

**An exploration of young people's experiences of posttraumatic growth and their understanding of what helps in this process following bereavement.**

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## **ABSTRACT**

Bereavement during adolescence is not a minority experience. Despite this, bereavement research has tended to neglect this cohort of individuals (Ribbens McCarthy, 2007). Psychological conceptualisations of trauma and grief have tended to focus on the negative impact of such events, potentially limiting our understanding of post-trauma reactions (Kilmer, 2006). Posttraumatic growth (PTG) is a construct that aims to encapsulate the experience of those who endure horror and trauma and yet still experience positive growth, which is transformative and goes beyond 'coping' (Kilmer, 2006). This is a relatively new construct and research exploring PTG in young people directly is in its infancy. This study sets out to explore young people's experiences following bereavement, in particular whether young people experience any personal or systemic growth and if so, what they feel helps in this process.

This study recruited 7 young people who had experienced bereavement at least one year previously. Participants were interviewed about their experience of growth and change following bereavement. Data was analysed using Interpretative Phenomenological Analysis. Three super-ordinate themes were identified following the analysis of data, these were: *being 'in-relation' with the deceased, the coping process and growth in self*. The findings from this study suggest that young people do experience growth and change following bereavement, both personally and within their surrounding systems. This growth appears to be a result of a coping process in which the young people took an active role. The findings also demonstrate the importance of an ongoing relationship with the deceased that is evolving and continuous rather than static. Clinical implications and recommendations for future research are discussed.

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## **1.0 INTRODUCTION**

Psychological conceptualisations of trauma and grief have tended to focus on the detrimental impact of such events which may be limiting our understanding of post-trauma reactions (Kilmer, 2006). Posttraumatic growth (PTG) is a construct that aims to encapsulate the experience of those who endure horror and trauma and yet still experience positive growth, which is transformative and goes beyond 'coping' (Kilmer, 2006). Adolescence presents some unique challenges and bereavement during this time is not uncommon. Despite this, research focusing on this cohort following bereavement is limited. This study sets out to explore young people's experiences following bereavement, in particular whether young people experience any personal or systemic growth and if so, what they feel helps in this process.

### **1.1 Literature Search**

Literature for this study was gathered using a number of criteria. Table 1 shows the specific literature searches and the process used to find relevant literature for this study. PsychINFO and PsychARTICLES were the databases used for the literature search. The screening measures used and the number of items found and reviewed are shown in the tables (original numbers are shown in brackets). Following the literature searches I then went through each study omitting any from my review if the literature was not translated into English or was not relevant to the research questions.

This study does not attempt to provide a systematic review of the literature but uses the most relevant material for the study. A number of literature reviews were done to gather material for different aspects of the study. These included a search of existing models and theories of adolescent bereavement, qualitative studies exploring bereavement, posttraumatic growth and more specifically posttraumatic growth in adolescence. Additional literature was used that was not gathered in the literature search if it was of particular relevance for the review. This study attempts to utilise existing research to place the current study within a wider context and to identify areas of research requiring further exploration.

Special attention has been paid to qualitative literature to learn more about the individual experiences of young people which is the main focus of this study.

*Table 1: Table of literature searches and outcomes.*

<i>Models and Theory of Adolescent Bereavement</i>		
<b>Search Items</b>	<b>Screened</b>	<b>Final number reviewed</b>
Bereavement OR Grief (15,248)		
AND		
Model OR Theory =	(3665)	
	Age: adolescence (360)	
	Academic Journals (124)	124
<i>Qualitative Adolescent Bereavement Literature</i>		
<b>Search Items</b>	<b>Screened</b>	<b>Final number reviewed</b>
Bereavement OR Grief (15,248)		
	Age: adolescence (1365)	
	Qualitative (110)	
	Academic Journals(89)	
		89
<i>Posttraumatic Growth</i>		
<b>Search Items</b>	<b>Screened</b>	<b>Final number reviewed</b>
Posttraumatic Growth (838)		
	Main heading (257)	
	Excluding dissertations (201)	
		201
<i>Posttraumatic Growth in Adolescence</i>		
<b>Search Items</b>	<b>Screened</b>	<b>Final number reviewed</b>
Posttraumatic Growth (838)		
	Main heading (257)	
	Age: adolescence (23)	
		23

## **1.2 Bereavement**

Grief has long been understood as a natural reaction to losing someone of significance. Conceptualisations of the death experience and cultural practices within the UK have shifted and changed throughout history. World events have altered human consciousness; mass death (through war), modern increases in life expectancy and a move towards secularism (Walter, 1997) have led to an evolving understanding of the meaning of death. Despite the changes in Western history, the affect involved in the grief experience appears to be fairly ubiquitous. Bereavement has been researched extensively throughout history and so this study does not set out to be inclusive of all research but rather draws upon the most up-to-date and relevant literature for this study (see Appendix A for literature search details).

### **1.2.1 Models of bereavement**

Freud was the first to offer a psychological conceptualisation of the grief experience (Freud, 1917). Freud wrote about the process which occurs following a loved one's death. He describes a form of re-living in memory the relationship had with the person who died until the bereft individual is able to 'give up' the lost attachment (Polmear, 2004). Later psychoanalytic theories of grief, presented by Lindemann (1944) argue that morbid grief occurs when the desire to prolong the existence of the deceased through fantasy is not prevented through a process of reality testing. Lindemann (1944) argued that resolution following a death cannot be achieved until brought into conscious awareness and processed. This is in line with a psychoanalytic understanding of the resolution of distress more generally, by bringing the unconscious to conscious awareness.

The idea of finality and resolution is a concept that was adopted by stage theorists of grief. Kubler-Ross (1969) developed her highly popularised five stages of loss model as a response to her work with terminally ill patients. She later adapted this model to include those who were grieving following bereavement (Kubler-Ross, 2005). This early stage model came at a time when the grief experience was still relatively under-researched despite a vast



proportion of Western society having witnessed mass loss and devastation during the World Wars. She argues for five distinct stages of denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1969). Bowlby and Parkes (1970), used their research in attachment and loss to expand on the work of Kubler-Ross (1969) and developed a classification of the phases of grief. These are numbness, yearning and searching, disorganisation and despair, and reorganisation (Bowlby & Parkes, 1970). In line with attachment theory, Bowlby (1980) argued that 'grief work' is necessary in order to reorganise and rearrange constructions of the deceased in relation to oneself.

Although not always linear and clearly differentiated, these stage models have been generalised to those grieving to help make sense of their experience. This was further developed by Worden (1991) who refers to the 'tasks' of mourning as opposed to the 'stages', emphasising personal agency in this process. The bereavement process has also been presented as a cyclical pattern, where the individual may find themselves experiencing various stages numerous times until 'recovery' is reached (Goodall, Drage & Bell, 1994). These models have provided an understanding of grief as a process through which all bereaved must pass to reach some form of resolution and if this is not reached it has been argued to be indicative of pathology (Parkes, 1985; Black, 1996). However, these uniformly structured models fail to encapsulate the complexities of human grief, which occur within a relational context and are highly varied and unique.

Conceptualisations of coping within the 'grief work' model have emphasised the need for the individual to confront their bereavement directly (Stroebe, 1992). Although this 'grief work' hypothesis once dominated the bereavement literature, such direct confrontation with the death of a loved one has in fact been found to be detrimental to the bereaved in some instances, preventing adaptive distraction and denial where needed. Stroebe and Schut (1999) propose a dual process model of coping with bereavement which indicates an oscillation between processing loss and engaging in non-grief work and direct coping. This model highlights the need for grief 'respite' in the post-death experience. This is in contrast to earlier models which emphasise a focus on the loss.

More recent models of bereavement have adopted a contextual, narrative approach and a move towards 'continuing bonds' (Klass, Silverman & Nickman, 1996), rather than resolution or recovery (White, 1989; Klass et al., 1996; Hedtke, 2001). Interestingly, Freud (1929) alluded to this theory many years earlier after the death of his daughter. Rejecting his previous theory of 'letting go' he spoke of the continued attachment he had with his daughter:

Although we know that after such a loss the acute state of mourning will subside, we also know we shall remain inconsolable and will never find a substitute. No matter what may fill the gap, even if it be filled completely, it nevertheless remains something else. And actually this is how it should be. It is the only way of perpetuating that love which we do not want to relinquish (Freud, 1929/1961, p.386).

Silverman and Worden (1993) highlighted the presence of continuing bonds in a qualitative study of bereaved children and young people. They found that the desire and need to retain a relationship with the deceased was far more common than resolution and letting go. White (1988) critiqued the stage models of grief, noting that when seeing bereaved individuals they had often been left with a sense of failure due to their inability to find resolution. What he noticed was that people did not want to sever their relationships with the person they had lost.

Myerhoff (1982, 1986) introduced the idea of 're-membering'. This refers to an active process of recollection and reconnection which leads to the development of the living person's life narratives through an ongoing interaction with the deceased. This is based upon a social constructionist epistemology that one's idea of reality, including memory, is not an individual conception and rather is constructed through conversation and discourse within a particular context (Hedke & Winslade, 2004). This concept was borrowed by White (1988) who found that re-membering conversations aided coping following bereavement and promoted continuing bonds. Hedtke (2001) also uses the concept of continuing bonds with terminally ill patients, helping them build a legacy for others after they

die. Some young people have been found to adopt the role of 'living legacy' as a response to the desire to maintain their relationship with the deceased (Normand, Silverman & Nickman, 1996). Such approaches have been found to offer comfort to those who have experienced the death of a loved one and those who are dying (Fredman, 1997). In their proposal of the continuing bonds theory, Klass et al. (1996) did not intend for the term to necessarily indicate a causal factor in coping with bereavement or imply its use as a therapeutic aid. This should be noted when considering using this approach therapeutically with those who are dying or bereaved. Saldinger, Cain, Porterfield and Lohnes (2004) found that in practice, pre-emptive preparation for after death felt too difficult for some families to engage in.

In a review of the work on continuing bonds, Epstein, Kalus and Berger (2006) found that the continuation of the post-death relationship was common in Western culture and religion and occurred as a result of different forms of ongoing interactions with the deceased. They built upon the work of earlier research which found that people often maintain connections with the deceased by talking with or sensing their presence (Shuchter, 1986). Research has also found that experiencing hallucinations of a deceased relative is common after death (Rees, 1971). Epstein et al. (2006) found that these features of the ongoing relationship were helpful for coping following bereavement. Silverman and Nickman (1996) also found that bereaved children reported sensing the deceased's presence and continuing a dialogue with them as a way of maintaining the relationship. Although historically some of these on-going post-death interactions may have been considered unusual in Western culture, maintaining an active relationship with someone who has died is a common feature of many non-Western cultures (Hedke & Winslade, 2004).

### 1.2.2 Bereavement during adolescence

Many common notions of grief and grieving have been premised on adult experiences. Young people who have been bereaved have often been neglected in research and adult models potentially fail to encapsulate the specific complexities of losing a loved one during childhood or adolescence (Balk & Corr, 2001). In a national survey of childhood bereavement 3.8% of 5-16 year olds had

experienced the death of a parent or sibling (Fauth, Thompson & Penny, 2009). In another survey, 78% of young people aged between 11 and 16 years reported that they had experienced the death of at least one relative or friend (Harrison & Harrington, 2001), indicating the high prevalence of young people who experience loss before the age of sixteen. This statistic increases to 92% when using subjectively significant relationships (which may include pets) (Harrison & Harrington, 2001). Such statistics highlight bereavement in youth as a majority experience. Despite this, death has become the realm of the expert as adults avoid breaking the illusion of childhood as “the kingdom where nobody dies” (Millay, 1934 cited in Webb, 2010, p.3).

Parents and carers attempt to protect young people from the notion of death by colluding with this ‘conspiracy of silence’. It is not surprising that death is a commonly avoided subject. The idea of the inevitability of death is something that as adults we struggle to accept and fully comprehend (Yalom, 1989). It is through our increasing confrontation with it that we come to gain a greater understanding of death and its impact. Even so, adults may continue to attempt to protect themselves from this existential dilemma through a process of distancing and denial about the inevitability of death. Therefore, as a child, our first time experience of death is something that presents a new and uncharted situation, from which we have often been closely guarded. This new experience is made even more complex by various other factors that may impact on our understanding and ability to manage such an event as outlined below.

Grief is a natural and necessary process and most young people will not experience any significant difficulties in response to it (Haine, Ayres, Sandler & Wolchik, 2008). The majority of young people who experience the death of a loved one will manage this process alone and with the support of those around them. However, approximately one in five young people will require additional support from services due to pervasive emotional distress (Dowdney, 2000). Navigating through the process of bereavement is tempered by many factors, including the relationship to the deceased, the manner of death, the complex secondary losses (Stroebe & Schut, 1999) and the very ability to understand the

death concept which is affected by the young person's developmental stage (Carr, 2006).

Nagy (1948) presented a flexible model of children's ability to understand death at different developmental stages. He expressed the importance of developmental age and ability to comprehend the finality of death which is something that is less likely to be present in early childhood. The 'death concept' (Carr, 2006) is a theory that has been based on the original work of Piaget (1932) who argued that the child's ability to comprehend the finality of death does not occur until the 'formal operational period' in adolescence and is mediated by the development of cognitive skills. This is significant when considering the application of child-based models to an adolescent cohort. The stages of cognitive development suggested by Piaget (1932) are highly variable and subject to many differences and exceptions depending on the child (Kenyon, 2001). In line with developmental theory Clark, Pynoos and Goebel (1994) suggested that children and young people are likely to re-experience mourning at different developmental stages. As the young person develops cognitively they are able to conceptualise the deceased's life and their relationship with the deceased in increasingly sophisticated ways (Bowlby 1980; Corr, 2010; Biank & Werner-Lin, 2011).

#### *1.2.2.1 Theories of adolescence*

The period known as adolescence as defined by Fleming and Balker (1996) includes those aged between 11 and 21 years and bereavement may offer unique challenges for this age group. They suggest that bereavement interferes with the progression through the conflicts and developmental milestones they argue to be central during these years. Adolescence has been divided into early, middle and late adolescence with the end point culminating in the separation from parents, development of independence and entering new and intimate relationships (Balk, 2000). Stages of adolescence are not linear or concrete, the end point of adolescence is not a clear age point. Adolescence as a discrete developmental category is arguably socially constructed (Brannen, 2002). Within the current financial climate young adults are remaining within their

parental homes and relying on parental support more so than in the recent past, potentially preventing reaching 'independence' by the age of twenty-one.

Theories of adolescence highlight the existence of this period as unique and distinct from childhood and adulthood. Hall (1904) made a first attempt to conceptualise some of the tasks involved in this developmental stage and spoke of the 'storm and strife' of adolescence. Erikson's (1968) theory of identity development proposed a stage model arguing that young people must navigate through different dilemmas at each stage. What was most central within his theory was the concept of the 'identity crisis' and the searching for a unique identity away from your family. Although stage theories are flawed in their generalisation of human experience and indeed it is incorrect to assume every young person experiences crises (Rutter, 1993), it does seem apparent that this period may present unique challenges.

Garcia Preto (1999) argues adolescence to be a significant time within the family lifecycle, requiring a number of shifts and changes to be made within the family structure. She highlighted young people's move towards independence away from their parents which is a result of a number of physical, social and emotional changes occurring during this time. Wolf (1991) speaks of adolescents requiring "nurturance without the fuss" (cited in Carter & McGoldrick, 1999, p. 279) and the delicate balance required for parents to permit an amount of autonomy whilst remaining present and enforcing boundaries where needed. As young people become more autonomous peer relationships become increasingly important (Balk, 2000). Family systems theories have asserted the importance of the position of the family in relation to a bereavement and the adaptation to a loss which is regulated by many factors including culture, family structure and 'lifecycle stage' (Walsh & McGoldrick, 2004). Bereavement does not happen in isolation and may require the renegotiation of family composition at a time of great anguish (McGoldrick & Walsh, 1999). This has implications for young people bereaved of a parent who may no longer be offered such protection due to direct loss and the impact on the family system. It may be that for bereaved adolescents the process of separating from the family occurs all too quickly or is

delayed as the young person holds on to remaining attachments as much as possible.

#### *1.2.2.2 The challenges of bereavement during adolescence*

Adolescence has been conceptualised as a period of vulnerability and essential powerlessness (Brannen, 2002). The construction of adolescence within society often positions young people as less capable than adults and more 'problematic' which may serve to subjugate this group (Lesko, 2012). Ribbens McCarthy (2007) wrote of the "double jeopardy" (p.286) of bereavement during adolescence as the two highly anxiety provoking states collide. She argued that adolescence and bereavement may share some characteristics such as change and uncertainty that when occurring together produce particular anguish:

Issues of power and vulnerability therefore interweave with young people's experience of bereavement in a great variety of ways, from the assertion and negotiations of cultural and racial differences, through aspects of material circumstances framed by class and locality, to the interpersonal and intra-personal dynamics of family, school and peer groups (Ribbens McCarthy, 2006. p. 291).

Ribbens McCarthy (2006) highlights the complexity of the adolescent experience, the multiple contexts and the potential impact of being in a position of subjugation whilst negotiating the challenges of bereavement.

Blos (1962) identified adolescence as a time where young people reconsider dilemmas that first surfaced in childhood, including questions about death. As a child, lack of inhibition may allow one to ask questions about what happens when someone dies and receive an answer considered age appropriate, such as "they go to Heaven/ they go to sleep". Such explanations offered by parents to young children as a way of offering comfort or a sense of ongoing life may be taken by a child concretely and may be deemed an adequate explanation. As children become adolescents and cognitive processes become more sophisticated, explanations of death received as a child may be deemed too simplistic and call

into question original anxieties about death. However, the ability to engage in abstract thinking about death also corresponds with a more developed understanding of social etiquette and sanctions; the increased knowledge that death is a taboo and should not be asked about (Luxmoore, 2012).

Young people are intricately connected to multiple systems and do not experience death within a vacuum. When experiencing their first bereavement young people will draw on multiple elements in their social and cultural contexts to help make meaning (Ribbens McCarthy, 2009). The post-death reactions of other family members are likely to have a significant impact on the grieving adolescent (Stoebe & Schut, 1999). Following the death of a parent, young people may be concerned about the grieving parent's ability to take care of them, as they oscillate between independence and a desire to be cared for (McGoldrick & Walsh, 1999). Other young people's responses towards a grieving peer are also extremely important at this stage in either aiding coping or not (Dopp & Cain, 2012; Balk, 2002). Experiencing bereavement at this stage of development may also make adolescents more vulnerable to responding to bereavement in potentially dangerous ways, such as engaging in self-injurious behaviour to help express emotional pain (McGoldrick & Walsh, 1999). It is often this behaviour that is identified by larger institutions and considered problematic.

### 1.2.3 Bereavement services for young people

In a review by the Department of Health (DoH, 2011) it was found that bereavement service provision for adults and young people was being provided by voluntary, social and health care services and that there is a current need to work across provision to ensure accessibility and availability. For many young people who experience the death of a loved one, social support is sufficient and they will not seek the support of specialist services (Dowdney, 2000). "Death talk does not necessarily require professional expertise" (Fredman, 1997, p.3) and group ritual and collective processing following death still appears to be highly powerful. Despite the movement towards secularisation, common practice in the UK is to have a funeral even if the family do not identify as religious. We may be able to learn about how to help those who are distressed by firstly understanding the practices that already exist. However, where support is sought from services,



due to the individual nature of the bereavement experience, services should provide individualised care packages where needed (DoH, 2011). Currently six-hundred voluntary services provide support across the UK (Walsh, 2007) and further work is required to build effective care pathways for optimal service provision (DoH, 2011).

For young people, the lack of useful liaison between bereavement services and child and adolescent mental health services (CAMHS) may be problematic. Young people can be identified as requiring more support than can be offered in the voluntary sector but NHS mental health teams often fail to offer support in the first instance. Many CAMHS teams do not accept referrals for bereavement alone but this means that young people are being referred for 'depression', 'anxiety' and 'conduct problems' triggered by a significant death and are being pathologised in the process (Pilgrim & Bentall, 1999). It may be that earlier intervention by mental health teams following bereavement could be preventative for later difficulties. However, by offering bereavement care in a CAMHS setting we are potentially pathologising this experience and due to this dilemma there is arguably a need for tertiary services to be provided at a primary or secondary care level.

Schools play a central role in the young person's life and may offer the opportunity for creating both positive and negative grief experiences. There are currently no national guidelines for managing and supporting bereavement in schools. Equally General Practitioners act as gatekeepers to services and it is important to address their role in supporting bereavement. Saunderson, Risdale and Jewell (1999) found that GPs did not have a unifying way of coping with issues of bereavement and relied upon their personal experiences to guide their actions. This may lead to a discrepancy in how bereavement reactions are currently perceived by professionals and supported.

#### 1.2.4 Bereavement as trauma

Bereavement can be experienced as traumatic regardless of the circumstances in which the death occurred. What is problematic about differentiating 'uncomplicated bereavement' and 'traumatic bereavement' (Cohen, Mannarino,

Greenberg, Padlo & Shipley, 2002) is the overlapping nature of 'symptoms' whether deemed traumatic or not by professionals. Cohen et al. (2002) offered a model of understanding childhood traumatic grief and differentiating it from 'uncomplicated bereavement' by the experience of trauma-related symptoms which prevent the natural grieving process. The experience of grief and trauma may be different and the interplay of the two through the experience of bereavement as traumatic is highly complex. Trauma overwhelms the 'normal' grieving processes and the ability to allow oneself to process the death is impeded by the need for the child to avoid highly distressing memories of the event, whether witnessed or informed of (Harris-Hendriks, Black & Kaplan, 2000). The nature of the death of a loved one (Cerel, Fristad, Weller & Weller, 1999) and the reaction of remaining parents and family members (Dowdney et al., 1999) have been found to influence the process of childhood grief. In a study of children who have experienced war, sixty per cent cited the death of someone close to them as their most distressing memory (Macksoud, 1996). It has been argued that if the death of a loved one is aggressive in nature, sudden, involving a parent or compounded by other deaths, the natural grief reaction may be complicated or prevented (Parkes, 1985; Black, 1996). However, it is possible to argue that 'uncomplicated bereavement' and traumatic bereavement lie on a continuum.

This is significant when considering work with younger people who will be experiencing multiple losses following the death of a parent or sibling. Traumatic grief has typically been associated with the death of a loved one in a 'traumatic' event. The diagnostic criteria for Post Traumatic Stress Disorder (PTSD) found in the DSM-IV-TR states a number of 'symptoms' which need to be present to qualify for classification (American Psychiatric Association, 2000). Criterion A requires the individual to have "experienced, witnessed or been confronted with an event that involved actual or threatened death" and have responded with "intense fear, helplessness or horror". The trauma response must include intrusive memories, images or thoughts, distressing dreams, re-experiencing, distress in relation to trauma-cues or physiological reactions. It also calls for avoidance of stimuli, increased arousal and impact upon functioning. All 'symptoms' required for diagnosis can be present following deaths that are not typically considered to be 'traumatising' and may exist beyond the one month

cross over into 'pathological'. For example, a young person losing their mother through cancer may experience many affective reactions and avoidance responses during their grief reaction which could be considered 'complicated' by some professionals and understandable for others in the context of losing a primary attachment figure to a devastating disease.

Rubin, Malkinson and Witzum (2003) proposed a two track model, presenting bereavement and trauma as interconnected. This model allows for consideration of individual interpretation of an event and the understanding that bereavement may be considered traumatic by the individual even if it is not perceived to be by others. It is too simplistic to try and understand the intensity of grief reactions in young people as solely reliant on the nature of death and trauma. Calhoun and Tedeschi (2006) argued that for an event to be considered 'traumatic' a person's narrative has to be significantly interrupted leading to a sense of life before and after the event occurred. Social disadvantage has also been linked to more complex grief reactions in young people (Ribbens McCarthy & Jessop, 2005) and this is highly significant when considering the role of social inequalities in both leading to increased mortality and subsequent systemic reactions to that. This needs to be considered when evaluating and developing bereavement service provision, particularly in areas of deprivation.

Understandings of post traumatic reactions in children and young people have been modelled upon well established conceptualisations of post traumatic reactions in adults. These models have been built upon an understanding of such reactions as a distinct and discrete diagnosis, 'post-traumatic stress disorder'. Due to the problematic nature of choosing to diagnose individuals with psychiatric labels and the highly individualised reaction to trauma and the nature of traumas, for the purpose of this study, an attempt will be made to move away from a diagnostic conceptualisation, towards a focus on individual experiences and reactions to traumatic events. Cognitive models of PTSD have been readily used to develop an understanding of reactions to trauma in adulthood (Foa, Steketee & Rothbaum, 1989; Ehlers & Clark, 2000; Brewin, Dalgleish and Joseph, 1996). Brewin et al., (1996) argue that everyday memories are processed autobiographically as verbally accessible memories (VAMs), however under

extreme stress memories are processed as situationally accessible memories (SAMs). This type of memory lacks a conceptual and autobiographical framework which means that SAMs are harder to recall voluntarily and more likely to appear as flashbacks (Krans, Näring, Becker & Holmes, 2009). Ehlers and Clark (2000) offered a model of the persistence of post-traumatic stress reactions. They argue that trauma reactions persist due to the appraisal of the trauma memory in a way that leads to a sense of current threat. Such appraisals of current threat and alterations in cognitions then lead to secondary reactions such as avoidance, which prevents processing of traumatic memories. They also highlighted the trauma memory as unique from non-trauma memories having been poorly integrated into autobiographical memory and instead being more sensory in nature. It is through the re-processing of such memories and cognitive reappraisal that post-trauma 'symptoms' are relieved.

Adult models have informed conceptualisations of childhood trauma and have been adapted to include developmental factors which may influence traumatic reactions in young people (Salmon & Bryant, 2002; Meiser-Stedman, 2002). Salmon and Bryant (2002) offered a conceptualisation of post-trauma stress in children and young people paying particular attention to developmental factors which had previously been neglected. Meiser-Stedman (2002) highlighted the lack of research into child and adolescent reactions following trauma and the use of adult assessment tools being used with this population. He presented a cognitive model of PTSD in children and young people arguing for the use of a "dual representation" (p.228) framework based upon the work of Ehlers and Clark (2000) and Brewin et al. (1996). He also highlighted the role of the family in post-trauma reactions and utilised the work of Salmon and Bryant (2002) to stress the importance of developmental factors.

Models of post-trauma reactions in adults and children have been based on research focusing on the negative impact that has been observed in researched populations, mainly those who reach classification for 'PTSD'. This may bias understandings of trauma reactions in favour of those who are struggling (Linley & Joseph, 2004). Ehlers and Clark's (2000) model is specifically focused on those experiencing persisting post-trauma stress reactions. As highlighted in their

paper, most experiencing trauma will not experience any post-trauma stress 'symptoms' or those experienced will be transitory. In an early qualitative study of childhood bereavement Silverman and Worden (1993) found that most young people do adapt to bereavement. The nature of the death was seemingly unrelated to type of reaction and for some young people they will adapt with "greater competency" (Silverman & Worden, 1993, p. 316). It is this other cohort of individuals who have been under researched. It is possible to argue that for this reason we only have limited understanding of post-trauma reactions which may limit our trauma models and conceptualisations. We may be able to learn valuable lessons from those who not only remain resilient through trauma but whom also experience change and growth (Kilmer, 2006).

### **1.3 Posttraumatic Growth**

Posttraumatic growth (PTG) is a construct that aims to encapsulate the experience of those who endure horror and trauma and yet still experience positive growth, which is transformative and goes beyond coping (Kilmer, 2006). It differs from the concept of 'resilience' which refers to a changing developmental process, reflecting strength in the face of adversity (Cryder, Kilmer, Tedeschi & Calhoun, 2006). Research which has examined posttraumatic reactions has generally focussed on those who are not coping, leading to a deficit in our understanding of how all individuals respond to trauma (Linley & Joseph, 2004). This is significant when considering the relatively low number of people who have experienced trauma who go on to experience posttraumatic stress reactions leading to a classification of PTSD (Hefferon & Boniwell, 2011). Calculations of those who develop what would be considered 'pathological' stress reactions following trauma range from 5% (Kangas, Henry & Bryant, 2002) to 35% (Cordova, 2008). Quantitative studies have attempted to calculate how many people may experience PTG, with studies showing figures ranging from 30-80% of individuals (Linley & Joseph, 2004).

Although only identified as a construct recently, this idea is well documented throughout history. The pursuit of positive meaning following hardship is a theme that runs through literature and philosophy (Calhoun & Tedeschi, 2006). It was

Nietzsche who professed that “what does not kill me makes me stronger” (Nietzsche, 1888 cited in Ridley & Norman, 2005, p. 157). Posttraumatic growth aims not to ignore the truly horrific experience of trauma or discount the potentially negative and highly distressing effects. Rather, it aims to expose alternative accounts of post-trauma reactions and capture individual experience that features growth and change out of adversity. It is believed that it is not the trauma itself that leads to PTG but the individual struggle to process the event and individual adaptation following it (Tedeschi & Calhoun, 1995).

### 1.3.1 Theories of posttraumatic growth

Tedeschi and Calhoun (1995) used qualitative methods to identify distinct categories of growth. These were changes in the perception of self, in relationships with others and in general philosophy of life. As a follow up to this study factor analysis was used to gain a clearer understanding of the emergent themes. Five domains of posttraumatic growth were identified; personal strength, new possibilities, relating to others, appreciation of life and spiritual change (Tedeschi & Calhoun, 1996). Research examining PTG has found participants expressing increased compassion (Talbot, 2002), being wiser and more accepting (Calhoun & Tedeschi, 1998), having increased tolerance, empathy, patience (Affleck, Tennen & Rowe, 1991), maturity, increased self-esteem (Schaefer & Moos, 2001), existential awareness (Yalom & Lieberman, 1991) and increased spirituality (Edmonds & Hooker, 1992). Calhoun and Tedeschi's (2006) transformational model argues that rumination following a catastrophic event, both intrusive (unintentional) rumination and deliberate rumination can lead to PTG.

Other theories of PTG include Janoff-Bulman's (1992) shattered assumptions theory and Joseph and Linley's (2005) organismic valuing theory. Shattered assumptions theory (Janoff-Bulman, 1992) understands PTG as the building of new assumptions around the traumatic experience which can, in the process, lead to growth. Similarly it is the positive accommodation of the trauma into our world view that leads to growth as conceptualised in organismic valuing theory (Joseph & Linley, 2005). They argue that following trauma there is an intrinsic motivation towards growth and a move towards emotional processing. The theory

postulates that there are a number of possible outcomes to this cognitive-emotional processing, these are assimilation, negative accommodation, and positive accommodation. It argues that if positive accommodation can occur within a supportive environment then growth following trauma is possible. Similar to cognitive models of PTSD, current models of PTG highlight the importance of processing the trauma and incorporating new experiences and understandings into our belief systems.

PTG has been studied in relation to many types of traumatic experience including; natural disaster (Xu & Liao, 2011; Cook, Aten, Moore, Hook & Davis, 2012), breast cancer (Koutrouli, Anagnostopoulos & Potamianos, 2012), life threatening physical illness (Hefferon, Grealy & Mutrie, 2009), HIV (Sherr et al., 2011), war (Tedeschi & McNally, 2011) and bereavement (Gerrish, Dyck & Marsh, 2009). It is important not to generalise findings from one study examining a particular trauma to another. Each has highly unique and individualised consequences, however the cross-context nature of posttraumatic growth highlights a fundamental feature of post-trauma reactions. The move towards researching growth reflects the broader view needed to understand the impact of trauma. Research has generally focused on the pathological nature of trauma reactions limiting our understanding (Ai & Park, 2005).

### 1.3.2 Posttraumatic growth in adolescence.

This relatively new construct has, in the main, been researched using adult populations and therefore theory has been based on adult literature. This is problematic for considering its application to a child and adolescent population. So far, twenty-seven studies have been published examining PTG in this age group, with 88% being published following 2006 (Meyerson, Grant, Carter & Kilmer, 2011; Taku, Kilmer, Cann, Tedeschi & Calhoun, 2012; Turner-Sack, Menna & Setchell, 2012). This reflects an emerging area of research that has been somewhat neglected. These studies have predominantly used standardised measures of PTG including the *PTG Inventory Revised for Children and Adolescence (PTG-IC-R)* to research this population (Kilmer et al., 2009). Meyerson et al., (2011) summarises pertinent themes emerging from the data so far which include the impact of social support and social inequalities on growth.

As with all constructs attempting to encapsulate some form of human experience, PTG is not a concrete entity that can be applied identically to each individual that has been affected by trauma. Growth and change are unique and are therefore, unsurprisingly, affected by systems and culture. “Individuals do not experience the aftermath of a crisis as socially isolated and disconnected persons” (Calhoun & Tedeschi, 2006, p. 12) and the role of the family and surrounding systems can be key in facilitating PTG. Social support was found to be positively related to PTG, this included from family (Kimhi, Eshel, Zysberg & Hantman, 2009), teachers and peers (Yu et al., 2010). The role of a surviving parent or guardian has been shown to have a significant impact on young people’s experience following bereavement (Worden, 1996; Hurd, 2004; Brewer & Sparkes, 2011). Positive changes within systems have been shown to encourage healing and reduce distress in some young people (Hernandez, Gangsei & Engstrom, 2007). One study highlighted positive changes that can occur in young people’s friendship groups following an individual’s experience of bereavement and how this can help that person in their grief (Brewer & Sparkes, 2011). It is therefore necessary when considering PTG to consider growth and change in the young person’s wider system.

Findings indicate that the role of the young person’s environment following trauma also has a significant impact on post-trauma reactions. This is in line with bereavement literature demonstrating the impact of social inequalities upon reactions (Ribbens McCarthy & Jessop, 2005). Ickovics et al’s. (2006) study of 411 adolescent females in the US, recruited a sample from an inner-city location from predominantly ethnic minority backgrounds and of low socio-economic status. Of those who remained in the study (n=328), 319 reported having experienced a traumatic event at some point in their lives. Of these, the death of a loved one appeared most commonly. It was found that those who had experienced trauma involving confrontation with mortality such as bereavement or chronic illness had the highest levels of posttraumatic growth, which is in line with other research (Park, Cohen & Murch, 1996; Tedeschi & Calhoun, 1996). What is most striking about this study is the prevalence of trauma (and multiple traumas) in young people’s lives. This is pivotal when considering service



provision within the UK due to the high level of relative deprivation and the impact this can have on psychological well-being (Wilkinson & Pickett, 2010). It is also highly likely that cultural scripts and religious beliefs impact upon how people navigate through trauma (Goss & Klass, 2005). Despite increasing research on adult PTG, research on PTG in relation to young people's experiences is still in its infancy, especially studies which involve young people directly.

#### **1.4 Qualitative Research with Young People**

Young people's voices have struggled to be heard within psychological research generally. This population has been somewhat marginalised in literature and therefore poorly represented in psychological theory. There may be a number of reasons for this including researchers' attempts to protect themselves from the associated personal distress of working with young people who are suffering (Dyregov, 1991), heightened ethical constraints (Alderson, 1995) and a misunderstanding of young people as equal to a child or adult cohort. There may also be a fear felt by researchers of doing harm through questioning young people about their difficulties resulting in a shying away from research (Chowns, 2008).

It is clear that young people may be positioned in a way that makes it very difficult for their perspectives to be noticed or heard, neither as a child in need of special 'protection', nor as an adult who can speak up with varying degrees of confidence and power about her or his own needs, and social science research has tended to collude with, and compound, this position. (Ribbens McCarthy, 2007. p. 230).

Qualitative research seems to be particularly lacking in adolescent bereavement research. In an examination of the bereavement literature (see Appendix A) which is abundant, currently only very few studies have been conducted asking young people directly about their experiences of bereavement, not including service evaluation (Silverman & Worden, 1993; Schultz; 2007; Bagnoli, 2003;

Forword & Garlie, 2003; Hurd, 2004; Christ, 2006; Rolls & Payne, 2007; Chowns 2008; Celeste, 2010a; Celeste 2010b, Brewer & Sparkes, 2011). Chowns (2008) used collaborative inquiry within a group context with young people whose parents were receiving palliative care. The findings from her study highlight the valuable role young people can take in research and the impact this can have on the development of effective support packages. Rolls and Payne (2005) stressed the need to study the complexity of experience in the adolescent bereaved population in order to illicit a more thorough understanding of individual experience. Within the posttraumatic growth literature similarly very little research has been conducted asking young people directly about their experiences. There is a significant need to conduct more qualitative research to begin to understand if this phenomenon is meaningful and applicable to a youth population.

## **1.5 Summary**

Bereavement during adolescence is not a minority experience. Despite this, research has tended to neglect this cohort of individuals (Ribbens McCarthy, 2007). Due to the increasing recognition of bereavement as highly individualised, conceptualisations of this experience have shifted from stage models of grief (Kubler-Ross, 1969; Bowlby & Parkes, 1970), to the idea of continuing bonds (Silverman & Worden, 1993; White, 1988). Theoretical models of grief are helpful, however due to the limited research conducted with adolescents further research is needed. Loss of someone at a young age is likely to be highly distressing if not life shattering, requiring the rebuilding of beliefs and contexts (Rubin et al., 2003). Psychological conceptualisations of trauma and grief have tended to focus on the negative impact of such events potentially limiting our understanding of post-trauma reactions (Kilmer, 2006). Posttraumatic growth is a construct that aims to encapsulate the experience of those who endure horror and trauma and yet still experience positive growth, which is transformative and goes beyond 'coping' (Kilmer, 2006). This is a relatively new construct and research exploring PTG in young people directly is in its infancy. There is a need for qualitative research to understand the complexity of the bereavement experience in adolescence. A more thorough understanding of this process may then be used to inform the

practice of clinical psychology and the development of services. Therefore this study sets out to answer the following research questions:

- How do young people experience systemic changes following bereavement?
- How do young people experience change and growth post-bereavement?
- What do young people experience as helpful following bereavement and what do they understand as helping PTG?

## **2.0 METHOD**

### **2.1 Selecting a Methodology**

#### 2.1.1 Epistemology

Epistemology is a branch of philosophy concerned with the acquisition of knowledge (Willig, 2001). All research should be rooted within a particular epistemology and philosophy. I will discuss the differing positions taken in clinical psychology research and the epistemology of the current study.

Realism forms the basis of most positivist research, asserting that there is a reality to be found and investigated and that data directly mirrors this reality. Within the social sciences this stance may be problematic as the researcher works to uncover laws governing human behaviour which are observable, objective and independent of researcher bias or influence. When considering the complex social and cultural context humans exist within, including the researcher, there is debate as to whether a realist stance should be taken in any social or psychological research (Joseph et al., 2009). Critical realism follows a similar ontological stance that certain experiences do exist (Fadé, 2004). However, critical realists take account of the difficulties of uncovering reality due to the ever changing complexity of social and cultural contexts. Therefore, uncovering what is 'real' is never fully possible and at best we may be uncovering our perception of reality. Social constructionism is a post-modern philosophy which argues that all experiences and concepts are constructed through language situated in a particular context. Therefore it is language which creates what we envisage as 'real'.

##### *2.1.1.1 Epistemology in Bereavement Research*

Research investigating bereavement has commonly used quantitative methods and a realist epistemology to develop models of grief. Studies have used deductive processes to develop stage and phase models of grief in a bid to develop theory applicable to the general population. The use of such approaches in bereavement literature may not be highly surprising due to the majority experience of bereavement and the wealth of available participants. What is likely

to be lacking however is a complex and rich understanding of this experience. Existing qualitative research has highlighted the complexity of bereavement and the highly individualised nature of it (Silverman & Worden, 1993; Christ, 2006; Rolls & Payne, 2007).

### 2.1.2 Rationale for use of qualitative methodology

The dominance of randomised-control trials (RCTs) and quantitative outcome studies fails to provide a thorough understanding of individual human experience. It is possible to argue that true experience cannot be directly accessed through observation and conversation alone. The human experience is far more complex than this. As clinical psychologists we pride ourselves on our ability to develop complex and thorough formulations of our clients' individual experiences, however our dominant quantitative research frameworks offer a very limited insight into the complexity of human experience. Developments in our understanding of human behaviour and experience have led to a need for research methods which explore the individual nature of experience and offer more in depth understanding. Qualitative research methods allow such an exploration. Different research epistemologies have diversified how we learn about distress and well-being, with qualitative methods offering a different way of examining experience from a different philosophical position. It is both philosophy and methodology that differentiate quantitative and qualitative research approaches.

### 2.1.3 Choosing a qualitative methodology

As discussed above, the adoption of a realist epistemology in a study of human experience is likely to be inappropriate and problematic. Therefore a qualitative method will be adopted to investigate the research questions being asked in this study. Differing qualitative methods rest on different epistemological assumptions about the world. To choose an appropriate methodology I considered the questions hoping to be answered as well as my personal epistemology. I identify as a critical realist and this therefore heavily influences the type of method believed to be helpful.

### *2.1.3.1. Comparing qualitative approaches.*

For the purpose of this study I will compare what are arguably the most popular types of qualitative research methodologies currently being used in clinical psychology although with an acknowledgement that other methodologies do exist. Grounded Theory was developed by Glaser and Strauss (1967), the main aim of this methodology is to develop theory which is firmly rooted in the data (McLeod, 2001). This method may be particularly helpful for areas where little theory exists in a hope to discover more about a particular area (Burck, 2005). In contrast, Thematic Analysis does not seek to generate new theory but rather aims to find patterns within the data and to provide a rich and in depth description of dominant themes (Braun & Clarke, 2006). Interpretative phenomenological analysis (IPA) is a methodology concerned with the study of human experience and how people make sense of these experiences (Smith, Flowers & Larkin, 2009). It is interested in close examination of individual accounts to interpret and go beyond the data to further understand such experiences. Narrative approaches are concerned with how individuals construct narratives of their lives (Gergen & Gergen, 1988). These approaches are based on the idea that individual reality is constructed through the development of narratives which are situated in and influenced by our contexts. Discourse analysis is another form of qualitative enquiry encompassing a range of methodologies interested in how experience is constructed through language (Georgaca & Avdi, 2012).

After considering possible qualitative methodologies it felt most appropriate to adopt an IPA approach for this study. Consideration was given to whether grounded theory may also be a viable option for this study. Grounded theory may be particularly helpful if you have a considerable amount of data hoping to be synthesised and if you are hoping to develop a higher level account of the data. My decision to use IPA is based upon the research questions I have developed and my aim to explore individual accounts and meaning making. I believe that my desire to explore young people's 'experiences' would be best served using a method where I am able to draw on the phenomenological and interpretative aspects of IPA. IPA's looser methodological protocol is also appealing, allowing the direction of interviews and analysis to be shaped by participants and my ongoing reflexivity. The choice of IPA will be discussed further below.

#### 2.1.4 Interpretative Phenomenological Analysis (IPA)

IPA is a qualitative methodology concerned with the study of human experience and how people make sense of these experiences (Smith et al., 2009). It is grounded in the philosophical underpinnings of phenomenology, hermeneutics and idiography. The philosophical underpinnings lend themselves to the study of major life experiences and the in depth study of small research populations.

##### *2.1.4.1 Phenomenology*

Phenomenology is a branch of philosophy concerned with the study of experience and is a central feature of IPA. Husserl (1927) discussed the notion that our understanding of experience is biased by our pre-existing assumptions and preconceptions of the world. He stressed the need for scientists to reflect upon their personal beliefs with the hope that by doing so one can 'bracket off' these assumptions from their research. Heidegger (1962), expanded on this theory arguing that to bracket off our assumptions is impossible, all we can ever aim for in our study of other people's experiences is an interpretation of people's meaning making. The work of Merleau-Ponty (1962) emphasised the embodied nature of human experience which is unique for each individual, although we may be able to empathise with another we can never truly share in another person's experience.

##### *2.1.4.2 Hermeneutics*

Hermeneutics is the theory of interpretation (Smith et al., 2009). The IPA researcher goes beyond attempting to understand the participants' experiences to construct an interpretative meaning which may offer new insights into meaning and experience. Heidegger (1962) offered insights into the philosophy of hermeneutics arguing that our access to all things is through a process of interpretation. As with his writings on phenomenology, our "fore-conception" (Heidegger, 1962, p.195) is always there, he described a cyclical process occurring where our own conceptions can be altered and revised through our ongoing interpretations. The hermeneutic cycle is central in IPA, it describes the process of the relationship between the whole and the part and the inability to understand one without the context of the other (Smith et al., 2009).

#### *2.1.4.3 Idiography*

Idiography is concerned with the 'particular' (Smith et al., 2009). It is interested in detail and the collection of rich data and in depth analysis. Therefore when using IPA, generalisations are made very cautiously due to the focussed nature of the research and findings are grounded in the sample used.

#### *2.1.4.4 Summary*

In summary, the study of bereavement and the study of PTG both lend themselves to the in depth analysis of individual human experience. When examining these phenomena I will adopt a reflexive approach in line with the philosophy of IPA, this is particularly important when researching an experience which is so complex and individualised.

### **2.2 Reflexivity**

Reflexivity is a key component to conducting IPA. The emphasis on the double hermeneutic requires me to be particularly vigilant and aware of my personal assumptions and beliefs based on my own historical context and my evolving personal experiences. Finley (2003) spoke of the 'hermeneutic turn' arguing that we are unable to keep ourselves out of the research. It is however through taking a reflexive position that we are more likely to be able to identify pre-existing thoughts and assumptions and bracket these off to some extent. As meaning making beings we do not necessarily have automatic access to our own assumptions and therefore a conscious effort needs to be made to reflect on our experiences and develop meaning.

#### **2.2.1 A reflexive note**

My interest in the area of posttraumatic growth developed from both personal and professional experience. As I began to experience more encounters with serious illness and death through friends and family members I was struck by how people were able to navigate through such events. What I also noticed was that following such events, rather than 'just getting through' they were able to notice changes in themselves as a result. A family member of mine experienced a serious illness



and after navigating through this very difficult time I am continuously reminded of the positive growth she has experienced as a result. Professionally, I am repeatedly struck by the strength of the human condition. Having worked in both adult and child physical and mental health services, I have repeatedly witnessed human suffering. This has included those with debilitating health conditions and those that have been forced to confront their own mortality. Of those that I've worked with, despite the challenges they have faced, some have spoken about how their appreciation for life has changed and how their relationships have strengthened as a result of such a trauma. To me, the concept of "what does not kill me makes me stronger" (Nietzsche, 1888 cited in Ridley & Norman, 2005, p. 157) seems part of the human experience and resonates very strongly, although this is clearly not something that everyone experiences. The posttraumatic growth construct effectively encapsulated what I was hoping to explore further (see Appendix A for reflexive journal).

I have offered this reflection to make the reader aware of the 'fore-structures' that may be guiding my research questions. These fore-structures are also likely to have influenced my interview schedule, however I have made every effort to be led by the participant and adapt to what they feel is important to them. This reflexivity will continue to run throughout the research to help in the process of bracketing. Results should be read as a process occurring between myself and the participant, the 'double hermeneutic'.

## **2.3 Conducting Interpretative Phenomenological Analysis**

### **2.3.1 Participants**

In line with the principles of IPA, participants were recruited using purposive sampling. Participants who would be able to provide the greatest insight into the experience being researched were sought. IPA hopes to provide an in depth exploration of individual experience and therefore recruiting the most appropriate participants to the study is vital. This is in contrast to common nomothetic approaches which tend to assert findings at a general group level and may therefore seek a randomly allocated sample (Smith et al., 2009).

### *2.3.1.1 Sample Size*

Sample sizes in IPA may vary depending upon the type of research being conducted and the experience of the researcher. As IPA is interested in in-depth and detailed analysis often a smaller sample is preferable. Smith et al., (2009) have offered a range of between 4 and 10 participants as appropriate for research being conducted as part of a professional doctorate study. Therefore, for the purpose of this study I aimed to recruit between 4 and 10 participants.

### *2.3.1.2 Homogeneity*

Homogeneity is sought in IPA research, with the degree to this varying from study to study depending on the phenomena in question. It is hoped that by recruiting as homogenous a sample as possible, the research questions will be relevant to all taking part. It also allows for cross participant analysis of the data and the examination of both congruence and divergence between data sets. When considering homogeneity for this study, I was interested in the experiences of young people who have been bereaved it felt essential to only recruit those aged between 13 and 18 years old and those who had experienced bereavement.

### *2.3.1.3 Inclusion Criteria*

- The young person must be aged between 13 and 18 years old.
  - I am specifically interested in the experience of bereavement during adolescence. Although the ages of 13 years and 18 years may be arbitrary cut off points, these ages have been used as 18 years is generally seen as the point of transition from child to adult services in clinical psychology settings.
- The young person must have had a bereavement that they deemed significant.
  - The young person must have experienced the death of someone who they consider themselves to have had a significant relationship with. I have not attempted to quantify this but have specified this during the recruitment process. I have not specified a particular type of relationship due to the understanding that it is not the relationship per se but the quality of that relationship that may lead it to be deemed significant.

- The young person must have been referred to the bereavement service used in the recruitment process.
  - The young person must have been referred and taken part in a young person bereavement workshop run by the bereavement service used. This is to increase homogeneity in the sample and also indicates a level of distress following bereavement to warrant referral to external services.
- The young person must be at least one year post-bereavement.
  - I am interested in exploring the phenomena of PTG. Due to this it is essential that a period of time has elapsed to allow growth to happen (if at all).
- The young person must be English speaking.
  - As an English speaker I require participants to also be English speaking. This is to avoid adding difficulty to the application of IPA to the data. To use an interpreter would add another level to the double hermeneutic already in place (Smith & Osbourne, 2003).

#### *2.3.1.4 Exclusion Criteria*

- The young person must not be considered particularly vulnerable by staff working in the bereavement service.
  - I have asked for any young person deemed to still be particularly vulnerable at the time of selection by the staff at the service to be removed from the potential pool of participants. This is felt to be ethically necessary when working with young people (a further exploration of ethical issues is presented later in the chapter).
- The young person must not be engaged in or have had any psychological therapy following the bereavement.
  - Young people are recruited from a bereavement support group which provides unstructured peer support. If participants have engaged in formal psychological therapy it may cause difficulties in interpreting data and any potential natural growth (if it occurs).

### 2.3.2 Recruitment

Seven young people were recruited from a bereavement service in the south of England (details of participants are provided below in Table 2). This service offers support workshops for young people who have been bereaved and who are seeking support to help manage their grief. The service also offers formal psychological therapy for those who have experienced particularly traumatic bereavements or who are having more complex grief reactions. For the purpose of this study young people who had had minimal input from the service, in the form of a workshop, were recruited.

Potential participants were approached by a member of staff at the bereavement service during a peer support group for adolescents. Young people were informed about the aims of the study and what it would require of them. Information sheets were given to interested participants (see Appendix B) as well as information sheets for their parents (see Appendix C). All young people were informed that participation would require consent from their parents unless they were 18 years old. Young people were provided with consent forms (see Appendix D) for themselves and their parents (see Appendix E) and asked to return them to the service in a stamped addressed envelope if they would like to take part.

After young people had returned their consent forms I telephoned the young person or their parent/guardian on the number they had provided. I arranged an appropriate time to meet with them for an hour and gave them the option of meeting in their home or at the service. All participants opted for meeting at their homes. The consultant clinical psychologist at the service was informed of the participants who were taking part (which had been explained in the information sheets, see Appendix B & C). This was to ensure ethical practice, ongoing links with the service should a young person become distressed and safe lone working.

*Table 2: Demographic and essential details of participants.*

Participant	Age	Sex	Ethnicity	Age at time of bereavement	Relationship to the deceased
Kate	17	Female	White-British	13	Uncle and Grandfather.
Nick	16	Male	White-British	11	Father
Jack	18	Male	White-British	12	Father
Laura	16	Female	White-British	11	Father
Jenny	14	Female	White-British	8	Brother
Mike	14	Male	White-British	6	Father
Suzie	14	Female	White-British	6	Father

### 2.3.3 Data Collection

#### 2.3.3.1 *Interviews*

One-to-one semi-structured interviews were conducted with the participants. Interviews lasted between 45 minutes and 1 and a half hours. Although I had an interview schedule (see Appendix F) an effort was made to follow the lead of the participant. Efforts were made to use ‘warm up’ questions to make the participant feel more comfortable and create a more conversational style of interviewing. Further measures were taken to ensure the participant felt comfortable during this time (see section on ethical considerations). Interviews were recorded using a digital voice recorder.

### 2.3.4 Ethical Considerations

#### 2.3.4.1 *Informed Consent*

As described earlier in the chapter young people and their parents were provided with detailed information sheets describing the research, its requirements and ethical considerations (see Appendices B and C). Consent forms were then talked through again with the young person and their parent/carer before the

research interview. At this point young people and parents/carers were offered the opportunity to ask any questions they had.

#### *2.3.4.2 Storage of Data*

Information sheets specified how the information would be stored as well as how and when it will be destroyed. Names of participants have been kept separately from audio recordings and transcripts. Anonymity was assured by assigning a pseudonym to each participant so that their identity remains anonymous, both during the process of the research and the write up. All information has been kept in locked filing cabinets. Only I will know and hold the identity of the participants. Only myself and the external supervisor who is the clinical psychologist in the service will know which young people have participated in the research. The identity of participants will be stored in accordance with the 1998 Data Protection Act, separate to all other material related to this study.

#### *2.3.4.3 Ethical considerations for Interviews*

All young people involved in this research were offered full anonymity and the ability to withdraw at any time. Participants and their carers were given a full explanation about the nature of the research at a developmentally appropriate level to ensure they understood. This was checked by asking participants to repeat back the information they had been told. Due to the nature of the research questions and research aims, which require participants to discuss potentially distressing material (although this is not the focus of the study), a number of measures were taken to provide support. Participants were able to stop the interview at any point. Participants were able to withdraw from the study during the interview process should they have wanted to. Participants were interviewed whilst a care-giver was at home so that they could be invited into the room by the participant if they were feeling distressed. Participants and carers were provided with information about support they could receive from external agencies and within the service. A named professional was able to offer ongoing support to the young person if it was felt necessary by the participant, their carer or myself and would be contacted by me directly to arrange this after the interview.

#### *2.3.4.4 Ethical Approval*

Ethical approval was sought and granted from the London- Harrow NHS Research Ethics Committee (Appendix G) and the University of East London Research Ethics Committee (Appendix H). This research was registered with the University of East London (Appendix I) and permission was granted from the recruiting service (Appendix J).

#### *2.3.5 Analysis*

There is not a universally prescribed method for undertaking IPA. What characterises the analytic method is an iterative and inductive cycle with commonalities in the processes used to interpret and analyse data (Smith, 2007). For the purpose of this study I have chosen to use the framework of analysis presented by Smith et al., (2009) in a flexible manner.

##### *2.3.5.1 Transcription*

Digital recordings of the interviews were transcribed. IPA requires full transcription of the whole content of the interview and exact wording from both the interviewee and interviewer (Smith et al., 2009). Although it may be helpful to record some additional features such as laughter, crying and emphasis this is not expected to be in minute detail as would be expected if using a discursive methodology. What is essential is that this is done consistently. I recorded emphasis (using capital letters) and visible emotion (in brackets).

##### *2.3.5.2 Analytic Steps*

Step 1 and 2: Re-Reading and Initial Noting.

I immersed myself in the data transcribed through a process of reading, re-reading and listening to recordings. At this stage initial noting began after I had familiarised myself with the transcripts. I spent time noting down personal reflections following interviews, as well as observations and initial thoughts about the content of the data. This was done in an attempt to bracket off existing assumptions and retain a reflexive style (Smith et al., 2009). At the same time the process of initial noting began which consists of reading the transcripts and commenting on descriptive comments, type of language used and conceptual ideas. Conceptual noting is the beginning of the interpretative analysis, asking

questions of the meaning, noting down ideas and interpreting meanings. This conceptual stage is a process of constant revision and reflection and requires explicit reflexivity in the process.

### Step 3: Developing Emerging Themes

At this stage I worked with the initial noting to identify emerging themes in the transcript. Initial notes were then summarised into phrases or words which encapsulated their content. These represented the emerging themes. This was done for all of the transcripts until a chronological list of themes was established (an example of the initial noting and emerging themes can be seen in Appendix K). At this stage as with earlier noting and subsequent cross-data analysis, efforts were made to ensure reading on different levels, not just at the descriptive level but the contextual and micro-analytic level, requiring in depth analysis of key areas of dialogue.

### Step 4: Searching for connections across emergent themes.

Abstraction and subsumption were used to identify super-ordinate themes in individual transcripts by either clustering similar themes together under an overriding theme title or by raising an emerging theme to super-ordinate status due to its connection to other themes. This process was aided by using contextualisation, where emerging themes were examined in terms of the participants' narrative and key life events. This was a creative process requiring constant revising. Once themes were organised a map was created (see Appendix L for audit trail of theme construction).

### Step 5 and 6: Moving to the next case and looking for patterns across cases.

Each transcript was analysed individually using the same process as described above. Once all transcripts were analysed I looked for patterns in themes across the entire data. This was done by writing down all themes which emerged across the transcripts separately and then looking for similarities, overlaps and connections across them. I engaged in a process of revision and reorganisation of themes until three super-ordinate themes were established (see Appendix M for a table of themes). During this process attention was paid to analysing the



data on different levels as discussed above and using my reflexive journal to help with the 'bracketing off' process where possible.

### 2.3.6 Quality assurance

In line with the epistemology of IPA, validity and reliability are not sought in the same way as in realist approaches. Rather, 'trustworthiness' is sought via a number of measures (Koch & Harrington, 1998; Yardley, 2000, 2008). I have offered a reflexive note to contextualise the research and highlight any 'fore-structures' that may influence question formation and analysis. This reflexivity has been made as explicit as possible throughout all stages of the research process. Credibility and dependability is sought by using direct quotations and grounding interpretations in data. Testimonial validity has been sought by sending a summary of results to participants and asking for feedback, although no response has been received. I endeavour to uphold qualitative measures of quality and validity throughout and these will be discussed in more detail in the discussion.

### 3.0 RESULTS

This section presents three super-ordinate themes that were identified during the analysis of participants' interviews. These are detailed in Table 3.

*Table 3: Super-ordinate themes and related subordinate themes.*

SUPER-ORDINATE THEMES	SUBORDINATE THEMES
<b>Being 'in-relation' with the deceased.</b>	<ul style="list-style-type: none"> <li>• <i>Re-membering: "it's all in the senses".</i></li> <li>• <i>Staying connected: "They're guiding you through life".</i></li> <li>• <i>Evolving relationship with the deceased.</i></li> </ul>
<b>The Coping Process</b>	<ul style="list-style-type: none"> <li>• <i>"I had all that inside me, I'm only little".</i></li> <li>• <i>The importance of positive relationships: "it takes a weight off your shoulders because you think I'm not the only one".</i></li> <li>• <i>Active Coping</i></li> </ul>
<b>Growth in Self: "Bereavement is a very powerful thing and it can change you big time"</b>	<ul style="list-style-type: none"> <li>• <i>"I know my time is limited so why spend it waiting for something to happen?"</i></li> <li>• <i>"All my mates call me granddad now".</i></li> <li>• <i>"I think you get stronger from it".</i></li> </ul>

The themes discussed are not entirely distinct and are interconnected and related. Each super-ordinate theme will be discussed with direct quotations being used to provide evidence for each theme. This study focuses on elements of growth and change in line with the research questions and for this reason focus is directed towards relevant themes. Acute grief reactions following bereavement were discussed by young people, however these do not relate to the research questions and are already well documented within the existing literature.

Descriptions of acute grief are only used in the analysis where they are relevant to the research questions.

### 3.1 Being 'In-Relation' with the Deceased

#### 3.1.1 Re-membering: "it's all in the senses".

'Re-membering' (Myerhoff, 1982, 1986; White, 1989) refers to the process of purposive recollection of memories of the deceased, which are particularly sensory in nature, to maintain a vivid association with that person. This differs from remembering in that it highlights the nature of the re-telling as something vivid and somewhat dynamic in its process. I have chosen to borrow this term as it seems to effectively encapsulate the experience being discussed by the young people. This concept was highlighted by all the young people interviewed as they retold stories of the deceased and themselves in relation to the deceased. Jack retells a memory he has of his father before he died in which the physicality of his father is clearly depicted:

Question: do you have any happy memories you'd be happy to share?

...I went into the kitchen and you just see my dad, he was a big bloke, about 6'4 I think and quite fat and um, he was standing absolutely starkers over the counter just eating this carrot cake with his fingers, and I just found him, I'm in my boxers, I'm just looking at him, like ok but I didn't say anything, but I went over to the drawer and picked two forks out, went over to him and gave him one and we finished the cake together. (p2: 46)<sup>1</sup>

Jack's retelling of this event which occurred within days of his father's death from cancer creates a sense of raw physicality as the two of them eat a cake, his father naked and him undressed. There's a primal sense of a return to the basics,

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<sup>1</sup> References to quotes are offered in brackets following the quotation. This includes the page number of the transcript and the line number.

to eating, something so interconnected with life, prior to his father's imminent death. The inclusion of details such as his father's height and weight, as well as him being naked presents an example of re-membering as images and details of memories are developed, presenting a somewhat three-dimensional version of a poignant memory.

Nick's retelling of a memory he has of his father prior to his death also presents an example of re-membering, where he uses dialogue as a method of storytelling. The direct dialogue he offers to explain the memory once again creates a 'thicker' description and a sense that this is a recent memory despite it occurring a number of years ago:

Sunday morning and dad would come into my room, shake me and go, "Nick do you want to go to the car boot sale?" and it would be "Whaaat?" before I knew it I would be in the back of the car. Mum would still be asleep by the time we got home. And it would be about 7am and we would be sitting in this field freezing cold and we'd think "Why do we do this?" and by the end of it we'd of bought a load of tat that we don't need and it would have been fun because we got up so early for no apparent reason (p1: 32).

Not only does Nick use direct dialogue to recall this memory but also a shared thought that both he and his father would have, creating a direct connection between the two of them. He includes the fact that his mother would still be in bed by the time they returned and this once again indicates a private memory and experience. Other young people used sensory descriptions and dialogue to retell privileged memories. Jenny re-members her younger brother who died as a baby, recalling her physical interactions with him "I'd always pick him up" (p14: 487) which helps her build a coherent narrative of a life that was very short.

The idea of re-membering is present in each of the young people's narratives of bereavement. The presence of vivid retelling seems to unite the cohort being

studied. Jack helps explain the importance of re-membering and the power of sensory retelling and recall for the continuance of someone's legacy and impact:

It's all the senses, speak to him, hear him, it's weird, my sister's still got a bottle of his aftershave and it's, it sounds weird but like, if you're really really feeling shit and you just miss him like crap you smell it and it just, everything comes rushing back. I wouldn't say it helps, I'd say it's comforting.  
(p12: 444)

The ability to engage in a process of re-membering may require a period of time to have elapsed since the bereavement. The young people interviewed had all had at least four years since the death of their family member. It is possible that such a process requires a period of reflection to have the opportunity to build a coherent narrative of the deceased.

Re-membering seemed to be, in part, a response to fear of forgetting and therefore a need to build and develop full and rich memories. Memories may be enhanced by the inclusion of sensory material, both in tangible reality such as when Suzie eats her father's favourite chocolate bar "...if I see anyone eating that it brings back memories...if I like eat some I try and remember him" (p9: 322) or through memory such as Kate remembering the playful interaction she had with her uncle before he died, "...urgh facial hair get it off me [laughing]" (p2: 61).

Laura explains her fear of forgetting:

My biggest fear is I'm going to forget what my dad looks like or I'm going to forget the sound of his voice or something like that, so it's really hard to think that one day it might happen but then I think I've got, I spent 11 years with him, I shouldn't forget, you know, there's enough memories in there, but [pause] they could just disappear like he did, it's really weird to think you could wake up one day and all your memories could be gone (p15: 546).

Laura highlights the fear of forgetting his voice and his appearance. The need to be able to hold the image and physicality of someone in mind with clarity may be a vehicle driving the need to re-member.

### 3.1.2 Staying connected: “They’re guiding you through life”

This theme is concerned with maintaining a connection with the deceased after death. Clearly this is not unrelated from the previous theme of re-membering and in fact may require an engagement in this for connections to be re-established and maintained. Young people interviewed identified connections they had with the deceased via memories, by likening the self to the deceased in relation to shared personality characteristics and physical traits and through continuing existential connections. Mike speaks of the memory of his father living on within him:

...keeping the thought of them alive inside you. Kind of like, if you’ve watched the ‘Lion King’, it’s kind of like that, the bit where they go down to the pool and they say he lives in you, and well he does because you still have that memory of the person (p3: 105).

Laura shares this sense of connection with her father explaining, “their memories are never going to fade, so they’re always going to be a part of you” (p15: 540). Ongoing connection depends on retention of memories but this seems to be more than just remembering the deceased and is instead about keeping the deceased alive within their thoughts.

Nick speaks of maintaining a somewhat existential relationship with his father from the point of his death, being able to communicate with him and understand ‘signs’ assumed to be from his father:

I always look at it as the day he died, the 23<sup>rd</sup> October 2009, I had a production, I had My Fair Lady, and I was only a background part and I always said to myself the only reason dad died this day was because he wanted a front row seat,

because he missed the production before and that was why he did it, and so I always think that and think he does want me to do this, because if he hadn't he'd have given me a sign to say stop (p5: 189).

This ongoing sense of communication and influence from 'beyond the grave' appears to be an important part of the connecting process. Suzie speaks of a presence of her father that she describes as "...listening or something" (p4: 166) and "...guiding you through life" (p4: 127). She speculates about her father's role in positive changes in her life:

I suppose I changed like that, ever since that I think my dad could have made that happen because I've always wanted to change and stand up for myself, every year, but every time there's a new beginning, even when I was young I was like "it's going to be a new beginning"...I kind of think he might have done that, he might of put it in me to do it and stuff like that and I've got a whole new friendship circle.  
(p11: 399)

Interestingly, Suzie reflects that her ability to embrace this connection with her father is something that has become easier to grasp since becoming an adolescent. When told by her mother that her father was "looking down" (p4: 127) on her she describes herself as a child thinking of "ghosts and things, people haunting you" (p4:121). This ability to imagine or retain an existential connection with the deceased is likely to require abstract thinking, something that is arguably absent or underdeveloped pre-adolescence.

A number of young people spoke about the qualities or character traits inherited from the deceased that they will carry with them during their lives. Jack talks about his black sense of humour that some of his friends find uncomfortable, "...it just really rubbed off on me and I know it's fine because my dad would of pissed himself laughing" (p15: 569). This seems to be something that others struggle to understand but that is acceptable to him because it is something that is shared

with his father. Nick speaks of his father's qualities and interests that he has adopted and that have "shaped" (p24: 991) him:

...his ethic about life, his ethic about work, his ethic about everything, you know his hard work, his music, you know all of his stuff has played in and it's put down into me, you know and I thank him for it because without it I wouldn't be the person I was today (p24: 984).

Mike extends this connection to the deceased further highlighting the irreversible genetic link he has with his father "through your genes...you're made up of them so there's nothing to say that they're still not there" (p4:120). It seems that Mike takes the concept of connection further by explaining that he is physically made up of his father and for that reason, his father is still present. Where the physical presence of the deceased is no longer available a biological connection may become especially significant. It may also provide a young person with a tangible explanatory framework for ongoing connection to another.

### 3.1.3 Evolving relationship with the deceased

Moving one step further than connecting and maintaining connections to the deceased, some young people seemed implicitly to depict an evolving relationship with the deceased that went beyond the relationship they had with them when they were alive. Through the process of storytelling Nick describes an ongoing re-evaluating of his father and their relationship. He describes feeling guilty saying "I hadn't become the person dad wanted me to be" (p5: 180), however during the interview later reflects on his father's actions making meaning and resolving his previous concerns:

...we went across the country, up to Rochester, up to Winchester, all these places just for me and now when I think about it, I think he drove all that way, and even when he was ill he still drove, he had to sit down through most of it but he was there for me and I think now that I, I was the person that I wanted to be and became stronger through it



however people mocked me or anything, I had that person beside me that said “go for it Nick” (p6: 225).

This process of evaluation and shift in relation to the deceased is also echoed by Laura who describes feeling angry towards her father for dying suddenly but seems to forgive him as she reflects:

...you left me when I was eleven, like now that I need you, I'm going into high school and everything and I need you and you've just gone... I didn't want to feel angry because it wasn't his fault, he didn't even know it was going to happen (p2: 70).

Laura seems to acknowledge the contradictory nature of her feelings towards her father, her yearning for him and her subsequent anger towards him because of his death. It is through reflection that she is able to establish the absence of intent on his part. It is possible that this is aided by her own ageing, the time since the death and increased understanding.

Jack's relationship with his father appears to be evolving and changing following his death, both immediately following and later. Jack reflects on his father's funeral:

The funeral actually was really nice, it was quite a big church but people were still standing in the hallway, it was nice to see that people care and I never really, I knew my dad was a nice guy and everything but I never really realised quite how much of an effect he made on people, he was the sort of guy who could walk into a room and change everyone's way of feeling about things so er, um I know it sounds cringey but it, I only really realised that at the funeral when so many people came from so far to come and see him off really (p4: 138).

Jack's father told the family he was homosexual six months prior to the diagnosis of terminal cancer. Jack talks about trying to reconcile his feelings about this news with his father's imminent death. Jack appears to continue to re-evaluate his relationship with his father, criticising the responses of certain family members, including his sister who "didn't speak to my dad even on his death bed, I didn't get why they wanted to do that" (p5: 174). It seems that through reflection upon others' actions that Jack is able to relate differently to his father post-death. The ongoing evaluating of relationships is likely to increase as young people develop cognitively and are able to engage in a process of reflection and reconsidering. Growth in the post-death relationship is likely to be more apparent at times of significant life-cycle transition as the young person is able to view the deceased relative from different positions, such as an adult or parent.

### **3.2 The Coping Process**

This super-ordinate theme comprises of three sub-themes which make up the coping process. Young people speak about coping as not merely a discrete event but an ongoing task which requires certain involvement from the young person themselves and those around them.

#### **3.2.1 "I had all that inside me, I'm only little"**

This theme is concerned with the management of emotion arising from bereavement and the expression of that emotion. Young people interviewed spoke of the need to "get rid of all that feeling" (p10: 378) as described by Jack. Nick describes the extent of his emotions:

I went through such an emotional rollercoaster when it came to 12 years old, that I didn't know what to think and so every single emotion got heightened by ten times (p9: 373).

A number of young people spoke about ways they had found to release their emotions. Jack speaks of the overwhelming combination of emotions experienced following his father's death and the need to release these feelings in some way. Jack describes using rugby as a vehicle for such expression:

...you could completely lose yourself in it, I could take up all the feelings that really, like worked me up, take it out on the pitch and walk off, even if it was only for half an hour, feeling a lot more relaxed and things... it was literally just a way of letting it out (p8: 352).

Physical activity was also used as a method of self-expression by Jenny who talks about using dance as an outlet for her emotions, "I can express my feelings in dance" (p16:573). The concept of needing to release emotions may be influenced by a cultural belief that the ability to express oneself is psychologically 'healthy'. Laura explains that she had written down how she was feeling as a way of releasing her feelings:

I'd write it to anyone, or I'd just write a load of rubbish on a bit of paper and read it through and then rip it up...once you've written it down and it's all out you look at it like wow, I had all that inside of me, I'm only little (p14: 520).

Music was also talked about by a number of young people as a means of emotional expression. Mike speaks of playing the drums after his father died, "I have my drum kit in there [pointing], it's a stress release" (p5:189). Kate, a musician before the death of her uncle and grandfather uses music as a resource for self-expression, she explains that "having that outlet can be helpful. When I'm frustrated I'll play something double the speed" (p16: 619). It is possible that as a young person self-expression through talking is not always possible. The overwhelming and confusing emotional experience that may result from bereavement may present a challenge to young people who live within a context that is dominated by the idea generated by adults that talking is important. Young people may not have access to language which is able to convey or explain their emotional state. The young people interviewed spoke of various alternative methods of self-expression which felt more accessible to them following bereavement.

The need for emotional expression seemed to, in part, be driven by fear of what could happen if emotions weren't released. Jack, Kate and Mike all speak about their use of cutting and self-harm as a way of managing emotions and releasing overwhelming feelings before they'd identified other ways of doing so. Mike explains:

I used to slit my wrists because I was really unhappy but I don't anymore because I thought this is just hurting me and it used to be a way to let the pain go but like, even though you had that pain it was a way of a release... It's like when you get a bruise and your mum goes have another one so you can forget about that one, it's kind of like that in a way...I saw it as a release and that was a window for my escape really (p4: 141).

Jack echoes Mike's need for release and spoke about how rugby became a substitute for self-harm, "a lot better way of me getting rid of all that shit, crap inside of me" (p9: 352). It seemed that all young people interviewed had a view on what constituted adaptive methods of self-expression and maladaptive ways of coping but that it took some time to identify what that best method was for them. It was also felt by some that talking may be useful but varied depending on who it was with and its purpose. Jack feels that "talking helps, it helps you process your thoughts but in terms of getting rid of all that feeling, I know a lot of people do physical things" (p10: 377). This highlights a distinction between processing death and coping with feelings and maybe the need for both to be recognised alongside each other. This may be particularly relevant for an adolescent population who may experience more physical bodily sensations in line with emotional responses. The new and galling nausea, pain and sorrow may be interpreted as bodily experiences for young people and therefore may require a more tangible solution whether that's playing sports or cutting oneself.

### 3.2.2 The importance of positive relationships: "it takes a weight off your shoulders because you think I'm not the only one"

The importance of reactions from existing friends and family as well as the development of new friendships was indicated by all the young people as

significant in the coping process. The young people speak about the forming of particularly special friendships that occurred as a result of their bereavement. It was apparent that post-bereavement, young people felt different from, and sometimes estranged from friends who didn't know how to respond to a distressed peer. Laura explains:

...at the age of 11 you don't really expect your own parents to die let alone one of your friends and to have to be there for them and so they just thought the easier way to not have to help is to be horrible so that she's not our friend (p6: 208).

Nick also experienced peers distancing themselves from him when he returned to school:

...they didn't know, who was to? You know we were all 12 years old, 12, 13, 11 years old and I've seen my father die, you know, most people normally at that time would, might have seen a split up between their parents and that's about it, they had no idea what to say (p16: 644).

As a result of some young people withdrawing from them, friendships that did sustain during this time appear to have grown and strengthened to a greater extent than would have been had the death not occurred. Kate explains that once she had confided in friends about her experiences they provided a vital support at a very distressing time:

Question: so when you're feeling sad now, what helps at those times?

I can ring one of my friends, I know that now they know, they know what to do now. I can say get me out the house, take me somewhere. Even if you're feeling really upset you can say can I come to yours and watch a film. (p14:524).

It is essential not to underestimate the importance of peer relationships during adolescence whether grieving or not. Adolescents may place more emphasis on the role of peer relations than their child or adult counterparts. This is likely to be due to the normative developmental tasks seen at this age including growing independence from family and increasing significance placed on peer group identity.

The importance of peer relationships is also shown by young people's experience of connecting with other bereaved young people as central to their coping. All young people interviewed had attended a peer support workshop offered within a bereavement service and had attended at least one of the monthly adolescent peer support groups offered. Mike explains the importance of the relationships formed in this setting:

...they have the same feelings and when you figure out that they have the same feelings, you're not the only person, that helps, it takes a weight off your shoulders because you think, I'm not the only one (p6:230).

The sense of being the only one and being different appears to be counteracted by the unity found in connecting with bereaved young people. Laura explains that it is not necessarily about talking about the bereavement experience that is important, rather it's merely the knowledge that others may be able to relate to your experience that can be soothing in itself, "it's like the problem goes even if you don't speak about it" (p10:423).

Although it appeared to be peer relationships that were central in the young people's coping stories, family members and other systems also featured as important in aiding this process. Suzie talks about the solace she found in her mother's maintenance of an established bedtime routine when her father died when she was a child, "my mum always tucked me in every night and that helped...I think it just helps having the comfort of her being there" (p14: 507). Kate, Jenny and Laura all speak about the strengthening of their relationships with their mothers as a result of the bereavements suffered. Jenny explains, "my

mum and me have got a lot closer” (p9: 303) and speaks about the bond they now share which she describes as “a twin thing” (p12: 417). It may be that the joint experience of extreme sorrow following the death of her baby brother allowed for a change in the parent-child relationship which resembled more of an equal sibling relationship. This could have arisen as a result of Jenny’s wish to maintain a sibling bond and her mother’s need for support for herself. Similarly, Laura shares the change in her and her mother’s relationship since her father died, presenting the relationship as more equal in nature as opposed to a traditional mother and child relationship:

My mum tells me everything no matter what it is, whether it’s good or bad, shocking, anything my mum tells me, same as me with her, we don’t keep anything from each other, that’s the way I like it, I wouldn’t have it any other way now (p8: 292).

These findings appear to relate to mother-child relationships which may be a result of the population studied, most of whom had experienced the death of a father. Such systemic changes in the family composition are likely to be influenced by developing maturity and caring responsibilities discussed later in the chapter.

Finally, school was also seen as a source of systemic support by some young people interviewed. Jenny speaks about a group at school which she attended following her brother’s death that she found helpful and supportive, “it had two teachers and a few other children and it’s like a confidence group” (p6: 206). It seems that school flexibility and sensitivity to the child is key in providing a positive post-death school experience. This extends to the actions of individual teachers as Nick describes a relationship he formed with one teacher who had had breast cancer and who offered support at school during Nick’s father’s illness and death, “I was able to confer with her, and it was really nice to have that sort of rock behind me inside school” (p2: 69). Jack however found the actions of his teacher less helpful as she made the decision to tell his class that his father had died without consulting him. He explains that his “form tutor told my class which

of course then it went around the whole school quicker than hell fire” (p8: 295). It is clear that positive systemic reactions can help the grieving process as well as establish and strengthen relationships.

### 3.2.3 Active Coping

Active coping refers to the ongoing effort of the young person to engage in behaviours and processes which purposively aid coping. Young people interviewed indicated a number of conscious processes they used to help them following bereavement. Turning negatives into positives, making meaning and establishing hope were all spoken about. Nick speaks about the effort he makes to move away from negative thoughts and emotions:

...look further than what the obvious problem is, oh I'm sad, you don't think that, you think actually I'm sad but what can I do to make myself happy again, what can I DO to do this, what can I DO to do that, and you do think forward and you think happy thoughts instead (p24: 1000).

Kate also speaks about finding “the littlest glimmer of hope” (p18: 699) and building on that. She indicates that this requires self-agency and is not something that is just going to happen. She explains that this requires you “not to dwell on the past” (p11: 423) which is likely to result in a negative outcome. Suzie chooses to focus on “education and trying to make my life better” (p12: 433) through the practical means of working hard and pursuing her hopes and dreams.

Mike eloquently explains how he learnt to take an active position in the management of his grief:

...it's like when you learn to ride a bike as well, when you take the stabilisers off you don't have that support so you have to learn fast or you just fall over and you have to learn how to deal with that and continue with your life otherwise you just go into this deep repression (p7: 247).



The image presented by Mike indicates a sense of immediacy in one's actions that is required following bereavement. The metaphor of learning to ride a bike reflects the uncharted world of loss that as yet has not been glimpsed and relates it closely with an event that is more easily accessible and more in line with childhood events. Active coping is likely to be propelled by the fear, as highlighted by Mike, about what may happen if you don't 'learn fast' how to cope. Other young people speak of the alternative to coping being "moping around for the rest of my days" (Nick, p7: 289) or feeling "depressed and horrible" (Kate, p1: 22).

As well as a cognitive engagement with managing thoughts and feelings, young people also spoke about hobbies and interests they used as methods of active or independent coping. All young people interviewed spoke about something that helped them which was distinct from school or family. Laura speaks about using music to help coping, explaining that "it takes you away a little bit" (p10: 363). Following the death of his father when he was a child, Mike became very involved in Beavers and Scouts clubs. On reflection he wondered whether it "was my body's way of saying, keep yourself busy so you don't remember" (p3: 80). Nick explains that he found attending drama classes helpful. It is possible that taking an active interest in an area separate from the family or school allows for much needed escape from the reality of life following bereavement. Using outlets such as drama or dance may allow a movement into a more creative or childlike position where life is 'safer'. Often following bereavement, maturity and 'adultness' are required and a place which allows a former self to be remembered or reunited with may be a great coping aid, a respite from grief.

### **3.3 Growth in Self: "Bereavement is a Very Powerful Thing and it Can Change you Big Time"**

#### **3.3.1 "I know my time is limited so why spend it waiting for something to happen?"**

Young people interviewed spoke about a change in their perspective on life as a result of their bereavement. This theme is concerned with new perspectives on

life and the effects of these changes in thinking. Kate acknowledges a change in her thinking after her bereavement:

...before anything, people say life's too short bla bla, and after you think, yeah it is, my dad's 50, my uncle was 45, you do see things differently (p9: 303).

Kate implies that it is not until you have someone close to you die that you actually take heed of clichés such as 'life's too short'. Similarly, Laura speaks of realising the fragility of life that may not have been in her consciousness prior to the death:

Question: is there anything else you think you've learnt as a result of what you've gone through?

I've learnt that life isn't promised to everyone and that although you shouldn't live everyday of your life like it's your last, just live, you know, tomorrow isn't promised (p16:603).

Developmentally, adolescence is often seen as a time for living in the present, of orientating one's existence to the immediate. Existential issues such as mortality may not be present or significant in the minds of young people on a daily basis; the first experience of bereavement is likely to throw one's previous assumptions about the world and existence into question. It may be that life perspective is particularly changeable in young people as it is indeed the first time that such experiences have occurred. Jack's perspective has also been altered after losing his father, "life's too short, I try not to get too hung up" (p.13: 495) and he feels that he distances himself from the everyday "dramas" (p13: 493) of adolescent life.

The changed perspectives on life as mentioned by the young people interviewed appear to have consequences for their lives. Kate explains that following her uncle's death and the imminent death of her grandfather, which she knew would happen that day, she decided to take her piano exam which had been scheduled.

She felt she was able to calm her nerves by having a different perspective on the exam, “this is a music exam, it’s not going to kill me, what’s the worse that is going to happen?” (p8: 283). Although this remark may seem flippant, in the context of the news of her grandfather’s death, the idea of ‘what’s the worst that can happen’, takes on a different meaning. For young people, the school structure and the emphasis placed on success and achievement may be challenged by bereavements in the family, where something suddenly becomes so all-consuming that the significance of activities of everyday life are questioned. Rather than this being a hindrance however, it empowers Kate to do the exam and to pass it, when prior to the knowledge of her grandfather’s dying she had been predicted not to pass.

As a result of Laura’s changed perspective on life, she feels it is vital to “be yourself and be happy” (p16: 606) and Jack explains that as a result he is “trying not to take life too seriously” (p13: 477). Mike explains that he chooses not to dwell on difficult events as “you’re losing precious time with others that you can be with” (p9:343). Such changes in perspective indicate the life altering impact of bereavement on young people that is often seen as detrimental but is in fact viewed by some young people as life changing in the form of growth and development.

### 3.3.2 “All my mates call me granddad now”

One of the main areas of growth young people talked about was an increased sense of maturity as a result of growing up quickly. This seemed to be, in part, a result of altering life perspectives. This may be due to the bereavement experience but also as a result of direct caring responsibilities that young people took on for dying parents or grieving parents. Nick talks about growing up as a result of his father’s illness and death:

...you can’t be immature, you can’t think about childish things or have childish tantrums because you’ve got someone in your household that is going through the end of their life (p4: 130).

Nick states that there is no room for being a child when confronted with someone's end of life. It also seems that Nick, despite being eleven years old, was able to make this transition and acknowledge the changes that needed to occur as a result of his father's circumstances. He seems to be making this assessment of the situation independently which implies a wisdom and maturity beyond what one might expect from a young person at this stage of their life. Mike also explains that "you have to grow up fast, you can't behave like a child your age would" (p7: 245). This comparison with other children at the time of his father's illness and death indicates the space for childlike behaviour being eclipsed by the impending death of a family member. Alternatively, it may indicate a change in perspective, a shift in what the child sees as important. Jack also speaks about the impact of his father's death on his childhood:

...because my dad was ill for so long I kind of grew up a lot, I didn't really consider myself to be that young, I mean I still, all my mates call me granddad now... I personally wouldn't consider myself to have had much of a childhood (p3: 114).

Interestingly, these young people all experienced their father's decline in health through cancer prior to death and this may offer a unique experience, different from a young person who experienced a sudden death of a family member.

Nick speaks of the caring responsibilities he adopted whilst his father was unwell:

I was making Movicol for him, constipation liquids, I was doing tablets for him, oh it was getting a routine for me but obviously dad, who was finding it really bad at the time, and he made that obvious, but I was coming down and saying "how are you doing today dad?" you know, and I ...wanted to be there for him all the time (p3: 118).

Other young people interviewed did not speak about caring responsibilities in relation to nursing dying loved ones. Those whose family members did die of terminal illness may not have adopted the role of carer like Nick did for a number of reasons: Suzie and Mike were only 6 years old at the time of their father's

death and therefore likely to be too young to have taken on caring responsibilities; Jack, whose father died of cancer, had left the family home two years prior to his death and was therefore not being cared for within the home. I have included Nick's account however as I feel it may offer a useful insight into the experience of a young person in early adolescence who has a loved one being cared for at home. Nick's age did not seem to act as a barrier for taking on such responsibility which is significant when considering an adolescent population.

Interestingly, caring responsibilities did seem to be adopted by more young people in relation to their grieving parent. Laura explains that since her father's death, "I do everything for my mum, even now if she's ever upset I'm always there, I took ages off school to look after her" (p3: 78). Laura took on responsibility for her mother, ensuring she was not on her own and worrying about her when she was not with her, to the extent that Laura did not want to be at school. Laura was eleven years old at the time of her father's death and it seems, like Nick, was at an age where she considered herself, or was considered by others, to have the resources to take on this role. Jenny also took on a caring role for her mother following the death of her baby brother, although this seemed to be a mutual caring relationship between her and her mother, "I can comfort her, she can comfort me" (p12: 418). As a young person experiencing a death for the first time, it is likely that witnessing the reactions of a grieving parent is going to be highly distressing, although this does not mean that hiding grief reactions would be a better approach. However, it is possible that a young adolescent may feel that they need to provide the emotional support for their parent; there may be a fear of what the parent's distress could result in, and adolescent fears could involve abandonment, neglect or even death of the remaining parent.

Although caring responsibilities and 'growing up fast' may be fuelled by fears about parental wellbeing, young people interviewed framed such roles within a positive light, explaining that such positions have led them to have increased maturity and a desire to help others. Suzie explains, "I think how my personality's changed, I think maybe if he was still there I would be more selfish and less

understanding of other people” (p7: 254). Laura talks about being different from other young people her age, she explains that:

I'd rather be in on a Friday night with my mum, my cousin, my boyfriend than go out and get drunk with a bunch of friends who are just going to end up in trouble (p9: 323).

Although this distancing from peers could be argued to be isolating, Laura appears to have developed a mature and independent sense of self and during the interview did not seem to see her separation from her peers as a negative thing. Nick explains that “I can't be this thirteen year old anymore, I've got to act mature” (p12: 505). The young people interviewed did not view their maturity in a negative way but rather appeared to have channelled this quality into future hopes and dreams.

Helping other people seemed to be a driving force in many of the young people's lives. This particularly extended to other young people who are experiencing bereavement. Kate explains that:

Question: What made you interested in joining the research?

I think once you've actually been through something significant and you think someone else might be struggling with the same thing, they might be able to benefit if I can use, you know, and say oh this helped me and this wasn't so helpful (p1: 10).

Young people said that this desire to help others also extends to friends who may be having difficulties not related to bereavement. Mike explains that his drive to help other people is because “I don't want them to have the same feelings that I would have had when I was younger” (p9: 335). It seems that the emotional pain he suffered pushes him to make sure other people don't experience what he did. This is similar to Jack who has started volunteering at the bereavement service

he attended. He explains that “even if I tried to help one kid stopping doing that it would be cool [referring to self-harm]” (p8: 283). It seems that the pain and emotional response to bereavement is something that young people do not want others to feel.

All the young people spoke of their hopes for the future. Interestingly the majority of young people interviewed hoped to work in caring professions, which they attributed to their bereavement experiences. Kate would like to combine her passion for music with her experience of emotional distress and pursue “music therapy” (p10: 402) at university. Laura explains that she would like to be a “bereavement counsellor or a care worker, something where I can help other people” (p9: 311). It seems that for Laura to be doing something where she can use her caring skills is the priority rather than what that job is specifically. Jenny would like to use the skills she learnt from having a baby brother before he died in her future career and hopes to study “child care” (p8: 287) at college. This both utilises her skills as a carer but also enables her to maintain a connection with her brother. Mike would like to join the police or army and explains his decision for this as “helping other people” (p11: 423). The desire by bereaved young people to pursue helping professions may indicate a drive to maintain a link to the deceased and make meaning out of a life ending prematurely.

### 3.3.3 “I think you get stronger from it”

This theme is concerned with one element of the overriding super-ordinate theme of Growth in Self. The young people speak of increased strength, confidence and self-sufficiency as a result of bereavement. Nick explains that he is “definitely DEFINITELY more driven” (p8: 336). This drive to succeed and do well seems to be a result of a desire to make meaning of his father’s life and death:

Dad didn’t die just because of cancer, I’ve, me and mum have both become stronger people, I’ve become someone who’s looked upon, up to, by various different people for different various reasons (p19: 784).

Nick speaks of an inner strength which has been born out of his grief. This strength is something that was spoken about by other young people as a quality that has grown in them as a result of a death. Jenny speaks about being identified by her grandfather as “a little strong girl” (p5: 145) after her brother’s death and later identifies herself as “stronger and I’m stronger round babies as well” (p8: 289). This sense of being more robust with infants has inspired her future hopes of pursuing a career in child care. Mike also feels “stronger” as a result of his experiences, “it’s a lot to deal with but I believe it moulds you as a person... and I think you get stronger from it” (p1: 8). Laura explains the extent of the changes that have occurred for her following the death of her father:

Question: and since it happened have you noticed any changes in yourself?

I’m a VERY different person. I look at things in a VERY different way, I wouldn’t be the person I am today if he hadn’t passed away, I’d have him back in a heartbeat but I wouldn’t change the person it’s made me become (p4: 143).

It is clear from Laura’s account that change has been dramatic for her following bereavement but that such changes have made her the person she is and that she values this.

Other young people identified increased self-confidence as an example of personal growth following bereavement. Self-confidence in one’s ability to cope in life was something that was mentioned by a number of young people and relates to the theme of Active Coping. Laura speaks about her increased belief in her ability to manage and cope, “I’ve gained a lot more self-confidence, a lot more self-esteem” (p5: 155). Mike offers a metaphor which effectively portrays his increased confidence in his ability to manage in life and going forward:

It’s like when you first learn to swim, you just jump in and go for it, you don’t at all know what’s ahead of you, you don’t know what’s going to happen but if you keep, if you keep



positive and you have the support of those around you who love you and care for you, you can eventually learn how to swim, which is kind of like learning how to deal with it (p4: 153).

This metaphor offers a glimpse into the world of adolescent bereavement, the uncharted realm of grief and the working out of how to cope as you go along with the support of those around you. This seems to then instil a sense of confidence and self-assurance in how to cope in the world more generally. Learning how to swim may have been something he shared with his father prior to his death and it positions Mike's experiences well within the realm of youth and childhood. He compares two experiences that on first glance seem so distinct but yet may in fact represent what childhood and youth amount to, a series of new and uncharted experiences where one frightening possibility is that you sink. Fortunately for the young people interviewed not only did they keep their heads above the water but they swam.

### **3.4 Interconnection of themes**

Arguably the results could be conceptualised as interconnected and indicative of a bi-directional process occurring. It seems that young people speak of an active coping process that they engaged in and it is likely that this influences the opportunity for growth. As spoken about by Kate without actively managing grief she may have been left feeling "depressed and horrible" (p1: 22). It is also possible that the continued relationship with the deceased may be instrumental for personal growth to be possible. Young people spoke of the deceased guiding them and supporting them. Had this ongoing connection not be maintained it is possible that young people would not have had the driving force behind them enabling growth. In turn, personal growth may enable and make possible active coping as young people feel "stronger" (Mike, p1: 8) and more determined. Therefore themes could be seen as separate elements of a wider post-death growth experience, with each element offering further opportunity for personal growth and coping.

## **4.0 DISCUSSION**

Following analysis of the data three super-ordinate themes were identified, these were: *being 'in-relation' with the deceased, the coping process* and *growth in self*. I will suggest how the findings address the research questions and themes will be discussed in relation to the existing literature to help locate them in a wider context. Individual themes will be discussed in more depth as research questions are answered. Suggestions for further research will be made and clinical implications of the findings will be discussed. Methodological robustness will also be considered and I will offer some personal reflections on the research process. As noted in the results section, themes do interlink and are connected, therefore there may be some overlap of discussion points.

### **4.1 Summary of Findings**

The findings from this study suggest that some young people do experience growth and change following bereavement both personally and within their surrounding systems. The findings from this study suggest that young people may experience growth and change following bereavement both personally and within their surrounding systems. This growth appears to be a result of a coping process in which the young people took an active role. It seemed that young people felt driven to take a pro-active role in coping as a result of fear of what could happen if they did not cope. The findings also demonstrate the importance of an ongoing relationship with the deceased that is evolving and continuous rather than static. This engagement in a relationship with the deceased could also be seen to aid the journey towards self-growth and coping. The themes illuminate how young people experience growth and change and offer insight into what they believe helps this process.

## 4.2 Addressing the Research Questions

### 4.2.1 How do young people experience systemic changes following bereavement?

Young people discussed systemic changes following bereavement in a number of different ways. They spoke extensively about the relationship with the deceased which I will discuss in relation to the experience of systemic change following bereavement. Young people also spoke about changes in their familial and peer relationships which acted as an aid to coping. I have chosen to address this subtheme here as it is an example of systemic change although it could equally be discussed as part of the research question examining what young people believe helps growth.

#### 4.2.1.1 *Being 'in-relation' with the deceased.*

This super-ordinate theme offers an interesting insight into systemic changes within the post-death relationship. It requires us to think beyond what we might traditionally imagine to equate to systemic change, to the consideration of a relationship with someone who has died.

- *Re-membering: "it's all in the senses".*

As defined in the previous chapter 're-membering' is a term first adopted by anthropologist Myerhoff (1982, 1986) to suggest a unique type of recollection. This was then adopted by White (1988) who introduced the idea to narrative therapy encapsulating a process of on-going active recollection of the deceased that goes beyond remembering. White (1988) uses the act of re-membering in conversations he has with the bereaved to encourage them to reconnect with the deceased for therapeutic purposes:

“Re-membering conversations are not passive recollection but about purposive reengagements with the history of one's relationships with significant figures and with the identities of one's present life and projected future” (White, 2007, p. 129).

Young people in the study drew on sensory experience to bring to life the memories of their loved ones. It seemed that by building thick descriptions of the deceased they were better able to hold onto the pre-death relationship. The idea of ‘thickening’ stories is borrowed from narrative therapy and the work of White and Epston (1990). It describes a way of enriching new stories through the process of adding detail to and allowing the witnessing of them. It seemed that the young people interviewed entered into this thickening process independently, enabling themselves to build coherent narratives of the relationship with the deceased which they could continue in their future lives.

The process of re-remembering appears to require on-going thought and reflection on the deceased and their death. Such ongoing recollection has been positioned by some as potentially pathological if deemed to be too all consuming or continuing too long (Lindemann, 1944; Polmear, 2004). Yet by others remembering and even rumination has been seen as necessary for growth (Calhoun & Tedeschi 2006). Young people seemed to be actively engaging in a process of recalling sensory information, purposively seeking this and incorporating it into memory. The need for engagement with sensory reminders of the deceased may highlight the importance of maintaining something tangible for young people as they manage the idea of the finality of death.

The findings of this study build upon stage theories and earlier psychoanalytic approaches which view grieving as a process resulting in recovery and an ending of the relationship with the deceased (Freud 1917; Kubler-Ross, 1969; Bowlby & Parkes, 1970). It was very clear that the young people in this study viewed the deceased as very much part of their on-going lives which is in line with the findings of Silverman and Worden (1993) and the literature on continuing bonds (Klass et al., 1996; White, 1988).

- *Staying connected: “They’re guiding you through life”*

This subordinate theme is connected to re-remembering and may in part, require young people to engage in re-remembering to help retain a connection with the

deceased. Young people spoke of maintaining a connection with the deceased through memories, physically through genetics and existentially through on-going interaction. The desire to maintain a connection with the deceased was highlighted by Bowlby (1980) in his work with bereaved children. Young people spoke of a form of existential communication with the deceased, speaking to them, feeling they were contributing to the events that happened in their lives and noticing signs from 'beyond the grave'. Epstein et al. (2006) suggest that on-going communication with the deceased, as well as sensing their presence, offers a form of continuing bond that rather than being pathological, can aid the bereavement process. In large studies of the population, people have also reported seeing the deceased in the early stages of grief following the death (Rees, 1971), further highlighting the complexity of the post-death relationship. Historically, continued communication with a deceased relative may have been seen as a form of 'complicated' reaction that could potentially impede the grieving process (Parkes, 1985; Black, 1996). What is apparent is that rather than continued communication always being seen as a sign of pathology, such connections may be useful in abating difficult emotional responses and aiding the grieving process.

Upon reaching adolescence young people may become increasingly aware of the death taboo (Fredman, 1997; Luxmoore, 2012) and this may prevent them from sharing their experience of continuing communication with the deceased, with adults or peers. Young people interviewed did speak of noticing signs from deceased parents but did not suggest having seen them or heard them following death. It is possible that these young people do have unusual experiences but are prevented from talking about them due to fear of being perceived as 'abnormal'. This may, in part, be due to the medicalisation of distress in Western society (Pilgrim & Bentall, 1999). This has the potential impact of leading to increased fear or concern for the young person. Equally, surviving adults may also hide their on-going connection with the deceased in a bid to protect children and this may mean young people do not have a model of how to think about and express such experiences.

Young people who had lost a parent expanded upon the idea of an existential connection to the deceased speaking of a form of on-going parenting as the deceased was 'watching over' them. This is interesting when considering the impact of parental bereavement and the possibility of dying parents being able to continue to parent after death. This will be discussed further below when considering the evolving relationship with the deceased but is clearly linked to the idea of staying connected. Interestingly, one young person felt that as a child she was unable to comfortably connect with the idea of her parent's continuing presence, taking her mother's words that her father was "looking down" concretely. Bowlby (1980) argues that children's abilities to adapt to bereavement in the long term is made more difficult by being given imprecise information or abstract explanations. This is significant when considering the developmental stages highlighted by the work of Piaget (1932) and Carr (2006) and how to implement models related to continuing bonds with children. As a child grows they are able to view death in a different way to how they originally experienced it (Corr, 2010).

Young people also spoke about remaining connected through their biological links to the deceased. Physical connection may offer young people a more tangible explanatory framework for the ongoing relationship with the deceased. Young people also felt that they were able to maintain a connection by the continuation of the deceased's personality traits and characteristics. This is congruent with research highlighting the role of remembering and storytelling for people in building legacies for those who have died. This may lead to young people becoming 'living legacies' as a way of giving meaning to and creating a sense of ongoing life (Normand et al., 1996). This concept is inextricably linked to the idea of the evolving relationship discussed below.

- *Evolving relationship with the deceased.*

This subtheme is concerned with young people's accounts of their continuing relationships with the deceased. Although this is connected with the themes previously discussed, the changing relationship seems to go beyond these. Clearly these themes are related and it may be best to consider *re-remembering*

and *staying connected* as methods which enable an evolving relationship with the deceased. This theme is closely related to the work of death theorists (White, 1988; Silverman & Worden, 1993; Klass et al., 1996; Hedtke, 2001) who reject the notion of resolution and moving on following bereavement. What appears to be an interesting finding is the continued change and progression in the relationship with the deceased. White (1988) spoke about the importance of the continuation of relationships but the findings of this study seem to take this further, implying that continued change within a relationship may also be possible. This may be particularly pertinent to a young population who yearn for a parental figure and therefore engage in a process of re-evaluation and re-consideration of the relationship (Biank & Werner-Lin, 2011).

Young people appeared to change their thoughts about the deceased, including ideas about what that person might hope for them in their future lives. As young people pass through life stages the ability to re-evaluate their relationship with the deceased is likely to change (Bowlby, 1980; Biank & Werner-Lin, 2011). As an adolescent reaches adulthood, changes in the relationship and bond with the deceased may occur in line with what would be imagined in a dynamic relationship with someone who is alive (Klass et al., 1996). Mourning is likely to be revisited at different stages as the child grows and reaches adulthood (Clark et al., 1996). Increasing perspective and maturing cognitive development are likely to contribute to this phenomenon (Corr, 2010). In Hedtke's (2001) work with the terminally ill she uses the concept of continuing bonds to create a legacy for after death and her work may offer an insight into how dying parents can maintain their role as a parent after death. This theme is consistent with practical interventions commonly recommended to terminally ill parents, such as making a 'memory store', which may include letters to the young person designed for specific times in their life promoting an evolving and continuing relationship.

#### *4.2.1.2 The importance of positive relationships: "it takes a weight off your shoulders because you think I'm not the only one"*

Positive relationships were seen as integral to coping but can also be viewed as representative of systemic change following bereavement. This is a subtheme

which is part of *The Coping Process* super-ordinate theme. Young people spoke of the strengthening of existing relationships with parents and friends. This is supported by the work of Dopp and Cain (2012) who found that peers had a significant impact on adjustment to the death of a parent. Tedeschi and Calhoun (1995) found that changes in relationships with others was one category of growth following trauma. The re-negotiation of existing relationships with family members is likely to occur in response to shared loss of another family member. Dowdney et al., (1999) speak of the importance of the remaining parent's response following the death of a spouse for the grief experience of a child. Hurd's (2004) single case study of a bereaved young person highlights the protective nature of the maternal relationship following the death of a father.

Young people spoke about changes in peer relationships following bereavement. Changes were seen to occur in both existing and emerging relationships as a result of this experience. It seemed that the reaction of existing friends was highly influential in how the young people experienced post-death support. Young people noticed almost a polarisation of friends who either became very close or conversely distanced themselves. In some cases the experience of bereavement led to certain friendships being lost (Balk, 2000). It is vital to understand the importance of peer relationships in the context of the adolescent period. Luxmoore (2012) offers a helpful insight into adolescent bereavement, highlighting how young people do not know how to react to death, experiencing fear and uncertainty whether it is a direct bereavement or a bereavement in the wider system. This is likely to make some young people apprehensive when another young person experiences a death and as a result they may retreat from that peer. Adolescence has been theorised as being, in part, defined by a moving away from parental relationships and an increased emphasis on the role of peer and intimate relationships (Balk, 2000; Wolf, 1991). For these reasons it seems that friends play a particularly important role in the adaption to bereavement for young people.

Young people also spoke of the importance of connecting with other bereaved young people they met following death, finding solace in the knowledge of having a shared experience. To 'fit in' and have a shared identity is significant in youth



and therefore the ability to connect with other young people who are grieving is particularly important. This is congruent with the findings of Metel and Barnes (2011) who found that bereaved young people experienced increased social isolation following bereavement and found bereavement peer-support groups helpful for relieving this.

#### 4.2.2 How do young people experience change and growth post-bereavement?

The results offer an interesting insight into young people's experience of change and growth following bereavement. Those interviewed reflected on the growth they experienced personally as both life-altering and positive. Three themes were found which were encompassed by the super-ordinate theme, *Growth in Self: "Bereavement is a very powerful thing and it can change you big time"*. This super-ordinate theme is consistent with the wider research on posttraumatic growth (Tedeschi & Calhoun, 1996; Kilmer, 2006) which postulates that from tragedy one can grow and change beyond the person one was pre-trauma. The following themes may also indicate a process occurring in this population which is consistent with the work of Janoff-Bulman (1992), who argues that growth occurs as a result of building new assumptions of the world following trauma. It could be argued that the young people in this study are building new understandings of the world and themselves in order to grow and adapt positively following bereavement. The subthemes below offer an insight into how young people experience growth and change post-bereavement.

##### 4.2.2.1 *Growth in Self: "Bereavement is a very powerful thing and it can change you big time"*

- *"I know my time is limited so why spend it waiting for something to happen?"*

This subtheme is concerned with changing perspectives on life that occurred as a result of the bereavement. It was found that as a result of bereavement, young people had different views about the nature of life and death and these new beliefs affected how they planned to live their lives going forward. Existential awareness and contemplation is consistent with the work of Yalom (2008) who argued that death is central to our understanding of what it means to be a human

being. It may be that developing such awareness early on offers more opportunity for growth for young people. Changes in life perspectives as an area of growth is supported by existing literature on PTG. Tedeschi and Calhoun's (1996) five domains of posttraumatic growth, based on research with an adult population, highlighted 'appreciation of life' as central in the PTG concept. The idea of time being limited certainly seemed to instil an increased appreciation of life and its fragility in the young people interviewed. This may be related to Janoff- Bulman's (1992) shattered assumptions theory which argues that growth following trauma occurs as a result of the development of new assumptions about the world. It may be that the young people in this study have gradually built new assumptions of the world and by effectively incorporating them into their new world view, have experienced them as positive. It may be that the ability to re-evaluate one's perspective on life is prefaced by the ability to understand both the 'death concept' (Carr, 2006) and engage in complex cognitive processes which are dependent upon one's developmental level (Piaget, 1932). It may therefore be that the ability to alter one's perspective on life and adapt this new framework to ongoing conceptualisations of the world differentiates an adolescent population from that of a child population as children may be unable to engage with this more abstract cognitive process (Biank & Werner-Lin, 2011).

- *"All my mates call me granddad now".*

Maturity was a clear theme that emerged from the analysis. Young people interviewed spoke of maturity and 'growing up' being a result of experiencing bereavement, as well as a result of caring for dying or grieving parents. An entering of adulthood following bereavement was suggested by Worden (1996) who found young women bereaved of a mother perceived the death to indicate the end of their childhood. Growth in the form of maturity is supported by existing PTG literature. Calhoun and Tedeschi (1998) found that individuals consider themselves wiser and more accepting following the experience of trauma. Affleck et al., (1991) also found that increased maturity was a feature of PTG. They found that mothers who had experienced the admission of their child to a neonatal intensive care unit reported increased tolerance, empathy and patience as a result of their experience. Balk (2000) highlights adolescence as a

developmental period where a young person gradually separates from their parents. For young people who have lost a parent, this process may be forced to happen sooner and this may result in them adopting an adult role earlier than their peers.

Results also found that young people adopted caring roles either for their parent who was dying or following death for the grieving parent. I have included additional literature on young carers to help understand this further. Historically, being a young carer has been studied in relation to the negative impact it may have on the individual (Rose & Cohen, 2010). Dearden and Becker (1999) highlight the impact of caring on emotional stress and isolation. However, findings also highlight that young people can associate their role with a sense of pride (Bolas et al., 2007) and integrate the role into their evolving identity in a positive way (Earley & Cushway, 2002). This is consistent with the findings in this research which found young people expressed satisfaction in adopting caring responsibilities. Existing research also supports the findings that young people often aspire to take on caring roles in their futures as a result of their experience at a young age (Earley & Cushway, 2002) which was apparent in the sample interviewed. Young people did not conceptualise caring as a negative experience and rather used these experiences as examples of increased ability and competence more generally in life. This is supported by the work of Dyregrov (1991) who argues that if there remains a mutually supportive role between the surviving caregiver and the young person, that increased responsibility can encourage positive growth.

- *"I think you get stronger from it".*

Young people also experienced increasing strength and independence as a form of growth following bereavement. This strongly fits with the writings of Nietzsche (1888) and the philosophy of growth out of adversity. It is congruent with the findings of Tedeschi and Calhoun (1996) who cite personal strength as one of the five domains they found in their early research on PTG. Participants spoke of their confidence in their own ability to cope in life generally following bereavement and increased self-esteem which was also found in the work by Schaefer and

Moos (2001). Adopting an identity of being strong is interesting when considering young people following bereavement. Although spoken about in terms of emotional strength it may also be associated with strength to survive physically; something poignant when considering loss of a parent at a young age and connecting with what is needed to survive as a human.

The desire of young people to reframe experiences of hardship into stories of strength may be representative of an instinctive desire to evolve in response to trauma (Joseph & Linley, 2005). It may be that through language and discourse young people are able to make this strength-based narrative a reality. This could be likened to the 'survivor movement' which has been apparent in a number of arenas. I will not attempt to give a comprehensive account of this movement but will offer a brief synopsis to contextualise the accounts of the young people interviewed. Survivor discourse has been used by service-users within the psychiatric system attempting to reclaim the language from medicine to a discourse that better represents their experience of mental health difficulties (Wallcroft & Michaelson, 2001). The term 'survivor' offers an alternative discourse to that of mental health patient. Survivorship has also been adopted as a dominant discourse within the field of oncology and has become synonymous with those who have had a diagnosis of cancer and survived it (Zebrack, 2000).

Bell and Ristovski-Slijepcevic (2013) note that survivor discourse now positions the diagnosis of cancer as a platform for personal growth and change. They argue that this idea of transformation following a cancer diagnosis is now dominant as a result of the survivor rhetoric and in stark contrast to the idea of the cancer 'victim'. Interestingly, cancer was once seen as a social taboo, being alluded to as "the big C" and seeming unfit for public discussion. Ongoing revision and consideration of discourses has now enabled many diagnosed with cancer to adopt a different role and relationship to their diagnosis (Mathieson & Stam, 1995). It may be that the young people interviewed are finding alternative discourses in which they can talk about the 'Big D' and frame their experiences as empowering rather than damaging. For young people who have been bereaved, using the language of growth and change may be their opportunity to

influence the current social boundaries surrounding death talk and in line with the work of Foucault (1972) are using discourse to assert power.

#### 4.2.3 What do young people experience as helpful following bereavement and what do they understand as helping PTG?

Results show that young people interviewed had a coherent and well defined view of what helped them following bereavement. These ideas are connected under the super-ordinate theme *The Coping Process*. It should be noted that these themes are related to the research questions discussed above and may act as the linking feature that enables self-growth and on-going growth in relation to the deceased. The features of coping that were discussed by young people seemed to implicitly foreground the PTG phenomenon.

##### *4.2.3.1 The Coping Process*

- *"I had all that inside me, I'm only little".*

Self-expression seemed central in the coping narrative of young people. Although talking was mentioned by the young people as being one vehicle for self-expression other ways of 'releasing' emotion were discussed. Needing to find an outlet for emotional expression is likely to be affected by adolescents becoming increasingly aware of the taboo of 'death talk' and in response seeking alternative outlets for overwhelming emotion where talking does not feel possible (Luxmoore, 2012). This may be particularly significant for an adolescent population who may still be developing skills in how to articulate their bodily and emotional experiences.

Young people did speak about self-harm as a method of releasing painful emotions which prefaced some young people's seeking out of alternative methods. Adolescents and young adults have been found to be at higher risk of deliberate self-harm as a form of emotion regulation and self-expression (Fliege, Lee, Grimm & Klapp, 2009). In a recent Swedish study of deliberate self-harm in young people parentally bereaved by cancer, it was found that one fifth of those bereaved engaged in deliberate self-harm, double the number of non-bereaved counterparts (Grenklo et al., 2013). Self harm has been found to be a predictor of

accidental and intentional suicide (Hawton et al., 2012) and is unlikely to promote positive ongoing growth. It is therefore extremely important to promote awareness when considering bereavement in youth. Young people in this study engaged actively in seeking alternatives to deliberate self-harm, substituting it with music and sports (Brewer & Sparkes, 2011).

- *Active Coping*

Young people expressed the need for self-agency in coping following bereavement. This included managing negative thoughts, engagement in remembering the deceased (as discussed above) and being active in this process. There was an implied sense from young people that to be passive in one's grief was dangerous and could lead to on-going experience of aversive emotional experiences. This is supported by Stroebe and Schut's (1999) dual process model of coping following bereavement, which stresses a need for people to move between grief and non-grief related activities. This is argued to be protective and prevent the bereaved from becoming overwhelmed by the death experience. Young people's active determination to manage negative thoughts, engage in pleasurable activities and think about the deceased's life, rather than death, may be an example of this.

Cognitive engagement in positive or coping thoughts requires a level of abstract thinking and complexity which may first emerge in adolescence (Carr, 2006). Adolescence as a developmental stage is often linked to an increased sense of autonomy and this has also been linked to increased self-agency in coping with difficulties (Balk, 2000). The active engagement in coping may offer further support for the findings of Joseph and Linley's (2005) organismic valuing theory. This theory proposes that following trauma there is a natural desire to move towards growth and emotional processing. This may indeed be what young people are doing when they seek to make meaning of death and focus on positive outcomes. Findings suggest that young people made the move towards growth independently from others but recognised the need for positive relationships to aid this.

## 4.3 Implications and Recommendations

### 4.3.1 Implications for further research

This study offers some thoughts about the experience of growth and change following bereavement for young people. The findings suggest that the posttraumatic growth phenomenon is relevant for the population studied and therefore suggests that further research may be required to understand this further. Current literature does not offer a comprehensive understanding of the post-bereavement experience for young people. Findings appear to suggest a process being engaged in by the young people interviewed following bereavement, which may contribute to personal growth. Adopting a grounded theory approach (Glaser & Strauss, 1967), as a follow up to this study, may be helpful in conceptualising the findings within a holistic theory. This could offer a helpful adjunct to the current research which required an initial IPA analysis to firstly focus on the individual experience of young people.

It may also be helpful to take a longitudinal approach to further research to understand more fully whether this phenomenon remains a constant in the lives of those who experience bereavement during adolescence. Existing research indicates the longitudinal nature of childhood bereavement (Worden, 1996; Biank & Werner-Lin, 2011). It would be interesting to understand how young people carry the growth experienced in adolescence into adulthood and whether their identities as strong, mature young people translate to later life. With this in mind it could be helpful to interview young people from shortly after the bereavement and at intervals throughout adolescence and early adulthood to track whether growth and change are dynamic and changing. If one is to draw on the work of Balk (2000) who noted early, middle and late adolescence as unique developmental periods, it may be helpful to look at young people in these different age brackets to learn if there is any difference in growth and change at different points during the adolescent period.

Findings highlighting the evolving relationship with the deceased may benefit from further research in the adolescent population as well as child and adult populations. The possibility of a dynamic relationship with the deceased is

currently under-researched and in need of further exploration. It would be interesting to understand how relationships with deceased family members change throughout adult life and at key stages of the family life cycle (Carter & McGoldrick, 1999). This phenomenon may benefit from specific investigation with further qualitative exploration in populations of bereaved young people, including those who have been bereaved of grandparents and other relatives to understand if this concept is unique to young people who have lost parents and siblings.

Research examining young people's experiences of bereavement may also benefit from the adoption of a whole family approach to research, with qualitative interviews being used to understand the systemic response to familial bereavement. This would offer an insight into whether PTG is experienced as a shared phenomenon within families or whether it is an individually occurring phenomenon. Findings from this study would suggest that young people's engagement in early caring roles, their emphasis on peer relationships and their need for tangible self-expression could be unique to a younger cohort. However, this is currently unknown.

Finally, another area that would be beneficial to study in more depth as a result of these findings is the role played by social inequalities in the ability to engage actively in the coping process following bereavement. Young people interviewed in this study were recruited from a particular area of England which is associated with low socio-economic status and a number of young people did refer to being from a background of disadvantage during their interviews. It may be helpful to replicate this research in different areas of the UK to understand whether young people from wealthier regions also identify as having grown and changed as a result of bereavement. Equally, with young people living in poverty it may be helpful to understand how they respond to bereavement and whether the same kind of growth is possible within this context.



## 4.3.2 Implications for Clinical Practice

### 4.3.2.1 *Implications derived from the findings of this study*

#### *- Public Awareness*

The findings from this research highlight a need to promote public awareness of young people's experiences of bereavement. This might be beneficial to prevent the pathologising of young people's behaviours following bereavement.

Adolescence is argued by some to be a socially constructed phenomenon and can position young people as powerless and vulnerable (Brannen et al., 2002). Young people's subjugation in contemporary society serves to position this cohort as less capable than adults (Lesko, 2012). Findings from this study suggest that when an event that is 'out of the ordinary' occurs, such as a death in the family, young people may be required to adopt adult roles regardless of age.

#### *- Service organisation*

Young people in this study spoke about the importance of support networks and positive relationships as an aid to coping. Young people spoke specifically about the opportunity to attend a bereavement service as beneficial. This suggests that specific bereavement services and the opportunity to meet other bereaved young people may be beneficial. Young people also spoke about the experience of bereavement within the school environment and the importance of teachers and peers responding in a way that is helpful, which may be different for different children. This suggests that working with schools to consider bereavement support may be useful. Findings from this study show that the repercussions of bereavement may still be present years after a death (such as deliberate self-harm) and it is possible to infer that the role of GPs may be key in ensuring young people are offered the most appropriate care.

#### *- Approaches to intervention*

The young people interviewed all spoke of the importance of group identity and connection. For this reason, group work may be particularly helpful for this population in enabling them to connect with others. This could come in the form of formal therapeutic groups but also peer support groups and workshops. What

appeared to be most important for the young people interviewed was merely having a peer link rather than what was actively done in the group. Young people spoke of the importance of a continued relationship with the deceased and it may be helpful to offer young people the opportunity to engage in 'continuing bonds' work, whether individually or in a group context. One of the most striking clinical implications of this research is the need to take note of the unique position of the adolescent and tailor approaches accordingly. This may be simple adaptations such as communication styles and thinking beyond the 'therapy room', to more creative interventions.

Findings suggest that during individual work clinicians should be cautious not to perceive young people as childlike and instead engage with them on a developmentally appropriate level. This study indicated that the young people interviewed were capable of performing roles within the family that would traditionally be assumed to be the realm of adulthood and clinicians should endeavour to treat young people accordingly.

#### *4.3.2.2 Implications of the findings in conjunction with wider research*

##### *- Public Awareness*

Due to society's positioning of young people as potentially incapable, the gap between their role in the family pre and post-death may be even greater. When considering the literature more widely, the adolescent construct and its associated stereotypes may also act to underestimate the impact of bereavement on young people, either by not recognising the level of insight young people have about death itself and their sensitivity to other's grief experiences. Young people interviewed emphasised the impact of other's reactions to bereavement and their desire to protect and help them. Working to deconstruct the 'problem teen' rhetoric may open doors to enable more diverse thinking about adolescent capabilities and encourage the incorporation of youth voices into the construction of bereavement support and intervention.

### *- Service Organisation*

This study, in conjunction with the existing literature on adolescent bereavement, highlights a number of pertinent issues relating to how generic mental health services for young people are organised as well as specific bereavement services. Findings from this study and the wider adolescent literature indicate adolescence to be a unique time and starkly different to that of childhood, as more complex thought processes are engaged with and yet the boundaries imposed by adults are still upheld. General child and adolescent mental health services have historically linked services for children and young people with clinicians providing support for both age groups. This may indeed be appropriate offering flexibility for young people who mature and develop at different times. However, it is vital that services maintain specialist understanding of the adolescent period and adapt provisions accordingly.

It is apparent from the findings that bereavement presented unique challenges and opportunities for growth in the young people interviewed. Previous research has indicated the prevalence of early grief experiences and although not all young people seek help following bereavement, this study and the wider literature indicates that specific bereavement services should be accessible to all young people seeking support. Bereavement support is predominantly being provided by voluntary services in the UK and these vary in what they are able to offer and to whom (Walsh, 2007). It is possible to argue that in conjunction with existing research, the findings of this study suggest that specialist services should be available to offer general support following bereavement but also more intensive interventions for young people who are experiencing difficulties. To honour the highly complex and individualised nature of bereavement, tertiary services should be equipped to provide individualised and optimal care for young people following bereavement (DoH, 2011).

This may present a dilemma when considering the pathologising of grief reactions. I believe that by providing bereavement care in specialist services we may prevent the need to refer young people in distress to general mental health services and may lessen the probability of attaching other diagnoses, such as 'depression' to those who are bereaved. It is also important to note the ongoing

nature of grief noted by participants in this study and the possibility of young people revisiting mourning at different points throughout their life (Bowlby, 1980; Biank & Werner-Lin, 2011). Therefore this study may provide some evidence for services being available to those who are revisiting grief and not just those in the early stages of bereavement.

It may also be important to skill up Tier 1 workers to enable frontline work to occur. This may be possible by offering further education and training to schools and those working in general practice. Schools play a pivotal role in the lives of young people and this may be particularly crucial following a close family bereavement where perhaps parents' own grief prevents them supporting young people to the extent they may require. Secondary schools may benefit from specific training in adolescent bereavement and how to offer support to this cohort. Adolescent bereavement research highlights a need for schools to be encouraged to engage in death talk openly, as a way of helping young people feel more comfortable and equipped to talk about death themselves. Being able to speak openly about death has been found to lessen the probability of experiencing mental health difficulties in adulthood (Saler & Skolnick, 1992). Findings from this study suggest it may be beneficial to have a designated bereavement officer at the school who is able to offer young people a forum should they need it. Schools may be able to help equip their pupils with the knowledge and resources to support bereaved peers, so that young people do not feel the need to shy away from grief due to a lack of experience (Balk, 2000). Policy should be created to offer schools a framework for supporting their bereaved young people.

General practitioners may also be central when considering optimal bereavement support. This study and wider research suggests that it may be helpful to offer specific training about adolescent bereavement, in a bid to prevent unnecessary referrals to CAMHS services or the inappropriate administering of anti-depressant or anxiolytic medication. Currently there is no unifying policy which informs the practice of GPs for their bereaved patients (Saunderson et al., 1999). In line with the findings of this study GPs are key to the delivery of support services for

young people in ensuring that funding is available for adequate bereavement support provision in their catchment area.

#### *- Approaches to Intervention*

This study supports existing research suggesting group work may be of benefit to young people who have been bereaved. It may be helpful to provide groups in the community, at school or in specialist services. Support groups may also be provided across different media if regular groups are not possible. Social media may be a relevant and useful vehicle for this and accessible for young people today. An example of this type of social communication can be seen on the Cruise UK website (Cruise Bereavement Care, 2012). It has a particular area for young people called RD4U, which is designed by young people for young people and has online forums and message boards. Young people should be informed of such websites and the different types of support on offer to them.

Findings from this study and existing literature also indicate that family work may also be useful when working with young people due to the importance participants placed on having positive family support following bereavement. Young people do not experience bereavement as isolated individuals (Ribbens McCarthy, 2009). The systemic impact of bereavement includes changes in family composition and structure, multiple grieving experiences and changing roles within the household. Adopting a systemic family approach to post-bereavement support may allow the sharing of death talk in a supportive context with a trained professional. It may also work to locate the distress within the system as opposed to an individual child or young person.

#### *- Individual Therapy*

Individual therapy should be considered for young people who require support following bereavement regardless of the relationship with the deceased or the nature of the death. Individual work may be more appropriate for young people who do not feel able to discuss their experiences in a group format or with family due. Young people interviewed reported not wanting to upset or burden grieving parents and this should be taken into account when working clinically. This does however come with the risk of enforcing the 'adult role' or problematising the

individual. For many young people psychological intervention will not be necessary (Dowdney, 2000). For those who do engage in individual work narrative therapy may be a helpful framework to use to promote re-membering and encourage an evolving relationship with the deceased in a way that moves away from locating the problem in the young person (White & Epston, 1990). This approach may also enable stories of strength to be brought forth and thickened within the therapeutic context. Stories of strength, new identities and qualities may offer young people an alternative to the identity of a bereaved child. Fredman (1997) and White (1988) offer helpful frameworks for clinical work with the bereaved, focusing on the promotion of continuing bonds. In line with the findings from this study and conceptualisations of PTG (Janoff-Bulman, 1992; Joseph & Linley, 2005) cognitive approaches may also be helpful for young people coping with bereavement. Cognitive approaches may help young people engage in a form of active coping and direct evaluation of thoughts.

#### **4.4 Critical Review**

##### **4.4.1 Validity and Quality in Qualitative Research**

Assessing quality and validity in qualitative research requires a different engagement with the historical notions of what equates to validity in quantitative projects (Smith, et al., 2009). For the purposes of this study Yardley's (2000, 2008) four criteria have been used to provide a framework for assessing validity and quality in qualitative research. Although I have used this framework to discuss issues of validity and quality I have done so with the acknowledgement that the guidelines are intended to be used flexibly and with the hope that many of the markers of quality and validity are recognisable inherently throughout the body of work thus far.

##### **4.4.1.1 *Sensitivity to context***

Throughout the research process I have endeavoured to remain sensitive to context from the outset. This is initially shown by my selection of IPA to answer my research questions. I felt that this under-researched phenomenon required careful consideration of individual experience and a close reading of the data. Due to the sensitive nature of the research questions, from the outset I was

engaging in creating links with outside organisations and attending to issues of ethics relevant to this population (see chapter 2 for further discussion of this). An awareness of the potential vulnerability of participants required a great sensitivity when using in-depth interviews and analysing the data. I have presented the themes as possible readings of the data but do not attempt to imply my readings are 'truth'. I attempt to remain tentative about implications of this research and the conclusions that can be drawn which also highlights sensitivity to the context of the research (Smith et al., 2009). I have used existing research to situate my findings within the wider context. Further research has been added at a later stage which demonstrates a reflexive and close engagement with the findings.

#### *4.4.1.2 Commitment and rigour*

My commitment to the research, sample and data has been demonstrated by my careful approach to recruitment which was conducted in line with recommendations made by the service I was recruiting from and ethics boards. I ensured participants were fully informed about the study and my intentions for doing it. I offered participants options about where the research could take place and made every effort to make them feel listened to and valued throughout the research process. One indication of this can be seen in the rich data collected despite conducting the study with a younger cohort often considered more challenging to interview. Rigour was attended to at all points in the process; choosing a sample of participants which would best fit the research questions and seeking homogeneity as much as possible. Rigour can also be examined by the thoroughness of analysis and an adherence to the expectations of IPA, going beyond description to a level of analysis (Smith et al., 2009). I have chosen extracts from the data believed to best represent the themes found and have grounded my interpretations within the data in a way which is intended to be clear to the reader.

#### *4.4.1.3 Transparency and coherence.*

I have presented the steps taken in this research transparently so that the reader can fully see the process of the research taken. As IPA is interpretative in nature and rests on the philosophy of hermeneutics I have presented an account and trail which should be traceable to the reader. I have presented each stage of the

process in the appendix, including an annotated transcript (appendix K) and table of themes (appendix L). An independent audit was conducted where another researcher offered an original reading of a transcript and themes were compared to ensure coherence in my reading of the data. This found convergence in the readings and implies thoroughness in my understanding of the data. Testimonial validity was sought by sending a summary of findings to participants and asking for their feedback (appendix M). I am currently awaiting responses from participants.

#### *4.4.1.4 Impact and importance*

Yardley (2000, 2008) states that the most important assessment of quality in all research is its usefulness and interest. I believe that the young people interviewed offered hugely valuable accounts of their experiences and I have endeavoured to encapsulate their experiences and develop them to build an analysis that is both interesting and important to the field of clinical psychology and bereavement. I have stated the clinical implications of this work above which provide evidence of the usefulness of conducting this research.

## **4.5 Methodological Limitations**

### 4.5.1 Recruitment and sample

Young people were recruited from a specialist bereavement service. Strict inclusion and exclusion criteria were adopted to enhance homogeneity but this meant that the sample recruited were all young people who had attended a bereavement workshop and at least one peer support group. This is likely to have implications for the findings. Young people interviewed are likely to have had different experiences of support to other bereaved young people, who either received no support or who engaged in formal psychological intervention. Because of this, it is impossible to say whether the growth and change found is, in part, a result of the service's input or if it would have happened anyway. Although this would be interesting to examine, this research is not attempting to ascertain causality and therefore this does not prevent the findings from being helpful. The young people who volunteered to join the research may also represent a group of young people who are happy to talk about their experiences



and this may reflect upon the findings of growth in this study. Young people interviewed were certainly very articulate and may not be representative of all young people. It may have been helpful to use a sample recruited from the general public to offer a broader understanding of this phenomenon as most young people will not require specialist service input. However, using a clinical sample may offer further insight into populations who will be seeking services and therefore have further clinical implications than a general public population.

The sample were homogenous in that they had all experienced a bereavement before the age of 13 years old and coincidentally, the young people interviewed were all between 5 and 8 years post-bereavement. Recruitment criteria specified that young people should be under the age of 17 years at the time of bereavement and under the age of 18 years at the time of interview, with at least one year post-bereavement to allow time for growth should it occur. An opportunistic sample was then sought and young people ranged in age from 14 to 18 years old at the time of interview. This may have implications for the findings as young people experienced bereavement either as a child or young adolescent. The time since death is also likely to have implications for the findings. It may have been useful to be more specific about the age at bereavement however, as young people are underrepresented in research and harder to recruit an opportunistic sample was necessary to ensure adequate numbers. All results were established with these limitations in mind. Young people were also recruited regardless of ethnicity, but all young people who joined the study were of white British ethnicity. This is not representative of the ethnic make-up of the area where the service is located and the sample was recruited from. This may be an interesting observation when considering service accessibility as well as cultural diversity in grieving practices.

#### 4.5.2 Challenges of working with young people

Young people have frequently been underrepresented in research for a number of reasons (Dyregov, 1991; Alderson, 1995; Chowns, 2008). Conducting this research with young people did offer unique challenges to the research process. Particular caution was taken to ensure ethical standards were upheld including the continued involvement of parents or carers throughout to ensure they were

also comfortable with the young person taking part. This meant offering different information sheets and consent forms to both participant (Appendix C) and parent (Appendix D). Although apprehension has been expressed about conducting interviews with young people and collecting rich enough data for analysis, the young people interviewed in this study all offered extremely detailed and thoughtful explanations of their experiences. For some young people I had to spend more time building rapport and ask more questions to encourage talking than one might expect from an adult population but this did not present great challenges with this particular group of young people.

#### **4.6 Personal Reflections**

Conducting an interpretative-phenomenological analysis of young people's accounts of bereavement has required adopting a position of flexibility and thoughtfulness throughout the process. The challenge of finding a balance between engagement with the data, my interpretations and the adoption of a particular analytic framework is encapsulated by the idea of "research-process-as-adventure" (Willig, 2001, p. 2). During this journey I have been forced to challenge some of my existing beliefs about the idea of grief and life beyond bereavement. As a novice IPA researcher I have had to gradually abandon the idea of using concrete methodological frameworks and adapt analyses to fit the sample I was working with. The research process has been challenging at times but has yielded findings that go beyond what may be expected if I had used a more rigid methodological framework.

##### **4.6.1. Reflexivity**

Whilst conducting this research I have aimed to stay within the position of reflexive researcher, engaging in what has been termed the "reflexive dance" (Finlay, 2008, p.1), moving between the data and my own presuppositions for interpretation. I have maintained a reflexive journal to record my observations, thoughts and feelings throughout this journey (Appendix A). Recording my immediate observations and ongoing thought process throughout the research allowed me to engage more accurately in the bracketing off process. Despite my research questions and my engagement in existing PTG literature, I occasionally

felt overwhelmed by the magnitude of bereavement literature centred on the negative impact of this experience. Although young people talked thoughtfully about the different aspects of the bereavement I would often leave with my mind focussed on the devastation of bereavement, rather than the growth they had noticed and the positive approach to life they had. I had to remain aware of this when I was analysing my data to ensure I could engage in the double hermeneutic rather than just expressing my own beliefs.

#### 4.6.2 Personal impact of working with young people who have been bereaved.

As expressed by Dyregov (1991) many researchers shy away from doing research with distressed young people for fear of the emotional impact on themselves. At times during the research process this was a concern to me as I wondered how I would manage immersing myself in the words of young people who although describing growth, also expressed sorrow. Keeping a reflexive diary helped me record my concerns and feelings throughout the process. I used supervision where needed to discuss my thoughts and share my experience of interviewing these young people. I also ensured that when immersing myself in the data I took breaks and engaged in other activities unrelated to the research. I believe that this was an important part of the research process, allowing time for reflection and without which may have made it difficult to adopt an interpretative and analytical perspective. I have in no ways been deterred from conducting research with young people and this experience has only encouraged me to conduct research in the future to promote the voices of young people in psychological literature.

### **4.7 Final Thoughts**

This study has attempted to offer a meaningful contribution to the existing literature on bereavement and posttraumatic growth. Although this is an emerging field I hope to have offered a different perspective on the impact of early bereavement experiences without negating the well-documented sorrow and devastation of grief. Although bereavement may be ubiquitous it should not

necessarily be considered any less a trauma than those commonly associated with diagnoses of PTSD. Bereavement services should be available to all who seek further support and this may require an acknowledgement from professionals that any type of loss can be traumatic and shatter assumptions of the world. This study does not attempt to be generalisable but does illuminate the voices of seven young people all of whom connect with the idea of growth following death and the desire to retain and develop their relationships with the deceased.

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## 6.0 APPENDICES

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## **Appendix A: Reflexive Journal**

### **Extract 1: Choosing to research bereavement during adolescence**

As a young adolescent the death of my grandmother, to whom I was very close, was an experience that was both shocking to me and highly distressing. As an adolescent I remember being frightened by the new range of emotions I was experiencing which until the age of 12 years, I had been protected from. Although death must have been discussed at home and at school I do not remember it being a reality to me. I remember as a child having fears about my family dying but I'm unsure about the trigger for these thoughts. I recall the confusion and disbelief that I felt following my grandmother's death. Shortly after she died I wrote her a letter asking her to leave a sign for me that she was still here. I hid the letter as I did not want anyone else to find it. I thought she would know where it was. I don't recall whether I went to look to see if she had taken it. A few years ago my mother showed it to me, she said she had found it. I wonder what I thought had happened to it at the time? I also remember having a very vivid dream about her after she died in which she told me she was safe and happy. I remember telling people about this dream and feeling privileged that I was the person whom she had given this 'message' to. I don't know what the true content of that dream was now and how much I'd added to it in the days after but I do remember it being comforting.

I'm also interested in researching adolescence in particular for personal and professional reasons. Not only do I remember this time being of particular change and anguish but after working with young people I've been struck by some of the common themes that seem to emerge in the work, often involving the desire for independence conflicting with the boundaries imposed by adults. I remember the arguments I used to have with my mother as a 14 year old as our priorities collided. I remember feeling consumed by the politics of peer relationships and weekend social events as my mother attempted to enforce boundaries around school work.

### **Extract 2: Following Nick's interview**

I'm leaving Nick's house feeling uplifted and positive despite spending the last hour talking about his bereavement experiences. Nick spoke a lot about his early bereavement reactions and I'm left wondering whether I should have spent so long talking about acute grief reactions with him as it is not in line with my research questions. I think I did this as I was feeling very cautious about taking a back seat in the interview process and following Nick's direction. Nick started talking about growth and change early on and seemed keen to impress upon me that this was something very real he had experienced. He was full of hope and excitement about the future and despite the hardship he had faced, feels stronger because of it. Despite this I can't help thinking what he has sacrificed for these changes. I wonder what makes him so determined to help others following bereavement, is it a way of alleviating pain or making meaning of his dad's death? I need to be careful not to allow my own assumptions to cloud my reading of Nick's transcript as he certainly at no point presented his growth and change as negative.

## **Appendix B: Young person information sheet**

### **SERVICE LOGO**

#### **Information Sheet and Invitation to Participate**

**Study title: An exploration of young people's experience of 'posttraumatic growth' (change and growth) and their understanding of what helps in this process following bereavement.**

We are asking if you would join in a research project to find the answer to the question: do young people experience any growth and change after someone they care about dies and if so what has helped them. Before you decide if you want to join in, it's important to understand why the research is being done and what it will involve for you. So please consider this leaflet carefully. Talk to your family, friends, member of staff at [SERVICE] or me if you want to.

#### **Why are we doing this research?**

Experiencing the death of someone you love when you're young, sadly, is not uncommon. In the past, when people have done research about these experiences they have focused on all the very sad things that happen. Although it may seem strange, some people find positive changes happening after someone they love dies. This does not mean that they are pleased it happened or aren't still very sad but what happened has made them change or grow in a different way. The idea that change or growth can sometimes happen after bad experiences has been called 'posttraumatic growth'. People have talked to adults about changing after the death of a loved one but not many people have asked young people themselves.

In this study I'm hoping to ask young people directly about their experiences of good change or growth happening after someone they love dies. My main hopes are:

- 1) To ask young people about changes that they have noticed following a loved one dying (did you notice any changes in yourself, what you thought of life or what you wanted for the future).
- 2) To ask about changes and growth within their families and friendships after someone they love dies (have they noticed changes in their friendships or in relationships with family members).
- 3) To ask young people directly about what they feel helped them following this difficult time (did friends help, was it useful coming to [SERVICE], did you find listening to music or a new hobby helpful)?

#### **Why have I been invited to take part?**

To find young people who would like to take part in this study I am giving this information sheet to a number of young people between 13 and 18 years old who have come to [SERVICE].

I am hoping to meet and talk to between 8 and 10 people. Research has been done before where young people have been asked about their experience of bereavement but as I mentioned earlier, I would like to focus on the change that has happened since and not just the very sad times you may have had.

### **Do I have to take part?**

No. It is up to you. We will ask you for your consent (permission) and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. You are free to stop taking part at any time during the research without giving a reason. If you decide to stop, this will not affect the care you receive.

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

1. If you decide you would like to take part you can contact me by email or telephone yourself or ask your parent or care-giver to contact me. You can also let a member of the [SERVICE] team know and they'll pass that on to me. If you would like more information before deciding please contact me and I'd be happy to answer any questions.
2. If you decide you definitely want to take part a time will be arranged that's easy for you to meet with me. We can think about where will be easiest to meet, this could either be at your home, at [SERVICE] or possibly at school. If you do want to meet at [SERVICE] we can give you the money for your travel.
3. When we meet for the research interview I'll go through the consent form with you and your parent/care-giver. It's great if they're available when we first meet. If they are not available at the same time as you I can arrange to speak to them on the telephone and post them the consent form to sign. If you're 18 years we do not need consent from a parent or care-giver and it is up to you if you want to talk to them about it.
4. We will then meet alone and have a conversation about your experiences. I'll ask questions about what has changed and how your experiences have been. I'll use a digital voice recorder so that I can record everything we've talked about and use it in my research.
5. This will probably last between 45 minutes to 1 hour but we can stop earlier if you want to or have a break in the middle. It's totally up to you.
6. This study only requires us to meet once.
7. There will be the opportunity to talk to myself after our meeting if you'd like to. There are members of the team at [SERVICE] who can offer

extra support if the interview has made you feel sad (although hopefully we can talk about that together if it happens).

8. Once I have finished the research I can let you know the results and give you some feedback so that you know your help has gone to good use!

**Is what I say private or will I have to tell other people?**

Everything we talk about will be kept completely private. This means that I won't tell your parent/ care-giver what you have said during our conversation. It's important that you feel you can say what you want without worrying about others finding out. The only time I would have to tell your parent/care-giver is if you said something that made me worry that you might hurt yourself in some way or hurt someone else. I will explain this to your parent/ care-giver too before we start the interview (sometimes adults worry and it's important that I explain why I won't tell them what we've talked about- you can of course tell them whatever you like, they can be useful to talk to).

Once again if you are over 18 years old we will not have to tell your parents/ care-givers but like above, if you did say something that made me worry about your safety or the safety of someone else I may have to inform other members of staff or agencies.

**Is there anything to be worried about if I take part?**

There is the possibility that you may feel upset if I ask you questions about losing the person you care about. This is very normal. You can always say if you would rather not answer a question in the interview and we can move on to something else. There are lots of people who will be available to support you if you feel sad following the interview and we can think about that together. However, the aim of this study is not to be upsetting but rather to think about what positive changes have happened, how your relationships have changed and maybe how you see life and the people you love. Hopefully this will be a positive experience.

**What are the possible benefits of taking part?**

Lots of people find talking about their experiences helpful, it can be useful to think about the changes that have happened since a loss and what you might hope for in the future.

We cannot promise the study will help you but the information we get might help other young people who have lost someone they love with better and more helpful support in the future. We can learn what helps people grow out of difficult experiences by learning from those who have already experienced it.

**My contact details:**

**If you have any questions please send me an email at [u1037641@uel.ac.uk](mailto:u1037641@uel.ac.uk). If you leave your details I'll email you back or call you if you'd rather. We could arrange to meet face-to-face to discuss it as well.**

**Thank you for reading so far – if you are still interested, please go to Part 2.**

## Part 2

**Part 2:** More detail – information you need to know if you want to take part.

### **What happens when the research is finished?**

After our interview I will type up what we talked about so I can begin the research. This would be kept completely private by changing your name and any other information that could show who you are (like friends or members of your family's names). You can leave the study at any time before I type up our conversation. Once I've done all my work with the conversation we've had, I'll destroy the recording I made. I'll keep the typed up conversations, with the names changed for 3 years in case I need them again but I'll lock them away.

### **Ongoing support:**

- ✓ I am available when we have finished the interview to talk about anything that the conversation has made you think about.
- ✓ **A member of staff at [SERVICE]** will be available to meet with if you'd like to speak to someone again. Please contact [SERVICE] if you would like to talk to someone.
- ✓ **RD4U** is a website for young people who have been bereaved and has been made by young people themselves (It is part of Cruse Bereavement). It's got lots of information about getting support on their website [www.rd4u.org.uk](http://www.rd4u.org.uk) or you can call 0808 808 1677 (mon-fri 9am-5pm). You can also contact someone via private email if you'd prefer by clicking on 'private message'.

You may not feel you need any more support and may feel you don't want to speak to anyone else, that's totally fine too.

### **Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the London- Harrow NHS Research Ethics Committee and the University of East London Research Ethics Committee.

Thank you for reading this – please ask any questions if you need to.

Yours Sincerely,

Anna Picton

Researcher/ Trainee Clinical Psychologist

## **Appendix C: Information sheet for parents or carers**

SERVICE LOGO

### **Parent/Care-giver Information Sheet**

**Study title: An exploration of young people's experience of 'post-traumatic growth' (change and growth) and their understanding of what helps in this process following bereavement.**

We are asking if you would consent to your child or the child in your care joining in a research project to find the answer to the question: do young people experience any growth and change after someone they care about dies and if so what has helped them. Before you decide if you are comfortable with them participating, it's important to understand why the research is being done and what it will involve for the young person. So please consider this leaflet carefully.

#### **Why are we doing this research?**

Experiencing the death of someone you love at a young age, sadly, is not uncommon. Sometimes young people are able to cope with the difficult times after someone dies by themselves but sometimes it's too difficult and they get support from other people like friends or services like [SERVICE]. In the past, when people have done research about these experiences they have focused on all the traumatic or difficult aspects of that experience. However, research has shown that often positive change and growth can occur after a very difficult experience. This of course does not mean that the young person is not still greatly affected by what has happened or that they are pleased about it. The idea that change or growth can sometimes happen after negative life experiences has been called 'post-traumatic growth'. Researchers have studied this in adults but very few have asked young people themselves.

In this study I'm hoping to ask young people directly about their experiences of good change or growth happening after someone they love dies. My main hopes are:

- 1) To ask young people about changes that they have noticed following a loved one dying (any changes in themselves, what they thought of life or what they wanted for the future).
- 2) To ask about changes and growth within their families and friendships after someone they love dies (any changes in their friendships or in relationships with family members).
- 3) To ask young people directly about what they feel helped them following this difficult time.

#### **Why has the young person in my care been invited to take part?**

To find participants who would like to take part in this study I am giving this information sheet to a number of young people between 13 and 18 years old and their parents/ care-givers who have been involved with [SERVICE].

I am hoping to meet and talk to between 8 and 10 people. Research has been done before where young people have been asked about their experience of bereavement but as I mentioned earlier, I would like to focus on the change that has happened since and not just the very sad times the young person may have experienced.

### **Do I have to agree to the young person in my care taking part?**

No. It is up to both you and the young person to decide if this is something they would like to do and if you'd be comfortable with them doing it. We will ask you for your consent (permission) and then ask if you would sign a form. We will give you a copy of this information sheet and your signed form to keep. The young person is free to stop taking part at any time during the research without giving a reason. If they decide to stop, this will not affect the care they receive.

### **What will happen to the young person in my care if they take part?**

1. If the young person in your care decides they would like to take part and you agree, the young person can contact me by email themselves or they may ask you to contact me on their behalf. You or the young person can also let a member of the [SERVICE] team know and they'll pass that on to me. If you would like more information before deciding please contact me and I'd be happy to answer any questions.
2. A time will then be arranged that's convenient for both of you to meet with me. We can think about where will be easiest to meet, this could be done at your home, at [SERVICE] or possibly at school. If you chose for the meeting to take place at [SERVICE] we can pay for travel expenses. If you are unavailable when I meet with the young person it's possible to speak with you over the telephone beforehand and send you a consent form to sign in the post.
3. If you are available before I meet with the young person (or over the telephone) I'll go through the consent form with you and ask you to sign it (and post back if necessary). You can ask me any questions at this time.
4. I will then meet alone with the young person and have a conversation about their experiences. I'll use a digital voice recorder to record what they say.
5. This will probably last between 45 minutes to 1 hour but we can stop earlier if they want or have a break in the middle. It may be that you want to wait for them to finish the interview or leave, that's up to you both to decide together.
6. This study only requires me to meet with the young person once.



7. The young person will have the opportunity to talk to myself or a member of the [SERVICE] team after our meeting if they'd like to. They will also be given information about other organisations who can offer extra support.
8. Although what we speak about would not be used in the research study I'd be happy to talk to you about your experiences if you'd like to.
9. Once I have finished the research I will let you and the young person know the outcome and give you some feedback.

### **Confidentiality**

Everything that is talked about during the interview will be kept confidential which means I will not be able to discuss the content of what the young person has said. It's important that the young person feels able to talk in confidence. I would inform you however if the young person said something that made me worry that they might hurt themselves in some way or hurt someone else. I will confirm the limits of confidentiality once again before asking you and the young person to sign the consent form.

### **Is there anything to be worried about?**

There is the possibility that the young person may feel upset if asked questions about their bereavement. This is very normal and not necessarily harmful. They are able to decline to answer any questions at any time. There are many sources of support available including from [SERVICE] and charitable organisations if deemed necessary by the young person or myself.

### **What are the possible benefits of taking part?**

Lots of people find talking about their experiences helpful and therapeutic, it can be useful for young people to think about the changes that have happened since a loss and what they might hope for in the future.

We cannot promise the study will help the young person but the information we get might help other young people who have lost someone they love by building an evidence base for psychological work with this age group. We can learn what helps people grow out of difficult experiences by learning from those who have already experienced them.

### **My contact details:**

**If you have any questions please send me an email at [u1037641@uel.ac.uk](mailto:u1037641@uel.ac.uk) or call [07793026761](tel:07793026761). If you leave your details I'll email you back or call you if you'd rather.**

**Thank you for reading so far – if you are still interested, please go to part 2.**

---

## **Part 2**

**Part 2:** More detail – information you need to know if you want to take part.

### **What happens when the research is finished?**

After the interview I will transcribe what was discussed prior to analysis. This would be kept completely confidential by changing names and any other identifiable information. The young person can leave the study at any time. Once I've completed transcription I'll destroy the recording. I'll keep the typed up conversations, with the names changed for 3 years in case I need them again they'll be kept in a locked cabinet.

#### **Ongoing support for parents/ care-givers:**

- ✓ I am available when we interview is finished to discuss any concerns you may have.
- ✓ **Cruse Bereavement-** If you have been affected by bereavement you can access support at [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk) or call **0844 477 9400** or email [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk).
- ✓ You can also visit your **GP** for advice on ongoing support.

#### **Ongoing support for young people:**

- ✓ **A member of staff at [SERVICE]** will be available to meet with the young person if they'd like to speak to someone.
- ✓ **RD4U** is a website for young people who have been bereaved and has been made by young people themselves (It is part of Cruse Bereavement). It's got lots of information about getting support on their website [www.rd4u.org.uk](http://www.rd4u.org.uk) or call [0808 808 1677](tel:08088081677) (mon-fri 9am-5pm). You can also contact someone via private email if you'd prefer by clicking on 'private message'.

You may not feel you need any more support and may feel you don't want to speak to anyone else, that's totally fine too.

### **Who has reviewed the study?**

Before any research goes ahead it has to be checked by a Research Ethics Committee. They make sure that the research is fair. Your project has been checked by the London- Harrow NHS Research Ethics Committee and the University of East London Research Ethics Committee.

Thank you for reading this – please ask any questions if you need to.

Yours Sincerely,

Anna Picton

Researcher/ Trainee Clinical Psychologist

**Professional Doctorate in Clinical Psychology  
University of East London**

## **Appendix D: Young person consent form**

Version 3: 18/09/12

SERVICE LOGO

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### **CONSENT FORM FOR PARTICIPANT**

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Title of Project: **An exploration of young people's experience of 'posttraumatic growth' (change and growth) and their understanding of what helps in this process following bereavement.**

Name of Researcher: **Anna Picton**

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated **18.09.12** (version **3**) for the above study. I have had the opportunity to think about the information, ask any questions and have had these answered so I understand fully.
2. I understand that my participation is voluntary and that I am free to leave the study at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that only the researcher(s) involved in the study will be able to see information with my name and details in it.
4. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from The University of East London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. It has been explained to me what will happen once the research study has been completed
6. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person  
taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix E: Parent/carer consent form

SERVICE LOGO

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### CONSENT FORM FOR PARENT/CARE-GIVER

---

Title of Project: **An exploration of young people's experience of 'posttraumatic growth' and their understanding of what helps in this process following bereavement.**

Name of Researcher: **Anna Picton**

Name of Young Person Participating \_\_\_\_\_

Please initial all  
boxes

1. I confirm that I have read and understand the information sheet for parents/care-givers dated **18.09.12** (version 3) for the above study. I have had the opportunity to think about the information, ask any questions and have had these answered satisfactorily.
2. I understand that the young person in my care/ child's participation is voluntary and that they are free to leave the study at any time without giving any reason, without their medical care or legal rights being affected.
3. I understand that only the researcher(s) involved in the study will be able to see information with the young person's name and details in it.
4. I understand that relevant sections of the young person's medical notes and data collected during the study, may be looked at by individuals from The University of East London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. It has been explained to me what will happen once the research study has been completed
6. I agree for the young person in my care/ child to take part in the above study and I believe they fully understand what they are consenting to.

\_\_\_\_\_  
Name of Parent/Care-giver

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person  
taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## **Appendix F: Interview Schedule**

### **INTERVIEW SCHEDULE**

The interview is designed for young people aged 13-18 years old. Participants will be aware of the themes that will be discussed in the interview before commencing and will have had the opportunity to discuss any concerns beforehand. They will also have been fully informed about support services available to them.

Participants can say “pass” if they do not wish to answer a question. They can request a break at any time during the interview and they can finish the interview when they would like to. Anticipated interview time is between 45 minutes- 1 hour which the young person will be aware of before the interview commences.

The interview will take a conversational style but will follow the following structure:

- Warm up questions- Tell me a bit about what you enjoy- hobbies/ doing at the weekends/ with friends etc. What made them interested in joining the study and how they are feeling about being here today?
- Can you tell me about one of your happiest memories? Do you have a sad memory you could tell me about? (If bereavement is not volunteered- ‘You came to [service] when things were particularly tough after you lost someone you cared about, I wonder if that was a difficult time for you?’)
- Since you lost X have you noticed any changes in yourself? (What’s different?) It might seem like a strange thing to ask about but sometimes after someone dies, as well as lots of sad things, some people also notice things changing in a different way. Some people say that certain things have got better for them or that they feel they have changed in a good way. I wonder if you’ve noticed anything changing in a good way? (Keep emphasising that this doesn’t mean that they’re pleased that the death happened or that positive change negates how awful it was). Examples may be given such as ‘trying harder at school’ or ‘starting a new hobby’ if the participant is struggling to think of change.
- Have you noticed any changes in the people around you? Have there been any changes in your family that have been good? Have there been any changes in your friendships? (Have you built any new relationships/ friendships or have any got stronger? Do you get on better with siblings/ care-givers- these examples will be given if the young person is struggling).

- Have you noticed any changes in how you think about your hopes and wishes for the future? (What are your hopes and dreams for the future? Are these different from before x died?) Are you religious? Have you noticed any changes in your beliefs?
- In your opinion what do you think has helped you since losing X? What has helped you achieve these changes at such a difficult time? (Particular people? Support networks? Professionals? Activities/ school/ friendships/ hobbies? Religion? Being able to talk about it?) Do you remember what helped when it first happened? What helps now when you're feeling sad?
- From your experience, if another young person had a loved one die, what advice would you give them? Any words of wisdom? Anything in particular you would recommend?
- Any other thoughts or things you would like to tell me about?

Once the interview is over the young person will have the opportunity to talk to me about anything that has come up for them, without it being recorded. Anything discussed following the interview will not be part of the research data.

## **Appendix G: NHS ethical approval**



### **Health Research Authority**

**NRES Committee London - Harrow**

Bristol Research Ethics Committee Centre

Level 3, Block B

Whitefriars

Lewins Mead

Bristol

BS1 2NT

Telephone: 0117 342 1384

Facsimile: 0117 342 0445

04 October 2012

Miss Anna Picton  
Trainee Clinical Psychologist  
Camden and Islington NHS Mental Health Trust  
University of East London  
Water Lane  
Stratford, London  
E15 4LZ

Dear Miss Picton

**Study title:** An exploration of young people's experiences of 'post-traumatic growth' and their understanding of what helps in this process following traumatic bereavement.  
**REC reference:** 12/LO/1121  
**Protocol number:** n/a

Thank you for your letter of 18 September 2012, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Ethical review of research sites**

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Covering Letter		21 June 2012
Interview Schedules/Topic Guides	2	29 August 2012
Investigator CV		21 June 2012
Letter of invitation to participant	Cover Letter for Participants, v3	18 September 2012
Other: Summary CV for Dr N Rees		21 June 2012
Other: UEL Registration Letter	1	17 May 2012
Other: UEL letter - Ethical approval and confirmation of indemnity	1	16 February 2012
Other: Letter from UEL Registration Board		01 February 2012
Participant Consent Form: Consent Form for Parent/Care-Giver	3	18 September 2012
Participant Consent Form: Consent Form for Participant	3	18 September 2012
Participant Information Sheet: Information Sheet and Invitation to Participate	3	18 September 2012
Participant Information Sheet: Parent/Care-Giver Information Sheet	3	18 September 2012
Protocol	1	21 June 2012
REC application		04 July 2012
Response to Request for Further Information		31 August 2012
Response to Request for Further Information		18 September 2012

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:



- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

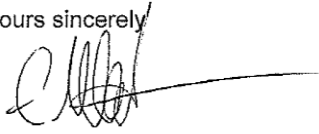
Further information is available at National Research Ethics Service website > After Review

**12/LO/1121**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

  
pp. **Dr Jan Downer**  
**Chair**

Email: ubh-tr.harrowrec@nhs.net

Enclosures: "After ethical review – guidance for researchers" [SL-AR2]

Copy to: *Dr Neil Rees*  
*Ms Vivienne Shaw, West Anglia and Community Care Research*  
*Governance and Research Support Services*

**Appendix H: University of East London ethical approval**

<b>ETHICAL PRACTICE CHECKLIST (Professional Doctorates)</b>
---

**SUPERVISOR:** Neil Rees

**ASSESSOR:** Bipasha Ahmed

**STUDENT:** Anna Picton

**DATE (sent to assessor):** 16/02/2012

**Proposed research topic:** An exploration of young people’s experiences of ‘post-traumatic growth’ and their understanding of what helps in this process following traumatic bereavement.

**Course:** Professional doctorate in clinical psychology

- |  |         |
|--|---------|
| 1. Will free and informed consent of participants be obtained?   | YES     |
| 2. If there is any deception is it justified?  | N/A     |
| 3. Will information obtained remain confidential?  | YES     |
| 4. Will participants be made aware of their right to withdraw at any time?   | YES     |
| 5. Will participants be adequately debriefed?  | YES     |
| 6. If this study involves observation does it respect participants’ privacy?   | NA      |
| 7. If the proposal involves participants whose free and informed consent may be in question (e.g. for reasons of age, mental or emotional incapacity), are they treated ethically? | YES     |
| 8. Is procedure that might cause distress to participants ethical?   | NA      |
| 9. If there are inducements to take part in the project is this ethical?   | NA      |
| 10. If there are any other ethical issues involved, are they a problem?  | NO / NA |

**APPROVED**

	YES, PENDING MINOR CONDITIONS	
--	-------------------------------	--

**MINOR CONDITIONS:**

- May want to consider suggesting shorter interviews (maybe start at 20 minutes?), bearing in mind interviews are conducted with children, and the nature of the topic – though not ideal for IPA, and in practice they may well be longer, the

option should be there so participants don't feel daunted by it, and the researcher also doesn't feel they need to 'push' the child to say more.

- Apparently only hard copies of anonymised transcripts will be kept for 3 years post study. Is this really the case? No soft copies will be kept?
- Is NHS ethics clearance not necessary? The student has answered 'unknown' to that question
- Will the child be provided with a separate (more child friendly?) info sheet? Or just spoken to? ( in procedure section not always clear if care-giver/parent gets opportunity to discuss/ask questions or the child)
- Finally – not an ethics issues as such – but the interview questions don't seem to be very 'IPA'!

Assessor initials: BA Date: 29/2/12

<b>RESEARCHER RISK ASSESSMENT CHECKLIST (BSc/MSc/MA)</b>
--

**SUPERVISOR:** Neil Rees

**ASSESSOR:** Bipasha Ahmed

**STUDENT:** Anna Picton

**DATE (sent to assessor):** 16/02/2012

**Proposed research topic:** An exploration of young people's experiences of 'post-traumatic growth' and their understanding of what helps in this process following traumatic bereavement.

**Course:** Professional doctorate in clinical psychology

Would the proposed project expose the researcher to any of the following kinds of hazard?

- |    |  |     |
|----|--|-----|
| 1  | Emotional                              | YES |
| 2. | Physical                               | NO  |
| 3. | Other<br>(e.g. health & safety issues) | NO  |

If you've answered YES to any of the above please estimate the chance of the researcher being harmed as: LOW

**APPROVED**

YES
-----

**REASONS FOR NON APPROVAL:**

Assessor initials: BA Date: 29/2/12

**SCHOOL OF PSYCHOLOGY**

Dean: Professor Mark N. O. Davies, PhD, CPsychol, CBiol.



**School of Psychology  
Professional Doctorate Programmes**

To Whom It May Concern:

This is to confirm that the Professional Doctorate candidate named in the attached ethics approval is conducting research as part of the requirements of the Professional Doctorate programme on which he/she is enrolled.

The Research Ethics Committee of the School of Psychology, University of East London, has approved this candidate's research ethics application and he/she is therefore covered by the University's indemnity insurance policy while conducting the research. This policy should normally cover for any untoward event. The University does not offer 'no fault' cover, so in the event of an untoward occurrence leading to a claim against the institution, the claimant would be obliged to bring an action against the University and seek compensation through the courts.

As the candidate is a student of the University of East London, the University will act as the sponsor of his/her research. UEL will also fund expenses arising from the research, such as photocopying and postage.

Yours faithfully,

Dr. Mark Finn

Chair of the School of Psychology Ethics Sub-Committee

Stratford Campus, Water Lane, Stratford, London E15 4LZ  
tel: +44 (0)20 8223 4966 fax: +44 (0)20 8223 4937  
e-mail: mno.davies@uel.ac.uk web: www.uel.ac.uk/psychology



The University of East London has campuses at London Docklands and Stratford  
If you have any special access or communication requirements for your visit, please let us know. MINICOM 020 8223 2853



## Appendix I: University of East London registration of research



Anna Picton  
35B Thornhill Road  
Barnsbury  
London N1 1JR

17 May 2012

**Student Number: 1037641**

Dear Anna,

### Registration as a Candidate for the University's Research Degree

I am pleased to inform you that the Research Degrees Subcommittee on behalf of the University Quality and Standards Committee, has registered you for the degree of Professional Doctorate.

**Title of Professional Doctorate:** Professional Doctorate in Clinical Psychology

**Director of Studies:** Dr Neil Rees

**Supervisor/s:** Dr Maria Castro

**Expected completion:** According to your actual date of registration, which is **1 October 2010** the registration period is as follows:

**Minimum 18 months maximum 48 months (4 years), according to a full time mode of study.**

Your thesis is therefore due to be submitted between:

**1 April 2012 – 1 October 2014**

I wish you all the best with your intended research degree programme. Please contact me if you have any further queries regarding to this matter.

Yours sincerely,

A handwritten signature in black ink that reads 'James J. Walsh.' The signature is written in a cursive style.

Dr James J Walsh  
School Research Degrees Leader  
Direct line: 020 8223 4471  
Email: j.j.walsh@uel.ac.uk

Cc: Neil Rees

## Appendix J: Permission to recruit from service.

### SERVICE LOGO

Anna Picton  
Trainee Clinical Psychologist  
University of East London

1<sup>st</sup> September 2012

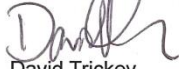
Dear Anna,

Request to complete research with clients from the Child Bereavement, Trauma and Emotional Wellbeing Service

This letter is to confirm that you have permission to complete your doctoral research with our clients, subject to gaining their appropriate consent as outlined in your proposal.

If you need any more information, please do not hesitate to contact me.

Yours sincerely



David Trickey  
Lead Consultant Clinical Psychologist and Research Lead

MEMBER OF  
**SOCIAL  
ENTERPRISE  
UK**



**Appendix K: Extract from transcript showing initial noting and emerging themes (Nick)**

	252	foundation for maybe children, you've got. I	
	253	know now i want to be someone that when i	
Emulate dad.	254	have children of my own i want to be that person	What he would be like when he was a father. Putting self in dad's position. Attempt to emulate dad.
	255	that's always with my children, not to the extent	
	256	it's excessive but i want to be there and i want to	
	257	make sure they enjoy what i've enjoyed or do	
	258	what they want to do because they want to do it,	make sure his children are able to do what they want like he did.
	259	not because someone else has told them what to	
	260	do and i want to make sure i am like dad and like	
	261	my mum, that i'm there and i'm always for them,	wants to be like his parents.
	262	no matter what they do and it really has bought	
	263	that perspective to things, that actually my dad	dad as ideal, perfect - 100% painful to be anything else?
Dad as amazing	264	was blummin amazing, especially when i talk to	Dad was "amazing".
	265	other people, "ohmy did this, my dad did that"	
	266	and i'm thinking for the 12 years i spent with my	compare to other's dads.
confirming importance of their relationship.	267	dad i've had so many more good experiences	Quality of time together the years of good experiences.
	268	with him than you have with your 16 years.	
	269	AP: having those 12 years of amazing memories,	
	270	of good things that happened compared to those	
	271	who have had 16 years so far and are	
	272	complaining, so is it something about the quality	
	273	of a relationship?	
	274	He was one of these people who completely	Dad's spontaneity.
Bring dad to life	275	spontaneously will turn around and go "wake up	dialogue related between self + dad. Bring to life.
	276	everyone"... why?... "we're going to France"...	
	277	what? [laugh], and so we'd be in this car and he's	
	278	be driving down to dover, before we'd know it	
	279	we'd be in Calais and then we'd hitch up in some	Family trip to France
	280	3 star hotel that's, it turns out to be really nice	
	281	and we're jumping on the beds, we'd had a	
	282	general good day, the next day we'd go	
	283	back...you know he'd be one of these people	
Dad as amazing	284	who would completely spontaneously do	Dad as spontaneous & fun.
	285	something completely barmy and we'd have such	
	286	a good time and it was them times, that i think of	
	287	and think of you know the good times because if i	needing to focus on the good times
self-agency in coping.	288	was to dwell on all the bad times then i'd be	To focus on bad times would impact on rest of his life. Horror of being sad person. Dad's end of life. Unpredictability of his condition.
	289	sitting there moping around for the rest of my	
	290	days]you know because there was a good week	
	291	or 2 weeks that he was in the hospice where he	
	292	went through ups and downs you know we were	
Fear of what would happen in doing cope.	293	told he was really good and then all of a sudden	could go over the bad memories but would make him feel worse taking control of reactions.
	294	he was really bad and then you know... i could go	
	295	through them in my head 500000 times a day	

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need to remember him pre-cancer.

Self-agency to wife.

fear of what would happen if don't take who I am now.

Making sense of death.

Making meaning of dad's behavior

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and it wouldn't make me feel any better about myself. So if i was to think about all of the good things, i've got more of a chance of remembering him for who he was not because he was ill because he had to face up with something else while he was talking, but who he was because that's who he was...

AP: amazing thing to be able to do and i'm wondering, it sounds like it's not necessarily as easy as just being able to do that, i'm wondering how you've managed that?

It's weird... it's..... it's one of the things, it's sort of you develop in your mind, obviously you've got the memories there but you look at them..... in times to show you how strong he was.....you turn, that's it, you turn the negatives into a positive all the time otherwise you do just go down into a spiral of depression and you don't get out for weeks and weeks and weeks.. but by turning everything that is negative into a positive you sort of realise whats happening and you think, well actually no-that shows me that you know he did this for a reason, it wasn't because of this or this or it was because he wanted to be a better man or because he wanted to show he was strong and he wanted to be there you know and all these times i'm sitting there thinking why didn't he let me do that it's because he wanted me to be who i am now, who i've come to be and now a couple of years down the line i can look back and i can see it but back then it might have been a completely different story which it probably was.

AP: thinking about change and you've mentioned that perspective on life and being able to turn those negatives into positives which i think is a real skill, i'm wondering about other changes you've noticed and maybe thinking about, change in yourself you've notice, either positive or you were saying at the beginning you'd noticed some changes in your drive...

Agency in making self think + help.  
To think of good times helps to remember dad aside from illness.  
need to remember him aside from cancer unhappy. desperate need to do this.  
Who dad really was.

something you do need yourself.  
Remind self of dad's strength. idea of thoughts as malleable.  
need to change negative thoughts to positive ones.  
what would happen if you think of negatives - Horror of allowing negative thoughts in. Avoid them?  
understanding dad's actions making sense of death. Dad wanting to prove his strength.  
wondering about some of dad's actions + making meaning. preventing having to think of dad badly.  
Hard to understand things at the time they were occurring.



Drive + determination  
a.k.a.

Time as limited

Changes in self.

Difference to other young people + old self.

Don't know what to think.

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I definitely DEFINATELY more driven, anything if anyone asks me to do something, instead of going oh ok and then when i get round to it i'll give it 150%, i'll do it straight away and i'd get there and i'd do it and i know my time is limited, so why spend it on waiting for something to happen, doing something and wasting that time and i've got, i can do it get it done and continue. And also i think negatively i've become quite a lot, my tempers been slightly shortened, it's lengthened again over the last couple of months, but when anything happened i was straight off, you know, i can't believe that just happened and it wouldn't normally turn aggressive, i don't think its ever turned aggressive but i definitely will voice my opinion about it and say "look..." if i'm in a class and it's the end of the day and people are talking normally that's just, just a thing that would happen, the teacher wouldn't let you go because you're talking, well it it, it came to one that i still remember in history, people constantly talking and i needed to get to an after school club or something and i just turned round and said "will you all please SHUT UP, SOME OF US NEED TO GET HOME" and it's like i 'm not the type of person that would normally turn round and say that to people but that time i just clicked, it was getting past the point and, that's not normally something that would happen, it's just them sort of things where it drives you to a point when people grind and grind and grind and all of a sudden you've just got to click and it takes a lot shorter time now than it used to, i just used to brush it off and think it doesn't matter  
  
AP: have you got any thoughts about why that might be?  
  
I don't know, it think i went through such an emotional rollercoaster, when it came to 12 years old that i didn't know what to think and so every single emotion got heightened by 10 times, when i felt happy i was really happy, when i felt sad i was really sad and then i think anger was just another one of them you know and feeling

more driven

Getting tasks done immediately when asked. Unprepared detail. Time as limited + no facility. Need to be efficient.

Loses temper more easily. Change in character.

new confidence? or intolerance? gives opinion. what i've like to be in class when people are 'talking': to waste time when life is limited is significant.

Really trying to emphasize how challenging it was for him. Different to how he normally is. Abnormal - change + difference.

People grind you to a point of snapping.

Used to be able to brush off similar situations. Self as changed.

Idea of being on ride + can't stop it. Run away. roller coaster - up + down emotions didn't know what to think. Emotions heightened + how should i think is there a right or wrong? multiple feelings.

Need to release emotions.

Fear of what could happen if feelings not released.

Don't know what to think / do.

381 guilt as well as constantly all the time, in my  
382 stomach, and then having anger put on top of it,  
383 it had to come out, there was no way of just  
384 sitting back and thinking about it, it just HAD to  
385 come out, otherwise it would be storing in there  
386 for days and just really wouldn't do me any good  
387 whatsoever, cos i'd end up doing something i  
388 really didn't mean to do.

389 AP: so being able to voice it when it got to that  
390 point was maybe a good thing in a way rather  
391 than it staying in and what that would have led to

392 Yeah definitely.

393 AP: so there were lots of emotions that were  
394 around after you lost your dad, contrasting  
395 emotions you said you didn't know what to think.  
396 Can you give me any examples?

397 Errrr, there were times where i would be talking  
398 socially to friends and that and all of a sudden i  
399 would be like... what am i supposed to think, i'm  
400 happy obviously because i'm talking to friends  
401 i'm having a laugh but id still have the guilt  
402 rumbling and i'd have a bit of anger running...

403 and it's like... what? What's happening? Why am  
404 i thinking, i'm having a good time, i'm trying at  
405 least to have a good time, i've got a smile on my  
406 face but then behind that i've got all these  
407 different emotions running through and that was  
408 a day to day thing, i call it my coping book, i've  
409 got a book about that think [showing how thick]  
410 and it's just got my emotions and everything, it's

411 all in code which i think helped as well because i  
412 had to think about it but i had my coping book  
413 and that i think numerous times in that i put 'i  
414 don't know what to feel anymore', i don't know  
415 whether to feel happy, i don't know whether to  
416 feel sad, i don't know whether to feel angry,  
417 guilty, depressed, i was in such a state that if  
418 anyone asked me to do anything i'd do that and  
419 not anything more you know, i'd do that to the  
420 letter and i wouldn't do anymore, and i would sit  
421 and i would hibernate within myself, i would  
422 become, i became errr an unsocial person

Awilt  
Feeling emotions in body  
idea of releasing something  
Emotions needing to  
come out. - otherwise  
would over flow.  
Fear of what would  
happen if didn't  
release feelings.

What would  
happen what  
is fear?  
Not wiping?  
Suicide?  
Aggression?

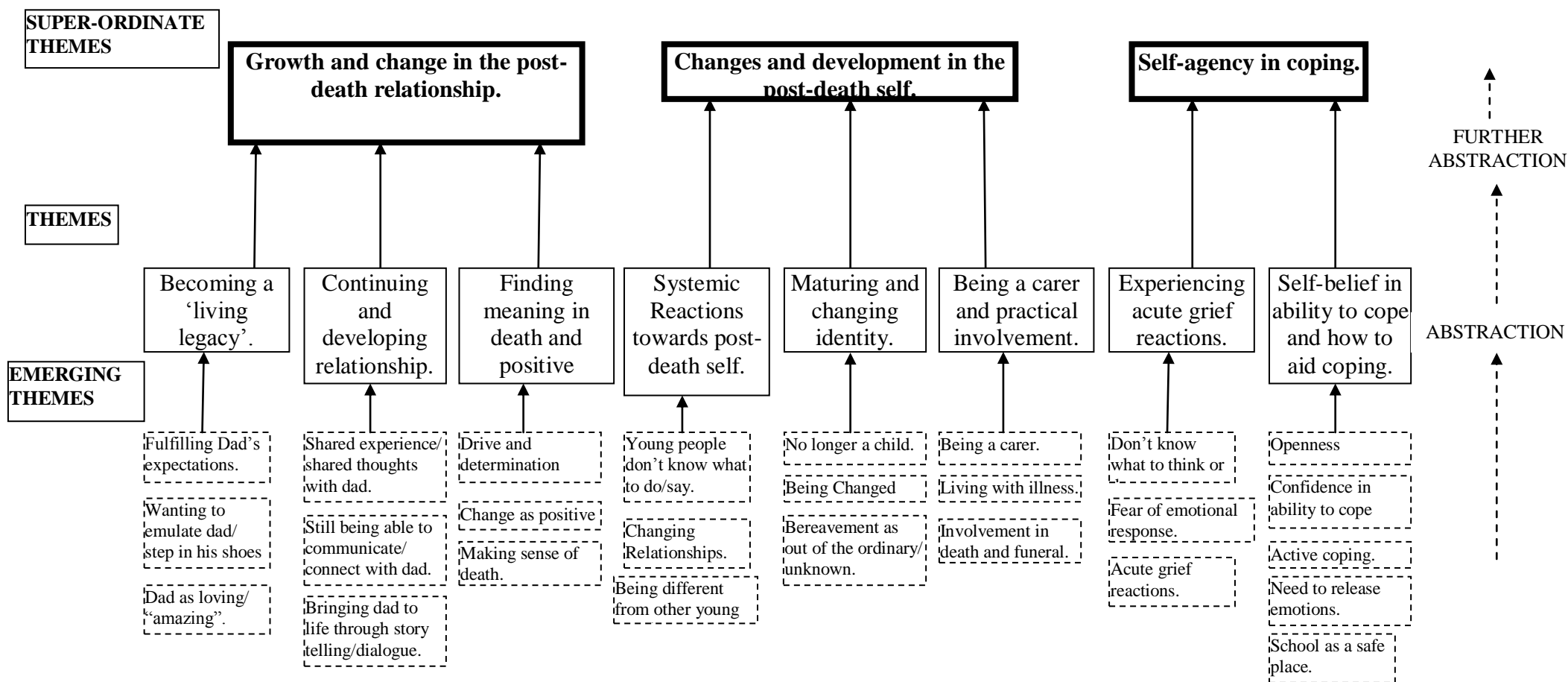
Is it betraying dad to  
laugh, meet other  
people?  
Not knowing what to  
think & how to behave  
with conflicting  
emotions.

Confusion & questioning  
of his reactions.  
Putting on a smile,  
hiding emotions, or  
writing about ext. of  
multiple emotions at the  
time  
writing down feelings  
needing to get  
feelings out.

Need to write the  
content of his writing  
Don't know how to feel.  
Wife on - right/wrong  
way to feel?

Being within himself,  
retreating  
What does it mean to be  
an unsocial person?

**Appendix L: Example of theme development for an individual participant (Nick).**



## Appendix M: Cross-transcript theme development.

Emerging Themes	Subthemes	Super-ordinate Themes
Dad's legacy continues.(5) <sup>2</sup> Physical presence of dad. (5) Remembering dad (4) Vivid recollection of dad (6)	Re-membering: "it's all in the senses".	<b>Being in-relation with the deceased.</b>
Becoming a 'living legacy' (2). Deceased as part of future self. Developing an ongoing relationship (3) Special relationship with dad as ongoing. (5) Sharing characteristics with dad.(5) Continuing and developing relationship (2) Looking down on you (6)	Staying connected: "They're guiding you through life".	
Developing relationship. (2) Finding meaning in death. (2) Ongoing evaluating of dad's sexuality and choices (5) Forgiving dad for dying and reflecting on anger (4) Re-evaluating feelings towards deceased (4) Being guided by them (6) He lives inside you (7)	Evolving relationship with the deceased.	
Systemic Reactions towards post-death self. (2) Utilising peer relationships in coping.(1) Positive relationships as crucial to coping (3) Use support of those around you for coping (7). Importance of new relationships with other young people (4) Growth in relationship with mum (4)	<i>The importance of positive relationships: "it takes a weight off your shoulders because you think I'm not the only one".</i>	<b>The Coping Process</b>
Need to release emotions. (4,2,6,5,3) Self-harm (7, 1, 5) Music to express emotion (1, 7)	<i>"I had all that inside me, I'm only little".</i>	
Self-belief in ability to cope and how to aid coping. (2) Self-agency in coping. (1,2,4,5,7) Coping as an independent process (5) Focusing on the future (6) Focus of the positives (7) Either sink or swim (7)	<i>Active Coping</i>	
Maturing and changing identity.(2,1,4) Being a carer and practical involvement (2,3,4) Maturity and care for others (3,1,2,5) Wanting to help others (5,4,7,6) Becoming an adult.(5) Staying at home to care for mum. (1) Helping professions (7, 4, 1, 6)	<i>"All my mates call me granddad now".</i>	<b>Growth in Self: "Bereavement is a very powerful thing and it can change you big time"</b>
Change in perspective on life (5,7,4,1) Putting things in perspective (1) Time doesn't stop for anyone (7)	<i>"I know my time is limited so why spend it waiting for something to happen?"</i>	
Positive changes in self (2,1,3,4,5,6,7) Strength (3) Independence and autonomy. (5) Self-esteem and confidence (4)	<i>"I think you get stronger from it".</i>	

<sup>2</sup> Participant is indicated by a number: (1) Kate, (2) Nick, (3) Jenny, (4) Laura, (5) Jack, (6) Suzie, (7) Mike

## **Appendix N: Feedback to participants**

SERVICE LOGO

24<sup>th</sup> April 2013

Dear [participant's name],

I wanted to write to you all to thank you again for taking part in my research and to also get some feedback from you. Over the past few months I have been analysing your interviews. The questions I set out to answer were:

- How do young people experience changes in their relationships following bereavement?
- How do young people experience change and growth after a bereavement?
- What do young people experience as helpful following bereavement and what do they understand as helping growth and change?

I have put the themes and ideas I found below. You might notice that some of the titles of the themes are direct quotes from people interviewed (they may be from you). I have chosen to use these as I think I couldn't summarise the idea better myself. There were a lot of hugely important and interesting things talked about, especially some of the difficult times people had but I had to focus on answering the questions above. For this reason it may seem like some bits of your experience are missing and for that, I'm sorry.

### **Main Theme 1: Being 'in-relation' with the deceased.**

This theme was about maintaining a relationship with the person that had died. This had three ideas connected to it:

- *Re-remembering: "it's all in the senses"*.

This was about remembering the person who died in a special way. 'Re-remembering' is an idea used in bereavement research which is a bit different to the normal idea of remembering. It refers to memories which are particularly strong or powerful, often they include things like bits of conversation and what the person looked like. Everyone spoke of some really wonderful memories of the person that died in great detail and I thought that the term 're-remembering' was a good way of describing it.

- *Staying connected: "They're guiding you through life"*.

Everyone spoke about different ways they stay connected to the person that died. This connection seemed to happen in many different ways. Some people spoke about holding onto memories as a way of staying connected. Others spoke about the idea that the person who died is looking down on them or in some way continuing to help them out in their lives. The biological connection to people who have died was also mentioned as something that keeps the

connection going. This seemed like a very important thing and something which helped people grow after bereavement.

- *Evolving relationship with the deceased.*

As people talked about their ongoing relationships with the person that died what seemed to be happening was that relationship continued to change as each of you changed. It seemed that as some of you grew and got older you were able to understand different things about the person who died and the relationship you had with them. This means that people's thoughts and beliefs about the person who died change over time and help the relationship stay alive even though the person is no longer here.

## **Main Theme 2: The Coping Process**

Everyone spoke about how they coped following their bereavement and what has helped them since this time. The main ideas that emerged are shown below.

- *"I had all that inside me, I'm only little".*

This theme is about expressing yourself. Everyone spoke about the importance of being able to express feelings and get rid of them when they needed to. It sounded like sometimes feelings built up and needed to be released. I heard about the different ways people have found to do this, such as using sports or music as an outlet. I thought all these ideas could be really helpful for other young people to know about.

- *The importance of positive relationships: "it takes a weight off your shoulders because you think I'm not the only one".*

I noticed that everyone spoke about how important it was to have supportive people around you following bereavement, whether this was from family or friends. I also noticed that lots of you spoke about the importance of meeting other young people who had been bereaved. It sounded like meeting other people who had had a similar experience helped a lot and made you feel like you weren't the only one.

- *Active Coping*

This refers to the idea of helping yourself cope. It's the idea that you don't sit back and wait to feel better but that you have to make the effort to do things that will help. It sounded like you had all done lots of things to try and help yourselves like changing negative thoughts into positive ones, thinking about the future, doing things you enjoy. I thought this must take a lot of effort and independence and was really impressed by all the things you had done to try and help.

## **Main theme 3: Growth in Self: "Bereavement is a very powerful thing and it can change you big time"**

One of the main aims of my research was to find out if young people can experience positive change and growth after bereavement. It seemed that this did happen in different ways.

- *“I know my time is limited so why spend it waiting for something to happen?”*

I heard that people’s perspectives and outlooks on life seemed to have changed as a result of the bereavement. People spoke about their appreciation of life, of not taking life for granted and of doing what makes you happy. I thought that these ideas would probably stay with you and be a positive driving force in your future lives.

- *“All my mates call me granddad now”.*

I was really struck by everyone’s desire to help other people as a result of their experiences. Some of you took on caring roles for family members before or after the death and I was impressed by the responsibility you were able to manage despite being young. Many of you said that you are better able to help other people who are having a difficult time now and I heard that lots of you wanted to go into helping careers. Overall, it seemed that having to grow up fast meant that you are all very mature for your age and I’m sure this will be a valuable quality in your future lives.

- *“I think you get stronger from it”.*

The final theme I found was that as a result of the bereavement many of you said you were stronger. I also heard about increased self-confidence and independence both contributing to the new strength that had emerged as a result of your experiences.

### **What now...**

#### **I’d like to find out what you think.**

I’d be very grateful if you could have a look at the ideas I have written above and let me know if you think they fit what your experience of growth and change since your bereavement. Any feedback from the interviews is also welcomed.

You can email me on: [u1037641@uel.ac.uk](mailto:u1037641@uel.ac.uk)

If you’d like to call or text me my number is: 07793026761

Finally, I’d like to thank you again for participating in this research. You all offered incredibly thoughtful and vivid explanations of your experiences. I hope this research will be used to improve the experiences of other young people who have been bereaved.

Kind Regards,

Anna Picton  
Researcher/ Trainee Clinical Psychologist