes. This allowed for the grief to oscillate and provided the participants with some respite from the intense emotions of loss when they felt they would be overwhelmed by these feelings.

### Continuing bonds with sibling

This theme will look at how the participants continued to have a relationship with their sibling after the death. Beatrice, Nora and Leon did not express wishes to have continuing bonds with their sibling, although as will be discussed below they had bonded with their sibling's children. The remaining participants expressed feeling comforted from having

different kinds of continuous bonds with their siblings. The bonds ranged from maintaining relationships associated with the sibling, to their personal relationship and spiritual experiences connected with the sibling.

The participants were surprised and grateful when their siblings' friends or colleagues continued to keep in contact. Francesca only came to know some of her brother's friends towards the end of his life but found comfort in the continued contact with them.

'So that was nice...umm...and now they [brother's friends] write to me at Christmas and things like that. (Francesca: 104)

Unlike many of the other participants Francesca did not find Christmas or other celebrations difficult following her brother's death. The communication with her brother's friends accentuated a joyful time and she greatly appreciated her brother being remembered by a greater number of people than she had initially expected.

Similarly, the majority of the participants appreciated learning that their sibling's life had involved more people and experiences than they had known about while their sibling was alive.

'...we still hear from people all the time and you realise how much, like, one life, even a small life like my brother's, a really small life, like touched so many people and so maybe I'm just relaxing...' (Caroline: 568)

Prior to her brother's death Caroline perceived that making a difference in the world needed to involve working in conflict zones, where serious danger and threat were part of daily life. After losing her brother she realised that he had influenced others and still had an impact on the world, albeit on a small scale.

The sibling's continuing presence in the smaller scale as described above by Caroline can also be seen in the participants' immediate family. Lucy includes her brother in everyday conversation and refers to him in present tense, illustrating the importance of continuous bonds.

'...he's still very much part of our lives...' (Lucy: 74).

In Nick's family there was little verbal communication about his brother. Instead, memories of his brother were manifested in the house by physical objects.

'...there is a picture of him about that big and there is a light by it which is always lit...'

(Nick: 177).

The continuing bonds are both linked to and separate from the previous theme of connecting with grief and the latter being kept in boxes. It seemed that the participants' experience of the boxes, metaphorical or actual, are emotionally charged with negative connotations. The different forms of continuing bonds, on the other hand, are experienced as positive and help the participants to not become stagnant in their grief process.

The continuing bond with the sibling resonates with some of the participants' wishes to provide their children with an extended family and a history. The participants who had children spoke of having strong needs to provide their children with an understanding of the sibling's personality. The participants who had young children at the time of the interviews were concerned with making their sibling present to the children and often included items such as balloons or photographs to make the connection less abstract. Although Rosie's son was still a baby at the time of the interview she was thinking of how she could show her son what kind of person his uncle had been.

'...I, as a parent, want to figure out ways of making him real to my son, because he was such a creative and interesting guy [......] we have pictures up...' (Rosie: 161)

The excerpt above shows her wish to provide her son with a family history and stories that would anchor her brother in the world. The wish to maintain a bond with her brother also appears to derive from not having an extended family and thinking of losing her parents in the future:

'...when they go, there's only me left and that...I have no other family, you know, that's it...'(Rosie: 47)

Lucy's daughters were older than Rosie's son and could to an extent develop a connection to their uncle, despite having been born after he died.

'...we've talked about Uncle Harry and the...heaven, just...ahm...it's up in the sky and on his birthday we let off balloons...' (Lucy: 207)

Lucy's reference to the heaven and the balloons conveyed the feeling that she and her daughters were sending messages to show their love and care, although they were not able to see him or meet him. It came across as a healing, albeit difficult, experience.

Losing a sibling awoke an interest in spiritual aspects for Lucy, Sally and Caroline:

'I have been a lot into, you know, heavily spiritual practising and like, I've been looking into a lot of ancestor practices and I have my ancestor altar...' (Caroline: 175)

Caroline's interest in spirituality was connected to a wish for her brother to have an impact in the future:

'...so I try......the way people in history can affect things now, we see it differently or you discover them later and then they have an effect....' (Caroline: 179)

The wish to find a spiritual aspect to the loss has two strands; referring to the past and maintaining an ongoing connection in the present and the future. As seen above, Caroline refers to the past by referring to her ancestors.

For Rosie photographs were important to make her brother and his family present to her son.

'...and there's a picture of my brother there and, you know, he [son] will know who that is and he'll know that the girls [sister-in-law and niece] are part of the family, hopefully...'

(Rosie: 167)

Despite the relationship between Rosie's family and her brother's widow being somewhat strained the quote above shows Rosie's wish for her son to have a relationship with his cousin and aunt. This continuing link to her brother appears to make Rosie's loss slightly less painful.

The majority of the participants presented continuing bonds as keeping the memory of their siblings' present by sharing it with others. They described continuous relationships to be the personal relationship between themselves and the sibling. However, Caroline, Lucy and Sally described how in addition to having continuing bonds to their sibling, the relationship with their sibling continues to develop despite the sibling's death. The relationship evolved with time, as they became older and had new experiences. As time passed and the initial shock subsided the participants often found a continuous relationship and an ongoing dialogue with their sibling to be soothing and meaningful.

'And grow and as I get older and I see him in different ways through the things that I live, I mean, my relationship with him continuous to develop although he's dead and that's something that I really want to...that's something that's important to me to keep.....keep

developing so that he's not like a static...like his life continues to have meaning....'
(Caroline: 173)

There are interesting parallels in the excerpt above between how Caroline described her brother and the overarching feeling of her grief in the interview. While wanting her brother's life to have meaning and have a developing relationship with him, her grief comes across as static and she expresses feeling unable to see any meaning in life. However, this may be related to Caroline's brother having died a year and some months ago and her moving to the UK at the same time. During the interview she often referred to the death as feeling abstract, as there were no visible marks or memories of her brother's life in the UK. Her personal relationship with him was thereby the only thing she can hold on to.

The experience of feeling connected to the sibling on a spiritual level emerged to be linked to the time passed since the sibling's death. At the time of the interviews, Sally had lost her brother nine years ago and Lucy had lost her brother five and a half years ago. Their grief journeys have included the raw grief and search for meaning described by most of the other participants who had lost their sibling more recently. Slowly Sally and Lucy found a connection to their sibling through spiritual practices.

'I am closer to my brother now than I was before he died, because I worked on developing a relationship and ok, it's completely different...ahm...but it's there. I'm aware that sometimes he's there supporting me...ahm...I will talk to him and use him as a point of reference...ahm...he is a source of inspiration...' (Sally: 184)

Sally's spiritual connection with her brother facilitated her change to a healthy life style neither of them had adopted prior to his death. She saw his death as the sacrifice for her realising that she was risking her own life. Lucy saw spirituality as a continuation of life and her relationship with her brother, as well as providing her with meaning at a time when she saw little point in life.

'And I channelled a lot into that [spirituality] and it gave me...ahm...a new...uhm...what's the word? Like a faith in something, that there....that there was something afterwards that was worth waiting for...ahm...and I got a lot of comfort from that...' (Lucy: 142)

Sally reported how the spiritual beliefs she had sought out after losing her brother had been very helpful. However, she was aware that not everyone would have the same experience or even believe that she had a spiritual connection to her dead brother.

'I've lost the physical but I don't have to lose whatever kind of connection I have with him and...you know...everybody is entitled to their own opinion but that is what supports me, that's what really nourishes me...' (Sally: 186)

Sally spoke of a connection and closeness with her brother which the other participants did not mention. It came across as more positive and continuously changing. This may be linked to Sally making radical changes to her life style after her brother's death and how she made active choices to improve her health, rather than destroy it.

'I'm really happy where I am now...and...you know, nothing but gratitude for my brother because, I suppose, when it gets into spiritual beliefs and whatever else, you know, I toyed with the idea and now I really have to accept that there was some kind of pact between us and that was one of the things that really got me through it in the early days.' (Sally: 222)

She felt that had she not experienced the grief following her brother's death she would not have been able to make the changes that improved her health and possibly saved her life. Naturally, continuing bonds are individual and unique experiences and as mentioned by Sally above, are up for debate.

#### Loss and having children

Some of the participants were concerned about how to convey their dead sibling's personality to their children. Four of the participants, Georgina, Rosie, Lucy and Caroline, who were grieving their loved sibling had tried to have a baby around the time their sibling died. Francesca had older children and Sally did not have children. The death of the sibling and the start of another life created a strong paradox of looking forward to having a baby while dealing with the grief and the sadness that the children would not meet their aunt or uncle. However, these participants regarded having children as something positive for themselves and their parents. Georgina's excerpt below is an illustration of this sadness.

'...lots of different grades of sadness, you know, the fact that she'd never see, you know, know my daughter when my daughter grew up............ and still is probably is still one of

my biggest sadnesses about it, a huge sadness that she [sister] wouldn't...uhm...you know, see her grow up... ...uhm...so I find that, I still find that, you know, I find my daughter's birthdays quite painful...uhm...and...so all these things that are generally happy times...'(Georgina: 18)

Georgina's sadness for everyday life, as well as for special occasions, illustrates the strong paradox of grieving for an adult sibling when having a baby or a young child. Further, she implies that her biggest sadness is the experiences that her sister will not have, which would have included the relationship with her daughter. Hence, the grief of an adult sibling can span the remaining life-time of the participants.

The loss of a sibling left these participants with a sense of meaninglessness and they saw having children as one way of finding meaning again. Lucy describes how her children helped her during the darkest time of her life.

'I was pregnant shortly afterwards and I feel that if that hadn't happened and I didn't have my daughters to focus on...ahm...things would have been very, even more darker than what they were...(Lucy, 20)

As seen in this quote the children provided a positive focus and hope of the future being less emotionally dark than the present. Similarly, Caroline's wish to have a child became stronger after her brother died, as she struggles to see any meaning in life.

'I wanted to have a kid even before Tom was sick and died, it's always been something, but
I guess it's like, in some ways, I think it will, like, give me some reason, you know, to live...'
(Caroline: 495)

Shortly before Rosie's brother died he had encouraged her to have children:

'...what he said to me was, which I took in a very different way at the time, was 'You need to get on and have babies'. So...'Ok' ...uhm... what he knew, but didn't know at the time, was that I'd had a miscarriage....(Rosie, 73).

At the time of the conversation in the quote above Rosie was frustrated by what she perceived as her brother's failure to recognise her as an individual, something that had been a reoccurring theme in their relationship. Her brother's wish for Rosie to have a baby is implicitly referring to him wanting his baby to have a cousin and an extended family, as he knew he was dying. However, at the time of the interview she was re-considering her initial reaction and mainly wanted her to have the experience of having a child. However, due to their relationship not being particularly close, some uncertainty about her brother's intention remained.

Several of the participants describe having a child around the time of their sibling's death to be both a joy and a difficult experience. The child became a positive focus for the whole family, although the void of the sibling became acutely present, as the child would not have a relationship with the aunt or uncle. The participants' parents found spending time with their grandchild to be a welcome distraction from their grief. Georgina could see how

her baby daughter provided her parents with hope for the future although the grief was constantly present.

'And, and, as to my parents, you know, I think she... my daughter has been their kind of lifeline and the cycle of life and something positive and new and so...yeah...very bittersweet (Georgina: 21).

Similarly, Rosie and her mum enjoyed the baby greatly but could be thrown back to their grief, as the baby's facial expressions were very similar to those of Rosie's brother.

'I sit there...... and every now and then, see glimpses of my brother in him because he looks quite similar and my mum's found it very...very good to be around Charlie but also very difficult because he looks, in some ways...(Rosie: 161).

Throughout the interview with Caroline she expressed a strong sense of responsibility for her family as well as vulnerable people in the world, which made it very hard to see her own brother dying without being able to save him. Specifically, she presented a strong urge to create hope for her immediate family and herself.

'I've had two miscarriages this year...after since he died and I'm trying to get pregnant, I think...do something positive for my family, you know...(Caroline: 74).

She saw having children as a way of keeping the family alive on an emotional level, although at the same time she struggled with emotional and physical tiredness. She also presented the continuation of the family line as important.

'And make us feel like we have a future...as a family and we're not just like...dying out...(Caroline: 76).

Caroline's reference to having a child for her family, rather than only for herself, is reiterated throughout the interviews with the participants who had had children since their sibling's death. It alludes to the participants feeling an increased responsibility for the future of their family.

# (Re-)connecting with sibling's children

Despite having a difficult relationship with their deceased sibling Beatrice, Leon and Nora saw an opportunity to create relationships with their sibling's children and re-connect with the extended family. Nick's brother did not have children. Once Leon's sister had been confirmed seriously ill he and his sisters started to meet up with their children.

'And we used to go and take all the kids together, cause she...Lisa's got kids and I've got Jacob and Beth got older ones, so there was a whole sequence of children, to meet each other and be cousins and all that sort of stuff' (Leon: 108).

Leon expressed a strong wish to allow his son to connect with the rest of the family without putting restrictions on relationships, which his parents had done to him.

'...people should still be allowed to see who they want to see and if someone is their relative they've got a right to see them....' (Leon: 104)

Thus, the freedom of bonds between relatives had the chance to develop organically when there was less control involved.

The death of Beatrice's brother evoked her own memories of not having been acknowledged and seen as a child, reinforcing her wish to ensure that her brother's children were seen and listened to.

'I'm trying to explain why the house is full of people they [brother's children] don't know, why people are screaming...(Beatrice: 188).

Beatrice's quote presumes that her nieces and nephews would be upset and frightened by their home being filled with grieving relatives. However, this is based on her own experiences of her family and her culture and there is a feeling that she is trying to repair the damage she felt was done to her. Thus, it appears that similarly to Leon she is trying to stop the vicious circle of restricting the children's relationships with their extended family.

'It was an absolute nightmare but it had to be done, for me...there's something about...there was something about taking care of the kids, it had to be done, and treating each child the same...(Beatrice: 198)

There is a sense that not only is she stopping the vicious circle of children not being acknowledged, additionally she appears to be challenging her culture and her family in a manner she had not felt able to do prior to her brother's death. Similarly, Nora is stopping the disrupted relationships in her family. Nora had ceased to see her nephews for a number of years due to her brother's abusive behaviour. Without the threat of her brother she felt free to spend time with the nephews whom she was still very fond of.

'...when I'm with them [nephews], the interaction is very enjoyable, very easy going...(Nora: 195)

The participants above came across as feeling settled both by providing support and by reconnecting with their sibling's children. Hence, despite the death there were positive aspects for the family.

### Break from everyday life heals

All of the participants worked or studied and provided emotional support to their family, which limited their own possibilities of having time away from everyday life to reflect on their loss. The lack of breaks often put their bereavement process on hold or allowed it to

emerge only when they had time off. The participants who had very young children and worked found it particularly difficult to find time and energy to grieve.

'I definitively find when I go to [dad's home country] at the moment that I crash lots there,
I spend my first four days of the holiday crying, solidly and then after about four or five
days I'm able to start enjoying myself and relaxing and I'm getting used to those patterns,
but it's definitively a pattern I see happening.' (Georgina: 63)

As illustrated by Georgina above, her bottled up grief surfaces when her dad looks after her daughter and she is able to connect with her grief without feeling guilty about crying in front of her daughter. Further, there is an unspoken part of her grief surfacing during family holidays, as her sister's absence becomes more poignant at these times. There is a sense that her grief is compartmentalised for it to not take over everyday life. The patterns described by Georgina are exhausting, yet cathartic, and appear to create movement in her bereavement.

The excerpt below shows how adult bereaved siblings are often without the practical and emotional support they are in great need of in their daily lives. The lack of any free time to rest accentuates the lack of energy brought on by the bereavement.

'Ah...yeah, it was a constant struggle for...two to three years, cause I had another daughter afterwards, there's not a great big gap between them and that was so very, very difficult when I was tired...ahm...just to...to handle things...' (Lucy: 80)

The 'gap' Lucy refers as not being big links to the lack of gaps or breaks the years following her brother's death. Her struggle to 'handle things' illustrates how her bereavement needs to come second if she is to cope with her everyday life.

For Nora, everyday life involved telephone contact with one of her nephews who struggled emotionally after losing his father.

'I spoke to him every day on the phone for hours...' (Nora: 57)'...to an extent that I'm quite exhausted...' (Nora: 59)

Throughout the interview Nora's exhaustion was rife with contradiction; while she expressed immense anger towards her abusive brother she had a strong wish to support her nephews after they lost their father. However, she did not want to burden her nephews with the negative aspects of the family history. Instead she felt that she needed to closely monitor herself when speaking to the nephew referred to in the excerpt above. Nora finally managed to obtain a break from supporting her nephew when he sought professional help. Only at this point was she able to regain some energy to connect with her own emotions.

To be able to grieve Sally needed to increase the free physical space and decrease the sounds around her.

'I'd lived in the city, I went back home to my mum's, which is in the country, I actually spent a lot of time outside in nature...so, going for walks and having that space...' (Sally: 102)

Prior to her brother's death Sally had been living in a large city, where her daily life involved drinking and taking drugs with her friends. The self-imposed change from a life of drugs combined with the auditory and visual impressions of the city to a healthy life on the countryside was drastic but provided the clear break Sally felt she needed. Her life choice was the most defined illustration among the participants of how a break can benefit the bereavement process. It should be noted that Sally and her brother shared the life style that contributed towards his death. Hence, she regarded his death as a warning to change her way of life if she wanted to continue living. The majority of the other participants made less drastic, although still defined, changes to their lives after the death of their sibling.

## Bereavement affects sense of time

The majority of the participants described feeling how time after the bereavement had become different to normal time of minutes, hours and days. Time seemed to slow down after the death as the participants tried to understand their loss.

Georgina spoke of the emotions connected to her grief as consisting of different cycles, rather than time defined by hours, days, weeks or months.

'I think it's just that cycle, that time, there's...you don't realise at the time, it's only when you look back you can kind of identify...uhm...how you were feeling' (Georgina: 12)

Georgina's experience of grief as cycles come across as a manner of approaching the grief gradually or keeping it at a distance. Due to the cycles, as well as the bereavement, not having been experienced before there is a delayed understanding of this new sense of time. Georgina's reference of being unable to identify how she is feeling shows the difficulty of grasping her emotions while being in a cycle of intense grief. In a similar manner, Caroline told of her grief coming in cycles, as she had been used to not seeing her brother for some months at a time.

'Yeah, every three or four months, yeah, so I had to go through a couple of cycles like that, it started to be like, he's still not here...' (Caroline: 221)

For Caroline the cycles were of a more predictable nature, as they coincided with the times when she would usually have seen her brother. Georgina, on the other hand, was only able to see the pattern of her cycles after they had occurred. There is a sense that many of the participants have come to experience time as a more personal matter after their bereavement, rather than the time set by the society they live in.

Similarly to Georgina and Caroline, Francesca experienced time differently after losing her brother, although she describes her brother's death as floating in time, rather than as cycles.

'...it [the death] kind of has quite a timeless quality to it, it was sort of shocking a final and doesn't quite sit in the chronology of my life, it sort of floats...' (Francesca: 76)

As seen in this quote, her brother's death does not fit in with the timeline Francesca had pictured prior to his death. Her description of his death as floating brings to mind how the stability provided by her brother has vanished with his death. Thus, Francesca's loss has left her with the feeling that not only is time floating, the loss of safety previously found in the sibling group has also left her with the feeling of floating in her life. The reference to floating brings to mind how both the grasping of time and the death of a sibling can be difficult to understand.

For many of the participants the time following the bereavement was experienced as slow compared to how friends, colleagues and the extended family perceived time. The shock following both sudden deaths and deaths due to illnesses often caused the participants to be unable to recall the initial period after the death.

Lucy and her family were still grappling with comprehending her brother's death the first two years after his death, partly on an emotional basis and partly due to waiting for overseas medical reports about his death. Lucy's excerpt below shows how she was still in the very early stages of her bereavement after the first year of her brother's death.

'...and people assume now that time's passed. I think we even felt this a year after...after his death, it was almost like people assumed that time had passed and everything was ok...' (Lucy: 138)

Lucy's reference to 'people' in relation to time points out how those who have not been bereaved regard time to have moved on and expect the bereaved to stop grieving. For Lucy, time was not a fast and healing process like the people around her appear to presume, rather it was a constant reminder that her brother had died. Hence, the time of the bereavement process can create a divide between the bereaved and others who had not been as close to the deceased.

A further connection to time and comprehension of the death involved the geographical distance between the participants and the siblings. The majority of the participants had not lived near their sibling and would not have seen them on a daily or weekly basis. Only Sally and Lucy had lived near their siblings and used to see them regularly. Geographical distance meant that it often took the other eight participants longer to comprehend the death, as weeks or months could go past without them seeing their sibling. Caroline's previous quote referring to cycles together with the quote below capture this.

'...cause I didn't see him, I didn't live with him, so I didn't see him all the time, every day, so it was normal for me to go a few months without seeing him, so in that way, like the amount of time, it's only it's starting to be longer than....you know.' (Caroline: 217)

Caroline's grief was particularly raw during the interview compared to the other participants. It is possible that she was more expressive about her grief than some of the other participants due to her culture, which involved greater verbal and emotional expression than the cultures of most of the other participants. However, there was a sense that she was in the very early stages of her grief due to being used to longer intervals between seeing her brother, leaving her feeling that her brother's death was unreal during her daily life in the UK.

The participants' experiences of the initial period after the death involved emotional and physical tiredness, which affected their perception of time and memory.

'It's so difficult, cause...it's had so many emotions...trying to recall the early days, which is such a blur, it's confusing, yeah...' (Lucy: 105).

Leon, Sally and Lucy lost their sibling eight, nine and five and a half years respectively prior to the time of being interviewed. They told of the bereavement changing, albeit slowly and over a number of years. They did not refer to specific incidents, rather how changes were organic and could not be forced in any way.

'...about four years was the turning point in my life where things all of a sudden...ahm...became a lot easier to deal with...' (Lucy: 84)

Despite Lucy mentioning a turning point and things changing suddenly she cannot think of why this happened after four years. In a similar manner to how her grief only involves her

immediate family she does not speak of connections between her grief and other areas of her life, which may have played part in the turning point of her grief. For example, she mentions separating from her partner and her children becoming older, although without explicitly linking this to having more time to herself and therefore more time to connect to her grief.

Finally, nine of the participants expressed wanting more from life and from the time they had available. An exception to this was Leon, who said that he was already spending all his spare time on his creative projects, which were his passion. The other participants restricted how they used their time and with whom they spent it. Life became less about pleasing others and more about spending time with the people, work and projects they found meaningful. This is demonstrated in Francesca's quote:

'...life is sort of about being with other people and showing them how you feel........!
wanted to sort of squeeze a bit more out of it, I suppose, or something, bring it to life a bit
more...' (Francesca: 34)

This excerpt shows how Francesca's loss made her more aware of the time limitations of her own life, meaning she became more expressive when spending time with her children and husband. The references to 'squeeze' a bit more out of life and 'bring it to life a bit more' illustrates how time is perceived as more precious and taken less for granted. By relishing the time she has available Francesca started to acknowledge meaningful moments in her daily life.

Sally's quote below captures the need for growth and evolvement as a way of living with and understanding the bereavement. Despite missing her brother Sally was grateful for gaining an understanding of how she wanted to use her time and thereby how to live her life.

'...we only grow and evolve through difficult times, you know, if we're comfortable and you're in a rut...you don't...or I know I didn't...' (Sally: 166).

Despite the difficulties of the bereavement the majority of the participants expressed gratefulness for understanding what mattered to them, such as spending time with family and on personal development. Further, the bereavement tended to create a change in how the participants perceived time. Instead of hours, days or months, time tended to be perceived as cycles or other less defined aspects of time. Finally, as the participants provided emotional care for family members there was a lack of time in their own daily life, which at times caused their own grief to be put on hold.

# The complexities of support

This super-ordinate theme has three themes; 'Lack of support is hurtful', 'The uncertainty of available support' and 'Paradox of wanting support but rejecting it'.

Support related to adult sibling bereavement can be complex and composed of many layers, as the whole family often need support after the death. The theme of support is

crucial for understanding what the participants found helpful, not helpful or even hurtful. The different experiences of receiving and providing support evoked strong emotions with all of the participants. The participants were all young adults or middle aged and felt that is was their role to support their parents or their sibling's family. As people outside of the immediate family often concentrated on the participants' parents' loss there was little support available for the participants.

## Lack of support is hurtful

The opposite of helpful support was presented by the majority of the participants as lack of support and acknowledgement of their loss. Two of the participants, Beatrice and Leon, did not express needing support in relation to their sibling's death. As mentioned previously their relationship with their sibling had been difficult and they expressed a sense of freedom rather than grief after their sibling's death. A further aspect of support was the unpredictability of who would offer support. The participants' old friends were not always able or willing to give the active and verbal support the participants needed and expected, while newer friends were at times more supportive. Rosie found the lack of support from one of her closest friends very hurtful and disappointing and the friendship subsequently ended.

'There are other people who have known me for much less time who at least expressed....
you know, a...a concern or an interest, like, that's more...rewarding...' (Rosie: 101)

Rosie's appreciation of support from newer friends conveys the importance of verbal recognition of the loss. There had been little or no verbal communication between the participants and the people they feel have failed to support them. Therefore, both parties often reached presumptive conclusions. Most of the participants' provide accounts reflecting a strong sense of conflict due to the lack of open conversation about their bereavement. Hence, many of the relationships slowly ended or involved minimal contact.

Lack of support became particularly poignant when people enquired about the participants' parents without asking how the participant was, as seen in Rosie's quote below.

'And people still say 'How's your mum?' with that slightly caring 'How's your mum?'.......!

get really cross half the time or I get really cross about that still.....because it's

not...somehow I should be caring for my mum or I should be caring for my dad and I

actually...just because my brother died, doesn't mean that our roles are reversed, it doesn't

mean they're not my parents anymore. How is that fair to expect that?' (Rosie: 218-222)

Rosie's anger in the excerpt above is two-fold; on the one hand she is angry with people asking how her mum is but not how she is, despite speaking directly to her. On the other hand, there is a sense that the question is an insincere gesture, rather than a wish to know how her mum is coping with her grief. Rosie's anger appears to be grounded in the passiveness of people presenting as supportive, although without actively contacting her mum or asking Rosie how she is.

The silence and lack of support often created great resentment among the participants.

The resentment was partly based on needing to carry the added pressure of losing relationships in addition to the bereavement and partly due to holding back their most personal thoughts and feelings when seeing friends or relatives who did not provide support.

Lack of support was manifested not only by conversations about the bereavement being avoided, conversations were also discontinued when those talking realised the participant was present. Lucy was quietly spoken during most of the interview but when describing the lack of support her voice became stronger and her voice was rife with disappointment.

'I also find that even simple conversations people avoid with me, like talking about their own family, they'll...they'll stop the conv...they'll suddenly realise that I'm there and think 'I don't want to ask, I'm not going to do that'. And I find that quite hurtful. I know it's difficult for other people but......' (Lucy: 70)

As seen in the excerpt above, Lucy acknowledges that bereavement can be a difficult topic to bring up but is still surprised that long-term colleagues and old friends would ignore her loss or even avoid meeting her in person. Indeed, Lucy illustrates this herself by stopping in the middle of a word. When colleagues and friends did not offer support the participants described feeling alone and abandoned. Lucy's quote below shows how the people she would meet on a regular basis did not have the words or the courage to offer their condolences.

'I was off work for about three months afterwards...ahm...and that was really, really difficult going back to work and just facing people...ahm...and I just found that people never, didn't ask, they didn't acknowledge it, a lot of people who I thought were really good friends never acknowledged it to me and I also felt that there were certain people...ahm...people that I'd went to school with, who I would have previously spoken to who, who would see me coming and went across the street.' (Lucy: 93)

The people described by Lucy above appear to have hurt her more by going to great lengths to avoid her than had they simply told her they did not know what to say. As the participants' bereavement was often a large part of their lives others' refusal to speak about it created a verbal vacuum in which neither party could find a topic of conversation. Similarly, Sally and Nora found themselves isolated and without any support at a very difficult time of their life.

'...it was one of those, probably most isolating experiences ever. You go back and you don't know what to say to people, people don't know what to say to you, so there's all this looking and staring and uncomfortableness and awkwardness...' (Sally: 30)

Sally's account starts off as personal but becomes removed, illustrating the isolation by her use of generic you and referring to people in general rather than to specific individuals. Although Sally tells of people not speaking to her the non-verbal communication is a strong example of lack of support, as those around her knew about her loss. While Sally reports others discomfort about her loss, Nora tells of an almost total lack of acknowledgement or reactions from others.

'I was quite shocked and hurt how little...uhm...recognition it found in the circle of friends, colleagues, maybe...in the sense, or I always remember now, which really struck me [.......]

I only got one card, one bereavement card or whatever, from my land lady...' (Nora:22)

Although Nora expressed relief following her brother's death she still wanted support. She mentions receiving little recognition, although the issue of recognition links to several aspects; she had wanted her brother to recognise his behaviour as abusive while he was still alive. Further, the absence of recognition may have come as a result of friends and colleagues having no or little knowledge about her brother due to the lack of contact between the siblings. Similarly, Rosie described how several friends and relatives were unwilling to acknowledge her loss.

'I think my relationship with friends has....has changed slightly too, because I think there are some that I...they weren't around and they just weren't able to help or they avoided me completely and they didn't know what to say.' (Rosie: 101)

Lack of support is strongly connected to the notion of people being unable to verbally mention the bereavement when meeting the participants face to face. Rosie's quote above shows her search for reasons for why some of her friends were unable to support her, although due to the lack of communication she is left guessing. There is a strong sense of disappointment, as her friends were unable to overcome their own difficulties in order to support her. Rosie found the lack of recognition of her loss especially hurtful when she visited a friend soon after her brother's death.

"...we've visited their son and we've chatted to him and made a special effort and I still sent a present and a card...nothing...not a thing...and I'm just, like, 'How?...we've both had life changing events, go on, and I've recognised that yours is truly life changing and you've never said a word"...how...how is that possible?' (Rosie: 105)

Rosie's willingness to give attention to her friend who had recently had a baby, despite grieving for her brother, was in strong contrast to her friend's unwillingness to offer a single word of support. It is interesting how she asks the question in the interview, while not being able to ask her friend the very same question directly. Her tone of voice became angry when she described how neither her friend nor her step-sister acknowledged her loss.

'...the younger one [step-sister] is just...there's just nothing, not even a 'I see that this might be difficult for you. I'm really sorry'.' (Rosie: 113).

These experiences prompted Rosie to stop spending time and energy on the people she felt had not offered her any support. Rosie's story tells of a combination of feeling betrayed and then becoming determined to not give anything to those who have let her down. Georgina had similar experiences.

'I've had a few friends that I've lost...uhm...I lost one very good friend. I'm no longer in touch with someone I was very close to, which I found very difficult and painful, who...uhm... just...wasn't able to deal with it and backed off and didn't make contact and if

we did, if there was contact it was on a very bizarre level, as if nothing had happened and...uhm...talked to me as if nothing had happened and talk about what had happened and that was...I couldn't be around that, that was very, very hard' (Georgina: 23)

The lack of support seems to show a side to the friends' personalities that the participants had not previously been aware of. Once witnessed, they felt an urgent need to distance themselves from these friends. There was no open communication about why the friends are unable to speak about the death of the sibling. For the majority of the participants who experienced a lack of support there was a sense that friends and colleagues were unable to relate to a younger person dying. The early death comes across as a wordless challenge to life expectancy.

Sally's sense of isolation and drastic changes to her life style meant she lost contact with the majority of her old friends.

'...there's very few friends that I'm still in contact with, from around that time, I mean, I think, there's only about two people in my life...now...ah...that were friends at the time, that are still there, literarily, the rest of my friends have all...disappeared...' (Sally: 37)

This excerpt from Sally shows how she finds it difficult to remember the time around her brother's death, partly due to the shock and partly due to her taking drugs on a regular basis.

The sense emerging from the theme of lack of support is of the participants having behaved in a socially unacceptable manner or somehow become contagious, therefore making people unwilling to approach them or mention the death.

#### The uncertainty of available support

The majority of the participants described the importance of support being actively offered after their sibling's death, as they did not have sufficient energy or mind space to contact those who could provide support. The participants, together with the extended family members and friends of the sibling, often felt responsible for looking after the parents or the sibling's family, which created a lack of active support for the participants. Most of the participants focused on support after the sibling had died, although Francesca expressed being very moved by the support both towards the end of her brother's illness and after his death.

"...the one's who cared more were people who before were strangers to me, but who rushed to see him, were very upset when they saw how ill he was...ahh...many of them travelling hundreds of miles to come to the funeral..." (Francesca: 138)

The effort and the time of the support described by Francesca appear to be crucial at a time when the participants were not in the frame of mind to contact people outside of their immediate family. The participants mainly refrained from asking friends or extended family for support for themselves. However, at times the support came from people who the participants would not have expected any support from.

'And they [brother's friends] came to see him and it was...I'm actually really pleased that that happened...umm...and they all came with us up to the Forest area and we scattered his ashes and we had a really nice day...' (Francesca: 88)

The two excerpts above shows the unpredictable nature of support, as Francesca had never met the people who gave her active and altruistic support.

Active support in forms of visits and phone calls was mainly offered to the participants and their families during the period immediately after the death. The participants greatly appreciated receiving tangible gifts in form of flowers, cards and food. The gifts continued to keep the support present after the visitors had left and reminded the family that people cared for them at a very difficult time. When the participants who lost their sibling suddenly were in shock after receiving the news the initial active support was particularly appreciated. When the participants were experiencing low moods and isolating themselves the active and selfless support from others became increasingly important. Despite not responding to contact at times, the messages from others acted as a lifeline to a support network when the participants felt able to resume contact.

'I would say that we got a lot of support from people...ahm...you know, in the very, very early days some people would come to the house with flowers, cards, cakes, food and they were very supportive.' (Lucy: 103)

Lucy's repeated use of the word 'very' captures her appreciation of the support immediately after her brother's death, while also highlighting how the support very rapidly dispersed. While Lucy lived near her extended family and friends, Nick lived further away from his, making telephone calls of greater importance.

'.... it was just being generally there for me......... just getting phone calls from people, just...you know....saying they feel really sorry, just knowing that these people are around, they're really, kind of...that was really, really helpful.' (Nick: 54)

The active approach of offering support was more important to the participants than the words actually spoken at the time the support was given. Nick's appreciation of 'knowing that these people are around' comes across as a safety net or a life jacket at a time of crises. In contrast to Lucy, Nick does not tell of feeling supported only during the initial period after his brother's death. However, his depression at the time of the interview may be part of a manifestation of the lack of active, long-term support.

Although the participants were appreciative of the support offered immediately after the death, the support tended to fade out at the same time as the initial shock subsided. Therefore, the participants were often left with little support at a time when the deeper understanding of their loss was sinking in. In particular, support at a later stage often focused on the participants' parents, which highlighted the lack of acknowledgement of the bereaved adult sibling.

The importance of active and tangible long-term support is illustrated by Georgina's excerpt below:

'...as I started to get more and more depressed I just stopped contacting people more and more and I think there were some people who without fail, you know, once a week, even just a little text, a message or an email, people...you know, I've got a friend that like almost every week wrote me a little postcard, three, four lines long, but just that real strong sentiment of 'We're thinking of you' and you know, 'We love you' or...or just that real, just that touching out and someone acknowledging that you were going through something very, very difficult and it really did make a difference...uhm...and particularly then as well if people when you met up with them, if they were...if they were brave enough to say things, particularly the first time you saw someone.' (Georgina: 27)

Georgina's use of the word 'brave' captures how some of her friends were able to overcome their own uncertainties about how to support her and ensure that she knew of their support despite not receiving replies from her. Indeed, the helpfulness of the support appears to come from her friends maintaining or increasing support when she ceased to contact them. Hence, the support derived from their understanding of her needs in combination with their willingness to continuously letting her know about their care for her without receiving responses from her.

Several of the participants had been in contact with a bereavement organisation in the UK which had recently developed support specifically tailored for bereaved adult siblings in the form of regional and national support groups. The active support and recognition of

their bereavement was welcomed, as the majority of the participants felt that their loss was often overlooked by people, bereavement literature and bereavement organisations.

'.....they organised the first....actual sibling retreat, so an overnight weekend meeting, which I went to.....' (Georgina: 88)

'....it is just that sharing of experience and that....that real identification...uhm...with someone else, so very small, sometimes very small, very key things....' (Georgina: 94)

The contact with other bereaved siblings and with the bereavement organisation formed a sense of the participants' bereavement being acknowledged. However, the most important aspect of this new development within the bereavement area comes across as the hope for attainable support for the participants themselves and other bereaved siblings in the future.

'...we've had support of The Bereavement Organisation, but I'd like to give something back to other people who maybe are at the stage when they feel that things will never get better for them.' (Lucy: 167)

Lucy's quote tells of how her grief has changed from a very dark place to an understanding that it may take several years to see a brighter future and reasons to continue living.

Some friends and extended family of the participants seem to have the impression that the participants do not recognise or appreciate the support provided. However, what the participants recall at a later stage is the continued active support that has reassured them that neither the sibling nor their own loss has been forgotten. When people were reluctant of bringing up the subject of the sibling the participants often became frustrated and angry, captured here by Caroline.

"...if I reach out to them and talk about Tom but they're not going to ask about him or...
and it's like they're trying to be respectful by giving me that space but it's not helpful."
(Caroline: 434)

Despite the participants being from a number of different countries and cultures the lack of active support about their bereavement did not appear to be restricted to one country or culture.

Friends, colleagues and extended family members come across as afraid of upsetting the participants and therefore hesitated to initiate conversations about the deceased sibling. Social interaction in general was often offered in ways that the participants are not comfortable with. The idea of going out for drinks or dinner in groups made some of the participants fearful of becoming upset in public or being generally low and therefore spoiling the evening for the rest of the group. Thus, a vicious circle of isolation and little support is created. The participants presented helpful support to be offered in selfless ways and on the bereaved person's terms.

All the participants were living in the UK at the time of the interviews and the majority were from the UK. Beatrice, Nora and Caroline were not from the UK and had a less

extensive support network here, consisting mainly of colleagues or friends who had not known their sibling. Instead, they sought out professional support from therapists or counsellors. For the remaining participants available support depended on cultural traditions, on the participants' community and for some also on support from different health professionals.

Bereavement support is deeply rooted in traditions and culture, as experienced by Nora.

'I was struck when the land lady [sent a card], who also has siblings from a Spanish family....... very heart felt and I was so moved and at the same time so shocked that I didn't get any other one from any friends or whatever. (Nora: 28)

Nora found it particularly difficult to only receive support from a person who she felt would not have been obliged to do so. Her Spanish landlady's ease of expressing condolences illustrates how traditions can connect the grieving person with those who will offer support. The participants often told of other people's difficulties in verbally acknowledging the death.

'I think it's just the whole subject of death, isn't it, people just...they want to avoid it...'
(Lucy: 76).

The lack of existing traditions around death and grief made active and verbal support largely unattainable for the participants. Furthermore, the death of a younger person

seems to deter support in a society that is not accustomed to deaths of young or middle aged people.

Some of the participants found support from books, contacting bereavement organisations and accessing internet forums for bereaved adult siblings. Georgina and her mum searched for information and support together.

'....we've [mum and Georgina] read lots on grief, we're part of a support network, like The Bereavement Organisation...' (Georgina: 69)

On the retreat for bereaved adult siblings Georgina found great comfort in hearing that other siblings also felt the burden of their own grief overwhelming, particularly when supporting their parents emotionally.

'...that was something that came up hugely in the group, when we met on...on that retreat, that sense of the difficulty and dealing with your parents grief, as well as your own grief and very much seeing your parents turn into...it's just...it's like part of them dies really, you...you know, you lose a huge...something of your parents...uhm...and I think that was really helpful......having that conversation with people and I guess, identifying that it's normal, sometimes that niceness, it's just nice to know that other people go through that as well.' (Georgina: 96)

The majority of the participants describe having difficulties in finding others with the same experience in the area where they lived. Lucy's description of her town as geographically

isolated further speaks of her community leaving her feeling isolated and unsupported during the most difficult time of her life.

"...where we live, it's so isolated and so far from anywhere..." (Lucy: 161)

When the participants found it difficult to access face-to-face support due to geographical distance and a lack of free time, the internet became a more feasible option.

The bereavement organisation mentioned above was setting up local support groups for bereaved adult siblings at the time of the interviews. Hence, none of the participants had yet benefited from being part of the groups. The participants saw the online forum as a positive development, in particular when they would find it difficult to meet with a weekly group in person due to family and work commitments.

'...at a time that suits you, you know, and when you're in the mood for it and when you feel like it but that's like sense of just that group support put out there...uhm...yeah, really, it's...it's been quite comforting and I think I would have found it really comforting if I had been able to access that [online support]......it's nice to know that there's something there for people to tap into and access...uhm...because there is so little else out there.' (Georgina: 112)

Georgina and Lucy expressed feeling that the online group would have been of greater benefit to them earlier on in their grief. However, they appreciated the new recognition of adult sibling bereavement within the bereavement organisation. The online community facilitated contact between bereaved siblings who lived near each other without knowing about the others' bereavement.

"...I'm in touch on email with a few people in the surrounding areas..." (Georgina: 90).

Thus, a supportive community can be a geographically local community, a monthly group or an online community.

'...I did find it useful when I met up in the retreat, no, I did find it useful, very useful actually...uhm...so I think I would find a monthly group...probably a bit like counselling...'
(Georgina: 94)

The participants who had moved away from their more intense grief at the time of the interviews expressed their wishes to support others who were at earlier stages of their grief. The wish to create a supportive community for adult bereaved siblings surfaced throughout the interviews but would require energy and concentration that the participants at times had difficulties in finding.

The participants described how their colleagues did not provide support, similarly to some friends and the extended family. However, the lack of acknowledgement from colleagues was different due to the participants meeting their colleagues on a daily or weekly basis. Hence, the colleagues could have been part of a support network but most did not express support verbally or in other ways. The response from most colleagues was to not mention the death or to become silent if the topic arose. Georgina's quote below gives

the feeling that she has behaved in an unsociable manner, despite being the person who is in need of support.

'...then very often there is quite an awkward reaction to that and...and again, I think it's very common, you almost feel that you have to comfort that person for having brought it up...' (Georgina: 31)

The main issue seems to be the colleagues' inability to verbally express condolences. Future communication and social interaction between the bereaved person and the colleagues therefore became limited.

Throughout the interviews there was a sense that providing support for the bereaved adult siblings on a continuing basis is not the responsibility of the society or community in which the bereaved person lives. Nick felt supported by the existing, albeit temporary, community of the university he attended at the time of his brother's death.

'I went to the lecturer who I felt most comfortable with, talked to her and she was instantly just much more...umm...ahmm...kind of supportive and calm and useful about it. (Nick:77)

The university lecturer was supportive in a way that the other participants' managers and colleagues were not, possibly due to the university staff feeling a responsibility for Nick, as he was young and a student. Sally had also looked for support while at university.

'I'd gone to the student counsellor at university [.......] I was getting counselling from her... anyway...ahm...so I went back to her...' (Sally: 108)

Most of the participants felt that a paid professional was more willing to support them than friends, extended family or colleagues were. Rosie had sought out counselling on her own to help understand and move on with her grief.

'I did go and have counselling to get me to that...to this place...' (Rosie: 177)

Rosie does not specify what 'this place' is, although it emerges from the interview that she has arrived there with the support from the counsellor, her parents and her partner. Caroline saw a counsellor for similar reasons and additionally due to not having family and friends in the UK. She was not entirely sure how much it had helped her but could not find anyone else to talk to.

'...it's [counselling] helped me like understand, I started going cause I just wanted to...I think I didn't have anyone to talk to, I didn't have any friends here...' (Caroline: 342)

The majority of the participants found professional help themselves, while Lucy was referred to a mental health professional in relation to her pregnancy. She found this to be of greater help than speaking to the volunteer from a bereavement organisation.

'I did afterwards...hrm...it was a good few months afterwards...have...go to see...a community psychiatric nurse and that was more helpful...'(Lucy: 199)

Most of the professionals mentioned above would have had training in dealing with different kinds of traumas and therefore be better prepared to support the participants than friends and extended family were. There is an ongoing theme of the participants being disillusioned that the society they live in is unable to support them voluntarily and on a continuing basis. The participants do not appear to want any grand gestures, rather they want regular acknowledgement of the difficult time they are going through.

The word community often implies a positive aspect, particularly in relation to support after a loss. Sally's experience of a community was however negative and unsupportive.

'...I was doing a lot of drugs and alcohol around the time that my brother died...' (Sally: 18)

'Amm...so, I wasn't particularly in a good crowd of people anyway...' (Sally: 20)

The community Sally belonged to at the time of her brother's death had strong connotations to how her brother had died and had been detrimental to her own mental and physical health. She had also found it difficult to trust anyone for much of her life.

'...my levels of trust where very damaged...ahm...by my experiences, by not having the support, or what I perceived, lack of support from my family...' (Sally: 112)

Hence, there was neither an established community of an extended family nor a new community of friends who could support her.

The excerpt below shows the kind of support Georgina received from friends. It sounded like the kind of support most of the participants would have appreciated from friends and their extended family.

'...the friends that are there and just willing to listen, yeah, have the guts really to come and spend some time, being around you if you are crying and miserable and you know, it's...so its...it's not a huge amount really, but it's...it's amazing how...how...the positive effect that had on you from other people, that...that did that, so...yeah...' (Georgina: 29)

In addition to coping with their own grief the participants felt responsible to provide support for their families and others who had lost a sibling. The death of the sibling dramatically increased contact with parents, nieces and nephews.

'I touch base with both my parents every day on the telephone even if it is just a five minutes, two minutes conversation 'Are you ok?', by the shortest you know...' (Georgina: 6)

The majority of the participants expressed feeling particularly concerned about their parents. Although dealing with their own loss, the participants took upon themselves the role of supporting their parents on different levels. Nick decided to move closer to his mum and sister.

'...I've wanted to be...ahm...kind of closer proximity to where my mum and sister live...'
(Nick: 83)

He found it difficult to talk to his mum about his brother's death but gave her support by moving and thus having more contact. Leon, on the other hand, lived further away from his parents but verbally expressed his willingness to support them.

'...I keep saying to them [parents] 'If you need me to come and help you with things at home and come and look after you'...' (Leon: 178)

Leon felt an intense need to protect his elderly parents from the accusations thrown at them by his dead sister's friends during the funeral.

'...he [dad] was crying, you know, he never cries and I had to go and walk with him, round, whilst all these strangers were watching...' (Leon: 126)

The need to support the parents on an emotional level was further expressed by Lucy.

'...she [mum]...really struggles with everything...ahm...and I feel like I have to be there to play a role of like constant support to her, cause she would just go to pieces otherwise...'(Lucy: 36)

Lucy's words above show how she is supporting her mum out of love as well as out of fear of her mum breaking down. Lucy cannot see how anyone else could understand her

mum's grief or be there for her on a daily basis. Hence, she is carrying her mum's grief in addition to her own. In a similar manner, Georgina is her mum's main support, something she does out of love although at times at the cost of her own well-being.

"...if I pick up the phone and speak to her and she's very depressed and angry and will again, be fixated on something...uhm...it can be really hard, cause it undoes all the work you've been trying to do with yourself, you know, I'll put the phone down and I'll feel an enormous sense of sadness again...' (Georgina: 96)

Georgina's change form first to third tense above reflects her struggle to support her mum without feeling drained. The third tense illustrates how she removes herself from the experience and simultaneously contains her own emotions by bottling them up in order to support her mum, despite draining herself of energy in the process.

Rosie has been supporting her parents and also feels supported by them, something the other participants did not experience.

'...I think my relationship changed with my parents in that...well, with my dad, in that he was able to rely on me and I on him, before my mum and I had done that already...' (Rosie: 34)

Despite grieving for her brother Rosie enjoyed having her new closeness to her dad. In a similar manner, Nora supported her nephews and received a letter of appreciation.

'....it's really true that someone is providing them [nephews] with some motherly care and then months later they sent me a hand written letter, which I've actually framed......thanking me for the enormous support I gave to them in the hardest time of their lives.' (Nora: 197)

For Lucy, it had become important to support people who are at the place when she felt that life was very dark.

'...I'd like to give something back to other people who maybe are at the stage when they feel that things will never get better for them.' (Lucy: 167)

At the time of the interview over five years had passed since Lucy's brother died and despite feeling very low for the first four years she had gradually started to feel better. Lucy referred to giving something back, although she had not received anything from the people she would potentially support, nor from her own friends and colleagues. The idea of supporting others who have lost an adult sibling came across as part of creating a new network and as part of healing for the participants.

## Paradox of wanting support but rejecting it

A further layer of support emerged when participants did not accept support when it was offered to them. There was a strong paradox of the participants wanting support, albeit

rejecting it when it is offered or being unable to ask for it when they felt they needed support. There is a wish to receive support only from others who have experienced a similar bereavement, illustrated by Caroline:

'I don't want to be around other people, who haven't suffered...' (Caroline: 46).

The support accepted by the participants was therefore limited and often included only the participants' immediate family or support groups for bereaved adult siblings. As the bereaved adult siblings were often supporting their family emotionally, the support available to them tended to be minimal. Six of the participants; Georgina, Francesca, Lucy, Sally, Rosie and Caroline, verbally expressed wanting more support, albeit without accepting it when it was offered. Thus, difficult situations arose when the participants felt resentful towards friends and family members.

The participants' rejection of support was often justified by how others would be unable to comprehend the loss.

'....we were the only people who really understood what...what we were going through, I mean, obviously differently from a sibling to a parent, but you know, still loss and love...'

(Georgina: 6)

Similarly, when Caroline is offered support she is unwilling to accept it.

'I just feel like they can't understand, so even if they try to be understanding, I'm like 'No'.'
(Caroline: 442)

The wish to only spend time with others who have had similar experience increases the participants' sense of isolation.

'...they [in-laws] are really nice people, but I've really been pushing them away, to be honest, I just feel really, like, I feel really resentful towards them...' (Caroline: 424)

Caroline acknowledges that her rejection of her husband's family limits any support and yet feels the support is not valid due to her in-laws not having had similar experiences.

Lucy expressed an understanding that her rejection of support was not the fault of others, although she still rejected possible support.

'Not their own fault, just I think that if they haven't suffered something similar...ahm....they can't contemplate the enormity of it all...' (Lucy:18)

Sally's understanding of support had changed since she lost her brother nine years ago.

She is now able to reflect on how her rejection of support had made her grief more difficult.

'I was very much in a place of 'I can do it on my own, because nobody understands me' which probably wasn't particularly helpful for me in the long run...' (Sally: 106)

These participants' unwillingness to accept support offered by those who cannot anchor the support in the same experience appears to complicate relationships and create increasing distance between the bereaved and others who could potentially offer support. Thus, the combination of lack of support, seen in the previous theme, and the rejection of support in this theme limits the possibilities of support.

# **Discussion**

This research aimed to investigate the experiences of losing a sibling in adult life. Eight women and two men took part in semi-structured interviews, which were analysed using

Interpretative Phenomenological Analysis (IPA). This section will include a discussion of the findings of the research and the literature previously reviewed. As stated by Smith et al. (2009) additional literature can be included to add greater depth to the findings of the research. The discussion will commence with the paradoxical emotions connected to loss, followed by the theme of living after loss. Thereafter, I will discuss the complexities of support. The most prominent findings will be discussed, followed by how the findings can be applied to therapeutic practice, reflexivity about the research and finally limitations and ideas for future research.

#### The paradoxical emotions connected to loss

The super-ordinate theme of paradoxical emotions connected to loss was cohesive and paradoxical at the same time. The cohesiveness derives from language, in spoken and at times in written form, having a central role for the participants. However, the paradox can be seen in half of the participants, Georgina, Francesca, Caroline, Rosie and Leon, finding closure from having the opportunity to speak to their sibling during the illness, while the remaining participants, Beatrice, Nick, Nora, Lucy and Sally, expressed feeling left with unanswered questions following the sibling's sudden death. The findings show that verbalised emotions did not come naturally to any of the participants, rather it was prompted by the sibling's illness or sudden death. The participants in the former group; Georgina, Francesca, Caroline, Rosie and Leon, had had the opportunity to speak to their sibling, which provided some closure. The future was spoken about in regards to the sibling's wishes for the immediate arrangements after their death, mostly without the future of the participants' and other family members being mentioned. This is similar to

existing literature about society prior to the First World War when the family and community would be present and aware of those dying (Jalland, 2010; Houlbrooke, 1998). Additionally, it echoes the community based care for the terminally ill created by Kübler-Ross and Saunders in the mid 20<sup>th</sup> century (Kübler-Ross, 1969; Saunders, 1959). Beatrice, Nick, Nora, Lucy and Sally lost their sibling suddenly and reported experiences similar to people who lost family members and friends during the First and Second World Wars, as conversations could no longer take place and questions about personal matters and the circumstances surrounding the death remained unanswered. Additionally, the loss of future conversations and relationships described by the participants is similar to the silent grief presented by Walter (1999). Up to this point the sub-themes of grief following terminal illness or sudden death is similar to existing literature (Jalland, 2010; Gregory, 1994; Walter, 1999; Kübler-Ross, 1969; Saunders, 1959).

Although there is some contemporary research about adult sibling loss much research has been carried out with medical matters in mind (Switzer et al., 1998; Cicirelli, 1991). Thus, the individual voices of the participants may not be heard over those of doctors and medical researchers. The choice of a qualitative method and IPA in specific for this research allows space for the participants' own personal thoughts, emotions and experiences and therefore new findings about the topic.

Yardley's (2000) criteria of adhering to the sensitivity of context when carrying out qualitative research is important for the findings in this theme, as the way in which the deaths occurred influenced the participants' possibility of speaking to their siblings or lack of such possibility. Sensitivity to the participants' experiences and a non-judgemental

approach was important firstly in the interviews and later on in the analysis and write-up of the findings. It was important for me to keep an open mind about the context of the participants being faced with either a short period of time to speak to their sibling following the diagnosis of a terminal illness or being left with numerous unanswered questions and a lack of closure after a sudden death.

All the participants had withheld verbal expression to different degrees while their sibling was alive and in good health, which illustrates how their families and the societies in which they live do not encourage people to speak about their emotions, unless timelimitations are present (Kastenbaum, 2011). This resonates with the work of the anthropologist Lévi-Strauss (1972), who strongly correlates language with the culture in which a language is spoken in order to understand specific aspects of the society studied. In particular, his personal observations of living in different cultures and his subsequent theories show how family relationships are closely interlinked with the vocabulary chosen by the different family members. The findings of the research presented here illustrate his ideas, as Georgina, Francesca, Caroline and Rosie expressed their love verbally to a greater extent and more explicitly to their sibling once the sibling was diagnosed with a terminal illness. There was a sense that there was no need for the participants to verbalise their thoughts and emotions prior to the illness. Although the above participants expressed their true emotions to a sibling they cared for, they struggled to find the words and were acutely aware of not knowing how much more time they would have. These participants' emotions appeared to often be paradoxical; gratefulness for being able to talk about their shared history and funny events whilst being with the sadness and urgency of the sibling's impending death. Lucy and Sally did not have time to verbalise their love to their sibling due to the death having occurred suddenly and were therefore left with feelings of unspoken emotions and questions. Similarly, Beatrice, Nick and Nora did not have the opportunity to speak to their sibling due to the death being sudden. However, they had associated their siblings with some form of abuse and the unspoken was therefore related to unanswered questions and apologies not received, rather than expressions of love.

The childhood abuse Beatrice and Nora's brothers subjected their sisters to only stopped due to the girls moving away from home. However, the risk behaviour of the brothers appears to continue in adulthood, as they abused alcohol and drugs, which finally lead to their violent deaths. The link between how young people's abusive behaviour and risk taking in their own families develops in to abuse in the community in adult life has been researched by Yates et al. (2012) in their small, quantitative study. They conclude that the participants who were not stopped from abusing within the family were more likely to take the risk of abusing children in their community. Continuing anti-social behaviour has been further investigated by Piquero et al. (2011), whose longitudinal research involved regular interviews and psychological tests of boys and men starting when they were eight years of age with the final meetings when the participants were 48 years old. Their results showed that failure to stop the anti-social behaviour in childhood and adolescent led to increased risk to the participants' own health and risk of committing criminal offences. The above studies support my own findings that abusive behaviour in childhood continues in adulthood, with severe and at times fatal, risk to others and the perpetrator, which as presented earlier prevents communication about the abuse and leaves the abused sibling with many strong emotions without finding closure to their experiences. In particular, the abused participants who felt relieved and free following their sibling's death reported feeling alone with these emotions, as their family was grieving.

Leon's experience was different from those of the other participants due to both the spoken and withheld words being present for him. He connected his sister with abusive behaviour and although they met with the extended family and hence spoke to each other politely, they did not speak about previous disagreements, nor did they have close or emotional conversations.

Caroline embraced the opportunity to tell her brother how much she loved him, while Georgina, Francesca and Rosie needed to push themselves to a greater extent to verbalise their emotions and thoughts. The emotions were paradoxical in regards of expressing love and care verbally, as it would mean accepting the impending death, which could be an explanation to why the participants struggled to express their thoughts verbally.

The theme of paradoxical emotions connected to loss relates to the four dimensions proposed in the existential literature; the physical, social, personal and spiritual dimensions (van Deurzen, 2010). As described in the literature review, Binswanger (1963) initially introduced the physical, social and personal dimensions to develop an in-depth understanding of the individual's world, to which van Deurzen (2010) subsequently added the spiritual dimension. The physical dimension is naturally present through the sibling's death. The social dimension reflects the society the participants are living in and their relationships with others, making verbal communication central to this dimension. The participants whose sibling died following an illness opened up by expressing themselves

more freely and at the same time there was a reduction in subjects talked about, as previous disagreements were often disregarded as no longer important due to the impending death. This is similar to Ricoeur's (2007 [1974]) idea of how spoken language can either reduce or open up the topic spoken about, depending on the specific circumstances. The personal and spiritual dimensions are present in the participants' emotions prior to and after the death of their sibling in how they felt in themselves and whether they were grieving or experiences relief.

The manner in which Georgina, Francesca, Caroline, Rosie and Leon had felt unable to express their feelings to their sibling freely prior to the terminal diagnosis is similar to what Heidegger (1962 [1927]) describes as 'hearing', 'keeping silent' or engaging in 'idle talk'. Often a more authentic and stronger relationship between the siblings was facilitated by language becoming more expressive or as in Leon's case, a possibility of at least spending time together. It appears that verbally expressing their thoughts, emotions and fears was a way for the participants to understand the loss they would inevitably experience shortly. Heidegger's idea (1962 [1927]) of how communication can create Mitbefindlichkeit, a co-state-of-mind, captures how spoken language is not only the words spoken, additionally it can intensify a relationship at the point when the participants realised that they did not have much time to express their thoughts. This opportunity of meeting and talking to their siblings provided Georgina, Francesca, Caroline and Rosie with some peace of mind, as they felt they had been able to meet their siblings on a deeper and more honest level. As mentioned above, Leon's experience was different to that of the other participants, as his sister's illness was the reason to why they started talking to each other again following several years of silence. However, these five

participants all met and talked to their sibling in a manner they would not have done had the sibling not become ill, which provided some closure.

Furthermore, the findings of the theme of paradoxical emotions connected to loss show how the participants whose sibling died from terminal illness felt the need to express their own thoughts and emotions, rather than experiencing an urge to hear what their sibling was thinking or feeling. The participants who lost their sibling suddenly similarly told of one-way speech, although they wanted answers regarding the circumstances surrounding the death and apologies from the sibling or authorities, i.e. doctors or police, who were investigating the death, rather than wanting to speak themselves. In a somewhat contradictory way all the participants attempted to make new connections with the sibling, or would have wanted to make connections, through language, albeit at times in form of monologue rather than by dialogue. This is similar to Derrida's (1997) idea of articulation showing the level of fluidity of language in meetings and specific relationships in society. The individual relationships and societies in which the participants live are reflected through articulation, or absence of such, as they had felt unable to verbally express their thoughts, questions and emotions unless being aware of a time limit to do so. Thus, the participants' language was prone to be hesitant, rather than fluid, possibly reflecting how emotions are conveyed in the society in which they live.

In order to understand the emotions expressed by the participants in connection with their sibling's death the participants' culture and their unique relationship with their sibling need to be considered. Withholding emotions while the sibling was alive and in good health is consistent with previous research of how displaying emotions following bereavement is culturally discouraged in contemporary UK society (Jalland, 2010; Gregory, 1994, Walter, 1999). Further, it is in line with Mesquita (2001), who has reviewed research as well as theories, with the aim of developing an understanding of how emotional expressiveness is culturally rooted. She concludes that culture is a strong influence regardless of whether emotions are shown or withheld. Additionally, her text reveals the importance of including the culture of the specific society investigated as well as the culture within each family and the sibling relationship being researched, which was very prevalent in the analysis of this super-ordinate theme.

The findings of this research shows that the emotions felt by the participants were disparate; Georgina, Francesca, Caroline, Rosie, Lucy and Sally were grieving for a sibling they had loved while Beatrice, Nick, Nora and Leon expressed relief due to having abusive connotations to the sibling. The phenomenological aspect of the analysis was particularly important for this super-ordinate theme, as it prevented assumptions about the participants' emotions and allowed space for each unique experience. This is similar to Bank and Kahn's (1982) qualitative research, which shows that losing a sibling can be either depleting or energising for the bereaved sibling. Furthermore, the focus on the individual relationship is similar to the work of Bonnano (2009) and Parkes and Prigerson (2010), as presented previously in the literature review.

Losing a loved sibling left the participants emotionally exhausted with a heightened sense of how unpredictable life can be, leading them to become more anxious about other family member's health and well-being. Further, they started to preserve their emotional energy to fewer people who they engaged with more deeply, as they became increasingly

aware of the uncertainty about what the future may bring. To provide an analogy, losing a loving sibling relationship can be unpredictable like the sea; emotions may turn from calm and still, to stormy with the risk of drowning or losing one's way without being able to gain control and swim to safety.

When the death of a sibling was followed by a sense of relief the participants' emotions were quite the opposite of those who had lost a sibling they loved. The former group expressed feeling free, more energised and having gained control over their lives for the first time. This freedom was however experienced in isolation, as the participants did not feel they could expose the abuse while other relatives were grieving. This is further reflected in Monahan's (2003) case study of a woman, whose recently deceased brother had sexually abused her in childhood, exploring the wide range of emotions experienced; from the freedom and joy of finally feeling safe, to anger and rage due to not getting an apology and frustration of others' focusing on only the positive aspects of the sibling's personality and actions. As Monahan (2003) suggests, therapists working with bereaved and abused clients need to develop an understanding of the past and present dynamics of each family while maintaining an open mind to the possibly contradictory emotions experienced by the bereaved sibling. Apart from therapeutic support the abused participants expressed wanting acknowledgement of the abuse, in particular from other family members who had been aware of the abuse without preventing or stopping it.

The findings that participants experience considerably diverse emotions are supported by Calhoun et al.'s (2010) theoretical publication, which explores the possibilities of improving clinical care for bereaved clients by focusing on positive post-traumatic growth

and the diversity of experiences following bereavement. This paper proposes a grief model in which post-traumatic growth is experienced in five different areas; 1. Self-perception, 2. Experience of changed relationships with other persons, 3. New possibilities, 4. Appreciation of life, 5. Existential/spiritual/religious elements. Although this publication highlights positive aspects of post-traumatic growth it is relevant for all the participants in my research, as they spoke of experiencing growth and change in the five areas presented in Calhoun et al.'s (2010) publication. Despite grieving for the loss of their sibling the participants who lost a loved sibling spoke of changes similar to Calhoun et al.'s (2010) model, which are further reiterated throughout the other super-ordinate themes in this research.

The existential literature incorporates the cultural aspects as well as the individual's experiences of emotions, providing a broad yet deep range of emotions from anxiety to a sense of freedom. The participants who lost a loved sibling expressed how they had developed deeper emotional relationships with their partner, children and parents, while being less emotionally engaged with extended family and friends. One reason for this appears to be their lack of energy, another reason their heightened sense of anxiety, which derived from the unpredictability of what else the future may hold. The unpredictability can be illustrated by Sartre's (1962 [1939]) view of how emotions prompt us to change how we live, although at times only because we find ourselves in situations where we feel we have no choice but to take a new path. Further, Sartre (1962 [1939]) states that when emotions become too strong they are balanced by emotions at the other end of the spectrum. For example; when the absence of the dead sibling became overwhelming at family gatherings the participants who were grieving their loved sibling

chose to not take part and instead spent time only with their immediate family. It appears that they experienced their loss as magnified in settings where the sibling would normally have been present and there was a sense that these participants were fearful of having to deal with their relatives' emotions in addition to their own, as this would further burdening them emotionally.

Although changes in life can be anxiety provoking they cannot be avoided, as was expressed by the participants who were grieving their loved sibling and found life after the loss unpredictable. This is similar to Jaspers' (1970 [1932]) idea of boundary situations, which shows how we cannot avoid the emotions or circumstances brought to us by life, as we are always in continuously changing situations. On the other hand, those who experienced a sense of freedom after the death of their sibling saw a range of new possibilities and therefore spoke of positive emotions and feelings of lightness after years of being suppressed. However, Jaspers (1970 [1932]) argues that total freedom does not exist, as there are always some limitations in a situation. Indeed, there was a contradiction for the abused participants; they were no longer living with the risk of being abused although there was now no hope of receiving apologies or speak to their sibling about their feelings of anger and injustice. Being free from the abuse allowed these participants to think about their lives and their experiences in ways that had not been possible while their sibling was alive. This freedom to think without, or with limited, constraints is similar to Fromm's (1960) idea of original thinking, which he argues can take place when thoughts and emotions are not restricted by general rules in the society we live in. The latter tend to assume a loving relationship between siblings. There can be an assumption of siblings having a loving relationship, which could be seen in the participants' suppression of their negative or hostile feelings when their siblings where alive. While the participants who lost their loved sibling described losing part of their sense of self, the participants who associated their sibling with some kind of abuse spoke of gaining a new, more defined self.

The participants' paradoxical emotions were present throughout this super-ordinate theme and ranged from anxiety, hope, courage and love around the time of the sibling's death, to comfort, sadness, regret and rumination after the death. The strong and varied emotions in this super-ordinate theme appear to be the beginning of how the two following super-ordinate themes, as the participants described considerably heightened emotions in their lives after the loss and in regards of support.

During the analysis and write-up, I considered alternatives to this theme of paradoxical emotions connected to loss. One option could have focused on how the participants experienced time before and following their sibling's death. Although this was indeed a topic which arose in most of the interviews, not all participants spoke of their experiences of time, nor was it as strong as the paradoxical emotions. Further, another option would have been to leave out illness and sudden death and concentrate only on the relationship between the participants and their sibling, which as had been seen above was loving for some and abusive for others. However, due to the strong emotional impact of whether the siblings died suddenly or following an illness, it would not be true to the findings to leave this out for this specific research.

## **Living after loss**

The findings of this super-ordinate theme showed how the participants tried to gain control over their loss in order to cope with daily life, illustrated often by references to metaphorical or actual boxes in which memories or memorabilia were kept. The participants' need to have some control over the grief is similar to the Dual Process Model as presented by Stroebe and Schut (1999) in the reviewed literature, in which the grief oscillates and hence provides the bereaved person with breaks from the intense emotions experienced.

Further, the analysis showed that continuing bonds exist, as presented earlier (Packman et al., 2006). However, the findings of this research show that it is necessary to further investigate the bonds, as the participants' continuing bonds were not always with the deceased sibling and depended on the relationship between the siblings. For Georgina, Francesca, Caroline, Rosie, Lucy and Sally the continuing loving relationship with their sibling provided a comfort, as did the presence of connections with others connected to their sibling, such as the participants' own children or children they wished to have in the future, as well as other relatives or friends of the sibling. The findings of children providing an emotional break while grieving is in line with Chidley et al.'s (2014) mixed methods research, which explores bereavement during motherhood. Their research shows that caring for children provided the participants with a sense of meaning, which in turn led to increased general wellbeing.

Bank and Kahn (1997) argue that a death will end life, although the relationship may continue. This is true for the participants in this research who lost a loved sibling, as they wished that their sibling could have lived longer. However, it does not resonate with the

findings for the participants who associated their sibling with some kind of abuse, as they did not wish to have an ongoing relationship with the deceased sibling. This finding is also in line with the work of Packman et al. (2006) and Weiss (2001), as they argue that continuing bonds would not be beneficial when abuse has been part of the relationship. Further, these findings show how relationships were re-initiated with the sibling's children or other family members after having been disrupted due to the abuse.

Another finding in this super-ordinate theme showed how the bereavement process was facilitated or impaired by whether the participants had energy and time for themselves. This is similar to existing literature on grief in general (Kastenbaum, 2008) as well as unacknowledged loss (Doka, 2002; Brabant, 2002; Flomenhaft, 2006; Mallon, 2008; Sobel and Cowan, 2003; Riches and Dawson, 2000), as the bereaved siblings were often expected to support other family members in practical and emotional matters following the death of their sibling. However, the findings of this research provide an in-depth account of how the bereaved siblings progressed in their grief when they managed to carve out some time for themselves. Often they did this by reducing their social circle and refrain from spending time with those who would not reciprocate the friendships. Further, physical space and clarity of mind enhanced the possibilities of coming to terms with life without their sibling. The newly found recognition of what one can take on, or needs deter form taking on, is similar to the coping strategies referred to in Smith et al.'s (2011) research on posttraumatic growth in adults bereaved by suicide. Their research shows that growth did not only imply positive aspects, indeed emotional stress was part of the findings. However, the growth consisted of each participant's newly developed awareness of what they were able to cope with in emotional and practical terms following their loss.

The majority of the participants, apart from Beatrice and Leon, no longer perceived time as clock-time, instead they described time as floating and experienced time as consisting of cycles, instead of hours or days. Additionally, all the participants apart from Leon felt they were making better use of the time in their daily lives following the death of their sibling. Leon was already filling his days with work and creative hobbies and continued to do so after his sister's death.

The existential literature adds further depth to the findings of the super-ordinate theme of living after loss. Relational aspects were particularly present, as the participants developed new relationships as well as needed to have time to be on their own. Buber (2006 [1947]) writes of the importance to start with oneself in order to understand the world, as changes in oneself will create changes in the world in which one lives. This correlates strongly with the participants' need to have time and space to themselves, in order to continue, re-establish or start new relationships when they felt ready to do so. van Deurzen (2010) states that relating to others means sharing space, as well as love, care and a sense of belonging. However, such closeness would only be able to take place once the participants were able to venture out of the initial isolation, something they often struggled to do. Heidegger (1962 [1927]) states that understanding something is always connected to a state-of-mind, emphasising that the latter is in the past while the understanding is based in the future. This illustrates how the participants needed time to comprehend their new life situation and once they had an understanding they were again able to venture in to relationships and society. Further, the continuing bonds with the sibling or those connected to the sibling are similar to Heidegger's (1962 [1927]) description of how one can be with the deceased by attending to memories and relationships, something the participants did through memorable items, connecting or reconnecting with others associated to the sibling.

The theme living with loss emerged through the participants relating how their lives had changed in regards of relationships with other family members, how they worked around connecting with their emotions in a safe manner and what prevented or facilitated their grief. The initial research idea and the very early themes during the analysis included how the experience of time had slowed down after the sibling's death, which could have been an interesting theme as this experience appeared to cause the participants be out of sync with others. Eventually, I decided to not use this as a super-ordinate theme as it was not brought up by all participants and additionally, I wanted to provide a holistic understanding of the participants lives, whereby I included their relationships and how they grieved.

### The complexities of support

The super-ordinate theme of support oscillates between the social and the individual. The findings show how support is a social matter, rather than an individual matter, which is closely linked with Walter's (1996) view of how loss mirrors society. The level of available support illustrates how the UK society has become more individualised in the last half-century. These changes in society can be seen in the changes of how theories of grief presented earlier in the literature moved from viewing grief as a cohesive social issue to focusing on the experiences of the bereaved individual (Kübler-Ross, 2003; Bowlby, 2005;

Bonnano, 2009; Parkes and Prigerson, 2010; Rubin et al., 2009; Stroebe and Schut, 1999; Worden, 2010).

The individual in contemporary UK society may have more freedom of how to grieve than in the past, although the reduction in traditions and closeness in communities provide little or no support for bereaved adult siblings, which is illustrated by the participants feeling unacknowledged following their sibling's death. When the participants felt the need to care for their grieving parents their own grief was delayed, which is in line with the findings of Cohen and Katz's (2015) study of grief and growth of bereaved siblings in relation to attachment and flexibility. Similarly, Eilegard et al.'s (2013) quantitative research of teenagers and young adults losing a sibling to cancer found that the participants felt there had been little space for their own grief and expressed how taking part in the research, although emotionally difficult at times, aided them in what had often been an extended grief process. The extensive amount of published research focusing on the parents of the deceased, rather than the entire family including the siblings, is evidence of how psychological support is unavailable for the latter group (Wilcox et al., 2015: Goodenough et al., 2004; Murphy et al., 1999). Additionally, due to the participants' friends and extended family being uncertain about how, or if, to offer support there was less social interaction overall, thus increasing the sense of loss and isolation for the participants. However, the paradox of the participants feeling that their loss was not considered and at the same time rejecting support point to the difficulties in bridging the gap between those who have lost a sibling in adult life and those who may wish to offer support. The findings of adult bereaved siblings feeling forgotten resonate with literature introduced earlier (Wray, 2003; Sandmaier, 1994; De Vita-Raeburn, 2004; Doka, 2007; Riches and Dawson, 2000), as does individuals' feelings of having specific rights to grieve or withhold support for others (Pietilä, 2002).

This research aims to add greater in-depth understanding of what kind of support the bereaved siblings would have found helpful and how others could offer them support in a more flexible way. The participants expressed the importance of support to be offered actively, particularly at times when they felt exhausted and struggled to contact friends and members of their extended family. Support was usually offered in public settings in which the participants did not feel emotionally safe, due to fear of becoming upset or not be able to take part in the social interaction expected of them. Difficulties arose as the participants did not speak about these feelings or fears and others did not take the risk of enquiring about what kind of support would have been appreciated. Further, the participants wished for support to last longer, specifying that a brief message on a post card, in a text message or electronic mail would be sufficient, as this would acknowledge their bereavement.

Communication following grief has been studied increasingly in recent years, for example by Rosenblatt (2008) who offers a phenomenological stance by working with and listening to the bereaved individual. This is in contrast to some of the models and theories of grief presented previously (Bowlby, 2005, [1979]; Kübler-Ross, [1969] 2003; Parkes, 1996). Thus, work with individuals, families and groups in a therapeutic setting could facilitate a deeper understanding of how the participants and their family and friends could support each other on a long-term basis.

The participants who had found support from other bereaved siblings had done so through bereavement organisations with specific branches for siblings, by searching for support on the internet using forums for others with the same experience. Thus, the participants who pro-actively searched for support outside their usual social circle were able to connect with others, both gaining and providing support. The capacity of drawing on different resources in order to cope in a difficult time has been researched by the medical sociologist Antonovsky (1987), who presents his own and others' research in order to increase the understanding of distressing events. He argues that those who are able to use different resources to deal with a stressful situation experiences greater feelings of meaning, while those who struggle to ask for help are less able to cope.

The super-ordinate theme of support is strongly connected to the social dimension in the existential literature. The relational aspects of support were strong throughout this theme and at times paradoxical, as the participants and those who could potentially support them struggled to communicate in how support could be both received and offered. The existential writer Buber (2004 [1937]) regards it essential for healthy relationships with others to be fluid, reciprocal and most of all, to include verbal communication. The participants spoke of the lack of support, including no verbal acknowledgement and conversations stopping, damaging the relationship with specific individuals and created a lack of trust in others in general, which together with rejection of support stalled communication. Heidegger's (1962 [1927]) concept of care is useful here; he proposes that care is cohesive and something that cannot be related to specific incidents. This is similar to how the lack of care and support was presented by the participants as being part of their daily life. Rather than being occasions that could be pinpointed there was an

overall sense that others did not regard support for bereaved siblings as necessary or did not know how to provide it. The participants presented others' unwillingness to try to offer support as uncaring due to the inflexible ways in which it was offered. Further, although the participants tended to receive some support initially after the death the majority of them felt that when they started to comprehend the impact the death had on their lives others expected them to stopped grieving. Rehnsfeldt and Arman (2012) carried out five interviews during one year with Swedish survivors of the 2004 Southeast Asian tsunami, which were analysed qualitatively and hermeneutically, specifically using Gadamer's work. Their findings show how courage and active support such as invitations for a specific date and time was greatly appreciated, rather than leaving the arrangement to the bereaved. Although a valid and interesting finding, there appears to be the assumption that the bereaved will have already established relationships with people who will have the willingness, energy and understanding of how to provide ongoing support. Indeed, my own research showed that this is not always the case. As suggested by Jaspers (2003 [1951]), in difficult times only a limited number of people will be supportive and even so, there is not a guarantee that these people can be relied on, which was described by the participants in my research as very hurtful.

There were multiple reasons to why support for the participants was complex; the gradual social change towards a more individualistic society provided less support for this specific group. Additionally, the participants were usually not considered to be the main grievers and the difficulty of finding other bereaved siblings to share experiences made support difficult. Alternatives to these findings could have been to explore more in depth the reluctance to accept and ask for support.

### **Important findings**

An overall prominent finding of this research was the paradoxical emotions expressed by the participants. Whilst the participants who had a sibling who was terminally ill appreciated the possibility to talk they wanted their sibling's suffering to end, although this could only happen by the sibling dying. The sudden deaths, on the other hand, meant that the siblings did not suffer for an extended period of time, however there were no opportunities to express love or receive apologies. Another important finding showed how the different emotions felt by the participants depended on the relationship with the sibling. Six of the participants were grieving for a sibling they had loved, while the remaining four participants found new freedom in their lives after the death of the sibling ended an abusive relationship. A further finding investigated how the participants were dealing with their lives on an everyday basis after their sibling had died. The final critical finding was the complexities of support, as communication about how support would be offered or received was often difficult or absent.

### **Application to practice**

In the process of carrying out this research it has become clear that a specific topic such as this can benefit from drawing on academic, empirical and experiential aspects to bring new knowledge to counselling psychologists (British Psychological Society, 2014). As Madison (2005) suggests, the existential viewpoint would be that bereavement was the starting point for seeking therapy, however, it should not be separated from other aspects

of the client's world. As short-term counselling is becoming more available through the NHS greater number of people can access counselling (NICE, 2009; IAPT, 2014), which requires therapists to work briefly with clients and at times recommend specific organisations for future therapy and support. Bereavement care has been and still is multidisciplinary (Parkes, 2002), increasingly so with referrals and closer communication between General Practitioner (GP) surgeries and counselling providers. In time-limited existential therapy the client and therapist would agree to work on a limited number of issues and therefore facilitate reflection on for example relationships and identification of paradoxes and meaning making (Strasser and Strasser, 1997). Indeed, these issues can be seen in this research, emphasising how the findings can be useful for counselling psychology and psychotherapy practice, whether short-term or long-term.

Due to the findings of this research showing that the death of a sibling is often not acknowledged, counselling psychologists and psychotherapists could deepen the therapeutic process for clients with this experience by working phenomenologically with what the loss and the unique relationship meant for them. Similarly, Neimeyer (2004) suggests a continuous collaboration between bereavement researchers, practitioners and possible with those bereaved to equally include theoretical and therapeutic work. At times, clients may have lost a sibling without having had time to consider their own emotions, as supporting other relatives has been their priority. Thus, counselling psychologists could create space in the sessions for these clients by acknowledging the death and enquire what it has meant for the individual client, particularly if the client concentrates mainly on others in the sessions. As seen in the first super-ordinate theme, I would recommend therapeutic work to be unassuming about the sibling relationship to

allow for loving as well as abusive sibling relationships. Additionally, I would advise that the wider family is discussed to create an understanding of the often complex emotions experienced by bereaved siblings, who may not have shared aspects of their relationships with their other family members. The second super-ordinate theme of living after loss show that it would be important to focus therapeutic work on what the clients need to grieve in regards of time and connecting with their grief. Further, from this theme it became clear that following the loss, relationships can be gained and can bring some positive aspects to difficult times. The findings of the third theme about support show how the death of a sibling in adult life can provoke low mood, lack of energy, isolation and anger, leaving the bereaved sibling in a vicious circle of wanting support albeit rejecting it. The gap between isolation and the client receiving and accepting support from family, friends and colleagues could be bridged by a combination of support from the counselling psychologist, support groups tailored specifically to this group and web based support available on a daily and ongoing basis. Following this research, it is clear to me that support for bereaved adult siblings is complex. Recommendations for working with this client group would include allowing others, who do not have the same experience, to support them.

Several of the participants spoke of wanting contact with others who had experienced a similar loss and some had joined, or were planning to join, therapeutic groups in face-to-face settings or online. Those of the participants who had lost their sibling several years ago expressed their wishes to support others who had lost a sibling in the last year or so. Therapeutic groups for bereaved adult siblings could be co-facilitated by two therapists, alternatively a therapist and a co-facilitator who has lost a sibling themselves, which

would ensure appropriate ethical and therapeutic boundaries in addition to the personal experience of the co-facilitator. The co-facilitator could enhance trust for the participants who regard others who have not lost a sibling as being unable to understand their loss and emotions. However, the co-facilitator would need to have dealt with their grief to some extent (Tedeschi and Calhoun, 1995). The reason for this is to provide a safe therapeutic setting for the facilitators and the group members. An example from the interviews is the great difference between Sally and Caroline. Sally, who lost her brother nine years prior to the interview, was able to reflect on her bereavement after having gone through the trauma of his sudden death, extensive therapy and slowly finding meaning in her life as a result of his death. Caroline, whose brother died just over a year before the interview, was in the very early stages in her grief and struggled greatly with strong emotions of intense sadness and anger. For someone to experience and be able to be with their own grief, it is a question of how much personal time and energy they have had to understand their loss and whether their emotions are oscillating, allowing time to rest. Thus, when someone would be ready to co-facilitate a group would depend on not only how much time had passed since the death but also where they are in their grief emotionally. The importance of time and personal understanding of the loss is to make it safe for the co-facilitator and to enable them to share the difficult and helpful aspects with the group members from a longitudinal perspective. Some counselling charities have expressed their interest in setting up groups for this group of clients, with the view of working with them on the practical and ethical aspects of such a group.

When running support groups it would be advisable to consider how the death of the sibling occurred, as the findings showed that when the participants expressed wishes to

connect with other bereaved siblings they found it comforting with some level of cohesiveness. An example is when Georgina searched for a support group shortly after her sister died following a prolonged illness but found herself struggling to connect with people whose sibling had been murdered, which was the only group she was able to find at the time. Further, as has been shown in this research the relational aspects of the relationship with the sibling can vary from loving and caring to abusive. Hence, the group facilitators would need to be aware of the wide range of emotions and experiences group members may bring. Additionally, social and cultural aspects should be considered due to losing a sibling in some countries would be more prevalent due to disease, violence or war. Considering that the contemporary UK population include many nationalities it would be advisable to be mindful of cultural differences, as well as of the setting of the group, i.e. the NHS, private therapy, charities etc.

### **Reflexivity**

During the research I was very mindful of researching an experience I had not had myself. When the participants expressed strong emotions it was somewhat of a relief to maintain the researcher's role without needing to relate to my own experiences. At the same time several of the participants regarded it impossible for others who had not lost an adult sibling to understand what they were going through, in which group they could have included me. However, they appeared to regard me in the role of researcher and trainee counselling psychologist to have an understanding of their experiences.

With about half the participants being British and half from different parts of the world I was intensely aware of my having grown up in Sweden, a country that has not been directly in war for about two centuries and, in my experience, grief in general and the deceased in specific are often spoken about in a more open manner. Being from a different country gave me the incentive to approach the social and historical aspects of grief with a curious and unassuming mind.

Throughout the research I kept a journal of the process, ideas, thoughts and questions I thought could be useful at a later stage. My supervisors and peer group were invaluable for ongoing discussion of ideas, developing the themes and providing feedback on the whole.

My understanding of the research topic gained greater depth as I developed further knowledge about the history of grief in the UK, which together with the findings about grief in contemporary society provided a comprehensive overview. In particular, the rapid social changes in the last 50 years highlighted the need to bridge the emotional and verbal distance between those grieving and people who could potentially offer support.

I found the process of interviewing, transcribing and analysing intensely emotional, as the participants often both spoke of and showed anger, grief and resentment. The participants' expressed their feelings verbally and non-verbally through crying, speaking with an angry tone of voice and struggling to find words to describe how they felt. This intensity stayed with me throughout the research process, which I believe was especially

beneficial to create depth in the analysis, although at times it could be exhausting due to the raw and strong emotions present.

The interviews naturally provided the participants with the time and space to talk, although at times I found it difficult to have one single interview without the possibility of knowing how they were the following days or weeks after the interview. However, all of the participants appeared to be able to seek professional support when they felt the need for it, which together with them having volunteered to take part in the research assured me that the interviews would not be harmful to them. Several of the participants expressed feeling some relief from talking about their experiences without needing to think about the emotions of relatives or friends.

### **Limitations and future research**

There were some limitations to this research, which became more apparent as I carried out the analysis. The initial research had not specified any criteria of how the sibling had died or whether the relationship had been loving or strained. This provided access to a wide understanding of the topic although imposed limitations to focus on a specific aspect or group of participants. As it took one year to find participants who fitted the criteria it was most likely advisable to not be more specific at this point in time. However, for future research it would be beneficial to be more specific. For example, future research could explore the experiences of either losing a sibling suddenly or through terminal illness, which could bridge the gap between the bereaved and those who may be able to offer support. Further, research about losing a loved sibling or a sibling with whom the

participants had a difficult relationship with could potentially add greater depth to the particular experience. By not specifying the relationship I believe my research findings exposed how complex sibling relationships can be, although for future research I would recommend that the researcher chose one criteria; participants who had a relationship with their sibling which was either loving or abusive. This may allow for greater depth about the relationship and the experience. If feasible, other criteria could be added, such as nationality and living location. However, to carry out research about sibling loss in adulthood with additional specific criteria it would be advisable to first carefully investigate how the participants would be contacted. While searching for participants I spoke to numerous people in charities, at universities and other settings who had lost a sibling in their adult life. However, more than 10 years had passed since the death and they could therefore not take part, although they described how the loss had affected them deeply and still did many years later. Thus, research and therapy groups with a greater time span would be interesting and possibly helpful for those who have lost a sibling more recently as they could gain support from those who had been bereaved for longer.

For future research of the topic I would recommend semi-structured interviews, as it allowed for exploration of the experience of losing a sibling in adult life, without stifling the expression and words of the person talking, nor diverting attention towards broader matters. An open approach to the topic appear to be crucial, as the analysis of this research shows that bereaved adult siblings have diverse experiences and emotions following their loss. Their experience of losing their sibling many years earlier than expected left them with strong, and at times contradictory, emotions towards the sibling,

family and friends and created a need to re-evaluate their lives and relationships. I hope that this research will be of use for individual adults who have lost a sibling in adult life as well as for bereavement organisations, counselling psychologists and medical professionals. As mentioned in the literature review referrals from doctors referring patients with specific medical issues, Huntingdon's decease or cancer, to counselling psychologists could provide ongoing therapeutic support to increase both physical and psychological recovery of bereaved adult siblings. I believe that it is worth mentioning that since I started this research new local support groups for this specific kind of bereavement have been set up and national retreats for this specific group have been arranged. Additionally, online options are increasingly providing bereaved adult siblings with possibilities of connecting and supporting each other without geographical restrictions. There have also been some research ideas for funded support interventions for young adults whose sibling has been diagnosed with a terminal illness, although this is still in the planning stages.

In relation to therapeutic practice, this research could prompt therapists to pay more attention to clients who come to therapy for reasons unrelated to having lost a sibling but bring this up in passing. The therapist can then enquire with an unassuming mind about the relationship and thus allow exploration of the experience, as has been presented in the research above. Due to this topic often not being spoken about openly it would be advisable that group therapists advertise for interest in local therapy centres, as this could be beneficial for the bereaved sibling from a therapeutic view point as well as making contact with others with the same experience. In this way the participants could possibly both gain and provide support in the area where they live. Support groups could be

advertised by establishing contact with bereavement charities and in this manner reach bereaved adult siblings on a national and local level by advertising on websites and through leaflets. Further, counselling psychologists and psychotherapists working in short-term settings in charities and the NHS would have the opportunity to mention groups to clients who have lost a sibling as adults and to colleagues who have clients with this experience. Short-term therapy may be the first step for a client acknowledging the need for support after losing a sibling, after which group therapy could be beneficial.

# Conclusion

The findings of this research demonstrate the importance of considering the individual relationship between the siblings, rather than pre-established, generalised theories of grief. In particular, the participants' emotions were paradoxical depending on whether they associated their sibling with love or abuse. Further paradoxes were found as the participants wanted emotional support although often refused it when family and friends offered support. Additionally, the study adds valuable insight into how continuous revision of how grief is experienced and viewed is required in order to incorporate social changes.

In the UK there has been a tradition of bereavement counselling being long-term, which Madison (2005) argues may be difficult to fund as there is a lack of research, which in turn makes funding applications based on empirical evidence difficult. While bereavement is often a long process, therapeutic support within the NHS is increasingly humanistic, whereby short-term counselling could provide the initial acknowledgement of the loss and

further guidance of specific support available (IAPT, 2012). Therefore, bereaved adult siblings can be allowed space for their individual experiences without their therapists working with pre-existing templates. With the possibility of working more holistically counselling psychologists and psychotherapists can provide this specific group of bereaved clients with support they may not receive from family and friends.

As suggested by Cooper (2003), time-limited existential therapy is still a new way of providing therapy and continuous developments will be needed. While I believe many clients engage well in time-limited therapy, the findings of this research indicate that the loss of an adult sibling takes time to comprehend. Therefore ongoing therapy, if possible, or blocks of time-limited sessions could provide support at a time when the client is struggling to engage with and gain support from others.

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### **Appendix I: Ethical Approval Application**



New School of Psychotherapy and Counselling

Royal Waterloo House 51-55 Waterloo Road London SE1 8TX

## **Request for Ethical Approval**

Applicant (specify):	PG Module:	DPsych		PhD Staff	
No study may proceed	until this fo	orm has been signed b	y an authorised	person indi	cating
that ethical approval ha	s been gra	nted.			
For collaborative resea all institutions involved.  This form should be ac employed, letters to information sheet for	companiec participan participar	I by any other relevants/institutions, advert	nt materials (e.g tisements or or other, inc	i. questionna recruiting n cluding app	aire to be naterials,
Is this the first submiss Is this an amended pro	ion of the p	oroposed study?	uy may be requ	¶ Yes	□ No

	or only)
Supervisor to initial here:	
Name of investigator(s):	Emma Jartell
Name of supervisor(s):	Elena Manafi
Title of Study	1, 1, 6, 7
existential phenomenological stu	alt life changes the experience and concept of time (an idy).
details of the procedure to be e	otion of the nature and purpose of the study, including mployed. Identify the ethical issues involved, particularly
	periences of participants, session length, procedures, on, and the storage and reporting of data.
stimuli, responses, data collection	on, and the storage and reporting of data.
	on, and the storage and reporting of data.
See attached project pro	on, and the storage and reporting of data.
See attached project pro	posal es result in any adverse reactions?
See attached project pro  2. Could any of these procedure  If "yes", what precautional The interview questions could which could be upsetting. They take part in the research. Further to withdraw at any time, should information about organisations.	posal  es result in any adverse reactions?  Ty steps are to be taken?  bring back memories or emotions for the participants, will be advised to think about this before consenting to rmore, they will also be informed that they have the right they feel unable to continue. The participants will receive a offering telephone support or face-to-face counselling, ght up questions and emotions they wish to discuss with a

(Ensure that your data handling complies with the Data Protection Act)

4. If participants other than NSPC or Middlesex University students are to be involved, where do you intend to recruit them?

(A full risk assessment must be conducted for any work undertaken off university premises)<sup>6,7</sup> I will contact bereavement services, such as Camden, City, Islington and Westminster Bereavement Service (CCIWBS), CRUSE and university students, for example at NSPC, Middlesex University and City University. I may also advertise in *Therapy Today* (journal of the British Association for Counselling and Psychotherapy). 5. When did you receive programme planning approval for this study: (If you were asked for revisions to your original proposal, this date should be when you received approval of the revisions) 4<sup>th</sup> January 2008 Please attach a copy of the programme planning approval 6. Does the study involve: ☐ Yes Clinical populations 🗐 No ☐ Yes ■ No Children (under 16 years) Vulnerable adults such as individuals with mental health problems, learning disabilities, prisoners, elderly, young offenders? ■ No 7. How, and from whom (e.g. from parents, from participants via signature) will informed consent be obtained? (See consent guidelines<sup>2</sup>; note special considerations for some questionnaire research) Informed consent will be obtained from the participants themselves. They will have received the Patient Information Sheet (PIS) together with the Consent Form via email or post prior to signing the Consent Form, in order to provide them with sufficient time to understand what the research will involve and decide whether they wish to take part. The participants will have time to contact the researcher after receiving the Patient Information Sheet and the Consent Form, should any matters need to be clarified. When the participants have received answers to any questions they may have they will be asked to return their signed consent form. 8. Will you inform participants of their right to withdraw from the research at any time, without penalty? Yes (See consent guidelines<sup>2</sup>) 9. Will you provide a full debriefing at the end of the data collection □ No phase? Yes (See debriefing guidelines<sup>3</sup>)

10. Will you be available to discuss the study with participants, if necessary, to monitor any negative effects or misconceptions? ☐ Yes ☐ No
If "no", how do you propose to deal with any potential problems?
NB: You are not at liberty to publish material taken from your work with individuals without the prior agreement of those individuals.
11. Under the Data Protection Act, participant information is confidential unless otherwise agreed in advance. Will confidentiality be guaranteed? (See confidentiality guidelines⁵) ☐ Yes ☐ No
If "yes" how will this be assured? (See 5)
All data collected will be stored, analysed and reported in compliance with the Data Protection Act 1998. All participant information will be allocated an alphanumeric key, which will be kept separately from any personal records which could identify the participant. When quotes from interviews are used in the writing up of the research any information which could identify the participants, such as workplace or ethnicity, will be changed.
If "no", how will participants be warned? (See 5)
12. Are there any ethical issues which concern you about this particular piece of research, not covered elsewhere on this form? ☐ Yes ☐ No
If "yes", please specify:

NB: If "yes" has been responded to any of questions 2,3,5,11 or "no" to any of questions 7-10, a full explanation of the reason should be provided if necessary, on a separate sheet submitted with this form.

13. Some or all of this research is to be conduc Middlesex University	ted away from	Yes	□No
If "yes", tick here to confirm that a Risk Assessment form is 14. I am aware that any modifications to the design this proposal will require me to submit a new applica-	n or method of		
approval.		Yes	□ No
15. I am aware that I need to keep all materials/doct to this study (e.g. participant consent forms, filled etc) until the completion of my degree.  16. I have read the British Psychological Society's Etfor Conducting Research with Human Participants (I	questionnaires,	¶ Yes	□No
relevant Universities Counselling and Psychothera guidelines (DProf) and believe this proposal to confor	py Association	Yes	□ No
Researcher:	Date:		
Signatures of Approval			
Supervisor:			
Ethics Panel: (Signed, pending completion of a Risk Assessment form if	_ Date: applicable)		

<sup>&</sup>lt;sup>1,2,3,4,5,6,7</sup> Guidelines are available from the Ethics page of Oas!sPlus

**Appendix II: Ethics Approval** 



## New School of Psychotherapy and Counselling

51-55 Waterloo Road, London SR1 8TX.

Telephone: 020 7928 4344/0029 Fax: 020 7401 2231

Email: admin@nspc.org.uk Website: www.nspc.org.uk

Emma Jarteli

3 November 2009

Dear Emma

Re: Research Proposal Resubmission & Ethios Approval

We held an Ethics Board on 7 October 2009 and the following decision were made.

Research Proposal Resubmission

Resubmission of Research Proposal has been approved

You have been granted ethics approval.

pp Marmi

Dr Gordon Weller Programme Leader DProf (Health) Middlesex University

Prof Digby Tantam Chair Ethics Committee

NSPC is a section of London City College. Its pergraduate courses in psychotheropy are validated by the University of Shefferd, Its MSc cases in commelling psychology is validated by Middlessex University



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   Dertificate in Edistorial Supervision & Training

## **Appendix III: Risk Assessments**

## INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following fieldwork situations:

- 1. All fieldwork undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).
- 2. All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).
- 3. Fieldwork undertaken by research students. Student to complete with supervisor.
- 4. Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.

## FIELDWORK DETAILS

Name Emma Jartell	Student No Research Centre (staff only)
Supervisor Jill Mytton	Degree course DPsych
Telephone numbers and name of next of kin who may be	NEXT OF KIN
contacted in the event of an accident	Name 
	Phone
Physical or psychological limitations to carrying out the proposed fieldwork	
Any health problems (full details)	
Which may be relevant to	
proposed fieldwork activity in	
case of emergencies.	

## **Locality (Country and Region)**

Travel Arrangements	London Transport
NB: Comprehensive travel and health insurance must always be obtained for independent overseas fieldwork.	
Dates of Travel and Fieldwork	TBC

## PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY

# <u>Hazard Identification and Risk Assessment</u> **CAREFULLY**

PLEASE READ VERY

List the localities to be visited or specify routes to be followed **(Col. 1).** Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' **(Col 2).** For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern **(Col. 3).** 

## **Examples of Potential Hazards:**

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders.

Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for

task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

## Give brief details of fieldwork activity:

Lone interviews with one participant at the time in the room on a floor where at least one psychotherapist is present in a nearby room.

.....

1. LOCALITY/	2. LAST VISIT	3. POTENTIAL HAZARDS
ROUTE		
Ludgate Hill Psychotherapy and Counselling Rooms, 89 Fleet Street, London EC4Y 1DH	July 2010	Lone working

The University Fieldwork code of Practice booklet provides practical advice that should be followed in planning and conducting fieldwork.

# Risk Minimisation/Control Measures CAREFULLY

PLEASE READ VERY

For each hazard identified (Col 3), list the precautions/control measures in place or that will be taken (Col 4) to "reduce the risk to acceptable levels", and the safety equipment (Col 6) that will be employed.

Assuming the safety precautions/control methods that will be adopted **(Col. 4)**, categorise the fieldwork risk for each location/route as negligible, low, moderate or high **(Col. 5)**.

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

## Examples of control measures/precautions:

Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs).

Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility. Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.

**Examples of Safety Equipment**: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/CONTROL MEASURES	5. RISK ASSESSMENT	6. EQUIPMENT
The psychotherapist running the service will be present to let me in to the building and will be present in a nearby room during the interview. Other psychotherapists are also likely to be present in rooms in nearby rooms, however, the times of these psychotherapists can change on a weekly basis.	Low	Mobile.

## PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB:	Risk	should	be	constantly	reassessed	during	the	fieldwork	period	and	additional
pre	cautio	ons take	n oı	r fieldwork	discontinue	d if the r	isk i	s seen to b	e unacc	eptal	ble.

Field	nature of dworker ndent/Staff)		Date	
_	nature of Student ervisor		Date	
APP	ROVAL: (ONE ONLY)			
Curi	nature of riculum Leader dergraduate students r)		Date	
Deg Mas or Tau	nature of Research ree Co-ordinator or sters Course Leader ght Masters riculum Leader		Date	
Cen	nature of Research tre Head (for staff dworkers)		Date	
	LDWORK CHECK LIST	r - s of the field party possess the following attri	hutes (where	
		opriate to the proposed activity and likely field	•	
	Safety knowledge and	training?		
	Awareness of cultural,	social and political differences?		
	Physical and psycholog	gical fitness and disease immunity, protection	n and awaren	ess?
	Personal clothing and	safety equipment?		
	Suitability of fieldwork	ers to proposed tasks?		

ave all the necessary arrangements been made and information/instruction gained, have the relevant authorities been consulted or informed with regard to:
Visa, permits?
Legal access to sites and/or persons?
Political or military sensitivity of the proposed topic, its method or location?
Weather conditions, tide times and ranges?
Vaccinations and other health precautions?
Civil unrest and terrorism?
Arrival times after journeys?
Safety equipment and protective clothing?
Financial and insurance implications?
Crime risk?
Health insurance arrangements?
Emergency procedures?
Transport use?
Travel and accommodation arrangements?

Important information for retaining evidence of completed risk assessments: Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the fieldworker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

## INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following fieldwork situations:

- 5. All fieldwork undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).
- 6. All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).
- 7. Fieldwork undertaken by research students. Student to complete with supervisor.
- 8. Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.

## FIELDWORK DETAILS

Name Emma Jartell	Student No Research Centre (staff only)
Supervisor Jill Mytton	Degree course DPsych
Telephone numbers and name of nekin who may be contacted in the everan accident	NEXT OF KIN Name
	Phone
Physical or psychological limitations to carrying out the proposed fieldwork	
Any health problems (full details) Which may be relevant to proposed fieldwork activity in case of emergencies.	
Locality (Country and Region)	
Travel Arrangements	London Transport National Rail

Dates of Travel and Fieldwork	TBC
health insurance must always be obtained for independent overseas fieldwork.	

### PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY

## **Hazard Identification and Risk Assessment**

### PLEASE READ VERY CAREFULLY

List the localities to be visited or specify routes to be followed (Col. 1). Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' (Col 2). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (Col. 3).

## **Examples of Potential Hazards:**

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders. Safety Standards (other work organisations, transport, hotels, etc.), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma allergies, fitting) general fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

## Give brief details of fieldwork activity:

Lone interviews with one participant at the time in the room in an office where one or tw
administrators will be present at all times.

1. LOCALITY/	2. LAST VISIT	3. POTENTIAL HAZARDS
ROUTE		
The Compassionate Friends,	Not visited yet	Lone working
53 North Street,		
Bristol,		
BS3 1EN		

The University Fieldwork code of Practice booklet provides practical advice that should be followed in planning and conducting fieldwork.

# Risk Minimisation/Control Measures CAREFULLY

PLEASE READ VERY

For each hazard identified (Col 3), list the precautions/control measures in place or that will be taken (Col 4) to "reduce the risk to acceptable levels", and the safety equipment (Col 6) that will be employed.

Assuming the safety precautions/control methods that will be adopted **(Col. 4)**, categorise the fieldwork risk for each location/route as negligible, low, moderate or high **(Col. 5)**.

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

## **Examples of control measures/precautions:**

Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs).

Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility. Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of

travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.

**Examples of Safety Equipment**: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/CONTROL MEASURES	5. RISK ASSESSMENT	6. EQUIPMENT
Two administrators run the administrators Monday to Friday. At least one of them will rema the office whilst the interview is taking place.	Low	Mobile. Office landlines.

## PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the fieldwork period and additional precautions taken or fieldwork discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker (Student/Staff)	 Date	
Signature of Student	 Date	
Supervisor		
APPROVAL: (ONE ONLY)		
Signature of Curriculum Leader (undergraduate students or	 Date	
Signature of Research		
Degree Co-ordinator or Masters Course Leader or Taught Masters Curriculum Leader	Date	
Signature of Research		

	tre Head (for staff lworkers)			Date	
FIEL	LDWORK CHECK LIST	<u>r</u>			
			ossess the following attriby and likely field condition	•	levant)
	Safety knowledge and	training?			
	Awareness of cultural	, social and political d	ifferences?		
	Physical and psycholo	gical fitness and disea	ase immunity, protection	and awareness	?
	Personal clothing and	safety equipment?			
	Suitability of fieldwork	kers to proposed task	s?		
			ade and information/instr informed with regard to:	ruction gained,	and
	Visa, permits?				
	Legal access to sites a	nd/or persons?			
	Political or military ser	nsitivity of the propos	sed topic, its method or lo	ocation?	
	Weather conditions, t	ide times and ranges	?		
	Vaccinations and other	er health precautions?	?		
	Civil unrest and terror	ism?			
	Arrival times after jou	rneys?			
	Safety equipment and	protective clothing?			
	Financial and insurance	ce implications?			
	Crime risk?				
	Health insurance arrai	ngements?			
	Emergency procedure	s?			
	Transport use?				
	Travel and accommod	lation arrangements?			
<u>lmp</u>	ortant information for	retaining evidence o	f completed risk assessn	nents: Once the	e risk

<u>Important information for retaining evidence of completed risk assessments:</u> Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the fieldworker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

## INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following fieldwork situations:

- 9. All fieldwork undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).
- 10. All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).
- 11. Fieldwork undertaken by research students. Student to complete with supervisor.
- 12. Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.

## FIELDWORK DETAILS

Name Emma Jartell	Student No Research Centre (staff only)
Supervisor Jill Mytton	Degree course DPsych
Telephone numbers and name of next of kin who may be contacted in the event of accident	NEXT OF KIN Name
	Phone
Physical or psychological limitations to carrying out the proposed fieldwork	
Any health problems (full details) Which may be relevant to proposed fieldwork activity in case of emergencies.	
Locality (Country and Region)	
Travel Arrangements	London Transport
NB: Comprehensive travel and health insurance must always be obtained for independent overseas fieldwork.	

TBC			
-----	--	--	--

## PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY

## **Hazard Identification and Risk Assessment**

## PLEASE READ VERY CAREFULLY

List the localities to be visited or specify routes to be followed (Col. 1). Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' (Col 2). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (Col. 3).

## **Examples of Potential Hazards:**

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders. Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

## If no hazard can be identified beyond those of everyday life, enter 'NONE'.

## Give brief details of fieldwork activity:

Lone interviews with one participant at the time in the room on a floor where at least one administrative member of staff is present.

.....

1. LOCALITY/	2. LAST VISIT	3. POTENTIAL HAZARDS
ROUTE		

New School of	February 2011	Lone working
Psychotherapy and		
Counselling,		
254 Belsize Road,		
London NW6 4B		

The University Fieldwork code of Practice booklet provides practical advice that should be followed in planning and conducting fieldwork.

# Risk Minimisation/Control Measures CAREFULLY

PLEASE READ VERY

For each hazard identified (Col 3), list the precautions/control measures in place or that will be taken (Col 4) to "reduce the risk to acceptable levels", and the safety equipment (Col 6) that will be employed.

Assuming the safety precautions/control methods that will be adopted **(Col. 4)**, categorise the fieldwork risk for each location/route as negligible, low, moderate or high **(Col. 5)**.

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

## **Examples of control measures/precautions:**

Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs).

Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility. Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.

**Examples of Safety Equipment**: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/ CONTROL MEASURES	5. RISK ASSESSMENT	6. EQUIPMENT
The administrative staff in the NSPC office will be present to let me in to the room and will be present in a nearby room during the interview.  There will also be reception staff at the entrance of the building.		Mobile and land lines

## PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the fieldwork period and additional precautions taken or fieldwork discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker (Student/Staff)	 Date	•••••
Signature of Student	 Date	
Supervisor		
APPROVAL: (ONE ONLY)		
Signature of Curriculum Leader (undergraduate students	 Date	
only)		
Signature of Research	 Date	
Degree Co-ordinator or Masters Course Leader or Taught Masters Curriculum Leader		
Signature of Research		
Centre Head (for staff	 Date	

fieldworkers)

## **FIELDWORK CHECK LIST**

3.	Ensure that <b>all members</b> of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:
	Safety knowledge and training?
	Awareness of cultural, social and political differences?
	Physical and psychological fitness and disease immunity, protection and awareness?
	Personal clothing and safety equipment?
	Suitability of fieldworkers to proposed tasks?
	Have all the necessary arrangements been made and information/instruction gained, and return the relevant authorities been consulted or informed with regard to:
	Visa, permits?
	Legal access to sites and/or persons?
	Political or military sensitivity of the proposed topic, its method or location?
	Weather conditions, tide times and ranges?
	Vaccinations and other health precautions?
	Civil unrest and terrorism?
	Arrival times after journeys?
	Safety equipment and protective clothing?
	Financial and insurance implications?
	Crime risk?
	Health insurance arrangements?
	Emergency procedures?
	Transport use?
	Travel and accommodation arrangements?
ass	essment is completed and approval gained the supervisor should retain this form and issue

risk copy of it to the fieldworker participating on the field course/work. In addition the approver must keep a copy of this risk assessment in an appropriate Health and Safety file.

#### INDEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1

This proforma is applicable to, and must be completed in advance for, the following fieldwork situations:

5. All fieldwork undertaken independently by individual students, either in the UK or overseas, including in connection with proposition module or dissertations. Supervisor to

- complete with student(s).
- 6. All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).
- 7. Fieldwork undertaken by research students. Student to complete with supervisor.
- 8. Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.

## FIELDWORK DETAILS

Name Emma Jartell	Student No Research Centre (staff only)
Supervisor Jill Mytton	Degree course DPsych
Telephone numbers and name of nekin who may be contacted in the eve an accident	NEXT OF KIN Name
	Phone
Physical or psychological limitations carrying out the proposed fieldwork	
Any health problems (full details) Which may be relevant to proposed fieldwork activity in case of emergen	
Locality (Country and Region)	
Travel Arrangements  NB: Comprehensive travel and healtl insurance must always be obtained f independent overseas fieldwork.	London Transport and National Rail
Dates of Travel and Fieldwork	TBC

## PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY

## **Hazard Identification and Risk Assessment**

## PLEASE READ VERY CAREFULLY

List the localities to be visited or specify routes to be followed (Col. 1). Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' (Col 2). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (Col. 3).

## **Examples of Potential Hazards:**

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders. Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio- hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

Give brief details of fieldwork activity:
Lone interviews with one participant at the time in a room in a therapy centre.

1. LOCALITY/	2. LAST VISIT	3. POTENTIAL HAZARDS
ROUTE		
Northern Guild	Not visited yet	Lone working
83 Jesmond Road		

Newcastle upon Tyne		
NE2 1NH		

The University Fieldwork code of Practice booklet provides practical advice that should be followed in planning and conducting fieldwork.

# Risk Minimisation/Control Measures CAREFULLY

PLEASE READ VERY

For each hazard identified (Col 3), list the precautions/control measures in place or that will be taken (Col 4) to "reduce the risk to acceptable levels", and the safety equipment (Col 6) that will be employed.

Assuming the safety precautions/control methods that will be adopted (Col. 4), categorise the fieldwork risk for each location/route as negligible, low, moderate or high (Col. 5).

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

## **Examples of control measures/precautions:**

Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs).

Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility. Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.

**Examples of Safety Equipment**: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/CONTROL MEASURES	5. RISK ASSESSMENT	6. EQUIPMENT
There are a number of other rooms in the building, which are used for individual, group and family work. In addition there is supervision and courses taking place in the building. There is always staff present at the centre.	Low	Mobile and land lines
and family work. In addition there is supervision and courses taking place in the building.		

## PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the fieldwork period and additional precautions taken or fieldwork discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker (Student/Staff)	 Date	•••••
Signature of Student Super	 Date	
APPROVAL: (ONE		
ONLY)		
<b>Signature of</b> <b>Curriculum Leader</b> (undergraduate students on	 Date	•••••
Signature of Research Degr Co-ordinator or Masters Course Leader or Taught Masters Curriculum Leader	 Date	
Signature of Research Cent Head (for staff fieldworkers	 Date	

## **FIELDWORK CHECK LIST**

4.	Ensure that <b>all members</b> of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:
	Safety knowledge and training?
	Awareness of cultural, social and political differences?
	Physical and psychological fitness and disease immunity, protection and awareness?
	Personal clothing and safety equipment?
	Suitability of fieldworkers to proposed tasks?
	Have all the necessary arrangements been made and information/instruction gained, and ve the relevant authorities been consulted or informed with regard to:
	Visa, permits?
	Legal access to sites and/or persons?
	Political or military sensitivity of the proposed topic, its method or location?
	Weather conditions, tide times and ranges?
	Vaccinations and other health precautions?
	Civil unrest and terrorism?
	Arrival times after journeys?
	Safety equipment and protective clothing?
	Financial and insurance implications?
	Crime risk?
	Health insurance arrangements?
	Emergency procedures?
	Transport use?
	Travel and accommodation arrangements?
ass	portant information for retaining evidence of completed risk assessments: Once the risk sessment is completed and approval gained the supervisor should retain this form and issue a by of it to the fieldworker participating on the field course/work. In addition the approversest keep a copy of this risk assessment in an appropriate Health and Safety file.
Th	DEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1 is proforma is applicable to, and must be completed in advance for, the following fieldwork uations:

9. All fieldwork undertaken independently by individual students, either in the UK or

- overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).
- 10. All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).
- 11. Fieldwork undertaken by research students. Student to complete with supervisor.
- 12. Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.

## FIELDWORK DETAILS

Name Emma Jartell	Student No Research Centre (staff only)
Supervisor Jill Mytton	Degree course DPsych
Telephone numbers and name of nekin who may be contacted in the everan accident	NEXT OF KIN Name
	Phone
Physical or psychological limitations carrying out the proposed fieldwork	
Any health problems (full details) Which may be relevant to proposed fieldwork activity in case of emergen	
Locality (Country and Region)	
Travel Arrangements	London Transport and National Rail
NB: Comprehensive travel and healtl insurance must always be obtained f independent overseas fieldwork.	

Dates of Travel and Fieldwork	TBC

## PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY

## **Hazard Identification and Risk Assessment**

### PLEASE READ VERY CAREFULLY

List the localities to be visited or specify routes to be followed (Col. 1). Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' (Col 2). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (Col. 3).

## **Examples of Potential Hazards:**

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic, cultural, socio-economic differences/problems. Known or suspected criminal offenders. Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma allergies, fitting) general fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio-hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

	-			
Give brief details of fieldwork activity:				
Lone interviews with one participant at the time in a room in a therapy practice.				
1. LOCALITY/	2. LAST VISIT	3. POTENTIAL HAZARDS		
ROUTE				

Central Scotland	Not visited yet	Lone working
Counselling &		
Psychotherapy		
5 York Place		
Edinburgh		
EH1 3EB		

The University Fieldwork code of Practice booklet provides practical advice that should be followed in planning and conducting fieldwork.

# Risk Minimisation/Control Measures CAREFULLY

PLEASE READ VERY

For each hazard identified (Col 3), list the precautions/control measures in place or that will be taken (Col 4) to "reduce the risk to acceptable levels", and the safety equipment (Col 6) that will be employed.

Assuming the safety precautions/control methods that will be adopted (Col. 4), categorise the fieldwork risk for each location/route as negligible, low, moderate or high (Col. 5).

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

## **Examples of control measures/precautions:**

Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs).

Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility. Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of

travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.

**Examples of Safety Equipment**: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/CONTROL MEASURES	5. RISK ASSESSMENT	6. EQUIPMENT
There are several rooms in the practice, which are used for individual, couple, group work as well as supervision and workshops. There will be therapists and staff present at the practice.	Low	Mobile and land lines

## PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the fieldwork period and additional precautions taken or fieldwork discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker (Student/Staff)	 Date	
Signature of Student Super	 Date	
APPROVAL: (ONE ONLY)		
Signature of Curriculum Leader (undergraduate students or	 Date	
Signature of Research		
Degree Co-ordinator or Masters Course Leader or Taught Masters Curriculum Leader	 Date	
Signature of Research Cent Head (for staff fieldworkers	 Date	

## **FIELDWORK CHECK LIST**

5.	Ensure that <b>all members</b> of the field party possess the following attributes (where relevant) at a level appropriate to the proposed activity and likely field conditions:
	Safety knowledge and training?
	Awareness of cultural, social and political differences?
	Physical and psychological fitness and disease immunity, protection and awareness?
	Personal clothing and safety equipment?
	Suitability of fieldworkers to proposed tasks?
	Have all the necessary arrangements been made and information/instruction gained, and ve the relevant authorities been consulted or informed with regard to:
	Visa, permits?
	Legal access to sites and/or persons?
	Political or military sensitivity of the proposed topic, its method or location?
	Weather conditions, tide times and ranges?
	Vaccinations and other health precautions?
	Civil unrest and terrorism?
	Arrival times after journeys?
	Safety equipment and protective clothing?
	Financial and insurance implications?
	Crime risk?
	Health insurance arrangements?
	Emergency procedures?
	Transport use?
	Travel and accommodation arrangements?
ass	portant information for retaining evidence of completed risk assessments: Once the risk sessment is completed and approval gained the supervisor should retain this form and issue a py of it to the fieldworker participating on the field course/work. In addition the approver ust keep a copy of this risk assessment in an appropriate Health and Safety file.
	DEPENDENT FIELD/LOCATION WORK RISK ASSESSMENT FRA1
	is proforma is applicable to, and must be completed in advance for, the following fieldwork uations:
	13. All fieldwork undertaken independently by individual students, either in the UK or

- overseas, including in connection with proposition module or dissertations. Supervisor to complete with student(s).
- 14. All fieldwork undertaken by postgraduate students. Supervisors to complete with student(s).
- 15. Fieldwork undertaken by research students. Student to complete with supervisor.
- 16. Fieldwork/visits by research staff. Researcher to complete with Research Centre Head.

## FIELDWORK DETAILS

Name Emma Jartell	Student No Research Centre (staff only)
Supervisor Jill Mytton	Degree course DPsych
Telephone numbers and name of nekin who may be contacted in the everan accident	NEXT OF KIN Name
	Phone
Physical or psychological limitations carrying out the proposed fieldwork	
Any health problems (full details) Which may be relevant to proposed fieldwork activity in case of emergen	
Locality (Country and Region)	
Travel Arrangements	London Transport and National Rail
NB: Comprehensive travel and healtl insurance must always be obtained f independent overseas fieldwork.	

Dates of Travel and Fieldwork	TBC

## PLEASE READ THE INFORMATION OVERLEAF VERY CAREFULLY

## **Hazard Identification and Risk Assessment**

## PLEASE READ VERY CAREFULLY

List the localities to be visited or specify routes to be followed (Col. 1). Give the approximate date (month / year) of your last visit, or enter 'NOT VISITED' (Col 2). For each locality, enter the potential hazards that may be identified beyond those accepted in everyday life. Add details giving cause for concern (Col. 3).

## **Examples of Potential Hazards:**

Adverse weather: exposure (heat, sunburn, lightening, wind, hypothermia)

Terrain: rugged, unstable, fall, slip, trip, debris, and remoteness. Traffic: pollution.

Demolition/building sites, assault, getting lost, animals, disease.

Working on/near water: drowning, swept away, disease (weils disease, hepatitis, malaria, etc), parasites', flooding, tides and range.

Lone working: difficult to summon help, alone or in isolation, lone interviews.

Dealing with the public: personal attack, causing offence/intrusion, misinterpreted, political, ethnic cultural, socio-economic differences/problems. Known or suspected criminal offenders.

Safety Standards (other work organisations, transport, hotels, etc), working at night, areas of high crime.

Ill health: personal considerations or vulnerabilities, pre-determined medical conditions (asthma, allergies, fitting) general fitness, disabilities, persons suited to task.

Articles and equipment: inappropriate type and/or use, failure of equipment, insufficient training for use and repair, injury.

Substances (chemicals, plants, bio-hazards, waste): ill health - poisoning, infection, irritation, burns, cuts, eye-damage.

Manual handling: lifting, carrying, moving large or heavy items, physical unsuitability for task

If no hazard can be identified beyond those of everyday life, enter 'NONE'.

## Give brief details of fieldwork activity:

Lone interviews with one participant at the time in the room in a therapy centre of nine rooms in total, although at present it is not known how many therapists will be there at the time of the interview.

1. LOCALITY/	2. LAST VISIT	3. POTENTIAL HAZARDS
ROUTE		

UKCP Canterbury	Not visited yet	Lone working
St Dunstan's Therapy Centre		
10 Station Road West		
Canterbury		
Kent		
CT2 ODE		

The University Fieldwork code of Practice booklet provides practical advice that should be followed in planning and conducting fieldwork.

# Risk Minimisation/Control Measures CAREFULLY PLEASE READ VERY

For each hazard identified (Col 3), list the precautions/control measures in place or that will be taken (Col 4) to "reduce the risk to acceptable levels", and the safety equipment (Col 6) that will be employed.

Assuming the safety precautions/control methods that will be adopted (Col. 4), categorise the fieldwork risk for each location/route as negligible, low, moderate or high (Col. 5).

Risk increases with both the increasing likelihood of an accident and the increasing severity of the consequences of an accident.

An acceptable level of risk is: a risk which can be safely controlled by person taking part in the activity using the precautions and control measures noted including the necessary instructions, information and training relevant to that risk. The resultant risk should not be significantly higher than that encountered in everyday life.

## Examples of control measures/precautions:

Providing adequate training, information & instructions on fieldwork tasks and the safe and correct use of any equipment, substances and personal protective equipment. Inspection and safety check of any equipment prior to use. Assessing individuals fitness and suitability to environment and tasks involved. Appropriate clothing, environmental information consulted and advice followed (weather conditions, tide times etc.). Seek advice on harmful plants, animals & substances that may be encountered, including information and instruction on safe procedures for handling hazardous substances. First aid provisions, inoculations, individual medical requirements, logging of location, route and expected return times of lone workers. Establish emergency procedures (means of raising an alarm, back up arrangements). Working with colleagues (pairs).

Lone working is not permitted where the risk of physical or verbal violence is a realistic possibility. Training in interview techniques and avoiding /defusing conflict, following advice from local organisations, wearing of clothing unlikely to cause offence or unwanted attention. Interviews in neutral locations. Checks on Health and Safety standards & welfare facilities of travel, accommodation and outside organisations. Seek information on social/cultural/political status of fieldwork area.

**Examples of Safety Equipment**: Hardhats, goggles, gloves, harness, waders, whistles, boots, mobile phone, ear protectors, bright fluorescent clothing (for roadside work), dust mask, etc.

If a proposed locality has not been visited previously, give your authority for the risk assessment stated or indicate that your visit will be preceded by a thorough risk assessment.

4. PRECAUTIONS/CONTROL MEASURES	5. RISK ASSESSMENT	6. EQUIPMENT
There are eight other rooms in the therapy centre, which are used for individual and group therapy.  There is also staff present at the centre.	Low	Mobile and land lines

## PLEASE READ INFORMATION OVERLEAF AND SIGN AS APPROPRIATE

**DECLARATION:** The undersigned have assessed the activity and the associated risks and declare that there is no significant risk or that the risk will be controlled by the method(s) listed above/over. Those participating in the work have read the assessment and will put in place precautions/control measures identified.

NB: Risk should be constantly reassessed during the fieldwork period and additional precautions taken or fieldwork discontinued if the risk is seen to be unacceptable.

Signature of Fieldworker (Student/Staff)	 Date	
Signature of Student Super	 Date	
APPROVAL: (ONE ONLY)		
Signature of Curriculum Leader (undergraduate students	 Date	
only)		
Signature of Research		
Degree Co-ordinator or Masters Course Leader or Taught Masters	 Date	
Curriculum Leader		
Signature of Research		
Centre Head (for staff	 Date	

## **FIELDWORK CHECK LIST**

6.	nsure that <b>all members</b> of the field party possess the following attributes (where relevant t a level appropriate to the proposed activity and likely field conditions:	t)
	Safety knowledge and training?	
	Awareness of cultural, social and political differences?	
	Physical and psychological fitness and disease immunity, protection and awareness?	
	Personal clothing and safety equipment?	
	Suitability of fieldworkers to proposed tasks?	
	ave all the necessary arrangements been made and information/instruction gained, and the relevant authorities been consulted or informed with regard to:	
	Visa, permits?	
	Legal access to sites and/or persons?	
	Political or military sensitivity of the proposed topic, its method or location?	
	Weather conditions, tide times and ranges?	
	Vaccinations and other health precautions?	
	Civil unrest and terrorism?	
	Arrival times after journeys?	
	Safety equipment and protective clothing?	
	Financial and insurance implications?	
	Crime risk?	
	Health insurance arrangements?	
	Emergency procedures?	
	Transport use?	
	Travel and accommodation arrangements?	

<u>Important information for retaining evidence of completed risk assessments:</u> Once the risk assessment is completed and approval gained the **supervisor** should retain this form and issue a copy of it to the fieldworker participating on the field course/work. In addition the **approver** must keep a copy of this risk assessment in an appropriate Health and Safety file.

## **Appendix IV: Interview questions**

Can you tell me how you have experienced your relationships with others after your bereavement?

Prompt: Relationships with family, friends, colleagues etc?

How has your health been since the loss of your sibling?

How have you found work and everyday tasks after losing your sibling?

Can you describe where you feel you are now in relation to the first period after losing your sibling?

### Appendix V

#### **Support Services**

Camden City Islington & Westminster Bereavement Service 3rd Floor 293 / 299 Kentish Town Road London NW5 2TJ

Service Tel No: 0207 284 0090 Admin line: 0207 424 9558 Email: cciwbs@btconnect.com

CCIWBS is a local bereavement service offering long-term counselling

Cruse Bereavement Care

Daytime helpline: 0844 477 9400 Email: helpline@cruse.org.uk www.crusebereavementcare.org.uk

Cruse is a national service and has local branches across England, Wales, Northern Ireland and the Isle of Man.

The Compassionate Friends Helpline: 0845 123 2304 Email: helpline@tcf.org.uk

www.tcf.org.uk

www.tcfsiblingsupport.org.uk

The Compassionate Friends is a national service and has a specific support group for those who have lost a sibling.

Samaritans

Helpline: 08457 909090 Email: jo@samaritans.org www.samaritans.org

The Samaritans is a national service, offering 24 hour support by telephone, as well as by email, letter and face-to-face at most branches.

#### **Appendix VI**

#### **Participant Information Sheet**

Researcher: Emma Jartell

Institution: New School of Psychotherapy and Counselling/Department of Psychology,

Middlesex University, The Burroughs, London NW4 4BT

#### 1. Study title

How the death of a sibling in adult life changes the experience and concept of time (an existential phenomenological study).

#### 2. Invitation paragraph

You are being invited to take part in a research study. Before you decide to participate, it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully, and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take your time to decide whether or not you wish to take part.

#### 3. What is the purpose of the research?

The research is part of a Doctoral Programme in Existential Counselling Psychology and Psychotherapy. The research aims to examine the experience of the death of a sibling in adult life.

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

You have been asked to participate in the research because you have lost a sibling in the last ten years, when you were between 20 and 55 years of age. You will be asked to take part in one interview, which will be audio taped and last between one hour and one hour and thirty minutes. Should more time be required a second interview could be arranged. The interview(s) will involve qualitative methods and be semi-structured, which means that the aim is to form an understanding of your experience by asking open-ended and non-directive questions. The interview(s) will take place in central London.

#### 5. What are the possible disadvantages and risks of taking part?

The interview(s) may bring back feelings relating to your bereavement or raise new questions for you. It is therefore important that you consider carefully whether you feel able to talk about your experiences before you decide to take part in the research.

#### 6. Consent

You will be given a copy of the information sheet and asked to sign a consent form prior to taking part in the research. Your participation in this research is entirely voluntary. If you decide to take part you may withdraw at any time without giving a reason. All personal information will be made anonymous in the write-up on the thesis. All data collected will be stored, analysed and reported in compliance with the Data Protection Act 1998.

7. Who is organising and funding the research? The research is organised by the researcher. There is no external funding.

## 8. Who has reviewed the study?

An Ethics Committee reviews all proposals for research using human participants before they can proceed. The Middlesex Psychology Department's Ethics Committee have reviewed this proposal.

Thank you for taking the time to read the information sheet.

#### **Appendix VII**

#### **Consent form**

New School of Psychotherapy and Psychology Department, Middlesex University School of Health and Social Sciences

Project title: How the death of a sibling in adult life changes the experience and concept of time (an existential phenomenological study).

I have understood the details of the research as explained to me by the researcher. I confirm that I have read the Information Sheet given to me and that I have consented to act as a participant.

I understand that my participation is entirely voluntary and that the data collected during the research will not be identifiable. I understand I have the right to withdraw from the project at any time without any obligation to explain my reasons for doing so and that any data that has been collected through my participation will then not be used in the research and will be destroyed.

I further understand that the data I provide may be used for analysis and subsequent publication in an anonymous form, and provide my consent that this might occur.

I understand that an audio recording is being made of this interview and will be securely stored until the write-up of the research is finished.

I understand that should I be indicating that I intend to harm myself or another person a third party may be contacted.

how

I wish to receive results of the study when it has be	en completed	Yes □ No □
If yes, please provide an email or a postal address you would like to receive it:	and indicate below one	option of
<ul><li>a brief summary (emailed)</li><li>a brief summary (hard copy in post)</li><li>the entire thesis (emailed)</li></ul>		
Email (if emailed copy of results requested): Postal address (if hard copy of results requested):		
Print name of participant	Participant's signature	
Print name of researcher	Researcher's signature	
Date		

# Appendix VIII: IPA analysis example

# IPA analysis extract from Rosie's interview

Emergent themes	P/R	Verbatim	Descriptive	Linguistic	Conceptual
Friends not providing support Friends unable to find words Not possible to know who will offer support Searching for own words Self not acknowledged by brother Support and culture Less support in urban society? Lack of extended family providing support	P/R P 101	II think my relationship with friends hashas changed slightly too, because I think there are some that Ithey weren't around and they just weren't able to help or they avoided me completely and they didn't know what to say. Ok, with people who truly don't know what to say, but if you've known me for 14 years and you still don't know what to sayI haven't got the space for that. There are other people who have known me for much less time who at least expressed you know, aa concern or an interest,	Some friends could not cope with her loss Some old friends could not find supportive words Newer friends expressed support	Articulate Hesitating Hesitating Repeating 'I' Hesitating Repeating 'has' Stopping mid- sentence Drifting off Searching for words Hesitating Repeating 'a' Hesitating Drifting off	Own person not acknowledged by brother What does lack of verbal recognition depend on? Person, culture, traditions? Urban living providing less support for bereaved?
	R 102	like, that's morerewarding  So, there were some friends that you kept?			
	P 103	Yeah			
	R 104	And some that you didn't keep?			
Cannot give more without receiving Not possible to know who will provide support Providing support depending on person Support and culture	P 105	Not necessarily didn't, but I just didn't have, you know, a friendone friend specifically, twotwo friends, who are very good friends, both had babies, one's born two days before he died and one's born two days after he died. The one that was born two days after he died hasn't ever acknowledged the fact that he diedyou know, we've been over and we've visited their son and we've chatted to him and made a special effort and I still sent a present and a cardnothingnot a thingand I'm just, like, 'How?we've both had life changing events, go on, and	Two different friends' babies born within days of brother dying, one did not acknowledge death Asking how it is possible to ignore death	Stopping mid- sentence Hesitating Repeating 'two' Articulate Pausing Pausing Pausing Pausing question	Is ability to acknowledge grief and provide support personal, cultural, or depending on other things? Giving attention but not receiving any back

	R 106	I've recognised that yours is truly life changing and you've never said a wordhowhow is that possible?'  Yeah, that's quite bizarre.			
Life changing events pleasurable	P 107	I thinkI thinkI think it really is! Especially whensome life changing events can be so pleasurable, you know	Life changing events can be pleasurable	Hesitating Repeating 'I think' Hesitating Hesitating Drifting off	What are her pleasurable life changes?
	R 108	Yeah			
Life changing events difficult Life changing events awful	P 109	And some really difficultand some really awful.	Life changing events can be difficult or awful	Pausing	Which events would she consider difficult and which awful?
	R 110	There was no space			
Support actively withheld Lack of support for dad from step-family Support needs to be altruistic Relationship with step-family superficial	P 111	No, nothing at all, nothing at alland the other step-sister is slightly different and I think she (draws in air)completely underestimated how she would feel about it, so she was away on holiday and she stayed away and she didn't come back for the funeral and she didn't come back for the relebration and they weren't particularly close and none of us grew up in the same house together and now we're all grown ups and we are just kind of thrown together by the fact that our parents live in the same house, you know	Other step- sister did not get involved when brother died Step-siblings not having much in common	Pausing Draws in air Hesitating Articulate Drifting off	Step-family unable to be involved for dad's sake Even if not close to step-brother, it was dad's son who died Nothing in common meaning no support?  Brother and dad counting as nothing to step-family?
Others owning loss Loss does not have a patent Lack of acknowledgement Searching for words	P 139	And I thinkmy stepmy younger step-sister got on very well with my brotherandI thinkwewe met for lunch once after he died and sheshe basically told me how awful it was that she'd lost her best friend andand I kind of sat there, going 'Mm, hm'.	Youngest step-sister expressing losing her best friend when brother died	Hesitating Stopping mid- word Hesitating Hesitating Repeating 'we' Hesitating Repeating 'she' Hesitating Repeating 'and' Quoting herself	Last straw? No recognition of Rosie's loss

	R 140	So, there was no recognition of your loss?			
Lack of recognition of loss Loss cannot be owned Loss cannot be measured Crises showing support offered Crises showing lack of support Loss depending on relationship Loss depending on history Lack of support tipping point in relationship	P 141	Nothing. 'This is my brother, you know, he may be your best friend, or you may think of him as a great friend and you may have been best friends for ten years, he's been my brother for thirty something years, actually'. And to want to measure the loss? Quite frankly, I do (laughing). It's just differentit's a different thing.	No recognition of Rosie's, or anyone else's, loss Measuring loss	Quoting own thoughts Asking question Laughing Hesitating	Brother's death showing who step- mother and step-sister really are? No support being tipping point in relationships?
	R 142	Yeah			
Grief creating loneliness Feeling lonely due to lack of support	P 143	IIfeelvery, very consciously lonely	Feeling lonely	Hesitating Repeating 'I' Hesitating Hesitating Repeating 'very' Drifting off	Lonely for sibling Lonely due to supporting parents as well? Doubling the grief?
	R 144	Mmmm			
Void cannot be filled Loss unique to each person No one understands what was lost Lonely triad in world Death not age related No gradual process of loss	P 145	There's nothing that I can getyou know, there's nothing thatcan get around that for me, there's no new friends or different friends andI am alone. It's me versusmeme and my parents versus the world orandand I think there's a sense of reality when parents, grandpafor a lot of people it's when grand parents die, they realise that their parents are the next level to go and they're the next level to go	No way around loneliness No one can stop loneliness R and parents versus the world No gradual process towards death when parents and grand parents still alive	Hesitating Hesitating Hesitating Repeating 'me' Hesitating Stopping mid- sentence Hesitating Repeating 'and' Drifting off	Nothing can fill the space of loss Not possible for anyone else to understand their loss?

## **Appendix IX** Master table of themes

## The paradoxical emotions connected to loss

#### The tensions of terminal illness

**Georgina:** I think that time rallying around her and being there for her when she was very ill made us closer... 4

**Francesca:** ... we always sort of...amm....sort of hoped that the next thing would sort of cure it but it just relentlessly got worse and worse... 2

**Leon:** ... with a slight hint even that, you know, it [the illness] might be our fault, which was not very nice... 96

**Caroline:** ...he was suffering more than I have even seen anybody... our psyches are not evolved to handle all that... 195

**Rosie:** ... he really was waiting until everyone was there, because he knew that they wanted to be there. 191

#### Being with limited time

**Georgina:** ... I think that time rallying around her and being there for her when she was very ill made us closer. 4

**Francesca:** ... I became much closer to my siblings, really felt they where were...they were my important people. 10

**Leon:** ... it was as good as it could be and we were all perfectly nice to each other. 108

Caroline: ... but then I had to come back here for work and stuff and then he died. 18

**Rosie:** ... as a result of his death...I suppose I've got the approval...the approval from him that I didn't necessarily have... 193

#### Sudden death leaves issues unresolved

#### **Unanswered** questions

Beatrice: ... I want to talk to him about what happened and why he was so mean to me...66

Nick: ... ... I tried to understand that and ... don't at all. 155

Nora: ...'I need at least an apology' or 'I need some reci...' and that he couldn't do that. 89

**Lucy:** ...and it somehow or other entered his system, but we don't know for definitive that that was what had caused it. 4

Sally: ... whatever happened, we're still not completely clear. 2

#### Meaninglessness

**Beatrice:** ...sometimes that person has so much power over you...you allow them or whatever, in a psychological way, that you're unable to have that conversation....68

Nick: ...but I don't think we'll properly understand ever. 163

Nora: ... if they don't recognise what you've suffered, there is only so much you can give. 158

**Lucy:** ...And after 18 months had passed we only actually found out ...cause it was like going back to the start again...109

Sally: ... the other people in the car... walked away from it too. 8

## **Grieving a loved sibling**

The impact on relationships and the future

Georgina: ...when you lose a sibling and you lose half of your parents as well...96

Francesca: ... a sort of slight shaking of a kind of inner security...60

Nick: ... .I would imagine...hanging out with him when we were older...207

Caroline: ... I felt just really floaty and disorientated...344

Lucy: ... there's a big hole that needs to be filled, that will never be filled...118

Sally: ... my brother did more for me dying than he would ever done staying alive...88

Rosie: ... the answer is no, it's not worth my effort...36

#### Death ending abuse and bringing relief

Newfound freedom

Beatrice: ... all these kind of desires and energy...freedom has started coming out. 62

Nick: ... it was kind of a fresh start...177

Nora: ... I first heard about it.....there was an element of relief...89

Leon: ... the whole thing is fraught in the sense of a fractured family....128

## **Living after loss**

## **Connecting with grief**

Beatrice: ...Well, I've written a play...ahmmm...in memory of him, ironically...48

Georgina: .....there's like a bucket in me that I haven't let out for a while...55

Francesca: ...if I really think about what I have lost I feel really upset and that's why I sort of put

it in a box and get it out occasionally. 148

Nick: ... just the incomprehensibility of it...249

Nora: ... my anger protects me from my own longing...243

**Leon:** ... I did go at times, to places, just quietly, remember when we were young...152

Caroline: ... thank god that I had work because otherwise I don't know what I would have done...131

Lucy: ...I can't physically open that box now...173

Sally: ...so, I took more drugs and whatever else...37

Rosie: ... I did go and have counselling to get me to that...to this place...177

## Continuing bonds with sibling

Francesca: ... I found all his walking friends, so people I didn't know at all...86

**Nick:** ... there is a sort of stained glass window in the dining room, which is from drawings he did...177

**Caroline:** ... trying to elevating him and let him be an ancestor, like protector, spirit, an elder...177

**Lucy:** ... ...my brother deserves to be spoken about and...you know, he's still very much part of our lives...74

**Sally:** ... I've lost the physical but I don't have to lose whatever kind of connection I have with him...186

Rosie: ... .l, as a parent, want to figure out ways of making him real to my son...163

## Loss and having children

Georgina: ... it was a terrible mix of, you know, yeah, life...life and death really...18

Francesca: N/A

Caroline: ... ...if I do manage to have a family...227

Lucy: ... if I didn't have my daughters to focus on...ahm...things would have been very, even

more darker...20

Rosie: ...it makes me very sad, that my son will never know who he was. 155

#### (Re-)connecting with sibling's children

Beatrice: ... taking care of the kids, it had to be done...196

Nora: ... they are a pleasure to be with and not all young kids are...195

Leon: ... So that he's got some kind of family context... 116

### Break from everyday life heals

Beatrice: ... almost everything seems to be settling...32

Georgina: ... just having the time to grieve...65

Nick: ... I hadn't thought about it since it happened...211

Nora: ...... remember that I could hardly get up anymore, so struck was I...268

Caroline: ...I can feel it when I go home, it's much more immediate...253

Lucy: ...after about four years the feeling like that...life suddenly became a...a little easier...22

Sally: ...[nature has] given me the space to reflect and understand...106

Rosie: ...I can't always deal with it [mum's grief], I don't always have space for it...123

#### Bereavement affects sense of time

Georgina: ...when I got time off I would then find myself...I'd just cry...18

Francesca: ... I wanted to sort of squeeze a bit more out of it...34

Nora: ..... I was sort of immensely struck by it, in a way that I could hardly get up anymore...254

Caroline: ... I just felt really like, like I was just drifting...151

Lucy: ....the time passing just makes it easier to deal with, never takes it away...142 Sally: ...I would do things that....I would never have done before he died......168

## The complexities of support

## Lack of support is hurtful

**Georgina:** ... I'm no longer in touch with someone I was very close to, which I found very difficult and painful...23

Nora: ... There's still a...deep longing, I guess, it would be different...225

Caroline: ...I could probably have used like a little bit more reaching out...141

**Lucy:** ...I also find that even simple conversations people avoid with me...70

Sally: ...it was one of those, probably most isolating experiences ever...30

Rosie: ...nobody talks about it or they're too embarrassed...214

## The uncertainty of available support

**Georgina:** ...other friends who were good friends, but I wouldn't have considered very close friends, who really were just fantastically supportive...my closest friends didn't maybe step up. 23

**Francesca:** ... the one's who cared more where people who before were strangers to me, but who rushed to see him. 138

Nick: ... all my friends just came over and sat with me and hugged me...56

Nora: ... You just basically have to say goodbye to them all, not expect anything from them...225

Leon: ... watching your mum being so upset, is sometimes more painful... and my dad too... 126

Caroline: ... it's very painful that we're all far away from each other....28

Lucy: ... I would rather that it wasn't avoided...72

Sally: ...it was one of those, probably most isolating experiences ever. 30

**Rosie:** There are other people who have known me for much less time who at least expressed......a concern...101

## Paradox of wanting support but rejecting it

**Georgina:** ...because it did feel so isolating, there was that sense of nobody really understanding certain levels of my sadness. 74

Nora: ...I know that the relationships were not reciprocal at all. 35

**Caroline:** ... it's like I only want to be around people who have suffered as much as me or more than me...48

**Lucy: ....**it has had such a massive, massive impact on our lives that other people don't...ahm...there's no understanding of it...14

Sally: ...everybody was too...too busy in their own grief...28

Rosie: ... we were the only people who really understood what...what we were going through. 6